

Living well with multiple long-term conditions:
young people's care experiences explored
within the frameworks of the early adaptation
process and ecological systems theory.

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Abstract

Background

Little is known about the care experiences of young people living with multiple long-term conditions (MLTCs) or of the care features that support them to live well. Applying Due-Christensen's early adaptation framework and Bronfenbrenner's ecological systems theory (EST), this thesis explores young people's care experiences with the aim of identifying features that supported them to live well.

Methods

A qualitative study involved a two phased telephone interview process with a purposive sample of 18-24 year-olds (n=19) living with at least two long-term conditions recruited from four GP practice patient lists across Brighton and Hove; in total 38 interviews were conducted typically lasting 40–85 minutes. Narrative data generated from audio interviews was inductively and deductively thematically analysed and counts of LTCs and time to diagnosis described.

Results

Participants were living with a combination of between two to seven comorbidities and morbidities; many (n=12) were living with complex multimorbidity. Anxiety and depression were the most prevalent morbidities (n=13) and comorbidities (n=9). For a number (n=9), the onset of their first symptoms started in childhood (<10 years of age) and most (n=13) were living with symptoms of ill health for several years before diagnosis. Thematic analysis generated nine subthemes and three overarching themes. They suggested the nature of the health condition and/or its symptom(s) presentation were associated with young people's stigma experiences which were key to their reconstruction of identities, view of illness, learning, and behaviour adaptations.

Discussion

Delays in diagnosis, arguably the result of societal structures and processes (i.e. the macrosystem), contribute to the conditions for stigma to unfold in young people's interactions with and between care professionals and their relational networks (i.e. the microsystem and mesosystem). *Outgroup derogation* and *othering* may explain

experiences in the microsystem and mesosystem that give rise to the enacted stigma of stigmatisers and bystanders, and the felt, anticipated, and internalised stigma of those stigmatised. Young people's access to similar others, validation of their *sick* role identities, and alleviation of the burden of illness seemingly moderated their stigma experiences by minimising the differences to their peers.

Conclusion

The onset of ill health symptoms prior to a formal diagnosis may initiate the early adaptation process for some young people. To moderate stigma experiences, the care management of children and young people should start early after symptom onset, be holistic in approach, and focus on strengthening similarities in peer role and social identities.

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Acronyms

Acronym	Detail
AMHS	Adult Mental Health Services
AYA	Adolescents and Young Adults
AYPH	Association for Young People's Health
CAMHS	Children and Adolescent Mental Health Services
CBT	Cognitive Behavioural Therapy
CF	Cystic Fibrosis
CPN	Community Psychiatric Nurse
CSM	Common-Sense Model of Self-Regulation
CVD	Cardiovascular Disease
DALY	Disability Adjusted Life Year
DES	Directed Enhanced Support
DoH	Department of Health
EST	Ecological Systems Theory
GP	General Practitioner
HCP	Health Care Professional
HIV	Human Immunodeficiency Virus
IAPT	Improving Access to Psychological Therapies
IMD	Indices of Multiple Deprivation
IoD	Indices of Deprivation
JRA	Juvenile Rheumatoid Arthritis
LSOA	Lower-layer Super Output Area
LTC	Long-term Condition
LTP	Long-term Plan
MLTCs	Multiple Long-Term Conditions
NHS	National Health Service
NHSOF	National Health Service Outcomes Framework
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
NMD	Neuromuscular Disease
NYA	National Youth Agency
PaHIV	Perinatally Acquired HIV
PCN	Primary Care Network
PHE	Public Health England
SCD	Sickle Cell Disease
T1DM	Type 1 Diabetes Mellitus
UKRI	UK Research and Innovation
WHO	World Health Organisation
YLD	Years of Healthy Life Lost due to Disability
YP	Young People

Definitions of long-term health conditions

Name of long-term health condition	Acronym	Brief description
Acne (cystic)		Acne is a common skin condition that affects most people at some point. It causes spots, oily skin and sometimes skin that's hot or painful to touch (NHS, 2022a). Cystic acne is the presence of large inflammatory nodules and fluid-filled cystic swellings as well as more superficial lesions. Systemic therapy with antibiotics or retinoids is usually required (WHO 2023)
Adenomyosis		Adenomyosis is a condition that causes the lining of the womb (the endometrium) to bury into the muscular wall of the womb (NHS, 2022b).
Agoraphobia		Agoraphobia is a fear of being in situations where escape might be difficult or that help wouldn't be available if things go wrong (NHS, 2022c).
Anorexia nervosa		Anorexia is an eating disorder. Those affected feel the need to keep their weight as low as possible (NHS, 2022d).
Anxiety		Anxiety is a feeling of stress, panic or fear that can affect your everyday life physically and psychologically (NHS, 2022e).
Asthma		Asthma is a common lung condition that causes occasional breathing difficulties (NHS, 2022f).
Atopic eczema		Eczema (atopic dermatitis) is the most common form of eczema that causes the skin to become itchy, dry and cracked (NHS, 2022g).
Attention deficit disorder/ Attention deficit hyperactivity disorder	ADD/ ADHD	Attention deficit hyperactivity disorder (ADHD) is a condition that affects people's behaviour. People with ADHD can seem restless, may have trouble concentrating and may act on impulse. ADD is without the hyperactivity (NHS, 2022h).
Autism		Autism is a lifelong developmental disability which affects how people communicate and interact with the world (National Autistic Society, 2022).
Body Dysmorphia		Body dysmorphic disorder (BDD), or body dysmorphia, is a mental health condition where a person spends a lot of time worrying about flaws in their appearance (NHS, 2022i).
Borderline personality disorder	BPD	Borderline personality disorder (BPD) is a disorder of mood and how a person interacts with others. It's the most commonly recognised personality disorder (NHS, 2022j).
Depression		Depression is a low mood that can last a long time or keep returning, affecting your everyday life (NHS, 2022k).
Dissociative disorder		Dissociative disorders are a range of conditions that can cause physical and psychological problems. They can follow a traumatic life event, and resolve on their own over a matter of weeks or months. Others can last much

		longer. Dissociation is a way the mind copes with too much stress (NHS, 2022l).
Endometriosis		Endometriosis is a condition where tissue similar to the lining of the womb starts to grow in other places, such as the ovaries and fallopian tubes (NHS, 2022m).
Hidradenitis suppurativa	HS	Hidradenitis suppurativa is a long term, recurrent, and painful disease in which there is inflammation (redness, tenderness and swelling) in areas of skin containing apocrine sweat glands (British Skin Foundation, 2022).
Inflammatory bowel disease	IBD	IBD refers to either ulcerative colitis or Crohn's disease. Both conditions involve inflammation of the gut. Ulcerative colitis affects only the large intestine whilst Crohn's disease can affect any part of the gastro intestinal tract (NHS, 1922n).
Irritable bowel syndrome	IBS	IBS is a common condition that affects the digestive system. Symptoms include, bloating, stomach cramps, diarrhoea, and constipation (NHS, 2022o).
Joint hypermobility syndrome		Joint hypermobility syndrome features include very flexible joints (double-jointed) that are painful (NHS, 2022p).
Migraine		A migraine is a moderate or severe headache which can include symptoms such as feeling sick, being sick and increased sensitivity to light or sound (NHS, 2022q).
Molar pregnancy		A molar pregnancy is where the embryo (fertilised egg) becomes a growth of abnormal cells or clusters of water filled sacs inside the womb. It is one of a group of conditions known as gestational trophoblastic diseases (GTDs). It requires chemotherapy treatment (Cancer Research, 2022).
Polycystic Ovary Syndrome	PCOS	Polycystic ovary syndrome (PCOS) is a common condition that affects how a woman's ovaries work. Three main features include irregular menstrual cycles, excess of hormone androgen and polycystic ovaries (NHS, 2022r).
Post-traumatic stress disorder	PTSD	PTSD is an anxiety disorder caused by very stressful, frightening or distressing events (NHS, 2022s).
Postural orthostatic tachycardia syndrome	PoTS	Postural orthostatic tachycardia syndrome (PoTS) is an abnormal increase in heart rate that occurs after sitting up or standing. Some typical symptoms include dizziness and fainting (NHS, 2022t).
Raynaud's disease		Raynaud's affects your blood circulation. When cold, anxious or stressed, fingers and toes may change colour. Other symptoms can include pain, numbness, pins and needles and difficulty moving the affected area (NHS, 2022u).
Spasmodic croup		The term <i>croup</i> now generally refers to an acute respiratory tract illness characterized by a distinctive barking cough, hoarseness, and inspiratory stridor in a young child. Some children have recurrent episodes of croup, however, which is often referred to as "spasmodic croup" (Bower and McBride, 2014).

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Dedication

This thesis is dedicated to my maternal grandparents Albert and Eleanor Berry for nurturing a curious mind and an interest in reading in my early formative years.

Declaration

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

Signed: 

Date: 7th February 2024

Chapter 1: Introduction

“It was really clear to me that I was not like other people and that was very painful. I felt very isolated, and I remember lying in bed and crying about it at night sometimes because I couldn’t put my finger on why.” (Prince-Hughes, 2013)

This extract is from a radio interview entitled “Learning to be human” with Dawn Prince-Hughes on living with undiagnosed Asperger’s syndrome. It highlights how as a young person she experienced feeling different to others. She did not understand why she felt different, but she experienced it as isolating and distressing. She struggled with communication as she found it hard to adjust to the speed of human communication. It left her feeling disconnected from people. She describes how she was bullied at school, and became homeless after she left school and home in her early teens. Her experiences resulted in her feeling stripped of her humanity. She explains that she felt she wanted to die, but by observing how gorillas communicated she learned about human communication.

The choice of extract to open the introductory chapter lies in its parallels with the themes generated in this doctoral thesis and some young people’s experiences of living with long-term conditions (LTCs). In this research, young people talked about feeling different to others and how alone and upsetting that made them feel. They experienced others’ cruelty to them which in turn shaped their own behaviours. Yet despite these challenging interactions, many young people were able to move on from these experiences, and live their lives with their LTCs. They went to university, travelled, formed intimate relationships, had children, and secured employment.

This thesis set out to explore the care experiences of young people living with multiple long-term conditions (MLTCs) through the lens of the early adaptation process to examine the features that enabled them to live well. There is scant research on young people’s experiences of living with MLTCs. A low estimated prevalence of multimorbidity in young people, compared with older aged groups, may have obscured interest in the area, despite evidence that the numbers of young people living with LTCs is seemingly on the increase. Moreover, there is limited research on young people’s care experiences once they have transitioned from

children to adult care teams. Yet this is a time when they are most at risk of disengaging from services, with potential negative consequences to their health. The focus of this research was therefore a timely exploration of a knowledge gap in the care experiences of young people living with MLTCs once they have transitioned to adult care teams. The timeliness of the research has been brought into sharper focus with the post-Covid surge in demand by young people requiring health care and in particular, mental health care.

In this study, rich in-depth qualitative data was generated with a sample of young people living with MLTCs recruited from primary care by applying a two staged interview process involving biographical mapping. Their experiences were explored within the frameworks of the early adaptation process (Due-Christensen *et al.*, 2018) and ecological systems theory (EST) (Bronfenbrenner, 1979). The narrative that unfolds in this thesis is of the experiences of a group of young people living with a range of morbidities and co-morbidities which do not typically feature in health care research. The data generated suggests some health conditions and their presentation of symptoms in children and young people can cast a shadow over their developing identities, as their differences from their peers become the focus of enacted, felt, anticipated, and internalised stigma. In a development of the early adaptation process, I suggest the reconstruction of identities for some young people starts with the onset of their health condition symptoms, which may be a considerable time before they receive a formal diagnosis.

Young people's experiences within this study highlight how structures and processes in the macrosystem¹ may have created delays in some diagnoses and ascribed to others negative judgements which shaped young people's interactions. Young people are particularly responsive to difference in themselves and others. I suggest in this study that young people moderated their stigma experiences by minimising their differences and strengthening their similarities to their peers.

In terms of adaptation to living with LTCs, the literature suggests that social withdrawal and social isolation are not supportive features. They may appear as a means of protecting young people from further stigma, but they are linked to fewer

¹ Macrosystem refers to the overarching patterns of ideology and organisation of the social institutions within a particular culture which indirectly affect the individual's growth (Bronfenbrenner 1979) discussed in Section 2.3., p.37.

health seeking behaviours. Young people in this study found it helpful to access on-line information and communities of other young people living with the same health conditions, from whom they could learn experientially (albeit virtually). I suggest the potentially anonymous communication with on-line communities enabled young people to protect their identities from further stigma whilst reconstructing new identities.

I propose that underpinning the actions of both those who stigmatise and the responses of those who are stigmatised is a drive to protect identities. In a development of the early adaptation process, I suggest the reconstruction of sense of self is the key construct around which other constructs (i.e. view of illness, learning, and behaviour) follow. The literature on adaptation to living with LTCs infers that as part of the adaptation process people must reconcile their previous healthy identities with their new *sick* identities. The evidence in this thesis suggests that others (i.e. family, friends, partners, HCPs, teachers, and employers) and organisational systems have roles to play in supporting this process. It brings into focus the importance of a holistic approach to caring for and supporting young people living with LTCs that goes beyond health care services and family, and includes involvement of peers, personal relationships, education, and employment.

Not all interactions with young people living with LTCs will result in enacted, felt, anticipated, and internalised stigma, and by association inform an *unhealthy* adaptation to living with LTCs. It is beyond the scope of this thesis to explore the features of others who do not enter into the power play underpinning the stigmatisation process, but to identify the behaviours of others that young people found supportive. I suggest others' behaviours that validated young people's *sick* role identities and eased the burden of illness may have minimised stigma experiences and supported participation in other microsystems. I contend that as young people began to manage their lives, there was a positive feedback loop that resulted in their inclusion and further participation in various spheres of life. I propose this was both a cause and effect of strengthening similarities of peer role and social identities and minimising the differences. What is not clear from this study's application of EST is the role of the passage of time and young people's developing maturity in facilitating this process.

This thesis set out to explore through the early adaptation process and EST how young people living with MLTCs can be supported to live well. I argue this thesis provides important contextual data to aid understanding as to why some features of experiences are supportive whilst others are not. Accessing similar others, validation of *sick* role identities, and easing the burden of illness may minimise triggers for outgroup derogation and othering, and moderate stigma experiences; strengthening peer role and social identities, health seeking behaviour, and participation in life spheres. By understanding the distal and proximal sources of young people's stigma experiences, recommendations for potential care/interventions may be developed. The sections below outline the content of each chapter of this doctoral thesis.

- Chapter 2: Setting the scene.

This Chapter lays out the background to this thesis by exploring what is already known about multimorbidity in young people in terms of the determinants and its prevalence. Young people make up a small proportion of the multimorbid population, but the association with being female, learning disability and wider determinants such as socio-economic deprivation and low educational attainment seen in older aged groups are present in younger people. I suggest the estimated increase in numbers of young people living with LTCs, together with the post-Covid increase in demand of young people requiring health care, especially from mental health care services, indicate now is the time to better understand the prevalence of multimorbidity in young people and their care experiences. This data could be applied to develop specific care management guidance for young people.

The term *living well* is explored and data suggest that a successful adaptation to living with LTCs requires managing the threat to sense of self. I describe the early adaptation process and the EST, and their selection as theoretical frameworks to examine young people's care experiences. I suggest that in applying these frameworks to understand the role of significant relationships (i.e. with families, partners, and peers), HCPs and care services in shaping adaptation, they may help to identify features of services and their delivery that could enhance self-management, and meet the NHS Outcomes Framework (NHSOF) domain two of enhancing quality of life for (young) people living with LTCs.

Finally, the health and care landscape in England is outlined to explain the positioning of this research project within primary care. It will highlight how workforce challenges exacerbated by the Covid-19 pandemic may serve as a barrier to the implementation of any research recommendations within clinical practice.

- Chapter 3: Literature review and defining the research question.

The narrative literature review identifies the gaps in existing knowledge of the care experiences of young people living with multimorbidity to arrive at the research question. It outlines the literature search strategy, and describes and critically assesses the papers retrieved from the literature search. In the absence of direct studies, the narrative literature review draws on young people's experiences of multiple care services, the transition process from paediatric to adult care teams, and of single disease care pathways. Features from the former two care pathways identified elements of services that, in the main, undermine young people's abilities, capacity, and motivation to self-manage. In contrast, those care experiences along a single disease care pathway identified features that could be argued to support young people to self-manage and live well. They included meeting young people's needs and preferences, focussing on positive behaviours to bring about behaviour change, minimising epistemic tension, and considering the influence of wider relational networks in young people's care.

This literature review raises questions about the transferability of these features to young people living with multimorbidity, and how far the supportive effects are sustained as young people experience living with subsequent health conditions. The research aim and question are outlined.

- Chapter 4: Methodology.

This Chapter outlines the research project's underpinning philosophical position and the theoretical perspective that will inform the study's research methods. It discusses how a relativist ontology, social constructionist epistemology, and an interpretive interactionist theoretical perspective facilitated the data generation and analysis to address the research question. At the heart of this research question is an "*experiential puzzle*" (Mason, 2018, p.12) which involves generating trustworthy data from young people's experiences of HCPs, care services, and significant others to understand how they shape the early adaptation constructs.

- Chapter 5: Methods.

Following on from Chapter 4, this Chapter outlines the research design and choice of research tools that were applied to generate the data in line with the underpinning philosophical and theoretical perspectives. It discusses the research process (guided by an interpretive interactionist framework) which informed the choice of study site (primary care), the recruitment of GP practices, the participant selection criteria, the two staged semi-structured telephone interviews, and the thematic data analysis. It details the recruitment challenges from conducting research during the Covid-19 pandemic, such as delays to recruitment, and how they were managed. Of note was the successful adaptation of biographical mapping so that it could be conducted remotely over the telephone.

The Chapter describes the study sample's (n=19) characteristics and details how researcher reflection, reflexivity, and patient and public involvement (PPI) maximised participant engagement, research integrity, and the generation of *thick* data.

- Chapter 6: Part 1 findings: multimorbidity in young people.

The first of two results chapters explores the data generated from the first semi-structured telephone interviews (i.e. health biographies) and the data describing participants' characteristics. It explores potential wider determinants of multimorbidity within the sample, such as level of educational attainment and socio-economic deprivation. The Chapter describes the numbers and types of morbidities and comorbidities present in participants and the shortcomings these findings suggest of the multimorbidity index applied in previous studies. Of significance, it also describes the ages of symptom onset and length of time young people experienced to diagnosis, and which health conditions experienced the longest time delays to diagnosis. Finally, the HCPs involved in young people's care are outlined, highlighting the services and HCPs most referenced by participants, and the breadth of service providers. The findings provide the context to young people's experiences recounted in the second in-depth telephone interviews that inform the data analysis discussed in Chapter 7.

- Chapter 7: Part 2 findings: young people's care experiences and the early adaptation process.

This Chapter discusses the themes generated from the second semi-structured telephone interviews to identify the features of young people's experiences that shaped the early adaptation process. In addition to HCPs, families, peers, and partners, the analysis suggests teachers, employers, and organisational systems were also influential in shaping the early adaptation process.

The themes are collated around the health care journey stages of (a) pre-diagnosis, (b) diagnosis and learning, and (c) living with LTCs, and are contrasted with Due-Christensen *et al.*, (2018). The main thread running throughout the themes is the role of stigma in shaping the early adaptation constructs. In the pre-diagnosis stage, many young people seemingly experienced disbelief and derision in response to their reports of ill health which impacted their sense of self and behaviours. When a diagnosis was made, young people recalibrated their sense of self in response to their and others' perceptions of the health condition which in turn informed learning and behaviour. Access to similar others on-line enabled young people to reconstruct new identities, learn about the health condition(s), and how to manage it (them). The data indicate that (a) behaviours of others which inferred young people were being heard validated their *sick* role identities, (b) the emotional and practical support of significant others and HCPs provided capacity to ease the burden of illness, and (c) teachers and employers who accommodated young people's health care needs enabled their on-going participation in the spheres of education and employment. Of note, the data suggest that the adaptation process starts for many young people with the onset of symptoms and the stigma that it engenders. Moreover, previous experiences of enacted stigma may inform anticipated, felt, and internalised stigma responses to future ill health symptom(s) presentation and diagnoses.

- Chapter 8: Discussion.

Drawing together the findings discussed in Chapters 6 and 7 and applying Bronfenbrenner's (1979) EST, I explore the relationship between the stigma dimensions at work in the macrosystem, microsystem, and mesosystem.

I suggest negative evaluations of some health conditions and delays in diagnosis of others generated in the macrosystem may have contributed to the social context for

stigma in young people's interactions with peers, teachers, employers, HCPs, and family to unfold in the mesosystem and microsystem. I propose these features shaped interactions in the microsystem as young people's difference triggered outgroup derogation and othering for non-conformance to expected roles, and young people responded with stigma avoidant and concealment self-care practices. I suggest the features that were identified to moderate young people's stigma experiences involved strengthening their peer role and social identity similarities through access to similar others, *sick* role identity validation, and easing the burden of illness. In the mesosystem, I explore how experiences in one microsystem could mitigate or compound stigma experiences in another microsystem.

Interventions to enable young people living with MLTCs to live well must therefore consider how to address the social contexts in young people's environmental systems that give rise to stigma, and to consider developing the suggested moderating stigma features. The implications of these findings for future health and care practice and research on young people living with multimorbidity are outlined. The study's strengths and limitations are discussed.

- Chapter 9: Conclusion.

In the final chapter I highlight the contributions to knowledge:

1. There are gaps in our understanding of the prevalence of multimorbidity in children and young people which include the nature and number of their morbidities and comorbidities.
2. An adaptation of a biographical mapping tool that is conducted remotely over two points in time can facilitate the generation of rich data.
3. The early adaptation process for some young people living with some health conditions starts not with the disruption of a diagnosis but with the onset of symptoms. Previous stigma experiences may shape young people's responses to future ill health symptom presentation and diagnoses.
4. Features that moderate some young people's stigma experiences can be contextualised as minimising peer role and social identity differences and strengthening their role and social similarities to protect from outgroup derogation and othering. Some of the protective features that arise in one microsystem may mitigate stigma experiences in another/others.

Chapter 2: Setting the scene

The Chapter will set the context to this doctoral thesis by defining the terms multimorbidity and young people, and exploring what is currently known about multimorbidity in young people, including gaps in knowledge. It will examine the term *living well*, and describe the early adaptation process and the ecological systems theory which will form the theoretical frameworks to explain and contextualise young people's care experiences. Finally, the health and care landscape in England will be outlined to explain the positioning of this research project within primary care.

2.1 Multimorbidity and young people

This Section will explore the definition, prevalence, and determinants of multimorbidity in general and specifically in relation to young people. It will highlight the variations in age band recordings, gaps in knowledge, and opportunities for further study.

2.1.1 Multiple long-term conditions (multimorbidity)

A long-term condition (LTC) is a condition that cannot be cured at present and is managed by medication and other treatments (Department of Health, 2012).

Multiple long-term conditions (MLTCs), also referred to as multimorbidity, can be described as two or more LTCs (National Institute for Health and Care Research [NIHR], 2020) and according to the Academy of Medical Sciences (2018, p.6) each condition is "*either a physical non-communicable disease of long duration, such as cancer..., a mental health condition of long duration such as a mood disorder..., or an infectious disease of long duration such as HIV ...*". It has been suggested that in the reporting of multimorbidity, health conditions/disease should be coded using a standardised classification scheme such as the International Classification of Diseases (ICD-10) (Academy of Medical Sciences, 2018). This is a medical classification list developed by the World Health Organisation (WHO). It contains codes for diseases, health conditions (acute and chronic), signs and symptoms, abnormal findings, complaints, social circumstances, and external causes of injury or diseases (WHO, 2020). It is a tool for recording, reporting, and grouping conditions and factors that influence health that allows for a comparison of morbidity and mortality between countries/regions and at different times (WHO, 2024).

The LTCs that constitute multimorbidity may also be referred to as comorbidities or morbidities (Valderas *et al.*, 2009; van den Akker *et al.*, 1996). Multiple or discordant morbidities refer to conditions/diseases that have no index condition/shared pathology (Valderas *et al.*, 2009) such as asthma and epilepsy, whilst comorbidities or concordant morbidities share the same pathology (Valderas *et al.*, 2009) such as diabetes and peripheral vascular disease. More usually multimorbidity describes a co-occurrence of two or more medical conditions, irrespective of pathology (NICE, 2016a; The Academy of Medical Sciences, 2018; van den Akker *et al.*, 1996). Barnett *et al.*, (2012) in their model to map multimorbidity break down this definition further by separating multimorbidity into numbers of physical conditions and classifying multimorbidity as either living with two or more, or three or more LTCs. They also introduced a third category for people living with both physical and mental health morbidities. These classifications have been applied in subsequent multimorbidity mapping studies (Public Health England [PHE], 2018; Brighton and Hove Clinical Commissioning Group [CCG] and Brighton and Hove City Council [CC], 2018). More recently the term complex multimorbidity has been generated for people living with four or more long-term conditions (NIHR, 2020).

In terms of multimorbidity recording, there is no standard index applied across research data (Diederichs, Berger, and Bartels, 2011). Thirty-nine different indices have been identified across research data spanning 49 years (1960-2009), and the common themes noted for inclusion are prevalent diseases that have a significant impact on health such as diabetes and stroke (Diederichs, Berger, and Bartels, 2011).

There is currently no global or UK monitoring of multimorbidity but in England there are five overarching priorities for the NHS in England for improving quality of life. The NHS Outcomes Framework (NHSOF) sets out the outcomes and measures to hold NHS England to account, and domain two of the Framework is to enhance the quality of life of those living with LTCs (DoH, 2013). Two of the measures are based on the GP patient survey and calculate the health related quality of life of people who self-report living with one or more LTCs (domain 2) and three or more LTCs (domain 2.7) (NHS Digital, 2019). Another domain (2.1) calculates the proportion of patients who felt supported to manage their LTCs. In 2018-2019, 45.3% to 66.6% of patients

reported that they felt supported to manage their LTC(s) (NHS Digital, 2020a), but how this information is applied to improve services is not clear.

2.1.2 Categorising young people in research

The United Nation's Youth Strategy defines young people as aged between 10-24 years (United Nations, 2018). It encompasses several developmental phases as young people move from childhood through to adulthood. In recognition of this rapid development and growth over a 14-year time span, Sawyer *et al.*, (2012) in their discussion on the nature of adolescence, merge youth and young adults in this age bracket of 10-24 years. They then subdivide it into three distinct bands of development where 10-14 years is defined as early adolescence, 15-19 years as late adolescence, and 20-24 years as young adulthood. These added distinctions are in recognition of the specific physical, cognitive, and social and emotional developments that take place within each of these age bands (Sawyer *et al.*, 2012). A young person can therefore be defined as someone whose age ranges from 10-24 years, and is undergoing an intense and rapid period of maturation which covers biological, emotional, and social developments as they move from early adolescence to young adulthood. However, in terms of disease surveillance and research data sets, the age bands that classify young people do not adhere to the 10-24 years definition and vary, for example, from a generic band of 0-24 years in a PHE study on multimorbidity (PHE, 2018) to a more targeted age banding of 16-24 years in a study on young people living with LTCs (Nuffield Trust and Association for Young People's Health [AYPH], 2019).

2.1.3 Young people and multimorbidity

The estimated number of young people (16-24 years) living with LTCs in the UK has increased from 13.5% in 2008 to 18.5% in 2019 (Nuffield Trust and AYPH, 2019). The UK has among one of the highest proportions of young people (16-24 years) living with LTCs when compared to comparable European countries, coming third after Finland (24%) and Sweden (20.5%) (Nuffield Trust and AYPH, 2019).

Across research data, asthma, depression, and anxiety are the most prevalent LTCs recorded in young people. In Australia, anxiety (11.3%) and depression (8.1%) were

the leading cause of disability adjusted life years (DALYs)² for females (15-24 years), whilst for males of the same age it was suicide and self-harm (both at 12.8%) and alcohol related accidents (7.2%) (Australian Institute of Health and Welfare, 2019). Among males and females aged 20-34 years, anxiety and asthma were the most frequently recorded diagnoses in Brighton and Hove (Brighton and Hove CCG and Brighton and Hove CC, 2018). Whilst among 20-24-year-olds, asthma and allergies were the most prevalent conditions in Denmark at 28%, (Larsen *et al.*, 2017). In terms of comorbidities, a study in Spain identified the most common comorbidities in the 19-24-year age group as anxiety and acne for females (0.9%), and acne and asthma for males (0.7%) (Violán *et al.*, 2014).

In the absence of epidemiological surveillance of multimorbidity, models have been developed to estimate its prevalence. In a seminal piece of work, Barnett *et al.*, (2012) developed a model to estimate multimorbidity prevalence and its determinants. The model was based on data from the 2001 census and 40 morbidities from a database of over 1.7 million patients registered to 314 medical practices in Scotland in 2007. They identified increasing multimorbidity with age, a correlation between multimorbidity in younger and middle-aged adults living in areas of socio-economic deprivation, an incremental relationship between physical and mental health (i.e. mental health deteriorated with the presence of more physical health conditions), and a higher prevalence of physical and mental health conditions amongst females. As a proportion of the multimorbid population, young people (aged under 25 years) made up a small number at 1.9% compared with 30.4% of 45-64-year-olds and 64.9% of 65-84-year-olds (Barnett *et al.*, 2012).

The relationship between increasing age and socio-economic deprivation (all ages), in addition to gender differences (i.e. more females than males are living with multimorbidity) were noted in a large systematic review of observational studies of multimorbidity in Spanish primary care (Violán *et al.*, 2014), and in a more recent PHE study (2018) of multimorbidity in the south-east of England. The latter study, applying the Barnett *et al.*, (2012) prevalence calculation model, and using data from the 2011 census, supported the correlation between increasing age, socio economic

² DALYs measure the years of life lost due to death (mortality), and lives lived adversely affected by disease and disability (morbidity). It is a calculation of the difference between the current data and an ideal, which is if everyone lived to a standard life expectancy in perfect health (Nuffield Trust and AYPH, 2019)

deprivation and multimorbidity. In addition, it noted gender differences with more females than males living with physical and mental health comorbidities at local authority level. It estimated that young people (aged 0-24 years) formed the lowest numbers living with multimorbidity across all three categories (i.e. physical health, mental health, and physical and mental health multimorbidity), comprising 3.5% (46,196) of those living with two or more LTCs (PHE, 2018). A Danish study, exploring the patterns of multimorbidity in a population, identified that female gender was linked to an increased likelihood of belonging to six out of seven multimorbidity classes³. The exception was the class of hypertension (Larsen *et al.*, 2017).

Some studies have explored educational attainment as a potential social determinant of multimorbidity. It has been suggested that there is an association between low educational attainment and numerous (i.e. six out of seven) disease classifications with the exception being in the asthma-allergy class (Larsen *et al.*, 2017). A cross-sectional Danish study of over one million people aged over 16 years in 2012 explored the association between physical and mental health conditions and educational attainment, and found that prevalence of multimorbidity was inversely related to education attainment (Schjøtz *et al.*, 2017). The proportion of people living with multimorbidity was calculated at 26.9% (95% CI, 26.8–26.9) among those with lower secondary education versus 13.5% (95% CI, 13.5–13.6) among people with post graduate education (Schjøtz *et al.*, 2017). This inverse relationship is supported in a cross-sectional study of the data derived from the German Health Update, which was a national telephone health interview study of 20,000 adults aged over 18 years, between March 2012-13 (Puth *et al.*, 2017). When the data was stratified by age, the authors suggested the inverse relationship between educational attainment and multimorbidity increased with each additional age group from the age band 30-39 years (Puth *et al.*, 2017). Of note was a pronounced increase in multimorbidity associated with low educational attainment in the 30-39 year age group when compared to the 18-29 year age group (Puth *et al.*, 2017).

Another feature of multimorbidity is its association with a learning/intellectual disability. Learning/intellectual disabilities are defined by the three criteria of i) lower

³ The multimorbidity classes included i) relatively healthy, ii) hypertension, iii) musculo-skeletal disorders, iv) headache-mental disorders, v) asthma-allergy, vi) complex cardiometabolic disorders and vii) complex respiratory disorders (Larsen *et al.*, 2017).

intellectual ability (usually an IQ of less than 70), ii) significant difficulty with social functioning, and iii) childhood onset (NICE, 2015a). Kinnear *et al.*, (2018) conducted a cross-sectional study of 1023 adults aged 16-83 years living with intellectual disabilities within the Greater Glasgow Health Board area. Multimorbidity was defined as having an intellectual disability plus two physical health conditions. The study identified 98.7% of participants were living with multimorbidity. The mean number of conditions was 11 with the most common conditions being visual impairment, epilepsy, constipation, ataxia (i.e. poor co-ordination) and gait disorders. The extent of the multimorbidity was the same for those with and without Downs Syndrome. For most conditions there was no association with age. There was also no relationship between area of deprivation and extent of multimorbidity (i.e. the number of adults with the most health conditions was not highest in the most deprived areas). However, the study identified that the more severe the intellectual disability, the higher the number of health conditions.

In sum, it is suggested that multimorbidity is associated with increasing age, being female, socioeconomic deprivation, low educational attainment, and living with a learning disability. In particular, physical and mental health comorbidities are associated with being female. It is estimated that whilst young people comprise only a small proportion of the multimorbid population, the inequalities seen in the distribution in older aged groups (i.e. living in socio-economic deprivation and being female), and being associated with low educational attainment and learning disability are seen in younger people. The census data on which the prevalence models (Barnett *et al.*, 2012; PHE, 2018) are estimated are now dated, and data on the increase in prevalence of LTCs in young people in the UK suggest that multimorbidity in turn, may be rising. Unfortunately, the extent of multimorbidity in young people may have been obscured by the low numbers of young people (aged under 25 years) as a proportion of the multimorbid population. The estimated low numbers may explain why younger age groups are aggregated in statistical reports, and why their data has been excluded from further interrogation on the wider determinants of multimorbidity (McLean *et al.*, 2014). There is therefore a potential gap in knowledge of the extent and composition of multimorbidity in young people.

2.2 Adaptation and living well

This Section will explore the process of adaptation to living with LTCs and identify the features of a successful adaptation. It will focus on how the early adaptation process may provide a helpful framework for exploring the relationship between young people's experiences with HCPs, care services, and significant others (i.e. partners, peers, and families) and their self-care behaviours in this thesis.

2.2.1 A successful adaptation to living with LTCs

Learning to live with LTCs requires undergoing a process of adaptation which is a coming to terms with the disease and altering one's lifestyle to suit the new situation (de Ridder *et al.*, 2008). Wright and Kirkby (1999) described it as "*adapting a new approach to being and living*" (Wright and Kirkby, 1999, p.270). Adaptation is a complex and dynamic process (Helgeson and Zajdel, 2017). There is no consistent definition of adjustment or way of measuring this construct (Moss-Morris, 2013). It may be understood as a process of responding to the functional, psychological, and social changes that occur with the onset and experience of living with a disability, chronic illness, or associated treatments (Bishop, 2005).

A successful adaptation outcome has been identified as self-management (Ambresin *et al.*, 2015; Campbell *et al.*, 2003; de Ridder *et al.*, 2008) which is "*an individual's ability to manage symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic condition*" (Barlow, 2001, p.178). It not only refers to the day-to-day practicalities of living with chronic illness but to the underlying skills, material, and personal resources such as supportive relationships, confidence, and knowledge to carry out the required tasks (Campbell *et al.*, 2003). Achieving self-management could be argued to enable people to live well. Living well is defined as "*a self-perceived level of comfort, function and contentment with life*" (Institute of Medicine 2012, p.32). More specifically, for younger people living with cancer, three features to living well were identified:

"First, they aim to live mindfully, focusing on the present without dwelling on sickness of the past or uncertainty about the future. Second, AYAs [adolescents and young adults] strive to create a healthy, productive lifestyle by identifying as healthy individuals, practicing nutritious, hygienic habits, and engaging in typical adolescent activities. Lastly, they emphasize the

importance of spending quality time with friends and family by having meaningful conversations and relationships.” (Schreiner et al., 2020, p.4)

Successful self-management for young people is therefore also about being able to participate in the world, and having fun and fulfilling close relationships.

Self-management is an on-going and evolving process (Audulv et al., 2012; Barlow, 2001; Corbin and Strauss, 1988) requiring illness management (e.g. managing symptoms and avoiding crises), role management (e.g. adapting to work routines, and family and social roles), and biographical work (e.g. managing one’s emotions and identity) (Corbin and Strauss, 1988). Audulv et al., (2012) suggest the management of chronic illness can be broken down into four phases: (a) seeking effective self-management strategies, (b) considering costs and benefits, (c) creating routines and plans of action, and (d) negotiating self-management that fits one’s life. This requires the mobilisation of resources, and the absence or presence of supportive social networks may make a significant difference in the course of adaptation to living with chronic illness (Bury,1982). Informal networks that are accommodating of people’s health conditions support the affected person to continue to live as normal a life as possible (Bury,1982). They can help to normalise and contextualise the health condition (Whitehead and Jacob, 2018), and facilitate the integration of treatment into the daily routine which enables people living with multimorbidity to balance illness management workload and capacity (Rosbach and Anderson, 2017).

In contrast, barriers to self-management include lack of motivation, capacity (Audulv, 2013), and the burden of illness and treatment. The burden of illness (e.g. pain) and treatment (e.g. added demands of attending medical appointments) occurs when workload demands of time and energy exceeds capacity (i.e. extent of the patient’s morbidity, their financial /social resources and literacy) creating an imbalance (Shippee et al., 2012) that could lead to:

“... a cohort of tired, distracted patients struggling to manage their lives in the face of multiple conflicting challenges, with insufficient energy for the level of personal agency required to deal with the self-management approach.”

(Francis, Carryer and Wilkinson, 2018 p.167)

The interaction of these features which complicate patient care is termed “*cumulative complexity*” (Shippee *et al.*, 2012, p.1042), and the role of the burden of illness on young people’s capacity to live well will be discussed in more detail in Chapters 7 and 8 (p.136 and p.179 respectively).

2.2.2 The route to adaptation and the early adaptation process.

Akyirem *et al.*, (2021) list the key theories underpinning the psychosocial processes of adaptation as (a) the Common-Sense Model of Self-Regulation (CSM) which explains adaptation through processes of perceptions of, and responses and actions to health threats (Leventhal *et al.*, 2016); (b) the self-efficacy and stress reappraisal model by Lazarus and Folkman (1984), which explains adaptation through processes of the individual’s appraisal of stressors, coping mechanisms, and abilities to affect the coping strategies; and (c) the Moss-Morris (2013) benefit finding model (Akyirem *et al.*, 2021). In the latter model it is argued that cognitive and behavioural skills informed by personality, early life experiences, social and environment factors, and illness-specific factors, underpin and enable the reinterpretation of the illness to see the benefits that lead to achieving balance (i.e. successful adjustment) (Moss-Morris, 2013).

The view of chronic illness as an underlying threat that must be managed predominates these models and with some justification. According to Charmaz (1983) living with severe chronic illness restricts daily life, and may lead to social isolation and experiences of being discredited or devalued. The sense of self is threatened as the previously held healthy identities are replaced by illness identities that are defined by physical impairments, emotional reactions to physical symptoms, and cognitive constructions of the illness (Charmaz and Rosenfeld, 2010). Bury (1982) articulates the development of a chronic illness as a “*biographical disruption*” (Bury, 1982, p.169) which involves a reappraisal of a person’s self-concept and biography. What then follows is a process of constructing a new sense of self, but this takes time to develop (Charmaz, 1983). The new identities are drawn from past social experiences, cultural meaning, and knowledge (Charmaz, 1983). Bury (1988) argues that there are two types of meaning in chronic illness; consequence and significance. Meaning lies in the consequences to the individual from the effects of illness on everyday life, and its significance in how different conditions carry different

meanings. The meaning people attach to their chronic illness may consequently have a profound effect on how they see themselves and how they think others will see them (Bury,1988). People living with chronic illness test the meanings against the reality of everyday experience to check if their perceptions are shared by others (Bury,1988). In a process Bury (1991) termed “*legitimation*” (Bury, 1991, p.456), it is suggested they repair the disruption that arises from any imbalance of others’ perception with their understanding. They do this by positioning their condition in their lives in such a way that it maintains their personal integrity, and minimises any threats to their social status.

The early adaptation process

Living with chronic illness therefore involves a reconstruction of identities. One framework that could arguably explain how people re-construct their identities following a diagnosis is the early adaptation process. Developed from a meta-synthesis of studies of people newly diagnosed with type 1 diabetes mellitus (T1DM), it attempts to understand the adaptive process in a formative diagnostic period identified as within the first five years of diagnosis (Due-Christensen *et al.*, 2018). The authors hypothesised that the adaptive strategies employed by adults newly diagnosed with diabetes in the initial adaptive period may impact on the risk of future medical complications and their psychosocial wellbeing (Due-Christensen *et al.*, 2018). Drawing on nine qualitative studies, Due-Christensen *et al.*, (2018) identified five constructs which described the underlying phenomena at play in this early phase. They explained how the interconnected constructs triggered by the disruption of the diagnosis shaped the view of illness, and informed the re-construction of view of self. These constructs in turn inform and are informed by learning about the condition and behaviour adaptations. There are five constructs of the early adaptation to T1DM:

1. The disruption construct describes people’s experiences of a diagnosis including people’s interpretations of and responses to a diagnosis. It is suggested the disruption construct was shaped by how people perceived the impact of the diagnosis on their employment, relationships, and life goals from which they then constructed a view of diabetes. Some may view a diagnosis as a major disruption to their future life plans (Due-Christensen *et al.*, 2018).

For some it was experienced as a shock (Johansson, Ekebergh, and Dahlberg, 2009) which was influenced by how the diagnosis was communicated and the support offered (Johansson, Ekebergh, and Dahlberg, 2009). For those who were unwell, a diagnosis was welcome as the start of medication eased their symptoms (Everett, 1999; Johansson, Ekebergh, and Dahlberg, 2009). But for those who experienced slow onset symptoms, they felt uncertain towards the changes to their bodies (Johansson, Ekebergh, and Dahlberg, 2009).

2. Constructing a personal view of diabetes describes how the person's adaptation to the illness was influenced by their perception of it and its impact on their lives (Due-Christensen *et al.*, 2018). The view of diabetes informed the way they engaged with others and their view of self. Some people minimised the impact (O'Hara *et al.*, 2013) whilst others became focussed on the potential severity of long-term consequences (Audulv *et al.*, 2013; Audulv *et al.*, 2012; Goldman and Maclean, 1998). The latter led to some associating with the disease where they became preoccupied and imposed restrictions on their lives (Everett, 1999; Goldman and Maclean, 1998; Johansson *et al.*, 2009). Some people disassociated from the illness leading to a relaxed approach to their diabetes management (Everett, 1999; Johansson, Ekebergh, and Dahlberg, 2009; O'Hara *et al.*, 2013; Samson, 2006).
3. Re-constructing a view of self describes how a diagnosis changed people's personal identity which influenced the way they engaged with others and thought about their future life goals (Due-Christensen *et al.*, 2018). Some found it difficult to identify with diabetes (Everett, 1999; Johansson, Ekebergh, and Dahlberg, 2009). This led to some disengaging from self-management behaviours (Everett, 1999). For others, having to redefine themselves impacted on mood and led to resentment (Everett, 1999; Goldman & Maclean, 1998; Johansson, Ekebergh, and Dahlberg, 2009) which in turn impacted on how they related to others, possibly leading to social isolation (Due-Christensen *et al.*, 2018). Relationships where the person felt that diabetes was not the focus of their interactions, and where they felt treated as before the diabetes diagnosis did not challenge their identity and were experienced as supportive of adaptation (Goldman and Maclean, 1998; Johansson, Ekebergh, and Dahlberg, 2009). To avoid stigmatisation some

people's behaviours were restrictive (Audulv *et al.*, 2012; Goldman & Maclean, 1998). Some people struggled to find a balance with their time on their self-management (Audulv *et al.*, 2012; Everett, 1999; Johansson, Ekebergh, and Dahlberg, 2009) which resulted in them viewing themselves negatively, and judging themselves harshly (Due-Christensen *et al.*, 2018).

4. Learning to live with diabetes describes the learning newly diagnosed people experienced as they made adaptations to living with diabetes which was influenced by the preceding constructs of view of illness, their reconstructed view of self, and their relationships with health and care professionals (Due-Christensen *et al.*, 2018). Learning that was supported and encouraged by HCPs had a positive impact on how they adapted to diabetes as did the timing of the learning (Due-Christensen *et al.*, 2018). An experiential learning style was preferred (Audulv *et al.*, 2013; Audulv *et al.*, 2012; Everett, 1999; Goldman and Maclean, 1998; Johansson, Ekebergh, and Dahlberg, 2009; O'Hara *et al.*, 2013; Samson, 2006). Seeking additional information outside the health care system whilst not always helpful was a way for those newly diagnosed with diabetes to learn about the condition and to take control of their diabetes (Everett, 1999). Understanding when to seek out more information in the early phases of living with the condition could be experienced as challenging. If changes occurred ahead of the person's understanding of the health condition and without the appropriate learning support, it arguably resulted in them reflecting negatively on their own ability to manage the condition. (Goldman and Maclean, 1998; Johansson, Ekebergh, and Dahlberg, 2009).
5. Behavioural adaptation describes the changes people newly diagnosed with diabetes made to their existing behaviours in addition to making new adaptations (Due-Christensen *et al.*, 2018). It was suggested differences in these adaptations were related to the previous constructs of their perception of diabetes, reconstruction of self-identity and learning style (Due-Christensen *et al.*, 2018). For some, having a life/work structure was helpful for making adaptations and bringing them into their daily routine (Audulv *et al.*, 2013; Audulv *et al.*, 2012; Johansson, Ekebergh, and Dahlberg, 2009). Some people were flexible. They tended to be more experiential learners and could be more adaptable to changing circumstances (Goldman and Maclean, 1998;

Samson, 2006). For others, they preferred more rigid strategies which gave them control but put restrictions on their lives (Auduly *et al.*, 2012; Everett, 1999; Johansson, Ekebergh, and Dahlberg, 2009) and meant they were less flexible in their adaption (Due-Christensen *et al.*, 2018). Some people would tend to be less flexible in their adaption strategies when they had limited knowledge of the health condition, or closely adhered to HCP prescribed diabetes management regimes (Due-Christensen *et al.*, 2018).

The early adaption process is influenced by people's learning styles, prior life experience, psychological orientation and interactions with others (Due-Christensen *et al.*, 2018). It supports the association between the emergence of illness and Bury's (1982) *biographical disruption*, but develops the interpretation of disruption from physical and identity changes to include the impact of psychological and social stress on the individual (Due-Christensen *et al.*, 2018). The movement between the constructs is not linear and experiences within one construct can inform others (Due-Christensen *et al.*, 2018) (see Figure 1, p.36). For example, a positive learning experience that simplifies blood glucose monitoring could inform and shift the view of disease as a condition that is hard to manage to one that can be accommodated into lifestyle. This in turn could reconstruct view of self as someone who is no longer defined by diabetes which may shape more flexible behaviour adaptations.

The early adaptation process describes the interrelationship between several adaptation constructs within a set time frame of five years post diagnosis on shaping self-management responses. As it is a formative time in people's health care journeys, the events/experiences of this time may be more readily recalled (Denzin, 2001). However, there is a question as to whether the constructs remain responsive over time or become fixed.

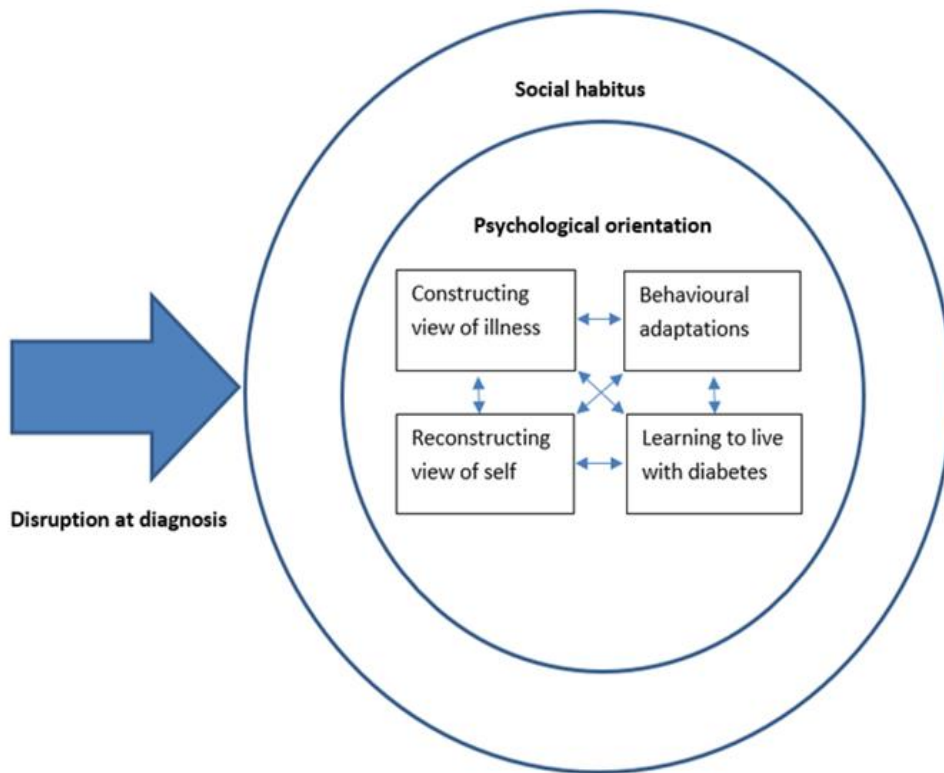


Figure 1. The interrelated process of adaptation in people newly diagnosed with type 1 diabetes (Due-Christensen et al., 2018, p.253).

In sum, learning to live with a LTC requires the person to transition through a process of adaptation to a position of achieving self-management, which in this thesis is aligned to the definition of living well. However, managing to live with a LTC requires several strands of management which involves resources (e.g. personal, material, and skills). Informal networks may support this by facilitating motivation and capacity. However, where the workload demand of self-management exceeds capacity it can become a burden and people may become overwhelmed, exhausted, and unable to self-manage. There are several psycho-social theories that have attempted to explain the adaptation process. The positioning of a LTC as an underpinning threat to self predominates. Of interest to this present study is the idea of the diagnosis as a threat to identity, the role of others in the reconstruction of self from this threat, and the resultant behavioural adaptations. Thus, a framework that may be helpful for exploring young people’s care experiences is the early adaptation process. It identifies several interrelated constructs that inform adaptation leading to

self-management within the early years of a diagnosis, which is a time in a (young) person's health biography that may be readily recollected.

2.3 Ecological systems theory (EST)

Ecological systems theory as described by Bronfenbrenner (1979) and latterly termed the bioecological model (Bronfenbrenner and Morris, 2006; Chuang *et al.*, 2018) is a theory of environmental interconnections and their impact on features (e.g. behaviour) of an individual's psychological development (Bronfenbrenner, 1979). It explores the features that are affected by the relationship between the growing person, their immediate setting, and the ideological and structural settings within which they take place. The features are interconnected and visualised as "*a nested structure each inside the next*" (Bronfenbrenner, 1979, p.3) where "*behaviour evolves as a function of the interplay between the person and environment*" (Bronfenbrenner, 1979, p.16). The contexts do not cause, but may influence behaviour, and developing persons are therefore bound with their various contextual (environmental) systems (Trudge *et al.*, 2016).

Bronfenbrenner (1979) identified four environmental systems: the microsystem, mesosystem, exosystem, and macrosystem. The microsystem is concerned with the immediate setting and the reciprocal interactions between the person and those who have a direct influence on their development. In a later definition of the microsystem, the influencing features were extended from people to include objects and symbols (Bronfenbrenner and Morris, 2006). The mesosystem refers to the connections and relationships between micro settings within which the person participates (e.g. between child and family microsystem and child and peers microsystem). The exosystem refers to one or more settings that do not involve the developing person as an active participant, but in which events occur that affect the developing person such as parents' work. Lastly, the macrosystem refers to the overarching patterns of ideology and organisation of the social institutions within a particular culture which indirectly affect the individual's growth (Bronfenbrenner, 1979).

The EST underwent three phases of development (Rosa and Tudge, 2013). In brief, it evolved from an ecological approach to human development in the first phase to focus on the role of the individual and developmental processes in the second

phase, and then finally, to the process–person–context–time model (PPCT) (Eriksson, Ghazinour, and Hammarström, 2018). Whilst Bronfenbrenner did not detail how to conduct EST research, it was in the PPCT model that key components of the bioecological research design were identified and described (Tudge *et al.*, 2016). The essence of this model is that the focus is on proximal processes (i.e. significant interactions) and how these proximal processes are informed by person characteristics, the context, and over time (Tudge *et al.*, 2016). There is an emphasis on the bio-system (i.e. the individual’s characteristics) and its role on development (Kamenopoulou, 2016). In a systematic review of papers on the application of EST to mental health research and how it has guided health policy, Eriksson, Ghazinour, and Hammarström (2018) suggest that the PPCT model, whilst arguably the most useful for guiding mental health policy and practice, has not been as commonly applied in EST research as the earlier models. Application has focussed instead on ecological systems concepts that (a) explore factors which affect mental health outside the individual without considering interactions between and within ecological systems, and (b) explore interactions within and between systems (Eriksson, Ghazinour, and Hammarström, 2018). It is this latter application I will be employing in this thesis, as it has been argued to be effective for developing practical recommendations for public mental health promotion and interventions (Eriksson, Ghazinour, and Hammarström, 2018).

This thesis is exploring how young people’s experiences of living with MLTCs shapes the early adaptation process. It is taking the findings (i.e. the features from interactions with specific groups of people in the early adaptation process that may shape health seeking and self-care practices/behaviours) and describing the context to those experiences. In so doing, I am examining interactions between and within young people’s environmental systems to locate specific recommendations to inform health and social care guidance, and meeting a key aim of the application of EST which is to mitigate “*developmentally disruptive influences*” (Bronfenbrenner and Morris, 2006, p.795). It’s application in this thesis will be discussed in detail in Chapter 8 (p.179).

2.4 Health and care landscape

This Section outlines how people requiring health and social care access the help they need (for non-emergency treatment) and gives examples of the care that is provided. It will discuss how care quality and management is implemented and the guidance available for caring for young people living with multimorbidity. It will draw on evidence of features of health and care experiences that young people have identified as youth friendly and compare them with the lived experience of young people transitioning from children to adult care teams. Finally the changes to the current health and care landscape will be outlined. Opportunities are presented for positioning the research findings within this new emerging landscape to affect change to young people's care management.

2.4.1 Access to health and care

Primary care is the first point of contact for people in need of non-urgent healthcare (NHS Providers, 2022). It includes general practitioners (GPs), dentists, opticians, and pharmacists (for medicines and medical advice). Health care professionals (HCPs) within GP practices aim to resolve problems with locally provided services such as the district nurse or through services provided by the practice. However, if a condition requires more specialised treatment or further investigation then patients may be referred to another healthcare provider in secondary, community health, or tertiary care (DoH, 2013; NHS Digital, 2022). Secondary care provides planned (elective) care such as knee replacement surgery, urgent and emergency care such as treatment for a fracture, and mental health care (NHS Providers, 2022; NHS Digital, 2022). Community health care services include district nursing, health visiting, child health services, and sexual health services (NHS Digital, 2022).

Access to both secondary care (with the exception of emergency care which patients can access directly) and community health care is by referral from a professional in primary care (The Medic Portal, 2022). Tertiary care which involves highly specialised treatment such as neurosurgery, transplants, and secure forensic mental health services (NHS Digital, 2022) can only be accessed via referral from a health professional working in secondary care (The Medic Portal, 2022).

Patients are entitled where possible to choose between different types of care and providers of their care, and they should be supported to make the choice that is best

for them (DoH, 2013). Care providers should work as an integrated care system as they refer a patient from one service to another ensuring continuity of care (NHS Digital, 2022). In addition to health care, social care or ‘care and support’ commissioned by local authorities provides a wide range of services and support designed to help people maintain their independence and wellbeing. Unlike NHS care, which is free of charge, with limited exceptions (Government UK, 2021a), state-funded social care commissioned by local authorities is means tested (DoH, 2013).

2.4.2 Care management

How health and care is delivered to those living with multimorbidity is informed by guidance provided by the National Institute for Health and Care Excellence (NICE) in the clinical assessment and management of multimorbidity (NICE, 2016a). NICE works to improve the quality, sustainability, and productivity of health and social care by producing evidence-based guidance and information for people working in and using the health and care sector in England (NICE, 2020). There is no specific guidance on the management of multimorbidity in young people. Guidance is located within care management pathways of diseases that both affect children and young adults, and where the pathology increases their risk of developing comorbidities. For this reason, NICE guidance on the diagnosis and management of diabetes (type 1 and type 2) in children and young people was reviewed, to provide an example of the care that is advocated.

Young people living with type 1 diabetes (T1DM) are at risk of developing comorbidities. High blood pressure, for example, was found in 26.7% of young people aged 12 – 24 years living with T1DM in the 2017-2018 National Paediatric Diabetes Audit (Royal College of Paediatrics and Child Health, 2019). Consequently, young people are monitored within diabetes specialist teams to identify high blood pressure, diabetic retinopathy, diabetic kidney disease, thyroid disease (type 1 only), and dyslipidemia (i.e. unhealthy cholesterol levels) (NICE, 2015b). NICE (2015b) guidance on diabetes service provision suggests that children and young people should be “*offered an ongoing integrated package of care provided by a multidisciplinary paediatric diabetes team*” (NICE, 2015b, p. 52). The services offered should include 24-hour access to advice, either home based or inpatient care management after the initial diagnosis, and regular liaison, education, and guidance

to school staff supporting children and young people. NICE (2015) suggests that the transition to adult services should not be dictated by age but by physical development, emotional maturity, local circumstances, and at a time of relative stability for the young person. Time should be allowed for familiarisation with the new team, and it should be made clear that the care provided will change. Underpinning these points are, at a care planning level, the involvement of children and young people, their families and carers in decision making about their care, and at a service level, local protocols for transferring young people from children to adult care teams. However, data suggests that young people living with T1DM are at risk of disengaging from secondary care once they have made the transition from paediatric to adult care services. The number of 20–24 year olds with diabetes having their HbA1c⁴ measured drops by >5% compared to the number of 10–19 year olds (Royal College of Paediatrics and Child Health, 2012). Whilst targets for HbA1c, cholesterol, and blood pressure were achieved by a higher percentage of young people pre transition than post (NHS Digital, 2017). There is a suggestion that this disengagement can have detrimental consequences for the young person and the NHS. The Royal Liverpool University hospital, reported a high non-attendance at diabetes clinics (DNA at 47%) and rising admission rates for diabetes-related emergencies among young adults aged between 19 and 25 years, (NICE, 2018). A systematic review of interventions along the transition pathway for young people living with T1DM suggest there is a gap in our understanding of young people's needs once they are in the care of adult services (Hart, Patel-Nguyen, Merkley, and Jonas (2019)

Globally, features that have been identified as a framework for adolescent friendly care include (a) equity (i.e. a right to obtain quality care, (b) effectiveness (i.e. effective care delivered at the right time), (c) accessibility and appropriateness, and (d) acceptability (i.e. meets young people's expectations) (World Health Organisation, 2002). Similarly, in a meta-synthesis of studies exploring characteristics identified by young people as being youth friendly (Ambresin *et al.*, 2013), young people valued being treated by HCPs with respect and understanding, and HCPs being approachable, non-judgemental, knowledgeable in their field, and

⁴ HbA1c is a measure of blood glucose. A healthy range in someone living with type 1 diabetes is between 43-53 mmol/mol (6-7%) (Diabetes UK, 2018)

trustworthy (Ambresin *et al.*, 2013). Some of these features can be identified in NICE guidance on diabetes management for children and young people (NICE, 2015b). In particular, accessibility and appropriateness of services that are tailored to young people's needs (e.g. the transition), and flexibility around care provision (e.g. inpatient or home-based management, and 24-hour access to advice). A detailed exploration of young people's experiences of transition and single disease care pathways will be explored in the literature review in Chapter 3 (p.49).

2.4.3 Changes to the health and care landscape

For the past decade the health and care landscape has been undergoing a protracted period of modernisation. With its antecedents in the Health and Social Care Act 2012, the underpinning case of modernising the NHS has centred around the need to manage rising demand and treatment costs with a need to improve outcomes in some areas of care/treatment, in particular, where England was lagging behind compared to other European countries (Government UK, 2012). A cross cutting theme of this Act was the promotion of better integration of health and care services. There is a recognition that the transfer of care between different departments/specialisms of health and social care have not been well managed, and the Act provides scope for more integration between services which are to be organised around the needs of the patient (Government UK, 2012).

A road map to its implementation, the NHS Long-Term Plan (formerly the Ten-Year Plan), outlines the framework that underpins the development of integrated care and place-based systems, with a focus on partnerships between professionals and patients (Kings Fund, 2020). It is a three-tiered model:

1. At system level is where strategy, managing resources, and performance takes place. It covers a population of 1-3 million.
2. At place level, changes to clinical services are designed and delivered, and population health management is used to target interventions to particular groups. This level is aligned with boroughs or councils covering a population of 250 – 500,000.
3. At neighbourhood level, GPs and community-based services work together to deliver co-ordinated and proactive care and support, particularly for groups and individuals with the most complex needs. Primary care networks (PCNs)

which are groups of GPs covering an area, and multidisciplinary teams operate at this level which covers a population area of between 30-50,000 people (King's Fund, 2020).

There are opportunities for young people to benefit from these proposed developments. There is a new children and young people transformation programme which oversees the delivery of commitments to children and young people (0-25-years) which includes tackling issues with transitions of care, increasing support for children with learning disabilities and autism, and improving mental health services. Moreover, of potential benefit to young people is the redesign of core community mental health services, with a focus on psychological therapies, physical health care, and employment support. Additionally, personalised care is to be introduced, and substance misuse support will be restored within mental health services (King's Fund, 2019).

2.4.4 Progress

Work has been underway since 2017 to develop the infrastructure to support these changes (Kings Fund, 2018). Since July 2019 almost all GP practices in England have come together to form about 1,300 primary care networks (PCNs). Each PCN covers a population of 30,000-50,000 people and brings general practices together, along with local providers to provide a wide range of professional skills and community services (Kings Fund, 2020). In January 2019, the five-year GP contract was agreed to allow it to deliver the features of the Long-Term Plan (LTP) which involves providing a wider range of services to patients (Kings Fund 2020). Additional finance was attached to the directed enhanced services (DES) aspect of the contract which was offered to PCNs (Kings Fund, 2020). In a rolling programme, they would deliver seven national service specifications: (a) structured medication reviews, (b) enhanced health in care homes, (c) anticipatory care, (d) personalised care, (e) supporting early cancer diagnosis, (f) CVD case-finding (to prevent cardiovascular disease), and (g) locally agreed action to tackle health inequalities (Kings Fund, 2020). An update to the contract was published in February 2020 to address the concerns of general practice and what it was reasonably expected to do (Kings Fund, 2020). The central features of the additions to the contract included: (a) recruitment of 20,000 additional staff working in GP Practices (2023/2024), to be

increased to 26,000 and to include four key roles (i.e. clinical pharmacists, physician associates, first contact physiotherapists and community paramedics, and social prescribing link worker roles); (b) plans to increase GP retention and recruitment; (c) updates to the specification around enhanced care home care, medication reviews and early cancer diagnosis; (d) to deliver 50 million more GP appointments, and (e) from October 2020, there was a new Investment and Impact Fund made available to incentivise PCNs to deliver the LTP objectives. In 2020/2021 the focus was on uptake of learning disability health checks and the flu jab, and prescribing and social prescribing referrals (Kings Fund, 2020).

2.4.5 Covid-19 pandemic

From early 2020, the UK along with the rest of the world was impacted by the global Covid-19 pandemic. Covid-19 placed unprecedented pressures on England's NHS and care system resulting in high numbers of deaths and hospitalisations particularly during the second wave (October 2020-February 2021). For example, on the 18th of January 2021, there were 39,254 Covid patients in hospital, occupying about 30% of all NHS hospital beds in the UK (Scobie, 2021). The indirect impacts of the Covid pandemic (national lockdowns⁵ and social distancing which restricted access to, and availability of health and care services) has created a backlog of people needing planned treatment, and a surge in demand for emergency care (Scobie, 2021). Urgent referrals for children and young people's health care services have surpassed pre-pandemic levels. There was a 47% increase in urgent GP referrals in early December 2021 to children and adolescence hospital services (Morris and Fisher, 2022). For mental health services, there has been an 81% increase in demand for services among 16–24-year-olds over the 2-year period from September 2019 to end September 2021 (Morris and Fisher, 2022). Unfortunately the imbalance in demand for and supply of mental health care is showing no signs of abating. A recent analysis of NHS data calculated that the number of urgent referrals of children

⁵ England was in national lockdown between late March and June 2020. Initially, all non-essential high street businesses were closed, and people were ordered to stay home, permitted to leave for essential purposes only. Starting in May 2020, the laws were slowly relaxed. People were permitted to leave home for outdoor recreation from 13th May 2020. On the 1st of June 2020, the restriction on leaving home was replaced with a requirement to be home overnight, and people were permitted to meet outside with up to six people (Parliament UK, 2021)

and young people (under 18 years) to mental health crisis teams has increased 46% (n= 21,555) in the year to March 2023 (YoungMinds, 2023).

2.4.6 Supply and demand workforce issues

The surge in demand for health care and treatment has coincided with work force supply-side issues. There is an increase in the numbers of health care staff leaving these services since the start of the pandemic (Palmer and Rolewicz, 2022). It has been calculated that 3.5% of nurses, midwives, and nursing associates in England have left the register at the year-end September 2021, and 8.4% of qualified permanent GPs have left in the year end to December 2021. Whilst these figures are argued to be relatively low (Palmer and Rolewicz, 2022), what is of concern are the underlying reasons which are exacerbated by the current workforce shortfalls. In the last decade, the numbers of nursing staff indicating work-life balance, lack of promotion opportunities, and health as reasons to leave has increased fourfold (Parisi *et al.*, 2019). The reasons cited by GPs for increased GP turnover include burnout, issues around job satisfaction, and physical working conditions (Parisi *et al.*, 2019). The situation within the GP workforce is anticipated to worsen as a group of older doctors who had been delaying their retirement now retire (Palmer and Rolewicz, 2022). The picture in social care is also of concern. Around 152,000 (equivalent to about one in nine or 11%) left the sector in 2020/21 (Skills for Care, 2021).

