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An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach

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Copyright statement

Abstract

Background: The United Kingdom, like many countries, has an increasing population of older people living with chronic conditions, which leads to an increased need for homecare. A systematic review was done to explore emergent models of homecare, focusing on the lived experiences of older people and perceptions of service providers on emergent homecare models. The systematic review showed that despite person-centred care being the emergent homecare model, older people criticized the lack of involvement in their homecare decision-making. Growing evidence shows that participatory research may help understand and address some homecare issues among older people.

Aim: To explore older people's perspectives of the future homecare they want and collaborate with them to co-produce concepts and principles that should underpin homecare.

Design: The research was a qualitative design with a participatory research approach.

Participants: There were 14 participants aged 63 to 89 from one community organisation in England.

Method: Individual semi-structured interviews explored participants' perceptions of future homecare. The participatory groups discussed themes that emerged from anonymised individual semi-structured interview findings. Participants contributed to the co-production of homecare concepts and principles that should underpin future homecare. Recruitment was done using emails. Interviews and participatory group discussions were done using virtual Zoom.

Data analysis: The thematic analysis of Braun and Clarke, now called reflexive thematic analysis, was used in this research analysis focusing on an inductive approach because the inductive technique is unbounded by theoretical commitments and based exclusively on data. This was to enable older people to participate in the analysis phase when they wanted. The lifeworld-led well-being and suffering theory of Galvin and Todres was used to discuss findings because it could capture the suffering and the potential well-being that older people expressed.

Findings: The co-produced future homecare concepts emphasised proactive planning of homecare, to have homecare that addressed the wants and needs of an older person and homecare services from a one-stop shop. Older people wanted homecare that enabled participation, and trustworthy relationships in community.

Contribution to knowledge and implication to practice was that older people contributed to co-producing principles that should underpin homecare. These principles would inform policymakers and care providers in decision-making.

Keywords

“Future-homecare”, well-being, “older people”, co-production, “virtual communication”

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Author’s declaration

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List of abbreviations

ADASS	Association of Directors of Adult Social Services
BMJ	British Medical Journal
BORDaR	Bournemouth University Online Research Data Repository
BU	Bournemouth University
CC Licence	Common Creative Licence
CINAHL	Cumulative Index to Nursing & Allied Health Literature
CSV	Comma-Separated Values
DDI	Document Data Index
DHSC	Department of Health and Social Care
DMP	Data Management Plan
DOI	Digital Object Identifiers
EHRC	Equality and Human Rights Commission
EMBRASE	Excerpta Medica Database
EU	European Union
FAIR	Findable Accessible Interoperable Re-useable
FG1M1	Participatory Group 1 Meeting 1
GDPR	General Data Protection Regulation
GMO	Genetic Modified Food
GPs	General Practitioners
ICM	Integrated Care model
LGA	Local Government Association
NCSCN	Nominated Community Social Care Nurse
NICE	National Institute for Health and Clinical Excellence
ORD	Open Research Data

PAF	Participant Agreement Form
PCCM	Person-Centred Care model
PGRA	Post Graduate Research Administrators
PIO	Patient/Population, Intervention and Outcomes
PICO	Patient/Population, Intervention, Comparison and Outcomes
PIS	Participant Information Sheet
PID	Participant Identity Number
PT	Participant
SOP	Standard Operating Procedures
UK	United Kingdom
UNDESA	United Nations Department of Economic and Social Affairs
WHO	World Health Organisation

Chapter 1 Introduction

Homecare is broadly understood to refer to services that allow primarily older people to continue to live in their own homes because there is an increasing number of older people choosing to live in their own homes instead of aged care facilities (Fang et al. 2022; O'Rourke and Beresford 2022). Many countries, including European societies, face an ageing population and have seen year-on-year increases in the number of older people using homecare (Kristinsdottir et al. 2021). The fastest growing demographic, with the percentage of people aged 65 years and over, is expected to almost double by 2050, and there are similar projections for developed countries such as the UK (Thomas et al. 2021). Due to older people living longer, they live with multiple chronic ailments, and because of that WHO’s Decade of Healthy Ageing emphasise increasing the number of years lived in good health (Wagner et al. 2020; WHO 2020b). Literature shows that as people get older and without adequate homecare support, there is an increased risk of losing independence, hospitalisation, care home admission and mortality, therefore, maintaining independence is a primary goal of community health and care services for older people (Crocker et al. 2017; O'Rourke and Beresford 2022). In Europe, older people are the primary users of health and care services, including homecare support services (Kristinsdottir et al. 2021; O'Rourke and Beresford 2022). However, there is considerable variation between countries in how homecare is organised and funded and what tasks and activities are regarded as constituting homecare (Contandriopoulos et al. 2022; O'Rourke and Beresford 2022).

Homecare in this thesis is described as care provided for an older person who cannot fully care for themselves at home or their residential address, and with or without formally assessed needs that include personal care, rehabilitative, supportive and technical nursing care, domestic aid as well as respite care provided by informal caregivers as adopted and modified from (Fagerström et al. 2011). Homecare includes a range of services designed to enable older people to function within the community, reduce hospitalisations, and provide an alternative to long-term institutional care (Pepin et al. 2017). Since homecare has no universal definition as it is also broadly understood to refer to services that primarily allow older people to continue living in their own homes (O'Rourke and Beresford 2022), there is a need for further research to explore the concept of homecare with older people. Literature shows that the formal homecare service structure is influenced by state service structures, regulations, financial aspects, and available workforce (Sanerma et al. 2020), and there is a need to include older people so that stakeholders get the perspective of older people in structuring homecare services since they are the core consumers of homecare support services, yet with limited access to homecare support (Henwood et al. 2022). In comparison, informal homecare is provided without payment or formal training, typically by a spouse, children, family, friends, or neighbours (Li and Song 2019) and the majority of older people rely on informal care due to a lack of access to the formal homecare (Li and Song 2019). With the ever-growing ageing population, there is a critical need to provide homecare as long as possible for older people to prevent hospital admissions (Fang et al. 2022; Lyhne et al. 2022; King et al. 2023). Homecare is classified under social care, and as social care expenditure increases in Europe, its economic and social consequences, such as demographic changes, put intense pressure on maintaining adequate provision and financial sustainability of the social systems (Vanhercke et al. 2017).

Providing welfare to citizens in Europe became a primary trait following the Second World War (Kus 2006), when the horrors caused by world wars, post-war economic and political crises and war-induced institutional transformations created a huge demand for social protection that states were well-placed to fill (Obinger et al. 2022). During that time, coverage of institutional and home-based care expanded greatly and social expenditures increased rapidly, and traditional relief systems assisted only deprived populations and were transformed into comprehensive systems of universal benefits through the welfare state (Kus 2006; Vabø et al. 2022). In the UK, the British welfare state was conceptualised through the lens of Beveridge's 1942 report, which identified disease as one of the concerns in society (Palley 2020). The concern about disease was solved with an expanded commitment to public health care (Palley 2020). Most European countries have more or less comprehensive welfare models, whereby the state has taken a central role in providing a range of social benefits, including care, which is considered costly (Begg et al. 2015). The critique that the welfare state gets is that with demographic changes of ageing populations, migration, globalisation and recession, the future possibilities for maintaining financing welfare benefits will become challenging (Ervasti 2012; Brosig and Hinrichs 2022). Due to economic recessions, countries such as USA, UK, Australia and New Zealand introduced neoliberal reforms that led to significant changes in health and social care systems worldwide, including Europe, because they emphasised the free market rather than the right to health (Sakellariou and Rotarou 2017; Barnett and Bagshaw 2020).

Neoliberalism reforms were introduced first by Prime Minister Margret Thatcher of the UK and Republican President Ronald Regan of the United States of America (USA) in the 1980s (Gill 1998). The USA, UK, Australia and New Zealand introduced liberal systems whereby income to support social services is less comprehensive and only partially funded, leading to the development of two-tiered systems with significantly greater levels of income inequality and access to care services (Barnett and Bagshaw 2020). Countries such as Norway, Finland, Sweden, Denmark and Iceland introduced the social democratic model (the ‘Nordic’ Model), whereby income support and social services are funded predominantly from taxation (Barnett and Bagshaw 2020). The Bismarckian (Social Insurance Model) was adopted by France, Germany, Italy, and the Netherlands, and with this model, income-supporting social services are primarily funded through employer and personal contributions with guaranteed access (Barnett and Bagshaw 2020). According to Barnett and Bagshaw (2020), the impact of neoliberalism reforms on social care remains enormous and is worse in more unequal-income countries such as the USA, UK and Portugal.

The neoliberalism social reforms impacted the care policy that involved governments’ decisions regarding cost, quality, delivery, accessibility, and evaluation of programmes and initiatives aimed at ensuring the well-being of the population, especially marginalised groups, including the older people (Rotarou and Sakellariou 2017). In most European countries, long-term care financing and provision involve a mix of intertwined health and social care, whereby professionals mostly provide healthcare in the community and institutions (Bouget et al. 2017). Meanwhile, long-term social care in homes relies heavily on unpaid care provided by relatives making it invisible care (Bouget et al. 2017). Nonetheless, long-term social care is gaining visibility in policy discourse and reforms at national and European Union (EU) levels, emphasising enhancing home-based and community-based care (Spasova et al. 2018).

Still, public financing for long-term care in European countries tends to be highly fragmented due to historical and organisational reasons, with different government authorities in charge of different strands (Bizottság 2018). This leads to challenges in determining basic facts about long-term health and social care expenditures (Bizottság 2018). The inability to follow up with exact social care finance is that most European countries rely on informal and formal care (Spasova et al. 2018). The fragmentation of long-term care in Europe also affects older people's access and adequacy, the quality of care and the financial sustainability challenge, despite homecare being the preferred place for long-term care (Spasova and Vanhercke 2020).

Home has become the most preferred place of care in most European countries, including the UK because, with many older people requiring long-term care, institutions cannot accommodate all older people (Boland et al. 2017; Poškutė and Greve 2017; Heger and Korfhage 2018; Nagode and Lebar 2019; Burns et al. 2023). Policymakers in most countries advocate for homecare as people age rather than relocation to long-term care facilities as a way of cost reduction (Kristinsdottir et al. 2021). Public expenditure on long-term care has been increasing over the past 20 years in European countries and is expected to grow by 70% between 2016 and 2070, due to the ageing population (Spasova et al. 2018). With the effort of countries to reduce their long-term care expenditures, homecare for ageing people is becoming increasingly important as it facilitates the postponement of transfer to a nursing home and the prevention of unnecessary hospital admissions (Næss et al. 2017).

Homecare is an increasingly important component of social care for older people but remains relatively under-researched (O'Rourke and Beresford 2022). Europe like the UK, has fragmented and multifaceted homecare support, whereby the homecare concepts have multiple definitions and are understood or perceived differently by the stakeholders as some use it for long and short term (Jasper et al. 2019; O'Rourke and Beresford 2022). Access to multiple care services is not easy with older people when these services are fragmented and operate in silos since older people have little to no understanding of these care services (Henwood et al. 2022; Kehoe MacLeod 2022). There are challenges in providing social care for older people with complex health and social care needs because older people with multimorbidity and long-term care requires coordination between care providers’ services (Aujla et al. 2023). Evidence suggests that many older people have unmet needs due to fragmented care, particularly when they live with multimorbidity and frailty because of their functional challenges (Michael et al. 2020). Boland et al. (2017) also attest that the challenge with multifaceted and fragmented homecare is that it affects older people’s access, adequacy, and quality of homecare.

1.1 Homecare in UK/England

In Britain, neoliberalism emerged in the 1980s as a solution to the crisis of Keynesian policies, as articulated by Thatcher, for the inefficiency of the key policy instruments in dealing with objective problems and challenges, such as stagflation (Kus 2006). The neoliberal policy is associated with a general orientation towards a strongly free market-based approach, emphasising deregulation, minimalization of the State, privatisation, and the emergence of individual responsibility (Sakellariou and Rotarou 2017). Health and social care were also affected by the neoliberal healthcare reforms presented as the restructuring of ineffective and costly healthcare systems by involving mechanisms that aim to satisfy the goals of a free-market system (Rotarou and Sakellariou 2017).

The free market is a disadvantage, and it exploits older people, especially those who self-fund, because they are vulnerable, as most of them cannot negotiate care with profit-oriented care providers (Henwood et al. 2022). England has implemented neoliberal reforms, which included a top-down re-organisation of care with emphasis on market orientation competition and consumer-based care, alongside target-setting policies that use financial incentives to improve the quality of care (Aujla et al. 2023). Consumer-based care creates a competitive, entrepreneurial, and individualistic market that views older people as individually responsible actors (Duncan 2022). Duncan (2022) perceives consumer-based care as the government abandoning its social and welfare functions, and at the same time, economic entities are becoming the new referent that people should care and worry about. According to Duncan (2022), within neoliberalism reforms, people are dehumanized because people become things, and things become people, since, the market becomes personified and humans become things.

The Care Act 2014 aims at well-being and personalised care, with individuals being best placed to define their own well-being (Lelkes et al. 2021). Under the Care Act, local authorities are expected to facilitate personalisation by encouraging market diversity and enabling people to make choices and take control of their support arrangements (Needham et al. 2020). In the procurement model, using time and task contracts for homecare limits choice and control for older people using these care services, and furthermore, quality concerns have also been raised (Needham et al. 2020).

The Care Act gives local authorities in England broad duties and market-shaping wider than their commissioning role, and it encourages them to work co-productively with stakeholders (Henwood et al. 2022). In addition, local councils do not fund social care for everyone. To be entitled to state funding for social care, older people are assessed on their need for care and their ability to pay for it (Baxter et al. 2020). While social care is a mixed economy of provision, the independent private sector is overwhelmingly dominant, in 2011, 81% of homecare were delivered by private sector changing from 5% in 1993 (Lewis and West 2014). According to Lewis and West (2014), the government believes that increasing market competition enables user choice of services and improves quality of care. Unfortunately however regular scandals show that care is absent, including neglect of nutrition, hydration, pressure sores, lack of dignity and both unkind and ill-treatment in domiciliary care (Lewis and West 2014). England has had a marketized care system for several decades, characterised by the dominance of for-profit providers and often considered to deliver a narrowly functional model of care (Needham et al. 2023). In addition, older people whose financial assets are over the threshold are unsupported and make their own care arrangements and pay higher fees for the same care provided to publicly financed care (Henwood et al. 2022).

Adult Social Care, which is practical assistance for frail or disabled people with activities of daily living such as getting up, getting washed/dressed, going to the toilet, eating, etcetera, is organised locally by locally-elected councils, is income-verified and access depends on meeting increasingly strict eligibility criteria (Glasby et al. 2021). Due to increasingly strict eligibility criteria, many older people are ineligible for local authority-funded homecare, and as a result, they have to purchase their home care support as self-funders (Henwood et al. 2022). Older people who meet the needs threshold for social care, have their financial assets reviewed, and if they fall above the means-test threshold, they must pay some or all of their care costs (Needham and Hall 2023a). As a result, some older people have to pay large amounts for care, whereas others pay nothing, an inequity that does not occur for other welfare such as NHS-delivered health care and education (Needham and Hall 2023a).

According to Schlepper and Dodsworth (2023), in 2022 there were at least 2.2 million people aged 65 years and above needing social support such as eating or dressing in England. Schlepper and Dodsworth (2023) also indicate that about 245,820 adults were waiting for needs assessment as of August 2022, with an additional 29,570 people waiting for social care and support or direct payments to begin. According to Bayliss and Gideon (2020), in 2015, more than 350,000 older people in England used domiciliary homecare services, 257,000 of whom had their care paid for by their local authority.

Older peoples' social care is provided by a mix of public, private and voluntary sector agencies in a sector characterised by low status and low pay (Glasby et al. 2021). Since social care characterises the type of homecare provided to older people based on the cost and the intense need for homecare services, it leads to older people waiting long periods to access homecare (Needham and Hall 2023b). Older people who self-fund, are those who have assets, including the value of their house above £23,250, because they are not entitled to any financial support from their local council (Baxter et al. 2020). The council pays all homecare costs for those with assets below the lower limit of £14,250 (Baxter et al. 2020). Older people who self-fund are excluded from homecare because of the local authorities' lack of readiness to manage care accounts for self-funders or to have a clear sense of the scale of demand from self-funders (Henwood et al. 2022).

Henwood et al. (2022) indicate that around 350,000 self-funders in 2015 purchased their care because they did not qualify for means-tested state support. Literature shows that self-funders experience challenges in accessing homecare support provided by different care providers because they lack information about available homecare since the local authorities do not provide such support for self-funders (Henwood et al. 2022). Heavey et al. (2022) also attest that searching for self-funded later-life care is complicated because engaging with multiple agencies and finding the necessary information is difficult. A part of the Care Act that encouraged local authorities to engage with self-funders was that local authorities should establish a care account to track self-funders' capped costs (Henwood et al. 2022). However, Glasby et al. (2021) state that the section about the cap for self-funders in the Care Act 2014 was never implemented, being first delayed and then abandoned due to concerns about the costs it would impose on local government.

Henwood et al. (2022) believe that local authorities attempt to shape the market without fully understanding the role or wishes of individual self-funders, since they assume little or no responsibility for helping self-funders and as a result, local authorities cannot map this population. Henwood et al. (2022) indicate that the Local authorities admit that the Care Act has not been transformational. Even though the Care Act 2014 objectives were to promote people's independence and well-being and give people more control over their care and support (Hunter et al. 2020). Most older people self-funding are primarily not participating in local authority market shaping strategies despite being impacted by those strategies (Henwood et al. 2019; Henwood et al. 2022).

Older people who are self-funders and those looking for care on their behalf feel relatively unsupported in seeking information and making choices about care (Henwood et al. 2022). They feel that being met with indifference and unable to share one's thoughts and experiences of life with others reinforces a sense of worthlessness, triggering an experience of meaninglessness and disconnection from life (Sjöberg et al. 2018). It is urgent to provide homecare support services to older people before they become vulnerable to prevent existential suffering

(Jonbäck and Ekstrand 2023). The homecare definition in the UK remains ambiguous and unclear, leading to the exclusion of older people needing homecare. It also leads to a lack of recognition of other stakeholders contributing to older people's homecare (Henwood et al. 2022). Homecare is a significant social care component for older people but remains under-researched in the UK (O'Rourke and Beresford 2022). According to Lewis and West (2014) long-term care markets pointed out that the inefficiencies and inequities of the social care market mean that care services are not always available to those who need them because information about services tends to be poor.

According to Hunter et al. (2020), policy decline is often caused by overly optimistic expectations, implementation in dispersed governance, inadequate collaborative policy-making, and the notions of the political cycle. Needham and Hall (2023a), indicate that policy drift is one type of delay in which a formal policy remains the same despite becoming less effective due to the rise of new or newly intensified social risks which existing programs are poorly equipped to manage. Hacker (2004) attests that policy drift results not from failures of foresight or perception but from deliberate efforts by political actors to avoid the recalibration of social programs. Furthermore, (Hacker 2004) states that the concept of policy drift has been applied to various welfare fields, including long-term care. Factors that lead to policy drift are anticipated expensive reforms, when policymakers do not prioritise the changes over other demands on their time (Hunter et al. 2020).

According to Hunter et al. (2020), the Care Act 2014 introduced significant changes in Social Care law in England. Given the complexity of the changes, the Department of Social Care and its key partners introduced an Implementation Support Programme (ISP) to increase the smooth implementation (Hunter et al. 2020). Despite preparatory work on implementation readiness, almost a decade after the Care Act, most of its goals have not been achieved (Hunter et al. 2020). The Care Act’s funding reforms were abandoned, the number of carers’ assessments fell below expectations, individualised care funding stalled, and investment in prevention was deprioritised (Burn et al. 2023).

For many years, there has been widespread awareness among policymakers, practitioners, researchers, people using social care services, their families and the media that England's Adult Social Care system needs fundamental reform (Glasby et al. 2021). The Care Act 2014 was seen as a significant part of a new approach to supporting older people with social care needs and the delivery of Adult Social Care services (Hunter et al. 2020). The Care Act 2014 supported local authorities in England in taking responsibility for the well-being of older people to ensure the availability of good quality, personalised social care and support services for older people who need them (Glasby et al. 2021). Despite the UK having a Care Act of 2014, older people in the UK still get their task-based homecare support from different sources, such as formal, private, voluntary, and informal, from family members such as relatives, partners, children, friends, non-governmental organisations and churches (Clements 2014).

According to (Abdi et al. 2019), older people living with chronic conditions are faced with challenges in their social lives and activities related to self-care, domestic lives and mobility. Despite these challenges, older people valued independence and demonstrated a desire to cope and remain at home (Abdi et al. 2019). A majority of older people in need of care prefer to remain in their known physical and social environment for as long as possible, leading to increased demand for homecare (Lehnert et al. 2019). However, lack of professional support and barriers associated with the organisation of some care services interfere with these efforts. This highlights that many services and care delivery models are still not based on the needs of older people (Abdi et al. 2019).

The Care Act 2014 transformed the regulation of social care in England, but still, with the new Care Act 2014 legislative model, regulatory complexity exists within the system (Harding 2017). Furthermore, Harding (2017) states that social care is a decentred regulatory system marked by complexity, fragmentation, interdependency, and a great deal of permeability between public and private domains. According to Harding (2017), regulatory complexity and fragmentation contribute to the social care crisis, such as the difficulties older people with homecare needs and their family carers experience navigating the system. The uneven applicability of human rights laws and norms; and the lack of robust frameworks for those harmed by poor care aggravate these challenges.

Atkinson and Crozier (2020), on the other hand, question the 15-minute short visits and view them as problematic and insufficient to address complex homecare needs. Atkinson and Crozier (2020) believe that time and fragmentation of social care raise substantial policy concerns that demand an urgent review. Atkinson and Crozier (2020) believe that it is uncertain whether market approaches can deliver the employment practices needed for high-quality social care. Similarly, Abdi et al. (2019) assert that the social care system in the UK is struggling, and to a certain extent failing, to meet the care and support needs of older people.

The Care Act 2014, which is informed by neoliberal policies, aims for the service users to participate in their care. However, older people are still highly excluded from care because there is a power imbalance in structural decision-making as powers lie more on the act, local authorities and the care providers (Baxter et al. 2020). Moreover, this high exclusion of older people remains a fundamental challenge for ageing societies as it is embedded in drafting these legal documents as they are in the form of legislation and require compliance (Walsh et al. 2017; Heenan 2021).

There is an increasing need for social care from formal and informal caregivers to help older people remain at home despite their high care needs and avoid costly institutional care (Lambotte et al. 2018). UK countries differ in the publicly funded care level, with Scotland, Wales and Northern Ireland spending proportionately more on older people’s care than England (Needham and Hall 2023b). Homecare structures founded on financial aspects and the available workforce result in inadequate homecare support services and accessibility for older people since the government defines the type of homecare the government can provide for older people (O'Rourke and Beresford 2022).

According to Burn and Needham (2021) the challenge that affects social care services in the UK is that the delivery of support sits within a complex policy environment. Whereby the local authority executes the needs, means assessments, and arranges support for older people who meet the assessment criteria. Meanwhile, in reality the private sector provides most care and a substantial proportion of older people purchase their care, as they have assets above the means-test threshold (Burn and Needham 2021).

Needham et al (2020) noted that commissioners within local case sites support the focus on well-being and the shift away from more functional and needs-based social care accounts. Concerning the Care Act and its principles, some new and untested ideas are likely open to interpretation, for example, a new focus on well-being, prevention, self-care and market-shaping (Peckham et al. 2020). The lack of definition of well-being leads to confusing interpretations by local authorities and care providers implementing homecare (Baxter et al. 2020). A key issue for stakeholders concerning the interpretation of personalisation was the range of associated definitions, which got in the way of a clear understanding of whether or not it was being done well (Needham et al. 2018). Some stakeholders argued that the definition of personalisation referenced a shift from expecting people to fit in with services to designing services around people’s lives, while some definitions defined it from a service provision perspective (Needham et al. 2018).

According to Peckham et al. (2020) the Care Act 2014 is meant to support adults with social care needs and the delivery of Adult Social Care services, and its overarching objectives are to reduce reliance on formal care, in order to promote people’s independence and well-being, and give people more control of their care and support. Homecare services offered to older people are defined and characterised by the local authorities, however, the local authority still excludes older people from participating in homecare decision making (Henwood et al. 2022). Peckham et al. (2020) believe that there is a need to understand the nature and extent of stakeholder engagement in social care, whether all key partners had been involved and the terms of their engagement in implementing the Care Act 2014 support programme.

Hudson (2021) believes that welfare has become too large to be manageable, therefore, the government should concentrate on making strategic policy decisions. Hudson (2021) critiques that the government is failing because policies do not seem to fulfil their goals and can also be worsened by public agencies becoming self-governing bodies run by self-serving professionals. In England, the national government establishes the legislation and policy that informs social care. Local governments are responsible for overseeing social care systems within their areas and for commissioning and monitoring the provision of care from a variety of providers (Hudson 2021; Humphries 2022).

According to (Henwood et al. 2019; Henwood et al. 2022), most older people who self-fund care are primarily left behind by local authorities in market shaping strategies despite being impacted by those strategies. The local authority does not engage the self-funding population because they assume little or no responsibility for supporting them. As a result, local authorities cannot map or monitor older people who are self-funders (Henwood et al. 2022). The Care Act requires local authorities to move from only influencing the care market through their commissioning activities, to a more proactive role where, with stakeholders they shape, facilitate and support the care market (Needham et al. 2018). But, according to Hupe and Hill (2016), aspirations and ideas often fail to translate into workable policy because of the top-down assumption that the hierarchy within which policy formation is more important than policy implementation. Peckham et al. (2020) believe that the government is slowly recognising that there are problems with the top-down approach to policy development and acknowledges that more needs to be done at the post-legislative stage to ensure intentions result in positive change. Harris and Rutter (2014) also indicated that implementing policies has become the weakness of the UK system.

According to Hall et al. (2020), the Care Act 2014, emphasises well-being from an outcome-based perspective focusing on physical and mental health, protection, and dignity. I argue that outcome-based well-being supports fragmented homecare services because care providers employ particular inputs to target a particular outcome. However, if the Care Act 2014 was founded on lifeworld well-being, it would nurture inclusion and participation, which support lifeworld well-being. Lifeworld-led well-being also supports a holistic approach whereby the older person’s homecare is approached from their existential point of view, leading to more humane homecare for older people. The local authorities’ eligibility criteria for homecare services means that early intervention in homecare is not accessible for older people because the needs assessment serves as an exclusion criterion for early homecare (Hall et al. 2020; Glasby et al. 2021). This authorities’ eligibility criteria for homecare services leads to older people's lack of control, access and reduced choices in homecare support (UK-Legislation 2014; Baxter et al. 2020; Henwood et al. 2022).

The literature indicates that the current homecare service is largely task-oriented with limited focus on the involvement of the older people themselves, and lack of involvement might reduce older people's quality of life (Bölenius et al. 2017). Typical responsibilities for successful self-management of older people with multimorbidity, whether with or without assistance, consist of tasks such as monitoring symptoms, managing diet, engaging in physical exercise, acquiring knowledge about various conditions, handling medications and appointments, and organising one's lifestyle to accommodate the complex and demanding requirements associated with self-care and treatment management (Smith et al. 2019). Having multiple responsibilities requires older people to be knowledgeable about managing the various types of care they need to continue living at home since the current homecare services are task oriented. As a result, the availability of information to older people is essential.

According to (Kristinsdottir et al. 2021), half of the homecare clients who need assistance receive only moderate or little assistance and believe this factor needs to be investigated more closely. Approaches to providing the required homecare service must be identified. It is still unclear for many older people as to what type of homecare support services social care offers for older people, which brings fear and anxiety to many older people (Abdi et al. 2019; Baxter et al. 2020). At the same time, Næss et al. (2017) indicate that unavailable or limited resources for homecare services can lead to further functional decline and unnecessary hospitalisation of older people. Homecare services are developed based on systems, structures and funding flows (UK-department-of-health 2014). This lack of clarity on what type of homecare support services the state offers for older people affected how homecare and support are personalised and integrated with other public services (UK-department-of-health 2014). Börsch-Supan et al. (2015) attest that being inclusive, innovative, and reflective is particularly challenging during demographic change, which stresses economic, political and social resources.

1.2 My positionality in this research

According to Manohar et al. (2017), the term positionality describes an individual’s view and the position he/she has chosen to adopt concerning a research task. Positionality is often shaped by politics, religious faith, gender, sexuality, geographical location, race, culture, ethnicity, social class, age, linguistic tradition, and so on (Manohar et al. 2017). Positionality is formed by both personal and philosophical perspectives (Hampton and Reeping 2019). While practices of identifying positionality are becoming common in qualitative social science research, the processes for conducting these activities are often poorly understood, ill-defined, and are left to the discretion of the researcher (Secules et al. 2021).

Roegman et al. (2016) posit that with regards to positionality, a researcher can be an insider and an outsider simultaneously because people carry multiple identities. Outsiders can be more like insiders if they identify with the perspective of the community they are researching. In this sense, being an insider or outsider is not a fixed social location but a fluid concept of positioning that supports researchers in reflexivity around qualitative research (Roegman et al. 2016). Fenge et al. (2019) also described how researchers could describe the roles and identities and sometimes the duality involved in their identities when trying to find their roles as an academic, a researcher and an activist. Furthermore, Fenge et al. (2019) attest that the duality involved in the researcher's role is true for researchers with previous professional backgrounds.

In the current research, the multiple identities in my positionality are influenced by holding the identities of an academic researcher, having experienced exclusion in the matters that affected me and holding a similar perspective of older people’s feeling of being excluded from participation as evidenced by the systematic literature review findings from chapter 2 of this thesis. In addition, my positionality comes from my previous professional experience working with vulnerable people to improve their access to public healthcare services. With my activist positionality, my view, homecare in the UK is structured from the top down, not the bottom up, and it is provider-led (Needham and Hall 2023a). The provider-led homecare, gives minimal to no power to older people to participate in the design of homecare support strategies (Henwood et al. 2022; Needham and Hall 2023a). Marston et al. (2020) claim that including vulnerable and marginalised groups can assist in identifying solutions, as they can provide insight into experienced structural barriers. Asaba and Suarez-Balcazar (2018), state that participatory research approaches have gained momentum in health and social sciences, intending to work towards bottom-up involvement to give voice to vulnerable individuals like older people to influence care. The participatory approach's goal is to create social justice, but participation remains an unclear concept with varied meanings because, at one end of the range, it could mean just a token involvement or only consultation (Kamruzzaman 2020). Conversely, it could imply an influential voice in decision-making (Warwick-Booth et al. 2021).

In the UK, because of the neoliberalist approach to homecare, homecare is shaped by a free-market system, which does not support the Care Act 2014 (Atkinson and Crozier 2020). My positionality is that excluding older people from designing the homecare they want will make it impossible to provide them with a homecare that meets their needs and wants or fulfils their well-being and dignity requirements. In addition, there will be more expenditure on repeated hospitalisations and lack of care in the home to enable hospital discharges due to a lack of inclusion of older people in problem-solving, as evidenced by (Legramante et al. 2016; Gane et al. 2022).

According to Vlachantoni (2019), the concept of need is central to how welfare states design or provide social policies for older people, including social care-related benefits and services. The definitions of need, whether they are explicit in policies and eligibility rules or implicit in the decisions made by welfare providers, are rationing devices as they determine who gets what (Vlachantoni 2019). After doing this research with older people, I believe that grounding homecare on older people’s concepts and principles of homecare could help local authorities and care-providers change their perceptions of homecare and view it from the older people’s perspective.

Culture, sensitivity and vulnerability lenses - My positionality in carrying out this research with older people was also founded on my 25 years in public health, where governments strived to provide equitable healthcare services for all people. However, barriers always hindered certain groups from accessing care services. In the past 25 years, I found that involving the affected people in exploring barriers and co-producing solutions with them allowed an in-depth understanding of the problem and knowing if the blockage emanated from social, cultural, policy or health systems. Marston et al. (2020) also believe that involving communities makes care providers far more likely to come up with innovative, tailored solutions that meet our diverse populations' full range of needs. Suitable mechanisms for community participation are hard to establish, but once established, meaningful relationships between communities and care providers should be nurtured to ensure sustainable and inclusive participation (Marston et al. 2020).

When building meaningful relationships with participants, culturally sensitive researchers assume that participants in their research bring their own culturally specific knowledge to the research and that this knowledge may often differ from that of the researcher (Roegman et al. 2016). During my 25 years of serving communities with different cultures, understanding the problems and solutions from the community's perspective enhanced and led to the co-production of simple and effective solutions that improved access and well-being for those people.

Joseph et al. (2021) also attest that when exploring or researching with communities, it is crucial to consider the group's culture, and the sensitivity around the topic and vulnerability of the groups. Respect and reciprocity are also vital when working with diverse cultural groups (Roegman et al. 2016). I ensured the participants and I had reciprocity, empathy, and respect. Manohar et al. (2017) argue that with cross-cultural and sensitive research, participants often accept the researcher as an insider or outsider, and being accepted as a cultural insider allows cultivating a trusting relationship with the participants. Roegman et al. (2016) view that, instead of privileging the outsider or insider, culturally sensitive researchers acknowledge the role of one's cultural self, examining how researchers' and participants' culturally specific knowledge interact because in so doing, researchers maintain an awareness of multiple and potentially conflicting identities for themselves and participants.

Vulnerability - The concept of vulnerability is central to research ethics (Shaw et al. 2019). The vulnerable are categories of people presumed to be more likely than others to be misled, mistreated, or otherwise taken advantage of as participants in research (Shaw et al. 2019). In this view, vulnerable persons are susceptible to being harmed or injured in some way or of being emotionally damaged, offended or exploited (Shaw et al. 2019). With my experience working in public healthcare and with multiple vulnerable groups, I ensured that participants or the community felt safe with me. I introduced myself to the group and expressed my intention to collaborate with them so that together, we could explore solutions from their perspectives. I am always empathetic, open-minded, nonjudgmental, and respectful to individuals when I am in the group. Furthermore, I handle discussions with sensitively because I learnt from my experience that what might be considered not sensitive and taken for granted by the larger community could be sensitive to vulnerable groups. Moudatsou et al. (2020) believe that being empathetic involves awareness and intuition. While compassion is a complementary social emotion prompted by observing the suffering of others, it is related to the feelings of concern and warmth associated with motivating support. I have never been rejected by vulnerable people because of being an outsider researcher/or from the public health discipline. My relationship with vulnerable people has always been a good one based on respect, reciprocity, trust and empathy.

Participation from my experience in public healthcare - The way we understand and generate knowledge is greatly influenced by our life experiences (Secules et al. 2021). I have learnt that community participation promotes inclusion, and co-producing better care solutions with affected people. Also, Steen (2021) attests that co-production positively impacts the efficiency and responsiveness of services and the democratic quality of service provision, referring to citizen empowerment, inclusion, equity and equal access to service delivery. Group participation is an organized process in which individuals are characterized by specific, collective, conscious and voluntary actions, ultimately leading to self-actualization and achieving goals (Dehi Aroogh and Mohammadi Shahboulaghi 2020).

My experience of engaging with communities for care solutions resulted in community-based approaches where healthcare teams were formed in the communities and led by community members who regularly called their communities for “kgotla” meetings to discuss health and social care challenges with nurses. Kgotla meetings are safe community assemblies where all community members freely gather to discuss various issues, including health and social care, to reach a consensus. In the kgotla meetings, everyone is free to express their views and all the views are respected. A saying in Setswana that motivates freedom of expression during kgotla meetings: “mahoko a kgotla a mantle otlhe”, meaning all the views expressed during kgotla meetings are worthy. Furthermore, for power balance and inclusion during the kgotla meeting, there is a saying, “Kgosi thotobolo e olela matlaka,” meaning that if one is leading the kgotla meeting, they should serve, value and listen to everyone equally without discrimination or preference and “matlakala” meaning diverse community. These statements are usually expressed at the start of the meeting as an introduction to welcome community members to the kgotla meeting.

Older people as experts - My positionality based on my past experience in public healthcare is that older people are experts in homecare and have knowledge that could contribute to homecare strategies and enhance the well-being of older people. Qualitative researchers often include narrow positionality statements, only disclosing identities relevant to the topic, but, identity informs our research more profoundly and complexly than these simple disclosures imply (Secules et al. 2021). Local authorities should enable older people to participate freely and express their views on homecare by providing safe platforms. Furthermore, it should be a platform where older people’s perceptions are valued and considered. A platform where local authorities or care providers engage with older people to listen to older people’s perceptions of homecare. Doing research with persons from vulnerable groups can be challenging, as there is the potential for a power imbalance between researchers and vulnerable groups as a researched population (Shaw et al. 2019).

Considering that qualitative research undertaken with vulnerable groups is usually sensitive, the platform should be where older people experience a power balance between themselves and the local authorities or care providers. Coming to the research as an outsider, my role was to listen to older people's perceptions of homecare and empathetically understand the meanings of their perceptions. Furthermore, to ensure that I got rich data from participants, I provided a safe environment with balanced power between participants and myself and between participants. I did a participatory approach research with co-production, ensuring a power balance throughout the co-production and participatory period. Balancing power in participatory research is crucial to ensure equitable and meaningful engagement of all participants (Higginbottom and Liamputtong 2015). Silverglow et al. (2021) perceive that since the research represents a shared space shaped by both researcher and participants, the identities of both researcher and participants have the potential to impact the research process.

Positionality has been operationalized as an activity in which a researcher identifies, examines, and owns their backgrounds, perspectives, experiences, and biases to strengthen research quality (Secules et al. 2021) During the current research, I created a warm and accepting environment where all older people were respected and valued. Moreover, as a result, everyone felt free to share their experiences. I used "we" because, like in the kgotla meeting, the issue or problem is "ours", meaning the "community problem", and that "we" community solve it together. This approach helped balance power when communicating with the participants, enhancing inclusion and equality. We were all equal, and because we were working as a team of individuals, we respected diverse values and emphasised that we were learning from each other. Using "we" allowed the group to understand that individuals brought different experiences and expertise, which we need to learn from.

Researching future homecare with older people as a PhD researcher -

Holmes (2020) believe that PhD student researchers in the social sciences are often required to explain their positionality because of the need to understand that PhD researchers' ontological and epistemological beliefs influence their research. According to Holmes (2020), a strong positionality statement includes a description of the researcher's lenses, such as their philosophical, personal, and theoretical beliefs and perspectives through which they view the research process. Positionality can impact access to participants, working relationships, and the generation and interpretation of knowledge (Glas 2021).

From my philosophical lens of participatory research approaches my position was that older people, are good candidates for participatory research because they are full of wisdom and have a great wealth of lived experiences which could improve care strategies. Jeste et al. (2019, p.3) define wisdom as “a uniquely human ability or trait that includes several specific components: social decision-making, emotional regulation, prosocial behaviour that is guided by capacities such as empathy and compassion, self-reflection, acceptance of uncertainty, decisiveness, and spirituality”. I believe that older people share information well when they feel the researcher’s approach is respectful, sincere and when their contribution is valued.

Co-produced research is also based on commitment to challenging the predominant views in a society which constructs ageing as a problem with a focus on illness and deterioration (James and Buffel 2022). At the same time, this research could represent a value-based approach to doing research which promotes the importance of diversity and a commitment to valuing older people’s perspectives and lived experiences (James and Buffel 2022). When I started to explore future homecare with older people in the UK, my experience in public healthcare and co-producing with vulnerable groups helped me to experience successful collaboration with older people in the UK. The most crucial aspect of co-production was understanding the benefits of involving older people in co-produced research and ensuring that the research was of value to older people.

I understood that respect, cultural respect, flexibility, transparency, enabling choices, ensuring security, and developing trustworthy relationships with older people would enable their participation. As an outsider academic researcher, I also ensured that I was prepared for the co-production research. The lenses I used for this preparation were vulnerability, empathy, cultural identity, and sensitivity. Older people are classified as a vulnerable group (Challis et al. 2021), and as a result, the ethical application included how I would engage with older people in a way that they were safe and protected. Furthermore, I ensured that the topic was of benefit to older people. The first task was to map out how I would get access to older people in the safest and most trusted way and also be approachable. Approachability communicates a non-threatening manner to the participants, whereby they can feel safe disclosing information and engaging in prolonged discussions without concerns about the researcher’s judgement (Bukamal 2022).

Gatekeepers are critical to accessing the research site in many communities because they are more than simply allowing access to the research setting (Joseph et al. 2021); they are a link between researchers and the participants. I ensured that I recruited participants through an organisation since we were on lockdown during the Covid-19 pandemic. Recruiting from an organisation was useful as I worked with the organisation’s gatekeepers since they were the trusted source for older people. My role as an outsider researcher was to ensure that older people felt safe in the environment and that the research should gain credibility for participants. According to Bukamal (2022) it is essential for researchers to ensure that the research is earning credibility with participants in order for them to believe the research is worthy of their time.

James and Buffel (2022), state that this type of research helps ensure that the topic under investigation matters locally and improves the significance of what is being investigated. I introduced myself to the gatekeepers for this study and requested permission from them. During the introduction, I indicated which project I worked for, the aim of the research, the university I was studying at and a short overview of my previous jobs. The gatekeeper requested my research flyer, which they could share with their members, and I shared it instantly. The gatekeeper shared my flyer with the organisation members. Going through the gatekeepers was similar to meeting the Chiefs first when I wanted to meet community members during community health visits in my previous roles. When I gained permission from the Chiefs, they introduced me to the community, similar to the gatekeepers who shared my research flyer.

For the reason that I approached older people from a trusted point, they could voluntarily initiate communication by expressing interest in participating in the research. Since the research and communications were online, I used a work email from my University which was in the UK. I had my email signature with my detailed name, qualifications, phone number, university address and 3 logos; my University logo, Project logo and Funder logo, so it was easier to trace me. The Participant Information Sheets, flyers and Participant Agreement forms had 3 logos and contacts of my Bournemouth University. I included a clause that if participants had any complaints, they could contact my Supervisor and Deputy Dean of Research and Professional Practice from Bournemouth University, and I provided their contact emails. As an outsider, all the preparations were to develop a sense of trust, credibility, safety and security for older people. Therefore, providing detailed information and not leaving anything to chance was necessary for gatekeepers and older people to feel reassured that the research was credible and authorised. It was also critical that I earn more credibility.

Manohar et al. (2017) posit that cultural insiders may be able to conduct research more sensitively and responsibly than outsiders due to cultural commonalities and that they are better placed to gain the trust of the research participants and build relationships. I believe that as an outsider, I could also conduct research sensitively and responsibly by being well-prepared and offering meaningful interactions. I had an open mind that older people were going to teach me about homecare in the UK, and I was very excited about it. Bukamal (2022) suggests that being a credible researcher with groups and communities and being perceived as one requires a researcher to approach connections with humbleness to adopt relational research practices.

Roegman 2019 posits that a researcher can be an insider and an outsider simultaneously because people carry multiple identities, and outsiders can be more like insiders if they identify with the perspective of the community they are researching. In this sense, being an insider or outsider is not a fixed social location but a fluid concept of positioning that supports researchers to be reflexive in qualitative research (Roegman et al. 2016).

I came into this research as an outsider because, according to (Merton 1972). Holmes (2020) posits that positionality may change over time, whereby a researcher initially viewed as an outsider will, as time progresses, increasingly be viewed as an insider due to familiarity. Furthermore, (Holmes 2020) argues that since the researcher and participant are co-partners in creating knowledge, talking about the dichotomy of insider and outsider is not helpful because both may change over time. den Houting et al. (2020) believe that power dynamics are key in participatory research and that what matters most and is associated with the success of participatory research is the quality of relationships between partners.

Managing power relations was critical for me, and throughout my study, I managed power relations between myself and older people. According to Hanson and Ogunade (2016), power plays an essential role in defining human relationships and the ability to influence or impact the actions of others. Hanson and Ogunade (2016) also suggest that the power relationship between the academic researcher and the community needs scrutiny to highlight how the method of power-sharing plays a central role in determining the kind of engagement that occurs during the participatory project. I treated older people as co-researchers and not as subjects. According to Egid et al. (2021), power relations during research partnerships can compromise participatory research approaches' ability to bring transformational and sustainable change. Facilitating participation in research processes has associations with relationships and power dynamics among persons engaged in a participatory research process (Arnold et al. 2022).

I ensured that a discussion on respecting each other during participatory research was held at the beginning of the meeting. I discussed with older people that we were all learning from each other. We also discussed that we would equally contribute to the research because this was a way of balancing power. Those who talked longer were politely informed to give others a chance. Furthermore, participants took no offence when being stopped in this way. Older people were informed that there was no wrong and right answer and that everyone's contribution was valuable and appreciated. Egid et al. (2021) testify that participants who do participatory research with academic researchers believe that knowledge sharing also helps to redistribute power as it enables co-researchers to share the knowledge they gain with other community partners.

This thesis aims to explore older people's perceptions of future homecare they want and collaborate with them to co-produce concepts and principles that should underpin future homecare delivery. The current thesis was founded on the systematic review findings. The systematic review explored the impact of the emergent homecare model on older people's well-being in the European Union. The question for the systematic review was *"What are the lived experiences of* *older people and perceptions of service providers on emergent models of homecare concerning the well-being of older people in the European Union?*

Findings from the systematic review showed that person-centred care was the emergent homecare model and was developed to involve older people in their care to improve the disease outcome of older people (Tønnessen et al. 2011; Spoorenberg et al. 2015; Turjamaa et al. 2015; Elfstrand et al. 2017); Oude Engberink et al. (2017); (Lynch et al. 2018; Gudnadottir et al. 2019). Despite person-centred care aiming to improve older people’s participation, older people still criticised the lack of older people’s participation, lack of consultation, and lack of respect, which caused older people to experience anxiety, fear of loss of control and unmet care needs, which affected older people’s well-being and dignity (Elfstrand et al. 2017; Lynch et al. 2018; Hay et al. 2020; Hoel et al. 2021).

In the meantime, the literature showed that the participation of older people in their care could lead to a feeling of increased control and empowerment for older people (Mayan and Daum 2016; Warwick-Booth et al. 2021). Therefore, this thesis used the participatory research approach to explore older people’s perceptions of future homecare and collaborate with them to co-produce concepts and principles that should underpin future homecare delivery. Literature showed that a participatory research approach could help older people’s roles change from being passive homecare recipients to becoming more active, autonomous, and involved in their homecare (Kerr et al. 2020; Segevall et al. 2021).

The research was conducted during the Covid-19 pandemic and when the government introduced restriction rules of social distancing whereby older people were strictly isolated in their homes. Some studies revealed that older people were scared, worried about getting sick, and suffered anxiety, while others feared what would happen in the future (Rapisarda et al. 2022). According to Bruine de Bruin (2020) older people were perceived to have more significant infection fatality risks and anxiety during the early phase of the Covid-19 outbreak. Rapisarda et al. (2022) also attested that some older people felt that the authorities did it on purpose to put people in a cage. Multiple contrasting information on Covid-19 concerning older people led to older people losing trust and living under fear and anxiety because of not being involved.

The online participatory research ensured that older people were involved and not left behind in determining the type of future homecare they wanted. The literature on the use of technology by older people was explored. The purpose of exploring the use of virtual technology by older people was to understand their capability level to use technology and to choose the digital method that older people were more familiar with during recruitment and data collection. While exploring the literature, no literature showed the use of virtual communication for data collection in participatory research with older people. Since older people were going to use virtual communication for data collection and recruitment, and yet there was no literature on the use of virtual communication for data collection with older people, one of the objectives was developed to explore older people's perceptions of the use of virtual communication as a tool for data collection in this participatory research approach.

1.3 Background of the study

This thesis focused on the type of future homecare that older people wanted because, as evidenced by Palmér et al. (2020), the ageing process varies in terms of health and well-being since, with ageing, there is an increased risk of ill health and impaired functions. The United Kingdom's (UK) increasingly ageing population is associated with baby boomers (Storey 2018). Literature shows that the UK population is getting older and suffering from multiple chronic illnesses, however, social care funding is reducing (Hughes and Burch 2020). The statistics show that in 2020, there was a total of 957,831 people in homecare in the UK (Munson 2021). With the increase of older people cared for at home, it is essential to understand the type of homecare they want so that appropriate care for older people can be designed to meet their care needs.

The next section is the thesis outline.

1.4 Thesis outline

The figure below shows the layout of the thesis chapters. The thesis consists of chapters one up to chapter fourteen.

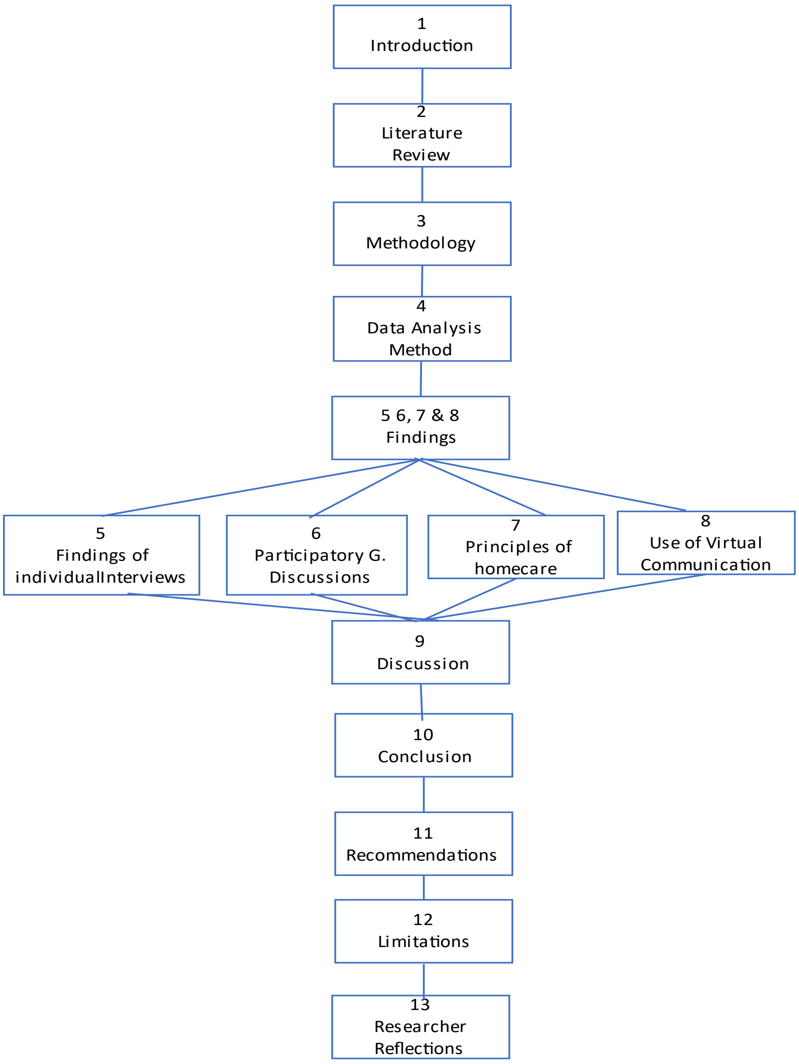


Figure 1-1 Outline of thesis

The rest of the thesis is organised into the following chapters:

Chapter 2: focuses on the literature review. The systematic review was conducted to identify the gaps for possible research. The chapter also explored conducting participatory research with older people. Furthermore, because of the Covid-19 restrictions, the use of technology by older people concerning online participation was explored. The chapter also defines concepts such as well-being in homecare, homecare, and dignity in homecare concepts. The chapter also describes the lifeworld-led well-being theoretical framework of Galvin and Todres (2013).

Chapter 3 describes the methodology of research, which begins with the philosophical assumptions underpinning qualitative research and participation. The chapter describes the qualitative research design and participatory research approach. It also describes the co-production, participants' responsibilities, my responsibilities as a researcher and stakeholders' responsibilities. This chapter also describes the recruitment method and the virtual data collection for individual semi-structured interviews and participatory discussion groups.

Chapter 4 describes the data analysis method, which is the 6 phases of Braun and Clarke's thematic analysis with inductive analysis.

Chapters 5, 6, 7 and 8 describe the findings. The findings from virtual individual semi-structured interviews are in chapter 5, virtual participatory discussion groups in chapter 6, co-produced future homecare principles in chapter 7 and the perception of the use of virtual communication as a data collection tool in chapter 8.

Chapter 9 is the discussion chapter. This chapter discusses the findings from the four chapters (5, 6, 7 and 8) in line with the study aim, objectives, study questions stated in chapter 1, and the literature.

Chapter 10 describes the conclusion. The conclusion is divided into three sections: Conclusion on future homecare older people want, principles underpinning future homecare and older people's perception of virtual communication as a data collection tool.

Chapter 11 covers the recommendations, which are the implications for practice and research. It also describes the co-produced dissemination of the research findings.

Chapter 12 covers the limitations of the research.

Finally, **chapter 13** describes my reflections as a researcher on participatory research.

1.5 Significance of the study

This present research is significant because older people participated in co-producing concepts and principles underpinning future homecare delivery from their lived experiences. The findings will be shared with the policymakers and care providers to consider older people's perceptions of homecare when developing strategies for homecare. Furthermore, the research will contribute knowledge towards using an online participatory research approach to enhance the inclusion of older people's participation in research.

The aim of the study:

- Explore older people’s perceptions of future homecare and collaborate with them to co-produce concepts and principles that should underpin future homecare delivery.

1.6 Objectives of the study

- Explore older people’s perceptions of how they would like their future homecare delivered.
- To collaborate with older people to co-produce concepts and principles to underpin future homecare delivery.
- To explore older people’s perceptions of the use of virtual communication as a tool for data collection in this participatory research approach.

1.7 Research question:

- What could future homecare look like based on the perception of older people in the United Kingdom?
- How does collaboration within research enable older people’s voices to be heard and allow meaningful engagement?
- What are the perceptions of older people on using virtual communication as a tool for data collection in a participatory research approach?

The next chapter is the literature review, which begins with the systematic review.

Chapter 2 Literature Review

The chapter starts with a systematic review to explore the impact of emergent homecare models on the well-being of older people in the European Union through the lived experiences of older people and care providers' perceptions. The systematic review found that older people criticised the lack of participation of older people in homecare. As a result, this founded the current research and its methodology. The chapter also includes a narrative literature review exploring participatory research with older people.

This is followed by a section that explores the use of technology by older people concerning online research with older people. Since the lockdowns and government restrictions imposed to control the transmission of the Covid-19 pandemic, this study was impacted, especially during the recruitment and data collection stage. New approaches needed to be explored to identify alternative ways of engaging remotely with older people in participatory research.

Lastly, to help answer the research questions, the chapter covers key concepts and their definitions in this research, such as homecare, well-being, dignity and principle. Conceptual definitions are important because they present the meaning of the studied concepts, even though in qualitative research, meanings of concepts usually come as the findings (Polit and Beck 2020). In this research, key concepts were defined to guide and enhance clarity for readers.

2.1 The rationale for a systematic review of emergent models of homecare

Ageing societies have become a challenge in most European countries due to the baby boom and reduced financial resources (Nagarajan et al. 2021). The United Kingdom, like other European countries, is experiencing declining fertility, mortality rates, and increasing life expectancy, impacting the economic and social dimensions due to an increased total dependency of 51.2%, which then puts pressure on the productive population (Storey 2018; Cristea et al. 2020; Nagarajan et al. 2021). Equally important, it is apparent that with an increase in the number of older people with multi-morbidities and complex care demands, new ways of organising care services, specifically effective coordination between multi-skilled workforces, are necessary (Araujo de Carvalho et al. 2017; Gudnadottir et al. 2019; Kennedy et al. 2019). Literature shows that two-thirds of people reaching retirement age in Europe have at least two chronic conditions (GCOA 2018). Wacker and Roberto (2010) indicate that we live in a unique period with an ageing society, and governments are obligated to consider numerous ageing social policy questions because the ability for older people to stay in their own homes, also known as ageing in place, presents many advantages compared to moving to residential care facilities (Deusdad et al. 2016; Sánchez et al. 2019). It is increasingly becoming evident that care for older people with long-term illnesses is shifting from institutional care to homecare (Rostgaard et al. 2022).

Homecare includes services designed to enable older people to function within the community, reduce hospitalisations, and provide an alternative to long-term institutional care (Pepin et al. 2017). Despite chronic, complex and multimorbidity health and care issues, older people are healthier and more active (Genet et al. 2012; Turjamaa et al. 2014; Araujo de Carvalho et al. 2017; Menéndez et al. 2018; Niculescu et al. 2021). Providing care for older people with multiple health issues is complex; therefore, further developments in care are needed (Sanerma et al. 2020).

The systematic review was focused on the European Union because it has a higher increase of older people compared to the rest of the world and was estimated at 20% by 2019 (UNDESA 2019). As the population ages, homecare service models and service delivery require rapid changes to maintain the quality of care for older people who prefer to be cared for at home (Araujo de Carvalho et al. 2017). Homecare consists of various medical and care professionals and lay people who care for older people, which is essential for the continuity of care (Ohta et al. 2020).

The present systematic review explores the impact of the emergent homecare models on older people’s well-being. The emergent homecare models for this review were defined as emergent strategies that respond to unexpected opportunities and problems and are usually developed from the locations at which business-level strategies are usually implemented, i.e. within business units and not at corporate headquarters (McGee et al. 2010). The pure definition of emergence requires the absence of intentions (McGee et al. 2010). For this review, emergent models were those that emerged in homecare in the last ten years, from 2009 until 2020 and were in the process of coming into being or becoming prominent. Homecare service providers in European countries work towards ensuring the availability and sufficiency of homecare services to fulfil the needs of older people (Sanerma et al. 2020).

Mintzberg and Waters (1985) describe that the emergent strategy suggests learning what works, taking one action at a time in search of that viable pattern or consistency. They clarify that it is essential to remember that emergent strategy means not chaos but, in essence, unintended order and how deliberate strategies change (Mintzberg and Waters 1985). In order to change the way healthcare is delivered, it is imperative to consider the present structures, attitudes and assumptions and how potential and actual challenges are handled by implementers and early adopters (Naldemirci et al. 2017).

Emergent strategies should be interpreted not as trivial solutions to problems in implementation but as a possible repertoire of tools, practices and skills developed in situ (Naldemirci et al. 2017). When exploring various names for homecare, various names for homecare such as residential care, coordinated care, integrated care, person-centred care, Buurtzorg or neighbourhood homecare were found (Monsen and deBlok 2013; Anker-Hansen et al. 2018; Henderson et al. 2018; Saitgalina and Council 2020; Scott and Funk 2022). These various types of homecare directed an exploration of an emergent homecare model.

Professionals and older people may have different understandings of the implementation of homecare, so it is crucial to include older people’s perceptions when evaluating outcomes (Naldemirci et al. 2017). The present systematic review explores the impact of emergent homecare models on the well-being of older people in the European Union through the lived experiences of older people and care providers’ perceptions.

Homecare is professional care provided with and for the older person who cannot fully care for him/herself at home or at the residential address of that older person with or without formally assessed needs, which include personal care, rehabilitative, supportive and technical nursing care, domestic aid as well as respite care provided to informal caregivers as adopted and modified from Fagerström et al. (2011). In order to explore homecare intervention models, I explored them through older people's experiences and care providers' perceptions. Exploring research papers on older people's and care providers' perceptions and experiences was essential to explore the themes and interpret and translate findings from the primary research. Qualitative reviews analyse human experiences and cultural and social phenomena (Munn et al. 2018).

2.2 Objectives

2.2.1 Aim for review.

A systematic review was done to conduct a cross-country exploration of the impact of the emergent homecare models on older people's well-being in the European Union. It was through this systematic review that gaps were identified, which led to this current research aim.

2.2.2 Review question

The systematic review question focused on the review's scope (Thomas et al. 2019). The framework used to develop the question was Population, Intervention and Outcome (PIO), the abridged version of Population, Intervention, Comparison and Outcome (PICO). According to Noyes et al. (2019), the PICO framework can be adopted in quantitative and qualitative studies. The PIO can be used for qualitative reviews (Munn et al. 2018; Noyes et al. 2019). Homecare models are care interventions aimed at improving the health of older people, which could prevent hospital admissions (Martinsen et al. 2018). As a result, the impact of emergent homecare models was explored from the perspective of older people and care providers because of their lived experiences to identify themes and interpret and translate findings. The framework was used to structure the qualitative research question and to define key concepts to identify relevant literature (Jahan et al. 2016). The question for this qualitative review read as:

“What are the lived experiences of older people and perceptions of service providers on emergent homecare models concerning the well-being of older people in the European Union?”

2.3 Design and methods

The present systematic review focused on qualitative studies to explore the impact of emergent homecare models on the well-being of older people in the European Union. The Cochrane systematic review handbook of Higgins et al. (2019) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist for a systematic review (Page et al. 2021a) were used as guidance. The PRISMA 2020 V2 flow diagram and PIO framework were used to search for articles and screen them (Noyes et al. 2019; Page et al. 2021a).

The Critical Appraisal Skills Programme CASP (2018) tool was used to complete the quality appraisal of the studies. Data extraction was a thematic synthesis which was guided by Thomas and Harden (2008), and the systematic review question “What are the lived experiences of older people and perceptions of service providers on emergent models of homecare concerning the well-being of older people in the European Union?” Findings were in the form of quotations from participants, subthemes and themes identified and my interpretations of these data as a researcher guided by Sandelowski and Barroso (2002). Findings were presented as a narrative, summarized, and displayed as tables (Noyes et al. 2019).

2.3.1 Inclusion/ exclusion criteria

The review included primary studies with a qualitative research component (Bulthuis et al. 2020). The studies needed to focus on the emergent homecare models on the well-being of older people in the European Union. Literature showed that the demographics of European countries were changing as older people, 65 years and above, were at around 20% in 2019 due to the baby boom (Mokhberi 2019; UNDESA 2019). Furthermore, older people had multiple ailments and preferred to be cared for at home (GCOA 2018; Rostgaard et al. 2022).

The inclusion criteria became the studies published in the last 10 years, from 2009 until 2019. The emergent homecare models for this review were defined as emergent strategies that respond to unexpected opportunities and problems for homecare (McGee et al. 2010). The English Oxford Dictionary defines emergent as the process of coming into being or becoming prominent. Due to limited funding, the studies chosen were those written in English due to insufficient funds for translators. This was acknowledged as a limitation for my systematic literature review since some European countries do not use English.

The target population was people aged +65years. The +65 years was chosen because the literature shows that they are growing in number and, while they are growing in number, they are at the same time affected by chronic illnesses and have complex needs which require long-term care (Turjamaa et al. 2014; Estabrooks et al. 2015; UNDESA 2019).

2.3.2 Search methods

According to Thomas and Harden (2008), searching for the inclusion of studies is to locate relevant studies that could address the research question. Thomas and Harden (2008) further indicate that aiming for conceptual saturation is better than getting several studies with the same concepts, as it would not change the findings. Information sources for this review were empirical studies in which the electronic databases were searched through the EBSCOhost platform. The peer-reviewed and academic journals searched were from Cinahl, the Cochrane Library, Embase Medline, PsycINFO, PubMed, Academic Search Ultimate, and NICE databases. The search was for studies published from 2009 until 2019. Studies should have been about Europe and written in English, which was acknowledged as a limitation in this review since vital information could have been missed since some European countries do not use English (Watson 2020). The search was done from the 5th of February to the 30th of April 2020 and updated in September 2021.

I used words in a Population, Intervention, Outcome (PIO) table as keywords for searches in Cinahl, the Cochrane Library, Embase Medline, PsycINFO, PubMed, Academic Search Ultimate, and NICE databases. The reference list was also used, which led to the inclusion of the World Health Organisation report in the systematic review. Searches were motivated by the eligibility criteria.

The research question developed through the use of PIO was “What are the lived experiences of older people and perceptions of service providers on emergent models of homecare concerning the well-being of older people in the European Union?”. I did the articles' search, screening, data extraction and quality appraisal with the guide from the Cochrane systematic review handbook (Higgins et al. 2019; Noyes et al. 2019). The search strategy was done with the help of a librarian. The keywords below were used to search for the records, including Boolean operators “AND” and “OR”, which combined the search terms (Bramer et al. 2018).

Key words: “Home care model”, Homecare, “Home care”, Europe, emergent, “Emergent homecare model”, “Residential model”, “Coordinated care”, “Integrated care”, “person-centred care”, “Buurtzorg care model” Dignity, well-being, respect, care providers, elderly, older people, “older adults”, +65 years.

The table below shows the article’s search framework used for the Participants, Intervention and Outcome (PIO).

Table 2-1 PIO framework used for searching

PIO search strategy	Keywords and phrases
P (participants)	Older people OR care providers, Elderly OR +65 years OR older adults AND
I (Intervention)	Homecare OR “Home care model” OR “Home care” OR emergent OR “emergent homecare model” “Residential model” OR “Coordinated care” “Integrated care” OR “person-centred care” “Buurtzorg care model” OR “Residential care.” AND
O (Outcome)	well-being and dignity of older people AND
Context	Europe OR “European Union”

The A desktop EndNote X9.3.3 was used to save and manage the identified articles and was backed up with an EndNote X9 online version (Hupe 2019). The EndNote X9.3.3 was used because the university library offered technical support for the EndNote X9.3.3. All the studies were exported into EndNote X9.3.3 reference management software for screening.

2.3.3 Selection process

I planned the search strategy with the help of a librarian. I identified and screened records either by title, abstract or full length. All records with studies concerning emergent homecare for older people aged 65 years and above using qualitative or mixed methods were included in the review. The systematic review studies were excluded because I included only original studies.

Studies were searched through the EBSCO host platform from the following databases: Cinahl, the Cochrane Library, Embase, Medline, PsycINFO, PubMed, and Academic Search Ultimate. All the studies were exported to EndNote X9.3.3 reference management software for screening.

Peer-reviewed studies focusing on the emergent homecare models were: Buurtzorg, the person-centred care model, and the integrated care model. Publications about emergent models included were those that were about older people’s experiences or perceptions of care providers under these homecare models. There was a total of 5491 studies after removing duplicates. After that, there were studies published before 2009 which were also excluded. Similarly, some studies were excluded as their titles were not about emergent homecare. Then 742 studies remained.

Of the 742 remaining studies, their abstracts were read, and 700 publications were excluded because either the publication used quantitative design, was a systematic review protocol, was about institutional care, and was not about older people. Subsequently, 42 publications remained. There were two publications whose full articles could not be accessed as they were only available as conference abstracts. The full text of 40 publications was read. When reading the 40 papers, none mentioned the origin of person-centred care and the integrated care models. One article that mentioned the World Health Organisation was identified with reference checks. The World Health Organisation website was searched, and four reports about older people and ageing were found. Only one report about integrated and person-centred care was relevant and included in the analysis.

Most publications about person-centred care or integrated care were from hospitals (Thornton 2011; Merino et al. 2016; Miguel et al. 2016). In addition, publications were disease-based, such as diabetes, dementia, palliative, end-of-life people, and cancer people, about those under the management of several specialists who mainly were General Practitioners (Moffatt et al. 2010; Thornton 2011; Ho et al. 2013).

The PRISMA V2 flow diagram 2020 was used to show the flow of information during the systematic review selection and screening process. The flow diagram is displayed below.

The figure below is the flow diagram of the selection process using the PRISMA flow diagram of 2020.

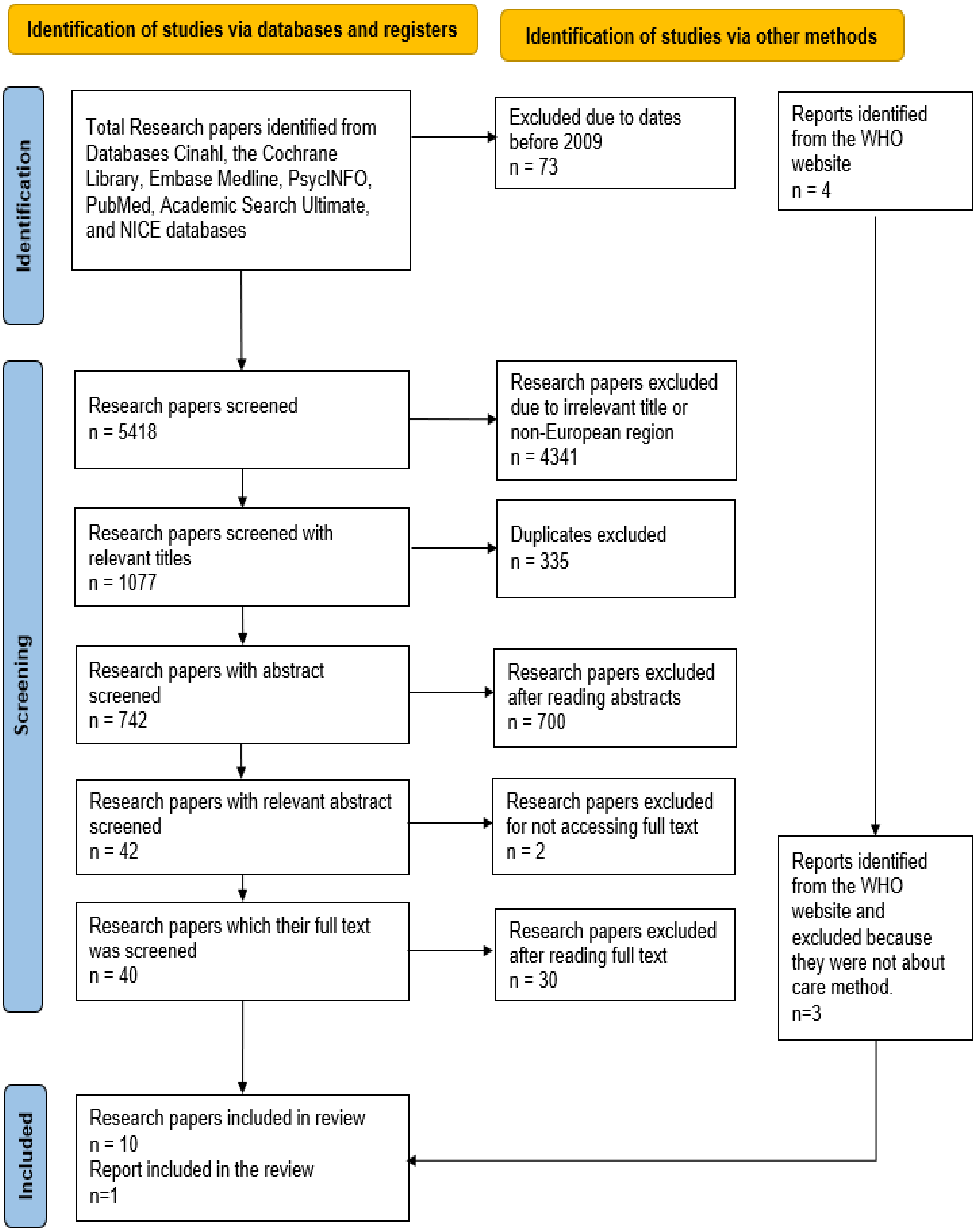


Figure 2-1 Selection process PRISMA V2 2020 flow diagram (Page et al. 2021b)

2.3.4 Quality appraisal

The present systematic review was qualitative. Often, qualitative studies are placed at the bottom of the hierarchy pyramid, implying that it is of little evidential value due to traditional issues concerning the quality of some qualitative studies (Davies 2019). The quality appraisal is an important step that needs to be conducted before the body of evidence can be made (Sambunjak and Franić 2012).

Critical Appraisal Skills Program (CASP) checklist for appraising the quality of qualitative studies was used to assess the studies' methodological strengths and weaknesses (Long et al. 2020). The CASP checklist had three sections which focused on the following: Are the findings of the study valid? (Section A), What are the findings? (Section B) and will the findings help locally? (Section C) (CASP 2018). All three sections had a total of 10 questions, which were used to rate the study. Each question had a selection from 3 responses: Yes-Y, Unclear/can't tell U and No-N (CASP 2018). I allocated points for each answer so that a total could be added for rating the quality of each study and easy comparison of quality. No articles were excluded for quality, but all included articles were unclear about the relationship between the participants. There was only one study that did not mention about the ethics considerations.

The below table shows the appraisal conducted using the Critical Appraisal Skills Program (CASP) checklist for appraising the quality of qualitative studies. The table shows the studies that were included in the review.

Table 2-2 Quality appraisal table

Authors	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q8	Q10
Åhlin et al. (2014)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Elfstrand et al. (2017)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Spoorenberg et al. (2015)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Lynch et al. (2018)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Drennan et al. (2018b)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Turjamaa et al. (2015)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Paljärvi et al. (2011)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Gudnadottir et al. (2019)	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Tønnessen et al. (2011)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Oude Engberink et al. (2017)	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
World Health Organisation, WHO (2015)	Y	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Y

Yes-Y; Unclear/cannot tell-U; No -N

CASP criteria for qualitative studies (CASP 2018).

1. Was there a clear statement of the aims of the research?

2. Was a qualitative methodology appropriate?

3. Was the research design appropriate to address the aims of the research?

4. Was the recruitment strategy appropriate to the aims of the research?

5. Was the data collected in a way that addressed the research issue?

6. Has the Relationship between the researcher and participants been adequately considered?

7. Have ethical issues been considered?

8. Was the data analysis sufficiently rigorous?

9. Is there a clear statement of the findings?

10. How valuable is the research?

2.3.5 Data extraction process

The systematic review includes the following steps: development of the research question, forming criteria, search strategy, searching databases, protocol registration, title, abstract, full-text screening, manual searching, extracting data, quality assessment, data checking, statistical analysis, double data checking, and manuscript writing (Tawfik et al. 2019). Since the protocol registration of the systematic review is not mandatory (Tawfik et al. 2020), I did not register the protocol for the present systematic review.

The first process for data collection was to identify the study characteristics to provide relevant data that could address the study's aim and question. I completed data extraction from the 10 selected articles. The selected studies were published from 2009 until 2019 from 9 European countries. Data extracted was on the authors, year of study and country, aims, designs, population, intervention, findings, funding sources, limitations, and outcome summary. The research question was also used to guide data collection. The research question was: What are the lived experiences of older people and perceptions of service providers on emergent homecare models concerning the well-being of older people in the EU?

2.3.6 Synthesis methods - eligibility for synthesis

2.3.6.1 Topic of interest

I included studies that were qualitative design and were about the impact of emergent homecare models on the well-being of older people.

2.3.6.2 Type of participants

The studies were about older people's experiences or care providers' perceptions of emergent homecare models.

2.3.6.3 Type of interventions

The systematic review was a cross-country exploration of the impact of the emergent homecare models on older people’s well-being in the European Union through the lived experience of older people and perceptions of care providers. Studies with emergent models of homecare were given priority.

