The school experiences of young people with a chronic health condition:

An interpretative phenomenological analysis

By: **Sarah Lakeman**

Supervised By: Dr Lorraine Campbell

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The University of Sheffield School of Education

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Abstract

It has been proposed that anywhere up to 28 per cent of young people in England have some form of chronic health condition (CHC) (National Health Service, 2019; Wijlaars et al., 2016) with most expected to attend a mainstream educational setting (Peters, Hopkins & Barnett, 2016). There is a wealth of research that identifies the "many, complex and varied" challenges that young people with a CHC face, including the potential impact on their education (Jackson, 2013). Yet there is little research that provides these young people with the opportunity to share their experiences of attending school.

Adopting a critical realist positionality, I aim to explore the lived experiences of secondary-aged young people with a CHC who attend a mainstream secondary school. The secondary aim is to understand what professionals working with these young people could learn from hearing these experiences. Five young people with a CHC between the ages of 13 and 16 were recruited to take part in the research. Participants were given the option of completing a creative task before engaging in an online semi-structured interview. The interviews were then analysed using interpretative phenomenological analysis (IPA). Five superordinate themes were identified in the analysis: autonomy, relationships & belonging, navigating the school day, the impact of a CHC on emotional well-being at school and planning for the future.

Additionally, I employed a secondary process where the superordinate themes were related to self-determination theory (SDT) and basic psychological needs theory (BPNT), (Ryan & Deci, 2017). A reflective framework, based around the key tenets of SDT, BPNT and ecological systems theory (Bronfenbrenner & Morris, 2006) was developed. This reflective SDT framework was used to consider and reflect the participants' experiences in relation to the satisfaction or frustration of the three basic psychological needs: autonomy, relatedness and competence. Possible implications of the study, specifically relating to the potential use of the reflective SDT framework, are then discussed and potential future research and recommendations for professionals working in schools with young people with a CHC are also explored.

Acknowledgements

This thesis is dedicated to the five participants; Amber, Autumn, JJ, Samuel, Willow and the pilot participant who took part in the study. I remain forever grateful for their patience, time, openess, courage and honesty. I also thank their parents and teachers who took the time to respond to emails, fill out forms and organise calls, especially whilst dealing with bigger things (like a pandemic!).

To the young people I have worked with in the past and family members who have a chronic health condition, I thank you also. You are the inspiration for this thesis and the drive behind trying to make things, even just a litle bit, better for you.

I am also extremely grateful for the support provided by my supervisor, Dr Lorraine Campbell, and my tutor, Dr Tony Williams, who have patiently provided guidance, advice and reassurance throughout the research process.

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Finally, a very big thank you to my husband Tom, and daughter Alex, who have put up with missed family activities, picked up the slack when needed and provided infinite encouragement, unwavering faith and endless optimism that it was all going to be alright!

Abbreviations

BPNT	Basic Psychological Needs Theory
CHC	Chronic Health Condition
DfE	Department for Education
DoH	Department of Health
EHCP	Education, Health and Care Plan
EP	Educational Psychologist
IPA	Interpretative Phenomenological Analysis
IHP	Individual Health Care Plan
LA	Local Authority
SEND	Special Educational Needs and Disabilities
SENCO	Special Educational Needs Coordinator
SDT	Self Determination Theory
TA	Teaching Assistant
TEP	Trainee Educational Psychologist
UK	United Kingdom
WHO	World Health Organisation

Contents

Chapter 1: Introduction

1.1 Overview

In this thesis I aim to explore the school experiences of young people who have a chronic health condition. It has been organised as follows:

- a critical review of the literature (Chapter 2);
- rationale for chosen methodology (Chapter 3);
- description of the procedures relating to the collection of data (Chapter 4);
- the findings of the interpretative phenomenological analysis (IPA) (Chapter 5);
- a discussion and interpretation of the results in relation to the research questions, literature and psychological theory (Chapter 6);
- conclusions, limitations and recommendations for practice and future research (Chapter 7).

1.2 Research Interest

My interest in this field of research is twofold. Firstly, it is related to my professional experiences while working in schools and secondly, it is linked to my personal relationships with family members who have attended school with a chronic health condition (CHC) or are just about to embark on this journey.

While working as a head of inclusion in schools, managing the medical needs of pupils always fell under my remit. It was a job that was never in the job description; I received no training and it felt secondary to everything else. There was a sense that these pupils were not a priority and not deemed as important as other pupils with additional needs, who we relentlessly tracked, monitored, and intervened with. There was never a consideration of the impact beyond the medical.

Over the years, it became glaringly obvious to me that there were broader, unspoken difficulties affecting this cohort of young people in relation to their education and wellbeing, and that their needs beyond the 'medical' were not being met. This

spurred me to look for additional information, support, and training, but I found it lacking, particularly in relation to the psychosocial impact I was seeing in the pupils I worked with. I began to talk to family members who had lived through school with a CHC, and they spoke of the frustrations, anxieties and challenges they had experienced and still remember vividly today. There are also younger members in my family with CHCs who are yet to start their school journey, for whom it feels with further insight there is an opportunity to consider what could be done differently.

As a trainee educational psychologist (TEP), I noted that we received no direct input on the training course in relation to this cohort of pupils and yet on placement I frequently worked with individuals who had varying health needs. As a TEP, I found the resources, training and support available in this field lacking.

Due to my professional and personal experiences, I am interested in exploring the viewpoints of young people with a CHC regarding their experiences of school. I also hope that by doing this there may be potential implications for the practice of professionals that work with young people with CHCs in schools.

1.3 Defining Chronic Health Conditions

1.3.1 Terminology

To explore this area further there must be some clarification of the terminology being used. Currently, there are a range of terms being used interchangeably to describe health conditions, including 'illness', 'medical condition', 'disease', 'disability' and 'special health care needs' (Mokkink, Van Der Lee & Grootenhuis, 2008; Van der Lee et al., 2007). Davis and Brosco (2007) suggest that children with CHCs do not all require 'special care', and as such argue that this term should not be used. The terms illness and disease are predominantly rooted in the medical model, indicating a focus on the physical or biological aspects of the condition and not the psychosocial elements. Defining in terms of illness can also be challenging "because illness implies a particular temporal relation – you get sick, you get well" (Berland, 2009, p.700). The term 'illness', therefore, fails to encompass the persistent and

long-term nature of these health needs. As such, the term 'chronic health condition' (CHC) will be used as this appears to be the most fitting for this study.

1.3.2 Categorical and Non-Categorical Definitions

There are two broad realist, medical approaches when considering defining CHCs, categorical and non-categorical. The categorical approach to defining a CHC is problematic on many levels because it relies on a diagnosis-specific model (Perrin et al, 1993). Pragmatically it is difficult due to the sheer number of health conditions that it encompasses. One study suggests that there are at least 285 different conditions which could be considered as a CHC, many of which are extremely rare (Mokkink et al., 2008). Further, the categorical approach does not account for the severity of the health condition, nor does it consider co-morbidity (Neff et al., 2002). Therefore, it tells little about the circumstances (severity, duration or medical care requirements) of the individual's unique presentation of their health condition.

Conversely, the non-categorical approach is a holistic model which highlights the common life experiences and functional impact of the CHC on the individual irrespective of their specific diagnostic label (Davis & Brosco, 2007; Van der Lee et al., 2007). There are various non-categorical definitions of CHC, but they all tend to consist of a combination of inclusion criteria which are related to the duration, origin, functional limitations and health care requirements of the condition (Mokkink et al., 2008). Although each condition can be considered to have a "biomedical uniqueness" (Wallander & Varni, 1998, p.29), there are also considerable commonalities in the impact and consequences for the individual. As this study looks to explore the impact of CHCs on the educational experiences of young people, irrespective of diagnosis, a non-categorical approach to defining CHCs has been adopted.

1.3.3 Alternative approaches to defining Chronic Health Conditions

In contrast to the medicalised and realist approaches to defining CHC, which are rife in the literature associated with the topic area, social constructionism offers a differing view, which encompasses the social, cultural, and historical aspects of

medical phenomena and suggests that "people enact their illness and endow it with meaning" (Conrad & Barker, 2010, p. 71). Through a social constructionist lens, there is a distinction between the concepts of 'disease', "the biological condition" and 'illnesses, "the social meaning of the condition" (Conrad & Barker, 2010, p. 67). From this perspective 'illness' moves away from the concept of disease, that is the objective reality of "abnormalities or disturbances of structural forms, regulation, and functional ends" (Bolton & Gillett, 2019, p112) and towards the individual's subjective perception of their experience of a medical condition, which is socially and culturally constructed. Social constructionists critique realist approaches to defining disease as reductionist and suggest that they fail to reflect and encompass the broader and complex experiential, social and cultural aspects of 'illness', which are distinct from the biomedical disease (Friedson, 1970).

This is an important consideration when attempting define CHCs, particularly when undertaking research which aims to understand the subjective experience of individuals. Using a purely medical approach to defining CHC becomes problematic, as definitions rooted in ideas of 'disease' do not encompass the very aspects of the phenomena that the research aims to explore, such as they ways in individuals "understand their illness, forge their identity, and live with and in spite of their illness" (Conrad & Barker, 2010, p. 76). However, there are also difficulties with adopting a social constructionist position, as concerns arise as to how possible it is be able to define and create homogenous groups with clear inclusion and exclusion criteria, given that 'illness' is constructed through a complex interplay between the individual and the social, cultural and temporal context they are in. Defining concepts and clarifying sample groups is a critical consideration when carrying out research, therefore the question becomes how to we research as phenomena if there is no clear definition of it?

This tension between requiring a definition and acknowledging the complexities of defining CHCs has arisen within this research. In an attempt to create a clearly homogenous group, there has been a drive to understand what a CHC 'is' by acknowledging the biological underpinnings of disease, whilst also reflecting on the broader aspects of illness that are socially and culturally constructed. One approach, which appears to provide balance between these opposing views, suggests that

there is a mid-ground in understanding what CHC is and how or if it can be defined. The biopsychosocial model (BPS) claims to provide "strong utility for those health researchers who wish to steer an illuminated course between naive realism on one side, and forms of radical social constructivism or of phenomenology, on the other" (Pilgrim, 2015, p.165). Aligned with critical realism, the BPS model attempts to field the "concerns of critical realists to respect both causes and meanings" (Pilgrim, 2015, p.167). The BPS model considers chronic illness to be a "complex range of and interaction between biological, social, moral and policy factors", whilst also acknowledging the potential 'realities' reflected in medical models (Bolton & Gillett, 2019, p.144). This approach includes the broader social and cultural contexts missing from the medicalised definitions but also provides a pragmatic approach to considering aspects of disease and illness which may be helpful in creating a meaningful definition through which a homogenous group of participants could be identified.

On this basis a BPS approach has been taken in defining CHC, by incorporating biological, social, and psychological aspects from key definitions. It is recognised however, that this is a pragmatic answer to a complex question. As such the following key aspects have been taken to define CHC. Firstly, Barraclough and Machek's (2010, p.132) definition which suggests that a CHC is a "medical condition, lasting for more than 3 months, which requires medical attention and interferes with a person's daily living". Theis (1999) provides a more detailed explanation of the potential impact of CHCs suggesting that alongside limitations in daily routines there may also be a reliance on medication, diets or assistive devices. Stanton, Revenson & Tennen, 2007 explore the ongoing nature of CHCs suggesting that they "do not resolve spontaneously and are rarely cured completely" (p.565). CHCs are therefore understood to be long-term, persistent and to have functional impact on the individual's life, incorporating the BPS model.

1.4 Prevalence of Chronic Health Conditions

The World Health Organisation (WHO) describes CHCs as "one of the greatest challenges facing health care systems throughout the world" (WHO, 2002, p.1). In 2012 it was estimated that approximately 15 million people in England had a CHC

with around 70 per cent of the health and social care budget per annum being spent on managing these needs (Department of Health, 2012). Research predicts that these figures are likely to significantly increase over the upcoming decades (WHO, 2014; Department of Health, 2010 and Department of Health, 2012).

It has been estimated there are 1.7 million young people in the United Kingdom with at least one CHC, with these figures increasing year on year (National Health Service, 2019). Medical advances ensure higher survival rates and greater life expectancy but do not typically offer a 'cure'. Therefore, it could be considered that for some young people mortality previously associated with their CHC has now been replaced with a "lifelong morbidity" (Mokkink et al., 2008, p.1442).

The percentage of the school-aged population with a CHC has been estimated at between 6 and 28 per cent (Shaw et al., 2010; Theis, 1999; Vitulano, 2003; Wiljars et al., 2016). As the figures indicate numbers of young people with CHCs are increasing, it stands to reason that so too are the numbers of young people who are managing a CHC in school (Peters, Hopkins & Barnett, 2016; Shaw & McCabe, 2008). Given the significant number of young people with CHCs in schools, it seems important to attempt to understand the possible impact that having a CHC may have on accessing education.

1.5 The COVID-19 Context

This research was carried out during the COVID-19 pandemic. In January 2020, the first cases of COVID-19 were identified in the UK and by 23 March 2020 a nationwide lockdown was announced requiring the closure of schools to all pupils and the shielding of 'extremely vulnerable' people, including those with certain CHCs.

At the time of writing this thesis in March 2021, the UK is starting on a roadmap out of its third lockdown since the start of the pandemic. This research has been impacted at various points including changes required to the initial proposal and ethical application, the cancellation of all face-to-face activities, difficulties with participant recruitment and the personal trials of completing research at home whilst

home schooling my child. There were also a range of concerns raised by a move to working online. Although significant advances have been made over the past year by the education community, particularly in respect of using technology creatively to work online with young people, at the start of the pandemic practice in this field was extremely limited. As a result, there was a need to rapidly identify appropriate technology that could be used and a need to consider the ethical and pragmatic challenges of working in this way. This all had significant consequences for the research and required me to adopt a flexible and reflexive approach to respond to new challenges as they arose.

1.6 Reflection Boxes

A reflective and reflexive approach is understood to be a "critical self-exploration of one's own interpretations of empirical material" (Alvesson and Skoldberg, 2000, p. 6) and is considered "a vital component" in qualitative research (Shaw, 2010, p.239). Clearly identified reflexive practice can enhance research as it provides space to explicitly name, explore and examine the researchers' thoughts, feelings, views, and values relating to the research process so that they can then "work actively with them in a research encounter" (Shaw, 2010, p.238).

I have used multiple tools to support me to embed a reflexive approach throughout the research. This has included engaging in regular formal supervision with my university tutor, research tutor and fieldwork supervisor alongside more informal peer supervision with colleagues and fellow TEPs. The use of a research diary throughout the research process from the planning stages through to the writing process is also recommended, as it is felt to increase the trustworthiness of the research (Cassell, 2005) and provide explicit opportunities to explore the "role and impact of the researcher" (Nadin & Cassell, 2006, p.209). This research diary allows the researcher to provide "rationale statements to indicate motivations for decisions in research design and inserting discussions of context – from the perspective of both the researcher and researched" (Shaw, 2010, p.242).

Extracts from my research diary that have been deemed as particularly illuminative and useful have been included in the thesis using reflection boxes. These are

spaced throughout the text to give the reader insight into specific issues raised throughout the research process.

Reflection Box: COVID-19 and Shielding

A major consideration regarding COVID-19 was the possible 'shielding' status of the young people I wished to work with. Their CHC meant that they were not only likely to be at home due to school closures but were also likely to be shielding, which at the time of the first lockdown announcement had no clear end point. This was a significant change and a potentially distressing time for them, and I wondered if this would impact on recruitment and their willingness and desire to engage with the study at a time when there were so many other challenges for them.

Chapter 2: Literature Review

2.1 Overview

This chapter is organised into five sections which expand on the focus of this study, culminating in the development of the research questions. I will begin by examining research relating to the impact of having a CHC both on young people's psychological wellbeing and their education. Next, I will review current government policies around supporting young people with CHCs in school and explore the possible resource implications. I will then reflect on the importance of listening to young people's voices, particularly in relation to exploring their unique experiences of living with a CHC.

2.2 Chronic Health Conditions and Psychological Wellbeing

2.2.1 Overview

Whilst research suggests that most young people with a CHC do not have a diagnosed psychological disorder (Madan-Swain, Katz & La Gory, 2004), there are higher rates of emotional difficulties and psychological distress reported in the population of young people with a CHC compared to their healthy peers (DfE, 2015; Madan-Swain et al., 2004; Shaw & McCabe, 2008; Wodka & Barakat, 2007). These figures suggest an increased risk of young people with CHCs developing psychological difficulties (Edwards & Titman, 2010). Estimates suggest that between 10 and 37 per cent of young people with a CHC develop some form of psychological difficulty in relation to their health needs (Glazebrook et al., 2003). There is some suggestion that these figures are not a true representation of the level of need, as it is proposed that emotional difficulties in young people with a CHC are often overlooked and underreported (Turner & Kelly, 2000) or misinterpreted as a physical symptom such as fatigue (Champaloux & Young, 2015).

Research indicates that the psychological difficulties experienced by some young people with a CHC are more likely to be emotional, rather than behavioural (Glazebrook et al., 2003). The emotional difficulties described in the literature are

wide ranging and include anxiety, depression, low self-esteem, difficulties around planning for the future, concerns around mortality, pain management, difficulties with adhering to treatment regimens and struggles with identity (Duff, 2001; Gallagher, Bentley & Barlow, 2014; Mahdavi, 2015; Modi & Quitter, 2006; Taylor, Gibson & Franck, 2008). Several models have been proposed regarding how the individual with a CHC may experience and manage psychological difficulties. The sections below briefly explore some key concepts in this area.

2.2.2 Adjustment, Adaptation and Coping

It can be understood that young people who have a CHC are managing a wide range of stressors which could be considered as an "ongoing chronic strain" (Wallander & Varni, 1998, p.31). Diagnosis, treatment, unpredictability, physical symptoms, concerns about the future and the impact on social relationships can all be considered a "major psychosocial burden" (Sawyer et al., 2007, p.1484). Over the past forty years there has been a plethora of literature produced which explores the ways young people and their families adjust, adapt and cope with the identified stressors associated with living with a CHC. While many young people and their families are resilient and cope well, there are others who appear to have more difficulties (Edwards & Titman, 2010). The variability seen between people's psychological adjustment has led to the production of several theoretical models which identify supportive and hindering factors in how people cope and adapt with a CHC.

Wallander and Varni's disability-stress-coping model (1998) is one key theoretical model that conceptualises the ways individuals and their families adjust to the chronic strain associated with a CHC. The non-disease specific model is rooted in previous theories of coping (Pless & Pinkerton, 1975) and encompasses cognitive appraisal theory (Lazarus & Folkman, 1984). Within the model, stressors associated with CHCs are perceived as "persistent objective conditions that require continual readjustment" to which individuals have various risk and resilience factors which either help or hinder adjustment and coping (Wallander & Varni, 1998, p.31). Risk factors were placed into three categories: disability/disease parameters, functional independence, and psychosocial stressors. Resilience factors were also

conceptualised into three categories: intrapersonal factors, factors related to how stress is processed and socioecological factors (Wallander & Varni, 1998).

The model proposes that individuals demonstrate a unique pattern of strengths and weaknesses across these risk and resilience factors, with high risk, low resilience profiles causing a detrimental impact on emotional wellbeing, psychosocial functioning and adjustment and adaptation (Brown, Doepke & Kaslow, 1993). Wallander and Varni (1998) suggest that by identifying possible risk and resilience factors, targeted interventions can be developed to support adjustment, adaptation and coping for those with a CHC. Within health psychology, theoretical models such as this can provide a 'universal' guide to help clarify the nature, interplay and mechanisms of risk and resilience factors which can support in the identification of children and families more likely to experience difficulties and the development of generalised intervention programmes (Edwards & Titman, 2010). However, more recently in clinical and health psychology there has been a move away from the generic theoretical models towards evidence-based practice and developing treatment programmes for specific conditions (Spirito & Kazak, 2006).

2.2.3 Self-Determination Theory in Health Research

Self-determination theory (SDT) (Deci & Ryan, 2000; Ryan & Deci, 2017) is an organismic, motivational meta-theory developed through field and empirical studies. SDT "illuminates the conditions and processes through which human growth is optimized" (Barrable & Arvanitis, 2018, p.2). These conditions focus on three basic psychological needs, autonomy, relatedness and competence. SDT posits that these needs being met supports an individual's "healthy psychological and behavioural functioning" (Ryan & Deci, 2017, p. 4). SDT takes a realist stance, proposing that these needs are objective and universal, and if not met, there is an observable impact on the individual, irrespective of their views, desires, preferences, or values (Ryan & Deci, 2017, p. 10).

Basic psychological needs theory (BPNT) is a mini-theory of SDT concerned with the satisfaction or frustration of the three basic psychological needs described above (Ryan & Deci, 2017; Vansteenkiste, Ryan & Soenens, 2020). BPNT proposes that

needs can be satisfied or thwarted. The meeting/thwarting of needs is not static and varies "within persons, over time, contexts and social interactions" (Ryan & Deci, 2017, p. 243). It is also recognised that "individuals face unique affordances and obstacles in development" (Ryan & Deci, 2017, p. 241), which impact the satisfaction of needs and wellbeing. This appears to be particularly relevant to this study, as a CHC would be considered a potential 'obstacle'. BPNT also indicates that there is a complex interplay between the meeting and thwarting of needs, suggesting that they are highly interdependent and intercorrelated (Chen et al., 2015). A balance in satisfaction of the three needs is thought to be important. High levels of variability between the meeting and thwarting of needs is proposed to have a greater impact on wellbeing and wellness than any one need being frustrated (Sheldon & Nieiec, 2006).

SDT is a popular psychological framework that has a broad reach across various domains within psychology, including health (DeWalt et al., 2009; Estabrooks et al., 2005; Koponen, Simonsen, & Suominen, 2018; Ng et al., 2012) and education (Barrable & Arvanitis, 2018; Inok, Chiu & Patrick, 2021; Liu et al., 2015; Nunez & Leon, 2019). Ryan et al. (2008) propose the use of SDT as a biopsychosocial approach to explore individual health related behaviours and motivation. Their behaviour change model, based upon the key tenets of SDT, illustrates the impact of satisfying the basic psychological needs on both mental and physical health (Figure 1). This model has led to the development of a range of health interventions that have been purported to be particularly effective in areas such as treatment adherence and increasing physical activity (DeWalt et al., 2009; Estabrooks et al., 2005; King et al., 2010; Koponen, Simonsen, & Suominen, 2018; Ng et al., 2012; Williams et al., 2009).

Ng et al. (2012), suggest in their meta-analysis of literature that SDT is a viable and valuable framework through which psychological interventions and behaviour change programmes can be developed. They propose that research should continue to explore "mechanisms by which SDT-based interventions in various health settings can improve the length and quality of individuals' lives" (Ng et al., 2012, p.337).
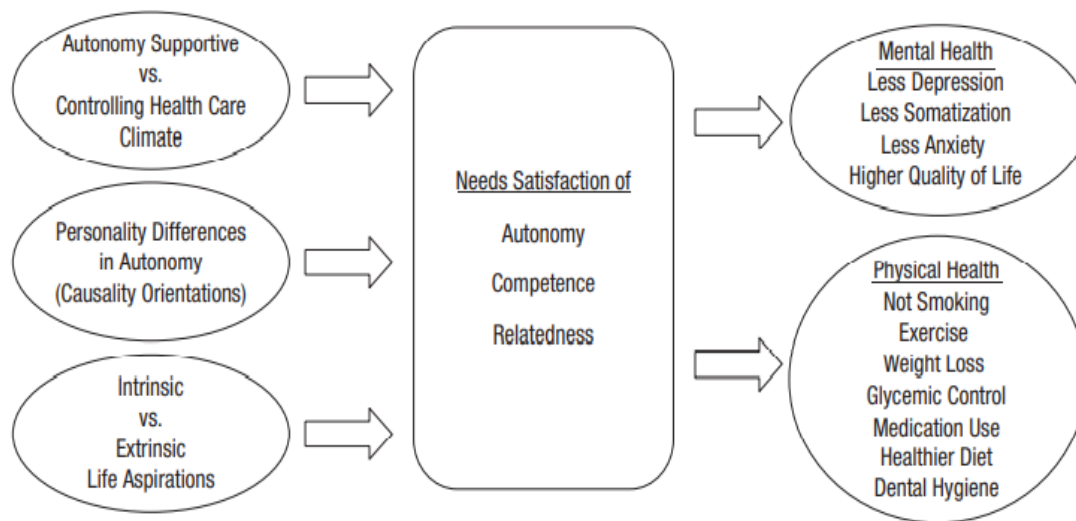
A systematic literature review by Eassey et al. (2020) synthesises qualitative studies related to living with a CHC and identifies links between SDT and the experiences of individuals with CHCs. This paper suggests that "chronic illness was considered by patients to be a disease if it challenged their sense of autonomy, competence and/or relatedness" (Eassey et al., 2020, p.276). The paper concludes that there is value in future qualitative research exploring how SDT can be used as a framework for understanding individuals' experiences of CHCs.

Finally, the 'Keeping Connected' study, in part explored the school experiences of young people with CHCs in Australia (Yates et al., 2010), also appeared to support a link between the experiences of young people with a CHC and SDT. Although there is no specific reference to SDT, the research identifies themes emerging from interviews with young people with a CHC closely relate to the three basic psychological needs. These include feeling disconnected from others (relatedness), sense of achievement linked to setting and meeting goals (competence) and a need to have their views heard and acted upon (autonomy).

2.2.4 Psychological Support

Edwards and Titman (2010) suggest that psychological support for children and young people with a CHC is essential so that they can adjust, adapt, function, engage in everyday activities and cope with the demands of their treatment regime. However, it is reported that only a relatively small number of young people with a CHC will access direct psychological input from a specialist clinical psychology team (Edwards & Titman, 2010). This support is primarily focused on providing evidence-based treatment programmes in a particular area of need such as pain management, treatment adherence or psychoeducation programmes for young people and their families (Kazak, 2006; Palmero, 2014; Power et al., 2003). These programmes appear to be stand-alone and medically orientated with little consideration of how this support could be generalised into education settings.

The 'Supporting pupils with medical conditions at school' policy document (Department for Education, 2015) indicates that "appropriate support should be put in place to limit the impact on the child's educational attainment and emotional and general wellbeing" (p.5) although it does not give any indication of what this 'appropriate support' is nor where or by who it should be delivered. There is reference to psychosocial support being provided by the school nurse, social workers and therapists, but educational psychologists are not mentioned (DfE, 2015; Edwards & Titman, 2010). Yet educational psychologists, who have experience and training in supporting mental health and an in-depth knowledge of school policies and processes, seem well-placed to provide the support being suggested. Jackson (2013) indicates that there are "unrealised opportunities" (p.8) for school staff to make links with external professionals, including psychologists, to explore the support available for young people with a CHC in relation to their education.

2.3 Chronic Health Conditions and Education

2.3.1 Overview

The framework document 'Getting the right start: National Service Framework for children: Standard for Hospital Services' (Department of Health, 2003) indicates that

"Education is vital" (p.11) and dictates that all children and young people who have health needs that require hospitalisation should access as much education as they can, given their medical needs. Literature, however, suggests that CHCs may affect young people's education in a myriad of ways including their attainment, attendance and relationships with staff and students. There are also implications in respect of resources and funding, and how the physical symptoms of a CHC are experienced by young people in school. These will be explored in the sections below.

2.3.2 Attainment

Research indicates that young people with a CHC appear to have poorer educational attainment in comparison to their healthy peers (Champaloux & Young, 2015; Needham, Crosnoe & Muller, 2004; Maslow et al., 2011; Thies, 1999). There are multiple reasons proposed for the link between CHCs and poor educational attainment. Poor attendance, the impact of physical needs associated with CHCs (fatigue, pain, lethargy), medication side effects and the social and emotional impact of having a CHC (Madan-Swain, 2004; Thies, 1999) are all thought to play a role.

Thies (1999) suggests that one possible factor leading to poor academic performance is the behaviour of the adults around the young person. It is suggested that they can prioritise health over academic performance, irrespective of the severity of the health needs at the time. If a young person is perceived to be acutely ill, teachers may see the physical and emotional distress, reduce expectations and workload to avoid 'overtaxing' them, even if they would be able to manage the level of work being given (Irwin & Elam, 2011). This subsequently leads to an inadvertent reduction in educational support which is proposed, over a prolonged period, to impact on progress in learning (Thies, 1999).

Poor school attendance, linked to CHC can also directly impact on academic attainment and lead to fragmented learning (Nisselle, Green & Scrimshaw, 2011). Missing lessons can be problematic for young people as it can often mean that 'catch up' learning is undertaken outside the classroom, often without appropriate teacher instruction. Without teacher support, young people are at risk of failing to fully grasp new learning (Needham et al., 2004). In some subjects which rely heavily

on the learning of core concepts, such as mathematics, frequent absence can mean that the young person fails to develop the 'building blocks' required to grasp more complex concepts (Thies, 1999). It has also been suggested that absence can create a cycle that consists of "falling behind academically leading to catching up" and that "catching up takes time away from keeping up" (Thies, 1999, p.395). This 'catch-up, keep-up' cycle can result in underachievement, which in turn can impact on the young person's self-confidence as a learner.

2.3.3 Attendance

Absence from school due to a CHC can impact on academic progress, motivation and interfere with a young person's ability to develop relationships and feel connected to their peers and staff at school (Diette et al., 2000; Dyson et al., 2007; Jackson, 2013; Sexson & Madan-Swain, 1993). Reduced attendance is also associated with a higher risk of engaging in emotionally based school avoidance behaviours (Jackson, 2013; Hogan, McLellan & Bauman, 2000; Olson et al., 2004; Shaw & McCabe, 2008). Government policy (Department for Education, 2015.) states that "long-term absences due to health problems affect children's educational attainment, impact on their ability to integrate with their peers and affect their general wellbeing and emotional health" (p. 5).

Absence due to a CHC can take several forms. It can include prolonged absences over several days and weeks (e.g., hospitalisation for administration of antibiotics for a young person with cystic fibrosis), shorter absences for parts of days (e.g., being sent home due to short-term physical symptoms of asthma or to attend medical appointments) or absences for parts of lessons for medical interventions (e.g., blood sugar monitoring in diabetes). Longer-term absences are more likely to be noticed, formally recorded, and monitored compared to the more subtle absences in lessons required for medical intervention. However, it is important to consider that these short absences can occur frequently throughout the day, every day. They accumulate over the school year and can equate to a significant amount of missed learning, even though this is not formally recorded. Absence (in any form) "can be subtle, but cumulatively potentially damaging" (Thies, 1999, p.395). Longer-term absences related to hospitalisation can also be problematic as they often occur "with

little or no prior warning" which can have a significant impact on planning for and access to the school curriculum (Peters, Hopkins & Barnett, 2016, p.143).

2.3.4 Peer Relationships

Young people increasingly place importance on peer acceptance and their intimate peer relationships as they approach the adolescent years (Christie & Viner, 2005). School is an important place that plays a central role in supporting young people not only academically, but also socially "in terms of interpersonal skills, making friendships beyond the family and achieving independence from parents" (McDonagh & Hackett, 2008, p.385). It has been suggested that the development and maintenance of peer relationships for young people with a CHC can be "complicated by their illness and periods spent in hospital" (Taylor, Gibson & Franck, 2008, p.3085). Maslow et al. (2011, p.7) report that there is a "concern among parents and health care providers that children with chronic illness are destined to face peer difficulties" as they try to balance peer relationships when their lives and daily routines are different to their healthy peers (Shiu, 2001).

These parental concerns may be warranted as absences from school due to hospitalisation or treatment regimens can mean that peer interactions for young people with CHCs are significantly disrupted or reduced (Shiu 2001; Edwards & Titman, 2010). This can cause them to experience exclusion from friendship groups, feelings of social isolation, reduced peer support and increased reliance on family members (Christie & Khatun, 2012; Ernst, Johnson & Stark, 2010; Nabors et al., 2008; Mahdavi, 2015; Quittner et al., 2009). While this disconnection from school and friendship groups can be considered a risk, being physically and socially connected through school could also be considered a protective and supportive factor (Blum and Libbey, 2004; Eames, Shippen & Sharp, 2016). As such, school has been described as playing both a "connecting role and an isolating role" (Ferguson & Walker, 2014, p.235).

Researchers have also explored the idea that young people with a CHC can be more 'visible' than their healthy peers. This increased visibility and 'difference' could be seen to occur in a range of ways including the need for specific treatment (e.g.,

physiotherapy), dietary requirements (e.g., menu checking for allergens), medication (e.g., enzymes required before food), differences in appearance (e.g., mobility difficulties) or specialist equipment (e.g., insulin pumps). Jackson, 2013 indicates that these additional accommodations can lead to young people with CHC being identified as different by their healthy peers and suggests that the response of peers can be to "ostracise or ignore the student living with chronic illness" (p.546). "Berland (2009) suggests that accommodations made in school for young people with a CHC may cause resentment and frustration for some of their healthy peers, subsequently impacting on their ability to maintain supportive relationships with them. Ferguson & Walker (2014) suggest that the young people in their study reported incidents of bullying which they suggest were "sometimes a consequence of perceived difference" (p.237).

Research suggests that young people with a CHC may feel different to peers or 'abnormal' at a time when conforming is extremely important to them (Jackson, 2013; Shiu, 2001; Yates et al., 2010). Jackson (2013) suggests that young people with a CHC desire to conform and strive for normalcy, but at times this feels unobtainable for them. There is a delicate balance for individuals with a CHC and their desire to be 'normal' that must be managed in their daily lives (Dailey, 2010). Yates et al. (2010) suggest that this desire to be normal creates challenges for the young people in their study "who wanted to be seen as normal by other people, but at the same time needed to acknowledge their limitations and the need for external support" (p.9).

2.3.5 Relationships with Staff

Teaching staff have been described as a front-line source of support for young people with CHCs as they are often the first to respond to their medical needs but are also central in supporting their academic and social development in the classroom (Huffman, Fontaine & Price, 2003). School staff are also well placed to monitor and support young people's emotional wellbeing in school. Despite being at the forefront of support, teaching staff receive little training about CHCs and the potential impact on the young person's education (Barraclough & Machek, 2010; Thies, 1999). Research demonstrates that often school staff appear to lack

knowledge and awareness about the needs of the young people with a CHC in their classrooms, frequently citing pragmatic reasons for this such as lack of time, unclear school policies, and lack of information being provided (Thies 1999; Thies & McAllister 2001; Shiu 2001; Strawhacker and Wellendorf 2004). For some staff however there appears to be a "level of scepticism" (Jackson, 2013, p.546) in acknowledging and accepting the invisible nature of the CHC (Berland, 2009).

Some studies have suggested that teachers have reported they do not feel confident in supporting young people with a CHC in their classroom and that this responsibility can cause them to feel overwhelmed and under prepared (Clay et al., 2004; Madan-Swain et al., 2004; Nabors et al., 2008; Olson et al., 2004; Thompson & Gustafson, 1996). Olson et al. (2004) suggest that teachers may lack knowledge and understanding of the true risks, fear potential medical emergencies, perceive that additional time and attention will be required or feel personally uncomfortable about having a young person with a CHC in their classroom. Surveys conducted with teachers who have young people with a CHC in their classroom suggest that the additional time required to support is not a perception but a reality (Nabors et al., 2008).

The relationship between parents and teachers is critical when young people have a CHC but can also be strained (Mukherjee, Lightfoot & Sloper, 2002). Parents are reported to perceive teachers as uninformed both about the specific medical interventions that may be required for their children but also about the wider limitations that these may cause in the classroom (Mukherjee et al 2000; Mukherjee et al., 2002). There also appears to be a tension in which parents are understandably concerned for their individual child's needs, but the school staff also need to consider how these can be managed so that a balance is found with the effective use of resources and other needs within the class and school (Band et al., 2002).

Young people with a CHC will also have a range of medical professionals involved in their care and the relationships between them and school staff can also be a source of tension. Training in both medical and education professions provides very few opportunities to discuss, explore or interact with the other and as a result there can

be a limited understanding of the other's settings, roles, limitations and perspectives on managing CHCs (Salm et al., 2010; Wilson, McNeill & Gillon, 2017). This can understandably cause difficulties when discussing and planning for the care of a child with a CHC in a school setting, with medical professionals having a limited understanding of how a school is run and education professionals having limited understanding of the complexities of the medical care required (Giroux, Wilson & Corkett, 2019). Collaboration between these two sets of professionals is essential for providing the right care in school settings but often these "deeply entrenched role identities can prevent collaboration" (Giroux et al., 2019, p.244), which is likely to impact the young person.

2.3.6 Physical Symptoms in School

The biological and physical impact of a CHC, that is the symptoms, side effects and treatment regimens on young people's school experience, vary depending on the CHC and the individual's experience of it. Whilst it would be impossible to identify all the possible ways physical symptoms could impact on a young person at school, Table 1 below provides examples of potential challenges for young people in school relating to physical symptoms associated with their health condition.

Table 1: Example of the impact of the physical symptoms of CHCs on education (adapted from Theis, 1999, p.394)

A young person...	May experience...
With cystic fibrosis may have "poor oxygen perfusion" (decreased oxygen levels in the blood)	Fatigue, confusion, and restlessness
Undergoing steroid treatment for an autoimmune disease with oral steroids	Anxiety, depression, memory loss or limited concentration
With diabetes, who has blood sugar levels that are too low	Fatigue, confusion, and significantly impaired executive functioning.
With cerebral palsy	Impact on functional ability and mobility
With Arthritis, who has swollen and stiff joints.	Difficulty with fine motor tasks. Difficulty walking, standing, or sitting.

Fatigue is described as the "universal symptom" (Dailey, 2010, p.12), commonly experienced across many people with CHCs (Kaffenberger, 2006; Shiu, 2001; Velsor-Friedrich, Pigott & Louloudes, 2004). It is suggested that many young people with a CHC may experience levels of fatigue which impact on their energy levels and can make it significantly more difficult to access and engage with school life" (Thies, 1999). Jackson (2013) suggests that the hidden nature of fatigue and pain, meaning that school staff and peers are not always aware of its effects, can make it particularly challenging to manage. Acute physical symptoms such as pain and discomfort in class can be distracting and impact on concentration and focus on learning (Ernst et al., 2010; Madhavi, 2015). It is suggested that young people managing these ongoing difficulties with invisible symptoms, such as pain and fatigue, may experience low self-esteem, low mood, depression, or anxiety as a result (Velsor-Friedrich et al., 2004). Finally, it is considered that some young people with a CHC may also experience longer-term biological effects on attention, memory and processing speed that may in turn affect their academic attainment (Sexson & Madan-Swain, 1993; 1995; Shaw & McCabe, 2008)

2.4 Government Policies

2.4.1 Overview

'Supporting pupils with medical conditions at school' (DfE, 2015) is the current government legislation in the UK regarding supporting children and young people with CHCs in schools. This documentation focuses on the provision of practical advice for school settings around managing emergencies and recording medication. There is some, albeit limited, recognition of the psychosocial impact of CHCs on young people suggesting that "arrangements should show an understanding of how medical conditions impact on a child's ability to learn, as well as increase confidence and promote self-care" (DfE, 2015, p. 7).

The policy places a focus on inclusion and person-centred practice, stating that it would be unhelpful to "assume that every child with the same condition requires the same treatment" (DfE, 2015, p. 23). Pupil voice is a further key message emanating through the policy, with recommendations made that "pupils with medical conditions

will often be best placed to provide information about how their condition affects them. They should be fully involved in discussions about their medical support needs" (DfE, 2015, p. 13). The policy sets out clear expectations that dictate adequate training and information sharing with staff and strongly suggests that schools should support young people with medical conditions though collaboration with health and social care professionals and with parents (DfE, 2015). Parents are labelled "key partners" (DfE, 2015, p. 13) who should be heavily involved in information sharing and planning but should not be considered the school's "sole trainer" (DfE, 2015, p. 18).

2.4.2 Resources and Funding

Young people with CHCs are likely to require additional support in school and as such there are resource implications. However, it is not clear where this additional resource is to be sourced from. Young people with CHCs have been at the "intersection between health, education and well-being" and as such, it is "unclear who bears responsibility for addressing the actual or perceived impact on learning" (Thies, 1999, p.392). Government policy (DfE, 2015, p. 5) states that "some children with medical conditions may be disabled under the definition set out in the Equality Act 2010" and "some may also have special educational needs (SEN)", implying that some young people will be considered in neither category. This fluidity can cause difficulties as young people with CHCs do not 'fit' within one specific definition, and therefore also do not qualify for the associated funding stream. Further, CHCs and associated needs are rarely static, being described as a "rollercoaster of changing needs moving between acute medical crises and long-term management of health" (Thies, 1999, p.396). This suggests then that CYP may frequently move in and out of varying systems depending on the severity of their needs at any given time. This increases the likelihood of being overlooked and missing out on needed resources that could provide them with the required support within school.

2.5 Listening to Young People's Experiences

2.5.1 The Importance of Hearing Young People's Experiences

It is increasingly recognised that young people are key sources of information about themselves and their social world (Hardy & Majors, 2017; Tisdall, Davis & Gallager, 2009). The act of listening to and acting on young people's voices can be empowering and emancipatory (Ingram, 2013). However, it has been suggested that there is a socio-cultural environment which "is supportive of asking for young people's views but is often resistant to really hearing and actioning these views" (Hardy & Hobbs, 2017, p.174). It has been implied that attempts to hear young people's voices often do not extend beyond tokenism (Alderson, 2001; Hart, 1992; Johnson, 2017). Research practice which excludes young people's voices or fails to hear their lived experiences perpetuates the cycle of researching 'on' young people rather than 'with' them which in turn marginalises and disempowers young people (Darbyshire, MacDougall & Schiller, 2005).

This appears to be highly relevant when considering young people with CHCs. The information gained when the focus of research is firmly trained on medical perspectives is likely to be considerably different to the subjective experiences that could be heard by speaking directly to those who live with a CHC (Forsner, Jansson & Sørlie, 2005). Yet there is an imbalance in research within the field which appears to prioritise knowledge from the 'expert' medical professional over insight from the individual's lived experience (Gabriel, 2004). It has been proposed that the prioritisation of the individual's "experiential expertise" ensures that research is "valued, valid and feasible" (Spencer, Fairbrother & Thompson, 2020, p.2).

There has been a reported shift in research approach when working with young people, moving from finding out about them using proxy reports to a focus on listening directly to their views and experiences (Punch, 2002; Santelli et al., 2003). There is increasing research which prioritises the voice of young people within health research (Spencer et al., 2020) but there is a tendency to attempt to understand these experiences through professional discourses of health, education or through young people's parents" (Moss, 2014; Yates, 2010; Yates et al, 2010). Bolton, Closs & Norris (2000, p.40) also suggest that research appears to be "medically, psychologically or sociologically orientated" and lacks focus on educational dimensions of their lives.

2.5.2 The 'Keeping Connected Project'

One recent study, 'The Keeping Connected Project', does appear to have both attempted to obtain young people's views and focuses, at least in part on their educational experiences (Yates et al., 2010). The study was a three-year multi-disciplinary research project, employing longitudinal case study, ethnographic, visual and narrative methodologies with 31 participants living in Australia who had all experienced "chronic illness-related interruptions to their schooling" (Yates et al, 2010, p.2). The study aimed to explore their experiences and and to understand factors that facilitated or hindered their "educational and social connections" and planning for the future (Yates et al, 2021, p.3). Whilst the primary focus was prioritising young people's voices, secondary data collection through interviews, focus groups and surveys was undertaken with parents, health, and education professionals.

Four key themes arose from the analysis. Firstly, a theme exploring the opposing concepts of normalcy, difference and the idea that young people with CHC are "the same as everybody else and yet being particularly vulnerable" (Yates et al, 2010, p.12). Secondly, the need for professionals to view young people beyond their medical label so that their individual and nuanced needs could be understood. The third theme highlighted that CHCs are highly variable and the impact on young people's lives can change significantly over time, therefore managing a CHC should be viewed "as a process, not a checklist" (Yates et al, 2010, p.13). Finally, a theme highlighting the need for clear communication between professionals, young people and schools to ensure increased advocacy so that they have their rights promoted and protected.

This study is, to my knowledge, the only study within this topic area which places such importance on the voice of the young person in relation to their experiences of living with a CHC and the impact this has on their education. However, the researchers do also then give significant space in which professional and parent views are also explored, which could be considered a dilution of the participants voices and perhaps a weakening of the message that young people are experts of their own lives, and that they are able to provide a unique insight living with a CHC.

This study also takes place in a single state within Australia, and therefore cannot speak to the nuances of the British education system or government policies and the impact that these ecosystemic factors are likely to have on young peoples' experiences.

2.6 Summary, Rationale and Research Questions

This chapter has highlighted that there is a large and increasing number of young people with CHCs in the UK, with the majority attending mainstream school settings. Research has indicated that there are a broad range of ways in which CHCs impact young people's psychological wellbeing and education. Whilst there is a plethora of research about living with CHCs, it tends to be clinically orientated, focused on adults or the information is obtained about young people by proxy and is focused on 'problem solving' medical issues rather than understanding experiences. It has been identified that there is much to be gained from listening to the lived experiences of people with CHCs (Yates et al., 2010) and there have been suggestions that research needs to move towards attempting to understand the "nuances surrounding living with a chronic illness" (Eassey et al., 2020, p.286).

This research aims to explore the lived experience of young people with a CHC who attend a mainstream secondary school. This will be done by talking directly to young people to ensure their viewpoints are listened, valued, and prioritised.

The research aims to answer two research questions:

1. How do young people with a CHC experience mainstream secondary school?

2. What can professionals working with young people with a CHC learn from these experiences?

Chapter 3: Methodology

3.1 Overview

In this section I will outline the ontological and epistemological positionality underpinning this research. I will then explore the decision-making process, referring to other approaches considered, before presenting the rationale for the selected methodological approach in this study, IPA. The core principles of IPA will then be outlined and implications to this study explored. Finally, consideration will be given to issues relating to the quality, rigour and trustworthiness of the research.

3.2 Ontological and Epistemological Positionality

A researcher's ontological position can be understood to be somewhere on a continuum between relativism and realism. Realist ontology acknowledges the existence of a 'reality' which is observable and objective (McEvoy & Richards, 2003), assuming therefore that 'something' exists and can be identified and described through research (Willig, 2013, p. 15). Contrastingly, relativism considers 'reality' to be a subjective human experience (Denzin & Lincoln, 2005) with as "many different realities as there are people" (Levers, 2013, p.2).

Critical realism is considered to fall on the continuum between the realist and relativist paradigms asserting an ontological realism and epistemological relativism (Maxwell, 2012). Critical realism suggests there is an objective reality, which is perceived in three distinct layers; the empirical, the actual and the real (Bhaskar, 2008). The epistemological relativist stance, however, suggests that this objective reality can never be perfectly known, accepting that research data is not a "direct reflection" of the phenomenon being explored (Willig, 2013, p. 16). Instead, there is an aim to get as close as possible to the 'real' social, psychological or physiological factors that may be underpinning the phenomenon in question to gain greater understanding of it (Madill et al., 2000; Willing, 2013).

Critical realism therefore acknowledges that there can be multiple perceptions of reality and that an individual's account will be subjective and fallible. (Fletcher, 2017). Critical realists propose that interpretation is required to "dig deeper" (Willig, 2013, p. 16) and recognise the integral role of the researcher in the interpretation (Mertens, 2015). Critical realism suggests that the nature of this interpretative process, and the lack of direct access to the 'real' means that the objective truth may never be uncovered (Danermark et al., 2002).

Much of the research in the field of CHCs is completed from a medical or clinical perspective and is often underpinned by a realist, positivist philosophical stance, suggesting that there is an objective reality around how CHCs are experienced and that this can be understood through research. This study aims to explore young people's experiences of living with a CHC whilst attending school and in doing so there is an ambition to promote and prioritise their voices. I accept, therefore, that there are multiple realities, each unique and subjective, and not a single 'truth' to be discovered (Ponterotto, 2005). From this perspective, a critical realist approach appears to be congruent with the aims and values of the research.

It feels important here to draw some distinction between the critical realist and phenomenological epistemological position and provide some explanation as to why the former has been adopted over the later. Like critical realism, phenomenological approaches assume there is an objective reality, and it is not possible to untangle the subjective experiences from the objective reality (Willig, 2013). Phenomenological research is focused on attempting to understand "the quality and texture of experience" within a specific context and time (Willig, 2013, p. 16), whereas critical realism is also concerned with the factors or mechanisms which may be underpinning this phenomenon.

As critical realism explores underlying structures or "causal powers or potentialities" (Bhaskar, 2013, p. XVIII), it makes it possible for critical realists to attempt to explore social problems and go some way towards making recommendations, although fallible, which could contribute to social change (Fletcher, 2017). Given my second research question, in which I attempt to consider the potential application of knowledge for education professionals working with young people with a CHC, this

feels important. As such, I consider critical realism to be a better fit to my views around knowledge; what there is to 'know', how we get to 'know it' and the potential of what can be 'done'.

3.3 Selecting a Methodology.

3.3.1 Overview

In the process of identifying an appropriate research methodology there are several factors that need to be considered. The research question and aims must be taken into consideration alongside the ontological and epistemological positionality of the researcher (Willig, 2013).

As my research study aims to explore the subjective experience of the participants, I rejected the use of quantitative, positivist, empiricist or hypodeductivist approaches, which suggest that reality is objective, stable, observable, measurable and testable (Swift & Tischler, 2010; Willig, 2013). Qualitative research, however, focuses on meaning and looks to "obtain insights into what it feels like to be another person and to understand the world as another experiences it" (Austin & Sutton, 2014, p.436). It does not seek to make predictions or identify correlations but instead offers a rich, in-depth exploration of a narrowly defined topic via the insights of a small group of people (Willig, 2001).

Creswell (1998) indicates that qualitative research generally tends be based in a relativist ontology and prioritises subjectivity and inductive reasoning. The literature review indicated that health research completed from a medicalised or clinical perspective has tended towards realist ontology, prioritised deductive reasoning, and preferences reports by proxy rather than insider accounts (Broom & Willis, 2007; Santelli et al., 2003). A gap in the research was identified regarding UK based studies with a particular focus on young people with CHCs' experience of mainstream school settings. As such this research can be considered exploratory, attempting to examine the less understood aspects of the phenomenon through inductive reasoning. Finally, I considered that qualitative approaches explore phenomena in real-life settings (Bryman, 2004). This is a particular consideration for

the study of CHCs, which are typically explored from clinical perspectives in research, often in isolation from the broader systemic structures that surround the individual. This excludes the possibility of considering experiences in the context of a real life setting such as a school.

There are a range of approaches that could be employed through qualitative research underpinned by a critical realist ontological and epistemological perspective. Whilst this offers a great deal of flexibility, it also requires a level of reflexivity and transparency to justify the chosen approach (Swift & Tischler, 2010). Two qualitative methodologies were congruent to the research purpose and the researcher's ontological position; interpretative phenomenological analysis (IPA) and thematic analysis (TA) and are explored below. Visual methodologies were also considered as a complementary approach.

