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An exploratory multi-case study of the health and wellbeing needs, relationships and experiences of health and social care service users and the people who support them at home in a regional area of Scotland.

HENDERSON, L.C.

2022

An exploratory multi-case study of the health and wellbeing needs, relationships and experiences of Health and Social Care Service Users and the people who support them at home in a regional area of Scotland

Louise Claire Henderson

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Acknowledgements

This thesis is dedicated to people who maintained *connection* when others were unable, during the ongoing Coronavirus global pandemic.

(Nakamura, 2020)

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“Together we can do great things.”

(Mother Teresa of Calcutta Center, 2010)

Abstract

Author: Louise Claire Henderson

Submission degree: Doctor of Philosophy

Title: An exploratory multi-case study of the health and wellbeing needs, relationships and experiences of Health and Social Care Service Users and the people who support them at home in a regional area of Scotland.

Aim: To explore the health and wellbeing needs, relationships, and experiences of Health and Social Care (HSC) Service Users and the people who support them at home in a regional area of Scotland.

Background: Current United Kingdom legislation sets a precedence of person-centred HSC that meets the health and wellbeing needs of Service Users and their families through improved experiences. Despite this, current research in the field focuses on evaluation of services and models of integrated HSC, with fewer studies investigating person-centred experiences and needs of people who use HSC.

Design & methodology: This qualitative multi-case study was designed with HSC key stakeholders. Eighteen participants were recruited across three participant groups: Service User [n=6]; Informal Carer [n=5]; HSC staff [n=7]. Service Users identified an Informal carer and HSC staff member to take part with them, creating a 'case' [n=7]. Qualitative data were collected via semi-structured interviews (December 2019 – March 2020) and principles of interpretive thematic analysis were employed to synthesise data and findings.

Main findings: Supportive relationships and interpersonal connections were instrumental in helping all participant groups to feel able to cope with their changing HSC needs and roles, promoting reassurance, information sharing, and reduced anxiety. When these connections and relationships were lacking, it negatively impacted upon Service Users' experiences of HSC. Service Users and Informal Carers wanted to connect with their local communities for support. These connections appeared more cohesive and collaborative than those with statutory NHS and Local Authority services because of their personal connections with individual community members. Supportive relationships within a community were instrumental in meeting the HSC needs of their individual members. The support that statutory services provided did not always meet the needs of the people who were accessing or providing it, and they were not always aware of the support that communities provided.

Conclusions: This study offers insight into indicators for improved HSC. Findings suggest a need to adopt Person-centred, Relationship-based HSC to encourage meaningful connections and improve experiences of accessing and providing HSC. Co-produced community-driven services that meet the needs of the people who use them, as defined by those people themselves, should be encouraged.

Keywords and phrases:

'Health and Social Care'	Experiences	Needs	Service User, patient or client	Informal Carer or family Carer
Relationship(s)	Connection(s)	Community or communities	People-centred or person-centred	Relationship-based care

List of outputs

Publications

HENDERSON, L., BAIN, H., ALLAN, E., KENNEDY, C. 2021. Integrated health and social care in the community: A critical integrative review of the experiences and well-being needs of Service Users and their families. *Health & Social Care in the Community*. 29(4), p1145–1168.

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Oral presentations

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Abbreviations

Abbreviations and their definitions

Abbreviation	Chapter of first appearance	Full text
COPD	4	Chronic Obstructive Pulmonary Disease
DN	1	District Nurse
GP	1	General Practitioner
HSC	1	Health and Social Care
HSCP	1	Health and Social Care Partnership
IHSC	1	Integrated Health and Social Care
IRAS	4	Integrated Research Application System (NHS Scotland)
ITA	4	Interpretive Thematic Analysis
PRHSC	6	People-centred Relationship-based Health and Social Care
NHS	1	National Health Service
NMC	3	Nursing and Midwifery Council
MS	4	Multiple Sclerosis
PCC	1	Person-centred Care
PPI	4	Patient and public involvement
RBC	6	Relationship-based Care
REC	4	Research Ethics Committee (NHS Scotland)
RGU	1	Robert Gordon University
SERP	4	School Ethical Review Process (RGU)
UK	1	United Kingdom

Glossary

Definition of key terms

Key term	**Working definitions for this thesis** *(Examples included in brackets)*
Community	A group of people who consider themselves as connected to each other through a shared point of interest (a geographical area; religion; caring role; medical condition).
Community-initiative group	A group of individuals from any given community who come together to support individuals to meet their wellbeing needs (a community-led foodbank service; a community-led bus service; a community-led library service).
Co-production	An equal relationship between individuals, communities and organisations who access and provide HSC, which focuses on working together to make joint decisions about the design and provision of HSC services.
Family member	An individual who is a relative of a Service User and does not provide them with support to meet their health and wellbeing needs.
Health and Social Care (HSC)	Delivery of health care services and social care services.
HSC Partnership	An organisation consisting of individuals from local authority and health care organisations that have joined together to manage and deliver HSC, in a regional area of Scotland.
HSC Staff	An individual who provides health and wellbeing support for an HSC Service User, through a contractual obligation to a health or social care organisation (a nurse; social worker; contractual Carer; physiotherapist).
Health and wellbeing	A state of physical, mental and social wellness.
Health and wellbeing needs	Anything that an individual feels they need to be physically, mentally and socially well.

Key term	**Working definitions for this thesis** *(Examples included in brackets)*
Health care organisation	An organisation that provides health care and wellbeing services (statutory National Health Service (NHS); private health care services).
Informal care	Help and support that enables the Service User to meet their health and wellbeing needs, provided without a contractual obligation (care that is given by an Informal Carer, see below definition of Informal Carer).
Informal Carer	An individual who provides support for a Service User to help them meet their health and wellbeing needs, in a non-contractual capacity (family member; neighbour, friend).
Integrated Health and Social Care (IHSC)	Care that is delivered jointly between health care and social care organisations, including third sector and community-initiative groups.
Integrated Joint Board	A group of individuals who have joined together at board-level to oversee partnership working, in a regional area of Scotland. Group membership aims to include representation from: an independent Chief officer; a financial officer; statutory HSC organisations; a General Practitioner; a third sector organisation; a Service User and a Carer.
Integration	A process in which two or more organisations, services or groups work together to support Service Users to meet their wellbeing needs (healthcare provider; local authority; third sector organisation; community-initiative group).
Key stakeholders	HSC Service Users, their Informal Carers and IHSC Staff Members.
People who access HSC	Service Users, Informal Carers and their families. N.B. In the context of this study, Informal Carers can be defined as both people who provide *and* access HSC.
People who provide HSC	HSC staff and Informal Carers. N.B. In the context of this study, Informal Carers can be defined as both people who provide *and* access HSC.

Key term	**Working definitions for this thesis** *(Examples included in brackets)*
Private sector organisation	An organisation that supports Service Users to meet their health and wellbeing needs, in return for financial gain or profit.
Service Users	Individuals who access HSC services to meet their health and wellbeing needs.
Social care organisation	An organisation that provides social care and wellbeing services (statutory local authority; community-initiative group; third-sector organisation).
Statutory Services/ organisations	Services offered by NHS and local authority organisations.
Third Sector organisation	A wellbeing organisation that supports individuals to meet their wellbeing needs, being neither in the public sector or private sector (a voluntary organisation; charity organisation; community-initiative group).

CHAPTER 1 INTRODUCTION: MY THESIS AND ME

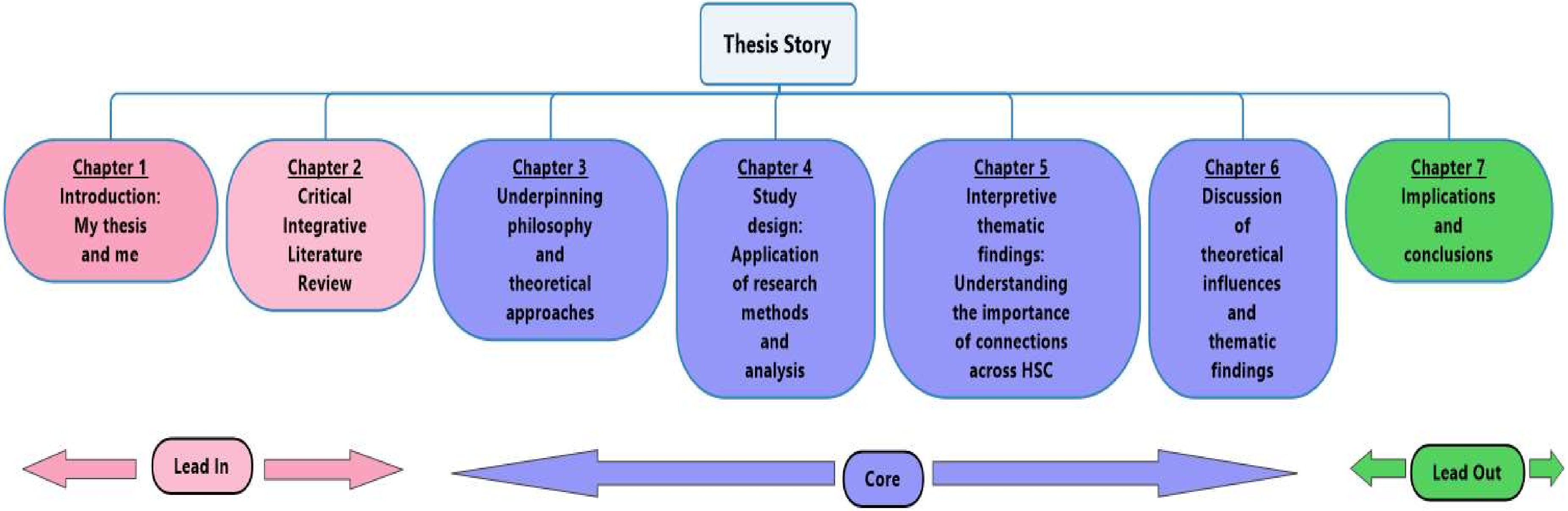
1.1 Chapter overview

Chapter 1 offers an introduction to my thesis, outlining the structure and introducing my perceptions of holism and holistic care to set the scene for this PhD research study. First, current knowledge in the field of Health and Social Care (HSC) is considered, exploring the context of HSC in Scotland and the United Kingdom (UK), against a global backdrop. Second, I place myself in this research study as a holistic individual with many viewpoints, by describing my personal background as a District Nurse, Lecturer, PhD researcher, and a member of the public who uses HSC services. I offer an outline of my rationale and motivation for embarking on this PhD study in the field of HSC. Furthermore, I consider the influence of the local context of HSC in the target region of this study, and this chapter concludes by using the information from these sections to inform the purpose and scope of this thesis.

1.2 Structure of this thesis

This section offers an overview of the structure of my thesis, which has been constructed around key topics of interest. Each topic is showcased within a chapter, collectively these chapters convey the research story. Chapters 1 and 2 set the scene, with the former exploring the background information, and the latter considering the evidence base for progressing this study through a Critical Integrative Literature Review. These initial chapters lead into the core sections of this thesis, where Chapter 3 outlines the methodologies and theories which provide a foundation for this study. Chapter 4 outlines the evidence informed aim and objectives and explores the methods chosen for data collection and analysis. Chapter 5 presents the narrative of my findings, considering data-derived typologies and offering a succinct critical synopsis; with Chapter 6 presenting critical discussion of these. Finally, Chapter 7 leads the research story in my thesis to its conclusion. It presents the implications of the findings from this study for HSC policy, practice, education and research, setting out recommendations and offering final reflexive insights to conclude (Figure 1).

Figure 1 Structure of thesis story



This study has been iteratively developed during my PhD through collaborative research practices involving members of the public and people who access and provide HSC services. I felt it important that their voices should be appreciated and incorporated to promote equality and inclusivity, on the premise of ‘no decision about me without me’ in co-produced research (Health Research Authority, 2019b; Coulter and Collins, 2011). Their contributions are conveyed across the evidence base that underpins this study’s development, its design, methods and findings. Furthermore, and in keeping with my desire to promote equality, I felt it fitting to conclude this research story by offering reflexive insights *with* members of the public and key stakeholders.

1.3 Current knowledge of HSC

This background section aims to offer an overview of some of the pertinent issues within HSC that are particularly relevant to this study and its context within the UK. To avoid repetition when presenting relevant background information, Chapter 2, Section 2.2, of my published Integrative Literature Review offers an account of the wider context of international HSC.

A close working relationship between HSC services has been advocated for many years, with a drive since the 1970’s to encourage health and care services to plan and deliver care in the UK (Cameron, 2016). Working together, across HSC organisations and sectors has been prominent in the HSC political agenda for many years, and is commonly referred to as IHSC within HSC practice, education and research (Humphries, 2015). Defining IHSC can be challenging with many explanations offered across the literature; it can be seen as a design feature of service provision, organisational structures, or as a medium for delivering person-centred care (PCC) in an efficient way (Kelly et al., 2020; Expert Group on Health Systems Performance Assessment, 2017; Goddard and Mason, 2017). However, for the purpose of adding clarity to its context within this thesis, IHSC is considered to be care that is delivered jointly between health care and social care organisations (including third sector and community-initiative groups).

As many populations across the globe are ageing, with growing numbers of people living with multiple long-term conditions, this has led to increased complexity of care provision and to rising demand for services (Care Quality Commission, 2021; World Health Organization, 2018b). IHSC services offer a potential solution to support individual citizens across these populations (Goddard and Mason, 2017). IHSC services should be tailored to the needs of the people and communities who use them, to help improve their experiences and promote health and wellbeing outcomes for the populations in which they operate (Audit Scotland, 2018; Buck et al., 2018; The Scottish Government, 2015b). If services are tailored to the population needs of their local area or region, it seems fitting that no two IHSC systems could be defined or modelled in the same way across diverse geographical locations. No single set of practices could be applicable to all international, national, regional or local contexts (Hughes et al., 2020). There is a plethora of literature containing evidence-based accounts of assessing need, planning, implementing and evaluating IHSC models to guide services and sectors in providing care, but a paucity of evidence on the experiences of those who use and deliver such services.

IHSC policies aim to promote improved experiences of HSC, both for those accessing and providing them (Hughes et al., 2020; The Scottish Government, 2015b). The reality of IHSC models, policies and guidelines is that they do not always meet the needs of people who are utilising services, leading to disjointed priorities across services and poor experiences for people who are accessing and providing them (Kozlowska et al., 2018; Thiel et al., 2013). The actuality for some people who access HSC reflects services that do not always work together to provide care in an integrated way (Henderson et al., 2021a; Bien et al., 2013). Equally, the funding and resourcing of IHSC can be disproportionate to the need and demand for services (Mackie and Darvill, 2016; Coupe, 2013). Regional and local access to IHSC can be variable, unequal and ill-suited to the needs of their citizens, reducing their access to support. Services are not always available at a time when they are felt to be needed (Smith et al., 2020; Smith et al., 2012a). Moreover, despite widespread acknowledgement in the literature that people who use IHSC should be involved in making decisions about their own care, they do not always feel as though they are (Henderson et al., 2021a).

In a bid to address such challenges, integration aims to promote greater simplicity in public services and facilitate timely, stream-lined access to appropriate HSC (Christie, 2011). Differences between health care provision in the four UK nations (Scotland, England, Ireland and Wales) appear to have exacerbated fragmentation in the way HSC services aim to meet population needs, as evidenced in the Christie Commission Report (Campbell, 2011). Furthermore, evidence points to wider European countries experiencing similar fragmented outcomes (Van Duijn et al., 2018). Autonomy of service providers and HSC systems (within specific regions) can directly impact both access to services, and variations in the ways integrated services meet the needs of respective populations (Amelung et al., 2017; Kehusmaa et al., 2012).

Within the UK, HSC policy and legislation was devolved to the respective home nations in 1999 (Kaehne et al., 2017). For all four home nations, meeting the health and wellbeing needs of individuals and their families through integrated HSC services, has been a priority of national policy since the inception of both the Health and Social Care (Community Health and Standards) Act 2003 and the National Health Service's (NHS) Reform (Scotland) Act 2004. These early legislative Acts encouraged closer scrutiny and monitoring of HSC to ensure the health and wellbeing needs of the population were met. This focus continues within current legislation which sets a precedence for collaborative PCC services, as set out in the Health and Social Care Act 2012 and the Public Bodies (Joint Working) (Scotland) Act 2014. These legislative changes are in keeping with international priorities and frameworks on integrated people-centred services, but within Scotland, the implementation and development of IHSC has been distinctly different from other UK home nations (Elliott et al., 2020; World Health Organization, 2016a).

In England and Wales, the scope of integration has been challenging, placing the onus on the NHS. Sustainability Transformation Partnerships in England provided autonomous and competitive health care, but more recently, there have been moves towards Integrated Care Systems that shift the focus towards local populations and collaborative improvement of HSC instead (Charles, 2021). These Integrated Care Systems do not currently hold any statutory authority, but there are plans to revise this stance in 2022 (Charles, 2021; Department of Health and Social Care, 2021). Whereas, in Wales, the NHS and local authorities were told they could merge in the event of poor HSC practices, without any stipulation to integrate otherwise (Kaehne et al., 2017). Despite this, integrated Local Health Boards and statutory Regional Partnerships have been set up across Wales and are tasked with planning a 'whole system' approach to HSC (Welsh Government, 2021; Welsh Government, 2019). Both Scotland and Northern Ireland appear to have embraced the nature of joint working through a collaborative approach to IHSC. In Northern Ireland, all regulation, funding and delivery of IHSC is integrated between HSC sectors (Kaehne et al., 2017). In Scotland, similar revisions to the delegation of funding for IHSC have offered a fresh commitment to meeting the needs of individuals and their families through integrated services (Baylis and Trimble, 2018a; Baylis and Trimble, 2018b).

IHSC in Scotland promotes the delegation of funding to 30 Integrated Joint Boards (IJB), with one further area choosing to elect a lead-agency approach instead (where one statutory body has been tasked with leading the other). Each was introduced to progress changes in legislation and they are tasked with translating those changes into HSC practice (Kaehne et al., 2017; The Scottish Government, 2015a). Each IJB has a Chief Officer who is appointed to a 'third seat' at the IHSC proverbial table. The Chief Officer represents neutrality in the IJB, with no affiliation to health or social care agendas; thus, ensuring the IJB partnership focuses on a cross-sectoral vision (Baylis and Trimble, 2018b). The Scottish Government (2015c) explain each IJB has autonomy for HSC spending in their local area. Furthermore, to facilitate the operational delivery of integrated services to meet local population health and wellbeing needs, Health and Social Care Partnerships (HSCP) have been introduced. Many IJB areas have more than one HSCP in their region, each with an integration strategy to outline how population health and wellbeing needs in their area will be met (Burgess, 2016). They use the Scottish Government's National Health and Wellbeing Outcomes to inform their delivery strategies, incorporating overarching themes around quality, safety, and improved Service User experience (The Scottish Government, 2015b). These outcomes provide the foundation for meeting Service User needs through integrated HSC across Scotland, with strong focus upon the importance of improving the quality and experiences for Service Users, those who care for them, and their families.

Putting people at the centre of HSC decision-making was seen as a ground-breaking shift in service provision that moved towards user-led improvements in the quality of HSC (Department of Health, 2007). This shift was subsequently legislated in the Health and Social Care Act 2012, acknowledging an existential global drive towards integrated ways of working within IHSC systems. They also advocated cross sectoral working between citizens, communities, third and private sectors, and statutory HSC services. IHSC aims to encourage a culture of 'co-produced' services, encouraging an equal partnership between these groups to make joint decisions about HSC (Feeley, 2021; World Health Organization, 2018b; Vennik et al., 2016; Loeffler et al., 2013). It has long been recognised that public involvement in HSC decision making is valuable to service provision and planning, facilitating input into services they will be accessing and promoting a distinctive focus upon their human rights (Beart, 2011; World Health Organization, 1978). Furthermore, it adds substance to the importance of Service User feedback in quality assessment and improvement within HSC (Jones et al., 2021). As such, co-production has been acknowledged as one of the principal foundations in public policy, promoting inclusion, equality and access to HSC, and encouraging citizens to actively participate in the provision of care in their own communities (Osborne et al., 2016).

The impact of this change has been realised in relation to Service User influence over the effectiveness and the quality of services (Foot et al., 2014; Haines and Warren, 2011). Using the experiences of Service Users to decipher health and wellbeing outcomes is recommended by many (Asmoredjo et al., 2017; Teale and Young, 2015). Their input is valuable in reviewing the quality of services, promoting a better understanding of the impact of service changes (Parahoo, 2014). Incorporating the experiences of those who use and deliver HSC in integrated improvement initiatives, can be helpful in promoting development and innovation that is relevant to current practices. With this in mind, and a clear understanding of the contextual background information of IHSC, the next section considers my place in this thesis as the researcher, and the overarching purpose and scope of this study.

1.4 Placing myself in this thesis: rationale, motivation and context of this study

This section explores my rationale for undertaking this study within HSC and considers my professional background, to build a holistic picture of me as the researcher in this study. Including an account of self can help to offer contextual information, promoting an understanding of potential influences over my thinking and insight into the rationale for decisions made in this study (Rosenblatt, 2016). Furthermore, in the interest of promoting transparency around other external influences, the context of HSC provision in the area where my research was conducted, details of funding and sponsorship are also included within this section.

1.4.1 My professional background

My motivation for exploring the experiences of people who use and deliver HSC in the community has developed over many years' experience of nursing practice. My passion for community practice was realised during my initial nurse training. Although I sought to maintain an open mind throughout my student nurse placements, when undertaking my final third-year community placement in 2002, I instantly knew it was the perfect fit for me. My perception at the time was that District Nurses (DNs) were privileged to have an increased opportunity to have repeated contact with the people they were supporting in their own real-world environment. This was in direct opposition to my perceptions of a nurse's contact with people in a hospital setting, where I perceived a strong focus on medical task-orientated contact with Service Users and their families and little opportunity to acknowledge or understand their world within their wider communities.

For many of the people receiving DN support, their contact with staff was long-term, for example, accessing PCC for bi-lateral lower leg dressings that may take some time to heal, or palliative care over the last months of a person's life. Not only that, supporting individuals, Informal Carers, families and the communities around them, was also a large part of the Community Nurse role. I liked utilising a wide variety of nursing skills to provide this holistic care and support for individuals and those around them. I was strongly attracted to the opportunity to get to know people who were using the service, with opportunities to develop a deeper level of relationship whilst supporting them at home. Furthermore, the multi-agency nature of providing community support was something that appealed to me, enjoying the opportunity to work with others to strive for best outcomes for the individual and those who supported them at home. 'Integration' was a relatively new concept in community practice at the time, relating predominantly to statutory NHS and local authority organisations (circa. 2002). Discussions between these two organisations (in the areas where I worked at the time) reflected two computer systems (one in community health care and one in community social work), that would 'speak to each other' to reduce duplication and improve information sharing between the two organisations.

Satisfied that District Nursing was the right choice for me (albeit somewhat oblivious to the significance of shifts in thinking within provision of community services), I quickly identified the best route into community practice and took steps to secure a post-registration Community Staff Nurse role. However, to my great disappointment, I was told as a pre-registration nurse I would not be able to work in a community setting until I had gained some experience in a hospital setting. Two years post-registration experience and progression to a senior level was the industry standard in my local areas at the time. However, I was given a glimmer of hope through advice to join the Community Nurse Bank as an Auxiliary Nurse (whilst I was still training) to gain valuable experience in the community before registering as a Staff Nurse. As a result of gaining experience in the community at the point of registration, I was able to work in the community as a Bank Staff Nurse upon qualifying. In addition, and to gain the widest range of experience possible within the obligatory two-year waiting period, I took on a rotational substantive post in the Medical Directorate within the local hospital, progressing to a Senior Staff position within eighteen months.

At this juncture I was fortunate to secure a full time DN studentship through my local NHS Board, qualifying in 2006 with a BSc in Community Health (DN) and taking on a caseload in a city location. However, as I continued to work there, I realised I was particularly drawn to rural DN services. I liked the sense of community that I felt when working in these areas. I had been placed in a rural town when training to become a DN and had predominantly undertaken Nurse Bank shifts in similar locations. Furthermore, I felt uneasy about impending changes that were to be made to the way community services were delivered.

Within the city, DNs were to be aligned to direct-delivery teams covering specific geographical 'cluster' areas. Each cluster and its staff covered multiple General Practitioner (GP) practices across the city, rather than being aligned to one local GP surgery and supporting people who were registered there (regardless of their location). Whilst I understood that clustering DN caseloads by geographical location might be more efficient for planning home visits by reducing travel time, I felt this could have an impact on forming meaningful in-depth relationships with people I would be supporting. Not only that, but I also perceived the potential for a negative impact on my working relationships with colleagues in a GP surgery. The close multidisciplinary way of working had been one of the elements that had initially attracted me to District Nursing, and I was apprehensive this might be stifled in a direct-delivery team. Therefore, I became a DN in a rural location, where moves to geographical 'cluster' areas for care were not planned. I worked across rural town and country locations and took on additional unplanned care duties, in a District Night Nursing and Weekend Nursing Service, to widen the scope of my experience.

After working for several years in this role, the opportunity to join a specialised neurological nursing team presented in 2010. I welcomed this move and became a Parkinson's Specialist Nurse, covering a wider regional area. This post was particularly appealing because I felt it offered greater opportunities to build up relationships with people who accessed the service, in comparison to my DN role. Furthermore, it offered a new challenge of delivering structured teaching sessions to student nurses in their practice education programme, which quickly came to be one of the most rewarding parts of my role. However, perhaps more significantly, not being immersed in local HSC services heightened my awareness of how multiple agencies worked together (or not) across the region. It broadened my understanding of the emerging IHSC landscape, and the impact this was having upon staff and people who accessed HSC services.

Wider exposure to the different ways statutory, third sector and private sectors were working together for people with Parkinson's was of great interest to me. I could see the benefits of improved experiences for people who accessed HSC when multi-sectoral organisations worked together well. However, I surmised that working together across HSC did not always go well, and when it did not it could prove detrimental to the individual's care. In my experiences of working with multiple cross-sectoral organisations, I encountered poor communication and disjointed expectations (about HSC practices) between HSC providers and the people who were accessing them. For example, health care organisations were not always aware of third sector services that were available to support Service

Users to meet their health and wellbeing needs. Furthermore, sharing information (about Service Users and their needs) was often lacking between social care and health care organisations.

The advent of legislative changes towards integrated HSC in Scotland, in the Public Bodies (Joint Working) (Scotland) Act 2014, coincided with my move to Robert Gordon University (RGU). For me, this new legislation sparked a reinvigorated interest in how different organisations were working together across HSC. With my recent move to academia, I was reinvigorated towards promoting the translation of HSC policy into community practice through education. I sensed there was a level of disparity between policy and practice and wanted to help bridge the gap between the two. In my past clinical roles I had felt as though I was far-removed from the policies that were implemented at an executive and governmental high-level. In my earlier career, I had struggled to see how these policies could be incorporated into my daily practice. However, I was clear that I wanted to support student nurses and other HSC practitioners to employ knowledge and principles of policy in their IHSC practice, to the benefit of those who were using their services.

Whilst teaching in the Health in Primary Care module (undergraduate nursing programme at RGU), I closely followed the strategies and plans HSC providers compiled to progress this new legislation. I endeavoured to help students better understand HSC strategies, and link associated guidelines to their own practice. However, at times, I questioned the evidence-base that supported some of these proposed guidelines. For example, when the National Health and Wellbeing Outcomes (The Scottish Government, 2015b) were published, I was particularly interested in how these had been formulated. This framework provided a backdrop for the strategies employed within each HSCP area across Scotland, shifting the focus of HSC from input and process measurement to a human rights-based approach centred on outcomes for individuals.

Key drivers for me in progressing this study related to principles of co-production, my own quest for further knowledge and a deeper understanding of IHSC. It was clear to me the Government had asked citizens of Scotland to help them produce the National Health and Wellbeing Outcomes, accessing their feedback via the National Health and Care Survey (The Scottish Government, 2014). However, I was curious to develop my understanding of an evidence-base that could further support or question these. I wanted to know more about the person-centred needs of people who were utilising IHSC, their experiences when accessing it and the relationships they had with people who supported them.

This document, along with my own experiences of HSC, acted as a catalyst for my interest in how people who access and provide HSC experienced it. Being clear on my key drivers for progressing this study, the next section places me, as a holistic individual, in this study.

1.4.2 Me, as a holistic individual in this study

My motivation for this study has been developed from my initial drive to investigate the evidence-base for people working together across HSC systems. This has been further fuelled by my desire to explore how HSC services might be improved to achieve the best outcomes for those using them. I wanted to better understand how integration had affected the people who were using HSC, what the impact had been for them, and what integration meant to *them*.

My DN background described above has directly influenced my resolve to investigate experiences of HSC. Originally, I planned only to consider those who used HSC services to maintain their health and wellbeing; for the purpose of this thesis I will refer to this group of people as Service Users. However, upon reflection and in acknowledgement of the influence that relationships had on my own experiences of HSC practice (Section 1.4.1), I felt it was fitting to also include those supporting Service Users, for example, Informal Carers or IHSC Staff Members.

1.4.3 The context of HSC within the region of the study

As discussed in Section 1.3 above, the provision of HSC across the UK can differ greatly. My intention was to collect data from one regional area of Scotland that incorporated a variety of different geographical divides across multiple HSCP locality areas. This study is set across an area where there are three HSCPs in a singular region. To promote the transferability of this study, HSC provisions within these HSCPs are outlined in bullet points below. Thereafter, the strategies employed within each HSCP area to meet the needs of their respective populations are outlined and differences in their strategies are also considered.

- HSCP 1 covers a vast geographical area that is largely rural in nature. There are a number of socio-economically diverse towns, with the population in the largest one town being circa 19,000 citizens. There are many small villages and remote rural locations in the area. There are several community HSC facilities within the boundaries of HSCP 1. They offer satellite services that are connected to wider main-stream HSC services in HSCP 2, in addition to stand-alone local HSC services. People living in HSCP 1 often travel to HSCP 2 to access wider main-stream HSC services if the HSC service they need to access is not available locally and/or a clinical need is identified.

- HSCP 2 covers a large city (circa. 207,000 citizens), including urban and suburban areas, and a small amount of some smaller outlying rural villages. It has a large HSC presence at the heart of the urban area, with further smaller HSC facilities across the area. HSCP 2 is socio-economically diverse, which is more pronounced in the inner urban areas of the HSCP.
- HSCP 3 covers a wide socio-economically diverse geographical area, including a very large town (circa 23,000 citizens), smaller villages and remote rural locations. The large town houses central HSC services that provide support across the HSCP area, with further smaller HSC facilities being located in some of the outlying areas. However, it is not uncommon for people living in HSCP 3 to travel to HSCP 2 to access wider main-stream HSC services, if they are unavailable locally and/or a clinical need is identified.

Focusing this study on a regional area with three HSCPs offered the opportunity to consider differences between the ways in which each HSCP area aimed to meet the needs of the people within their geographical areas. Each HSCP has introduced their own individual delivery strategy that aims to meet the needs of individuals and communities. These strategies emphasise each HSCPs commitment to providing PCC at a time when it is needed, and prevention of ill health by empowering resilient individuals and communities who support their members as their health and wellbeing needs change. In the interest of offering further relevant contextual information in each HSCP area of the study, I have summarised the key points of interest from each strategy below (Table 1).

Table 1 Key points of interest from HSC strategies in this study

	HSCP 1	**HSCP 2**	**HSCP 3**
Vision Values/ aims	To build a person's abilities, through high quality PCC, to enhance their wellbeing in their community setting. Promoting the 5 strategic priorities below (shaped with citizens) help the IJB make decisions about HSC provision.	A caring partnership that works in and with communities to enable people to fulfil healthier lives. *Aims:* Prevention; resilience; personalisation; connections; communities.	Working together as equal, valued partners to promote health and wellbeing, at all ages. *Aims:* Dignity; respect, PCC; compassion; safety; efficacy and responsiveness.
Delivery plans/ priorities:	• Prevention and early intervention. • Reshaping care. • Engagement. • Tackling inequalities & public protection. • Effective use of resources at the right time.	• Working together for positive health outcomes. • Helping people to cope with changing health and wellbeing. • Right care at the right time. • Developing meaningful community connections and relationships. • Help communities to support each other.	• Encouraging people to take responsibility for their own health and wellbeing. • Supporting people at home (or homely setting) where possible. • Encouraging people to take control over decisions affecting their care.

Each strategy aims to encourage collaborative ways of working, taking account of individuals’ own health and wellbeing needs and those of the communities in which they live, to promote healthy lifestyles. Furthermore, they incorporate a focus upon improved experiences for people who are utilising HSC and the people who support them. These strategies offer a similar vision, aims and values. However, there are some subtle differences in the perspective from which they have been written, with one highlighting how the IJB will use the strategy to help *them* (the IJB) make decisions about HSC. Although members of the public and people who used HSC were involved in developing the priority areas across all three HSCP areas, this could give the impression that they are not always involved in making vital operational decisions about HSC.

1.4.4 Considering my existing knowledge of influential HSC theories

Although I did not identify any specific theoretical frameworks to inform my research from the outset of this study, to present a holistic picture of myself and promote transparency it is important to offer an account of my previous knowledge of influential theories. As acknowledged above (Section 1.3), one of the central aims of IHSC was the provision of PCC with each HSCP area actively promoting its principles in their strategies (Table 1). Acknowledging my previous exposure to PCC and its application to IHSC allowed me to capture and recognise my position in this thesis and distinguish how this might influence my thinking. I anticipated (in the development stage) participants would outline their experiences and my default might be to compare these to my previous knowledge of PCC. However, this recognition helped me to realise it was not up to me as the researcher to determine if their experience had been person-centred or not. Furthermore, it strengthened my resolve to allow the participants’ data to inform the theoretical backdrops of this thesis during my analysis and interpretive processes. To that end, these data suggested a need for a blended approach to the theoretical underpinnings. My understanding of PCC and other influential theories are explored, applied and blended throughout this thesis, being particularly prominent in Chapters 3, 5 and 6.

1.4.5 Funding and sponsorship

In the interest of promoting further transparency and integrity in ethical research conduct, in line with the declaration of Helsinki from the World Medical Association (2013), the funding for this PhD has been provided through an agreement between RGU and an NHS provider organisation. This has been in the form of a PhD studentship stipend payment from the NHS organisation and sponsorship of course fees by the School of Nursing, Midwifery and Paramedic Practice at RGU.

It is important to highlight these sources of funding to acknowledge their influence in this study. In keeping with my drive to help those working in HSC to translate knowledge generated in this study into their practice (Section 1.4.1 above), I conducted this study in the region where NHS funding was awarded. I wanted to produce an in-depth exploration of participants' experiences that would inform development of IHSC services. To promote clarity and transferability of the findings from this regional area to other IHSC areas, detailed description of the context of IHSC in the region is clearly outlined in Section 1.4.3, being further explored in Chapter 4 (Section 4.6.1). Current knowledge outlined above, along with my experiences and the context of HSC provision in the HSCPs across the region, informed the development of the overarching purpose of this study, which is outlined in the next section.

1.5 The purpose and scope of this thesis

The purpose and scope of this thesis have been informed by the background information offered above, my rationale and motivation, with the influence of my professional background and the relevant context of HSC in mind. The extent to which these experiences are relevant to current HSC policy, practices and research is widely acknowledged in current literature above. Many HSC organisations across a variety of sectors are clear that experiences of those who use and deliver services can be informative, accessible and valuable in improving quality of care and research (National Institute for Health Research, 2021a; UK Public Involvement Standards Development Partnership, 2019a; Burt et al., 2017; Tefera et al., 2016; Howie et al., 2014; Lehrman et al., 2014). To that end, the overarching purpose of this study is to explore and better understand the health and wellbeing needs, relationships and experiences of people who access HSC and the people who support them at home.

1.6 Chapter summary

This chapter has outlined the structure of my thesis, explored relevant background information and offered an account of my own HSC experiences. These should be acknowledged as influential in the progression of my thinking, this thesis and my conduct in this research study. I have offered a clear working definition of IHSC for the purpose of this study and outlined the context of how it is delivered in the region where it was conducted. Background information clearly indicates there is a need for greater involvement of those who use IHSC, in planning, organising, delivering of services. There is an abundance of evidence that explores appropriate models of IHSC across different contexts. Equally, there is widespread recognition of the value in using experiences of people who access IHSC to inform and improve services. In conjunction with the background information, my own experiences of working within HSC have motivated me to explore experiences, needs and relationships of people who use and deliver it. In the next chapter, I will develop the abovementioned purpose and scope of this study, using them to inform a scoping review and subsequent Integrative Literature Review, which explores the evidence-base for progressing this study.

CHAPTER 2 CRITICAL INTEGRATIVE LITERATURE REVIEW

2.1 Chapter overview

Chapter 2 of this thesis explores the Critical Integrative Literature Review evidence base that builds upon the purpose and scope of this study (Section 1.5). This review has been blind peer reviewed by scientific peers and published in a leading journal within the field of IHSC. It is entitled 'Integrated HSC in the community: a critical integrative review of the experiences and well-being needs of Service Users and their families' (Henderson et al., 2021a). This review builds on previous literature in the field (Section 1.3) that highlighted gaps in knowledge around the experiences of people who use HSC services, with many papers focusing on implementing policy and integrated ways of working. There was a lack of scientific evidence exploring the needs of people who use IHSC services, as defined by the people themselves. In summary, this review emphasises the importance of communication between stakeholders to promote collaborative IHSC practices; the importance of relationships in HSC; the negative effects fragmentation of services can have on health and wellbeing and highlights a need for further research in these areas.

To capture further research that was published after conducting this review, papers published since April 2018 are also considered, and questions that arose from the literature review are outlined. Current knowledge in the field (Section 1.3), findings of this integrative review and subsequent key evidence, along with feedback from the public, collectively informed a preliminary research question that was meaningful to people who use and deliver HSC services. Finally, this chapter concludes by summarising a preliminary aim and objectives for this study, to inform the following methodology chapter and appropriate application of research methods and analysis.

The text that follows in Sections 2.2 - 2.8 has been published as outlined below. There have been minor amendments since publication: Section 2.6 is a new addition; Section 2.3.2 has additional information about inclusion and exclusion criteria, and information about the nature of research methodologies has been added to the Table of Evidence in Appendix 1.

HENDERSON, L., BAIN, H., ALLAN, E., KENNEDY, C., 2021a. Integrated Health and Social Care in the Community: A critical integrative Review of the Experiences and Well-being Needs of Service Users and their Families. *Health & Social Care in the Community*. 29(4), pp. 1451–1168. DOI: https://doi.org/10.1111/hsc.13179.

2.2 Review introduction

Over the past decade, an increased focus on the way that IHSC services are delivered and a growing demand for improved Service User experience have driven forward improvements in worldwide HSC (World Health Organization, 2016b). Person-centred IHSC systems aim to follow principles of participatory care and governance, which are coordinated around Service User needs. These systems and strategies offer a balance between population health and wellbeing and ill-health prevention (World Health Organization, 2016a; Marks et al., 2011). Internationally, IHSC interventions aim to include meeting individuals' needs, disease-specific interventions and IHSC that spans across population health (World Health Organization, 2016b).

Across Europe, countries are at different stages of integrating their HSC services, with the common goal of delivering better outcomes of care through collaborative working (Expert Group on Health Systems Performance Assessment, 2017). IHSC services take many different forms to improve population health, with varying levels of coordination across geographical boundaries (Wodchis et al., 2015; Robertson et al., 2014). A lack of understanding of organisational cultures, repeated complex structural changes and ineffective communication are common barriers in IHSC (Mason et al., 2015; Burgess, 2012). These issues can impact upon the experiences of people who use IHSC, their families and professionals involved in their care, resulting in unmet needs (World Health Organization, 2015a).

The aim of this integrative literature review was to explore the experiences of people who access IHSC services and their health and wellbeing needs. The overarching research question for this review asked, 'what are the health and wellbeing needs and experiences of people who use IHSC?'. For the purpose of this review, key terms and stakeholders in IHSC were defined and agreed by the reviewers (Table 2). Specific exploratory questions of the literature were constructed and iteratively refined to expand upon the overarching research question. Questions of the literature highlighted areas of researcher interest around experiences of IHSC and how people met their health and wellbeing needs through access to and utility of IHSC, in the context of a home setting (Table 3).

Table 2 Agreed key terms and stakeholders in IHSC

Key term/stakeholder	Definition
Home	A permanent residential environment.
Health and wellbeing needs	The needs that when met enable people to live healthier lives and feel well.
Integrated health and social care (IHSC)	Where two or more organisations, across two or more sectors, work together to deliver health and social care wellbeing services, (e.g. healthcare sector; social care sector or third sector, including community groups)
Service user	Individuals who access IHSC services to meet their health and wellbeing (health and wellbeing) needs.
Informal Carer	An individual who provides help and support for a Service User, which enables the Service User to meet their health and wellbeing needs, in a non-professional or non-contractual capacity (e.g. family member; neighbour, friend).
IHSC Staff Member	An individual who provides health and wellbeing support for an IHSC Service User, through a contractual obligation (e.g. a nurse; social worker; paid Carer; physiotherapist).

Table 3 Research question & questions of the literature

Overarching research question	
What are the health and wellbeing needs and experiences of people who use IHSC?	
Questions of the literature	**Rationale**
1. How do people access IHSC at home?	To explore how people connect with health and social care that is delivered in an integrated way, in a home environment.
2. What do people, who utilise IHSC at home, perceive as their health and wellbeing needs?	To explore perceived health and wellbeing needs, as defined by people who access IHSC services.
3. How do people meet their health and wellbeing needs through their utility of IHSC?	To explore how access to IHSC can help people to meet their health and wellbeing needs.
4. What are the experiences of people who access and receive IHSC at home to meet their health and wellbeing needs?	To explore the experiences of people who utilise HSC to meet their health and wellbeing needs.

2.3 Review methods

2.3.1 Design

A critical integrative review methodology was used to guide the review process (Murray, 2017; Oliver, 2012). Review methodologies that favour quantitative analysis were considered. For example, systematic reviews that focus primarily on experimental studies to investigate a specific intervention for a clinical problem (Whittemore and Knafl, 2005). However, researchers anticipated that evidence that was relevant to the research questions and the phenomenon of interest, may be diverse in nature. As integrative review methodology advocates the inclusion and analysis of both experimental and non-experimental studies to explore perspectives of a phenomenon in depth, it was judged to be the most appropriate methodological approach for this review (Souza et al., 2010; Whittemore and Knafl, 2005).

Rigor in the review process was enhanced by monthly meetings of the review team and by following an ‘integrative review framework’ (Whittemore and Knafl, 2005). This integrative review framework included several steps; namely, identifying the research problem; literature search; data evaluation; data analysis and presentation of the findings. A PROSPERO protocol was published to outline the intentions of the research team in conducting this review and to promote objective reporting of findings (Henderson et al., 2018b; Sideri et al., 2018; Booth et al., 2012). Key stakeholders were offered an opportunity to express their views on the aim, review questions and scope of the review via a focus group (Boote et al., 2011). Additionally, stakeholders were also asked to offer their comments on interpretation of preliminary review findings, via a workshop seminar (Boote et al., 2011). Key search terms, topic focus and contextual settings for this review were iteratively refined as a result of their feedback (Kreis et al., 2013; Boote et al., 2011).

2.3.2 Identifying relevant studies

Search Strategy

To ensure that this literature review would be sensitive to picking up studies pertaining to relevant IHSC services, an initial scoping search was performed in October 2017 using a PICo framework (Moule et al., 2017) (Table 4). Subsequently, key terms were revised by researchers and the fields in which they were employed were iteratively refined within the search strategy (Table 5).

Table 4 Scoping search terms

Population	“Patient($)” OR “Client($)” OR “Service User($)” OR “individual($)” OR “staff” OR “employee($)” OR “healthcare worker($)” OR “manager($)” OR “Carer($)” OR “relative($)” OR “family($)”
Intervention	“Health and Social Care” OR “health and social care partnerships”
Context	“Experience($)” OR “perception($)” OR “attitude($)” OR “view($)” OR “feeling($)” OR “health outcome($)” OR “outcome($)” OR “health and wellbeing outcome($)” OR “healthier life” OR “healthier lives”
Language	English
Databases	CINAHL; MEDLINE; AMED; TRIP over a ten-year period
Timeframe	Jan. 2007- Dec. 2017

Table 5 Search strategy

Search strategy	
Population	(Patient* OR client* OR “Service User*” OR individual* OR staff OR employee* OR “healthcare worker*” OR manager* OR Carer* OR relative* OR famil*)
AND	
Intervention	((integrat* OR amalgamate* OR partner* OR join* OR merged) AND (health OR healthcare OR “health care” or health-care) AND (“social care” OR “social work” OR care))
AND	
Context	(Experience* OR perception* OR attitude* OR view* OR feeling* OR outcome* OR “healthier li*” OR needs OR model*)
AND	
Setting	(primary OR community OR home)
Filters	
Language	English
Databases	CINAHL; MEDLINE; AMED; TRIP; Web of Science; Science Direct
Timeframe for search	1st March 2018 and 30th April 2018
Field	By title (after abstract field limiters produced excessive results)

The search for this review was performed across six digital databases between March 2018 and April 2018. Employing filters by abstract, language, timeframe and field initially generated excessive results that could not be screened meaningfully. These results largely appeared to relate to integration of a specific specialist health service into a wider health care service, which was not concurrent with the aims of this review. As researchers had iteratively refined the search terms throughout the scoping review process and were satisfied that these terms were appropriate for the purpose of this review, search fields were reconsidered (Hewitt-Taylor, 2017; Oliver, 2012). Filtering field by ‘Title’ generated more specific results that were relevant to the wider context of IHSC services and the aims of this review.

Inclusion and exclusion criteria

To ensure that the search was rigorous and transparent, inclusion and exclusion criteria were agreed (Table 6) and underpinned by the agreed definitions of key stakeholders in IHSC (Table 2). Empirical studies were included to ensure that the review was based on empirical research data (Snyder, 2019; Xiao and Watson, 2019). Although systematic reviews can be classed as original research, they were excluded to reduce the possibility of repeated data points. Instead, they were employed to frame key issues from the data in the discussion and background sections of this review (García-Perdomo, 2016). To mirror the researchers' particular area of clinical interest, inclusion criteria were based on the context of IHSC in a home setting. To reflect the context of a community setting, all papers that solely related to acute hospital-based services were excluded. Included papers were also required to relate to one or more of the following four questions asked of the literature. Namely, the experiences of people who use IHSC (Service Users, informal Carers and their families); access to IHSC services; perceptions of health and wellbeing needs, or utility of IHSC services to meet health and wellbeing needs. Papers that were not published in English were excluded.

Table 6 Inclusion and exclusion criteria

Exclusion Criteria	
Sources	Books; Grey Literature.
Language	Papers published in languages other than English.
Timeframe	Papers published before 2007.
Geographical Location	Nil.
Types of Studies	Secondary research; Systematic reviews.

Types of Interventions	• Papers which outline 'Integration' that refers to the integration of one specific specialist service [e.g. specialist cancer service; specialist mental health service; specialist stroke service], into a mainstream generalised healthcare service [e.g. integration of a specialist mental health service to mainstream older adult healthcare]. • Studies relating specifically to in-patient hospital health care setting.
Types of Participants	Children under the age of 18.
Types of Settings	Acute care; tertiary care; secondary care.
Inclusion Criteria	
Sources	Primary research; published in peer-reviewed journals.
Language	English language papers only.
Timeframe	Publication date 2007 – 2018.
Geographical location	All geographical areas included.
Types of Studies	For the purpose of this review, 'Integrated Health and Social Care' is defined as 'two or more organisations, each from a separate sector, working together to deliver health and social care wellbeing services (e.g. healthcare sector; social care sector or third sector, including community groups)'. Included papers will explore one or more of the below points: • Two or more wellbeing services delivered across two or more sectors (e.g. healthcare organisation, social care organisation, third sector organisation or community group) that are delivered in an integrated/amalgamated/joined/ merged way ('integration'). • Individual and/or family and/or Carer's and or staff experiences of integrated health & social care (HSC). • Individual and/or family and/or Carer's and or staff perceptions of health and wellbeing needs. • Focus on primary care, community or home setting.

	• Service user/family utility of integrated services to meet health & wellbeing needs. • Access to ’integrated’ HSC services, for individuals and their families.
a) Types of Interventions	All integrated delivery of health and social services.
b) Types of Participants	Adult’s aged 18 and over who access or deliver health & social care services.
c) Types of Context	• Experiences/perceptions/attitudes/views/ feelings. • Health and wellbeing needs. • Models of integrated health & social care to meet health & wellbeing needs.
d) Types of Settings	Community, primary care and home.

2.3.3 Quality Appraisal

A triangulated approach was adopted to appraise the quality of each paper and facilitate systematic comparison of included studies. First, papers were subject to screening assessment questions, enabling early identification of those relevant to key areas of interest. Second, the quality of evidence was appraised using the Critical Appraisal Skills Programme (CASP) framework (Critical Appraisal Skills Programme, 2018a; Critical Appraisal Skills Programme, 2018b). CASP appraisal frameworks offered rigor to meaningful representation of the quality of each source. Each CASP quality appraisal was tailored to the qualitative data or quantitative methodological nature of the evidence (Hopia et al., 2016; Whittemore and Knafl, 2005). For papers using a mixed methodology, both qualitative and quantitative quality appraisal tools were utilised to maximise rigor in quality appraisal (Creswell and Plano Clark, 2018; Miles and Gilbert, 2006). Furthermore, each paper’s original contribution to the academic and clinical fields of practice were also deliberated, with a final decision highlighting any intended progression to data extraction. All quality assessments were carried out by the lead researcher with a selection of assessments also being reviewed by the wider supervisory team.

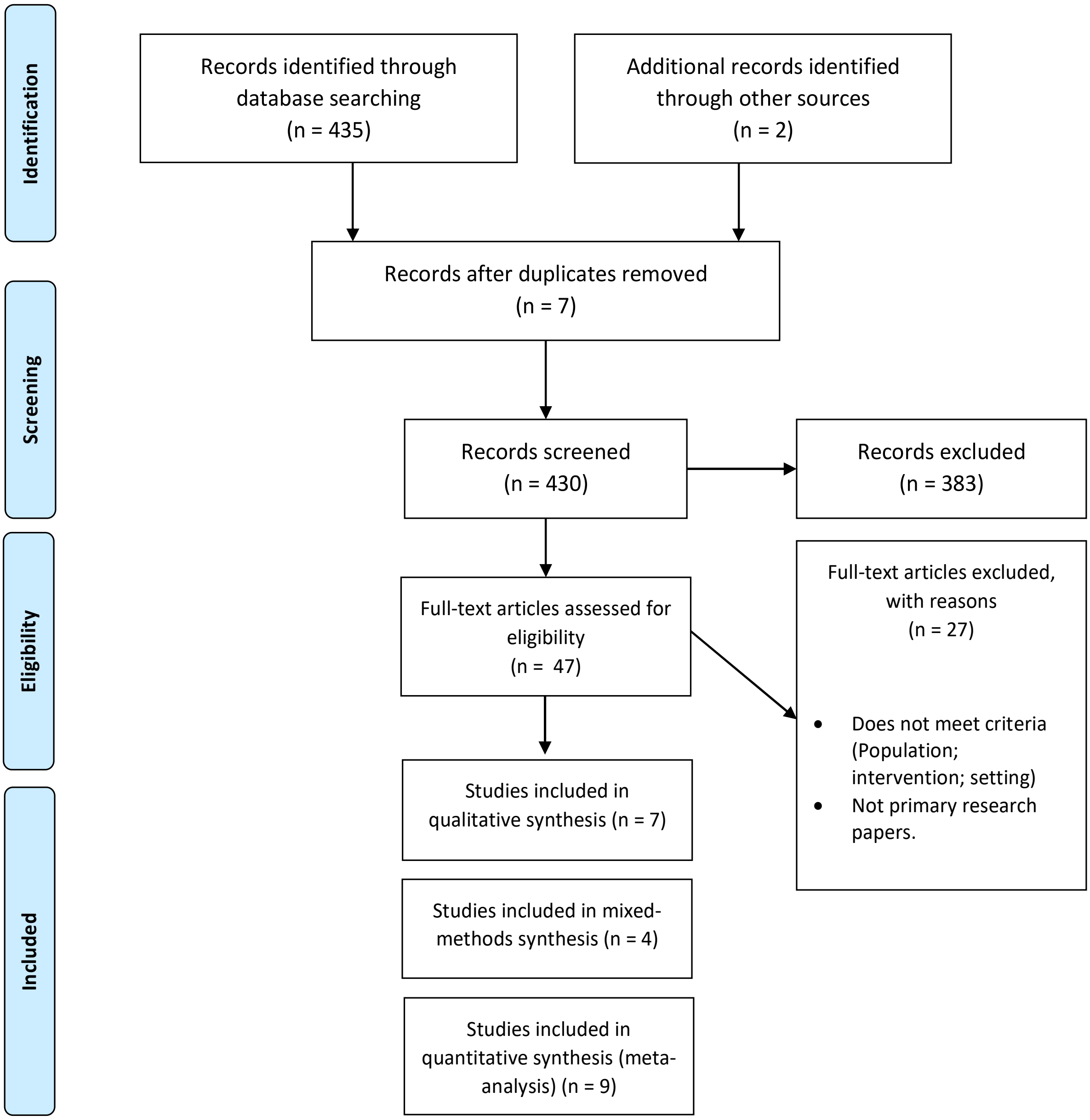
2.3.4 Study selection, extraction and analysis.

To ensure rigor and transparency in the selection of papers for inclusion during screening, all members of the supervisory team met monthly between April – July 2018. Papers were screened by title or abstract by the lead researcher and one other member of the supervisory team. Papers that were not agreed between first and second screener were discussed with the wider supervisory team, to promote open lines of communication until an agreement was met. Data from included studies were extracted, quality appraised and then collated using Microsoft Word. The research design, aims, sample population, outcome measures and findings were extracted from each of the included studies. Quantitative findings were analysed through visual inspection of data trends; identification of outcomes; reliability and validity, heterogeneity and bias and the reporting and synthesis of findings (Creswell and Plano Clark, 2018; Critical Appraisal Skills Programme, 2018b). Qualitative data analysis explored justification of study aims; sampling and recruitment strategies; rigor of data analysis strategies and the clarity of discussion to support findings (Critical Appraisal Skills Programme, 2018a). Initial thoughts on key findings were iterative**ly** developed and new concepts derived on the basis of two or more papers reporting on it and mapped in a Thematic Matrix (Creswell and Plano Clark, 2018; Hewitt-Taylor, 2017; Microsoft® Corporation, 2016a; Ingram et al., 2006). Themes were iteratively developed as researcher understanding expanded around emerging concepts, in accordance with similarity and perceived meaning (Ingram et al., 2006).

2.4 Review findings

Search and screening pathways and outcomes are detailed in a PRISMA statement (Moher et al., 2009) (Figure 2). 435 papers were imported to 'EndNote X8.2' reference manager software (Calarivate Analytics, 2018). Twenty full-text papers were included, from seven countries worldwide. Included papers ranged from 2007 to 2017, reflecting the search parameters which were applied during the scoping and main searches and corresponding with the start of the review process in 2017. Nine quantitative, seven qualitative and four mixed-method studies were included.

Figure 2 PRISMA statement



Key information from each study is presented in a Table of Evidence (Appendix 1). A large proportion of papers originated from the UK (total 13). Seven papers were from England and one was from Wales, in the UK. Two UK papers included study-sites across Scotland & England and three papers did not outline where in the UK the studies had been carried out. Geographical locations and service delivery models of included papers have been summarised in Appendix 2.

Quality appraisal of qualitative data revealed that a description of samples and justification for their selection was not always clear (Brown and Howlett, 2017; Curry et al., 2013; Petch et al., 2013; Challis et al., 2011). Additionally, the researcher-participant relationship was not always considered (Cook et al., 2017; Elbourne and Le May, 2015; Spiers et al., 2015; Hu, 2014; Curry et al., 2013; Petch et al., 2013; Challis et al., 2011). For papers that included quantitative data, quality appraisal, methods of randomisation were not always highlighted (Lewis et al., 2017; Murphy et al., 2017; Craig et al., 2016; Elbourne and Le May, 2015; Bien et al., 2013; Peters et al., 2013; Kehusmaa et al., 2012; Bjerkan et al., 2011; Challis et al., 2011); attrition was not always stated (Lewis et al., 2017; Craig et al., 2016; Elbourne and Le May, 2015; Hu, 2014; Curry et al., 2013; Kehusmaa et al., 2012) and consideration of bias was not always identified (Lewis et al., 2017; Murphy et al., 2017; Craig et al., 2016; Hu, 2014; Bien et al., 2013; Curry et al., 2013; Peters et al., 2013; Kehusmaa et al., 2012; Challis et al., 2011). Overall, the quality of papers varied but was generally observed to be low. However, low quality papers do not necessarily indicate ineffectual evidence (Health Protection Scotland, 2017). Therefore, papers were not excluded on the grounds of low quality.

A large proportion of included studies incorporate Service User data (15 papers) (Bonciani et al., 2017; Brown and Howlett, 2017; Lewis et al., 2017; Murphy et al., 2017; Craig et al., 2016; Boudioni et al., 2015; Elbourne and Le May, 2015; Spiers et al., 2015; Daveson et al., 2014; Hu, 2014; Curry et al., 2013; Petch et al., 2013; Peters et al., 2013; Kehusmaa et al., 2012; Hammar et al., 2007). Data from staff who deliver IHSC is represented in six papers (two qualitative, one quantitative and three mixed methods) (Cook et al., 2017; Elbourne and Le May, 2015; Curry et al., 2013; Bjerkan et al., 2011; Challis et al., 2011; Baumann et al., 2007). Three of the twenty included papers include families and informal Carer data in their study (Boudioni et al., 2015; Daveson et al., 2014; Bien et al., 2013). This suggests that there is need for further exploration of the needs and experiences of informal Carers.

This literature illuminates how health and wellbeing is influenced through IHSC services, including a degree of understanding of some of the needs and experiences of people who use them. Three overarching themes were identified; namely, relationships as a cornerstone of wellbeing in IHSC, maintaining and promoting wellbeing through IHSC and delivering services to meet health and wellbeing needs. Sub-themes incorporate emerging key concepts and distinguish the essence of meaning around each theme (Hewitt-Taylor, 2017; Spencer et al., 2014b) (Table 7).

Table 7 Overview of themes

	Over-arching themes	Sub-themes
1	**Relationships as a cornerstone of integrated health & social care**	The importance of relationships and their impact upon wellbeing
2	**Maintaining and promoting health and wellbeing through integrated health & social care**	Feeling able and learning to cope with changing health and social care needs
		Promoting wellbeing through improved quality of life; inclusion, feeling safe and functionality
3	**Understanding and navigating integrated collaborative systems of care**	Collaborative services and communication in integrated care
		Connecting with services and providers to achieve health and social wellbeing

Concepts that run through multiple themes/sub-themes
Collaboration (co-production) Service user voice, having a say working together
Communication
Relationships & trust
Community and social roles and contacts

2.4.1 Relationships as a cornerstone of IHSC and wellbeing

This overarching theme focuses on relationships as a cornerstone of IHSC and wellbeing. Seven papers from the UK and Canada explore the significance of relationships that people who access IHSC have with others (Brown and Howlett, 2017; Craig et al., 2016; Boudioni et al., 2015; Spiers et al., 2015; Daveson et al., 2014; Hu, 2014; Petch et al., 2013). The importance of relationships in IHSC was also considered along with maintenance and promotion of familial relationships and friendships, being a part of the wider community and relationships with IHSC staff (Brown and Howlett, 2017; Craig et al., 2016; Boudioni et al., 2015; Spiers et al., 2015; Petch et al., 2013). Three papers included qualitative Service User data (Brown and Howlett, 2017; Spiers et al., 2015; Petch et al., 2013); two included qualitative data from Service Users and informal Carers (Boudioni et al., 2015; Daveson et al., 2014); one included quantitative Service User data (Craig et al., 2016) and the last used mixed methodology to collect Service User data (Hu, 2014). Quality appraisal indicated that six of these papers were of low quality (Brown and Howlett, 2017; Boudioni et al., 2015; Spiers et al., 2015; Daveson et al., 2014; Hu, 2014; Petch et al., 2013) and one paper was of average quality (Craig et al., 2016) (Critical Appraisal Skills Programme, 2018a; Critical Appraisal Skills Programme, 2018b).

The importance of relationships and their impact on wellbeing

This sub-theme explores the importance of relationships and their impact on wellbeing. Informal Carers acknowledged a need for support with their caring role (Boudioni et al., 2015; Daveson et al., 2014) (n=4 & n=27). When interviewed, Service Users and informal Carers highlighted familial and informal Carer relationships as important sources of support in coping with changing health care needs (Boudioni et al., 2015; Spiers et al., 2015). However, Service Users found that the logistical support required to maintain and establish relationships, such as transport and equipment, was difficult to access (Boudioni et al., 2015; Petch et al., 2013). Timely access to equipment and environmental adaptations were reported as particular challenges in maintaining relationships (Boudioni et al., 2015; Hu, 2014; Petch et al., 2013).

Service users spoke of their need for logistical support in order to develop new skills and maintain relationships within the wider community (Boudioni et al., 2015; Spiers et al., 2015; Petch et al., 2013) (n=10; n=35; n=20). There were mixed reports of social isolation and differing models of IHSC in the UK and Canada. Some Service Users reported social isolation while accessing IHSC services on an intermediate basis and in a wider context (Brown and Howlett, 2017; Craig et al., 2016; Petch et al., 2013). Social isolation experienced by some Service Users accessing IHSC had a negative correlation with emotional health and wellbeing (Brown and Howlett, 2017; Craig et al., 2016; Petch et al., 2013). However, in the UK, relationships with IHSC staff were seen to help combat this (Petch et al., 2013) (n=20). Service users perceived that maintaining and promoting positive and supportive relationships between themselves and IHSC staff was important (Daveson et al., 2014; Hu, 2014; Petch et al., 2013).

Multiple sources in the UK provided evidence of the value of staff continuity as a requirement for building trusting relationships (Boudioni et al., 2015; Daveson et al., 2014). These were linked to Service Users' perceptions of 'good' relationships or 'special bonds' (Boudioni et al., 2015; Hu, 2014; Petch et al., 2013). Where relationships were built on trust and respect, the level of care coordination was enhanced (Boudioni et al., 2015; Daveson et al., 2014). Furthermore, UK Service Users living with an advanced progressive illness and their informal Carers indicated that 'good' relationship with staff influenced not only their improved experiences of IHSC but also participant outcomes (Spiers et al., 2015; Daveson et al., 2014).

To summarise, findings indicated that maintenance and promotion of both existing and new relationships were fundamental cornerstones of IHSC for Service Users, their informal Carers and IHSC staff. Relationships were closely linked to health and wellbeing and Service Users needed extra support to maintain familial and social relationships. Communication and maintenance of trusting relationships with professionals and family appear to influence experiences of IHSC and wellbeing. Continuity of staff was important in maintaining trusting relationships with professionals and these relationships hold significance in IHSC, being considered as a cornerstone of wellbeing.

2.4.2 Maintaining and promoting health and wellbeing through IHSC

This overarching theme focuses on maintaining and promoting health and wellbeing through IHSC. It encompasses 'feeling able and learning to cope with changing HSC needs' and 'promotion of wellbeing through improved quality of life, inclusion, feeling safe and functionality', for Service Users and informal Carers. Of the eleven papers relating to this theme, five papers present quantitative Service User-derived data in Canada, Finland, Ireland and the UK (Lewis et al., 2017; Murphy et al., 2017; Craig et al., 2016; Peters et al., 2013; Hammar et al., 2007). Three papers present qualitative UK Service User-derived data (Brown and Howlett, 2017; Spiers et al., 2015; Petch et al., 2013). One paper presents mixed-methods Service User data (UK) (Hu, 2014). One paper presents qualitative Service User and informal Carer data (UK) (Boudioni et al., 2015) and the final paper offers UK Service User and IHSC staff data (Elbourne and Le May, 2015). Quality appraisal indicated that ten of these papers were of low quality (Brown and Howlett, 2017; Lewis et al., 2017; Murphy et al., 2017; Boudioni et al., 2015; Elbourne and Le May, 2015; Spiers et al., 2015; Hu, 2014; Petch et al., 2013; Peters et al., 2013; Hammar et al., 2007) and one paper was of average quality (Craig et al., 2016) (Critical Appraisal Skills Programme, 2018a; Critical Appraisal Skills Programme, 2018b).

Feeling able and learning to cope with changing health and social care needs

This sub-theme focuses on feeling able to cope and learning to cope with changing HSC needs. Findings across Europe indicate that Service Users wanted to feel able to cope with their changing HSC needs and strengthen their own sense of wellbeing (Brown and Howlett, 2017; Lewis et al., 2017; Murphy et al., 2017; Craig et al., 2016; Boudioni et al., 2015; Elbourne and Le May, 2015; Spiers et al., 2015; Hu, 2014; Petch et al., 2013; Peters et al., 2013; Hammar et al., 2007). They cited autonomy and control as important in achieving this (Brown and Howlett, 2017; Craig et al., 2016; Spiers et al., 2015). Service users and informal Carers in the UK and Canada also reported concerns about coping with their changing HSC needs and subsequent decisions about their care. This caused them to experience uncertainty, anxiety and stress (Brown and Howlett, 2017; Craig et al., 2016; Boudioni et al., 2015) (n=9; n=3; n=100). In addition, UK Service Users wanted their voices to be heard in directing their own care (Brown and Howlett, 2017; Boudioni et al., 2015; Spiers et al., 2015; Hu, 2014; Petch et al., 2013). Autonomy, control and decision making were key factors in determining experiences of IHSC (Spiers et al., 2015; Peters et al., 2013) (n=35) (n=2563). However, a lack of control over IHSC services was acknowledged by Service Users and informal Carers (Brown and Howlett, 2017; Boudioni et al., 2015; Spiers et al., 2015; Hu, 2014; Petch et al., 2013; Peters et al., 2013).

Furthermore, UK Service Users and informal Carers appeared to hold a 'sense-of-self', confidence building, decision making and independence as important to their emotional wellbeing (Boudioni et al., 2015; Spiers et al., 2015; Petch et al., 2013). Service users linked confidence to resilience and they associated the ability to 'get out of the house' with maintaining independence (Spiers et al., 2015; Petch et al., 2013). Some Service Users felt a loss of dignity and respect when accessing IHSC (Boudioni et al., 2015; Hu, 2014). However, some Service User and informal Carer participants in qualitative interviews felt that these feelings changed over a six-month 'emotional journey'; as time progressed they felt more content and relaxed about their changing health care needs (Boudioni et al., 2015) (n=10). Arguably, this could signify that participants who are new to accessing IHSC, may have a different experience to those participants who have received IHSC for a longer period.

Overall, Service Users felt anxiety and stress about their changing HSC needs and they wanted to be able to cope with these changes. Dignity, respect, autonomy and control over their own services were identified as important to Service Users. Both Service Users and informal Carers valued joint decision making with IHSC professionals.

Promoting wellbeing through improved quality of life: inclusion, feeling safe and functionality

This sub-theme explores some of the strategies used by Service Users as they accessed IHSC services to promote their wellbeing through improved quality of life. Studies relating to this theme were based in Canada, Finland, Ireland and the UK (Brown and Howlett, 2017; Lewis et al., 2017; Murphy et al., 2017; Craig et al., 2016; Elbourne and Le May, 2015; Spiers et al., 2015; Hu, 2014; Petch et al., 2013; Peters et al., 2013; Hammar et al., 2007). Factors that helped Service Users to promote their wellbeing included: continuing in previous roles and preserving personal safety. Additionally, avoiding isolation through the maintenance of social roles and contacts, maintaining functional abilities and preserving quality of life also helped them to promote their wellbeing. The UK literature relating to Service Users indicates that they also sought to maintain their psychological wellbeing through continuing to fulfil previously held occupational roles both within their community and on a more personal level (Brown and Howlett, 2017; Boudioni et al., 2015; Spiers et al., 2015; Hu, 2014; Petch et al., 2013; Peters et al., 2013).

The ability to maintain housework routines within the home environment was important to UK Service Users. They cited feelings of helplessness and self-resentment when they were no longer able to fulfil these roles due to functional decline (Brown and Howlett, 2017; Hu, 2014). UK Service Users felt that appropriate housing environments, allowing access to all areas of the house with necessary adaptations, were important (Brown and Howlett, 2017; Spiers et al., 2015; Hu, 2014). Participants experienced frustration at the inaccessibility of every-day items such as washing machines and work-top spaces when they were awaiting further equipment and adaptation. These frustrations provoked negative perceptions of reduced levels of confidence, social inclusion and self-esteem, emphasising the multifactorial nature of psychosocial wellbeing (Boudioni et al., 2015; Spiers et al., 2015; Petch et al., 2013).

Environmental adaptations were seen by Service Users as crucial in maintaining social contacts and previous roles, affording an opportunity to be able to get ‘out and about’ independently (Spiers et al., 2015; Hu, 2014). Service users from the UK and Canada acknowledged the importance of maintaining social contacts with others while using IHSC (Brown and Howlett, 2017; Craig et al., 2016; Boudioni et al., 2015). They highlighted that environmental adaptations, personal safety and routines (such as showering) are linked to independence, self-confidence and wellbeing (Spiers et al., 2015; Petch et al., 2013) (n=35) (n=20). Additionally, Service Users and their informal Carers highlighted the importance of financial and emotional security and the knowledge that help was available (Craig et al., 2016; Petch et al., 2013).

