The educational experiences of children and young people with cystic fibrosis

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Abstract

Children with medical conditions may experience significant challenges in education, of which there is often low awareness within schools. Yet, there is a dearth of research into cystic fibrosis (CF) and education. Research about CF commonly takes a medicalised or psychological standpoint and therefore the educational experiences of children and young people with condition are largely unknown. Educational research has focused on children with varying medical conditions, although most studies regard them as a homogenous group. CF remains distinctive from other conditions because it is invisible, it has an erratic profile, and a vast regime of treatments are needed in order to manage symptoms on a daily basis.

The impact of CF upon the educational experiences of children and young people with the condition is a neglected research area. The study has begun to address this research gap. As an adult who has CF, this cross-disciplinary education and health study benefitted from an 'insider' research approach, which exemplifies the value of experiential knowledge. The research employed a two-phased, mixed methods design and drew upon an ecological, biopsychosocial approach to take account of the interacting systems in which children participate. First, questionnaires were administered to 75 school-aged individuals with CF at a large regional paediatric CF centre. Second, online interviews took place with 5 children and young people, and telephone or face-to-face interviews were conducted with parents, teachers and CF nurse specialists.

The findings demonstrated that children's needs are obscured in the school setting and they often experience low teacher awareness and understanding of the condition. Subsequently, children and young people may be subjected to vulnerable educational circumstances. The research informs developments in the education of children and young people with CF through the identification of their specific needs and challenges, and recommendations for educationally supportive practice.

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Abbreviations

ADHD	Attention Deficit Hyperactivity Disorder
BMJ	British Medical Journal
CF	Cystic Fibrosis
CFA	Children and Families Act
CFTR	Cystic Fibrosis Transmembrane Regulator
DDA	Disability Discrimination Act
DfE	Department for Education
DfES	Department for Education and Skills
DoH	Department of Health
DRC	Disability Rights Commission
GCSE	General Certificate of Education
HCSA	Health Conditions in Schools Alliance
HLTA	Higher Level Teaching Assistant
HRA	Health Research Authority
IHP	Individual Healthcare Plan
IT	Information Technology
IV	Intravenous
LA	Local Authority
NHS	National Health Service
NRES	National Research Ethics Service
OFSTED	Office for Standards in Education, Children's Services and Skills
PE	Physical Education
PEP	Positive Expiratory Pressure
REC	Research Ethics Committee
RS	Religious Studies
RQ	Research Question
SATs	Standard Attainment Tests
SEN	Special Educational Needs
SENCO	Special Educational Needs Coordinator
UK	United Kingdom
UNCRC	United Nations Convention on the Rights of the Children

Chapter 1 Introduction

1.1 Background to the study

I became interested in issues relating to inclusive education with the completion of my undergraduate degree in Community Studies, which coincided with the introduction of the Labour government circular 10/99; Social Inclusion: Pupil Support (DfES, 1999). The policy aimed to improve educational standards for vulnerable and disadvantaged children and young people. I gained employment as a 'Social Inclusion Officer', and this involved supporting children in vulnerable circumstances in order to minimise their exclusion from education. Subsequently, I worked in a variety of roles in Local Authorities (LAs), mainstream and specialist educational provisions in both supportive and advisory capacities. This developed my understanding of inclusive educational practice, government policy and legislation relating to Special Educational Needs (SEN) and disability. Throughout this time it became apparent that children with special or additional educational needs and their families were facing some disparity in the provision available within different schools. While many children and young people were well supported, I worked with parents who often felt that securing appropriate provision for their children was an arduous process (see for example: Lamb 2009). For this reason, I wanted to further develop my knowledge of education policy and practice. Therefore, I enrolled on a Masters Degree in SEN, which provided me with an insight into the theoretical background of inclusive education. The course also gave me the opportunity to engage with research in the field. This ignited an interest in conducting my own research and is one of the reasons for pursuing a PhD.

A major motivation for researching the educational experiences of children and young people with CF is that I believe I am uniquely placed to conduct the study. As well as having a professional background in the field of education, I was also born with CF. Therefore, my personal experiences of living with the condition, as well as the knowledge gained throughout my employment, and my interest in issues of inclusive education have significantly influenced my decision to carry out this research. As a researcher with CF, I can offer greater empathy and understanding to children and their families who participate in the study, than researchers who do not have CF. Indeed, the merits of being a 'user' or 'insider' researcher have also

been argued elsewhere (Beresford, 2007; McLaughlin, 2009; Edwards and Boxall, 2010).

I was surprised to learn there is a paucity of social research into issues relating to CF (Ullrich, 2013). Consequently, there is a dearth of research into the education of children with the condition. Research about CF generally takes a medicalised or psychological standpoint rather than an educational or ecological view of the condition. Therefore, the educational experiences of children and young people with CF are largely unknown. Educational research studies have focused on children with varying medical conditions, including CF (see for example: Bolton 1997; Lightfoot et al, 2001; Asprey and Nash 2006a; Yates et al. 2010). While this body of research evidences that children with medical conditions may experience particular difficulties in education, a significant limitation of all of these studies is that they are not specific to children with CF. However, CF remains distinctive from other conditions due to the time consuming and complex treatment regimes that must take place on a daily basis, and the erratic and variable nature of the condition. CF could potentially impact children's education in different ways. Existing research that considers children with different medical conditions as a homogeneous group therefore reaches generalised and unspecific conclusions about the educational experiences of children with CF.

1.2   Cystic fibrosis

CF is a progressive, chronic and life limiting condition caused by a genetic mutation resulting in abnormal production of a protein called the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) (Conway et al., 2008). Sometimes CF is thought of as a respiratory condition. However, given that CFTR is necessary to regulate sodium, chloride and bicarbonate in and out of cells throughout the entire body, CF is a multisystem condition affecting many different organs (Conway et al., 2008). Nevertheless, CF does predominantly affect the lungs and the digestive system. Consequently, people with the condition must complete a range of significantly time consuming therapies and treatments on a daily basis in order to control disease symptoms, which can include: chest physiotherapy, exercise, oral and nebulised antibiotics, inhaled steroids, nebulised drugs to thin the mucus, pancreatic enzymes, vitamins, high calorie supplements and tablets for the liver.

In the lungs, the inactive or inefficient functioning of CFTR results in the airways becoming clogged with thick, sticky mucus which provides a favourable environment for bacterial infection (Conway et al., 2008). Chest infections can occur

and in some cases on a frequent basis which can permanently damage the lungs and lead to breathing difficulties (Conway et al., 2008). Infections often require intravenous (IV) antibiotic therapy in addition to the daily maintenance treatment regime. Courses of IVs commonly take place over a two-week period, either in hospital or at home, during which antibiotics are injected several times a day. However, longer courses of IVs are sometimes required depending on the severity of the chest exacerbation. Despite maintenance therapies and IV courses, over time infection and inflammation severely damage the lungs beyond repair and it is still the case that nearly all patients with CF will die from pulmonary difficulties (Bakker, 2007). Median predicted survival in the UK currently stands at 45.1 years (CF Trust, 2016a).

The majority of people with CF are pancreatic insufficient which means that the pancreas does not produce enough digestive enzymes (Conway et al., 2008). Therefore, most people with CF are treated with pancreatic enzyme supplements such as Creon. Without this treatment, the digestion and absorption of food is severely impaired leading to unpleasant digestive symptoms, malnutrition, poor growth and vitamin deficiencies (Littlewood et al., 2006). Despite enzyme supplementation, some people with CF struggle to maintain a healthy weight due to difficulties with consuming enough food to meet their increased energy requirements. Such difficulties can include poor appetite, infection related anorexia, gastro-oesophageal reflux and abdominal pain (Duff et al., 2003). Therefore, in such cases dietary supplements are administered orally, via a nasal cannula or through a tube placed directly into the stomach, which may help to improve energy intake (Conway et al., 2008).

It is estimated that there are between 70,000 and 100,000 people with CF worldwide (Cystic Fibrosis Worldwide, 2013). CF affects people of many ethnicities, although it is most common in the Caucasian population. In the United Kingdom (UK), CF affects over 10,000 people and approximately 3000 are of school-age (CF Trust, 2016a). CF remains highly complex and generally, any physical features of the disease are difficult to see. It affects those with the condition in different ways, with varying degrees of severity and each person's health can change considerably from month-to-month or even day-to-day (CF Trust, 2007). It is also difficult to predict the course the condition will take. Therefore, school-age children and young people with CF are likely to have uneven profiles of learning and may not fall easily into categories of SEN and/or disability, which might bring support. Despite this, the extent of support needed in education for students with CF, if any, remains unclear.

1.2.1 Cross-infection

A further challenge for people with CF relates to the risks associated with cross-infection. Cross-infection risks prevent those with the condition from meeting face-to-face. This is because people with CF are vulnerable to the different bacteria that grow in their lungs. These bacteria can also be easily transmitted from one person with CF to another (CF Trust, 2013). While these bacteria are usually harmless to people who do not have CF, they can settle in the lungs and be harmful to those who do. Given that people with CF should not physically meet with one another, the risk of cross-infection presents a number of ethical and practical considerations for this research. As a researcher with CF, it means that I am unable to physically meet with other children and young people with the condition. Further, I am unable to meet with other participants in the physical spaces that children with CF might occupy, such as their schools or their family homes.

1.3 Research aims and questions

In light of there being a dearth of research into CF and education, this study had the broad aim of exploring issues in education related to children and young people with CF. Having this broad aim was important, because the educational experiences of children with the CF are not well understood and this aim enabled children and young people to self-identify what is of significance to them in their education. This study also aimed to address some of the gaps in current research by giving precedence to the views of children and young people with different lived experiences of CF, as reflected in the chosen methods discussed later. This approach is consistent with the position that children are active, engaged participants in their lives and in society, with their own views and goals (Hill and Tisdall, 1997), and is further expressed in legislation such as the United Nations Convention on the Rights of the Child (UNCRC, 1989). Article 12 to 14 is concerned with the rights of the child to express their views on matters that concern them and in Article 23; the rights of children with disabilities to active participation (UNCRC, 1989).

This research did not assume that all children with CF have the same educational experiences and needs, and recognised them as a heterogeneous group of individuals. Their heterogeneity was therefore considered in the sampling approach taken during the study. Given that children and young people have different lived experiences of CF, this sampling approach enabled a variety of perspectives on education to be explored and analysed. In addition, there are ecological and

interactional influences in children's lives (Robinson and Summers, 2012) that necessitated the involvement of other stakeholders in the research. The involvement of parents was therefore important to the study. Parents have unique perspectives and insights into their child's needs. Indeed, many government education policies recognise this (DfE and DoH, 2015; OFSTED., 2015), which emphasises the value of listening to parental perspectives. In addition, it is now firmly established that services for children and families must work together to ensure integrated and collaborative support is available (Davis, 2011; DfE, 2011). Therefore, the perspectives of professionals from both education and health settings were also of interest to the research. To this end, in addition to the broad research aim presented at the start of this section, the study also had four further sub-aims, which were:

- To explore and analyse the perspectives of children and young people with CF about their educational experiences
- To explore and analyse other key stakeholder understandings of the needs of children and young people with CF in education
- To make recommendations for appropriate educational provision for children and young people with CF
- To contribute to methodological knowledge by developing an appropriate method for research involving children when the proximity of the researcher and/or other participants is problematic.

The aims of the study were addressed through the following research questions:

RQ1. What is the current research evidence about the links between CF and Education?

RQ2. What are the perspectives of children and young people with CF on their educational experiences and needs?

- To what extent do they feel their needs are understood, identified and met in their current educational provision?
- What factors do they perceive to be helpful to their educational experiences?

RQ3. What are the perspectives of other key stakeholders on the education of children and young people with CF?

RQ4. What issues and challenges arise in relation to the specific research context; namely:

    i.   A person with CF conducting research about CF?

    ii.   Involving children in the research?

    iii.   Conducting the research as a mixed methods study?

- How can these issues and challenges be responded to?

RQ5. How can the study data inform developments in the education of children and young people with CF?

1.4 The research approach

This study adopted a two phase, mixed methods research design to generate data that would enable the exploration of the educational experiences of children and young people with CF. The first phase involved the administration of a questionnaire with school-aged children and young people with CF (5-17 years) at a large regional paediatric CF centre in the north of England. The second phase of the research aimed to explore children's educational experiences in further depth and so employed the use of online interviews with the children and young people with CF who took part, in order to prevent the risk of cross infection. Since I wanted to consider the interactional and ecological factors that make up children's educational experiences, the second research phase also utilised different interview approaches with stakeholders in addition to children with CF. A combination of face-to-face and telephone interviews were used with parents, and health and education personnel. A biopsychosocial approach to understanding children's educational experiences was applied so that the multiple systems in which children and young people with CF participate could be taken into account. Throughout the research, I employed a reflexive approach that enabled me to critically reflect on the influence of my researcher position(s) and my subjective experience as a person with CF conducting the study.

1.5 Significance of the research

The significance of this study lies in the increased understanding of issues in education specifically related to children and young people with CF. As discussed earlier, there is very little research on CF and education specifically. This study reveals what children and young people identify to be significant in relation to their education. Insights arising from the research contribute to possible recommendations for CF clinicians and education providers and for interdisciplinary

working between these agencies, all of which are likely to foster more positive educational experiences for children and young people with CF. The study offers a social research perspective on CF and contributes to existing CF literature, which tends to focus on the clinical and psychological factors associated with the condition. The study also contributes to the body of literature on the education of children with medical conditions and within the broader context of inclusive education. Of further significance are the methodological understandings that can be gained from the research. The study presents a new approach for involving children in research through the use of online interviews. The approach is likely to be of value where the proximity of a researcher and/or the participants is problematic. Additional insights can be gained as a result of my unique position within the study, which add to the literature on the issues of conducting research as a 'user' or 'insider' researcher. The study also has implications for conducting social or educational research within the NHS.

1.6   Thesis overview

The thesis is divided into eight chapters.

Chapter 1 is this introductory chapter.

Chapter 2 considers current understandings of CF in the educational context and aims to situate the study in a context of the research evidence relating to the education of children with medical conditions. Given the dearth of research into CF and education specifically, the general literature on the education of children with medical conditions is included in the review where it could be established that children with CF were included in the research alongside those with other conditions. The legislation and policy context is also discussed. The chapter demonstrates that much of the literature considers children with medical conditions as a homogenous group, and fails to account for the unique characteristics and variability of CF. Finally, the chapter sets out the theoretical framework for the study which draws on a biopsychosocial approach for understanding health and disability.

Chapter 3 Sets out the rationale for the research design and methodology selected. It describes the methods used in the two phases of research in order to generate data to address the research aims and questions. The chapter also describes the processes used when analysing the data from the questionnaires and interviews. Lastly, it provides an account of how I ensured the trustworthiness of the research and addressed the ethical issues that arose in the study.

Chapter 4 presents the results of the questionnaire data analysis. I discuss my interpretations of the results from children and young people's responses to the questionnaire items, and the non-parametric statistical tests conducted on the data, in relation to children's educational experiences.

Chapter 5 describes the findings of the data analysis pertaining to the interviews with children and young people, parents, and education and health personnel. It describes seven overarching conceptual categories and twenty-three themes constructed through the coding and analysis of the interview transcripts, in relation to the educational experiences of children with CF. The chapter uses participant quotations to exemplify the analytical narrative that supports my own interpretation of the categories and themes constructed.

Chapter 6 provides a reflexive account of the specific issues and challenges that arose when conducting the study with reference to certain aspects of the research process. The issues and challenges experienced in relation to three key contextual factors are discussed: being a person with CF conducting research about CF; involving children in the research; and conducting the research as a mixed methods study.

Chapter 7 discusses the findings of the research in a context of the existing literature on the education of children with medical conditions. Particular attention is made to the findings related to the educational needs and challenges experienced by children and young people with CF, and associated areas of supportive practice that is likely to be beneficial to them at school. Towards the end of the chapter, the implications of the research for policy and practice are discussed, followed by the biopsychosocial implications of the research.

Chapter 8 concludes the research. It provides a summary of the key research findings and highlights the original contribution the study makes to understanding the educational experiences of children and young people with CF. The chapter also discusses the methodological contribution of the study in terms of the novel methods used, the insider research context and in relation to conducting educational research in a clinical setting. Dissemination activities are considered along with the limitations of the study and possible areas for further research. Finally, the chapter provides a reflection on my personal research journey.

Chapter 2 Current understandings of cystic fibrosis in the educational context

2.1 Introduction

In this chapter, existing literature and empirical research relating to the education of children and young people with CF is reviewed. The discussion contained within this chapter therefore addresses the first research question:

RQ1. What is the current research evidence about the links between CF and Education?

The first research question was developed because there is a dearth of research into CF and education specifically. Only one article and one study that solely concern the education of children with CF have been located (Bailey and Barton, 1999; Puckey et al., 2006). There are studies on the education of children with medical conditions that have involved individuals with CF, although this body of literature is general in nature, with the majority of studies regarding children with medical conditions as a homogenous group. However, it is arguable that CF is distinctive from other medical conditions because it is invisible, it has an erratic profile, and a vast regime of treatments and medication are needed by those with the condition in order to manage symptoms on a daily basis. Therefore, to ensure that the body of literature reviewed was relevant to the education of children and young people with CF, the review of the literature was conducted with reference to guidance on systematic reviews (EPPI, 2010). Subsequently, specific inclusionary and exclusionary criteria were applied to the literature referred to during this chapter.

Empirical research studies and academic papers over the last 20 years relating to the education of children with medical conditions are included in the review, where children with CF were involved in the research, either exclusively or alongside children with different conditions, or where the subject of the literature is of significance to the education of children with CF (e.g. disability and needs identification). Some of the studies reviewed were not explicit about the number of children with CF involved in the research. Therefore, the term 'children with medical conditions' is adopted where appropriate throughout the review, and this term is inclusive of children and young people with CF. The literature search disregarded

research studies and papers on the education of children with medical conditions where children with CF were not explicitly involved or discussed within the research.

The literature over the 20 year time period is likely to be of relevance to the study within the context of clinical developments in the area of CF. In addition, given that CF affects people globally, international studies relating to education and children with medical conditions are also included. However, I recognise that countries outside England may operate different systems and procedures in relation to children's education, which may affect the outcomes discussed. The literature also covers education across all phases although there are differences between primary and secondary provisions. A search of the medical literature was not discounted despite the probable medical model perspective. Studies from medical journals that illustrate the importance of understanding educational factors and CF (e.g. employability and cognition) are therefore not excluded. Further information relating to the literature search strategy is contained in appendix 1.

The chapter begins by considering the potentially vulnerable educational circumstances experienced by children and young people with medical conditions. I then explore the policy and legislation context and discuss issues of SEN and disability, along with recent developments in relation to the legal duty placed upon schools to support children with medical conditions. Following this, I discuss the various reasons why education is of importance to children with CF. The discussion contained in these first three sections offers a contextual understanding of educational issues relating to CF, which then leads into the specific challenges and issues associated with the education of children with medical conditions. Subsequently, I explore some of the educational, social and health implications of having a medical condition at school, and examine some of the supportive practices of those involved in children's education. Finally, I consider the use of an appropriate framework for understanding the educational experiences of children with CF.

2.2   Vulnerable educational circumstances

The research evidence on the education of children with medical conditions positions children in vulnerable educational circumstances (Lightfoot et al., 1998; Bailey and Barton, 1999; Harris and Farrell, 2004). As Closs (2000, p3) argues:

Children with medical conditions have an increased likelihood of experiencing at some time, or frequently or constantly, a 'constellation of factors' which may directly or indirectly place their education at risk. Some of these factors are not unique to this group of children; it is their duration, combination and complexity which are potentially, particularly educationally, disadvantageous.

In addition to the factors that may place children's education at risk, which are considered later in section 2.5, it is concerning that children with medical conditions, and particularly children with low incidence or invisible conditions such as CF may 'languish largely unnoticed in the education system' (Bailey and Barton, 1999, p.81). Several studies have identified that the visibility of a medical condition may play a major part in whether a child receives appropriate help at school. For example Porter et al (2008) conducted research on the use of a parent questionnaire to enable schools to identify disabled pupils. They found that some children who were identified as disabled via the questionnaire had disabilities which were previously unknown to schools. Some of these children had a disability arising from a medical or mental health condition that did not necessarily lead to an SEN. Porter et al (2008) concluded that children with unseen medical or mental health conditions are at risk of underachievement, as they may not be picked up by school support systems. Comparably, Mukherjee et al (2000) who investigated the support needs of children with chronic illness or physical disability, found that teacher awareness of pupils' needs and willingness to believe that a child was ill was related to the visibility of the condition. Mukherjee et al (2000) also argued that pupils with a chronic illness may not be seen as at risk of educational difficulty. Similar concerns about the relationship between the provision of educational support and the visibility of a student's medical condition have also been raised elsewhere (Bolton, 1997; Cavet, 2000; Yates et al., 2010).