3.3.2 Thematic Analysis

TA is a qualitative method in which the researcher codes the data by looking for important and relevant patterns of meaning (themes), thought to describe the phenomenon being explored (Braun & Clarke, 2006). There are questions as to whether TA is a methodology in its own right, or if it is better considered an analysis tool that is used within other qualitative methodologies (Joffe, 2012). TA can work across constructionist, phenomenological and realist approaches but relies on the researcher to determine an "epistemological logical and theoretical framework" (Willig, 2013, p. 57). Without a philosophical grounding, it is proposed that TA can lead to themes which are either meaningless, add no value or are strongly orientated away from the participant's experience towards the researcher's agenda. This limits the possible insights and understanding that can be gained from the data (Willig, 2013). On this basis, I decided that I viewed TA as an analytical tool, rather than my selected methodological approach.

3.3.3 Visual Methodologies

Although IPA felt a fitting research approach, I considered that the most common data collection method associated with IPA, the semi-structured interview, had some

restrictions when considering the ages of the participants in this study. Billington (2006) proposes five question themes to consider when working with young people; two that seem particularly relevant here are "how do we speak with children?" and "how do we listen to children?" (p.8). Semi-structured interviews have been considered adult-centred (Pole, Mizen, & Bolton, 1999) and rely on "people's capacity to verbalise, interact, conceptualise and remember" (Mason, 2002, p. 64). Therefore, to speak and listen to young people it felt important to explore other methodologies which may be more sensitive to the adult/child power differentials and the pragmatic difficulties of using interviews with young people (Greene & Hill, 2005; Punch, 2002).

The use of visual methodologies has been proposed as an alternative to support young people to explore and explain their experiences in a way that "words alone cannot" (Clark-Ibanez, 2007, p. 171). Alongside supporting reflection, visual methodologies are proposed to promote engagement, motivation, and the voice of marginalised groups (Drew, Duncan & Sawyer, 2010). Visual methodologies are increasingly popular in research with young people and in the field of health and education (Fairbrother et al., 2016; Kirkham et al., 2015; 2013; Vindrola- Padros et al., 2016; Wall, Hall & Woolner, 2012).

A purely visual approach would prioritise the use of artefacts over verbal data (Drew, Duncan & Sawyer, 2010) but visual methodologies can also be used as a way of "eliciting verbal data" (Willig, 2013, p. 157). As eliciting young people's voice through interviews is a key aim of the research, this approach feels extremely relevant. As such, it is proposed that this study will include an option for the young people to engage in a visual method of representing their experiences to encourage engagement and provide support to develop their reflections prior to the semi-structured interview.

Reflection: Visual Approaches

There was much thought and discussion around my desire to include visual approaches in my research. My previous experience of working with young people indicated to me that for some, a one-off semi-structured interview alone would restrict their ability to reflect and describe their experiences with depth and breadth. My practice as a teacher, SENCO and trainee educational psychologist frequently relied on creative approaches to engage and motivate young people when carrying out tasks to elicit their views. A review of literature (see above) supported this view.

However, the addition of visual methodologies also brought ethical and pragmatic challenges in relation to the way in which the creative tasks would be completed, stored, analysed and shared. There were also questions around their role within the research and if they themselves would be analysed. This was compounded by COVID-19 as my initial plans to work creatively with a young person face-to-face could no longer happen, meaning that all creative endeavours would have to be completed online or away from the researcher. This brought further challenges relating to equipment, motivation, performance anxiety and data and GDPR compliance in sharing items over email. At times, I was unsure on whether to continue to explore their use as the barriers seemed to be offsetting the advantages of using the approach.

Through reflection and supervision, I decided to offer the option to use a creative approach alongside the interview. This was not taken up by all participants, but for those who did I felt it added value to their reflections and interview and was pleased I was able to overcome the challenges to include this approach. I did feel disappointed, however, that I was unable to complete the creative aspects of the project as originally planned as I feel that the visual methodologies would have been extremely enlightening and helpful for the young people involved.

3.3.4 Interpretative Phenomenological Analysis (IPA)

IPA aims to explore the ways in which individuals make sense of their own experiences. It attempts to get close to the individual's lived experience whilst also attempting to provide a clear account of the researcher's interpretation and

understanding of it (Smith, Flowers & Larkin, 2009, p. 80). In placing the participant at the centre of the research, IPA aims to give 'voice' to a particular phenomenon (Wagstaff et al, 2014; Mertens, 2015). IPA has been used extensively in the field of health psychology and its focus on lived experiences particularly lends itself to the exploration of individual's experiences of illness (Brocki & Wearden, 2006; Smith, 2011; Swift & Tischler, 2010; Smith et al 2009, p. 121). There are three core concepts of IPA that I needed to review and consider in relation to their appropriateness and fit with my research: phenomenology, idiography and hermeneutics.

3.3.4.1 Phenomenology

Phenomenology (Husserl, 1927) was initially proposed as a concept which highlighted the importance of focusing on the perception of experience" in contrast to the popular positivist views of the time which prioritised scientific and objective 'knowledge' (Smith et al 2009, p. 21). Husserl advocated for a 'phenomenological attitude' in which an individual would employ reflexivity and intentionality to examine the 'essence' of human experiences. To achieve this, he proposed a method, 'bracketing', which involved leaving the preconceptions and assumptions about an experience so that the focus can be trained on the core subjective experience of the phenomenon in question (Husserl, 1927).

Over the 20th century, phenomenology was further developed by Heidegger (1927, 1962), Merleau-Ponty (1962) and Sartre (1943, 1956). Heidegger moved away from Husserl's concept of bracketing, claiming that there could be no "knowledge outside of an interpretive stance" (Smith et al 2009, p. 21). Heidegger also suggested that the individual is embedded in the world and cannot be detached from it (Horrigan-Kelly, Millar & Dowling, 2016). This "inter-relationship and inter-connectedness" is thought to be the basis of human experience (Tuffour, 2017, p.3). The implication for the researcher is that interpretation (hermeneutics) must be used to investigate and attempt to make sense of experience. This next section will focus on hermeneutics and explore these ideas further.

Merleau-Ponty prioritised physical and perceptual experiences in a way that other phenomenological philosophies did not (Anderson, 2003). This viewpoint feels particularly relevant to this research as it recognises the importance of the body and linked physiology to human experience (Tuffour, 2017).

Finally, Sartre's existential phenomenology proposed the concept that humans are continually developing through their experiences, describing individuals as "constantly in the process of becoming" (Kierkegaard, 1974, p. 79). Sartre provides insight into the phenomenological analysis of experience and suggests it should consider "the embodied, interpersonal, affective and moral nature of encounters" (Smith et al., 2009, p. 21).

Visual methods can be considered as a "good way" of supporting the researcher to "enter the life world of the participant" (Willig, 2013, p.161) by encouraging participants to discuss the way in which visuals have allowed them to express and explore the ways in which they make sense of the phenomena in question. In this research the visual methodology is used within the semi structured interviews, through open ended questioning. Care has been taken to ensure that the visual materials are not considered as a route to understanding the "factual, objective 'reality'" or "unchanging memories" of participants (Willig, 2013, p.162) but are instead seen as an exploration the participant's sense making of previous experiences.

3.3.4.2 Hermeneutics

Linked to the phenomenology section above, a further core concept associated with IPA is the role of interpretation (hermeneutics) in the analysis of experience. Four key theorists have been linked to the development of hermeneutics: Schleiermacher (1768), Heidegger (1927, 1962), Gadmer (1991) and Ricouer (1981).

Schleiermacher initially proposed that through systematic grammatical and psychological interpretation a researcher can "offer a perspective on the text which the author" cannot (Smith et al., 2009, p. 23). Heidegger then suggested that investigation is required to uncover and make sense of experience. This process is

facilitated by a researcher who brings with them prior experiences, assumptions, and preconceptions, which he names fore-conceptions (Smith et al, 2009). These fore-conceptions are considered ever present and potential "obstacles" to interpretation (Smith et al., 2009, p. 25). Gadmer 1991 suggests that in order to mitigate for the impact of these, reflexivity and openness are essential during interpretation in that "the important things is to be aware of one's own bias, so that the text can present itself in its otherness and thus assert its own truth against one's own fore-meanings" (Gadmer, 1990, p. 269).

Heidegger's and Gadmer's views underpin IPA's assertion that it is impossible for the researcher to fully separate (bracket) their own perceptions and experiences when interpreting data and instead suggest that the researcher's knowledge and assumptions are utilised in this sense making process (Larkin, Watts, & Clifton, 2006). A key feature of IPA is the 'double hermeneutic' which describes the way in which the interpreter makes sense of the participant's sense making. Consideration also needs to be given to the non-linear approach undertaken within IPA, a cycle of interpretation that moves between the part and the whole at multiple levels. IPA posits that a part cannot be understood without the whole and vice versa, meaning that the researcher must employ an iterative approach throughout the analysis (Smith et al, 2009, p. 26).

This iterative approach and the "double hermeneutic" (Willig, 2013, p87) is clearly demonstrated within this research. There is a clearly detailed systematic analysis process which focuses on the individual transcripts before cross case analysis is undertaken (detailed in Chapter 4). This process can be clearly tracked through detailed charts which indicate the interpretative path taken and close links to the transcript though the addition of illustrative quotes at all stages. Furthermore, a reflexive approach, using research diaries, supervision and reflection boxes highlights how I have attempted to identify and use my "presuppositions and assumptions" in and attempts "to unravel the meanings within" (Smith, 1997, p.189).

Reflection Box: Bracketing

IPA's description of hermeneutics feels a more comfortable explanation of interpretation than 'bracketing' proposed by Hurssel (1927). My previous experiences and 'knowledge' of working with young people with a CHC in schools is described in the introduction and was a driver for wishing to complete this research. I feel, therefore, it would be impossible for me to completely step aside from this. As such, the concepts of a reflexive and open attempt to understand my fore-conceptions and the employment of the double hermeneutic cycle within IPA feels more appropriate to my research than other phenomenological approaches.

3.3.4.3 Idiography

The third key tenet of IPA involves the idiographic approach, which has been described as an attempt to understand "the particular" (Smith et al, 2009, p. 29). IPA suggests therefore that an individual offers a "personally unique perspective on their relationship to, or involvement in" a "phenomenon of interest" (Smith et al, 2009, p. 29).

Given that a key, and unique, aim of this research is to consider the participant's experience of their CHC within their mainstream school setting, the consideration of context feels important. IPA's concern with both idiography and the participants' lifeworld (Brooks, 2015) allows for a rich and detailed view of how the phenomenon under investigation is experienced by the individual (Pietkiewicz & Smith, 2014). When considering the secondary aim of this research study and the implications for education professionals working with young people with a CHC, I consider that a rich, in-depth and holistic view of their experiences may help facilitate greater understanding and enhanced support (Oxley, 2016).

Idiography as a concept "does not eschew generalisations" but requires the researcher to employ a different approach in identifying patterns and shared experiences (Smith et al 2009, p. 29). Tuffour (2017) describes IPA as a "detailed

and nuanced analysis, valuing each case on its own merits" (p.4) before cautiously seeking to explore convergence and divergence with other cases. This feels important, particularly as this research considers five individual and unique cases, and seeks to both represent these distinctive, individual experiences whilst also exploring any shared themes that may be important and helpful for educational professionals working with young people with a CHC.

An idiographic approach is adopted throughout this research, from the recruitment of a small homogeneous group of young people with experience of the same phenomenon, through the open ended, semi structured interviews to the systematic, and detailed analysis of each individual case.

3.3.4.4 Epistemological considerations

Finally, I considered how IPA fits with my critical realist positionality. IPA is open to a range of epistemological stances, although there is an indication that the philosophical stance should generally be situated somewhere between constructionism and critical realism (Oxley, 2016). IPA suggests that everyone will have a unique experience, meaning that there is likely to be multiple realities associated with what is considered the 'same' phenomena (Larkin, Watts & Clifton, 2006). This is highly congruent with the philosophical assumptions made in critical realism. This research aims to explore the experiences of a small group of young people who are experiencing a shared phenomenon: attending a mainstream school whilst living with a CHC. As such, it makes no assumptions about reality and 'truth', instead acknowledging this will be unique to the individual experiencing it.

After thorough consideration IPA was selected as the most appropriate methodology for this research. I also decided to use visual methodologies to complement this approach.

3.4 Quality in Research

Qualitative research employs an interpretative stance, meaning that there is an assumed level of subjectivity within the approach. This raises questions of quality,

particularly in comparison to quantitative research and the application of robust frameworks to assess the reliability, validity, generalisability and objectivity (Willig, 2013, p. 169).

It is suggested that if qualitative research is going to be meaningful and applicable for the reader, there needs to be some common understanding as to what constitutes qualitative research of a high quality, an equivalent to the guidelines used in quantitative research (Yardley, 2000). Yardley's guidelines (2000 & 2008) propose four overarching concepts which support the assessment of quality within qualitative research: sensitivity to context, commitment and rigour, transparency and coherence and impact and importance. The reliability of criteria is considered throughout the research and the table detailing the steps taken in meeting the four criteria can be found in Appendix 1.

3.5 Generalisability

Willig (2012) suggests that interpretive research needs to be modest about its findings, indicating that it "can never do more than shed light on one small part of a much bigger whole" (p. 57). Given the epistemological underpinnings of this research which recognises the multiple truths, the small sample size used within IPA studies, and subjective nature of interpretation it does not feel possible to make these claims of representation and generalisation. I understand therefore that the generalisability of my research is extremely limited. Rather than generalisability, IPA considers transferability a more likely possibility. Transferability is the identification of factors or similarities that could be applicable beyond the narrow research context (Hefferon & Gil-Rodriguez, 2011).

Chapter 4: Procedure

4.1 Overview

In this chapter, the design of the research will be described including ethical considerations during the research design and data collection. I will describe the sample and selection criteria and then explore my pilot study explaining any implications for the main research study. I will then explore the specific procedures carried out within the main study regarding participant recruitment, data collection and transcription. Finally, the analytic strategy of the research will be explained, including further exploration of the ethical considerations of applying a secondary process in which the analysis is related to psychological theory, particularly in relation to the style of interpretation and the commitment to an idiographic approach.

4.2 Ethical Considerations

4.2.1 Overview

There are ethical considerations required at all stages of research and decision-making processes should be robust, reflexive, and dynamic (Sanjari et al., 2014). Qualitative research is thought to be particularly saturated with ethical challenges due to its exploratory nature, the interactions between researcher and participant, the in-depth nature of interviews, the interpretative quality of analysis and the aim of qualitative research to attempt to shed light on the "human condition" (Brinkmann & Kvale, 2008). This was particularly pertinent considering the age of the participants and the topic, meaning that I classified the research as sensitive and the young people taking part as potentially vulnerable.

All ethical considerations were guided by the University of Sheffield ethics board, the British Psychological Society's (BPS) 'Code of human research' (2010) and the Health and Care Professions Council (HCPC) 'Guidance on conduct and ethics for students' (2016). An ethics application was submitted in April 2020 (See Appendix 2) and after several revisions was approved in June 2020 (see Appendix 3 for approval

letter). The ethical considerations in relation to this research will be briefly explored below. Further detail relating to these issues can be found in Appendix 2, ethics application.

4.2.2 Safeguarding and Minimising the Risk of Distress

Smith, Flowers and Larkin (2009) indicate that "avoidance of harm" should always be the first consideration of any research project, and this includes any risk to participants' "psychological well-being and dignity" (p. 53). As this research involves young people who are considered potentially vulnerable due to their age and health status, this is particularly pertinent. The research also focuses on their CHC and the impact on their lives, which could be considered a sensitive research topic. I therefore considered that there was potential for the participants to experience some level of distress whilst participating in the research. However, I was also aware that the assumption that these young people are inherently vulnerable is also problematic. On this basis, the research focused on ensuring important safeguards whilst acknowledging the participants' ability to exercise agency. Several key points will be explored below but a full exploration of considerations in relation to safeguarding, minimising harm and the steps taken to mitigate these can be found in the ethics application (Appendix 2).

The risk of distress was felt to be minimal, but possible. As such, proactive strategies to reduce the risk of distress were employed. This included a check-in session that was used to build rapport and reduce anxieties prior to the interview (Coyne, Hayes & Gallagher, 2009). The interview schedule was also carefully considered, and an accessible visual format was provided prior to the interview to allow the participants to prepare, which was thought to help reduce the risk of distress (Ireland & Holloway, 1996). The possibility for participants to use creative methodologies was also thought to provide a more comfortable method of research for young people, to support them to reflect on sensitive issues that arise and provide an alternative to the intensive process of discussion within interviews (Drew, Sawyer & Duncan, 2010; Guenette & Marshall, 2009; Matthews, 2007).

Finally, the possibility of distress also highlighted the need for me to be sensitive and attuned to the participant during all contacts, both in respect of the content of the interview or discussions, and to their presentation and non-verbal communication (Hefferon & Gil-Rodriguez, 2011). A 'distress protocol' was written indicating the steps to be taken should there be any apparent rising levels of stress or emotional distress observed me (Appendix 4).

Only one participant showed signs of distress during the interview when discussing her future. The distress protocol was followed. Questioning was stopped and her parent was called into the room for a debrief. A follow-up email was sent to the parent and the contact sheet and signposting to further support were sent again. The parent responded to indicate that the participant was no longer distressed, being monitored closely and that no further support was required.

4.2.3 Gatekeepers, Informed Consent and Right to Withdraw

Research with young people can cause significant ethical challenges due to access to participants only being possible through adult gatekeepers (Coyne, Hayes & Gallagher 2009). The combination of the age of the participants and online procedures due to COVID-19 meant that recruitment of participants took place via several layers of gatekeepers: educational psychologists, SENCOs and then parents. This method of recruitment positions the adult as the primary source of consent, raising concerns that young people could feel pressured or coerced into participating. To attempt to mitigate the challenges associated with gatekeepers, both a parent and participant information sheet explaining the research in detail was produced (Appendix 5 and 6). Given that the research was centred around young people, the participant information sheet was designed to be accessible by reducing the length and simplifying vocabulary to ensure they could fully understand and consent to taking part (Coyne et al, 2009; Vindrola-Padros et al., 2016). The inclusion of a separate, differentiated information sheet for the young person was an attempt to increase their sense of participation and agency within the recruitment process.

I considered consent to be a dynamic process which required continual renegotiation throughout the research (Parker, 2008). Additional opportunities to ensure the participant's understanding of the research and to renegotiate consent were built in throughout. Alongside seeking both written and verbal consent, I also felt it important to monitor for non-verbal signs that the participants no longer wished to take part, such as becoming non-responsive or ignoring contact.

4.2.4 Confidentiality and Anonymity

Ensuring confidentiality and anonymity was a key consideration in the research. Any identifiable information from the consent form was stored on a Google Document on a password-protected area of the Google Drive attached to my university account. This information was stored separately to all other data and was only accessible by the researcher and supervisor.

Participants were asked to identify a preferred pseudonym which was used throughout transcription, analysis and write up of the research. Any identifiable information such as parent/carer, peers, teacher, professional or school names were also anonymised using pseudonyms.

I also considered how I could ensure the confidentiality of any visual materials made by the participants during the creative project. I ensured that any creative materials produced and shared by the participants did not contain any identifiable images or text or potentially sensitive material.

4.2.5 Power Dynamics

A key consideration of qualitative research is the potential power imbalances between researcher and participant (Hesse-Biber, 2007; Willig, 2013; Yardley, 2000). This was particularly relevant to working with young people (Drew, Duncan & Sawyer, 2010). This research aims to provide an opportunity to hear the voices of the participants and seeks to place the young person at the centre. I consider this to be one-way potential power imbalances are tackled (Vindrola-Padros et al., 2016). Further, the research draws on participatory approaches, providing the participants

with choice and opportunities for agency wherever possible. This places value on the voice of the young person and ensures that there are no assumptions made about what they want (Riessman, 2008). Smith at al., 2009 also suggest that building rapport and making the participant feel comfortable can go some way to redressing the "power play where research expert may meet experiential expert" (p. 180). The inclusion of multiple contact points, providing choice, being flexible in the approach to meet the participants' needs and producing additional differentiated visual materials are all ways in which I attempt to address potential power imbalances.

4.2.6 Ethical Considerations Linked to Interpretation of the Data.

One final area to consider in relation to ethical approaches, is linked specifically to the interpretive nature of the analysis in IPA. Willig (2012) suggests that there are three core strategies that should be considered throughout the interpretation. Firstly, she proposes that there should be "modesty" (p.56) around claims made from the research. To do this, she proposes that the researcher ensures close links to the research question and is reflexive and transparent about any claims in respect of generalisability and transferability. This is explored further in Chapter 3 and again in Chapter 6 and 7. Secondly, she proposes that researchers need to ensure a commitment to the participant's voice and a careful consideration of who "owns the interpretation" (Willig, 2012, p. 12). This is taken into consideration through the creation of the visual maps and the offer (although not largely taken up) to share and hold a 'member check' session with participants.

Finally, Willig, 2012 recommends that the researcher is open to the possibility of alternative interpretations. She suggests that this can be achieved by carefully examining the text and considering the social, temporal, and cultural context and by avoiding "top-down" interpretations (p.59). This is achieved in this study by ensuring that the text is carefully examined with curiosity and openness within the IPA analysis before embarking on the suspicious analysis using psychological theory. This is explored further in the analytic strategy section of this chapter (section 4.8).

4.3 Sample

4.3.1 Sample Size

IPA methodology requires a small, homogenous sample to explore a specific phenomenon, and as such only a small sample size is required (Smith & Osborn, 2003). It is recommended that for a thesis linked to a professional doctorate course, between four and ten participants are needed for an IPA study (Hefferon & Gil-Rodriguez, 2011).

This research also provided the option for participants to complete a creative activity using visual methodologies. Although visual methods are thought to support in the gathering of detailed, rich interview data, they take longer than a qualitative interview study (Drew, Sawyer & Duncan, 2010). These creative sessions were predicted to add anywhere between one and four weeks to the length of the data collection for each participant. This, combined with the addition of an introductory session, check-in session and member check post-analysis made the already tight timescale of the research even more restrictive. This was also exacerbated by the COVID-19 pandemic which caused delays obtaining ethical approval and additional challenges in recruitment. Therefore, I felt that I needed to operate at the lower end of this proposed sample size. As such, I decided to recruit one participant for the pilot study and a further five for the main study.

4.3.2 Selection Criteria

The selection criteria for the research are indicated below:

1. The young person has a CHC defined using the working definition (this has been explored in section 1.2 and will also be explored further below).
2. The young person attends a mainstream school or college setting.
3. The young person is aged between 11 and 18 years.

Given the wide range of health conditions that could be classified as a CHC, considerable time was taken to clearly identify this term to ensure a level of

homogeneity within the sample group. Further detail regarding the decisions made in respect of defining CHCs can be found in Chapter 1.

I felt that there were some health conditions that required additional clarification in respect of their inclusion (or exclusion) in the study. Asthma and eczema are extremely common childhood CHCs but were specifically excluded from the study due to the broad range of severity that can be seen across individuals with the condition (Maslow et al, 2011). Most young people with eczema and asthma require only minimal primary care (RCPCH, 2020), and this suggests for these young people that there would a reduced impact, in comparison to other CHCs, when considering some areas of the selection criteria detailed above, e.g., medical intervention required, threat to life and functional impact.

A similar decision was taken to exclude young people with anaphylaxis, due to vast differences in treatment plans, threat to life and severity between individuals. Finally, childhood cancer was also excluded due to the differences in the education of young people with cancer during their treatment, which tends to be within a hospital school or through home tuition. This means that reintegration into school is required, making this significantly different from other young people with a CHC in this study who attend school throughout the duration of their CHC (Gravestock et al., 2013). This is not to suggest that these CHC do not have significant and severe impact on young people's lives nor that they should not be considered in further research, but merely that inclusion within this study would impact the homogeneity of the sample group, a key factor for carrying out high-quality IPA.

It should be noted that this definition, along with a list of possible CHCs that would be included and those that would be excluded (see above), was sent to the SENCOs and EPs who acted as the gatekeepers during the recruitment phase. I proposed that this filter would ensure that only participants fitting the selection criteria would be provided with the information sheets. I did not ask participants to include a description of their CHC on the consent form, as I felt that this would be sensitive data that could not easily be categorised. Instead, we discussed their CHC along with their parents during the introductory session.

4.4 Recruitment Process

Due to restrictions in place during the COVID-19 pandemic recruitment took place online. An email containing the information sheets was sent to all educational psychologists (EPs) within my service, and trainee educational psychologists (TEPs) on the course with a request to send this to SENCOs or inclusion leads at their secondary schools. SENCOs were then asked forward an email to the parents of any potential applicants. This email included a short introductory email and the two information sheets (Appendix 5 and 6). I also provided my email address so that they could contact me prior to completing the consent form, should they wish.

A link was included on the initial email to an explicit, opt-in, online consent form hosted on a secure, university approved website, Gorilla (Appendix 7). Interested participants were asked, with their parent or legal guardian to complete the secure consent form. This included providing a contact email for the parent/legal guardian.

Once the initial consent form was completed, I contacted the parent/legal guardian to set up an initial video call on the university recommended, secure platform Google Meet. The meeting was attended by both participant and parent and the purpose was threefold; to discuss the information sheet, verbally gain informed consent from both the participant and parent and to explore the creative project further with the participant. During this meeting I presented a PowerPoint (Appendix 8) which visually depicted some possible options. If the participants chose to complete the project, we discussed their preferences and equipment requirements. Finally, further dates were set for check-ins, which were offered either via online calls or through email and for the interview.

> *Reflection: COVID-19 and Recruitment*
>
> I understood from previous TEPs that recruitment was a challenging aspect of the research and this was made even harder by the COVID-19 pandemic. Initially I had indicated that I would attend locality meetings within my service to present the research to them, explain the process and answer any questions. All the recruitment was done via email, which I felt meant that it was much harder to 'keep on the radar'. I was also aware that the SENCOs and EPs were unlikely to have direct contact with young people to talk to them about the research and gauge interest.
>
> I was acutely aware that I was asking school staff to do more just at a time when energy reserves were depleted, and they were in survival mode managing online teacher and key worker bubbles. The young people I wished to recruit were likely to be at home, shielding and managing all that came with being isolated from school and peers. Parents were grappling with home schooling and the additional pressures associated with the pandemic. EPs and TEPs were coming to grips with moving work online. As such, it felt that research was not a priority for anyone, which I understood, but also felt the pressure of the tight timescale to recruit. I remain incredibly grateful to the participants, parents and professionals who gave up their time during this challenging period to take part.

4.5 Participant Information

Table 2 includes the participant's chosen pseudonym alongside key information. It should be noted that there were several contact points with the participants during the study which took place over several months. As such, the table indicates the year group they were in at the time of the interview. To reflect the importance of staying close to the lived experiences of participants within IPA, I chose to include the participant's description of their health condition.

Table 2: Participant details

Pseudonym	Age	Year group	Chronic Health Condition
Autumn	12	8	Type 1 diabetes.
JJ	13	8	Epilepsy. JJ also has a diagnosis of autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), dyslexia and dyspraxia.
Samuel	14	10	Type 1 diabetes (Samuel names this "T1D").
Willow	15	10	Cerebral palsy which impacts on mobility and speech. Willow also describes herself as deaf and explains that she wears a hearing aid.
Amber	15	10	Mitochondrial (genetic) disease which impacts on mobility, balance, muscle weakness and causes joint pain, particularly in the hands. Amber explained that her condition can also impact on her speech and cause fatigue.

During the research process, I made reflective notes regarding the contact I had with each young person detailing my observations, thoughts and feelings. These notes were helpful in providing both context and transparency to the research process as well as proving useful in noting any practical considerations or adaptations that were required. An overview of my reflections, comprised of the notes made at the time, is provided within the Appendix 9 for each participant.

4.6 Pilot Study

4.6.1 Purpose

The main purpose of my pilot study was to help to develop the interview schedule to ascertain if any of the questions or prompts needed modifying (Willig, 2013). I had also developed a visual interview schedule to support the participant before and during the interview (Appendix 10) and used the pilot study to establish if this was

useful and appropriately pitched. As IPA was a new methodology to me, I also considered the pilot study as an opportunity to practice my interviewing technique and to ensure I was competent at using the technology required for online interviewing. I aimed to uncover any potential difficulties which could impact on the reliability of the data (Harding, 2013).

4.6.2 Recruitment

I recruited the pilot participant through a SENCO at one of the schools within my patch. This young person met all the selection criteria and I had not worked with them previously in my role as a trainee educational psychologist (TEP). The parent and the participant were each sent a pilot study information sheet (Appendix 11 and 12) and asked to complete an online pilot consent form (Appendix 12) as described above for the main study.

The pilot study consisted of only the semi-structured interview; the creative project was not undertaken due to time constraints.

4.6.3 Implications

A key outcome from the pilot study related to the creation of a 'visual theme map' at the end of the interview to reflect the key themes identified (Appendix 14). The pilot participant requested feedback from the interview and when considering how best to present this information in an accessible and engaging way, I decided to trial the use of the visual map to represent key information. Although the pilot study was not fully analysed using IPA, the process of creating a concise visual map to feedback key ideas to the young person was helpful, as indicated in the feedback from the young person and their parent. As the main IPA study offered member checks with participants, it was important to ensure the information from the analysis was accessible for them. Therefore, a visual map was created which included photographic presentations of themes and simplified theme labels to ensure the participants could understand and engage with them. I also felt it useful to include quotes from the transcripts with each subordinate theme so that the young person could see how these linked to their original descriptions. An example visual theme

map for Willow demonstrates the presentation of themes in a way that ensures accessibility for the young people taking part (Appendix 15).

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Reflection: Visual Theme Map

While not identified as part of the IPA process, I felt that creating visual maps was reflective of my commitment to a participatory approach wherever possible. I felt it was important that the young people taking part were able to view my interpretations in a way which was accessible to them.

Just as it is important to show the analytic journey form raw date to superordinate themes in IPA procedures, I also felt that the visual map should do the same for the participants. Hence, I added key quoted from their description of their experiences to the visual map.

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4.7 Data Collection

4.7.1 Overview

Data collection took place between July and October 2020. Figure 2 describes the steps that took place in the data collection stage of the research after written consent forms were received.

Figure 2: Description of the stages within the research project

1: Introductory call.
- Google Meet call with parent and participant to discuss information sheet and obtain verbal informed consent.
- Creative project discussed; the participant makes decision about taking part. Visual project guide offered if required to support decision making (Appendix 8).
- If taking part, style, content, equipment and timescale of project are decided.
- Date is then set for check-in and semi-structured interview.
- Both parents and participants present for this session.

2. Creative project.
- If taking part, participant carries out creative project as agreed in stage 1.
- Support provided through the project guide PowerPoint (Appendix 8), which can be referred to at any time, and contact sheet to ensure participant and parent can access support from researcher or other approximate service if required (Appendix 16).

3. Check- In.

- If taking part in the creative project, a 'check- in' secure online Google Meet call is offered. This provides an opportunity for the young person to discuss any concerns and problem solve with the researcher.
- Timescales are renegotiated if required. Project guide PowerPoint (Appendix 8) and contact sheet (Appendix 16) are referred to and resent if required.
- Participants choose if parents are present in the room for the session. However, parents must be accessible if not in the room.
- Secure sharing via email and Google Drive of visual materials is organised if required.

4. Semi-Structured Interview

- A semi-structured interview with the participant will then be carried out on a secure online platform, Interviews will be audio recorded, using a Dictaphone. No visuals are recorded during the interview.
- Interviews may include any participant descriptions or reference to the creative materials produced.
- Participants choose if parents are present in the room for the session. Parents must however be accessible if not in the room.
- At the end of interview, participants are thanked and a debrief is carried out with both participant and parent. This prompts around the contact sheet and signposting to further support services that may be appropriate if required.

5. Member Check

- Once transcription and analysis has been completed participants are offered the opportunity (via email to parents) to be sent the visual map of key themes from their interview (see Appendix 15 for example) and take part in an online member check session. Participants were able to opt into both, either or none of these.
- It should be noted that I did not I complete the member checks for the participants to verify my interpretation but wished to offer an opportunity for them to provide any differing views and insights, which needed to be highlighted (Henwood & Pidegon, 1992).

4.7.2 Creative Project

As indicated above the data collection drew on two methodological approaches: visual and semi-structured interviews. The creative project aims to provide a reflective space in which the young people can retrospectively explore their experiences of managing a CHC while attending a mainstream school. The creative project is used to support their semi-structured interview. I strongly felt that I needed

to ensure that the research was as participatory, young person-centric and as engaging as possible. Whilst I recognised the advantages of visual approaches in supporting participants, particularly young people, to reflect on their experiences (Drew, Duncan & Sawyer, 2010). I did not wish to make any assumptions about the participant's personal preferences or whether they would enjoy or benefit from the visual approach on offer.

As such, I decided that it should be offered as an optional creative task, to be completed however the participant saw fit and found helpful. It was seen to complement the semi-structured interview. The content, method and presentation style of the creative project was explored with, and not decided for, the participants to support their participation and agency. I recognised that this open choice may be overwhelming for some young people and so I developed a project guide PowerPoint (Appendix 8) that was shared with them over email prior to our initial discussion and again during the initial conversation. The sharing of materials created was also optional as the purpose of the task was to stimulate and support reflection in the interview, not so that visual material could be analysed.

Four of the five participants decided to engage in the creative task, three completed the project and two consented to share the creative materials they produced (Amber's watercolour paintings, Appendix 17, and Samuel's animation, Appendix 18). One participant did not express an interest in the creative task, suggesting that they did not feel that this would help them to discuss their experiences, instead stating that they "just preferred to talk". I felt that for those participants who did complete and share their creative project it was helpful and added depth to some of our discussions in the interview. The other participants also seemed able to take part without using it. Hence, it felt appropriate that I had offered everyone the choice and not made assumptions about what would work for the individual participants.

4.7.3 Semi-Structured Interviews

The aim of an interview is to provide an opportunity for participants to "tell their own stories in their own words" (Smith et al, 2009, p. 57). This research was a retrospective opportunity to share their experiences of having a CHC whilst attending

a mainstream school. I was aware that without providing additional information about the timeframe for reflection that the participants could talk in general about their experiences spanning preschool, primary and secondary school. Therefore, at the start of the interview I asked them to focus on exploring their recent experiences of being in secondary school. Most participants spoke purely about secondary experiences although two participants (Samuel and Autumn) briefly explored the differences in treatment plans and equipment between primary and secondary schools. I did not attempt to redirect this part of the interview as I felt the information being shared was relevant as it enabled participants to make a comparison between the two, hence allowing an in-depth and detailed exploration of the current situation.

A semi-structured interview, guided by an interview schedule, allowed me to plan key areas of discussion but also provided space and flexibility to follow the participant's agenda and allow them to share their viewpoints as they see fit (Langdridge, 2007). To ensure that the research remained in line with phenological approaches, it was critical the interview questions were "open-ended and non-directive" (Willig, 2013, p.87. I also considered guidance from Smith, Flowers & Larkin, 2009 that suggests that the interviews are structured in a "logical" order for questions starting with "scene setting" and "funnelling" towards potentially more sensitive issues (Smith et al, 2009, p.61). I also included an open-ended question within the interview schedule for the participants who completed the visual task so that they could talk openly about their personal experiences and sense making, using this medium. It was hoped that this would allow me to guide them away from "closed questions" (Willig, 2013, p.161). The interview schedule was then shared and refined based on discussions with peers and my research tutor.

An interview schedule was devised (Appendix 19) which contained seven open, exploratory questions based around key areas I hoped to discuss in the interview (eight for those participants who had completed the creative project). Further I identified additional prompts for each question, to ensure that participants were fully encouraged to talk fully about their experiences. Within the interviews I was also alert to occasions when I needed to encourage participant to elaborate on what had been said, taking care not to just offer my opinion so that they could "agree or disagree with statements offered" (Willig, 2013, p.87), which is not fitting with the

phenomenological approach. I found that some participants responded well to the prompt "can you tell me more about that?" and this enabled them to explore their views in more depth. This did result in a lengthy schedule, not necessarily in line with the "less is more" principle (Hefferon & Gil-Rodriguez, 2011, P.757). However, I felt that this detailed interview schedule allowed me to avoid collecting thin data by preparing for participants who are not used to being interviewed and who perhaps felt less able to talk.

The question and prompts within the schedule are likely based around my prior knowledge of the subject, despite best efforts to remain objective (Larkin, Watts & Clifton, 2006). I was also aware that "participants' talking may be determined by questions asked by the interviewer" (Smith at al., 2009, p. 58). Therefore, I acknowledged that by preparing such a detailed schedule there was potential for me to guide the content of the interview. I endeavoured not to rely heavily on the interview schedule and additional prompts and attempted to use this as a guide rather than a script. However, as a first time IPA interviewer the schedule also provided me with reassurance, meaning that I could be an attentive listener in the interviews and not anxious about what to ask next (Smith et al., 2009, p. 59).

At times, I did feel that the young people struggled to "talk at length" (Smith et al, 2009, p. 59) in response to questions, particularly initially. I wondered if it was a particular challenge considering the age group of the young people I was working with, my own inexperience as an IPA interviewer, having to work online or if there was not enough time spent on rapport building. The interviews with the young people who had completed the creative project started with them talking about their work. This appeared to work well and provided an opportunity for them to openly describe what they had done, which they were able to do at reasonable length. This also seamlessly led onto other areas with minimal input required. This again supported the idea that visual methodologies were helpful for at least some of the participants. On a few occasions, I found that "deliberate naivety" (Oxley, 2016) was also helpful and elicited some further exploration of the subject form the participant if the interview stalled and they seemed unsure of what to say.

Interviews were conducted online, over Google Meet, and audio recorded. Recordings were stored in line with General Data Protection Regulations (GDPR) on a secure, university Google account. There were some logistical issues relating to sound quality and connectivity, and in at least three interviews there were periods in which I was unable to hear sections of speech, requiring me to ask the participant to repeat. I also needed to clarify and check what had been said at times within the interview and I felt that this impacted on the natural flow of the interview.

Reflection: Visual Interview Schedule

The feedback from the pilot study indicated the visual supports were useful to the participant. As a result, I created an amended visual version of the interview schedule (Appendix 10). This was sent to participants prior to the interview. I hoped that this would reduce any anxiety or feelings of uncertainty of the questions being asked, as well as allow the participants to reflect on their experiences beforehand which could support them to provide rich and detailed accounts within the interview. However, I worried that this could also be potentially leading and directive to certain topic areas. On balance, I decided that it would be helpful for the participants to have this support available even if it was not used.

I asked participants if they would like me to share the visual schedule during the interview, hoping that by providing choice I would promote agency, rapport and avoid unnecessary use. Four participants either did not want to see this or referred to it very briefly, instead preferring to talk more openly about their experiences, which was more fitting of an IPA semi-structured interview. One participant relied more heavily on visual support. Due to this participant's additional learning needs we agreed with the participant to adapt the interviews into three shorter sessions, and I then created a different visual schedule for each session (Appendix 20).

4.7.4 Transcription

The interviews were transcribed verbatim, apart from the anonymisation of identifying features, and stored under the chosen pseudonym. IPA dictates that as it is largely interested in the content, only additional details such as laughing, crying, hesitations or pauses were recorded (Smith et al, 2009, p. 73). A code for transcription can be found at the top of every transcript (see Appendix 21 for an

example). Text lines are numbered to ensure that they can be referred to with ease within the thesis.

4.8 Analytic strategy

4.8.1 Overview

This section aims to provide a description and explanation of the analysis process and findings from the raw data through to the identification of overarching themes and finally their links to psychological theory.

IPA shares a common set of analytic processes but there can be flexibility and creativity in their application provided the focus does not deviate from "the participants' attempts to make sense of their experiences" (Smith et al,2009, p. 79). Within this study a procedural approach to analysis, traversing from individual experiences to shared experiences and from the phenomenological to the interpretative, is outlined in Figure 3.

Reflection: Using a Computer for Analysis:

Smith, Flowers, and Larkin (2009) recommend that hard copy material is used by novice researchers in order that they can show the "flow of the analysis" (p. 100). I was immediately concerned about the use of hard copy material as during previous research experiences (using thematic analysis) I had become quickly overwhelmed by physical copies of the text, particularly when sorting emergent themes. This led to some confusion which was only resolved by me translating hard copy theme sorts onto a computer, which I found far easier to manipulate. Despite recognising that this choice was right for me and within the 'flexibility' of IPA, I was very mindful that I was not following the recommendations suggested for novice researchers. I felt at times this may have led to me creating more evidence (tables and provision of key quotes) than perhaps was necessary.

Figure 3: Staged approach to analysis developed with reference to common IPA processes detailed in Smith, Flowers and Larkin (2009).

1. IPA Analysis of Data

Stages 1-3 completed for all participants

Stage 1: Transcription phase

Stage 1: Listening and line by line **transcription of interviews.**

Stage 2: Exploratory phase

Stage 2: **Exploratory notes** made, and **emergent patterns and themes** identified.

Stage 3: Thematic phase

Stage 3: Interpretation of the transcript and emergent themes to identify patterns and connections within emergent themes leading initially to the formation of **subordinate themes** and finally **superordinate themes**.

Stage 4: Patterns across the cases

Stage 4: Identification of areas of **convergence and divergence** within sub and superordinate themes across the participants.

2. Relating Findings to Psychological Theory

Stage 5 completed for all participants.

Stage 5: Application of theory

Stage 5: Sub and superordinate themes for each individual participant were then explored within the **context of existing psychological theory and literature**. Within this research the findings from the analysis were explored through the lens of self-determination theory (SDT).

4.8.2 Analysis of Data, Stage 1: Transcription

Each audio recorded interview was transcribed verbatim. I chose to transcribe the interviews myself and although a lengthy process, I felt that it provided an opportunity to gain familiarity with the transcripts prior to the analysis. The transcribed interview was read several times to gain familiarity with the text.

4.8.3 Analysis of Data, Stage 2: Exploratory phase

The exploratory phase consisted of reading the transcript on a line-by-line basis whilst making exploratory notes. During the first re-reading, notes were recorded at a

descriptive, content level only and colour coded in blue. During a second reading, I focused on a linguistic level and this was colour coded green. A third reading worked at an interpretive level, using personal reflection to interpret the transcript to move beyond the initial descriptive level of analysis in the first reading, "away from the explicit claims of the participant" (Smith et al, 2009, p. 88). These notes were colour coded pink.

A further reading of the transcript, moving between the notes made and the text, allowed these comments to be viewed in a broader context to ensure that the interpretation remained in line with the overall description of experience from the participant. Throughout this iterative process the double hermeneutic was held in mind as I attempted to make sense of the participant's attempts to make sense of their experiences of attending school with a CHC (Smith & Osborn, 2003).

Initial comments were then explored with a view to reducing and streamlining the content by identifying emergent themes. The creation of emergent themes at this stage involved, moving between the participant's description of their experiences and my interpretation of them to develop a statement which reflected the "psychological essence" of what was being said (Smith et al,2009, p. 92).

Reflection: Notes to Emergent Themes

I felt that identifying and labelling emergent themes which "capture something of the essential quality of what is represented by the text" (Willig, 2013, p. 88) was a challenging and confusing task at times. It felt a delicate balance to create a statement which spoke both to the unique experience of the individual and my interpretation of it whilst also ensuring it was "concise and pithy" (Smith, Flowers & Larkin, 2009, p. 2). I found that a dynamic, multidirectional analytic approach was useful here. Moving back and forth between text and themes to look both in part and in whole (Willig, 2013, p. 86) helped to create and name the emergent themes. Reviewing the emergent themes frequently throughout the analysis process enabled me to refine and amend them over time.

4.8.4 Analysis of Data, Stage 3: Thematic phase

During the thematic phase, individual transcripts were explored with a view to identifying patterns and connection across the identified emergent themes to create subordinate themes. Initially this was completed via abstraction, described as "putting like with like" (Smith et al 2009, p. 96) and identifying a subordinate title for the group. Most of the themes were created using this analytic method, but there were a number that could not be connected in this way. For these emergent themes, differing analytic techniques were applied. Some emergent themes could be grouped through their oppositional relationship to one another, and several emergent themes were grouped together based on the context in which they were described by the participant. Connections were then identified within the subordinate themes, and they were grouped to create superordinate themes using both abstraction and subsumption.

Superordinate themes were given titles which described the "conceptual nature of the themes therein" (Eatough, Smith & Shaw 2008, p.12). A table of superordinate themes was produced that shows the subordinate and emergent themes alongside illustrative quotes from the transcript for each participant (example in Appendix 22). Key phrases from the text are identified next to each emergent theme within the table to ensure that the "integrity of the participant's experiences has been preserved as much as possible" (Eatough & Smith, 2006, p.487).

Stages 1-3 were repeated for all five interview transcripts before completing stage 4, the cross-participant analysis, and onto a secondary phase which involved the application of psychological theory. Making a clear distinction between these phases enabled the analysis to be completed free from the influence of pre-existing theory. This supported the analysis to remain intricately linked to the IPA principles of idiography, hermeneutics and phenomenology (Smith et al,2009,).

4.8.5 Analysis of Data, Stage 4: Cross Participant Analysis

This stage consisted of a cross participant analysis comparing the sub and superordinate themes across all participants. A cross participant analysis table was created identifying patterns of convergence and divergence (Appendix 23) and an overview table of superordinate themes and illustrative quotes across all participants was also created (Appendix 24).

4.8.6 Stage 5: Relating Findings to Psychological Theory

During the analysis of the data, I noted that there were repeated themes linking to autonomy, relatedness and competence emerging across all the participants' transcripts. I subsequently identified potential links to self-determination theory (SDT) (Ryan & Deci, 2017) which centres on the three innate psychological needs, competence, relatedness and autonomy and their role in motivation, wellbeing, and growth. Strong links between SDT and health research were identified and explored in Chapter 2. The recent systematic review completed by Eassey et al. (2020) highlights the use of SDT as framework through which "to understand people's experiences of living with and managing a chronic condition" (p.284). As such, I felt that this further indicated that SDT could be a helpful analytic lens through which the participants' experiences could be further explored.

Therefore, I decided that I would include a secondary process in which I viewed the findings of the analysis through the lens of SDT. The superordinate themes identified in the analysis were reviewed, restructured and renamed in respect of their perceived links to SDT. This process is explored further in Chapter 6.

This additional and distinct layer of interpretation is not present in all IPA studies. The implications of this additional layer of interpretation are explored further in section 4.9.

Reflection: Exploring Analysis through Psychological Theory

The decision to view the analysis through the lens of SDT was difficult. I felt that by employing this differing approach to interpretation I was somehow accepting an 'expert' position and claiming to be able to understand or shape the participants' experiences in a way that they perhaps would not recognise. This felt at odds with my first research question and my commitment to listening to and reflecting young people's voices. However, I also recognised that by linking the analysis to theory I had the potential to provide a way in which the participants' experiences could be presented in a concise and accessible without attempting to generalise the findings.

I felt that there was value in this secondary process and additional layer of interpretation of the analysis especially when considering application in a school setting and my second research question. So, despite my concerns I included it as part of the analytic strategy, making sure that I was explicit and reflexive about my intentions and the method of interpretation during both the analysis and whilst relating the findings to psychological theory.

4.9 Interpretive Approaches

4.9.1 Empathetic and Suspicious Interpretation

This research encompassed a primary IPA analysis and a secondary process in which I related the findings to psychological theory. The IPA analysis was in line with

an empathetic interpretation of the transcripts while the secondary process consisted of a form of interpretation in which the findings of the analysis were explored through psychological theory in line with suspicious interpretation. Willig (2012) suggests that an empathetic interpretation focuses on what is presented in participant transcripts, attending to features and noting patterns to increase understanding rather than attempting to uncover underlying meaning. Suspicious interpretation instead uses pre-existing psychological theory to uncover deeper meaning (Ricoeur, 1996, p. 152). There is therefore an assumption made when using this layer of interpretation that "to experience something is not the same as understanding it" (Willig, 2012, p.13). It could be considered that there is some distance between the interpretation of the participants' experiences through theory (Smith, 2004). As such, the exploration of findings through SDT, although useful in providing novel insight, should be viewed as more "tentative and speculative" (Willig, 2013, p. 92).

Eatough & Smith, 2008 suggest that good IPA studies engage with a "dual reading" of the data (p.191). Willig, 2012 suggests that this is rooted in both in initial "sense making" of participants' experiences and a "deeper hermeneutic interpretation which may be different from the one the participant may offer" of them (p.18). It has been suggested connecting findings to psychological research can help to "shed light on existing nomothetic research" (Smith et al,2009, p. 38) and support the researcher in attempting to understand the participant's world (Danermark et al., 2002).

4.9.2 Commitment to an Idiographic Approach

The participants' experiences are subjective and therefore care needed to be taken regarding attempts to generalise findings beyond the parameters of the study. However, I felt that the secondary process, linking the findings of the analysis to SDT, could be helpful in potentially providing a way of further understanding my findings while also remaining close to their experiences. I also felt that it could be applicable for education professionals working with young people with a CHC while also remaining close to their experiences. Hence, this layer of interpretation links to my second research question: What can professionals learn from these experiences?

4.10 Evidence of Analytic Journey

It is hoped that the provision of documentation of each of the six stages of analysis undertaken in this study (Appendix 21-25) provides robust evidence of the analytic journey (Eatough & Smith, 2008) so that a clear pathway from raw data to the overarching superordinate themes can be seen.

Chapter 5: Findings

5.1 Overview

This research study attempts to hear the voices of young people (YP) who have a CHC so that the two research questions identified in Chapter 2.6 can be further explored. This chapter addresses the first research question: 'How do young people with a CHC experience mainstream secondary school?'. It does so by exploring in detail the first step of the analytic strategy (Figure 3), an analysis of the participants' transcripts, using IPA. The secondary process, also outlined in the analytic strategy, in which the findings are related to psychological theory, will then be explored in Chapter 6.

During the initial exploratory phase of the IPA, 91 emergent themes were identified across the five participants' interviews. I then completed the steps of analysis as outlined in the analytic strategy (Figure 3) and attempted to make sense of these themes by reducing the volume whilst still ensuring that the complexity and uniqueness of the individual's experience was retained (Smith et al., 2009, p.91). As a result, 22 subordinate themes were created which were then subsumed under five overarching superordinate themes. The five superordinate themes identified in the analysis were felt to reflect key facets of the five participants' experiences. These are illustrated below in Figure 4.