For the purpose of this systematic review, homecare was defined as:

Homecare: Professional care provided with and for the older person who cannot fully care for themself at home or at the residential address of that older person with or without formally assessed needs, which include personal care, rehabilitative, supportive and technical nursing care, domestic aid as well as respite care provided to informal caregivers as adopted and modified from Fagerström et al. (2011).

For this systematic review, older people were defined as:

Older people: Meant everyone from the age of 65 years and above (UNDESA 2022).

For this systematic review, Well-being was defined as:

Well-being: Well-being is related to many factors, including everything from physical health, psychological state, level of independence, family, education, wealth, religious beliefs, a sense of optimism, local services and transport, employment, social relationships, housing and the environment (Minucciani and Saglar Onay 2020). According to Harvey and Taylor (2013) the meaning of well-being is not fixed and cannot be. It is a primary cultural judgement, just like what makes a good life (Harvey and Taylor 2013). Huppert (2009) defined well-being as the combination of feeling good and functioning well, the experience of positive emotions such as happiness and contentment, as well as the development of one's potential, having some control over one's life, having a sense of purpose, and experiencing positive relationships.

2.3.6.4 Synthesis methods - preparing for synthesis

I conducted data extraction, synthesis and data analysis of the studies using the thematic approach of Thomas and Harden (2008). In addition, the systematic review question "What are the lived experiences of older people and perceptions of service providers on emergent homecare models concerning the well-being of older people in the European Union?" was used. My Supervisors reviewed and gave technical guidance. Studies were characterised using Cochrane and PRISMA guidance (Noyes et al. 2018; Page et al. 2021a). Study characteristics checked were the authors, title of articles, type of design, conclusion, CASP tool and countries where research was carried out. According to Page et al. (2021a) synthesis allows healthcare providers and policymakers to evaluate the applicability of the findings to their settings.

2.4 Synthesis findings

The 10 studies and 1 report that met the inclusion criterion were (Paljärvi et al. 2011; Tønnessen et al. 2011; Åhlin et al. 2014; Organization 2015; Spoorenberg et al. 2015; Turjamaa et al. 2015; WHO 2015; Elfstrand et al. 2017; Oude Engberink et al. 2017; Drennan et al. 2018b; Lynch et al. 2018; Gudnadottir et al. 2019). The World Health Organisation report was included because it was about the person-centred care model (WHO 2015).

The table below shows study characteristics and methodological limitations using the Critical Appraisal Skills Program (CASP) tool.

Table 2-3 Study characteristics, including methodological limitations

Authors	**Title of an article**	**Type of Design**	**Conclusions in article**	**CASP tool**	**Country**
Åhlin et al. (2014)	Care providers' experiences of guidelines in daily work at a municipal residential care facility for older people.	Qualitative descriptive design	Working with guidelines in municipal residential care of older people is a burdensome issue for care providers.	Q6- Cannot tell. The relationship between researchers and participants is not stated.	Sweden
Elfstrand et al. (2017)	The impact of personality on person-centred care: A study of care staff in Swedish nursing homes	Qualitative cross-sectional survey	Personality traits have a significant impact on user orientation and that the perception of the working environment plays an important role for the outcome of care.	Q6- Cannot tell because the relationship between researchers and participants is not stated	Sweden
Spoorenberg et al. (2015)	Experiences of community-living older people receiving integrated care based on the chronic care model: A qualitative study	Qualitative control trial grounded theory	Enhances existing understanding regarding what the consequences of aging mean to older people. And whether and to what extent their needs and wishes can be met through integrated care services such as those provided by Embrace.	Q6- Cannot tell because the relationship between researchers and participants is not stated	Netherlands
Lynch et al. (2018)	The development of the Person-Centred Situational Leadership framework: Revealing the being of person-	Qualitative complex action research	Study demonstrates how the dynamism of the relationship between the leader and the follower	Q6- Cannot tell because relationship between the researchers and	United Kingdom

	centredness in nursing homes		enables person--centredness to be brought into practice on an everyday basis.	participants is not stated	
Drennan et al. (2018b)	Tackling the workforce crisis in district nursing: can the Dutch Buurtzorg model offer a solution and a better patient experience? A mixed methods case study	Mixed method case study	Renewed focus on patient and carer-centred care and the self-managing team, were implemented in ways that people, carers, other health professionals and nurses could identify the difference it made to both the nursing care and also the nurses' working lives.	Q6- Cannot tell because relationship between researchers and participants is not stated	United Kingdom
Turjamaa et al. (2015)	Is it time for a comprehensive approach in older homecare clients' care planning in Finland?	Mixed method	Based on descriptions and evaluation of contents of older (+75 years) home-care clients' electronic care and service plans, I found that current care planning is classification-based, instrument-oriented approach whereby the clients' perspective, including individual needs and resources, were missing in the majority of the CS plans.	Q6- Cannot tell because the relationship between researchers and participants is not stated	Finland
Paljärvi et al. (2011)	What happens to quality in	Qualitative	Findings should be seen	Q6- Cannot tell because	Finland

	integrated homecare? A 15-year follow-up study.	Case study	as tentative due to the methodological weaknesses to be successful in integration, structural integration with organisational mergers requires strong change management.	relationship between researchers and participants is not stated	
Gudnadottir et al. (2019)	Perception of integrated practice in homecare services	Qualitative	Integration does not come about instantly simply by combining work groups under one roof with a single overall manager but requires active leadership to set the direction for integration. Integration is an active process, whereby priority must be given to providing time and space to bring staff together for common reflection and information sharing.	Q6- Cannot tell because relationship between researchers and participants is not stated. 7. There is no reference to ethical approval	Iceland
Tønnessen et al. (2011)	Rationing home-based nursing care: professional ethical implications.	Qualitative hermeneutic methodology.	They reveal that legal and organisational boundaries constrain nursing practice in such a way that individual nursing care based on an inclusive approach is jeopardised. This has implications for the nursing role	Q6- Cannot tell because relationship between researchers and participants is not stated	Norway

			and responsibility in home-based care.		
Oude Engberink et al. (2017)	Patient-centredness to anticipate and organise an end-of-life project for people receiving at-home palliative care: A phenomenological study.	Qualitative	The development and organisation of coordinating structures, whether institutional or within primary care facilities and networks, has become critical to provide coordinated and diversified care to people from a multi-disciplinary team, integrating and complementing the activities of GPs.	Q6- Cannot tell because relationship between researchers and participants is not stated	France
World Health Organisation WHO (2015)	WHO global strategy on people-centred and integrated health services	Report		NA	Switzerland

The table below shows the data extraction, which was a thematic synthesis and guided by Thomas and Harden (2008), and the systematic review question “What are the lived experiences of older people and perceptions of service providers on emergent models of homecare concerning the well-being of older people in the European Union?” The extraction was performed in 10 articles and the World Health Organisation Report of 2015.

Table 2-4 Findings of individual studies - outcomes

Table 2: Extraction of qualitative research data through the use of research question, objective, PIO and a thematic synthesis guided by Thomas and Harden (2008).								
What are the lived experiences of older people and perceptions of service providers on the emergent models of homecare concerning the well-being and dignity of older people in Europe?								
	Authors/year	**Title**	**Aim/ Objective**	**Experiences of older people on the emergent models of homecare in EU**	**Perceptions of the service providers on the emergent models of homecare in EU**	**Emergent model of homecare**	**Population**	**Funding**
01	Åhlin et al. (2014)	Care providers' experiences of guidelines in daily work at a municipal residential care facility for older people	To describe care providers' narrated experiences of guidelines in daily work at a municipal residential care facility for older people.	Not reported	Burn out, stress in balancing guidelines and care work. Guidelines controlling, coming from above Guidelines were stealing time from residence. guidelines were colliding with each other. Not sufficiently anchored and hence making care difficult.	Municipal Residential Care	Care providers for older people in a residential care home	Swedish Research Council

					Guidelines lack practical use.			
02	Elfstrand et al. (2017)	The impact of personality on person-centred care: A study of care staff in Swedish nursing homes	To explore how personal and situational factors relate to the provision of person-centred care (PCC) in nursing homes.	Not reported	work environment pressures, quality of person-centred care. Importance of emotional stability in the implementation of PCC	Person Centred Care	Care providers for older people in nursing homes	Funder is the Municipality Research Council
03	Spoorenberg et al. (2015)	Experiences of Community-Living Older Adults receiving integrated care based on the chronic care model: A qualitative study	The objective of this study was to evaluate the opinions and experiences of community-living older people with regards to integrated care and support, along with the extent to which it meets their	Experiences with ageing, with the themes “Struggling with health,” “Increasing dependency,” “Decreasing social interaction,” “Loss of control,” and “Fears;” Relationships between	Experiences with Embrace, with the themes “Relationship with the case manager,” “Interactions,” and “Feeling in control, safe	Integrated care based on the chronic care model	Older people and Care providers	The Embrace study was funded by the Netherlands Organisation for Health Research and Development (Zoom: grant number 314010201; http://www.zonmw.nl). The healthcare professionals involved were funded by the Dutch Healthcare Authority (NZa: file number 300-1021; http://www.nza.nl)

			health and social needs.	participants and case managers were based on equality. Interactions, feel supported				
04	Lynch et al. (2018)	The development of the Person-Centred Situational Leadership Framework: Revealing the being of person-centredness in nursing homes	To implement and evaluate the effect of using the Person-Centred Situational Leadership Framework to develop person-centred care within nursing homes.	Leaders thought PCSL could help PCC. Older people wanted respect for their space to be treated as a home. Leaders observe and show carers how to treat older people.	Carers were not giving PCC to older people. Care Managers observed that the carers did not provide person-centred care to older people. They disrespected older people and did not engage older people when performing care activities on older people.	Person-Centred Situational Leadership (PCSL) Framework	Carers in the nursing home. Managers in care home older people	The Swedish Research Council's research ethical principles for the humanities and social sciences
05	Drennan et al. (2018b)	Tackling the workforce crisis in the district nursing: can the Dutch Buurtzorg model offer a solution and a better patient experience? A mixed methods case study	What is the impact of the adapted Buurtzorg model on feasibility, acceptability and effective outcomes? in an English district nursing service?	People happy, nurses listened, follow up care, nurses spent little bit longer time. Compared to District nurses' people praised Neighbourhood Nurses	Positive outcome reported by GP. Good for end-of-life care. Lack of time to complete the work. Challenges were reported in. relation to the recognition and support of the concept of self-managing teams within a large	Dutch Buurtzorg model	People across all ages Nurses and Managers GPs	The impact on costs was reported to be too early to assess. The ways to measure impact on costs were being discussed by managers.

					bureaucratic healthcare organisation. Difficult to unlearn dependence. The flat structure was considered a problem because staff wanted to progress up the ladder.			
06	Turjamaa et al. (2015)	Is it time for a comprehensive approach in older homecare clients' care planning in Finland?	The aim was to describe the contents of older (+75 years) homecare clients' electronic care and service plans and to evaluate how the clients' resources have been taken into account.	Low psychological well- being may contribute to older clients electing to live in institutional care rather than remaining in their own homes. Documentation was based on the philosophy of 'doing for clients.' All the cases in the study lacked the older clients' perspective,	current care planning is classification based. Homecare plan is designed from the homecare Professional point of view.	Comprehensive approach of homecare	+75 years	Grants from the Foundation for Miina Sillanp€a€ and Foundation for Municipal Development.
07	Paljärvi et al. (2011)	What happens to quality in integrated homecare? A	To explore the impact of structural integration on	Wanted cleaning services that were cut by municipality. Not	despite extensive mergers of health and social care organisations and the cuts in staff	Integrated homecare	Clients over 65 years, relatives and staff,	Not stated

		15-year follow-up study.	homecare quality.	well informed by staff. Staff were going through a difficult time due to the planned cost containment, including compulsory unpaid layoff for two weeks planned to occur just before the 2009 measurement.	and services, quality of homecare was almost stable throughout the follow-up period in most areas investigated.			
08	Gudnadottir et al. (2019)	Perception of integrated practice in homecare services	The aim of the study was to explore the impact of the integration of homecare nursing and social services in an ostensibly fully integrated work setting on the nature of the services. It was guided by the research question: RQ1. How do the homecare nursing and social services work together?	Not reported	The study showed that the process of integration was incomplete. weaknesses were identified in collaboration between care workers. unclear about their own role in coordinated teamwork and lacked a shared vision.	Integrated practice in homecare services	Managers and care workers in social services and homecare nursing	Not stated

09	Oude Engberink et al. (2017)	Patient-centredness to anticipate and organise an end-of-life project for people receiving at-home palliative care: A phenomenological study.	Aimed to examine how French GPs approached and provided at-home palliative care.	Not reported	Recommended training program of palliative care for GPs. GPs tapped from their personal experience, family and friends to develop palliative care.	Patient Centred Care	General Practitioners (GPs)	Study had no funding
10	Tønnessen et al. (2011)	Rationing home-based nursing care: professional ethical implications	To investigate nurses' decisions about priorities in home-based nursing care	Not reported	Services are governed by a shortage of time rather than by the people's particular and individual needs, leading to degrading care. Legal boundaries limit individual nursing care	Rationing home-based nursing Care	Care workers Managers Homecare Nursing	Not Stated
11	World Health Organisation WHO (2015)	Report: WHO global strategy on people-centred and integrated health services	To act as strategic guidance to the WHO member countries	Not reported	Not reported	People-centred and integrated health services	Not specified	World Health Organisation, 2015

Notable findings about these emergent homecare models were*:*

2.4.1 Dutch Buurtzorg model

One study from the UK was about the Dutch Buurtzorg model (Drennan et al. 2018b). This model began in the Netherlands (White 2016), and this article evaluated communities where this model was piloted in the UK (Drennan et al. 2018b). With this model, they formed smaller self-managing teams of nurses to organise their work processes by cutting off managers and luxurious offices to reduce care costs (Kreitzer et al. 2015; White 2016). The Buurtzorg model was performed in the UK with people of all age groups at home (Drennan et al. 2018b). The participants were people of all ages, nurses, and GPs engaged in implementing or receiving this model (Drennan et al. 2018b). Visiting nurses' services served mainly older people with chronic conditions, like strokes and disabilities, who were housebound.

The table below shows the identified themes from the older people's experiences and care providers' perceptions of the Buurtzorg model.

Table 2-5 Themes identified on the Buurtzorg model

Themes:	**Perceptions and experiences of older people and care providers on the Buurtzorg model**
Older people's perspectives on the model	People's perceptions of the Buurtzorg model contrasted with the District Nurse services (Drennan et al. 2018b). *Listened to: A*s they stated that Nurses gave them attention and addressed their concerns and questions (Drennan et al. 2018b). *Improved communication:* people felt that Nurses had good communication with them regarding follow-up visits and plans on what had been done or was going to happen (Drennan et al. 2018b).
Care providers' perspectives on the model	*Difficulty in Retaining Nurses: A*ttracting and retaining nurses in home visiting services is a recognised problem (Tourangeau et al. 2017). There was attrition of nurses after interviews and shortly after starting work. Some concerns were on questionable longer-term issues with the model (Drennan et al. 2018b). *Appreciation:* Nurses enjoyed the positive feedback from people, GPs and other health professionals for their work (Drennan et al. 2018b). *Challenges of the model:* the challenge was managing differing team opinions and having a one-level ranking of employees, which most questioned in terms of progression (Drennan et al. 2018b). *Managers' interference:* Nurses stated that managers still wanted to manage them despite their self-management teams (Drennan et al. 2018b).
Managers' perspectives on the model	Managers were committed to testing and championing the model (Drennan et al. 2018b). Managers stated it was too early to assess the costs related to the model (Drennan et al. 2018b). Managers believed that streamlined decision-making saved time and paper during referrals (Drennan et al. 2018b). GPs were happy that Nurses seemed committed to solving people's problems instead of reporting them (Drennan et al. 2018b).

2.4.2 Integrated care model

Studies about integrated care were from the Netherlands, Finland, and Iceland. None of the studies stated to have developed an integrated care model, but they used the integrated care concept in care (Paljärvi et al. 2011; Spoorenberg et al. 2015; Gudnadottir et al. 2019).

The Embrace model was one model that was piloted in the Netherlands, and it was considered to be a population-based, person-centred, and integrated care service (Spoorenberg et al. 2015). This model was also piloted with community-living older people, combining the Chronic Care model and the Netherlands' population health management (Spoorenberg et al. 2015). Older people were sampled from the Embrace clinical trial intervention group from frail and complex care needs people who received care under the Embrace model (Spoorenberg et al. 2015). Subsequently, care providers profiled participants into three groups (Spoorenberg et al. 2015). Gudnadottir et al. (2019) explored the perception of integrated interdisciplinary coordination between nurses and social care in homecare services.

2.4.2.1 The themes from the participants and care providers

The research focused on frail patient participants (Spoorenberg et al. 2015; Gudnadottir et al. 2019). As a result, people had difficulty reflecting on the Embrace model. They only discussed community meetings as support (Spoorenberg et al. 2015).

The table below shows the identified themes from the older people's experiences and care providers' perceptions of the Integration model.

Table 2-6 Themes identified in the Integration model

Themes:	Perceptions and experience of older people and care providers on the integration model
Older people's perspectives on the model	*Struggling with health:* people were struggling with health deterioration and had a fear of life-threatening conditions such as fear of stroke(Spoorenberg et al. 2015). *Increasing dependency* was a concern for everyone as they feared losing control (Spoorenberg et al. 2015). A comment from one of the people about losing control "*Well, I want to clean out the cabinets; I really want to get that done. It all needs to be sorted out, but I can't do that either. It makes me angry"* F4F (Spoorenberg et al. 2015). *People felt equality with Embrace Managers* because they felt managers did not look down on participants. *"Well, she always asks 'What time can I come?' or 'Does that suit you?'"* (F4F) (Spoorenberg et al. 2015).
Care providers' perspective on the model	The teams reported a lack of time to meet, communicate and share knowledge from team members' contributions (Gudnadottir et al. 2019). Researchers reported methodological weakness during follow-up as some sections were not answered and participants were not the same as the first implementation of research (Paljärvi et al. 2011). Weakened collaboration between nurses and social care services, for they felt unclear about their own role in coordinated teamwork and lacked a shared vision (Gudnadottir et al. 2019).

2.4.3 Person-centred care model

Studies analysed in the review about the person-centred care approach in homecare or residential care homes were from the Netherlands, Finland, France, the United Kingdom, Norway, Sweden and Iceland (Tønnessen et al. 2011; Spoorenberg et al. 2015; Turjamaa et al. 2015; Elfstrand et al. 2017; Oude Engberink et al. 2017; Lynch et al. 2018; Gudnadottir et al. 2019). It showed that the model was named differently as person-centred care, patient-centred care, person-centredness, and Comprehensive approach (Spoorenberg et al. 2015; Turjamaa et al. 2015; Elfstrand et al. 2017; Oude Engberink et al. 2017; Lynch et al. 2018; Gudnadottir et al. 2019). At the same time, the World Health Organisation (WHO) called it people-centred and integrated health services (WHO 2015). The model seemed poorly understood by caregivers, which impacted the successful implementation of person-centred care (Elfstrand et al. 2017; Lynch et al. 2018). Some authors reported the limitation of having sampled from their pilot study participants with frail and complex care needs. As a result, those older people could not give feedback on their experiences of the model (Spoorenberg et al. 2015). Similarly, Elfstrand et al. (2017) stated that personality traits impact the implementation of person-centred care.

Themes that were identified in the integration model and the Dutch Buurtzorg were not repeated in the person-centred care model to avoid repetition. The two models emphasized the person-centred care approach.

The table below shows the identified themes from the older people's experiences and care providers' perceptions of the person-centred care model.

Table 2-7 Themes identified in the person-centred care model

Themes:	Perceptions and experience of older people and care providers on a person-centred care model
Older people's perception of the model	*Older people experienced anxiety* because they were less satisfied with the care they received in-home and nursing homes (Elfstrand et al. 2017). *Unmet care needs* because care services were rationed and prioritised by carers because of staff shortages (Tønnessen et al. 2011; Turjamaa et al. 2015). *Lack of consultation by care providers* older people were concerned that carers did not consult when doing certain activities for older people. *Lack of respect for the older person's boundaries* – this was where one of the residents indicated that in one's home, a visitor could not come in and change the TV channel, so why were caregivers doing this to residents? Caregivers should treat residents' areas as residents' homes (Lynch et al. 2018). *Loss of control*- All the participants wanted to stay in control to keep up with their daily schedule. The loss of control also stemmed from the fear of dependency (Spoorenberg et al. 2015).
Care providers' perspective on the model	*The negative perception of the working environment* - Staff expressed that they experienced stress in the work environment, and that affected the quality of implementing PCC (Elfstrand et al. 2017). Furthermore, this was where preconditions were perceived as inferior and stressing staff (Elfstrand et al. 2017). *Managers fear delegating certain tasks to team members* because they are unsure if they will adequately perform that activity. Some felt uncomfortable when they observed and saw that carers did not relate to older people during activities like feeding (Lynch et al. 2018). *Difficulty in balancing compliance* and person-centredness because compliance outweighed person-centredness because of the constant emphasis on paperwork (Lynch et al. 2018). *Ununited team leaders* with different leadership styles in the same household made it difficult to implement a person-centredness approach (Lynch et al. 2018). *Lack of understanding of the person-centred care model* (Turjamaa et al. 2015; Elfstrand et al. 2017; Lynch et al. 2018; Gudnadottir et al. 2019)

2.5 Discussion

The purpose of a systematic review was to conduct a cross-country exploration of the impact of the emergent homecare models on older people's well-being in the European Union. The question that was used was: "W*hat are the lived experiences of older people and perceptions of service providers on emergent models of homecare concerning the well-being of older people in the European Union?"*

2.5.1 The person-centred care approach as the emergent model

The present findings show that person-centred care is the emergent model of homecare (Tønnessen et al. 2011; Spoorenberg et al. 2015; Turjamaa et al. 2015; Elfstrand et al. 2017; Oude Engberink et al. 2017; Lynch et al. 2018; Gudnadottir et al. 2019). Even though person-centred care is seen as emergent, the concept was first introduced by Carl Rogers in 1961 in psychotherapy and counselling (Koubel and Bungay 2017). Koubel and Bungay (2017) state that person-centred care should be in the community. Correspondingly, Coulter and Oldham (2016) state that person-centred care means treating people as individuals and as equal partners in the business of healing; it is personalised, coordinated and enabling.

One of the themes demonstrated that still, to date, care providers do not understand the person-centred care model, and this impacts the successful implementation of person-centred care (Turjamaa et al. 2015; Elfstrand et al. 2017; Lynch et al. 2018; Gudnadottir et al. 2019). Killingback et al. (2022) also attest that challenges exist around how the concept of person-centredness is defined, operationalised, and implemented, with different professions focusing on different elements. On the other hand, literature shows that patient-centred care has been researched more in hospital and institutional care where it was disease-based (McCormack and McCance 2016; Kilpatrick et al. 2019; Jardien-Baboo et al. 2021; McCormack et al. 2021; Wade and House 2022).

Some practitioners are now developing guidelines and frameworks for person-centred care, which could eventually help implement the model (Jardien-Baboo et al. 2021; Killingback et al. 2022). Edvardsson (2015) understands person-centred care to be more than a set of techniques, skills or procedures. In addition, he also understands this to mean a personal way of approaching, connecting and partnering with people and families that builds on social and interpersonal ethics and skills as much as professional skills (Edvardsson 2015).

2.5.1.1 Care providers’ perceptions of person-centred care

Several confounding factors affect the successful implementation of person-centred care (Lynch et al. 2018). The themes concerning this were that managers fear delegating specific tasks to team members, and carers struggle to balance compliance and person-centredness (Lynch et al. 2018). Furthermore, ununited team leaders with different leadership styles in the same team affected the implementation of person-centred care (Lynch et al. 2018).

As a guide for countries to practise a person-centred approach, WHO (2015) developed in 2015 a WHO global strategy for people-centred and integrated health services and made recommendations for institutions. Certain researchers, like Herps et al. (2017), highlighted the challenges of measuring the degree of person-centredness in practice while there was little consensus about the definition of person-centred care. In addition, the argument was that the existing instruments were not developed in cooperation with the main stakeholders: clients, their relatives and professional caregivers. Similarly, Spoorenberg et al. (2015) piloted a patient-centred care approach, and older people who participated had difficulties reflecting on their experiences with the piloted approach. Spoorenberg et al. (2015) assumed that the difficulties of older people reflecting on their experiences with the piloted approach could have been due to frailty, memory problems, or their generation was not used to expressing their experiences and feelings.

The present review findings showed that care providers did not understand what person-centred care meant and had difficulty implementing it. Therefore, it does not come as a surprise that older people could not reflect on their patient-centred care experiences (Spoorenberg et al. 2015; WHO 2015; Herps et al. 2017; Lynch et al. 2018; Killingback et al. 2022). Edvardsson (2015) contends that the applicability of person-centred care may also threaten the aggregation of knowledge and conceptual consistency if not carefully attended to because it is based on subjectivity and individuality. His other concern was the rapid increase of publications based on various concepts such as person-centred, patient-centred, client-centred, consumer-oriented, person-oriented, et cetera, and understanding the extent to which these concepts remain comparable is also challenging (Edvardsson 2015). While person-centredness has become a widely-used term, it has led to confusion among many commentators, and the perception of person-centredness is that it is poorly defined, non-specific and overly generalised (Dewing and McCormack 2017). In their review of person-centred care, Harding et al. (2015) identified three fundamental concepts which are not mutually exclusive. These are:

1. Person-centred care is an overarching grouping of concepts, which include care based on shared decision-making, care planning, integrated care, patient information and self-management support (Harding et al. 2015).
2. Person-centred care emphasising personhood: people being immersed in their context and a person as a discrete human being (Harding et al. 2015).
3. Person-centred care as a partnership: care imbued with mutuality, trust, collaboration, and a therapeutic relationship (Harding et al. 2015).

2.5.1.2 Older people’s experience of person-centred care

The present systematic review findings revealed some themes regarding older people’s experiences of person-centred care (Edvardsson 2015; Spoorenberg et al. 2015; Herps et al. 2017; Lynch et al. 2018). Findings showed that different stakeholders did not fully understand person-centred care, leading to inconsistent implementation (Edvardsson 2015; Spoorenberg et al. 2015; Herps et al. 2017; Lynch et al. 2018). The themes that came up were:

2.5.1.2.1 Older people experience anxiety

Older people experienced anxiety because they were less satisfied with their home and nursing home care (Elfstrand et al. 2017). The pressure on homecare nursing has increased in recent years because of a reorganisation of healthcare systems focused on discharging people early from hospitals with more complex healthcare needs and supporting them at home (Martinsen et al. 2018; Phelan et al. 2018). As a result, more older people lived at home with multiple ailments, yet literature showed that most carers who spent more time with older people had insufficient training and knowledge to assist older people in their homecare effectively (Smith et al. 2019).

At the same time, nurses working in homecare were skilled and could provide care ranging from basic to advanced levels and including complex procedures in older people’s homes (Martinsen et al. 2018; Fjørtoft et al. 2021). While nurses were skilled and efficient professionals, there were some problems with unskilled carers who spent more time with older people in homecare (Fjørtoft et al. 2021). Carers have expressed challenges in understanding care plans for older people since a healthcare professional or homecare organisation manager designed care plans. As a result, carers failed to meet the needs of older people (Smith et al. 2019; Fjørtoft et al. 2021). In this case, it meant that for carers to contribute meaningfully to critical and complex ailments of older people in their homecare, it is crucial to upskill them so that even their reporting to the professional could be of a quality to benefit an older person (Jansen et al. 2017). Furthermore, carers and nurses were not the only care providers. Older people receive services from living in homecare since multiple care providers also contribute towards the care of older people (Hamiduzzaman et al. 2022).

Likewise, McCormack et al. (2021) pointed out that it was difficult to ascertain whether stakeholders understood person-centredness and talked about the same thing. They posited that health professionals did not have a shared language because they referred to the model using different terms, such as person-centred care, patient-centred care or client-centred (McCormack et al. 2021). However, stakeholders needed to accept the fuzzy nature of person-centredness and instead focus on using a constellation of multiple ideas which could be used to critically guide practice (Pluut 2016; Aittokallio and Rajala 2020; Killingback et al. 2022). Developing person-centred cultures in organisations requires a sustained commitment to practice development, service improvement and ways of working that embrace continuous feedback, reflection and engagement methods that enable all voices to be heard (McCormack and McCance 2016).

2.5.1.2.2 Unmet care needs

Unmet care needs were another theme because older people’s care services were rationed and prioritised by carers due to staff shortage (Tønnessen et al. 2011; Turjamaa et al. 2015). In particular, current homecare service is primarily thought to be task-oriented with a limited focus on the involvement of older people (Bölenius et al. 2017). The participants did not fully understand the organisation of the care and support they received from the homecare services. However, they adapted to the service without asking for changes based on their needs or desires (Hoel et al. 2021). Although person-centred care is recommended, older people experience tiny inclusion in defining the service they received, and it was perceived as unclear how they could participate in shared decision-making (Hoel et al. 2021).

Studies show that a lack of involvement might reduce older people’s quality of life (Bölenius et al. 2017). Person-centred care has been believed to improve satisfaction with care and quality of life in older people cared for in hospitals and nursing homes, with limited published evidence about the effects and meanings of person-centred interventions in homecare services for older people (Bölenius et al. 2017). Some managers had identified that some carers did not relate well nor engage older people when they carried out care activities, and with managers who mentored and guided carers on a person-centred approach, they became better (Lynch et al. 2018).

Similarly, São José (2020) expressed that how homecare encounters were forged depended on the care settings' conditions and the older people's actions. Person-centred care focuses on the person’s autonomy, values, and care needs, which encourages older people’s participation (Corlin and Kazemi 2020; Sanerma et al. 2020). However, literature still shows that care providers decide what they consider essential care, prioritising care for older people, leading to unmet needs for older people (Tønnessen et al. 2011). On the other hand, immediate care workers who are engaged daily in defining older people’s needs have no formal influence on the care decisions of an older person (Söderberg and Melin Emilsson 2022); Smith et al. 2019; Fjørtoft et al. 2021)

2.5.1.2.3 Lack of consultation by care providers

Lack of consultation by care providers – older people were concerned that carers did not consult when doing certain activities for older people (Lynch et al. 2018). Some older people experienced little shared decision-making in the services they received, even though participation is essential to person-centred care (Hoel et al. 2021). Older people were not always forthcoming in expressing their needs and wishes about purposeful activities to staff because they believed one should not be burdensome or create additional work for others (Owen et al. 2021). The lack of older people's forthcoming in expressing their needs requires care providers to offer older people opportunities to participate in meaningful activities regularly (Owen et al. 2021). Older people became happy with communication in areas where enhanced homecare was piloted because older people reported more communication between the carers and older people, even though care providers pre-planned care activities (Drennan et al. 2018b).

It is believed that exceptions and pockets of person-centred practice appeared in other fields of practice, as found in private mental health services using Rogers' person-centred therapeutic approaches (Rogers 1961; McCormack et al. 2015). On the other hand, there is no evidence that these teams have a specific framework to direct person-centred practice (McCormack et al. 2015). Care providers reported that there was little time to dedicate to person-centred care because they reported that risk assessments and predetermined electronic documentation systems take over (McCormack et al. 2015). Carl Rogers, an American psychologist, created the notion of person-centeredness in the early 1940s (Rogers 1961; Morgan and Yoder 2011)

The principles of his theory were that each individual possesses considerable qualities, can draw strength from available resources, and can find a way to remedy difficulties (Rogers 1961; Morgan and Yoder 2011). The practice of person-centred care depends on the setting in which care is provided, which creates confusion and affects the implementation of person-centred care practices (Morgan and Yoder 2011). In instances where managers mentored carers to implement person-centred care successfully and effectively, carers highlighted that inspection and regulation authority requirements interfered with the effective implementation of person-centred care since they needed to fill in required checklists and papers (Lynch et al. 2018).

This highlights that despite person-centred care being meant to increase the autonomy and participation of older people, there is still a top-down approach in decision-making and in-care design which makes older people to remain as recipients (Spoorenberg et al. 2015; Turjamaa et al. 2015; Drennan et al. 2018b) In addition, findings of the present systematic review demonstrate that the person-centred care models that were piloted were designed or developed without contribution from older people (Spoorenberg et al. 2015; Turjamaa et al. 2015; Drennan et al. 2018b).

Also, literature shows that staff with low emotional stability were more vulnerable to stress, affecting the quality of implementing person-centred care (Elfstrand et al. 2017). While on the other hand, literature shows links between home carers' low health literacy level and poor health outcomes (Palesy and Jakimowicz 2020). Lack of literacy could cause a low quality of homecare, making older people experience unmet needs, anxiety, and lack of consultation and respect (Lynch et al. 2018; Smith et al. 2019; Palesy and Jakimowicz 2020; Fjørtoft et al. 2021).

2.5.1.2.4 Lack of respect for an older person's boundaries

Older people felt that carers did not respect the territories of older people who lived in the residential home (Lynch et al. 2018). Older people reported that a visitor could not come in and change the TV channel in their homes. However, the caregivers changed the TV for residents without consulting older people. Older people felt disrespected due to caregivers' lack of consultations (Lynch et al. 2018). A care home typically refers to a location where an individual lives continuously in a community with other residents and receives care and support (Emmer De Albuquerque Green et al. 2022). Several older people consider moving to a care home not easy because older people find it challenging to maintain their independence and be helpful to those around them when in care homes (Man-Ging et al. 2019; Hay et al. 2020).

Literature has shown the importance of engaging older people to participate in decision-making and that it should be done respectfully (Hay et al. 2020). Older people should have a choice to participate to avoid potential coercion by staff or care partners verbally or physically, hence making older people feel pressured to engage in facility programs and also feeling disrespected (Hay et al. 2020). To work towards an increased person-centred care process within elderly care to ensure inclusion and respect for older people, policymakers and organisational leaders need to recognise that care staff is working in a context where personality traits matter (Elfstrand et al. 2017). Caregivers should treat residents' areas as residents' homes (Lynch et al. 2018). Care, home Managers, need to consider the atmosphere in nursing homes, that they develop a caring culture for the provision of holistic care to older people and make the nursing home as close to home as possible (Vaismoradi et al. 2016).

2.5.1.2.5 Fear of loss of control

All participants wanted to stay in control to keep up with their daily schedule, but the loss of control also stemmed from the fear of dependency (Spoorenberg et al. 2015). The literature demonstrates that older people consider the ability to live independently and safely an essential factor for their quality of life in their advancing years (Zander et al. 2020). At the same time, older people living with complex chronic illnesses require complex care; to date, conceptualisations of complex care for older people are based primarily on biomedical models, whereby most definitions of complex care emphasise chronic care management, such as medical care and nursing tasks (Johnson and Bacsu 2018). It is, therefore, important that when defining complex care, the continuum of care needs from both the biomedical and the social determinants of health perspectives are considered, as well as the integration and coordination of care required to address older people's needs across multiple levels such as policy, practice, community, and family (Johnson and Bacsu 2018).

It has become evident that the possibility for older people to live independently and safely is a high priority in some countries (Zander et al. 2020). Several studies show that homecare models are developed to improve chronic disease outcomes and reduce management costs, without focusing on the well-being and dignity of an older person (Hartman et al. 2009; Coburn et al. 2012; Barzel et al. 2013; Alvarez et al. 2017; Almalki et al. 2018; Baird and Fraser 2018). People-centred and integrated health services should not be regarded as a new model of service delivery with a set of core components, but as a service design principle that can help to support and improve strategies that seek to enhance access, encourage universal health coverage, and encourage primary and community-based care (WHO 2015).

In summary, it is clear that the homecare models are designed by care providers from different areas in health or hospital institutions, Outpatient Clinics, communities, municipalities, and social care and unprofessional carers (Genet et al. 2012; Bone et al. 2016; Vaismoradi et al. 2016; Elfstrand Corlin et al. 2017; Lynch et al. 2018), and this is because of the health care system that has primarily been built on the medical reductionist model of disease, which has resulted in the specialisation and fragmentation of services as well as authoritative professionals who prioritise treatment, care, and service provision (Ruggiano and Edvardsson 2013).

2.6 Conclusion

The conclusion of the systematic review starts by highlighting the aim of the systematic review and the question applied to conduct the systematic review. The systematic review was conducted on a cross-country exploration of the impact of the emergent homecare models on older people’s well-being in the European Union. The question that was applied to conduct the systematic review was “What are the lived experiences of older people and perceptions of service providers on emergent models of homecare concerning the well-being of older people in the European Union?”

The analysis showed that the person-centred care model was identified as the emergent care model in homecare. According to Morgan and Yoder (2011), the term person-centred care was frequently used in the literature, nonetheless, there was no consensus about its meaning, and again, the concept was vague. The person-centred care model was developed to improve the person’s involvement in their care. However, the gaps identified were that the person-centred care model was based on improving disease outcomes, reducing costs, and improving care providers’ working conditions (Tønnessen et al. 2011; Spoorenberg et al. 2015; Turjamaa et al. 2015; Elfstrand et al. 2017; Oude Engberink et al. 2017; Lynch et al. 2018; Gudnadottir et al. 2019). The model was not based on improving the well-being of a person of older people. Older people experience anxiety, lack of consultation, lack of respect, fear of loss of control and unmet care needs despite receiving care under person-centred care (Elfstrand et al. 2017; Lynch et al. 2018; Hay et al. 2020; Hoel et al. 2021). During evaluations of health care outcome, the literature was silent on well-being and dignity but focused on the disease outcomes and costs expenditures and how care providers could improve their working environment (Spoorenberg et al. 2016; Drennan et al. 2018b; Lynch et al. 2018). Older people's well-being concerning dignity, respect and humane care was not evaluated, as some literature indicates that well-being cannot be measured (Spoorenberg et al. 2016).

Stakeholders interpreted and understood person-centred care differently (Edvardsson 2015; Herps et al. 2017). The literature did not show the engagement of older people in developing this model; again, the model was also not interpreted or understood in the same way by users (Spoorenberg et al. 2015; Turjamaa et al. 2015; Drennan et al. 2018b; Hoel et al. 2021).

The gaps identified were that older people lacked participation and consultation during person-centred care and still experienced unmet care needs, anxiety, lack of respect, and fear of losing control (Elfstrand et al. 2017; Lynch et al. 2018; Hay et al. 2020; Hoel et al. 2021). As a result of the gaps identified from the systematic review, a qualitative methodology with a participatory research approach was adopted to ensure that the older people's voices led the research and findings.

The following section, 2.7, explores literature about participatory research with older people because a participatory research approach could help older people's roles to change from being passive homecare recipients to being more active, autonomous and involved in their homecare (Kerr et al. 2020; Segevall et al. 2021).

2.7 Literature review- involvement of older people in participatory research

This section explores the involvement of older people in the participatory research approach. The barriers to the involvement of older people in research were explored, and it helped in understanding factors to consider when doing participatory research with older people, such as to what extent older people are involved in participatory research.

Participatory research methods are problematic to explain because they are interconnected and because individual researchers use their disciplinary backgrounds and understanding to shape approaches to their specific context (Brown 2022). Participatory research is regarded as political and activist because it is considered that it cannot provide scholarly enlightenment but practical outcomes and actions (Selener 1997). The literature shows that the participatory research method has been explored more in schools, educational programmes and social research in arts, but not in the health and care sectors (Rix et al. 2021; Seale et al. 2021).

A participatory research approach could help older people's roles change from being passive homecare recipients to becoming more active, autonomous and involved (Kerr et al. 2020; Segevall et al. 2021). On a similar note, the person-centred care model was meant to engage older people, however, the literature showed that older people criticized the lack of involvement in decision-making during homecare (Lynch et al. 2018). According to McCormack (2003), ageism is also a cause of the lack of involving older people because of the assumption that older people cannot participate in research or other decision-making processes because getting older certainly leads to reduced capacity for involvement. Other factors that lead to the exclusion of older people from participation are age, gender, ethnicity, sexuality and disability (Ogrin et al. 2020).

Users' participation is advocated because it facilitates respecting citizens' rights, supports care ethics, and upholds service users' acceptability and accessibility (Cook and Klein 2005; Jorge et al. 2019). Similarly, older people believe that person-centred goal-setting would be better supported by providers who take time to see beyond age, engage in relational communication, facilitate participatory goal setting and collaborate more effectively (Giosa et al. 2022). It is essential to realise that Dizon et al. (2020) demonstrate that during a consultative phase of policy-making, there is a need to engage with diverse older people and to use participatory methods.

Participation is a broad concept that is interchangeably used with involvement, engagement and collaboration (Snyder and Engström 2016). Participation refers to participating in everything that enables people to influence decision-making processes and get involved in the actions that affect their lives (Casado et al. 2020). Participatory research actively engages participants in some or all stages of the research process (Mey and van Hoven 2019). By involving older people in the participatory research process, older people are potentially given a voice in debates on relevant issues to influence decisions and negotiate a change (Mey and van Hoven 2019) in the type of homecare older people want. It is essential to collaborate with older people to know what matters to them in their homecare (Galvin et al. 2020).

The participatory approach in the current thesis intends to facilitate communicative spaces to develop a democratic communicative approach to power instead of a top-down approach (Righi et al. 2018; Abma et al. 2019; Mey and van Hoven 2019). Participation in research with older people can be done through collaboration, discussions and dialogues (Mayan and Daum 2016; Schubotz 2020). When Martin Buber, the philosopher, talked about discussion and dialogue, he said it was not “you” and “I” in communication, but something that was being created together in the space between those who discuss and which the two responded to or contributed to (Friedman 2002). He called the created thing the interpersonal world. Buber tried to teach people how powerful they were during the discussion or dialogue and stressed that dialogues became even more effective when people in the dialogues were open-minded and saw the other as a subject and not as an object (Friedman 2002).

Comparatively, Paul Ricoeur, the philosopher, said that the only way to achieve some form of knowledge is to come to that knowledge through discussion or dialogue because when one comes to knowledge without dialogue, one would only have one perspective of that knowledge (Saorsa 2011). In the present research, older people were approached to collaborate, discuss and dialogue on homecare, subsequently co-producing future homecare concepts and principles.

The literature generally shows a need to involve older people in a participatory research approach (Pappne Demecs and Miller 2019) to discuss treatment options (Casado et al. 2020). The concern shown by the literature is that the diversity in interpreting participation might lead to challenges in the participation of older people since workers, relatives, or older people understand it differently (Casado et al. 2020). However, there is a need to manage expectations in participatory research involving older people (Branco et al. 2017; Mey and van Hoven 2019) since older people may choose not to participate more fully in the research (Pain and Francis 2003). As a way of strengthening older people's participation, involving them in some of the research processes makes participatory research produce inclusive knowledge without overwhelming older people since participatory research is flexible (Pain and Francis 2003; Mey and van Hoven 2019).

Following the literature on participatory research with older people, the use of technology by older people concerning online participation was explored.

2.8 Exploring older people’s participation in the use of technology

The following section explores older people’s participation in the use of technology to understand which technology older people use to participate in online activities. In 2010, one researcher, Mukherjee (2010), explored older people’s engagement in virtual volunteerism, using the internet to volunteer partially or totally from their homes or off-site locations. In Mukherjee (2010) research, only two females of the 9 participants volunteered, which might reflect that fewer women were engaged in technology. Furthermore, according to Mukherjee (2010), people were motivated to participate in virtual volunteerism to see their volunteering efforts making a difference in someone else’s life. Furthermore, Mukherjee (2010) concluded that virtual volunteering bridged the distance to volunteering sites, facilitated positive health behaviour among older participants and that older people should be assisted with increased access to the internet.

Recent research shows that digitalisation is both an opportunity and a challenge for individuals, communities, and societies (Fischl et al. 2020). Even though older people are increasingly using digital technology, those with multiple morbidities and functional impairment or advanced old age cannot keep up with smartphones that could give access to the internet (Schlomann et al. 2020). Moreover, as a result, older people are more likely to be excluded from digital services because they do not use the internet or lack the necessary devices or experience to use technology (Goldman et al. 2022).

Integrating digital technology services into society is believed to provide opportunities for older people to achieve good and equitable health and welfare, as well as independence and participation in community living (Fischl et al. 2020). While there is a need to train older people in the use of technology, there is also a need for advocacy to increase access to digital technology by older people since it would benefit the health and well-being of older people (Gibson et al. 2020a).

The unevenness of digital access and literacy across the older demographic is problematic for an increasingly digital society, where vital services are accessed through online accounts and interfaces, leading to inequalities in access to information resources and services (Bossio and McCosker 2021). According to Layng (2016, p.177), virtual communication is the simulated process of people exchanging information using computers or the Internet. Layng (2016, p.177) defined virtual as “very close to being something without actually being it or existing/occurring on computers or the Internet” and defined communication as “the act or process of using words, sounds, signs, or behaviours to express or exchange information or to express your ideas, thoughts, feelings, etc., to someone else.”

Of late, the Covid-19 pandemic has disrupted healthcare delivery to vulnerable older people, prompting the expansion of telemedicine usage (Tan et al. 2022). According to Tan et al. (2022) virtual consultations appear acceptable to older people. This acceptance is dependent on the older person’s possession of an electronic device, the living arrangements of the older person, and the perceived familiarity with virtual platforms (Tan et al. 2022). Terason et al. (2022) believe that virtual communication will be with us for a long time, and exploring ways in which older people can use this tool efficiently to prepare for the future is needed. The purpose of exploring the use of virtual technology by older people was to understand the capability of older people to use technology and then choose the digital method that older people are familiar with during recruitment and data collection in the current participatory research.

Video conferencing via Skype is one digital technology that has been popular in the last decade and used in job interviews (Nehls et al. 2015). Still, for some older people, it showed that using video conference tools like Skype could be challenging due to physical frailty and cognitive decline (Moyle et al. 2020). Another challenge in using virtual communication by older people is that nonverbal communication between people can be challenging to interpret in video conferences, leading to cognitive overload and confusion (Terason et al. 2022). According to Fischl et al. (2020) some older people need help primarily with moving within the virtual environment and using the tools and commands.

Literature shows that as the use of digital technology becomes more widespread globally, older people remain among the group with the lowest access and usage (Ekoh et al. 2021). In addition, communication technology and availability among older people are lacking (Moyle et al. 2018). Some older people also experience exclusion from digital technology because of not having digital devices and the internet because of low income (Gibson et al. 2020a). Ekoh et al. (2021) believe that the Covid 19 pandemic could lead to a digital divide and double exclusion since older people have social distancing guidelines and cannot use digital technology.

However, it is also believed that sometimes technology tools are rejected by certain members of society (Terason et al. 2022). At the same time, video conferencing is an unfamiliar technology for many older people and, as a result, older people might require assistance in using this technology (Moyle et al. 2020). Nonetheless, online conferences are believed to reduce the need to travel, can be held at any time and reduce the need for food (Terason et al. 2022).

The literature shows that even though more organisations used video conferencing for their meetings during Covid-19 (Terason et al. 2022), no literature shows the use of virtual communication as a data collection tool in participatory research with older people. Others believe that video conferencing on iPads is inhibited by age-related cognitive decline and physical frailty (Moyle et al. 2020). However, older people's engagement with digital technology remains largely under-researched (Damant et al. 2017), and more attention should be given to virtual communication as a data collection research instrument.

During systematic review and literature reviews, concepts about homecare and participation, which had various interpretations, were identified, and these concepts would be clarified concerning the present study. The next section explores key concepts and definitions in this thesis.

2.8.1 Definition of concepts

The construction of concepts concerning the research topic could be done during the literature review (Subramaniam 2022). Conceptual definitions are important because they present the meaning of the studied concepts (Polit and Beck 2020). Furthermore, concepts capture, elicit and represent the interpretation of perceptive structures and meaning-making in the research, even though in qualitative research, concepts come from the findings (Subramaniam and Esprívalo Harrell 2015; Polit and Beck 2020). The systematic review showed that the following concepts, homecare, dignity in homecare and well-being in homecare were conceptualised or interpreted differently (Rehnsfeldt et al. 2014; Rosa et al. 2017; García-Sánchez et al. 2019; Simões and Sapeta 2019; Kabadayi et al. 2020).

2.8.1.1 Homecare

Residing in a home and community is the desired choice for older people as they would like to live the rest of their lives in the comfort of their homes (Kelley 2022). In addition, older people tend to want to live in the community because of the familiarity and history of the environment (Kelley 2022). According to Lämås (2020), self-determination and social relationships are essential for older people's thriving when receiving homecare services. Living with multi-morbidity is always challenging because of its association with poor health outcomes such as frailty, disability, mortality, poor quality of life, and increased care costs (Boehmer et al. 2018).

Homecare is care provided for older people who cannot fully care for themselves at home or their residential address, and with or without formally assessed needs that include personal care, rehabilitative, supportive and technical nursing care, domestic aid as well as respite care provided to informal caregivers as adopted and modified from (Fagerström et al. 2011). Homecare includes a range of services designed to enable older people to function within the community, reduce hospitalizations, and provide an alternative to long-term institutional care (Pepin et al. 2017).

Assessing the quality of life among older people living at home has been criticized for being too focused on health-related factors and for not taking into account the complex factors that are important when living at home with declining health (Vanleerberghe, De Witte, Claes, Schalock, & Verté, 2017). Maximising care at home aims to improve the quality and appropriateness of care as part of rebalancing the focus away from institutional care to re-enablement (Rahman, 2017).

2.8.2 Dignity in homecare

Homecare for older people means that their physiological needs, and their psychological, social, and environmental needs, must be fully met when providing care in their home environment by either formal or informal carers (Van Houtven et al. 2020; Dostálová et al. 2021). Older people are from different ethnic backgrounds, religions, genders, and education levels, which could influence the older person's interpretation of dignity (Peterson and Brodin 2022). Similarly, Galvin and Todres (2015) described how intertwined and interrelated dignity founded from Heidegger’s lifeworld constituents was. The various types of dignity from the lifeworld constituents were spatial, temporal, embodied, interpersonal, identity, mood, and finitude (Galvin and Todres 2015). In comparison, the Swedish philosopher (Nordenfelt 2004) described four types of dignity (dignity as merit, dignity as moral stature, the dignity of identity, and the dignity of menschenwurde).

And when looking into the type of dignity described by Galvin and Todres (2015) and Nordenfelt (2004), dignity is about how one exists in the world as a Being. Moreover, how one relates to the environment, themselves, and others shows the complexity and depth of dignity. Older people in homecare are also at varying stages of ailments, leaving older people at different levels of vulnerability and requiring different care needs (Dostálová et al. 2021; Peterson and Brodin 2022). Nevertheless, in homecare environment, providers have trouble balancing compliance and person-centredness because compliance outweighs person-centredness, resulting in challenges in meeting older people’s care needs (Lynch et al. 2018). It would be interesting to see how dignity would emerge from older people’s discussions during this research and what it means for them even though, according to Galvin and Todres (2015), dignity is one complex concept reflected in various nuances that human beings refer to meaningfully.

The concept of dignity is recognised as a fundamental right in many countries. It is embedded into law and human rights legislation and is often visible in organisations' philosophy of care, particularly in aged care (Kane and de Vries 2017). However, older people still feel not respected and not included in making decisions in their homecare (Spoorenberg et al. 2015; Lynch et al. 2018). Harstäde et al. (2018, p.8) describe dignity as embracing a basic intrinsic aspect, including personal, subjective valuing of oneself, and an extrinsic dynamic aspect, including others’ valuing of oneself and the surrounding context. However, it shows that the articulation and interpretation of this dignity policy varies. There is also unawareness of the policy goals, while other care providers feel that the dignity policy has unreachable goals (Andersson and Sjölund 2020).

Some informal caregivers state that their lack of giving homecare that is dignified is due to inadequate knowledge about the care job (Voogd et al. 2021). As a result, they want health professionals to take them seriously in their caring role by keeping them informed, helping them build skills in providing good care, and ensuring education about care and the patient’s disease (Voogd et al. 2021).

Dignity in homecare is fragmented by the ailments that challenge older people, observed by Ostaszkiewicz et al. (2020) that, although dignity is subjectively experienced, the critical attributes of dignity-protective continence care are privacy, respect, autonomy, empathy, trust, and communication in the caregiving encounter. Understanding the critical characteristics of dignity as perceived by older people could allow caregivers and healthcare professionals to challenge practices that violate dignity and identify caring opportunities for protecting the dignity of vulnerable and care-dependent older citizens (Ostaszkiewicz et al. 2020).

Many authors describe difficulties defining dignity and how it can be preserved for people living in long-term care (Kane and de Vries 2017). According to Bayer et al. (2005), substantial agreement about the meaning and experience of dignity in older people's everyday lives can be considered a relevant and critical concept, enhancing self-esteem, self-worth and well-being (Bayer et al. 2005). The study done by (Jakobsen and Sørlie 2010) found the balance between the ideal, autonomy and dignity to be a daily problem.

2.8.3 Well-being in homecare

Literature shows researchers disagree on what constitutes well-being (Goodman et al. 2018). Although professionals and policymakers embrace well-being, its definition is unresolved and still holds an ambiguous meaning, and various conceptions of it exist despite considerable attention devoted to it (Prys and Matthews 2022). According to Minucciani and Saglar Onay (2020), well-being is related to many factors, including everything from physical health, psychological state, level of independence, family, education, wealth, religious beliefs, a sense of optimism, local services and transport, employment, social relationships, housing and the environment. Well-being is multidimensional and deep, highly complex, and vast and it also provides an alternative that has had substantial influence in developing a post-humanistic position that has the potential to bear fruit in ecological, urban, psychological and other fields (Galvin 2018). It can be looked into from the psychological or existential viewpoint, as explained by (Galvin 2018; Wood 2020).

Older people live with multiple ailments and exploring the type of future homecare they want could help understand the well-being of older people. According to van Deurzen et al. (2019, p.2), people’s contextual lived worlds beyond the consulting room and the here-and-now feelings might illuminate their more expansive world of past experiences, current events, and future expectations. Furthermore, van Deurzen et al. (2019, p.2) attest that all human experience is intrinsically inseparable from the ground of existence, or being in the world, in which we constantly and inescapably participate. According to Hemingway et al. (2015), how people relate to their environment and the kind of that environment can have a positive or negative impact on their well-being.

2.9 Lifeworld-led well-being theoretical framework

Previous research on homecare services has focused more on health outcomes, such as mortality, hospitalisations and health-related quality of life (Hsieh and Kenagy 2020). Nevertheless, satisfaction with health only partially mediated satisfaction with homecare services (Kadowaki et al. 2015). The lifeworld-led well-being and suffering theory of Galvin and Todres (2013) was considered to be suitable for discussing findings because it could explore the suffering and potential well-being expressed by older people concerning homecare. It is essential to realise that the use of the lifeworld-led well-being theory of Galvin and Todres (2013) in discussing the findings in a participatory research approach in homecare has not been previously explored in the discussions of the findings. Only constituencies of the theory confirmed by the findings would be applied for the present discussion.

2.9.1 Lifeworld-led well-being and suffering theory

The lifeworld-led well-being theory framework of Galvin and Todres (2013) shows that failure to meet any of the constituents of well-being may make people experience suffering. The lifeworld refers to the everyday existence in and through which people live (Husserl, 1970/1936). According to Galvin and Todres (2011), the lifeworld-led approach concerning care provides ways to describe health-related conditions and needs more complexly than conventional medical and diagnostic descriptions of health and illness. The lived experience, as described by van Manen (1997), refers to experiencing the world while living it. Norlyk, Martinsen and Dahlberg (2013) report that the lifeworld forms the foundation of understanding humans, their lives, health, suffering, and well-being. Furthermore, they believe that humans can never be fully understood without considering their lifeworld (Norlyk, Martinsen and Dahlberg, 2013).

Galvin and Todres (2013) discussed their theory using the constituents of the lifeworld, such as: spatiality, temporality, inter-subjectivity, mood, identity and embodiment, to come up with 18 different kinds of well-beings which are intertwined and interrelated but were meant to give directional power that well-being inductive data-driven coding of themes during analysis enabled analysis to be purely informed by the data rather than a theory (Proudfoot 2022). The themes and subthemes developed from the data showed the suffering and well-being of older people in the constituency of lifeworld-led well-being of dwelling-well-being and dwelling suffering, which inspired me to use some of its concepts during the discussion section.

The table below shows the six constituents of the lifeworld-led dwelling well-being and suffering theory by Galvin and Todres (2013), which were found to be relevant to discuss the results of the current study.

Table 2-8 Constituents of lifeworld-led dwelling well-being and suffering theory by Galvin and Todres (2013)

	Dwelling Well-being	**Dwelling-Suffering**
SPATIALITY	At- homeness	Exiled
TEMPORALITY	Present centredness	Elusive present
INTER-SUBJECTIVITY	Kinship and belonging	Alienated Isolation
MOOD	Peacefulness	Agitation
IDENTITY	I am	I am an object or a thing
EMBODIMENT	Comfort	Bodily discomfort or pain

Galvin and Todres (2013) indicate that well-being is the essence of being in the world and how it feels to be in the world. Galvin and Todres (2013) state that individual bodies know what well-being is, and we can recognise it in different forms or its absence in suffering. At the same time, Hemingway (2013) attested that the perspective on well-being moves away from separating well-being into social, economic, political, physical and mental and focuses on people as healthcare consumers.

The following section from 2.9.1.1 to 2.9.2.6 is an overview of the lifeworld-led dwelling-well-being and suffering theory of Galvin and Todres. The theory would be used to discuss the research findings.

2.9.1.1 Spatiality dwelling: At-homeness

In spatiality- dwelling at-homeness means a sense of being at home, whereby a person feels stillness in their environment in valued or wanted ways (Galvin and Todres, 2013). Galvin and Todres (2013) believe that a sense of at-homeness also happens because people have their belongings around them to connect to their familiar sense of place and belonging. Nonetheless, when a person is taken to an institution, they might feel alienated and dislocated (Galvin and Todres, 2013).

2.9.1.2 Temporality dwelling: present centredness

Galvin and Todres (2013) indicate a well-being experience that emphasises present-centredness in temporality dwelling as when a person is absorbed in the present moment and is tuned into a temporal focus that offers oneness (Galvin and Todres, 2013). In addition, one senses intimacy, belonging, or a deep connection with what is happening in valued or wanted ways.

2.9.1.3 Intersubjective dwelling: kinship and belonging

In Intersubjective dwelling, Galvin and Todres (2013) believe that an interpersonal well-being experience emphasises a sense of kinship and belonging because a person feels at home with another or others. They further state that it is where a person feels an interpersonal connection from relaxed ways of meeting that makes a person feel they belong (Galvin and Todres, 2013). Well-being is a sense of kinship and belonging that occurs when one can find at-homeness with others and feel security and togetherness where there is a sense of, we and not “I” and “you” (Galvin and Todres, 2013).

2.9.1.4 Mood dwelling: peacefulness

Galvin and Todres (2013) highlight a well-being experience that emphasises the mood of peacefulness, which they express a lot about the mood that has the qualities of stillness, settledness, or reconciliation. Galvin and Todres (2013) state that one feels peaceful when they are fulfilled by completing a task or responsibility requiring commitment or effort.

2.9.1.5 Identity dwelling: I am

According to Galvin and Todres (2013), the well-being experience in touch with one’s sense of personal identity is when one experiences a sense of I am. During this time, one experiences a sense of historical support and contexts that are continuous with one’s sense of self and are not questioned or at stake (Galvin and Todres, 2013). They state that the “I am” is experienced as a familiar continuity, a sense of effortless connectedness, a certain peacefulness, and a lack of dilemma of who and what I am (Galvin and Todres, 2013). Moreover, they explain that the I am that a person feels is not I am this, or I am that, which is often objectified, but it is the feeling of being at home with oneself (Galvin and Todres, 2013).

2.9.1.6 Embodiment dwelling: comfort

According to Galvin and Todres (2013), embodiment dwelling is a well-being experience whereby one is in touch with one’s sense of comfort as a body experience. In this state, a person feels a sense of body warmth when body comfort is felt, and they also feel relaxed, still, satiated or rooted (Galvin and Todres, 2013).

2.9.2 Suffering lifeworld-led theory

2.9.2.1 Dwelling suffering in the spatial dimension: exiled

There is a sense of spatial exile in spatial dwelling suffering, whereby a person may feel cast out and left in an inhospitable or unfamiliar space with limited chance for relief (Galvin and Todres, 2013). When a person is placed in this kind of place, they may feel separated, estrangement, alienation, or far from home with a painful longing (Galvin and Todres, 2013). For example, some people may not feel at home in an institution, making it impossible to settle (Galvin and Todres, 2013).

2.9.2.2 Dwelling suffering in the temporal dimension: elusive present

According to Galvin and Todres (2013), suffering emphasises a sense of temporal unsettledness, whereby a person cannot be in the present but is somewhat pulled to the future or the past. Some people live with anxiety and restlessness because they are so focused on the future that they hardly get to relax (Galvin and Todres, 2013). Galvin and Todres (2013) describe that this is seen more where the time tick-tock has become persecutory and findings in the core existential dilemma of life passing oneself by. It makes one feel like there was no good time to be there, living with the experience of numbness, restlessness, ambivalence to extreme anguish (Galvin and Todres, 2013).

2.9.2.3 Dwelling suffering in the intersubjective dimension: Alienated isolation

According to Galvin and Todres (2013), interpersonal suffering emphasises the experience of alienation and isolation, where one feels lonelier as they are uninvited or excluded from interpersonal connections. This is whereby one’s kinship and belonging are broken in various ways and to the degree that one feels cast out, exiled and forced to roam far away from the interpersonal warmth of other people (Galvin and Todres, 2013). In this case, one can feel like a stranger or foreigner in a room full of people because they feel cast out from meaningful engagement, left out or wronged (Galvin and Todres, 2013). Furthermore, a person can feel inhospitable, isolated, lacking in belonging, and unwanted (Galvin and Todres, 2013).

2.9.2.4 Dwelling suffering in mood: Agitation

Galvin and Todres (2013) highlight a form of suffering that emphasises the mood of unsettled restlessness, whereby agitation is characterised by anxiety, irritation, and disturbance with a feeling that something is wrong. Galvin and Todres (2013) further indicate that when one has this feeling, one wants the current circumstances to change, be different and stabilise. In this state, one feels like they are fighting the outside world, creating an unpleasant fit between oneself and the world. It is also indicated that the person never feels at home during this state because of anxiety.

2.9.2.5 Dwelling suffering in the identity dimension: I am an object or a thing

Galvin and Todres (2013) highlight a form of suffering in which the self or others identify one as a thing or an object. It is experienced when one is judged, forcefully or subtly, being told the kind of person he should become. Being judged forcefully or subtly and being told the kind of person one should become make one feel the anxiety of being turned into something or someone because inwardly, one feels like they could scream for being deformed, having soul murder or soul suicide (Galvin and Todres, 2013). Galvin and Todres (2013) also indicate that this can happen from self-sabotage, whereby an individual may feel lost or unreal. Furthermore, loss of identity is because they feel nothing more than what is being measured or how it is measured or compared. In some cases, one is identified by the disease they suffer from or their health system, which makes them more categorised and statistics because of their injuries or the pains they experience than people (Galvin and Todres, 2013).

2.9.2.6 Dwelling suffering in the embodied dimension: bodily discomfort and pain

According to Galvin and Todres (2013), physical suffering is characterised by bodily discomfort, pain and a sense that something is wrong as the body will be in a state that signals that certain parts are not okay, making it difficult for one to feel at home. The suffering is often experienced in different ways, such as itchiness, tenderness, irritation, nausea, dizziness and many others. When one experiences this discomfort, their projects are interrupted, while on the other hand, the feeling of pain and discomfort is difficult to measure or differentiate (Galvin and Todres, 2013). Still, the pain can become so overwhelming that deep protective strategies of the body are lost, and consciousness is lost (Galvin and Todres, 2013).

Having understood Todres and Galvin’s lifeworld well-being theory, the next chapter will discuss methodology. The methodology chapter will begin with the philosophical assumptions/ or paradigms for the participatory research approach.

The next chapter presents the methodology to achieve the research aim and objectives.

Chapter 3 Methodology Chapter

This research aimed to explore older people's perceptions of future homecare and collaborate with older people to co-produce concepts and principles that should underpin future homecare delivery. Concepts are mental representations of perception or other domain-specific systems; concepts represent thought's representational elements (Quilty-Dunn 2021). According to Lloyd et al. (2011, p.4), concepts are ideas. For this thesis, concepts were labels, which gave meaning to older people's categorisation and interpretation of the future homecare phenomenon. Principles provide a basis for the rational development of a field of purposive endeavour and guide the conduct of its proceedings (Rescher 2013, p.72).

A systematic review influenced this research aim in chapter 2, which explored the impact of the emergent homecare models on the well-being of older people in the European Union through older people's lived experiences and care providers' perceptions. In the systematic review, the person-centred care model was found to be the emergent model of homecare, and it was developed to improve a person's involvement in their care (Tønnessen et al. 2011; Spoorenberg et al. 2015; Turjamaa et al. 2015; Elfstrand et al. 2017; Oude Engberink et al. 2017; Lynch et al. 2018; Gudnadottir et al. 2019). The literature gaps identified were that the model focused on disease outcomes, cost reductions, and improving care providers' working conditions (Elfstrand et al. 2017; Lynch et al. 2018; Hay et al. 2020; Hoel et al. 2021). The literature does not show a person-centred care model performed to focus on the well-being of older people. Older people still experience anxiety, lack of consultation, lack of respect, fear of loss of control and unmet homecare needs despite person-centred care (Elfstrand et al. 2017; Lynch et al. 2018; Hay et al. 2020; Hoel et al. 2021).

Some studies evidenced that when older people were not consulted in the decision-making, it made older people feel unsafe and a lack of control (Hemingway and Green 2013). As a result of the gaps identified from the systematic review in chapter 2, qualitative methodology with a participatory research approach was found suitable to ensure that older people's voices led the research and findings. In addition, it increased the participation and engagement of older people, which would help care providers understand the type of homecare older people would like.

The objectives of the present study were, therefore, to:

- Explore older people's perceptions of how they would like their future homecare delivered.
- To collaborate with older people to co-produce concepts and principles to underpin future homecare delivery.
- To explore older people's perceptions of the use of virtual communication as a tool for data collection in this participatory research approach.

The third objective was informed by the literature review that explored the use of technology by older people concerning online participatory research with older people. The literature revealed that virtual communication has not been explored as a data collection tool for online participatory research with older people. Since it was the Covid-19 pandemic, with no contact with older people, there were stay-at-home orders from the government (Valdez and Gubrium 2020). Data collection was done virtually with older people. It was believed that integrating digital technologies services into society could provide opportunities for older people to achieve excellent and equitable health and welfare, as well as independence and participation in community living (Fischl et al. 2020). On the other hand, it showed that communication technology and availability among older people was lacking (Moyle et al. 2018) because older people were often excluded from digital services because they did not use the internet or lacked the necessary devices or experience to use technology (Goldman et al. 2022). The gap identified in this literature review was that virtual communication as a data collection tool was not fully explored because researchers referred to face-to-face or in-person interviews as the golden standard (Nehls et al. 2015).

The next section explores a qualitative design and participatory approach's philosophical assumptions/paradigms.

3.1 Philosophical assumptions/paradigms

According to Creswell and Poth (2016), it is crucial to understand the philosophical assumptions underpinning qualitative research because they shape how researchers formulate their problem and research questions and how they seek the information to answer the questions. Additionally, philosophical assumptions such as ontology, epistemology, axiology and methodology are vital premises in qualitative research (Creswell and Poth (2016).

3.1.1 Ontological assumption

Ontology has long been the central issue for philosophers (Lehmann et al. 2014), and It studies being, existence, and reality (Jacquette 2002). Creswell and Poth (2016) indicate that ontology matters relate to the nature of reality and its characteristics, and they explain that qualitative researchers report multiple realities by reporting different perspectives as themes develop from the findings. Braun and Clarke (2013) indicate that individuals have multiple realities dependent on human interpretation and knowledge. This research means that older people's perspectives and opinions on future homecare will be reported from different themes and not be the same because of their different cultures, values, and backgrounds.

According to Goertz and Mahoney (2012), concept formation raises the issue of ontology because it involves specifying what is essential in the empirical phenomenon signified by a perception. Meanwhile, Woolgar and Lezaun (2013) state that more focus on ontology should be on how practices endorse ontology and the consequence of enactment in practice. The current systematic review showed that care providers enacted person-centred care differently (McCormack et al. 2021). For instance, Edvardsson (2015) contends that the applicability of person-centred care may threaten conceptual consistency because his concern is about the variety of concepts for person-centred and understanding the extent to which these concepts remain comparable was also challenging.

Different stakeholders' lack of complete understanding of person-centred care led to inconsistent implementation (Edvardsson 2015; Spoorenberg et al. 2015; Herps et al. 2017; Lynch et al. 2018). On the contrary, older people experienced anxiety because they were less satisfied with their homecare and not involved even though person-centred care was an emergent model of care (Bölenius et al. 2017; Lynch et al. 2018; Hay et al. 2020; Hoel et al. 2021).

In the present study, the question was: what could future homecare look like based on the perceptions of older people in the United Kingdom? And collaborate with older people to co-produce concepts and principles that should underpin homecare.

Literature showed that Jean-Paul Sartre advocated for participation because Sartre believed that the participation of people in decision-making was vital (Reynolds 2014; Sweeney 2016). He believed that enabling people to have the freedom to make choices brings dignity for people (Flynn 2006; Reynolds 2014). The ontological foundation of this thesis is with the assumption that humans are not determined but that their past, present and future influence them (Lemm 2014). The systematic review showed that older people in care felt they had no control over their care due to a lack of participation.

Clarke and Braun (2021) specify that individuals have multiple realities dependent on human interpretation and knowledge. Older people have multiple realities from their experiences: past and current homecare, health, lifestyle, culture, values, economic background and other lived experiences (Clarke and Braun 2021). These multiple realities informed older people's perception of the future homecare they wanted.

3.1.2 Epistemological assumption

Epistemology involves knowledge and embodies a specific understanding of what is needed to know, representing how we know what we know (Pabel et al. 2021). Epistemology deals with the nature of knowledge, its possibility, scope and general basis Crotty (1998: p.8). Furthermore, Crotty (1998: p.8), explains that epistemology focuses on providing a philosophical grounding for what kinds of knowledge are possible and how one can ensure that they are both adequate and justifiably entailed. In interpretivism of epistemological assumption, the subjective meanings and social phenomena focus on details of a situation, for example, reality details and subjective meanings motivating actions (Al-Ababneh 2020).

A participatory approach was used to explore with older people the type of future homecare they wanted and then co-produced concepts and principles that should underpin future homecare. From older people's perceptions the meanings of older people's perceptions were interpreted to understand the type of future homecare older people wanted. A thematic analysis using an inductive approach was used to ensure the findings of homecare were informed by data. The traditional conception of the epistemologist's task was to allay the doubts attached to the common beliefs by constructing a theory of knowledge which provided a detailed account of how people arrived at a knowledge of things through sense-perception (Ross 2015, p.159).

3.1.3 Methodological assumption

Qualitative research addresses questions about understanding the meaning and experience dimensions of humans' lives and social worlds (Fossey et al. 2002). The qualitative methodology is grounded in the interpretivism paradigm (Al-Ababneh 2020). The interpretivism approach looks for culturally derived and historically situated interpretations of the social lifeworld (Hammond and Wellington 2020). Central to good qualitative research is whether the research participants' subjective meanings, actions and social contexts, as understood by them, are illuminated (Fossey et al. 2002). The knowledge is developed by focusing on a subjective and descriptive method to deal with a complicated situation (Hignett and McDermott 2015; Al-Ababneh 2020). Like in the present study, qualitative research focused on how older people made sense of their world, interpreted it, and experienced different events in homecare.

Since the research was a qualitative design and participatory approach, to ensure that a theory did not drive older people's voices, an inductive process for analysis (bottom-up) was used to contrast, develop and explore relationships between data as supported by McAbee et al. (2017). Most accounts of the inductive analysis highlight its fluid nature because it is not based on any theory and is data-driven, allowing participants to engage in the analysis (Hammond and Wellington 2020). Furthermore, the data-driven analysis in a thematic analysis enabled the simultaneous mutual shaping of factors when emerging theme categories were identified during the research process (Liu 2016; Hammond and Wellington 2020). On the other hand, the participatory approach ensured collaboration. It involved working together on a shared goal between the researcher and participants (Hammond and Wellington 2020). Using inductive analysis in participatory research enabled accurate and reliable verification of the findings by the participants since it was not driven by any theory (Liu 2016).

Collaboration with participants has become normal in most cultures (Hammond and Wellington 2020).

3.2 Research design

The research design was influenced by the conclusion from systematic review findings, which identified that older people criticised the lack of being involved in the decision-making of their care and that the current models of homecare were developed by either the funders or the care providers without the involvement of the older people (Bone et al. 2016; Spoorenberg et al. 2016; Drennan et al. 2018a).

The present research is a qualitative design using participatory research with a co-production approach (Polit and Beck 2020). Qualitative research investigates phenomena in-depth by collecting rich narrative materials (Creswell and Poth 2016; Polit and Beck 2020), and hence, the best methodology to explore older people's perceptions of the type of future homecare they want and collaborate with them to co-produce concepts and principles that should underpin future homecare. In addition to the qualitative design, a participatory research approach was used since the participatory research approach sees research as a relational process through which knowledge is produced collectively rather than by an individual (Abma et al. 2019). In this research, the knowledge that would inform future homecare through concepts and principles was co-produced with older people.

According to Warwick-Booth et al. (2021, p.7), participatory research is an umbrella term for approaches that share a core philosophy of inclusivity and recognise the value of engaging in the research process. The participatory research approach is also viewed as a systematic inquiry involving those affected by the problem for action or enacting positive change (Blair and Minkler 2009; Ritchie et al. 2014). In participatory research, the community members can contact the researcher to partner with in research, or the researcher can contact a community or group of individuals to collaborate with them (Higginbottom and Liamputtong 2015; Schubotz 2020). In this study, I contacted the community members/older people, I ensured that participatory research was more than a means to transcend power dynamics but enabled participants to be involved in, take charge and be responsible for the research process as informed by (Brown 2022).

3.2.1 Participatory research approach

This section discusses participatory research, its range, intent and limitations. The participatory research approach is not new because it has been used for years in several disciplines like education, environmental science, social sciences, agricultural science, management sciences and development studies (Abma et al. 2019). Participatory research approaches have gained momentum in the health and social sciences, giving voice to vulnerable individuals like older people with few opportunities to influence care strategies (Asaba and Suarez-Balcazar 2018). The advantage of including older people in participatory research is that older people have a wealth of valuable experiences relevant to knowledge building, which can benefit care programs (Schubotz 2020). According to Macaulay (2017), participatory research was founded on increasing social justice by helping vulnerable populations to increase their voice and promoting research with and not on or about or for individuals and communities. Despite participatory goals of creating social justice, participation is an unclear concept that has acquired varied meanings over time (Warwick-Booth et al. 2021).

