

# Journeys into and out of psychiatric hospitals: Supporting the recovery of young people with severe mental health disorders in health and education settings

Doctorate in Education

Institute of Education

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## **Declaration of Original Ownership**

I confirm that this is my own work and the use of all material from other sources has been properly and fully acknowledged.

Regina Cobbinah

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## **Abstract**

The burgeoning demand for specialist child and adolescent mental healthcare is placing a considerable strain on an overburdened system in England (Eley, 2022). Adequately and effectively supporting children and young people with mental health difficulties is essential to alleviate pressures on the system, especially on inpatient child and adolescent mental health services (CAMHS). Existing qualitative research has focused on gaining the views of children and young people about being supported by different professionals, in a range of settings, at discrete stages of their mental health recovery journey. However, few studies have explored the lived holistic experiences of young people who have been admitted to psychiatric hospital and their views about the support they receive. This qualitative study sought to listen to young people's voices and stories about their experiences of being supported in healthcare and education settings, as they journeyed into and out of psychiatric hospital.

This research adopted a narrative inquiry approach which was viewed from a constructivist interpretivist philosophical perspective. Semi-structured interviews were conducted with eight young women aged between sixteen and twenty-seven years. Prior to the interviews, data was collected using experience timelines completed by the participants. All verbal interviews were transcribed by the researcher and analysed using Thematic Analysis (Braun & Clarke, 2006).

By using Self Determination Theory (Deci & Ryan, 1985) as a theoretical framework, the findings from this study provided further evidence that young people's basic psychological needs of autonomy, relatedness and competence are frustrated when their needs are not placed at the heart of their healthcare. The young people's needs were: to be listened to and be part of decision-making; to receive personalised care and support; and to receive compassionate and respectful care. Additional needs that young people expressed were: to feel a sense of connectedness to their school and have continuity of learning as well as connectedness with peers. Although the sample size was small, this study highlighted the young people's desire to have a sense of autonomy in their mental health recovery. By supporting this basic need as well as providing environments in which relatedness and competence can be fostered, healthcare and education professionals can support young people more effectively to encourage positive health and education outcomes.

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## List of Acronyms

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
A&E	Accident and Emergency
AMHS	Adult Mental Health Services
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Services
CAQDAS	Computer Assisted Qualitative Data Analysis
CBT	Cognitive Behavioural Therapy
CFT	Compassion-Focused Therapy
COVID-19	Coronavirus Disease 2019
CPA	Care Programme Approach
CYPMHS	Children and young people's mental health services
DSL	Designated Safeguarding Lead
DSM	Diagnostic and Statistical Manual of Mental Disorders
EMHP	Educational Mental Health Practitioners
GCSE	General Certificate of Secondary Education
GP	General Practitioner
HCP	Health Care Professional
HRA	Health Research Authority
IAPT	Improving Access to Psychological Therapies
ICD	International Classification for Diseases
IPA	Interpretative Phenomenological Analysis
LADO	Local Authority Designated Officer
MHFA	Mental Health First Aid
MHST	Mental Health Support Team
NHS	National Health Service
OCD	Obsessive Compulsive Disorder
PICU	Psychiatric intensive care unit
PSHE	Personal, Social, Health and Economic (Education)
SDT	Self-determination Theory
UNCRC	United Nations Convention on the Rights of the Child
UREC	University of Reading's Ethics Committee
WHO	World Health Organization

# 1 Introduction

Supporting the mental health of children and young people has become a national and global priority, especially in the wake of the 2020 global pandemic of coronavirus disease 2019 (COVID-19) (Cowie & Myers, 2021; Young Minds, 2021). In England, the provision for children and young people with mental health difficulties has received a considerable amount of media attention (BBC News, 2023; The Guardian, 2023). A plethora of government initiatives and plans have also been introduced in recent years to address this pressing issue and the parity of esteem between physical and mental health (Department of Health, 2015; Department of Health and Department for Education, 2017; Mental Health Taskforce, 2016). However, meeting the needs of young people with mental health difficulties, especially those with complex and severe needs which require psychiatric hospitalisation, continues to be a challenge (Children's Commissioner, 2022). The purpose of this research therefore, was to add young people's voices to the public discourse about the provision of support for children and young people in England experiencing mental health difficulties.

This qualitative research focused on the lived experiences of eight young people with mental health disorders, who had journeyed into and out of psychiatric hospitals. By adopting an interpretivist constructionist stance and conducting data-prompted semi-structured interviews (Kwasnicka et al., 2015; Wilson et al., 2007), this study explored the perceived support needs of this population of young people. By listening to their voices and stories, the ultimate aim was to gain insight into the views of young people about how healthcare and education professionals in particular, can support young people's needs more effectively.

The following sections of this introductory chapter provide an overview of the study. Firstly, a case is made for this research by presenting background to the topic under consideration. It outlines the research problem and rationale for the study. An overview of this research then sets out the aims of the research and the research questions. This is followed by an explanation of the significance of the study and the origins of the study. An overview of the structure of this thesis concludes this chapter.

## 1.1 Context for the Study

Globally, it is estimated that between ten and twenty percent of adolescents experience mental disorders (World Health Organization, 2020), with half of these beginning by the age of fourteen and three-quarters by mid-twenties (Kessler et al., 2005). In England, the prevalence of mental disorders in children and young people has increased during the past two decades (Vizard et al.,

2020). The impact of the COVID-19 global pandemic has also been significant. Between 2017 and 2021, rates of mental disorder in 6 to 16 year olds, increased from one in nine to one in six, and from one in ten, to one in six in 17 to 19 year olds (Newlove-Delgado et al., 2021). According to the Royal College of Psychiatrists, the number of children under the age of eighteen who were referred to mental health services in 2021 increased by 134% and 96% compared to figures in 2020 and 2019 respectively (Royal College of Psychiatrists, 2021). Furthermore, although a slight decreasing trend has been reported for the number of children and young people under the age of eighteen years admitted in inpatient psychiatric wards (Statistics Briefing, 2021), there has been a stark increase in the number of young people admitted to accident and emergency departments with psychiatric problems in the past decade (Lintern, 2020). The COVID-19 global pandemic has also made this issue of child and adolescent psychiatric inpatient admissions a growing concern (Reece & Sams, 2021).

## **1.2 Identifying the Problem**

The increasing prevalence of mental health disorders in England is placing a strain on child and adolescent mental health services (CAMHS), the specialist mental health services for children and young people in England (Children's Commissioner, 2020; Department of Health, 2015). Mental health problems also affect the educational outcomes of young people (Veldman et al., 2014). Children and young people with complex or serious mental health difficulties are more likely to experience poorer educational outcomes without adequate support (Lereya & Deighton, 2019). Their mental health disorders can result in poor school attendance (Finning et al., 2017) and academic attainment (Johnston et al., 2014). Young people are also at risk of school exclusion (Ford et al., 2018; Parker et al., 2014), dropping out (Hjorth et al., 2016) and not being in education, employment or training (Cornaglia et al., 2015). Furthermore, young people with mental health disorders can face major challenges with stigma, isolation and discrimination (Henderson & Gronholm, 2018; Moses, 2010b). These experiences can undermine a young person's sense of wellbeing and even contribute to suicidality (Corker et al., 2016; Henderson & Gronholm, 2018).

Adolescents who experience inpatient psychiatric admissions are at even greater risk due to the amount of time they are absent from school before, during and after hospitalisation (Clemens et al., 2011; Edwards et al., 2015; Iverson, 2017). While in hospital, young people also have concerns about falling behind with their school work which can lead to stress of having to catch up (Claveirole, 2005; Painter, 2008). This can have an impact on young people's long term goals such as the opportunity to take examinations. Furthermore, young people can be exposed to trauma, risks and unhelpful and even harmful experiences during their hospitalisation (Edwards et al., 2015;

Moses, 2011). There is also the possibility of rehospitalisation following discharge from inpatient care (Ådnanes et al., 2020; Feng et al., 2017). Psychiatric hospital readmissions and young people's dependence on support from inpatient healthcare services are costly and also places extra demand on already struggling services (Miller et al., 2020). The impact on the young person's educational attainment and achievement as well as peer relationships and social connectedness also continues. In addition, rehospitalisation can cause young people and their families significant psychological distress (Joyce et al., 2019).

Supporting young people with mental health difficulties, especially those with complex and severe disorders, is therefore important to help them to navigate what can be a difficult and traumatic time in their lives.

### **1.3 Significance and Importance of the Study**

Despite the known challenges faced by young people with severe mental health disorders, few studies have focused on listening to the voices of adolescents about their experiences and the support they receive. This is in spite of the recognition that the perspectives of mental health service users, including children and young people, is essential in improving healthcare outcomes (Worrall-Davies & Marino-Francis, 2008). In addition, it is important to listen to the views of young people about the joint working between health and education professionals, which lies at the heart of child mental health policy in the UK (Department for Children Schools and Families, 2008; O'Reilly et al., 2013; Salmon, 2004).

Existing qualitative studies have sought young people's views about health-related support from outpatient mental health services (Bone et al., 2015; Davison et al., 2017; Persson et al., 2017) and inpatient psychiatric hospitalisation (Gill et al., 2016; Haynes et al., 2011; Moses, 2011; Wallstrom et al., 2020). Others have explored support in mainstream educational settings (Hart, 2017; O'Connor, 2012) as well as in inpatient hospital schools (Ward, 2014). A few others have highlighted young people's experiences of returning to school after inpatient psychiatric hospitalisation (Iverson, 2017; Preyde et al., 2018; Preyde et al., 2017; Simone, 2017). However, there is a lack of research which considers the holistic experience and support of young people who have been admitted to psychiatric hospital (C. Hayes et al., 2020). Furthermore, an ecological perspective offered by Savina et al. (2014) highlighted the need for more research about "children's feelings and experiences associated with hospitalisation and the transition back to family, school and community" (p. 740).

This research therefore sought to make a significant contribution to the existing body of literature by listening to the voices and stories of young people who had been through the holistic experience of being supported by healthcare and education professionals in community and inpatient CAMHS and education settings. The aim of this study was to gain insight into young people's experiences of journeying into and out of psychiatric hospital and explore their retrospective views about the support they received from healthcare and education professionals and how this could be improved. These experiences and suggested improvements could be of interest to professionals as they work together to enable successful outcomes in terms of recovery for young people with severe mental health disorders.

#### **1.4 Research Questions**

The main research question (MRQ) and sub-questions (SRQs) that this study aimed to address were as follows:

MRQ: How do young people with severe mental health disorders perceive their experiences within the systems of healthcare and education as they journey into and out of psychiatric inpatient hospital?

SRQ1: How do young people experience receiving support in healthcare settings?

SRQ2: How do young people experience receiving support in education settings?

SRQ3: What do young people want to share with healthcare and education professionals about supporting their mental health recovery journey?

#### **1.5 Origin of the Study**

This study originates from a developing interest in young people's mental health, initiated when I became a teacher in an adolescent psychiatric hospital teacher five years ago. My role as a hospital teacher places me in a unique position of working collaboratively with healthcare professionals and education professionals in a wide range of settings to support young people with severe mental health disorders. These young people, some with complex issues and backgrounds, would most often have received a significant amount of support in the community prior to their hospitalisation. A noticeable proportion would also have experienced multiple psychiatric hospitalisations. Being acutely aware of the pressures faced by CAMHS in meeting the burgeoning demand on services, I was curious to know about the young people's stories and the impact that the support they received had had on their recovery journeys. This study therefore provided an opportunity to gain insight

into the personal journeys of adolescents who have been through the experience of psychiatric hospitalisation. By exploring the support provided by healthcare and education professionals during their journeys, this study would inform my practice as a hospital teacher, working alongside other professionals.

## **1.6 Overview of Thesis**

This thesis is made up of six chapters. The first chapter has outlined the problem under consideration, namely that young people with severe mental health disorders who experience inpatient psychiatric hospitalisation are at risk of poor outcomes without adequate and effective support. It has also established the aims of the study and the research questions that will be addressed.

Chapter Two is a review of existing literature. It outlines the conceptual and theoretical frameworks for this research and briefly discusses the healthcare and education systems designed to support young people with mental health difficulties. This chapter reviews existing literature which explore young people's experiences and views about some of the factors that influence their mental health recovery.

Chapter Three details the methodological approaches adopted for this study. It is recognised that there are risks in seeking the views of young people who have had a mental health disorder and who may still be vulnerable, hence the steps taken to ensure that this research adheres to sound ethical principles are also outlined in this chapter.

Chapter Four presents the findings from eight adolescents interviewed in this study. Their individual retrospective experiences and views about the support they received as they journeyed into and out of inpatient psychiatric hospitals are presented.

Chapter Five is a discussion of the common themes raised by the eight research participants.

Chapter Six concludes the thesis and discusses the implications of this research for policy and practice and suggests recommendations for future research. It also acknowledges the limitations of this study. Finally, the researcher's reflections on personal and professional development as a result of this research are shared.

## 2 Literature Review

### 2.1 Introduction

This chapter discusses literature that is relevant to the focus of this study which is supporting the recovery of young people with severe mental health disorders in healthcare and education settings. Due to this breadth of focus, the search for literature covered a wide range of topics including child and adolescent mental health, child and adolescent mental health services (CAMHS), mental health recovery, psychiatric hospitalisation and re-hospitalisation, mental health support in schools and school reintegration. Databases such as Education Research Complete (ERC), the University of Reading's Summon Discovery Service, EThOS and Google Scholar were extensively searched between January 2019 and December 2020 and continued throughout the research study. Studies conducted from 2000 onwards were included as this year represents a key milestone in modernising the NHS and mental health services in the UK (Department of Health, 2000). Nonetheless, any significant research conducted prior to this date was included to provide context where necessary. 'Grey literature' including government documents and independent reports from relevant institutions were also included to add breadth and depth to discussions. Additional studies were also identified by searching the reference lists of key papers retrieved from database searches.

Existing literature was screened against exclusion criteria including: papers not written in English Language; newspaper articles and book reviews; literature about the experiences of children aged less than twelve years and adults; papers unrelated to young people with mental health difficulties; and papers related to the CAMHS experience of specific groups of children and young people (e.g. homeless, children in care, refugees). Quantitative studies and literature related to the psychology of mental health were also not considered.

The purpose of this literature review is twofold. Firstly, it aims to examine the current healthcare and education provision to support young people with mental health difficulties. Secondly, this review seeks to explore some of the factors that facilitate or hinder the mental health recovery of young people. In order to provide context for this study, the key concepts and the conceptual and theoretical frameworks adopted are discussed. The terminology used in this thesis for some of the key concepts are also stated. This is followed by a brief overview of existing health and education systems in place to support children and young people with mental health difficulties. The third section explores literature that highlight some of the factors that facilitate and hinder the mental health recovery of young people. The chapter concludes with the research questions that have been formulated from this review of the relevant literature.

### **2.1.1 Concepts and Conceptual and Theoretical Frameworks**

As the focus of this study is to listen to the voices of young people, the terms adolescence and the concept of the ‘child’s voice’ are briefly explained in the first instance. A discussion of mental health and mental health recovery and associated conceptual and theoretical frameworks are then discussed in the remainder of this section.

### **2.1.2 Adolescence**

It is widely acknowledged that adolescence is a “distinct period of biological, psychological and social development” (Blakemore, 2019, p. 2030). However defining the ages associated with adolescence seems to be less straightforward (Sawyer et al., 2018). Commonly cited age ranges for adolescence proposed by The World Health Organization (WHO) (1965, 2001a) include 10 to 20 years and 10 to 19 years. However, Sawyer et al. (2018) argue that age definitions are arbitrary and can be influenced by cultures and contexts in different countries. They suggest that the age range of 10 to 24 years is a “better fit with the development of adolescents nowadays” (p. 5). Other terms used in literature which either encompass or which are sub-sets of this age group include children, young people, young adults and youth (Sawyer et al., 2012; United Nations Convention on the Rights of the Child, 1989; World Health Assembly, 1989). In this thesis, the participants were aged between 16 and 27 years. Although this falls outside of the age ranges outlined, the terms children, adolescent, young people and young adult are used interchangeably for simplicity in this thesis.

### **2.1.3 Child’s Voice**

The concept of the ‘child’s voice’ was partly influenced by the United Nations Convention on the Rights of the Child (UNCRC) (1989) which set out the rights of children to be informed, involved and consulted about decisions that affect their lives. In the UK, several sectors including health and education, are also obligated to consult children and young people in decision making processes (“Children Act,” 2004; “Children and Families Act,” 2014; Department for Education and Department of Health, 2015). This has resulted in a growing body of literature related to the rights of children and young people to participate in healthcare research (Clarke, 2015; Claveiro, 2004) and the concept of pupil voice or participation in education settings (Lundy, 2007; Rudduck & Flutter, 2000). It can be argued that in research, the topic under consideration may not be fully explained without the views of all the stakeholders including children and young people (Kellett,

2010). Listening to the child's voice is therefore paramount in getting the child's truth and capturing what their life experiences are. However, conducting research with adolescents with mental health difficulties can be challenging (Claveirole, 2004) and needs to balance young people's rights against the requirement to protect their best interests (Greig et al., 2013). Nonetheless, Persson et al. (2017) argue that involving young people in developing "youth-friendly services" (p. 140) has important implications in young people's help-seeking behaviours. Indeed, the outcomes for young people supported by mental health services are increasingly being linked to their empowerment via their inclusion in decision-making and engagement in processes (Larsson et al., 2018). Similarly, pupil participation in decision-making in education settings has the potential to improve engagement, productivity and behaviour (Flutter & Ruddock, 2004).

In summary, young people have great insight into what they need and what is right for them. It is therefore important to listen to them so that they feel empowered. This study sought to give young people with severe mental health disorders, a voice to tell their experience of being supported in healthcare and education settings, from their point of view. This stance influenced the methodology and choice of research design adopted for the study which are explained in Chapter 3.

#### **2.1.4 Adolescence and Mental Health**

Adolescence, as previously mentioned, is a period of significant mental and emotional development accompanied by unique physical and mental health needs (World Health Organization, 1965). Although most young people develop into healthy adults, adolescence is a time when individuals are vulnerable to mental health problems (Blakemore, 2019). Kessler et al. (2005) reports that half of the mental health difficulties experienced by young people begin by the age of fourteen and three-quarters by mid-twenties.

Mental health is a complex multifaceted construct which is often associated with the concept of mental or psychological wellbeing. Michaelson et al. (2012) defines mental wellbeing as "how people feel and how they function, both on a personal and a social level, and how they evaluate their lives as a whole" (p. 6). It is therefore an indicator of social, emotional and physical wellness (Robson, 2019) and is often referred to using terms such as life satisfaction, happiness and subjective wellbeing (Diener et al., 2018; Maccagnan et al., 2018). The World Health Organization's (WHO) (2004) definition of mental health is commonly cited in literature and reflects its symbiotic relationship with mental wellbeing.

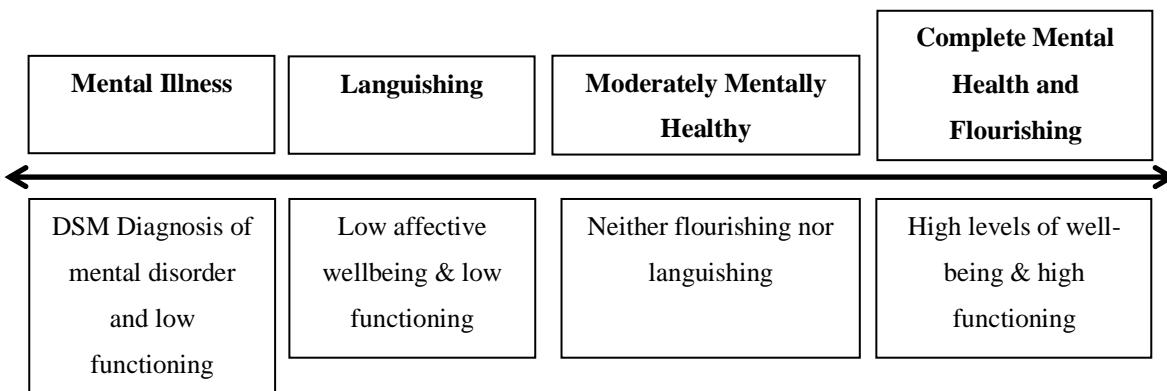
*“Mental health is a state of wellbeing in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.”* (p. 10)

It is clear from this definition that the ability to manage life’s stresses is essential to maintain good physical and mental health and wellbeing.

However, Galderisi (2017) argues that the World Health Organization’s definition “might be misleading and convey the false expectation that mental health coincides with happiness and productivity” (p. 1). They highlight the relationship between mental health and the concept of resilience, a defence mechanism which enables people to respond to adversity or traumatic and challenging situations (Aburn et al., 2016; Herrman et al., 2011). Galderisi et al. (2015) also suggest that while an individual’s mental health can vary throughout life in a state of “dynamic internal equilibrium” (p. 231), mentally healthy individuals have sufficient resilience to restore this internal equilibrium when they experience difficult emotions in the course of their lives. Their view of mental health therefore acknowledges the fact that different life epoch such as adolescent crises, requires a young person’s resilience as well as their active and continuous search for mental equilibrium.

This dynamic state of internal equilibrium is aptly captured in Keyes’ (2002) mental health continuum model illustrated in Figure 2.1. He describes the dynamic range in which individuals function from an extreme state of low functioning with mental illness at one end to high functioning with complete mental health and flourishing at the other. Keyes’ model demonstrates that it is possible for individuals living with mental health disorders to experience positive mental health but also for individuals to experience poor mental health without a mental health disorder (Constitution of the World Health Organization, 1946).

Figure 2.1 Mental Health Continuum (Keyes, 2002)



As previously discussed, mental health problems can start to develop for some individuals, when the normal stresses of life cannot be adequately managed. These problems can be hard to be define (British Medical Association Board of Science, 2006) but cover a range of problems from normal worries and concerns about everyday events, to serious disabling conditions which require medical treatment including intensive care and treatment in hospital (Frith, 2017; Kinsella & Kinsella, 2015). The Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association, 2013) is an internationally recognised system of psychiatric classification for mental or behaviour disorders. Common classifications for child and adolescent disorders include emotional disorders such as anxieties, phobias and depression; hyperkinetic disorders such as attention-deficit hyperactivity disorder (ADHD) and attention deficit disorder (ADD); conduct disorders; autism spectrum disorder (ASD); and psychotic disorders. The International Classification for Diseases (ICD) (World Health Organization, 2019) is also another recognised system which classifies these disorders. Although different levels of severity of mental health problems exist, this research focused on young people with diagnosable mental disorders which resulted in significant difficulties with their emotional, behavioural or social functioning and which caused personal distress (World Health Organization, 2001b). The participants in this study had all suffered from debilitating illness which resulted in psychiatric hospitalisation. The terms mental health problems, mental health difficulties and mental health disorders are also used interchangeably in this thesis to describe the health issues that the participants experienced.

### **2.1.5 Mental Health Recovery**

Recovery is a concept whose definition has shifted in recent decades. Historically, recovery from physical illness or disability was viewed as a single outcome where an individual regained their health completely after an illness (Resnick et al., 2005). However, this perspective has shifted to one where an individual can recover from illness, even though the symptoms and suffering still exist or functioning may not be completely restored, as illustrated in Anthony's (1993) well cited definition:

*Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. (p. 527)*

Anthony (1993) further asserts that recovery from a mental health disorder is a complex process involving not only recovery from illness, but also recovery from stigma and the adverse effects of medical treatment as well as the lack of opportunities to exercise self-determination. Furthermore, young people with mental health disorders in Drake and Whitley's study (2014) described mental

health recovery as a journey “characterized by a growing sense of agency and autonomy, as well as greater participation in normative activities, such as employment, education, and community life” (p. 236).

In order to provide clarity and a comprehensive understanding of personal recovery, conceptual models or frameworks have been proposed. Based on a large systematic study of schizophrenia, Resnick et al. (2005) identified four domains of mental health recovery: “empowerment, hope and optimism, knowledge and life satisfaction” (p. 119). An additional systematic review by Leamy et al. (2011) provided a conceptual framework made up of three domains comprising “characteristics of the recovery journey, recovery processes and recovery stage descriptions” (p. 449). The five recovery processes were “connectedness, hope and optimism about the future; identity; meaning in life; and empowerment (giving the acronym CHIME)” (p. 445).

These two conceptual frameworks were based on studies involving adults and have been criticised for their limited application to young people (Friesen, 2007; Law et al., 2020). Law et al. (2020) argue that definitions and models of personal recovery based on the adult population “may fail to account for developmental and contextual factors specific to young people” (p. 464). Nonetheless, their qualitative study with twenty-three young people identified similarities with adult literature but also highlighted the importance of young people’s social systems in their personal recovery. These findings are echoed in a thematic model of young recovery proposed by Rayner et al. (2018). Their model, made up of “ecological systems and youth recovery processes” (p. 335), identified several systemic and macro level factors such as family, peers, school and access to professional support, which influence young people’s mental health recovery. At a personal level, Rayner et al. (2018) found that self-belief and resilience were important in recovery. This link between developing resilience, a concept discussed in the previous section and mental health recovery was also reported in a study by Friesen (2007). Service providers in his study acknowledged the need to incorporate resilience-building interventions when supporting young people within mental health services. Furthermore, at a systemic level, Rayner et al.’s (2018) model highlights the important role that education plays in the recovery of young people with mental health disorders (see section 2.3).

The conceptual frameworks discussed in this section are summarised in Table 2.1. Ralph & Muskie’s (2000) review of recovery literature identified four key aspects of recovery from personal narratives, namely “internal factors; self-managed care; external factors; and empowerment” (pp. 11-12) which aptly sums up these frameworks.

Table 2.1 Recovery Processes in Conceptual Models

Resnick et al. (2005)	Leamy et al. (2011)	Rayner et al. (2018)
Empowerment	Connectedness	Self-Belief and Resilience
Hope and Optimism	Hope and Optimism about the future	Responsibility and Personal Agency
Knowledge	Identity	Identity, Awareness and Acceptance
Life Satisfaction	Meaning in Life	Connection
	Empowerment	Hope and Positive Expectation

In this study, Rayner et al.'s (2018) conceptual model for mental health recovery was adopted due to its relevance for supporting young people with severe mental health difficulties. It provided a conceptual framework to explore some of the barriers and facilitators of mental health recovery as the participants journeyed into and out of psychiatric hospitals.

Nonetheless, Mancini (2008) asserts that the concept of mental health recovery also needs to be supported by a sound theoretical framework. He suggests that there is an overlap of the key conceptual ideas of recovery and those of Self-determination Theory (Ryan & Deci, 2000). This is also supported by Onken's (2003) view that self-determination is a fundamental part of personal recovery. This theoretical framework is briefly discussed in the next section.

### 2.1.6 Self-determination Theory

Self-determination Theory (SDT) is a theory of motivation, development and wellness (Deci & Ryan, 1985). According to this theory, autonomously motivated individuals experience a sense of volition in pursuing activities that are a source of interest, enjoyment or value. This can result in enhanced wellness, engagement or performance. Self-determination Theory posits that satisfying an individual's need for autonomy as well as their additional basic psychological needs of relatedness and competence, results in optimal outcomes in terms of wellness, engagement and performance (Ryan & Deci, 2000).

Self-determination Theory can therefore help to make sense of the motivations behind an individual's behaviour. Research studies using a SDT approach suggest that mental healthcare environments can foster treatment engagement and health recovery when a patient has a sense of

autonomy, feels cared for and has opportunities to develop competence (Gaine et al., 2021; Mancini, 2008). Similarly, satisfying these needs in education settings has been found to enhance autonomous motivation in students and promote positive outcomes such as an “interest in learning, a valuing of education, and a confidence in their own capacities and attributes” (Deci et al., 1991, p. 325).

In this study, Self-determination Theory was adopted due to its close alignment with the conceptual ideas of mental health recovery discussed in the previous section. It provided a theoretical framework to explore some of the factors that helped or hindered the participants’ motivation and determination to make steps towards recovery in healthcare and education settings. This theory also influenced the methodological design choices for this study which are discussed in Chapter 3.

### **2.1.7 Section Summary**

This section discussed the key concepts of this research, namely adolescence, the child’s voice, mental health and mental health recovery. The review of relevant literature has highlighted that young people’s support networks form part of an ecological framework which is central to the understanding of mental health recovery. The next section of this chapter briefly discusses the existing healthcare and education systems designed to support children and young people with mental health difficulties.

## **2.2 Supporting young people with mental health difficulties**

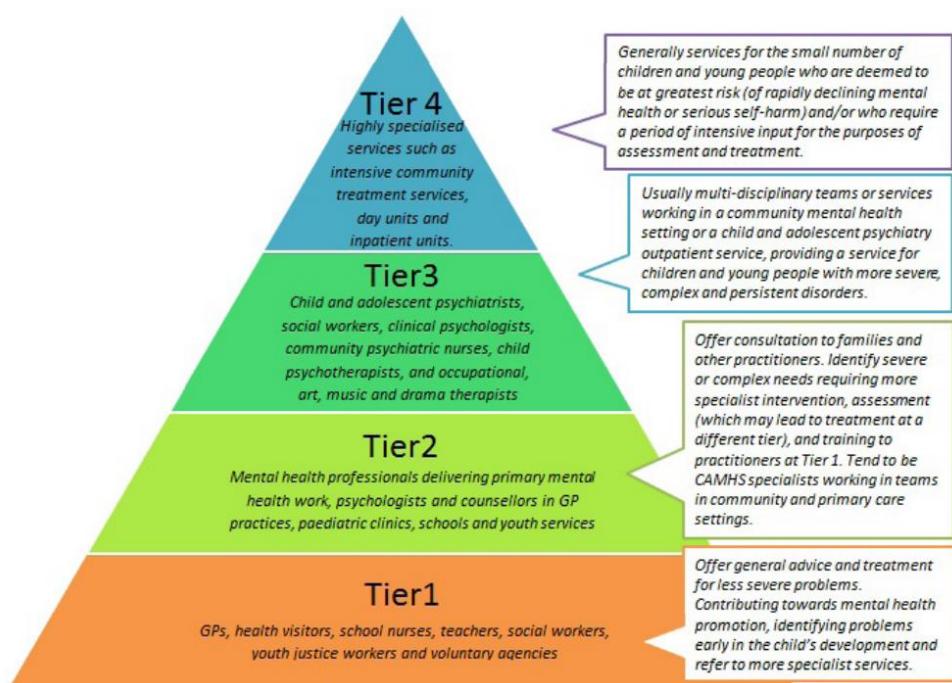
Children and young people experiencing mental health difficulties will come into contact with a wide range of professionals within the mental health services. Professionals in schools and colleges also provide support as they navigate the healthcare system. This section briefly explains the mental health services in the UK and the role of education settings in meeting young people’s health and education needs.

### **2.2.1 Support in Mental Health Services**

In the UK, children and young people’s mental health services (CYPMHS) is an umbrella term that refers to all types of services that work with children and young people up to the age of eighteen, who experience difficulties with their mental health and wellbeing (National Health Service, 2019). The more common term, child and adolescent mental health services (CAMHS), refers to specialist mental health services funded by the National Health Service (NHS). CAMHS was originally

commissioned and established to improve mental health services for children, young people and their families, by addressing a disjointed organisation of mental health provision and inequality in delivery of services (NHS Health Advisory Service, 1995). The four-tiered model of care (Department of Health, 2017), which was conceptualised based on the severity and complexity of young people's mental health difficulties, is still widely used today (see Figure 2.2).

Figure 2.2 The four-tiered CAMHS model of care (Department of Health, 2017, p. 5)



Within Tier 4 CAMHS, care is offered in different types of services and includes general adolescent units (GAU) and psychiatric intensive care units (PICU) (National Health Service, 2014). The creation of CAMHS was widely viewed as a positive step to raise the profile of the specific needs of children and young people. It also helped to establish a national strategy to organise, plan and deliver a comprehensive mental health service to meet the holistic needs of this population (Cottrell & Kraam, 2005). Although the CAMHS model is helpful to identify the different forms of support available to children and young people (House of Commons Health Committee, 2014), it is considered to be outdated and unhelpful because it "reinforces distinctions between different types of services" (Parkin & Long, 2021, p. 9). The system has also been described as being "complex and fragmented" (Care Quality Commission, 2017, p. 2) and criticised for disparities in provision based on location (Lidchi & Wiener, 2020). In order to address some of these criticisms of CAMHS, some NHS children's mental health services are based on an alternative model of care, the THRIVE

framework (Wolpert et al., 2014). This approach is considered to be “needs-led” rather than being based on “severity, diagnosis or health care pathways” (Wolpert et al., 2019, p. 4).

Nonetheless, the whole system of children’s mental health care is reported to have “serious and deeply ingrained problems” (House of Commons Health Committee, 2014, p. 10) and has been described as a “‘Cinderella service’ within the NHS” (Children’s Commissioner, 2021, p. 5) due to the large number of children and young people unable to access treatment. The postcode lottery in mental health remains where young people experience lengthy waiting times for a CAMHS referral, sometimes only to have their referral closed before treatment is accessed. In addition, less than a third of children who are likely to have a clinically diagnosable condition are being treated in some areas (Children’s Commissioner, 2021).

Schools and colleges are therefore widely recognised as best placed to play a key role in early intervention support of adolescents experiencing mental health difficulties (Thorley, 2016). The next section explores the support that education settings such as schools and colleges offer children and young people experiencing mental health difficulties.

### **2.2.2 Support in Education Settings**

Education settings such as schools and colleges are considered to be in a unique position to help promote, protect and prevent young people’s mental health problems from escalating to more serious mental health difficulties (Department of Health and Department for Education, 2017). Through a whole-school targeted approach, these settings can help to foster an environment where positive mental health and wellbeing is promoted. In addition, they can intervene early when there are signs to indicate that a young person is experiencing mental health difficulties (Carroll & Hurry, 2018; Weare, 2000). By delivering mental health awareness sessions widely within schools and colleges, the stigma of mental health which is perceived to be more obvious in school, can also be challenged and the services available to young people can be promoted (Coyne et al., 2015; Davison et al., 2017).

Hart (2017) also suggests that schools need to “work hard at promoting a safe, more caring, empathetic, and compassionate environment” (p. 27) for young people with mental health difficulties. She asserts that adolescents benefit from having time and space to regulate their negative emotions in an allocated quiet and private space. Young people also need to be able to voice their difficulties and needs in school (Hart, 2016). This view was also expressed by young people in Cefai and Cooper’s study (2010) who saw the school system as “oppressive” and

“suffocating” (p. 189), with few opportunities to express their voice. Furthermore, young people have expressed the need for whole school activities that enhance emotional health as well as readily available, confidential and sympathetic school-based help sources (Kidger et al., 2009). In addition, the school social environment and organisational climate, as well the way school is structured, all have a negative impact on some young people when they return after inpatient hospitalisation (Preyde et al., 2017).

There are concerns, however, that these expectations put significant pressures on teachers who do not feel adequately trained and confident to fulfil this role without the support of specialist mental health professionals (House of Commons Education and Health and Social Care Committees, 2018; O'Reilly et al., 2018; Rothi et al., 2008). In an attempt to address these concerns, a Mental Health First Aid (MHFA) training programme was introduced to upskill teachers, increase their mental health literacy and train them to recognise the signs and symptoms of mental ill health and provide support (Department of Health and Social Care and Department for Education, 2017; MHFA England, 2017). Research suggests that in addition to increasing teachers' knowledge about mental health, this training has “changed beliefs about treatment to be more like those of mental health professionals, reduced some aspects of stigma, and increased confidence in providing help to students and colleagues” (Jorm et al., 2010, p. 9). Additionally, Mental Health Support Teams (MHSTs) have been introduced to provide additional mental health and wellbeing support through schools and colleges by NHS mental health professionals (Department of Health and Department for Education, 2017). Educational Mental Health Practitioners (EMHPs) working as part of this team across education and healthcare, provide early interventions to support children and young people with less severe needs and support the promotion of good mental health and wellbeing in schools (Children's Commissioner, 2021; Parkin & Long, 2021). By identifying problems in young people more quickly and intervening early with ongoing support, these initiatives aim to reduce the burden on CAMHS.

Schools, colleges and academies also have a statutory duty to support young people with medical conditions including mental health disorders (Department for Education, 2015). Adequate alternative educational arrangements outside the mainstream school system must be provided for children and young people of compulsory school age who are unable to attend school for health reasons (Department for Education, 2013). For young people with mental health difficulties, education may be provided in alternative provision settings such as psychiatric hospital schools, pupil referral units, special schools or home teaching services (Department for Education, 2013, 2018).

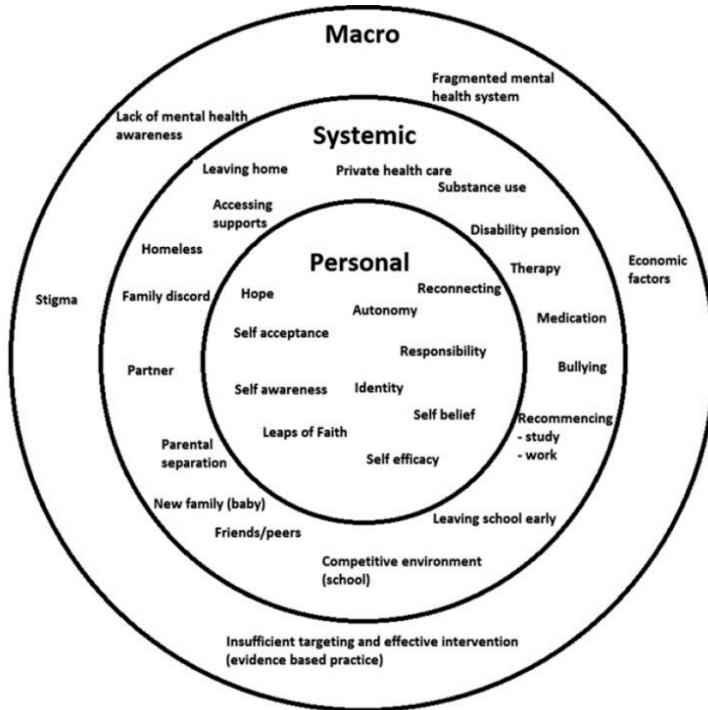
In addition, education professionals play a key role in engaging young people with their education and creating a sense of normalcy while they are in hospital (Mintz et al., 2018). Alongside core subjects in their curriculum, young people can engage in subjects such as Art and Music which can benefit their sense of wellbeing. While effective collaboration between education and healthcare professionals is necessary to support young people during their time in hospital, it is also essential for the hospital education setting to liaise constructively with the young person's mainstream school to support a successful return following hospitalisation (Simon & Savina, 2010).

Although these systems are in place to support young people with mental health problems in healthcare and education settings, concerns have been raised about the effectiveness of this support in addressing the needs of those with severe difficulties (Children's Commissioner, 2022; Hart & O'Reilly, 2017). This study therefore sought to gain insight into this issue by seeking the views of young people as they journeyed into and out of psychiatric hospitals. The next section reviews existing studies which explore young people's experiences at different stages in their recovery journey.