Within the mental health workforce, staff numbers have been increasing by about 1% annually for the last nine years, but the numbers of mental health nurses have been declining by about 3% over the same period (Rolewicz, 2021). Demand for mental health services however has been increasing. Improving access to psychological therapies (IAPT) has seen an 89% increase in referrals over the same period (Rolewicz, 2021). There were 337,000 referrals to children and young people's mental health services between April and September 2021, which is 81% more than the number of referrals during the same period in 2019. This compares to only an 11% increase in referrals for adults (Morris and Fisher, 2022). As an outcome of the increase in demand is an increase in waiting times. Between April 2020 and March 2021, 20% of patients seen by children and young people's mental health services waited over 12 weeks for a second appointment (Morris and Fisher, 2022). Funding

has been prioritised to increase staffing numbers and access to some mental health services, such as a £75 million allocation to meet the needs of people living with learning disability and autism in 2022/2023 (NHS England, 2022). In the meantime existing staff are feeling the work pressure. The sickness absence data shows mental health and learning disability trusts have the second-highest rates of sickness absence out of all trust types (Rolewicz, 2021).

Given these challenges, it is not surprising that patient satisfaction with the NHS has fallen. With overall satisfaction of the NHS falling to 36%, this is the lowest level of satisfaction recorded since 1997, when satisfaction fell to 34%. More people (41%) were dissatisfied with the NHS than satisfied (Kings Fund and Nuffield Trust, 2022). Whilst this fall was across all ages, income groups, sexes and affiliations to different political parties (Kings Fund and Nuffield Trust, 2022), an earlier GP survey identified that young people living with LTCs were less likely to say they received enough support from local services than adults (NHS Digital, 2018). Both groups' views on feeling supported have continued to worsen during the pandemic. It has dropped 6% between 2018 (74% of young people and 80% of adults) and 2021 (68% of young people and 74% of adults) (Government UK, 2021b).

In sum, non-emergency access to health care is generally via primary care with the starting point for anyone seeking NHS medical support usually being the GP. For social care, which is commissioned through the local authority, services can be approached directly but payment is required dependent on means. Health and care quality in England is informed by recommendations from NICE. There is currently no specific guidance on managing multimorbidity in young people and what is available can be found in the care management guidance for specific health conditions, such as diabetes. This suggests that those health conditions that are cared for at primary care level and do not require specialist support in secondary care are not subject to the same care management attention. A meta-synthesis of international studies has identified the key features that underpin a friendly health care experience for young people, and many of these features can be found in service providers' specifications for the care of young people living with diabetes in England. For the last decade the health and care system has been undergoing a period of modernisation to manage increasing demand whilst aiming to reduce costs and improve health outcomes. The new landscape offers opportunities for primary care to be responsive to local need

which positions geographically located research that can inform local health and care planning at an advantage. However, optimism at the opportunities to influence health and care provision/services needs to be tempered in the light of the workforce supply and patient demand imbalances within health and care, exacerbated by the Covid-19 pandemic.

2.5 Summary

There are gaps in the knowledge base regarding the extent of multimorbidity in young people (of all age bands), and of the morbidities and comorbidities with which they live. There is evidence that wider determinants of educational attainment and socio-economic deprivation seen in older adults may be associated with an increased incidence of multimorbidity in younger people, as does the presence of learning/intellectual disabilities and being female. The estimated low prevalence of multimorbidity in young people may have deterred past exploratory studies of young people's experiences, and may have contributed to the absence of care management guidance on young people living with multimorbidity. Guidance on the care management of young people living with T1DM suggest that they are underpinned by youth friendly features but data indicate that it is in adult services where young people are more likely to disengage from services with negative consequences for them and the health and social care network. Moreover, with the estimated increase in numbers of young people living with LTCs, together with the post-Covid increase in demand of young people requiring health care, especially from mental health care services, now is the time to better understand the prevalence of multimorbidity in young people and their care experiences to inform specific care management guidance. This PhD thesis is therefore particularly timely.

Learning to live with LTCs involves people to undergo a process of adaptation to reconcile their former healthy identities with their new *sick* identities. Adaptation requires resources such as skills, and material and personal resources (e.g. supportive relationships, confidence, and knowledge) to carry out the required self-care. Families and HCPs have a role in supporting and or equipping *sick* people with these resources. The early adaptation process (Due-Christensen *et al.*, 2018) draws together several interrelated constructs in the early years of receiving a T1DM diagnosis, and offers potential explanations for the disruption of that experience on

shaping the view of illness, re-constructing view of self, learning, and behaviour. Applying this framework to understand the role of significant relationships and HCPs in shaping young people's adaptation may help to identify features of services and their delivery that may enhance their self-management.

The EST is a theory of environmental interconnections and their impact on features of an individual's psychological development (Bronfenbrenner, 1979). Application of this model to the research findings may help to identify the environmental contexts that shape the early adaptation process and, in particular, inform health seeking and self-care practices. In so doing, it may determine potential outcomes and measures to meet the NHSOF domain two of enhancing quality of life for (young) people living with LTCs.

Whilst the new structure of the NHS provides opportunities for geographically located research covering primary care networks to shape local health care planning, there are historical workforce challenges that have been exacerbated by the Covid-19 pandemic, which may in the short-term undermine any attempts to implement recommendations to meet the health needs of the younger aged population.

The next Chapter will describe a narrative literature review of the care experiences of young people living with LTCs. It will explore the features from their interactions with HCPs and services that young people identified as seemingly supportive and encouraging of self-care practices.

Chapter 3: Literature review

This Chapter presents a literature review which identifies from the existing literature features of the care experiences of young people living with MLTCs that support them to live well. In the preceding Chapter, living well was defined as achieving “a *self-perceived level of comfort, function, and contentment with life*” (Institute of Medicine, 2012, p.32), and for young people this includes their participation in the world, and having fun and fulfilling close relationships (Schreiner *et al.*, 2020). Living well with LTCs is attributed to people’s abilities, skills, resources (Barlow, 2001), and motivation (Auduly *et al.*, 2013) to self-manage their health conditions (Ambresin *et al.*, 2015; Campbell *et al.*, 2003; De Ridder *et al.*, 2008). This Chapter will present the literature search strategy, and describe and critically assess the findings of this literature review. It will identify features of young people’s care experiences with HCPs and services that could be argued to shape their self-care behaviour. It will explore how these features may undermine or support young people to live well. Finally, the research aims and research question will be outlined.

3.1 The literature search strategy

In this Section, the literature review framework, data sources, literature identification criteria, numbers of studies retrieved, and limitations of this narrative literature review will be outlined.

3.1.1 Literature review framework

A narrative literature review is a non-systematic summary and critique of the literature on a specific topic for which there are no formal guidelines for their completion (Gregory and Denniss, 2018). A narrative review attempts to summarise the literature in a way that is not explicitly systematic (Baethge, Goldbeck-Wood, and Mertens, 2019) and its key contribution is to deepen understanding of the area under study (Greenhaigh, Thorne and Malterud, 2018; Rodgers *et al.*, 2009). In the absence of a systemised evaluation framework, it could be argued that narrative literature reviews lack consistency and produce variable results (Gregory and Denniss, 2018). Incorporating some of the features of structured systematic reviews may add structure and transparency to the narrative style literature review (Ferrari, 2015) to instil confidence in the results. Elements of the systematic review

methodology that have been applied to narrative reviews include the use of selection criteria and data extraction criteria (Dunham *et al.*, 2013; Hayes *et al.*, 2018). Other features that have been identified as providing a quality benchmark for narrative literature reviews include describing the literature search in detail and identifying the search terms (Baethge, Goldbeck-Wood, and Mertens, 2019).

To add structure and create transparency, this narrative literature review applied some aspects of the systematic review methodology and good practice guidance for narrative literature reviews by:

1. Identifying the search terms. See Table 1 (p.52) for the query strings applied in the search of records.
2. Applying selection criteria for identifying studies which any given study had to meet to be included in the literature review (Popay *et al.*, 2006). See Table 2 (p.53) for the literature review inclusion and exclusion criteria.
3. Applying the PRISMA framework for the identification and inclusion/exclusion of literature (Moher *et al.*, 2009). See Figure 2 (p.54) for the summary of the identification process of studies included in the review. See Appendix A (p.267) for the detail of the numbers of studies identified from each source, numbers of duplicates, and numbers excluded.
4. Applying data extraction criteria which included details of each study purpose, sample, study design, findings, limitations, and confirmation the findings drew on young people's care experiences. All studies that met this criteria were included in the study (Popay *et al.*, 2006). See Appendix B (p.268) for the list of studies that met the data extraction criteria.
5. Conducting the synthesis which is the process of bringing together the findings from the studies to draw conclusions based on the evidence (Popay *et al.*, 2006).

This current narrative literature review did not set out to systematically collect all literature on the care experiences of young people living with MLTCs, but to select and critique those studies of young people's experiences that identified features of services and HCPs' behaviours that affected their self-management. The following questions were applied in the review to focus the identification of appropriate studies:

1. What are the key messages from young people living with multimorbidity about their experiences of care?
2. How do their care experiences shape their self-care behaviour?

3.1.2 Data sources and literature identification

The literature search focused on four databases: CINAHL (Child Development and Adolescent Studies, CINAHL Plus, E books collection, E Journals, Medline, and PsycInfo); Scopus (a multi-disciplinary abstract and citation database of peer-reviewed literature including scientific journals, books, and conference proceedings), Cochrane (Independent high-quality evidence for healthcare decision making), and Pub Med (indexes US MEDLINE and biomedical journal articles from 1948). The databases were searched between October 2019 - May 2020 and updated in 2021. An additional search of Google Scholar and a targeted search of an integrated care journal took place in 2021.

Search terms

Two query strings were developed to identify studies exploring the care experiences of young people living with MLTCs. The first query string included terms for integrated care which is defined as person-centred and co-ordinated within healthcare settings, and across mental health, physical health, and health and social care (Government UK, 2015). The rationale for including this term was to capture studies of young people being cared for along several disease specific care pathways. As the term integrated care in health and social care has been in use since 2010 (Nuffield Trust, 2011) the publication time-period of the literature selected was 2010-2020. Search strategies of Cochrane systematic reviews identified a variety of terms to apply when searching the literature for studies on young people (Gilligan *et al.*, 2019), integrated care (Smith *et al.*, 2017), and multimorbidity (Butterworth *et al.*, 2019). These terms were applied to the first query string which retrieved 245 records of which 30 were assessed for eligibility and 12 were included in the review (see Appendix A, p.267).

Given the limited eligible studies identified, a second query string was developed to expand the literature search. Particular health conditions were included to capture young people's care experiences associated with these health conditions. Diabetes was selected as an example of a health condition with concordant comorbidities, and

asthma was identified as an example of a condition with discordant comorbidities. Patient outcomes such as “well controlled”, “poorly controlled”, and “disengagement from health services” were included to identify a range of potential consequences from the care experiences associated with living with these specific health conditions. Table 1 (below) illustrates the search terms applied in the first and second query strings.

Table 1. Search terms applied in the query strings.

	Terms for young people	Terms for multiple LTCs	Terms for care experiences
First query string	“young people” OR “young adult*” OR “adolescen*” OR “youth”	Multiple “long-term conditions” OR “long term conditions” OR “chronic disease*” OR “chronic illness*” OR “chronic condition*” OR “multimorbidit*” OR “multi-morbidit*”	“integrated care experience*” OR “health care experience*” OR “co-ordinated care experience*” OR “coordinated care experience*” OR “shared care experience*”
Second query string	“young people” OR “young adult*” OR “adolescen*” OR “youth”	Multiple “long-term conditions” OR “long term conditions” OR “chronic disease*” OR “chronic illness*” OR “chronic condition*” OR “multimorbidit*” OR “multi-morbidit*”	“chronic disease*” OR “chronic illness*” OR “chronic condition*” OR “diabetes” OR “asthma” OR “long-term condition*” AND “well controlled” OR “poorly controlled” OR “care experience*” OR “disengagement from health services”

An additional search was conducted in Google Scholar with the search terms all in title: “integrated care experiences of young people”, and in *the International Journal of Integrated Care* with the terms “young people” AND “multimorbidity”.

Identifying studies

All records were screened to select studies that were primary studies or systematic reviews that offered insight to the care experiences of young people living with multimorbidity or long-term conditions. The definition of experience applied in this current thesis is taken from a narrative review (Sinfield *et al.*, 2009) which investigated health care experiences of men living with prostate cancer:

“Patients’ reports of how care was organised and delivered to meet their needs. Patients’ reports could refer to either experience of health-care

services delivery and organisation overall, or their experiences of care by specific health-care personnel” (Sinfield et al., 2009, p.301).

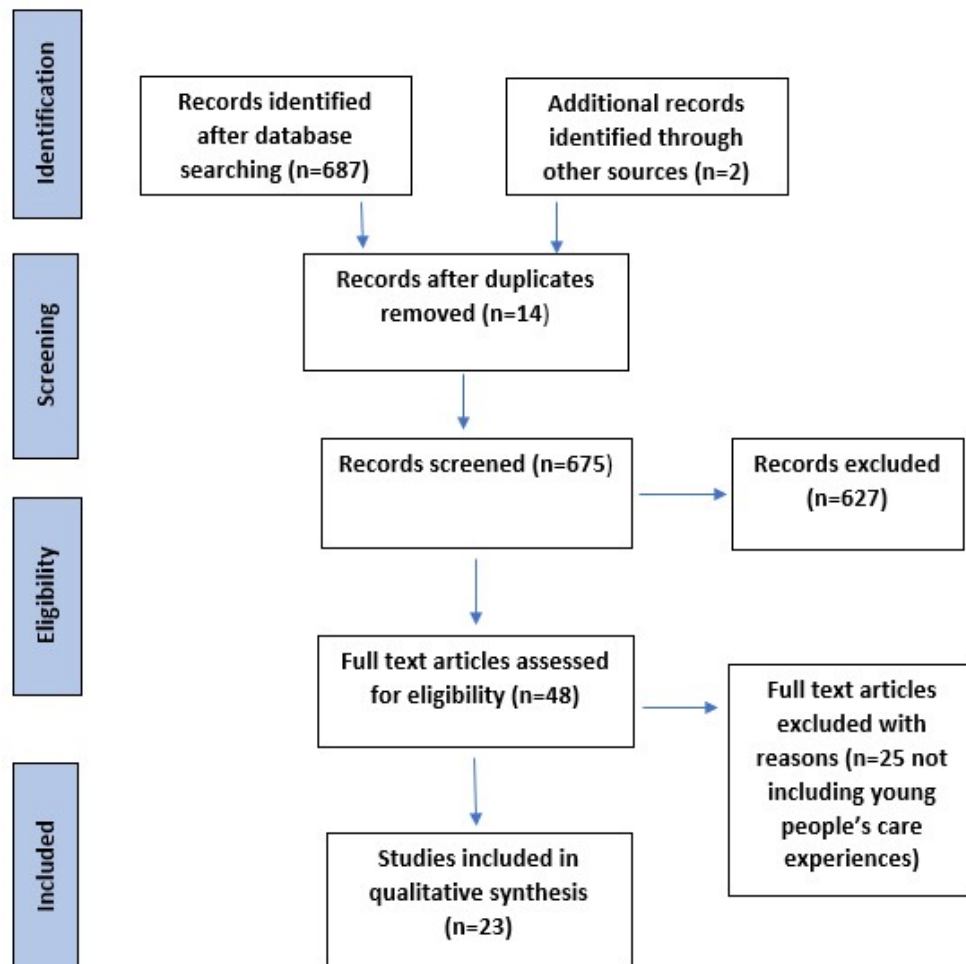
Studies that met the inclusion criteria were assessed for eligibility. The key features of the participants’ criteria included their age (10-24 years) and that they were living with multimorbidity or a LTC (physical and/or mental health conditions). The studies had to draw on young people’s care experiences, be published within a specific time frame, and published in English. Young people’s transition experiences from paediatric to adult care services were included along with integrated care and single condition care pathways. The transition process is complex and requires coordination and continuity of health care (Zhou et al., 2016). For many young people, transition will involve multiple services (NICE, 2020) and as such is potentially a good example of how services for young people living with multimorbidity may be delivered and experienced. See Table 2 below for the detail of the inclusion and exclusion criteria.

Table 2. Literature review inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
Multiple long-term conditions (multimorbidity)	Short term health conditions and care experiences such as oral health care and maternity/ante natal/post-natal care experiences
Long-term condition (chronic health condition)	Parental, family, health & social care professionals or other third-party perspectives of young people’s care experiences
Integrated care, transition care or single condition care pathway experiences	Studies on service/health outcomes not directly based on young people’s care experiences
Young people (no set parameters of age range in studies selected but to include young people aged ≥ 10 years and ≤ 24 years)	
Physical and/or mental health long-term conditions	
Publication date 2010-2020	
Records published in English	
Primary studies (qualitative, quantitative, or mixed methods study design)	
Systematic reviews where studies included young people ≤ 24 years and ≥ 10 years and where studies drew on care experiences of young people.	

Number of studies retrieved

A total of 689 studies were retrieved from the literature searches of four databases and the additional searches of Google Scholar and the *International Journal of Integrated Care*. See Figure 2 (below) for the summary of the identification process and see Appendix A (p.267) for the breakdown of numbers of studies retrieved and excluded from each source.



Adapted from Page et al., 2020

Figure 2. PRISMA framework summarising the identification process for the inclusion of studies in this narrative literature review

The application of the first query string retrieved most studies to be assessed for eligibility from Scopus (n=14) and PubMed (n=12), whilst the application of the second query string retrieved most studies to be assessed for eligibility from CINAHL

(n=13). Of the 48 studies assessed for eligibility, 25 studies were excluded. The two main reasons for the exclusion of studies from the review were attributed to (a) not meeting the criterion of drawing on young people's care experiences (the focus was on third party perspectives such as those of HCPs and parents), and (b) data specific to young people (10-24 years) could not be extracted from the findings. The literature review drew on the 23 studies that complied with the literature search inclusion and exclusion criteria. See Appendix B (p.268) for the list of studies included in the literature review and the data extracted from each study which included authors and publication date, title of the paper, study purpose, confirmation that findings were drawn from the experiences of young people, sample, geographical remit, diagnoses, methods of data collection and analysis, study findings, and limitations.

3.1.3 Limitations

Given the paucity of direct studies on the care experiences of young people living with multimorbidity, this review has included young people's experiences of the transition process and of single condition care pathways. Some studies included perceptions of parents and HCPs of the transition process, but only young people's experiences were included in this review unless it was to highlight how the perceptions of parents and HCPs contrasted with those of young people. Some primary studies in the systematic review of the transition process (Zhou *et al.*, 2016) were included separately as they contained relevant features to this review that had not been drawn out in the original paper.

3.2 Findings and synthesis

The eligible studies considered in this narrative literature review included two studies that explored young people's experiences of multiple care services, 12 studies of young people's experiences of transition from paediatric to adult care services, and nine studies of young people's experiences of a single disease care pathway. This Section will explore young people's experiences of HCPs and relational networks within each grouping of experiences to identify (a) features of care services that shaped young people's self-care behaviours, and (b) how these features undermined or supported their self-care.

3.2.1 Young people's experiences of multiple care services

Potential barriers to, and facilitators of young people's self-management behaviours are drawn from two studies that explored their experiences of multiple care services. Ådnanes and Steihaug (2016) conducted a qualitative study with nine young adults (18-30 years), most of whom were female, and living with mental health and complex needs in Norway. Four semi structured interviews resulting in a total of 32 interviews were conducted over a course of a year. The aim of the study was to capture young people's experiences and views about treatment and consistency of care throughout that year. The study highlighted that most of the participants experienced fragmented services as demonstrated by shifts between HCPs and problematic transitions between organisations. The participants with various diagnoses and difficulties were treated separately in different units instead of holistically by the same provider. Despite young people's need for long-term and collaborative relationships with the clinician, these were only present among the participants whose problems were less complex, for example, when not also involving substance abuse. Whether this lack of continuity with an allocated HCP is a result of service failings and/or participants' potential chaotic behaviour (e.g. missed appointments) due to their illness is not discussed. Many of the participants who had experienced trauma felt that HCPs chose to avoid talking about these experiences which led to participants closing-down communication with HCPs. Many of the participants in the study reported feeling they had only been consulted to a limited extent and therefore did not feel they were given sufficient information and had little influence on the choices made for them. Several participants reported feeling uncertainty and unpredictability from not being involved in decisions about their care.

A similar sized study in Australia involved six children and young people (aged between 7-15 years) living with chronic health. It described their experiences of integrated care in a paediatric hospital with a specialist unit for young people seeing multiple specialist teams (Johnson *et al.*, 2020). This study included experiences of parents and HCPs, but for this present narrative review only the six children and young people's experiences have been highlighted. Two recurrent themes were generated from semi structured interviews with children and young people following an interpretive phenomenological approach (IPA) and interpretive thematic analysis. The first theme described the anxiety that young people experienced from going to

hospital which made them feel reluctant to be there. Many children and young people felt they weren't included in discussions about their care or making choices about their care. They were unable to express their emotions in the context of care because they didn't feel heard. The children and young people recognised that they must participate in their care because it was an expectation of HCPs and their parents. They resigned themselves to procedures and processes to get them done, rather than being fully present and involved. Where participants did not communicate openly with HCPs, it was because they did not feel heard or understood. This response has also been referred to as social silencing and will be discussed later in this Chapter. The second theme described the impact of organisational structures, systems, and supports where young people associated positive experiences with people being kind to them, watching television, playing with toys, drawing, or having their parents beside them at point of care. The sample of young people is small comprising about a third of the total sample of participants. They were from one geographical location and predominantly female (n=5), suggesting the findings are gender and location specific.

In sum, these studies whilst limited provide rich insight into the care experiences of young people (both older and younger age groups) living with complex health needs requiring support/interventions from several services. Some young people experienced fragmented services and a lack of continuity of care (Ådnes and Steihaug, 2016). Young people (aged 18-30 years) living with complex mental health conditions and young people (aged 7-15 years) living with chronic health felt that they didn't have enough say in their care (Ådnes and Steihaug, 2016; Johnson *et al.*, 2020). They didn't feel their voices were heard by HCPs (Ådnes and Steihaug 2016). When young people did not feel involved in their care, it led to feelings of uncertainty (Ådnes and Steihaug, 2016) and of disempowerment (Johnson *et al.*, 2020). These negative care experiences may result in young people disengaging from services by either adapting a passive role (i.e. doing what is expected) (Johnson *et al.*, 2020) or not communicating openly with HCPs about their experiences and needs (Ådnes and Steihaug, 2016).

3.2.2 Young people's experiences of transitional care

Compared to the previous Section, many more papers (n=12) were identified on young people's care experiences of transition from paediatric to adult care services. Planning for transition from paediatric to adult care services usually commences between the ages of 13-14 years and is completed by 25 years (NICE, 2016b). NICE guidance states that the planning should (a) be developmentally appropriate, (b) allocate a named worker, (c) involve the young person in the planning, (d) build independence, (e) offer support before transfer, and (f) involve parents and carers in the process (NICE, 2016b). From the literature extracted on young people's experiences of the transition process, there were three themes generated: (a) transition is an anxious time for young people, (b) they experience inconsistent transitional care, and (c) they experience feelings of exclusion from decision making. Each theme will be discussed in turn.

Transition is an anxious time for young people.

The studies reviewed suggest that the transition process from paediatric to adult care services is an anxious time for young people with concerns about staff competency, quality of care, their safety, and of leaving behind care staff with whom they have become familiar and feel comfortable. How young people express anxiety has implications for their care, potentially resulting in an exacerbation of their health conditions. Young people who are anxious may become guarded in their communication with HCPs, conceal pain, or engage in social silencing with HCPs. HCPs consequently may not understand the full extent of how young people's symptoms are impacting them. A comprehensive integrative review of research-based evidence from 61 studies across four countries (USA, UK, Netherlands, and Canada) conducted between 2010-2014 on the transitions of care, identified that young people express negative feelings towards the idea of transition, and are anxious about the process and whether they would be accepted by the adult care teams (Zhou *et al.*, 2016).

The causes of young people's anxiety during the transition period were explored in a qualitative study of six case studies in the north west of England. The experiences of young people living with a physical LTC, disability, or mental health condition were triangulated with those of their parents/carers and health care professionals. The

health conditions per case study were not stated. Young people's anxiety was identified as rooted in i) not feeling ready to operate in the adult world, ii) getting to know new people, and iii) concerns about their safety and the competence of the new staff members (Medforth and Huntingdon, 2018). Concerns about staff competency and safety were echoed in two further studies. The first was a qualitative longitudinal study in two cities in England of 48 young people (13-21 years) living with sickle cell disease transitioning to adult care services (Renedo *et al.*, 2020). The participants came to recognise that their disease outside the specialist team was poorly understood. As a result they lacked trust in hospital staff to treat them correctly which led to them avoiding hospital. The second study was a systematic review (22 studies) on the outcomes and experiences of transition for young people living with cystic fibrosis ([CF] (Coyne *et al.*, 2017). This study in line with Medforth and Huntingdon (2018) also generated themes around young people's concern over the quality-of-care provision, and leaving behind previous HCPs with whom they had become familiar and felt comfortable.

For some, anxiety was stoked by negative perceptions of what adult care would be like. A qualitative study with focus groups of 15 young people living with irritable bowel disease (IBD) in Cincinnati, USA, identified that young people, their parents, and providers held negative beliefs of what adult care would be like based on their perceptions of adult care doctors. For example, there were common concerns that the young people would receive less quality care due to shorter appointment times and adult providers not communicating well with patients (Gray *et al.*, 2015).

How anxiety is expressed by young people varies and has implications for their care. For young people living with sickle cell disease, their anxiety about not wanting to worry others, of not being listened to or understood, led them to conceal their pain or engage in social silencing. Social silencing was referenced in the preceding Section on young people's experiences of multiple care services and is described by Renedo *et al.*, (2020) as "*a reluctance to talk about and disclose their condition for fear that others will not listen or will not understand*" (Renedo *et al.*, 2020, p.vii). For young people (13-19 years) living with epilepsy, anxiety about being judged negatively (e.g. for not taking medication) resulted in them becoming guarded and less open in their communication with HCPs (Lewis *et al.*, 2010). This study was a mixed methods

systematic review of the knowledge and information needs of young people living with epilepsy and their parents during transition.

Young people experience inconsistent transitional care

An integrative review on the transitions of care suggests an effective transition process is hampered by a lack of transition planning, insufficient preparation, poor health care service, inaccessibility, and ineffective communication between health care providers (Zhou *et al.*, 2016). Non-existent, inadequately followed through, or late commencing transition planning was reported in four of the six case studies in a small qualitative study of six case studies in north west England (Medforth and Huntingdon, 2018).

Young people's experiences of transition vary between service specialisms, service provision claims, and young people's experiences (Colver *et al.*, 2018). A two-year longitudinal mixed methods study of the transition experiences of young people living with complex needs described the extent to which service providers offer the nine beneficial⁶ features that underpin the NICE guidance, and compared this with young people's reported experience of them. Young people (n=304) were recruited from outpatients' clinics in England and Northern Ireland for diabetes (n=128), cerebral palsy (n=85), and autism with additional mental health conditions (n=91). Using quantitative data to measure exposure to service features, the study identified a higher proportion of young people living with diabetes experienced the beneficial features of transition services compared to the young people living with cerebral palsy or autistic spectrum disorder. For example, 83% of young people living with diabetes experienced age banded clinics compared with only 5% of young people living with autism, and 13% of young people living with cerebral palsy. The authors suggest this is due to diabetes services being more organised for supporting young people's transition. Of the differences between service provider claims and young people's experiences of service features, only 19% of young people experienced meeting the adult team when the service stated it was provided, (Colver *et al.*, 2018). This contrasted with age banded clinics and the promotion of self-efficacy where 77% and 80% of young people respectively agreed with the service providers that

⁶ Age banded clinics, meeting the adult team before transfer, promoting health self-efficacy, having a written transition plan, appropriate parental involvement, holistic life skills training, a key worker, a co-ordinated team, and a transition manager for the clinical team (Colver *et al.*, 2013)

they had received these services. The extent of these differences should be treated with some caution as some of the features implemented by service providers were expressed in a slightly different way to young people, which may have influenced the responses. However, the authors concluded that the nine beneficial features of transition services were poorly provided (Colver *et al.*, 2018).

In contrast, two quantitative studies in the Netherlands identified only slight differences across health condition specialisms. The two studies (one longitudinal) formed part of a large-scale evaluation exploring the differences and similarities in the experiences of young people (12-25 years), their parents, and providers across three care pathways before and after transition (i.e. juvenile idiopathic arthritis [JRA], type 1 diabetes mellitus [T1DM], and neuromuscular disorders [NMD]). Sonneveld *et al.*, (2013) concluded few differences between health condition groups in the satisfaction scores, and in the longitudinal study there was no difference in the mean gap scores of perceived satisfaction across specialisms (Cramm *et al.*, 2013). In both studies there was an imbalance in the sample as those living with NMDs made up only 10% of participants (Cramm *et al.*, 2013; Sonneveld *et al.*, 2013). This imbalance was not weighted in the statistical analysis. In response to this limitation, Cramm *et al.*, (2013) commented their findings were similar to other studies and Sonneveld *et al.*, (2013) highlighted that their findings with the NMD group were in line with the other participating groups.

Young people experience exclusion from decisions about their care

The lack of young people's involvement in decisions about their care and treatment has been noted in numerous studies of young people's transition experiences (Renedo *et al.* 2020; Sonneveld *et al.*, 2013; Ödling *et al.*, 2019; Broad *et al.*, 2017; Lewis *et al.*, 2010; Bundock *et al.*, 2011). Renedo *et al.*, (2020) identified participants felt that their knowledge and needs were disregarded outside specialist services. They felt the health-care staff refused to recognise patient expertise and reduced patients' say in decisions about their own care, particularly during unplanned care in accident and emergency departments (Renedo *et al.*, 2020).

Reduced involvement in decisions was reported by young people in a quantitative study in the Netherlands that compared transitional care experiences of young people (n=127 aged 12-25 years) living with a variety of long-term conditions with

their parents' experiences (Sonneveld *et al.*, 2013). Young people's satisfaction ratings on opportunities to make their own decisions and be seen without parents were much lower than their parents' ratings.

Some young people want to be involved in making decisions about their care and treatment (Ödling *et al.*, 2019). A qualitative study of young adults living with severe asthma recruited from an ongoing Swedish population-based cohort (n=16, mean age 23.4 years) aimed to explore how young adults with severe asthma experienced the transition process (Ödling *et al.*, 2019). Young people in this study reported that they needed to be involved in decision making but felt left out of the system which did not engage with them, and yet they felt there was an expectation they took responsibility for their care (Ödling *et al.*, 2019). The tension between young people wanting to be involved in decision making but not being overwhelmed with responsibility was noted in a qualitative thematic synthesis of youth transitional care experiences from child to adult mental health services in England (Broad *et al.*, 2017). The review of 18 studies, representing 14 datasets and the experiences of 253 young people identified the importance of services adapting to individual's needs and preferences for autonomy and independence. Of note was young people who experienced gaps in their service provision, or had a decreasing amount of formal support, welcomed and valued continued involvement and support from services (Broad *et al.*, 2017).

Young people's exclusion from discussions around their health condition was explored by Lewis *et al.*, (2010) in a mixed methods systematic review of the knowledge and information needs during transition of young people (13-19 years) living with epilepsy and their parents. Young people felt the discussion focused on the parent, and their feelings of exclusion were exacerbated by not understanding what was being said due to use of medical jargon. They wanted to be as equally informed as their parents and have discussions at their level, but often obtained the information from their parents at a later stage. The presence of a parent whilst supportive and boosting confidence could have a negative impact on information exchange. Their presence could hinder important disclosures from young people around private and sensitive issues. Of concern is when young people had difficulty understanding information given to them, they lost interest in the consultation, stopped listening, and adopted a passive role. Young people wanted HCPs to be

knowledgeable about their developmental stages and be responsive to their needs (Lewis *et al.*, 2010). However, in practice the study suggested HCPs avoided discussions about young people's emotional issues even when young people would have liked to address them. It was suggested HCPs didn't know how to respond and manage such conversations (Lewis *et al.*, 2010).

When the right balance of promoting independence and supporting with information is achieved, it can be experienced by young people as having a positive effect on their health (Bundock *et al.*, 2011). A quantitative study exploring the satisfaction surveys of young people living with perinatally acquired HIV (PaHIV) in England, and diabetes (type not specified) in Australia, identified that 68% and 72% of participants respectively believed that the transition had a positive impact on their health. The features cited as strongly important by three quarters of young people living with PaHIV included being treated as an individual, encouraged to be independent, and being given detailed management explanations. The questionnaire design for the diabetes cohort was shorter and omitted preferences so these responses couldn't be compared (Bundock *et al.*, 2011).

In sum, children and young people living with a LTC and receiving specialist care must make the transition from paediatric to adult care services. This review has drawn on the transition experiences of young people living with epilepsy, T1DM, asthma, JRA, IBD, NMD, sickle cell disease, cerebral palsy, autism with additional mental health conditions, and PaHIV. Transition is a period of anxiety for many young people. Anxiety is centred around the process (Zhou *et al.*, 2016), not feeling ready, worry about getting to know the new team (Medforth and Huntingdon, 2019), staff competency and safety (Coyne *et al.*, 2017; Medforth and Huntingdon, 2019; Renedo *et al.*, 2020), reduced quality of care (Coyne *et al.*, 2017), and preconceptions of adult care doctors, (Gray *et al.*, 2015). Fear of not being understood may lead to concealment of pain (Renedo *et al.*, 2020) and social silencing (Renedo *et al.*, 2020). Fear of negative judgements from HCPs may lead to guarded communication (Lewis *et al.*, 2010). This anxiety and fear is arguably justified given that young people's experiences of the transition process in England vary across providers and disease specialisms (Colver *et al.*, 2018), although little difference was noted across disease specialisms in two Dutch quantitative studies (Cramm *et al.*, 2013; Sonneveld *et al.*, 2013).

There is a strong theme running through several studies on transition experiences regarding decision making. Some young people expressed a lack of shared decision making in their care (Renedo *et al.*, 2020; Sonneveld *et al.*, 2013) and a disregard for their expertise (Renedo *et al.*, 2020). Others felt that a lack of involvement/exclusion from discussions was exacerbated by HCPs' use of medical jargon and focussing on the parent in consultations (Lewis *et al.*, 2010). Some young people want to be involved in decision making around their care, but others felt pressure to take on this responsibility (Ödling *et al.*, 2019). It was advocated that responsibility should not be forced on young people but should be appropriate to the individual's wishes and capacity (Broad *et al.*, 2017; Ödling *et al.*, 2019).

The consequences of these shortcomings on young people's transition experiences are that they can lead to young people disengaging from being actively involved in working with HCPs to manage their care. This can take the form of social silencing (Lewis *et al.*, 2010, Renedo *et al.*, 2020), adapting a passive role in their care (Lewis *et al.*, 2010), hospital avoidance (Renedo *et al.*, 2020), and concealing pain (Renedo *et al.*, 2020). However, the transition experience that young people feel is beneficial to their health is one where they feel that they are treated as an individual, are encouraged to be independent, and are given detailed management explanations (Bundock *et al.*, 2011).

3.2.3 Young people's experiences of a single condition care pathway

From the nine studies of young people's experiences along a single condition care pathway, there are several features of care services, HCP behaviour and relational networks (e.g. family and peers) that have been identified to either support or undermine young people's abilities and motivation to live well. These features could potentially be extrapolated to inform the delivery of multiple care services supporting young people living with multimorbidity. In this current review, the service features that may retain young people in care services and support treatment adherence have been collated into four themes. They involve services (a) meeting individual needs and preferences, (b) focussing on positive care experiences, (c) minimising epistemic tension, and (d) considering the wider relational behaviours that may undermine or support treatment adherence.

Meeting individual needs and preferences

Meeting the needs and preferences of young people was identified in a qualitative study in Australia as being important for maintaining their engagement in services (Wiley *et al.*, 2015). This study explored the experiences of young adults (18-35 years) living with T1DM with a variety of medical staff involved in their care. Through 150 surveys and 33 interviews they identified not only key disincentives to service retention, but young people's needs and preferences which included (a) joint consultation with multi-disciplinary team clinicians, (b) flexible access to advice by email or telephone consultation, and (c) shared decision making. Failing to meet young people's individual needs and preferences was highlighted as the cause of a high attrition rate of young people from adult services (Wiley *et al.*, 2015).

To meet young people's needs and preferences, HCPs need to consider the cultural context of young people's lives. Sligo *et al.*, (2019) conducted a qualitative study of the experiences of young people living with chronic illness in New Zealand and the health system's responses to meeting their needs. The study targeted Māori young people who made up 80% of the sample, and the remaining 20% were young people from other minority ethnic communities. The sample (n=21) of 16 females and five males were recruited from two urban areas. They were aged between 17-26 years and were living with asthma (n=10) or cancer (n=11). Despite some positive experiences with individual HCPs, young people in the main reported a health care system inconsistent in meeting their needs. The main gaps centred on HCPs lack of cultural understanding, and lack of recognition of how chronic illness impacts on relationships and changes their lives through altered life trajectories.

Focussing on positive care experiences

Negative care experiences can have counterproductive impacts on young people's self-care behaviour. Datype *et al.*, (2019) explored barriers to self-care adherence in two focus groups (n=11) of 17-21-year-olds to help improve the diabetes educator's role in supporting young people living with T1DM. In this study, some young people commented that interactions with some educators focussed on what was going wrong, what needed to change, and the long-term consequences of poor glucose control. This was viewed as a negative experience with some young people

expressing feelings of increased anxiety. One participant reported feeling nervous while waiting for the results of the (Hb)A1c blood test. This was a small study of the experiences of young people being treated at the same medical centre, so experiences were likely to be similar. However, the authors note that focussing on what's wrong does not bring about behaviour change, and the interaction needs to focus on what is important for the young person.

Feeling criticised and under attack from HCPs and parents can sometimes result in young people behaving rebelliously and disengaging from care. Starkman *et al.*, (2019) conducted a qualitative study (n=9) that explored interactions between young adults (13-19 years) with poorly controlled blood glucose, their parents, and health care professionals. Young people along with parents and HCPs reported feelings of failure, frustration, and anger, but unlike their parents and HCPs, the young people reported "*feeling dehumanised*" (p.33). They felt that they "*were trying to do one's best*" (p.35) but hidden feelings in the consultation were a source of reactive behaviours resulting in the young adult behaving rebelliously, the parents critically, and the HCPs remotely. The authors suggested that these interactions resulted in misunderstandings, conflict, and often young people's disengagement from diabetes care.

In contrast, a nurturing health care environment can be empowering for young people. A qualitative study (n=11) of young people (aged 14-21 years) living with NMDs in Australia explored their perceptions of health, health behaviours, and healthcare engagement (Travlos *et al.*, 2016). Longstanding, trusting, and non-judgmental relationships were identified as helping the young person to feel safe to openly discuss and ask questions which made it easier to learn about and manage their health. Lack of continuity of HCPs and perceived lack of interest were described as barriers to healthcare engagement (Travlos *et al.*, 2016).

Minimising epistemic tension

Where relationships with HCPs are not supportive and are combative, this may be the result of epistemic tension (Gibson-Scipio and Krouse, 2018). Lindström and Karlsson (2016) conceptualise epistemic tension as epistemic asymmetry in knowledge in relation to (a) access (the patient's access is to first-hand knowledge of the condition, whilst the doctor has superior general knowledge about the condition);

(b) rights (who has the right to know and what); and (c) responsibilities (doctors are responsible for giving adequate diagnoses and treatments and this requires trust). Gibson-Scipio and Krouse (2018) conducted a qualitative synthesis of literature published in the USA between 2005-2017 on the barriers to asthma self-management among African American adolescents. Their synthesis of 23 papers identified five themes that were related to disease management: (a) knowledge and skills, (b) beliefs and attitudes, (c) physical and emotional factors, (d) caregivers, and (e) schools. The results of the synthesis and proposed recommendations is an example of epistemic tension and how to resolve it. Three of the studies reported that familial methods such as use of steam were favoured by the caregivers over the evidence-based recommendations promoted by the health care team. The authors suggested that health care practitioners should think about including culturally based practices, in addition to past experiences and personal beliefs, into the asthma management plan to encourage self-management adherence with these families.

Haw, Cunningham, and O'Doherty (2018) explored epistemic tension between people living with asthma and healthcare professionals in clinical encounters and how they impact on self-management such as resisting expert knowledge. The sample (n=70) of participants who either had asthma or had a child with asthma were recruited in Canada through snowballing sampling to achieve a diverse cohort. The sample was not specifically younger people. Fifty-one females and 19 males aged between 18-80 years were recruited. They were interviewed between 2012-2013 about their health care experiences. Seventeen participants including two aged 18-21 years who took part in semi-structured interviews reported a negative encounter, defined as sharing expressions of disagreement and confusion or frustration with HCPs. They were asked about the object of the tension, how it was experienced, and their response to the tension. The analysis identified that in response to epistemic tension, patients fell into two camps where they either took up the expert knowledge or resisted it. The resistance took the form of walking out, arguing, or seeking alternative treatments. The catalyst for this response was highlighted as conflict in the patient's experience/knowledge of their body in relation to an asthma attack and the health care provider's response in line with clinical data. Haw *et al.*, (2018) argued that if clinicians incorporated the lay knowledge into the patient's care plan then it would lead to improved clinical care.

Considering wider relational behaviours that may undermine or support treatment adherence.

Evidence suggests that fear of stigma may result in poor adherence to self-management care. Monaghan and Gabe (2019) conducted a qualitative study in Ireland on stigma and young people living with asthma by looking at the experiences of young people from Traveller and settled middle class communities. Interviews were conducted with young people (n=31 and aged 5-17 years) living with mild to moderate asthma of which 16 were female and 15 were male. Data generated suggested that children seek to normalise their illness to integrate with peers so that they do not receive unwanted social reactions or asthma related stigma. This response was noted in the Gibson-Scipio and Krouse (2018) review of barriers to asthma self-management among African American adolescents. Two of the studies reviewed identified that young people living with asthma didn't want to be seen as weak or needing protection in physical activities, and so would ignore asthma symptoms to maintain a sense of normalcy. Peer relations in a school setting can be seen as challenging, consequently young people performing diabetes care focus on avoiding attention from others and minimising the risks of being bullied (Datye *et al.*, 2019).

Anderson and Tulloch-Reid (2019) reported that taking control and resisting being controlled was a key theme for young people living with T1DM in Jamaica. This qualitative study (n=19) of the diabetes management of non-compliant adolescents living with T1DM interviewed 14 girls and five boys with an average age of 14 years in focus groups in rural and urban locations. Young people tried to control who knew they had diabetes. They usually explained this as preventing unwanted information dissemination and the resultant stigmatisation. They also tried to control disclosure by hiding aspects of their diabetes management. However, when young people felt controlled by diabetes and others' understanding of it (e.g. when family members and others tried to ensure adherence with frequent reminders), they would become resistant by being non-compliant in their diabetes management. Of those young people who had become more compliant with their diabetes management, they did not feel controlled by their diabetes. Features associated with not feeling controlled by diabetes included being positive about their experiences, feeling supported by

close family and friends, identifying with a greater purpose, and normalising the condition. It was suggested that not feeling controlled by diabetes or others resulted in these young people being able to reject the negative meanings associated with living with diabetes (Anderson and Tulloch-Reid, 2019).

In contrast, young people (14-21-years) living with NMDs described their parents' unquestioning, always-ready-to-assist practical support as valuable in supporting their overall health and wellbeing, comparing themselves as healthier than peers who did not have access to such family support (Travlos *et al.*, 2016). Participants highlighted how their parents had helped them acquire knowledge through seeking and deciphering health information, and reinforcing important advice that had been given during health consultations. Of further assistance was the support of others living with NMD with the same or similar conditions. Connections, local and international, via social media and personal connections were named as very helpful to gain information, especially when they perceived that their HCPs disease specific knowledge was limited.

In sum, studies of young people's experiences along a single condition care pathway have identified four key features of care services and HCP behaviour that could support living well by maintaining service engagement and treatment adherence:

1. Meeting young people's needs and preferences (Wiley *et al.*, 2015) which includes considering the cultural contexts of young people's lives (Sligo *et al.*, 2019).
2. Focussing on positive and not negative behaviours to bring about behaviour change (Datye *et al.*, 2019). The interaction needs to focus on what is important for the young person (Datye *et al.*, 2019). Being critical of young people's abilities to self-manage results in feelings of failure, frustration, and anger that may provoke rebellious behaviour in young people (Starkman *et al.*, 2019). In contrast, a nurturing healthcare environment as exemplified by longstanding, trusting, and non-judgmental relationships helps young people to feel safe and to openly discuss and ask questions; making it easier to learn about and manage their health (Travlos *et al.*, 2016).
3. Minimising epistemic tension. This builds on point (i) and the importance of HCPs understanding a young person's culture in managing illness. By

incorporating lay and cultural knowledge into treatment plans, it will reduce tension and encourage treatment adherence (Gibson-Scipio and Krouse 2018; Haw et al., 2018).

4. Considering the influence of wider relational networks. This review has highlighted that care of young people cannot be viewed in isolation of the role of families and wider relational networks in shaping young people's self-care behaviour (Anderson & Tulloch-Reid, 2019; Datye *et al.*, 2016; Gibson-Scipio and Krouse, 2018; Monaghan and Gabe, 2019; Starkman *et al.*, 2019; Travlos et al., 2016). The role of families and relational networks can be either a source of supporting or undermining self-care behaviours. Fear of health condition related stigma and unwanted social reactions can result in young people seeking to normalise their illness by ignoring asthma symptoms to integrate with peers (Datye *et al.*, 2016; Gibson-Scipio and Krouse, 2018; Monaghan and Gabe, 2019) and hide aspects of their treatment routine (Anderson and Tulloch-Reid, 2019). Parents and peers can have an important supportive role by helping young people to acquire and understand health information (Travlos *et al.*, 2016). Support of others living with the same condition was important when HCP's knowledge is perceived as limited (Travlos *et al.*, 2016). However where families and communities try to ensure treatment adherence with for example frequent reminders, it can result in young people becoming resistant with non-compliant self-management (Anderson and Tulloch-Reid, 2019).

3.3 Summary

As discussed in Chapter 2 (p.23) the underlying premise of this thesis is that living well is associated with young people's abilities, skills, resources, and motivation to self-manage their health conditions so that they can achieve "*physical, mental and social well-being*" (Institute of Medicine, 2012, p. 32), which includes their participation in the world, and having fun and fulfilling close relationships (Schreiner *et al.*, 2020). Care services and HCPs have a valuable role to play in supporting young people to live well through encouragement, providing capacity, and developing young people's skills and knowledge to self-manage. However, data suggest that once in the care of adult care teams some young people living with

T1DM may disengage from support. There is a paucity of direct studies on the care experiences of young people living with multimorbidity. In response, this narrative literature review has drawn on young people's experiences of a range of care experiences; multiple care services, the transition process, and of single condition care pathways. The review has identified features (of services, HCP behaviours, and relational networks) that have been suggested to undermine or support young people's self-care, and could be potentially extrapolated to inform an understanding of the care experiences of young people living with MLTCs.

Young people's experiences of multiple care services have identified predominantly negative service features (such as fragmented services, lack of continuity of care, excluding patients from decision making, and not listening to patients) which resulted in feelings of uncertainty and disempowerment. These negative care experiences may result in young people disengaging from services by either adapting a passive role or not communicating openly with HCPs about their experiences and needs.

Young people may approach the transition period to adult care services with trepidation which stems from several sources. They are anxious about (a) not feeling ready to move on, (b) getting to know the new team, (c) staff competency and safety, and (d) experiencing a reduced quality of care fed by preconceptions that adult care doctors won't give them enough time, or will give complicated explanations and instructions that are difficult to understand. This anxiety is arguably justified given that services vary across disease specialisms in the features they provide and therefore care experiences will differ. Some studies have highlighted young people experience lack of involvement/exclusion from discussions prompted by HCPs' use of medical jargon and focussing on the parent in consultations. One study identified that young people felt HCPs had a disregard for their expertise. Fear of not being understood may lead to concealment of pain, hospital avoidance, and social silencing. Fear of negative consequences may lead to guarded communication and taking a passive role in their care. These responses suggest young people become demotivated and disengage from working with HCPs to manage their care which may undermine their self-management behaviours. However, where services and HCPs achieve the balance of promoting independence with information and support, it is suggested the transition process is perceived by young people as beneficial.

In contrast to the features of services that shape negative self-care behaviours as described above, young people's experiences along a single condition care pathway have identified features (of services, HCP behaviour, and relational networks) that could be argued to support young people to remain engaged with services, and to adhere to treatments and care plans. These features include meeting young people's needs and preferences, focussing on positive and not negative behaviours to bring about behaviour change, minimising epistemic tension, and considering the influence of wider relational networks in young people's care. The role of family and relational networks is significant in this dynamic either providing a supportive or undermining function.

This narrative literature review raises two questions. Are the features of HCPs, care services, and relational networks that shape self-management behaviour (a) transferable to young people living with MLTCs, and (b) sustained over time?

3.4 Research aim(s) and research question

The overarching aim of this research is to understand young people's lived experiences of care services, HCPs, and their relational networks as they live with MLTCs once they have transitioned to adult care teams, and to explore the features that support them to live well. Through the application of the early adaptation process, this research aimed to generate data to identify the features of these experiences that potentially shape the early adaptation constructs and inform young people's self-management behaviour. The application of the ecological systems theory to the data analysis in this research aimed to understand and contextualise how these features arise. Additionally, it aimed to explore how the early adaptation constructs in subsequent diagnoses are shaped by previous health and care experiences.

This present research theoretically relies heavily on Due-Christensen's early adaptation framework (Due-Christensen et al., 2018) as well as Bronfenbrenner's (1979) ecological systems theory. In doing so the following research question is addressed:

As young people (18-24-years) learn to live with multiple long-term conditions, how do their experiences of health and care services, care

professionals, and their significant relationships with family, peers, and partners shape the early adaptation process to enable them to live well?

This research question is answered via the achievement of the following activities/actions:

1. Identifying and describing the features of young people's interactions with HCPs, relational networks, and care services, and how they shaped the early adaptation process (the disruption from diagnosis, view of illness, reconstructing view of self, learning to live with the illness, and behaviour adaptations).
2. Identifying and describing how features of previous experiences with care services, HCPs, and relational networks may inform the early adaptation constructs of subsequent diagnoses.
3. Identifying and describing aspects of personal identities (e.g. age and gender) and potential wider determinants (e.g. level of educational attainment and socio economic deprivation) on young people's interactions with HCPs, care services, and relational networks, and the shaping of the early adaptation constructs.

The next Chapter will outline the underlining methodology of this thesis to generate and analyse the data to answer the research question.

Chapter 4: Methodology

Methodology concerns the justification of the research design and choice of research methods to generate and analyse data (King and Horrocks, 2010). It is informed by the researcher's theoretical perspective which is in turn shaped by their ontological and epistemological positions (Crotty, 2003). This thesis explores the meanings young people take from their interactions with health care services, professionals and relational networks as they learn to live with MLTCs. The focus is on how those meanings may shape the constructs of the early adaptation process (Due-Christensen *et al.*, 2018), and in turn young people's self-management behaviour. This chapter outlines how a relativist ontology and social constructionist epistemology informed the choice of research method (qualitative research) and theoretical perspective (interpretive interactionism) to generate and analyse the data to address the research question.

4.1 Philosophical position

The choice of theoretical perspective is informed by the researcher's beliefs about the nature of reality (i.e. ontology), and how we know what we know about the world (i.e. epistemology) (King and Horrocks, 2010). This Section will outline the researcher's ontological and epistemological positions, and how this informs her understanding of the research question and the choice of research method.

4.1.1 Ontology

In brief, a relativist ontological position holds that the world is unstructured and diverse (Angen, 2000). Human experiences and human understanding of those experiences are relative to the cultural and social constructs within which they live and how they interact with them, and as such they are open to diverse interpretation (Angen, 2000). Described also as idealist (Bourgeault, Dingwall and de Vries, 2013), this ontological view posits that we only have access to our ideas and subjective experiences. There is no access to the real world except through these ideas (Bourgeault, Dingwall and de Vries, 2013). Within this paradigm, when researchers are studying the world and in particular human experiences, they are studying their own understanding of others' interpretation and recounting of their experiences. Data

is generated from the researcher's representation of it (Bourgeault, Dingwall and de Vries, 2013).

The background chapter of this thesis (see Chapter 2, p.23) found that the prevalence of young people living with multimorbidity is skewed towards females (Barnett *et al.*, 2012; PHE 2018; Violán *et al.*, 2014) and those living with learning disability (Kinnear *et al.*, 2018). There are also social determinants to multimorbidity which have been identified as socio-economic deprivation (Barnett *et al.*, 2012; PHE 2018; Violán *et al.*, 2014) and low educational attainment (Larsen *et al.*, 2017; Puth *et al.*, 2017; Schiøtz *et al.*, 2017). My relativist ontology holds that each young person's interactions (with care services, HCPs, and significant relationships) in their social world of living with multiple LTCs will be informed by the socially constructed underpinnings of their multimorbidity.

4.1.2 Epistemology

Epistemology is the theory of knowledge (Bryman, 2016; Mason, 2018). The underpinning epistemological position of research refers to the principles by which the social phenomena under study can be known (Bourgeault, Dingwall and de Vries, 2013; Mason, 2018) and "*how knowledge can be validated*" (Mason, 2018, p.7). The shape of these phenomena follows from the researcher's ontological position (Creswell and Poth, 2018).

This study is focussed on young people's lived care experiences and how they shaped their view of the health conditions, reconstructed their sense of self, learned about the health condition and made behavioural adaptations. As knowledge is derived from how lives are experienced from encounters in the world (Mason, 2018), it could be argued that encounters/experiences and an absence of encounters/experiences form the building blocks and scope of our knowledge.

As a theory of knowledge, social constructionism deems that the world is derived from our construction of it in our daily interactions (Locke *et al.*, 2010). Unlike social constructivism, which focusses on the individual's role in editing meaning to make sense of their experiences (Burr, 2015), social constructionism "*... places the origin on social process*" (Gergen, 2015, p.30). Social constructionism is centred on the interaction and social practices and the process by which interaction leads to knowledge (Burr, 2015), which is then communicated through language (Gergen,

2015; Locke *et al.*, 2010). Based on a relativist ontology, how we construct meaning is informed by the social, cultural, political, and economic contexts of our lives. These macro forces, out of an individual's control, set the scenes in which people negotiate their lives. They are by association tied up with power relations because they have implications for what is socially, culturally, politically and economically permissible for different people to do/be (Burr, 2015; Locke *et al.*, 2010). However, whilst their influence is pervasive, they do not directly determine people's behaviour (King and Horrocks, 2010), as how we each interpret these influences on our world will differ (Locke *et al.*, 2010). Social constructionism as a theory of knowledge could be argued to comprise three elements: (a) symbolic interactionism, which locates meaning in encounters and interactions and so data is generated from these; (b) interpretivism, which refers to the sense that people make out of their lives, and the researcher seeks to interpret people's meanings; and (c) critical theory, which contends that life is shaped by social and historical processes, and the researcher seeks to identify and question these processes (Mason, 2018). To this latter point, I would also add socio-cultural, political, and economic processes as identified by Burr (2015) and Locke *et al.*, (2010).

4.1.3 Qualitative data generation

Qualitative data generation involves taking participants' accounts of their experiences which are then explored by the researcher through theoretical frameworks aligned with their ontological and epistemological positions to co-construct knowledge (Mason, 2018). The features of this type of research method include (a) a focus on nuanced aspects of social reality (such as social interactions), (b) contextualising understanding by placing the participant as the point of orientation, (c) seeking a close relationship with the participant to understand the world through their eyes, and (d) the application of words in presenting analyses of the social world (Bryman, 2016).

Qualitative research methods focus on making sense of participants meaning of the issue under study and generating data that provides rich and multiple perspectives (Creswell, 2009). The data generated provides descriptions and themes within a specific context and as such is not generalisable (Creswell, 2009). It is generated from a heterogenous group of participants, some of whom may be affected in their

responses by the presence of a researcher (Creswell, 2009). The researcher who is a co-creator of the generated knowledge may be influenced in their interpretation by their own backgrounds, history, contexts, and prior understanding (Creswell, 2009; King and Horrocks, 2010). Given the potential for generated data to be influenced by the research process, it is important to conduct research with integrity. Research integrity “*upholds values of honesty, rigour, transparency and open communication, as well as care and respect for those involved in research and accountability for a positive research environment*” (UKRI, 2022⁷). How research integrity is evidenced in the research methods of this thesis is addressed in Chapter 5 (p.82).

In sum, the underpinning ontology of this thesis is that the world is made up of multiple realities (a relative ontology). How young people learn to live with multimorbidity is socially constructed (a social constructionist epistemology) where meaning is construed through young people’s interpretations of their interactions (Burr, 2015; Gergen, 2015; King and Horrocks, 2010; Locke *et al.*, 2010) with care professionals and relational networks. These meanings are shaped to varying degrees by social and historical (Mason 2018), socio-cultural, political, and economic processes and structures (Burr, 2015; Locke *et al.*, 2010). These meanings are in turn interpreted by the researcher’s understanding of the world (Bourgeault, Dingwall and de Vries, 2013). As meanings are communicated through language (Gergen, 2015; Locke *et al.*, 2010) the emphasis is on words rather than units of quantity in data generation and analysis (Bryman, 2016). The features of this type of enquiry are aligned with qualitative data generation approaches (King and Horrocks, 2010; Creswell, 2009). However, this process has the potential to subtly influence both the responses of the study participants and the researcher’s interpretation in the data generation which places a stress on evidencing research integrity in the process.

4.2 Theoretical perspective

A theory is “*an interrelated set of constructs ...that specify the relationship between variables*” (Creswell, 2009, p.51). A theoretical perspective that brings together the researcher’s epistemological (i.e. social constructionism) and ontological (i.e.

⁷ UKRI 2022. Available at <https://www.ukri.org/about-us/policies-standards-and-data/good-research-resource-hub/research-integrity/>

relativism) constructs with a methodology to generate and analyse data (Crotty, 2003) to answer this study's research question is interpretive interactionism.

Interpretive interactionism was developed by Denzin (1989) as a critical interpretive approach that relates to people's experiences at key moments in their lives to better understand and respond (Denzin, 2001). It is a synthesis of several interpretive approaches including symbolic interactionism, interpretivism and critical theory which is aligned with social constructionism. It was developed in response to failings in social programmes to understand participants' meanings behind their actions:

"We must grasp, understand and interpret correctly the perspectives and experiences of those persons who are served by applied programs (sic) if we are to create solid and effective programs (sic)." (Denzin, 2001, p.3)

There are three features of interpretive interactionism that make it particularly appropriate for the purpose of this study which are discussed in this Section. They include its (a) suitability to health care research, (b) application of social constructionism to generate meaning, and (c) unit of analysis to facilitate the recall of past experiences.

4.2.1 Health care research

Interpretive interactionism was developed as an evaluation research method to assess policy success (Denzin, 2001; Mohr, 1997). It sets out steps for generating the data to describe a participant's meaning and understanding of a social problem with the aim of implementing a public response/action that will address it (Denzin, 2001). The questions that this approach raises are to its suitability and application to this study. Mohr (1997) argues that interpretive interactionism is suited to health care research. It situates the participant within a time and place and captures the participant's interpretations of their experiences and in so doing brings into focus the *"interventions they find helpful or not helpful and under what circumstances"* (Mohr, 1997, p.284). By extension it is identifying how an individual's personal ill health can be supported/improved through publicly funded health care systems (Mohr, 1997). Shaw (2003) concurs with Mohr that interpretive interactionism can influence outcomes enquiry. As such interpretive interactionism is an appropriate perspective for meeting the aim of this study which is to understand the features of young people's experiences with HCPs, care services and significant relationships on

shaping the early adaptation constructs and young people's self-management behaviours.

4.2.2 Generating meaning

The key perspective upon which interpretive interactionism is developed is symbolic interactionism (Flick, 2018; Mohr, 1997). Symbolic interactionism is a methodological position developed by Herbert Blumer (1969) on how meaning is constructed (Bourgeault, Dingwall and de Vries, 2013). It builds on three premises drawn from the empirical work of the anthropologist George Herbert Mead which include: i) human beings act rather than react towards things based on meanings that objects have for them, ii) meanings arise out of social interactions, and iii) these meanings are modified through an interpretive approach using the symbols of interpretation or by identifying the meaning of another's actions (Blumer, 1969).

The essence of symbolic interactionism is that meaning making is a dynamic and evolving process derived from individual and collective action where:

“Social reality is people individually and collectively, adjusting, meeting, and handling situations. It is people forging lines of action based on what they note, what they indicate to themselves – well or carelessly, wittingly or unwittingly. All social phenomena are emergent processes.” (Morrione, 1988, p.7)

Structural features are identified in symbolic interactionism as objects that humans act towards and these features, such as culture and social systems, may set the conditions for action but do not determine it (Blumer, 1969). Blumer (1969) contends that participants can have some control by deciding how to act towards the object and therefore they are *“freed from a coercive response to it”* (Blumer, 1969, p.69). This point has been criticised for not acknowledging how structural features can limit an individual's capacity to respond and act: *“It is interaction that shapes the self, but it is the social structure that constrains, and so within limits shapes interaction”* (Stryker, 1988, p.38).

Interpretive interactionism addresses the limitations of symbolic interactionism by drawing on critical theory and the role of socio-cultural, political, and economic constructs of wider society in shaping meaning. The focus of interpretive

interactionism is on the individual's experience at points in time, but it situates those experiences and their meanings within the broader constructs that shape people's lives (Denzin, 2001).

To develop an understanding of how these broader constructs shape young people's care experiences and meanings, I will explore their experiences through the lens of ecological systems theory (Bronfenbrenner, 1979). Described in Chapter 2 (p.23), ecological systems theory is a theory of environmental interconnections and their impact on the forces directly affecting psychological growth. Bronfenbrenner (1979) asserts that one needs to understand the interactions between and within the systems and individual factors to understand and explain the developmental outcome. I will be looking to contextualise the meaning young people attach to their interactions with care services, professionals, and relational networks by applying ecological systems theory in the data analysis.

4.2.3 The unit of analysis (epiphany)

Asking young people to recount their health care experiences located in the past poses a challenge that meaning may be forgotten/lost in the recollection and re-telling. Interpretive interactionism has as its unit of analysis the epiphany (Mohr, 1997). Epiphanies are the lived experiences that radically shape meanings people give to themselves (Denzin, 2001). A person is never the same again in these defining moments which are turning points for change (Denzin, 2001). At these significant events, the influence of structure on meanings that people attach to experience become more obvious (Denzin, 2001).

Denzin (2001, p.37), identifies four types of epiphanies: (a) major, where life is never the same again; (b) cumulative, which is the result of a series of events; (c) minor, where underlying tensions and problems in a situation are revealed; and (d) illuminative, which is minor but revealed retrospectively.

The data generation of this thesis will look to identify epiphanies in young people's lives as they live with multiple long-term conditions to explore meaning when it may be at its most clear. This unit of analysis dovetails with the disruption construct in the early adaptation process (Due-Christensen *et al.*, 2018). Described in Chapter 2 (p.23), the early adaptation process is a psycho-social account of how the view of illness in response to a diagnosis (i.e. the disruption) shapes the view of illness and

reconstruction of view of self, which in turn shapes learning and behaviour (Due-Christensen *et al.*, 2018).

4.3 Summary

My philosophical position holds that reality is relative where an individual's knowledge of the world is socially constructed, and where interpretations of social interactions are shaped by historical, social, cultural, political, and economic structures and processes. Some of the features that steer how young people's interactions are experienced will be informed by the socially constructed underpinnings of their multimorbidity. In the data generation and analysis, young people's perceptions of their experiences will in turn be interpreted by the researcher's understanding, informed by her life experiences and view of the world. This nature of enquiry lends itself to the application of a qualitative research method.

A theoretical position that aligns with these beliefs and will inform the data generation and analysis is interpretive interactionism. It focusses on the lived experiences of young people with MLTCs and their interactions with HCPs, care services, and significant relationships, and how these experiences shape the early adaptation process to address the research question. Interpretive interactionism is suited to generating meaning from young people's care experiences as it is aligned with social constructionism with its underpinning symbolic interactionism and critical theory. It will generate meaning which recognises the influence of broader societal, cultural, historical, political, and economic constructs. Interpretive interactionism can be applied to a research design that requires participants to recall past experiences and meanings. The unit of analysis is the epiphany which in this doctoral thesis is aligned to the disruption construct in the early adaptation process and helps to root experiences and aid memory recall. These features of interpretive interactionism facilitate the application of the ecological systems theory (Bronfenbrenner, 1979) and the early adaptation process (Due-Christensen *et al.*, 2018) in the data generation and analysis.

The next Chapter will describe the methods applied to this research topic to generate and analyse data in line with a social constructionist philosophy and interpretive interactionist theoretical approach.

Chapter 5: Research methods

This Chapter will outline the research methods that align to the study's methodology to address the research question. It will detail the research design, the choice of study setting and sample, the recruitment and interview processes, and the data generation and analysis processes. In line with a critical interpretive interactionist perspective (Denzin, 2011), the research methods will highlight (a) the use of multiple case studies (Section 5.3., p100), (b) finding crises in participant's lives (Section 5.1.5., p.91), (c) connecting to public issues and institutional formations (Section 5.1.6., p.93), (d) employing sophisticated rigour (Section 5.9., p.117), (e) presenting in the language/emotions of those participating in the study (Section 5.8., p.113), (f) stating one's value position on the phenomena under study (Section 5.1.2., p.85), and (g) the application of the five steps of interpretation (see Figure 3, below).