Sherry Arnstein’s writing in 1969 regarding the degree of citizen participation in the United States described a ladder of citizen participation that showed participation ranges (Dobson 2021). Arnstein’s original ladder focused on citizens' different levels of power concerning urban redevelopment (Arnstein 2019). The ladder is a guide to seeing who has power when making important decisions (Arnstein 2019). Here are how the 8 steps of the degree of citizen participation are described in Arnstein’s 1969 Ladder of citizen participation. The first and second steps on the participation ladder are considered non-participation (Arnstein 2019). The first and second steps on the ladder are called Manipulation and Therapy (Arnstein 1969). Both are considered non-participative, and the aim is to cure or educate the participants (Dobson 2021). With these two steps, the job of participation is to achieve public support through public relations (Dobson 2021). This first and second step would not give older people a voice because the power lies on the local authorities and is not distributed to older people.

The third step on the ladder for involvement is called Informing (Arnstein 1969). Schubotz (2020) remodelled the ladder of participation using Arnstein's ladder of participation, in which he excluded the first two steps because he indicates that his participation steps demonstrate the different levels of control participants have in collaborative research practice. With this level, older people may be consulted about the research and receive information about it. The older people may participate in data collection without influencing how the project is run. According to Arnstein (2019) the third to fifth steps on the participation ladder are considered tokenism. The third step on the ladder for involvement is considered the most crucial first step to legitimate participation. However, most commonly, the emphasis is on a one-way flow of information without a channel for feedback (Dobson 2021). The fourth step on the ladder of involvement is called Consultation (Arnstein 1969). However, Arnstein still feels this is just a window-dressing ritual (Dobson 2021). When older people are consulted in this step, power still lies with the carer providers or service providers, and it is considered one-sided since all the decisions lie with care providers. This way, it would look like older people were involved while older people had no control over the situation.

The fifth step on the ladder of involvement is called Placation (Arnstein 1969), and is described as, for example, the co-option of hand-picked worthies onto committees, and even though citizens are allowed to advise or plan ad infinitum, the power holders hold the right to determine the authenticity or practicality of the advice (Dobson 2021). In this step, older people may be involved in the research steering groups as members or have advisory roles. Older people in this step are consulted about the research process and results and provide feedback to the researchers. Schubotz (2020) calls this type of involvement “giving advice.”

The sixth to eighth steps on the participation ladder are considered citizen power (Arnstein 2019). The sixth step on the ladder of involvement is called Partnership (Arnstein 1969). This involvement redistributes power through negotiation between citizens and power holders (Dobson 2021). Planning and decision-making responsibilities are shared in this involvement, for example, through joint committees (Dobson 2021). The seventh step on the ladder of involvement is called Delegated power (Arnstein 1969). In this involvement, citizens keep a majority on committees with those delegated powers to make decisions (Arnstein 1969). In this seventh step, older people would be involved as co-producers or peer researchers. In this step, older people might not have had an original idea of the study but are involved and sometimes could be paid to run the study. In this step, older people would help collect and process data, and they would contribute to report writing and dissemination. Schubotz (2020) calls this step "co-production or peer research." The eighth step and the top on the ladder of involvement is called Citizen Control (Arnstein 1969). The vulnerable communities handle the entire job of planning, policy-making and managing a programme (Dobson 2021). In step 8. older people initiate and lead the research process and are involved in all stages of research. In this stage, older people may ask the researcher to join the project or seek professional advice, and older people are decision-makers. Schubotz (2020) calls this step "leading the research."

Before Arnstein 1969's Ladder for Participation, in 1940, Kurt Lewin proposed a cycle of continuous inquiry, action and evaluation undertaken with society's marginalized peoples, and his action research promoted empowerment and social equity (Lewin 1948). Subsequently, to Lewin's action research, there are multiple types of participatory research approaches, such as co-inquiry approaches, participatory action research, action research/inquiry, co-production in research, collaborative inquiry, community-based participatory research and inclusive research (Warwick-Booth et al. 2021). These participatory approaches use different methods, and the centrality of these methods is on how vulnerable communities are involved in research, such as how power is balanced between the researcher and vulnerable communities and how actively the community participates at all stages of the research process (Schubotz 2020).

3.2.1.1 Participatory Paradigm

Palmer (2020) reveals that the science of participation is, by nature, interdisciplinary, and it intersects with paradigms across participatory design, participatory research methods, and transversely approaches for engagement, collaborative decision-making, and change. Palmer (2020) believes that the rationale for the science of participation is that we are amid a scientific revolution in the participatory paradigm, and there is a need for a unifying language. In addition, (Kjellström et al. 2019) express concern about co-production losing meaning because it is overused without attendance to the values, principles, and practices that ought to underpin it, such as mutuality and reciprocity. Participation through co-production is a concept that emerged in the 1970s in the private sector and was used in the public sector as a partnership between service providers and service users, which may be interpreted as citizens' participation in the democratization of services (Avci 2023). The term co-production is increasingly being applied by those working in the health and social care sectors to refer to forms of collaboration between users and providers of services (Kjellström et al. 2019). Collaboration offers the possibility of fundamentally challenging and changing predominant ways of thinking by moving from focusing solely on the delivery of healthcare and social care towards co-producing health and well-being (Kjellström et al. 2019).

The present research used participatory research with a co-production approach. Participation through co-production during research was a way of engaging older people in contributing to underpin the design of their homecare strategies because policymakers or care providers could use the recommendations from older people in developing homecare strategies. Co-production of homecare concepts and principles with older people would balance power between older people and care providers since care providers would use recommended co-produced homecare concepts and principles as guidance for homecare. The participatory paradigm was central to the co-production approach because it emphasized active involvement, collaboration, and shared decision-making among researchers and stakeholders (Warwick-Booth et al. 2021).

Even though co-production refers to the involvement of users in the earliest production of services, the intention behind this term shapes its goal (Avci 2023). For the current research, the intention was to engage older people in co-producing the concepts and principles of future homecare they want since the design of homecare had always been solely the responsibility of policymakers and care providers, with the exclusion of older people (Beresford 2019). The participatory paradigm was articulated by Heron (1996), which he also called the participative inquiry paradigm, and by then, he used it to underpin their work of cooperative inquiry.

In this thesis, the participatory paradigm underpinned the co-production approach because with the participatory paradigm, balancing power and inequalities was part of creating a transformative space for older people so that they could freely share their knowledge of homecare from different areas of knowing. The transformative, inclusive space was created, and older people felt safe, valued and belonged. In addition, at the end of the participatory discussion, older people were left with ultra-viewpoints of the type of homecare they wanted after co-producing concepts and principles of future homecare. Creating transformative spaces for co-production also enabled opportunities to use older people's knowledge capabilities meaningfully to inform future homecare.

Concerning the knowledge capabilities, the participative worldview, with its notion of reality as subjective-objective, involves an extended epistemology whereby a knower participates in the known and articulates a world in at least four interdependent ways of experiential, presentational, propositional, and practical, leading to action to transform the world in the service for human flourishing (Heron and Reason 1997). In the current research, older people knew and articulated homecare in four interdependent ways of knowing: experiential, presentational, propositional, and practical. Heron and Reason (1997) affirm that expanding our awareness to articulate any fundamental way we frame our worldview is essential, for differences in epistemology, methodology, and political perspective are usually based on paradigmatic assumptions.

The four types of knowing in the participatory paradigm are described as Experiential knowing, generally understood as a way of knowing and understanding through direct engagement (Heron and Reason 1997). Furthermore, much of this knowledge is regarded as tacit, meaning that it is carried and transmitted through actions and ways of doing rather than communicated verbally and with a being so that one feels both attuned to it and distinct from it as a knower (Heron and Reason 1997; Nimkulrat et al. 2020). Presentational knowing emerges from and is grounded in experiential knowing (Heron and Reason 1997). It clothes our experiential knowing of the world in the metaphors of aesthetic creation in expressive spatiotemporal forms of imagery

(Heron and Reason 1997). In this case, humanising spaces must be created by weaving authentic, vulnerable, and embodied narratives to allow creation in expressive presentational knowing (Welch et al. 2020). Humanizing is about having an inclusive space that welcomes and holds diversity within our common human story (Welch et al. 2020). Propositional knowing is at the level of conceptual development, which is knowing by describing some entity, person, place, process, or thing (Carlgren 2020). Practical knowing is knowing how to do something, demonstrated in a skill or competence (Heron and Reason 1997).

The participatory paradigm prioritizes the empowerment of stakeholders. It recognizes their expertise from different knowings in co-producing knowledge, policies, services, or interventions because a worldview based on participation and participative realities is more helpful and satisfying (Heron and Reason 1997; Higginbottom and Liamputtong 2015). The participation paradigm was also emphasised by Jean-Paul Sartre, the French Philosopher in the 1940s, who indicated that existentialism is humanism (Sartre and Mairet 1960). He emphasised that when individuals participated in decision-making, it enhanced their freedom and choices (Sartre and Mairet 1960).

Correspondingly, an individual’s perception should not be considered as less than since their perceptions are shaped by how they experience and view the world (Sartre and Mairet 1960; Sartre 1965). In his emphasis on the importance of participation, Sartre attested that expected individual participation was vital because individuals were ambassadors of their communities (Sartre 1965). With the current thesis, participation ensured that co-produced future homecare concepts and principles emanated from what mattered to older people. Ensuring reciprocal collaboration and valuing their knowledge emanating from multiple realities contributed to informing future homecare strategies that would enhance the well-being and dignity of older people.

3.2.1.2 Participatory research purposes and limitations

A growing body of work uses participatory approaches to enhance culture change in health and social care (Buffel 2018). With increasing inadequacies for governments and agencies to provide desired change to the people, particularly the marginalized, participatory approaches have been advocated for and considered suitable approaches (Kanyamuna and Zulu 2022). Participatory research, with its focus on engagement and collaboration, is viewed as uniquely suited to engage the expertise of older people to promote collective action aimed at improving the quality of life in long-term care (Buffel 2018). The participation of affected community members is assumed to contribute to enhanced efficiency and effectiveness in systems (Kanyamuna and Zulu 2022).

Effectiveness is necessary for providing good health and social care because resources should be assigned to care that benefits affected people (Littlejohns et al. 2019). Participation of stakeholders and the wider public is meaningful because it adds to the views and values that are considered when making decisions (Littlejohns et al. 2019). Participatory approach also enables affected groups to contribute to decision-making, ensuring that different views are heard and that special needs are understood (Littlejohns et al. 2019). Hall et al. (2021) indicate that participatory approaches advocate actively involving stakeholders, whether citizens, members of the government or experts, in a collaborative decision-making process, which can involve participation in planning, implementation and evaluation of a given topic.

Social exclusion is defined as the inability to participate in the relationships and activities available to most people in society, and literature reveals that older people experience social exclusion (Yarker and Buffel 2022). However, participatory approaches are conducted to bring the principle of solidarity, that we are all in it together (Littlejohns et al. 2019). In the participatory research approach, participants are placed at the centre of the research rather than the researcher or the question that the research seeks to address (Abma et al. 2019). Participatory approaches are conducted to bring the principle of solidarity that we are all in it together (Littlejohns et al. 2019). Hall et al. (2021) believe that participatory approaches encourage openness and equity in sharing knowledge, experience, expertise and ideas and provide diverse perspectives on a research topic. Participatory approaches also enable transparent decision-making, and it is one way in which institutions can ensure that decisions are made on grounds that the wider public considers fair and not biased (Littlejohns et al. 2019).

According to Livingstone (2013), participation means taking part in something and identifying what that something is or what is important because one does not participate or seek to increase participation merely for the sake of it. Participation is never a wholly individual act and always advances particular interests (Livingstone 2013). Similarly, Abma et al. (2019) attest that action may be invisible or intangible, such as understanding a situation from the learning that took place. Participatory research intends to build relationships with community members and establish partnerships that actively engage local stakeholders throughout the research process (Amauchi F. J. et al. 2022). According to Schubotz (2020), not all research projects lend themselves to co-production due to a lack of time or resources, leading to a varied degree of active participation. However, Schubotz (2020) encourages researchers to continue trying for the highest level of active participation because involving local people actively as participants in research and planning could potentially enhance the research's effectiveness. Participatory research emphasises power sharing, equalising power hierarchies, and engagement of vulnerable community members who are often excluded (Higginbottom and Liamputtong 2015; Marrone et al. 2022).

According to Bendien et al. (2022) what is conducted by older people can lead to impacts spreading like circles at various levels. The emancipatory effect of PAR has enabled personal growth of the team members through their collective learning process and has promoted most of them into a position of community leadership. According to (Jonasson et al. 2023), the participatory approach enables the complex concept of participation to be understood from micro, meso and macro perspectives. Since, at the micro level, older people should participate in meaningful to address social and existential challenges that older people experience (Jonasson et al. 2023). The purpose of participation of older people at the macro level is to enable them to express their opinions to influence decision-making, participate in dialogues and be co-producers (Jonasson et al. 2023).

Limitations of Participatory research are that it requires establishing credible and trusting relationships between researchers, individuals, groups and communities, which is time-consuming, while funders may require rapid results, creating tensions between the research and funders (Higginbottom and Liamputtong 2015). Schroth et al. (2020) perceive methodological challenges as particular reasons why participatory processes are not often implemented. Higginbottom and Liamputtong (2015) indicate that relationship building is fundamental for successful participatory and co-production during research. Participatory research encourages community members to lead the research (Schubotz 2020). However, sometimes community members do not want to take the lead in research for ethical reasons because some may feel uncomfortable handling personal data from the people they know (Warwick-Booth et al. 2021). Again, where resources are scarce, conducting participatory research becomes not a priority as they cannot afford it (Warwick-Booth et al. 2021).

3.2.1.3 Types of participatory research

The following section concerns the types of participatory research and the decision to choose the type for this study. Participatory approaches are collaborative approaches developed to create critical perceptions of existing traditional research practices and respond to the lack of its social impact, relevance and usefulness to those at the research centre, like older people (Schubotz 2020). Traditional research has been criticised for using the principles of neutrality and objectivity and being used by professionally trained people from society who are advantaged while over-researching vulnerable groups (Bennett 2004; Warwick-Booth et al. 2021). Participatory research actively engages participants in some or all stages of the research process, such as deciding on the scope and problem statement to actively collect data, disseminate findings and effect change (Mey and van Hoven 2019).

The participatory approach emphasizes the participation, power sharing and influence of non-academic researchers in the engagement of the process of generating knowledge (Mey and van Hoven 2019). participatory approach has flexible and adaptive processes for the best fit rather than using a method as a standardised approach to be adhered to without deviation (Abma et al. 2019; Mey and van Hoven 2019; Warwick-Booth et al. 2021). There is, however, no specific type or model for the participatory approach (Israel 2012; Lawson et al. 2015; Rovio-Johansson 2020; Warwick-Booth et al. 2021). Various participatory research categories also overlap in terms of practices and foundational features that possess irreconcilable theoretical features (Martinez Vargas 2022). Moreover, to a certain extent, this overlap complexity explains the current difficulties of classification and differentiation in the literature, which is concealed by an ethos of embracing the diverse and extended family of participatory approaches (Martinez Vargas 2022). The focus of participatory research is on action and having a power balance with the vulnerable people and effect change, which initially focused on social justice but now has expanded to other areas like health and social well-being (Higginbottom and Liamputtong 2015; Abma et al. 2019). Lewin designed a research methodology which, through cycles of action and reflection, could act as a catalyst for social change as a desirable aim through a pragmatic and positivist frame of human behaviour (Martinez Vargas 2022). This positivist frame presumed that universal laws motivated human behaviour and were a cause-effect problem (Martinez Vargas 2022).

Lewin’s research, especially in the early stages, aimed to change habits according to policy recommendations or the researcher’s interest, with the participants’ involvement going no further than their being changed as per the researcher’s desired outcome (Martinez Vargas 2022). Later in his career, Lewin also tried to democratise the research process by introducing into his research the participation of communities or groups excluded from his initial approach, even though there are challenges in how participation is understood due to Lewin’s historical moment and his positivist scientific background (Adelman 1993). In the 1960s, participation was added to AR as an ideological sign that participation came first and not action (Martinez Vargas 2022).

The traditional research approaches are criticised for power imbalance between the researcher and the researched since it is being used by professionally trained people from sections of society who are advantaged while over-researching vulnerable groups (Warwick-Booth et al. 2021). On the contrary, PAR was a practice focused on the liberation of oppressed groups and classes and the unlocking of deplorable injustices arising from the politics of knowledge, which made the principal aim of PAR the combination of different knowledge supporting excluded groups or communities through investigative techniques (Rappaport 2017).

In this section, the commonly used participatory approach that will be discussed covers Action Research, Participatory Action Research, Community Based Participatory Research, Cooperative inquiry, Collaborative Inquiry and Co-

Production in research (Schubotz 2020). According to (Schubotz 2020), action research(AR) is one of the collaborative approaches that Lewin used to study the resolution of significant social or organisational issues together with those who experience these issues directly (Schubotz 2020). AR is, therefore, fundamentally built on emancipatory, democratic and social justice values, which are core to the theoretical and conceptual founding blocks of AR (Schubotz 2020).

Participatory action research (PAR), as the name implies, involves goal-oriented action resulting from the research products. Participatory Action Research (PAR) is a form of engaged human inquiry that places the researcher toward action-centred practice, focusing on reflection and collaboration with participants to bring about meaningful change in the context of social justice (Guy et al. 2020). Diverse methods informed by ideological principles associated with the work of Paolo Freire (1970) may be employed (Campos and Anderson 2021). Fundamentally, Paolo Freire maintained that acknowledging, recognising, and reducing power differentials are fundamental to eradicating inequalities (Higginbottom and Liamputtong 2015; Campos and Anderson 2021). He also believed these principles might be exercised in several fields of pursuit, including education and health (Higginbottom and Liamputtong 2015). The chosen method should be suited to the needs of the research focus and those involved in the research, and critical conscientisation is a key feature, along with educative processes for all involved (Higginbottom and Liamputtong 2015; Abma et al. 2019). According to Guy et al. (2020), the concept of action within PAR is challenging to define and achieve. Therefore, PAR projects frequently fail to reach a concrete action step.

Schubotz (2020) attest that although AR and PAR share many theoretical and conceptual roots, PAR also emphasises that study participants are regarded and treated as experts in the field and play a vital role in the research as peer researchers or co-researchers. PAR, like AR, aims to use the research process to change and improve the situation of those researched (Schubotz 2020). According to Warwick-Booth et al. (2021), despite the need to involve vulnerable people in all stages, people do not have time, and some community members do not want to be involved at all. Furthermore, not all want to actively participate in all research processes (Abma et al. 2019).

In the current research, ethical considerations were enforced to ensure that older people were enabled to participate in areas where they wanted and were comfortable without being coerced or made to feel guilty that if they did not participate in all processes, the study would not meet the standard of participatory studies. In addition, they had the right to withhold or withdraw without explaining, which came back to giving older people choices to participate. The current research avoided focusing more on checking boxes for characteristics of participatory research. However, it ensured that older people held more balanced power during the participation and that older people’s choices and contributions were valued and respected.

Older people were placed at the centre of research, enabling them to make choices with dignity and confidence and feel valued. Older people believed that safe spaces were created for them to enable them to share their experiences of homecare. They stated that a small number of people in the group was inclusive and not overwhelming, as they could all contribute and simultaneously see each other. They believed that I facilitated the research processes well and with shared consensus. Researched ideas were placed at the core and looked at the process of thinking together as researchers and aimed not to focus on the transformational paradigm but to ensure a process of participatory paradigm whereby the outcome was co-produced from the epistemic capability of the involved older people (Martinez Vargas 2022).

Community-Based Participatory Research (CBPR) is a participatory design where research activities are carried out in local settings in which community members actively collaborate with professionally trained researchers (Duke 2020). It involves partnerships between academic researchers, communities and services, usually intending to develop interventions and programmes to address them (Warwick-Booth et al. 2021). Community-based participatory research (CBPR) is an innovative research paradigm that combines knowledge and action to improve community health and reduce health disparities (Wallerstein et al. 2017). According to Collins et al. (2018), CBPR emphasizes collaborative, equitable partnerships among researchers, stakeholders and community members throughout all phases of research. Researchers acknowledge power differentials and improve these by building trust, mutual respect, and community empowerment (Collins et al. 2018). Communities are involved in decision-making throughout the research process, from developing research questions to disseminating research findings (Collins et al. 2018).

According to (Abma et al. 2019), the health field was slower to adopt a participatory approach, especially in some highly specialised areas, compared to health promotion and primary health care, particularly in the regions that are under-resourced or where there are fewer established health systems. Abma et al. (2019) also state that health professionals were slow to adopt participatory research because, historically, they have been trained to give information and advice based on evidence from the randomised controlled trials developed in clinical medicine. Health professionals' knowledge was always relied on because expert knowledge was considered the only truth (Abma et al. 2019). All other forms of knowledge were suspect because it was believed that where evidence was not translated into practice, this was either because the researcher had not communicated it correctly or the practitioner or community had not understood (Abma et al. 2019). However, through the work done in knowledge translation, it is now acknowledged that the knowledge-action process is complex, and advances in public involvement in science demonstrate the value of user involvement in research (Boote et al. 2015). In the UK, service user involvement is a social policy development reflecting a participation agenda in public services, which was part of Labour’s modernisation agenda in the 1990s (Warren and Cook 2013).

The co-production research approach draws on the principle of participatory action research (PAR) (Warwick-Booth et al. 2021). The co-production approach is seen as more ethical and transformative due to collaborative work with vulnerable people (Warwick-Booth et al. 2021). Co-production is guided by the principles of power-sharing, inclusion, equality, reciprocity, principle of openness, and valuing knowledge as experience (Warwick-Booth et al. 2021). In the Co-production, participants are involved in the research process and knowledge production is interactive (Warwick-Booth et al. 2021). The use of Co-production is now gathering across health and social well-being (Abma et al. 2019).

In the present research, the co-production approach was operationalised to enable older people to be meaningfully engaged in the decision-making of their future homecare. By having an enabling safe space to speak up, participate, experience themselves, and be experienced as the person with the right to express themselves and have their expression valued by others as similarly attested by Abma et al. (2019). Furthermore, this co-production was guided by the principles of power-sharing, inclusion, equality, reciprocity, openness, and valuing knowledge as experience, focusing more on understanding everyone's perceptions than consensus-making. The older people's intention was not to transform homecare, as they indicated that politicians often influenced the transformation of systems since politicians, policymakers and care providers still held more power to decide whether to implement the older people's recommendations. Nevertheless, there is an inadequate understanding of navigating the emerging tensions in these co-production processes because some of the literature shows that the bottom-up transformation process at times encounters some resistance by those with power, while co-production efforts seek to unite ways of knowing and acting to create transformation (Wyborn et al. 2019; Chambers et al. 2022). Older people believed that engaging in the research process and co-production of future homecare enabled the decision-makers to understand what mattered to older people and their homecare wants and needs.

The participatory with co-production approach was used because the systematic review done in chapter 2 of this thesis showed that older people criticised the lack of participation in the decision-making of their homecare. Co-production is believed to enable transitions that could change institutional arrangements that govern relationships between knowledge and power, science and society, and state and citizens (Wyborn et al. 2019). However, literature shows that people who participate in their care are more likely to be satisfied with their care than those who do not (Segevall et al. 2021). The benefit of using a co-production approach in research and practice with different societal actors is argued to play an important role in sustainability transformations (Chambers et al. 2022).

The ontology of co-production emphasises the importance of engaging and integrating the multiple perspectives of stakeholders that can shape the understanding and processes of knowledge generation and use (Rycroft-Malone et al. 2016). Co-production offers opportunities to promote inclusion, interrogate power relations and hegemonic knowledge systems and create the new knowledge or interventions required to promote more just and sustainable health and well-being (Daykin et al. 2017; Wyborn et al. 2019). Several expectations characterise the knowledge production and consumption processes with respect to knowledge supply and demand (Twalo 2019). The literature shows that researchers, who are conservatively knowledge producers, and policy-makers, who are conservatively knowledge users, have conflicting interests, expectations, concerns, and priorities, which often leads to power dynamics (Twalo 2019).

Nevertheless, implementing research through co-production with older people who would be the beneficiaries of homecare, their participation would inform the researcher’s decisions. This also effectively reduces power inequalities between researchers and participants, making research more locally informed and potentially transformative (McSweeney et al. 2022). Knowledge inputs from older people would allow for the homecare programme to be designed to align with older people's reflections about what needed improvement and what was already working, as informed by their multiple realities. As similarly evidenced by Rich and Misener (2020), partnerships with those affected by research could effect systematic change within communities.

3.2.1.4 The rationale for the participatory research approach

Participatory approaches arose to address unequal power relations and overturn the top-down imposition of ideas from the outside following the recognition that local populations possess a vast wealth of proven, experiential knowledge that was equally valuable as modern or scientific approaches (Daykin et al. 2017). The aim of the current participatory research with co-production approach was that instead of having older people be objects in the research, they were at the centre of the participatory process during the implementation of the research. A participatory research approach involves planning and conducting research with those whose lifeworld and meaningful actions are being studied (Bergold and Thomas 2012). As identified during the systematic review, there is still less engagement of older people in the person-centred care model despite its effort to increase the participation of older people in their care (Spoorenberg et al. 2015; Drennan et al. 2018a). Service user inclusion is a critical component of a human rights-based approach to healthcare services, leading to the rapid development of models of inclusion (Roberts et al. 2012).

The recent literature shows the co-production research approach as another category of participatory research (Warwick-Booth et al. 2021). According to Warwick-Booth et al. (2021), the co-production approach in research draws from the doctrines of participatory action research (PAR) principles, whereby collaboration between the researcher and the stakeholders aims to dissolve boundaries between providers and users and all forms of expertise are considered valuable to contribute to knowledge production (Warwick-Booth et al. 2021).

This research used the co-production approach because I intended to construct (Norström et al. 2020) concepts and principles of homecare with older people and with the aim to transform care providers' approach to designing and implementing homecare support to older people. It recognised that the co-production of knowledge should be grounded in context, respect multiple ways of knowing, work towards shared goals and support frequent interactions (Norström et al. 2020). Since older people expressed being often excluded in research, which usually includes the younger population, even when researching older people (Lindeman and Report 2017), co-production was found to be a powerful approach because, according to Norström et al. (2020), it aided academics and non-academics to work closely together and offered the opportunity to co-produce more than just knowledge.

Liamputtong et al. (2015) point out that when older people are involved in co-production, we benefit from their valuable epistemic knowledge in participatory research projects. Arguably, collaborative engagement with service users and carers is beneficial in delivering high-quality care services that are safe, effective and adherent to agreed values (Keogh 2013). A growing number of studies suggest that participatory research (PR) with older people may hold promise for understanding and addressing some of the complex health and social problems confronted by older people while simultaneously contributing to individual and community capacity building (Liamputtong et al. 2015). Additionally, there is a growing focus on incorporating older people's needs and preferences in health and social service delivery and public policy decision-making (Liamputtong et al. 2015).

Co-production was able to work in this research because older people viewed the research positively as a need and priority topic for discussion and wanted to contribute in co-production of the concepts and principles that should underpin future homecare. Furthermore, there was a balanced sharing of power in critical decisions, inclusion, equality, reciprocity, valuing older people’s knowledge and developing trustworthy relationships between myself as a researcher and older people and amongst older people. There was no conflict of interest. The funders were not concerned about the type of knowledge or scientific findings. The research aimed to use findings for either policy or management decisions (Warwick-Booth et al. 2021). In addition, Warwick-Booth et al. (2021) attest that co-production is more than participation because it is about sense-making in all areas of co-produced knowledge, co-produced ideas, co-produced methods, co-produced data collection, co-produced data analysis and co-produced dissemination.

Co-produced ideas; The changing role of citizens from clients to co-producers significantly affects how present and future local governments will be designed, re-designed, and managed, which has led to citizens becoming resources, hence making co-production a popular concept in the public sector (Brix et al. 2020). In this research, older people did not have the original idea of the study. Schubotz (2020) indicated that in co-production, participants may not have had the original idea regarding the level of participation. According to Macaulay (2017), participants are involved because inclusive and equitable research is an ethical imperative. It can bring meaningful outcomes to vulnerable people and also minimises the stigmatising effect of research on the partners. According to Farr et al. (2021), The gap between co-production principles and practice is a tricky territory because working with everyone interested in an issue, focusing on meeting the priorities of communities and people we work with, and co-producing all aspects of a project from beginning to end could be challenging to deliver in many projects in health and social care research.

Older people were invited to join the research if they wanted to participate. Due to limited financial and time resources, older people volunteered their time and were not reimbursed or paid. However, with older people volunteering their time, older people did not feel like they were working for the funder and sponsor but felt like equal partners who had control to make their decisions without being obliged to align with the funder’s requirements. Participatory research is a complex and dynamic process and may be beyond some projects' resources (Marrone et al. 2022). However, when implemented skilfully and authentically, participatory research can benefit by empowering the voices of those marginalized in society and underrepresented within research (Marrone et al. 2022).

Co-produced methods move culture and practice away from traditional and less person-centred methods of doing to people towards doing with people in the context of public service provision (Conquer 2023). Co-production has been developed from the concepts and practice of personalising care within health and social care because, individually, being involved in co-productive programmes has been seen to improve health, well-being and recovery from long-term conditions (Fox et al. 2018). Power sharing is often highlighted as a critical principle when co-producing research (Farr et al. 2021). However, as with many other academic disciplines, health and social care research is carried out within embedded hierarchies and structural inequalities in universities, public service institutions, and research funding systems (Farr et al. 2021). Farr et al. (2021) specify that bringing co-production principles into practice needs changes within research practices, cultures and structures to understand what knowledge is and how different forms of knowledge are valued.

Regarding the participation of vulnerable communities in all stages of participatory research in order for the research to qualify as participatory research, Brown (2022) attests that not all participants can be involved in all stages of the research process because participants might lack skills in some areas, which might lead to more harm and disadvantage to the targeted people. According to Farr et al. (2021), maintaining all co-production principles within the real world of structural inequalities and uneven distribution of resources is a constant challenge. Older people faced different challenges, which ranged from mental, physical, health, ethnic minority, and low socio-economic background that interfered with older people’s will to participate in all stages of co-production in participatory research and therefore, whichever areas older people chose to participate in, their choices were valued and supported.

A fundamental premise was that homecare users and potential homecare users, which in this thesis was older people, had a fundamental role in co-producing concepts and principles that should underpin future homecare. The homecare subject was essential to them and, therefore, equalising relationships and balancing power between older people and myself (researcher) was the major focus to enable older people to have active, meaningful participation during research as guided by(Williams et al. 2020). The egalitarian and democratic principles of co-production mean that service users, who may have been marginalised and receive professional expertise, now become equal partners in research (Williams et al. 2020).

In the current research, there was active consideration of learning and support to individual older people whereby the clarification of meanings of concepts and principles were discussed with older people so that they could actively and meaningfully participate. Older people acknowledged that they had learnt much about homecare from other older people and online participatory research during their participation, which they thought would not have happened if they had not participated in research with co-production. Higginbottom and Liamputtong (2015) state that people should not be assumed to be empowered only by participation in most research stages because choosing not to participate can be empowering. Nonetheless, Brown (2022) states that the participants' well-being remains the researcher's responsibility, and participatory research is not and should not be the complete cession of control or power.

Some older people clarified to the group that their involvement would also benefit other older people since their contribution to the type of homecare they want could enhance future homecare for older people, bringing social justice and social change. Older people indicated that the lack of participation in research by some older people was because not all older people were familiar with digital technology. It could be a challenge for older people to participate in online participatory research to address the issues that affect them. They felt that with future research, there should be a deliberate lookout for older people who could be easily forgotten or ignored. Older people believed homecare issues were a long overdue priority and should be on everyone’s table for discussions.

Participatory research requires stakeholders or the community to choose the research questions, aims, and objectives (Warwick-Booth et al. 2021). My experience in this research showed some challenges to putting this principle of co-production into practice. This has been observed and questioned by Williams et al. (2020), such as how challenges and changes of some structural inequalities within academia could impede co-production. One of my challenges was that my university required ethical approval before approaching older people. In addition, the Ethics Review Committee classified the research as high risk because I would research with older people and older people were regarded as a group. A research proposal of what would be done was developed. The proposal elaborated on how the research would be done, and how I would protect older people and prevent harm or exploitation.

The protocol was ethically approved upon satisfying the BU and InnovateDignity Ethics Review committees. As a result, research questions, aims, and objectives were developed before meeting older people. Developing a research protocol and being ethically approved before older people were involved interfered with co-production and participatory research principles of involving older people in all stages. In addition, doing research with vulnerable people is often considered too risky, too difficult, or too expensive (Henrickson and Fouché 2017). Vulnerable people can be unnecessarily excluded from research. Their needs can be unknown, ignored, or even suppressed, often with the best intentions to protect individuals from any hypothetical harm researchers pose (Henrickson and Fouché 2017).

In this research, a systematic literature review in chapter 2 of the thesis was used as an innovative way to objectively inform the participatory research's questions, aims and objectives from the literature on the experiences of older people. “What are the lived experiences of older people and perceptions of service providers on emergent homecare models concerning the well-being of older people in the European Union?” The older people were the primary stakeholders who collaborated with me and made a collective inquiry and co-production through discussions to address the question: *What could future homecare look like based* *on the perception of older people?* Collaboration and co-production show that vulnerable groups could still participate even when they had not initiated the research.

3.2.2 Covid-19 pandemic as the rationale for online participatory research approach with older people

The outbreak of coronavirus disease 2019 (Covid-19) in December 2019 rapidly spread to countries and regions, leading to a global pandemic (Chen et al. 2022), which also impacted work, economic, social, educational and academic activities. The World Health Organisation classified the virus as a global pandemic in 2020 (WHO 2020a). The Covid-19 pandemic caused significant disruption to academic researchers because the priority was to understand the virus by tracking the spread of it through diagnosed individuals, conducting epidemiological studies and mobilizing innovative diagnostics to speed up disease management (Cooner et al. 2022).

The Covid-19 pandemic had an enormous impact on the ability to design and deliver research for older people in the United Kingdom (UK) because the United Kingdom announced a nationwide lock-down and a policy of social distancing, which includes self-isolation and working from home where possible (Jaspal et al. 2020). It forced researchers to move to remote follow-up by telephone or video or to defer or abandon follow-up altogether (Richardson et al. 2020). This posed key challenges and opportunities in continuing to conduct face to face research with and for older people, both during and after the Covid-19 pandemic (Richardson et al. 2020).

Nonetheless, the online participatory research approach was found suitable to allow older people to participate in research and capture the voices of older people and not leave them behind. As Richardson et al. (2020) indicated, we did not know how many pandemic waves there would be or whether the world would live with Covid-19 as an endemic infection. Furthermore, there was no certainty of long-term controls on the movement of people and contact end date. Consequently, research must be robust against future shocks to the healthcare system and to research delivery (Richardson et al. 2020). It means, wherever possible, a significant redesign of existing studies, embedding fundamental principles of flexibility and resilience into future study designs (Richardson et al. 2020). The first months were about familiarisation with various ways to facilitate continuation in a remote capacity (Valdez and Gubrium 2020). Literature on the use of virtual technology with older people and how one can conduct online participatory research with older people was explored. The participatory discussions and individual interviews were undertaken using virtual Zoom platforms, and recruitment was done by e-mail. Conversely, virtual communication was more convenient and could be accessed from older people's mobile telephones, even in different geographic locations (Tamí-Maury et al. 2017).

3.2.3 Co-production with older people in online participatory research

Co-production is a questioned term because it means different things to different people and is used differently in different disciplinary contexts (Brandsen et al. 2018). Various definitions of co-production exist, and how the term is used often depends on a combination of factors, including the field in which it is applied, what is being produced, and the individuals and organisations involved (Hallam-Bowles et al. 2022). Warwick-Booth et al. (2021, p.21) define co-production as people working together jointly who traditionally would have been separated into different groups, such as researcher versus participant.

According to Hallam-Bowles et al. (2022), co-production in health and social care research is considered to be the involvement of service users, professionals and academics working together in equal partnership and sharing responsibility for generating knowledge and solutions to problems. Brandsen et al. (2018, p.9) explain that co-production finds its scholarly origins in the public sector, in the work of Ostrom and other economists who studied collaboration between public departments and citizens. Co-producing research can enhance a research's impact, provide solutions to problems, and positively influence people's lives (Smith et al. 2022).

The purpose of participatory research and co-production was that it enabled older people to meaningfully participate and co-produce future homecare concepts and principles with me. Traditionally, researchers and care providers hold higher decision-making power over older people or service users, and participatory research and co-production balance the decision-making power (Beresford 2019). The collaboration seeks to serve all humans with research that respects their dignity and supports their rights, and this includes advocating for fair and inclusive service experiences, starting with fair and inclusive access to service, fair and inclusive service encounters and fair and inclusive ability to exit the service (Fisk et al. 2020).

During co-production in the current research, older people valued feedback and feedback loops engaging all participants were critical to the success of the participatory research because I led feedback from each previous participatory discussion session to introduce the next participatory discussion session. I also shared feedback across each participatory discussion group, which enriched or cross-fertilised older people's knowledge for discussions of their experiences of homecare. Again, older people requested individual bookings to provide feedback following participatory group discussions.

Another feedback was through exploring older people's perceptions of the use of virtual communication as a tool for data collection in this participatory research approach since the literature showed that older people had limited digital involvement in participatory research, which could broaden and enrich the goals of care field (Grigorovich et al. 2021). Yet there is increased interest in participation of older adults as part of a broader movement to bring about greater public participation in scientific knowledge production to enhance its societal impact (Grigorovich et al. 2019).

Co-production in health and social care in the UK involves people who use health and care services, carers and communities in equal partnership and engage groups of people at the earliest stages of service design, development and evaluation (NHS-England 2023). The care services include homecare, and in the UK, there are various types homecare and multiple homecare service providers (O'Rourke and Beresford 2022). Despite these multiple homecare services, the systematic literature in chapter 2 of this thesis showed that older people were not engaged in the decision-making of their health and homecare services since care providers held upper power and decided on the type of homecare older people needed (Lynch et al. 2018). In this current research, in order to engage older people meaningfully in research about the type of future homecare they wanted, the power hierarchy boundaries between myself and older people were dissolved. We worked together, sharing power and responsibility to generate knowledge, including a strategy to disseminate findings, with guidance from Warwick-Booth et al. (2021, p.22). Hickey (2018) suggests that those affected by research are best to be engaged and that their skills are as essential as those of professional researchers.

Literature shows that care providers have been developing homecare models without engaging older people, which has led to a lack of meeting the care needs of older people (Lynch et al. 2018). Also, Hickey (2018) attests that there is no one set way of co-producing in research since it is principle-driven, meaning co-production can assume various formats. The co-production in this current research focused on power balance and creating the safest space/ or environment whereby older people did not feel intimidated or felt that others had valuable knowledge from them. Instead, they all felt valued and were reassured that everyone’s knowledge was valuable for this research, and in that way, they felt free to discuss and share their homecare experiences and perceptions. According to Smith et al. (2022), co-production recognises, values, and utilises the participants' experiential knowledge.

The experientially informed co-production was used in the collaboration process that endeavoured to address epistemic injustice by engaging relevant people with lived experience in the research process (Smith et al. 2022). In the present online participatory research, co-production was done with older people to co-produce concepts and principles that should underpin homecare and generate knowledge and ideas for future homecare. In addition, older people contributed to data collection because older people posed and responded to each other’s questions in a more dialogical way than in a debate (Kagan 2013).

According to Warwick-Booth et al. (2021), a collaboration between the researcher and the researched could be done to generate knowledge through partnership involvement and co-produce. In this research, there was a co-production of concepts and principles that should underpin future homecare. A co-production approach was considered to be more just, and the principles of co-production, which covers inclusion by embracing diversity and ensuring that older people equally contributed were supported by Warwick-Booth et al. (2021). Equality for older people was exercised because there was equal importance to everyone; they were all respected, and everyone's knowledge and contribution were valued (Warwick-Booth et al. 2021). Besides, there was also reciprocity, openness and reflexibility (Warwick-Booth et al. 2021). Following Hickey (2018) ground rule on co-production, ground rules were established, and there was an ongoing discussion between older people and me to ensure joint ownership of decisions, flexibility, and building and maintaining relationships.

According to Kagan (2013), co-production is more than participation because of the co-produced knowledge, co-produced ideas, and co-produced data collection and dissemination plan, in which the end product in this study was co-produced future homecare concepts and principles with older people. Also, according to Schubotz (2020), participants may not have had the original idea for the study in co-production. However, they are involved in various stages of research. The next section will indicate older people and my responsibilities in this study.

3.2.4 Utilising participatory research in a PhD

Participatory research can help postgraduate students make a difference through meaningful collaboration with left-out groups like older people (Klocker 2012). Academic research is often criticised for its lack of social impact in the real world, and study findings are often not used effectively to shape policy-making and practice (Shucksmith 2016; Donnelly et al. 2019). Participatory research differs from traditional research methods as it assumes that all research participants are knowledgeable co-researchers rather than objects of study (Areljung et al. 2021). In addition, participants are involved in the research process, possibly contributing to decision-making, project planning, research design, data collection and analysis, and dissemination, depending on participants' preferences (Oldenhof and Wehrens 2018).

Academic researchers are conceived as the ones who start the process of knowledge production, which is then passed on to and applied in practice (Abma et al. 2017). As a PhD researcher, a systematic review about "W*hat are the lived experiences of older people and perceptions of service providers on emergent homecare models concerning the well-being of older people in the European*

Union? It was vital because it informed on challenges older people faced when not engaged in homecare decision-making. Notably, decisions for the participatory approach with older people were informed by available research evidence. In addition, the systematic review evidenced that decisions were demonstrably rooted in that knowledge (Bettany-Saltikov 2016). Unlike traditional literature reviews, which are criticised for bias, systematic reviews are perceived to reduce bias from researchers (Bettany-Saltikov 2016). Also, the PhD researcher avoided using a survey for data collection because, according to Schubotz (2020), surveys have difficulty eliciting the more intricate and meaningful aspects of social interaction and its context and the empiricist, positivist and objectivist nature.

I was guided by Abma et al. (2019) principles that, as I conducted participatory research, I should be open to expanding or changing the ideas to adapt to the interests of participants. Change and participation were the core of why the participatory research took place. It attracted participants and brought them together. The change that older people wanted to make was in the type of future homecare they wanted.

In the present research, participants were enabled to make choices on the level of participation, bearing in mind that older people were volunteering their time and may not have time to be involved in every aspect of the research (Warwick-Booth et al. 2021). Participants did not want to engage in lengthy academic reports and, because of respecting older people's ethical rights, which are emphasised by Warwick-Booth et al. (2021), I took the facilitation and production of the report.

Intensifying older people's participation does not mean coercing older people to take roles they feel uncomfortable with or do not want to meet the criteria of a defined method for participatory but being flexible to accommodate the participation of the non-academic members (Higginbottom and Liamputtong 2015; Liamputtong and Higgingbottom 2015; Abma et al. 2019). It was essential to explain and help older people understand the options for participation. Reasonable alternatives for participation were made and probed more about the older person's preferences (Southby 2017; Cook et al. 2019).

According to Areljung et al. (2021), the idea of ownership is a given, especially since ownership may also come with risks and obligations and that ownership may transform from being a benefit or a right to being a burden as it moves between participants. Participants were regarded as homecare experts because, according to Schubotz (2020), the participatory research approach is perceived to be empowering for older people participating. However, one does not do empowerment for or to people (Abma et al. 2017). According to Abma et al. (2019) empowerment is a reflexive activity, a process capable of being initiated or sustained by the subject that seeks power or self-determination. Others can only aid and abet this empowerment process (Abma et al. 2017).

The section below describes the roles and responsibilities of the stakeholders of this current study. In the present research, there were multiple stakeholders involved. European Commission funded the study through the InnovateDignity project, and the Agreement number is 813928. Bournemouth University was the beneficiary of the European Commission and the Sponsor of this participatory study. I was a PhD researcher at Bournemouth University. Older people were significant stakeholders, and they co-produced concepts and principles underpinning homecare because they would receive future homecare services. The gatekeeper supported data collection by permitting me to recruit participants from their institution.

According to Warwick-Booth et al. (2021), stakeholders could be involved in the research process, knowledge production, dialogues, funding and co-production. Besides, according to Schubotz (2020), co-production first emerged in the UK and emphasised putting people first by using joint collaborative partnerships.

3.2.4.1 Bournemouth University’s responsibilities in online participatory research with older people

Bournemouth University was the sponsor of the study. Its responsibilities were to oversee and monitor that the study was carried out in an ethically appropriate way. The Bournemouth University Ethical Review Board assessed and approved the research protocol. The University provided all the necessary training to ensure that I fully complied and was competent to conduct the research. The university was the data owner, and they were responsible for data storage and protection.

3.2.4.2 InnovateDignity project's responsibility in online participatory research with older people

The Funder had the research ethics board, which assessed the study protocol for approval. InnovateDignity project provided extra training to ensure that I fully complied and was competent to conduct the research. It was the owner of the data.

3.2.4.3 Participants' responsibility during co-production

Older people were the primary stakeholders. The research involved people whose lives are at the centre of research in making critical decisions for the research project. Older people chose the preferred method to be used. Set a realistic time scale with the group based on what should be done, who was involved, where it would take place when each stage would happen and how it would be done. Participants were also guided by their calendars, whereby they moved around their already planned activities to fit in the research times. This required much flexibility, and older people did it with ease. Participants were also flexible and accommodated the time in between meetings for analysis of findings.

The participants agreed that I should facilitate the meetings. They were involved in research because they were allowed to ask questions to each other, including me. All the questions were respected and answered and influenced the discussion flow of the meeting. Participants agreed on the principles of working together. Participants perused the co-produced future homecare concepts and principles and made comments or recommendations. Participants validated the findings. Participants in virtual participatory groups discussed and co-produced concepts and principles after individual participants had read and commented on a draft.

3.2.4.4 PhD researcher's responsibility during co-production

In this participatory research, I partnered with older people using the inside-out pathway of co-production. According to Smith et al. (2023), an inside-out pathway is when an academic researcher invites partners to co-produce a research project. In this research, I co-produced with older people the concepts and principles that should underpin the type of future homecare that older people want. I stepped out of my comfort zone and felt challenged because, throughout the research process, I had to self-reflect and self-assess to ensure that everyone was equally involved and that no one, including myself, dominated the discussions.

Equitable and experientially-informed co-produced research acknowledged and mitigated the excessive influence of power differentials between collaborators (Smith et al. 2023). Because this was my doctoral research and during Covid-19 with lockdown and restrictions, I did a lot of organisation and preparation to ensure that the research satisfied the doctoral expectations and, simultaneously, allowed the participation of older people and to be of value to older people. Older people felt the homecare agenda was overdue and should be on everyone's table for discussion. Some older people indicated that they volunteered to participate in the research because they agreed with the agenda and objectives of the research.

When conducting qualitative research, researchers tend to find themselves closely connected to the participants in the field (Hill and Dao 2021). I fostered an inclusive decision-making process by creating opportunities for open and inclusive discussions where all participants contributed their perspectives and expertise. I ensured flexibility and availability and was sensitive to older people's fears and anxiety as I promoted transparent communication within the groups. I maintained clear and open communication channels and promptly shared information, updates, and findings with all participants. This helped build trust and ensured everyone had access to the same information. Older people were engaged in the agenda setting, which was the goals and objectives of participatory discussions.

One of my responsibilities was to enhance participation and capitalize on participants' skills and capabilities. At the same time, I ensured that participants were the key decision makers, the ones responsible for how, when, and why a project proceeds. That did not mean I was not participating in the decision-making processes. I was responsible for embodying that role in ways that reflected the participants' desires. I was responsible for drafting the protocol for ethical approvals. I facilitated interviews and discussions and balanced those that appeared more dominant than others to ensure equal and active participation by every participant.

3.2.4.5 Gatekeeper's responsibility

The responsibility of the gatekeeper has been elaborated under the method section.

The next section presents the ethics that guided this research.

3.3 Ethical Considerations

3.3.1 Permission to conduct research

This study was funded by InnovateDignity.eu project (European Commission). The Protocol for the research and the supporting documents were approved by the Bournemouth University Ethics Review Committee and the InnovateDignity project's Ethics Review Board. The ethics review for research involving human subjects is essential to protect participants' rights and safety (Ezzat et al. 2010).

3.3.2 Scientific honesty

Since the research engaged humans, all activities complied with the Declaration of Helsinki, followed good practice guidance (EU Reg. no. 536/2014), and adhered to the Charter of Fundamental Rights European Union, 2000/C 364/01 (INNOVATEDIGNITY, 2019). I have a master's in public health (MPH). Besides, I was guided by three experienced Supervisors, a Professor and a Doctor from Bournemouth University and another Professor from Aarhus University in Denmark. I completed all of the ethics courses BU required before conducting research. The courses covered research implementation and human research subjects.

According to Polit and Beck (2020), the Belmont Report covered three principles, which I complied with: beneficence, respect for human dignity, and justice.

3.3.3 Beneficence

Beneficence ensured that the research benefits were maximised and the risks were minimised because human research intended to produce benefits for the participants (Polit and Beck 2020). The older people’s voices were captured in co-producing the concepts and principles that should underpin future homecare.

3.3.4 Respect for human dignity

Polit and Beck (2020) state respect for human dignity includes the right to self, determination and full disclosure. By the right to determination, Polit and Beck (2020) meant that the prospective participants could voluntarily decide whether to participate in the study without the risk of prejudicial treatment. Not at any stage were participants coerced to participate in the study. No monetary or any form of incentives were provided to the participants (Mayan 2016).

3.3.5 Justice

Polit and Beck (2020) stated that the principle of justice included participants' rights to fair treatment and the right to privacy. The participants were not discriminated against because of their age, gender, ethnicity, economic status, religion, or education. Furthermore, they were not prejudiced for opting to terminate or withdraw from the study (Polit and Beck 2020).

The second principle of justice was the right to privacy, which was maintained, and it required that the research was not intrusive and that the participants’ privacy was maintained (Polit and Beck 2020). The study participants’ data was protected during the study, and video and audio recordings were not publicly used.

3.3.6 Consent, verbal and written

Informed consent was obtained before older people underwent any participatory research activities. Polit and Beck (2020) emphasise getting consent before any research activities. Consent was an essential document from the potential participants (Creswell and Poth 2016). It was a form of showing respect to older people. It promoted the right to required information at the right time, presented in an appropriate format to allow people to decide whether to participate in research (Smith et al. 2009).

The initial consent was through ethical application and approval from the BU and InnovateDignity project. The second consent was getting permission from the Gatekeeper. The third consent was getting permission from the potential participants to volunteer in the study. Oral consent was requested each time there was an interview or a participatory discussion group. The participants were invited to take part in a research project. Before they made any decisions, they needed to read through the Participation Information Sheet (PIS) for Interview and Participatory discussion group to understand why the research was being done, what it involved, and what they would be expected to do during participation.

The PIS covered elaborated information under these headings: Invitation to take part; Who organised/funding the research; What was the purpose of the project; Why had I been chosen, Do I have to take part; Could I change my mind about taking part; If I changed my mind; what would happen to my information; What would taking part involve; What were the advantages and possible disadvantages or risks of taking part. It also included: What information would be sought from me, and why was collecting this information relevant for achieving the research project's objectives? Would I be recorded, and how would the recorded media be used? How would my information be managed; publication, security and access controls; Further use of your information; Keeping your information if you withdrew from the study; Research findings and contacts for further information. There was a section that informed the participants about anonymised qualitative data deposited in the BU BORDaR and EU Open Access database at the end of the study, which the participant would consent for in the PAF.

Participants were advised to read the information carefully and discuss it with others if they wished. They were also to reach back if anything was unclear or if they would like more information. They could sign the Participant Agreement Form for the Interview and Participatory discussion group when they agreed with what was in the PIS. Participation was voluntary, and they could withdraw from the study at any time or choose to withhold information without penalty. Furthermore, there were email addresses of my Supervisor and Deputy Dean of Research and Professional Practice at Bournemouth University for participants to channel any complaints they could be having about the research or if their complaints related to the research were not addressed. The PAF and PIS are attached as appendices for this thesis.

3.4 Participant withdrawal

Right from the time the participant had read the Participant Information Sheet (PIS), the participant could exercise their rights to withdraw from the study. Participating in the research was voluntary. When a participant was invited into the research project, the participants' questions were considered. The questions were addressed, so the participant was well-informed when deciding to participate. In addition, participants' questions arising from contents in the flyer, PIS, and PAF during the enrolment phase were addressed.

It was specified in both the Interview and Participatory discussion group PIS that participation was voluntary, and the participant could withdraw from the study anytime they chose. The participant did not need to give any reason for withdrawal or withholding any information and did not incur any penalties. Throughout the study, the participant was respected and not intimidated or coerced to do any activity that he/she did not want.

3.4.1 Participant data when they withdraw from the research

The identifying data that could link to the participant was from the Participant Agreement Forms (PAF) and the e-mails. The participant filled in her/his age on the PAF. There was no identifiable information generated during the interviews and participatory discussion group discussions. The audios for interviews and participatory discussion groups were transcribed, anonymised, and labelled with the participant's identity number (PID), which was used instead of the participant's name.

All the identifiable and anonymised data was saved in separate folders in the BU laptop with password protection. If the participant withdrew from the study, their identifying data would be destroyed with the rest of the study participants' identifiable data when the study is closed or complete. However, none of the participants withdrew from the study after data collection. But, if the participant had requested that her/his data be removed, a note to file would have been made. The identifiable data would have been removed, but the anonymised data would remain. This was because the anonymised data would not be linked to the participant. I also managed all participants' information in a specific manner for the research to be reliable and accurate. I, therefore, protected any form of data and avoided losing it, as that might affect our analysis.

Nevertheless, if the participant was concerned about how this would affect him/her personally, the participant could raise these with the research team. Data policies were used to ensure that the participant's already collected data was safe, and those complied with were the Data Protection Act 2018 (confidentiality) and the General Data Protection Regulation (GDPR).

3.5 Risk assessment

The participants' risks of being coerced through the use of money or by a person in power, such as a researcher, were avoided (Mayan 2016). For any distress shown by a participant during the interview, they would be referred to the counsellor from the older person's care practitioner (Mayan 2016). However, throughout the research process, there were no participants that showed emotional distress.

The following risks were considered: Risks Related to the Participant, Risks Related to the Topic, Risks Related to the Relationship, Risks Related to the Environment, Risks Related to the Outcomes of the Research, and Risks Related to the researcher. During recruitment, the participants were informed that confidentiality would only be breached when risks were identified, especially risks for self-harm, harming others, and resulting from participating in the research. In this research, I did not anticipate any risk. However, discussions about future care, mainly if one talked about end-of-life care, could bring deep emotions that would be observed throughout the interviews or participatory group discussions. Should that happen, the interview or the meeting would have been stopped to address the participant's emotions. I would have recommended that the participant meet with their preferred healthcare provider if they felt they needed emotional support, as stated in the PIS.

3.5.1 Minimising risk

The risk assessment was reflexive and ongoing, and the risks were prevented. Responsibility to minimise risks was first to the participant and the setting and second to the goals of the research (Mayan 2016).

3.6 Data storage and management

The initial online Data Management Plan (DMP) under Horizon 2020 for my InnovateDignity project was created before submitting the research proposal for ethics review. See the attached appendix document for the DMP. Any data with identifiable information would be deposited in the open access at the end of the project for confidentiality. The BU Ethics review and InnovateDignity project ethics review approved the research protocol before collecting data. BU Ethics observed that there were plans to maintain participants' security and safety, including data safety and protection.

The research met the terms of BU's Data Protection Act 2018, Data Protection Policy 2020, GDPR, 8B – Research Ethics Code of Practice: Policy and Procedure (2022). There was a version control log with each version's date and a short description of an amendment made to the previous version. This made it easier for the user to track the changes on all versions. Versions were numbered sequentially as they were developed, for example, v1.0, v1.2, etc. Different versions must never hold the same version number and date nor the same version number with different dates.

The data to be collected did not exceed the storage amount required and would not require extra financial costs but would require time costs to prepare the data and have it ready to deposit into the BU BORDaR and EU Open-Access database. The financial amount needed for depositing data into BORDaR was included in the tuition fees for my PhD. As a researcher, I generated data, used it for analysis, managed it, cleaned it, and monitored data backups, which would be maintained until data was deposited into the open-access database.

During the three years of research implementation, the identifiable data from the study enrolment, the Participant Agreement Form (PAF) and enrolment e-mails and telephones were kept safe in BU laptop with double-password protection. It was only me that had access to all the identifiable data. The identifiable data was kept until the PhD viva completion.

Upon completion of PhD viva, the identifiable data would be disposed of within a post-completion month. The identifiable data would be permanently deleted from all the BU network drives. The File Shredding and Secure Deletion with the IT

Officers' help would be used to ensure that the information would not be retrieved. A report would be written to explain how identifiable data was erased, which date data was destroyed and who destroyed the data. Information about identifiable data shredding would be saved for the research audits if needed.

The qualitative data collected during the semi-structured interviews and participatory group discussions had no identifiable data. However, the transcriptions were anonymised in case the participant said something during the audio recording that could identify him/her or other participants. All the anonymised data from semi-structured interviews and participatory group discussions were kept in the BU. H drive and L drive and backed up in One Drive. The inbuilt virtual communication audio recording system was used to record the interview and participatory group discussions. Audios were saved in the BU H drive and L Drive in the BU laptop with password protection.

Data was backed up in three places, and the laptop was double password protected, which had 14 characters, and the password was changed every 60 days. BU used a network server, preventing data loss in case the laptop crashed. Once transcripts were anonymised, the Supervisors and the auditors had access to that data. Supervisors and auditors ensured that quality assurance was carried out throughout the study.

I had a probationary review and a major review as a form of quality control by Bournemouth University, and both were successfully achieved and met the required research criteria. Furthermore, I met with my Supervisors once every week for the first year and then once every three weeks until the completion of her project. During these Supervisory meetings, we discussed the project's technical issues, and they provided guidance and feedback on what I had previously submitted to them. In addition, they provided psychological support during the Covid-19 pandemic and lockdowns.

Upon completing my PhD viva, I will use the next three years to publish all the required publications. After three years post-publication, I will prepare the anonymised qualitative data to deposit into the BU BORDaR and EU Open Access database within three months. The anonymised qualitative study data will be made available for re-use by other researchers on the 30th of March 2026.

That is when the completion of publishing articles is anticipated, as per the InnovateDignity project agreement. Before depositing qualitative data in the EU Open Access database and BORDaR, the qualitative data collected from semi-structured interviews and participatory group discussions will be further anonymised, cleaned, and formatted in plain text comma-separated values (CSV), and Geo-referenced. This format was chosen because the UK Data Service recommends it for data sharing, re-use, and preservation. Microsoft Excel was not selected because of its proprietary, which limits its openness to being accessed by the public. Audio recordings would not be deposited into the open-access database.

Standardised, interchangeable or open formats ensured the long-term usability of data. Data was more explicit to understand and easy to use. Comprehensive data documentation was done right from the start of data generation. There were study documents/forms codes and version control list forms, which had all names, codes, and versions of the study's documents, with amended versions and dates. Files structuring was done to enable a more accessible location of documents. I provided the keywords recommended by the social and health sciences field for other researchers to reach the data when using them.

The anonymised qualitative data would be deposited in the EU Open Access database and BORDaR, which used the Dublin Core metadata standard. In addition, the UK Data Service was used for guidance on organisation, versioning, transcription, quality and formatting. The data that was produced at BU aligns with the Findable, Accessible, Interoperable and Re-useable (FAIR) principle because this maximised the utility and value of research data. The controlled vocabulary used to describe datasets will be documented and resolvable using globally unique and robust identifiers.

This documentation would be easily findable and accessible by anyone using the dataset. Standard vocabulary or keywords would be used to allow easy understanding and inter-operation ability by researchers between different disciplines. The data will then be deposited into the EU Open Access database, and BU BORDaR and made available on Creative Commons License (CC License) because it would allow other researchers to access data for various purposes with copyrights or acknowledging the source or creator of the data. The

Digital Object Identifiers (DOI) will be generated for the dataset. This DOI would be found in the thesis or other publications that would be written from this data. BU BORDaR Open Access Data will be kept for ten years as dummy data after depositing data into the EU Open Access, where the data would remain there.

InnovateDignity project was part of the Horizon 2020 pilot for Open Research Data (ORD) to improve and maximise access to and re-use research data generated by Horizon 2020 projects. The InnovateDignity project enabled the research findings to be included in a confidential policy document for national and international policymakers. Once the data was in the BU BORDaR Open Access Database, it would be deposited or dumped in the EU Open Access Database, and BU BORDaR would manage the dummy data.

3.7 Reflection on methodology

In summary, chapter 3 described why qualitative design with the applied participatory research approach became the methodology of choice. The participatory approach methods are dynamic and cannot be one size fits all. Participatory research methods are still developing. Again, their characteristics overlap, and the dynamics of the disciplines and population in which they are being applied could make it challenging for researchers who want to implement the methods. The major strength of Participatory Research is its strength to potentially integrate academic and theoretical perspectives with lay and implicit knowledge to unveil new insights and understanding of the phenomena under investigation (Higginbottom and Liamputtong 2015).

The participatory research enabled the lived experiences of older people to be integrated with academic knowledge and the lifeworld-led well-being and suffering theory of Galvin and Todres. And again, because of the flexibility of the participatory approach, there was collaboration and co-production of future homecare concepts and principles with older people. Higginbottom and Liamputtong (2015), attest that researchers can retain some authority when there is a representation of older people through collaboration. Retaining some authority helps the PhD researchers to own the research. Participatory research was applied because, according to Higginbottom and Liamputtong (2015), older people, who could be the vulnerable group, experience a lack of autonomy or voice in their homecare. In the systematic review, older people criticised the lack of engagement for older people in the decision-making of their homecare. Participatory research focused on the needs of older people, and co-production enabled older people to effect changes in homecare. In addition, co-production gave power to older people because older people learnt from the rich and dynamic lived experiences of other older people.

The use of creative methods within co-production, like the data-generating approach through discussions and dialogues and older people perusing draft documents findings from co-produced future homecare concepts and principles, lends itself to the production of research outputs that are non-traditional and move away from text-based formats (Higginbottom and Liamputtong 2015). Co-production deepened trust because older people generated information from their lived experiences, put across questions during discussions, and perused findings of co-produced future homecare concepts and principles.

3.8 Research method

3.8.1 Engaging older people as co-researchers

According to James and Buffel (2022), in the past 20 years, the interest in co-research with older people has grown, yet few published studies have addressed why and how older people have been involved as partners in research. Again, Buffel (2018) attests that due to the ageing of the population, there is a need for more inclusive and responsive policies and services, leading to growing interest in co-production and co-research with older people. Some literature reveals that some factors contributing to the interest in using co-production methods with older people are the growth of self-advocacy movements, with groups of older people asserting their right to be active participants in research, policy and service (Goulding and Phillipson 2019).

Co-research in this thesis refers to research conducted with older adults rather than about them as research subjects. The prime motivation for doing co-production research with older people was to explore the type of future homecare they want and co-produce the concepts and principles that should underpin homecare and reshape future homecare with older people. The research is meant to improve the health and well-being of older people by understanding what really matters to older people in homecare. The systematic literature review in chapter 2 of this thesis showed that older people want to have their voices heard, their experiences understood, and their skills recognised and used by care providers. They also want care providers to involve them in designing strategies for their homecare. We need to co-produce homecare strategies with older people to meet their care needs.

Understanding what mattered to older people required small or big actions from individual older people or collectives to which older people volunteered their time to make a successful co-production (Jonasson et al. 2023). I wanted to co-produce homecare concepts and principles underpinning future homecare for older people so that they can inform care providers when designing or implementing homecare for older people. I co-produced with older people because my perception was that older people were experts and had the knowledge and skills to create innovative solutions for future homecare. James and Buffel (2022) believe that older people should be involved in creating change in policy, services and practice.

Cotterell and Buffel (2023) describe that co-research situates participants as joint contributors, involving them throughout all stages of the research process, from the design to the dissemination of findings. However, as a PhD researcher, it was impossible for me to include older people in all co-production stages. However, open discussions, transparency, flexibility, enabling choices, developing trustworthy relationships, enabling safe discussion spaces, and balancing power dynamics gave older people a meaningful co-production. When I met with individual older people, I first explored to understand what homecare, meant to them and if they found the homecare subject of value. This helped me understand older people's intention to participate in the co-production of future homecare concepts and principles.

The current research was funded by the European Commission and sponsored by Bournemouth University. The idea was generated before I met with older people. Cowdell et al. (2022), attest that, to some extent, research idea generation is inevitable because until researchers know the question they are addressing, they are not able to seek older people with the required knowledge and experience. In addition, all research activities have to be resourced, and until funding is secured, it is not always possible to progress (Cowdell et al. 2022). The expectations from university and academic sponsors also influence the depth of participation. As a PhD researcher, I needed to follow all the stages of the research process whereby I had to review the literature, develop the proposal and have the proposal approved by the University Ethics Review Committee (ERC) and the project ethics board before meeting with the potential participants.

The funding acquisition process and academic expectations challenge older people's participation level because, in this case, the citizen control level of participation cannot be attained, whereby older people initiate and drive the research with total control. In addition, as an academic PhD researcher, I needed to show my academic sponsors and funder the skills I acquired during the research process. As a result, older people were involved in co-production from the data collection stage to the analysis stage by reviewing the drafted and analysed findings, discussing them in the participatory discussion groups, developing dissemination of findings plan, and disseminating the findings.

Again, regarding the involvement of older people in all stages, since the intention was to have joint action and shared responsibility, older people chose how they wanted to participate. James and Buffel (2022) expressed that sometimes, co-researchers resist the participatory nature of the study and that active involvement was not always what older people wanted or could commit to. I believe older people should be empowered to make choices in the current co-production. As a result, I provided older people with information regarding different roles, empowering them to make informed, independent decisions. When older people said no to active participation in analysis and report writing, I did not consider it as resistance to participation but rather that older people were empowered to say no and exercised their freedom to make authentic choices.

However, older people instead chose to peer review the findings draft, which I considered exceptionally valuable as we also discussed the draft following their contributions. And those who did not contribute on the written draft contributed their view during draft discussions. I did the best possible way to ensure flexibility so that co-production does not burden older people. I ensured that older people felt safe and listened to and that all their participation levels and contributions were equally valued and appreciated. I also ensured that all participants, including me, held equal power during co-production research and that the level of participation did not reduce their power level during co-production.

Littlechild et al. (2015) point out that an acknowledgement of power differentials and a willingness to share professional power are fundamental to establishing successful research relationships in co-research with older people. In the current research, the participation, power sharing and ownership of research were discussed and determined from the onset of the initial meeting with older people. Since the co-production was online, older people were provided with information to understand why they would be involved and hence made informed choices. Participatory information sheets were used to enhance transparency in addition to the discussions held when older people agreed to participate.

Other limitations of co-research in which I developed participatory information sheets (PIS) were acknowledged and shared with older people during the individual interviews and initial participatory discussions. Older people acknowledged that sharing PIS enhanced transparency and clarity in knowing what they would be involved with, enabling them to make informed decisions and choose to participate in the research when they knew what it was about and if it was valuable. Furthermore, it helped them clarify their roles and the researcher's roles in the co-production research.

Some limitations were that the academic funder and sponsor required that, as a PhD researcher, I produced outputs such as a thesis upon completing the participatory research. Again, being a PhD researcher, I was also required to show that I owned the research and that it was my original idea. My level of involvement in research was also observed through my level of participation and power-sharing, which, in my case, was slightly restrained as a PhD researcher and with co-researchers. To gain the support and cooperation of older people, I discussed the co-production limitations from the beginning during the individual interviews because I also wanted to be open and transparent about the whole process. Littlechild et al. (2015) state that a key learning point for an academic researcher is that if the research has to be genuinely co-research in practice, openness, flexibility, sensitivity, and responsiveness are paramount requirements.

As a PhD researcher, I always had a slightly upper power, and what was important was that I had open, inclusive, transparent communication with older people, which older people understood and supported and ensured the project's success. Co-production actively uses service users' implied knowledge, skills and experiences (Farr 2018). Older people felt equally valued because they acknowledged the academic funders and sponsors for allowing me to research homecare matters as a PhD researcher.

Another way that I achieved power balance was that I created safe spaces for older people to co-produce future homecare concepts by excluding care providers as co-producers and working solely with older people. Older people believed that care providers protected their strategies and would not genuinely co-produce with older people. However, as a PhD researcher and an outsider researcher, older people felt free to discuss all health and social care provision sectors that impacted their care at home. Most importantly, I informed older people that I would learn from them as an outsider researcher. Being an outsider also helped prevent the biased analysis of their perceptions, such as if I belonged to one of the UK care providers. And because older people valued and regarded the co-production of future homecare concepts and principles as their essential project, they wanted the outcome to reflect what mattered. Older people guided the discussions since unequal power imbalances were resolved and equal inclusion was enhanced, giving equal weight to every older person's opinion or perception. Older people advised the researcher because they all shared their unique homecare experiences and described how the UK homecare system worked, where they experienced barriers or challenges from the homecare system, and the type of future homecare they wanted.

As a researcher, I used skilful facilitation to manage the dominant and silent participants to prevent tensions that could arise when there was a power imbalance and limited inclusion during the discussions. I respected, valued, listened to, and engaged all older people, ensuring that I was committed to empowering all participants. I equally received respect, was valued, and listened to, and all older people engaged me, and they all committed to empowering and supporting me. Older people were very empathetic towards me. The relationship was reciprocated since older people made me feel valued, heard and engaged when I facilitated the homecare discussions. Older people valued the relationships I developed with them and how I facilitated the co-production processes. Older people were also committed to empowering me with the homecare system of the UK and their perceptions, experiences and barriers in the homecare. Mey and van Hoven (2019) attest that older co-researchers can converse and empathise with interviewees, who then feel more at ease sharing their perspectives with a peer researcher, leading to richer data. In this research, positive relationships were developed, nurtured and maintained since I found it not time-consuming.

Despite the restrained co-production as PhD researcher, I took the following steps to enhance co-production. I used the systematic literature review, which explored the impact of emergent homecare models on older people's well-being, which I carried out in chapter 2 of this thesis to inform the current research aims, objective and methodology. The recruitment was open and inclusive of all older people in the community. According to Cowdell et al. (2022), some projects included only researchers or older people from specific groups, like working only with older persons with dementia to prepare and support them. This research included all older people because homecare services are provided to all older people with complex ailments. However, in the current research, I recruited older people from an organisation to create a safe space since the research was done during the Covid-19 pandemic lockdown and was done online. We participated in discussions and dialogues using the virtual Zoom platform, as older people preferred Zoom.

The participatory research team consisted of older people and me as the academic researcher. Together, we dialogued about future homecare. During these dialogues, it was not “you” and “I” but “we” and together, co-producing concepts and principles for homecare that we all responded to differently and contributed to. These dialogues enabled openness between older people to come closer to what mattered to them in homecare. During these discussions, when older people moved between past and present homecare experiences and perceptions of future homecare, older people created meanings of their experiences and perceptions of future homecare.

I openly recognised and acknowledged older people’s valuable contributions during interviews and participatory discussions since they experienced homecare support services. Older people’s experiences shaped the type of future homecare they wanted. The co-production of concepts and principles underpinning future homecare was considered at the earliest stage of engaging older people, since the co-produced product could impact the design and implementation of future homecare. Care providers and policymakers would be guided by the recommendations from concepts and principles co-produced with older people.

I ensured that older people meaningfully contributed to co-production and that older people’s contributions directed how I worked with older people. Furthermore, I openly ensured that what was addressed was informed by older people and that it mattered to older people. Since co-production encouraged learning, older people were taught definitions of concepts and principles so they could knowingly describe what concepts and principles meant for them during the participatory discussions. Simultaneously, older people taught me how the homecare system worked in the UK.

I also clarified the use of digital technology, which facilitated access and participation of older people in the co-production of future homecare concepts and principles. Participation of older people did not stop after the 4 meetings with older people but continued because as I wrote the thesis, I regularly consulted older people on the progress of the report and all other events related to disseminating the findings. Older people were invited to conferences so that they could participate. However, the challenge was that all conferences held were outside the United Kingdom, and the limitation of funds strained their attendance. Some older people contributed to presenting findings during conferences because I used the Pecha-Kucha model to present findings at one of the conferences. I needed 20 slides with pictures to present the findings. Older people contributed pictures that did not have their identities to be used during the presentation. Also, some older people were contacted during the thesis write-up to clarify certain sections. The findings on a homecare tree were shared with older people for their opinions, which I believed was another co-production peer review that older people contributed to. Older people shared the findings with their groups. Some older people simplified findings in a layman's language to present to other older people in board meetings. They shared their presentations and requested that I review language simplicity for them to present.

My position was that older people should actively participate in the co-production research because they were experts in homecare and had massive valuable knowledge and lived experiences that contributed to the co-production of concepts and principles that should underpin future homecare that older people want. Furthermore, co-production could enhance older people's well-being and dignity. My role in this research was to facilitate co-production research activities such as discussions, data collection, analysis and co-production of home concepts and principles, and co-production of dissemination of findings plan. In addition, I also explored older people's perceptions of the use of virtual communication as a data collection tool for participatory research. This was to understand how older people viewed their involvement in the current co-production during the Covid-19 pandemic lockdown.

My experience of co-producing with vulnerable groups

Even though I had not worked in homecare, I had worked in different levels of healthcare at community, regional, national, and international levels. I have worked with health and care projects in developing and developed countries to support governments in strengthening health systems to ensure that people who could not access certain healthcare services were supported to access those services. The vulnerable or excluded groups I had supported from accessing certain public health services were children, women, lesbians, gays, bisexuals, transgender people, queers, sex workers, prisoners, people living with HIV, nurses and immigrant women. From my experience, the success of developing pertinent solutions was through the involvement of the affected people in exploring perceptions and co-producing a solution. From my experience, when involving affected people, I got an in-depth understanding of perceptions from different angles as described by affected people because, as an outsider, I valued every piece of information and took nothing for granted.

Co-production with older people is more than participation.

Participation of older people in this research was more than participation in data collection because, in addition to the knowledge from lived experience that older people brought into the co-production research, they actively planned the time schedules for interviews or discussions. Older people chose virtual Zoom as a platform for carrying out virtual meetings. Furthermore, older people decided on the type of future homecare to discuss. They contributed to the report writing by peer-reviewing the drafted co-produced concepts and principles of future homecare. Older people also peer-reviewed the homecare tree that presented findings during thesis writing. They produced materials used in conference presentations. They co-produced a dissemination plan, and some older people disseminated the findings. During the meetings, I ensured an equilibrium of power, and there were no signs of a power struggle between older people and myself as we all agreed to be inclusive, respectful, empathetic and listen to each other.