### **2.3 Young People's Experiences**

The conceptual models discussed in section 2.1.5 highlighted some of the facilitators and barriers to mental health recovery. Participants in Law et al.'s (2020) qualitative study identified systemic factors including "meaningful activity, appropriate support networks, access to mental health services, a meaningful alliance with health care professionals and a collaborative approach to recovery" (p. 469). Rayner et al.'s (2018) study with young people aged between eighteen and twenty-three also reported additional ecological factors including family, peers and school (see Figure 2.3).

Figure 2.3 Ecological youth recovery model (Taken from Rayner et al. (2018, p. 335))



The remaining sections of this chapter discuss other studies which provide insight into young people's experiences of some of these factors at various points in their recovery journey.

### 2.3.1 Interpersonal Relationships

The relationship that young people with mental health disorders have with professionals, their family and peers are important issues in narratives of their experience before, during and after inpatient hospitalisation. The sections that follow discuss their views of these three interpersonal relationships.

#### 2.3.1.1 Relationship with Professionals

Young people with mental health difficulties will come into contact with a range of professionals from healthcare, social care and education settings (Hughes, 2018; O'Reilly et al., 2018). The relationship that these adolescents have with adults is a recurring theme in the literature. The "relational aspects of care" (Persson et al., 2017, p. 141) are important to young people receiving both outpatient and inpatient mental health care. The literature shows the value of individuals feeling listened to, having their views and opinions valued and respected as well as feeling genuinely cared for and liked (Davison et al., 2017; Moses, 2011). Being friendly, easy to talk to,

non-judgemental, a good listener, reliable, supportive and empathetic are key attributes also valued by young people in their interactions with adults (Buston, 2002). However, Kapur et al. (2014) described the feeling of isolation from CAMHS professionals that some young people experienced which made them feel that they were “less deserving of the mental health professionals time and resources” (p. 4).

Frequent and dedicated contact with mental health professionals is also viewed as important for young people to develop trust and build positive relationships (Davison et al., 2017; Plaistow et al., 2014). However, frequent staff changes, inconsistent contact with staff, lack of staff punctuality for appointments, cancelled or changed appointments and discontinued access to specific staff over time are all experiences that young people find difficult and have a negative impact on building these positive relationships (Coyne et al., 2015). Adolescents highlight the need for support from healthcare professionals (HCPs), parents and particular teachers and appreciate HCPs liaising with schools (Coyne et al., 2015).

In inpatient settings, young people have also expressed that professionals with lived experience of mental health difficulties may be able to relate to young people genuinely rather than “just doing their job” (Moses, 2011, p. 133). Sharing information about themselves and experiences that they have been through are seen by young people to show a caring attitude and a real connection to the young person. The supportive relationships the young people establish during inpatient treatment are viewed as a benefit (Gill, 2014; C. Hayes et al., 2020) while Jones et al.’s study (2017) with older adolescents aged sixteen to eighteen years also found that adults acknowledging their distress was an important factor in facilitating their engagement with mental health professionals to seek help. However, young people who transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) view the loss of familiarity with a professional involved in their care and the need to re-tell their story to them as an unhelpful aspect of this transition (Feehan, 2017). In addition, attachment to hospital staff and the hospital setting can result in young people experiencing significant anxiety related to discharge (Savina et al., 2014).

In school, the relationships that young people build with significant adults are identified as important to support academic attainment and promote well-being (Cefai & Cooper, 2010). They need to feel safe and trust the adults supporting them. However, findings from Hart’s study (2016) suggest that young people’s teachers are sometimes unaware of the complex difficulties that a young person may be experiencing due to their mental health difficulties. Even though parents are aware of the difficulties that their children are experiencing at school, young people are reluctant for their parents to intervene due to concerns that their experience at school will be made worse (Hart, 2017).

In summary, the literature shows that the relationship that young people have with significant adults within health and education settings can influence the nature of their experience before, during and after psychiatric hospitalisation. The next section explores the impact of young people's mental health disorders on their family.

### **2.3.1.2 Relationship with Family**

Young people require support from their families to cope with the stresses of everyday life, especially when they are experiencing difficulties with their mental health (Puotiniemi & KyngÄS, 2004). Families and parents in particular, play a crucial role in supporting young people as they navigate their health journey of crisis and recovery (Association for Young People's Health, 2016). Prior to hospitalisation, life for adolescents with severe mental health challenges and their families typically lacks normalcy (C. Hayes et al., 2020). Caregivers in Hayes' study (2020) described experiences of "being on edge and on-watch" (p. 116) in managing their child's daily mental health struggles. Nonetheless, adolescents and their families saw inpatient hospitalisation as the final option after other strategies had been unsuccessful.

Severe mental health disorders can also have a significant impact on family relationships, especially during hospitalisation (Moses, 2011). Separation away from family can result in homesickness for young people (Claveirole, 2005) and lead to difficulties in sleeping while in hospital (Moses, 2011). Some also feel that their family hold negative attitudes towards them due to the stigma associated with mental health disorders (Moses, 2010b). Young people's feeling of being 'connected' to their family is also found to change after hospitalisation (Czyz et al., 2012). While frequent family visits and contact are important while a young person is in hospital, strict visitation rules and admissions in hospitals far from home can be obstacles in maintaining regular contact (Edwards et al., 2015).

Young people's views about how their family's experiences could be improved could therefore contribute to a positive outcome for them. The next section explores the role of peers in hospital and schools.

### **2.3.1.3 Relationship with Peers**

Young people struggling with mental health difficulties can see their experience as one where their identity is changing and therefore feel a sense of isolation (Offord et al., 2006; Painter, 2008; Thabrew et al., 2020; Wu & Harrison, 2019). However, within an inpatient setting, some adolescents find interactions with peers to be helpful (C. Hayes et al., 2020; Moses, 2011). Young

people feel that fellow inpatients provide support, companionship and advice and they can be themselves without pretence. This helps to normalise their experience and relieve the sense of isolation and feeling of being different felt by some young people who have a mental health disorder. Caregivers have expressed concern though about the intense relationships that can be fostered by their children while in hospital, sometimes at the expense of family relationships (C. Hayes et al., 2020).

Furthermore, the opposite can happen and verbal and physical abuse has been reported by some young people in inpatient settings (Moses, 2011). Hart (2016) found that young people's experience of bullying by their peers in school added to their unhappiness and resulted in them "masking their difficulties and remaining silent about their problems" (Hart, 2017, p. 27). Bullying and teasing by peers also adds to a sense of victimisation by young people and can result in them getting into trouble, ending up in isolation and absenteeism (Cefai & Cooper, 2010).

Studies have reported strained relationships with friends when a young person is hospitalised (Offord et al., 2006; Painter, 2008). Young people express concerns about being judged negatively by their peers and indeed by adults (Moses, 2010a), with some feeling that they may be perceived as "attention-seekers" (Davison et al., 2017, p. 102). In addition, the stigma associated with mental health disorders make adolescents cautious about telling friends (Mitchell-Lowe & Eggleston, 2009, p. 288). The role of peers in the engagement of older adolescents with mental health services was noticeably absent from the narratives of young people in Jones et al.'s study (2017) and attributed in part to stigma and being judged by peers.

In summary, positive relationships between adults and peers are therefore important in supporting young people's mental health and well-being. These interpersonal relationships are also important factors in the school environment, which is a key part of young people's experiences.

### **2.3.2 School Environment**

Young people spend a significant amount of their time in school (Rutter, 1982). The impact of the school environment or climate on young people's mental health is therefore an important consideration (Suldo et al., 2012). The school climate is a complex, multi-faceted construct which can consist of the school's ethos and values, its physical environment, the interpersonal relationships between teachers and peers, as well as the quality of teaching and learning (Aldridge & McChesney, 2018; Long et al., 2021). Young people are reported to have better mental health when they feel safe at school and have positive relationships with staff and peers, as previously

discussed (see section 2.3.1). The positive association between an inclusive school climate and good mental health and wellbeing has also been explored (László et al., 2019). Furthermore, young people's mental health has also been found to be adversely affected by school climates that place an emphasis on academic performance (Byrne et al., 2006). In addition, competitive school environments can have an impact on the process of mental health recovery in young people with mental health difficulties (Rayner et al., 2018). It is therefore beneficial to explore young people's views about their experiences in education settings and the support that was provided.

Health and education professionals also play a crucial role in providing adequate information and facilitating young people's access to support. These are discussed in the next section.

### **2.3.3 Access to Information**

Even though mental health and mental health disorders are concepts that are increasingly being spoken about, there still remains a lack of understanding from young people who express the need for more information about mental health in general and CAMHS in particular (Plaistow et al., 2014). The stigma associated with mental health disorders can cause young people to fear others knowing about their illness and being judged negatively (Davison et al., 2017). Young people experiencing mental health problems themselves may even offer negative definitions and interpretations of their own mental health (Davison et al., 2017). These factors can contribute to an unwillingness for young people to seek help (Bowers et al., 2013; Radez et al., 2020). Nonetheless, young people feel that quick and easy access, as well as earlier intervention, would help to prevent their mental health difficulties from escalating (Buston, 2002). Adolescents in Coyne et al.'s study (2015) reported that they found it difficult to access help from child and adolescent mental health clinics due to lack of information and availability of services.

In addition, young people experience anxiety about what to expect from CAMHS (Watsford et al., 2013) and when they will be discharged from hospital (Street, 2004). A qualitative study with older adolescents and adults attending an early intervention outpatient mental health programme found that not knowing what to expect can lead to apprehension and uncertainty (Armstrong et al., 2018). Lack of education about mental health can also lead to gaps in knowledge being filled by information and images from the media. Effective communication between young people and CAMHS professionals would therefore help to address these concerns (Street, 2004). This is supported by Moses' study (2011) which reported that young people developed a better understanding of their illness when they were given access to information. This was found to be helpful during their psychiatric hospitalisation.

Lack of basic information about the transition process is also highlighted as an issue with young people who transition from CAMHS to adult mental health services (AMHS) (Feehan, 2017). While the lack of a clear time-scale regarding the transition can lead to uncertainty, the feeling of being left without support from both health and education professionals during times of fluctuating mental health and transition into adulthood can also lead to fear and anxiety (Feehan, 2017). Furthermore, “joint working and relational continuity” (p. 1) in the transition between CAMHS and AMHS were valued by adolescents in Broad’s study (2017).

Having access to adequate information is therefore an important factor in young people’s mental health recovery journey. Access to information about inpatient mental health care in particular can also help to alleviate young people’s anxieties about inpatient admission. The next section explores young people’s views of support in the inpatient environment.

#### **2.3.4 Inpatient Hospital Environment**

The inpatient hospital environment, although necessary to keep a young person safe from harm either to themselves or others, can also be an environment fraught with many risks, according to Edwards et al. (2015). The structured setting can, on the one hand, “create inner peace” (Moses, 2011, p. 128) and a distraction from troubles for some young people. The inpatient hospital environment is also described as “safe and comfortable” (C. Hayes et al., 2020, p. 117) and provides the opportunity to suspend or take time out of normal life (Moses, 2011; Offord et al., 2006). However, young people in Gill’s study (2014) described their inpatient experience as “living in a fake world” (p. 56). They considered their inpatient hospitalisation to be a drawback due to the challenges experienced when they transitioned back into the community.

Furthermore, aspects of the structure of inpatient hospitalisation and the stresses on young people with mental health disorders have the potential to have unintended side effects and be counterproductive. Young people are separated from their family and friends and have to live with strangers, possibly for the first time in their lives. They also need to make quick adjustments to the structure and rules of inpatient hospitalisation (Moses, 2011). Inpatient hospitalisation can lead to a sense of confinement with the loss of autonomy and privacy for some young people which can be seen as unnecessary, unreasonable and cause aggravations. Young people feel that their need for independence and mobility is curtailed while they are in hospital (Buston, 2002).

The inpatient hospital environment can also appear uninviting and contribute to a young person’s sense of isolation. The location of the hospital or clinic, the cleanliness of the surroundings and the

quality of food are all aspects of the physical environment that young people view as important (Buston, 2002). Access to activities helps to encourage interactions and relieve young people's sense of boredom while they are in hospital. Furthermore, young people need to experience normal activities outside of hospital which will help with the transition back home following discharge (Painter, 2008). However, restrictions on access to personal items such as mobile phones and on verbal interactions or physical contact with peers are viewed as counter-therapeutic by young people (Edwards et al., 2015; Moses, 2011). There is also the potential for young people to witness distressing behaviours such as self-harming or cutting in inpatient settings. Witnessing things like panic attacks can also be a frightening experience for young people in hospital. Others have commented on the experience of being sectioned (Buston, 2002).

Young people appreciate and enjoy the supportive aspect of inpatient education (Buston, 2002). However, concerns about the quality of this provision, teacher shortages and training of teachers to understand the needs of young people have been raised (Edwards et al., 2015; Hannigan et al., 2015). Young people in Preyde et al.'s (p. 522) study also identified support needs including "professional support such as counselling or therapy, coping skills training, social skills training, monitoring progress and emotional support" (p. 522) which would be helpful following discharge from psychiatric hospital. This has implications for addressing the concerns of young people returning to school after hospitalisation in order to decrease barriers to successful school reintegration. Gill et al. (2016) suggest that "transition back home provides opportunities for personal growth and consolidation of skills learned to cope with difficulties" (p. 56). However, young people can experience high levels of stress in relation to planning for returning to school including modifications to accommodate young person's needs as well as catching up with schoolwork (Iverson, 2017; Preyde et al., 2018). Lack of plans for school re-entry and integration can also result in delays in discharging a young person from hospital. Furthermore, not all young people are able to return to school or college due to difficulties in managing social situations, academic pressures and emotions (Preyde et al., 2018). Re-hospitalisation is also a real concern as some young people are unable to cope with the demands on them following discharge (Savina et al., 2014). Nonetheless Iverson (2017) reported that support from school staff, peers and family have a significant impact on adolescents' transition to school.

In summary, inpatient hospitalisation can be a traumatising experience for some young people but can also provide a supportive environment. The clinical support and treatment that young people receive are key ingredients in their journey to recovery. This issue is explored in the final section that follows.

### 2.3.5 Medical Treatment of Mental Health Disorders

In addition to keeping young people safe from harm, inpatient hospital admission aims to provide effective therapeutic treatment and interventions (Frith, 2017). Cognitive and behavioural coping skills delivered in therapy sessions form a key part of treatment of young people with mental health disorders. In the UK, psychological therapies such as NHS talking therapies services (also known as Improving Access to Psychological Therapies (IAPT) services) are used with young people with common mental health problems like stress, anxiety and depression (National Health Service, 2018). These sessions, delivered either one-to-one or as part of a group are viewed as helpful by some because they offer the opportunity to set goals, repeat and practise essential coping skills. However, while the opportunity to share personal information may remove the sense of isolation felt by some young people with mental health disorders, others may not like exposing themselves in this way. Others also feel that it is unhelpful to hear other young people's problems and prefer having some autonomy over the people they share information with (Moses, 2011).

Medications routinely prescribed to treat mental health disorders in young people can be monitored and regulated within the hospital setting. While some young people have found access to medication helpful, it can cause distress for others, especially when they disagree with the course of treatment (Buston, 2002; Claveirole, 2005). Young people in Buston's study (2002) reported a lack of empathy, understanding and being listened to in relation to their treatment and a lack of information about medication. They felt that there was a reliance on medication and not enough talking. This view was also supported by young people in Coyne et al.'s study (2015) who felt that they were not part of the decision-making process. Coyne et al. (2015) suggest that young people's recovery is supported when they are able to "have an active and meaningful voice in their treatment and care planning" (p. 567). From a human rights perspective, Damodaran and Sherlock (2013) found that the decision to commence medication in children and young people with ADHD is sometimes taken unilaterally and available information is not always provided to children. They argue that this lack of being given the choice to engage with treatment risks damaging the relationship between parents and their children who are blamed for wider issues within the family.

Lack of sufficient inpatient treatment or one-to-one therapy with doctors have also been reported as unhelpful (Moses, 2011). Young people feel that care is not individualised (Offord et al., 2006) with some feeling that their treatment is delivered in a "conveyor belt" fashion rather than being viewed as an individual (Colton & Pistrang, 2004, p. 312). Treatment was also seen as focused towards discharge with some young people feeling that they were being discharged before they were ready (Broad et al., 2017). The retrospective views of some young people were that they did not agree with being hospitalised and felt that being in an inpatient setting was detrimental to them but they

also recognised that being discharged could be damaging (Hannigan et al., 2015). The practice of restraint sometimes used in inpatient settings to ensure the safety of a young person or others can also be frightening for other patients and heighten their sense of anxiety and distress (Polvere, 2011).

Furthermore, a lack of consideration of the stage of development of older adolescents in Jones et al.'s study (2017) was highlighted by the use of words such as "patronising" and "condescending" (p. 9) in relation to their treatment. However, treatment techniques that gave the young people the opportunity to be actively involved in aiding their therapy were found to facilitate their engagement with mental health services. In contrast, young people compared the daunting approach in adult services in relation to CAMHS as they transitioned between the two services (Feehan, 2017).

This section has highlighted that although the medical treatment of young people's mental health disorders may be a vital part of their recovery, young people desire some autonomy in the process. Young people's experiences also suggest that they want to be listened to and to receive individualised support from professionals.

## **2.4 Chapter Summary**

This chapter firstly outlined the conceptual and theoretical frameworks for this research which influenced the methodological choices adopted (see Chapter 3). Secondly, the healthcare and education systems designed to support young people with mental health difficulties were briefly discussed. Lastly, a review of existing literature highlighted key themes in relation to young people's experiences and views about some of the factors that can have an impact on their mental health recovery.

An extensive search of existing literature revealed one Australian study that explored the inpatient model of care over time from admission through to post discharge, from the perspective of adolescents and their caregivers (C. Hayes et al., 2020). However, no study was found which explored the holistic healthcare and education experiences of young people with severe mental health disorders as they journey into and out of psychiatric hospitals. Furthermore, a significant number of existing studies were written from clinical perspectives rather than through an educational lens. These two areas therefore represented identified gaps in the literature which this thesis sought to address by answering the following main research question (MRQ) and sub-questions (SRQs):

MRQ: How do young people with severe mental health disorders perceive their experiences within the systems of healthcare and education as they journey into and out of psychiatric inpatient hospital?

SRQ1: How do young people experience receiving support in healthcare settings?

SRQ2: How do young people experience receiving support in education settings?

SRQ3: What do young people want to share with healthcare and education professionals about supporting their mental health recovery journey?

The next chapter discusses the methodological approaches adopted to address these research questions.

### 3 Methodology

#### 3.1 Introduction

The purpose of this study was to explore the retrospective views of young people with severe mental health disorders. The aim was to gain insight into the young people's perceptions of how the support they received from healthcare and education settings met their recovery needs as they journeyed into and out of inpatient psychiatric hospitals.

This chapter gives an overview of the methodological approaches adopted for this research which are based on the conceptual and theoretical frameworks discussed in the previous chapter. Firstly, the philosophical assumptions underpinning the design of the study and the rationale for making the stated choices are explained. This is followed by a description of the research design and the approaches to sampling and data collection. Finally, a discussion of ethical considerations and issues related to ensuring quality in the research process concludes the chapter.

#### 3.2 Paradigm Rationale

The research process is influenced by ontological assumptions about the nature of the social phenomena being studied and epistemological assumptions related to how the research should be conducted (Crotty, 1998). This research adopted a relativist stance in which the reality of the young people's experiences were created by "individual cognition" (Cohen et al., 2018, p. 5). In other words, the young people's experiences were social constructions created from their own perceptions and actions. This constructivist or constructionist perspective supports the view that social actors continually construct their interpretation of human and social phenomena in a subjective way to make sense of their experiences (Cohen et al., 2018). The opposing objectivist position assumes that an individual's experiences and the meaning that they attach to them exist externally and independently of the individual (Bryman, 2016). Tebes (2005) describes this realist perception of understanding the world as a "mind-independent reality" (p. 219) and is a view not supported in this study.

This research also aligns itself with an interpretivist epistemological position where the aim was to gain insight into the young people's experiences. The approach to acquiring this knowledge therefore respected the fact that experiences would be "personal, subjective and unique" (Cohen et al., 2018, p. 5) to each individual young person. The positivist epistemological position on the other hand requires knowledge to be obtained through gathering facts which provide the basis for laws or law-like generalisations as with natural phenomena (Cohen et al., 2018). This positivist view is that knowledge about social reality is gained objectively by using methods of the natural sciences

(Robson, 2013). The researcher is also assumed to be detached from the subject being studied and the methods used to collect and analyse the data must be free from personal bias, perceptions and interpretations. As this research adopted the concept of the child's voice (United Nations Convention on the Rights of the Child, 1989) to explore young people's experiences, this positivist stance was not appropriate for this study. Issues of subjectivity and reflexivity (Braun & Clarke, 2013) were therefore considered to address the issue of bias in research (see section 3.8).

In summary, the research questions for this study focused on the individual young person's experiences and understandings. The study therefore started with the assumption that the young people constructed their own reality of mental health recovery as they journeyed into and out of psychiatric hospitals. This construction was based on what they thought and how they felt about their experiences. This study also respected the differences between each young person and required the researcher to understand the subjective meanings of the young people's individual experiences (Bryman, 2016). The different perspectives of the young people contribute to the wider understanding of mental health and education provision which are the focus of this thesis.

This research therefore adopted a constructionist ontological perspective and an interpretivist epistemological position when making decisions about the research design approach adopted which is discussed in the next section.

### **3.3 Research Design**

In carrying out social research, a choice needs to be made with regards to how to conduct the study (Creswell & Poth, 2018). Bryman (2016) describes "two distinct clusters of research strategy" (p. 32) which have fundamental differences in terms of their theoretical, ontological and epistemological orientations. In quantitative research, numbers are used to examine the relationships between variables and test objective theories. This type of research typically adopts an objectivist and positivist perspective to social reality. Qualitative research in contrast, uses non-numerical approaches to explore and understand the meaning that social actors give to a human or social phenomenon (Bryman, 2016). This research strategy is inductive, constructivist and interpretivist in its approach. An additional strategy widely used in research, mixed methods research (Creswell & Poth, 2018), draws on elements of both quantitative and qualitative approaches.

While the research questions posed for this study could be answered using a quantitative approach, a qualitative research strategy was chosen for two reasons. Firstly, the constructionist interpretivist stance adopted for this study lent itself to a qualitative research strategy. This approach allowed the young people to share their experiences of journeying into and out of inpatient psychiatric hospitals,

using their own words, in a way that suited them and with few constraints. Each young person's interpretation of these experiences was different. It was these varied views, told through the voices of the young people themselves, that this research sought to explore. Secondly, a qualitative research approach allowed the researcher to engage intuitively and empathetically with participants and offer the flexibility to explore issues sensitively and safely (Robson, 2013).

The specific approach adopted for this qualitative research sought to explore young people's experiences by listening to their stories. According to Riessman (1993), individuals make sense of their experiences by telling stories or narratives. As a methodology, narrative inquiry can be used to investigate these experiences and the impact of social, cultural and environmental factors on these experiences (Clandinin & Connelly, 2000). A narrative research design approach was therefore adopted in this study for two reasons. Firstly, young people's mental health recovery is influenced by systemic and macro level factors (see section 2.1.5), which include the social, cultural and environmental dimensions typically explored in narrative research. There is therefore alignment between the concept of mental health recovery and narrative inquiry. This is supported by Spector-Mersel and Knaifel (2018) who argue that at a philosophical level, the narrative inquiry paradigm and mental health recovery paradigm are "sister paradigms given the philosophical closeness between them" (p. 301). They outline ten common emphases which typify the foundations of both the narrative inquiry and mental health recovery paradigms: "meaning, identity, change and development, agency, holism, culture, uniqueness, context, language and giving voice" (p. 298). Secondly, narrative research, like other qualitative methodologies, is based on the relationship between researcher and participant (Clandinin, 2007). This relational perspective of narrative inquiry provides the opportunity for participants to develop trusting relationships with researchers. Indeed, Haydon and van der Riet (2017) describe narrative inquiry as a "compassionate methodology" (p. 86) which allows participants to share their stories and provide a deeper understanding of their experiences. This study sought to explore young people's views about the support received in healthcare and education settings. The narrative research approach therefore allowed an exploration of the participants' experiences and perceptions of being supported during their mental health recovery journey.

When planning this qualitative research, it was important to consider all possible ethical issues, due to the vulnerability of the participants who had experienced severe mental health disorders, some of whom were still in recovery. The next section discusses the ethical considerations and steps taken to manage potential risks in this research.

### **3.4 Ethical Considerations**

Ethical issues are a prime concern at each stage of the research process and requires careful consideration especially when vulnerable young people are involved (Greig et al., 2013). The steps taken to ensure that this research adhered to sound ethical principles are outlined below.

#### **3.4.1 Gaining Access to Participants**

Given the sensitive nature of this research and the vulnerability of the population being studied, comprehensive ethics review processes were undertaken (Alderson & Morrow, 2011). An original plan to recruit potential participants from NHS settings was abandoned due to complexities in applying for Health Research Authority (HRA) Ethics approval. This project was subsequently reviewed following the procedures of the Institute of Education Ethics Committee and the University Research Ethics Committee (UREC) and was given a favourable ethical opinion for conduct (see Appendix A and Appendix C). Permission was granted from UREC to advertise the study in public areas such as libraries, mental health charities or other support groups and online using social media. However, attempts to recruit participants through schools and colleges as well as physical and online advertising, were hampered by the COVID-19 pandemic. Planned face-to-face meetings with potential gatekeepers and participants were also cancelled due to imposed restrictions on social contact. Further ethical approval was therefore sought from UREC (see Appendix D), to extend the participant age range and widen the target audience. Although the original plan was to recruit twelve participants, eight young people eventually participated in this research.

#### **3.4.2 Informed Consent**

The need to gain informed consent and assent from research participants is fundamental in all ethical considerations (Alderson & Morrow, 2011). In this research, information sheets and privacy notices (see Appendix G to Appendix M) fully informed parents or carers and young people about the purpose of the study and how the data would be collected, stored and used. All information sheets informed the participants of the approval obtained from the University Research Ethics Committee to conduct the research, as previously discussed. The information sheets also contained contact details for the student researcher and main supervisor, and information about how parents or carers and young people could withdraw from the research project at any time, should they wish to do so. An additional pamphlet (see Appendix H) written in more accessible language for young people,

was provided to ensure that all the information and advice relevant to their understanding the consequences of participation were clearly explained. All the participants gave written ethical consent prior to their interviews (see Appendix J). Consent was also obtained from the parent of one young person who was sixteen years old (see Appendix M). Furthermore, the researcher sought the participants' verbal assent at the beginning of each interview.

### **3.4.3 Sensitivity**

The exploration of intensely personal experiences in qualitative research can have a significant impact on participants (Hiriscau et al., 2016). In this study, there was the recognised risk of emotional distress for participants who were still recovering from their mental health disorders, even though steps had been taken to ensure that they were well enough to take part. The methods for data collection were therefore carefully considered and conducted with utmost sensitivity (see section 3.6). Contingency plans were also devised for situations where a participant became distressed or disclosed sensitive information (see Appendix B).

### **3.4.4 Researcher Safety and Risk**

While it is important to stress the potential risks to participants when researching a sensitive topic with a vulnerable population, the potential risk to the researcher also needs to be considered (Braun & Clarke, 2013; Robson, 2013). A risk assessment addressing the researcher's personal safety when interviewing young people face-to-face highlighted issues such as a careful consideration of the interview location, lone working and the researcher's response to possible aggressive or threatening behaviour from participants (see Appendix B).

The internet is also an increasingly popular tool in recruiting participants for research (Hokke et al., 2018). Recruiting children online and obtaining parental consent can be challenging due to the absence of face-to-face communication. In this study, an online survey tool approved by the University of Reading was used by the researcher to recruit some of the participants. In addition, official University contact details were used in all correspondence and all online responses to the research advertisement were followed up with telephone call conversations with young people and the parents of those under sixteen years of age.

### **3.4.5 Confidentiality and Anonymity**

All data collected was held in strict confidence and no real names were used in this study or would be used in any subsequent publications. The records of this study were kept private. No identifiers linking the participant or any person or institution to the study would be included in any sort of report that might be published. The participants were assigned a pseudonym by the researcher and referred to by that in all records. In addition, any identifiable information such as the names of people, places and schools were changed to protect the identities of the young people. Where a young person disclosed that they had been harmed by an adult or that they were at risk of abuse or the researcher suspected this was the case, the Local Authority Designated Officer (LADO) or the NHS Foundation Trust's Safeguarding team would be contacted (see Appendix B).

### **3.4.6 Data Security**

Research records were stored securely in a locked filing cabinet and on a password-protected computer and only the researcher and supervisor had access to the records. In line with the University's policy on the management of research data, anonymised data gathered in this research would be preserved and made publicly available for others to consult and re-use.

### **3.4.7 Reciprocity**

Researchers have some obligation to participants who have helped them in their research (Cohen et al., 2018). The use of appropriate incentives in adolescent research participation has been widely debated (Crane & Broome, 2017) however, no incentives were offered to participants in this study. As a matter of courtesy, all participants were sent an email of thanks to acknowledge their participation in the study. They were also offered a copy of any written articles based on the results of the study.

### **3.4.8 Section Summary**

All the young people who participated in this study had experienced severe mental health disorders and some were still in the process of recovery. There was the potential that their participation in this research could cause harm during the process of recalling their experiences. This section has discussed the ethical considerations and outlined the steps taken to manage the potential risks. The next section discusses issues related to obtaining a sample for this research.

### **3.5 Sample Selection**

The approach taken to sampling was theoretically consistent with a qualitative research strategy. Based on specific inclusion criteria (see section 3.5.1), participants who could offer insight into the experience of inpatient psychiatric hospitalisation were sampled purposively rather than through probability methods. The participants were an opportunity sample (Cohen et al., 2018) recruited via referrals from the researcher's social networks and school contacts and also from respondents to research advertisements placed on online platforms such as Twitter. The inclusion criteria applied to sampling and the resulting sample size are outlined in the following two sections.

#### **3.5.1 Inclusion Criteria**

The original aim of this research was to recruit children and young people aged between twelve and eighteen years, which is the typical age range for admission to Tier 4 CAMHS General Adolescent Units (National Health Service, 2014). However, recruiting adolescents for this study was challenging due to the sensitive nature of this research and the vulnerability of the population being studied (see section 3.4). The adolescent age group on which this research was focused can also be difficult to engage (Hawke et al., 2018). As a result, the inclusion criteria was purposefully broad in order to increase the target audience for this study. Young people hospitalised during their adolescent years and who were well enough to share their stories were therefore accepted for this study.

#### **3.5.2 Sample size**

In qualitative research, decisions about sampling and sample size must not only be fit for the purpose of the study but also allow the researcher to provide a thick and rich description of the phenomenon being studied (Bryman, 2016; Cohen et al., 2018). Eight young women, aged between sixteen and twenty-seven years, responded to the researcher's advertisement and participated in this study. This number of participants was considered adequate to answer the research questions posed in this study due to the richness of the data that was collected (see section 3.6 and Chapter 4). Seven of the participants had experienced psychiatric hospitalisation in inpatient adolescent units and two had been admitted to inpatient adult units. Three quarters of the participants had been hospitalised multiple times, with their length of hospital stay ranging from two days to twenty-one months. The reasons for their hospital admissions, as stated by the participants, included low mood, depression,

self-harm, suicidal ideation, eating disorder and psychosis. Detailed information about each participant is presented Table 3.1.

Table 3.1 Information about participants

Participant	Age when interviewed	Age when first admitted	Sequence of hospital admissions <sup>1</sup>	Duration of hospital admissions	Reason for admission (as stated by participant)
Abigail	24	16	Adolescent Adolescent	6 months 2 months	Depression; unable to keep myself safe; eating issues
Josie	19	13	Adolescent Adolescent	8 months 15 months	Suicide
Violet	18	14	Adolescent	1½ – 2 months	Suicidal; self-harm; low mood
Amelia	20	14	General General Adolescent General Adolescent General Adolescent Adolescent	1 day 8 days 10 months 5 days 5 months 10 days 2 days 5 months	Overdose; depressive disorder with psychotic symptoms due to hearing voices
Helena	16	13	General General Adolescent Adolescent	10 days 2 weeks 5 months 5 months	Eating disorder
Irene	27	17	Adolescent Adult Adult ED Clinic	7 weeks 7 months 6 months 21 months	Eating disorder
Imogen	18	13	Adolescent	4 months	Suicide attempt
Lucy	24	19	Adult Adult	3 weeks 3 weeks	Acute psychosis

The potential risks associated with researching this vulnerable population required careful consideration of the methods chosen to collect data for this study. These data collection methods are discussed in the next section.

<sup>1</sup> Type of hospital:

General = Non-specialised General Hospital for adults and children

Adolescent = Adolescent psychiatric inpatient unit

Adult = Adult psychiatric inpatient unit

ED Clinic = Adult Eating Disorder Clinic

### **3.6 Data Collection**

The focus of this study on the experiences of the participants meant that it was important to give the young people the opportunity to freely express their views without the constraints of the researcher's perspective or established theories (Robson, 2013). The vulnerabilities of the participants also needed to be carefully considered. The methods chosen to collect data for this study are discussed in the next two sections.

#### **3.6.1 Semi-structured Interviews**

The research questions designed for this study sought to explore young people's "understandings, perceptions and constructions" (Braun & Clarke, 2013, p. 81) of their experiences as they journeyed into and out of inpatient psychiatric hospitals. The narrative inquiry approach adopted for this research allowed different methods of data collection to be used such as interview transcripts, letter writing and documents such as plans and pictures (Connelly & Clandinin, 1990). Interviews were considered to be the most appropriate qualitative method to allow the participants to talk about their experiences (Rubin & Rubin, 2012).

In-depth one-to-one semi-structured interviews were chosen for the following reasons. Firstly, using one-to-one interviews, a rapport was developed between the researcher and participants who were allowed the space to think, speak and be heard. Secondly, semi-structured interviews rather than questionnaires gave the participants the opportunity to offer detailed personal accounts of their experiences. The young people had the opportunity to reflect on their experiences, recount their stories freely and express their views. Lastly, semi-structured rather than an unstructured interview format gave the researcher the structure and flexibility to redirect participants to areas of interest for the study.

The original plan was to initially contact each participant and their parent or carer where applicable, for a short introductory meeting and to arrange a first interview. This would then be followed by a second face-to-face verbal interview. The researcher met with two of the participants in person in their education settings in March 2020. However, the onset of the 2020 global pandemic of coronavirus disease 2019 (COVID-19) and subsequent restrictions regarding social contact meant that face-to-face interviews in person could not be conducted. The participants were therefore offered different interview options including voice/video calls on WhatsApp or Skype; video conferencing using Microsoft Teams; or the opportunity to respond to the researcher's written interview questions via email (see Table 3.2). All the interviews took place between March and

August 2020. With consent, all the verbal interviews were recorded using a digital voice recorder and transcribed by the researcher (see Appendix P).

Table 3.2 Modes of Data Collection

Participant	Type of Data	Duration of Interview (minutes)	Timelines completed?
Abigail	WhatsApp Interview	50	Yes
Josie	WhatsApp Interview	65	Yes
Violet	Skype Interview	70	Yes
Amelia	WhatsApp Interview	116	Yes
Helena	Face-to-face Interview Email	25 -	No
Irene	Microsoft Teams Interview	48	Yes
Imogen	Email	-	Yes
Lucy	Email	-	Yes

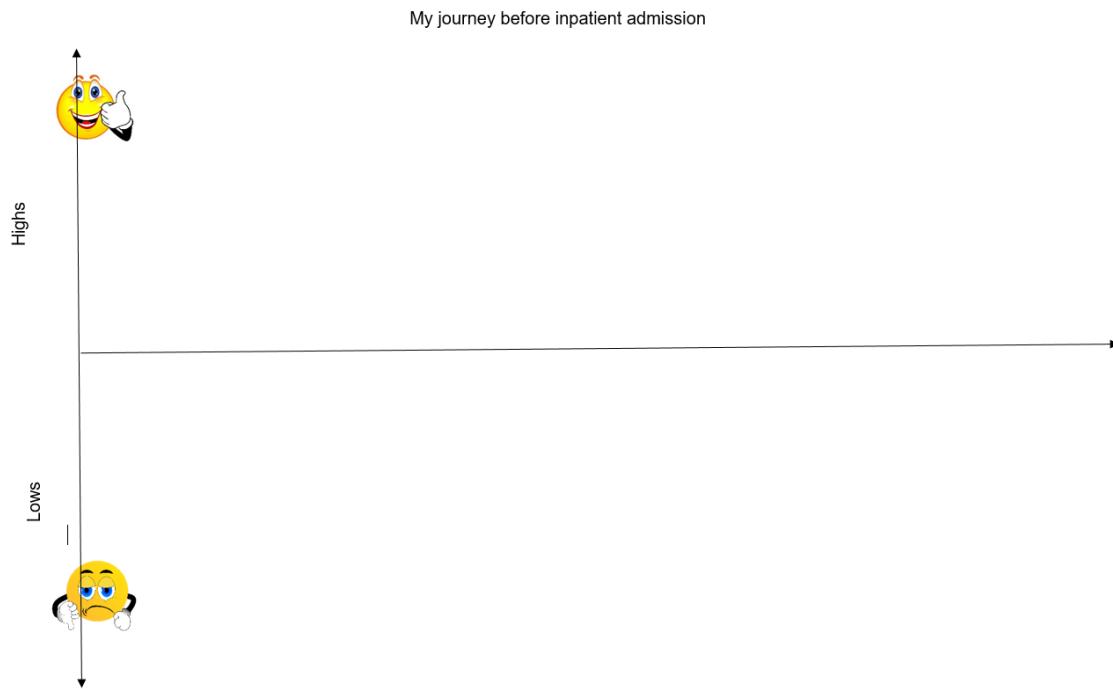
Although a second interview was initially planned for each participant, this was not conducted in consideration of the young people's wellbeing at a difficult time during the pandemic. Nonetheless, one of the participants agreed to answer follow-up questions in a subsequent email communication.

In order to provide the opportunity for young people to reflect on their experiences prior to their interview and also facilitate the interview process, an additional method of data collection was adopted for this study. This is discussed in the next section.

### 3.6.2 Data Prompted Interviews (DPIs)

Physical tools are an effective way of breaking the ice when conducting qualitative research about potentially sensitive issues with young people (Ritchie et al., 2014). Data-prompted interviews "use personalized prompts such as photos, videos, audio recordings, graphs and text to stimulate discussion in a qualitative interview setting" (Kwasnicka et al., 2015, p. 1191). In addition, the participants have a "degree of control over the disclosure of sensitive issues" (Wilson et al., 2007, p. 9) at their own pace. In this study, due to the potential sensitivities of interviewing young people who had and were still recovering from severe mental health disorders, each participant was offered timelines to complete prior to their interview. These timelines indicated 'highs' and 'lows' during different phases of their journeys into and out of inpatient psychiatric hospitals (see Figure 3.1).