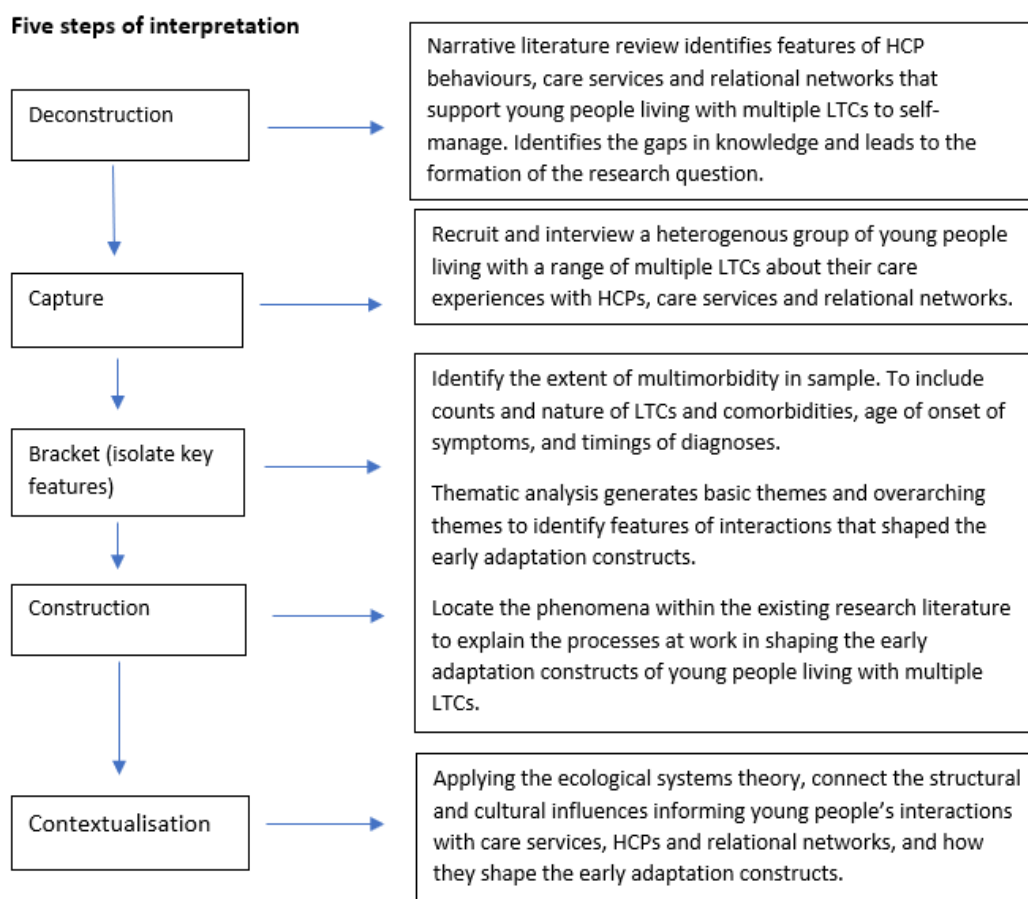


Figure 3. Alignment of study's research processes with the five steps of interpretation.

Figure 3 above (p.82) illustrates how the research processes from literature review (see Chapter 3, p.49) through to data generation, analysis (see Chapters 6, p.123 and 7, p.136), and discussion of the data (see Chapter 8, p.180) align with Denzin's (2001) five steps of interpretation.

5.1 Research design

As described in Chapter 4 (p.74), the underlying methodology of this study which is a relativist ontology, social constructionist epistemology and interpretive interactionist approach, is particularly suited to a qualitative research design (Creswell, 2009). It is specifically a cross-sectional qualitative research design as the data generation and analysis has been conducted with each participant within a particular time frame (Pandis, 2014). This Section will discuss the choice of data generation and analysis tools applied in this thesis.

5.1.1 Qualitative interviews

Data was generated through a two-phased semi-structured interview process to enable a remote adaptation of biographical mapping to support participants with memory recall (See Section 5.1.5., p.91). A semi structured interview employs a topic guide for each participant interviewed which consists of a list of questions or themes to guide the researcher through the interview (Bourgeault, Dingwall, and de Vries, 2013). The semi structured interview keeps the interview focussed on the topic (e.g. care experiences) but the participant in response to open ended questions is free in how to respond (Bryman, 2016). The flexibility of this interview structure allows the interviewer and interviewee to probe each other's understanding of meanings. It is an approach that enables the interviewer to be responsive to young people's cognitive, auditory, and verbal capacities (Mason, 2018).

How the study and the interview questions are communicated to participants in recruitment materials and in the topic guide underpin the data generation and analysis processes (Bourgeault, Dingwal, and de Vries, 2013). It is important that these are communicated in language that young people can understand and in a manner that builds a rapport. Rapport is described as an "*accountable, meaningful engagement with participants*" (Kolar *et al.*, 2015, p.15). It encourages participants to engage and remain involved in the interview (Bryman, 2016), and to put them at ease to talk about their experiences (King and Horrocks, 2010). Patient and Public

Involvement (PPI) had a significant role to play in facilitating a rapport in this thesis. The PPI contributions to the text and how it was presented in public facing materials and topic guide will be discussed later in Section 5.1.3. (p.87).

There is a fine balance to achieving a relaxed and comfortable experience for the participant to put them at ease to talk with the researcher, but not so relaxed that the boundary between researcher and participant becomes blurred and the participant inadvertently discloses more than they intended (Mason, 2018). In conducting semi structured interviews, researchers have to take care to avoid influencing the performance of the research participant (McCambridge, de Bruin and Witton, 2012). Demand characteristics refers to *“participants being aware of what the researcher is trying to investigate, or anticipates finding, and what this implies for how participants are expected to behave”* (McCambridge *et al.*, 2012, p.1). Demand bias may occur for example when the participant discerns the purpose of the interview questions and answers the question in accordance with what they thought the interviewer wanted to hear (Chan *et al.*, 2022). Some interview techniques may tend to generate demand bias. For instance, leading questions and the researcher’s inferred judgements may direct a participant’s response resulting in potential data omissions (Chan *et al.*, 2022). One way to minimise demand characteristics is for the researcher to be reflective of the interview process. Reflection-in-action is thinking in the process of conducting the interview and reflection-on-action is thinking after the interview (Schön,1983). Both focus on the researcher’s feelings and reference relevant theories to learn from the experience to shape current and subsequent actions (Smith, 2016). Maintaining a fieldwork journal to reflect on (a) how well I thought an interview went, (b) where any challenges lay that disrupted the interview/interviewee rapport, and (c) what I could have done or did to minimise them was a helpful learning process and served to refine my interview techniques. See Table 3 (p.85) for an excerpt from my fieldwork journal highlighting my reflections on the interview techniques with a participant who gave limited detail and very short responses to my questions.

Table 3. Excerpt from the researcher's fieldwork journal.

Interview ID no.5 Date: 12 th March 2021 Time: 3.30pm
<p><i>"This was a challenging interview as the participant would give short replies that lacked detail. I needed to follow up most responses with a question to try and tease out further detail. Unfortunately, I found myself asking closed questions which defeated the object of what I was trying to achieve and missed opportunities to capture the participant's voice:</i></p> <ul style="list-style-type: none">• Interviewer (I): 'So, what was the tipping point then, when you thought this isn't right, I need to see somebody about it?'• Participant (P): 'Probably when I went on a school trip, and I started wheezing and coughing and couldn't breathe properly.'• I: 'Was that frightening?'• Pt: 'Yeah.' <p><i>I should have asked an open question such as, 'tell me how that felt?'</i></p> <p><i>Discussion around their experiences of asthma felt particularly laboured but when we started to discuss their experiences of living with [name of health condition] they became more forthcoming (as this is an ongoing issue) but I still needed to ask questions to obtain detail. It felt more like a question-and-answer session than a discussion. I need to be mindful in interviews where participant's need to be asked for further detail to focus on open ended questions and not get caught in a cycle of asking closed questions to elicit the detail of their experiences".</i></p>

5.1.2 Reflexivity

Reflexivity in contrast to reflection focuses on how the researcher's sense of self impacts on how they see the world, others, and their place in relation to it and them (Smith, 2016). To be reflexive is to critically reflect on the impact of one's background, assumptions, positioning, feelings, and behaviour on constructing meaning (Smith, 2016). Reflexivity in qualitative research *"is an invitation to look 'inwards' and 'outwards', exploring the intersecting relationships between existing knowledge, our experience, research roles, and the world around us"* (King and Horrocks, 2010, p.125).

A requirement of an interpretive interactionist researcher is to state their value position on the area under study (Denzin, 2001). For social constructionists meaning is not waiting to be discovered but is brought into being in the act of social exchange. The researcher is part of that process (King and Horrocks, 2010) and their perspective therefore needs to be acknowledged. Sandberg *et al.*, (2016) relate this view to Heidegger's philosophical stance. He argued that to be able to interpret lived experience the researcher needs to have some understanding of the lived experience they are researching. Denzin (2001) contends that having lived experience enhances the process of generating rich and detailed *thick* descriptions

and interpretations which are “*deep, dense, detailed accounts*” of experience (Denzin, 2001, p.98). However, this comes with a note of caution to the researcher not to overestimate their capacity to empathise or know the *other* just because of prior experience (Mason, 2018). Reflexivity is important to acknowledge in the thematic analysis that the researcher’s theory of knowledge informs their values and positions on the analysis (Clarke, 2017). Themes do not emerge but are a result of the researcher’s subjective stance and the data generation tool (e.g. interview) (Clarke, 2017).

I come to this PhD research with experience of both working as a HCP and of being a patient. I have seen how my professional behaviour can either motivate or disengage the people I am supporting to make lifestyle changes to manage their health. As a patient, I have experienced HCP attitudes/behaviours where their cultural assumptions about my life have led to my disengagement from their support. With reference to young people, I have two children who are now young people. I have witnessed in my professional life the impact of both positive and negative interactions on young people’s lives. Young carers, for example, who were bullied by their peers for being different, but found support and acceptance when given opportunities to socialise with other young carers.

I believe that structural inequalities and personal challenges in young people’s lives impact on their everyday experiences. How these experiences are interpreted and understood can be shaped by the interactions in their relational networks and with those whose role it is to support and enable them to live well.

In my data generation and analysis, I was vigilant to identify features in young people’s recollections of their interactions with HCPs and relational networks that could impact on shaping the early adaptation constructs. In the interview process, I probed participants’ responses where I identified a potential link between these features and young people’s views and behaviours. See Table 4 (p.87) for an excerpt from an interview transcript in which I ask the participant to elaborate on their perceptions of the parent’s same diagnosis, and how this understanding informed their view of the health condition and its management.

Table 4. Identifying a young person's perception of an illness: an excerpt from an interview transcript.

ID no.3 Second interview
<p><i>I: 'Did you know that your Mum had IBS before you experienced symptoms?'</i></p> <p><i>P: 'Yes, my Mum has a number of health conditions... I never paid much attention to it as a child growing up. It was only when I started getting symptoms that I talked to her, and she told me that she takes peppermint oil capsules daily when she gets flare-ups, and she takes probiotics to help manage her IBS. When she's not having flare-ups, she's absolutely fine.'</i></p> <p><i>I: 'So how did that make you feel?'</i></p> <p><i>P: 'It definitely helped knowing that my mum had flare ups and that you could manage them whereas when I first started getting the symptoms, I wondered if it was ever going to end.'</i></p>

The participants in this study had experienced a number of challenges in their lives where they reported feeling bullied by peers, unsupported by family, teachers, and employers, dismissed by HCPs, and felt that the health care, employment, and education systems had compounded the challenges they experienced. This triggered in me a protective maternal response and I felt angry towards the bullies, and both disappointed in and angry towards the unsupportive family, teachers, employers, HCPs, and the underpinning organisational systems. To mitigate the data generation and thematic analysis being shaped by my emotional responses to hearing these experiences, I focussed on applying an asset-based approach both to the questions I asked and in the data analysis. An asset-based approach draws on Antonovsky's (1979) theory of salutogenesis which refers to the study of the origins and assets for health and wellbeing as opposed to the origins of disease and their risk factors (Mittelmark and Bauer, 2016). Assets may include (a) an individual's resources such as character traits and social attachments, (b) family resources such as finances and supportive relationships, and (c) community assets such as schools and youth groups (Idan, Eriksson, and Al-Yagon, 2016). These are resources that people draw upon and influence their wellbeing. I focussed on features of the relational networks (i.e. families, partners, and peers), teachers, employers, HCPs, and organisational systems that young people felt were supportive of them as they were living through challenging life events.

5.1.3 Patient and Public Involvement (PPI)

The study incorporated patient and public involvement (PPI) in the research design; specifically in developing the wording of the participant materials, design of the data

generation tool, and the timing of the interview schedule. “*Public involvement in research means research that is done ‘with’ or ‘by’ the public, not ‘to’, ‘about’ or ‘for’ them.*” (Health Research Authority, 2021). There are advantages to involving participants/public and other stakeholders in the research design as (a) they focus on current issues that are important for them, but which may not be apparent to researchers/clinicians, therefore making the research relevant to practice, and (b) they make suggestions to improve accessibility for participants who may positively influence research (Stocker *et al.*, 2021). In the development and implementation of this research, I established a young people’s advisory group for the duration of the study, and involved wider stakeholders such as youth workers⁸ for guidance on engaging young people remotely, and a GP for guidance on GP practice recruitment (i.e. the intended study setting).

The young people’s advisory group (see Appendix C p.278 for Terms of Reference) comprised two young people living with long-term conditions (see Appendix D p.280 for Roles and Responsibilities). One member was recruited through a local diabetes nurse specialist, and the other through a colleague. Neither advisors were included as participants in the study.

As the research design was carried out during the Covid-19 pandemic, social distancing guidance was in place and communication with advisors was conducted over the telephone or via text messages. The advisors’ involvement included informing the wording of the public facing content such as the text invitations, the participation information sheet (PIS), and the webpage content. They made suggestions to make the wording more concise and therefore more likely to engage potential participants. See Figure 4 (p.89) for an advisor’s feedback on the wording and layout of the participant information sheet (PIS). The advisors were also consulted on the images, sound, and words of a digital story of the literature review. Their feedback included changing some of the images and sound track to improve accessibility and hold the attention of young people. See Figure 5 (p.89) for the advisors’ feedback on the video.

⁸ What is Youth Work (National Youth Agency, 2022)

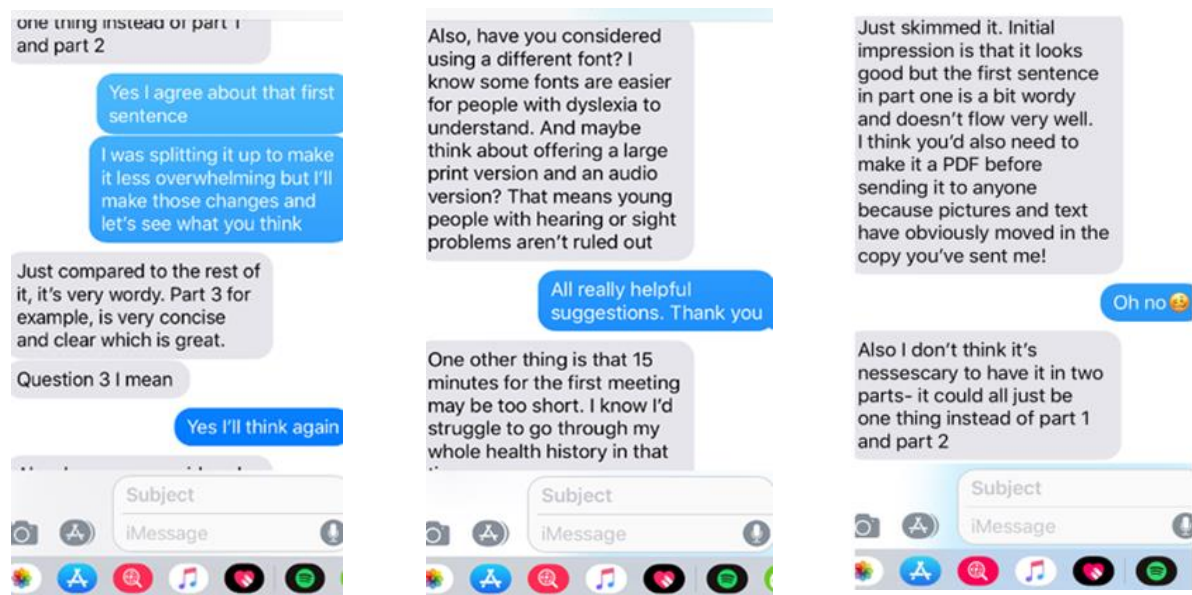


Figure 4. Extracts from text correspondence with the young people's advisory group members on the PIS.

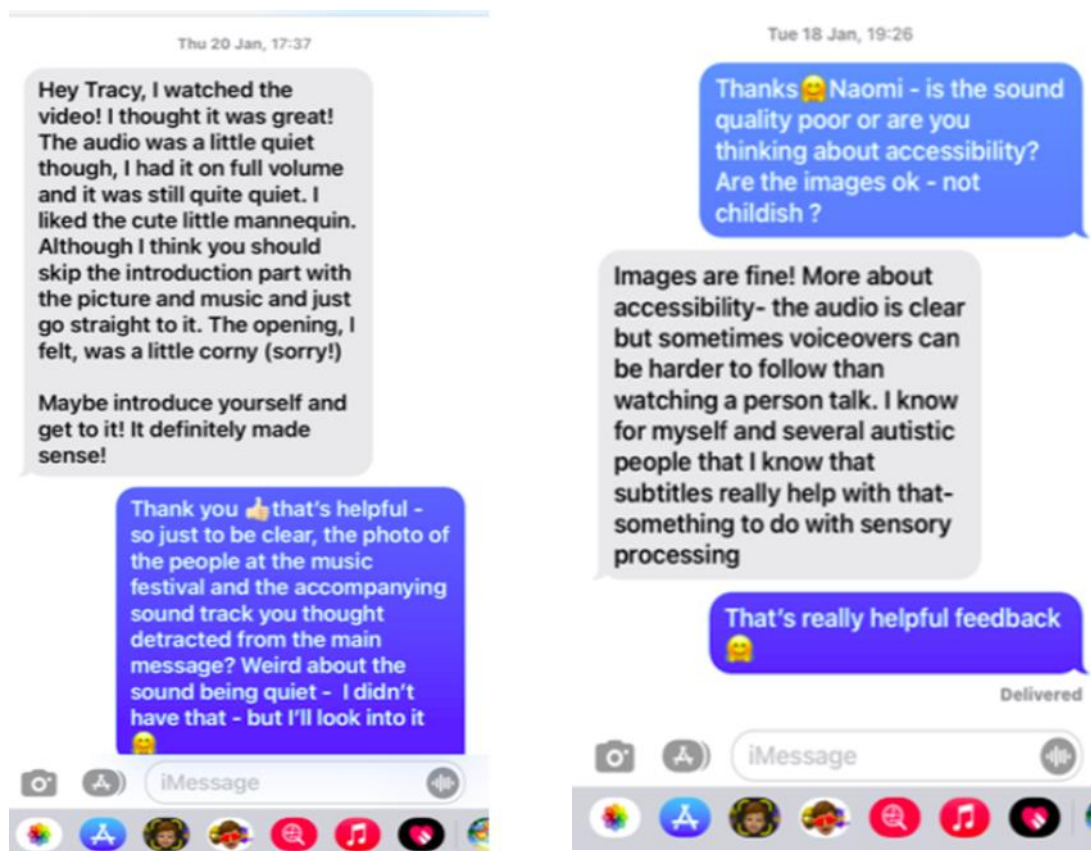


Figure 5. Feedback from advisors on the video of the literature review.

In addition to the advisory group, a GP outside the study (whose role in establishing the study setting will be discussed in Section 5.1.3., p.87) and youth workers were consulted. The youth workers work with young people (aged 11-25 years) in community settings helping them with personal, social, and educational development (National Youth Agency, 2022). Youth workers in my initial choice of geographical location for the study setting were approached about how to best engage remotely with young people. Their guidance was invaluable. My initial thought of conducting interviews with participants over Zoom was discounted based on feedback from their experiences. They had reported they had not been able to engage young people in activities over Zoom during the first national lockdown citing the demographic's poor internet connections, lack of access to privacy, and limited data availability. This feedback focussed my attention on telephones as a more appropriate data generation tool for the study sample.

5.1.4 Telephone interviews

Following the PPI feedback and an exploration of research methods literature, telephone interviews were identified as a suitable data collection method with this study's demographic. Mobile telephones potentially make young people more accessible to researchers (Flanagan *et al.*, 2015). They give the researcher direct access to young people rather than having to gain access via a household landline where messages may not be relayed. Young people may still choose not to answer a mobile telephone call, but one potential access barrier has been removed.

Telephone interviews may facilitate rapport building and comfort with talking to a researcher because of the anonymity of the remote nature of the interview (Flanagan *et al.*, 2015), and the familiarity it provides for those used to virtual conversations (Trier-Bieniek, 2012). It may also put the participant at ease because they have the flexibility to hold the interview in a space of their choice whether it's in their bedroom or on a park bench. It has been argued that this method of data generation contributes to developing rich data around topics that may be perceived by participants as sensitive (Drabble *et al.*, 2015). However, a potential limitation to telephone interviews is that without the usual visual cues of friendliness, such as smiling or maintaining good eye contact evident in face-to-face interviews, rapport maintenance may be harder to develop and sustain (Bryman, 2016). Opportunities to build a rapport were built into the study design in (a) the two phased interview

process which involved a remote biographical mapping activity in the first phase before the in depth second interview, and (b) showing respect and appreciation for the participants' experiences and time. This latter point involved giving participants opportunities to check the data generated from the interview process for accuracy, offering a thank you voucher, and asking if they would like to be sent a copy of the thesis, and consulted on the dissemination of the findings.

5.1.5 Unlocking memories

As a reminder, this study explores young people's past and current experiences of care services, HCPs and relational networks to identify features that supported/support them to live well. In applying Due-Christensen's early adaptation process, the starting point for plotting the health biography was young people's experiences of receiving their first and then subsequent diagnoses which informed the shaping of the disruption constructs (Due-Christensen *et al.*, 2018). It is suggested in my research that receiving a diagnosis can be likened to a crisis point/epiphany in young people's lives (Denzin, 2001).

How the study design helped to unlock these memories was through the co-creation of a health biography in the first interview which was then referenced and served as a memory aid in the second interview. The health biography is argued to be particularly suitable for studying the course of health and illness over time. It visualises an individual's health and wellbeing over time and within the social context of the individual's wider life course (Schubring, Mayer, and Thiel, 2019). The recall of age appropriate "*flashbulb*" events (Berney and Bane, 1997, p.1521) beyond the health care experience such as school and family transitions (Graham and Hill, 2003) are incorporated to draw on wider significant experiences in a young person's life. This brings into focus "*other longer term and diffuse influences*" (Wilson *et al.*, 2007, p.141) that may be missed if the focus of recall was just on a specific life event. It has been argued that the application of life history data generation focusses on the positive aspects of life transitions. In so doing it operates from an affirming and strengths-based approach rather than a deficit and risk approach (Harris and Rhodes, 2018). This perspective as discussed in the Section (5.1.2., p.85) underpinned my data generation and analysis.

Recounting upsetting and challenging experiences may lack a coherent structure; the “*chaos narrative*” (Frank, 2013, p.97) which is hard for the listener to follow. The interviewer may struggle to keep track of the chronological sequence and timing of critical events (Kolar, Ahmad, Chan, and Erickson, 2015). By mapping the health biography prior to the in-depth exploration of participant’s experiences, the interviewer has an *aide memoire* of timings of events which enables them to follow the narration during the second interview without interrupting the participant’s flow, and distracting them from their narration; potentially leading to a loss of valuable data. The visual prop may assist with memory recall to maximise opportunities to generate *thick* descriptions. As highlighted earlier, *thick* in the context of interpretive interactionist data generation refers to detailed and rich descriptions (Denzin, 2001).

Biographical mapping is a valuable visual elicitation tool for retrospective health analysis. As a data elicitation tool, biographical mapping has been evidenced to show a positive impact on a) participants’ memory recollections (Schubring, Mayer and Thiel, 2019), b) the interview dynamic, seemingly making participants comfortable with the process (Harris and Parisi, 2007; Schubring, Mayer and Thiel, 2019), and c) data management and interpretation, allowing follow up questions and facilitating data clarification (Harris and Parisi, 2007).

In my application of biographical mapping, I created a visual representation of the participant’s biography in the form a health and life grid based on the data generated from the first semi-structured telephone interview (see Appendix E, p.282 for an example of the visual representation of the participant’s biography). The participant has an opportunity to add to and amend the visual image to ensure its accuracy before proceeding to the second interview.

Visual biographies offer research participants the opportunity to identify and discuss subjectively important life events, and for participants and researcher to explore together the events and experiences in greater depth (Bagnoli, 2009; Goldenberg *et al.*, 2016). This participatory approach may challenge the traditional interviewer/interviewee dynamics as participants may control the pace and order of the recounting of their biographical accounts (Parry, 1999; Wilson *et al.*, 2007). In the application of the process to this thesis, I did take control and directed the order of participants’ recounting of their experiences. The starting point for the interview was

the lead up to the first diagnosis. Subsequent diagnoses were asked to be recounted sequentially with the aim of capturing the influence of earlier care experiences on the ensuing early adaptation processes.

Biographical mapping is a dynamic data elicitation method. It traditionally combines a semi-structured drawing activity and a narrative interview, where narrative interview questions shape and respond to the evolving biographical map (Schubring, Mayer, and Thiel, 2019). Due to its interactive nature, it is conducted in a face-to-face setting and combines creating the image with the interview (Harris and Parisi 2007; Kolar *et al.*, 2015; Parry, 1999; Schubring, Mayer, and Thiel, 2019; Wilson *et al.*, 2007). As a result of the Covid-19 pandemic and the need to maintain social distancing to minimise risk of infection, I had adapted this tool to be conducted remotely over the telephone and over two interviews several days apart.

5.1.6 Data analysis

This thesis generated data from two sources: (a) young people's health biographies from the first interviews, and (b) the in-depth accounts of their experiences from the second interviews. The health biographies enabled the collation of timings of symptom onset, diagnoses, treatments, and HCPs consulted, in addition to the number and nature of morbidities and comorbidities. Against this backdrop, the in-depth second interviews generated data that explored how young people derive meaning of their health conditions through their interactions with care services, HCPs, and relational networks and, how these interpretations shape the early adaptation constructs.

Data from the health biographies from the first interview took the form of descriptive counts whilst themes were generated from the second in-depth and semi-structured interviews. Themes are recurrent features of participants accounts which the researcher deems as pertinent to the research question (King and Horrocks, 2010). Thematic analysis is a generic process (Bryman, 2016; Creswell, 2009; Flick, 2018), which captures patterns within the data (Braun and Clarke, 2006). It is not tied to a particular epistemological or theoretical perspective and therefore the researcher needs to make clear from the outset which approach they are using (i.e. what is underpinning the analysis) (Clarke, 2017). The type of thematic analysis that aligns with the underpinning epistemology of this doctoral thesis is reflexive/organic

analysis (Clarke, 2018). Meaning is contextual and the researcher acknowledges multiple realities and his/her subjectivity. This analysis is an iterative process and is fluid and flexible. There is deep engagement in the data with the researcher at the centre (Clarke, 2018).

Thematic analysis can take the form of inductive analysis which is the development of themes grounded in the data (Clarke, 2017; Flick, 2018) and deductive analysis which is the development of themes from existing knowledge and theories (Clarke 2017; Flick 2018). In this doctoral thesis, both inductive and deductive analyses were applied. In the deductive analysis, themes were developed that captured how young people's experiences with HCPs, care services, and relational networks shaped the constructs of the early adaptation process such as view of illness and view of self (Due-Christensen et al., 2018). In the inductive analysis, patterns within the data, such as experiences of bullying and inflicting self-harm, were coded and explored to identify the features accompanying this behaviour, such as it being experienced by some young people living with neurodevelopmental conditions post diagnosis.

The thematic analysis process has been detailed by Attride-Stirling (2001) who offers steps to analyses using thematic networks and Braun and Clarke (2006) who offer a step-by-step guide to thematic analysis in psychology. Features from both guides were applied in this research. Themes were developed in stages from basic themes generated from the text to organising themes which are groups of basic themes, through to global or overarching themes which encapsulate the underpinning meaning/interpretation of the basic and organised groups of themes (Attride-Stirling, 2001). Attride-Stirling (2001) represents the themes as web-like maps to illustrate the relationship of the thematic networks. I did not choose to do that, preferring to group the themes in tabular format. See Table 12 (p.116) for an example of tabular formatting. The themes were identified at a semantic level (i.e. the themes are generated from the surface/explicit meanings of the data) but the grouping of themes involved a progression from description (of themes) to interpretation (of themes) where the significance of the patterns is generated (Braun and Clarke, 2006). For example excerpts from interviews that captured how young people experienced their ill health symptoms in relation to others were identified such as *not like other kids*, *standing out*, and *always felt wrong*. These codes were grouped deductively to form a basic theme that interpreted and described these codes as young people's

awareness of how their illness/symptoms made them feel different to others pre-diagnosis. This theme was then grouped with other themes that interpreted the meanings to suggest that feeling different informed their reconstruction of view of self, pre-diagnosis.

In the final analysis, the data from health biographies and the themes from the semi-structured interviews are explored through the lens of the ecological systems theory (Bronfenbrenner, 1979) to bring into focus the connection between structural processes and individual issues (Denzin, 2001).

5.1.7 Piloting the research methods

Piloting (testing) the research methods was carried out to ensure the research processes (i.e. participant recruitment and retention) and instruments (i.e. topic guides) functioned well (Bryman, 2016). This was particularly pertinent as the health biography mapping exercise as explained earlier (Section 5.1.5., p.91) is usually conducted face-to-face and at one point in time, but had been adapted to be carried out remotely over the telephone, and over two points in time.

The pilot was incorporated as part of the research design so that after the recruitment of the first three participants from GP practice 1 (GPP1), recruitment would pause so that I could undertake data analysis. In February 2021, seven participants were recruited during phase 1 of the study but only five completed the two staged interview process. Given the small numbers, the pilot analysis was conducted on the 10 interviews with the five participants aged 20–24 years living with between two to four long term conditions, and registered to a GP practice in an area of high socio-economic deprivation. The choice of study setting and details of the participant selection criteria are discussed in Sections 5.2 and 5.3 (p.97 and p.100 respectively).

The pilot interviews were thematically analysed inductively and deductively, and NVivo 12 software used to collate, store, and manage the identified codes. See Section 5.8 (p.113) for the detail of how these processes and software were applied in the data analysis.

The 26 organisational themes were consolidated into four overarching themes. See Appendix F (p.283) for the pilot data extracts. The four overarching themes

generated from the interviews highlighted (a) the importance of young people having their symptoms heard by HCPs and significant others, so that they could receive a diagnosis and start the early adaptation process; (b) the role of the condition and its symptoms on their perception of feeling different, and how this played out on their view of illness and sense of self; (c) the resourcefulness and optimism underpinning young people's behavioural adaptations as they learned to live with multiple LTCs; and (d) the role of the health condition and symptoms on young people's health seeking behaviours, and on others' responses to them.

From this analysis there was emerging evidence that (a) the early adaptation journey begins for many young people with the onset of symptoms prior to the disruption of a diagnosis; (b) the nature of participants' long-term conditions resulted in the care being managed at primary care level, with limited experience of secondary care pathways; (c) the nature of the health condition and its symptoms informed young people's care experiences, shaping how young people viewed their illness(es), reconstructed their sense of self, and learned to live with multiple LTCs; and (d) the geographical mobility of young people made it difficult to associate multimorbidity with socio-economic deprivation. Two of the participants registered with the GP practice were not permanent residents in the area. One had moved to the location to study at a university and the other had moved in with his partner's family during the Covid-19 pandemic. GP practice catchment areas and the people who live within them do not fall into neat categories. Social categories are perspectival as there is no independent way of assigning a person to their *true* category (Gillespie, Howarth, and Cornish, 2012). In subsequent GP practice recruitment, the practicalities of being able to recruit a GP practice quickly superseded the GP's geographical location.

The pilot did identify that a couple of changes were required to (a) the wording of the demographic form and (b) obtaining verbal consent. With regards to the former, I realised quickly when going through the demographic form with the first participant that the wording on gender was binary and out-dated (see Appendix G, p.286). The wording asked participants if they identified as male or female. I changed this wording in subsequent interviews and asked how they would describe their gender. With regards to obtaining verbal consent (see Appendix H, p.288), I later added an explanation of the process I would follow in the event of a safeguarding concern

being raised. This additional detail was in response to a safeguarding disclosure where I stopped the interview to seek advice, but then was unable to continue the interview as the participant did not respond to my messages. I believe the participant was surprised and unnerved by the disruptive process to the interview which had not been made explicit prior to the interview, and thus deterred them from further involvement.

The pilot work evidenced that the research methods were recruiting participants who met the research criteria and engaged them to talk in depth about their health care journey experiences. The generated themes illustrated the role of relational networks, HCPs and care services in shaping the early adaptation constructs and young people's self-management behaviours. As I was satisfied that the research processes and instruments worked well, the interviews from this pilot were included in the final data analysis.

5.2 Study setting

Primary care, often referred to as the first point of contact for people in need of non-emergency healthcare (NHS Providers, 2022), and specifically GP practices, was selected as the setting to recruit a sample of young people living with a diverse range of MLTCs.

As highlighted in Chapter 3 (p.49), the health care experiences of young people living with multimorbidity in England has been studied in relation to secondary care experiences, referred to as hospital and community care, (NHS Providers, 2021), which could be argued does bias the participant sample to those who are more likely to attend clinical appointments. Once young people have transitioned to adult care teams this sample may be further diminished in size. As mentioned previously in Chapter 2 (p.23), young people are at risk of disengaging from secondary care once they have made the transition from paediatric to adult care services, (NHS Digital, 2017; NICE, 2018; Royal College of Paediatrics and Child Health, 2012). Moreover, as secondary care is managed along single disease care management pathways (e.g. diabetes and asthma), a study situated within secondary care would have limited the sample to a finite number of conditions and comorbidities. A requirement of interpretive interactionist researchers is to have multiple case studies (Denzin, 2001) which involves recruiting a diversity of experience. Participant recruitment for

this doctoral thesis was therefore selected to take place in primary care and working through GP practices which could identify potential participants who met the selection criteria from their patient databases. However, as the GP practices would only be able to communicate by text messaging to patients, not having access to text messaging was included as one of the participant exclusion criteria (see Table 6, p.102).

5.2.1 Identifying GP practice sites

As noted previously in Chapter 2 (p.23) young people living with multimorbidity are more prevalent in areas of high socio-economic deprivation (Barnett *et al.*, 2012; PHE, 2018; Violán *et al.*, 2014). In England, the Index of Multiple Deprivation⁹ (IMD) is the relative measure of deprivation. The areas with the least deprivation (i.e. they make up 10% of the least deprived neighbourhoods) have an IMD score of 10 whilst an IMD score of one is made up of 10% of the most deprived neighbourhoods (Government UK, 2019a). In 2019, Brighton and Hove had an IMD score of 6 (n = 16,605) but within the city there are some very deprived communities (Brighton and Hove CC, 2019). The Indices of Deprivation (IoD) in England are a measure of relative deprivation at a small local area level termed lower-layer super output areas (LSOAs) (Government UK, 2019b). GP practices located in the most deprived 20% of neighbourhoods were initially targeted in an email invitation to take part in the study.

Two GP practices came forward and both were located in the same Primary Care Network¹⁰ (PCN) which covered a swathe of the city from east to central Brighton (Brighton and Hove CC, 2019). GP practice (GPP) 1 was in the east of the city in an LSOA experiencing very high levels of deprivation. A ranking of 100% for the IoD is the most deprived of the 20% most deprived wards in England, and GPP 1 was in an area that ranked 62.6% (n= 8,854) (Brighton and Hove CC, 2019). It had 6,206 registered patients (Health GPs, 2019). GPP 2 was more centrally located in the city

⁹ IMD and IoD combine indicators under seven different domains of deprivation: Income Deprivation; Employment Deprivation; Education Skills and Training Deprivation; Health Deprivation and Disability; Crime; Barriers to Housing and Services and Living Environment Deprivation (Gov.UK 2019).

¹⁰ PCNs are made up from groups of neighbouring general practice. Their formation requires existing providers of general practice to work together and to share funds to improve the range and effectiveness of primary care services. (The Health Foundation, 2019)

and was in an LSOA of high deprivation (IoD; n= 4,845) which was ranked at 23.4% (Brighton and Hove CC, 2019). It had 14,398 registered patients (Health GPs, 2019).

As only 12 participants had been recruited from these two GP practices, recruitment sites were expanded. The pilot had identified that postal code was an unreliable indicator of this study's participants' socio-economic deprivation and therefore GP practice recruitment was opened to geographical locations outside areas of high socio-economic deprivation.

With the support of GP practice staff, a further two GP practice sites were recruited to the study. GPP 3 was in a more affluent part north of the city and not ranked in the top 20% of deprived communities (Brighton and Hove CC, 2019). It had 13,555 registered patients (Health GPs, 2021). GPP 4 was located to the north-west of the city. It had 8,175 registered patients (Health GPs, 2021) and had an IoD ranked at 14.4% (Brighton and Hove CC, 2019). See Table 5 below for numbers of registered patients, percentage of patients living with a limiting LTC, and ward ranking for IoD for each GP practice site.

Table 5. Summary of GP practice patient information and Ward deprivation ranking

GP practice (GPP)	PCN network	Nos of registered patients	% of adults 16-64 years living with a limiting long-term illness in ward. England average 12.7%	Ward ranking in most deprived 20% of neighbourhoods. England average 20% (100% most deprived)
GPP 1	East and Central Brighton 1 PCN	6,206	19.6%	8,854 (62.6%)
GPP 2	East and Central Brighton 1 PCN	14,398	10.5%	4,845 (23.4%)
GPP 3	Preston Park Community PCN 3	13,555	9.4%	Not ranked in this category
GPP 4	West Hove PCN 4	8,175	13.7%	1,438 (14.4%)

5.2.2 GP remuneration for time

I sought advice from a GP outside of the study about how to engage the support of GP practices with participant recruitment and was advised to offer remuneration for their time. GPs are health care providers operating as businesses and they are familiar with operating within a payment for results system. The Quality and

Outcomes Framework¹¹ (QOF), for example, is a voluntary annual reward and incentive programme for all GP practices in England detailing practice achievement results for which they receive payment (NHS Digital, 2021). GP practices are familiar with payment for additional work with patients, and it was suggested by the GP advisor that without an offer of remuneration I would struggle to engage their support.

Remuneration offered to the first two GP practices consisted of a flat fee for identifying patients on their database who met the study's selection criteria and an additional *thank you* sum per participant recruited who completed both interviews. The additional *thank you* was for practice staff support in answering any researcher queries about medical conditions and participant's eligibility to take part in the study. One participant, for example, described several symptoms but was unclear of the diagnoses. With the participant's written permission, the Practice was asked to clarify their diagnoses. It was confirmed that the symptoms were related to only one health condition and consequently they did not meet the selection criteria and could not take part in the study. However, the funder of this current PhD (South Coast Doctoral Training Partnership) argued that the remuneration package was too high and subsequent GP practices (3 and 4) recruited to the study were offered reduced financial remuneration for staff time and good will. The roles and responsibilities of both parties (researcher and each GP practice) were documented as a requirement of the Health Research Authority (HRA) ethics submission in a non-commercial participant identification centre (PIC) agreement. See Appendix I (p.289) for a copy of a PIC agreement.

5.3 Sample

Purposive sampling is employed to identify participants with characteristics that would likely generate meaningful data to answer the study research question (Bourgeault, Dingwall and de Vries, 2013; Mason, 2018). The sample population is young people aged 18-24 years living with at least two LTCs. This Section will outline the rationale underpinning the list of selected LTCs, the approach to

¹¹ The QOF contains four domains: Clinical, (across 20 clinical areas); Public Health (covers three areas: obesity 18+, smoking 15+ and blood pressure); Public Health – Additional Services (which refers to cervical screening), and Quality Improvement (across two areas, early cancer screening and care of people with learning disabilities), (NHS Digital 2021).

identifying young people likely to have multiple care experiences, and sample size. It will list the participant inclusion and exclusion criteria and summarise the sample's characteristics.

5.3.1 Identifying young people living with multimorbidity

As mentioned in Chapter 2 (p.23) there is currently no standard index of multimorbidity. In this PhD research therefore, the criteria of 40 health conditions identified by Barnett *et al.*, (2012) and applied by PHE (2018) was adapted to make it applicable to younger people; excluding, for example, dementia. The final list of 26 health conditions was given to the GP practice sites to identify the associated read codes so that a list of potential participants living with at least two of these health conditions could be established (see Appendix J, p.295).

During the screening interview the researcher checked with the potential participant that they met the study selection criteria. Participants were asked to name their health conditions which the researcher cross referenced with the list of health conditions. Diagnoses additional to the list reported by participants were noted and are discussed in Chapter 6 (p.123).

5.3.2 Identifying multiple care experiences

One approach to identifying participants with multiple care experiences could have been to apply registered disability status as one of the participant recruitment selection criteria. In legal terms, disability under the Equality Act 2010 refers to having a physical or mental impairment that has a substantial and long-term negative effect on a person's ability to do normal daily activities. Substantial is more than minor or trivial, such as taking a long time to complete a daily task (e.g. getting dressed), and long term means present for 12 months or more (Government UK, 2020a). A young person living with multimorbidity may meet the long-term element of the disability definition but may not always meet the substantial element. Moreover, a person living with a disability does not always present with additional morbidities, although there is an increase prevalence of multimorbidity with learning disability (Kinneer *et al.*, 2018). An alternative criterion to disability for identifying multiple care experiences is moderate frailty score. The frailty rating identifies the substantial element of impairment (Improvement Academy, 2020).

The moderate frailty rating was designed initially to identify those aged over 65 years who have a moderate to severe frailty rating (NHS England, 2021). It applies a cumulative deficit model that uses existing patient data and measures frailty based on several deficits which include clinical signs (e.g. cognitive problems), diseases (e.g. diabetes), disabilities (e.g. social vulnerability) and abnormal test results (e.g. anaemia). There are 36 deficits and around 2000 read codes (i.e. a coded thesaurus of clinical terms). The score is predictive of adverse health outcomes. A moderate frailty score for example (eFI score 0.25 – 0.36) identifies people who have difficulties with outdoor activities and may have mobility problems or require help with activities such as washing and dressing (Improvement Academy, 2020). It suggests that they will require support from health and social care services.

The GP practices involved in the study had disclosed that this measure had been applied across the whole population on their patient lists and they could identify young people in the study’s selected age range who were classified as having a moderate frailty rating. GPP 1 had identified 85 young people who met the selection criteria of age, two LTCs, and having a moderate frailty rating. In the event that insufficient numbers responded, the recruitment design included a second recruitment stage which replaced moderate frailty rating with experience of several HCPs involved in their care. See Table 6 below which lists the inclusion and exclusion criteria for participant selection.

Table 6. List of participant inclusion/exclusion criteria.

Participant inclusion/exclusion criteria		Part 1 recruitment	Part 2 recruitment
Inclusion criteria	Aged 18-24 years	x	x
	Living with 2 or more long-term conditions (from a list of 26 health conditions provided)	x	x
	Moderate frailty score	x	
	Experience of involvement (current or past) of several health care professionals in their care (e.g. GPs, practice nurse, dietician, condition specialist)		x
Exclusion Criteria	Insufficient command of the English language	x	x
	Lacks mental capacity	x	x
	Not contactable by text messaging	x	x

5.3.3 Identifying sample size

Qualitative research aims to recruit participants who represent a diversity of views in relation to the research subject (King and Horrocks, 2010) and to recruit participants until the point of saturation is reached. Data saturation is reached when there are no new insights generated from the data (Bryman, 2016). The Health Research Authority (HRA) and University of Brighton ethics approvals required this saturation point to be quantified. Mason (2010) conducted a systematic analysis of samples of PhD studies via theses.com that used qualitative approaches and interviews. Of the 560 studies, the author calculated the mean sample size as 31. However, the sample size depends on the group under study (Mason, 2010) and the study design (Mason, 2018). Where a study is focussing on a homogeneous group, fewer participants will be required to provide the necessary diversity (Mason, 2010). For example, Guest *et al.*, (2006) conducted a systematic review of their data of 60 women's reproductive health care experiences in Africa and identified that 34 out of their 36 codes were elicited in the first six interviews, and 35 of the codes were achieved with 12 participants. They argued that the sample's high homogeneity resulted in data saturation being reached at six interviews. The key feature in determining sample size in qualitative interviews is not number but whether the sample provides access to enough data (Mason, 2018).

This doctoral thesis required a heterogeneous sample to provide a diversity of lived care experiences. Bryman (2016) argues that the more comparisons between groups in a sample, for example, between male and female, different age groups, and different types of research participants, then a larger sample size may be required. One activity of this study outlined in Chapter 3 (p.49) was to explore features of personal characteristics such as gender in shaping young people's experiences of care and relational networks. Based on Mason's (2010) analysis the target sample size was set at around thirty participants. The recruitment was staged and alternated between GP practices so that recruitment uptake could be managed and assessed for data saturation. In part 1 of the recruitment process eligibility focussed on age, two LTCs and a moderate frailty score. Once part 1 had been completed, and if data saturation had not been reached, part 2 recruitment was initiated. In part 2 recruitment, eligibility focussed on age and two LTCs (see Figure 6, p.104) for the recruitment flow chart).

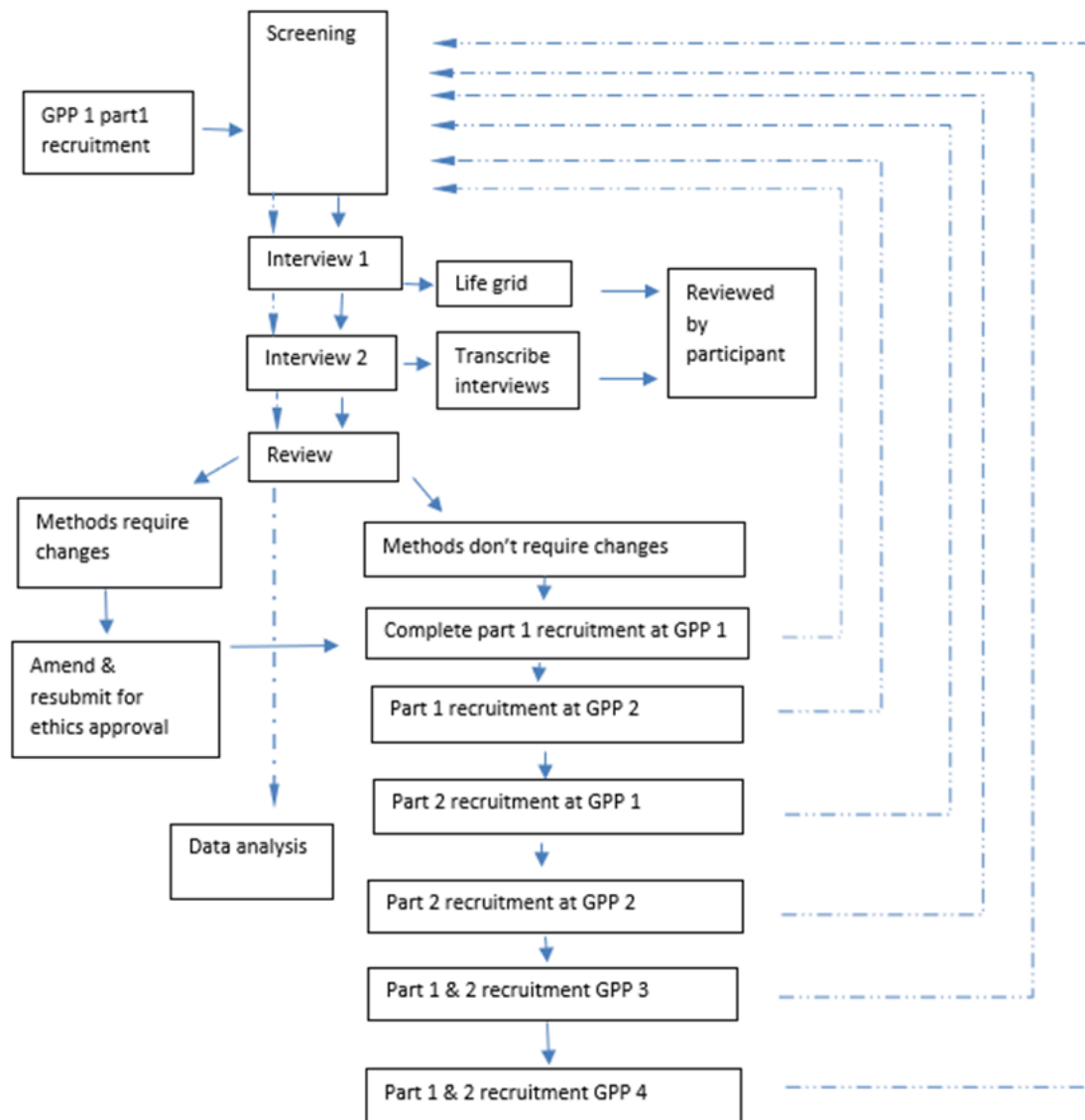


Figure 6. Participant recruitment flowchart

As the recruitment, data generation, and analysis progressed, it became clear that the sample had distinct features. Young people were living with a combination of physical health conditions, mental health conditions and neurodevelopmental conditions. The final counts on morbidities and co-morbidities are discussed in Chapter 6 (p.123). The significance of these young people’s health conditions on their care experiences will be discussed in Chapter 8 (p.179). Given the emerging uniqueness of the sample, sample saturation was reached much earlier at 19 participants.

5.3.4 Characteristics of the sample

Of the 29 potential participants who contacted the researcher to be involved in the study, 23 met the selection criteria and 19 completed both interviews. See Table 7 below for the reasons for participant non-completion of study.

Table 7. Reasons for study non-completion.

Reason for participant non-completion of study		Nos	Total
Did not meet selection criteria	Did not meet age criteria	2	
	Did not meet number of LTCs criteria	1	
	Lacked capacity	3	
			6
Withdrew from study	Did not respond to researcher's communications after first interview	2	
	Withdrew before first interview citing health reasons	1	
	Did not attend first interview. Researcher unable to contact to reschedule	1	
			4
		Total	10

Most participants identified as female (n=15), White British (n=14), and as heterosexual (n=13). One participant identified as non-binary and asexual. More than half the participants were in the older age of the age criteria with six aged 23 years and four aged 22 years. The majority (n=18) had obtained GCSEs and 15 had obtained A level/diplomas. Nine described themselves as students and 12 were in employment. Two were self-employed and eight were in part-time employment.

Most of the participants described themselves as being in a relationship with a partner (n=12). Two of the women had children under the age of five years. Most of the participants (n=16) were registered to a GP practice in 20% of the most deprived neighbourhoods. Where 100% represents the most deprived neighbourhoods, four participants were registered to a GP practice ranked at 14.4%, six were in a neighbourhood ranked at 23.4% and a further six were in a neighbourhood ranked at 62.6%. Just under half the participants (n=9) were living in shared accommodation whilst eight were living in the family home and two were living alone.

More than half the participants (n=10) identified themselves as living with a disability. The length of time they had lived with the disability ranged from six years to 19 years with mode values of six years, 10 years and 18 years. Six of the participants had been identified by the GP practice as having a moderate frailty rating. See Appendix

K (p.299) for the detail of the sample's demographic characteristics. The health conditions, number of morbidities and health professionals involved in their care will be discussed in Chapter 6 (p.123).

5.4 Participant recruitment

Recruitment of participants began in January 2021, and data saturation was reached in February 2022. Following the outbreak of the Covid-19 pandemic, research had to be designed and carried out within the parameters of social distancing guidance (Government UK, 2020b). All the recruitment processes were conducted remotely to minimise the risk of Covid transmission with invitations sent via email, study information made available on the GP practice websites, and direct communication with stakeholders and participants via text, email, or telephone. As discussed in Chapter 2 (see Section 2.4.5., p.44), post Covid-19 lockdowns¹² saw increased resource pressure on primary care services that created delays to the recruitment process which will be discussed in this Section. It also impacted on participants experiences of accessing new or ongoing treatments which will be described in Chapter 7 (see Section 7.3., p.157).

Once ethics approvals had been obtained from the University of Brighton External REC Review Panel (ERRP) on 23rd November 2020 and the Health Research Authority (HRA) on 1st February 2021 (see Appendix L, p.301), recruitment commenced at GPP 1 in February 2021. Web content about the project was uploaded onto the practice website (see Appendix M, p.304). GP practice staff searched the patient database for patients who met part 1 eligibility criteria (which included age, two or more long-term conditions and moderate frailty rating). Once these patients had been identified, they were contacted by the GP practice in a text to obtain consent to be sent information about the study. Only patients who had given a mobile telephone number in their contact details could be invited (see Table 8, p.108 for the numbers of patients per GP practice who met the selection criteria and were contactable by text messages). Those who consented were sent a text invite containing the link to the webpage which held the researcher's contact details

¹² In England, the first national lockdown was from March-June 2020. The second national lockdown was from October 2020-February 2021 with some easing of restrictions in December 2020 (Parliament UK 2021). During these periods all non-essential high street businesses were closed and people were ordered to stay home and permitted to leave for essential purposes only (Parliament UK 2021).

(see Appendix N, p.307). A reminder text invite was sent two weeks later (see Appendix O, p.308). Participants who contacted the researcher were screened to check that they met the eligibility criteria. If participants agreed to take part in the study they were sent an information pack by email containing a welcome letter, PIS, and an information sheet about organisations to contact for help and support (see Appendix P, p.309). An appointment for the first interview was made after the screening conversation which was scheduled to take place within seven days. The second interview was scheduled to take place within seven days of completing the first interview.

After recruitment (part 1) was completed at GPP 1 (end of February 2021), and the pilot data generation and analysis completed, the same process was followed at GPP 2 in mid-May 2021. As there was only one eligible patient who met part 1 criteria and they had agreed to take part in the study, part 2 of the recruitment was completed at the same time. Eligibility criteria for part 2 recruitment included age and two or more long-term conditions. Recruitment at GPP 2 was completed by mid-June 2021. Recruitment (part 2) at GPP 1 was concluded by mid-August 2021. Only part 2 of the recruitment process was completed at GPP 3 (November 2021) and GPP 4 (February 2022) as there were no participants who met part 1 eligibility criteria.

A challenge with the two-part recruitment strategy and working with GP practices during the Covid-19 pandemic was the considerable time that it took to complete. My contacts were HCPs, and we completed the recruitment processes working around their clinical practice commitments. We would have to frequently reschedule appointments to plan the recruitment or shift back the timeline because of other demands on their time such as covering clinics when there were staff absences, or being called at short notice to work at the Covid-19 vaccination centres.

After five months of data collection, I had only reached 40% of the proposed target sample size. I decided to extend the geographical reach by recruiting another GP practice to the study. With the support of the HCP contacts involved in the study, I secured agreement of GPP 3 and 4. There were delays to recruitment at these study settings due to working round HCPs busy schedules, making changes to the research process documentation, and notifying ethics approval organisations of these changes (HRA and University of Brighton). A minor amendment to the

recruitment process had to be made for GPP 3 and 4 as they did not have a two-way communication system for participants to respond to a text message requesting their consent to be sent information about the study. The process was adapted so that in the consent text to potential participants, the practice asked them to reply 'YES' directly to the researcher who would then contact the potential participant. This made sending the text invites redundant. As can be seen in Table 8 below the numbers of young people who consented directly to the researcher were much lower at GPP 3 and 4 than those who had consented directly to GPP 1 and 2.

Table 8. Breakdown of participant numbers (eligible, contactable, and actual) recruited per GP practice

	GPP 1	GPP 2	GPP 3	GPP 4	Total
No. of young people aged 18-24 years (% of total patient list)	612/6206 (9.86%),	1285/14398 (8.92%)	1050/13555 (7.74%)	584/8344 (6.99%)	3,531/42,503 8.3%
No. of young people met selection criteria part 1 and were contactable by text (% against total number of 18-24-year-olds)	85/612 (13.89%),	1/1285 (0.078%)	0/1050 (0%)	0/584 (0%)	86/3,531 2.4%
No. of young people met selection criteria part 2 and were contactable by text (% against total number of 18-24-year-olds)	26/612 (4.25%)	263/1285 (20.47%)	306/1050 (29%)	176/584 (30%)	771/3,531 21.8%
Total no. of eligible participants (% against total number of 18-24-year-olds)	111/612 (18.1%)	264/1285 (20.5%)	306/1050 (29.1%)	176/584 (30%)	857/3531 (24.3%)
No. young people consented to be sent information about the study (% against those eligible)	37/111 (33.3%)	44/264 (16.7%)	7/306 (2.29%)	9/176 (5.1%)	97/857 11.3%
No. young people contacted researcher (% against those consented to be sent information)	8 /37 (21.6%)	8/44 (18%)	6/7 (85.7%)	7/9 (77.7%)	29/97 29.9%
No. screened and met selection criteria	8	7	4	4	23
No. withdrew before interviews completed	2	1	1	0	4
No. completed interviews (% against those who contacted researcher for screening),	6/8 (75%)	6/8 (75%)	3/6 (50%)	4/7 (57%)	19/29 (65.5%)

However, the numbers who contacted the researcher for further information about taking part were roughly the same across all four sites. The table also illustrates the number of young people eligible and contactable to participate in each part of the two part recruitment process, and the numbers who consented to be sent information, commenced the interview process, withdrew from the process, and completed the interviews.

5.5 Data generation

As discussed previously in Section 5.1 (p.83), the data generation tools were selected and adapted to support young people to identify and reflect on their health epiphanies, and the role of care services, HCPs, and relational networks in shaping the meaning they attached to these experiences. This Section will outline the data generation processes involved in conducting the two phased interview process.

Each interview phase involved conducting a semi-structured interview. A shorter semi-structured interview in the first phase took on average 40 minutes and involved mapping the young person’s health biography (see Table 9 below for the range and mean times of the first interview phase). The participants were asked to recount their health biography against a broader chronological life mapping exercise from earliest memory of being unwell to the present day.

The second semi-structured interview phase was longer in length, taking on average 1 hour and 25 minutes (see also Table 9 below). It involved referring to the data from the mapping of the health biography and asking the participant to expand upon what had happened, how significant others and HCPs had behaved towards them, and how they had interpreted these interactions.

Table 9. Range and mean times of each interview phase.

	Number of interviews	Range of time of interviews (hh:mm)	Mean time of interviews (hh:mm)
First interview phase	19	00:20 – 1:25	00:40
Second interview phase	19	00:34 – 2:10	01:25
Total	38		

Topic guides were used in both interviews (see Appendices Q, p.318 and R, p.319). The first interview phase which generated the health biographies identified potential

triggers for participants to become upset in the more in-depth second interviews, such as recounting incidents of sexual assaults and bullying which I would need to carefully navigate. Wilson *et al.*, (2007) argue that if events are raised by respondents it gives permission for the researcher to refer to them in subsequent interviews with care, or avoid if requested. Two participants in this study had experience of a historical sexual assault which was disclosed in the first interview phase. At the point of disclosure the study's safeguarding protocol was followed and the participant was asked if they have reported it, spoken about it to anyone, or sought help and support. The researcher offered to send them information about local organisations which could support them. The assault was not raised by the interviewer in the second interview unless the participant had raised it as having a bearing on their health care journey, and agreed for it to be referenced by the researcher. In the extract below from a second interview (see Table 10 below) the participant mentioned how seeing the alleged perpetrator in a café was a factor in triggering a down-turn in their mental health. I quickly shifted the focus of the conversation to her Mum's response, and then asked the participant to reflect on her mental health to move the conversation along from dwelling on the incident itself.

The topic guide in the second interviews facilitated more in-depth recollections of the participant's health biography. It was designed to tease out the role of HCPs and relational networks in shaping the adaptation constructs to living with LTCs. As a consequence, the interview generated *thick* descriptions of the participants experiences at the key points in their health biography.

Table 10. Excerpt from an interview: managing a potentially upsetting memory recollection.

Second interview. ID no.14
<p>"I 'You find a new partner and move in together, then Covid hits and then things start to unravel?'</p> <p>P: 'Yeah, lockdown really and I bumped into that person, and I also spoke to my mum and told her about it for the first time.'</p> <p>I: 'How was your mum about it?'</p> <p>P: 'It made much more sense to her why I'd been that way and everything.'</p> <p>I: 'Did it help your relationship?'</p> <p>P: 'I think so yeah.'</p> <p>I: 'So with these triggers after a period of not self-harming, you're self-harming. Do you have a sense when your mental health is deteriorating?'"</p>

Questions were asked to encourage participants to develop their initial responses and add depth to their answers (King and Horrocks, 2010). They were asked to clarify words and meaning and to complete accounts of their health-life journey such as what they understood of their experiences in terms of what and who had supported them to manage their LTCs. Some participants had undergone and were still going through experiences they found upsetting such as being bullied. The closure of the interview involved showing appreciation to the participant for sharing their experiences. See Table 11 below for examples of questions and closure statements.

Table 11. Sample of questions/statements applied during interviews.

Types of questions/statements	Examples of extracts from interviews
Introduction: e.g. asking for description	<i>"I: 'Going back to when you were 8 years old and starting to experience regular headaches. How did that impact on you, on how you lived your life?'" (Taken from interview with ID no. 01)</i>
Clarification	<i>"I: 'So you are saying with hindsight that it was never going to work for you because you are neurodivergent'" (Taken from interview with ID no. 09)</i>
Completion	<i>"P: 'I remember chasing my friends around with a toilet plunger and the teacher walked in ...'"</i> <i>"I: 'And you got into trouble for that?'" (Taken from interview with ID no.21)</i>
Elaboration	<i>"I: 'Can I just take you back and ask what happened to bring your self-harming behaviour to the school's attention, as up to year 8 you were under the radar?'" (Taken from interview with ID no. 14)</i>
Closure statement: showing appreciation	<i>"I: 'I think we've covered everything. Thank you for your time and for sharing your experiences with me.'" (Taken from interview with ID no. 10)</i>

5.6 Interview procedures

Within the same day that the potential participant contacted the researcher, the researcher responded and arranged a time at the participant's earliest convenience to talk over the telephone. The telephone call was an opportunity for the researcher to check the participant met the study selection criteria, outline the project, and what participation involved. If they confirmed they wanted to take part, an appointment was booked for the first interview to take place within seven days. An information pack containing a welcome letter, PIS, and information sheet of where to go for help and support (Appendix P, p.309) was sent via email immediately after the telephone call.

Before commencing the first interview, the researcher confirmed the participant had read the PIS, obtained verbal consent which was digitally recorded (Appendix H, p.288), and took demographic details (Appendix G, p.286).

At the end of interview, the researcher asked the participant how they were feeling, and they were reminded of the supporting information sheet with the list of organisations (with contact details) that could provide support if they required it. The researcher explained the next steps. An appointment for the second interview was booked within seven days of completion of the first interview. The researcher transferred her notes of the interview into a health and life grid (see Appendix E, p.282, for an example) which was emailed to the participant a couple of hours before the second interview.

At the start of second interview, the researcher asked how the participant was feeling, and if they were happy to continue. They then checked the health and life grid together for accuracy. Any changes required were noted and made after the interview. The updated version was emailed to the participant. Consent was digitally recorded before the start of the second interview. After the interview, the researcher followed the same process for interview one to check-in on the participant's well-being. The next steps were outlined and consent sought to contact in future about final report dissemination. The interview was transcribed by the researcher and emailed to the participant to read and check for errors in the researcher's transcription. Some participants added comments to some of their responses which provided additional context. For example, one participant (ID no.9) noted in a comment on the interview script why she described her presentation of PoTS¹³ as comparable to experiencing a panic attack. After emailing the interview script for checking, the participant was sent an electronic 'thank you' voucher to a value of £20 by text or email.

5.7 Data analysis of the first phase of interviews (health biographies)

The data from the first interviews which included the age of onset of ill health symptoms, age of diagnosis, types of numbers of morbidities, sequence of

¹³ Postural orthostatic tachycardia syndrome (PoTS) is an abnormal increase in heart rate that occurs after sitting up or standing that can cause dizziness and fainting.

diagnoses, and health and care professionals/services consulted were transferred into spreadsheets. Morbidities and the HCPs consulted were described and counted. Morbidities were categorised and coded as a physical health (P), mental health (M), or neurodevelopmental (ND) condition. The age of onset of symptoms and the age of diagnosis for each health condition were plotted starting with the first health condition for each participant. The time (approximate in years) between age of symptom onset and diagnosis was counted and plotted in a second spreadsheet against the age (approximate) for each coded health condition. For symptoms for which there was yet no diagnosis, the age of onset was recorded and coded as live (L). The analysis of these descriptions and counts are discussed in Chapters 6 (p.123) and 8 (p.179).

5.8 Data analysis of the second phase of interviews

The interview transcripts from the second interviews were analysed thematically referencing Attride-Stirling (2001) *Steps to Analyses Using Thematic Networks* and Braun and Clarke (2006) *Step-by-step Guide to Thematic Analysis in Psychology*. The deductive analysis was informed by Due-Christensen's early adaptation process and Denzin's interpretive interactionist approach. As with the pilot interviews, NVivo 12 software was used to code the scripts and collate, manage, and store the identified codes. NVivo is a computer-assisted qualitative data analysis software that enables the researcher to code, collate, and store large chunks of text from the interview scripts (Bryman, 2016). The analysis will be described from establishing a coding framework to generating themes and constructing a thematic network.

5.8.1 Establishing a coding framework

Braun and Clarke (2006) state the first phase in thematic analysis is to become familiar with the data. After the interview scripts had been checked for accuracy by the participants and amended as necessary, they were read repeatedly by the researcher to familiarise herself with the text. Reading scripts in this manner is an iterative process which enables the researcher to start eliciting patterns in the data from which initial codes (i.e. labels for pieces of information) and themes are generated (Braun and Clarke, 2006). The researcher was reading the scripts and making deductive links between interpretive interactionism (i.e. interpretations of interactions with HCPs, care services, and relational networks) on shaping the early adaptation constructs (i.e. disruption from diagnosis, view of health condition,

reconstructing view of self, learning, and behaviour). The scripts were also read inductively to elicit other patterns across the scripts.

In the second phase of analysis, the scripts were uploaded to NVivo 12 and codes derived from asking questions of the data (Attride-Stirling, 2001; Braun and Clarke, 2006) such as (a) what does this participant's experience of an interaction with HCPs, their friends, and family suggest about how they thought/felt about the health condition? or (b) view of self? or (c) how they learned about the health condition? or (d) how they shaped behaviour? Codes included descriptions such as participants' emotional responses, thoughts, and perceptions of their own behaviour and that of others in relation to their diagnoses and care. Code labels need to work independently of the data (Braun and Clarke, 2006). For example, several participants described how their health condition/symptoms affected them and made them feel that they stood out from other children. The text was coded, *not like other kids*, to capture the essence of how they felt different. A number of these codes were then collated under one group (a parent node) labelled *feeling different* (see Figure 1, Appendix S, p.322).

Codes were also generated to capture participants' descriptions of others' responses to their symptoms/ symptom management behaviours, such as HCP responses which young people felt were helpful because they explained the health condition and treatment options. Such codes were grouped under one label *helpful HCPs* (see Figure 2, Appendix S, p.322).