Research data presents a mixed picture of Service Users' functional abilities and the impact of functionality upon quality of life when accessing IHSC (Brown and Howlett, 2017; Lewis et al., 2017; Murphy et al., 2017; Elbourne and Le May, 2015; Spiers et al., 2015; Hu, 2014; Hammar et al., 2007) (UK; Finland; Ireland). Largely, functionality for Service Users who used IHSC was inconclusive. International studies reported little or no improvement in participant functionality while accessing IHSC services, in comparison to those who were not accessing IHSC (Lewis et al., 2017; Murphy et al., 2017; Hu, 2014; Hammar et al., 2007). For example, a cluster randomised trial in Finland showed a reduction in participants' activities of daily living which corresponded with a Service User-perceived reduction in their quality of life in comparison to those in a control group (Hammar et al., 2007) (n=669). Furthermore, Service User participants who were accessing an IHSC Day Unit once weekly, showed no improvement in functionality in comparison to the control group who accessed weekly care from Community Nurses (Murphy et al., 2017). However, when some UK Service Users accessed IHSC and suitable housing and environmental aids were put in place, their functionality was enhanced (Spiers et al., 2015; Hu, 2014).

Overall, research findings here suggested that the benefits of IHSC in relation to Service Users' functionality were mixed. Where appropriate environmental adaptations and aids were provided, some activities of daily living were maintained or restored and potentially resulted in enhanced social inclusion and psychosocial wellbeing. These adjustments were essential for Service Users to maintain their own personal safety. Hence security, safety, functionality and social inclusion appeared to be intrinsically linked and their absence had a negative impact upon Service Users' experiences of IHSC.

2.4.3 Understanding and navigating integrated and collaborative systems of care

This overarching theme focuses on issues related to understanding and navigating integrated collaborative care systems. It encompasses care delivered through collaboration and communication between IHSC services and the connections between Service Users and providers that can enhance health and wellbeing. Nineteen papers discussed elements of understanding and navigating integrated collaborative systems of care. Thirteen papers focused on services in the UK (Brown and Howlett, 2017; Cook et al., 2017; Murphy et al., 2017; Boudioni et al., 2015; Elbourne and Le May, 2015; Spiers et al., 2015; Daveson et al., 2014; Hu, 2014; Curry et al., 2013; Petch et al., 2013; Peters et al., 2013; Challis et al., 2011; Baumann et al., 2007). Six papers explored services in wider European countries including Norway, Finland, Germany, Italy, Greece, Poland, Ireland and Sweden (Bonciani et al., 2017; Lewis et al., 2017; Bien et al., 2013; Kehusmaa et al., 2012; Bjerkan et al., 2011; Hammar et al., 2007) (Appendix 2) Quality appraisal indicated that all eighteen papers were of low quality (Bonciani et al., 2017; Brown and Howlett, 2017; Cook et al., 2017; Lewis et al., 2017; Murphy et al., 2017; Boudioni et al., 2015; Elbourne and Le May, 2015; Spiers et al., 2015; Daveson et al., 2014; Hu, 2014; Bien et al., 2013; Curry et al., 2013; Petch et al., 2013; Peters et al., 2013; Kehusmaa et al., 2012; Bjerkan et al., 2011; Baumann et al., 2007) (Critical Appraisal Skills Programme, 2018a; Critical Appraisal Skills Programme, 2018b).

Collaborative services and communication in IHSC

This sub-theme focuses on the factors that enhance collaborative services and interprofessional communication systems to deliver IHSC across Europe. It considers a diverse landscape of models of IHSC that promote collaboration and communication between Service Users, informal Carers and IHSC staff. It also explores the importance of clarity and information giving and the influence that these can have upon the experiences of people who use and deliver IHSC (Bonciani et al., 2017; Cook et al., 2017; Murphy et al., 2017; Bien et al., 2013; Curry et al., 2013; Petch et al., 2013; Challis et al., 2011; Baumann et al., 2007).

In comparison with those accessing non-integrated HSC models of care, Service User satisfaction was improved for people living in Italy when they frequently accessed an IHSC 'Primary Care Centre (PCC)' model (Bonciani et al., 2017) (n=2025; p<001). Furthermore, psychosocial wellbeing was thought to be improved for Service User participants who accessed an IHSC Day Unit model of care, in comparison to those who accessed Community Nurse care alone (Murphy et al., 2017) (n=63). Geographical and regional comparisons between services and models of IHSC that were included in this review, presented a mixed picture of IHSC models (Bien et al., 2013; Kehusmaa et al., 2012; Bjerkan et al., 2011; Challis et al., 2011; Baumann et al., 2007). Some researchers explored utility and access to models of IHSC, identifying organisational arrangements, strategic priorities and the location of staff as instrumental in the provision of IHSC (Challis et al., 2011; Baumann et al., 2007).

Models of IHSC varied across different regions and nations (categorised in Appendix 2). In a randomised-control trial across Finland, the experiences of frail elderly Service Users highlighted the relationship between the effective use of social services and an improvement in their health status, in comparison to those who accessed non-integrated services (Kehusmaa et al., 2012) (n=732). However, informal Carer participants in a multi-European nations cross-sectional survey highlighted fragmented and uncoordinated services (Bien et al., 2013) (n=2629). They found that involvement of multiple social services did not invariably result in less unmet needs. Intermediate IHSC services (that look to facilitate discharge from or prevent admission to hospital) were found to go some way to addressing the fragmentation of IHSC.

In the UK and Ireland, intermediate service models offered a 'whole-system' approach that supported collaborative communication across organisational and professional boundaries (Cook et al., 2017; Lewis et al., 2017). UK Service Users indicated that fragmentation was reduced when practitioners who specialised in a particular condition became involved. This was indicated even though these specialist practitioners were not regular members of the IHSC team (Petch et al., 2013) (n=20). This suggests that the most effective way to ensure that Service Users' needs are met could be to involve a sub-section of the IHSC team. Furthermore, specialist input for a particular condition, such as a long-term condition specialist practitioner, can also compliment their care further. From a survey of Service Users in Italy, co-location was believed to reduce fragmentation for people with complex care needs who frequently access IHSC, in comparison to those who did not have access co-located services (n=2025) (Bonciani et al., 2017).

Co-located services offered an opportunity to develop close working relationships, better understand the roles of other staff and increased Service User satisfaction (UK) (Boudioni et al., 2015; Elbourne and Le May, 2015; Daveson et al., 2014; Hu, 2014; Curry et al., 2013; Petch et al., 2013). Nevertheless, Service Users, informal Carers and IHSC staff prioritised 'effective' communication over co-location (Daveson et al., 2014; Baumann et al., 2007) (n=42; n=83). The clarity of IHSC systems and the information provided about them were also identified as essential to achieve effective IHSC (Bonciani et al., 2017; Cook et al., 2017; Murphy et al., 2017; Bien et al., 2013; Curry et al., 2013; Petch et al., 2013; Challis et al., 2011; Baumann et al., 2007). Transparency was found to be important in facilitating the coordination and delivery of IHSC services (Elbourne and Le May, 2015; Daveson et al., 2014; Curry et al., 2013; Baumann et al., 2007). Lack of clarity could lead to increased feelings of powerlessness and difficulties for Service Users when attempting to navigate the systems that had been set up to coordinate and provide their care. This had a negative impact on their experience (Boudioni et al., 2015; Daveson et al., 2014).

Overall, the quality of Service Users' experiences of IHSC are influenced by several organisational factors. IHSC services can be fragmented but intermediate services and co-location of professionals appeared to reduce this. Collaborative interprofessional communication was perceived as beneficial by Service Users and staff alike, whether the latter were based in one or several locations. Collaborative services should be organised in a way that can be easily grasped so that clear information can be given about them. Transparent communication channels must exist between professionals. Equally, communication about IHSC systems must be clear between informal Carers, Service Users and IHSC professionals.

Connecting with services and providers to achieve health and social wellbeing

This sub-theme explores how individuals connected with services and providers to achieve health and social wellbeing. It encompasses three elements; first, the need for effective communication for collaboration between people who use and deliver IHSC (UK and Norway) (Cook et al., 2017; Boudioni et al., 2015; Elbourne and Le May, 2015; Daveson et al., 2014; Hu, 2014; Curry et al., 2013; Petch et al., 2013; Bjerkan et al., 2011; Challis et al., 2011; Baumann et al., 2007). Second, it considers the value of promoting trust and enhancing the quality of care for Service Users through professional knowledge (UK) (Cook et al., 2017; Boudioni et al., 2015; Daveson et al., 2014; Peters et al., 2013; Challis et al., 2011; Baumann et al., 2007). Finally, it considers the importance of Service Users being able to access the right professional at the right time (multi-national) (Cook et al., 2017; Lewis et al., 2017; Spiers et al., 2015; Bien et al., 2013; Petch et al., 2013; Peters et al., 2013; Kehusmaa et al., 2012).

Early communication between Service Users, their families, informal Carers and professional services added to the success of IHSC services (UK) (Boudioni et al., 2015; Elbourne and Le May, 2015; Daveson et al., 2014; Hu, 2014; Curry et al., 2013; Baumann et al., 2007). Data from Service Users and informal Carers also suggested that wherever communication was ineffective and decision-making was not shared, Service Users felt a sense of powerlessness (Boudioni et al., 2015) (n=10). Care planning for IHSC provided a way to facilitate cross-organisational communication and was found to follow diverse forms. Some researchers investigated 'individualised care plans' led by local authorities in Norway (Bjerkan et al., 2011) (n=59). Some areas of the UK adopted a 'case management' approach to care planning (Challis et al., 2011) (n=56). However, the effectiveness of these approaches in relation to meeting Service Users' needs, was not explored. Nevertheless, a single-shared assessment process, as part of a 'partnership working' approach to IHSC, was found to positively influence Service User-identified and valued outcomes (Petch et al., 2013) (n=20).

Service users and IHSC staff in the UK & Ireland emphasized the importance of gaining access to the right professional at the right time via a coordinated team (Cook et al., 2017; Lewis et al., 2017; Spiers et al., 2015; Petch et al., 2013; Peters et al., 2013). Several factors enhanced communication in collaborative care. The use of inter-disciplinary meetings (including the housing department) enabled services to meet and communicate simultaneously (Cook et al., 2017; Challis et al., 2011). Service users and IHSC staff highlighted reduced duplication when Service Users held their own records or when a single-assessment process was adopted (Brown and Howlett, 2017; Craig et al., 2016; Challis et al., 2011). In addition, Service Users and IHSC staff also indicated that specialist practitioners played a key role in coordinating inter-disciplinary communication. Input from a specialist practitioner, who focused on one specialty area of practice, helped to ensure that care was tailored to an individual's specialist needs (Cook et al., 2017; Petch et al., 2013) (n=35) (n=20). However, even when specialists were not involved, Service Users wanted the professionals providing their care to have a good level of expertise in their condition and needs. Regular multi-organisation meetings provided valuable opportunities for enhancing knowledge (Boudioni et al., 2015; Peters et al., 2013; Baumann et al., 2007).

Overall, models for delivering IHSC services were diverse. No consensus could be found regarding which of the many models for delivery of IHSC best met Service Users' needs. Early communication and accessing the right professional at the right time was important to Service Users who accessed IHSC. Professionals were expected to have a high standard of knowledge about the Service User's condition and a lack of knowledge had a negative influence on the experiences of some Service Users.

2.5 Review discussion

Co-ordinated integrated PCC is at the forefront of HSC in communities across the world (World Health Organization, 2016a). Existing scientific reviews of IHSC largely focus on the characteristics of IHSC systems, exploring models of care, values of IHSC and their impact and effect upon service delivery outcomes (Kelly et al., 2020; McClean et al., 2019; Baxter et al., 2018; Zonneveld et al., 2018; Robertson et al., 2014). Many reviews explore integrated ways of working, policy drivers, implementation strategies and funding (Billings and De Weger, 2015; Mason et al., 2015; Cameron et al., 2014; Rout et al., 2011; Maslin-Prothero and Bennion, 2010; Weatherly et al., 2010; Rummery, 2009). Service user needs and experiences of IHSC are explored in part; however, specific contexts limit the scope of some of these reviews; for example, Service Users who are homeless or living with long-term conditions (Omerov et al., 2020; McGilton et al., 2018). This review adds an important new perspective to the wider body of research knowledge, relating to needs and experiences of Service Users, informal Carer and staff key stakeholders in IHSC.

Access to IHSC at home was reported to rely on effective collaboration between all three stakeholders. International sources suggest that effective collaboration can be facilitated through co-location of services, which can enhance professionals' understanding of each other's roles (Bonciani et al., 2017; Cook et al., 2017; Murphy et al., 2017; Bien et al., 2013; Curry et al., 2013; Petch et al., 2013; Challis et al., 2011; Baumann et al., 2007). However, UK IHSC staff highlighted inter-professional communication as important to collaborative working, regardless of co-location (Baumann et al., 2007). This corroborates the suggestion in wider literature that communication is an underpinning driver for IHSC (Bonciani et al., 2017; Cook et al., 2017; Murphy et al., 2017; Mackie and Darvill, 2016; Scheele and Vrangbæk, 2016; Bien et al., 2013; Curry et al., 2013; Petch et al., 2013; Kaehne and Catherall, 2012; Challis et al., 2011; Baumann et al., 2007).

There are clear links to Service Users' need for environmental adaptations and aids to meet their functionality and personal safety needs, which can also be linked to emotional wellbeing. Review findings are inconclusive about the relationship of IHSC and improved functionality for Service Users. It cannot be assumed that the provision and utility of IHSC invariably results in improved Service User functionality. Fulfilling previous roles (such as completing housework and gardening tasks) and remaining independent can result in significant improvements in emotional wellbeing, facilitating maintenance of social contacts (Brown and Howlett, 2017; Spiers et al., 2015; Hu, 2014; Petch et al., 2013; Peters et al., 2013). Equally, people who utilise IHSC at home expressed a need to have their voices heard and be involved in making decisions about their own care (Brown and Howlett, 2017; Boudioni et al., 2015; Spiers et al., 2015; Hu, 2014; Petch et al., 2013; Peters et al., 2013). Feeling empowered and prepared to deal with the uncertainty that changing health and care needs brings, is important to Service Users and informal Carers. It could be argued that this is an integral role of professionals who deliver IHSC (UK) (Brown and Howlett, 2017; Boudioni et al., 2015; Spiers et al., 2015).

Helping stakeholders meet their needs through a collaborative approach to IHSC is challenging for many IHSC providers, with a diverse range of strategies evident in the wider literature (Expert Group on Health Systems Performance Assessment, 2017; World Health Organization, 2016a; World Health Organization, 2015a; Marks et al., 2011). A lack of papers that explored the benefits of IHSC models of delivery, through comparison to non-integrated HSC, was noted. However, many papers considered different models of IHSC. IHSC providers must pay careful attention to levels of continuity of staff and the degree of coordination within their services (Boudioni et al., 2015; Elbourne and Le May, 2015; Spiers et al., 2015; Daveson et al., 2014; Hu, 2014; Bien et al., 2013; Curry et al., 2013; Petch et al., 2013; Peters et al., 2013; Baumann et al., 2007). Fragmentation of systems and services should be avoided since this has a negative impact on the experiences of users of IHSC. The use of intermediate IHSC services along with more effective coordination can potentially to go some way to address this issue (Cook et al., 2017; Lewis et al., 2017).

Service Users and Informal Carers experienced reduced levels of autonomy, self-worth and confidence and a lack of dignity and respect when utilising IHSC services, resulting in unmet health and wellbeing needs (Boudioni et al., 2015; Spiers et al., 2015; Hu, 2014; Petch et al., 2013; Peters et al., 2013). Maintaining and promoting existing and new relationships can be seen as a fundamental cornerstone of IHSC that influences the experiences of people who use IHSC and should be considered when planning IHSC services (Eastwood et al., 2019; Boudioni et al., 2015; Spiers et al., 2015; Petch et al., 2013). Relationships are closely linked to promotion of wellbeing, reducing social isolation and a foundation of trust between Service Users, informal Carers and professional staff (Brown and Howlett, 2017; Craig et al., 2016; Boudioni et al., 2015; Cameron et al., 2014; Daveson et al., 2014; Glasby, 2014; Hu, 2014; Petch et al., 2013). It could be argued that a gap exists in the current body of knowledge with further scope to explore the significance of these supportive relationships in IHSC.

2.6 Critique of the literature

Overall, the quality of literature in this review was generally low. Some studies that employed mixed-method data collection focused upon quantitative data and under-reported important qualitative methodologies; others were unclear regarding approaches to sampling. Seven papers consider qualitative data, two of which included staff data (Cook et al., 2017; Baumann et al., 2007). Three of these qualitative papers included Service User data (Brown and Howlett, 2017; Spiers et al., 2015; Petch et al., 2013) and two offered Service User *and* informal Carer data (Boudioni et al., 2015; Daveson et al., 2014). It could be argued that there is a need to further explore needs and experiences of IHSC, that combines all three stakeholders. Furthermore, two papers in this review explore Service User health and wellbeing needs as defined and perceived by the Service User (Spiers et al., 2015; Petch et al., 2013). It could be further argued that exploring the needs of people who access HSC is warranted. Further research that explores Service User and Informal Carer-derived health and wellbeing needs, would add to the current body of evidence.

2.7 Review strengths and limitations

The strength of this paper lies in its underpinning integrative methodology. While a systematic review methodology may have produced differing results, integrative review methodology and rigorous data analysis represent the complexity of the research questions and the diversity of data that are key to developing evidence-based practice in this field (Hopia et al., 2016; Whittemore and Knafl, 2005). Rigorous adherence to the underpinning integrative framework of this review and transparency were promoted amongst researchers through monthly meetings for the duration of the review, thus reducing the potential for bias. The results of this review present a level of understanding around experiences of IHSC services and highlight gaps in current IHSC practice.

A further strength of this paper lies in the involvement of stakeholders in identifying the review topic and the interpretation of results (Kreis et al., 2013; Boote et al., 2011). However, time constraints meant that stakeholder involvement was not possible throughout the *whole* review process and is acknowledged as a limitation of this review. Whilst researchers strove to ensure that results could be meaningfully screened by filtering of 'Title' field, they recognise that the scope of this review may have been limited by their decision. Identifying relevant studies from abstract, rather than the title alone, may have highlighted further studies for inclusion. In addition, researchers also acknowledge that papers that have been published since the literature search was performed in 2018, are not included in this review. The scope of this review is also limited by the exclusion of papers that related solely to in-patient setting as they were more likely to represent integration of a specialist health care service to another acute health care service (for example, the integration of a singular specialist health service into another pre-existing health service). Nevertheless, it is recognised that excluded literature may have offered additional examples of IHSC.

2.8 Review conclusions

Overall, findings from this review outline that the potential impact of relationships between professionals and Service Users must not be underestimated; these grow stronger when providers approach care planning with involvement and collaboration. Difficulties in navigating the integrated systems can be overcome by ensuring that new and existing structures are clear. More evidence is needed on the effectiveness of IHSC as an intervention that promotes health and wellbeing and its impact on the experiences of those who receive it. Further research that focuses upon the needs of people who use IHSC services, as defined by those people themselves is also warranted. Research that explores supportive relationships and involves participation of all three IHSC key stakeholders would provide valuable insights to enhance knowledge in the field and support future developments in IHSC practice.

Section 2.8 marks the end of the amended version of the published Critical Integrative Literature Review. The sections that follow consider key research evidence that has been published since the review was conducted and questions that arose from the literature.

2.9 Key research evidence, following publication of the review

My review of relevant papers and evidence was an iterative process, being continuous for the duration of this study (Hart, 2018; Murray, 2017). Whilst completing the above outlined search strategy in Section 2.3.2, I utilised ongoing auto-search facilities that re-ran the search parameters monthly. These aimed to capture new research evidence that fit those parameters (from April 2018- Sept 2021); hand-searches were also performed elsewhere using the same parameters (Scopus; Zetoc; Google Scholar). The greatest concentration of empirical publications (n=32) recovered continued to centre on evaluation and impact of models of IHSC delivery in different regional and international areas (as outlined in Section 2.5). They outlined examples and strategies for integrating workforces, summarising implications of joint working for professional identity, and qualities and requirements for effective multi-agency leadership across sector. These papers were screened at abstract and excluded on the basis that they did not meet the inclusion criteria under one of two categories: the ‘Types of Studies’ or the ‘Types of Context’ (Table 6). However, one further empirical study did fit the inclusion criteria, relating to relationships and experiences in HSC (Bredewold et al., 2019). Details of this qualitative paper have been incorporated in an addendum to the tables of evidence and service delivery (Appendix 1; Appendix 2). A brief synopsis of the main findings and what it adds to this review is outlined below.

Bredewold et al. (2019) reaffirm findings from the published review, also highlighting the importance of a bond between those who provide care and those who are receiving it (Boudioni et al., 2015; Hu, 2014; Petch et al., 2013) (as discussed in Section 2.4.1). However, Bredewold et al. (2019) also explores the significance of close emotional social bonds between those who receive and provide informal support (family members, friends or neighbours). For some family member carers in their study, taking on an informal caring role added pressure to the relationship dynamics they had with their relative. For example, negotiating boundaries to disengage with Informal Carers could be perceived as difficult by both parties when a child with a disability was growing up and wanted to detach from their parents' caregiving to exercise their own self-reliance. People who received care were aware of these pressures and wanted to avoid them, feeling that self-reliance helped to promote their independence and emotional wellbeing (Bredewold et al., 2019; Boudioni et al., 2015; Spiers et al., 2015; Petch et al., 2013) (as discussed in Section 2.4.2). Care recipients felt embarrassed or ashamed of their increasing care dependency and did not want to over-burden their Informal Carers to ask for help in maintaining their health and wellbeing. Moreover, they also wanted to preserve boundaries around personal care to avoid embarrassment, for example between a father and daughter, to avoid putting unnecessary pressure on the relationship (Bredewold et al., 2019).

Whilst this paper from Bredewold et al. (2019) adds further emphasis to the voice of Service Users and Informal Carers in highlighting their needs, experiences and relationships in HSC, the number of empirical studies exploring these topics of interest remains limited. Completing the Critical Integrative Literature Review and exploring further key research evidence from after the review period, raised several critical questions for me. These are outlined in the following section and support a case for further research in the field.

2.10 Questions arising from the literature

These questions related to gaps in knowledge identified within the review, relating to one of three topics of interest (Parahoo, 2014; Braun and Clarke, 2013). First, the nature of experiences and needs for Service Users, Informal Carers and IHSC Staff Members was not clear; I wanted to know more about what these were. Second, I wanted to better understand the relationships these groups had and how those influenced their experiences of IHSC. Finally, I questioned whether HSC could truly be described as integrated, with evidence of fragmented, solitary services and practices. These questions have been summarised below, in Table 8.

Table 8 Questions arising from the integrative review

	Questions arising from the integrative review
Needs	What are the perceived health and wellbeing needs of Service Users who access IHSC?
	What are the health and wellbeing needs of informal Carers and family members who work with IHSC in their supporting role?
Experiences	What are the experiences of Service Users who access IHSC to meet their health and wellbeing needs?
	What are the experiences of informal Carers and family members who work with IHSC in their supporting role?
Relationship	What are the relationships between the experiences of services users, their families/informal Carers and caring professionals when receiving IHSC?
	What are the experiences of key stakeholders (Service Users, their families or informal Carers and staff) who participate in co-produced collaborative IHSC?
IHSC	If services are lacking collaborative, cohesive, working practices can they be classed as ‘integrated’?

After considering the last question, I resolved to refer to HSC services (rather than IHSC) in the remainder of this thesis, until I could be clearer on whether this was an accurate description or not (with further discussion on this being included in Chapter 6, Section 6.4.3). These questions helped me to pinpoint what I was looking to explore in this study and to develop an evidence-informed preliminary research question, which is considered below.

2.11 Developing an evidence-informed preliminary research question, aim and objectives

Current knowledge in the field and the context of the local region, and findings and questions raised from the above review, informed a preliminary research question. This question was embedded in local and national research priorities in primary care and person-focussed health and wellbeing needs (NHS Research Scotland, 2018; Robert Gordon University, 2016b; Parahoo, 2014) (Table 9).

Table 9 Evidence informed, preliminary research question

Preliminary research question
For Service Users and people who help them at home, what is the relationship between health and wellbeing needs and their experiences of HSC in a regional area of Scotland?

This initial research question offered guidance and direction for formulating an initial aim and objectives for the study (Table 10). Collectively, these were used to identify appropriate methodologies (discussed further in Chapter 3) and refined later, during the application of appropriate research methods (Chapter 4, Section 4.3).

Table 10 Preliminary aim and objectives

Preliminary aim
To understand the experiences of HSC, for Service Users and people who they rely upon, in a regional area of Scotland.
Preliminary objectives
1. To describe the health and wellbeing needs of Service Users and their families and/or Informal Carers.
2. To explore the experiences of key stakeholders who access health and social care services.
3. To investigate the relationship between health and wellbeing needs and experiences of key stakeholders who receive HSC.

2.12 Chapter summary

This chapter has considered the evidence-base for the progression of this research study, through a published Critical Integrative Literature Review, and ongoing iterative review of key empirical papers. Although these sources highlighted some of the health and wellbeing needs of people who use HSC services and their experiences of accessing and utilising those services, high quality qualitative data that explored needs and experiences (from the perspective of the individual using the services) were lacking. Questions that arose because of these review processes were considered and used to inform a preliminary research question, an overarching aim and objectives of this study. Using these as a guide, the next chapter will consider my underpinning research philosophy, methodological choices and position within the research.

CHAPTER 3 UNDERPINNING PHILOSOPHY AND THEORETICAL APPROACHES

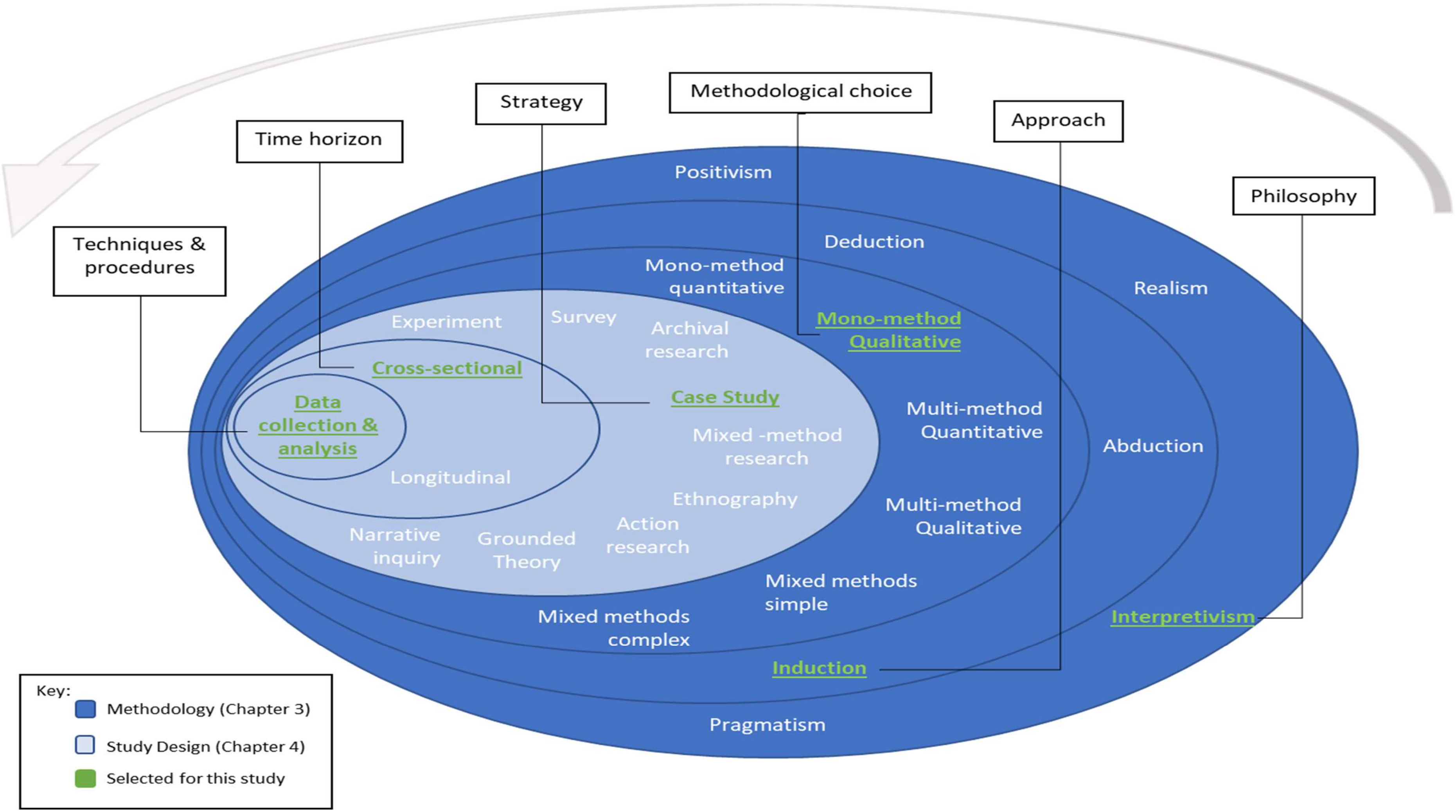
3.1 Chapter overview

Chapter 3 outlines the research philosophy and theoretical methodological approaches that underpin this thesis. First, I explore the interpretive epistemological nature of my knowledge acquisition, and the relativist and constructivist ontological progression of my understanding. Second, I outline how these epistemological and ontological positions informed the exploratory foundation of this study, and the choices I made when developing it. Third, my discussion includes relationship and connection theory, acknowledging the influence that attachment theories had over my thinking. These theories are based in the realms of Social Psychology and facilitated interpretation, analysis and reporting of my findings throughout this study. Finally, the rationale for my inductive qualitative methodology is outlined whilst considering the relationship that binds these epistemological, ontological and Social Psychology theories to my position as a researcher in this study.

3.2 Underpinning philosophy

When considering appropriate underpinning philosophies and methodologies, I opted to use a research framework that clearly identified the different considerations between these theoretical principles. ‘The Research Onion’ added clarity to the process of identifying appropriate theories and reporting them in a cohesive manner (Spencer et al., 2014b). Figure 3 highlights the relevant research theories observed in this thesis (Saunders et al., 2011).

Figure 3 The Research Onion (Saunders et al 2011)



Philosophical and methodological choices in the dark blue layers are discussed below (subsequent light blue layers will be discussed in Chapter 4). Choices I have made are highlighted in green underline, with rationale for these choices being offered in the sections that follow (Table 11).

Table 11 Sections that expand on layers of the Research Onion

Research Onion layer	Corresponding section in this chapter
Philosophy	3.2.1; 3.2.2; 3.2.3; 3.2.3; 3.2.4
Approach	3.3
Methodological choice	3.4

3.2.1 Epistemological position: Understanding the nature of knowledge through interpretivism

Informed by the findings of the integrative literature review, this study investigated the human meaning of experiences and needs in HSC within the wider social world. Research methods from natural sciences are not well suited to investigating human social experiences and meaning, being underpinned by positivist concepts of observation and measurement (Gerrish and Lathlean, 2015; Lewis and McNaughton Nicholls, 2014; Spencer et al., 2014b). Instead, this study aimed to *understand,* rather than measure, their experiences of the social world. Therefore, I incorporated philosophical underpinnings that embraced participants' personal interpretations of those experiences (Bryman, 2016).

Unlike Positivist and Pragmatist epistemological positions that considered knowledge and reality as objective understanding, I considered phenomenological epistemologies at first. Phenomenology's close link to exploring experiences was tempting. However, a primary focus of this was not on how individual participants made sense of those experiences (gaining an *internal* perspective), instead describing and exploring them across multiple perspectives (Bryman, 2016; Gerrish and Lathlean, 2015; Smith et al., 2012b) (discussed further in Section 4.5). I wanted to develop a deeper level of understanding across the multiple perspectives of people who used HSC services and those who supported them at home (as per Table 9), whilst also acknowledging the influence of my own perspectives (discussed further below in Sections 3.2.2 and 3.2.4) (Bryman, 2016; Parahoo, 2014). I believed that the experiences of people who use and deliver HSC cannot be measured in an objective way, with the person who is experiencing HSC being the only person qualified to define *their* knowledge of the phenomenon.

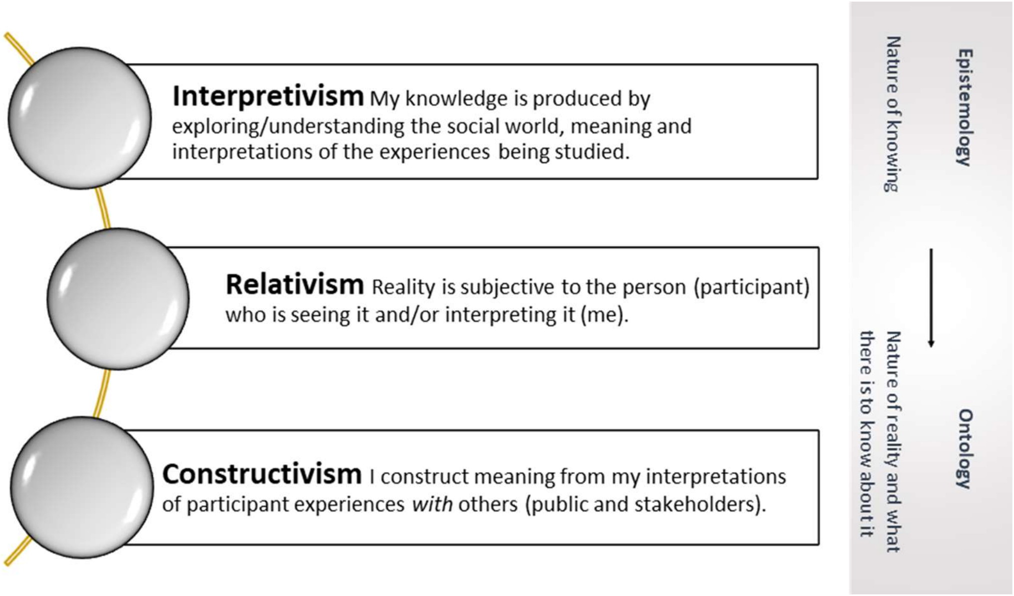
Therefore, I considered interpretivism as it acknowledges the belief that a phenomenon (experiences and needs) can be understood by the subjective meaning people give to it and the context in which it happens (in HSC). Interpretivism respects and celebrates the differences between individuals' knowledge. It is often used as an underpinning philosophy in HSC research that looks to describe and understand experiences and interactions of care (Moule et al., 2017). However, considering an interpretive position of knowledge on its own would not facilitate a full and varied picture of experiences. To build a more holistic picture, there was also a need to recognise participants view of their individual reality, and ontological lenses that helped me to better understand this are discussed in the section below.

3.2.2 Ontological positions: Understanding the nature of reality through relativism and constructivism

When first considering my ontological position, I identified with the underlying principles of relativism (a polarised perspective of realism), on the premise that reality can only be viewed from multiple perspectives, never really knowing if it is reality or not (Braun and Clarke, 2013). I was attracted to this understanding of reality as the beholder (participant) sees it. With multiple accounts of experiences of HSC anticipated in this study, the notion of one participant's reality not having precedence over another's was appealing, each representing their own truth about the phenomena (namely, needs and experiences in HSC). I did not feel in a position to judge whether their experiences were real or not, freely accepting they would share a reality relative to their own perceptions. A relativist position supported the aim, objectives and research questions of this study, believing that incorporating the experiences, health and wellbeing needs and relationships across multiple-realities would enrich the findings.

Although I recognised the need to adopt a relativist ontological lens, I felt this did not fully cover the knowledge and reality that had to be represented in this study. I also needed to acknowledge *my own* part in interpreting and reporting participants' realities. Unlike other ontological positions that view social entities as objective to the research, a constructivist lens favours multiple subjective views of meaning in the social world (Lapan et al., 2012a). Adopting a blended relativist and constructivist lens allowed me to recognise that I am an active part of this study, in that, I have developed the findings from my own interpretation of participants' reported realities (Spencer et al., 2014b). Blending these two ontological positions not only embraced a collaborative approach to developing new knowledge, it also highlighted *my* explicit role in interpreting *their* interpretations of *their* reality (Bryman, 2016). For clarity, my philosophical positions have been illustrated in Figure 4, and further discussion on influential social theories follows in the next section.

Figure 4 Underpinning philosophy: epistemology and ontology



Interpretivism My knowledge is produced by exploring/understanding the social world, meaning and interpretations of the experiences being studied.

Relativism Reality is subjective to the person (participant) who is seeing it and/or interpreting it (me).

Constructivism I construct meaning from my interpretations of participant experiences *with* others (public and stakeholders).

3.2.3 Influential Social Psychology theories

Having acknowledged my epistemological and ontological positions above, it is also important to recognise the influence of Social Psychology theories in this thesis. Whilst I did not embark on this study with any pre-determined philosophical theories in mind, it became evident during the data analysis phase that I needed a point-of-reference to fully interpret and understand participants' needs, experiences and relationships in HSC. As patterns were identified and explored across the data, I was aware that all participants had emphasised their relationships with people who supported them, as instrumental in shaping their experiences of HSC, and this influenced my use of theory. It became apparent early in the analysis process that one theory was not likely to capture the meaning of the rich and diverse data collected, prompting a combined or blended approach (Kim et al., 2017). Theoretical underpinnings needed to offer flexibility in the process of analysis, to allow my interpretations to be driven by the data themselves, and not my own preconceptions about a suitable theoretical framework (Sandelowski, 2010). Therefore, I explored a range of theories and considered how to position these at the centre or periphery of my interpretation.

I considered Social Network Theory, on the initial (preconceived) understanding that relationships in HSC were network-based across different contexts and organisations. I wanted to know more about interactions between people in an HSC network. However, upon further reading, Social Network Theory appeared to focus more on mapping and evaluating behaviours within the networks (most commonly to identify gaps and highlight areas for improvement) (Valente and Pitts, 2017; Huerta and Dandi, 2014). Revisiting the findings of my literature review helped me to refocus my attentions. The literature highlighted a need to know more about relationships in HSC and the influence they could have over experiences and needs of people who use services, rather than behaviours within networks. Moreover, relationships were only *one* aspect of HSC experiences that I wanted to explore. I continued my search and identified that Social Psychology Attachment theory, and its concepts of interpersonal connection and relationships, helped me to interpret and analyse the data. Attachment Theory is the fundamental bedrock of my philosophical position in this study, recognising an individual's essential desire and intrinsic need to connect with others around them (Karremans and Finkenauer, 2020).

Attachment Theory is based on the premise that each person has an affiliative and enduring tie with another, and that they go on to display 'attachment behaviours' that promote closeness between two individuals (Hewstone and Stroebe, 2020; Kaplan, 1998). The principles of Attachment Theory lie in child - caregiver attachment and loss of connection, usually in the context of maternal connections, originating from Bowlby's work spanning back to the 1950's (Bowlby, 1982; Bowlby, 1980; Bowlby, 1973). Bowlby had been one of the first researchers to draw together principles of Attachment Theory. Nonetheless, there was some debate around the underpinning methodologies employed, opening up increased possibilities of bias; however, more rigorous studies have since replaced some of Bowlby's weaker investigations (Frost, 2005). Equally, Rutter (1972) questioned Bowlby's focus on maternal connection as a representation of attachment, suggesting that the use of 'maternal connections' limited the application of attachment indicators. He argued that several indicators of attachment, such as objection or anguish when a person that an individual is attached to leaves, can be evident for a diverse range of figures including fathers, siblings or peers. Later seminal adaptations to Bowlby's

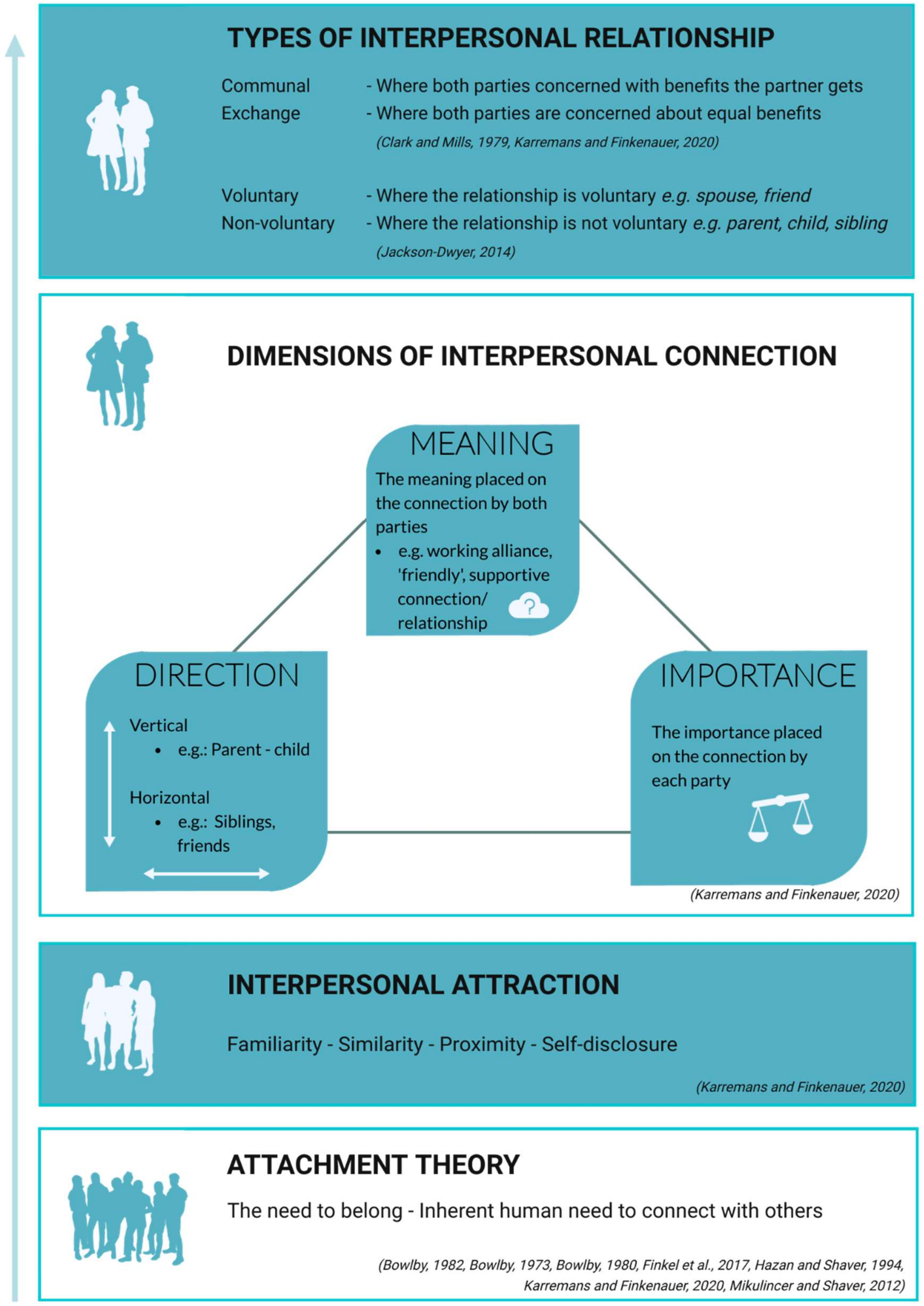
Attachment Theory in the 1990's by Hazan and Shaver (1994) also shift emphasis away from Bowlby's focus on maternal connections. Instead, they promote the application of attachment principles to adult relationships, on the understanding that the process of attachment happens across the life-span (Finkel et al., 2017; Mikulincer and Shaver, 2012).

The application of these principles across the life-span seemed more relevant to my purpose of identifying a point-of-reference that could inform my interpretations of adult participants' experiences of HSC. Equally, the principles of Bowlby's (1980) theory on loss, depression and sadness are also important in considering interpersonal connections and relationships between adults. For example, reactions to loss, namely feelings of protest, searching and despair, may be present in HSC relationships when someone dies or their health and wellbeing needs change (Stroebe and Archer, 2013). Mikulincer and Shaver (2012) advocate Bowlby's (1982) proposition that attachment and loss, at any age, can be viewed as a system of behaviours that lead to a common goal of seeking care, protection and security. Whilst becoming familiar with my data in the analysis phase of this study (discussed in Section 4.8.1) the significance of how relationships were formed, developed and maintained became apparent. The principles of Attachment Theory gave me an opportunity to embrace the inter-woven nature and influence of experiences and relationships in HSC, and it offered a relationship-based lens I could use to interpret those in my data.

Within Attachment Theory, I identified three key areas that helped me to understand and interpret participants' data. These included: principles of interpersonal attraction, dimensions of interpersonal connections, and the types of interpersonal relationships that were formed because of those connections. Karremans and Finkenauer (2020) highlight interpersonal attraction (the appeal of another person) as one of the fundamental drivers in forming an adult attachment. They go on to explain that familiarity, similarity, proximity and the level of self-disclosure between two individuals, are important when making a connection with another person. Forming a connection involves three dimensions: the meaning, direction and importance placed on the connection by both parties. Parity in these dimensions is crucial for the successful development of a relationship thereafter (Karremans and Finkenauer, 2020). For example, if the connected individuals place a different meaning on the relationship, or if they place differing levels of importance on it, it may be unbalanced or tumultuous.

Forming a relationship requires a significant amount of time investment, necessitating sustained contact or interaction, seeking of the other when distressed and use of the other as a point of safety from which to explore the world (Berscheid and Regan, 2016; Gillath et al., 2016; Gillath and Karantzas, 2015). To this end, relationships can be communal, where both parties exchange benefits (of the relationship) without expecting anything back from the other (Karremans and Finkenauer, 2020; Clark and Mills, 1979). Alternatively, they can be exchange based, where both parties are concerned with the equal benefits that they get from the relationship (Karremans and Finkenauer, 2020; Clark and Mills, 1979). An example of this might be when a tradesman carries out a home improvement, the tradesman receives the benefit of payment, and the customer receives the benefit of the home improvement. Furthermore, relationships can also be formed on a voluntary basis, for example with a spouse or friend, or they can be non-voluntary, such as those with a parent, sibling, or in an arranged marriage (Karremans and Finkenauer, 2020; Jackson-Dwyer, 2014). An overview of how these theories were observed within the data analysis phase of this study is included below (Figure 5). The below illustrates my understanding of how they dovetail and offers clarity of definitions for terminology in Chapters 5-7. The application of these theories, to the findings and discussion, is also explored further in Chapter 6 (Section 6.2).

Figure 5 Overview of influential Social Psychology theories



TYPES OF INTERPERSONAL RELATIONSHIP

Communal	- Where both parties concerned with benefits the partner gets
Exchange	- Where both parties are concerned about equal benefits

(Clark and Mills, 1979, Karremans and Finkenauer, 2020)

Voluntary	- Where the relationship is voluntary *e.g. spouse, friend*
Non-voluntary	- Where the relationship is not voluntary *e.g. parent, child, sibling*

(Jackson-Dwyer, 2014)

DIMENSIONS OF INTERPERSONAL CONNECTION

MEANING

The meaning placed on the connection by both parties

- e.g. working alliance, 'friendly', supportive connection/ relationship

DIRECTION

Vertical
- e.g.: Parent - child

Horizontal
- e.g.: Siblings, friends

IMPORTANCE

The importance placed on the connection by each party

(Karremans and Finkenauer, 2020)

INTERPERSONAL ATTRACTION

Familiarity - Similarity - Proximity - Self-disclosure

(Karremans and Finkenauer, 2020)

ATTACHMENT THEORY

The need to belong - Inherent human need to connect with others

(Bowlby, 1982, Bowlby, 1973, Bowlby, 1980, Finkel et al., 2017, Hazan and Shaver, 1994, Karremans and Finkenauer, 2020, Mikulincer and Shaver, 2012)

Producing the above diagram allowed me to develop a solid understanding of the way in which social theories might shape my thinking and interpretation of these data. This process also highlighted a need to further acknowledge other personal experiences and connections that might shape my understanding in the analysis and reporting phases of this study. Therefore, my place in the research (as an individual and researcher) is explored in the next section.

3.2.4 Placing myself in the research

After highlighting my professional background in Chapter 1 (Section 1.4.1) and my epistemological and ontological positions above, recognising the influence these had on my research felt like a natural progression. I could not ignore the influence of my philosophical positions or background experience, with a need to acknowledge *me* (as an individual) in the research (Braun and Clarke, 2013). It could be argued that my previous experiences or roles, might classify me as an 'insider'. As a Nurse, Service User, Informal Carer and Lecturer, I have intimate knowledge of HSC practice, research and the utility of HSC services in a variety of capacities. Furthermore, as an HSC professional who is now working in an educational setting, I could be considered an 'outsider'. However, I am still a Registered Nurse who adheres to the Nursing and Midwifery Council (NMC) professional Code (Nursing and Midwifery Council, 2018). Although I am not regularly working in a clinical setting, the influence of the knowledge I have, and knowledge I gain from students I support, is still applicable. This 'emic' (insider) knowledge can pose challenges with the-researcher being *too* close to the participants, the phenomenon of interest or the context, thereby, compromising objectivity (Chammas, 2020; Unluer, 2012). However, conversely, it can also mean the researcher is able to develop a deeper understanding of the phenomenon with their unique insights informed by their insider position (Chammas, 2020; Kerstetter, 2012).

With this in mind, and, in keeping with my interpretivist epistemological stance, objectivity was not something I was striving for. Instead, I wanted to acknowledge the subjectivity in my position(s), both past and present, and the influence it had over my interpretation of findings. Being open about my position offered an opportunity to promote clarity and transparency about any potential biases and the influence my background might have on the study (Moore et al., 2012). In Chapter 1 (Section 1.4.1), I outlined a variety of experiences from my backgrounds that could impact upon my position as a researcher in this study. These have been summarised and their potential influence has been considered in Table 12.

Table 12 Previous experiences that may influence my decisions in this study

Position	Experiential influence in this study
District Nurse	'Insider' knowledge, with experiences of working in an HSC system in a community setting within the region where the study was to take place. Intricate knowledge of the operational, strategic ways in which HSC organisations work together (or not). Assumption/experience: as a Community Nurse I had more time to build up relationships with people who accessed the service (in comparison to those in an acute setting), and that Community Nurses are a source of support for people who access HSC (discussed further in Section 4.7.5).
Feminist and social justice views	I hold a belief that women should be empowered to reach their full potential in society, which is defined only by an individual woman herself. I feel that everyone should be treated equally within the work environment. Social justice is an entitlement of all people, regardless of gender, race, religion, sexual orientation or socio-economic background (discussed further in Chapter 6, Section 6.4.1 and 6.5)
Specialist Nurse	Experience of working with people who have long-term neurological conditions, across acute (hospital based) and community HSC services in the region where the study was taking place. Aware of region-wide HSC services and some of the challenges that Service Users face when accessing them; particularly, those who have a long-term condition.
Lecturer	There could be an assumption by people who access and deliver HSC that I might be perceived as an expert in HSC research, policy and systems. Furthermore, knowledge of current HSC practices that students feed back to me, and my potential influence over HSC policy and practice (through consultations with HSC partnership organisations) should also be acknowledged.
Masters Student	Previous exposure to research methods (quantitative), albeit not at PhD level. Perhaps there would be an assumption (from others) that I 'know' how to conduct research.
HSC Service User	Regularly accessing HSC services in the community, working with HSC staff to meet my own health and wellbeing needs. Aware of contextual Service User needs.
Informal Carer (previously)	Experience of caring for a relative who had significant disabilities following a stroke. I supported them with personal care and working with HSC staff (in an informal Carer capacity). Experience of supporting relative and family through eventual HSC transition to private Nursing Home care. Aware of contextual informal Carer needs.

Position	Experiential influence in this study
Covid-19 pandemic	***Addendum: June 2021.*** *Lockdown from March to June 2020, during data analysis. Working from home. No contact with others. Heightened awareness of the impact of isolation and its influence on mental health in society.*

In addition to acknowledging previous experiences that had influenced the way these findings have been interpreted, I also felt it important to highlight my ongoing experiences in the Covid-19 pandemic (as per last entry in the table above). Although data had been collected prior to the first lockdown in March 2020, the analysis was ongoing during this period of lockdown. In the interest of promoting transparency, I wanted to acknowledge the potential influence of this experience, which will be discussed further again in Chapters 6 and 7 (Sections 6.4.1; 6.5; 7.2.4). The sections that follow will explore further influences over my thinking throughout this thesis, outlining my approach and methodological choices for interpreting my data.

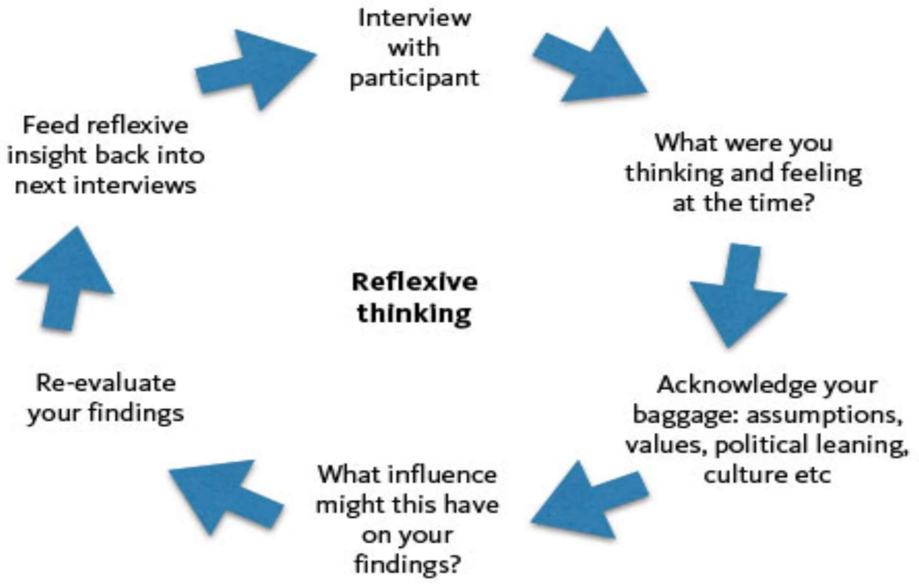
3.3 Adopting an inductive approach

The preliminary aim, objectives and research questions pointed towards findings that would be derived from my interpretations of reported experiences from proposed participants. In keeping with my interpretivist epistemology and my relativist and constructivist ontological lenses, an inductive approach to this study seemed appropriate; in that, knowledge is developed from the base up, moving towards generation of hypotheses (Bryman, 2016; Moule, 2015; Spencer et al., 2014b). Unlike a deductive approach (where theory is generated first and then tested), induction starts the reasoning process with raw data. This raw data is then used to develop an understanding, as a basis for generating new knowledge (Ormston et al., 2014). This fitted well with my underpinning philosophies, aligning with my understanding of how knowledge is generated and the constructs of reality being the 'eyes of the person' beholding it.

3.4 Reflexivity in this thesis

The inductive process of developing and constructing new knowledge has been captured in this thesis through reflexive journal entries. Reflexivity in qualitative research not only offers an opportunity to document new learning, by capturing self-development that occurs as a result of undertaking the research process, it can also promote rigour through conformability (Palaganas et al., 2017; Darawsheh and Stanley, 2014; O'Brien et al., 2013). The concept of reflection was not new to me, as I had applied its principles in relation to my clinical and teaching practice for many years. However, I was less confident in my grasp of reflexivity in qualitative research. To meet a self-declared need for direction on *how* to think reflexively and *become* a reflexive researcher, and to add clarity, transparency and uniformity to my reflexive journal entries, I utilised Wilkie's (2015) Cycle of Reflexive Thinking (Attia and Edge, 2017) (Figure 6).

Figure 6 Wilkie's (2015) Cycle of Reflexive Thinking



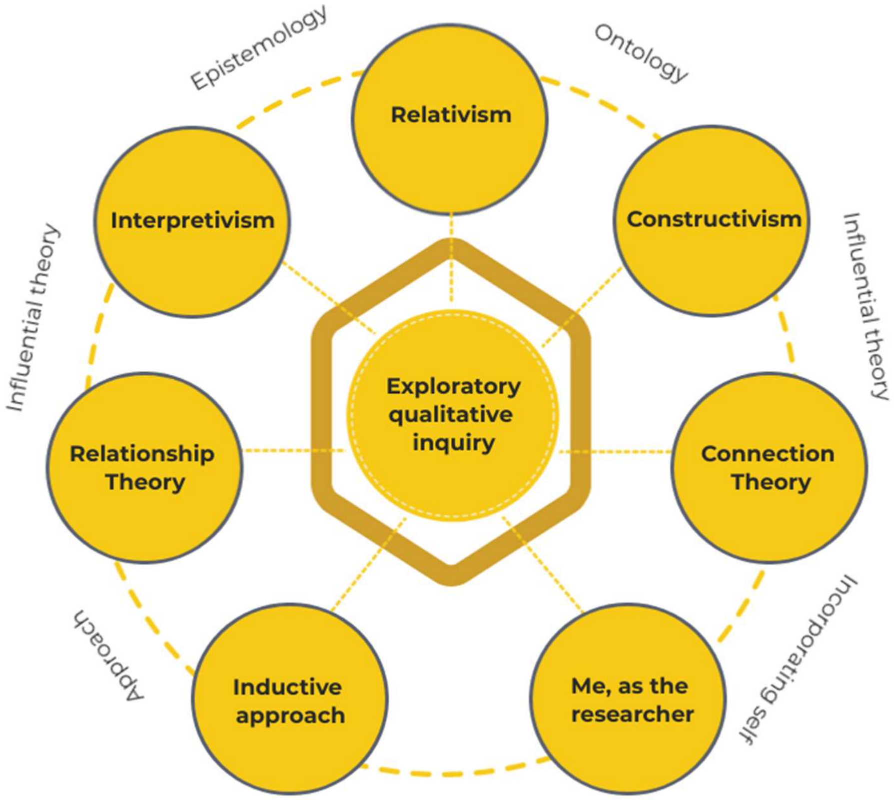
Although Wilkie's (2015) framework pertained specifically to the interpretation of findings, I found the generic principles were applicable to most topics of interest in my study. In these instances, I amended the wording to omit 'interview with participant' and replaced it with 'topic of interest' to broaden application of the framework to other areas of my development and understanding. For example, when I was developing methods and analysis, I used the framework to explore how data were shaping my understanding during data collection and analysis (explored further in Sections 4.6.7, 4.8.1 - 4.8.5). Adopting and using Wilkie's (2015) framework to document and develop my thinking promoted a continual cycle of self-reflection (Darawsheh and Stanley, 2014). Moreover, it further promoted transparency about my subjective role as the researcher within the research (as explored in Section 3.2.4 above).

3.5 Methodological choices: Mono-method qualitative inquiry

Preliminary research questions, aims and objectives and underpinning philosophies, were indicative of an exploratory qualitative study, because they looked to search for answers to topics that incorporated human responses to questions about their experiences. Not only that, the experiences were reality, as perceived by the individuals, and could not be measured in an objective, quantitative, mathematical way (Reiter, 2017; Reiter, 2013). Furthermore, as my integrative review highlighted in Chapter 2 (Section 2.6), there were many studies that had objectively quantified the needs of people who use IHSC. Their needs were often viewed as being met or unmet by asking HSC staff, rather than Service Users or their Informal Carers.

Data in this study were likely to be participants' descriptive words, reporting perspectives of HSC care and relationships through the eyes of the people who were delivering and receiving it. To embrace and understand this descriptive spoken-word data, a mono-method qualitative inquiry methodology was chosen (Johnson, 2014; Ormston et al., 2014; Parahoo, 2014; Braun and Clarke, 2013). To help me visualise the connections between my philosophical choices in this chapter, it was helpful for me to draw these together in a diagram (Figure 7). This diagram draws together the outer dark blue areas of the 'Research Onion' above (Figure 3) the underpinning philosophies, methodology, influential theories, and my resulting choice of a qualitative inquiry for this study. I used this as a point of illustration and reference throughout this thesis.

Figure 7 Underpinning philosophy and methodology



3.6 Chapter summary

This chapter has outlined the methodology and research design of this exploratory study. I draw on interpretivist, relativist and constructivist epistemologies and ontologies to explore experiences, needs and relationships in HSC. Recognising the importance of Social Psychology in exploring interpersonal relationships, I reflected upon how connection and relationship theories have underpinned my thinking throughout this thesis, built on a foundation of Attachment Theory. An inductive approach and a mono-method qualitative inquiry are highlighted as appropriate methodological choices, and the positions outlined have been drawn together to represent the philosophical core of this thesis. In my next chapter, I will outline how these philosophical positions were applied to an appropriate research design, methods and analysis, to bring this study to fruition.

CHAPTER 4 STUDY DESIGN: APPLICATION OF RESEARCH METHODS AND ANALYSIS

4.1 Chapter Overview

Chapter 4 justifies an appropriate study design that aligns the research aims with methodology discussed in Chapter 3. This design has also been influenced by feedback from people who use HSC services and members of the public. First, research methods and ethical considerations are explored, and the underpinning principles for data analysis are outlined. Limitations in selected research methods are deliberated along with ethical considerations, offering reflexive insight into my position as a researcher. Finally, the trustworthiness of this study is considered, highlighting strategies employed throughout the research process to promote safety, reliability, credibility and rigour.

4.2 Underpinning principles of study design

The design of this study follows the relevant layers of the 'Research Onion' framework, which offers a clear structure for reporting its design and research methods (Figure 3) (Saunders et al., 2011). Involving people who use HSC and members of the public in research, can improve the quality and relevance of a study. It acknowledges the value of research participants' experiences, helping to design a study that is closely aligned to their needs (Health Research Authority, 2019b). Involving people who use HSC services in the development and design process allowed *them* to be at the centre of this study. I wanted to co-produce a study that was relatable and relevant to their HSC. This section discusses the research strategy that was developed with them, including the time horizon, the research questions, aims and objectives and preliminary proposition statements.

4.2.1 Developing and designing a research study with people who use and deliver HSC services and members of the public

The inclusion of people who use and deliver HSC services helped to guide the design, questions and topics of this study. I wanted to ensure that people who use HSC services and members of the general public were involved in its development and conduct (UK Public Involvement Standards Development Partnership, 2019b). I felt strongly that people who use and deliver HSC services were the experts of their own experiences and health and wellbeing needs, and I wanted to produce a study *with* them that was relevant to *their* circumstances (Brett et al., 2014; Foot et al., 2014; Morrow et al., 2012).

To ensure that health and wellbeing needs and experiences (as identified by Service Users themselves) were explored fully, I consulted a local Patient and Public Involvement (PPI) group and HSC Staff Member group during study development. To allay the potential of being perceived by members of the group as an 'expert' in HSC (being a nurse), I took time to explain my role and build a relationship with them as a researcher and fellow member of the HSC community in this context. Preliminary findings from the literature review were shared verbally with these groups, and they were invited to discuss and give feedback on the proposed study design. Their participation helped to strengthen the co-operative nature of this research, promoted patient and public inclusivity, and offered an opportunity to discuss pertinent points and questions about the research (Appendix 3). HSC Staff Members were also invited to do the same (Appendix 4).

Feedback from these groups highlighted their desire to know more about perceived health and wellbeing needs. They also wanted to know more about information and communication, involvement of Carers and Service Users and relationships that were important to them in HSC. Feedback from both groups was used, in conjunction with current knowledge in the field (Section 1.3) and the literature review findings (Section 2.4), to develop the study design. Their feedback has been summarised and included Table 13.

Table 13 Summary of PPI and Staff Member groups feedback

PPI group wanted the study to explore participants' perceptions of:	HSC Staff Member group wanted the study to explore participants' perceptions of:
Clarity of information	Relationships
Navigating systems of care	Equipment
Communication	Communication
Their own health and wellbeing needs	Service user needs
	Service user voice and experiences
	Family Carer involvement

4.2.2 Research strategy: Exploratory case study design

The exploratory research strategy for this study was informed by the preliminary research questions (Section 2.11), the underpinning qualitative methodology (Section 3.4) and the feedback from PPI groups (Table 13). PPI group members had emphasised the value of applying a multi-faceted focus for the study, and a desire to learn about experiences of HSC from multiple perspectives. They wanted to understand more about the experiences of people who used HSC across their local areas *and* those who supported them (multiple populations).

Equally, the nature of the phenomenon being explored was complex, and the inclusion of a variety of different geographical contexts across multiple HSCP localities added to this complexity. These geographical divides encompass three HSCPs that are tasked to progress legislative changes into HSC practice. As outlined in Chapter 1 (Sections 1.3 and 1.4.3), each HSCP has an integration strategy, system and budget to meet health and wellbeing outcomes in their area. As HSCPs have independent jurisdiction over how monies were used, service delivery was different in all three HSCP localities. This presented an opportunity to explore a diverse range of experiences across the region (Burgess, 2016; The Scottish Government, 2015b). Moreover, I also wanted to explore areas of interest identified in the literature review, namely experiences of communication, relationships, and health and wellbeing needs, within the contexts (Chapter 2, Section 2.4).

A variety of potential research strategies were considered to explore these collective complexities and phenomena. The objective properties of strategies and methods in natural sciences (for example, those concerned with prediction and experimentation) did not appear suited to exploring the human meaning from anticipated social-world data. Nevertheless, exploring data of a social-world nature was a pivotal aim of this study. Therefore, strategies encompassing the underpinning qualitative and relativist methodological stance on knowledge generation were reviewed (Bryman, 2016; Parahoo, 2014; Spencer et al., 2014b; Braun and Clarke, 2013). I revisited the proposed research questions, PPI and HSC staff feedback and looked for a research strategy. It was clear to me that the strategy needed to incorporate multi-faceted descriptive participant data, across a variety of locality settings.

Initially, I considered a grounded theory approach, focusing on the generation of theory that is ‘grounded’ in the data. The iterative processes were in keeping with the inductive epistemology I had favoured in Chapter 3 (Section 3.3) (Bryman, 2016). However, the aim of this study was not to develop new concepts as building blocks with which to generate new theory. Instead, it looked to represent the reality of experiences for people who were intrinsically linked to other participants in the study. I felt the context of that association had to be more explicitly bound and drawn out in the data. I discounted an ethnographic observational research strategy after concluding that data about participants could not be 'observed' by another, such as the researcher. Instead, it had to reflect the participant's unique perception of their own experiences. This view was further compounded by my relativist epistemological stance, where knowledge about such personal accounts of human experience could only be generated from the perspective of the individual participant (where knowledge on the topic relates to the person that is beholding it). This study required a strategy that would embrace these complexities, offering a platform for multiple (and linked) in-depth descriptive accounts of experiences in HSC to construct new knowledge on the topic.

A qualitative case study appeared suited to generating the in-depth and descriptive data on experiences this study sought to explore. It embraced the participants' unique perspectives, whilst recognising a need for them to be bound in accordance with their connection to other people in their case, and within their HSCP localities (Thomas, 2016). Moreover, it encouraged the assimilation of multiple data sources to enrich understanding of the context and 'completeness' of those unique experiences (Yin, 2018; Bryman, 2016; Thomas, 2016; Njie and Asimiran, 2014; Moore et al., 2012). However, case study research methods and their purpose can often be misrepresented and misunderstood by researchers. For example, a poor understanding and definition of the case could diminish the trustworthiness of the whole study (Baškarada, 2014).

To avoid this, an appropriate framework was needed to protect the integrity of the study and promote confidence in data collected, methods, analysis and findings (Tight, 2017). Several frameworks are available, with some focusing more on mixed-methods and quantitative case study strategies. Most operate on the premise of choices of what and how to study a phenomenon, and how analysis could be undertaken (Tight, 2017). Yin's (2018) components of case study research, with their clear and straightforward structure for any case study. In the early stages of this study whilst feeling relatively inexperienced in research methods, I found it difficult to apply Yin's (2018) principles to my solely qualitative study. At times, I perceived that the framework leaned more towards quantitative methods. I resolved to read wider for other case study frameworks that might be more suited to the qualitative nature of this study, considering frameworks from Tight (2017) and Thomas (2016). However, as time progressed, my understanding of research methods developed and I became more familiar with Yin's (2018) work, gaining confidence in how it might be applied to solely qualitative research.

Yin's (2018) framework case study strategy was proposed to the PPI and HSC staff groups. Their feedback, along with the above rationale, the underpinning methodology and literature review findings, led me to adopt a qualitative multi-case study strategy. Yin's (2018) components offered a logical plan for progressing this strategy, and the remainder of this chapter largely follows these principles (Table 14). The first four of these components relate to identifying appropriate methods for data collection (components 1-4), with the last relating to anticipated methods of analysis (component 6). However, to promote the integrity of this study I felt it important to modify this model, adding further explicit sections on ethical considerations and promoting trustworthiness (components 5 & 7). Being clear on the necessary components of this study's design, I then refined the research question, aim and objectives, in the section that follows.