Figure 3.1 Blank timeline for part of young person's journey



The timelines used in this research were based on Wilson et al.'s (2007) use of a life grid, "a visual tool for mapping important life events against the passage of time" (p. 135). This method of data collection was tested in a short pilot telephone interview conducted with a twenty-two-year-old female, with a life-threatening physical illness which resulted in periods of hospitalisation during her adolescent years. The pilot highlighted potential difficulties in completing the timeline electronically. As a result, participants were given the option to complete the documents by hand and return to the researcher as a scan or photograph (see Appendix O). All but the first participant completed the timelines as she consented to be interviewed on the day of her initial introductory meeting.

The timelines were returned to the researcher prior to each interview and provided background information about each participant. They also informed the researcher's interview schedule for each young person so that the questions were individualised, open and expansive without making many assumptions about the participants' experiences or concerns (Kwasnicka et al., 2015). Finally, this additional mode of data collection facilitated a comfortable interaction with the participant which enabled them to provide detailed accounts of their experiences (Brinkmann & Kvale, 2015).

Having obtained a rich account of the eight young women's experiences of journeying into and out of inpatient psychiatric hospitals, this data was analysed. An explanation of the approach chosen to analyse the interview data follows in the next section.

### **3.7 Data Analysis**

An inductive thematic approach was adopted (Braun & Clarke, 2006) to analyse the narratives of the young people, shared through experience timelines, emails and spoken interviews,. This approach allowed the commonalities and differences in themes across the datasets of the research participants to be explored. The next two sections discuss the steps taken to explore and make meaning of the data collected using this approach.

#### **3.7.1 Data Transcription**

An important first step to analysing the interview data was transcription of the spoken interviews (Brinkmann & Kvale, 2015). The style of transcription adopted for this study was chosen to suit the approach to analysis, namely Thematic Analysis (Braun & Clarke, 2006). This approach focuses more on what was said by the participants rather than how it was said (Andrews et al., 2008). As such, orthographic or verbatim transcription which focused on transcribing the words that were spoken was used to transcribe the interview data. This contrasts with transcription styles used in discursive psychology and conversation analysis which include more phonetic or paralinguistic features (Lapadat & Lindsay, 1999). In addition to the requirement that transcribed interviews are indeed recorded, Brinkmann and Kvale (2018) also stipulate that the recorded conversation is audible to the transcriber. In this study, the participants' narratives were transcribed word-for-word by the researcher. However, this process was made difficult as during some of the interviews, the audio quality either dropped or became delayed, possibly due to poor network performance. This made the recordings of some of the participants' speech inaudible and difficult to transcribe as a result. Nevertheless, the gist of the conversations could be gleaned from the participants' timelines and notes made by the researcher during the interviews. In addition, the participants' words were corrected for spelling or grammar if the meaning was not evident.

A discussion of the qualitative data analysis method chosen for this study follows in the next section.

#### **3.7.2 Thematic Analysis**

The approach adopted for qualitative data analysis in this study was primarily inductive and comparative (Glaser & Strauss, 1999). Through repeated listening of the interview recordings, multiple readings of the transcripts and comparing elements of text, codes and themes which described important aspects of the data were identified (Miles et al., 2020). This was the basis of the inductive Thematic Analysis approach (Braun & Clarke, 2006) adopted for this study Narrative

approaches to analysis were not considered due to their focus on contingent sequences in data whereby events and the actions of actors are linked temporally and sequentially (Riessman, 1993). In narrative approaches, the aim is to reduce the data to a set of core narratives rather than a set of core themes or findings (McAllum et al., 2019).

The six steps outlined by Braun and Clarke (2006) for Thematic Analysis were followed in this research. In the first phase of the analysis, interview transcripts were read and re-read “actively, analytically and critically” (Braun & Clarke, 2013, p. 205), to create a list of initial ideas about what young people were talking about and what was interesting about what they said. Through transcription of the verbal intervals previously described and this repeated reading of the transcripts, the researcher became familiar with the data. The interview transcripts were also re-visited several times throughout the process of thematic analysis. The second phase of analysis involved the coding of data which Saldana (2016) describes as “a word or short phrase that symbolically assigns a summative, salient, essence capturing, and/or evocative attribute for a portion of language-based or visual data” (p. 4). Initial codes were generated by assigning a word or phrase to interesting segments of text in individual participant transcripts. Initially, a Computer Assisted Qualitative Data Analysis (CAQDAS) software program, NVivo (Richards, 1999) was considered to manage and organise the codes and relevant data. However, as the process of assigning codes became iterative and cumbersome, manual techniques such as highlighting and annotating transcripts and well as using the comment function in word processing software, were also used.

The next phase of thematic analysis involved the identification of themes which “capture something important about the data in relation to the research question, and represent some level of patterned response or meaning within the data set” (Braun & Clarke, 2006, p. 82). Broader patterns or provisional themes were searched for across the participants’ transcripts by identifying similarity and overlap between the codes generated in phase two. In addition, relationships between codes and themes were considered to identify potential overarching themes and sub-themes. This was followed by the next phase of re-visiting the interview transcripts to refine these potential themes. The process of re-reading transcripts and revising codes and themes was a recursive process (Kiger et al., 2020) and allowed themes to be checked against coded extracts to ensure that they adequately reflected the coded data for each participant and across the whole data set.

In the next phase of thematic analysis, themes were analysed further to generate clear definitions and descriptions that provided a “rich, coherent and meaningful picture of dominant patterns in the data” (Braun & Clarke, 2013, p. 249). These refined themes and sub-themes were situated within the body of existing literature and a relevant theoretical framework. They were also related to the research questions of this study and told the overall story of the analysis. The last phase involved

the write-up of the final analysis which provided a “concise, coherent, logical, non-repetitive and interesting account of the story the data tell – within and across themes” (Braun & Clarke, 2006, p. 93).

The issues of quality and trustworthiness in qualitative research have been extensively debated (Patton, 1999). The steps taken to address these issues in this qualitative study are discussed in the final section of this chapter.

### **3.8 Research Quality**

There is a lack of well-defined and universally agreed criteria to establish and assess the quality of qualitative research (Bryman, 2016; Yardley, 2000). Formal criteria for evaluating quantitative research such as reliability, validity and generalisability on the other hand, are widely agreed upon (Bryman, 2016; Cohen et al., 2018). Attempts have been made to adapt these quantitative research criteria to qualitative research (LeCompte & Goetz, 1982; Lincoln & Guba, 1985). However, some qualitative researchers argue that the difference in epistemological assumptions of quantitative and qualitative research requires different approaches to demonstrating the value and validity of qualitative research (Tracy, 2010; Yardley, 2000). Yet still, others view attempts to establish standardised criteria for evaluating qualitative research as unhelpful given the diversity of theoretical approaches employed within qualitative research (Hammersley, 2007). This section discusses the steps taken in this research to ensure rigour based on five criteria commonly used to assess the trustworthiness of qualitative research: credibility, dependability, confirmability, transferability and reflexivity (Lincoln & Guba, 1985; Stenfors et al., 2020).

#### **3.8.1 Credibility**

In order for qualitative research to be credible, the research findings must be plausible and trustworthy (Stenfors et al., 2020). According to Patton (1999), credibility in qualitative enquiry depends on three distinct but related elements: “rigorous techniques and methods for gathering high-quality data”; “the credibility of the researcher”; and “philosophical belief in the value of qualitative inquiry” (p. 1190). In this study, the methodology chosen for this study was explained and justified so that the theoretical framework, research questions, sampling strategy, data collection and analysis were aligned (see sections 3.2 – 3.7). As the researcher played a central role in data collection, the issue of researcher credibility needed to be addressed and is discussed in more detail in section 3.8.5.

Tracy (2010) also suggests that qualitative credibility can be achieved through the practice of ‘thick description’ (Geertz, 1973). Ponterotto (2006) asserts that “the interpretation of what is being observed or witnessed” (p. 542) is a central component of ‘thick description’ which manifests itself in describing the participants, procedures, results and discussion of an interview study. Accordingly, the participants in this study were fully described without compromising their anonymity and included their relevant demographic and psychological characteristics. Secondly, description of the interview procedure including information about the location, length and recording provided a sense of credibility to the study. Thirdly, a ‘thick description’ of the results from this study presented adequate ‘voice’ of the young people using quotes from the participants. Lastly, the discussion chapter of this thesis was thickly described by merging the young people’s lived experiences with the researcher’s interpretations of these experiences. This also provided plausibility to the interpretive conclusions drawn from the research findings.

### **3.8.2 Dependability**

The argued unsuitability of the term ‘reliability’ in qualitative research (Stenbacka, 2001; Winter, 2000) has resulted in the use of the notion of ‘dependability’ (Lincoln & Guba, 1985). Stenbacka (2001) views a measurement method whereby research conducted by different researchers, on a similar participant sample, using the same defined methods, yields the same results, as irrelevant in qualitative research. Stenbacka (2001) advocates a “thorough description of the whole process, enabling conditional intersubjectivity” (p. 552) as an indication of good quality when using a qualitative method. In addition, Stenfors et al. (2020) suggest that although another researcher may reach different conclusions after following the same defined procedural steps, access to sufficient information provides some version of reliability in a qualitative research study. In this study, ‘dependability’ of the methods of data collection and analysis was achieved by providing a detailed description of the procedures employed (see sections 3.6 and 3.7).

### **3.8.3 Conformability**

Although complete objectivity in qualitative research is not possible in qualitative research (Bryman, 2016), ‘confirmability’ in qualitative research is about “establishing that data and interpretations of the findings are not figments of the inquirer’s imagination, but are clearly derived from the data” (Tobin & Begley, 2004, p. 392). In this study, the relationship between the research data and findings were explained through detailed descriptions and the use of quotes from the

interview transcripts and timelines of the participants (see Chapters 4 and 5). Lincoln and Guba (1985) also suggest the use of techniques such as audit trail, reflexive journal and triangulation to establish confirmability in qualitative research. Details of the process of data collection and analysis adopted in this study were discussed in sections 3.6 and 3.7. Although a comprehensive reflexive journal was not compiled for this study, informal notes and ideas were kept by the researcher for the duration of the research process which was useful in cross-checking information. The researcher's reflexivity is also discussed in detail in section 3.8.5.

### **3.8.4 Transferability**

Debates about the issue of generalisability in qualitative research are well recognised (Cohen et al., 2018; Lincoln & Guba, 1985). The concept of transferability, which refers to the extent to which research findings may be transferred to another setting, context or group of participants, is considered to be a more meaningful measure of generalisability in qualitative research (Lincoln & Guba, 1985). Lincoln and Guba (1985) argue that it is the responsibility of the researcher to provide the “data base that makes transferability judgements possible” (p. 316) by the reader of the research. This study therefore sought to fulfil this final criterion of research quality by providing rich detail such as descriptions of the research context and participants as outlined in the previous sections of this chapter.

### **3.8.5 Reflexivity**

As the “instrument in qualitative inquiry” (Patton, 1999, p. 1198), it was important that I, as the researcher, reflected on my role in this research. In addressing the issue of reflexivity, I drew on the three forms of reflexivity outlined by Wilkinson (1988): personal, functional and disciplinary reflexivity. Personal reflexivity referred to my identity as a teacher in an adolescent psychiatric hospital. My position in this research was therefore one of an ‘insider’ (Greene, 2014; Ross, 2017) in the sense that I had some prior knowledge and understanding of the population that I was studying, as well as the setting under consideration. As such, steps were taken to ensure trustworthiness in this research as previously described. Secondly, functional reflexivity involved the consideration of the epistemological stance of the research which Wilkinson (1988) argues is intricately related to personal reflexivity. This interpretivist research as discussed in section 3.2, required that I address not only my personal values and assumptions about the world, but also how the methods and other aspects of the research design shaped the study and the knowledge produced.

Also linked with this was the final form of reflexivity, disciplinary reflexivity, which involved continuous reflection on how disciplinary frameworks and assumptions informed and framed this research.

### **3.9 Chapter Summary**

This chapter outlined the methodological approaches adopted for this study. The main research question that this study sought to answer required a constructivist interpretivist philosophical perspective. A narrative inquiry approach was adopted to explore young people's perceptions of their experiences of being supported as they journeyed into and out of inpatient psychiatric hospitals. This chapter also outlined important ethical considerations which were paramount due to the vulnerable population who participated in this research. Semi-structured interviews were conducted by the researcher and the transcripts were analysed using Thematic Analysis. Finally, issues related to ensuring quality in the research process were also discussed. The next chapter presents the findings from the eight participants who participated in this research.

## 4 Findings

### 4.1 Introduction

The previous chapter outlined the methodology adopted in this study to explore the experiences of eight young women who had been hospitalised in inpatient psychiatric hospitals. The aim of this research was to give the participants the opportunity to share their views of receiving support within the healthcare system and child and adolescent mental health services (CAMHS) in particular as well as within the education system. Some participants also experienced support from adult mental health services (AMHS). The participants' experience timelines and interview transcripts were analysed using inductive Thematic Analysis (Braun & Clarke, 2006), in order to identify codes and themes that not only captured the spirit of the young people's stories but also to inform the research questions posed for this study.

This chapter presents each young person's story by providing brief background information followed by a description of their experiences. This is done by presenting each young person's experiences within healthcare and education settings in separate sections. Quotes from the participants are included to ensure that their voices are reflected in this research. Most of the excerpts used are from spoken interviews. However, where this was not the case, the letters 'EM' are used to indicate participant responses communicated via email. Extracts from the young people's experience timelines are also included and denoted by the letters 'TL'. Due to difficulties experienced during data collection (see section 3.6), the term 'inaudible' is inserted within interview extracts to denote speech which was difficult to transcribe. The symbol [...] is also used to replace some of the participants' spoken words in order to make the excerpts more focused.

In the final section for each participant, a summary of the main points from their experiences are highlighted. The chapter concludes with a summary of the common themes and sub-themes across all the participants. These form the basis for further discussion in Chapter 5.

In the next eight sections of this chapter, the stories of each of the participants interviewed are presented.

### 4.2 Abigail

Twenty-four-year-old Abigail said that her mental health difficulties started at the age of fifteen. She spoke about a complicated background which involved the police and law courts.

*I just went through a bit of a traumatic teenage life and things sort of came to a head over time ... and as soon as I spoke about what was going on in my life, my mental health just deteriorated even more [...] causing more issues, more problems ...*

Abigail shared her experience of being hospitalised in two different psychiatric adolescent units for a total of eight months, the first when she was sixteen years old. Abigail also mentioned that she was transferred to adult mental health services when she turned eighteen.

#### **4.2.1 Abigail's experience in healthcare settings**

Abigail spoke repeatedly about the support and care that she received prior to and during inpatient hospitalisations. She explained that after being on a CAMHS waiting list for almost a year, a lack of consistency in staffing and approach to care were unhelpful in establishing relationships with community CAMHS professionals.

*... it felt like I was being passed from person to person [...] I was going through a couple of people and obviously, that's not helpful for someone that's got issues because actually they need that stability and then it took obviously [time to] bond with someone ...*

Abigail mentioned that due to a lack of information about her inpatient psychiatric hospitalisation, she did not know what to expect when she was eventually admitted.

*It was almost like, right, well I can't deal with you in the community so right, we're gonna throw you in here without even really explaining what was going on.*

She also commented a few times about her experience of the care that she received in the first hospital.

*... the care that I received, I felt was completely inadequate. I felt that people weren't trained enough, that people weren't qualified enough [...] there was lack of staffing.*

Nonetheless, Abigail stated some positive aspects of her inpatient care which included the routine hospital environment, helpful treatment interventions such as aromatherapy exercise and opportunities to do normal activities such as visiting community shops and going for a walk. She also mentioned that fun leisure activities such as swimming, mountain biking and abseiling aided her recovery.

However, Abigail commented on the lack of individualised care, especially with regards to restricted eating times.

*Treated more as a setting of illness than individuals. 'Don't care' attitudes (TL2<sup>2</sup>)*

She also spoke about her views and needs not being considered in healthcare decisions related to agreeing her care plan, considering her desire to move to another hospital and her views about medication.

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<sup>2</sup> TL represents participants' experience timelines.

*... care plans were written, rather than [...] sitting down and coming up with a care plan together [...] there was a medication that I was taking that really wasn't agreeing with me [...]. I remember [telling] the doctor about it and them going, "oh well, you've got to take it". [...] I never felt like my needs were taken in ...*

Abigail also expressed a lack of compassion from staff.

*The staff weren't treating the young people with respect. The last port of call is to restrain them, inject someone whereas that was their first port of call. [...] I just felt that actually people didn't care, that I was just a job to them. Whereas like me, you know, doing my job, it's not just a job to me. Actually, I care. I'm human.*

She reflected on her adolescent psychiatric inpatient experience by saying:

*Some of the stuff I witnessed, some of the stuff I experienced [inaudible] unfortunately first hand myself was horrific. The care that I got was just completely inadequate. I wouldn't wish it on my worst enemy. It was very traumatic [inaudible]. People who have been through trauma and are having issues in their life ... to go into somewhere like that, to be treated like they have been, was just [inaudible] more cruel than good ...*

Another important aspect of her inpatient admission that Abigail talked about was the opportunity to develop friendships.

*... in a place like that, you always need people around you. You need people your age, who you can form a bond with, who you can socialise with, who you can do things with. Because actually, that's something that will keep you going throughout the whole experience [...]. It's a lot better than actually sitting on your own, sitting in your own mind ...*

However, she stated that she wanted the freedom to decide whether to take part in social activities.

*almost felt very forced into participating with things I didn't want to (TL2)*

Finally, Abigail explained the impact that these experiences had on her subsequent engagement with professionals in adult mental health services.

*... I became very bitter towards mental health practitioners, anyone who worked in regards to mental health. I became very bitter with CAMHS [...] I'm one of these people that actually, I can be very headstrong and luckily that meant with time I did become very headstrong. I was like, right, well they can't help me. They can't do anything so actually, I'm gonna do it on my own ... and that's what I did.*

She summed up her experiences by saying:

*It's almost like that journey through my life has actually helped me through my everyday life and made me actually stronger than I ever was ...*

Abigail also spoke about the support she received from hospital and mainstream education professionals during her journey of hospitalisations. The next section presents Abigail's experiences in her mainstream school and in the school located within the psychiatric inpatient hospitals.

#### 4.2.2 Abigail's experience in education settings

Abigail described the impact of her mental health disorder on her education.

*I was barely in lessons. My work was going from B's to Ds [...] everything was just too much. School was just diabolical for me ... found it very difficult to cope with my mental health and plus go to school and carry on as normal, so it became very, very difficult ...*

She spoke about the specific support that her Head of Year in school offered, but highlighted a lack of individualised support more generally in school.

*... the only person that I had to [...] comfort [me] was [Name] because there was no other support in place. [...] the way that things were communicated between teachers I don't think was from an outsider looking in, I don't think was at all helpful, you know. Maybe they could have done a bit more to actually support me; give me longer deadlines, like little things like that*

...

Abigail described contrasting experiences of the support that she received while she was in hospital. She spoke about a lack of consideration of her individual education needs, especially with regards to continuing her GCSE studies, during her first admission.

*... Teachers seemed very untrained and treated us as a group rather than catering for our individual ages and needs. (TL2)*

*... a couple of life skills ... some was just completely irrelevant ... and that was literally the only thing that they offered for us [...] when really actually you should [...] try to encourage people to go back into learning, rather than [...] just sit there and do craft.*

She also said that there was no communication between the hospital teachers and her mainstream school teachers. In contrast, Abigail described a more positive outcome from the support that she received during her second inpatient admission.

*I actually was able to complete my science GCSE while I was in the NHS Hospital [...] so that was actually a massive thing and the fact that they [teachers in mainstream and hospital school] communicated between each other [...]. The lady helped me do it on, you know, near enough a one-to-one basis [...]. That was brilliant because it helped me gain a GCSE out of it considering that I went with none ...*

Abigail explained that she continued her education in college and achieved GCSE passes in Mathematics and English, alongside her main programme of study in childcare. Abigail shared that she trained to become a childcare worker after leaving college. At the time of interview, Abigail stated that she was working as a childcare professional.

A summary of the main points identified from Abigail's experiences are presented in the next section.

### 4.2.3 Summary of Abigail's experiences

Abigail stated that she was strong-willed and expressed her desire to be listened to and participate in decision making related to her healthcare. She also spoke about her need to be nurtured by healthcare professionals and treated with compassion and respect. However, Abigail's perception was that healthcare professionals categorised her as an illness rather than treating her as an individual with specific health needs.

In addition, Abigail expressed her desire to continue with her education during her psychiatric hospitalisations. She stated a need for education professionals to be understanding of her difficulties and make suitable adjustments to accommodate her individual needs in mainstream school and in hospital.

Abigail explained that her inpatient hospital experiences left a legacy of bitterness towards mental health professionals. However, she expressed her sense of self-determination to recover from her mental health disorder without the support of professionals. Abigail also mentioned that with tailored support and effective collaboration between mainstream school and hospital teachers, she was able to work towards and achieve a GCSE qualification while she was in hospital.

The second participant is presented in the next section.

## 4.3 Josie

Nineteen-year-old Josie described a complex family background in which her mother, brother and sister all had serious mental health issues. Josie also explained that she was bullied from a very early age in primary school and continued to be bullied when she started secondary school. She added that she became depressed, suffered from anxiety and had suicidal thoughts. Josie also stated that she was diagnosed with autism when she was in Year 7. She shared her experience of being hospitalised in two different psychiatric adolescent units for almost two years, the first taking place when Josie was thirteen years old.

### 4.3.1 Josie's experience in healthcare settings

Josie described the extensive support that she received from community CAMHS once she started secondary school.

*... I saw a psychiatrist there who ... cos I was really suicidal, he told me what would make things better. He got the school to like stop me doing a couple of things. So I stopped doing PE, cos I got bullied in PE quite badly and things like that. I got more help from school. Then I saw a*

*therapist there and a family therapist as well. So I was seeing someone twice a week there and I was getting help from school.*

Josie explained that the decision to hospitalise her was made by her psychiatrist after she mentioned her plan to kill herself to a school staff member. Josie said that she was subsequently hospitalised in two inpatient units which were a long distance from home. She recalled her reaction to the decision to hospitalise her by saying:

*I was angry. I was fuming. I was fuming at everyone and I was sad like crying as well cos I was quite worried about school and what would happen about school. [...] it was my first time of being away from home so I didn't want to like leave my family.*

Josie described contrasting experiences of the care she received from staff during her first psychiatric hospital admission.

*The first ward, the staff was very understanding. They were really good. [...] when I moved upstairs to the other ward, the staff were horrible. I started getting like episodes and they used to tell me I was making it up and like, that I was just doing it for attention like and like banned my mum from seeing me for a little while which was just stupid. They didn't listen. [...] they had their own opinions. They wouldn't listen to you ...*

In addition, Josie singled out the treatment that she received from the doctor on the unit.

*The doctor there [...] he would just mess my medicine around constantly. I would be on like 700 mg of one med and then he would put it down to like zero and he would like change it constantly. He was just awful ...*

Josie also said that she did not feel listened to with regards to her treatment and decisions to discharge her from hospital.

*... they wanted to discharge me but I said I wasn't ready and they didn't wait. [...] my CAMHS team and my [inaudible] doctor kinda had like a massive argument while I was like in the room [...] the doctor there saying that I wasn't ill, but the CAMHS doctor is like "yeah, she is ill" ...*

Josie described her experience during her second inpatient admission.

*... they called themselves a therapeutic community [...] they called it a hospital but it was more like a care home [...] I was there for 15 months and I just spent that in bed ...*

In contrast to her first hospital admission where she was reluctant to be discharged, Josie stated her feelings about her second admission by saying:

*I hated being in that hospital; hated it. It was awful. [...] I wanted to get out as soon as possible.*

Nonetheless, Josie recalled some positive experiences such as the opportunity go out to the shops or pick a movie to watch. She also said that she liked group sessions offered such as art therapy.

Josie stated that she “*didn't really get on with anyone*” from CAMHS when she was discharged from psychiatric hospital. However, she spoke positively about the support given to her by her social worker.

*... I had a really good social worker. She'd come and see me a couple times a week and [I had] quite good like care plan with her ...*

Josie also recounted the helpful support which her social worker offered in seeking alternative specialist healthcare support as well as alternative education providers. This will be discussed in more detail in the next section which details Josie's experience of support in different education settings including her mainstream school, schools located within the psychiatric inpatient hospitals, an alternative provision setting, a further education college and an organisation which provided an emotional wellbeing mentoring programme.

#### **4.3.2 Josie's experience in education settings**

Josie explained that she received support in a "special group" due to her speech and language difficulties during her first four years in primary school.

*... so the school that I went to there was like a resource for like the kids that have like problems being in mainstream school*

Josie elaborated on the difficult relationships that she had with peers after she left this group.

*... got bullied by a friend who turned against [me], felt awful, didn't want to go to school (TL1)*

*... I made friends but later on they turned out to be like not very nice people. They were kind of using me but I was very naive at the time so they weren't real friends ...*

She also made several comments about her continued difficulties with peers when she started secondary school.

*Year 7, had fake friends who made fun of me, was getting a bit sad [TL1]*

*Second half of year 8 got bullied badly, become depressed, had anxiety and had thoughts about suicide. [TL1]*

*Year 9 bullying got really bad that I started not going to school [TL1]*

Josie mentioned that although her psychiatrist suggested that Josie stop doing physical education in an attempt to address the bullying in secondary school, it continued nonetheless. Josie also commented on the helpfulness of the pastoral support that she was given in Year 7.

*I: [...] Was it helpful to have this kind of support?*

*P: Well ... to an extent ... I mean, they were never really there when I wanted to talk to them anyway so I mean, I didn't really see the point of them setting me someone when they were never there.*

She also spoke about her school's response when she expressed her plan to kill herself to her pastoral support teacher when she was in Year 9.

*... they basically like kicked me out of school for a little while. They kicked me out of school. [...] so if I had like managed to do something in that school, they can't keep an eye on me 24/7 and they basically said that they can't keep [me] safe here; [I] can't come to school anymore.*

Josie expressed how she felt about her school's decision by saying:

*... they didn't want me in the school so that's great ...*

Josie explained that shortly afterwards, she was admitted to the first of two inpatient adolescent units where she was supported with her education. Josie stated that her mainstream school sent work in key subject areas such as English, Mathematics and Science to her hospital school teachers. However, Josie explained the impact of her illness on her education.

*... was very depressed so didn't do any education [during first eight-month admission], then I start going down and getting some work done for school. After about two months things got worse and didn't do any school work at all. (TL2)*

*... started doing some work [during second fifteen-month admission], but I [got] depressed and just spend my days in bed so didn't do any work. (TL2)*

Nonetheless, Josie said that when she was well enough, the hospital teachers supported her with her favourite subjects which were Business and Child Development.

Josie stated that she did not return to her mainstream school following her second inpatient admission. She explained the key role that her social worker played in suggesting options for her education provision. Josie reflected on her experience at an alternative and special education provider (ASEP), where she attended for almost seven months.

*... They put me for like my level one but they didn't really teach me very much. They'd give me worksheets, but it was just like really simple stuff. So I failed all my exams and then my second year [...] they brought all of them [other students] to this place that I was in so it was very packed with teenagers and I'm terrified of teenagers ...*

Josie stated that she eventually refused to attend ASEP and attended adult evening classes at a college with the support of her father. In contrast to her experience at ASEP, Josie spoke more positively about the college and highlighted the support that she found helpful.

*... they are really [good]. They help me a lot, allowing my dad to [sit] in the classrooms with me while I worked. They took it at my own pace meaning that, all the gaps of information were filled. [TL3]*

*... If there was going to be like an exam [...] they would tell me like a couple of like weeks before so I had time to prepare for it. [...] if they can see me getting anxious, they will like speak to me outside to see how I'm doing and they will like do kind of sessions to like kind of like try to see how I'm doing and ask class if they think I'm struggling ...*

Josie stated that she achieved Functional Skills qualifications in Mathematics and English with this support in small class sizes. At the time of interview, Josie said that she was still attending college and mentioned that she was coping with an increase in class size of between twelve and fifteen

students. Josie reflected further on the support she was receiving from the college before having to engage with online learning during the COVID-19 lockdown.

*Oh it was incredible. The teaching is really good there. But all the teachers I've had there ... it's two teachers called [Names] who are incredible. They're really good ...*

In addition, Josie explained that her social worker recommended support from an organisation which provided an emotional wellbeing mentoring programme alongside Josie's college attendance. Josie explained her initial response to this support by saying:

*I was in a state of mind that I think I didn't deserve any help so I kind of ... I would like sabotage the good things ...*

However, she described the support that she was given.

*... every time I was there I would meet with one person and that person [...] I really like her. She's lovely. [...] They got me to kinda bond with the animals and they got me to like make my own decisions. So like if I don't want to turn up, if I don't want to come in, they wouldn't force me to talk or anything. They would always tell me like "I'm here if you want to talk about anything". [...] At the beginning, when I was scared of boys, they would always make sure that there was no boys round and slowly they kind of like introduced boys in sessions when I was there ...*

Abigail added:

*... probably like six months in, I started to like really like the place and the animals.*

At the time of interview, Josie was working towards her Mathematics GCSE and Level 2 Functional Skills qualification in English at college. She also mentioned that she was hoping to complete an NVQ qualification in animal care with the mentoring organisation. Josie stated that she was "learning quite a lot" by looking after the animals and spoke about her plans to become a groom in the future.

Josie commented on her experience with the mentoring organisation:

*... [it is] where I feel comfortable and that I feel that I have connected with the people and I have just bonded with the animals. I feel like really safe there and it's like secure. It's a place that I like being ...*

She added that while in lockdown due to COVID-19, she was "really missing" the animals and the people. Josie concluded the interview with several statements about her peer relationships.

*I don't have any friends so I don't have friends to bully me, I suppose.*

*I'd like to have friends but I just don't seem to be able to ...*

*It's been rubbish really but nobody seems to want to be friends with me so I'm kinda on my own ...*

A summary of the main points identified from Josie's experiences are presented in the next section.

### 4.3.3 Summary of Josie's experiences

Josie's recollections highlighted the difficulties she experienced with social communication and peer relationships from an early age. She stated links between these difficulties and her mental health as well as her engagement with education. Although Josie explained that she was eventually diagnosed with autism and received a significant amount of support from professionals, she expressed her need for them to show compassion and sensitivity towards her. She described mixed experiences where on the one hand she said that healthcare professionals were uncaring towards her. Josie expressed her need to feel listened to with regards to her medical treatment and decisions to discharge her from hospital. On the other hand, Josie spoke about her social worker who was more understanding and supported Josie to find alternative specialist healthcare treatment and educational provision which met her needs once she was discharged from hospital. Josie stated that healthcare professionals' lack of compassion resulted in her disengagement from CAMHS professionals once she was discharged from hospital.

Josie's narrative was also characterised by her description of multiple moves to different education settings. She stated that some education professionals in her mainstream school and alternative provision setting did not understand her difficulties. She said that her specific social, academic and pastoral needs were therefore not always considered or addressed. In contrast, Josie said that her further education college made efforts to help her to settle in. She also described staff from her mentoring programme who were patient and persevered in supporting Josie when she initially resisted their help.

The third participant is presented in the next section.

### 4.4 Violet

Eighteen-year-old Violet explained that she moved to England at the age of seven. She mentioned that she had a difficult relationship with her mother during her early teenage years as well as a "*toxic relationship*" (TL1) with her boyfriend. Violet added that her mother struggled with her own mental health issues. Furthermore, Violet explained that at the age of fourteen years, a "*traumatic event*" (TL1) happened to her and she reported this to the police. Violet recalled that repeated flashbacks and panic attacks resulted in her worsening low mood, increasing self-harm and becoming suicidal. She shared her experience of being admitted to an adolescent inpatient unit for almost two months when she was fourteen years old. Violet also mentioned that she was placed in foster care after she was discharged from hospital due to her mother's serious health difficulties. In

addition, Violet stated that she was transferred to adult mental health services when she turned eighteen.

#### 4.4.1 Violet's experience in healthcare settings

Violet recounted her positive experience of receiving support from outpatient CAMHS.

*... I was quite lucky cos obviously waiting lists are usually years sometimes for people [...] they kind of listened to what just happened. I think they kind of said "we got to do something". They took me in quite quickly ... so I got this lady [CAMHS worker], and she was lovely. She was really good. So she supported me for quite a long time, a couple of years, I think. I built quite a strong relationship with her. So I think that was very lucky ...*

Violet stated that similarly, she received consistent support from her psychiatrist, who later supported Violet during her assessment to transition from CAMHS to adult mental health services. Violet explained the importance of having these relationships.

*... some people obviously when they go to CAMHS and they're constantly changing [...]. That's partly why it's so traumatic because you are having to like, just keep changing your relationship all the time. So that was really good that I got to stay with her [CAMHS worker] for such a long time.*

*... you kind of have to explain your story over and over and over again. And obviously, when it's a therapist, you need to speak to them in a lot of detail about things and that bond to build ...*

Violet also mentioned that her CAMHS worker played a key role in informing Violet of the decision to admit her to an adolescent inpatient unit due to her deteriorating mental health. She stated a range of emotions about her hospitalisation.

*... I thought, "Oh, wow, like there might be a way out of here". [...] I felt a bit relieved but at the same time I felt quite hesitant, like I didn't really want to go.*

*... you don't really know what to expect like ... I didn't really know that something like that existed*

*... when I went into the unit, I was very kind of numb like [...] there was just so much going on in my head like I just couldn't process what was happening ...*

Nonetheless, Violet spoke about some positive aspects of her admission.

*... they do try to stop you from doing anything bad. Like you are kind of watched like quite a lot. So that did kind of stopped me from harming myself and also, medication wasn't always my strongest point cos me and my mum would forget for me to take them for quite a long time. So I'd be on and off. So in that amount of time, I kind of took it every day ... so they make you take it. So obviously that was one thing that was good cos I was actually taking it. So I could see how it was impacting me ...*

However, Violet expressed a different view about the medical treatment that she received.

*Because of the wide age range, some therapy felt very simple. Because I felt slightly more mature at that point, I felt it was unhelpful and found some activities to be quite childish (TL2)*

Violet also offered her views on her involvement in decisions made regarding her medical care.

*... I think they did involve me in a lot of them. I was in the meetings and I do think they asked me personally what I wanted so I do think they had done that quite well. But obviously with all these care plans [...] it's just more about just having something written down on paper ...*

In addition, Violet stated the following:

*threats to be moved away if I did not get better on time (TL2)*

Furthermore, Violet expressed a lack of support and flexibility in modifying procedures and regulations to meet her needs when she was in hospital.

*... I've been dancing since I was a little. I haven't done it for quite a while now but that was a massive thing just for me. It was my own thing that made me feel better. [...] they were really adamant about me not doing it, but it just didn't make any sense as to why they couldn't just change the days like ... if they're going to release me, why can't they release me on a different day? [...] I remember just getting very upset. [...] ... they would allow me to go home. So if they're allowing me to go home and they trust me at home to not run away or do anything, then how was it any different? It didn't make much sense.*

Furthermore, although Violet described positive relationships with her CAMHS worker and her psychiatrist as well as the consistent support that they offered, this was not the case with one of her two social workers.

*We had one specific social worker and she was just very, very unhelpful. Like now I look back at it, I thought it was very unprofessional. She kind of made things [inaudible] worse and made situations worse to the point where me and my mum couldn't even speak to each other. We couldn't look at each other. [...] the relationship just went so bad. I do like look back at it and think she did kind of impact it a lot in a negative way ...*

Violet recalled that the situation did not improve when she was admitted to hospital.

*... I think she was kind of saying that she expected this to happen and like that I just got to get through it. She didn't really help in a lot of ways ...*

Furthermore, Violet recalled the difficult relationships that she had with other patients when she was admitted to the adolescent unit.

*I've always been quite a confident kind of person. [...] I was part of [...] the popular group [in school] [...] So obviously when I walked into the inpatient unit, [...] I think from the second they saw me, I think they kind of built an image of me. I think a lot of people get that when they see me. They think [...] I'm a bitch or something. So I think when I joined the unit, I think that instantly happened.*

*... I just felt they never really used to speak to me about stuff like, as much as I tried to like create like relationships. Cos that's kind of what you want to do if you're living with people. They kind of stayed distant towards me and they obviously started going on about the eating disorder, and that just made me feel really bad. I wasn't really happy at that point. But I think*

*that affected me a bit just because I just thought in that place, I could kind of just get away from everything but then it kind of just made it even worse for me ...*

Violet also stated the impact of being “surrounded by individuals with different types of issues”

*... because everyone was in a low place, advice [I] was given from others was not healthy. [TL2].*

She commented about the lack of support that she received from inpatient staff.

*I think because everyone was in there for their own personal like reasons, they can't really tell someone how to act because obviously they might act that way because of their issues. So they couldn't really tell 'em off because maybe they don't understand or something. I don't know. But it was quite difficult, they couldn't really do much about it ...*

Violet recalled mixed emotions about her discharged from the adolescent unit.

*... I remember being quite happy like ... I'm gonna get out of here now ... like I can actually start doing what normal people do again. [...] the way I thought of it [inpatient admission] ... it was a break, but it didn't change anything that was going on. It can't change anything that's going on. So obviously when I was leaving, it was partly like “Oh yes, I'm out” but then [...] when you're out of there, it feels like you're looking at things from [a] different perspective because you're out and it's exciting and stuff and you just want to get on with everything. But then you realise like well, everything's still how it was. So it was kind of ... it was a balance of the two things.*

Violet reflected on her journey by saying:

*... when I think about how I was, I think I'm one hundred times better. My mood has really improved but I'm waiting for adult trauma therapy cos I've just turned eighteen. So I'm waiting for that. So I've kind of had a break cos I've only been eighteen since October so that's when I stopped CAMHS. So after all these years, this is the longest I have been without CAMHS ...*

The next section focuses on Violet's experience of support in the three mainstream schools she attended, in the school located within the psychiatric inpatient hospital and in an alternative provision setting.

#### **4.4.2 Violet's experience in education settings**

Violet recalled the impact of her inability to speak English when she first arrived in England, on her friendships at primary school.

*... I couldn't actually speak the language at all, whatsoever. And then primary school ... obviously that was a bit difficult because I went straight in without speaking. [...] when I look back at it, it was such little things, but obviously, like friendships and stuff were quite difficult. [...] I used to get quite upset about it.*

Violet explained that the friends she eventually made later attended a different secondary school to her due to Violet's family moving house. Violet stated that she did not fit into the school and

described the bullying that she later experienced in Year 8. She commented on the support she received from school staff.