Older people showed much empathy for one another, and participatory discussions were therapeutic for most older people as they were counselled by other older people when they shared emotional experiences, which some reported they had never shared. Some older people provided advice on how they resolved homecare issues similar to those shared by some older people. During the individual interviews and participatory discussions, it was agreed that older people could also pose questions to each other or the researcher during the interviews. As a result, their questions were discussed and addressed during the participatory discussions. When older people posed questions during interviews, I shared the questions during the participatory discussion group. Questions posed during the participatory discussion groups were also shared with other participatory groups for discussion. Asking questions was an innovative way to involve older people in co-producing interviews and participatory discussion questions during collaboration, which made older people feel valued since every piece of information was valued. It also balanced power sharing in co-generating the information about the type of future homecare that older people wanted. The environment was conducive and safe because we agreed that everyone's contribution during the discussions was valuable. In addition, there was no right or wrong answer during participatory discussions, and questions directed to individuals or groups were to be answered before moving on with the participatory discussion.

Future homecare subject was valuable

After all, older people considered future homecare an essential subject because they indicated they were baby boomers. As a result, the co-production of homecare strategies with older people should have started ten years ago. During individual interviews, older people described the type of future homecare they wanted. There were no prepared survey questions, and the lack of prepared survey questions gave older people the independence to discuss their unique individual experiences of homecare. Co-production methods emphasise the importance of breaking the barrier between the researcher and the researched by harnessing the non-academic, local knowledge of the people to act upon and solve local problems and create a meaningful impact relevant to policy and practice (Littlechild et al. 2015).

3.8.2 Research setting

The research setting is where the data was collected (Polit and Beck 2020). I acknowledge that the importance of involving all older people's in this research was limited because of funding, limited time of 36 months for the project, time delays due to Covid-19 pandemic lockdowns challenges that made it challenging to include the general population of older people, including the easy to ignore older people who often do not join organisations or lack capacity. When discussing reasons for choosing the organisation as a research setting with older people, they indicated that it is often difficult to find an organisation with all the various types of older people. The reason was that not all older people joined the organisations as they found membership subscriptions expensive. Some older people indicated they had friends from certain ethnicities who did not join organisations because they felt they did not belong, even though the organisations supported diversity.

Literature shows that despite rigorous efforts from organizational leaders to promote diversity and inclusion, inequity concerning diversity and inclusion persists in many organizations and sectors (Bernstein et al. 2020). Bernstein et al. (2020) argue that the dynamics that sustain self-segregation undermine inclusion by minimizing opportunities for meaningful interactions. Due to this limitation, older people recommended that with future research, researchers could deliberately target the easy-to-ignore older people from various ethnicities and socio-economic backgrounds for diversity and enhanced inclusion. Older people also discussed how easy-to-ignore older people could be easily affected by structural barriers.

Removal of structural barriers and engagement of older people without structural coercion because structural coercion often arose due to factors connecting to socioeconomic context, research design and power relations among research stakeholders (Nyirenda et al. 2020). Nyirenda et al. (2020) further attest that socioeconomic disadvantages compelled some people to enrol in research expecting economic support without fully understanding the specific research objectives or the risks involved. For the current research, older people were not coerced to join the research. Transparency and ethical standards were upheld to prevent harm from structural coercion to older people.

Permission was requested from an organisation that had people who met the study’s enrolment criterion. For confidentiality, the organisation's name would not be revealed. The identified organisation conducted learning and leisure activities for older people in the United Kingdom (UK). The organisation had a countrywide connection in the UK of learning groups to inspire older people to share their knowledge, skills, and interests in a friendly setting. The organisation had 1,057 branches with over 450,000 members in the UK.

The organisation encouraged lifelong learning, and its members comprised a diverse group of older people and carried out various activities. The following were some of the organisation’s group activities: Arts, history, literature and language, crafts, gardening, photography, computer, and digital technology skills. The groups sometimes arranged trips to museums, concerts, and theatres. People could become members when they had ended full-time employment, making the organisation attract members 50 years and above.

3.8.3 Study population

The study population is the people, things or events that are being studied (Holland and Rees 2010). In participatory research, people who are being researched become co-researchers or active participants in research, where they can volunteer to participate in all other stages of research (Schubotz 2020). Nonetheless, the literature suggests that the characteristics impacting participation are broad and their effects multifaceted, directly impacting participation (Petriwskyj et al. 2017). Understanding inclusion in ageing communities needs to consider the complexity and diversity of the older population within its context and the breadth of ways diverse characteristics can influence how and why people may be excluded from opportunities or limited in their contribution (Petriwskyj et al. 2017).

Despite that, co-production work has become increasingly valued in care, it is used less with older people (Cowdell et al. 2022). According to Cowdell et al. (2022), co-production could represent lay people and professionals working as equals at every stage in the research process, even though in most research, details about the constitution and expertise of the research teams in these studies are sparse. Such considerations include but are not limited to knowledge production and dissemination, including paying attention to diversities in the research (Waymer et al. 2023). Current participatory research intended to have diversity and inclusion of all older people through transparency since diversity and inclusion of older people enhanced older people's voice, power, and feeling equally valued and heard in co-producing the type of homecare that older people wanted. The current research also focused on co-producing concepts and principles for designing future homecare, and co-production required that older people and myself ensured that all the necessary views, experiences, skills and knowledge were included and informed the project, as guided by (Cowdell et al. 2022).

Any older person who could read and respond to the research flyer was included to boost the inclusion of all older people. Reading was a prerequisite because the research was online participatory research and required one to be able to read shared documents before one volunteered to participate. It is worth noting that environments could be diverse and non-inclusive concurrently. Nevertheless, inclusion is vital as a connecting thread that stitches diversity and equity together to create welcoming and participatory climates (Waymer et al. 2023). Emerging participatory governance approaches strive for genuine and inclusive participation by all citizens (Petriwskyj et al. 2017). However, opportunities for inclusive participation by older people in local governance are made more complex by their diversity, which can shape who participates, in what ways, and how effectively (Petriwskyj et al. 2017).

Literature also shows that researchers need to consider diversity in their samples to enhance inclusion by participation (Waymer et al. 2023). Diversity refers to all aspects of social identities and human differences, including but not limited to creed, colour, culture, (dis)ability, ethnicity, gender identity, political perspective, race, religion, sex, sexual identity, and socio-economic status (Waymer et al. 2023). Inclusion refers to fostering an environment where all members experience a sense of belonging and feel they are respected (Waymer et al. 2023). Nevertheless, sometimes, the involvement of community leaders, government stakeholders, and power inequalities among research stakeholders often affect some participants’ ability to make autonomous decisions about research participation due to profound structural power imbalance (Nyirenda et al. 2020). Despite that, the key premise of co-production is that to address complex problems, scientific expertise alone is insufficient and that the contribution of stakeholders’ knowledge is vital to create knowledge that is not only of high scientific quality but also socially robust (Turnhout et al. 2020).

In the current research, older people were not mixed with care providers during participatory research with co-production to minimise structural power imbalance based on social-cultural biases, that care providers could better articulate a contribution that was considered relevant and essential because they were considered to have more knowledge and skills (Turnhout et al. 2020). Biases towards elite actors are worrying because they exacerbate existing inequalities (Turnhout et al. 2020), and this also affects the outcomes' quality, usefulness, and legitimacy since they often produce solutions that are less likely to resonate with and are usable for laypeople.

Older people were better alone with the researcher, and this enhanced trustworthy, safe participatory discussions and active co-production without older people feeling less knowledgeable and assuming the socio-cultural bias that care providers, were more knowledgeable and hence needed to make final decisions during the research. As a researcher, I needed to acknowledge and understand the more inclusive participatory processes that achieve successful empowerment in co-production projects (Turnhout et al. 2020). Furthermore, identify social processes that contribute to or hinder the development of values and actions that enable inclusive and reciprocal co-production (Kjellström et al. 2019).

3.8.4 Sampling

Emerging participatory governance approaches strive for genuine and inclusive participation by all citizens (Petriwskyj et al. 2017). However, opportunities for inclusive participation by older people in local governance are made more complex by their diversity, which can shape who participates, in what ways, and how effectively (Petriwskyj et al. 2017). Literature also shows that researchers need to consider diversity in their samples and enhance inclusion by participation (Waymer et al. 2023). Diversity refers to all aspects of social identities and human differences, including but not limited to creed, colour, culture, (dis)ability, ethnicity, gender identity, political perspective, race, religion, sex, sexual identity, and socio-economic status (Waymer et al. 2023).

Kjellström et al. (2019) argue that concerning inclusion in co-production, we are witnessing a political and socio-cultural mindset shifting from “experts know and decide everything” to “we need to decide things together’’ as a way of enhancing the voice of service users. Conquer (2023) also concurs that co-production moves culture and practice away from more traditional and less person-centred methods of ‘doing to’ people towards a ‘doing with’ in the context of public service provision. In the context of health and care services, people are increasingly characterised as designers, learners and actors who can take responsibility for their health and shape the outcomes they desire from organisations. Inclusion refers to fostering an environment where all members experience a sense of belonging and feel that they are respected (Waymer et al. 2023).

The systematic literature review in chapter 2 of this thesis showed that older people criticised the lack of their involvement in the decision-making of their homecare(Lynch et al. 2018). Lack of involvement made older people feel like their freedom has been taken away, leaving them with fear and anxiety (Spoorenberg et al. 2015; Elfstrand et al. 2017; Lynch et al. 2018). I intended to include all older people who could read and respond to online flyer regardless of social identity, creed, colour, culture, (dis)ability, ethnicity, gender identity, political perspective, race, religion, sex, sexual identity, and socio-economic status. Receiving homecare services was neither a requisite for inclusion because my assumption as a researcher was that all older people should be given the opportunity to describe the type of future homecare they wanted. Again, an increasing ageing population is leading to greater demand for care services in the future to help maintain older people in their homes (Horgan et al. 2020). Furthermore, Horgan et al. (2020) attest that there has been strong interest in developing innovative and cost-effective interventions to support older people living in their homes and, in turn, to reduce demand for acute hospital services and residential care provision.

Engaging all older people to inform the type of future homecare was a way of enhancing democracy, transparency, voice and inclusion of older people in informing the design of future homecare. Because with guidance from Gheduzzi et al. (2020), co-production enabled older people to participate and express their needs and expectations and influenced the definition and implementation of future homecare services, reducing the divergence and mistrust older people had towards care providers. In addition, co-production offers a valuable opportunity for vulnerable groups of actors to be heard (Gheduzzi et al. 2020).

The purposive sampling method was used. Purposive sampling is a group of sampling techniques that rely on the researcher's judgement when selecting the units, people, cases/organizations to be studied (Sharma 2017). Homogeneous purposive sampling is a form of sampling which focuses on candidates who share similar traits or specific characteristics (Etikan et al. 2016). For example, participants in homogenous sampling would be similar in terms of ages, cultures, jobs or life experiences (Etikan et al. 2016). The idea is to focus on this distinct similarity and its relation to the researched topic (Etikan et al. 2016). The current research sampled a homogenous group of older people to explore older people’s perspectives on how they would like future homecare to be delivered and collaborate with older people to co-produce concepts and principles that should underpin future homecare delivery. All older people were included despite whether or not they receive homecare. This was because discussing the type of future homecare one wanted does not require that one should be currently on homecare.

3.8.4.1 The demography of the research participants

There were 14 participants who volunteered for the virtual individual semi-structured interviews. The same 14 participants also volunteered to join the virtual participatory group discussions. All participants were consistently involved except one who missed two out of 4 meetings due to being hospitalised. In contrast, another missed one meeting out of 4 meetings because of attending the burial of a family member. Participants could read and write. 13 participants contributed to perusing the draft of co-produced future homecare concepts and principles because the 14th participant was hospitalised then. They also appreciated how I facilitated the participatory meetings and interviews.

The participants were all older people. Service providers were not included in the samples to minimise the structural power of service providers, influencing the perception of older people on the type of future homecare they want because care providers have their perception of homecare. Different perceptions from those perceived as knowledgeable and skilful to those considered to be lay sometimes lead to collaboration power tensions (Turnhout et al. 2020). Literature shows that co-production studies have significant gaps because they never discuss how the tensions between service providers and users may influence engagement and collaboration since researchers discuss only the process and outcomes (Park 2020). Park (2020) argues that the lack of attention to service user-provider tensions significantly undermines co-production studies' potential to evaluate the strengths and limitations of collaborative efforts and explore alternative means of co-production beyond traditional user-provider collaboration.

Turnhout et al. (2020) recognised the depoliticising of co-production whereby many co-production projects are led by a rationale of science-driven impacts and do not challenge existing hierarchies between scientific and other knowledge holders, which then means that co-production serves to reinforce existing structures of power that privilege scientific knowledge over other ways of knowing. In addition, depoliticization can be recognized in the tendency of co-production projects to strive for consensus and rational solutions according to elite perspectives. However, it may cover fundamental differences among participants in terms of stakes, power, access to resources, vulnerability, and risk (Turnhout et al. 2020).

The current research did not focus on reaching a consensus with questions and findings older people perceived. However, it focused on understanding what various older people perceived as significant. As a result, the exclusion of care providers was in recognition of the politics of co-production in research to create a safe and trustworthy space with a power balance for older people to have dialogue and share experiences for successful co-production. With the desire to give older people space on the table to visibly illuminate their perceptions on the topic that mattered to them, older people were treated equally as experts and felt valued because everyone’s knowledge contribution was valuable.

The study participants were all English from the United Kingdom and were all from the white ethnic group. It showed through the discussion that some had parents from other white European ethnic groups. Diversity, equity, and inclusion

(DEI) are increasingly referenced ideas in planning practice (Ashley et al. 2022). Despite the research being open to all ethnicities, it showed that other ethnicities did not join. According to Gagnon et al. (2022), inequality, diversity and inclusion studies, there is some belief that research will advance equality and inclusion. However, scholars increasingly point to a gap between theory and practice to achieve change (Gagnon et al. 2022).

The chosen organisation was a research site with diverse and inclusive structures; nonetheless, it showed that not all older people from diverse backgrounds joined the research. Bernstein et al. (2020) argue that sometimes there is self-segregation whereby people get attracted to people they perceive as similar, called homophily in the sociological literature, creating distancing between racial and ethnic groups. Without deliberate intention to look out for these older people and invite them to join the research to enhance inclusion, those older people could be easily ignored, missed and underrepresented in the samples (Bernstein et al. 2020).

With the current research, I could not expand on a targeted approach to look for other ethnicities or older people of particular socio-economic backgrounds because the research protocol was general in inclusion and did not label specific ethnicities or certain socio-economic backgrounds. This sample could help future researchers target ethnicities and particular socio-economic backgrounds that did not join the research to understand their perception of future homecare. When engaging with diverse groups of older people and building the relationship between the researcher and older people, Gill et al. (2018) indicated that focusing on cross-cultural communication is vital when approaching diversity in groups. During communication, I validated different perspectives and demonstrated a willingness to talk about differences, which helped me achieve a positive outcome, and this involved listening, reflecting, and non-judgemental methods, as supported by (Gill et al. 2018).

The 14 participants were aged between 63 years and 89 years. Of the 14 participants, there were only five males. Herlofson and Brandt (2020) indicate that European family members care for their older parents at home. Furthermore, these carers are often females compared to males (Sharma et al. 2016). This could also have been the reason that more females participated than females. In their homecare research, Gruneir et al. (2013) found that women outnumbered men but that men presented with higher levels of need in homecare.

All participants had capacity even though they suffered from various chronic ailments. Most participants considered themselves as middle class, though some considered that they could not economically afford the homecare services and depended a lot on volunteers and family to care for them. Those older people with better socio-economic backgrounds also described the challenges they experienced in homecare because the UK has fragmented and multifaceted homecare support. UK, social care is currently centralised, standardised and with institutional power through the national care service, giving policymakers more power to decide on the type of homecare for older people (Needham and Hall 2023b). In addition, older people in the UK still get their task-based homecare support from different sources, such as formal, private, voluntary, and informal, from family members such as relatives, partners, children, friends, non-governmental organisations, churches, formal from, social care services and NHS (Clements 2014).

Table 3-1 Demography of the study participants.

Participants	Age	Gender	Residence	Type of homecare	Racial ethnicity
PT01	74	Female	Home	Self-funder +informal	White English
PT02	63	Female	Home	Not in homecare	White English
PT03	89	Female	Home	Informal homecare	White English
PT04	73	Male	Home	Self- funding Private homecare	White English
PT05	82	Female	Home	Not in homecare	White English
PT06	78	Male	Home	Not in homecare	White English
PT07	74	Female	Home	Informal/voluntary	White English
PT08	68	Male	Home	Not in homecare	White English
PT09	78	Female	Home	Informal + self-funder	White English
PT10	80	Female	Home	Informal + self-funder	White English
PT11	75	Female	Home	Informal + self-funder	White English
PT12	78	Male	Home	Not in homecare	White English
PT13	79	Female	Home	Informal	White English
PT14	80	Male	Home	Not in homecare	White English

One organisation with people who met the study's enrolment criterion was purposively chosen as the study site. The sample size depended on whether there were no more new themes emerging from the participants' responses during virtual interviews (Saunders et al. 2018). I facilitated three separate series of virtual participatory discussion groups.

- Participatory discussion group 1 (FG1)
- Participatory discussion group 2 (FG 2)
- Participatory discussion group 3 (FG 3)

Fewer persons per group were because virtual communication was used, and so that every member could be visible and have time to contribute. Qualitative research used a small sample because the interviewer interviewed participants in-depth to understand the phenomenon under study (Dworkin 2012). Each virtual participatory discussion group met 3 times and had up to a maximum membership of 5 participants. In order to integrate the findings and maintain the older people`s participation, on completion of meeting 2 of the virtual participatory discussion groups, a draft of co-produced concepts and principles for homecare was shared with all participants to comment on via e-mail. The draft of co-produced future homecare concepts and principles was discussed with older people in meeting three where, in addition, participants shared their experience of virtual data collection.

3.8.5 Virtual recruitment

Recruitment is the process of inviting older people to participate in the study (Ritchie et al. 2014). Different methods can be used to generate study awareness and encourage participation, like using flyers and emails (Ritchie et al. 2014). Recruitment materials should be adapted to the target group to ensure they are clear to the target audience (Ritchie et al. 2014). The flyer and email were used to invite and recruit older people into the study. Gatekeeper shared the flyer with organisation members.

The diagram below shows the 10 steps of the virtual recruitment process for the current study. The initial step was with the gatekeeper, whereby approval was requested to use the research site for data collection. The final step was sharing the findings with participants and the gatekeeper.

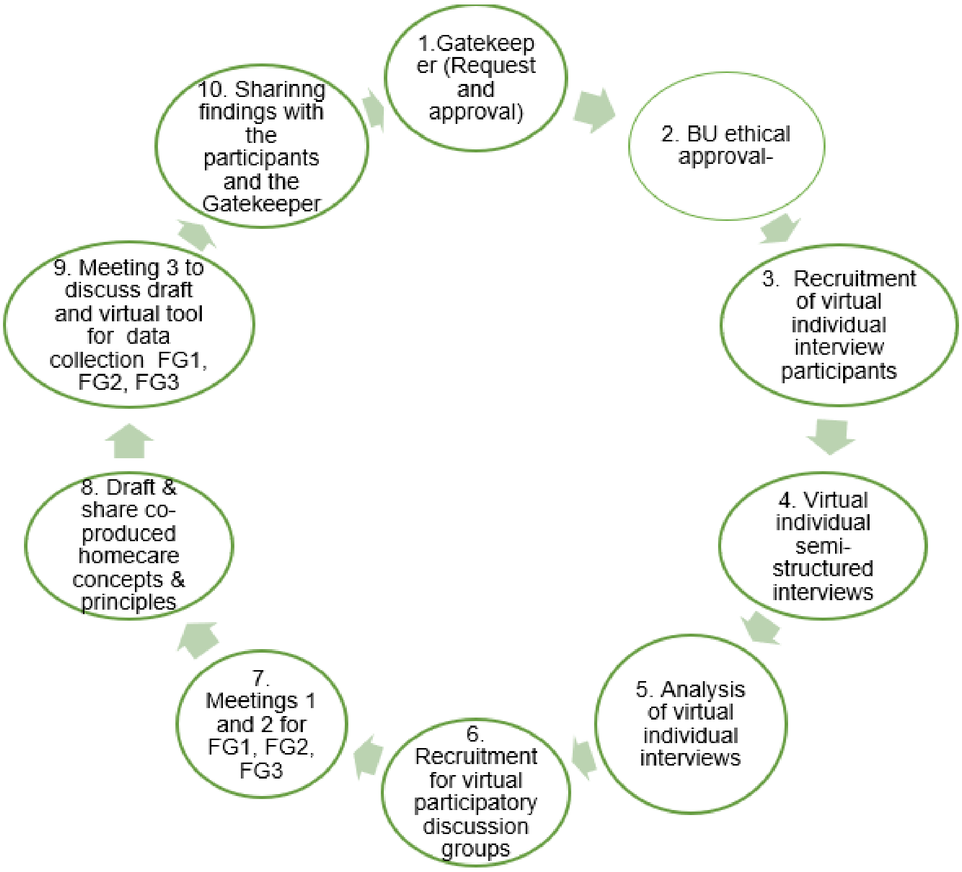


Figure 3-1 10 steps of the virtual recruitment and data collection process

The table below shows virtual recruitment and data collection dates.

Table 3-2 Virtual recruitment and data collection dates

Virtual recruitment and data collection		
1	Gatekeeper (Request and approval) Jan-Feb 2021	Feb 2021
2	Ethical approval BU ethical approval- InnovateDignity ethical approval-	08 April 2021 05 June 2021
3	Recruitment of Individual interview participants	12-23 July 2021
4	Individual semi-structured interviews -	23 July-02 September 2021
5	Analysis of Individual interviews	06-20 September 2021
6	Recruitment of Discussion group participants	06-20 September 2021
7	Meeting 1 FG1, FG2, FG3	20-24 September 2021
	Meeting 2 FG1, FG2, FG3	18-22 October 2021
8	Analysis of FG and draft of co-produced future homecare concepts and principles	22 Oct-3 November 2021
9	Meeting 3 FG1, FG2, FG3	8-12 November 2021
10	Sharing the findings with the participants and the gatekeeper	29 August 2022

*FG is a Participatory Group

3.8.5.1 Gatekeepers' importance in virtual recruitment

A gatekeeper is an essential mediator for accessing the study setting and participants within social research (Andoh-Arthur 2020). It might be a person within the organisation who can grant or withhold access to people or situations during research into an organisation (Andoh-Arthur 2020). A gatekeeper may also represent any individual who may be invaluable for gaining access primarily due to their knowledge, connections with or membership in a research population (Andoh-Arthur 2020)**.**

Permission was requested from the gatekeeper to collaborate with their community. Permission was sought from the UK President of the organisation that facilitated lifelong learning for older people.

The following were discussed with the Gatekeeper:

- The purpose of the study.
- Who the research sponsor/funder was.
- The reason for selecting the study site.
- How the research would benefit the community.
- How the data would be collected and used.
- What participants would be expected to do in the study.
- How recruitment of participants would be done.
- The required characteristics of participants and how virtual individual interviews and participatory group discussions would be held.

The Gatekeeper had questions that were clarified. The gatekeeper also clarified that sometimes it was not that gatekeepers refused to grant permission to researchers but, as gatekeepers, they always wanted to protect their community members, who were older people. The gatekeeper happily linked me to the regional office where I conducted the research. The study's advertising flyer was shared electronically by e-mail with the organisation's gatekeeper to share it with the members. At the end of the study, the gatekeeper was given feedback on the research outcome and the findings.

3.8.5.2 What gatekeepers did in virtual recruitment

The gatekeeper was requested to share the study's advertising flyer with their members. The risk of coercion from using the gatekeeper to share the research flyer with members was minimised. The gatekeeper shared the research flyer because the organisation had the e-mail contact addresses of their members, and they did not share their members' contacts with the public for safety and security. The gatekeepers were the point of contact, and since the recruitment and data collection were done online using e-mail and virtual communication, the gatekeeper added my research flyer to their weekly newsletter. The weekly newsletter was shared with the members. The flyer had contact details such as my e-mail address and phone number. The members interested in participating in the study contacted me directly by e-mail or telephone. They did not contact gatekeepers, which prevented possible pressure from gatekeepers and enabled members to join the research of their own will. The flyer invited people aged 50 years and above to participate in the research.

3.8.5.3 What potential virtual participants did in virtual recruitment

The potential participants were asked to volunteer to take part in the participatory research. The participants were asked to take part in individual semi-structured interviews and participatory group discussions, depending on their preferences. The individual semi-structured interviews were carried out before the participatory group discussions to collect data and evidence for discussions by participatory groups.

The virtual participatory discussion group collaborated to make a collective inquiry by discussing the developed themes from the individual interviews' analysis, prompt questions, and ideas and opinions from the participants themselves. The participatory discussion group members reflected shared decision-making in concluding the discussions, validated the findings and co-produced future homecare concepts and principles. The data analysed from the interviews was anonymised when used during virtual participatory discussion groups.

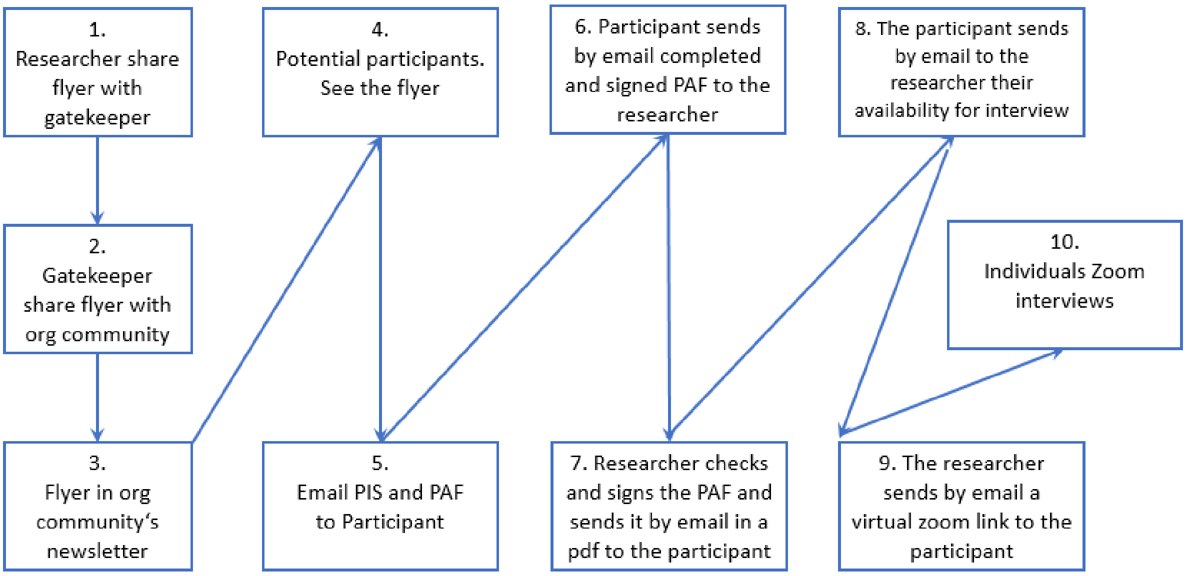
3.8.5.1 How potential virtual participants were contacted

The table below shows the dates on which potential virtual participants expressed interest in volunteering in the research and when they signed a consent form.

Table 3-3: Recruitment/Consent schedule

Dates when expression of interest received	Expression of interest form potential virtual participants	Completed consent forms for virtual individual interviews	Did not complete consent forms for virtual individual interviews
07th July 2021	Met with Organisation Gatekeepers		
Week of 12th July 2021	To share with members		
15th July 2021	9 1 liked the study but would not participate	7	2 didn't want to participate after reading the consent form 1 too much to do 1 apologised that she will jump off ship
16th July 2021	1	1	0
17th July 2021	1	1	0
22nd July 2021	4	4	0
23rd July 2021	1	1	0
TOTAL	16	14	2

The figure below shows 10 steps for the virtual enrolment process for virtual interviews. The initial step was when the research flyer was shared with a gatekeeper, and the last step was when an older person had an individual Zoom interview. The process took place during online participatory research.



*PAF is a participant agreement form
*PIS is a participant information sheet

Figure 3-2 Virtual enrolment process for virtual interviews

When the organisation members received the flyer from the gatekeeper, the organisation members interested in participating in the research responded through the e-mail address provided on the flyer to express their interest.

When an e-mail was received from a potential participant interested in the study, the participant was thanked for expressing interest. I avoided overwhelming potential participants with several documents for virtual participatory discussion groups and individual interviews at once to read and decide on. Therefore, the Participant Information Sheets for Interviews and Participatory discussion groups and Participants Agreement Forms for Interviews and Participatory discussion groups were not sent simultaneously to participants.

Participant Information Sheet for Interviews and the Interview Participant Agreement Form were sent first. This was because the interviews were conducted and completed before starting with the participatory group discussions. The potential participants read, completed, and e-mailed back to me if they still would like to participate after reading. Participating in the study was voluntary. When the participant finished reading the Participant Information Sheet (PIS) for an interview and decided to take part, she/he was asked to complete the Interview Participant Agreement Form. The Participant Agreement Form was the Microsoft Word document the participant received with the PIS. The participant typed in the needed information and then e-mailed it back to me.

The participant was asked to write their age in the Participant Agreement Form to allow verification of their age. In the Participant Agreement Form, the participant was asked to type his/her name and surname in full and in capital letters again in the signature space. When the Participant Agreement Form, which the participant had completed, were received, I completed my section and then e-mailed the participant the final Agreement Form in a pdf format. The participant was asked to file the Participant Information Sheet and the final pdf copy of a completed Interview Participant Agreement Form (PAF) until the data collection activities were completed.

In the Interview Participant Agreement Form, a question asked if the potential participant would like to be contacted for virtual participatory group discussions. Supposing the participant indicated that he/she would like me to contact him/her for virtual participatory group discussions, I verbally asked the participant again during the interview if they would like to be contacted for virtual participatory group discussions. If the participant wanted to be contacted for the participatory group discussions, I sent him/her the Participant Information Sheet for Participatory group discussions and the Participatory discussion group-Participant Agreement Form when they completed their interview. The potential participant read, completed, and e-mailed this to me if he/she still wanted to participate after reading.

When I had completed her section in the Interview Participant Agreement Form from the participant, she converted it to pdf. I sent an e-mail with a completed PAF in pdf to the potential participant and requested an appointment for an individual semi-structured interview. The research interviews were conducted using Zoom, as all participants chose Zoom over Skype or Teams. Furthermore, interviews were held on a first-come, first-served basis. The interviews took place according to the time preferred by participants. The interview conversation took between 56 minutes and 70 minutes.

I facilitated three separate series of virtual participatory discussion groups. Each virtual participatory discussion group met 3 times and had a membership of 3 to 5 participants. Each group met for 1 hour per meeting, once every two weeks. Fewer group members were because virtual communication was used, and every member was visible and had time to contribute during the participatory group discussions.

3.9 Virtual data collection method

Wang et al. (2020) state that the COVID-19 pandemic has forced researchers to develop alternative research methods. Furthermore, due to social distancing measures, the fieldwork that was initially planned for face-to-face methods was undertaken using virtual communication (Samaratunga and Amarasinghe 2020). Recruitment was done through e-mail, while virtual individual semi-structured interviews and virtual participatory group discussions were done using Zoom. Data collection started after the Bournemouth University Ethics Committee approval and InnovateDignity project’s ethical approval, from May 2021 to December 2021.

Virtual participants were given identity numbers (PIDs) as they enrolled in the study. The PIDs were used to ensure the confidentiality of participant identity. The tracking tools were developed to avoid losing valuable information. I was the only one with access to the document with the link of PIDs to the participants. The PID tracking form was not shared with anyone. The PID tracking form helped in meeting the required standard of H2020. It could track data sources under the study period should auditing be required.

The Participant's Identity (PID) numbers were used to label the interviews. When labelling various interviews or participatory discussion group discussions for storage, the recordings and transcriptions were labelled with the participant's identity number (PID), which was created and used instead of the participant's name to ensure the participant's confidentiality. This PID was not written on the PAF/PIS for confidentiality. For an interview logging, it was labelled as for example, PT03/INT01 01022021 MNB. Notes and reflections recorded for the same interview had the same label and interview code, date, and researcher's initials. The sequence for the labelling of participatory discussion group was similar. Nevertheless, for the participatory discussion group, the first number was the members who attended the discussion that day, for example, PT05/FG1M2-03022021 MNB. This code shows five members in participatory discussion group 1: their second meeting on the 03rd of February 2021, and that data was collected by MNB.

3.9.1 Testing the virtual data collection tools

Pilot studies are commonly associated with the quantitative approach to test a particular research instrument (Majid et al. 2017). The importance of pilot work has been expanded to qualitative inquiry, where it is carried out as preparation for the major study (Majid et al. 2017). Piloting for the interview is an integral aspect and valuable in conducting qualitative research as it highlights the improvisation of the major study (Majid et al. 2017).

Following the ethical approval from BU and the Innovatedignity project, the pilot interviews were conducted from the second week of May to the first week of June 2021 to explore the appropriateness of the interview question and to seek information on the context this study hopes to explore. It was a preparation for the major study. Notably, the pilot study enabled practising the interviewing techniques over Zoom and enabled the modifications (Majid et al. 2017).

The table below shows virtual individual semi-structured interview dates. The codes signified the participants' code, the interview code, the interview date, and my initials as a researcher. The enrolment log form and the study activity log form were used to capture this information.

3.9.2 Virtual individual semi-structured interviews

Table 3-4 Virtual Individual Interviews dates

Virtual Individual Interview meetings			
23/07/2021 PT01/INT01-23072021 MNB	02/08/2021 PT04/INT01-02082021 MNB PT04/INT02-02082021 MNB	09/08/2021 PT07/INT01-09082021 MNB	16/08/2021 PT10/INT01-16082021 MNB
27/07/2021 PT02/INT01-27072021 MNB	04/08/2021 PT05/INT01-04082021 MNB	11/08/2021 PT08/INT01-11082021 MNB	20/08/2021 PT11/INT01-20082021 MNB
29/07/2021 PT03/INT01-29072021 MNB PT03/INT02-22102021 MNB	06/09/2021 PT06/INT01-06092021 MNB	13/08/2021 PT09/INT01-13082021 MNB	23/08/2021 PT12/INT01-23082021 MNB
			25/08/2021 PT13/INT01-25082021 MNB AND PT14/INT01-25082021 MNB

*PT is a Participant
*INT is an Individual interview
*MNB is researcher's initials

The labelling codes assisted in knowing which date a particular participant did a virtual individual interview, if it was 1 interview or subsequent interviews for clarification and who did the interview. Despite that, participants were scheduled for 1 virtual individual interview; some interviews were participant-initiated. Some participants reached out when they wanted to discuss further what they had previously shared with me. PT04 initiated an interview with me after a virtual individual interview, while PT03 initiated an interview with me after a virtual participatory group discussion for FG3M2. She was in a participatory discussion group 3, and it was the second meeting for this group.

Flexibility was enabled during participatory research because it also gave older people power and voice to channel their perception of the future homecare they wanted. Interviews and participatory discussions were not on the terms of both me and the participants, hence a balance of power. When a completed Interview Participant Agreement Form from the participant was received, the e-mail was sent to the potential participant on a first-come, first-served basis for an appointment for an individual semi-structured interview.

Ritchie et al. (2014) clarify that knowledge is created and negotiated during an interview when both the researcher and the interviewee actively participate and interpret. Notably, Ritchie et al. (2014) emphasise that the researcher is an active player in the development of data. The research interviews were conducted using virtual Zoom and were semi-structured to allow older people to elaborate on their homecare experiences.

There were 14 semi-structured interviews conducted, which were stopped when there was no more new information from the participants' interviews. The interviews took place at whichever time the participant preferred. The conversations took around 56 minutes to 70 minutes.

The virtual invitation link for the interview was shared two days before the interview. On the day of the interview, the necessary equipment was set up an hour before the interview to ensure that everything worked and that the required equipment was available. I ensured that the room I used was silent. The cell phone was muted during the interview. Background noises from pets, radio, or television (TV) were avoided. The windows were closed to prevent noise from the outside. I dressed appropriately for the interview, not too formal or casual.

Participants were treated with respect throughout the interview. I introduced myself, the institution, and the study to the participants. The participants were informed that the study was a participatory approach and that they could participate in more research stages than data collection. Participants were informed that should they wish to participate in analysing data, they should inform me.

Participants were informed that the analysis was made easier because it was a data-driven thematic analysis. In any case, lack of participation in other areas would not affect their participation in the study as that would not lead to them being removed from the study. I thanked the participants, explained why the meeting will be recorded, and then requested permission from the participants to record the meeting. I spoke slowly and politely to be well understood. I was respectful and empathetic to the participants during the interviews and did not interrupt when the participants talked. Even when I thought the participants had not understood the question, I did not interrupt too quickly.

The semi-structured interviews were conducted to explore how the participants perceived current homecare, their opinions about how future homecare should be delivered, and opinions about co-producing concepts and principles that should underpin future homecare. I started with a prompt question to guide the conversation into the topic of interest. It showed that after self-introduction, most participants continued to talk about their experiences in homecare and the type of future homecare they want.

There were some participants who, when asked a prompt question after introductions, would respond that they were going to talk about that. They knew what the discussion would be about and that I asked a little earlier. This was a good sign because it showed that participants read the participant information sheet and understood what would be discussed. The prompt question was: If you were to need homecare in future, how would you like your homecare to be like? More questions came from the participant's story to maximise the opportunities for informal, detailed, and highly textured participant responses. Questions were asked dynamically, keeping in mind both the interview's objectives and the substance of the participant's previous answers. The semi-structured interviews were in a one-on-one format because they enabled me to focus precisely on the interviewee's responses, pay close attention to the content, and the participant could go in-depth on the topic.

Questions were asked based on the interviewee's responses and simultaneously linked to the research objectives to produce the meanings, insights, and causal chains that provided qualitative data richness. The interviews with different participants continued until no more new information came from the participants' responses. The interview data was subsequently analysed in preparation for virtual participatory discussion group discussions.

The table below shows virtual participatory discussion group dates. The table shows the participants who were involved in the meeting. The code FG1M2 reflects the participatory group number, while M2 reflects the meeting number.

3.9.3 Virtual participatory discussion groups

Table 3-5 Virtual participatory discussion groups dates

Virtual participatory discussion groups meetings		
20/09/2021 **FG1M1** PT06 PT09 PT10 PT14 PT13	**18/10/2021** **FG1M2** PT02 PT06 PT09 PT10	**08/11/2021** **FG1M3** PT02 PT05 PT06 PT09
22/09/2021 **FG2M1** PT01 PT02 PT04 PT07 PT12	**20/10/2021** **FG2M2** PT01 PT04 PT12 PT07	**10/11/2021** **FG2M3** PT01 PT07 PT10 PT12 PT04
24/09/2021 **FG3M1** PT03 PT08 PT011	**22/10/2021** **FG3M2** PT03 PT05 PT08 PT11 PT14	**12/11/2021** **FG3M3** PT03 PT08 PT11 PT14

*FG is a Participatory Group
*M is a Meeting
*PT is a participant

Virtual participatory discussion groups collaborated and made a collective inquiry by discussing developed themes from an analysis of the virtual individual interviews, prompt questions, and ideas and opinions from the participants. The participatory discussion group enabled reflection and shared decision-making when concluding the discussions. Together with older people, we co-produced future homecare concepts and principles. The virtual participatory discussion group reviewed the co-produced future homecare concepts and principles draft. They made inputs through their comments on the draft and during the meeting when the draft was discussed. Finally, participants developed the roadmap draft to disseminate the findings and validated research findings.

3.9.3.1 Virtual participatory discussion group process

Those potential participants who showed an interest in the Interview Participant Agreement Form indicating that they could be contacted for a virtual participatory discussion group received the Participant Information Sheet to read. The potential participant also received the Participant Agreement Form for the Participatory discussion group to complete and e-mail back if they wanted to participate in the research after reading the information sheet. Participating in the study was voluntary. There were 14 older people who participated in the virtual participatory discussion groups. All participants from the individual interviews volunteered to participate in virtual participatory discussion groups.

Participants were requested to safely file the Participant Information Sheet for the Participatory discussion group and the completed Participatory discussion group - Participant Agreement Form until the participatory discussion group activities were complete. When a completed Participatory group Participant Agreement Form from the participant was received, an e-mail was sent for an appointment to begin the participatory group discussions after grouping the participants. The participatory group discussions were conducted using Zoom, because it was preferred by participants over Skype or Microsoft Teams. In the Interview Participant Agreement Form, the participant chose the method preferred for a virtual meeting.

Participants chose Zoom because they were familiar with the method and used it in their organisation for virtual activities. An appointment was made with the participant 3-4 days before the virtual individual interview or participatory group discussions. The link was sent to the participant's email, and sent a calendar invite with Outlook. The passcode was easy and not complicated, and the passcode for an interview and participatory group discussions differed. Each passcode was a combination of 8 characters with 3 categories, which were 6 numbers 1 lowercase and 1 unique character. Using simple, unique characters enabled only participants to connect to the link during an interview or participatory discussion group meeting. There were 2 participants during interviews and 2 during participatory group discussions that missed the unique character. Some called, while others emailed, and it was easy for older people to realise what had been omitted when I mentioned the passcode on the phone. I facilitated 3 separate series of virtual participatory discussion groups.

- Participatory discussion group (FG1)
- Participatory discussion group (FG 2)
- Participatory discussion group (FG 3)

Each participatory discussion group met 3 times and had 3-5 participants. The fewer group members were because virtual communication was used, and every member was visible and had time to contribute during the participatory group discussions. Fewer group members also enabled easier moderation of the group.

In order to integrate findings and maintain older people`s participation, on completion of the second participatory group discussion, the draft of co-produced future homecare concepts and principles was prepared, which was shared with all participants for their comments via e-mail. The draft was discussed on the 3rd meeting and explored older people's experiences with using virtual communication for data collection.

Each group met for 1 hour per meeting, once every two weeks. The participatory group discussions took place from the time that members decided. Through an e-mail, I informed participants about the next meeting week, and participants sent dates and times during that week that they were available. I then grouped them according to dates into 3 groups. Invitations were sent to individuals, and participants were informed that there would be up to a maximum of 5 participants in a group. Meeting appointments went swiftly because participants were dedicated and responded very fast.

During the meeting, I introduced myself, the institution, and the study to the participatory discussion group. Permission was requested from the participants to record the meeting so that she could easily facilitate it without thinking of taking notes. The Participant Information Sheet for the participatory discussion group informed participants that the meeting would be recorded only for research purposes. The recording was transcribed and used for data analysis.

The findings were anonymised. The recording was not used for commercial or media purposes, and I was the only one with access to the recording. Once the recording was transcribed and anonymised, the transcription was shared with the research team. The recordings were kept in the Bournemouth University password-protected computer. When the recording of the meeting was started, the recording request appeared on the participant's screen. This enabled the participant to consent to a recording by checking either yes or no.

I spoke slowly and politely to be well understood when talking to participatory discussion group members. The participatory discussion group members were thanked for volunteering. I enhanced group trust and safe space by encouraging group members to share within the group and explained that there would be no wrong or right answers during the discussions. Everyone's perceptions and opinions were essential and needed to be shared in the participatory discussion group. The participatory discussion groups were encouraged to keep the discussions within the group. The risk of maintaining confidentiality in a participatory discussion group was that the nature of a participatory discussion group was such that confidentiality could not be guaranteed. Participants were provided with procedures to minimise the risk of losing confidentiality. The participants were encouraged not to discuss what was discussed in the group with anyone outside the group. The Participant Agreement Form for the participatory discussion group had a non-disclosure statement, in which the participant typed their initials to agree that they would comply with confidentiality in the group. The group members were encouraged to respect and listen to each other without judgement. Furthermore, members should treat each other with respect and kindness. If a group member was uncomfortable with something, he/she was encouraged to say so to get the issue resolved or clarified.

3.9.3.1.1 Virtual participatory discussion group meetings

The following diagram shows the participatory group discussion process during a meeting.

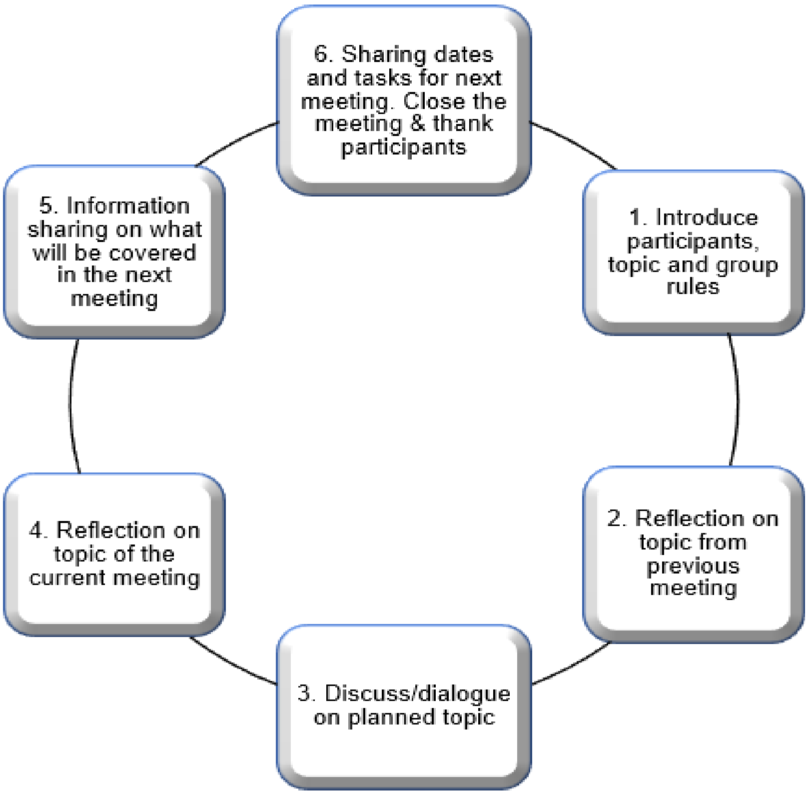


Figure 3-3 Participatory group discussion process

Meeting 1

The purpose of meeting one was to collaborate to make a collective inquiry by discussing the themes generated from the individual interview's analysis, prompt questions, and ideas and opinions from the participants.

The participatory discussion group agreed on how the participatory discussion groups would run, how decisions would be made, appropriate behaviour during group meetings and how to disseminate information to others. The participatory group also verbally agreed on power-sharing during data collection, that all group members were equal. The group agreed that everyone's knowledge/experience was valuable. The participants also agreed on having a reciprocal relationship in the group. All participants agreed that they would respectfully ask each other questions from their stories. In addition, they would be inclusive of each other's knowledge and value each other's diversity.

Participants were encouraged to be open because all group members were learning from each other, but, at the same, they should share with the group what they felt comfortable with. Participants were once again invited that should anyone wish to take part in the data analysis, they should contact me. And that the analysis method was made easier as it will be a thematic analysis with an inductive approach. Each participatory group discussion was analysed in preparation for the following participatory group discussion.

Meeting 2

The purpose of meeting two was to collaborate with older people to co-produce concepts and principles to underpin future homecare delivery.

The participatory discussion group did reflections from the first meeting. The participatory discussion group discussed how individual group members perceived future homecare. The participatory discussion group discussed and co-produced future homecare concepts and principles. This was based on perceptions from individual interview findings and analysis of participatory discussion group meeting one. The prompt question for this discussion was, "How do you want to characterise the type of future homecare you want based on the findings that we discussed from meeting 1?"

Participants were asked another prompt question for homecare co-producing principles in the second half of the meeting. The prompt was: What could be done to ensure that the characteristics or concepts of homecare we had just come up with are maintained?

Upon completion of discussions/dialogue and co-producing ideas and knowledge, I drafted the ideas and knowledge of co-produced future homecare concepts and principles based on virtual participatory discussion group members' contributions during the previous and current discussions. The co-produced draft document was shared with the participants five days before the following participatory group discussion via e-mail. The participatory discussion group members read/reviewed and made comments for the subsequent participatory group discussion.

Meeting 3

The purpose of meeting three was to explore the participatory discussion group members' perceptions of the use of virtual communication as a tool for data collection in this participatory research and to discuss the draft document of co-produced future homecare concepts and principles with older people. During this meeting, the participatory group discussed the draft document of co-produced future homecare principles and concepts that had been shared with older people. They discussed the draft contents, the participants' perspective of the draft, and the preliminary research findings. The draft was revised based on the contribution of the participatory discussion group.

The participatory group discussed and co-produced the roadmap for disseminating co-produced future homecare concepts and principles and whom the findings should be shared with, when, and how should the findings be shared. The participants suggested that the findings be shared with a broader group of older people at the end of the study through organisations online, for instance. The participants also discussed how they felt active and regular, meaningful participation of older people should be sustained in research.

The participants were thanked for their dedication throughout the participatory group discussions. Participants were thanked for their commitment to volunteering in the research. The participants were informed that the final document of co-produced future homecare concepts and principles merged with the road map for dissemination would be shared. The participants were notified that they were welcome to contact me if they wanted to share some information that could benefit the research. I also requested permission from the participants that they could be contacted during the deep analysis of the findings and write-up of the thesis for clarification. They were happy to be contacted.

The next chapter describes the data analysis method in this research. The participatory analysis reduces the issue of dominance by academic researchers because it engages older people to participate and fosters dialogue and reflection with the researcher, as also evidenced by Warwick-Booth et al. (2021). Challenges with participatory analysis could range from time, money and skills to methods like online participatory research. In this present study, Braun and Clarke's thematic analysis, which was data-driven, was used because the method has 6 phases which allow older people to choose the phase they could participate in (Clarke and Braun 2021; Warwick-Booth et al. 2021). One ethical factor that was considered was that even though participatory research advocates for more participation in various stages of research, older people were not coerced, manipulated, or made to feel bad that they had to participate in more stages. In addition, older people did not need to explain their option of not participating.

Chapter 4 Data analysis method

One of the principles of participation in participatory research is to engage participants in more than data generation, including data analysis if they prefer (Schubotz 2020; Clarke and Braun 2021; Warwick-Booth et al. 2021). However, in this study, the older people involved did not want to engage in the data analysis stage. Participants felt that they did not have enough time to perform and perceived that academic documents were large. Nonetheless, all older people in the study volunteered to peruse the draft document of co-produced future homecare principles and concepts. The analysis was a challenging and exciting stage of the qualitative research process as it required a mix of creativity and systematic searching (Ritchie et al. 2014)

4.1 Overview of data analysis strategy

A qualitative research design was used with a participatory research approach to explore the perception of older people on the future homecare they would like. The thematic analysis of Braun and Clarke, now called reflexive thematic analysis, was performed in this research analysis (Braun and Clarke 2019) using an inductive approach because the technique is unbounded by theoretical commitments and based exclusively on data. Furthermore, reflexive thematic analysis (TA) identifies, analyses, and interprets patterns of meaning (‘themes’) within qualitative data (Clarke and Braun 2017; Braun and Clarke 2019). Reflexivity involved a disciplined practice of critically interrogating what I did, how and why I did it and consequently, the impact and influences (Clarke and Braun 2021).

The other reason why the TA of Braun and Clarke was suitable was that qualitative research using a participatory approach was done. The research investigated and explored older people’s perceptions of future homecare and collaborated with them to develop principles that should underpin homecare. Inductive or data-driven thematic analysis was appropriate to accommodate participants if they wanted to participate in data analysis. The inductive or data-driven approach also generated codes that were solely reflective of the content of the data and free from any predetermined theory or conceptual framework

(Byrne 2022). Additionally, the TA of Braun and Clark was a good fit to generate codes, develop themes, see the patterns of themes, and interpret meanings from the data (Braun and Clarke 2006).

In order to accommodate participants in participating in the analysis, data was not coded to fit a pre-existing coding frame but instead, open coded to represent meaning best as communicated by participants (Braun and Clarke 2013). In the present participatory research, the generated codes were presented to participants. The participants then discussed or dialogued on the generated codes. The codes' meanings influenced the generation of themes, which were also presented to participants. The level of themes was also influenced by how participants discussed the themes during participatory group discussions.

Braun and Clarke (2013) indicated that individuals have multiple realities dependent on human interpretation and knowledge. While Creswell and Poth (2016) indicate that ontology relates to the nature of reality and its characteristics, researchers report this multiple reality when researching individuals with different perspectives. It meant that older people’s perspectives and opinions on future homecare differed because of their different cultures, values, and backgrounds.

The research question that needed to be addressed was “*What could future homecare look like based on the perspective of older people in the UK?”* The advantage of TA was its flexible approach to meaning generation, as patterns were identified within and across data concerning participants’ views and perspectives on future homecare. The six phases of Reflexive thematic analysis were followed as depicted in figure 4 1.

4.2 Reflexive thematic analysis

The diagram below shows the 6 phases of thematic analysis for Braun and Clarke (Braun and Clarke 2006; Clarke and Braun 2021)

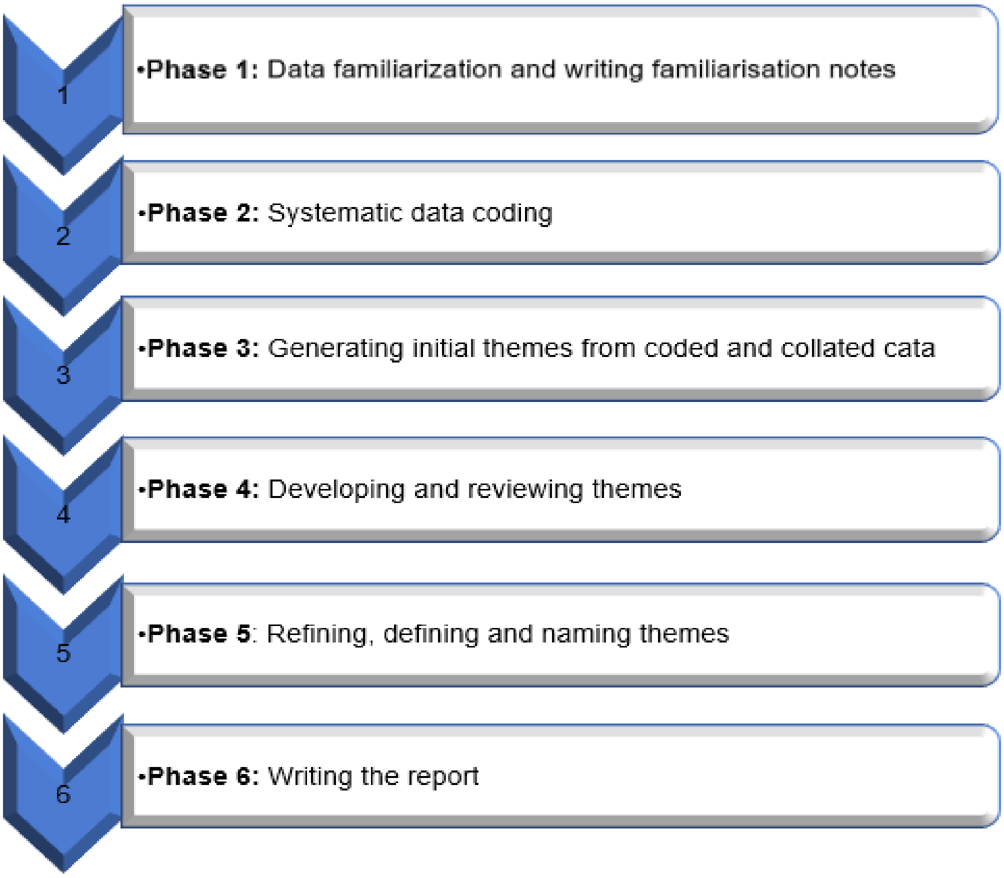


Figure 4-1 6 Phases of Braun and Clarke thematic analysis

4.2.1 Phase 1: Data familiarisation and writing familiarisation notes

Phase 1: I familiarised myself with the data. I listened to the audio recording each time I completed a semi-structured interview with a participant. I listened to the audio recording more than once to compare it with the transcript for readability to get a sense of intonation and language use, where sentences stopped and started and where the pauses were. There were also word errors in the transcripts, which were corrected using audio. As the transcripts were read, notes were added with a pencil in the transcripts' margins.

I immersed myself in the data and actively read and re-read the data. Familiarisation with data helped in identifying issues or topics of interest relevant to the research question and its recurrence in data. I first started coding manually with a pen and pencil. Because of multiple interviews, I changed coding from pen and pencil to Microsoft Word. I later changed to NVivo 12 Pro because of difficulty managing data from hand analysis. A distinguishing feature of thematic analysis is its flexibility to be used within a wide range of theoretical and epistemological frameworks and to be applied to a wide range of study questions, designs, and sample sizes (Kiger and Varpio 2020). Qualitative data can produce meaningful findings if they are managed properly, even though these data can often be multifaceted (Dhakal 2022). NVivo 12 Pro is a computer software program that enables data management, analysis, and visualisation of qualitative data and documents systematically and individually (Dhakal 2022). When switching to NVivo Pro 12, I uploaded the transcripts and began developing annotations and memos guided by Braun and Clarke's 6 phases of thematic analysis.

4.2.2 Phase 2: Systematic data coding

Following familiarisation with the data, I worked with the data to systematically code the data. Coding explored the dataset's diversity and patterning of meaning, developing codes and applying code labels to specific segments of each data item (Clarke and Braun 2021). While code was defined as the output of the coding process, ideas, concepts or meanings were refined during the coding process (Clarke and Braun 2021). Codes are also defined as the smallest units of analysis that capture interesting data features (potentially) relevant to the research question (Braun and Clarke 2013). Furthermore, because codes are not themes, I could not use a code to capture multiple meanings.

Each data item was read, and all text segments with potentially relevant meaning to the research question were tagged with an appropriate label as supported by (Clarke and Braun 2021). Some texts were not tagged with codes if nothing was found to be relevant to the research question. The line-by-line coding was done with constant comparison until data saturation was reached. Although Clarke and Braun (2017) believed that Thematic Analysis provided systematic procedures for generating codes, the process was not linear, and steps were repeated back and forth (Braun and Clarke 2006). I did open code, and that is code with description, text search and memo. Because an inductive analysis was used, the coding was done without thinking about the study question to avoid missing essential codes from the research data. When I coded line by line, I first focused on the context of the sentence. I could not structure the coding process as she moved back and forth in data. Clarke and Braun (2021) also affirm that the coding process is unstructured and organic, and the potential codes evolve to capture a deepening understanding of the data.

4.2.3 Phase 3: Generating initial themes from coded and collated data

Phase 3 began when all data had been initially coded and collated, and I had a long list of the codes identified across the data set as also supported by Braun and Clarke (2006). I re-focused the analysis on the broader themes rather than codes during this phase, as embraced by Braun and Clarke (2006). Phase 3 involved sorting the different codes into potential themes and collating all the relevant coded data extracts within the identified themes (Braun and Clarke 2006). During this stage, different codes were combined to form an overarching theme. A concept map was developed, and coding comparisons and coding reports were made. Codes were compiled in one place, and themes were developed. As a result, I used mind maps, visual representations, names, and a brief description of codes to help sort different codes into themes as guided by (Braun and Clarke 2006).

At this stage, I started thinking about the relationship between codes, between themes and between different levels of themes and used some initial codes to form main themes and sub-themes guided by Braun and Clarke (2006). Some codes seemed to belong nowhere and, according to Braun and Clarke (2006), that was perfectly normal and acceptable at this stage. There were miscellaneous themes that were created to temporarily house codes that did not seem to belong in the principal codes.

Since Reflexive TA was about identifying patterns and meanings, my coding task was to draw the difference and start to see the shared or similar meanings (Clarke and Braun 2021). Because inductive analysis was used, the dataset became the starting point for engaging with meanings. Dahlberg and Dahlberg (2019) indicated that understanding meaning was easy and uncomplicated and, at the same time, challenging.

When looking for meanings, I had this philosophy of meaning in mind and was assisted by these four questions; the first question was about openness to meaning, I did not take what I saw or understood from the data for granted. When I thought I had absorbed the information too quickly or too carelessly, I slowed down and reflected on the process of understanding, and this process was adopted from Dahlberg and Dahlberg (2019). Secondly, the question of content showed how important the question of meaning was, and this research recognised that there was no pure content to operate within qualitative research because the meaning was always there (Dahlberg and Dahlberg 2019). Thirdly, in this stage, description and interpretation could not be separated because meanings evolved (Dahlberg and Dahlberg 2019). And fourthly, an open and reflexive attitude was essential at this stage because the open approach was guided by the quest for meaning and revealing the phenomenon that was the study's objective (Dahlberg and Dahlberg 2019).

According to Clarke and Braun (2021), this was evoked by the idea that qualitative analysis gave voice to the participants and told their stories in a straightforward manner. During the theme development, interpretations were made and stayed oriented to the research question during the interpretive analytic process to avoid losing sight of the analytic focus and purpose (Clarke and Braun

2021). During phases 3 to 5, the following questions were asked to deepen understanding of meaning interpretations:

What assumptions were part of this pattern of meaning?

What broader meanings or ideas did this pattern rely on?

Why might this pattern of meaning matter?

What were the implications of this pattern?

4.2.4 Phase 4: Developing and reviewing themes

Phase 4 began when a set of themes were from the previous stage. The themes were reviewed and revised. During this phase, it became distinct that some themes were not themes, and the data was diverse to support them. Some themes were collapsed into each other to form 1 theme, while some themes were broken into separate themes, and it was ensured that data between themes cohered together meaningfully (Braun and Clarke 2006). At the same time, there should be clear and identifiable distinctions between themes. If the principal themes did not fit, the data extracts were checked to see if they fit this theme. Subsequently, a new theme would be created, and a home would be found for the extracts that did not work.

Once content that the principal theme adequately captured the contours of coded data, a thematic map was developed and then moved to the next phase level. The same was done at this level but to the entire data set (Braun and Clarke 2006). During this time, the validity of individual themes concerning the data set was considered, and whether the principal thematic map correctly reflected the meanings evident in the data set as a whole with guidance from Braun and Clarke (2006). The data set was read to establish whether the themes worked and coded any additional data within the themes that had been missed in earlier coding. This was done until the thematic map worked.

4.2.5 Phase 5: Refining, defining and naming themes

Phase 5 began when there was a satisfactory thematic map of data. During this phase, the themes were defined and further refined. According to Braun and Clarke (2006), defining and refining meant identifying the essence of each theme and determining what aspect of the data each theme captured. A detailed analysis of each theme was conducted, and then wrote what was interesting about the themes and why.

4.2.6 Phase 6: Producing the report

Phase 6 began with a set of fully worked-out themes. It involved the final analysis and write-up of the report. It was ensured that the write-up provided sufficient evidence of the themes with the data. And enough data was extracted to demonstrate the prevalence of the theme with guidance from Braun and Clarke (2006). The examples that captured the essence of what the data demonstrated were chosen, and extracts were embedded within an analytic narrative that compellingly illustrated the story being told about the data. The analytic narrative went beyond the data description and addressed the research question (Braun and Clarke 2006).

The next chapter covers the research findings. The findings were divided into four chapters. The four chapters address the study questions in chapter 1:

- What could future homecare look like based on the perception of older people in the United Kingdom?
- How does collaboration within research enable older people’s voices to be heard and allow meaningful engagement?
- What are the perceptions of older people on using virtual communication as a tool for data collection in a participatory research approach?

The four chapters are as follows: chapter 5: findings from individual semi-structured interviews, chapter 6: findings from participatory discussion groups, chapter 7: is co-produced future homecare concepts and principles and chapter 8 is findings on the use of virtual communication as a tool for data collection.

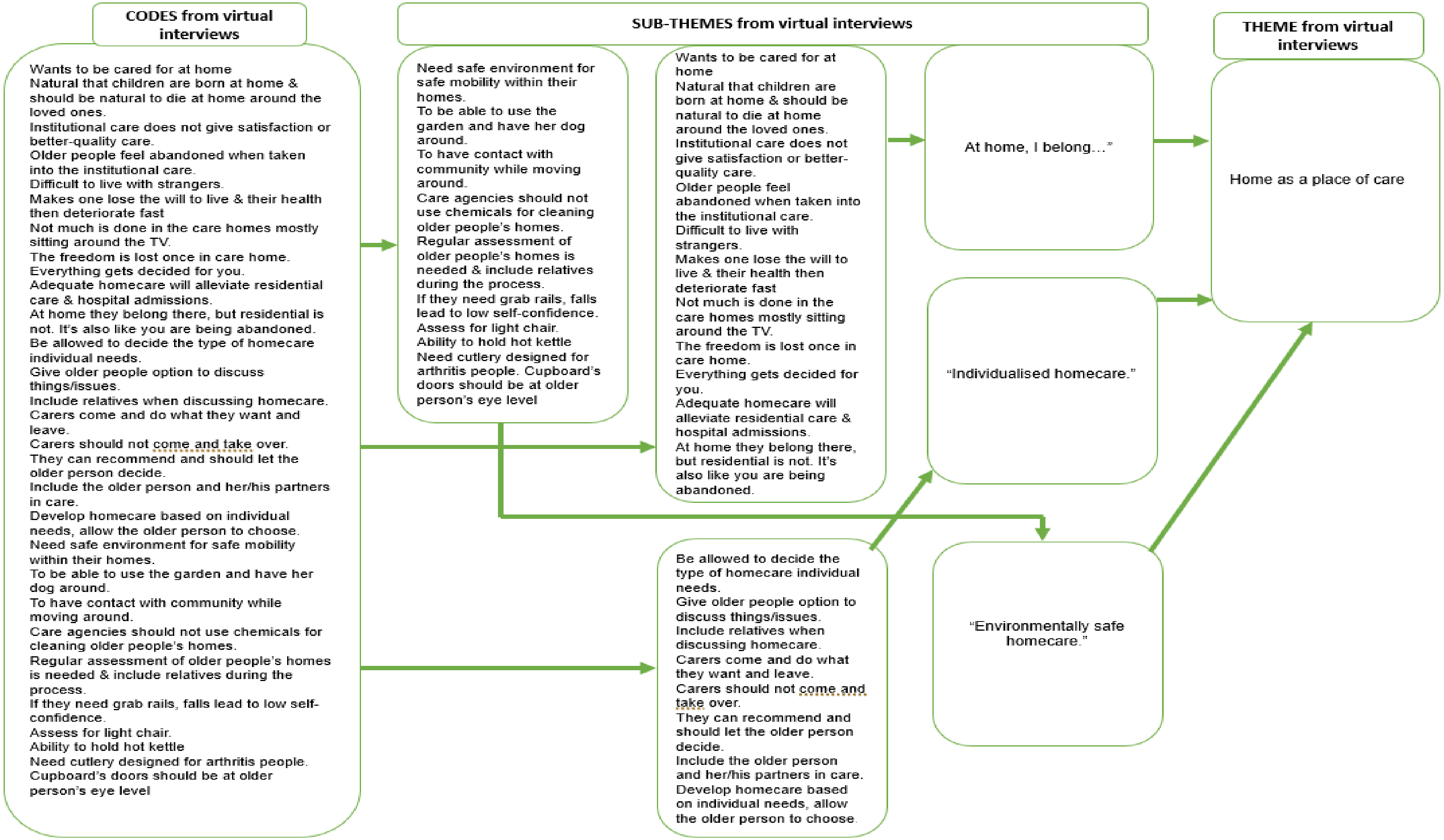
Chapter 5 Findings for virtual semi-structured individual interviews

The findings in chapter 5 will be presented as 5 themes and 18 sub themes developed from the reflexive thematic data driven analysis. The table below shows the themes and sub-themes that will be presented in this chapter.

Table 5-1 Themes

Themes	Sub-themes
Theme 1: Home as a place of care *"At home, I belong…"*	i) "We want homecare that addresses individual's wants and needs of an older person."
	ii) "Regular assessment of older people's homes is important to ensure safety and independence."
Theme 2: "I want homecare that is proactive and sustainable."	i)"Community-based homecare is sustainable."
	ii)"Avoid reactive homecare."
	iii) **"**Homecare should be reliable and sufficient." iv) "Homecare should be easily accessible and sufficient."
Theme 3: Promoting belonging and well-being in homecare	i) "We are community beings; we need community to thrive."
	ii) "There should be much more emphasis on linking of food and health because everything is about what you eat."
	iii) "The mental health is increasingly evident and can no longer be ignored in homecare."
	iv) "Homecare that promotes engagement in community social activities."
	v) "We become aware as we constantly adjust and adapt."
Theme 4: Independence and dignity in homecare	i) "We are not just older people, we are individuals."
	ii) "I want homecare that empowers to promote independence."
	iii) "We need to be educated and get homecare support without having to beg for it."
Theme 5: Inclusive and accessible homecare	i) "Homecare should be for everyone."
	ii) "Can homecare be reasonably priced and be available in community?"
	iii) "Health inequalities found in homecare."
	iv) "I want to be involved in everything in my care."

The diagram below is an example of how a theme was developed using data.



CODES from virtual interviews

Wants to be cared for at home
Natural that children are born at home & should be natural to die at home around the loved ones.
Institutional care does not give satisfaction or better-quality care.
Older people feel abandoned when taken into the institutional care.
Difficult to live with strangers.
Makes one lose the will to live & their health then deteriorate fast
Not much is done in the care homes mostly sitting around the TV.
The freedom is lost once in care home.
Everything gets decided for you.
Adequate homecare will alleviate residential care & hospital admissions.
At home they belong there, but residential is not. It's also like you are being abandoned.
Be allowed to decide the type of homecare individual needs.
Give older people option to discuss things/issues.
Include relatives when discussing homecare.
Carers come and do what they want and leave.
Carers should not come and take over.
They can recommend and should let the older person decide.
Include the older person and her/his partners in care.
Develop homecare based on individual needs, allow the older person to choose.
Need safe environment for safe mobility within their homes.
To be able to use the garden and have her dog around.
To have contact with community while moving around.
Care agencies should not use chemicals for cleaning older people's homes.
Regular assessment of older people's homes is needed & include relatives during the process.
If they need grab rails, falls lead to low self-confidence.
Assess for light chair.
Ability to hold hot kettle
Need cutlery designed for arthritis people.
Cupboard's doors should be at older person's eye level

SUB-THEMES from virtual interviews

Need safe environment for safe mobility within their homes.
To be able to use the garden and have her dog around.
To have contact with community while moving around.
Care agencies should not use chemicals for cleaning older people's homes.
Regular assessment of older people's homes is needed & include relatives during the process.
If they need grab rails, falls lead to low self-confidence.
Assess for light chair.
Ability to hold hot kettle
Need cutlery designed for arthritis people. Cupboard's doors should be at older person's eye level

Wants to be cared for at home
Natural that children are born at home & should be natural to die at home around the loved ones.
Institutional care does not give satisfaction or better-quality care.
Older people feel abandoned when taken into the institutional care.
Difficult to live with strangers.
Makes one lose the will to live & their health then deteriorate fast
Not much is done in the care homes mostly sitting around the TV.
The freedom is lost once in care home.
Everything gets decided for you.
Adequate homecare will alleviate residential care & hospital admissions.
At home they belong there, but residential is not. It's also like you are being abandoned.

Be allowed to decide the type of homecare individual needs.
Give older people option to discuss things/issues.
Include relatives when discussing homecare.
Carers come and do what they want and leave.
Carers should not come and take over.
They can recommend and should let the older person decide.
Include the older person and her/his partners in care.
Develop homecare based on individual needs, allow the older person to choose.

At home, I belong…"

"Individualised homecare."

"Environmentally safe homecare."

THEME from virtual interviews

Home as a place of care

Fig 5-1 Theme development

5.1 Introduction

The previous chapter presented data analysis of virtual individual semi-structured interviews. It explained how the patterning of meanings across the data set led to the developed themes using Braun and Clarke’s thematic analysis.

Individual semi-structured interviews aimed to explore participants’ perceptions of the future homecare they wanted. Semi-structured interview findings were to inform discussions for participatory groups. The findings were anonymised before presenting them to the participatory group for discussion. This chapter will present findings from the individual semi-structured interviews through themes, sub-themes, and meaning interpretation.

5.1.1 Themes and sub-themes from virtual semi-structured interviews

The themes and sub-themes were data-driven. There was no pre-designed theory. There were 5 themes, and 18 sub-themes were developed from data. The themes and sub-themes captured every participant’s perceptions. The diagram below shows 5 themes and 18 sub-themes that will be described in this section.