In addition to the theory driven codes, codes were generated inductively from the data. For example, several participants described significant events in their biographies such as moving to a new location/country or parents divorcing which altered the geographical or social/familial landscape within which they negotiated the early adaptation process. These codes were grouped and labelled as *family context* (see Figure 3, Appendix S, p.322)

Where possible the codes were organised according to the sequence of the health condition diagnosis to generate themes relating to the order of the health condition diagnoses. For example, where codes associated with subsequent diagnoses were generated they formed a sub-category (i.e. child node), *3rd diagnoses* under the parent node label such as, *response to a diagnosis* (see Figure 4, Appendix S,

p.322). The coding process is an iterative process as codes (both parent and child nodes) are reclassified and ordered into meaningful groups. Some child node labels were disregarded and the text aggregated into the parent node. For example, coding (i.e. child nodes) for the sequence of the health condition such as LTC 2, 3, etc. had to be abandoned as I could not consistently capture the order of health care experiences with every participant. These codes were aggregated into the existing parental codes.

5.8.2 Generating themes and constructing the thematic network

Themes are generated from codes and are presented in the language and emotions of those being studied (Denzin, 2001). Generating themes and developing the thematic network involved searching for themes within the codes, reviewing themes, and defining and naming themes. They make up phases 3-5 of the thematic analysis process (Braun and Clarke, 2006). Attride-Stirling (2001) describe this process as constructing thematic networks. The parent and child nodes were copied from NVivo into a word document where they were moved and grouped to form themes.

Where basic themes did not inform the development of the constructs of the early adaptation process, the underpinning codes were, where possible, reorganised and redistributed to other themes. For example, a basic theme coded as *trigger for diagnosis* contained codes that captured the features *fear*, *crisis*, *worsening condition*, and *others' concerns*. The basic theme and the codes, *fear*, *crisis*, and *worsening condition* were disregarded as they did not relate to the role of HCPs and relational networks in shaping the early adaptation constructs. The references within *other's concerns* captured the role of others in encouraging participants to seek medical guidance for their symptoms. These references were redistributed to other codes (i.e. *supportive parents*, *supportive partners*, *supportive employers* and *supportive teachers*).

The deductive analysis is the fourth stage of interpretation and is the pulling together of themes to interpret the event /process fully stating, "*how the structures and parts of the phenomena cohere into a totality*" (Denzin, 2001, p.78). See Figures 1 and 2 in Appendix T (p.324) for an illustration of the stages of constructing the thematic network from the grouping of codes in NVivo to the formation of basic themes,

subthemes and an overarching theme, and their alignment to the early adaptation process.

Nine organisational (sub) themes were arranged into three overarching (main) themes that described how young people’s experiences of living with first, the symptoms of a health condition, and then a diagnosis shaped the early adaptation constructs of disruption, view of illness, reconstructed view of self, learning, and behaviour. Table 12 (below) illustrates the codes and subthemes that underpin the overarching theme: *before diagnosis: the disruption begins*. See Appendix U (p.326) for the code and theme data extracts.

Table 12. The organisation of codes and themes underpinning the overarching theme: *before diagnosis: the disruption begins*

Descriptive and group codes	Basic Themes	Subtheme	Overarching theme
Not like other kids Standing out Always felt wrong	Young people living with undiagnosed neurodevelopmental conditions are aware of their difference.	Feeling different and reconstructing a view of self	Before diagnosis, the disruption begins
Bullied Keeping quiet Trying to fit in	Young people try and fit in with their peers and keep a low profile so as not to attract unwarranted attention.	An undiagnosed neurodevelopmental condition makes the young person be seen as different to their peers. It shapes their sense of self as different	
Family context (unsupportive families, mental health taboo)	Prolonging the delay in seeking support can be shaped by unsupportive families and negative familial attitudes towards some health conditions such as mental health conditions	Others' disbelief and a "spoiled social identity" (Goffman 1963, p31). Disbelief and derision experienced or anticipated by many young people from others in response to the symptom presentation of their undiagnosed health conditions may lead to fear social rejection and adoption of avoidant health seeking behaviours	
Disbelief, attention seeking, being dramatic, faking it. Not visible – you're young. It's normal	Response of others such as HCPs, peers and families to undiagnosed symptoms is one of disbelief and derision.		

Data generated from the descriptive counts of the health biographies and the themes generated from the second interviews highlighted specific participant characteristics (i.e. the health conditions/ symptoms and age of onset) which arguably had a significant role to play in how others interacted with young people. This in turn affected young people’s perceptions of the health condition(s), symptoms, and self. The interpretations and interplay of these features were

seemingly key to shaping the early adaptation constructs and the findings were contextualised within Bronfenbrenner's (1979) ecological systems theory in the discussion (see Chapter 8, p.179).

5.9 Evidencing research integrity

Employing rigour to data generation is a requirement of the interpretive interactionist approach (Denzin, 2001). Rigour involves creating an account of method and data which can stand independently and produce a convincing and comprehensible explanation of the phenomenon under study (Mays and Pope, 1995). Lincoln and Guba (1985) and later Nowell *et al.* (2017) argue demonstrating that research has been conducted with research integrity can persuade others their research is worthy of attention. They developed this idea further by introducing the criteria of credibility, transferability, dependability, and confirmability to counter the conventional quantitative assessment criteria of validity and reliability (Lincoln and Guba 1985; Nowell *et al.*, 2017). Credibility ensures that there is a fit between the respondent's views and the researcher's recording. It has been built into the design of this thesis with the involvement of PPI and stakeholders (i.e. young people living with LTCs, youth workers, and a GP) as discussed previously in this Chapter (Section 5.1.3., p.87). Their involvement and the pilot of the research methods (Section 5.1.7., p.95) together with the researcher's reflexivity of her position on the subject and on-going reflection of the interview process discussed in Sections 5.1.1., (p.83) and 5.1.2., (p.85) evidenced the research design and processes applied the appropriate tools to recruit and retain the target sample, and generated credible and relevant data to answer the research question. The transferability, dependability, and confirmability elements of research integrity are underpinned in the data generation and analysis methods. Transferability is possible because of the rich *thick* descriptions elicited from the interview design which makes the links between codes and themes more transparent for others to follow (see Section 5.8.2., p.115). Dependability (i.e. ensuring the process is logical, traceable, and clearly documented) and confirmability (i.e. establishing the research findings and conclusions are clearly derived from the data and demonstrating how conclusions are reached) are possible because of (a) opportunities for participants to correct the data generated during the two phased interviews (see Section 5.6., p.111), which suggests the data on which

the analysis is developed has been confirmed and is dependable; (b) the staged thematic analysis, which is documented (see Section 5.8., p.113) and provides an evidence trail of the data analysis as discussed above under transferability, and c) regular meetings with the supervisory team to discuss progress and feedback on chapter drafts which served to question and clarify the research processes to strengthen the transferability, dependability and conformability of the data generated.

UK Research and Innovation (UKRI, 2022) suggest research conducted to a high degree of integrity is underpinned by the “*values of honesty, rigour, transparency and open communication in addition to care and respect for those taking part in the research and accountability for a positive research environment*”¹⁴. There is some overlap of three of these values with the accounts of credibility, transferability, dependability, and confirmability discussed above. Honesty, rigour, and transparency are evidenced in (a) the involvement of PPI and guidance and scrutiny of the supervisory team which underpin an honest and rigorous research design to generate data to answer the research question, (b) opportunities for participants to check the accuracy of their data upon which the codes and themes are developed, and (c) rich descriptions and staged thematic analysis which provides an evidence trail of how data was generated.

The evidence of open communication, care, and respect for participants, and creating a positive research environment are demonstrated in how the study is aligned to Gray’s (2014) four overarching ethical principles of (a) avoiding harm to participants, (b) respecting the privacy of participants, (c) ensuring informed consent, and (d) avoiding deception. Application of each of these principles to this study is discussed below.

Avoiding harm to participants

There were potential risks to participants of distress from recounting past or current upsetting events, and of potentially becoming infected with Covid-19 if a quiet space on the university campus or in a community venue had to be organised for the participant to hold the interview. To minimise participant distress the interviews were approached with an asset-based focus which aimed to identify features of their

¹⁴ <https://www.ukri.org/about-us/policies-standards-and-data/good-research-resource-hub/research-integrity/> (UKRI, 2022)

experiences that they felt were supportive as discussed previously in this Chapter. Any potential distress triggered by recounting their health biography were minimised and managed with protocols for raising a safeguarding alert (see Appendix V, p.330), and managing participants in distress over the telephone (see Appendix W, p.333). Participants were issued with a list of local and national organisations in the welcome pack that they could contact for advice and support on issues that may have arisen during the interview (see Appendix P, p.309). Additionally, I could contact my lead supervisor for support and guidance on fieldwork concerns which was necessary to manage a potential safeguarding concern discussed in Section 5.1.7., *piloting the research methods* (p.95).

To eliminate the risk of Covid-19 transmission and in line with the social distancing guidance (Government UK, 2020b), interviews were conducted over the telephone. If participants could not access a private space to hold the telephone interview, a space would have been organised either on the university campus or at a community venue. This would have been checked to confirm that it had in place measures to minimise transmission of Covid-19 such as wearing of face masks, maintaining social distance, use of hand sanitisers, and room cleaning after use. The participants would have been reminded to follow the above guidance and taxi journeys to and from the venue would have been funded if the participant did not have access to private transport.

Particular attention was given to the research design to ensure young people would be able to engage with it and that any potential opportunities for distress or discomfort were minimised. The two-phased interview process staged several days apart served to mitigate existing health condition symptoms such as tiredness. At the start of each interview participants were asked if they felt well enough to take part and the researcher monitored participants' wellbeing. There were protocols in place should this change during interviews (see Appendices V, p.330 and W, p.333).

Respecting the privacy of participants

Participants disclosed identifying features and sometimes private and sensitive information about their lives in the demographic characteristics, interview transcripts, and health biography timelines. Interviews and verbal consent were recorded in audio digital format. Demographic characteristics and interview transcripts were

recorded in digital format, and the researcher's fieldwork notes were recorded in hard copy formats. These data were kept confidential to the researcher. To prevent a breach to participants' confidential data, interviewees' data were labelled with a unique code. Personal (i.e. identifying) details were stored separately from the interview data and any potential identifying details were removed from the health biography timelines and interview scripts. In reviewing chapter drafts supervisors fed back on results sections that could potentially identify individual participants. All audio digital and digital data were stored electronically on the university's password and network protected storage cloud. The researcher's fieldnotes and the audio memory disc were stored securely in a locked filing cabinet in the researcher's home. Participants were informed of how their data would be protected in the PIS.

To minimise the risk of others overhearing the telephone interviews, the researcher asked the participant to find a quiet, private space where their conversation could not be overheard or interrupted. If they did not have access to a private space, one would be made available for them to use but this offer was not taken up. The researcher had a quiet and private space at home where she could not be overheard or interrupted.

Ensuring informed consent

During the screening process and obtaining consent prior to the interviews, participants were asked if they (a) understood the information relevant to the decision (i.e. that they understood what the study was about and what was expected of them), and (b) could retain that information and use/assess that information as part of the process of making the decision (Mental Capacity Act, 2005). The PIS, and web page content had been designed with the feedback of young people from the advisory group discussed earlier (see Section 5.1.3., p.87) to maximise its accessibility to young people.

At the screening interview, participants were asked what they understood about the project based on the information they had seen on the GP practice website. This process assessed whether they had been able to retain the information and how far they understood what the study was about. If they had not read the information on the website, the researcher outlined the study. It was explained that the study design was dependent on participants' being able to recall their past experiences and life

events. If a potential participant did not understand at the point of obtaining verbal consent what they were agreeing to take part in, or that they hadn't retained any of the information that had been relayed in writing or verbally and with repetition, they were advised that they could not take part in the study. Three potential participants were excluded from the study as from interactions with them over the telephone, via text, and email, they were assessed as lacking the capacity to understand and consent to what was being asked of them.

Participants were sent an information pack at least 24 hours prior to the interviews. Verbal consent was obtained prior to each interview and digitally audio recorded. To minimise the risk of coercion, the PIS and the verbal consent checklist (see Appendices P, p.309 and H, p.288) contained a statement that informed participants they did not have to take part in the study. It included the information that they could withdraw from the study at any point in the process without explanation, although their data could not be withdrawn once the transcripts had been aggregated and themes generated.

Avoiding deception

There may be occasions during interviews when a participant may disclose incidents around safeguarding of children or vulnerable adults, or criminal acts and the researcher may need to inform another professional. A protocol was established for managing such incidents (see Appendix V, p.330). Participants were informed in the PIS (see Appendix P, p.309) of the nature of disclosures and the processes that would follow if the participant made such disclosures. However, one of the verbal consent statements was expanded to make the process of my seeking advice in response to the participant raising a safeguarding concern clearer to participants. This amendment discussed earlier (see Section 5.1.7., p.95) arose from an incident when an interview was paused following a participant's disclosure after which the participant would not reschedule the interview and withdrew from the study.

5.10 Summary

The methods described in this Chapter facilitated the recruitment and retention of participants, and the generation and analysis of data in line with a social constructionist epistemology and an interpretive interactionist theoretical approach.

Despite limitations to research design imposed by the Covid-19 pandemic, I adapted biographical mapping to be conducted remotely over the telephone. This involved a two-phased interview process carried out over two points in time. The biographical mapping activity provided an opportunity for participant and researcher to develop a rapport in preparation for the second interview when the biographical map was explored in greater detail. Moreover, conducting the interviews over two points in time spread the emotional load of recounting the health journeys, and potentially mitigated exacerbating the participants' symptoms of ill health such as tiredness.

As a qualitative research design, the methods applied throughout this study have been underpinned by clear rationale and transparent processes to evidence research integrity. They include PPI and stakeholder involvement in recruitment and interview design, guidance from a supervisory team, rapport building with a two-phased interview process to elicit *thick* descriptions, conducting a pilot, staged thematic data analysis, and consideration to participant safety and wellbeing.

The research methods have generated data to form a compelling study of how the care experiences of young people living with multiple LTCs are informed by the nature and symptom presentation of some health conditions which mark them as different to others. Application of the early adaptation process has identified how stigma may shape the view of illness, reconstruction of identities, learning, and behaviour. The application of EST has located the potential distal and proximal sources of stigma in young people's environmental systems, and the features that may moderate young people's stigma experiences to facilitate an early adaptation to enable them to live well.

The next Chapter will describe the findings from the biographical mapping exercise which includes the number and nature of morbidities and comorbidities, the length of time from symptom onset to diagnosis, and the care services and HCPs involved in young people's care.

Chapter 6: Part 1 findings: multimorbidity in young people

An activity underpinning the research question was to identify and explore aspects of personal identities (e.g. age and gender), and potential wider determinants (e.g. level of educational attainment and socio-economic deprivation) on young people's interactions with HCPs, care services, and relational networks, and how they shaped the early adaptation constructs. Drawing on data generated from the first phase of interviews with participants (n=19) from four GP practices in Brighton and Hove, and the participants' demographic characteristics, the Sections below will identify and describe the features of young people's multimorbidity in this study. In addition to their demographic details, it will include the number and types of comorbidities and morbidities present, the age of onset of their LTCs, the length of time from onset of symptoms to diagnoses, and the HCPs and care services involved in their care.

6.1 Multimorbidity in the sample and associated features

As a reminder to the reader, multimorbidity is defined as living with two or more LTCs (Nice, 2016a; The Academy of Medical Sciences, 2018). In Chapter 5 (p.82), it was calculated that the proportion of young people who met the selection criteria of living with multimorbidity from the four GP practice patient lists ranged from 18.1% to 30% with a mean figure of 24.3% (see Table 8, p.108). These figures represent the numbers of young people from four of 35 GP practices that cover Brighton and Hove (Brighton and Hove CCG, 2023). Those who came forward to be interviewed were predominantly female. It was therefore not possible to explore the association between multimorbidity and being female identified in previous studies (Barnett *et al.*, 2012; PHE 2018; Violán *et al.*, 2014)

In Chapter 2 (p.23), I discussed how a review of previous multimorbidity studies suggested that socio-economic deprivation (Barnett *et al.*, 2012, PHE, 2018, Violán *et al.*, 2014), low education attainment (Larsen *et al.*, 2017; Puth *et al.*, 2017 and Schiøtz *et al.*, 2017), and living with a learning/intellectual disability (Kinnear *et al.*, 2019) were associated with multimorbidity. In this study, it has not been possible to establish these links. As already discussed in Chapter 5 (Section 5.1.7., p.95), the geographical mobility of some of the participants identified in the pilot suggested that place of residence may be an unreliable indicator of socio-economic deprivation with this sample. Moreover, the comparison of four GP practice sites (although covering

areas of different levels of socioeconomic deprivation) was too small to meaningfully explore the link between socio economic deprivation and multimorbidity in this sample. The association between multimorbidity and educational attainment and learning/intellectual disability could not be explored due to incomplete data. Whilst the demographic details of young people in this study (see Appendix K, p.299) indicated the majority of participants (n=18) had obtained GCSEs and A level/diplomas (n=15), the grades of their educational qualifications or the numbers of GCSEs and A levels were not obtained. Three participants had completed an undergraduate degree course, but several young people in the study were still working towards completing their degree or thinking of applying for a place on a degree course. Moreover, although learning/intellectual disability was included in the selection criteria, none of the participants disclosed or were asked if they regarded themselves as having a learning/intellectual disability, but three young people were excluded from the study for lacking mental capacity.

In sum, the number of young people living with multimorbidity across the four GP practice sites represent a comparably significant proportion of their age group. It has not been possible in this study to establish an association between multimorbidity and socio economic deprivation, being female, low education attainment, and learning/intellectual disability.

6.2 Morbidities: numbers and types

The 19 participants in this study reported 28 different morbidities totalling 74 diagnoses (see Table 13, p.126). The majority of participants (n=16) were living with at least one mental health or neurodevelopmental health condition. See Appendix X (p.333) for the list of health conditions reported by each participant.

Less than half of the health conditions in the selection criteria (10/26) were reported by participants (see Table 13 p.126). Of note, under the heading *painful condition*, six specific painful conditions were reported of which three were related to female reproductive health, (i.e. endometriosis, polycystic ovary syndrome [PCOS], and adenomyosis). A sizeable number of diagnoses reported by participants (23/74) were additional to those on the selection criteria list issued to GP practices. These conditions were categorised into two additional groups:

1. Sixteen of the conditions were classified as other and included, for example, post-traumatic stress disorder (PTSD; four diagnoses), borderline personality disorder (BPD; two diagnoses), and postural orthostatic tachycardia syndrome (PoTS; two diagnoses).
2. Three conditions were classified as neurodevelopmental conditions and included autism (four diagnoses) attention deficit hyperactivity disorder (ADHD; two diagnoses) and attention deficit disorder (ADD; one diagnosis).

Neurodevelopmental conditions are classified as mental disorders in the International Classification of Diseases 11th Revision (ICD-11). They are defined as:

“Behavioural and cognitive disorders that arise during the developmental period that involve significant difficulties in the acquisition and execution of specific intellectual, motor, or social functions.” (WHO, 2022a)¹⁵

As they are also termed neurodevelopmental disorders or disabilities (Ismail and Shapiro, 2019; Patel and Merrick, 2020) I have included them in this study as a separate classification to mental health conditions.

Of the morbidities reported by young people, depression (13 diagnoses) and anxiety (13 diagnoses) were the most frequently cited health conditions in this study. This finding chimes with the results of an earlier study in Brighton and Hove where anxiety and depression were identified as the top two common morbidity diagnoses in both females and males aged 20-34 years, irrespective of area deprivation status (Brighton and Hove CCG and Brighton and Hove CC, 2018). A more recent survey in England suggested more females (27.2%) than males (13.3%) in the 17–22-year age group are likely to report probable mental health conditions (NHS Digital, 2020b). Higher reported morbidity generally in females compared with males has been recognised as a feature of adolescent health in developed countries (Torsheim et al., 2006) with more females in particular self-reporting general ill health and physical symptoms as well as psychological distress in early to mid-adolescence (Sweeting and West 2003). Whether this phenomenon is a consequence of gendered societal expectations being played out by young males and females will be discussed in Chapter 7 (section 7.2., p. 144).

¹⁵ <https://www.who.int/news-room/fact-sheets/detail/mental-disorders>

Table 13. Long-term conditions in total sample by gender.

Long term conditions		Male	Female	Non-binary	Total
Depression		2	11		13
Painful condition	Polycystic ovary syndrome		2		
	Endometriosis		3		
	Back pain	1			
	Sciatica		1		
	Adenomyosis		1		
	Hypermobility		1	1	
					10
Asthma			4	1	5
Anxiety & other neurotic, stress related & somatoform disorders		2	11		13
Irritable bowel syndrome		1			1
Inflammatory bowel disease		1			1
New diagnosis of cancer in last 5yrs			1		1
Psoriasis or eczema		1	2		3
Migraine		1	1		2
Anorexia or bulimia			2		2
Neurodevelopmental condition	Attention deficit disorder (ADD)		1		
	Attention deficit hyperactivity disorder (ADHD)		2		
	Autism		3	1	
					7
Other	Body dysmorphia		1		
	Borderline personality disorder (BPD)		2		
	Postural orthostatic tachycardia syndrome (PoTS)		2		
	Raynaud's disease	1			
	Cystic acne		1		
	Post-traumatic stress disorder (PTSD)		3	1	
	Spasmodic croup		1		
	Hidradenitis suppurativa		1		
	Agoraphobia		2		
Dissociative disorder			1		
					16
TOTAL					74

The number of morbidities per participant ranged from two to seven with a mode value of four health conditions reported by just over a third of participants (n=7), see Figure 7 below). One participant reported living with seven morbidities. As living with four or more LTCs meets the definition of complex multimorbidity (NIHR, 2020), more than half of young people in this sample (n=12) could therefore be described as living with complex multimorbidity.

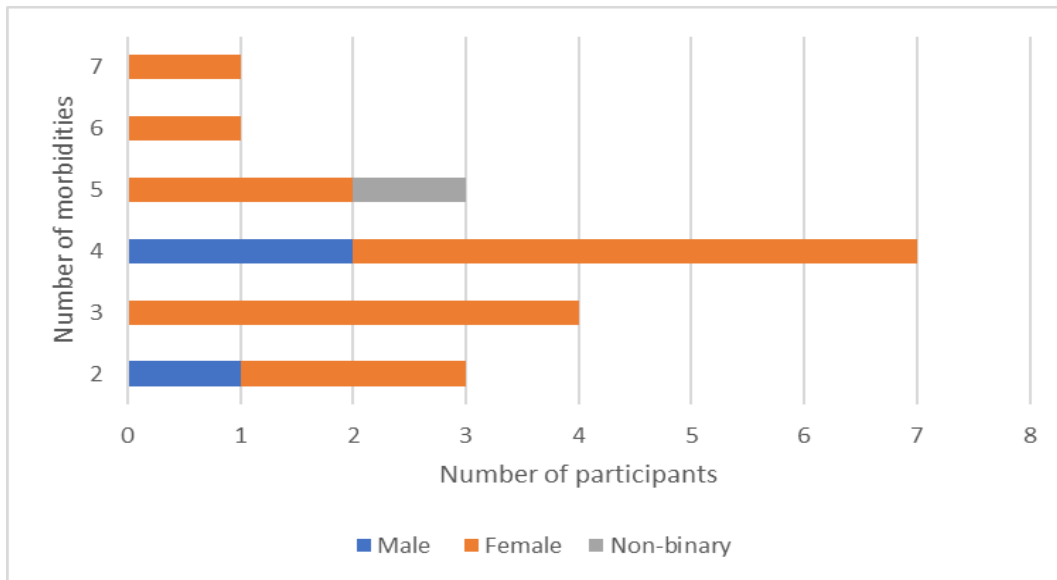


Figure 7. Distribution of morbidities by gender.

6.3 Comorbidities or multimorbidities?

Previous studies on multimorbidity have sought to group morbidities into three classifications: a) physical health morbidities, b) mental health morbidities, and c) physical and mental health comorbidities (Barnett et al., 2012; PHE, 2018; Schiøtz et al., 2017). The picture of morbidities and comorbidities in this sample was much more complex. In Chapter 2 (Section 2.1., p. 23), it was concluded that little is known of the comorbidities present in young people living with MLTCs. As a reminder, comorbidities is the category of having several medical conditions with a primary or index condition (related condition) whereas multiple morbidities refer to conditions that have no index condition/shared pathology such as asthma and epilepsy (Valderas *et al.*, 2009). The data from this sample was explored to identify which of the health conditions reported by young people were comorbidities and/or multimorbidities. Comorbidities were categorised as mental health comorbidities,

neurodevelopmental comorbidities, and physical health comorbidities. Where a shared pathology for any of the health conditions could not be found, the health conditions were classified as morbidities. Most of the participants (n=12) were classified as living with two or more morbidities (multimorbidities; MM) (see Figure 8, p.129).

Mental health comorbidities

In this current study, nine participants were classified as living with mental health comorbidities which included anxiety, depression, and agoraphobia (see Figure 8, p.129). Depressive symptoms are frequently accompanied by symptoms of anxiety (NICE, 2009) and where these conditions concur in a participant they have been classified in this study as mental health comorbidities (MHC). Comorbid mental health conditions have been reported in national youth surveys conducted around the world. Anxiety, mood, behaviour, and substance misuse were identified among American young people (13-17 years) (Kessler *et al.*, 2012). Unfortunately, variations in mental health inclusion criteria across studies makes comorbidity comparisons difficult. For example, in a German survey there were more children and young people (7-17 years) living with two or more mental health conditions (8.7%) than one (5.8%). The conditions included in the mental health criteria were ADHD, in addition to anxiety, conduct, and depressive disorders (Ravens-Sieberer *et al.*, 2008).

Neurodevelopmental comorbidities

Five participants in this study who were female and non-binary were categorised as living with neurodevelopmental comorbidities which included autism, ADHD, depression, BPD, ADD, anxiety, associative disorder, and an eating disorder. People living on the autistic spectrum have a high chance of being diagnosed with comorbidities (Lai *et al.*, 2014; Hebron and Bond, 2018). Psychiatric conditions for example are common and frequently multiple in children (10-14 years) with autism spectrum disorders (Simonoff *et al.*, 2008). These conditions include specifically psychotic disorders such as schizophrenia (Kincaid *et al.*, 2017) and eating disorders (Lucarelli *et al.*, 2017). For children and young people (9-16 years) diagnosed with high functioning autism (HFA), comorbid psychiatric conditions include behavioural disorders, anxiety, and tics (Mattila *et al.*, 2010).

There is also evidence of autism overlapping with other neurodevelopmental disorders such as ADHD (Gillberg, 2010; Russell *et al.*, 2013, Simonoff *et al.*, 2008) in addition to personality disorders (Gillberg *et al.*, 2016; Lugnegard *et al.*, 2012).

Where mental health conditions, ADHD, ADD, personality disorders, and eating disorders have been diagnosed in young people living with autism, they have been classified as neurodevelopment comorbidities (NDC) in this study.

Physical health comorbidities

Two participants were classified as living with physical health comorbidities which were related to the respiratory system (asthma and spasmodic croup) and the female reproductive system (PCOS, endometriosis, and adenomyosis). See Figure 8, below for the distribution of comorbidities, multimorbidities, and morbidities among participants.

In sum, the picture that emerges of the distribution of morbidities, comorbidities and multimorbidities amongst participants is complex. Only three participants presented with just comorbidities. They were mental health comorbidities (n=2) and neurodevelopmental comorbidities (n=1). Three participants presented with just multimorbidities. The remaining participants (n=13) reported living with a combination of morbidities and/or comorbidities and/or multimorbidities.

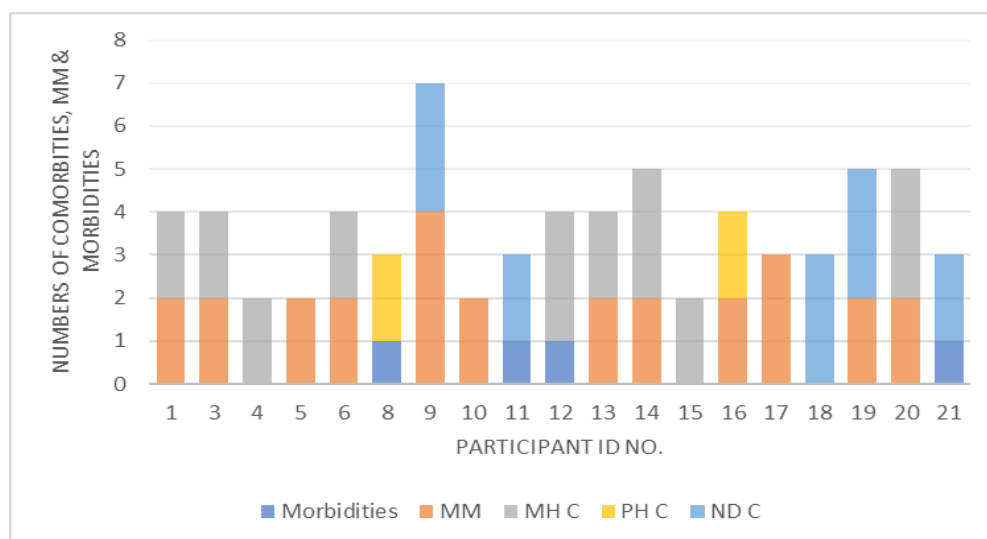


Figure 8. Distribution of comorbidities, multimorbidities, and morbidities by participant.

6.4 Time between onset of symptoms and diagnosis

Most participants (n=17) reported experiencing their first symptoms of ill health aged 15-years and under. Just over half of this number (n=9) were aged 10-years and under, of which four were aged 5-years and under.

More than half of participants (n=11) received a diagnosis in under a year from the onset of their symptoms. Of these, eight participants received a physical health diagnosis (IBS; n=1; migraine; n=1; eczema; n=3; asthma; n=3). However, for a sizeable number (n=7), it took three years or more for a diagnosis. Of these, four participants waited for a mental health diagnosis and one participant for a neurodevelopmental diagnosis. The maximum length of time between onset of symptoms and diagnosis was nine years for a mental health diagnosis (ID no. 4., see Table 14, p.131).

Just under half of participants (n=9) reported the onset of symptoms of a secondary condition aged 11-15 years and six were aged 16-20 years. A sizeable number of participants (n=8) did not receive the secondary diagnosis for three years or more. For five participants (ID no.4,6,14,16,21), there was a longer time (mode value of 3 years) between onset of symptoms and second diagnosis compared with the length of time between onset of symptoms and diagnosis for the first condition (see Table 14, p.131). For four of these participants (ID no.4,6,16,21), the data suggest the symptoms of the second condition were present at the time of the first diagnosis. For two of these participants (ID no.4,6), their conditions were mental health comorbidities.

Of those living with the symptoms of a third health condition (n=15), six were living with symptoms of ill health for between 3 to 10 years (mode value 3 years) before diagnosis. Three of these morbidities were physical health conditions related to female reproductive health which included endometriosis (n=1; ID no.6), PCOS (n=1; ID no.8), and endometriosis and adenomyosis (n=1; ID no.16).

Table 14. Years between onset of symptoms and diagnosis of a LTC

ID	1 st LTC Yrs.	Age Yrs.	2 nd LTC Yrs.	Age Yrs.	3 rd LTC Yrs.	Age Yrs.	4 th LTC Yrs.	Age Yrs.	5 th LTC Yrs.	Age Yrs.	6 th LTC Yrs.	Age Yrs.	7 th LTC Yrs.	Age Yrs.	8 th LTC Yrs.	Age Yrs.
01	7 P	≤ 15	1 P	≤ 20	1 M	≤ 24	1 M	≤ 24								
03	≤ 1 P	≤ 20	≤ 1 P	≤ 20	≤ 1 M	≤ 20	≤ 1 M	≤ 20								
04	9 M	≤ 10	12 M	≤ 10												
05	1 P	≤ 15	1 P	≤ 20												
06	6 M	≤ 15	9 M	≤ 15	9 P	≤ 15	≤ 1 M	≤ 24								
08	4 P	≤ 10	4 P	≤ 10	3 P	≤ 15	3 ML	≤ 20								
09	≤ 1 P	≤ 15	2 M	≤ 15	2 M	≤ 15	≤ 1 P	≤ 20	≤ 1 M	≤ 24	≤ 1 ND	≤ 24	≤ 1 ND	≤ 24	1 PL	≤ 24
10	≤ 1 P	≤ 5	≤ 1 P	≤ 20												
11	5 ND	≤ 5	3 M	≤ 15	3 M	≤ 15	≤ 1 P	≤ 15								
12	≤ 1 M	≤ 15	≤ 1 M	≤ 15	≤ 1 M	≤ 15	≤ 1 M	≤ 20								
13	≤ 1 P	≤ 5	1 M	≤ 15	1 M	≤ 15	4 P	≤ 15								
14	≤ 1 P	≤ 5	4 M	≤ 10	4 M	≤ 10	≤ 1 M	≤ 20	2 P	≤ 20						
15	5 M	≤ 15	5 M	≤ 15	11 ND	≤ 15										
16	3 M	≤ 15	12 M	≤ 15	10 P	≤ 15	10 P	≤ 15	1 P	≤ 24						
17	≤ 1 M	≤ 20	≤ 1 P	≤ 20	3 P	≤ 20										
18	≤ 1 ND	≤ 5	2 M	≤ 20	2 M	≤ 20										
19	≤ 1 P	≤ 5	≤ 1 P	≤ 5	8 ND	≤ 15	2 M	≤ 15	7 M	≤ 20						
20	≤ 2 M	≤ 15	≤ 2 M	≤ 15	≤ 2 M	≤ 15	≤ 1 M	≤ 24	8 P	≤ 20	6 PL	≤ 24				
21	≤ 1 P	≤ 10	≤ 10 ND	≤ 15	2 M	≤ 20	1 M	≤ 24								

Key

P = Physical health condition		Living with symptoms of a mental health condition for ≥ 3yrs before diagnosis
M = Mental health condition		Living with a neurodevelopmental condition for ≥ 3yrs before diagnosis
ND = Neurodevelopmental condition		Living with a physical health condition for ≥ 3yrs before diagnosis
		L = Live symptoms but no diagnosis

For participants living with four or more conditions (n=12), the majority (n=8) lived with the symptoms for a year or under before diagnosis. Three participants (ID no.13,16,20) and one participant (ID no.19) waited three years or more between

onset of symptoms and diagnosis for a physical health condition and a mental health condition respectively. For participant ID no.16, the condition was a comorbidity of the third diagnosis and the onset of symptoms had coincided with the onset of symptoms of the third condition.

At the time of the study, six participants (ID no.8,9,15,17,20,21) were living with symptoms of a health condition that had not yet been formally diagnosed.

In sum, the timings of diagnoses from onset of symptoms in this study suggest some children and young people experience protracted delays depending on the type of health condition. Young people living with multimorbidity present with their first morbidity in childhood and early adolescence (aged 15 years and under). Symptoms that lead to a physical health diagnosis are diagnosed in the main relatively quickly; within a year from onset of symptoms. The notable exceptions to this are physical health conditions linked to female reproductive health. Children and young people presenting with symptoms of a mental health or neurodevelopmental condition live with the symptoms for three years or more before diagnosis. For some participants, the length of time between onset of symptoms and diagnosis was longer for the second diagnosis than for the first, which suggests that their symptoms were present at the time of the first health condition diagnosis. For a couple of participants, it is suggested that these symptoms were undiagnosed mental health comorbidities.

6.5 Health and care professionals

In addition to the GP, the asthma nurse was the other main provider of care from primary care services to this study's sample (n=5). Within secondary care, 21 specialist HCPs were involved in young people's care. These included two dietitians, 16 specialist consultants, of which the majority (n=6) were consultants in gynaecology, and three were specialist teams (i.e. for ADHD in children, BPD and eating disorders in children, and adult oncology outpatients).

Of significance was the involvement of counselling services provided by schools, colleges, and universities which supported seven participants. There was involvement of private consultants (n=5) and third sector advice and support services (n=4). See Table 15 (p.133) for the list and numbers of HCPs and services involved in young people's care.

Table 15. List and numbers of HCPs and care services involved in young people's care.

Health care area	Specialist/specialism	Number
General practice services	GP	19
	Asthma nurse	5
	Nurse (role not specified)	1
	Mental Health Nurse (GP)	1
	Total	26
Mental Health Services	Adult Mental Health Services	8
	Children & Adolescent Mental Health Services	8
	Psychiatrist	3
	Counsellor (adult services)	3
	Psychologist	1
	Community Psychiatric Nurse	1
	Inpatient care	1
	1:1 Cognitive Behavioural Therapy	1
	Group therapy service	2
	Wellbeing service	4
	Total	32
Secondary care	Paediatrician	2
	Gynaecologist	6
	Gastroenterologist	2
	Neurologist	1
	Cardiologist	2
	Dermatologist	2
	Respiratory consultant	1
	Dietician	2
	Specialist team ADHD (children's services)	1
	Specialist team for BPD & eating disorder children)	1
	Adult cancer services/outpatients	1
	Total	21
	Other	Private consultant
Private counsellor		2
Physiotherapist (private)		1
Student support (university)		1
School/college/university counsellor		7
Third sector advice and support		4
Total		20
Total	99	

Given that mental health and neurodevelopmental diagnoses (45/74) outnumbered physical health diagnoses (29/74), the services most referenced were mental health services (32/99). Eight participants respectively reported involvement of adult mental health services (AMHS) and children's and adolescent mental health services (CAMHS). Participants also noted participation in group therapy (n=2), counselling (n=3), 1:1 cognitive behavioural therapy (CBT, n=1), and the Wellbeing service (n=4).

6.6 Summary

The findings from these first interviews set the context to the care experiences that young people recounted in detail in the second interviews, and which are discussed in Chapter 7. Many young people (n=13) were living with a combination of comorbidities and morbidities (i.e. mental health, physical health, and neurodevelopmental conditions) ranging from two to seven health conditions. More than half of young people (n=12) were living with complex multimorbidity (i.e. living with four or more LTCs). Whilst anxiety and depression were the most prevalent morbidities (n=13) and comorbidities (n=9), a large number of the morbidities reported (13/28) have not been included in the multimorbidity index of previous studies, despite neurodevelopmental conditions in particular being strongly associated with other morbidities.

Of note in this thesis is the proportion of young people in the 18-24 year age group from the four GP practice patient lists living with multimorbidity. It has been calculated at 24.3%. It has not been possible in this study to explore the association between multimorbidity and low educational attainment, learning disability, being female, and living in an area of high socio-economic deprivation.

For many young people in this study (n=9) the onset of their first symptoms started in childhood (under 10 years of age), and many (n=13) were living with symptoms of ill health for several years before a diagnosis, particularly for those living with mental health and neurodevelopmental conditions, and conditions associated with female reproductive health. The number and range of HCPs and care services involved in the participants' care were diverse. In addition to GPs, they included specialist consultants/teams in secondary care, mental health care services, counselling services provided by schools, and advice and support services provided by the third sector. HCPs and services relating to secondary mental health care were the most frequently referenced.

How the nature and number of morbidities, the age of onset of first symptoms, and length of time to diagnosis contributed to shaping young people's care experiences and the early adaptation constructs will be discussed in Chapter 8 (p.179). The next Chapter will describe the findings from the second interviews. It will identify the

features of young people's care experiences which are suggested to have shaped their early adaptation constructs.

Chapter 7: Part 2 findings: young people’s care experiences and the early adaptation process

This thesis set out to understand how young people’s interactions with HCPs, care services, and significant others shaped the early adaptation constructs as they lived with MLTCs, with the aim of identifying the features that supported them to live well. Of interest to this study was identifying features of previous care experiences on moulding the early adaptation process of subsequent diagnoses. Three main themes were generated from the second semi-structured interviews with young people (n=19) about their health and care experiences. Within each main theme there were between two to four subthemes that captured elements of young people’s experiences of significant others (i.e. families, peers, and partners), HCPs, teachers, employers, and organisational systems (i.e. education, employment, and health) which I suggest shaped the early adaptation constructs. See Figure 9 below for the main themes and subthemes.

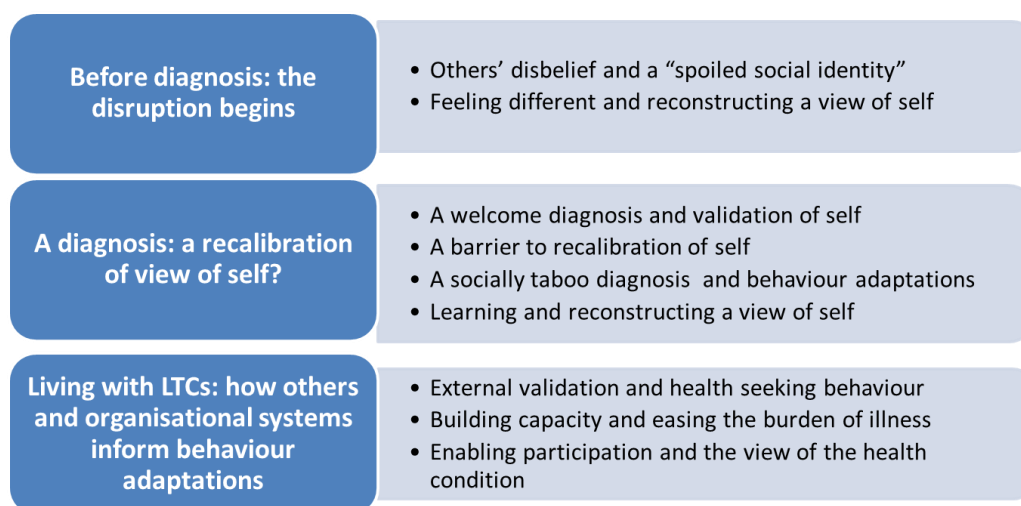


Figure 9. Overview of main themes and subthemes.

In this thesis the main themes locate features around the key stages of young people’s health care journeys of pre-diagnosis, diagnosis and learning, and living with health condition(s). The subthemes are then structured around young people’s experiences with others at each of these stages of their health care journey and explored to identify how they shaped the early adaptation constructs. The findings within the main themes and subthemes are contrasted with Due-Christensen’s account of the early adaptation process.

7.1 Before diagnosis: the disruption begins.

This theme captures young people's experiences of living with the symptoms of an undiagnosed health condition and how others' interactions with them moulded their reconstruction of self, pre-diagnosis (see Figure 10 below).

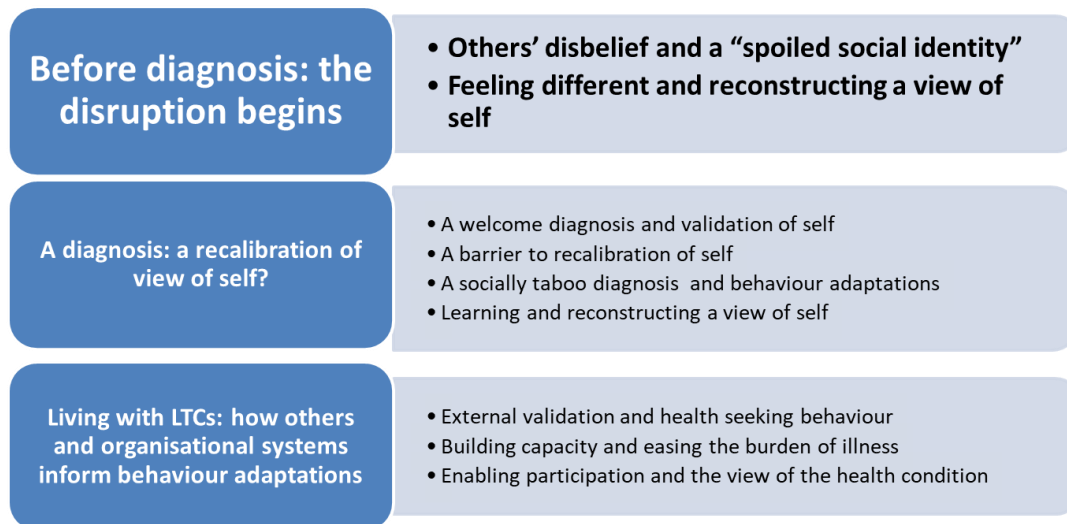


Figure 10. First main theme and two subthemes.

I suggest these experiences caused disruption to some young people's lives which indicated that the early adaptation process started not with the diagnosis, but with the onset of symptoms. During this time they were living with unexplained symptoms of ill health arguably impacting and disrupting their everyday lives. This is in contrast to Due-Christensen *et al.*, (2018) who suggest the starting point of the early adaptation process for people newly diagnosed with T1DM is the diagnosis and its ensuing disruption to people's life plans and hopes for the future (see Chapter 2, Section 2.2., p.29).

The two subthemes within this first main theme capture the impact of young people's experiences on the formation of their reconstructed view of self and behaviour pre-diagnosis. The first subtheme describes how young people living with undiagnosed physical health, mental health, and neurodevelopmental health conditions experienced having their symptoms dismissed when they sought help from HCPs and parents. I propose the ambiguous nature of some symptoms (e.g. low mood and dizziness) and associations with female reproductive health (e.g. menstrual cramping pains) may have resulted in young people experiencing stigma prejudice (Stangl *et al.*, 2019), which in turn shaped their sense of self as *abnormal*. It is

mooted in this thesis that delays in seeking medical advice could have been compounded by young people being reluctant to talk to their parents because of anticipated stigma based on previous direct or indirect stigma experiences. The second subtheme explores how young people living with undiagnosed neurodevelopmental conditions became aware of and managed their difference to their peers. It is proposed that from their experiences of felt and enacted stigma, they were viewed and viewed themselves as different to their peers which informed their reconstruction of self and behaviour.

7.1.1 Subtheme 1 of 2: others' disbelief and a "spoiled social identity"

Analysis of the narrative data indicated some young people in this study (n=9) experienced or anticipated disbelief and derision from others in response to the symptom presentation of their undiagnosed health conditions. I propose that for some young people, others' disbelief of their expressions of ill health ascribed to them an undesired difference from what is expected of young people (Goffman, 1963). They were perceived as, and perceived themselves to be, not quite normal and this subsequently informed not only others' behaviours but their own.

For some young people (n=5) the presentation of symptoms such as dysmenorrhea and irregular menstrual cycles in undiagnosed endometriosis, PCOS, and adenomyosis were ostensibly dismissed by HCPs as just part of normal physiological development. Young women/girls were seemingly advised to alleviate symptoms with over-the-counter pain relief medication (ID no. 6, 8, 16, 17)¹⁶ and the application of heat via a hot water bottle (ID no. 5). Consequently, some participants felt others downplayed their recurrent complaints of discomfort. They felt their symptoms were not normal, but commented their concerns were not addressed by HCPs:

"Doctors just don't listen. They do what they've done to me and say it's just your period, you're just heavy. But I'm in pain and it's just not normal to have such a painful period, or such a heavy period. And doctors just fob you off with get some extra big tampons, or some extra big pads, or here's some pills you can take." (ID no. 6)

¹⁶ See Appendix X (p.334) for the participants' health conditions.

Having symptoms met with disbelief by family and peers was a response experienced by some participants before diagnosis of a health condition in childhood and early adolescence (n=5). For one young person living with undiagnosed BPD, their parent reportedly dismissed the symptoms by calling out the young person as “a dramatic teenager” (ID no.12). For another participant living with frequent severe headaches (undiagnosed migraine), their peers disbelieved the frequency of their symptoms:

“There was kind of this sense of disbelief about the frequency...I clearly remember a friend of mine prodding me on my head ... and [I] kind of recoiling and saying, ‘I’ve got a headache’, and him saying ‘yeah, like you said that yesterday’.” (ID no. 1)

This disconnect between others’ beliefs of young people’s symptoms and their own arguably caused them to question themselves as described by one participant presenting with dizziness and breathlessness which was explained by others (i.e. HCPs, peers, parents, and teachers) as stress, but would later be diagnosed as postural orthostatic tachycardia syndrome (PoTS): *“I felt like I was going mad because everyone around me was saying, ‘it’s in your head. This is stress, not real”* (ID no. 13). Whilst another was seemingly told by their parents that they were faking illness and so they began to question themselves: *“I thought maybe I am faking it”* (ID no. 9).

Of note was some participants (n=3) reported delays in seeking medical advice to potentially avoid critical responses from parents. Of living with and self-managing severe headaches, one participant said:

“It wasn’t worth them [my family] telling me that I didn’t have a headache or that I had one yesterday ... I just didn’t want any hassle about how her [mother] life was so much harder and to get on with it.” (ID no. 1)

Another participant whose family had previously accused them of faking illness stated emphatically they didn’t talk to their family about their mental health symptoms: *“I never talked about my mental health with my family. Never talked to them about it”* (ID no. 9).

One young person was reluctant to disclose their low mood to a close family member because they were concerned that they would be negatively judged which they had witnessed in this relative's behaviour to another family member:

“He [relative] makes a lot of jokes about things – ‘that’s [mental health] not real, that’s really crazy, people are taking days off work just because they want to pull a sickie’... so I assumed that me being depressed makes me like her [another relative], which makes him not like me.” (ID no. 4)

In this first subtheme (1 of 2), I draw on my analysis of young people's narratives to argue the symptoms of young people's undiagnosed health condition(s) which presented to others as vague, invisible, or too frequent to be believed initiated the stigmatisation process. Bury (1982) noted in his study of adults living with rheumatoid arthritis (RA) that the vague symptoms and insidious onset of the condition caused problems with the recognition and legitimisation of the health condition. Whilst in Bury's study some participants rationalised their symptoms as a consequence of their activities, these responses were not evident from the young people in this study. I suggest the onset of the young people's vague symptoms and delay in diagnosis resulted in young people experiencing stigmatisation. I propose that these experiences were an unwelcome disruption to young people's lives and shaped the formation of the early adaptation constructs of reconstructing view of self and behaviour. Charmaz (1991) has suggested that people can experience the intrusiveness of illness long before the disruption. I suggest the stigma experienced by young people pre-diagnosis is an example of young people experiencing the intrusiveness of illness. Stigma takes several forms depending on how it is experienced (e.g. felt, anticipated, and internalised) and each type will be discussed as it arises in this Chapter. Evidenced within this subtheme is felt stigma in the form of fear of others' reactions (Scambler and Hopkins, 1986) such as the disbelief and apparent ridicule to the reports of their ill health. The data suggests that these responses shape a negative reconstruction of self. According to Goffman (1963), people who have been stigmatised learn and incorporate the standpoint of the *normal* and so acquire the identity beliefs of wider society (Goffman, 1963). They become sensitive to others' intentions and meanings in interactions which informs their reappraisals of self (Charmaz, 1983). Consequently, they begin to take on board others' perceptions such as *“it's in your head”* (ID no. 13). This process has

also been termed internalised stigma (Yigit *et al.*, 2020). Stigmatisation creates a discrepancy between young people's virtual identity (e.g. the "*dramatic teenager*" [ID no. 12]) and their actual identity (e.g. I'm an unwell person) which results in a "*spoiled social identity*" (Goffman 1963, p.31). Stigmatisation is divisive and young people are made to feel by social expectations that they are different.

The young people's experiences in this study indicated that they also sometimes anticipated stigma. Like felt stigma, anticipated stigma is a fear of rejection or exclusion with the distinction that it is only "*made real*" as people experience it in social interaction (Pescosolido and Martin, 2015, p.6). Perceived and anticipated stigma are based on stigma experiences (Logie *et al.*, 2011). In this study, I argue young people who deferred saying anything to their parents about their health condition did so because they had experienced previous enacted stigma in the form of prejudice (ID no. 1,9), or witnessed prejudice towards others (ID no. 4). This would also suggest that previous stigma experience may inform young people's future responses to the symptom presentation and diagnoses of some health conditions.

In a development of Due-Christensen's model, I therefore argue an unwelcome disruption to some young people's lives arises from stigmatisation pre-diagnosis, rather than at the point of diagnosis. More specifically, I suggest the internalisation of others' perceptions/judgements on their character as a result of their differences informed a negative reconstruction of self (e.g. as "*mad*" (ID no.13), and "*faking it*" (ID no. 9). Moreover, it shaped concealment behaviours (e.g. not speaking out about symptoms) in response to stigma probably to protect their sense of self.

7.1.2 Subtheme 2 of 2: feeling different and reconstructing a view of self

Neurodevelopmental diagnoses were reported by six participants. This second subtheme (within the overarching main theme: *before diagnosis the disruption begins*) refers to young people's experiences of living with an undiagnosed neurodevelopmental condition in childhood (n=3). The data suggest how the health condition symptoms presented in young people informed their and others' interactions with them pre-diagnosis. In this subtheme, I explore the role of interactions with peers to undiagnosed difference which I propose were shaped by stigma and experienced as an unwelcome disruption to young people's lives. I suggest it is within the sphere of their interactions with peers that some young

people's dissimilarity was acutely felt, and shaped their behaviour as they tried to minimise their differences. Young people reported growing up feeling inherently unlike others: *"I always felt different. I thought I was just weird"* (ID no.11), and *"I could tell that there was something just different about me"* (ID no. 21).

A reason for feeling dissimilar was described by one participant to account for why they described themselves as feeling *"outcasted"* from her peers: *"I remember I didn't like talking to people and making friends. It wasn't something that came naturally to me"* (ID no. 21).

They were fearful that they would be judged by their peers which impacted on their behaviour: *"Being scared that the other kids would make fun of me or judge me, so it was just better to be quiet and then they don't have anything to judge me on"* (ID no. 21).

For another participant, their strategy to try and fit in with their peers backfired. Rather than deflecting attention from how they differed, it could be argued their behaviour drew attention to it by trying too hard to fit in:

"I was bullied quite a lot. I couldn't understand what I was doing wrong because I was doing what they were doing to try and fit in. Apparently, that was the wrong thing to do." (ID no.19)

This subtheme (2 of 2) captures how living with an undiagnosed neurodevelopmental condition in childhood could inform interactions particularly with peers, and thus shape the view of self and behavioural adaptations. Goffman (1963) argues that when someone possesses something that is different from others in their category it is perceived as less desirable, and the person is reduced in our minds from *"a whole and usual person to a tainted discounted one"* (p.12). It is not the attribute itself such as the withdrawn behaviour of someone who doesn't find talking to others easy that is singled out, but the person who possesses it; she is stigmatised (Goffman, 1963; Link and Phelan, 2001). This possession of an undesired difference from what is expected results in others perceiving them as not quite normal and they discriminate against them (Goffman, 1963; Link and Phelan, 2001).

Enacted stigma from others which I contend is evidenced in this Section, includes practices such as stereotyping (i.e. attaching beliefs about characteristics associated

with the stigmatised), prejudice (i.e. negative evaluation), stigmatising behaviour (e.g. exclusion), and discriminatory attitudes (e.g. shouldn't be allowed to participate) (Stangl *et al.*, 2019). Stigma prejudice and stigmatising behaviour in this subtheme were experienced by young people as being teased, bullied, and excluded, but they also experienced felt stigma in the form of fear of others' reactions (Scambler and Hopkins, 1986). Young people attempted to minimise the enacted and felt stigma by concealing symbols of stigma (e.g. withdrawn behaviour) to pass as normal (Goffman, 1963).

In this subtheme I have noted that it was in their interactions with peers and not with family that young people living with undiagnosed neurodevelopmental conditions notably experienced being different.

In sum, the main theme *before diagnosis: the disruption begins*, explores the stigma processes on the formation of the early adaptation constructs of disruption, reconstruction of view of self, and behaviour from living with the symptoms of a health condition prior to a diagnosis. For young people living with a range of undiagnosed health conditions with unclear symptomology, it is suggested the delay in legitimisation of their symptoms was associated with their experiences of stigma prejudice which informed the reconstruction of sense of self as seen by others. These experiences were internalised resulting in a "*spoiled social identity*" (Goffman, 1963, p.31). The data suggests past experiences of enacted stigma and of witnessing stigma can result in anticipated and felt stigma which may inform future health seeking behaviour, and result in young people being reluctant to disclose their symptoms to family and HCPs.

For young people living with an undiagnosed neurodevelopmental condition, their differences, notable in interactions with peers, led to attempts to enhance their similarities and/or hide their differences.

The implication of this main theme is the disruption construct of the early adaptation process for many young people in this study started not as Due-Christensen *et al.*, (2018) argue with the diagnosis, but rather with the onset of symptoms pre-diagnosis. The data suggest the symptom presentation in young people both shaped and was shaped by their social interactions. The ensuing enacted stigma and felt stigma caused an unwelcome disruption to some young people's lives. Their

reconstruction of view of self as different to their peers shaped behaviours to conceal their difference, or enhance similarities to *pass*. It is thus proposed in this thesis that stigma (enacted [prejudice and discrimination], felt, and anticipated) is critical to moulding the constructs of disruption, reconstructing view of self, and behaviours, and this process starts pre-diagnosis.

7.2 A diagnosis: a recalibration of view of self?

This second main theme describes the impact of a diagnosis on young people’s view of the health condition and its repercussions on the reconstruction of their view of self, learning, and behaviour. See Figure 11 below for the second main theme and four subthemes.

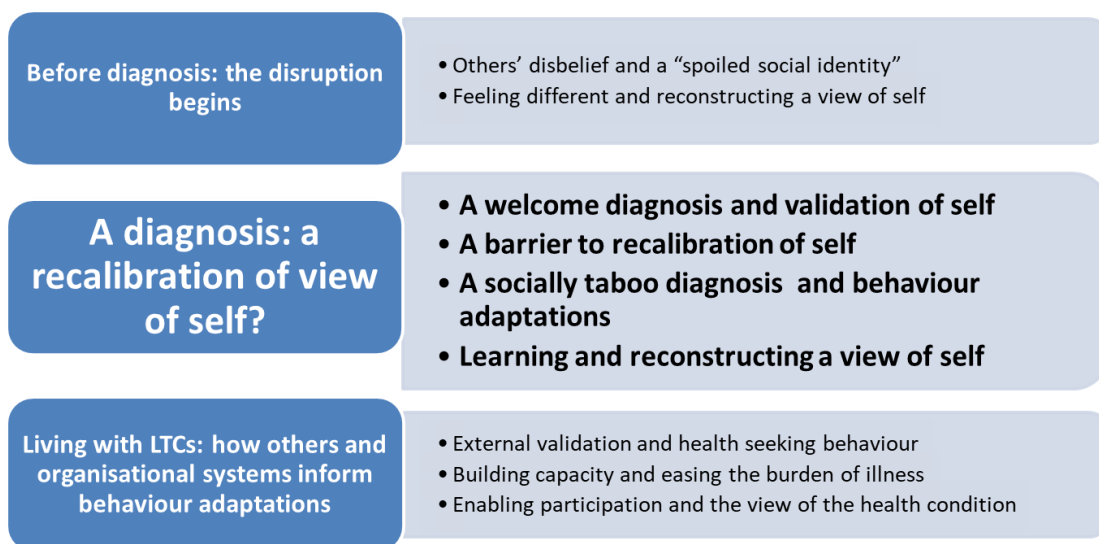


Figure 11. Second main theme and four subthemes.

In the preceding Section (*before diagnosis: the disruption begins*), I argue some aspects of the early adaptation process (i.e. the disruption, reconstructed view of self, and behaviour) to some health conditions precedes the diagnosis. I propose in this main theme that once a diagnosis is made, it is a point of further disruption to the adaptation process. It may be experienced as either welcome or unwelcome dependent on the actual or anticipated stigma responses to the diagnosis, and the impact on reconstruction of self. Specifically, it is suggested from the data that the underlying processes of stigma avoidance, managing enacted stigma, and fear of stigma are key drivers in shaping how far young people associated with the

diagnosis, which in turn informed their reconstruction of view of self, learning, and behaviours.

Due Christensen *et al.*, (2018) (see Chapter 2, Section 2.2., p.29) argue that adaptation is influenced by people's perception of the illness and its impact on their lives. Those concerned about the potential severity of a diagnosis may have had a strong attachment which informed restrictive self-care practices. A lesser attachment was associated with a relaxed approach to diabetes management. From the young people's narratives in this study, I argue their perceptions of the diagnosis were informed by their stigma experiences which may have shaped the reconstruction of *self* post diagnosis, and informed behaviours that could be described as either constructive or harmful to living well.

The first subtheme explores how a diagnosis which brings young people into the fold of normative society is a label that could facilitate a reconstruction of self as *sick* and minimise further stigma experiences. In the second subtheme, it is suggested that stigma discrimination experienced by those with a mental health and/or neurodevelopmental diagnosis may act as an environmental stressor, compounding a negative sense of self, potentially resulting in self-harming, arguably as a means of communicating their distress. In the third subtheme, it is proposed a diagnosis the young person perceives as socially taboo may be met with fear of social rejection and stigma avoidance, which I contend may shape socially restrictive behaviour to pre-empt the stigmatising behaviour of others, and to protect their sense of self. The fourth and final subtheme highlights how following a diagnosis some young people accessed online communities to seek out information about their diagnosis and how to manage the health condition. The data suggests that online learning about the health condition(s) counteracts the "*spoiled social identity*" (Goffman, 1963, p.31) through the reconstruction of their view of self.

7.2.1 Subtheme 1 of 4: a welcome diagnosis and validation of self

This first of four subthemes explores how after some time of living with undiagnosed ill health symptoms and stigma experiences, a diagnosis is welcome for some (n=6) as it ostensibly validates them and their experiences. Validation has been defined as a form of understanding and acceptance of another person's internal experience, distinct from agreement or approval (Hall, 2011). Young people's experiences

suggests that validation reorientates self-perceptions that the symptoms are not their characters/personalities, but are part of their health condition(s) and can be a prompt to act.

For one participant who had started to experience an exacerbation of their undiagnosed migraine symptoms, the diagnosis brought relief that their experiences were normal as they had been attributed to a recognised health condition:

“It was relief when my GP told me. I think it was relief when the optician said there's nothing wrong with your eyes go and see your GP, and then there was relief that this is a thing. It's obviously abnormal but I'm having a normal abnormal experience.” (ID no.1)

Being validated as normal was also repeated by other participants: *“It's like normal because there's a label on it, if that makes sense?”* (ID no.6), and *“It was comforting to have a label ... to know that other people have it and that I'm not going crazy”* (ID no.4).

For some participants, a diagnosis helped to explain their prior behaviours. For one participant living with undiagnosed PoTS, they had thought their symptoms were part of their personality: *“I went away and looked it [PoTS] up and I thought, half these symptoms were my personality, not my problem.”* (ID no.13). Whilst for another, the diagnosis felt like it confirmed their experiences:

“I felt seen. The depression felt about right. It always felt like it was pretty bad as in like it was pretty severe. Hearing that made me think ok that makes sense and validating.” (ID no.15)

A diagnosis for one participant highlighted the severity of the health condition and motivated them to engage with treatment:

“I was nearly put in hospital. I was right on the cusp of the chart for being admitted. I realised how much I didn't want that, and that led me to try and recover, and I'm now with the outpatients.” (ID no.21)

This subtheme (1 of 4) explores how after a period of living with symptoms of undiagnosed health conditions for which they have experienced stigma, young people indicated they experienced feeling validated from receiving a diagnosis. Bury

(1982) argued a diagnosis made people living with the symptoms of RA feel their behaviour of seeking medical help was justified. In this thesis, a diagnosis provided young people with a label for their symptoms. Their sense of self, previously shaped by stigma prejudice and stigma discrimination involving others dismissal and rejection of them because of their difference (Goffman, 1963; Link and Phelan, 2001), had an opportunity to recalibrate. It could be argued that as the origin of their stigma experiences has now been disproved (e.g. they're not *faking it*), and the source of their symptoms has a legitimate explanation (e.g. they have a health condition), young people believe that others will now respond more favourably to them (Link *et al.*, 2004).

Research suggests a diagnosis can offer reassurance to women living with PCOS (Copp *et al.*, 2019), and to people living with IBS, it indicates there is no serious underlying cause of their symptoms (Thompson 1999; Dalton and Drossman 1997). A diagnostic label can lead to perceptions of empowerment, transformation, and self-reinforcement (Sims *et al.*, 2021). For some women living with fibromyalgia, research suggests a diagnosis brings relief after a period of uncertainty, in addition to access to financial assistance and potential treatments to alleviate symptoms (Rau and Russell, 2000). For some conditions such as autism spectrum disorder, a diagnostic disclosure can potentially mitigate stigma (O Connor *et al.*, 2022). Whilst a mental health diagnosis may bring knowledge that there are potentially effective therapies, which in turn brings hope and a sense of control (Probst, 2014). However, not all diagnoses bring such relief and affirmation. For those with minimal symptoms of PCOS, a diagnosis may cause more harm than benefit due to long-lasting anxiety and altered life plans (Copp *et al.*, 2019). Whilst for those living with autism spectrum disorder, beyond the damage of stigma, a diagnostic label may threaten and devalue young people's self-concept (O Connor *et al.*, 2018).

Williams (2000) argued that in response to a diagnosis, girls (aged 15-18-years) showed greater adaptation to diagnoses, incorporating their conditions and any diabetes and asthma care routines into their personal identities. In contrast, she argued that boys of the same age tried to keep their asthma and diabetes management out of their identities, and to conceal their care management to pass. An argument put forward for this difference in behaviour is gendered societal expectations where boys are expected to "*react to illness with displays of stoicism,*

strength, control, and independence” (Maclean, Sweeting, and Hunt, 2010, p.599), whilst expectations for girls are less censorial (Maclean, Sweeting, and Hunt, 2010). From the gender composition of this thesis, it is not possible to explore the role of gender on young people's responses to a diagnosis, and how far the largely female welcome response to a diagnosis was informed by conforming to gendered expectations.

This study suggests that for young people living with symptoms of ill health for which they have been stigmatised, a diagnosis may be welcome. It legitimises their initial concerns about their bodily changes and seemingly brings them into the fold of normative society. They are not *faking it* but living with recognised health conditions, and the disruption is an opportunity to recalibrate their sense of self.

7.2.2 Subtheme 2 of 4: a barrier to recalibration of self

In the preceding subtheme, a diagnostic label could be argued to (a) provide reassurance (Copp *et al.*, 2019; Thompson 1999; Dalton and Drossman, 1997), (b) access to resources (Rau and Russell, 2000), (c) mitigate stigma (O Connor *et al.*, 2021), (d) empower (Sims *et al.*, 2021), and (e) facilitate self-awareness (O Connor *et al.*, 2018). However, a diagnosis has the potential to threaten young people's sense of self (O Connor *et al.*, 2018), and cause long-lasting anxiety and altered life plans (Copp *et al.*, 2019). This second of four subthemes explores how a diagnosis which prompts enacted stigma from others is not experienced as a welcome disruption for some young people, and may trigger harmful behavioural adaptations.

Seven young people (all female) in this study reported self-harming behaviours. All were living with diagnosed anxiety and depression, and two were also living with a neurodevelopmental diagnosis. I suggest from the analysis of young people's narratives that their experiences of stigmatising behaviour (e.g. bullying and exclusion) and stigma prejudice (e.g. negative attitudes such as not being taken seriously) may have acted as environmental triggers. I argue that in some young people stigmatisation could compound a negative sense of self leading to the adaptation of self-harming behaviours.