*... they weren't actually very supportive. [...] there was a lot of people with like behavioural issues and I never really had a problem with that. But I think that's where it kind of began cos I wasn't really like the other kids. [...] it was just getting worse and worse and it got to the point where the teachers physically weren't really doing anything. Like they used to put me in isolation and like the kids who wanted to bully me, they'd like run into the actual room and then they'd tell me to like hide under the table or something. It was actually like crazy [...] it got to a point where like, I didn't go to my lessons. They'd [school staff] like escort me round the school to get my lunch and stuff. It was really weird ...*

Violet also explained the cyber bullying that she experienced.

*... then there'd obviously be stuff on social media where they'd be like editing like newspapers, putting my face on there and stuff and saying horrible things. [...] it was quite difficult ...*

She elaborated on the impact of the bullying.

*... throughout this whole thing, we were fighting really hard to get me into [another school]. Obviously, like there was no way I could even stay in [the first school]. I was kind of refusing to, like I would not get out of bed and I think they were concerned about my school cos I physically just couldn't go anymore. Then they tried to put me into [a second school], the girls' school and I went there for one day and it was awful. It was awful, so I said I'm not going again.*

Violet explained the difficulties she experienced in the second school.

*... the second I walked in, I felt very like targeted. [...] on that first day, a group of like the popular girls came up to me [...] and just kind of was a bit threatening; [...] I just literally felt like "I'm not gonna be very happy". Like I just knew that problems were gonna come ... girls didn't usually like me ...*

She recalled the support that she received from one senior member of staff, Mrs A in her third school.

*... so we fought. We wrote a lot of letters and stuff and then luckily, I got into [the third school]. I think Mrs A was actually the one who kind of organised it all in the first place. So that's how I built a really good relationship with her ...*

Violet also elaborated on the additional support that she received from Mrs A when she was admitted to psychiatric hospital.

*... when I landed in the adolescent unit, I was really worried about that because obviously we fought so hard to get in there [third school] and now like, I'm not in there anymore. I was worried but [...] Mrs A kind of said "that's absolutely fine" and [that] it will be waiting for me when I get back and stuff.*

*... [Mrs A] came to see me [in hospital]. But she just reassured me that it's fine to just be here. That it's right to have a break ...*

*So I was very worried about missing a lot of it [school] and stuff but she [Mrs A] just made sure that I was up to date and it would be fine. So that was really helpful, just knowing that I don't have to worry about that ...*

Violet also spoke about the support that she received from other teachers in her third school.

*... because I was quite new as well, it was kind of difficult for them to judge what exactly I need help on and stuff [...] but I think they tried as best as they could to provide [work] ...*

However, Violet explained that she did not have much opportunity to complete the work provided by her school. Violet explained that “*school was either too easy or too demanding*” (TL2). She described being taught with other patient patients.

*... it was usually the whole group. It was kind of rare for us to do it separately and do our own work. So obviously cos there was different people who were at different ages, that sometimes the work I thought was a bit ... I just didn't really see the point of doing it. I just found it a bit pointless.*

She also stated that some days were challenging.

*... there were days where you just feel so like crap and you just don't wanna do anything. I remember them having to wake us up and get us in there [school], just encourage us to do the work and stuff which obviously that's what they need to do but I remember just hating it. I just thought it was awful cos I just wanted a break. I didn't want to talk to anyone. I didn't want to see anyone and just having to do that ... So I remember that being a bit difficult at times.*

Violet explained the support she received to reintegrate back to her mainstream school towards the end of her hospital admission.

*... they kind of organised for me to just go at my pace I guess. So I was going in, so kind of I could do my work in the office and then they kind of said “Well, is there any lessons you feel like you could go into like properly to the actual lesson?”. And I think it was just about just doing that a bit, and then kind of going in the end. I think I remember, cos I was quite happy with doing that so soon, I think they kind of just pushed me straight in there [lessons] after. So I had to go into all my lessons. I thought it happened so suddenly. So I think they could of kind of waited a little bit longer.*

Violet mentioned that she was placed in foster care. She described the impact that some of the difficulties that she experienced during this time had on her education.

*I used to get taxis over [between foster home and school] and it was alright at first and then everything just kind of got worse again and I just couldn't do my work ...*

*So while I was in foster care, all the court stuff started happening [...] that was a massive thing going on and I couldn't cope with school at all [...] my mood went down again and they moved me into [a Pupil Referral Unit]*

Violet recalled in particular, the helpful support that she received from her Art teacher at the Pupil Referral Unit. She added that she was supported by teachers and was able to achieve passes in most of her GCSE subjects including Mathematics, English Language, Science and Art.

At the time of interview, Violet said that she was studying at College. She stated her plans to go to university and reflected positively on her achievements.

*Everything's kind of just turned around. Last year, I did my Level 2 [qualification] and I got a Distinction Star. So that's like the best you can get so I think somehow, it's all changed. So school is actually going quite well for me.*

A summary of the main points identified from Violet's experiences are presented in the next section.

#### **4.4.3 Summary of Violet's experiences**

Violet recounted many challenges, including familial mental health problems and relationship issues as well as trauma and difficult peer relationships, which had an impact on her mental health. Violet's narrative was characterised by her description of multiple moves to different education settings due to the bullying that she described. Although she stated that her inpatient psychiatric hospital offered respite from her difficulties, Violet was concerned about the impact on her education.

Violet also spoke about the positive impact of having positive relationships with professionals and being nurtured by them. She stated that the consistent support from her community CAMHS worker and psychiatrist allowed trusting relationships to be developed. Similarly, Violet described the reassurance and support of education professionals in mainstream and alternative education settings which enabled her to achieve academic success. However, Violet mentioned a lack of flexibility in modifying rules and regulations and tailoring support to meet individual patient needs in the strict and structured inpatient hospital environment.

The fourth participant is presented in the next section.

#### **4.5 Amelia**

Twenty-year old Amelia explained that she experienced anxiety and depression from an early age and was also bullied in secondary school. She spoke about her fluctuating emotions, low mood, self-harming behaviours, multiple medication overdoses and suicide attempts, which resulted in her being hospitalised for the first time at the age of fourteen. Amelia offered explanations for her self-harming behaviours.

*... I used to get a lot of pent up kind of anger about [...] feeling so low and so I would do that to try and get rid of it and try and make me feel better and a lot of the time it did make me feel better. [...] My emotions used to be up and down [inaudible] but then later, I went so low [...] that I kind of didn't want to live. And that was the reason. And then I took a lot of different tablets and I was quite unwell ...*

She shared her two-year journey of being admitted to general hospital on four separate occasions and being hospitalised in four different adolescent psychiatric inpatient units.

#### 4.5.1 Amelia's experience in healthcare settings

Amelia described contrasting views about the different healthcare professionals who supported her in general hospital.

*... obviously, all the nurses were lovely but with the mental health team, I always found it quite frustrating cos they never came when they said they were coming, they never did what they said they were going to do, so because it happened several times, it was not very helpful ...*

Similarly, Amelia recalled contrasting experiences at the four different psychiatric hospitals that she was admitted to. Amelia explained that with the exception of the first hospital, her subsequent inpatient admissions were in hospitals which were a long distance from home. She said that the long journeys were difficult for her family and she worried that they would be unable to visit her every week.

*it was really horrible cos I was so young [...] I was only 15 by then [...] my mum actually left work [...] she left her job so that she could come and see me every week [...] she was actually able to come over every other day to visit me ...*

Amelia also stated that lack of psychiatric inpatient beds delayed her discharge from general hospital prior to her first and third psychiatric hospitalisations. She spoke about the support that she received during her first psychiatric inpatient admission.

*... you kind of went from all or nothing. So in the week, there was people there all day, all night, that you could talk to if you were struggling. And then at the weekends, it would be that they weren't even open so you couldn't even call them and [talk to them] on the weekends [inaudible]. It all felt a bit like a struggle at the weekends. [...] ... we were just told by the crisis team, that [Name of place] at that time didn't have an out of hours like team that would like come out to you or anything, so if you were not great you had to go to A&E ...*

Nevertheless, Amelia recalled her view about inpatient psychiatric care during her first admission.

*... at that time, my view on inpatient was that they'd help me and they'd make me better and that it was like a good [thing] ...*

However, Amelia shared experiences in subsequent psychiatric hospitals which were in contrast to her first experience. For example, she described the scene which greeted her at the third hospital, a psychiatric intensive care unit (PICU).

*... there was no doctor to admit me or anything [...] and a patient had just thrown a chair through a window and the glass had scattered everywhere so the unit was covered in [glass]. [...] there was just police all over the place and I begged my parents not to leave me there, cos the alarm was going off, everyone was [shouting]. It was like a horror movie. It was awful.*

Amelia also explained that she was “unmanageable” (TL2) during her brief stay at the PICU.

*... probably the worst point was when I was there and I was on two to one. I had two staff with me all the time because I kept trying to hurt myself and I still managed to like steal needles from the doctor's room when I had an assessment [and they were not looking] and locked myself and*

*things like that. So they decided that they couldn't treat me there, cos they didn't have enough staff to put more staff with me ...*

In addition, Amelia further described the care that she received.

*... I'd say [it was] like I was in prison because I obviously had nothing in my room. My room was completely stripped [inaudible]. I didn't sleep with any bedding or things like that so I just felt like a prisoner cos they watched me get changed, shower, bathroom ... So it was [inaudible] bizarre.*

Amelia described a similar of the care that she received at the fourth PICU.

*... the actual care I got there was awful and I was quite ... mentally the staff were quite abusive and had a lot of unlawful things happen with being injected and then not seen by a doctor, being restrained when I shouldn't have been ... things like that.*

Amelia explained that her family was unhappy about her care but experienced difficulties in getting her discharged from hospital because she was detained under Section 3 of the Mental Health Act<sup>3</sup> ("Mental Health Act," 1983).

*So the last couple of months of my admission, my parents said they wanted me [...] I wanted to leave but I was on a Section so they wouldn't let me. So it was a fight to the very end of my parents ...*

She also recalled her reaction when she was detained under Section 2 of the Mental Health Act<sup>4</sup> after a decision to allow her to leave hospital was rescinded during her second psychiatric admission.

*... at the time, I don't think I understood much because I was so unwell. I didn't really get what it meant. I was just very [angry] about the fact that I wasn't allowed to leave.*

Amelia explained the support that she received from her family to stay out of hospital after her fourth inpatient admission.

*... when I had that blip we said like right we're not going into hospital for them [to help me] to get better [...] and so I just had a couple of weeks of medication and a couple of weeks of my parents spending the night and things like that ... and them doing everything they could to keep me safe without actually going into hospital.*

She also spoke about the support that she received from outpatient CAMHS, which enabled her to remain at home following discharge from the fourth PICU.

*I went back to having care with CAMHS. Through this whole time, I actually had the same consultant at CAMHS and met me for the whole five years that I was with CAMHS. She stayed but all my others, they'd left [...]. Every two weeks I would see her for medication review and to make sure I was well enough [to be at home] because I wasn't really meant [to be at home]. [...] it was her decision as to whether or not [I stayed at home] ...*

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<sup>3</sup> Section 3 of the Mental Health Act 1983 allows detention for up to six months.

<sup>4</sup> Section 2 of the Mental Health Act 1983 allows allow detention for up to 28 days.

Amelia recalled the medical treatment that she received in the psychiatric hospitals. She mentioned the support of the CAMHS consultant in her first inpatient unit.

*... there was a consultant there, but we couldn't see them at all. We'd only see him in case team meetings which were not that often and when I was there, they were very keen to not put you on any medication really, so we had to push them to get me put me on some more to support me and [they were] reluctant ...*

In contrast, Amelia explained that she was “*put on much medication*” during her second inpatient admission.

*I hadn't really realised that's what it was beforehand ... so then that was my first time of getting support and medication and having treatment for hearing voices ...*

She recalled her view of the treatment she received.

*... I felt like I had made a lot of improvements and that the medication I was on stabilised me quite a bit. I was quite happy to leave there and be coming home and just felt quite different to when I had gone in.*

Amelia explained that her mental health continued to fluctuate after discharge.

*... so it was very frustrating [...]. Everything had got a lot better and I was on the right track. But with my mood, there was often never any trigger. So I found that from the very beginning, that people would try and look back and find a trigger [...] so within the space of two weeks I went from doing okay and I wasn't much like better but I was doing quite well, to feeling awful and ending up in [General Hospital].*

Amelia also talked about the different forms of therapy that she received from CAMHS. She described contrasting views of cognitive behavioural therapy (CBT) treatment that she received at different points in her recovery journey.

*I found [CBT] worked really well and I really liked the lady who did it with me. I found her approach really good. I wouldn't say it [anxiety and low mood] massively went, but I learned quite a lot of tactics for coping with it. [for social anxiety prior to inpatient hospitalisation]*

*... I didn't find that as helpful and I didn't really get much from that so I think I might have dropped it a bit early ... [from mood clinic prior to inpatient hospitalisation]*

*... the CBT lady that ran it I didn't really like how she was doing it. I didn't get on with her very well ... [after fourth inpatient admission]*

Amelia recalled other therapeutic interventions that she received during her first inpatient admission.

*It was more therapy groups and art therapy; things like that which were enjoyable. When I first went to [Name] hospital, it had just changed from being an all eating disorder unit, so a lot of [patients] were there for eating disorder. There were only a few of us who weren't.*

She commented that the medical treatment was therefore more structured around the needs of patients with eating disorders and did not address her specific needs.

Amelia stated that as her health improved following her final psychiatric admission, she started to receive treatment for other difficulties which she described as “*things that weren’t the biggest problems in my life*”. She explained how an eight-week course of exposure therapy that she received for her anxiety and obsessive compulsive disorder (OCD) was helpful.

*... it was the first time I’d ever really spoken about anyone or about these issues ... [...]. She helped me understand why I had these feelings and thoughts [...] and that made me feel better about it.*

Amelia mentioned that following these sessions of exposure therapy, she made a conscious decision to stop self-harming when she realised that it did not help.

Furthermore, Amelia explained that at the age of eighteen, she was transferred to adult mental health services (AMHS). She said that after a six week wait for her first AMHS appointment, the team sought to provide an alternative form therapy treatment that she had not tried before, but which would address her needs. Amelia stated that because of her “*anxiety about how I looked to others*”, she attended a twelve-week compassion-focused therapy (CFT) course which was focused on “*learning to love yourself*”. However, Amelia expressed mixed feelings about the CFT group sessions which mostly comprised adults.

*... I struggled with the other people in the group being quite negative. So they would cry quite a lot and [use] negative words. When I went to the session, I would have had a good day at college with my friends and going there brought me down a bit so towards the end, I was looking forward to finishing ...*

Amelia stated other support that she received from AMHS which included access to a crisis team even in the evenings and at weekends, and regular home visits by a social worker which she said helped her from “*getting worse*”.

She also shared how she felt about moving from CAMHS to AMHS.

*I was nervous about leaving my consultant because I’d known her around five years and she knew everything there was to know about my illness. So if I started to get ill again, she’d know how to deal with it. I was worried about explaining it all to someone new and whether they’d understand it. But I was really relieved to be out of CAMHS apart from leaving her ...*

In addition, Amelia expressed mixed views about the family therapy she and her family received in the inpatient psychiatric hospitals and in the community.

*... at [first hospital] person who ran it [...] for the whole session didn’t say much and [resulted in] the family arguing and upsetting each other whereas at [second hospital] [...] she had a plan of what we’d talk about each time. We didn’t just end up going into an argument or talking about something off-track ...*

She explained that these experiences influenced the level of engagement of her family in this support. Abigail described a difficult relationship with her sister who had autism but mentioned that things improved after sessions of family therapy.

*... me and her didn't get on very well to understand each other. So there was quite a lot of struggles at [home]; didn't really like home life. So we spoke a lot about that and how we could change it.*

Finally, Amelia commented on the negative influence of other patients during her psychiatric hospitalisation.

*... I think that being around other people my age who were ill the whole time I was young were all bad influences. [...] you learned things, you copied things, like picked up things.*

The next section focuses on Amelia's education experience in two mainstream schools that she attended and the support that she received from home tutors and educational professionals in sixth form college and in the psychiatric hospitals.

#### **4.5.2 Amelia's experience in education settings**

Amelia stated that she was bullied in Years 8 and 9 in her first mainstream girls' school. She explained her reluctance to return to this school after her first psychiatric hospital and the managed move to a second mainstream secondary school which was subsequently arranged for her. However, Amelia said that she was unable to return to this second school after her second psychiatric hospitalisation. Amelia explained that home tutors supported her until she completed her GCSE examinations and started college. She shared a mixed experience of being supported in these settings.

Amelia expressed her view that staff "*didn't really do much for me to cope with the bullying*" that she experienced.

*... when we told the school about the bullying, the only option they really had was to put me and the girl who bullied me in the same room [inaudible] to talk about it. But the girl who bullied me was kind of part of the friendship group I was in [so] they didn't want to be friends with me*  
...

She also commented on counselling support that she received in school.

*... they didn't really do much talking about coping mechanism. It was more just chatting [inaudible] about what I had done that week, things like that.*

*... found it quite pointless [...] it wasn't really doing very much for me ...*

Nevertheless, Amelia said that she had access to a safe space in school when she was struggling during the school day.

*... we had an area called 'Student Support' and there were about four ladies working in it and one of them became my kind of point of contact to see that I was alright, cos I used to have panic attacks [inaudible]. So when I had a panic attack, I could leave class and go over there.*

She also commented on the support that she received from her school during her first inpatient psychiatric admission.

*... they were really quite good actually [inaudible]. We had my deputy head teacher who was our contact. He would come to my case team meetings and keep in contact with us. So he knew about what was going on.*

However, Amelia stated that she did not want to return to her school because of the bullying that she had experienced. She explained that a managed move to a second mainstream school was arranged.

*... I think the move was a great idea. We found the support at [second school] much better than [first school] for me and they kind of came up with a [plan] that helped me get into lessons. They were really supportive [inaudible] with my mum and keeping her in contact ...*

Amelia also spoke about the support that she received from two named members of staff at her second mainstream school, to help her cope with her anxiety.

*... they kind of came up with a [plan] that helped me get into lessons ...*

*... they wouldn't throw me in at the deep end ...*

Amelia explained that she was initially given a safe space to do her work with a designated adult and was gradually introduced to her teachers and classmates. She expressed her view about a later arrangement to sit outside classrooms to do her work.

*... I didn't mind at that point cos I didn't really know anyone, so I didn't [feel] like anyone knew what was going on with me.*

However, Amelia said that she was concerned about having to repeat the school year because she had missed a lot of school due to her illness.

*... it worried me a lot because I didn't want to be behind everyone else my age ...*

Amelia said that the opportunity to discuss her “anxiety over being behind” with staff at school helped to allay some of her concerns.

Nevertheless, Amelia said that after her second psychiatric hospitalisation, plans for her education changed.

*“I wasn't well enough to go back into any school and I didn't want to ...”*

She explained that arrangements were made for her to be taught Mathematics, English and Science at home by subject specialist teachers who liaised with her second school. Amelia described herself as “quite high achieving at school” and was studying twelve GCSE subjects. She explained that

she was reluctant to reduce this to the three core subjects of Mathematics, English and Science while she was in hospital and so continued studying German as well. Amelia described the support that she received from her home tutors.

*... they were amazing. [...] probably the only way I managed to ever get my GCSEs [...]. They would come into my house because it was a lot easier for me. They would do however long I could handle with my medication [...] one or two hours. And they were quite flexible as to when I was not feeling great [...]. They were also [good] friends to me and my mum. They were the only people that I really saw because I just stayed at home and they were really kind and they worked with the syllabus well so that I was on track and I didn't get behind ...*

Amelia also reflected on the provision of an invigilator so that she could sit her exams at home.

*... not having to go to school made my anxiety a lot better. It was hard but I managed to do it ...*

Amelia stated that she achieved A and B grades in six subjects including Mathematics, English Language and Literature and Double Science and recalled the reaction of her family to her GCSE success.

*... I remember my sister and my mum cried when I got my results cos they were so happy ... they didn't care at that point whether I'd passed them or not because I had been ill ...*

Amelia also elaborated on the “*amazing support*” (TL3) provided by her sixth form college tutor.

*... from the beginning they wanted to know about issues I'd had in the past and how they could support me and he was brilliant. He made my timetable so that every day I had a half day but still got all my lessons in so I wasn't in College more than I could handle. So he was really good with that. He spoke to my mum and emailed her about everything that was going on. If my attendance was low, he stopped the college from contacting me, getting me worried about it. He told all my teachers about the issues I'd had and that I might be off ...*

In addition, Amelia explained the extra steps taken by her tutor to facilitate her A-level studies by asking her Psychology teachers to pre-warn her of any topics which could be “*quite triggering*”. Amelia mentioned that she achieved pass grades in her three A-level subjects. At the time of her interview, Amelia stated that she was in her first year of a five-year apprenticeship.

Amelia expressed mixed views about the education support that she received during her psychiatric hospitalisations. She described her experience during her second admission.

*... I was too unwell to attend it [school] most of the time. When I did attend it was so [horrible]. They were not in contact that much with my school, they didn't have enough teachers [to teach the lessons]. [They only did] artwork and things like that. So the whole time I was in there, I didn't do any schoolwork really ...*

Amelia described a contrasting experience during her first psychiatric admission.

*... [teachers requested] work from [mainstream school] that I completed there so I was kind of doing things I would have done at school [...]. I found the teachers really good and they didn't put too much pressure on me ...*

Amelia said that she was supported by specialist Mathematics, English and Science teachers. In addition, Amelia explained that she was offered other activities such as poetry competitions which “made it a bit more interesting”. Similarly, she stated other lessons that she received during her fourth inpatient admission.

*... they did some lessons with all of us, like PSHE, religion, artwork, food technology. But then they'd do other lessons [depending on what Year] we were in.*

In addition, Amelia described a strict daily routine during her fourth inpatient admission.

*... you had to be up and dressed, had breakfast. You'd have a break between your lessons where you'd have a snack. You'd come back over [to the ward] for lunch ... so it was a lot more normality [...] we weren't allowed to be in our rooms during the day. You got forced to go to school or else you'd lose your leave or things like that so I was in school from nine till three every day and then you'd do therapy afterwards. So it was a normal school day regardless of how ill you were. But like if you went and you were ill, they'd let you stay [in school]. They had like kind of mood corner where you could relax and do things like playing with playdough; things like that to calm you down. They'd let you do that for an hour and then they'd try and encourage you to do school lessons ...*

She also added that there were sanctions if patients refused to attend school such as being refused access to mobile phones or denied leave requests.

Finally, Amelia explained the impact of being hospitalised on her peer relationships.

*... I probably stayed [in contact with] about four of them and they were my only friends really. And at the time, I hated socialising, talking to people [inaudible] so I never really did see them that much. The only times I did, my mum would like push me to [because she was] worried that I would lose them as friends if I didn't see them. I never really wanted to see them.*

She also reflected on how her peer relationships influenced her choice of school for sixth form studies.

*I went and visited school sixth forms for next year and did all my open days [...] which were a big deal cos I hadn't been in school for long and I didn't have many friends. I wanted to go to a different [sixth form] that I didn't know anyone at. So I didn't [...] want to go to sixth form at a local one so we ended going to [College] cos it was so big. I thought I'd have more opportunities to make new friends who don't know that I'm a year behind ... don't know about what's happened ...*

A summary of the main points identified from Amelia's experiences are presented in the next section.

#### 4.5.3 Summary of Amelia's experiences

Amelia's narrative was characterised by multiple hospital admissions and her descriptions of the impact of difficult peer relationships on her education. She spoke about her desire to be nurtured by health and education professionals. Amelia said that the consistent support of her CAMHS consultant fostered the development of a positive relationship which was beneficial during her recovery journey. Amelia also shared examples where her relationship with different therapists and their approach to delivering therapeutic interventions influenced her engagement with the treatments. In education settings, Amelia stated that having access to a designated adult to talk to and a safe place in school were helpful when she was struggling with her difficulties. She also explained that the compassionate support of mainstream education professionals and home tutors contributed to her academic success.

Amelia however, also spoke about issues that did not facilitate her mental health recovery. She mentioned the lack of compassion and respect in one inpatient unit where she was restrained and sedated. Amelia also stated that she was not listened to on occasion and the therapeutic interventions that she received were not always tailored to meet her specific needs. In contrast, she described the willingness of education professionals to make suitable adjustments to accommodate her educational needs.

In addition, Amelia's narrative suggested that her relationship with peers had an impact on her education. Amelia stated that she was bullied in her mainstream secondary school and said that she changed schools as a result. Amelia also said that her decision to attend a different education setting for sixth form was influenced by her concern about other students knowing her 'story'.

The fifth participant is presented in the next section.

#### 4.6 Helena

Sixteen-year-old Helena shared her experiences in a face-to-face interview and via email. She spoke about the start of her mental health difficulties at the age of twelve and her struggle to seek help.

*I started struggling with body image issues and low mood and wanted to lose weight. I didn't receive any support at that time because I struggled to tell people how I was feeling. (EM)*

She shared her sixteen-month long experience of journeying into and out of general and inpatient psychiatric hospitals due to her eating disorder. Helena explained that at the age of thirteen, after being referred to CAMHS for an assessment, she was admitted to general hospital on two separate occasions for ten days and two weeks respectively. This was then followed by a five-month inpatient

psychiatric hospital admission and a subsequent re-admission also for five months. Helena also mentioned that she was supported by community CAMHS in between hospital admissions and by hospital and mainstream education professionals throughout her journey. Helena's experience within CAMHS follows in the next section.

#### **4.6.1 Helena's experience in healthcare settings**

Helena explained that her general practitioner (GP) played a role in helping her to receive support for her difficulties.

*... I then had a problem with my foot and went to the doctors who questioned my weight and referred me to a dietician. I then managed to tell my mum how I was feeling and I was sent to hospital after an assessment with CAMHS. (EM)*

She briefly shared her experience in general hospital.

*I felt very scared and out of control when I was admitted but I didn't really receive any support because it was in a general hospital so I was very stressed. (EM)*

Helena expressed mixed views about the outpatient and inpatient CAMHS support that received. Examples of her many comments about the availability and helpfulness of the medical treatment that she received at different stages of her journey are presented below.

*When I was discharged from hospital [1<sup>st</sup> General Hospital] I had twice weekly CAMHS appointments and regular blood tests which wasn't the most helpful because I didn't receive any therapy at that moment. (EM)*

*When I was discharged [after 1<sup>st</sup> inpatient admission] I had regular CAMHS appointments and I started therapy which was kind of helpful. (EM)*

*I was given music therapy [during 2<sup>nd</sup> inpatient admission] which wasn't helpful at all so I stopped and wasn't given any other therapy. (EM)*

Helena also spoke about the difficulties that she continued to experience when she was not in hospital, although she was receiving community CAMHS support.

*I still struggled a lot at home and as I wasn't managing I was sent back to hospital [2<sup>nd</sup> General Hospital] (EM)*

*I was still struggling a lot mentally at this time which led to me losing weight again, being taken out of school and admitted to hospital [2<sup>nd</sup> inpatient hospital]. (EM)*

She mentioned the compassion shown by staff during her first inpatient admission in a psychiatric hospital which was far from her home.

*When I was sent there I felt very nervous because I was over an hour away from home and I wouldn't have any family or friends there [...]. The staff there were very supportive and helpful which was reassuring and I started receiving therapy which helped a lot. (EM)*

Helena also briefly stated the support that she received from other patients during her first psychiatric inpatient admission.

*... the other patients were really nice and welcoming.*

However, Helena described a contrasting experience when she was re-admitted to the same hospital.

*This time was worse than the first time because I wasn't expecting to be admitted again and wasn't as physically unwell so didn't see the point of it as much. I was very unhappy most of the time and the staff were less supportive and understanding so it was a lot harder. (EM)*

This dichotomy between her first and second inpatient admissions was also present in the statements that Helena made regarding her discharge from psychiatric hospital.

*When I was discharged [after 1<sup>st</sup> first inpatient admission] I felt anxious because I wouldn't have the support of the hospital if I needed it and the last time I was discharged [from general] hospital it ended badly. (EM)*

*I felt more prepared to be discharged this time [after 2<sup>nd</sup> inpatient admission] because I knew I didn't want to go back to hospital so I was more determined. (EM)*

At the time of interview, Helena reported that she was receiving support from community CAMHS.

*At the moment I have been discharged from the eating disorder team and referred to the anxiety and depression part of CAMHS and am hoping to start therapy with them. (EM)*

As well as being supported by health professionals, Helena also mentioned that she was supported by hospital and mainstream education professionals. The next section presents Helena's experiences in her mainstream school and in the school located within the psychiatric inpatient hospital.

#### **4.6.2 Helena's experience in education settings**

Helena explained that her admission to psychiatric hospital was a double-edged sword.

*I think at first it kind of like took a bit of weight off my shoulders and like stress off my shoulders. But then it's also kind of stressful being in hospital because you're like, kind of getting behind [with schoolwork] ...*

She explained that the hospital teachers supported her with the core subjects of Mathematics, English and Science as well as her optional subjects which were Geography and French. Helena also said that communication between the hospital school teachers and her mainstream school helped to address her concerns about falling behind. In addition, Helena mentioned adjustments that were made in the hospital school to support her.

*I: ... were you encouraged to go [to school]? Were you given a choice?*

*P: I think it's more like we had to go [...] if you were like in the classroom and you like didn't feel up to doing any work, and they had like, different activities, like colouring and stuff like that you could do ...*

She also mentioned the difficult relationships that she had with peers in mainstream school prior to her hospitalisation.

*... I just didn't feel very happy at school anyway [...] I didn't really feel like I had any like close friends in school.*

Helena therefore expressed her displeasure that information about her hospitalisation was shared with her peers in school.

*... when I went into hospital, my Head of Year like told my whole class that I'd gone into hospital and I hated that cos I didn't want everyone to know ...*

Nonetheless, Helena shared a more positive view of her peers when she returned to school after being in hospital.

*... they were just really kind and they were like, if you like need any help, you can ask and stuff like that ...*

Helena also described a sense of anxiety about her return to school as she moved towards discharge during her first inpatient admission.

*When I first went back to school part-time it was very nerve racking because I hadn't been there for months and everyone knew I had been in hospital so it felt like all eyes were on me. I was gradually led back in which was helpful and less stressful and I was given a pastoral to go to if I needed support. (EM)*

Nonetheless, she explained the positive impact of gradually reintegrating back to her mainstream school with the support of school staff.

*When I returned to school full time I was kind of nervous but more at ease because I had been in before the summer. I was also quite excited to get back to normal and start my GCSEs. I still had a pastoral and I started at the same place as others as we were all starting GCSEs so I wasn't as far behind. (EM)*

*... all my teachers were supportive in helping me catch up which was good. (EM)*

At the time of interview, Helena stated that she was in Year 11 and was working towards her GCSE examinations. Helena reflected on her ongoing recovery and shared her exam success as well as her future plans.

*I am still struggling now but I'm in a better place than I was. For the next academic year. I am going to College to do a course in Public Services. (EM)*

A summary of the main points identified from Helena's experiences are presented in the next section.

#### 4.6.3 Summary of Helena's experiences

Helena spoke about her need to be nurtured and shown compassion by healthcare professionals. However, her narrative appeared to be characterised by a tension between this need and having a degree of control over her health. She stated that she wanted to 'control' her weight but spoke of her feeling out of control when she was hospitalised. Helena described a reliance on healthcare professionals who were understanding and supportive of her needs. However, she stated a self-determination to stay out of hospital when she experienced care and support that was lacking in compassion.

In addition, Helena talked about her need to have continuity in her education and remain connected to her mainstream school. Although she spoke about her struggles to cope with the demands of mainstream school when she was ill and her sense of relief when initially admitted to psychiatric hospital, Helena voiced her concern about the disruption that this would have on her education. Helena expressed her desire to keep up with her schoolwork when she was in hospital which she said was supported by education professionals who showed compassion towards her and addressed her educational needs.

Finally, Helena spoke about her relationships with school peers. Again there appeared to be a tension between her having a sense of connection with peers on the one hand, but concern about them knowing about her illness on the other.

The sixth participant is introduced in the next section.

#### 4.7 Irene

Twenty-seven-year-old Irene recalled that her difficulties "*just kind of spiralled*" from a New Year's resolution that she made when she was seventeen years old.

*... I remember thinking, I'll just try and lose a little bit of weight, but I know that's not the underlying cause of it [illness]; that just was the kick-starter ...*

Irene stated that she started "*missing meals [and] cutting out certain foods*" like carbohydrates and fats and was eventually hospitalised for the first time at the age of seventeen. Irene shared her five-year journey of being admitted to an adolescent psychiatric inpatient unit, followed by two adult psychiatric inpatient admissions and then hospitalisation in a specialist eating disorder clinic.

#### 4.7.1 Irene's experience in healthcare settings

Irene explained that she initially refused to see a GP when encouraged to do so by her mother, but was later persuaded to do so. She said that her subsequent referral to the outpatient CAMHS team was “*quite difficult*” and she was “*teetering on the brink of an admission for about 4 months prior to being admitted*” (TL1) to an adolescent inpatient unit. Irene explained her view that appointments with the outpatient CAMHS team were mainly about adjusting meal plans to help her gain weight, but without any psychological input or therapy. She said that she was not honest about complying with her meal plans.

*... and all the while I was like not really doing what they said – follow this meal plan [...] and I wasn't really doing it. I would like kind of pretend and trick my parents and family into thinking that I was, but I wasn't ...*

Irene stated that her behaviour resulted in an increase in the number of appointments that she had every week as part of “*hospital at home*” CAMHS support, an alternative to inpatient psychiatric hospital admission. She commented on this support by saying:

*... “hospital at home”. They used that phrase and I just wasn't interested in that at all. I had no inclination in getting better at that point.*

Irene stated that this support did not work for her as she was at home on her own for hours during the day. She also described her interactions with the specialist eating disorder nurse and clinical psychologist involved in her care.

*I really didn't get along with this other nurse. I used to walk out of appointments, kick things in front of her and do all these things [...] there's absolutely no way I was going to do anything that they said and it very much was me versus them. Like I never felt they were on like my side [...] it just felt like it was me with my eating disorder [...]. It was all against me ...*

Irene also commented that her parents were “*desperate*” for support from CAMHS.

*... appointments with my outpatient team always caused tension and arguments with my parents. [...] I think basically my parents just wanted me to be better and could see that it wasn't working with CAMHS in outpatient unit.*

Irene expressed the view that she should have been admitted to a specialist inpatient unit a lot sooner rather than being in outpatient care for four months. She also stated that she had viewed many attempts by mental health professionals to have her sectioned and admitted to hospital as “*idle threats*”. Irene stated her view that a lack of funding and available specialist inpatient beds as well as the fact that she was “*basically sneaky*”, contributed to the delay in admitting her to an adolescent psychiatric unit.

Irene recalled being “*petrified*” at the prospect of being hospitalised.

*I had heard these horror stories about units. Oh, you're going to be pinned down. You're going to be tube-fed. You're going to be locked up. You're going to come out with an overweight BMI. It's just going to be feeding frenzy. They'll crush up chips and put them down your tube. All these sort of horror stories.*

She also mentioned that she did not feel that she had any choice in the decision to admit her to an inpatient psychiatric unit. Irene said that a lack of available beds in a specialist eating disorder unit resulted in her admission to a general psychiatric inpatient ward which catered for different mental health disorders. She described her experience in the adolescent unit as “*difficult from day 1*” (TL2), as she was the only patient with an eating disorder during her first three or four weeks in the unit.

*Other patients with complex mental health needs were forced to wait for me to finish meals before they could have dessert/leave the table/go on leave which just added to my guilt as it felt they were being punished for something I was struggling with – this didn't seem to be reciprocated; there was never any kind of “shaming” or punishment for other people if for example, another patient with other mental health problems acted on their compulsions.* (TL2)

She also described a “*reward/punishment system*” of treatment where she “*felt blackmailed and coerced into eating*”.

*Their attempts at treatment were governed by fear [...] They made it clear that I had no control over my treatment and they (staff, including HCAs<sup>5</sup>) could do what they wanted including up my meal plan without the say-so of a registered dietician.* (TL2)

Irene expressed her view that the underlying causes of her eating disorder were not worked on while she was in the adolescent unit.

*The aim of my admission was to show I could follow a meal plan – I essentially “ate to get out” of hospital – which they knew I was doing and basically condoned it. I didn't feel there was much actual care involved. Just ticking a box to say I'd completed or not completed a meal.* (TL2)

Irene added that her specific needs regarding her mental health disorder were not considered and said that there was a lack of tailored support and eating disorder therapy groups. She also commented on a lack of experienced staff to deal with acute crises on the inpatient ward.

*There were a lot of negative behaviours and difficult situations on the ward with other patients which I was exposed to – passing of sharps<sup>6</sup>, suicide attempts and psychotic episodes – arguably which were not managed well by the staff.* (TL2)

Irene said that she was “*very pleased to be out of hospital*” but stated that her health continued to deteriorate even before she was discharged. She explained that even though she gained some weight because she followed most of her meal plans while she was in hospital, she reverted to her previous unhelpful behaviours when she was on home leave at the weekends.

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<sup>5</sup> HCA: Health Care Assistant

<sup>6</sup> ‘Sharps’: sharp objects that could be used to self-harm.

Irene described ensuing disagreements between herself and healthcare professionals and perceived threats to section her regarding her subsequent admission to a specialist adult ward for eating disorder.

*... I was furious cos I knew where I was going ... adult unit of the same hospital that I'd just been in. So I knew what food was coming. I knew kind of the ethos of it ...*

Irene acknowledged nonetheless, the more tailored approach to the care that she received from the specialist adult ward compared to her previous experience in the general adolescent unit. She said this included access to staff experienced with eating disorders and more specialist groups and treatment.

She also described other aspects of her admission in the adult unit as “*a bit of a nightmare*” and “*quite a traumatic experience*”.

*“it was very, very strict and [...] I was threatened with being sectioned a few times, had section assessments [...]”*

Irene said that she did not engage with healthcare professionals’ approach of “*being forced to eat*”.

She commented on the fact that there was never much discussion about her care plan when she was in the adolescent inpatient unit.

*... it was very much you went in, you got told what was happening like the consultant said to you, “You’ve lost weight [...] or you can go on weekend leave for two hours”. Yeah, there was never any discussion, really. I never felt even if you asked for things, unless he said you can have this, like there’s no point asking, cos he’d just say no.*

In contrast, Irene stated that even though her requests were either denied or deferred when she was in the adult units, she was given the opportunity to discuss her care plan.

She also commented that due to lack of available bed in inpatient units, she noticed that she was only admitted when her body mass index (BMI) became dangerously low.

*... I definitely noticed the change in kind of funding because with each admission that I had, they waited until my BMI was lower, lower, lower each time before I was admitted ...*

Irene stated her perception of her three years of inpatient hospitalisation.

*... a lot of this I think may have been avoided if my care initially was more specialist and not targeting my fear of food and weight gain, or using coercion to force me to eat. (TL3)*

She also offered her views about how things could be improved.