Figure 4: Superordinate themes across the participant group
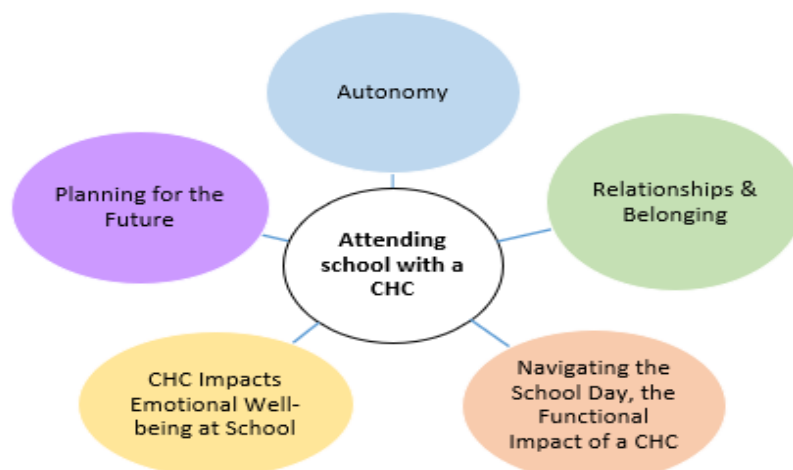
In keeping with IPA, excerpts from the participants' transcripts feature throughout this chapter (Smith et al, 2009). As such, the superordinate themes identified in the analysis, are also presented alongside their component subordinate themes and an example illustrative quote from the participants' transcripts in Table 3.

Table 3: *Table of overarching super and subordinate themes*

Superordinate Theme	Subordinate Theme	Illustrative Quotes
1. Autonomy	1.1 Lack of Person-centred practice	**Willow**- "sometimes they just seem to be like oh everyone is the same".
	1.2 Loss of control.	**JJ**- "No. They just chose it".
	1.3 Lack of Independence.	**Samuel**- "They feel that I can't manage it myself".
	1.4 Feeling empowered.	**Autumn:** ""I just do it!"
2. Relationships and Belonging	2.1 CHC impacts relationships with adults.	**Autumn**- "None of the teachers are really helpful".
	2.2 Conflict with adults.	**Samuel**- "relationship has never been good."
	2.3 Support provided by adults.	**Willow:** "it's like a different TA in each lesson."
	2.4 CHC impacts relationships with peers.	**Amber**- "they push me towards to being friends more with disabled people"
	2.5 Feeling different.	Willow: "...don't want to be treated differently to everyone else but sometimes I need to be treated differently"
3. Navigating the School Day, the Functional Impact of a CHC.	3.1 CHC impacts learning.	**Autumn**- "I can't really concentrate".
	3.2 CHC impacts attendance.	**Samuel**- "I missed a lot of time".
	3.3 CHC limits social and extracurricular opportunities in school.	**Amber**- "I couldn't sit with my friends at lunch."
	3.4 Physical symptoms of CHC impact on the school day.	**Amber:** ""Monster in the background is fatigue"
	3.5 The School environment.	**Amber:** "Bigger classrooms ...some are small and hard to get around."
4. CHC Impacts Emotional Well-being at School.	4.1 CHC impacts self-esteem.	**JJ**- "basically I am really bad".
	4.2 CHC results in undesirable emotions being experienced in school	**Autumn**- "I just get frustrated".
	4.3 Loss of normality	**Amber:** ""I can't just go with my friends."
	4.4 Coping mechanisms	**Willow:** "some time to myself ...just like relax for a bit"
5. Planning for the Future	5.1 Setting goals	**Samuel**- "Going to try to (- -) not involve T1D in my future". **Willow**- "I would like to be a human rights Lawyer
	5.2 Concerns for the future	**Willow:** "when I go into uni the big worry is around making sure that I've got the right support and the right accessibility"

In this Chapter, each of the superordinate themes identified in the analysis will be discussed in turn, providing overarching interpretations of the theme and an exploration of the connected subordinate themes. Illustrative quotes will be used throughout to highlight links to the original transcripts.

5.2 Convergence and Divergence of Themes

It is critical that the analysis carried out within IPA studies determine shared themes but also reflect "the particular way in which these themes play out for individuals" (Smith, 2011, p.10). Therefore, consideration will also be paid to the patterns of convergence and divergence between participants' individual descriptions of their experiences and the overarching superordinate themes. An overview of the convergence and divergence with super and subordinate themes can be seen in Table 4 (Appendix 23). Patterns of convergence and divergence between participants within each theme will be explored in the individual theme sections.

Table 4: Convergence and divergence across the super and subordinate themes

Participants	Autonomy				Relationships & Belonging.					Navigating the school day, the functional impact of a CHC.					CHC impacts emotional well-being at school.				Planning for the Future	
	Lack of person-centred practice.	Lack of control	Lack of independence.	Feeling empowered.	CHC impacts relationships with peers.	CHC impacts relationships with adults	Feeling different.	Support provided by adults.	Conflict with adults.	CHC Impacts learning	CHC Impacts attendance	CHC limits social and extracurricular opportunities in school.	Physical symptoms of CHC impact on the school day.	The school environment.	CHC impacts Self-esteem.	CHC results in undesirable emotions being experienced in school.	Loss of Normality	Coping mechanisms	Setting goals	Concerns for the future
Willow	☑	☑	☑	☑	☑	☑	☑	☑	☒	☑	☑	☑	☑	☒	☑	☑	☑	☑	☑	☑
Samuel	☑	☑	☑	☒	☑	☑	☑	☒	☑	☑	☒	☑	☑	☒	☑	☑	☑	☑	☑	☒
JJ	☑	☑	☑	☒	☑	☑	☒	☑	☒	☑	☑	☑	☑	☑	☑	☑	☒	☑	☒	☒
Autumn	☑	☑	☒	☑	☑	☑	☑	☒	☑	☑	☑	☑	☑	☑	☒	☑	☑	☑	☒	☒
Amber	☑	☑	☑	☑	☑	☑	☑	☑	☒	☑	☑	☑	☑	☑	☒	☑	☑	☑	☑	☑

5.3 Superordinate Theme 1: Autonomy

5.3.1 Overview

Figure 5: Autonomy: Superordinate Theme and Subordinate Themes
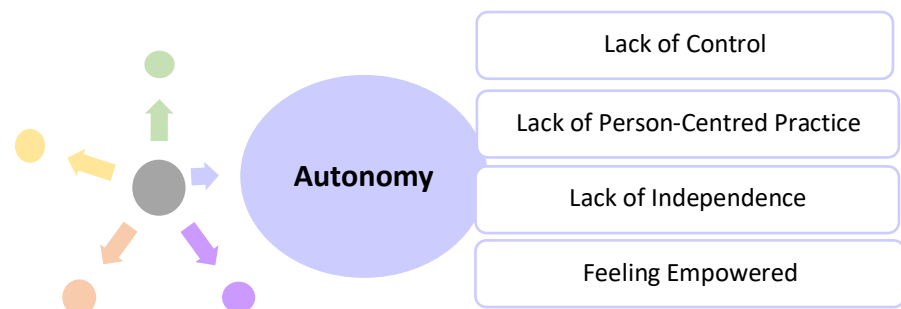
Autonomy was identified as a theme in the analysis across all five of the participants' transcripts. Autonomy can be described as "the ability to think, feel, and make decisions by oneself" (Nunez & Leon, 2015, p276) and autonomous behaviour as "volitional and self-endorsed" (Eassey et al., 2020, p.272). For the purpose of this study autonomy is interpreted as the young person having opportunities to be independent, to feel in control and to make choices that influence their environment. The superordinate theme 'autonomy' was conceptualised from four subordinate themes. Three of the subordinate themes represent a sense that the participants are experiencing a lack of autonomy. In contrast, one subordinate theme represents feeling autonomous and empowered. It felt important that these were grouped together, as analysis of three participants' transcripts identify subordinate themes of 'feeling empowered' alongside themes of 'lacking autonomy' in their interview. This suggested to me that being autonomous is not a consistent state for the participants but is contextually driven. As such, keeping them together in one superordinate theme felt appropriate despite them being polarised states.

Lack of autonomy comprised three subordinate themes: lack of control, lack of person-centred practice and lack of independence. Lack of control and lack of independence can be clearly mapped onto the understanding of autonomy described above. However, the connection to person-centred practice may need further

explanation. Person-centred approaches place the young person at the centre of planning and decision making. Young people are considered experts of their own experiences and therefore their views drive the support they receive (O'Brien & O'Brien, 2002). The use, or lack of person-centred practice, by the adults around the participants can therefore be viewed as either a support or a barrier to them behaving autonomously, hence the link to the superordinate theme.

5.3.2 Subordinate Theme: Lack of Control

The subordinate theme describing a lack of control was identified across all five participants' transcripts. Lack of control was interpreted to consist of emergent themes describing feelings of helplessness, limited choice and power imbalances. Limitations in choice and power imbalances were consistently identified across all participants, but the feelings of helplessness were only identified in Amber and Willow's transcripts.

Emergent themes associated with limited choice and a sense of being excluded from decision making were identified in four of the five participants' transcripts, with only Autumn not appearing to have any emergent themes in this area. I noted that participants consistently referred to adults making choices for them, particularly regarding the management of their health conditions.

> JJ: "No they just choose it." (Line 126)
>
> Samuel: "Tell me…" (Line 26) "Told me…" (Line 230) "Pull me out…have to go." (Line 284)
>
> Amber: "I want to do something else other than school, but I can't." (Line 310)

Themes associated with power imbalances also feed into the subordinate theme of lacking control. All five participants described experiences in which there appeared to be an unequal power balance between themselves and the adults around them in school. The language used by participants describes being forced or done to rather than consulted, encouraged or supported. This is suggestive of a power imbalance, with the adults holding the power and therefore being in control of these situations.

Amber: "Held back..." (Line 24)
JJ: "Take me..." (Line 371)
Willow: "They don't let me out." (Line 151)

These perceived power imbalances were largely centred around interactions with teachers and teaching assistants (TAs) although some participants (Samuel, JJ and Amber) also describe their experiences with external medical professionals such as the school nurse, speech therapist and doctors.

Samuel: "My management was fine. There wasn't an issue. At all. But all of a sudden, she* made me miss a lesson which I liked. She* made me miss my break and this happens a lot." (Line 261)
*she= school nurse

Further there was a sense from Autumn and Samuel that adults do not explain themselves or the reasons for decisions they make. This could be interpreted as the adults assuming power and compliance, the effect on the participant being a feeling that they lack control.

Samuel: "She began to just stop doing it. I'm not sure why." (Line 287)

Amber demonstrates a sense of helplessness when she described a situation in which she repeatedly requests help from adults with fixing a broken disabled toilet door. I inferred that Amber felt hopeless and despondent when she recounted their inaction, which I felt highlighted the lack of control she feels over practical decisions which directly impact on her school life, wellbeing and health condition.

Amber: "I wanted (/) to change for a while now but they haven't done anything about it." (Line 351)

5.3.3 Subordinate Theme: Lack of Person-Centred Practice

Subordinate themes describing a lack of person-centred practice was identified in all five of the participants' transcripts. This subordinate theme consisted of emergent

themes of not feeling heard and a perceived lack of understanding of the unique circumstances surrounding the individual. Emergent themes indicating that adults in school lack an awareness and understanding of both the individual's needs and their experience were identified for all participants. There were, however, significant differences in both the magnitude and context between the participants.

Analysis of Samuel's transcript suggested to me that he felt that school staff lacked an understanding of his individual needs because they were too focused on applying generalised external policies rooted in the medical model and set by the government or health professionals. There is a sense that Samuel felt that by doing this staff were missing his unique experiences and failing to understand the variability of symptoms, management procedures and different ways that the CHC can impact individuals. Samuel appeared to perceive that this lack of understanding led to them imposing "blank" (line 25) procedures and rules in school which he felt were unnecessary and unhelpful for him. This appeared to be a source of great frustration for Samuel, and he consistently reported feeling that these policies, procedures, and rules are "annoying" (line 47) and "pointless" (line 58). The idea that staff over involve themselves in aspects of the management of his health condition because of their limited awareness of his unique experiences was a strong theme emerging from Samuel's transcript.

Image 1: Still from Samuel's animation depicting perception of government involvement in decision making.
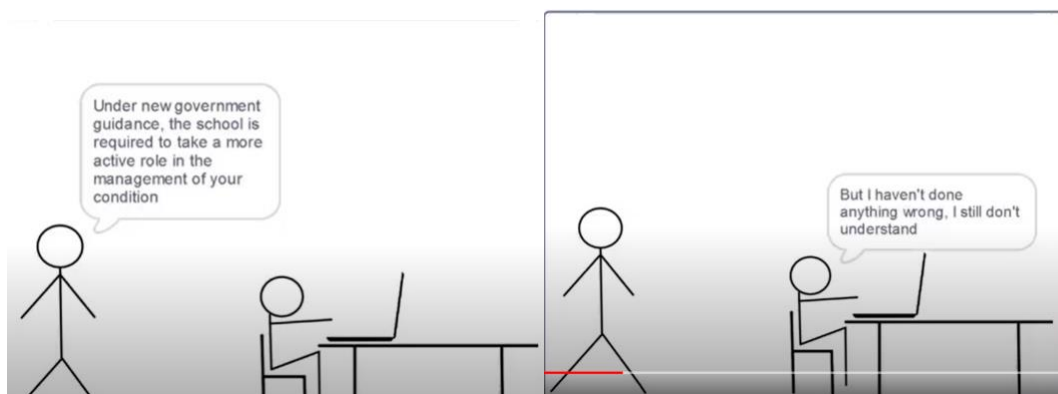
> Samuel: "If something goes wrong with one person then the government assumes that it applies to every single other person. So, if one school makes a mistake then the government thinks all of the other schools also are making that mistake and because of that everyone is affected, just because of that one person." (Line 7-11)

Similarly, Willow indicated she also felt staff lacked an understanding of her needs because they were applying a generalised medical model of disability looking at what is wrong, rather than focusing on her as an individual and considering what she needs.

> Willow: "it's just like trying to understand what a disability is like for some other people and what it's like for others. Everyone is different and (- -) I think sometimes they just seem to be like 'oh everyone is the same in a disability place and it just (/) Sometimes I wish they would just understand more." (Line 363-369)

Unlike Samuel, Autumn indicated that a limited understanding of her medical condition by school staff led to failure to act or intervene, rather than an over involvement. In the interview, Autumn discusses the increased impact of catching common illnesses such as a cold which, in comparison to her peers, requires additional recovery time away from school due to her CHC. It appears that Autumn feels that the focus on '100 per cent attendance' creates an ethos which encourages peers to attend school when they are unwell. Autumn appears to consider that these policies demonstrate a lack of awareness and consideration to the increased risk this may pose to her and other students with CHC.

> Autumn: "So when the school say come in even if you've got a cold then I have to get that cold and I have to have a week off school if I get that cold because I can't go to school with it (--)"
> Interviewer: "And what is that like?"
> Autumn: "(- -) It's annoying because they could just prevent that by one person with a cold not coming to school." (Line 37-42)

Willow also highlighted the impact of teachers not fully understanding her physical symptoms, specifically her fatigue and her headaches, which subsequently affects the support they provide in school and negatively impacts on her ability to focus and learn when in the classroom. Willow appears to indicate that she feels a person-

centred approach when managing her physical symptoms would have a positive impact on her school experience.

> Willow: "...because they say I'm not different to everybody else when you are tired but it kind of is (- -) Because (- - -) I'm using more energy than everybody else is and it's just (-) annoying when they say that because it means that they don't really have much information about what it actually feels like." (Line 251-256)

Emergent themes relating to participants expressing that their voices were unheard by adults in school were present in four of the participants' transcripts, but there was variation regarding the context and by whom this was felt. I inferred that Autumn and Willow both feel that school staff do not listen or act on their views in relation to the management of their symptoms within school. Autumn described a situation in which she was unwell with a cold, which can impact on the stability of blood sugar levels, and the adults around her did not listen to her requests to go home, resulting in a risky delay. Similarly, Willow described situations in which she requests to leave the classroom, as the noise exacerbates her headache, but adults do not listen and refuse to let her leave. Both these scenarios undermine core concepts of person-centred practice by failing to hear and act on the individual's views.

> Willow: "I guess that I'm allowed to ask but I think it is a bit annoying when they say no as they don't really understand how bad my headaches can get because of the noise." (Line 137-139)

Emergent themes around feeling that their views and opinions are not considered in respect of the support they receive from teaching assistants were also identified in Autumn and Willow's transcripts. There is a sense that they both accept the variability in support provided and understand the logistical reasons for this, however not being involved in planning or having their opinions considered by decision-makers also indicates that the school is not always employing person-centred practice.

> Willow: "I have just started to get used to it, because I can't really decide what TA I get." (Line 95-96)

5.3.4 Subordinate Theme: Lack of Independence

A subordinate theme reflecting a lack of independence emerged in four of the participants' transcripts, with only one participant, Autumn, not appearing to describe any experiences linking to this theme.

I inferred that both Samuel and Willow described that some adults in school are too involved at times, almost bordering on interference, which appears to be a significant barrier to their independence and a source of frustration. Samuel appeared to describe a lack of trust from adults in his ability to manage his CHC and medication by himself. Willow's description of adults impairing her independence, however, appears to refer more broadly to her interactions across the school day in various contexts. I wondered if this difference was due to the visibility of Willow's health needs, which impact her mobility and require equipment such as a wheelchair at times. I considered that this visibility may act as a constant reminder of Willow's condition and affect the adults' behaviour leading to enhanced adult involvement, whether needed or not, in all aspects of her school life. Both Willow and Samuel clearly indicated a desire to be independent and reduce the level of adult involvement.

> Samuel: "They feel that I can't manage it myself and that's mostly because that is what they have been told. But, yeah, they just like feel that they have to control it and they feel that they need to be active in managing it and that I can't do it myself." (Line 360-363)
> Willow: "Some of them just like try to do everything for me." (Line 83)

> Samuel: "it's important for them to like just (-) let me manage it because I'll be able to..." (Line 203-204)
>
> Willow: "I definitely prefer to have that independence." (Line 81)

In her interview, Amber recounted situations where adults "grab" (line 413) her wheelchair to take her where they want her to go without consulting her. I sensed a deep frustration regarding both her lack of independence but also the at the loss of control. I felt that Amber strongly desired independence and felt confident and

competent in her use of her wheelchair, even if this was not seen and understood by the adults around her.

> Amber: "It's taking away my rights to do it myself." (Line 415)
>
> "I like doing stuff for myself. It's like I can't do that…" (Line 432).

5.3.5 Subordinate Theme: Feeling Empowered

Despite subordinate themes relating to lack of autonomy emerging for all participants, three participants also discussed scenarios in which I interpreted that they felt empowered and autonomous. I theorised that the environment, interactions, support and context of a situation were all impacting on the participants' feelings of autonomy. I further recognised that there appeared to be a balance between the lack of autonomy and feeling empowered and that this varied for the participants. My interpretation of Autumn's experiences led me to believe that, on balance, she felt empowered and autonomous, particularly in regarding the management of her health needs.

> Interviewer: "do you have a particular adult in charge of the medical needs in school?"
> Autumn: "No that's me."
> Interviewer: "You are in charge?"
> Autumn: "Yep. (- - -)" (Line 214-217)

Willow also appeared to desire increased autonomy and appreciated opportunities to be independent. Her sense of autonomy and empowerment is supported at times by some teaching assistants who help her to work more independently in the classroom, although she recognised that this is not a consistent approach from all staff.

> Willow: "It depends on what TA you've got like um some TAs will let you be really independent, and some won't and it's just depending on what they have been told to do …" (Line 57)

Amber discussed her involvement in making decisions around how to manage her fatigue and I interpreted this as an example of taking control and feeling empowered.

However, for Samuel, despite a strong desire to be autonomous in managing his health in school and a confidence in his ability to do so, I perceived that this balance was skewed towards not feeling empowered.

5.4 Superordinate Theme 2: Relationships and Belonging.

5.4.1 Overview

Figure 6: Relationships: superordinate theme and subordinate themes
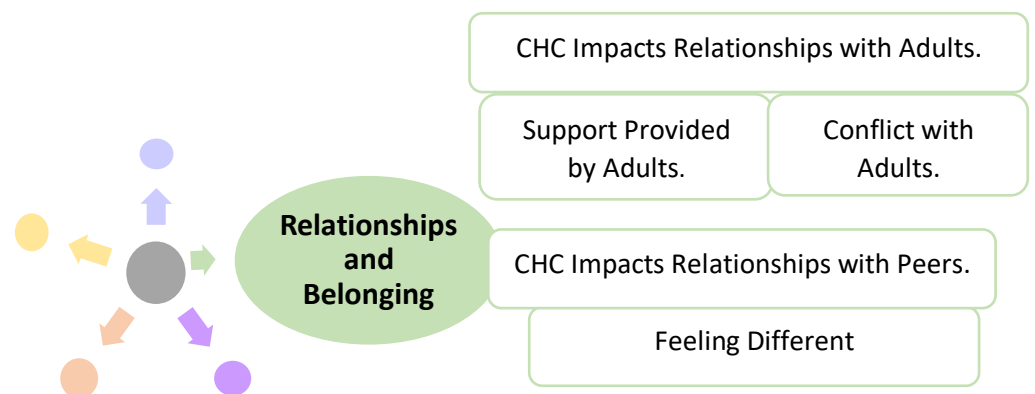
The second superordinate theme that emerged from the participants' transcripts was linked to the impact of their health condition on their relationships. I considered this superordinate theme to consist of five subordinate themes as shown in Figure 6.

My interpretation of the transcripts suggested that all five participants were indicating that they felt their health condition impacted on both their relationships with adults and peers in some way. There was, however, variation as to how this was experienced by each of the participants. The five identified subordinate themes will be explored in the sections below.

5.4.2 Subordinate Theme: CHC Impacts Relationships with Adults

I inferred that all five of the participants experienced positive relationships with at least some of the adults at their school. Three of the participants identified a particular member of staff with whom they had developed a strong bond and felt were helpful and supportive to them. Willow appears to have a special bond with a

teaching assistant (TA) that she has worked with over several years, and whom she describes as her "main" (line 104) TA. I interpreted that this relationship developed over time, suggesting to me a familiarity and that the extended periods of time spent together was the key factor in this relationship being so successful. Amber, however, appeared to describe a close relationship with an adult whom she feels is particularly supportive, not because of the time spent together, but because this adult makes the effort to understand her health condition and provide additional support in class in a way that other teachers do not. This idea that teachers think about her and keep her needs in mind when planning their lesson (line 379), appears to be an important factor for Amber in identifying this as a positive relationship.

> Amber: "My English teacher is really supportive and makes sure that I have the work that they are doing on the board. She prints them off for me." (Line 379-381)

Autumn also appeared to highlight one adult as being particularly supportive; a member of staff who also has diabetes. This shared experience seems to be important to Autumn and there is a sense that this member of staff is not only helpful from a practical point of view, in terms of helping with medical equipment, but also provides Autumn with an opportunity to feel understood by an adult in school. I wondered whether this helped Autumn to normalise the additional routines and responsibilities she is expected to undertake as part of managing her diabetes in school.

> Autumn: "I mean I've got a teacher at the moment who is also a diabetic too so if I am in her class and my pump stops or something, she'll know that I've got to do stuff and she doesn't mind." (Line 259-261)

JJ and Samuel also described positive relationships with staff, but this appeared to be in more general terms and not specifically related to their health condition. Samuel described having good relationships with all staff members except for his PE teacher and the school nurse. I Inferred from Samuel's interview that there is a respectful relationship with teachers based on his hard work, polite nature and "grades" (line 109). I surmised, therefore, that potential difficulties in his relationships with the PE teacher and medical staff were perhaps due to the nature of their roles

because Samuel's diabetes could be considered to feature more heavily in these areas of his life at school. The school nurse has a direct involvement in the management of Samuel's medical needs, and the physical activity in PE has an impact on his diabetes not seen in other subject areas. In my opinion, Samuel expresses a strong desire to be independent and aims to reduce adult input into his life wherever possible. I wonder if the increased adult intervention by the school nurse and PE teacher, and Samuel's frustration at this, may be a factor impacting on the relationships with these staff.

> Samuel: "Well. So, I think most of my teachers apart from my PE teacher and the school nurse umm (-) some of other ones but um (tuts) um I mean I try to do my best to sort of show them as I want to manage it, but umm…" (Line 213-216)

When talking about the adults who work with him at school, JJ made frequent references to their sense of humour, their ability to make him laugh and their shared interests. I sensed that these relational aspects appear to be an important factor for JJ when developing relationships with staff at school. I also noted that in the interview JJ generally tends to refer to either pastoral staff (his form tutor and head of year) or his 1:1 TA when identifying adults, he feels positive about. I felt that this may be due to the pastoral staff focusing more on relational aspects of school life in a way that subject teachers may not.

> JJ: "He makes me laugh. He calls me (laughs) 'xxxx'"… (Line 300)

Whilst all five participants do refer to positive relationships with adults in school, four of the participants also appear to identify several factors related to their health condition that negatively impact on their relationships with adults at school. I inferred from four of the participants' transcripts that the adult's level of awareness and understanding of their health needs impacts on their relationship with them. Samuel and Autumn discussed the variability between adults at school in the knowledge of their health condition, particularly regarding the physical symptoms, treatment, equipment and accommodations needed in the classroom. This suggested to me that the lack of knowledge from the adult impacts the quality of support provided in school, which in turn appears to impact on the quality of the

relationship. There is a sense from Samuel and Autumn that they feel better able to relate to the adults that know and understand the impact of their health conditions than those who appear to be unaware. Supply staff were identified as adults who particularly demonstrate poor knowledge and awareness of their CHC.

> Samuel: "And it's important to maybe (- -) know about what's going on and um know about my condition…" (Line 207-208)

Amber also appeared to identify variability in how school staff understand the impact of her CHC. I understood from her interview that Amber felt she could relate better to staff who not only attempted to understand the impact of her CHC but were also accepting and supportive of the factors impacting her learning.

> Amber: "Some teachers that are really nice about work and don't get upset and angry when I can't do much. Some teachers are more accepting of it." (Line 476-478)

Emergent themes were identified in three of the participants' transcripts relating to their perception of the adult's emotional responses to managing a student with a CHC. I felt that in their interviews Samuel and Amber both implied that some adults appeared fearful about having to manage their health needs in school. Samuel in particular frequently discussed his view that he perceives adults in school are worried about the potential impact of mismanagement resulting in a medical emergency in which he is harmed. Amber discusses this more subtly but described decisions being made for "safety reasons" (line 39). I interpreted this as adults being risk averse, due to their fear about incorrectly managing medical needs in school.

These perceived insights into the adult's emotional state appear to lead Amber and Samuel to question the adult's motivation for providing support and not necessarily viewing the adult's behaviour as caring and supportive. Samuel seemed to believe adults were supporting him with his medical need so that they could not be "blamed" (line 186) for any errors or oversights. Amber, however, appeared to be suggesting that adults were supportive to ensure that there were no problems so that they had "peace and quiet" (line 369).

> Samuel: "They just like feel that they have to control it and they feel that they need to be active in managing it and that I can't do it myself. Otherwise, I'm going to die, and they are going to get blamed." (Line 361-364)

I perceived that Willow also noticed the emotional responses of the adults working with her. She did not appear to describe fear from adults like Samuel and Amber, but instead describes occasions where she feels that adults are stressed or frustrated. This appeared to impact on her relationship with them. Amber appears to be less willing to approach adults for help when she anticipates a reactive response. Willow gives an example of this when she described how she perceives her TA was behaving differently due to the COVID-19 pandemic. She infers that this more "sensitive" (line 108) and "serious" (line 111) behaviour makes their previously positive relationship more challenging to maintain.

Finally, it was also noted that emergent themes linked to the role of parents were identified in four of the participants' transcripts. I interpreted that for these participants their parents are perhaps more involved in their school life compared to other peers their age due to their health condition. Parents appeared more involved in a range of ways, attending additional meetings with staff (Samuel), supporting on trips (JJ) and advocating in school for changes in support (Autumn and Amber). I felt that this was an important factor to consider as this increased parental involvement, especially during adolescence, a time when parental involvement generally decreases. I considered that this could potentially impact on the participant's relationship with their parents and peers.

> Samuel: "My mother she is always there, she's always having meetings with my PE teachers, all the time." (Line 154-156)

5.4.3 Subordinate Theme: Conflict with Adults.

Themes relating to conflict with adults were identified in two of the participants' transcripts, Samuel, and Autumn. There appears to have been conflict between Samuel and the school nurse, and I sensed that this has led to the breakdown of their relationship. Samuel refers to a particular event in which the school nurse

contacted his parents via email and called him "rude" (line 391). I wondered if the school nurse contacting home felt aligned with the concept of consequence in a school behaviour policy that would be imposed by a member of school staff. The school nurse is, however, a medical professional and so holds a different role to school staff. By engaging in an action linked to a behaviour policy or consequence, it feels that the school nurse has potentially blurred boundaries and roles which may have been frustrating and difficult for Samuel to accept. I also wondered if the failure to discuss the difficulty with Samuel directly, instead calling home, felt like a betrayal and caused a lack of trust between Samuel and the nurse. Trust and respect feel an important basis for an effective and supportive relationship, especially with a medical professional and as such, I felt that this could have been particularly unsettling for Samuel.

> Samuel: "I was a bit (tails off) I didn't understand at first, because again I was polite to her. But then eventually it sunk in that like the moment I left she had called my mother to tell her that I had been rude." (Line 388-391)

Autumn also describes conflict with school staff around the management of her health needs in an emergency, albeit expressed in a more passive way than Samuel. I inferred from the description of the incident that Autumn and her mother disagreed with decisions made by staff. However, instead of direct conflict with them, they agreed and implemented a plan between themselves that allows Autumn to feel safe if similar situations arise. I inferred from Autumn's transcript that she felt that staff need to agree to the plans that she, with her mother's support, propose even if they are unhappy.

> Interviewer: "And are school happy with that.?"
> Autumn: "Not really. They've got to be really though after…" (Line 149-150)

5.4.4 Subordinate theme: Support Provided by Adults.

There was significant variation in how the participants talked about the support they received in school. Samuel's focus tended to be on the over involvement of adults managing his health condition, but he provides little detail about the practicalities of

adult support he receives, and I perceived that he found the support unhelpful. There is a sense from Autumn's transcript that she feels that adults tend not to get involved unless she specifically requests help from them.

Emergent themes relating to the variability in support from adults throughout the school day were identified in Amber, JJ and Willow's transcripts. JJ and Willow describe being supported by a range of adults. I sensed that Willow was frustrated and has a preference to work with adults with whom she already feels she has a "bond" with (line 99). She describes needing time to get to know the adults and their approach, as I inferred each TA provided differing practical and emotional support.

> Willow: "Um at first quite frustrating as you'd like one TA then you wouldn't like the other." (Line 90-93)
> Willow: "…some patience to be able to build a bond with the TA." (Line 100)

Amber, however, appeared to describe a fluid approach to providing adult support in her school, indicating that she was never sure if she would have and adult to support her. She described a range of functions for the support provided by TAs from practical to emotional. Amber also identified that she has a keyworker who is accessible throughout the day so that she can check-in and support her to problem solve any difficulties that arise during the day. Interestingly, Amber is the only pupil who identifies having a named keyworker.

> Amber: "I have a key worker who um helps me throughout the school day and um and when I am in trouble. I can go talk to them." (Line 197-198)

5.4.5 Subordinate Theme: CHC Impacts Relationships with Peers

Analysis of the participants' transcripts suggested that all five participants felt that their CHC impacted on their relationships with their peers in some way, although there was variation within this. Four of the five participants described having positive and supportive friendships in school and there was sense of how important these friendships were to them. The participants described a range of ways that their friends provided support and connection.

Autumn seems to place importance on being 'kept in mind' by her friends. She describes them staying in touch online when she is off school sick and waiting for her when she needs to complete treatment routines in school. This contact appears to minimise the impact she feels when missing school.

> Autumn: "I have these two best friends and they (-) call me a lot and we Face Time so it doesn't really matter." (Line 188-189)

Willow discussed times that her friends made effort to include her by deciding on accessible activities both inside and outside of school. JJ simply refers to friends who help him and make him laugh. When Amber talks about her friends there is a real sense that her friends try to ensure that she feels included and that she is the 'same'. I surmised that feeling included, a sense of belonging and being perceived as 'normal' is crucial for her in feeling connected to peers.

Despite being positive about their friends, several themes were identified relating to the negative impact of their health condition on relationships with their peers. For four participants, I identified emergent themes suggesting that they felt their health condition limited opportunities to spend time and connect with their peers at school. Willow, Amber and JJ all attend a lunch club which is for pupils with special educational needs and disabilities (SEND). Whilst they all appeared to recognise the positive outcomes of attending, there is also a sense, particularly from Willow and Amber, that they feel excluded and isolated from their peers who do not attend this club and that this separation and lost time impacts significantly on maintaining existing friendships and developing new relationships with peers.

Amber painted a picture (Image 2, Appendix 17) depicting being separated from her friends at lunchtime. In the interview, she talks about this and repeatedly uses strong language to describe feeling how she feels forced apart from her peers. She also appears to describe feeling forced into making new relationships with pupils with disabilities who also attend the club. I feel that this frustration runs deeper for Amber than just not being able to spend time with her friends; that she feels that adults at school are making judgements and have control over who they deem to be appropriate people for her to have relationships with. I wonder if there is a frustration from Amber around this sense of segregation, and a desire to assert herself away

from the disabled identity that the adults appear to have given her. Amber also indicates that the being separated from friends in school has a broader impact, also affecting her relationships with them outside school.

> Amber: "So I couldn't sit with my friends at lunch. Its um really (/) cos I've got quite a few friends. So, I haven't been speaking to them as much as I wanted." (Line 29-30)
>
> Amber: "Cos if you are not speaking to them inside school you are not going to speak to them much outside school much either. (/) more like different friends." (Line 63-65)

Image 2: Amber's watercolour depicting being kept apart from peers at lunchtime.

I perceived that Willow feels attending the lunch club limits opportunities for her to connect with her friends. Samuel did not describe attending a lunch club but does refer to missing breaktimes due to spending time in the medical room. JJ suggested that missed time from school impacts on the time he has with his friends at school.

In contrast Autumn described that she feels she has lots of opportunities to spend time with her peers in school and that does not appear to be a concern for her. However, she did discuss the how the management of her health condition impacts on her relationships in school during extracurricular activities and trips. She particularly referred to the impact at lunchtime and in PE lessons, where additional

monitoring and management of her blood sugars is required. The impact on time away from friends is limited and subtle, but I felt that this was important to Autumn, as it sets her apart from her peers and is something she would rather not have to do.

Autumn: "Well when I eat food I can't just go with my friends. I have to remember to put it into this, which takes half a minute. So, it doesn't take that long but it is just remembering really."
Interviewer: "What does that half a minute mean to you?"
Autumn: "I'd rather have it, they do wait for me, they do stay with me but I'd rather have it. I'd rather walk away from lunch and just do something." (Line 328-334)

5.4.6   Subordinate Theme: Feeling different

Emergent themes relating to 'feeling different' to peers were identified in four of the five participants' transcripts, with only JJ not appearing to raise this in his interview. Through analysis of the participants' interviews, I understood that there were a range of situations in which they felt that the differences relating to their medical condition were made more visible which led to comparisons being made to their peers. How this was processed and experienced varied between them with emotional reactions ranging from apparent feelings of embarrassment (Samuel), frustration (Amber) and isolation (Autumn). I inferred that Willow, was experiencing a state of cognitive dissonance in which she has conflicting views of being seen and treated as 'different'. I decided that it was possible to categorise the range of experiences discussed by participants which appeared to highlight 'difference' into four categories: adult management, physical symptoms and associated treatment, missing out on activities and having additional responsibilities.

Firstly, physical symptoms, equipment and treatment plans were identified by four participants as a way in which their health condition was made more visible and subsequently was a key factor in making them feel different. For Samuel and Autumn, this related to their insulin pump, phone and in some situations the requirement to eat sweets. For Amber, this related to her managing her wheelchair and for Willow was linked to her mobility and speech.

> Autumn: "Yeah its sometimes funny when I get my thing out (*pump/monitoring phone)* I have this and when I get it out sometimes teachers are like 'is that a phone? put it away' and I'm like 'oh yeah, it's a definitely phone isn't it, look at that' *(laughs)."* (Line 121-124)

Secondly, there was a strong sense that the management of their health condition in school was another factor in making four of the participants 'feel different'. For Samuel and Autumn, this appeared to be around how teachers reacted to and managed these differences in the classroom. By obviously checking-in, taking them out of class for testing or openly questioning treatment in front of peers (e.g., having sweets in class) teachers inadvertently drew attention to the medical condition, increasing feelings of difference. For Willow and Amber this appears to relate to the choices staff make about managing their health condition throughout the day, for example having different collection times, staff pushing their wheelchair or not adjusting the layout of chairs in the classroom making it difficult for her to get seated.

> Samuel: "...I just want to (-) do (- -) I just want to learn and like be in school and talk to my friends. I don't want to you know have to go to the school nurse all the time or check in with my teachers, so they know I'm ok." (Line 191-194)

Thirdly, there is a sense that three participants felt different because they missed out on or had to alter activities that their peers, without health conditions, are able to do without requiring any differentiation. This includes missing out on or having additional adult support on trips (Autumn and Willow) and during extracurricular activities (Samuel).

Finally, Willow, Samuel and Autumn appeared to indicate that the additional responsibilities that they have due to their health condition (e.g., treatment regimes, remembering equipment, attending appointments) is another way that makes them feel different to peers who do not have this level of responsibility. Even when this additional responsibility appears to have a minimal and subtle impact, I perceived that it represents difference and hence feels important to the participants.

> Autumn: "I just have to watch it if I'm doing something, like lots of energy. Like if I go to fitness club then I have to do a blood test before we start and if I'm under seven I have to have a biscuit or some sweets and then I start and then at the end I have to do another blood test." (Line 63-66)

Willow appears to explore the concept of feeling different more deeply than the other participants and provides insight into how she feels that adults and peers react to difference and the management of this at school. I inferred that Willow feels that some staff do not agree that she requires different treatment for her health condition as this is unfair to her peers. I understand from Willow's interview that this then impacts on the support she receives in school and her learning and physical well-being suffers when adults are reluctant to provide what she needs. There is a sense of frustration from Willow about this, especially as she appears to believe her peers do not actually feel this way and the concept of it being unfair lies solely with the adults.

> Willow: "I think the main issue is, is when they say that you can't have a break because it's not fair on everyone else. And I understand it wouldn't be fair on everybody else but if you want me to do well, I'll need that break…" (Line 273-276)
>
> Willow: "Ummm (- - -) I think (-) It's not necessarily the children, it's the staff." (Line 397)

I also noted that Willow made contradictory statements around needing and wanting different treatment to others. I wondered if holding these two opposing views represented a state of cognitive dissonance which would cause tension and unease for Willow. I interpreted her description of being annoyed as a representation of discomfort related to not being able to resolve this internal conflict.

> Willow: "yeah. It does get a bit annoying because (-) yeah I don't want to be treated differently to everybody else but sometimes I need to be treated differently…" (Line 258-260)

5.5 Superordinate Theme 3: Navigating the School Day, the Functional Impact of a CHC.

5.5.1 Overview

The third superordinate theme emerging from the participants' transcripts was titled 'impact on school life' and comprises five subordinate themes related directly to school.

Figure 7: Impact on school life: superordinate Theme and subordinate themes
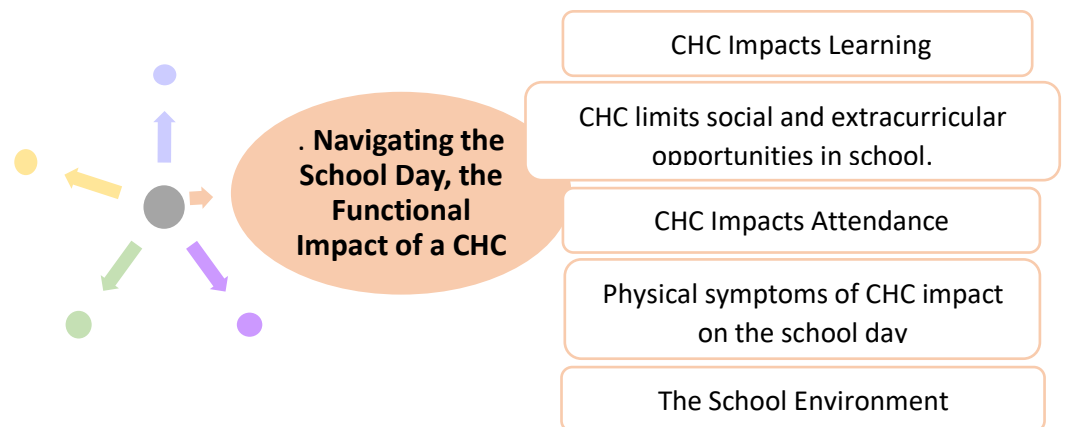
Subordinate themes detailing the impact of having a CHC on learning, social and extracurricular activities at school were identified for all five participants, although there was variation between them reflective of each participant's unique experience. The impact of physical symptoms on the school day was also identified in all five of the participants transcripts, but again there was variation relating to the type, severity and frequency the physical symptoms experienced by the participants. The subordinate theme of discussing the impact of a CHC on school attendance was thought to be present in four of the five participants' interviews. The subordinate theme relating to the school environment was identified in three participants' transcripts.

5.5.2 Subordinate Theme: CHC Impacts Learning

There was a sense from all the participants that their CHC impacts on their learning at school. It should be noted that Samuel explicitly says that he does not feel that his health condition impacts on his learning but then goes on to discuss the learning that he misses due to meeting the school nurse. I therefore interpreted this to mean that although Samuel's health condition may not impact on his attainment or prevent him from achieving academically, it does not mean that there is no impact on how he experiences learning in school. As such, I have considered Samuel's comments alongside other participants within this subordinate theme.

The five participants talk about 'missing lessons' which I infer as missing learning. I noted that the amount of learning time missed by the participants ranged from parts of lessons (Samuel, JJ and Willow), whole lessons (Samuel and Willow) days (Amber) and even whole weeks, but less frequently (Autumn). Samuel discusses missing lessons or parts of lessons due to meeting with the school nurse. However, he does also indicate that the time out of lessons has significantly reduced since being fitted with an insulin pump as he can monitor and manage fluctuations in blood sugars with a phone within the classroom. This was reiterated by Autumn who also has reduced time out of class due to her insulin pump.

> Samuel: "So now if I have a small issue, I just treat it and its back to normal it takes me about 15 seconds to handle it instead of 30 minutes." (Line 297-299)

> Amber: "So when I miss a lot of work it er can't it's all er problem when I get to GCSEs because everyone is getting on with the work more now well more than I am getting on with it." (Line 264-266)

Participants appeared to indicate that missing any learning time, whether for a short period or longer stretch, was impactful. I surmised that there were four key reasons in the participants' transcripts which illuminated specifically what they appeared to be finding difficult with missing learning: 'keeping-up' with the content of the lesson, catching-up with missed work, missing out on enjoyable or preferred learning and the perceived impact on attainment or exam success. Amber particularly seemed to be concerned about the impact of the learning she had missed, specifically in relation to

sitting her GCSEs. She makes comparison between her work output and her peers, who do not have CHC, and I interpreted this as feeling disadvantaged.

I noted that two participants (Samuel and Autumn) describe a difficulty in understanding the content of the lessons when returning after missing some learning. They do not describe any attempts by staff to provide an update, nor do they that they asked for further explanation. I wondered if this lack of support to 'keep up' may have been because of the logistical challenges associated with providing this support during the lesson when the teacher is still expected to be teaching the rest of the class. Some of the participants refer to having access to support from an additional adult (Willow, JJ and Amber) which is helpful in 'keeping up'. They report, however, that this support is not always consistent. Samuel and Autumn do not have TA support to help with learning. As such, I inferred that they felt 'thrown in' and left to fend for themselves whilst trying to establish what the lesson they were returning to was about, catch up on the information missed and keep up with the pace of the lesson. It is possible to envisage that if participants regularly miss key content from lessons (even if for short periods) there would be an accumulative effect and subsequently a significant impact on their learning, attainment and possibly motivation in that lesson.

> Samuel: "When I went back in for the first ten minutes, I had no idea what was going on." (Line 257)

> Amber: "Well er the teachers have to talk to me a lot more because I have missed a lot of work (/) er so they have to talk to me about the work that I have missed." I (Line 273-274)

Amber described a similar difficulty when she misses whole days of learning, stating that she only "sometimes" (line 285) knows what the lessons are about when she returns. However, she receives additional verbal support from staff to catch up on this missed learning. There is a sense, however, that Amber feels that whilst this appears to be a supportive endeavour, I wondered how successful the verbal catch up sessions were and if it is possible for staff to relay an entire lesson verbally and in

a timely manner so that Amber can fully catch up and is not confused on her return to the next lesson.

I interpreted that all participants, except Samuel, felt that they needed to catch up on missed learning which was a significant challenge for them and often led to a sense of being overwhelmed. I perceived that four of the participants felt that there was an expectation from their teachers that they were solely responsible for catching up at home. For JJ, Autumn and Willow, there appeared to be minimal support from adults with this, except with Amber, who appeared to suggest that she was provided with some. Amber did, however, indicate that most of the work was still expected to be completed at home alone. I sensed that for Amber, Willow and Autumn catching up fully on missed lessons felt like an impossible task, and one that they felt they were often unable to complete regardless of the effort they put in.

Amber and Willow appeared to indicate in their interview that they felt an additional pressure to catch up, which was a source of frustration. Both also suggested that they felt teachers lacked understanding, particularly in respect of the impact catching up at home has on their life outside school. There was a sense that they feel the additional work required to keep up and then catch up was an unreasonable request, particularly when considering the fatigue that they are already experiencing because of their CHC.

> Amber: "if I have a lot of days off it's quite hard to catch up with work as there is quite a lot, a lot to do at home" (Line 291-292)
>
> Amber: "home it's supposed to be like a place away from school but like - it just feels like more work at home" (Line 300-301)

> Willow: "I am expected to catch up with all the lessons that I miss but because I've got stuff to do after school I don't always manage to catch up on stuff because I've already got other stuff planned. So it's just (-) I think the teachers don't really understand that you've got other stuff to do" (Line 208-212)

Autumn appeared, however, to take a more pragmatic approach and describes that she just has to "skip" (line 59) anything she misses. I wonder if perhaps this is

different to the response of Amber and Willow due to her age. Amber and Willow may place more importance on catching up because they are approaching formal examinations and therefore expectations and workload are higher.

5.5.3 Subordinate Theme: CHC Limits Social and Extracurricular Opportunities in School.

There were three types of school activity that were raised by the participants as being particularly impacted by their health conditions: trips and extracurricular activities, break and lunchtimes and PE lessons, which I identified as extracurricular and social opportunities occurring throughout the school day.

Autumn, Samuel and JJ all indicated that while they had been able to access trips and extracurricular activities, they felt that they either had to have additional support or monitoring from adults (Autumn, Willow and JJ) or needed to complete extra monitoring or treatment routines (Autumn and Samuel) so that they could attend. As such, there was a sense that they experienced the trip differently to their peers due to the restrictions and/or additional responsibilities. I interpreted that there were mixed reactions from the participants regarding this, which included embarrassment (JJ), frustration (Samuel), guilt about the impact on others (Autumn) and feeling isolated and excluded (Willow).

Autumn: "In primary school we went to x for a week, and they would sometimes come in at night and ask me to do a test and I'd wake up everyone else in the room…" (Line 74-75)

JJ: "…that would be very embarrassing having my dad and granddad with me." (Line 161)

Willow: "…would be unable to run around in the playground or climb the climbing frame that they have or just do general things that I would want to do. I was not allowed to do but I think that is where I felt a bit left out." (Line 337-340)

Physical education (PE) was also raised in several of the participants' transcripts as being impacted by their health condition. For Autumn and Samuel their CHC meant that any physical activity required additional monitoring and potential treatment, extra

checking-in by adults and at times being 'left behind' by peers while they carried out these additional tasks. Willow appeared to indicate that her mobility impacted on how safe she felt on the playground at lunchtime while others were "running around" (line 302). For Amber, she described requiring extra support for any practical activities and for JJ, who appeared to have a real passion for sport, I inferred that he was disappointed that it had been decided by the adults around him that he would be unable to access GCSE PE with his peers.

> Samuel: "I wasted my time trying to get out my devices to hand them to my PE teachers and then like my PE teachers are like asking me every (-) 15 minutes if I'm OK." (Line 165-167)

Break and lunch times were also raised by participants as a part of their school day that was impacted by their health condition, apart from Samuel. As discussed in section 2.4, JJ, Amber and Willow attend a lunchtime club due to their health condition meaning that they do not access the same lunch and break time activities as their peers. Willow's mobility difficulties impact on the accessibility of the playground at lunchtime and Autumn described that she is required to give herself insulin prior to eating but does not appear to see this as having a significant impact. Amber is no longer allowed to eat in the lunch hall with her friends after the speech therapist highlighted a choking risk. There is a sense that for Amber that this is a continual source of frustration as she feels it impacts on her ability to make and maintain friendships with peers.

5.5.4 Subordinate Theme: CHC Impacts Attendance

The subordinate theme exploring the impact of their CHC on attendance' was identified in four of the participants' transcripts. These four participants suggested that medical appointments impact on their attendance at school. Willow and Amber placed great importance on attending school, particularly so close to their GCSEs. I inferred that the participants felt frustrated that medical appointments, and for Amber her fatigue, at times prevented full-time attendance at school. Willow described the number of different appointments she must go to and despite her efforts to reduce the impact by scheduling outside school time wherever possible, there is a

cumulative effect meaning that overall, she feels there is a significant loss of time at school. Autumn indicates that common illnesses affect her more than her peers and lead to a longer time off sick.

> Willow: "I haven't had to be off for my disability, but I've had to be off for the hospital appointments that I have and that can add up sometimes. So especially now I am in year 10 it's leading up to the exams, but I got them next year so it's like trying to take, trying not to have the hospital appointments in school time." (Line 177-180)

> Willow: "When they are close together it feels like a lot of appointments but when they are spread across the year it doesn't feel that much but when I think about it I do have quite a lot of appointments that I go to" (Line 186-189)

JJ talked passionately about his desire to attend school every day so that he can earn a reward for 100 per cent attendance, a gold sticker. He described that he has only once been able to do this once with the implication that medical appointments have prevented him from being able to achieve this again. JJ appears frustrated when talking about this and I wondered he felt that 100 per cent attendance was unobtainable for him through no fault of his own. I surmised that he felt this was inherently unfair. There appears to be a lack of consideration and adjustment to the attendance policy on the school's part, which could be considered discriminatory and inequitable as it is in effect rewarding peers for their good health.

> Interviewer: "Ok. Why is 100 per cent attendance important to you?"
> JJ: "You get A GOLD STICKER. and once I DID GET a GOLD STICKER."
> Interviewer: "Once you got one?"
> JJ: "at the end of term and now I haven't got any MORE (growls)" (Line 436-442)

5.5.5. Subordinate Theme: Physical Symptoms of CHC Impact on School Day.

The subordinate theme linking to the impact of the physical symptoms of their CHC on the school day was identified in all five of the participants' transcripts, although there was significant variation relating to the differing medical conditions and how these are experienced by the participants.