Bullying at secondary school was reported by four young people in this study, three of whom reported self-harming (ID no.20,11,15). One participant described how the self-harming progressed when they continued to experience bullying on moving

secondary schools. Their response was to become emotionally and physically detached from their peers:

“The self-harming was when I was at my first school, just before changing schools. The changing schools was a catalyst because of the self-harm, because I was just getting very bad, very quickly... The bullying wasn’t as bad. It was bitchy... By that point I was so numb to emotions that I didn’t react anymore. I just kept my head down and cut myself.” (ID no.20)

Another participant described how their experiences of social rejection by their peers affected their mental health and triggered suicidal thoughts:

“People just didn’t get me, so they took everything I said as offensive. If I made a joke that people didn’t understand they would see that as offensive, or I was too annoying. So I got the hint that nobody wanted to be around me, so I started to feel depressed. That was the first time I started thinking, if no one wants me around I could walk across the road and something hits me, and no one would care ... That was the first time I started seeing death as an option.” (ID no.11)

Considering suicide was also an option described by a participant living with anxiety and depression: *“I always hoped that I would never get to that door [suicide] but it was always there for me”* (ID no.4).

In one narrative, a young person living with autism described how they felt they could not conform to the school’s academic expectations which arguably exacerbated their mental health as they felt that they would be responsible for not doing well in life:

“It felt that if you weren’t going to university you weren’t going to do well for yourself...I had all this frustration in my head about why couldn’t I have applied myself and gone [to university], and what are you going to do with your life – and it was all a frustration in my head so that process of self-harming was taking out those frustrations on myself... and it felt like a relief....” (ID no.18)

This second subtheme (2 of 4) explores how a diagnosis does not always bring about a positive recalibration of self. The data suggest some young people who received a diagnosis of a mental health and/or neurodevelopmental health condition

may have experienced enacted stigma from their peers, which I propose initiated their self-harming behaviour. It was discussed in the preceding subtheme that girls may more readily adapt their diagnoses into their identities (Williams, 2000). However, some symptom presentations and their association with negative consequences may inform a more masculine gendered *stoic* response in girls (Maclean, Sweeting, and Hunt, 2010). Data in this study indicate that these young females' responses were neither an expression of readily accepting their diagnosis into their identity, or of male stoicism to their diagnosis. This finding will be discussed in detail in Chapter 8 (see section 8.2.2., p.195).

In summary, some young people who receive a diagnosis of a mental health or neurodevelopmental condition may not experience it as a welcome disruption, a positive recalibration of self, or respond with male stoicism. Due-Christensen *et al.*, (2018) argue a strong association to a diagnosis may lead to restrictive self-care practices. The data in this thesis indicate some young adolescent females living with a neurodevelopmental or mental health diagnosis, who were bullied, arguably reacted strongly by self-harming.

7.2.3 Subtheme 3 of 4: a socially taboo diagnosis and behaviour adaptations

This third subtheme explores the experiences of those (n=4) living with a diagnosis they perceived to be socially taboo. It was argued in the subtheme *feeling different and reconstructing a view of self* (see Section 7.1.2., p.141) that felt stigma was experienced by some participants who feared rejection and exclusion due to the symptom presentation of their undiagnosed neurodevelopmental condition. In this current Section, it is argued a diagnosis of a condition perceived by the participant to be socially taboo, similarly generated felt stigma. Due-Christensen *et al.*, (2018) noted stigmatising behaviour in the form of others imposing rules and judgements could lead to individuals adopting unhelpful behavioural practices to comply with the expectations of others. An example cited was to become preoccupied with diabetes control rather than taking a balanced approach (e.g. Goldman and Maclean, 1998). In this present research, I suggest some young people living with a diagnosis which triggered felt stigma adopted unhelpful behavioural practices, not to comply with others' expectations of how they should behave, but to minimise others' opportunities to stigmatise. Their behavioural practices took the form of inhibiting

their communication with close friends as described by one participant living with IBS:

“There is such a taboo around it [IBS], and having bowel issues is unpleasant and embarrassing and no one really wants to talk about it, so my friends were aware - I’d mentioned it to them - but they didn’t really know the extent to which it was affecting me.” (ID no.3)

The impact on their behaviour was to change their routine to preserve the secrecy around their health condition:

“I would get one of the earliest buses to college so that I could go to the toilet before I started, and I would never admit that to my friends. We all used to get the same bus as we live in different towns near to each other, so I would say, ‘I’ve got a bit of extra work to do so I won’t meet you on the bus’.” (ID no.3)

Young people’s narratives indicated there was a fear that their health condition, which they perceived as socially taboo, made them vulnerable to others’ rejection of them, if not now, in the future, with fears of devastating consequences for their social lives:

“Even though I knew my friends wouldn’t judge me, I always felt embarrassed about it. I thought if I tell one of my friends and we end up falling out one day - as this happens - I thought I have these unpleasant bowel issues and they might go and tell everyone, and that would be the end of my social life.” (ID no.3)

Similar concerns were expressed by another participant living with anxiety and depression who after disclosing her symptoms to a friend regretted it:

“I wouldn’t talk to her anymore and I started to pull away from my friends because I thought she was going to tell someone... no, she didn’t. It was all in my head.” (ID no.4)

Such fears can inhibit how open participants can be with family and friends as this one participant living with depression and additional mental health and neurodevelopmental diagnoses conditions described about conversations with her partner’s family: *“The reason why I’m slightly inhibited to talk to them sometimes is*

that I'm worried I will be judged" (ID no.9). It can also seemingly impact on how they manage their condition which may involve restricting activities such as stopping a favourite sport (ID no.14) and changing plans: "*Quite often I'd cancel plans because of the fear of an IBS flare up.*" (ID no.3)

This subtheme (3 of 4) explores young people's responses to a diagnosis that generated felt stigma, where fear of social rejection shaped their behaviour to minimise opportunities for others to engage in stigmatising behaviour. If one believes others will devalue and reject people with their health condition, then they fear the rejection will apply to them (Link and Phelan, 2001). As young people feared becoming *discredited* by others (Goffman, 1963), they managed information about their difference by employing information control strategies such as concealment of stigma symbols (e.g. frequently going to the toilet), dividing contacts (e.g. separating those who know and those who don't), and keeping their distance emotionally and physically. These actions served to restrict the ability of others to build up a picture of their personal identity and disclosure of stigma (Goffman, 1963). It is thus both simultaneously a self-protective and socially isolating strategy.

7.2.4 Subtheme 4 of 4: learning and reconstructing a view of self

This fourth and final subtheme explores how participants responded to living with a diagnosis of a LTC and how it shaped their view of self. Young people in this study (n=11) reported being active on the internet and social media to learn about the health condition and how to manage it. They located condition specific websites such as Endometriosis UK, and condition specific groups, or individuals living with the same condition on social media platforms such as Facebook and Instagram. Due-Christensen *et al.*, (2018) identified seeking additional information outside the health care system, whilst not always helpful, was a way for those newly diagnosed with diabetes to learn about the condition and to take control of their diabetes. In this thesis, I suggest seeking information was pivotal to young people learning about the health condition as there was an absence of information from the usual healthcare channels: "*I looked at the NHS website but that didn't say much at all [about IBS]*" (ID no. 3). In a development of Due-Christensen's model, I propose the anonymity and reach of online information, such as social media platforms and condition

specific websites, enabled young people to safely seek out others like them to reconstruct their sense of self and to learn experientially.

For young people in this study (n=4; ID no.8,15,10,13), the data suggest online platforms enabled them to find others living with the same condition, and this made them feel less alone as described by one participant living with IBD (ID no.10) and another living with living with PCOS (ID no.8):

“They do magazines and online articles with information and support for my condition, and I think I learned a lot from that and understood it wasn’t just me.” (ID no.10)

“They’ve got pages where you can hear other people’s stories. It helps you feel so much less alone...I was just overwhelmed by the amount of people that had gone, ‘oh yeah, I had that’.” (ID no.8)

For another participant, she described a sense of collective identity from finding an online platform of others living with anxiety and depression: *“It’s anonymous but there’s something about a sense of community. It’s a strange thing to bring people together but it does”* (ID no.4).

It is inferred from the data that having access to information about their health condition was essential to young people’s understanding of how the health condition affected them, as described by one participant living with a neurodevelopmental condition:

“I did [research the condition] because at first, I didn’t think I fit the type for autism, but I did a lot of research on autism in women, and how it manifests very differently than in men, and that made everything make a lot more sense.” (ID no.21)

The data indicate these on-line groups/websites filled an information void. One participant living with PoTS stated: *“If it wasn’t for that [website] I don’t know what I would have done. They had lists of symptoms. They had advice...”* (ID no.13). For another living with endometriosis and adenomyosis said: *“Adenomyosis Support UK is really helpful, that’s where I found out about my condition”* (ID no.16). One participant found the responsiveness of the condition specific on-line community helpful: *“[I] contacted them and mentioned what I’m struggling with and what I’m*

trying, and that did help and few of them did suggest probiotics” (ID no.3). It was through a specific condition Facebook group that one participant reported they learned how to make a complaint through the NHS Patient Advice and Liaison Service (PALS) about their treatment for a gynaecological condition (ID no.16).

It is suggested from the data young people (n=4; ID no.3,12,13,17) preferred information provided by other young people with condition and experience similarities. One participant described how she enjoyed reading the blogs of two young women, a little older than her, living with the same health conditions, but further on their treatment journeys:

“I love reading blogs about people’s experiences... There are [two names of girls] ... they’re a few years older than me and more recovered. Their experiences and different treatment plans - that’s really interesting.” (ID no.12)

The data indicate (n=9) for those living with health conditions such as low mood (n=5; ID no.4, 6,15,18,19) and pain (n=4; ID no.5,9,17,20), it took time to manage the respective symptoms. It is a lengthy process of trial and error with medications and lifestyle adaptations. Due-Christensen *et al.*, (2018) argue experiential learning is a key strategy for the newly diagnosed with diabetes. It has also been identified as key to adolescents developing self-management skills and independence (Spencer *et al.*, 2013). Within this thesis, lifestyle adaptations to manage mood and pain included using a TENS¹⁷ machine (ID no.20), testing out different medications (ID no. 9,15), finding safe spaces with people they liked and where they felt supported (ID no.4,15), exercise (ID no.6), and distractions (ID no.18,15). Ultimately, it is about identifying what works for the individual such as not getting too tired and making adaptations as described by this participant living with IBD:

“Sometimes even now I will have to turn down events or social gatherings because I don’t feel up to it. Even though I know I will enjoy it, I just know I will get too tired. I still get that fatigue sometimes and I know I have to take it easy and rest. I’ve also done some meditation apps and things like that, and mindfulness things which are great at reconnecting with yourself mentally if

¹⁷ A transcutaneous electrical nerve stimulation (TENS), machine is a small, battery-operated device with electrodes that are applied to a local area on the body. The machine produces electrical impulses which are transmitted through the electrodes to the area which may help to relieve pain and relax muscles (NHS 2022a).

you're getting worked up about everything going on around you. So I've found those really helpful." (ID no.10)

This final subtheme (4 of 4) explores how following a diagnosis young people learned about their health conditions and reconstructed a sense of self. In contrast to Due-Christensen *et al.*, (2018), the information they seek is not additional but essential to their learning. The reach and anonymity provided by online channels enabled young people to access others like them, and they learned from their experiences through adoption and adaptation. Experiential learning was a key strategy noted by Due-Christensen *et al.*, (2018), and has been identified as important for developing young people's independence and self-management skills (Spencer, 2013). In a progression of Due-Christensen's model, I propose the anonymity and reach of online information, such as via social media platforms and condition specific websites, enabled young people to *safely* seek out others like them and reconstruct their identities. Goffman (1963) argues that people learn to manage the potentially devastating effects of being socially stigmatised by employing strategies of identity management such as *passing* and concealment. I propose online content and social media forums (e.g. Facebook and Instagram) provided anonymity as young people could control the information they shared about themselves whilst learning about the health condition(s). Data indicate social media use is an important developmental aspect for young people as they interact and present their forming identities (Bartsch and Subrahmanyam, 2015). A literature review on the impact of social media on the health of children and young people identified both positive and negative mental health impacts which ranged from improved self-esteem to depression with the determining feature being the psychological nature of the individual and how they use social media (Richards, Caldwell, and Go, 2015). Of interest to this thesis is that some studies have evidenced online communication to be a source of (a) support for individuals who perceive stigma associated with their health condition (Tanis, 2008; Wright & Rains, 2013), and (b) information and esteem support to people living with health conditions where there is a visible stigma (Yeshua-Katz *et al.*, 2020). The data in this thesis suggests that a diagnosis and access to others (of the same age and gender) living with the same health conditions initiates a process of recalibration of self. They transition from being isolated due to their difference to belonging to a community of

others living with the same health conditions. Access to similar others therefore enabled young people to learn how to manage their health conditions whilst also reconstructing a more positive sense of self.

In summary, this second main theme, *a diagnosis: a recalibration of self?* explores how a diagnosis is a further point of disruption to the early adaptation process. I suggest young people experienced a strong association with the diagnosis that in a development of the Due-Christensen's model, may be welcome or unwelcome with helpful and harmful behavioural consequences dependent on the impact on sense of self (real and anticipated). I propose for those who have been living for some time with undiagnosed ill health symptoms for which they have experienced enacted stigma (e.g. prejudice and discrimination), some diagnoses provided a welcome label; facilitating a positive reconstruction of self by bringing them into the fold of normative society. For some participants living with a diagnosis of a mental health and/or neurodevelopmental condition, the data indicate the diagnosis, which prompted enacted stigma from others, may have contributed to their self-harming. For young people who perceived the diagnosis to be socially taboo, it is proposed felt and anticipated stigma from peers may have led to behaviours that were socially isolating to protect their sense of self. Due-Christensen *et al.*, (2018) noted the stigmatising behaviour of others could lead to individuals adopting restrictive behavioural practices. In this study, the data indicate experiences of felt stigma in response to a perceived *socially taboo* diagnosis could inform socially restrictive behaviour to pre-empt the stigmatising behaviour of others. Finally, in the absence of information from health care providers about the health conditions, access to online information and communities was not additional as described by Due-Christensen *et al.*, (2018), but pivotal to young people's learning about the health condition and how to manage it. I propose access to online information and communities gave young people opportunities for experiential learning; a key strategy for people learning how to manage diabetes (Due-Christensen *et al.*, 2018) and to develop their self-management skills (Spencer, 2013). Moreover, I suggest the anonymity and reach provided by online communities to others of the same age, gender, and health care symptoms provided a *safe space* for young people who had experienced stigma to learn and take control of their self-management, whilst reconstructing their sense of self.

7.3 Living with LTCs: how others and organisational systems inform behaviour

The third and final main theme presented in this results Chapter explores the role of others in supporting young people's behaviour adaptations as they live with MLTCs (see Figure 12, below). Due-Christensen *et al.*, (2018) argue relationships with others can influence the adaptive process of people newly diagnosed with T1DM. For example, Johansson *et al.*, (2009) noted relationships, where the person newly diagnosed with T1DM was treated in the same way as before the diagnosis, were seen to be supportive of adaptation as the newly diagnosed didn't feel controlled. In a development of the Due-Christensen model, I suggest young people's interactions with others and organisational systems shaped their reconstruction of sense of self, and was critical to shaping their social and self-care behaviours.

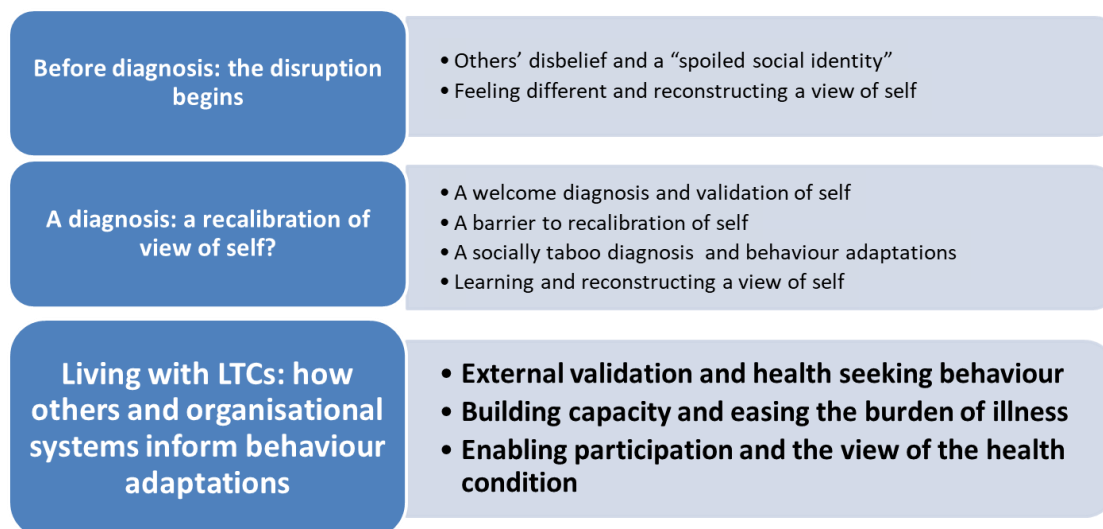


Figure 12. Third main theme and three subthemes

In the first subtheme, it is proposed when significant others (i.e. family, peers, and partners) and HCPs acknowledged and acted upon young people's health condition symptoms and diagnosis, it supported a favourable reconstruction of self by creating a sense of belonging and validation of their view of self as *sick*. This in turn, the data suggest, supported health seeking behaviour. When significant others and HCPs did not act on young people's health concerns, or responded with derision or indifference, I contend this fed into young people's reappraisal of self as *discredited*.

In the second subtheme, the data indicate the practical and emotional support offered by significant others, and the support of HCPs to help young people

understand their diagnoses and how to manage them was experienced as empowering; developing young people's capacity to self-manage their LTCs. Care systems contributed to this sense of empowerment by providing timely, appropriate, and continuity of care which encouraged health seeking behaviour. However, this sense of empowerment could be undermined by care systems that provided fragmented, untimely, and arguably conflicting care which exacerbated the burden of illness; potentially contributing to a deterioration in some young people's health conditions.

In the third and final subtheme, I explore how education and workplace people and systems that supported young people's participation in education and employment alleviated the burden of illness, and minimised the impact of living with MLTCs; possibly informing a view of the health condition as manageable. In contrast, where there was a lack of support/adaptations to accommodate young people's health needs, I suggest it did not alleviate the burden of illness and acted as a barrier to young people's participation. In so doing, it may have exacerbated the impact of living with MLTCs; potentially informing a view of the health condition as unmanageable. In a development of Due-Christensen *et al.*, (2018), I propose young people's ensuing isolation arises from barriers to participation, rather than from interactions arising from young people's frustration at the impact of living with LTCs on their lives.

Each of the three subthemes will be presented to illustrate how interactions are experienced as supportive of the adaptive process to enable young people to live well, and contrasted where possible with those interactions that are potentially undermining.

7.3.1 Subtheme 1 of 3: external validation and health seeking behaviour

This first subtheme explores features of relationships and health and care services that may validate young people's symptom presentation and diagnoses. I suggest these features contributed to young people's sense of belonging and validated their reconstruction of view of self as *sick*, shaping health seeking behaviour adaptations.

Significant others: validation through acceptance

Data in this thesis indicate significant others (i.e. family, peers, and partners) may have helped to validate young people's *sick* roles through their acceptance of the health symptoms and diagnoses, and in so doing may have prompted young people to seek health advice.

Acceptance by families was experienced by young people when parents had the same condition (n=3), and young people could ask for advice on symptom management (n=2; ID no. 3, 5), and gain reassurance (n=1; ID no.3). Good relationships with parents where young people felt safe enabled them to talk about their concerns (n=2; ID no 3,10), and they were the first port of call before seeking medical advice (ID no 3,10,17).

Data suggest that supportive peers (n=4) demonstrated acceptance when young people did not have to explain their appearance and/or behaviour (n=1; ID no.1), when peers provided a distraction/diversion from the health condition (n=1; ID no.4), were supportive about treatment (n=1; ID no.15), and wanted the best for the young person (n=1; ID no.21).

Whilst partners (n=4) seemingly played a significant role through expressions of their concern in encouraging young people's health seeking behaviours (n=4; ID no.1,3,14,18) such as pursuing medical support (ID no.1,3), and encouragement to follow life goals (n=1; ID no.14). Concern expressed by partners was a prompt for action:

"My boyfriend said, 'I still want to be with you, but I'm worried about you. This is not ok. These thoughts. This self-loathing. It's not ok and it's making you act not like you. You're not this person.' So I went back to the Wellbeing Service."
(ID no.18)

Being known and valued is central to a secure sense of belonging and personal identity (Robinson et al., 2020) and has been associated with feelings of community acceptance, participation, and wellbeing in studies of people living with intellectual and developmental disabilities (Jansen-van Vuuren and Aldersey, 2020). It could therefore be argued that when people do not feel a sense of belonging, they feel insecure in their sense of self which may impact on their behaviour. In this thesis,

young people reported that they experienced as unsupportive significant others who showed disbelief or lack of concern/care towards young people. Some peers (n= 7) were reported to lack tolerance and empathy with young people, such as getting annoyed when the young person had to cancel plans when unwell (n=1; ID no.16), accusing the participant of attention seeking (n=1; ID no. 20), of faking it (n=2; ID no.21,13), defacing books with hurtful comments (n=1; ID no.14), name calling (n=1; ID no.8), and keeping their social distance (n=1; ID no.13). It could be argued these experiences resulted in young people not feeling a sense of belonging and in response, they minimised their health condition symptoms to be included in social events, as one young person living with physical and mental health diagnoses described:

“You don’t get as close to people and very few people want to bother to be your friend or include you in things. I’d rather pretend and carry on and hide it and be included, and deal with the symptoms the next day and give myself 1-2 days to get over it afterwards.” (ID no.13)

Similarly unsupportive behaviour of families (n= 3) was seen where the participant’s behaviour was questioned by siblings and dismissed as being attention seeking by parents (n=1; ID no.16), or went unacknowledged (n=1; ID no.9,1). The lack of understanding and empathy could similarly be argued to be experienced by young people as a rejection of self; stoking feelings of resentment. One participant living with mental health and physical health diagnoses said of her sisters:

“They have never understood, and it’s come across as judgemental or they question how you’re feeling, and I’ve found at the time it doesn’t help and it makes you feel quite angry and annoyed.” (ID no.16)

HCPs: validation through action

The data indicate that HCPs’ behaviours which made young people feel heard were validating of young people’s sense of self as *sick* rather than *“it’s in your head”* (ID no.13).

Accommodating young people’s needs (n=5) was one way in which young people felt HCPs were listening to them. Examples included applying numbing cream to a site before inserting a needle (n=1; ID no.8), providing a secluded space for

treatment away from older adults (n=1; ID no.17), putting in place support from other services (n=1; ID no.1), signposting to other services (n=3; ID no.1,16,2), and recognising and acting on a participant's disclosures (n=1; ID no.16).

Further actions/behaviours of health and care staff that seemingly evidenced to young people they were listening (n=13) included responding by showing concern, and asking questions to identify the issues and how they could support them (n= 5; ID no.1,8,11,12,17), acting on their concerns about treatment (n=1; ID no.16), reacting to feedback regarding an absence of post consultation follow up (n=1; ID no.10), providing affirmation that the young person is ill and needs to take sick leave (n=1; ID no.18), and initiating investigations and referrals to other services (n= 6; ID no. 5, 6,3,4,15,17). One participant living with mental health and physical health diagnoses said of the GP:

“She [GP] checks if I’m ok. She asks, ‘how are you doing? Are you ok? How’s the pain now? Are you coping.’ She checks on me as a person not just on my symptoms. Whereas there have been other doctors that I’ve called, and they’ve been, ‘there’s nothing I can do.’ Haven’t asked if I’m ok. If I need help. So in that way she’s very invested.” (ID no.17)

Of note was such actions and behaviours built trust between young people and HCPs and therefore they would more likely seek advice from an HCP in the future. A participant living with physical and mental health morbidities explained:

“I feel like if I see my doctor about anything she will care, and she will help me, which is a relatively normal experience but it’s not something I’ve ever felt before.” (ID no.1)

Charmaz (1991) has argued that when people lack a doctor's validation they think they will not be believed. I suggest that HCP behaviours that were experienced as listening and accommodating their needs served to strengthen the legitimacy of young people's sense of self as *sick*, and therefore may have encouraged future health seeking behaviours.

In contrast, the data suggests that when HCPs apparently lacked knowledge (n=11) and empathy (n=8), it was arguably interpreted by young people as invalidating their experiences. The behaviours included HCPs not knowing about the condition and

giving basic information (ID no.3), not explaining the condition (“which is not even on the NHS website” [ID no.16]), and deferring explanations and referring participants to online sites (ID no.5,10). One participant was advised to Google PCOS (ID no.5) and another to look up support groups (ID no.10). It was in young people’s recounting of their consultations with HCPs for pain (n=6) and mental health care (n=5) that young people clearly felt unheard:

1. Of seeking help for painful conditions (n=6), young people reported HCPs seemingly did not understand or empathise with the challenges of living with debilitating painful conditions (ID no.3,6,9,16,19,20). One participant after being admitted to A&E with severe pain (caused by a dislodged contraceptive device fitted to treat the symptoms of a gynaecological condition) was evidently told by the doctor on discharge:

“... it was period pain and couldn’t be that bad. I was told by doctors in A&E, where I’d been waiting 9-10 hours to go home, to take some Buscapan and peppermint tea.” (ID no.20)

2. Of their experiences of mental health care, the data (n=5) suggest young people felt they were not getting the help they needed. This understanding came from therapists following their own agendas which young people felt did not include their concerns (ID no.4,20), feeling that words were put in their mouths (ID no.12), the consultation was a tick box exercise (ID no.12), and the HCPs just wanted to diagnose the participant and move on (ID no.14). One participant experienced the community psychiatric nurse (CPN) not turning up to an appointment or sending an apology, and she had to contact several people to reschedule the appointment (ID no.9). One felt she was spoken to patronisingly and accused of being difficult (ID no.20), and another reported being called deceptive after the therapist had spoken to the participant’s mother (ID no.14).

I suggest that despite young people’s lived experiences of ill health and seeking health care support for their symptoms, the cursory, unempathetic and disbelieving responses of some HCPs sent a message to young people that they were not ill, or not ill enough to warrant HCP time and attention. According to Charmaz (1983) and discussed in Section 7.1.1. (see p.138), it may have fed into their reappraisal of self

and contributed to shaping their sense of self as *discredited* (Goffman, 1963) which is associated with more concealment self-care practices to pass (see Section 7.2.3., p.150).

In sum, it is suggested in this first subtheme (1 of 3) that significant others who are accepting of young people's health symptoms and diagnoses, and HCPs who seemingly listen to young people and act on their health concerns may be experienced by young people as giving credence to their symptoms and diagnoses. In turn, it may facilitate the adaptive process by shaping the reconstruction of sense of self as *sick* and encouraging health seeking behaviour. In contrast, the data indicate disbelieving attitudes and indifference to young people's health concerns from significant others and in particular HCPs were experienced by young people as not having their lived experiences corroborated, and may have fed into their sense of self as *discredited*.

7.3.2 Subtheme 2 of 3: capacity building and easing the burden of illness

In this second subtheme of the main theme: *living with LTCs: how others and organisational systems inform behaviour adaptations*, the data suggest the practical and emotional support offered by significant others and HCPs, together with health care systems that enabled access to timely, appropriate, and continuity of care could provide valuable capacity to ease the burden of illness.

Significant others: capacity building through emotional and practical support

The data indicate some young people's partners provided valuable practical and emotional support ranging from help with household chores (n=1; ID no.10), direct care (n=2; ID no.1,9), being understanding of their health condition and how it affected the young person (n=2; ID no.12,3), to accompanying to appointments (n=1; ID no.17). One participant who reported having treatment for mental health comorbidities, described their partner's pivotal role in caring for them as they changed their medication regime:

"I had to go through the withdrawal process, which was horrendous, like real medical withdrawal. My partner had to supervise me 24 hours a day for at least a couple of days." (ID no.1)

One partner was supportive and encouraging of this young person living with mental and physical health conditions achieving her life goals:

“He was the one who inspired me to get on the access course. So I definitely applied for it when we were together. I started it in September of 2019 and finished it in early 2020. That was a positive experience to go back to education and do really well at it.” (ID no.14)

Parental support took the form of accompanying to appointments and treatments (ID no.8,11,17), providing practical support with childcare (ID no.16), practical help (ID no.17,12), seeking out information about the condition, and applying for mitigating circumstances for examinations (ID no.10), in addition to direct support to manage the health condition (ID no.14). One participant described the support they received from their father with their mental health comorbidities:

“My dad was a lot of help during that time for giving me – you can do it just do it, don’t think just do it – and not going into the emotions too much. Just really being there for me. Physically doing things for me - opening opportunities. He would come along when I’d be terrified about handing in a CV. He’d give me a little pep talk and then I’d go in the shop with my CV and come out and he’d give me a debriefing – ‘Well done, you’ve done it!’” (ID no.14)

Peers raised concerns with teachers when they saw signs the person wasn’t well (n=1; ID no.12). They provided practical support (n=1; ID no.14) and companionship (n=3; ID no.3,14,15). One participant living with mental health comorbidities described the impromptu support they received from their friends:

“They understood what was going on and were supportive. I was having a bad day and not going to college, and they came round and surprised me by buying me my favourite ice lollies and just sat with me. That was really lovely.” (ID no.15)

HCPs: capacity building through imparting knowledge

When HCPs took time to explain the diagnoses (n=2; ID no.21,17), the side effects of medication (n=1; ID no.1), and importantly contextualised their mental health and neurodivergent behaviour (n=4; ID no.1,6,9,21), young people reported feeling

reassured. For one participant living with mental and physical health diagnoses, the reassurance mitigated the previous impact on sense of self as a *bad mum*:

“He [the GP] said, ‘being a new mum, a lot of new mums do get these thoughts and it’s a part of having anxiety, you are going to think of the worst thing, even though it’s not really going to happen.’ It makes me feel better...I thought I was a bad mum.” (ID no.6)

Being addressed respectfully and knowledgably could be argued to encourage young people to learn about the health condition and follow self-care guidance, as one participant living with physical, neurodevelopmental, and mental health diagnoses said of the team supporting them with their eating disorder:

“They’re really nice... I think a lot of it is how they don’t talk to you as if you’re stupid. This type of mental illness can alter your way of thinking and you’re not really in your right mind and you don’t believe things that are scientifically correct. They clarify things and help you understand things without making you feel dumb.” (ID no.21)

Care systems: enabling capacity building

The data suggest where care systems facilitated communication, and timely and continuity of care, young people were enabled to develop their capacity to self-manage. The data indicate a clear treatment plan (n=3; ID no.8,11,20), continuity of care (n=3; ID no.3,17,18), support by specialist teams (ID no.17), and access to nurse specialists (n=3; ID no.5,19,17), arguably built trust (ID no.3), enabled the quick resolution of any emerging difficulties (ID no.5,19), and potentially prevented health and social care problems in the future. A participant living with physical and mental health diagnoses described the role of the midwife in recognising she was in an abusive relationship, and the support she offered through the relationship break-up:

“She [midwife] helped me navigate through the manipulation post break up and helped me realise ... I’d disclosed something to her, and she said, ‘that’s not ok’, and made me flag it with my GP and get help with the Survivors’ Network. She made me realise what was going on and I saw her at first every 2 weeks and then it went to every month. She helped me put in safety plans,

told me when I was saying things that weren't ok - which no one had ever done before.” (ID no.16)

Experiencing services that are responsive may also encourage young people to continue to seek medical/health advice as described by this participant living with asthma:

“My GP has a really helpful asthma nurse so any time I've had problems they've been solved instantly. They quickly up my puffer [medicine via inhaler] until my breathing gets better. They are quite helpful and it's easy. I just phone the practice and ask to speak to the asthma nurse. I get an appointment and I'm in and out.” (ID no.19)

Of note were the features of supportive care identified by young people who had accessed private health care (n=3). They included being seen quickly (ID no.17), feeling heard (ID no.15), having time with HCPs to have information explained (ID no.10), and feeling cared for by HCPs knowledgeable about the health condition (ID no.10). Young people's experiences of private care were reported as reassuring (ID no.17,10) which imbued confidence in the care given. One participant living with an undiagnosed physical health condition whose family sought private health care following a reported unhelpful NHS consultation, compared the NHS and private care experience:

“The comparison between the NHS to going there – how quick it was, how knowledgeable they were. They knew exactly what the problem was – what investigations they needed to do. I felt at ease again. These people actually know what's going on and I can get help here and I did, really quickly.” (ID no.10).

In contrast, it is inferred from the data that health care systems could exacerbate young people's health conditions with delays and lack of continuity. As discussed in Chapter 2 Section 2.4.5. (p.44), the Covid-19 pandemic has created a backlog of people requiring planned treatment (Scobie, 2021) and some participants (n=7) in this study, who were trying to access new or on-going treatments, did report experiencing some difficulties. They included being informed there was no access to talking therapies (ID no.14,16), cancellation of operations (ID no.14) and clinics (ID no.20), being informed of long waiting lists (ID no.15,16), and feeling left in a vacuum

not knowing when a procedure would happen (ID no.17). One participant reported that it was suggested they pay privately for talking therapies (ID no.9). However, as most of the participants' health condition symptoms pre-dated Covid-19, many participants' experiences of lack of service continuity and delays in treatment also pre-dated Covid-19.

Young people reported long waits for scans (ID no. 5,9), autism assessments (ID no.21), and referrals to adult teams (ID no.11). They reported failures in communication between systems that impacted on their care such as no follow up on scans which had shown anomalies (ID no.6), the GP referral not arriving in A&E resulting in the participant, *"having to beg to see the gynae team"* (ID no.20), *"no Clic Sargent"*¹⁸ (ID no.17), and *"radio silence"* (ID no.8). For a couple of participants, the lack of continuity/communication between secondary and primary care resulted in medication supply delays. One participant living with mental health comorbidities described the impact of not having their prescription delivered in time:

"I hate missing days. They are really bad days when I miss them... When I miss a day, I get really disassociated and really out of it, which makes it difficult to do pretty much anything. Especially now that I'm on higher doses than I was then, I can't function for the day." (ID no.15)

This lack of continuity was also noted when having to see different GPs which involved having to explain their medical history each time (ID no.15), and seeing different GPs about the same condition, so GPs don't see the condition develop (ID no.14) which can inhibit trust (ID no.3) and lead to confusion: *"so many different answers to questions I was asking depending on who I was talking to"* (ID no.11).

One participant living with mental and physical health diagnoses described their frustration at HCPs, feeling that they did not understand how the health conditions impacted their life:

"Even learning to live with it – there doesn't seem to be any sense of urgency for the condition either, so they don't realise it does impact on lives. I've almost lost my job a couple of times. I can't pick up [name of child] from school sometimes. I can't move. I can't eat. I can't cook. I can't clean. And

¹⁸ Clic Sargent is a UK children's cancer charity offering children and their families care and support (NHS 2022b)

there's no urgency, to be told at the scan that there's nothing wrong, it's just adenomyosis, so immediately undermining it." (ID no.16)

It was in the care of mental health services that lack of continuity and access to timely and appropriate support arguably prevented young people from getting the support they felt they needed. Some participants perceived that they were passed around HCPs (ID no.19,20). One participant reported being moved to different waiting lists trying to find a counsellor she could work with (ID no.20), and another felt passed on to other HCPs because they were a complex case (ID no.19). Services were provided Monday-Friday, 9am-5pm, and there was seemingly no provision of out of hours services to accommodate childcare needs resulting in the participant being unable to attend treatment sessions (ID no.6). One participant experienced her service cut short after a few weeks of telephone appointments when she was discharged with no explanation (ID no.18). For another participant, after her counsellor left, she was informed that rather than seeing the next available counsellor, she would be moved to the bottom of the waiting list (ID no. 20).

One participant reported that she saw lots of different people every few weeks (ID no.14). Another was apologetically informed by the AMHS that she had been referred to an inappropriate therapy (CBT for a bereavement; ID no.16). A couple of participants were informed that they were not sick enough to receive a service (ID no.4,20). One young person, as an inpatient, heard staff seemingly talking about her condition in a derogatory way (ID no.9). One participant felt "*palmed off*" with being signposted (ID no. 6), and another felt that what was offered was insufficient for their needs: "*all CAMHS offered was medication and review, no other help and I was very unwell.*" (ID no.19).

There was a tension experienced by some participants between wanting a mental health service but not having confidence in the service. One young person didn't want to engage with CAMHS when it was offered by the GP because it had a bad reputation in their peer group (ID no.15), and there was a belief that there weren't many services available, and what services were provided had very long waiting lists (ID no.14).

I suggest experiences with health and care services that undermined young people's ability to receive timely and appropriate care may have exacerbated their existing

health conditions (ID no.4,16,20) and created additional stresses in the participants' lives (ID no.16,20). As one participant living with mental and physical health diagnoses explained after being discharged from mental health services:

“Once I’d been dropped from all services and I wasn’t receiving any help and with the college stress as well, I took a very bad turn. I began very badly self-harming, different parts of my body.” (ID no.20)

In sum, it is suggested in this subtheme: *capacity building and easing the burden of illness*, that the practical and emotional support from (a) significant others in the form of direct action (e.g. seeking out information) and providing comfort, and (b) HCPs who contextualised diagnoses to help young people understand their health conditions were providing capacity so that young people could combine managing their health conditions whilst living their lives. The data indicate health care systems have a role to play in enabling capacity building by providing young people with access to treatment plans, specialist services, timely care, and continuity of care. I suggest these features helped young people to cope, and coping underpins empowerment (Grealish *et al.*, 2016). Empowerment is the process by which individuals gain control over their lives by being equipped with the skills and abilities to act on issues that are important to them (Zimmerman, 1995). It could also be argued to ease the burden of illness (Shippee *et al.*, 2012) which was referenced in Chapter 2 (see Section 2.2.1., p.29, *a successful adaptation to living with LTCs*).

As a reminder, the burden of illness and treatment of those living with multimorbidity are composed of workload demands (demands of time and energy to manage conditions¹⁹) and capacity²⁰ (Shippee *et al.*, 2012; Rosbach and Anderson, 2017). If workload expands and capacity contracts, ill people may pass their tipping point in one sphere of life or another becoming overburdened and unable to carry out the required self-care tasks. To care for themselves, unwell people need agency and motivation, in addition to capacity to engage with their health problems and others. Agency can be defined as *“a person’s capacity to intervene in their surrounding physical and social environment in order to pursue their goals and interests”* (Bergen

¹⁹ Workload demands include numbers of LTCs, number of medications and health status (Shippee *et al.*, 2012; Rosbach and Anderson 2017).

²⁰ Capacity involves functional morbidity (extent of debilitation from ill health), financial and social resources and literacy (Shippee *et al.*, 2012; Rosbach and Anderson, 2017).

et al., 2022, p.668). Social networks also termed “*relational networks*” (May *et al.*, 2014, p.3) are channels through which agency can be expressed and distributed (May *et al.*, 2014).

I suggest in this thesis that in supporting young people to develop their knowledge and skills and meet the practical and emotional demands of living with MLTCs, significant others, HCPs, and care systems were contributing to easing the burden of illness. Young people were empowered to manage their health conditions and their lives, and they actively engaged with care services and sought medical help. Of note in this thesis was young people’s experiences of fragmented, untimely, and conflicting care as highlighted in their treatment by mental health care services which served to exacerbate the burden of illness. Young people struggled to manage the various spheres of their lives, and in some instances their health conditions deteriorated. In the final subtheme below, I explore how employment and education people and systems could similarly ease or aggravate the burden of illness and impact on young people’s early adaptation process.

7.3.3 Subtheme 3 of 3: enabling participation and view of the health condition.

This third and final subtheme of the main theme *living with LTCs: how experiences with others and organisational systems inform behaviour* examines how education and workplace people and systems that acknowledged young people’s health condition, and made the necessary adaptations, eased the burden of illness and enabled young people to continue to participate in education and employment.

Enabling participation: a manageable health condition

In this thesis, the data suggest participation in education was facilitated by having a physical safe space where young people (n=4) could go if they were feeling unwell (ID no. 1,9) or unsafe (ID no. 20,11), and putting in place learning support plans (LSPs), including physical adaptations to make studying more comfortable (ID no.1). These were seemingly valued by young people and enabled them to continue their education. For others (n=4), systems that allowed flexibility for the teaching staff to put support in place to meet young people’s needs included a referral to a SEN department, where staff could meet the participants’ needs and make education accessible (ID no.19), and enabling studying from home (ID no.20).

Further accommodations included classroom passes with no questions asked, which allowed the participant to leave the classroom to go to the toilet or see the matron (ID no.16), to have time out (ID no.21), or to leave class five minutes early to avoid the rush of students during classroom changeover:

“I expressed to my tutor at the time that I was really scared of going through the corridors in the rush hours. It makes me really anxious. So they gave me a 5 minute early leave pass so I could get to my next class without the rush of the other students, and I was allowed to take a friend with me if I wanted to, to help me feel better. And if I wanted someone to talk to, there was always someone there if I needed.” (ID no.17 living with physical and mental health diagnoses)

Some schools/colleges provided counselling services which provided a safe space for young people where they didn't feel judged (n=4; ID no 4, 6,14,20), and could vent and be reassured that it was ok to feel that way (ID no.20). One service worked with teaching staff to put other support in place (ID no.14), and referred the participant to a third sector agency for additional support (ID no.14). One participant living with physical and mental health diagnoses described the contrasting experiences they had with CAMHS and the counsellor at their school:

“I had gone along to a few CAMHS things, and you'd be feeling that you'd not said the right thing. They didn't get the response from me that they'd wanted. I just didn't open up much, but with this counsellor she was a play therapist as well, so she'd let me do a lot of artwork. That was good. It was also a place ... I could go out of class and sit in a safe space. She got really involved in the later years, showing me that I could go the self-study route rather than being in class. She helped with some of the teachers, so I could go and pick up work and sit in the library and do work there, and then with like some of the other pastoral sessions, the teachers would let me sit in their office and let me do my own study there, and then hand it in at the end of the day and then go home. I wouldn't have to interact with students. I did end up building a lot of trust with her.” (ID no.14)

Employers who were supportive of diversity made adaptations when they had been made aware of the participant's health condition (n=3; ID no.10,16,18), and checked

on the participant, made them feel valued and cared for, and enabled them to continue with their work. One participant living with neurodevelopmental and mental health diagnoses described the support they received from their manager:

“My colleagues were very supportive. My manager, he was fantastic. He rang on my week off and said, ‘I just want to check in with you to see if you’re ok’. I found that amazing because he really cared. When I went back, he was really supportive of me and gave me all the tools I needed. He just wanted to make sure I was ok.” (ID no.18)

Impeding participation: an unmanageable health condition

Education and workplace people and systems that did not make accommodations for young people’s health conditions made it hard for them to participate as it added to their workload (time and space) as discussed earlier (see Section 7.3.2., p.163), and acted as a barrier to living well.

Concern was expressed by some participants (n=4) that some education institutions did not see mental health as health related (ID no.15), staff were unsympathetic to low attendance (ID no.16), and there was an absence of support when trying to catch up on missed work (ID no.9,17). Some participants had to persist to get support and were denied it (ID no.17), which resulted in one participant living with physical and mental health diagnoses to leave college:

“I would have probably stayed and finished. But because they weren’t supportive of me – and because of what I was going through as well – there was a lot to handle and I couldn’t quite deal with all the workload on top of that, and the fact that they weren’t being supportive at all was just like – I’m done.” (ID no.17)

There was seemingly a lack of understanding of implications for learning for some treatments and diagnoses (n =4; ID no.11,13,19,20,) such as chemotherapy for molar pregnancy, and neurodevelopmental health conditions. Young people talked about being treated critically for their difference. One participant with a neurodevelopmental diagnosis was called and treated as a *“really naughty child.”* (ID no.19). This participant didn’t have an education and health care plan (EHCP),

although one had been applied for, and they had to wait for a year, but during this time their mental health *“plummeted”* (ID no.19).

Another participant living with mental health diagnoses perceived that they were not supported by teaching staff during a panic attack; *“we don’t have time for that nonsense”* (ID no.20), and was labelled as difficult:

“Once I had the diagnoses, I went from being a problem child to a child who needs help. It was ridiculous how long it took for the school to realise that I wasn’t being difficult. I couldn’t believe that the school were waiting for a bit of paper to say that they could be nice to me.” (ID no.20)

Another child who was made irritable and uncomfortable from eczema was frequently reprimanded by teachers for taking off items of uncomfortable clothing. They seemingly internalised that they were the class *“monster child”* (ID no.13). Their behaviour impacted on their friendships which stayed with them throughout school, even when the eczema symptoms receded:

“I was already that person. It’s your personality and it takes people a long time to change their opinion of you even if the reality has changed.” (ID no.13)

Some behaviours of teaching staff were experienced by young people as marginalising. One participant reported they were advised to change their behaviour to fit in (ID no.20), thus condoning and perpetuating the bullying they had been receiving for being different. Another young person reported being named and grouped with other young people who self-harmed and taken out of class for an intervention which served to highlight them to the rest of the school, and resulted in them experiencing enacted stigma in the form of having their textbooks defaced with comments such as *“slits wrists”* (ID no.14).

Similarly some young people reported experiencing unsupportive workplace systems where their mental health symptoms were seemingly not accommodated which made them feel it was not treated seriously:

“I would have days when I would not be feeling great and in a low mood and especially at work, it just wouldn’t be considered. Whereas if someone had a sprained ankle that day, they could sit down at the register, but it was very much, it’s just in your head so you can get on with it.” (ID no.15)

Another participant reported they felt coerced to deny their mental health to meet the organisation's targets for a happy workforce:

“They do your well-being scale because they are wanting people to be healthy and he even, if I did a low score, it would be questioned, and I would be coerced to try and make it higher. They know what I suffer with, and I don't want it to be an excuse. It's better they be aware than me try to tackle it than not be aware, but again they don't really seem to care about that.” (ID no.16)

The pressure they experienced felt like the managers were trying to “*micro-manage me out of the business*” (ID no.16).

This final subtheme (3 of 3) explores how education and employment people and systems that are supportive of diversity, provide safe spaces to take shelter (e.g. quiet/ panic or sick rooms and counselling), and accommodate individual needs, arguably enable young people's ongoing participation in these spheres of life. They provide capacity (e.g. time and space) to enable young people to cope with/manage their health conditions. This prevents the workload demands of being unwell in the spheres of work and employment exceeding young people's capacity to manage as discussed in Section 7.3.2. (see p.163). They do not become overburdened and are able to maintain their place in education and/or employment. In contrast, people and systems in education and employment that do not provide safety or flexibility to accommodate needs create a workload and capacity imbalance which may exclude young people from achieving their potential in these areas. This is a development of the Due-Christensen model as it explores how employers, teachers, and organisational systems may minimise or exacerbate the impact of a health condition on a young person's life. I suggest social isolation is compounded not as Due-Christensen *et al.*, (2018) suggest by interactions shaped by young people's frustration at the impact of LTCs on their lives, but by inflexibility and lack of empathy creating barriers to full participation in these spheres of life. This can have a lasting negative impression as one participant who left college because it could not accommodate their needs, (for time and support to catch up on missed work when they were having regular outpatient treatments), stated:

“Interviewer: ‘From your health care experiences, if we could wave a magic wand what would a good service, professional look like?’

Participant: 'The only thing I think about – probably weekly – is college. The college support system I had was shocking. I would love to have a job that would fix this problem.'” (ID no.17)

In sum, the main theme, *living with LTCs: how others and organisational systems inform behaviour* explores the role of significant others, HCPs, teachers, employers, and organisational systems (i.e. health care, education, and employment) in shaping the early adaptation process. In a development of the Due-Christensen model, I suggest the supportive behaviour of significant others and HCPs created a sense of belonging and validated young people's sense of self as *sick*, but where significant others and, in particular, HCPs lacked empathy and knowledge and were uncaring, young people did not feel believed and they felt their ill health was not given legitimacy. The practical and emotional help provided by significant others, and support with learning about the LTCs provided by HCPs which were underpinned by care systems that facilitated timely care and treatments, and continuity of care was experienced as empowering, as it created capacity to ease the burden of illness. These experiences were seemingly associated with young people's health seeking behaviour. This thesis also identified care systems that did not provide timely or continuity of care exacerbated young people's burden of illness and in some instances, young people could not cope with the demands of managing their LTCs and, for some, their health conditions deteriorated.

Finally, Due-Christensen *et al.*, (2018) argue people newly diagnosed with diabetes constructed a view of diabetes that was influenced by their perception of the condition and its impact on their lives. I suggest employers, teachers, and their underpinning organisational systems which provided opportunities and support for participation, minimised the impact of living with MLTCs on young people's lives by making them manageable. In contrast to Due-Christensen *et al.*, (2018), I suggest the social isolation arises not from interactions informed by young people's frustration at the impact of LTCs on their lives, but from the lack of support/adaptations to accommodate their health needs so that they can fully participate. This in turn may have led to a view of the health condition as unmanageable.

7.4 Summary

In this thesis, the early adaptation process has been examined through a social constructionist lens. Living with MLTCs has been explored in relation to how young people's experiences have shaped and been shaped by their interactions with others (i.e. significant others, HCPs, teachers, and employers) and organisational systems. Of significance is the nature and presentation of the health condition as a possible trigger for stigma responses in interactions with others. This informs the early adaptation constructs of reconstructing their sense of self, their view of the health condition, their learning, and their behavioural adaptations.

The data suggest that for many young people living with symptoms of ill health for some time before diagnosis, the disruption was triggered not by the diagnosis as described by Due-Christensen *et al.*, (2018), but by the onset of symptoms which presented as an unwelcome disruption to young people's lives. I propose young people's repeated reports of their symptoms, often presenting as seemingly vague to their families, peers, and HCPs were met with enacted stigma responses from which young people may have reconstructed a negative sense of self. I contend that they may have perceived themselves as *abnormal* and acted to minimise their differences to others, thus concealing their self-care and social behaviours. It was from the narratives of young people's experiences of living with undiagnosed neurodevelopmental conditions that the divisive effects of stigma on sense of self were arguably brought into sharp relief. Moreover, the data indicate that some young people responded with felt and anticipated stigma in interactions where they had previously experienced or witnessed enacted stigma. These responses informed concealment behaviours, probably as an attempt to protect their sense of self.

A diagnosis is then a point of further disruption to the early adaptation process. Due-Christensen *et al.*, (2018) contend the strength of association to a diabetes diagnosis shapes behaviours with, for example, a strong attachment leading to restrictive self-care. In this thesis, I suggest young people had a strong attachment to their diagnoses informed by past and current stigma experiences. How stigma impacted on the reconstructed sense of self may have been responsible for shaping behaviour. I contend that a diagnosis which minimised previous stigma experiences by leading to a reconstruction of self from *weird* to *sick* was welcomed, potentially

shaping health seeking behaviours. In contrast, a diagnosis that was perceived as socially taboo was not welcomed, and felt stigma may have resulted in concealment behaviours to protect sense of self. For young people living with mental health or neurodevelopmental diagnoses, bullying by peers may have created an unwelcome association with the diagnosis and compounded a negative sense of self, which conceivably made them vulnerable to self-harming behaviours.

Due-Christensen *et al.*, (2018) noted stigmatising behaviour in the form of others imposing rules and judgements could lead to individuals adopting unhelpful behavioural strategies. In this thesis, data indicate unhelpful behavioural strategies such as concealment and social withdrawal were responses to enacted stigma and felt and anticipated stigma to minimise the actual and potential for others' stigmatising behaviour.

A diagnosis is a springboard for learning about relevant health condition(s). Due-Christensen *et al.*, (2018) identified seeking additional information outside the health care system, whilst not always helpful, was a way for those newly diagnosed with diabetes to learn about the condition and to take control of their diabetes. I suggest that in the absence of information from the health care system and HCPs, seeking information outside it/them was essential to enable young people to take control of managing their LTCs. In particular, online communities seemingly provided opportunities (with anonymity and reach) to learn whilst providing a safe space to manage their personal information.

Due-Christensen *et al.*, (2018) propose relationships with others can influence the adaptive process of people newly diagnosed with T1DM. In this thesis, the data indicate acceptance from others in the form of supportive families, partners, peers and HCPs may have validated young people's sense of self as *sick*, shaping health seeking behaviours. When significant others and HCPs were seen as unsupportive, such as not being responsive to addressing health concerns, I suggest it was experienced as *discrediting* sense of self as *sick*. I propose behaviours/actions of significant others and HCPs that provided emotional and practical support, and developed young people's knowledge and skills to manage their health conditions were experienced as empowering, and contributed to building their capacity and agency to ease the burden of illness. Health care systems providing timely,

appropriate, and continuity of care contributed to young people's potential for capacity building. However, care systems that delivered fragmented, untimely, and arguably conflicting care as indicated by some young people's experiences of mental health care services, may have increased the burden of illness and exacerbated some young people's health conditions.

Due-Christensen *et al.*, (2018) argue people, newly diagnosed with diabetes, constructed a view of diabetes which was influenced by their perception of the condition and its impact on their lives. I suggest in the spheres of education and employment, people and systems that were flexible and accommodated young peoples' needs minimised the impact of living with MLTCs on their lives; potentially informing a view of the health condition as manageable. Whilst the lack of support and/or adaptations to accommodate their health needs may have acted as a barrier to young people fully participating in education and employment, conceivably informing their view of the health condition as unmanageable.

Finally, in a development of the Due-Christensen *et al.*, (2018) model, the data in this thesis suggest for some young people living with LTCs the defining feature shaping the constructs of the early adaptation process was stigma associated with the health condition and/or its symptom presentation, and its impact on actual and anticipated interactions (with others and systems) on sense of self and view of the health condition. From these interactions, young people's perception of self and view of health condition shaped their learning and behaviour. For health conditions with a slow onset trajectory, the disruption of adaptation commenced at the onset of symptoms.

The next Chapter will explore these findings through the application of EST to examine how and why the stigma responses described in this thesis unfolded, and to identify potential intervention points to moderate young people's experiences of stigma to enable them to live well.

Chapter 8: Discussion

This thesis set out to explore how young people's interactions with HCPs, care services, and significant others shaped the early adaptation constructs as they lived with MLTCs to identify the features that supported them to live well. In Chapter 6 (p.123), I described the data produced by the first interviews which included the numbers and nature of the morbidities and comorbidities of the young people in this study, and the length of time from symptom onset to each diagnosis. In Chapter 7 (p.136), I presented the data generated from the second interviews and suggest the genesis of shaping the early adaptation constructs were attempts by young people to reconstruct their sense of self in response to stigma (i.e. enacted, felt, internalised, and anticipated) as they lived first with the symptoms, and then diagnoses of LTCs. This Chapter will explore the findings generated from both interviews in relation to the ecological systems theory (EST) described in Chapter 2 (see Section 2.3., p.37). Bresnahan and Zhuang (2016) state the five dimensions of stigma involve *"stigmatisers, the stigmatised, bystanders, the process of stigma, and the social context in which stigma occurs"* (p.1284). The EST will provide the framework to explore more fully the relationship between young people (i.e. stigmatised), their stigmatisers and bystanders, and their environments (i.e. the social context in their environmental systems), and how stigma may be facilitated or moderated/mitigated in their interactions (i.e. the social process). Figure 13 (p.180) illustrates the interrelationship between young people's environmental systems in this thesis and the features facilitating the unfolding and moderation/mitigation of their stigma experiences as they lived with MLTCs.

Starting with the macrosystem, I propose potential bias in (a) multimorbidity classification, recording, and reporting; (b) age and gender diagnostics; and (c) disease classification contributed to the social context (in the form of diagnostic delays and negative value judgements) for stigma to unfold in the microsystem and mesosystem. In the microsystem, I explore outgroup derogation and othering as possible explanations for the enacted stigma of stigmatisers and bystanders, and the stigma avoidance strategies of the stigmatised. I suggest the moderating features of stigma identified in this thesis minimised peer role and social identity differences and strengthened peer role and social identity similarities; shaping the reconstruction of

more favourable identities of those stigmatised. I will then examine the mesosystem and the interrelationship between microsystems, and how interactions in one microsystem could inform interactions in others to compound or mitigate young people's stigma experiences. I will draw on these findings to suggest how young people living with MLTCs could be supported to live well. The strengths and limitations of the study will then be outlined, and finally recommendations for future research and care practice will be proposed.

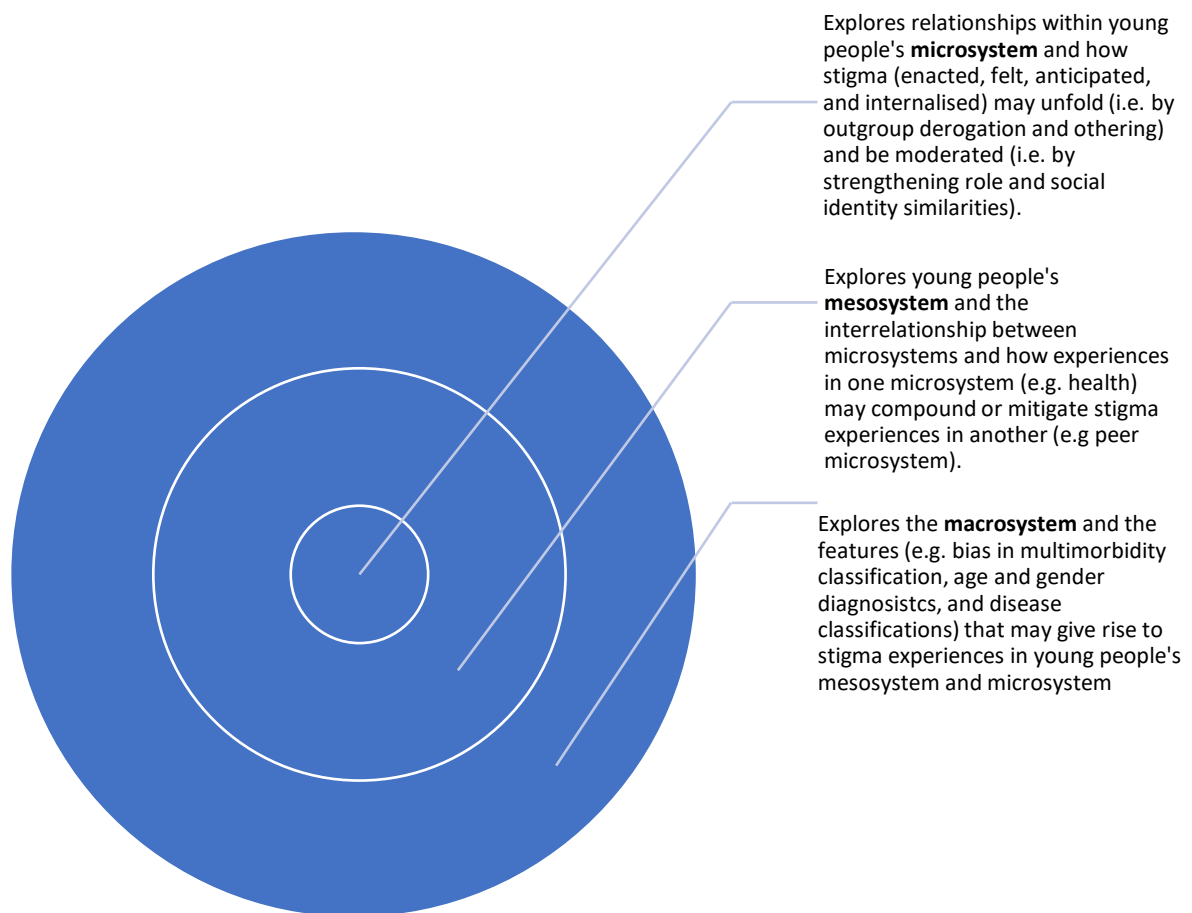


Figure 13. Interrelationship of young people's environmental systems and their stigma experiences

8.1 Macrosystem: facilitators of stigma

The macrosystem refers to the overarching ideologies and organisation of a society which includes for example judicial, political, and economic systems and the unwritten norms of behaviour/conduct of the social institutions within a particular culture, which indirectly affect the individual's growth (Bronfenbrenner, 1979). In this thesis, I argue the genesis of shaping the early adaptation constructs is stigma as young people experienced and responded to enacted stigma and felt, internalised,

and anticipated stigma pre and post diagnosis. I suggest that whilst stigma is enacted, felt, anticipated, internalised, and avoided in the microsystem, and its repercussions are experienced across the mesosystem, its tendrils stem from the structural conditions of the macrosystem and societal power inequalities (Link and Phelan, 2001; Parker and Aggleton, 2003; Pescosolido and Martin, 2015). The process of stigmatisation is a form of social control (Goffman, 1963) initiated by the dominant culture and its institutions which hold social, economic, and political power (Link and Phelan, 2001; Parker and Aggleton, 2003). But as with oppression, it is maintained by all of us simply “*following the unquestioned norms, habits, and symbols, in the assumptions underlying institutional rules and the collective consequences of following those rules*” (Young, 2014, p.41). Foucault (West, 2018) refers to this as the power capillary which flows in all directions and where we all intentionally or unintentionally exert power over others through defining and upholding what is normal and what is abnormal. It is the duality of oppression (Freire, 1996) where the oppressed become oppressors.

Stigma is therefore a function of the power struggles that underpin social life. Parker and Aggleton (2003) argue that at its roots are the key social actors seeking to legitimise their own dominant status within existing structures of social inequality. The process involves distinguishing and labelling human difference and then linking people with these differences to undesirable characteristics and negative stereotypes (Link and Phelan, 2001). It could be argued those who do not comply with the dominant culture’s expectations (for example, of being unwell) are therefore labelled negatively.

Labelling separates ‘us’ from ‘them’ and through the separation from the normative culture, people who are labelled experience loss of status and discrimination (Link and Phelan, 2001), and arguably marginalisation. As one of the five faces of oppression, marginalisation has been described as the process by which “*a whole category of people is expelled from useful participation in social life and thus potentially subjected to severe material deprivation...*” (Young, 2014, p.18). As discussed in Chapter 7 (see Sections 7.1., p.137 and 7.2., p.144) I suggest young people who presented with symptoms of both diagnosed and undiagnosed ill health, which marked them as different from other young people internalised negative labelling. They described how the enacted stigma of others (such as bullying and

teasing) seemingly excluded them from participation in some social groups. They also described how felt, anticipated, and internalised stigma prompted them to exclude themselves (through social withdrawal) from school attendance and participation in some social groups to protect their identities and minimise further stigma experiences (see Section 7.2.3., p.150). Data generated in this thesis suggests therefore that stigma is experienced as a form of oppression where *“people suffer some inhibition of their ability to develop and exercise their capacities and express their needs, thoughts, and feelings”* (Young 2014, p.40). It plays a key role in producing and reproducing relations of power and control. It causes some groups to be devalued and others to feel they are superior in some way. For stigmatisation to occur power must be exercised (Link and Phelan, 2001). Ultimately therefore, stigma is linked to the workings of social inequality (Parker and Aggleton, 2003). I argue that inequalities in access to timely care has its roots in the macrosystem features of age, gender, and health condition bias which enables stigma to evolve in the mesosystem and microsystem.

Stigma feeds upon, strengthens and reproduces existing inequalities of class, race, gender, and sexuality (Parker and Aggleton, 2003). I would add inequalities of age to this list. Whilst not all young people will experience inequalities due to their age, I propose there is an age blind spot with categorising, recording, and reporting of multimorbidity in young people which arguably results in their circumstances not being recognised. Moreover most of the participants were dependents (aged under 15 years) at the age of onset of their first LTC, and were therefore reliant on adult gatekeepers to access medical support.

The following subsections will discuss how bias around multimorbidity classification, recording, and reporting, and age and gender bias in diagnosing some health conditions may have contributed to the time delays in diagnosis that created the conditions for stigma to unfold in young people’s mesosystem and microsystems. Moreover I suggest bias around disease categorisation may have attributed the bearer of some diagnoses with negative evaluations, which may have contributed to some young people’s stigma experiences in the mesosystem and microsystems.

8.1.1 Multimorbidity age bias: if it can't be seen, it doesn't exist

It is contended here that there is an age bias towards classifying, recording, and reporting of multimorbidity which focusses on older aged adults at the expense of younger people, where multimorbidity prevalence and extent of comorbidities go unseen and therefore unaddressed. My literature review yielded scant results on young people's care experiences of living with multimorbidity (see Chapter 3, p.49). Data suggests that as a proportion of the multimorbid population, younger people comprise a small number compared to older adults. As a reminder to the reader, it has been estimated young people (0-24 years) make up 1.9% (Barnett *et al.*, 2012) and 3.5% (PHE, 2018) of the multimorbid population compared with for example, 65-84-year-olds who comprise 64.9% of those living with multimorbidity (Barnett *et al.*, 2012). The view is therefore that the prevalence in younger people is considerably lower. However, the focus on reporting prevalence as a proportion of the multimorbid population can distract from absolute numbers within age groups (Ryan *et al.*, 2018). This research at four GP practices in Brighton and Hove indicated there was a high percentage of young people (18-24 years) who met the definition of living with multimorbidity. As highlighted in Chapter 6 (see Section 6.1., p.123), they accounted for just over 24% (857/3531) of all 18-24-year-olds registered across four out of 35 GP practices. I suggest future focussed research to explore how far these figures are replicated across wider geographical areas.

It is also proposed here that the multimorbidity estimates in previous studies underestimated young people's prevalence because some of the health conditions diagnosed in young people and included in this study did not feature in those multimorbidity indices. In this study, 23 out of 74 diagnoses were of health conditions not included in the indices of previous studies (i.e. Barnett *et al.*, 2012, PHE 2018, Ryan *et al.*, 2018). Consequently some caution over multimorbidity estimates must be taken. Hayanga, Stafford, and Bécares (2022) noted in the absence of a standard multimorbidity index, the conclusions that can be drawn from systematic reviews of studies exploring MLTCs are arguably limited.

The variety of applied multimorbidity indices was noted in a systematic review of tools used to assess multimorbidity between 1960-2009 discussed in Chapter 2 (see Section 2.1.1., p.23). As a reminder, it identified 39 indices which included a wide

range of health conditions (4-102) (Diederichs, Berger, and Bartels, 2011). Across the indices, the two common themes for inclusion were health conditions that were prevalent and had a significant impact on health such as diabetes and stroke (Diederichs, Berger, and Bartels, 2011), which arguably is weighted towards older aged adults. In global recordings of non-communicable diseases (NCDs) also termed LTCs, NCDs account for 71% of deaths world-wide annually (WHO, 2018). The top four NCDs reported upon are i) cardiovascular disease (17.9 million deaths), ii) cancers (9 million deaths), iii) respiratory diseases (3.9 million deaths), and iv) diabetes (1.6 million deaths) (WHO, 2018). However, these health conditions only made up 8.1% (6/74; cancer [1] and asthma [5]) of the diagnoses in this study.