Table 14 Components for case study design

Yin's (2018) components for case study design *(modified)*	**Corresponding section in this thesis**
1. A case study's questions	4.3
2. The propositions, if any	4.4
3. Its cases	4.5
4. The logic linking data to the propositions	4.6
5. Ethical considerations, reviews and approvals	4.7
6. The criteria for interpreting the findings	4.8
7. Promoting trustworthiness in this study	4.9

4.3 Refining research questions, aims and objectives with PPI groups

To ensure that this study would be relevant and meaningful to people who use HSC services, and recognising the value of their involvement in promoting this, the preliminary research question, aim and objectives (Section 2.11) were proposed to PPI and HSC staff groups (Black et al., 2018; Morrow et al., 2012). In summary, they indicated that they wanted to know more about relationships, needs and experiences of people who use HSC. Using their feedback, the findings of the literature review (Section 2.4) and current knowledge (Section 1.3), the preliminary research question (Section 2.11) was expanded to incorporate three pertinent issues and strengthen the focus on relationships (Table 15).

Table 15 Case study research questions

Research Questions	
Needs & Experiences	What are the perceived health and wellbeing needs of HSC Service Users and the people who support them at home?
	What are the experiences of Service Users and the people who support them at home, when accessing or providing HSC?
Relationships	How do the relationships between Service Users and the people who support them at home, influence health and wellbeing and experiences of HSC?

On reflection, it seemed the ‘relationships’ topic had been misrepresented in the preliminary research question, aim and objectives. In the earlier versions (Table 9; Table 10), I had referred to the relationship between health and wellbeing needs and experiences of HSC. However, as relationships between individuals in HSC was a pertinent point from PPI group members and a key finding of the Critical Integrative Literature Review (Section 2.4.1), it warranted further exploration (leading to its inclusion above in Table 15). However, the original focus upon the relationship between health and wellbeing needs and experiences of HSC, remained a topic of interest. Perhaps more accurately, it was how health and wellbeing needs *influenced* experiences of HSC that I wanted to investigate, rather than the relationship between them. This was included in revisions to the original aim and objectives of the study and incorporated in Objective 3 (Table 16). Reviewing these then prompted me to compile proposition statements that are outlined in the next section.

Table 16 Research aim and objectives

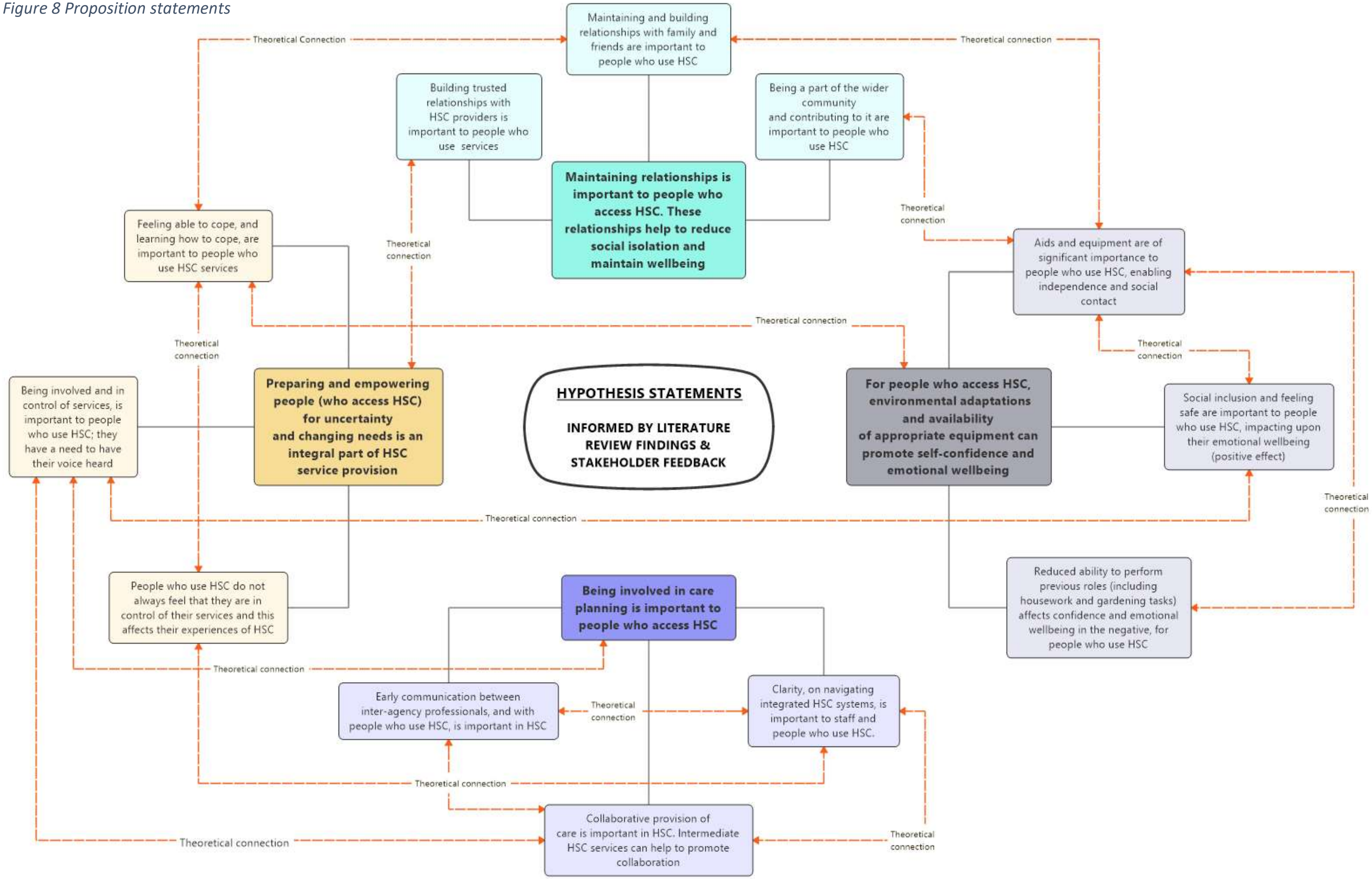
Research Aim
To understand the health and wellbeing needs, relationships, and experiences of HSC Service Users and the people who support them at home (key stakeholders).
Research Objectives
1. To explore the health and wellbeing needs of key stakeholders in HSC.
2. To explore key stakeholders' experiences of HSC.
3. To investigate how health and wellbeing needs influence experiences of HSC.
4. To explore relationships and connections between key stakeholders in HSC.
5. To investigate the significance of key stakeholder relationships on health and wellbeing, and experiences of HSC.

4.4 Proposition statements

In accordance with component two of case study design (Table 14), proposition (or hypothesis) statements were considered. Each statement directs attention towards a phenomenon of interest identified from the literature review findings, the research question, aims and objectives and the above-mentioned feedback from the PPI and HSC staff groups (Yin, 2018; Lee and Saunders, 2017). However, not all case studies will require proposition statements that direct focus towards topics of interest; some might outline a general purpose and principles for exploration (Yin, 2018; Thomas, 2016). The concept of acknowledging and formalising propositions ahead of data collection and analysis was not freely embraced by me in the first instance. I felt that introducing a pre-conceived idea or proposition may go against the inductive approach to this study that looked to build knowledge from the bottom-up (outlined in Chapter 3, Section 3.3) (Bryman, 2016; Braun and Clarke, 2013; Saunders et al., 2011). The risk of diluting or influencing the meaning and interpretation of the participants' experiences caused me some concern.

As my thinking and understanding developed, I recognised that it would be impossible to start a study with a ‘blank canvas’, without recognising the influence of my previous experiences and knowledge gleaned from the literature. Furthermore, acknowledging theoretical orientations before undertaking research can help to reduce bias in a study, and it offers a valuable opportunity for recognition of the researcher’s position (Yin, 2018; Parahoo, 2014; Moore et al., 2012). Statements were subsequently drawn up and potential theoretical or conceptual connections between the propositions were identified (Moore et al., 2012). They represented key concepts from the literature and provided a theoretical ‘blue-print’ for the study, recognising my previous knowledge and exposure to the research topic and my learning from the literature (Yin, 2018; Baxter and Jack, 2008). Propositions focused on aspects of wellbeing in IHSC for people who accessed services. They explored social isolation, changing health and wellbeing needs, environmental adaptations, equipment and user involvement in their own care. These statements were used to help shape the study when defining cases, linking data to the propositions and interpreting the findings, and have been included below (Figure 8) (Yin, 2018).

Figure 8 Proposition statements

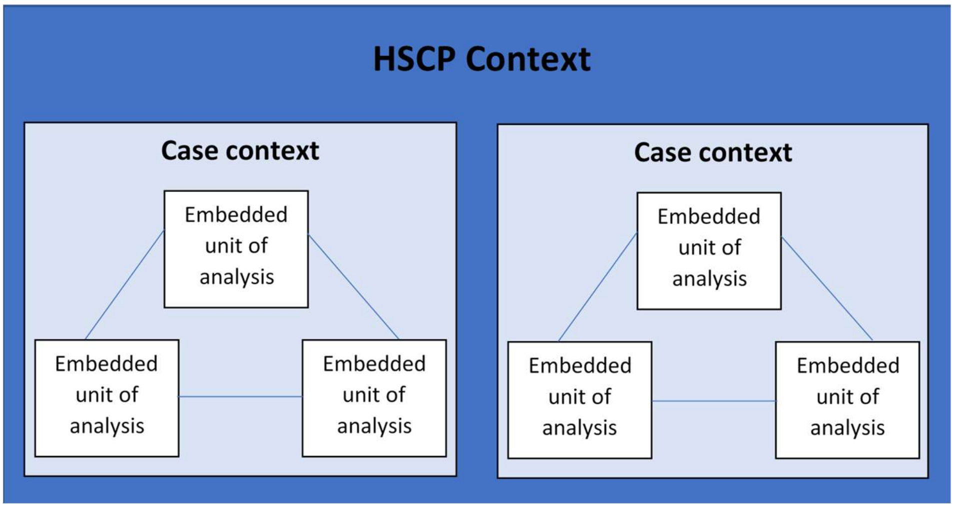


4.5 Defining the case

When considering the definition of a case, I questioned how a 'case' should be constructed. First, I considered a singular case study, where a single case would be placed in one context. However, my earlier decision to explore the experiences of participants across three HSCP localities suggested that multiple contexts should be incorporated, not just one. This study also aimed to include a variety of participant groups within each of these contexts. In addition there was a need for further linking of specific participants who were interconnected to each other, for example, a Service User, their Informal Carer and an HSC Staff Member who helped them at home.

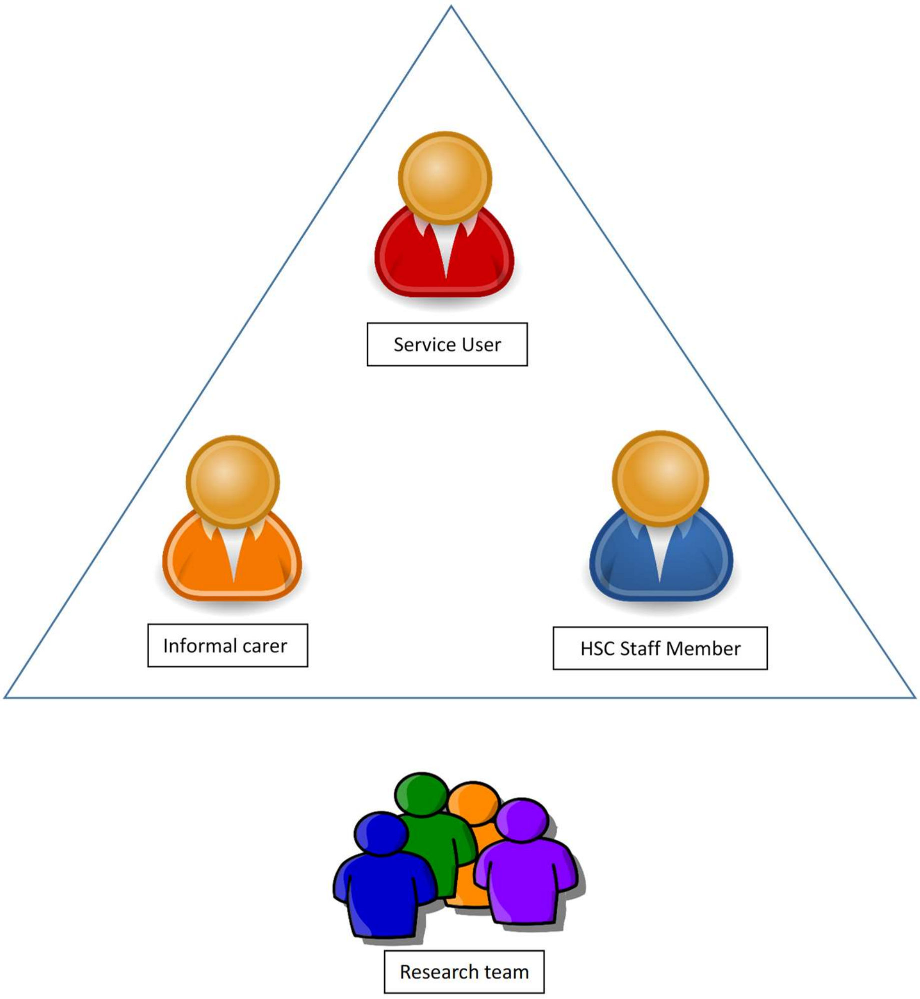
As the literature review highlighted the importance of Service Users' relationships with those who support them, and in keeping with an embedded case study design, each Service User participant could not be considered as 'a case' in isolation. Including perspectives of people who support Service Users to meet their HSC needs would add a richer, multifaceted, level of understanding around experiences of HSC. Therefore, an embedded or 'nested' multi-case study design was adopted to allow several groups of inter-connected participants to be placed within the specific context of their case; each participant represented a 'unit of analysis' (Yin, 2018; Lee and Saunders, 2017; Thomas, 2016). Each case was then placed within the context of their corresponding HSCP (see Figure 9).

Figure 9 Embedded multi-case study design



This model was then replicated across all three HSCP localities, where different strategies for delivering HSC were employed to meet the needs of their respective populations. An embedded design promoted in-depth exploration of the experiences of HSC from multiple, inter-connected, perspectives. Accessing multiple sources of data promoted an in-depth understanding of the social phenomenon (experiences of HSC) through contrasting units of analysis in each case (Yin, 2018; Bryman, 2016). Each case was defined as one Service User and two people who supported them at home: an Informal Carer and an HSC Staff Member (Figure 10).

Figure 10 Case Diagram



Defining the case in this way supported the recognition that each participant brought their own unique, but interconnected and equally valuable, experiences of HSC to the case (Yin, 2018). As the recipients of care, Service Users were asked to identify two people who fitted their perception of this criterion and might be willing to participate in the study with them. After defining the case, I then considered how the data could be linked to the above propositions through my research methods, which are outlined in the section that follows.

4.6 The logic linking data to the propositions: Research methods, time horizon, techniques and procedures

Research methods, a time horizon, techniques and procedures were devised with underpinning methodologies and the propositions statements in mind, to address the research aim and questions and link the data to the propositions. Ontology, epistemology and methodology are influential in deciding appropriate methods for any study (Braun and Clarke, 2013). As discussed in Chapter 3 (Section 3.2.1), since this study aims to explore human meaning, methods encompassing a relativist stance on knowledge generation (through interpretivist and constructivist philosophical lenses) were employed and formalised in a research protocol document. This protocol offered explicit guidance on planned research techniques and procedures throughout the research process (Bryman, 2016; Parahoo, 2014; Spencer et al., 2014b; Braun and Clarke, 2013).

Both longitudinal and cross-sectional timeframes (or horizons) were considered for this multi-case study. A longitudinal case study would offer the opportunity for me to connect with participants and explore their experiences over a particular period, which can be advantageous if a phenomenon develops over time (Moule et al., 2017; Lewis and McNaughton Nicholls, 2014; Parahoo, 2014). As the findings from the literature review highlighted the importance of relationships for people who use HSC, this option was appealing. A bond of trust could develop, resulting in deeper levels of disclosure and understanding, as a rapport built between a participant and I over time.

However, a longitudinal timeframe could lead to increased attrition, subsequently resulting in missing data and reduced reliability (as a result of participant death or withdrawal) (Caruana et al., 2015; Jones et al., 2015). Furthermore, it can be more costly and time consuming. Time-constraints of my studentship, efficient project time-management and potential cost implications of participant follow-up, were influential in selecting a cross-sectional timeframe. The benefits of adopting this approach were three-fold. First, a shorter time frame captured the complexity and diversity of different stages of participant experiences, providing a snapshot of reality for the participant at that point-in-time. Second, it promoted greater efficiency in exploring a number of data sets across different units of analysis. Finally, it facilitated adherence to agreed study timeframes with funders and sponsors (Bryman, 2016; Parahoo, 2014).

4.6.1 Contextual 'sampling' across multiple Health and Social Care Partnership localities

In this multi-case study, the context of HSC services was significant in selecting participants. Sampling in case study research does not aim to represent a portion of a whole population (Yin, 2018; Thomas, 2016). Instead, a case study looks to represent the 'completeness' of a point of interest (or phenomenon – experiences of HSC), and sampling can be described as a 'choice' or 'selection' of participants (Thomas, 2016). As discussed in Chapter 1 (Section 1.4.3), there are three HSCPs operating across the regional area of this investigation [HSCP 1; HSCP 2; HSCP3]. Each HSCP has an independent strategy for delivering HSC and meeting population needs, with variances in the way in which this is achieved in each area. To reflect the diversity of the experiences and health and wellbeing needs of participants across these areas, this study aimed to select two cases of three participants. This proposed sample not only aimed to offer representation from each of the three contextual HSCP localities, it also aimed to offer an opportunity for in-depth exploration of experiences via two cases of three participants in each area (Table 17).

Table 17 Proposed participant sampling

HSCP Area	**Cases**	**Service User participants**	**Informal Carer participants**	**HSC Staff Member participants**
HSCP 1	2	2	2	2
HSCP 2	2	2	2	2
HSCP 3	2	2	2	2
Total	**6**	**6**	**6**	**6**
Total individual participants		**18**		

4.6.2 Recruitment strategy

All participants were recruited between November 2019 and February 2020 through one of two recruitment strategies. The first involved the distribution of an advertisement addressing all three participant groups (approved by the Executive Board and Chief Officers of each HSCP and through the regional HSC Research and Development departments). These were posted to social media channels via my professional Twitter and Facebook accounts and those of the sponsoring and funding organisations (Appendix 5). Recruiting via this route generated public and HSC staff awareness of the study, resulting in ten enquiries.

The second recruitment method was through direct contact with an HSC Staff Member who had received a letter of invitation. A letter-of-access to participants was sent to the Chief Executive of the HSCP localities, along with the cascade letter of invitation and further information about the study (Appendix 6). HSC staff were also asked to pass information on to Service Users and Informal Carers who may have been interested in taking part. Five enquiries were received via this strategy, but NHS and local authority cascade recruitment was challenging. Some staff disclosed they deleted the email as they felt they did not have time to read it or to participate. However, invitations had also been cascaded with wider HSC providers, namely, within private and third sector HSC organisations. These generated a further sixteen enquiries.

The above multifaceted recruitment process resulted in a total of thirty-one enquiries. In addition, there were two further enquiries where the source of information about the study was not disclosed. Those who enquired were advised that Service User, Informal Carer and Staff Member participants should be recruited simultaneously. Every person who enquired was given written information about the study in a Participant Information Sheet (PIS) (Health Research Authority and Medical Research Council, 2020; Good Clinical Practice Network, 2019; NHS Research Scotland, 2016) (Appendix 7; Appendix 8). A copy of the PIS was sent to the participant's home address in printed form, or electronically via their personal email address. The PIS was written in plain language specific to their projected participant group, namely, Service Users, or the people who helped them at home (Informal Carers and Staff members).

4.6.3 Ethical inclusion and exclusion criteria

Inclusion and exclusion criteria were established prior to recruitment to this study. To be included, potential participants were required to meet five inclusion criteria (Table 18). Any potential participants who *did not* meet these were excluded from taking part.

Table 18 Inclusion criteria

Inclusion Criteria
1. Age 18 years or over
2. Living in one of the selected HSCPs
3. Able to speak and read in English
4. Using HSC services or Currently supporting someone who is using HSC services: Informal Carer or HSC Staff Member.
5. Has capacity to give informed consent.

In addition to the above, the independent Ethical Review Committee (REC) recommended further specific exclusions, to reduce the risk of harm for individual participants. They asked for specific groups to be excluded from this study, namely, people who had learning difficulties, profound mental health issues and vulnerable adults who lacked capacity to give informed consent (Health Research Authority and Medical Research Council, 2020). Their rationale for this was based on reducing harm to participants. They felt that people in these groups should be excluded because of their increased vulnerability, compared to the anticipated multitude of potential participants who had neither a learning disability nor a mental health issue. The ethical implications of these exclusions are discussed further below and again in Sections 4.6.5; 0; 7.2.4 and 7.5.

It was important to me to avoid marginalising people who were living with a learning disability or mental health problem. The positive contributions of people who live with these issues are widely acknowledged in HSC research, adding depth of understanding and promoting relevance to practice areas (Mietola et al., 2017; National Institute for Health Research, 2013; Szmukler et al., 2011). In the interest of promoting transparency, I recognised that I was not an expert in these areas. I was keen to explore definitions of ‘profound’ mental health issues, vulnerability and learning disabilities.

I sought further guidance and clarification from fellow researchers working in mental health and learning disability fields, in relation to defining these issues. Their feedback reiterated my thoughts above on the importance of including people who have a learning disability or mental health issues; it was instrumental in helping me to define my position and a way forward with the REC recommendations. I felt potential participants themselves were best placed to self-determine and disclose any profound mental health issues, vulnerabilities or learning disabilities they were living with that might impact upon their participation in the study. Screening questions were devised to promote self-disclosure, and these are outlined in the section that follows.

4.6.4 Screening

After reviewing the PIS, answering any resulting questions and expressing a desire to take part in this study, all potential participants were screened to determine their eligibility. I compiled a comprehensive screening record in Microsoft Word Excel (Microsoft® Corporation, 2016a), incorporating questions related to the above inclusion and exclusion criteria. Screening questions were devised to act as prompts. Potential participants were asked about any perceived vulnerabilities and their capacity to take part in this study. If a potential participant answered ‘no’ to any of questions 1-5, or if they answered ‘yes’ to questions 6 or 7 (Table 19), they were informed that they did not meet the inclusion criteria (in accordance with feedback from the Research Ethics Committee, Section 4.6.3).

Table 19 Screening questions

Screening Questions	
From Inclusion/exclusion criteria:	
1. Do you live in HSCP areas 1,2 or 3?	Yes/No
2. Are you over 18 years old?	Yes/No
3. Do you speak English? If English is not your first language, would you like an interpreter to be available when we meet?	Yes/No Yes/No
4. Are you currently receiving help, or supporting someone who receives help, from HSC services?	Yes/No
5. Are you legally able to make your own decisions? (or does someone have an active power-of-attorney to help you make decisions)	Yes/No
Following Research Ethics Committee review:	
6. Do you consider yourself to be a vulnerable adult or living with a learning disability?	Yes/No
7. Do you have any physical or profound mental health issues that you feel might prevent you from taking part? *Prompt on 'profound': does it impact on your decision-making or ability to function day-to-day?*	Yes/No

For question 7, some potential participants were looking for clarification around terminology, asking 'what do you mean, profound?'. I recognised the subjective nature of this term, but in keeping with my relativist ontological lens, I felt it was appropriate for the participant (as the expert of their own issues) to decipher a meaning relating to their own reality. However, I also acknowledged their need for further clarification and devised a prompt to help them formulate their own definition of 'profound'. Those who asked this question (n=3) shared that they had experienced depression, anxiety or worry. However, they did not feel these could be classed as profound mental health issues and they were subsequently recruited to the study.

Every potential participant who met the above criteria was recruited to the study. Any potential participants who did not meet the required criteria in the above table were thanked for their interest and time to-date and informed they would not be able to participate in the study. This applied to three people; one was 17 years old, and two were not currently receiving HSC services. Responses to screening questions were recorded in the abovementioned record, along with interview dates and consent status. For participants who met the screening criteria, a mutually convenient appointment was agreed to clarify any issues from questions raised, promoting participant understanding, informed consent and their right to withdraw at any time in the process. To promote equality and inclusion across the diverse population in the regional area, participants whose first language was not English were to be offered interpreter services if needed, but none were required (Health Research Authority, 2015). Once any questions had been satisfactorily answered, written consent was obtained and we proceeded with the interview (in line with local informed consent guidance) (Health Research Authority and Medical Research Council, 2020; Health Research Authority, 2019c).

To promote inclusivity, interview locations were negotiated with participants, on the basis of convenience, and an adequate level of comfort, privacy and quiet (King et al., 2018; Mann, 2016). Most commonly, this was at home for Service Users and Carers, or a place of work for HSCPs. To manage and track progress of recruitment, participants who agreed to an appointment were assigned a preliminary case letter (to identify the inter-connected dataset they belonged to) and participant ID code (to differentiate them from others in their case) (Table 20).

Table 20 Preliminary case and participant ID codes

Anticipated case letter:		**A**	**B**	**C**	**D**	**E**	**F**	***Total***
Location:		HSCP1	HSCP1	HSCP1	**HSCP2**	**HSCP2**	HSCP1	
Proposed participant Codes:	*Service Users*	A-SU	B-SU	C-SU	D-SU	E-SU	F-SU	6
	Informal Carers	A-IC	B-IC	C-IC	D-IC	E-IC	F-IC	6
	Staff Members	A-SM	B-SM	C-SM	D-SM	F-SM	F-SM	6
Total:		3	3	3	3	3	3	***18***

Preliminary case letters were assigned alphabetically in the order participants came forward. Despite extensive advert distribution and cascade emails across all three HSCP localities (to achieve contextual sampling), no participants were successfully recruited from HSCP 3. Reasons for this were unclear. However, informal feedback from HSC staff suggested there may be a geographical divide. Historically, HSCP 3 identified themselves as a ‘separate entity’ from the wider regional HSC area, something that was perhaps reflected in the alternative framing of their HSCP strategy (discussed in Chapter 1 (Section 1.4.3). The prospect of an ‘external’ researcher attending may not have been welcomed, despite my best efforts to attend local events in the area to be participant-facing through existing HSC staff networks. I was disappointed that I could not recruit from this area, especially with the notable difference in the way in which their strategy had clearly aimed to embrace the sprit and principles of co-production (Section 1.4.3). I believe inclusion of experiences from that area would have enriched the data set and offered further opportunities for cross -case analysis.

4.6.5 Withdrawal of interest in the study

During the post-screening face-to-face appointment, three potential participants exercised their right to withdraw their interest in the study, prior to giving consent for enrolment [B-IC, F-SU & F-IC]. After enquiring about the exclusion criteria for the study, proposed participant B-IC strongly objected to the ethical exclusion criteria pertaining to people who had a learning disability. I clarified that I recognised the value of contributions from people with learning disabilities, but the REC panel had indicated the ‘potential for harm’ for this vulnerable group was greater. However, B-IC explained her son had a learning disability. She felt strongly that this *perceived* vulnerable group could make a valuable contribution to the study, and they should not be excluded on those grounds. I respected and accepted F-IC’s decision and clarified whether Service User [B-SU] and Staff Member [B-SM] still wished to proceed with enrolment in the study. B-SU & B-SM both indicated that they wished to continue, resulting in a dataset of two for Case B.

On the day of a planned interview appointment, F-SU felt unwell and decided not to enrol in the study. Consequently, F-IC chose not to enrol in the study too. However, the individual interview for F-SU’s Staff Member (F-SM) had already been completed immediately prior to F-IC’s appointment, resulting in a data set of one for Case F. This meant that data for F-SM was already recorded, with consent to participate and share her experience of HSC. The supervisory team and I discussed the ethical implications of including data from F-SM. F-SU and F-IC had not consented to F-SM discussing the care she provided for F-SU, or interactions she had with both F-SU and F-IC. Although F-SM had discussed care for F-SU at length, she had also discussed her generic experiences of HSC (as most Staff Member participants did, giving anonymous examples of care for other people they had helped). Further consultation with members of the local ethics committee led me to the conclusion that the data provided by F-SM should be included. However, any data relating specifically to F-SU and F-IC were omitted as they had not consented to the disclosure of information that related to them.

4.6.6 Confirmed selection of participants

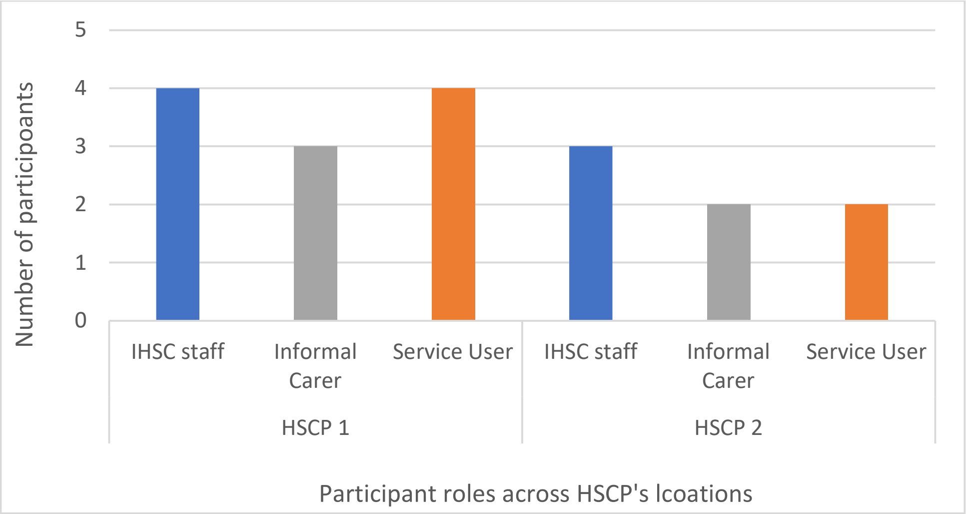
The recruitment process was still in progress when the participants discussed above withdrew their interest in taking part in the study. Therefore, a further case of three participants was successfully recruited, ensuring the target numbers of total participants were met. The confirmed final sample, along with case letters and participant ID Codes, are included below (Table 21).

Table 21 Confirmed selection of participants - case letters and participant ID codes

Case:		**A**	**B**	**C**	**D**	**E**	**F**	**G**	***Total***
Location:		HSCP1	HSCP1	HSCP1	**HSCP2**	**HSCP2**	HSCP1	HSCP1	
Participant Codes:	*Service Users*	A-SU	B-SU	C-SU	D-SU	E-SU	*F-SU w'drew*	G-SU	6
	Informal Carers	A-IC	*B-IC w'drew*	C-IC	D-IC	E-IC	*F-IC w'drew*	G-IC	5
	Staff Members	A-SM	B-SM	C-SM	D-SM	E-SM	F-SM	G-SM	7
Total participants:		3	2	3	3	3	1	3	***18***

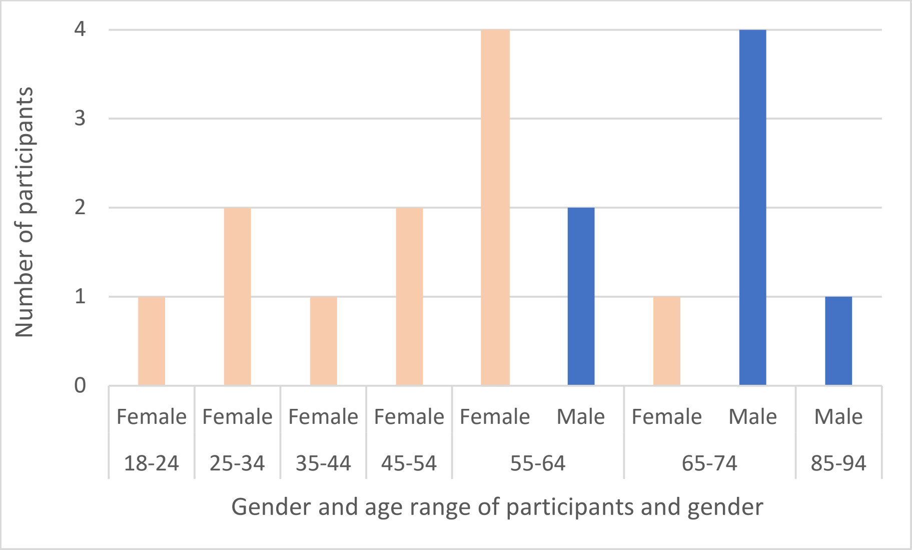
Although the target number of Service User participants was recruited (six), Informal Carer participants (five) were lower than anticipated by one. Staff Member participants were higher than anticipated (by one) across the two HSCP localities, attributed to withdrawal of the Informal Carer in Case B, and the withdrawal of Service User and Informal Carer in Case F (Figure 11).

Figure 11 Location of recruited participant groups



The confirmed sample included eleven women and seven men across a range of ages, with women largely being younger than men. The most common age bracket for women was 55-64, with 65-74 being most common for men (Figure 12).

Figure 12 Count of age groups by gender



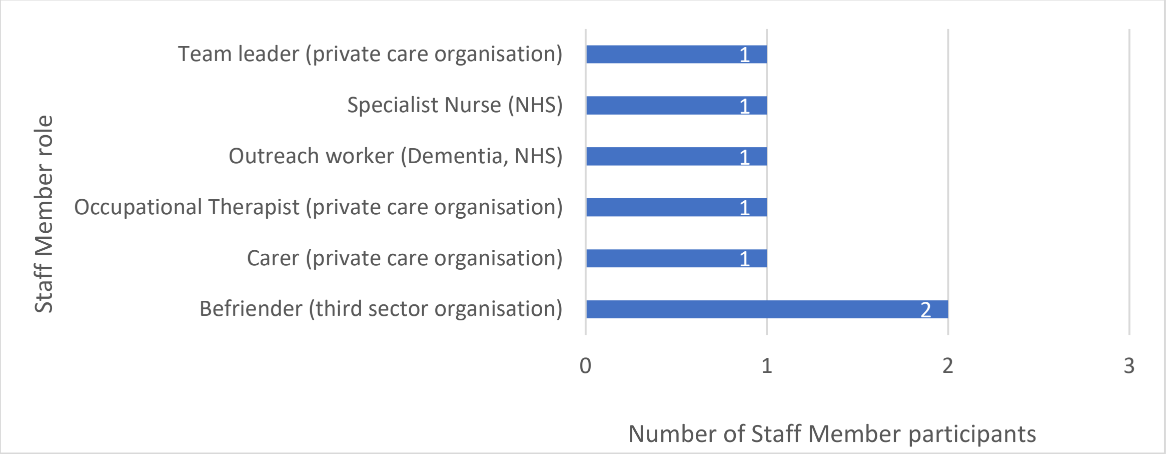
Service User participants had asked someone, whom they identified as an Informal Carer, to take part with them. In each case, they identified someone who was their spouse or child, outlined below in Table 22.

Table 22 Relationships between Service Users and Informal Carers

Case	Service User	Informal Carer	Relationship
A	A-SU	A-IC	Husband - Wife
B	B-SU	-	-
C	C-SU	C-IC	Wife - Husband
D	D-SU	D-IC	Wife - Husband
E	E-SU	EIC	Father - Daughter
F	-	-	-
G	G-SU	G-IC	Father - Daughter

For Staff Members who were recruited to the study, two participants were working within the NHS [A-SM, C-SM]. Three participants were from private care agencies [B-SM, D-SM, E-SM] and two participants worked within a voluntary third sector organisation [F-SM, G-SM]. Their roles within these organisations are outlined below in Figure 13.

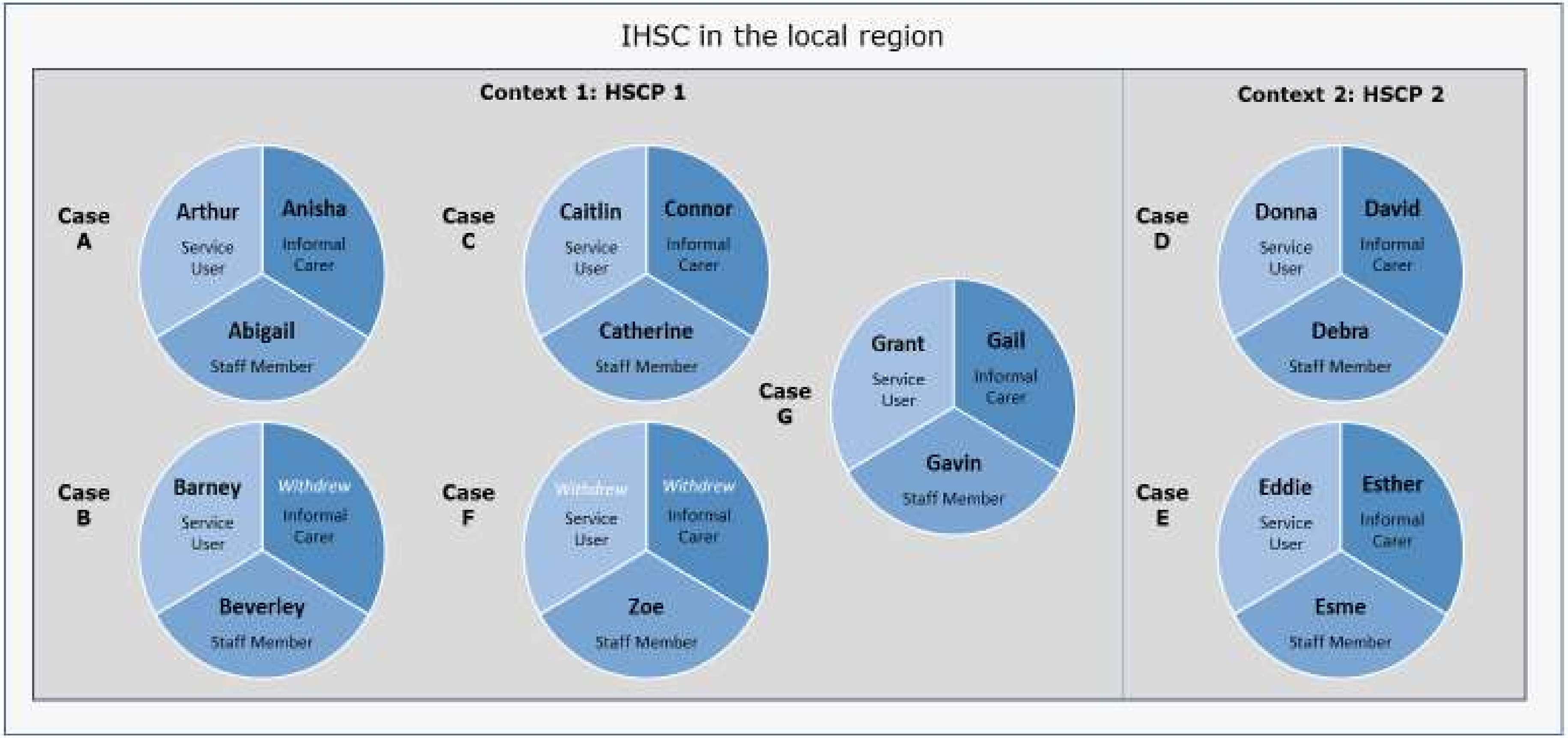
Figure 13 Role and sector of recruited Staff Members



All Service User participants indicated they were living with one (or more) long-term condition(s): multiple sclerosis (MS) (n=3; C-SU, D-SU, E-SU); chronic kidney disease and heart failure (n=1; B-SU); chronic obstructive pulmonary disease (COPD) (n=1; G-SU) and early-onset dementia (n=1; A-SU). These resulted in reduced mobility for three Service User participants (B-SU, C-SU, G-SU). Four of the five Informal Carers shared conditions they were living with [A-IC, C-IC, D-IC, E-IC]; two out of whom highlighted they were living with Diabetes and/or anxiety, worry or depression [A-IC, E-IC]. Three of those Informal Carers reported having multiple conditions [A-IC, D-IC, E-IC].

Initially, I referred to participants by the ID code which I had assigned them upon successful recruitment (see Table 21). However, I quickly became uncomfortable with this lettering as I had already started to identify with my participants as individuals and their data. To promote a more person-centred connection between the participants, their data and myself, pseudonyms were allocated to each participant. Nevertheless, I was mindful this could also promote a sense of personal attachment to the participants, potentially compromising my objective position as a researcher. To that end, I endeavoured to strike a balance between suitable levels of detachment from the participants, whilst adopting pseudonyms and recognising that complete objectivity was impossible in the qualitative nature of this study (as acknowledged in Sections 1.4 and 3.2.4) (Bryman, 2016; Braun and Clarke, 2013). To facilitate easy identification of a participant's case and their associated participants, the first letter of their pseudonym correlated with the case they belonged to, for example Arthur, Anisha and Abigail. There was one exception to this rule: Case F had only one participant whom I named Zoe. This helped me to identify at a glance that there were no other data in her case during analysis. Participant pseudonyms, their grouping, the case they belonged to and the contextual location of their HSCP are outlined in the overview below (Figure 14).

Figure 14 Overview of participants recruited to this study



4.6.7 Data collection techniques: Semi-structured interviews

Data collection techniques appropriate for a qualitative, interpretive methodology were considered, namely, qualitative surveys, diaries and focus groups (Braun and Clarke, 2013). Qualitative surveys, although suited to very sensitive topics (through the anonymity offered to participants) felt somewhat prescriptive in their nature, with little opportunity for open discussions and probing further on a topic. Furthermore, qualitative participant diaries that aimed to collect data over a period of time (longitudinal), were not in keeping with the cross-sectional timeframe of this study. Having spoken to multiple people together in the PPI groups, focus groups were appealing as they offered the opportunity to explore experiences from multiple perspectives (Bryman, 2016; Parahoo, 2014; Braun and Clarke, 2013). The logistics of having multiple participant groups together at once in a focus group was challenging. I considered different set-ups for the groups, perhaps meeting as a group according to the nature of their role, for example, Staff Members meeting with other Staff Members. However, this felt as though I was losing sight of 'bounding' the cases, which I had been striving to achieve to enrich the data collected (Yin, 2018; Thomas, 2016). Furthermore, those in the Staff Member participant group had many clinical demands on their time. Co-ordinating staff from specific cases, across different HSCP localities in a diverse geographical region, was not possible logistically within the timeframe of the study.

Qualitative semi-structured interviews were then considered, allowing the collection of rich data in case study research designs (Yin, 2018; Bryman, 2016). Unlike the constraints of structured interviews, these offered the opportunity to loosely channel focus with room for deviation, and develop balance and rapport between participants and me (Mann, 2016; Parahoo, 2014). Often resembling a guided conversation, they are valuable for qualitative inquiry and fit well with an interpretive paradigm, allowing the conversation to be guided towards *why* and *how* participants' experiences came about (Yin, 2018; Mann, 2016). Furthermore, the value of loosely structured group interviews was acknowledged when witnessed first-hand in early field work (Appendix 3). Speaking to PPI members as a group incited rich conversation amongst them. Therefore, Service Users, as the recipients of care, were given the choice of an individual interview or a group interview with one or both additional case participants. Interviews were held in a location convenient for the participant(s), most often the Service user's home or place of work. A total of fourteen interviews were conducted across seven cases (Table 23).

Table 23 Group and individual interviews

Case Letter		**A**	**B**	**C**	**D**	**E**	**F**	**G**	***Total:***
Participants	*Group Interviews*	Arthur Anisha		Caitlin Connor	Donna David			Grant Gail	4
	Individual interviews		Barney			Eddie			2
						Esther			1
		Abigail	Beverley	Catherine	Debra	Esme	Zoe	Gavin	7
Interviews per case:		2	2	2	2	3	1	2	***14***

Ten interviews were with a singular participant. Four interviews involved dyads of two, with the Service User and Informal Carer being interviewed together. Dyad interviews provided rich dialogue between participants, offering an opportunity to build a dialogue and further detail around experiences. However, when participants were interviewed separately, reflexive field notes were helpful in promoting this clarity too. The experiences and perceptions of participants seemed to differ more widely when the participants in Case E were interviewed separately. This pertained mainly to variations in perceptions of the care input, and the needs of the Service User (Eddie). Equally, Esther described her experiences, feelings and perceptions of supporting Eddie in greater depth compared to other Informal Carer participants who were interviewed with their Service User. When interviewed alone, Esther appeared less guarded in expressing her own individual needs as a Carer. In recognition of this, data gained through group interviews may have been softened by Informal Carers. They may have given a diluted account of their experiences of supporting their Service User to avoid causing them offence, which is recognised as a limitation of this method of data collection (Section 7.2.4).

Reflexive field notes were taken during and after the interview process (King et al., 2018), using Wilkie's (2015) framework of Reflexive Thinking as a guide (Figure 6) (Chapter 3, Section 3.4). These included general observations and my impressions, participant body language, prolonged silences and any points discussed that I wanted the participant(s) to elaborate on (from previous interviews in their case). Reflexive notes were captured in a journal, which helped me to acknowledge the active role I had in the research process. This journal provided a 'bread-crumb' trail of how my familiarity, and knowledge and understanding of data were developing over time (Attia and Edge, 2017; Palaganas et al., 2017; Bryman, 2016; Braun and Clarke, 2013).

Initially, reflexive journal entries were captured in a Microsoft Word document (Microsoft® Corporation, 2016b). However, this was too restrictive, as navigation between multiple documents was cumbersome and disjointed. I decided to capture my thoughts in a more linear fashion, utilising a Microsoft Excel sheet to facilitate more efficient navigation through my thought-processes (Microsoft® Corporation, 2016a). In this new document, journal entries were recalled quickly and filtered to a particular case, participant, or group of participants with ease. Using the Microsoft Excel document in this way allowed me to see the progression of my thinking on specific topics, for example, topics that had been raised in a Service User interview that I wanted to discuss further with their HSC Staff Member. Moreover, it led me to reflect upon how the data were shaping *me* (Palaganas et al., 2017; Wilkie, 2015). Developing understanding of my own attitudes, values and biases in this way promoted a deeper level of personal insight into the data and supported a strong focus on the research and participants (explored further in Sections 4.8, 4.9.3 & 4.9.4) (King et al., 2018).

4.6.8 Topic guide

Initially, a Service User topic guide was developed using literature review findings and exploratory PPI and HSC staff group fieldwork feedback (Appendix 11). A second topic guide for Informal Carers and Staff Members was also developed. This second guide incorporated minor adaptations to acknowledge novel perspectives of providing care and support (Appendix 12). Opening, probing and closing questions were outlined within both topic guides. Prompt questions were included, should participants require further clarification on the meaning of a topic (Appendix 11; Appendix 12). For example, if a participant did not understand the key term ‘Integrated Health & Social Care’ in question 2 (Appendix 11), one or more prompting questions (a – c) were used to explore their perceptions of how their services worked together, if at all. On reflection, using the term ‘integration’ could have been perceived as a leading phrase, reflecting my own assumption that participants would see services as integrated (or working together). They might have perceived services in a different way and using the term ‘integrated’ may have led to an unintentional bias.

During the interview, I used the appropriate guide(s), navigating between both when there were participants from different groups. On further consideration, this was cumbersome and producing a third *combined* topic guide might have streamlined the process of navigating through both documents. The topic guide was iteratively developed throughout the interview process, in three ways. First, developments were based on my personal reflections of participants' interpretation of the intended meaning of topics. For example, some participants misinterpreted the language used in question 2 c (Service User topic guide, Appendix 11). They often asked for further clarity around the use of the word 'view'. This was reworded to 'tell me *how you feel about* the help they give you'. This wording better reflected my intended meaning and embraced a need for terminology that held significance and relevance for the participants themselves. This was in keeping with my Relativist ontological lens, discussed in Chapter 3, Section 3.2.2.

Second, iterative developments reflected any recurring points of interest raised across multiple participant interviews. Prompting questions on both topic guides, under question 4 (Service User; Appendix 11) and question 3 (Informal Carer/Staff Member; Appendix 12), were expanded to ask if there were any community services supporting Service Users, as the first two interviewees discussed the importance of those.

Finally, when the interviews were conducted separately within each case, topic guides were also developed iteratively between sessions. If a participant highlighted something of particular interest, this was recorded in a field note and discussed with the other participants in their case during their interview(s). For example, when Service User Arthur and his Informal Carer Anisha discussed a specific episode of support Abigail had provided, she was asked to offer a further perspective in her interview. Recognising that each participant had their own perceptions of the reality of the experience, this approach enriched the data by helping to build a comprehensive picture of experiences. This three-fold method of iteratively developing the topic guides allowed me to improve the interview experience for participants and promote relevance during data collection, striving for better quality research (DeJonckheere and Vaughn, 2019). This drive for better quality research was promoted further through my consideration of ethical issues, reviews and approvals, which are considered in the next section.

4.7 Ethical considerations, reviews and approvals

In the interest of developing a high quality ethically sound study, the consideration of research ethics was viewed as an integral part of all stages of the research process (DePoy and Gitlin, 2020; Parahoo, 2014; Braun and Clarke, 2013). Six fundamental principles of ethically sound research, listed by Polgar and Thomas (2020), underpin the ethical considerations and review process of this study (Table 24).

Table 24 Fundamental principles of ethical research

Fundamental principles of ethical research	Corresponding section in this chapter
Informed consent and self-determination	0
Scientific excellence and quality	4.7.2
Minimising risk and harm to participants	4.7.3
Confidentiality and participants right to privacy	4.7.4
Lack of conflict of interest	4.7.5
Independent review	4.7.6

4.7.1 Informed consent

As outlined in Section 4.6.2, before being given the choice of whether they would like to take part in this study, participants were given information about its nature via a PIS (Health Research Authority and Medical Research Council, 2020; Polgar and Thomas, 2020) (Appendix 7; Appendix 8). Participants were given at least 48 hours to review the PIS (Health Research Authority and Medical Research Council, 2020; Good Clinical Practice Network, 2019; Health Research Authority, 2019c; NHS Research Scotland, 2016). Following this, participants were contacted to ask if they had any questions about the study. Questions were minimal, but for Service Users and Informal Carers they generally related to the logistics of speaking to their Staff Member without impacting upon their workload. They were aware their Staff Member had many demands on their time and did not wish the research to draw them away from their duties.

Participants who indicated they understood the PIS and had no further questions were asked whether they would like to take part, and reminded of their freedom of choice and their right to withdraw from the study at any point (Health Research Authority and Medical Research Council, 2020). The informed consent process was explained, and written consent was gained using a standardised consent form pertaining to their participant role: Service User (Appendix 9), or Informal Carer/HSC Staff Member (Appendix 10).

A participant's decision to take part in this study was not perceived as linked to a specific condition they might be living with, such as a mental health condition. Instead, it was viewed as a reflection of their own perceptions about their decision-making qualities and characteristics (Biros, 2018). For example, having a formally diagnosed mental health condition does not mean that someone has an impaired ability to make decisions about their daily life (Biros, 2018). However, in accordance with the inclusion and exclusion criteria discussed above (Section 4.6.3), anyone who self-identified as having a 'profound' mental health issue or learning disability was not recruited (N.B. no potential participants identified as having either of these issues). Written consent for all participants was witnessed and signed by the researcher (Health Research Authority and Medical Research Council, 2020).

4.7.2 Promoting scientific excellence and quality

The scientific excellence and quality of this study was considered throughout the research process (DePoy and Gitlin, 2020; Polgar and Thomas, 2020). Internal and external scientific reviews were undertaken in three different ways at varying points over the duration of this study. First, scientific excellence was promoted in the early stages through institutional ethical review of the study protocol and accompanying documents, by the School Ethical Review Process (SERP) within the School of Nursing, Midwifery and Paramedic Practice, RGU. They examined whether the proposed methodology, methods and procedures were appropriate and suited to its aims and objectives.

Following this, scientific excellence was promoted through a full external ethical review by an NHS Research Ethics Committee, with submission of all study documentation via the NHS Scotland Integrated Research Application System (IRAS). Although welcomed and entirely necessary, the review process for IRAS was lengthy and difficult to navigate. Prior to submission, there had been a change to the submission process. IRAS had introduced the 'Operational Information Document' as a replacement for the previous 'Service-level Agreement' between RGU and HSC organisations (where data might be collected). With this new documentation came degrees of uncertainty, not only for me as the researcher but for staff within RGU who normally liaised with HSC organisations. This led to lengthy delays in processing my application and delayed progress towards ethical approval, data collection and analysis and the write-up stages of the study timeline.

Second, the rationale for this study, research questions, design, methods and my suitability as a researcher were further reviewed within RGU at both the initial stage and the mid-way point of this study. These reviews were conducted by established researchers in RGU (external to the supervisory team). They involved submission of academic assignments that outlined study progress, and latterly, full study protocol documentation. Results of these reviews were favourable, with constructive feedback from reviewers helping to refine iteratively and develop study methods and methodology. It was reassuring to hear from experienced researchers (in addition to the supervisory team) of the potential contribution this study might make, and its potential value within the field of HSC research and practice. Finally, external scientific reviews were undertaken via academic and clinical engagement platforms, professional networks and in the HSCPs where the study was taking place. I participated in research seminars, post-graduate symposia, external conference presentations and submitted the Critical Integrative Literature Review for blind peer-review and publication.

4.7.3 Minimising risk and harm to participants: professional responsibilities and protecting vulnerable groups

In accordance with the Declaration of Helsinki (World Medical Association, 2013), risks to participants were minimised wherever possible (Polgar and Thomas, 2020; Parahoo, 2014; Braun and Clarke, 2013). In keeping with the stipulations of the NMC Professional Standards of Practice and Behaviour for Nurses, Midwives and Nursing Associates, I observed my professional responsibility as a registered nurse to promote participant safety, adhering to my duty of Candour throughout this study (Nursing and Midwifery Council, 2018). I considered the possibility that participants may describe poor or unsafe HSC practices during data collection. If this happened, it might be necessary to take action that could result in the disclosure of the participants name, address and details of the poor or unsafe HSC event. To maintain transparency and help participants understand my position and accountability as a researcher *and* registered nurse, participants were advised of my professional duty of Candour and this ethical stance in advance via the PIS (Health Research Authority and Medical Research Council, 2020; Health Research Authority, 2019c) (Appendix 7; Appendix 8).

To minimise risk of harm to participants, I devised an action strategy, should poor or unsafe practice be disclosed. Under the ethical governance of the NMC Code, I agreed with the wider supervisory team I would report such disclosures in line with the local HSCP and regional protocols and guidelines (Nursing and Midwifery Council, 2018). If it was at all possible to escalate a report of poor/unsafe practice whilst protecting the participant's identity, this would be considered. However, if this was not possible, my intention was to advise any participant(s) of the need to identify them in any reports generated. I would make it clear to them that every effort would be made to safeguard them against any negative consequences (during and/or after completion of the study) if they disclosed unsafe/poor practices; however, none were divulged.

In addition to my duty of Candour, I also considered minimising any risks to vulnerable groups. This study includes individual human subjects who may be classed as ‘vulnerable’ (Service Users, Informal Carers and Staff Members). As mentioned above (Section 4.6.3 and 4.6.7; Table 19), I asked participants to self-declare if they felt they were ‘vulnerable’ (following REC recommendations). However, there was a possibility some participants would not *identify* themselves as vulnerable, but by the nature of a health condition or their circumstances they could still be at increased risk. People in this category require additional ethical considerations, such as prevention of harm. My actions to protect those who were vulnerable (self-declared or otherwise), were three-fold. First, I observed regional and HSC national ethical research guidelines throughout. Second, principles of safeguarding adults underpinned my research practice. I aimed to work in partnership with participants, empower, prevent harm and protect them, whilst remaining accountable and proportional in my approach (Social Care Institute for Excellence, 2021). Finally, an updated Protecting Vulnerable Groups report was requested by Funders and Sponsors to check my suitability to work with vulnerable people, in accordance with the Protection of Vulnerable Groups (Scotland) Act 2007.

4.7.4 Confidentiality and the participant’s right to privacy

Maintaining participants’ right to privacy encompassed data management, and the secure storage and destruction of personal information upon completion of the study, complying with the Data Protection Act 2018 (DePoy and Gitlin, 2020; Polgar and Thomas, 2020; Bryman, 2016; Braun and Clarke, 2013). I compiled a data management log in Microsoft Excel (Microsoft® Corporation, 2016a) to track all stages of data-handling. For example, a log was kept of the recording or transcription of data, thus achieving efficiency, consistency and a high standard of data management (Robert Gordon University, 2020b). A comprehensive data management strategy for all data (personal and anonymised) was developed. Local and national data protection and research data management policies guided the development of the strategy. The latter was included in the Study Protocol and submitted and approved by the REC panel and is summarised in the below paragraphs (Robert Gordon University, 2020a; Health Research Authority, 2019c; Robert Gordon University, 2016a).

In accordance with the Data Protection Act 2018, no personal (identifiable) information about participants was shared out with the supervisory team or stored on laptops, portable electronic media or mobile devices other than temporarily (Robert Gordon University, 2020a; Robert Gordon University, 2016a). Participant documentation that included private and confidential information was confined to confidential storage. As outlined in local Research & Development study documentation guidelines and to prevent personal information being linked to anonymised data, all personal information was held in separate 'Annexed Study Site Files' (electronically, in my secure R: Drive at RGU; hard copies, in a locked drawer located in my workspace – an electronic-access only room, RGU).

Although anonymity cannot be guaranteed in research, steps were taken to promote this as far as reasonably practicable. Anonymised participant data were stored in a master 'Study Site File' (electronically, in a folder of that name; hard copies, in a secure lever-arch binder). Interview data were audio recorded and held on an electronic voice recorder, on an encrypted format USB or on a password-protected electronic device. This was on a temporary basis when being transported from an interview location. Interview data were then transcribed by an RGU approved administrative company. In accordance with local institution and regional Data Protection policies, all identifiable personal data will be stored for a total of four years (project duration) (Robert Gordon University, 2020b). Anonymised research data will be retained for no more than 10 years (to allow for further dissemination and publication). All data will be destroyed in accordance with RGU Data Protection policy, 10 years from the 'end of study' date, which is defined as the submission date of this thesis.

4.7.5 Lack of conflict of interest – Relationships, funding and sponsorship

The power balance between the participant and me could be a source of relationship bias. As a District Nurse, participants might have perceived me as an 'expert' in HSC with the resulting hierarchical power relationship influencing their responses to interview questions (Braun and Clarke, 2013). My duty of candour (as a nurse and researcher) and any action strategies to protect vulnerable adults (as outlined above) were made explicit to all participants in the PIS, and reiterated prior to obtaining informed consent (Health Research Authority, 2019c; Nursing and Midwifery Council, 2018). However, I was able to promote transparency and differentiate between my two roles by explaining that during the interviews I would be adopting the perspective of a 'researcher' rather than a nurse. I had not had any previous contact with participants (in a nursing capacity) and the role of 'researcher' felt easy to adopt as a result.

The Declaration of Helsinki (2013) stipulates that funding and sponsorship of research involving humans must be transparent. This study was funded through the award of a studentship stipend from the regional HSC organisation. Funding was awarded on the understanding this study would include participants in the local region. This, along with the anticipated time frame for completion, influenced my decision to focus on HSCP localities in the HSC region. PhD course fees were sponsored by Robert Gordon University.

4.7.6 Independent review with statutory organisations

To protect the safety and integrity of the research project, and in accordance with the UK Policy for Health and Social Care Research, this study has been subject to three internal and external independent reviews (Health Research Authority, 2019c). All permissions and approvals were filed within the Study Site File (NHS Research Scotland, 2016). First, full internal ethical approval was gained through the SERP (Appendix 13). Second, external independent ethical approval was awarded through IRAS (Appendix 14) (Health Research Authority, 2019a; NHS Research Scotland, 2016; Robert Gordon University, 2016c). Finally, the local Research and Development department reviewed this study and issued an NHS Scotland Research Passport and Letter of Access.

To promote inclusion for all, I had hoped only those lacking capacity to give informed consent would be prevented from participating. As outlined in Section 4.6.3, external ethical review bodies determined people with learning disabilities, profound mental health issues and those lacking capacity to consent should be excluded from this study. I felt strongly about the need for inclusion of under-represented participant groups in HSC research and believed there was a strong moral case, based on social justice, for their inclusion (Mietola et al., 2017; Durell, 2016; National Institute for Health Research, 2013). Nevertheless, time constraints following delays with ethical approval (outlined in Section 4.7.2) and time-limited funding, were instrumental in my decision to consent to these exclusions as stipulated by the REC panel on this occasion. Being clear on the ethical implications, I then considered criteria for interpreting my findings, which is considered in the next section.

4.8 Criteria for interpreting the findings: Underpinning principles of Interpretive Thematic Analysis

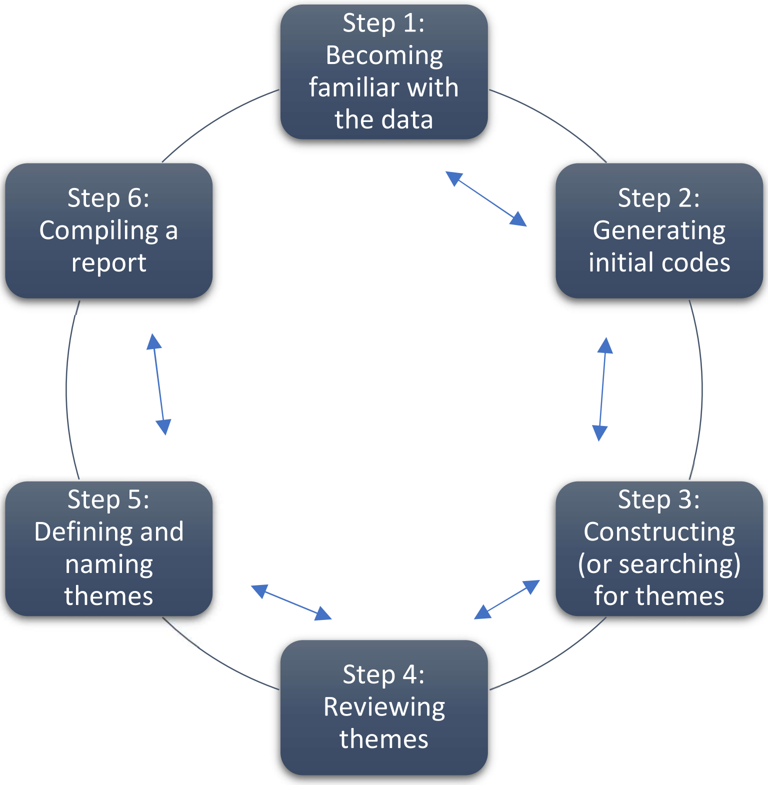
To ensure a solid infrastructure that helps to link proposition statements to data for later analysis, it is important to outline appropriate analytical criteria and techniques for a case study design (Yin, 2018). Recorded open responses from participant interviews were transcribed to allow the organisation of the data and reflection on aspects of the interviews (Mann, 2016). The data analysis strategy for this study needed to incorporate inter-case and cross-case analysis simultaneously, to explore the diversity of experiences and HSC needs across cases in the region (Yin, 2018; Braun and Clarke, 2013).

Pattern-based analytical methods offered an opportunity for me to do more than simply describe the nature of these data, allowing me to pose questions and explore a deeper level of meaning through conceptual similarities (Baškarada, 2014; Braun and Clarke, 2013). Initially, Interpretive Phenomenological Analysis (IPA) appealed to me; however, this focused more on *how* participants perceived, reported and made sense of their experiences, rather than the underlying meaning behind the experience. Furthermore, this was not designed as an IPA study. Similarly, pattern-based discourse analysis was also discounted on the understanding this method focused more on the *language patterns* participants used to describe the reality of their experiences

Adopting an Interpretive Thematic Analysis (ITA) approach to interpret and analyse the primary data offered a framework for developing insights, concepts and patterns of meaning across these data (Yin, 2018; Braun and Clarke, 2013). ITA was in keeping with my inductive, base-up constructivist ontological stance explored in Chapter 3 (Section 3.2.2), analytic induction aimed to follow a bottom-up approach to building knowledge (Braun and Clarke, 2013; Lapan et al., 2012a). ITA advocated that analysis should be data-driven rather than being shaped by existing theory on a topic (Yin, 2018; Braun and Clarke, 2013). This recognised that my previous knowledge and epistemological standing was likely to shape my analysis, to a degree. Furthermore, ITA allowed me to recognise the influence of my prior knowledge on proposition statements (Section 4.4), providing logical links between the data and the propositions (Yin, 2018; Thomas, 2016).

To promote rigor, credibility and dependability in adopting ITA methods, I adopted a six-step framework for data analysis (Nowell et al., 2017; Braun and Clarke, 2013). The supervisory team and I met every two weeks to ensure transparency, incorporating different researcher perspectives and to discuss emerging concepts (Nowell et al., 2017). It became apparent these steps of analysis were often blurred and overlapped. For example, writing up the findings report (Step 6) prompted further reflexive review of themes (Step 4) and redefinition of theme names (Step 5). Therefore, the steps of the framework acted as a general guide that was fluid in nature. Some steps happened concurrently, whilst others resulted in revisions to earlier conclusions as new thinking developed (Figure 15) (Nowell et al., 2017).

Figure 15 Nowell's steps of thematic data analysis



As Braun and Clarke (2013) point out, data analysis in a qualitative study is not always clearly separated from data collection. Elements of these data analysis steps were recognised across the data collection phase. For example, reflexive notes were taken during data collection, helping me to become familiar with the data (Step 1) (Table 25).

Table 25 Reflexive journal entry - Data collection corresponding with Step 1

Reflexive journal entry: 20/03/20 **Interview: Informal Carer, Esther (Case E)**
What was I thinking/observation?
• A more comprehensive overview of Eddie’s needs (than the account Service User Eddie gave). Shopping, housework, keeping him company, finances, household shopping, help with online shopping. I feel like Esther understands how important social contact and community are to Eddie. I feel reassured given my concerns after Eddie’s interview. This has highlighted the importance of different perceptions to strengthen the data! • Esther suggests she is reassured that Carers are there to ‘keep an eye on him’ [line 82]. She has felt overwhelmed and guilty, having the Carers there appears to have alleviated that somewhat [line 89 onwards]. The notion of ‘keeping an eye’ on Eddie appears important to Esme, to keep her in the loop, so to say. Perhaps this is a need for reassurance. **• Esther appears to link socialising to Eddie’s mental wellbeing – being socially active. [line 175-196].** • Checking dad’s care appears to be important to Esther. [line 282]. This possibly ties in with ‘keeping an eye on him’? • This transcript highlights the challenges of Carers support only being available during office hours when she is at work, she would like to go along but can’t. There’s a need there for further out-of-hours Carer’s support [line 308 onwards] & [lines 362-380 – this made me feel quite sad. She doesn’t want to walk around her office talking about ‘permanent catheters’ – understandable!]. Would like to attend care reviews but can’t and would have liked the opportunity to meet at a weekend/evening [lines 388-396]. • This transcript also highlights mental health issues for Carers – depression, worry, anxiety, burden of responsibility [line 416 onwards].

Additionally, initial ideas for potential concepts of interest (Step 2) were considered during data collection, as preliminary patterns in the data (Step 3) emerged in reflexive notes. For example, the following excerpt from my reflexive journal focuses on ‘remaining active’ and what that means to participants. When this was mentioned in another case (Case G) (Table 26), I was able to identify the emergence of a pattern, enhancing my understanding of this as a concept.

Table 26 Reflexive journal entry - Data collection corresponding with Step 2

Reflexive journal entry: 08/07/2020. **Interview: Service User Grant & Informal Carer Gail (Case G)**
What was I thinking/observation?
Gail and Grant talk about 'remaining active' in the sense of getting out of the house, and in a social sense (maintaining contacts with others). Remaining active – this is a potential concept of interest. This is not just referring to a physical sense (as I previously thought), it also relates to remaining socially active. Revisit Case E (and Esther's data in particular), as this is also picked up there. Ensure Informal Carer's desire for Service User to remain socially active is categorised (coded) correctly too, under remaining active.

4.8.1 Becoming familiar with the data

As transcripts were being typed by an approved external source, it was important to take time to engage with their content by repeatedly listening to the interview recordings (Braun and Clarke, 2013). Transcripts (n=14) generated vast amounts of diverse data (circa 105,000 words across 241 pages). Becoming familiar with large amounts of data was challenging. Data for each case incorporated perspectives of experiences from multiple sources (units of analysis) (Yin, 2018; Nowell et al., 2017). Whilst the use of an external transcriber allowed me to adhere to the timeline set for the study, it deprived me of an opportunity to familiarise myself with the data. At times the task of becoming familiar with the data seemed overwhelming, notable in a reflexive journal entry below (Table 27).

Table 27 Reflexive journal entry – Initial thoughts on becoming familiar with the data

Reflexive journal entry: 01/09/2020. **Becoming familiar with the data**
What was I thinking/observation?
The data are vast. How do I organise my thoughts and notes to help me start identifying patterns across the cases? This seems like an impossible task; it's like wading through treacle. I feel as though I am not making progress and feel the (self-imposed) pressures of having to stick to my timeline too. Supervision in two days' time. Hoping for some guidance there.
Baggage: My assumptions, values, political leanings, cultures etc. that have a potential to influence?
Value/Assumptions: Fear - this is too huge. How can I organise all this data and make it into a coherent report of findings; it seems impossible.
What influence might this have on my findings?
Negative thoughts lead to zero progress!
Re-evaluation findings/Action required
Speak with supervisors and decipher a way forward.
Reflexive insights
This is tough. However, my team are there to help and I need to be honest on how I am feeling.