The impact of fatigue on the school day appeared to be a significant factor for both Amber and Willow and somewhat for JJ after having a seizure. Amber is particularly descriptive about her experiences of fatigue, which is a key feature of mitochondrial conditions (Filler et al, 2014), especially when she talked about the painting she made in the creative task, in which she depicts fatigue as a monster behind her (Image 3). Fatigue is mentioned frequently throughout Amber's interview and I perceived that it is ever present and infiltrates all areas of Amber's life, making it incredibly challenging to focus on her learning at school as well as impacting on her ability to engage in social activities. Amber appeared to be constantly looking for ways to balance her fatigue with the expectations placed on her at school. She described an accumulation of fatigue over the week and has made the decision with her mother to have a day off school every two weeks to attempt to manage this. I interpreted this as Amber being proactive in communicating her needs so that she can take back some control and achieve some balance in order that she has the energy she feels she needs to continue to successfully access the remaining time at school.

> Amber: "I would say it is like a monster because it takes away my ability to do anything else."
> Interviewer: "It takes away your ability to do anything else.?"
> Amber: "Uh-huh."
> Interviewer: "You are facing forwards in the picture do you want to tell me anything about that? why did you choose to draw it like that?"
> Amber: "Because it's like leaning over. It's like coming over." (Line 442-448)

Similarly fatigue features heavily in Willow's transcript indicating that it also plays a significant part in her life at school. Willow appeared to focus on the invisible nature of her fatigue and how others around her fail to recognise its presence or the impact on her life. She describes that some everyday activities are extremely tiring for her in a way that she feels are not for her peers. I perceived that this highlights the sense of being 'different'. I inferred that Willow perseveres through her feelings of fatigue wherever she can, but that she relies on frequent breaks throughout the day as a coping strategy. I sensed that Willow frequently felt frustrated that adults around her lack awareness of her fatigue and on occasion prevent her from taking the breaks that she needs.

Willow: "You've just got to be (-) because they say I'm not different to everybody else when you are tired but it kind of is (- -) Because (- - -) I'm using more energy than everybody else is and it's just (-) annoying when they say that because it means that they don't really have much information about what it actually feels like." (Line 251-256)

Image 3: Amber's watercolour depicting 'fatigue'.

JJ, Willow and Amber also indicate in their transcripts that they experience pain during the school day. JJ describes that he tends to experience pain in the form of headaches after having a seizure. Willow states that she experiences headaches, and these are described as are frequent, prolonged, and exacerbated by noise and the use of hearing aids. I considered noise sensitivity is a likely barrier in school as Willow described the "loud" (line 125) classroom as a trigger for her headaches. Willow indicates that her headaches interrupt her ability to focus and subsequently learn.

Willow: "They don't really understand how bad my headaches can get because of (-) the noise ummm and then obviously, especially if it's the first lesson of the day then that headache will drag on all day. So, it is just trying to er get them to understand how bad it is sometimes, especially with my hearing aids making it, the noise extra loud because that is what my hearing aids do anyway um (/) so it's just annoying sometimes when they don't let me go out." (Line 138-144)

Amber describes experiencing pain in her hands, particularly during tasks that involve prolonged periods of writing or manipulation of equipment.

During her interview Autumn discusses physical symptoms that she experiences in school related to her blood sugar levels. She describes how they can impact on her concentration in class if they are not managed. There is a sense that the impact on her concentration is subtle, and the full impact may go unnoticed by staff as it would be difficult for staff (and potentially Autumn) to notice when this is happening. As such, the accumulative effect of frequent, but minor lapses in concentration throughout the school day could be quite extensive and yet invisible. Contrastingly Samuel suggests that his blood sugars are managed well in school and that he has never experienced them to be "high or low" (line 138), hence he does not appear to have experienced the impact on his concentration in the same way that Autumn has.

> Amber: "I mean it can make me like (- -) I can't really concentrate sometimes but it's not so bad that I can't do work at all."
> Interviewer: "Can you tell me a bit more about that?"
> Amber: "When I'm low and when I'm high because I've not got the right amount of sugar in my blood my brain is either getting more or less energy to do things (-) so ..."
> (Line 91-96)

Amber and Willow's medical conditions on also impact on their mobility, which appears to impact on areas of school including the playground, during PE and more practical lessons such as science. Amber also appeared to indicate that fatigue impacts directly on her mobility and when fatigued requires a wheelchair. I sensed that the wheelchair adds a further barrier to accessing school as Amber described some difficulties in navigating around the classrooms, particularly when they are small, like a science laboratory, or teachers have not considered the impact of the wheelchair on the classroom layout or seating.

> Amber: "On the fatigue days it's quite hard to like move around..." (Line 256-257)

Four of the participants had some form of treatment routine, meaning that medication was required at points throughout the school day. I surmised that the biggest impact of medication on school life was for Autumn and Samuel, who both require their

blood testing kits, insulin pumps (a small device attached to their body) and phones daily. They both generally describe this equipment as small and portable, with only minor issues of wires getting caught on doors on occasion. This suggests, therefore, that on the surface this equipment appears to have a limited impact on their lives. However, on some occasions in the interview, their descriptions of the equipment seemed to give the idea that perhaps they felt a bigger impact. This is demonstrated in the quote below in which Samuel, who has previously described his device as small and portable, describes it as "heavy" (line 232). I wondered if this was less to do with the physical status of the equipment and instead reflects a more abstract perception of the 'weight' of the impact having to carry the equipment at all.

> Samuel: "So I do this running club and for some reason the teacher, I mean the teacher is great but he told me that I need to carry my phone around 'cos he was told to tell me that. So all of a sudden I had to like start carrying my phone. For no reason. And that just. It's a bit worse because I had to carry this heavy thing around." (Line 228-233)

5.5.6. Subordinate Theme: The School Environment

This subordinate theme comprises of emergent themes linking to practical aspects of the school environment linked to the management of the participants' CHC.

Three participants, JJ, Samuel and Autumn, discussed their use of the medical room in school. I interpreted that all three felt that the medical room was not a helpful place that they would choose to use, despite having a CHC. While Samuel and Autumn were dismissive of the medical room, JJ appeared to actively dislike it. He describes it as boring, busy, and filled with children who are hurt or sick. I found this interesting as it suggested to me that JJ was differentiating between himself and other 'sick' children. He did not appear to consider himself as part of this group and hence did not feel he needed the medical room.

> JJ: "Really bored once you are in there. There is NOTHING what TO DO once you are in the medical rooms. You just have to WAIT."
> Interviewer: "Who is with you in the medical room?"
> JJ: "Just a load of kids who are not feeling very well or have just like hurt themselves."
> (Line 414-417)

Amber also referred to the school environment, particularly regarding the size of the building and classrooms and the impact it has on manoeuvring her wheelchair, which she finds challenging. It also requires support and draws attention to her, building on the sense of feeling different. At the end of the interview when Amber responds to a question about her ideal school, she talks about the school being bigger, and as such I interrupted that was a significant concern for her.

> Amber: "Bigger classrooms because some are small and hard to get around."
> Interviewer: "Ok, bigger classrooms - anything else?"
> Amber: "Making school bigger. Making it all bigger." (Line 460-462)

5.6.1 CHC Impacts Emotional Well-Being at School

Figure 8: CHC Impacts Emotional Well-Being at School: Superordinate and Subordinate Themes

CHC Impacts Self Esteem

Loss of Normality

CHC results in undesirable emotions being experienced in school.

Coping Mechanisms

. **CHC Impacts Emotional Well-Being at School**
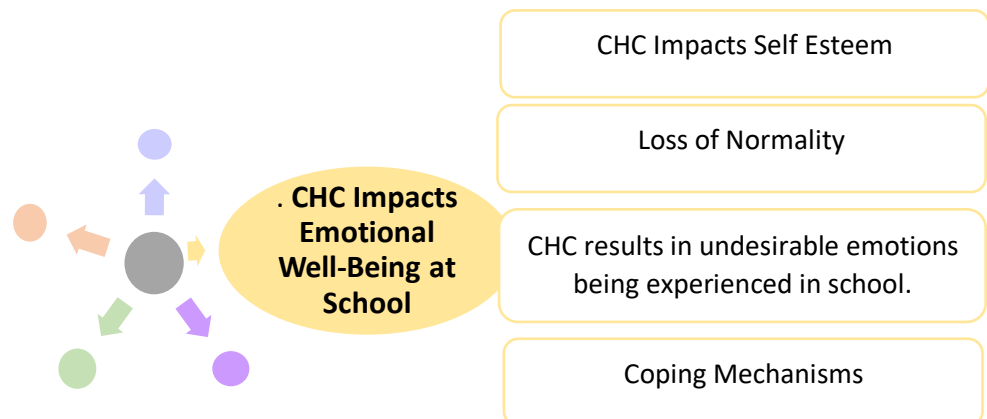
This superordinate theme emerged across all five transcripts and refers to the emotional responses experienced by the participants in relation to managing their health condition and the impact on their emotional well-being at school. This superordinate theme was thought to comprise of four subthemes; impact on self-esteem, a sense of a loss of normality, experiencing undesirable emotions at school and the coping mechanisms employed to manage stressors relating to their CHC. All four of the subthemes emerged in the five participants' transcripts, except for JJ for whom a theme of 'loss of normality' was not identified, and Autumn and Amber for whom a theme relating to impact on self-esteem did not emerge. It should be noted, however, that there was significant variation within these subthemes pertaining to the

types of undesirable emotions experienced by participants and the differing coping strategies used.

5.6.2 Subordinate Theme: CHC Impacts Self Esteem.

In the interviews three participants referred to their positive or negative views of themselves, which I understood to provide insight into their self-esteem. I sensed that two participants, JJ and Willow, at times described themselves negatively. JJ, particularly in terms of his learning, and Willow in respect of her physical abilities.

> JJ: "Basically I am really bad. I have really bad handwriting and I always make a big mess. Ugghhh. I always make the letters too big." (Line 259-260)

> Willow: "People are running about and people are doing all that and I can't really do that (-) It just (- - - -) I think it just (- -) It just gets to me a bit as I want to be able to be outside and stuff but I think my confidence is why it's like that." (Line 303-305)

Conversely, Samuel mentioned his academic attainment and achievements both at school and in extracurricular activities in the interview. He described himself as "hard working" and I understood this to mean that he took pride in this and felt respected by staff at school due to his positive approach to learning. I sensed that Samuel was confident in his academic abilities and proud of his attainments. I interpreted this as healthy self-esteem as a learner. However, I also noted that on occasion this was tempered by an apparent self-consciousness when describing his accomplishments. He also frequently referred to his grades with modesty, describing them as being just "fine", which was in contrast to his description of winning awards and being in "top set" (line 119). Upon reflection I noticed that Samuel appeared to use this language when talking about the impact of his health condition on his attainment and I wondered if this was an attempt to demonstrate that he felt his CHC had limited impact rather than a true reflection of his views on his achievements.

> Samuel: "science and academic excellence. It sounds a bit weird if I say it out loud" (Line 115)

5.6.3 Subordinate Theme: Loss of Normality

This subordinate theme reflects that four of the participants appeared to feel a 'loss of normality' because of their CHC. I identified this subordinate theme in all transcripts apart from JJ's.

Samuel, Willow, Autumn and Amber appeared to express a loss of normality in two ways. Firstly, in respect of activities they missed out on. These ranged from extracurricular activities such as trips, clubs, and time to relax at home to school-based activities such as learning, lessons and lunchtimes. Secondly, I felt that participants implied a loss of normality when they described the additional responsibilities that they had to manage due to their health condition. These additional responsibilities are not typical for a young person their age. As such I considered them to impact on their ability to engage in activities as 'normal'.

> Autumn: "A school with a cure for diabetes."
> Interviewer: "With a cure for diabetes? Can you tell me a bit more about that?"
> Autumn: "Because then I could just go to school and I don't need to think about having this (points to pump) or anything." (Line 320-323)

> Samuel: "and I just want to (-) do (- -) I just want to learn and like be in school and talk to my friends. I don't want to you know have to go to the school nurse all the time or check in with my teachers" (Line 191-194)

5.6.4 Subordinate Theme: CHC Results in Undesirable Emotions Being Experienced in School.

The subordinate theme relating to participants experiencing 'undesirable emotions' was identified in all five of the participants' transcripts, however there was significant variation between the participants in the emotions they described experiencing.

Willow was the most descriptive during her interview in terms of the range of undesirable emotions that she was feeling in relation to managing her health condition at school. I interpreted that she was experiencing a range of emotions; frustration, guilt, embarrassment, overwhelm and fear. Willow also talked about other actions being "hurtful" (line 155) by the lack of consideration from others during some situations, which could be interpreted in a myriad of ways. My understanding of hurt was a sense that Willow was feeling sadness.

> Willow: "If they say that 'just ask and then we will take you out' and then they don't let me out and it's just a bit hurtful because they haven't really taken my, my health not my health but my (- -) education into thought. They've just (- - -) …Yeah it's a bit hurtful sometimes ." (Line 151-155)

Sadness was also an emergent theme identified in both JJ and Amber's transcripts. JJ's description of 'sadness' in relation to a disappointment of not being able to do the same subjects as his friends appeared to be minimised using the qualifying phrase "kinda" (line 703) and there was a sense that this did not have a significant impact on him. There was, however, in Amber's interview, a strong sense of sadness even though she did not specifically name it. Sadness was interpreted by Amber's reaction to questions relating to her future (see below for further explanation).

I perceived that four of the participants were experiencing frustration and annoyance. Samuel appeared to be particularly frustrated and frequently verbalised his annoyance at what he perceives to be excessive adult intervention in his health condition, which he describes as wasting his time.

Samuel: "It's just annoying. So, it's pointless everything that's happening. So, my time is being wasted, their time is being wasted." (Line 190-191).

In contrast to this, Willow, describes frustration at the lack of adult intervention and failure of adults around her to intervene and support her, particularly when she explicitly asks for help. There is a sense from Amber that she is frustrated about not

feeling listened to or heard by adults. Willow and Amber also describe their frustration, more generally, around the impact that their health condition has on accessing activities and on their ability to be independent in daily life.

> Willow: "So my cerebral palsy can get a bit much some days. It can be like really frustrating. Umm (-) and especially when you want to do something that you can't do." (Line 44-46)

Three participants, Autumn, Willow and Amber, all also described significant frustration in relation to the impact of their health condition on their attendance and learning.

> Autumn: "...but I just get frustrated I don't know what to do." (Line 61)

Three participants described experiences in which I perceived that they felt embarrassed. For JJ and Samuel this relates to adult intervention and feeling different to peers. JJ describes feeling embarrassed at the possibility of having his family attend a trip with him. For Willow this relates to feeling "awkward" (line 490) in asking adults for help, which I interpreted as embarrassment.

> JJ: "...would be very embarrassing having my dad and granddad with me." (Line 160-161)

Two participants discussed incidents in school in which their health condition meant that they found themselves in situations that did not feel safe and as a result they were fearful and anxious. For Willow, this was around being in the playground without any support for her mobility. Despite her desire to be with peers at playtime, her fear of being hurt means that she chose to access a group away from peers, apparently preferring potential isolation to the anxiety of being on the playground at lunchtime. Autumn described an experience in which she was unwell, in a situation affecting her blood sugars, and despite explaining to staff that she needed to go home it was not actioned for some time. Although Autumn appears to talk in a way that reduces the seriousness of this incident, there is an undercurrent in her description that I interpreted to be fear, not only because there could have been serious implications to her health due to the adult's inaction but also due to the lack of control.

> Autumn: "Once I was in school and I had high blood sugars no, it was either high or low and I had to go home because I was ill, and I was sat in the office waiting for an hour for them to call my mum as they hadn't called my mum and it wasn't good as I needed to get home." (Line 138-140)

Finally, Willow described feeling guilt, specifically in relation to the impact of her health condition on her friends. There is no indication that this has been explicitly said by peers, but I inferred that Willow felt that she is imposing restrictions from her health condition on them, resulting in feelings of guilt. 'Feeling guilty' is not expressed in any of the other participants' transcripts.

> Willow: "…but the problem was that I would feel guilty because I was, I thought that they wanted to do something else." (Line 321-323)

5.6.5 Subordinate Theme: Coping Mechanisms

Coping mechanisms can be understood to be the cognitive, emotional, and behavioural strategies used by individuals to manage the internal and external demands caused by external stressors, such as a CHC (Lazarus & Folkman, 1984; Folkman, 2010). Folkman (2010) describes three types of coping mechanisms: problem-focused, emotion-focused, and meaning-focused. Problem-focused coping, as the name suggests, attempts to address the problem directly by problem-solving and adapting the environment or behaviours accordingly. Emotion-focused coping is described as "efforts to regulate emotional states that are caused by, or related to the stressful event" (Closs, 2000, p. 34). Meaning-based coping also refers to an effort to regulate emotional states but differs in that it "draws on deeply held values and beliefs" (Folkman, 2010, p.902). Coping is a dynamic response in which no one coping strategy should be perceived as superior to another, instead a best fit model, selecting an appropriate coping strategy for the context, is thought to be the most effective (Lazarus & Folkman, 1984). Folkman (2010) proposes that this best fit often relies on a complex interplay of the three types of coping strategies.

Four of the participants discussed the use of coping strategies that I perceived to be emotion-focused, although this varied between participants. Denial, rumination, catastrophising, avoidance and acquiescing were all considered to be examples of emotion-focused coping strategies used by the participants in response to stressors, which appeared to be maladaptive in the context.

I sensed that Samuel was ruminating on incidents with the school nurse throughout the interview, which I surmised to be an unhelpful coping strategy in dealing with the conflict between them. Samuel also discussed the idea of keeping his health condition 'out' of his future, with no desire to share details of it with anyone at university. I considered that this could be a form of avoidance, and an unhelpful coping strategy, as it could reduce access to support relating to his health in the future.

> Samuel: "They won't know, and they won't need to." (Line 447)

Autumn appeared to have a balance between what I perceived to be adaptive and maladaptive coping strategies. I thought that sarcasm, avoidance, and wishful thinking were potentially maladaptive emotion-focused strategies. However, I also perceived a strong sense of positivity, humour and acceptance which I inferred as adaptive meaning-focused coping strategies. One coping strategy, benefit finding, appeared at several points throughout the interview and seemed to be demonstrative of one-way Autumn effectively managed her stress.

> Autumn: "That was (-) the best thing." (Line 238)

Acceptance, in which the participant assents to a situation, has been considered both an adaptive and maladaptive coping strategy when coping with ill-health (Nakamura & Orth, 2005). In this study I have interpreted acceptance as an adaptive coping strategy in Autumn, Willow and Amber's transcripts. Although the stressors discussed varied there was a sense in all three participants' transcripts they acknowledged and found positive ways to live with and manage the stressor, in this case their CHC.

> Willow: "…I understand why." (Line 336)
> Willow: "…so, I missed out on that one unfortunately." (Line 350)

Three participants discussed the use of coping strategies which I interpreted as problem focused. Amber discussed making the decision to proactively take time off school to manage her fatigue and Willow and JJ reflected on the importance of taking time to relax. Willow also indicated that she placed importance of sharing her coping strategies with others and would find further opportunities to access support groups to discuss coping strategies helpful.

> Willow: "I would sometimes do swimming or just have some time to myself that I would not be able to have during the day and just like relax for a bit 'cos my head can feel like it's going to explode." (Line 219-222)

5.7 Superordinate Theme 5: Planning for the Future.

5.7.1 Overview

Figure 9: The future: superordinate and subordinate themes
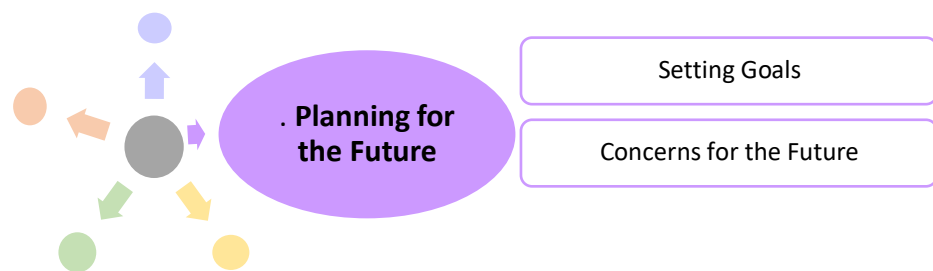
5.7.2 Subordinate Theme: Setting Goals

'Planning for the future' was identified as a theme emerging from the analysis of three of the participants' transcripts. This superordinate theme was conceptualised from two subordinate themes, one interpreted as being hopeful and future facing, 'setting goals', and one more pessimistic, 'concerns for the future'.

Attending university was an emergent in three of the participants' transcripts. Willow describes a well organised plan to attend college, then university culminating in her longer-term aspirations of becoming a human rights lawyer. Samuel talks about his future with a sense of certainty that he will be going to university but does not give any indication that he feels his health condition will impact on this. Amber identifies that she would like to pursue a future in art.

5.7.3 Subordinate Theme: Concerns for the Future

Willow spoke articulately and with a sense of hope and passion about her future aspirations, yet she also appears aware of potential barriers that could arise due to her health condition. Willow has strong desire to succeed and discussed achieving her lifelong educational goals but worries about the inclusivity of future educational settings as well as the support and accessibility that may or may not be available to her. When talking about what she requires in the future, Willow repeats the phrases "making sure" (line 453) and "right support" (line 449) which I interpret to mean that she would need assurances from college and university that they would use person-centred approaches to understand her individual needs and provide tailored support.

> Willow: "When I go into uni the big worry is around making sure that I've got the right support and the right accessibility and I've just er. Er. It's a bit of worry because that's what I don't want, to be excluded from what I want to do. Um, um I want to be able to do the stuff that I've wanted to do my whole life what I haven't been able to do yet. It's just trying, making sure that I've, that I do get to that stage where I feel that I've achieved everything." (Line 448-454)

Unlike Willow, who considers the impact of her health condition and the support she may need in the future, Samuel approaches his future with a health condition differently. Samuel described wanting to completely distance himself from his health condition and does not want to consider it as part of his future. Samuel does not plan to discuss his health condition with future education settings, does not feel it will impact on him and does not want any support. I wonder if Samuel views others' involvement in the management of his health condition as something to be endured while he is at school and considered a child. I sense that he places great importance

on his autonomy (see sections above) and sees going to university as a milestone after which he can be free of adult involvement.

> Samuel: "When I go to university like I won't tell people about T1D. I won't. So, the university probably won't know, and they won't need to (-) but yeah so I am going to try to (- -) not involve T1D in my future." (Line 445-447)

One participant, Amber, became distressed during the interview when talking about the impact of her health condition on her future aspirations. Similar themes are raised in literature, indicating that young people with a CHC may have difficulties planning and feel uncertain about what the future holds for them, which can cause distress (Christie & Khatun, 2012; Yates et al., 2010). I also noted that earlier in the interview there was a sense of increasing pressure and worry when Amber described missing out on schoolwork due to her health condition and the subsequent impact, she felt this would have on her GCSEs. Although Amber did not explicitly make connections between her GCSEs and future goals in the interview, I wondered if one way to interpret Amber's distress may be as worry and uncertainty about whether steps to her longer-term goals e.g. GCSEs could be achieved.

> Amber: "So when I miss a lot of work it er can't it's all er problem when I get to GCSEs because everyone is getting on with the work more now well more than I am getting on with it." (Line 264- 266)

5.8 Summary

This chapter has provided an overview of the five superordinate themes identified from the participants interviews through IPA analysis including a description interpretations and convergence and divergence between participants.
Further exploration in which sub and superordinate themes identified in this chapter are linked to "theoretical frameworks within mainstream psychology" (Smith et al., 2009, p.186) is detailed in the next chapter.

Chapter 6: Interpretation and Discussion

6.1 Overview

In this thesis I aim to explore the educational experiences of young people with CHCs. By prioritising their voices, I looked to understand what educational professionals may be able to learn from hearing their lived experiences and consider how this may be useful for them in developing their practice to support young people with CHCs in school. As such, this chapter attempts to address the two overarching research questions:

1. How do young people with a CHC experience mainstream secondary school?
2. What can professionals working with young people with CHC learn from these experiences?

When addressing these two research questions within this chapter, I will provide a brief overview of the secondary process described in the analytic strategy (Figure 3, Section 4.8) in which I relate the findings from the IPA analysis presented in Chapter 5 to self- determination theory (SDT) and basic psychological needs theory (BPNT), (Ryan & Deci, 2017). I will then describe how, through this secondary process, I developed a reflective framework informed by SDT. Finally, I will demonstrate how this reflective framework was used to help me to make sense of my understanding of the participants' experiences.

Chapter 2 describes the breadth of research detailing the use of SDT within the field of health research and more recently its use to explore the experiences of individuals with CHCs. I feel that this research supports the argument for SDT as a lens through which the findings within this study can be explored. I do recognise however, given the nature of IPA and the role of the researcher within the double hermeneutic, that this interpretation of the results was my own and that another researcher may not have come to this conclusion.

6.2 Relating findings to Self-Determination Theory.

6.2.1 Links Between Analysis and Self-Determination Theory

Table 5 below illustrates how the five superordinate themes identified in the analysis were deemed to link to the three basic psychological needs within SDT and BPNT. An extended version of this table which includes links to key phrases from the participants transcripts can be found in the appendices (Appendix 25). These links will be explored further in the subsections below.

Table 5: Links between IPA Analysis Superordinate Themes and Self-Determination Theory

IPA Superordinate Theme	IPA Subordinate Theme	Links to Self Determination Theory (SDT) (Deci & Ryan, 2017)
1. Autonomy	1.1 Lack of control. 1.2 Lack of Person-centred practice. 1.3 Lack of Independence. 1.4 Feeling empowered.	Autonomy
2. Relationships and Belonging	2.1 CHC impacts relationships with adults. 2.2 Conflict with adults. 2.3 Support provided by adults. 2.4 CHC impacts relationships with peers. 2.5 Feeling different.	Relatedness
3. Navigating the School Day, the Functional Impact of a CHC.	3.1 CHC impacts learning. 3.2 CHC limits social and extracurricular opportunities in school. 3.3 CHC impacts attendance. 3.4 Physical symptoms of CHC impact on the school day. 3.5 The School environment.	Competence No Link to SDT, identified as 'Biological' factor. No link to SDT, identified as 'Environmental' factor.
4. CHC Impacts Emotional Well-being at School.	4.1 CHC impacts self-esteem. 4.2 Loss of normality. 4.3 CHC results in undesirable emotions being experienced in school. 4.4 Coping mechanisms.	Can link to Autonomy, Relatedness, or competence dependent on context.
5. Planning for the Future	5.1 Setting goals. 5.2 Concerns for the future.	Competence

6.2.2 Autonomy

The first basic psychological need identified within SDT is autonomy, which can be understood to be an individual acting on their own volition and in a way which is "congruent with one's authentic interests and behaviours" (Ryan & Deci, 2017, p. 10). It is proposed that if the need for autonomy is satisfied in an individual's experience, a sense of "integrity" is achieved but when this need is thwarted there is an experience of "pressure and often conflict, such as feeling pushed in an unwanted direction" (Vansteenkiste, Ryan & Soenens, 2020, p.3).

Through the IPA analysis, Autonomy was identified as a superordinate theme across all five of the participants' transcripts (illustrated in Table 3 & Table 4). Subordinate themes that described the participants' sense of a lack of control, independence and person-centred practice in school were identified. These subordinate themes were interpreted to impact negatively on the participants' sense of autonomy in school. It should however be noted that the superordinate theme 'autonomy' and its associated subordinate themes were experienced differently by the participants in the study (explored in section 5.3). Irrespective of differences between participants, there was a strong sense that 'autonomy' was an important theme, emphasised by all participants.

While BPNT clearly establishes that the three basic psychological needs are equally important and interdependent, it is also acknowledged that "When there is support for autonomy, people are also more able to seek out and find satisfactions for both competence and relatedness, as well." (Ryan & Deci, 2017, p.247). Therefore, there is an additional, contextual role that support for autonomy, plays in the satisfaction of the other basic needs. This could be an explanation regarding the popularity of 'autonomy' as a focus in research and literature relating to SDT (Bartholomew et al, 2011; Gange, 2003; Sheldon & Krieger, 2007). I therefore considered that this may also explain the reason for the emphasis on autonomy by the participants within this research.

It is important to note that SDT posits that autonomy should not just be considered a lack of independence (Ryan & Deci, 2006) but instead active action in which

individuals make choices aligned with their values (Arvanitis & Kalliris, 2017). This is particularly pertinent as lack of independence was a subordinate theme considered to be a part of the superordinate theme autonomy. However, it was not considered alone but was combined with other subordinate themes relating to lack of control, lack of person-centred practice and the polarised theme of empowerment. As such, I felt that this comprised a well-rounded description reflective of autonomy.

As 'Autonomy' was already identified as a superordinate theme in the IPA analysis, I felt it linked directly to SDT, without any further reinterpretation, restructuring or re-naming required. I therefore decided that this would remain as a superordinate theme within this secondary phase of relating the analysis to SDT. The findings from the analysis related to autonomy were explored in detail in the Chapter 5.3.

6.2.3 Relatedness

BPNT indicates that relatedness can be understood to be the positive experience of feeling connected to others (Ryan, 1995) and through building strong interpersonal relationships (Deci & Ryan, 2000). When this need is met individuals feel that they belong, are included and cared for (Ryan & Deci, 2017). If this need is unmet the individual is reported to experience loneliness and feels excluded or isolated (Vansteenkiste, Ryan & Soenens, 2020). I felt the essence of the superordinate theme 'Relationships and Belonging' identified in the analysis was in line with this description of 'relatedness' and as such this superordinate theme was renamed during the process of relating the findings to SDT.

The findings from the analysis considered to link to 'relatedness' were explored in detail in the Chapter 5.4.

6.2.4 Competence

SDT suggests that 'competence' can be understood to be related to experiencing effectiveness, efficacy and mastery (DeHaan, Hirai & Ryan, 2016; Ryan & Deci, 2017). The sense of feeling competent is thought to occur mostly in environments in which there are opportunities to feel effective and achieve goals (Deci & Ryan, 2000)

and where there are opportunities to "extend skills and expertise" (Vansteenkiste et al, 2020, p.3). I considered that parts of the school day, particularly learning activities, but also other school-based, social, and extracurricular activities can provide a sense of achievement and mastery. As such I considered that three of the subordinate themes within the superordinate theme 'Navigating the School Day, the Functional Impact of a CHC'; 'CHC impacts learning', 'CHC impacts attendance' and 'CHC limits social and extracurricular opportunities in school' fit within 'competence'. Using this definition of competence, I also considered that the superordinate theme 'Planning for the Future' links to setting and working towards future goals which is closely related to competence.

The superordinate theme 'CHC impacts emotional well-being at school' was slightly more complex, as it did not fit neatly within one of the three basic psychological needs. I still considered that the theme did relate to SDT but recognised that the link was contextual. As such I looked separately at each subordinate theme and the context in which it was experienced, to identify where I felt it was best placed within the SDT framework. For example, I considered that feeling frustrated around a lack of independence would best fit with the need 'autonomy', feeling isolated and excluded from peers would link to 'relatedness' and feeling a sense of pride and positive self-esteem around learning would relate to 'competence'.

The findings from Phase A of the analysis relating to competence were explored in detail in Chapter 5.2.2; 5.3.3; 5.3.4; 5.6; 5.7.

6.2.5 Ecological Systems

I considered that two subordinate themes describing biological and environmental factors within the 'Navigating the School Day, the Functional Impact of a CHC' superordinate theme did not map onto the SDT framework. I proposed that these themes were part of the ecological system surrounding the young person within the individual's micro and mesosystems (Brofenbrenner & Morris, 2006). I therefore recognised that I would need to adapt the SDT framework to incorporate the aspects of the ecological systems theory (Brofenbrenner & Morris, 2006).

6.2.6 Creating a Reflective Self-Determination Theory Framework

A visual representation illustrating this reflective SDT framework was created (Figure 10, a larger copy is available in Appendix 26). At the centre, the framework has the three psychological needs relating to SDT, reflecting the understanding of them as "inner human conditions" (Ryan & Deci, 2017, p. 255). The physical and environmental needs were considered part of the ecological system surrounding the young person (Brofenbrenner & Morris, 2006) and hence are included on the reflective SDT framework in concentric rectangles.

It should be noted that the reflective SDT framework is not an attempt to generalise findings or to claim a 'truth' that can explain the experiences of all young people with a CHC attending mainstream secondary settings. This framework is instead considered an approach through which subjective experiences can be explored and represented. This framework may potentially provide a concise way in which to reflect and share young people's experiences with a broader audience.

Figure 10: Reflective SDT framework for analysing subordinate themes.
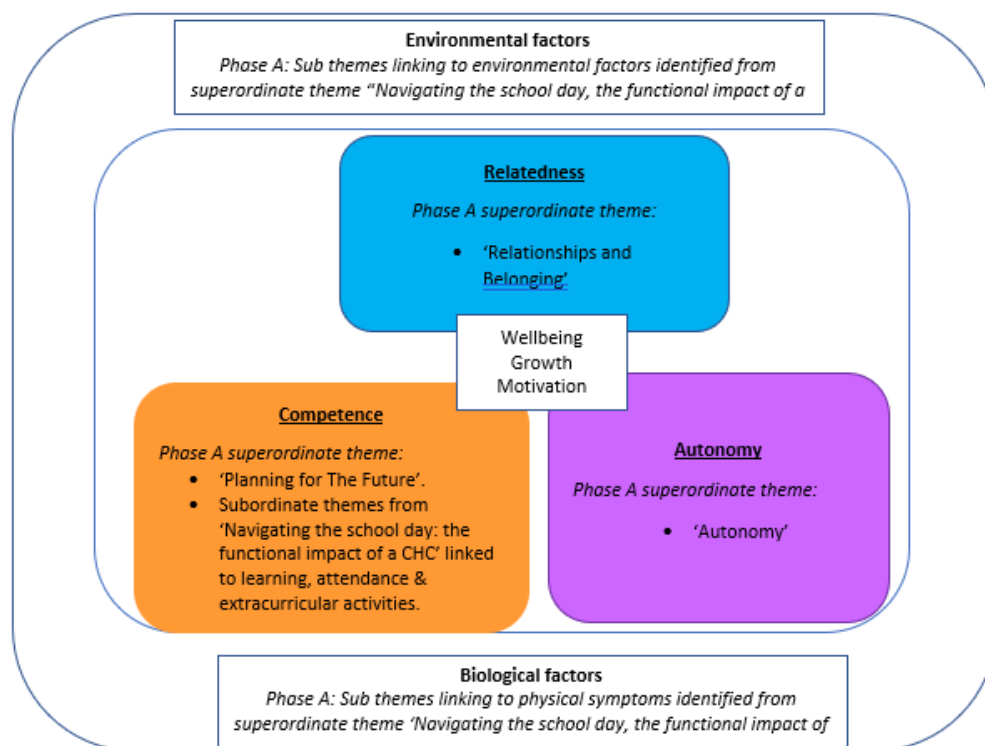
6.3 Satisfaction and Frustration of Basic Psychological Needs

6.3.1 BPNT; Needs Satisfaction and Frustration

As I considered the links between SDT and the themes identified in Chapter 5, I interpreted that the participants were describing themes as either being supportive or a barrier for them in school. I therefore recognised links to BNPT, a mini-theory of SDT which discusses the concept of 'needs satisfaction' and 'needs frustration', with the former being considered to contribute to "human thriving or flourishing" and the later as leading to "diminished growth, integrity, and well-being" (Ryan & Deci, 2017 p. 242). BPNT posits that the satisfaction of needs is variable and dynamic and that these temporal and contextual variations cause "moment to moment or situation to situation variations in well-being" (Ryan & Deci, 2017, p. 243). This theory felt particularly relevant to the findings in Chapter 5. I also considered that it may be useful in my sense-making and interpretation by potentially adding further understanding of the participants experiences.

The concept of helping and hindering factors is also found within other psychological models in health and disability research. Wallander & Varni's disability-stress coping model (1998) proposes that there are risk and resilience factors impacting on an individual's ability to adapt and cope with a CHC. Runswick-Cole & Goodley (2013) identify that each individual has a unique profile of adaptation and support that impact on their resilience. Through the lens of BPNT, helping/hindering is related to needs being met (satisfied) or thwarted (frustrated). Therefore, when considering the subordinate and superordinate themes identified in the analysis through the lens of SDT/BPNT, I felt it was possible to categorise them as either being linked to the satisfaction or frustration of one of the three basic psychological needs.

6.3.2 Incorporating the Satisfaction and Frustration of Needs into the Reflective SDT Framework

In an attempt to clearly conceptualise this, I further developed the reflective SDT framework (Figure 10), so that it also included the concept of needs satisfaction and frustration. The updated framework categorises each subordinate theme identified in

the IPA analysis as either a satisfying or frustrating factor for the psychological need it was linked to. Figure 11 (larger copy can be found in Appendix 27) is a visual depiction of the reflective SDT framework, including the perceived 'satisfying' and 'frustrating' subordinate themes. For clarity, a colour coded key demonstrating the links between the reflective SDT framework, and the subordinate themes identified in the IPA analysis in Chapter 5 is also included below (Figure 12).

Figure 11: Reflective SDT framework including satisfying and frustrating factors.
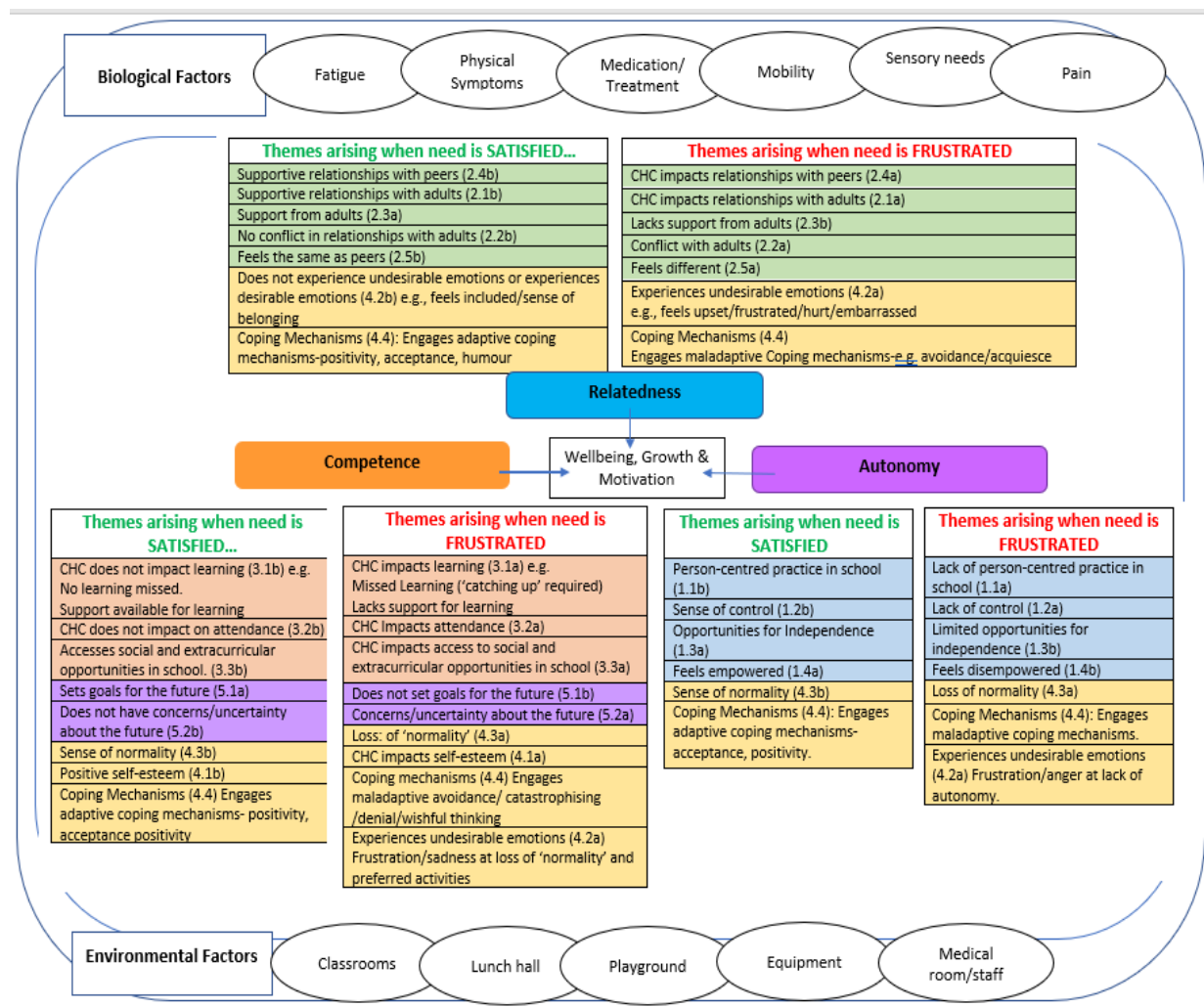
Figure 12: Colour coded key demonstrating the links between the reflective SDT framework, and the subordinate themes identified in the IPA analysis.

Superordinate Theme	Subordinate Theme	Alternative emergent themes arising for some participants. (Detailed in Chapter 5)
1. Autonomy.	1.1a Lack of control	1.1b Sense of control
	1.2a Lack of Person-centred practice	1.2b. Person centred practice in school
	1.3a Lack of Independence	1.3b Opportunities for independence
	1.4a Feels empowered.	1.4b Feels disempowered
2. Relationships and Belonging.	2.1a CHC impacts relationships with adults.	2.1b Supportive relationships with adults
	2.2a Conflict with adults	2.2b No conflict in relationships with adults
	2.3a Support provided by adults	2.3b Lack of support from adults
	2.4a CHC impacts relationships with peers.	2.4b Supportive relationships with peers
	2.5a Feeling different	2.5b Feels the same as peers
3. Navigating the school day: the functional impact of a CHC.	3.1a CHC impacts learning.	3.1b. CHC does not impact learning
	3.2a CHC limits social and extracurricular opportunities in school.	3.2b. Accesses social and extracurricular opportunities in school.
	3.3a CHC impacts attendance.	3.3b. CHC does not impact attendance
	3.4a Physical symptoms of CHC impact on the school day	
	3.5a The School environment	
4. CHC impacts emotional well-being at school.	4.1a CHC impacts self-esteem	4.1b Positive self-esteem
	4.2a Loss of normality	4.2b Sense of normality
	4.3a CHC results in undesirable emotions being experienced in school	4.3b. Does not experience undesirable emotions or experiences desirable emotions
	4.4a Coping mechanisms (adaptive and maladaptive)	
5. Planning for the Future.	5.1a Setting goals	5.1b Does not set goals for the future
	5.2a Concerns for the future	5.2b Does not have concerns for the future

6.4 Creating Individual Self-Determination Theory Reflective Framework Map

As indicated above, BPNT proposes each psychological need is essential but that individuals have a unique pattern of needs satisfaction and frustration which is temporally and contextually driven (Reis et al., 2000; Sheldon, Ryan & Reis, 1996). To reflect this, it was possible to create an individual reflective SDT framework map for each participant. The individual's reflective SDT framework map highlights which of the subordinate themes identified within their interviews were categorised as linking to the satisfaction of needs and which were considered to relate to the frustration of needs. The environmental and biological factors were then represented

within the ecosystem. The subordinate themes identified within the individual's interview highlighted in yellow on the map, provide a clear, concise, visual overview. The highlighted reflective SDT framework map allows the researcher to represent the meeting or thwarting of the participant's needs through a one-page overview, making it possible to easily compare and note patterns of convergence and divergence between the participants. I felt that the production of these individual reflective SDT maps reflects a commitment to the idiography associated with IPA and speaks to the uniqueness of each of the participants' lived experiences.

Both Amber and Autumn's reflective SDT framework maps (Figure 13 and Figure 14, larger versions available in Appendix 28 and 29) are provided as examples. It is possible to see from Amber's map that there appears to be limited satisfaction of her needs relating to competence and autonomy, suggesting that these would be possible areas to consider intervention and support in school. There appears to be a more balanced meeting of needs in relation to relatedness, suggesting that this may be an area which is particularly supportive for her and could be drawn upon as a support. Amber also has significant biological and environmental factors highlighted and therefore practical support would need to be considered for these. There is a lack of overall balance between the psychological needs which could be explored further with Amber. It is also possible to see that Amber has several themes which appear to be both satisfied and frustrated e.g., lack of control/sense of control and supportive relationships/impacted relationships. This demonstrates the contextual and temporal nature of the meeting and thwarting of needs as indicated in BPNT (Ryan & Deci, 2017). This could potentially be considered a concept to explore further with Amber.

Autumn, however, appears to have more balance across the meeting of the three needs. Her needs also appear to be particularly satisfied in terms of her relatedness, which again could be considered an area of support. There are significantly less biological and environmental factors highlighted, so potentially less practical or environmental considerations needed. There is however a section of competence relating to learning which appears to be particularly thwarted. As such this may be an area in which support could be considered in school. The remaining participants' SDT frameworks can be found in the appendices (Appendices 30, 31 and 32)

Figure 13: Amber's Reflective SDT map indicating in yellow the subordinate themes identified in her interview.

Biological Factors: Fatigue | Physical Symptoms | Medication/Treatment | Mobility | Sensory needs | Pain

Themes arising when need is SATISFIED…
Supportive relationships with peers (2.4b)
Supportive relationships with adults (2.1b)
Support from adults (2.3a)
No conflict in relationships with adults (2.2b)
Feels the same as peers (2.5b)
Does not experience undesirable emotions or experiences desirable emotions (4.2b) e.g., feels included/sense of belonging
Coping Mechanisms (4.4): Engages adaptive coping mechanisms-positivity, acceptance, humour

Themes arising when need is FRUSTRATED
CHC impacts relationships with peers (2.4a)
CHC impacts relationships with adults (2.1a)
Lacks support from adults (2.3b)
Conflict with adults (2.2a)
Feels different (2.5a)
Experiences undesirable emotions (4.2a) e.g., feels upset/frustrated/hurt/embarrassed
Coping Mechanisms (4.4) Engages maladaptive Coping mechanisms-e.g. avoidance/acquiesce

Relatedness

Competence → Wellbeing, Growth & Motivation ← **Autonomy**

Themes arising when need is SATISFIED…
CHC does not impact learning (3.1b) e.g. No learning missed.
Support available for learning
CHC does not impact on attendance (3.2b)
Accesses social and extracurricular opportunities in school. (3.3b)
Sets goals for the future (5.1a)
Does not have concerns/uncertainty about the future (5.2b)
Sense of normality (4.3b)
Positive self-esteem (4.1b)
Coping Mechanisms (4.4) Engages adaptive coping mechanisms- positivity, acceptance positivity

Themes arising when need is FRUSTRATED
CHC impacts learning (3.1a) e.g.
Missed Learning ('catching up' required)
Lacks support for learning
CHC Impacts attendance (3.2a)
CHC impacts access to social and extracurricular opportunities in school (3.3a)
Does not set goals for the future (5.1b)
Concerns/uncertainty about the future (5.2a)
Loss: of 'normality' (4.3a)
CHC impacts self-esteem (4.1a)
Coping mechanisms (4.4) Engages maladaptive coping mechanisms: avoidance/ catastrophising /denial/wishful thinking
Experiences undesirable emotions (4.2a) Frustration/sadness at loss of 'normality' and preferred activities

Themes arising when need is SATISFIED
Person-centred practice in school (1.1b)
Sense of control (1.2b)
Opportunities for Independence (1.3a)
Feels empowered (1.4a)
Sense of normality (4.3b)
Coping Mechanisms (4.4): Engages adaptive coping mechanisms- acceptance, positivity.

Themes arising when need is FRUSTRATED
Lack of person-centred practice in school (1.1a)
Lack of control (1.2a)
Limited opportunities for independence (1.3b)
Feels disempowered (1.4b)
Loss of normality (4.3a)
Coping Mechanisms (4.4): Engages maladaptive coping mechanisms-Experiences undesirable emotions (4.2a) Frustration/anger at lack of autonomy

Environmental Factors: Classrooms | Lunch hall | Playground | Equipment | Medical room/staff

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Figure 14: Autumn's Reflective SDT map indicating in yellow the subordinate themes identified in her interview.

Biological Factors: Fatigue | Physical Symptoms | Medication/Treatment | Mobility | Sensory needs | Pain

Themes arising when need is SATISFIED…
Supportive relationships with peers (2.4b)
Supportive relationships with adults (2.1b)
Support from adults (2.3a)
No conflict in relationships with adults (2.2b)
Feels the same as peers (2.5b)
Does not experience undesirable emotions or experiences desirable emotions (4.2b) e.g., feels included/sense of belonging
Coping Mechanisms (4.4): Engages adaptive coping mechanisms-positivity, acceptance, humour

Themes arising when need is FRUSTRATED
CHC impacts relationships with peers (2.4a)
CHC impacts relationships with adults (2.1a)
Lacks support from adults (2.3b)
Conflict with adults (2.2a)
Feels different (2.5a)
Experiences undesirable emotions (4.2a) e.g., feels upset/frustrated/hurt/embarrassed
Coping Mechanisms (4.4) Engages maladaptive Coping mechanisms-e.g. avoidance/acquiesce

Relatedness

Competence → Wellbeing, Growth & Motivation ← **Autonomy**

Themes arising when need is SATISFIED…
CHC does not impact learning (3.1b) e.g. No learning missed.
Support available for learning
CHC does not impact on attendance (3.2b)
Accesses social and extracurricular opportunities in school. (3.3b)
Sets goals for the future (5.1a)
Does not have concerns/uncertainty about the future (5.2b)
Sense of normality (4.3b)
Positive self-esteem (4.1b)
Coping Mechanisms (4.4) Engages adaptive coping mechanisms- positivity, acceptance positivity

Themes arising when need is FRUSTRATED
CHC impacts learning (3.1a) e.g.
Missed Learning ('catching up' required)
Lacks support for learning
CHC Impacts attendance (3.2a)
CHC impacts access to social and extracurricular opportunities in school (3.3a)
Does not set goals for the future (5.1b)
Concerns/uncertainty about the future (5.2a)
Loss: of 'normality' (4.3a)
CHC impacts self-esteem (4.1a)
Coping mechanisms (4.4) Engages maladaptive avoidance/ catastrophising /denial/wishful thinking
Experiences undesirable emotions (4.2a) Frustration/sadness at loss of 'normality' and preferred activities

Themes arising when need is SATISFIED
Person-centred practice in school (1.1b)
Sense of control (1.2b)
Opportunities for Independence (1.3a)
Feels empowered (1.4a)
Sense of normality (4.3b)
Coping Mechanisms (4.4): Engages adaptive coping mechanisms- acceptance, positivity.

Themes arising when need is FRUSTRATED
Lack of person-centred practice in school (1.1a)
Lack of control (1.2a)
Limited opportunities for independence (1.3b)
Feels disempowered (1.4b)
Loss of normality (4.3a)
Coping Mechanisms (4.4): Engages maladaptive coping mechanisms-
Experiences undesirable emotions (4.2a) Frustration/anger at lack of autonomy.