The prevalent health conditions in this study were depression and anxiety reported by 13 participants respectively. Depression and anxiety are the leading causes of global morbidity among adolescents (10-19 years) in both sexes (Guthold *et al.*, 2021). As discussed in Chapter 2 (see Section 2.1.3., p.25), depression was reported as the leading cause of DALYs among Australian females (15-24 years) (Australian Institute of Health and Welfare, 2019). Whilst anxiety was identified as a leading comorbidity in Spanish females 19-24 years (Violán *et al.*, 2014), and a leading morbidity in both males and females (20-34 years) living in Brighton and Hove (Brighton and Hove CCG and CC, 2018).

Living with mental health conditions puts younger people under 17 years at risk of experiencing comorbidity (Green *et al.*, 2005; Lawrence *et al.*, 2015). Delays in diagnosing younger people (under 11 years) living with autism spectrum disorder may put them at risk of developing mental health comorbidities (Hosozawa, Sacker, and Cable, 2021). This current study identified nine young people living with mental health comorbidities.

Mental ill health prevalence is of concern globally. It has been estimated that 32-42% of years of healthy life lost to disability (YLDs²¹) are attributed to mental health conditions (Vigo, Thornicroft, and Atun, 2016). Moreover, a systematic review and meta-analysis of mortality among people with mental health conditions calculated the median years of potential life lost was 10 years, and mental health conditions

²¹ YLD - One YLD represents the equivalent of one full year of healthy life lost due to disability or ill-health (WHO, 2022b)

contributed to 14.3% of deaths worldwide, or approximately eight million deaths each year (Walker, McGee, and Druss, 2015). Of interest is that this figure is almost on a par with global deaths from cancers (the second most prevalent cause of mortality in NCDs) at nine million deaths (WHO, 2018). I suggest mental health conditions should be included in the WHO's NCDs category rather than reported on separately so as not to lose sight of the extent of mental health conditions comparable to physical health conditions.

As for young people globally, mental health and substance misuse are the leading cause of disability in children and youth, accounting for a quarter of all years of life lost to disability (YLDs) at 54.2 million (Erskine *et al.*, 2014). In terms of DALYs, they ranked sixth with 55.5 million DALYs (5.7%) and rose to a fifth when mortality burden of suicide was included (Erskine *et al.*, 2014). Of note is the risk of young people with mental health conditions developing additional morbidities. A systematic review of clinical and behavioural cardiometabolic risk factors of young people (under 25 years) admitted to child/adolescent mental health inpatient units identified an association between the presence of cardiometabolic risk factors, such as being overweight, and having elevated levels of cholesterol and blood sugars. The review identified the presence of behavioural risk factors such as smoking, alcohol use and physical inactivity (Carney *et al.*, 2021). Similarly, Hermens *et al.*, (2012) suggested frequent use of alcohol, nicotine, or cannabis was evident among young people (12-30 years) seeking mental healthcare. The individual personal costs to young people (12-25 years) of living with poor mental health includes experiencing high levels of psychological distress, days of being unable to function, and moderate difficulties with social and occupational functioning, which for some necessitates income support (Scott *et al.*, 2012).

To summarise, multimorbidity calculation models which report prevalence as a proportion of the multimorbid population, and the application of multimorbidity indices linked to prevalence and mortality (associated with older aged groups) may fail to capture the total volume of multimorbidity in younger people. I suggest these practices arguably result in a medical and societal blind spot which requires addressing. If one argument for recording and monitoring multimorbidity is to monitor the impact on higher health care use and costs (Boyd and Fortin, 2010), then

monitoring multimorbidity in young people should arguably have greater priority; given the potential longer-term costs to the individual, family, and wider society.

8.1.2 Age and gender bias in diagnostic delays

As discussed in Chapter 6 (see p.123), more than half of participants (n=11) in this study, particularly those living with mental health conditions, neurodevelopmental conditions, and conditions associated with female reproductive health, were living with symptoms of ill health for several years before a diagnosis. In Chapter 7 (see Section 7.1., p.137) I discuss how living with unclear symptoms of an undiagnosed health condition may have informed enacted stigma from others. I suggest in this thesis that the diagnostic delays experienced by participants in this study could have been a feature in triggering enacted stigma, and those diagnostic delays could have been exacerbated by diagnostic age and gender bias.

Young women living with female reproductive health conditions reported in this thesis feeling their concerns about the level of pain and extent of bleeding they experienced were not taken seriously by the GPs they consulted. Diagnosing endometriosis, adenomyosis and PCOS can be challenging for clinicians. Symptom presentation of endometriosis and PCOS in younger aged females may go uninvestigated as it may be considered part of normal physiological development (Pena and Metz, 2017; Staal, Van Der Zanden, and Nap, 2016). There are a wide variety of diagnostic criteria for PCOS (Skiba *et al.*, 2018) based on symptoms presenting in adult females (Pena and Metz, 2017). Endometriosis and adenomyosis share symptoms and the two conditions can coexist (Bruun *et al.*, 2018). Diagnostic delays may be created by time spent managing symptoms with oral contraceptives or analgesics, and eliminating alternative diagnoses (Staal, Van Der Zanden, and Nap, 2016). Fundamentally, diagnosis confirmation of endometriosis and adenomyosis involves a surgical procedure (Zonderfan *et al.*, 2020) requiring a referral to a gynaecologist in secondary care. It could be argued that given the diagnostic challenges described, these health conditions may take some time to diagnose. A recent study of women's (aged 18-60 years) experiences of PCOS reported that just over a third of participants (n=15) reported a lengthy diagnostic journey and the majority (n=37) reported dissatisfaction with the care they received (Elghobashy *et al.*, 2023). The median time for diagnosis of endometriosis has been calculated at

7.4 years (Staal, Van Der Zanden, and Nap, 2016) and for younger women this can be longer. Where onset of symptoms occurs before 19 years of age, diagnosis can take 12.1 years (median) to diagnosis (Arruda *et al.*, 2003). Moreover, it has been calculated young women (under 18-years) experienced longer delays between the first consultation and diagnosis than older women (40-49 years), estimated at 34.5 months versus 12.4 months ($p = 0.0009$) (Soliman *et al.*, 2017). These studies suggest an age bias towards older aged females in diagnosing female reproductive health conditions. Of concern, which has been born out in this thesis, is young females are living for considerable periods of time with undiagnosed, unmanaged, painful, and sometimes debilitating reproductive health conditions.

Delays in diagnosing neurodevelopmental conditions could arguably be the result of gender bias in diagnostic criteria. Both autism and ADHD have a slightly higher prevalence rate in primary school age young children (Russell *et al.*, 2013; Rowland *et al.*, 2013; O'Leary, Bourke, and Ansell, 2014). But both are diagnosed more in males than females (Fombonne *et al.*, 2011; Russell *et al.*, 2013; O'Leary, Bourke, and Ansell, 2014). It has been estimated that autism affects four to five more males than females (Fombonne *et al.*, 2011; Russell *et al.*, 2013). In young people presenting with mental health symptoms in adolescence (e.g. depression, mixed anxiety and depression, and psychotic conditions), a higher number of males than females are referred for autism spectrum disorder (ASD) assessment (Aggarwal and Angus, 2015). It has been argued as females meet diagnostic criteria for autism in different ways to males (Lai *et al.*, 2014), they are less likely to be identified (Krahn and Fenton, 2012). The young people in this study living with neurodevelopmental conditions were all female and therefore gender diagnostic bias may have contributed to the delay in diagnosis experienced by some.

Clinicians may however have reasons for being cautious about applying a diagnostic label. Anxiety, for example, may present with ambiguous symptoms initially and in some circumstances may resolve over time without clinical intervention. GPs consequently may not immediately offer a diagnostic label, preferring instead to monitor over time (Ford *et al.*, 2016; Walters *et al.*, 2012). Diagnostic labelling of mental health conditions has had mixed reviews on its impact both on the individual and on social responses to it (O Connor *et al.*, 2021). A diagnosis may mitigate stigma for those with an autism spectrum disorder diagnosis (O Connor *et al.*, 2021).

For the individual, beyond the damage of stigma, a diagnostic label can threaten self-concept, but it can facilitate self-awareness (O Connor *et al.*, 2018) and lead to perceptions of empowerment (Sims *et al.*, 2021). A mental health diagnosis may bring knowledge that there are potential therapies which in turn brings hope and a sense of control (Probst, 2014).

In sum, there may be reasons for clinicians to be cautious about readily applying some diagnostic labels. However, I suggest there is an age and gender bias in the diagnosis of some female reproductive health conditions and neurodevelopmental conditions that may have contributed to delays in diagnosis. The delays experienced by this study's predominantly female sample may have been responsible for triggering the stigmatisation process in their interactions with others.

8.1.3 Bias underpinning some disease/health condition diagnoses

In Chapter 6 (see Section 6.4., *time between onset of symptoms and diagnosis*, p.130), it was calculated that for a number of young people (n=7) it took three years or more for a diagnosis, and in Chapter 7 (see Section 7.1., *before diagnosis: the disruption begins*, p.137), it was suggested that this was due to unclear symptom presentation which may have set the scene for stigma to evolve.

One explanation for this pattern could be that some health conditions (described as organic health conditions) are more readily diagnosable from biological changes whereas others (described as functional) are not (Kendler, 2012). It has been argued that functional/non-organic is often applied to indicate there are no diagnosable functional changes to account for the presentation of symptoms (Bell *et al.*, 2020). But the distinctions between organic and non-organic/functional are not always obvious. The uncertainty around distinctions has been evidenced in several cases in neuropsychiatry (David, 2009; Bell *et al.*, 2020). Bell *et al.*, (2020) contend in psychiatry and neurology there are no accepted criteria for distinguishing 'functional' from 'organic' across diagnoses, nor are there reliable concepts to which the terms apply across all cases. That there exists a distinction in how some diseases/health conditions carry more kudos, influence, and credibility than others by both professionals and the public has been noted by Album and Westin (2008) which may also expose the bearer of some diseases/health conditions to discrimination (Kidd and Carel, 2017). People with neurological conditions, for example, may be subject

to unjustified dismissals of their valid concerns because of perceived ideas the conditions are equated with the character trait of unreliability (Kidd and Carel, 2017). In a recent Australian study of young people's (aged 17-25 years) experiences of seeking emergency treatment for self-harming, Byrne *et al.*, (2021) suggested negative stereotypes associated with young people may impact HCPs' behaviour. They proposed that young people judged as attention seeking, for example, may have had their worries dismissed by HCPs.

Of concern is how these associations between negative assumptions of personal characteristics associated with some health conditions may impact the bearer's care experiences. The distinctions between organic and functional/non-organic conditions in gastroenterology, for example, may lead to faulty judgements and ineffective care (Drossman, 2006). Physicians, for instance, may interpret the health-care impact and disability of patients with functional gastrointestinal (GI) disorders as considerably less seriously than the patients, and make more negative value judgments on these patients. Moreover they may set different standards for evaluation and treatment depending on whether they perceive the patient to have a functional or organic GI diagnosis (Drossman, 2006). This distinction has also been argued to underpin the negative staff attitudes and uncaring behaviours shown towards patients who do not conform to the preferred patient role (Jeffrey, 1979; Kelly and May, 1981) which will be discussed later in the Chapter (see Section 8.2.1., p.190).

Some diseases/health conditions may therefore ascribe to the bearer character traits which may inform medical judgements and treatments, and public attitudes. For those bearing the label of a disease classification that generates negative medical and public judgements, their formal and informal treatment and care may be compromised.

In sum, this thesis suggests power differentials operating in the macrosystem which take the form of bias in (a) classifying, recording, and reporting of multimorbidity, and (b) some age and gender diagnostics may set the scene for inequalities in accessing timely and appropriate health care. I argue these macrosystem features created delays in diagnosis of some young people's health conditions which contributed to the social context (e.g. presenting with unexplained differences) for stigma in young people's interactions with peers, teachers, employers, HCPs, and family to unfold in

their microsystems and mesosystem. For some young people, a diagnosis of a condition on which medicine confers negative evaluations may have informed their interactions with HCPs and public resulting in “*labelling, stereotyping, separation, status loss, and discrimination co-occurring in a power situation*” (Link and Phelan, 2001, p.367). The next Section will explore how these macrosystem features may have shaped interactions in the microsystem to enable stigma to unfold. Drawing on this thesis findings, interactions that may potentially moderate stigma will be examined.

8.2 Microsystem

The microsystem is concerned with the immediate setting involving the people, objects, and symbols the person interacts with, and where connections and relationships between the individual and others influence the developing person (Bronfenbrenner and Morris, 2006). In the preceding Section, I identified potential features (i.e. delays in some diagnoses and the negative value judgements attached to others) that I suggest may have informed young people’s interactions in other environmental systems. In this Section, I explore how these features which identified them as different to other young people may have shaped experiences, notably in young people’s peer, family, and health care microsystems leading to (a) the enacted stigma of stigmatisers and bystanders, and (b) the anticipated, felt, and internalised stigma, and concealment behaviours of those stigmatised. I suggest features that arguably moderated stigma, minimised peer social and role identity differences, and strengthened their social and role identity similarities between stigmatised, and stigmatisers and bystanders, thus facilitating young people’s reconstruction of more favourable role and social identities.

8.2.1 Stigmatisers and bystanders

“Stigma is not solely the product of the mark itself, but rather of social interactions and relationships in which the mark is constructed as a reflection of its possessor’s tarnished character.” (Earnshaw and Chaudoir, 2009, p.1161)

Role and social identity theories may help to explain why others (i.e. notably peers, family, and HCPs) in young people’s microsystem stigmatised and stood by as

others enacted stigma in response to young people's difference. I suggest the stigmatisers and bystanders practiced outgroup derogation and othering triggered by this sample's seeming non-conformity to expected peer roles.

Outgroup derogation and othering arise as part of children and young people's identity development. Identity development is a dynamic and iterative process which is created through transactions between individuals and their social contexts, and adolescence is a time of testing out identities (Schwartz *et al.*, 2013) in the transition to adulthood (Erickson, 1968). Young people are sensitive to social experience (Bennett, 2011; Harter, 2012) and to social inclusion as part of their evolving social identities (Tanti *et al.*, 2011).

Social identities are the social categories or groups to which a person perceives they belong (Hogg and Abrams, 1988). The groups are numerous and include identifying with specific groups aligned to for example, an individual's gender, age, and ethnicity (Jackson and Sherriff, 2013). People will therefore have numerous social identities (Stets and Burke, 2000). Through a social comparison process, people who are similar to the self are grouped with the self and are labelled the ingroup, whilst people who differ from the self are categorised as the outgroup (Stets and Burke, 2000). People accentuate the perceived similarities between the self and others in the ingroup (termed self-categorisation) and highlight the perceived differences with others in the outgroup (termed social comparison) (Stets and Burke, 2000). Within their interactions people enhance their similarities within (inter) a social group and differences between (intra) social groups (Benish-Weisman *et al.*, 2015; Jackson and Sherriff, 2013). Judging those in the outgroup negatively is termed outgroup derogation (Tajfel, 1982).

In addition to forming social identities, young people are constructing their role identities. Role identities refer to the roles people occupy (Stets and Burke, 2000) such as the role of being a student or living with ill health. People incorporate into the self the meanings and expectations associated with the roles and their functions (Burke and Tully, 1977). In role-based identities, some form of interaction and negotiation is usually involved as one performs a role (Stets and Burke, 2000). In the process of othering, one identifies those that are different from self or the mainstream (Johnson *et al.*, 2004), but it is also a process by which people construct

their own identities in reference to others (Weis 1995; Gillespie 2006). A person's actions develop meaning through the reactions of others and over time (Burke and Tully, 1977). They do not stand alone but are shaped by their relationship with their other roles (Burke and Tully, 1977).

I suggest the act of stigma discrimination (i.e. bullying and teasing) experienced by some young people living with symptoms and/or a diagnosis of ill health discussed in Sections 7.1.1 (p.138); 7.1.2 (p.141), and 7.2.2 (p.148) were employed by young people's peers to accentuate the perceived differences between the self and their ingroup, and those in the outgroup. It also arguably enhanced similarities between the self and others in the ingroup (Stets and Burke, 2000; Johnson *et al.*, 2004). Belonging to a social group provides its members with a sense of social identity, which not only describes them but also ascribes appropriate behaviours (Ojala and Nesdale, 2004). Inter-group conflicts during childhood are more likely if ingroup members think that their status might be enhanced by outgroup derogation, or if they believe that their status is threatened in some way by members of an outgroup (Nesdale and Scarlett, 2004). By judging their peers symptoms of undiagnosed ill health negatively, as evidenced in Sections 7.1.1 (p,138) and 7.1.2. (p.141), and their diagnoses negatively (see Section 7.2.2., p.148), the ingroup peers potentially strengthened their own social identity and self-esteem (Tajfel and Turner, 1986). This was particularly noted in the interactions of young people living with undiagnosed and diagnosed neurodevelopmental conditions and their peers (see Sections 7.1.2., p.141 and 7.2.2., p.148). In response to their peers' outgroup derogation, some young people living with neurodevelopmental health conditions attempted to enhance their similarities with the ingroup and downplay their difference. Unfortunately, these interactions were not always successful and may have served to heighten their differences (see p.142).

Within their interactions people enhance their similarities within (inter) a social group and differences between (intra) social groups (Benish-Weisman *et al.*, 2015; Jackson and Sherriff, 2013). The extent to which young people practice intergroup bias is influenced by the extent to which young people value their group membership (Sherriff, 2007). I propose that young people's presentation of behaviour (visibly different to their peers) arising from their undiagnosed conditions (see Sections 7.1.1., p.138 and 7.1.2., p.141) or particular diagnoses (see Section 7.2.2., p.148)

posed a threat to the group identity leading to pressures for ingroup distinctiveness (Tajfel and Turner, 1986). I contend that enacted stigma in the form of bullying and exclusion were expressions of outgroup derogation from peers to repair their damaged self-esteem (Branscombe and Wann, 1994). Ojala and Nesdale (2004) reported ingroup member children tended to consider bullying more acceptable when it was consistent with group norms, and when it was directed towards an outgroup member who represented a potential threat to the ingroup. Concerns with social identity may account for why some young people who may empathise with the person being bullied may remain on the sidelines and not challenge the behaviour (Salmivalli and Voeten, 2004).

Data in this thesis indicate conformity to peer group behaviour/actions represents a salient identity feature in young people's developing role and social identities. It may help to account for why some unexplained health symptoms where young people were behaving differently to others such as being withdrawn, not talking to others, or complaining about frequent headaches were met with enacted stigma from peers (see Sections 7.1.1., p.138 and 7.1.2., p.141). Even when symptoms were attributed to a diagnosis, young people were not always brought in to the fold of the ingroup (see Section 7.2.3., p.150). Some mental health diagnoses, for example, may exacerbate the stigma that symptoms of mental illness already attract (Ben-Zeev *et al.*, 2010; Corrigan, 2007).

In interactions with their family some young people seemingly experienced disbelief or ridicule from family members when they did try and seek help for unexplained health symptoms. Mahomed *et al.*, (2019) identified stigmatising behaviour in the form of prejudice (e.g. being called *mad*) and discrimination (e.g. avoidance) from family members towards close relatives living with mental ill health in Gujarati in India. In this thesis, I suggest these experiences may have led to anticipated stigma and deterred young people from seeking further advice when the symptoms continued or became more severe (see Section 7.1.1., p.138). I propose the families' reactions could also be explained as outgroup derogation. The symptoms that were marking their children as different to other children could have made them fearful of also becoming stigmatised. This form of stigma is referred to as secondary or courtesy stigma (Ali, Strydom and King, 2012; Mak and Cheung, 2008) and stems from an association to a stigmatised group (Cattloor *et al.*, 2015). These fears may

be justified. In a systematic review of studies of families with members living with intellectual disabilities and autism, Mitter, Ali, and Scior (2019) identified family carers experienced courtesy stigma or affiliate stigma.

However another interpretation of families' responses of disbelief or ridicule could be explained as othering for the young people's non-conformity to an expected son/daughter/sibling /child role. Conformity is argued to be greater among strongly identified members (Terry and Hogg, 1996), such as families. Ingroup non-conformists may be judged more harshly than outgroup non-conformists as it upholds the group's distinctive values and the validity of their norms (Marques *et al.*,1988). In a national survey of transgender discrimination conducted in the United States, 57% of transgender people reported experiencing significant family rejection with 19% experiencing domestic violence (Grant *et al.*, 2011). This line of argument suggests some family structures/dynamics may lend themselves to responding in a punitive way to members who do not conform to expected roles within the family. Unfortunately, it was not possible from the data generated in this thesis to explore this potential relationship.

Othering could also underpin the unsupportive responses of some HCPs experienced by young people when they sought medical advice for their symptoms and management of their health conditions, notably painful conditions associated with female reproductive health and symptoms of mental ill health (see Section 7.3.1., Subheading: *HCPs: validation through action*, p.160). I suggest clinicians' practice, informed by age and gender bias in diagnosing some health conditions (see Section 8.1.2., p.186), and bias in attitudes towards some diagnostic classifications such as mental health conditions (see Section 8.1.3., p.188), may have influenced interactions. In this thesis, I suggest when young people presented with ill health symptoms, the clinicians' lack of knowledge of some diagnoses and lack of empathy, arguably a result of negative stereotypes, may be explained as othering for young people's non-conformance to a preferred patient role (see Section 7.3.1., Subheading: *HCPs: validation through action*, p.160). Young people's presentation of seemingly minor symptomology for example, could arguably fit the stereotype of the "*rubbish patient*" who falls outside "*the boundaries of what staff define as appropriate to their job*" (Jeffrey 1979, p.94) or "*bad patient*" who withholds "*legitimation*" (Kelly and May 1981, p.154) of the HCP role.

In sum, outgroup derogation and othering offer plausible explanations for the enacted stigma experienced in some young people's peer, family, and HCP microsystems. How these influences may shape the experiences of those who are stigmatised will be unpacked below.

8.2.2 The stigmatised

In some young people's interactions within their peer and family microsystems identified in this thesis, I suggest their diagnoses or unexplained symptoms may have made them aware not only of their difference to others, as they developed their social and role identities, but of the potential for others to categorise them as part of the outgroup or the other. Their stigma avoidance behaviours could therefore be interpreted as preventative acts, to protect their sense of self from outgroup derogation and othering.

As young people are developing their social identities, the effects of a diagnosis on identity may as a consequence be more acutely experienced (O'Connor *et al.*, 2018). I suggest some young people in this study experienced anticipated stigma from witnessing mental health prejudice towards others which could have informed their reluctance to disclose their symptoms/diagnosis to family and friends (see Section 7.1.1., p.138). It was noted earlier in the literature review (see Chapter 3, p.49) that children and young people seek to normalise their illness and to perform restrictive self-care practices to integrate with peers so that they do not receive unwanted social reactions (Gibson-Scipio and Krouse, 2018; Monaghan and Gabe, 2019, Datye *et al.*, 2019).

Some young people also experienced felt stigma. Those diagnosed with health conditions they perceived as *taboo* (see Section 7.2.3., p.150), and living with symptoms that marked them as different which prompted enacted stigma from others (see Sections 7.1.1., p.138 and 7.1.2., p.141) are examples of felt stigma, and informed restrictive behaviours. Restrictive behaviours such as seeking to conceal or selectively disclose their diagnosis are forms of stigma avoidance (Meisenbach, 2010; O'Connor *et al.*, 2018) as is resisting seeking help (Herek, 2009; Nearchou *et al.*, 2018) to avoid the discrimination and stigma of the health condition label (Corrigan, 2007; Clements *et al.*, 2015; Chambers, 2015).

Stigma avoidance has been argued to preserve people's sense of self, dignity, and quality of life (Geurtsen *et al.*, 2005), and in people living with mental ill health it may lower distress and impact more positively on identity than those who accept the mental illness identity (Thoits, 2016). However, concealment is also argued to be destructive as it may lead to loss of self-respect (Bresnahan and Zhuang, 2016). The data generated in this thesis indicate the cost of concealment through socially restrictive practices to protect from outgroup derogation and othering can impact negatively, as young people socially withdrew from their friendship/peer groups, potentially leading to feelings of isolation (see Sections 7.1.2., p.141; 7.2.3 p.150).

Moreover people who feel and internalise stigma may generate affective reactions such as embarrassment, fear, and shame (Chambers, 2015; Corrigan, 2004; Herek, 2009). As evidenced in Section 7.1.1 (p.138) young people's stigma experiences impacted negatively on their sense of self and their behaviours viewing themselves as for example *crazy* and practising social and self-care concealment behaviours to *pass*. Internalised stigma may lead to self-stigma. Self-stigma is the reduction of an individual's self-esteem or self-worth caused by the individual labelling themselves as socially unacceptable (Herek, 2009; Vogel, Wade and Haake, 2006). I suggest young people in this thesis who referred to themselves as *weird* and *abnormal* (see Sections 7.1.2., p.141; 7.2.1., p.145) in response to their stigma experiences were displaying low self-esteem from labelling themselves negatively.

Of note in this thesis was the response of some young people diagnosed with a mental health or neurodevelopmental health condition, who also experienced bullying and reported self-harming (see Section 7.2.2., p.148). Evidence suggests that self-harming is potentially an older, adolescent, and female gendered response. It has been estimated that self-harm in adolescents is common with one in four reporting self-harming thoughts and one in six engaging in self-harming behaviour over a one-year period (Stallard *et al.*, 2013). It is approximately twice as high in females compared with males and is more prevalent in older compared with younger adolescents (Lawrence *et al.*, 2015). In any 12-month period, about 8% of all 12-17-year-olds report engaging in self-harming behaviour without suicide intent. This prevalence increases with age to 11.6% of 16-17-year-olds (Zubrick *et al.*, 2016). It is associated with depression and anxiety (Moran *et al.*, 2012), long duration of depressive symptoms (Zubrick *et al.*, 2017), and autistic spectrum disorder (Oliphant

et al., 2020). Mental health related stigma has been identified as a contributor to suicidal ideation. As noted by Oexle *et al.*, (2017), perceived stigma and its association with concealment behaviours may have negative consequences on emotional wellbeing.

Bullying as an act of stigmatising behaviour is arguably an environmental stressor (Garisch and Wilson, 2010) that may be a trigger for self-harm when an adolescent has poor emotion regulation, communication skills, and mood difficulties (Garisch and Wilson, 2010). In one study, one third (34.3%) of 11-17-year-olds who were living with a mental health condition had been bullied in the previous 12 months (Lawrence *et al.*, 2015). This figure is much higher for young people living with severe depressive conditions. Based on self-reports, 62.8% of young people had been bullied in the previous 12 months and they were bullied more often (Lawrence *et al.*, 2015). Being a victim of bullying has been linked to poor mental health (Oexle *et al.*, 2019) but it's not clear how far poor mental health makes someone vulnerable to bullying, and/or being a victim of bullying leads to poor mental health. Research suggests some young people who are sensitive to negative social cues such as exclusion and others approval may be at risk of self-harming (O'Connor, Rasmussen, and Hawton, 2010; Sebastian, Viding, Williams, and Blakemore, 2010). Alternatively, it has been suggested that the act of self-harming may serve as an escape from a distressing situation, and to show others their unhappiness (Boergers, Spirito, and Donaldson, 1998; Hawton, Cole, O'Grady, and Osborn, 1982).

To summarise, some young people who presented with ill health which marked them as different to other young people in their social and role identities experienced stigma. Felt and anticipated stigma responses could trigger self-stigma and the reconstruction of negative identities defined by others (e.g. *acting weird*). Many young people in this thesis engaged in stigma avoidance strategies which have been argued to be protective of identities (particularly for people rejecting mental health identities). However, self-imposed social isolation to protect from outgroup derogation and othering could unwittingly contribute to the development of *the other* (i.e. outgroup role and social identities). Within the context of social and role identity development, self-harming for some older female adolescents living with a mental health or neurodevelopmental condition could be a response to the distress caused by othering and outgroup derogation.

8.2.3 Stigma moderating features

If we accept the premise of the argument thus far that stigmatisers and bystanders defined and protected their social and role identities through the enacted stigma of outgroup derogation and othering, and young people living with LTCs protected their identities from stigma experiences by concealing their differences, then it could be argued the moderating influences of stigma lie in interactions that minimise peer social and role identity differences and strengthen their identity similarities.

Access to similar others

The data generated in this thesis suggests some young people were able to protect their identities and reconstruct new identities through online access to other young people living with the same health conditions (see Section 7.2.4., p.152). Tajfel and Turner (1986) suggest when social identity is unfavourable people will strive to join a more favourable group, but it is one that compares to other lower social status groups rather than higher status groups. Butler (1997) argues individuals desire social and cultural recognition and will therefore accept the recognition in which their identities are subordinate rather than have no recognition. But rather than perceiving acceptance of lower status in negative terms, Young (1994) argues that finding a new social identity is a means to empowerment. For Young (1994) empowerment is a process in which:

“individual, relatively powerless persons engage in dialogue with each other and thereby come to understand the social sources of their powerlessness and see the possibility of acting collectively to change their social environment.” (Young, 1994, p.167)

Thus, one function of a diagnosis is to alert young people that there are others *like them* (O'Connor *et al.*, 2018). It has been noted elsewhere in this thesis that support of others living with the same health condition (i.e. NMD and T1DM) was important to young people when HCP's knowledge was perceived as limited (Due-Christensen *et al.*, 2018; Travlos *et al.*, 2016). For young people in this thesis, access to on-line communities of others living with the same health condition was important to them. Evidence suggests on-line communities support with forming a collective identity (Elkington *et al.*, 2012; Jones *et al.*, 2015; Mogensen and Mason, 2015) and feeling more connected to the outside world (McDaniel, Coyne, and Holmes, 2012), which

has been associated with creating a sense of belonging, validation (Jones *et al.*, 2015), and wellbeing (McDaniel, Coyne, and Holmes, 2012). In one study of LGBTQ+ Latinx²² young people, their development of health autonomy via self-education enabled them to resist cultural stigma (Schmitz, Sanchez, and Lopez, 2017). I propose some young people in this study through their on-line access to other young people living with the same health conditions/symptoms were able to reconstruct their role and social identities. As evidenced in Section 7.2.4. (p.152), they identified with the *sick* identity of the diagnosis and reconstructed their role and social identities, becoming part of a condition specific ingroup, learning to manage their health conditions and symptoms, and how to navigate the health and care system.

Sick role identity validation

In Section 7.3.1. (p.158) I suggest interactions with families, partners, peers, HCPs, and care systems in which young people's health concerns were acknowledged, supported, and acted upon could validate young people's sense of self as *sick*, paving the way to reconstructing more favourable identities (e.g. *I am sick* as opposed to *I am abnormal*), which in turn supported health seeking behaviour. Bergen *et al.*, (2022), in a recent study of young people's experiences of seeking emergency support for a mental health crisis, identified that HCPs' validation of young people's experiences prevented undermining young people's sense of agency in a clinical interaction. However, a lack of validation which took the form of dismissing or contradicting the young person's feelings or experiences was perceived to cause increased distress and a poor rapport between HCPs and young people (Bergen *et al.*, 2022). In this thesis, when HCPs lacked empathy and knowledge of the health condition (see Section 7.3.1., p.158), it was experienced by some young people as invalidating their health concerns. It has been noted previously in the literature review (see Chapter 3, p.49), some HCP behaviours that were experienced by young people as lacking interest in their concerns (Travlos *et al.*, 2016; Wiley *et al.*, 2015), being judgemental (Lewis *et al.*, 2010), and lacking knowledge of a health condition served as potential barriers to young people's healthcare engagement (Travlos *et al.*, 2016; Wiley *et al.*, 2015), and informed

²² A person of Latin American origin or descent. It is used as a gender-neutral or non-binary alternative to Latino or Latina (Encyclopaedia Britannica, 2023).

guarded communication (Lewis *et al.*, 2010), concealing pain (Renedo *et al.*, 2020), and social silencing (Renedo *et al.*, 2020; Ådnanes and Steihaug, 2016). Additionally young Māori people experienced HCPs' lack of cultural understanding and recognition of how chronic illness impacts on relationships and changes their lives, as not meeting their needs (Sligo *et al.*, 2019). I suggest in Chapter 3 (see p.49) these encounters were experienced as disempowering with the result that young people resisted engaging with HCPs. In a development of this analysis, I suggest some young people in this thesis who did not have their health concerns acknowledged, experienced this as disempowering as it did not give credence to their *sick* role identity. In so doing, it prevented them from feeling they had agency to affect change.

Validation of young people's health concerns could conceivably act in the same way as a diagnosis. As discussed in Section 7.2.1 (p.145), a diagnosis after a period of living with unexplained symptoms that resulted in stigma (i.e. enacted, felt, anticipated, and internalised) enabled young people to recalibrate their view of self.

A diagnosis has been evidenced to validate self (O'Connor *et al.*, 2018) and provide a sense of relief and self-understanding by implying symptoms result from a real independent disease entity (Hayne, 2003; Horn *et al.*, 2007). For people whose difficulties were previously dismissed as imaginary or self-inflicted, a diagnosis can be welcomed as validating their authenticity and severity (Dinos *et al.*, 2004; Hayne, 2003; Punshon *et al.*, 2009). Moreover, by attributing their behaviour to a disease entity, a diagnosis allows young people to externalise their difficulties from their inner self and thereby protect their self-image (O'Connor *et al.*, 2018). It could therefore be argued that the supportive and validating interactions in the microsystem legitimated the *sick* role identity pre and post diagnosis. Young people could harness this validation (i.e. agency as described by Bergen *et al.*, 2022) to develop role and social identities with others like themselves as described by young people in Section 7.2.4. (p.152).

I propose that coupled with the validation of the *sick* role, is a feeling for young people of being accepted (see Section 7.3.1., p.158). As mentioned in Chapter 7 (see Section 7.3.1., p.158), acceptance may contribute to a sense of belonging (Robinson *et al.*, 2020) and a sense of belonging promotes wellbeing because it

mitigates stigma (Govindasamy *et al.*, 2020). Being accepted by a social group is a protective feature for young people from enacted stigma (i.e. bullying) (Demaray and Malecki, 2003; Pellegrini and Bartini, 2000), as are positive friendships (Bollmer *et al.*, 2005; Schmidt and Bagwell, 2007). Social inclusion has been argued to mitigate stigma for people living with HIV by reducing social withdrawal and social isolation (Chambers *et al.*, 2015; Lindau *et al.*, 2006). It could therefore be argued in this study that supportive families, friends, HCPs, and in particular partners, moderated young people's experiences of stigma by seemingly validating their sense of self as *sick* which informed feelings of acceptance and belonging to the new reconstructed *sick* role identity. Young people then had agency to develop their reconstructed identities and learn about the health condition and how to manage it.

Sick role identity validation has the effect of bringing young people into the fold of normative society. It has been discussed previously in Chapter 2 (see Section 2.2., p.29) that informal networks are important for enabling people to live normal lives (Bury, 1982; Whitehead and Jacob, 2018). Applying Bury's (1991) concept of *legitimation*, the validation of young people's *sick* role by informal networks and HCPs enabled young people to recalibrate the meaning (i.e. the consequences and significance) of living with LTCs (e.g. *I'm normal abnormal*) so that they maintained their personal integrity and minimised threats to their social status.

Easing the burden of illness

Supportive families and HCPs also provided practical and emotional support which I propose eased the burden of illness as young people were empowered to self-care (see 7.3.2., p.163). In Chapter 2 (p.23), Rosbach and Anderson (2017) argue that informal networks can support people to integrate their treatment into their daily lives so that they can balance the illness management workload and capacity. In Chapter 3 (p.49), it was noted that practical support by family was valued by young people living with MND (Travlos *et al.*, 2016), and helped young people living with T1DM to not feel controlled by the disease. Not feeling controlled was suggested to enable young people to reject the negative meanings associated with living with diabetes (Anderson and Tulloch-Reid, 2019).

Young people living with PaHIV transitioning from paediatric care services to adult care found HCP support with detailed explanations beneficial (Bundock *et al.*, 2011).

Feeling supported seemingly instilled trust in health care services and professions in this thesis (see *care systems: enabling capacity building*, p.165) which has been evidenced to create positive emotional states and is associated with increasing trust in unfamiliar people which aids disclosure (Dunn and Schweitzer, 2005). Such actions could arguably counteract resistance to seeking help which, as referenced earlier, is a form of stigma avoidance (Herek, 2009; Nearchou *et al.*, 2018).

In sum, outgroup derogation and othering may explain the enacted stigma of stigmatisers and bystanders, and the stigma avoidance strategies employed by young people who felt stigmatised. The features that have been presented as moderating stigma in young people's microsystem include accessing similar others, *sick* role identity validation, and easing the burden of illness. I suggest they may have shaped the reconstruction of more favourable identities and developed agency and health seeking/engagement practices through minimising triggers for outgroup derogation and othering.

8.3 Mesosystem

The mesosystem refers to the connections and relationships between two or more microsystems each containing the developing individual such as home and school, and home and peer-groups (Bronfenbrenner 1979). Mesosystem features in this study refer to the interrelationship of young people's microsystems and how interactions in one or more microsystem could potentially compound or mitigate stigma in another. The data in this thesis suggest there is an interrelationship between young people's health care, education, and peer microsystems and young people's stigma experiences.

8.3.1 Compounding stigma

I discuss in Section 7.3.2. (p.163) how interactions with HCPs and care systems may have exacerbated young people's health conditions and by association burden of illness with lack of continuity and access to timely and appropriate support and treatments. I suggest in this Section that an increase in the burden of illness generated in the health microsystem had repercussions in other microsystems such as employment, family, and education. I propose they created challenges that negatively affected young people's interactions and ongoing participation; potentially

acting as triggers for outgroup derogation and othering. For one young person, a lack of treatment and support in her health care microsystem to manage adenomyosis impacted on her employment and family microsystems. The condition was debilitating and some days she couldn't pick up her child from nursery, having to rely on family members to help, whilst her sickness record reportedly meant she nearly lost her job on more than one occasion. Another participant was not allocated a Clic Sargent (i.e. support and advocacy worker) as part of her cancer treatment. She reportedly struggled to communicate her condition and treatment effects to the college where she was having difficulty managing her workload. She was not offered extra time to catch up on missed work, and she left college before completing her studies. When health care systems do not run smoothly, they can have repercussions on other microsystems. One young person reported how not having her prescription delivered on time made her so unwell that she couldn't function in her daily activities. I suggest when young people were unable to participate fully in other microsystems because of barriers to treatment and support in the health care microsystem, it highlighted their peer role and social identity differences. As discussed in the preceding Section (8.2.1., p.190), the difference in behaviours it generated may have served as a salient identity feature for intergroup bias and outgroup derogation among peers, and a trigger for othering from employers and teachers.

It was in the microsystem of school where lack of support/adaptations to accommodate young people's health needs described in Section 7.3.3. (p.170) laid bare the impact of the burden of illness on young people's ability to continue to fully participate in education, with consequences in young people's peer microsystem. Of note was the enacted stigma of some teachers towards young people presenting with undiagnosed and/or misunderstood health conditions where one young person felt the teachers labelled them as "*difficult*" (p.173) and another was directly called "*really naughty*" (p.173). One young person talked about how it impacted on her peer microsystem. She recounted being repeatedly told off by teachers for removing items of clothing that were irritating her skin. She felt she was labelled as the class "*monster child*" (p.173) and reported that her friendships were affected. Another participant recounted how a school intervention for young people who self-harmed identified her to the rest of the school which impacted on her peer microsystem as

she reported experiencing enacted stigma. Teachers are authority figures and may influence their pupils' behaviours (Gini, 2006). Teachers who are tolerant of aggression communicate their lenience to students, who may also act more positively towards aggressive peers (Chang, 2003). An association has been identified between negative school environmental factors (such as low levels of adult monitoring) and an increase in the frequency of bullying among peers (Meyer-Adams and Conner, 2008; Pellegrini and Bartini, 2000; Wienke Totura *et al.*, 2008) which suggests actions in the school microsystem may impact on the peer microsystems.

8.3.2 Stigma mitigation

Whilst stigma resistance is the capacity to resist, counteract or otherwise remain unaffected by stigma (Ritsher *et al.*, 2003), I suggest stigma mitigation in the mesosystem refers to how the moderating features in one microsystem could reduce the potential for young people to experience stigma in another microsystem.

In Section 7.3.2. (p.163), I proposed the practical and emotional support offered by significant others (i.e. families, partners, and friends) and HCPs, together with health care systems that enabled access to timely, appropriate, and continuity of care was experienced as empowering as it developed young people's capacity and agency to self-manage. Being emotionally supported in a peer or family microsystem, for example, may have informed interactions in the health microsystem as was evidenced by young people who sought medical advice on the concerns expressed by partners and families. Feeling socially accepted has been identified to positively shape self-care behaviour such as adherence to medication regimes, and access to health care and community services (Chambers *et al.*, 2015, Kane *et al.*, 2019).

As discussed in the Section on *stigma moderating features* (p.198), feeling socially accepted may reduce social withdrawal and social isolation for people living with HIV (Chambers *et al.*, 2015; Lindau *et al.*, 2006). I propose feeling accepted in one microsystem may have reduced feelings of stigma and enabled young people to minimise their role and social identity differences by entering new peer appropriate microsystems. In Section 7.3.2. (see Subheading: *significant others: capacity building through emotional and practical support*, p.163), some young people recounted how the practical and emotional support provided by families and partners facilitated their pursuit of employment and education opportunities.

The data indicate that as stigma was moderated in one microsystem it enabled young people's participation in others. As young people conformed to acceptable peer role and social identities, the triggers for outgroup derogation and othering in, for example, family and peer microsystems were reduced. Opportunities to develop peer role and social identities in different microsystems enabled young people to accentuate the perceived similarities between the self and others in the group, and as discussed earlier, the social comparison process grouped them with people similar to form an ingroup (Stets and Burke, 2000).

Some authors have proposed that people who are stigmatised do not like or accept being stigmatised and little can be done to reverse this condition or status (Brown, Billings, Mastro, and Brown-Devlin, 2015; Pachankis, 2007). This thesis suggests that for young people, stigma generated from living with MLTCs can be moderated in the microsystem and further mitigated in the mesosystem with opportunities to seek similar others, *sick* role identity validation, and easing the burden of illness which strengthen similarities in peer role and social identities. In this application of EST, the distal and proximal influences on young people's stigma experiences have been located. However, it does not explore the role of an individual's psychological orientation on the processes at play (Tudge *et al.*, 2016), or the passage of time. Bronfenbrenner and Morris (2006) recognise that a person's characteristics will change over time as they develop and therefore interactions will also change. McKeague and Hennessy (2015) noted for young people living with ADHD or depression that there were changes in their experiences of self-stigma as time passed, social networks changed, and LTCs were managed. Similarly adolescents living with T1DM showed a clearer understanding of the illness and felt more in control of their diabetes with increasing age, which was associated with the development of feelings of acceptance and/or reduction in feelings of rejection (Fortenberry *et al.* 2014). Bronfenbrenner and Morris (2006) address the significance of time in shaping interactions in the environmental systems in the development of the bioecological model referenced in Chapter 2 (see Section 2.3., p.37) which proposes that studies should be longitudinal (Bronfenbrenner and Morris, 2006). Due to time constraints a longitudinal research design was not feasible in this study.

8.4 How can young people living with MLTCs be supported to live well?

As a reminder to the reader, *living well* in this thesis is defined as “*the best achievable state of health that encompasses all dimensions of physical, mental and social well-being ... and is defined by a self-perceived level of comfort, function and contentment with life*” (Institute of Medicine 2012, p. 32). For young people, it also includes being able to participate in the world, have fun, and have fulfilling close relationships (Schreiner *et al.*, 2020). The data generated in this thesis suggests young people’s experiences of stigma (felt and anticipated) and the resultant stigma internalisation and avoidance behaviour strategies could shape the early adaptation constructs to stymie young people’s abilities to live well. However, this outcome is by no means a *fait accompli*. In line with Due-Christensen *et al.*, (2018), data indicate the early adaptation to living with LTCs is a dynamic process of reconstructing sense of self in relation to view of the health condition, learning, and behavioural adaptations. For young people living with LTCs pre-diagnosis and post diagnosis, I propose features that enabled access to similar others, *sick* role identity validation, and easing the burden of illness may have moderated young people’s stigma experiences; strengthening peer role and social identities within their microsystems and mesosystems. As their role and social identities are brought within normative expectations, the trigger for outgroup derogation, othering, and therefore stigma (enacted, felt, internalised, and anticipated) is reduced. Accompanying these changes are less concealment and restrictive self-care and social practices. As young people seek help and receive help, they are able to participate in the world, develop their role and social identities, and pursue life goals which serves to strengthen similarities in peer social and role identities and minimise their differences.

8.5 Summary

The EST provides a helpful framework for exploring the role and interplay of the stigma dimensions as some young people live first with the symptoms and then a diagnosis of a LTC.

According to Bronfenbrenner and Morris (2006) “*it is a basic premise of ecological systems theory that development is a function of forces emanating from multiple settings and from the relations among these settings*” (p.817). This thesis has

demonstrated how some young people's experiences of living with LTCs has been shaped by stigma arising from structural processes within the macrosystem that have informed experiences in the microsystem and been compounded or mitigated in the mesosystem.

For young people living with multimorbidity whose first symptoms of ill health present in childhood, it is suggested that stigma has its antecedents in age and health condition bias in multimorbidity classification, recording, and reporting, and age and gender bias in the diagnostics of some health conditions. These features together with young people's lack of autonomy and dependency on adult gatekeepers to health and care may have led to diagnosis delays. I propose the delays in diagnosis and the negative evaluations attached to some disease categorisations set the social context for enacted stigma from outgroup derogation and othering to play out in the microsystem and mesosystem.

Data generated in this thesis indicate as young people are developing their role and social identities, they are vulnerable to becoming stigmatised. They are responsive to difference in themselves and others. Outgroup derogation of the stigmatisers and bystanders has been argued to enable peers to distance themselves from young people's differences. In the case of othering, peers, families, and HCPs were conceivably punishing young people's non-conformity to expected social/role identities. Stigma avoidance strategies, such as concealment self-care practices of those experiencing stigma, have been argued to protect young people's identities by minimising their differences. Although it could be argued that the social withdrawal and isolation of some young people compounded the development of their role and social identities as the *other*. Of note was the response of older adolescent females living with a neurodevelopmental or mental health condition who were bullied. They reportedly self-harmed possibly as a response to othering and outgroup derogation.

Moderating features of stigma in the microsystem included (a) access to similar others, (b) *sick* role validation, and (c) easing the burden of illness. Of note in this thesis was the accessibility of social media and on-line platforms for young people to reach out to others like them, bypassing health and care gatekeepers, and educating themselves about the health condition, its management, and navigation of the health

and care system. These virtual interactions were key to developing young people's social identities from *other* to *us*, and role identities from for example *weird* to *sick*.

Within the mesosystem there was evidence of how stigma experiences and the stigma moderating features in one microsystem could compound or mitigate young people's stigma experiences across other microsystems. Failure to receive treatment and support in the health care microsystem could create challenges and potential triggers for outgroup derogation and othering in family, peer, education, and employment microsystems. Moreover peer microsystems were negatively affected by school microsystems that highlighted differences in young people's role and social identities. In contrast supportive family and partner microsystems could encourage health seeking in the health care microsystem, and facilitate access to other microsystems such as employment and education, thus minimising differences in peer role and social identities.

Interventions to enable young people living with MLTCs to live well must therefore consider how to address these social contexts within the environmental systems that facilitate stigma, and develop the stigma moderating features that have been identified in this thesis.

8.6 Study's strengths and limitations

This thesis applied a social constructionist approach to explore the care experiences of young people living with MLTCs to understand the features of their interactions with significant others, HCPs, teachers, employers, and organisational systems that may support them to live well. The early adaptation process provided a framework for guiding and contextualising young people's narratives of their experiences, whilst the EST facilitated the organisation and articulation of the interconnected mechanisms at work in shaping how young people experienced being unwell, received a diagnosis, and learned to make adaptations in their lives. As a qualitative research project the data was generated and analysed through a process of interpretation, from the participant's interpretation of the questions to the researcher's interpretation of the responses which were then framed within theoretical models (i.e. stigma theory, identity theories and cumulative complexity model [i.e. burden of illness]). This Section will discuss the study's limitations and strengths and implications for future research and practice.

This research was designed and conducted during the Covid-19 pandemic and whilst the pandemic did slow the recruitment process, 19 participants from four GP practice sites were recruited over the course of a year, and they each completed a two part interview schedule. The research design was adapted to be conducted remotely to reduce the risk of Covid transmission. Telephone interviews were employed after consultation with youth workers who had reported challenges in engaging young people in activities over Zoom during the national lockdowns (see Section 5.1.3., p.87). Whether in person interviews as opposed to telephone interviews would have increased numbers of young people who engaged in this study or the quality of the data generated is an unlikely limitation of this study. As discussed in Section 5.1.4. (p.90), telephone interviews via mobile phones may make young people accessible to researchers (Flanagan et al., 2015) and provide familiarity to those who are used to virtual conversations (Trier-Bieniek, 2012). Whilst the lack of visual clues during telephone interviews could be argued to hinder rapport building, the anonymity provided by the telephone may help put people at their ease (Flanagan et al., 2015), and has been evidenced may elicit rich data around topics considered sensitive by participants (Drabble et al., 2015). In order to develop a rapport with the participants the interview was designed in two parts with the first interview a light touch biographical mapping exercise before the more in-depth data elicitation in the second interview.

Whilst this number of participants may be considered a small sample size, the two part interview schedule facilitated the generation of data rich in descriptions. The sample was predominantly female, but the analysis included the experiences of all genders. Many told of their experiences of living with symptoms of ill health since early childhood and of living with a combination of physical health, mental health, and neurodevelopmental health conditions, many of which could be argued to be comorbidities. Consequently, the recruitment and data generation captured the experiences of many young people living with complex multimorbidity (i.e. living with four or more LTCs). These voices are not traditionally captured in health care research.

As discussed in Section 6.2. (p.124), many of the LTCs reported by young people were additional to those in the selection criteria adapted from previously applied multimorbidity indices. It therefore suggests a potential underreporting of MLTCs not

only amongst young people in the multimorbidity literature but across the wider multimorbid population. It also indicates that multimorbidity is insidious in its evolution and that HCPs' vigilance is required to explore associations between the onset of new symptoms in patients and the potential development of comorbidities to reduce delays to diagnoses and onset of treatments.

The qualitative interview design and semi structured interview schedules with a focus on participants' health biographies did not restrict young people's narratives to their experiences of health care pathways. The data generation and analysis identified the role of teachers, employers, and organisational systems (in addition to HCPs and significant others) in supporting young people to live well, and has therefore widened the scope of our understanding of what and who impacts on young people's abilities to self-care.

From the data generated, I was not able to explore other possible explanations such as young people's appearance, mannerisms, or social circumstances that may have contributed to identifying them as different to others, and added to their experiences of enacted, felt, anticipated, and internalised stigma. The data suggests that if these influences were present, they were moderated and mitigated by the actions and behaviours of others who enabled them to reconstruct more favourable identities.

One of the research activities was to explore the intersectionality of personal characteristics and/or wider determinants on young people's interactions with HCPs, relational networks, and care services. Whilst age, gender, and health condition pathology and presentation featured as potentially shaping experiences, comorbidity number and educational attainment were not present in this analysis. Experiences of financial hardship could not be explored. As was discussed in Chapter 5 (see Section 5.1.7., p.95), many participants recruited to this study were geographically mobile which highlighted that GP catchment area was an unreliable indicator of socio-economic deprivation in this study. Furthermore, the link between multimorbidity and learning/intellectual disabilities discussed in Section 2.1.3 (p.25) could not be fully explored. Whilst learning/intellectual disability featured on the participant selection criteria (see Appendix J, p.295), none of the participants disclosed they were living with learning/intellectual disabilities. As the research design required participants to recount their past health care experiences, it was

therefore not accessible to those with some forms of learning/intellectual disabilities. As referenced in 5.3.4. (p.105) three young people were excluded from the study due to their lack of capacity to understand and to engage in what was expected of them.

One of the observations from this study was the absolute number of young people (24.3%) who met the definition of living with multimorbidity across the four GP practices. The data on which this claim is made was provided by GP practices (i.e. participant identification centres [PIC]). There are reported differences between GP registered populations and the Office for National Statistics (ONS's) population estimates resulting in the former being higher than the latter. Overcounting in GP practices is one potential cause of this difference (UK Parliament, 2016). I was not able to check the database search terms/codes for errors and double counting to confirm the numbers provided by the PICs.

Many young people in this study talked about their symptoms and diagnoses that occurred in early childhood and several young people were living with symptoms of ill health for more than five years before diagnosis. Despite the temporal distance between onset of symptoms and young people's participation in this research project, detailed recollections of their lived experiences were facilitated through mapping young people's health biography by telephone interview at two points in time, and exploring their health in relation to key life events. As a rich data elicitation tool, it may be of use to researchers and clinicians working remotely with young people about historical events/experiences. The first interview generated the health timeline, and topical blocks (e.g. on detail of experiences) enabled the interviewer and participant to keep the interview focussed on that topic guide (Holter *et al.*, 2019). The second interview gave both the interviewer and participant an opportunity to reflect on what was raised in the first interview and develop new insights (Polkinghorne, 2005). The two points in time enabled a clear delineation of interview modes and facilitated a joint understanding of young people's experiences (Holter *et al.*, 2019).

One of the study's actions was to explore the health care experiences (both formal and informal) of young people living with MLTCs with a view to examining how the early adaptation constructs could be shaped by prior experiences and the number of

prior experiences of ill health diagnoses. My analysis of the data generated in this study identified an association between prior stigma experience and future responses to ill health symptom presentation. However, I was not able to explore the relationship between number of LTCs on shaping subsequent early adaptation constructs.

8.7 Recommendations for health and care research and practice

Studies that have applied EST to explore interactions within and between systems have been criticised for identifying too specific recommendations that may not be easy to implement as they require complicated interventions (Eriksson, Ghazinour, and Hammarström, 2018). Based on this study's findings, I suggest they may be deemed complicated because young people's stigma experiences emanate from an interrelated web of distal and proximal sources. Consequently, they will require a multifaceted approach that includes further research and the development of monitoring and recording tools, but the recommendations are feasible.

8.7.1 Future research

- 1) Addressing age and health condition bias in multimorbidity reporting and recording, and age and gender bias in making some diagnoses require cultural and structural changes that will take time. A recommended starting point is to establish the absolute numbers of young people living with morbidities and comorbidities, their wider determinants, and a multimorbidity recording system that is inclusive of the health conditions that impact young people:
 - i. Based on the data available from the four GP practice recruitment sites, it was calculated that approximately 1:4 young people (18-24-years) met the definition of living with multimorbidity. This study suggests the absolute numbers of young people living with multimorbidity may therefore much higher than initially assumed based on estimates of young people living with one LTC, but a larger and in depth study of absolute numbers is required to confirm this claim.
 - ii. This study was unable to establish links between multimorbidity and educational attainment, gender, ethnicity, learning/intellectual disability,

and socio-economic deprivation. Future research could explore how far these personal characteristics and wider determinants inform young people's experiences of living with multimorbidity.

- 2) The choice of primary care as the study setting for this research project recruited a sample of young people living with a number of morbidities that did not feature in the multimorbidity index applied in previous studies. It is suggested further research to capture the type and number of morbidities and comorbidities presenting not only in young people but the population as a whole could inform the development of an inclusive standardised multimorbidity index.
- 3) Of note in this thesis was the perceived disconnect between young people's lived experiences and HCPs and significant others' assumptions of the health conditions and how they should be experienced by young people. Exploring and assessing approaches to improve how HCPs communicate and care for young people is advocated. For example, irrespective of the symptoms and diagnosis, an agential approach as proposed by Bergen *et al.*, (2022) with its focus on validating and empowering young people via communication techniques could be piloted as the starting position for others supporting young people seeking health care attention (see Appendix Y, p.335). Additionally, the application of a tool such as the EQ-5D-5L (for those aged 18 years and over) or EQ-5D-Y (for children and adolescents) in clinical encounters with young people will capture a measure of their lived experiences of the symptoms and impact on their daily living activities which may guide HCPs in young people's care management (Euroqol, 2023). An assessment of the regular application of such a tool where HCPs and young people work holistically (e.g. with families, schools, employers, and other HCP specialist services) could provide valuable insight to young people's management of living with LTCs.
- 4) Building on the findings in this thesis, future research could explore how the identified features that moderate stigma in the microsystem and mitigate stigma in the mesosystem (a) are shaped by the passage of time, and (b) could be developed/applied in health, care, and education systems design, and workforce learning and development programmes.

- 5) Finally, this study suggests peers' enacted stigma may inform self-harming behaviours in some older adolescent females living with a mental health or neurodevelopmental diagnosis. It was suggested this could be a female gendered response to outgroup derogation and othering. Further research with young people who self-harm could explore these associations.

8.7.2 Informing local health and care practice

- 1) In Chapter 2 (see p.23), the positioning of this research project within primary care was outlined to take advantage of changes within the health and care landscape which will allocate responsibilities to GPs/PCNs and community-based services to work together to meet the health care needs of the local community. Moreover there is a new children and young people (0-25-years) transformation programme²³ which will oversee the delivery of commitments to children and young people. It will include increased support for children with learning disabilities and autism, and improved mental health services. It is intended the findings from this thesis will be shared with the Brighton and Hove PCN Network and Sussex Health and Care Partnership to potentially inform the development of young people's services, staff development, and future local research.
- 2) This study suggests that multimorbidity is insidious in its onset and therefore raising awareness amongst HCPs of the comorbidities associated with, in particular, mental health and neurodevelopmental health conditions, not only in young people but the multimorbid population as a whole, could reduce potential delays to diagnoses and onset of treatments.

²³ <https://www.sussex.ics.nhs.uk/wp-content/uploads/sites/9/2022/06/CYP-Local-Transformation-Plan.pdf>

Chapter 9: Conclusion

Learning to live with MLTCs requires people to undergo a process of adaptation. Reconciling previous healthy identities with new *sick* identities is recognised as central to that process. Living well with MLTCs necessitates young people adapt so that they are able to self-manage their health conditions to achieve a self-perceived level of physical, mental, and social well-being, in addition to participating in the world and having fun and fulfilling relationships. HCPs, families, peers, partners, teachers, and employers, in addition to organisational systems have a role in that transition for young people living with MLTCs.

The early adaptation process, developed by Due-Christensen *et al.*, (2018), explained how people newly diagnosed with T1DM made adaptations to their lives following a diagnosis. It identified how experiences from the disruption of a diagnosis informed the view of diabetes and the reconstruction of view of self, which in turn informed learning and behaviour. These constructs, shaped by individual psychology and background, are interconnected and changes to one construct such as a learning experience may inform others. In this thesis, I take the early adaptation process and, with a social constructionist approach, apply the framework to the experiences of young people living with MLTCs, and pinpoint the role of stigma on identity reconstruction as a key influence on the early adaptation process. The application of EST to the findings has located the potential sources of young people's stigma experiences, and identified features that could be argued to moderate and mitigate stigma.

The data generated in this thesis (a) provides insight into gaps in our understanding of the prevalence of multimorbidity (i.e. the nature and number of morbidities and comorbidities) in children and young people, (b) evidences an adaptation of biographical mapping that can be conducted remotely over the telephone to generate rich data, (c) develops the early adaptation process to understand young people's adaptation to living with some health conditions, and (d) contextualises the supportive behaviour of others, and the opportunities this offers for interventions. Each point will be detailed in the sections below.

9.1 Multimorbidity in young people

Little is known about multimorbidity in young people other than it has been estimated to comprise a small proportion of the multimorbid population. The data in this thesis suggests this measurement approach, and previously applied multimorbidity indices, may be obscuring the absolute numbers of young people living with multimorbidity.

From information provided by the four research sites (i.e. GP practice patient registers), I was able to calculate that in absolute terms just under 1:4 (24.3%) young people (aged 18-24 years) were living with two or more LTCs, and met the definition of living with multimorbidity. Whilst the sites represented just four GP practices in Brighton and Hove, the number of young people living with MLTCs was greater than had been anticipated when compared to the estimate of 20% of young people living with one LTC (Nuffield Trust and AYPH, 2019). This finding warrants further research to determine if the figure is representative of young people aged 18-24 years registered at all GP practices across Brighton and Hove.

Moreover, the number and types of morbidities and co-morbidities presenting in this sample raises important questions about the current recording and reporting of multimorbidity, not only in young people, but potentially across the multimorbid population as a whole, and of the health conditions that comprise multimorbidity indices. The young people in this thesis were living with a range of co-morbidities and morbidities ranging from two to seven LTCs. Many (n=12) were living with complex multimorbidity (four or more LTCs). A sizeable number of diagnoses (23/74) reported by participants were additional to those in the selection criteria list of the previously applied multimorbidity index adapted for this study. It is suggested in this thesis that the current reporting and recording of LTCs may be masking the extent of multimorbidity across the multimorbid population, and it is proposed that epidemiological models should a) calculate the absolute numbers of people of younger age bands living with multimorbidity, and b) devise a standardised multimorbidity index that is inclusive of the population as a whole.

Given the recent increase in urgent GP referrals to children and adolescent hospital services, and the dramatic increase in referrals (of 16-24-year-olds) to mental health services discussed in Chapter 2 (see Section 2.4.5., p.44), having a clear picture of multimorbidity in young people is timely. Understanding its extent and the nature and

number of comorbidities and morbidities is necessary to inform service planning so that the NHS is prepared to manage rising demand and its associated treatment and care costs.

9.2 An adaptation of biographical mapping

Conducted during the Covid-19 pandemic, data generation was designed to be carried out remotely to prevent the risk of Covid-19 transmission. Biographical mapping is usually undertaken in a face-to-face interview and at one point in time. To accommodate this data elicitation tool to remote usage, I created a two staged interview process, several days apart. The first telephone interview generated biographical details of young people's health and life journey to date which was transcribed by the researcher post interview into a health and life map/grid. The map/grid was sent (via email) to the participant before the second interview to check for accuracy. The second interview referenced the biographical map/grid which provided a structure for the second interview and served as an *aide memoire* for both participant and interviewer.

Separating the biographical mapping process from the in-depth interview over two points in time was an effective development of the data elicitation tool. It provided an opportunity during the first interview for participant and researcher to develop trust and a rapport, in preparation for the second interview when the biographical map was explored in greater detail. Conducting the interviews over two points in time potentially mitigated exacerbating the participants symptoms of ill health, such as tiredness, by spreading the emotional load of recounting their health journeys.

The data generated from the second interviews was rich in detail and brought out the diffuse influences on young people's experiences of living with LTCs which included the role of HCPs, teachers, family, peers, employers, partners, and organisational systems. As a data elicitation tool, it may be of use to researchers and clinicians working remotely with young people to capture historical events/experiences.

9.3 The early adaptation process and the stigma process

In applying the early adaptation framework to young people living with MLTCs, the themes that have been generated as shaping the early adaptation process have identified features relevant to children and young people and of their experiences of

living with the symptoms and diagnoses of health conditions that a) take time to diagnose, b) where symptoms are not visible or vague, or c) where a diagnosis is not recognised, understood, or carries negative associations. These features have been identified to shape and be shaped by young people's interactions with others. I suggest the experiences young people described of others' responses to their difference are examples of enacted stigma, whilst their responses to their difference are examples of felt, anticipated, and internalised stigma.

That stigma should play such a key role in the early adaptation process of young people is attributed to age and identity formation. Childhood is a time when identity is elastic and young people are sensitive to social experience. As a consequence, they may be more vulnerable to the effect of a diagnosis on their evolving identities. In a development of the Due-Christensen model, I suggest the disruption to some young people's lives begins with the onset of ill health symptoms when stigma experiences begin to shape their reconstruction of view of self (see Figure 14, p.219).

A diagnosis then becomes a point of further disruption to identities. How a diagnosis shapes identity reconstruction is attributed to young people's perceptions and whether or not it is welcome. A diagnosis that provides a more favourable label for young people's behaviour may be welcome; encouraging health seeking behaviour. A mental health and/or neurodevelopmental diagnosis that generates enacted stigma from peers may inform self-harming behaviour in some older adolescent females. A diagnosis that is considered socially taboo may inform internalised stigma responses and concealment behaviours. But access to online communities of other young people living with the same health conditions may act to moderate stigma, with the anonymity of communication providing some element of identity protection whilst they reconstructed new identities and learned (experientially) how to manage their symptoms.

This thesis has widened the scope of our understanding of who and what informs the adaptation process and supports young people to live well. It goes beyond the role of families, HCPs, and peers discussed in the literature review in Chapter 3 (p.49), and identifies the role of partners, teachers, employers, and organisational systems in moderating stigma, and facilitating an adaptation so young people can live well.

Moreover, it has identified that previous stigma experiences may shape young people's responses to future ill health symptom presentation and diagnoses.