*I think the main thing I think would be that you can’t treat everybody with an eating disorder in the same way. [...] just like listening to them and listening to their experiences and being able to focus kind of on them as an individual and individualising their care ...*

The next section presents Irene's experience of education in mainstream school and in the adolescent psychiatric hospitals she was admitted to.

#### **4.7.2 Irene's experiences in education settings**

Irene stated that her mainstream school did not acknowledge her illness or offer her or her family any support. However, she admitted that she was "*in denial*" about her illness and "*one-track minded*" about wanting to continue her education.

*If anything, I just like ploughed more energy into that and more effort into that cos it would like take my mind off everything else [...] like it never had an impact on my school stuff.*

Irene acknowledged however, that her illness had an impact on her education.

*I managed to complete my AS levels and then was forced to take a year out of studying in between years 12 and 13 due to my health. (TL1)*

She stated that she was "*furious*" at this decision by CAMHS professionals. Nonetheless, Irene said that once she was admitted to the psychiatric adolescent unit, the three hours of education every weekday morning were a lifeline for her,

*The education sessions were probably the highlight of my day as I could focus on my sixth form work and try and ignore everything going on in my head and around me" (TL2).*

Irene also spoke about the support that the hospital teachers offered.

*... they kind of just took an interest in you as a person, like they could see past ... they only saw you. They didn't see whatever was going on. They never saw you at the table or whatever and that really like helped me. Like I'd actually look forward to education and then dread after education because it was lunch ...*

She reiterated the importance that she attached to being treated as an individual with specific needs rather than an illness by the teachers in the adolescent unit.

*... I think they probably treated me the most as a person than anyone else. They only came in for like the hours of education in the morning and they treated me as a person ... like they took an interest in me and my life, rather than my eating disorder ...*

Irene explained that she was "*really self-driven*" to continue her education while she was in hospital, even though she had been asked to "*take a year out*" of school between Years 12 and 13. She also stated that the hospital teachers were very supportive of whatever she wanted to do or learn about.

Irene re-stated the lack of acknowledgement and support that she received from her mainstream school when she returned to continue her A-level studies after a year's absence due to her hospitalisation.

*There wasn't any acknowledgment, to be honest with you. [...] there was nothing like "Oh, how are you getting on and stuff". Yeah, there was nothing really. And I was kind of not doing very well when I went back into Year 13 ... kind of hanging on by the skin of my teeth being out of hospital ...*

In spite of this, Irene stated that she completed Year 13 and achieved the A-level grades required to study Medicine at University. However, she explained that after two semesters at University, she deferred her studies after she became unwell again and was hospitalised. Irene also mentioned that it was helpful to live in rented accommodation close to University rather than at home once she was discharged from the eating disorder clinic.

*... that really helped me because at home, I had all these triggers ... all these negative behaviours, negative experiences that I'd had, like either on leave or when I was getting iller*

At the time of her interview, Irene was in her fifth year of her University studies.

The next section summarises the main points identified from Irene's experience.

#### **4.7.3 Summary of Irene's experiences**

Irene's narrative seemed to suggest a desire to have a degree of control over her health and the medical treatment that she received. However, she described a tension between this desire for autonomy and a stated need to be nurtured by mental health professionals. She described a lack of compassionate and respectful care as well as support that was considerate of her specific needs. According to Irene, these factors had an impact on her willingness to engage and comply with medical treatment.

In addition, Irene spoke about her desire to maintain continuity with her education in spite of her mental health disorder and periods of psychiatric hospitalisation. She expressed her view that education was a lifeline for her and spoke of her desire to be shown compassion by education professionals. Irene explained that in contrast to mainstream school staff who did not acknowledge and support her difficulties, hospital staff were sensitive to her needs and supported her.

The penultimate participant is presented in the next section.

#### **4.8 Imogen**

Eighteen-year-old Imogen chose to share her experiences by email, in which she explained that she had experienced difficulties from a very early age. Imogen mentioned that she started experiencing "*depression, anxiety, self-harm [and] suicidal thoughts*" at the beginning of Year 8 when she was twelve years old. Imogen stated that she was admitted to a psychiatric adolescent unit for four

months at the age of thirteen years due to a “*suicide attempt*” from an overdose. Imogen also said that she was diagnosed with autism during her inpatient admission. She shared her experience of receiving community and inpatient CAMHS support.

#### **4.8.1 Imogen’s experience in healthcare settings**

Imogen recalled that her initial involvement with CAMHS was at the age of six years for “*social communication issues*”. She spoke about the outpatient CAMHS support that she received when her parents raised concerns about her low mood and self-harming behaviour six years later. Imogen explained that she was offered counselling by the outpatient CAMHS team and was on a waiting list for CBT but was admitted to the adolescent unit before it started. She commented on the counselling support that she received.

*... not very helpful because I was too shy to talk to the counsellor and didn't feel comfortable with her anyway as she wasn't very understanding. My parents gave her my diary without me knowing and she spent the sessions mostly reading it aloud and commenting on it which I found very uncomfortable. Due to my autism I have difficulties identifying my own emotions and linking them to what caused them so I wasn't really able to discuss what was going on as I wasn't sure myself. Appointments were irregular and infrequent.*

Imogen also expressed her feelings about her subsequent inpatient admission.

*I was scared and didn't want to go but didn't have a choice. I guess a lot of people have misconceptions about mental health wards and I wasn't really sure what to expect.*

Imogen stated that she had a “*good relationship*” with her individual therapist in the adolescent unit but explained that they did not “*really do a lot of therapy*” due to the length of time it took Imogen to build trust and confide in her therapist. Imogen added that her therapist left a few weeks before she was discharged from hospital.

She said that although art therapy was helpful, all other group therapy sessions that were offered “*weren't very good*”. Imogen also commented on the medication she was given as part of her treatment.

*Also was given medication which I didn't want and gave me side effects my psychiatrist didn't take side effects seriously.*

In addition, Imogen described the structure of her days when she was in hospital.

*Most of the time there was nothing to do. There was one group after school which lasted maybe an hour but other than that from 5pm-10pm there was nothing to do. On weekends nothing to do at all. There were no activities, no phone/computers allowed so I was very bored and spent many hours bored and staring into space.*

She described the impact that this had on her and other patients.

*Some people would kick off when bored. Then they'd be restrained by lots of staff and sometimes injected. This would lead to other people also kicking off.*

Imogen commented that this environment was distressing for her due to her “*sensory issues*”. She also mentioned her difficulties in building friendships during her inpatient admission.

*I find it hard to make new friends and it takes me a long time so didn't form friendships on unit so became isolated. [...] when I did make friends I didn't feel I was able to bond with them in the same way other people seem to bond with their friends*

She stated that she did not keep in touch with any of the friends that she made during her admission.

In addition, Imogen described the support that she received from her outpatient CAMHS when she was discharged from hospital.

*... nothing. received a total of 3 sessions in 9 months. they mostly just reviewed my medication and checked I wasn't suicidal.... they only saw me three times in the period of time between discharge from inpatient and discharge from camhs.*

She also commented on the decision by her CAMHS team to discharge her from their care.

*... they said that they don't work with autism so they discharged me. They didn't even say it to my face they sent a letter out of the blue saying we don't know how to help so you're discharged so I was left with no support at all.*

The next section explores Imogen’s education experience in mainstream school and in the adolescent psychiatric hospital she was admitted to.

#### **4.8.2 Imogen’s experience in education settings**

Imogen explained that she had experienced difficulties from a very early age.

*I have had some difficulties since I started school throughout primary school and also struggled with starting secondary school.*

She also stated that she had attended four different primary schools. Imogen commented on her experience in mainstream secondary school when she started experiencing her mental health difficulties.

*didn't really cope. mostly used self-harm to cope*

*no support from school – didn't even acknowledge anything was wrong (TL1)*

Imogen described herself as “*academically high achieving*” (TL2) at school and prior to her psychiatric hospitalisation and stated that this was “*probably the only strength [she] had*” (TL2). She said that her mainstream school did not send her any work when she was admitted to the adolescent unit because “*they couldn't be bothered and weren't very proactive*” (TL2). Imogen made comments about the impact that the lack of work from her home school had on her.

*... fell behind and became disengaged with education [...] falling behind [affected] my confidence in general as well (TL2)*

*... lost motivation to go to school and do the work [...] worried about the future and felt stupid*

She also described the work provided by the school in the adolescent unit as “not very academic” (TL2).

*mostly they gave you your own work to get on with or gave everyone some arts and craft. They had a lot of PSHE<sup>7</sup> lessons as well.*

In addition, Imogen wrote about the support she received in the hospital school.

*Although the hospital school had very few pupils I mostly got ignored because I was very very shy quiet and rarely spoke so the students who were loud and outwardly challenging got all of the attention (TL2)*

*... sometimes I wouldn't go to the hospital school at all because hospital staff would forget I even existed and so forget to take me when they took everyone else. Then when they realised I hadn't gone with the others they couldn't be bothered to take me across the road to school*

She stated her view that professionals “didn't feel they cared about me and [I] felt alone”.

Imogen also mentioned that even though she had leave from the unit to attend her mainstream school on occasion, there was no plan for her continued education when she was discharged. She explained her experience when she returned to when she was discharged from hospital.

*... the way they spoke to me changed and I could tell I wasn't wanted. They acted like I was a risk to others which was upsetting to me because I wasn't a risk to anyone but myself. They excluded me from certain lessons where there may be tools and also only let me come part time. If I struggled or left a lesson then they immediately called my parents to take me home (e.g. if I cried about anything)*

Imogen added that because she had no support to help her catch up on work that she had missed, she was behind in her school work and confused, which she said made her more unmotivated. She stated that this experience affected her willingness to go to school and resulted in her attendance of twenty-five percent. When asked how her school could have supported her better, Imogen responded, “*treat me less like a criminal*”. She said that she left her school after one term and started a new secondary school and commented about this move.

*... nervous but excited as it would be a new start and I thought things might get better*

Imogen explained that she did not receive any support from her new school to help her catch up and “*caught up educationally by going through textbooks*” herself. Nevertheless, Imogen stated that her new school trusted her more and allowed her to return to school full time. She suggested support that her new school could have offered.

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<sup>7</sup> PSHE refers to Personal, Social, Health and Economic education.

*... maybe help with catching up e.g. telling me what I'd missed and providing catch up sessions and maybe provide some 1-1 tuition to help me catch up. Maybe they could have checked in on me sometimes and asked me how I was/ emotional support.*

In relation to peer relationships, Imogen stated that she had a “*good group of friends in school*” (TL1) prior to her inpatient hospitalisation.

*... was good as I had people I could confide in and also people I could just have fun around*  
However, she explained that she was unable to keep in touch with her friends from school while she was in hospital as there was no internet and phones were not allowed on the ward.

Imogen stated that she “*fell out*” with her group of friends when she returned to school after being in hospital and said that she was “*upset and lonely*” as a result.

*... they didn't want to deal with my mental illness and got sick of it. Starting excluding me and spreading rumours ...*

In addition, Imogen said that she did not make new friends when she moved to her new secondary school. Imogen stated that she has been “*socially isolated with zero friends since*” but said that she made some “*online friends*” who she spoke to on occasion.

At the time of her interview, Imogen explained that it had been four years since she was discharged from CAMHS. Imogen added that she had completed Year 13, was taking a gap year and hoped to apply to study medicine at University.

A summary of Imogen’s experience is presented in the next section.

#### **4.8.3 Summary of Imogen’s experiences**

As a young person with autism, Imogen described the difficulties that she experienced especially in the inpatient hospital setting. In addition, she stated the challenges that she experienced in establishing relationships with professionals and peers. Imogen expressed her desire for healthcare and education professionals to show compassion towards her and support her needs. According to Imogen, professional support which addressed these needs fostered her sense of belonging and had an impact on her mental health and wellbeing.

The final participant is presented in the next section.

## 4.9 Lucy

Twenty-four-year-old Lucy, unlike all the other participants in this study, said that she became unwell as an adult. She also chose to share her experiences by email. Lucy explained that she “initially became very ill” when she started a full time night-shift job after her A-levels. She described her first acute psychotic episodes which occurred when she was eighteen years old.

*... became increasingly disorientated and confused: hearing voices, delusions, paranoia, and visual hallucinations. [...] I became very odd: acting strangely, saying unusual and untrue things, accusing people of things they had not done or said. I also believed I had some sort of increased mental powers and could fly. I thought I was being persecuted and that if I did not say things that I was told to that terrible things would happen.*

Lucy said that she was initially hospitalised at the age of nineteen and diagnosed with schizophrenia about six months after this admission. She shared her experience of being hospitalised twice in adult psychiatric inpatient hospitals over a period of about six months.

### 4.9.1 Lucy’s experience in healthcare settings

Lucy recalled the support that she received prior to her hospitalisation.

*I ended up going to a GP with my father, however the GP thought that we had just had a disagreement and I was being a disagreeable teenager. I then went to a second GP, who again sent me home and suggested some out-patient care. The CAMHS emergency team came for about an hour a few days later and suggested some out-patient care.*

She explained that she was admitted to A&E a day or two later and then to an adult psychiatric hospital.

*When I was admitted I was told that I would be staying, whether I wanted to or not. So, either I could be sectioned or I could be a ‘voluntary’ patient. I agreed to go in as a voluntary patient, but did not believe that I was ill, or that it was that voluntary.*

Lucy explained her state of mind at the time she was hospitalised.

*... spent the first two weeks in hospital convinced that there had been a serious mistake [...] It would have been helpful if somebody had told me why they had decided to admit me, because although it might have seemed obvious from the outside, from within it was not at all, and I spent a long time ruminating the situation and thinking it was a kind of trap. I spent most of my time lying on my bed, aside for when I had to take my medication or eat.*

Lucy mentioned that fellow patients, rather than medical professionals, helped her to understand her illness.

*I talked a little to the other patients, many of who had been on a ward before and knew their diagnoses and symptoms. It was from them that I realised what was wrong with me, not a doctor or medical professional, who never said.*

Lucy described the support that she received during her admission.

*P: I had an initial consultation, a twice-weekly meeting with a psychiatrist, met another doctor on two occasions. I was in hospital for 3 weeks.*

*I: How helpful was this support?*

*P: Not very.*

She also recalled the support that she received after a specific incident.

*... I did not lock my door and one night a large, and clearly very ill man, came into my room and climbed on top of me and tried to take my clothes off. I shouted for help, but it took quite a while for the staff to arrive (I think they were used to shouting and didn't think it was anything that important). No one said sorry, the man stayed on the same ward and I was told to remember to lock my door at night. I was honestly very on edge and wanted to get out as fast as possible from the hospital.*

In spite of this experience, Lucy expressed positive feelings about her second psychiatric admission.

*I felt happier, relieved almost, because last time I went in they had managed to get rid of the voices (for the most part) and so I hoped they would this time also.*

She also described a more positive experience compared to her first admission.

*The staff tried to get the patients to engage with activities and talk. There was a full timetable of classes and activities, and communal spaces so that people did not have to spend all their time alone in their room. People were calmer, kinder and happier.*

Lucy also described contrasting outpatient support that she received from different professionals including support workers, psychiatrists, GPs and psychologists. She mentioned that she rarely saw her support worker after her first hospitalisation due to delayed or cancelled weekly home visits. Lucy stated that after three months during which she received about five visits, the support worker stopped seeing her altogether. On the other hand, Lucy explained that the quick intervention of her support officer when she became very unwell again at University, resulted in Lucy's immediate admission to a second psychiatric hospital which was a distance away from University and from home.

Similarly, Lucy recalled the helpful support she received from another support worker when she returned home following her second psychiatric hospitalisation. She mentioned that this support worker encouraged her to get out of the house by meeting her in coffee shops. Lucy said he always attended their meetings and also encouraged her to join community art classes and to apply for personal independent payment (PIP<sup>8</sup>) so that she would have some money to do other activities. Lucy commented on how this support was “*really helpful*”.

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<sup>8</sup> Personal Independent Payment (PIP) is extra money that can be claimed by an individual with a long term physical or mental health condition or disability, to help with extra costs.

*... I otherwise would not have really left the house. It gave me some structure and after a while I began going out to meet people, because I could act more normally ...*

Lucy also described the psychiatrist that she saw once a month after her first admission as “*excellent*” and also mentioned her local GP who was very helpful in giving her out-of-hours appointments to get prescriptions for her medication. When Lucy left home to start university, Lucy said that she continued to have consultations with a GP and psychiatrist at the local hospital. However, Lucy said that when she became unwell again, daily phone calls by outpatient professionals to check how she was coping were unhelpful. Lucy explained that she would sometimes miss these calls which were made close to the office closing time and when she attempted to return the call, the office would be closed. She commented on the impact of this and how it resulted in Lucy’s second psychiatric admission.

*It sounds silly and small, but the situation I was really desperate and it was the final thing that really tipped me over.*

Once Lucy returned to University following her second hospitalisation, she continued see a GP and had weekly appointments with a psychologist for about four months which she said “*did not stop the voices at all, but was very helpful*”.

Finally, Lucy commented that she was taking a lot of medication and did not find them to be effective, stating that none of the medications worked for longer than eight weeks. She also mentioned that she was encouraged by medical professionals to either “*confront the voices*” or take medication to stop them. However, Lucy stated that neither of these approaches worked for her and she rather adopted a policy of “*total non-engagement*” with her hallucinations which she said was more effective. Lucy also said that she decided to stop taking her prescribed anti-psychotic medication after two years. She commented on her health at the time of interview.

*... have constant auditory hallucinations, although these have reduced immensely over the past 3 years in volume and intensity. [...] I feel fine. I still hear voices all the time, but I have a lot more energy, can do a lot more things, and am happy.*

The next section explores Lucy’s views about the support she received at University.

#### **4.9.2 Lucy’s experience in education settings**

Lucy reported that although she found school to be “*quite monotonous and dreary*”, she did well in her GCSE and A-level examinations and “*in general, it was fine*”. She explained that she started university a few months after her first psychiatric hospitalisation but was re-admitted to a second hospital shortly afterwards. Lucy spoke of the support that her college chaplain at University provided when she became unwell.

*The college chaplain was very kind and allowed me to move room in college to an isolated staircase see if it would help (which it did, briefly).*

As a result, she was out of university for the remainder of the academic year but was able to return the following year. After missing most of the previous academic year, Lucy expressed mixed feelings about returning to university.

*... pleased. I just wanted to study the subject I had applied for and couldn't wait for that. (Although I was also slightly nervous to see some of the people I had made a fool of myself in front of from last year.)*

She also commented on the support that she received once she returned to University.

*I was assigned a university support person to see once a week for an hour [...]. However, they mainly did academic support and were a bit flummoxed by the situation, I think. I stopped going after a term or two.*

Lucy described the impact of taking anti-psychotic medication on her University studies.

*I was incredibly lethargic from the medication (and would sleep 16 hours most days, whilst still doing my university work). I stopped taking the medication during my fieldwork project at the end of first year, because I just did not have the option to sleep that much, and people kept asking [me] why I looked so awful and tired. I was so drowsy it became impractical and I saw no benefit, so I stopped.*

Four years after initially being hospitalised due to her mental health disorder, Lucy said that she graduated with a first-class Bachelor of Arts (BA) degree. At the time of interview, she was looking forward to starting a Master of Arts (MA) degree in the autumn term.

The next section summarises the main points identified from Lucy's experiences.

#### **4.9.3 Summary of Lucy's experiences**

Lucy's narrative seemed to suggest that she wanted to have a degree of freedom to make informed choices about her healthcare. Lucy stated her perception of not being given a choice in the initial decision to hospitalise her. She said that having access to information would have helped to address her concerns and confusion. Lucy also stated that she adopted an approach to treatment that suited her needs, against the advice of professionals. This appeared to demonstrate Lucy's sense of self-efficacy in terms of her mental health recovery.

In addition, Lucy said that the compassionate support of professionals who addressed her specific needs was helpful in her recovery. She stated examples where hospital staff offered coping strategies and encouraged participation in structured and normal activities. Lucy also said that they offered a welcoming environment which was conducive to her recovery. Similarly, she mentioned

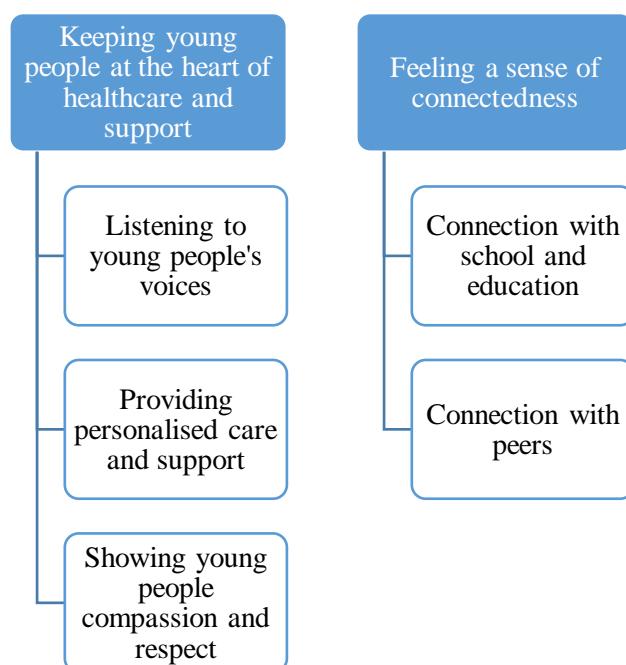
the role of her support worker in encouraging her to socialise and be financially independent, which were also beneficial.

This chapter concludes with a brief summary of the common themes that were identified from the eight participants' experiences.

#### 4.10 Chapter Summary

The young people recounted many similar experiences of being supported in healthcare and education settings. On the one hand, the young people spoke of these settings as safe places where they were nurtured and shown compassion and respect as well as places where they felt listened to and had their individual health and education needs met. These experiences appeared to foster a sense of connectedness, optimism and hope as the young people journeyed towards mental health recovery. On the other hand, the young people recalled experiences where their stated needs were not addressed. They spoke about the stress, anxiety and isolation that they experienced as they struggled to cope with their difficulties. Based on the codes identified from the young people's experience timelines and interview transcripts (see Appendix Q), two main themes and associated sub-themes were identified as shown in Figure 4.1.

Figure 4.1 Main Themes and Sub-Themes



A detailed discussion of these themes and sub-themes follows in the next chapter.

## 5 Discussion

### 5.1 Introduction

Supporting young people during mental health crises is critical to their recovery and social cohesiveness. Although the views of children and young people have been sought about their experiences of being supported within the mental healthcare system (Bone et al., 2015; Persson et al., 2017) and in education settings (Hart, 2017; O'Reilly et al., 2018), few focus specifically on the needs of those who require inpatient psychiatric hospitalisation (Evans et al., 2017; Gill et al., 2016). This qualitative study therefore sought to address this gap in the literature by exploring the experiences of young people as they journeyed into and out of psychiatric inpatient hospitals. By listening to their voices and retrospective views about their experiences of being supported in healthcare and education settings, this study aimed to gain a better understanding of the support required to meet the needs of these vulnerable young people.

Following ethical approval and consent, semi-structured interviews which focused on the recollections and reflections of eight young women's personal journeys were conducted. The accounts of the participants were analysed using thematic analysis (Braun & Clarke, 2006) and two main themes and associated sub-themes were identified. Within the first main theme, 'keeping young people at the heart of healthcare and support', which focused on the young people's experiences within the mental healthcare system, were three sub-themes: 'listening to young people's voices'; 'providing personalised care and support'; and 'showing young people compassion and respect'. The second main theme was 'fostering a sense of connectedness' which focused mainly on the young people's experiences in education settings. This second theme comprised two sub-themes: 'connection with school and education' and 'connection with peers'.

The remainder of this chapter is therefore divided into two main sections to discuss these themes and address the main research question (MRQ) and sub-questions (SRQs) posed for this study as follows:

MRQ: How do young people with severe mental health disorders perceive their experiences within the systems of healthcare and education as they journey into and out of psychiatric inpatient hospital?

SRQ1: How do young people experience receiving support in healthcare settings?

SRQ2: How do young people experience receiving support in education settings?

SRQ3: What do young people want to share with healthcare and education professionals about supporting their mental health recovery journey?

## 5.2 Keeping young people at the heart of healthcare and support

A key finding that was identified from the young people's narratives was that their voices and individual needs were not always central to the care and support that they received from professionals in healthcare settings. Josie's experience with her inpatient psychiatric hospital consultant was an example of this.

*"I felt like he wanted to kind of mess me up more than get me better and he just wanted me to like ... leave his hospital instead of actually [inaudible] ... listening to what I needed and wanted ... "* (Josie – Interview)

The importance of implementing a person-centred approach to care within CAMHS has been widely reported (Care Quality Commission, 2018; Gondek et al., 2017). The practice of person-centred care is well-recognised to have a favourable impact on young people's self-esteem, self-management, self-efficacy, patient empowerment and treatment outcomes (Kerr, 2022; The Health Foundation, 2016). Analysis of the participants' interviews identified three themes related to person-centred care: 'listening to young people's voices', 'providing personalised care' and 'showing young people compassion and respect'. A discussion of these sub-themes follows in the next three sections.

### 5.2.1 Listening to young people's voices

Research shows that participating in shared-decision making and having a voice contribute to young people's "self-efficacy, self-esteem, treatment engagement, outcomes and satisfaction" (Bjønness et al., 2020, p. 2). However, all the participants in this study shared experiences of not having a voice in aspects of their mental healthcare. Many said that they did not feel that they had much of a say in decisions about their psychiatric hospitalisation or discharge. Young people also stated that they were not given access to adequate information which would help them to understand the reasons for their hospitalisation and what to expect in the psychiatric hospital. Some of the participants explained that they experienced significant anxiety, apprehension and feelings of fear about the unknown due to the lack of information about their psychiatric hospitalisation. One young person added that her fear of being hospitalised stemmed from her perception of being stigmatized due to her psychiatric admission. Stigma among young people's social networks is known to undermine their wellbeing (Moses, 2010b) and also influence help-seeking behaviours (Aguirre Velasco et al., 2020). Indeed, young people in Mitten et al.'s study (2016) reported experiences of being stigmatized by healthcare professionals in healthcare settings.

The results from the current study are consistent with Plaistow et al.'s review (2014) of young people's views of UK mental health services. They found that a lack of access to information resulted in young people feeling less prepared and experiencing anxiety about the unknown in relation to impending psychiatric admission. Bone et al.'s study (2015) also found that children and young people who were referred to outpatient CAMHS expressed a fear of the unknown which had an impact on engagement in their treatment and mental health recovery. Psychiatric inpatient hospitalisation, whether voluntary or involuntary, has the potential to cause additional significant psychological distress in young people already experiencing severe mental health disorders (Department of Health and Social Care, 2018; Walker et al., 2019). It appears that for young people in the current study, the anxiety and confusion that they experienced could have been minimised by giving them access to comprehensive and accurate information prior to their hospital admission.

Participants in the current study also stated that their views about medication they had been prescribed were not acknowledged or taken seriously by staff. Some of the young people commented on the adverse side effects of medication that they were given. Oruche et al. (2014) reported a similar finding in which young people perceived that they were being "doped" (p. 244) by medication. This was found to be a barrier to treatment participation as the young people stated that they were not listened to by professionals who preferred to use medication rather than consider other therapeutic treatment approaches which would address their specific needs (see section 5.2.2).

A further issue that resonated especially in the narratives of young people with eating disorders was the loss of control over their eating when they were hospitalised. There appeared to be tension between the young people's desire to have some degree of control over their treatment and professionals' approach to supporting their needs. Other studies have reported the difficult challenge that professionals face in balancing "control battles" (Offord et al., 2006, p. 385) and a more collaborative approach where young people are involved in their treatment and recovery (Colton & Pistrang, 2004; Thabrew et al., 2020).

Within the context of CAMHS, young people feel empowered in their mental health recovery when they are involved in decision making. D. Hayes et al. (2020) suggest that shared decision making "helps create 'buy in' through the process of co-creation around treatment and values" (p. 65). However, professionals face specific challenges with regards to managing the perceived risk posed by vulnerable young people and respecting their right to be consulted and have their voices heard (Abrines-Jaume et al., 2016; Pelto-Piri et al., 2013). According to Pelto-Piri et al. (2013), paternalism in which mental health professionals provide good care and assume responsibility to promote and restore patients' health is considered to be the most dominant ethical perspective in mental healthcare. However, professionals are also aware of the need to balance this perspective

with the patients' rights to autonomy and reciprocity, where they are involved in the planning and implementation of their care.

Although mental health recovery is conceptualised as a personal process (Leamy et al., 2011), factors within young people's wider ecological system can significantly impact the mental health recovery in young people (Rayner et al., 2018). At a personal level, young people's recovery process is very individual and involves the development of a sense of agency and control in their lives as well as self-belief and resilience (Rayner et al., 2018). Providing opportunities for young people to express their views and be part of decisions related to their care therefore enhances their sense of autonomy and has a positive impact on their mental health recovery. Deci and Ryan's theory of self-determination (1985) offers further support to this argument whereby an individual's sense of wellbeing is enhanced if their basic need for autonomy is fulfilled (Gaine et al., 2022). In the current study, many of the young people stated that they refused to engage with professionals or adhere to their treatment due to fact that they were not part of the decision-making process. These findings suggest that although the young people were significantly unwell, they would have liked to be given opportunities to participate in healthcare decisions.

While listening to the voices of the young people and involving them in decision-making was important in fostering their sense of autonomy, providing personalised care and support was also crucial in their mental health recovery journey. This is discussed in the next section.

### **5.2.2 Providing personalised care and support**

Although there were several similarities in the participants' narratives, each young person's mental health experience was unique. Consequently, they each required an individualised approach to their care and support. However, the experiences shared by the young people highlighted that the care and support that they received from professionals in healthcare settings was not always tailored to meet their individual and unique needs as they journeyed into and out of inpatient psychiatric hospitals.

A few of the young people explained that the inpatient psychiatric hospitals were safe environments which provided relief from some of the stresses that they experienced such as academic pressures as well as peer and family difficulties. They valued the structure and routine in hospital which included the expectation to attend hospital school, psychological therapeutic sessions as well as fixed meal and bed times. Similarly, young people in Moses' study (2011) reported that "the simplicity of being in an environment where their time was completely structured served to create

inner peace and distract from their troubles” (p. 128). The mental health benefits of maintaining daily living routines including engaging in physical activities are well recognised, especially during the COVID-19 pandemic in 2020 (Ren et al., 2021). In an inpatient setting, having a routine was even more important to maintain a sense of normality for young people.

On the other hand, some of the participants in the current study described a regimented inpatient environment which they found difficult. This was consistent with Haynes et al.’s study (2011) in which young people characterised their inpatient admission as an “alternative reality” (p. 152) in which they felt restricted and disconnected. In the current study, the young people accepted the need for some of the inpatient practices such as locked doors and limited access to belongings. However, participants also stated their desire for staff to consider their needs and make suitable adjustments to accommodate them where possible. As their health improved, the young people appeared to develop self-awareness and self-confidence. By providing an environment in which the young people’s sense of self-efficacy could be fostered seemed to be an important part of their recovery process (Rayner et al., 2018).

The young people in the current study also expressed mixed views about the medical treatment that they received in the psychiatric hospitals. Those who were admitted due to eating disorders spoke about professionals who treated their illness rather than considering their individual personal needs.

*... it was a hospital that I felt just categorised me rather than actually treating me as an individual person ... (Abigail – Interview)*

A common experience recounted by participants was the focus on weight restoration which is consistent with other studies (Colton & Pistrang, 2004; Mitrofan et al., 2019; Offord et al., 2006). Some participants in the current study expressed a feeling of being victimised in non-specialist general adolescent units which catered for different mental health needs. These young people stated that they wanted their treatment to address the underlying causes of their eating disorder rather than weight management. Mitrofan et al. (2019) argue that “a stronger emphasis on psychological needs and individualised care” (p. 1) improves the quality of young people’s experiences of care. Their study also highlights the need for professionals to focus on the psychological aspects of eating disorders from an early stage rather than an emphasis on weight-focused treatment.

It was beyond the scope of this thesis to explore the nature of psychological therapies in depth. However, young people in the current study with other mental health disorders offered mixed views about the psychological treatments that they received. Some explained that psychological therapies that offered useful coping strategies were helpful. The young people’s perceptions of the therapeutic interventions also seemed to be influenced by their relationships with professionals delivering the treatment. However, other participants stated that group therapy sessions were not always adequate

in meeting their needs. This was in contrast to the views of adolescents in Pingitore and Ferszt's study (2017) who found that group psychotherapy was a "natural fit" (p. 360) due to the benefits of group participation. The young people valued the opportunity to be supported and listened to by peers who "totally got it and totally got me" (p. 367). Contrasting views about therapy and psychoeducation were also found in Moses' study (2011) in which on the one hand, some participants spoke of group therapy and activities being unhelpful or childish. On the other hand, young people valued the opportunities to learn "cognitive and behavioural coping strategies" (p. 125). The findings from the current study and others suggest that an environment in which young people can develop competence in managing their illness by learning helpful strategies, therefore seems to be a key factor in young people's motivation to improving mental wellbeing and mental health recovery (Deci & Ryan, 1985; Rayner et al., 2018).

Although the young people in this study desired a degree of control over their recovery journey by having a voice in treatment decisions which were tailored to meet their individual needs, they also wanted to be treated with compassion and respect. This final aspect of delivering person-centred care is discussed in the next section.

### **5.2.3 Showing young people compassion and respect**

Within healthcare and social care, empathy, respect and kindness are at the heart of compassionate care (Chochinov, 2007; Tehranineshat et al., 2019). Compassion is also fostered through relationships and is about "how care is given through relationships based on empathy, respect and dignity" (NHS England, 2015, p. 4). A recurring theme in the participants' narratives was their desire to be nurtured and valued by professionals in community and inpatient healthcare settings. The young people's basic psychological need of relatedness was fostered by having warm, caring and genuine interactions with these professionals (Deci & Ryan, 1985). However, the young people recalled mixed experiences of the care they received.

Within the inpatient hospital environment, the young people valued the care and understanding of healthcare staff. Some who were admitted in their early teenage years, spoke of the support of staff who helped to alleviate the young people's anxieties and concerns about aspects of their healthcare treatment. The young people said that it was important that professionals took time to get to know them in order to develop trusting mutual relationships. Consistency in staffing therefore enabled professionals to support the young people's need for relatedness which was important to foster positive engagement with treatment (Deci & Ryan, 1985). This need for staff to take an interest in the young people and spend time with them is also reported in other studies (Haynes et al., 2011;

Moses, 2011). In Byrne et al.'s study (2021), young people who sought care for self-harm from emergency departments "felt more at ease and optimistic" (p. 7) when staff showed care and concern towards them. Young people in Gill et al.'s study (2016) also considered it a "life saver" (p. 60) to develop a significant relationship with staff and valued the persistent approach of staff to support them and not give up on them.

It could be argued however, that with this over-reliance on healthcare professionals, young people risk becoming institutionalised (Wirt, 1999). In Gill et al.'s study, (2016) young people developed an attachment to inpatient staff and considered them as family as a result. This led to concerns about becoming too attached to staff and other patients which made it harder for the young people to leave hospital. Similarly, some young people in the current study expressed concerns about coping once discharged from hospital. Others were also resistant to being discharged although they described inpatient hospital experiences which lacked compassion. This finding seems consistent with Wirt's (1999) total institution model of institutionalism in which "the restrictive environment of institutional settings coupled with oppressive staff is capable of producing institutionalism in almost any person regardless of diagnosis, predispositions or personality" (p. 260). Nevertheless, there was little evidence to suggest that the young people in the current study were institutionalised. In fact, many expressed their desire to remain connected with the world outside of the psychiatric hospital (see section 5.3).

Although participants in this study described some positive interactions with healthcare professionals, many experienced a lack of compassion which had a significant impact on the young people. Some spoke about a lack of understanding from professionals about their mental health disorders and the difficulties they were experiencing as a result. Others mentioned a lack of consideration of additional difficulties such as those associated with autism which resulted in feelings of discomfort during their interactions with professionals. Byrne et al.'s study (2021) reported similar feelings of discomfort due to young people's perception of a "lack of care, warmth or empathy" (p7) from professionals when dealing with self-harm. Participants acknowledged that they were reluctant to talk to staff about their true feelings as a result. This was echoed in the current study where young people stated that they were reluctant to seek support from inpatient staff due to their uncaring approach to care.

Other young people spoke about the anxiety and distress of either witnessing or experiencing the use of restraint in psychiatric hospital.

*I found all the screaming and alarms very distressing especially as I have sensory issues which make me sensitive to sound. (Imogen – Interview)*

Restraining hospital practices have the potential to undermine young people's self-confidence and can have an impact on their feelings of relatedness and competence (Gaine et al., 2021). While the use of restraint may be necessary in mental health services to keep young people and others safe, a calm inpatient environment where staff and young people know each other better can help to reduce frustration, agitation and the need for restraint (MIND, 2015). Furthermore, a more respectful approach to restraint where the need for paternalism and keeping young people safe is balanced by an awareness of the young people's right to autonomy and the need to show compassionate care is also advocated in mental health settings (Pelto-Piri et al., 2013). Nonetheless, the experiences shared by participants in the current study suggested a lack of a calm environment or a respectful approach to restraining young people.

According to the young people in this study, their experiences of uncaring and unsupportive inpatient mental health staff, resulted in their reluctance to engage further with mental health professionals. This had the potential to jeopardise the young people's mental health recovery. However, participants spoke about their resolve and determination to get better and avoid further psychiatric rehospitalisation. This finding seemed counterintuitive to the view that the young people's well-being and sense of motivation to recover was adversely impacted by the lack of relatedness with professionals (Deci & Ryan, 1985). One possible explanation was that the young people developed a sense of confidence, self-efficacy and resilience as they journeyed towards mental health recovery (Rayner et al., 2018). However, the compassion shown by professionals could not be overstated and enabled successful outcomes for some young people.

#### **5.2.4 Section Summary**

The aim of Tier 4 CAMHS is to support children with complex and severe mental difficulties and meet their needs as they journey towards mental health recovery (McDougall et al., 2008). However, young people in the current study perceived the mental healthcare system as one in which their basic psychological needs of autonomy, relatedness and competence were sometimes not met. They described some experiences which were characterised by a lack of care. Young people said that they did not feel that they had a voice in decision-making and did not receive personalised, compassionate and respectful care and support from professionals. This study did not allow causal links between the lack of person-centred care and outcomes for the young people to be drawn specifically. However, many of the participants shared roller-coaster journeys of mental health recovery and cycles of psychiatric re-hospitalisations. This study therefore seems to provide further evidence to support the view that meeting young people's needs for autonomy, relatedness and

competence fosters their sense of wellbeing and intrinsic motivation to work towards mental health recovery (Mancini, 2008; Stanton et al., 2020). Based on the recollections of the young people in the current study, it is therefore argued that an approach to care and support which was person-centred and addressed the specific needs of the young would have had a significant impact on their mental health recovery and possibly, the need for multiple psychiatric hospital admissions.