Environmental Factors: Classrooms | Lunch hall | Playground | Equipment | Medical room/staff

6.5 Chapter Summary

This chapter has summarised how I have used SDT and BPNT (Ryan & Deci, 2017) and ecological systems theory (Brofenbrenner & Morris, 2006) to support me to further explore and make sense of the findings detailed in Chapter 5. This further exploration and interpretation have led to the development of a reflective SDT framework, through which it is proposed the participants' individual subjective experiences can be viewed and illustrated.

The possible implications for practice will be explored further in Chapter 7.

7. Implications for Professional and EP Practice

7.1 Overview

In this chapter I will reflect on my findings in relation to my second research question by considering what educational professionals, may learn by listening to the voices of young people who have a CHC. I will consider how the reflective SDT framework developed in Chapter 6 (Figure 11) may be helpful for school staff, educational psychologists and health professionals when considering how best to support young people with CHC in mainstream secondary schools. I will also identify the possible tensions that have arisen between the development and use of this reflective framework and the ontological underpinnings of IPA. Finally, I will explore the limitations and impact of the study and then discuss recommendations for further research.

7.2 The Reflective SDT Framework

7.2.1 Using Reflective SDT Framework

The reflective SDT framework developed in Chapter 6 (Figure 11 and Appendix 27) is proposed as one way of viewing the participants' experiences in relation to the meeting or frustrating of the three basic psychological needs identified in SDT and BPNT. I considered that the reflective SDT framework may be transferable to a broader population of young people with a CHC attending school, and therefore may have implications for educational professionals' practice. The strengths, limitations, risks, and possible impact of this proposal are explored below.

7.2.2 Raising Awareness.

Some school staff feel overwhelmed when they are asked to support a young person with a CHC which has been attributed to limited training opportunities and subsequent gaps in knowledge and understanding (Barraclough & Machek, 2010; Nabors et al., 2008; Madan-Swain et al., 2004). There is also an indication that some education professionals can struggle to acknowledge the impact that having a CHC

can have on a young person, particularly when the CHC is less visible, such as for the participants with diabetes in this research (Jackson, 2013). Interpretations of the interviews suggested that four participants in this study felt that at least some of the adults working with them lacked awareness of how their CHC impacted them, which at times had negative implications on their experiences of school (see Chapter 5.4). Further, I inferred those three participants felt that a staff member really understanding them as a person, including the specific presentation of their CHC, enhanced their relationships and helped them to feel supported. It therefore appears that raising staff awareness of the individual's experiences, particularly those beyond the medical, would be an extremely helpful step in supporting young people with a CHC in school.

I considered that the reflective SDT framework (Figure 11 and Appendix 27) could, with further development and careful presentation, be used as a tool to raise awareness about the potential broader psychosocial impacts of having a CHC on education, beyond the purely medical. The reflective SDT framework presents an accessible and coherent overview of some of the potential psychosocial factors related to SDT that could be considered either a support or barrier for a young person's psychological wellbeing in school. I propose that this framework, in conjunction with the information already available to schools, could provide a way for staff to view these needs (and strengths) more holistically, considering potentially overlooked factors at both an individual and broader systemic level.

There are, however, risks that need to be thought through when considering the use of this framework in practice. Firstly, given that this framework was developed through an IPA process, there would need to be some consideration as to how to ensure that professionals have a level of understanding that the framework sits within a process rooted within phenomenology, and that the complexities of this form of 'meaning making' are made clear. Secondly, it would be important to ensure that the framework is presented in such a way to ensure that it was not viewed as a definitive list applicable for all young people with CHC. To suggest that a single framework could identify all the unique and subjective experiences of young people with a CHC would be unhelpful and undermine the concepts of phenomenology and idiography in IPA. Thirdly, professionals would need to understand that the

framework represents young people's experiences through the lens of one psychological theory and that alternative interpretations are possible. It may be possible that development of guidance or training encompassing these points could be a potential next step.

There is still much to consider when operationalising the framework, but if seen as a starting point to introduce the potential factors impacting on a young people with CHCs emotional wellbeing at school, it is possible to see how this may be helpful.

7.2.3 Prioritising Young People's Voices and Person-Centred Planning

I consider a primary focus of good practice within educational psychology to be related to the empowerment of young people and the use of approaches which allow their voices to be meaningfully heard (Greig, Hobbs & Roffey, 2014; Todd, Hobbs, & Taylor, 2000). I propose that the approach undertaken in the research highlights the importance of prioritising young people's voices and promoting them as active participants in their lives and as experts of themselves and their CHC (Gabriel, 2004; O'Brien & O'Brien, 2002; Todd 2003). It is argued that prioritising their voice provides opportunities for them to experience a sense of agency, empowerment, confidence, and self-esteem (Jelly, Fuller, & Byers, 2013; Plummer, 2007; Weare, 2015). This feels particularly important as the literature indicates that research within the field is dominated by the voice of others; parents, medical professionals, and teachers (Close & Norris, 2000; Yates, 2010). I feel that a particular strength of the reflective SDT framework is its use to represent individual experiences, promoting the voice and unique experiences of the young person (Appendix 28, 29, 30, 31 and 32).

Person-centred meetings have been promoted in schools for some time, particularly in relation to reviews for young people with special educational needs and disabilities (SEND). Guidance, materials and training have been developed to support key school staff to ensure they are competent and confident in the approach (DfE, 2015b). Yet the same expectation or support is not yet available when considering the development or review of individual healthcare plans (IHPs) which are legally required in schools for young people with CHCs. The lack of person-centred practice

in place at school was also identified as an emergent theme in all five of the participants' interviews. There was a sense that they all, although in different ways, felt that staff at school had not all fully understood them or what their CHC meant for them in all areas of their school life. This therefore feels like a key implication for practice and a potential gap in support for adults supporting young people with a CHC in their education.

Whilst it would be impossible for school staff or EPs to be able to recreate the same level of interviewing and analysis undertaken in this study, it may be possible to adapt and apply the approach to support the facilitation of person-centred conversations in school. This would also require professionals to be supported to have a level of understanding of phenomenology as described above.

I consider there are two tools developed during this research which may, with further development, be useful for EPs and school staff when working with young people with a CHC. Firstly, the visual interview schedule (Appendix 10) may provide a useful guide in facilitating person-centred and collaborative conversations. Through this conversation, I consider that it may be possible, with some additional support and training, that EPs or school staff could use the reflective SDT framework (Figure 11 and Appendix 27) to illustrate the content of these conversations. This process would provide young people with CHCs an opportunity to share their unique experiences of attending school, beyond the medical which is often the only priority. This would also provide a concise overview of the individual's unique profile of psychosocial needs in relation to SDT which could be shared with staff to raise awareness and consider areas of school life that may require further support. This would be complementary to the individual health care plan which is a current legal requirement and outlines the physical needs and practical support.

I recognise that this approach will need significant further development. I also acknowledge that by attempting to operationalise this framework it moves away from the core concepts of IPA and as such there is the risk that conversations with school staff could become tokenistic gestures undermining the process, preventing meaningful participation and genuine collaboration which could feel disempowering

for the young people (Hart, 1992). This would need to be carefully considered in any future development of the materials.

7.2.4 Identifying Support for Wellbeing in School

Specific psychological support is only offered to a relatively small number of young people with CHCs, predominantly through clinical psychology teams within hospital settings (Edwards & Titman, 2010). However, the reflective framework (Figure 11), which draws on SDT (Ryan & Deci, 2017) and ecological systems theory (Bronfenbrenner, 1979), attempts to highlight the important role that the systemic, environmental, and social factors in the school system play in supporting or hindering the wellbeing of the participants. This framework suggests that there is much to be explored within and with schools, and without the need of specialist psychological support, to assist young people with CHCs.

BPNT proposes that individuals will display a unique profile of basic psychological needs being met or thwarted based on their subjective experiences. The approach taken within this research suggests that it is possible to reflect this unique presentation using the reflective SDT framework. This individual framework could then be used to identify areas where support, or intervention, could be offered and those that could be drawn on as strengths.

Due to the individual nature and huge variation in these profiles, it is not practically possible, nor in line with the ontological underpinnings of the research to provide a definitive list of strategies or recommendations that could be used by schools to support the satisfaction of each of the basic psychological needs. Providing a checklist for good practice feels unhelpful as it is likely to undermine the phenomenological approach and the subjective nature of individuals' experiences and once again devalue the voice of the young person. The reflective SDT framework is therefore considered a demonstration of how through a careful, person-centred, collaborative approach undertaken *with* the young person, it could be possible to identify and develop personalised support in relation to meeting the three basic psychological needs.

7.3 Impact of Research

Impact is of growing importance in the field of research and is described as the "effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia" (University of Sheffield, 2021). Throughout this research I have been concerned with the possible impact and been keen to consider how the thesis could have wider implications in practice. Educational psychologists are applied practitioners, who use and translate psychological theory and research to support young people, their families, and schools. Therefore, I consider that impact, an attempt to turn research into something of practical benefit, feels highly congruent with the values of the profession. However, I recognise that there is tension at an ontological level between claiming impact, reach and significance and the phenomenological approach I have undertaken in this thesis.

Throughout the research I have aimed to balance the key tenets of IPA; phenomenology, hermeneutics and idiography with my desire for impact. I have attempted to make clear the limitations in generalisation, identified the possible risks and considerations that would be needed in operationalising the reflective framework.

On balance, I consider that the reflective framework developed in this thesis (figure 11) is an idea in its infancy that has the potential to be built upon to create a tool which is impactful and potentially of benefit to the community that educational psychologists serve.

7.4 Limitations of the Research

In respect of the data collection within the study, I recognised that there were limitations in my research design regarding my interview schedule (Appendix 19) and the accompanying visual interview schedule (Appendix 10). The visual prompt sheet was shared with the participants prior to the interview and referred to when required throughout to reduce anxiety and support their reflections. I was aware that the increased questions and prompts may have influenced the participants' answers and

impacted on data collected. It is possible, therefore, particular questions asked, and prompts provided led to specific themes being identified through analysis.

I also considered that there were some limitations in respect to rapport building and the brevity of contact with the participants (Alderson, 2000), particularly given their age and the online nature of contact. Limited contact with young people can present challenges for the researcher in identifying their level understanding impacting on how questions are asked (Davie, 1991). Attempts were made to support rapport building by offering an introduction and additional check-in sessions, the inclusion of accessible visual prompts, provision of differentiated sessions and materials when needed and by being flexible in my approach to interviewing. However, I recognise that these steps do not replace more face-to-face contact sessions over a longer period.

Finally, I considered there were limitations regarding the creative project. The online nature of the research meant there was variation in the uptake and completion of this aspect of the research. I could see the benefits of the approach for those who accessed the creative task but did not analyse their outputs. I considered this a limitation as I felt they would have provided another layer of depth to the analysis and further insight and understanding. I also felt that for those who did not engage, complete or share the outcome of the creative project that this may have been a useful aspect for them in different circumstances.

7.5 Recommendations for Future Research

This research has ultimately led to the development of a reflective SDT framework (Figure 11 and Appendix 27) through which it is considered possible to facilitate discussion with young people and represent their experiences of school through the lens of SDT considering the satisfaction or hindrance of their basic psychological needs. Given that this research was carried out with a small number of participants, it may be useful for future research to evaluate the use of the framework as a potential tool in exploring the views of young people with a CHC. Employing mixed methods or empirical approaches could also be a possibility for this future research. Tools such as the basic psychological need satisfaction and frustration scales (Chen

et al., 2014) could be used in conjunction with qualitative interviewing to explore the efficacy of SDT as a model in relation to a larger sample. Care would need to be taken to ensure that the subjective and unique experiences of the participants are not minimised or dismissed.

It may also be helpful to extend the sample size and selection criteria used when recruiting participants beyond the specified age range, e.g., to include primary aged or post-16-year-old pupils and for those with a CHC potentially considered less severe e.g., eczema and asthma.

I also feel that there may be some merit in future research using visual and participatory methods, e.g., photo elicitation and auto-photography, to explore young people's lived experiences of CHCs and school. Whilst attempts were made to incorporate elements of this within the research, it was challenging while working online. I therefore feel that this is an area worth exploring further in future research.

7.6 Concluding Summary.

This research aimed to address an identified gap in literature relating to listening to the voices of young people with a CHC in respect of their lived experiences of attending mainstream secondary school. Flexibility and reflexivity were required to negotiate the challenges of completing the research online throughout the COVID-19 pandemic. Despite these difficulties, five participants were recruited and offered the option to engage in a creative project before taking part in an online semi-structured interview. Through IPA analysis of the interviews, five superordinate themes were identified which related to the participants' autonomy, relationships and sense of belonging, the functional impact of having a CHC on the school day, the impact on their emotional wellbeing at school, and their views about their future. A secondary process was employed based on my continued interpretation of the findings and the superordinate themes were linked to psychological theory; SDT and BPNT.

It was argued that SDT and BPNT provide one way in which the participants' experience of school can be further understood. As a result, a reflective SDT

framework, based around the key tenets of SDT, BPNT (Ryan & Deci, 2017) and ecological systems theory (Bronfenbrenner& Morris, 2006) was developed and used to visually represent the subjective experiences of the participants. It was proposed that this framework, with further development and research, may have broader impact and be useful for education professionals working with young people who have a CHC in school. The framework was considered of potential benefit in several ways which included: raising professionals' awareness of the potential broader psychosocial impact of having a CHC, promoting pupil voice, supporting person-centred practice and developing targeted, personalised interventions to support young people with a CHC in school.

It is recognised, however, that this is only one possible interpretation based on a small-scale study. However, it is hoped that it does fulfil both research questions in highlighting the school experiences of the participants and also provides a framework through which some potential practical support and professional development for those working with these young people could be further explored.

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Appendix 1: Table detailing steps taken within the study to meet the Reliability Criteria (Yardley 2000)

Reliability Criteria	Description of reliability criteria	Demonstrated in this research by…
Sensitivity to Context	Yardley, 2000 suggests that to be considered "good" research must demonstrate "sensitivity to the context". This is multifaceted and includes demonstrating awareness of the "socio-cultural milieu in which the study is situated" (Smith, Flowers & Larkin, 2009, p.180). This awareness should be alongside close attention to current literature within the field and the data from participants (Smith, Flowers & Larkin, 2009, p.180).	• Exploration of existing literature within the field (Chapter 2: Literature review) • Findings related to existing literature (Chapter 5&6 Results & Discussion) • New literature referenced in discussion (Chapter 6).
	In respect to the methodology Yardley, 2000 further suggests that researchers need to demonstrate their research approach, including philosophical theory.	• Exploration of philosophical underpinnings and rationale for choice of IPA (Chapter 3: Methodology)
	During data collection it is suggested that the researcher can demonstrate sensitivity to the context through their interview; how they develop rapport and demonstrate empathy, that they are attuned to any interactional difficulties and where possible address any power imbalances that may exist (Smith, flowers & Larkin, 2009, p.180)	• Development of adapted interview materials including differentiated visual supports and prompts for participants (Chapter 4: Procedure and available in appendices 7. 9 & 19) • Additional online sessions built into design in attempt to develop rapport.

	During analysis and reporting researchers should demonstrate a sensitivity to the data by providing transparent links to the raw material e.g. transcripts (Smith, Flowers & Larkin, 2009, p.181) Reissman (1993) suggests that sensitivity can be shown by seeking participants' views on the researcher's interpretation of their interview, although does not prescribe to changes being made to interpretation on the basis of this. Yardley, 2000 also recommends that care is taken during analysis that any claims recorded are made cautiously	• Analysis shows sensitivity to 'raw' material e.g., high number of verbatim extracts used (Chapter 5: Results) • Member Checks offered to all participants via a visual 'theme map (appendices 13, 14) • Claims made are appropriate to the sample analysed and interpretations reported cautiously. (Chapter 5 & 6, Results & Discussion) Findings related to existing literature and new literature referenced in discussion. (Chapter 6)
	Yardley, 2000 describes commitment as "thoroughness in data collection, analysis and reporting". Emersion in the data over a prolonged period leading to development in skills in the field is also thought be an indicator of research with a high degree of commitment. It is also indicated that commitment can be demonstrated	• Frequent supervision with research supervisor. • Development of a peer supervision group for TEPs completing IPA. • Research diary, selections of which are shared through the thesis through the use of 'reflection boxes'. Contains

Commitment & Rigour	through multiple areas within 'sensitivity to context'. I identified that a commitment to reflexivity, that is a continual openness and reflection on the impact on the research of my assumptions, intentions, and actions (Yardley, 2000).	reflections, questions and concerns around the research. • Pilot study to develop interview technique (Chapter 4: procedure) • See examples above detailed in 'sensitivity to context'.
	Rigour, or thoroughness is proposed to begin by ensuring participants are carefully selected in line with the research question and there is a homogeny to the group. Further Rigour at the data collection stage is shown within the interview through probing and "digging deeper" (Smith, Flowers & Larkin 2009, p.181).	• Clarity in definitions established before participant recruitment (See Chapter 1: definitions) • Recruitment of 5 participants, homogenous with age, school status and CHC. (See Chapter 4: participants section for further details). • Interview schedule and visual prompts designed to 'dig deeper' (See appendix 10 & 18 and 20)
	Finally, rigour is considered in the context of the analysis of data. Rigour can be demonstrated by explorations moving beyond the descriptive "common sense understandings" (Yardley, 2000). Smith, Flowers & Larkin also describe that it is important that links between analysis (themes) and raw data can be made using verbatim quotes. They suggest that there are	• Analysis moves beyond descriptive in transcripts and then themes tables for each participant (Chapter 5: Results and Appendices section including transcripts and theme tables) • Verbatim quotes throughout results section and key quotes provided for every super and subordinate theme

	quotes provided for each theme by each participant and use of quotes are even across the participants.	for each participant (Theme Tables as seen in appendices 21,23 & 25)
	This principle is linked to the write up of the thesis. Transparency refers to "degree to which all relevant aspects of the research process are disclosed." (Yardley, 2000)	• Clear description of research design and procedure including pictural representation of analytic strategy (Chapter 4: procedure) • Evidence of 'paper trail' (Yin, 1989) e.g. research proposal, interview schedule, interview recordings, electronically annotated transcripts, evidence of various stages of analysis through theme tables.

Transparency & Coherence	Coherence can be demonstrated in two ways. Firstly, the presentation of a coherent argument throughout the thesis, ensuring that contradictions are fully explored (Yardley, 2000). Secondly, there should be a coherence between the research and the methodology and philosophical stance taken. With IPA this would be a commitment to the underpinning principles of phenomenology, idiography and hermeneutics. Claims on generalisability should be cautious due to the subjective nature of interpretation and experience. (Smith, Flowers & Larkin, 2009, p.182).	• Clear description links between research philosophy and research (Chapter 3: methodology) • Clear description of analytic strategy and the relationship between these and research methodology and philosophy (Chapter 3, Chapter 5 and Chapter 6) • Clear explanation of how hermeneutic cycle has been applied within analysis (Chapter 5: Results) • Caution expressed in relation to claims made (Chapter 5&6 results and discussion)
Impact & Importance	This refers to the "impact and utility" of the research (Yardley, 2000). It is suggested that unless researcher aim to tell the reader something "interesting, important or useful" it cannot be valid (Smith, Flowers & Larkin, 2009, p. 183).	• Identified 'gap in research, which is focus of research (Chapter 2: Literature Review) • Development of 'new' framework to reflect findings and links to psychological theory (Presented in Chapter 5: results & discussed in Chapter 6) • Discussion about potential use and impact of research in educational settings.

Appendix 2: Ethics application

Section C: Summary of research

1. Aims & Objectives

There is a plethora of research, often completed by academics rooted in the medical model, suggesting that young people with chronic health conditions face multiple, varied and complex challenges, particularly in regards to their education. However, research in this field often focuses on pupils who have, due to their condition, had to take prolonged periods out of school and continue their education through tuition services or hospital-based schools. It is also noted that research has predominately focused on the detrimental impact of having a chronic health condition on young people's educational outcomes and less on their lived experiences of living with their condition whilst attending school. Research with young people with chronic health conditions who attend mainstream educational settings and who have not been in receipt of specialist educational support is also more sparse. It, therefore, feels important to give a voice to this specific group of young people to explore their lived experiences of attending mainstream education whilst *managing chronic health conditions*.

As such this research aims to explore the experiences of young people, aged 11-18 years, who have a chronic health

condition and attend a mainstream education setting. Further, it aims to consider how any insights gained from the research may inform the practice of professionals working to support young people with chronic health conditions within mainstream education settings.

To achieve this, the research aims to explore two broad questions:
1. How do young people with a chronic health condition experience mainstream school and post-16 education settings?
2. In what ways can an interpretation of the key themes arising from accounts of these experiences inform the practice of professionals working with young people with chronic health conditions within mainstream educational settings?

The working definition of a chronic health condition throughout this research will be:
A medical condition that has lasted a minimum of 3 months or more that requires regular medical interventions e.g. medications, assistive devices or specialist diets which can be considered to interfere with a young person's daily life. Chronic health conditions are considered to have the potential to be life-threatening but do not pose an immediate danger to life. They are not (yet) curable.
Examples of chronic health conditions include, but are not limited to; diabetes, cystic fibrosis, sickle cell anaemia, epilepsy, cerebral palsy, congenital heart difficulties (requiring ongoing treatment)and spina bifida.

It should also be noted that participants in this study will, despite their chronic health conditions, have been attending mainstream educational settings (before school closures related to the COVID-19 pandemic) and will not have been deemed appropriate candidates to access hospital schools or home tuition services.

2. Methodology

I intend to collect data using two approaches. Firstly, the participants will be asked to engage in a creative project of their choice which aims to retrospectively reflect their experiences of attending a mainstream setting whilst managing their health condition. To increase the participation of the young people in the planning of the research, the content, method and presentation style of the creative project will be explored and decided with them, not for them. Examples of possible creative projects may include; retrospective photo diaries, artwork, comic strips, animation, PowerPoint or films. This list is not exhaustive and the format chosen will be led by each participant's interests. The project should speak to and reflect the participants lived experience, and as such, the approaches to completing the project may to vary significantly between individuals.

The creative project will be completed at home, over 1-3 weeks, with telephone support from the researcher as required. The participant's parent/carer will be involved in all initial planning and be made fully aware of the creative project and all that it entails. It is hoped that the addition of the visual methodology within the creative project will increase participant engagement, motivation and act as a catalyst which supports young people to reflect on and share their complex experiences in a way which verbal interviews alone may not. The participant will have the opportunity to decide on what (if any) of their creative project to share with the researcher.

On completion of the creative project, the participant will be asked to take part in a semi-structured video interview. Video interviews will take place over a secure university-approved platform (google meet). If the participant has agreed to share materials from their creative project, they will be asked about them directly and they will be and they will be provided with an opportunity for participants to talk about the significance of the creative material they have produced. They will also then be used as a stimulus for the remainder of the interview. Should the participants choose not to share materials from the creative project, they can still refer to them throughout the interview whenever they choose. It is intended that the process of engaging with a creative task to explore experiences will provide the young person with time and space to reflect on what they would wish to share with the researcher, even if they do not wish to share the creative materials directly.

The video interview will be audio recorded using a dictaphone (no video will be recorded and no screenshots will be taken) transcribed and analysed using Interpretive Phenomenological Analysis (IPA). Transcripts will be stored in a secure google drive attached to the researcher's university account.

Once the participants have been identified and consented to take part in the research (discussed in section D) the research is planned to take place over 5 distinct phases:

Phase 1-Introductory video call.

A video call, via google meet (university approved secure platform), will be made to the participant and their parent/carer to introduce the researcher and discuss the aims and approach of the study. Given the difficulties with obtaining informed consent from young people, consent will, in addition to the written consent provided during recruitment, be verbally renegotiated at this stage. To do this the consent form and information sheet will be discussed, providing the young person or parent/carer an opportunity to ask any further questions before they provide verbal consent. This will ensure that participants are fully informed about the research and will remind them of their right to withdraw at any time should they wish to do so.

The researcher will then discuss the creative project with the young person and their parent/legal guardian. The researcher will explore the young person's interests and preferences in regards to the creative project, providing examples of possible projects if required by the participant. The researcher will then ascertain the young person's preferred creative approach to the project and discuss the logistics (including access to required materials) relating to

the chosen method. Should the young person be struggling to engage with a specific creative methodology, the researcher will provide ideas and scaffolding as required.

The approaches taken towards the collection, sharing, storage and dissemination of visual images will ensure that there are no ethical issues raised with anonymisation, consent and confidentiality when using this visual methodology.

The participant, parent/legal guardian and researcher will then agree on a project timescale including the date for a scheduled 'check-in' with the researcher. The project is predicted to be between 1-3 weeks for completion, but there is flexibility within these timescales to accommodate individual participant's preferences. Given the nature of the participants health needs the opportunity to reschedule any activity in the project will be offered if they feel tired or unwell.

Following on from the initial discussion the young person and parent/legal guardian will be provided with a 'project prompt sheet' via email (or post if there is no access to technology). The project prompt sheet will provide practical advice to support the young person and parent complete the project and will also contain the contact details of the researcher, the research supervisor and further information to signpost the young person and parent/legal guardian to support services should the young person become distressed or require further support whilst completing the creative project.

The researcher will also ensure that the young person has any required materials whilst adhering to social distancing requirements.

Phase 2: Creative project.

The creative project aims to provide a reflective space in which the young people can retrospectively explore their experiences of managing a chronic health condition whilst attending a mainstream school or post-16 setting. The participant will carry out the project at home as agreed in the initial discussion.

Ethical considerations dictate that the research should not contain identifiable (or potentially identifiable) images of people or places. However due to the nature of the research it is a possibility that the young person may wish to include images or text in their creative project which could be identifiable because they depict people (e.g. parents or teaching assistants) or places (hospitals, education settings) that are important to them and key in explaining their lived experiences. This will mean that all identifiable images will need to be censored (by being covered or blurred) by the researcher before use. Any text references to people or places will be replaced by pseudonyms agreed with the young person.

Phase 3: Check-in.

The researcher will 'check-in' via a video call using a secure university-approved platform with the participant and parent/legal guardian on the date agreed in the initial meeting to discuss any concerns/difficulties during the creative project at home providing support and adjusting timescales as required. Contact can be made at other times outside this check-in period via the researcher's contact details as provided on the information and prompt sheets.

Consent will also be verbally renegotiated at this stage of the research, particularly in regards to the sharing of the materials created in the project. This ensures that participants continue to be fully informed about the use of creative materials and provides them with an opportunity to withdraw or retract their consent to share visual materials should they wish to do so.

Once the project is completed the participant will share a copy of the visual materials (e.g. photographs of artwork) with the researcher via a secure google drive, or in the absence of access to this technology, via post. They will keep the original visual materials. Copies of visual materials shared via the post will be scanned and stored on the secure google drive attached to the researcher's university account. before being shredded and disposed of using confidential waste bins. The consent form (signed by both participant and parent at recruitment, and verbally agreed during the initial discussion) will give detailed information about the storage and use of visual materials to ensure that participants can give informed consent about sharing the visual materials they create. If the young person does not consent to share the materials before the interview, they may still use them as a personal stimulus or refer to them during the video interview, should they chose to do so, as no video or screenshots will be taken.

Phase 4 Semi-structured video interview.

Consent will be verbally renegotiated the beginning of the interviews, ensuring that participants are fully informed about taking part in the semi-structured interviews. A semi-structured video interview with the participant using the materials produced during the creative project as stimulus will then be carried out. The participant will be able to decide if they would like their parent/carer to be present in the room with them during the interview, or if they will just be accessible in the house.

An interview agenda informed by the IPA interview guidelines produced by Smith (1995) will be followed. This will consist of a combination of open-ended and non-directive questions and will be guided by the young person. Some flexibility will be required to allow participants to refer to the visual materials they have created during the task. As these are likely to differ between individuals it is likely the interview process may be different for each young person. Video interviews are expected to last around 40 minutes.

Should the participant indicate that they are experiencing a high level of stress or emotional distress throughout the interview the distress policy (attached) will be followed.

Debriefing of participants will take place at the end of the semi-structured interview. Participants will be thanked for taking part, their time and for sharing their experiences. They will be reminded of the purpose of the research, how the information will be used, how it will be disseminated and of their right to withdraw from the research until the point that data analysis has been completed (which is currently proposed to be December 2020). The researcher will ensure that they have access to the information sheet which contains the researcher's contact details and details of where and how to access further support should they require it.

The interview will be recorded using a dictaphone and transcribed. Interview recordings and transcripts will be stored securely on a google drive attached to the researcher's university account. Transcripts will then be analysed using IPA.

The semi-structured interviews will be the main focus of the analysis, rather than the creative materials produced by the young people however, it is difficult to know what might be of interest during transcription and analysis. As such the young people's (and their parent/legal guardian) consent will be sought (both through the initial written consent form and verbally renegotiated during the initial discussion) to allow the visual materials to be shared with the researcher and securely stored. Shared creative materials will serve as reminders for the researcher of the discussions within the interviews, to put what could be quite abstract conversations into context during transcription. Visual materials may also be used in the final write up of the project but will be censored and attributed to the young person's pseudonym to avoid potential issues of around anonymity. The reasons for this will be explained in the information sheet and can also be explored with the young person during the initial discussion. Young people will be made fully aware of how the creative material will be shared, stored and disseminated and of their right to withdraw consent for their use at any time.

Phase 5: Member checks

Once the analysis of the transcripts has been completed the themes will be presented via video call on a secure university-approved platform to participants (with parent/legal guardian present) to check for accuracy and resonance with their experiences.

There will be a discussion between the researcher, participant and their parent/legal guardian regarding the use of pseudonyms in the write up of the research. This information will be contained within the information sheet and have already been discussed during the initial video discussion. The reasons for the anonymising of research participants in publications will be explained again to the young people and they will be encouraged to choose their pseudonyms.

Dissemination of research

Once the research has been completed a copy of the research will be shared with the young people and their parent/legal guardian. Consideration will need to be given as to the format it is presented in, as it will depend on the young people who take part and their ability to access the written material. Judgements will be made by the researcher as to whether the participants require an alternative method of feedback, which is more accessible for them e.g. verbal presentations.

The needs of the young people taking part in the research have been at the core of decision making when considering the methodology of this study. Ethical considerations are ongoing, reflexive and have been informed by the guidelines provided by the University Research Ethics Committee (UREC) titled 'Ethical considerations in research with children and young people' (https://www.sheffield.ac.uk/polopoly_fs/1.165641!/file/SREGP-Children-Young-People.pdf).

Every effort has been made to identify all potential ethical considerations, however, that it may not be possible to identify every eventuality that may arise in the course of a research project. Should an unexpected event occur that raises any issues of personal safety, physical or mental well-being of anyone involved the researcher will contact, at the earliest opportunity, the research supervisor to make them aware of the situation. This is informed bu the guidelines provided by the University Research Ethics Committee (UREC) titled 'Participant and researcher well-being' (https://www.sheffield.ac.uk/polopoly_fs/1.112751!/file/Research-Ethics-Policy-Note-3.pdf).

Further considerations have been made in light of the COVID-19 pandemic. Participants within this research will be considered to medically vulnerable due to their chronic health condition and as such are highly likely to be on the government shielding list, which requires them to isolate at home for an extended period. The research takes this into account and has been designed to adhere to the social distancing and shielding requirements to ensure the health and safety of both the participant and researcher.

The following documents are referred to in the text below; written consent form (both parental and participant), information form, project prompt sheet and distress policy. They are attached to this application for reference.

3. Personal Safety

Have you completed your departmental risk assessment procedures, if appropriate?

Not applicable

Raises personal safety issues?

No

The research project is not considered to raise any issues of personal safety, physical or mental well-being for the researcher.

The research will take place remotely and as such there are not considered to be any associated health and safety issues. To ensure the health and safety of both the participant and researcher any correspondence, sharing of materials or delivery of items will either take place online or will adhere to the social distancing and shielding requirements in place due to the COVID-19 pandemic. Should personal data (addresses) need to be shared for the delivery of materials to complete the creative project, this will be done during the initial discussion which will take place on a university-approved secure video platform. The address will be stored on a google document, on a password-protected area of the google drive attached to the researcher's university account. This information will be stored separately to all other data.

There are not considered to be any risks to the researcher's mental well-being, however regular supervision sessions with the research tutor are scheduled to provide opportunities to explore any concerns should the need arise.

It should be noted, however, that it may not be possible to identify every eventuality that may arise in the course of a research project. Should an unexpected event occur that raises any issues of personal safety, physical or mental well-being for the researcher contact will be made with the research supervisor to make them aware of the situation. This is informed bu the guidelines provided by the University Research Ethics Committee (UREC) titled 'Participant and researcher well-being' (https://www.sheffield.ac.uk/polopoly_fs/1.112751!/file/Research-Ethics-Policy-Note-3.pdf).

Section D: About the participants

1. Potential Participants

The research aims to explore the lived experiences of young people with a chronic health condition who attend a mainstream education setting. This group of young people have been under-represented in research to date particularly in regards to hearing their voices and sharing their experiences. To gain insight into their lived experiences of this unique phenomena, it is necessary, despite their potentially vulnerable status that they are the participants in the research.

Participants will, therefore, be identified based on the following criteria:
1. The young person is aged between 11-18 years.
2.. The young person has a chronic health condition, defined using the working definition (discussed in section C)
3. The young person attends a mainstream secondary school or post-16 education setting.

Due to the use of both visual methodologies and IPA between 3-6 participants will be recruited. 1 participant will also be recruited to complete the pilot study. It is not anticipated that there will be more than 7 potential participants. In the unlikely event that more than the desired number of participants volunteer, the selection will then be based on which young people who return the consent form most promptly. If there are additional volunteers who are disappointed at not being included despite having given consent, the creative project could still be given to them to carry out. This would help them to feel that they have contributed but would not affect the research schedule.

Given this research involves young people who are potentially considered vulnerable due to their age and health status, ethics was a key consideration. However, the assumption that these young people are inherently vulnerable and all experience the same degree of vulnerability is also problematic. On this basis, the research focuses on both ensuring important safeguards are in place whilst also recognising the participant's ability to exercise agency.

2. Recruiting Potential Participants

The above criteria will be shared via email with Educational Psychologists (EP) and Special Needs Coordinators (SENCO) within the Local Authority. They will be asked to forward the information sheet and online written consent form to the parents/legal guardian of any relevant pupils within their settings/ on their caseload. They will share this via email, but should the potential participants not have access to email, paper copies will be shared by post and a stamped addressed envelope will be included for the return of the consent forms. Participants will be requested to retain an electronic copy of the information sheet and consent form. Two paper copies will be sent, should the participant not have access to email to ensure that they own second copy for reference.

In order to obtained informed consent from the participants, it is imperative that young people and their parent/legal guardian are given comprehensive information about the research before they decide whether to participate or not. The information sheet will be written in clear, accessible language, appropriate for the age range of the potential participants, and in a style which is engaging yet comprehensive. It will explain:
-The nature and purpose of the research (including a full explanation of any technical terms used);
-The research methods to be employed by the project;
-What is required of the young person (and their parent/legal guardian) throughout the research;
-The right to withdraw from the research (up until the pint of analysis, currently predicted to be October 2020);

-What information will be recorded and how it will be used;
-How their information will be stored and kept safe (including how personal data will be processed and creative materials will be stored and used);
-The legal basis for the collection and use of the participants' data (as set out in the University's Privacy Notice: https://www.sheffield.ac.uk/govern/dataprotection/privacy/general);
-How their participation will be kept confidential (including how and why their identity will be anonymised);
-The possible risks/inconvenience and benefits of taking part;
-What to do and who to contact if something should go wrong including how to raise concerns, or to complain, about the research, and to whom;
-What the researcher will do if they are concerned about the young person's safety or wellbeing (safeguarding);
-What will happen to the findings of the research (dissemination);
-How and by whom the research has been ethically reviewed.

The researcher's contact details should potential participants or parent/carers wish to discuss the research further should they wish and contact can also be made/ queries raised through the EP/SENCO who made the initial contact.

It is recognised that direct access to young people is limited due to the COVID-19 pandemic and this approach relies on SENCOs/EPs and then parents/legal guardian as gatekeepers. There are ethical considerations regarding this approach to recruitment as the adult is then positioned as the primary source of consent which could potentially raise concerns of young people feeling pressured or coerced into participating in research by adults around them. Whilst the consent form does require signatures form both the participant and the parent/carer, it will be completed without the researcher being present and as such it is important to consider how informed consent from the young person can be confirmed. There are, however, several opportunities throughout the research during which the researcher and participant can renegotiate consent verbally, which should mitigate the concerns raised in regards to the initial written consent form. It should also be noted that there are multiple contact points with the young person throughout the project, which will enable monitoring for any non-verbal signs that the young person no longer wishes to participate, such as becoming non-responsive or ignoring contact. Should this happen this will be explored with the young person and their parent/carer to provide them with an opportunity to withdraw.

If participants and their parents/legal guardians are interested in taking part in the research following on reading information sheet and exploring it further with the researcher if required, they will complete the consent form (consent process detailed below).

3. Consent

Will informed consent be obtained from the participants? (i.e. the proposed process) Yes

Written consent will be obtained through an explicit, opt-in informed consent process. As the participants are likely to be under the age of 18 years written consent will be sought from both the participants and their parents or legal guardian.

Potential participants and their parent/legal guardian will have been sent the information sheet about the study which will (as described above) explain all aspects of the research. The participants and their parent/legal guardian will be asked to read the information form carefully, discuss the research, and to take time over deciding whether to participate. The researcher's contact details will be provided so that the young person or their parent/legal guardian should they wish to make contact for further information about the research.

Should the young person wish to participate, both the participants and the parent/ legal guardian must complete the google consent form (or paper consent form if there is no access to technology) which will be sent alongside the information sheet. The consent form will need to be completed by both the parent/legal guardian and participant ticking and signing the appropriate sections (see attached consent form). The potential participants will be provided with a return date, which will be set 2 weeks after initial contact is made.

Once completed the google form will be shared securely and stored on a password-protected area of a google drive attached to the researcher's university account. If there is no access to technology and the SENCO/EP has sent out a paper copy of the information and consent forms, these can be returned using the addressed stamped envelope directly to the researcher. In this scenario, the researcher will scan the consent form and store it on the secure google drive and then shred and dispose of the paper consent form in a confidential waste bin.

Written consent will then be followed up with an initial video call in which the information sheet and consent form will be explored further to ensure all details of the project have been understood. Potential participants will be reassured that their participation is entirely voluntary and that they can withdraw at any time (until data analysis begins) without providing reason and that their data can be destroyed if they wish. An effort will be made to reassure participants it is not problematic to withdraw. Verbal consent will then be renegotiated with both the participant and parents/legal

guardian.

Informed consent will be verbally renegotiated throughout the study, with ongoing reminders of the right to withdraw (until data is analysed). Verbal consent will be sought on at least three separate occasions throughout the research in addition to the initial written consent form.

5. Potential Harm to Participants

What is the potential for physical and/or psychological harm/distress to the participants?

As the research requires the young people involved to reflect on their chronic health condition and the impact on their lives, meaning that the research may touch on sensitive issues. As such there may be potential for the participants to experience some level of distress whilst participating in both the creative project and video interview.

Whilst care has been taken not to assume that young people with a chronic health condition should find talking about their lives upsetting, the possibility of distress requires that appropriate risk management procedures be put in place as detailed below.

The creative project will be carried out without the researcher being present. This means that they are not available to provide support and reassurance throughout. Therefore there is a possibility that the young person may suffer from performance anxiety about the creative work that they produce and feel uncomfortable sharing it. It is hoped that this can be mitigated by using the check-in to offer support, reassurance and problem solve any concerns the young person may have about the creative project over the period that it is being completed. Further the young person will be able to curate their work, only sharing and creative materials that they happy with at the end of the project. This may mean that they share all, some or none of the creative project. This is made clear to the participant and parent/carer in the information sheet.

The extent to which the participant's health affects the participant's vulnerability will also need to be carefully considered. The nature of a chronic health condition is such that symptoms will vary in severity and frequency over time and can be experienced differently between individuals. As such no assumptions can be made about the health of an individual at any point in time. To ensure that the young person is physically well enough to participate in the research this should be discussed with the participant and parent/carer during each contact point. Should they be unwell options should be discussed with the participant and their parent/carer and decisions made as to whether they will require a break, to reschedule, additional time to complete or to withdraw.

The use of visual methodologies requires careful management in regards to ensuring that confidentiality and anonymity are maintained. The safeguards are discussed below.

Finally, it is recognised that the participants and parent/carers will be inconvenienced by taking part as there will be a significant investment of their time in the project. This will include three separate video contacts with the researcher, time taken to complete the creative project. an interview lasting approximately 40 minutes and then contact several months later to take part in member checking processes. It is hoped however that this degree of harm is not only justified by the project's objectives but also by the opportunity for the young person to share their story. Further, it is hoped the visual and creative approach to the research will mean that young people will find it more engaging and enjoyable than traditional qualitative research-based purely in verbal methodology. The young person and their parent/carer will be informed of the potential advantages and disadvantages of taking part in the information sheet and reminded that they should only take part if they think the project will be enjoyable and beneficial for them.

How will this be managed to ensure appropriate protection and well-being of the participants?

The risk of participant distress, although thought to be minimal, could occur during two phases of the research; during the creative task and interview. It is felt that using a creative, arts-informed approach in the first part of the research, demonstrates an ethical approach as it can be a more comfortable way for young people to reflect on sensitive issues that arise. The participant and their parent carer will be provided with the researcher contact details and the details of support services that can be accessed should they experience distress during this task and feel that they need additional support. The well-being of the participant and levels of distress will also be discussed at the 'check-in' phase of the research, and the distress protocol followed if required.

The interviews in the second phase of the project will be based around the creative work produced by the young person, supporting them in verbalising their experiences and allowing them to strongly influence the direction of the interview, hence minimising the risk of distress. Any questions asked within the interview will also be carefully and sensitively planned. Throughout the interview should the young person (or their parent/carer) indicate that they are experiencing a high level of stress or emotional distress or exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc. the interview will be stopped immediately and the distress protocol (attached) followed. Time will be explicitly allocated to a 'debrief' at the end of each video call for participants or their parent/carer to reflect upon the discussion or interview, ask any questions or raise anything that may be of concern.

The use of creative and visual methodology requires some sensitive thought and careful negotiation regarding the visual material produced to ensure the safety, confidentiality and anonymity of the participant. Images that feature young people can carry the risk of misuse if it falls into the wrong hands, may reveal the participant's identity or may embarrass the young person be later in life. As such it will be made clear to the young person that any visual materials produced must not contain pictures of people and must not show identifiable places (e.g. hospital signs, addresses). This will be clarified in the information sheet and examples of what can and cannot be provided in the project prompt sheet and both will be discussed again, before the project starting with the young people and their parent/carer.

To ensure that the young person kept safe throughout the research it is essential that child protection guidelines are followed should the young person disclose abuse. It will be made clear to the young people and their parent/carer in both the information sheet and follow up discussions that the anonymity and confidentiality (e.g. using pseudonyms so they are not recognisable and not disclosing what is said) is not the same as keeping the information secret. They will be informed (and reminded) that should there be any concerns about their's or other safety that child protection procedures will be followed. If a young person discloses abuse the researcher will inform the university's safeguarding lead immediately and, if necessary, contact the local authority safeguarding lead in your local area. If there is any indication that a young person might be at risk of harm then the research must be stopped until that young person's safety is secured.

The researcher will obtain informed consent (both written and verbal) from both the participant and their parent/carer. There is also a recognition that informed consent is an ongoing process and as such there are multiple opportunities to verbally renegotiate consent at key points in the research. The research also provides opportunities wherever possible for participants to make their own choices and providing options for example; choices around the visual methodology and timescales. This places value on the voice of the young person ensuring that participants are listened to and assumptions about what they want are not made.

A clear complaints procedure will be outlined in the information sheet which will be made available when obtaining consent.

3. Data Confidentiality

What measures will be put in place to ensure confidentiality of personal data, where appropriate?

To ensure that data is collected in a 'fair, lawful and undertaken in a transparent manner', the participants will be provided with appropriate information (how their data will be used, how it will be stored and for how long, the uses to which data will be put and any risks that might be involved). This will be detailed in the information sheet (attached) and discussed with the participant and parent/carer during follow up discussion. Written consent from both the participant and the parent/legal guardian (consent form attached) will be obtained for both the recording and transcribing of the interview and to share and use the visual data produced during the creative task. This will be discussed and

renegotiated in follow up video calls.

Should personal data (addresses) need to be shared for the delivery of materials to complete the creative project, this will be done during the initial discussion which will take place on a university-approved secure video platform. The address will be stored on a google document, on a password-protected area of the google drive attached to the researcher's university account. This information will be stored separately to all other data.

Information that may be identifiable to others will be avoided, this will be particularly pertinent with visual materials and the participants will be informed that people and identifiable places should not feature in their creative project.

Through the information sheet and follow up discussions it will be made clear to participants and their parent/carer that their responses will be made anonymous, through the use of pseudonyms for any identifiable information (including participant, parent/carer, professional, school or hospital names). The young people will be encouraged to create their pseudonyms through discussion with the researcher. Care will be taken to maintain the pseudonyms throughout transcription, analysis and writeup of the research. It may be necessary to describe certain features of the school during the write-up of the research, this will be done with care so as not to reveal the identity of the institution, and therefore compromise the anonymity of the participants involved. By maintaining the anonymity of the school and assigning pseudonyms, the anonymity of particular professionals or staff members who may be mentioned will also be maintained.

4. Data Storage and Security

In general terms, who will have access to the data generated at each stage of the research, and in what form

Researcher-Sarah Lakeman, all data.
Research Supervisor- Lorriane Campbell, anonymised data.
2nd Research Supervisor-Tony Williams, anonymised data.

What steps will be taken to ensure the security of data processed during the project, including any identifiable personal data, other than those already described earlier in this form?

The information collected will be kept secure at all times on a digitally organised, password protected google drive attached to the researcher's university account. This will include visual materials produced and shared by the participant, voice recordings of interviews and transcriptions of interviews. The consent forms will be stored separately from the data in a password-protected secure location on the google drive attached to the researcher's university account. No video will be recorded during video interviews, only verbal information via dictaphone. The password will be shared with the research supervisor. Information will be destroyed 3 years after the successful completion of the viva. Should the participant not have access to the appropriate technology to access the google form or google drive then the information will be shared on paper by post. Upon receiving the paper copies of the consent form or visual materials the researcher will scan and save to google drive, deleting any files immediately and shredding the paper copy before disposing of in a confidential waste bin.

Data files will only be available to the research project team.

Any data made publically available will be fully anonymised in accordance with the UK Data Protection Act. Participants will be referred to anonymously in publications arising from the project. Data that does not breach participants' confidentiality will be made available more widely upon request.

Should any participant choose to withdraw from the study, all data referring to them will be immediately destroyed.

Will all identifiable personal data be destroyed once the project has ended?
Yes

Please outline when this will take place (this should take into account regulatory and funder requirements).

All data will be destroyed 3 years after the viva is successfully completed.

Appendix 3: Ethical Approval Letter

The University Of Sheffield.

Sarah Lakeman
Registration number: 180107441
School of Education
Programme: Doctorate in Educational Psychology

Dear Sarah

PROJECT TITLE: Exploring young people's experiences of living with a chronic health condition while attending a mainstream education setting: An Interpretive Phenomenological Analysis study.
APPLICATION: Reference Number 034344

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 23/06/2020 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 034344 (form submission date: 12/06/2020); (expected project end date: 01/05/2021).
- Participant information sheet 1079044 version 4 (12/06/2020).
- Participant consent form 1079046 version 2 (12/06/2020).
- Participant consent form 1079045 version 2 (12/06/2020).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

David Hyatt
Ethics Administrator
School of Education

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy:
  https://www.sheffield.ac.uk/rs/ethicsandintegrity/ethicspolicy/approval-procedure
- The project must abide by the University's Good Research & Innovation Practices Policy:
  https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix 4: Distress Protocol

Distress Protocol

If during the interview the participant indicates they are experiencing a high level of stress or emotional distress or they exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc. The following response will be undertaken by the researcher:

Stage 1 response:

1. Stop the discussion/interview.
2. The researcher will offer immediate support.
3. The researcher will assess well-being by asking:

-Tell me how you feel?

-Do you feel you are able to go on about your day?

-Do you feel safe?

REVIEW:

If the participant feels able to carry on; resume interview/discussion.

or

If participant is unable to carry on Go to stage 2

Stage 2 response:

Discontinue interview.

Inform parent/carer of distress.

Encourage the participant, supported by their parent/carer to access support through the additional support services as signposted on the information sheet or their GP should they feel it is appropriate.

FOLLOW UP:

Follow participant up with courtesy call (if participant consents)

Encourage the participant to call either if he/she experiences increased distress in the hours/days following the interview.

Modified from:

https://livinglifetothefullesttoolkit.com/ethics/ (retrieved 27th April, 2020)

adapted from:

Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. Archives of Psychiatric Nursing 23 (5) pp 343-350

Appendix 5: Participant Information Sheet

Hello!

My name is Sarah and I am training to be an Educational Psychologist at the University Of Sheffield. As part of my training I am carrying out some research about what going to school or college is like for young people with chronic health conditions.

I would like to invite you to take part in my research, but before you decide it is important that you know more about the research. I have tried to answer any questions that you might have in this letter so that you can talk to your parent/carer and decide together. If you have any more questions about the research, ask your parent/carer and I can let you know the answer.

Thank you for taking the time to read this.

Sarah

Why have I been invited?
You have been invited to take part because you are 11-18 years old, attend a mainstream school or college and live with a chronic health condition.

What is the project about?
This project tries to give you the space to reflect on your experiences of going to school or college as a young person with a chronic health condition. I think it is important that people hear about your experiences from you and not adults around you (like your parent or teacher) and that you are given a fun creative way to express them. I want to share the research with the adults who work with young people with chronic health conditions to try to help them have a better understanding of what life might be like for them. I hope that this will help them to think about how they might support other young people in the future.

What would I have to do?
There are three parts of the project: the **creative project, check-in** and an online video **interview.**

During the **creative project,** you will be asked to think about a way to express what attending school or college whilst managing a chronic health condition is like for you. The project is set up so that you can be as inventive as you like. Your creative project could include artwork, photography, PowerPoint, creative writing, animation, or anything else that you can think of. It might show what you enjoy about school, what is difficult, what helps you, what doesn't and what you would like from your education in the future. You might also think of other things to include. I can help you to think about what you might like to do if you get stuck.

You will complete this project at home, and you can choose when and how you want to do it. I will make sure you have everything you need to do it. You can tell me how long you think you will need to do your project, but I don't think it would take more than 3 weeks. While you are doing the project, I will organise a time to video call on 'google-meet' to **check-in** with you and see how things are going.