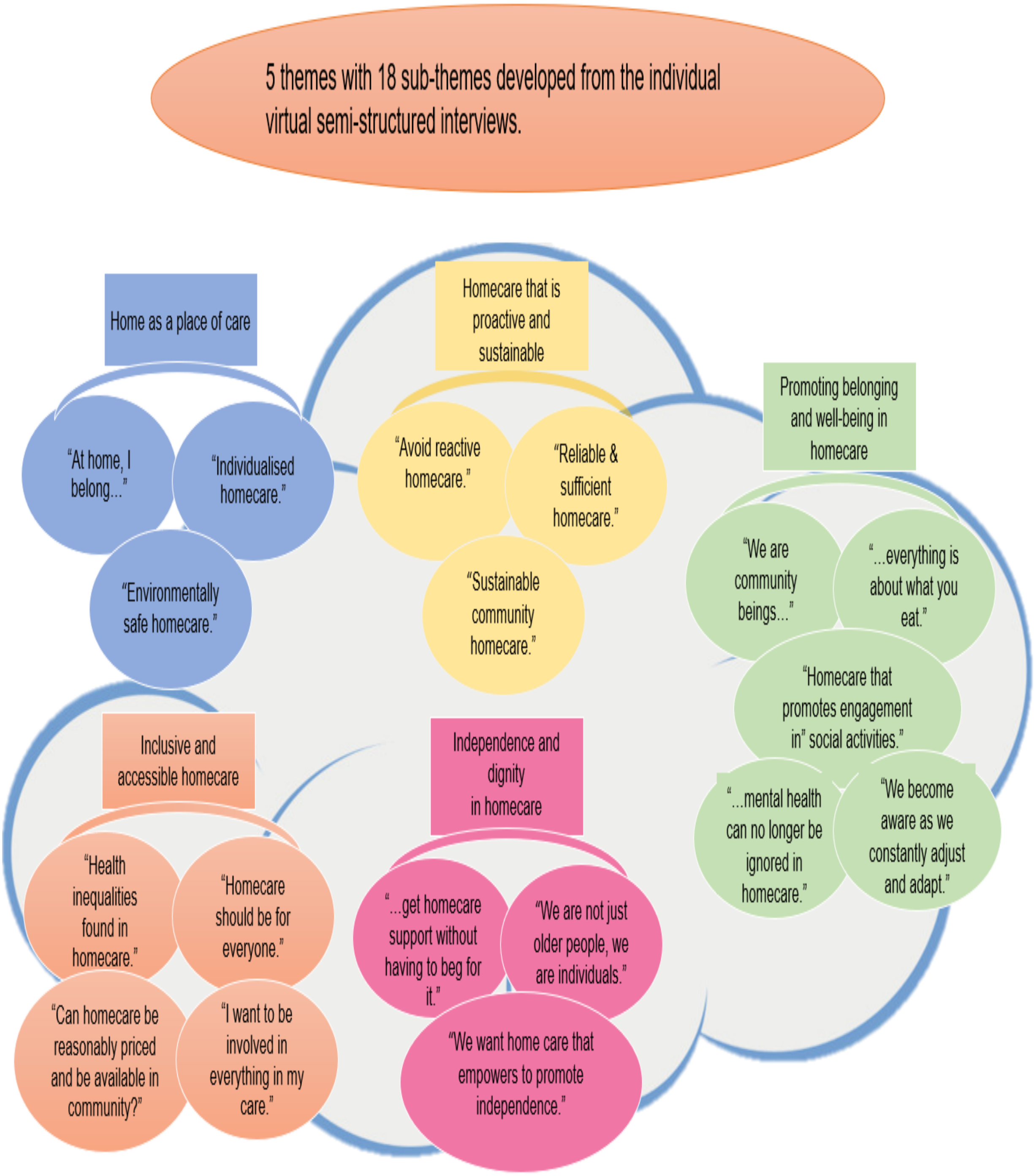


Figure 5-2 The 5 themes and 18 sub-themes from virtual semi-structured interviews

5.2 Theme 1: Home as a place for care

Findings from 14 participants showed that home as a place of care was essential. All the participants lived in their homes or retirement homes, and none lived in care or nursing homes. The participants wanted to be cared for at their homes or retirement homes where they lived. None of the 14 participants wanted to be cared for in the nursing home. Home as a place of care had multiple meanings for participants because home meant freedom, control and belonging.

5.2.1 Sub-theme i - “At home, I belong”

Participants believed that they had more power and control at home than in nursing homes, and they also associated nursing homes with being abandoned by relatives. Older people point out that losing freedom and control meant feeling hopeless. The participants stated that once in the nursing homes, decisions were made for an older person, whereas, at home, an older person could determine what they wanted to do. Participants asserted that it meant losing freedom and control if older people could not decide. The experience of a home was based on their lived experiences, while the experience of nursing homes was based on experience from caring for their spouses, parents, relatives and friends.

“In your own home, it is all your own things you know you belong there. You go into a residential home and quite clearly, you don’t belong there. you’re just there because there does not seem to be any other alternative, and you know perfectly well in the main you’re being dumped it’s just a place where you can be contained, you’re with a whole load of strangers.” PT06

Participant PT01, who cared for her late mother, spoke about transferring her mother back from the nursing home because her mother could not control what was happening to her at the nursing home. Her mother, who by then did not have dementia, was in a nursing home with older people who had dementia. They would walk into her room at night, and some would take her belongings. Her belongings always went missing and were found in other rooms. Another challenge was that her mother liked going out, but no one took her. Her mother became worried. As a result, PT01’s mother notified her that she wanted to be out of the nursing home and be back at her house. PT01 found a house for her mother across from where she lived, and her mother started participating in day-care centre activities. Her mother’s mental and physical health flourished. Due to witnessing her mother’s experience of loss of control and freedom in the nursing home, this was how PT01 responded to a question about where she would like her care in the future.

“I would prefer home. Everything I’ve seen about being in an institution frightens the pants off me. I would like to have maybe a team of two or three people locally who could coordinate my care.” PT01

Other participants reported that older people loved to rear their chickens, keep their animals, and make their vegetable gardens at home because it was therapeutic for them. Participants indicated that older people used gardening time to maintain relationships with their neighbours, which helped them feel connected, a sense of belonging and independence and enhanced their well-being.

“I would like to remain in my own home I would like to live independently, and I feel I love being outside and talking to my neighbours.” PT02

The home was not just four walls for older people but a place filled with freedom, belonging, connectedness, and control and was therapeutic for older people, enhancing their well-being and dignity.

5.2.2 Home means belonging and memories

Participants reported a sense of belonging because of memories older people had about their home. They described that their belongings and pictures on the walls reminded them of different events and people who have been part of their lives. The home was also perceived as a natural and perfect place to age and die. One participant indicated that children used to be born at home, and it should be natural for older people to die at home. Participants described dying at home around their loved ones as enhancing the well-being and dignity of older people who feel abandoned in institutions.

“…it used to be natural for children to be born at home, and it should be natural to die at home around loved ones.” PT07

“On the walls of my living room, you will see pictures of my late husband and the places we had visited together. I miss him.” PT10

Some participants highlighted that while relatives sometimes took their older people to a nursing home to avoid loneliness, for older people, being transferred to a nursing home meant being abandoned. As a result, older people experienced a loss of independence, erasing the memories that older people built in their homes. Memories that gave them hope and the resilience to keep doing more because memories enhanced their self-identity of who they were and where older people were coming from. Memories of their life’s journey and memories of whom older people had walked their journey with.

Participants justified that when an older person was taken to a nursing home, it was in the best interest of relatives or an older person’s children to remove the guilt of knowing that their parent lived at home alone. Participants described that when older people were taken to an unfamiliar place like a nursing home, they spent much time with people they did not know, which older people called strangers and could not connect with. As a result, an older person’s self-identity and personality would be lost. Subsequently, an older person would feel lost and hopeless. In most cases, older people would sit quietly around the TV and, with time, sink into a depression.

“And I’ve been in so many homes over the years, visiting not just people but visiting because that was my job. And you see people are just as lost. They lose their personality. They know they are only one of many. They’re in a strange place. They do not even have their familiar things around, they might have a few photographs, but they would not have very much else.” (PT06).

Participants described that instead of taking them to an unfamiliar place, it would be more satisfying for an older person if care were organised and delivered in their homes where older people had freedom, control, and memories and felt they belonged.

This was how PT04 expressed the benefits of being cared for at home.

“…I know you will say I’m lonely, but here at home, I have my things around me and I can do what I want, and I can plan my day. I did a course in Zoom this morning” (PT04).

5.2.3 Sub-theme ii - “We want homecare that looks into the individual wants and needs of an older person”

Participants explained that older people were individual people, and their lifestyle and needs or want for care as older people were all different. Participants further explained that carers or service providers had the attitude of ‘I know it all’ or ‘I know better’, which made it difficult to engage the older people in developing the care older people wanted. Moreover, as a result, carers or care providers often came with a checklist, and when an older person disagreed with the checklist, the older person would be termed ‘problematic’.

“Well, this questionnaire does not enable me to describe my needs to them very well, so I have sort of kept them all on ice. Because I do not need them at the moment, but I can see that within 4 or 5 years, I may well need them.” (PT04).

A concern was raised about homecare service providers who often brought homecare service products and asked older people to choose from them. Participants point out that offering an older person what was already predetermined was not engaging but instead manipulating them. One participant explained how he came to a `stalemate` relationship with one homecare agency that sent him an email indicating he should choose from their homecare services list. However, he found nothing relevant to his needs. He indicated that he refused to choose. After all, he believed he should get what he wanted because he was paying.

“This organisation Z is pestering me, but our relationship reached a stalemate two years ago. They cannot let me have what I want. They wanted me to choose from what they had. So I could not answer some of their questions. I believe that if we pay, we should make choices.” (PT04).

5.2.3.1 Individualised homecare means dignity, self-identity

Participants believed that indignities and loss of self-identity were brought about by how care was done or the approach to which older people were treated. Individualised homecare meant participants' freedom to choose, a sense of control, self-identity, respect and dignity. Some participants felt that being given a choice to discuss care showed respect and caring because participants had evidenced that carers came to an older person’s home to do what they wanted and left. They want the older person and their partners or next of kin to be involved in care choices.

Some participants described how they refused treatment from their General Practitioners (GPs) because GPs refused to listen to them and were considered difficult people. The participants believed that care providers made older people feel like nothing or worthless.

“I refused treatment, and they forget that we are the ones who have to bear all these side-effects at home. It has been seven years now, and I am still fine.” PT03

“Dignity is the most important thing. You know, like with my father, I’ve now learned about dementia. And I still used to talk to him, like he was my dad.” PT02

5.2.4 Sub-theme iii - “Regular assessment of older people’s homes is important to ensure safety and independence”

Participants expressed that their homes had potential hazards and were mainly for falls. Participants wanted older people’s homes to be regularly assessed to ensure mobility, safety, independence, and freedom in the homes. Adapting homes made them safer and enhanced older people’s independence. Participants indicated that adjusting their internal home surroundings helped them improve their mobility and independence because some indicated that they could not go upstairs without the help of stairlifts. Participants clarified that if they did not install stairlifts in their homes, their living space would contract to the areas they could access without a stairlift. However, when they installed stairlifts, they expanded their living space in their home, increasing their mobility and independence.

“..one of the biggest risks is falls. Elderly falls. They lead to deterioration in whatever conditions they have got. A deterioration in confidence. They are no longer confident after a fall. They are shaken up and think they will fall again.” (PT11).

Older people wanted to move around freely and do daily activities for themselves independently. Older people wanted to be independent even if carers assisted them. One participant expressed how she adapted her space to maintain independence and safety. She said that she removed all loose rugs on the floor due to chronic dizziness to avoid slipping and falling. In addition, she believed that cupboard doors should be at the eye level of an older person’s eyes to prevent falls.

“So can the cupboards be put up at eye height to avoid bending down under the work surface.” (PT11).

She described that falls led to low self-confidence and, as a result, older people reduced movement around the house. Some risks were that older people could fracture their hips or legs, which took longer to heal, leading to some being confined to bed. Participants clarified that confinement to bed could lead to stasis pneumonia, a complication resulting in premature death for older people.

“…now looking back to falls, I think, falls, there has to be more done to prevent falls because it is the biggest cause of lack of confidence, and it is the start of the end because people stop doing things because they are frightened.” (PT11).

5.3 Theme 2 - "I want homecare that is proactive and sustainable"

Participants expressed concern about the sustainability of current homecare because most participants depended a lot on volunteering friends, family members, church members and charity organisations for their homecare. Participants perceived homecare accessibility as a current problem. The uncertainties of availability or accessibility of homecare meant worries and fear of the unknown, which usually left participants with anxieties.

"I always wondered about visitors for young mothers. if you have a small child, they will be behind the door all the time. But once you are old, well, I think they want you to die." (PT13).

One participant described how she was worried and experienced anxieties about her future homecare due to her and her partner being the same age. Her concern was that if they both needed homecare in the future, where in the community would they get homecare services because they depended a lot on each other and friends.

"I don't know what will happen to me if I become very ill. Who's going to look after me, because he may be ill himself. You know. We are both of the same age and we just don't know." (PT13).

One participant indicated that when she called her GP or the emergency department, both the GPs and the doctors at the emergency department responded negatively, assuming that she only sought attention because she was lonely. The participant said she was now reluctant to call her GP or emergency. Her partner told how, following her decision, they almost lost her, and, luckily, he was around when she had a heart attack. He called the emergency services, and she was hospitalised for a week.

"I had contact and a few visits to the A&E, because I have had some bad episodes, and I was frightened that I was going to get a heart attack. And this one time, I went because my arm was very heavy and I couldn't do anything about it, and this young doctor, she said, Oh.you're back again." (PT13).

"it's, just that, they have no time for you. You can't talk about two subjects, two different problems in one meeting. They will say, that's another thing, and you feel so frustrated." (PT13).

Participants explained that if there was a nurse in the community whom older people could contact regarding their homecare, it would reduce the anxieties and worries older people currently experience.

“You know, knowing that there is someone there, that you could call on. You know, somebody to speak to and explain to you about things.” (PT13).

5.3.1 Community-based homecare means accessibility of homecare services

Participants believed that community-based homecare services were necessary because older people would access services. The provision of homecare through charity organisations was considered not durable and dependable. Some participants indicated that they used charity organisations for their homecare and perceived those services as expensive. Participants also believed that charity organisations needed donations to operate and would cease working without donations.

“I would rather have it carried out on a local level each town or area, has a small group. A small team that does this care and you can contact, you know. And they could check and pick individuals.”(PT01).

Participants believed that families were no longer as close-knit as in the past, leaving more older people living alone or with their partners. As a result, participants emphasised more about community-based nurses who should contact older people in the community.

“… it’s the locality, this is what people do need and involve people in the town as much as you can. We’ve got to build up that community.” PT01

One participant described how he provided round the clock care for his late wife with a terminal illness and never had an uninterrupted night’s sleep in three months. He only realised the mental and physical exhaustion he was suffering from after his wife was taken into hospice care. Carers came in for 15-minute tasks, and he was left to solely provide care to his wife the rest of the day. Furthermore, he was not trained to care for his wife in her condition. So, every time he thought he cared and carried his wife down and upstairs, it led to more injury to his wife. These three months were when his wife was utterly dependent on him. His wife's suffering affected him psychologically, but he never received counselling. He only received bereavement counselling following his wife's death.

“…but after her death, the hospice offered me bereavement counselling but during her lifetime, I wasn’t offered any, life counselling on coping with a cancer patient.” (PT08).

5.3.2 Sub-theme ii _ "…avoid reactive homecare"

Participants believed that the current homecare was reactive, fragmented, and not easy to access. They perceived that reactive care was more costly than planned care. However, homecare had so much potential to reduce the costs of hospitalisation and residential care. Some participants believed the system was firefighting because it let the problem happen before addressing it. One participant stated that people should be taught to prepare their meals to practice healthy eating instead of leaving people to become obese and then treating complications that come with obesity.

"..and if only instead of reactive the proactive was setting up things now to make it easy for an older person to face their deterioration to death." PT11

"Getting somebody comfortable talking about a future that may not be as rosy, as it once was, you know as you deteriorate, you've got to be strong. But if you prepare someone and get them comfortable, talking about it before they need it, not when they're sitting there in pain desperate for it." PT10

Participants perceived that proactive homecare meant economic freedom, independence, and well-being.

5.3.3 Sub-theme iii - "Homecare should be reliable and sufficient"

Participants reported that their current homecare was not sufficient. Participants indicated that the current carers could only provide care for 15 minutes to an older person. Consequently, some of the older people's needs were left unmet. Participants explained that some older people used other services, especially from the fire department, to complement homecare support. It showed that women mainly used the fire department services when their spouses fell or could not walk them upstairs. One participant shared the experience of how his late mother, in her old age, used firefighters' services for over 12 years because she could not carry her husband upstairs.

"You want it to be sufficient in the sense of sufficiently frequent. There's no point going once a week, if what help you want is getting dressed. And you want the range of what these people will do. You want the range to be sufficient. Not just getting you out of bed and then off they go." PT06

Some participants believed that caring agencies triggered untrustworthy homecare services by using multiple carers for one person, in which older people and carers hardly got to know each other. Since there was no relationship between older people and carers, carers never understood older people's needs, while older people, on the other hand, felt unseen, unsatisfied and frustrated.

"I can say you would want somebody who's coming into your home after all. And there's a big thing they come through your front door, therefore, you want them to be trustworthy you want them to be, friendly, and ideally personable." (PT06).

Participants had also experienced cases where carers never showed up, giving no explanation or could only do limited tasks for the older person. Participants attested that this left older people feeling worried and anxious. Some participants experienced a lack of homecare when being discharged from hospitals following surgeries. Most participants described that older people relied on the kindness of volunteers such as neighbours, friends and their family members to complement the insufficient homecare services.

"It's always a matter of monies and when I had that back operation. I had limited visits of an hour, the first three days. And then, if I wanted more, I had to pay somebody to come and help me or do the shopping for me, which I couldn't afford. Luckily, I had a neighbour that could help me with shopping, otherwise I wouldn't have managed. If you don't have money, you just have to rely on the kindness of people around you which sometimes it's not always there." PT13

Trustworthy and reliable homecare services were imperative for older people to minimise their frustrations and helplessness. Besides, the anxieties and worries which older people experience would be reduced.

5.4 Theme 3 - Promoting belonging and well-being in homecare

5.4.1 Sub-theme 1 - "We are community beings"

Participants expressed that older people were community beings and community meant belonging, participation and togetherness. Participants expressed that most older people lived alone or with their spouses, and they experienced loneliness due to a lack of participation in community activities. Lack of involvement also led to worries because participants felt unsafe.

"I don't have children. I haven't got anyone to oversee my care, but my parents had lots of friends and they were younger, and they could help." PT01

Most participants felt that their families were fragmented. Some expressed that families no longer lived in the same places; therefore, older people could not rely on their family members. Most older people had their families living outside their towns, and some had their children living abroad. Knowing that family members were not there to assist when older people needed homecare made them experience worries and fear of the unknown. Some believed that since the family support system had weakened, the community could be strengthened to become more inclusive to older people to feel safe and belonging.

"In the past family members all lived together as a family or community. And we've lost that and it's now single-family units and, in some cases, single-parent units. We have not got that sense of community and I think it is getting back community..." PT07

Participants wanted community centres where people of different ages could attend to make friends of all ages, most importantly younger friends. Younger friends meant having supporters who could speak out for them when older people could not. Participants also reported that some older people from other ethnic backgrounds felt uncomfortable joining organisations because they believed they did not belong. Moreover, most older people were excluded from community participation, which could greatly help their social, mental and physical health and well-being.

"I do not know whether I can afford to have a Carer to take me out. You know I would want to go out." PT01

"We had two ladies in our group, one was of Indian origin, and the other was of Chinese origin. They lasted only two months and said they felt like they did not belong. I told them to stay, but they would not." PT03

Participants wanted organised social meeting places which were older people-friendly within their communities because those places would be the most significant lifeline. Networking was said to bring a feeling of togetherness and safety to older people. It also enhanced their confidence, social, mental, and physical health and well-being.

"I want to have young buddies, and where can I find them? Community. My parents had young and older friends, and they could help. I have none." PT01

Some participants wanted carers who could regularly take them out in future homecare. One wanted to be taken for coffee and walks along the beach, while the other wanted to be taken to a jazz club where she could listen to her favourite live music.

"I love the theatre I love live music and to think that you know at 85 they could push me to a nightclub, and I could see a jazz band, that could be something fabulous." PT02

5.4.2 Sub theme ii - “Everything is about what you eat”

Participants believed that nutrition was vital for older people and that ailments could be prevented with good nutrition. One participant explained that he ate healthily to keep himself healthy and age well. Not only did he monitor his meals, but he also exercised daily. He cycled and wanted to ensure that he lived his active life, ensuring independence and good health. He had successfully lost weight down to his high school weight.

“ I do rowing 5-6 times a week, watching my breathing and recovery rate. I cycle, eat healthy, and reached my goal weight last week. I now have the same weight I had in high school.” PT12

“Annual consultation with the dietitian that’s as far as I can see now looking ahead. I do not know how my body is going to fail at the end.” PT12

Another participant also reported being mindful of her food because she believed that older people should eat more organic food as it heals the body than GMO-genetic modified food. For her, good nutrition meant good health, control and well-being. She ate only organic food, and for 11 years, she had been without cancer medicine. She had reduced the size of her tumour by eating the right food. She also believed that older people needed to be empowered to heal themselves with food. She believed that too much reliance on medicine led to some diseases caused by the side effects of the drugs. She thought that some medications caused side effects. Then, the person would be given another medicine to treat the side effect, causing a domino effect. After refusing chemotherapy eleven years ago, she mainly ate raw organic vegetables, healthy fats and no sugar. She read food labels and avoided genetically modified food. She avoided certain methods of preparing foods, such as frying. Furthermore, this helped her reduce her body inflammation and body pains. She said she listened to her body more, and the pain was not bad but a sign that something needed to be addressed.

“ you cannot throw everything in your body and expect it to be clean. Let us feed our body with good nutrition and keep it clean.” PT07

“…pay the farmer and not the doctor, meaning that you pay a little more for your food and avoid all the health problems.” PT07

Some participants thought that older people’s nutrition needed to be monitored. One participant shared that nutrition was important, but she observed that carers would come and drop the bag of food next to her mother’s chair without seeing that her mother ate. She would discover that her mother had nothing to eat when she arrived from work because the food bag would still be next to her chair. Putting food beside her mother's chair meant indignity and a lack of respect. One participant said he had not cooked for four years, and he no longer found pleasure in eating since the death of his wife. He used only the kitchen table and had not used the dining table after losing his wife. Losing their loved ones meant the loss of interest in the things older people used to enjoy with their loved ones, which could result in an older person having poor nutrition.

5.4.3 Sub-theme iii - "The mental health is increasingly evident and can no longer be ignored in homecare"

Participants believed that mental health issues seemed to affect older people before physical health. Still, older people had noted that when one had mental health issues, especially dementia, the affected person hardly received help for homecare. Older people experienced fear and distress. After all, they did not know what would happen if they experienced more than mild dementia because those whose economies were considered sufficient were not supported with homecare services. Older people expressed that sometimes they needed technical guidance from social care services, but it was not easy to get. Participants have also observed that carers did not provide mental health care services to older people.

"There's a lot more to it than that. It is not just the physical stuff. The mental stuff is the emotional thing, and it is increasingly evident, too, just about everybody. The aspect of loneliness. So, at what point how far does the care in the home cover aspects of loneliness when just sitting down and listening is a very good and valuable service." PT06

Participants reported that older people experienced fear and distress because they emphasised that when older people had dementia, it became challenging to negotiate homecare with private homecare providers, mostly profit-making companies. Participants also expressed the challenges of negotiating with private providers even in the current state because older people were less informed about homecare services. Older people reported the vulnerability to negotiate emanated from multiple factors such as dementia, age, absent family members, and less information on homecare services.

Older people believed that an office should be set up to help those who require homecare services because having an office for homecare in the community meant access to homecare services and hope.

“I think the important thing is to see that people have a life, you know, that all the things that give people joy in life are available to them and that there is encouragement.” PT07

Apart from loneliness, older people expressed that their physical and mental health constantly changed. As a result, older people constantly had to adapt and live with the changes brought about by health conditions they suffered. These changes required regular mental health services in homecare to experience joy and hope. Participants wanted older people to be offered continuous emotional support throughout their lives and not only bereavement counselling.

“And yeah, so the way I would approach this bottom-up. It’s primarily coaxing information out of people through the equivalent of a sort of annual MOT check without appearing too intrusive. and maybe you have the option to opt-out of all or part of that.” PT08

Lack of mental health care in homecare made it difficult for some older people to cope well with life. Some expressed how older people lost hope and joy while caring for their terminally ill spouses because they never received mental health care. One indicated that she tried to end her life several times since losing her husband. At the same time, one told how his spouse, taking care of him, terminated her life due to a lack of mental health care and inclusion in decision-making.

“They certainly got the psychology wrong with my wife. Yeah, she thought they had changed their attitude toward her and that she was no longer my wife. She was my carer. I think she felt that decisions have been taken away from her.” PT04

5.4.4 Sub-theme iv - “Homecare that promotes engagement in community social activities”

Participants expressed that engaging in community social activities was essential for older people to combat loneliness. Older people wanted to engage in social activities because it meant community, togetherness, feeling at home and belonging. Some described that belonging to different social clubs brought a sense of community and togetherness, even though it was not enough since they met using Zoom.

“We are very lonely. Even though it is some interaction, it is not enough, and also, you have to rely on the technology.” PT02

They believed that not all older people got this opportunity to join clubs because some older people did not have the funds to join these clubs and, therefore, did not belong to any group. Participants reported that older people who did not belong to social clubs were mostly home and lonely. Some missed on gaining knowledge from their peers.

“...my song writing group, because we cover all subjects in song writing we sort of have quite deep conversations, so I know how they feel about death and things like that, without it being upsetting to them it’s part of what I do.” PT11

One participant explained that during the Covid-19 lockdowns, because she had no children and was single, no one had touched her for the whole year, and she felt lonely because she had not met with her friends. She expressed that getting a hug is soothing. She emphasised that, still, if an older person is home alone and never participating in social activities, the older person could easily go for years without a hug, which affected them mentally.

“…Can you imagine that, as you get older, if you’re on your own and you have got no family, and nobody touches you. You must be home.” PT02

5.4.5 Sub-theme: v - “We become aware as we constantly adjust and adapt”

Participants reported that older people reflected a lot about life. Reflection meant an awareness of situations and giving attention to those situations, especially where adaptations were required. Data showed that participants thought about life changes and what changes meant for them. Participants expressed that life reflection helped them plan, cope and act on changes in their lives. Participants related that they were aware of physical and mental health changes. They addressed that by adapting their physical living space and activities. Similarly, some participants expressed that those who did not have children reflected greatly on what might happen if their independence was suddenly altered. On the other hand, a similar experience was felt by those whose children lived far away because they observed that those with children or relatives around relied extensively on them.

Participants reflected a lot about life and the meaning of life. Some were working on completing the nomination for power of attorney.

“As I get older, I think a lot about life, and I never used to do that when I was younger.” PT02

“…but unfortunately, I mean my son and my daughter both live in Country A, so the chance of them ever help me is zero.” PT14

5.5 Theme 4 Independence and dignity in homecare

5.5.1 Sub-theme I - “We are not just older people, we are individuals”

Participants illuminated that dignity and respect were essential for older people, yet care providers often overlooked them. Dignity and respect meant not discriminating against older people, independence, listening to older people with respect, and not patronising older people. It was about understanding older people and how to communicate well with them. Participants have observed that carers often came in to do their tasks and considered the older person as less important. Participants noted that once a person was perceived to be older, care providers also perceived that the person was just there for care and had nothing to say.

“I do not think his carers considered him very much, they were just coming in to do the job, and that was it. So, I think you got to consider the person.” PT03

Participants clarified how people perceived older people. It showed that older people want capacity-neutral language, which is a way of talking about people without assuming their capacity. Some participants did not perceive themselves as older people because they had observed that the term ‘older people’ is associated with dependency. In the current research participant information sheet, a statement read, “I will speak slowly so that they will understand.” One participant pointed out that the statement would not be written for other groups. She believed that the statement was there because it was assumed that older people had difficulty hearing. She thought that the statement was not required and, rather, one should wait for an older person to self-report that they could not hear the interviewer well. The participant gave an example of excusing herself during the meeting to collect her hearing aids because she realised that she needed her hearing aids for the interview.

“I don’t know whether you drafted the outline or not. You sort of said that. When you are talking to me, you will speak slowly. Why wouldn’t you wait for me to tell

you that I cannot hear instead of assuming that I don't hear? That sentence was not necessary." PT03

The participants emphasised that the assumption about older people was that older people could not do anything. The participant believed that through engagement, older people would feel seen, valued, and respected. She indicated that even though she was 89, she felt she had a mind of a 55-year-old. She was still independent as she drove herself, participated in philosophical group debates with her club members, and did her shopping. Moreover, after the interview, she said she was given full attention and felt respected. Furthermore, she also expressed that she liked me and felt that she got along very well with me, which made her openly share her feelings and perceptions without reservation.

"I would suggest that elderly people be addressed as, you know, retired people, people of a certain age, you know. Because also, you might get someone who is sort of probably, they are just in their 60s, and yet in their bodies and their minds, they feel 10 years older than I am. So, it's just awful to classify." PT03

Other participants believed that dignity meant being valued and worthy of respect. Nevertheless, often, older people did not feel valued by carers. Carers hardly engaged older people in conversations and, instead, they were more interested in completing their tasks and getting to the next client. Participants believed that dignity and respect were guided by how carers treated or related to an older person during their daily activities. Participants believed that dignity and respect were mostly about how things were done for the older person or the approach. One participant described that carers would sometimes come and push a bag with food in on the side of the older person's chair instead of serving meals properly to an older person. She explained that those were the indignities experienced by older people.

"In one way, I would say, this is about 90% is the approach. And you know, even if lots of personal things have to happen, it has to be done with that dignity." PT03

Older people also felt that carers saw older people as people with nothing to say because the carers or service providers had the attitude that they knew everything. Participants had observed that most care providers liked patronising older people. Some older people reported that they would not like to be patronised. Dignity meant including older people and not discriminating against them or their ideas.

"I would like to be the one who makes the decisions about the care. Somebody might recommend it, but it's going to be up to me to say whether I wanted it or

whether I don't. And now the doctors usually say, don't argue with me, listen to me, but I think sometimes it's important for a doctor to listen to the patient." PT03

"Cares need to stop the I know it all attitude." PT04

"Do not look at older people as elderly. Refer to them as people." PT03

Older people felt that dignity disappeared once a person felt devalued, unseen, unheard or not respected.

5.5.2 Sub-theme ii - "I want homecare that empowers to promote independence"

Participants thought that independence was critical for older people. They wanted homecare that empowered them to be independent. Participants believed that homecare should not be about doing for an older person. Instead, it should empower an older person to stay independently at home for the longest time. Older people reasoned that empowering older people to be independent should not wait until when an older person needs homecare. Independence meant knowledge, freedom of choice, and the ability to cope and sustain their well-being. Participants posited that the well-being of older people could be accomplished with contributions from both older people and care providers. They illuminated that older people should be empowered with the right knowledge to participate in their homecare.

"I can say I'm in charge of my will for health and wealth even. My funeral is paid for, and I will be next to my husband. So, I thought about everything. When you're on your own, you must arrange everything to perfection, the way you want it." PT10

"So for me, the more we can get this message across to people that they are responsible for their own well-being and, you can't just take a pill for it." PT07

"Independence is what I strive for till I go." PT02

5.5.3 Sub-theme iii - "We need to be educated and get homecare support without having to beg for it"

Education meant knowledge and empowerment. Participants stated that older people in the community needed regular education about homecare services for older people. Their concern was that, at the moment, older people lacked education on homecare. Some participants said older people would need homecare support soon because their memory deteriorated with time. Still, they feared that they did not know where to start because they had no information about homecare and where to get the services.

"But even if they're not in hospital, there should give more support to keep people at home." PT06

"I think I will need homecare soon, but I don't know where to start." PT04

The concern mentioned by participants was that their knowledge of homecare was inadequate. Furthermore, older people did not know where to access homecare in the community when they needed it. Participants also did not know how homecare services functioned. In fact, participants wanted regular seminars about homecare services in their communities and how older people can access those services. One participant expressed wanting a live-in carer but was uninformed about its operation. He was unsure how live-in carers got their leave days. He pondered how the security of an older person was taken care of and was also unsure of what live-in carers were allowed to do in an older person's home.

"They could have programs for us on the radios." PT09

"..education from a much earlier age, even in schools, about the ability of people to take some responsibility for their own health" PT07

5.6 Theme 5: Inclusive and accessible homecare

5.6.1 Sub-theme i - "Homecare should be for everyone"

Data showed that being inclusive in homecare was regarded as critical by participants. Participants described that in their current homecare older people were excluded from participating in their care. Some participants described that accessing homecare for their parents and spouses was challenging. For the future homecare, participants wanted homecare that would be accessible for everyone because they worried that some older people did not have children, and there would be no one to help them if homecare remained the same.

"So I think it would be nice if there was a role where there was a family liaison for people with families as well, and for people without family, so you had somebody fighting your corner for what you wanted." PT02

"…and someone whom I would be able to know that I would be able to access easily on the phone and discuss my needs." PT01

Another point raised by participants was that older people were victimised when they complained about their care. Due to fear of victimisation, older people did not want to complain about their homecare. Participants conveyed that there was a need for older people to express their complaints without being victimised by carers because fear of victimisation prevented them from seeking the homecare services that they needed. Moreover, secure channels should be created for older people.

“Do you think I can complain about my care? Who knows what will happen next time that carer comes...” PT06

“We need a way in which vulnerable older people can state their problem without being victimised by the carers.” PT06

Some participants wanted to be involved in community or social activities. Still, older people had realised that carers had no extra time to take older people out since they only had 15 minutes for their physical care. Participants reported that going out would help an older person meet other people, which could help them combat loneliness. Meeting other people could help enhance their mental, social and health well-being. Participants believed that meeting other people instead of being isolated in the house could enhance more positive feelings in older people’s lives. Older people would be happy to be included in community activities.

“..yeah you know the sinks are a bit dirty and we don’t want it dirty but people look at those things when they mark, how you are caring. but actually if the older person’s is happy it doesn’t matter as long as it’s not a health hazard…” PT02

Participants also expressed that private and charity entities currently managed most homecare services, and the poor or less privileged people did not have money to purchase those homecare services.

5.6.2 Sub-theme ii - “Can homecare be reasonably priced and be available in community”

Participants revealed that the majority of older people self-funded their homecare services. Participants clarified that homecare was expensive because homecare service providers were private and were profit-making. For that reason, most older people used voluntary homecare services from their family members, partners, friends and churches. The data also showed that some older people engaged private providers to complement voluntary services.

“They should have services that at least somebody come, a visitor comes that enquires about the older person. Knowing that there is someone there that you could call on. You know, somebody to speak to, and explain to you go about things.” PT13

Participants believed that affordable homecare meant being available and inexpensive. Participants suggested that homecare should become more community-centred and reduce reliance on voluntarism by family and friends. Participants believed that if homecare was community-centred, it could provide sufficient affordable care with a range of services. Participants also believed that community-centred homecare would allow the regulation of prices and avoid using more private profit-making companies.

"Yes, it is time that these things were known and acted upon. They only act upon the moment something happens. But having a central point is much more important and much better, from an economic point of view." PT14

5.6.3 Sub-theme iii - "Health inequalities found in homecare"

Health inequalities in homecare were an issue of concern. Participants mentioned that financial and social status led to health inequalities in homecare. Participants believed that the classification or categorisation of older people by lowest assets and highest needs aggravated health inequalities in homecare. Other participants stated that even if the social care services provided care to people with the highest needs and lowest assets, those people had no choice in the type of homecare they would like. Most of them were placed in nursing homes even if they wanted homecare.

Some participants reported that older people experienced worries and stress because older people who were regarded as economically capable of funding their homecare felt excluded from homecare. Older people lacked technical support from the social care services.

"there's a value for getting through to people who don't normally have much of a voice. They are on their own for whatever reason, they probably are poorer. Possibly less well educated, less well able to present their case, less knowledgeable as to where to go, whom to talk to.."PT06

Participants were concerned that most older people were not assessed and, therefore, could not get the classification that would assist them in being included in homecare. Most participants stated that older people experienced anxiety and fear because they did not know what would happen when they needed homecare support for dementia. One participant described that it took her father many years to be assessed and that it was when he became aggressive that he got assessed for homecare support. The participant indicated how she got frustrated and felt powerless when she sought help for her father. Now that she did not have children, she wondered what would happen to her should she face a similar situation as her father. She reported that the health inequalities that she experienced with her father made her revise her pension plans. She planned to sell her property, downsize and spend her money to expedite her future homecare assessment.

"So that made me think differently about how I'm probably going start living now and, the next few years, because you know I think we all try and accumulate money to safeguard for our future, so you got something, But then I see like my father, suddenly it's taken away and everything you've worked for its gone." PT02

One participant said that his late brother had dementia, and he never received an assessment to confirm his dementia despite family members approaching social services on several occasions until the brother died after ten years. The brother received voluntary care from family members and private carers.

"We seem to rely upon an absolute army of family volunteers, with anybody who suffers dementia and associated illnesses." PT14

One participant described that rich people had the power to get what they wanted in homecare, unlike when one was poor and lacked that power of authority. He described that one of his former clients in homecare was a former pilot with paraplegia, got the homecare he wanted because he spoke with authority, and everyone listened to him because he had money and power. He said that when one did not have money, they could not ask for choices but had to accept what was provided even if they were unhappy. Furthermore, even if they spoke, nobody would consider them.

"And because he was so severely disabled. you would think, how on earth can he stay at home, but it was possible to care for him at home because he had the money and he was compos mentis, he knew what was going on around him. and if he didn't like it, he could dismiss this person, or he could tell him what he wanted." PT06

5.6.4 Sub-theme iv - "I want to be involved in everything in my care"

Most participants reported that they lived alone or with their partners. Additionally, those who had children their children lived far outside the country. Participants, especially those who did not have children, expressed worries about whom to give powers of attorney to if they become mentally incapable of making decisions for themselves. Participants voiced that older people needed to delegate the powers of attorney when they still had full capacity since they did not want the courts to decide that for them. Their challenge was that they did not know to whom to allocate the powers because most of their friends were around the same age as them and might be unable to make critical decisions on their behalf. They wanted a one-stop-shop coordinated by the Community Nurse with whom they could develop an early relationship. Moreover, they would refer older people to trusted screened community members to support older people with advocacy.

"I would like to have an advocate, someone like you, a nurse or a social worker and somebody who knew the situation. who had weighed up my situation to advocate for me." PT01

"My sons can make decisions they've got a power of attorney. When I'm incapable of making those decisions, I will leave it up to them." PT05

Participants stated that older people wanted to be involved in everything under their care for future homecare. One participant described that his wife was excluded from the decision-making of his care, and his wife was treated more as a carer. As a result, his wife became depressed and terminated her life. Similarly, one other participant expressed how a lack of decision-making when caring for his spouse left him with constant fear and anxiety.

Participants specified that for older people to continue feeling independent and valued, they should be involved in decision-making. Participants said that when the power was taken from an older person, and they could no longer decide over their care, they felt powerless and felt that they had lost freedom, which made them feel like they had nothing to live for.

"…because you feel powerless not to make a decision. You've lost your own power to make decisions that affect you." PT02

"You find a certain level you've only got this much power, and you can only change this much so, you must get to the next level to be able to do better." PT11

The next chapter will cover the virtual participatory group discussions of meetings 1 and 2, elaborated in section 3.4.3.1.1 of this thesis.

Chapter 6 Findings for virtual participatory discussion groups

Virtual participatory group discussions of older people discussed and dialogued about the type of future homecare they wanted. Older people’s main discussion was:

- Explore older people’s perceptions of how they would like their future homecare delivered.
- To collaborate with older people to co-produce concepts and principles to underpin future homecare delivery.

Older people co-produced with me the future homecare concepts presented in this chapter as themes and subthemes. Following the co-production of concepts, they co-produced future homecare principles. The co-productions were founded on their perception of future homecare and their experiences of past and current homecare services. The co-produced future homecare principles will be elaborated on in chapter 7.

The diagram below gives the synopsis of the themes and subthemes of the findings that were developed from the participatory group discussions and will be described in this

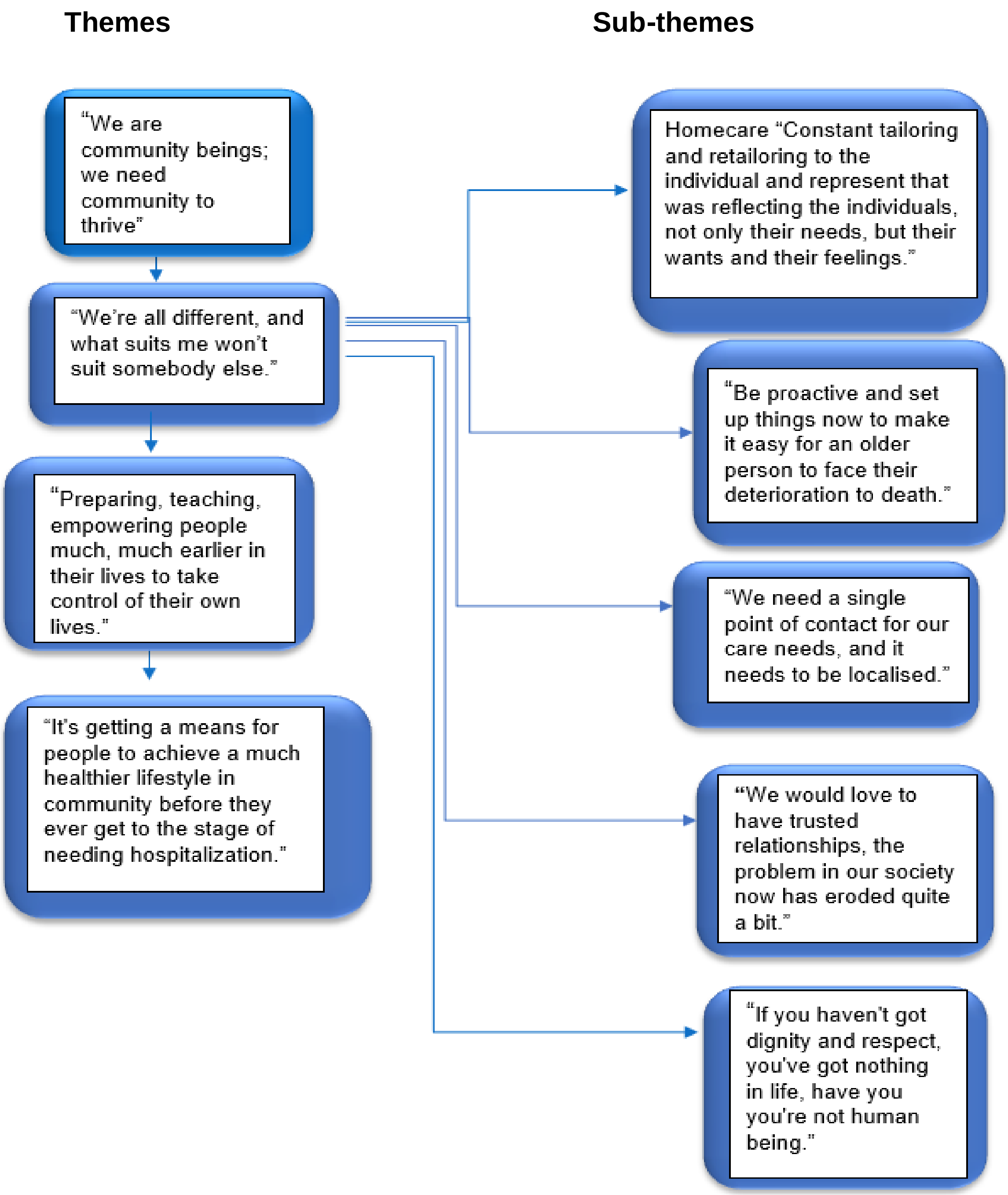


Figure 6-1 Themes and sub-themes showing synopsis of homecare wanted by older people

6.1 Introduction

The findings from the previous chapter provided insight into the perception of older people on the type of future homecare they would like.

The semi-structured individualised interview findings were presented to the participatory groups for discussion. Participants acknowledged that the findings were comprehensive and that the themes and subthemes reflected their perceptions of homecare. Participatory research values all forms of knowing, so perceptions and local understanding were incorporated and explored. Additionally, the non-hierarchical approach to knowing was reflected in how people related to each other during the research process (Abma et al. 2019).

The findings from virtual individual semi-structured interviews had five themes and 18 subthemes, which were not placed in hierarchical order to ensure that the voices of those participants were central to the discussions, fairly presented and given equal value and opportunity.

The findings in this chapter will give an insight into themes developed from the participatory group discussions when exploring the perceptions of older people in the type of future homecare older people would like. The themes would reflect how older people conceptualised their future homecare. According to (Lloyd et al. 2011, p.5), concepts are abstract notions and ideas. For the purpose of this thesis, concepts are labels, which give meaning to the type of homecare that older people want. In this case, older people enable us to categorise, interpret and structure a phenomenon, but older people are not the phenomenon itself. The concepts and principles of homecare were developed from participants' perceptions of homecare.

Principles provide a basis for the rational development of a field of purposive endeavour (Rescher 2013, p.72). The principles that should underpin future homecare will be discussed in chapter 7. Participants also discussed their own perceptions of using virtual communication as a tool for data collection in this participatory research, which will be presented in chapter 8.

Even though the discussion was about future homecare, participants still discussed current homecare. Data showed that current and past experiences of homecare influenced participants' perceptions of future homecare.

Figure 6-2 shows some frequent words used when describing future homecare. The words were created from the themes and subthemes as meanings were interpreted. The words helped in seeing the patterns and relationships in meanings and interpretations.

Figure 6-2 **Frequent words used in describing future homecare**

6.2 Theme 1: Community engagement “We are community beings; we need a community to thrive”

The theme below is about community engagement, whereby participants believed that older people are community beings and need a community to thrive.

Table 6-1 Theme 1 - Community engagement

Themes
Theme 1- Community engagement: “We are community beings; we need a community to thrive”

One of the preliminary findings showed that participants perceived older people receiving homecare to be less engaged in community activities. However, community engagement could reduce loneliness in older people. The community was perceived as fragmented, and older people were isolated and excluded. Fragmentation and isolation were observed in fragmented families, community members, and homecare service providers.

Participants reported that community fragmentation, isolation, and exclusion led to fear and worry. Participants felt vulnerable because they could not make friends who could assist them in need. One participant described that she did not know her neighbours, and she revealed that it was not easy for older people to be self-reliant in exploring new networks in the community without assistance.

PT01, during FG2M1, stated, *“I’ve just moved to area C, and I don’t know my neighbours, and sadly, the pandemic happened a couple of weeks after I moved. I haven’t been out, and goodness, I can’t wait to go back into various groups and, art groups, music groups. You know it’s not always possible. And some people are not talking personally, but some people cannot get out at all to form those groups”.*

PT07 during FG2M1 expressed that historically, family members were close by, and it was easy to support each other “*In the past, family members all lived together as a family or community. And we’ve lost that.”*

There was a concern that as people got older, they became more excluded and discriminated against in community engagement or were made to participate in activities that were only for older people. Some believed that socio-economic status and ethnic background worsened the chances of engaging and networking. *"I don't think things are getting better. I do think it's more fragmented, and there are more concerns…." PT11*

PT07 during FG2M1 said about the loneliness of older people from exclusion: *"Yeah, I was coming back on that about community, because I do think it has got to be about giving back to people forming their own societies, their own groups, their own abilities. I know that, when I was recovering from my operation in a very expensive private nursing home. There were people in there, they were almost permanent residents. Thank God I was temporary. There were people there, who would sit in the window waiting for somebody, the son that never came, somebody to come and talk to them."*

One participant explained how lonely she was during the Covid-19 lockdown. She expressed that getting a hug was soothing. However, if an older person was home alone and never participated in social activities, older people could go for years without a hug, affecting them mentally. Participants believed that the lack of engagement in the community was because most organisations that organised social networking activities required membership fees, which older people with low socio-economic status could not afford and were often left out. Participants believed that people have the assumption that older people should stay at home and not participate in community activities, and this resulted in more older people being isolated and lonely.

PT02 expressed isolation and lack of community engagement *"…Can you imagine that, as you get older, you're on your own and you've got no family, and nobody touches you. You must be home." PT02*

Some participants expressed that their friends of other ethnic groups did not want to join their organisations because they did not feel they belonged. Their concern was that people who were excluded were the ones who experienced more loneliness and feelings of not belonging.

PT10 said, *"It is the people that don't go out. People have to belong to different things. Then they can make friends. But here in town, there are lots of lonely people."*

Participants felt that being together with and belonging in the community would enhance older people's physical, mental, social, and health well-being.

"I love the theatre, I love live music, and to think that, you know, at 85, they could push me to a nightclub, and I could see a jazz band, that could be something fabulous."(PT02)

PT07, during the FG2M1 discussion, shared how she wanted to contribute to community care for older people by starting an organisation that would support older people. However, the rules and regulations made it difficult for her.

“I wanted to run an agency called Adopt A Granny. But the trouble is with health and safety and all the rules and regs. Today you can't just do that, and that's all the rules that we're getting are killing any enterprise, any real loving care. We can't do that out of love. It's got to follow the rules. That is where I think we've really got to address the system and give people the freedom and trust people.” (PT07)

6.2.1 Community engagement meant belonging and well-being

Participants reported that it was important for older people to join various community organisations to enhance their well-being and belonging. Their concern was that as people aged, older people suffered various chronic health challenges that worsened with time. As a result, older people experienced shrinking spaces and relationships. So, older people required community engagement despite their ailments because various activities would activate older people’s brains and allow them to have healthy relationships, improving their well-being. This was what PT07 said about community engagement during discussions of FG2M1 and FG2M3.

PT07 during FG2M1 said *“I think the key word is community. Because that’s what everybody needs as they get older, they’re losing their close family links. They’re losing the friendships they’ve worked hard on all their lives. And so, then there needs to be a community, and I think it’s so important”.*

PT07, during FG2M3 discussion, said*, “And for the elderly most of the time, and what they need is community and that you know that’s where the things like X Organisations are so brilliant. Because it does give people the opportunity to get out of their homes and to join together in a common activity. And it’s keeping older people active and their brains active, that is really to me, the fundamental of healing with fun and wellness for all the older people, so I think they should be much more.”*

Most participants believed that communities should be empowered to avoid discriminating against older people and account for the hard-to-reach older people to facilitate the smooth integration of older people into community activities. Participants also believed that there should be a way of encouraging older people from certain ethnicities to participate in community activities. A concern was that some older people from certain ethnicities did not want to join or participate in certain organisations because some felt that they did not belong.

PT03, during the FG3M3 meeting, discussed about reaching out to the hard-to-reach older people and engaging them through community organisations*. “Yeah, again many people do live in particular areas, not everywhere, so you have to account for them. And I know a couple of times we had X-ethnicities. They lasted about three weeks because they felt they didn’t fit in with the group. they didn’t feel comfortable with the group.”*

PT06, during the FG1M1 discussion, talked about using inclusive community organisations to combat loneliness and bring a sense of belongingness. “*Well, you know, joining organisations such as X Organisation which does quite a lot of good in the sense of informally, combating loneliness and that sort of thing. So, it pays to integrate that within the whole series of thoughts as you progress through that thought chain, going from younger age to older and more dependent age. To me, we’re all human beings. I may be in the minority of a few.”*

6.2.2 Community engagement meant safety and togetherness

Participants wanted safe meeting places within their communities run by community members. Participants wanted places where older and other generations met and participated in various activities such as music, theatre, knitting, etcetera. A place where children could sing Christmas carols and older people could read storybooks to children.

PT01, during the interview, said, *“On a local level, you could link with society and schools. X Organisation doesn’t do anything like that, we are going there for classes, but something like that is important for well-being.”*

6.3 Individualised homecare “We’re all different and what suits me won’t suit somebody else”

The table below displays the second theme, Individualised homecare, whereby participants believed that older people’s homecare needs and wants differed from each other. *“We are all different, and what suits me won’t suit somebody else*”PT04. The theme has five sub-themes and will be presented in this section.

Table 6-2 Theme 2 - Individualised homecare *“We’re all different and what suits me won’t suit somebody else”*

Themes	Sub-themes
Theme 2: **Individualised homecare** “We’re all different, and what suits me won’t suit somebody else.”	
	1. Needs and wants in homecare “Constant tailoring and retailoring to the individual and represent that was reflecting the individuals, not only their needs, but their wants and their feelings.”
	2. Proactive homecare: “Be proactive and set up things now to make it easy for an older person to face their deterioration to death.”
	3. Collaboration and coordination: “We need a single point of contact for our care needs, and it needs to be localised.”
	4. Homecare that is trustworthy and reliable: “We would love to have trusted relationships, the problem in our society now has eroded quite a bit.”
	5. Dignity in homecare: “If you haven't got dignity and respect, you've got nothing in life, have you? You're not a human being.”

During the discussions, participants wanted future homecare that would be individualised for an older person. Participants referred to individualised homecare as customised homecare for an older person. Customised homecare meant homecare where its planning and design would be informed by the needs and wants of an older person. Participants wanted carers or care providers to work with older people to develop their homecare goals. Participants went on to reason that older people were different and had different needs and wants. Therefore, the active participation of older people in planning and designing their homecare would help capture their needs and wants based on their experiences. Older people believed that customised care could constantly be readjusted to reflect an older person’s homecare needs and wants at that particular time because needs and wants change depending on the general state of an older person.

PT06 during FG1M3 said about customising homecare for an older person and continuously adjusting with time, *“what is most important to each individual, and these different needs will occur at different times in your life. And, therefore, be a constant tailoring and retailoring to the individual and represent that was reflecting the individuals, not only their needs, but their wants and their feelings.”*

PT04 during FG3M2: voiced the importance of considering the needs and wants of an older person to tailor-make their homecare*. “Well, because we’re all different, and what suits me won’t suit somebody else. So, it’s got to be tailor-made to the individual.”*

PT08, during an interview, stated that he was happy with the approach of exploring the type of future homecare for older people because it was bottom-up approach to developing the package and not presenting the ready-made package*. “One particular thing to add I think it’s a very, very good idea that you are looking at this bottom-up approach. Approaching the customer to come with a package, because just over four years ago, very sadly and very quickly, I lost my wife to brain cancer.”*

6.3.1.1 Individualised homecare meant improved access to homecare services

Participants stated that older people were not fulfilled in homecare because when carers or service providers approached them with a list of services, they often made an assumption as to what older people would need. Participants believed that service providers did not give them the independence to express their desired homecare. Those who wanted freedom over homecare choice often reached loggerheads with the service providers. Participants wanted care providers to be active listeners when talking with older people so that they would have a shared understanding of older people’s experiences and how older people were experiencing it to guide customised homecare. Participants believed that understanding the older people’s experiences and how they were experiencing them would help develop customised homecare services informed by older people’s needs and wants.

PT04, during an interview, reported that one of the homecare providers continuously followed him to choose from their list of services. *“Well, this questionnaire doesn’t enable me to describe my needs to them very well, so I’ve sort of kept them all on ice, because I don’t need them at the moment, I wanted the discussion, and all they wanted to do was fill in a form.”*

PT06 during FG1M2 said about wants and needs in customising homecare *“I was thinking about the split between the relative importance of basic needs or* *personal wants, you know how far one wouldn't need to have your basic requirements resolved. But, not forgetting the fact that a satisfactory service, one that you really welcome and cherish would be one actually provides, something more personal, something more want lead".*

Participants highlighted that older people might not access homecare services when carers or service providers focused only on need-based assessment for planning. Some participants expressed that their GPs did not listen to them when they had to discuss their medications. Some indicated that they refused their treatment because their GPs did not listen to them when they expressed themselves about their treatment.

Some participants suggested that they would like to have programmes that have a little bit of flexibility in homecare even if they were to pay a little more because that would allow older people to access homecare. Participants wanted care providers to empathise with older people and support and involve the older person's family or next of kin. Their argument was that when older people were certain about access to homecare it would alleviate their fears and worries and allow them to stay calm. This was how participant PT05 expressed it in one of the participatory group meetings.

PT08 during FG3M1 stated the importance of involving relatives in the care of an older person. *"I think it is important to have a surviving partner or spouse. And those children or near relatives that can be involved if they want to be involved, and should be consulted, to be part of the round approach around an older person."*

PT05 during FG1M3 suggested that the care should be flexible even if they could pay a little extra. *"...those are just peripheral anyway, I mean it's not like a basic medical need or caring need, but it would be nice if there could be flexibility and whatever programs offered. Even maybe if you pay a bit if you have to pay for an extra thing that you would like."*

6.3.2 Subtheme 1 - Needs and wants in homecare "Constant tailoring and retailoring to the individual"

Participants wanted homecare that addressed both needs and wants of an older person because needs and wants constantly changed with time. There was a concern that wants and needs of homecare should be regularly revised to reflect an older person at that particular time. Participants believed that addressing the needs and wants of an older person would be through the engagement of an older person. Most participants described that considering older people's needs and wants meant older people could access homecare services. Furthermore, participants clarified that older people would be able to make their true choices because participants elucidated that with the current homecare, participants were forced to choose from what was already offered by the service providers and did not reflect what participants needed or wanted.

PT06 during FG1M1 said about the importance of engaging older people in their homecare. *"The person's need is best assessed by the person in need."*

PT06 during FG1M3 also said about customising homecare for an older person and continuously adjusting with time, *"..what is most important to each individual, and these different needs will occur at different times in your life. And, therefore, be a constant tailoring and retailoring to the individual and represent that was reflecting the individuals, not only their needs, but their wants and their feelings."*

Participants reported that older people's homecare choices would also be authentic when they produced their homecare with carers because the carers would listen to an older person and support what older people wanted. Participants worried that carers concentrated only on implementing their tasks on the checklist without considering an older person or letting an older person negotiate. Still, with choices, some believed that older people paid for homecare and should, therefore, be enabled to have homecare choices. Similarly, others supported that it would be fitting to enable older people to make choices because older people vary and want different things and tailoring homecare for them could make them happy.

PT02 during FG1M3: expressed her point on how varied older people's needs and wants were and that listening to an older person would make them happy. *"But then that goes back to every person's needs are completely individual. With the cooking well, if they don't cook, you supply ready meals because that's what some people want to live on anyway, just something being delivered, but for me,* *it would be more communication and getting out. So, I wouldn't want to do online shopping even if I'm very old and frail. I've never done it. I'm quite young. I don't do online shopping, but not for food. For me, it would be the getting out and going into the supermarket that would be a good experience."*

Participants explained that the lack of having homecare choices interfered with access to their homecare, which most of the time forced them to get help from neighbours or volunteers to attain certain homecare services. The lack of homecare choices left older people with fears and anxieties because older people were unsure of what would happen when volunteers and neighbours were no longer available to meet their wants and needs.

This was how PT13 expressed the situation when one could not make choices: *"It's always a matter of monies and when I had that back operation. I had limited visits of an hour, the first three days. And then, if I wanted more, I had to pay somebody to come and help me or do the shopping for me, which I couldn't afford. Luckily, I had a neighbour that could help me with shopping, otherwise I wouldn't have managed. If you don't have money, you just have to rely on the kindness of people around you, which sometimes it's not always there."*

6.3.2.1 Needs and wants in homecare meant the ability to feel valued

The majority of participants believed that when the care providers and carers listened to older people and supported their needs and wants, older people would feel valued. Respecting the decisions of an older person and acting on them would make them feel valued and improve their confidence. Moreover, for older people, making choices for their homecare meant enhanced control, respect and independence. Some participants described that it would be nice for an older person to have the same person if they liked them in order to develop a relationship where the carers could understand the personality of an older person. They believed carers devalued older people because they did not understand them.

PT02: *"It would be nice to have the same people, but if you like them, rather than different people, so they would understand your personality, as well as your needs as an elderly person because I think people forget that you were a young person once they just see you as an old person with nothing to say. So I think if you had continuity of care would be nice, in an ideal world."*

PT06 during FG1M3 expressed his point that people should be enabled to make individual choices because collaborative decisions enhanced independence*. "But in the long run, as we all know, it's in our own interest to be at least semi-clean about not only the person, little about the house. So, it's about how far do you* *have an individual choice and when do you apply it, how far does somebody else. Or say impose their judgment on when you need it, how you need it, and at what point do you instigate all these things that will enhance independence, rather than hinder your independence."*

Some participants reported that including older people in assessing their needs and wants would empower them to actively be involved in their care rather than merely being care recipients. Participants added that when older people informed care providers about the type of homecare services older people wanted or needed, it would enhance an older person's confidence as they would feel in control of their decisions for care. In a way, it would also give an older person a feeling of being valued and respected, enhancing trust between an older person and a carer. Dignity was also said to be about including older people and not discriminating against them or their ideas.

PT03 said about being enabled to make choices, *"I would like to be the one who makes the decisions about the care. Somebody might recommend it, but it's going to be up to me to say whether I wanted it or whether I don't. And now the doctors usually say, don't argue with me, listen to me, but I think sometimes it's important for a doctor to listen to the patient." PT03*

6.3.2.2 Needs and wants in homecare meant respect and dignity

Some participants felt that all older people should be able to make choices in the type of homecare they wanted regardless of their economic background. Their view was that often, for those regarded as having insufficient funds to pay for their homecare, the social care services paid for them. However, they lacked an opportunity to make choices.

PT03, during FG1M1, expressed her view that all should have a say in their homecare. *"I still think you should be able to make a choice, I mean, the majority of people may not have any money, but they have paid into various systems, say taxes, all their lives. Which surely entitles them to have some saying and all. They may even have been working in a low paid job, which is why they haven't got anything, but the low paid job could have been helping the community generally."*

Participants believed that carers should also consider how an older person felt towards homecare. Understanding how an older person felt with regards to homecare was a way of respecting and considering an older person, which enhanced their dignity and feeling of being valued and happy. Some participants indicated that they refused treatment or advice from their care providers because they did not feel valued, respected or listened to by their care providers.

PT03 expressed herself when her GP would not listen to her regarding her treatment. *"I refused treatment, and they forget that we are the ones who have to bear all these side-effects at home, it has been seven years now, and I am still fine."*

PT07, during an interview when she expressed about the need to consider an older person when planning future homecare with an older person: *"I think the important thing is to see that people have a life, you know, that all the things that give people joy in life are available to them, and that there is the encouragement." PT07*

Older people wanted homecare that considered their needs, wants and feelings, enhancing their participation in their care.

6.3.3 Subtheme 2 - Proactive homecare "Be proactive and set up things now"

Participants believed that care providers should begin conversations with older people about their homecare wants and needs earlier before an older person becomes vulnerable or desperate for homecare. Participants believed that early discussions would help older people to think more about their future homecare. Their concern was that some older people had fears and anxieties about their future homecare because of their current homecare suffering and weakened family and community structures. Participants feared that the assessment took too long and that it was not easy for an older person to get in the homecare support loop without assessment.

PT02's perception for the delays in assessing an older person for homecare needs said, *"I think they sort of hope that the poor person passes away and it solves the problem."*

PT14 expressed his concerns about weakened family structures that leaves an older person alone with no one to help. *"But unfortunately, I mean my son and my daughter both live in Country A, so the chance of them ever helping me is zero."*

PT11 talking about the importance of proactive homecare: *"I really strongly passionately believe that we should have a proactive system and not reactive so at the earliest stage, people are meeting with people whose health is deteriorating before it actually gets to the point that they need emergency stepping."*

Participants believed that discussing future homecare would help older people choose the type of homecare older people would like ahead of time and alleviate their anxiety and fears. At the same time, others stated that mental health, like dementia, seemed to affect older people faster than other physical challenges.

As a result, when the care providers waited until later, older people would be in a vulnerable state where they could not negotiate their homecare.

PT02 during FG1M2 said about planned homecare: *“Negotiating for care is hard work, you couldn’t do it if you are vulnerable.”*

PT11, during FG3M2, said, *“...and if only instead of reactive the proactive was setting up things now to make it easy for an older person to face their deterioration to death.”*

Other participants mentioned that people should be empowered to prepare for their future homecare at an early age, as that would reduce the stigma attached to homecare and fear and anxiety. On the other hand, it would help older people maintain their independence and control at homecare. One explained how she wished her children in their 30s, 40s, and 50s could look at what she is going through and then begin to think about what older people might need for their future homecare.

PT07 also expressed that early empowerment about homecare was vital to remove the stigma associated with homecare at an older age. She also indicated that it would significantly reduce the reliance on social care structures as older people would be independent and have control over their homecare. She also believed that people would practice a better lifestyle and prevent hospitalisation when they had a more precise care understanding rather than being uninformed.

PT07 about preventive care *“I´m much into the prevention rather than cure side. It’s getting a means for people to achieve a much healthier lifestyle in community before they ever get to the stage of needing hospitalisation or that sort of care.”*

PT11 during FG3M2 said about her children *“But they should be thinking I don’t know what my needs are going to be when I reach my late 60s early 70s late 70s early 80s and I should be providing now, while I can. If I can. So that there’s no stigma attached at the end, everybody gets equal.”*

6.3.3.1 Proactive homecare meant access, control, and active participation in homecare planning

Most participants believed in proactive care rather than reactive care. Participants stated that the lack of assessment was the one aspect that interfered with proactive homecare. Some clarified that older people were not assessed for fear of accountability because participants perceived that if something happened to an older person and records showed that an older person was assessed, but the action was not taken, problems might arise.

PT06 during FG1M3 clarified delays in assessment for homecare: *"If a person in an official capacity assesses somebody and that assessment says that the person is in need and then does nothing about it, there is a potential problem. And that is the reason why quite often you find that people are not assessed because everybody's frightened of making the assessment and recognising that there is a need which, they then know will be unfulfilled."*

Participants described that proactive homecare was essential and believed that older people could be supported better if their future homecare was planned ahead of time. Planning ahead of time would help engage older people in understanding their homecare needs and contributions, giving them control and power over their care. It would also empower them to carry out certain homecare services to fulfil their choices before reaching a stage where older people would have to beg for their homecare. Participants thought some older people were embarrassed to beg and would fail to access the needed homecare services.

PT11's perception on proactive planning for homecare: *"A time when they need help. They are embarrassed to ask for it. And if something proactive was going on in the first place. They wouldn't have to ask it should be offered."*

Participants' other reasoning was that residential care would not be required if there was proactive care. Furthermore, they believed homecare had so much potential, but little was taken advantage of.

PT06 interview: *"I strongly feel that residential care isn't needed if only it could be dealt with adequately before you get to that state. So that is my feeling about homecare that it has got so much potential, but so little is taken advantage of it."*

6.3.3.2 Proactive homecare meant participation and having choices in homecare planning

Participants alleged that it would not be easy for an older person to make choices of the type of homecare older people wanted when one was in a vulnerable state. Some participants indicated that because of the weakened family system, they had been working on trying to identify younger people they could build a relationship with, but it was not easy. Participants indicated that the people they trusted were the same age as them and could not assist them in future. Participants believed that the Community Nurses could help older people if they were given a role in coordinating homecare. Participants desired that a Community Nurse visit an older person in their home as a form of early assessment to establish the type of homecare an older person might need in the future and the type of homecare for those who were receiving homecare services.

Participants elucidated that early assessment would prepare an older person to be able to think about possible changes in their body as they got older and potential future needs. It also empowers an older person to have a positive attitude to enhance her/his well-being. Participants also believed that early assessment for future homecare would increase older people's independence, freedom, control and active participation in their homecare planning. Participants wanted the Community Nurse to also assess older people's home surroundings for safety to enhance independence and freedom.

PT11 said about early consultations: *"Getting somebody comfortable talking about a future that may not be as rosy, as it once was. you know as you deteriorate, you've got to be strong. But if you prepare someone and get them comfortable, talking about it before they need it, not when they're sitting there in pain desperate for it."*

PT13 said during an interview that *"they should have services that at least somebody come, a visitor comes that enquires about the older person. Knowing that there is someone there that you could call on. You know, somebody to speak to, and explain to you go about things."*

The majority of participants were concerned about proactive care in terms of lifestyle. Participants believed that older people should be empowered to live a healthier lifestyle to prevent spending much money treating chronic illnesses. Some participants believed that proactive homecare would keep older people healthy if participants strengthened their communities because strong communities could empower or support their older people.

PT07 during FG2M1 said that *“I´m much into the prevention rather than cure side. It’s getting a means for people to achieve a much healthier lifestyle in the community before they ever get to the stage of needing hospitalisation or that sort of care.”*

Participants also believed that the participation of older people in their homecare could be improved through proactive planning of homecare services. Some participants expressed that living with their partners delayed them from planning their future homecare because they relied extensively on each other. They feared that if something happened to the partner they depended on, they would be left without homecare support. There were a few partners who planned their future homecare, and that was because participants had an experience of home caring for their parents.

One participant experienced that her mother-in-law was separated from her husband after many years of marriage because her father-in-law had Alzheimer's. Because of her mother-in-law's situation, this participant and her husband had previously lived in a privately owned retirement place that had services for partners, with one having Alzheimer’s. She indicated that they went to a house in a community because of excessive payment.

PT11 said that the lack of proactive homecare led to the separation of partners, and she did not want to be separated from her partner.

“But when we first retired, we went to an independent flat within a care facility so that we lived independently within a retirement village. If you needed care, you’ve got the facility there, there was assisted care for everyone that needed that, and there was also nursing care. More importantly, for me, there was an Alzheimer’s wing, because my husband’s mother and his elder brother had developed Alzheimer’s. And then I saw both separated from their other half, after many years of marriage.”(PT11)

Participants stated that having a proactively planned homecare would help develop baseline knowledge about the older person’s well-being.

6.3.4 Subtheme 3 - Collaboration and coordination "We need a single point of contact for our care needs, and it needs to be localised"

Participants described the importance of collaboration and coordination of homecare. Participants were concerned that multiple and fragmented homecare providers intended to assist older people's well-being. However, older people were not involved and did not know how to access these various homecare services.

Participants feared that if homecare services remained fragmented, most older people would not access the homecare services because most older people lived alone and did not have children around to help them navigate these services when needed. Some participants stated to had experienced suffering and that it was not easy to navigate the fragmented homecare service providers to help their parents, partners and relatives.

PT01, during FG2M2 discussion, talking about having one services point for older people in relation to their needs and wants for homecare, said, *"we do need these points of contact where we can get in touch with someone, maybe it's someone you know, who can fill in some forms for us for our health needs or our home needs. I keep receiving brochures from these care companies. I don't know whether they're good or bad. I suppose you have a choice, but if you're not quite with it. It's so hard to decide if you haven't got somebody to advocate for you, you know, so I want somewhere locally where I can phone and be in touch."*

Participants wanted future homecare services for older people to be coordinated from one office in the community to alleviate their fears of potential failure to access homecare. Participants desired an office that would be a one-stop-shop, which would serve all older people with their homecare support in the community irrespective of their socio-economic background. Participants wanted an office where the Community Nurse would coordinate and link older people to the needed homecare services following holistic assessment. Their argument for having a Community Nurse was that older people lived with complicated health issues requiring a skilled professional who could make professional decisions and then link them with the relevant homecare service.

PT11, during FG3M3, described that she needed a nurse for her homecare because carers were not knowledgeable in older people's health challenges and were unreliable. *"I need a nurse every day because carers at the moment are hit* *and miss, and it depends on whether you get a good one. They are hit or miss on their understanding of the need. Some of them are just simply to earn their money. I'll go in and make a cup of tea or make the bed or dress this person. I'll shoot off. I've got 15 minutes. And that is not beneficial to anybody so there's got to be some sort of system where there's a better understanding and a better training."*

6.3.4.1 Collaboration and coordination meant enhanced communication and participation in homecare for older people

Some participants indicated that challenges from memory loss that resulted from conditions such as dementia made it difficult for older people to navigate various homecare providers when older people needed services. Similarly, some participants voiced their challenging experiences when seeking homecare for their relatives, whilst others had challenging experiences filling out forms for their homecare needs. Participants stated that forms were often long and complicated for older people to understand and complete independently. Participants believed that a one-stop-shop where older people could get all the help and support for care would improve communication for older people and, alleviate their stress and anxiety and improve their well-being. A one-stop-shop was referred to as a place where all information about homecare services that older people needed would be under one roof.

PT01 during FG2M2: *"We want citizen's advice, who can fill in some forms for us, for our health or home needs. I keep receiving brochures from these care companies. I don't know whether they're good or bad. It's so hard to decide if you haven't got somebody to advocate for you, you know, so I want somewhere locally, where I can phone and be in touch."*

One participant, who was home and independent in a wheelchair, expressed how he felt that he might need homecare soon because his memory was deteriorating. His concern was that he did not have enough information about homecare, and he did not know where to get that information which could help him make his choices and plans for homecare. *"I think I will need homecare soon, but I don't know where to start."PT04*

PT09 expressed that radio could also be used to dedicate a programme to teaching or sharing information with older people. *"They could have programs for us on the radios, there was one lady who used to represent old people. I think her program is finished."*

PT04 during FG2M2: He wanted services not to be at the GPs but be under one roof. *"I wasn't expecting the doctors to be there on my beck and call at every time, and then be worried well, but I did expect that we coordinate the services through a single point of access. A single point of contact for our care needs."*

Participants believed that older people could only get the homecare they needed or wanted if care services were provided by a person who knew and understood older people. They believed that Community Nurse was skilled and could coordinate homecare in the community to improve access to homecare services by older people. They wanted the Community Nurse to be provided with a centralised system to manage a database for older people in her area. One participant explained that relationship-building between care providers and families was influential in the past. She said that GPs knew /understood the whole family in the past, making people feel safe and valued.

PT11 during FG3M2: *"Look at our old system of GPs. When I was a child, the GP knew the whole family. They knew my mum, her children, her husband. We always asked for the same doctor. She knew implicitly what we had before, even though it was in written notes. She knew everything about the family and the individuals, which doesn't happen anymore in any sphere of social work."*

Participants also wanted the stakeholders to be educated that the Community Nurse would be vital in coordinating homecare for older people. They indicated that certain care cadres undermined other care roles, like caring for older people.

PT11 during FG3 M2: expressed the importance of empowering the community and various cadres about the role of a Community Nurse. *"…they are very aware that some roles are considered lesser than, for instance, if you work on a stroke unit, but if you go to elderly care, you've been side-lined. You want them to know what a vital role, not just an important role, a vital role this NCSCN is going to be because it's going to link nursing and social care and holistic patient care."*

Participants stated that there was a need for older people to express their complaints without being victimised by carers, and safe channels should be created for older people. Participants reasoned that the communication and feedback loop could be enhanced if older people collaborated and developed a trusting relationship with a Community Nurse. Their perception was that with the current homecare, communication was mostly one way and even if an older person wanted to give feedback about their care, they were unaware of the channels to do that, but feared complaining to the carers' managers because they had not developed a trusting relationship with them nor carers.

PT06 indicated that it was not easy for older people to share their concerns*. “Do you think I can complain about my care? Who knows what will happen next time that carer comes? We need a way in which vulnerable older people can state their problem without being victimised by the carers.”*

PT08 during FG3M2 described how beneficial it would be to include older people in providing feedback in homecare. *“Where it is possible, where the patient still has the mental capacity, and this is an area that is rather grey. I think that the patient should give feedback about the performance of his or her nominated care nominees’ community social care nurse. So that the NCSN learns, it’s a continuous process of the feedback that improves the contact between NCSN and patient. At the moment, it’s all rather one-way traffic, I think.”*

Collaboration and coordination of homecare services from a central place meant easy access to information for older people. Participants alleged that having an office that supported older people would help them access homecare service information to enhance their well-being and independence. Their argument was that without a designated office that supported older people in accessing information about their needs and wants to enhance their independence and well-being, older people would be powerless, leading to faster deterioration of their health and well-being. Most older people stated that older people wanted to be supported with enough information to avoid burdening the community or system.

PT04 during FG2M2, said about the need for one point of contact for older people. *“I was really trying to say that we coordinate the services through a single point of access, which would be the health centre. We need a single point of contact for our care needs, and it needs to be localised.”*

Participants asserted that through networking, older people gained the information older people needed to manage their deteriorating health and remain independent for a longer time. One participant gave an example of her suffering. She said a one-stop-shop would rescue many isolated older people who could not easily network. Her concern was that accessing all these multiple service providers was not easy.