This section has discussed the young people's views about keeping their needs at the heart of care and support in healthcare settings. However, they also spoke about having these needs met in education settings. This is discussed in the sections that follow.

### **5.3 Fostering a sense of connectedness**

The second key finding that was identified from this study was the young people's desire to remain connected to their education setting and with peers as they journeyed into and out of psychiatric hospitals.

The role of education professionals in mainstream schools, schools located within the psychiatric inpatient hospitals, further education colleges and alternative provision settings in meeting these needs are discussed in the next two sections.

#### **5.3.1 Connection with school and education**

Young people in this study expressed a desire to remain connected with their mainstream school setting and their education when they were in hospital. The challenges that young people experience in school and the negative impact of mental health disorders on their educational outcomes are well recognised (Esch et al., 2014; O'Driscoll et al., 2015). An increasing number of studies also provide evidence to show that a sense of school connectedness has the potential to reduce feelings of loneliness and protect mental health among young people (Santini et al., 2021). The support of education professionals is therefore an important factor pertaining to school connectedness (Kidger et al., 2012).

Some of the participants in the current study spoke about their struggles to cope with the academic demands of school and their mental health disorder. They expressed their desire for professionals to acknowledge their difficulties and listen to their needs. Although some of the participants singled out individual staff who showed compassion towards them, others perceived that their difficulties were not recognised or understood by professionals. This finding is echoed in other studies which report that children and young people with behavioural, emotional and social difficulties feel that

they are not understood, listened to or supported by teachers (Cefai & Cooper, 2010; Cosma & Soni, 2019). Feelings of frustration and negative behaviours can also be triggered in children who feel ignored (Dolton et al., 2019). This was supported by findings in the current study whereby some of the young people said that they used self-harming behaviours as a coping mechanism. It was therefore important for the young people to experience a compassionate environment which supported their mental health and wellbeing (Al-Ghabban, 2018).

There are a number of factors, however, that appeared to contribute to the young people's perceived lack of compassion from professionals. Participants stated that some professionals lacked understanding about their mental health disorders and the impact on their learning. This has also been reported by Lloyd (2022) in relation to teacher's understanding of eating disorders. Furthermore, Hart (2016) suggests that teachers are sometimes unaware of the complexity of the issues that young people are dealing with. Other possible factors include teachers' attitudes to mental health disorders as well as their mental health literacy (Hart, 2017). It was therefore important that information about the young people's individual needs was shared with relevant professionals in the young people's education setting so that their unique needs could be supported.

Young people also spoke about having access to safe spaces in school and designated trusted adults who provided pastoral support to help them cope with their difficulties and anxieties. These findings are again echoed in Hart's study (2016) which found that young people with mental health problems who experienced good relationships with their school teachers felt a stronger sense of connectedness with their school. Hart's study (2017) also highlighted the need for schools to promote a "safe, more caring, empathetic, and compassionate environment for all children" (p. 27). Further studies show that healthy relationships with school teachers helps to promote a young person's wellbeing (Patton et al., 2000) and attachments to school (Hallinan, 2008) which have an impact on young people's academic performance.

Education plays an important role in the recovery journey of young people with medical illness (Mintz et al., 2018; Rayner et al., 2018). All of the participants in this study expressed concerns about the impact of psychiatric hospitalisation on their academic progress. The young people stated that they wanted professionals to support them with their learning so that they would not fall behind with their education. Young people in Preyde et al.'s study (2018) also mentioned similar concerns about their academic work while they were in hospital and wanted to keep abreast with their school peers. Maintaining continuity with their education while in hospital facilitates the process of reintegration back to the young people's schools following discharge from hospital (Ådnanes et al., 2020; Hall & DuBois, 2020). For some of the participants in the current study, education also provided a sense of normalcy and was a lifeline while they were in psychiatric hospital. A sense of

having control over their educational achievement, expressed mostly by participants with eating disorders, is echoed in other studies (Schilder et al., 2021).

The educational provision for children who are in hospital and unable to attend school is also a shared responsibility between their mainstream and hospital education setting (Department for Education, 2015). Collaboration between professionals is therefore crucial to support the needs of these young people and enable them to remain connected to their schools (Cortina et al., 2019; Salmon, 2004). This was echoed by participants in this study however, the experiences shared by some of the young people highlighted the impact that a lack of collaboration had on their mental wellbeing and sense of belonging to their school.

Participants in the current study also described a mixed picture of the quality of inpatient education which has been reported in other studies (Edwards et al., 2015). Maintaining continuity with learning in hospital involves a balance between the therapeutic medical treatment and offering a range of school activities that provide a reasonably balanced curriculum within a hospital setting (Mintz et al., 2018). The stated needs and preferences of young people in the current study suggests that achieving this balance was challenging at times for hospital school professionals.

While the young people's experiences suggest that education professionals had a significant impact in fostering the young people's desire to be connected to their schools and to their education, another important aspect of school connectedness stated by participants was their relationships with peers. The next section discusses the young people's views about the additional role that professionals played in fostering their need for social connectedness with their peers.

### **5.3.2 Connection with peers**

Young people with mental health problems have difficulty with peer relationships (O'Driscoll et al., 2015). Those absent from school due to periods of psychiatric hospitalisation are at further risk of social exclusion (Saeri et al., 2018; Wu et al., 2016). In the current study, most of the participants described difficult relationships with peers in secondary school prior to their psychiatric hospitalisation. Some who stated that their difficulties started in primary school, experienced social communication issues at a young age and were diagnosed with autism spectrum disorder (ASD) later in their adolescent years. Children and adolescents on the autism spectrum are at higher risk of experiencing mental health crises (Widnall et al., 2022) and psychiatric hospitalisation (Mandell, 2008). As peer relationships are an important factor in young children's development and have an effect on their mental health in adolescence (Shin et al., 2016), the support of professionals,

especially in the early years and during the transition from primary to secondary school, can help to minimise the impact on young people (Cross et al., 2018). Santini et al. (2021) also suggest that “fostering social connectedness at school may prevent loneliness, which in turn may promote mental well-being and prevent mental health problems during the developmental stages of adolescence” (p. 2). It was not clear from the current study whether the young people voiced their concerns to school staff in primary school. However, the experiences of young people highlights the need for timely and effective support from professionals. Taylor et al. (2019) also suggest that for young people with ASD, specialised inpatient units may be more effective for those in need of psychiatric hospitalisation.

Participants in this study also spoke about their experiences of bullying which had a detrimental impact on their school attendance. Bullying and victimisation are seen as indicators of risk of various mental disorders in adolescence (Islam et al., 2022; Kaltiala-Heino et al., 2000). Due to the current study’s design, the causal relationship between the bullying that young people reported that they experienced and the onset of their mental health disorders could not be confirmed. Even though there is evidence in literature to support a causal relationship between bullying victimisation and mental health difficulties, the direction of causality is less clear (Moore et al., 2017). Nonetheless, young people in the current study described the distress and isolation which had an impact on their school attendance. This highlights the importance of young people having support in schools and interventions to address negative behaviours (Ford et al., 2017).

However, research suggests that young people are reluctant to seek help with peer relationships and emotional difficulties for a number of reasons. Reported barriers include young people’s perception of social stigma and embarrassment (Aguirre Velasco et al., 2020; Radez et al., 2020) as well as concern about perceived confidentiality and how disclosure will be handled by professionals (Mulfinger et al., 2019). Fear of losing friendships (Mishna & Alaggia, 2005) and help-seeking being viewed as a sign of weakness (Kendal et al., 2014) have also been reported as reasons why young people are reluctant to disclose peer victimization. Furthermore, Rüschen et al. (2014) suggest that disclosure is especially difficult for individuals with recent inpatient psychiatric hospitalisation. In the current study, some participants explained that bullying took place not only in school spaces, but outside in the community as well as online. For some of the young people, these factors may have influenced their relationships with school peers and their reluctance to seek help. Due to the difficulties that young people have in disclosing emotional problems, Hart and O'Reilly (2022) suggest that professionals should be “better tuned into the subtle signs of bullying and manage disclosure more sensitively by working collaboratively” (p. 4) with adolescents. They argue that this is possible when teachers know their students well.

Schools adopt a wide variety of interventions to deal with bullying (Rigby & Johnson, 2016; Thompson & Smith, 2011). Although prompt intervention to respond to or prevent bullying can help to minimise the detrimental impact on young people, some strategies can be ineffective and counterproductive in some cases (Juvonen & Graham, 2014; Rivara & Le Menestrel, 2016). This was supported by participants in the current study who stated that some of the “reactive strategies” (Rigby, 2014, p. 409) employed by staff to address the bullying they experienced were unhelpful. One participant said that she was withdrawn from physical education lessons. Another stated that she was supported in rooms away from peers but explained that this resulted in further victimisation. Nonetheless, other restorative practices have been reported to have a high success rate in schools (Rigby, 2014). However, one participant in the current study explained that attending a meeting with the girl who bullied her, resulted in further isolation from the friendship group. Although education settings are obliged to have whole-school proactive or preventative measures in place (Department for Education, 2017), this study suggests that bullying was a significant issue for young people which had a considerable impact on their sense of social connectedness and psychological wellbeing.

In addition to social connectedness in school, some of the participants said that they valued the sense of connection that they experienced with fellow inpatients in psychiatric hospital. This finding was consistent with the views of young people in Gill’s study (2014) who valued their relationships with fellow inpatients and considered them and staff as a “substitute family” (p. 92). Similarly, young people in Colton et al.’s study (2004) described positive experiences with others with similar eating difficulties which made them feel “no longer alone or ‘a freak’” (p. 311). However, some participants in the current study expressed a feeling of isolation from established cliques in the inpatient environment. In addition, others stated that they learned behaviours that were not conducive to their recovery. These identified risks of inpatient psychiatric hospitalisation (Edwards et al., 2015; Moses, 2011) affected the young people’s need for relatedness with peers (Deci & Ryan, 1985) and had an impact on their mental health recovery (Rayner et al., 2018).

### **5.3.3 Section Summary**

Fostering a sense of connectedness with school, education and peers had a significant impact on the recovery journey of the young people in this study. Some participants said that difficult relationships with peers resulted in school refusal and a cycle of multiple school admissions. Nevertheless, most of the young people stated that they remained motivated and determined to succeed academically. This study therefore provided further evidence that by nurturing young people’s need for autonomy,

relatedness and competence (Deci & Ryan, 1985) within education settings, young people developed a sense of hope in their mental health recovery (Rayner et al., 2018).

#### **5.4 Chapter Summary**

This research sought to seek the views of young people with severe mental health disorders, about the support required to meet their needs in healthcare and education settings. The young people described a lack of person-centred care by professionals within healthcare settings. Young people also said that they did not feel that they had a voice in their medical treatment. Furthermore, they stated that the care that they received was not individualised and delivered with compassion and respect. These experiences appeared to frustrate the young people's basic psychological needs of autonomy, relatedness and competence, which had a significant impact on their mental health recovery journey. In contrast, all of the young people spoke about positive educational outcomes even though some said that they were not supported to continue their education, remain connected to their schools when in hospital or have positive peer relationship.

The final chapter of this thesis explains the significance of these findings, reflects on the implications for policy and the practice of health care and education professionals and makes recommendations for future research.

## 6 Conclusion

### 6.1 Introduction

Young people with mental health difficulties are supported by a wide range of professionals within healthcare and education settings. However, it is not always the case that these young people feel well supported (Children's Commissioner, 2022). This can result in poor mental health and education outcomes (Fraser & Blishen, 2007; Lereya & Deighton, 2019).

This qualitative study explored young people's views about the support that they received from healthcare and education professionals within community and inpatient CAMHS and education settings. Eight young people were interviewed to gain insight into their experiences as they journeyed into and out of psychiatric hospitals. This research aimed to give young people a voice and explore their respective views about being supported during their mental health recovery journey. It therefore set out to answer the following main research question (MRQ) and sub-questions (SRQs):

MRQ: How do young people with severe mental health disorders perceive their experiences within the systems of healthcare and education as they journey into and out of psychiatric inpatient hospital?

SRQ1: How do young people experience receiving support in healthcare settings?

SRQ2: How do young people experience receiving support in education settings?

SRQ3: What do young people want to share with healthcare and education professionals about supporting their mental health recovery journey?

In this final chapter, the research questions posed for this study are succinctly answered. This study's limitations are acknowledged and its original contribution to the existing body of literature highlighted. The potential impact of the research findings on professional practice are also outlined and recommendations for future research suggested. Finally, this chapter concludes with an autobiographical reflection on the research journey and a few concluding remarks.

The next section is a summary of the main research findings presented and discussed in chapters 4 and 5, which address RQ1 and RQ2.

### 6.2 Main Research Findings

The first two sub-research questions focused on how the participants experienced support within healthcare and education settings. Although the young people recalled some positive experiences

in healthcare settings, their narratives suggested that the support and care that they received from healthcare professionals was not always person-centred (see section 5.2). The young people explained that did not feel listened to with regards to their medical treatment and decision-making about their healthcare. The young people also said that the medical treatment and support was not always individualised to meet their needs. Furthermore, the young people shared experiences where they were not treated with compassion and respect. These findings were consistent with other studies (C. Hayes et al., 2020; Moses, 2011; Offord et al., 2006). In the current study, the young people stated that their perceived lack of person-centred care had a significant impact on their level of engagement with their medical treatment and ultimately, their mental health recovery.

The young people's views of their experiences suggested that by supporting their psychological needs of autonomy, relatedness and competence, a positive sense of well-being and intrinsic motivation in their recovery process could be fostered (Deci & Ryan, 1985). However, the findings seemed to suggest that at times, there was tension between professionals' need for paternalism, and the young people's desire for autonomy and reciprocity (Pelto-Piri et al., 2013). In inpatient settings, young people described a sense of losing their autonomy, as professionals exercised their duty to keep them safe from harm. However, as the young people's health improved, they described the development of recovery processes such as confidence and resilience (Rayner et al., 2018). According to the participants, these positive steps towards mental health recovery did not appear to be nurtured by professionals so that the young people could develop and regain the skills needed to maintain their mental health recovery without intensive support.

Findings from this research about the support that the young people received in education settings was also mixed and consistent with other studies (Hart, 2016; Preyde et al., 2018; Williams, 2021). In mainstream education settings, some of the young people stated that they struggled to cope with academic pressures, difficulties with peer relationships and their deteriorating mental health. A significant number of the young people said that they experienced bullying in school which appeared to have a considerable impact on their mental health and well-being (see section 5.3.2). The strong association between bullying and mental health problems is supported in literature (Islam et al., 2022; Kaltiala-Heino et al., 2000). Young people in the current study also mentioned that they were supported with the bullying they experienced in schools. However, according to the young people, the support that they received was unhelpful and they recounted cycles of school refusals and multiple school admissions as a consequence. In addition, some of the young people's narratives suggested that the inpatient environment provided a safe space where the pressures that they experienced were alleviated. However, the young people explained that they wanted to remain connected to their mainstream schools, continue their education and have positive relationships with

their peers. Most of the young people stated that they were concerned about the impact of their psychiatric hospitalisations on their academic progress. However, the collaborative and tailored support of hospital and mainstream education professionals described by the young people, appeared to enable continuity of learning during hospital admissions, successful school reintegration following discharge and ultimately, positive educational outcomes (see section 5.3.1).

These main research findings highlight important issues for the young people during their mental health recovery journey in healthcare and education settings. While these results echoed many of the findings reported in the literature, this study had a number of limitations which are discussed in the next section.

### **6.3 Limitations of Study**

A key strength of this study was its focus on the voices of a vulnerable population. However, three limitations need to be acknowledged.

Firstly, this was a small-scale study with eight participants obtained through purposive sampling. This resulted in a sample made up only of female participants who stated diverse reasons for their psychiatric hospital admissions. Although this study captured the voices of young people who had experienced severe mental health disorders, the views expressed were from those who had achieved relatively successful outcomes in terms of their mental health recovery and education achievement. Young people who were struggling with their mental health difficulties may not have been in a position to participate in this research. As such, the perceptions and experiences of the eight young women who took part in this study cannot be representative of the wider population of young people in England with mental health disorders. The small sample also limits to some degree, the implications that can be drawn for the practice of healthcare and education professionals (see section 6.5).

Secondly, it must be acknowledged that the length of time between the young people's inpatient hospital admissions and this study could have an impact on recollections of their experiences. Providing an experience timeline for the participants to complete prior to their interviews, gave them the opportunity to reflect on the timings of events as well as their thoughts and feelings about their experiences. However, the young people's experiences may not reflect current provision for young people with mental health difficulties due to the retrospective nature of this study.

Thirdly, due to social restrictions imposed as a result of the COVID-19 pandemic, planned face-to-face interviews for this research were unable to take place. Most of the interviews were therefore

conducted using voice and video calls on WhatsApp or Skype or via video conferencing using Microsoft Teams. Two participants chose to answer interview questions via email, possibly due to sensitivities about discussing their mental health difficulties. The pandemic also had an impact on the opportunity to collect further data in planned second interviews with each participant, especially as poor internet connectivity compromised the audio quality during some interviews. Although the data collected was rich and sufficient to answer this study's research questions, additional interviews would have allowed for further exploration of the young people's views about their experiences.

In spite of these limitations, this small-scale research offered some different perspectives which are outlined in the next section.

#### **6.4 Original Contribution to Knowledge**

This research makes three original contributions to knowledge about supporting young people with mental health difficulties, specifically those with severe mental health disorders who require inpatient psychiatric hospitalisation. Firstly, it offers the unique voices of young people with lived experience of receiving support from both healthcare and education professionals, as they journey towards mental health recovery. This research, conducted through the lens of an education practitioner, therefore offers a multi-agency perspective to supporting young people.

Secondly, this research adds knowledge about the support that young people receive from multiple healthcare and education settings. It provides insight into the outpatient and inpatient mental health support that young people receive throughout their entire mental health recovery journey. Alongside this perspective, this study also raises awareness of the challenges that young people experience as they seek to maintain continuity with their education throughout their mental health crisis. This research therefore contributes to gaining a more holistic picture of the support that young people receive.

Finally, this study adds to burgeoning literature about young people's views about support in CAMHS and education settings. It was important to explore young people's perceptions about the unhelpful aspects of care and the support needed. However, by highlighting their positive experiences, this study provides real life success stories of young people who overcame significant challenges and thrived educationally. The young people in this study viewed this as an important part of their identity as they journeyed towards mental health recovery.

The third and final sub-research question focused on what young people wanted to share with healthcare and education professionals about supporting their mental health recovery journey. These are discussed in the next section of this chapter.

## **6.5 Implications and Recommendations for Practice and Policy**

The views and perceptions of participants in this study provided valuable insight into supporting the mental health and education needs of young people with severe mental health disorders. The implications and suggested recommendations for the practice of healthcare and education professionals and policy makers, which are based on this study's findings, are outlined in the following sections.

### **6.5.1 Promote compassion in mental healthcare settings**

Compassion is recognised as a gold standard of care and a key aspect of patients' healthcare experiences (Tehranineshat et al., 2019). Young people in this research spoke about some of the professional qualities, skills and behaviours involved in providing compassion (Sinclair et al., 2020). These included the provision of personalised care, treating the young people with warmth and understanding, acknowledging their concerns and communicating effectively. The findings from this research suggest that there were significant inconsistencies in the practice of providing compassion in community and inpatient mental healthcare settings. The young people in this study stated that they did not feel listened to, and the care received was not always tailored to meet their individual needs. Some also perceived a lack of respectful care in their interactions with professionals, especially in the use of restraint. The following two recommendations are therefore suggested:

#### **Recommendation 1: Provide Compassion Training**

The nature versus nurture debate with regards to whether compassion can be taught is ongoing in the literature (Malenfant et al., 2022; Sinclair et al., 2020; Sinclair et al., 2016). A number of approaches such as the Creating Learning Environments for Compassionate Care (CLECC) Programme (Bridges & Fuller, 2015), the Leaders for Compassionate Care Programme (LCCP) (Landers et al., 2020) and the Mindfulness Based (MB) CARE program (Brun et al., 2023) have been developed to support healthcare professionals' delivery of compassionate care. It is recommended that these programs are considered and rolled out at local and national level.

Additional research may also be required to develop compassion training programs that are tailored to individuals (Malenfant et al., 2022) and also to ascertain the effectiveness of these programs (Bridges et al., 2018). Other approaches such as the Patient Evaluation of Emotional Care during Hospitalisation (PEECH) tool (Murrells et al., 2013) can also be used to gather patient-reported evaluations of emotional care. This can be used to inform practice at a local level.

Furthermore, alternative options need to be considered to minimise the significant detrimental impact that physical restraint can have on patients and healthcare practitioners. Existing interventions such as ReSTRAIN YOURSELF (Duxbury et al., 2019) and strategies which build upon empathic relationships between patients and healthcare professionals (Butterworth et al., 2022) may be helpful. Nonetheless, it is acknowledged that restrictive practices may be required in mental healthcare settings. A recommendation is that specialist training and supervision are provided to ensure safe implementation of restrictive practices. In addition, “reflective and emotional support” (Butterworth et al., 2022, p. 9) for young people and healthcare professionals would be beneficial in managing the effects of these practices.

Lastly, compassionate care is provided, “not in isolation, but in the context of an organization and team environment” (Durkin et al., 2022, p. 1123). Young people in this study stated that a lack of staff contributed to their needs not being met. The impact of systemic issues such as staff shortages, on the ability of mental health professionals to deliver compassionate care cannot therefore be overstated. It is therefore recommended that these systemic issues are considered at policy level and the recruitment of adequately trained staff placed high on the agenda.

#### Recommendation 2: Promote good practice in the Care Programme Approach (CPA)

The Care Programme Approach (CPA) (Department of Health, 2007) was introduced to ensure that people with mental health disorders and under the care of mental health services, have care plans which are reviewed regularly or as necessary and a mental health worker who coordinates care delivery (Kingdon & Amanullah, 2005). The findings from this study suggest that although young people had care plans, they were not part of discussions when they were reviewed. Kingdon (2019) also reports that although professionals and regulatory bodies have accepted the broad principles of the CPA, “there remains no evidence as yet that CPA criteria are applied consistently across services, or that this has improved over the years” (p. 101).

This study recommends that professionals promote the elements of good practice outlined in the CPA as follows:

- Involve young people at every stage of the process including the assessment of their needs.
- Develop a plan that responds to these identified and agreed needs.
- Share responsibility with key stakeholders including professionals, family and friends, in order to put plans into action.
- Review the plan regularly.

In addition, further research at policy level is required to establish how CPAs are applied within CAMHS and whether they meet the needs of young people with mental health disorders.

### **6.5.2 Promote a compassionate environment in mainstream education settings**

A school environment and culture which is based on compassion, can promote young people's mental health and well-being (Al-Ghabban, 2018). Although some of the young people in this study stated that they were high academic achievers, they spoke about their struggles to cope with the academic demands of school and their mental health difficulties. The research participants reported a lack of mental health literacy and negative attitudes to mental health disorders which contributed to the perception of a lack of compassion from education professionals in mainstream settings. The young people also stated that school environments with compassionate and empathetic professionals helped them to cope with difficulties they experienced.

Education professionals therefore need to be sensitive to the impact that mental health difficulties have on young people who may appear to be coping academically. The following three recommendations are suggested:

#### **Recommendation 1: Provide a safe space and a designated trusted adult**

Schools need to provide access to a trusted adult and a space where young people feel free to be open and honest about their difficulties (Hart & O'Reilly, 2017). The young people in this study were self-aware and had views about ways in which they could be supported. It is important that young people feel listened to, and their needs considered in decision making.

#### **Recommendation 2: Share relevant information with key stakeholders**

Schools need to have robust systems in place to ensure that there is regular communication between staff in schools to highlight young people's specific mental health difficulties, the impact on their

learning and any interventions that are required to support their needs. Generally, the designated safeguarding lead (DSL) (Department of Health and Department for Education, 2017) would be responsible for this information sharing. The CPA framework discussed earlier provides the perfect opportunity for education professionals to be part of discussions about a young person's needs and the support required.

#### Recommendation 3: Provide training for education professionals

A reasonable approach to address the issue of teachers' lack of mental health literacy and understanding about specific mental health disorders could be through professional training and continuous professional development. Mental health training programmes, such as 'We can Talk' (Healthy Team Minds, 2017), which are co-produced by professionals and children and young people with lived experiences of being supported in mental health crisis, have been found to improve outcomes not only for young people but also for professionals (Kerr, 2022). Furthermore, the introduction of educational mental health practitioners (EMHPs) to support young people in schools (Department of Health and Department for Education, 2017) can also be a useful resource for education professionals. It is therefore recommended that Mental Health Support Teams (MHSTs) continue to receive funding from government to facilitate the essential joint working between schools and the NHS.

#### **6.5.3 Promote connection and continuity with education**

Education plays an important role in the recovery journey of young people with physical health or mental health difficulties (Mintz et al., 2018; Rayner et al., 2018). The participants in this research expressed their desire to maintain connections with their mainstream education settings and continue their education during periods of hospitalisation. They also stated the positive impact of effective communication between hospital and mainstream education professionals. However, the findings from this research suggest that there were inconsistencies in practice which had a significant impact on the young people's sense of school connectedness.

As mainstream and hospital education settings have shared responsibility for young people's education while they are in hospital (Department for Education and Department of Health, 2015), this study recommends that appropriate systems for information sharing are put in place as a priority as soon as a young person is admitted to hospital as follows:

- Hospital schools establish communication with the young person's mainstream education setting within the first week of admission.
- Hospital settings involve mainstream education professionals in CPA (discussed in section 6.5.1) at earliest opportunity.
- Mainstream schools establish robust systems to ensure that information which will assist hospital professionals to support young people's education is provided in a timely manner.
- Hospital education professionals support young people to continue their education so that they do not fall behind their peers.
- Hospital and mainstream education settings maintain regular communication throughout young person's admission and establish reintegration plans as soon as discharge date is known.
- Involve young person in discussions about school reintegration.

#### **6.5.4 Promote social connection with peers**

Participants in this research described the detrimental impact of bullying victimisation on their mental health and also on their ability to maintain continuity with their education. They recounted multiple school admissions due to perceived ineffective interventions. Although many schools adopt a whole-school approach to prevent and tackle bullying (Department for Education, 2017), the findings of this study suggest that a more person-centred approach needs to be considered. Hart and O'Reilly (2022) also reported similar findings and the need for professionals to be proactive in terms of identifying signs of bullying and working sensitively and collaboratively with young people to address difficulties. The following two recommendations are therefore proposed:

##### **Recommendation 1: Professional training and support**

Training professionals to spot signs of bullying, especially those of a covert nature and providing the skills to approach young people sensitively could ensure that the right support is put in place in a timely manner. As discussed in section 6.5.2, education professionals can be supported by educational mental health practitioners (EMHPs) and work collaboratively to support young people experiencing mental health difficulties.

## Recommendation 2: Address whole school policies and procedures

Greater efforts are required to convey key messages about the damaging impact of bullying on individuals, especially those who are experiencing mental health difficulties. Whole school policies therefore need to reflect the close links between bullying and mental health. While restorative practices (Rigby, 2014) may address some incidents of bullying, it is essential that young people are at the centre of efforts to address the bullying that they experience. By listening to their views, a more person-centred approach can be adopted to meet their needs.

These recommendations have the potential to improve the care and support that young people with mental health difficulties experience in healthcare and education settings. However, as previously stated, they are based on the views of a small purposive sample. In order to further extend the knowledge and understanding of the support needs of this vulnerable population identified in this study, the next section offers some recommendations for future research.

### **6.6 Recommendations for Future Research**

The current study could be enhanced by future research in a number of areas. Firstly, this qualitative study focused on the retrospective views of a small number of participants. A study which sought the views of young people in hospital was not possible partly due to complexities in applying for Health Research Authority (HRA) Ethics approval. Future research could adopt a longitudinal approach with a greater number of participants. Reviews of children and young people's mental health services (Care Quality Commission, 2018) have adopted such an approach with young people as they journey through the mental healthcare system and echo several of the key findings from the current study. Research which tracks young people who are hospitalised in psychiatric hospitals could further strengthen the arguments made to improve the support provided by healthcare professionals. In addition, a longitudinal study which focused on young people's experience of maintaining continuity of education throughout their mental health recovery journey would also help to add to the gap in existing research which focuses on mental health support in schools (Hart, 2016) or the school reintegration experience of young people (Preyde et al., 2018; Williams, 2021).

Secondly, the needs of young people with different diagnoses may differ. There appears to be an extensive body of literature which focuses on the needs of young people with eating disorders in particular (Colton & Pistrang, 2004; Wu & Harrison, 2019), but fewer studies about other disorders and difficulties (Kline et al., 2013). In the current study, participants stated that their healthcare needs were sometimes not met in general psychiatric adolescent units due to the focus on young people with eating disorders. Research on the views of young people with other mental health

disorders such as psychosis or other groups such as those with autism would therefore help to identify their unique support needs.

Thirdly, this study did not explore in depth the specific nature of the mental health interventions and treatments that the young people received. This issue was not pursued due to the researcher's lack of expertise in this subject. However, this study gave young people the opportunity to express their views that some of the interventions and treatments that they were offered were not helpful. This is echoed in other studies which highlight the fact that some school-based interventions for example, may not be effective in preventing some mental health difficulties (Caldwell et al., 2021). Qualitative research which explores the effectiveness of therapies in schools to address young people's difficulties would therefore provide valuable insight in this area.

Finally, the findings from this study would have been enhanced by adopting an ecological perspective on supporting young people at all stages of their recovery journey (Savina et al., 2014). This could be achieved by seeking the views of other actors such as healthcare, social care and education professionals in different settings as well as the perspectives of parents or carers.

This chapter concludes with some personal reflections on this research and final remarks.

## **6.7 Autobiographical Reflections**

My original intention when I embarked on my education doctorate journey was to find out about a unique group of education professionals who work in psychiatric hospital settings. This was of interest to me because I had started a new job as a hospital teacher at the time, with no experience of teaching in this setting. Having come from a mainstream teaching background, I was curious to know about the career paths of other hospital teachers and their experiences of teaching young people with severe mental health disorders. However, the decision to change my focus to the young people themselves was made after careful consideration of the potential impact that such research could have on the practice of professionals working with this very vulnerable group. Indeed, by gaining the perspectives of the young people that we support, education professionals can develop and progress in their practice. On reflection however, including professionals in my study may have enhanced the current research findings.

My research journey has been a roller-coaster of experiences and emotions which have given me a deeper understanding of the challenges of conducting research with a vulnerable group of participants. For example, I had not anticipated how much time it would take to recruit participants for the study and with the benefit of hindsight, applying for Health Research Authority (HRA)

approval to recruit participants from NHS settings at an earlier stage could have helped in this regard. During data collection, I quickly realised that I could not separate my original intention of focusing on the young people's experiences of education, from their holistic experiences, including of their mental healthcare. I was surprised by how willing the young people were to share their experiences with me. I reflect whether this would have been the case if I had met them in person, which was not possible during the COVID-19 pandemic. At times, it was difficult for me to listen to the young people's stories, but I was also struck by how composed the young people appeared as they recounted their experiences, some of which were particularly difficult. I became acutely aware of the impact on my own mental health and often needed time away from my research to look after my wellbeing.

The analysis of the young people's data and writing up this thesis has challenged my understanding of qualitative research. My doctorate studies have helped me to realise that my scientific background and teaching career in mathematics have shaped the way I view the world. My positivist perspective had to give way to a more constructivist stance. This has not been easy and I have grappled with the intricacies of identifying codes and themes in Thematic Analysis (Braun & Clarke, 2006) and interpreting the young people's experiences in a way that remained true to my aim of giving the young people a real voice in this research.

This doctorate journey has developed my understanding of the research process in general and has made me interested in research related to teaching my mathematics subject specialism.

Above all, I have been privileged to gain insight into the world of young people with severe mental health disorders. The young people's heart-breaking stories of their struggles, but also their indomitable spirits and triumphs on their road to recovery, have raised my awareness of the detrimental impact that professionals can have on these vulnerable members of our society. The key message that I take away from my research and which I hope to share with colleagues in my workplace, is that young people want to be shown humanity by professionals. In my personal professional practice, I am striving to show young people compassion and foster their joy in learning, which I believe is a key part of their journey to mental health recovery.

## 6.8 Concluding remarks

Although some progress has been reported in terms of improving the state of children's mental health services in England (Children's Commissioner, 2021), this study has highlighted the difficult journey that some young people experience on their road to mental health recovery. The title of a review by The Care Quality Commission (2018) posed the question, 'Are we listening?'. Are we

listening to what young people say they need and want in order to help them cope with their mental health difficulties? Are we listening to what they say will help them to make meaningful progress as they recover from their mental health disorders? The young people in the current study said that they did not always feel listened to, especially with regards to their mental healthcare treatment. This study therefore adds to other calls for the voices of young people to be listened to, in order to establish what they really need to regain and maintain good mental health. Young people also expressed their desire to be given more opportunities to develop the skills they need to meet these goals and return to being contributing members of society. Finally, young people said that they wanted to continue with their education in spite of the difficulties they were experiencing. It is therefore incumbent on healthcare and education professionals to listen to the needs of young people with severe mental health disorders and support them as they journey towards mental health recovery.

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## Appendix A. Ethics Review Application Form

### To be used for School or University level review

Please append all relevant and supporting documentation to this project application form when submitting for School level (SREC) or University (UREC) review. Text boxes will expand as required and all language used to explain or justify the application should be comprehensible to a lay person.

Application form and all associated documents should be submitted electronically.

Submission deadline dates for UREC can be found on the [UREC webpage](#).

### Section 1: APPLICATION DETAILS

1.1 PROJECT AND DATES				
Title	The experience of adolescents with severe mental health disorders in hospital and mainstream school following hospitalisation in an inpatient unit			
Date of submission	13/08/2019			
Start date	01/01/2019			
End date	31/01/2021			
1.2 APPLICANT DETAILS				
Chief Investigator	Professor Catherine Tissot			
Please note that an undergraduate or postgraduate student cannot be a named Chief Investigator for research ethics purposes. The supervisor must be declared as Chief Investigator.				
Is the project being carried out in whole or in part to support a student degree?				
<input checked="" type="checkbox"/> Yes		<input type="checkbox"/> Undergraduate	<input type="checkbox"/> Masters	
<input type="checkbox"/> No		<input checked="" type="checkbox"/> PhD		
School	Institute of Education			
Department	Click here to enter text.			
Email	c.tissot@reading.ac.uk			
Telephone	0118 378 2674			
All other Applicants	Name:	School	Position	Email
	Mrs Regina Cobbinah	Institute of Education	Research Student	r.t.cobbinah@pgr.reading.ac.uk
	Dr Holly Joseph	Institute of Education	Associate Professor	h.joseph@reading.ac.uk

### 1.3 WHAT REVIEW IS NEEDED?

Please tick the appropriate box below to confirm which review your ethics application requires.

Please tick all that apply.

<input checked="" type="checkbox"/> School Level Review (SREC)	<input type="checkbox"/> External (for example, HRA)
<input checked="" type="checkbox"/> University Research Ethics Committee Review (UREC)	

Projects expected to require review by the University Research Ethics Committee (for example; research involving NHS patients, research involving potential for distress to participants) must be reviewed by the Chair of the School Ethics Committee or the Head of School before submission to UREC. For further information see Section 16 of the [UREC Guidance](#).

### 1.4 EXTERNAL RESEARCH ETHICS COMMITTEES

Please provide details of other external research ethics committees from whom a favourable ethics opinion will be required (for example; HRA REC)

Name of Committee	Date of submission / approval	Reference	Status
Click here to enter text.	Click here to enter a date.	Click here to enter text.	-

### 1.5 PROJECT SUBMISSION DECLARATION

On behalf of my co-applicants and myself,

- I confirm that to the best of my knowledge I have made known all information relevant to the appropriate Research Ethics Committee and I undertake to inform the Committee(s) of any such information which subsequently becomes available whether before or after the research has begun
- I understand that it is a legal requirement that both staff and students undergo Disclosure and Barring Service checks when in a position of trust (for example; when working with children or vulnerable adults)
- I confirm that if this project is an intervention study, a list of names and contact details of the participants in this project will be compiled and that this, together with a copy of the Consent Form, will be retained within the School for as long as necessary.
- I confirm that I have given due consideration to equality and diversity in the management, design and conduct of the research project.
- (For Chemistry, Food & Pharmacy (CFP) only) I confirm the Internal Review has been undertaken by Click here to enter text. and I have made the changes requested.

### SIGNED, CHIEF INVESTIGATOR

Click here to enter a date.

Where required by the School's Research Ethics Procedures, this ethics application should be signed off by the appropriate person to confirm the School Body are content for this application to be reviewed by UREC.

Chemistry, Food & Pharmacy – will require sign off from: Chair of SREC, Head of Department and School Ethics Administrator – insert rows below as required.

### SIGNED, AUTHORISING SIGNATORY

Signature:	Position:	Date:
	Head of School	08/08/2019

## Section 2: PROJECT DETAILS

### 2.1 LAY SUMMARY

Please provide a summary of the project in plain English that can be understood by a non-specialist audience, which includes a description of the background of the study (existing knowledge), the questions the project will address, the methods to be used and the key ethical issues.

Please note the lay summary should not contain references and be no more than 500 words.

*Adolescents with severe mental health disorders may require hospitalisation in an inpatient psychiatric unit if they are at risk of harm to themselves or others. Existing research highlight the significant number of children and young people hospitalised in these secure inpatient units however little is known about their experience of returning to school following hospitalisation. When discharged from hospital, some young people do not have adequate coping mechanisms to deal with the stresses of school or to engage within the school environment. This can result in a higher probability of readmission to services which are already overstretched.*

*This study therefore aims to explore the perceptions of previous inpatients regarding their hospital school experience and their home school reintegration experience. The purpose is to gain a better understanding of the young people's views regarding the most effective support received to help them transition back to their mainstream school successfully following hospitalisation.*

*The main research question that this study will address is:*

*How do young people with severe mental health -disorders make sense of the education support they received in a secure inpatient adolescent unit and in their mainstream school following hospitalisation?*

*Twelve young people aged between 12 and 25 years will be interviewed on two separate occasions either face-to-face, by telephone, WhatsApp, Zoom, Skype, text or email. An artefact and timeline of helpful and unhelpful experiences provided by the participants will be used as prompts to encourage the young people to share their experiences. Due to the current restrictions due to COVID-19, no-face-to-face interviews will be conducted.*

*Information sheets and an additional child-friendly pamphlet will be provided to fully inform parents/carers and young people about the purpose of the study and how the data will be collected, stored and used. They will also contain contact details for the researcher and main supervisor, and information about how the parents/carers and young people may withdraw from the research project at any time, should they wish to do so.*

*The participants will be assigned a pseudonym and will be referred to by that in all research publications. Research records will be stored securely in a locked filing cabinet and on a password-protected computer and only the researcher and supervisors will have access to them. All data collected will be held in strict confidence. However, if a child or young person discloses concerns related to safeguarding, the parents or carers will be informed if to do so will not place the child at risk of harm from the family. A named CAMHS or Child Protection professional in the Berkshire Healthcare NHS Foundation Trust's safeguarding team will be contacted (see Appendix 9).*

*There is a potential risk that a young person may recall events or incidents that cause emotional distress. If a young person begins to sound distressed, the researcher will remind them of their right to refuse to answer any question, take a break or stop the interview. If the interview is adjourned as mentioned in the consent forms, the researcher will promptly inform parents/carers and offer information about support services that could be of help.*

### 2.2 PRIMARY RESEARCH QUESTION

Please detail the primary research question this project will answer.