Once you have completed your creative project you can decide what parts of it you might like to share with me. You might decide to share it all, some, or none of your work, which is all ok.

After you have done the project, you will be asked to take part in a video **interview** with me on 'google meet'. You can decide whether you want your parent/carer to join us in the interview or just be around in the house in case you need them. If you have chosen to share your creative project, we will talk about it and discuss what it means to you. If you choose not to share your creative project, you can just use the creative project as a chance to think about what matters to you. We can then just talk in the interview and we don't need to look at your creative project if you would prefer not to.

I will audio record the interview (just the sound) and use this to write down what we both said. After I have looked at what was said and written up the research, I will video call you to check that you agree with my ideas about your experiences. Should you feel unwell or tired at any point we can wait to do any of the activities until you feel better.

What are the possible advantages and disadvantages of taking part?
This project has been designed so that you have a say in what you do and how you represent your experiences. Taking part should also be fun! It also gives you a chance to share your experiences and to contribute to a research project that is trying to give adults a better idea about the school lives of young people with chronic health conditions.

I do not think that there will be any serious disadvantages for you if you take part in the research but sometimes reflecting on our lives, especially if there have been challenges, can make us feel upset. If at any point throughout the project you feel upset, I will be available to talk to you or I can give you and your parent/carer ways to get in touch with other people who can help. If you find the creative project upsetting you can stop at any time and you do not have to explain to anyone about why you chose to do this. If you find any questions in the interview difficult or upsetting you do not have to answer and you can choose to stop the interview, skip the question, or take a break until you are ready.

You should only take part if you think you will enjoy and benefit from the project.

What will happen to the interview recording and my creative project if I choose to share it?
The recording of the **interview** will only be used for me to remember what was said and write it down. No one else will hear this recording. Anything you choose to share from your **creative project** might be used in the write up of the research but will not be used anywhere else without your written permission.

I will make sure that no one knows that you are taking part in the project unless you choose to tell them. I will ask you to decide on a fake name that I can use in the research instead of your real name. I will also ask you to think of one for any important people or places you talk about. Anything you share from your creative project that shows anything that could identify you (like the hospital you attend) will also be covered up so that there is nothing used in the research which would

identify you. I will keep the information you give me in a safe online space that no one else can get to without a password. After three years I will delete the information.

What if something goes wrong?

If you or your parent/carer are concerned or worried that something has gone wrong, you or your parent/carer can get in touch with the researcher or Dr Lorraine Campbell, the project supervisor.

	Researcher/Trainee Educational Psychologist Sarah Lakeman School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW slakeman1@sheffield.ac.uk 07879113440
	Project Supervisor: Dr Lorraine Campbell l.n.campbell@Sheffield.ac.uk 0114 222 8107 School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW

Appendix 6: Parent Information Sheet

Exploring young people's experiences of living with a chronic health condition while attending a mainstream education setting: an Interpretive Phenomenological Analysis study.

Your child is being invited to take part in a research project. Before you decide whether they should participate, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please contact me if you have any questions or would like any further information. Thank you for reading this.

The purpose and aims of the study.

This research project seeks to explore how young people aged 11-18 years with a chronic health condition (hereby known as CHC's) experience mainstream school or college. Working in partnership with young people, the project aims to provide a space in which young people with CHC can use creative approaches to reflect on and share their experiences. It is hoped that by hearing directly from young people with CHC about their experiences the professionals who work with them will have a better understanding of what life might be like for them at school, so they can consider how they might support young people with CHC at school in the future.

The research is being carried out by Sarah Lakeman, who is a 2nd-year trainee educational psychologist. The research is being completed as part of the Doctor of Educational and Child Psychology (DEdCPsy).

Why have I been chosen?

Your child has been invited to take part as they are aged 11-18 years, attend a mainstream school or college and live with a chronic health condition.

What would my child have to do?

An initial video call using the video calling platform 'google meet' will be organised to allow you and your child to discuss the project further with the researcher. Support will be provided in setting up the video calling technology if required.

During this video call, the researcher will explain the three parts of the project: the **creative project, check-in,** and the video **interview.**

The **creative project** is designed so that your child can use creative arts to express what attending school or college whilst managing their CHC is like for them. The project is flexible and an opportunity for your child to be as inventive as they like. Projects could include artwork, photography, powerpoints, creative writing or animation amongst others. The researcher will support your child in deciding how they will carry out the creative project and provide all of the materials or equipment they need.

The researcher will organise a video call **check-in** to discuss how your child is doing during the project.

Once the creative project has been completed your child can decide which of the materials they created (if any) they would like to share with the researcher via a password protected google drive (or through the post if you can't access this). To ensure that your child's identity is anonymised the researcher will support your child to cover any identifiable people or places in their creative work.

Your child will then be asked to take part in a 1:1 video **interview** on 'google meet'. It is expected that a parent/carer will be accessible throughout the interview to provide support should it be required. The interview will start by the researcher asking your child about the creative materials they have chosen to share (if any) and what they mean to them. The researcher will then ask your child some questions about their experiences in school.

The video **interview** will be audio-recorded, and the researcher will use this to make a transcription of what was said. The researcher will look at the information to see if there any themes in your child's description of their experiences. The researcher will contact you once the data has been analysed (likely to be around November 2020) to check with your child that they agree with the researcher's ideas about their experiences.

Should your child be unwell or tired at any point all research activities can be rescheduled as required.

What are the possible advantages and disadvantages of taking part?

The research has been designed to be fun and led by your child. It will be a chance for your child to share their experiences and to contribute to a research project that aims to provide professionals with greater insight about the school lives of young people with CHC.

Participating in the research is not felt to have any serious disadvantages or risks. However, sometimes reflecting on our lives can be distressing. You will be provided with contact details for both the researcher and a range of external organisations who can provide support in the event that your child becomes distressed. The interview will be in a supportive space: meaning that your child can take time out, skip questions that feel uncomfortable or stop the interview whenever they wish.

Your child should only take part if they think they will enjoy and benefit from the project.

What will happen to the data collected?

The audio recording of the **interview** will only be used for transcription and no one outside the project will be allowed access to the original recordings. The materials your child makes in a **creative project** and chooses to share may be used in the write up of the research if it is thought they will be useful, but no other use will be made of them without your written permission and no one outside the project will be allowed access to them. The interview recording, transcriptions and creative materials will be saved securely on a password protected google drive. This data will be stored for a maximum of three years after the completion of the research (predicted to be June 2024) and then all data will be destroyed.

How will my child's confidentiality be maintained?

Your child's participation in the project will be kept strictly confidential. The researcher will ask your child to decide on a pseudonym and your name and or any other identifying details about you, your school/college, or any medical institutions you attend will not be used. Any visual materials used in the research will also be anonymised so they cannot be identified.

All data (the interview recording, the written version of the interview (the script) and any visual materials made during the creative project) will be kept securely on a password protected google drive only accessible by the researcher and supervisor.

Does my child have to take part?

No, Participation is entirely voluntary. Also, if you and your child change your mind about taking part during the research, they can withdraw by contacting the researcher. You will not need to provide any explanation about withdrawing. You or your child can withdraw at any point until the information from the interview has been transcribed and anonymised (likely to be December 2020).

What if something goes wrong?

If you or your parent/carer are concerned or worried that something has gone wrong, please contact the researcher or Dr Lorraine Campbell, the project supervisor. You can find these contact details at the end of this document.

Who has ethically reviewed the project?

This project has been ethically approved via Sheffield University's School of Education ethical review procedure. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

Thank you for your time.

	Researcher/Trainee Educational Psychologist Sarah Lakeman School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW slakeman1@sheffield.ac.uk 07879113440
	Project Supervisor: Dr Lorraine Campbell l.n.campbell@Sheffield.ac.uk 0114 222 8107 School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW

Appendix 7: Hard Copy of Gorilla Consent Form

Exploring young people's experiences of living with a chronic health condition while attending a mainstream education setting: An Interpretive Phenomenological Analysis study.

Please tick the appropriate boxes	Yes	No
I have read and understood the project information sheet dated 11.06.2020 or the project has been fully explained to me. If you answer 'no' to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.		
I have been given the opportunity to ask questions about the project.		
I agree that my child can take part in the project. I understand that taking part in the project will include completing a creative project and taking part in an online interview that will be audio recorded.		
I understand that taking part is voluntary and that my child can withdraw from the study before December 2020; I do not have to give any reasons for why my child no longer wants to take part and there will be no adverse consequences if I choose to withdraw.		
I understand mine and my child's personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.		
I understand and agree that my child's words may be quoted in publications, reports, web pages, and other research outputs. I understand that my child will not be named in these outputs unless I specifically request this.		
I understand and agree that the materials created by my child as part of the creative project may be used in publications, reports, web pages and other research outputs. I understand that my child will not be named in these outputs unless I specifically request this.		

I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.		
I understand and agree that other authorised researchers may use my child's data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.		

Participant (Your child)	**Please print name here:**	**Date:**
Parent/Legal Guardian	**Please Print here:** **Please sign here:**	**Date:**
Researcher	**Please Print here:** **Please sign here:**	**Date:**

Participant consent form

Please tick the yes or no box to answer each question

| I have read and understood the project information sheet dated and the project has been fully explained to me. | Yes ✓ | |
| | No ✗ | |

| I have had the chance to ask questions about the project. | Yes ✓ | |
| | No ✗ | |

| I understand that taking part in the project will mean that I will take part in a creative project at home and an | Yes ✓ | |
| | No ✗ | |

| I understand that the interview will be audio (voice only) recorded, and that bits of what I say may be used within the research. This means that people who read it would be able to see it but it would always have your fake name on it, not your real name. | Yes ✓ | |
| | No ✗ | |

| I understand that if I agree to share the work that I make in the creative project, it may be used and shown in the final write up of this project. This means that people who read it would be able to see it but it would always have your fake name on it, not your real name. | Yes ✓ | |
| | No ✗ | |

| I understand that I can choose if I want to share a copy of my creative project. I can choose to share all, some or none of it. | Yes ✓ | |
| | No ✗ | |

| I understand that I do not have to take part in the study. I know that during the research, I am free to stop at any time, for any reason and I do not have to explain why. | Yes ✓ | |
| | No ✗ | |

| I understand that my real name will not be used, and instead, I will be given a fake name so that no one will know | Yes ✔ | |
| | No ✘ | |

| I agree to take part in the project | Yes ✔ | |
| | No ✘ | |

Name of participant	Signature of participant	Date
Name of Researcher	Signature of researcher	Date

Appendix 8: Participant Visual Project guide

Thank you for choosing to take part in this project.

This project guide is designed to help you think about how you might like to complete the creative project and what kinds of information to include.

You can choose one of these projects or decide on one of your own. This guide is to give you ideas but how you do the project is totally up to you!

Have a look at the slides and see of any of them look interesting to you. Don't worry if you aren't sure what to do, we can talk about it more and I can help you decide when I call you.

If you have any questions please get in touch with me: slakeman1@sheffield.ac.uk

Looking forward to speaking to you soon.

Sarah
Trainee Educational Psychologist

What is the project about?

This project gives you the space to reflect on your experiences of going to school and college as a young person with a chronic health condition. It gives you the opportunity to share your experiences in a creative way.

I think it is important that people hear about your experiences from you and not from adults around you (like your parent or teacher). I think being able to present your views in a creative way is not only fun to do, but also helps other people to understand what you want to say.

I want to share the research with the adults who work with young people with chronic health conditions to try to help them have a better understanding of what life at school might be like for them. I hope that this will help them to think about how they might support other young people in the future.

Everybody with a chronic health condition will have had very different experiences in school or college so it is hard to say what sorts of information you might want to include in your project but below are some ideas :

Routines like physiotherapy or a special diet that might affect your day at school or college	Practical arrangements you might have to make when you attend school e.g. transport, equipment or medication.	How your attendance to school, lessons, clubs and trips is affected by your health condition (or not)
Anything you find particularly difficult at school because of your health condition.	Anything that doesn't help you in school.	Anything you really enjoy or find helpful at school.
How your health condition affects your friendships (or not).	Your hopes and dreams for your future education. Has anything changed for you because of your health?	Any worries or concerns about you might have about your education or the future.

What type of creative project could I do?

Everyone has different interests and skills, so I would like people to have the chance to do something they enjoy. This project is led by you and so you can choose how you want to reflect your experiences.

There are some ideas about how you could do the creative project in the following slides which might help you decide, but you do not need to choose any of these, you can do something different.

When you have had time to look at this I will organise a call with you and we can plan together how we do the rest of the project.

Photographs

You might decide to take a series of photographs of things that you think reflect what going to school is like for you and the impact that your health condition has on your education.

These pictures were taken by young people with health conditions in a similar project in Australia.

Visual Diary

You might create a visual diary, which explains (using photos, pictures or objects) important things that happen in school. You could explain what a 'normal' day for you is like at school or you might choose to reflect on a few particularly good or bad days you can remember.

You might choose key times in the day which you think are affected by your health condition and use pictures, drawings or objects to help explain what they mean e.g. broken sleep the night before, getting ready for school, having lunch, PE lessons or appointments or treatments after school.

You can use photos, pictures, doodles or objects. You can add labels or writing if you think it would be helpful.

You might like make a real diary or you could have a go at using an online tool such as padlet (https://padlet.com).

Collage

You might choose to use collage to help you represent what school is like for you. You might think about the different areas mentioned on slide 4 and choose images that represent your experiences of these.

You could cut out pictures from magazines or include your own.

If you wanted to make an online version you could use:

Jamboard (https://edu.google.com/products/jamboard/?modal_active=none)

Adobe spark (https://spark.adobe.com/make/photo-collage-maker/)

PowerPoint

You might make a PowerPoint using pictures or photographs and text around some of the areas mentioned on the slide 4 .

Jamboard

Jamboard is a free google app. It is an online whiteboard that you can draw on, add pictures, sticky notes and text boxes. You might use this to collect your ideas.

Mind map

You might decide to create a mind map using pictures, drawings, text or objects about what school is like for you. You could make a 'real' one or have a go using an online tool such as mindmeister:

https://www.mindmeister.com/mm/signup/external_user

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Art work

You might like to paint, draw or even make a sculpture which represents how you experience school.

Comic Strip

You could design a comic strip which showing a story of that describes what going school is like for you. You might choose to do the story of a typical day for you at school or might choose a particularly good or bad day that you can remember.

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Animation

If you are technologically minded you might like to make a short animation explaining what school is like for you.

Animaker https://app.animaker.com/moments is a free online tool you could use.
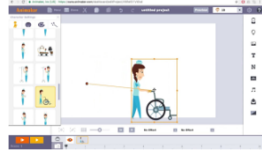
Fictional messages or social media posts

You might create a series of fictional picture messages or social media posts that show important things that happen in school;

Or something else…

This is your project so you might have another idea about what you want to do. Don't worry if you aren't sure how you could make it work we can talk about it together.

Thank you for joining the research!

Looking forward to talking to you about your project soon.

Appendix 9: Reflections about Participants taken from Research Diary.

<u>**Samuel:**</u>

Throughout my discussions with Samuel, I noted that he appeared to be an articulate, confident, and capable young person. He was clear what he wanted to do for the creative project and completed it quickly. Samuel created an animation (Appendix 18) which described the impact of external professionals and government organisations on the management of individual's health within school. Samuel was deeply passionate about this, and he clearly felt that this 'involvement' was unnecessary and unhelpful. It was very apparent that this was Samuel's focus and the main 'message' he wanted to get across to me in his interview. It was only through more targeted questioning that Samuel was willing to explore other areas of his experiences of school.

Samuel appeared to be keen to discuss his achievements in both school and extracurricular activities. He did not consider his T1D to impact these and wished to discuss them as 'separate' from his diabetes. This distancing between himself and his T1D ran through the interview and particularly when talking about his future. There were also frequent points throughout the interview in which Samuel expressed his annoyance over situations at school. Feeling that his time 'wasted' with activities associated to his T1D appeared to be a particularly frustrating for him.

Samuel did not request his visual theme map when it was offered as part of the member checks.

Autumn:

When I initially spoke with Autumn, she was very keen to create a stop-frame animation using air dry clay and she described to me some of the scenarios she would like to represent e.g., working with supply teachers. However, at subsequent check-in's Autumn's parent informed me that although Autumn had started, the animation had been 'lost' on the computer which caused her to become frustrated and disengaged. Autumn told me that she had not 'had time' but was still keen to talk with me.

Autumn appeared to be a confident, independent young person who was comfortable talking about her experiences and about her medical condition. She generally spoke positively about her relationships and described feeling empowered at school in managing her health condition. Throughout the interview there was a sense of acceptance of her health condition, however at the very end of the interview she still indicated that she wished for a "cure". Autumn had a good sense of humour which she demonstrated at several points when talking about her experiences. It was apparent that using humour was a helpful coping mechanism for Autumn.

Autumn requested her visual theme map and commented, via her parent that she agreed that the content was reflective of her views.

Amber:

I spoke with Amber online on one occasion prior to the interview, during the initial discussion about the project. We spoke together with her mother present in the room. Amber was happy to talk and was not reliant on her parent, she seemed keen and eager to take part. Amber explained that she enjoyed art and that the creative project had particularly attracted her to the project. Amber was confident in the creative task and explained that she had a clear idea what she wanted to represent in her paintings. She created two watercolours reflecting her experiences (Appendix 17).

Amber explained to me that her health condition could at times impact on her speech intelligibility. This was also exacerbated using an online platform, in a way which may have not so challenging if interviews were conducted face to face. I was mindful of this throughout the interview, and built-in additional questions, checking my understanding of what had been said. At times, this additional 'checking-in' interrupted the flow of the interview, perhaps inhibiting fuller answers and descriptions. However, I felt it necessary to clarify what had been said. I tried as much as possible to repeat back to Amber using direct quotes to avoid any 'leading' on my part.

During the interview Amber chose to speak to me on her own, with her mother in the room next door. She explained that they both felt she would speak more freely without being concerned about upsetting her mother. Initially Amber appeared withdrawn at the start of the interview, answering questions with single word utterances. However, when she discussed her two pieces of artwork, she became more open and descriptive, which largely continued for the remainder of the interview. Amber's artwork focused on two areas; the impact of fatigue and being separated from her friends at lunchtime. It was apparent that these two aspects were especially important, and they became key topics of discussion and arising at several throughout the interview.

Towards the end of the interview Amber became upset when discussing the future and I asked her if she wished to stop. This was clearly an exceedingly difficult area for Amber to discuss and it did not feel appropriate to continue, particularly in the context of an online interview. Amber's mother returned to the room, and we discussed options available to support Amber together, following the distress protocol (Appendix 4). I then followed up with Amber's mother later that day and was reassured by her mother that she was ok.

Amber did not request her visual theme map when it was offered as part of the member checks.

JJ:

I initially spoke over the online platform with JJ and his dad. JJ's dad explained to me that JJ had several additional diagnoses alongside his epilepsy; ASD, ADHD, dyslexia, and dyspraxia. Although JJ was willing to talk to me throughout the initial discussion he relied heavily on his parent for prompts and support to answer, so I needed to reframe questions, consider my language use, and allow for additional processing time. I had designed a visual project guide (Appendix 8) and visual interview map (Appendix 10) which I had sent to participants prior to our initial discussions. While no other participant used this, I found it was extremely helpful in guiding the discussion with JJ and enabled us to plan for him to complete a creative project using Lego in which he would build scenes about his experiences of school.

I organised an online check-in with JJ two weeks later and his dad informed me that he had found the Lego models difficult to make and had been unable to finish these. JJ was however happy to talk to me using the visual interview map as a guide, without completing the creative project. As the purpose for the creative project was to support the young people to process their ideas, I was happy to proceed with the interview without the project, as it had clearly not been helpful for JJ.

JJ spoke to me without his parent, who waited in the room next door. At points throughout the interview JJ shouted questions through to them in the next room, but JJ showed no signs of being uncomfortable talking to me without them there. Using the structure of the visual interview map I attempted to engage JJ with the interview. He found it difficult to answer initially but this became easier when I was sharing my screen and we could not see each other. I found that JJ was able to talk more easily about experiences which involved concrete ideas e.g., the environment, trips, his teacher than those involving abstract concepts e.g., feelings or relationships, so I focused on these areas of the visual interview map initially. At several points JJ engaged in behaviours which I understood to be indications that he may wish to stop the interview (banging on the table, putting his head down, shouting answers), although he did not say so. I checked in and reminded JJ we could stop at any time. Eventually we agreed to stop the first interview and discussed options moving forward. We agreed that we would split the interview schedule into three shorter interviews, and I would provide a smaller visual interview map prior to each interview so JJ could be prepared about what we may discuss. Each map had a narrower focus of 1-2 questions from the interview schedule (Appendix 20). JJ and his dad felt it would work best if the interviews were close together and so these were set for daily over three days the following week.

Even with this additional planning and adaptation the interviews with JJ were challenging at times, resulting in a transcript that was difficult to analyse. JJ's attention was limited, and he struggled to remain on topics of conversation relating to the research, often preferring to talk about his specialist interests (sports). In one interview JJ struggled to engage as he was still dysregulated from an incident earlier in the day. I felt it important to spend time building a relationship with JJ and so did engage in discussions around non research topics and looked for opportunities to guide the conversation back to the interview schedule where possible. I found I needed to be careful around my use of "open and expansive" questions (Smith et al., 2009: 59) and found myself moving away from the interview schedule and asking more and closed questions in a way which I did not with other participants. JJ also tended to give short answers, lacking depth or answers which deviated quickly from the related point. I found that prompts and probes suggested in IPA to encourage expansion on descriptions did not work, and often resulted in JJ becoming frustrated, confused, or withdrawn.

JJ continued:

spent quite some time considering how to ensure how that I gave JJ the right opportunities to share his experiences whilst remaining within the framework of IPA interviews. I questioned if this style of interview was the best way to engage JJ and wondered if he would find different approaches to obtaining his views easier e.g., questionnaire, scaling activities. I was also mindful throughout that JJ may be finding the process challenging and increased checks with him that he did still want to talk to me.

strongly felt that as JJ was committed to taking part, I had a responsibility to find creative ways to attempt to hear his views. However, I feel that my attempts to work with JJ creatively were significantly impacted by both the time limitations of the research and by working online.

JJ requested his visual theme map as part of the member checking but did not provide any comments.

Willow:

Willow was articulate and keen and appeared extremely comfortable in sharing her experiences. She told me that she did not want to engage in a creative project, instead preferring to "just talk". We did briefly use the visual interview map at the start, but very quickly I realised that Willow had a noticeably clear idea of what she wished to talk about and did not need to rely on this. Willow spoke to me independently, but her parent was available in the background and gave input when Willow requested.

There were some difficulties with the connection during the interview which at times interrupted the flow of some of Willows descriptions, but she was generally able to recount experiences in detail, with only minimal prompting and probing required from me. Willow was particularly reflective around 'feeling different' and about the impact of her health condition on her relationships. She also talked at length about the ways in which her physical symptoms and mobility impact on her throughout the school day.

Willow requested her visual theme map as part of the member checking but did not provide any comments.

Appendix 10: Visual Interview Schedule

Likes/dislikes in school

Attendance
(school, lessons, lunchtime, clubs)

Learning
(in class, homework, revision, exams)

Relationships with adults in school
(teachers, supply staff, TA, mentor, specialist nurse)

Relationships with other students
(friends, others in class)

Your Creative Project
I would like to hear about what being in school is like for you.
Your creative project might show some of these things which you might want to explain more about in the interview.
This sheet might also give you some ideas about other things you might want to talk about in the interview which may not be included in your creative project.

Facilities in school
(classrooms, toilets, lunch hall, equipment playground, first aid room)

The school day
Any special routines you need in the day e.g. physiotherapy or medication. Any times in the day that are particularly difficult?)

The future
(further education, training or career. Anything you are looking forward to? Anything you are worried about?)

The Ideal school
(If you could wave magic wand what would school be like? What has helped you? What hasn't been helpful?)

Something else?

Appendix 11: Pilot Participant Information Sheet

> *Hello!*
>
> *My name is Sarah and I am training to be an Educational Psychologist at the University of Sheffield. As part of my training I am carrying out some research about what going to school or college is like for young people with chronic health conditions.*
>
> *I would like to invite you to take part in a pilot study for my research, but before you decide it is important that you know more about it. I have tried to answer any questions that you might have in this letter so that you can talk to your parent/carer and decide together. If you have any more questions about the research, ask your parent/carer and I can let you know the answer.*
>
> *Thank you for taking the time to read this. Sarah*

Why have I been invited?
You have been invited to take part in the pilot study because you are 11-18 years old, attend a mainstream school or college and live with a chronic health condition.

What is the project about?
This project tries to give you the space to reflect on your experiences of going to school or college as a young person with a chronic health condition. I think it is important that people hear about your experiences from you and not adults around you (like your parent or teacher) and that you are given a fun creative way to express them. I want to share the research with the adults who work with young people with chronic health conditions to try to help them have a better understanding of what life might be like for them. I hope that this will help them to think about how they might support other young people in the future.

What would I have to do?
There are two parts to the pilot study: a **creative task** and an online video **interview.** This will take approximately 1 hour and will take place online using 'google meet'. You can decide whether you want your parent/carer to join us in the interview or just be around in the house in case you need them

During the **creative task,** you will be asked to choose from a selection of creative tasks which are designed to help you express what attending school or college whilst managing a chronic health condition is like for you.   Once you have completed your creative project you can decide what parts of it you might like to share with me. You might decide to share it all, some or none of your work, which is all ok.

After you have finished the creative task, you will be asked to take part in a video **interview**. We will talk about your creative project and discuss what it means to you. If you choose not to share your creative project, you can just use the creative project as a chance to think about what being at school is like for you. We can then just talk in the interview and we don't need to look at your

creative project if you would prefer not to. I will audio record the interview (just the sound) and use this to write down what we both said.

The interview should take around 30 minutes. We might also talk about what doing the creative task and taking part in the interview was like for you and if there is a way we can make it easier for other young people to take part in. Should you feel unwell or tired at any point we can wait to do any of the activities until you feel better.

What are the possible advantages and disadvantages of taking part?
This project has been designed so that you have a say in what you do and how you represent your experiences. Taking part should also be fun! It also gives you a chance to share your experiences and to contribute to a research project that is trying to give adults a better idea about the school lives of young people with chronic health conditions.

I don't think that there will be any serious disadvantages for you if you take part in the research but sometimes reflecting on our lives, especially if there have been challenges, can make us feel upset. If at any point throughout the project you feel upset I will be available to talk to you or I can give you and your parent/carer ways to get in touch with other people who can help. If you find the creative project upsetting you can stop at any time and you do not have to explain to anyone about why you chose to do this. If you find any questions in the interview difficult or upsetting you do not have to answer and you can choose to stop the interview, skip the question or take a break until you are ready. You should only take part if you think you will enjoy and benefit from the project.

What will happen to the interview recording and my creative project if I choose to share it?
The recording of the **interview** will only be used for me to remember what was said and write it down. No one else will hear this recording. Anything you choose to share from your **creative task** might be used in the write up of the research but won't be used anywhere else without your written permission.

I will make sure that no one knows that you are taking part in the project unless you choose to tell them. I will ask you to decide on a fake name that I can use in the research instead of your real name. I will also ask you to think of one for any important people or places you talk about. Anything you share from your creative project that shows anything that could identify you (like the hospital you attend) will also be covered up so that there is nothing used in the research which would identify you. I will keep the information you give me in a safe online space that no one else can get to without a password. After three years I will delete the information.

What if something goes wrong?
If you or your parent/carer are concerned or worried that something has gone wrong, you or your parent/carer can get in touch with the researcher or Dr Lorraine Campbell, the project supervisor.

	Researcher/Trainee Educational Psychologist Sarah Lakeman School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW slakeman1@sheffield.ac.uk 07879113440
	Project Supervisor: Dr Lorraine Campbell l.n.campbell@Sheffield.ac.uk 0114 222 8107 School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW

Appendix 12: Pilot Parent/Carer Information Sheet.

Exploring young people's experiences of living with a chronic health condition while attending a mainstream education setting: An Interpretive Phenomenological Analysis study.

Your child is being invited to take part in a pilot study for a research project. Before you decide whether they should participate, it is important for you to understand why the pilot study is being done and what it will involve. Please take time to read the following information carefully. Please contact me if you have any questions or would like any further information. Thank you for reading this.

The purpose and aims of the study

This research project seeks to explore how young people aged 11-18 years with a chronic health condition (hereby known as CHC's) experience mainstream school or college. Working in partnership with young people, the project aims to provide a space in which young people with CHC can use creative approaches to reflect on and share their experiences. It is hoped that by hearing directly from young people with CHC the professionals who work with them will have a better understanding of what life might be like for them at school, so they can consider how they might support young people with CHC at school in the future.

The research is being carried out by Sarah Lakeman, who is a 2nd-year trainee educational psychologist. The research is being completed as part of the Doctorate of Educational and Child Psychology (DEdCPsy).

Why have I been chosen?

Your child has been invited to take part in the pilot study as they are aged 11-18 years, attend a mainstream school or college and live with a chronic health condition.

What would my child have to do?

There are two parts to the pilot study: a **creative task** and an online video **interview.** This will take approximately 1 hour and will take place online using 'google meet'. It is expected that a parent/carer will be accessible throughout the task and interview to provide support should it be required.

During the **creative task,** you will be asked to choose from a selection of creative tasks which are designed to help your child to express what attending school or college whilst managing a chronic health condition is like for them. The task will be completed online with the researcher. Once the creative task has been completed your child can decide which of the materials they created (if any) they would like to share with the researcher via a password protected google drive (or through the

post if you can't access this). To ensure that your child's identity is anonymised the researcher will support your child to cover any identifiable people or places in their creative work.

After they have finished the creative task, they will be asked to take part in a video **interview**. The interview will start by the researcher asking your child about the creative materials they have chosen to share (if any) and what they mean to them. The researcher will then ask your child some questions about their experiences in school.

The interview will be audio recorded and the researcher will use this to make a transcription of what was said. The researcher will look at the information to see if there are any themes in your child's description of their experiences. The researcher will contact you once the data has been analysed (likely to be around November 2020) to check with your child that they agree with the researcher's ideas about their experiences.

Should your child feel unwell or tired at any point we can wait to do any of the activities until they feel better.

What are the possible advantages and disadvantages of taking part?

The research has been designed to be fun and led by your child. It will be a chance for your child to share their experiences and to contribute to a research project that aims to provide professionals with greater insight about the school lives of young people with CHC.

Participating in the research is not felt to have any serious disadvantages or risks. However, sometimes reflecting on our lives can be distressing. You will be provided with contact details for both the researcher and a range of external organisations who can provide support in the event that your child becomes distressed. The interview will be in a supportive space: meaning that your child can take time out, skip questions that feel uncomfortable or stop the interview whenever they wish.

Your child should only take part if they think they will enjoy and benefit from the project.

What will happen to the data collected?

The audio recording of the **interview** will only be used for transcription and no one outside the project will be allowed access to the original recordings. The materials your child makes in a **creative project** and chooses to share may be used in the write up of the research if it is thought they will be useful but no other use will be made of them without your written permission and no one outside the project will be allowed access to them. The interview recording, transcriptions and creative materials will be saved securely on a password protected google drive. This data will be stored for a maximum of three years after the completion of the research (predicted to be June 2024) and then all data will be destroyed.

How will my child's confidentiality be maintained?

Your child's participation in the project will be kept strictly confidential. The researcher will ask your child to decide on a pseudonym and your name and or any other identifying details about you, your school/college or any medical institutions you attend will not be used. Any visual materials used in the research will also be anonymised so they cannot be identified.

All data (the interview recording, the written version of the interview (the script) and any visual materials made during the creative project) will be kept securely on a password protected google drive only accessible by the researcher and supervisor.

Does my child have to take part?

No, Participation is entirely voluntary. If you and your child change your mind about taking part during the research they can withdraw by contacting the researcher. You will not need to provide any explanation about withdrawing. You or your child can withdraw at any point until the information from the interview has been transcribed and anonymised (likely to be December 2020).

What if something goes wrong?

If you or your parent/carer are concerned or worried that something has gone wrong, please contact the researcher or Dr Lorraine Campbell, the project supervisor. You can find these contact details at the end of this document.

Who has ethically reviewed the project?

This project has been ethically approved via Sheffield University's School of Education ethical review procedure. The University's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

Thank you for your time.

	Researcher/Trainee Educational Psychologist Sarah Lakeman School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW slakeman1@sheffield.ac.uk 07879113440
	Project Supervisor: Dr Lorraine Campbell l.n.campbell@Sheffield.ac.uk 0114 222 8107 School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW

Appendix 13: Pilot Hard Copy Consent Form

Exploring young people's experiences of living with a chronic health condition while attending a
mainstream education setting: An Interpretive Phenomenological Analysis study.
Pilot project Consent Form

Please tick the appropriate boxes	Yes	No
I have read and understood the pilot project information sheet dated 11.06.2020 or the project has been fully explained to me. If you answer 'no' to this question, please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.		
I have been given the opportunity to ask questions about the pilot project.		
I agree that my child can take part in the pilot project. I understand that taking part in the pilot project will include taking part in an online interview that will be audio recorded.		
I understand that taking part is voluntary and that my child can withdraw from the pilot study before August 2020; I do not have to give any reasons for why my child no longer wants to take part and there will be no adverse consequences if I choose to withdraw.		
I understand mine and my child's personal details such as name, phone number, address and email address etc. will not be revealed to people outside the pilot project.		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield.		

Participant (Your child)	Please print name here:	Date:
Parent/Legal Guardian	Please Print here: Please sign here:	Date:
Researcher	Please Print here: Please sign here:	Date:

Appendix 14: Pilot Visual Theme Map

"Sometimes when I wake up I just feel really tired and I don't feel like getting up "

"I get really tired really easily. I find it difficult to handle a full day in school but I try my best"

Tiredness

" Sometimes I don't feel like doing sports or doing what I want, because then the next day (when I can't do things) no one will understand (why I can't do it) so I do stop myself from doing things a lot."

Changes from day to day

The school day

"I love sports and really enjoy it. Sometimes I do it too much because I get excited and happy and then the next day I'm really tired and that's when I feel the pain. I don't realise I'm pushing myself too much"

Pushing myself

2

"I'm judged quite a lot at school. People judge me on what they see and not what they know"

"I find it quite hard to fit in with some people"

"When I first started school I had an operation and when I came back I used the teacher chair so I was more comfortable with my legs. Everyone asked me lots of questions about why have I got this chair you don't need it"

Feeling judged

"Its just really difficult because I want to join in with everyone, but I don't know how to and I don't know how to explain what is going on

"My best friend knows a bit about what I'm going through. She is really supportive and helps me throughout the day. She makes me laugh and think about other things"

"I get asked questions a lot. Why are you like this? Why are you doing this when you can't do that? It makes me quite upset as I don't know what to say to them or how to avoid it"

"Sometimes in school I feel like people avoid me."

Supportive relationships

Fitting in

Questions

Relationships with other students
(friends, others in class)

"I don't really want to tell people what I am going through, but if I don't tell them they wont understand"

Telling people

"When I want to do something with them and then another day don't want to, like run around in PE I get asked questions like you did it yesterday but you aren't doing it now?"

4

5

7

"A school my hands get tired. I'm not given enough help with that. A computer or a tablet would help with that. I'm always struggling with that"

" The only facility in school I have is going in the lift, but I don't like using it. It's a slow lift, so then I have to leave the class a few minutes early (to use the lift) and I don't want to miss those"

"When I had a teachers chair in class (after an operation) when none of the teachers really understood I was told that if I wanted to be involved in sports I couldn't have my chair. It made me really upset for a long time. Later on when the teachers understood me more it changed"

" In class when teachers say do you have any ideas I want to put my hand up, but I am trying to focus on what I am writing so I can't participate in what they are talking about. If I had something to help with writing I could focus on my ideas."

The lift

Writing equipment

Chair

" I want to participate as much as I can but (not having help with writing) is slowing me down"

Facilities in school

facilities

" The facilities in school could be much better there could be more for me"

" People understanding what I am going through"

"The teacher's to know how I feel"

"I was told by my doctor to have a more stable chair because I'm pushing on my hips instead of my legs, but because my legs are short my feet don't touch the ground.

I had a box, but I didn't like it. It was uncomfortable. I want something different"

The Ideal school
(If you could wave magic wand what would school be like? What has helped you? What hasn't been helpful?)

"More understanding between my teachers and my friends"

" More time"

"To be able to be myself"

Appendix 15: Exemplar Participant Visual Theme Map: Willow**.**

Appointments for my health condition sometimes impact on my attendance and means I miss learning opportunities .

"I've had to be off for the hospital appointments that I have and that can add up sometimes."

When I miss out on learning I am expected to 'catch up'- this can be really difficult and impacts on my home life and free time.

"I am expected to catch up with all the lessons that I miss"

My health condition sometimes affects things in school like my PE lessons, break/lunch times, the start /end of the day and trips

"at break time I go to this room because it is a bit quieter and its easier for me"

Fatigue and headaches have a big impact on my life. It impacts my learning, my ability to focus in school and how much I can do with friends.

"I just feel like going to sleep straight away because of how much energy I don't have and its just (-) tiring."

My health condition & school
(Impact on school life)

I feel that adults don't always keep me and my individual needs at the centre of plans to support me in school

"Everyone is different and (- -) I think sometimes they just seem to be like oh everyone is the same"

The support from adults in school can differ depending on who is supporting me, how they are feeling and how much they know and understand of my health condition

"you'd like one TA then you wouldn't like the other but then I have just started to get used to it, because I can't really decide what TA I get."

Sometimes my teachers say that I "you are the same as everyone else" then don't always give me the things I need. I think it is because they are worried about being 'unfair' to everyone else

"you can't do stuff that you need to do because "I'm no different to everybody else"

I don't always feel that adults listen to what I need to support me in school

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"If you won't let me go out what's the point of asking?"

Support for my health condition
(Relationships & Belonging)

My health condition impacts on how I feel. It can mean that I can sometimes feel:
- Frustrated
- Guilty
- Embarrassed
- Overwhelmed
- Sad
- Scared

"I would feel guilty"
"I would feel awkward"
"I always feel annoyed"
"It's a bit hurtful"
"It can be like really frustrating."
"my head can feel like its going to explode."
"Its not safe for me"

I feel like I can't always be independent and make my own decisions in school.

I really want to be able to be more independent

"Just leave me to it"

"I definitely prefer to have that independence."

Sometimes I act more like a grown-up and take on more responsibility than other people my age

"just takes some patience to be able to build a bond with the TA"

My health condition impacts on how I feel
(Emotional Impact)

I cope with my health condition in different ways. Relaxing at home is especially important for me. I want adults to know about and respect that I need this time.

"some time to myself .....just like relax for a bit"

I tend to try and accept the challenges my health condition brings and just 'get on' with it and not think too much about what I am missing.

KEEP CALM AND CARRY ON

"I did think... I am not missing out on anything"

I'd really like to have some support groups so I can talk to peers in school who also have health conditions like me.

"there never seems to be any support group about disabilities or about how I am coping or anything like that."

How I cope with my CHC
(Emotional Impact)

I have plans for the future but sometimes I worry about how I will be supported to meet my goals.

"obviously when I go into uni the big worry is around making sure that I've got the right support and the right accessibility "

My future

Appendix 16: Project Contact Sheet

Project Contact Sheet

Participating in the research is not felt to have any serious disadvantages or risks. However, sometimes reflecting on our lives can be upsetting or distressing. If you feel upset or distressed throughout the research and would like further support you or your parent/carer can contact the researcher:

	Researcher/Trainee Educational Psychologist
	Sarah Lakeman School of Education Edgar Allen House, 241 Glossop Rd, Sheffield, S10 2GW slakeman1@sheffield.ac.uk

or if you would prefer access support through one of these organisations:

Get general information and access to a online toolkit and 'childline helper' to provide advice about how to support your mental health: https://www.childline.org.uk/. You can speak to a childline counsellor between 9am-12pm on: 0800 1111 or using the online 1:1 chat: https://www.childline.org.uk/get-support/1-2-1-counsellor-chat/
Parents & carers can contact the parent helpline on: 0808 800 5000

Get advice about how to support your mental health: https://youngminds.org.uk/. You can access 1:1 text support through the Crisis Messenger by texting YM to 85258, All texts are answered by trained volunteers, with support from experienced clinical supervisors
Parents can access the parent helpline on: 0808 8025544 (for parents/carer helpline)

You can access short term telephone counselling for support with mental health and emotional well being, register at: https://www.themix.org.uk/get-support/speak-to-our-team/the-mix-counselling-service
Call for general advice and support to find local organisations that may be able to help you further. 7 days a week from 4pm to 11pm on 0808 808 4994 You can access the crisis messenger 7 days a week, 24 hours a day by texting THEMIX to 85258.

Appendix 18: Samuel's Animation
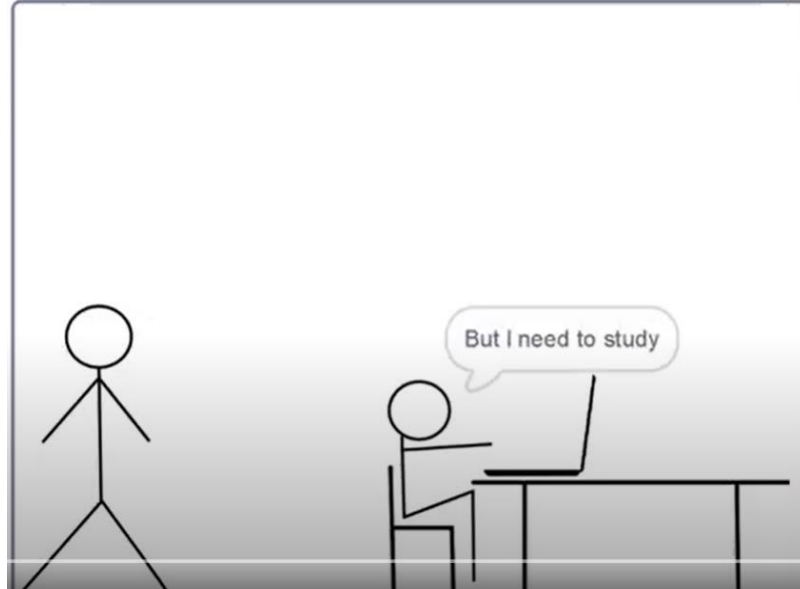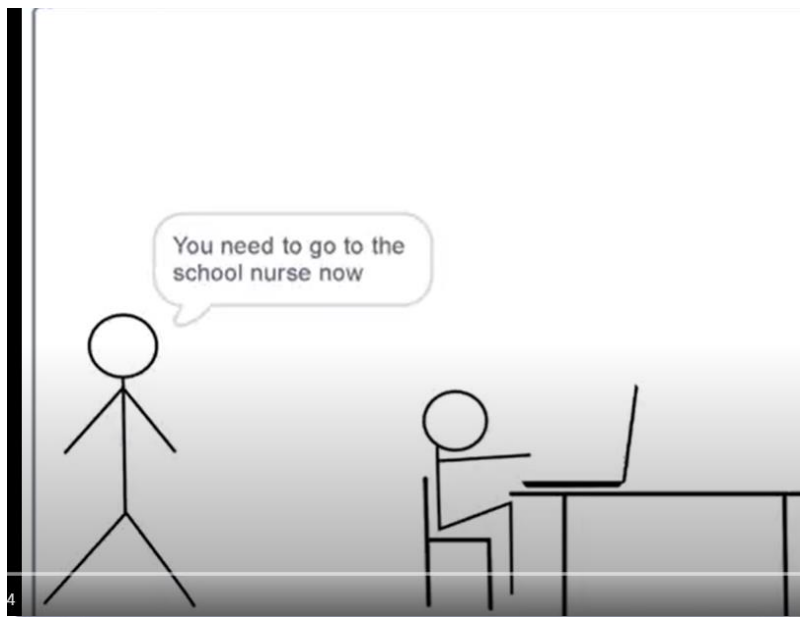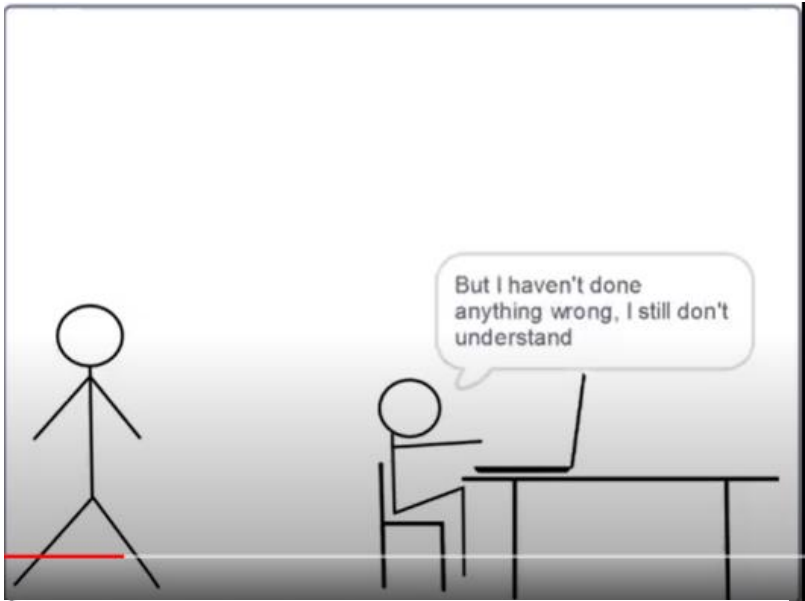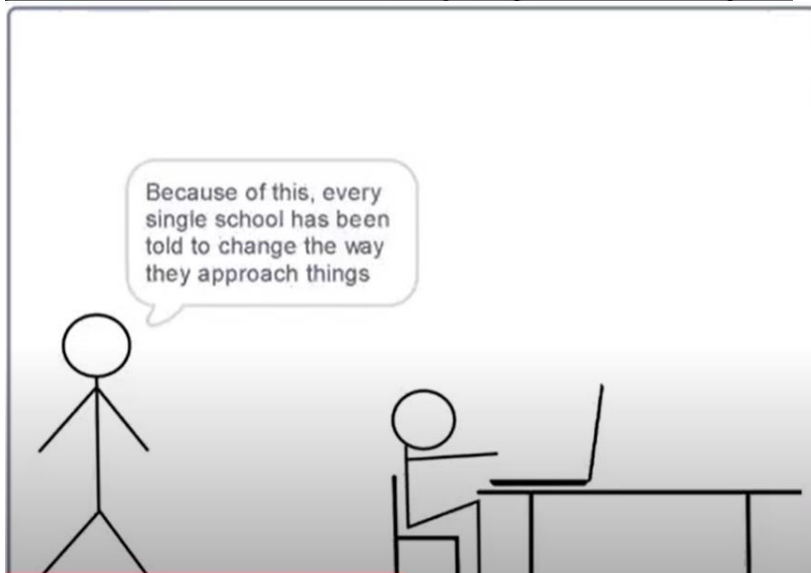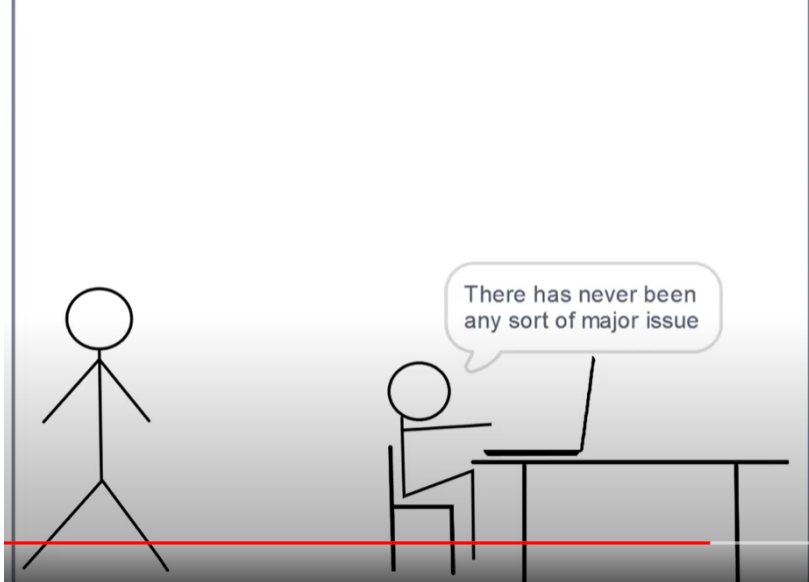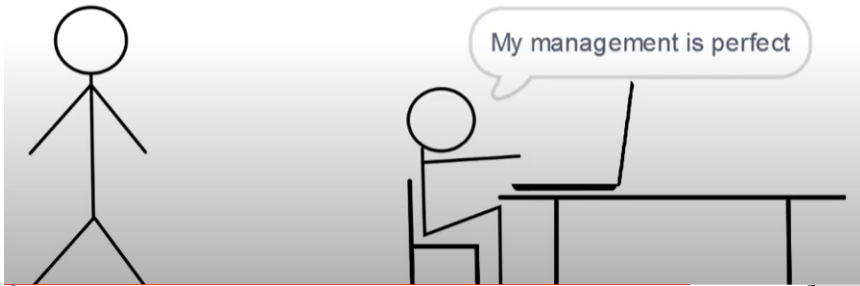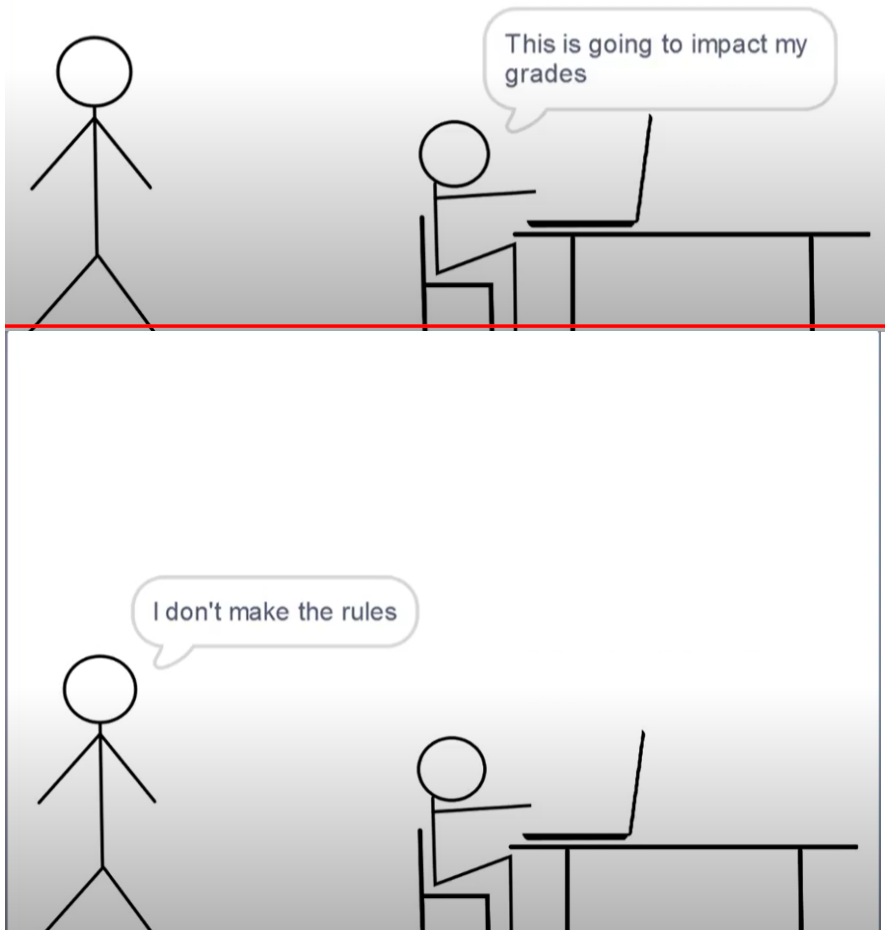
Appendix 19: Interview Schedule

A: Introduction

1. *Thank you.*
2. *Purpose*

To hear your experiences

To talk about your creative project

3. *Style*

- Interested in what you have to say.
- There are no right/wrong answers.
- May ask some obvious questions.
- May not say much as listening to what you have to say, but might ask a few questions.
- Take as long as you need to think/answer.
- If you want to stop or skip a question let me know.