It is perhaps not surprising that some authors have suggested children with medical conditions may have many unmet support needs in their education (Close, 2000; Lightfoot et al., 2001; Robinson and Summers, 2012). However, in addition to the invisibility of a child's condition, children may have unmet educational needs due to a lack of support for the teachers working with them. For example, Robinson and Summers (2012) conducted an international literature search to evaluate support for teachers of children with a life-limiting illness in schools. They found that wider support systems for communicating children's needs, beyond parental communication, is required by teachers (Robinson and Summers, 2012). Similar findings have also been reported in other research (Norris and Close, 1999;

Mukherjee et al., 2000; Nabors et al., 2008). That there is a need for greater teacher support, would appear to be consistent with one CF patient's experience, who writing in the British Medical Journal (BMJ) stated that there was no dialogue between health and education professionals when she was at school (Wicks, 2007). No research has been identified that considers the support needed by teachers to meet the educational needs of children and young people with CF specifically. Nevertheless, there is uncertainty about where responsibility lies amongst school staff for children with chronic illness (Bolton, 1997; Norris and Closs, 1999; Closs, 2000). There are subsequent concerns that children needing support may therefore lose out in the competing demands upon teachers' time (Mukherjee et al., 2000).

The potentially vulnerable circumstances experienced by individuals with CF in education, along with teacher perspectives in this regard, is of interest to the study. Educational vulnerability in a context of this research is therefore defined as children being disadvantaged in education due to two major factors; as a result of CF and its management and/or due to existing structural and attitudinal barriers within the school setting. These two factors, their combination and interactions may have implications for the child's participation in *all* school related activities, both in and out of the school setting, including activities related to learning and those related to the social and developmental needs of the child.

2.3   The legislation and policy context

2.3.1   Special educational needs and disability

A resounding feature of much of the literature concerning the education of children with medical conditions, is the discussion of children's needs in a context of the support available through the SEN framework (Bolton, 1997; Lightfoot et al., 1998; Norris and Closs, 1999; Thies, 1999; Closs, 2000; Asprey and Nash, 2006a; Jackson, 2012). It is notable that some studies within this field have discussed children's school placements in terms of the preference for mainstream or special school (Asprey and Nash, 2006b; Hewitt-Taylor, 2009). However, my own experience of living with CF has led me to believe that the option of specialist provision for children with CF would not usually be considered. This shows that studies involving children with CF in addition to those with various medical conditions may reach unspecific conclusions that lack relevance to the context of CF and education, and highlights a need for research that solely focuses on the education of children and young people with CF.

There are uncertainties as to whether children and young people with CF are deemed to have SEN and this can be evidenced when turning to how SEN is defined in law. The concept of SEN is contained within the Education Act (1996) which makes clear that children only have SEN if they have a learning difficulty. The definition of learning difficulty is linked to two factors; that the child has significantly greater difficulties in learning than their peers, or that the child has a disability that prevents them from making use of educational facilities of a kind provided for children of the same age within the same LA (The Education Act 1996, s.312). Therefore, in order for children with CF to have SEN, they must be considered to have a learning difficulty or disability. However, it has been argued that the term 'SEN' is poorly defined (Norwich 2009) and lacks clarity (Lunt 2007). Subsequently, there are varied understandings of 'learning difficulties', 'disabilities' and 'difficulties in learning' (Closs, 2000). Therefore, in practice, apart from those who are overtly physically disabled or appear to experience a cognitive impairment, many children with medical conditions may not be deemed to have SEN (Closs, 2000).

Some children with CF may experience physical disability, through a reduced lung capacity (Conway et al., 2008), and it is notable that research is beginning to demonstrate a link between CF and impaired cognitive function (Koscik et al., 2004; Chadwick et al., 2015; Chadwick et al., 2016). Further, it is possible that difficulties in learning can coexist alongside CF, yet it is not uncommon for education staff to put such difficulties down to a child's condition as opposed to an identified problem that can be addressed proactively (Puckey et al., 2006). Significantly, previous research suggests that where there is no obvious disability or cognitive impairment, children with medical conditions may not be able to access the kinds of support that would most benefit their education (Bolton, 1997; Closs, 2000; Asprey and Nash, 2006a). This issue was particularly apparent in a study by Asprey and Nash (2006b) that explored the education of children and young people with CF and degenerative neuro-muscular conditions. Asprey and Nash (2006b) stated that individuals with CF were often not considered to have SEN or a disability by the special educational needs co-ordinators (SENCos) interviewed for the research. One SENCo felt that the high profile of young people with behavioural difficulties in school had led to 'the side-lining of young people with CF, whose needs did not impinge on school life in the way that an autistic child does' (Asprey and Nash, 2006b). Asprey and Nash (2006b) also described the case of a young person with CF who had not been included on the information circulated to staff about pupils with medical needs, as the SENCo did not consider her needs to be sufficiently serious. The SENCo said;

'No we haven't done that with her. We've done that for other children, like epilepsy, that sort of thing, but we haven't for this particular child [with CF]…Because my understanding is that her needs aren't that great that we needed to do that'.

(SENCo of a middle school in Asprey and Nash, 2006b, p59)

In practice, it is likely that there is a focus on learning difficulties within the SEN and disability context, resulting in an unclear application of the SEN code of practice to students with chronic illness or disability (Lightfoot et al., 2001).

Disability is a term that is often used interchangeably with SEN, although not all disabled children have SEN and not all children with SEN have a disability (Porter et al., 2011). In a similar manner to the concept of SEN, there are problems with defining disability (Oliver, 1996) as it is a complex term and not well understood (Porter et al., 2011). The legal definition of disability in the UK lies in the Disability Discrimination Act (DDA) (2005) and the Equality Act (2010). There are four important aspects contained within the DDA (2005) definition of disability: that a disability arises from an impairment; that the condition is long-term; that it has an impact on day-to-day activities; and the effect is substantial (that is, not trivial) (DfES and DRC, 2006). These aspects certainly suggest that some children with CF may be considered to be disabled under the DDA (2005) definition.

Yet, as discussed earlier, the Porter et al (2008) study demonstrated that schools may experience difficulties with identifying disabled pupils, particularly where a disability may not be visible. Certainly, SEN and disability tribunal case law has shown this to be the case in practice. For example, the Upper Tribunal case of CP v M Technology School (2010) UKUT 314, described the permanent exclusion of 'C', a 13 year old boy with a statement of SEN (as replaced by Education and Health Care (EHC) plans in 2014). C's parents initially lodged a claim under the DDA (2005) with the First-Tier Tribunal, arguing that the governing body of what was then C's school, had unlawfully discriminated against him through less favourable treatment, exclusion, and failure to make reasonable adjustments. C's parents explained that C was disabled because he had mental health issues which caused him huge anxieties and was receiving counselling. Yet, during the First-Tier Tribunal, consideration turned to whether C did in fact have a disability, and it concluded that he was not disabled within the DDA (2005) meaning. In this case the Upper Tribunal found that C's parents should not have been expected to prove his 'unseen' disability and that a new tribunal should reconsider the original appeal. This demonstrates the difficulties that schools and other relevant bodies may

experience with the identification of invisible disabilities, which may have subsequent implications for children's rights under disability legislation.

The identification of children who might be classed as disabled therefore remains problematic. Children and young people with CF may experience long periods of being relatively well or 'stable', during which the condition has a lesser impact on daily functioning. They may also experience frequent episodes of illness, or periods of neither being very ill or very well. In the CF context, this makes the notion of impairment a tricky concept (Porter et al., 2011). Like the term SEN, the disability label may be rejected by individuals with CF and/or their parents, because when difficulties are identified and labelled, children and young people may be treated differently and could experience stigmatisation. Yet, it is possible that children with medical conditions, without SEN and who are not identified as disabled, may be vulnerable in education (Porter et al., 2008). Therefore there is an opportunity for this research to advance knowledge on the issue of needs identification and for this reason, the perspectives of children and young people with CF on this matter are of concern to this study.

2.3.2 The duty to support children with medical conditions

From a legal perspective then, it is unclear as to whether children with CF might be considered to have SEN or disability, which subsequently creates uncertainty about the kinds of support that children might access in their education (Closs, 2000). However, a new duty has been placed upon schools to support children with medical conditions, and this is contained within section 100 of the Children and Families Act (CFA) (2014). Schools must make arrangements for supporting pupils at school with medical conditions, and in meeting that duty they must have regard to the reviewed and amended statutory guidance on 'Supporting Pupils at School with Medical Conditions' (DfE, 2015). This suggests that children with CF may be able to access support at school without the need for 'incorporating sick children into SEN policy' (Bolton, 1997).

The supporting children with medical conditions duty has been in place since September 2014 and was therefore active for part of the study period; specifically throughout the interview phase of data generation, which took place between October 2014 and January 2015. Key points within the statutory guidance (DfE, 2015) include:

- Pupils at school with medical conditions should be properly supported so that they have full access to education, including school trips and physical education;

- Governing bodies must ensure that arrangements are in place for schools to support pupils with medical conditions;

- Governing bodies should ensure that school leaders consult health and social care professionals, pupils and parents to ensure that the needs of children with medical conditions and properly understood and effectively supported.

A further key aspect of the DfE (2015) guidance is the option for schools to record children's health, educational, social and emotional needs within an Individual Healthcare Plan (IHP). The guidance (DfE, 2015, p9) states that;

> *…an IHP will often be essential in cases where conditions fluctuate or where there is a high risk that emergency intervention will be needed, and are likely to helpful in the majority of other cases, especially where medical conditions are long-term and complex. However, not all children will require one.*

This creates some ambiguity about the suitability of initiating an IHP for children with CF. Given the condition is long-term and complex the guidance suggests that such a plan may well be suitable. However, it is possible that schools may see that an IHP is required only in cases where medication needs to be administered in the school setting or where an emergency situation may arise as a result of the child's medical condition. The guidance states that healthcare professionals and parents should agree whether or not such a plan would be appropriate, although the final decision rests with the headteacher if a consensus cannot be reached (DfE, 2015, p.10).

The administration of medicines in schools is an issue also discussed within the DfE (2015) guidance. In previous years, concerns have been raised by teaching unions that the provision of support for children with medical needs at school had been unregulated (UNISON, 2006), with others suggesting that former guidance was disturbingly vague (Ross, 2008). The current guidance makes clear that school staff should receive sufficient and suitable training, and achieve the necessary level of competency before they take on responsibility to support children with medical conditions (DfE, 2015). The guidance also contains information about liability and indemnity cover in relation to administering medication, which may be seen as an improvement on the advice given in previous years (UNISON, 2006; Ross, 2008).

Nevertheless, administering medication remains a voluntary task for school staff, and although any member of staff may be asked to provide such support, they cannot be required to do so (DfE, 2015). Therefore, ambiguity remains around who should be identified to supervise or administer children's medication at school. While previous research has shown that parents have been expected to come into school to administer children's medication (see for example Lightfoot et al., 2000), the guidance now states that this practice is generally unacceptable and that no parent should have to give up working because the school is failing to support their child's medical needs (DfE, 2015).

Despite the introduction of the new legal duty upon schools (Children and Families Act, 2014), concerns have been raised that this duty is not being effectively or consistently applied in practice. For example, the Health Conditions in Schools Alliance (HCSA) (2016) contacted 120 randomly selected schools across England in 23 LA areas to investigate how widely the new duty is being implemented. Only 27 schools responded to their request for information, however, the HCSA found that just 14 schools had a policy that was fully compliant with the legal obligations under the CFA (2014) legislation. The HCSA believe that compliance with the CFA (2014) duties is imperative in ensuring that all children in England have equal access to education irrespective of any long-term medical condition which they happen to have (Health Conditions in Schools Alliance, 2016).

Further statutory guidance is provided by the DfE on the provision of education for children who cannot attend school due to their health needs (DfE, 2013). An important issue addressed in this guidance relates to the education of children who are away from school for 15 days or more, whether consecutive or cumulative (DfE, 2013). The guidance states that LAs should arrange education provision and should do so at the latest by the sixth day of absence, yet aiming to do so by the first day of absence (DfE, 2013). This duty may be seen as an improvement on guidance from previous years, which was ambiguous in its discussion of access to education for those with 'prolonged or recurring absence' (DoH and DfES, 2001).

In current practice, tensions may remain around the provision of education for children with CF who are unable to attend school, given the condition can be erratic in nature, making it difficult to predict if there will be several episodes of illness that would total 15 days, or none at all in any school year. Research relevant to this issue was conducted by Yates et al (2010). They used a longitudinal case study approach with 31 young people to investigate the education of children with chronic illness. The longitudinal design was a particular strength of the research, as Yates

et al (2010) were able to demonstrate that some young people experience their health condition as a series of ups and downs, not something that is uniform in its effect or a simple trajectory over time (Yates et al., 2010); an important factor relating to planning educational provision for those who cannot attend school. This raises questions about how current systems of needs identification, that may involve a one off assessment when a child starts a new school, can pick up the potentially changing needs of children with CF. As Yates et al (2010) suggest, a one-off assessment is insufficient to identify and respond to the variability/changeability of living with a chronic illness.

2.4   The importance of education to children with CF

CF was once a fatal disease of childhood yet, is now a chronic disease of children, adolescents and adults (Demars et al., 2011). Today diagnostic tools such as new-born and antenatal screening and carrier testing, together with better understanding and treatment of the disease, has led to increased life expectancy and quality of life (CF Trust, 2016b). Therefore, the attainment of age-related developmental tasks, such as going to university and obtaining employment, is now an important and achievable part of life (Claxton, 2012). However, the achievement of such tasks coexist with the challenge of a demanding treatment regime and coping with the additional difficulties that occur as a result of disease progression (Besier and Goldbeck, 2012). Research has not yet addressed uncertainties as to whether improvements in disease management are positively influencing the achievements or future aspirations of individuals with CF.

The connection between the educational experiences of children and young people with CF and the implications of these experiences for life as an adult with the condition therefore forms part of the rationale for this research. Indeed, there is evidence that a significant predictor of employment in individuals with CF is educational attainment rather than disease severity or disability (Burker et al., 2004; Laborde-Castérot et al., 2012). There is further evidence that the employability of those with CF is associated with improved quality of life (Besier and Goldbeck, 2012) which is considered an important indicator of health status. In addition, it has been tentatively suggested that aspects of quality of life may be predictors of survival in CF (Abbott et al., 2009). While, these factors are located in the medical literature, they emphasise the importance of education to children and young people with CF and this necessitates better understanding of the educational experiences of individuals with the condition.

The importance of education to children with medical conditions has been raised in several studies. Yates et al (2010) found that almost all of the 31 young people involved in the study had long term aspirations that were very important to them and these were linked with their educational goals. Research by Bolton (1997), which involved the use of interviews and questionnaires with 100 parents and 40 children, also demonstrated that while education served a variety of purposes to children with medical conditions, the power and value of education was an overwhelming theme within the study. As one parent participant commented:

> *'I think education's very important. I don't see why they shouldn't be allowed to fulfil their potential as much as they can. Especially now when it's so hard to get jobs. You need as many exams as you can get and if you don't educate them it's like throwing them on the scrap heap'.*
>
> (Mother of a fifteen year old with renal failure in Bolton 1997, p15)

Bolton (1997) further suggested that the role of education may reflect the different stages of children's illness, but noted a balancing act is also required. Arguably, the balance may change quickly and shift from a health need taking priority, to all other aspects a child's 'normal' life being necessary to support the recovery process (Bolton, 1997).

While the link between the importance of education and future career plans has been raised within some of the research, few studies have discussed how children with medical conditions might be supported to plan for a career after leaving full-time education. Research on the employment of adults with CF has found that they experience many practical and prejudicial barriers preventing them from attaining their occupational aspirations (Edwards and Boxall, 2010; Demars et al., 2011; Claxton, 2012). In addition, the CF Trust (2007) have raised concerns about there being an absence of appropriate careers advice for adolescents with CF. Yet, educational importance is not always linked with future career aspirations in the research literature. There are many other unique benefits of attending school experienced by children with chronic conditions that have been identified.

A study by Closs and Burnett (1995), examined the wishes of parents in relation to the education of their children who were in the advanced stages of a life-threatening condition. The parents of two children with CF, who had died a few years previously, both at aged 21, were involved in the study. They commented that their children had been 'conventionally bright achievers' for whom the pursuit of knowledge and understanding was a pleasure in itself, despite frequent school absence and increasing fatigue (Closs and Burnett, 1995). Further, the parents

hoped that education would offer their children opportunities for intellectual satisfaction and success, which might have compensated for their physical limitations (Closs and Burnett, 1995). Even where children may not live far into adulthood, Closs and Burnett (1995, p387) suggest that through children's participation in education;

> …they can achieve success or fulfil their potential, experience peer friendships or companionship, have interests and activities which may distract them from the unpleasant aspects of their condition, leave behind a marker of their existence and above all, experience some aspects of a 'normal' life.

Closs and Burnett's (1995) position indicates that education remains important to all children with medical conditions, and for a variety of reasons which may be dependent on the health needs and experiences of individual children. Other research has suggested that adolescents with CF often encounter an array of challenges that can affect their overall attitude towards school, and these can have important implications of their academic success (Grieve et al., 2011). This suggests that awareness of children's attitudes towards school is significant in this research context. For example, understanding children and young people's overall happiness at school could be important in terms of the other educational experiences they encounter.

2.5   The educational and social implications of having a medical condition at school

The literature demonstrates that there are a number of educational and social implications experienced by children with medical conditions, including those with CF, in their education. The educational and social implications of having a medical condition at school are often linked to the overarching theme of school absence. Absence from school appears to have varying consequences for children's educational experiences within the literature.

2.5.1   School absence and keeping up with school work

A study by Lightfoot et al (1998) aimed to identify what National Health Service (NHS) support was needed by mainstream schools for children with a chronic illness or physical disability. The qualitative study generated data via focus groups with 35 teachers, semi-structured interviews with 33 pupils, 3 of whom had CF, and a combination of interviews and focus groups with 58 parents. Focus groups were

also conducted with education and health personnel. Young people, parents and teachers recounted the importance of attending school for academic and social reasons and all participants had similar concerns about how pupils were supported during periods of absence due to illness (Lightfoot et al., 1998). The academic implications of school absence were raised by the study, including the difficulties associated with being off school and missing school work. Young people talked about their dissatisfaction with the lack of arrangements in place to help them keep up with work, and this was also of concern to parents. Lightfoot et al (1998) also found that schools did not have procedures in place for sending work home automatically when a student with a medical condition was unable to attend.

Concerns about keeping up with school work have also been raised in the literature that specifically relates to the education of children with CF. Puckey et al's (2006) article on meeting the long term educational needs of children with CF, stated that children may miss a considerable amount of time at school, which might lead to feelings of anxiety about falling behind with schoolwork. Significantly, the article acknowledged that school absence may arise, not only for reasons relating to illness, but also due to frequent hospital appointments that are necessary for children's care (Puckey et al., 2006). A study by Bailey and Barton (1999) also identified similar issues. The research investigated the impact of hospitalisation on school inclusion and described the case studies of two young people with CF. Both students involved in the research expressed concerns about falling behind in their school work while in hospital. As with the study by Lightfoot et al (1998), the Bailey and Barton (1999) research found there were no specific arrangements for continuing school work for either student, with one student relying on her friends and parents to provide her with work to do while she was absent.

Research by Asprey and Nash (2006b) also suggested that gaining access to work while children could not attend school was a problem encountered by those with CF. As one young person said;

> *'I came back Monday, and English and some of the other subjects, I had totally lost them…this week I haven't understood a thing. If I don't know what's going on I can't really do the work properly. If teachers sent me work, actually sent me work instead of saying they will then don't'.*

(14 year old boy with CF in Asprey and Nash 2006b, p160)

Asprey and Nash (2006) reported that very few successful arrangements for catching up with school work were discussed by the children and young people interviewed for the study. However, a secondary school teacher involved in the

research did talk about one helpful strategy which had enabled a young person with CF to receive education during long periods of absence:

> *'She deteriorated, her last year was bad, but we had a very good relationship with the hospital…She might be there for weeks and we would send work up and they would liaise and then I would go up and visit her and she always enjoyed that, that was always good, we'd go up for meetings and things'.*
>
> (Assistant secondary headteacher in Asprey and Nash, 2006, p165)

This perspective demonstrates that remaining in contact with students with CF during periods of absence is a helpful school practice that could reduce the possibility of children falling behind with their schoolwork. Yet, the research would suggest that there is inconsistency between schools in helping children to carry on with schoolwork when they are unable to attend school (Bolton, 1997; Lightfoot et al., 1998; Bailey and Barton, 1999). It is possible that some teachers may experience uncertainty as to whether it would be appropriate to make contact with families who have a chronically ill child absent from school. Nevertheless, much of the literature states that for the majority of the time, social contact from school is welcomed by families (Close and Burnett, 1995; Bolton, 1997; Close, 2000; Mukherjee et al., 2000; Asprey and Nash, 2006a; Robinson and Summers, 2012).