PT01 gave an example about herself: she had MS and could not hold anything. She got support from her partner.

PT01 during FG2M2 expressed her concern about the difficulty of accessing multiple service providers. *“Like we mentioned last week, it’s a tricky one because you do have to be able to contact people, and we know we live all very individual lives now. It’s so tricky now you know if I think about contact, I don’t have a mobile phone, I have an iPad, which I work very nicely, and I’ve got some little robot over there, who plays music to me. I don’t need to really touch anything, particularly.*

My issue is my hands don't work, and it's not because they're arthritic. It's the nerves. It's multiple sclerosis. They just don't operate. How do you access these people?"

6.3.4.2 Collaboration and coordination in homecare meant enhancing trustworthy relationships and belonging

Participants believed that homecare coordination office occupied by a Community Nurse would link older people and provide them with a signpost to improve older people's access to homecare. This office would collaborate with homecare service providers.

Participants felt that having a Community Nurse would alleviate older people's fears and anxiety because they sometimes needed someone to share their care worries and fears with. Some participants said they felt frustrated and were scared to call their GPs when they experienced some health uncertainties. Because their GPs thought they were seeking attention because they were home alone. The problem was that they were consulted for one booked health problem at a time, and if older people experienced another health problem, older people were told to book separately for that other health problem. However, that frustrated the participants because older people would have been to the doctor and wanted all the problems that transpired during that consultation visit to be addressed.

This was how PT13 expressed her frustration because her GP could not attend to all her ailments in one consultation visit. She then said*, "They have no time for you. You can't talk about two subjects, two different problems in one meeting. They will say, that's another thing, and you feel so frustrated because then, I feel embarrassed, to phone again for another appointment."*

PT13 said during an interview that *"they should have services that at least somebody come, a visitor comes that enquires about the older person. Knowing that there is someone there that you could call on. You know, somebody to speak to and explain to you go about things."*

Participants preferred a nurse to coordinate homecare because older people perceived that a nurse would holistically address older people's care issues. Participants believed that having a Community Nurse would be valuable because older people have multiple chronic illnesses, and that the Community Nurse was skilled. The majority wanted the Community Nurse to be independent of the GPs and be in the community because participants wanted the Community Nurse to map all older people in her area independently. Participants wanted GPs to liaise with the Community Nurse so that when GPs spot an older person who might need homecare, they could refer an older person to the Community Nurse.

PT06 during the FG1M2 about coordinating office for homecare: *"Yeah, having a signpost, can guide older people to go to the right places when they need homecare."*

PT08 stated that she preferred one person. *"If I could choose, I think I would prefer to have one person that I get to know well and that I empathise with. I think the drawback of having multiple people if it's not carefully managed, you don't get to know them, you don't build up an empathetic approach."*

Participants wanted a Community Nurse. After all, they believed there was a stigma in using Social Workers because people associated Social Workers with people of low socio-economic background or needing benefits. Older people wanted technical guidance to ensure their well-being was maintained, and older people remained independent at home. Participants also thought that social workers prioritised cases of children and people with a low socio-economic background. Other participants then suggested that the Community Nurse could be called the Nominated Community Social Care Nurse (NCSCN) to coordinate health and social care in the community.

FPT08, during FG3M3 discussion about the stigma that people had towards receiving Social Workers' services, said, *"that's why that's why I would plead that we try and move away from the two words social worker because it's going to look to a certain segment of the population, like, oh dear I have descended into the bath pit of those people who require social workers."*

Most older people alleged that since their ailments would get worse with time, it was critical to ensure that older people coped well and adapted so that they could live a happy life. Some participants described that once an older person failed to cope, their health would deteriorate quickly and become a burden. For this reason, participants believed that relationship-building, and early assessment were vital. PT11 reported that the coordinating office should establish relationships with older people by meeting and assessing them early before they needed homecare.

PT11 during FG3M1 said: *"They should have somebody coming in, or less telling them what to. If that relationship is built up earlier, you'll have a proactive element. We're preparing you. What do you want, what do you think your needs would be, and they will know them well by the time it comes in years to come."*

Most of the participants described that nowadays, it appeared that older people experienced dementia first before the deterioration of physical ailments.

However, their challenge came when a vulnerable older person had to negotiate for care with multiple homecare providers, some of which were private profit-making companies. Participants indicated that older people were interested in developing deepened relations by dealing with one person because participants believed that deepened relationships or connectedness created an empathetic approach between the carer and an older person. In addition, older people know where to go when participants need support or advice. Furthermore, participants believed that the coordinating office would do things in the best interest of an older person. Participants believed that the coordinating office would be in some way acting in a role that would have been carried out by their children, friends or relatives, which showed that families had weakened and were no longer nearby to support their elder parents or relatives.

PT01, during FG2M2 discussion, talking about having one service point for older people in relation to their needs and wants for homecare, said, *"we do need these points of contact where we can get in touch with someone, maybe it's someone you know, who can fill in some forms for us for our health needs or our home needs. I keep receiving brochures from these care companies. I don't know whether they're good or bad. I suppose you have a choice, but if you're not quite with it. it's so hard to decide if you haven't got somebody to advocate for you, you know, so I want somewhere locally where I can phone and be in touch."*

Participants discussed that homecare for older people should not be politicised because it was an issue that affected everyone in the UK. They emphasised that they would get one version of the story if it got politicised and engaged MPs to explore their thoughts on their plans for future homecare for older people. It showed that trusting and having a sense of security in a relationship was as crucial because they trusted the local government more than political MPs to plan homecare for older people.

PT14 during FG3M1: responding to contacting MPs to hear what they have planned for homecare for older people said. *"This is not really a political issue or shouldn't be, because it affects every individual in the United Kingdom in different ways and if you politicise it, you'll get one version of homecare. Surely homecare is much more general than that. I feel it has to be from the local areas because the local areas know how their constituents are built up. The government can look at an overview, then you have to have the other areas, the groups that worked with that particular people."*

6.3.5 Subtheme 4 - Homecare that is trustworthy and reliable “We would love to have trusted relationships, the problem is, our society now has eroded quite a bit”

During the discussions, the participants indicated that most of their homecare services depended on informal carers, volunteers, family members, partners and private carers. Their concern was that most older people had family members who lived far away or did not have children. In addition, there is a lack of community-centred engagement, making it hard for them to network and develop trusting relationships with other community members. Participants also experienced that when private carers were engaged, they were only concerned with doing tasks and omitted the mental and social health of the older person.

PT01, during FG2M2, shared her experience in trusting private care services. *“I’m not happy with the private healthcare, you know you really don’t know what you’re getting, and I used it for my mother.”*

PT13 indicated that she relied on volunteers even though it was hard to have people who still volunteered. *“If you don’t have money like me, you rely on the kindness of volunteers.”*

PT01 suggested that communities, including older people, must be revived by formalising people’s engagement in community activities*. “… it’s the locality, this is what people do need and involve people in the town as much as you can. We’ve got to build up that community*.”

Most participants felt that recruiting the right people with the right skills and the right attitude for homecare jobs was essential because older people cared a lot about their well-being. Some participants believed that carers were not equipped with the right skills because people who made decisions in higher offices did not understand the complexity of the care needed by older people at home. Older people stated that decision-makers often assumed homecare was about social care that entailed laundry, bathing, and cooking and did not consider the older person and their health, while it was more than that.

PT06, during FG1M1, talked about the importance of having the right people with the right skills, saying, *“Recruitment of the right people in the first place. With the right attitude, and I’ve long held the belief that it’s, the most important thing you need for that sort of job is the right attitude. You can always be trained, but you’re going to have as much training, but if you haven’t got the right attitude for the job, you’re never going to do a good job.”*

PT11, during FG3M3, talked about the carers’ skills said, *“carers at the moment are hit and miss on whether you get a good one. They are hit or miss on their* *understanding of the need. Some of them are just simply to earn their money. I'll go in and make a cup of tea or make the bed or dress this person I'll shoot off I've got 15 minutes. And that is not beneficial to anybody, so there's got to be some sort of system where there's a better understanding and a better training."*

6.3.5.1 Homecare that is trustworthy and reliable meant feeling safe, be free from worries and anxiety

Participants reported that there were many older people in the UK because of the baby boomers. This refers to the babies who were born after World War 2 when there was a significant rise in the number of births. The majority of participants believed that the current homecare arrangement was not prepared to manage a large number of older people in need of homecare services. Lack of preparedness in the current homecare arrangement means an increased vulnerability of older people and anxiety.

PT11, during the interview, said, *"I'm from the baby boom era. After the war, there was a baby boom that's why the elderly are going up. I actually think it's 27% per year for the Over 60s. We are going to have an older population, and that older population is not being cared or catered for. We needed to have looked at this 10 years ago and see what the needs of the elderly population were that's growing. And it's still not too late. You're doing part of it with your research."*

Participants wanted homecare that was consistent and reliable. Consistency was considered necessary because they wanted someone who would regularly care for an older person to develop that trusting relationship. Homecare that was trustworthy and reliable meant that the older person would feel safe and be free from worries and anxiety. Other participants believed that consistency would help older people develop social relationships with their carers. Participants said that when there is trust, carers would be able to advocate for an older person.

This was what PT02 during FG1M2 said about consistency of carers, consistency, "*I should think is important, you know somebody who is regularly coming, and so you know that is consistent and permanent and you're not going to be left with someone not turning up because you know the care company isn't joined up if someone's gone sick or something. There's lots of things that I'm sure lots of people have got other things to say about consistency, I think is pretty important."*

FPT09, during FG1M2, in agreement with PT02, added by saying, *"Because you can often form a formal social relationship with a person if it's one or two people that come on a regular basis. They can in a way befriend the elderly person and therefore, get more value, I think, to the service they are giving."*

Most participants expressed that older people would like to have trusted relationships with their carers, but the challenge was that they felt that society was eroded. Participants believed that some carers betrayed older people’s trust by stealing from older people. Participants believed that even if a person could be trained, they would never be good at their job if they did not have the right attitude. Participants believed that some carers lacked dedication in their careers. However, others commented that some carers were loving and gentle but did not have the skills to assess an older person.

PT06 indicated that older people wanted trustworthy, friendly and personable carers. *“But equally, I can say you would want somebody who’s coming into your home after all. And there’s a big thing they come through your front door, therefore, you want them to be trustworthy, you want them to be friendly and ideally personable.”*

Sufficient care was also mentioned, for participants felt that carers should provide sufficient care and 15 minutes was sometimes not enough for the care needed by an older person. Participants believed that most older people were always worried about their care because some care providers promised to deliver certain homecare services to older people and then failed to deliver.

PT06, during the interview, also talked about reliable and sufficient care, *“Whatever you receive should be reliable. Are they going to turn up when they say they are going to turn up, and they’re going to provide what they say they’re going to provide? You want it to be sufficient in the sense of sufficiently frequent. There’s no point going once a week, if that help you want is getting dressed. And you want the range of what these people will do. You want the range to be sufficient. Not just getting you out of bed and then off they go. Trust is so important because if you haven’t got that, then you’re only going to go so far. And you want somebody to be personable somebody you can get on with.”*

PT08 also talked about trust and reliability, saying that he would like to have somebody he trusted and came in regularly for his homecare. He also spoke about the Hippocratic oath of not harm, emphasising trust. He believed that carers should have the best interest of an older person at heart.

PT08 during FG3M3 said, *“Hippocratic oath of do no harm also extends to the trust and trustworthiness, and that, a person should look upon this new role. This person who comes to them as a friend, A friend is someone who has the interests of the older person at heart.”*

Participants believed that communication affected the trust and reliability of care services. One participant gave an example of doctors who did not consider an older person when talking to them over the phone. The participant reported that older people felt older people were not listened to by doctors in most cases because of their attitude towards older people. Other participants raised a similar point: older people wanted carers or multiple stakeholders that an older person dealt with to consider and listen to them.

PT14, during an interview, said: *"I think communication is very important. That can be on the phone and so on to have certainly improved things, but I do think that doctors have got to come into the real world and remember that at the end of a discussion, there is a real person that they need to know about. A very complex person, probably unwell, because what is unhealthy is very complex."*

Others expressed that there was always an assumption that when one had children, they would care for an older person when they needed homecare. They believed it was not always the case because some family relationships were broken.

PT03 described that some younger people had broken relationships with their parents, and their parents could not trust them for their care. *"I know some younger people where they've completely broken off relationships with parents, and there's no way they could use them as an advocate, so they wouldn't do it as I could. So it just depends. Again, you're coming back to personality as much as anything else."*

6.3.6 Sub-theme 5 - Dignity in homecare "If you haven't got dignity and respect, you've got nothing in life"

Participants believed that a lack of individualised care meant a lack of relationships with older people and a lack of participation. Lack of participation meant isolation, and isolation meant undignified deaths and a lack of security. Participants reported that some older people die in their homes, and they go for weeks without anyone noticing their death. Participants believed that having a relationship could help people care for each other with empathy. One participant gave an example of how one of her friends lost a friend who was in his 60s. The friend died alone in his apartment and was not discovered for weeks.

PT02 during FG1M2 discussion: *"Her friend, who was in his 60s, lived in what you would call sheltered accommodation. His own very, very small sort of one-room department, and he died in his room a few weeks ago and wasn't found for weeks. Nobody has knocked on his door."*

Some participants asserted that dignity meant simply being aware and sensitive to an older person's perception of themselves and others. It was about understanding an older person and how to communicate with them. A point brought up was that once a person was perceived to be older, it was also perceived that the person was just there and had nothing to say.

"I don't think his carers considered him very much, they were just coming in to do the job, and that was it. So, I think you got to consider the person." PT03

Some participants felt that fragmented services eroded the dignity of older people in homecare, because of a lack of communication in fragmented institutions that cared for an older person. Participants described that homecare is isolated from National Health Service. To justify this concern, participants explained that as soon as NHS had repaired an older person's broken leg, an older person would be abandoned by the care system to look after themselves. PT14 indicated that older people were treated in parts and not holistically because he believed that health is about the individual from birth to death and that everything should come through a central source, yet it does not. It is broken down. He also gave an example of dealing with mental health and homecare separately.

PT14 during FG3M2 said about dignity and fragmented services: *"One of the things that need to happen is a change of attitude, and for some obscure reason homecare is isolated away from the NHS, but really, we call it the National Health Service. As soon as your broken leg is repaired, you're dumped on the street again to look after yourself. But really, health is about the individual from birth to death. And everything should come through a central source, and yet it doesn't it breaks down. Mental health is dealt with separately. Homecare is dealt with separately, with separate budgets, separate organisations. You've got to bring all of these together, and there has to be a complete change of attitude."*

Participants believed that being heard and treated appropriately could enhance older people's dignity. Some participants indicated that because of fragmented services, participants engaged with multiple service providers to get some support to manage their ailments at home. Conversely, their concern was that some service providers displayed negative attitudes towards older people, making them feel less valued.

This was how PT13 narrated her experience with health care providers, *"Well, because they might feel that we are seeking attention, especially if we live on our own and have something that is recurring frequently. I went to the hospital not so long ago. I had contact and a few visits to the A&E because I have had some bad episodes. This young doctor said, Oh. You're back again. She said we did tell you we have done all the tests and that there is nothing wrong with your heart. Why did you come again? You should go to your GP. I did not come about my heart or my usual episode"*

Additionally, PT14 responded to PT13’s statement about the exclusion of older people by saying, *“You are forgotten, you are an embarrassment, you are a cost.”*

Participants wanted older people to be included in planning and executing their homecare and community activities to enhance independence. Their concern was that often homecare planning decisions were made by care providers. Participants pointed out that older people should be active players in their care and be enabled to make choices in their homecare despite their socio-economic background. Participants acknowledged that some older people might not have what was required to contribute to their homecare because they previously had low-paying jobs. But despite that, they might have contributed to the system differently.

PT09, during the FG1M1 meeting, said about having choices concerning maintaining older people’s dignity; *“I still think you should be able to make a choice, I mean the majority of people, they may not have any money, but they have paid into various systems, say taxes all their lives. Which surely entitles them to have some saying and all. They may even have been working in a low paid job, which is why they haven’t got anything, but the low paid job could have been helping the community generally.”*

6.3.7 Dignity in homecare meant good communication and respect to older people

Caregivers did certain tasks to help an older person with their daily activities, but older people perceived those tasks as eroding their dignity. As a result, some participants stated that communicating and discussing the tasks to understand an older person’s perception and what those tasks meant to them was essential to maintaining their dignity. Letting an older person choose how they wanted the task to be done also made older people feel respected.

One participant explained how her mother did not want to have care support when she cared for her husband, who had been together for 70 years. She observed that her mother wanted to do those tasks by herself, even though she had difficulties. She discussed this with her mother to understand her perception. She understood that her mother did not want to get support from carers because her mother expressed that she did not want people to come and make her bed. Her mother felt that her dignity would be eroded if strangers came in to make her bed when she could do it by herself. It also affected her self-worth because it would appear that she could not take care of her husband, and older people wanted to be independent.

PT02 during FG1M3 said, *“My mother had that. She’s 89 my father died last year, she didn’t want to put him into a home. They’ve been together for 70 years but she couldn’t cope with him. I still was working virtually full time. And I eventually persuaded her to get care in, but she didn’t even want to receive care. Because I suppose she felt it was eroding a lot of her dignity, I don’t want people coming into my house and changing sheets. She had it eventually.”*

Some participants felt that letting older people express their appreciation to carers was vital because it uplifted their worthiness. Most older people felt unappreciated when they offered little gifts to show their gratitude, and people refused their tokens of appreciation. Older people believed they lived in a society where people were not enabled to care about each other. One participant described how she could not express her gratitude to her carer during Christmas because the carer said they were not allowed to receive anything from their clients.

PT07, during the FG2M3 meeting, said, *“she said to me I’m not allowed to accept this PT07 and I just cried. I just thought, what society are we in, that we’re not even allowed to show our appreciation of people. And this is something I think is fundamental to older care, but we are living in a society that is not allowed to care. It is not allowed to accept gifts. It’s allowed to do these things, and that is what damages everybody. And, to me, it’s fundamental.”*

Some participants felt that people should be taught to treat each other with dignity from a young age. Their perception was that it should be practised from preschools so that people grow up knowing how to care about each other. One participant mentioned expressions like ‘do unto others as you would have them do unto you’. Other participants said that sometimes things were set out with the best intention, but people turned a blind eye due to pressure from above when the harm occurred. So, one also thought expressions like ‘do no harm’ from the Hippocratic oath should be prioritised in homecare.

PT07 during FG2M3 said, *“I think it would be a good idea to have the Hippocratic oath at the top, do no harm, treat with dignity and respect and give individuals every possible right to have a say in their care.”*

PT03 during FG3M2 said about this, *“I think the expression ‘do unto others as you would have them do unto you’ and should be practised from preschool way up.”*

PT03, during an interview, indicated that care had changed and that there was no dignity in homecare. She voiced that dignity was about how things were done. She gave an example that carers zoomed in and out to do what they wanted. She meant that carers rushed in, completed their jobs and rushed out. They did not consider the older person as important.

PT03, during an interview, *"I think homecare probably has changed. The fact is that carers tend to be robotic in what they are doing. They just come in and do this, they zoom in, and they do it, they zoom out. It's almost like they treat the person in different parts. I know it's expensive and there are other people around. In one way, I would say this is about 90% is the approach. And you know, even if lots of personal things have to happen, it has to be done with that dignity."*

Participants felt that dignity was the most important thing because it is about how older people were made to feel. Participants believed that carers should treat older people with respect even if they had dementia. Participants reasoned that carers should treat older people who suffered from dementia with dignity because that older person would be made to feel worthless if not treated right. One participant linked the conversation to her father, who had dementia. She indicated that when she talked and held conversations with her father, relatives thought that she was ridiculous because her father did not understand anything. She posited that people should respect diversity and treat everyone with dignity.

PT02 during an interview, said, *"I think diversity is the most thing. I have to treat someone with dignity because you don't know what part of them still remembers everything as they were. If you haven't got dignity and respect, you've got nothing in life, have you you're not a human being. You wouldn't want to live if you were not treated with dignity and respect. I wouldn't. If I don't have those things, what would be the point. Would you?"*

PT03 also raised a similar point during an interview that carers need to have courtesy and gentleness when caring for older people to accord them the dignity they need. She said older people needed someone who cared for them. It should be someone an older person liked and is prepared to present themselves to.

PT03 said during the interview, *"but you need someone as you're going to have someone in to care for you. And even if it's only intermissive, you need someone, who will care for you, will like you, someone you like. Someone you are prepared to present yourself too as well."*

6.4 Theme 3 – Resilience in homecare “preparing, teaching, empowering people much earlier in their lives to take control”

The table below shows a theme about resilience in homecare. Participants believed that education and empowerment about homecare should be conducted in the whole society because this would reduce stigma and help older people cope and maintain control in their lives.

Table 6-3 Theme 3 - Resilience in homecare

Themes
Theme 3: Resilience in homecare: “Preparing, teaching, empowering people much earlier in their lives to take control of their own lives.”

During the discussion, it was clear that participants exhibited some characteristics of resilience in the way they described how they managed to rebound from hindrances caused by their deteriorating health and ageing. Furthermore, participants described how older people thrived in the face of poor conditions, which could be from lack of access, isolation, their home environment and dealing with multiple players that support them at homecare.

PT08 described how he cared for his wife, who was terminally ill, because he made an oath with his wife that he would be there for her for better or for worse, in times of sickness or good health. And those three months were when his wife was utterly dependent on him, and the state in which caring for his wife affected him psychologically was significant. Yet, he never received any counselling for this. Above all, when his wife was taken to a hospice for the final two weeks of her life, he felt enormous guilt and distress as he felt he had failed his marital vows because he was unable to look after her any longer, and the communication received from the care providers made him sad.

“…I suddenly broke down and sobbed, because the way it was coming across to me was, I’m guilty. I can’t manage my wife any longer, I had tried to the best of my ability, honouring my marriage vows, of in sickness and in health, to manage her the best I could.”PT08

PT08, during the FG3M2 discussion, felt how, despite being the next of kin and managing his wife through a condition that emotionally affected him, he was determined to care for his wife, but he never received counselling during his caring period. "…*but after her death, the hospice offered me bereavement counselling, but during her lifetime, I wasn't offered any life counselling on coping with a cancer patient." PT08*

PT07 during FG2M1 said: *"I just think it comes back to, preparing, teaching, empowering people much, much earlier in their lives to take control of their own lives. It´s not being reliant on your GP for any little thing."*

It showed that their resilience was influenced by the fact that older people wanted to be independent and have freedom, control and dignity despite the challenges older people faced from deteriorating health, ageing and shrinking relationships. Many participants believed that most chronic conditions older people suffered from would worsen as they grew older. They were ensuring that older people lived with dignity and as well beings despite their ailments was necessary.

PT06 indicated that older people need to be trained in life skills to help them cope. *"And it's about being involved learning all these skills and being involved in society and not being reclusive. So that when you get older, you're not suddenly on your own, you have life skills, you know what's around you, you have people that you can talk to or you can go to for advice."*

Participants described how they solved or prepared for safety challenges in their home environment due to the health alterations they experienced. One participant reported that she anticipated her legs would be amputated soon for health reasons. She reported that, at times, she spent sleepless nights thinking about it. Despite that, she vowed that she would never give up because she explained that once a person gave up, they sank into a depression and then their health deteriorated very fast. So, she was currently planning for a chairlift to prevent her shrinking space and maintain her independence.

PT11, during an interview, said*, "there's a possibility, in the not-too-distant future, I'm going to need a chairlift on the stairs. We've got two flights of stairs in our flat. We live in the upstairs of a house. I need a chairlift and because, I've been careful and I have a husband, who was an accountant so he's very careful with money."*

To prepare for her life after amputation, herself and her husband had been looking for different options for stairlifts so that she could continue to use the upper floor of their house. She appreciated that her husband, whom she had been married to for over 60 years and an accountant, had managed their financial accounts so well that now she could afford a chairlift.

Several other participants reported the installation of grab rails in their showers for safety. Sometimes, grab rails did not solve participants' challenges, and, as a result, they had to implement other alternatives. One participant reported that she could not grab the rail and shower handle simultaneously, so she installed a walk-in tub to be able to sit and hold a shower handle without the risk of falling due to her chronic dizziness. Participants believed that older people should prevent falls because falls affected their confidence. Then, they stopped participating in the activities they liked.

PT11, during an interview, said, *"...there has to be more done to prevent falls, because it is the biggest cause of lack of confidence. And it's the start of the end because people stop doing things because they're frightened."*

6.4.1 Resilience in homecare meant self-reliance, control and dignity

Participants believed that for future homecare, they wanted older people to be empowered to enable them to develop a more vigorous attitude of self-reliance, to take control of their lives and participate actively in their homecare. Participants described that the relationship older people had with the care providers could be traumatising for older people because participants felt older people were not prioritised. The other factor was excluding older people because older people stated that older people generally wanted to continue to lead productive lives in their communities.

PT11, in an interview, said, *"If older people are educated to help themselves. And given the support, they need without them having to beg for it. I think that makes them feel they are not a burden, and they are still a useful part of the human race."*

PT07, during FG2M1, discussed the need for empowering older people and said, *"I just think it comes back to preparing, teaching, empowering people much, much earlier in their lives to take control of their own lives. It´s not being reliant on your GP for any little thing."*

Some participants explained their stress when they cared for their partners. PT08 described that after the death of his wife, he was emotionally affected, and he joined X-Organisation, where he met other retired people and did activities together to avoid isolation. His view was that X-organisation helped to strengthen and soothe his emotional and social side following his loss because he had a smaller social circle. It also enabled him to continue contributing meaningfully to his community as he voluntarily taught French to a group of older people.

PT08: *“Sadly, my wife was suddenly diagnosed with an inoperable brain grade 4 global tumour. So, after her passing, I moved down here on my own, and I got involved with the X-Organisation. We run all sorts of activities for older people, semi-retired or fully retired. And I’ve ended up actually leading a group in advanced French conversation and also take part in a group on speaking German.”*

PT10 also described that losing her husband affected her emotionally to the degree that she was taken to a psychiatric hospital because she went into depression. However, she believed she needed bereavement counselling instead. She stated that being taken to a mental hospital affected her dignity and decreased her sense of belonging, making her feel less able to cope. She joined various associations to meet other people. In addition, this prevented her from feeling lonely and depressed.

PT10 *“I had a nice bungalow, but after my husband died. I couldn’t go back in the bungalow. I ended up in G-hospital, and they sent me to M-hospital. I had to go voluntary otherwise, they would have sanctioned me. So, I went in there and then, I don’t know why I was in there actually. I think I should have had bereavement counselling. Not being sent there.”*

PT10 described that she joined various organisations to heal herself mentally*. “I now belong to X- organisation. It is the people that don’t go out. People have to belong to different things then they can make friends. But here in B-town, there are lots of lonely people that haven’t got money. You need to have people you can call on in case of need. If people haven’t got their independence, it’s not right, is it? If you don’t have independence, there is no life. I think I am a bossy boot.”*

Older people described their ability to cope with different challenges and how they recovered. Despite various challenges, older people believed in freedom, independence and control of their lives.

6.5 Theme 4 - Empowerment of older people “It's getting a means for people to achieve a much healthier lifestyle in the community”

The table below shows a theme about the empowerment of older people. Participants believed that empowering older people would enhance competence skills that would help older people to achieve a much healthier lifestyle in the community.

Table 6-4 Theme 4 - Empowerment of older people

Themes
Theme 4: Empowerment of older people “It's getting a means for people to achieve a much healthier lifestyle in community”

During the discussions, participants indicated a need to empower older people to practise a healthy lifestyle to enhance their independence and well-being. Participants believed that enhancing well-being would reduce and prevent hospitalisation and burden on the already inadequate staff of social and health care providers. Their concern was that the current homecare did not empower older people because older people did not know where to get important information that could help them make decisions. Participants reported that failure to access information by older people led to worries and frustration.

PT06 indicated that community engagement could help older people develop coping skills. *“If somehow this helps to encourage people to be more engaged in the wider society and community and not get to the point where suddenly at an older age, they're isolated and have insufficient skills to cope.”*

Participants reported that the number of older people was increasing, so there would be a burden on health or care services as the demand increased. So, participants reported that there would be a shortage because they had already observed a trend whereby the services that participants used to get from NHS were no longer accessible. Participants now had to sort The NHS previously supported services from private care providers.

PT02 indicated that her mother had varicose veins and used to access services for varicose veins on the NHS. She emphasised that she(herself) also had varicose veins but sought services from private care as the NHS no longer offered those services. So, she felt that the NHS was diminishing, and her perception was that even old age care would not be enough for everyone in the future. She suggested empowering everyone, including older people, would be vital for better health.

“NHS is diminishing anyway. And it's not going to get better because services that my mother could access, like years ago varicose veins, problems that I have now inherited, are not on the national health. I've had to pay privately to have all of that done. Those were the general care. So, the old age care is not going to

be there for us. Things are going to diminish. I mean, they've diminished in my last 30 years an awful lot of the services you can get from the NHS."

Participants suggested that getting everybody healthy through empowering people would be significant because they believe prevention would be better than treating people or hospitalisation. Participants raised concerns that most older people's health issues were caused by unhealthy lifestyles, which could have been prevented if older people had been empowered in lifestyle issues.

This was PT07 during FG2M1, describing that empowering people to achieve a healthy lifestyle was essential. *"I'm much into the prevention rather than cure side. It's getting a means for people to achieve a much healthier lifestyle in community before they ever get to the stage of needing hospitalization or that sort of care because I do believe that we can or take great steps to better our own health."*

Participants believed that to enable older people to get empowerment support, there was a necessity to build communities and nominate a Community Nurse who would build trustworthy relationships for homecare with older people. Older people believed that since the nurse was skilled in health and social care and could make suitable decisions, the Nurse would be the right person for this assignment. Participants wanted the nurse to work with an older person to carry out an early assessment to address the homecare wants and needs of an older person.

Participants indicated that older people wanted a central point where they would seek advice and support. Their view was that older people did not know where to go when older people needed information about homecare and could not negotiate homecare services with private care providers who are profit-making companies. The inability to negotiate care with private care providers was because older people felt uninformed or unempowered about homecare information.

PT02 during FG2M1*: "…getting better health into everybody because you can see one 65-year-old you're really good and another one that's in a chair and so it's trying to get that, but I don't I think we're looking at utopia, and maybe on a pessimistic."*

6.5.1 Empowerment of older people means ability to make the right decisions, independence and enhanced well-being

Participants believed that empowering older people with the right education and knowledge would strengthen their independence and participation in their care. Participants justified that older people lived with various health challenges and cared for their partners and relatives. Older people needed to be empowered with the right information at the right time to make the right decisions and to take the appropriate action at the right time. Older people often became frustrated when they lacked information and experienced difficulties seeking information from various care service providers.

PT07 during FG1M1 described the importance of knowing which places to go to when they needed information. *"And over time, so all this stuff rubs off on you, and when you need something, you think: Oh, I know, if I go down to there, I'm sure there's somebody there who can tell me, that might be a way through. So anyway, there is no one other place to go, other than citizens advice."*

Participants wanted programs on radio and TV. Some participants reported abuse of older people in their homecare, and participants felt that if older people were empowered, they would know the right paths to seek help.

PT11 on abuse: *"older vulnerable adults that were being abused and you wonder how that has slipped by during the pandemic without the concentration being on things like that."*

PT14: *"Yes, it is time that these things were known and acted upon. They only act upon the moment something happens. But having a central point is much more important and much better, from an economic point of view."*

6.5.2 Empowerment of older people means the ability to make healthy lifestyle choices

Participants believed that nutrition was vital for older people and that diseases could be prevented with good nutrition. Most participants reported that they ensured that they ate healthy for the optimal functioning of their bodies.

Participants believed that older people's well-being was more than being given medicine. They believed empowerment was essential for older people's well-being because it meant older people would gain power and independence to sustain their well-being through healthy lifestyles.

"So for me, the more we can get this message across to people that they are responsible for their well-being and, you can't just take a pill for it." PT07

One participant explained that he ate healthy to keep himself healthy and age well. Not only did he monitor his meals, but he also exercised daily. He cycled and wanted to ensure that he lived an active life, ensuring independence and good health. He had succeeded in losing weight down to the weight he had in high school.

PT12 said about keeping healthy at 78 years, *"I do row 5-6 times a week, watching my breathing and recovery rate. I cycle, eat healthy, and reached my goal weight last week. I now have the same weight I had in high school."*

PT12 wanted health validation from health providers like a dietician through an annual check visit. *"Annual consultation with the dietitian that's as far as I can see now looking ahead. I do not know how my body is going to fail at the end."*

Another participant reported that she was mindful of her food because she believed that older people should eat more organic food as it heals the body rather than GMO-modified food. For her, good nutrition meant good health. She ate only organic food, and for 11 years, she had been without cancer medicine. She had reduced the size of her tumour by eating the right food. She also believed that older people needed to be empowered to heal themselves with food. She believed that too much reliance on medicine led to some diseases caused by the drugs' side effects. She thought that some medications caused side effects, and then the person would be given another medicine to treat the side effects, and resulting in a domino effect. After refusing chemotherapy eleven years ago, she mainly ate raw organic vegetables, healthy fats and no sugar. She read food labels and avoided genetically modified food. She avoided certain methods of preparing foods, such as frying. Furthermore, this had helped her reduce her body inflammation and body pains. She said she listened to her body more, and the pain was not a bad thing but a sign that something needed to be addressed.

PT07 emphasised nutrition empowerment. *"You cannot throw everything in your body and expect it to be clean. Let's feed our body with good nutrition and keep it clean."*

PT07 talking about the benefits of eating healthily: *"…pay the farmer and not the doctor, meaning that you pay a little more for your food, you avoid all the health problems."*

Some also thought that older people's nutrition needed to be monitored. One explained how his father, with dementia, often forgot to eat his meals, even if they left food on the table for him to eat while they were at work. One participant shared that nutrition was important, but she observed that carers would drop the bag of food next to her mother’s chair without seeing that she ate. Pushing food next to her mother’s chair meant indignity. Instead of carers serving her mother correctly at the table, they pushed the food next to her chair or on her knees. Her concern was that older people experienced some indignities because of a lack of empowerment.

PT07 during FG2M3 discussion: *“in my mother's house when she had live-in carers, they were just bringing her stuff to her knee and not letting her sit at a table. And that is such a lack of respect of people. Again, we're back to respect and dignity, and they knew you don't just give somebody rubbish food on their knees and it's about again quality, not quantity.”*

Some participants reported that they hardly cooked. One said he had not cooked for four years, and he no longer found pleasure from eating since the death of his wife.

The next chapter presents future homecare principles co-produced with older people. The co-produced principles were meant to guide carers and care providers to understand older people’s perception of homecare.

Chapter 7 Co-produced future homecare concepts and principles

This chapter addresses the study objective: To collaborate with older people to co-produce concepts and principles to underpin future homecare delivery. The research question for this objective is: How does collaboration within research enable older people's voices to be heard and allow meaningful engagement?

The chapter focuses on the principles since the concepts were described in chapters 5 and 6. According to (Lloyd et al. 2011, p.5), concepts are abstract notions and ideas. Principles provide a basis for the rational development of a field of purposive endeavour (Rescher 2013, p.72). Principles guide the conduct of proceedings, and different principles are operative in different domains (Rescher 2013, p.72). The concepts and principles co-produced with older people are not rigid rules but guidance that care providers and policymakers could understand how older people want homecare to be customised for older people to live as well-beings and in dignity.

This chapter also presents the revolutionary homecare tree of life used to present the study findings. The name *"revolutionary homecare tree of life*" came from the participants after findings were shared with participants in the form of a tree. The green tree was used to present the findings more simply to the readers. Participants were requested to state their perceptions of the tree being used to share the findings. The other tree without leaves was used to show how older people perceived their current homecare.

The diagram below shows the participants' virtual participatory discussion process during the co-production of future homecare concepts and principles. The participatory groups began by describing the future homecare they wanted. Participatory groups completed with reflections on the dissemination of study findings. This chapter addresses the findings of stage stated on a blue bubble that older people discussed principles to guide in preserving the co-produced homecare concepts.

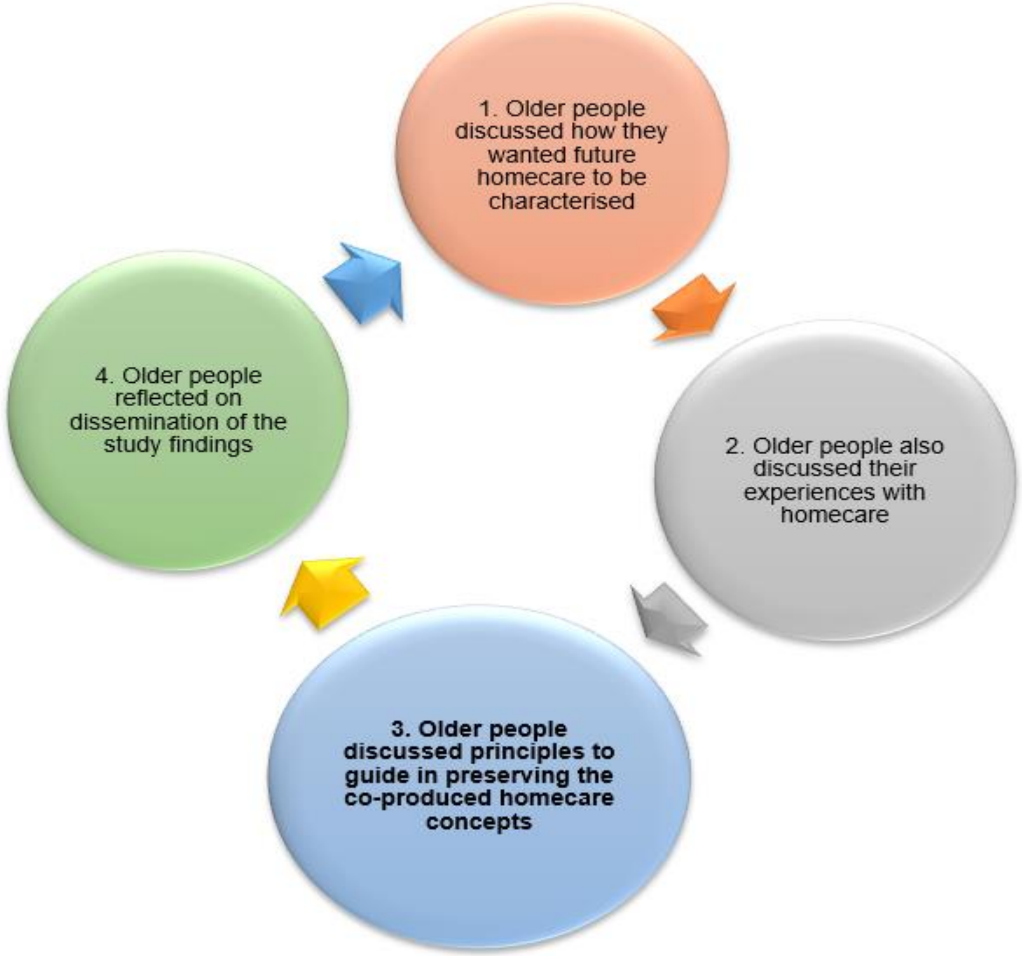


Figure 7-1 Diagram showing virtual participatory discussion process during co-production of future homecare concepts and principles

This section will begin with a tree that displays co-produced concepts, principles, and well-being and dignity that older people want in future homecare. Participants perceived that research findings that were displayed on a tree gave more meaning because they perceived that the tree resembled strength, anchor and independence. Participants named the tree “revolutionary homecare tree of life” because just like a tree which has multiple benefits to people homecare would benefit older people in multiple ways for their well-being.

The green tree in this section was to visualise the type of future homecare that older people wanted, while the dry tree was to show, from older people’s perception, how it looked like to have inadequate or lack of access to homecare services.

7.1 The revolutionary homecare tree of life

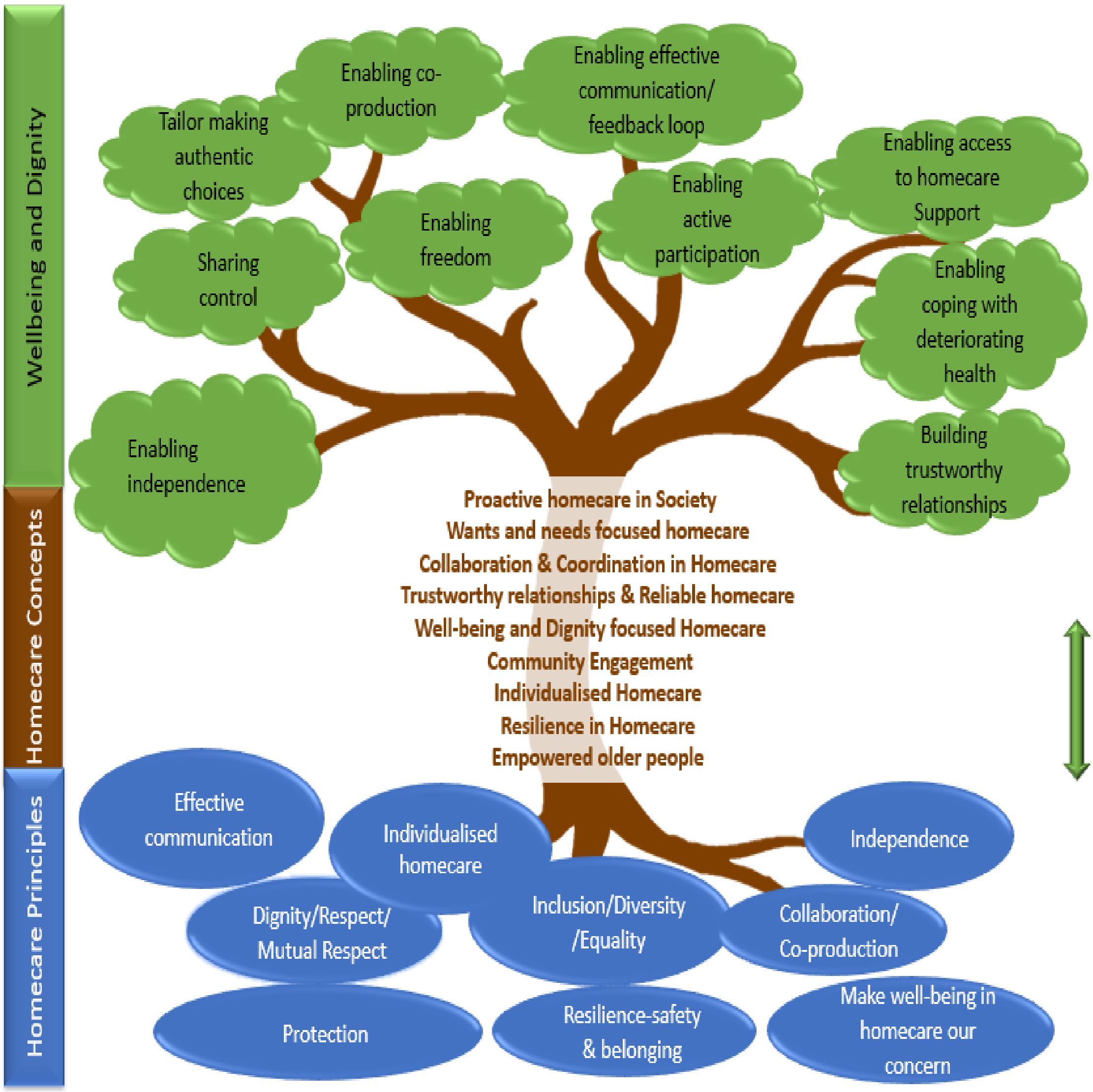


Figure 7-2 The revolutionary homecare tree of life

7.1.1 Perception of older people study findings presented on the tree

Participants agreed to be contacted when their perceptions were needed or if there was any clarity during the write-up of the thesis. "*I am happy to continue to be contacted." PT12 during FG2M3.* The participants were contacted to share their perceptions of the research findings displayed on the tree. The initial draft of a tree that was shared with participants had three birds on the branches and a cat and dog under the tree. The animals and birds were meant to reflect that older people had animals as pets and that some older people loved nature, like bird watching. Participants felt that the appearance of the animals and birds on the display reduced the value of the findings. They wanted the animals and birds removed to give value to research findings.

"I feel that the birds and dogs make it look like a Disney world, which reduces the value of the findings. We want these findings to be taken seriously. we want to be taken seriously." PT01

Participants also reflected on from which angle should findings be interpreted, whether it should be top-down or bottom-up. Participants reasoned that findings could be reported in 2 ways from the tree presentations. According to participants, findings could be interpreted from leaves to the roots or from the roots to the leaves. Participants recognized that when they co-produced future homecare concepts and principles, they began from the top going down. Participants thought that care providers could develop homecare strategies that were underpinned by co-produced concepts and principles. Which in that way, findings would be interpreted from the bottom up.

"*At first, when I saw the tree, I did not know in which direction the results should be reported. But I saw that the leaves are what we started with and I think from the bottom would be for care-providers"* PT12

The leaves showed older people how older people's well-being and dignity would flourish in future homecare that are underpinned by co-produced concepts and principles.

Participants called the tree *"Ooh, this is the tree of life for homecare, the tree shows strength, anchor, independence and interconnectedness. The tree of life give hope. Let me show you a picture frame of a tree on my wall. You see."* PT01

While PT03 said *"the revolutionary tree",* PT03

The co-produced concepts displayed on the tree trunk coincidentally appeared as an image of a house, making them appear like building blocks of a home on a grounded tree.

7.1.2 The reasons for using the revolutionary homecare tree of life

The findings are presented in three different sections of a tree: the roots, the trunk and the leaves. The co-produced future homecare principles were presented on the roots section of a tree. The co-produced future homecare principles like roots would go deep in the ground to keep homecare grounded and give it balance and steadiness. These co-produced principles of homecare, like roots, are interconnected. The homecare principles like roots would ground the homecare system.

The co-produced future homecare concepts were displayed on the tree trunk.

The homecare concepts like the trunk, give balance to the implementation of homecare. Co-produced concepts, like a trunk, would help care providers to underpin homecare with principles to ensure that the well-being and dignity of older people were enhanced.

The green tree leaves, like older people in homecare show thriving older people when they received the homecare they wanted. Like the leaves, older people in homecare were individuals and dynamic. The individual older people's perception was what made an older person thrive and achieve their well-being and dignity.

The diagram below shows the tree without leaves which reflect how older people perceive the current homecare support. The tree looks dry without leaves because older people perceived that the current homecare was not accessible for older people leading to the suffering of older people hence impacting older people's well-being and dignity.

7.1.1 Reflection of older people's perceptions of current homecare

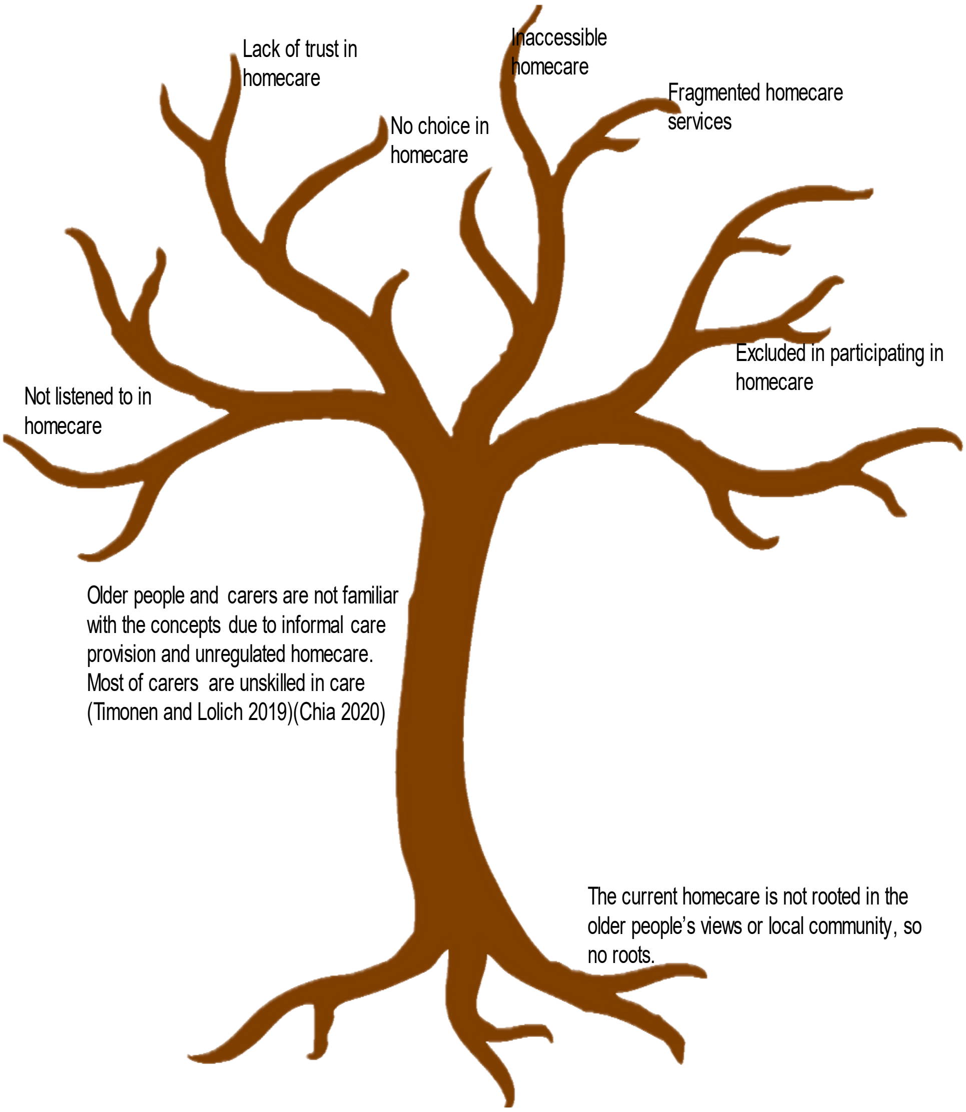


Figure 7-3 Reflection of perceived current homecare

7.2 Co-produced future homecare concepts

The co-produced future homecare concepts would guide care providers in planning and implementing homecare for older people. Each participant described and conceptualised the type of future homecare older people would like during the virtual individual semi-structured interviews. Participants further discussed and co-produced future homecare concepts from virtual individual semi-structured interviews in the participatory discussion groups, chapters 5 and 6 and will not be discussed in this chapter.

The co-production of future homecare concepts with older people was necessary because the systematic review informed us that older people felt excluded from the decision-making regarding their care and expressed fear of losing control, feared lack of choice and lack of negotiation (Hemingway and Green 2013; Vaismoradi et al. 2016). Engagement of older people in co-producing concepts promoted partnership and meaningful engagement of older people in their care. Public participation has become an essential element of governance in many countries (Agger 2012).

The future homecare concepts co-produced with older people are found in chapters 5 and 6 and these were:

1. Proactive Homecare
2. Wants and Needs-focused Homecare
3. Collaboration and Coordination in Homecare
4. Trustworthy and Reliable Homecare
5. Community Engagement
6. Dignity-focused Homecare
7. Individualised Homecare
8. Resilience Homecare
9. Empowered older people

7.3 Co-produced future homecare principles

Co-produced future homecare principles with older people were informed by older people's lived experiences and perceptions. Older people value homecare that would focus on their well-being and dignity and be inclusive to every older person regardless of their ethnic background. The following are co-principles that will be described in this section: Protection of older people in homecare; Inclusion/ diversity/equality for older people in homecare; Dignity for older people in homecare; Homecare system linkage/ collaboration/ co-production in homecare; Independence in homecare; Individualised homecare; Well-being focused in homecare; Effective communication in homecare; Resilience with safety and belonging in Homecare.

7.3.1 Principle of protection of older people in homecare

Participants discussed that protecting older people and ensuring their safety should be a fundamental principle of homecare, because most older people experienced abuse in their homes. Their concern was that most older people were vulnerable around their carers or people around them since those people knew that older people were often isolated and excluded from or engaged in a few social activities. Older people believed that limited contact with the outside world increased the vulnerability of older people because perpetrators knew older people would not complain or people would not know about the abuse since older people were isolated from the community.

PT11 on abuse *"older vulnerable adults that were being abused and you wonder how that has slipped by during the pandemic without the concentration being on things like that."*

PT06, during the interview, said, *"we need a way in which vulnerable older people can state their problem without being victimised by the carers."*

Participants indicated that due to fear of victimisation, it was discovered that older people did not want to complain about their homecare even if older people were not satisfied. Older people believed that there was a need for older people to express their complaints without being victimised by carers. They suggested that safe channels should be created for older people.

PT06, during an interview, indicated how an older person could feel victimised for reporting abuse. *"Do you think I can complain about my care? Who knows what will happen next time that carer comes*."

Solution

Older people emphasised that there was a need to ensure that carers or care providers' actions would cause no harm to the older person. Participants also suggested the need for enforcing a principle of protection of older people in homecare by engaging skilled carers since unskilled carers could cause more harm to older people with complex illnesses. Engaging Community Nurses in coordinating homecare could also help enforce this principle of protection of older people since Community Nurses could make independent assessments from care providers. In addition, older people could have a direct link with a community Nurse. The protection principle should also emphasise empowering older people to challenge abuse because participants mentioned that older people who were not empowered faced more abuse than those who felt empowered.

7.3.2 Principle of inclusion/ diversity /equality for older people in homecare

Health inequalities in homecare were a concern for older people. Participants believed that classifying or categorising older people by lowest assets and highest needs when being assessed for homecare led to aggravated health inequalities.

Participants believed older people were discriminated against because of their age due to society's stereotypes that older people should be at home. *"We don't seem to matter. We are a burden on society."* PT13

"People look on old people as nothing but old people." PT03

Lack of inclusion was also because the family system had weakened, and their children or relatives were not around to engage or assist older people to participate in community activities. Participants revealed that older people were isolated in the community. Other participants reported that some older people from minority ethnic groups were often excluded from participation because older people did not feel that they belonged to certain associations. Economic background also led to the exclusion of older people as most associations required subscriptions for older people to participate, and those with low economic backgrounds were often excluded.

Participants stated that health and social inequalities led to unobtainable homecare and a lack of choices in homecare.

Solution

Participants concluded that the inclusion/ diversity /equality principle for older people in homecare should be enforced. They desired that homecare should be inclusive and leave no older person behind regardless of one's ethnic, cultural, religious, or economic background. Participants believed that the principle of inclusion/ diversity /equality for older people in homecare could be enforced by consideration of early co-production of future homecare plans with all older people in the community. They suggested that older people should be assessed whilst still mentally capable of making decisions about their future homecare.

Community Nurses should keep a database of all older people in the community. Participants suggested that the principle of inclusion/ diversity /equality for older people in homecare could be enforced by ensuring that older people knew that a Community Nurse was their point of contact in homecare services. A single point of entry for homecare services would enable older people to know where to go when they need homecare services. Participants wanted the Community Nurse to regularly assess an older person for future homecare needs so that older people could be supported accordingly or empowered to gain independence. Participants wanted the Community Nurse to evaluate the older person's house, the older person and their next of kin's capability to advise and recommend adjustments or refer when needed. The older person should be enabled to be involved and make decisions in homecare.

7.3.3 Principle of dignity for older people in homecare

Participants expressed that dignity was often not about what was being done but how it was done and how it made the older person feel. Participants stated that the feeling of not being respected could be experienced when there were untrustworthy relationships between carers, care providers, family members and older people.

Participants believed that the principle of dignity for older people in homecare could be enforced by care providers looking at older people as individuals rather than as the other or older people who had nothing to contribute. Participants suggested that the principle of dignity for older people in homecare should be enforced because older people felt frustrated when not being valued or not being listened to by care providers or carers.

*“Principle of dignity that the interaction by the professional with the older person should be as you yourself would expect to be interacted with, that's rather convoluted.”*PT08

Participants indicated that this principle could also protect older people with a lack of communication because it made them feel less valued and that older people were considered a burden and just left out to die. The lack of dignity also came from caring for older people in parts and not holistically because it reduced older people to objects while the tasks were robotic.

Some perception was that, at times, older people felt ignored by their carers. Yet, lack of participation made older people feel a lack of self-worth.

Solution

Promoting the principle of dignity for older people in homecare should underpin future homecare because older people highlighted that if one did not have dignity, they were nothing and had nothing to live for. Participants suggested that the principle of dignity for older people in homecare, could be promoted by ensuring that carers communicated with the older person with respect and dignity. The carers should involve older people throughout their care and avoid ageism and humiliation.

The principle of dignity for older people in homecare should be promoted by carers talking or treating older people as equal partners and not carers talking over older people because it made older people feel disrespected and patronised. Older people would like to have a continuation of good quality homecare following discharge from the NHS. The carers should be loving and compassionate, treat older people as individuals, and maintain their independence. Homecare should be prioritised and ensured that trained and skilled staff were engaged.

7.3.4 Principle of homecare system linkage/ collaboration/ co-production in homecare

The participants believed that the principle of collaboration/co-production could increase older people’s access to homecare services in the multi-layered fragmented homecare services. Participants wanted care providers to collaborate with older people early before health deterioration since health deterioration meant an increased risk of vulnerability.

PT02, during FG1M2, said about planned homecare, *“Negotiating for care is hard work, you couldn’t do it if you are vulnerable.”*

Participants wanted a Community Nurse to be the linkage or collaborating office which links older people to relevant services. Ensuring that older people are linked early would enhance older people's well-being and dignity.

“*You do depend on someone being on your side, someone who will do that the legwork to go around and ask the right questions. Also, know when to say no.” PT06*

7.3.5 Principle of independence in homecare

Participants believed that the principle of independence should be enforced in homecare to ensure that older people remained independent in homecare. Independence was considered as letting older people participate in their homecare and collaborating with care providers. Independence in homecare was early collaboration and early empowerment of older people with the knowledge that would aid their decision-making and choices.

“Education of the older people before they leave hospital. But even if they're not in hospital, there should be more support to keep people at home.” PT11

Independence was that homecare providers should help in devising a homecare plan that was less reliant on family members since the family composition had changed significantly over time, and most older people lived alone. Older people believed that they were different individuals with different needs and wants, and being actively involved in their care would support their uniqueness.

Solution

Participants believed that the principle of independence could be enforced when future homecare was proactively planned because it would facilitate early education and empowerment of older people. A proactive approach meant that health carers should meet with older people before their ailments deteriorated to co-plan for their future homecare. Older people should be reached at an earlier stage to assess and determine what future homecare they might need so that they can be advised or supported accordingly. An earlier approach would help older people to make an informed choice and enhance their coping and independence. Older people should not be overlooked until their health or homecare became an emergency and required critical decisions that often left them with no choice. When older people were independent, they coped well and continued to adapt and adjust their homes to increase the shrinking space for more freedom to move around their houses.

7.3.6 Principle of individualised homecare

Participants believed that it was essential to have the principle of individualised homecare because older people were not a homogenous group. They clarified that regarding older people as a homogenous group led to care providers designing homecare for older people without engaging older people.

They worried that task-oriented homecare led to care providers not focusing on an older person as a whole but in parts or fragments because care providers focused on the specific disease they were treating. Failure to treat an older person holistically or as a whole led to most older people not accessing the homecare they needed or wanted. It also denied older people being able to choose their needs and wants.

PT04 during FG3M2: when he voiced why it was essential to consider the needs and wants of an older person to tailor-make their homecare: *"Well, because we're all different, and what suits me won't suit somebody else. So, it's got to be tailor-made to the individual."*

PT08 during FG3M1 stated the importance of involving relatives in the care of an older person. *"I think it is important to have a surviving partner or spouse. And those children or near relatives that can be involved if they want to be involved, and should be consulted, to be part of the round approach around an older person."*

Solution

Participants wanted future homecare to be underpinned by the principle of individualised homecare for older people. This principle would help care providers understand an older person and see the world from the older person's perspective to design homecare that would meet the needs and wants of an older person. It was about recognising that older people were unique and that they perceived homecare support differently based on their lived experiences.

Participants felt that individualising homecare for older people should allow flexibility because that would enable older people to access homecare support. Furthermore, with this principle, carers and older people would develop trustworthy relationships because older people would participate in their care, enhancing an older person's independence. The involvement of older people in active decision-making should be a continuous process from an early age. The older person should feel that they are part of the team, involved, respected, and supported. Planning of homecare should be approached from an older person's angle to a carer or care provider since the other way around gives more dominance to the carer or care provider.

7.3.7 Principle of well-being focused in homecare

Participants wanted homecare to be underpinned by the principle of well-being to reduce older people's suffering. They wanted well-being to be everyone's concern because if it were, older people's concerns would be looked into and resolved from the older person's perception. Participants indicated that the well-being principle would ensure a holistic approach to caring for an older person. Participants pointed out that carers promoted mainly physical well-being while neglecting other types of well-being for an older person. Participants also perceived that the well-being principle meant that care providers co-produce the future homecare that older people want early before any health deterioration.

"Have a proactive system and not reactive so at the earliest stage, people are meeting with people whose health is deteriorating before it actually gets to the point that they need emergency stepping." PT11

Participants felt that to address this principle, care providers should prevent isolation among older people because it brought a feeling of exile, loneliness, and stress and led to health deterioration among older people. Furthermore, regular, frequent psychosocial care would benefit most older people. A reinforcement of community well-being could be enforced for those elders who lived alone. Mindfulness and awareness of the suffering and well-being that was happening to older people in the present homecare could enable co-produced homecare for older people's well-being.

Solution

Participants indicated that the well-being principle would guide care providers to empower older people early because empowered older people could make informed choices and decisions. The principle of well-being in homecare would encourage the inclusion and participation of older people to inform care providers about their lived experiences. Furthermore, empowered older people were often independent and self-reliant in making choices to keep well. Early empowerment of people would also minimise the stigma. It would encourage people to take responsibility for their lives and health from an earlier age. It also enhanced the self-identity of older people because they would feel that they belonged, were valued and were safe in homecare.

7.3.8 Principle of effective communication in homecare

Older people wanted homecare to be underpinned by the principle of effective communication. They stated that communication was critical in homecare because most older people lived alone, and ineffective communication led to poor access to homecare services. Participants worried that communication between older people and carers exposed older people to vulnerability since care providers did not listen to older people.

PT14 indicated during the interview that *“I think communication is very important.*

PT13 lived with a complicated heart disease, and her experience with GPs had not been good. She lived in fear because she thought she could die alone at home and worried that she did not know whom to talk to when her GPs did not listen to her.

PT13, said *“of course, they blame you for going frequently. Well, if you get all this fear and you don’t know what it is, you always blame your heart. If you’ve got a pipe blocked, especially when you know you’re not sure. Do I ask for help? Will I be better by the time they get here? Will they say I’m wasting their time? You know, all these goes in your head and you’re bearing this heaviness you know. Meaning you’re feeling all these. It’s not a nice situation to be in.”*

Participants believed that the principle of effective communication could reduce older people’s suffering because older people experienced worries and anxiety about what could happen if their health deteriorated. Furthermore, older people were abused, and the principle of effective communication could guide care providers to develop homecare strategies that would facilitate older people to have a safe way of communicating their concerns without fear of victimisation.

PT13, during an interview, said about communication*. “I mean, yes, they keep on saying how busy they are. Well, yes, they’re busy but. I mean, some people do feel neglected, you know so that’s what we could do, more communication.”*

Solution

Older people mentioned that effective communication should be one of the underpinning principles for homecare. They believed that there should be awareness of effective communication for care providers. Due to weakened family structures, older people depended greatly on developing trustworthy relationships, which could save older people.

PT09 said about facilitating effective communication: *“I think we should be provided with a sort of questionnaire regularly rather than having to initiate a complain. If there is a solid quality control opportunity through any for every year also.”*

Participants believed that the principle of effective communication could enhance inclusion, participation, independence, control, authentic choices and co-production. Effective communication meant that more older people could access the homecare services they wanted. They would feel valued and appreciated and have a sense of belonging because care providers would listen to older people and allow meaningful participation of older people in homecare. The care provider would design a feedback loop, and communication would be two-way. Participants expressed that trust between care providers, carers, and older people would be developed with effective communication. Working with an older person would become more manageable because care providers would understand that an older person was also an expert because they had lived with or experienced the ailment. Carers would understand how older people felt about situations and that both parties would always provide solutions.

7.3.9 Principle of resilience, safety and belonging in homecare.

Participants believed in the principle of resilience, safety and belonging in homecare. Resilience meant care providers would design empowerment strategies whereby older people would be able to cope and be in control of their well-being and dignity. Participants believed that older people should be educated early about homecare and healthy lifestyles to enhance older people’s competency skills. Participants believed that a personalised and proactive homecare could enhance the principle of resilience, safety and belonging in homecare.

“We'd all like to be self-reliant, yes, we all are, in fact, here because we are preparing. “ PT01

Solution

The principles of resilience, safety and belonging in homecare should underpin homecare because older people lived with ailments that changed their well-functioning. Care providers could develop early proactive assessments and enforce measures that would empower older people to adapt to changes caused by ailments or age. Providing older people with the right tools and support meant independence and freedom for older people.

The next chapter will present findings from virtual participatory discussion groups where the aim was to explore older people’s perceptions of the use of virtual communication as a tool for data collection in this participatory research approach.

Chapter 8 Findings of perception of the use of virtual communication as a tool for data collection

This chapter presents the findings of the exploration of older people's perceptions of the use of virtual communication as a tool for data collection. Since there was the Covid-19 pandemic and social distancing restrictions, I conducted participatory research online with older people. As seen in chapter 2, the literature showed that the use of virtual communication as a data collection tool with older people had not been fully explored because researchers referred to face-to-face or in-person interviews as the golden standard (Nehls et al. 2015).

Despite the literature showing no evidence of older people using virtual communication as a tool for data collection, older people in this study used virtual Zoom for individual semi-structured interviews and participatory group discussions. In addition, older people used email to share attached Microsoft documents for research. Some older people used the track changes tool in Microsoft Word to make comments, whilst others wrote comments by email and some preferred commenting during the virtual meeting.

Following older people's experience of using virtual communication as a tool for data collection, older people's experiences of using virtual communication as a data collection tool were explored. The question that needed to be addressed was: What are the perceptions of older people on using virtual communication as a tool for data collection in a participatory research approach?

The prompt question that was posed to participants was: "What are your perceptions of the use of email and Zoom as a virtual data collection tool?"

The chapter will describe the findings of participants' reflections on the use of email and Zoom as data collection tools.

The diagram below shows the eight themes that emerged from virtual data collection. The themes will be described in this section.

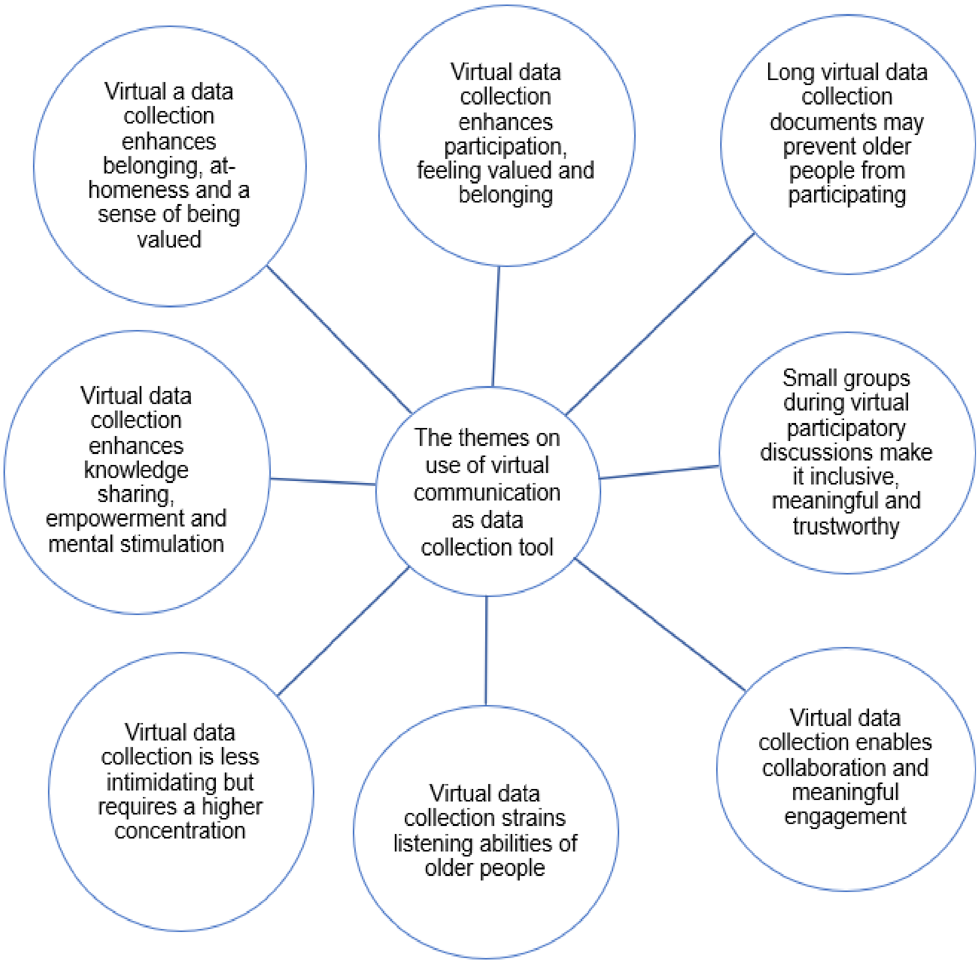


Figure 8-1 Themes from virtual data collection

8.1 Virtual data collection enhances participation, feeling valued and belonging

Participants expressed that they felt comfortable with me and, as a result, felt comfortable sharing their experiences with me. Some expressed that I was a good listener. Some participants expressed that they were naturally introverted. However, when they talked with me, they could speak freely because I was a good conversationalist. *“you are a good conversationalist.”* (PT12).

This was what PT03 expressed when asked how she felt about using virtual Zoom for an individual interview.

PT03, said, *“I mean it’s fine I’m happy to talk to you about anything, you are amazing person. And you know I might have met someone, who has a completely different personality. Whom sort of, as much as I would probably want to get down to the table with her, I would say, " Oh, I don’t like you very much, and you probably don’t like me very much either. But with you, I feel I could get on very well with you. And I think the whole point is that it’s got to be someone to whom you can relate.”*

PT12, reflected on how he felt about the virtual Zoom individual interview and said, *“you are who you are with. I don’t believe I’ve got a fixed personality. I do believe that my personality differs according to whom I’m speaking to. As I am speaking to you now, people would not recognise me in my free-flowing conversation. But actually, I’m a functional introvert. I am talking in a free-floating way, when I’m with you now, because you are a good listener. Because I am who I am with.”*

Participants felt mentally stimulated by the virtual Zoom individual interviews. One of the older people stated that she enjoyed the virtual Zoom individual interview because she held valuable discussions and wished it could be done more often.

PT01, during the individual interview, expressed her reflection on the virtual Zoom individual interview and said, *“I really enjoyed this, you see. You should be brought in for my care to talk to me every week. That will be great. A nice, intelligent discussion every week, there we are.”*

Participants felt they contributed and engaged meaningfully in virtual Zoom individual interviews and participatory group discussions because there were no ready-made survey questions in the initial virtual Zoom individual interviews. Older people alleged that the lack of ready-made questions enabled a deeper engagement with older people despite their professional or lived experience knowledge. It made older people to critically reflect on their experiences because more questions were derived from older people's stories of their lived experiences.

This was how one of the participants expressed his perception regarding individual virtual interviews and participatory group discussions.

PT08, during FG3M3 said, *"I was actually quite grateful that MB conducted the initial one-to-one talks without much preparation beforehand of the sort of questions we will be asked. I think, actually, you got a great deal out of us. Whether we had detailed professional background work to answer the questions you were going to ask, or whether we were directly or partially closest family users of previous healthcare experience systems. I thought that was very good, actually."*

Participants were of the opinion that I was available and accessible and that I helped participants when they experienced a technical problem with their forms, which they received by email. In addition, some received help when entering the virtual meeting or completing the PAF during the enrolment process. For instance, some could not see the code's last character when joining a virtual Zoom interview meeting; all participants who called for help were assisted.

PT05, talking about her perception of the code for the link to attend the virtual Zoom individual interview, said, *"Sorry, I didn't notice the full stop. Then I always remembered seeing there's the full stop."*

PT05, during FG1M3 explained how I was available and assisted her in completing her forms during the virtual communication enrolment period, said, *"I didn't quite know how to fill the figures, and you did it for me. I didn't know what tools I should use when, you have to fill in the age and a couple of other things I emailed you and said I don't know how to do it, so you did it from your end for me."*

PT01 shared her perception of virtual communication: *"there are glitches with doing things virtually, when it works, it's wonderful."*

8.2 Long virtual data collection documents may prevent older people from participating

Some participants believed that the Participant Information Sheet and the Participant agreement forms were too long and too officious. Some participants stated that the PIS and PAF forms were like one was going to attend a top-secret meeting. Older people indicated that if forms were too long during virtual data collection, it might make older people not participate. Other participants asserted that they had attended several university research projects, and the forms were always long so that participants could know everything that would happen in the research. She also clarified that the forms were detailed because they were meant to protect participants should anything happen during the research.

PT06, during the FG1M3, stated his perception of virtual communication, saying that, *“It was very heavy-handed and officious. It appeared to me a little bit unnecessary to be fair. You either agree or you don’t join if you don’t agree. But you know, two fairly lengthy forms. One information and the other was read all this and then sign at the end. They are self-defeating the longer it is.”*

PT02, during FG1M3 responding to PT06 about the length of forms and the detailed context in the forms, said, *“PT06 I’m on a couple of university health studies and the terms and conditions are always pretty long, but you got to sign it. So, they covered every aspect, should anything happen.”*

8.3 Small groups during virtual participatory discussions make it inclusive, meaningful and trustworthy

Participants were of the view I had a good relationship with older people and that my facilitation of individual virtual interviews and virtual participatory group discussions using a softer approach made older people feel included. They contributed meaningfully, for they felt there was trust in the group during virtual interviews and participatory discussions.

PT01 also added her perception of the online research during FG2M3: *“I also appreciate the light touch of your chairing of these sessions, MB.”*

PT05 said during the FG1M3: *“I find when you are a small group like today good, because we can watch each other. We all get the timing right to add something. But when you’re in a big group of people, it just becomes overwhelming and there’s no personal feeling. I also feel there is no personal input on one’s part.”*

Similarly, participants stated that individual virtual interviews and virtual participatory group discussions were beneficial. Because participants believed that the subject of homecare that they discussed in virtual communication was essential for older people. Participants explained that discussing what mattered to older people made them feel valued. Older people also hoped that decision-makers could use older people’s ideas and perceptions.