3. *Support*

Distress protocol, contact sheet.

5. *Confidentiality*
6. *Safeguarding*
7. *Data*

- Audio recorded- no video/picture.
- Transcribed
- Stored securely no access other than researcher, unless have permission.
- Creative materials- choosing to share, storage, use, confidentiality.
- Pseudonyms

8. *Analysis & member checks*
9. *Withdrawing*
10. *Questions*
11. *Ready to start? Recording?*

B: Interview Schedule

1. *Creative project:* Can you tell me about your creative project?

Prompts:

Can you tell me about the X part?

What does x represent?

Why is x important to you?

What is x? Why did you choose that image?

How did it feel when you did X?

Is there something else you would like to tell me about your project?

The following question areas within the schedule will need to be used flexibly depending on the outcome of asking about creative projects.

2. *Enjoying school:* Can you tell me about what you enjoy about school? / Can you tell me about anything you do not enjoy in school?

3. *Attendance:* How do you think you CHC affects your attendance (to lessons, clubs, trips, school, punctuality)?

Prompts:

How do you feel about that?

How do any difficulties with attendance affect you?

What helps when you find attending difficult?

What does not?

4. *Learning:* How does your CHC affect your learning in school?

Prompts:

How does that make you feel?

What helps you to learn?

What does not?

5. *Relationships:* How does your CHC affect your friendships in school? How does your CHC affect your relationships with adults in school?

Prompts:

Can you tell me about any adults in school that are helpful? Why are they helpful?

Can you tell me about any adults in school that are not helpful? Why aren't they helpful?

Can you tell me about your important friendships in school?

Are any there any helpful peers (young people) in school? Why are they helpful?

Are any there any unhelpful peers (young people) in school? Why are they unhelpful?

6. *Environment:* Can you tell me about anything in the school building that is difficult for you because of your CHC?

Prompts:

e.g., toilets, lunch hall, classrooms, first aid room, equipment, medical room, bag, locker, books, chairs, stairs/lifts, locker

What helps you with these things?

What doesn't?

7. *The School day:* Can you tell me about parts of the school day that your CHC particularly affects?

Prompts

e.g., before school, getting ready, travelling to school, break, lunch, lessons, after school, homework.

8. *The future*: What are your hopes and dreams for the future? Has your CHC impacted on this?
Prompts

Now? College? University? Training? Job?

8. Conclusion: Is there something else you would want other people to know about what it is like going to school with a CHC?

If I could wave a magic wand to design an ideal school for you, what would it be like?

Any questions?

Thank You

Appendix 20: JJ's Adapted Visual Interview Schedule

Hi JJ,

Thanks for talking to me today. It was great to get some ideas from you about what school is like for you.

I know that you prefer to talk for a short time, so I have arranged to call you on Monday, Tuesday and Wednesday next week just for 20 minutes each time.

I thought it might be helpful to concentrate on just one or two things about school thing each time. So I done a picture for each session on the next few slides about the things we might talk about. If you want to talk about other things in the session that is also fine.

If you want to draw me a picture before the session about those things, that would be fantastic, but if you would just prefer to just talk that would be fine too.

I hope all of that makes sense, but if you have any questions- let your dad know and he can email me.

I am really looking forward to speaking to you again next week.

Sarah

Session 1- Monday

The people in school

Session 2-Tuesday

The school day

Which adults are important to you in school? E.g. TA, mentor, Teachers

Why are they important?

Which adults help you?

What are they like?

What do they do that helps?

Do they do anything that doesn't help?

Is there something else you would like adults to do to help you?

Adults in school

Can you draw me a picture/pattern that shows me what the adults or young people are like at your school?

Something else you would like to tell me?

Which Young People are important to you in school?

Why are they important?

Which Young People help you?

What are they like?

What do they do that helps?

Do they do anything that doesn't help?

Is there something else you would like other Young People to do to help you?

Young people in school

Slide 5

The school day

- What did you not like about going to school?
- What did you like about going to school?
- What is it like if you miss school for an appointment?
- What are the mornings before school like?
- Are they are any spaces in school that you use that are helpful for you? Medical room, Lunch club, mentor's office?
- What was it like being in the classrooms?
- What is it like if you miss school because you are not well?
- What was the learning like?
- What is it like after school?
- What is the building like e.g. toilets/classroom/equipment? Is there anything you would change to make it easier for you?
- What were lunchtimes and breaktimes Like?
- What is it like if you are unwell in school?
- Can you draw me a picture/pattern that shows me what the school day is like for you?
- Is there something else you would like to tell me?

5

Slide 6

Session 3 -Wednesday

My Ideal School

6

Slide 7

The Ideal school
If you could wave magic wand what would school be like?

- What would the learning be like?
- What kind of adults would there be in your school?
- What would the rooms be like? Would you have any special rooms?
- What kind of Young people would there be in your school?
- What special equipment would you have in the school?
- What would the building be like?
- Can you draw me a picture/pattern that shows me what your ideal school would look and be like?
- Is there something else you would like to tell me?

7

<u>**Willow Transcript**</u>

Willow is 15 years old. She is in Year 10. Willow has cerebral palsy. Willow chose not to take part in the creative project as she felt that she was "not very creative and better at just talking".

<u>Interview Key:</u>
(-) approx. 0.25 second pause
(- -) approx. 0.5 second pause (repeated dashes= increase of pause by approximately 0.25 seconds)
(/) inaudible word
(/ ?) inaudible word and suggested word
- overlapping speech
Italics action

<u>Exploratory comments Key</u>
Descriptive
Linguistic
Conceptual

Transcription

1 I: So I sent you last week and email with the pictures of things that we
2 might talk about. Did you get a chance to look at it?
3 W: Not really (laughs)
4 I: That's ok, don't worry would you like me to put it up on the screen?
5 W: er yes please
6 I: This is where its gets a bit interesting with technology! I might have
7 to..., lets see if I can do that... here we go got it! Tell me when you can
8 see it. Can you see now?
9 W: I can see it now.
10 I: So these are things we could talk about, but we don't have to, we
11 can talk about whatever you like. Its just for ideas. Is there any of
12 those that you think you'd like to think or talk about first?
13 W: (------) uummmmmmm
14 I: So we've got likes and dislikes in school, attendance, learning, adults
15 in school other children?
16 W: (- -) yeah I think I already know what I want to talk about.
17 I: You think you know what you would like to talk about?
18 W: (- -) yeah
19 I: Ok, so do you want to tell me what school is like for you?
20 W: (- -) umm I enjoy, like PE and stuff like that.Umm but then PE can
21 get a bit like competitive and um and um It gets a bit much in PE now
22 so I don't really do that any more.
23 I: Right
24 W: Ummm (- - -)
25 I: Can you tell me...
26 W:I um I think um (-) that I (-) I like um history and stuff like that cos
27 its just like there seems to be a lot of debates and stuff like that. And I
28 like doing debates and stuff so its just (-) some subjects are interesting
29 some days and some subjects aren't interesting on other days, just
30 depending on what you are working on. Ummm and it also depends
31 on the teachers as well and how the teacher is and stuff like that
32 (laughs)
33 I: (laughs) so is there anything in school that you don't like then?

Exploratory comments

20: PE lessons bit much'. Tiring? Physically?
21: CHC- affects engagement with physical activity/PE lessons
22 :Enjoys PE but no longer able to take part.
22: Unable to access enjoyable activity- Loss?

26: Enjoys mix of curriculum
28: Variability in interest day to day
31: Variability of interest dependent on teacher

Emergent Themes

Fatigue

CHC impacts on participation in physical exercise (PE)

CHC impacts on participation in school day

Loss of pleasurable activity

	Exploratory comments	Emergent Themes
34 W: (--) ummm I don't enjoy maths or science, science is just a topic I 35 absolutely hate. 36 I: What about maths? 37 W: That's a touchy subject is maths. One day I like it and one day I 38 don't. 39 I: Ok, so it just depends on the day? 40 W: yeah 41 I: Yeah. Ok. So do you want to tell me a little bit about your health 42 condition and what that is like for you in school, to have your health 43 condition in school. 44 W: Yeah. So my cerebral palsy can get a bit much some days. It can be 45 like really frustrating. Umm (-) and especially when you want to do 46 something that you can't do. So like when in I know we don't go on 47 trips like we used to, but you know when you used to be able to go on 48 like day trips and stuff like that umm it used to be like the other 49 students would go off and do whatever they want to do but I would 50 always have to stay with someone (-) 51 I: Right 52 W: and then that's what would really frustrate me.(- -) 53 I: So that was frustrating? 54 W: um, yeah definitely and then um (-) I think (-) sometimes it 55 depends on what TA you've got like um some Tas will lets you be 56 really independent and some won't and its just depending on what 57 they have been told to do (-) Does that make sense? 58 I:yeah 59 W: UMM 60 I: So it kind of depends on what? Who tells them to do things? Who? 61 W: (- - -) Just there is like the um whats it called? Mum what's miss X's 62 job? 63 W Mum: Shes the head of SEN,the SENCO or head of … 64 W: SENCO. Do there is like a teacher called a SENCO yeah and they like 65 organise stuff like that and then if there is a problem then like um they 66 would answer um its just its basically what, who sorts out who goes 67 where and stuff like that. 68 I; Ok, so she tells that Tas what to do? Is that? 69 W: (- -) um yeah more or less yeah.	44: 'my' cerebral palsy- part of identify? Own it? Have control? 44: 'bit much' repeated, emphasising how difficult it is. 'bit' downplaying how hard it really is? 45: sense of overwhelm 45: Frustration/annoyance 45/46: Loss of normality? Not able to do everything that she wants. 46: Physical impact of CHC or emotional- what is the barrier to accessing he wanted activity/ 49: comparison to peers- treated differently 49: Loss of autonomy- not able to be independent- make own choices on trips 50: Increased adult involvement in comparison to peers. 50: Lack of independence 53: Frustration 54: fillers/pauses- difficult to articulate feelings? 55: Variability in approaches/support from different TAs 56: Amount of autonomy varies depending on TA. 57: TA's 'told' to do something- cannot think for themselves. Who tells them? 64: SENCO directing TAs 65: SENCO involved in managing support for pupils with CHC. 65: SENCO answers if there is a problem. Problem with what? Who do they answer? 67: SENCO- functional support- coordination of staff.	Feeling overwhelmed Variability in impact of CHC day to day Frustration Loss of normality Comparison to peers Feeling different to peers Treated differently to peers Impact on trips Sense of helplessness Sense of loss of control Loss of opportunities to interact socially Loss of access to preferred activities Frustration at restriction to activities/ different treatment to peers. Loss of autonomy Additional adult support/involvement. Additional adult support/involvement highlights differences Frustration Seeks Independence TA support variable TA support can offer independence TA support can inhibit independence Power differential between SENCO and TA SENCO 'holds power' TA lacks autonomy

Line	Transcript	Codes (middle)	Codes (right)
70	I: Yeah, ok. And so some times the TAs gave you a bit more, you could	76: Seeks independence, prefers it when given?	Seeks independence
71	bea bit more independent it sounded like with some TAs? And other	80 Fillers/pauses- hard to describe TA good practice for supporting	Prefers limited adult
72	TAs don't give you as much independence?	independence.	involvement/ support
73	W: yeah	81: "leave me to it"- not get involved- allow independence.	TAs provide practical support-
74	I: And what do you prefer?	81: W able to seek help if needed.	scribe
75	W: Yeah	82: Variability in TA approach re independence	Variable TA support
76	I: What's better for you?	82: Some TAs overly involved "do everything"	Increased Adult involvement.
77	W : I definitely prefer (/) to have that independence.	82: lack of pupil voice. Lack of independence. No input- not person centred.	Variable level of person- centred approaches used.
78	I: And what things do they do that help you have that independence	84: Pauses- difficult to describe how this makes her feel- frustrated?	Pupil input/views not always sought
79	that you enjoy?	88: full time TA support in lessos.	Some Adults inhibit
80	W: (- -) they like um (- -) I would like do some writing um and they	89: Range of TA's- no consistency	independence
81	would just leave me to it. Whereas some like, and they would tell me	91: pauses- Difficult to describe how she feels- frustration?	Frustration
82	to just let them know if they needed to do anything for me. Whereas		Enhanced TA adult support throughout day
83	some of them just like try to do everything for me without letting me		Different adults supporting throughout the day
84	have some input, and it just fr (- -) yeh huh (- -)	93: frustration	Variable /different adult support frustrating.
85	I: and that is frustrating is it, is that what you said?	93: Variable relationships with TAs	Variable /different adult support inhibits ability to
86	W: definitely (-)	94: Difficult to 'get used to' different TA approaches. W has to adapt to their	develop relationships with adults
87	I: Yeah. Ok. And so do you have a TA with you all day or?	approaches and not TA to her. Adult-centic? Lack of person centred	Adapts/accepts to variability in support
88	W: (- -) basically I have a TA every lesson. Um its like a different TA in	approaches?	Adapts/accepts different relational approaches of adults
89	each lesson. You have a Ta for each subject. You have another TA in	95: no say in TA support- power with SENCO? Lack of control. Sense of	Lack of power/control
90	another subject. Some Tas I have more than once, and then some of	helplessness and then acceptance of adult decisions. Passive? Way of coping	Lack of input/voice around support
91	them I just have once and a week and its just (-) yeah.	with situation?	Feelings of helplessness
92	I: And how is that having lots of different TAs?	98: Would like to be involved in decisions around TA support.	Acceptance of adult decisions
93	W: Um at first quite frustrating as you'd like one TA then you wouldn't	98: Being involved in decisions about support would be helpful.	Passive coping mechanisms
94	like the other but then I have just started to get used to it, because I	99: Would choose TA's based on positive relationships. Relationship	Acquiesce/comply
95	can't really decide what TA I get.	with TA more important than anything else?	Variable relationships with TAs.
96	I: And if you could decide what TA you got, would that be better for	99: 'good bond'- relationships most important?	Demonstrates maturity, beyond developmental level.
97	you?	100: Takes on adult role- thinking about how to develop 'bond' with TA,	Positive relationships with TA supportive
98	W: Um, It would actually be better for me because I would choose the	normally responsibility of adult?.	Positive relationships/ bond with some staff
99	ones that I get on well with and have a good bond with um but I guess	100: Takes patience to develop relationship with different TAs. Frustrating at	Time needed to develop relationship with TA.
L00	it just takes some patience to be able to build a bond with the TA.	times? Development over time.	Patience required to manage variability in staff approaches
L01	I: Umm and you talked about some TAs you have a good relationship	103: Main TA? Contradiction to previous descriptions of different TAs in	Relational approaches more important than practical support
L02	with? What are those TAs like?	every lesson. Is she the main TA because she has known her so long rather	
L03	W: Yeah the one who like , the one who I've had since year 7 is like my	than the time she spends with her?	
L04	main TA and she is really nice and is like very understandable Um but	104: Understandable? Speech? Makes the work clear?	
L05	since I've gone back in September everything has just been a bit	104: 'nice'- how she makes her feel more important that practical support?	

Line	Transcript	Codes	Themes
106	different um because I had this, even though I've still got this TA she	106; Impact of COVID on support staff- practical support still there but adult feels different. Picking up on adult's stress within the pandemic?	Notices adult stress
107	seems to be like, she doesn't seem to be as much um (- -) what do you		COVID impact on support
108	call it? Um (- -) she seems to be more sensitive now. Does that make	108: fillers, pauses- difficult to describe changes in adult behaviour?	Impact of adult stress on support/ relationship
109	sense?	108: Feels a change in adult behaviour since the pandemic- more 'sensitive'	COVID has impacted on relationships with adults in school
110	I: Yeah	111: TA more serious since pandemic	
111	W: She's more serious and stuff like that and Its just (- - -)	113: Pandemic- change in TA behaviour impacting relationship. Harder to form relationship.	Impact of physical symptoms- writing difficult
112	I: Is that harder when she is more serious?		Impact of physical symptoms- speech
113	W: (- - - -) definitely yeah (laughs)		CHC impacts on learning languages (speaking)
114	I: (Laughs) ok yeah. (- -) so what about learning and the classroom,	116: Physical impact of CHC- writing	CHC impacts some assessments
115	how is that for you?	118: Impact of CHC on speech- impacts learning in languages	Physical impact: impacts intelligibility
116	W: (- - - -) um (- - - -) I think it's the (-) writing and stuff like that um um	118: CHC impacts some assessments	Physical symptoms highlight CHC making differences more visible
117	(--) its just not like, its hard to explain but like when you are doing um		Physical impact: hearing impacts on learning.
118	like for example in French you've got to do a speaking exam	120: Physical symptoms lead to comparison to peers- feels different? Makes CHC more visible?	Missed learning due to noise levels in classroom.
119	I: mmm	121: Physical impact: impacts intelligibility	Noise levels in classroom impact on physical symptoms.
120	W: and I can't really pronounce words properly like the other students	120: Impact of CHC on speech- impacts learning of languages	Willing to seek help form adults
121	can and it can get really frustrating (- -)	121: Frustration	Good awareness of own limitations
122	I: so it gets frustrating?	123: Impact of CHC on hearing.	Adults sometimes don't listen when needs are communicated in class
123	W: mm and its also, cos I'm also deaf as well so that doesn't help	123; Impact of hearing on learning.	
124	I: Right	125: Classroom noise levels important- impacts on ability to access and learn. If too noisy then needs to leave classroom	
125	W: mmmm so if the class is loud it gets a bit much ummm we have	125: Leaving classroom impacts on learning.	
126	this thing where we have a cover teacher if the teacher is off and that	126: Noise levels worse with supply teacher.	
127	is when the students start to play up a lot like they start to mix the		
128	seating plan up and sit with their friends and it gets (- - - -) cos I (/) if it	133: W asks to be taken out of the class when required	Power differential- Power lies with adults
129	gets too noisy I would have to be taken out of the class., which would	133:W has good awareness of her limitations.	Lack of agency
130	then mean that I would be missing out on my learning.	134: Adult don't always listen to request to leave class.	Loss of autonomy
131	I: hmmm and do you decide, who decides when it is time for you to	134: Power ultimately lies with adults.' Won't let me'. Loss of autonomy/agency.	Frustration
132	come out of the class?		Adults ask for input- but don't act on it
133	W: Ummm I ask them to I ask to be taken out of class but sometimes		
134	they won't let me sometimes they wont so its just, they fully decide if I	137: annoyance/frustration	
135	can but I'm the one that ummm asks them if I can be taken out (- -)	137: adults ask for feedback form W but then don't act upon it.	Headaches
136	I:And how do you feel about that?	138: W feels that adults don't understand impact of CHC	Classroom noise impacts on headaches
137	W: Umm I guess that I'm allowed to ask but I think it is a bit annoying	138: CHC can cause headaches- impact on learning/attendance to lessons	Headaches last all day
138	when they say no as they don't really understand how bad my	139: Classroom noise impacts on headaches	Headaches impact learning
139	headaches can get because of I- the noise ummm and then obviously,	140: Headaches can last all day- impact throughout the day	Takes on adult role
140	especially if it's the first lesson of the day then that headache will drag	141: 'trying' to get them to understand- responsibility lies with W and not the adults? Taking on adult role?	Adults don't understand severity of CHC symptoms.
141	on all day. So its just trying to er get them to understand how bad it is	141: Adults not understanding impact of physical symptoms.	

Line	Transcript	Exploratory comments	Themes

142 sometimes, especially with my hearing aids making it, the noise extra
143 loud because that is what my hearing aids do anyway um (/) so its just
144 annoying sometimes when they don't let me go out.
145 I: And how does it make you feel when you've asked to go out and
146 they say you can't go?
147 W; (- - -) It feels a bit like I shouldn't have asked in the first place if
148 that's it. Umm if you won't let me go out what's the point of asking?-
149 I: mmm
150 W:- especially if they say that, just ask and then we will take you out
151 and then they don't let me out and its just a bit hurtful because they
152 haven't really taken my, my health not my health but my (- -)
153 education into thought. They've just (- - -)
154 I: Ok
155 W: Yeah it's a bit hurtful sometimes (- --)
156 I: Yeah. Umm. So you mentioned your headaches you get do they have
157 an impact on your learning?
158 W: Yeah. Um Definitely because it feels, like it gradually gets worse as
159 one- Cos I have like medicine at school but I am trying not to take it (- -
160) because I also have another medication that I am on, so its trying not
161 to have both medications (-) umm so it is like trying to control my
162 headaches so that I don't have to have the medicine (-)
163 I: Right. Ok. So you are trying to control your headaches so you don't
164 have to take two medicines and you are thinking about that?
165 W: yeah (-) yeah because the medication that I have for my headaches
166 is just normal calpol right but then I am also on, I'm also on another
167 medication for my disability anyway. (- -)
168 I: Right. Ok. And do you have to take that medication in school or is
169 that at home?
170 W: No um I work it out so I don't have to take it in school which is ok
171 because (- - -) because it's a bit too much hassle having it at school.
172 I: Um ok, Have you ever taken it at school or has it always been at
173 home?
174 W: I've only had it for 6 months but I haven't had it at school yet.
175 I: Ok. Ok. Um OK. So do you think that you have to have time off?
176 Does your health affect your attendance?

Exploratory comments

142: Impact of equipment- hearing aids amplify noise.
144: annoyance/frustration
144: 'don't let me'-Power with adults?
144: sometimes not allowed to leave classroom even when need to due to physical symptoms of CHC.
147: Doesn't feel heard? Not person centred?
147: Feels that adults don't trust/ believe her?
147: Power with adults- lack of autonomy?
147: Impact of repeatedly not feeling heard- less likely to ask for help. Feels asking for help is pointless?
150: W feels that adults can't always be trusted- say one thing but don't always follow through?
151: 'hurtful'- change from frustration/annoyance- more personal.
152: Pauses, repetition, reviews- difficult to explain how this impacts?
152: Repetition of my health- emphasis
152: W questioning adults motivation for decision making. Feels they have not considered her health or education? Feels they are more focused on keeping her in class learning. Have not considered her views?
153: 'They've'- me vs them? Previously named them TAs- distance in relationship when discussing this point?
153: Lack of understanding of impact of CHC from adults?
155: Repetition of 'hurtful'- emphasis.
158: physical symptoms impact on learning.
159: has medication at school
159: Trying to manage medication and make decisions about when is best to take it. Another consideration throughout the day. Additional responsibility peers don't have. Adult responsibilities?
166: multiple medications needed to be managed throughout the school day.

170: medication plan so that there is not medication to be taken in school- why? Easier for W/school both?
171: 'Hassle' in school- disruptive to school day? Difficult for staff? Who made this decision?

Themes

Frustration
Loss of autonomy
Power differential- Power lies with adults

Adults sometimes don't listen when needs are communicated in class

Feels adults don't trust her judgements about her CHC and management

Hurt/upset

Lack of trust in adults' motivation for support

Adults lack understanding of CHC

Hurt/upset
Management of medication regime in school
YP controls medication regime in school
Trying to control pain
Headaches/pain impact on ability to focus/learn

Difficult to manage taking medication at school.
Required to take on adult/role/ responsibilities

225

Line	Transcript	Exploratory comments	Emergent themes
177	W: Um I haven't had to be off for my disability but I've had to be off		CHC as Disability
178	for the hospital appointments that I have and that can add up	**Exploratory comments**	Disability part of identity
179	sometimes. So especially now I am in Year 10 its leading up to the	177: Use of 'disability'-Is W considering herself disabled? How does she	Attendance impacted by medical appointments
180	exams but I got them next year so its like trying to take, trying not to	view her CHC- is disability part of her identity?	Missed learning due to medical appointments
181	have the hospital appointments in school time um but other than that	177: separates missed time for 'disability' and appointments- sees them as separate entities?	
182	(-) it depends cos I haven't had a day off where its because of my d- its	178: missing school due to medical appointments	Missed learning time impacts exams and attainment
183	like I've only had a day off where because of hospital appointments or	179: "add up"- increasing pressure of missing time?	Missed learning time requires catch up time
184	because I'm really ill ummm butt other than that I've just umm (/) (/)	180: Impact of missed time of exams and attainment.	Desire to attend school
185	I: Do you have lots of hospital appointments?	181: Tries not to have appointments in school time- how much power does W have over this?	
186	W:Umm when they are close together it feels like a lot of	182: reiterates that missed time not due to CHC but appointments around it. Possibly trying to prove it that it is the result of others and not her that's	
187	appointments but when they are spread across the year it doesn't feel	he has time off?	
188	that much but when I think about it I do have quite a lot of	184: only off if "really" ill-implying that's he would not take time off for	
189	appointments that I go to.Ummm cos I've got one tomorrow and that	'minor illness?	
190	one is in Leeds and that is taking a full day out of my school. Ummm.	186: Spacing of hospital appointments important- when close together- lots	Missing parts of lessons.
191	So (- - -)	of learning missed- difficult to catch up. Lots together feels like a more	Missing whole days due to medical appointments
192	I: So sometimes they build up together and it feels like you have lots if	significant amount of time off.	Takes on adult
193	they are close together and you miss lots of school then?	190: specialist appointments further away mean longer time off school.	role/responsibilities outside school
194	W: yeah.	191: long pause, difficult to explain impact of having a day off school?	
195	I: And when you come back after having missed the day because		
196	you've got to go to a hospital appointment how is that?		Expectation from teachers to catch up on missed learning in own time
197	W: Umm if I have to like leave in the middle of a lesson its frustrating	197: Leaving part way through a lesson difficult- miss key learning.	
198	because that lesson is important. Umm and then when I come, it	197: frustration at missing lessons	
199	depends how long the appointment takes. So if I only takes like an	199: different medical appointments different amount of time of school.	
200	hour I'll go back to school. But then if it takes up to two hours then	Shorter/close appointments mean can return to school quicker.	
201	there is not point me going back to school. And it depends where the	200: some appointments mean missing whole day at school	
202	appointment is, so if it is at a big hospital you've got to get there so	203: practical aspects of hospital appointments- impact on amount of time	
203	you can get parked and stuff like that so it just depends.	missed. Adult considerations- would most young people W's age- consider this?	
204	I: So when you come back into school?	205- unable to finish sentence- difficult to explain the impact of coming	
205	W: That, it depends on what kind of time you come back in cos over	back in part way through a day?	Catching up on work means loss of preferred activities at home
206	lunch isn't just by that and it just yeah		Catching up on missed work
207	I: Do you feel like you miss things being off?		impacts on home life outside school.
208	W: I am, ummm I am expected to catch up with all the lessons that I	208: Expectation to 'catch up' after missed learning.	Limited understanding from staff
209	miss but because I've got stuff to do after school I don't always	209: Catching up impacts of home life.	about impact of having to 'catch up on work'
210	manage to catch up on stuff because I've already got other stuff	209: Catching up= missing out on other (more preferred) activities.	Teachers perceive W as different
211	planned. So its just (-) I think the teachers don't really understand	211: Teachers don't understand impact of having to catch up on W's home	to peers- not as having a life' at home
212	that you've got other stuff to do as well as awork. Umm so some	life. Expect focus just to be on learning- W feels that they don't see her as a young person with 'things to do' at the weekend? Perceived Identity different to other peers- assumption that she is at home not engaged in normal teenage activities and has the time to 'catch up'?	

Line	Transcript	Coding Notes	Themes
213	teachers are really strict about what homework you've got to do	213: variability in teachers expectation for work completed at home.	Teachers expectations on 'catching up' variable
214	whereas some teachers are like, some teachers understand that	214: some teachers understand 'home' life.	Frustration
215	you've got stuff to but then some teachers don't and that's the	215: annoying when teachers do not consider W's home life and hobbies.	Teachers don't understand the 'whole' person- don't think about
216	annoying bit.	215: Identity- teachers don't consider likes/dislikes/hobbies/home life- don't have a holistic view of who she is? Not person centred?	the pupil outside school.
217	I: Umm. So what kinds of things do you do outside of school?		Stress/overwhelmed
218	W: Umm I do like obviously at the moment we aren't really able to do		Physical symptoms of stress
219	stuff because of everything that is happening but I would sometimes	220: relaxation time important.	Coping strategy: relaxation time at home
220	do swimming or just have some time to myself that I wouldn't be able	221: Head feels like it is going to 'explode'- metaphorical or physical?	
221	to have during the day and just like relax for a bit cos my head can feel	Headaches or stress? too much to think about & do? Needs rest and	
222	like its going to explode. Umm yeah (laughs)	relaxation time.	
223	I: Is it important to you that you have that time?	221: Head 'exploding' describing physical symptoms of overwhelm.	
224	W: Definitely yeah (laughs)	224: relaxation time important.	
225	I: Yeah (laughs) When you come back in and you've missed out on		
226	learning , how does it feel to come back into the next lesson? Do you		
227	feel like you know what is happening or do you have to try and catch	229: TA supports with catching up on work missed.	TA provides physical support: scribe
228	up with friends?	229: TA support variable	TA support variable
229	W: Um I have to catch up with my TA cos normally my TA would write	231: Some TA's recognise importance of note taking in catching up on	Frustration at variable TA support
230	it in my book for me. But it depends which TA I have that lesson umm	missed work, some don't.	TA's have variable understanding
231	because some, one of my TAs will write stuff in my book because she	232: annoyance/frustration when TA support to write notes not completed.	of their role
232	knows how important it is, but other TAs won't and its just annoying	233: W considers support to catch up e.g. writing notes with learning key to	
233	when they don't do that. That is what they are really there for to help	success of TA support- not any pastoral emotional support?	
234	support me .	223: ? TA role- W feels it is not consistently understood by all adult?	
235	I: So it's a bit of a mix depends on which TA you have, depends on how		
236	easy it is to catch up?		
237	W: Yeah, Yeah		
238	I: And is there anything else about your learning you think is important	240: PE difficult lesson- tiring.	
239	for me to know about?	240: PE increases feelings of fatigue	
240	W: (- -) I think, you know when you've done PE and I'm more tired	241: Feels different to peers- more tired with same amount of exercise?	Impact on PE lessons
241	than everybody else because I've got to use my energy up um that and	242: PE lessons/timetable impacts of following lessons.	Physical exercise increases fatigue
242	then you've also got another lesson after PE that's really bad because	243: needs recuperation time after PE lesson	More tired compared to peers
243	(-) I'm trying to catch my breath after doing a lot of PE and sometimes	244: feels sleepy after exercise.	Uses more energy at school than
244	I just feel like going to sleep straight away because of how much	243-245: Energy I don't have, 'catch my breath' 'feel like going to sleep'-	peers on everyday activities.
245	energy I don't have and its just (-) tiring.	phrases emphasise extreme feelings of fatigue	Fatigue after PE impacts on
246	I: So does that impact the next lesson you have after PE then?	245; repetition of tiring & pause before 'tiring'- emphasis?	learning in other lessons
247	W: (- -) Definitely , especially when the lesson I've just got next is	247: PE and energy levels affect following lessons/	'Pushes through' fatigue to attend
248	really important because I cant really not, I can't miss that lesson.	248; Doesn't want to miss lessons – wants to learn, places importance on learning.	lessons
		248: repetition of 'can't' to emphasise how importance attendance to lessons /learning is to her.	Place importance on learning
			Attending all lessons important

249 I: And is there anything in school to help you with that? When you are
250 feeling really tired?
251 W:Um, not really no (laughs). You've just got to be _(-) because they
252 say I'm not different to everybody else when you are tired but it kind
253 of is (- -) Because (- - -) I'm using more energy than everybody else is
254 and its just (-) annoying when they say that because it means that
255 they don't really have much information about what it actually feels
256 like .
257 I: Yeah
258 w: and it just- yeah. It does get a bit annoying because (-) yeah I don't
259 want to be treated differently to everybody else but sometimes I need
260 to be treated differently (- -)
261 I: And do you think there are teachers in school who understand that
262 well?
263 W: Not, not the way I want them to understand it.
264 I: What way do you want them to understand it? If you could tell
265 them anything, if you could get them to understand anything what
266 would be the big thing you want them to understand about what it is
267 like for you?
268 W: (-) I'd want them to understand, like how much energy I really use
269 up just being sat down and doing all that and obviously what it feels
270 like to be told that you can't go outside or you can't , you can't take a
271 break because you need a break or you can't , you can't do stuff that
272 you need to do because "I'm no different to everybody else"
273 apparently. (-) so just (-) when – I think the main issue is , is when
274 they say that you can't have a break because its not fair on everyone
275 else . And I understand it wouldn't be fair on everybody else but if
276 you want me to do well, I'll need that break (- -- -)
277 I: You need it ?
278 w: Yeah. Yeah. (- -)
279 I: Ok. So thinking about friends then? Does your cerebral palsy impact
280 on your friendships?
281 W: Umm (- -),to be honest it impacts quite a lot because umm (-
282)when, when they ask if they can meet up outside of school because
283 feel really tired and you cant , I don't want to do that after school so I
284 have to say no. Um at the weekends its ok being its ok like I want to

251: No support for fatigue in school. Staff have not understood how much impact fatigue has?
251: 'you've just got to be'- emphasis on the fact that there is no support for support. W feels she needs to find inner strength to continue- no one else will help?
252: W feels that the message from adults in school that W is not different to others. She needs to get on and behave the same as her peers.
253: W Feels different to others- feels like has less energy and has fatigue that others don't have. Means that more energy is required just to do the same levels of activity as peers.
255: W feels that adults don't understand how her CHC impacts on her. They don't know or attempt to know what it feels like to be her. Teachers don't have the 'information'- where should this come from?
258: pauses- fillers/unfinished sentence- difficult t explain how it feels?
258: Annoyance/frustration- adults not understanding.
259: Recognises differences between her and peers but does not want to be treated differently?
259: contradictory statement- reflecting confusion about her identity and the help she needs. Not wanting support because it makes her feel different but needing it? Cognitive dissonance?
263: Doesn't feel teacher understand how she feels
263: Not being understood her way? Think they understand- been explained to by someone else not W. W's voice hasn't really been listened to. Heard but not understood?
268: Expends more energy used than her peers- just to do 'normal' activities. Fatigue.
270: Power with adults- 'told' she can't do things
271: repetition of 'can't'- emphasis
272: Adults not allowing her to do things that she needs to do to support herself- her judgement not trusted or listened to about what she needs?
273: Told by staff she is not different to others
273: 'apparently'- emphases point that she is not the same as everyone else
273: Pauses, fillers- difficult to discuss/articulate issues?
274: 'you'- sense of me vs them- fight/battle- not on same side?
274: not being allowed to access support strategies because it would be seen to be unfair on peers. Teachers concerned about how additional support e.g. breaks would be considered by peers? No attempt to explain W's needs to peers?
276: recognises what support she needs to access learning and that this may be different to peers.
276: Breaks/rest opportunities important

No support in school for fatigue
Adults don't understand impact of fatigue
Adult don't listen or act on request for help with fatigue
Strength to manage fatigue comes from within.
Feels unsupported with fatigue.
Adults tell W she isn't different to peers.
W feels different to peers
W identifies that she has less energy than her peers.
W Identifies that she needs different treatment to her peers at times.

Contradiction: I don't want to feel different but I need different things sometimes.
Contradiction from adults: You are the same as everyone else but you can't do these things.
Cognitive dissonance
Adults don't understand severity of CHC symptoms.
Adults lack understanding of CHC
Although teachers have 'heard' what she needs they haven't really listened or understood.
'Normal' daily activities extremely tiring

Adults don't trust her judgement of what she needs.
Adults tell her she is no different to others.
Adults don't make accommodations because it would be 'unfair to peers'.
Requires regular breaks throughout the day.
Breaks not always available

Line	Transcript
285	meet up with them but <u>its</u> just the things they want to do like all they
286	want to do is just go to town and like town isn't really a safe space for
287	me because I will get picked on and it just (-). They try and make <u>it,</u>
288	they try and make it easy but not boring if that makes sense. (- -)
289	I: Yeah. Ok (-<u>) and</u> what about in school? How do your friendships
290	work in school?
291	W: Umm In school I don't really see my friends because <u>I,</u> at break
292	time I go to this room because it is a bit quieter and its easier for me.
293	And <u>also</u> at lunchtime I do the same because like er at lunchtime they
294	are all in side and it gets busy it gets loud and I cannot stand that. And
295	obviously at breaktime if they want to go outside and I don't like
296	going outside because it just doesn't feel (- -)Because I'm (--(I'm on
297	my own when I am outside because people are running about and
298	people are doing all that and I can't really do that (-) It just (- - - -) I
299	think it just (- -) It just gets to me a bit as I want to be able to be
300	outside and stuff but I think my confidence is why <u>its</u> like that.
301	I: <u>So</u> at the moment you are inside? Are you with a TA or do you have
302	<u>any friends</u> with you or?
303	W: <u>Yeah Im</u> with. There are some other, there are some other people
304	in <u>there</u> but they are not really friends. They are just people who have
305	a disability or have autism or something like that (<u>-</u> - -) <u>Its</u> not like.
306	Cos like before I, I would be able to take a friend in with me but now
307	I'm not allowed.
308	I: And when you could take a friend in, how was that?
309	W: (- - -) That was better (- - - - -) <u>ummm</u> (- -) but the problem was that
310	I would feel guilty because I <u>was.I</u> thought that they wanted to do
311	something else. (- - -).
312	I: Right. <u>So</u> did you decide you weren't going to bring a friend or was
313	that a decision school made?
314	<u>W:I</u> think it was partly me and partly the teachers and stuff like that,
315	because obviously they are trying to get people to have as much fresh
316	air as possible um but er I think it was their decision.
317	I: Right ok <u>But</u> break and lunchtime is something you find difficult at
318	school? <u>Its</u> hard for you?
319	W: Yeah.

Middle column (annotations):

286: CHC impacts on friendships

288: Fatigue impacts on friendships and access to activities outside school. <u>Have to</u> turn down activities outside school with peers.

290: Feels different to peers- cannot take part in same activities?

290: Loss of normality? cannot access preferred activities, those that peers are taking part in.

292: W worries about bullying and negative reaction from others about her CHC.

292: CHC makes her feel unsafe in some situations?

293: Friends supportive and inclusive, try to include W in activities

293: Sense that W feels a burden of friends? That she impacts on what activities they can do?

296: Limited opportunities to spend time with friends in school.

298: Accesses alternative breaktime arrangements, away from friends

298: 'this room'- feels stark and depersonalised. No sense of fun and enjoyment in description.

298: Noise at lunchtime a barrier to accessing mainstream activities.

298: room- quieter and easier- but not fun and enjoyable for lunch/break. Sense that needs have outstripped wants at this point.

300: Pauses, unfinished sentences-Difficult to explain why <u>doesn't</u> like to go outside.

300: Sense that outside feels unsafe?

301: No support outside at breaktime- W wants this? Would help her to feel safe?

303: Feels different to peers- physical differences- <u>can't</u> join in with 'normal' playground games. Loss of normality?

304: Pauses- difficulty to discuss impact on feelings.

304: gets to me- upset, hurt, internalising feelings of being different/loss?

305: Wants to be able to join in with peers.

305: Lacks confidence in her own physical abilities/capability to keep herself safe in busy environment.

309: Impacts on friendships as breaktimes ate spent with others who have needs /'disability' but <u>aren't</u> considered friends.

310: Pupils with disabilities separated from non-disabled pupils at lunchtime. Exclusion. Feels isolated/separated from other peers?

310: something like that'- sense that all different disabilities have been considered together without much through from adult about what the YP in the 'room' would like/enjoy/get on together.

310: Wanting to be part of 'friends' but feels that others view her as "disabled"- how she views her identity vs. others perception.

312: Pauses, repetitions- upset/frustrated explaining this.

312: "not allowed" to take a friend- sense of being 'kept' away from friends

312: Power with adults, no consultation- lacks voice- decisions being made without W's input/ideas.

Right column:

<u>Emergent Themes</u>

CHC impacts friendships.
Fatigue impacts on friendships.
CHC impacts on engagement in activities with peers outside school.
Loss of normality
Concerned about negative reactions from peers.
Concerns that others will 'pick on' differences.
Fear.
Feels <u>unsafe</u>
Friends supportive and inclusive
Feels guilt at imposing her CHC on <u>friends</u>
Loss of opportunities to interact socially outside <u>school</u>
CHC limits independence outside school.
Loss of opportunities to interact socially in <u>school</u>
CHC impacts break and lunchtimes.
CHC impacts ability to access playground.
Noise difficult to be in lunchhall/playground.
Lacks confidence in physical ability in the playground.
Does not feel safe in playground.
No support given to access playground.
Accesses SEND lunch club at lunchtime away from friends.
Lack of feasible options given for lunchtime.
Sad/ Hurt/Upset
Craves normality (playground)
Feels <u>excluded</u>
Feels isolated from peers.
Feels that others perceive her to be 'disabled'.
Adults label her as disabled.
Pupils with SEND/CHC lumped together, no consideration of individual differences.
Wants/needs/views not considered by <u>adults</u>
Lack of pupil voice.
Power with adults

Line	Transcript
320	I: Yeah. Ok. Ok. And what about? You mentioned about trips earlier.
321	Have you been on any trips with school?
322	W: err no, not in secondary. Not in secondary school no. In primary
323	they would always take extra precautions and but fair enough I
324	understand why they would have to do that but (-) when I (/) it just
325	meant That I would be unable_to run around in the playground or
326	climb the climbing frame that they have or just do general things that I
327	would want to do. I wasn't allowed to do but I think that is where I felt
328	a bit left out.
329	I: mmm yeah ok.
330	W: And I've been (_-_-) yeah (sigh) (- --)
331	I: but youv'e not been on any trips in secondary school?
332	W: No.
333	I: Is that because no one has been on trips? Has there not been any?
334	W: There was, there was like erm a trip in Year 7 that I could have
335	gone on and it was like a um trip to France (-) but it was like a lot of
336	walking and I wanted to do it but when I looked into it it would have
337	been too tiring for me to do, so I missed out on that one
338	unfortunately.
339	I: And how was that? How was it missing out? How did you feel about
340	not going on that trip?
341	W: Um (- - -) I felt a bit (- -) upset about it because umm (- -) I knew it
342	was going to be the only trip that I-that my mum was going to be able
343	to afford and I would have been interested in because I was doing
344	French anyway and I was like (- -) it would have given me a bit more
345	insight into what France is like and then I would have understood
346	French a bit more. Ummm so at first I did (-) At first I did think er it will
347	be, I am not missing out on anything but then when I saw the phots of
348	people that went. I was just like I wish I was one of those people that
349	went (- - --)
350	I: Right so that was really difficult?
351	W: Yeah.
352	I: Yeah. Ok. (- -) So I was just wondering about the school environment,
353	thinking about the classroom, the toilets, the medical room, the lunch
354	hall and things like that. Is there anything about that to talk about?
355	W: (- - - -) ummm I school is better than the other schools because our
356	school has had a blind kid there its had like loads of people there so it

Exploratory comments

320: Enjoyed spending time with friends during breaktimes

322: Pauses- difficult to explain feelings?

322: Guilt- imposing alternative playtime of peers- making them different because of her CHC? Sense that peers wanted to be out at breaktimes- feels she is imposing limitations associated with CHC on peers?

326: contradiction- starts as joint decision and by the end of the sentence is a teacher decision.

327: Discusses that teachers want peers outside- sense that this isn't truly believed? Teachers want others to have fresh air, but not her? Feels others needs more important?

327: Loss of power- Teachers hold power- voice/views not considered.

335: 'they'- me vs them?

335: extra precautions- overly cautious/protective? Not needed?

336: Fair enough- I understand why- does she? Sense that perhaps she does not agree with the extra precautions being taken?

336: Acceptance of adult intervention, even though not agreeing with it. Acquiesces. Coping strategy?

338: Adult intervention prevented her from joining in with peers/'normal activities'- made to feel different to peers- loss of normality?

339: Adult intervention/support prevents her from doing what she wants

339: Feels different to peers.

340: Sigh, pauses, unfinished sentences- difficult to talk about- difficult to explain impact/how she feels?

340:'left out'- Feels excluded?

346: Impacts on trips

346: Loss of opportunities- 'missed out'

350: 'unfortunately' very calm, 'adult' phrase to explain on missing out. Distances herself from feelings?

350: Acceptance/acquiesces- passive coping mechanism?

349: Fatigue impacts on access to trips

353: Feels upset at missing out- loss of normality?

Emergent themes

Guilt.
Loss of preferred activity.
CHC impacts friendships.
Need to balance physical limitations of CHC with peers wants/needs in friendships
Feels guilt about imposing limitations of CHC on friends
Questions friends motivation when providing support.
Lacks trust in teachers motivation.

Feels that staff place more importance of peers wellbeing.
Teachers don't want to be unfair to peers.
Views not being considered.
Power with adults.
Adults overprotective.
Adults treat her differently to peers.

Acceptance- coping strategy.
Acquiesces.
Loss of normality
Adult intervention highlights differences to peers.
Loss of preferred activities
Feels excluded.
CHC impacts on trips.
Loss of extracurricular opportunities
Takes on adult role.
Acceptance-coping mechanism?
Upset
Loss of normality

357 just like_so (--) they kind of know what they are doing, but like I said its
358 just like trying to understand what a disability is like for some other
359 people and what its like for others. Everyone is different and (- -) I think
360 sometimes they just seem to be like oh everyone is the same
361 In a disability place and it just. Sometimes I wish they would just
362 understand more.
363 I: So understand more about you and how you are different?
364 W: Yeah. Yeah about how I cope and (- -)
365 I: So for you its not really about. There aren't really any problems with
366 the school itself so there are toilets and plenty of room but it is more
367 about their understanding of you?
368 W: Yeah.
369 I: Yeah, Yeah Ok. So I was just wondering bout the school day then. Are
370 there any times in the school day that are difficult for you? You've
371 talked about lunchtime and breaktime but is there anything else you
372 find difficult or enjoy?
373 W: Because now we've got to line up outside. At first I was a bit like,
374 hold on. Have I got to do that? because normally I get collected form
375 the office. I would go to the reception area and wait for someone to
376 pick me up. So I was a bit nervous about that because I was wondering
377 what was going to happen. But then I found out that I would just do
378 what I normally do anyway and that was ok. But when at first when
379 people saw me walking up to reception I thought they think "oh, she is
380 skipping the line" or whatever because they have to wait in the rain and
381 I don't . I feel guilty because its just I don't want them to get wet and
382 stuff.
383 I: ummm has anyone ever said anything to you? Any difficult
384 conversations with other children in school?
385 W: Ummm (- - -) I think (-) Its not necessarily the children, it's the staff.
386 Umm But I have had dirty looks from the children (-) but I haven't had
387 like (-) I haven't had anything really bad.
388 I: And when you said its mainly the staff, what did you mean by that?
389 W: Like some staff are like "oh what are you doing inside" and stuff like
390 that and its just like the other week, see we have to wear face masks
391 but I, I'm exempt from wearing a face mask so I wasn't wearing a face
392 mask. And a member of staff came up to me and she was like "oh why
393 aren't you wearing a face mask?". At first I said I don't need to wear one
394 because of my hearing aids and she was like "oh are you sure about

359: tried to convince herself that she would not be missing out?
Avoids thinking about it?
360: Photos emphasised the fact that she feels different to peers?
360: Loss of experiences/normality?
361: longs for normality and to be able to access trips?

367: Comparison of her CHC to the 'blind kid'- contradiction to earlier where she emphasises differences in disabilities? 'loads of people (with disabilities?)- feels that strategies/support are all the same?
369: Places importance on understanding the individual- rather than the general needs? Person- centred practice important?
370: Wants adults to understand what it feels like to have a CHC. Places importance on this rather than the practical resources/ supports in place?
372: Understanding the individual important- not everyone is the same. Sense that school &the staff currently don't do this?
372: Wants staff to have more understanding of individual's needs.
376: Wants staff to understand how she 'copes' with CHC

386: Alternative collection routines in place at start/end of day helpful
387: Collected from school- increase parental involvement? Highlights differences with peers? Loss of normality?
389: Changes to routine cause anxiety
389: Changes to routine not always communicated well.
391: Aware of other people's perceptions- that others might perceive her as different or getting preferential treatment?

Emergent Themes

Avoidance.
Loss of opportunities
Loss of normality
Craves normality
Craves access to activities.
Missing out on trips/extracurricular activities emphasises differences.
Identity: CHC as a disability
Understanding individual needs important.

Wants adults to understand individual needs
Wants adults to understand impact of CHC.
Places importance on pastoral support from adult.
Important for staff to understand the individual impact of CHC on wellbeing.
Important for adults to understand coping strategies.

Physical support: alternative collection/drop off routines.
Alternative collection routine highlights differences with peers.
Increased parental involvement in school day.
Feels that peers may feel she is receiving preferential treatment.

Line-numbered transcript	**Exploratory comments**	**Themes**

395 that?" and then luckily one of my other teachers yeah, she she came
396 across and said "what are you asking?" and then she, she was like "oh
397 she doesn't need to wear a face mask and she has like a lanyard thing"
398 and but it just sort of- what, what would I have said if that TA hadn't
399 have come up when she did because I always (/) so I just (/) thankful
400 that she.
401 I: Sorry it cut out a little bit then- where you saying you were thankful
402 that the TA came when she did?
403 W: Yeah. Yeah.
404 I:Ok have you had any other situations like that in school that you would
405 like to talk about?
406 W: (- - - -) errrm I don't think I can remember cos I've been at the school
407 4 years and looking back on...
408 I: Yeah its hard to remember isn't it? (laughs)
409 W: (Laughs) Yeah
410 I: Ok. So Shall I put the picture back up again just to remind ourselves
411 and see if there is anything else we need to talk about?
412 W: Yeah
413 I: Hang on a minute I'll put it back up. (- - -) hang on (- - - - - -) Do you
414 know I wish I was quicker at this! I'm trying (laughs)
415 W: (Laughs)
416 I: Can you see now?
417 W: Yeah
418 I: So we have talked a little bit about your likes and dislikes, your
419 attendance, learning in class, You've talked about your TA adults in
420 school- are there any adults who you feel we haven't talked about?
421 W: (- - - - -) nah
422 I: We've talked a little bit about relationships with other students and
423 your friends (- - -) and facilities in school you said you felt ok, you didn't
424 really have anything about that. Um we talked a little bit about the
425 school day but is there anything else? The morning before you come to
426 school? That you need to think about? That would be important to talk
427 about?
428 W: No.
429 I: No Ok. So there are two bits left on here. One was about the future.
430 How you feel about future plans for your education and what you want
431 to do.