2.5.2   Returning to school following absence

In addition to the issue of falling behind with schoolwork, other academic implications arising from school absence have been reported in the literature. Reintegration into school following a period of illness is likely to be of concern to children with CF. As Harris and Farrell (2004) have noted, it is important to establish reintegration objectives as soon as it is appropriate. The two participants with CF in Bailey and Barton's (1999) study reported that thoughts of returning to school and home after being in hospital were dominated by worries about school work and the need to catch up. One young person appeared to suggest that catching up with work was his own responsibility, adding that his teachers would not run over the work he had missed (Bailey and Barton, 1999). Similarly, the parents involved in Bolton's (1997) research suggested there was varying support available to help their children to catch up when returning to school after a period of ill health.

It may be possible that teachers face particular difficulties with enabling pupils to catch up on work missed during prolonged periods of absence. Norris and Close (1999) have suggested that in the drive towards raising school standards, it is

perhaps not surprising that some teachers come to view pupils with chronic conditions who fall behind in their work as problematic or even 'bad' pupils, rather than pupils of equal value who require additional support. This view mirrors one young person's experience in the Lightfoot et al (1998) study, who discussed feeling to blame for being behind when returning to school following a period of illness:

> *'Some of the teachers, if I asked them to explain it they would just say it's your own fault for not being here and I'd say 'well it ain't my fault' I would like more help with the work. I just couldn't understand it sometimes'.*

(Female student, aged 13 in Lightfoot et al 1998, p52)

Lightfoot et al (1998) described such experiences as a form of 'exclusion from the curriculum'. Indeed, similar forms of exclusion from the curriculum have been reported in research elsewhere. For example, Yates et al (2010) described the case of one young person who due to being hospitalised, was told she would not be able to complete the work required to allow her to study her chosen subject of Visual Communications, and would have to select a different course. Ultimately, the inflexibility on the part of her school led the young person to change her school placement in order to study the subject she had originally chosen (Yates et al., 2010). Nevertheless, the research would suggest that as a consequence of school absence, children may experience significant gaps in their subject knowledge (Bolton, 1997) and problems with educational attainment (DfE, 2015). The issues of falling behind and catching up with school work, along with the help and support required by children with CF during school absence, represent important areas of interest to this study.

2.5.3 Disconnected peer relationships

Falling behind and catching up with school work are not the only implications of school absence discussed within the literature. Other significant consequences of school absence have been described, such as children being socially isolated from their peers. For many children and young people, a significant aspect of school may be the friendships that they form, rather than academic learning. For children with medical conditions, relationships may be even more significant since absence can disrupt relationships and create loneliness (Closs, 2000). Indeed the Yates et al (2010) study found that the majority of young people who participated in the

research had experienced some disconnection from friends during their absences from school.

Bolton (1997) argues that children who are out of school long term may find that their social contacts diminish quite dramatically in the early stages, unless their peers are encouraged and helped to stay in touch. Bolton (1997) presented the experiences of one parent who explained that no matter how ill her son was, the school never sent him a card or telephoned to see how he was, and his closest friend was not told when he was absent. The parent felt that her son needed more reassurance with each school absence, and his close friend also needed information about her son and support to maintain their friendship (Bolton, 1997). Certainly the participants involved in the Lightfoot et al (1999) research were appreciative of any concessions teachers made to allow them to spend time with friends during school time. Contact with their friends was sometimes limited at school due to spending break times having treatments, and some participants reported that their teachers would allow their friends to keep them company so they did not feel excluded from social activities (Lightfoot et al., 1999).

The literature suggests that children with medical conditions experience challenges in relation to school absence and this demonstrates that there are wider implications of CF in the educational context that extend to falling behind with school work and disconnected peer relationships. The literature also raises issues around the help and support available in relation to school absence. Therefore, it follows that exploration of the educational and social needs of children with CF in this study is needed in order to more fully understand their educational experiences.

2.6   The medical implications of having CF at school

The medically orientated impact of having a medical condition at school is likely to be influenced by the individual condition that a young person lives with. This section therefore considers some of the medical implications of having CF at school. Puckey et al (2006), writing as specialists in the area of CF, identify a number of scenarios where the condition can impact on school experiences:

- CF treatments are time consuming and the child must get up much earlier if they are not to be late for school;
- It is vital that the child coughs to remove the mucus from their lungs and this can lead to persistent coughing which may cause the child to need to leave the classroom, or be teased as a result of coughing;

- Medication must be taken at regular intervals throughout the day, particularly with food; children observed taking capsules may be teased as "druggies";
- Mealtimes are supplemented with high calorie snacks; this is contrary to what is perceived as healthy eating and an ignorant teacher may unfairly stigmatise the child;
- Some children with CF may have steroids as part of their treatment and this can change the shape of their face, which may make the child self-conscious and may lead to teasing from other children;
- A child may be less than average height and weight for their age which again may make the child self-conscious and may lead to teasing from other children;
- A child may need to leave the classroom urgently to go to the toilet due to diarrhoea and/or stress incontinence and an ignorant teacher may try to prevent the child leaving the classroom.
(Puckey et al., 2006)

Indeed, research studies involving children with CF have discussed children's experiences of their health needs at school. The following sections consider some of the specific medical implications of having CF in the school context, along with some of the challenges related to the health needs of children and young people with CF.

2.6.1 Toilet needs

One problematic area raised in the literature in relation to the impact of CF at school relates to the need for children with CF to use the toilet urgently due to the unpleasant digestive symptoms caused by CF. The Asprey and Nash (2006b) study described young people's experiences of this issue in detail. Problems included being denied permission to use the toilet during lesson time, being afraid to use the toilet due to a lack of privacy or children having to explain to staff on duty why they were using the toilet and finding it difficult (Asprey and Nash, 2006b). Similar concerns have been raised in other research involving children with CF (Bolton, 1997; Lightfoot et al., 1998; Closs, 2000). Asprey and Nash (2006b) did however report that for some children, special arrangements had been made which provided a workable solution to such difficulties. For example, some schools allowed children with CF to use an accessible toilet, while others provided children with 'exit cards' which allowed them to leave the classroom when necessary (Asprey and Nash, 2006b).

2.6.2 Administering CF treatments

Another issue that may affect children with CF in the school setting relates to the practical implications of administering treatments and medications around the school day. The research involving children with CF frequently discusses the administration of Creon or other pancreatic replacement therapies, which must be taken whenever children eat at school. Some negative experiences of needing to take Creon at school were reported in the Asprey and Nash (2006b) research. One primary school student experienced a problem in gaining access to his Creon that he needed for a break time snack as it was locked away in a classroom. Asprey and Nash (2006b) claimed that the best arrangement is usually to have children take responsibility for their own Creon. This approach would be consistent with government guidance which states that children who are competent should be encouraged to take responsibility for managing their own medicines (DfE, 2015). It is possible that some schools may have concerns about the safety of other pupils who may come into contact with such medications. However, Puckey et al (2006) note that except if taken in vast quantities, Creon would cause no more that mild discomfort if taken by a child without CF.

Children and young people who had received regular courses of IV antibiotics, nasogastric feeding and gastrostomies were involved in the Asprey and Nash (2006b) research. However, they did not discuss the administration of associated treatments at school, yet referred to school practices that would protect them from physical harm, such as making adjustments during physical education (PE) or at break times. There is an absence of children and young people's experiences of having physiotherapy or doses of IV antibiotics in the school setting. This may be because the majority of treatments for a 'typically affected child' can take place at home, before and after the school day (Puckey et al., 2006). Nevertheless, other research has shown that there may be difficulties in following a medical regime in the school setting. The Lightfoot et al (1998) study found that parents had concerns about the appropriateness of school buildings for pupils having medical treatments in school. For example, one parent in the study mentioned there was no hygienic space available at school for their child to administer treatment and they often used the toilets instead (Lightfoot et al., 1998). Another parent said that their child had to finish his physiotherapy early because the room they were using was needed for other purposes (Lightfoot et al., 1998).

A further concern identified by Lightfoot et al (1998) related to the administration of medication during school trips. They discussed the case of a child with diabetes

who needed help with her injections in order to participate. Some children with CF can develop CF related diabetes, although this is more common in adults with the condition (Conway et al., 2008). A teacher in the study spoke about his willingness to learn how to give the injections, but was advised by the LA not to take on such responsibilities and consequently, the child was unable to attend the school trip. The argument that ambiguity remains around the identification of who should be responsible for administering medicines at school is therefore reflected in this case.

2.6.3 Symptoms and side effects

The literature would certainly suggest that children with medical needs can experience symptoms arising from their condition, or side effects as a result of treatments, which could potentially interfere with their school life (Bolton, 1997; Lightfoot et al., 1998; Closs, 2000). In the context of CF, Grieve et al (2011) claim that the chronic nature of the condition, illness complications and treatment side effects can have a cumulative effect on academic achievement. Thies (1999) states that oral steroids used to treat inflammatory processes in CF can cause depressed mood, anxiety, weepiness and difficulties with sleep. However, steroids are unlikely to be prescribed for all children with CF, or used in the long term except for a minority of cases (Conway et al., 2008). Thies (1999) does acknowledge that fatigue is a major side effect of many chronic conditions and treatments, and that this may make it difficult for students to keep up with school work. This compares with Jackson's (2013) view who also suggests that fatigue may have effects on attention and memory. Significantly, she notes that such effects may not always be obvious to teachers (Jackson, 2012). The children and young people with CF involved in both the Asprey and Nash (2006b) research and Bailey and Barton's (1999) study widely discuss the symptoms of the condition and side effects from treatments in relation to the associated impact on their school experiences. Such examples included; experiencing breathlessness in PE; finding it hard to move around the school building, having a coughing fit and being sent home; stomach ache; lacking energy; and feeling tired in class (Bailey and Barton, 1999; Asprey and Nash, 2006b). Therefore, the literature demonstrates how the symptoms and side effects associated with CF might have implications for children's educational experiences.

2.6.4 The CF diet

Puckey et al (2006) cite the particular importance of nutrition for children with CF, stating that a dietary intake with high fat and protein content is necessary, with some children and young people requiring as much as 150% of a normal calorie

intake. Difficulties may be experienced by children with CF around lunchtimes at school. For example, Puckey et al (2006) point out that a government and media focus on healthy eating make it increasingly difficult to negotiate with schools for a child with CF to bring in high fat snacks such as crisps and chocolate, which may be necessary to ensure that they are receiving adequate nutrition. This view compares with findings in the Asprey and Nash (2006) study, which often saw that schools would only allow children to eat fruit at break times due to their healthy eating policies. One parent in the research said that such policies had somewhat paradoxically resulted in her daughter's school not taking her health needs into account (Asprey and Nash, 2006b). This suggests that maintaining a CF diet at school may be problematic for some children with CF.

2.6.5 Cross-infection

While CF is a rare condition, there remains the possibility that more than one child with CF could attend the same school. This may introduce the risk of cross-infection. There is little research that uncovers what school practices are helpful in this scenario. The CF Trust (2007) explains that a thorough risk assessment and plan would need to be in place to ensure that the risk of cross-infection is minimised at school, but in the case of siblings, a different approach to cross-infection will be taken, given that they inevitably share space together at home. The Asprey and Nash (2006b) study discussed the case of one young person who was placed in the same class as another girl with CF, despite her mother's frequent visits to the school to explain why this should not happen. It is therefore possible that some schools may not appreciate the risks involved with cross-infection, which may be detrimental to the health of children with CF. A study by MacKay (2011) on the effects of segregation in adolescents with CF, discussed the issue of cross-infection within a context of hospital teaching services. She stated that the young people with CF involved were generally not permitted to socialise amongst each other or attend group activities in the hospital school, unless it involved non-CF children only (MacKay, 2011). This suggests that the issue of cross-infection may have consequences for the kinds of education that children with CF can receive whilst admitted to hospital, and therefore justifies the involvement of the hospital school within this research. In addition, given the dearth of literature on the area of cross-infection at school, this represents an opportunity for this study to highlight new information in relation to this issue.

2.6.6 Significant areas of the curriculum

The literature suggests that there may be specific areas of the school curriculum that are particularly significant to children with CF. For example, PE is one area reported in the literature that some students with CF might struggle with (Bailey and Barton, 1999; Lightfoot et al., 1999; Asprey and Nash, 2006b). Asprey and Nash (2006b) reported that some children and young people found it difficult to participate in PE if they were particularly breathless or had an IV line or gastrostomy fitted. Conversely, they also noted that individuals with CF often really enjoy taking part in sport and are encouraged to participate by their health teams due to the beneficial effects of exercise (Asprey and Nash, 2006b). Another area of the curriculum mentioned in the Asprey and Nash (2006b) research of significance to individuals with CF was school science. Asprey and Nash (2006b) stated that there was sometimes a lack of awareness amongst school science teachers that there was a student with CF participating in the class. They reported several upsetting situations experienced by young people when participating in science lessons relating to genetics. Such lessons had used CF as an example of a genetically inherited condition, and the young people reported that information about CF used in the lessons was inaccurate and outdated. They also noted that these scenarios were at least as upsetting for the teachers involved when they discovered one of their students had CF, as they were to the young people themselves. This demonstrates that significant curriculum areas to children and young people with CF are an important consideration for this study. These areas have implications for addressing not only the needs of students, but also for the needs of those who teach within such areas.

I have discussed some of the medical implications of having CF at school. This has highlighted a need for the research to address some of the practical considerations of being a school-aged child with CF such as; being able to use the toilet at school; the administration of medications; symptoms and side effects; the CF diet; cross-infection; and significant areas of the school curriculum. The literature in this area also emphasises that the research should consider the perspectives of parents, school personnel, and members of the hospital school in addition to children and young people with CF.

2.7   Educationally supportive provision

This section considers what the literature reveals in relation to some of the supportive practices of those involved in the education of children with medical conditions, including those with CF.

2.7.1   Awareness and understanding

By far the most reported helpful and supportive practice identified within the literature concerning the education of children with medical conditions relates to awareness and understanding of the child's condition in the school context (Bolton, 1997; Lightfoot et al., 1998; Closs, 2000; Asprey and Nash, 2006a; Taylor et al., 2008; Yates, 2014). Asprey and Nash (2006a) found that there were specific problems around awareness and understanding associated with less visible conditions such as CF for whom 'the level of awareness in school was often low' (Asprey and Nash, 2006a, p16). They described problems with teacher understanding of the symptoms of and treatments for CF, the consequences of which were a heightened sense of difference for the young people resulting from unexpected incidents which drew attention to them and their CF in the classroom (Asprey and Nash, 2006b). Similar problems relating to awareness and understanding were not reported by the young people with degenerative neuromuscular diseases involved in the research who were often wheelchair users and so their condition was visible to other people at school.

It seems likely this lack of awareness of CF may lead to there being little consideration within the school context about the emotional and psychological impact of having CF as well as the other ways that CF might impact children and young people's experiences at school. In Bailey and Barton's (1999) research, they found that there appeared to be no special efforts made by teachers to positively include the two participants with CF at school. They argue that the failure to be proactive in considering the needs of students with CF could be construed as a passive form of exclusion with an absence of such proactive measures being a form of 'exclusion by neglect' (Bailey and Barton, 1999).

While the invisibility of CF may lead to a lack of awareness and understanding of the condition, it is also possible that children with CF may avoid telling teachers about their CF as a way of maintaining 'normality' (Taylor et al., 2008). Indeed, many other studies have identified that 'normalisation' is a factor used by individuals with CF to help them cope with and adjust to living with the disease (Bailey and Barton, 1999; Yates et al., 2010; MacKay, 2011). The participants in the

MacKay (2011) research also discussed keeping their condition private by way of maintaining the perception of being 'normal'. Findings discussed by Ferguson and Walker (2012), based on research with 31 young people with chronic illness, highlighted a clear message told by participants that they were not their illness, in the sense that they did not want it to define their identity. However, the normalisation of CF raises a complex situation in which individuals with CF may not gain adequate understanding of their condition in the educational context. It is therefore of significant interest to the research that children may reject or miss out on having support at school that could be beneficial to them due to their desire to fit in and appear normal (Bailey and Barton, 1999; MacKay, 2011; Ferguson and Walker, 2012). Of further consideration is how the participants in this study may view the need for educational support for children with CF. It follows that if children and young people prefer to adopt a normalised persona, the idea of having support at school may be rejected by them. To this end, I believe that the research questions should allow children and young people with CF to self-identify, and to articulate their own understanding of their condition, in order to consider how this might influence their educational experiences.

2.7.2 Communication

Closely related to teacher awareness and understanding is the issue of communication. As Asprey and Nash (2006a) argue, if a school does not manage to communicate effectively with children and other stakeholders, awareness of the child's needs in school is likely to be low. Closs (2000) suggests that good communication enables better education and is best established by staff who understand the basis of interpersonal relationships. In the Bolton (1999) study, there were some successful examples of schools maintaining good communication throughout pupil's absences and children clearly valued school staff who made an effort to initiate contact with them. One parent discussed the use of a home-school diary that the teacher could write notes in to inform her of her child's health at school (Bolton, 1997). The Bolton (1999) research, along with other studies, identified three key practices that were important for good school communication. These key practices included, one person taking a lead at school, inter-agency working and schools taking ownership of children with medical conditions (Bolton, 1997; Lightfoot et al., 1998; Norris and Closs, 1999; Farrell and Harris, 2003; Harris and Farrell, 2004; Asprey and Nash, 2006b; Dixon, 2012). Therefore, it is to each of these practices that I now turn.

The significance of having one key person at school is discussed by Dixon (2012), who argues that this is particularly important in the secondary school context. Bolton's (1999) view is that in the case of large secondary schools, good communication intentions can be cast aside due to the sheer volume of work and calls for teachers' time and attention. Bolton's (1999) perspective therefore calls into question who exactly might be an appropriate key school person for other stakeholders to communicate with about the needs of children with medical conditions. One participant in Dixon's (2012) study describes the role of student welfare officers as the right person to be a 'key contact' in secondary school, while other research identifies the school SENCo as an appropriate key person (Bolton, 1997; Lightfoot et al., 1998; Asprey and Nash, 2006b). Despite the research demonstrating the significance of having one key person as a contact in the school context, the DfE (2015) guidance would suggest otherwise. While the guidance states that there should be a named person who has overall responsibility for policy implementation, it notes that there should be 'a commitment that all relevant staff will be made aware of the child's condition' and further, that 'any member of school staff may be asked to support pupils with medical conditions' (DfE, 2015). This suggests that communication with various stakeholders in relation to a child's educational and health needs may therefore be the responsibility of several teachers within a school.

A number of studies discuss the importance of inter-agency working within a context of educational support. Findings from the study by Lightfoot et al (1998) indicated a general need for a culture of inter-agency working. Results from the focus groups conducted in the study involving education and health personnel, suggested that professionals may need to meet on a more routine basis to discuss issues of common interest in supporting local children and families (Lightfoot et al., 1998). However, this approach may not be practical or feasible for the support of children with CF, given that medical professionals in CF care are highly specialised and the CF population is relatively small compared to that of other conditions. Several studies claim that there are often difficulties with engaging health agencies in school and education processes (Bolton, 1997; Lightfoot et al., 1998; Asprey and Nash, 2006b; Hopkins et al., 2014). For example, Hopkins et al (2014) claim there are complications with the co-ordination required between education and health care providers, and that these complications often result in difficulties with engaging health professionals in the process of implementing student health plans. Similar findings were reported by Asprey and Nash (2006a) who argue there is a very real need to instigate a regular dialogue between health and education agencies so that

teachers and support staff can be reliably and accurately informed and supported by health professionals. The research evidence therefore illuminates a need for this study to consider how health and education services work together to address the educational needs of children and young people with CF.

A central component of an interdisciplinary approach to educational support has been suggested by Bolton (1998) and Harris and Farrell (2004) . Both these studies identify the significance of 'mainstream ownership' in joint working practices. Harris and Farrell (2004) state that mainstream ownership can be conceptualised as the pupils' mainstream school maintaining a high profile during the time their pupil is receiving education in an alternative setting due to illness. Similarly, Bolton (1997) argue that the school has a key role in maintaining educational continuity. A key message from the parents involved in Bolton's (1997) research was that they wanted mainstream schools to be active partners with hospital teachers and home tutors in their child's education out of school, as well as the provider of education inside the school setting. This shows that when children and young people are absent from school and are admitted to hospital, it is important that schools remain in communication with alternative educational providers such as the hospital teaching service, to allow education to be appropriately continued. Again, this suggests a need for the hospital teaching service to be involved in the study, and further demonstrates that this research should consider interagency working arrangements in relation to children and young people's educational experiences.

2.8 Frameworks for understanding the educational experiences of children with CF

2.8.1 The SEN framework

I have already stated that much of the literature on the education of children with medical conditions often discusses children's education in a context of the support available through the SEN framework (see section 2.3.1). While arguments relating to the different understandings of SEN terminology, and debates around children's access (or lack of) to educational support under the SEN framework remain of interest to this study, it is not the intention of the research to assume that children and young people with CF do or do not have SEN, or that their needs should or should not be considered within a context of SEN. Existing research has not revealed if children and young people with CF are generally considered to have SEN, nor has it given an indication of the number of individuals with CF who might

access educational support through SEN systems and procedures. Further, it follows that children and young people with CF may not consider their educational experiences within a SEN or disability context as they may reject any label that they perceive to be negative (Shakespeare, 2006; Yates et al., 2010). It is therefore important that the research allows children with CF to articulate their own understanding of their needs in education. There are many different factors that are likely to influence children's educational experiences, and these factors may not specifically relate to SEN, disability or any obvious difficulty in learning. Therefore, I would argue that applying the SEN framework to the study would be counter to an ontological position that enables children to self-identify their educational needs and experiences.