Although I felt overwhelmed, support from the wider supervisory team helped me to consider a way forward. To increase my familiarity with the data, I listened and relistened to recordings whilst reviewing the written transcripts. I made iterative reflexive notes of my own thoughts as I became increasingly immersed in the data. Repeated listening afforded an opportunity to reflect upon previous interview field notes, building on these with further reflexive analytical notes. As I became increasingly familiar with each case, its participants and their data, I felt able to take the next step and start categorising the data by generating initial codes.

4.8.2 Generating initial codes using data management software

NVivo Qualitative Data Analysis Software (2012) was used to assist with data management and manoeuvrability, and to generate initial codes (or categories) for these data (Bryman, 2016; Saldaña, 2016; Miles et al., 2014). This programme helped to promote efficiency, organisation, identification and visualisation of key patterns within the data (Yin, 2018; Bryman, 2016; Spencer et al., 2014b; Braun and Clarke, 2013). Initially, grasping the basics of NVivo and navigating the different functions within it were challenging. However, a podcast series illustrated standard procedures and enabled me to learn how to operate the software more efficiently (Hull University Library, 2019).

My original understanding of how NVivo software could be operated was basic. A training session indicated that the most appropriate starting place for coding was a the creation of a list of 'nodes' (the programme's mode of coding that advocated folder-like 'nodes' to house points of interest in the text) (Wiredu, 2019). Node folders were generated based on areas of interest from the research questions and proposition statements, and a small section of the first transcript text was coded to those pre-conceived codes (with an example being given in Table 28) (Wiredu, 2019).

Table 28 Initial node folders

Initial Node Folder Names
Adaptations - Environmental
Availability, suitability of or access to services
Budget & funding of services
HSC service provision, processes and structures
Co-location
Needs
Social isolation
Systems of care

However, feedback from the supervisory team suggested that this was not in keeping with the inductive approach of this study, since it resulted in moulding the data to fit preconceived nodes rather than allowing the data to drive their formation. The coding process was reframed, this time ensuring text was coded to nodes specifically derived from the data. The table below represents a small sample of some of the data driven nodes that were introduced (Table 29).

Table 29 Example of data-driven nodes

Data-driven nodes
Additional roles
Advice - guidance
Clarity (of service provision, processes and structures)
Community help
Continuity or previous connection
Knowledge
Mood
Previous exposure or contact
Services - Availability of
Stress or worry
User involvement
Work - employment

Nodes were formed on the basis of similarity of the meaning of a block of text; for example, a place, people or topic of interest within the text (Castleberry and Nolen, 2018; Bryman, 2016; Saldaña, 2016). A block of text could be as little as a few words, or multiple lines. As the meaning of the transcripts were deciphered, blocks were coded (placed) into a node classified as having a similar meaning or topic of interest. When no nodes had a similar meaning, a new node was introduced (Nowell et al., 2017; Bryman, 2016). Node names were rudimentary in nature, capturing the essence of the topic of interest in simple, clear language. For example, participant doubt or not knowing about the future were categorised under the term 'uncertainty'.

The use of reflexive journaling during the coding process proved invaluable in revising the coding approach, producing a close audit trail of my thought processes and recorded team meetings (Nowell et al., 2017; Braun and Clarke, 2013). Furthermore, any progression of thinking around potential nodes was documented in my reflexive journal throughout the research process (Nowell et al., 2017; Bryman, 2016; Braun and Clarke, 2013). For example, the reflexive journal entry below summarises my thinking about similarities between nodes and the need to refine the node names as my understanding of the data developed. Furthermore, I considered the impact this might have upon later stages of analysis and findings (Table 30).

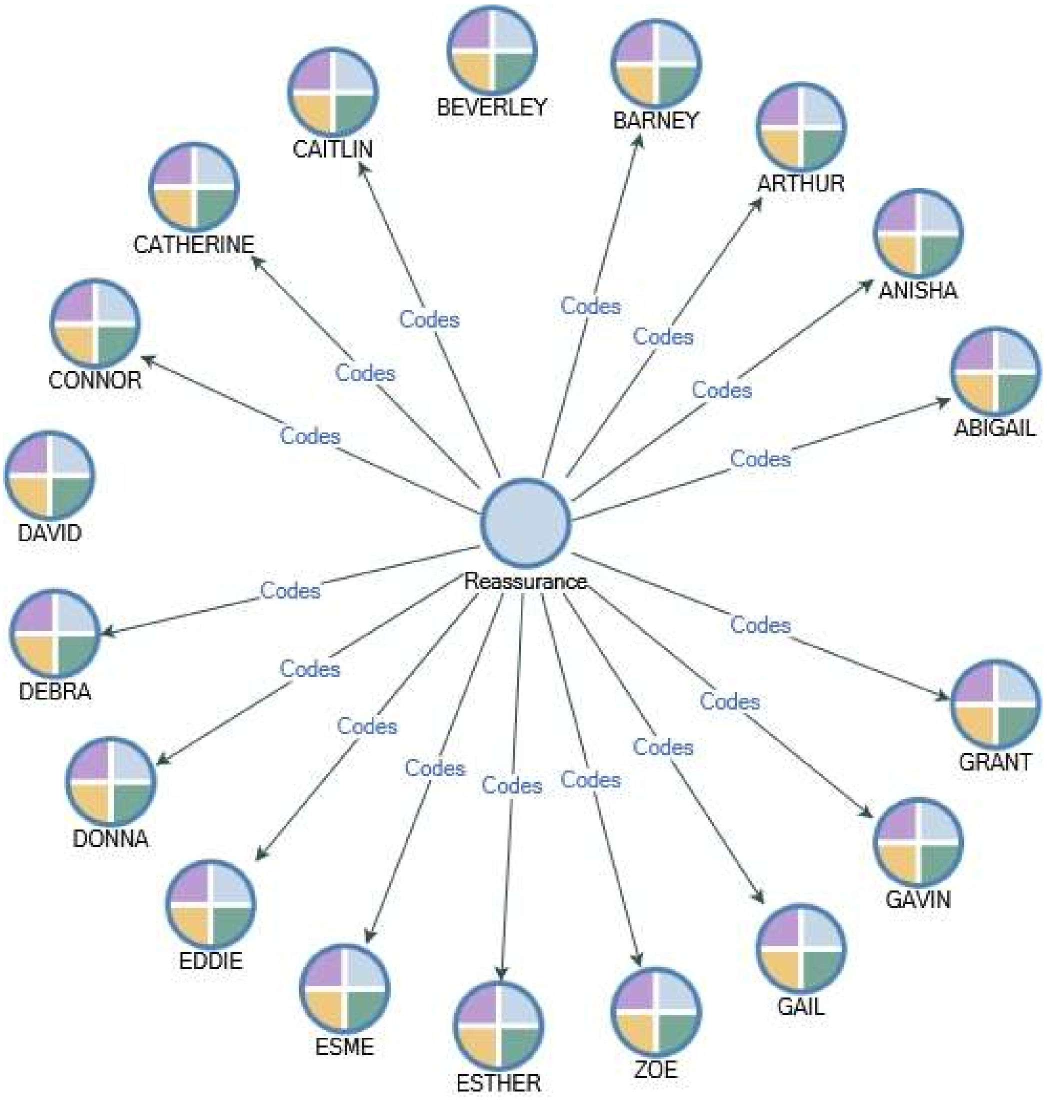
Table 30 Node development

Reflexive journal entry: 10/02/2021 **Node development**
What was I thinking/observation?
Nodes: Clarity and **confusion** – these seem very similar. Do I need to be this specific in defining these? **Node: Care needs** – is this an accurate description of the content? Perhaps Care interventions better describes this content.
Baggage: My assumptions, values, political leanings, cultures etc. that have a potential to influence?
Assumption: I am not familiar with or efficient at coding. Nodes need to be accurately defined and specific. I'm not going to remember which codes I was using during my last session. Values: Perfectionism – I'm worried about not doing it right!
What influence might this have on my findings?
If nodes are too specific at this stage it could influence later steps of data analysis (breaking the data down too much); subsequently, influencing the way in which findings are interpreted/reported.
Re-evaluation findings/Action required
Try to keep the nodes generic and refine them in the later stages.
Reflexive insights
Don't put the apple cart before the horse, Louise. Start to determine different concepts/terms across node in Step 3. Utilise the reflexive journal more, to help me keep a track of my thought processes between coding sessions.

4.8.3 Constructing themes

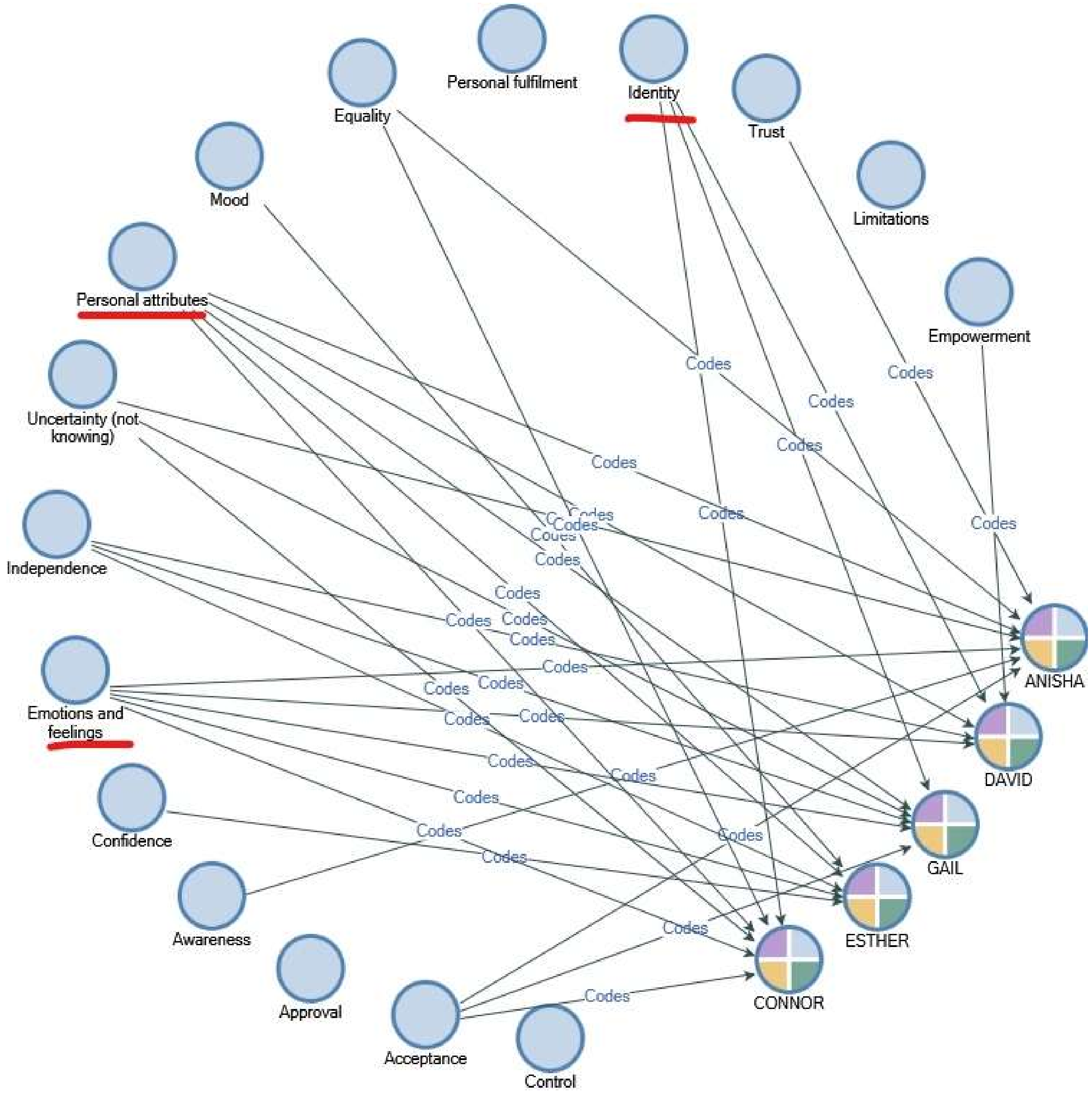
The process of constructing themes from the data was iterative in nature, and at first it was difficult to conceive themes from the mass of initial nodes (n= 242). Using NVivo, I generated framework matrices and diagrams to cross-tabulate concepts or nodes of interest with participant groups, particular cases, individuals or HSCPs (Hull University Library, 2019; Wiredu, 2019; Braun and Clarke, 2013). For example, I did this when I wanted to know which participants were talking about a concept of interest (or not). In the below example, I explore the ‘reassurance’ node, cross-referencing it with all participants to see if it is a recurring topic. I produced a diagram to represent a pattern that might be emerging, with all but two of the participant’s discussing it [Beverley & David] (Figure 16).

Figure 16 Identifying key concepts



Initial codes were re-organised across the data set, and clustered into groups with similar meanings. Patterns were defined as topics or nodes of interest within the data, which were consistently recurring for more than one participant, as shown in the diagram below (Saldaña, 2016) (Figure 17). This diagram presents a small sample of concepts that Informal Carers discussed. It emphasises a need to further explore their data around the supportive personal attributes (of others), the emotions they were feeling, and their identity around their role as a Carer (see red underlines in Figure 17).

Figure 17 Identifying patterns in the data



These tools helped me to identify patterns across the data set, facilitating cross-case analysis by building a picture of the data as a whole. However, the more nodes I included in my matrices the larger my diagrams became, making it difficult to decipher an overall view of the main concepts across the data. This was challenging at times but being specific about node selection, when generating cross-tabulated queries, helped me to ‘play with the data’ and identify and explore key topics (Baba and Yusoff, 2011).

While NVivo was helpful in the earlier stages of analysis when coding and identifying patterns in the data, it fostered a process of simply coding-and-retrieving information, resulting in a fragmented and decontextualised understanding of what participants were saying (Bryman, 2016; Schensul, 2012). I found this to be a limitation of NVivo, as it encouraged ‘over-coding’. I was breaking the data down too much, creating too many codes (or nodes) that deconstructed and lost sight of the valuable rich context.

I felt I needed to devise a new tactic for exploring the data, and to help me move data and concepts around freely. Equally, the narrative of the ‘story of the data’ needed to be enhanced in order to establish connections between the data and the participants (Vaismoradi et al., 2016). I wanted to consider what participants were trying to tell me about their experiences and any potential themes from that narrative. Returning to the raw meaning and the original quotes that had stood out for me (when listening and re-listening to the original interviews) helped me to decipher and construct preliminary themes. This was highlighted in the reflexive journal entry below (Table 31).

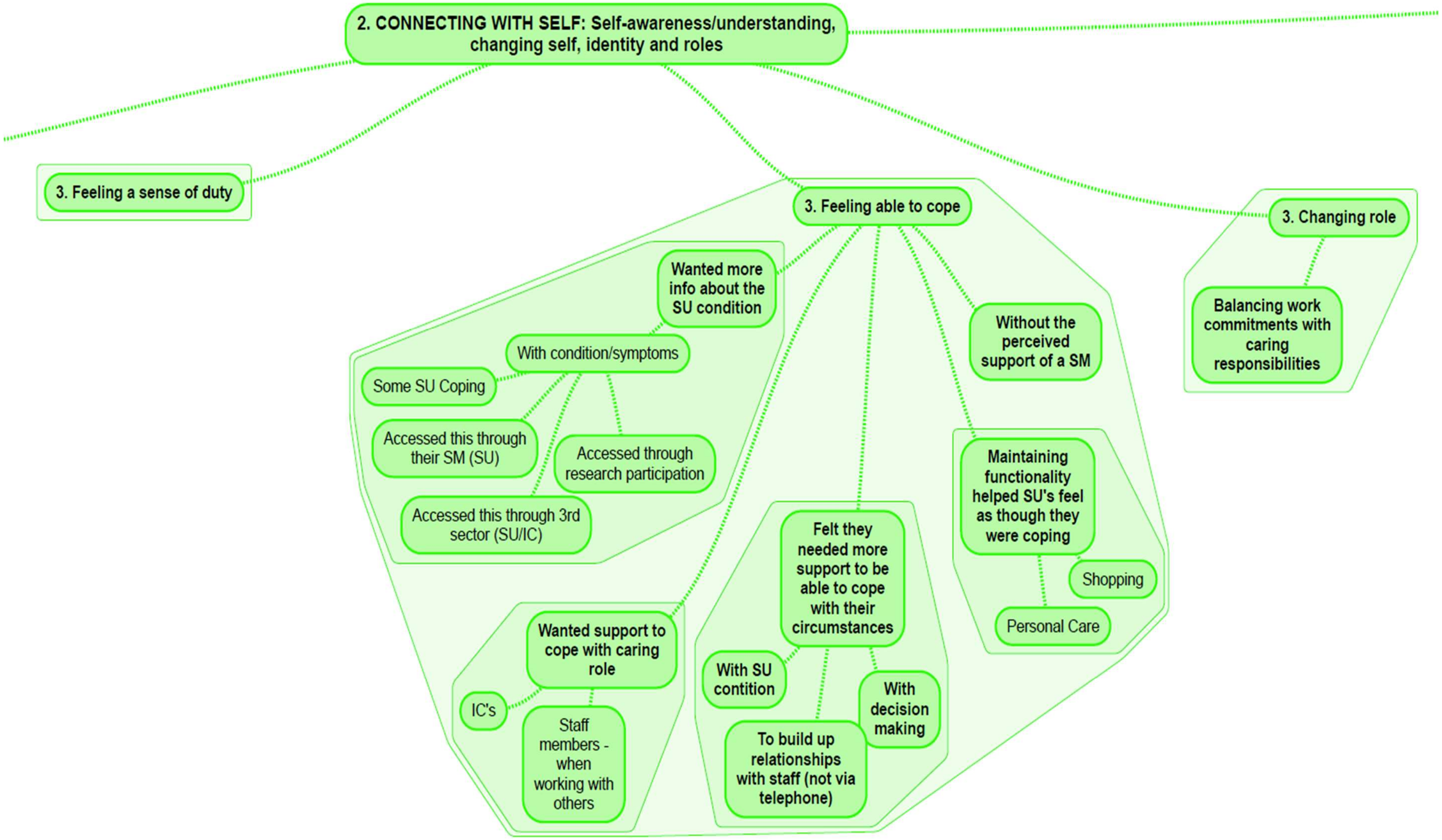
Table 31 Reflexive Journal Entry - Developing the 'story' of the data

Reflexive journal entry: 08/09/2020 **Developing the ‘story’ of the data**
What was I thinking/observation?
I have struggled this morning to start my findings ‘story' whilst using the 'all cases' framework matrix in NVivo to explore what participants across all cases are saying. Due to the size of the matrices, it is difficult to decipher where there are correlations to be able to build a 'findings story'.
Baggage: My assumptions, values, political leanings, cultures etc. that have a potential to influence?
Baggage/assumption: The data is too big to find correlations.
What influence might this have on my findings?
I need to produce an overview so I can be clear on what it is I am writing about, and where that might fit into the participants' story. I need to try and present it in a coherent manner.
Re-evaluation findings/Action required
Focus upon what my participants are trying to tell me. Their narrative story. Start by revisiting the raw data – what stood out for me initially when I first read the transcripts? What were the ‘power quotes’ (quotes that when I first heard/read it, I thought: ‘that has to be in the finding’s’, to represent what participants are saying across the data).
Reflexive insights
Remember this when writing up – this is a motivational point. Dial it back to what the participants are trying to tell me. What message are they trusting me (as the researcher) to get out there?

Initially, key observations were drawn from the raw data and grouped together in a Microsoft Excel document (Microsoft® Corporation, 2016a). Key data and their sources were extracted and recorded, moving them around the Excel document freely to identify commonalities and build a picture of what participants were saying across the cases. Potential preliminary themes were drawn together and constructed from separate pieces of data that appeared to be connected or related. They were formed on the basis of researcher observations of recurring phenomena in the text across cases (Yin, 2018; Miles et al., 2014). An example is included in Appendix 15, where the beginnings of a preliminary theme were explored. However, although this process had been helpful in identifying initial correlations between the cases, data were vast and this process was cumbersome, with a need to further distil potential themes and their meaning.

After experiencing these struggles and to identify what participants were saying *across* cases, I returned again to the raw data to highlight 'power quotes' that had stood out for me when first reading the transcripts. These quotes were categorised into potential themes using thematic diagrams, in 'mind map' format, to help develop the themes further and align them with the participants' narrative (Thomas, 2016). Below, an extract from my mind map, outlines the further development of my earlier preliminary observations during data extraction (as outlined in Appendix 15). It highlights my initial thoughts around key concepts from the original Excel sheet, which were clustered together to form the beginnings of a preliminary theme 'connecting with self' in the data (Figure 18). Subsequently, this preliminary theme contributed to the formation of the 'understanding and coping with changing health and wellbeing needs' theme (explored further in Section 5.3 and Figure 20).

Figure 18 Mind map of developing preliminary theme



This preliminary mind map was iteratively developed as my thinking progressed, with subsequent versions identifying connections between and across concepts, helping to make sense of the potential themes observed in the data. Furthermore, after constructing the mind map I felt I had a better understanding of the proposed themes and moved towards consolidated meaning in each potential theme (Saldaña, 2016). Initial thoughts around proposed themes for further review are summarised in the below table (Table 32).

Table 32 Proposed preliminary themes

Preliminary themes from mind map.	
Overarching theme	Connectedness
Theme	Connecting with self
Theme	Connecting with people
Theme	Connecting with service providers
Theme	Connecting with HSC systems & communities

4.8.4 Reviewing themes

The recursive nature of qualitative analysis suggests a need to iteratively review data and themes, resisting the temptation to become possessive over fixed ideas of what should be included in a theme and how it should be defined (Braun and Clarke, 2013). Preliminary themes and their proposed content were outlined in a revised 'thematic mind map'. Themes were constructed on the basis that a pattern (from across the data) represented something meaningful to me (as the researcher), with relation to the research questions, aims and proposition statements (Braun and Clarke, 2013). This extensive diagram posed challenges around the inclusion of all data, due to the volume and complexity of information within it. Subsequently, an overview document was composed to help review, formalise and summarise proposed names for themes and suggested sub themes (Nowell et al., 2017; Braun and Clarke, 2013). This overview document helped to draw focus towards key findings that needed to be included, recognising that not *all* data can be reported (Bryman, 2016). Furthermore, it linked the original research questions and aims to the data, by reflecting the proposition statements.

Both the overview document and mind map were reviewed by the supervisory team regularly, and themes were tested for referential adequacy by returning to raw data and previous reflexive notes about their development (Scharp and Sanders, 2019; Nowell et al., 2017) An example is outlined in the reflexive journal entry below, which highlights development and review of a potential theme around ‘connecting with self’ (Table 33) (Nowell et al., 2017).

Table 33 Reflexive journal entry – Theme development and review

Reflexive journal entry: 10/02/2021 **Theme development and review**
What was I thinking/observation?
Proposed theme: 'Connecting with self'. Is this an accurate reflection of the content I have grouped in this potential theme? I feel I need to refine the name of this theme to reflect what it is the participants are saying about this topic. Looking back at the raw data, what stands out for me is that it's more about understanding their changing needs (or those of the person they are supporting) and being able to cope with those changes.
Baggage: My assumptions, values, political leanings, cultures etc. that have a potential to influence?
Values/assumptions: Maybe the initial name of this theme relates more to my journey of self-discovery during the PhD. Understanding *myself*; who I am as a person; my identity as a researcher and what I feel passionate about (within the data). I think understanding changing needs is more accurate for participant theme name here.
What influence might this have on my findings?
I wonder if this journey of personal discovery is influencing the way I interpret the meaning behind the concepts in these themes. Need to be mindful of that.
Re-evaluation findings/Action required
Acknowledge and accept that these thoughts and feelings influence my decisions and interpretations of the data.
Reflexive insights
Perhaps I'm being presumptuous relating this to inner 'self'. Perhaps I am internalising the meaning behind the concepts in this theme (relating it to my journey of self-discovery during the PhD). I'll try to think about this in a more abstract way and focus more on the participant’s meaning.

4.8.5 Defining, refining and naming themes

To identify a solid thematic foundation for building interpretive knowledge and understanding of the findings, theme names were iteratively defined and named during the write-up (Yin, 2018; Miles et al., 2014; Spencer et al., 2014a; Lapan et al., 2012b). Supervisory team meetings focused on the active process of refining themes and gaining consensus on their names, and all progress and discussion were documented in my student progress records (Nowell et al., 2017). Although the restrictions of movement (due to Covid-19) reduced my ability to meet with PPI members face-to-face, I was able to share proposed findings, themes and their content with individuals who use HSC (discussed further in Section 5.10). Furthermore, I was able to engage and present proposed themes to a Staff Member group of HSC Staff Members online via a regional event. Feedback from these events helped to shape and define themes and are further explored in Section 5.10. Themes were represented on three different levels. An overarching theme encompasses the essence of the findings and is further explored through five main themes. Each contains pertinent findings that have been grouped together (subthemes). The names of all themes are outlined below (Table 34).

Table 34 Outline of theme names

	Theme names
Overarching theme	Interpersonal connections as a principal foundation of health and social wellbeing and care.
Main & sub-themes	Understanding and coping with changing health and wellbeing needs. • Understanding changing health and wellbeing needs. • Feeling able to cope with changing health and social care needs.
Main & sub-themes	Fostering connections and supportive relationships with others for health and wellbeing. • Building supportive relationships between Service Users, Informal Carers and HSC Staff. • Key characteristics of supportive relationships.
Main & sub-themes	Connecting with communities for health and social wellbeing. • Maintaining and promoting practical tasks with support from the local community. • Improved health and wellbeing through social contact with people in the local community. • Connecting with other Service Users and Informal Carers to feel supported.
Main & sub-themes	Connecting with HSC services for help to maintain and promote health and social wellbeing. • Availability of, and access to, services at a time when they were needed. • Coordinating and organising services within an HSC system. • Utilising HSC services to help meet health and wellbeing needs.
Main & sub-themes	Working together, across health and social care services and systems, to maintain and promote health and wellbeing.

Wherever possible, theme and subtheme names adopted language participants used to highlight the essence of the theme (Bryman, 2016). They were derived on the basis of descriptions of theoretical concepts reflective of the participants' substantive meaning in the data (Spencer et al., 2014b). As they were iteratively developed, theme names aimed to be evocative, concise and informative, incorporating a data-driven description of the key concept, the context and outcomes (Braun and Clarke, 2013). The reflexive journal entry below (Table 35) offers an example of how preliminary theme ‘connecting with self’ (in Table 32), developed into the abovementioned theme name ‘fostering supportive relationships and connections with others for health and wellbeing’ in Table 34.

Table 35 Reflexive journal entry - Defining and naming themes

Reflexive journal entry: 16/03/2021 **Theme development and review**
What was I thinking/observation?
Current theme name: Connecting with people: This needs to be developed to better understand the nature of what is contained within it. Consider the main point the participants are trying to convey in the data within this theme. The name needs to be more specific, to reflect the context and why it was important (the outcome?). *Refined name suggestion:* • Connecting with individuals to achieve health and wellbeing o This doesn’t feel as though it details enough of the context. Also, I need to reflect the relationships and support that participants, who are part of relationships, gain from them. The data suggests connection comes first, developing into a relationship. o Across the data, participants are clear on what a supportive relationship looks like to them, but I need to be clear on the difference between a connection and a relationship. *Refined name suggestion:* • Fostering connections and supportive relationships with others for health and wellbeing
Baggage: My assumptions, values, political leanings, cultures etc. that have a potential to influence?
Assumption: Connection is different from a relationship. Relationships develop over time.
What influence might this have on my findings?
Is this an assumption that I had prior to becoming so familiar with my data – the lines are becoming blurred.
Re-evaluation findings/Action required
To ensure I remain true to participants meaning, return to the raw data to confirm this assumption is data driven. Discuss data driven concepts and definitions (of connection and relationships) with the supervisory team.
Reflexive insights
As I become more and more immersed in the data, the parameters of where my own assumptions and values end and the raw data begins, becomes hazier. It’s good to recognise and acknowledge this; a reminder to return to the data regularly to ensure I convey participants true meaning.

In the above excerpt, I acknowledge my perceived blurring of boundaries and my need to return regularly to the raw data to confirm developing theme names were accurately reflecting the participant's intended meaning. It also highlighted a need for further clarity (my own) on key terms that were incorporated into theme names in Table 34. To provide clarity, data-driven definitions and contexts of key terms 'Connection' and 'relationships', are outlined in Table 36.

Table 36 Defining connections and relationships

	Key term		
	Connection	**Relationship**	
Definition supported by the data	Feeling a link or association with another person or group of people who hold a shared point of interest	An affiliation that develops between two or more people after a connection has been made	**Definition supported by the data**
Contextual examples in the data	Relative	Familial	**Contextual examples in the data**
	Friend	Friendship	
	Colleague	Professional and/or friendship	
	Staff Member – Service user/Informal Carer	Professional	
	Community	Community of people who have a similar role or medical condition	

4.8.6 Producing a report

The sixth and final step of analysis involved generating a written account of analysis and findings (Nowell et al., 2017). Throughout the later stages of the framework, the findings were subjected to review by the supervisory team and debriefings following presentations to key stakeholders and fellow researchers (Nowell et al., 2017; Braun and Clarke, 2013). The written report of findings in this thesis includes reasons for theoretical, methodological and analytical choices, explored throughout this chapter with descriptions of contextual influences.

It is not always necessary to outline every single case in a multi-case study (Yin, 2018; Tight, 2017; Bryman, 2016; Thomas, 2016). An interpretive narrative offered the opportunity to be descriptive and explore explanations and interpretation of the data (Moore et al., 2012). Quotations are used from single cases to illustrate key findings and topics of interest from across the cases. In this thesis, each case acts as a source of evidence to support and illustrate cross-case findings and topics of interest (Yin, 2018; Thomas, 2016). Initially, I had preconceived ideas of how the data would be reported. I planned to present inter-case findings for each case and then compile an overview section of cross-case findings. For me this represented deductive organisation of the data into a framework based on my previous knowledge, understanding and experiences. On reflection, I was trying to organise the data (or findings in this case) rather than allowing the data to shape *me*, my thinking and my report, in an inductive way.

However, qualitative analysis can often involve elements of both inductive and deductive methods (Armat et al., 2018; Azungah, 2018). After discussions with the wider supervisory team it was decided to allow the data to drive the shape of the report through the narrative 'story' of the findings, on the understanding there would need to be elements of deductive organisation when developing and reporting potential themes (Armat et al., 2018; Azungah, 2018; Vaismoradi et al., 2016). I had to explore what participants were trying to tell me and use this premise as a lens from which to look at the data. Participants described their perceptions and experiences of connecting with people on a personal level, encompassing connections with individuals, communities, services and across HSC systems. Therefore, findings were reported using a multi-case study interpretive narrative format that showcased cross-case analysis, with each section of the report being devoted to a particular theme (Yin, 2018; Moore et al., 2012). Once I was satisfied that I had established appropriate criteria for interpreting my findings, I considered how I might promote trustworthiness in this study and the next section outlines the strategies I employed to do so.

4.9 Promoting trustworthiness in this study

Trustworthiness in qualitative studies can involve four criteria; review of credibility, transferability, dependability and confirmability (Korstjens and Moser, 2018; Bryman, 2016). Strategies to establish these elements are outlined below, and have been observed throughout this study to promote rigour and high standards of research practice (Braun and Clarke, 2013).

4.9.1 Credibility

When conducting credible qualitative case study research, it is important to demonstrate a measure of ‘reality’, to show correlation between what the study claims to show, and what it *actually* shows (Korstjens and Moser, 2018; Braun and Clarke, 2013). For case study designs, Yin (2018) offers a series of tactics to ‘test’ the design of each one, outlining the stages at which these tactics should be considered. However, these tests use language best suited to mixed-methods or quantitative studies. Construct credibility identifies the correct operational measures for the concepts being studied, and external credibility shows whether (and how) a case study’s finding can be generalised through transparency in methods of analysis (Yin, 2018; Lewis et al., 2014; Mertens, 2012). For the purpose of testing the credibility of this study, the general principles have been outlined below and the language has been adapted to mirror its qualitative nature (Table 37).

Table 37 Tactics for testing case study design

Test	**Case Study Tactic** (Yin 2018)	**Phase of case study in which tactic is addressed**	**Corresponding sections in this chapter**
Construct credibility	• Use of multiple sources of evidence • Have key stakeholders review draft case study report	• Data Collection phase • Stakeholder engagement and review of preliminary findings • Composition of report section	• 4.6.7 • 4.2.1; 4.2.2; 4.8.5 • 4.8.6
External credibility	• Pattern matching • Explanation building	• Data analysis.	• 4.8.2; 4.8.3; 4.8.5

4.9.2 Transferability

Enhancing the transferability of the findings was considered throughout the planning and conduct of this study. Transferability cannot be assured, as no other area or participants will have the *exact* same characteristics described in this study. However, transferability in qualitative research focuses on depth of understanding of a group of people who share common characteristics (in this study, their common interest of utilising or supporting someone who accesses HSC services) (Bryman, 2016). To that end, the details of specific contexts, participants and settings are outlined in the methods section of this chapter, to promote transferability of findings to *similar* contexts (Braun and Clarke, 2013).

Transparency and accuracy are promoted through 'thick-description' of the specific context of this study (Bryman, 2016; Lewis et al., 2014; Braun and Clarke, 2013). Findings first outline an overview of participant groups and their demographics. Second, a description of the contextual setting of HSCPs (the location of participants and cases) is included. Finally, individual participants, their connection to other participants in their case and their circumstances are also described. Collectively, these steps help to promote transparency in the application of research methods and findings to other HSC practice areas outside of the sample (Lewis et al., 2014).

4.9.3 Dependability

Dependability in qualitative research (often viewed as the equivalent of 'reliability' in quantitative studies) can be fostered through the clear and transparent reporting of research procedures and methods (Lewis et al., 2014). A comprehensive research protocol provided an audit trail of conduct and decisions made throughout the study and ensured transparency and rigour of methods and procedures (Yin, 2018). Regular scientific review has increased the dependability of the data and findings (as outlined in Section 4.7.2). In addition, progress of this study has been monitored and documented as detailed below.

First, regular supervisory team meetings were held throughout (Bryman, 2016; Braun and Clarke, 2013). These promoted openness, integrity, and consistency and happened every 2-4 weeks. This monitoring allowed acknowledgement of any personal bias, helped to maintain authenticity and conformability, and meant that I (as a researcher) was accountable to others when developing this study (Lapan et al., 2012b).

Second, study progress has also been monitored through regular external peer-feedback in existing post-graduate networks through publications and oral and poster presentations. These presentations highlighted any need for adjustments, bias or omissions, and challenged my thinking throughout the development and application of the research methods (Lapan et al., 2012b) (see pages v, vi and viii).

Third, ongoing key stakeholder engagement in research planning, design, analysis, findings, and progress has been maintained throughout this study. This feedback has supported underpinning study principles that are closely aligned to stakeholder needs and areas of interest (Health Research Authority, 2019b; UK Public Involvement Standards Development Partnership, 2019b).

Finally, regular reflexive journaling throughout this study provided an audit trail of my developing understanding, potential themes and study progress (Attia and Edge, 2017; Palaganas et al., 2017; Bryman, 2016; Braun and Clarke, 2013). After becoming familiar with the process of reflexive journaling (during data collection), I found the process therapeutic in nature. In addition to providing an auditable trail it allowed me to process my thoughts and feelings during my PhD. Journaling helped me to work through and cope with challenges I faced, including contentious ethical considerations (discussed in Section 4.6.3), my decisions about the study, or personal issues that arose during that period. A more personal example is outlined in Table 38, where I discuss my feelings around external influences over PhD progression and data analysis, in the form of a period of sickness, home-schooling and the Covid-19 pandemic.

Table 38 Reflexive journal entry - Influence of the pandemic

Reflexive journal entry: 14/12/2020. **Personal entry**
What was I thinking/observation?
I am feeling unwell and being tested for Covid. My daughter is home-schooling, and I am finding it challenging to balance all of my commitments. Feeling apprehensive and worried.
Baggage: My assumptions, values, political leanings, cultures etc. that have a potential to influence?
Assumptions: values, cultures: Concerned for family, and my own health. I'd like to carry on as best I can (absence will influence PhD timeline). Poor progress and time off of PhD may be required. Re: Data collection - has data analysis been influenced by my experiences of isolation, and lockdown restrictions? I have revisited previous journal entries to review this today. I've been journaling throughout data analysis stages, and I feel that the central theme around interpersonal connections can be seen in journal entries pre-lockdown. These concepts were developing whilst 'familiarising myself with the data' and during data collection phases which was happening from December last year (2019, pre-pandemic).
What influence might this have on my findings?
Time off required over the festive period, progress with findings report will be minimal. I was planning 2 weeks off anyway. Hopefully, I will be feeling better soon.
Re-evaluation findings/Action required
Rest and recuperation.
Reflexive insights to feed into my next phase
It may be that this does delay progress into the next phases of analysis. Revisit this again in a few weeks - see how I feel then. Keep Supervisors in the loop meantime - their support may be needed and a revised 'plan of action' for PhD timelines may be required.

4.9.4 Confirmability

Confirmability (paralleling objectivity in quantitative research) aims to demonstrate that the intentions and actions of the researchers were in good faith (Bryman, 2016; Mertens, 2012). In recognition of the subjective nature of qualitative research, personal values, influences and development of interpretations of data are captured in my reflexive journal entries (Braun and Clarke, 2013). These entries provide explicit acknowledgement of my thinking and development of findings, my previous experiences within HSC and my perceptions of the data which potentially help to shape my interpretation of the findings (Palaganas et al., 2017; Wilkie, 2015; Mertens, 2012). As a reflexive, qualitative researcher, I acknowledged and openly embraced my assumptions, values and preconceptions, which influenced the way in which I constructed themes and findings from these data. Sources of data have been provided in-text with the findings to illustrate the conclusions reached from the data, thus, enhancing the confirmability of these findings (Mertens, 2012).

4.10 Chapter summary

This chapter has described the application of principles to this qualitative multi-case study design and the relevant research methods adopted within this study. Ethical principles were discussed relating to consent, the promotion of scientific excellence, the strategies required to minimise risk to participants, and the avoidance of conflicts of interest. The principles underpinning thematic data analysis were described. The analysis process was summarised, and the use of an appropriate analysis framework was discussed. Finally, trustworthiness in this study has been considered, outlining strategies to promote rigour throughout the research process. In the subsequent chapters, the findings of data analysis are presented. The next chapter will outline an interpretive narrative of inductive, data-driven themes.

CHAPTER 5 INTERPRETIVE THEMATIC FINDINGS: UNDERSTANDING THE IMPORTANCE OF CONNECTIONS ACROSS HSC

5.1 Chapter overview

In Chapter 5, I explore findings from data collected during semi-structured interviews, relating to the needs, experiences and relationships of people who access and provide HSC. First, I offer a description of how participants, their cases and their data are represented in this thesis. Second, a concise overview of thematic findings that are presented in the subsequent sections is offered. Third, a combination of themes and subthemes present the interpretive narrative of these data. Fourth, members of the public and I explore the development and interpretation of thematic findings, focussing on key 'take-home' messages about participants' experiences of HSC. Finally, to conclude this chapter I offer a concise critical synopsis of findings, along with typologies that have been developed from them.

5.2 Representing participants, their cases and their data in the findings

In this chapter, participants, their cases and their data are represented in several ways in order to maintain anonymity. Participant data and relevant additional information is presented below and includes background information about the people who took part in this study. This background information gives a contextual overview of individual participants, their cases and additional information relevant to these findings.

5.2.1 Anonymised information and participant data

To maintain participant confidentiality all identifiable information was anonymised. Any information felt to be at risk of revealing the identity of people who were not recruited to this study, locations, organisations or companies was removed and is represented with a hyphen. Participant data are presented in direct quotations that can be differentiated from the main text of this thesis by their use of italics, inverted commas and indented justification. At the end of each quotation the participant's name, their role and their HSCP area will be included. Any words that participants placed emphasis on are written in bold text. Where more than one person is represented in the dialogue, each respondent's pseudonym is stated above their dialogue. When the interviewer is represented in the dialogue, the title 'Interviewer' will be used. For example:

Single participant:

> *I went to see Dr – at the surgery that day. Arthur, Service User, HSCP 1.*

Multiple participants:

> *INTERVIEWER*
>
> *How did you feel about that?*
>
> *ARTHUR*
>
> *It was a* ***horrible*** *day!*
>
> *ANISHA*
>
> *Yes, I thought so too. Arthur Service User & Anisha Informal Carer, HSCP 1.*

5.2.2 Significant additional information

Additional information thought to be significant and beneficial to the reader is included in squared brackets. Examples include in-text references to a participant who is represented in the findings; a participant's non-verbal communication, such as body language or quips that relate to their quotation; or contextual information relating to anonymised or removed information.

Non-verbal communication example:

> *Yes, [grimace, deep breath] I thought so too. Anisha, Informal Carer, HSCP1.*

Contextual information example:

> *I visited Dr –. He is based at the - [healthcare facility].*

5.2.3 Background information for participants and their cases

I felt it important to introduce the participants in this case study to contextualise their experiences. On a more personal level and in keeping with the findings of this study, I wanted to offer an opportunity for the reader to connect with participants, develop a deeper understanding of the individuals and bring their experiences to life. Relevant background information about the participants and their cases can be found in the overview of cases (Table 39). This is followed by an overview of thematic findings in Section 5.3

Table 39 Relevant background information for participants and their cases

Case	Participant Group	Participant	Participant/case background Information
A	Service User	Arthur	Arthur is retired and has early-onset Dementia. Although Arthur can move around independently, he struggles with sensory overload and impairment. He often forgets to attend to some of the functional tasks that help him to maintain his health and wellbeing (e.g. taking his medication, personal hygiene, maintaining an adequate fluid intake). He lives with his wife Anisha in the family home.
	Informal Carer	Anisha *(Wife)*	Anisha is living with multiple long-term conditions and helps Arthur with prompting for medication, washing, dressing, meal and drink preparation and access to HSC services. They have two daughters who do not live near them; Anisha likes to visit her daughters regularly, leaving Arthur at home alone.
	Staff Member	Abigail *(NHS Outreach Worker Dementia)*	Abigail supports Arthur and Anisha by offering information on his condition, helping them to access HSC services, and she reviews their needs regularly via 'support visits' at home, in outpatient clinics and on the telephone.
B	Service User	Barney	Barney is retired and is living with multiple long-term conditions (Chronic Kidney Disease amongst them). He lives in the family home with his wife. He experiences reduced mobility because of his multiple long-term conditions and needs help with washing and dressing and administering prescribed creams. Members of his local community support him with regular social contact visits.
	Staff Member	Beverley *(Carer)*	Beverley visits Barney daily to help him with washing, dressing and application of prescribed creams. She performs some housework tasks while she is there and collects prescriptions from the pharmacy for him.

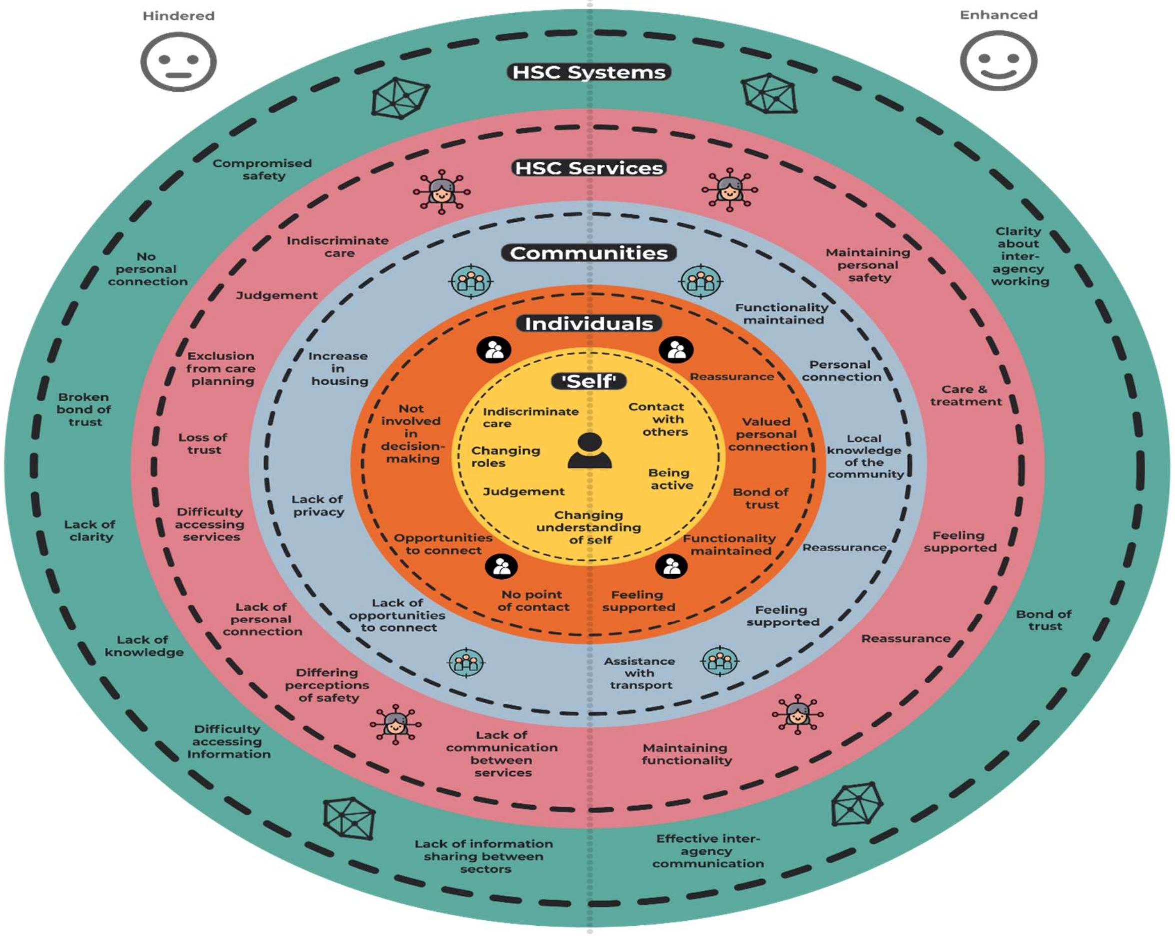
C	Service User	Caitlin	Caitlin works part-time and she has MS. Caitlin had an operation recently (unrelated to MS) and has found that she now needs increased help with housework tasks because of increased leg pain (unrelated to her surgery).
	Informal Carer	Connor *(Husband)*	Connor is retired and lives with Caitlin in their family home, along with their teenage sons. He has been helping with housework tasks (Caitlin would have done these previously), and he helps her to access required HSC services (physio and GP).
	Staff Member	Catherine *(Specialist Nurse)*	Catherine offers support to both Caitlin and Conner via outpatient clinics, telephone calls and home-visits.
D	Service User	Donna	Donna is retired and has MS. She lives with her husband David (semi-retired) in their family home. Donna is not able to stand unaided and needs the assistance of two people to help her transfer between bed and chair (Stand Aid or full body hoist). She has an automatic wheelchair which helps her to attend various hobby and interest groups independently. She uses public transport to attend these groups and goes to the shops independently in her wheelchair. Donna organises her own care through participatory budgeting. She employs carers to attend throughout the day to help with washing, dressing, toileting and transfers.
	Informal Carer	David *(Husband)*	David helps his wife Donna in between carer visits (if needed) with meal preparation and empties her catheter bag. Occasionally he will help with washing and dressing if no carers are available. David has an adapted car that he and Donna use to go out together.
	Staff Member	Debra *(Occupational Therapist)*	Debra has helped Donna, David and Donna's care staff with monitoring health and safety, manual handling training and equipment. She maintains contact with Donna via home visits and telephone.

E	Service User	Eddie	Eddie is retired and has MS. He has recently moved into a sheltered housing complex with a resident warden. He mobilises independently with a three-wheeled trolley. Eddie socialises with others at the sheltered housing complex regularly. He walks to his local shop for social contact with the shopkeeper and to buy occasional-use small grocery items.
	Informal Carer	Esther *(Daughter)*	Esther, lives in a nearby location to her father Eddie. She does not drive and takes the bus or gets a lift from friends to see Eddie every week. Esther works full time and helps Eddie with shopping, housework tasks and accessing required HSC services.
	Staff Member	Esme *(Carer)*	Esme visits Eddie daily with other care staff who help him with washing and dressing, housework tasks (when required), meal and drinks preparation and catheter management.
F	Staff Member	Zoe *(Befriender)*	Zoe is a Befriender who works for a voluntary organisation. She has been a Befriender for a ‘few years’ and shared her personal and voluntary experiences of HSC.
G	Service User	Grant	Grant is retired and lives alone in his own home. Members of his local community support him with social contact visits regularly, sometimes providing cooked meals. He has COPD but can move about independently; however, he is limited in the length of time he can mobilise, because of shortness-of-breath linked to his COPD. He drives to the local shop for a small number of groceries, but Gail helps him with larger amounts of shopping, and accessing required HSC services.
	Informal Carer	Gail *(Daughter)*	Gail lives in a neighbouring area to her father Grant and visits him three times a week, helping with housework tasks. Gail submitted a request for a Befriender to visit Grant weekly, to ensure that someone had contact with Grant daily (Monday – Friday). A local cleaner has contact with him on the other day that Gail or the befriender does not visit.
	Staff Member	Gavin *(Befriender)*	Gavin is a voluntary Befriender who has been visiting Grant once a week for two hours, for around two years. They talk about common hobbies, interests and family, and reminisce about historical events. Gavin does not help Grant with practical tasks, but he has offered to collect milk from the shops on his way to Grant’s house, on occasion.

5.3 Overview of thematic findings

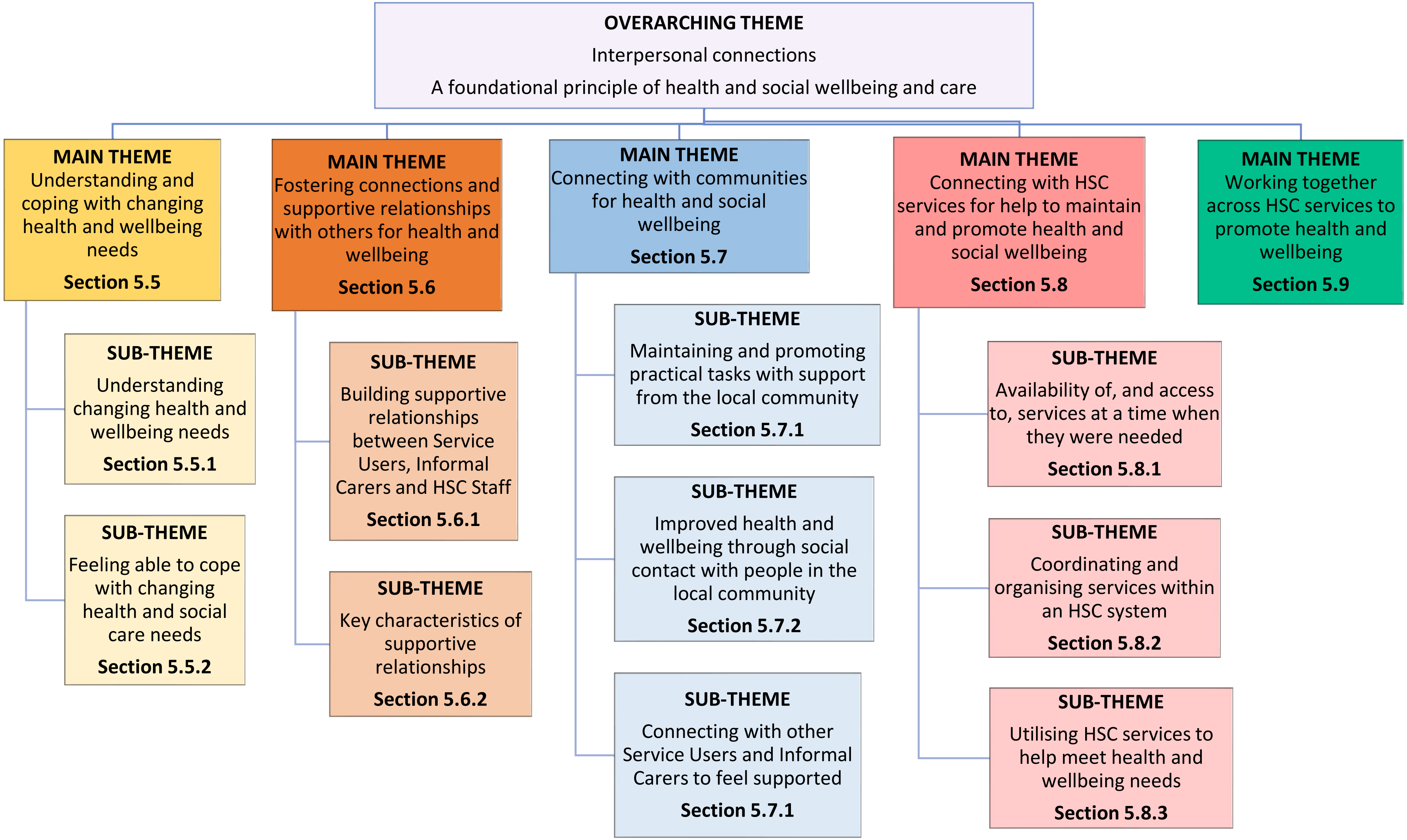
Participants discussed their connections with others, the impact these had upon their health and wellbeing, and their experiences of HSC. Making connections across different HSC contexts was central to meeting participants health and wellbeing needs, they helped them to build supportive relationships with individuals. HSC contexts in which these connections were made ranged from understanding themselves, to linking with wider HSC systems. Each participant made multiple connections of differing natures to establish, maintain or promote health and wellbeing for themselves (Service Users) and/or for others (Informal Carers and HSC Staff Members). Furthermore, they highlighted supportive relationships as key drivers in achieving health and wellbeing across these HSC contexts. Participants' experiences when accessing HSC were shaped by their ability to establish effective connections and relationships. For example, their ability to experience connections with services was hindered when they were not involved in care planning, and it was enhanced when they felt supported (see red services circle in the hindered and enhanced sections). Participants' connections and experiences across HSC contexts, along with factors that enhanced and hindered them, are summarised below in Figure 19.

Figure 19 Factors that enhanced and hindered connections and experiences across HSC



Participants’ connections and experiences across HSC contexts and their influential factors, outlined above in Figure 19, will be explored in themes and subthemes named in Table 34. These theme names and their corresponding sections in the findings are outlined below in Figure 20. To indicate where examples of the above experiences across HSC contexts are located in the findings, the colours adopted in Figure 19 also correspond with the themes in Figure 20.

Figure 20 Overview of themes



OVERARCHING THEME

Interpersonal connections

A foundational principle of health and social wellbeing and care

MAIN THEME
Understanding and coping with changing health and wellbeing needs
Section 5.5

- **SUB-THEME**
  Understanding changing health and wellbeing needs
  Section 5.5.1
- **SUB-THEME**
  Feeling able to cope with changing health and social care needs
  Section 5.5.2

MAIN THEME
Fostering connections and supportive relationships with others for health and wellbeing
Section 5.6

- **SUB-THEME**
  Building supportive relationships between Service Users, Informal Carers and HSC Staff
  Section 5.6.1
- **SUB-THEME**
  Key characteristics of supportive relationships
  Section 5.6.2

MAIN THEME
Connecting with communities for health and social wellbeing
Section 5.7

- **SUB-THEME**
  Maintaining and promoting practical tasks with support from the local community
  Section 5.7.1
- **SUB-THEME**
  Improved health and wellbeing through social contact with people in the local community
  Section 5.7.2
- **SUB-THEME**
  Connecting with other Service Users and Informal Carers to feel supported
  Section 5.7.1

MAIN THEME
Connecting with HSC services for help to maintain and promote health and social wellbeing
Section 5.8

- **SUB-THEME**
  Availability of, and access to, services at a time when they were needed
  Section 5.8.1
- **SUB-THEME**
  Coordinating and organising services within an HSC system
  Section 5.8.2
- **SUB-THEME**
  Utilising HSC services to help meet health and wellbeing needs
  Section 5.8.3

MAIN THEME
Working together across HSC services to promote health and wellbeing
Section 5.9

5.4 Interpersonal connections as a principal foundation of health and social wellbeing and care

Building connections with individuals, communities and organisations across HSC was identified by all participants as key to health and social wellbeing and care. This overarching theme captures participant experiences of connections in HSC through five themes and ten sub-themes related to the people they connected with, and the nature and contexts of their connections. Service User and Informal Carer participants outlined their understanding of their changing health and wellbeing needs and highlighted factors that helped them cope with these changes. All participant groups described the importance of supportive relationships and highlighted how these were instrumental in helping them to maintain their health and wellbeing.

Personal, friendly, connections were important to all participant groups, whether these involved individuals, communities, service provider organisations or across HSC systems. Personal connections emerged as a foundational building-block of fostering supportive relationships. When participants did not experience supportive relationships with individuals across communities and HSC services and systems, they felt detached from others, under-represented and less supported as they endeavoured to understand and cope with their changing needs and roles.

5.5 Understanding and coping with changing health and wellbeing needs

This first theme explores participants' understanding of their changing health and wellbeing needs and how they coped with these changes through two sub-themes. The first sub-theme explores Service Users' and Informal Carers' need to understand and accept their changing health and wellbeing needs, and the things that shape their understanding. They perceived these changes as an indicator of their deteriorating condition(s) and an increased need for support, acknowledging a loss of control over their own wellbeing. Additionally, they reported perceptions of facing judgement from others when they accessed HSC services. They felt that their care was not person-centred, with some HSC staff labelling them by their medical condition. Informal Carers and Staff Members described their understanding of their caring role, and the challenges they faced when helping Service Users. These encompassed their changing role, for example when a daughter became a Carer, the emotions and feelings that were triggered for them, and difficulties in balancing work commitments with caring responsibilities.

The second sub-theme explores factors Service Users and Informal Carers felt helped them cope with changing health and wellbeing needs. Accessing support from HSC services, being able to manage practical tasks and remaining active in their day-to-day life helped them to cope with these changes. Service Users and Informal Carers described feeling lonely and isolated; however, they also stressed the need for time alone, to help maintain their mental health and wellbeing.

5.5.1 Understanding changing health and wellbeing needs

Service User and Informal Carers shared their changing health and wellbeing needs. They highlighted the challenges they faced as their needs (or the needs of their Service User) altered, and how their roles developed during periods of change. As understanding of those needs developed, Service Users and Informal Carers felt it important to be accepting of the Service User's changing condition and increased need for support. In the excerpt below, Grant not only highlights his acceptance of his changing needs (because of his advancing COPD) but a necessity to accept the support he receives to meet them:

> *"You know, there are flaws in your, your health and your physic, er, physical [abilities], that you've nothing to do with your health or, er, if I've got this [COPD] and there's no way that I, personally, have changed my behaviour to get rid of them or cope with it, so I'm stuck with the, the support." Grant, Service User, HSCP 1.*

Staff Member participants recognised that Service Users and Informal Carers looked to them for help to better understand their changing needs, and for assurances and certainty about disease progression in the future. However, Staff Members believed uncertainty was an inevitability:

> *"There's obviously uncertainty about the future [for Service Users and Informal Carers], which, we can't provide any further certainty regarding that, but can offer support just, really, around it". Catherine, Staff Member HSCP 1.*

Staff Members felt that they could support Service Users to understand and accept uncertainty about their future and felt well placed to achieve this when they had built up a relationship or rapport with Service Users and Informal Carers. For Informal Carer Anisha, a lack of assurances about the future was further compounded by a perceived reluctance from some social care staff to make provisions or plans to meet anticipated changes in Arthur's health and wellbeing needs:

> *I'm very uncomfortable about the future, cause as I say, I don't know who does what and when, you know. I know that we're going to have to come to a crisis for anything to happen, and I dinna think that's right at all. Anisha, Informal Carer, HSCP 1.*

Arthur and Anisha had raised concerns with social services about the need for support with personal care and medication management for Arthur. These were tasks he needed support with because of his Dementia and there was uncertainty regarding the provision of this support additional services in the future, should Anisha be indisposed (as she did not keep well herself). Arthur and Anisha perceived HSC staff as being short-sighted in their understanding and planning for Arthur's changing needs. They highlighted a lack of co-ordination, communication and planning for care. Furthermore, they perceived a need to face crisis for action to be taken, suggesting a 'fire-fighting' approach from some social services that focused on problem-solving and solutions rather than working in a planned, anticipatory way. Both Anisha and Arthur experienced anxiety about the levels of uncertainty around Arthur's care. Their anxiety was two-fold, they wanted reassurance both about planning for the future and about healthcare provisions at a time when they were needed. Informal Carer participants experienced increased stress and anxiety as a result of uncertainty about the future, their finances and their caring responsibilities, while reduced frequency of social contacts (for Service Users) was reported as a source of concern and worry.

Staff member participants highlighted the role third sector organisations can play in supporting Service Users in times of change. Zoe and Gavin, who were both Befrienders in the third sector, emphasised their Service Users' need for support when their health and wellbeing needs had changed. They felt it was particularly important when Service Users were admitted to an acute in-patient setting or moving from their own home to a residential care home. They highlighted the positive effect Befriender contact could have when Service Users were learning to accept these changes and to adapt to new circumstances. Zoe explained her perceptions of the struggle that Service Users faced, as they learned to understand and accept their changing health and wellbeing needs when moving to a care home setting. She felt the third sector Befrienders had a role to play in facilitating this:

> *[It can be] really, really disorientating for them [Service Users] and they can struggle for weeks, you know, or longer, just adapting to having moved and wanting to go home and, erm, yeah, getting used to the fact the care home is their new home so,*

> *I can see, you know, that's there, that people could be helped more with that transition. Zoe, Staff Member, HSCP 1*

Zoe recognised a need for further work to support people who were transitioning between HSC settings. She (and the HSC organisation she worked for) faced challenges around recruiting more voluntary befrienders, and there was a need for formal agreements between HSC sectors to facilitate cross-sectoral working and support for Service Users. Service Users and Informal Carers also highlighted some of the challenges they faced as they learned to accept their changing needs. They were worried about disease progression and concerned that the care they required could be burdensome for their Informal Carers, particularly when physical help with moving and handling was required. All Service Users highlighted a desire to maintain their independence, to the best of their ability, as their health and wellbeing needs changed. Informal Carers recognised this and endeavoured to support their Service User to achieve a level of independence appropriate to their abilities.

Some HSC staff, across healthcare and social care settings, made assumptions about the Service User and Informal Carer’s desire to mix (or not) with others in a similar position (via condition-specific support groups), to help them better understand their changing needs. As a result, they perceived their care was not always focused on their individual needs. Some healthcare staff appeared to focus on the Service User’s medical condition rather than them as a person. Although their health and wellbeing needs were changing because of their medical condition, Service Users did not want to be defined by those changes. Some HSC staff had chosen to only ‘see’ their medical condition when supporting them, suggesting some staff may not be adopting a person-centred approach to their care. Service User Caitlin highlights this below in a consultation with a surgeon regarding an issue unrelated to her MS. The Surgeon used her condition as a label to identify and define her. This resulted in feelings of being ‘a number’, rather than receiving care centred on her needs as an individual:

> *CAITLIN*
>
> *[Caitlin, quoting her Surgeon’s referral letter; gestures air-quotes with both hands]*
> *“Met with Caitlin, slim lady with MS, and I recommend that you give her a stoma*
> *… [pause, then Caitlin furrows brow and rolls eyes]*
>
> *… I've got MS and maybe down the line that is something that's going to be an issue, but it's not just now. So, that, that was a...*

> *CONNOR*
>
> *That's when you were a 'number'.*
>
> *CAITLIN*
>
> *...that's when I was an [gestures air-quotes] 'MS person' and nothing else. Caitlin Service User, & Connor Informal Carer, HSCP 1.*

Although Caitlin's condition had been used to label and define her by a member of HSC staff, some Service Users and Informal Carers reported the opposite. Where the Service User's condition or symptoms were not immediately obvious because they did not have an obvious physical disability, HSC staff underestimated their need for support and projected what were perceived to be judgemental attitudes. Informal Carer Anisha described an encounter with an HSC Staff Member where she felt she faced judgement about her caring role and responsibilities she *should* be fulfilling. The Social Worker questioned her commitment as a wife and to her role as Arthur's informal Carer:

> *"The quote I got thrown back at me was, 'a good wife would do that for her husband', and I thought, yeah, if a good wife's* ***here*** *type of thing but, I didn't say it, I should've said it really or, maybe I should've just turned round and said, 'well, I'm nae a good wife then!', you know [crosses arms, frowns]. Anisha, Informal Carer, HSCP 1.*

Anisha went on to emphasise the pressure and stress she felt from the unexpected support she provided for Arthur with daily activities and tasks, such as prompting him to take his medication and wash and dress daily. She perceived that the Staff Member did not fully understand the pressures and stress that she faced as an Informal Carer. To cope with the pressures and stress of her caring role Anisha identified her need for respite services, which she and Arthur did not receive after their Social Worker felt it unnecessary:

> *"A lot of my, my pressure comes from the stress of having to, you know, think for him, at times, erm, which you dinna expect to have to do for your husband when he's only 61 and, to combat that, you need to get away for a while, respite, erm.*

> *Now, to get respite, I need somebody to look in on him but, he didn't get that.” Anisha, Informal Carer, HSCP 1.*

Anisha highlighted how her role in helping Arthur meet his health and wellbeing needs was not commensurate with her own expectations. She describes how caring for Arthur had changed her role and responsibility, as she became his Carer as well as his wife, which led to her to her feeling stressed. She also perceived that HSC staff lacked a clear understanding of the demands she faced as Arthur’s Carer. Anisha had anticipated that a holistic approach to his care would also include support for *her*. Both Service User and Informal Carer participants groups acknowledged similar challenges they faced in coming to terms with and accepting the changing roles they held within the household and the family, whether expected or not. Service Users reported changes to their ability to perform physical tasks, such as gardening and housework tasks. Maintaining independence in these areas was important to Service Users and their Informal Carers, and all Service User participants reported difficulties in completing these tasks because of reduced mobility or physical ability.

Informal Carers, private cleaners and HSC Staff Members supported the Service User with these tasks. In addition to housework, which was not included in the contractual obligations of HSC staff, Staff Member participants were regularly undertaking extra duties. These included collecting the Service User’s prescriptions from the pharmacy, shopping and attending to wounds (for Staff Members who did not normally support Service Users with wound management). For Staff Member Beverley, a Social Work carer, it was not uncommon for her to offer additional visits to Barney in her own time, to accommodate changes he wished to make to his scheduled care. This demonstrated flexibility in the way Beverley delivered care, but also highlighted her perceived need to donate her own time to her HSC staff role:

> *He got a, a bad part on his shoulder and, erm, he got a plaster on it so, he didn't feel up to his normal shower on a Thursday so, I used my break time on the Friday to go in and, and wash him, cause normally he would just get a 15 minutes [time slot for care]. So, that, I went in early, instead of having my break, and just showered him down. Beverley, Staff Member, HSCP 1.*

This highlighted a potential lack of adequate staffing and resources to meet the needs and expectations of Service Users, and HSC organisations’ reliance on the goodwill of care staff. It also emphasised a potential need for more frequent needs' assessments from HSC providers, to meet the changeable nature of Barney's health and wellbeing needs. Staff Members who were directly involved in delivering HSC appeared flexible and adept at dealing with changes in the scheduled care they provided, even when it involved using their own time to meet rescheduled commitments. However, for Informal Carers the changing nature of their role was challenging.