Exploratory comments

392: Feeling of guilt when being treated differently to peers

397: Difficult conversations with staff about being 'treated differently'
398: Peers don't say anything but give 'dirty looks'

401: Staff not all aware of CHC & support in place
401: Staff openly questioning support strategies in front of others
404: Staff challenge/ 'tell off' as not the same as peers
408: Sense of being protected by those staff who have knowledge?

410: 'thankful'- situation anxiety provoking- sense that she was 'saved' by staff member who knows her and understands her CHC.
Felt scared/upset/shocked? Felt unable to explain herself?
410: W doesn't feel that all staff trust/believe her when she is being treated differently?
410: COVID has highlighted another difference-between her/her peers- not wearing a mask.
'

Themes

Feels guilty

Some Peers have given dirty looks.
Some peers feel support is 'unfair'.
Some adults not accepting of support in pace.
Some adults feel support is unfair to peers.
Some staff challenge W about support in place
Some staff 'protect W

Feeling anxious
Feels scared.
Feels grateful for support from staff.
Feels staff do not trust her.
Not wearing a mask highlights difference.

Transcript	Exploratory comments	Emergent Themes

432 W: Yeah. Umm so when I leave um secondary I am going to go onto
433 college. er The worry for me at college is obviously if I've got everything
434 that I need like support wise and accessibility and stuff like that. I have
435 to use the lift, um so its just making sure I've got all that. And then
436 obviously when I go into uni the big worry is around making sure that
437 I've got the right support and the right accessibility and I've just er. Er.
438 It's a bit of worry because that's what I don't want, to be excluded from
439 what I want to do. Um, um I want to be able to do the stuff that I've
440 wanted to do my whole life what I haven't been able to do yet. Its just
441 trying, making sure that I've, that I do get to that stage where I feel that
442 I've achieved everything.
443 I: And what is it you want to do at university?
444 W: I want to study law.
445 I: You want to be a lawyer? Do you know what kind of law?
446 W: I would like to be a human rights lawyer.
447 I: Ok wow. Hard work then!
448 W: (laughs) yeah.
449 I: So just thinking about everything we have spoken about. The whole
450 point of this was to try and get your point of view about what school is
451 like for you. You've told me lots about how school is for you but is there
452 anything else that you would like to tell me about?
453 W: Umm (- - - -) err probably that there never seems to be any support
454 groups in school it always has to be outside of school. Because there
455 are support groups of people who have been through some tragic
456 things which is good but there never seems to be any support group
457 about disabilities or about how I am coping or anything like that. Its
458 always got to be me going to the teacher if I feel like something is
459 wrong. Whereas that can get a bit (-) I wouldn't have time to do that or
460 it would just feel like I was bothering the teachers. So it would be nice
461 to have a support group in school and not have to go to ones outside of
462 school.
463 I: Would that be with other pupils or would that just be time with a
464 teacher. What would that look like?
465 W: Probably both. Maybe have a 1:1 at least once a week or have a
466 group a least once a week. Just be able to express how you feel without
467 being judged. (- - -_
468 I; mmmm ok. So that would be something that would make it better for
469 you at school?

Exploratory comments:

444: Future hopes to attend college
445: concerns about support in place for further education
447: Currently uses lift in school.
448: Future hopes to attend university
449: Wants to ensure support and accessibility for future education
450: Worries about being excluded
450: Worries about not being able to access education to ensure that she can achieve future hopes
453: Wants to feel sense of achievement.
453: Does not want CHC to impact on future achievement

465: Wants support groups with other peers with CHC in school
466: Feels support groups are available to other marginalised groups but not peers with HC.

Emergent Themes:

Wants to attend college
Wants to attend university
Concerns about support in future education
Concerns about accessibility in future education.
Concerns about being excluded in further education.
Concerns that CHC will impact on future goals

Would like further peer support groups.
Would like peers support groups for YP with CHC
Limited support available for those with CHC in school
Support generalised- nothing available specifically for CHC.

Line	Transcript
470	W: Yeah. Yep,
471	I: Is there anything else at all?
472	W: Yeah. When there is a problem and I go and speak about it but when
473	I eventually do speak about it the teachers, the teachers always seem
474	to be annoyed at me. because I haven't brought it up the first time it
475	happened. But then there is a reason for why I didn't bring it up the first
476	time it happened, because I don't feel its something that big that needs
477	to be brought up or I feel uncomfortable bringing it up because I would
478	feel awkward and I, I don't want to feel like that because its not my fault
479	if I feel like that because I always feel annoyed with me if I don't bring
480	it up the first time and that can get to me a bit.
481	I: so feeling like ummm it would be useful to feel comfortable enough
482	to be able to bring things up and then when you do bring things up
483	feeling like people aren't annoyed with you then. That's important to
484	you?
485	W: Yeah.
486	I: Yeah OK. I've got one more question if that's alright?
487	W: Yeah
488	I: And it kind of links in with some of the things you've said already but
489	if I had a magic wand and could make the perfect school for you and it
490	could look however you want. What kinds of things would be really
491	important to have in the school for you?
492	W: (- - - -) errr Like I said probably understanding teachers, um a PE that
493	is less tiring or I could have a break if I needed one or I could umm (- -
494	)have proper Physio like I used to because I don't have physio anymore.
495	I should be having I should be doing it it at home but I don't because
496	I'm too tired and I just can't. do it so I just, It would be nice to have
497	some proper physio because I used to go to group outside of school
498	with some other kids and be able to do some fun physio, but we , I don't
499	do that any more. Errm so it would be nice to also have at least a group
500	everyday or something like that. It would be nice to have a room I could
501	take my friends so I could talk to them. Ummm (- -) it would be nice to
502	(/) now we aren't allowed to cross bubbles but most of my friends are
503	in the year below me so it ould be nice to be able to (/) (/)
504	I: spend some time with them?
505	W: Yeah. (- - -).
506	I: It been fa tatsic to talk to me today and there are lots of things you
507	have told me. Thank you so much for talking to me and being so open

Exploratory comments

468: Wants opportunities to discuss coping strategies with peers
470: Feels that support to talk never offered- always has to be sought.
472: Feels guilt? For 'bothering' teachers when asking for opportunities to talk about how she feels

473 : Wants additional support to talk with peers and adults.
479: Wants to discuss feelings/thoughts without judgement. Feels judged by others at other times?

484: Will seek help with 'problems'
486: Teacher annoyed when W seeks help as she has not brought it up before and they feels she has waited too long?
489: Can feel uncomfortable seeking help from adults in school to deal with 'problems'
490: Feels awkward/embarrassed seeking help from adults in school
491: Wishes she doesn't feel embarrassed awkward
491: repetition that teachers are annoyed- emphasis

504: Wants further understanding form teachers
505: Wants reduction in PE lessons to reduce fatigue
505: Wants additional breaks when requests them

Emergent Themes

Would like to share coping strategies
Has to seek emotional support from adults, not offered.
Feel guilty
Doesn't want to seek adult support.
Doesn't trust that adults want to help.
Doesn't believe adults in school have time to support emotional needs.
W

ants adults to offer help without having to seek it.
Wants support group in school.
Wants support without feeling judged.
Can feel judged by adults when seeking help.
Can feel teachers are frustrated when she seeks help.
Can feel uncomfortable seeking help from adults in school.
Feels embarrassed seeking help.

Wants teachers to understand CHC
Wants teachers to understand her as an individual.
Wants less PE sessions to reduce fatigue.
Wants more breaks to reduce fatigue.

		Exploratory comments		Themes
508	in explaining the things that are important to you. I just want to check			Would like further support for physical needs
509	that there isn't anything else you would like to talk about today?	506: Wants physio		
510	W: No			Wants peer support group.
511	I: Have you got any questions for me or anything you aren't sure about?	506: no longer has physio in school		
512	W: No, not really.			Wants to access friends at breaktimes.
513		512: Wants access to group support with peers		
514				
515		513: Wants room in which friends can access at breaktimes so they can have opportunities to interact.		
516				
517		515: Friends in year group below in school		
518				
		515: Impact of COVID on friendships		

Appendix 22: Exemplar Theme Table & Illustrative Quotes: Amber

Superordinate themes	Subordinate themes	Emergent themes		Page/line	Key phrases
Autonomy	Lack of person-centred practice	Lack of pupil voice	Voice not heard	356	"I am not being listened to."
			No consultation with A.	420	"…do they ask you? A: No."
			No input into TA support allocation	210	"it's just whenever they can"
		Lack of understanding of individual needs	Teachers lack person-first approach.	391 412	"…bend down to talk to me". "if they are taking me to a place they just grab my wheelchair and start pushing me."
			Feels some teachers treat her as a child.	397	"…got a child you do that"
	Lack of Control	Power with adults	Balance of power with adults	27 24 79	taken away "…held back." "Push me"
				235	"…she sends me home"
		Limited choice	Lacks choice	310	"…because I want to do something else other than school, but I can't"
		Feels helpless	Feels helpless.	351	"I wanted (/) to change for a while now but they haven't done anything about it."
	Lack of Independence	Independence	Loss of independence	415 423	"It is taking away my rights to do it myself." "Its like I can't do that."
			Seeks independence	422	"I like doing stuff for myself."
			Frustrated at lack of independence	400	"- Its quite annoying. (- -)"
	Feeling empowered.	Sense of control	Taking back control	97	"…got out at one point"
			Asserting independence	397	"I am not a child anymore"
			Collaborative decision making	256	"Did you decide that? A: Well, um it was both me and my mum"
			Proactive management of fatigue	244	"…attendance is really important but um I have to I have a day off every two weeks."

Superordinate themes	Subordinate themes	Emergent themes		Page/line	Key phrases
Relationships & Belonging	CHC impacts. Relationships With adults	Adult's lack of understanding impacts on relationship	Staff not considering reasonable adjustments	334	"I want to say something like moving chairs"
			Teachers lack understanding	391	"…sort of always bend down to talk to me"
			Feels some teachers treat her as a child.	397	"If you've got a child, you do that"
			Lack of awareness/understanding from staff.	413	"…they just grab my wheelchair and start pushing me"
		Lacks trust in supporting adult's motivation	Questions teachers' motivation for support.	369	"…they don't want to do anything that cause problems."
			Feels teachers don't want to be involved in CHC management.	369	"I: …so they- A: Have a peace and quiet"
			Teachers take a "hands-off" approach	368	"Teachers are quite (/? Chill)"
		Risk adverse staff/professionals	Risk averse staff/professionals	39	"…for like safety reasons"
			Overprotective staff	40	"I had (/ ? to) (/? go) IR for lunch"
			Staff fear of serious implications if CHC not being manged.	37	"…possibility of me choking."
	Support provided by adults.	Supportive adults	Teachers provide practical support with equipment.	171 / 213	"…the teacher helps me out with get stuff". / "…help me get out stuff"
			Finds practical support from teachers helpful.	182	"…yeah, It is quite helpful"
			Likes adult support in school.	191 / 194	"…some people that help me around school". / "…they help me. That helps me"
			Teachers Support with workload	371	"…repeat work so I don't have more work"
			Some Supportive staff	379	"…my English teacher is really supportive"
			Some teachers supportive with learning	476	"Some teachers that are really nice about work"
			Some teachers accepting	477	"Some teachers are more accepting of it."
			Teachers provide verbal support for missed learning.	**272**	"…the teachers have to talk to me a lot more"
		Lack of support from adults	Feels teachers cannot provide much support.	177	"…not much else that they can do"
			Feels teachers limited in type of support they can provide.	176	"…apart from that sort of thing"
			Some teachers frustrated and angry when work not completed.	482	"…they are annoyed because I can't do much"
		Inconsistent TA support	TA support inconsistent	192	"…work with me sometimes"
			Lack of clarity around TA role	214 / 193	"…probably help". / "…kind of work with me"
			TA support in lessons more inconsistent.	201	"…someone who comes in every so often"
			Not aware of when TA support will be available.	210	"It's just whenever they can."

			Has keyworker	197	." I have a key worker"
			Keyworker supports to problem solve	198	"…when I am in trouble"
			needs to initiate emotional support- from adult	198	"I can go"
			Keyworker accessible throughout day	197	"…throughout the school day"
		Staff provide Emotional support	Emotional support- talking/problem solve	199	"…talk to them"
			Emotional support from TA- check in	225	"make sure (/ ?I) (/? feel) (/? comfortable?"
			Keyworker supports with attendance	229	"…makes sure that I can go to school as much as possible"
Relationships & Belonging (Cont.)	Support provided by adults (Cont.)		Keyworker has good understanding of CHC	228	"…she knows that I um I have fatigue"
		Health professionals as experts	Other professionals involved in school day	36	"…speech therapist"
			Limited relationships with health professionals	39	"…she said"
			Teachers lack power- power with health professionals. Health professionals as experts- not teachers.	74 78	"…and they can't do anything about it. they've tried different things, but it hasn't"
			Health professionals have 'power' make decisions over school staff.	39/40	"for like safety reasons I had (/ ? to) (/? go) IR for lunch"
		Support for learning: staff	Teachers provide practical support with equipment.	171	"…teachers help me out with get stuff"
			Practical TA support- scribe	214	"…hand hurting. they would probably help me"
			Practical support TA- organisation	220	"…making sure that I've got my work"
			Teachers provide verbal support for missed learning.	272	"…the teachers have to talk to me a lot more"
			Practical support from TA with 'keeping up' with work	223	"…making sure that I can keep up with the schoolwork "
			Practical support: printed information.	380	"She prints them off for me."
			Practical support: reducing writing load	383	" So I am not writing everything down.

Superordinate themes	Subordinate themes	Emergent themes		Page/line	Key phrases
Relationships & Belonging (Cont.)	**Feels different**	Comparison to peers	comparison to peers: Learning	266	"…everyone is getting on with the work more now… than I am getting on with it"
			Comparison to peers: more work at home	310	"I have to do more work at home"
		Management of CHC highlights difference	Treated differently to peers.	103	"…people without disabilities can't really go in"
			Exclusion of 'disabled' students.	10	"…just for disabled people."
			Adults involved with managing friendships.	97	"…push me towards to being friends more with disabled people"
			Catching up on missed learning at home leads to loss of preferred activities	310	"I want to do something else other than school, but I can't"
			Wheelchair highlights difference.	329	"…go round it with the wheelchair"
			Feels excluded/ isolated at lunch	29	"…I couldn't sit with my friends at lunch."
			Teachers' response (bending down) highlights difference to peers.	391	"…bend down to talk to me which is quite annoying"
			Frustration around being kept from peers	44	"(deep breath) it's hard"
	CHC impacts. relationships With peers (Cont.)	Feels excluded by peers.	Feels excluded/ isolated at lunch	29	"…I couldn't sit with my friends at lunch."
			Feels excluded	48	"…they want to sit with the other people
				65	More like different friends"
			Friends choosing to break over time with A.	83	"Friends wouldn't come up with me"
			Friends choosing other relationships over A	84	"Come up with their friends"
			Friends developing other relationships in her absence	47	"They want to sit with their friends"
		Limited opportunities for connection with peers	Health condition limits tie with friends	55	""They are not in my lessons all the times so I only had dinner times to speak to them"
			Lost time for connection with friends.	31 46	"haven't been speaking to them as much as I wanted."' "I didn't talk to them as much"
			Limits opportunities for connects with 'non-disabled' peers	108 109	"It's also hard for me to make other friends outside of the IR (Integrated Resource room)"
			Loss of time with friends in school impacts on relationships at home.	64	"…if you are not speaking to them inside school, you are not going to speak to them much outside"
			Seeks further opportunities for connection with peers.	464	More staff in the dinner hall so I do not have to stay away from my friends.
			Opportunities to connect with friends only in lessons	119	have like English together and we sit together in English
			Adults involved with managing friendships	97	"…push me towards to being friends more with disabled people"

				Page/line	
Relationships & Belonging (Cont.)	**CHC impacts. relationships With peers (Cont.)**	Management of CHC impacts on peer relationships	Management of CHC impacts on interaction with peers	29	Being held back from friends"
			Lunch club a barrier to developing wider friendships.	108	" …hard for me to make other friends outside"
		Supportive relationships with peers	Has friends at school	30	I've got quite a few friends
				53	"…actually (/) different friends in lessons"
			Supportive friendships in school.	113	"…really good friends with me"
			Feels accepted and understood in relationships with other peers with a disability.		"…really friendly and nice to me all the time."
			Friends don't view 'differences	129	"…they just treat me like I'm a friend, not like they are forced."
			Friendships important	474	"Having my friends around me."
			Differentiates between 'disabled' and 'non-disabled' friends.		"…friend who has also got a disability"
		Others view of Identity beyond CHC & disability	Disconnect between others perceptions and self-identity	98	"…push me towards to being friends more with disabled people."
			CHC considered a 'disability' by staff	108	"…safe space for people with disabilities and I go there."
			Teachers unable to see identity behind the CHC/disability.	393	"…bend down to me"

Superordinate theme	Superordinate themes		Emergent Themes	Page /line	Key words
CHC impacts emotional well-being at school.	**Experiences Undesirable Emotions**	Undesirable emotions	Sad	497	"Do you think your health condition affects the future for you. A: yeah. (- -) (sniffles)"
			Frustration	407	"Its quite annoying"
	Coping mechanisms	Problem-focused coping	Coping strategy: Proactive strategies to manage fatigue	254	"It's to stop me being tired."
			Coping strategy: controlling attendance	256	"Um it was both me and my mum because on the fatigue days"
	Loss of normality	Physical losses	Loss of independence	415	"It is taking away my rights to do it myself."
			Loss of preferred activities	310	"I want to do something else other than school, but I can't"
			Loss of time with friends	64	"…if you are not speaking to them inside school you are not going to speak to them much outside"

Superordinate themes	Subordinate themes	Emergent themes		Page/line	Key phrases
Navigating the school day: the functional impact of a CHC.	**Physical symptoms of CHC impact on school day**	Fatigue impacts attendance	Fatigue accumulates over the week.	164 239	"Towards the end of the week is quite hard". "Thursdays and Fridays I get that tired"
			Fatigue impacts on attendance to school	166	"…going to school every day is hard."
			Balance between fatigue and attendance	229	"…go to school as much as possible without tiring myself out too much".
			Sent home when fatigued	234	"…send me home"
		Fatigue impacts learning	Fatigue impacts learning.	480 484	"…just get to the point when I can't do much work". "if I get tired and stop doing it."
			Fatigue impacts ability to access lessons	148	"…hard for me to go to the lessons with fatigue. "Going to the lessons really tired"
			Fatigue impacts learning/ability to 'keep up'	153 155	"…hard for me to keep up with the work". "Hard to keep up, yeah."
		Managing fatigue	Coping strategy: Proactive strategies to manage fatigue	254	"It's to stop me being tired."
			Coping strategy: acceptance and control	256	"Um it was both me and my mum because on the fatigue days"
			Fatigue improving	237	"I don't get that tired as a much."
		Daily impact of fatigue	Fatigue overwhelming and powerful	8 437 442 448	"Monster in the background is fatigue". "It overpowers everything else." "…like a monster" "Its like leaning over. Its like coming over"
			Fatigue a barrier to everyday life	443	"It takes away my ability to do anything else"
			Constant Fatigue	9	"Every day"
		Mobility	Mobility	171	"can't move around."
			Fatigue impacts mobility	256/257 328	"…on the fatigue days its quite hard to like move around". "I get really tired I can't walk as well"
			Use of wheelchair difficult	329	(- -) Its quite hard.
	CHC limits social and extracurricular opportunities in school.	CHC impacts break and lunchtimes	CHC impacts on lunchtimes.	27	"…taken away from the lunch hall."
			CHC impacts lunch/ eating	37	"…possibility of me choking"
			Break/lunch in 'club' away from peers	101 103	"…I go there at breaktime and lunchtime". people without disabilities can't really go in there
			Some supportive aspects to lunch club	108	"…its good"
		CHC impacts on practical activities at school	Health condition impacts mobility.	257 328	"…on the fatigue days its quite hard to like move around"

					"…but then I get really tired I can't walk as well"
			Mobility needs impact on access to practical lessons- science.	171 172	"Science is hard because of the practical stuff." "you've got to move around the lab"
			Adult support in science lessons due to mobility needs	213	"…science they would help"
			Wheelchair required at times	329	"…go round it with the wheelchair."
			CHC causes pain in hands		"…my hand is like hurting"
Navigating the school day: the functional impact of a CHC. (Cont.)	**CHC Impacts Learning**	Missed learning	Missed learning	248 273	"…quite a lot of work that I miss out on". "I have missed a lot of work"
			Frustrated at missing work	248	- "It annoying"
			Missed learning increasingly important as gets older.	261	"Missing out on work is quite important now."
			Missed learning- concerns about exams.	262	"…getting close to my GCSE"
			Concerns about keeping up	264	"…miss a lot of work it er can't it's"
			Missed learning impacts on attainment/ exams/results.	265	"a problem when I get to GCSEs"
			Missed learning comparison to peers	266	"…everyone is getting on with the work more now well more than I am getting on"2
			Overwhelm: missed learning	279	"…there is a lot of work to do"
			Missed learning: sometimes impacts on understanding in class.	285	"I: you know what is going on? Or- ? A: sometimes"
			Understanding depends on amount of learning missed.	287	"…depends how much of that lesson I've done that day"
			Seeks reduction of workload	471	"…less work to do"
			Heavy workload in lessons.	143 146	"…lessons have got quite a lot of work." "…lots of work"
		Catching up on missed learning.	Practical support from TA with 'keeping up' with work	223	"…making sure that I can keep up with the schoolwork"
			Teachers provide verbal support for missed learning.	**272**	"…teachers have to talk to me a lot more"
			Concerns about keeping up	264	"….miss a lot of work it er can't it's"
			Catching up difficult	277	"…quite hard"
			Catch up/keep up cycle.	291 295	"…if I have a lot of days off its quite hard to catch up with work" "If there there is a lot of work it gets a lot harder."

			Catching up sometimes done at home	292	"…done at home"
Navigating the school day: the functional impact of a CHC. (Cont.)	**Impacts learning (Cont.)**	Catching up on missed learning (Cont.)	Catching up sometimes done at school	293	"…have to do in classrooms"
			Catching up with missed work impact on home life.	292 303 310	"…quite a lot, a lot to do at home". "It just feels like more work at home". "I have to do more work at home."
			Boundaries between home and school blurred due to 'catching up'	301	"…its supposed to be like a place away from school"
	CHC Impacts Attendance	Impacts Attendance	Attending school important to A.	243	"(/) attendance is really important"
			Regular time off school to manage fatigue.	244	"…have to I have a day off every two weeks."
			Frustrated at missing school.	309	"Its annoying"
			Difficult to return to school after time off	277	"Quite hard"
	School Environment	Limitations of the physical environment	Physical environment not big enough for wheelchair.	315 329 460	"…not really made for wheelchairs". "…try and go round it with the wheelchair". "Making school bigger. Making it all bigger." "Bigger classrooms because some are small and hard to get around."
			Physical environment: classrooms	318 322	"Some classrooms are kinda hard." "classrooms have put in rows of chairs"
		Lack of Reasonable adjustments	Physical environment: seating	320	"hard to get out of a wheelchair to get into your seat"
			Reasonable environmental adjustments not in place.	335 344	"moving chairs a bit more but because I just can't just get round"
		Support for learning: environment/ Equipment	Safe space available at lunchtime	100	"IR which is like a safe space"
			Support for learning: laptop	157	"I've got a laptop ..do work on that if its harder."
			Laptop used occasionally.	159	"in some lessons"
			Laptop sometimes helpful	161	"I:helpful thing that's been? A: yeah."

Superordinate themes	Subordinate themes		Emergent themes	Page/line	Key phrases
Planning for the future	**Future goals**	Setting goals	Identifies future goals.	492	"…something to do with art"
			Identifies preferred activities/hobbies.	493	"…because I like "
	Concerns about the future	Concerns about the future	CHC impacts on planning for future goals. Difficult to talk/think about future.	493	"I; Do you think your health condition affects the future for you. A: yeah. (- -) (sniffles"
			Upset Sadness	500	"is it too difficult? Do you want to leave that question? A: Yeah"
			Difficult to think about future.	492	"Have you thought more about that? A: no, not really."
		Concerns about Exams	Concerns about GCSEs	265	"a problem when I get to GCSEs"
				262	"…getting close to my GCSE"
		Concerns about future impact of missing learning	Increasing impact of CHC on learning.	261	"….missing out on work is quite important now."

Appendix 23: Cross Participant Analysis Table, showing Convergence and Divergence across the super and subordinate themes.

Participants	Autonomy				Relationships & Belonging.					Navigating the school day, the functional impact of a CHC.					CHC impacts emotional well-being at school.				Planning for the Future	
	Lack of person-centred practice.	Lack of control	Lack of Independence.	Feeling empowered.	CHC impacts relationships with peers.	CHC impacts relationships with adults	Feeling different.	Support provided by adults.	Conflict with adults.	CHC Impacts learning	CHC Impacts attendance	CHC limits social and extracurricular opportunities in school.	Physical symptoms of CHC impact on the school day.	The school environment.	CHC impacts Self-esteem.	CHC results in undesirable emotions being experienced in school.	Loss of Normality	Coping mechanisms	Setting goals	Concerns for the future
Willow	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓
Samuel	✓	✓	✓	✗	✓	✓	✓	✗	✓	✓	✗	✓	✓	✗	✓	✓	✓	✓	✓	✗
JJ	✓	✓	✓	✗	✓	✓	✗	✓	✗	✓	✓	✓	✓	✓	✓	✓	✗	✓	✗	✗
Autumn	✓	✓	✗	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✗	✗
Amber	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓

Appendix 24: Overview Theme Table: All Participants

Superordinate Themes	Subordinate Themes	Key phrases
1. Autonomy	1.1 Lack of control. 1.2 Lack of person-centred practice. 1.3 Lack of independence. 1.4 Feeling empowered.	**Willow-** "Everyone is different and (- -) I think sometimes they just seem to be like oh everyone is the same". **Samuel-** "They feel that I can't manage it myself". **JJ-** "No. They just chose it". **Amber-** "It's taking away my rights to do it myself." **Autumn-** "I have to control the diabetes"
2. Relationships and Belonging	2.1 CHC impacts relationships with adults. 2.2 Conflict with adults. 2.3 Support provided by adults. 2.4 CHC impacts relationships with peers. 2.5 Feeling different.	**Willow-** "don't want to be treated differently to everybody else but sometimes I need to be treated differently". **Samuel-** "she is worried that you know she is going to get blamed if something goes wrong". **JJ-** ""Kinda sad cos a lot of my friends are doing PE". **Amber- "**they push me towards to being friends more with disabled people". **Autumn-** "None of the teachers are really helpful"
3. Navigating the school day, the functional impact of a CHC.	3.1 CHC impacts learning. 3.2 CHC limits social and extracurricular opportunities in school. 3.3 CHC impacts attendance. 3.4 Physical symptoms of CHC impact on the school day. 3.5 The School environment.	**Willow-** "I don't always manage to catch up on stuff". **Samuel-** "I missed a lot of time". **JJ-** ""I just forget what happens." **Amber-** "I couldn't sit with my friends at lunch." **Autumn-** "make me like (- -) I can't really concentrate"
4. CHC impacts emotional well-being at school.	4.1 CHC impacts self-esteem. 4.2 Loss of normality. 4.3 CHC results in undesirable emotions being experienced in school. 4.4 Coping mechanisms.	**Willow-** ""I would feel awkward". **Samuel-** "it's annoying…it's pointless". **JJ-** "basically I am really bad". **Amber-** "It's annoying" **Autumn-** "I just get frustrated"
5. Planning for the Future.	5.1 Setting goals. 5.2 Concerns for the future.	**Willow-** "to do the stuff that I've wanted to do my whole life what I haven't been able to do yet". **Samuel-** "Going to try to (- -) not involve T1D in my future". **JJ-** "I really want to do PE but I'm not going to do it." **Amber-**"a problem when I get to GCSEs"

Appendix 25: Overview Theme Table, Links to SDT: All Participants

IPA Superordinate Theme	IPA Subordinate Theme	Links to Self Determination Theory (SDT) (Deci & Ryan, 2017)
1. Autonomy	1.1 Lack of control. 1.2 Lack of Person-centred practice. 1.3 Lack of Independence. 1.4 Feeling empowered.	Autonomy
2. Relationships and Belonging	2.1 CHC impacts relationships with adults. 2.2 Conflict with adults. 2.3 Support provided by adults. 2.4 CHC impacts relationships with peers. 2.5 Feeling different.	Relatedness
3. Navigating the school day, the functional impact of a CHC.	3.1 CHC impacts learning. 3.2 CHC limits social and extracurricular opportunities in school. 3.3 CHC impacts attendance. 3.4 Physical symptoms of CHC impact on the school day. 3.5 The School environment.	Competence No Link to SDT, identified as 'Biological' factor. No link to SDT, identified as 'Environmental' factor.
4. CHC impacts emotional well-being at school.	4.1 CHC impacts self-esteem. 4.2 Loss of normality. 4.3 CHC results in undesirable emotions being experienced in school. 4.4 Coping mechanisms.	Can link to Autonomy, Relatedness, or competence dependent on context.
5. Planning for the Future	5.1 Setting goals. 5.2 Concerns for the future.	Competence

Appendix 26: Reflective SDT framework for analysing subordinate themes (enlarged version).
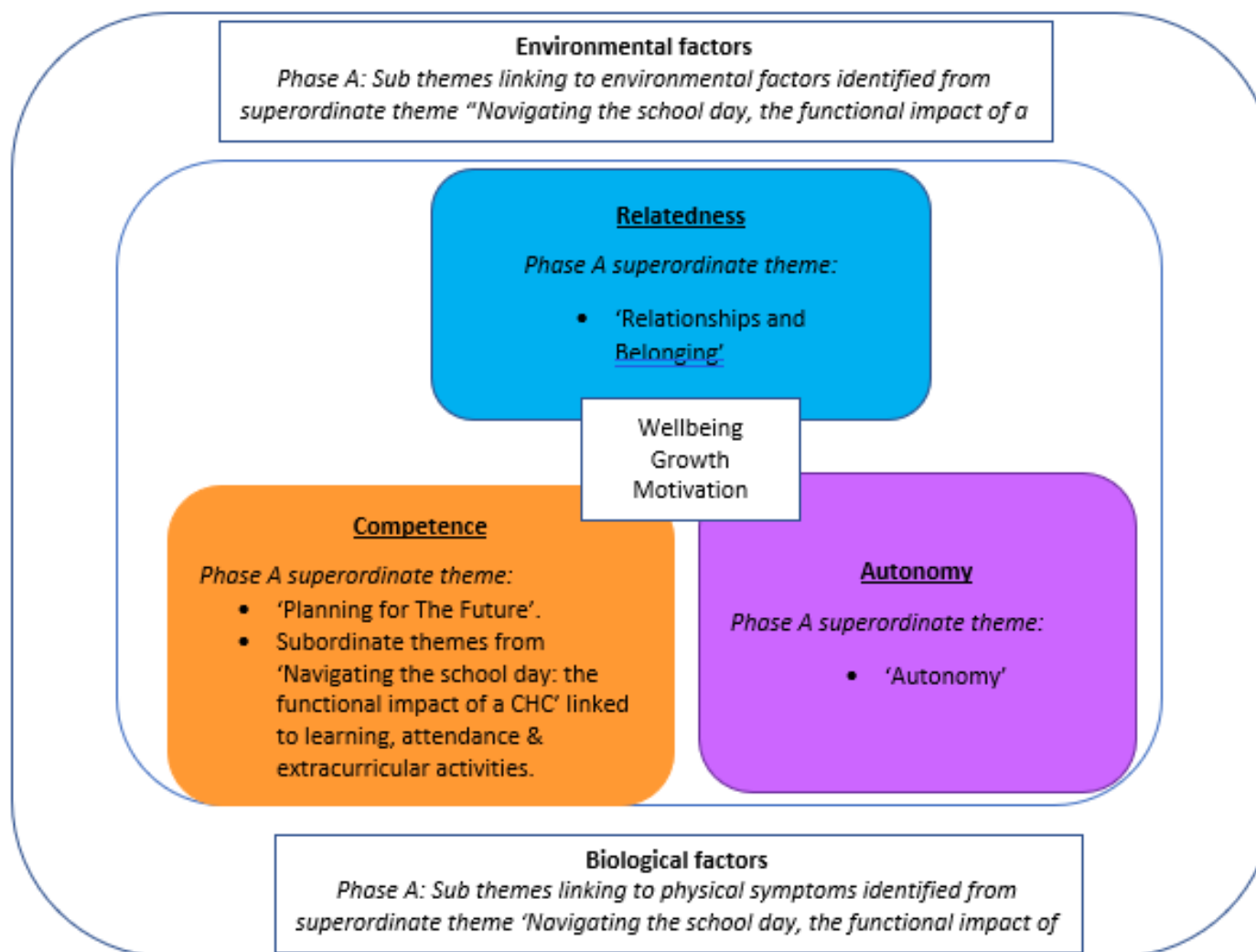
Appendix 27: Reflective SDT framework including needs satisfaction/needs frustration for analysing subordinate themes (enlarged version).

Biological Factors

Fatigue · Physical Symptoms · Medication/Treatment · Mobility · Sensory needs · Pain

Themes arising when need is SATISFIED...
- Supportive relationships with peers (2.4b)
- Supportive relationships with adults (2.1b)
- Support from adults (2.3a)
- No conflict in relationships with adults (2.2b)
- Feels the same as peers (2.5b)
- Does not experience undesirable emotions or experiences desirable emotions (4.2b) e.g., feels included/sense of belonging
- Coping Mechanisms (4.4): Engages adaptive coping mechanisms-positivity, acceptance, humour

Themes arising when need is FRUSTRATED
- CHC impacts relationships with peers (2.4a)
- CHC impacts relationships with adults (2.1a)
- Lacks support from adults (2.3b)
- Conflict with adults (2.2a)
- Feels different (2.5a)
- Experiences undesirable emotions (4.2a) e.g., feels upset/frustrated/hurt/embarrassed
- Coping Mechanisms (4.4) Engages maladaptive Coping mechanisms-e.g. avoidance/acquiesce

Relatedness

Competence → Wellbeing, Growth & Motivation ← **Autonomy**

Themes arising when need is SATISFIED...
- CHC does not impact learning (3.1b) e.g. No learning missed.
- Support available for learning
- CHC does not impact on attendance (3.2b)
- Accesses social and extracurricular opportunities in school. (3.3b)
- Sets goals for the future (5.1a)
- Does not have concerns/uncertainty about the future (5.2b)
- Sense of normality (4.3b)
- Positive self-esteem (4.1b)
- Coping Mechanisms (4.4) Engages adaptive coping mechanisms- positivity, acceptance positivity

Themes arising when need is FRUSTRATED
- CHC impacts learning (3.1a) e.g. Missed Learning ('catching up' required)
- Lacks support for learning
- CHC Impacts attendance (3.2a)
- CHC impacts access to social and extracurricular opportunities in school (3.3a)
- Does not set goals for the future (5.1b)
- Concerns/uncertainty about the future (5.2a)
- Loss: of 'normality' (4.3a)
- CHC impacts self-esteem (4.1a)
- Coping mechanisms (4.4) Engages maladaptive avoidance/ catastrophising /denial/wishful thinking
- Experiences undesirable emotions (4.2a) Frustration/sadness at loss of 'normality' and preferred activities

Themes arising when need is SATISFIED
- Person-centred practice in school (1.1b)
- Sense of control (1.2b)
- Opportunities for Independence (1.3a)
- Feels empowered (1.4a)
- Sense of normality (4.3b)
- Coping Mechanisms (4.4): Engages adaptive coping mechanisms- acceptance, positivity.

Themes arising when need is FRUSTRATED
- Lack of person-centred practice in school (1.1a)
- Lack of control (1.2a)
- Limited opportunities for independence (1.3b)
- Feels disempowered (1.4b)
- Loss of normality (4.3a)
- Coping Mechanisms (4.4): Engages maladaptive coping mechanisms- Experiences undesirable emotions (4.2a) Frustration/anger at lack of autonomy.

Environmental Factors

Classrooms · Lunch hall · Playground · Equipment · Medical room/staff

Appendix 28: Amber's Reflective SDT map indicating in yellow the subordinate themes identified in interview (Larger Version)

| Biological Factors | Fatigue | Physical Symptoms | Medication/ Treatment | Mobility | Sensory needs | Pain |

Themes arising when need is SATISFIED...
- Supportive relationships with peers (2.4b)
- Supportive relationships with adults (2.1b)
- Support from adults (2.3a)
- No conflict in relationships with adults (2.2b)
- Feels the same as peers (2.5b)
- Does not experience undesirable emotions or experiences desirable emotions (4.2b) e.g., feels included/sense of belonging
- Coping Mechanisms (4.4): Engages adaptive coping mechanisms-positivity, acceptance, humour

Themes arising when need is FRUSTRATED
- CHC impacts relationships with peers (2.4a)
- CHC impacts relationships with adults (2.1a)
- Lacks support from adults (2.3b)
- Conflict with adults (2.2a)
- Feels different (2.5a)
- Experiences undesirable emotions (4.2a) e.g., feels upset/frustrated/hurt/embarrassed
- Coping Mechanisms (4.4) Engages maladaptive Coping mechanisms-e.g. avoidance/acquiesce

Relatedness

Competence

Wellbeing, Growth & Motivation

Autonomy

Themes arising when need is SATISFIED...
- CHC does not impact learning (3.1b) e.g. No learning missed.
- Support available for learning
- CHC does not impact on attendance (3.2b)
- Accesses social and extracurricular opportunities in school. (3.3b)
- Sets goals for the future (5.1a)
- Does not have concerns/uncertainty about the future (5.2b)
- Sense of normality (4.3b)
- Positive self-esteem (4.1b)
- Coping Mechanisms (4.4) Engages adaptive coping mechanisms- positivity, acceptance positivity

Themes arising when need is FRUSTRATED
- CHC impacts learning (3.1a) e.g. Missed Learning ('catching up' required)
- Lacks support for learning
- CHC Impacts attendance (3.2a)
- CHC impacts access to social and extracurricular opportunities in school (3.3a)
- Does not set goals for the future (5.1b)
- Concerns/uncertainty about the future (5.2a)
- Loss: of 'normality' (4.3a)
- CHC impacts self-esteem (4.1a)
- Coping mechanisms (4.4) Engages maladaptive coping mechanisms: avoidance/ catastrophising /denial/wishful thinking
- Experiences undesirable emotions (4.2a) Frustration/sadness at loss of 'normality' and preferred activities

Themes arising when need is SATISFIED
- Person-centred practice in school (1.1b)
- Sense of control (1.2b)
- Opportunities for Independence (1.3a)
- Feels empowered (1.4a)
- Sense of normality (4.3b)
- Coping Mechanisms (4.4): Engages adaptive coping mechanisms- acceptance, positivity.

Themes arising when need is FRUSTRATED
- Lack of person-centred practice in school (1.1a)
- Lack of control (1.2a)
- Limited opportunities for independence (1.3b)
- Feels disempowered (1.4b)
- Loss of normality (4.3a)
- Coping Mechanisms (4.4): Engages maladaptive coping mechanisms- Experiences undesirable emotions (4.2a) Frustration/anger at lack of autonomy

| Environmental Factors | Classrooms | Lunch hall | Playground | Equipment | Medical room/staff |

Appendix 29: Autumn's Reflective SDT map indicating in yellow the subordinate themes identified in her interview (Larger Version)

Appendix 30: JJ's Reflective SDT map indicating in yellow the subordinate themes identified in interview.

Biological Factors — Fatigue — Physical Symptoms — Medication/ Treatment — Mobility — Sensory needs — Pain

Themes arising when need is SATISFIED...
- Supportive relationships with peers (2.4b)
- Supportive relationships with adults (2.1b)
- Support from adults (2.3a)
- No conflict in relationships with adults (2.2b)
- Feels the same as peers (2.5b)
- Does not experience undesirable emotions or experiences desirable emotions (4.2b) e.g., feels included/sense of belonging
- Coping Mechanisms (4.4): Engages adaptive coping mechanisms-positivity, acceptance, humour

Themes arising when need is FRUSTRATED
- CHC impacts relationships with peers (2.4a)
- CHC impacts relationships with adults (2.1a)
- Lacks support from adults (2.3b)
- Conflict with adults (2.2a)
- Feels different (2.5a)
- Experiences undesirable emotions (4.2a) e.g., feels upset/frustrated/hurt/embarrassed
- Coping Mechanisms (4.4) Engages maladaptive Coping mechanisms-e.g. avoidance/acquiesce

Relatedness

Competence — Wellbeing, Growth & Motivation — **Autonomy**

Themes arising when need is SATISFIED...
- CHC does not impact learning (3.1b) e.g. No learning missed.
- Support available for learning
- CHC does not impact on attendance (3.2b)
- Accesses social and extracurricular opportunities in school. (3.3b)
- Sets goals for the future (5.1a)
- Does not have concerns/uncertainty about the future (5.2b)
- Sense of normality (4.3b)
- Positive self-esteem (4.1b)
- Coping Mechanisms (4.4) Engages adaptive coping mechanisms- positivity, acceptance positivity

Themes arising when need is FRUSTRATED
- CHC impacts learning (3.1a) e.g. Missed Learning ('catching up' required)
- Lacks support for learning
- CHC Impacts attendance (3.2a)
- CHC impacts access to social and extracurricular opportunities in school (3.3a)
- Does not set goals for the future (5.1b)
- Concerns/uncertainty about the future (5.2a)
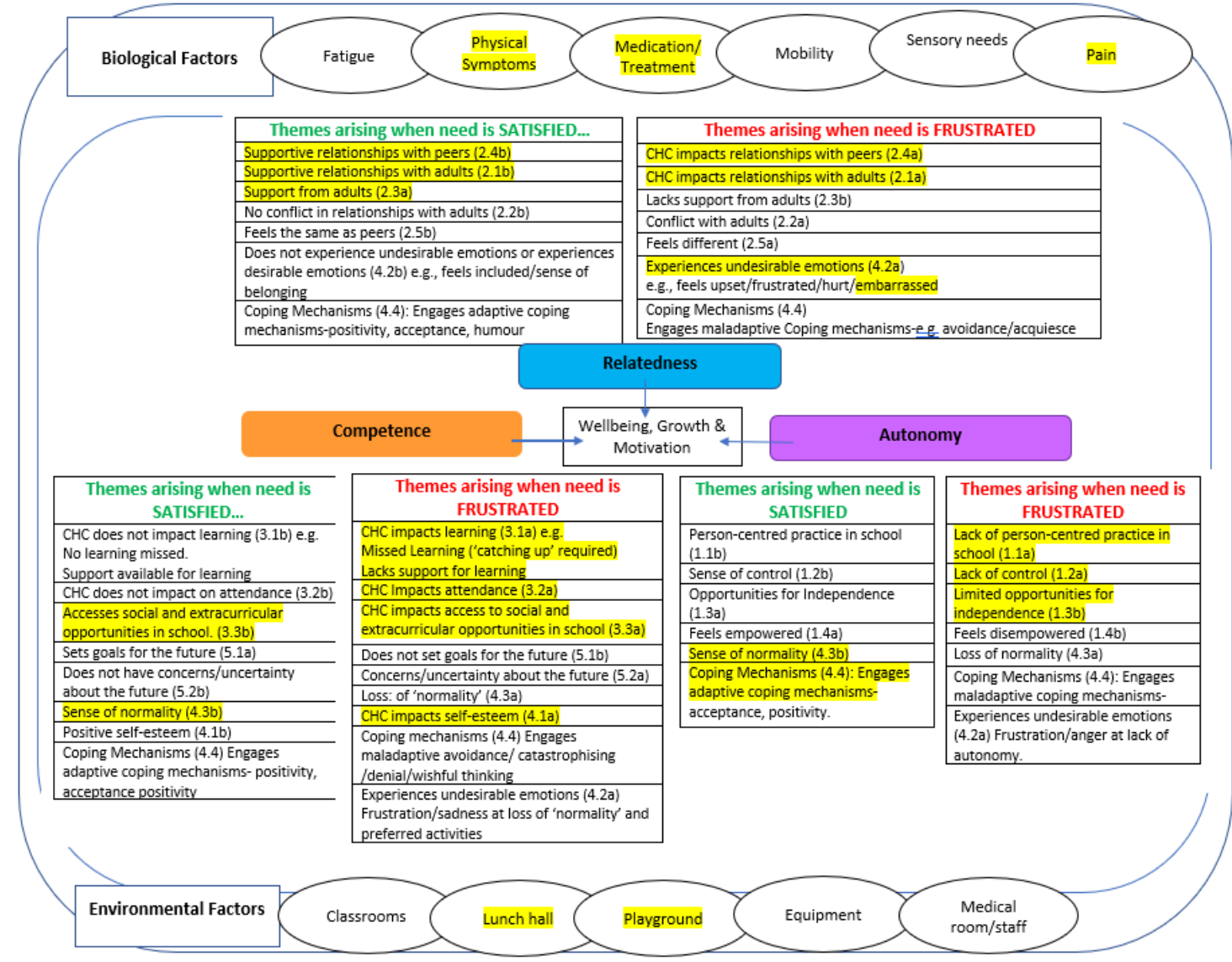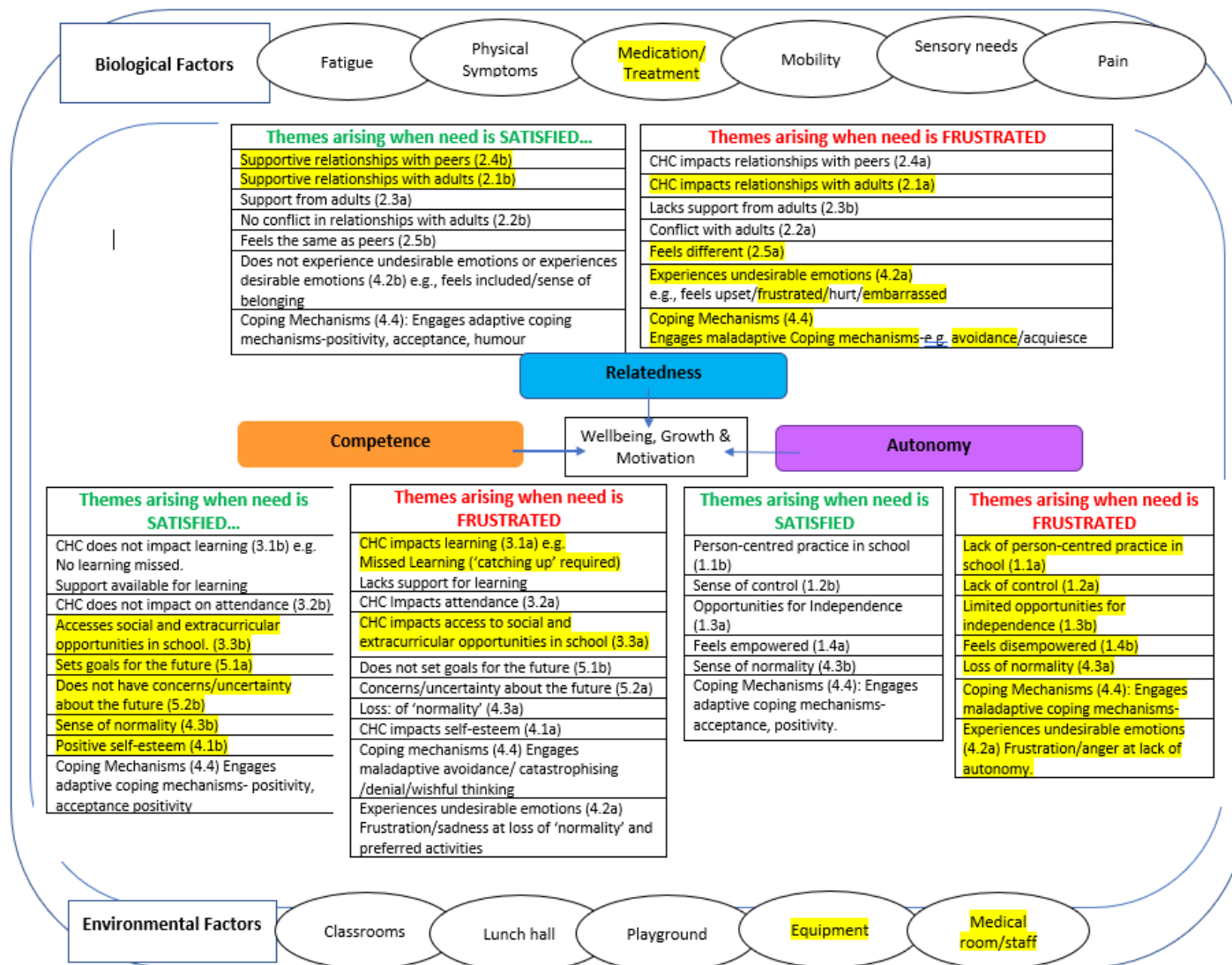- Loss: of 'normality' (4.3a)
- CHC impacts self-esteem (4.1a)
- Coping mechanisms (4.4) Engages maladaptive avoidance/ catastrophising /denial/wishful thinking
- Experiences undesirable emotions (4.2a) Frustration/sadness at loss of 'normality' and preferred activities

Themes arising when need is SATISFIED
- Person-centred practice in school (1.1b)
- Sense of control (1.2b)
- Opportunities for Independence (1.3a)
- Feels empowered (1.4a)
- Sense of normality (4.3b)
- Coping Mechanisms (4.4): Engages adaptive coping mechanisms- acceptance, positivity.

Themes arising when need is FRUSTRATED
- Lack of person-centred practice in school (1.1a)
- Lack of control (1.2a)
- Limited opportunities for independence (1.3b)
- Feels disempowered (1.4b)
- Loss of normality (4.3a)
- Coping Mechanisms (4.4): Engages maladaptive coping mechanisms- Experiences undesirable emotions (4.2a) Frustration/anger at lack of autonomy.

Environmental Factors — Classrooms — Lunch hall — Playground — Equipment — Medical room/staff

Appendix 31: Samuel's Reflective SDT map indicating in yellow the subordinate themes identified in interview.

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Appendix 32: Willow's Reflective SDT map indicating in yellow the subordinate themes identified in interview.