The term 'inclusion' is often used synonymously with SEN, as it came to be used out of a concern to educate students with SEN and disabilities in mainstream settings (Lunt, 2007). I take a broader view of inclusion such as the position adopted by Florian (2008) that inclusion is the principle that local schools should provide for all children regardless of any perceived difference. Booth and Ainscow (2011), who developed the 'Index for Inclusion', have a similar standpoint and suggest that inclusive principles are relevant to all children, schools and education personnel. I see the principles contained within the Index for Inclusion as being of significance to children and young people with CF. For example, the Index suggests reducing barriers to learning and participation for all students, not only those with impairments or those who are categorised as having SEN (Booth and Ainscow, 2011). Therefore this study draws on a broader view of inclusion in a context of the education of children and young people with CF.

2.8.2 Disability and health frameworks

The main paradigm of classification and intervention for children with medical conditions is primarily medical, in that the medical labels assigned to them tend to be aetiological and pathological (Bailey and Barton, 1999). There are criticisms of a medical model approach to understanding issues of health and disability, because it considers that a person's functional difficulties are located entirely within the person and are the source of any disadvantages (Barnes and Mercer 1996). Within this ideology there is a focus on medical intervention and rehabilitation in response to difficulties (Shakespeare and Watson 2001) and educational solutions are often perceived in terms of treating or 'fixing' the child (Close, 2000). The medical model has been widely rejected within the education sector because it categories children with different medical conditions into groups and attributes difficulties to the

condition itself (Asprey and Nash, 2006a). The medical model may also encourage a distanced attitude in teachers, who may feel that responsibility for the child lies predominantly with health professionals and so may consequently disregard the need to take active steps to include such children in the education setting (Bailey and Barton, 1999).

Critics of the medical model often favour a social model approach to health and disability. For example, Jackson (2013), suggests that a more empathetic approach through a social model of disability would ensure that students are more actively involved in their interactions with education. The social model views disability as a form of social oppression (Shakespeare and Watson, 2001) and difficulties are presented as a result of an excluding society and structural factors which fail to consider or adapt to people with impairments (Beresford, 1997). In this respect, Bolton et al (2000, p41) argue that;

> *Children and their families are systematically disadvantaged by societal*
> *systems and attitudes when trying to achieve normal human*
> *aspirations, including accessing effective education.*

A social model approach to difficulty or illness therefore involves identifying and removing exclusionary barriers in society (Oliver, 1996). Many authors argue for the implementation of a social model approach within education systems, (Jung, 2002; Oliver, 2004; Jackson, 2012), as this is likely to foster a more helpful attitude towards the difficulties experienced by children and young people with medical conditions, attributing any problems to the educational systems rather than the child's illness (Asprey and Nash, 2006a). While the social model approach has been described as a fundamental principle in initiating the disability rights challenge, and has been effective in highlighting the human-created obstacles to participation in society (Shakespeare, 2006), the model is not without problem. The social model overlooks the transformative effect of medicine that reduces symptoms and impacts the survival of those with CF. It also underplays the difficulties arising from the burden of medical treatment such as drug related side-effects, pain and discomfort, fatigue or the subsequent reduction of time left to participate in other activities. The social model fails to recognise the role of impairment, as well as the range of different impairment and disability experiences (Shakespeare, 2006). Given the social model is based on society as oppressive and excluding, and CF is mostly invisible, it may not consider those with the condition to be disabled or in need of the removal of exclusionary barriers to

participation. As Shakespeare (2001) argues, visible impairments trigger social responses, while invisible impairments may not.

That is not to suggest that people with CF are disabled, even though in practice it is hard to say that people with multiple sclerosis , HIV or CF are not disabled people, and it has been important to include such conditions in disability discrimination legislation (Shakespeare, 2006). There is overlap, particularly in the large grey areas between disability and illness, and fitness and sickness, and there are gaps (Closs, 2000). Therefore, children and young people with CF, their parents and other stakeholders may or may not consider that having CF also constitutes having a disability. Indeed, they may or may not consider that people with CF experience oppression in society, for some or all of the time. Nevertheless, different conceptualisations of disability are salient to the research as these offer varied understandings of CF in different contexts and in relation to children and young people's participation and learning at school. This is important because descriptions and categorisations of disability are often context specific. This is well exemplified in medical conditions when the same condition can lead to different experiences, dependent in part on its severity and the school response (Porter et al., 2008).

When considering the current study, neither the social or medical model alone is satisfactory for understanding CF and the educational experiences of children with the condition. Some researchers argue for a combination of the social and medical model to be used, particularly in relation to the education of children with medical conditions. Robinson and Summers' (2012) literature review identified that children and parents need teachers to know and understand the child's symptoms and how the treatment regimes affect their school experiences and psycho-social aspects of their lives. Similarly, Asprey and Nash (2006a, p16) express that:

> *It is imperative that awareness of the individual's health needs is raised*
> *so that the young person can be adequately supported in their school.*
> *In addition, the problems arising from the education system itself, or*
> *from individual teachers' attitudes and practices, also need to be*
> *identified.*

Indeed, this study also considers that both the medical and social models of disability are needed in order to explore and understand the educational experiences of children with CF. However, I would argue that in addition to the adoption of medical and social models, consideration of the interactions between the individual and structural factors is also needed (Shakespeare, 2006). Therefore,

consideration now turns to an interactional and ecological approach for understanding the educational experiences of children with CF.

2.8.3 Towards an interactional approach for understanding the educational experiences of children with CF

In this study, I draw on the view that disability is an interaction between impaired bodies *and* excluding environments (Shakespeare and Watson, 2001). I adopt this approach to enable the medical and social models to actively engage with one another (Thomas, 2004) and to recognise the additional interconnected and interactional factors that make up children's experiences: bodily, psychological, cultural, social and political (Shakespeare and Erickson, 2000). Therefore, the research seeks to consider children's educational experiences within an interactional and ecological framework so that the multiple systems in which children and young people with CF participate are taken into account. As Robinson and Summers (2012, p204) have noted;

> *Ecological models seek to acknowledge the real-life interplay of the medical and social models by focusing on the dynamic systems in which they operate, such as the home, school and health service.*

One such ecological model is the biopsychosocial approach which was originally adopted by Engel (1982) who discussed the need for medicine to adopt a more inclusive scientific model to understanding patient care. The biopsychosocial model takes account of the role of the biological, psychological and social factors in children's health and therefore represents a useful approach to understanding the educational experiences of children with CF. The model allows consideration of the ecological interactions between: the biological factors relating to CF; the school, home and health environment; and the social, emotional and academic factors at play in children's lives (Figure 2.1). Further, the model is sensitive to the different lived experiences of CF and can therefore account for the heterogeneity of children with CF as a group of individuals.
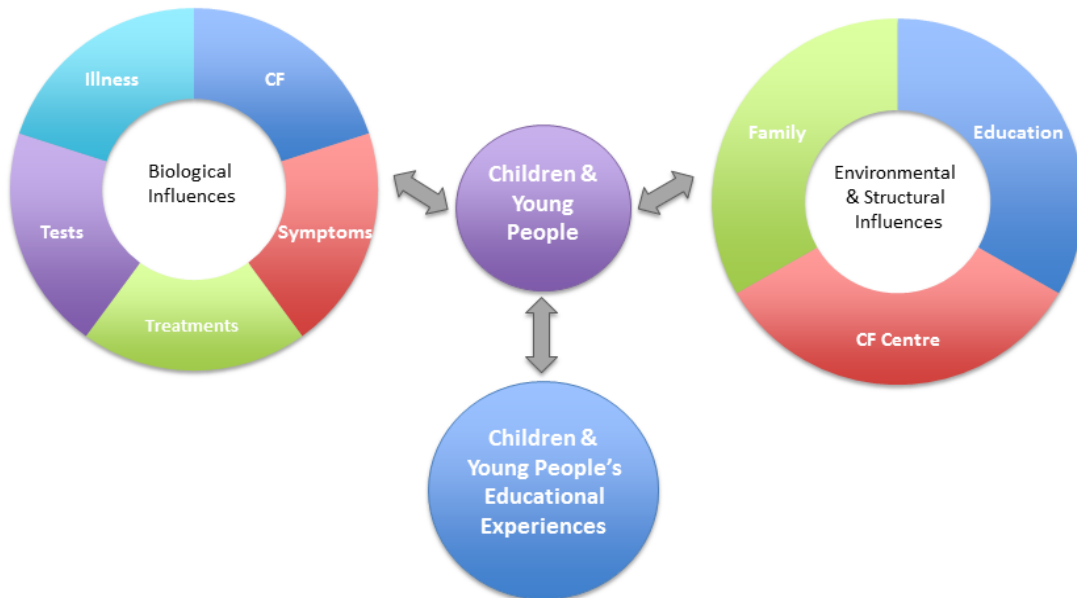
Figure 2.1 *Biopsychosocial interactions involved in the education of children with CF*

The distinctive feature of the biopsychosocial approach is the way in which the psycho-social systems and internal and external biological systems interact and influence one another (Cooper et al., 2013). By way of example, in terms of the education of children with CF, a biological and environmental interaction may involve the influence of CF symptoms on the child at school, which may then have the influence of the child falling behind in their schoolwork (Figure 2.2). This experience for the child may have further interacting influences at the environmental level, such as the child getting into trouble for not keeping up at school, particularly if the factors at the biological level are not taken into account, for example.
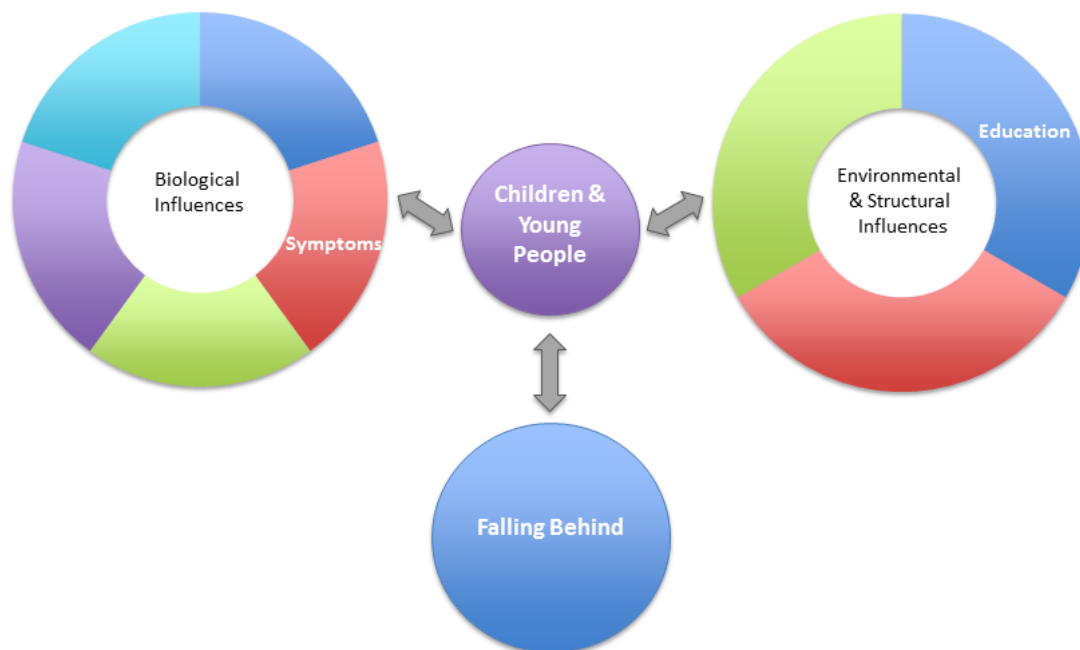
Figure 2.2 Example of a biopsychosocial interaction influencing a child's educational experiences

The biopsychosocial model has been applied in various contexts, including the treatment of chronic pain disorders (Gatchel et al., 2007), interventions for children with social, emotional and behavioural difficulties (Cooper et al., 2013), as well as the education of children with medical conditions (Robinson and Summers, 2012; Hopkins et al., 2014). The biopsychosocial approach can be seen as being essentially ecological in nature, making it truly holistic and therefore capable of capturing the complexities of the educational experiences of children and young people with CF (Cooper et al., 2013). Therefore the model can provide greater insights into children's educational experiences than a simple combination of the social or medical models, or use of these approaches in isolation of each other.

There are criticisms of the biopsychosocial model, although these mostly lie in the field of medicine. For example, Ghaemi (2010) argues against medical physicians attempting to understand all the factors that make up a person's ill health. He argues that the physician who adopts the biopsychosocial model is in real danger of losing clear boundaries with regard to their knowledge and expertise (Ghaemi, 2010). However, this perspective appears contradictory to the 'good practice' approach of integrated children's services, which involves having an understanding of the multiple interacting factors in children's lives so that services are able to work together more effectively (Davis, 2011). The insights from different agencies who work with children and young people may pave the way to more effective support

for them. This is the crux of a biopsychosocial approach to understanding the educational experiences of children with CF. Nevertheless, as Porter et al (2009) have rightly argued, the views of children, parents and other stakeholders are also integral to understanding the impact of CF on children's education, and primacy should be given to their reports.

2.9 Summary

The current research evidence about the links between CF and education illustrates that children and young people with the condition may experience vulnerable educational circumstances. However, much of the research considers children with medical conditions to be a homogenous group and fails to account for the unique characteristics and variable nature of CF. Therefore, the specific vulnerabilities experienced by children with CF in education remain largely unknown. The duty placed upon schools to support children with medical conditions is new in its approach and it may be too early to establish the impact of this government policy (DfE, 2015). Further uncertainties around the application of SEN and disability policy to children and young people with CF could mean that they are unable to get the support they need most in their education.

Some of the themes arising in the body of research reviewed may well be of concern to both primary and secondary children with CF. The literature has demonstrated the importance of education to children with medical needs, regardless of disease severity. This has shown education to be important for reasons that extend beyond future aspirations or career plans. There are likely to be educational and social implications arising from having CF at school. Issues within the theme of school absence such as falling behind and keeping up with school work, and disconnection from friends are all of relevance to this study. Nevertheless, school absence does not necessarily affect all children with CF. Indeed, many children are able to attend school while receiving intensive treatment for chest exacerbations and some may rarely experience ill health at all during their time at school. Existing research has examined the issue of receiving treatment in hospital in a context of school absence. Yet, there are no studies that have considered children's experiences of having intensive treatments while attending school. Further, little is known about the education received by children and young people with CF when they are not well enough to attend school or when they are hospitalised. These factors are likely to be significant to the educational experiences of some children with CF and they raise questions relating to inter-

agency working between education and health care providers, parental experiences, teacher knowledge of CF and importantly, children and young people's experiences of education during such periods.

The majority of children with CF will have a vast regime of daily treatment in order to stay well. Puckey et al's (2006) article goes some way to identifying how CF might impact on children while they attend school, but there is an absence of the voices of children, parents and other stakeholders in the paper. Other studies have also suggested there are certain health implications of having CF at school, such as the need to use the toilet urgently, the administration of CF treatments, possible symptoms and side effects, following a CF diet and issues relating to cross-infection. These areas highlight a need for this study to address some the practical considerations of being a school-aged child with CF, such as how children experience CF symptoms, their treatments and procedures for administering CF medication or having treatments at school. It is possible that primary and secondary students could have different experiences in relation to these issues, due to the variations within and between the systems and structures associated with different provisions.

The presupposition that children with medical conditions are in need of educational support is a key feature of much of the literature. Supportive provision in relation to the awareness and understanding of children's medical conditions at school was identified in several studies, in addition to the closely related theme of maintaining good communication. However, the subject of receiving 'support' to children with CF may be contentious as the research also shows that they have a strong desire to be seen as 'normal'. The literature further revealed there are dilemmas that exist within the issue of educational support. For example, some children may choose to keep their condition private in order to maintain a sense of normality and this could result in a lack of understanding of CF and any subsequent needs by school staff. Consequently, this research is primarily interested in the views of children and young people with CF on their own needs in education, alongside the perspectives of parents and education and health personnel.

Finally, an exploration of the possible frameworks for understanding the educational experiences of children with CF revealed the biopsychosocial model to be superior to other approaches, within a context of this study. It was argued that this model allows the interconnected and interactional factors that make up children's experiences to be considered. A review of existing literature has also demonstrated the need for an exploratory approach to the research, because it cannot be

established if the conclusions made by more general studies on the education of children with medical conditions are also applicable to all children and young people with CF, even where such studies have included those with the condition. Nevertheless, existing studies have provided possible areas of exploration that may be relevant to the education of individuals with CF. The literature has further evidenced the need for the involvement of stakeholders in addition to children with CF, including parents, and education and health personnel, in order to enable a deeper understanding of issues in education relating to children with CF from multiple perspectives and contexts.

This chapter has addressed the first research question by identifying the current research evidence about the links between CF and education. Three further research questions for this study were informed by the review of the literature contained within this chapter:

- What are the perspectives of children and young people with CF on their educational experiences and needs?
- What are the perspectives of other key stakeholders on the education of children and young people with CF?
- How can the study data inform developments in the education of children and young people with CF?

The next chapter provides the rationale for a further methodologically related research question and revisits all the research questions relating to this study. It describes the development of the methodology and research design that will generate the data needed to answer these questions.

Chapter 3 Methodology

3.1   Introduction

This chapter provides the rationale for the methodology chosen for this study. I begin by discussing four key overarching factors that orientated the research decisions and led me to position the study within a mixed methods tradition. Then, I revisit the research aims and questions relating to the study. Following this I provide details about the research design including: the participants; the data generation methods and data analysis; and the validity and reliability of the study. Finally, the ethical considerations relating to the research are discussed.

3.2   Orientating the research decisions

Much of the research relating to CF is concerned with furthering clinical improvements and therefore adopts a positivist ideology more commonly associated with the medical sector. Therefore, it is unsurprising that there is a dearth of interpretivist research that considers the views of people with CF on non-medical aspects of living with the condition. In the current study, four key overarching factors governed the methodological decisions made. These factors led me to conduct the research from a pragmatist perspective. In addition the factors informed the development of a methodologically orientated research question which will be introduced at the end of this section.

The first factor related to the heterogeneity of children with CF. I needed to consider ways of capturing children's heterogeneity within the study. While there are many features of CF that are common to all those with the condition, such as breathing and digestive difficulties of various intensities, there are also many distinctions. One such distinction can be found in the treatment routines of those with CF. Some children may require regular aggressive treatments requiring numerous hospital admissions, while others may complete such treatments at home. Further, there are those who may not require extra therapies in addition to their daily maintenance routines and therefore may rarely be admitted to hospital, if at all. It follows that these treatment differences have the potential to impact children's educational experiences in different ways. It was therefore necessary to take account of the

diversity of children with CF and their different treatment experiences in the research design.

A second factor governing the methodological decisions taken during the research related to there being ecological and interactional influences on the educational experiences of children with CF. Discussion of a biopsychosocial interactional model as a means to explore children's educational experiences has been discussed previously in Chapter 2 (see section 2.8.3). In summary, the research recognised the interconnected and interactional biological and environmental factors that make up children's experiences. Therefore, the study design considered the multiple systems in which children and young people with CF participate in connection with their educational experiences.

A third factor that influenced the research decisions related to the issue of cross-infection (see section 1.2.1). This was an important ethical and practical issue that concerned the safety of both the children and young people with CF who participated in the study and myself as the researcher. The risk of cross-infection is greatest when people with CF are together in the same physical space. Therefore, all aspects of the research process needed to take place without physical meetings either with children with CF or with other individuals within the spaces that children with CF might reside.

A forth overarching factor connected to the methodological choices made throughout the study concerned the value of experiential knowledge, both in terms of my own experiences as a researcher with CF and the experiences of the participants. Indeed, some service user researchers have sought to gain credibility and legitimacy for experiential knowledge claims alongside other sources of knowledge and evidence (Glasby and Beresford, 2006). Therefore, the methodological tools selected have enabled participants to impart aspects of their experiential knowledge. In addition, the process of reflexivity has been adopted in order to consider the influence of my researcher positioning throughout the study.