*How do young people with severe mental health -disorders make sense of the education support they received in a secure inpatient adolescent unit and in their mainstream school following hospitalisation?*

### 2.3 SECONDARY RESEARCH QUESTION(S)

Please detail any secondary research question(s) this project will answer.

## 2.4 DESIGN AND PROCEDURE

Please describe concisely what the study will involve, how many times and in what order, for your participants and the procedures and methodology to be used.

Note: Any questionnaires or interview scripts should be appended to this application.

1. *Study advertised (Appendix 1) on the premises of non-NHS settings such as mental health organisations and charities, other organisations such as the Autistic Spectrum Service for Information Support and Training (ASSIST) and Parenting Special Children as well as using social media (e.g. on Facebook group chats, Twitter, Instagram, Snapchat, TikTok). Researcher also contacts schools, colleges, universities and providers of alternative provision by email.*
2. *Potential participants respond to advertisement by contacting the researcher directly.*
3. *Researcher emails information sheets and consent forms (Appendices 2 & 3), demographic information form (Appendix 4) and experience timelines (Appendix 5) to potential participants and their parents, who initially agree to participate.*
4. *Researcher contacts potential participants and their parents by telephone to address any questions or concerns and to confirm participation in study.*
5. *Participants and their parents/carers email completed consent forms to researcher or bring to first face-to-face interview to confirm participation in study.*
6. *Participants email a photograph of an artefact to the researcher if they wish to do so. The artefact can be an object, picture, photograph, drawing or piece of writing which reminds them of their school experience in the unit.*
7. *Participants email their experience timelines to the researcher if completed. The timelines show helpful and unhelpful people, incidents and experiences the young people had prior to and during admission and on discharge from hospital. Researcher will annotate the timeline during the first interview if participant is unwilling to complete it or finds the activity difficult to do without support.*
8. *Researcher analyses completed timelines to produce prompts for first interview.*
9. *Researcher contacts participants and their parents to arrange date and time for first interview either in person, by telephone, text, WhatsApp, Skype, Zoom or email.*
10. *Researcher conducts first semi-structured interview (see Appendix 6A for interview schedule) using young person's artefact and timelines as a way of encouraging them to share their experiences. Interview is expected to last between 30 minutes and an hour.*
11. *Researcher transcribes and analyses first interview to identify key themes. These will be shared with the participants for verification.*
12. *Researcher contacts participants to arrange second interview.*
13. *Researcher conducts second semi-structured interview (see Appendix 6B for interview schedule) to follow-up on themes from first interview.*
14. *Participants can be offered the option of providing written responses to interview questions via text or email if they are unable or unwilling to conduct face-to-face or spoken interviews.*

## 2.5 LOCATION

Please describe where the research will take place.

*The interviews will be conducted either in person, by telephone, WhatsApp, Zoom, Skype, text or email. Face-to-face interviews will be conducted at London Road, Room L16.*

Please state whether an appropriate risk assessment/ local review has been undertaken.

Yes (Appendix 11)  
 No  
 Not required

Notes:

- Ensure specific risk assessments have been undertaken for non-University locations (for example; schools or participant homes). Please consult either your School Ethics Contact or UREC for guidance.
- If the project is to take place in Hugh Sinclair Unit of Human Nutrition, it must be reviewed and approved by the Hugh Sinclair Manager.

## 2.6 FUNDING

Is the research supported by funding from a research council or other external source (for example; charities, businesses)?

Yes  
 No

If "yes", please,

(a) Give details of the funding body;

*Click here to enter text.*

(b) Confirm if the funder specifically stipulates review by the University Research Ethics Committee.

Yes  
 No

## 2.7 ETHICAL ISSUES

Please summarise the main ethical issues, including harms and risks, arising from your study and explain how you have addressed them.

*Informed consent and participants' right to withdraw*

- *Information sheets (Appendices 2 & 3) fully inform parents/carers and young people about the purpose of the study and how the data will be collected, stored and used. They also contain contact details for the researcher and main supervisor, and information about how the parents/carers and young people may withdraw from the research project at any time, should they wish to do so.*
- *An additional pamphlet (Appendix 2) written in more accessible language for children and young people provided to ensure fully informed consent.*
- *Parents/carers and young people asked to provide written consent having read the information sheets and pamphlet.*
- *Researcher will confirm consent from children and young people by reiterating details from signed consent forms and by obtaining verbal assent to participate in study.*

*Gaining access to young people*

- *Permission to advertise study on the premises of ASSIST and Parenting Special Children has been sought (Appendices 7 & 8) and will be subject to ethical approval.*
- *Other non-NHS settings such as mental health charities or organisations will be contacted for permission to advertise study on their premises.*
- *Permission to advertise study on Facebook group chats will be sought from administrator if required.*
- *Parents/carers of young people who respond to advertisement will be contacted.*

*Risk of emotional distress for young people*

- *Selection criteria will exclude young people who are not in stable mental health.*
- *Initial phone call conducted with young people and their parents prior to interviews to build rapport.*
- *If young person begins to sound distressed, researcher reminds them of their right to refuse to answer any question, take a break or stop the interview.*
- *Offer information about relevant support services (Appendix 10).*
- *Advise that parent or responsible adult be at home while interviews are conducted by phone, WhatsApp, Skype or Zoom.*
- *If interviewed in person, participants can have a parent or trusted adult present inside or outside the room.*
- *Allow debriefing opportunity at the end of interview.*

*Confidentiality*

- *All data collected will be held in strict confidence. However, where a child or young person discloses concerns related to safeguarding, parents or carers will be informed if to do so will not place the child at risk of harm from*

*the family. A named CAMHS or Child Protection professional in the Berkshire Healthcare NHS Foundation Trust's safeguarding team will also be contacted (Appendix 9).*

- *Other contacts if disclosure is made:*
  - *Local Authority Designated Officer (LADO) (Tel: 0118 9746141)*
  - *Berkshire West Safeguarding Children Partnership (Tel: 01635 503090)*
  - *Reading Local Safeguarding Children Board (LSCB): Children's Single Point of Access (Tel: 0118 937 3641)*
  - *Wokingham Borough Council (WBC) Referral and Assessment Team – Children's Safeguarding and Social Care Team (Tel: 0118 9496000)*

*Risk to researcher*

- *Engage in regular self-reflection (e.g. keep a log of emotional responses)*
- *Seek support from supervisors*

## 2.8 DECEPTION

Will the research involve any element of intentional deception (for example; providing false or misleading information about the study)?

Yes  
 No

If "yes", please justify and append a description of the debriefing procedure.

*Click here to enter text.*

## 2.9 PAYMENT

Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

Yes  
 No

If "yes", please specify and justify the amount.

*Click here to enter text.*

## 2.10 DATA PROTECTION

What steps will be taken to ensure appropriate secure handling of personal data? Give comprehensive details on the collection, retention, sharing and disposal of participant personal data.

Personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

For guidance on data protection please, see the [Data Protection for Researchers Guidance](#) document.

- *All data collected will be held in strict confidence and no real names will be used in this study or in any subsequent publications.*
- *The records of this study will be kept private.*
- *No identifiers linking the participant or any person or institution to the study will be included in any sort of report that might be published.*
- *The participants will be assigned a pseudonym and will be referred to by that in all records.*

- *Research records will be stored securely in a locked filing cabinet and on a password-protected computer and only the researcher and supervisors will have access to the records.*
- *In line with the University's policy on the management of research data, anonymised data gathered in this research may be preserved and made publicly available for others to consult and re-use.*
- *The results may be presented at national and international conferences, and in written articles. Copies of these can be provided to the participants if they wish.*

Will the research involve any activity that requires [a Data Protection Impact Assessment](#) (DPIA)?

Yes  
 No

If "yes", please append the "[DPIA Appendix A – Screening Questions](#)".

## 2.11 INFORMED CONSENT

a. Will you obtain informed consent from, or on behalf of, research participants?

Yes (go to question b)  
 No (go to question c)

b. If "yes", please describe the process by which they will be informed about the nature of the study and the process by which you will obtain consent.

c. If "no", you are not obtaining consent, please explain why (for example; 'opt-out' methodology without the acquisition of consent)?

Please append all relevant participant facing information documentation for participants, parents or guardians. Please note, age-appropriate information sheets must be supplied for all participants wherever possible, including children. Assent should be obtained from children, under 16 years, in addition to the consent required from parents, guardians or carers.

- *Information sheets (Appendices 2 & 3) will fully inform parents/carers and young people about the purpose of the study and how the data will be collected, stored and used. They will also contain contact details for the student researcher and main supervisor, and information about how the parents/carers and young people may withdraw from the research project at any time, should they wish to do so.*
- *An additional pamphlet written in more accessible language for children and young people will be provided to ensure fully informed consent.*
- *Parents/carers and young people will be asked to provide written consent having read the information sheets and pamphlet.*
- *Researcher will confirm consent from children and young people by reiterating details from signed consent forms and obtaining verbal assent to participate in study.*

## 2.12 GENOTYPING

Are you intending to genotype the participants?

Yes  
 No

If "yes", which genotypes will be determined?

*Click here to enter text.*

### Section 3: PARTICIPANTS DETAILS

#### 3.1 PARTICIPANT NUMBER

How many participants do you plan to recruit?

Please briefly explain why the number is appropriate to answer the study's research question(s).

*Two participants for pilot study to test the proposed research method.*

*Twelve participants for main study – sample size is small to allow a manageable analysis of the data for each young person.*

#### 3.2 PARTICIPANT CHARACTERISATION

What age-range of participants will you recruit?

*12 – 25 years old*

Please list the principal inclusion and exclusion criteria.

*Inclusion criteria:*

- *Children and young people aged 12 – 25 years*
- *Previous patient in an adolescent inpatient unit*
- *Currently in stable mental health*

*Exclusion criteria:*

- *Children outside inclusion age range*
- *Children or young people considered unwell by parent/carer*

#### 3.3 RECRUITMENT

Please describe the recruitment process and append any advertising if used.

- *See Appendix 1 for advertisement poster*
- *Request has made to advertise the study on the premises of the Autistic Spectrum Service for Information Support and Training (ASSIST) at the Woodley Airfield Centre, Woodley (Appendix 7) and Parenting Special Children, Reading (Appendix 8)*
- *Other mental health charities and support groups will also be contacted to recruit participants.*
- *Study will also be advertised using social media (e.g. on Facebook group chats)*

#### 3.4 NHS AND SOCIAL SERVICES INVOLVEMENT

Will participants be recruited because of their status as NHS patients or Social Services clients, or identified through those services' records?

Yes  
 No

If "yes", please give details of current status of the HRA REC review.

*Click here to enter text.*

Will the study involve adult participants unable to consent for themselves as defined by the Mental Capacity Act 2005 or other vulnerable adults?

Yes  
 No

If "yes", please detail the associated procedures as set out in the HRA REC application.

*Click here to enter text.*

## CHECKLIST

1. The Application form has the appropriate signatories		Yes
2. The Participant Information Sheet includes a statement to the effect that the project has been reviewed by the appropriate Research Ethics Committee and has been given a favourable ethical opinion for conduct.		Yes
3. The Participant Information Sheet contains the relevant Data Protection information.		Yes
4. EITHER	a) The proposed research will not generate any information about the health of participants;	<input checked="" type="checkbox"/>
OR	b) If the research could reveal adverse information regarding the health of participants, their consent to pass information on to their GP will be included in the consent form and in this circumstance I will inform the participant and their GP, providing a copy of the relevant details to each and identifying by date of birth.	<input type="checkbox"/>
OR	c) I have explained within the application why (b) above is not appropriate.	<input type="checkbox"/>
5. EITHER	a) The proposed research does not involve children under the age of 5;	<input checked="" type="checkbox"/>
OR	b) My Head of School (or authorised responsible person) has given details of the proposed research to the <a href="#">University's insurance officer</a> .	<input type="checkbox"/>
6. EITHER	a) The proposed research does not involve the taking of blood samples;	<input checked="" type="checkbox"/>
OR	b) For anyone whose proximity to the blood samples brings a risk of Hepatitis B, documentary evidence of immunity prior to the risk of exposure will be retained by the Head of School or authorised responsible person.	<input type="checkbox"/>
7. EITHER	a) The proposed research does not involve the storage of human tissue, as defined by the <a href="#">Human Tissue Act 2004</a> ;	<input checked="" type="checkbox"/>
OR	b) I have explained within the application how the requirements of the Human Tissue Act 2004 will be met.	<input type="checkbox"/>
8. EITHER	a) The proposed research does not involve the use of ionising radiation;	<input checked="" type="checkbox"/>
OR	b) I am aware the proposed research will require <a href="#">HRA REC review</a> .	<input type="checkbox"/>

## Version control

VERSION	KEEPER	REVIEWED	APPROVED BY	APPROVAL DATE
1.0	UREC	Annually	UREC	Sept 18

## DATA PROTECTION DECLARATION FOR ETHICAL APPROVAL

This document can be used to provide assurances to your ethics committee where confirmation of data protection training and awareness is required for ethical approval.

### By signing this declaration, I confirm that:

- I have read and understood the requirements for data protection within the *Data Protection for Researchers* document located here:  
[http://www.reading.ac.uk/web/files/imps/Data\\_Protection\\_for\\_Researchers\\_Aug\\_18\\_v1.pdf](http://www.reading.ac.uk/web/files/imps/Data_Protection_for_Researchers_Aug_18_v1.pdf)
- I have asked for advice on any elements that I am *unclear on* prior to submitting my ethics approval request, either from my supervisor, or the data protection team at: [imps@reading.ac.uk](mailto:imps@reading.ac.uk)
- I understand that I am responsible for the secure handling, and protection of, my research data
- I know who to contact in the event of an information security incident, a data protection complaint or a request made under data subject access rights

### Researcher to complete

Project/Study Title: The experience of adolescents with severe mental health disorders in hospital school and mainstream school following hospitalisation

NAME	STUDENT ID NUMBER	DATE
Regina Cobbinah		27 <sup>th</sup> June 2019

### **Supervisor signature**

Note for supervisors: Please verify that your student has completed the above actions

<b>NAME</b>		<b>DATE</b>
Prof Catherine Tissot		27 <sup>th</sup> June 2019

Submit your completed signed copy to your ethical approval committee.

Copies to be retained by ethics committee.

<b>VERSION</b>	<b>KEEPER</b>	<b>REVIEWED</b>	<b>APPROVED BY</b>	<b>APPROVAL DATE</b>
1.0	IMPS	Annually	IMPS	

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## Appendix B. Risk Assessment

Brief outline of Work/activity:	<p>An initial phone call with each young person and their parent/carer to explain the research project in detail, obtain basic demographic information, answer questions and address concerns.</p> <p>Two semi-structured interviews conducted with young person either in person, by phone, text or using WhatsApp, Skype or Zoom. Option for young person to provide written responses to interview questions via email if preferred.</p> <p>First interview prompted by an artefact (e.g. object, picture, photograph, drawing, piece of writing) and a timeline of helpful/unhelpful experiences provided by young person.</p> <p>Second interview to follow up on emerging themes from first interview.</p>
Where will data be collected?	<p>By telephone, text or using WhatsApp, Skype, Zoom or email.</p> <p>Face-to-face interviews conducted in Room L16, London Road</p>
Significant hazards:	<ol style="list-style-type: none"> <li>1. Personal safety during face-to-face interviews</li> <li>2. Online safety</li> <li>3. Participant distress or anxiety during discussion of a sensitive subject</li> <li>4. Aggression from participant</li> <li>5. Participant disclosure which makes researcher believe they are in danger of harm to themselves or others</li> </ol>
Who might be exposed to hazards?	<p>Participants</p> <p>Researcher</p>
Existing control measures:	<ul style="list-style-type: none"> <li>• Researcher to use a professional account to advertise study on online platforms.</li> <li>• Researcher follows up any expressions of interest with a phone call to prospective participants including parents/carers.</li> <li>• Researcher to use University telephone to contact participants when possible. If researcher's personal telephone is used, withhold number by dialling 147 before participant's telephone number.</li> <li>• Researcher offers option of face-to-face interviews at University only.</li> <li>• Researcher provides easy to follow instructions for participants to find interview location.</li> <li>• Researcher to book Room L16 using google calendar so that interviews are logged.</li> <li>• Researcher to email supervisors to inform them of interviews arranged.</li> </ul>

	<ul style="list-style-type: none"> <li>• Researcher to provide identification to participants using University photo ID card.</li> <li>• Room L16 has door with glass panels so that activity inside is observable from outside.</li> <li>• Researcher to choose a seat which faces the doorway and allows safe access to exit in an emergency.</li> <li>• Participants should have an adult representative (parent, carer or guardian) present during interviews.</li> <li>• If the presence of a parent / guardian is considered distressing or likely to stress the interviewee during face-to-face interviews, the accompanying adult can observe from outside Room L16.</li> <li>• During interview, researcher to monitor participants for signs of impending aggression (e.g. facial expression, verbal threats, clenched fists and / or increase in breathing rate).</li> <li>• If researcher feels participant is becoming angry, researcher will try to appear calm, speak slowly, clearly and softly, use simple language, stop the interview and inform parents/carers.</li> <li>• If researcher feels participant is becoming distressed, researcher will stop the interview, inform parents/carers and signpost to support services if appropriate.</li> <li>• If participant makes a disclosure, researcher will follow safeguarding procedures: <ul style="list-style-type: none"> <li>○ Inform parents/carers if to do so will not place child at risk</li> <li>○ Contact named safeguarding or CAMHS professional at the Berkshire Healthcare NHS Foundation Trust: Heather Owoo (Tel: 07827978419)</li> </ul> </li> <li>• Other contacts if there is risk of harm: <ul style="list-style-type: none"> <li>○ Local Authority Designated Officer (LADO) (Tel: 0118 9746141)</li> <li>○ Berkshire West Safeguarding Children Partnership (Tel: 01635 503090)</li> <li>○ Reading Local Safeguarding Children Board (LSCB): Children's Single Point of Access (Tel: 0118 937 3641)</li> <li>○ Wokingham Borough Council (WBC) Referral and Assessment Team – Children's Safeguarding and Social Care Team (Tel: 0118 9496000)</li> </ul> </li> <li>• In the event of an emergency, call supervisor.</li> </ul>
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Are risks adequately controlled:	Yes
----------------------------------	-----

If NO, list additional controls and actions required:	Additional controls	Action by:

## Appendix C. Favourable Opinion Response from UREC



Coordinator for Quality Assurance in Research  
Dr Mike Proven, BSc(Hons), PhD

### Academic and Governance Services

Whiteknights House  
Whiteknights, PO Box 217  
Reading RG6 6AH

phone +44 (0)118 378 7119  
email urec@reading.ac.uk

Professor Catherine Tissot  
Institute of Education  
University of Reading  
London Road  
RG1 5AQ

15 November 2019

Dear Cathy

### UREC 19/54: The experience of adolescents with severe mental health illness in hospital and mainstream school following hospitalisation in an inpatient unit. *Favourable opinion*

Thank you for the response (your email, dated 12 November 2019, from Karen Jones refers) addressing the issues raised by the UREC Sub-committee at its September 2019 meeting (*my Provisional Opinion email of 16 October including attachments refers*). On the basis of these responses, I can confirm that the Chair is pleased to confirm a favourable ethical opinion.

Please note that the Committee will monitor the progress of projects to which it has given favourable ethical opinion approximately one year after such agreement, and then on a regular basis until its completion.

Please also find attached Safety Note 59: Incident Reporting in Human Interventional Studies at the University of Reading, to be followed should there be an incident arising from the conduct of this research.

The University Board for Research and Innovation has also asked that recipients of favourable ethical opinions from UREC be reminded of the provisions of the University Code of Good Practice in Research. A copy is attached and further information may be obtained here:

<http://www.reading.ac.uk/internal/res/QualityAssuranceInResearch/reas-RSqr.aspx>.

Yours sincerely

Dr M J Proven  
Coordinator for Quality Assurance in Research (UREC Secretary)  
cc: Dr Karen Jones (SREC Chair); Regina Cobbinah (Research Student);

*This letter and all accompanying documents are confidential and intended solely for the use of the addressee*

## Appendix D. Amendment Favourable Opinion Response from UREC



**University of  
Reading**

*Coordinator for Quality Assurance in Research  
Dr Mike Proven, BSc (Hons), PhD*

**Academic and Governance Services**

Whiteknights House  
Whiteknights, PO Box 217  
Reading RG6 6AH

*phone +44 (0)118 378 7119  
email urec@reading.ac.uk*

Professor Catherine Tissot  
Institute of Education  
University of Reading  
London Road  
RG1 5AQ

25 June 2020

Dear Cathy,

**UREC 19/54: The experience of adolescents with severe mental health illness in hospital and mainstream school following hospitalisation in an inpatient unit. *Amendment favourable opinion AM011954***

Thank you for your application (email dated 4 June 2020, from Dr Karen Jones and including attachments, refers - requesting and detailing amendments to the above project (*extension of participant age range, further expansion of approved means for remote interviewing and confirmation that face-to-face interviews will not take place while Covid-19 regulations make this impracticable*)). I can confirm that the UREC Chair has reviewed that request and is happy for the project to continue.

Yours sincerely

Dr M J Proven  
Coordinator for Quality Assurance in Research (UREC Secretary)

*cc: Dr Karen Jones (SREC Chair); Mrs Regina Cobbinah (PhD Student)*

*This letter and all accompanying documents are confidential and intended solely for the use of the addressee*

## Appendix E. Mental Health Help and Support Services

### 1. Samaritans

Telephone: 116 123

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Website: <https://www.samaritans.org>

### 2. Mind Infoline

Telephone: 0300 123 3393 or text 86463

Email: [info@mind.org.uk](mailto:info@mind.org.uk)

Website: [www.mind.org.uk/information-support/helplines](http://www.mind.org.uk/information-support/helplines)

### 3. Rethink Mental Illness Advice Line

Telephone: 0300 5000 927

Email: [online contact form](#)

Website: <http://www.rethink.org/about-us/our-mental-health-advice>

### 4. Saneline

Telephone: 0300 304 7000

Website: [www.sane.org.uk/what\\_we\\_do/support/helpline](http://www.sane.org.uk/what_we_do/support/helpline)

### 5. The Mix

Telephone: 0808 808 4994

Email: [Helpline email form](#)

Crisis Support: [Text 'THEMIX' to 85258](#).

Website: [www.themix.org.uk/get-support](http://www.themix.org.uk/get-support)

### 6. ChildLine

Telephone: 0800 1111

Website: [www.childline.org.uk](http://www.childline.org.uk)

### 7. Elefriends

Website: <http://elefriends.org.uk/>

### 8. YoungMinds

Parents' Helpline: 0808 802 5544

Website: <https://youngminds.org.uk/>

Source: <https://www.time-to-change.org.uk/mental-health-and-stigma/help-and-support>

## Appendix F. Advertisement Poster



### Have you ever been supported by CAMHS? Would you consider participating in a research study?

#### What is the research about?

This study is designed to raise awareness of the challenges faced by young people who have had an inpatient admission and find ways to improve the education support they receive.

#### What will I do?

I will arrange to interview you twice about your experience and your views about the support you received. This will be done with utmost sensitivity.

Each interview will last between 30 minutes and an hour and will be private and confidential.

You can choose to be interviewed in person, by telephone, Skype text messenger or email.

#### Who can participate?

You are aged between 12 and 25 years.

*You will need your parent or carer's consent if you are under 16.*

You were admitted to an inpatient unit while at school or college.

You feel comfortable sharing your experiences and views.

#### Who do I contact?

Please contact **Regina Cobbinah** for further information.

Doctoral Researcher, Institute of Education, University of Reading.

**Mobile:** A redacted phone number.

**Online:** <http://tiny.cc/v66ukz>

**Email:** [r.t.cobbinah@pgr.reading.ac.uk](mailto:r.t.cobbinah@pgr.reading.ac.uk)



## Appendix G. Information Letter for Young Person

**Researcher:**

Name: Regina Cobbinah  
Email: r.t.cobbinah@pgr.reading.ac.uk

**Supervisor:**

Name: Professor Cathy Tissot  
Email: c.tissot@reading.ac.uk  
Telephone: 0118 378 2674

**August 2019**

Hi!

My name is Regina Cobbinah. I am a qualified teacher and have experience of teaching in a school in an inpatient unit. I have also taught in mainstream secondary and primary schools. This information sheet will tell you about a research project I am doing as part of my studies at the University of Reading.

***What is the research about?***

Some young people with mental health disorders spend time in an inpatient unit to help them get better. I want to learn more about what it is like for them to attend school in the unit and then return to their own school or college after being in hospital. I hope this will help adults in schools, colleges and hospitals to understand the experiences of young people so that we can support them better.

***Why am I being invited to take part?***

You are aged between 12 and 25 years and I am interested to hear your experience of what attending school in the unit was like and how you felt when you returned to your own school.

***What will I have to do if I agree to take part?***

I will phone you and your parents/carers to describe the study in more detail, obtain some background information about you, answer any questions you may have and arrange a first interview with you either in person, by phone, text or using WhatsApp, Skype or Zoom. It can sometimes be hard to talk about difficult experiences and feelings. To help with this, you may like to send me a picture of an object, picture, photograph, artwork or writing that reminds you of your time in hospital which you are happy to talk about. If you wish, I will also send you a timeline for you to write down any helpful or unhelpful experiences that we can discuss. We will use these to talk about what attending school in hospital was like and how you felt about returning to your own school after being in the unit. If you prefer to write down your answers to my questions, we can do this using email. At the end of our chat, I will ask if I can call you again in about two weeks' time so that we can talk more about what you have told me to make sure that I have understood your experiences correctly. I will ask your permission to record all our conversations so that I have an accurate record of what you tell me. Our conversations should last between 30 minutes and an hour and it would be good if your parent, carer or a responsible adult could be around while we chat.

### ***Will anyone know about my answers?***

Only me and my two supervisors at University will know about your answers. We will not tell anyone else what you say to me unless you tell me something that makes me worried for you or someone else's safety. If that happens, I am required by law to tell a member of the safeguarding team at CAMHS.

### ***What will happen to the information I give you?***

The information you give me will be stored securely in a locked filing cabinet and on a password-protected computer and only me and my supervisor will have access to them. I will write a report of this project for my studies and I may use some of the words you say but I will not use your name or the names of your school and the inpatient unit in anything I write. I may also present the results of this study at conferences or in written articles. I can send you electronic copies of these publications if you wish. The Privacy Notice included with this information sheet will help you understand what I will do with the personal information you give me.

### ***Will it help me if I take part?***

I hope you will find it helpful to talk about your experiences to someone who will listen and really wants to understand your views. Your experiences will help adults in schools and hospitals to improve the support given to young people who return to their home school after they have been in hospital.

It is possible that you may recall events or incidents that cause you to become upset. I will treat you with respect and let you guide the interviews. You can decide which questions to answer, how much information you want to share with me and if you want to pause or stop the interviews. If I see that you are becoming distressed, I will stop the interview and inform your parent or carer.

### ***Do I have to take part?***

No, not at all. This is up to you and you can change your mind at any time. You do not have to give a reason and there will be no consequences. If you do not want to continue in the research project at any time, contact me using the details above. Recordings of your interviews will be destroyed.

### ***Has anyone checked that this study is safe?***

This research has been checked by the Research Ethics Committee at the University of Reading. They have agreed that it is safe to do this study.

### ***What happens if something goes wrong?***

If you are unhappy about the way you've been treated in this study or have any worries about it, you can contact my supervisor, Professor Cathy Tissot, University of Reading; Tel: 0118 378 2674, email: [c.tissot@reading.ac.uk](mailto:c.tissot@reading.ac.uk), who will do her best to answer your questions and deal with any issues.

***What do I do if I want to take part in this study?***

If you would like to take part in this study, please contact me using the details above or ask your parent/carer to contact me. You will be asked to complete a consent form to make sure you fully understand what will happen in the study and that you are happy to take part.

Thank you for taking the time to read about this research project. I hope that you will choose to take part and look forward to hearing from you.

Regina Cobbinah

Doctoral Researcher

## Appendix H. Information Pamphlet for Young Person

### Could anything bad happen if I take part?

During the interviews, you might talk about your personal feelings which can sometimes be difficult. It's fine to stop our conversation or take a break at any time. It's completely up to you how much you want to tell me. If you don't want to answer a question, that is also OK. There are no right or wrong answers.

### Is there any support if I feel upset or worried?

If we talk about anything that makes you feel upset or worried, I will stop the interview and let your parents or carers know. I will also offer you details of organisations which can offer you support.

### Do I have to take part?

No, not at all. It's completely up to you if you want to take part and you can change your mind at any time. Just let me know and you don't need to give a reason. No one will be upset or annoyed with you.

### Has anyone checked that this study is safe and allowed?

My research has been checked by the Research Ethics Committee at the University of Reading. They have agreed that it is safe to do this study.

### I want to take part. What do I do now?

Please contact me for further information about the study.

#### Telephone:

**Online:** <http://tiny.cc/v66ukz>

**Email:** r.t.cobbinah@pgr.reading.ac.uk



As well as asking for your permission, I will also ask for your parent or carer's permission for you to take part.

**Thank you for taking the time to read this. If you have any questions, please do not hesitate to contact me.**

**I look forward to hearing from you!**



### Have you ever been admitted to an adolescent inpatient unit?

**Students needed for a research project**

Hi! My name is Regina Cobbinah and I am doing a research project for my studies at the University of Reading.

### **What is the research about?**

Some young people who are admitted to an adolescent inpatient unit struggle to return to their school or college when they are discharged. I want to understand the challenges they have and how they can be better supported. My aim is to listen sensitively to the experiences of young people who have been in this situation and find out their views about how adults in schools, colleges and hospitals can provide better support.

### **Who can take part?**

I am really interested in talking to you if you are between 12 and 25 years old and were admitted in an adolescent inpatient unit while you were at school or college. If you want to take part but are not sure if you can, please contact me anyway. My contact details are on the back of this leaflet.

### **What will I have to do?**

I will meet with you or telephone you initially to introduce myself and explain my research. I will also get to know you a bit by asking you some questions. You can also ask me any questions that you have. You will then have two interviews with me, each lasting between 30 minutes and an hour. We can chat either face-to-face, over the phone or using Skype text messenger or email. During your first interview, I will ask you about your education experience and what you think about the support you received. In your second interview a few weeks later, I will ask you a few more questions to make sure that I have understood your experience and views correctly. With your permission, I will record all our conversations so that I have an accurate record of everything that you tell me.

### **Will the information I give be shared with anyone else?**

Only myself and my two supervisors at the University will know about your answers. We will not tell anyone what you say to me unless you tell me something that makes me worried for your own or someone else's safety. If that happens, I am required by law to tell a member of the safeguarding team at CAMHS.

### **What will happen to the information I give you?**

Some of the words and information you share may be used in a report for my studies, but your name or the names of your school or college and inpatient unit will never be used or mentioned in anything I write.

### **Why should I take part?**

I hope that you will find it helpful to talk about your experiences with someone who will listen and really wants to understand your views. By sharing your thoughts, you will help other young people who are going through a similar experience.

## Appendix I. Privacy Notice for Young Person

This sheet will help you understand what we do with your personal information.

We have a University Data Protection Officer at the University of Reading who will make sure that we are careful with your information. They can be contacted at [imps@reading.ac.uk](mailto:imps@reading.ac.uk), or in writing to: Information Management & Policy Services, University of Reading, Whiteknights, P O Box 217, Reading, RG6 6AH.

### ***What personal data will I ask you for?***

‘Personal data’ means any information which can identify you. We will only ever collect personal information that is necessary for this research project. The information that we will collect about you for this study will include your name, gender, age, school year, year of hospital admission, the time you spent in hospital, the date you returned to your own school and your psychiatric diagnosis.

### ***What can you ask us to do with your personal information?***

You can ask us to:

- Tell you how your details are being used
- Give you a copy of all the details we have about you
- Correct the details if they are wrong or out of date
- Delete all the details we hold on you (unless we have a good reason not to)
- Stop using your details in a certain way

Some of these rights may not always apply. There are sometimes special rules that mean we need to hold on to certain information. Don’t forget that if you have told us we can use your information in a certain way and you would like us to stop, you can tell us to stop at any time.

You can find out more about your rights on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>.

If you have any questions or are unhappy about something, please contact the University Data Protection Officer using the details above.



## Appendix J. Consent Form for Young Person

**Research Project (Title): The experience of adolescents with severe mental health disorders in hospital and mainstream school following hospitalisation in an inpatient unit**

Please make sure you have read the Information Sheet or pamphlet before filling in this form.

Please read the statements below and put a tick next to each one if you agree with them.

I have read the Information Sheet/pamphlet about the project and received copies of them.	<input type="checkbox"/>
I have had explained to me what information will be collected about me, what it will be used for, who it may be shared with, how it will be kept safe, and my rights in relation to my personal data.	<input type="checkbox"/>
I have had time to think about the information and ask questions. All my questions have been answered.	<input type="checkbox"/>
I confirm that I am choosing to take part in this project and have not been forced to.	<input type="checkbox"/>
I understand that what I say will be recorded so that there is an accurate record.	<input type="checkbox"/>
I understand that I can withdraw from this project at any time without giving a reason and there will be no consequences.	<input type="checkbox"/>
I understand that I can choose not to answer some questions if I don't want to and I can stop the interview at any time.	<input type="checkbox"/>
I understand that the data collected from me in this study will be made available in anonymised form for others to look at or use.	<input type="checkbox"/>

Thank you for completing this form.

Name: \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix K. Information Letter for Parents/Carers

**Researcher:**

Name: Regina Cobbinah  
Email: r.t.cobbinah@pgr.reading.ac.uk

**Supervisor:**

Name: Professor Cathy Tissot  
Email: c.tissot@reading.ac.uk  
Telephone: 0118 378 2674

**August 2019**

**Research Project (Title): The experience of adolescents with severe mental health disorders in hospital and mainstream school following hospitalisation in an inpatient unit**

Dear Parent/Carer,

I am a doctoral researcher at the University of Reading. I am also a qualified teacher with DBS clearance and have experience of working with young people in a school in an inpatient unit as well as mainstream secondary and primary schools. I would like to invite your child to take part in a research study to find out young people's views about attending hospital school and returning to their home school after being in hospital.

***What is the study?***

The aim of this study is to understand the experiences of young people who have been in hospital due to mental health disorders. It hopes to make recommendations regarding how young people can be best supported to successfully reintegrate back to their home school after being in hospital.

***Why has my child been chosen to take part?***

Your child has been invited to take part in this study because he/she is aged between 12 and 25 years and has had experience of returning to school after being hospitalised in an adolescent inpatient unit in the past year. I am interested in finding out their views about this process.

***Does my child have to take part?***

It is entirely up to you and your child whether they participate in this research study. Your child may also withdraw at any time during the study, without any repercussions to them, by contacting me using the details above.

***What will happen if my child takes part?***

I will contact you and your child by telephone to describe the study in more detail, obtain some background information about your child, answer any questions you may have and arrange a first interview with your son or daughter either in person, by phone, text or using Skype, WhatsApp or Zoom. Your child may like to send me a picture of an object, picture, photograph, drawing or piece of writing which reminds them of their hospital

school experience to talk about during this interview. I will also send your child a timeline for them to write down any helpful or unhelpful experiences that we can discuss if they wish. If your child prefers to write down their answers to my questions, we can do this using Skype. At the end of our interview, I will ask your child's permission to arrange a second interview about two weeks after the first, to ask a few follow-up questions about the experiences they shared. The interviews will last between 30 minutes and an hour and I would request that a responsible adult is available - during this time. With your permission, the interviews will be recorded so that I can transcribe and analyse the results.

***What are the risks and benefits of taking part?***

I will ask you to confirm that your child is currently in stable mental health before they take part in the study. There is however a potential risk that your child may recall events or incidents that cause him/her emotional distress. If your child is becoming upset, I will pause the interview to give them time to recover. I will remind your child of their right to choose not to answer certain questions or to fully withdraw participation from the research study at any point. If during the interview, I feel that your child is becoming unduly distressed, I will adjourn the interview, promptly inform you and offer you information about support services that could be of help. If your child discloses information that makes me think they or someone else is at risk of harm, I am required by law to share the information with a member of the safeguarding team at the Berkshire Healthcare NHS Foundation Trust.

I anticipate that the findings of this study will help to improve the support that education and health professionals offer to young people who return to their mainstream schools after being admitted to an inpatient psychiatric unit.

***What will happen to the data?***

Any data collected will be held in strict confidence and no real names will be used in this study or in any subsequent publications. The records of this study will be kept private. No identifiers linking you, your child or their school to the study will be included in any sort of report that might be published. Your child will be assigned a pseudonym and will be referred to by that pseudonym in all records. Research records will be stored securely in a locked filing cabinet and on a password-protected computer and only the researcher, Regina Cobbinah and the Supervisor, Professor Cathy Tissot will have access to the records. In line with the University's policy on the management of research data, anonymised data gathered in this research may be preserved and made publicly available for others to consult and re-use. The results of this study may be presented at conferences, and in written reports and articles. I can send you electronic copies of these publications if you wish. The legal basis for processing your child's personal data are outlined in the attached Privacy Notice.

***Who has reviewed the study?***

This project has been reviewed following the procedures of the University Research Ethics Committee and has been given a favourable ethical opinion for conduct. The University has the appropriate insurances in place. Full details are available on request.

***What happens if I change my mind?***

You or your child can change your mind at any time without any repercussions. If you change your mind after the interviews have been conducted, I will discard all recordings and transcripts made.

***What happens if something goes wrong?***

In the unlikely case of concern or complaint, you can contact my supervisor, Professor Cathy Tissot, University of Reading; Tel: 0118 378 2674, email: c.tissot@reading.ac.uk.

***Where can I get more information?***

I do hope that you will agree to your child's participation in this study. If they would like to take part in this study, please contact me using the details above.

You and your child will be asked to complete separate consent forms to make sure that you both fully understand what will happen in the study and that you are happy for them to take part.

Thank you for taking the time to read about this research project.

Yours faithfully,

Regina Cobbinah

## Appendix L. Privacy Notice for Parents/Carers

The organisation responsible for protection of your child's personal information is the University of Reading (the Data Controller). Queries regarding data protection and your child's rights should be directed to the University Data Protection Officer at [imps@reading.ac.uk](mailto:imps@reading.ac.uk), or in writing to: Information Management & Policy Services, University of Reading, Whiteknights, P O Box 217, Reading, RG6 6AH.