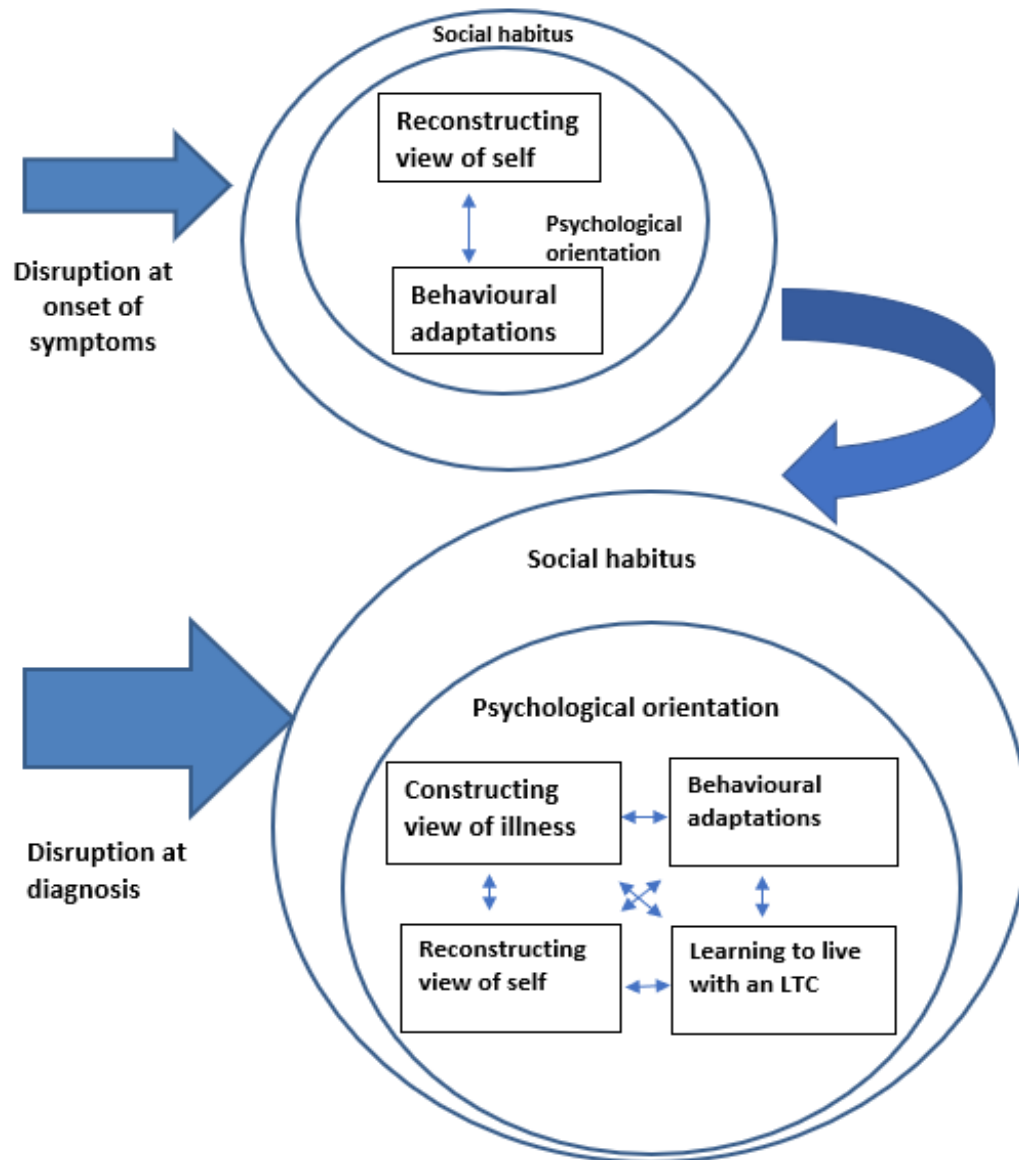


Figure 14. Development of the early adaptation process to illustrate disruption at symptom onset

Supportive behaviours of others such as making young people feel heard, providing emotional and practical support, accommodating needs, and explaining and contextualising diagnoses/medications/treatments in accessible language may have helped to validate their *sick* identities, and created a sense of belonging, built capacity, and enabled participation in education and employment. I suggest these

features may have underpinned a reconstruction of more favourable identities and in turn facilitated health seeking behaviours. In contrast, unsupportive behaviours that were dismissive of young people's symptoms did not accommodate their needs, and health and care systems where HCPs were unable to provide continuity, personalised, and timely care influenced the reconstruction of *discredited* identities; facilitating concealing self-care and social practices.

9.4 Contextualising the supportive behaviour of others and implications for interventions.

In the application of the early adaptation process and EST, this thesis contextualises why some features in interactions between young people, others, and organisational systems may support or undermine young people's adaptation to living with MLTCs.

Of significance in this thesis is the role of stigma on the reconstruction of identities in early adaptation as young people reconcile their previous identities (e.g. healthy and pre-symptom) with their new identities (e.g. *sick*, and presenting as different, and feeling different to others). I have suggested that the enacted stigmatising behaviours of others are expressions of outgroup derogation and othering for young people's non-conformance to expected or preferred roles. I propose these expressions accentuate young people's (i.e. the stigmatised) social and role identity differences to the ingroup and normative roles. However, features I contend may have moderated stigma are those that minimise the differences in their peer role and social identities and strengthen their similarities which include access to similar others, validation of the *sick* role, and easing the burden of illness.

The application of EST has identified the source of some young people's experiences of stigma in the microsystem and mesosystem as having their roots in the macrosystem. Interventions therefore need to be multileveled in approach. Longer term solutions include research to address the diagnostic delays arising from age and gender bias and to challenge the negative evaluations associated with some health conditions in young people, with the aim of informing care management guidance. Minimising and managing diagnostic delays and treatment in young people is consequently not just about preventing an exacerbation of the health condition(s) but about limiting opportunities for the stigma process to manifest in the microsystem and mesosystem. In the shorter term, the care management of young

people aimed at moderating stigma experiences should start with the onset of symptoms and be holistic in approach. Guidance to HCPs, schools, employers, and families should stress the importance of validating the *sick* role, promoting inclusivity, facilitating participation, and supporting with capacity building to strengthen peer role and social identity similarities.

On a final note, young people's experiences as reported in this thesis inform our understanding of *sickness* on their evolving identities. Both those experiencing ill health and those in close contact to them are sensitive and responsive to the difference in peer social and role identities that ill health engenders. The stigma process is a response by stigmatisers, bystanders, and the stigmatised to protect their respective identities. I suggest approaches by those who care and support young people that strengthen peer role and social identities will help to moderate young people's stigma experiences and the harmful behavioural responses it generates with the primary aim of empowering young people to live well.

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Appendices

Appendix A. Numbers of studies identified from search terms, sources, numbers of duplicates, and numbers excluded and included

Search terms	Sources	Retrieved	Duplicates	Assessed for eligibility	Excluded	Included
First query string	CINAHL	5	2	3	0	3
	Cochrane	1	0	1	0	1
	Scopus	204	3	14	13	1
	PubMed	35	3	12	5	7
Total		245	8	30	18	12
Second query string	CINAHL	411	5	13	5	8
	Cochrane	28	0	1	1	0
	Scopus	0	0	0	0	0
	PubMed	3	1	2	1	1
Total		442	6	16	7	9
"integrated care experiences of young people"	Google Scholar	1	N/A	1	0	1
"young people" AND "multimorbidity"	International Journal of Integrated Care	1	N/A	1	0	1
Totals		689	14	48	25	23

Appendix B. Data extraction table

No.	Author(s)	Paper title	YP's voices	Purpose	Sampling	Diagnoses	Geographic remit	Data collection & analysis	Findings	Limitations
1	Colver <i>et al.</i> , 2018,	How well do services for young people with long term conditions deliver features proposed to improve transition?	YES	Aimed to describe the extent to which service providers offer the nine beneficial features and to compare this with young people's reported experience of them	374 YP transitioning from paediatric to adult care. 304 took part in second interview	T1DM 128, cerebral palsy 85, autism with mental health conditions 91	UK	Longitudinal (2yrs), mixed methods. Questionnaires and interviews. Qualitative analysis	UK services provide only some of the nine proposed beneficial features for supporting healthcare transition of young people with long term conditions.	Some beneficial features were operationalised for service providers in a slightly different manner from the way in which they were discussed with young people.
2	Broad <i>et al.</i> , 2019	Youth experiences of transition from child mental health services to adult mental health services: A qualitative thematic synthesis	YES	This systematic review aims to provide a more comprehensive understanding of youth experiences of transition from CAMHS to AMHS.	18 studies representing 14 datasets and the experiences of 253 service-user. Youth experiences of moving from CAMHS and AMHS	Mental health condition	Inter-national	Followed ENTREQ guidelines for transparency. Applied CASP tool. Studies examining youth with chronic physical health conditions were excluded. Qualitative thematic analysis	YP experiences influenced by concurrent life transitions and their individual preferences regarding autonomy and independence. Youth identified preparation, flexible transition timing, individualised transition plans, and informational continuity as positive factors during transition. Youth also valued joint working and relational continuity between CAMHS and AMHS. Youth experience a dramatic culture shift between CAMHS and AMHS which can be mitigated by individualized and flexible approaches to transition.	All primary research included given equal weight but quality varied. Due to convenience sampling (recruiting through service providers), participants could have had more positive experiences. Didn't consider relationship between researcher and participant
3	Zhou <i>et al.</i> , 2016,	Transitioning adolescent and young adults with chronic disease and/or disabilities from	YES	To provide a comprehensive review of the research-based evidence	61 studies were included.	Chronic illness/co ndition in general (24),	USA, UK, Canada, Netherlands	An integrative review was conducted using a five-stage process: problem	In the last five years, there has been improvement in health outcomes of adolescent and young adults post-transition by applying a structured	The main weakness of the included studies in this integrative review was the lack of objective data resulting from

		paediatric to adult care services: An integrative review		related to the transitions of care process for adolescents and young adults with chronic illness/disabilities since 2010.		disabilities (9), and diabetes (5).		identification, literature search, data evaluation, data analysis, and presentation. Meta-analysis of statistics assessment and review instrument (MAStARI) and qualitative assessment review instrument (QARI), were used to assess the methodological quality of the studies	multidisciplinary transition programme, especially for patients with cystic fibrosis and diabetes. However, overall patients' outcomes after being transitioned to adult health care services, if recorded, have remained poor both physically and psychosocially.	compromises made to research design. More than half of the included studies (32/61) were nonexperimental self-report surveys. Only two out of 15 included qualitative studies specified the methodology and underlining philosophy being employed. Not all studies draw on young people's experiences
4	Wiley <i>et al.</i> , 2015	Multidisciplinary diabetes team care: The experiences of young adults with T1DM	YES	This research examined whether young adults with Type 1 diabetes engage with the multidisciplinary consultation process and if not, then why	18-35 yrs. 150 respondents	T1DM	Australia	Mixed methods. Quantitative involved web based self-reporting survey methods of self-management. Qualitative involved 33 focus group interviews. Quantitative analysis applied SPSS 20.0. Qualitative analysis applied thematic analysis.	Interviews identified 8 key disincents to service engagement. The identified needs and preferences included joint consultation with multi-disciplinary team clinicians, flexible access to advice by email or telephone consultation, and shared decision making. Patient engagement in health-service re-design has implications for improved health-service delivery and enhanced treatment outcomes.	Recruitment was through self-selection. Sample biased in favour of participants who were female, more highly educated, had health insurance and better glycaemic control than national average.
5	Ödling <i>et al.</i> , 2018	Lost in the transition from paediatric to adult healthcare? Experiences of young adults with severe asthma	YES	This study aimed to explore how young adults with severe asthma experienced the	Young adults with severe asthma were recruited from an ongoing Swedish population-based cohort n=16 mean age 23.4yrs	Asthma	Sweden	Qualitative semi structured interviews. Systematic text condensation analysis.	Four categories emerged based on the young adults' experiences: "I have to take responsibility", "A need of being involved", "Feeling left out of the system", and "Lack of engagement". Further, they wanted healthcare providers to	One circumstance that could have affected the results in a negative way is that some of the young adults (as is common in that age period) moved from their hometown to studies in another city,

				transition process.					involve them in self-management. In general, they felt that their asthma received insufficient support from healthcare providers.	and therefore experienced a lack of continuity and regularity in healthcare.
6	Sligo <i>et al.</i> , 2019	The experiences of young people with chronic illness in New Zealand: A qualitative study	YES	This study explored the experiences of young people with two very different chronic conditions (asthma and cancer) and their perception of the New Zealand health system's response to their needs.	17-26 years. 21 (16 female & 5 male) purposeful sampling ethnic minorities (80% Māori and 20% range of ethnic minorities	Asthma (10), cancer (11)	New Zealand	Collaborative research process. Open ended semi structured interviews. Thematic analysis	Chronic illness disrupted the trajectory of young people's lives and had significant effects on their relationships. The New Zealand health system generally did not respond well to the needs of these young people, but many encountered individuals who supported them effectively. The experiences of some indigenous participants indicate that health professionals require effective cultural competence training.	The collaborative nature of the methodology did impact on the style and quantity of data from some of the asthma aspects of the project
7	Medforth and Huntingdon 2018	Still lost in transition?	YES	This article explores findings from six case studies of young people who have recently experienced transition to adult health and care services, triangulating inter-related perspectives, those of young people, parents and carers and where possible	Purposive sampling of YP who have transitioned in previous 6 months to 3 years	LTC, mental health condition or disability	Clinical Strategic Network NW England	Case study (semi structured interviews). Thematic analysis	Analysis of emerging themes across the case studies leads to key messages from families to inform strategic development of services and practice.	Not discussed but 6 very small sample but it's the triangulation of experiences that's interesting: e.g. parents and HCPs not recognising YP's anxiety

				the professionals						
8	Renedo <i>et al.</i> , 2020	Understanding the health-care experiences of people with sickle cell disorder transitioning from paediatric to adult services: This sickle cell life, a longitudinal qualitative study	YES	Understand health-care transitions of young people with sickle cell disorder and how these interact with broader transitions to adulthood to improve services and support.	YP aged 13-21 yrs. 48 participants (30 female & 18 male)	Sickle cell disease	2 English cities	Longitudinal study. 80 qualitative interviews 27 one off and 53 repeat. Interviewed 10 sickle cell disease specialists. Analysis inductive and co-produced.	Participants said that they lack trust in staff's ability to treat them correctly and that they try to avoid hospital. Engaging in social silencing (i.e. reluctance to talk about and disclose their condition for fear that others will not listen or will not understand) outside hospital. For instance they would avoid mentioning cell sickle disorder to explain fatigue. Self-management tactics include internalising their illness experiences, for instance by concealing pain to protect others from worrying.	Findings restricted to YP in England and not representative of all YP living with SCD
9	Sonneveld <i>et al.</i> , 2013	Gaps in transitional care: what are the perceptions of adolescents, parents and providers?	YES	The main aim of this paper was to explore differences and similarities in perspectives between adolescents with chronic conditions, their parents and providers on transitional care. A secondary aim was to explore the extent to which such perspectives are disease specific.	127 YP (12-25 years no history of mental health conditions), 166 parents and 19 providers	JRA, NMD, T1DM	Netherlands	Quantitative using Mind the Gap instrument. Part of larger evaluation study on quality improvement.	Adolescents rate current care significantly worse than parents on: i) opportunities to make their own decisions ii) be seen without parents present, and iii) social skills. Adolescents are more satisfied than their parents about transitional care aspects such as co-ordination and communication between providers. Both groups indicated that the care process offers room for improvement. There was only a small difference in perceptions (not quantified) between disease specialisms.	Group of NMD smaller than other groups. Adolescents were all pre-transfer and still receiving paediatric care

10	Bundock <i>et al.</i> , 2011	Crossing the divide: Transition care services for young people with HIV-their views	YES	Compared reported satisfaction surveys of health care experiences and preferences of young people with PaHIV attending a UK transition outpatient service with young people attending a young persons' diabetes transition service in Australia.	21 UK k, 39 Australian, mean age 19yrs. UK 67% black African, Australia 74% white	PaHIV diabetes	UK and Australia	Quantitative.	Being treated as an individual, being encouraged to be independent and detailed management explanations were cited as strongly important factors by 3/4 participants with PaHIV. Careful transition can be a positive event for this patient group comparable to that of well-established diabetes services	Australian questionnaire was shorter. Preferences questions omitted
11	Datye <i>et al.</i> , 2019	Experiences of adolescents and emerging adults living with type 1 diabetes	YES	To identify barriers to adherence in T1DM management and to use this information to determine how diabetes educators can have a positive impact on their patients' diabetes management.	N= 11 (17-21yrs)	T1DM	Nashville USA	Focus groups x2 . YP treated in same medical centre. Inductive and deductive thematic analysis. Data coding and analysis was conducted by following the COREQ guidelines.	Biological, psychological, and environmental situational influences emerged that influence self-care behaviours. In addition, facilitators of selfcare behaviours, including the health system and diabetes education were identified. Together the interaction between situational influences, facilitators, and self-care behaviours influenced adherence to diabetes treatment	Small numbers and all treated at same medical centre therefore experiences likely to be similar
12	Starkman <i>et al.</i> , 2019	Listening to adolescents with uncontrolled diabetes, their	YES	Few studies have reviewed concurrent perspectives and experiences	9 adolescents (3-18 yrs. {7 females and 2 males} with T1DM > 1 year and A1C > 9.0%),	T1DM	New Jersey, USA	Semi structured interviews with parents and separate interviews	Adolescents tended to rebel and became more nonadherent to diabetes-related tasks. Parents became angry, nagged, threatened, and often blamed	Limited by the cross-sectional nature of its design as well as by the selection of interview subjects from a single

		parents and medical team.		of parents, HCP, and adolescents when their T1DM is uncontrolled. Applied a qualitative interview approach to explore these feelings and interactions.	their parents and 10 HCPs			with HCPs. Thematic analysis	and shamed their teen. Health care providers became less patient-focused, distancing themselves from patients and their parents. This resulted in misunderstandings, conflict, and often disengagement from diabetes management	regional diabetes centre. Mainly white, female adolescents participating may have concealed sex and cultural differences related to the uncontrolled diabetes experience
13	Gibson-Scipio and Krouse 2018	Barriers to self-management in African American adolescents with asthma	YES	To review the literature on barriers to asthma self-management among African American adolescents	23 papers met criteria. YP (12-19 yrs.)	Asthma	USA,	The search was limited to U.S. studies published between 2005 and 2017. Thematic analysis	Five common themes were found that related to barriers in disease self-management for African American adolescents: (a) knowledge and skills, (b) beliefs and attitudes, (c) personal/emotional factors, (d) caregivers, and (e) schools. Researchers should seek to develop interventions to address the unique contextual and culturally based needs of African American adolescents that support the development of effective asthma self-management behaviours.	Study methods, sample size, and noted limitations were categorized but were not considered as a basis for exclusion.
14	Anderson and Tulloch-Reid 2019	"You cannot cure it, just control it": Jamaican adolescents living with diabetes	YES	This study investigates the experiences of Jamaican adolescents living with diabetes to determine how their needs can be addressed.	19 adolescents average age 14yrs. All non-compliant in diabetes management. Majority girls (14/19)	Diabetes of which T1DM 1 (15/19)	Jamaica	4 focus groups (2 urban {10}, and 2 rural {9}). Narratives and pictures/drawings of experiences. Also 4 focus groups with care givers. Thematic analysis & drawings were analysed using a variation of	Control was the central theme; children felt controlled by diabetes and the people in their lives. Diabetes restricted their activities and imposed a sense of difference. Support from those around them could be both helpful and constricting.	Small numbers, mainly female therefore mainly a gendered experience recounted

								Lauritsen and Mathiasen's (2003) method.		
15	Monaghan and Gabe 2019	Managing Stigma: Young People, Asthma, and the Politics of Chronic Illness	YES	To explore the relationship between asthma and stigma.	31 YP (5-17yrs). 15 boys and 16 girls. From traveller communities (n=14). From middle-class communities (n=17).	Mild to moderate asthma	Ireland	Interviews and abductive approach to analysis	Asthma as a discreditable stigma, negative social reactions (real, imagined, and anticipated) and stigma management. Reflects upon macro-social structures (e.g. ethnicity, class, gender) which underlie stigma and the management of a potentially spoiled identity. This raises issues about the politics of chronic illness, embodying health identities and efforts to tackle stigma in neoliberal times.	Selected traveller community because of poor health more likely to have an asthma diagnosis. But intersectionality of ethnicity could be informing the more marked stigma stories.
16	Haw <i>et al.</i> , 2018	Epistemic tensions between people living with asthma and healthcare professionals in clinical encounters	YES	To examine epistemic tensions in negative clinical encounters from a patient perspective, with an aim to better understand how patients respond to these tensions	Purposive and snowball sampling. N=17 with lived experiences of asthma or who having a child with asthma. Experience of negative clinical encounters	asthma	Canada - South Ontario	As part of a larger qualitative study (n=70) examining the lived experiences of people who have asthma or a child with asthma. Semi-structured interviews Thematic analysis	The context and people's history of living with asthma informs a patient's confidence in claiming epistemic access and asserting epistemic rights when epistemic tensions arise Epistemic tensions can make visible the power relations in the patient-clinician relationship. May lead to the exertion of medical authority, or the taking up of patient's lay knowledge.	Only 2 participants 18-21yrs (11.7%) and 8 parents (doesn't say age of child). Clinicians weren't interviewed so their accounts of these encounters may differ.
17	Cramm <i>et al.</i> , 2013	The longitudinal relationship between satisfaction with transitional care and social and emotional quality of life among chronically ill adolescents	YES	To identify the aspects of the transitional care process that informed a satisfactory experience for adolescents living with	12-25 years. YP 138 (31%) filled first questionnaire and 188 (43%) filled it 1 yr. later	Chronic ill health: T1DM, JRA, and NMD	Netherlands	Longitudinal study. Part of larger evaluation study on quality improvement (On your own feet) Structured survey. Quality of life assessed using	Satisfactory experiences are informed by having a staff member for co-ordinating adolescent care, staff to provide information and support and to signpost to other services, help with planning for the future, and opportunities to meet other	Imbalance in study sample - more female (58.9%) more YP living with diabetes (53%) and danger of non-response bias. Relationships over time only (not predictive)

				chronic ill health				DISABKIDS. Mind the Gap tool applied for assessing satisfaction with transitional care. Statistically analysed structured survey data. Multiple regression saw relationships between satisfaction and quality of life after accounting for other variables such as age	young people with the same condition. The young people also highlighted the importance of the interpersonal skills of the new team such as knowing how to talk and listen to young people	
18	Travlos <i>et al.</i> , 2016	A fine balance and a shared learning journey: Exploring healthcare engagement through the experiences of youth with neuromuscular disorders	YES	To explore youths' perceptions of health, health behaviours and healthcare engagement.	N=11 (14-21 yrs.) wheelchair users recruited from a concurrent, population-based study (MyLifeMyVoice) for variability of age, gender, type of NMD, severity of co-morbidities and ratings of motivation and engagement .	NMD	Australia	Qualitative study. Semi structured interviews. IPA (interpretive phenomenological analysis)	Healthcare engagement is a dynamic, multifactorial process enabled through shared knowledge, expectations, intrinsic motivation and adequate support	The opt-in sampling strategy of the MyLifeMyVoice study likely limited the response to youth who felt confident and empowered to participate in research. The inclusion of youth experiencing different NMD disease trajectories limits generalisability to individual diagnostic groups
19	Lewis, Noyes and Makereth 2013	Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review	YES	To identify what is known to be effective in delivering information to young people aged 13-19 years with	Total 19 studies (5 intervention and 15 knowledge and understanding {4 quantitative and 10 qualitative})	Epilepsy	Inter-national	Evidence for Policy and Practice Information Coordinating Centre systematic mixed-method approach was adapted to identify, assess, extract and	Healthcare professionals in adult services report that young people with epilepsy enter adulthood ill-equipped and lacking in knowledge or self-care expertise, and sometimes find it difficult to live independently of their parents. Young people are	This review focused on the information needs and knowledge exchange of young people with epilepsy at transition as this was a period that required most modifications to epilepsy management.

				epilepsy and their parents.				evidence. Applied Ley's cognitive hypothetical model of communication	critical of healthcare professional practice, but there are few effective interventions that healthcare professionals can draw on	
20	Johnson <i>et al.</i> , 2020	Understanding young people and their care providers' perceptions and experiences of integrated care within a tertiary paediatric hospital setting using interpretive phenomenological analysis	YES	This paper describes the experiences of integrated care in a paediatric tertiary hospital.	N=19 (6 children, 7 parents, 6 HCPs). Recruitment via Connected Care Program (CCP). Eligibility for CCP are children and young people aged <16 years for new patients, or <18 years for continuing patients until discharged from paediatric care. Criteria is based on chronicity, complexity, fragility, and intensity of care needs.	Long-term condition requiring intense care	Australia	Semi-structured interviews were conducted. IPA approach and interpretive thematic analysis	Two recurrent themes were applicable across the three cohorts: agency and empowerment and impact of organisational systems, supports and structures. Stakeholders' experiences of integrated care highlighted the need to examine the discrepancies between healthcare strategies, policies and service delivery within a complex, and often inflexible organisational structure. Power imbalance and family agency (including directly with children and young people) needs to be addressed to support the implementation of integrated care.	Parents were present during the interview with their child, and this may have influenced how the participants responded to the questions. A limitation of the study is that the findings may not be generalisable beyond the tertiary environment studied.
21	Ådnanes and Steihaug 2016	"You never know what happens next" - Young adult service users' experience with mental health care and treatment through one year	YES	The aim was to capture their experiences and views about treatment and care, focusing on (dis)continuities and episodes occurring through that year	N=9 (18-30 yrs.) Females (8) and males (1)	Mental health and complex needs	Norway	4 interviews over a year. Total 32. Semi structured interviews focused on the patients' experience of present treatment and care and on interruption of care. Four-step analysis method of systematic text condensation (type	The participants' experience fragmented care and lack of user involvement in important decisions. The users' experiences were affected by shifts and transitions between institutions, units and practitioners while their need was for predictability and stability. Some felt rejected when they tried to tell the therapist about their trauma. They reported a lack of user-involvement and they desired	The sample were experiencing life changes and to some extent chaos in their lives. The authors note that the desire for change and development may be stronger in this sample than for older service users. Study is not able to consider men's experiences.

								of thematic analysis).	to become more engaged and included in important decisions concerning treatment and medication.	
22	Gray <i>et al.</i> , 2015	Concerns, barriers, and recommendations to improve transition from paediatric to adult IBD care: Perspectives of patients, parents, and health professionals	Yes	To identify concerns and needs surrounding transition to adult care.	15 young people, 16 parents and 15 providers	IBD	Cincinnati USA	YP with IBD (40% transferred to adult care) parents, and health providers (53.8% adult providers) participated in 1 of 6 focus group structured interviews on concerns and needs surrounding transition to adult care. Data were analysed through directed content analysis.	Transition needs/concerns focused on: (1) losing relationships with paediatric providers, (2) perceptions of poorer quality care from adult providers, (3) high parent involvement preventing the development of youth self-management skills, and (4) finances and insurance.	Recruiting participants who have already left the care facility may have resulted in lower recruitment numbers. There may have been selection bias but the authors note that participants were demographically representative of the health facility's IBD population as well as those reported in other paediatric IBD research.
23	Coyne <i>et al.</i> , 2017	Improving transition to adult healthcare for young people with cystic fibrosis: A systematic review	YES	This paper provides a systematic review of the empirical literature on the outcomes and experiences of transition for young people with CF	Papers published between 2011 - 2015. All study designs were eligible for inclusion and papers were not excluded due to quality assessment.	CF	International	22 articles synthesised. 7 studies examined the impact of transition and 18 explored transition experiences from the perspective of young people, parents or healthcare professionals. Outcomes data were subject to a narrative synthesis and a thematic synthesis of experiences data.	Four themes emerged from the synthesis: (1) concerns about transition, (2) transition readiness, (3) psychosocial needs and (4) variations in care. Young people's concerns included leaving behind previous caregivers, differences in care provision and infection risks.	Review includes papers assigned with weak quality score

Appendix C. Advisory group's terms of reference

Living well with multiple long-term conditions.

Young People's Consultation Group (YPCG)

Terms of Reference

Purpose

The YPCG has been set up to help develop the research methods of the research project named, "Living well with multiple long-term conditions: Interrogating young people's experiences of integrated care services". A long-term condition cannot currently be cured but is controlled by medication and/or other treatments/therapies (Department of Health, 2012). Long-term conditions refer to more than one physical condition or a combination of physical and mental health conditions.

The research project aims to explore how young adults' experiences of their care teams, family and social networks, including social media platforms, at various milestones along their health care journey, can help to develop their confidence to manage their conditions.

It has been set up by the researcher, Tracy Whittle. The aim of the group is to work with her to develop research methods that are meaningful to young adults living with long term conditions in order to maximise their participation and gather full accounts of their experiences.

The YPCG's role will help to meet these aims through their involvement and guidance on:

How best to recruit young people living with multiple long-term conditions to the research project. For example, by making suggestions on where to recruit and what methods to use.

How to maintain the interest and involvement of participants over the course of the research. For example, by contributing messages to a social media platform specifically set up for the research project

How best to gather the participants' experiences? For example, by involvement in a pre-data gathering activity to test out the methods.

How best to promote the research findings to young people living with multiple long-term conditions.

Membership

The YPCG will be made up of 4-6 young people aged between 18-24 years who are living with one or more long-term conditions.

Members will be recruited through condition specific support networks and the contacts of the researcher and supervision team.

Membership is voluntary and members will not be able to be research participants.

Membership will continue over the course of the project ending with the project in September 2022.

Way of working

We will work in a relaxed and informal way. We can meet as a group or one-to-one. Due to Covid-19, we will need to maintain social distance and so contact will be conducted remotely at an agreed place and time, over the phone/Skype/Zoom.

Contact with the researcher during the first phase (6 months) of the project, when developing the research methods, will be more frequent, such as every two weeks. The frequency of contact can be reduced once the research is underway.

The researcher will circulate a couple of days before contact an outline of what is to be discussed and any materials, she would like feedback on. She will write up and circulate to members, notes and actions from the meetings.

Payment

There is no payment for members' time but there are funds to reimburse members' travel costs. A voucher for the value of £25 will be given at the end of the project as a thank you for the member's time and support

Responsibilities and maintaining privacy

All members will feed back ideas and comments to the researcher who will collate and act on this information to develop the research.

The valuable role of members in developing the research methods will be acknowledged in the research publication. Individual names will only be disclosed with the permission of the member concerned.

The researcher will provide opportunities for members to attend training events to develop their skills relevant to their role.

The researcher will provide opportunities for members to attend events and conferences to promote their role and to meet/hear from others working on research and/or developing services in the area of young adults living with long term conditions and integrated care services.

All members are asked not to share the project's documents outside of the group or to disclose members' names and contact details, and who said what, to others outside the group.

All incidents or concerns experienced by members during their time in the YPCG should, in the first instance, be reported to the researcher (T.Whittle2@brighton.ac.uk Mobile: 07533 867972)

Members can also approach the research supervisors, Professor Nigel Sherriff, (N.S.Sherriff@brighton.ac.uk) Professor Jorg Huber (J.Huber@brighton.ac.uk Telephone: 01273 64 4078) or Dr Anna Zoli (A.Zoli@brighton.ac.uk)

Review

The terms of reference will be reviewed as and when a need arises.

Final version 1. Date reviewed 3rd June 2020

Appendix D. Advisory group role descriptor

Member's Role Description

Background

The YPCG has been formed to advise on the research methods of the project named, "Living well with multiple long-term conditions: Interrogating young people's experiences of integrated care".

It is a group of 4-6 young adults (aged 18-24 years) who have lived experiences of long-term conditions. A long-term condition cannot currently be cured but is controlled by medication and/or other treatments/therapies (Department of Health, 2012). Long-term conditions refer to more than one physical condition or a combination of physical and mental health conditions.

The group will be responsible for working with the researcher to develop research methods that are meaningful to young adults living with long-term conditions, in order to maximise their participation and gather full accounts of their experiences.

Your responsibilities

To meet with the researcher as required (possibly every 2 weeks in the first year of the project), in a group or one-to-one. Due to Covid-19, we will need to maintain social distance and so contact will be conducted remotely at an agreed place and time, either over the phone/Skype/Zoom. The meetings should last between 30 – 60 minutes.

Members will be asked to feedback their views and comments on any materials or ideas presented by the researcher and to contribute their own thoughts and ideas as they arise.

Topics for discussion/consultation and any documents requiring feedback will be circulated (electronically via email or text) a few days before the meeting. Members are asked to look through any documents in advance of the meeting.

Members will be invited to take part in remote activities to test out the identified data gathering method. This activity will involve members reflecting on their own health care journey. Each activity should last about an hour.

All members are asked to maintain the confidentiality of other group members, i.e. not disclosing to others the names and contact details of the members and who said what in meetings. Members are also asked not to share the project's documents outside of the group.

Researcher responsibilities

To create a safe and comfortable setting for members to contribute to the research design.

To provide socially distanced opportunities for members to attend training events to develop their skills relevant to their role.

To provide socially distanced opportunities for members to attend events and conferences to promote their role and to meet/hear from others working on research and/or developing services in the area of young adults living with long-term conditions and integrated care services.

To involve members in the dissemination of the research findings

To acknowledge the member's role in the research publication. Individual names will not be disclosed without the express permission of the individual member.

Duration of role

For the lifetime of the project which will come to an end in September 2022.

Payment and expenses

Payment will not be given for member's time but reasonable travel costs to attend any group meetings or to carry out activities related to the work of the group will be reimbursed. The researcher will provide a claim form. A voucher for the value of £25 will be given at the end of the project as a thank you for the member's time and support

Person specification

Essential:

To be living with at least one long term medical condition and with experience of health care services.

To be able to reflect on and critically assess own health care journey.

To be confident to voice own opinion in a one-to-one and small group settings.

To be reliable, trustworthy and responsive

Desirable:

To have had experience or knowledge of a condition specific support network(s)/group(s)

Contact details

Tracy Whittle, PhD Researcher, School of Applied Social Science, University of Brighton, Watson Building, Falmer, Brighton BN1 9RH

Email: T.Whittle2@brighton.ac.uk Mobile: 07533 867972

Final version 1: date reviewed 3rd June 2020

Appendix E. Example of a health and life grid

ID no.8

Age (years)	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22
Year	2007	2008	2009	2010	2011		2013	2014	2015	2016	2017	2018	2019	2020	2021
Health and wellbeing	Started to experience symptoms of breathlessness. Managed by family GP. Saw a number of different doctors but condition became worse. Had a number of emergency hospital admissions including admission to resus and ICU				Referred to Royal Brompton hospital for further investigations. Diagnosed with asthma and spasmodic croup. Remained under the care of children's service until 16/17 years and transitioned to adult services				Under the care of adult services (seen at a couple of clinics) and then discharged to care of GP			Moved to Brighton. Registered with GP practice		Seen by asthma nurse at practice. Hadn't been seen for a couple of years. Registered with new GP Dec 2020	
								Aware periods painful and irregular	Consulted GP	Referred for ultrasound-diagnosed PCOS and commenced treatment	Awareness of low mood			Ran out of treatment supply	
													Starting to lose weight, feeling nauseous and full. Endoscopy clear but colonoscopy		
Significant events														Covid pandemic	
Parents															
Residence												Moved to Brighton		Spent time between family home and residence in Brighton	
Siblings															
Education												At university			
Friends															
Romantic relationships												Met boyfriend			
Work														Working part time	

Appendix F. Pilot data extracts

Overarching theme	Organisational theme	Basic theme
Listen to me! This is not normal	Seen but not heard	Adults (family members, teachers, school counsellors) and friends are dismissive of/play down the generic symptoms of ill health in childhood (1) Just because a young person says that they're ok still needs to be probed to identify the cause and to assess the effectiveness of medication (19)
	Validation of symptoms	The validation of symptoms by an adult (including paramedics) lead to young people either seeking a GP consultation or being accompanied by a parent to a GP consultation (5)
	I'm normal	Investigative tests are perceived by young people as validating their concerns (31) Having a mental health diagnosis is giving a scary monster a name and this makes the young person feel normal (35)
	Understanding the symptoms/condition and treatments	Explaining conditions and medicines helps people to make informed choices about their treatment (21) Seeking information about the condition, through websites, people they know, and on-line forums helps young people to understand the illness and how to manage it. BUT It is not helpful to hear accounts of others who are older or whose condition is not as severe as theirs (6). Mental health medication is a concern for some; the stigma associated with it and the belief that it is just covering up the problem. (38) Following a diagnosis, a young person is signposted to the NHS website to find out further information. This information is often basic and young people search the internet and on-line forums, Instagram accounts where they can find stories of other people's experiences (33) Recovering from mental ill health is important for young people. Reframing behaviours can help young people manage them. Anxiety is an overdrive of normal maternal protective instincts. Drinking problem is an anxiety problem. (39) Referral for further investigations can make people feel optimistic that something can be done. It is deflating when the tests come back normal (37) Therapies that explain behaviours can be helpful and provide young people with insight that helps them understand why they behave the way they do (23) Seeing a regular GP(s) can help to build trust and enable young people to talk about "embarrassing" symptoms (18). Validation of both symptoms and young people's experiences/ knowledge of their condition is important for building a trusting partnership between patient and doctor (20). Positive experiences with health and social care professionals can instil confidence to seek future advice (40) Just because a young person says that they're ok but are presenting with symptoms needs to be probed to identify the cause and to assess the effectiveness of medication

	Importance of a label	Understanding the condition and what is behind the symptoms helps them to identify strategies to manage it (the scary monster has a name) but in the absence of explanations that they understand, they feel they are being controlled by an external forces (there's a monster in my head) (11)
I'm normal abnormal. Managing Difference	Taboo	Young people feel shame, withdraw, self-harm, just get on with it, or act out in response to how the symptoms make them feel and how people around them respond to the symptoms (2).
		Symptoms that are perceived to carry a stigma (being anxious, going to the toilet a lot) make young people fear that they will be seen as weird. They worry about sharing their symptoms with friends in case they tell others (3)
		Unusual physical health conditions in young people can compound the sense of feeling different from their friends (15) Young people's mental health can decline slowly. They have an awareness that they are not right, but it takes external pressure from a partner or teachers to provide the impetus for them to seek help (34)
		Symptoms that are perceived to carry a stigma (being anxious, going to the toilet a lot) make young people fear that they will be seen as weird. They worry about sharing their symptoms with friends in case they tell others (3) Socially taboo symptoms can lead to adapting a routine that is socially isolating (14)
	Irritation	For a common physical health condition, the GP can prescribe medication and provide annual health checks to help the young person manage the condition (8).
	Illness as adversary	Where a label is present, but the mental health condition is not being managed, it can feel like a monster in the head of the young person (36)
Living a normal life. Managing ill health	Unhelpful H&SC profs/services	Feeling pitied, passed around from service to service leads to loss of confidence in and exasperation with the service (25) Therapies that raise painful issues but do not provide any resolution, or focussing on issues that are not a priority for the young person are unhelpful (24) The transition from child to adult mental health services can be scary (22)
	Being accepted	A supportive study environment where adaptations are made to accommodate the needs of the young person make them feel cared for (32) Seeking information about the condition, though websites, people they know, and on-line forums helps young people to understand the illness and how to manage it. BUT It is not helpful to hear accounts of others who are older or whose condition is not as severe as theirs (6) How far young people can manage their condition is influenced by the acceptance and support of the close adults around them,(not being able to rest at home, not feeling happy at home, supportive parents, supportive partner and family, siblings with the same condition) (7) E.g. not helpful: Parents/carers who dismiss or deride mental health conditions, makes it difficult for young people to talk about what's going on for them at home (17)
	Lifestyle adaptations	Young people find strategies to manage their lives living with a LTC which include being with people and in places where they feel happy, doing activities that make them feel good, eating sensibly, reducing the amount and type of activities they once did.(12)

		In preparation for ill health episodes, course work is kept on top of, cheat days are taken when there are no work commitments the next day.(13) Young people set themselves small bite size and long-term goals which help to motivate them and keep them going through difficult incidents/times.(10)
	Optimism	Hopeful that a cure will be found, and he will be able to eat normally again (43) Although still currently undergoing treatment or about to start treatment, the desire to get better and not keep doing this underpins an optimism for the future and for treatment (42)
	Sharing experiences	Having had experience of living with a mental health condition, some step into the informal role of expert patient, providing advice and support to their friends which makes them feel valued and develops their confidence as others listen to them (9)
The significance of the symptoms and diagnoses.	Persistent symptoms/change in symptoms	Persistent symptoms, or sudden exacerbation of, or development of new (scary) symptoms in young people prompt a medical consultation (4). Frequent abdominal discomfort (not associated with periods) thought to be dietary related and different remedies tried (29) Symptoms akin to painful periods are tolerated for a long period of time where they are thought of as normal, particularly when the participant doesn't know any better as it has never been explained. It was a taboo subject growing up (28) Sudden onset of physical symptoms results in concern from adults around and young people seek medical advice (26) Young people experience chronic pain for several months with advice to get on with it and be patient. They need to be persistent and forthright for GPs to refer for further investigation or to consider an alternative diagnosis. Sometimes a crisis admission to A&E can trigger a diagnosis (30)
	Mental health symptoms	Mental health decline is gradual and young people have an awareness of it and may take part in displacement activities (27)
	Inconclusive cause	Validation of both symptoms and young people's experiences/ knowledge of their condition is important for building a trusting partnership between patient and doctor (20). Referral for further investigations can make people feel optimistic that something can be done. It is deflating when the tests come back normal (37)

Appendix G. Demographic questionnaire

Demographic questionnaire

Information about you (obtained over the telephone)

I would like to ask some questions about you. I will use this information when I analyse the information everyone has given me about their experiences. If you prefer not to answer some or all of the questions, let me know.

- 1 How old are you? _____
- 2 What is your gender Male Female Intersex
- 3 Would you describe yourself as having a disability? Yes No
If yes, for how long have you had a disability (*an approximation*)?

- 3 How would you describe your ethnic group? (*please tick one box only*)

White

- British
Irish
Traveller of Irish heritage
Gypsy/Roma
Other (please specify)

Asian or Asian British

- Indian
Pakistani
Bangladeshi
Other (please specify)

Black or Black British

- Black Caribbean
Black African
Other (please specify)

Mixed/dual heritage

- White & Black Caribbean
White & Black African
White & Asian
Other (please specify)

Other Ethnic Group

- Unknown
Other Ethnic Group
If Other please state/explain _____

- 4 Do you have a religion that you follow or practice?
 Yes No
If yes, which religion? _____

- 5 How would you describe your sexual preference?
Lesbian Gay Bi-sexual Trans Heterosexual/straight
Unsure Other (please specify) _____

- 6 What is your current relationship status? (*please tick one box only*)
 Single
 Living with partner
 Civil partnership
 Married

Other (please describe) _____

7 What educational qualifications do you have? *(please tick all that apply)*

None

GCSE's / O levels

A levels / diploma / City & Guilds

Undergraduate degree

Postgraduate degree

Professional qualification (please specify) _____

8 Are you currently: *(please tick all those that apply)*

Employed?

Self-employed?

Out of work and looking for work? **OR** Out of work and not looking for work?

A homemaker?

A student?

Unable to work?

9 Where is your main place of living? *(please tick which one applies)*

At your family home

On your own

In shared accommodation

In supported housing

Other

If other, please state _____

10 What is the first part of the postcode where you live? *For example:BN1*

THANK YOU!

VERBAL CONSENT: TELEPHONE INTERVIEWS

To be recorded

(Note to researcher: All points on this consent form should be read out and individually agreed by the participant prior to each interview)

Can I just read you the following before I start and tell me for each statement whether you agree or disagree with it please?

I agree to participate in a telephone conversation to share my experiences of health and social care and my close relationships, and to talk about how these experiences supported me to make adaptations as I learned to live with long-term conditions.

The researcher has explained to my satisfaction the purpose of the study and how the information will be used.

I have read the participant information sheet/recording sent to me beforehand.

I agree to the discussion being digitally (audio only not video) recorded for the purposes of this research study.

I understand that everything I say will be treated in strict confidence and no comments identifying me or my household will be passed on to anyone other than members of the research team.

I understand that my details will not be shared with anybody outside the research team; however, I know that the researcher is obliged to inform another professional if I disclose that I, or someone I know, is at risk of harm or that criminal acts have been or will take place.

I understand that I can withdraw from the study at any time (without explanation), but my data cannot be withdrawn once it has been added to others to be analysed.

Date of verbal consent (first interview) _____

Date of consent (second interview) _____

Participant code _____

Appendix I. Example of a participation identification centre (PIC) agreement

MODEL NON-COMMERCIAL PARTICIPANT IDENTIFICATION CENTRE AGREEMENT

UNIVERSITY OF BRIGHTON, University of Brighton, Mithras House, Lewes Road, Brighton,
BN2 4AT

(referred to as “the Participating Site”)

AND

NAME AND ADDRESS OF MEDICAL PRACTICE

(referred to as “the PIC”)

Which are collectively referred to as the “Parties” or individually referred to as a “Party”

NOW

WHEREAS the Sponsor is a University

WHEREAS the Funder is a Government Funding Stream

WHEREAS the Participating Organisation wishes to sub-contract with the PIC to undertake Data Processing for the purpose of identifying potential Participants for the Study.

WHEREAS the Study is a QUALITATIVE STUDY.

In respect of the clinical research Study entitled LIVING WELL WITH MULTIPLE LONG-TERM CONDITIONS: INTERROGATING YOUNG PEOPLE'S EXPERIENCES OF CARE the above Parties HEREBY AGREE AS FOLLOWS:

1. DEFINITIONS

1.1. The following words and phrases have the following meanings:

Agent(s)	Includes, but shall not be limited to, any person undertaking a function in connection with this Agreement (including the Principal Investigator, any nurse or other health professional), any such person's principal employer in the event it is not the Participating Site or PIC and where such person is providing services to a Party under a contract for services or otherwise (including clinical academics), and/or any contracted third party providing services to a Party under a contract for services or otherwise.
Agreement	This agreement, together with the schedules annexed hereto.
Controller	Shall have the meaning set out in the Data Protection Legislation.
Data Protection Legislation	All applicable data protection and privacy legislation, regulations and guidance including but not limited to Regulation (EU) 2016/679 (the "General Data Protection Regulation" or "GDPR"), the Data Protection Act 2018, the Privacy and Electronic Communications (EC Directive) Regulations 2003 and any guidance or codes of practice issued by the European Data Protection Board or Information Commissioner from time to time (all as amended, updated or re-enacted from time to time).
Data Subject	As defined in the Data Protection Legislation.
Participant	Any person who consents (where consent is necessary) and is enrolled to take part in the Study. All references to Participants in this Agreement refer to those recruited by or through the Participating Site.
Participating Site	The contracting body for the Site/s.

Personal Data	Any and all information, data and material of any nature received or obtained by any Party in connection with this Agreement which is personal data as defined in Data Protection Legislation and which relates to any Participant or his or her treatment or medical history.
Participant Identification Centre (PIC)	The organisation named on page one of this Agreement, being an organisation sub-contracted by the Participating Site to Process Personal Data on behalf of the Sponsor to identify potential Participants for the Study.
Principal Investigator or PI	The leader responsible for a team of individuals conducting the Study at the Site.
Process	As defined in the Data Protection Legislation (and "Process" and "Processed" shall be construed accordingly);
Processor	Shall have the meaning as set out in the Data Protection Legislation;
Protocol	The full description of the Study with the reference number set out on the front page of this Agreement, together with any amendments thereof, and incorporated into this Agreement by reference.
Site	Any premises occupied by the Participating Site in which or through which the Study will be conducted.
Sponsor	The individual, company, institution, or organisation that is (or the institutions or organisations, where there is more than one sponsor under a co-sponsorship or joint-sponsorship arrangement, that are), that takes responsibility for the initiation, management, and financing (or arranging the financing) of the Study.
Study	The clinical research study that is the subject of this Agreement.
Sub-Processor	The PIC contracted by the Participating Organisation to Process Personal Data on behalf of the Sponsor (as per GDPR Article 28, 2).

2. GENERAL

- 2.1. As the mutual exchange of obligations and promises is regarded as consideration, this Agreement forms a legally binding contract.
- 2.2. Any reference to a statutory provision, code or guidance shall be deemed to include reference to any subsequent modification or re-enactment of it.
- 2.3. The PIC will Process Personal Data to identify potential Study Participants as follows:
 - 2.3.1. The PIC will undertake a database search for potential Participants meeting the following criteria
 - 2.3.1.1. There will be two parts to the selection of potential participants. The first part will identify and invite participants who meet the criteria of age 18-24 years, living with 2 or more long-term conditions (LTCs) provided by the Participating Site and have a moderate frailty score. If more participants are required after this round of recruitment, part two will extend selection to include those who meet the age and LTC criteria but who do not have a moderate frailty score.
 - 2.3.1.2. The INCLUSION criteria include age 18-24 years, moderate frailty score and living with two or more LTCs from the list of 26 conditions provided by the Participating Site. The list includes: Hypertension, Depression, Painful condition, Asthma (currently treated), Diabetes, Thyroid disorders, Rheumatoid arthritis, other inflammatory polyarthropathies &

systematic connective tissue disorders, Hearing loss, Anxiety & other neurotic, stress related & somatoform disorders, Irritable bowel syndrome, Inflammatory bowel disease, New diagnosis of cancer in last 5 years, Alcohol problems, Other psychoactive substance misuse, Chronic kidney disease, Diverticular disease of intestine, Epilepsy (currently treated), Schizophrenia (and related non-organic psychosis) or bipolar disorder, Psoriasis or eczema, Migraine, Blindness & low vision, Chronic sinusitis, Learning disability, Anorexia or bulimia, Viral Hepatitis, Cystic Fibrosis. The EXCLUSION criteria include potential participants who meet the above criteria but who do not speak/understand English and who lack capacity. Please note that part two of the recruitment will exclude participants who have a moderate frailty score.

- 2.3.1.3. The PIC will be provided with the following information to provide to potential participants: Content for a page for the PIC website and wording for texts to be sent to potential participants inviting them to contact the researcher.
- 2.3.2. Participants who meet the study criteria will be approached directly by PIC staff who will ask potential participants if they give their permission to be sent information about the study. Those potential participants who give their consent will be sent a text by PIC staff inviting them to take part in the study and a reminder text will be sent two weeks later.
- 2.3.3. The PIC will use its best endeavours to identify 15 potential participants AND during the recruitment period starting 11th October 2021 or after notification of site addition to the Health Research Authority and ending 31st December 2021
- 2.4. By entering into this Agreement the Parties agree that the conduct of the Study at the PIC is governed by and subject to the national laws and regulations of the PIC. However any other issue, including any issue as to the construction of this Agreement, shall be governed and construed in accordance with the laws governing the country of the United Kingdom in which the Sponsor is established, namely, the laws of England and shall be subject to the exclusive jurisdiction of the Courts of the Sponsor. Save, that where both Parties agree, having taken into consideration that it would be more reasonable and expeditious both as to time and costs, in such instance to do so, for the agreed issue pertaining to this Agreement, to be subject to the jurisdiction of the defendant.

3. CONFIDENTIALITY AND DATA PROTECTION

Confidentiality The Parties agree to comply with all applicable statutory requirements and mandatory codes of practice in respect of confidentiality (including medical confidentiality) in relation to Participants.

- 3.2. The PIC agrees to treat the Confidential Information in this Agreement (including the Protocol) and the Results, excluding any Clinical Data of the Study, as Confidential Information of the Participating Site and the Participating Site agrees to treat Personal Data and confidential patient information as Confidential Information.

Data Processing Terms

- 3.3. For the purposes of the Data Protection Legislation, the Sponsor is the Controller, the Participating Site is the Sponsor's Processor and the PIC is the Sub-Processor of the Participating Site in relation to all Processing of Personal Data that is Processed for the purpose of this Study and for any future research use under the Controllorship of the Sponsor, that would not have taken place but for this Agreement regardless of where that Processing takes place.
- 3.4. The Parties acknowledge that whereas the Sponsor is the Controller in accordance with Clause 3.2, the PIC is the Controller of the Personal Data collected for the purpose of providing clinical care to the Participants. This Personal Data may be the same Personal Data, collected transparently and processed for research and for care purposes under the separate Controllorships of the Sponsor and PIC.

- 3.5. Where the PIC is the Participating Site's Sub-Processor and thus where the Processing is undertaken by the PIC for the purposes of the Study, Clauses 3.5 to 3.9 below will apply. For the avoidance of doubt, such Clauses do not apply where the PIC is Processing the Participant Personal Data as a Controller.
- 3.6. The PIC agrees only to Process Personal Data for and on behalf of the Participating Site in accordance with the instructions of the Participating Site or Sponsor and for the purpose of the Study and to ensure the Sponsor's and Participating Site's compliance with the Data Protection Legislation;
- 3.7. The PIC agrees to comply with the obligations applicable to Processors described by Article 28 GDPR including, but not limited to, the following:
 - 3.7.1. to implement and maintain appropriate technical and organisational security measures sufficient to comply at least with the obligations imposed on the Controller by Article 28(1);
 - 3.7.2. to not engage another Processor without the prior written authorisation of the Sponsor (Article 28(2));
 - 3.7.3. to Process the Personal Data only on documented instructions from the Participating Site or Sponsor unless required to do otherwise by legislation, in which case the PIC shall notify the Participating Site before Processing, or as soon as possible after Processing if legislation requires that the Processing occurs immediately, unless legislation prohibits such notification on important grounds of public interest (Article 28(3a));
 - 3.7.4. to ensure that personnel authorised to Process Personal Data are under confidentiality obligations (Article 28(3b));
 - 3.7.5. to take all measures required by Article 32 GDPR in relation to the security of processing (Article 28(3c));
 - 3.7.6. to respect the conditions described in Article 28(2) and (4) for engaging another Processor (Article 28(3d));
 - 3.7.7. to, taking into account the nature of the Processing, assist the Participating Site and/or the Sponsor, by appropriate technical and organisational measures, insofar as this is possible, to respond to requests for exercising Data Subjects' rights (Article 28(3e));
 - 3.7.8. to assist the Controller, to ensure compliance with the obligations pursuant to Articles 32 to 36 GDPR taking into account the nature of the Processing and the information available to the PIC (Article 28(3f));
 - 3.7.9. to, at the choice of the Sponsor, destroy or return all Personal Data to the Sponsor at the expiry or early termination of the Agreement, unless storage is legally required (Article 28(3g)) or where that Personal Data is held by the PIC as Controller for the purpose of clinical care or other legal purposes; and
 - 3.7.10. to maintain a record of Processing activities as required by Article 30(2) GDPR.
- 3.8. The PIC shall ensure that:
 - 3.8.1. its Agents do not Process Personal Data except in accordance with this Agreement (and in particular the Protocol);
 - 3.8.2. it takes all reasonable steps to ensure the reliability and integrity of any of its Agents who have access to the Personal Data and ensure they:
 - 3.8.2.1. are aware and comply with the PIC's duties under this clause;
 - 3.8.2.2. are subject to mandatory training in their information governance responsibilities and have appropriate contracts including sanctions, including for breach of confidence or misuse of data; and
 - 3.8.2.3. are informed of the confidential nature of the Personal Data and understand the responsibilities for information governance, including their obligation to Process Personal Data securely and to only disseminate or disclose for lawful and appropriate purposes.

- 3.9. The PIC agrees to:
- 3.9.1. allow the Participating Site and/or Sponsor(s) or another auditor appointed by the Participating Site and/or Sponsor(s) to audit the PIC's compliance with the obligations described by this Agreement, Data Protection Legislation in general and Article 28 GDPR in particular, on reasonable notice subject to the Participating Site/Sponsor complying with all relevant health and safety and security policies of the PIC and/or to provide the Participating Site or Sponsor with evidence of its compliance with the obligations set out in this Agreement; and
 - 3.9.2. obtain prior agreement of the Sponsor to store or Process Personal Data outside the European Economic Area.
- 3.10. Where the PIC stores or otherwise Processes Personal Data outside of the European Economic Area as the Sponsor's Processor, it warrants that it does so in compliance with the Data Protection Legislation.

Data Sharing Terms

- 3.11. Personal Data shall not be disclosed to the Participating Site or Sponsor by the PIC, save where this is required directly or indirectly to satisfy the requirements of the Protocol, or in relation to a claim or proceeding brought by a Participant in connection with the Study.
- 3.12. The Participating Site agrees to use Personal Data solely in connection with the operation of the Agreement, or otherwise for purposes not incompatible with this original purpose (Article 5, 1 (b) GDPR), and not otherwise. In particular,
- 3.12.1. Not to disclose Personal Data to any person except in accordance with applicable legal requirements and codes of practice.
- 3.13. The Participating Site represents that the Sponsor has agreed to comply with the obligations placed on a Controller by the Data Protection Legislation. This is not limited to, but includes, being responsible for and able to demonstrate compliance with the principles relating to Processing of Personal Data (Article 5 GDPR)
- 3.14. The Participating Site agrees to ensure persons processing Personal Data under this Agreement are equipped to do so respectfully and safely. In particular:
- 3.14.1. To ensure any persons (excluding employees, honorary employees, students, researchers, consultants and subcontractors of the PIC) Processing Personal Data understand the responsibilities for information governance, including their obligation to Process Personal Data securely and to only disseminate or disclose for lawful and appropriate purposes.
 - 3.14.2. To ensure any persons (excluding employees, honorary employees, students, researchers, consultants and subcontractors of the PIC) have appropriate contracts providing for personal accountability and sanctions for breach of confidence or misuse of data including deliberate or avoidable data breaches.
- 3.15. The Participating Site agrees to proactively prevent data security breaches and to respond appropriately to incidents or near misses. In particular,
- 3.15.1. To ensure that Personal Data are only accessible to persons who need it for the purposes of the Study and to remove access as soon as reasonably possible once it is no longer needed.
 - 3.15.2. To ensure all access to Personal Data on IT systems processed for Study purposes can be attributed to individuals.
 - 3.15.3. To review processes to identify and improve processes which have caused breaches or near misses, or which force persons Processing Personal Data to use workarounds which compromise data security.
 - 3.15.4. To adopt measures to identify and resist cyber-attacks against services and to respond to relevant external security advice.

- 3.15.5. To take action immediately following a data breach or near miss.
- 3.16. The Participating Site agrees to ensure data are Processed using secure and up to date technology. In particular;
 - 3.16.1. To ensure no unsupported operating systems, software or internet browsers are used to support the processing of Personal Data for the purposes of the Study.
 - 3.16.2. To put in place a strategy for protecting relevant IT systems from cyber threats which is based on a proven cyber security framework such as Cyber Essentials.
 - 3.16.3. To ensure IT suppliers are held accountable via contracts for protecting Personal Data they Process and for meetings all relevant information governance requirements.

Intellectual Property Rights

- 3.17. All Background Intellectual Property Rights (including licences) and Know How and their improvements used in connection with the Study shall remain the property of the Party introducing the same and the exercise of such rights for purposes of the Study shall not knowingly infringe any third party’s rights.
- 3.18. All Intellectual Property Rights and Know How in the Protocol, and in the Study Data, excluding clinical procedures developed or used by the PIC independently of the Study, shall belong to the Sponsor. The PIC hereby assigns all such Intellectual Property Rights, and undertakes to disclose all such Know How, to the Participating Site.
- 3.19. At any time within the duration of the Study, the PIC shall at the request of the Participating Site or Sponsor and at the expense of the Sponsor execute all such documents and do all acts necessary to fully vest the Intellectual Property Rights in the Sponsor. To give effect to this clause 3.19, the PIC shall ensure that its Agents involved in the Study assign such Intellectual Property Rights and disclose such Know How to the Participating Site.

SIGN OFF*

Each Party represents that it has ‘redlined’ or otherwise called attention to all changes that it made and sent to the other Party in previously sent drafts of this Agreement, including but not limited to drafts of the schedule.

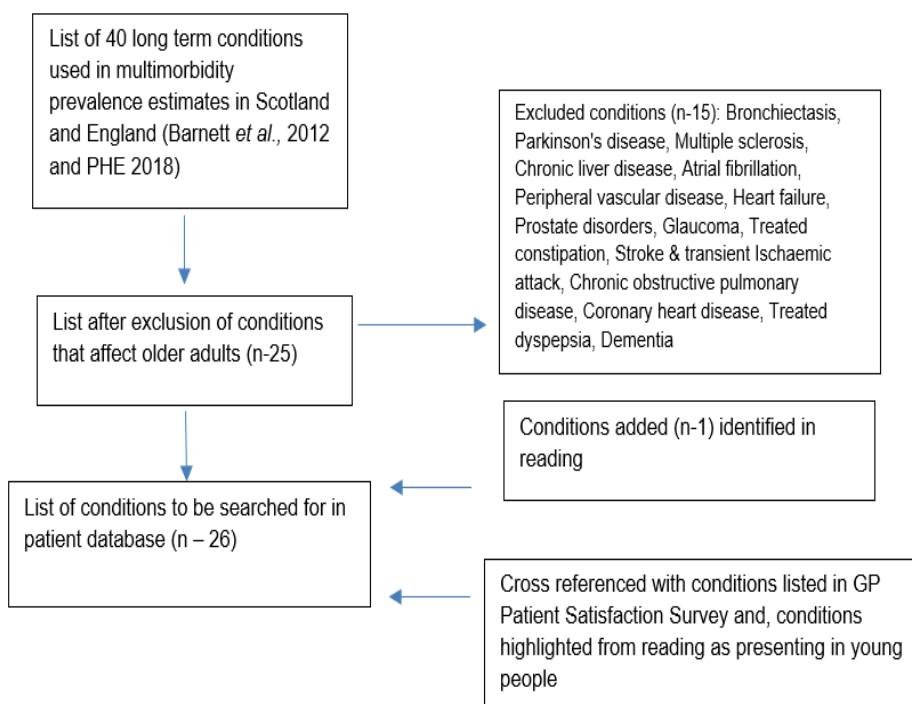
Signed by the duly authorised representatives of the Parties.

SIGNED ON BEHALF OF THE PARTICIPATING SITE [Name, Position, Signature, and Date]

SIGNED ON BEHALF OF PARTICIPANT IDENTIFICATION CENTRE {Name, Position, Signature, and Date]

[Appendix J. Long-term conditions included in the participant selection criteria](#)

Decision making process to determine the long-term conditions to include in search of patient database



Final list of long-term conditions

Condition	GP patient satisfaction survey	Supporting data	Comment SNOWMED and QoF codes where identified
Hypertension	√	Presents in young people with T1DM	QoF HYP001

		high blood pressure (hypertension) was found in 26.7% of young people aged 12 – 24 years living with T1DM in the 2017-2018 National Paediatric Diabetes Audit (Royal College of Paediatrics and Child Health, 2019, p7)	
Depression	√	Identified as one of top 5 LTCs amongst young people (20-34yrs) in Brighton and Hove 2017 (Brighton and Hove Council and CCG 2019)	QoF DEP003 (18+ diagnosed in last yr. & reviewed within 10-56 days after initial diagnosis) SCTID: 35489007
Painful condition	√	Other conditions under the MSK heading that may be experienced by young people – ankylosing spondylitis, juvenile idiopathic arthritis, and back pain (Versus Arthritis 2020)	Chronic back pain SCTID: 134407002
Asthma (currently treated)	√	Identified as one of top 5 LTCs amongst young people (20-34yrs) in Brighton and Hove 2017 (Brighton and Hove Council and CCG 2019)	QoF AST001 (register) SCTID: 195967001
Diabetes	√	Recognised LTC in young people. An index condition with increased risks of comorbidities	QoF DM017 (register) SCTID: 73211009
Thyroid disorders	Not specifically	Hypothyroidism identified as one of top 5 LTCs amongst young females (20-34yrs) in the least deprived areas in Brighton and Hove 2017 (Brighton and Hove Council and CCG 2019)	Hypothyroidism SCTID: 40930008
Rheumatoid arthritis, other inflammatory polyarthropathies & systematic connective tissue disorders	√	Other conditions under the MSK heading that may be experienced by young people – ankylosing spondylitis, juvenile idiopathic arthritis, and back pain (Versus Arthritis 2020)	RA001 register of patients over 16yrs Rheumatoid arthritis SCTID: 69896004 Ankylosing spondylitis SCTID: 9631008 Juvenile idiopathic arthritis SCTID: 410502007
Hearing loss	√		
Anxiety & other neurotic, stress related & somatoform disorders		Anxiety is the most common condition for males and females (20-34yrs) across most and least deprived areas of Brighton and Hove 2017 (Brighton and Hove Council and CCG 2019)	
Irritable bowel syndrome	Not specifically	Most commonly affects people 20s – 30s and females more than males (NICE 2017)	SCTID: 10743008
Inflammatory bowel disease			
New diagnosis of cancer in last 5 years	√	Small numbers but there has been an increase of 25% in diagnosis of cancers in under 24s since early 1990s (Cancer Research UK 2020) Lymphomas, carcinomas and germ cell tumours most commonly diagnosed in young people (Cancer Research UK)	CAN001 –register but need to be selective Lymphomas, SCTID: 118600007 Carcinomas SCTID: 722688002 Germ cell tumours SCTID: 402878003
Alcohol problems	Not specifically		
Other psychoactive substance misuse	Not specifically	In the top 5 common condition of all males and females(20-34yrs) in most deprived areas in Brighton and Hove 2017 (Brighton and Hove Council and CCG 2019)	

Chronic kidney disease	√	1:50 young people have CKD (age range not specified, National Kidney Federation 2020)	QoF CKD005 register SCTID: 709044004
Diverticular disease of intestine	Not specifically		
Epilepsy (currently treated)	√	Recognised LTC in young people that is monitored in childhood. Weatherburn et al 2016, cross sectional analysis in Scotland of 1.5 million electronic records in primary care identified 69.9% of those diagnosed (14+yrs) with epilepsy were living with one or more LTC.	QoF EP001 (register) SCTID: 84757009 Must be receiving drug treatment
Schizophrenia (and related non-organic psychosis) or bipolar disorder	√	Identified as one of top 5 LTCs amongst young men (20-34 yrs.) in the most deprived areas in Brighton and Hove 2017 (Brighton and Hove Council and CCG 2019)	QoF MH001 (register) Schizophrenia SCTID: 58214004 Bipolar SCTID: 13746004 Patients stay on the list when they are in remission
Psoriasis or eczema	Not specifically		
Migraine	Not specifically		
Blindness & low vision	√		
Chronic sinusitis	Not specifically		
Learning disability	Taken off after 2016	Identified as one of top 5 LTCs amongst young men (20-34 yrs.) in the most deprived areas in Brighton and Hove 2017 (Brighton and Hove Council and CCG 2019) Learning disability identified as marker for multimorbidity (Kinnear et al 2018)	
Anorexia or bulimia	Not specifically		
Viral Hepatitis	Not specifically		
Cystic Fibrosis	Not specifically	Rare 10,500 in the UK are living with cystic fibrosis	NOT ON MM LISTS (Barnett <i>et al.</i> , 2012 and PHE 2018)

Appendix K. Participant characteristics

ID	GP	Age							Gender			Ethnicity					Disab- -ility Yrs.	Mod frailty	Sexuality			
		18	19	20	21	22	23	24	Male	Female	Other	White British	White Black African	White Asian	White Black Carib- bean	other			Gay	Les- bian	Het ero sex ual	Other
1	1						x		x			x					x			x		
3	1				x				x			x					x	x				
4	1			x						x			x				x			x		
5	1					x				x		x					15	x			x	
6	1							x		x		x						x			x	
8	1					x				x		x						x			x	
9	2						x			X		x									bi	
10	2					x			x			x									x	
11	2		x							X				x							x	
12	2						x			X				x							x	
13	2			x						X		x									x	
14	2						x			X		x									bi	
15	3				x					X					Jewish		7				bi	
16	3							x		X		x									x	
17	3						x			X		x									x	
18	4							x		X		x									x	
19	4	x								Non- binary		x										asexual
20	4						x			X		x									x	
21	4	x								X					White Europ ean						x	

ID	Relationship		Education				Employment/study					Residence			
	Single	Partner	GCSE	A level/dip	Undergrad degree	Comment	In work	Self-employed	Looking for work	Student	Comments	Family home	Own home	Shared	Comments
1		x	x	x	x	Medical training				x				x	
3		x	x	x	x		x							x	With partner & his family
4	x		x	x			x			x	Part time	x			
5		x	x	x			x			x	Part time	x			
6	x					Health & social care cert			x				x		With children
8		x	x	x			x				Part time			x	
9		x	x	x		Trained as chef			x					x	With partner & his family
10		x	x	x	x		x								With partner
11		x	x	x						x				x	In shared with partner
12		x	x	x			x			x	Part time			x	With partner & his family
13		x	x	x						x	Part time	x		x	Home and student accommodation
14		x	x			Completed access course	x				4 p/time jobs			x	Split between grandma's home and friends' homes
15	x		x	x		Foundation degree		x				x			
16	x		x	x		Completed access course	x				Part time			x	With sisters & son
17	x		x	x		Open university		x					x		
18		x	x	x			x				Full time	x			
19	x		x							x		x			
20		x	x	x						x	Full time	x			
21	x		x			Studying A levels	x			x	Part time	x			

Appendix L. Ethics approvals



Ms Tracy Whittle
Postgraduate Researcher
University of Brighton
School of Applied Social Science
Watson Building, Falmer
Brighton
BN1 9RH

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

01 February 2021

Dear Ms Whittle

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title:	Living well with multiple long-term conditions. Interrogating young people's experiences of integrated care
IRAS project ID:	288218
REC reference:	20/EE/0288
Sponsor	University of Brighton

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "[After Ethical Review – guidance for sponsors and investigators](#)", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 288218. Please quote this on all correspondence.