The four overarching factors governed the research decisions and taken together, they orientated the study towards a 'what works' approach in order to generate data that would address the research questions. This ultimately led me to position my study within a mixed methods tradition. I therefore consider that there are both singular and multiple accounts and interpretations of reality. Consequently, the research utilised a pragmatic approach and valued both quantitative and qualitative data generation. In addition, elements of the feminist paradigm were adopted in

order to give consideration to my research positioning. As Letherby (2013, p81) suggests;

> *Feminist researchers argue that we need to consider how the researcher as author is positioned in relation to the research process; to ignore the personal involvement of the researcher is to downgrade the personal.*

As an adult living with CF who is also researching issues relating to CF, from a naturalistic perspective, one might argue that this position enables me to get closer to the 'inside'. I understand that the research design and the way that the study was conducted could not take place in isolation of my own biography as the researcher and the wider society, and that the findings could not be unaffected by these (Hammersley and Atkinson, 2005). In this respect, a methodologically focused research question was developed in light of the factors that governed the research decisions:

- What issues and challenges arise in relation to the specific research context and how can these be responded to?

3.3   Research aims and questions

My study has one broad aim which is to explore issues in education related to children and young people with CF. This aim stems from there being little research that concerns the education of children and young people with CF specifically. I therefore considered that this study should regard children's education from a broad perspective to enable child participants to self-identify educational areas of significance to them. This study also has four sub-aims which are:

- To explore and analyse the perspectives of children and young people with CF about their educational experiences
- To explore and analyse other key stakeholder understandings of the needs of children and young people with CF in education
- To make recommendations for appropriate educational provision for children and young people with CF
- To contribute to methodological knowledge by developing an appropriate method for research involving children when the proximity of the researcher and/or other participants is problematic

These aims will be met through addressing the research questions. The research questions consist of five main questions and sub-questions:

RQ1. What is the current research evidence about the links between CF and Education?

RQ2. What are the perspectives of children and young people with CF on their educational experiences and needs?

- To what extent do they feel their needs are understood, identified and met in their current educational provision?
- What factors do they perceive to be helpful to their educational experiences?

RQ3. What are the perspectives of other key stakeholders on the education of children and young people with CF?

RQ4. What issues and challenges arise in relation to the specific research context; namely:

i. A person with CF conducting research about CF?

ii. Involving children in the research?

iii. Conducting the research as a mixed methods study?

- How can these issues and challenges be responded to?

RQ5. How can the study data inform developments in the education of children and young people with CF?

All of the research questions will be addressed through the data generated from the methodological approach discussed in this chapter, except for research question one, which has already been addressed through the review of the literature discussed in Chapter 2.

3.4   Overview of the research design

The research employed a mixed methods design with two phases of data generation. The first phase utilised a questionnaire that was administered with 75 school-aged children with CF under the care of one regional paediatric CF centre in the north of England. In the second phase of the study a total of 14 interviews took place. Online interviews were used with 4 school-aged children with CF and 1 post-

school aged young person with CF. A combination of face-to-face and telephone interviews were used with 4 parents, 3 education personnel and 2 health personnel.

3.5   The use of mixed methods

The research design employed was considered the most appropriate for meeting the aims of the study, answering the research questions, and in light of the overarching factors governing the research decisions. The research utilised a sequential two-phase mixed methods approach generating the data using questionnaires and interviews. There were a number of reasons for the use of mixed methods in the study. Through the use of mixed methods I was able to use different forms of triangulation in order to increase the trustworthiness of the research. A range of participant sources were recruited to the study, which Denscombe (2010) refers to as informant triangulation. Between-methods triangulation (Denzin, 1978; Bryman, 2006; Denscombe, 2010) was also planned to allow the findings from each research phase to be combined. Bryman's (2006) notion of 'completeness' was another reason behind the mixed methods approach, in that the questionnaire and interviews allowed a more comprehensive account of children's educational experiences to be gained. The questionnaire allowed a larger sample of children with CF to take part in the research, while the interviews allowed an in-depth exploration of children's educational experiences. Having the results and findings of the two phases of research increased the amount of data available and allowed thicker, richer data to be obtained. Therefore the 'completeness' of the data enhanced my understanding of the educational experiences of children with CF. Finally, the use of the questionnaire and interviews allowed me to 'offset' the weaknesses of each method and draw on the strengths of both (Bryman, 2006).

3.5.1   Connecting the two research phases

The research was conducted as a mixed methods study, not only through the use of both quantitative and qualitative methods, but also through five major characteristics that connected the two phases of data generation. The two phases of research were connected by way of the following:

- Through the overarching factors that governed the methodological decisions (see section 3.2)
- Through generating and analysing data based on the same research questions (see section 3.3)

- Through the same eight broad constructs used to collect information about children's educational experiences throughout the questionnaires and interviews (see section 3.8)

- Through the participants; all the school-aged children and young people interviewed in phase two had completed a questionnaire in phase one (except one young person who was recruited directly via the CF centre, see section 3.6.2)

- Through combining the data generated by each research phase in order to consider confirmatory, explanatory or conflicting findings (see section 6.4.2)

3.6   The sample

3.6.1   Access and recruitment

Access to participants was primarily gained through a CF clinical setting within the National Health Service (NHS). However, conducting this educational research study in an NHS setting led to a number of challenges that needed to be negotiated in order to gain access to children and young people with CF and other stakeholders connected to them. Despite being an adult with CF and an insider researcher, I am not employed in a clinical setting, and as an educational researcher I am an 'outsider' to the NHS. My experience mirrors Beresford's (1994) view that there is a lack of extensive crossover between educational research and medical and social policy research in relation to the education of children with medical conditions and physical disabilities. The lack of crossover has resulted in there being little research into CF and education. Therefore, gaining approvals and permissions for the study via the ethical and research and development sections of the NHS was a complex and time consuming process. At least seven separate approvals and permissions were required before the study could begin, including written permission from the local NHS trust that would allow me to access the research site. The implications of the study for conducting student social research in the NHS are considered in Chapter 8. Additional issues and challenges relating to the NHS governance process have also been considered elsewhere (see Gathercole, 2015).

Initially, the study approached two regional children's CF centres for their support with recruitment to the study. However, one of the centres was unable to provide such support due to clinical research being prioritised during the study period.

Despite this issue, it was later discovered that there would be a number of complexities involved in conducting research across two CF centres. The approvals process would need to have been repeated for each hospital trust where the CF centre was located. Consequently, a multi-centre study proved to be unworkable. Instead, it was decided that a single centre study in one of England's larger CF centres would be a viable alternative. Therefore, the largest regional CF centre in the north of England inclusive of both rural and urban areas, was approached and they agreed to be involved in recruiting participants to the study.

3.6.2   Children and young people

There are at least 236 CF patients that attend the regional CF centre and approximately 100 of these are of compulsory school-age (ranging from 5 years to 17 years at the time of the research). However, some of the patients receive shared-care with their local hospitals and therefore may not be seen as often in the regional CF centre. Further, the frequency of appointments attended varies amongst children and young people and are influenced by the incidence of CF chest exacerbations. These factors created some uncertainty about the sample that could be achieved during the questionnaire phase of the study. Therefore, a degree of flexibility was required in terms of the length of time needed to recruit a relatively large and diverse sample of questionnaire respondents. In total, 75 children and young people responded to the questionnaire. However, the questionnaire ran for a longer period than first anticipated to achieve this sample (see section 3.9.4).

The heterogeneity of children with CF was influential in recruiting children and young people to phase two. Therefore, the study employed a purposive sampling approach in the form of a dimensional sample. Dimensional sampling involves identifying various factors of interest in a population and obtaining at least one respondent that relates to each factor (Cohen et al., 2011). Children and young people who had completed the questionnaire in phase one were asked to volunteer for the phase two interviews. The aim was that one school-aged child or young person would be recruited to phase two for each of the following factors of interest:

- Received IV treatment in hospital during term-time, in the last 12 months
- Attended school while receiving home IV treatment, in the last 12 months
- Not received IV treatment at home or in hospital during term-time in the last 12 months

Unfortunately, some difficulties were experienced with the recruitment of a child or young person who had received hospital treatment during term-time as there was a shortage of volunteers for this factor of interest. Initially, I had thought that one of the young people recruited to phase two had been in hospital. Yet, I later discovered that that this was not the case and the young person had in fact received IVs at home. However, I had already recruited another young person for this factor of interest. Nevertheless, to avoid excluding the young person from the research, I subsequently decided to recruit two children and young people who had received home IVs during term-time to be interviewed. In order to recruit a young person who had been in hospital, and in the absence of other volunteers, a decision was made to contact the paediatric CF centre and ask them to nominate a potential participant for this factor of interest.

In addition to the four school-aged children and young people recruited to phase two, one post-school leaving age young person with CF was also recruited to the research. There were two distinct reasons for the involvement of a young person who had left school. Firstly, there is evidence that young people who have left school more readily discuss their educational experiences as they are less fearful that any negative issues will be shared with their school (Cavet, 2000; Yates et al., 2010). Therefore, it was possible that this participant might reveal other aspects of educational experience not discussed by other school-aged children and young people, adding to the richness of the data. A total of five children and young people were recruited to phase two of the study.

3.6.3 Parents, and education and health professionals

The mothers of the four school-aged children and young people recruited to the interview phase of the research were also involved in the study. Gaining parental perspectives on their children's educational experiences was seen as important, given they have unique perspectives and insights into their child's needs; a theme of many government education policies (see for example DfE & DoH 2014; Ofsted 2015).

Each of the school-aged children and young people recruited to phase two of the study were asked to nominate an educational professional connected to them, who could be approached for their participation. The involvement of education personnel enabled the exploration of school based factors in relation to the educational experiences of children with CF. Asking the children and young people to nominate an appropriate person was considered to be appropriate as they may have had varied relationships with different school staff such as teachers, or teaching

assistants for example. Further, the research needed to account for the variations in systems and structures within and across different schools. I sought to involve a member of the school staff for each of the four school-aged children and young people recruited to the research. However, this was not achieved for two of the child participants. In one case, the child participant informed me that the teacher he nominated was not aware of his CF. I experienced concerns that had I contacted the nominated teacher, I may have been the first person to inform them about the young person's CF. For ethical reasons, I did not consider this to be appropriate as I would not have been in a position to answer any questions that the teacher may have had. In the other case, the young person did not want the school to be contacted about anything relating to his CF as generally, he preferred not to share it with others at his school. I therefore considered it to be of greater importance to respect the young person's wishes around his privacy than to have the involvement of his teacher in the research. Teachers from the schools of the remaining two children and young people with CF agreed to take part in the study. One of the young people nominated her physical education (PE) teacher, while the other nominated her former class teacher.

Given that some children with CF are frequently hospitalised and receive education in hospital, in addition to school personnel, the hospital school with responsibility for educational provision for inpatients at the paediatric CF centre was also approached for their participation in the study. A higher level teaching assistant (HLTA) with particular responsibility for co-ordinating the hospital education of children with CF agreed to participate. Further, the paediatric CF clinical team who assisted with participant recruitment in phase one was also asked for their involvement. Two children's CF nurse specialists volunteered to take part.

The sampling approach taken was based on the idea that children with CF participate in multiple interactional systems, and have interactions with different stakeholders in their lives, which may impact their educational experiences. It was envisaged that the involvement of parents, education and health personnel, could generate a richer picture of children's educational experiences than simply involving children alone. This approach also allowed the research to take account of the 'multiple truths' of the situation (Wellington, 2000; Merriam, 2009; Cresswell, 2013).

3.6.4 Summary of phase two interview participants

The following table provides a summary of the characteristics of the children and young people who took part in the interview phase of the research, along with the

adults connected to them and other interviewees involved in the care or education of individuals with CF.

Children (factor of interest)	Post school age	Home IVs	Home IVs	No IVs	Hospital admission	Number of participants
Gender	Male	Female	Female	Male	Male	
School type	6th Form	Secondary (fee paying)	Primary	Secondary	Secondary	
Year group	Yr 12	Yr 9	Yr 5	Yr 7	Yr11	N=5
Age	17	13	9	11	16	
Parents	✗	✓	✓	✓	✓	N=4
Teachers	✗	✓	✓	✗	✗	N=2
Hospital HLTA	N/A					N=1
CF Nurses	N/A					N=2
					Total Phase 2 Participants	14

Table 3.1 *Summary of interview participants*

3.7   A note on informing participants about being a researcher with CF

All participants were informed that I am a researcher who also has CF. This was felt to be necessary for two main reasons. Firstly, in the interest of openness and transparency, I felt that participants needed to be informed about my CF in order to help them to decide whether or not to take part in the study. This was important in terms of being aware of the risk of cross-infection, despite the measures taken to avoid such a risk throughout the research. Secondly, I considered that my CF status would have particular implications for the interviews as I have 'insider' knowledge about the management of the condition, which could influence what the participants discussed. All participants were informed that I also have CF within the participant information sheets (see appendix 2). However, participants were explicitly informed during the questionnaire phase through the use of a coversheet that contained a small researcher biography; and during the interview phase upon contact via the telephone.

3.8   Developing the initial constructs to explore children's educational experiences

Creating the constructs from which to explore children's educational experiences was an iterative process that began by identifying salient issues that had been reported in a review of the literature concerning the education of children with medical conditions (see Chapter 2). Once all the themes and issues had been identified within the literature, it was clear that there were overlaps and repetitions that could be collapsed into individual areas of concern, and this enabled me to produce an initial list of constructs that could be explored throughout the questionnaire and interviews. However, the knowledge I have gained as a result of my own experience of living with CF allowed me to recognise that some of the issues raised in previous literature were not relevant in the context of this study. For example, both Asprey and Nash (2006) and Hewitt-Taylor (2009) discussed the preference for mainstream schooling over specialist provision in their research that involved children with CF. From my own experience, I know that in the vast majority of cases the option of attending specialist provision would not be applicable to young people with CF yet, this distinction was not mentioned in the aforementioned studies. Consequently, some of the themes in the literature were excluded from the initial construct list on this basis.

I then considered where there were gaps in the literature in order to avoid there being an absence of possible constructs that could shape the questionnaire items and interview questions. For instance, Puckey et al (2006) claim that the majority of CF treatments can be done at home, before and after the school day. However, the literature did not widely discuss children's experiences of managing a CF treatment regime whilst attending school. Further, while existing research has identified that people with CF may experience barriers to employment, there was a lack of discussion in the literature about the choices that young people with CF make after leaving compulsory schooling. Therefore, the gaps in the literature presented additional areas of interest for the development of the constructs.

The process of reviewing the literature, excluding particular themes and identifying the gaps resulted in the identification of the following eight broad constructs that could be used as a basis to collect information within the questionnaire and interviews: happiness at school; communication; awareness and understanding; help and support; CF treatments; the impact of CF on school related activities; plans after school leaving age (secondary students only) and illness and school

absence. These constructs subsequently informed both the items included in the questionnaire and the questions included in the semi-structured interview schedules.

3.9   The questionnaire phase

3.9.1   Questionnaire rationale

A questionnaire was chosen to generate data with school-aged children and young people in the first phase of the study. In order to ensure that the questionnaire was accessible to as many children as possible, two separate questionnaires were designed with age-related capabilities in mind; one for primary school children between the ages of 5 and 11 and one for secondary school children between the ages of 11 and 17 (see appendix 3 and appendix 4 respectively). There are contrasting perspectives on the appropriateness of using questionnaires with children. As Barker and Weller (2003) argue, surveys are not renowned to be children friendly. Yet, contrary to this view, Lewis and Lindsay (2000) suggest that children often respond to questionnaires in magazines. There are certain advantages to using questionnaires in research with children. They allow children to remain anonymous (Hill, 1997; Barker and Weller, 2003; Cohen et al., 2011) which is essential, particularly when the research is of a sensitive nature. Further, some children may find it easier to answer questions in this way rather than face-to-face with a stranger (Hill, 1997). Indeed, there are studies that have successfully used questionnaires and surveys in research with children (Borgers et al., 2003; Porter et al., 2008; Christian et al., 2010; Lloyd and Devine, 2010; Locke et al., 2010). There were a number of reasons for using a questionnaire in this study: the questionnaire approach enabled a relatively large sample of school-aged children with CF to take part which was reflective of children's heterogeneity; it could be administered without the need for me to be present at the research setting (the regional CF centre); and it could be easily adapted for children of different ages.

3.9.2   Questionnaire items

The primary and secondary questionnaires each had 19 items and 22 items respectively, derived from the aforementioned constructs (see section 3.8). A rating scale item was also included that measured the level of CF associated difficulty on 12 separate school related activities likely to be of significance to children with CF; getting ready for school; getting to school on time; keeping up with school work; doing well at school; breaks; dinnertime; sports/PE; getting around; getting on with

others; school trips; being well enough to attend school; and using the toilet. The questionnaire was divided into four sections, namely: questions about school; questions about CF and school related activities; questions about being poorly; and demographic questions. The questionnaire for secondary school-age participants had an additional section containing questions relating to plans after leaving school. Figure 3.1 on the following page outlines the questionnaire constructs with the associated item number and section within the questionnaire.
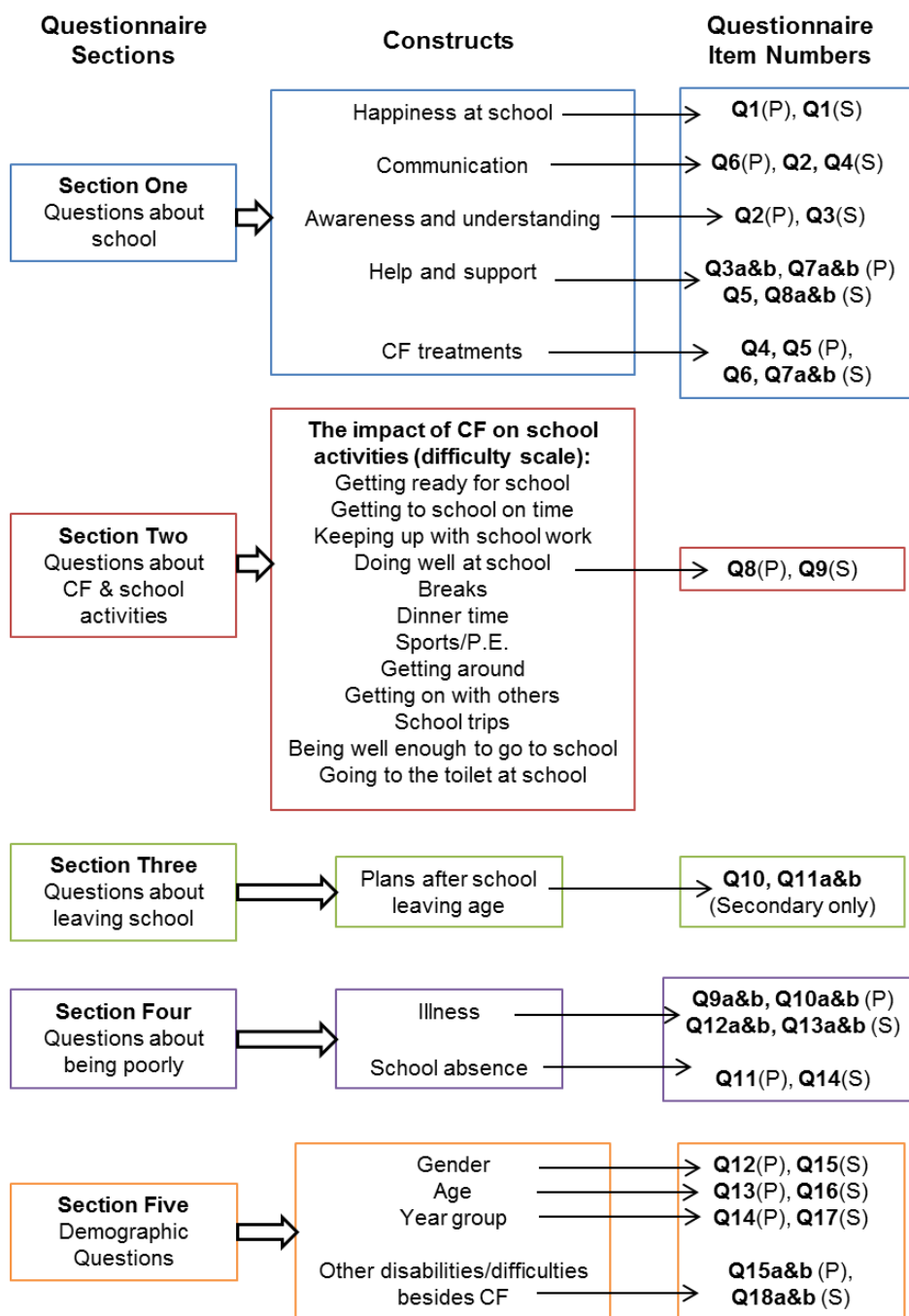
Figure 3.1 *Questionnaire constructs and associated item numbers and sections*

Rating scales, dichotomous and multiple-choice questions, some with the option to write a small amount of text, were used across the questionnaire sections to enable comparisons across groups to be made in the sample (Oppenheim, 1992). When administering questionnaires with children, Cohen et al (2011) suggest a particular problem is that they may answer with anything, rather than nothing at all. Therefore, to avoid this possibility, items included in both questionnaires gave respondents the option to answer with 'not sure' where this was appropriate. Open-ended questions were kept to a minimum to improve the organisation of the questionnaire and to save the participants' time. Instructions about how to answer the questions accompanied each item throughout the questionnaires. The primary school questionnaire used pictorial ratings scales and other pictures to aid understanding of the questions asked (Punch, 2002; Mishna et al., 2004; Phelan and Kinsella, 2013).