PT08 during FG3M2 expressed that the government would soon be in crisis of homecare system which he believed was not being addressed said, *“The government of whatever political colour it is, and our newly combined local government are all sitting on a time bomb. They need to look after the ageing* *baby boomers. It is an issue that is not going to go away. Which is why I'm very grateful to MB to have been advised to prepare this for her PhD thesis."*

PT11 during FG3M3 shared her perception that participating in individual virtual interviews and virtual participatory group discussions and after perusing of the draft documents of concepts and principles which was co-produced with older people and said: *"Thank you for what you're doing because what's coming over to me from the draft, you're incorporating all the things that I hold dear."*

PT07, during FG2M3 stated: *"Thank you for giving us the opportunity to contribute to this because we all hope very much that something will make real progress coming from it."*

8.4 Virtual data collection enables collaboration and meaningful engagement

Some participants mentioned that it had been a blessing to have individual virtual interviews and virtual participatory group discussions because participants could meet and collect data during the Covid-19 pandemic and social distancing restrictions. For participants, virtual data collection was an enabler for older people to participate and make valuable contributions even when older people did not have face-to-face meetings. Virtual data collection gave older people control and a sense of value to discuss the future homecare they wanted. In addition, they co-produced principles that should underpin homecare since that would inform policymakers and care providers.

PT07, during FG2M3 said: "*And I think technology has been an absolute blessing during this time. When we can't meet together, and you have given us this opportunity. Imagine that we couldn't have a discussion like this without it. So, I just think it may be a mixed blessing on occasion, but I think, on the whole, it's been amazing."*

According to participants, virtual data collection enabled older people to attend individual virtual interviews and subsequent virtual participatory group discussions, unlike when they had to travel to a particular place for meetings. Participants clarified that, at times, it would not be easy to travel. Whereas with virtual data collection, older people attended meetings from their homes. This meant that virtual data collection enabled easier access, increased chances of control and freedom to participate in valuable activities and enhanced a feeling of belonging and valued research.

PT02 indicated her reflection about Zoom meetings during FG1M3: *"yeah, I think the benefits of Zoom are that you will probably get most people to attend the meeting."*

PT11, during the FG3M3, said about the perception of virtual communication: *“The main advantage is that we don’t travel anywhere. And everything seems to be conducted at quite a speed, and people talk, and you’ve got it in the right setting, only one person talks at once.”*

FPT12, during FG1M3 commented on the relevance of virtual communication as a data collection method, said: *“The online research has been absolutely relevant to the circumstances we find ourselves. In this worldwide pandemic.”*

8.5 Virtual data collection strains the listening abilities of older people

Participants believed that although there were positive aspects of virtual data collection, some technical glitches also happened. During the last meeting, one participant could not hear some participants. Nonetheless, she made her contributions during the discussion and attended the whole meeting. Some participants alluded that with face-to-face, they could observe each other’s nonverbal reactions during the discussions. However, older people perceived that virtual data collection could be alternated with face-to-face data collection.

PT11 during FG3M3 reiterated the difficulty of observing nonverbal communication from others during a discussion, said, *“but the disadvantage for me is the communication aspect. You’re staring at a screen, looking at somebody’s face, and you do not see the whole-body. Communication is three parts listening. The way feet point gives an awful lot of whether somebody is positive or negative towards the subject. There’s so much nonverbal you don’t see, and of course, the eyes, you do not get a closer look at eyes. You cannot see mine through the glasses. You can’t see when my pupils have an involuntary action once you ask a question.”*

8.6 Virtual data collection is less intimidating but requires a higher concentration

Participants indicated that they felt free during virtual participatory group discussions. After all, they expressed that I made them feel valued by having small virtual groups and giving everyone time to talk. Some participants perceived virtual data collection as less intimidating than face-to-face; therefore, one could get a lot from participants, the same way as when using a phone call. One could get more when you do not see a person. Some participants indicated that with virtual data collection, one has to come to the camera so that people would not feel ignored. Other participants indicated that given the situation of the Covid-19 pandemic and with government restrictions, participants felt that even though some participants wanted round table discussions, the present virtual participatory group discussions were well conducted.

PT03, during FG3M3, responded to PT11's perception that the virtual data collection was missing nonverbal communication. *"It just becomes probably a little less intimidating, though. I don't know, sometimes the telephone call you can get more on the phone call when you can't see the person because, as you say you're constantly looking at somebody. I try to come at the window often so that people do not think I'm ignoring them."*

PT08, during FG3M3 responded by saying, "*I think that given the constraints we have with national government health guidelines at present, I think the experience has been interesting and has been conducted very well."*

Participants believed that the virtual participatory group discussions were good because it was a small group during a discussion. They supported that a small group enabled participants to see each other and had good timing to respond to each other. In contrast, a larger group would be overwhelming and not feel like a personalised meeting.

PT11, during FG3M3, said about the virtual participatory group discussion atmosphere: *"Everything seems to be conducted at quite a speed and people talk. You've got it on the right setting,"*

Participants also believed that older people were sometimes shy to communicate in public, but virtual data collection could be a better option.

PT02 During FG1M3, said, *"I think, maybe sometimes people would say more that perhaps if they're quite shy or nervous in public speaking than we're doing when they're on a Zoom. Meeting on your computer rather than in a room and feeling intimidated if I put my hand up, I might look silly."*

8.7 Virtual data collection enhances knowledge sharing, empowerment and mental stimulation

Participants asserted that participating in individual virtual interviews and virtual participatory group discussions was beneficial because it helped them to reflect on their future homecare.

"In a word, it worked for me. I've enjoyed belonging to your research group MB. It forced me to think about things in a way I haven't fully got. I really, really appreciate this research group." (PT12, during FG1M3)

Likewise, participating made older people think about preparing for their life until death. Some participants believed that participating in individual virtual interviews and virtual participatory group discussions fine-tuned or reset their minds to think about the type of future homecare they wanted. Participation in individual virtual interviews and virtual participatory group discussions meant knowledge sharing, empowerment and reflection to participants. Views and perceptions changed from participation because participants felt valued, belonged, at peace and empowered.

This was what PT01 during FG1M3 had to say regarding her participation in individual virtual interviews, and virtual participatory group discussions said: *"Yes, it has focused the mind, it's excellent I mean."*

Participants stated that participating in individual virtual interviews and virtual participatory group discussions had been empowering and therapeutic. During these discussions, participants opened up and shared emotional experiences they had not shared with anyone before. Some participants indicated that they shared their experiences, which participants had never talked to anyone about.

PT08, during FG3M3 stated his perception of participating in individual virtual interviews and virtual participatory group discussions and said: *"Particular emphasis in the draft report. So, in conclusion, it's a great report MB. Thank you very much for sharing with us and allowing us to have our input, and I've been very grateful. It's been somewhat therapeutic for me as well."*

Similarly, after reviewing the draft document of co-produced future homecare concepts and principles shared with participants via email, some participants believed that it was beneficial and empowering. Some participants commented about how co-produced future homecare concepts and principles were elaborated more than what they could have thought if they had been home alone.

PT12, during FG1M3, gave his perception of the draft of co-produced future homecare concepts and principles: *"And the variety of things that have come up. I mean, the detail in the two lists of concepts and principles is wider than I would have thought just sitting in an armchair. Trying to think about this, I'm really grateful to have this draft paper, you know."*

PT01, during the FG1M3 discussion, said: *"I'm really grateful to have a copy of the draft paper MB. Thank you."*

8.8 Virtual data collection enhances belonging, at-homeness and a sense of being valued

Most participants reported that virtual data collection contributed positively not only to data collection but also to the family and the wider community. Older people stated that they started using virtual Zoom during the Covid-19 pandemic and the social distancing that the government imposed to prevent the spread of Covid-19. Participants now found virtual Zoom a valuable tool for communicating with friends and family members. Some grew to like virtual Zoom communications because it enabled them to join their children's birthday parties and the funerals of friends and relatives. Some were inspired by the virtual Zoom participatory group discussions and wanted to learn more about virtual Zoom because they wanted to learn how to create virtual Zoom meetings to be in contact with their loved ones. The participants for this research were from an organisation that dealt with lifelong learning for older people. They believed virtual communication could keep older people connected to the rest of the community.

PT04, during FG2M1 discussions, stated his perception of virtual communication was that it could change the lives of older people, *"Well, I mean computer technology is absolutely fantastic. I mean, the fact that we're all sitting around this meeting table in virtual reality. I mean, it's just incredible. It's the thing that's got me through Covid. The fact that I still have interaction with people. So, we ought to be using that technology to a greater extent, you know, having someone who can just log on and just check that you're all right that doesn't have to be health visitors, these days, could be done by using the Internet."*

8.9 Virtual data collection could exclude older people who lack virtual technology skills

Some participants were worried that using virtual data collection could exclude those older people who lacked technological skills. Participants were worried about older people who could not join Zoom meetings because they lacked IT skills. They believed that older people without IT skills would be left behind and not participate in meaningful research. They believed that their generation would need to be empowered in using technology even though some older people did not want to learn computer skills because they were of the view that technology was complicated. Participants believed that other retired generations were technology-skilled since they had used computers in their workplaces. Some older people wanted to learn more about the use of virtual communication because they wanted to be able to set up virtual Zoom meetings by themselves. For older people, being empowered to use virtual Zoom meant independence, freedom and control.

PT05, during FG1M3, said about her regular use of Zoom since the government-imposed lockdown during Covid-19 *"I never used virtual Zoom in my life before lockdown. Now with the family, I use it constantly. Some people cannot join Zoom and have great trouble joining us because they don't have the skills."*

PT09, during the FG1M3 discussion, talked about how she felt empowered by participating in virtual Zoom meetings and now wanted to learn more about creating Zoom meetings*: "I haven't set up a meeting which is really what I should attempt to do. I've got a video Zoom sent me, but I haven't actually set up one yet. And because I don't use this particular iPad very often, I see trouble with the send, but I would quite like to use it."*

Participants considered that virtual data collection would be better than excluding older people and doing nothing. After all, that was how conversations would happen in future. Some found that virtual participatory group discussion was slightly challenging as they could not observe clearly when the next person would speak. They thought that when it was face-to-face, one could also observe the reaction of those listening to see how they took in comments from the speaker. They believed that virtual data collection was a new skill they would like to learn more because they believed that the use of technology would be a thing of the future.

PT06, during FG1 M3 participatory group discussion, giving his reflection about virtual data collection said: *"I feel that these little alternatives are presumably better than no method, but I have to say that. I find talking in person and seeing the other person's facial expressions as you say something, whether it's received well or in differently, etc, and there's no sort of. it's almost a staccato sort of conversation when you don't know when the other person is going to talk on Zoom that makes it more difficult, but it is surely a lot better than not doing it at all, and also that's the way things are going to happen. So it's been quite an interesting experience, actually."*

This section above was the fourth chapter in the findings section of the thesis. The next chapter is a discussion section of research findings from Chapters 5, 6,7 and 8.

Chapter 9 Discussion

This chapter will discuss the findings from the four chapters (5, 6, 7, and 8) in line with the study aim, objectives, study questions stated in chapter 1, and the literature. The study aimed to explore older people's perceptions of future homecare and collaborate with them to co-produce concepts and principles that should underpin future homecare delivery. However, the findings that are discussed in this discussion chapter are from older people's perceptions. The past and present experiences in the home as perceived by older people would be discussed concurrently because it showed that it was interlinked to the perception of the future homecare that older people wanted.

The study objectives, as seen in chapter 1 that will be discussed using findings and literature, are:

- Explore older people's perceptions of how they would like their future homecare delivered.
- To collaborate with older people to co-produce concepts and principles to underpin future homecare delivery.
- To explore older people's perceptions of the use of virtual communication as a tool for data collection in this participatory research approach.

The study questions, as seen in chapter 1, that will be discussed using findings and literature are:

- What could future homecare look like based on the perception of older people in the United Kingdom?
- How does collaboration within research enable older people's voices to be heard and allow meaningful engagement?
- What are the perceptions of older people on using virtual communication as a tool for data collection in a participatory research approach?

This chapter comprises three parts. The first part discusses the findings to show the findings concerning the applied well-being theory. The second part will discuss the findings of chapters 5, 6, 7, and 8 in relation to the well-being theory concepts and literature.

The diagram below shows a relationship between well-being and suffering as perceived from the Galvin and Todres theory of well-being and suffering. According to Galvin and Todres (2013), well-being theory gives more direction to care in critical and more complex ways than the narrower ideas of health and illness on their own. In this theory, I would not focus only on the illness and health of older people but their feelings on what mattered to them in homecare. In addition, well-being theory provides a productive way of thinking about what matters to people and what human care means (Galvin and Todres 2013). The discussion section will give an understanding of older people's experience of suffering when there were barriers to accessing homecare. The theory also describes how well-being is experienced when homecare needs are met, as evidenced in the findings.

Older people reported that fragmented homecare services make it impossible for them to access homecare services because older people lack information regarding the type of available homecare services. Literature also shows that challenges preventing older people from meeting homecare needs emanated from the UK's fragmented and multifaceted homecare support provided to older people (Kaehne et al. 2017). Galvin and Todres (2013) justify that by employing a broader focus on the seamlessness of everyday life and its well-being possibilities, care concerns may become meaningfully connected to more holistic conceptions of what is needed in humanely sensitive care. Galvin and Todres (2013) further report that experiences of well-being and suffering are related to one another, and care providers need to understand both if they want to provide humanely sensitive care.

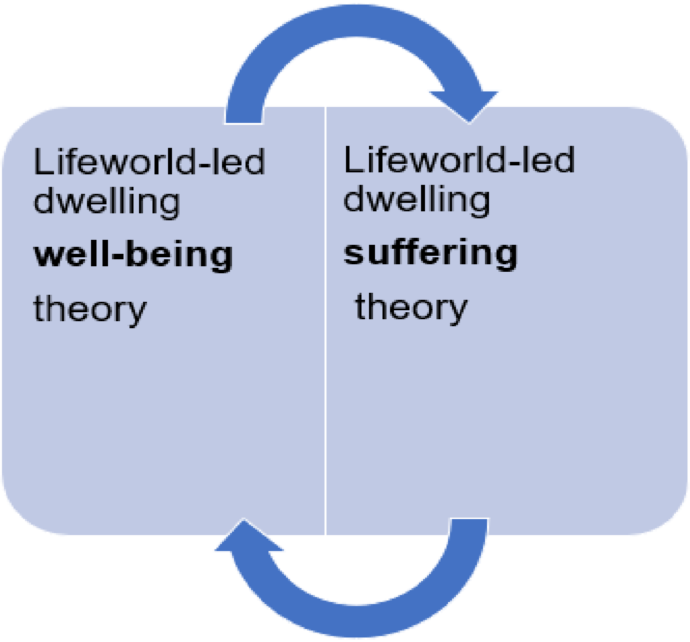


Figure 9-1 Dwelling well-being and Dwelling suffering theory relations

The present study showed that older people's perceptions of future homecare were informed by their lived experiences as Beings in the world and beings in existence (Heidegger 2011). The only reality of our existence is what we are conscious of and relate to ourselves in the moment (Ownsworth and Nash 2015). The current research findings show that with the demographic change leading to an increase in older people, there is a need to focus awareness or consciousness on lifeworld-led well-being in the context of urgency for homecare to older people and provision of community-based one point of entry for homecare support needs and wants. In addition, being conscious of the type of future homecare older people want, it is crucial to start articulating conceptualizations of homecare support, well-being in homecare, participation/collaboration in homecare, lived experience in homecare as that can bring understanding to the essence of what they are and their variations from the perspective of older people's lives.

Findings show that older people's existential issues and uncertainties about the future of homecare were the primary source of older people's inability to obtain well-being in homecare, experienced by suffering from stress, fears, worries, anxieties, worthlessness, and hopelessness. Most older people in the community experience shrinking relationships and spaces due to the dynamics of family and community structures and exclusion. These, in turn, affect older people's lifeworld-led well-being as they experience despair, loneliness, worry and anxiety about the lack of safe platforms to discuss and plan the type of future homecare they want.

One of the participatory research principles involves people with lived experience of what is being researched (Higginbottom and Liamputtong 2015). How homecare support is defined and categorised in the UK excludes older people who receive certain types of homecare. As a result, most older people cannot access homecare support or participate in co-producing the type of homecare they want. It is due to an extreme power imbalance in the decision-making between care providers and older people's participation and co-production of the type of homecare support that older people want because power remains with the care providers or local authorities (O'Rourke and Beresford 2022). The reason for care providers' dominance in deciding which older people participate in research for homecare support is that care has been categorised. This leads to care providers categorising participation from the homecare experiences of older people to fit the type of support that care providers give to older people. Categorising participation is observed in care areas such as mental health, cancer, dementia, disabilities, and palliative care at home (Hum et al. 2018; Niculescu et al. 2021; Kelley 2023).

Nevertheless, homecare support for older people is affected by how homecare support is governed, structured and eligibility criteria in the UK. Despite repeated policy statements that the personal budget in the Care Act 2014 would usher in radical changes to Adult Social Care, there was minimal discussion of whether and how this could be achieved within existing legal structures (Tarrant 2020). Personal budget Social care policy was about improving the life chances of disabled people and enhancing choices and control (Tarrant 2020). When this policy is applied in homecare it will not promote the well-being of older people because even though a personalised budget sounds good, it fragments an older person with a pinned label of disabled people. As a result, the majority of older people who use homecare services and do not meet this criterion will still be excluded from homecare support.

The conditions for well-being, such as economic, political, social, health-related, physical, mental, and emotional, may either support or hinder well-being. Care providers need to understand that lifeworld-led well-being in homecare for older people can provide a holistic approach to well-being because it focuses on existence and caring, whereby suffering is much more complex than illness, and well-being is much more complex than health (Galvin and Todres 2011). According to Galvin and Todres (2011), the conditions for well-being are not always sufficient or necessary for the experience of well-being to occur. In this research, all older people reported to have experienced difficulties accessing homecare services. For participants in this research, the type of particular homecare support was not a prerequisite to enrolling in the study, meaning that even those not receiving homecare were enrolled.

Yet it showed that even those who did not receive homecare experienced homecare challenges when they cared for their parents, spouses, work, and volunteer carers for community members in need of care. These experiences affected their well-being because they lived in fear, anxiety, anguish and despair since they were worried about the possibilities of accessing their homecare support services in the future. Older people experienced the different healthcare delivery systems of the UK as they repeatedly said things started with Margret Thatcher. This statement expressed by older people became clear to me when I read that in Britain, neoliberalism emerged in the 1980s as a solution to the crisis of Keynesian policies, as articulated by Thatcher, for the inefficiency of the key policy instruments in dealing with objective problems and challenges, such as stagflation (Kus 2006).

According to Galvin and Todres (2011) lifeworld-led approach to care provides ways to describe health-related conditions and needs in more complex ways than conventional medical and diagnostic descriptions of health and illness. Dwelling well-being and Dwelling suffering theory emphasise care and caring. Findings showed that although some participants considered themselves healthy and were religiously eating healthy and exercising, they still experienced worries and anxieties about the inability to do regular check-ups with a dietician. They were worried that they did not know how their health would be like as they aged. However, meeting with a dietician would enhance older people’s well-being, with freedom and empowerment, as they would be taught or encouraged to maintain their healthy lifestyle. From the lifeworld perspective, this older person was not experiencing a sense of well-being because he was not living in the now. He was worried and had anxiety about his future. Fear of the unknown caused worries and anxiety due to lack of access to dietician services where he could be assured of his diet and health and be provided with the necessary information, creating a sense of well-being. Furthermore, he could be empowered to maintain his excellent lifestyle.

Henwood et al. (2019) attest that although people have few expectations of their local council to provide them with any help, they also have little idea of where else to go for guidance in navigating the complex world of care and support. According to Tew et al. (2023), prevention is relatively recent within the field of adult social care, and its strategic implementation has been somewhat inconsistent. In Adult social care, prevention is conceptualised as an activity designed to promote well-being and to prevent, reduce or delay the need for social care services (Tew et al. 2019). Tew et al. (2023) point out that the Care Act 2014 also focused on prevention care, a statutory requirement on local authorities, and one which applied to all adults irrespective of whether they were likely to have needs and financial circumstances that could make them eligible for funded services. Tew et al. (2019) report that despite prevention care being part of Care Act 2014 local authorities still express that they do not have the duty to provide prevention services. Instead, they must support people to meet unmet needs (Tew et al. 2019). Tew et al. (2023) also believe there is no commonly held strategic vision or understanding across the social care sector regarding how to take this agenda forward. As evidenced by the findings, the unavailability of prevention care services in social care leads to older people experiencing some worries and fear, impacting their lifeworld-led well-being.

Homecare is primarily understood to refer to services that allow older people to continue living in their homes through access to health care (O'Rourke and Beresford 2022). Access to homecare support services has been impacted by the notion that in neoliberalism, health was not a universal right but regarded as a private good for sale and also failed to underline the inequalities between various social groups like older people (Rotarou and Sakellariou 2017). While it is argued that a well-functioning health system should improve the health of individuals, protecting individuals against the financial costs of bad health by providing equitable access to care that has people at its centre and enabling people to participate in decisions that affect their health and health system, neoliberalism does not share the same goals as it is guided by spending cuts, deficit cutting, downsizing, and competitiveness (Rotarou and Sakellariou 2017). This has led to the UK homecare support services being influenced by markets in public services, which are premised on the assumption that competitive allocation of contracts will provide a diverse and affordable supply of quality services (Considine et al. 2020; Dickinson et al. 2022). England has had a marketized care system for several decades, characterised by the dominance of for-profit providers and often considered to deliver a narrowly functional model of care (Needham et al. 2023).

The present study findings showed that older people's perception of future homecare was viewed from their lifeworld-led well-being rather than their ailments or health. Findings also showed that offering homecare support services based on older people's ailments/ disease-based well-being leads to older people missing homecare support services. Care providers and policymakers should recognise that when well-being, which includes the existential dimensions of freedom and vulnerability, is not understood, care practices and policies might be in danger of assuming that health is just the absence of illness (Galvin and Todres 2013, p.39). This, in turn, affects older people's dwelling well-being as it heightens the worries and anxieties of dwelling-suffering of older people (Galvin and Todres 2013). The well-being and suffering theory could be used in all older people, including those who were healthy and had no ailments, since it is able to capture the suffering and well-being that older people experience in homecare support.

Participants believed that the current homecare was not easily accessible and sufficient, leaving most of older people's homecare needs unmet. In addition, homecare service tasks were limited to 15 minutes, and during that time, carers did not have time to talk to older people and understand older people's wants. Older people wanted to connect with carers to develop relationships. However, carers were concerned about completing their daily tasks and moving to the next client on their list. This, in turn, left older people feeling unfulfilled, unvalued, frustrated, unseen, burdened, and unwanted. Participants believed that indignities also happened because carers treated older people like they did not exist. The homecare support service structuring in the UK is also influenced by the neoliberalism economic approach of the free-market or laissez-faire market, where care market competition is believed to enhance innovation and affordable quality services (Rotarou and Sakellariou 2017; Dickinson et al. 2022). Yet this type of homecare support services has led to older people experiencing unequal access and dehumanising homecare support services. Good care has been discussed in the literature but focused mainly on informal, unpaid care work and more on the carer than on the person cared for, and it also questioned the idea that care work could ever be reduced to tasks such as bathing, feeding and toileting, that could be commodified (Lewis and West 2014).

The UK homecare support services markets are shaped by a procurement market, managed market, open market and partnership market, which talks a lot about the relationship between the local authority and the service providers (Needham et al. 2023). The types of homecare services are co-produced by the local authorities and the service providers because local authorities use the outsourcing model to procure homecare services from care providers (Needham and Hall 2023b). In contrast, most older people who directly purchase these homecare support services are self-funders since they do not qualify for means-tested state support (Henwood et al. 2022). According to Henwood et al. (2019), the Care Act created new duties for local authorities and their partners, new rights for people who use services, and new rights for their carers.

Henwood et al. (2022) believe that the Care Act 2014 gave local authorities in England broad duties and market-shaping wider than their commissioning role, and it encouraged them to work co-productively with stakeholders. Needham et al. (2023) report that market-shaping duty includes enabling personalised support for older people using social care services and co-production with partners in line with the broader principles of the Care Act. Davies et al. (2022) believe that local authorities do not consider older people as key stakeholders for partnerships to discuss their current and future homecare. Instead, care providers are the principal stakeholders that partner with local authorities, shaping and managing the care market within localities (Davies et al. 2022).

The market-based and strict eligibility criteria in social care control what homecare support services older people can receive based on their ailments, making it challenging to support their well-being. It has also been attested by

Henwood et al. (2022) that one of the reasons for the delay in full implementation of the Care Act was allegedly the lack of readiness of local authorities to manage homecare accounts for self-funders, or to have a clear sense of the scale of demand from self-funders. Henwood et al. (2022) further state that the delay in implementation does not appear to have been used by local authorities to engage more effectively with their self-funding population, or to address the implications of this group who are being left to find their way around the care system largely unaided for market-shaping.

Findings showed suffering experienced by older people in homecare. As a result, older people wanted future homecare that enhanced older people's lifeworld-led well-being and dignity. Older people's meanings and patterns in the perception of the future homecare that they wanted, emulated Galvin and Todres's work on lifeworld-led well-being and suffering theory, which was supported by the philosophy of lifeworld (Galvin and Todres, 2013). Subsequently, relevant concepts from the theory of dwelling-well-being and dwelling-suffering by Todres and Galvin (2013) were used during the discussion. The theory was elaborated on in chapter 2.9 of this thesis. The discussion will cover the dwelling spatiality, dwelling intersubjectivity, dwelling mood and dwelling identity.

The findings in chapters 5, 6, 7 and 8 emphasised older people's well-being and suffering concerning the environment, relationships, participation, inclusion and empowerment of older people. These were found under themes: proactive homecare, wants and needs-focused homecare, collaboration and coordination in homecare, trustworthy and reliable homecare, community engagement, dignity-focused homecare, individualised homecare, resilience homecare, and empowered older people.

9.1 Spatiality in dwelling well-being or dwelling suffering

This section discusses how older people perceived a place of care in relation to spatiality in dwelling well-being or dwelling suffering. Spatiality refers to our human environmental context and our experience of living in that environment, and the way we interact with our environment and the qualities of that environment can have a positive or negative impact on our well-being (Hemingway et al. 2015, p.2). The places we inhabit are one of the cornerstones of the lifeworld experience, and they either influence or are influenced by other lifeworld perspectives (Van Manen 1997; Førsund et al. 2018). Findings showed that older people's perceptions of the home had multiple meanings: A home meant self-identity, memories, independence, at-homeness, peacefulness, belonging, protection, control, dignity and well-being. Literature shows that home has multiple meanings because home also means security, having someone close by, living in a familiar neighbourhood, freedom, memories, personal space, protection, safety and a place for reflection (Dahlin-Ivanoff et al. 2007; Norlyk et al. 2013).

There is a need to understand the perception of older people because the literature shows that space/place can affect an individual negatively or positively depending on the individual's perception (Hemingway, 2011). Participants perceived their homes as private places, which were considered safe, and they had control and freedom as they applied their own rules in their homes. Feeling safe and having control and freedom in their environment enhanced well-being related to their identity. The structure of homecare in the UK is that older people who self-fund their homecare remain invisible because the local authority does not map them, and it appears they also continue to see self-funders as a separate group of little relevance to market-shaping (Henwood et al. 2022). The structure is that self-funding older people were only seen as significant by local authorities if they ceased to be self-funding, having spent down their capital and savings to the eligibility threshold and required public support, which also includes mortgaged properties of older people (Henwood et al. 2022). When older people reach this level of qualifying for health and social care homecare support, it is when an older person's dignity has been totally stripped off, leaving older people feeling a sense of worthlessness and feeling like they are a burden.

If care providers or local authorities used and understood the well-being and suffering theory of Galvin and Todres (2013) which is based on the lifeworld, they would understand the impact of losing homes on older people because it causes suffering. Care providers assume that when an older person loses their home and becomes eligible for homecare support by the government, older people's well-being will be enhanced because they will be taken to care home institutions. Well-being will remain a dream for self-funding older people as they experience fear and anxiety due to living in the future and constantly thinking about depleting funds, leading to losing their homes. According to Galvin and Todres (2013), a home enables a person to have simply a sense of being and an effortless connectedness with their environment, knowing who they are and that they are bigger than their ailments. Similarly, Norlyk et al. (2013) attested that home represented a safe haven and sanctuary for people, as they considered home to have healing effects and lead to a person feeling peacefulness. What was also healing at home was being surrounded by one's belongings and, at the same time, having private moments alone (Norlyk et al. 2013).

According to Carey (2021), welfare systems are becoming more conditional, with access to state support increasingly rationed using a section of legally defined and financially driven restrictions and rules. Carey (2021) states that conditionality includes eligibility and assessments of the need for receipt of social care support, followed by an analysis of the related policies of personalised and asset-based support. The current study showed that older people did not have frailty or suffered dementia. Nevertheless, they had other multiple ailments that impacted the execution of their daily activities and, as a result, used private, voluntary and informal homecare support services. Findings showed that older people experienced challenges in getting homecare support services from Social care services.

Similarly, Baxter et al. (2020) affirm that older people experience challenges in navigating Social care and finding information about self-funded care. The Care Act 2014, on the other side, advocates for participation and co-production with users (Needham et al. 2020; Henwood et al. 2022), yet in reality, older people are still excluded from participation and co-production, leading to the voices of self-funding older people being unheard and what matters for them remains unknown. The free-market of neoliberalism also exploits self-funded older people yet when the Care Act 2014 was created, it was also meant to put a limit on the amount anyone paid towards the costs of their care to protect them from the volatile care markets (Henwood et al. 2022; Needham et al. 2023). Henwood et al. (2019) believe that the shelving of the implementation of part 2 of the Care Act 2014 left considerable uncertainty about future arrangements for self-funders and anticipate that it is highly likely in the future that there will be some variant of a cap on care costs and shared responsibility for funding between the state and individuals. Needham and Hall (2023a), in their study "Dealing with drift: Comparing social care reform in the four nations of the UK," discussed some recommendations from previous reports concerning social care funding being more sustainable.

One of the recommendations from Needham and Hall (2023a) was to align social care with how the NHS was funded. Needham and Hall (2023a) also mentioned that Sutherland (1999) recommended free personal care, which covered help with daily living tasks such as washing and meals. And according to Needham and Hall (2023a), the UK rejected Sutherland's recommendation on the basis that it was expensive and unaffordable. Another recommendation (Needham and Hall 2023a) report is from the Dilnot (2011) Commission, which indicates that individuals with assets above the means-test threshold continue with private payments for care, but the individual contribution should be capped. Sturrock and Tallack (2022) report that Dilnot (2011) recommendation was considered and passed into law in the Care Act 2014. Glasby et al. (2021) revealed that the cap was first delayed and then abandoned due to concerns about the costs it would impose on local government. Needham and Hall (2023a) report that England is planning to phase in a care cap passed into legislation in 2014 and 2022, which will limit private liability for care expenditure.

Most older people in the current study were self-funded and, therefore, purchased their homecare support services from private markets that were not regulated. Besides, private care providers charged older people high prices to supplement the low prices they got from government-funded older people (Needham et al. 2023). This showed that homecare support services were market-based and disease-based, leading to care providers targeting a particular ailment and funds availability while not considering the older person and their well-being. This led to older people experiencing dwelling suffering. When homecare support services were founded on the well-being and suffering theory of Galvin and Todres (2013), the interconnectedness of home and older people's well-being would be considered as the point of departure for homecare for older people. And understanding what home means to an older person would be vital for the care providers to co-produce meaningful homecare for older people, understating that at home, an older person could exercise their competence and skills in performing activities like reading or learning. Galvin and Todres (2013) substantiate that when a person experiences a sense of competence to perform a certain task, it uplifts one’s self-identity, which is a form of well-being. Van Haitsma et al. (2019), like Galvin and Todres (2013), also attest that having competence uplifts one’s self-identity.

Therefore, understanding older people’s perceptions of an environment for care would help carers and care providers work with an older person to prevent suffering and promote well-being.

9.1.1 Spatial dwelling at-homeness

The findings illustrated that the environment for care for older people seemed to play a significant role in the well-being and dignity of older people with memories, independence, freedom, control, self-identity and belonging. Similarly, Førsund et al. (2018) also affirmed that experienced lived space was described as belonging, meaningfulness, safety, security and autonomy. Board and McCormack (2018) also affirmed that having possessions or stuff was important for the meaning of home. Furthermore, being familiar with the local environment was also homely, with certain textures and familiar sounds and smells. Other researchers also confirmed that home had multiple meanings which could negatively or positively impact an individual's well-being (Dahlin-Ivanoff et al. 2007; Norlyk et al. 2013).

Similarly, Malone (2003) argued that all humans were spatial beings and that the spatial aspect of their lives included familiar routines that contributed to their identity. In addition, people could be displaced from these everyday time-space routines when they leave their homes and enter an unfamiliar environment, like care homes or hospitals (Malone 2003). For participants, home meant everything, and it was a place older people wanted to fight to stay in until they died. Similarly, Norlyk et al. (2013) also indicated that home was a personal space where one slept in their bed and had their daily routines while feeling that at home, one could be themselves.

Residing in the community is often the desired choice of older people who prefer to age in place or live out the rest of their lives in the comfort of their own homes because of individualized attention and presumed better quality of care (Kelley 2022). Even though older people wanted and valued living in their homes, findings illustrated that the sphere of their lived spaces was continuously shrinking due to the progression of health ailments. However, since older people were in their homes, they felt in control. Older people increased their shrinking lived spaces by using assistive technology, engaging carers or redesigning their homes to maintain their freedom and independence, which maintained their feeling of at-homeness and enhanced their well-being. Galvin and Todres (2013) described that adjusting home spaces prevented mobility-suffering in the spatial dimension, whereby one would feel imprisoned because they could not move freely in their homes. According to Palmér et al. (2020) life is meaningful only when it is lived as one wishes, and ageing usually brings consciousness of the fact that the finality of life is approaching, even if a person is still in good health.

Galvin and Todres (2013, p.82) defined at-homeness in spatiality- dwelling as a sense of being at home, whereby a person may be tuned into the spatial possibilities of their environment that offer settling or stillness in valued or wanted ways. Similarly, findings illustrated that older people had self-acceptance and a positive relationship with their environment, especially homes, because, despite the weakened family structures and physical and health changes, older people felt at home and experienced peacefulness and personal identity in their homes.

Roxberg et al. (2020) indicated that the home constituted a private space and a place for personal growth and everyday life, which also provided the freedom to live according to one´s routines and preferences. According to Hinck (2004, p.784) home represents the intersection of familiarity, independence, and autonomy, as well as ties to past memories and relationships. "…*this is our family home for over 60years" PT05*. Older people had diverse lifeworld experiences about home, showing that living or being in their homes significantly influenced their well-being and dignity because they felt the power, freedom, memories, control and self-identity in relation to their homes.

9.1.2 Dwelling suffering in the spatial dimension: exiled

Galvin and Todres (2013) described that lived space referred to the encounter with an environmental world, a world of places, things and situations that had meaning for living and, subsequently, for health. In the findings, participants perceived the decision to transfer older people to a care home as abandoning an older person because carers considered a burden when at home. The perception of being abandoned in an institution was a sign of suffering in the spatial dimension of exile, negatively affecting well-being (Galvin and Todres 2013). Older people, in turn, felt hopeless and could not enjoy their last days of life. Institutional space was found to be an alien space compared to a home because the space there was complex and had a potentially intimidating web of power, and power structures were related to the institutional structures, the institutional norms and the interactions with the professionals (Malone 2003; Norlyk et al. 2013).

Participants perceived that some relatives took older people to care homes to avoid loneliness in their homes. However, participants perceived that being in a care home would not prevent loneliness because the older person was with strangers with whom they did not associate. Other studies showed that even if those residential places shared communal places for social events, most older people in those places spent much of their time in their rooms and were isolated from each other (Ouden et al. 2015; Nordin et al. 2017). Some literature identified that rates of depression and anxiety were high at baseline and the follow-up of people admitted in the care home (Davison et al. 2021).

Participants believed that the older person would become one of the many in a strange place, making an older person feel a loss of self-identity and loneliness when in a care home. The suffering occurs when the environment negatively impacts an older person’s well-being. Galvin and Todres (2013) describe this suffering as dwelling suffering in the intersubjective dimension of alienated isolation, whereby one feels exiled or cast out from their people, such as relatives and friends, because they may feel like they are being cut off or wronged. Furthermore, they feel like strangers and lonely in these new places.

9.2 Intersubjectivity in dwelling well-being or dwelling suffering

This section discusses how older people perceived homecare in relation to intersubjectivity in dwelling well-being or dwelling suffering. According to Galvin and Todres (2013), intersubjectivity is interpersonal relationships that people develop within an environment with themselves and the people around them. Urquhart et al. (2021) stated that respectful relationships must be developed before planning or decision-making to build trust and understand what is valued. Galvin and Todres (2013) described that a lack of interpersonal relationships could cause suffering, while developing good relationships enhances well-being. Galvin and Todres (2013) also indicated that when well-being was experienced, a person would feel at-homeness and peacefulness in an environment. They would feel that they belong and were at-home with the other, and there would be a sense of security and togetherness (Galvin and Todres 2013).

Hemingway et al. (2015) explain that in intersubjectivity, people make sense of their interpersonal world and others who share it, which also allows people to frame their thinking, identity, and relationships in time and space. Participants believed that trustworthy relationships in homecare were meaningful for older people’s well-being and dignity. Participants’ concerns were that family structures had weakened, and most older people lived alone or with their partners.

As a result, older people would rely on trustworthy relationships in the community because they were worried that without trustworthy relationships, older people could be forgotten and unconsciously be excluded from homecare. Older people believed that proactive co-production of homecare and collaboration could facilitate the early development of trustworthy relationships.

According to Galvin and Todres (2013), intersubjectivity is interpersonal relationships that people develop within an environment, themselves and people around them. Urquhart et al. (2021) stated that respectful relationships must be developed before planning or decision-making to build trust and understand what is valued. In addition, that would offer an opportunity to understand each other and share power and collective solutions. Galvin and Todres (2013) describe that a lack of interpersonal relationships could cause suffering, while good interpersonal relationships enhance well-being. Galvin and Todres (2013) indicate that when well-being is experienced, a person would feel at-homeness and peacefulness in an environment. They would feel that they belong and at-home with the other; there would be a sense of security and togetherness (Galvin and Todres 2013).

Olsson et al. (2013) indicate that a confirmation that one is no longer capable of engaging in desired activities, a change in one's daily independent life, could be negative and lead to feelings of inadequacy and reduced well-being. Older people in this study also experienced worries and a lack of access and participation, leading to fears, anxiety, depression, isolation, feeling unwanted, and increased vulnerability. This kind of suffering was where the person felt exiled, alienated, isolated, depressed and like an object or a thing (Galvin and Todres 2013; Hemingway et al. 2015). Hörberg et al. (2019) believed that once people were not seen as people but as patients, they would be reduced to numbers. It was believed that reducing people living with ailments to numbers would lead to care providers focusing on the disease outcome, obscuring other dimensions of human care that could lead to well-being (Galvin et al. 2020).

9.3 Older person's wants and needs focused homecare

This section discusses how older people perceived the needs and wants in homecare concerning kinship and belonging. The wants and needs were cross-cutting in all other themes and sub-themes of homecare. Participants wanted individualised homecare to include the following concepts: concentrate on the wants and needs of an older person, be proactively planned, active participation of older people, enhanced community engagement of older people, with improved collaboration and coordination, reliable and trustworthy relationships, and enhanced dignity and respect. The current UK homecare services are needs-based, determining when the social care services should assess an older person (O'Rourke and Beresford 2022). This method has been found to leave the majority of older people on the waiting list for assessment, whereby most of them die without assessment (O'Rourke and Beresford 2022). In addition, older people are not included in designing homecare strategies because homecare is free-market based, and hence, local authorities consider care providers as those that shape the homecare market (Henwood et al. 2022).

Participants wanted resilience in homecare and homecare that empowered older people. Participants believed that receiving this type of homecare would enhance their well-being and dignity because the interpersonal connections would strengthen, there would be shared decision-making, open feedback, regular engagement of older people, and collaborations with trustworthy relationships. When interpersonal well-being was experienced, people would feel at home with others. In addition, they would feel a sense of belonging and kinship because there would no longer be “I” and “you” but “we”, making people feel a sense of security and togetherness (Galvin and Todres 2013).

Holmberg (2021) argues that well-being could be represented by a subjective, personal, and holistic perspective when introducing the life we lived. In addition, the life we experienced and the life which we communicated to others was necessary (Kraus 2015). Findings from this study showed that participation and communication would be enhanced when carers or service providers actively listen to an older person’s perceptions because carers would be able to understand older people’s homecare needs and wants. Active listening was consistently rated as a critical factor in supportive interactions (Jones et al. 2019). Active listening consists of: cognitive processes like attending, understanding, or interpreting messages; affective processes like being motivated and energised to attend to another person; and behavioural processes like verbally and nonverbally signalling that a message has been received and understood (Jones et al. 2019). Through active listening, older people would also feel heard and respected because providing emotional support was an essential interpersonal resource (Jones et al. 2019).

Planning and designing homecare that started with an older person’s perception, and developed trusting relationships, making older people feel wanted, valued, respected and belonging, could reduce older people’s suffering and improve their well-being and dignity. The literature demonstrates that dignity was about how people thought, felt and behaved concerning the worth or value of themselves and others, and to treat someone with dignity was to treat older people as being of worth in a way that was respectful of older people as valued individuals (Tranvåg et al. 2019).

Active listening to older people could increase access to homecare services because care providers would understand what older people wanted, and also, older people’s voices would be heard. In addition, older people would have fewer worries and anxiety but calmness and comfort, hence displaying some well-being of embodied dwelling: comfort (Galvin and Todres 2013). In this type of well-being, one felt welcome, had a sense of being at home, and felt body comfort which was experienced through trust (Galvin and Todres 2013).

9.4 Proactive co-production of homecare services with older people

This section discusses how older people perceived proactive co-production of homecare when the principle of protecting older people in homecare was used. The principle of protecting older people in homecare is in chapter 7 of this thesis. Co-production of homecare would involve care providers and an older person collaborating and co-producing the plan for the type of future homecare that an older person wants. Participants felt that the protection principle for older people could enhance proactive co-production of homecare to develop early trustworthy relationships with care providers that older people could rely on and feel safe, wanted, valued, and belonging.

Galvin and Todres (2013) attested that with healthy relationships, the person felt protected and safe, and this enhanced their well-being, for they would experience a sense of at-homeness, kinship and belonging. When older people felt understood, it would allay their fears and anxiety. In addition, participants believed that developing trustworthy relationships enhanced the effective communication feedback loop whereby older people would receive the information needed about homecare. Also, Galvin and Todres (2013) state that an empowered person is competent and often completes tasks that are valuable to them.

According to Tew et al. (2019), the Care Act 2014 was hoped to help increase the capacity and capability of individuals, families and communities, thereby contributing to preventing or delaying the need for Adult Social Care services. Whittington (2016) also states that the 2014 Care Act 2014 has been called the most significant reform in England since 1948, introducing a core legal entitlement of adults to care and support based on the principle of promoting the well-being of the person and their carers through a person-centred, holistic approach. Glasby et al. (2021) perceive that despite the focus of the Care Act 2014 on promoting well-being, the worthy intentions of the new legislation were instantly undermined by the austerity agenda that was already in place and begun by the Coalition Government in 2010. According to Hudson (2021) State social care is a means-tested service, and for several decades, the majority of provision has been by the private or not-for-profit sector. In addition, Needham and Hall (2023a) attest that people who meet a needs threshold for care will have their financial assets reviewed, and if they fall above the means-test threshold, they must pay some or all of their care costs. Glasby et al. (2021) report that due to strict eligibility criteria and means-tested requirements for social care, one in seven older people and 14% of people aged 65 years and above are living with some unmet needs. The systematic literature review done in chapter 2 of this thesis and the current findings also showed that older people felt excluded and neglected and felt that there was no sense of urgency in their homecare. They did not feel safe, and they lived with anxiety because they could not access or navigate all various homecare support services. At the same time, those who accessed the homecare service experienced unmet care needs and a lack of well-being.

Burn and Needham (2021) state that *"the Care Act gave local authorities a duty to create effective care markets that stimulate provider innovation and diversity to offer choice and control to people using services".* This statement shows how the power goes. It is a top-down approach and market-based approach where much power lies on the Care Act, local authorities, and care providers. At the end of the market chain, service users will be offered care services. The approach does not support enhancing well-being, personalised care, choices and control, participation, and co-production with older people. It also does not support the proactive planning of homecare services because only frail and older people with a certain level of dementia and older people with a certain amount of money are eligible to access the homecare. The inclusion of older people does not mean offering what has already been co-produced by other stakeholders in the absence of older people.

Older people expressed from the findings that they were excluded from designing their homecare support. In addition, the choices they were being offered were not authentic because stakeholders designed services in the absence of older people. Besides, homecare support offered to older people often did not meet their homecare needs. Older people wanted proactive homecare with co-production of future homecare planning before their health deteriorated so that they could develop early relationships with care providers and develop tailor-made homecare that would meet their care needs and wants. Inclusion, proactive planning and co-production of future homecare would also enhance tailor-made homecare and authentic choices. In addition, it would enhance easy access to homecare support and being heard, feeling safe and valued, and experiencing dignity and well-being. It has also been noted that Peckham et al. (2022), when discussing the Care Act 2014 policy success, indicated that this Care Act 2014 enhanced the involvement of close partnership between the Department of Health and Social Care (DHSC), the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS). This list of partnerships showed that older people were excluded as stakeholders. These structural inclusion barriers should be addressed to create a more inclusive environment where older people would be included early for homecare co-production. This exclusion from the co-production of homecare was also noted by Henwood et al. (2022), who indicated that older people who are self-funders in the English social care market were bystanders or on-lookers because they were not recognised. Findings showed that older people experienced challenges in getting the information for homecare support because they were self-funders. This has also been observed by (Baxter et al. 2020) that self-funders experienced difficulties in finding information about self-funded care for those seeking care.

Literature shows that older people draw on their strengths, both resourcefulness and emotional resilience, and on the strengths of others in their families, communities and local services to achieve an acceptable level of felt safety for themselves (Sherwood-Johnson et al. 2022). However, this sense of safety could not be disentangled from wider aspects of living well, including maintaining reciprocal relationships, preserving key markers of self-identity, and contributing to the well-being of families and other social groups they felt a part of (Sherwood-Johnson et al. 2022).

Having co-produced homecare proactively would alleviate the stress/worries of older people thinking about the possibility of losing control and being taken to care homes in the future out of their choice. Galvin and Todres (2013) pointed out that this was some kind of suffering that people experienced when they felt unsupported, not valued or seen as other and not belonging. Life was considered a valuable experience to be managed in a proactive manner for as long as possible (Palmér et al. 2020). Such thoughts also generated a desire to plan for the future and not relinquish the idea that life proceeds (Palmér et al. 2020).

Galvin and Todres (2013) attest that vulnerabilities precipitate suffering. Participants perceived that older people were embarrassed to beg for homecare support and would fail to access the needed homecare services. So, planning ahead of time would help to actively engage older people in understanding their homecare needs and wants, giving older people control and power over their care. Hage et al. (2022) attested that having a plan was the best gift one could give to those they cared about. It would also empower older people to carry out certain homecare services to fulfil their choices before reaching a stage where they would have to beg for their homecare or were in a vulnerable state. Galvin (2018) stated that in the event that well-being was not experienced, it caused suffering.

Changing the perspective of homecare and broadening it could help address the lifeworld well-being of an older person, whereby care providers would not consider the well-being of an older person from the fragmented disease labels pinned to an older person. Older people would be treated holistically from their existential perspective, as it could enhance the proactive co-production planning of homecare that older people want. Proactive planning could start with primary proactive planning, aimed at older people without current health or care, and support needs to be provided resources that may help an older person evade developing needs for homecare. Besides, it also provides support by maintaining independence and good health and promoting well-being. Participants believed that early discussions would help older people to think more about their future homecare before losing their independence. Their other concern was that some older people suffered from fear and anxiety because they did not know what to do if they reached a state of emergency. Galvin and Todres (2013) attest that fear and anxiety are experienced when a person does not live in the now and is worried about the future and that this is a sign of suffering that interferes with one’s well-being. Lack of connection, worries and fears were suffering that led older people to lose hope and feel unvalued, unwanted, or even lose identity, dignity and well-being. Galvin and Todres (2013) also attested that when one felt not valued, they lost their dignity and identity, and when one was in this state, the person would not experience well-being but suffering.

Relationships were important for older people’s well-being because they were a safety net to fall back on when homecare was needed. Lack of or weak relationships impacted older people’s well-being as they would feel unwanted, excluded, not belonging and be seen as the other. Seeing older people as the other perpetuated exclusion, and exclusion of older people makes them feel exiled, unwanted and not belonging, as described by Beauvoir (1972) and Galvin and Todres (2013).

Participants believed care providers needed to include older people’s next of kin and relatives in the proactive co-production of future homecare. It was reported that some excluded next of kin committed suicide due to feeling unwanted and not belonging. Galvin and Todres (2013) also related exclusion, isolation and a feeling of unwantedness led to suffering. Furthermore, if the causes of suffering were not addressed, the person would feel unvalued and unloved. Hence, well-being would not be maintained. This case showed that suffering affected older people’s next of kin because of inclusion. Next of kin were not sick, but how health care providers treated them caused some suffering that impacted their well-being negatively. This is a common worry to most participants who experienced fear of losing control and the unknown of the future, leading to older people thinking much about their future homecare. Galvin and Todres (2013) explained that these fears affected older people's well-being, and older people lived with these sufferings because they would not live in the now, for they were worried about the future.

9.5 Collaboration and coordination of homecare with older people

This section discusses how older people perceive collaboration and coordination of homecare with homecare service providers with regard to the principle of making homecare everyone’s concern.

Collaboration and coordination with service providers were essential because it was believed to increase older people's access to homecare services.

Participants were concerned that those offices that supported older people with homecare support to live independently at home were fragmented. This made it difficult for older people to develop interpersonal relationships with various care providers. Galvin and Todres (2013) attest that one becomes at-homeness or feels at home when they are familiar with the environment because it gives them stillness, making them feel welcome, a sense of belonging and a sense of peacefulness.

One can ask when the right time is to collaborate with older people. Collaboration is meant to increase the participation and empowerment of vulnerable groups such as older people by inviting them to participate in policy and decision-making and co-create care arrangements in their communities (Warwick-Booth et al. 2021). Participation has been found to increase access to care services and increase the voice of older people (Higginbottom and Liamputtong 2015). Yet, the majority of older people in the UK are self-funders. In addition, local authorities do not collaborate with older people nor map or track them because they only want to deal with older people considered eligible for homecare support services (Henwood et al. 2022).

Local authorities are guided by the Care Act 2014, which clarifies the care people should expect and with minimum eligibility available for people to access these care services. (UK-Legislation 2014). Older people perceive what future homecare should be based on their lifeworld-led experience of homecare. Local authorities perceive homecare as a social care service (Vlachantoni 2019), and this was not the same perception from older people in the study because the social care approach to homecare no longer aligns with the current and future needs of older people. Older people perceive that they are living longer with multiple chronic ailments at home, and homecare, from their perspectives, was not exclusively social care. They viewed it as also including healthcare, digital healthcare, rehabilitation care, prevention care, palliative care and many more types of care received at home. Older people’s homecare ideals of homecare demanded an integrated care approach. Homecare is a sensitive topic because older people feel unheard and excluded from participation in designing homecare strategies, while local authorities shape the social care markets.

In the UK, homecare support collaboration mainly resumes during the implementation of homecare support services because the planning relies heavily on a top-down approach, relying on higher authorities to determine the laws and program goals that filter down to the implementers (Sabatier 1986). Similar examples are the Care Act 2014 and the NHS and Social care implementation strategies, which Parliament and local authorities created. The top-down approach assumes that the framers of the policy decision (e.g. statute) are the key actors and that others are impediments, hence ignoring target groups to get around policy and divert it to their purposes (Sabatier 1986). Nevertheless, arguments exist that the distinction between policy formulation and policy implementation is confusing (Sabatier 1986). When the bottom-up approach is implemented, it is mostly when the local implementers are involved in the policy area (Sabatier 1986).

This was the caveat of implementing the Care Act 2014 and homecare support services for older people. Since those with higher power had already created these legal guiding documents, and those who implemented them were expected to follow what had been planned. This does not support collaboration with older people since the care that older people can receive has already been decided. Furthermore, it prohibits older people and care providers from contacting each other at a certain period of the older person’s life since the eligibility criteria determine when care providers and older people can start engaging (DHSC-UK 2023). In addition, implementing the Care Act 2014 involves multiple stakeholders, including the government, private service providers and charitable organisations (DHSC-UK 2023).

Due to this fragmentation, older people were delayed or hardly accessed homecare services. Fragmentation of services also made older people feel not seen nor valued by care providers because care providers were only interested in the diseases older people suffered from. In fragmented homecare services, older people were seen as either patients, older people or by their ailments but not as whole individuals. This, in turn, affected older people’s well-being. Again, Gibson et al. (2020) affirmed that service providers judged people based on age and that basic health communication skills were vital to delivering accessible and responsive services. Galvin and Todres (2013) argued that people suffered from losing identity because they were fragmented and cared for according to their diseases, ailments and needs. In addition, Rhodin et al. (2022) attest that fragmented care is associated with a reduction in overall survival and that more studies are needed to identify the people who are most vulnerable to the negative impacts of fragmented care. Although person-centred care (PCC) has gained increasing importance over the last few decades, its practical implementation has been challenging (Nilsen et al. 2022). Allen et al. (2023) describe person-centred care as personalisation and tailoring care services to the uniqueness of the individual, emphasising the importance of service coordination. However, Edvardsson et al. (2016) state that despite the intention to do person-centred homecare, the current homecare services are primarily traditional and focus on assisting with basic activities of daily living to meet physical needs. Allen et al. (2023) attest that in the UK, personalisation of care services is embedded into the legal framework for adult social care, whereby the Care Act used the mechanism of individualised funding, requiring local authorities to give all eligible users a personal budget. However, Slasberg and Beresford (2020) indicate that scepticism has been articulated about whether having a personal budget leads to genuine choice and control.

On the contrary, Harrison (2022), suggests that care providers fragment care to older people to be profitable. As a result, Harrison (2022) also believes that older people’s needs are rationalised and quantified so that they can be met by standardised care visits, ignoring the unpredictability of elderly bodies. According to Edvardsson et al. (2016), task-based care has been critiqued for not being person-centred, as older people living at home report a high prevalence of unmet care needs. In order to address the impact of task-based and fragmented care, Reed et al. (2021) indicate that the integration of health and social care has been a policy goal in England, with various attempts at creating new structures and funding incentives. Meanwhile, Pearson et al. (2018) state that the personalisation of social care is not implemented because task-based and fragmented care services for older people are still significant challenges in the UK. Labelling of older people with their ailments or as vulnerable by care providers leads to older people feeling powerlessness, loss of identity, anxiety and fear (Langmann 2023). It is fundamental to avoid labelling, not only to respect but also to place the autonomy of the older person at the centre of care (Langmann 2023). However, Barker et al. (2019) state that acting according to an identity that individuals identify with can result in autonomous behaviour in line with this identity, such as increased motivation to communicate with others. Galvin and Todres (2013) advocate for well-being that supports caring for people holistically and humanely because the loss of identity makes a person see themselves as a thing or an object, and, in some instances, they suffer from fragmented identities because they feel fragmented and not whole (Galvin and Todres 2013).

Furthermore, a sense of fragmented identity was basically founded on the deep existential character of surrendering to overwhelming objectifying forces that also made one powerless (Galvin and Todres 2013). Objectifying older people affected their identity and counteracted their independence, freedom, sense of control, value and participation in homecare. Older people suffered multiple ailments that affected their daily activities to various degrees. Keramat Kar et al. (2022) found that older people used proactive coping or anticipatory coping for an anticipated possible loss of independence instead of ongoing ones and planning and responding in advance to promote independence and resilience. Galvin and Todres (2013) also described interpersonal well-being because people felt at home with others and felt a sense of kinship and belonging.

9.6 Cultivate an environment that nurtures trustworthy relationships with older people and reliable homecare

This section discusses how older people perceived trustworthy relationships and reliable homecare with regard to effective communication and the principle of inclusion/diversity/equality in homecare.

Participants believed that untrustworthy relationships with care providers impacted older people’s access to homecare. The untrustworthy relationships made older people feel worthless, worried, left out and anxious, which caused suffering and affected older people’s well-being. Since there was no relationship between older people and carers, carers never understood older people’s needs and wants, while older people, on the other hand, felt unseen, unsatisfied and frustrated. Participants stated that a lack of trustworthy relationships also affected the reliability of homecare services since older people were not informed when carers failed to show up at an older person’s home.

Participants wanted homecare that would be consistent and reliable. When carers were trustworthy and provided reliable homecare services, there would be effective communication and feedback to older people who would feel safe and free from worries, fears and anxiety. Galvin and Todres (2013) explained that lifeworld well-being that intersubjectivity or relationships were essential because when an individual experienced a good, trustworthy relationship, one felt a sense of kinship, belonging and being at home with another or others. These feelings reduced worries and fear since there would also be a sense of familiar interpersonal relationships with a sense of ‘we’ rather than ‘you and I’. In addition, there was an effortless being together with one another, a sense of accustomed security and togetherness (Galvin and Todres 2013). Suddick et al. (2021) argued that, for older people, being vulnerable was not safe but real, and perhaps it was necessary to bring older people to a position and space of openness and exposure from which they could connect sensitively and in a meaningful encounter with another.

Other participants believed that consistent and reliable homecare would help older people develop a social relationship with their carers and community. Galvin and Todres (2013) stated that for some people to feel at-homeness well-being, they may need interpersonal kinship experiences that moved beyond the cultural level to include interests and infinities that were very specific and not necessarily related to the cultural heritage. Galvin and Todres (2013) also explained that people could experience peacefulness and well-being when there was a felt acceptance of things, circumstances and changes. Participants said that when there was trust, carers would be able to advocate for older people and help them participate in community activities. Care providers would understand older people’s care needs and want by listening respectfully to their stories. Listening involved a carer listening to understand how older people conceptualised well-being-focused homecare. However, maintaining respect for a person was pertinent in care (Gibson et al. 2020b).

9.7 Cultivate an environment that nurtures dignity in older people in homecare

This section discusses how older people perceived dignity in homecare with regards to the principle of dignity/respect/mutual respect in homecare.

Participants believed that homecare should be founded on the principle of dignity, respect or mutual respect so that dignity in older people could be maintained. They believed that loss of dignity and self-identity were brought about by how carer providers treated older people during homecare. Participants reported that older people were not listened to by carer providers and were looked at as the other. When older people wanted to contribute to their care, they were made to feel like they did not know anything. As a result, this left older people feeling worthless, unvalued, feeling like a burden, not belonging and unwanted. According to Galvin and Todres (2013, p.12), loss of dignity could result from the dehumanisation of care because humanisation valued what it meant to be human, while dehumanisation could occur when people were objectified. In objectification, people were made into an object by care providers focusing excessively on the ailment, statistics and labels pinned on people but did not consider what made one intimately human. Galvin and Todres (2013) explain that when a person experiences a sense of effortless connectedness, a certain peacefulness or lack of dilemma of who and what they are, they feel at home with themselves, and their identity well-being gets enhanced.

Galvin and Todres (2013) elucidated that for a person to achieve this ‘I am’ well-being, carers could support people and connect them with activities in which people felt that they belonged. In other cases, Galvin and Todres (2013) clarified that people could be supported with their ailments and would feel that despite their anguish, they still felt bigger than their ailment. Participants in the study experienced a feeling of being bigger than their ailments because they revealed that despite their shrinking spaces from challenging ailments, they still readjusted and adapted to their living spaces in order to enhance their independence, freedom, control and well-being.

According to Clancy et al. (2021) the concept of dignity can be defined as a core value grounded in respect and associated with human rights and subjective experience related to autonomy and identity. Participants believed that dignity encompassed respecting the rights of an older person and the cultural values of an older person. And in that case, they stated that it was not merely what was done but how things were done that affected older people’s dignity. Tranvåg et al. (2015) acknowledged that dignity-preserving care for older, vulnerable, home-dwelling people depended upon carers’ kindness and gentleness and developing a caring culture in which the person cared for could experience themselves as equal human beings. On the other hand, Staats et al. (2020) described two types of dignity relevant to what participants described: Absolute and relative dignity. Absolute dignity was inherent in all people, inalienable and granted under being a human being. It involves both a right and a need for each individual to be recognised as a unique and worthy person (Staats et al. 2020).

Similarly, relative dignity was an adjustable form of dignity influenced by everyday life's sociocultural factors. It concerned feelings of self-worth as well as worthiness in relation to other people. It could be strengthened through the support and confirmation of others but could also be torn down and violated (Staats et al. 2020). Older people wanted care providers or carers who respected and cared about older people and could develop trustworthy relationships, which could improve older people’s active participation, feeling valued, self-worth, well-being and dignity. According to Torossian (2021), when people under care feel that they are not heard, they lose self-esteem and feel inferior, causing them not to communicate with their carers. Gibson et al. (2020b) affirmed that listening respectfully to a person and their story included social and emotional well-being experiences. Gibson et al. (2020b) further emphasised that listening and not just hearing the person was a sign of respect. It involved understanding how the person conceptualised social and emotional well-being and experiences in life, including their hopes and dreams for living a fulfilling life (Gibson et al. 2020b). Tranvåg et al. (2019) indicated that the idea of feeling and being valued were essential elements of defining dignity, and this is where a person feels that they can express themselves freely and still feel valued.

9.8 Cultivate an environment that nurtures community engagement for older people

The section discusses how older people perceived community engagement with regard to the principles of resilience, safety and belonging. Most participants indicated that older people were isolated and excluded from community engagement, and older people were unfairly judged and considered to know little. Participants also believed that the community was fragmented. Because of the fragmentation, older people found it challenging to develop trustworthy relationships and actively engage meaningfully in community activities. Lack of trustworthy relationships and community engagement made older people feel lonely, isolated, and unsafe and had difficulty coping with their lack of belonging.

The community is like a bigger unit of the home; therefore, homecare cannot be confined to an older person's home but to the community. Findings showed that when older people perceived the well-being, they wanted to experience enabling independence, enabling co-production, enabling active participation, building trustworthy relationships, enabling coping with deteriorating health, enabling effective communication/feedback loop, tailor-making authentic choices, enabling access to homecare support, enabling freedom and sharing control. When looking at the homecare that older people want to experience, the thread line for well-being is the inclusion/participation of older people in homecare discussions.

Well-being can only be achieved by including older people and seeing well-being and homecare from an older person's existential perspective or lifeworld. There should be an enabling environment for inclusion because, according to (Galvin 2018), feeling at home in a place requires typically not only the capacity to negotiate it effortlessly but also the ability to pursue one's ordinary activities without any impediments. In this sense, I also refer to the community where older people want to participate actively. For older people to get on with their activities, the environment needs to be unobtrusive from the exclusion of all forms, such as structural barriers, by removing the perception of seeing older people as the other, not listening to older people and seeing them as a burden.

The Care Act 2014 emphasizes participation in work, education, training or recreation, but when it comes to homecare participation, is limited because of how homecare is defined and structured. Most older people were excluded from participation because they did not meet the eligibility criteria for homecare. The exclusion was for the reason that they were considered healthy. And with the assumption that they did not need homecare led to older people self-funding their homecare. In addition, well-being in the Care Act 2014 is limited to individual aspects of well-being or outcomes which are set out in the Care Act and are most relevant to people with care and support needs and carers (DHSC-UK 2023). DHSC-UK (2023) also states that the principle of promoting well-being should be embedded through the local authority care and support system, but how the local authority promotes well-being in practice will depend on the particular function being performed. It further states that during the assessment process, for instance, the local authority explicitly considers the most relevant aspects of well-being to the individual concerned and assesses how their needs impact them (DHSC-UK 2023). One could see that this approach led to disease-based well-being, fragmented and limited because well-being has already been linked with a particular function by the Care Act 2014 and local authorities. Having lifeworld-led well-being as a point of departure for care would mean providing care to an older person in a holistic approach.

With a holistic approach the focus would be on offering a humane care where an older person would feel recognised as a person because they will be offered opportunities and possibilities to reflect on one’s own existence and life circumstances. And from the findings, older people perceived that care providers did not value older people's lives and their well-being but the tasks they should complete before they left for the next client. Galvin (2018) brings awareness regarding well-being as she questions whose definition of well-being is accepted when discussing well-being. She further clarifies that embracing the power of language raises questions about how we conceive and frame well-being as much as how we view disability. According to Galvin (2018), an individual's or group's well-being cannot be discussed apart from lived relationships with their worlds, including where they find themselves. This is because people are immersed in the world and there is only a people-world entwinement and blending and existentially realized as one (Galvin 2018).

Galvin and Todres (2013) indicate that when people are not engaged or are isolated, they experience suffering where they feel like they are in exile, separated and estranged. They will not feel at home, for they feel unwanted and alienated. Furthermore, Galvin and Todres (2013) posit that being cut off or disconnected from others may lead to experiencing interpersonal suffering that makes people experience the feeling of alienation and isolation from others, feeling wronged or cast out from meaningful engagement. Similarly, Sjöberg et al. (2018) pointed out that a lack of engagement in activities could lead to older people feeling a lack of purpose, feeling left out in the community, not feeling at home, and having a sense of emptiness. Galvin and Todres (2013) justify that these sufferings are experienced when well-being is not achieved. Yet, well-being can be achieved by understanding the essence of well-being and what matters to people.

According to Gibson et al. (2020b), service providers judged people based on old age and thought people were stupid. Participants also explained how they experienced similar situations with care providers who did not listen to older people and disregarded their views during care. It made older people feel frustrated, unsafe, unvalued, hopeless, worried and anxious. Huxhold et al. (2014) explained that providing the individual with the opportunity to participate and have social connections was crucial for the individual’s well-being. Furthermore, people with closer social relations tend to be more optimistic about their future and are healthier (Huxhold et al. 2014).

9.9 Cultivate an environment that nurtures the resilience and empowerment of older people

This section discusses how older people perceived resilience and empowerment of older people with regard to the principle of independence of older people in homecare.

Participants considered that older people should constantly learn new competencies and skills to cope and adapt to physical, health, mental, social, and environmental changes. Competencies enabled older people to have their self-identity, independence, control, coping, belonging and freedom. Participants described overcoming the hindrances that caused their deteriorating health and ageing. Participants indicated that they constantly needed to adjust and adapt to their living space/environment to thrive in these unfavourable conditions. Older people's resilience in their deteriorating health, ageing, shrinking spaces and relationships was because they wanted to be independent and maintain their well-being, freedom and dignity. Participants believed that for future homecare they wanted older people to be empowered to develop competencies that facilitate coping and self-reliance.

According to Van Haitsma et al. (2019), people were intrinsically motivated toward personal growth when their environment was supportive and their psychological needs were met, specifically, their need for autonomy, competence, and relatedness. According to Galvin and Todres (2013), when people participated and felt valued, it heightened their dignity and well-being. Van Haitsma et al. (2019) pointed out that a positive outcome of well-being was reflected when there was a balance between a person and an environment where goals are achieved, and needs are met.

Cultivating an environment that nurtured trustworthy interpersonal relationships between older people and care providers could promote resilience in older people because Galvin and Todres (2013) expressed that intersubjectivity was about interpersonal relationships where people felt at home with others, a sense where people felt like they had known each other a long time ago. As a result, they experienced well-being and a feeling of belonging and kinship.

Older people felt like outsiders because of the exclusion. At the same time, they wanted to continue leading productive and independent lives in their communities. Sometimes, they wanted carers to create time to sit and talk with older people. The inability to participate negatively impacted older people's well-being and exacerbated their suffering. This alienation is some form of suffering experienced when one feels isolated from others (Galvin and Todres 2013).

9.10 Virtual data collection in participatory research

This section discusses the findings of a research question: What are the perceptions of older people on using virtual communication as a tool for data collection in a participatory research approach? The research objective was: To explore older people's perceptions of the use of virtual communication as a tool for data collection in this participatory research approach. The findings discussed here are from older people aged between 63 and 89 who participated in the study.

The section will discuss the findings in relation to some concepts of the well-being theory of Galvin and Todres (2013). This theory is used because older people described their perceptions of the use of virtual communication as a data collection tool from older people's suffering and well-being perspectives.

9.10.1 Virtual data collection enhanced inclusive participation and the feeling of being valued.

The findings showed that participants perceived that virtual data collection enhanced the active participation of older people even though some older people experienced poorer internet access. Bossio and McCosker (2021) described poorer internet access, less education for new technical skills, and experiencing attitudinal barriers to digital inclusion affected participation. From the findings of this research, participants indicated that they were appropriately assisted when they needed digital technology. They were helped with their online documents or password codes when they joined virtual data collection meetings. Again, participants felt that they could contribute meaningfully because the environment was conducive. As a result, they could talk about anything during the virtual data collection without feeling judged. According to Galvin and Todres (2013), inclusive participation is essential for the well-being of an individual because it develops interpersonal connections and feelings of belonging, kinship and being valued in meetings. The individuals experiencing interpersonal kinship and belonging were those whose relationships were based on trust that they would be supported (Galvin and Todres 2013). Trustworthy interpersonal relationships make individuals feel safe and effortless of being together, at home with another or with others (Galvin and Todres 2013).

Gann (2019) reasoned that to ensure that nobody was left behind in the digital revolution, there was a need to identify creative, community-based approaches that built digital access and confidence so people could become active partners in their health. Participants believed that communicating by email and sharing documents was simple because they used email to receive the draft document of the co-produced future homecare concepts and principles. Older people perused the draft, shared it with me via email, and used virtual Zoom to discuss this draft. Participants felt confident and valued because they believed virtual data collection enabled them to participate in research during the Covid-19 pandemic lockdown when it was impossible to meet face-to-face. Galvin and Todres (2013) attested that experiencing the feeling of being able to achieve what one values enhances one’s sense of well-being. Older people hoped that care providers would recognise and put their contributions to good use. Galvin and Todres (2013) also posited that one’s sense of personal identity of “I am” was experienced when one felt that they were able and supported. Furthermore, they felt valued in ways that made them experience effortless connectedness and peacefulness, thus enhancing their well-being (Galvin and Todres 2013). Galvin and Todres (2013) further stated that when one achieves one's goals through hard work, one feels their capacities and potential.

Furthermore, Galvin and Todres (2013) mentioned that regular engagement of a person with goals they successfully achieve, builds a well-being identity of “I can” because one would feel able and capable of achieving what one values. The participants’ good feelings from achievement indicated that meaningful engagement of older people in community activities or research could enhance their “I can” well-being because it improved their value and identity. According to Potter et al. (2022) digital communication increased flexibility in collaboration on various projects where participants could not collaborate in face-to-face interactions, promoting the person's well-being.

It was evidenced in the current study that during virtual data collection, participants expressed that they felt included and safe and had a sense of “being able” because participants contributed to a subject they found valuable. Galvin and Todres (2013) posit that when a person is not being supported to achieve their goals, they could feel a sense of not being able to, a degree of incompetence, and lack of confidence and self-belief, leading to pessimism about their self-capacities. Unlike health research rooted in medical science and positivist approaches (Cook et al. 2019), virtual data collection enabled participants to engage meaningfully, drawing from their lived experiences. In participatory research, there was no single form of knowledge, and academic knowledge was not given precedence over participants' knowledge (Cook et al. 2019). As a result, a sense of "being able to" was promoted, giving older people self-confidence in their competency skills and self-confidence was some form of well-being, as mentioned by (Galvin and Todres 2013).

9.10.2 Virtual data collection improved relationship building and feeling safe

This section discusses virtual data collection and how it enhanced: inclusive and less intimidating participation, valued engagement, peacefulness, belonging, and kinship. Findings showed that participants perceived individual virtual interviews and virtual participatory group discussions as beneficial because older people could participate in research despite the Covid-19 pandemic and social distancing. Participation meant inclusion and belonging because older people could participate in research that concerned older people. Online participatory research brought older people together, and during this period, older people felt safe space was enabled. In addition, because of the safe space, older people developed relationships as they worked together on three occasions. Upon completion of virtual data collection, older people indicated that participation was therapeutic for them because they could share personal stories that they had not shared before. With guidance from Toft et al. (2021), during virtual participation, I maintained a trustful relationship with the participants to improve sensitivity to participants' vulnerabilities.

From the literature, Twis et al. (2020) indicated that face-to-face qualitative data collection methods were time-intensive for the researchers, and as a result, researchers may exclude from the study individuals who were homebound or unable to participate in an in-person interview. With virtual communication, older people participated in virtual interviews and participatory group discussions. They did not require travel to meeting places, and participants felt it was convenient and they felt safe to participate from their home spaces.

Handke et al. (2018) state that virtual communication benefits include time and cost savings and increased flexibility. Participants believed that individual virtual interviews and virtual participatory group discussions were less intimidating than face-to-face, and older people felt that it helped me gain substantial data from them because they felt comfortable. Galvin and Todres (2013) stated that when people felt less intimidated and comfortable in a space or place, those people experienced a sense of at-homeness and peacefulness well-being.

Furthermore, Galvin and Todres (2013) attested that a sense of familiar interpersonal connection could be from a relaxed meeting in a way that made one belong and effortlessly be together with one another. In this research, participants believed that individual virtual interviews and virtual participatory group discussions were chaired with a light touch and that I was a good listener and conversationalist. In addition, participants expressed that they were respected and given equal opportunity to talk during the virtual participatory group discussions. The present virtual data collection with older people placed a relational process at the centre of the process. Online participatory research brought together older people with varied knowledge, perspectives and experiences and aspired to be a non-hierarchical, relational, collaborative endeavour (Cook et al. 2019).

9.10.3 Virtual data collection improved the feeling of empowerment and belonging

This section discusses the use of virtual communication as a data collection tool that enhances inclusive participation, knowledge sharing, at-homeness, belonging and peacefulness. The section also discusses strained listening abilities and the potential exclusion of those with limited digital knowledge.

According to Mukherjee (2010), the involvement of older persons in virtual volunteering was an unexplored area of research. For the moment, Weil et al. (2021) also indicated that in virtual volunteerism by older people, there was some exclusion based on the haves and the have-nots. Exclusion made some older people feel like a burden to others, leading to distress (Losada-Baltar et al. 2020). During virtual data collection, participants were worried about older people who were less skilled in technology and missed contributing to important issues. The findings showed that digital technology was unusual for older people because some experienced strained listening and difficulty hearing during discussions. Nonetheless, a hospitable environment enabled older people to continue volunteering in virtual data collection. According to Galvin and Todres (2013) a person may feel inhospitable in an unusual place or space, where one felt that they did not belong or were unwelcome, and when one felt unwelcome, they felt worried and unwanted, leading to feeling exiled. This suffering affects one's well-being.