All Informal Carers reported increased stress, related to the shifting nature of the role they were adopting as a Carer. They highlighted the impact that increased stress had upon their wellbeing, resulting in low mood, depression, emotional strain, physical exhaustion and a sense of pressure and responsibility in providing care for their relative. For Informal Carer David, the responsibilities he perceived when caring for his wife Donna led to him feeling exposed to physical and psychological infirmities, with a need for support not met through his HSC services:

> *The spouses, erm, are in a position, they're in an exposure position, they're in an exposed position physically, in terms of fatigue and stress, and also psychologically, in terms of emotions, and I don't think it's accounted for… I'm picking up things [tasks around the house] quite a bit. It's, all pressure and stress in little ways. David, Informal Carer, HSCP 2.*

They described an increased sense of caring responsibility and progression of the Service User's symptoms as sources of increased anxiety and worry. Balancing caring responsibilities with other family and work commitments was difficult for some Informal Carers who were in employment. For Informal Carer Esther, this led to her feeling bad about reduced contact with her father (Eddie), when the constraints of her family and work commitments delayed her support visit(s) to him:

> *I think maybe I worry too much about dad, you know, when I do have weeks where I just don't have time or, I'm too depressed or I'm too knackered to go up to Dad's at a weekend, I'll feel really bad, and think, oh God, I haven't seen Dad for a week or two weeks. Esther, Informal Carer, HSCP 2.*

Furthermore, when asked how she felt about the caring role that she had taken on for her father, Esther felt overwhelmed by the experience and responsibility, and struggled with worry and feelings of guilt:

> *There's been times when it's been really kind of overwhelming and, I feel like it shouldn't feel like it's overwhelming, erm, there's a lot of guilt involved, I think. Like, oh, I should go up and see Dad or, I should've done this for Dad, erm, it's that kind of thinking, like I should, I should, I should not. Esther, Informal Carer, HSCP 1.*

For all Informal Carers, increased worry and anxiety about their caring responsibilities, negatively impacted their health and wellbeing. Carers often felt overwhelmed by their caring responsibilities, suggesting a need for further support to manage or alleviate these. They described several strategies that helped them to feel well and cope with their changing role. Maintaining social contact with friends and sharing their caring responsibilities with others in their family helped them to reduce stress. For some Informal Carers, getting out of the house to pursue outdoor activities, hobbies and interests was also helpful. Informal Carers were also looking for HSC staff to help them worry less. Some third sector organisations, such as those relating to people living with MS, offered specific sessions for Carers to support each other. However, despite a desire to go along to these groups, Informal Carer Esther explains that times often clashed with work or caring commitments, which compounded existing worries:

> *"They have regular, like Carers meet ups so that I know that there is support there, erm, I have not made use of it as much as I would've liked or, probably should have. Erm, a lot of the, a lot of the services are through the day so, they will have a sort of coffee, a Carers cafe kind of thing but, it's always like 10am on a Thursday or, 11am on a Wednesday and, I'm just not able to go, erm, if they maybe had more things on in the evening I would find it much more useful and definitely would make use of it, cause there's been times where it's just been, argh, super stressful, anxious, depressing, I feel like I'm a terrible daughter because I'm getting stressed-out about things and sort of, I know that it would help to talk to other people that are in the same boat…" Esther, Informal Carer, HSCP 2.*

Like Esther, all Informal Carer participants highlighted the impact their caring role had on their health and wellbeing. They experienced increased anxiety and worry relating to their Service User's health and wellbeing, resulting in low mood or depression for some Informal Carers. They felt more able to cope with their own changing role (as a Carer) when their Service User's needs were perceived as being met by appropriate HSC services. Knowing that someone from HSC services had regular contact with the Service User offered reassurance. Informal Carer Gail explained that she felt much happier knowing someone visited with her father (Grant) daily, because she worried that he would not let her know if he was struggling with something at home from-day-to-day. This helped to improve her wellbeing and feel more able to adjust her caring responsibilities to her father's changing needs:

> *So I know there's people coming in every day, Monday to Friday, there's somebody touching base, which is, I'm much happier when that's happening, 'cause he never phones up and says, I'm in trouble. Gail, Informal Carer, HSCP 1.*

Service User contact with HSC staff was not only beneficial in reducing stress and worry for Informal Carers, but it also enabled them to feel more comfortable with and reassured about their Service User's desire and maintenance of levels of independence. Furthermore, there were advantages for HSC staff in offering reassurance too. Befriender Staff Member participants Zoe and Gavin both reported the benefits they felt as result of ongoing contact with their Befriendee's. The connections and relationships they were able to build up with their Service User allowed them to connect over common interests, which was a source of personal fulfilment, confidence boosting and enjoyment:

> *"I actually enjoy it [the connection and common interest with her Service User] and I benefit a lot from it as well … You get a sort of confidence boost from you're doing something good for somebody else and helping them in their lives so, so, yeah, it's a win, win in lots of ways really." Zoe, Staff Member, HSCP 2.*

In summary, this sub theme highlighted that participants' understanding of their changing health and wellbeing needs and how these could be met, was shaped by their connections with others. Service Users and Informal Carers felt that their experiences when accessing HSC could be challenging. They described feeling judged by HSC staff about their abilities, which led to perceptions that their care was not always focused on their individual needs. Informal Carers experienced increased stress, worry and anxiety around their caring responsibilities and role. Staff Member participants acknowledged their role in supporting Service Users and Informal Carers whilst their health and wellbeing needs were changing. Strategies that helped participants to cope with their changing health and wellbeing needs are discussed in the sub-theme below.

5.5.2 Feeling able to cope with changing health and social care needs

Service Users and Informal Carers reported strategies that helped them cope with their changing health and wellbeing needs and the needs of the Service Users they were supporting. For Informal Carers, coping strategies included taking a break away from their caring role which was important to maintain their mental health and wellbeing. Having a holiday, socialising with friends or accessing respite, helped them to feel as though they were coping with their caring responsibilities. They also needed time on their own with HSC staff to discuss issues that might be perceived as delicate or upsetting to the Service User. Staff Member Abigail indicated that speaking with Informal Carer Anisha alone offered an opportunity to meet Anisha's individual support needs, as Arthur's Informal Carer:

> *"We chat, the three of us, for a wee while and then he'll go and put on the kettle or take the dogs out and that, just to give Anisha and I a chance… to have that wee bit time to speak on her own [Anisha], cause she's very open and she does say the majority of what she needs to say in front of Arthur, erm, but there are somethings, I think, that she's struggling with her health and she just needs to have that wee bit extra support… it just gives her a chance to sort of say what she needs to say without upsetting her husband [Arthur]…" Abigail, Staff Member, HSCP 1.*

Abigail's experiences not only highlighted the collaborative nature of providing care and support both with and for Arthur and Anisha, but it also emphasised the key role HSC staff played in helping Informal Carers to cope with their caring responsibilities. Informal Carers faced logistical challenges in executing these coping strategies when access to appropriate transport was reduced (Service Users), and when no one was available to support the Service User in their absence (Informal Carers). Informal Carer David offers an example of his reluctance to leave his wife Donna without someone to support her. His body language suggesting this as a source of worry or concern for him, with Informal Carers across all other cases also expressing similar feelings when their Service User was left alone. In particular, David felt if someone was available to be with Donna, he would be able to have time to himself to pursue his own hobbies and interests:

> *"If I prepare Donna's tea or something, somebody else can come and serve it… that would enable me to go out, erm, for a long walk, erm, in the summers… but, at the moment, erm, to leave Donna [looks at Donna, hesitates with furrowed brow] … we need to try and avoid doing it too often." David, Informal Carer, HSCP 2.*

Service User isolation and loneliness were a source of concern and worry, for their Informal Carers. All Service User participants reported feeling lonely and isolated. They felt lonely when they lived alone, as they grew older (after observing that others of their age had died), and as Staff Member Gavin explains below, when family were away or occupied elsewhere in the home:

> *"He [Service User Grant] was lonely… he enjoys company, you know, his daughter [Informal Carer Gail] does go back and forth to him regularly, she lives in - [location] but, you know, she, they go away on holiday quite a lot and he, he gets a bit lonely."*
> *Gavin, Staff Member, HSCP 1.*

Service Users employed strategies to help them combat these feelings. Getting out and about to meet others socially, and regular contact with family (in person and on the telephone) helped them to reduce and cope with feelings of isolation and loneliness. Service User and Informal Carers also looked to HSC staff for social contact when learning to cope with their changing health and wellbeing needs. They wanted to build a rapport with HSC Staff Members face-to-face, feeling that telephone calls did not offer the depth of connection they were looking for when seeking support. Service User Arthur and his wife Anisha (Informal Carer) felt they needed information on Arthur's Dementia, along with support and guidance to help them make informed decisions about their care:

> *"We get an appointment [face-to-face] with them, just to go through things, erm, they [HSC staff] don't make up your mind for you but, they give the necessary information to allow you to come to a sensible decision. Erm… you canna make a*

> *decision on anything, if you don't have the facts, you know." Arthur, Service User, HSCP 1.*

Access to guidance and information about their condition helped Service Users and Informal Carers to make informed decisions, thus helping them to feel in control and involved as their needs changed. Coping with changing health and wellbeing needs was also linked to being able to attend to practical tasks (for both Service Users and Informal Carers). Practical tasks, in their view, related to managing their finances, carrying out personal care, eating and drinking, managing continence, housework and shopping tasks. When attending to financial matters, Service User and Informal Carer participants groups both described lengthy bureaucratic processes and struggled to find time, resulting in pressure and stress. In this excerpt, David explains how increased demands on his time to meet his caring responsibilities led to perceived pressure, resulting in him not being able to attend to his financial bills in a timely manner:

> *"That's pressure, and I find the tax system has probably created more pressure than just about anything else…because you end up and stressed about it [not finding time to attend to bills], so you don't actually see it through properly, quickly [paying his bill]." David, Informal Carer, HSCP 2.*

Maintaining independence with practical tasks was important to all Service Users and helped them to feel they were coping with their changing health and wellbeing needs. Informal Carers and HSC Staff member participants helped to promote functionality for Service Users by supporting them with practical tasks and provision and use of equipment, such as hoists, adapted cutlery and wheelchairs. Access to appropriate equipment helped Service Users to maintain their independence and promoted confidence. Service User Donna highlighted how she used her electric wheelchair to maintain her independence when shopping and how it was important to her to purchase personal items herself, with minimal support:

> *"I just go, er, I mean, I've been in the bus and go into town and, and er…there's usually people floating around. I mean, er, workers, and they'll help you and, I, you know, I manage that way and I get bits and pieces and anything I need myself,*

> *personal things, and that, I would go and buy them myself." Donna, Service User HSCP 2.*

Donna's excerpt also emphasises the key role shop keepers played in supporting her to shop independently; a perception that was also shared by Service Users Eddie and Barney. Online shopping and 'click and collect' services were also instrumental in promoting Service Users' independence for larger volumes of shopping and non-grocery items. Service Users viewed online retailers as part of their support network, along with frozen 'ready-meal' companies. Staff Member and Informal Carer participants helped with shopping for smaller grocery items like milk and bread. Informal Carers highlighted the need for a balance between providing their Service User with support in practical tasks, and encouragement to maintain independence (as appropriate). The latter helped Service Users to feel empowered. Staff Member Esme highlighted the need for reassurance and empowerment, through a reciprocal power-balance between Carer and Service User during decision making, which could influence the Service User's independence:

> *"I just like check his bed and make him a cup of coffee and see if he's needing, wanting to get washed and that, but sometimes, sometimes he will, sometimes he won't, like it just depends and obviously, we can't force him to do it and he, like he will manage himself as well but, at least we're there, you know, if he did feel he was maybe having a bit of a bad day, we could get him washed and that." Esme, Staff Member, HSCP 2.*

Providing reassurance was a large part of the supporting roles undertaken by Informal Carers and Staff members while Service Users' needs were changing. The principle of reassurance was threefold. First, reassurance, from Informal Carers and Staff Members, helped Service Users to cope with their changing health and wellbeing needs. Second, for Informal Carers, reassurance from HSC staff helped them to better cope with their caring role and responsibilities. Third, when they were unsure of changes in their Service User's needs, Staff Members valued the reassurance they received from colleagues. Staff Member Debra, an Occupational Therapist with a private care company, offers an example of how reassurance from a colleague helped her to cope with her Service User's changing needs after spinal surgery. Reassurance from her colleague helped to boost her confidence and calm her nerves when supporting her Service User following an unfamiliar procedure:

> *"The hospital OT in - [location], she really just reassured me, settled my nerves, she said, spinal surgery is, to me, it's something I see every day, it's not as big a procedure as you would think it was." Debra, Staff Member, HSCP 2.*

For Service Users and Informal Carers, remaining active helped them to feel they were coping with changing health and social wellbeing needs. They promoted their mental wellbeing when they were able to maintain their hobbies and interests, such as attending the gym, social events, completing puzzles and playing board games. Getting 'out of the house', to walk the dog or go shopping, also helped Service Users and Informal Carers to feel engaged with others in their communities and promoted social contacts. Service User Eddie reported his experiences of attending a social event in his sheltered housing complex; he attended events like this regularly. They promoted his social contact with others in his community and on this occasion, it had the added benefit of a meal provision, with some to take home:

> *"Well, we'd er, a Burns Supper night, aye, up in the top common room [within the sheltered housing complex], I think everyone was there. In fact, when I came out, I was given some, aye, small plastic containers, there was two of them, that'll do you Eddie, and it was meals they'd actually put into the containers, and that'll do me fine, aye [smiles widely and nods]." Eddie, Service User, HSCP 2.*

In summary, this sub-theme emphasised Service User and Informal Carer participants need for support from HSC staff to help them cope with their changing health and wellbeing needs. They needed support from staff to make decisions about their care, and to maintain their functionality through provision of equipment and reassurance. Remaining active helped them to feel they were coping with their changing health and social wellbeing needs. Although Service Users reported feeling lonely and isolated, they employed strategies to help them cope and reduce these feelings. However, accessing additional support from Informal Carers and HSC Staff Members was imperative to help them implement these strategies.

5.6 Fostering connections and supportive relationships with others for health and wellbeing

Theme two explores participants' perceptions of fostering connections and supportive relationships with others for health and wellbeing, and it incorporates two sub-themes. The first summarises participants' experiences and perceptions of building supportive relationships with people who support them at home. All participant groups identified their need for a personal connection, which was perceived as the bedrock of a supportive relationship. They described continuity, trust and co-location factors as facilitating connection with others on an individual level and across HSC services and systems. The second sub-theme describes participants' perceptions of the key characteristics and attributes of supportive relationships, for example, empathy and reassurance, discernment and reliability. Furthermore, participants highlighted communication as a medium to promote reassurance, information sharing and supportive relationships, outlining strategies to promote it and challenges they faced when doing so.

5.6.1 Building supportive relationships between Service Users, informal Carers and HSC staff

All participant groups identified factors that helped them to build a supportive relationship. A friendly approach was highlighted by all participants as the foundation of a supportive relationship. Commonalities, personal identification and friendship were key qualities of these connections. Service User Donna, who had carers supporting her for a number of years, offers an example of this when she described her experiences of connecting with her HSC Carer:

> *"She's [Donna's Carer] chatting to me when I'm showering and I, I find out about her family and things, chat about her family and, you know, that sort of thing…*
>
> *… I considered them as friends [her Carers] and, I mean, I have a Carer now, who's been coming for, four, over four years, in this company, and she's, I mean, she's really efficient and, you know, I'm made to feel really comfortable and all that but, I mean, I said to her one day, do you think of me as a friend or, or just another client [hesitates, looks down]… she [the Carer] said, 'well, just another client'. Donna, Service User, HSCP 2.*

When she directly asked her regular Carer if she reciprocated the feeling of friendship, her Carer explained that she viewed Donna as ‘just another client’. During the interview, Donna’s non-verbal body language suggested she was disappointed with the disparity between her Carer’s response and her own feelings about the interpersonal connection they shared. She had placed a ‘friendship’ meaning on the connection she had with her Carer (see Figure 5 for further illustration), whereas her Carer perceived their connection as a ‘working alliance’. This disparity in meaning attached to the interpersonal connection was challenging for Donna. However, she offered further insight on why she thought interpersonal connections with HSC staff were challenging. Imposed time constraints of care visits negatively impacted upon the ability of both individuals to connect on a deeper level:

> *“In practice, they're maybe only here 35, 40 minutes, ‘cause they've got to travel somewhere else, they're supposed to be somewhere else at the same time as they're supposed to finish here but, you know, they're very good, the women, they do all the, erm, and they never go away without saying, have you got everything you want and that so, yes, but, there's no time for any sort of friendliness.” Donna, Service User, HSCP 1.*

In this excerpt, Service User Donna highlighted the complexities of workload planning for Carers when they were often rostered to visit two Service Users at the same time. The lack of time for social interaction did not promote a ‘friendly’ connection within their relationship. When a Staff Member visited to support her with personal care, the precise nature of time keeping was felt to restrict time for any social interaction. Social contact was important to Donna and she felt the HSC system (not the Carer) was at fault in determining the time constraints of her visit.

Time with HSC Staff Members, for support or social contact, was viewed as a precious commodity by all participant groups. Service Users and Informal Carers perceived that the time commitments, in an HSC workload, created pressure for Staff Members. Elevated workload pressures, extra duties and a lack of previous experience in a caring role, negatively affected Service Users’ and Informal Carers’ connections with staff. Staff Member participants highlighted the impact staffing issues had upon their time and ability to connect with Service Users. They reported a need for agency workers to fill personnel gaps when a Carer left and was not replaced, and difficulties in retaining staff which created further vacancies. This resulted in an increased demand on staff time, which impacted negatively on the experiences of people who were accessing their services. Service Users and Informal Carers felt it was difficult to connect with staff when they were pressed for time.

Having a personal ‘friendly’ connection (outlined above by Donna) was important to all participant groups when building supportive relationships, and seeing people face-to-face was a key factor in encouraging this. When this was not possible due to lengthy waiting times for access to HSC services and staff, connecting via the telephone was not perceived by Service Users and Informal Carers as an effective way to build a supportive relationship. When face-to-face contact was missing, all participants felt it was inconvenient, disruptive to lines of communication and isolating, which is highlighted in Staff Member Debra’s experience below:

> *“They're [other HSC Staff Members] based at GP practices, they just go along to the office and speak about who they want to speak about, whereas I feel like that runs a lot more smoother than having to pick up the phone and ask a question, you feel like you're bothering someone a lot more than just a, a general conversation across the corridor.” Debra, Staff Member, HSCP 2.*

Although Debra faced challenges when trying to foster a personal connection with others across HSC services and systems when she was not located near to colleagues, all participant groups said that services located together promoted stronger personal connections. Staff Member Abigail emphasised how her experiences of co-located services helped her to gain insight and knowledge of others’ roles and promoted better communication between individuals:

> *“We work quite closely together [with a third sector organisation], erm, we used to have an office in - [location], which was right next door to the - [third sector organisation] so, we kind of know them quite well now, so. And we've got a link worker works with us as well [from the third sector organisation].” Abigail, Staff Member, HSCP 1.*

For all participant groups, having a common link or developing knowledge about the individuals that participants were connecting with, as highlighted in Abigail's experience above, was beneficial in building supportive relationships. Having a named point-of-contact who had previous interaction with the Service User provided continuity and was important to all participant groups. All Service Users and Informal Carers perceived that continuity of HSC staff allowed them to build a rapport, which was mirrored by HSC staff participants. Building a rapport promoted a supportive relationship between Service Users, Informal Carers and Staff Members, opening lines of communication for 'tough' therapeutic discussions about condition-related issues:

> *"I think that...as you get a named person, if you're in hospital, that's your go-to person, I think GPs should have a named person for, erm, conditions such as Dementia or, my, my physical conditions. Erm, so that you can go to this person and build up a rapport with them so that it's easier to talk about some of the, the tougher issues with them, and I really think that's quite important." Anisha, Informal Carer, HSCP 1.*

It was also important to Service Users and Informal Carer participants that their named point-of-contact, when they had one, was knowledgeable about their circumstances and the Service Users condition. This previous knowledge and continuity offered reassurance around 'tough' condition-related issues (particularly in times of uncertainty around disease progression) and unfamiliar people entering their homes. Furthermore, it also helped to alleviate unnerving thoughts and worries about accepting support for their changing health and wellbeing needs, as Staff Member Esme highlights in her excerpt below:

> *"It is regular agency staff that we use as well so, erm, it's good for them… the client kind of has gotten to know the staff and they'll be a bit more eased-off about them going in, cause I think it can be daunting for like clients to begin with, and thinking, 'oh God, there's people I don't know coming in to my house' but then, once they get to know them and know that it is just regular staff, and regular faces and it's, kind of, they're a bit more like, oh, I'm glad I've actually got somebody going in, cause it's less of a worry for them. Esme, Staff Member, HSCP 2.*

However, conversely to Anisha and Esme's experiences above, Service User Donna highlighted that continuity and a 'point-of-contact' were not always available or maintained within HSC services or systems. Not having that continuity through point-of-contact led to reduced access and levels of care coordination:

> *"I've no point of contact now, used to have, the care manager would coordinate with all the other things but, there's not, there's no, you know, I've not got a definite point of contact to, to get to, you know, if I want other, other things." Donna, Service User, HSCP 2.*

For Service Users, having a continuous personal connection with people who were supporting them promoted trust within their supportive relationships. When the personal connection was strong between individuals, a close bond was formed and led to exchange of information classed as personal, which appeared to strengthen the relationship on both sides. For example, Informal Carer Anisha highlighted her experience of sharing information (she would not normally tell others) with her Staff Member Abigail. Anisha shared her feelings and challenges she was facing with Abigail. Furthermore, Staff Member Gavin gave a similar account below of his experiences of the bond of trust he felt with Service User Grant, in his befriending role:

> *I could tell him [Service User Grant] things that I maybe wouldn't tell other people, you know, because, you would know that he, it wouldn't go any further if it was something, and I think he's the same, he would tell me things that he wouldn't tell other people, you know." Gavin, Staff Member, HSCP 1.*

However, in contrast to Anisha and Gavin's accounts above, Service User Barney shared a very different experience. He highlighted the importance of trust in a supportive relationship, and the positive or negative impact it can have on health and wellbeing. For example, Barney emphasised the importance of the ongoing bond of trust he had with Staff Member Beverley. However, he also outlines how his negative experiences with another HSC Carer left him feeling frightened, with conflicted feelings of mistrust for someone with whom he had made a personal connection. When trust was lacking in a supportive relationship, it left one or both parties feeling vulnerable and troubled:

> *"I don't know, I'm sure, she [the Carer who was caught stealing] might've taken ten, ten quid out of my wallet or something… but that frightened me a bit, because you can see, look, my wallet is lying there [points to wallet on the table] but, erm, I absolutely and completely trust Beverley, erm, she is, is, I'm sure she wouldn't do anything like that but, mind you, the woman that did all this [the Carer who was caught stealing] … I liked her… so you have the, the dissidence, if you like, of somebody who you liked, but who's also been, er, thieving off people that she's supported, and I think that must've, for the care company, that must be a worry, you know, you can vet people to a certain extent but, you can never trust people entirely so..." Barney, Service User, HSCP 1.*

In summary, this sub-theme highlighted the depth of interpersonal or 'friendly' connections as a necessary foundation for building supportive relationships. Connecting with others across HSC services, organisations and sectors to build a supportive relationship was facilitated through face-to-face interactions, with Staff Member and Service User participants highlighting co-location of services as a means of promoting this. For all participant groups, supportive relationships were fostered over a period of time, from a place of trust between two individuals, services or sectors. The opportunity to build up a trusting bond was afforded through continuity of contact between these groups, leading to more collaborative supportive relationships and HSC practices.

5.6.2 Key characteristics of supportive relationships

Participants across all cases and groups described similar characteristics and attributes of a supportive relationship. Across all participant groups, individuals were looking for people whom they connected with to have sufficient discernment, to decipher the challenges they might be facing. They also wanted them to offer appropriate support in a kind and caring way. Furthermore, people with whom they had a supportive relationship were perceived as having a calming influence over them, they were adept at listening, exercised patience and were knowledgeable about the Service Users condition and circumstances. Empathy was identified as a key attribute to promote understanding of their circumstances and the Service User's condition:

> *ARTHUR*
>
> *"You need empathy, at the very least, coming back to you."*
>
> *ANISHA*
>
> *"She's [Staff Member Catherine] empathic as well, you know, erm, it's like a having a friend coming in to have a chat, rather than a professional coming in." Arthur, Service User & Anisha, Informal Carer, HSCP 1.*

For all participant groups, reliability was a fundamental attribute in fostering supportive relationships and closely linked to offering reassurance. Reliability was considered to be important, as demonstrated when HSC staff turned up to support them when they said they would. This quality was perceived as providing reassurance that help would be provided when it was needed. This was important to all participant groups, particularly when they had questions regarding their diagnosis, prognosis or disease progression.

> *"I think Beverley works well because I can, I can count on her… I know that she'll be there and that, that she won't, you know, she won't turn up sometimes and not others, that's really quite important to me." Barney, Service User, HSCP 1.*

Once a supportive relationship had been established, reassurance was commonly offered via telephone contact. Service Users and Informal Carers were grateful for the opportunity to connect in this way, particularly when a face-to-face meeting was not logistically possible because their HSC Staff Member had commitments elsewhere. Staff Member participants recognised the value of this contact. They felt it was an important part of their role because it strengthened their supportive relationship with Service Users and Informal Carers and facilitated access to the service:

> *"They both benefit from just continued contact with the service and being seen regularly. Erm, yeah, it's knowing that if there are any changes, they can call us and discuss them over the phone or, we would bring forward a clinic appointment if necessary." Catherine, Staff Member, HSCP 1.*

All participant groups identified communication as a vital component in building a supportive relationship. and it was instrumental in offering reassurance. For all participants communication was face-to-face or over the telephone. Staff Member participants and a small number of Service Users and Informal Carers were also communicating with others in HSC via email. Participants looked to share information, offer support and reassurance when communicating with others. For Service Users and Informal Carers, regular communication with people who were supporting them helped to maintain their safety, feel connected to others and manage symptoms. For all participant groups, regular communication also promoted collaborative problem-solving between Service User, Informal Carers and HSC services. However, all participant groups faced challenges when communicating with other individuals and across HSC services and systems.

For Informal Carers, communication with services about their Service Users' care was difficult when information was not delivered or received in a timely manner, or if it was received at an inappropriate time. Informal Carer Esther offers an example in the below excerpt. She indicated that communication with HSC services, about sensitive issues pertaining to the Service Users' care, was difficult at work:

> *"It's just really difficult to sort things out and work at the same time, erm, I can't always make phone calls at work. I'm in and out of meetings, erm, it's sometimes hard to even find just a kind of private place at work to have a chat on the phone about things like, I don't want to kind of like walk around my office chatting about permanent catheters and stuff, erm, so, that's definitely been my main struggle."*
> *Esther, Informal Carer, HSCP 2.*

This highlighted a need for HSC services to consider appropriate methods and timing when communicating with Informal Carers who had commitments elsewhere (work commitments, or otherwise). Communication across organisations and HSC sectors was challenging for all participant groups and they emphasised information sharing issues. For Staff Member participants, issues centred around a lack of information sharing, or around the way in which communication happened across organisations and sectors. Inefficient communication methods negatively impacted upon the Service Users' access to HSC and the way services worked together. Poor communication practices led to cross-sectoral misunderstandings, reduced efficiency and repeat workload:

> *"Once they [Social Work] get the referral, they'll phone the patient and ask what kind of help they want and they'll [the patient with Dementia] say, 'I da' need any help'… [scoffs and throws hands out to the side, palms facing up]* ***a Dementia patient****?! And then that's it, they close the case rather than getting back to us and saying, right, we've got this referral, can you give me a wee bit more information? … even if I write on the referral, please dinna contact the patient, contact the daughter or contact the husband or the wife or whatever, but they dinna seem to take that onboard, erm, they go directly to the patient, and I understand that it's the patient that has got to accept the help but, to phone someone with Dementia and ask if they want help, they're going to tell you no, ken, I think just a wee bit better maybe communication between the different services would help better." Abigail, Staff Member, HSCP 1.*

This highlighted a need to revise the way in which sectors, organisations and services communicated. It also emphasised the differences in the ways organisations from different sectors assessed and prioritised Service Users circumstances, questioning the depth of understanding social services had around Service User's needs when they had Dementia.

For some Service User participants, data protection considerations hindered the effectiveness and efficiency of the communication with organisations and HSC sectors. Service User Arthur outlined his perception that different organisations and sectors did not communicate effectively and efficiently. This led to frustration for Service Users and Informal Carers, emphasising assumptions from HSC staff that there was no need or desire for further support and Service Users' lack of control over their own data and how it was shared. Furthermore, it compounded Arthur's perceptions that the services he needed were not working together to share information where it would have been helpful:

> *"Because of all the data protection there is now. Erm, so, it's really a case of, at some point, somebody from the, the joint health and social care board, need to ask a question, 'would it be okay for me to pass on your details to charities or voluntary organisations that may be able to help you?' and that's all it would need." Arthur, Service User, HSCP 1.*

In summary, this sub-theme outlined key characteristics required for fostering a supportive relationship, as perceived by all participant groups. These included personal attributes of empathy, trust, discernment and reliability. Furthermore, when Service User and Informal Carer participants were looking to foster a supportive relationship with HSC staff, they also wanted those staff to be knowledgeable about their condition and circumstances. All participant groups looked to share information, offer support and reassurance when communicating within supportive relationships. However, communication was perceived as challenging across HSC organisations or sectors due to inefficient methods and issues around data protection.

5.7 Connecting with communities for health and social wellbeing

This third theme explores Service User and Informal Carer participants' perceptions and experiences of connecting with communities for health and wellbeing. Communities were defined by Service User and Informal Carer Participants in one of two ways. Firstly, all Service Users and Informal Carer participants described their local geographical community, indicating that people who lived nearby supported them to maintain their health and wellbeing. Secondly, all participants across both groups described how wider contextual communities, where people had a common interest or role such as a religious church group or a group of Informal Carers, helped them to maintain their health and wellbeing.

The first sub-theme outlines the significant role local geographical communities played in helping Service Users to meet practical health and wellbeing needs. These included providing support with transport, shopping and gardening and, as identified in Sections 2.5 and 5.5.1, maintaining these was important to Service Users. It also highlights some of the challenges Service Users and Informal Carers faced when connecting with their local community, including the increasing size and changing demographics of their communities. The second sub-theme highlights Service Users' improved health and wellbeing through social contact with people in the local community; it improved mental wellbeing, but they expressed a need for balance between social contact and time alone. Finally, the third sub-theme outlines the ways' participants connected with wider contextual communities of other Service Users and Informal Carers to feel supported, share their experiences and gain knowledge of their condition. All participant groups outlined the benefits and challenges of Service Users and Informal Carers connecting with others in their condition-specific communities. These communities facilitated information sharing, but the information was not always perceived to be accurate or appropriate.

5.7.1 Maintaining and promoting practical tasks with support from the local community

Support from local geographical communities helped Service Users to attend to practical matters, such as shopping, transport and gardening tasks. They would also offer practical support for the Service User, if their Informal Carer was taking a break from their caring responsibilities on holiday. In these circumstances, Informal Carers asked members of the community to 'check-in' with their Service User, provide items of local grocery shopping and support with putting their rubbish bins out for collection. Furthermore, connections Service User and Informal Carers had with members of their local community often appeared more cohesive than the connections with HSC staff, services and systems. Service User and Informal Carer participants attributed this to the depth of connection they held with individuals in their community, linking it to the community members' prior knowledge of the Service Users' circumstances:

> *"People that I, that support me, are often people who are integrated into the local community so, so people know them, erm, and they kind of know me so, that's quite important to me, like… they know what I need and they, they know that I can't walk too far so if, for example… I'd went and got some very heavy shopping; they would pick it up and put it in the car for me." Barney, Service User, HSCP 1.*

Support from local members of the local geographical community, both when Informal Carers were around or on holiday, helped Informal Carers and Service Users to feel reassured that the Service Users' needs were being attended to and they had social contact with others. However, one of the challenges to accessing support from people in a local community was highlighted by Grant, a Service User. He perceived a reduced level of community members' knowledge about him and his needs, attributing this to the increased size and changing demographic of their community. This led to a reduced resource of people to support him with practical tasks, particularly when his daughter, Informal Carer Gail, was away on holiday. Furthermore, Grant also perceived an increased reliance on HSC staff to meet health and wellbeing needs of the population, due to reduced community resources:

> *"The village is expanded so much, everybody before knew who I was and knew who the kids were but, no… you don't know all the people now, you see, and there isn't that contact, village contact, if you like … I think people are so much tied up in their own lives, very often you see nowadays, husband and wife both work, even the family's, after a few years, the kids go to creches and that and right back at work. So, I don't think they've the time now to devote much… I don't think it's that open, er, neighbourly kind of care then that used to be. The people probably are more dependent on, er, trained professional people." Grant, Service User, HSCP 1.*

Being able to build supportive relationships with people in their community, through friendly connections, was important to Service Users and helped them to feel supported. This suggested a need for HSC services to work closely with local communities to provide and compliment support for Service Users. Furthermore, offering communities an opportunity to build up their knowledge about Service Users and their circumstances was also important.

In summary, this sub-theme considered the connections that Service Users and Informal Carers made with their communities for support with practical tasks and valued reassurance, especially whilst Informal Carers were unavailable. The connections that Service Users and Informal Carers had with people in their communities often appeared more cohesive than those they had with people from statutory HSC services. This was attributed to their knowledge of the Service Users' circumstances. However, for Service Users, connecting with people in their communities had become more challenging as local populations increased. People in these increased populations did not have knowledge of the Service Users' circumstances, leading to reduced community resource and Service Users feeling disconnected from their communities.

5.7.2 Improved health and wellbeing through social contacts

For all Service Users and Informal Carers alike, social contact with others in their community improved mental wellbeing. Social connections were promoted through contact with singular members of their local geographical communities, and through wider contextual community exercise and church groups. As Esther explains below, social contact with others had a positive effect on her father, Service User Eddie, and suggested it offered her reassurance that it was improving his mood:

> *"They meet up every Saturday, there's like a coffee room, erm, they have, you know, the odd evening, they'll do like a Burn's Supper or they'll have like fish and chips, like every couple of months, and have a meet up. I think that's really helped his mood and, yeah, his just general happiness levels. It's been good." Esther, Informal Carer, HSCP 2.*

Eddie corroborated Esther's account above, explaining the effect that social contact had on him when someone from his local community moved into his sheltered housing complex. He highlights their previous knowledge of each other's circumstances and family, with reminiscence helping to re-establish a renewed connection between them that positively affected his spirits.

> *"Oh, it was great! [eyes become animated, wide smile] … he was speaking about a pub he had worked in, I said '[my] old man used to work in there', he says, 'aye, I mind your old man, Eddie', I mean, he's older than me, the guy, and he says, 'aye, we used to have some rare times together', aye, I ken we did! [winks, laughs and smiles widely again]." Eddie, Service User, HSCP 2.*

Informal Carer participants shared Eddie and Esther's positive perceptions of social contact for Service Users. They felt that reduced social contact was a 'dangerous thing' that led to isolation and loneliness. All Informal Carer participants actively encouraged their Service Users to maintain social contacts; however, Service Users also pointed out that there were times when they were happy to be on their own:

> *"He'll [Eddie] sort of remind us, 'I'm in my 70s! I actually quite like just sitting on my own sometimes and, like just having, having a wee rest and taking it easy'." Esther, Informal Carer (talking about her father, Service User Eddie), HSCP 2.*

Eddie and Grant felt the level of social contact their Informal Carers encouraged them to maintain was not always what they wanted or necessary. This suggested a difference in expectations and perceptions of the two participant groups, and a need for Informal Carers to be mindful of that when supporting the Service User and encouraging social contact with others.

This sub theme has outlined the positive influence of social contact on mental health and wellbeing. Previous knowledge of the Service Users' circumstances helped participants to connect with others socially, and Informal Carers felt their Service Users' social contact with others should be encouraged to promote mental wellbeing. Although Service Users did want to maintain and make new social contacts, they also needed time to themselves and reminded Informal Carers of this when the latter were encouraging them to have social contact with others.

5.7.3 Connecting with other Service Users and Informal Carers to feel supported

Service Users and Informal Carers described their experiences of connecting with others in a similar position to help them feel supported (namely, other Service Users and Informal Carers), via third sector support groups. When these groups were accessible to Informal Carer participants, they perceived them as a valued opportunity to connect with other Carers for peer-support. Groups appeared to adopt a strengths and assets based approach to support, where members worked together to share their experiences and information about further support and changing HSC needs (discussed further in Section 6.5). Service User participants who attended these groups felt supported because they were able to exchange accounts of treatment options, discuss symptoms and disease progression, and connect with people who knew and understood their circumstances. However, it also presented challenges as highlighted by Staff Member Catherine:

> *"I suppose, so, the - [third sector organisation], it's a great charity that patients, erm, get a lot out of [the support group], I'm sure. Sometimes their opinions can be quite forceful, and we have to look at, say, treatment options from an evidence-based practice [point of view] as opposed to perhaps what's purported by the - [third sector organisation]." Catherine, Staff Member, HSCP 1.*

Catherine's account highlighted the risk of raising participant expectations without an evidence-base to fully explore the suggestions of others within the group. It also emphasised variances in the way services from different sectors worked (some being evidence-based and others not). In some instances, Service Users and Informal Carers reported that some HSC staff made assumptions about their desire to connect (or not) with others in condition-specific support group communities. These opportunities were not always welcomed. Some Service Users and Informal Carers perceived these groups as being for older people, with others feeling they did not want to observe advanced symptoms in others for fear that the same symptoms might be ahead of *them*. As Informal Carer Esther explains:

> *"My dad was sort of freshly diagnosed, he was sort of advised [by another person who also had MS] not to go along, like, that he might find it a bit upsetting because there would be people there further along in the disease so, in wheelchairs and really unwell. So, I think he sort of put off going". Esther, Informal Carer, HSCP 2.*

Being cognisant of Service Users disease progression, their individual circumstances and their desire (or lack of) to attend these meetings was important to ensure that their care and signposting was individualised and centred on their own desires.

In summary, this sub-theme outlined the vital role communities play in supporting Service Users, promoting connections and supportive relationships with people who knew and understood their circumstances. Maintaining and making connections with other Service User and Informal Carers offered an opportunity for participants to share their experiences and access information about their condition or caring role, whilst offering peer support and social contact. However, not all Service Users and Informal Carers wanted to connect with communities of people who had similar circumstances or conditions because of a risk of mis-matched expectations around treatments and progression for their condition.

5.8 Connecting with HSC services for help to maintain and promote health and social wellbeing

Theme four explores participants' experiences of connecting with HSC services to help them maintain and promote their health and wellbeing. It describes participants' access, availability, coordination and organisation, and utility of HSC. The first sub-theme outlines Service Users' and Informal Carers' experiences of accessing HSC services, highlighting the need for greater flexibility in service delivery and an increase in the number of respite facilities. It also presents the challenges they faced in accessing services through perceived gatekeepers. The second sub-theme describes how HSC services were organised and coordinated, and strategies that promoted this. Having a named point-of-contact had a positive effect on coordination of care, but this happened more quickly when Service Users were involved in the process. The final subtheme considers utility of HSC services to meet the needs of participants across all groups. Service Users and Informal Carers described long waiting lists and perceived that HSC services were not always appropriate to meet their needs. However, they felt supported when they had regular contact with services they used frequently. Staff Members also highlighted the importance of support from more experienced staff across HSC services; this support promoted Staff Member wellbeing by helping them to feel reassured and boosted their confidence.

5.8.1 Availability of, and access to, services at a time when they were needed

Service User and Informal Carer participants described their experiences of accessing HSC services, reporting fragmentation and reduced availability. It was important to participants across all groups to have access to services, such as physiotherapy and GPs, at the time when people felt they were needed. Some Service Users acknowledged increased frequency of review appointments with a GP, social work services and condition-specific specialist services, in comparison to Service Users in other geographical areas. For Service Users, timely access to their GP was important in helping them to feel supported:

> *"She gives us [Barney and his wife] such good support. Erm, it seems to me to be a bit of a lottery [access to a supportive GP], it depends very much on the nature of the, of the particular GP but, this one, she comes and sees me regularly, every four weeks." Barney, Service User, HSCP 1.*

Although Barney had highlighted timely access to his GP, his perception of an access 'lottery' was corroborated by other Service Users and Informal Carers who reported reduced availability and access to GP services. Some Service Users were also aware of geographical limitations for access to specialist services, such as specialist Dementia or neurological services. When they knew about this limited access, as Arthur did, they felt these services should be available to other people who had the same condition(s), regardless of their geographical location. They expressed a desire for parity across their local HSC system and nationally, feeling the specialist service they were accessing would be of benefit to the wider population:

> *“It's a very good team [Dementia care team] and, it should be rolled out certainly, you know, over - [the local region] but, probably - [UK country], but certainly - [local region] but it isn't, I know it isn't.” Arthur, Service User.*

For Service Users and Informal Carers, specialist services specific to the Service User’s long-term condition were limited by geographical location in their HSC area. For example, access to a specialist Dementia consultant was not available to all Service Users across the region, only to those in the local HSCP area:

> “We've actually found *that this [access to the Dementia] team is only because we're with Doctor -, it's not post-coded, it's consultant based, other* consultants in - [health care facility] do not have this and we know this for a fact…” Arthur, Service User, HSCP1.

Service Users and Informal Carers also experienced reduced access to rehabilitation services, third sector support services (such as peer-support groups) and social services (for help with personal care). Furthermore, Service User participants who had long-term conditions and their Informal Carers highlighted reduced availability of respite services for Informal Carers across their HSC region, because of long waiting lists and lack of funding:

> *“The trouble is – [respite facility] just didn't have the money, which is really tough because that respite home served not only - [neighbouring HSCP location], it served people north of - [neighbouring HSCP location], and we came up from here, you know, so it served a whole, a huge area.” David, Informal Carer, HSCP 2.*

Participants across all groups perceived funding and resourcing of respite and wider HSC services to be challenging, with widespread belief that social care services (in particular) were underfunded. Service User and Informal Carer participants who needed to access respite services thought monies could be spent in better ways to increase respite facilities, and on the premise of spending money now to save money in the future:

> *"The local authority's very defensive about budgets and they're, yeah, they're very loath to spend for the future." Arthur, Service User, HSCP 1.*

When Service Users and Informal Carers encountered reduced availability of respite care in the region, they felt that this was 'tough'. For example, Service User Donna outlined challenges she faced around the Direct Payments method of funding her care, and the availability of respite facilities in her HSCP locality. She explained this method of managing finances for her care was restrictive. She had to arrange respite herself in a care home, as no dedicated respite facilities were available in her HSPC area. Subsequently, Donna felt she had to settle for delayed access to respite in a setting that she did not want to use, with no alternative options:

> *"Respite is a big issue, isn't it, David [Informal Carer]? I mean, I was told I don't qualify for, er, for, the only one there is in - [participant's HSCP locality], there is - [a dedicated respite facility] and, I don't qualify for that because I'm Direct Payments and she said, 'oh if you want respite, just ring up a care home' but… I don't particularly want to go there, if you ring care homes, they all have waiting lists…" Donna, Service User, HSCP 2.*

Donna's perceptions about availability and suitability of respite services were also mirrored by other Service User and Informal Carer participants who felt they needed to access respite care, suggesting an unmet need across both included HSCP areas. Furthermore, some Staff Members and Informal Carers reported that allocated timeslots for the Staff Member to visit the Service User, did not always fit with the Service User and Informal Carer's needs. For example, Service User Eddie sometimes liked to get up and dressed early before his care staff arrived to help with personal care. Whilst Staff Members had negotiated with Eddie to arrange a suitable time to support with washing and dressing, there was little opportunity for flexibility in the allocated timeslot. Eddie often wanted to get up and dressed earlier than previously agreed. However, although carers were not able to support Eddie with their original intended care tasks on these occasions, Staff Member Esme indicated that they used those opportunities to check that he was 'doing okay' and to connect with him socially:

> *"We go in every morning to kind of check on him [Eddie], see if he wants assistance to get dressed or washed or anything, check his bed, have a yap with him and make*

> *sure he's had his coffee and his breakfast. Sometimes he has already had it ‘cause he gets up sometimes about three, four in the morning but, we're there kind of really to have a, a wee yap and make sure he's doing okay.” Esme, Staff Member, HSCP 2.*

The inflexibility in service delivery highlighted by Eddie was mirrored by Informal Carers; they felt that HSC services needed to be more flexible in the ways that they supported *them*. They thought that financial support for Carers should be more closely aligned with the individual needs of the Informal Carer. For example, Anisha (Informal Carer) had been awarded a generic Carer’s financial package that was not tailored to her needs. Additionally, this generic Carers’ package did not allow flexibility in the way in which awarded monies could be spent by the Informal Carer:

> *“They're [Social Services], not willing to fund really practical help issues whereas, they're quite happy to, to fund, erm, non-practical things. For example, I get a budget to go to a beautician. Now, I would far rather spend that on somebody coming in to do the garden but, I can't do that, you know, there's no, erm, flexibility in these plans that they give you.” Anisha, Informal Carer, HSCP 1.*

For some Service User participants, they faced challenges around limited access to services, attributing this to perceived counter-productive gatekeepers. These gatekeepers were perceived as moderators who controlled access to HSC services. Service User Barney, who was living with Chronic Kidney Disease, highlighted an example of this in the continence service, feeling he had to persuade the gatekeeping staff that he needed the intended services:

> *“But there's a woman in [local location] who, you have to convince that you're in need of the services.” Barney, Service User, HSCP 1.*

Barney’s perceptions of this particular continence service were mirrored by Staff Members Beverley and Catherine, with similar observations within wider physiotherapy and rehabilitation services from Service Users Donna and Caitlin. Gatekeeping staff in these services inadvertently deterred Service

Users and other staff from accessing them. As a result, Service Users perceived a lack of control over their own care, choosing to regain control by accessing private sector alternatives that were perceived as more suited to their needs. Service Users' and Informal Carers' lack of control over access was also highlighted in their perceptions of having to 'push' for services when they felt they needed them. Service User Donna experienced structural changes to the way her care was provided by HSC services. She explained that she had previously accessed occupational therapy support for her long-term condition through a dedicated rehabilitation facility in the area. However, access to this provision was denied once she reached the age of 65; she perceived she then had to 'push' to continue her rehabilitation through an alternative route:

> *"I feel once you're 65 and chronic, that's it, when it comes to going to, you know – [rehabilitation facility]. I mean, I had to push to get an OT." Donna, Service User.*

To summarise, this sub-theme outlined participants' experiences of accessing services, when they were available, in their local HSCP areas. Service Users and Informal Carer participants reported reduced access to respite services, a need for greater flexibility in the way services were delivered, and reduced opportunity to access HSC because of perceived gatekeepers. When participants could gain access to services at a time when they thought they needed them, they felt supported and that their health and wellbeing needs were being met.

5.8.2 Coordinating and organising services within an HSC system

All participant groups were looking for further clarity on the way HSC was set up and organised across their services. Service Users and Informal Carers perceived that having a named point-of-contact helped them achieve this. However, not all Service Users had a point-of-contact, and for some, this led to reduced access and levels of care coordination. Service User Donna explained that when she had been discharged from the rehabilitation service upon turning 65; as above (Section 5.8.1), she no longer had an identified point-of-contact who knew about her care and circumstances. She felt less supported, highlighting a need for consistency and further contact provisions for Service Users if their method of care, or HSC staff, changed:

> *"Having a Care Manager [as a named point-of-contact] that, you know, coordinated things, that would refer you if you needed physio or OT or anything like that, that worked very well… the Social Worker was my Care Manager, and an OT and physio and the Rehab Nurse, and they were all there [at the rehabilitation facility] and everything seemed to, erm, go great… but I found since about 2015, I've not had, I don't have a Care Manager anymore." Donna, Service User, HSCP 2.*

Having been to the rehabilitation centre where services co-located, Donna recognised the positive effect on care coordination, and she outlined her own involvement in organising and coordinating her services since being discharged from there. She emphasised the positive effect her involvement had on the speed of arranging services to support her when there was no need to go through a point-of-contact or gatekeeper. This suggested care coordination via HSC services could be a lengthy process, and that coordination was timelier when organised by the Service User themselves:

> *"I found - [private care organisation] myself. Erm, I did have a visit from a [duty] Care Manager then but, she said she couldn't find anyone so I, I just did it myself and went online and just rang up and, within less than a day I'd got it sorted [raises eyebrows., looks over the top of her glasses]." Donna, Service User, HSCP2.*

However, other Service Users felt that they had not been involved in coordinating and organising their care. Eddie highlighted his experience of his Informal Carer's input into the decision-making process of organising his frozen meals; he indicated his input was minimal. He explained he had once ordered meals himself and enjoyed social contact with telephone operators at the meal company every week. However, his daughter and Informal Carer, Esther, had been concerned he was forgetting to order food at times, and she arranged to place the order on Eddie's behalf. For Eddie, this resulted in him feeling as though he had little involvement in making decisions about his meals. Furthermore, Esther had inadvertently blocked an opportunity for enjoyable social contact, which was of high importance to him:

> *"EDDIE*
>
> *No, she tells **me**… No, she just tells me what's happening and what I'll do for meals and whatever, you know.*
>
> *INTERVIEWER*
>
> *Is that something you're happy with?*
>
> *EDDIE*
>
> *Oh, I've, I've no option, have I [smiles]?" Eddie, Service User, HSCP 2.*

When Service Users and Informal Carers were involved in organising and planning their care, they wanted HSC staff to help them to plan for the future. They identified a need for contingency planning should unforeseen circumstances arise such as an Informal Carer being unable to provide care for the Service User. Informal Carer Anisha, reflected upon the instinctive nature of her support for Arthur (Service User). She highlighted her need for reassurance that her support for Arthur would be realised and provided by a social work Carer should she be indisposed:

> *"If I had to go into hospital, 'cause that would, that would throw him completely, would somebody come in and would they [a Carer] check he'd taken his medicine, would they check that he'd shaved properly? Would they check that he kept putting on clean clothes, that he was eating, drinking? All of these things I'm doing, unconsciously." Anisha, Informal Carer, HSCP1.*

After Anisha had requested support for Arthur in the above circumstances and been told that she should provide the care herself (Section 5.5.1), both she and Arthur felt their Social Worker had demonstrated a short-sighted lack of pre-emptive planning for this potential scenario. Anisha explained that this made her feel as though she had fraudulently requested potentially unreasonable support; her non-verbal communication during the interview portrayed a sense of anger and distaste.

> *[crosses arms, purses lips, raises eyebrows and clicks tongue on the roof of her mouth] "It made me feel, erm, almost fraudulent, as though I was asking for*

> *something that I shouldn't have been asking for at that stage, or at this stage.”*
> *Anisha, Informal Carer, HSCP 1.*

Both Anisha and Arthur perceived a lack of insight from the Social Worker into Arthur’s Dementia diagnosis, the associated changeable nature of his health and wellbeing needs, and the requirement for anticipatory care planning that aimed to meet those needs.

In summary, this sub-theme outlined participants’ experiences of coordinating and organising care within HSC services. Access to services was improved by connecting with an identified point-of-contact, facilitating coordination and organisation of care. Service Users and Informal Carers felt disempowered when they were not involved in organising their care. When they participated in the planning, their care was more efficient and timelier. They sought the support of HSC staff to plan for the future in order to ensure their changing health and wellbeing needs would be met.

5.8.3 Using HSC services to help meet health and wellbeing needs

All participant groups outlined their positive experiences of using HSC services to meet their health and wellbeing needs. or when helping other to meet theirs. This was particularly evident when Service Users and Informal Carers sought post-diagnosis support from specialist services and wheelchair services. They attributed these to the supportive relationships they had developed with HSC staff there. However, Service Users felt that this level of support was not available across all services, feeling that connection with other staff and services was lacking.

Services on offer from HSC providers did not always meet the needs of people who utilised them, in a way that felt appropriate to them. Service Users stated that their usual HSC providers offered unsuitable continence supplies and waiting times. An example of this was offered by Barney (Service User). He outlined his experiences of accessing the Continence Service offered by his HSC provider. His perceived need and understanding around suitable continence product supplies differed from the assessment and perceptions of the Continence Service staff at the HSC provider. This led to him feeling frustrated and his utility of alternative means, to purchase continence pads via an online retailer:

> *“She [HSC Staff Member] always tries to get you, give you pads which are smaller than the ones that you need, well, I think they're smaller than the ones I need and, erm, and I've just got so fed up of it that I, I buy them myself privately, erm, on the net, erm, and they're reliable and the right size.” Barney, Service User, HSCP 1.*

All participant groups highlighted the Service User would benefit from regular reviews of their condition by an appropriate HSC professional, but that this had not been established. Furthermore, one Informal Carer wished to be further involved in the regular review appointments for her father’s care, stating that the timing of contact with services was an obstacle. Although the review process offered a valued opportunity for reassurance on how her father was doing, Esther (Informal Carer) felt she was only informed of the outcome of the review. With the above recognition from her father (Eddie) that Esther was heavily involved in coordinating and making decisions about his care (Section 5.8.2), Esther would have valued the opportunity to be part of the review process:

> *“They do a review with Dad, where one of their team managers will go round and see how Dad is, see how he's feeling about everything, and they did call me about that, the last review they had with him, and would I like to be there and, I kind of would've liked to have been there but, again, I would've had to take time off work to go…” Esther, Informal Carer, HSCP 2.*

Service Users were not able to meet their needs through their usual HSC providers when accessing physiotherapy, hearing care, and continence management services. When they encountered this, they utilised alternative services at their own expense. Service User Catlin explained that when she could not access physiotherapy help via her HSC provider (at the point when she felt she needed it), utilising private services meant she did not have to endure symptoms for an extended period, preserving her mental wellbeing:

> *“The waiting list is 15 weeks [for physiotherapy input], which isn't handy if you can't walk down the stairs! I couldn't get away from it being sore, with standing, sitting, lying, stretching, it was just there so, I mean, I think 15 weeks of that I would just be round the bend.” Caitlin, Service User, HSCP 1.*

Caitlin and her Informal Carer Conner felt that HSC students offered a valuable contribution to the HSC system, particularly around the provision of exercise classes (physiotherapy students). In the past, student-led physiotherapy services (hosted in a Higher Education Institute) had also been instrumental in helping Caitlin access timely treatment, when there were long waiting lists for statutory physiotherapy services. HSC students were also making valuable contributions within social care organisations, where they were viewed by Staff Member participants as valuable in easing workload pressures from staffing vacancies. However, Staff Member Esme highlighted the challenges her care organisation faced when HSC students became qualified, and the negative impact this could have on resourcing and retention of staff:

> *"They're maybe doing, maybe like their nursing degree or training to be an OT [occupational therapist] at uni, and they'll be 'Relief' so, zero-hour contract, and then obviously once they qualify, they go off and do what they've been training to do." Esme, Staff Member, HSCP 2.*

For Staff Members who were new to an HSC role, either after qualification or when newly recruited from another HSC organisation, support from colleagues who had worked in the HSC service for some time helped them to cope with the demands of their new role. New staff valued knowledge and reassurance from existing staff, which boosted their confidence when making decisions about Service Users' care. Previous experience in a similar role helped Staff Members to understand the demands of their current role. Furthermore, for Staff Member Zoe, her previous experiences when caring for her own mother also influenced her decision to take on her role as a third sector Befriender. A shared common interest was a way to connect with her Befriendee's, and her support to help them get out and about was a key element of her role as a Befriender:

> *"I know from my own experience, my parents both went into care and, erm, certainly in the case of my mother, she was one of these cases in point… we were very lucky that a good friend of hers, who shared a common interest in walking, rambling, did take her out quite regularly in the early weeks and that made a massive different to her." Zoe, Staff Member, HSCP 1.*

To summarise, this sub-theme outlined that participants' use of HSC services to meet their health and wellbeing needs were mixed. Some Service Users and Informal Carers were able to meet their needs through their use of HSC services, finding support in regular contact with a GP, specialist or wheelchair service. For some Service Users and Informal Carers, use of HSC was more challenging. They encountered lengthy waiting times and thought their care was not always appropriate, resulting in their use of similar services in the private sector at their own expense. Time constraints of support visits exerted negative pressure on the relationships Service Users and Staff Members were able to form. For Staff Members, the relationships they formed with more experienced colleagues were instrumental in helping them to feel supported and boosting their confidence in their role.

5.9 Working together, across health and social care services and systems, to maintain and promote health and wellbeing

This fifth and last theme focuses on participants' mixed experiences of working together, across HSC services and systems, to encourage and help Service Users to maintain their health and wellbeing. Participants across all groups outlined their understanding of working together in an integrated way. Some were clear on the collaborative nature of integrated services, while others reported siloed, disjointed services. Open lines of communication and information sharing were important in promoting trusting supportive relationships between participants. However, when these were not present, this compromised safety for Staff members and Service Users, and resulted in Service Users feeling that their HSC system was not cohesive and collaborative in nature. Participants described mixed perceptions, experiences and realities of HSC systems; as a concept, 'integration' provoked different meanings and applications for them. For example, some participants (across all groups) were clear in their understanding it represented service providers working together to support individuals and their families. When they expressed their understanding of an 'integrated HSC system', they perceived it as a potentially positive way of working. They perceived that integrated working promoted coordinated and supportive services, and that it facilitated information and resource sharing between health care, social care and third sectors. However, some Staff Member and Service User participants were not aware of integration or what it meant for HSC systems, while others understood it as an abstract concept that they (as Service Users and Informal Carers) were not a part of:

> *"I think it's a wonderful idea that it's integrated but… it may be communicated between the two sides, you know, what was once upon a time, considered social*

> *care, and health board, it may be communicated between those two but, it's not communicated in enough detail to those are on the receiving end." Anisha, Informal Carer, HSCP 1.*

Anisha's perception of integration, as an abstract concept, was also mirrored by Staff Member participants. Although some of them were aware of integration and thought it was a good model for HSC care with resources and information being pooled together, it was not evident in their ways of working with others across HSC systems:

> *"I think integrated HSC would mean for us [private sector], and I guess NHS staff as well, that we would have access to everything [information and resources], just everything together, [and it] would make a huge difference." Debra, Staff Member, HSCP 2.*

Debra's account highlighted further compounded experiences of poor information sharing across HSC organisations and sectors, expressed by Staff Member Abigail in Section 5.6.2. Service Users and Informal Carers expressed a need for more information about how their services worked together across HSC systems, and they looked for clarity on how information about them was shared with others. Prior knowledge of how HSC systems were operated and organised helped people (within those systems) to work together and navigate them. However, Staff Member participants indicated they did not have the necessary information or clarity they needed about integration and management within the HSC system, suggesting a need for further staff engagement and transparency:

> *"Integrated HSC started up here maybe a couple of years ago, we were never really given a lot of information about it, naebody ever came to speak to us about it and, to be quite honest, we're nae really sure how it's supposed to work 'cause naebody's ever discussed it with us. Erm, I think a lot of our Locality Managers now are HSCP, as opposed to being health board." Abigail, Staff Member, HSCP 1.*

Staff Member participants also suggested they needed further information about other HSC services working with their Service User and Informal Carers. Occupational Therapist Staff Member Debra, who was working in a private care organisation, highlighted a challenging incident when there had been a breakdown in communication with others in another sector within the HSC System. In this instance, her personal safety was compromised because of a communication breakdown, which left her feeling vulnerable and uncomfortable. She felt that, had communication in the HSC system been better (through a join-up electronic information system), this situation could have been avoided:

> *"I had a patient who was very sexually inappropriate towards me, erm, I was just on my own in his house, so I called the Community Nursing staff to let them know [that the person had been inappropriate] but, they'd known about this for a long time and they had already made him double-visits [where two members of staff attend at the same time]. So, I'd been going in for months without knowing this so, that was communication breakdown, it wasn't nice what happened, and that could've been prevented had communication been that little bit better or, had we all been on the same system [electronic information system] and that would've flagged up for me. That would've saved a lot of uncomfortable feeling for myself [looks towards the floor, laughs uncomfortably, hesitates] … so."* *Debra, Staff Member, HSCP 2.*

Sharing information between organisations across the HSC system was seen by all participant groups as beneficial in facilitating collaborative ways of working together, promoting supportive relationships between Service Users, Staff Members and Informal Carers. However, bureaucratic processes and systems prevented information sharing at times, which negatively impacted upon the experiences of both Service Users and HSC Staff Members. Service User Arthur offers an example of this when describing his experiences of utilising third sector services to help him meet his health and wellbeing needs. He explains he himself contacted the third sector service for support, and felt this could have been done after his initial contact with HSC services, highlighting a lack of insightful forward planning and collaborative HSC practice between sectors:

> *"It's not beyond the wit of man that at the very beginning of the situation [when first referred to an HSC service] you are asked: 'if in the future, you think you could*

> *do with advice from an outside organisation' [third sector organisation], could we give them your name?' But they don't [ask], so you can't [be referred on]." Arthur, Service User, HSCP 1.*

Further to Arthur's account above, Staff Member participants felt services did not *always* work together across sectors. NHS Staff Member Abigail explained that although she had found individual Staff Members supportive and approachable, her experiences of working with HSC staff from other organisations reflected disjointed services. They were not working together as one integrated system but instead, working in individual siloed systems, for example, a healthcare system and a separate social care system:

> *"They've been supportive and they're approachable, but as for working together, like the Care Manager and us sort of working together and joint integrated, it doesn't always work." Abigail, Staff Member, HSCP 1.*

This perception was shared by Service Users and Informal Carers; they felt that they did not 'mix' or seem to be 'related' to each other. Service Users perceived services as separate entities, where communication and contact between them was minimal and the people within lacked knowledge of other organisations (in the HSC system). This was mirrored by Informal Carers who felt they were not involved in the HSC system. Informal Carer Gail explained she did not feel 'joined-up' with Staff Member Gavin when supporting Service User Grant. This suggested a need to further include Informal Carers, as integral providers of HSC care, in efforts to work together across HSC systems:

> *GRANT*
>
> *"I think these supporters [Informal Carer Gail, Staff Member Gavin, private cleaner] are operating more or less individually rather than collectively and in contact with each other.*

> *GAIL*
>
> *I think we [Informal Carer Gail, Staff Member Gavin, private cleaner], we don't feel joined up, I think. It's three different points of contact and, I don't feel joined up to the other two, yeah." Grant, Service User, and Gail, Informal Carer, HSCP 2.*

Staff Members also held similar views about disjointed services when reporting their experiences of working with other organisations they needed to help *them,* as they supported Service Users and Informal Carers. Abigail offered an example of this, explaining the external administration organisation being used in her area was not cohesive, efficient or convenient, and she and her team had made alternative local arrangements for filing their Service User records. This highlighted disjointed administrative services that were not commensurate with the needs of staff who were using them, and a further need for review of collaborative working practices:

> *"We just put one box [of Service User records] down to - [an external sub-contracted filing company] to try and see what it was like, erm, and then of course, within about six weeks, we needed a set of notes back out of it. Erm, we waited just under four weeks, I think, for them to come back so we just thought, no, this isn't going to work." Abigail, Staff Member, HSCP 1.*

Although disjointed services had been highlighted by Abigail, Occupational Therapist Staff Member Debra offered an example of when services and sectors *did* work together to assess Service Users' health and wellbeing needs. She highlighted an inter-dependency between the private care organisation she worked for and NHS District Nurses and explained her perception of one relying on the other to achieve the best outcomes for their Service Users. For Debra, working with the District Nurses promoted cross-sectoral collaboration that facilitated safety and decision making (in both organisations) to meet a Service Users' health and wellbeing needs:

> *"District Nurses obviously specialise in pressure care, erm, whereas they might need a little bit more of my help to know whether, actually, that person's not safe sitting on that pressure cushion because it's increased the height of the chair and they're transfers so, we work quite closely together to make that call, well, I have done in*

> *the past anyway, and without each other I think it would've been quite tricky.” Debra, Staff Member, HSCP 2.*

All participants wanted HSC staff to be experienced in their role, since this promoted trust, confidence and the establishment of supportive relationships between participants. These individuals were adept at making themselves available to colleagues from other sectors in the HSC system, promoting timely access to their service for both Staff Members and Service Users. Abigail highlights an example in her excerpt below, describing how a Social Work colleague recognised her professional judgement (about a timely need to see a Service User together). Revising expected working procedures to support and accommodate others offered flexibility, and reinforced positive experiences and connections with others:

> *“They were really good [local Social Work department] and, they says, ‘right, okay, we shouldn't do this [without the necessary paper-based referral or waiting-time] but, we'll come out with you the next day’ so, we arranged, we went up and we went out and seen her and, there was services in place by the end of the week. Ken, a lot of the times it does work well, and I think a lot of the time it's nae down to the [HSC] system, sometimes it's down to the individual… we've got a lot of Care Managers [who] are willing to go just that extra wee bit to get things, and I think it's the ones that are more experienced, and that have been in the job for a long time, ‘cause maybe a lot of them have done it the old way, as well as the new way they do it now.” Abigail, Staff Member, HSCP 1.*

In addition to reinforcing collaboration between services and sectors, Abigail’s experience suggested ‘the old’ ways of working together (when a paper referral came after a verbal referral if there was a perceived urgency) might have been preferable to meet the health and wellbeing needs of the Service User in a timely manner. The efficacy of administrative referral processes and the bureaucracy that accompanies them could be deemed as unsuitable, delaying access to services at a time when they are most needed.

In summary, this main theme has outlined participants’ experiences of working together across HSC services and systems to promote and maintain health and wellbeing needs. Participants highlighted their understanding of ‘integration’ and the positive effect that this *could* have on HSC services, with pooled information and resources to promote better outcomes for Service Users and Informal Carers. However, ‘integration’ appeared to be an abstract concept to many participants (across all groups). Services were disjointed, adopting unsafe communication and information sharing practices when bureaucratic processes did not meet the needs of HSC staff, the services or their HSC system. Nonetheless, promoting trust between people within HSC systems helped to strengthen their supportive relationships, and collaboration was achieved when people were experienced, knowledgeable and flexible in their approach to working with others.

5.10 Developing understanding and interpretation of findings with members of the public

The above findings were shared with members of the public and key stakeholders during data analysis, construction of themes and write-up phases of this study. Their input has contributed to my interpretation of participant’s needs, experiences and relationships in HSC. It would have been my preference to return to the PPI group who initially contributed to study development. However, they had been temporarily disbanded and were unable to provide input. Therefore, I invited members of the public through a PPI group in an RGU ‘Involving People and Communities’ network, many of whom were Service User and Informal Carer stakeholders in HSC. Preliminary findings were also presented in an international HSC scientific forum and through relevant HSC forums. Feedback from these groups, along with my reflexive comments and actions, are summarised below in Table 40.

Table 40 Summary of stakeholder feedback on findings

	Group	Feedback	Comments/actions
A.	HSC staff	“Personal connections make such a difference to how our patients feel.”	I need to convey the level of depth that incorporates the *feelings* in the connection between participants.
B.	HSC staff	“Relationships are so important... they really help us get to know our colleagues across the organisation. Communication between HSCP is crucial.”	Confirmation and agreement from stakeholders that I was on the right track with my interpretations of the findings; these concepts were identified within the themes of my findings.
C.	HSC staff	“Trust is a foundational building block of a positive supportive relationship.”	
D.	HSC staff	“Relationships are key - between patient & staff for health and wellbeing, and between staff across HSC for improved care.”	
E.	Members of the public	“Working in partnership and building relationships seems to be important for practitioners, Carers and Service Users alike. Well done you for starting the change process with your research. Hope that this study will be picked up by the Government and other Health board areas.”	

	Group	Feedback	Comments/actions
F.	Members of the public	“*TIME* is essential to ensure that social care Carers have enough time to spend with their client; they can help to reduce isolation, but it can be difficult for them to stick to planned timelines when there is someone in need of additional help (while the Carer is there).”	These experiences reflect what participants are saying and potentially, these needs to be considered as an important concept in IHSC.
G.	Members of the public	“Continuity is important when receiving care. Building up knowledge about the individual and their circumstances helps me to connect with HSC staff.”	
H.	Members of the public	“The Scottish Government and the NHS produce lots of glossy, magazine-type, ageist and very long-winded documents, (very, very badly written and grammatically incorrect thereby making these very difficult to read unfortunately) which do not translate into good practice and performance.”	This is something that ties in with my own understanding outlined in Section 1.4.1. I need to review this (perhaps in the discussion), are the policies evident in practice? (See subsequent Sections 6.4.3; 6.4.5; 6.5).
I.	Members of the public	“Some HSC staff do not understand how they fit into the master plan (of how services are delivered in a collaborative way) – information wasn’t given about integration – there is a need for better information sharing and shared goals between staff, patients, and families.”	This concurs with participants data that highlights a lack of information sharing and clarity across IHSC systems.
J.	Members of the public	“Service providers consistently don’t engage with people (staff, Carers [informal], patients, families, or communities) during implementation.”	

	Group	Feedback	Comments/actions
K.	Members of the public	"Communities need to be included in providing integrated HSC. There is a need for communities to be considered in different contexts, e.g. it is not only geographical areas that can be considered as communities (e.g. church groups, condition specific, informal Carers too)."	Although I had a clear understanding of what community was in the context of this study, I hadn't been clear in defining this. Therefore, a data-driven definition of community was added, as perceived by the participants themselves.
L.	Members of the public	"Findings are spot on! I'm disheartened because I'm not convinced the system can meet the ideal set out in this study."	Good to have this positive feedback – I feel as though I am on the right tracks, reassured.
M.	Members of the public	"I think your research and finding have raised some really interesting points. The graphics and charts you used were very informative and useful. Well done! An excellent morning. It's good that we have been able to talk to you about your study today. Thank you!"	

Feedback at these events was invited and contributed to refining proposed themes and findings and stakeholders' understanding of the meaning of the key terms we were using. For example, after defining connection, I wanted to be more specific in conveying the depth or type of connection participants were referring to, initially opting for 'personal connection'. However, I was also wary of projecting an unprofessional association between Service Users and Staff Members. Nonetheless, HSC staff feedback indicated their clear understanding of the term, the importance of 'personal connection' in their HSC practice and their agreement with this as a true representation of its meaning (see A & D above).

Furthermore, some key points were also highlighted by members of the public, with relation to defining communities (point K) and IHSC policy (point H). Members of the public wanted a clearer definition of community (point K) and recognition that communities do not always relate to geographical areas. Although I was clear on this understanding myself, I was mindful that my definition should be drawn from the data and be led by the participants. I was able to refine and develop this data-driven definition, which has been included at the beginning of Section 6.5. Additionally, members of the public also wanted to express their perceptions of IHSC policy (point K), a perception that I had already acknowledged myself in Section 1.4.1. Our similar perceptions prompted me to discuss this further in Chapter 6, across Sections 6.4.3; 6.4.5; 6.5.