### ***How the University of Reading processes your child's data***

The University of Reading collects, analyses, uses, shares and retains personal data for the purposes of research in the public interest. Under data protection law we are required to inform you that this use of the personal data we may hold about your child is on the lawful basis of being a public task in the public interest and where it is necessary for scientific or historical research purposes. If your child withdraws from the research study which processes his/her personal data, dependant on the stage of withdrawal, we may still rely on this lawful basis to continue using your child's data if his/her withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your child's personal data.

### ***Your child's personal data and its processing***

'Personal data' means any information which can identify your child. We will only ever collect personal information that is appropriate and necessary for the specific research project being conducted. The specific information that we will collect about your child will include their name, gender, age, school year, year of hospital admission, duration in hospital, date of return to home school and his/her psychiatric diagnosis.

### ***You and your child's rights***

You and your child have certain rights under data protection law which are:

- Withdraw your consent, for example if you opted in to be added to a participant register
- Access your child's personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about your child
- Be forgotten, that is your child's details to be removed from systems that we use to process his/her personal data
- Restrict uses of your child's data
- Object to uses of your child's data, for example retention after your child has withdrawn from the study

Some restrictions apply to the above rights where data is collected and used for research purposes.

You can find out more about your rights on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>

You also have a right to complain the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.

## Appendix M. Consent Form for Parents/Carers

**Research Project (Title): The experience of adolescents with severe mental health disorders in hospital and mainstream school following hospitalisation in an inpatient unit**

I have read the Information Sheet about the project and received a copy of it.

I have read the Privacy Notice and received a copy of it.

I have received a copy of this Consent Form.

I understand what the purpose of the project is and what is required of my child and me. All my questions have been answered.

I agree to the arrangements described in the Information Sheet in so far as they relate to my child's participation.

I understand that my child will be interviewed and that the interviews will be recorded and transcribed.

I understand that my child's participation is entirely voluntary and that he/she has the right to withdraw from the project at any time, without giving a reason and without repercussions.

I understand that the data collected from my child in this study will be preserved and made available in anonymised form, so that they can be consulted and re-used by others.

Name of child: \_\_\_\_\_

Please tick as appropriate:

I consent to my child taking part in the research project.

I consent to the interview with my child being recorded.

I confirm that my child is currently in stable mental health.

Signed: \_\_\_\_\_

## **Appendix N. Interview Schedule**

1. Clarification of participation in research, consent and rapport building
  - Thank young person for agreeing to take part in interview.
  - Address any outstanding concerns or questions about the research project from initial meeting and reiterate details from signed consent forms returned by post.
  - Remind young person that there are no right or wrong answers and that they can refuse to answer any question, take a break or stop the interview at any time.

2. Discussion about young person's artefact (if provided)

- Thank young person for sending photograph of artefact.
- Tell me about your object/picture/photograph/art piece/piece of writing.

Possible follow-up questions:

- When did you make/draw/take/write it?
- What made you choose it?

3. Discussion about timeline (if provided) and experiences in hospital

- Are there any experiences you have written down on the timeline that you do not want to talk about?
- Tell me about ... (refer to experiences on timeline)
- Tell me about your experience in hospital/attending hospital school

Possible follow up questions:

- How would you describe what it was like?
- What did you think about it?
- What happened there?
- What do you remember most about being there?
- What did it mean to you to be there?
- How did you feel about it?

- If there was anything you could have changed about your experience in hospital school, what would that have been?
- Is there anything else that you think is important for others to understand about attending hospital school?

3. Discussion about timeline (if provided) and young person's experiences of returning to school

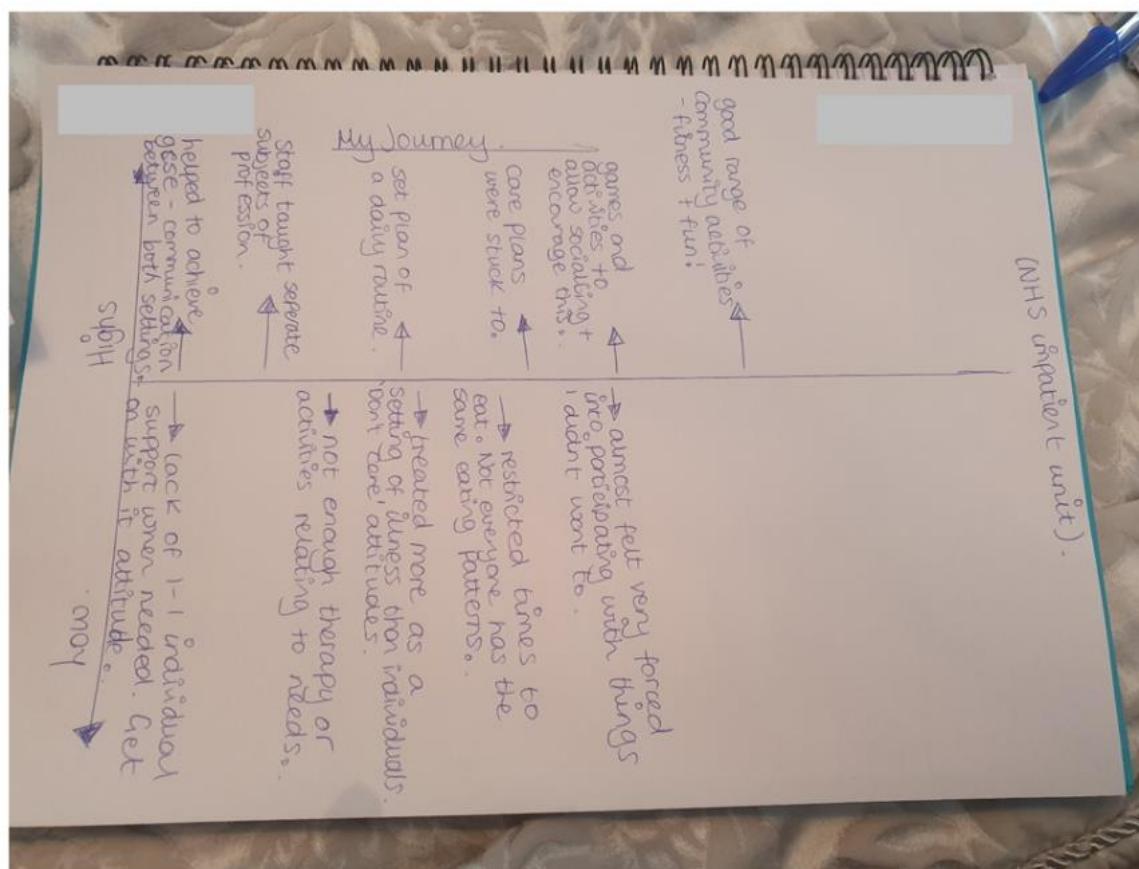
- Are there any experiences you have written down on the timeline that you do not want to talk about?
- Tell me about ... (refer to experiences on timeline)
- Tell me about your experience of returning to your home school

Possible follow up questions:

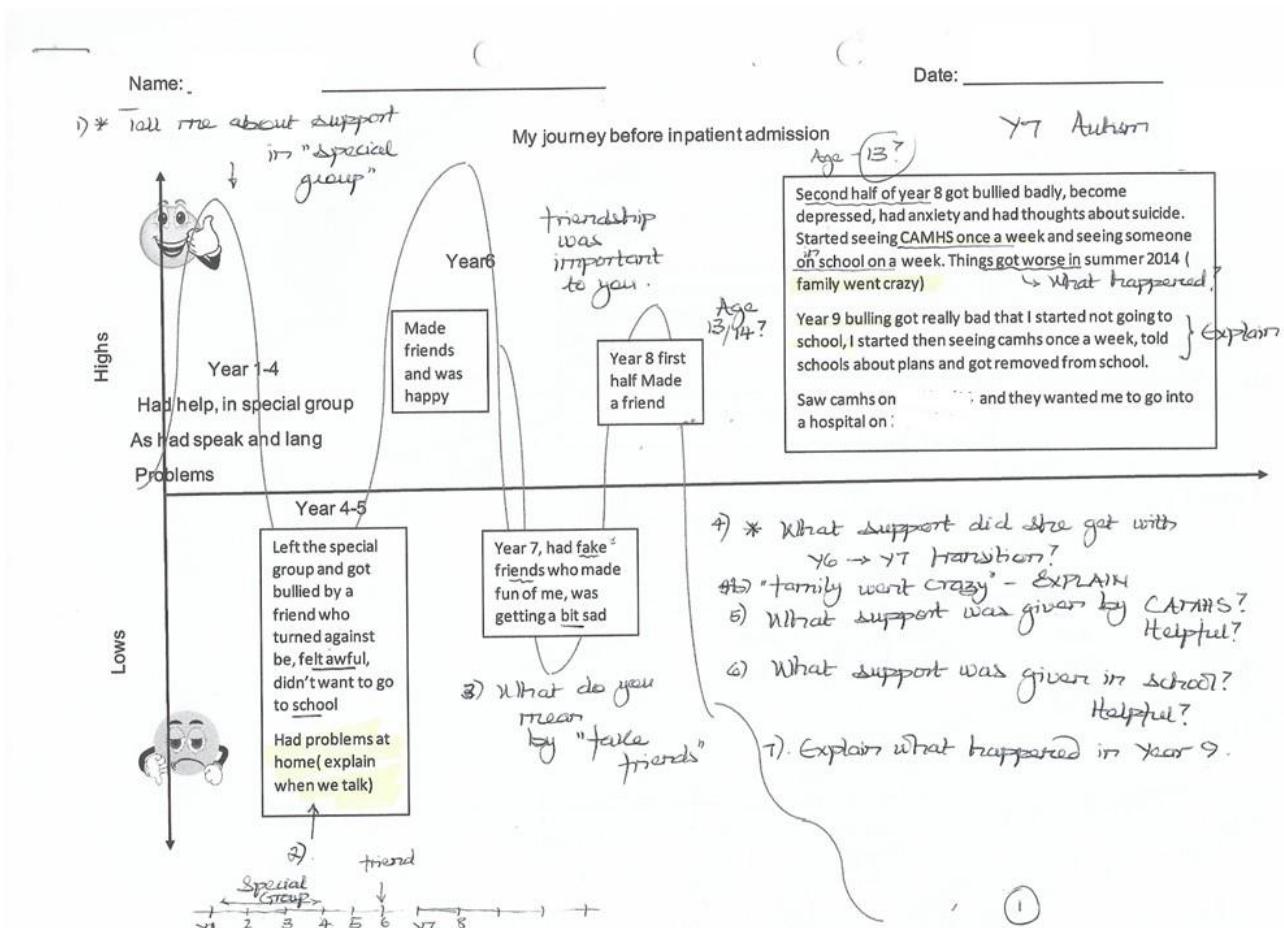
- How would you describe what it was like returning to school?
- What did you think about returning to school?
- What happened when you returned to school?
- What do you remember most about returning to school?
- What did it mean to you to be back at school?
- How did you feel about returning to school?
- If there was anything you could have changed about your experience of returning to school, what would that have been?
- How are things now?

## Appendix O. Examples of Participant Experience Timelines

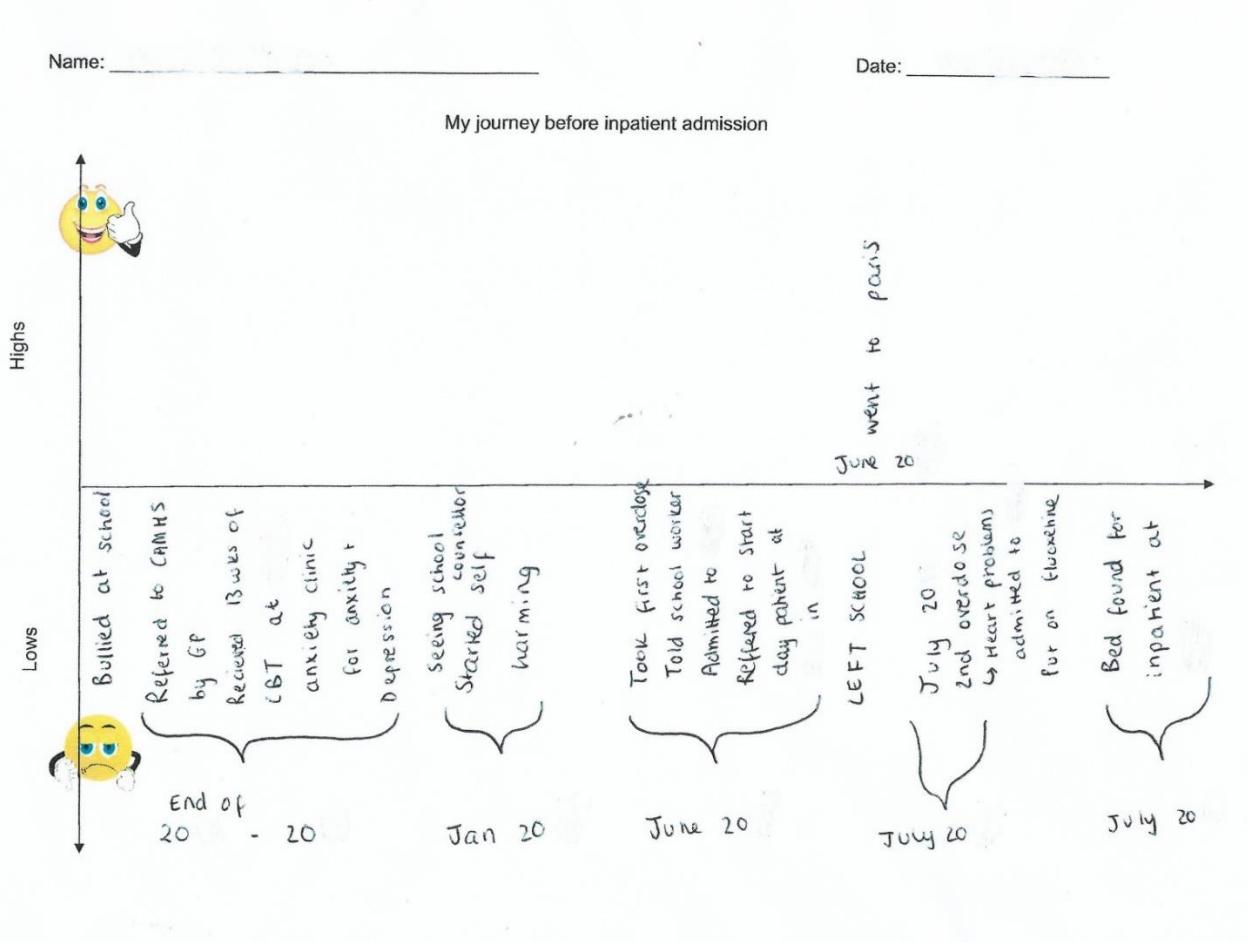
Example 1: Abigail's Timeline 2



### Example 2: Josie's Timeline 1



Example 3: Amelia's Timeline 1



## Appendix P. Example of Transcript

### Sections of Josie's interview transcript

good ... and then ... Year 7 (P: Yeah ...) ... Year ... Year 7. What ... what made it a happy time? Was it just ... ? 11:42

**Commented [RC1]: Friendships – Made friends in Year 6 and was happy**

P: (Inaudible speech) ... the thing I didn't put on there is that I made friends but later on they ... turned out to be like ... not very nice people. They were kind of using me but I was very umm ... naive at the time so they ... they weren't real friends ...

I: Okay. So is that why you said umm ... you called them "fake friends" I think you put on your sheet? Umm ... you said that they ...

P: No, the Year 7 is completely different. I went to a different ... (inaudible – school?)

I: Okay, okay. So even though you felt that you'd made friends in Year 6, umm ... you felt that they were using you ... and they were not really good friends. 12:25

**Commented [RC2]: Friendships – Friends in Year 6 turned out not to be very nice people, were using her; there were not "real friends". She was naive at the time**

P: (Pause) I mean ... they did use me ... they umm ... they used to ... right ... they weren't very nice to my family, they used to like ... take my money and take my things and like they used to ... uh... run away from me ... didn't particularly ... they just liked the things that I had ... umm ... cos the school that I went to was in like in a council estate ... and I don't live in that council estate. I live in ... (inaudible speech)

I: Okay, okay. Umm ... that's ... that's great, Josie. So umm ... the transition from Year 6 to 7 ... umm ... I noticed that also was a bad experience for you. So I just wanted to find out. Did you have any support when you moved from primary to secondary school? Was there any transition support for you?

P: No ...

**Commented [RC4]: Friendships – Friends in Year 6 were not nice to her family; took her money and her things; school was in a council estate**

I: Nothing, nothing, even though you'd had quite a lot of support in Years 1 to 4 ...

P: Yeah ... no ... I had nothing ...

I: Okay, okay. So you were ... so you went into Year 7 and then umm ... (pause) and then you ... you mentioned that second half of Year 8; how ... how old were you, Josie?

P: Umm ... second half of Year 8 ... so like ... 12, 13 ... ?

I: ... 12, 13 ... that's what I thought, okay. So you ... you ... you got bullied really badly. Umm ... and then you ... you ... you went ... you became depressed, anxiety and suicidal. So you started seeing CAMHS at that time, did you?

**Commented [RC5]: Education (support) – no primary to secondary school transition support**

P: Yeah ... (I: Okay) yeah ...

I: What ... what kind of support was CAMHS giving you?

P: (Long pause) ... umm ... just umm ... therapy ... and then ... umm ...

I: What kind of therapy?

P: (Long pause) ... I don't know ... just therapy ...

I: Okay, okay. (Pause) So you had that once a week?

**Commented [RC6]: Education (support) – no support despite having support from Years 1 to 4 due to speech and language problems**

**Commented [RC7]: Difficulties – Bullied really badly; became depressed; had anxiety and thoughts of suicide (TL)**

I: Umm ... yeah ... so ... you've put that you went into hospital ... actually before we go to hospital two ... umm ... what ... what ... how ... what ... did you feel about the help you got from the others who weren't in education ... the other staff? 29:23

P: Oh ... they were horrible (said with emphasis) ...

Commented [RC8]: Healthcare – staff were “horrible”

I: Oh ... in what way ... in what way?

P: (Pause) ... so the staff ... [there was two wards that I was in]. The first ward the staff was very understanding, they were really good. Umm ... [the staff ... when I moved upstairs to the other ward the staff were horrible ... They would like ... umm ... I started getting like episodes and they used to tell me I was making it up and like ... that I was just doing it for attention like ... and like ... umm ... banned my mum from seeing me for a little while which was just ... st... stupid ... they didn't listen ... they were just so ... they had their own opinions ... they wouldn't listen to you ... and the doctor ... there was ... he was very much (inaudible) ... he would come (inaudible) and he would just ... mess my medicine around constantly he would ... I would be on like 700 mg of one med and then he would put it down to like zero and he would like change it constantly ... he was just ... awful ...]

Commented [RC9]: Healthcare – different experiences in two wards she was in

Commented [RC10]: Healthcare – staff in 1st ward (downstairs) were understanding and really good

I: Okay. So ... umm ... [why were you changed between different floors within the same hospital?]

P: Umm ... cos they thought I was a lower risk to myself ... (I: Okay ...) ... so that hospital ... umm ... the ... [the lower secure ward had like ... TVs and stuff in there so ... it was more like a ... a patient group before you get discharged ... but like I was (huge chunk of inaudible speech) ... but I just got worse up there. ~30:00

Commented [RC11]: Healthcare – staff in 2<sup>nd</sup> ward (upstairs) were “horrible”  
Viewed her episodes as made up and attention-seeking  
Mum unable to visit  
Staff had own opinions  
Staff wouldn't listen to her  
Doctor constantly changed medication

Commented [RC12]: Healthcare – treatment on different floors was based on risk

Commented [RC13]: Downstairs ward was a lower secure ward

I: Okay. Umm ... Josie, you keep on breaking a lot. Do you mind if we try just audio to see whether it will be clearer?

P: Pardon? Yeah ... that's fine ...

I: Okay, let's ... let's just see whether audio on its own will be clearer because you keep breaking up a lot.

P: All right ...

I: Okay, all right. So, umm ... Josie ... the ... [the ... the second ... when you got moved, that experience wasn't nice at all from what you ... you've explained.

P: Yeah. |

Commented [RC14]: Healthcare – Experience in 2<sup>nd</sup> hospital

I: Okay ... and then was it from then that ... [so were you discharged after the 8 months?]

P: Umm ... so ... umm ... so they wanted to discharge me umm ... but my CAMHS team said I wasn't ready so ... they umm ... so they found me like another place where I could ... kind of get the help ... so ... I got moved to a different place ...

Commented [RC15]: Healthcare – Decision to discharge from hospital to a different place

I: Okay. So was the first umm ... was the first place an NHS or a private

## Appendix Q. Examples of codes used in Thematic Analysis

	Abigail	Josie	Violet	Amelia	Helena	Irene	Imogen	Lucy
Having a voice	✓	✓	✓	✓	✓	✓	✓	✓
Participating in decision-making	✓	✓	✓	✓	✓	✓	✓	✓
Having choice	✓	✓	✓	✓	✓	✓	✓	✓
Being in control	✓				✓	✓		✓
Self-determination/motivation	✓			✓	✓	✓	✓	✓
Addressing individual needs	✓	✓	✓	✓	✓	✓	✓	✓
Being treated with care/understanding	✓	✓	✓	✓	✓	✓	✓	✓
Relationship with professionals								
Being treated with respect	✓	✓	✓	✓	✓	✓	✓	✓
Anxiety about hospital admission		✓	✓	✓	✓	✓		✓
Anxiety about hospital discharge		✓	✓	✓	✓			
Concern about education	✓	✓	✓	✓	✓	✓	✓	✓
Desire to continue education	✓	✓	✓	✓	✓	✓	✓	
Collaboration between professionals	✓	✓	✓	✓	✓		✓	
School reintegration support		✓	✓	✓	✓	✓	✓	✓
Relationship with school peers		✓	✓	✓	✓		✓	
Perception of peers				✓	✓			✓
Bullying at school			✓	✓	✓			
Relationship with other patients	✓		✓		✓	✓	✓	✓
Routine in hospital	✓	✓	✓	✓	✓	✓	✓	✓
Family challenges		✓	✓					
Personal trauma	✓		✓					

## Appendix R. Examples of phases of Thematic Analysis

### Example 1: Manual coding of Imogen's Timeline 3

Name: \_\_\_\_\_ Date: \_\_\_\_\_

lost touch with friends in school → isolation

- couldn't keep in touch with friends from school because no internet and phones allowed. I find it hard to make new friends and it takes me a long time so didn't form friendships on unit so became isolated. I eventually made some friends but not the same strength as the others had between each other and didn't keep in touch after I left

→ isolation

- no plan for education before discharge → lack of discharge planning → isolation

My journey after discharge

after I moved schools I caught up educationally by going through textbooks myself. Although didn't receive extra help, they did trust me more and let me return full time

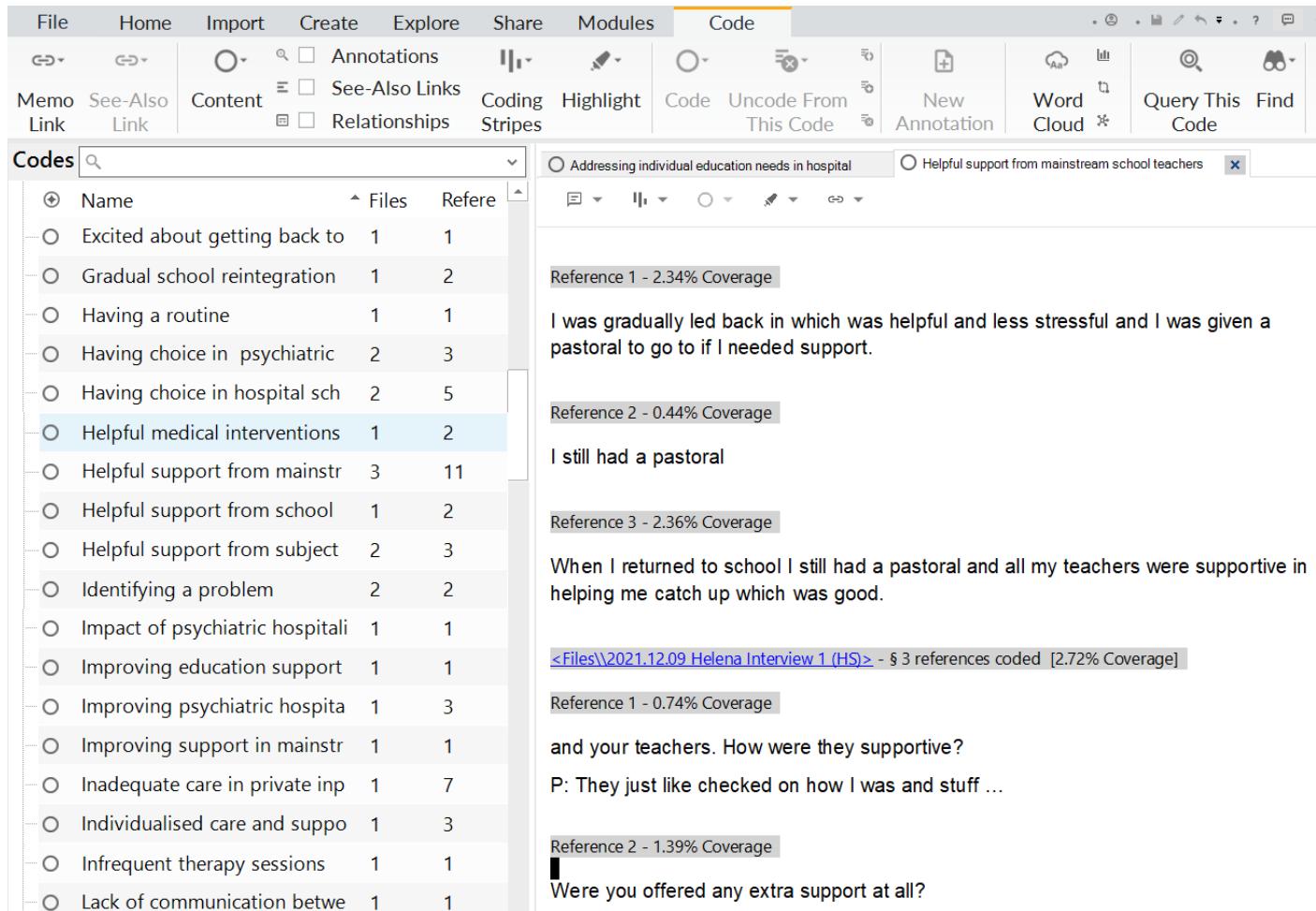
Positive relationship w/ 2nd school. (mutual facilitated sense of self-worth & self-determination) → self-motivation/ self-determination

My school treated me differently. They didn't want me back. They said that if I self harmed in front of other students (I had not done anything like that before) it would be a health and safety concern for other student so I was excluded from cooking and design and technology and textiles lessons. I had no help catching up on what I had missed out on so I was behind and confused which made me more unmotivated. I wasn't allowed to go back full time. I fell out with my group of friends. Due to all this didn't really feel I wanted to go back and only had 25% attendance → poor school attendance

Lack of trust → negative relationship → hindered self-motivation

(3)

## Example 2: Coding in NVivo



File Home Import Create Explore Share Modules **Code**

Annotations See-Also Links Relationships Coding Stripes

Memo See-Also Content

New Annotation Word Cloud

Query This Find Code

**Codes**

Name	Files	References
Excited about getting back to	1	1
Gradual school reintegration	1	2
Having a routine	1	1
Having choice in psychiatric	2	3
Having choice in hospital sch	2	5
<b>Helpful medical interventions</b>	1	2
Helpful support from mainstr	3	11
Helpful support from school	1	2
Helpful support from subject	2	3
Identifying a problem	2	2
Impact of psychiatric hospitali	1	1
Improving education support	1	1
Improving psychiatric hospita	1	3
Improving support in mainstr	1	1
Inadequate care in private inp	1	7
Individualised care and suppo	1	3
Infrequent therapy sessions	1	1
Lack of communication betwe	1	1

Addressing individual education needs in hospital

Helpful support from mainstream school teachers

Reference 1 - 2.34% Coverage

I was gradually led back in which was helpful and less stressful and I was given a pastoral to go to if I needed support.

Reference 2 - 0.44% Coverage

I still had a pastoral

Reference 3 - 2.36% Coverage

When I returned to school I still had a pastoral and all my teachers were supportive in helping me catch up which was good.

<Files>\2021.12.09 Helena Interview 1 (HS) - § 3 references coded [2.72% Coverage]

Reference 1 - 0.74% Coverage

and your teachers. How were they supportive?

P: They just like checked on how I was and stuff ...

Reference 2 - 1.39% Coverage

Were you offered any extra support at all?

### Example 3: Manual coding of sections of Helena's email interview transcript

*from* hospital it ended badly. When I was discharged I had regular CAMHS appointments and I started therapy which was kind of helpful.

I: How did you feel about returning to school? How were you supported to return to school part-time? What other support did you receive? How helpful was this support?

P: When I first went back to school part-time it was very nerve racking because I hadn't been there for months and everyone knew I had been in hospital so it felt like all eyes were on me. I was gradually led back in which was helpful and less stressful and I was given a pastoral to go to if I needed support.

I: How did you feel about returning to school full-time after the summer holidays? How were you supported to return to school full-time? What other support did you receive? How helpful was this support?

P: When I returned to school full time I was kind of nervous but more at ease because I had been in before the summer. I was also quite excited to get back to normal and start my GCSE's. I still had a pastoral and I started at the same place as others as we were all starting GCSE's so I wasn't as far behind.

I: What led to this 2<sup>nd</sup> inpatient admission? How did you feel about being admitted again? What support did you receive? How was this support different from your 1<sup>st</sup> admission?

P: I was still struggling a lot mentally at this time which led to me losing weight again, being taken out of school and admitted to hospital. This time was worse than the first time because I wasn't expecting to be admitted again and wasn't as physically unwell so didn't see the point of it as much. I was very unhappy most of the time and the staff were less supportive and understanding so it was a lot harder. I was given music therapy which wasn't helpful at all so I stopped and wasn't given any other therapy.

I: How did you feel about being discharged for a 2<sup>nd</sup> time? How were you supported once you were discharged? How helpful was this support?

P: I felt more prepared to be discharged this time because I knew I didn't want to go back to hospital so I was more determined. I still had regular CAMHS appointments but I didn't receive therapy because it didn't help the first time.

I: How were you supported when you returned to school? How helpful was this support?

P: When I returned to school I still had a pastoral and all my teachers were supportive in helping me catch up which was good.

*Understanding caring profs.*

*more effective community CAMHS support*

*Perception of stress re the nervous about return to school*

*Understanding caring profs.*

*full-time return to school*

*Nervous re education*

*Having a say in hospital decision/into sharing?*

*Unexpected 2<sup>nd</sup> admission*

*Understanding caring profs?*

*Determined by stay out of hospital*

*Support from teachers & pastoral support.*

P: Yeah, yeah ... everything she did and the support that she gave me was useful and enough but ... my ... unfortunately my mental health just continued to deteriorate even though she was ... do you know what I mean? ... She was helping so...

Understanding  
Caring  
proj

I: Okay. Okay. So really you ... you would you say that you were not coping at all with your schoolwork by then?

P: Umm ... by then ... I was barely in lessons. I was ... my work was going from B's to Ds in ... it ... it was just literally ... everything was just too much ... umm ... school was just ... diabolical for me ... found it very difficult to cope with my mental health and plus go to school and carry on as normal ... (I: Okay ...). Umm ... (I: Okay ...) so ... yeah, it became very, very difficult ...

Dealing w/  
academic & life  
difficulty  
in coping

I: ... very difficult ... yeah. You use the word diabolical. In what ways was it diabolical apart from the ... the work? Was there anything else that was making it quite umm ... difficult for you?

P: (Pause) The thing is ... the only person that I had to ... that even comfort ... was Mrs ... umm ... because there was no other support in place ... There was no one else there to support me. So actually, I didn't have that support network round there that really a school needs.

Understanding  
Caring  
proj  
Lack of support  
network in school

I: Okay ... Well, what ... what would it ... what do you think would have helped in terms of support?

P: (Pause) I'm not 100% sure. I ... I just ... I don't know. Umm ... actually, you know, the way that things were communicated between teachers I don't think was ... from ... from an outsider looking in ... I don't think was at all helpful, you know, maybe they could have done a bit more to actually support me. Give me longer deadlines ... like ... little things like that?

Understanding  
Caring  
proj  
Lack of  
support in  
school

I: Okay. (P: Umm ...) So giving you deadlines for your work, for example

P: Yeah (I: Okay ...) Yeah, so I think things like that would have been a lot more helpful than ... you know ... what I got there ... does that actually make sense?

Understanding  
Caring  
proj

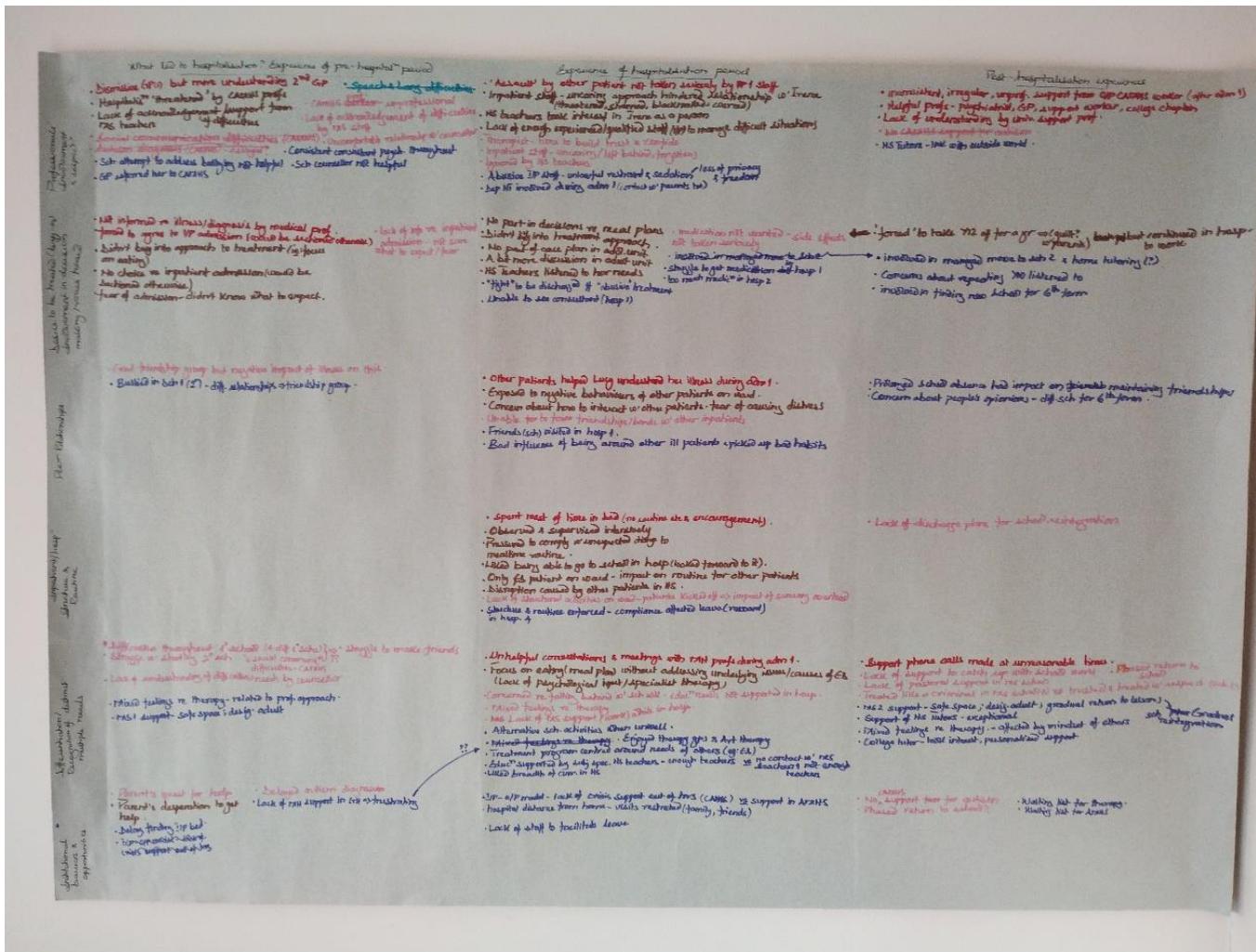
I: Yeah ... so I get the feeling that some teachers did not know about what we ... what you were going through, so they expected you to be carrying on as usual.

P: Yeah ... I think ... I think ... some ... some did ... you know ... I think they must have had some sort of conversation about ... you know ... my ... the way I am ... I had one or two teachers that were really good ... you know ... were like look, "Do you need any extra help?" (inaudible) there were other teachers who were just like "Get on ... deal with it ... get on and deal with it".

Understanding  
Caring  
proj  
Mixed  
support from  
teachers

I: Okay ... and that added to your already deteriorated mental state. Yeah. Okay. So, umm, so we're leading up really to the point at which

#### Example 4: Process of identifying themes



## **Appendix S. COVID-19 Impact Statement**

**Thesis Title:** Journeys into and out of psychiatric hospitals: Supporting the recovery of young people with severe mental health disorders in health and education settings

The activities which were disrupted due to the impact of COVID-19 were as follows:

### ***Participant Recruitment***

Recruiting participants for this study was a challenging process. Although attempts to recruit participants through schools, colleges, mental health charities and physical and online advertising started before the onset of the COVID-19 pandemic, planned face-to-face meetings with potential gatekeepers and participants were cancelled due to imposed restrictions on social contact. The researcher was able to meet two young people in person (prior to COVID-19 restrictions) which was beneficial in order to develop trust with these vulnerable young people. However, the process of recruiting participants for this study was impacted by COVID-19. The original plan was to recruit twelve participants and five were recruited prior to the pandemic. A further three were recruited after the pandemic, in spite of concerted recruitment efforts.

### ***Data Collection***

It was planned to contact each participant and their parent or carer (where applicable) for a short introductory meeting and arrange a first face-to-face interview. This would then be followed by a second interview. However, the impact of COVID-19 was that most of the interviews were conducted using voice/video calls on WhatsApp or Skype or via video conferencing using Microsoft Teams. However, this mode of data collection was reliant on the quality of the internet connection between the researcher and the participant, which was poor on some occasions. This resulted in communication difficulties during interviews.

The pandemic also had an impact on the opportunity to collect further data in subsequent interviews with each participant. The second interviews planned for each participant were not conducted in consideration of the young people's wellbeing at a

difficult time during the pandemic. Nonetheless, the researcher was able to collect data that was rich and sufficient to answer this study's research questions. However, the limitations posed by COVID-19 restricted the researcher's ability to observe the nuances of in-person interactions that face-to-face interviews could provide in order to enrich the data collected.