In the virtual data collection, I became sensitive to older people's potential suffering that could be caused by virtual space. I ensured that there was good hospitality for older people. In the current virtual data collection, there was a maximum of up to 5 participants per participatory discussion group to make it easier for older people to focus and participate. Participants believed that small groups for virtual data collection made it inclusive with meaningful engagement and trustworthy relationships.

The participants did not report fear or anxiety regarding virtual Zoom for virtual participatory discussions and individual interviews. Instead, participants were worried that there were older people who had limited skills in using technology, which led to the exclusion or lack of participation in virtual data collection. O'Connell et al. (2022) stated in their study that older people who were reluctant to try a new technology saw it as a chore and preferred only telephone use. All participants in the present study belonged to an organisation that promoted lifelong learning for older people. Participants used virtual Zoom in their organisation to conduct various group activities. Studies about how older people effectively learn in online settings and virtual courses are still developing (Weil et al. 2021).

Some studies showed that in a virtual environment, compared to an in-person one, people had an inherent drive to participate (Xiong and Zuo 2019). Similarly, it was noted in the present research that participants were motivated, active and dedicated during the virtual Zoom and online enrolment. Participants felt included and empowered. In addition, virtual Zoom participatory discussions comprised a small number of participants, making older people feel at home and belonging.

Galvin and Todres (2013) indicated that care providers could facilitate belonging by being sensitive to older people and getting older people to engage more in various events. Since there was a trustworthy relationship during virtual participatory discussions, participants felt at home and peaceful in the virtual group discussions. In addition, everyone felt valued, involved and empowered to share their experiences. Again, Dania and Griffin (2021) also indicate that effective networks improve interaction at thresholds that enable members to upgrade skills, attributes and knowledge. Virtual data collection enabled older people to co-produce future homecare concepts and principles which would inform policy strategies. It also gave older people a clear, common purpose and goal (Dania and Griffin 2021), which, in turn, boosted older people's "I can," "being able to," and self-confidence.

Chapter 10 Conclusion

The research aimed to explore older people’s perceptions of future homecare and collaborate with older people to co-produce concepts and principles that should underpin future homecare delivery. The study questions, as seen in chapter 1 were:

- What could future homecare look like based on the perception of older people in the United Kingdom?
- How does collaboration within research enable older people’s voices to be heard and allow meaningful engagement?
- What are the perceptions of older people on using virtual communication as a tool for data collection in a participatory research approach?

The conclusion was divided into three sections and informed by the research questions: Conclusion on future homecare older people want, principles that should underpin future homecare and perception of virtual communication as a data collection tool.

10.1 Conclusion on future homecare based on the perception of older people

This conclusion concerns the research question of “what could future homecare look like based on the perception of older people in the United Kingdom?” The research showed that homecare was more than care provided for older people who could not fully care for themselves at home with formally assessed needs. Above all, the research showed a need to revamp homecare support and build it on lifeworld-led well-being because older people will be cared for holistically. Furthermore, with lifeworld-led well-being, older people will co-produce their homecare support with care providers. Equally important, care providers should not view older people only as mere consumers of services but as experts and partners who could inform homecare strategies from their lived experiences. Enabling active participation, enabling co-production, tailoring authentic choices, enabling effective communication with a feedback loop, enabling access to homecare support, enabling independence, and building trustworthy relationships were crucial in enhancing a sense of well-being. Older people valued inclusion and being able to participate in activities that they valued because it enhanced their sense of well-being. The well-being and suffering theory of Galvin and Todres 2013 is suitable for exploring older people’s experienced well-being and suffering in homecare. The balanced approach would help care providers understand the barriers that prevent achieving older people's well-being in homecare. Understanding the well-being and suffering of older people also helps in co-producing an individualised/customised homecare support plan, which contributes to sustaining older people’s well-being and dignity.

The other recommendation was that homecare should be centred in the community and be inclusive for all diverse older people despite their ethnicity or socio-economic background. From the research findings and discussion, homecare could be described as a coordinated care service in the community that promotes the lifeworld-led well-being of an older person in their natural home environment. This care considers a sense of agency for older people through proactively co-producing homecare support plan with an older person before their health deteriorates to enhance the older person’s easy access to homecare support at the right time, delivered by the right people in the community to sustain an older person’s lifeworld-led well-being, dignity, trustworthy relationships, active participation, independence, and authentic homecare choices.”

Older people are worried that cognitive capacity seems to decline faster than physical health. The increasing number of older people with complex care needs from multiple chronic ailments leads to significant pressure on the use of social care services (Morciano et al. 2020). From the findings, older people expressed that homecare services were fragmented for older people and that their family members were not around to help them navigate these services. According to (Bäck and Calltorp 2015; Morciano et al. 2020), integrating health and social care services has become a cornerstone policy in many developed countries to support older people with complex care needs to navigate between homecare, rehabilitation and primary care. However, many countries, including the UK, organise and fund health and social care separately, creating problems in providing integrated health and social care because of differences in cultures, traditions, professionals, legislations, ways of working and communicating (Bäck and Calltorp 2015; Harlock et al. 2019). In the UK, homecare is under social care, led by the local authority (Hughes and Burch 2020). Older people believe that because of the complexities of their care needs, Social care is insufficient to maintain their well-being, and therefore, they complement their social care with preventive care, rehabilitation and healthcare. Lette et al. (2020) attested that many older people live at home, often with complex and chronic health and social care needs. Therefore, integrated care programs for older people living at home are increasingly being implemented in primary and community care settings (Lette et al. 2020). Older people recommend a one-stop shop for homecare support services and proactive assessment of older people to ease their worries and fears of inability to access homecare services when needed. Integrated care programs have the potential to address a wide range of problems that could undermine older people's ability to live independently at home (Lette et al. 2020). Michael et al. (2020) also attest that older people are generally satisfied with their care when referred to services without difficulty, and interprofessional communication is perceptible and shared with older people. Older people's perception of future homecare varied from social care-defined homecare because older people's perception of homecare was founded on lifeworld-led well-being, enhancing a holistic and integrated care approach for older people. Hughes and Burch (2020) also attest that despite the challenging landscape of homecare services, care delivery can be improved when care supports self, identity and autonomy and when it values the relationship between care providers and older people.

Older people recommend that the Community Nurse coordinate one-stop-shop for older people's homecare, map all older people in the community, and proactively plan with an older person to co-produce a customised empowerment plan. Older people want Community Nurses to be nominated and reserved to focus on coordinating the integrated health and social care one-stop-shop for older people. They proposed that the nominated community nurses be called Nominated Community Social Care Nurses (NCSCN) since they will integrate health and social care services for older people. Older people believe there is a stigma attached to visiting Social Workers in older people's homes. Having Nominated Community Social Care Nurses as coordinators for a one-stop-shop for integrated homecare services will minimise the stigma attached. Furthermore, they felt that Social Workers were burdened with caring for children and disadvantaged people and felt that older people were not prioritised. Hajira et al. (2021) indicate that drivers for integration in the primary care and social services context harness the dynamic key individuals or teams to drive integration forward, especially on the value of new interface roles. Older people wanted the Nominated Community Social Care Nurse to oversee the one-stop-shop of integrated care between health and social care sections. According to Deschodt et al. (2020), integrated care models are highly recommended to overcome care fragmentation in the multimorbid older population. Furthermore, Deschodt et al. (2020) state that nurses are potentially ideally situated to fulfil the role of care coordinator to guide integrated care (Deschodt et al. 2020). Older people wanted Nominated Community Social Care Nurses because, due to their complex care needs, they believed Nominated Community Social Care Nurses were skilled in coordinating health and social care and understanding older people's care needs. Integrated care requires collaboration between health and social care providers to address an older person's multiple care problems, identified by performing a comprehensive assessment and integrated with a tailored care plan (Deschodt et al. 2020). Older people wanted community nurses to support them in traversing between homecare, rehabilitation, and primary care by integrating homecare planning, information sharing, and collaborative problem solving and fostering interactions between professionals and teams. They recommend that the Nominated Community Social Care Nurse manage a database of older people in the community where she could proactively map older people's homecare needs.

According to Bäck and Calltorp (2015), integrated care for older people can be enabled by changing existing national legislations or national laws that impact the implementation of integrated care for older people because they believe that no older person should be a victim of poor integration of care. Bäck and Calltorp (2015) also highlight that structural barriers that can impact the implementation of integrated care for older people are differences in cultures, traditions, professionals, legislations, and ways of working and communicating between health and social care. Older people also believe that early development of trustworthy relationships would enhance older people's well-being and dignity because they would have a sense of belonging, identity, safety and at-homeness while enabling active participation. Trustworthy relationships will promote an effective communication loop, making older people feel safe and preventing suffering such as isolation or loneliness, abandonment, feeling exiled or imprisoned or feeling unwanted.

10.2 How collaboration within research enables older people's voices to be heard and meaningful engagement

Older people want to participate actively in the decision-making of their homecare support. In the current research, older people co-produced future homecare concepts and principles, making them feel valued. Older people emphasised that individualised and co-producing homecare principles were essential because they would facilitate the participation/inclusion of older people and enable authentic choices in homecare needs and wants. Understanding that older people are different and have different wants, values, cultures, ethnicities, social backgrounds, and needs would enhance tailor-made homecare support services for older people. Furthermore, care providers will understand where their homecare systems are weak or lead to the suffering of older people and be able to explore resolutions from older people's perspectives.

Care providers would do things differently in homecare support when they considered the co-produced principles and concepts of homecare to understand older people's well-being and suffering. Furthermore, co-produced concepts and principles of homecare can guide care providers in designing homecare support empowerment strategies to enhance the independence, authentic choices, control and well-being of older people.

Older people recommend strengthening the principle of effective communication and developing trustworthy relationships. Effective communication through active listening and active and reliable feedback channels in homecare would promote understanding of older people's suffering and well-being in homecare, enabling older people to flourish and feel independent, safe, free and in control.

10.3 Virtual data collection in participatory research

Older people believe that virtual data collection enhances the participation and inclusion of older people in research despite challenges like the lockdown during

Covid-19 pandemic. They believe that some older people cannot easily travel, and virtual data collection enables older people to participate and achieve what they value, leaving no older person behind. In addition, unlike in-person meetings, older people feel safe expressing themselves from their homes.

Older people believe a larger number of people in virtual data collection could overwhelm an older person. Older people attest that small groups of a maximum of five people enabled older people to contribute meaningfully during participatory virtual discussions. Furthermore, a smaller number of older people in virtual data collection made older people feel personalised, safe, belonging and valued. Older people did not like long information sheets. They thought that long, and too formal consent forms and participatory information sheets could discourage older people from participating in virtual data collection. Older people believe that reliable technology assistance can enhance the participation and inclusion of older people in virtual data collection tools.

For older people, virtual data collection enhances networking and developing a trustworthy relationship with the researcher and other participants. Feeling respected and valued during virtual discussions would enhance participation and a sense of self-identity during virtual data collection. In addition, older people indicate that by creating a safe virtual space, older people can share their experiences, even those that they had not shared before. As a result, older people consider virtual data collection therapeutic and enhancing their well-being.

Despite the benefits of virtual data collection, some older people prefer face-to-face data collection meetings. Older people believed that observing other participants' reactions made it hard to know if they agreed or disagreed with what others were saying. Similarly, those with hearing aids think virtual data collection requires higher concentration because they had to watch other participants' lips closely due to delays in sound and were sometimes unclear. Therefore, virtual data collection should not replace in-person data collection but complement it since they believe older people should meet people in person because most older people live alone. Nonetheless, virtual data collection can enhance an older person's well-being of togetherness as they build relationships during virtual data collection.

Chapter 11 Recommendations

11.1 The implications to practice and policy

When I started this research with older people to explore the type of future homecare that older people wanted, some people perceived that older people would come with homecare desires that would be very expensive for the government while the government had limited funds. Yet, it showed that older people wanted future homecare where they would be included in participating in the co-production of homecare support plans that they needed and wanted. Based on the research findings, my positionality is that the limited or lack of participation was the restriction for implementing homecare that meet older people's needs and wants. Participation is about inclusion and balancing power. However, care providers and local authorities define inclusion and participation in the homecare. Their definitions of inclusion and participation are founded on health diagnosis and economic and human resources, and older people are often excluded when forming these definitions because older people’s lived experiences are not considered expertise.

The lack of consideration of older people as experts in homecare leads to a constant power imbalance and exclusion of older people since their perception of home, homecare, and well-being is not voiced out and is unknown or not understood. For example, care providers perceive care homes as homes. However, with these research findings, care homes are not perceived as homes by older people because in care homes, the power for inclusion and definition of inclusion/participation terms lies with the care providers and care home authorities. The inclusion/participation terms are what, how and when an older person can and cannot participate or contribute towards their care when living in the care home.

The inclusion/participation terms have also extended to homecare whereby care providers hold the power of defining “what”, “how” and “when” in homecare. Older people believe that exclusion or lack of participation is taking away their independence, freedom, authentic choices, building trustworthy relationships, active participation, co-production, and belonging, preventing them from coping with their deteriorating health. Older people perceive independence, freedom, authentic choices, building trustworthy relationships, active participation/inclusion, co-production, and belonging as components of well-being as opposed to the care providers' well-being of physical, mental, psychological, and health well-being. Home is a complex definition and can only be understood by including older people to participate in the definition of home and what home means in connection with their care.

Findings show that the perception of home and care by older people has a greater impact on older people's well-being. For example, older people perceived home as a natural place with many memories, free to practice a particular culture and values, feeling control and belonging. In addition, I learnt that home is not limited to their homes but connected to the communities, cultural values, people, family members, memories, inclusion, and power to make authentic choices and a feeling of belonging. The most essential perceived home was older people's communities and homes where older people had power and control to freely exercise their choices to homecare. For example, some expressed their homes as their parents' homes because the power and control for decision-making lay with their parents.

11.1.1 Older people's agency well-being and inclusion

Local authorities and service providers should enhance ways of including older people to co-produce future homecare services before older people need rigorous homecare services. This research demonstrated that initial structural and functional barriers to including older people come from the current definition or meaning of the terms home, care, homecare and well-being. As a result, structural and functional bottlenecks/barriers that interfere with including older people must be tackled. One of the bottlenecks that also needs to be addressed is an incongruence between the Care Act 2014 and its implementation. The complexities of the Care Act 2014 are that it is being used to address well-being and prevention in older people, while the free-market principle from Neoliberalism was the starting point for its development. According to Sakellariou and Rotarou (2017), the power differentials produced through neoliberal policies that focus on economic rather than human rights indicators can lead to a category of disempowered people whose health needs are subordinated to the markets. The effects of this range from catastrophic out-of-pocket payments to compromised access to healthcare (Sakellariou and Rotarou 2017), and findings showed that older people lacked information, access to homecare services and support from care providers or local authorities, they were excluded from co-production or participation in designing homecare strategies because they were considered self-funders.

Local authorities should understand how older people perceive their well-being in homecare because older people do not express well-being as classified by care providers such as (physical, mental, and psychological well-being). Older people perceived well-being in terms of what they could and could not do in the community and homecare since the community was included in the meaning of homecare. Participation, authentic choices, freedom, independence, two-way communication, trustworthy relationships, and being valued and treated with dignity were vital for preserving older people's well-being and preventing suffering. All these can only be achieved by including older people in co-production rather than doing for older people what care providers assumed older people needed.

The recommendation is that homecare should be founded on lifeworld well-being, not on the well-being categorised by care professionals to suit their fragmented homecare. Galvin and Todres well-being and suffering theory provide a productive way of thinking about what matters to people and what humane care could mean because Galvin and Todres (2013) justify that by employing a broader focus on the seamlessness of everyday life and its well-being possibilities, care concerns may be meaningfully connected to more holistic conceptions of what is needed in humanely sensitive care. Furthermore, experiences of well-being and suffering are related to one another, and care providers need to understand both if they want to provide humanely sensitive care.

Older people perceived proactively co-produced homecare plans before older people needed homecare to preserve older people's well-being and prevent suffering from fear and anxiety of the unknown. Since proactively co-produced homecare plans would maximise urgency and early inclusion/participation of older people in their homecare. Older people believed care providers did not value and prioritise older people, making them feel like a burden. Older people had the perception that the lack of prioritising older people's well-being by care providers was due to a lack of valuing older people's lives and well-being and the assumption that older people consume more resources than the rest of the population. In this regard, older people want care providers to exercise a sense of urgency and prioritise older people's inclusion/participation in homecare and older people's lifeworld-led well-being, as this will prevent emergencies, deterioration of older people's well-being, and hospitalisation. Lette et al. (2020) posit that in an attempt to address older people's complex social care needs, care commissioners and service providers are increasingly adopting transformations towards integrated care. Through these integrated care approaches, primary and community care providers aim to organise services so that they are person-centred, proactive, seamlessly joined up across different care providers, and responsive to people's multidimensional needs (Lette et al. 2020).

Older people believed that they lived with multiple chronic ailments and, therefore, required complex care wants and needs to improve their lifeworld-led well-being and live independently at home. They believed that they experienced unmet homecare needs with social care services because of their complex care needs and also that homecare is available on a needs-based. As a result, findings showed that older people complemented their unmet homecare needs with other types of care outside social care services to meet their complex homecare needs. Vlachantoni (2019) attest that the prevalence of unmet needs among older people in England is significant in whichever type of difficulty one focuses on. Vlachantoni (2019) also states that the dynamic nature of older people's care needs can directly affect the amount and type of support required from various care provider sources. When older people's relationships with their GPs were impacted by lack of participation in their care or when they felt they were not listened to, it impacted their well-being and caused them lots of suffering. And that is why when older people call their GPs and their GPs do not listen to them, older people call the emergency department for help because it causes older people to experience fear and anxiety of the anticipated possibilities if they cannot access the care they want. This affects older people's well-being because they fear dying alone in their homes, making them feel unwanted, unvalued and not prioritised.

Care providers and local authorities should understand that homecare is complex but not complicated, and exploring the drivers and barriers to effective and efficient homecare cannot be done without the participation of older people and understanding what all these different components of homecare mean to them. In addition, care providers' choices of "what", "how", and "when" in homecare take precedence over older people because care providers and local authorities choose when older people should be included in homecare, how homecare should be defined and what should be done in homecare and this led to a significant exclusion of older people that impact on their well-being. According to Vlachantoni (2019), understanding the nature and extent of unmet needs for social care among older people is critical policy priority in the UK, as the local authorities juggle providing adequate social care for a growing older population with competing funding priorities.

Vlachantoni (2019) states that numerous factors can increase the occurrence of unmet needs among older people, such as their family environment, health, and socio-economic status. Kontrimiene et al. (2021) postulate that partnership between healthcare and social service providers is proven to have a positive impact on user satisfaction as well as leading to more efficient use of the resources and as a result, more focus should be on the establishment of clear procedures for formal cooperation between the health care and social care sectors. Kontrimiene et al. (2021) clarify that resistance to the integration of health and social care to address the complex care needs of older people is due to uncertainties about professional roles and functions and a lack of mutual formal communication pathways. According to Deschodt et al. (2020), integrated care models are highly recommended to overcome care fragmentation and address the complex needs of older people living at home and preferring to age in place. Deschodt et al. (2020) argue that nurses are potentially ideally situated to fulfil the role of a care coordinator to guide integrated care because nurses are often people's first contact with care professionals, are part of the local community, and holistically focus on core activities.

In the current research, older people wanted to have a Community Nurse to coordinate homecare in the community because it would enhance older people's lifeworld-led well-being by knowing that someone would be available to build a trustworthy relationship with and listen to them when they need to talk about their homecare. Collaboration with older people in homecare design and implementation was vital. When care providers could co-produce a homecare plan from an older person's existential point of view, it would help care providers understand what matters to an older person and be able to preserve the well-being of older people. It would prevent fragmented homecare services and foster a holistic approach through intersectoral action, improving access to homecare services and the well-being of older people. Research findings show that fragmented homecare services did not fulfil older people's well-being and dignity due to their suffering when they are excluded or cannot easily access homecare services at the right time, right place and by the right people. Homecare services should be inclusive and accessible for all diverse older people regardless of their social or economic background, ethnicity, colour, cultural values or geographical distance to reduce the suffering of older people.

The local authorities were interested in the current research findings because the research was conducted with older people, and they were interested in discovering and understanding older people's perceptions of homecare. The local authorities felt that this research was a good piece of work. I gave them recommendations from the findings to inform their integrated care strategy, which they perceived was doable and could also inform their health prevention strategy. This was a positive step that local authorities made to ensure the voices of older people would be included and understood.

11.2 Implication to research

The online participatory research was undertaken with older people who had capacity. Findings showed that participatory research with a co-production approach with older people could enhance their well-being and dignity in homecare. Further participatory online research could be conducted with older people who lack capacity so that their voices and participation could be enhanced through participatory research. Exploration of participatory research with a broader group of older people from different ethnicities and colours, using Galvin and Todres' theory of well-being and suffering to discuss findings, would be essential because the theory brings a balanced understanding of older people's perceived suffering and well-being, while the broader groups of older people bring the diversity and inclusion in homecare services. Galvin and Todres' theory of well-being and suffering also unearthed the structural or system blockages that interfere with the inclusion and participation of older people in the co-production of homecare strategies/plans because of its balanced, unbiased and lifeworld approach when interpreting or understanding the meaning of older people's perceptions of homecare. There is a need for local authorities and care providers with the inclusion of older people to assess the legal environment that guides the implementation of homecare by Health and Social Care Services to establish areas that cause barriers to participation/inclusion, co-production and access to homecare services by older people in the UK. Local authorities should design a community-centred homecare strategy founded on lifeworld well-being and with guidance from the co-produced homecare concepts and principles from this thesis that older people want.

11.3 Dissemination of research and its findings

This section covers the co-produced dissemination of findings plan with older people. Dissemination of findings seeks to facilitate the utilisation of evidence-based approaches to improve the quality and effectiveness of health promotion, health services, and healthcare (Koorts et al. 2020). A reflection was done with older people on the dissemination of findings to engage other people beyond those who participated in the research.

As major stakeholders, older people embraced the area of research, for they thought that discussions about future homecare for older people should be brought up on various platforms. Older people argued that issues related to the homecare and well-being of older people should be on everyone's agenda. PT11, during FG3M3 stating that homecare should be on the agenda for everyone, said,

"We've got to get this profile into people's agenda for no other reason than information and practice and build it into associations. And there's the saga, there's organisation X, Y, Z, and I think it should be part of the program now to inform and educate everybody."

This was what PT03 during FG2M3 felt that dissemination should start with the local health authorities, said "*I feel it has to be from the local areas because the local areas know how their constituents are built up. The government can look at an overview, then you have to have the other areas, the groups that worked with that particular people."*

The table below shows the dissemination of the research and its findings.

Table 11-1 Dissemination of the research and its findings.

Activity Number	Research Product	Target date	Audience	Lead contributors	Status	Notes
1	To develop 3 minutes video describing what the research would be about and share it with the public through the project website.	26/12/2020	Public	Researcher	Done	I developed 3 minutes video describing what the research was about and shared the video on the project webpage.
2	To use a Twitter account to share research progress and its findings.	From 12th February 2020	Public	Researcher	Done	I tweeted about the research progress, Tweets about some meetings with stakeholders, conference presentations, network meetings with peer researchers and exhibition of the results
3	To present preliminary research findings in two sessions at the Caring Science conference in Sweden	27th April 2022 & 28th April 2022	International Researchers.	Researcher and Stakeholder Organisation X	Done	The stakeholder Organisation X provided some pictures I used for the pecha-kucha presentation in one of the sessions about older people's perception of community engagement in homecare. The other session was about a sense of home for older people in homecare.
4	To share the co-produced draft of future homecare concepts and principles with participants	FG1-03/11/2021 FG2-05/11/2021 FG3-07/11/2021	Research participants	Researcher and Research participants	Done	The co-produced draft of concepts and principles for future homecare was shared and discussed with the participants.
5	To inform participants that research findings would be shared at an international caring science conference that would take place in Sweden, Furthermore, inform the gatekeepers that findings will be shared with the team	10/03/2022	Research participants	Researcher	Done	Participants were informed about presenting research findings at the international conference of Caring Science and were also informed that I was invited to present the research findings to the team developing an integrated care strategy in England.

	developing the integrated care strategy in England.					
6	To use a diagram of a green tree to display the research findings and share with participants to get their view of the display.	29/08/2022	Research participants	Researcher and Research participants	Done	The draft of a tree diagram displaying the research findings was shared with the participants for their views. I received the participants' feedback.
7	To share research findings with the committee developing integrated care strategy in England.	30/06/2022	The committee that was developing the integrated care strategy committee in England.	Researcher	Done	I shared the research findings with the Team Lead for the committee that was developing the integrated care strategy in England to share with the team.
8	Shared research findings with stakeholder organisation X	17/02/2022	organisation X, enabled me to conduct data collection with their organisation members.	Researcher	Done	I thanked Organisation X and briefed the gatekeepers on the progress of data collection and preliminary research findings. They later gave feedback to the organisation-X's Board members.
	To inform stakeholder organisation X about my intention to participate in the exhibition at the Danish Nursing Museum in Denmark to share research findings with the public in an art form. To inform Organisation-X that the findings were shared with the integrated care strategy team.	15/09/2022	Stakeholder Organisation X	Researcher	Done Done	I shared with gatekeepers about the exhibition to share research findings with the public in Denmark. I informed gatekeepers that research findings were shared with the Team Lead for the committee that was developing the integrated care strategy.

9	To develop a 3-minutes thesis video to share with stakeholders. To contribute to a policy brief paper.	28/10/2022	Early-Stage Researchers (ESR), academic team and public	Researcher Researcher ESRs and academic team	Done	I developed 3 minutes thesis video and shared it with Early-Stage Researchers (ESR) from 9 universities in 5 different countries. The video was uploaded in Växjö University portal and the project webpage. I, contributed her research findings the draft for developing policy influence.
10	To share the 3-minute thesis video with the stakeholder that I was seconded to.	08/11/2022	Stakeholder organisation S in Sweden	Researcher	Done	I shared 3 minutes thesis video with organisation S. in Sweden.
11	To use the arts to share the findings of complex issues with the public. Displayed the exhibition and developed a 1-minute video about the exhibition, which would be replayed in the Danish nursing museum during the period of the exhibition.	02/02/2023 until 31/05/2023	Public	Researcher Danish nursing museum Aarhus University in Denmark and InnovateDignity team	Done	The exhibition was displayed in Denmark Danish nurse museum for two months and the museum staff indicated that lots of people were visiting the museum and requested if the display could be extended by another two months. The1-minute video was to describe the research in short with the in relation to the displayed trees in the picture frames and a tree artifact with findings. Another exhibition and oral presentation about the research findings would be done end of June 2023 in Birmingham in UK.
12	To contribute to the Bournemouth University researcher's public engagement and policy influence group that wanted a contribution from members on how members collaborate with NGOs to tackle the Sustainable Development Goals (SDGs) through research programmes in 3 sentences.	19/10/2023	university policy office	Researcher	Done	I informed the policy office that her research falls under SDG 3- well-being -because it addresses the well-being of older people, SDG 10- inequalities- which inequalities in homecare and SDG 17- a partnership through participatory research with older people.

	Which they contributed to international universities' SDG rankings.					
13	To develop a policy brief and share it with stakeholders and policymakers	1st May 2023	Stakeholders, policymakers	Researcher	pending	To be done by 1st May 2023
14	To write articles and publish the research findings and research methodology in June,	30th June 2023	Public, policymakers global community	Researcher	pending	To be done 30th June 2023.
15	To join and participate in organisations for older people and contribute towards making impact by using research findings.	from January 2022	Older people and the public	Participants Researcher	ongoing	Participant PT12 has been providing feedback to board of directors for organisation X on research findings and how findings have been used like in conferences, exhibitions and informing integrated strategy team. PT01 after participating in research she reported to have got a position as a committee member in a national organisation Z in UK that advocate for the accountability by policy makers on the well-being of older people. PT11 shared the findings with her small music group. She taught music and said it was the right platform to encourage older people to think of their future homecare. Following the experience of conducting participatory research, I got an offer to the position of international research project manager to manage global health research project. They would use a human centred approach to develop an intervention strategy for country B. she would coordinate collaborating research teams from 4 universities and 2 stakeholders both local and international for this project.
16	I would continue to scout for opportunities to disseminate research findings	From 09 March 2023	Older people, Public, policymakers,	Researcher	ongoing	ongoing

			care providers, university students and politicians			

Chapter 12 Limitations

This research has some limitations. Participatory research is a method known for in-person or face-to-face. Due to the Covid-19 pandemic and social distancing rules, I used alternative research methods when the traditional research approaches were not feasible (Adom et al. 2020). This might have affected vital processes or principles of participatory research with a co-production approach. Participants learnt about research from the internet platform from their organisation's website. The organisation promoted lifelong learning for older people, and participants responded by email.

Participants preferred to use virtual Zoom because they had used it for various organisational activities. This is acknowledged as a limitation because some older people who are not active online and those who do not have Wi-Fi could have been digitally excluded not by choice but because of the method used. The organisation was chosen to ensure that older people were recruited from safe spaces and could freely volunteer their time without pressure. Older people were already overwhelmed by the Covid-19 isolation information which was negatively portrayed about older people and Covid-19.

As a result, this limitation gives potential future research with older people who are not active on the internet or organisations or cannot explore their perceptions of the type of future homecare they want. This would ensure that the easy-to-ignore older people are included in the decision-making of their homecare. Also that, no one is left behind. Again, the population consisted of only white people, which was considered a limitation since people of other ethnicities might have various perceptions because of cultural values and experiences.

Chapter 13 Researcher's reflections on Participatory research

13.1 My positionality during and after research

According to Buffel (2018), the population's ageing and the need for more inclusive and responsive policies and services have led to an increasing interest in co-production and co-research with older people. To date, however, only a limited number of studies have addressed how the participation of older people as research partners can be practically realized (Buffel 2018). I learnt from this research that ethical considerations were essential when collaborating with older people and doing online participatory research with them to protect older people and ensure their safety throughout the research. I used emails and virtual Zoom to do participatory research during the Covid-19 lockdown. Online technology is a broad and deep area that could be an enabling tool or risk for older people. Literature shows that most older people are not equipped with good skills in the use of technology, which increases the risk of vulnerability when using online technology (Blažič and Blažič 2020). With all these in mind, I enabled older people to use online to address homecare issues for older people. I later explored their perception of the use of virtual communication as a tool for data collection to understand their experiences of using online participation in this research.

The risks were reduced by ensuring that when older people signed the consent forms, they were not using their signatures, but instead used capital letters for writing their surnames because it reduced potential signature security risks, which scammers or fraudsters could steal. During the interview, I confirmed that they signed the participant agreement form without being coerced by anyone. I also ensured older people's safety by creating a simple password to join a virtual Zoom meeting to ensure that only people with the password could join the virtual meeting for privacy. All these simple security measures were an enabling environment for older people to participate online with minimal safety and security risks.

Older people are usually considered vulnerable, but participants showed so much dedication that they moved around their daily schedule to accommodate research activities. (Makita et al. 2021); Langmann (2023) indicates that vulnerability is frequently interchangeably used with frailty, dependence, or loss of autonomy, promoting a connection between older age and deficits. James and Buffel (2022) posit that co-research challenges the predominant discussions, which construct ageing as a problem and focus on illness and deterioration. As a result, co-research represents a value-based approach to research that promotes the importance of diversity and a commitment to valuing older people’s perspectives and lived experiences (James and Buffel 2022). Participants could choose the date and time they wanted to participate, and there were no dropouts during the research.

According to Marschalek et al. (2022) participatory methodologies are highly flexible regarding research practices, and implementation depends on the specifics of local settings and people. I also learnt that when I applied flexibility to allow older people to choose the date and time to attend the participatory discussion and choose the research stages they wanted to be included in, it enhanced the participation of older people in the research and prevented withdrawal from the research. Furthermore, I also learnt that when I approached older people to discuss the type of homecare older people wanted without giving them the definition of homecare, older people were able to conceptualise homecare from their lived experience freely, and they felt more empowered and valued because their experiences and perceptions took precedence in the discussion and were valued.

All 14 older people who volunteered for virtual individualised interviews also volunteered in the virtual participatory discussions. No one withdrew from the virtual participatory discussions. Older people committed to the research and were compassionate to me. I felt respected and grateful for the opportunity to have participated in this research. Older co-researchers can communicate and empathise with interviewees, who feel more at ease to share their perspectives with a peer-researcher, leading to richer data (Mey and van Hoven 2019). Doing online participatory research with older people was unconventional and resulted from lockdowns during the Covid-19 pandemic. Participatory research is known for its face-to-face approach (Cook et al. 2017).

Expressing my gratitude and appreciation to older people and providing constructive feedback during online participatory research made older people feel valued, appreciated and respected for their contribution. The word participation can be applied to a broad range of engagement processes, from research that might involve the public merely as part of a research steering committee or commenting on the content of a questionnaire to approaches where the creation of and meaning-making from research is initiated and led by those who would be directly affected by the study (Cook et al. 2017). By being transparent and clear and giving older people adequate information to make informed choices, older people feel valued. Older people indicated that they valued participation because they were able to choose what, how and when to participate. Therefore, they believed that this online research was well-planned, clear, and organised and that time was not wasted. Older people considered that clear and well-planned sessions enabled them to prepare for the next session and make valuable contributions. I learned that participation of older people does not mean coercing them to lead research or participate in all phases of research but to enable them to make choices to included and participate in areas or stages they want.

During this study, I learned that participatory research approaches varied, and the method demanded participants to invest more time, intense collaboration, and labour to volunteer in participatory activities (Abma et al. 2019). In the current research, participants were informed that they could choose not to engage if they did not feel like it. Also, they should not feel guilty if they cannot participate in all stages of research.

Smaller participatory discussion groups

I learnt that older people appreciated smaller groups of 4-5 people for participatory discussions because it allowed older people an equal opportunity to participate and have input during participatory discussions. It also created a warm and accepting environment because every older person could describe their perception of the type of future homecare they wanted. Older people felt valued because they could engage and contribute during the participatory discussions. According to Littlechild et al. (2014), older co-researchers are more likely to know what to ask if they shared similar experiences with the interviewees. In addition, the interviewees appeared to feel more relaxed and at ease with a peer interviewer, leading to richer, fuller data (Littlechild et al. 2014). Participants felt the space was safe to discuss because bigger groups were overwhelming.

Littlechild et al. (2014) verify that the main benefit of older people's involvement is feeling comfortable in the interview situation and opening up about their experiences again, feeling comfortable results from the informal, conversational style that older people bring to the interviews. If one wants to make meaningful engagement with older people in discussions or dialogues, it is important to consider having smaller groups to enhance older people's contributions. Again, Arnold et al. (2022) posit that it is essential to accept that each person can and wants to participate with different intensity and that, there are differences in participation that should not be denied or suppressed. I also found that discussing the roles or how participants wanted to participate during virtual individual semi-structured interviews instead of leaving it to discussion groups developed a stronger, trustworthy relationship between the participants and me. It also enhanced power sharing for inclusion and independent decision-making without peer pressure. Furthermore, it helped older people to be on the same pace as other participants when they started participatory group discussions. According to Arnold et al. (2022), in participatory research and qualitative research designs, initiators of research projects should establish relationships based on trust with persons directly addressed by the research.

In addition, standard features of participatory research include creating spaces for hearing the voices of persons in marginalized positions and including their perspectives (Arnold et al. 2022). Participants expressed feeling comfortable and safe to engage in smaller participatory groups and that a 1-hour meeting seemed short, and time went unnoticed. Arnold et al. (2022) also indicate that during their participatory research, participants experienced that they were not alone during the group meetings, they were able to experience that they were not alone with their everyday problems and that made them support each other during the meetings. And at the beginning of the meetings, they greeted each other warmly and inquired about each other's well-being (Arnold et al. 2022). Similar actions were observed from older people in the current research. Participants expressed that the research was good because each meeting was planned for, and they knew what they would do next and prepared for it. Some participants brought notes. Time planning was to avoid wasting participants' volunteered time. Littlechild et al. (2014) indicate that research involvement can give older people a sense of purpose and satisfaction that they contribute to significant changes and increase their knowledge, skills and self-confidence.

13.2 What changed me during the research

Awareness of existing power dynamics could impact research outcomes. According to Hoppania et al. (2023), co-research methods are meant to realise aspirations for social justice and empowerment, but despite these benefits, there are many methodological and ethical questions to tackle. In addition, critiques surrounding co-research methods are that they can be tokenistic and, in the worst case, contribute to the oppression of service users (Hoppania et al. 2023). During participatory research, I reduced the dominance of some participants by agreeing as a group that we give each other a chance to speak. When one spoke long, I told them it was time to allow another person to speak, and they did not take it as an offence because it was already agreed that we would give each other a chance to speak. Older people's perception of future homecare gave me a deeper understanding of homecare and made me retrospect on my perception of homecare.

At the beginning of the research project, I had a similar definition of homecare just like other health and care professionals, though I did not share it with older people. Through active listening, dialogue, and shared experiences, I gained a deeper understanding of the complexities and nuances of homecare issues in the UK. Arnold et al. (2022) state that participatory approaches create opportunities for cooperation, building relationships, gaining knowledge, rethinking, and eventually changing power structures. My reflection on these new understandings, interpretations and meanings led to a comprehensive approach of co-produced concepts and principles to inform future decision-making. It also enhanced my sense of empathy and sensitivity toward the suffering that older people experienced and their desires for inclusion/participation and a holistic, lifeworld well-being-focused future homecare.

A detailed preparation for ethical consideration was necessary to provide older people with enough information to make choices and participate meaningfully in the research. I respected confidentiality and privacy to protect their safety. I built meaningful relationships and connections with participants, which allowed me to contact older people for further support to review and give perceptions of the homecare tree used to display the findings. This was because of the deeper appreciation for the knowledge and expertise that older people brought to the research and co-production. The relationships with older people were based on mutual respect and reciprocity. These relationships were transformative as they led to my professional growth and personal growth of older people. One of the participants got a position on the committee of an organisation that monitored the government to ensure that they were accountable for the well-being of older people in the UK.

I found this research to have been a very enriching experience. My supervisors were valuable and available to provide guidance and motivation throughout the journey. My supervisory meetings were regular, and I never felt alone because my supervisors were available and supportive. During the data collection, I listened empathetically and did much reflective listening because I needed to understand how participants felt and the distinctions that older people used in homecare. Furthermore, reflecting on what older people said helped me understand their suffering and well-being in homecare. What changed me was also understanding that excluding older people from the beginning when defining well-being and homecare based on the “what”, “when”, and “how” led to structural and functional barriers which prevented the inclusion/participation of older people and did not preserve the well-being of older people. One older person said, *“It is not what is being done, but how it is being done”.*

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Ref: IDP003I &
Version 2.0
Ethics ID:34566
Date: **05042021**

Appendices

Appendix 1 Participant Information Sheet for Interview

Bournemouth
University

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

INNOVATE DIGNITY

The full title of the project:

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach

Invitation to take part

You are invited to take part in a research project. Before you make any decisions, you need to read through the participation information sheet to understand why the research is being done and what it would involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to take part. If you have trouble when completing your Participant Agreement Form (PAF) you should inform me. You would be assisted in completing your form.

Who is organising/funding the research? - We are researchers from Bournemouth University (BU). The European Commission is the Funder of the research projects in the INNOVATEDIGNITY project, and this research project is one of them. The Grant Agreement number is 813928, and our website is https://innovatedignity.eu Our address is Bournemouth Gateway Building, St Pauls Lane, BH8 8GP, Bournemouth.

What is the purpose of the project? Previous research show that number of people aged 65 years and above is increasing in Europe. Some people at a later age require care in the home. Studies show that homecare service providers currently developed the homecare models without engaging people who would need the services. The research aims to work with older people to explore their perspectives on future homecare they would like. It is also to collaborate with them to co-produce concepts and principles that should underpin future homecare delivery. The data collection for the research would take place in 2021.

Why have I been chosen? - We would like to gain the opinions, perceptions, and views of people in your age group. We anticipate recruiting up to 20 people, but data saturation will determine the final number of people aged 50 years and above for the individual semi-structured interview.
You are invited because you have capacity. You are aged 50 years and above and are, according to UK Mental Capacity Act 2005, not considered to lack capacity. UK Mental Capacity Act 2005 considers one to have capacity when one can understand the information given to make a decision, one can weigh up the information to make a decision and can communicate their decision. The process of informed consent requires that you should have capacity to understand the study flyer from the newsletter, Participant Information Sheet or what would be verbally explained to you should you need clarifications. You should be well informed for you to decide whether you voluntarily agree to participate in this research. No one should decide for you to volunteer, nor should they complete the agreement form without your knowledge.

Do I have to take part? - It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to file this information sheet, and you will also be asked to complete an Interview Participant Agreement Form. We want you to understand what participation involves before you make a decision on whether to participate. If you or any family member have an ongoing relationship with Bournemouth University or the research team, e.g. as a member of staff, as a student or other service user, your decision on whether to take part will not affect this relationship.

Can I change my mind about taking part? - Yes, you can stop participating in study activities at any time, without giving a reason.

If I change my mind, what happens to my information? - If you decide to withdraw from the study, we will not collect any further information from you. As regards information we have already collected before this point, your rights to access, change or move that information are limited. This is because we need to manage your data in a specific way for the research to be reliable and accurate. Further explanation about this is in the Personal Information section below. In this research, your data will be anonymised and will not be identifiable.

What would taking part involve? - If you decide to take part in the research, you will participate in an individual semi-structured interview. First, do not feel like you do not know anything in this area because your experiences and opinions are worth informing this research. When you finish reading this Participant Information Sheet (PIS) for an interview and decide to take part, you will be asked to complete the Interview Participant Agreement Form. The Participant Agreement Form is the word document you received with this PIS. You should type in the needed information and then e-mail it back.

You will be asked to write your age in the Participant Agreement Form so that I can verify the age range. In the Participant Agreement Form, you will be asked to type your name and surname in full and in capital letters again in the signature space. When Participant Agreement Form, which you have completed is received, I will complete my section and then e-mail you the final Agreement Form completed by you and myself in a pdf format. You will be asked to file this Participant Information Sheet and the final pdf copy of a completed Interview Participant Agreement Form (PAF) completed by you and me until the data collection activities are completed.

The purpose of the interview is to explore your opinions and views on the current homecare, and it is also to get your opinions about how you would like your future homecare to be like in-case you need it at a later age. We will also get your opinions and views on what you believe should be the concepts and principles for future homecare. Lastly, to explore how you feel regular, older people’s meaningful participation should be sustained in research. The prompt questions will be used during the interview to guide the conversation into the topic of interest. The prompts are constructed to maximise the opportunities for informal, detailed, and highly textured participant responses. Prompt questions will be asked dynamically, keeping in mind both the interview’s objectives and the substance of the participant’s previous answers.

When the completed Interview PAF form pdf copy is e-mailed back to you, an e-mail for an appointment to have an interview with you will be included. The interview will be conducted using either Zoom, Skype, or Teams, whichever you prefer. There will be a section on the agreement form where you will be asked to indicate the preferred method for virtual communication. If you need guidance in the use of the virtual link, inform me to guide you. The interview will take place anytime from 0900hrs, and whichever time you prefer. The conversation is anticipated to take approximately 1 hour. The virtual link will be shared with you 2 days before the interview.

On the day of the interview, I will introduce myself and the study to you. I will use this opportunity to confirm if you completed the agreement form yourself. I will explain why the meeting will be recorded and request your permission to record the meeting. I will be respectful to you throughout the interview and will speak slowly so that we can understand each other.

At the end of the interview, I will thank you for your time, for sharing information of your perspectives and opinions, as this will be used in the co-production of the concepts and principles that should support future homecare delivery. The interview data will be analysed and anonymised to prepare for participatory group discussions. The research findings will be shared with you if you are interested.

The findings of the interview will be anonymised before being used in a participatory group discussion. If you are interested in being contacted for participating in a participatory group discussion, you will be asked to indicate that in the Interview Participant Agreement Form. Suppose you indicate that you want to be contacted for the 3 participatory group meetings; the Participant Information Sheet for Participatory Group and Participatory-Group Participant Agreement Form will be sent to you to read, complete, and e-mail it back if you still would like to take part after reading.

Our research team regrets that we anticipate recruiting up to 20 people for the entire participatory groups. We will recruit the participatory group participants from the individual interviews sample. If we do not get enough sample size, we will recruit from the organisation’s broader group.

During the recruitment for individual interviews, if we receive a higher number of people who want to take part in the study, than the anticipated sample size of up to 20 people, we will enrol people on a first-come, first-serve basis until we reach the required number of people or data saturation. However, one will be notified if they were unfortunately not enrolled in the study. We will still offer to share the research findings with all those who participated and all those who wanted to take part but due to higher numbers could not, if they are interested.

What are the advantages and possible disadvantages or risks of taking part? - Whilst there are no immediate benefits to you, it is hoped that your participation in this research will help generate information that care providers and policymakers can use to design and develop individualised, sustainable and dignified future homecare for people at a later age. Whilst we do not anticipate any risks to you in taking part in this study, should we realise that you are emotionally moved during the interview, we will recommend you to meet with your preferred health care provider if you feel you need some emotional support.

What type of information will be sought from me, and why is the collection of this information relevant for achieving the research project's objectives? The information sought from you will be your perspectives, opinions and views about how you would like your future homecare to be delivered. We will also explore your opinions and views on what you believe should be the concepts and principles for future homecare delivery. Lastly, to explore how you feel regular meaningful participation of older people should be sustained in research.

Will I be recorded, and how will the recorded media be used? - Only with your permission you may be recorded during the interview. All the audio recorded will be stored in a password-protected computer, and I will be the only one handling the recorded information. The recording will be used only for transcription. The recording will be transcribed, anonymised and will be used for data analysis. You will not be identified in any presentation of the findings because your name will not be used. None of the recordings will be played for the media or anyone outside the research team.

How will my information be managed? - Bournemouth University (BU) is the organisation with overall responsibility for this study and is the Data Controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. Research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and generating information about you. We manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control uses of information about identifiable individuals but does not apply to anonymous research data: “anonymous” means that we have either removed or not collected any pieces of data or links to other data that identify a specific person as the subject or source of research result.

BU’s Research Participant Privacy Notice sets out more information about how we fulfil our responsibilities as a data controller and your rights as individuals under the data protection legislation. We ask you to read this Notice to fully understand the basis on which we will process your personal information. Innovatedignity project is part of the Horizon 2020 pilot for Open Research Data (ORD) to improve and maximise access to and re-use research data generated by Horizon 2020 projects. Once the required publications are published at the end of the project, the anonymised data will be deposited in the BU BORDaR, and the EU Open Access Repository recommended by the Innovatedignity project and be openly available for other researchers to use it. To safeguard your rights concerning your personal information, we will use the minimum personally identifiable information possible and control access to that data as described below.

Publication - You will not be identified in any external reports or publications about the research. Otherwise, your information will only be included in these materials in an anonymous form, i.e., you will not be identifiable. The study will be published in Bournemouth University Open Access Library, and articles with findings will be published in health and care journals.

Security and access controls - BU will hold your completed agreement form on a BU-password protected secure network. Personal information that has not been anonymised will be accessed and used only by right, authorised individuals and when this is necessary for the research or another purpose identified in the Privacy Notice. This may include giving access to BU staff responsible for monitoring and auditing the study, as they need to ensure that the research complies with applicable regulations.

Further use of your information - The information collected from you will be used in an anonymous form to support other research projects in the future, and access to it in this form will not be restricted. It will not be possible for you to be identified from this data. To enable this use, anonymised data will be added to BU and EU's Open Access online Research Data Repository: this is a central location where data is stored and accessible to the public.

Keeping your information if you withdraw from the study - If you withdraw from active participation in the study, we will keep information that we have already collected from or about you. This may include your personal-identifiable information. As explained above, your legal rights to access, change, delete or move this information are limited as we need to manage your data in specific ways for the research to be reliable and accurate. However, if you have concerns about how this will affect you personally, you can raise these with the research team when you withdraw from the study. You can find out more about your rights concerning your data and how to submit queries or complaints in our Privacy Notice.

Retention of research data - Project governance documentation, such as the completed Participant Agreements Form: will be destroyed within a month upon completion of the research. Project governance documentation, such as the research database will be further prepared and anonymised more to be deposited in the BU BORDaR and European Union open-access online repository.

Research results: As described above, we will anonymise the information we have collected from you as an individual during the study. This means that we will not hold your personal information in identifiable form after we have completed the research activities. I will keep anonymised research data for three years after I have completed my PhD and published articles. The data will later be deposited into EU Open Access for other researchers to use.

Contact for further information: If you have any questions or would like additional information, please contact; the researcher, Mavis Bengtsson(mbengtsson@bournemouth.ac.uk), or the Project Supervisor Prof Ann Hemingway (aheming@bournemouth.ac.uk).

In case of complaints contact; Any concerns about the study should be directed to the researcher or the Project Supervisor. If the supervisory team has not answered your concerns, you should contact Professor Vanora Hundley, Deputy Dean Research and Professional Practice at Bournemouth University, by e-mail to researchgovernance@bournemouth.ac.uk.

Finally - If you decide to take part, you will be asked to file an electronic copy of this interview participant information sheet and a completed interview participant agreement form. Thank you for considering taking part in this research project.

Ref: IDP003F &
Version 2.0
Ethics ID:34566
Date: **05042021**

Appendix 2 Participant Information Sheet for Participatory Group Discussions

Bournemouth University

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

INNOVATE DIGNITY

The full title of the project**:**

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach

Invitation to take part

You are invited to take part in a research project. Before making any decisions, you need to read through the Participation Information Sheet to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you want to take part. If you have trouble when completing your Participant Agreement Form (PAF) you should inform me, and you will be assisted in completing your form.

Who is organising/funding the research? –We are researchers from Bournemouth University (BU). The European Commission is the Funder of the research projects in the INNOVATEDIGNITY project, and this research project is one of them. The Grant Agreement number is 813928, and our web site is https://innovatedignity.eu Our address is Bournemouth Gateway Building, St Pauls Lane, BH8 8GP, Bournemouth.

What is the purpose of the project? - Previous researches show that number of people aged 65 years and above is increasing in Europe. Some people at a later age require care in the home. Studies show that homecare service providers currently developed the homecare models without engaging people who will need the services. The research aims to work with people aged 50 years, and above to explore their perspectives on future homecare they would like. It is also to collaborate with them to co-produce concepts and principles that should underpin future homecare delivery. The data collection for the research will take place in 2021.

Why have I been chosen? – We would like to gain the opinions, perceptions, and views of people in your age group. We anticipate recruiting up to 20 people for the research. We will recruit the participatory group participants from the individual interviews sample. If we do not get enough sample size, we will recruit from the organisation's broader group. The inclusion age is anyone aged 50 years and above.

You are invited because you have capacity. You are aged 50 years and above and is, according to UK Mental Capacity Act 2005, not considered to lack capacity. UK Mental Capacity Act 2005 considers one to have capacity when one can understand the information given to make a decision, one can weigh up the information to make a decision and can communicate their decision. The process of informed consent requires that you should have capacity to understand the study flyer from the newsletter, Participant Information Sheet or what is verbally explained to you should you need clarifications. You should be well informed for you to decide whether you voluntarily agree to participate in this research. No one should decide for you to volunteer, nor should they complete the agreement form without your knowledge.

Do I have to take part? - It is up to you to decide whether or not to take part. If you decide to take part, you will be asked to file this information sheet, and you will also be asked to complete a participant agreement form. We want you to understand what participation involves before you decide on whether to participate.

If you or any family member have an ongoing relationship with Bournemouth University or the research team, e.g., as a staff member, as a student, or other service users, your decision to participate will not affect this relationship.

Can I change my mind about taking part? - Yes, you can stop participating in the study activities at any time, without giving a reason.

If I change my mind, what happens to my information? - If you decide to withdraw from the study, we will not collect any further information from you.

Regarding the information we have already collected before this point, your rights to access, change or move that information are limited. This is because we need to manage your data in a specific way for the research to be reliable and accurate. Further explanation about this is in the Personal Information section below. In this research, your data will be anonymised and will not be identifiable.

What would taking part involve? – If you decide to take part in the study, you will participate in a participatory group. The participatory group will have 3 meetings. The participatory group will collaborate to make a collective inquiry by discussing the topics that emerged from previously conducted individual interviews. The analysed data from the interviews will be anonymised before being used in participatory group discussion. The participatory group members will validate research results and co-produce concepts and principles that support future homecare delivery. They will also review the draft document of principles and concepts supporting future homecare. Furthermore, we will co-produce the road map to share the results.

This is how the participatory group discussions will proceed:

First, do not feel like you do not know anything in this area because your experience and opinion are worth informing this research. Second, when you finish reading this Participant Information Sheet (PIS) and decide to take part, you will be asked to complete the Participatory Group Participant Agreement Form. The Participant Agreement Form is the word document you received with this PIS. You should type in the needed information and then e-mail it back. You will be asked to write your age in the Participant Agreement Form to verify the age range. In the Participant Agreement Form, you will be asked to type your name and surname in full and in capital letters again in the signature space. When the Participant Agreement Form you have completed is received, I will complete her section and e-mail you the final completed Agreement Form in a pdf format.

You will be asked to file this Participant Information Sheet and the final pdf copy of a completed Participatory Group Participant Agreement Form (PAF) until the data collection activities are completed. When the completed PAF form pdf copy is emailed back to you, an e-mail for an appointment to begin the participatory group discussions will be included. I anticipate facilitating up to four separate series of participatory groups.

- Participatory Group 1 (with 5 participants)
- Participatory Group 2 (with 5 participants)
- Participatory Group 3 (with 5 participants)
- Participatory Group 4 (with 5 participants)

Each participatory group will meet 3 times and will have a maximum membership of 5 participants. The small group membership is because virtual communication will be used and that every member can be visible and have time to contribute during the participatory group discussions. Each group is anticipated to meet for 1 hour per meeting, once every 2 weeks. The participatory group meeting will take place anytime from 0900hrs, and the members will decide the time for the meeting. The participatory group discussions will be conducted using either Zoom, Skype, or Teams, whichever the participants prefer. There will be a section on the Participatory Group Agreement Form, where you will be asked to indicate the preferred method of virtual communication.

On the day of the first meeting, I will introduce myself and the study to the participatory group members. The group trust and safe space will be enhanced by encouraging group members to share only within the group and that there will be no wrong or right answers during the discussions. Everyone’s perceptions and ideas are important and need to be shared in the participatory group. The participatory group members will, therefore, be encouraged to keep the discussions within the group. In addition, the group members will be encouraged to treat each other with ultimate respect and listen to each other.

The purpose of the 3 participatory group meetings:

The purpose of the first meeting will be to collaborate to make a collective inquiry by discussing the themes that emerged from the individual interview’s analysis, prompt questions, and ideas and opinions from the participants themselves.

The purpose of the second meeting will be to collaborate with participants to co-produce concepts and principles that should underpin future homecare, informed by individual interviews' findings and discussions from the first participatory group meeting. Co-production enhances active and meaningful participation of older people in research. The participatory group will discuss the roadmap for sharing research findings. A draft of co-produced concepts and principles underpinning future homecare will later be developed.
The purpose of the third meeting will be to explore the participatory group members' perception of the use of virtual communication as a data collection tool in this research. The participatory group will discuss the drafted document of the co-produced principle and concepts that should underpin the future homecare and the roadmap to disseminate the results. The participants will be thanked for their dedication. In order to integrate the findings and maintain the participants' participation, upon completion of all the participatory discussion groups, the integrated findings will be shared with all participants via e-mail for their input.

The participatory group members would be encouraged to ensure confidentiality. They should not repeat what has been said in the group to the outside members. What will be discussed in the group should stay in the group. Use only your first names to join in the virtual meeting. There is a statement in the agreement form that is about disclosure. You are encouraged to type your initials to show that you agree with confidentiality during a participatory group.

Our research team regrets that we anticipate recruiting up to 20 people for the entire participatory groups or, as determined by data saturation of those from individual interviews. We will recruit first from those that participated in individual interviews. We will open recruitment to wider organisational members if the participants from individual interviews do not wish to join participatory group discussions. If we receive a higher number than the anticipated sample size of up to 20 people, we will enrol people on a first-come, first-serve basis until we reach the required number of people. However, one will be notified if they were unfortunately not enrolled in the study. We will still offer to share the research findings with all those who participated in the research and all those who wanted to take part but, due to higher numbers, couldn’t, if they are interested.

What are the advantages and possible disadvantages or risks of taking part? Whilst there are no immediate benefits to you, it is hoped that your participation in this research will help generate information that care providers and policymakers can use to design and develop sustainable and dignified future homecare for people at a later age. Whilst we do not anticipate any risks to you in taking part in this study, should we realise that you are emotionally moved during the interview, we will recommend you meet with your preferred health care provider if you feel you need some emotional support.

What type of information will be sought from me, and why is the collection of this information relevant for achieving the research project’s objectives? -

The information sought from you will be your perspectives, opinions, and views about how you would like your future homecare to be delivered. We will also explore your opinions and views on what you believe should be the concepts and principles for future homecare to enhance meaningful participation of older people in research.

Will I be recorded, and how will the recorded media be used? - Only with your permission you will be recorded. The participatory group discussions will be recorded. All the audio recorded will be stored in a password-protected computer, and only I will be the only one handling the recorded information. The recording will only be used for transcription. The recording will be transcribed, anonymised and will be used for data analysis. You will not be identified in any presentation of the findings because your name will not be used. None of the recordings will be played for the media or anyone outside the research team.

How will my information be managed? - Bournemouth University (BU) is the organisation with overall responsibility for this study and is the Data Controller of your personal information, which means that we are responsible for looking after your information and using it appropriately. In addition, research is a task that we perform in the public interest, as part of our core function as a university.

Undertaking this research study involves collecting and generating information about you. Therefore, we manage research data strictly in accordance with:

- Ethical requirements; and
- Current data protection laws. These control use of information about identifiable individuals but do not apply to anonymous research data: “anonymous” means that we have either removed or not collected any pieces of data or links to other data which identify a specific person as the subject or source of a research result.

BU’s Research Participant Privacy Notice sets out more information about how we fulfil our responsibilities as a data controller and your rights as individuals under the data protection legislation. We ask you to read this Notice to fully understand the basis on which we will process your personal information. Innovatedignity project is part of the Horizon 2020 pilot for Open Research Data (ORD) to improve and maximise access to and re-use research data generated by Horizon 2020 projects. Once all the required publications are published at the end of the project, the anonymised data will be deposited in the BU BORDaR and the EU repository recommended by the Innovatedignity project and be openly available for other researchers to use it. To safeguard your rights concerning your personal information, we will use the minimum personally-identifiable information possible and control access to that data as described below.

Publication - You will not be identified in any external reports or publications about the research. Otherwise, your information will only be included in these materials in an anonymous form, such as. you will not be identifiable. The study will be published in Bournemouth University Open Access Library, and articles with findings will be published in health and care journals.

Security and access controls – BU will hold your completed agreement form on a BU-password protected secure network. Personal information that has not been anonymised will be accessed and used only by right, authorised individuals and when this is necessary for the research, or another purpose identified in the Privacy Notice. This may include giving access to BU staff responsible for monitoring and auditing the study, as they need to ensure that the research complies with applicable regulations.

Further use of your information - The information collected from you may be used in an anonymous form to support other research projects in the future, and access to it in this form will not be restricted. However, it will not be possible for you to be identified from this data. To enable this use, anonymised data will be added to BU and EU's Open Access Research Data Repositories: this is a central location where information is stored and accessible to the public.

Keeping your information if you withdraw from the study - If you withdraw from active participation in the study, we will keep the information that we have already collected from or about you. This may include your personally identifiable information. As explained above, your legal rights to access, change, delete or move this information are limited as we need to manage your data in specific ways for the research to be reliable and accurate. However, if you have concerns about how this will affect you personally, you can raise these with the research team when you withdraw from the study. You can find out more about your rights concerning your data and how to submit queries or complaints in our Privacy Notice.

Retention of research data - Project governance documentation such as the completed Participant Agreements Form: will be destroyed within a month upon completion of the research. Project governance documentation such as the research database will be further prepared and anonymised more to be deposited in the BU BORDaR and European Union Open-Access Online Repository.

Research results: As described above, we will anonymise the information we have collected from you as an individual during the study. This means that we will not hold your personal information in an identifiable form after we have completed the research activities. We will keep anonymised research data for three years after the completion of my PhD and published articles. The data will later be deposited into EU Open Access for other researchers to use.

Contact for further information: If you have any questions or would like additional information, please contact; the researcher, Mavis Bengtsson(mbengtsson@bournemouth.ac.uk), or the Project Supervisor Prof Ann Hemingway (aheming@bournemouth.ac.uk).

In case of complaints, contact; Any concerns about the study should be directed to the researcher or the Project Supervisor. If the supervisory team has not answered your concerns, you should contact Professor Vanora Hundley, Deputy Dean Research and Professional Practice at Bournemouth University, by e-mail to researchgovernance@bournemouth.ac.uk.

Finally - If you decide to take part, you will be asked to file the electronic copy of this Participant Information Sheet for Participatory Group and a completed Participatory Group Participant Agreement Form. Thank you for considering taking part in this research project.

Appendix 3 Interview Participant Agreement Form

Ref: IDP002I &v2.0
Ethics ID number:34566
Date: 05042021

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

The full title of the project:

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach

Name, position and contact details of researcher: Mavis Bengtsson, Postgraduate Researcher, mbengtsson@bournemouth.ac.uk.

Name, position and contact details of supervisor: the Project Supervisor Prof Ann Hemingway (aheming@bournemouth.ac.uk)

To be completed prior to data collection activity

Section A: Agreement to participate in an interview in the study

Would you like to tell us how old you are? **Age** _______yrs. Your age is being collected to verify the age range of our participants.

If you want to sign up for participation, please choose a communication method you will prefer to use. You can choose 1 or 2 or all 3. 1 being the most preferred and 3 being the least preferred.

☐ZOOM ☐SKYPE ☐MICROSOFT TEAMS

Would you like to be contacted for the participatory group discussion? ☐Yes ☐ No

We invite you to take part in an interview using virtual communication (Microsoft teams, zoom or skype). The discussion is anticipated to take approximately 1 hr. The interview will be held anytime convenient to you from 0900 hrs. The conversation will be confidential and informal with individuals aged 50 years or above. The conversation will focus on future homecare you would like.

The purpose of the interview is to explore your opinions and views about how you would like your future homecare to be delivered. We also want to get your opinion and views on what you believe should be the concepts and principles for future homecare to enhance regular, meaningful engagement with older people

The prompt questions will be used during the interview to guide the conversation into the topic of interest. The prompts are used to maximise the opportunities for informal, detailed, and highly textured participant responses. Prompt questions will be asked dynamically, keeping in mind both the interview's objectives and the substance of the participant's previous answers. Please do not feel as though you have nothing to contribute, as we are interested in your experiences and opinions, which will add value to this research.

You should only agree to participate in the study if you agree with all the statements in this table and accept that participating will involve the listed activities.

I have read and understood the Participant Information Sheet for an Interview and have been given access to the BU Research Participant Privacy Notice, which sets out how BU researchers collect and use personal information (https://www1.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy).
I have had an opportunity to ask questions.
I understand that my participation is voluntary. I can stop participating in research activities at any time without giving a reason, and I am free to decline to answer any particular question(s).
• I understand that taking part in the research will include the following activity/activities as part of the study: ▪ Participating in an individual semi-structured interview ▪ Discussing the future homecare, I would like. ▪ Discuss how older people should be engaged meaningfully in research by discussing concepts and principles that should underpin future homecare.
• My words will be quoted in publications, reports, web pages and other research outputs without using my real name.
I understand that if I withdraw from the study, I may not be able to remove my already collected data from further use as it is anonymised. It may also be harmful to the project. My collected information will be managed in specific ways for the research to be reliable and accurate.
I understand that my data will be included in an anonymised form within a dataset to be archived at BU's Online Research Data Repository and EU Open Access Repository.

I understand that my data will be used in an anonymised form by the research team to support other research projects in the future, including future publications, reports or presentations.

	Initial box to agree
I consent to take part in an interview of the project on the basis set out above in (Section A)	

Section B: The following parts of the study interview is optional

You can decide about each of these activities separately. Even if you do not agree to any of these activities, you can still participate in the study. If you do not wish to give permission for an activity, do not initial the box next to it.

	Initial boxes to agree
I understand that taking part in the research interview will include the following activity/activities as part of the research:	
• being audio recorded during the project	

I confirm my agreement to take part in the project on the basis set out above. *(You may type your name in the block capitals again on the signature line).*

Name of participant (BLOCK CAPITALS)	Date (dd/mm/yyyy)	Signature
Name of researcher (BLOCK CAPITALS)	Date (dd/mm/yyyy)	Signature

Once an Interview Participant Agreement Form has been completed and e-mailed to me, **please file the completed electronic copy:**

- The received electronic copy will be filed in the local investigator's electronic file.

Ref: IDP002F &
Version 2.0
Ethics ID:34566
Date: **05042021**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

Participatory Group Participant Agreement Form

The full title of the project:

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach

Name, position and contact details of researcher: Mavis Bengtsson, Postgraduate Researcher, mbengtsson@bournemouth.ac.uk.

Name, position and contact details of supervisor: the Project Supervisor Prof Ann Hemingway (aheming@bournemouth.ac.uk)

To be completed before data collection activity.

Section A: Agreement to participate in the 3 participatory group meetings in the study

Would you like to tell us how old you are? Age ________yrs. Your age is being collected to verify the age range of our participants.

If you want to sign up for participation, please choose a communication method you will prefer to use. You can choose 1 or 2 or all 3. 1 being the most preferred and 3 being the least preferred.

☐ZOOM ☐SKYPE ☐MICROSOFT TEAMS

We invite you to take part in 3 participatory group meetings using virtual communication (Microsoft teams, zoom or skype). Meetings will take place anytime from 0900 hrs, and conversation is anticipated to take approximately 1 hour. I anticipate facilitating 4 separate series of participatory groups.

Participatory Group 1 (with 5 participants)
Participatory Group 2 (with 5 participants)
Participatory Group 3 (with 5 participants)
Participatory Group 4 (with 5 participants)

Each participatory group will meet 3 times and will have a maximum membership of 5 participants. The small group membership is because virtual communication will be used so that every member can be visible and have time to contribute during the participatory group discussions. The meetings will be held once every 2 weeks (3 times). The talks will be confidential and informal amongst anticipated five adults aged 50yrs or above. The discussions will focus on future homecare the participants would like.

The purpose of the first meeting will be to discuss the themes that emerged from the findings from the individual interviews, prompt questions, and views from the participants themselves.

The purpose of the second meeting will be to co-produce concepts and principles that should underpin future homecare. The findings from the first meeting of the participatory group will be used to co-produce future homecare concepts and principles to enhance meaningful participation of older people. Meeting three will explore the participatory group members' perception of the use of virtual communication as a data collection tool in this research. The participatory group will discuss the drafted document of co-produced principle and concepts underpinning future homecare.

The prompt questions will be used during the discussions to guide the conversation into the topic of interest. The prompts are constructed to maximise the opportunities for informal, detailed, and highly textured participant responses. Prompt questions will be asked dynamically, keeping in mind both the interview's objectives and the substance of the participants' previous answers.

We stress that discussions will be confidential, and that no knowledge is needed. Please do not feel as though you have nothing to contribute, as we are interested in your experiences and opinions, which will add value to this research.

You should only agree to participate in the study's participatory group discussions if you agree with all the statements in this table and accept that participating will involve the listed activities.

I have read and understood the Participant Information Sheet for a Participatory Group and have been given access to the BU Research Participant Privacy Notice, which sets out how the BU researchers collect and use personal information (https://www1.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy).
I have had an opportunity to ask questions.
I understand that my participation is voluntary. I can stop participating in research activities without giving a reason, and I am free to decline to answer any particular question(s).
I understand that taking part in the research will include the following activity/activities as part of the study: Participating in 3 participatory group discussions Discussing the future homecare I would like. Collaborate with me and co-produce the concepts and principles that should underpin future homecare. Review and comment on the drafted document of co-produced concepts and principles. Collaborate with me to co-produce a dissemination plan of the research results. Discuss my experience of the use of virtual communication for this research.
I understand that words could be quoted in publications, reports, web pages and other research outputs without using my real name.
I understand that if I withdraw from the study, I may not be able to remove my already collected data from further use in the study as it is anonymised and may be harmful to the project. My collected information will be managed in specific ways for the research to be reliable and accurate.
I understand that my data will be included in an anonymised form within a dataset to be archived at BU's Online Research Data Repository and EU Open Access Repository
I understand that my data will be used in an anonymised form by the research team to support other research projects in the future, including future publications, reports or presentations.

	Initial box to agree
I consent to take part in a participatory group of the project on the basis set out above in (Section A)	
I agree to maintain the confidentiality of the information discussed by all participants and researcher during the participatory group session.	

I understand that taking part in the research will include being audio recorded during the project.	

I confirm my agreement to take part in the project on the basis set out above.

(You may type your name in the block capitals again on the signature line).

Name of participant (BLOCK CAPITALS)	Date (dd/mm/yyyy)	Signature

Name of researcher (BLOCK CAPITALS)	Date (dd/mm/yyyy)	Signature

Once a Participatory Group Participant Agreement Form has been completed and emailed back, **please file the completed electronic copy:** The electronic copy she receives in the local investigator's electronic file will be filed.

Ref: IDP006 &
Version 2.0
Ethics ID:34566
Date: **05042021**

Appendix 4 Interview and Participatory Guide

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach

NB: This document was a guide to discuss the prompts with the participants. Simple language that the participant could understand was used. There was no use of jargon. This guide was used to prompt more follow-up questions to understand participants' story better. The participants were regarded as an expert and were involved in the research to explore the type of future homecare they wanted, co-producing concepts and principles and exploring their perception of virtual data collection. The prompts in this document were for Individual semi-structured, Participatory group discussions in co-producing concepts and principles, virtual data collection and dissemination plan.

1. Individual semi-structured interview prompts

- What are your experiences in homecare?
- "In the future, if you need care, where will you prefer to be cared for and why?"
- "Can you describe the type of future homecare you would like?

1b. Follow-up prompts from participant stories were made in individual and group discussions by paraphrasing what the participant said, and when the participant nods in agreement, I will then put a follow-up question like what do you mean?
You said**…" paraphrase" …….** what do you mean?

You said………… how did it make you feel?

You said………… how could the situation have been handled?

- Participants reflected on the current meeting.

2. **Meeting 1. Participatory group discussion co-producing future homecare concepts**

- Participants reflected on the previous meeting.
- Following this summary from individual interviews, what are your views of future homecare?
- Can you describe how you want your future homecare to be characterised and why?
- The ***1b*** follow-up prompts stage was followed by participant stories.

3. **Meeting 2. Participatory group discussion co-producing future homecare principles**

- Participants reflect on the previous meeting.
- When discussing principles, the initial question was:
  After summarising how older people described the future homecare they wanted, I then asked. Now that you have painted a picture of what future homecare should look like, can you describe what should be done to maintain that picture?
- How do you want to be involved in your future homecare?

I repeated the***1b*** follow-up prompts stage from participant stories.

4. **Meeting 3. Participatory group discussion co-producing future homecare principles**

- Participants reflect on the previous meeting.
- What are your views on the draft summarising your views on future homecare and ideas that could guide in maintaining future homecare. (Meaning concepts and principles).
- Now that you have all participated in this online research, what are your perceptions of using virtual communication for data collection?

I repeated the***1b*** follow-up prompts stage from participant stories.

Can we now reflect on whom we want to share the results with and why?

What can we use to share our results?

Thank everyone, for the tremendous job.

Ref: IDP009 & v1.0
Ethics ID:34566
Date: **30112020**

Appendix 5 Reporting and Tracking Forms

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

Enrolment log form

NB: This form must be completed when enrolling the participant. Indicate the activity that the participant is enrolled for, whether interview or participatory group or both.

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach					
ETHICS ID: **34566**					
RED I.D: **10655**					
AGREEMENT NUMBER: **813928**					
STUDY PERIOD: **19 Dec 2019 _ 17 March 2023**					
PID#	**Date PIS/PAF sent**	**Date PAF Signed**	**Interview**	**Participatory Group**	**Researcher Initials/date**

Ref: IDP010 & v1.0
Ethics ID:34566
Date: **30112020**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

Study activity log form

NB: This form must be completed when holding any research activity.

Date	PID#	Enrolment	Interview #	Participatory Group #	Participant # in PG	Reflections	Researcher Initials

Ref: IDP015 & v1.0
Ethics ID:34566
Date: **30112020**

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

Exit/withdrawal form

NB: This form must be completed when a participant withdraws or exits from the study, indicate the activities the participant had participated in. Exiting is those that completed the study meetings.

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach

ETHICS ID: **34566**

RED I.D: **10655**

AGREEMENT NUMBER: **813928**

STUDY PERIOD: **19 Dec 2019 _ 17 Mar 2023**

PID #	**Date W/E**	**Interview #**	**Participatory Group #**	**Withdrawal (W)**	**Exit (E)**

Ref: IDP012 & v1.0
Ethics ID:34566
Date:
30112020

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

Incident reporting form

NB: This form must be completed when any of the risks occur. The mitigation action that was done, to whom the incident and mitigation report was shared with and the reason for sharing the report with that authority.

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach				
ETHICS ID: **34566**				
RED I.D: **10655**				
AGREEMENT NUMBER: **813928**				
STUDY PERIOD: **19 Dec 2019 _ 17 Mar 2023**				
OFFICE REPORTED TO:				
PID #	**Incident date**	**Interview #**	**Participatory group #**	
Reporting notes				
Mitigation notes				
Date Reported		Reporting Officer (Researcher)		

Ref: IDP014
& v1.0
Ethics
ID:34566
Date:
30112020

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 813928.

Data/interview/participatory groups credibility tracking form

NB: This form is to be filled when transcripts, peer review to confirm credibility is shared with participants, peers, supervisors etc.

An exploration of older people's perspectives of future homecare in the United Kingdom and principles for its design: A participatory approach						
ETHICS ID: **34566**						
RED I.D: **10655**						
AGREEMENT NUMBER: **813928**						
STUDY PERIOD: **19 Dec 2019 _ 17 Mar 2023**						
PID#	**Date shared**	**Date Returned feedback**	**Document shared**	**Reasons for sharing**	**Sharing Researcher Initials**	**Reviewer Initials/PID#**