Yours Sincerely,

Beverley Mashegede

Email: approvals@hra.nhs.uk

Copy to: *Dr Lucy Redhead, Sponsor Contact*



University of Brighton

External REC Review Panel

424 Watts Building
Lewes Road
Brighton
BN2 4GJ

23/11/2020

Ref: 2020-7289-Whittle Living well with multiple LTCs? Young people's care experiences

Dear Tracy,

Thank you for your submission to the External REC Review Panel (ERRP). Your application Living well with multiple LTCs? Young people's care experiences has now been reviewed by the panel.

The reviewers have returned a favourable opinion and are happy for your application to go forward for external review. Please notify us if you experience an adverse incident whilst undertaking the research or if you need to make amendments to the original application.

We shall provide insurance for appropriate external agencies as necessary. You can find a copy of the University's insurance letter [here](#).

We wish you well with your research. Please send annual updates on your progress and an end of study summary of your research.
Best wishes

Dr Lucy Redhead

Chair, External REC Review Panel

Appendix M. Wording for GP practice website

Web page content for GP practice website



University of Brighton

SC.DTP. South Coast
Doctoral Training
Partnership



**Economic
and Social
Research Council**

Research project title

Living well with multiple LTCs? Young people's care experiences

Long title: Living well with multiple long-term conditions: Interrogating young people's experiences of integrated care



What is it about?

We know very little about the care experiences of people aged 18-24 years living with several long-term health conditions. This research project wants to explore how young people's experiences of health and social care services and the close people in their lives support them to make the adaptations to live well. The findings may inform the future planning and delivery of health and social care services for younger people living with multiple long-term conditions

This research will be carried out by the University of Brighton and will work with three GP practices in Brighton.

The GP practices will identify people on their patient database who meet the research criteria. The practices will then contact them to get their permission to send a text with further information.

The study would like to recruit around 30 people who will be asked to take part in two telephone interviews about their experiences of their health journey. They will be given a £20 Amazon e voucher for the contribution of their time in taking part.

The information that people share will be confidential to the research team and in the final report, the data will be anonymised so individuals cannot be identified.

Who can take part?

People will be invited to take part in this study if they are:

- aged 18-24 years
- living with two or more long-term health conditions which can be physical health conditions or physical and mental health conditions and
- may have a moderate frailty score OR have/had the involvement of at least 3 health and social care services in their care

Information for participants

Participant Information Sheet. This sheet outlines what the study is about, what is going to happen and how the information you give will be used. – [HYPERLINK TO PAGE ON PRACTICE WEBSITE](#)

List of helpful organisations. This sheet contains a list of organisations for young people to contact for help and support- [HYPERLINK TO PAGE ON PRACTICE WEBSITE](#)

The NHS Research Ethics Committee has approved this research

Who is carrying out this research?



Hey, I'm Tracy Whittle and I'm a postgraduate researcher at the University of Brighton who has been funded to carry out this research project. I have had a varied career. Here are examples of some of the work I've been involved in, from raising awareness of young carers (those who care for family members) [A day in the life of Eddie](#)

..... and the benefits to residents, staff and young people of [Volunteering in Care Homes](#)

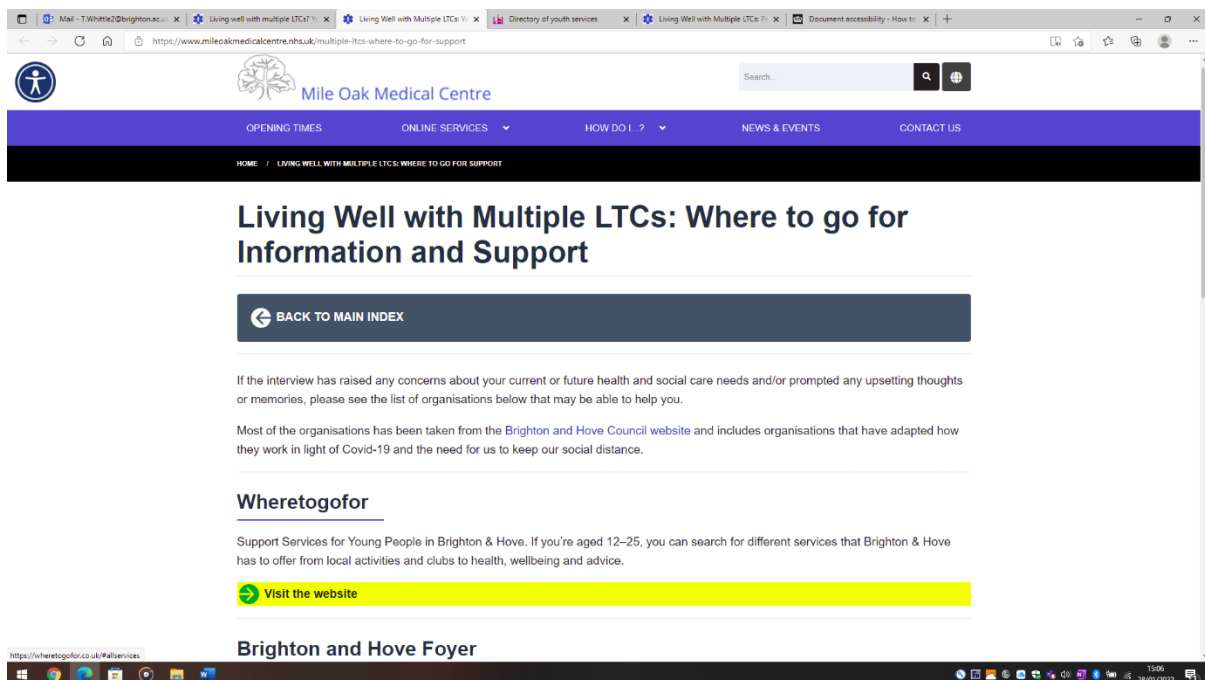
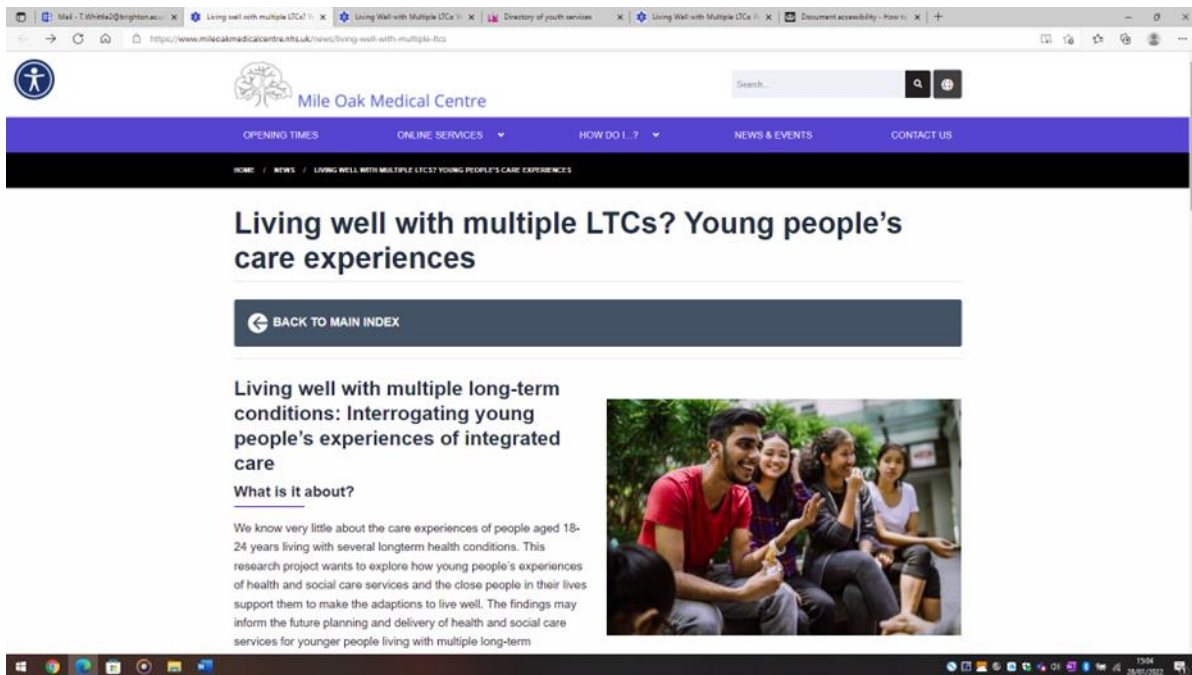
For more information and to get in touch:

Contact: Tracy Whittle, T.Whittle2@brighton.ac.uk or text/phone mobile: 07533 867972

Funding

[The South Coast Doctoral Training Partnership](#) is funded by the Economic and Social Research Council. It awards several studentships annually to social scientists carrying out PhD studies, (and Masters + PhD studies) at its three partner institutions which are the Universities of Brighton, Portsmouth and Southampton. "Living well with multiple LTCs? Young people's care experiences", is a 3-year PhD research project funded until the end of September 2022 (grant reference number ES/P000673/1)

Screenshot of layout of wording and images on a GP practice website. Note the images were altered to comply with the GP practice digital policies



Appendix N. Wording for first text invite

First invitation to participate by text

This first text will be sent to young people on the GP register who meet the selection criteria. Due to data protection legislation, the surgery will need to obtain consent from young people before they can send the text, so it will be expected.

“Hey [first name]

The [name of GP practice] is supporting a research study at the University of Brighton and you have been chosen to take part. You will be interviewed about your care experiences to shape future guidance for health and social care staff and given a voucher for your time. Click on this {hyperlink} to take you to a page on our website for further information and who to contact.

Best wishes

Staff at [name of GP practice]

(Practice telephone number)

Appendix O. Reminder text invite

Reminder invitation to participate by text

This second, reminder text will be sent to potential participants two weeks after the first invite has been sent.

“Hey [first name]

We sent you a text a couple of weeks ago inviting you to take part in a study at the University of Brighton. You will be given a £20 Amazon e voucher for your time being interviewed about your care experiences to shape future guidance for health and social care staff. If you have already responded please ignore this text, but if not and you are able to help, your contributions would be greatly valued. Click on this {insert hyperlink} to take you to a page on our website for further information and who to contact.

Best wishes

Staff at [name of GP practice]

(Practice telephone number)



University of Brighton
School of Applied Social Sciences
Watson Building
Falmer
Brighton
BN1 9PH

Dear [name]

It was great to talk to you and thank you for agreeing to consider taking part in this study on people living with multiple long-term conditions (LTCs). I want to explore how young people's experiences of health and social care services and their close relationships support them to make the adaptations to live well.

Further to our chat, I have attached the participant information sheet and an information sheet of organisations which provide support and advice to young people living in Brighton. This information can also be found on the project page on the GP practice website which you can reach by clicking [hyperlink to GP practice website]. If you have any questions about the study or need any more information please do not hesitate to get in touch either by email T.Whittle2@brighton.ac.uk or by text/phone on 07533 867972

I look forward to talking to you about your health experiences on the [date and time of first interview]

Kind regards,

Tracy Whittle

Tel: 07533 867972

Email: T.Whittle2@brighton.ac.uk <mailto:tracy.whittle@ntlworld.com>



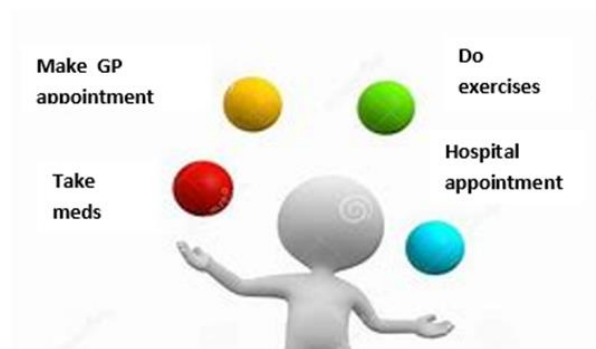
PARTICIPANT INFORMATION SHEET

Please let me know if you would prefer this sheet as an audio recording 

Title of study: Living well with multiple LTCs? Young people's care experiences

1. Invitation

I would like to invite you to take part in a study to explore how young people's experiences of health and social care services and their relationships with others support them to make the changes to live well. Before you decide whether to take part it is important for you to understand what I am trying to do and what it will involve. Please take time to read the following information carefully. Do talk to family and friends and do ask any questions you may have about any part of the study.



2. Why am I doing this research?

Very little is known about the experiences of young people living with multiple long-term conditions (LTCs) as they navigate many adult care services. How I have chosen to collect information and the questions I will ask, have been selected so that the findings can inform the future planning and delivery of health and social care services for young people living with multiple long-term conditions.

A long-term condition is a health condition that cannot be cured but the symptoms are managed with medication and other treatments.

3. Why have you been asked?

You have been invited as you meet my research requirements. You are aged between 18-24 years. You are living with two or more long-term conditions, and you may have a moderate frailty score. Importantly, you will have experiences of being diagnosed and supported to manage living with your health conditions.

4. Do you have to take part?

No. It is entirely up to you whether you take part. You will be asked to agree to take part and for interviews to be digitally audio recorded. You are free to stop taking part at any time during the research without giving a reason and your information (data) can be withdrawn up to the point that I start to analyse it. I will remind you of this at the time of the interview. Your care or treatment will not be affected if you do not want to take part or stop taking part in the study.

5. What will happen to you if you decide to take part?

This study involves being interviewed by me - a post graduate researcher. I will have two interviews with you over the phone. It is important that you have a private space to take the calls so you can talk freely. If you don't, let me know and I'll organise a private space for you either on the university campus or in the community and pay back your travel costs.



The first interview will last about 15 – 30 minutes and will involve me asking you about your key life and health experiences. After the interview, I will plot this information as a life grid diagram which will help our discussion at the second interview.

The second interview which will take place a week later will last about 30 – 45 minutes. I will start by sharing with you (sent to you by email at this point in the interview) the life grid diagram and we can check it for accuracy. The interview will involve me asking some questions about your experiences and what they meant to you. There are no right or wrong answers.

I will write up the interviews and you can check them for accuracy. With your permission, some anonymised quotes may be used in publications I write. These quotes will not refer to you by name at any point. Before the first interview you will be asked some personal questions such as your age and where you live and to give verbal consent. I will ask you for your permission again before the second interview.

Once you let me know you would like to take part, I will contact you to arrange the interviews at times that are convenient to you.



6. What are the benefits of taking part?

Your responses will be used to influence the design and delivery of health and social care services for younger people living with multiple long-term conditions. However, I cannot guarantee that services will be improved as a result of your participation and/or the findings from the study. I will offer you a £20 “thank you” Amazon e voucher for your time in taking part in this study.

7. Points to think about

There are no foreseeable risks to taking part in this study. However, if the interview raises issues for you that cause you to become upset, I will talk with you to agree what to do. We could skip parts of the interview or stop it. If you want, I will contact someone to support you. I will also provide you with a list of services that could help and support you.

8. What if something goes wrong?

If you do not feel happy with the interviews you can stop at any time without giving a reason. If you have any complaint or concern about any part of the study, you can contact my lead supervisor or the Head of the School of Applied Social Sciences.

Supervisor: Professor Nigel Sherriff, Email: N.S.Sherriff@brighton.ac.uk or phone: 01273 644539

Supervisor: Professor Jorg Huber, Email: J.Huber@brighton.ac.uk or phone: 01273 644078

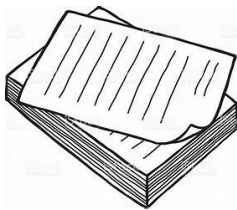
9. Will anyone else know I'm doing this?

The research team which includes me, and my three supervisors will know that you are taking part. Any information you provide will be kept confidential. The only exception to this is if something you say means that criminal acts have been or will take place, or you, a child or vulnerable adult has been, or is at significant risk of harm. In these cases, I have a responsibility to report these to my supervisors and the relevant authorities. However, I will privately tell you first if I feel this may be necessary.

Recordings of interviews will not be marked with your name but will have a unique code. Your personal details will be stored separately from the data and any potential identifying details will be removed when your interview records are written up and stored on computer.

All data information will be stored securely using locked filing cabinets and password and network protected computers. Personal data is securely destroyed at the end of your involvement in the project whilst the research data is stored securely for 10 years.

10. What will happen to the results?



The findings will be reported in my doctoral thesis. I will also aim to present the results at conferences and publish in academic journals. I would like to hear your ideas for presenting and publishing the findings.

Reports may include direct quotes from interviews. However, any names or other identifying information will be removed. A summary of the results can be sent to you if you wish to see them. You will not be personally identified in any reports or publications of the research.

11. Who has checked this research?

The University of Brighton's External REC Review Panel and the Cambridge South Research Ethics Committee have approved this study.

12. Who has funded this study?

This study is funded for three years by the Economic and Social Research Council which is managed by the South Coast Doctoral Training Partnership (SCDTP) (grant reference number ES/P000673/1).

13. Contact for further information

If you would like further information about this study, please contact:



- Name: Tracy Whittle
- Role: PhD Researcher (University of Brighton)
- Email: T.Whittle2@brighton.ac.uk
- Phone/text: 07533 867972

Thank you for taking the time to read this. If you would like to take part, I look forward to hearing from you.



Where to go for information and support



If the interview has raised any concerns about your current or future health and social care needs and/or prompted any upsetting thoughts or memories, please see the list of organisations below that may be able to help you.

Most of the organisations has been taken from the [Brighton and Hove Council website](#) and includes organisations that have adapted how they work in light of Covid-19 and the need for us to keep our social distance.

➤ **Wheretogofor**

Support Services for Young People in Brighton & Hove. If you're aged 12–25, you can search for different services that Brighton & Hove has to offer from local activities and clubs to health, wellbeing and advice.

<http://wheretogofor.co.uk/#allservices>

➤ **Active for Life**

Active for Life is a project run by Brighton & Hove City Council to support people in the city to lead active lifestyles. For more information on the Active for Life Project please contact the Healthy Lifestyles Team by phoning 01273 294 589 or sending an email to healthylifestyles@brighton-hove.gov.uk.

Follow on Twitter: [@BHhealthylife](#), or visit [Active for Life Facebook](#) page.

➤ **Allsorts**

Allsorts Youth Project listens to, supports & connects children & young people under 26 who are lesbian, gay, bisexual, trans or unsure (LGBTU) of their sexual orientation and/or gender identity.

<https://www.allsortsyouth.org.uk/>

➤ **Amaze**

Amaze is a charity that gives information, advice and support to families of children and young people with special educational needs and disabilities (SEND) in Brighton & Hove and Sussex. We also support young people with SEND up to 25.

<https://amazesussex.org.uk/> helpline 01273 772289

➤ **Black and Minority Ethnic Young People's Project (BMEYPP)**

The BMEYPP offers regular text messages to all members, 1-2-1 support through phone calls, emails and messages, and text messages to members, group meetings with some invited young people and young volunteers, online social groups - in development

To get in touch, you can send an email to info@bmeyp.org.uk. You can also send a message to 07918 621423, or get in touch through the [BMEYPP Facebook](#) page or the [BMEYPP Instagram](#).

➤ **Brighton and Hove Foyer**

Located in Brighton city centre, at Brighton and Hove Foyer, we provide support for 50 young people aged 16 to 25, encouraging them to develop their skills and live as independently as possible.

Telephone: 01273 242700

<https://www.sanctuary-supported-living.co.uk/find-services/young-people/east-sussex/brighton-and-hove-foyer>

➤ **MIND Brighton and Hove**

The Brighton and Hove Wellbeing Service for Children and Young People (age 4-25) offers support to young people who are experiencing mild depression, anxiety, low self-esteem and relationship issue

<https://www.mindcharity.co.uk/advice-information/local-services/services-for-young-people/>

➤ **Samaritans**

If you are having a difficult time or worried about someone, the Samaritans provide a confidential listening ear. They're available 24 hours a day, 365 days a year. **Call free on 116 123**

For further information on the services they provide: <https://www.samaritans.org/>

➤ **Survivors Network**

Independent Sexual Violence Advisor Service: 1-2-1 support provided over text, WhatsApp, Skype, Zoom, phone. Young person's therapy: 1-2-1 sessions over Zoom, Skype, phone and some text

Make a [self-referral through the Survivors' Network](#) website

➤ **The Trust for Developing Communities**

Offers online group hangout spaces, social media challenges, fun, games and activities, wellbeing sessions, 1-2-1 phone call check-ins, 1-2-1 health and wellbeing youth work, 1-2-1 youth coaching, Youth Worker available to chat on Instagram and Facebook, weekdays midday to 8pm

[Trust for Developing Communities on Instagram](#), on Twitter @trustdevcom, or on [Facebook](#).

➤ **Touchbase Centre**

TouchBase offers support to people aged between 5 and 25 years old. They support people recovering from abuse, neglect and other adverse childhood experiences and their carers, adoptive parents and the education and social care professionals around them.

info@touchbase.org.uk.

➤ **YMCA Positive Placements**

YMCA Positive Placements recruits adult volunteers to be trained as mentors in order to support young people towards a positive future. Offers mentoring - getting support to set and work on goals to do with general wellbeing, mental health, education, employment or training. Communicating with a mentor over the phone, by email, or video chat for roughly an hour a week

Send an email to positiveplacements@ymcadlg.org

➤ **YMCA Youth Advice Centre (YAC)**

Is running all 4 of its services remotely. No face-to-face appointments. It is continuing to accept new referrals.

To get in touch, phone 01273 624 432 and you'll be connected to right team. Or you can email teams directly:

- Housing Advice yacbrightonhousingadvice@ymcadlg.org
- Family Mediation YAC.FamilyMediation@ymcadlg.org
- Support and Advice yacbrightonservices@ymcadlg.org

Find YMCA YAC on:

Instagram [@yac_brighton](https://www.instagram.com/yac_brighton) Facebook [@yacbrighton](https://www.facebook.com/yacbrighton)

➤ **Young People's Centre**

The Young People's Centre (YPC) is a safe and social space with a café located in the centre of Brighton where young people aged 13-25 can access free advice, support and counselling, as well as affordable food, activities and free access to computers and the internet.

They will respond to new enquiries through email: youthsupport.ypc@impact-initiatives.org.uk or through telephone enquiries to 07928 808825. Neither provide 'emergency' support but they will follow up with 48 hours.

➤ **Young People's Support Network**

Counselling and life coaching online on the [Young People's Support Network](http://www.youngpeople.org.uk) website.

To get in touch, send an email to enquiry@yopsn.org.uk

Appendix Q. Topic guide: Interview 1

Interviewer:	
Interviewee ID:	
Date:	

- Received, read, understood Participant Information Sheet (PIS) – Questions?
- Obtain verbal consent – recorder on
- Participant characteristics form completed – not to be recorded
- Introductory statement – commence recording

Introductory Statement (to be read only after recorder started)

Living with a number of long-term health conditions means people need to make changes to how they live their lives. Young people’s experiences of health and social care and their close relationships can influence that process of adaptation.

I want to understand who and what in a young person’s health journey supports them to make the changes they need to live well. The findings will inform guidance on how health and social care services for young people living with multiple LTCs are delivered.

This first interview should last a maximum of 30 minutes. The purpose of this exercise is to document your key life and health experiences to date, as remembered by you, which will help us in the discussion at the second interview.

I will transfer your experiences into a diagram (life grid) and send it to you by (encrypted) email shortly before our second interview. We will go through it to check for mistakes and/or any missing information.

The purpose of this exercise is to document your key life and health experiences to date as remembered by you.

Tell me about the main events in your life – starting where you want. I will make some notes as you talk and will ask questions if I need you to explain or repeat something.

Notes to researcher

Let the narrative flow.

Prompts – To help people get going suggest remembering by importance/significance e.g. starting to feel unwell or remembering illness by ascending or descending chronology e.g. – first or last diagnosis. After this initial prompt let the participant decide what they want to remember next. Memory recall does not have to follow a prescribed pattern.

After the interview

- Check in with how they are feeling and thank you
- Clarify where to access sources of further support
- Re-check consent
- Outline next steps – date and time of next interview

TOPIC GUIDE Phase 2 Telephone interview: Health journey explored

Interviewer:	
Interviewee ID:	
Date:	

- Touch base (how is participant feeling)
- Received life grid?
- Verbal consent – to be recorded
- Received, read, understood Participant Information Sheet (PIS) – Questions?
- Introductory statement (recorder on)

Questions in the main schedule are mapped to the research question and objectives.

Introductory Statement (to be read only after recorder started)

Living with a number of long-term health conditions means people need to make changes to how they live their lives. Young people’s experiences of health and social care and their close relationships can influence that process of adaption.

I want to understand who and what in a young person’s health journey supports them to make the changes they need to live well. The findings will inform guidance on how future health and social care services for young people living with multiple LTCs are delivered.

The interview should last about 45 minutes. I will ask you some questions about the key health and life experiences you told me about in the first interview. I want to hear about who and what you found helped you to make the changes to manage your health conditions. There are no right or wrong answers, I just want to hear about your experiences, what they meant to you and how they affected your self-management behaviour.

SECTION ONE – Recalling the first memorable event

In this section I would like to hear about the most memorable/significant health event you talked about in the first interview, what it meant to you and how it impacted on how you lived your life. Talk me through what you put on your chart first?

Prompts to cover the stages of early adaption to a diagnosis of a health condition:

How far was it disruptive? Tell me about this event. Describe what was going on (symptoms) and where, and when it happened. What else was going on in school, work, family) and its context (your age and where it was in relation to your health history - was it the first time you were ill?).

Did you go to the GP/hospital? How did it feel in this place? Was anyone else present with you? Was it supportive, If not, what could have been done differently? When did you get a diagnosis? How was your experience – being told? How did your family react? Did you tell your friends? Did you have to tell anyone at school/college/uni/work? Do you remember how you were feeling at the time?

Constructing a personal view of the condition (that the event relates to). What happened after you knew you had a health condition? Had you heard of it before? Did you know it was something you would have to live with for the rest of your life? Did you have to make any adjustments to your life? E.g. mealtimes. If so, what were they? How did it feel making these changes – were they easy to make or was it hard? If easy why? If hard what could have made it easier for you? How did your routine change? Did you feel that you knew what you were doing and why you were doing it?

Reconstructing view of self. (How far did having this condition change their sense of self?) E.g. Did you think of yourself as different? Did your relationship with others change? Did your family support you? If yes, how? E.g. did they attend hospital appointments and ask questions? If not, what would you have liked them to do? How was your relationship with friends at the time? Would you have liked them to have behaved in a different way? If so how? What was the impact on work/school/uni/college? How could these changes have been improved?

Learning to live with the condition. Were you given any treatment/medication? Did you feel supported by the health care staff? If so why? What was good about these experiences? If not good, what would you have liked them to do? Were you given advice about any changes you may need to make? Was this advice/information helpful? If yes, why? If not, how could it have been improved? Did you have support from family/friends to make changes? If yes was it helpful? If not, what would you have liked them to do to support you?

Behavioural adaption How far did you have to make changes to your study/work, personal care routine, social life, play? What helped/ could have helped you make the changes? Have you had to make changes to plans for your future? Are you ok about these changes?

SECTION TWO – Recalling the next memorable event.

In this section I would like to hear about the next most memorable/significant health event on your life grid and how it impacted on how you lived your life. Talk me through what you put on your chart next?

I also want to understand about this event and your experience of it in relation to the previous event

Prompts to cover the stages of early adaption to a diagnosis of another health condition:

How far was it disruptive? Tell me about this event. Describe what was going on (symptoms) and where and when it happened. What else was going on in school, work, family and its context (your age)? **What was the relationship of this event to the other? Did it come before or after? Was it related to the earlier condition? Did it have an impact on your earlier condition - making it worse/ or di it feel less important?**

Did you go to the GP/hospital? How did it feel in this place? Was anyone else present with you? Was it supportive, If not, what could have been done differently? When did you get a diagnosis? How was your experience – being told? How did your family react? Did you tell your friends? Did you have to tell anyone at school/college/uni/work? Do you remember how you were feeling at the time?

Constructing a personal view of the condition (that the event relates to). What happened after you knew you had **ANOTHER** health condition? Had you heard of it before? Did you know it was something you would have to live with for the rest of your life? Did you have to make any other adjustments to your life? If so, what were they? How did it feel making these changes – were they easy to make or was it hard? If easy why? If hard what could have made it easier for you? **How did these changes relate to the earlier changes you had to make at previous event(s)? Did it feel harder/easier? If so why? If harder what could have made it feel easier? Did having this new condition feel more significant/important than the earlier condition? If more important why? If less important why?**

Reconstructing view of self. How far did having this **NEW** condition change your sense of self? **How did you feel being diagnosed with another health condition? What was the reaction of family and friends to another diagnosis? How did this make you feel? Would you have liked them to have behaved differently? If so how?** What was the impact on work/school/uni/college? How could these changes have been improved?

Learning to live with the condition. Were you given any treatment/medication? Did you feel supported by the health care staff? If so why? What was good about these experiences? If not, what would you have liked them to do? **How did your experiences with H&S care staff differ from previous experiences? If not as good how could they have been improved? What additional adjustments did you have to make? Did managing this new condition take precedence over the previous condition?** **Were the two conditions related (concordant)? Was it the same team? How are the two conditions managed?**

Behavioural adaption. How far did you have to make changes to your study/work, personal care routine, social life, play following this new diagnosis? Have you had to make changes to plans for your future? Are you ok about these changes? **Did having an additional health condition stop you from getting on and doing the things you wanted? If so how?**

SECTION THREE – recalling additional health events

In this section I would like you to continue talking me through the remaining health events on your life grid, one at a time, in the order of your choosing.

Prompts – follow as for section 2.

CLOSURE

- Check in with how participant is feeling and thank you
- Clarify how to access sources of further support
- Confirm that they can share their experiences and content of the study with general practice staff
- Clarify email/text contact details for voucher
- Recheck consent and next steps (reading interview transcript)
- Does the participant want to be sent a copy of the report
- Does the participant want to be consulted on how to publicise the findings

THANK YOU

Appendix S. Screenshots of codes collated and stored in NVivo.

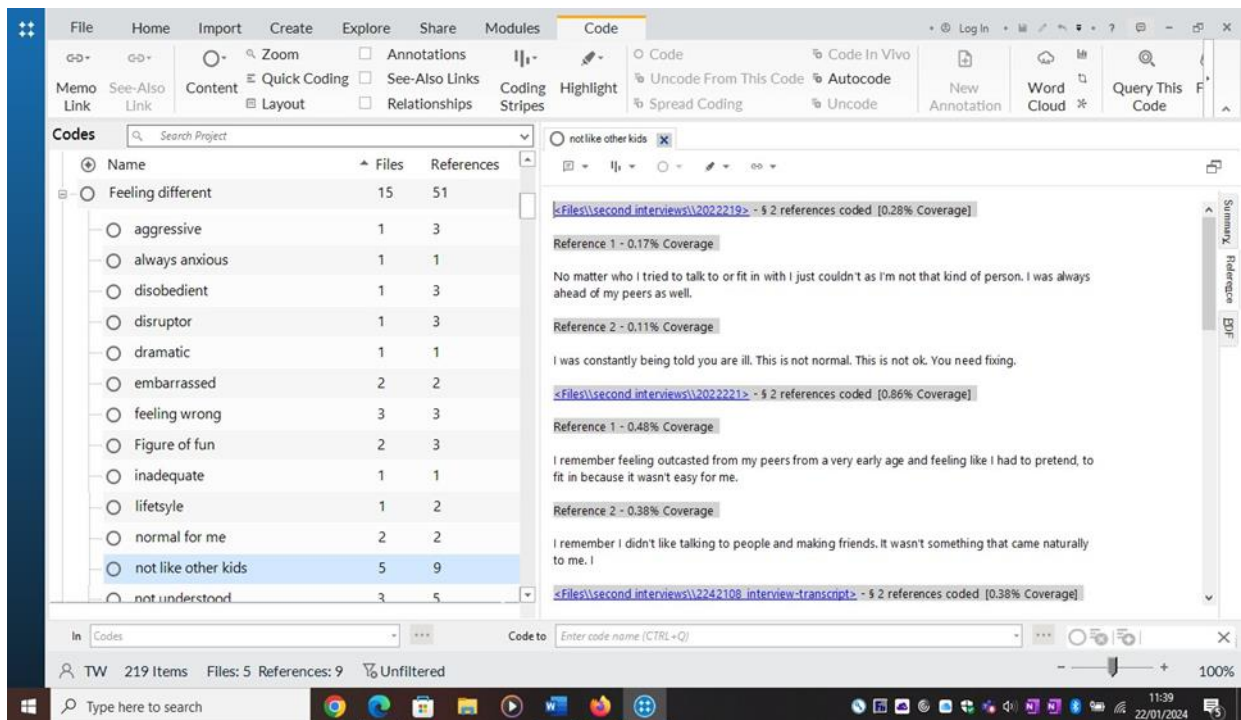


Figure 1. Parent node *feeling different* illustrating the variety of child nodes contained within it and highlighting examples of text that made up the child node *not like other kids*.

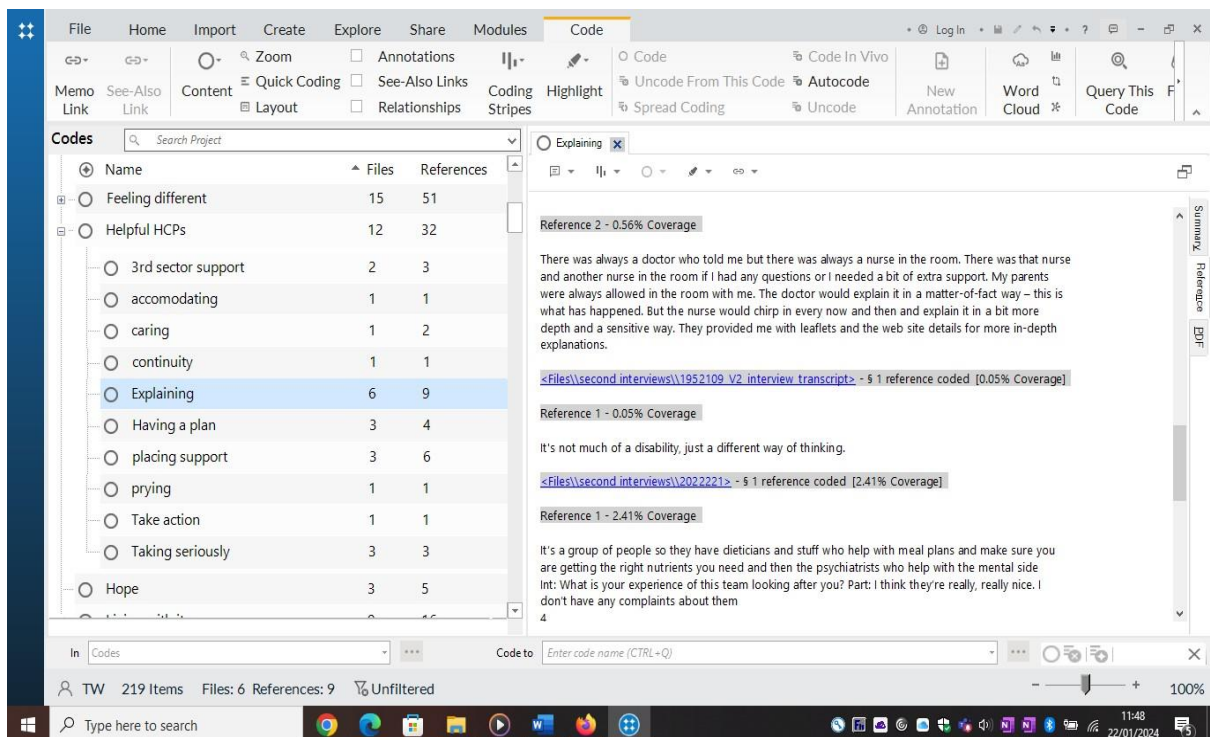


Figure 2. Parent node *helpful HCPs* illustrating the variety of child nodes contained within it and highlighting examples of text that make up the child node *helpful HCPs*

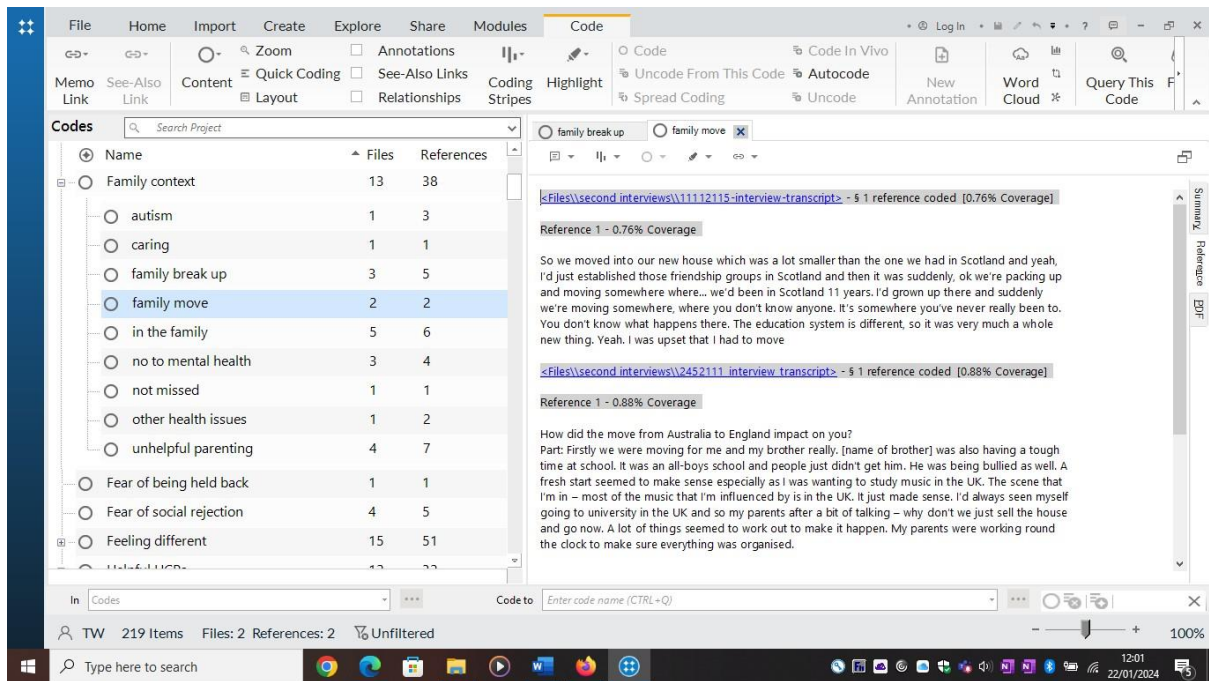


Figure 3. Parent node *family context* illustrating the variety of child nodes contained within it and highlighting examples of text that make up the child node *family move*.

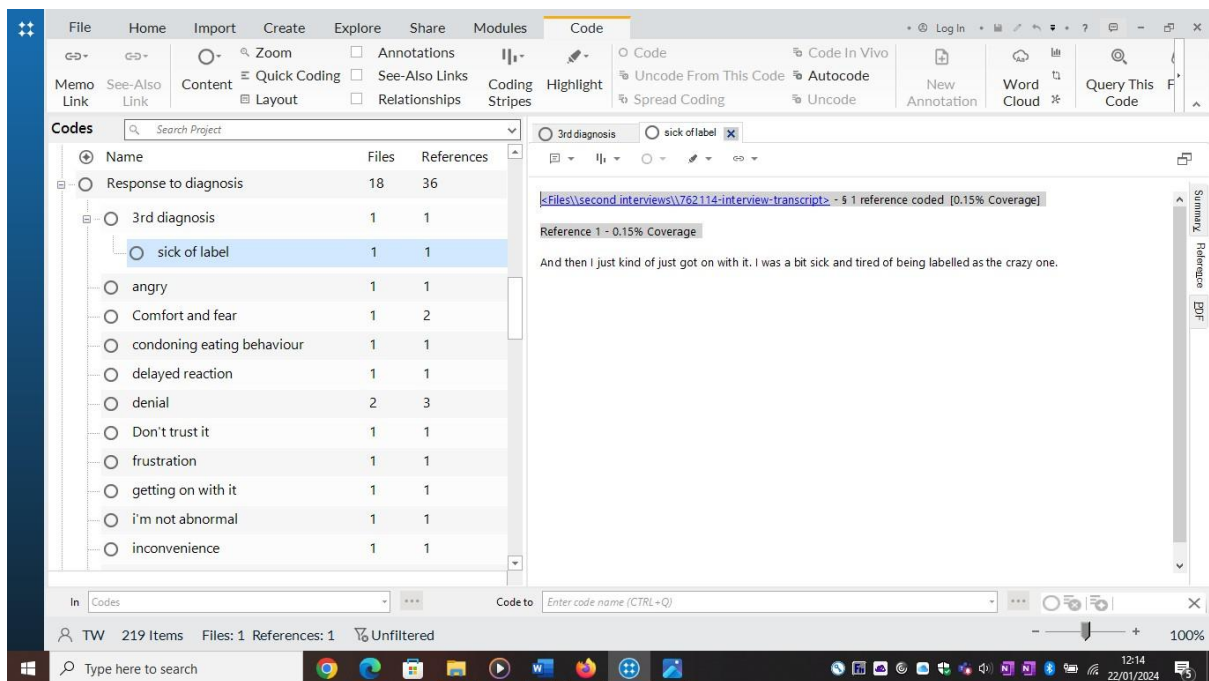


Figure 4. Parent node *response to a diagnosis* illustrating the 3rd diagnosis child node and the text within it

Appendix T. Screenshots of my development of the thematic network.

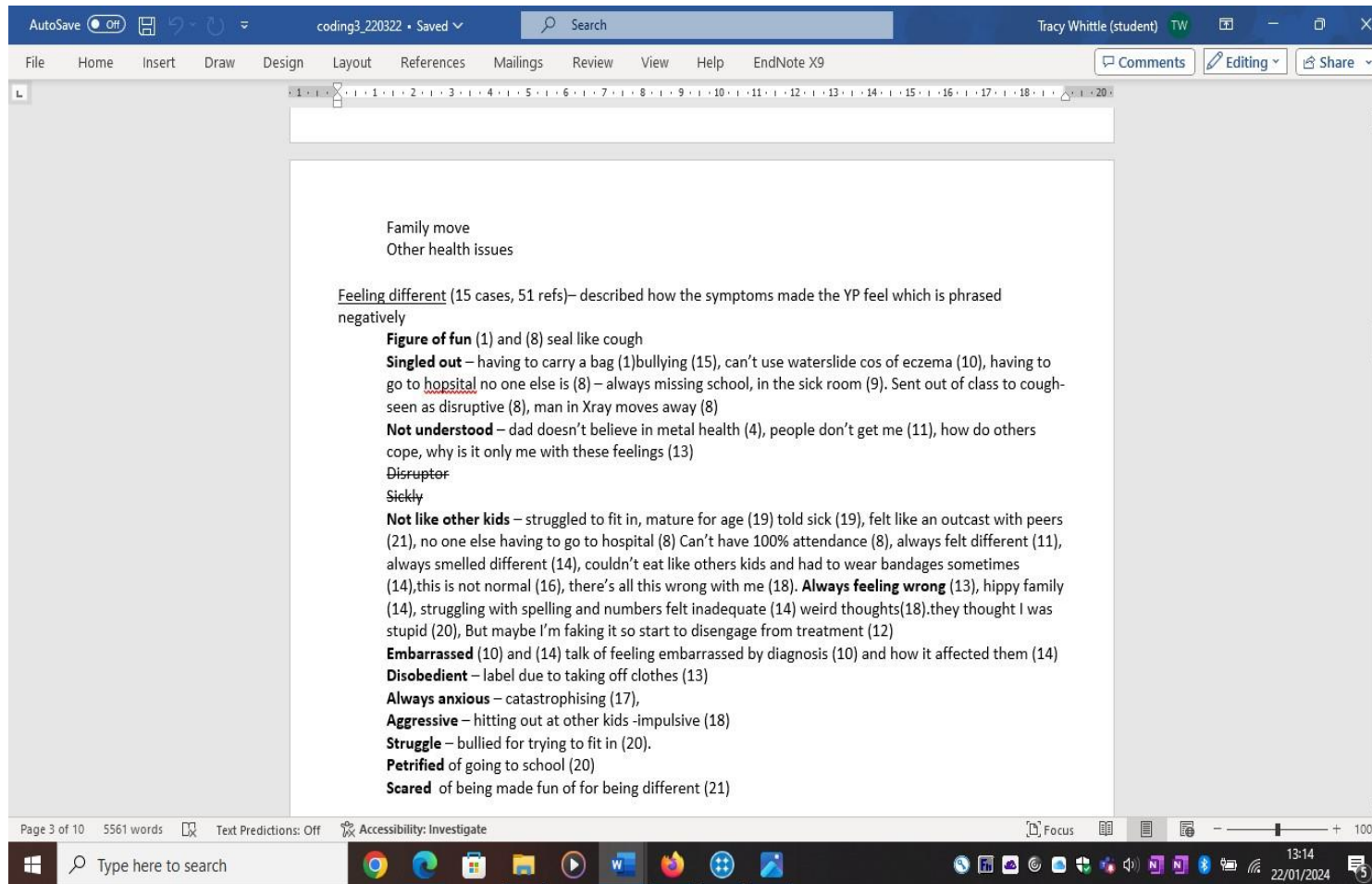


Figure 1. Parent nodes and child nodes are moved into a Word document and given a brief summary including context.

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File Home Insert Draw Design Layout References Mailings Review View Help EndNote X9

Data generation from codes to basic themes, subthemes, and overarching themes

Theme

How young people experience their health condition symptoms and how others respond to their difference shapes their view of self and adaptive behaviours pre-diagnosis.

- My health condition symptoms make feel and be seen as different to you.
- How you respond to my difference makes me feel judged and punished.
- I feel helpless and initiate self-harming coping mechanisms

Shaping view of self and adaptations: living with physical symptoms of a health condition in early childhood e.g. their looks, smells, sounds, and behaviour makes them feel different. Ambiguous symptoms of a health condition and calls for help not believed – others’ reactions negative – naughty, disruptive. How they then view themselves weird, monster child and coping behaviours can be self-harming.

Basic themes from codes	Subthemes	Relationship to early adaptation process
Difference - can't use waterslide, can't have 100% attendance, always missing school, going to hospital, can't eat like others, self-harm marks, smells different, wears bandages, Feelings - irritable, aggressive, Struggles to fit in, mature for age, something wrong with me, people don't get me, always feeling wrong. Others' responses - name calling – funny sounding cough, figure of fun, carrying bag, slits wrists, naughty, disobedient, excluding	Health conditions/ symptoms that make young people stand out. They feel, look, smell, sound different to their peers. Their condition makes them behave differently. Responses of peers, teachers to behaviours is one of disapproval, exclusion	Shaping sense of self and adaptations
Self-harming - hitting head to distract from headache (9) Controlling eating - it's something I can control Drinking/smoking – distraction Not acting on symptoms - carrying on living with symptoms and not seeking help (periods and IBD) Trying to fit in - but gets into trouble, doesn't work (21)(19) Note self-harming when being bullied (20)	Not getting help, feeling helpless, doesn't know why different and what's wrong leads to potentially self-harming behaviours	Shapes sense of self and adaptations (pre-diagnosis)

Page 1 of 11 2964 words Text Predictions: Off Accessibility: Investigate Focus 100%

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Figure 2. Themes are identified and grouped. Illustrated are themes around pre-diagnosis, how young people felt, how they behaved, and how offers responded. The basic themes are aggregated to form subthemes from which an overarching theme is composed.

Appendix U. Code and theme data extracts

Codes and group codes	Basic themes	Sub theme	Main theme
THEME 1			
Not like other kids Standing out Always felt wrong	Young people are aware of their difference.	Feeling different and reconstructing a view of self	Before diagnosis: the disruption begins
Bullied Keeping quiet Trying to fit in	Young people try and fit in with their peers. They try to keep a low profile so as not to attract unwarranted attention	An undiagnosed neurodevelopmental condition makes the young person be seen as different to their peers. It shapes their sense of self as different	
Family context (unsupportive families, mental health taboo) It's normal	Delay in seeking support can be shaped by unsupportive families and negative familial attitudes towards some health conditions (mental health)	Others' disbelief and a " <i>spoiled social identity</i> " (Goffman 1963, p31). Disbelief and derision experienced or anticipated by many young people from others in response to the symptom presentation of their undiagnosed health conditions may lead to avoidant health seeking behaviours	
Other's disbelief, attention seeking, being dramatic, faking it. Not visible – you're young. It's normal	Response of others such as HCPs, peers and families to 'invisible' undiagnosed symptoms is one of disbelief and derision.		
THEME 2			
Relief Making sense of behaviour Validating You're not right	Having a diagnosis after a period of experiencing ill health symptoms and not being believed is validating.	A welcome diagnosis and validation of self	A diagnosis: a recalibration of view of self
This is serious	A near admission to hospital, requiring chemotherapy underlines the seriousness of my condition.	After some time of living with undiagnosed ill health symptoms, a diagnosis is welcome for some as it validates them and their experiences and be a prompt to act	
Not like other kids Standing out Always felt wrong Bullied Keeping quiet Trying to fit in	Young people living with neurodevelopmental conditions feel different and are treated differently	A barrier to recalibration of self Self-harming behaviours of young people living with diagnosed mental health and neurodevelopmental health conditions prompted by others (bullying) responses to them.	
Release/relief Feeling in control Escaping sadness Suicide is an option Self-harming Transition to secondary school	They feel helpless, don't know why they are different and what's wrong. Self-harm helps young people feel in control, brings relief and escape		

Taboo condition Family denial No voice Comfort and fear Fear of social rejection	A diagnosis can be unwelcomed – the condition could be perceived as embarrassing – taboo, something else that marks them as different,	A socially taboo diagnosis and behaviour adaptations Living with a health condition diagnosis that they perceive to be socially taboo and for which they will be judged negatively could lead to individuals adopting restrictive behavioural practices	
Head down, Withdrawal Secrecy Getting on with it	There is an anticipated belief that they will be socially rejected and keep their diagnosis to themselves and socially isolate		
Eye to the future Hope Living with it Supporting others Forgetting about it New start	Young people support others, got life ahead of me, sick of these patterns, want to get rid of label, go travel, don't let it stop me Scan will find something, having investigations new medication	Learning and forming a new social identity Young people are active on the internet and social media locating condition specific websites, Facebook groups, and Instagram accounts to learn about the condition and how to manage it. In the absence of information from health care providers they seek information elsewhere and manage their symptoms by trial and error.	
Researching condition Prioritising Research rationale	For conditions about which little is known, little information provided, seeks info in back spaces, where I find others like them. Some prioritise seeking help for one condition over another		
Taking time Trial & error Pain management Driven Don't know where to turn Managing triggers Finding what works	There is no clear care pathway, trial and error with some medication - takes time to find one with few ill side effects. There is a sense of desperation for some, focus on learning to live with it, trying different medications, seeking alternative help, holding out for investigations that may find something and lead to treatment		
THEME 3			
Symptom management (Supportive parents, supportive partners, Supportive peers)		Significant others, belonging and empowerment It is suggested that supportive others through their validation of young people and their health conditions may create a sense of belonging and validation of self, mitigating the effects of stigma experiences. Through their emotional and practical support, it is suggested they ease the burden of illness, facilitating health seeking behaviour and thus potentially enabling young	Learning and living with health conditions: belonging validation, capacity building and behaviour adaptations
Unhelpful peers Unsupportive family	My health conditions that are not visible make you disbelieve me and take my actions (result of illness) as personal insults (peers) or attention seeking (peers and family)		

		people to manage their conditions and their lives. This contrasts with unsupportive significant relationships which it is mooted, compounds experiences of enacted stigma and may underpin concealment and other restrictive social and self-care practices.	
<p>Helpful HCPs (Explaining; Taking seriously; Prying. Placing support; Accommodating. Having a plan Continuity; Take action) Could, would and can help Trust in GP They're listening Invested Supportive</p> <p>Positive private care experiences</p>	<p>When you explain and contextualise my health condition, put support in place, provide personalised care and your systems give you time, allow continuity then I feel that my health condition is important.</p>		
<p>Failed by HCPs: (End of the road; Felt ignored; Passed around; Delay in diagnosis. Look it up, Blaming, Denial of experience) Primary Care (unhelpful GPs, no referral, lack of empathy, they're just painful periods, no follow up, don't understand, not taken seriously, lack of consistency, keen to medicate</p>	<p>Young people feel let down by HCPs. Health conditions not easy to diagnose and treat. HCPs respond : blaming, pathologizing, ignoring, passing around, unhelpful (look it up). Don't understand the wider impacts on my life of feeling so unwell.</p>		
<p>System - Nothing's happening, it's not tailored, it's scary, off putting HCPs behaviour/ attitudes</p>	<p>These features of services create for a stressful interaction - unfriendly, being surrounded by lots of sick people, being told off, (makes YP fearful of needles/ A&E), not accommodating for age makes for an unpleasant experience</p>		
<p>Mental health services (CAMHS bad reputation, not getting help, not heard, not sick enough, inappropriate, unfriendly adult services, wrong therapy, peer influences, passed around, it's</p>	<p>Young people's experiences of mental health services were particularly challenging</p>		

my fault, services not good, being judged, high staff turnover.			
Supportive work Supportive schools (councillors, teachers) Finding safe space Trigger for seeking help (others' concerns) Could, would, can help	Education systems that are flexible, accessible and provide a safe space help me to manage my health conditions so I can engage in school, work life and reach my full potential.	Education and workplace people and systems in supporting participation. education and work-place people and systems that acknowledge the health condition and make the necessary adaptations enable young people to continue to participate in education and employment. The lack of support/adaptations to accommodate their health needs act as a barrier to young people participating in education and employment and fulfilling their potential to live well.	
Sympathetic others	Work/bosses that are aware of my health conditions, ask what support I need and check in with me enable me to continue with work		
Unhelpful schools Could, would, can help Singled out Transition to secondary school	School work pressure and bullying in secondary schools and teachers who behave in a way that colludes with bullies, unsympathetic, don't give extra time do not validate my health conditions and can an exacerbate my health conditions.		
Unsympathetic others Could, would, can help	How you respond to my need for help so that I can work makes me feel that my health condition is not taken seriously - I am not poorly enough		

Appendix V. Protocol for raising a safeguarding concern

Information in this protocol has been adapted from the Sussex safeguarding adults' procedures and Oxfordshire Council's safeguarding vulnerable people from acts of extremism guidance.

Defining adults at risk

Under the Care Act 2014, specific adult safeguarding duties apply to any adult (18 years or over) who:

- has care and support needs (are receiving or may need community care services because of learning, physical or mental disability, age, or illness) and,
- is experiencing, or is at risk of, abuse or neglect and,
- is unable to protect themselves from harm or exploitation because of their care and support needs.

Safeguarding is protecting an adult's right to live in safety, free from abuse or neglect. It is everyone's business to prevent abuse by raising any concerns they may have.

Defining abuse

Abuse and neglect take many forms and the following list is not exhaustive:

- Domestic violence

This refers to psychological, physical, sexual, financial or emotional abuse by someone who is a family member or is, or has been, in a close relationship with the adult being abused. This may be a one-off incident or a pattern of incidents or threats, violence, controlling or coercive behaviour. It also includes so called 'honour' based violence, being forced to marry or undergo genital mutilation.

- Physical

This includes being pushed, shaken, pinched, hit, held down, locked in a room, restrained inappropriately, or knowingly giving an adult too much or not enough medication.

- Neglect

This refers to others (informal and formal carers) not meeting an adult's physical, medical or emotional needs, either deliberately, or by failing to understand these. It includes ignoring an adult's needs, or not providing them with essential things to meet their needs, such as medication, food, water, shelter and warmth.

- Self-neglect

This refers to a vulnerable person being unable, or unwilling, to care for their own essential needs, including their health or surroundings (for example, their home may be infested by rats or very unclean, or there may be a fire risk due to their obsessive hoarding).

- Sexual

This includes rape, indecent exposure, sexual harassment, inappropriate looking or touching, sexual teasing or innuendo, taking sexual photographs, making someone look at pornography or watch sexual acts, sexual assault or sexual acts the adult didn't consent to or was pressured into consenting.

- Psychological

This includes emotional abuse, threats of harm or abandonment, depriving someone of contact with someone else, humiliation, blaming, controlling, intimidation, putting pressure on someone to do something, harassment, verbal abuse, cyber bullying (bullying which takes place online or through a mobile phone), isolation or unreasonable and unjustified withdrawal of services or support networks. It can include being pressurised to take part in illegal activity such as moving drugs and money (County Lines and Cuckooing).

- Financial or material

This includes theft, fraud, internet scamming, putting pressure on someone about their financial arrangements (including wills, property, inheritance or financial transactions) or the misuse or stealing of property, possessions or benefits.

- Modern slavery

This covers slavery (including domestic slavery), human trafficking and forced labour. Traffickers and slave masters use whatever they can to pressurise, deceive and force individuals into a life of abuse and inhumane treatment.

- Discriminatory

This includes types of harassment or insults because of someone's race, gender or gender identity, age, disability, sexual orientation or religion. Discriminatory abuse can also be called a "hate crime".

- Radicalisation

This refers to people who may be at risk of radicalisation and under the Prevent Strategy (2011), persons vulnerable to radicalisation should be supported to prevent any illegal activity taking place. The aim is to reduce the likelihood of individuals who support a violent extremist ideology of becoming terrorists.

There is no single profile of a person likely to become involved in extremism and the process of radicalisation is different for every individual. Radicalisers use normal social processes such as loyalty, self-perception, and fear of exclusion to influence others.

Signs that an individual may be being groomed into extremism could be:

- vulnerable individuals becoming withdrawn and stopping participating in their usual activities
- they may express feelings of anger, grievance injustice or go missing from their home, school or care setting
- a new group of friends who have an extremist ideology
- using language that supports 'us and them' thinking
- or possessing or searching for extremist literature online.

Abuse or neglect can take place at home, in a care home, in a hospital, in a day centre, at work, school or college or outside in the community. The harm may be caused by a partner, carer, relative, friend, care worker, stranger or someone else with care and support needs and it may be deliberate or unintentional. Whatever the circumstances, it is important that you report your concerns.

What to do if you suspect someone is at risk of abuse:

- Make an evaluation of any risks and take steps to ensure that the adult or others are not in immediate danger. Ensure that other people are also not in danger.

- If a crime is in progress, or life is at risk, dial emergency services on 999.
- Encourage and support the adult to report the matter to the police if a crime is suspected and not an emergency.
- Safeguard any potential evidence. Do not tamper with, clean up or move any potential evidence if a crime is suspected. Expert advice may be needed from the police.
- If you believe a crime has been committed, contact the police and then contact Adult Social Care.
- **Contact Children’s Services if a child or young person is at risk.** Brighton and Hove City Council (<https://www.brighton-hove.gov.uk/>), Telephone: 01273 290 400 or email: FrontDoorForFamilies@brighton-hove.gcsx.gov.uk
- Record any information received and all actions taken.

Good practice guidance to disclosure

- Talk with the adult as soon as possible unless this would put them, others or you at risk.
- Speak in a private and safe place.
- Accept what the adult is saying without judgement.
- Don’t ‘interview’ the adult - just gather information to establish the basic facts. This will help when you inform Adult Social Care or the police. Ask the adult what they would like to happen.
- Never promise the adult that you’ll keep what they tell you confidential; explain who you will tell and why.
- If there are grounds to override an adult’s consent to share information, explain what these are.
- Explain to the adult how they will be involved and kept informed.
- Provide information and advice on keeping safe and the safeguarding process.
- Keep an accurate record of your conversations, and actions or decisions taken by you and others.

Who to contact (for vulnerable adults in Brighton and Hove)?

In an emergency, phone the police on 999.

Monday to Friday, 8:30am to 4.30pm, phone the Access Point on 01273 29 55 55, or send an email to hascsafeguardinghub@brighton-hove.gov.uk. Outside these hours, calls will be answered by Carelink Plus.

If you think a crime has taken place, but it’s not an emergency, phone Sussex Police on 101.

Appendix W. Protocol for managing a participant in distress over the telephone

This protocol has been adapted from Draucker *et al.*, (2009) and Haigh and Witham (2013). Most participants tolerate research on sensitive subjects and benefit from taking part. Some participants may experience unanticipated upset, and this does not mean that they will go on to harm themselves. It is rare, but some participants may report a negative experience, (Draucker *et al.*, 2009).

At the start of the interview

- Minimising the risk of exacerbating distress

The first step is to check in with the participant at the start of the interview with how they are feeling and as part of obtaining informed consent that they agree to continue with the interview. If they are not, feeling ok and this is not a good time for them, then an alternative interview date and time needs to be set.

During the interview

- Indicators of distress

A participant indicates they are experiencing a high level of stress or emotional distress which may be suggested by them stating that i) they are finding the interview difficult/stressful or exhibiting symptoms such as becoming choked when talking or alternatively withdrawn/non-communicative, ii) they are considering hurting themselves, or iii) they are considering hurting someone else.

- Stage 1: response

Stop the discussion/interview.

Ask them: Tell me what thoughts you are having? Tell me what you are feeling right now? Do you feel you are able to go on about your day? Do you feel safe?

- Review

If the distress reflects what would be expected in an interview on a sensitive topic, ask if participant feels able to carry on; resume interview/discussion

If the distress is acute, they are not feeling safe and at risk of hurting themselves Go to stage 2

- Stage 2

Encourage the participant to contact their GP or mental health provider OR

Offer, with participant consent, to do so on their behalf.

Ask if there is a family member or friend, they can contact to keep them company whilst support is being sought

In the event that someone is in imminent danger then call the emergency services (999).

- Follow up

Follow participant up with courtesy call (if participant consents)

Appendix X. List of participants ID numbers and correlating health conditions

Participant's health conditions associated with their numerical identity.

ID no.	Health conditions
1	Migraine, back pain, anxiety, and depression
3	Irritable bowel syndrome (IBS), Raynaud's disease, anxiety, and depression.
4	Anxiety and depression. Reported self-harming
5	Asthma and polycystic ovary syndrome (PCOS)
6	Anxiety, depression, body dysmorphia, and endometriosis
8	Spasmodic croup, asthma, and polycystic ovary syndrome (PCOS). Having investigations for weight loss and nausea.
9	Migraine, anxiety, depression, asthma, postural orthostatic tachycardia syndrome (PoTS), attention deficit hyperactivity disorder (ADHD), borderline personality disorder (BPD), and autism. Having further investigations for gastric symptoms, breathlessness and sinus tachycardia.
10	Eczema and ulcerative colitis
11	Attention deficit disorder (ADD), anxiety, depression, and cystic acne. Reported self-harming.
12	Eating disorder, anxiety, depression and borderline personality disorder (BDP). Reported self-harming.
13	Eczema, depression, anxiety and postural orthostatic tachycardia syndrome (PoTS).
14	Eczema, depression, anxiety, agoraphobia and hidradenitis suppurativa (HS). Reported self-harming.
15	Severe depression and generalised anxiety disorder. Waiting to be assessed for attention deficit hyperactivity disorder (ADHD). Reported self-harming
16	Depression, post-traumatic stress disorder (PTSD), adenomyosis and endometriosis, and sciatica.
17	Generalised anxiety disorder, post-traumatic stress disorder (PTSD), and molar pregnancy.
18	Autism, depression, and anxiety. Reported self-harming.
19	Asthma, hypermobility, autism, associative disorder, and PTSD.
20	Anxiety, depression, agoraphobia, hypermobility, PTSD and having investigations for endometriosis. Reported self-harming
21	Partially diagnosed autism, asthma, and an eating disorder. Has been living with symptoms of ADHD since childhood

Appendix Y. The agential approach to communicating with children and young people seeking support in a mental health crisis.

Aspects of agency	Goals	Examples of techniques
An agent is a subject of experience and their perspective matters.	Validate	Treat the person's feelings as valid: <i>"It's a really horrendous event."</i> <i>"That's a scary thought."</i> Treat the person's story as important: <i>"Thank you for being so open and honest about these things."</i>
An agent can take action to change their situation by seeking help.	Legitimise help seeking	Commend the person for seeking help: <i>"Well done. . . you did exactly the right thing."</i> Encourage future help seeking: <i>"Our message to you today is that it's okay to talk to people about these things and it's very important that you do."</i>
An agent may have multiple and conflicting needs and interest	Refrain from objectification	Acknowledge a multiplicity of factors contributing to the mental health crisis: <i>"There's lots of things we've already talked about that are contributing to you feeling low at the moment."</i> Ask what may have been missed: <i>"Is there anything else we haven't talked about you think is important?"</i>
With adequate support, an agent can contribute to positive change.	Affirm capacity to contribute to change	Acknowledge changes they've already made: <i>"I think you should be really proud of what you've done."</i> Emphasise teamwork: <i>"It's about enabling you or supporting you to develop strategies and skills. . . And that's what the [mental health team] will be doing."</i>
With adequate support, an agent can participate in decision making	Involve in decision making	Ask for the person's perspective on treatment: <i>"What do you think about that [treatment option]?"</i> Ask about past experiences with treatment: <i>"What about the [previous treatment] was most helpful?"</i> Provide an overview of the options: <i>"Different things are right for different people. . ."</i>

(Bergen et al., 2022)