Given the variations in the ages of the respondents, there were some differences in the items making up the primary and secondary questionnaires. In view of the limited previous research in the area, I experienced some uncertainty around the extent of younger children's involvement in talking about CF, given the potentially more troublesome or worrying aspects of the condition as a progressive disease. For this reason, item 2 in the secondary questionnaire that asked 'has anyone from school ever talked to you and/or your parents about your cystic fibrosis?' was omitted from the primary questionnaire.

An item relating to the help and support that students receive at school was worded differently within each questionnaire (item 3 primary, item 5 secondary). In the primary questionnaire, respondents were asked 'do you get extra help with anything at school?' Where children answered with 'yes' to this question they were invited to expand on what they received extra help with. However, I was concerned about including the same item in the secondary questionnaire because previous research has suggested that some young people with medical conditions may reject the idea of having support due to having a strong desire to appear normal (Bailey and Barton, 1999; Taylor et al., 2008; MacKay, 2011; Ferguson and Walker, 2012). With this in mind, and to avoid evoking a negative emotional response, I decided to include a closed multiple-choice question which instead asked 'if you ever needed help or support with anything at school, are you happy that you would get what you need?'. Participants were asked to respond with one of the following options; 'yes', 'no' 'don't know' or 'I do not need any help or support at school'. As Gorrard (2003) argues, closed questions should ideally be as inclusive as possible and as flexible as open-ended ones.

A final difference was that the secondary questionnaire included a section that contained three items relating to respondents' plans after school leaving-age. Items within this section were not relevant to those of primary school-age and therefore, were not included in the primary questionnaire. All other items in the primary and secondary questionnaires remained the same. Demographic items comprising of gender, age and school year-group were included in the final section at the very end of the questionnaires. This is because respondents are often reluctant to provide demographic data and need to be put at ease before being presented with such questions (Cohen et al., 2011). In order to determine whether any particular responses may have been unrelated to CF, participants were also asked if they had any other difficulty or disability within this section.

3.9.3 Checking the questionnaire

Access to children with CF prior to gaining NHS permissions for the research proved to be very difficult (see section 6.3.1). Consequently, it was not possible to pilot the questionnaire with this group of children. However, at least four quality checks were made on the questionnaire prior to its administration. In order to achieve NHS permission and approvals for this study, the questionnaire was checked throughout this process by means of peer review, university sponsor review, NHS Research Ethics Committee (REC) review and NHS research and development review. Only the NHS full REC review panel recommended that a change should be made. This was to item 9 (item 8, primary) in the questionnaire (see appendix 5). In version 1 of the questionnaire, the item listed a number of school related activities and asked the respondent to indicate how much CF affected each activity by marking a number on a Likert scale of one to five; one being 'not at all' and five being 'a lot'. However, the panel requested that this question should be reworded as it did not provide information as to whether the answer given would reflect a positive or negative opinion. The item wording was subsequently changed and in version 2 respondents were asked to indicate how *difficult* CF affected each activity listed.

3.9.4 Questionnaire administration

From the outset of the research design, I knew that I would not be able to physically approach children and young people for their participation in the study at the CF centre. Therefore, it was necessary to plan the administration of the questionnaire with a specialist research nurse at the regional CF centre, in line with NHS research approval procedures. Prior to the phase one data collection period, I met with the research nurse at the CF centre in person, to discuss all aspects of the study and to

hand over the paper questionnaires. The questionnaire administration was planned to begin early in December 2013. However, this was not possible for two reasons. Firstly, gaining the final NHS approval needed for the study was particularly arduous and delayed the start of the research. Secondly, during December 2013, there was a clinical study taking place at the CF centre, thus giving rise to operational difficulties in running the questionnaire simultaneously. Therefore, the phase one data collection period was rescheduled to start during early January 2014. From this point on, all patients of compulsory school age who were in attendance at outpatient clinics or admitted for inpatient treatment on the ward were approached for their involvement in the research and given a primary or secondary questionnaire to complete.

All children and young people who agreed to take part in the study were encouraged by the research nurse to complete the questionnaires on their own. Parents of younger primary school children were asked to assist their child only if needed. The study acknowledges that there are concerns about this approach as parents may influence children's responses (Fargas-Malet et al., 2010) and children sometimes have different views to their parents (De Schauwer et al., 2009). However, the possibility of parental influence on children's responses needed to be balanced against the importance of including younger children in the study. To this end, questionnaires were designed with regard to different age-related capabilities in order to encourage all children to complete the questionnaire on their own where possible.

The initial plan was for the questionnaire to run for four months. However, it became apparent that the administration period would need to be extended beyond four months as by the end of April 2014, only 49 responses had been received. This was due to there being limited numbers of school-aged children attending the CF clinic who could be invited to take part in the study, rather than there being a shortage of volunteers. Following a discussion with the research nurse, it was agreed that the questionnaire could be administered for a further three months to attempt to achieve a larger sample size. This proved worthwhile as by early August 2014, there had been 75 respondents to the questionnaire. In total, the questionnaire ran for almost eight months between January and August 2014.

3.9.5 Questionnaire reliability

Reliability in quantitative analysis can be established through measures of internal consistency. This refers to the degree by which the items that make up a scale 'hang together' or measure the same underlying construct. Both the primary and

secondary questionnaires included a 12 item likert scale that aimed to measure the level of CF difficulty on school activities (Q8 and Q9 respectively). Therefore, the reliability of the scale could be calculated by using one of the most commonly used indicators of internal consistency called the Cronbach's alpha coefficient (Pallant, 2010). The overall alpha for the 12 item scale was 0.9. Values above .7 are considered acceptable, however, values above .8 are preferable (Pallant, 2010). Therefore, the scale had very good internal consistency reliability. In four cases the scale was not completed fully, therefore the alpha coefficient reported is for 94.7% of respondents.

3.9.6 Questionnaire data analysis

Before data analysis could begin, it was necessary to input and code the data from the paper questionnaires into a data management and analytical software programme. I had received previous training and subsequently gained practical experience of working with IBM SPSS Statistics for my MSc Educational Research Methods critical study research. Therefore, this software was chosen to analyse the questionnaire data.

Once the data from each questionnaire had been manually inputted into SPSS, the dataset was explored for any missing data. As Osbourne (2013) suggests, 'missingness' can be informative as it can contribute to a more accurate understanding of the population studied. Data was omitted for eight of the variables. However, the completed questionnaires with missing data were not removed from the overall data set to avoid limiting the sample size. Instead, for certain statistical tests conducted, the 'exclude cases pairwise' option was used in SPSS so that cases were excluded only where data was missing for the specific analysis (Pallant, 2010). This allowed the questionnaire data to be included in all analysis where it contained the necessary information. A simple descriptive analysis of each item was generated. Frequency and percentage tables, charts and cross-tabulations were produced to give a general picture of the findings (Pallant, 2010). Responses to open-ended questions were organised thematically.

Where descriptive analysis revealed apparent differences between groups on the questionnaire items, non-parametric statistical tests were used to check if such differences were statistically significant. The grouping variables explored were school type (primary and secondary respondents) and treatment type (hospitalised in last 12 months, home IVs in last 12 months, no IVs in last 12 months). Other grouping variables such as 'gender' were not used in the data analysis. Any results relating to gender differences were not deemed to be relevant to the aims and

scope of the study. Non-parametric statistical tests were chosen above parametric tests given that in statistical terms the sample size was relatively small. Another reason for selecting non-parametric techniques was that they are ideal for use on nominal (categorical) and ordinal (ranked) scales (Pallant, 2010) which are used throughout the questionnaire. Further, non-parametric tests make fewer assumptions than parametric tests about the type of data on which they can be used; such as when the data is not 'normally distributed' (Field, 2013). The Chi Square test for association was used to explore the association between participants' demographics and responses to certain questionnaire items (Pallant, 2010; Field, 2013). The Mann-Whitney U test was used to test for differences between groups of participants (school type or treatment type) on the impact of CF on school activities scale (Pallant, 2010; Field, 2013). *P* values for statistical significance are reported. However, the use of p values is not without problem, since statistical significance does not denote the size of an effect (Harlow et al., 1997). Therefore, effect sizes are also reported where statistically significant results are found. A further key reason for reporting effect sizes also related to the possibility that type I errors could occur in the analysis due to multiple testing (finding a significant result when it does not exist) (Field, 2013). Corrections for type I errors have not been used in this research as this increases the likelihood of committing a type II error (finding no significant result when it does exist) (Pallant, 2010). In order to address the possibility of committing type I errors, effect sizes are reported in addition to values of statistical significance (p) to assess the importance of a finding (Pallant, 2010).

3.10 The interview phase

3.10.1 Interview rationale

Throughout the second phase of the research, data was generated through the use of semi-structured interview schedules with all participants. Interviews are widely used in qualitative research with children who experience chronic illness and/or disability (Cavet, 2000; Connors and Stalker, 2007; Yates et al., 2010), and with their parents and professionals who work with them (Bolton, 1997; Lightfoot et al., 1998; Robinson and Summers, 2012). There are many claimed advantages to using the interview approach. Interviews enable participants to discuss their own interpretations of the world in which they live and to express how they regard situations form their own point of view (Cohen et al., 2011). Further, they allow the researcher to investigate and prompt things that cannot be observed such as an

interviewee's thoughts, values, prejudices, perceptions, views, feelings and perspectives (Wellington, 2000).

Semi-structured interviews were used with all participants. This allowed for changes and modifications to the question wording where appropriate, such as to aid understanding of the interview questions. This was necessary when interviewing children who were varied in age and development. Semi-structured interviews also gave me the opportunity to use probing or further questioning where participants discussed new issues that related to the research questions. Further, the semi-structured schedule enabled me to alter the order of the questions in some circumstances. This was useful when participants had previously answered a question that would appear later in the schedule.

An initial pilot interview took place with a post-school aged young person with CF in June 2014. All other interviews with children and young people, parents and education and health personnel took place between October 2014 and January 2015. The time taken to complete the interview phase of the research was longer than initially anticipated. This was a direct consequence of conducting research with a group of children and young people who experience periods of illness. The interviews with three of the children and young people and two of the parents, needed to be rearranged for a later date than was originally planned. Equally, finding a convenient time during the school day to interview two of the education professionals was also challenging. There were times when I had arranged to interview the teachers and they were unavailable due to other issues taking priority at the schools in which they worked.

3.10.2 Children's interviews

3.10.2.1 Developing the children's interview schedule

The semi-structured interview schedule used with children and young people (see appendix 6) was developed through an iterative process with guidance from an 'expert group' comprising of: adults with CF; parents of children with CF; a person with CF who was a former deputy head teacher of a primary school; a nurse from the paediatric CF team; and a person with qualitative research experience. The first iteration of the schedule was developed with reference to the eight broad constructs described earlier (see section 3.8). Following this, the expert group was consulted about version one of the schedule. A key aim of consulting the expert group was to reduce the influence of my own unhelpful subjective experience in the design of the schedule. In addition, the group was consulted to ensure that the interview

questions were valid, sensitively worded, unambiguous and flowed well. The group were also given the opportunity to comment on any areas of questioning that should be added or removed from the schedule.

Following the consultation, no changes were made to the eight initial constructs that informed the interview questions. However a number of recommended changes were made to the semi-structured interview schedule based on the comments from the expert group. The former deputy head teacher member of the group raised an important point relating to the wording of some of the questions and the issue of bias. She stated:

> 'Overall I thought there were a good range of questions that were very balanced, although question 16 was worded in a way that might imply that the school may not be catering properly for the child's needs, which could sway the interviewee slightly'.

(Former deputy head teacher with CF)

Due to these comments, question 16 was subsequently changed from 'has anything ever been put in place at school to try and help you?' to 'do you get any extra help or support because you have CF?'. A further change to the interview schedule was recommended by another member of the expert group. A young adult with CF suggested that an additional question could be included in the schedule:

> 'In terms of CF routine, I always found that when it came to my treatment adherence, I struggled around stressful periods such as exam time (I still do at uni!). Although it is sometimes hard for a young person with CF to admit their adherence is suffering for fear of getting into trouble, maybe you could provide an additional question about whether there are any particular times when you really struggle with treatments?'.

(Young adult with CF)

The question suggested by the young adult with CF was considered to be relevant and appropriate given the frequency of treatment adjustments arising from the variability of CF. It was therefore included in the interview schedule (question 3). Following the consultation with the expert group, the interview schedule was revised. The second iteration of the interview schedule was subsequently piloted with Bob (post school-aged young person) who was the first of the children and young people to be interviewed. Bob was asked what he thought about the content of the questions and if there was anything else important or useful that he wanted me to know about. He replied:

'I think the questions were quite good actually. I think they covered everything around CF and school. I don't think there's anything I've got to add'.

(Bob, post-school aged young person with CF)

Following Bob's comments, the second iteration of the interview schedule was finalised for use with all children and young people in the study. Open questions were devised relating to each construct and a series of interview prompts were used to encourage the flow of discussion (see appendix 6). Given, there were no changes made to the interview schedule at this stage, Bob's interview data was therefore included in the main study.

3.10.2.2 The use of vignette and fantasy wish questions

The semi-structured interview schedule used with children and young people included a vignette question and a fantasy wish question (see Figure 3.2).

Fantasy wish

If you could make some wishes about things that would make school better or easier, what would they be?

Vignette

Imagine that you have a friend called Sam whose parent is a teacher at another school. This teacher has just found out that a young person with CF is going to be starting at their school very soon. Sam's parent knows you have CF and so comes to you for ask for advice.

- What advice would you give so that young person is happy at school?
- What do you think would be helpful for this young person at school?
- Is there anything that the school should/shouldn't do?

Figure 3.2 Vignette and fantasy wish questions

Both these interactive questioning approaches have been used successfully in interview research involving children (Hazel, 1995; France et al., 2000; Asprey and Nash, 2006b). Further, there is evidence that vignette questions in particular, engage young people to participate in research and explore and identify with a range of sensitive subjects that may have remained untapped elsewhere in the interview (Barter and Renold, 2000). The issue of receiving help and support at school was one area of questioning identified as a potentially sensitive area.

Therefore, the vignette and fantasy wish questions were used to gain additional information in the area of help and support and to provide participants with the opportunity to be more reflective of their wider and personal experiences of education. One parent member of the expert group agreed that these questioning approaches seemed very useful. She stated:

> *'It is easier to speak hypothetically and about a third party rather than yourself'.*
>
> (Parent of young person with CF)

It was hoped that the vignette and fantasy wish questions would help to address some of the issues and challenges that could arise as a result of the potential for a power imbalance between the child participants and myself as the researcher.

3.10.2.3 The use of 'photovoice'

The decision to use the photovoice technique stemmed from concerns about building rapport with children and young people who I could not meet in person. Similar concerns have been raised about using telephone interviews (Irvine et al., 2013). Photovoice was originally developed by Wang and Burris (1994) in the area of health promotion. It involves the process of using photographs or pictures to tell a story (Wang and Burris, 1997). Photovoice has been used to facilitate group-based interviews and discussions (Wang et al., 2000; Bolton et al., 2001; Pearson and Ralph, 2007; Beresford, 2012). This study was interested in using the technique at the start of individual interviews with children and young people in order to get to know their diverse interests and characteristics as well as their educational experiences. However, there are other benefits of the approach. As Yates et al (2010) suggests, visual methods are often a more appealing activity for young people and they are a well-established means of opening up dialogue. It has also been claimed that photo elicitation techniques are more likely to result in candid discussion of sensitive issues (Drew et al., 2010). Indeed, the approach has been used successfully in research elsewhere involving young people with chronic illness (Drew et al., 2010).

The four school-aged participants were invited to take part in the photovoice activity. They were provided with an iPad to enable their participation in all aspects of the interview. For the purpose of the photovoice activity, participants were invited to use the camera function on the iPad in order to take images that focused on areas of greatest significance to them in relation to their education and other aspects of their lives. Although participants were asked to select particular images

in a context of 'a day in the life of me, my CF and school', no specific criteria were given on what the images should contain. This was to ensure that the photovoice method was child centred and participant led. Due to ethical concerns relating to the confidentiality and anonymity of participants and other children or adults that may appear in such photographs, the images were only used to facilitate discussion during the interviews, and subsequently not included in the thesis.

3.10.2.4 The use of Adobe Connect

Adobe Connect is a web conferencing software that is frequently used for online learning and the creation of virtual classrooms[1]. For the purpose of this study, I decided to utilise Adobe Connect as a method for conducting online interviews with children and young people. It has been suggested that social research carried out online can give a voice to groups who would otherwise be very difficult to interview face-to-face (O'Connor et al., 2008). In addition, online methods represent a considerable advantage over offline methods when the research group of interest is 'hard to reach' such as those with disabilities or illness (Mann and Stewart, 2000). Further, the role of digital communication as a method of data collection and as a medium for intervention with young people with long-term conditions and disabilities is increasing in popularity (see for example Weller, 2015; Griffiths and Sturt, 2015; Pennington, 2015). I wanted to replicate a physical face-to-face interview as far as possible while avoiding any cross-infection risk and so I explored the use of various internet mediated communication technologies such as Skype, FaceTime, Google Hangouts and Adobe Connect. There are arguments that such internet technologies allow researchers to reap the benefits of both telephone interviews and traditional face-to-face interviews within one approach (Hanna, 2012).

There were three major reasons why Adobe Connect was chosen. Firstly, Adobe Connect did not require the participants to register their personal details in order to create a user account, which is not the case with other similar technologies. The children and young people involved in the study could simply log into the software as a 'guest' by using a pseudonym instead of their real name. This was ethically advantageous as it helped to maintain their right to anonymity. This is a salient issue when involving children in research (Mahon et al., 1996; Morrow and Richards, 1996; Birbeck and Drummond, 2007). Secondly, Adobe Connect offered greater functionality over other software options. I was able to employ aspects of Adobe Connect that are used synchronously in virtual classrooms such as audio

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[1] Further information about Adobe Connect is available at:
http://www.adobe.com/uk/products/adobeconnect.html

and video discussion and sharing image files. The latter was particularly useful for the photovoice activity discussed in the previous section. Further, Adobe Connect also enables users to present note 'pods' to participants which are boxes of text that can be flashed up on screen. Note pods were used twice during the interviews to assist understanding of the vignette and fantasy wish questions. It was hoped that this approach would also maintain engagement and interest in the interview. Another synchronous function that is beneficial for research with children is the 'chat' facility. This allows participants to type out answers to interview questions. In some circumstances this facility may be preferable over voicing responses, for example if the research is of a sensitive nature (Pearce et al., 2013). However, in this study all children chose to talk to me using synchronous audio and video. A third reason for using Adobe Connect was its recording function. The video and audio from the interviews could be recorded without the need for third party software. More is said on the recording of data in section 3.10.4.

3.10.2.5 The use of the iPad

There were five main reasons why the iPad was selected to enable children and young people to take part in the online interviews. Firstly, I wanted to make sure that no child would be excluded from the research based on limited access to the technology needed to take part in the online interviews. Therefore, the iPad was provided to avoid any such exclusion. Secondly, it was important that the device chosen would not present a risk to cross-infection, particularly because the same device would be handled by myself and all participants with CF. Devices with a keyboard, such laptops, were discounted due to substantial evidence that keyboards are a source of infection transmission (Neely and Sittig, 2002). The touchscreen function of the iPad eliminated this particular problem as it could be cleaned thoroughly with disinfectant wipes between uses. Thirdly, Adobe Connect could be accessed via an iPad application with relative ease. Fourthly, the iPad has a built in camera and microphone. This meant that participants were able to take part in the photovoice activity and the interview without the need for additional equipment, excluding the headphones that were needed to maximise sound quality (see section 3.10.2.6). Lastly, I considered that the iPad would be familiar to the children and young people involved in the study given its general popularity and the fact they are considered to be 'digital natives' (Weller, 2015b).

3.10.2.6 Testing the interview equipment and software

Before the interviews took place with children and young people, Adobe Connect was tested with another researcher in order to familiarise myself with the software

and to see how it would perform on the iPad during an interview situation. The testing revealed an issue with the sound quality in that there was an echo produced by the internal microphone picking up the sound of the speaker. To overcome this problem, each child was provided with headphones to eliminate the echo, maximise sound quality and reduce potential distractions. It also became clear that uploading and displaying images within the Adobe Connect software, which was necessary for the photovoice activity, was quite an involved process. I was concerned that asking participants to do this may have risked disengaging them from the research. In order to save participants' time, children and young people were asked to email their images to me instead so that I could upload and prepare them for discussion at the start of the interview.