5.11 Critical synopsis of findings

This critical synopsis presents a synthesis of five key assertions drawn from the thematic findings, following the order in which they are presented above. The purpose is to draw together pertinent points from the findings that have informed both the construction of a typology of interpersonal connections and supportive relationships in HSC (in the following section), and the discussion chapter that follows. These key assertions included: understanding and coping with changing health and wellbeing needs; the role of interpersonal connections and supportive relationships in HSC; experiences of community connections; utility of HSC services for health and wellbeing, and experiences of integration and working together.

First, findings of this study suggest that understanding, accepting and coping with changing health and wellbeing needs or caring and HSC staff roles was challenging across all three participant groups. Service Users and Informal Carers experienced anxiety about the uncertainties of disease progression and planning for future care provisions. Connecting with HSC staff provided practical help and enabled them to make provisions for the future. However, Service Users perceived that HSC staff and services did not always provide care centred on the person who was accessing the service, and some felt social care services demonstrated a lack of insight and forward planning for the future.

Remaining active helped Service Users and Informal Carers to feel they were coping with their changing needs and circumstances with equipment and support from HSC services helping them achieve this. Informal Carers needed to connect with respite services to enable them to take a break from their caring responsibilities and cope with their changing role. An uncertain disease trajectory, variations in the availability of services and a lack of person-centred focus by HSC services impacted on the support experienced by Service Users and Informal Carers. Appropriate respite services in their HSCP areas (or nearby) were lacking, and a lack of regular breaks had a negative impact on their mental health and wellbeing. They experienced increased pressure, stress, anxiety and low mood and this impact was not always recognised by HSC staff. The availability of respite care, to help Informal Carers maintain their own health and wellbeing and continue caring for their Service User, was important to Service Users and their Informal Carers.

Second, evidence from this study highlights the fundamental role interpersonal connections play in fostering relationships. Where these relationships worked well, it led to participants across all groups feeling better supported and able to cope with their changing health and wellbeing needs. Service Users and perceived a need for time with staff, to build up bonds of trust and foster a supportive relationship with them. Key characteristics of these across the three participant groups included: empathy, caring, kindness, reliability, trust, listening skills and patience, a calming influence and discernment to decipher challenges they might be facing and offer appropriate support. Face-to-face contact offered continuity and promoted a bond of trust that helped participants (across all groups) to develop supportive relationships. For Staff Member participants, connecting with other HSC staff located in the same facility, promoted closer working relationships leading to them feeling more supported. HSC practices that promoted and enabled connections through continuity of contact with HSC staff were perceived by all participant groups as beneficial in developing supportive relationships.

Third, Service User and Informal Carer experiences of their community connections highlighted how communities (geographical or otherwise) were an integral part of their HSC provision. Connections with their communities helped them to manage practical tasks, promoted social contacts and an exchange of knowledge, information and experiences of their condition and circumstances. Previous knowledge (or similarity) with the Service Users condition and circumstances helped individuals to foster supportive relationships with Service Users within their communities. As a result of the knowledge, familiarity and continuity of contact they had with members of their communities, those relationships appeared more cohesive than the ones they had with members of HSC services. Staff Members seemed unaware of the support Service Users and Informal Carers received from the communities they were part of. This suggested a disjointed connection with communities who were a large part of HSC provision.

Fourth, this study identifies that utility, availability and access to services did not always meet the needs of the people who were using them, and they encountered long waiting lists and unsuitable continence supplies. For five Service Users participants, who did not receive Direct Payments, organisation and coordination of HSC services lacked clarity, with Service Users feeling they were not involved in this process. When Direct Payments were received by one Service User participant, the process of organising care was efficient and timely, but it also resulted in segregation (from a point-of-contact) within HSC services. Service Users felt that HSC provision was selective based on location, with the perception that HSC was underfunded, particularly respite facilities and social care services. They highlighted staff workload pressures because of staffing vacancies and Staff Members reported they were regularly taking on extra duties in their own time to meet service demands. Constraints on the time HSC staff and services had to support their Service User negatively impacted upon the Service Users' connection with them, compromising their ability to foster a supportive relationship (as outlined above). Furthermore, Service Users and Informal Carers experienced trouble accessing services when they did not have a point-of-contact, or when they encountered gatekeepers whom they perceived as obstructing their access. These findings suggest a need for more flexible and transparent ways of working, and revision of the way HSC services are organised and delivered to promote clarity, transparency and inclusion.

Finally, my findings clarify participants' understanding of 'integration' in HSC and their experiences of working together. Although some participants (across all groups) were aware of integration and the notion of working across HSC organisations, the reality for them was that cross-sectoral working was disjointed. Services continued to work in sectoral silos but working with one other HSC group was common. One example was an Occupational Therapist working with a District Nurse to assess a Service

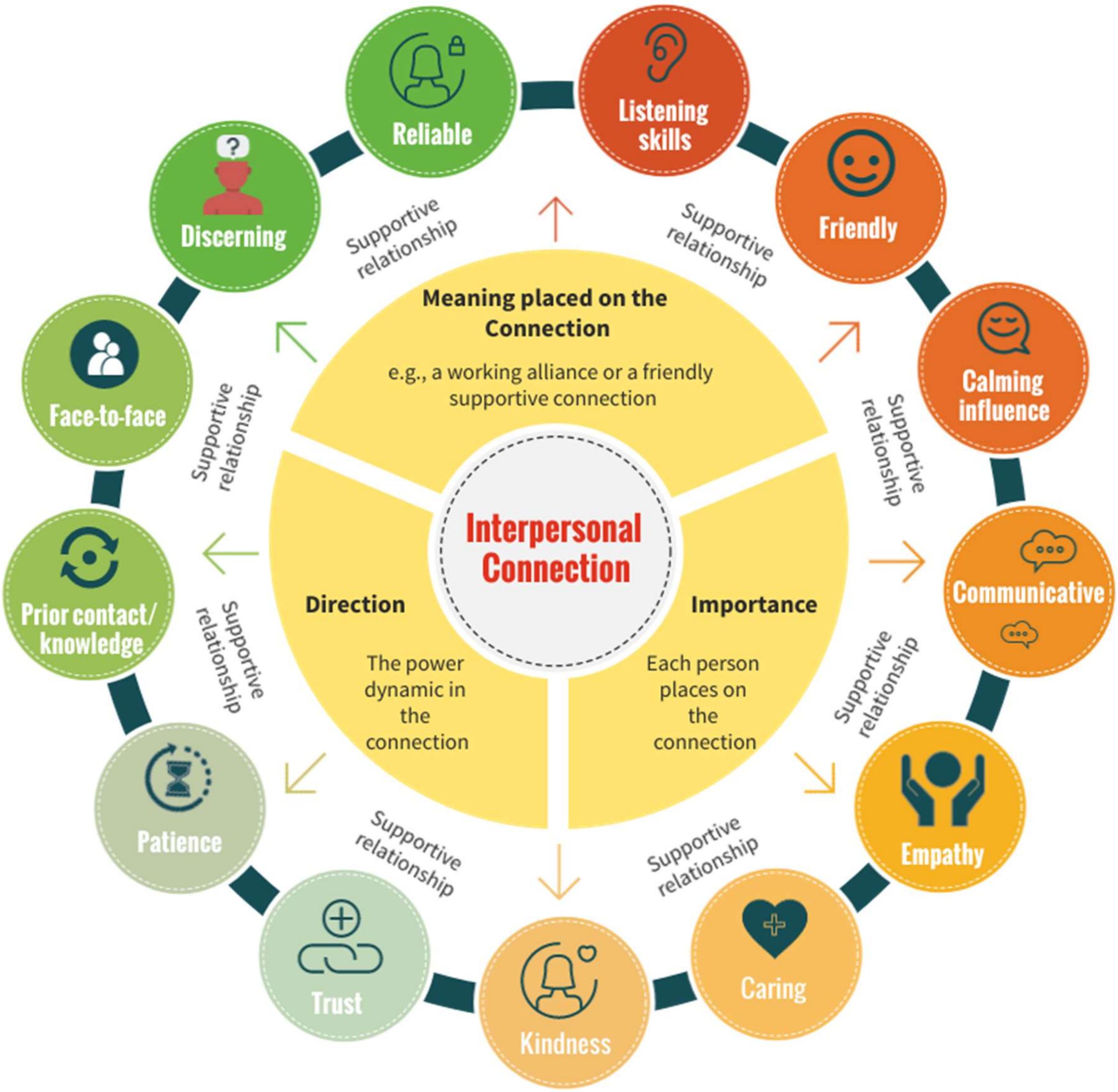
Users condition and circumstances. Working together in this way promoted a positive connection which was supportive in nature and promoted trust between HSC staff. Those who were willing to deviate from referral protocol and procedures (when there was an urgent need) were perceived as particularly supportive and accommodating of others professional opinions. However, inter-sectoral working on a wider collaborative and cohesive way happened less often. There was a lack of information sharing across sectors, particularly about which individuals (from other services and sectors) might be involved with their Service User and Informal Carers, leading to personal safety concerns for Staff Members. This highlighted a need for revision of collaborative information sharing in HSC practices to promote and foster cohesive interpersonal relationships between HSC staff. Furthermore, it questions whether the term 'Integrated Health and Social Care' (commonly used by people in HSC) is an accurate representation of HSC systems. This term suggests that the process is in the past tense, having already happened. Instead, findings from this study support the notion that HSC systems are *integrat**ing*** (present tense), with some way to go to achieve more collaborative cross sector working.

5.12 Typologies of supportive relationships and health and wellbeing needs in HSC

The above thematic findings and critical synopsis have highlighted several key concepts about connections and supportive relationships in HSC. Defining and refining these concepts has been part of my analytical and reporting process for the findings of this study, helping me to better understand what the participants were saying across these data (Spencer et al., 2014a; Collier et al., 2012). The typologies below are conceptual representations of my own knowledge of social psychology theories outlined in Chapter 3 (Figure 5). To construct a conceptual typology figure in an inductive way (from the bottom-up), I have applied my understanding of these underpinning theories to my interpretation of participants' data in the thematic findings above (Bryman, 2016; Moule, 2015; Spencer et al., 2014b).

The typology figure below (Figure 21) aims to highlight conceptual dimensions of connections and relationships that have been derived from participant data, with the objective of illustrating types (or categories) of interest (Spencer et al., 2014a; Collier et al., 2012). Participants outlined some of the essential components of the connections they had with others in HSC (Section 5.6). They also described the key characteristics (as they perceived them) of people with whom they had developed supportive relationships. These components and key characteristics have been included in the typology figure, with the central premise of a personal connection. Personal connections carry specific meaning, direction and importance as explored in Chapter 3 (Section 3.2.3); when all three are realised, a supportive relationship is formed.

Figure 21 Typology of interpersonal connection and supportive relationships in HSC



In addition to the key characteristics of interpersonal connections and supportive relationships, I was also able to identify and formulate a list of the health and wellbeing needs which participants across all groups reported in their data. The below typology outlines the needs that each participant group identified as important in helping them to maintain their health and wellbeing (Table 41).

Table 41 Health and wellbeing needs in HSC

Health & wellbeing needs	Service Users	Informal Carers	HSC Staff Members
Being involved	✓	✓	✓
Information sharing	✓	✓	✓
Service needs *(timely access/utility/suitability)*	✓	✓	✓
Planning for the future	✓	✓	✓
Continuity of care	✓	✓	✓
Financial Support		✓	
Psychosocial wellbeing *(social contact/respite)/reassurance)*	✓	✓	✓
Physical and functional wellbeing	✓		

5.13 Chapter summary

This chapter has outlined the importance of interpersonal connections with others across HSC. These connections were built on dimensions of the direction and meaning that participants placed on the connection they shared with others, and the importance that those connections with others across different HSC contexts held for them and their experiences of HSC. Interpersonal connections helped to foster supportive relationships across HSC. When present, these connections helped Service Users to understand and cope with their changing health and wellbeing needs. Furthermore, interpersonal connections helped Informal Carers to cope with their changing role when becoming an Informal Carer, and they helped HSC Staff Members to cope with the demands of their HSC role. These relationships promoted supportive contact between individuals, communities and HSC services and systems; those contacts facilitated access, coordination, utility and collaboration in HSC. In the next chapter, three key findings around connections and relationships, promoting principles of People-Centred, Relationship-based care, and community involvement in HSC are discussed further. The application of these key findings and the above outlined typologies are considered in HSC practice, and original research questions and proposition statements are revisited.

CHAPTER 6 DISCUSSION OF THEORETICAL INFLUENCES AND THEMATIC FINDINGS

6.1 Chapter overview

In Chapter 6, I discuss the thematic findings and typologies from Chapter 5. Findings that carry particular significance in both HSC practice and research from across the themes and subthemes of Chapter 5 are presented below, drawing on relevant theory and current literature to underpin the discussion that follows. In keeping with my focus on the participants at the heart of this study, it was important to me that topics discussed centred around their perceptions and experiences of HSC, and the implications these could have. First, I will set the scene for the discussion that follows by revisiting the underpinning methodologies and typologies from Chapters 3 and 5. These theories, along with my previous experiences and current HSC contexts in Scotland, influenced the way I have interpreted and discussed the findings. Second, I discuss critical insights emerging from the thematic findings, in relation to health and wellbeing needs, experiences and relationships in HSC. These insights are inter-connected, each dovetailing with the other to construct a narrative tapestry of participants' perceptions; they inform this discussion, the recommendations and conclusions of my subsequent final chapter. Three critical insights are included in this chapter. They relate to three key findings: connections and relationships that promote health and wellbeing, promoting principles of People-Centred, Relationship-based care, and community help to maintain health and wellbeing (Table 42).

Table 42 Key findings

Key findings	Corresponding section
• Understanding the importance of connections and relationships in promoting health and wellbeing through HSC.	6.3
• Promoting principles of People-centred, Relationship-based Care across HSC.	6.4
• Recognising the significant role of communities who help their citizens to maintain their health and wellbeing.	6.5

Finally, this chapter concludes by re-visiting the evidence-informed research questions, and the aim and the objectives of this exploratory case study (Table 16). I debate the extent to which these have been addressed, and re-evaluate the proposition statements (Figure 8) to determine if they were represented in my findings and explore alternatives (Yin, 2018).

6.2 Recognising influential theories and contexts to inform the discussion of thematic findings

To promote transparency and understanding of how this discussion has developed, it is important to acknowledge the influence of research philosophy, methodology and Social Psychology theories on the interpretation of my findings and discussion. I did not start with a predetermined theoretical framework in mind at the outset of data analysis. However, as I considered the overarching theme of 'interpersonal connections as a foundational principle in health and social wellbeing and care' (Table 34), theoretical points of reference helped me interpret and understand the data. As highlighted in my introductory chapter (Section 1.4.4), I recognised that one single theory would not inform all my analyses and interpretations. Therefore, this section outlines the blended way that influential theories come together to underpin this discussion.

As outlined in Chapter 3 (Section3.2.3), Attachment Theory (Bowlby, 1982; Bowlby, 1980; Bowlby, 1973) offered a medium to develop my understanding of interpersonal connections and relationships; its principles underpinned my interpretation and analysis of participants' data. Attachment Theory was particularly relevant in an HSC setting because it highlighted elements of connection that could be a precursor to supportive relationships. It helped me to explore the essence of how relationships were formed between care givers and those who received care, for example, between an Informal Carer or Staff Member and a Service User. These interpersonal connections and the subsequent supportive relationships are a foundational principle of HSC. Therefore, I have drawn on Attachment Theory to inform and explain my interpretations both as I reported my findings in Chapter 5, and in their discussion within this chapter.

During data analysis, I recognised elements of participants' accounts (of their experiences in HSC) that were concurrent with principles of Attachment Theory, helping to develop my analyses and interpretations. More specifically, attachment theory described elements of interpersonal attraction, which were evident in both the connections' participants were making with others, and the types of relationships formed. One example was evident when people who accessed HSC services talked about the interpersonal connections they shared with HSC staff. When exploring their data through an Attachment Theory lens, they talked about the different dimensions of interpersonal connection within those relationships (Figure 5). More specifically, they explored the meaning, or perceived disparity of meaning, each person placed on the connection. Although they were not explicit in their reference to this theory per se, as I interpreted and distilled the data during the recursive steps of analysis (Figure 15) the principles of Attachment Theory helped me to build a deeper understanding. However, as I continued through this process, I was mindful that I needed to acknowledge and consider the application of this theory in the specific context of HSC to fully appreciate their experiences.

To do this, I had to acknowledge the influence of care-provision in an HSC environment. I chose to employ a blend of theoretical lenses at different stages of the analysis and synthesis process, namely, Attachment and Caring Theories. Attachment behaviours are instrumental in fostering connections and relationships, including the provision of security between two individuals, and the promotion of care (Gillath et al., 2016). These behaviours are particularly pertinent in a caring environment, and I was keen to develop my understanding on their promotion within an HSC context, where principles of care might dovetail with principles of Attachment Theory. The underpinning theory of this discussion also had to acknowledge principles of care recipient - care provider relationships, and how the ‘promotion of care’ influenced the way in which people became attached.

In caring contexts, the type of connection that recipients and providers have could be classed as voluntary, where there is an element of choice in forming the relationship, for example, when a Service User’s Informal Carer is a spouse. Alternatively, the connection could be classed as non-voluntary where the connection and relationship are dictated by an employment contract or familial tie, such as an HSC Staff Member, parent or child (Jackson-Dwyer, 2014) (Figure 5). Furthermore, caring relationships focused on the benefits of each individual within them, being either exchange-based or communal. If the relationship was exchange-based, it benefitted the Service User through the support they received, and Staff Members by fulfilling their contractual role. If the relationship was communal in nature, both parties were concerned with the benefits the other received, when a Service User is concerned with the benefits that an Informal Carer receives and vice versa (Karremans and Finkenauer, 2020; Clark and Mills, 1979) (Figure 5).

Caring Theory is often viewed as the epitome of nursing, with its principles being applied to caring relationships of all types, and it has been adopted by other HSC professionals and applied to wider disciplines in HSC (Utley, 2017; Watson, 2016). To help me explore and apply Attachment Theory in an HSC context, I first considered Caring Theory from Watson (1996), a seminal theory that has developed since the 1970's and underpins HSC practice across many disciplines (Watson and Woodward, 2010). The transpersonal nature of this theory appealed to me, focusing on a supportive, protective environment and the use of creative problem solving. Whilst I found its reference to values and the development of a trusting, helping relationship useful, I felt it focused more on teaching and learning elements of relationships, and there was need to identify a theory more relatable to the context of HSC practice in this study.

Swanson's (1991) Caring Theory offered a relevant framework that incorporated five dimensions of caring; knowing, being with, doing for, enabling and maintaining belief. As I explored these principles, a link between my participants' data, PCC (or the plural people-centred care) and Relationship-base Care (RBC) became apparent. They appeared to share closely linked concepts and as Guanci (2016) explains, both PCC and RBC have foundations in Caring Theory. The principles of each theory promoted working together with people on an equal level, which fitted well with the dimensions of interpersonal connection, in that, the direction of the connection should be equal, with no one person having more power over the other (see 'Direction', Figure 5). This was further compounded in participant data where they highlighted their desire to be involved, share decision-making and the importance they placed on others knowledge and understanding of their own HSC conditions and/or circumstances and roles.

Both PCC and RBC highlight the importance of interpersonal connections, relationships, shared decision making and the promotion of Service User involvement in their own care. PCC has developed from the seminal psychotherapy work of Carl Rogers (1961) around Person-centredness, where the therapist would facilitate self-direction for the person (or client) who was accessing therapy, empowering them to make self-directed autonomous decisions about their difficulties (McCance and McCormack, 2021; McCormack and McMillan, 2019; Thorne and Sander, 2012; Josefowitz and Myran, 2005). These principles have been applied to nursing and HSC contexts over many years and in a variety of settings, with many staff being motivated to provide PCC (McCormack et al., 2021; McCormack and Dewing, 2019; Sharma et al., 2015; Merrell et al., 2012). Whilst PCC focuses strongly on the person who is accessing HSC, an RBC based approach recognises and embraces the human nature of our behaviours and how they influence our experiences of supporting people who use HSC (Dix et al., 2019).

Social Work practices focused on RBC have been renewed in recent years, signifying a move away from routine assessment and intervention processes that emphasised a service delivery – Service User consumer position in Social Work, in the early 1990's (Dix et al., 2019; Murphy et al., 2013; Wilson et al., 2011). Like PCC, RBC incorporates psychodynamic understandings of connections and relationships in HSC. However, it also offers a four-stage Relationship Model framework that can be adopted to help develop relationships effectively (McColgan and McMullin, 2017). First, the framework includes consideration of initial engagement (or connection) to start the process of building up a relationship. Second, it incorporates the negotiation of the expected parameters of the relationships (in this case, the meaning, direction and importance of the relationship outlined in Figure 5). Third, it includes the enablement of change through open sharing of information that facilitates appropriate advice-giving in the capacity of an HSC role. Finally, it considers the introduction of endings, where closure of the relationship is equally accounted and planned between people who access and provide HSC service (where appropriate – some relationships may last for the lifetime of the person who is accessing the service). Importantly, RBC does not only focus on the relationship between Service Users and HSC staff. It also emphasises the need to consider relationships between other providers and the communities in which they operate, and each individuals' understanding of self (McColgan and McMullin, 2017; Soklaridis et al., 2016; Nundy and Oswald, 2014; Ledesma, 2011). I felt this theoretical perspective supported my findings and my model illustrating the nature of connections across HSC, where the importance of self-understanding is a central component of forming relationships (Figure 19).

Therefore, in this discussion the PCC and RBC theories dovetail to facilitate my application of Attachment and Caring Theories through their overlapping concepts, promoting caring interpersonal connections and supportive relationships between those who access and deliver HSC. Each of these theories offered original contributions to the development of my thinking. It was helpful for me to produce a comparative table, which included some of the key attributes of PCC and RBC that were pertinent to this study (Table 43).

Table 43 Comparative table for PCC and RBC

Person -centred nursing framework (McCance and McCormack, 2021)	**Key principles of RBC** (McColgan and McMullin, 2017; Soklaridis et al., 2016)
Engagement	Understanding experiences
Holistic	Self-awareness
Sympathetic presence	Caring environment
Shared Decision Making	Communication
Working with	Relationships are therapeutic and a medium for care
Knowing self	Being involved
Clarity and acknowledgement of values and beliefs	Communities
Professional competence and skill mix	Colleagues
Power sharing	People who use HSC services and their families

In addition to recognising constructs of these theories as relevant to my findings, the contextual considerations of HSC were also influential in developing the discussion below. On balance, the context of HSC in this study had prompted me to select a multi-case study design and, in the interest of continued transferability (through my thick-description of context), I felt it was equally important to maintain this focus in my discussion. I wanted to be clear and transparent about my understanding of the influential contexts of HSC in Scotland and across the UK (Section 1.4.3). Therefore, I extracted key concepts from my current knowledge in Section 1.3, and considered the scope of current key issues in HSC, as I understand them. These have been summarised below and they informed the application of PCC and RBC to my discussion.

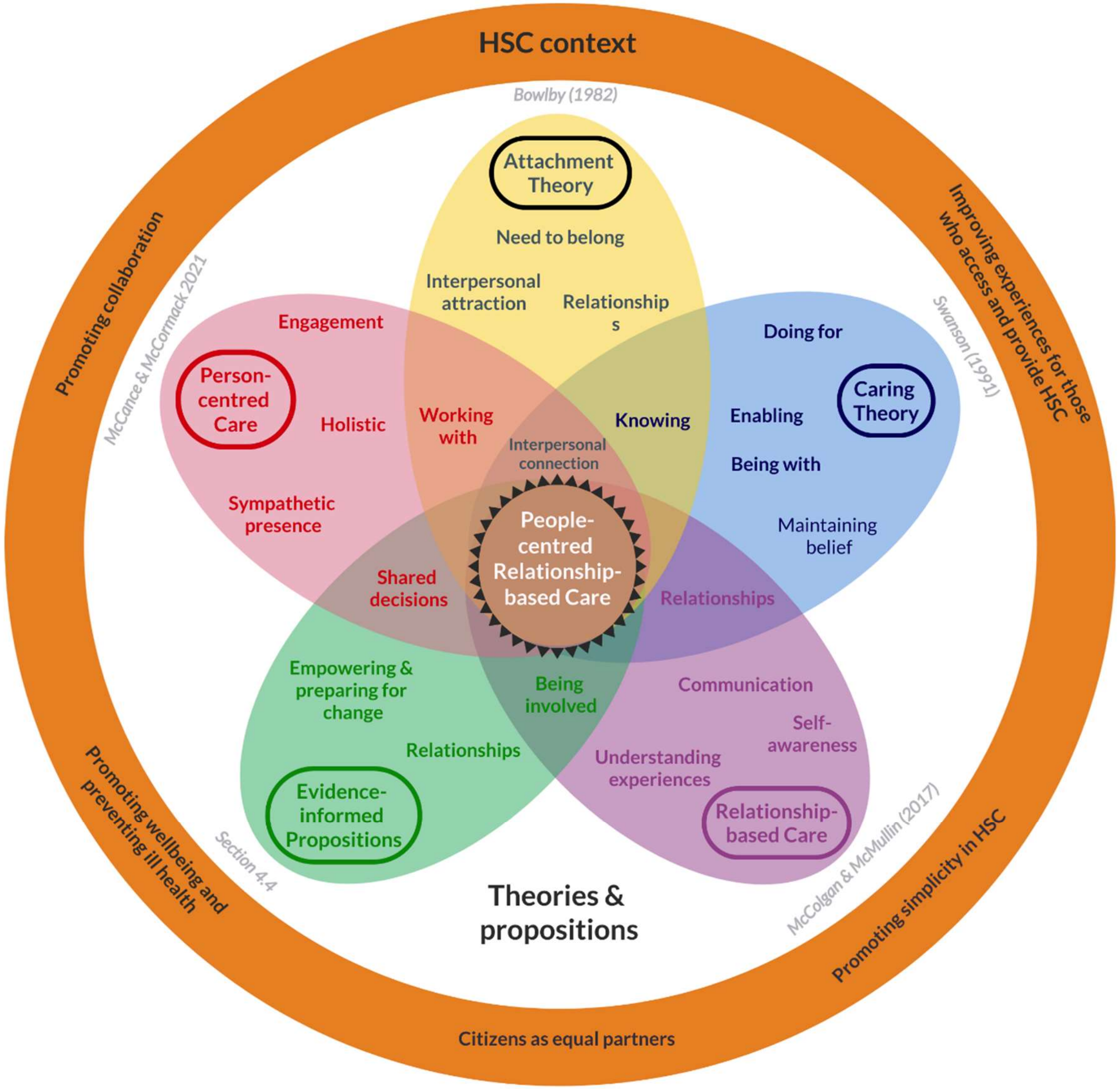
Table 44 Summary of key concepts and issues in HSC

Key concepts in HSC	Scope of current issues in HSC
No single set of practices is applicable to all international, national, regional or local contexts. (Hughes et al., 2020)	A plethora of HSC models to help services and sectors integrate have been reported.
HSC policies aim to promote improved experiences of HSC, for people who are accessing and providing them. (Hughes et al., 2020)	HSC does not always meet the needs of people who use it, leading to poor experiences for people who are accessing and providing services.
Collaboration between individuals, communities, statutory and 3rd sector services, and private organisations are promoted through integrating HSC (Feeley, 2021).	HSC services do not always work together to provide care in an integrated way.
Integrating HSC should promote greater simplicity in public services and facilitate timely, stream-lined access to appropriate services (Christie, 2011).	Regional and local access to services can be variable, unequal and unsuitable.
HSC services aim to invest in promoting wellbeing and preventing ill health, whilst expanding access to services (Audit Scotland, 2018).	The funding and resourcing of HSC can be disproportionate to the demand for services.
Citizens should be viewed as equal partners in HSC (Loeffler et al., 2013).	People who access HSC do not always feel as though they are involved in their care

In addition to the contextual influences on this discussion, I felt it important to acknowledge that propositions discussed in Chapter 4 also represented proposed theories drawn from the literature review (Yin, 2018; Tight, 2017; Bryman, 2016; Thomas, 2016). Proposition statements had been a way of linking previous knowledge and data collected in this study to potential theories about experiences, needs and perceptions of HSC (Figure 8) (Yin, 2018; Bryman, 2016; Njie and Asimiran, 2014). These statements had initially guided the formulation of appropriate methods and analysis, and returning to them helped me to develop an in-depth understanding of how the theories generated in the discussion might be applied to HSC practice and research (Yin, 2018). Furthermore, it also offered me an opportunity to explore whether these initial propositions were reflected in the thematic findings (discussed further in Section 6.6 below).

In summary, each of the theories considered above, the context of HSC in the UK and my propositions, come together to inform my discussion. To provide a clear overview of how they dovetail, I produced a diagram to help me develop and illustrate my own understanding of them (Figure 22). The key principles of each underpinning theory are included in a coloured oval, with some examples of overlap between the concepts being highlighted towards the centre of the figure. Each of these theories led me to consider the formation of an integrated model (in the centre of the figure) that might help to inform HSC in the future. For this thesis, I have chosen to refer to it as 'People centred Relationship - based Care' (PRC).

Figure 22 Theoretical and contextual influences: Person-centred Relationship-based Care (PRC)



The intersection in the middle of this figure highlights a proposed theoretical model of PRC that encompasses the influence of the theories and propositions I have discussed above. It has been shaped by individual participants' data and my interpretation of the findings of this thesis. In naming the central focus of the model, I recognised that the term person-centred could convey a singular value of one person. Based on my understanding that RBC cannot relate to only one person (after all, it takes at least two people to form a relationship), I employed the plural form of 'people'. The next section includes my discussion, which aims to offer rationale for its development and application to HSC.

6.3 Understanding the importance of connections and relationships in promoting health and wellbeing through HSC

This section discusses the significance of individuals' interpersonal connections with others across a variety of HSC contexts, including their connections with people who support them in communities, HSC services and systems. Connections were founded on interpersonal attraction through familiarity and similarity (relating to prior knowledge of an individual and commonalities between two individuals); proximity (being available to the other person); and self-disclosure (giving something of oneself to the other), with each of these being precursors to developing the necessary dimensions of an interpersonal connection (Figure 5).

The meaning an individual places on an interpersonal connection can vary across different contexts. For example, the meaning someone places on their relationship with a parent, may be different from the meaning they place on their relationship with a friend (see Figure 5) (Karremans and Finkenauer, 2020). Within the findings, this is illustrated in an HSC context through an experience that Service User Donna shared. Donna highlighted how there was disparity in the meaning that she and her carer had placed on their connection (Section 5.6.1). Donna's carer perceived their connection as a 'working alliance', whereas Donna placed a friendlier meaning on it. For me, this raised the question of whether HSC staff were aware of the potential impact that connections and relationships could have upon health and wellbeing. Furthermore, questions remain around how HSC staff can promote similarity in the expectations and meaning of interpersonal connections they make, and how these could be further developed across HSC systems more consistently to help meet health and wellbeing needs.

Maintaining an equilibrium between the dimensions of an interpersonal connection and supportive relationship (Figure 5) can also be challenging when those dimensions alter. For example, when a spouse becomes an Informal Carer and provides care for their partner, the level of reciprocity between them might alter (when one partner receives more than they are giving), changing the relationship dynamic (Bredewold et al., 2019; Chappell et al., 2015) (as outlined in Section 2.9). Some participants talked about the challenges they faced when taking on their caring responsibilities. They found it difficult to balance a dual relationship, where they were a husband or wife *and* Carer. Often Informal Carers described a heightened sense of responsibility, pressure and stress when supporting their Service User (Jarling et al., 2020; Lize et al., 2020; Whitmore et al., 2015). Arguably, the voluntary nature of such a relationship could swing to the opposite end of the scale, becoming involuntary in nature because of these pressures and a heightened sense of responsibility. My findings support a need for further inquiry into the impact of taking on a caring role, in relation to the changing dynamics of a relationship which had previously been perceived as voluntary.

For HSC staff participants, they also faced challenges in achieving a balance between the dimensions of an interpersonal relationship whilst still maintaining a level of professionalism. Achieving an authentic Service User - provider interpersonal connection with people who access their services is an essential part of any role in HSC (Pratt et al., 2021; Arnold and Boggs, 2019). Standards of care and codes of conduct across HSC focus on the need for professionalism, a necessity for all who work across an integrating HSC system. Over-involvement, over-familiarity and subjectivity can have a negative effect on the status of someone who is providing HSC, blurring the boundaries between a working affiliation, friendship and an appropriate Service User - provider interpersonal relationship (Arnold and Boggs, 2019). This can be particularly evident within remote and rural locations, where HSC professionals may face a need to switch between overlying roles such as being a Staff Member in an HSC provider organisation and a citizen in the local community (Brownlee et al., 2019; Hechinger et al., 2019).

There is a need to maintain standards and professionalism in HSC; however, in her seminal work on caring professionals, Noddings (1996) highlights a difference between professionalism and professionalisation. She indicates the latter is focused on rule-bound interactions which provoke negative connotations for the connections between HSC staff and people who access services. My findings suggest the professionalism HSC staff strove to project was perceived by some people who use HSC services as unfriendly or distant, acting as a barrier to building a supportive relationship. This highlighted a need for balance between the two-opposing ends of this scale, striving for equilibrium between the two and emphasising a need for RBC (Guanci, 2016). Furthermore, it also highlighted the need for professionals to ensure a shared understanding of their roles and boundaries with Service Users and their Informal Carers, whilst striving to achieve a friendly professional manner through empathetic communication with them (Williams et al., 2019; Jeffrey and Downie, 2016).

Relationship-based models of care, founded by incorporating the two theories of caring from Swanson (1991) and Watson (1997) are not a new concept. By promoting knowledge of the others and self, they encourage caring connections and relationships between people who access HSC services and the people who support them, and between colleagues. Furthermore, they aim to value and empower individuals within relationships contained in HSC systems (Guanci, 2016; Woolley et al., 2012). Findings from this study highlighted the positive effect relationships can have on the health and wellbeing of people who access and provide HSC, supporting a shift in HSC towards a relationship-based model for integration. The principles of RBC have been applied in social work fields for many years (Hollinrake, 2019; Ruch, 2018). However, their wider application to healthcare contexts has become increasingly noticeable in primary care and in supporting specific communities of people with cognitive difficulties, chronic conditions, or older adults (Rushton and Edvardsson, 2018; Soklaridis et al., 2016; Dewar and Nolan, 2013; Ehrlich et al., 2012; Beaty, 2006). It is only since around 2015 onwards, relationships have been considered specifically in integrating HSC, acknowledging a need for further research in this context (Hughes et al., 2020; Welsh and Cooney, 2017).

This section has explored the importance of interpersonal connections in HSC, and how they can help to foster supportive relationships between individuals who access and provide it. It is important HSC staff are aware of the significance of these concepts and the significance of relationship-based care to HSC practice, recruitment and education. Similarly, it is essential that staff aim to maintain a balance between professionalism and meaningful interpersonal connections with people who use HSC and other staff who also provide it across HSC systems. How these concepts and principles can be promoted in HSC, is discussed further in the next section.

6.4 Promoting principles of People-centred, Relationship-based Care across HSC

This section further explores the need to promote people-centred RBC across HSC, discussing characteristics that encourage individualised care. My ‘Typology of interpersonal connection and supportive relationships in HSC’ (Figure 21) draws these conditions and characteristics together.

Many frameworks that identify key principles for integrating, improving and delivering HSC and PCC exist in the literature (Henderson et al., 2021a; World Health Organization, 2016b). For example, Ward et al. (2016) offer a procedure for developing service improvement plans that looks to link integrated care experiences and practices in their SUFFICE framework. They not only identify markers for integrated team working, but they also highlight key observations of the Service Users' journey to promote relevance in HSC improvement; a priority that is promoted nationally through person-centred National Voices (National Voices, 2021). With relation to the delivery of integrated care, one model is unlikely to fit all services or geographical regions or countries. It could be argued that trying to achieve a 'one size fits all' delivery model for integrated care opposes the need for individualised PCC and RBC that is cognisant and responsive to the HSC needs of local communities and their populations (Care Quality Commission, 2021; Feeley, 2021; Nundy and Oswald, 2014). Recently, the International Foundation for Integrated Care have outlined nine key conceptual 'Pillars of Integrated Care' to inform HSC beyond the COVID-19 pandemic (International Foundation for Integrated Care (IFIC), 2021; Lewis and Ehrenberg, 2020) (Appendix 16).

Whilst it is valuable to have these pillars to inform and develop HSC strategies going forward, it is not clear if people who use and deliver HSC at a grassroots level have been involved in developing this framework. My findings add an original perspective to key concepts of integrating HSC, as perceived by the people who are at the very centre of accessing and providing it (Service Users, Informal Carers and Staff Members). Their concepts of 'integrating HSC' have been derived directly from data across all participant groups and they are underpinned by the theoretical model of PRC above (Figure 22). Service Users, Informal Carers and HSC Staff Members outlined five areas of significant interest from their own perspectives, and these are explained below.

First, they highlighted the importance of continuity to build up the knowledge and trust required to make interpersonal connections and build supportive relationships. Second, they focused on encouraging understanding between people who access and provide HSC. Third, they highlighted a need for people who access and provide HSC to be involved in making decisions about their own care or role; a concept that is promoted in the HSCP strategy for HSCP 2 but that appears less prominently in HSCP 1 (Table 1). Fourth, they emphasised a need for individualised care. Finally, they outlined an essential need to have timely access to suitable people and services in HSC for support, when they felt it was needed. To add clarity to my discussion, these concepts have been framed from the viewpoint of the people who access and provide HSC, and are entitled ‘My People-centred Relationship-based Health and Social Care’ (PRHSC) (Figure 23):

Figure 23 My People-centred Relationship-based Health and Social Care (PRHSC)

My People-centred Relationship-based
Health & Social Care *(PRHSC)*

As observed by people who access and provide HSC

◆◆◆◆◆

Connected

Building relationships with others to help me meet my HSC needs and/or those of others

Understanding

Understanding and seeing **me** and others in an inclusive and holistic way without judgement, not just seeing my HSC needs or role

Involved

Making decisions about me, my care or my role and wider HSC, *with* me not *for* me

Individualised

Centred on me, the people who matter to me and our needs, while focussing on suitable solutions to help meet them

Access

Accessing people and services who can support me at a time when I feel I need them

Whilst developing this model, it became clear each concept was interlinked and connected to the others, resulting in the need to further question the definition of each (outlined at the bottom of each concept in the above Figure). For example, within ‘Connected’, connecting with others in an HSC system involved elements of collaboration, and the ‘Access’ concept required the facilitation of timely access to suitable services. In keeping with the principles of PCC, it could be argued that timely access to suitable collaborative care and information could be encompassed under the same banner of the individualised care (Martin et al., 2021). I was keen to establish clarity in my own understanding of the differences between the ‘Access’ and ‘Connected’ concepts.

To further explore this potential overlap of concepts, I revisited participants raw data and my reflexive notes to determine if there was a need to combine them. This process helped me to grasp the importance participants placed on each of these concepts individually, within a context they defined clearly. They felt timely access to suitable services was a significant issue, with an expectation that HSC providers should facilitate it. They also perceived they should be able to access those appropriate services within an equally suitable timeframe, where they did not have to wait for lengthy periods before being seen. As participants emphasised the latter as being significantly important to them when accessing individualised care, I felt reassured that despite the similarities between the ‘Access’ and the ‘Connected’ concepts, they should be represented separately.

Overall, it could be argued that adopting a PRHSC could complement the aforementioned Lewis and Ehrenbergs’ (2020) ‘Pillars of Integrated Care’, by adding the priorities and perspectives of people who access and deliver HSC to the fundamental components promoting integrating HSC. Arguably, the PRHSC conceptual framework offers the building blocks for a theoretical framework that observes the voices of people who access and provide HSC, by showcasing what matters to *them*. Furthermore, if applied to HSC practice, this framework could help to promote PRC (Figure 22) that is focused on the needs, experiences and relationships important to people who access and provide integrating HSC. The sub-sections below explore and discuss each of the PRHSC concepts in more depth.

6.4.1 Connected

The concept of being connected explores the importance of feeling connected when accessing or providing HSC. My findings support the notion that when participants (across all groups) felt connected to people who supported them in HSC systems, and were able to build relationships with them, it helped them to meet their health and wellbeing needs and those of people they were supporting. The concept of connection, through continuity of contact with someone who offers support, has long been acknowledged in relevant literature as a fundamental principle of PCC for people who access HSC services. It has been advocated across a variety of contexts for many years to help reduce admissions to hospital, lower HSC costs, and promote Service User and staff satisfaction (Chen and Cheng, 2021; Goodwin, 2021; Biringer et al., 2017; Gjevjon et al., 2013; Guthrie et al., 2008; McCormack et al., 2008; De Maeseneer et al., 2003). Similarly, the importance of continuity has also been recognised in RBC, promoting improved outcomes, satisfaction and wellbeing for people who access PCC (Riley et al., 2020; Rudebeck, 2019; Jackson and Ball, 2018).

Findings of this study support a significant investment in facilitating and protecting the allocation of HSC staff time to help them develop supportive relationships with Service Users, Informal Carers and other staff across HSC systems alike. This is based on the understanding those in the relationship maintain contact or interaction over a period of time through continuity (MacInnes et al., 2020a; World Health Organization, 2018a; Soklaridis et al., 2016). Continuity of contact can not only help to promote supportive relationships, but it can also have a positive effect on collaboration, improving information sharing, shared decision-making, facilitating open lines of communication and building collaborative networks (Chen and Cheng, 2021; Street et al., 2019; Bunn et al., 2018). Participants across all groups identified continuity of contact with others as important in building supportive relationships in HSC, because it helped them to build up a knowledge base about the people they were connecting with. As outlined by Service User Barney (in Section 5.7.1), building up knowledge about others was important in helping participants to feel connected and supported. However, findings suggest that continuity of contact that promoted knowledge exchange with a supportive individual was identified as challenging to achieve.

Participants across all groups highlighted a lack of resources, poor communication and separate office locations of HSC services as barriers to achieving continuity, which is commensurate with wider literature in the field (MacInnes et al., 2020a; Street et al., 2019; World Health Organization, 2018a; Bonciani and Barsanti, 2017). Furthermore, when these barriers related to communication in particular, misinformation and missing information played a crucial role in a reduced level of personal safety for one Staff Member participant, Debra. She had been placed in a precarious position after a breakdown in communication with staff from an NHS service, which resulted in her feeling uncomfortable and at risk during a home visit. Had collaboration and communication been more open and transparent through the continuity of contact with her NHS colleagues, who were based in a different location, she felt this could have been avoided. For the HSCP 2 where Debra was based, this raises questions around the appropriateness and effectiveness of current communication systems and ways of working together with other providers. This issue is highlighted in many HSC systems across the country, where ways of working together within them (or not) can adversely block open lines of communication, leading to a negative team climate between HSC organisations (MacInnes et al., 2020a; MacInnes et al., 2020b; Bunn et al., 2018).

Affording the vital time needed for staff within HSC systems to make meaningful connections is imperative for fostering supportive relationships. One of the main challenges to investing continuous time in building up HSC relationships is striking a balance between the demand for caring commitments in an HSC role, with the need to resource HSC implementation and delivery efficiently and effectively (Ha et al., 2019; Street et al., 2019). Staff Members time could be viewed as an expensive commodity when the demands of service provision outweigh the available resource (Charlesworth and Johnson, 2018; Wittenberg and Hu, 2015). My findings support investment in this commodity, to help people who access services connect with HSC staff and build supportive relationships. This investment of time could help to improve experiences for people who access and provide HSC; a particularly timely endorsement, with many underpinning HSC policies and guidelines encouraging improved experiences for Service Users and staff alike (Charles and Ewbank, 2021; Feeley, 2021; NHS England, 2019; The Scottish Government, 2019; The Scottish Government, 2018; World Health Organization, 2016b; The Scottish Government, 2015b; World Health Organization, 2015a).

For all participant groups in this study, having a named ‘point-of-contact’ or link worker promoted the development of interpersonal connections and supportive relationships. For Staff Member participants, they often identified colleagues as an instrumental point-of-contact in assisting them in their HSC role. This connection could be in a formal capacity, where their point-of contact was a leader or manager, or it could be in a more informal capacity with a colleague who had more experience in a similar HSC role. For Service User and Informal Carer participants, their point-of-contact (if they had one) would often be a member of HSC staff. They relied on their point-of-contact for reassurance and to facilitate access to services they needed to maintain their health and wellbeing.

For all participants, interaction with a key contact, link worker, or supportive colleague in times of distress was seen as a point of safety from which to explore changing health and wellbeing needs, or a changing HSC role (Hewstone and Stroebe, 2020). An identified point-of-contact facilitated information sharing between people who access HSC services and people who provide them, helping to coordinate and orchestrate care through collaborative, cohesive relationships. These relationships put people who used HSC services at the centre of their focus, in keeping with the HSCP strategies outlined in Table 1 (also supported in the 'Individualised' concept, Section 6.4.4 below). Identifying a point-of-contact for those who utilise and provide HSC, strengthens communication and collaborative practices; they positively influenced access to, and across, services (Petch et al., 2013). Although a point-of-contact had been identified by some participants across the three groups in this study, the availability of this option was fragmented, not routinely offered to all across the local region. Not having a point-of-contact led to reduced access to services. This negatively impacted collaboration and communication, which had a further negative influence on participants' experiences of HSC across all groups.

Participants who described their connections and relationships with a named point of contact valued seeing them face-to-face. This helped to build trust in their interpersonal connections, subsequently encouraging development of supportive relationships between people who accessed and provided HSC. For Service Users and Informal Carers, face-to-face contact helped them to share sensitive personal information about their condition and circumstances, promoting knowledge and understanding of their needs. Service User and Informal Carer participants placed importance on their face-to face-contact with their GP's, in particular. This is in keeping with current wider literature in the field, and it can be linked to a 'deeper level' of connection between people who access HSC and those who provide it (MacInnes et al., 2020a; Strandås and Bondas, 2018; McSwiggan et al., 2017). However, after an interpersonal connection had been made and a strong supportive relationship developed, telephone contact was felt to be a convenient supplementary means of maintaining it. This was particularly true on occasions where Staff Members were not available for face-to-face contact, for example, when staff had commitments elsewhere. Furthermore, it signified a shift from the importance participants across all groups placed on face-to-face contact when building a relationship, towards an acknowledgement that once the relationship had been established, telephone contact was perceived as an acceptable way to maintain it.

These findings are particularly significant in the COVID-19 pandemic. Since March 2020, in some circumstances, face-to-face contact with others has been impeded or forbidden. Isolation, restricted movement and lockdown have impacted upon the connections and relationships of those who access and provide HSC. Reduced face-to-face contact may have impacted on the opportunities to establish interpersonal connections and supportive relationships. This could have long-term emotional and physical effects, such as increased mortality, loneliness, cognitive impairment, and it could lead to people feeling disconnected (Brooks et al., 2020; Pietrabissa and Simpson, 2020). This raises questions about the (as yet) untold impact of the pandemic in this context, warranting further exploration.

6.4.2 Understanding

This concept highlights participants' need and desire to receive understanding from others, when accessing and providing HSC. The findings from this study indicated that individuals across all participant groups wanted to be understood, with their knowledge and experiences of HSC being acknowledged, respected and valued. The reality of their experiences highlighted some of the barriers to understanding others in HSC. For Staff Member participants, there were challenges in understanding differences in professional practices between sectors, for example, the different approaches Social Work colleagues adopted to anticipatory care (illustrated in Section 5.8.2). Service Users emphasised the importance of HSC staff seeing them as individuals, and not just their condition. Together with Informal Carers, they described experiences of judgemental actions and reactions from HSC staff. These responses led to perceived silencing of those who were accessing their services, creating a sense of 'epistemic injustice' (Buchman et al., 2017; Carel and Kidd, 2014; Fricker, 2007).

In this context, epistemic injustice relates to the power and ethics attached to an HSC staff members' privilege of 'knowing' about HSC, and the silencing of Service Users and Informal Carers who do not 'know' or know less about it (Carel and Kidd, 2014). For example, an HSC professional can be considered by some to have an epistemic advantage over people who access HSC services. This advantage can be defined through their professional abilities, skills and knowledge of HSC; having this knowledge puts them in a position of privilege or power over someone who does not (Service User or Informal Carer) (Buchman et al., 2017; Carel and Kidd, 2014). However, as highlighted in the dimensions of interpersonal connections above (Figure 5 and Section 6.3), the need to maintain parity in a relationship is imperative in making an interpersonal connection that can develop into a supportive relationship. Informal Carer Anisha highlighted an example of how this power-balance and the interpersonal connection she had with the Social Work member of staff had been compromised, when she asked her Social Worker for support with anticipatory care planning for Arthur (Section 5.5.1). She felt she had been met with a “retort”, which left her feeling as though she had made an unreasonable request, disconnected from her Social Worker, angry and frustrated. Drawing on this theoretical perspective of epistemic injustice, it could be argued that her Social Worker had exercised an epistemic advantage to pass her own judgement upon Anisha.

In Anisha’s case, it could be argued the action of the Staff Member was also bureaucratic, exerting dominance and expectations (as an HSC practitioner) to undermine Anisha’s voiced opinion and need for support. This action was counter-productive in this case and directly opposed principles of co-production, where individuals are involved in making decisions about and coordinating their own care (which is further explored in the ‘Involved’ pillar below) (Ärleskog et al., 2021; Agid and Chin, 2019; Kaehne et al., 2018). Furthermore, when considering the HSCP strategy within the area (HSCP 1), this reluctance to consider anticipatory care planning also seems to counter their priority to tackle inequalities by keeping vulnerable people safe (as per Table 1). This example was mirrored by other Service User and Informal Carer participants and suggests there is a need to further educate staff on epistemic injustice, to promote better understanding of the needs and the value of experiences of others in integrating HSC systems. There is a need to recognise unconscious bias in self and others, and better understand the effect it can have on communication, connections, trust and relationships in HSC, along with the negative impact it can have on treatment, care planning and experiences of HSC.

Service Users also perceived bias and judgement related to their age and use of certain services. Service User Donna described her experiences of accessing a co-located rehabilitation service, which she was then discharged from on her 65th birthday. Donna perceived this service was reserved for under 65’s only and she had been ‘forgotten about’ after reaching that age, despite her perception that she still required it. There is wide recognition that the demographics of society are changing within the UK, with longer lifespans and the population of over 65’s anticipated to increase by an additional 7.5 million in fifty years’ time (Office for National Statistics, 2021). Negative stereotypes of aging and the aging process can be detrimental to mental health and access to HSC (Blood and Guthrie, 2018; Lyons et al., 2018). There are many reasons a service could be limited to people under 65, including commissioning and funding restrictions, or conscious or unconscious bias’s about the perceived limitations to the effectiveness of services for people of an older age (Ayalon and Tesch-Römer, 2018; São José et al., 2017). However, Donna felt people in her HSC services lacked understanding about her needs and how those did not change on the advent of her 65th birthday.

Similarly, Service User Barney also described his experiences of an allocated ‘gatekeeper’ who would assess and judge the appropriate type of continence management product he required. He perceived the continence gatekeeper had not understood his needs and had made generic decisions about his care and appropriate products, without involving him; a perception that was also shared by some Staff Member participants. These judgements about the suitability of services and products, as decided by the HSC providers, were perceived by Service Users as non-negotiable. They felt they had to conform to system-wide organisation-imposed restrictions and expectations. These concepts are in direct opposition to PCC (McCance and McCormack, 2021; McCormack and Dewing, 2019). Subsequently, Service Users perceived access to services they felt they needed had been reduced, their opinions and experiences were marginalised, and HSC staff lacked understanding about their wellbeing needs; all of which could be considered as a form of passive-harm (Shepherd and Brochu, 2021; Vauclair et al., 2017; Fiske, 2012). These findings suggest a requirement to better understand the needs of Service Users, and how operational or system level influences might be perceived as discriminatory or obstructive by people who are accessing HSC.

6.4.3 Involved

This concept emphasises the importance to participants of being involved in making decisions about their own care or their HSC role. People who accessed HSC wanted to actively participate in discussions about their care, or caring role. Service User and Informal Carer’s expressed desire to be involved collaboratively in the decision-making process. Co-production of services involves re-setting historical power balances between people who ‘provide’ HSC and those who ‘receive’ it (Ärleskog et al., 2021; Agid and Chin, 2019; Kaehne et al., 2018). It focuses on developing reciprocity between the two, building relationships and equal partnerships, and respecting the values and knowledge of others, coming together to explore and discover shared solutions in HSC provision (National Co-production Advisory Group, 2021; Holland-Hart et al., 2019; Vennik et al., 2016; Social Care Institute for Excellence, 2015).

The above discussion about Anisha’s experiences (Section 6.4.2) relates to resetting the power balance between people who provide and access HSC. My findings suggest it would not be unreasonable to promote a shift in power to avoid marginalising the contributions Service Users and Informal Carers offer in HSC, to promote recognition of their valued involvement. It could be argued that some of the terminology employed within HSC promotes disparity of power and inequality in the direction of interpersonal connections formed (Figure 5). The use of the term ‘services’ is an example of this.

Terminology in HSC can act as a barrier to co-production, with different individuals, communities and HSC organisations developing their own understanding of key terms (Connolly et al., 2020). For me this term ties in with the notion of ‘delivering to/for’ rather than ‘producing with’. If HSC is to be co-produced *with* people who access it as equal partners or leaders in their own care, there is a need to reconsider the terminology in common use within the field. This caused me to reflect on my use of terminology for participant groups (Service User/Informal Carer and Staff Member).

I became increasingly aware that these terms, which were simply employed to differentiate between participants, might also evoke a sense of power. I wondered if there might be power neutral alternatives. After much deliberation the terms of ‘people who access HSC’ and ‘people who provide HSC’ were perceived as more amiable and neutral. Nevertheless, the need to differentiate between individuals who fell into each category remained. For example, within the ‘people who access HSC’ category, there might be an individual who primarily accessed HSC (Service User) *and/or* a family member who supported them (Informal Carer) (reflected within key term definitions in the Glossary). With this in mind, and for the purpose of adding clarity to concise discussions about participant groups, I continued with these terms. However, I also resolved to use them only when there was a need to differentiate between groups, adopting the more neutral and amiable terms above wherever possible, to promote equality of power and inclusion between participants and me.

Following publication of the Christie Commission report (2011) on the delivery of public services within the UK, there has been a strong focus on including or integrating people who access HSC as equal partners in their own care. Indeed, for HSCP 3 (where no participants were successfully recruited), this was a strong focus in their HSC strategy (see Table 1). However, the perceptions of people who accessed and provided HSC (in HSCP 1 and 2) suggested they were not involved in organising their own care or working in a collaborative way with others across HSC. On reflection, having data from HSCP 3, would have been useful to see if the strategy influenced the way HSC staff worked with people who accessed their services (explored further in Section 7.2.4). There has been a move towards legislative changes to promote collaboration in the Care Act 2014 and the Public Bodies (Joint Working) (Scotland) Act 2014, with further legislative moves to promote inclusion across the lifespan in the Children and Young People (Scotland) Act 2014. These legislative changes have influenced an increasing focus on co-production in HSC policy and guidelines over the past ten years (Buck et al., 2021; The Scottish Government, 2018; Social Care Institute for Excellence, 2015; The Health Foundation and Nesta, 2015; World Health Organization, 2015a; Loeffler et al., 2013). However, my findings suggest there is still some way to go in achieving collaborative co-production. All participants in this study expressed their experiences of exclusion, judgement and disjointed HSC that seemed far removed from the ideals promoted in current HSC policy and guidance. This raises questions about the disparity between HSC policies, practices and the reality of experiences for people who access those services.

My findings suggest there is a need for further clarity about how services are organised and coordinated and how information is shared across HSC systems, to promote inclusive co-produced services. The need for clarity is acknowledged in the HSCP 1's strategy (Table 1), but my data suggest this is lacking across both included HSCP areas. A lack of clarity and information sharing can lead to exclusion of not only Service Users but of other HSC staff and organisations within an integrated HSC system; it can lead to disjointed communication and services (Henderson et al., 2021a; Van Houdt et al., 2013). My findings add to the wider body of evidence supporting a need for increased collaboration between people who access HSC and those who provide it (Henderson et al., 2021a; Thorstensen-Woll et al., 2021; Social Care Institute for Excellence, 2015). While individual relationships with (and between) HSC staff were instrumental in helping all participant groups to feel supported, relationship gaps were evident between HSC organisations across both HSCPs included in this study.

This raises question of whether HSCPs were aware of the gaps the people who access and provide their services were experiencing. It could also suggest disparity between perceptions of policy makers, leaders and managers in HSC, and the reality of experiences for people who are accessing and providing HSC at grassroots level. These findings further compound evidence from my Integrative Literature Review Chapter 2 (Section 2.10), suggesting a need to revise the terms used to describe services working towards collaborative practice. Employing the progressive tense 'integrating' on the proviso that integration is a recursive process, rather than a destination, might be a more accurate term. Whilst participants across all groups were clear they were looking for more transparent, collaborative ways of working together, they also expressed their desire for HSC services to be more flexible.

Service Users and Informal Carers suggested some HSC staff tried to offer increased flexibility by taking on extra duties to support them. These were practical in nature, often running small errands for the people they supported. The perceived necessity to take on extra duties is widely acknowledged by many HSC staff who do this in their own time or in the form of extra shifts to help the people they support (Baines and Daly, 2021; McIlroy, 2019; Marangozov et al., 2017; Cunningham et al., 2015; O'Neill, 2015). Staff routinely took on additional tasks they were not contracted or paid to do. For example, HSC staff often collected small grocery shopping in their own time or answered work-related phone calls out with their working hours during breaks and in the evenings. It could be argued there is a need for increased support systems for practical tasks and out-of-hours telephone support.

6.4.4 Individualised care

This concept outlines the significance individualised care held with participants in this study. My findings suggest the HSC services in place did not always recognise or address *all* of the needs of people who were accessing HSC within both HSCP areas. HSC was not always individualised or centred around the needs of the people who were accessing or providing it. For Staff Members, the organisational resources they utilised to help them when they supported their Service Users and Informal Carers, were not always tailored to their needs, for example, inadequate administrative services (see Staff Member Abigail's excerpt, Section 5.9). For some Service Users and Informal Carers, HSC staff lacked insight into their health condition and circumstances, which reflected negatively on the ways their HSC services were coordinated and planned. Anticipating and planning for the future was highlighted by Service Users and Informal Carers as an area that caused them anxiety and worry, being widely acknowledged as a subject of concern for people who access HSC (Senger et al., 2016; Kimbell et al., 2015). When interpersonal connections were superficial in nature, the opportunity to build up a supportive relationship with them was impaired, resulting in care that was not focused on the individual who was receiving it.

Superficial connections also led to disjointed expectations between people who accessed and provided HSC services. They also led to a perceived superficial level of knowledge about the Service Users and Informal Carers condition and circumstances. Promoting a deeper level of connection between two individuals to foster a supportive relationship, could lead to increased knowledge and understanding of the individualised health and wellbeing needs of people who access integrating HSC (Pratt et al., 2021; Strandås and Bondas, 2018; Bridges et al., 2013). Furthermore, a deeper level of interpersonal connection could also promote more equal perceptions of the direction, meaning and importance placed on the relationship between the individuals (Figure 5). Negative perceptions about the insincere nature of a connection and relationship impacted on the ways Service Users, Informal Carers and HSC staff worked together to make provisions and plans for their HSC provision in the future. These negative perceptions about insincere connections are further supported in wider literature and highlights the need for authenticity in the connection (Pratt et al., 2021; Strandås and Bondas, 2018; Uhrenfeldt et al., 2018; Van Sant and Patterson, 2013).

Service User and Informal Carer participants perceived a lack of knowledge from their HSC staff (about them as individuals and their HSC needs). They felt that some HSC staff lacked insight into their needs and how to meet them. Examples of this were evident within Service User and Informal Carer experiences of Social Services. They experienced disparity between HSC services, in relation to whether anticipatory care planning was undertaken routinely (Section 5.8.2). Anticipatory care planning can promote principles of PCC such as inclusion in decision-making, encourage a proactive approach to managing unplanned care interventions and help to improve the quality of life for people who have long-term conditions (Brazil et al., 2020; Neves et al., 2020; Tapsfield et al., 2019; Denvir et al., 2015). My findings suggest that participants welcomed their NHS services' use of anticipatory care planning, and there is a need to offer more of this within Social Care services and across wider HSC sectors. Staff Members Zoe and Gavin highlighted a situation where this might be appropriate (Section 5.5.1). They felt the role of a third sector befriender could potentially support Service Users in times of transition between care settings, in particular, when being admitted to hospital or a care home. Moreover, it could be argued this could be taken one step further, incorporating third sector support into anticipatory care plans. Their input at these times could promote continuity and help to maintain supportive relationships during transitional periods of care.

In addition to anticipatory care planning, ensuring support for Informal Carers was individualised to their needs was important to participants in this study. Informal Carer participants reported feeling stressed, anxious and low in mood. The responsibilities of their changing role negatively impacted upon their mental health and wellbeing. This impact is widely acknowledged in broader literature, often increasing as the intensity of support grows (Bom and Stöckel, 2021; Lees et al., 2021; Mak et al., 2021; Carers UK, 2019; Hand et al., 2019; Carers UK, 2018). For some, it could be argued the changes in their role, and health status of their Service User, incited feelings of loss. These could challenge the attachment Informal Carers had to their Service User (Kaplan, 1998). For example, the meaning an Informal Carer placed on the relationship they held with their Service User (see dimension in Figure 5) may change as they take on more caring responsibilities.

This sense of loss was evident through Informal Carers' descriptions of their changing role, considering its impact on their freedom. As their caring responsibilities increased, their freedom to remain active and pursue their own interests and hobbies decreased. Similarly, an element of anticipatory grief may be experienced in response to the worsening condition of their Service User (Nielsen et al., 2016; Kaplan, 1998). Their perceptions of their Service Users' changing needs and increasing dependency, caused a sense of loss of the relationship they had previously held with their Service User. As their Service Users' declining health and wellbeing became more evident, their role and relationship became increasingly focused on the caring tasks rather than their previous role of being a daughter or spouse. It could be argued this further compounded their perceptions of loss, recognising the Service User's loss of functionality and reduced levels of health and wellbeing, and loss or changing nature of the previous connection they shared with this person.

To cope with this change, Informal Carers in this study emphasised the importance of the connection they shared with the Service User. They expressed the importance of *their* support being individualised to their specific needs and circumstances (Section 5.8.1). Support to be able to fulfil their informal caring role, and regular breaks from caring helped them to cope better and maintain their own mental health and wellbeing whilst caring for their Service User. The impact of an informal caring role can be profound for people who support HSC Service Users (Carers UK, 2019; Carers UK, 2018). Informal Carers can feel 'tied-down' to their caring responsibilities, with a perception of having no time to themselves (Rodger et al., 2015). Despite a need for increased Carer support being widely acknowledged within current literature (Feeley, 2021; Finucane et al., 2019; Hand et al., 2019; World Health Organization, 2017; Rodger et al., 2015), my findings suggest recognition of the support Carers provide can still be underrated by HSC organisations.

Informal Carers perceived they needed Respite care that was individually tailored to their needs and those of their Service User. Furthermore, they also needed a 'Carer's Package of Care' that was appropriate and individualised to their support needs. They perceived existing care packages as generic and not suited to their needs. For example, financial packages that could only be used to purchase goods or services from a restrictive provider-determined list. This led to them feeling their HSC providers had limited understanding of their HSC needs. On balance, it could be strongly contended that Informal Carers themselves are best placed to determine how their own individualised care should help them to meet their health and wellbeing needs, and that HSC staff are best placed to *facilitate* this, rather than impose their perceptions of 'individualised care' (McCance and McCormack, 2021; Stears and Janesh, 2021). My findings suggest there is a need to be more inclusive of the perceptions of individuals who access HSC when planning their care, and HSC staff should aim to facilitate their involvement in this process.

Furthermore, a strength-based approach to providing support can often be helpful to promote wellbeing and empowerment when people are struggling with a sense of loss. It involves a collaborative process between someone who accesses HSC and the people who are supporting them. It also aims to identify individuals strengths, values, and motivations, all of which can help people to feel empowered and build resilience (Yu et al., 2020; Blood and Guthrie, 2018). Moreover, it is in keeping with the principles of co-production, PCC and RBC outlined in the above sections, focussing on things that are going well for the individual and building on those to facilitate a self-directed solution (Caiels et al., 2021). It could be argued adopting a strengths-based approach may help Informal Carers to feel more supported. It could promote an authentic relationship with HSC staff, recognise Informal Carers' need for individualised support that empowers them to focus on their strengths, and help them to cope with their changing situation and losses.

6.4.5 Access

This concept focuses on the importance of being able to access suitable and timely services and information to support people to meet their HSC needs, or those of others, at a time when they were perceived to be required. Findings indicate timely HSC information sharing, interventions and access to services were important to all participant groups. Being able to access the information needed about individuals, services and systems, is a crucial element of HSC which promotes clarity, transparency and timely collaborative practices (Henderson et al., 2021a; World Health Organization, 2018a; Klinga et al., 2016; Van Houdt et al., 2013). However, in my findings a lack of information sharing was identified by all participant groups as a significant barrier to timely collaborative services, leading to reduced knowledge of individuals, their circumstances and their medical conditions. As outlined above (Sections 6.4.1 and 6.4.3), gathering information about people whom individuals were connecting with was a fundamental principle of developing a supportive relationship. When communication between individuals, services and systems was lacking, it led to untimely access to key information and knowledge. Subsequently, these delays led to untimely actions or decisions about HSC. Findings support the notion that more cohesive, transparent and clear lines of communication would facilitate timelier access to key information and HSC services for people who need them. Furthermore, for HSC staff more efficient ways of sharing information would also help them to work more closely with other services that support *them,* while they are supporting people who are accessing their service.

Access to services which met the needs of the people who needed them, at a time when they felt they were required, was highlighted as an area of concern for Service Users and Informal Carers. The benefits of facilitating access to the 'right person at the right time and place' are widely acknowledged in HSC policy and practice; it can promote timely contact with staff and services to improve experiences for people who are accessing HSC (NHS England, 2021; The Scottish Government, 2017; Burstow and Cordery, 2015; World Health Organization, 2015b; Timmins and Ham, 2013). However, for people who accessed HSC in this study, the reality of this differed from the standards set within these policies. They experienced delayed access due to waiting-lists, reduced availability of services because of age limits (age-specific services for under 65's only) and inequality across geographical HSCP areas.

Regional inequalities in the provision of HSC, or 'post-code lotteries' are widely reported in HSC (Smith et al., 2020; Brand et al., 2012; Smith et al., 2012a). The impact of these variations in care provision can lead to what might be perceived as unfair or discriminatory provision of services (or lack thereof). The location in which an individual resides could influence the services that are available, rather than 'positive local choices' that respond to the needs of the local population (Black, 2015). However, current literature and policy suggest there are ongoing systems and strategies to reduce inequalities (NHS England, 2019; NHS Health Scotland, 2018; Bendaoud, 2017; NHS Health Scotland, 2017; Public Health England, 2017; Walker et al., 2016; Turner et al., 2013). If this is the case, the systems employed to reduce inequalities were not evident within the localities included in this study; HSCPs may not have been aware of disparities across the region. The experiences of participants in this study suggest there is a need for increased information sharing about the availability of services in different localities. Moreover, findings further support earlier calls for community profiling, via wider Social Network Analysis, to improve awareness and information sharing between services and facilitate equal and timely access to HSC services for the citizens in the region (discussed further below in Section 6.5) (De Brún and McAuliffe, 2018; Moradianzadeh et al., 2018; Valente and Pitts, 2017).

In summary, this section of the discussion has identified the key concepts underpinning PRHSC by highlighting the experiences and perceptions of people who access and provide HSC. Interpersonal connections play a significant part in building knowledge to foster supportive relationships between people within HSC systems. When individuals were not able to make these connections to form relationships, it negatively impacted their experiences of HSC. Not having these supportive relationships led to reduced levels of collaboration, information sharing and disjointed services. It was important to Service User and Informal Carer participants that HSC staff understood their needs and helped them to find suitable solutions to address them. They wanted those solutions to be individualised to their own needs and they wanted to be involved in making decisions about them and their care. Finally, they wanted to be able to access suitable care, services and information at a time when they felt they needed it, to improve their experiences of HSC. The next section recognises the significant role that communities held in meeting the health and wellbeing needs of their citizens.

6.5 Recognising the significant role of communities who help their citizens to maintain their health and wellbeing

This section discusses the findings, in relation to the significant role played by communities in helping participants to meet their health and wellbeing needs. In the context of this study, the definition of community is defined by the participants themselves. For members of the public, Service Users and Informal Carers, the term community related to any group of people who considered themselves connected to each other through a shared point of interest (as discussed in Section 5.10). That point of interest could be represented through a common medical condition such as MS or Dementia, a geographical area, a religious group, or an Informal Carers role that they had undertaken. However, for Staff Member participants, their reference to community was to a local geographical community. These definitions highlight a potential disparity between perceptions of community and their influence and contribution to health and wellbeing of their citizens.