3.10.2.7 Children's interview procedure

Children and young people participated in the online interviews from their own home, while I was based in a different location. All participants' homes had internet access. However, it was possible to provide them with access to the internet via a wireless wi-fi hotspot device should this have been required. Parents of the children and young people who took part in the study agreed to meet with me at a location away from the family home so that I could hand over the iPad and other equipment needed for children's participation in the interview, without any risk of cross-infection. Detailed instructions about using the iPad, taking part in the photovoice activity and accessing Adobe Connect were also given in verbal and paper form. Parents were asked to give the iPad and instructions to their child. It was important to remain mindful of the time commitments that children and their parents had in relation to the administration of CF treatments, school work and other activities when planning the timing of the interviews and some flexibility was required in this regard. Interviews with children and young people all took place during the evening as preferenced by parents and the children themselves.

3.10.3 The parents' and professionals' interviews

The same constructs and areas of questioning used within the children's interview schedule were also used to provide a focus for the questions in the schedules used with parents and education and health professionals (see section 3.8). Given that one member of the expert advisory group had discussed the usefulness of being able to reflect hypothetically about CF and education, the parent and teacher interview schedules included the following question: 'What advice would you give to other schools that have a student with CF attending?'. Interview schedules began with an 'introducing question' and finished with a 'clean-up question' to allow

participants to raise important issues not previously mentioned in the interview (Braun and Clarke, 2013). The schedules were tested out with a research colleague. Following this, a small change was made to the ordering of the questions in the parent interview schedule. The parent, education and health personnel interview schedules can be found in appendix 7, appendix 8 and appendix 9 respectively.

3.10.3.1 Parent interview procedure

Parents were given the options of a telephone or face-to-face interview. I was concerned that face-to-face interviews may not have been convenient for busy parents managing the CF routines of their child. Nevertheless, I favoured the face-to-face interview approach as it has been argued that during telephone interviews, both parties are deprived of several channels of communication and the establishment of a positive relationship (Arskey and Knight, 1999). In order to overcome problems with forging a relationship with parents, I contacted them prior to their involvement in the study to arrange a face-to-face meeting. During face-to face meetings with parents I introduced myself, provided information about the study and gave them the opportunity to ask any questions. This allowed me to gain parents' trust and build rapport which was also an important part of obtaining consent to interview their child. This also meant that I overcame some of the limitations involved with telephone interviews and this made them a viable alternative to the face-to-face approach. Despite my concerns, only one parent opted for a telephone interview and interviews with the other three parents were conducted face-to-face.

Face-to-face interviews could not take place at the family home due to cross-infection risks. Therefore, parents were given the opportunity nominate an alternative location at a suitable date and time. One parent chose to be interviewed at her workplace, another asked to be interviewed at a supermarket café, while the other selected a pub restaurant. The public locations selected presented a risk to the privacy of the interviews. However, this in itself was not an issue as the timing of the interviews took place during quieter periods at the café and pub when other people were not in proximity. There was a further possibility of being interrupted during the interviews. However, interruptions only occurred during the interview that took place in the participant's workplace. Nevertheless, both these issues needed to be balanced against the ease and convenience of taking part to the participants and removing the risk of cross-infection.

3.10.3.2 Education and health personnel interview procedure

Due to the nature of the roles of school staff, hospital teachers and CF clinical team members, it was thought that telephone interviews would be the most convenient data generation approach for them. I expected that conducting face-to-face interviews at their places of work may be unrealistic due to the likelihood of children with CF being present within these spaces which would present a risk of cross-infection. I also anticipated that attending an interview away from the work spaces of education and health personnel may not be possible due to time limitations associated with their roles. However, I was able to interview the HLTA face-to-face at the location of the hospital school. There was no risk to cross-infection through being present at the hospital school during the interview as children with CF were not permitted to access the hospital school classroom facility. Access to the school was considered to be unworkable for multiple numbers of inpatient children with CF at the time of the research. I was also able to conduct a face-to-face interview with the CF ward nurse. This took place at a hospital café during a quiet period when there were no other people nearby. All other interviews with education and health personnel took place via the telephone at a time of their choosing.

3.10.4 Interview data recording and transcribing

Online interviews conducted with children and young people were recorded through the Adobe Connect software. At the end of each interview the video and audio recording was downloaded as an .flv file and saved on the university M drive. Both face-to-face and telephone interviews conducted with parents, teachers, members of the CF clinical team and hospital school were recorded via a Dictaphone device. Following each interview, the recording was transferred and saved to a password protected, secure drive within the university and deleted from the portable Dictaphone device. Interviews were transcribed verbatim and where participants discussed any factors that may have revealed their identity or any other participant's identity, these were removed from the transcripts to anonymise the data. Pseudonyms were used for all participants in the research.

3.10.5 Interview data analysis

3.10.5.1 Coding and analysing the interview transcripts

There are a number of different analytical approaches to coding interview transcripts such as grounded theory (Glaser and Strauss, 1967), interpretative phenomenological analysis (Smith et al., 2009) and thematic analysis (Braun and Clarke, 2006). Interpretive phenomenological analysis was considered to be

inappropriate for the context of this study given its focus on language and linguistics. Rather than strictly following one analytical method, I selected elements of both grounded theory (Glaser and Strauss, 1967) and thematic analysis (Braun and Clarke, 2006) with the aim of developing a systematic approach to coding the transcripts. I also adapted a coding strategy developed by (Saldaña, 2013) who recommends dividing coding into specific cycles using an iterative process. The computer-assisted qualitative data analysis software (CAQDAS) - NVivo was used throughout the coding process as well as manual coding techniques such as writing notes on the text I was analysing and using highlighter pens to indicate possible patterns. Two major coding cycles were used to develop the final themes and conceptual categories from which to base the write-up of the study.

3.10.5.2 First cycle coding

The first level of analysis began by breaking down the data into units of analysis or segments of text. The segments included a sentence, a paragraph or a single word, however, the unit of analysis was determined by the content of the text rather than the length of the text. For example, if several sentences within a paragraph contained more than one code, the unit of analysis was a sentence or in some cases a single word. Each segment of text was then given a code name. This approach is similar to open coding in ground theory and is commonly used in qualitative research (Attride-Stirling, 2001; Braun and Clarke, 2006; Miles et al., 2014). Further, as Braun and Clarke (2013) point out, coding is not an exclusive process where extracts of text can only be coded in one way. Therefore, where it was deemed appropriate, two or more different codes were also applied simultaneously to the same data segment to enable 'multiple meanings' to be considered in the analysis (Miles et al., 2014). The following extract from Bob's interview provides an example of first cycle coding and the associated units of analysis (Table 3.2).

Unit of analysis	Code name
'Yeah, I've always felt that people don't really understand'	'Understanding CF'
'Definitely morning and evening because if I ever had to have anything during the day I would always have it as soon as I got back from school so. I live quite close to the school I could just walk up home at about 3pm and have the medication I needed at night a little bit later'	'Doing treatments away from school'
'I didn't like to get changed in front of all the guys because I always felt like I was too thin'	'Body image'
'Yeah, my form teacher was the one that really pushed for me'	'Form tutor supportive'
'Eventually you can't lie forever, you have to tell your mates, your best mates and everything you've got CF'	'Not telling others' and 'Revealing CF'

Table 3.2 *Units of analysis and allocated code name*

My earlier thinking about coding initially led me to preference data driven codes over researcher derived codes. This is because the research relating to the education of children with CF is limited and any predetermined codes that are based on literature relating to the education of children with medical conditions generally, could give rise to an *a priori* coding system that is ill moulded to the data (Miles et al., 2014). I was also reluctant to develop a list of researcher-generated codes based on my own predictions of what might be found in the data as I was concerned that I may not have the objectivity needed for this task given my own experiences of living with CF. However, following an early attempt at coding some of the interview transcripts I began to notice some thematic similarities with the existing literature on the education of children with medical conditions. Therefore, these themes provided an additional focus during the first cycle of coding.

3.10.5.3 Transition to second cycle coding

Following the first cycle of coding, the next analytical activity employed an organisational approach called 'code mapping' (Saldaña, 2013). Two iterations of code mapping took place before proceeding to second cycle coding. As Saldana (2013) suggests, one advantage of having several iterations of code mapping is that it provides an auditing process. Consequently, I was able to document how a list of codes became categorised, re-categorised and conceptualised throughout the analysis (Saldaña, 2013). The first iteration of code mapping involved the

creation of a simple list of all the codes from the first cycle of coding. This yielded a total of 159 codes. During the second iteration, the 159 codes were compared and sorted to look for replications and to determine which codes seemed to group together. At this point some of the codes were discarded and others went on to form main themes. A visual representation of this procedure is presented in Figure 3.3.

```
┌─────────────────┐
│ I always want   │
│   to fit in     │──┐
└─────────────────┘  │
┌─────────────────┐  │      ┌─────────────────┐
│ Don't make      │──┤──────│ Being like      │
│ them different  │  │      │ everybody else  │
└─────────────────┘  │      └─────────────────┘
┌─────────────────┐  │
│ Being like      │──┤
│ everybody else  │  │
└─────────────────┘  │
┌─────────────────┐  │
│    Normal       │──┘
└─────────────────┘

┌─────────────────┐
│   Hiding CF     │──┐
└─────────────────┘  │
┌─────────────────┐  │      ┌─────────────────┐
│ Not telling     │──┤──────│ Keeping CF      │
│   others        │  │      │   private       │
└─────────────────┘  │      └─────────────────┘
┌─────────────────┐  │
│  Avoiding       │──┘
│  medication     │
└─────────────────┘
```
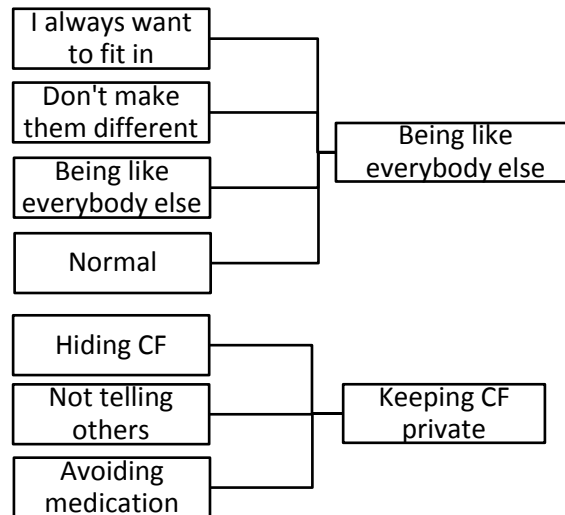
Figure 3.3 *Example of second iteration code mapping*

This process yielded a total of 55 codes that required further organisation and analysis during the second cycle of coding.

3.10.5.4 Second cycle coding

Saldana (2013) suggests that the goal of second cycle coding should be to transform existing codes into categories and subcategories which will then progress towards major themes and conceptual categories and then into assertions arising from the research. This is similar to a stage of thematic analysis which focuses on sorting all codes into potential themes and collating all the relevant units of data into the identified themes (Braun and Clarke, 2006). To this end, I began to consider how the existing codes might be combined to form overarching conceptual categories. This involved looking for similarly coded data, grouping the codes under a theme and attributing meaning to the group by giving it a name. As the second coding cycle continued and codes and themes were reviewed at the level of the entire data set, I found that some segments of text did not entirely fit the code that had been assigned. Where this was the case, the text was assigned to a code that was a better fit or codes were reworked, renamed or removed. At the end of this process, the themes that captured something important about the data and were

related in meaning to other themes, were grouped together to form conceptual categories. In some circumstances a sub-category was devised. The following diagram exemplifies the second cycle coding process (Figure 3.4).
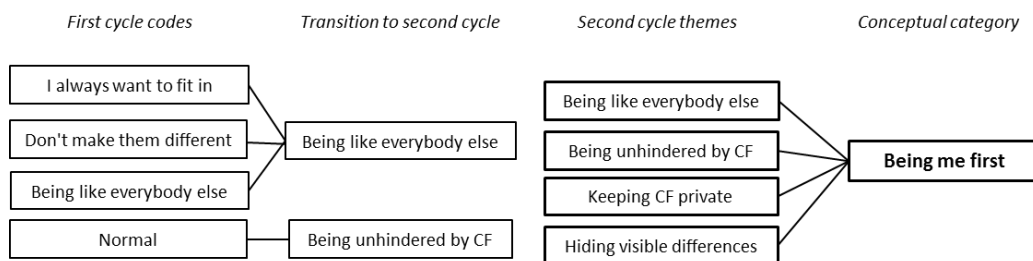
Figure 3.4 *Example of second cycle coding process*

This process of refining and reviewing codes and themes was followed until I developed a satisfactory thematic map of all the data (Braun and Clarke, 2006). This yielded a total of 7 overarching conceptual categories and 23 themes. Clear and operational definitions of all the conceptual categories were established that were specific enough to be discrete and broad enough to encapsulate a set of ideas contained in numerous units of analysis (Attride-Stirling, 2001). The categories and associated definitions were subsequently recorded in a codebook (see appendix 10).

3.10.5.5 Establishing trustworthiness of the interview data analysis

The use of qualitative approaches in research acknowledges that there are multiple realities, and therefore, reliability is argued not to be an appropriate criterion for judging qualitative procedures such as coding (Braun and Clarke, 2013). That being said, there are procedures that can be followed in order to establish the trustworthiness or 'dependability' of the data analysis methods (Braun and Clarke, 2013). One such approach is to engage another researcher in the coding activities to confirm the robustness of the analysis (Strauss and Corbin, 1998; Braun and Clarke, 2013). In this study, three colleagues with experience of conducting qualitative research cross-checked the conceptual categories derived from my own analysis. They were provided with a selection of the interview transcripts and asked to assign three specific conceptual categories to the data contained within the codebook. This process allowed all conceptual categories to be independently checked across a sample of the data set. Discussions with colleagues following the checks resulted in a change to one of the conceptual categories. It was agreed that

that the category; 'Support for Learning' should be renamed 'Educational Support'. This was because the issue of 'learning support' may have had negative connotations for the participants, and it was not explicitly discussed in the dataset. All other categories assigned to the data were agreed upon by colleagues who checked my analysis.

3.11 Validity and reliability or trustworthiness of the research

I have already acknowledged that my own subjective experiences have influenced both the questionnaire and interview phases of the research. Therefore, the positivist concept of reliability does not seem applicable to all aspects of this study, where reliability might refer to the replication of results with the same participant group by a different researcher (Cohen et al., 2011). However, Lincoln and Guba (1985) argue that reliability does indeed apply to both quantitative and qualitative research paradigms, though in different ways. They suggest that issues of reliability, along with validity, should be thought of as part of the broader concept of research trustworthiness (Lincoln and Guba, 1985). As Dellinger and Leech (2007) argue, in mixed methods research the dichotomy of quantitative and qualitative validity and reliability criteria may need to be blurred. Therefore, consideration of the explicit strategies employed to ensure validity and reliability in terms of the trustworthiness of the research would seem more appropriate given the mixed methods context of the study. These strategies can be summarised as follows:

- Before the research began the study protocol and all research materials were subjected to four main quality checks through the NHS approvals process. This resulted in a slight change to the phase one questionnaire.
- A heterogeneous sample of children were involved in the research to take account of the varied lived experiences of children with CF.
- A variety of methods were used and different stakeholders were involved in the research to take account of the multiple truths of the educational experiences of children with CF.
- A reliability analysis of the questionnaire was carried out on the CF difficulty on school activities scale and this showed very good internal consistency (see section 3.9.5).
- The interview schedules were developed through an iterative process involving consultations with an expert group of individuals connected to the CF community. The iterative process reduced the possibility of

including 'loaded' questions in the interviews and also resulted in the inclusion of important questions that I had not previously considered.

- Interview transcripts were shared with all interview participants and they were invited to verify what they had said and offer any additional information or insights. However, no participant provided any further perspectives beyond those given during their interview.

- A transparent account of the process involved in coding and analysing the interview data, including establishing the trustworthiness of my analysis, has been provided.

3.11.1 Reflexivity

In addition to the previous points, a key strategy involved with establishing the trustworthiness of the research was the practice of reflexivity throughout the study. That is, I have recognised and critically reflected on my role and positions within the research and the significance of these to the production of knowledge (Letherby et al., 2013). Therefore, I now turn to the reflexive process employed in the study. According to Teddlie and Tashakkori (2009), reflexivity is more often associated with the qualitative strands of mixed methods research. However, reflexive processes have also been applied by researchers who use methods that are typically connected with quantitative approaches, and the value of these processes have been discussed elsewhere (Finlay, 1998; Ryan and Golden, 2006; Fries, 2009). In this study, a reflexive process was used in both the questionnaire and interview phases of the research. I kept a research journal and used this to record my thoughts about methodological procedures carried out. I recognised that my own subjective experiences as a researcher with CF contributed to the design of the research. The recordings in the journal helped me to formulate an audit trail of why and how I arrived at the interview themes, and this was useful throughout the data analysis. I also practised reflexivity through talking with my research colleagues, which gave me analytical distance from my own subjectivities when constructing important themes and categories. Further reflexive discussion of the methodological issues and challenges experienced in the study is contained in Chapter 6.

3.12 Ethical considerations

Ethical approval for the study was given by the NHS National Research Ethics Service Committee Yorkshire and the Humber - Bradford Leeds in November 2013

after the REC recommended I made a small number of methodological and ethical changes to the study (see appendix 5 and appendix 11 respectively). Research and development approval was given by the Leeds Teaching Hospital NHS Trust in late December 2013 (see appendix 12). Research in the NHS must follow standardised procedures in relation to informed consent, and therefore, consent/assent forms (and participant information sheets) were designed with reference to Health Research Authority (HRA) guidance (Health Research Authority, 2013) (see appendix 13 and appendix 14). The following summarises the key ethical practices that were implemented following the negotiations with the NHS REC:

- Where parents provided consent for their children to take part in the research, children and young people were also asked for their own consent and were not expected to take part if they did not wish to do so.

- Questionnaires did not ask children and young people to provide any personal identifiers such as their name or date of birth, in order to ensure anonymity. It was difficult to assure complete privacy during in the interview phase of the research, as participants revealed aspects of their identity during the interviews, such as treatment routines and children's ages for example. Any personal identifiers were changed or removed in the transcript data and in publications and presentations arising from the research. This approach also protected the identities of other individuals connected to the children with CF.

- Children and young people who participated in the online interviews were invited to choose their own pseudonym at the start of the interview.

- All participants were informed of their right to withdraw from the research at any time and without giving a reason. During the interview phase of the research the right not to take part or to withdraw from the research was reaffirmed with each participant at the start of the interview.

- Completed questionnaires, consent forms and interview transcripts were stored in a locked filling cabinet to protect participant's data. Interview recordings from the Adobe Connect platform were downloaded as an .flv file and stored securely on a password protected computer network location.

Following ethical and research and development approval, there were other unanticipated ethical challenges that I needed to reconcile during the study that were not previously considered through the ethical review process. By way of example, two such ethical issues are now discussed. These two issues concerned; checking the process of informed consent had occurred with children and parents

during the questionnaire phase; and children's rights to confidentiality during the interview phase. I had initially planned for children's consent to be implied through their completion of the questionnaire. However, the NHS REC disagreed with this decision and asked that assent and consent forms should be signed by both child participants and their parents. It was their view that filling in the questionnaire alone did not constitute children's assent/consent to take part and I agreed that giving children the opportunity to give their consent separately would reaffirm their right not to take part in the research. However, it became apparent that this approach meant that I had no means of checking whether consent/assent had been obtained for each child that took part. To overcome this problem, every completed questionnaire was allocated a patient identification number by the research nurse. The same number was written on the parent consent form and child assent form and then further recorded on a separate participant identification sheet. Questionnaires could then be cross-checked with the identification sheet to ensure that informed consent/assent had taken place.

The confidentiality of participant's data was addressed during the NHS ethical review process, e.g. through the anonymisation of participant data and the use of pseudonyms. However, a confidentiality issue that I had not initially anticipated arose, in that three of the parents asked me if I could tell them what their child had discussed during their interview. Such requests led to further discussion with the parents on issues of confidentiality, privacy and anonymity when children take part in research. I explained that I would not expect to share any aspect of children's interviews with anyone else, apart from their anonymised quotes used in any public documentation, unless there were child protection concerns. The parents appeared to understand this important ethical issue and did not withdraw consent for their children to take part. Further discussion of some of the ethical issues relating to involving children in the research is contained in Chapter 6 (see section 6.3.2).

3.13 Summary

This chapter has described and justified the methodological approach adopted for this study. The following two chapters present the analysis of the data generated through the questionnaires and interviews.

Chapter 4 Phase one: Questionnaire results

4.1   Introduction

This chapter presents the results of the primary and secondary questionnaire data analysis. Together with the analysis in the following chapter, it addresses the following research question and sub questions:

> RQ2. What are the perspectives of children and young people with CF on their educational experiences and needs?
>
> - To what extent do they feel their needs are understood, identified and met in their current educational provision?
> - What factors do they perceive to be helpful to their educational experiences?

Demographic data relating to the questionnaire respondents is presented first. Following this, the results are organised according to each section of the primary and secondary questionnaires, namely; section one: questions about school; section two: questions about CF and school activities; and section three: questions about being poorly.