Contributions of communities in HSC have received increased recognition over the past ten years, as principles of co-production have been incorporated in HSC practice, recognising the value of their resource, skills and influence (Buck et al., 2021; Thorstensen-Woll et al., 2021; Green et al., 2019; McGeachie and Power, 2015; Social Care Institute for Excellence, 2015; Loeffler et al., 2013). In the current context of the COVID-19 pandemic, the value of a communities' unique ability to get to the heart of HSC in their local region, has become particularly tangible (Kaur et al., 2021; McGeachie and Power, 2015). They offer proximity, unique insight, knowledge and flexibility which can help to co-produce HSC in their local area (Kaur et al., 2021; Loeffler and Masiga, 2021; Thorstensen-Woll et al., 2021; McGeachie and Power, 2015; Graven, 2013). Findings suggest that the relationships people who access HSC had with those in their communities, were often more cohesive than those they held with HSC staff in statutory services. They also indicate the valuable knowledge community members have of individuals, their families, Carers and their circumstances. This knowledge help to foster strong supportive relationships, facilitating timely access to support that was individualised to their health and wellbeing needs. Building stronger connections between HSC providers and the communities in which they are operating, could foster more collaborative, co-produced services that complement each other and align with the needs of the people who are using them. Although local geographical communities had been highlighted by Service Users and Informal Carers as instrumental in providing HSC in this study (Section 5.7), an increase in new housing developments was perceived to challenge their access to support from their community. Service Users and Informal Carers perceived two barriers to making community connections, relating to housing.

The first barrier highlighted that an increase in housing led to a perceived influx of people who had reduced levels of crucial knowledge about the local area and about vulnerable individual community members, their circumstances and their health and wellbeing needs. When members of the community did not *know* these vulnerable residents and vice versa, they were less able to make fundamental interpersonal connections and develop vital supportive relationships with them. As discussed above in Sections 3.2.3 and 6.3, building up knowledge about an individual and their health and wellbeing needs through familiarity, similarity and proximity is vital (Hewstone and Stroebe, 2020). Participants indicated that they had reduced opportunity to do this because of an influx of new residents in their local areas, which changed their perceptions of community dynamics. There was a perception that more houses, meant more residents whom Service Users and Informal Carers did not know (and vice versa). When Service Users and Informal Carers did not know the people in their community, they felt they could not connect with them to form a supportive relationship and ask for support.

A recent campaign from a conglomerate of organisations across the private sector, the arts and cultural sector and the Scottish Government, has recognised the positive impact that good community design and housing can have on citizens' quality of life in their 'What if …?/ Scotland' exhibition (Scotland + Venice Partnership, 2021). This project aims to reconsider the role of designers and architects in civic contexts. Their initiative fosters collaboration between citizens, architects and designers to explore imaginative ideas. Through this collaboration, they aim to co-design community housing and spaces across five areas of Scotland, as their 'Scotland + Venice Partnership' considers 'How we live together?' (Biennale, 2021). My findings support promotion of opportunities to build community knowledge, connections, networks, and resources. It could be argued there is a need for greater focus on these and the health and wellbeing needs of communities and their individuals when considering planning applications and residential developments. My findings also add credence to a need for further co-produced community-focused projects that incorporate the housing needs of communities, as perceived by the citizens themselves. Similarly, they support an imperative need for social spaces and initiatives or events that can be housed within a local area to be included in these community design projects. Providing social spaces could help to facilitate vital community connections that encourage knowledge exchange and supportive relationships, to meet the health and wellbeing needs of their citizens. For me, this raised a question about the authorisation and planning of new housing, and how this can impact upon community members' opportunities to connect and develop supportive relationships, especially for those who could be classed as vulnerable.

People who accessed HSC perceived that when they had not built-up supportive relationships within their community, they had an increased reliance on statutory services. They turned to individual members of HSC staff to help them with practical tasks members of their local community had once fulfilled (for example, small grocery shopping or reassuring 'check visits' to Service Users when their Informal Carers were away on holiday). When HSC staff were asked for this support, time constraints of their workload dictated these were considered extra duties (out with their contractual agreements) and they were regularly done in the staff's own time (as explored above in Section 6.4.3). Building knowledge and supportive relationships, through community networks, could help individuals to meet straight forward practical needs and potentially reduce a need for increased support when Informal Carers are unavailable. Building these connections and relationships could be encouraged by creating common values, interests or purpose within a community to evoke a sense of accountability for each other's wellbeing (Bruhn, 2011). Community-led events or specific health and wellbeing initiatives that promote connections between individuals and HSC organisations could help their members to connect, build up knowledge and foster supportive relationships. Adopting a community strengths and assets approach could facilitate health and wellbeing promotion through community initiatives and activities.

A community strengths and assets-based approach aims to improve health and wellbeing for community members by focusing on personal and social networks (Daly and Westwood, 2018). Similar to community profiling (discussed in Section 6.4.5 above) the knowledge and skills that individuals offer a community, along with local buildings and their facilities, are mapped to better understand and promote wellbeing (National Institute for Health and Care Excellence, 2017). Community-initiative groups are viewed as a source of strength within communities, providing a rich resource of support with HSC. They often support with practical tasks such as transportation and small grocery shopping, which was identified as a health and wellbeing need of participants in this study (Sections 5.5.2 and 5.7.1) (Kobayashi et al., 2020). However, strength and asset-based approaches encourage communities to work with providers to recognise existing assets and identify areas where these can be developed, which is particularly relevant to earlier discussions on inclusion and co-production (Section 6.4.3). Furthermore, Community-initiative groups can offer more flexible ways of empowering members to support each other. They can offer early interventions and are not confined by the same parameters as more formal Local Authority and NHS HSC providers (Bainbridge and Lunt, 2021).

My findings support the need to offer communities an opportunity to build their knowledge about the people within them and their circumstances, to meet the expectations outlined in the National Health and Wellbeing Guidelines (The Scottish Government, 2015b). These guidelines set out an expectation that people who access services can engage and participate in their local community. It could be argued that individuals in local communities need more opportunities to come together. Community events and initiatives such as gala-days, open days at the community centre, and community farms could encourage contact, connections and relationships between members in local communities. This adds to a wider body of evidence suggesting continuity, through repeated contact, contributes to development of knowledge about individual community members and helps to build supportive relationships (Chen and Cheng, 2021; MacInnes et al., 2020a; Bunn et al., 2018; Jackson and Ball, 2018; World Health Organization, 2018a; Bruhn, 2011). On reflection, all relationships need to be nurtured and developed over time, with proximity and continuity of contact being key for forming trusting connections between individuals, and community connections are no exception to this.

The second barrier to receiving HSC support from local communities related to Service User and Informal Carers perceptions that an increased number of new houses in their local areas impacted upon the demographics of their populations. When considering changes within his local village community, Service User Grant, offered further insight into the impact housing and socio-economic changes had on his health and wellbeing. He stated that ‘in years gone by’ there would have been an array of parents with young children at home to support him. Grant reflected on an increasing number of parents who were now in employment (see Section 5.7.1) and the negative impact on their availability to offer support, particularly with practical task such as ‘putting out the bins’ and picking up small grocery shopping. Although Grant had not been explicit in referring to women, historically it may have been the mother of a family who assumed the role of caregiver, stayed home with children and supported older relatives or members of the community (Karremans and Finkenauer, 2020; Matthews, 2015). In recent literature, there is also wide-spread acknowledgement that the majority of Informal Carers are women, with 58% of Informal Carers in the UK being female (Carers UK, 2019; World Health Organization, 2017).

Recognising my previous acknowledgement of my Feminist position (Table 12), I wondered if this could potentially be a contentious observation. Feminist movements have influenced societal changes for many years, including the Women's Suffrage Movements from 1830's – 1900's; the broadening of that debate from the 1960-80's to include sexuality and reproductive rights; gender equality in the 1990's; and a more recent focus on the #MeToo and #TimesUp movements that speak out against sexual and workplace harassment and discrimination (Ghadery, 2019; Hillstrom, 2019; Cavanaugh, 2018a; Cavanaugh, 2018b). I strongly advocate the mobilisation of women within the workforce and the equality and empowerment advocated by Feminist movements. However, Grant's poignant point forced me to look out with my own ethical and moral position. I was clear in *my* position that Feminist movements had a positive influence in society, but I also reflected upon whether we as a society had considered how this might impact on the provision of HSC as our societal views of equality, women's rights and Feminist ideology started to change. Furthermore, I questioned whether policymakers and Government had considered the changing face of HSC provision during these times of societal change. It could be argued HSC providers had been short-sighted in their plans to meet the HSC needs of our society, when women were initially mobilising within the workforce. Moreover, in the interest of combining resources and meeting HSC needs, a move towards integration could have been warranted fifty years ago when society started to change.

Despite the barriers outlined above, examples of community connections, relationships and support were evident. However, when local communities supported their members, HSC staff were largely unaware of the contribution they made to help Service Users maintain their health and wellbeing. This lack of awareness further compounded perceptions of disjointed information sharing and HSC provision. Both national Government and local policies within HSCPs promote HSC at a de-centralised local level, advocating care specific to the individuality of each local community area (Care Quality Commission, 2021; National Co-production Advisory Group, 2021; The Scottish Government and COSLA, 2021; Montero et al., 2016). Reflecting on my own District Nursing background (Section 1.4.1) and use of community profiling to become aware of community resources and contributions to HSC, this raised questions for me.

Community profiling became increasingly popular in the 1990's, offering an opportunity to assess the needs of citizens and build up a picture of communities and their resources in which HSC services are provided (van der Waldt, 2019; Chilton, 2018; World Health Organization, 2016c; Cleary et al., 2014; Hawtin and Percy-Smith, 2007; Roberts and Anstead, 1996). Profiling helps to build up a resource of local knowledge, improve collaborative working practices and information sharing (Chilton, 2018; Bynner and Whyte, 2016). It is not clear from my findings if HSC staff across all disciplines, services and organisations were employing community profiling strategies; had they been doing so, it is possible it may have led to their increased awareness of community involvement with the people they were supporting. It could be argued that wider application of local-level community profiling in HSC practice and education would be beneficial in fostering more collaborative partnership working between communities, their members and HSC providers.

This section has explored the significance communities play in helping their citizens to meet their health and wellbeing needs. My findings have identified a need for greater collaboration between statutory HSC providers, third sector organisations and members of the community in which they are based. Community support in the form of help with practical tasks and reassurance was perceived by Service Users and Informal Carers to be less readily available. Staff Member participants were often unaware of the level of support communities were providing to help Service Users and Informal Carers maintain their health and wellbeing. Strengths and assets-based community profiling may help to raise awareness of the support people who access HSC receive from their communities. The advent of increased housing and an increase in parents who worked during the day within participants' local areas led to a reduced level of knowledge about vulnerable people who lived in their communities. Subsequently, Service Users and Informal Carers felt less supported. To conclude this chapter, I will revisit my evidence informed research questions and propositions statements below.

6.6 Revisiting research questions and propositions

Revisiting the research questions, aim and objectives from this study was important to help me determine to what extent those questions have been answered. I also wanted to further explore alternative perspectives of the theories generated in my proposition statements (Yin, 2018; Bryman, 2016; Thomas, 2016; Njie and Asimiran, 2014). After reviewing the findings and formulating my discussion, I first revisited the evidence-informed research questions (Table 15) that centred on the needs, experiences and relationships of people who accessed and provided HSC. From the findings, I could clearly identify health and wellbeing needs that participants had highlighted, when describing and discussing their HSC experiences with me (summarised in Table 41). Equally, I also outlined participants' experiences and the nature of connections they had made across a variety of HSC contexts (which were summarised in Figure 19). Therefore, I felt satisfied my findings had addressed the research questions.

Second, I revisited my original aim and objectives to explore the extent to which this study had addressed these (Table 16). My aim was to develop my understanding of health and wellbeing needs, relationships and experiences for people who accessed and provided HSC. In exploring those, I had hoped to investigate how relationships and health and wellbeing needs influenced those experiences. To this end, I feel I have explored these to the best of my ability using evidenced and appropriate research methods. However, when evaluating this and referring back to objective 3 in particular (Table 16) and considering the findings I have reported and the above discussion, perhaps this should have also encompassed the influence of relationships on experiences of HSC. My findings highlight that connections, relationships and wellbeing needs are intrinsically linked, each influencing the other to shape the experiences of people who access and provide HSC.

Third, when revisiting the proposition statements and my reflexive journal entries from around the time of developing them, I could see that my proposition around the importance of people who access HSC 'being involved in planning their care' (purple box, Figure 8) emerged in my findings (Section 5.7.2) and was further explored further in my discussion (Section 6.4.3). However, I had further thoughts and insights on the remaining three proposition statements. Although I realised the statement related to 'preparing and empowering people who accessed HSC' was evident within my findings (yellow box, Figure 8), it was also clear to me that I needed to be more inclusive in this statement. The need to empower and support people during uncertainty and change was not just reserved for those who accessed HSC. Staff Members had also highlighted the value of the support the support they received themselves when they were supporting their Service Users and Informal Carers (Section 5.5).

It was clear to me now that the proposition statement relating to environmental adaptations had been centred on practical tasks and their importance in promoting emotional wellbeing (see grey box, Figure 8). Whilst this was informed by my literature review and was evident in the findings, it was not a prominent theme in the data, much to my surprise. Perhaps this highlighted a subliminal assumption on my part that people who are accessing HSC in the community will rely heavily on equipment. However, my findings followed an alternative narrative, with only two participants (Donna and Eddie) highlighting the importance of having equipment to help them. Perhaps more importantly, when they were talking about their equipment and how it helped them to maintain their health and wellbeing, they always linked it to how it enabled and empowered their contact with others in their communities. For me, this emphasised the need for equipment, support and HSC interventions to promote and facilitate interpersonal connections. Those connections empowered people who used and delivered HSC to fulfil their inherent basic need for human relationships, positively influencing their health and wellbeing (as discussed in Chapter 3 Section 3.2.3 and Figure 5).

Similarly, I also reconsidered my proposition statement that refers to relationships (see turquoise box, Figure 8). Although I had acknowledged the need for people who access and provide HSC to build trusted relationships, and the part community members played in tackling social isolation, I hadn’t made a connection between the two. To this end, findings emphasised the two-fold importance of building trusted interpersonal connections with people in a local geographical community. They helped to reduce isolation, and they were instrumental in helping people to meet their health and wellbeing needs through their assistance with practical tasks (as discussed in Section 5.7 above). Moreover, the connections and relationships they had within their communities were often more cohesive than those which they had with statutory HSC providers.

During this process, it became apparent my initial expectations were largely focused on needs and experiences of HSC. I had anticipated these would be the main findings in this study, and the relationships people held within HSC would be secondary to those. Whilst I had recognised some of the health and wellbeing needs of people who access and provide HSC at the outset, on reflection, the significance of their relationships in HSC was underrepresented in these statements. It was clear to me that by adopting an inductive data-driven approach (outlined in Section 3.3), I had been able to move away from my preconceived ideas and expectations to explore these data fully, which allowed me to decipher the significance of relationships and connections in HSC.

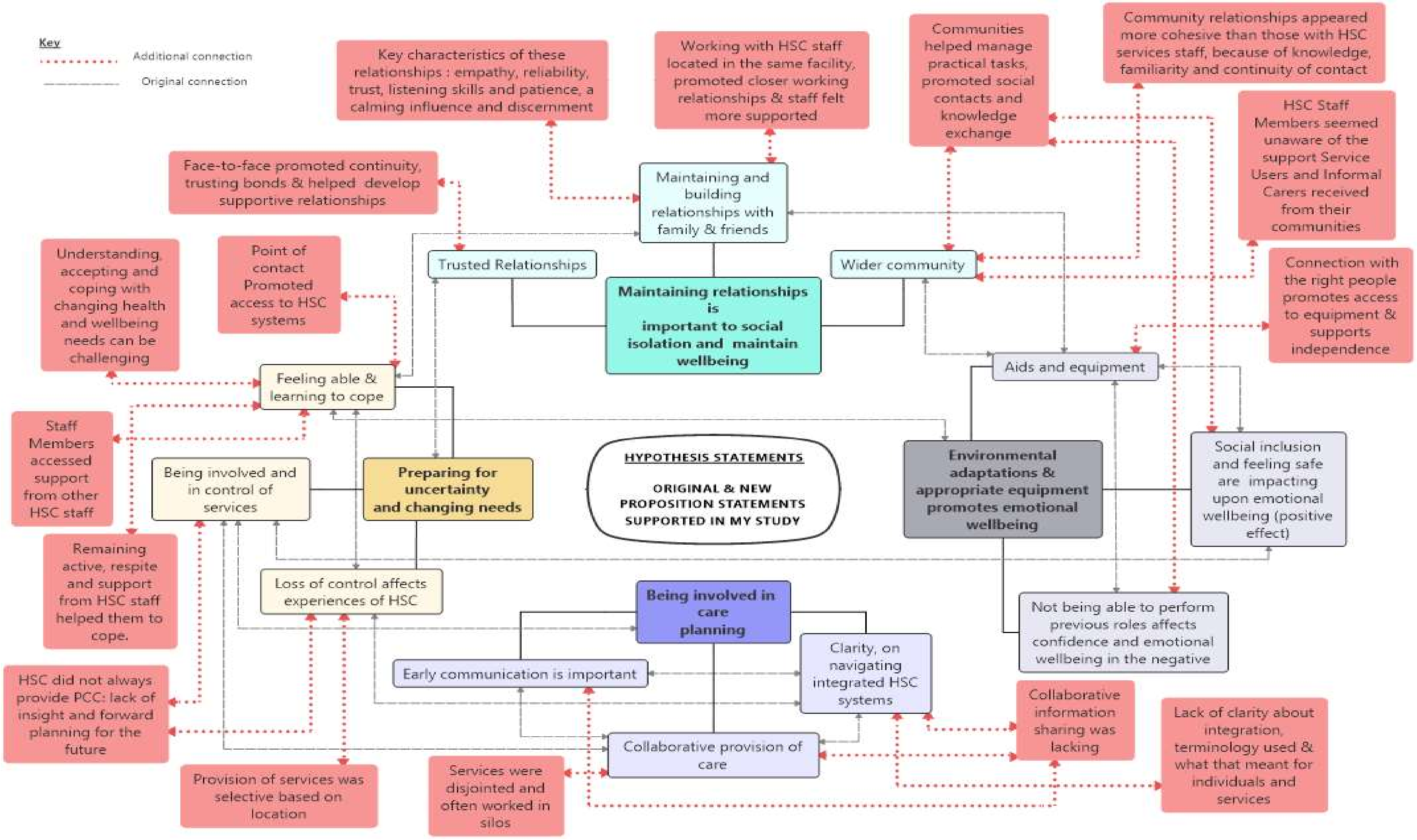
Reconsidering the proposition statements at this stage allowed me to reflect on my previous position and explore the progression in my own knowledge and understanding, highlighting my own development. It presented an opportunity to offer a concise account of the key findings from this study, which have been summarised in Table 45. Furthermore, I recognised that my findings could add further detail and explanation to the original proposition statements in Figure 8. I have highlighted links to the original statements in Table 45, and further illustrated them in Figure 24. Original statements have been abbreviated in Figure 24 and key findings, with their relationships to existing statements, highlighted in red.

Table 45 Key findings and their area of relevance to original propositions

Key findings (*Abbreviated in red boxes in Figure 24)*	**Relevance to original statements**	**Location in Figure 24**
Face-to-face contact offered continuity and promoted a bond of trust and helped to develop supportive relationships.	Relationships	Turquoise statement
Key characteristics of these relationships included: empathy, reliability, trust, listening skills and patience, a calming influence and discernment (to decipher challenges they might be facing and offer appropriate support)		
For Staff Member participants, connecting with other HSC staff located in the same facility, promoted closer working relationships and led to them feeling more supported		
Communities helped their citizens to manage practical tasks, promoted social contacts and an exchange of knowledge, information and experiences of their condition and circumstances	Relationships & Social inclusion and feeling safe & Practical tasks	Turquoise & Grey statements
Relationships with communities appeared more cohesive than those Service Users and Informal Carers had with HSC services/staff, because of the knowledge, familiarity and continuity between members of communities	Relationships	Turquoise statement
HSC Staff Members seemed unaware of the support Service Users and Informal Carers received from their communities		

Key findings *(Abbreviated in red boxes in Figure 24)*	**Relevance to original statements**	**Location in Figure 24**
People and connections are of significant importance - connection with the right people help those who use HSC to access equipment that supports their independence	Aids/equipment	Grey statement
There was a lack of clarity about integration, the terminology used within it, and what that meant for individuals and services	Clarity of navigating IHSC systems	Purple statement
Collaborative information sharing was lacking	Clarity of navigating IHSC systems & Collaborative provision of care	
Services were disjointed and often worked in silos	Collaborative provision of care	
Provision of services was selective based on location	Feeling in control of services	Yellow statement
People who accessed HSC perceived they did not always receive care centred on them: it could lack insight and forward planning for future needs	Feeling in control of services & being involved	
Remaining active, respite and support from HSC staff helped them to cope.	Feeling able to cope	
Staff Members accessed the support they need through other HSC staff		
Understanding, accepting and coping with changing health and wellbeing needs can be challenging for people who access HSC		
Having a point of contact helped people who used HSC to access the support they needed in HSC systems		

Figure 24 Revised proposition statements



When considering each original statement developed from the literature (coloured boxes, centre), further explanation is offered in the lighter middle layers. To map the relevant findings, offer further detail and build upon existing knowledge from the literature, I reviewed each of these statements and added the key points from my findings. Examples of how my findings have added to the original statements are evident through the red dotted arrows. For instance, when considering the turquoise relationships statement at the top of the figure, the literature had highlighted that building and maintaining relationships with family and friends was important to people who accessed HSC. However, my findings suggested it was not only relationships with family and friends that were important to them, or that relationships would only be important to Service Users and Informal Carers; the scope of important relationships was much wider. Participants across all groups had not been prescriptive in their description of the relationships. Instead, Service Users, Informal Carers and Staff Members alike had referred more to contextual settings for relationships with individuals, regardless of their blood-relationship or friendship. Relationships extended to other Staff Members and their communities too. Furthermore, participants across all groups had identified characteristics that were important in building and maintaining them. Therefore, these points were represented in the red key findings boxes across the top of the figure.

The process of reworking the proposition statements was helpful in distilling down to what was important to the participants in this study, and in conveying those key points in a concise manner. Although I considered the possibility of gaps between the original and additional statements, it appeared I was able to expand on all the original statements and detail around them, in some way. The clarity these statements offered was valuable when reviewing the impact, recommendations and conclusions of this thesis, which are explored next, in the final chapter.

6.7 Chapter summary

This chapter has outlined the development of underpinning theories to inform my discussion. Attachment Theory offers a base to explore contextual applications to an HSC context. Within those Caring Theories, key elements of RBC are combined with concepts of PCC. Collectively these theories inform a proposed combined theoretical model for HSC that has been used in my discussion to underpin key areas identified from my findings. These explore the importance of relationships in HSC, highlighting the delicate recipe of trust, professionalism and interpersonal connections, to help build trusting, supportive relationships. A further key area in the discussion focuses on promoting PRHSC, conveying concepts of being connected, understood and individualised, whilst exploring access to HSC, as determined by the people who use and provide services themselves. The significant contributions communities make to the health and wellbeing of their members were also considered. Demographic and housing changes negatively impacted on participants' ability to connect with people in their communities. However, adopting a strengths and assets based approach to promote health and wellbeing through community initiatives and activities, could help communities overcome these challenges. In the next chapter strengths and limitations of this study are considered. The underpinning methodology and methods employed to address the original purpose of this study will be reviewed, outlining the implications for HSC research, education and practice, and concluding remarks and personal reflections will bring this thesis to a close.

CHAPTER 7 IMPLICATIONS AND CONCLUSIONS

7.1 Chapter overview

The overarching purpose of this study was to explore and better understand the health and wellbeing needs, experiences and relationships of people who accessed HSC and the individuals who supported them at home. My underpinning motivation for this study was driven by the hope its findings could contribute to improved experiences for those accessing and providing HSC. I wanted to promote better understanding of other's needs and experiences and build awareness of the impact these, along with the relationships they have, can determine their care or role. Furthermore, I wanted to explore how these influenced the way in which people experience HSC. It was important to me that this study was produced with people who accessed and provided HSC. I wanted it to focus on what was important to *them*, and any benefits from influential recommendations to drive forward change and improvements that could directly benefit *them.*

In this final chapter, I consider the implications of this study, the recommendations I can make and the conclusions which can be drawn from it. First, I revisit and review my selected research design to address the original purpose of this study. Second, I explore the public value this study may have through its contribution to contextual HSC theory, policy, practice and education. Third, I consider the application of my findings to HSC by outlining pertinent recommendations for these contextual fields. Finally, I offer critical reflexive insights on this research study by returning to members of the public and key stakeholders to offer a platform to reflect. Together, we offer our final thoughts and conclude this thesis.

7.2 Review of research design: Highlighting the strengths and limitations of this study

This section offers a reflexive review of the study design and its strengths and limitations. To promote clarity, transparency and trustworthiness around the research methods I have used in this qualitative multi-case study, it considers how I might have done some things differently (Korstjens and Moser, 2018; Bryman, 2016). I have used the research onion again, as a point of reference to guide each section and for clarity around terminology (Figure 3).

7.2.1 Review of underpinning methodology

I have reviewed and offered a rationale for underpinning Attachment and Caring Theories and considered principles of PCC, RBC and proposition statements in my discussion. In addition, I revisited my research methodology and methods choices to consider the credibility and transferability of my findings (Bryman, 2016; Lewis et al., 2014; Braun and Clarke, 2013). As outlined in Section 3.2.1, I adopted an interpretivist philosophy to help me explore and understand the nature and meaning participants placed on their experiences of accessing and providing HSC (see Figure 5 for further illustration). I also adopted two ontological positions to help me better understand the nature of the reality for the participants who were perceiving it. First, I assumed a relativist lens to acknowledge the subjectivity of the reality each participant perceived (Braun and Clarke, 2013). Second, as an equal partner in building new knowledge, I employed underpinning theoretical principles of constructivism to help me (as the person interpreting their data) to construct new meaning from the reality of their experiences (Spencer et al., 2014b; Lapan et al., 2012a).

Adopting these philosophical positions fostered an opportunity for me to develop a deeper level of understanding around the experiences of the participants. Additionally, blending these theories, with principles of RBC and PCC also prompted a combined theoretical approach to interpreting and reporting my findings. The inductive, qualitative approach I had favoured in Chapter 3 allowed me to build data driven knowledge from the bottom up, to develop four original theoretical models to be considered within integrating HSC (Sections 3.3 and 3.4).

Collectively, my theoretical positions, approach and qualitative methodological choices helped me to recognise it was not only participants' experiences of HSC which were important in this study. Of equal importance was the way in which participants interpreted those experiences, the meaning participants placed on those interpretations and the way in which participants perceived their influence over their health and wellbeing needs. The original purpose of this study was to develop a deeper understanding of experiences of people who accessed and provided HSC. I felt the clarity these elements offered, in relation to the construction of new knowledge, was tangible and appropriate to meet this purpose. Satisfied that my theoretical positions had been in keeping with the original purpose of this study, the next section will review my research methods.

7.2.2 Review of research methods

The methods I had chosen to address the original purpose of this study were informed by members of the public, key stakeholders in HSC and underpinning philosophies and methodologies. Feedback from PPI and key stakeholder groups was a foundational bedrock of this study, upon which choices about its development were made. Their input helped me to bring the wishes of the public to the forefront from its inception, when developing the Critical Integrative Literature Review (Section 2.3.1) and influencing the selection of study philosophies and methodology. Members of the public highlighted what *they* wanted to know about experiences of HSC, promoting relevance to people who access and provide HSC and current practices (National Institute for Health Research, 2021b; Health Research Authority, 2019b; Hoddinott et al., 2018). This feedback, along with evidence-informed research questions (Table 9) prompted me to select interpretivist and constructivist philosophical positions and an inductive approach for qualitative exploration through a multi-case study design (Section 4.2).

Further feedback from members of the public and HSC stakeholders highlighted their desire to better understand how people worked together and communicated in HSC, and the relationships they had with others when accessing it (Table 13). Adopting a case study strategy was particularly pertinent to the contextual nature of the qualitative data about needs, experiences and relationships in HSC that I aimed to collect. Additionally, it embraced a desire to explore multiple accounts (Service Users, Informal Carers, Staff Members) of related HSC experiences across a number of HSCPs, as expressed by members of the public and key stakeholders (see questions raised, Appendix 3). The reasons for this were two-fold. First, it allowed me to acknowledge the differences between the HSCPs that provided HSC in different way (Section 1.4.3). Second, it also accommodated the need for multiple perspectives to be bound together under one 'case' to explore the reality and depth of the phenomenon of interest, namely, participants' experiences of HSC. On reflection, I feel that multi-case study strategy and methods, helped me to promote an HSC practice-focused study, with participants as the central focus (Starman, 2013). However, as outlined in Section 4.2.2, the selection of Yin's case study model was *initially* perceived as leaning towards quantitative studies, and there may have been value in further exploring case study qualitative case study designs.

I chose to adopt an ITA approach for data analysis, preferring to use Nowel's (2017) six-stepped approach to guide me in this process. Nowell offered thick-description around each step which I found easily relatable. I was aware it was also in keeping with most other frameworks such as Braun and Clarke's principles for Thematic Analysis (Braun and Clarke, 2013), and the more multifaceted processes offered by Bryman (2016) and Spencer et al. (2014b). Using NVivo software (2012) had been initially challenging (as outlined in Section 4.8.2), with a tendency to promote the compartmentalising of data, perhaps being deconstructed too much. However, once I became more proficient in navigating the different ways in which I could ‘play with the data’ in NVivo, I found it to be a helpful tool that facilitated efficient data management during the analysis process. Engaging with members of the public and key stakeholders about the key findings from the study was a valuable exercise when considering my interpretations of the data (Section 5.10). Although they had a comprehensive understanding of the findings, they asked for further clarity in reporting some of the key terms in the data. For example, they asked for further definition of communities and were explicit that it should not only be limited to geographical communities, and this was helpful in adding clarity to the findings (Chapter 5) and the discussion (Chapter 6).

7.2.3 Reflexive account of things I may have done differently

This section considers things I may have done differently in the design and process of this study. During this PhD and whilst writing up this thesis, reflexive journaling afforded me the opportunity to consider things I might have undertaken differently, promoting my own self-awareness (Korstjens and Moser, 2018). Despite my best efforts to recruit participants across all HSCP areas in the region, the difficulties faced when recruiting participants from HSCP 3 were regrettable (as highlighted within Chapter 6, Section 6.4.3). There would have been value in exploring the differences in experiences in that area, given their strategy document appears to be more inclusive and embraces the spirit of co-production more comprehensively (Chapter 1 Section 1.4.3 and Table 1).

Furthermore, Service Users were asked to identify people who supported them at home, in an informal and formal HSC capacity (Informal Carer and Staff Member). However, it was noteworthy to me (from my DN perspective) that no Service Users identified their Community Nurses to take part along with them. I reconsidered my own previous influential experiences of building relationships with Service Users in District Nursing (Table 12 - District Nurse row), and I was surprised Community Nursing staff were not represented in the Staff Member participant group. Whilst I recognised that not all HSC staff could be included in a study of this size, it seemed I had been presumptuous in my statement. I had assumed participants would feel the same way about the relationships they formed with their Community Nurses in HSC (subsequently leading to my surprise). This raised a question for me as to why no one had identified their Community Nurse for provision of support and wondered if this might be attributed to District Nursing teams that may have been reorganised within their local area. I recognised the time constraints of my studentship were not conducive to investigating this further, but I resolved to include further exploration of the relationships Community Nurses have with people who access HSC in my further recommendations below (Section 7.4).

A central premise of this study has been to work with people who access and deliver HSC to ensure my findings are relevant to key stakeholders. I have often wondered if there are ways in which engagement could have been improved. On reflection, I would have liked to have returned to participants to offer an opportunity to verify their data and my interpretations of that. However, time constraints and delayed ethical approval processes dictated that this was not possible. I could have worked more closely with members of the public to develop the discussion sections of this thesis. Their valuable input may have highlighted other areas in the data that could have been discussed in Chapter 6. However, I found existing processes for accessing members of the public and communities ‘clunky’ at times. It was sometimes difficult to know how to access communities and then to know which ones would be best to speak to. Although the communities I accessed were entirely relevant and had a stakeholder investment in HSC (through their utility or provision of HSC), most often the communities I accessed were convenient and I recognise there is further work to be done around engaging communities in research.

To promote further engagement, there is scope to include a member of the public on an advisory basis within the supervisory team. This would not necessarily need to be monthly at every team meeting, but perhaps on a quarterly or six-monthly basis (to avoid it being too labour intensive for members of the public, if this was a consideration for them). However, in the spirit of true co-production, I would envisage this could be agreed between the supervisory team, student and the individual member of the public. Having their valued input on an ongoing basis would have allowed us to further develop the study together and offered an opportunity to make a valued connection and promote continuity, all of which have been identified as fundamental in HSC. I argue that ongoing involvements could also be translated into HSC research to develop an even deeper understanding of the experiences of people who access and deliver them. This continuity of contact could have supported continuous quality improvement from a grassroots and inclusive perspective and added further depth to my experiences and growth as a researcher.

Finally, on reflection across the four years of this study, there were times where I was worried about 'doing it right' to ensure I remained true to the research methodology, methods and the message that participants wanted to convey. Whilst this is admirable in terms of accuracy and attention to detail, sometimes it prevented me from moving forward. At times, I focused on finer details to ensure they were accurate in fear of moving forward into the unknown as the project progressed. Advice had been free flowing from Supervisors on this point, with encouragement and acknowledgement that 'it is ok not to know, it is a research apprenticeship, if you will?'. In hindsight, I wish I had been less concerned about doing it right and more concerned with just doing it, whilst learning on the way. A lesson I have become more proficient in, as time has progressed. The next section considers the strengths and limitations of this study and its design.

7.2.4 Strengths and limitations of this study

The most prominent strength of this study has been the active part that members of the public and key stakeholders have played in the development of ideas, study design and in refining my interpretations of the findings. With the exception of speaking to participants during the data collection phase, being closely engaged with members of the public has been the most enjoyable element of this study for me as a researcher and as a nurse. Researching *with* people who had an invested interest in this study, its outcomes and how those might influence HSC practice was significant in developing a study that was relevant, inclusive and trustworthy. Furthermore, their involvement promoted credibility, dependability and confirmability by checking the truth-value of these data with people who access HSC (Korstjens and Moser, 2018; Bryman, 2016; Braun and Clarke, 2013). Combined with the findings of the literature review, their valuable engagement highlighted the significance of relationships in HSC and supported its inclusion in the final series of research questions. Using this combination provided a credible evidence-base upon which to build the research study design and collect and analyse my data.

A further strength of this study is its multi-case embedded design (Section 4.2). It allowed multiple perspectives of participants' reality to be represented in the data within each case. Moreover, stakeholder and PPI feedback informed its development, adding further strength to its credibility (Korstjens and Moser, 2018; Yin, 2018; Braun and Clarke, 2013). During analysis, my use of reflexive journaling acted as another strength of this study, providing an auditable breadcrumb trail. It supported the need for thick-description to promote transferability of findings to other contexts (as outlined in Section 4.9.1), giving an in-depth account of the HSC context from which data were collected (Bryman, 2016; Lewis et al., 2014; Braun and Clarke, 2013). Furthermore, reflexive journaling also helped me to promote continued transparency around my initial position as the researcher, and throughout the research process, acknowledging the ongoing influence of my experiences (Section 4.6.7 , with further reflection in Sections 4.8 and 7.7) (Berger, 2015).

In Section 3.2.4, I highlighted the influence of my ongoing experiences during the Covid-19 pandemic. Although data had been collected prior to the first lockdown in March 2020, data analysis commenced during March 2020 in lockdown. Whilst acknowledging this has undoubtedly strengthened my reflexive thick-description and promoted transparency of influences over my thinking during data analysis, it may have also introduced an unwitting bias. The pandemic had a significant impact for many people, with many feeling isolated during periods of restricted movement (Hagerty and Williams, 2020). Although I documented the impact for me was minimal at the time, this could have influenced my interpretation of these data and emphasised the importance of connection in the findings, with recognition of my earlier acknowledgement of the fundamental drive for human connection (Chapter 3, Section 3.2.3) (Karremans and Finkenauer, 2020). However, I believe I have taken the necessary steps, through my reflexive accounts (and later review of those, see example in Table 12) to explore and document how I was feeling.

Reflexive journalling in this way helped me to maintain transparency about the influence of lockdown and acknowledge my own position and bias', whilst remaining true to the participant's intended meaning rather than my own emotions or experiences. However, this journalling process also helped me to view interpersonal connections and supportive relationships during lockdown through a different lens. This lens offered an improved understanding of connections and relationships in the context of the pandemic, and I surmised that it could potentially contribute to future HSC practice. As this study had highlighted the negative influence that a lack of interpersonal connections and supportive relationships can have on health and wellbeing, exploring experiences of making and maintaining these in HSC during the pandemic is warranted. Although there are many contexts in HSC where access to services was restricted or revised to meet governmental guidelines, one example of this could be considered in the context of GP contact. As outlined in Section 6.4.1, Service Users and Informal Carers perceived face-to-face contact with their GP to be important to them. In many GP surgeries during the pandemic face-to-face contact was reduced. GP's increased their use of online and telephone consultations where possible, to follow government advice on remote working and offer an 'approximation' of face-to-face contact (Car et al., 2020; Clarke et al., 2020). Exploring experiences of making and maintaining connections under such circumstances could add to knowledge in the field (considered further in Section 7.5).

A further potential limitation that should be acknowledged refers to the contextual nature of HSC within one region in Scotland in this study (Section 1.4.3). Even though there were three HSCPs included in the recruitment drive in the region, participants came forward from only two of the three areas. It could be argued that had participants from the third HSCP come forward, or had I recruited from additional regional areas within Scotland or across the UK, this may have further enriched the data and findings by offering a wider range of experiences across different areas. However, the need to adhere to prescriptive timelines of my studentship were instrumental in influencing the geographical boundaries in my recruitment strategy. Upon reflection, incorporating a lesser number of HSCPs promoted my focus on the aim and objectives of the study to explore needs, relationships and experiences of HSC (Table 16). It potentially avoided the temptation to examine differences between cases in different HSCPs. With these benefits and challenges of recruitment in HSCP 3 in mind, I endeavoured to offer in-depth thick-description to facilitate transferability of findings to other HSC areas.

The target number of recruited participants to each group was six; however, this was challenged after the withdrawal of interest from one potential Service User and two potential Informal Carer participants. The final numbers represented more Staff Member participants (n=7), than Service Users (n=6) and Informal Carers (n=5). Although this was out with my control and remedial action was taken to recruit a further case to reach the overall target number of participants, I recognise this could be observed as a limitation of this study, with Informal Carers being underrepresented. Similarly, in the interest of promoting further inclusion and diversity in the sample, inclusion of people who have learning disabilities or profound mental health issues would also have been preferable (as discussed in Section 4.6.3). Their exclusion, in line with the REC panel recommendations, is recognised as a limitation of this study.

Finally, as identified in Section 4.6.7, data were collected via semi-structured interviews in either singular or group format. One Informal Carer participant (Esther) appeared less guarded in vocalising her own individual needs (as a Carer) when interviewed alone. When this happened, it highlighted that data gained through group interviews may have been censored in the presence of the Service User to avoid causing offence, which is recognised as a limitation of this method of data collection.

This section has explored and reviewed the underpinning methodology and methods employed in this study. Being clear on my understanding and rationale for choices I have made and highlighting the strengths and the limitations of this study, promotes further dependability through transparency and reflexive review of my scientific methods. The next section will explore the value and impact of this study through its contributions to HSC policy, practice, education and research, and the dissemination of my findings.

7.3 Exploring the public value of this study: Contributions to HSC theory, practice, education and research

I considered the public value of this study and how my findings might contribute to each area of HSC as a field of interest. These considerations add to my findings and discussion to inform my recommendations in the next section. This thesis offers a contribution to HSC theory, by combining aspects of Attachment and Caring Theories with principles of RBC and PCC, to better understand experiences of integrating HSC services in the community. I have provided an outline of how these theories dovetail to offer a blended underpinning for interpretation of the findings, and how they inform my discussion in Chapters 3 and 6 (Sections 3.2 and 6.2). To summarise, theoretical outputs that could be considered of public value in HSC are highlighted below in Table 46.

Table 46 Original, theoretical contributions of public value in this thesis

Theoretical model	Figure
HSC connections and factors that enhanced and hindered them	Figure 19
Typology of Interpersonal connections and supportive relationships	Figure 21
Person-centred Relationship-based Care (PRC)	Figure 22
My People-centred Relationship-based Health and Social Care (PRHSC)	Figure 23

Relevant literature appears to suggest these models have not been applied to integrating HSC in the community before. RBC and PCC have been combined by previous authors in the context of providing exemplary standards of healthcare through excellence recognition programmes, such as Magnet® (Koloroutis and Abelson, 2017; Guanci, 2016; Mellott et al., 2012). However, combining Social Psychology theories (Attachment Theory), nursing care theories (Caring Theory and PCC) and social care theories (RBC) based on supportive relationships between HSC practitioners and those whom they are supporting, appears to be an original contribution to integrating HSC contexts. These theoretical underpinnings, along with the findings and typologies developed within this thesis provide a new knowledge base. This theoretical base could help people who access and provide HSC to better understand connections and relationships that shape their experiences of HSC, and guide educationalists in preparing HSC students.

In highlighting the significance of interpersonal connections across HSC, my findings detail their nature across five HSC constructs pertinent to participants: connecting with self; with other individuals; with communities; HSC services and connections across HSC systems (Figure 19). This figure also highlights the influential factors participants perceived as either enhancing or hindering their ability to make connections within these contexts. Drawing key elements of participants' experiences together in Figure 19 highlighted the potential impact these connections can have upon access to and provision of HSC, helping to inform practice, education and HSC policy going forward. When revisiting my motivation for this study (Section 1.4) and the significance of the National Health and Wellbeing Outcomes for Scotland in prompting my initial inquiries about this study (The Scottish Government, 2015b), it could be argued there is a need for relationship-based outcomes derived directly from the experiences of people who access and provide HSC. Equally, there is also a need to consider incorporating the needs participants have explicitly outlined in this study (Table 41), in the form of measurable outcomes that matter to the people themselves.

The importance of interpersonal connections is identified in my foundational theme and further explanation of the necessary dimensions of interpersonal connections in Figure 21. This highlights the essential characteristics that participants perceived as conducive to developing a supportive relationship with an individual they had connected with. Using this typology to inform integrating HSC education and practice could support the development of strong interpersonal connections between individuals across HSC services and systems. In turn, those connections could help individuals to foster supportive relationships, which could improve the experiences and satisfaction of people who access and provide HSC. With the significance of these connections being clear in my thesis, it could be argued there is a need to consider the relationship building proficiency of HSC staff. Their awareness of the characteristics that help to foster connections with people who are accessing their services could help to improve their experiences of providing HSC support. Furthermore, offering an evidence-based definition of what a supportive relationship looks like in an HSC context, as perceived by the people who access and deliver integrating HSC, could help staff to strive towards excellence in their supportive role.

The PRHSC concepts (Figure 23) offer a significant addition to existing literature and frameworks for integrating HSC services and systems, from the original perspective of people who use and deliver those services. Adopting this framework in integrating practice and education could embrace the principles of co-production. The PRHSC framework could promote relevant, meaningful engagement with the public and key stakeholders in HSC to develop and improve services for people who access and provide them. Moreover, it could help to encourage provision of integrating HSC that closely aligns with the needs of people who are accessing it and promote collaborative ways of working between individuals across HSC services, sectors and systems.

When considering other frameworks for HSC, there are models that have been favoured by one sector over another, highlighted in Section 6.2. For example, relationship-based care has been widely used in social care sector for a number of years, but from personal experience and observation this is less so in health care (Hollinrake, 2019; Ruch, 2018). The PRHSC model offers a framework that can span across all sectors of HSC, because Service User and Informal Carer participants in this study were accessing a range of HSC services across all sectors. It was clear from their data they wanted the concepts outlined in the PRHSC model to be promoted by all staff, regardless of which organisation or sector they were working for.

Arguably, the principles in the PRHSC concepts could be universally applicable to all who access and provide HSC in the community. Furthermore, when considering these concepts out with the context of HSC, there could also be value in promoting this framework in other forums. I considered these concepts in the context of my PhD student experience, feeling these principles were applicable to my expectations of interacting with others in my student role (students and established researchers alike). It could be argued the PRHSC concepts align closely with fundamental human rights, contributing to social justice by promoting equality and inclusion. They could be applicable to interactions between other groups of people, communities or industries out with HSC. For example, student and higher education communities, human resources and employee relations, and other public sectors such as policing services incorporate elements of caring within their roles. It could be argued that they may also benefit from a deeper understanding of interpersonal connections and supportive relationships to inform caring elements of their work. However, further exploration of the potential transferability of findings beyond HSC would be warranted.

Finally, my thesis also offers a contribution to HSC research. As outlined in my Integrative Literature Review (Sections 2.5 and 2.6), there were gaps in current knowledge. Current research focuses strongly on models of integrating HSC and their implementation. Research in the field is orientated towards the vital characteristics to strengthen integrating services and systems. There are many studies exploring collaboration, management and leadership and workforce capacity and capabilities, and how those may have been achieved (or not) in geographical areas. I identified a need for further qualitative research that explored the phenomenon of experiences of people who were accessing and delivering HSC; it encompassed inquiry into health and wellbeing needs and the relationships they had across HSC. Equally, there was a need to engage with those groups and focus on including them in the research process to collect data about them, generated *with* them (instead of being generated by HSC staff, for example). This thesis presents an empirical qualitative multi-case study that goes some way to addressing these gaps. It adds to an existing body of wider research around the impact of HSC, offering an original contribution from a regional area in Scotland.

This section has explored this study's contributions to the field of HSC practice, considering how they might influence HSC policy, education and research. This study contributes to HSC by highlighting the significance of contextual connections, defining what they look like, how they might be promoted and how supportive relationships can be fostered from them. I have devised models and frameworks driven by participants to showcase their experiences. Validation of these models is warranted. There is potential for a pilot study that evaluates the initial implementation of these models and frameworks. If validated, there is scope for a further contribution to the field through their wider implementation across HSC policy, practice and education. This study has gone some way to addressing existing gaps in the literature through qualitative exploration of participant's experiences, focusing not only on their data but on their inclusion in the research process. With these contributions to the field in mind, recommendations that could improve experiences of HSC and enhance national health and wellbeing for people who access and provide it, are outlined in the next section.

7.4 Recommendations for policy, practice and education

This section considers how the above contributions might be translated into HSC policy, practice, and education, to bridge the gaps in applying research in practice (Livingood et al., 2020; Greenway et al., 2019). In the interest of maintaining focus on participant-derived key concepts in HSC, my recommendations are framed in their respective concepts within the PRHSC framework (Figure 23). They follow a bullet-point format and cross references are provided to evidence their development from the findings and discussion chapters of this thesis. Thereafter, I consider propositions for further work in the field and how the impact of this study might be maximised.

Fostering connected HSC practices

- To help people who access and provide HSC to form supportive relationships, interpersonal connections through continuity of contact with staff should be promoted by HSC provider organisations (as discussed in Sections 6.4 - 6.6).
- HSC providers should consider incorporating protected time into staff workloads. This time could allow staff to make interpersonal connections and foster relationships with people who access their services, and with colleagues in their organisation and across wider integrating HSC systems (as outlined in Section 5.8.3 and 6.4.1).
- HSC educators and providers should consider a reinvigorated focus on the value of community profiling for healthcare students and practitioners, adopting a strengths and assets-based approach within HSC delivery teams (as discussed in Sections 6.4.5 and 6.5).
- HSC providers should consider networking opportunities and activities to build stronger connections between statutory and third sector HSC services, and the communities in which they are operating. Doing this could offer an opportunity to develop collaborative, co-produced HSC services aligned with the needs of those accessing them (as discussed in Sections 6.4.5 and 6.5).
- Local Authority community planners and HSC providers should consider facilitating opportunities and resources that allow members of local geographical communities to contribute their knowledge, connections and networks to planning initiatives (as discussed in Section 6.5). Incorporating social spaces and offering wellbeing initiatives in their housing

development plans could facilitate community interactions that encourage health and wellbeing amongst citizens.

Encouraging understanding in HSC

- HSC staff and providers should consider wider recognition of Informal Carers as active contributors to HSC, and the need to adopt practices that promote improved non-judgemental interactions between people who use services and other HSC providers (as discussed in Section 6.4.2).
- To acknowledge Informal Carers' need for flexibility in their HSC support, their inclusion in coordinating and organising their own care should be considered to promote a greater level of understanding of their needs, with appropriate means to help them meet those needs. Adopting this approach could promote greater collaboration between Informal Carers and HSC services (as discussed in Section 6.4.4).

Involving people and working with others in HSC

- Ongoing dialogue and review of terminology used in HSC would be helpful in promoting a co-produced culture of equality (Section 6.4.3). Current terminology, relating to past tense 'integrated HSC' rather than the notion of 'integrating care', does not reflect participants experiences of siloed and disjointed HSC.
- Where possible, the co-location of HSC staff should be considered when redesigning HSC services to promote trusted interpersonal connections and supportive relationships amongst staff (Section 5.10 and 6.4.2).
- As highlighted in Sections 6.4 and 6.5, there is a need to ensure HSCP strategies are more inclusive of the principles of co-production, and HSCPs may need to consider revisions to current strategies to achieve this.
- Governing bodies that influence the development of HSC policy, practice and education should consider further inclusion of experiential evidence to support the development and implementation of HSC that is centred on the individuals who access and provide it (Section 2.8).

Promoting individualised care

- HSC support practices should be centred on the needs of people who access and provide HSC, as determined by the individuals themselves, to promote their health and wellbeing or help them to support others in doing so (discussed in Sections 2.8 and 6.4.4).
- Consider applying principles of anticipatory care planning across wider HSC sectors, and the inclusion of third sector support within them. Contact with third sector organisations in this context could promote individualised care, encourage continuity, help to maintain supportive relationships and improve HSC experiences (as discussed in Sections 6.4.2 and 6.4.4).

Facilitating access to support in HSC

- Acknowledging the positive influence that a named point-of-contact had upon experiences of HSC (Sections 5.8 and 6.4.1), HSC policymakers and providers should consider promoting this model more equally across wider HSC sectors. Adopting a named point-of-contact approach across HSC could facilitate equality of timely access to services and improved information sharing, promoting supportive relationships between people who access and provide HSC.
- Informal Carers needed to take a break from their caring responsibilities to maintain their own health and wellbeing and enable them to continue their provision of support for their Service User (Section 6.4.4). To that end, appropriate local respite services should be provided by HSC organisations to promote accessibility, continuity and support.

7.5 Considering further work in the field of HSC

Throughout the research process I have captured ideas for further work in my reflexive journal. I have summarised my thoughts on gaps that exist in the current theoretical body of knowledge, with a need for further empirical research in the areas outlined below:

- There is a need to replicate this study with a larger sample size across wider geographical areas.
- People with a learning disability or profound mental health issue were excluded from this study at the request of the REC panel (Section 4.6.3); however, there is a need for further research that explores their experiences, needs and relationships within HSC.
- Further exploration of the contributions made by community and third sector groups to HSC systems (Section 6.5), and their representation whilst planning, organising and coordinating HSC is warranted.

- The application of the PRHSC model should be tested across a variety of HSC settings to establish the viability of its use in HSC. There is also scope for further testing within organisations, groups and communities beyond HSC (as discussed in Section 7.3).
- As Community Nurses and wider HSC Staff Member groups were underrepresented in the study (discussed in Section 7.2.3), there is a need to explore their contributions to integrated HSC.
- Acknowledging my desire to include a member of the public on an advisory basis within this study (Section 7.2.3), there is scope to explore other researchers' experiences of this by reviewing relevant literature to establish if further research in this area would be warranted.
- As acknowledged in Section 7.2.4, further exploration is warranted in relation to experiences of making and maintaining interpersonal connections and supportive relationships when face-to-face contact is restricted. For example, during periods of restricted movement and contact during Covid-19.

7.6 Maximising the public impact of this research: Disseminating contributions

Disseminating the contributions this study can make to HSC and the changes that can come from the recommendations above is important to help inform policy, practice, education and future research (Tracy, 2019; Reed, 2016). I have endeavoured to undertake oral and poster presentations, publications, networking and social media drives to raise the research profile locally, nationally and internationally. I recognised these as good methods for sharing information that will be beneficial to others (Hewitt-Taylor, 2017). As outlined in Chapter 4 (Section 4.7.2) and Chapter 5 (Section 5.10), ongoing scientific review, along with input from key stakeholders in HSC and members of the public, has been important to me. Engaging with these groups (online and in person through feedback sessions), has helped me to remain engaged with the people for whom my findings might have the greatest impact.

Scientific outputs from this PhD study (to-date) are outlined at the front of this thesis, with notable outputs including: an oral presentation at the International Conference for Integrated Care 2021 (Henderson et al., 2021b); an award for the People's Choice Prize during the RGU heat of the Vitae ThreeMinuteThesis® competition (Henderson et al., 2021c); and a poster presentation at the Transforming Community and Public Health: Inspiring Future Generations conference for the International Collaboration of Community Health Nurse Researchers (ICCHNR) (Henderson et al., 2018a). My most recent presentation has been to an NHS Executive Board, who are currently developing post-pandemic strategies for delivering HSC in the coming years.

In addition to the above outlined presentations and engagement, I have made efforts to align myself with key HSC organisations that can help to disseminate my findings after submission of this thesis, including ongoing engagement with funders, sponsors and HSCP partners. My intention is to continue to hold 'Research Engagement Sessions' for wider dissemination amongst key stakeholders in HSC (with the first being held in July 2021, discussed further in Section 7.7 below). Furthermore, I will continue to present at local, national and international conferences. I also aim to further raise the profile of the study findings through social media channels.

Following publication of the Critical Integrative Literature Review in Chapter 2, I have identified several potential publications to work on after my PhD. Publication can offer valuable insights into my work and maximise the impact this research could have on HSC practice (Hewitt-Taylor, 2017; Reed, 2016). Potential publications are outlined below, with my rationale for considering them.

- There is scope to publish an overview of this study, its methods, findings and discussion.
- In acknowledgement of the vast amount of data collected, I believe there may also be scope to produce a subsequent short series of more in-depth accounts of the thematic findings and discussion from my thesis.
- Publishing an explanatory paper about the thick-descriptive methods and analysis in this study could add to the wider body of evidence around qualitative multi-case study methodology.
- There is scope to produce a book chapter about experiences of HSC and the significance of interpersonal connections, supportive relationships (Figure 19; Figure 21) and the PRHSC framework (Section 6.4). I anticipate that this could be included in a textbook considering the necessary components of providing and improving HSC.
- I have also considered publishing two opinion pieces. First, a paper relating to my experiences of completing the NHS Scotland IRAS ethical approval application. In doing this, I aim to raise awareness of the complexities that researchers face when completing this process, and the need to include those who have profound mental health and Learning disabilities, representing a large proportion of the population who access HSC (as outlined in Section 4.6.3). Second, my experiences of working with members of the public and key stakeholders throughout this

study, could add to wider literature and encourage other researchers to adopt practices that promote inclusivity and equality for members of the public and key stakeholders.

- When undertaking reflexive journaling, I found it difficult to identify relevant frameworks to guide me in this process. Literature often highlighted the importance of reflexivity, adding to the trustworthiness of qualitative work. However, I felt that further discussion on how this might be carried out was lacking. Outlining my experiences of reflexive journaling in a publication, with potential to offer a framework that might support researchers in this task, could help others with this process.
- Using a qualitative case-study methodology was an enjoyable experience for me. Planning and constructing cases within contextual boundaries accurately reflected the complexities that influenced my data. It also incorporated multiple data sources, which enriched the credibility of this study. When searching for textbooks on case-study methodology for qualitative studies, I adopted several key texts; however, they were often referred to qualitative methodology and methods *or* case-study methods (focusing on mixed methodologies). There is scope to consider combining the two through publication of a foundational qualitative case-study textbook, and this is something I will consider further whilst developing my skills as an Early Career Researcher.

7.7 Final reflexive insights, with members of the public and key stakeholders in HSC

Throughout this thesis I have strived to ensure people who access and provide HSC had a platform to have their voices heard, and I wanted this to be mirrored in final reflexive insights about this study. As outlined in the acknowledgements at the beginning of this thesis and in recognition that the voice of participants is the lifeblood of this study, I reflected and posed a rhetorical question to myself; how could a collective effort from so many people be *just mine*? Therefore, at this juncture, I felt it fitting to conclude this thesis by inviting members of the public to attend an informal Research Engagement Session in July 2021, to hear their final thoughts about this study.

We engaged in an open discussion about the study, its findings and what we felt those might mean for HSC in our local areas. Members of the public and key stakeholders were clear on the value of this study. They were pleased to have been involved and satisfied it would help to develop HSC (Table 40, points B, E, L and M), all of which were in keeping with the original purpose outlined in Sections 1.5 and Section 7.1. They also expressed their desire for further distribution of the findings from this study.

In recognition of this, I will prioritise further dissemination to help promote a wider appreciation of the experiences, needs and relationships in HSC for participants in *our* study.

Offering closure of this study through reflexive journaling and further engagement with the public continues to promote the credibility and dependability, promoting inclusion and equality in this co-produced research study (National Institute for Health Research, 2021b; UK Public Involvement Standards Development Partnership, 2019b; Bryman, 2016). Together, we have drawn our final conclusions from this qualitative exploratory multi-case study, and they are represented in the bullet points below:

- “This study highlights that multi-disciplinary working is very important and entirely necessary for integrating HSC services. No one person or service can provide the whole care-package.”
- “Everyone needs to be an equal partner round the HSC table, everybody needs to have an equal voice, and authoritarian hierarchical systems, services and meetings need to be reviewed.”
- “Carers and health professionals need time (incorporated into their roles) to build relationships that help them to care for and support others.”
- “It is important that policy makers and HSC providers recognise the contribution communities can make to HSC; those communities come in many forms, and one model of integrating HSC does not fit all of them.”
- “Achieving the balance between needs, expectations and the reality of what can be delivered in HSC is a sizable challenge. Equality and inequality are perceived by different communities in different ways.”
- “If the integration of HSC is to be improved, we as a society, must be clear on what is expected of HSC services and systems, and how we prioritise the limited resource across all contexts of HSC to meet health and wellbeing needs.”

From a personal viewpoint, this study challenged my thoughts, beliefs and perceptions of HSC. At the outset, I felt I had enough life and professional experience to know what this study was ‘all about’. My focus on Social Psychology for the interpretation of my findings was something I did not expect; I assumed findings would relate to nursing theories only. Whilst there is clear overlap (Figure 22), when I reconsider these feelings now, I realise these had been naïve. As I write today, I feel I have come full circle, realising there is no one theory, model of practice, policy or research study that fits all circumstances. This PhD has encouraged me to become a more integrative HSC practitioner, whilst establishing there is still much more to learn. Subsequently, I feel my understanding of the needs, experiences and relationships for people who access and provide HSC has grown beyond that which I could have imagined at the outset.

Finally, for me, one of the most significant findings from this study has been the importance of community support to promotes citizens' health and wellbeing. It has been brought into sharp focus at a time when the pandemic continues to impact upon individuals, communities and wider society. I am no exception to this and because of that, I have personally increased my own involvement and contribution to the communities I am part of, through voluntary roles. Fittingly, the quote I shared in the beginning of this thesis in my acknowledgments (see Page i) not only relates to the people who have supported me to develop this deeper understanding, it also highlights the ethos of this study beautifully; together we can do that which we could never do on our own, to achieve great things (Mother Teresa of Calcutta Center, 2010). A statement that is appropriate to reflect the very essence of integrating HSC: working with individuals, communities, services and systems to improve HSC and achieve what could never be done alone.

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Appendix 1 Table of evidence

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
1	BAUMANN, M., EVANS, S., PERKINS, M., CURTIS, L., NETTEN, A., FERNANDEZ, J. and HUXLEY, P.	2007	Organisation and features of hospital, intermediate care and social services in English sites with low rates of delayed discharge.	Health & Social Care in the Community	15(4), pp. 295-305.	UK, England, 4x southern (1 London) & 2 northern metropolia.	To investigate discharge practice and the organisation of services at sites with consistently low rates of delay, in order to identify factors supporting such good performance.	Total: 42. Social services (n= 19), acute trusts (n= 14), intermediate care (N= 5) and PCTs (N= 4). Staff included: senior strategic managers (e.g. directors of nursing); operational management leads (social work) and operational staff (e.g. care managers and discharge facilitators)	Qualitative – investigative	Semi-structured interviews	Participants identify outcomes that are important to them. They identify personal comfort outcomes; economic & social participation; autonomy outcomes and relationships are evident between these outcomes.	Study identifies a range of factors that contribute to lower amounts of delayed discharge.	Under-representation of elderly people and nurses in the study. Un-segmented interviews led to participants focusing on changes health, rather than delayed discharge circumstances. Some valuable analytical insights lost through division of labour during analysis.		X	

	Author(s)	**Year**	**Title**	**Journal**	**Vol./No/Page**	**Country**	**Study Aim(s)**	**Sample (N=) Characteristics**	**Study Design**	**Data Collection**	**Key message(s)**	**Strengths**	**Limitations**	**Wellbeing through IHSC**	**Co-production in IHSC**	**Relationships**
2	BIEN, B., MCKEE, K.J., DOEHNER, H., TRIANTAFILLOU, J., LAMURA, G., DOROSZKIEWICZ, H, KREVERS, B. and KOFAHL, C.	2013	Disabled older people's use of health and social care services and their unmet care needs in six European countries.	European journal of public health	23(6), pp. 1032-1038.	Germany, Greece, Italy, Poland, UK & Sweden.	To compare health and social service use in older people who receive support from a family (informal Carer), using data from a cross-Sectional study of family (informal) Carers in six European countries.	Total: 2629 [Family (informal) Carers].	Quantitative – exploratory survey	Cross-Sectional face -to-face survey	Southern-Eastern European countries appear to have the lowest level of social service use and the highest number of unmet care needs; with Northern-Western European countries, appearing to offer a more socially oriented and greater variety of services, have the lowest levels of unmet care needs.	Findings offer some empirical under-pinning to integrating social and medical services for frail older people in the community to improve care outcomes, potentially decreasing overall costs of care	Cross-sectional data collection prevented any determination of causality in the relationships revealed in analysis. Collected data about older people from family carers but did not ask the older people themselves to be involved.		X	

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
3	BJERKAN, J., RICHTER, M., GRIMSMO, A., HELLESO, R. and BRENDER, J.	2011	Integrated care in Norway: the state of affairs years after regulation by law.	International Journal of Integrated Care	11	Norway, Multi-municipal.	To explore the use of Individual Care Plans in Norwegian municipalities that are responsible for primary care and social services.	Total: 59 [Leaders in Health & Social Care (n=32) & 'Professionals' (n=27), across 61 Municipalities].	Quantitative – exploratory postal survey	Questionnaire	Legislative care planning approach to integrated care; however, uptake and utilisation of individual care plans (ICP's) have been low, despite legislation. Service users and family (informal) Carers do not often initiate ICP's (despite training and awareness raising). The study suggests ICP's are not meeting needs of Service Users and acknowledges that sustainable integration and cross-organisational working, is complicated.	Study supports earlier research that suggests that introducing and establishing integrated care can be complex and diverse in nature across different regions. Discussion in this paper is lacking.	Some participants may have had a limited understanding of the overview of work done locally, limiting their responses. The sample was relatively low, covering only a 5th of the population. Respondents were not geographically or demo-graphically diverse.		X	

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
4	BONCIANI, M., BARSANTI, S. and MURANTE, A.M.	2017	Is the co-location of GPs in primary care centres associated with a higher patient satisfaction? Evidence from a population survey in Italy.	BMC Health Services Research	17, pp. 248.	Italy, Tuscany.	To verify whether the co-location of GPs in Primary Care Centres (PCC) is associated positively with Service User satisfaction with the GP when their Service Users have experience of the multidisciplinary team.	Total: 2025 GP Service Users.	Quantitative - evaluative	Cross-Sectional population survey	Co-location of GPs with other professionals in PCCs appears to be of benefit to Service Users and works particularly well for Service Users with complex needs. ‘Multidisciplinary’ working in both PCC areas and non-PCC areas, was found to have higher rates of Service User satisfaction.	This study provides evidence of a positive association between co-location and patient satisfaction (in PCCs). Large population based survey with consistent response rate.	Association between satisfaction and co-location cannot be interpreted casually. Potential bias related to the selection of GPs in PCCs.		**X**	

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
5	BOUDIONI, M., HALLETT, N., LORA, C.R. and COUCHMAN, W.	2015	More than what the eye can see: the emotional journey and experience of powerlessness of integrated care Service Users and their Carers.	Patient Preference and Adherence	9, pp. 529-540.	UK, England, London.	To present the emotional journey and experience of powerlessness of integrated care Service Users and Carers.	Total interviews: 7 Service Users. Some participants were interviewed on an individual basis and some with a family (informal) Carer. 2 interviews were with a Carer only (both of whom had cared for someone who had died recently).	Qualitative Evidence-Based Co-Design (NHS Institute for Improvement in England)	Audio-visual video interviews	Feelings of powerlessness were very common among integrated care Service Users and their Carers in this study and informal Carers can be anxious to talk about their experiences and how things can be improved. Carers were found to be outwardly caring towards their Service User.	'Powerful' data collections techniques (video stories) that allowed exploration of non-verbal ques. Analysis was carried out in collaboration with service users who were independent to the study.	Limitations placed on design by funding organisations, the use of private space to collect video stories was not offered and could have potentially influenced the nature of data collected (e.g. restricting the sharing of sensitive data).	X	X	X

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
6	BROWN, H. and HOWLETT, F.	2017	A critical evaluation of the "short stay project" - Service Users' perspectives .	Housing Care and Support	20(2), pp. 71-84.	UK, Rotherham	Critical evaluation of an integrated intermediate service (health, social and housing services) to explore the perceptions and experiences of the Service Users who accessed that service and consider the effectiveness of the service model.	Total: 3 [participants who had been living in the 'short-stay apartments' for at least two weeks and have an identified Health, social or housing need].	Qualitative – exploratory interpretive phenomenology	Semi-structured interviews	Benefits of a "short-stay project" are highlighted, in relation to the location and physical environment of the apartments. This study suggests that this model of integrated intermediate care can prevent hospital admission and facilitate discharge, with the psycho-social needs of participants (who access integrated intermediate services) also being highlighted. Psycho-social unmet needs and occupational balance/imbalance were highlighted, and participants expressed distress at this.	In depth representation of participant experiences and analysis of those (due to low number of participants) . Data highlight that appropriate housing alone in HSC is not enough to support a short-stay model, without the use of HSC support.	Small number of purposive sample (n=3) could not fully represent the wider population, limiting transferability. Potential for researcher bias because the researcher worked within the service, directly delivering care to participants (although efforts were made to reduce contact by realigning care with other professionals in the service).	X	X	

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
7	CHALLIS, D., HUGHES, J., BERZINS, K., REILLY, S., ABELL, J., STEWART, K. and BOWNS, I.	2011	Implementation of case management in long-term conditions in England: survey and case studies.	Journal of health services research & policy	16, pp. 8-13.	UK, England-wide.	To highlighting the service characteristics of Primary Care Trust's for long-term condition case management and explore links with other services and self-support services.	Survey (n=56) of Directors of Nursing and Lead Practitioners in case management for people with LTC's. Case studies across 4 sites in England: semi-structured interviews with 1 service manager per site (N=4); 1 focus group of 5-11 practitioners per site (participant N=?).	Mixed Methods – survey and case studies	Cross-Sectional postal survey, interviews & focus groups	The model of care for Service Users with long-term conditions within this study (Case Management) includes some elements of integrated working. Funding and budgetary control does not lie with the case manager and this was acknowledged as a barrier to integrated service provision in this study. Local variations in service arrangements can affect care planning and integration of services in a case management model.	Describes case management arrangements and self-care support for those living with long term conditions in Primary Care trusts in England. Highlights the importance of care planning and information sharing with patients.	Data were collected at an early stage of service development. Services that did not provide evidence of the interface between case management and self-care support were excluded; they could have had other data that may have added to the study. Study did not address the impact of organisational arrangements on the equity and efficiency of the service.		X	

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8	COOK, G., MCNALL, A., THOMPSON, J., HODGSON, P., SHAW, L. and COWIE, D.	2017	Integrated Working for Enhanced Health Care in English Nursing Homes.	Journal of Nursing Scholarship	49(1), pp. 15-23.	UK, Gateshead.	To explore the views and experiences of practitioners, social care officers and Carers involved in the enhanced health care in a care home programme.	Total: 35 [11 staff and managers from 16 care homes (where the model of integrated care is used); 27 NHS health care professionals & 7 social workers].	Qualitative – constructivist exploration	Interviews	This study outlines a model of IHSC delivery that appears to have been successful in areas where there is a shared culture of joined-up working, across organisations and professional boundaries. This model provides a whole system approach to integration, with key personnel who coordinate care and promotes cross-professional communication and problem-solving.	Effective, resident-centred outcomes were achieved by enhancing health care in nursing homes programme, in situations where there is a shared culture of working together across organizational and professional boundaries.	All staff in the care home were not included in data collection, due to time scale of the study. No description of 'multi-professional' sample; reported details of the sample were limited.		**X**	

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9	CRAIG, S., FRANKFORD, R., ALLAN, K., WILLIAMS, C., SCHWARTZ, C., YAWORSKI, A., JANZ, G. and MALEK-SANIEE, S.	2016	Self-reported patient psychosocial needs in integrated primary health care: A role for social work in interdisciplinary teams	Social work in health care	55(1), pp. 41-60.	Canada (urban).	To examine and review the critical factors in psychosocial needs of Service Users integrated Health & Social Care, as self-reported by Service Users.	Total: 100 [new Service Users who had been referred to the social worker in a Primary Care Team].	Quantitative – exploratory examination	Cross-Sectional survey	Anxiety and/or depression are the most common psychosocial need self-reported in this paper and influenced priorities for Service User access to social workers within the Primary Care Teams. Family and work relationships, poor health status and social support, and impaired task cognition were found to be significant contributors to anxiety and or depression in this study.	Provides further evidence that primary care patients frequently present with significant mental health, relational and stress-related challenges. Anxiety and depression were associated with poor social relationships, compromised health status and underdeveloped problem-solving skills.	Sample was limited to new Service Users who were scheduled to see a Social Worker in primary care, limiting the transferability of findings. This study used cross-sectional data; therefore, causality cannot be inferred. Anxiety and depression were not measured separately.	X	X	X

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10	CURRY, N., HARRIS, M., GUNN, L.H., PAPPAS, Y., BLUNT, I., SOLJAK, M., MASTELLOS, N., HOLDER, H., SMITH, J., MAJEED, A., IGNATOWICZ, A., GREAVES, F., BELSI, A., COSTIN-DAVIS, N., NIELSEN, J.D.J., GREENFIELD, G., CECIL, E., PATTERSON, S., CAR, J. and BARDSLEY, M.	2013	Integrated care pilot in north-west London: a mixed methods evaluation.	International Journal of Integrated Care	13, e027	UK, London.	To evaluate the introduction of a pilot integrated care delivery (across hospital, community, mental health and social care) in North-west London locality of the UK.	Semi-structured interviews (n=37) with senior leaders & GP (n=11); 4 focus groups with care professionals & managers (participant n=?); health professionals survey (n=51); Service User survey (n=405). Healthcare statistical harvesting of integrated care intervention Service Users (n=1236) & control group (n=5963).	Mixed Methods – evaluation and observation of pilot study	Multi-method: Interviews, focus groups, observation; survey & comparative healthcare statistical analysis	Service users in this study felt more involved in their care if they have an integrated care plan in place and a high proportion of Service Users felt they had better opportunities to develop a better relationship with their general practitioner during this pilot study and some felt that they were more involved in decisions about their care, if they had a care plan in place. Emergency admissions to hospital were not reduced in the Integrated Care Pilot intervention group.	Offers some insight into the components required for integrated care and the impact it can have on health outcomes and patient experiences. Mixed method approach to evaluating the study offered contextual under-standing of how the intervention was shaped.	The inclusive nature of the pilot had a tendency to make decision-making unclear. Care plans were not always completed consistently.	X	X	X

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11	DAVESON, B.A., HARDING, R., SHIPMAN, C., MASON, B.L., EPIPHANIOU, E., HIGGINSON, I.J., ELLIS-SMITH, C., HENSON, L., MUNDAY, D., NANTON, V., DALE, J.R., BOYD, K., WORTH, A., BARCLAY, S., DONALDSON, A. and MURRAY, S.	2014	The Real-World Problem of Care Coordination: A Longitudinal Qualitative Study with Patients Living with Advanced Progressive Illness and Their Unpaid Caregivers.	Plos One	9(5), pp. e95523.	UK, Scotland & England.	To understand the perspective of people living with advanced progressive illness and their caregivers, in relation to care coordination, and develop a model of care coordination.	Total: 83 [56 Service Users & 27 linked unpaid caregivers; 29 Service Users interviewed alone, 27 unpaid Carer dyads; 90 Service User interviews & 60 unpaid Carer interviews (either alone or with the Service User) over the series].	Qualitative – longitudinal multi-perspective case study	Participant-led semi-structured interviews	The relationships that Service Users and their unpaid Carers in this study had with professional staff appeared to influence their experiences. Relationships that professional staff have with other professional staff; communication/information exchange, appears to impact upon the integrated coordinated care experiences of Service Users and their unpaid Carers. In addition, the structural transparency and the way in which that structure works for the Service User and their unpaid caregiver appeared to influence the Service User's experiences of integrated coordinated care.	The multi-perspective, longitudinal qualitative nature of the study resulted in an empirically derived model of care coordination. Quality indicators were embedded into the study design. Detailed investigation of contextual factors due to case study design.	There was a lack of observational data which could have reduced the trust-worthiness of the study. Loss of data during inductive thematic analysis was acknowledged by researchers as probable.		X	X

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12	ELBOURNE, H.F. and LE MAY, A.	2015	Crafting intermediate care: one team's journey towards integration and innovation.	Journal of Research in Nursing	20(1), pp. 56-71.	The UK, suburban setting.	To explore how a Person-Centred Intermediate Care team developed and how effective it was.	Total: 106 [Staff (n=12) across varying agencies; Service Users (n=94) admitted to the Intermediate Care (IC) unit for in-Service User (step-up or step-down).	Mixed Methods – case study	Multi-method: Semi-structured interviews & descriptive statistical	Service users largely appeared satisfied with their care at the Person-Centred Intermediatory Care Centre (PCIC). Care outcomes around functionality appeared to be positively influenced (increased functionality) for Service Users who accessed this intermediate service and a high proportion of Service Users who accessed the PCIC model could be discharged to their own home.	This model of care resulted in service users' improved functionally, discharge home and satisfaction with the service. The use of a mixed-methods design exposed convergent and divergent findings and to explain why these occurred.	Details of the data collection interval were lacking with further detail required on which 12 months (during the first two years of operation) the data were collected in. Some methods are unclear (e.g. questionnaire use for data collection and application to findings).	X	X	

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13	HAMMAR, T., PERÄLÄ, M. and RISSANEN, P.	2007	The effects of integrated home care and discharge practice on functional ability and health-related quality of life: a cluster-randomised trial among home care patients.	International Journal of Integrated Care	7, pp. e29.	Finland.	Evaluation of the effects of a particular model of integrated care and discharge practice and consider the impact (as viewed by the Service User) of integrated care, on functionality and quality of life, for older people.	Total: 669 Service Users [integrated care intervention (n=354), control (n=314) over 22 municipalities].	Quantitative – cluster randomised trial	Cluster comparison scoring	Service user perceptions of functionality appear reduced, despite their functionality score remaining the same (at 6 months; both groups), with Activities of Daily Living and quality of life appearing unaffected. Largely, improvement of quality of life and functionality was not noted as a result of the intervention (with the expectation of physical mobility at 3 weeks).	Background pilot study informed study development. Methodological issues clearly reported to offer contextual information when drawing conclusions.	The researchers guided and supported the personnel in developing the practices in the municipalities. Researcher involvement in this process may have weakened the objectivity of the study.	**X**		

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
14	HU, M.	2014	The impact of an integrated care service on Service Users: The Service Users' perspective.	Journal of Health Organization and Management	28(4), pp. 495-510.	UK, England, Cambridgeshire.	To explore the impact that integrated services, in the Cambridgeshire area, have had on Service Users.	Total: 127 Service Users.	Mixed Methods - evaluative	Questionnaire & semi-structured interviews	Integrated care had met some of the needs of some participants in the study area (these tend to be discipline specific, e.g. occupational therapy, rather than with relation to integrated services as a whole); however, a high proportion of Service User needs appear unmet.	Adds to wider body of evidence suggesting that when monetary and human resources are lacking, services were not always tailored to the needs of the people who were using them. Study findings highlight some unmet domestic needs around cleaning, shopping, gardening, nails care and home hairdressing.	Post-implementation non-comparative study design. Little exploration of one of the main findings that social care service user group experienced fewer positive outcomes and had a lower level of satisfaction than occupational health and physiotherapy user groups.	X	X	X

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
15	KEHUSMAA, S., AUTTI-RAMO, I., HELENIUS, H., HINKKA, K., VALASTE, M. and RISSANEN, P.	2012	Factors associated with the utilization and costs of health and social services in frail elderly patients.	Bmc Health Services Research	12, pp. 204.	Finland.	To develop an understanding of why people (elderly) are using health and social care in Finland, and the equitability of access to these services.	Total: 732 frail, elderly persons [from a variety of Health & Social Care settings, across 41 municipalities].	Quantitative – exploratory hierarchical analysis of multi-level variables	Randomised controlled trial	A clear link between the use of health and social care services appears to be evident in this study and access to social services appeared inequitable in the study areas; access to health services appears as more equitable. The administrative structure does not appear to ensure positive effects of integration and informal care and support appeared to be instrumental in supporting social care services around Service User functionality and financially.	Individualized data were obtained from a Randomised Controlled trial where data were collected form a variety of public and private sector Health & Social Care settings across a wide range of regional municipalities.	The results of this study cannot necessarily be generalised to apply to the aged population as a whole. Focus on measuring administrative integration, which may not be insufficient to describe the multi-dimensional phenomena of integration.	X		

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16	LEWIS, C., MOORE, Z., DOYLE, F., MARTIN, A., PATTON, D. and NUGENT, L.E.	2017	A community virtual ward model to support older persons with complex health care and social care needs.	Clinical Interventions in Aging	12, pp. 985-993.	Ireland, North Dublin.	To determine if an integrated Community Virtual Ward reduces presentation to the emergency department and hospital admissions.	Total: 54 [older people, over 65 years old].	Quantitative - observational	Descriptive statistical analysis	The Community Virtual Ward model of care within this study met some needs of older people who are at high risk of admission and ED presentation. Service users who were living with someone correlated with more presentations at the emergency department and hospital admissions.	The findings from this study are consistent with previous research and add further evidence to the benefits of a Community Virtual Ward model, from an observational perspective.	Small sample size, lack of comparison group and use of retrospective data. Healthcare related quality of life was not measured.	**X**	**X**	

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
17	MURPHY, F., HUGMAN, L., BOWEN, J., PARSELL, F., GABE-WALTERS, M., NEWSON, L. and JORDAN, S.	2017	Health benefits for health and social care clients attending an Integrated Health and Social Care day unit (IHSCDU): a before-and-after pilot study with a comparator group.	Health & Social Care in the Community	25(2), pp. 492-504.	UK, Wales	To establish if attending an integrated health & social care day centre affected functional mobility, the number of prescribed medications and physical/psychological wellbeing.	Total: 281 [Service users: intervention (n=207); comparator (n=74)].	Quantitative – comparison pilot study	Cohort comparison statistical analysis	Physical wellbeing appeared to improve, with input from the Integrated Day Centre (IDC), in the intervention arm while it declined in the comparator arm. Mental health appeared to reduce less quickly for those attending an IDC, in the intervention arm.	Comparator arm well matched with relation to geographical location. Interventions were individualised to the needs for the people who were accessing the intervention service. Use of the SF-12® standardised assessments for intervention and comparison arms.	Comparator group was not matched in age, functional mobility and mental wellbeing. Study designed as a single site, exploratory study of volunteers and thus, findings might not be generalisable to other settings. Interventions were not standardised.	X	X	

18	PETCH, A., COOK, A. and MILLER, E.	2013	Partnership working and outcomes: do health and social care partnerships deliver for users and Carers?	Health & Social Care in the Community	21(6), pp. 623-633.	UK, England & Scotland	To explore whether integrated health & social Care partnerships (HSCPs) are delivering the outcomes that are important to people who access them and develop an effectiveness tool from the interview schedule.	Total: 20 [Service Users].	Qualitative – exploratory development and pilot	Semi-structured interviews	Participants have highlighted team working within their services as a key element of access, sharing information, communication, and social & emotional, physical and mental health wellbeing. Relationships with others were highlighted as participant need and also as a feature of partnership working. Participants experienced safety, both emotional and physical, knowing help was on-hand form their health and social care partnership.	Study included Service User participants from three user-led organisations, Service User Research Enterprise, Central England People First and Older People Researching Social Issues. Developing a robust and accessible framework summarising the outcomes important to people using services is an important output of this project. Indices of partnership working also identified.	Study relied on service providers to recruit interviewees, which could have led to bias in selection of participants. Having a theory of change, upon which to base the research would have strengthened the study. Staff perspectives on perceived effects on aspects of partnership such as cultural integration and improved communication could have contributed to a fuller picture, particularly if related to a theory of change.	X	X	X

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
19	SPIERS, G., ASPINAL, F., BERNARD, S. and PARKER, G.	2015	What outcomes are important to people with long-term neurological conditions using IHSC?	Health & Social Care in the Community	23(5), pp. 559-568.	UK	To identify health & wellbeing outcomes that are important to people who have a long-term neurological condition.	Total: 35 people with a long-term neurological condition [across 5 Neuro-Rehabilitation integrated teams (NRT's) site; more than half of whom had Multiple Sclerosis].	Qualitative – multi-case study	Semi-structured interviews	Participants identified three domains of outcomes that are important to people with long-term neurological conditions: namely, personal comfort, economic and social participation, and autonomy outcomes. Service user-derived outcomes appear to contribute to assessing the effectiveness of health and social care integration in this study.	Outcomes were observed by Service User research participants and 're-written' in accordance with their own perceptions of what was important to *them* (rather than outcomes that had been identified through previous research).	Target recruitment number were not met (n=40), with 36 being successfully recruited. Sample diversity was challenging. Underrepresentation for ethnic minorities, sample skewed to those with MS (as opposed to other neurological conditions).	X	X	X

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
20	PETERS, M., FITZPATRICK, R., DOLL, H., PLAYFOLD, E.D., JENKINSON, C.	2013	Patients' experiences of health and social care in long-term neurological conditions in England: a cross-Sectional survey	Journal of Health Services Research and Policy	18(1), PP.28-33.	UK	To assess the experiences of Service Users with a long-term neurological condition, with relation to health and social care.	Total: 2563 Service User members of leading 3rd sector charities [Multiple Sclerosis Society (n= 1157); Motor-Neuron Disease Association (n=505); Parkinson's UK (n=901).	Quantitative	Cross-Sectional survey	A mixed picture of experiences is presented in results and many problems, with IHSC, being reported by participants. People with Multiple Sclerosis appeared to be more likely to report problems with their integrated care; however, people with MS appeared to be over-represented in the overall results.	Large sample size. Diversity of experiences is evident. Findings highlight the difficulties in developing generic services. Patient experience is highlighted as an important measure in driving forward service improvement.	It is not possible to know how the sample in this study differs from the overall population. 49% response rate, meaning caution should be exercised when interpreting the results.		**X**	**X**

Addendum – Paper 21 - September 2021

	Author(s)	Year	Title	Journal	Vol./No/Page	Country	Study Aim(s)	Sample (N=) Characteristics	Study Design	Data Collection	Key message(s)	Strengths	Limitations	Wellbeing through IHSC	Co-production in IHSC	Relationships
21	BREDEWOLD,F., VERPLANKE, L., KAMPEN, T., TONKENS, E., DUYVENDAK, J.W.	2019	The care receiver's perspective: How care-dependent people struggle with accepting help from family members, friends and neighbours.	Health and Social Care in the Community	28, pp.762– 770.	Netherlands: 6 Dutch cities	To determine to what extent Dutch care-dependent people want to rely on social network members and what reasons they raise for accepting or refusing in-formal care.	Total: n=65 'kitchen table talks' (where social workers assessed citizens' care needs and examined to what extent relatives/friends/ neighbours provided help and care). Also, interviewed n=50 professionals and n=30 people in need of care.	Quantitative	Observation & interviews	Informal care was given in 46 out of 65 cases, especially between people who have a close emotional bond. People who needed care found it difficult to ask for it from friends, family and neighbours; they did not want to over burden them and felt ashamed of becoming dependent.	Triangulation of data through multi-methods of data collection. General findings, in particular the conclusion that every relationship has its own balance of giving and receiving which people tend to live up to, concur with previous research.	Small sample size of n=65, meaning firm conclusions that are transferable to the wider population cannot be drawn. Data collected in city locations only, and care givers were not included in data collection.	X		X

Appendix 2 Service delivery models

	Author(s)	Yr	Title	Journal Name	Journal Vol./No./pages	Country	Integrated Health & Social Care Model/Structure
1	BAUMANN, M., EVANS, S., PERKINS, M., CURTIS, L., NETTEN, A., FERNANDEZ, J. and HUXLEY, P.	2007	Organisation and features of hospital, intermediate care and social services in English sites with low rates of delayed discharge.	Health & Social Care in the Community	15(4), pp. 295-305.	UK, England, 4x southern (1 London) & 2 northern metropolis.	Outlines how people access integrated health & social care via hospital, intermediate services and primary care trusts (within 4 sites in England) when their discharge from acute hospital services has been delayed.
2	BIEN, B., MCKEE, K.J., DOEHNER, H., TRIANTAFILLOU, J., LAMURA, G., DOROSZKIEWICZ, H., KREVERS, B. and KOFAHL, C.	2013	Disabled older people's use of health and social care services and their unmet care needs in six European countries.	European journal of public health	23(6), pp. 1032-1038.	Germany, Greece, Italy, Poland, UK & Sweden.	Outlines distinctive health and social services for 'disabled' older people by highlighting the range of different professional services used in each nation and the number of areas of unmet needs that correspond to the range of integrated professionals delivering care; reduced use of social services corresponds with higher unmet needs.
3	BJERKAN, J., RICHTER, M., GRIMSMO, A., HELLESO, R. and BRENDER, J.	2011	Integrated care in Norway: the state of affairs years after regulation by law.	International Journal of Integrated Care	11	Norway	Norwegian government legislative approach: Individual Care Plans, as a model of collaborative integrated working in health, social care and beyond to other public services (e.g. teaching etc.) and is mandatory for all service providers equally throughout Norwegian municipalities.
4	BONCIANI, M., BARSANTI, S. and MURANTE, A.M.	2017	Is the co-location of GPs in primary care centres associated with a higher patient satisfaction? Evidence from a population survey in Italy.	BMC Health Services Research	17, pp. 248.	Italy, Tuscany.	Co-location of general practitioners and wider multi-agency team within a Primary Care Centre.

	Author(s)	Yr	Title	Journal Name	Journal Vol./No./pages	Country	Integrated Health & Social Care Model/Structure
5	BOUDIONI, M., HALLETT, N., LORA, C.R. and COUCHMAN, W.	2015	More than what the eye can see: the emotional journey and experience of powerlessness of integrated care Service Users and their Carers.	Patient Preference and Adherence	9, pp. 529-540.	UK, England, London.	Integrated care system of health and social care that includes primary care, community matrons, social workers and the voluntary sector; designed to respond to identified cases of high-risk individuals with long-term, multiple and age-related conditions who needed preventive interventions.
6	BROWN, H. and HOWLETT, F.	2017	A critical evaluation of the "short stay project" - Service Users' perspectives.	Housing Care and Support	20(2), pp. 71-84.	UK, Rotherham	Outlines intermediate access to IHSC services within a community setting, housed in local authority housing environment with generic environmental adaptations, supported by referring professional and the Enabling Team.
7	CHALLIS, D., HUGHES, J., BERZINS, K., REILLY, S., ABELL, J., STEWART, K. and BOWNS, I.	2011	Implementation of case management in long-term conditions in England: survey and case studies.	Journal of health services research & policy	16, pp. 8-13.	UK, England-wide.	Case management model with personal care plans and self-care support services, for people with a long-term condition. Includes elements of integrated working between Primary Care Trusts and local authority social care services, although no widespread.
8	COOK, G., MCNALL, A., THOMPSON, J., HODGSON, P., SHAW, L. and COWIE, D.	2017	Integrated Working for Enhanced Health Care in English Nursing Homes.	Journal of Nursing Scholarship	49(1), pp. 15-23.	UK, Gateshead.	Outlines a multi-sector whole-system approach to integrated care in the Gateshead Care Home Programme (enhanced healthcare in care homes with nursing beds) and explores multi-professional working, with link GP's, nursing home team and the Older Peoples Specialist Nurse being key practitioners.

	Author(s)	Yr	Title	Journal Name	Journal Vol./No./pages	Country	Integrated Health & Social Care Model/Structure
9	CRAIG, S., FRANKFORD, R., ALLAN, K., WILLIAMS, C., SCHWARTZ, C., YAWORSKI, A., JANZ, G. and MALEK-SANIEE, S.	2016	Self-reported patient psychosocial needs in integrated primary health care: A role for social work in interdisciplinary teams	Social work in health care	55(1), pp. 41-60.	Canada (urban).	Interdisciplinary Primary Health Teams that include social workers, physicians, nurse practitioners, pharmacists and dieticians, all based in one physical location or through a 'hub'.
10	CURRY, N., HARRIS, M., GUNN, L.H., PAPPAS, Y., BLUNT, I., SOLJAK, M., MASTELLOS, N., HOLDER, H., SMITH, J., MAJEED, A., IGNATOWICZ, A., GREAVES, F., BELSI, A., COSTIN-DAVIS, N., NIELSEN, J.D.J., GREENFIELD, G., CECIL, E., PATTERSON, S., CAR, J. and BARDSLEY, M.	2013	Integrated care pilot in north-west London: a mixed methods evaluation.	International Journal of Integrated Care	13, e027.	UK, London.	Model of integrated care pilot North-West London that includes primary and secondary healthcare providers, social care providers, mental health providers and non-government organisations who work collaboratively in the Integrated Management Board to coordinate care, through operational and multi-disciplinary groups.

	Author(s)	Yr	Title	Journal Name	Journal Vol./No./pages	Country	Integrated Health & Social Care Model/Structure
11	DAVESON, B.A., HARDING, R., SHIPMAN, C., MASON, B.L., EPIPHANIOU, E., HIGGINSON, I.J., ELLIS-SMITH, C., HENSON, L., MUNDAY, D., NANTON, V., DALE, J.R., BOYD, K., WORTH, A., BARCLAY, S., DONALDSON, A. and MURRAY, S.	2014	The Real-World Problem of Care Coordination: A Longitudinal Qualitative Study with Patients Living with Advanced Progressive Illness and Their Unpaid Caregivers.	Plos One	9(5), pp. e95523.	UK, Scotland & England.	Care coordination model for partnership working across health and social care is generated using the data from the study, encompassing influential factors in coordinated working: clinical; resourcing; views on entitlement; relationships and systematic clarity and function.
12	ELBOURNE, H.F. and LE MAY, A.	2015	Crafting intermediate care: one team's journey towards integration and innovation.	Journal of Research in Nursing	20(1), pp. 56-71.	UK, suburban setting.	Intermediate care delivered by health and social care services in conjunction with a third sector charity for step-down/up care and rehabilitation; offered within a 20 bedded unit that encompasses a variety of living environments (independent, warden assisted or rehabilitation beds), to promote early discharge or prevent hospital admission.
13	HAMMAR, T., PERÄLÄ, M. and RISSANEN, P.	2007	The effects of integrated home care and discharge practice on functional ability and health-related quality of life: a cluster-randomised trial among home care patients.	International Journal of Integrated Care	7, pp. e29.	Finland.	Integrated health and social care encompassing multi-professional teamwork, with the addition of a ‘paired case manager’ consisting of two different professionals (one health and one social care) who coordinate and manage integrated care for each patient jointly.

	Author(s)	Yr	Title	Journal Name	Journal Vol./No./pages	Country	Integrated Health & Social Care Model/Structure
14	HU, M.	2014	The impact of an integrated care service on Service Users: The Service Users' perspective.	Journal of Health Organization and Management	28(4), pp. 495-510.	UK, England, Cambridgeshire.	Unified care system that is delivered by integrated locality teams, consisting of health and social care staff (Community Nursing, therapies, social care and intermediate services) that uses a single key-worker model to guide care.
15	KEHUSMAA, S., AUTTI-RAMO, I., HELENIUS, H., HINKKA, K., VALASTE, M. and RISSANEN, P.	2012	Factors associated with the utilization and costs of health and social services in frail elderly patients.	Bmc Health Services Research	12, pp. 204.	Finland.	Municipality model of health and social care in use within Finland which promotes autonomy and can lead to fragmentation of services; these are instrumental in universal access and variation in the way in which municipals deliver their services.
16	LEWIS, C., MOORE, Z., DOYLE, F., MARTIN, A., PATTON, D. and NUGENT, L.E.	2017	A community virtual ward model to support older persons with complex health care and social care needs.	Clinical Interventions in Aging	12, pp. 985-993.	Ireland, North Dublin.	Community Virtual Wards that consist of an integrated team, with a nursing Clinical Case Manager appointed to oversee, connect and coordinate services; direct access to integrated team (wider integrated team consists of GP, Public Health Nurse, Occupational Therapist, Physio Therapist, Social Worker and Pharmacist) and the day hospital, for rehabilitation services.
17	MURPHY, F., HUGMAN, L., BOWEN, J., PARSELL, F., GABE-WALTERS, M., NEWSON, L. and JORDAN, S.	2017	Health benefits for HSC clients attending an Integrated Health and Social Care day unit (IHSCDU): a before-and-after pilot study with a comparator group.	Health & Social Care in the Community	25(2), pp. 492-504.	UK, Wales	Day centre unit that provides single-location IHSC interventions to out-patients and includes assessment, individualised tailored programmes of treatment, coordination of care within a multi-professional team, nutritional support, and activities to combat social isolation.

	Author(s)	Yr	Title	Journal Name	Journal Vol./No./pages	Country	Integrated Health & Social Care Model/Structure
18	PETCH, A., COOK, A. and MILLER, E.	2013	Partnership working and outcomes: do health and social care partnerships deliver for users and Carers?	Health & Social Care in the Community	21(6), pp. 623-633.	UK, England & Scotland	Services operating as a 'mainstream' partnership (partnership agreement in place) involving health and social care as lead organisation, with regular routine contact between professionals (who fulfil differing roles to meet the needs of individuals and are accountable to health & local authority); shared mission, objectives, assessment/consultation and information systems with a single point of entry and joint management, planning and pooled/aligned budgets.
19	SPIERS, G., ASPINAL, F., BERNARD, S. and PARKER, G.	2015	What outcomes are important to people with long-term neurological conditions using IHSC?	Health & Social Care in the Community	23(5), pp. 559-568.	UK	Neurological Rehabilitation Team's that adopt a joint working arrangement with social, secondary care and a multi-disciplinary team (both formal and informal agreements).
20	PETERS, M., FITZPATRICK, R., DOLL, H., PLAYFOLD, E.D., JENKINSON, C.	2013	Patients' experiences of health and social care in long-term neurological conditions in England: a cross-Sectional survey	Journal of Health Services Research and Policy	18(1), PP.28-33.	UK	Integrated health & social care model is not outlined/defined within this study. (Table continues on next page

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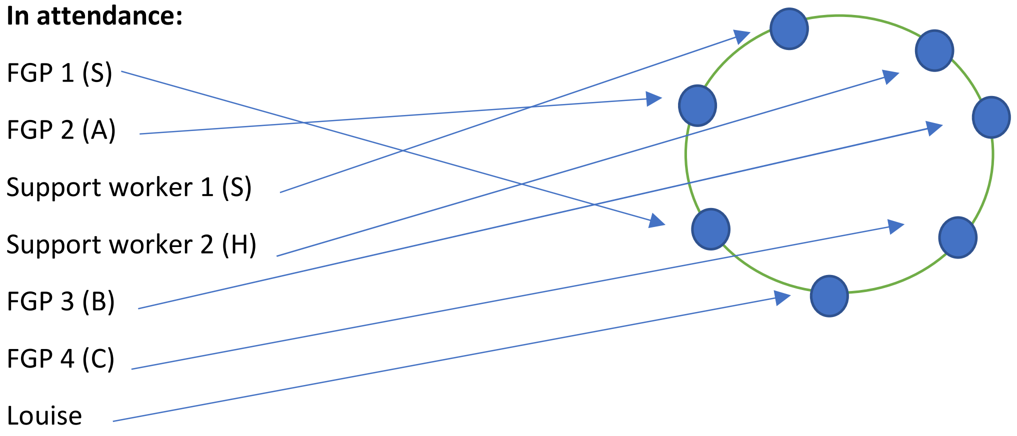
21	BREDEWOLD,F., VERPLANKE, L., KAMPEN, T., TONKENS, E., DUYVENDAK, J.W.	2019	The care receiver’s perspective: How care-dependent people struggle with accepting help from family members, friends and neighbours.	Health and Social Care in the Community	28, pp.762– 770 .	Netherlands	Social District Teams are the first point of contact for people in the community who require health and wellbeing support. These teams include multiple HSC professionals across HSC sectors, but social workers lead initial ‘kitchen table talks’ with the Service Users and Informal Carers about support that is required.

Appendix 3 Patient and Public Involvement group feedback

In attendance:



Key: Concepts from the literature

Teal: Clarity

Yellow highlight: Communication

Brown: Systems

Orange: Needs

<u>Suggestions for content of study</u>

- "Are you clear on the meaning of terminology around 'integration'?"
- "How far does integration go?" [how integrated are the services you receive]
- "What is integration, and did you know it was happening?"
- "Have you noticed a change in your health & social care (HSC) since it was integrated; if so, what are the differences?"
- "Do your care professionals know that they are integrated?"
- "About equality of service provision - postcode lottery?"
- "Do you know what is available [services] and do you know how the 'system' works?"

- “**What do you need?”**
  - Discussion turns towards what is needed to maintain health and wellbeing:

“Need to have clarity and system knowledge. Need good communication.”
“Succession planning [is it happening]. When my social worker left, I was never told who I could contact after that.”
“Clarity around integration” [is it required].
“Simplification of the processes involved with delivery”
“A ‘leader’ who coordinates my care; a single point of contact [identified by all members] who can signpost to necessary services required to meet my needs”.
“Do the HSC professionals know they are integrated?”
“What do/would you **want from integrated HSC**?”

- Discussion turns towards the group's experiences of integrated HSC:

“Financial information only, from social workers. Should they not be putting us in contact with others who can help and setting us up with other services?”
“Provisions for absences - **Carers are cancelled last minute and I have to try and do things on my own; I don’t have family to help**.”
“Good lines of communication. Making it clear about services that are out there that I can use.

- **“What does health and wellbeing mean to people [Service Users and their families]?”**
  - Discussion turns towards what group members feel health and wellbeing is:

“Happy” [relating to emotional/psychological wellbeing].
“**Equality at work** – no discrimination because of my disability. I need a job to do; I need to do something, I’m young!” [approx. age 50]
“I need to feel like I am **doing something, not wasting away**; a purpose… a reason to get out of bed and do something. I need a purpose and to feel fulfilled.”
“**I need to contribute**” [to community/society]; I need support from the HSC professionals to do this [referring to the above comment]. It’s frustrating that I can’t do it on my own or that I can’t contribute in the ways I used to. The third sector charities are very helpful… they have done so much to support me with this [referring to the above comment again].”

Appendix 4 Regional HSC staff group feedback

Key: Concepts from the literature	
Red: Relationships	**Orange:** Needs
Yellow highlight: Communication	Blue: Patient voice
Green: Equipment	Purple: Experience
Grey: family Carer involvement	

Stakeholders Present	Clinical NMAHP staff
	3rd Sector volunteers
	Chief Officers for Health & Social Care Partnerships (HSCPs)
	Local Research & Development
	Louise Henderson
	Health care assistant staff
	Non-executive Board members
	NMAHP Director
	Nursing & AHP Clinical Professors
Presentation	Given by Louise Henderson. File location: (R:\R-PHD-LH-0916091\0. Study Site File\1. Study Master File\1.11 Miscellaneous\Dissemination\Presentations\2018\NMAHP Excellence Event- OCT),
Feedback method	Delegates invited to feedback to Louise during break time and via post-it notes provided (due to time constraints).
Questions raised:	"How important is it for Service Users to be able to form a relationship with the Health & Social Care (HSC) team? Do you see the same folk all the time?"
	"Have you been given the opportunity to ask all the questions you have; and if so, have they been answered?" Communication
	"Do family Carers **feel involved** as they would like to be in care for their relative?" **(EMPOWERMENT &** Experience)
	"Are **family Carers** as involved as they would like to be with decisions about the person they care for?"
	"Have **expectations of treatment** and estimates of timescales been made clear?" **(meeting needs** & experience)
	"To what extent has the care or treatment you receive been explained to you?"
	"How happy are Service Users with the information about your situation/needs are shared among the team involved in your care?"
	"Do appointment time/venues impact on your experience in receiving care?"
	"How has your experience of communication (letters, email, meetings, texts) before, during and after your treatment been; was it clear and understandable? What about staff experiences of communication too?"
	"Have you been shown how to manage your illness /condition to keep you as well as possible?"
	"For treatment in NHS buildings/council buildings, are there sufficient **toilets/access to refreshments; is signage sufficient**?"
	"As a patient of a Carer do you **feel listened to**?" [Delegate has drawn picture of an ear and someone speaking into it].

	"What do **people want from their HSC**?" "Do people know what their **health and wellbeing needs** are and how to define them? If they do, how do they know?"
Open feedback	"How did *we* come up with **the health and wellbeing needs** from the government?" "Sounds like you have really thought this through, and the ultimate goal is improving services for the Service User and their family" "Really timely study; I will be looking out for the results". "I wasn't aware **that housework** was that important to Service Users… I assume that family would be picking it up for them." "It's amazing how all the different elements of your study [literature review] are actually linked to one another… I think Service Users will benefit greatly …I think they [Service Users and Carers] need to be more involved in decision making and that we need to help them to do that". "I hadn't thought **about equipment for patients to be able to meet friends** in the community and that. I think there's an assumption that they won't want to work either". "Relationships with Service Users and their family can be difficult; It's funny how that has come out on the project [literature review]; that the relationships are really important to them, even with the staff that look after them".

Appendix 5 Social media advert

Would you like to take part in a research study about Integrated Health & Social Care?

Interested? If the answer is yes to any of the below questions, we would like to hear from you…

- Do you access Integrated Health & Social Care services regularly in [redacted]
- Do you help someone at home that accesses Integrated Health & Social Care services regularly in [redacted]
- Are you an Integrated Health & Social Care member of staff in [redacted]

If you would like to join our **research study about your experiences of Integrated Health & Social Care**, please contact:

Louise Henderson
Louise is a Registered General Nurse and District Nurse, who works as a Lecturer & PhD Student at Robert Gordon University.

@Lou_Henderson2
☎ 01224 263157
✉ l.c.Henderson@rgu.ac.uk

V2- Social Media Advert
18-09-2019 LH
IRAS ID: 247771

Appendix 6 Letter of invitation

Dear Sir/Madam,

We are a team of researchers from RGU and [redacted]. We are writing to ask if you would like to take part in a research study that we are doing with [redacted] and Robert Gordon University (RGU). We want to find out more about the experiences and needs of people who access Integrated Health and Social Care (HSC) and about the experiences of the people who help them (informal Carers and HSC staff).

We would like to speak to people across all areas of the [redacted] region. We are doing this study because it is important to understand the experiences and needs of the people who access and deliver HSC to help further develop health and social care services in the future. The attached leaflets tell you more about the study.

- If you **are someone who accesses HSC services**, you should read the

  ‘Service User - Participant Information Sheet’.

- If you ***help*** someone who accesses HSC, you should open the

  ‘Informal Carer_HSC Staff - Participant Information Sheet’.

We would like to thank you for considering this invitation to take part in our study. If you have any further questions or if you would like to take part in this study you can contact us via email, telephone or in person. Please contact one of the researchers, Louise Henderson, using the contact details above.

Yours faithfully,

Louise Henderson

Louise Henderson, on behalf of the research team.

Appendix 7 Service User Participant - Information Sheet

1. Study title and Chief Investigator

Title

A case study of Service User, informal Carer and staff experiences of Integrated Health and Social Care

Chief investigator

[redacted]

Research Team

Louise Henderson (PhD student), [redacted]

2. Invitation

You are being invited to take part in a research study. Before you decide if you would like to be involved, it is important for you 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, such as your health and social care workers and your relatives, if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether you wish to take part. Thank you for reading this.

3. What is the purpose of the study?

This research study looks to explore and understand your experiences of using Integrated Health and Social Care (HSC) to help us develop HSC services in the future. In addition, we would also like to invite two people who contribute to your care to talk to us. For example, one could be a family friend, an unpaid Carer or a relative.

The other person should be an HSC worker who helps you at home. This could be a healthcare worker, a paid Carer, a social worker, or a charity worker. We would like to collect information about experiences of HSC through a conversation which should take around one hour in a place that is convenient for you.

4. Why have I been chosen?

You have been invited to take part in this study because you access HSC services. We hope that six people from across the local region, will take part in our study and that each of these six people will identify two people that help them at home and will also take part in the study (with one being an HSC worker).

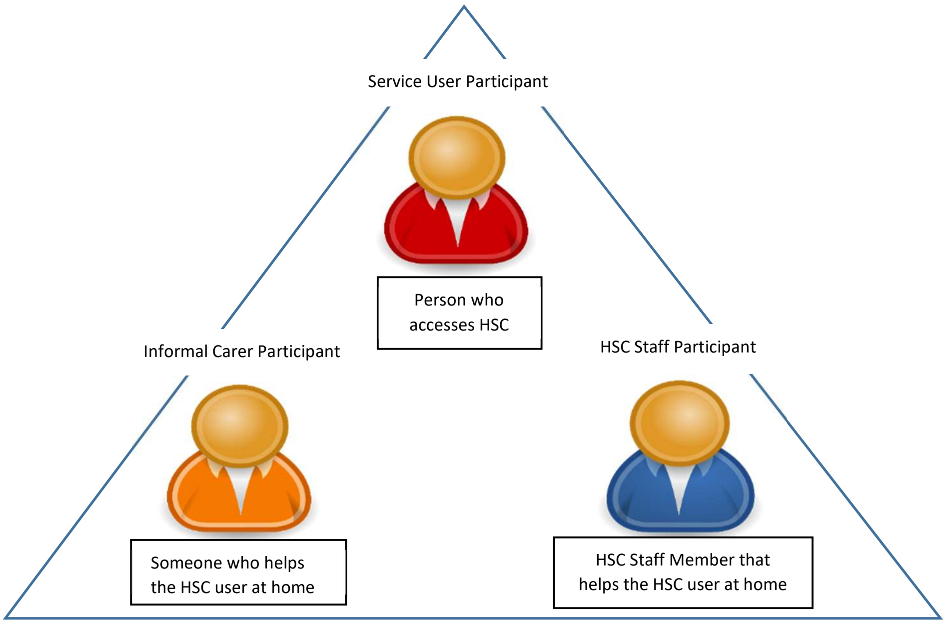
5. Do I have to take part?

It is up to you to decide whether to take part or not. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. If you decide to withdraw at any time, or you decide not to take part, it will not affect the standard of care you or any other participants receive.

6. What will happen to me if I take part?

If you choose to take part in this study, you will be the 'Service User participant' as we wish to hear about your experiences of HSC. We will ask you to identify two people who contribute to your care experiences of HSC. One person could be a relative, a family friend or an unpaid Carer. The second person should be an HSC worker (e.g. a healthcare worker, a paid Carer, a social worker, or a charity worker).

We will contact the two people you identify to invite them to join the study with you. You do not need to arrange this, but you may wish you discuss the study with those people before we make contact with them. Their acceptance decline or withdrawal from the study at any point will not stop you from taking part in the study and it will not affect the standards of care that you receive.



A suitable time, date and place will be agreed to meet with you. Louise Henderson (one of the researchers) will meet with you to have a conversation about your experiences of HSC. She will ask some questions that may help you to explore and describe your experiences of HSC. You can ask questions at any point before, after or during your conversation with her. You can choose how you would like the conversations (about your experiences) to take place. There are three options available:

i. You can choose to meet Louise on a one-to-one basis, with the two people who help you being seen on a one-to-one basis too.

or

ii. You can choose to meet Louise with *one* of the people who helps you; for example, you and a family member, friend or HSC worker. The second person that helps you could be interviewed on a one-to-one basis.

or

iii. You can choose to meet Louise with *both* people who help you, for example, with a family friend and an HSC worker.

Individual interviews will last for around one hour; group interviews may last up to two hours. When you meet Louise, the conversation that you have with her will be voice recorded with a small digital voice recorder. Your recording will be stored in a password-protected file on Louise's password-protected computer, at Robert Gordon University. Louise will use the voice file to listen to your recording and the words that you have said will be typed onto an electronic document.

We, the research team, do not anticipate a need to contact you again in the future to take part in any further research for this study. However, we may need to contact you by telephone to confirm your meaning or words, should the voice recorder not be clear at the time of listening to the recording. We are the only people who will access your recording and your recording will not be used for any other research study or purpose.

Once the study is complete, we will delete your recording. If you wish to withdraw from this study at any point, data collected up until the point that you withdraw may still be used in the analysis. Should you divulge any information that could put you or others at risk, we have a duty to protect you, along with children, vulnerable adults, and the public. If this happened, we would inform you of our intent to report this to the appropriate organisation and/or authorities.

7. What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages, but should you become upset for any reason when recalling your experiences of HSC, we will ensure that you have access to appropriate support and signpost you to someone who can help you.

8. What are the possible benefits of taking part?

If you take part in this study, there is no intended clinical benefit. The information we get from this study may help us to make HSC services better for the people who access them.

9. What if something goes wrong?

If you have a concern about any aspect of this study, you should contact us, and we will do our best to address these [Louise Henderson; Tel. 01224 263157]. If you would like to speak to someone from Robert Gordon University that is not involved in the study, [redacted] would be happy to discuss any concerns [[redacted]].

If you remain unhappy and wish to complain formally, you can do this by following the Robert Gordon University Public Complaint's Procedure. If you would like help to make a complaint, you can access guidance on making a complaint by clicking here: Guide to the Complaint Handling Procedure for Members of the Public (PDF 47KB) or by accessing the following website: https://www3.rgu.ac.uk/footer/complaints/complaints.

You can make a complaint by email [complaints@rgu.ac.uk], on the telephone [01224 262195], or in a letter to:

[redacted]
Assistant Chief Academic Officer and Secretary to the Board
The Robert Gordon University
Garthdee House
Garthdee Road
Aberdeen AB10 7QB

10. Will my taking part in this study be kept confidential?

If you decide to take part in this study, you will need to give us permission to use and store the information collected about you. All reasonable efforts will be made to ensure that information collected about you is kept in **strict confidence** at Robert Gordon University.

We will store two types of information about you:

i. Information that can identify you personally (personal details).
ii. Information that you have given us in the course of our conversation about your experiences that does not have your personal details on it (anonymised).

Your information will be stored in password-protected secure electronic files. Only the research team will have the secure password to access your electronic files. These electronic files will be kept in a secure folder that is dedicated to this research, on the Robert Gordon University secure server.

Your information will also be stored in a paper file. The paper file will be kept in a locked cabinet that is dedicated to this research study. We, the research team, are the only people who have access to the key for the locked cabinet. The cabinet is located in a locked room within Robert Gordon University.

Any information that can identify you will be kept separately from your information that has been anonymised. Any information about your experiences of HSC that leaves the University will have your name and address removed (it will be anonymised).

11. What will happen to the findings of the research study?

Findings from the information that you have given us for this study will be published. Information that will identify you or link you to the information about your experiences, will *not* be published. The results of this study will be published in the PhD Thesis of the PhD student who is involved in this study (Louise Henderson). They will also be published in relevant health and social care journal(s). Results are likely to be published in 2020-2021 and a summary of these results can be sent to you upon completion of the study.

12. Who is organising and funding the research?

This research is a joint study between Robert Gordon University, [redacted] and the Research Team that aims to put people who use HSC services at the centre of the project.

Funding for this research study has been awarded by [redacted], in the form of a stipend for a PhD student. Robert Gordon University have sponsored the educational fees of the PhD. Louise Henderson is the PhD student; [redacted] are supervising Louise and this research study.

13. Who has reviewed the study?

The Vice Principals Office for Research at Robert Gordon University, along with the School of Nursing and Midwifery Ethics Review panel have reviewed this study. [redacted] Research Ethics Committee (NHS Scotland) have also reviewed this study.

14. Contacts for Further Information

If you have any questions or points that you wish to discuss, please contact Louise Henderson or [redacted] for further information.

Louise Henderson
School of Nursing & Midwifery
Robert Gordon University
Garthdee Road, Aberdeen. AB10 7QB.

Tel. 01224 263157. Email. l.c.henderson@rgu.ac.uk

[redacted]
School of Nursing & Midwifery
Robert Gordon University
Garthdee Road, Aberdeen. AB10 7QB.

[redacted]

Thank you for considering this invitation to take part in our study.

Appendix 8 Informal Carer & HSC Staff Participant - Information Sheet

1. Study title and Chief Investigator

1. Title

A case study of Service User, informal Carer and staff experiences of Integrated Health and Social Care

Chief investigator

[redacted]

Research Team

Louise Henderson (PhD student), [redacted]

2. Invitation

You are being invited to take part in a research study. Before you decide if you would like to be involved, it is important for you 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, such as other people you know who may be involved in this study, if you wish. Ask us if there is anything that is not clear or if you would like more information. Please take time to decide whether you wish to take part. Thank you for reading this.

3. What is the purpose of the study?

This research study looks to explore and understand your experiences of helping someone at home who uses Integrated Health and Social Care (HSC), to help us develop HSC services in the future. We will also invite the person that you help at home to take part in our study, along with one other person who helps them at home too.

One of the people that helps them could be a family friend, an unpaid Carer or a relative. The other person who helps them should be an HSC worker. This could be a healthcare worker, a paid Carer, a social worker, or a charity worker. We would like to collect information about experiences of HSC through a conversation with you, which should take around one hour in a place that is convenient for you.

4. Why have I been chosen?

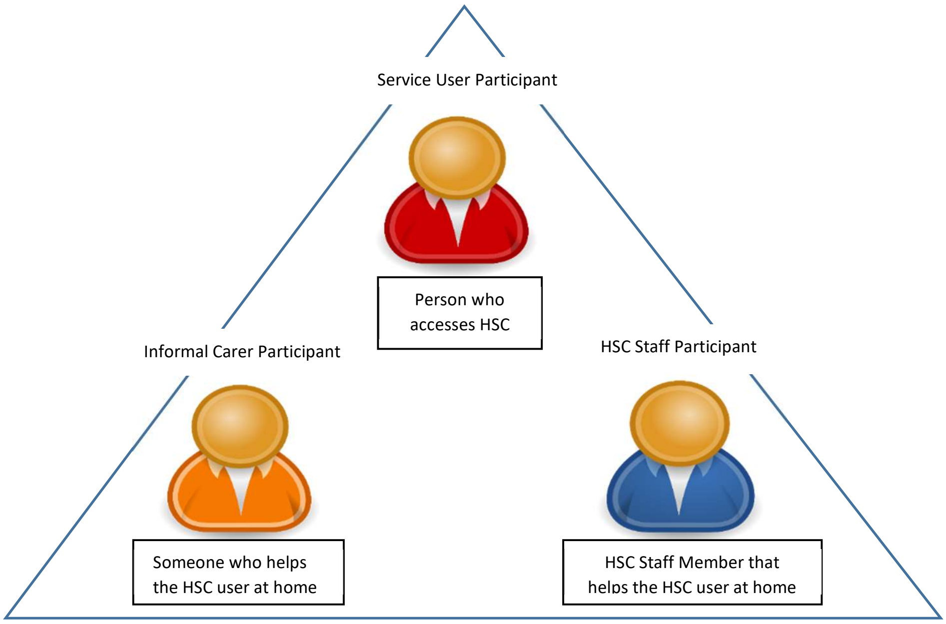
You have been invited to take part in this study because a person (who accesses HSC) has told us that you help them at home. We hope that six people who use HSC across the local region will take part in our study. We hope that each of these six people will identify two people that help them at home, to take part in the study with them.

5. Do I have to take part?

No. It is up to you to decide whether to take part or not. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time without giving a reason. Your decision to withdraw at any time or your decision not to take part will not affect your employment (if you are an HSC Staff Member) or the standards of care that you or any other participants receive; it will not affect the participation of any other people that are part of the study with you. If you decide to withdraw at any time or you decide not to take part, it will not affect your employment or your professional role and responsibilities (HSC staff); the standard of care you or any other participants receive will not be affected.

6. What will happen to me if I take part?

If you choose to take part in this study, you will take part along with the person who receives HSC and one other person that helps them at home. The person who receives HSC has identified you as someone that contributes to their experiences of HSC. You may be a relative, a family friend or an unpaid Carer (Informal Carer). Alternatively, you may be an HSC worker (e.g. a healthcare worker, a paid Carer, a social worker, or a charity worker). Your acceptance decline or withdrawal from the study at any point will not stop any other participants from taking part in the study and it will not affect the standards of care that they receive.



A suitable time, date and place will be agreed to meet with you. Louise Henderson (one of the researchers) will meet with you to have a conversation with you about your experiences of HSC. She will ask you some questions that may help you to explore and describe your experiences of HSC. You can ask questions at any point before or after and during your conversation with her. You can choose how you would like these conversations (about HSC) to take place. There are three options available:

iv. You can choose to meet Louise on a one-to-one basis, with the two other participants being seen on a one-to-one basis too.

or

v. You can choose to meet Louise with *on*e of the other participants; for example, you and the Service User participant. The third person would be interviewed on a one-to-one basis.

or

vi. You can choose to meet Louise with *both* participants; for example, you, the Service User participant, and the other person that helps them at home.

Individual interviews will last for around one hour; group interviews may last up to two hours. When you meet Louise, the conversation that you have with her will be voice recorded with a small digital voice recorder. Your recording will be stored in a password-protected file on Louise's password-protected computer, at Robert Gordon University. Louise will use the voice file to listen to your recording and the words that you have said will be typed onto an electronic document.

We, the research team, do not anticipate a need to contact you again in the future to take part in any further research for this study. However, we may need to contact you by telephone to confirm your meaning or words, should the voice recorder not be clear at the time of listening to the recording. We are the only people who will access your recording and your recording will not be used for any other research study or purpose.

Once the study is complete, we will delete your recording. If you wish to withdraw from this study at any point, data collected up until the point that you withdraw may still be used in the analysis. Should you divulge any information that could put you or others at risk, we have a duty to protect you, along with children, vulnerable adults, and the public. If this happened, we would inform you of our intent to report this to the appropriate organisation and/or authorities.

7. What are the possible disadvantages and risks of taking part?

We do not anticipate any disadvantages, but should you become upset for any reason when recalling your experiences of HSC, we will ensure that you have access to appropriate support and signpost you to someone who can help you.

8. What are the possible benefits of taking part?

If you take part in this study, there is no intended clinical benefit. The information we get from this study may help us to make HSC services better for the people who access them.

9. What if something goes wrong?

If you have a concern about any aspect of this study, you should contact us, and we will do our best to address these [Louise Henderson; Tel. 01224 263157]. If you would like to speak to someone from Robert Gordon University that is not involved in the study, [redacted] would be happy to discuss any concerns [[redacted]].

If you remain unhappy and wish to complain formally, you can do this by following the Robert Gordon University Public Complaint's Procedure. If you would like help to make a complaint, you can access guidance on making a complaint by clicking here: Guide to the Complaint Handling Procedure for Members of the Public (PDF 47KB) or by accessing the following website: https://www3.rgu.ac.uk/footer/complaints/complaints.

You can make a complaint by email [complaints@rgu.ac.uk], on the telephone [01224 262195], or in a letter to:

[redacted]
Assistant Chief Academic Officer and Secretary to the Board
The Robert Gordon University
Garthdee House
Garthdee Road
Aberdeen AB10 7QB

10. Will my taking part in this study be kept confidential?

If you decide to take part in this study, you will need to give us permission to use and store the information collected about you. All reasonable efforts will be made to ensure that information collected about you is kept in **strict confidence** at Robert Gordon University.

We will store two types of information about you:

iii. Information that can identify you personally (personal details).
iv. Information that you have given us in the course of our conversation about your experiences that does not have your personal details on it (anonymised).

Your information will be stored in password-protected secure electronic files. Only the research team will have the secure password to access your electronic files. These electronic files will be kept in a secure folder that is dedicated to this research, on the Robert Gordon University secure server.

Your information will also be stored in a paper file. The paper file will be kept in a locked cabinet that is dedicated to this research study. We, the research team, are the only people who have access to the key for the locked cabinet. The cabinet is located in a locked room within Robert Gordon University.

Any information that can identify you will be kept separately from your information that has been anonymised. Any information about your experiences of HSC that leaves the University will have your name and address removed (it will be anonymised).

11. What will happen to the results of the research study?

Findings from the information that you have given us for this study will be published. Information that will identify you or link you to the information about your experiences, will *not* be published. The results of this study will be published in the PhD Thesis of the PhD student who is involved in this study (Louise Henderson). They will also be published in relevant health and social care journal(s). Results are likely to be published in 2020-2021 and a summary of these results can be sent to you upon completion of the study.

12. Who is organising and funding the research?

This research is a joint study between Robert Gordon University, [redacted] and the Research Team that aims to put people who use HSC services at the centre of the project.

Funding for this research study has been awarded by [redacted], in the form of a stipend for a PhD student. Robert Gordon University have sponsored the educational fees of the PhD. Louise Henderson is the PhD student; [redacted] are supervising Louise and this research study.

13. Who has reviewed the study?

The Vice Principals Office for Research at Robert Gordon University, along with the School of Nursing and Midwifery Ethics Review panel have reviewed this study. [redacted] Research Ethics Committee (NHS Scotland) have also reviewed this study.

14. **Contact for Further Information about this research study:**

If you have any questions or points that you wish to discuss, please contact Louise Henderson or [redacted] for further information.

Louise Henderson
School of Nursing & Midwifery
Robert Gordon University
Garthdee Road, Aberdeen. AB10 7QB.
Tel. 01224 263157. Email. l.c.henderson@rgu.ac.uk

[redacted]
School of Nursing & Midwifery
Robert Gordon University
Garthdee Road, Aberdeen. AB10 7QB.

[redacted]

Thank you for considering this invitation to take part in our study.

Appendix 9 Consent form – Service User

Participant ID	
Title of Study:	A case study of Service User, informal Carer and staff experiences of Integrated Health and Social Care
IRAS reference:	247771
Name of CI:	
Please initial:	

Initial

1. I confirm that I have read and understood the information sheet Version No:______ Date: ______________ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. Data collected up until the point of withdrawal may still be used in analysis. ☐

3. I understand that data collected during the study, may be looked at by individuals from Robert Gordon University, the regulatory authorities if appropriate, or from the NHS Board/Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

4. I agree to my interview being audio recorded. I understand that anonymised quotations from this interview may be used for presentations and publications. ☐

5. I agree for my information to be stored on Robert Gordon University servers. ☐

6. I agree to the people who help me discussing my care. ☐

7. I agree to take part in the above study. ☐

Name of participant	**Date**	**Signature**
Name of researcher	**Date**	**Signature**

One copy for participant, one copy for researcher

Insert version number and date above

Appendix 10 Consent form - Informal Carer /HSC Staff

Participant ID	
Title of study:	A case study of Service User, informal Carer and staff experiences of Integrated Health and Social Care
IRAS reference:	247771
Name of CI:	
Please initial:	

Initial

1. I confirm that I have read and understood the information sheet Version No:____ Date: __________for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. Data collected up until the point of withdrawal may still be used in analysis. ☐

3. I understand that data collected during the study, may be looked at by individuals from Robert Gordon University, the regulatory authorities if appropriate, or from the NHS Board/Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

4. I agree to my interview being audio recorded. I understand that anonymised quotations from this interview may be used for presentations and publications. ☐

5. I agree for my information to be stored on Robert Gordon University servers. ☐

6. I agree to the person that I help discussing the care I give them. ☐

7. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of researcher	**Date**	**Signature**

One copy for participant, one copy for researcher
Insert version number and date above

Appendix 11 Indicative topic guide – Service User participants

(Yin, 2018; Mann, 2016; Braun and Clarke, 2013)

Study Title A case study of Service User, informal Carer and staff experiences of Integrated Health and Social Care		
Interview Duration 1 hour	**Method** Semi-structured interview	**Material to be understood** Participant's own perceptions and sense of meaning

Intention	Topic	Prompt questions	Evidence source	Rationale
Icebreaker	**1.** Start by telling me a little bit about the things you need some help with.	**a.** Tell me about anything at all that you need some help with, e.g. in your home life, your work life or getting out-and-about.	(Mann, 2016; Braun and Clarke, 2013); literature review.	To put the participant at ease and establish a friendly and welcoming tone to the interview.
Opening topic	**2.** You have identified two people who help you at home for this study. Tell me more about them and how they help you…	**a.** Can you tell me more about what they do for you?	Literature review; stakeholder feedback (staff); proposition statements.	To explore the relationships that participants have with people who help them and their significance to their experiences of Integrated Health and Social Care (IHSC)
		b. Perhaps you could give me some examples of how they help you?	Literature review; stakeholder feedback (staff).	
		c. Tell me your views on the help that they give you?	Literature review; proposition statements.	

Probing topic	**3.** What does 'Integrated Health and Social Care' mean for you?	**a.** Tell me about the way your IHSC services work together…	Literature review; stakeholder feedback (PPI & staff).	To establish the participants understanding of IHSC services and which services they access.
		b. Tell me more about the services you need to help you…	Literature review; proposition statements & stakeholder feedback (PPI & staff).	
Probing topic	**4.** Talk me through some of your experiences of IHSC…	**a.** Can you think of an example of what works well for you in IHSC?	Literature review; stakeholder feedback (staff & PPI).	To explore the reality of IHSC experiences and needs of those who use it, as perceived by the participant (Yin, 2018).
		b. What, if anything, could be done differently?	Literature review; stakeholder feedback (staff & PPI).	
		c. Tell me about what you feel you need for your own wellbeing?	Literature review; stakeholder feedback (staff & PPI).	
		d. Perhaps you could tell me more about how your care looks on a day-to-day basis…		

Probing topic	**5.** Tell me about how your IHSC care is organised…	**a.** Tell me about the people involved in planning/organising your IHSC…	Stakeholder feedback (PPI); literature review; proposition statements.	To explore the participant’s voice in IHSC services and communication between Service Users and people that help them.
		b. Tell me about your communication with these people…	Stakeholder (staff & PPI); literature review; proposition statements.	
		c. Tell me about your involvement in organising your care…	Stakeholder (staff); literature review.	
Closing question	**6.** Reflecting back on our conversation today, are there any other experiences of IHSC that you would like to share with me today?	**a.** Anything you feel we haven’t covered that you would like to share with me?	(Mann, 2016; Braun and Clarke, 2013)	To draw the interview to a close and offer an opportunity for the participant to share anything further that may not have been prompted by the topics.

Appendix 12 Indicative topic guide – Informal Carer & IHSC Staff participants

(Yin, 2018; Mann, 2016; Braun and Clarke, 2013)

Study Title A case study of Service User, informal Carer and staff experiences of Integrated Health and Social Care		
Interview Duration Around 1 hour	**Method** Semi-structured interview	**Material to be understood** Participant's own perceptions and sense of meaning

Intention	Topic	Prompt questions	Evidence source	Rationale
Icebreaker & opening topic	**1.** Tell me about the person you help…	**a.** Can you tell me more about what you do to support him/her?	Literature review; stakeholder feedback (staff); proposition statements	To put the participant at ease and establish a friendly and welcoming tone to the interview and explore the relationships that participants have with people who they.
		b. Perhaps you could give me some examples of how you help him/her?	Literature review; stakeholder feedback (staff)	
		c. Tell me about your views on the help that you give them?	Literature review; proposition statements	
Probing topic	**2.** What does 'Integrated Health and Social Care' (IHSC) mean for you?	**a.** Tell me about the way IHSC services work together…	Literature review; stakeholder feedback (PPI & staff)	To establish the participants understanding of IHSC services and which services they access/deliver; care scenarios, needs and experiences.
		b. Tell me about how *you* use/deliver IHSC when you are helping the Service User participant…	Literature review; stakeholder feedback (staff & PPI)	

Intention	Topic	Prompt questions	Evidence source	Rationale
		c. Tell me more about the services that support you when you are helping the Service User participant…	Literature review; proposition statements & stakeholder feedback (PPI & staff)	
Probing topic	**3.** Talk me through some of your experiences of IHSC…	**a.** Can you think of an example of what works well in IHSC? **b.** What doesn't work so well?	Literature review; stakeholder feedback (staff & PPI)	To explore the reality of IHSC experiences, as perceived by the participant (Yin, 2018). To explore the participant's voice in IHSC services and communication between Service Users and people that help them.
		c. What, if anything, could be done differently?	Literature review; stakeholder feedback (staff & PPI)	
		d. **Informal Carer**: Tell me about what you feel you need for your own wellbeing. or **IHSC staff**: Tell me what you feel the wellbeing needs are, for people who access IHSC (Service Users, families, informal Carers).	Literature review; stakeholder feedback (staff & PPI)	

Probing topic	**4.** Can you tell me about how the IHSC care services that your *(insert relationship, e.g. patient, mum dad, neighbour)* uses are organised…	**d.** Tell me about the people involved in planning/organising IHSC…	Stakeholder feedback (PPI); literature review; proposition statements	To explore the participant's voice in IHSC services and communication between Service Users and people that help them.
		e. Tell me about your communication with these people…	Stakeholder (staff); literature review	
		f. Tell me about your involvement in organising care…	Literature review; stakeholder feedback (staff)	
Closing question	**5.** Reflecting back on our conversation today, are there any other experiences of IHSC that you would like to share with me today?	**b.** Anything you feel we haven't covered that you would like to share with me?	(Mann, 2016; Braun and Clarke, 2013)	To draw the interview to a close and offer an opportunity for the participant to share anything further that may not have been prompted by the topics.

Appendix 13 SERP approval

Louise Henderson

PhD student

School of Nursing and Midwifery

Robert Gordon University

(Page 1 of 2)

27/6/19

SERP reference number: 19-12

Dear Louise

Research proposal name: **A case study of Service User, informal Carer and staff experiences of Integrated Health and Social Care**

The School of Nursing and Midwifery Ethics Review panel has now reviewed the above research proposal. Please find details of the outcome and recommended actions below.

Your proposal has been approved. You may go ahead with your research, providing approval from any relevant external committee/s has been obtained. *

** Where the project involves NHS patients, approval through the NRES system must be obtained.*

Where the project involves NHS staff, approval through the NHS R&D Office must be obtained.

Members of the School Panel can advise on this process if necessary.

Please email a copy of this approval letter along with your study protocol to [redacted] who tracks NHS IRAS applications on behalf of Sponsor [redacted].

Please communicate directly with the convenor named below in any process of proposal revision.

SERP approval is valid for 1 year from the date of this letter. If your data collection period progresses beyond 1 year, please notify the SERP convenor.

Please include your SERP reference number in a footer on all documents related to your study.

Yours sincerely

[redacted]

Panel member 1

Position held: SERP convenor/lecture

[redacted]

Panel member 2

Position held: SERP member/lecture/[redacted]

(Page 2 of 2)

Appendix 14 IRAS ethical approval

(Page 1 of 4)
1 October 2019

School of Nursing & Midwifery
Robert Gordon University
Garthdee Road
ABERDEEEN
AB10 7QB

Dear [redacted]

Study title: A case study of Service User, informal Carer and staff experiences of Integrated Health and Social Care
REC reference: 19/NS/0148
Protocol number: N/A
IRAS project ID: 247771

Thank you for your letter of 27 September 2019, responding to the Committee's request for further

information on the above research and submitting revised documentation.
The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion
The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host Organisations Registration of Clinical Trials.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Registration is a legal requirement for clinical trials of investigational medicinal products (CTIMPs), except for phase I trials in healthy volunteers (these must still register as a condition of the REC favourable opinion).

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral:

https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at:

https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We will audit these as part of the annual progress reporting process.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:
- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at

https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites listed in the application subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

- The final list of documents reviewed and approved by the Committee is as follows:
- *Document Version Date*
- Copies of advertisement materials for research participants:
- Social Media Advert 2 18 September 2019
- Covering letter on headed paper: Chief Executive - Letter of Access1 28 June 2019

-

- Evidence of Sponsor insurance or indemnity (non-NHS Sponsors only): Indemnity Insurance - 01.08.2019 -31.07.2020 1 August 2019
- GP/consultant information sheets or letters: GP Advisory Letter 1 8 July 2019
- Interview schedules or topic guides for participants: Service User 1 30 May 2019
- Interview schedules or topic guides for participants: Informal Carer/HSC Staff 1 20 May 2019

- IRAS Application Form: IRAS Form 07082019 247771/1356759/37/1107 August 2019
- IRAS Checklist XML: Checklist 01102019 1 October 2019
- Letters of invitation to participant: All Participants 1 2 July 2019
- Study Withdrawal Form 1 19 April 2019
- Amendment Log 1 19 April 2019
- Note to File 1 19 April 2019
- Chief Officers - Letter of Access 1 28 June 2019

Document Version Date

- GDPR Participant Information Booklet 1 18 September 2019
- Response to Provisional Opinion 1 27 September 2019
- Participant Consent Form: Service User 1 7 June 2019
- Participant Consent Form: Informal Carer/HSC Staff 1 30 May 2019
- Participant Information Sheet (PIS): Service User 2 18 September 2019
- Participant Information Sheet (PIS): HSC Staff 2 18 September 2019
- Referee's report or other scientific critique report: Scientific Critique Report #1 - [redacted] 25 April 2019
- Referee's report or other scientific critique report: Scientific Critique Report #2 - [redacted] 15 April 2019
- Research protocol or project proposal 2 27 September 2019
- Summary CV for Chief Investigator (CI): [redacted] 13 June 2019
- Summary CV for Student: Louise Henderson 1 11 June 2019
- Summary CV for Supervisor (student research): [redacted] 29 August 2019
- Summary CV for Supervisor (student research): [redacted] 1 September 2019

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high-quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known, please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities – see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

With the Committee's best wishes for the success of this project.
Yours sincerely

[redacted]
Chair

Enclosures: "After ethical review – guidance for researchers" SL-AR2
Copy to [redacted]

Appendix 15 Initial data extraction and observations, for preliminary themes

CHANGE AND UNCERTAINTY							
When thinking about the future Links: Feelings - uncertainty	**x**		**x**	**x**			
Some participants were looking for certainty about the future	Arthur and Anisha		Catherine				
Some participants accepted that uncertainty was to be expected	Abigail		Caitlin & Catherine	David			
Some participants were worried about the future	Arthur						
For some Participant's, learning to accept change is important **Links: Social contact**	**x**	**x**	**x**	**x**	**x**		**x**
Necessary to accept waiting for services			Connor				
Accepting of compromises, to ensure progress (towards discharge and re: equipment)		Barney		Donna			
Accepting of IC influence and support					Eddie		
HSC services acceptance of younger and more vocal Servie User's	Arthur & Anisha						
Information about changing symptoms and needs	Arthur & Anisha			Donna	Eddie		Grant
Some participants accepted that uncertainty was to be expected	Abigail		Caitlin & Catherine	David			
Accepting the diagnosis	Anisha & Abigail						Grant

Some participants felt that they needed more support to be able to cope in their current circumstances Links: Coping - support - needs	**x**			**x**	**x**		
With the SU's condition	Anisha & Abigail						
Telephone contact did not offer a chance to build up a relationship					Debra		
With decision-making				Debra			
As they promoted stronger working relationships				Debra			

Balancing work caring commitments vs opportunity to work and earn money				David			

Appendix 16 9 Pillars of Integrated Care

	Pillar	Description
1	Shared values and vision	Improving population health and wellbeing requires collective action to address the social determinants of health and reduce health inequalities.
2	Population health and local context	In most places, attempts to achieve better population health and wellbeing fall short because efforts tend not to focus on addressing the root causes – the determinants of health and the reduction of health disparities.
3	People as partners in care	People are living longer, but not healthier lives. The burden of care is increasing and, with it, complexity, as many people live with multiple chronic conditions. There is a growing imperative to place people and communities, and what matter to them, at the centre of health and care services.
4	Resilient communities and new alliances	There is growing evidence to demonstrate that empowering local communities is essential for citizens' wellbeing and for the care system to function effectively.
5	Workforce capacity and capability	Health and care workers are our greatest asset, working alongside family Carers, community partners and local networks of support. However, without reforms, sustaining the workforce is also one of our greatest challenges.
6	System wide governance and leadership	Network governance models can be used to rethink the way cross-organisational services and joint actions are contracted and funded, coordinated, inspected and regulated, and on how outcomes and benefits are assessed for the care recipient, care teams and the system.
7	Digital solutions	As each integrated care building block is reliant on information, digital solutions could be seen as the cement that holds the blocks together.
8	Aligned payment systems	Integrated care has often emerged, or been accelerated, in times of crisis. The impact of COVID-19 again tells us that "where there's a will, there's a way" to solving problems, including to long-established policies and fragmentations in financing.
9	Transparency of progress, results and impact	Just as there is no 'one size fits all' model of integrated care that suits all ambitions, situations and contexts, there is no one single tool or approach that can be used to measure the progress, results and impact of an integrated care initiative which consists of a number of interrelated interventions, rather than a single one.

(International Foundation for Integrated Care (IFIC), 2021)