Frequencies and percentages of responses to items in the questionnaire are displayed through bar graphs and charts. Two separate questionnaires were administered to primary and secondary students and a small number of items differed within each questionnaire. For example, some questionnaire items were administered to respondents from only one school type. Therefore, the percentages displayed for such items are reflective of the proportion of participant responses from the corresponding school type, rather than the total number of all primary and secondary respondents. However, where a comparison of primary and secondary participant responses is contained within the same graph, the percentage quoted reflects the proportion of the whole participant group. Cross-tabulations are used to compare the results of one or more variables with another. The Chi Square test of association is used to explore the association between participants' demographics and responses to certain questionnaire items. The Mann-Whitney U test is used to test for differences between groups of participants on the impact of CF on school activities scale. Where items have missing data, this will be indicated when presenting the item results.

4.2   Demographic data

Seventy-five children and young people, 61.3% male, 37.3% female (1.3% missing data), mean age 10.7 years (range 5 to 17 years) responded to the questionnaire within the administration period. Two young people opted not to complete the questionnaire when approached for their participation in the study at the CF centre. Table 4.1 summarises the demographic details of the participants.

N = 75	Frequency	Percent
School Type		
Primary	42	56
Secondary	33	44
Gender		
Male	46	61.3
Female	28	37.3
Missing data	1	1.3
Year Group		
Reception	4	5.3
Year 1	7	9.3
Year 2	3	4.0
Year 3	4	5.3
Year 4	10	13.3
Year 5	8	10.7
Year 6	6	8.0
Year 7	3	4.0
Year 8	5	6.7
Year 9	4	5.3
Year 10	6	8.0
Year 11	10	13.3
Year 12	5	6.7
Mean Age (years)	10.7 ± 3.7	
Respondents who had been in hospital in the last 12 months	32	42.7
Respondents who received home IV treatment in the last 12 months	29	38.7
Respondents who had no hospital or IV treatment in the last 12 months	34	45.3
Respondents with difficulties/disabilities other than CF	3	4.0

Table 4.1 *Respondent characteristics*

Primary school students made up 56% of the participants (*n*=42). All school year groups were represented although years four and eleven had the majority of respondents (n=10 respectively). Of those who responded to the questionnaire, 42.7% (*n*=32) had been in hospital and 38.7% (*n*=29) had received home IV treatment in the last 12 months. Cross-tabulation revealed that 26.7% of these respondents (*n*=20) had been in hospital and also required home IVs in the last 12 months. Further cross-tabulation showed that almost half of participants had neither

been in hospital nor received home IV treatment in the last 12 months (*n*=34). This evidences that the sample was relatively diverse in terms of the treatment they undergo, and included respondents who had recently required more aggressive CF treatments in addition to daily maintenance regimes, and those who did not. Three respondents reported that they had other difficulties or disabilities in addition to CF. These included visual and hearing difficulties, Crohn's disease and dyslexia.

4.3 Section 1 – Perceptions of teacher/school support

4.3.1 How do you feel about school? (Q1. Primary and Secondary)

On the whole, children and young people who responded to the questionnaire indicated that they were always happy at school (*n*=24) or were mostly happy at school (*n*=31). A small minority stated they were mostly unhappy (*n*=3) or always unhappy at school (*n*=1), while the remainder were neutral (*n*=16) (Figure 4.1).
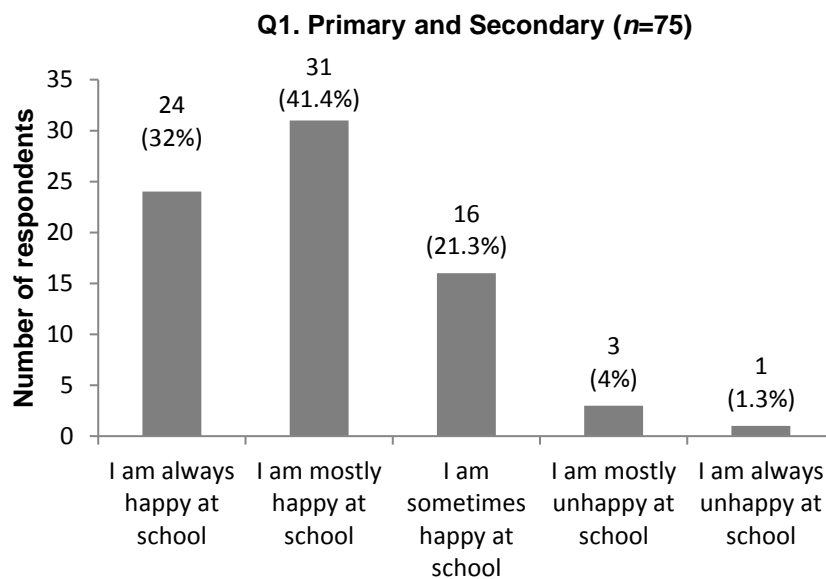
Figure 4.1 How do you feel about being at school?

4.3.2 Has anyone from school ever talked to you and/or your parents about your cystic fibrosis? (Q2. Secondary)

Only the secondary questionnaire included the question above. Just over half of all secondary school participants (*n*=17) indicated that someone from their school had

talked to them or to their parents about their CF. However, almost half answered 'no' to this question or were 'not sure' (n=12 and n=4 respectively) (Figure 4.2).

Q2. Secondary *(n=33)*

Figure showing a bar chart with three bars. Yes: 17 (51.5%), No: 12 (36.4%), Not sure: 4 (12.1%). Y-axis labelled "Number of respondents" from 0 to 18.
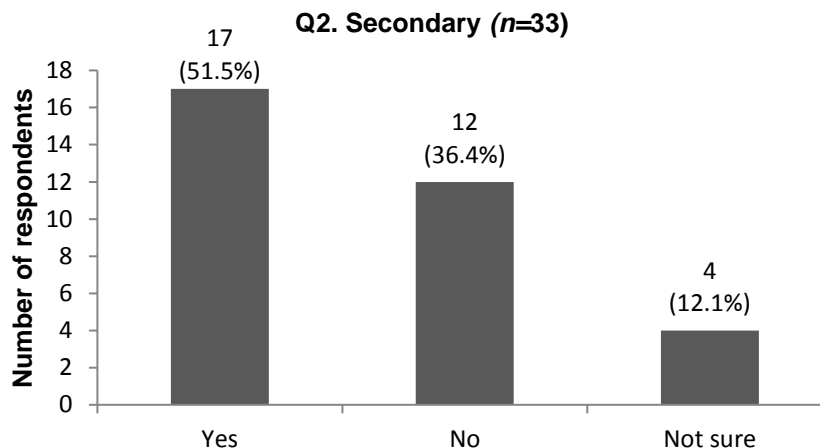
Figure 4.2 *Has anyone from school ever talked to you and/or your parents about your CF?*

4.3.3 Do you think that your teachers understand cystic fibrosis? (Q2. Primary, Q3. Secondary)

Initial analysis of responses to this item revealed that the majority of questionnaire respondents answered 'no' (n=18) or 'not sure (n=28) to this question, while 29 children and young people answered 'yes' (Figure 4.3).

Q2. Primary Q3. Secondary (*n*=75)

Figure showing a bar chart with three bars. Yes: 29 (38.7%), No: 18 (24%), Not sure: 28 (37.3%). Y-axis labelled "Number of respondents" from 0 to 35.
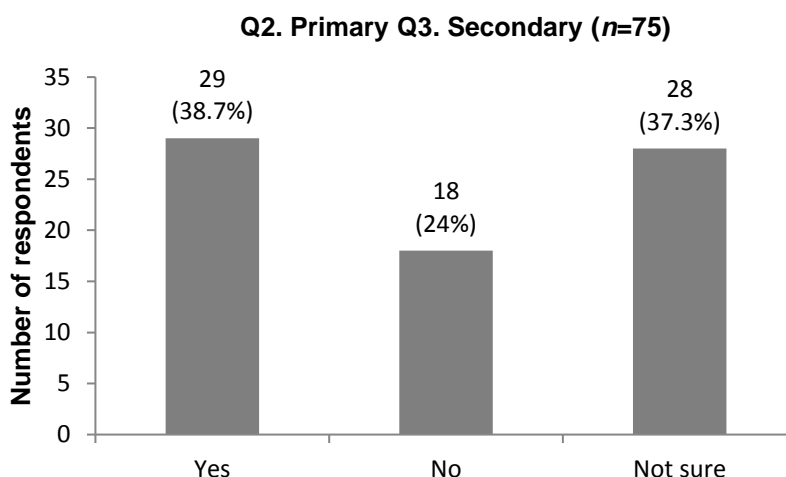
Figure 4.3 *Do you think that your teachers understand what CF is?*

Further analysis of the questionnaire data relating to this item led me to consider if there was an association between the respondents' school type and the responses given (Figure 4.4).

Q2. Primary Q3. Secondary (*n*=75)
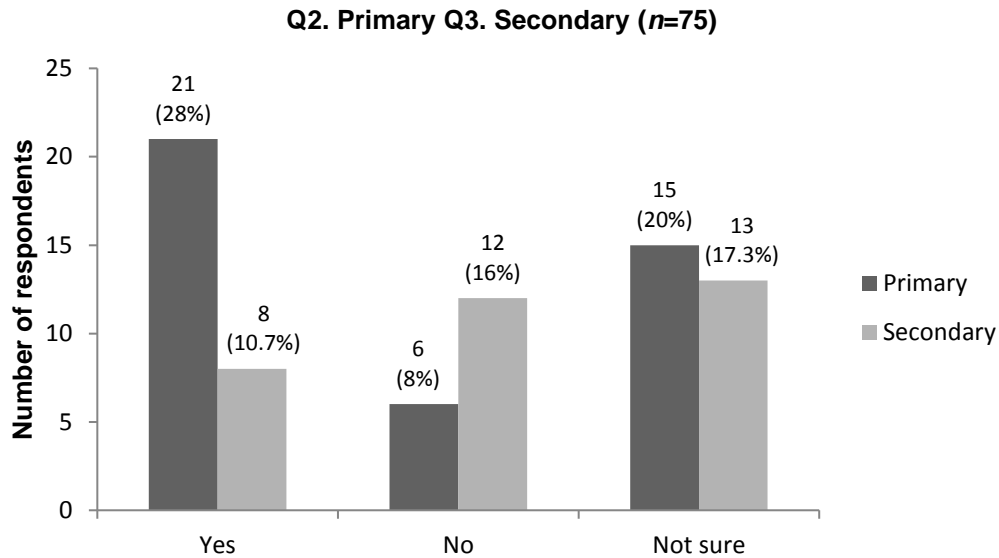
Figure 4.4 *Respondent's school type: do you think that your teachers understand what CF is?*

A Chi Square test of association indicated a significant association between the respondents school type and the responses relating to teacher understanding of CF. Phi indicated a medium effect size (Cohen, 1988) (Chi Square = 6.991, df = 2, p = .03, Phi = .30). This shows that the respondent's school type significantly influenced how they answered the question and may therefore suggest that primary school students were more likely to feel their teachers understood CF than secondary school participants.

Further analysis using the Chi Square test of association revealed there was no significant association between participants indicating they had been in hospital in the last 12 months and the responses relating to teacher understanding (Chi Square = 1.795, df = 2, p = .408, Phi = .155). Similarly, there was no significant association between participants indicating they had received home IVs and the responses relating to teacher understanding (Chi Square = 2.724, df = 2, p = .256, Phi = .191). This may indicate that where respondents potentially experienced increased treatment demands and/or periods of ill health, they were neither more likely or unlikely to feel that their teachers understood CF, than students who had not been in hospital or had home IVs in the last 12 months.

4.3.4   Do you get extra help with anything at school? (Q3a. Primary)

This question was included in the primary questionnaire only. Just over half of primary school participants (*n*=24) indicated that they get extra help at school, while 14 respondents answered 'no' and 4 were 'not sure' (Figure 4.5).

Q3a. Primary (n=42)
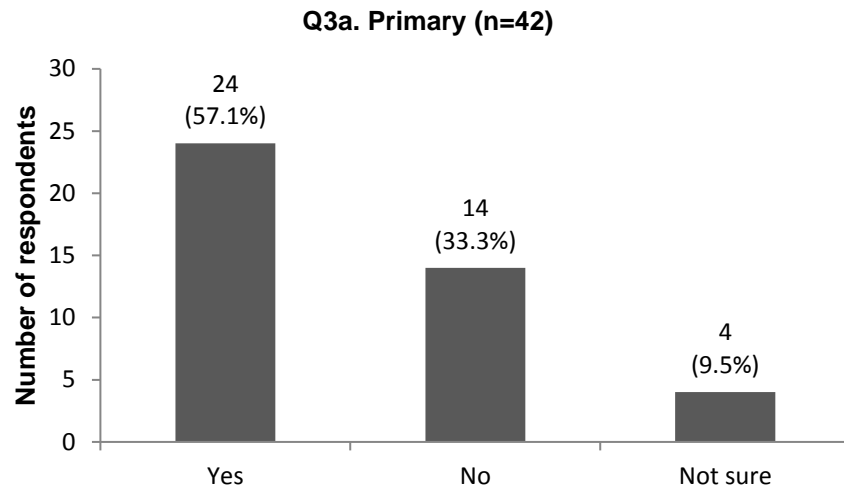
Figure 4.5 Do you get any extra help with anything at school?

4.3.4.1   If yes, what do you get extra help with? (Q3b. Primary)

Of the 24 primary school respondents that indicated they receive extra help at school, 22 participants identified a range of extra help and support that they receive. Some participants indicated that they receive help in more than one area. All responses were organised into similar thematic areas including; help with learning needs and help with medical needs. Responses relating to help with medical needs were further categorised into help with doing treatments and help with eating well. The thematic organisation of responses are presented in Table 4.2 on the next page.

Thematic organisation of responses: 'What do you get extra help with at school?' (Q3b. Primary)		
Help with learning needs	Help with medical needs	
	Doing treatments	Eating well
"Phonics" "Reading and maths" "Sometimes with reading" "Maths, literacy, guided reading, and geography" "With reading" "Maths" "Reading and writing" "I get extra help with Maths and English" "With my behaviour"	"A member of staff gives me my enzymes" "I get extra help with my tablets at lunchtime" "Teachers help me with Creon" "Physio" "Help with taking tablets" "Having my tablets, reminding me" "The teachers give me my Creon" "My Creon and problems with CF" "Sprinkles" "Help with my Creon at lunchtime" "Lunchtime with my Creon" "Creon and exercise" "Springles" "Help with medication at lunchtimes" "Meds"	"I get to choose my school dinners at the start of the week" "Packed lunch" "They let me eat more"

Table 4.2 Thematic organisation of responses: what do you get extra help with at school?

4.3.5 Is there somebody at school who you feel you can talk to if you need to? (Q6. Primary, Q4. Secondary)

The overwhelming majority of respondents (n=58) indicated that they do have somebody at school who they feel they can talk to. Seven participants answered 'no' to this question while 10 children and young people stated they were 'not sure' (Figure 4.6).

Q6. Primary, Q4. Secondary (*n*=75)
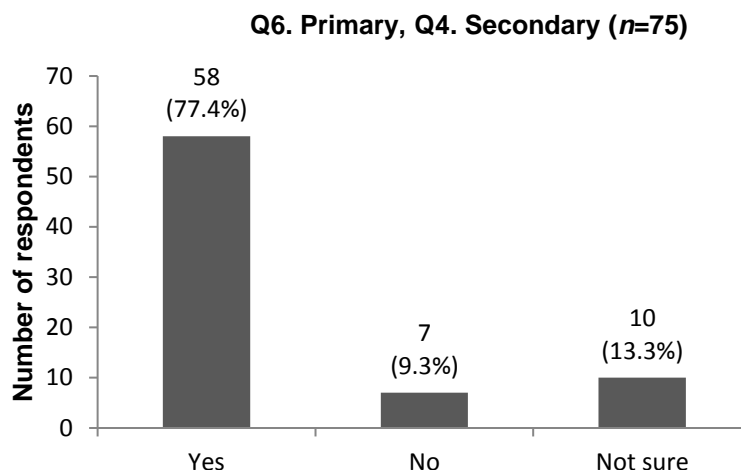
Figure 4.6 Is there somebody at school who you feel you can talk to if you need to?

A side-by-side comparison of the primary and secondary responses to this item led to further analysis of the data in order to establish if there was an association between the respondents' school type and the responses given (Figure 4.7).

Q6. Primary, Q4. Secondary (*n*=75)
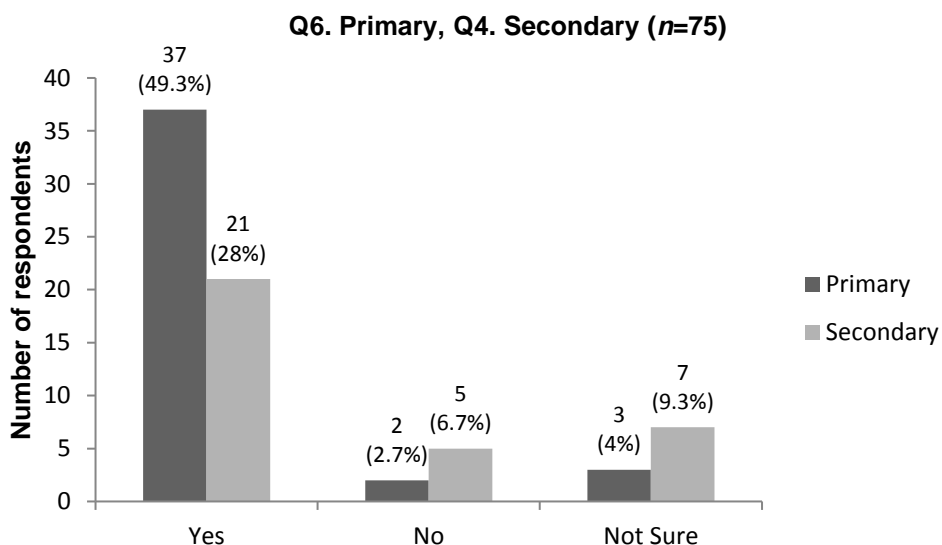
Figure 4.7 Side-by-side comparison: is there somebody at school who you feel you can talk to if you need to?

A Chi Square test of association indicated a significant association between the respondent's school type and the responses relating to having someone to talk to at school. Phi indicated a medium effect size (Cohen, 1988) (Chi Square = 6.310, df = 2, p = .047 Phi = .29). This shows that the respondent's school type influenced how they answered the question and therefore suggests that primary school students

were more likely than secondary school students to feel they had someone to talk to at school.

4.3.6 If you ever needed help or support with anything at school, are you happy you would get what you need? (Q5. Secondary)

In answer to this question, 15 secondary school participants stated that they were happy they would get what they need. Only 1 respondent answered 'no', while 7 were 'not sure'. Ten participants indicated they did not need any help at school (Figure 4.8).
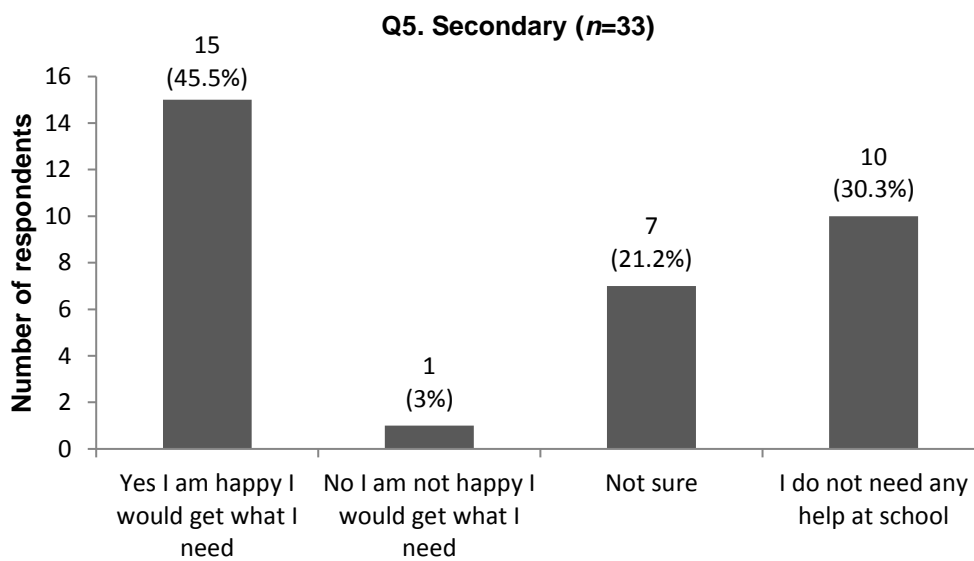
Figure 4.8 *If you ever needed help with anything at school are you happy you would get what you need?*

4.3.7 Do you think anything could be done to make things better for you at school? (Q7a. Primary, Q8a. Secondary)

Most respondents (*n*=40) indicated that they did not think anything could be done to make things better for them at school. However, 16 children and young people answered yes to this question, while 19 indicated they were 'not sure' (Figure 4.9).

Q7a, Primary, Q8a. Secondary (*n*=75)
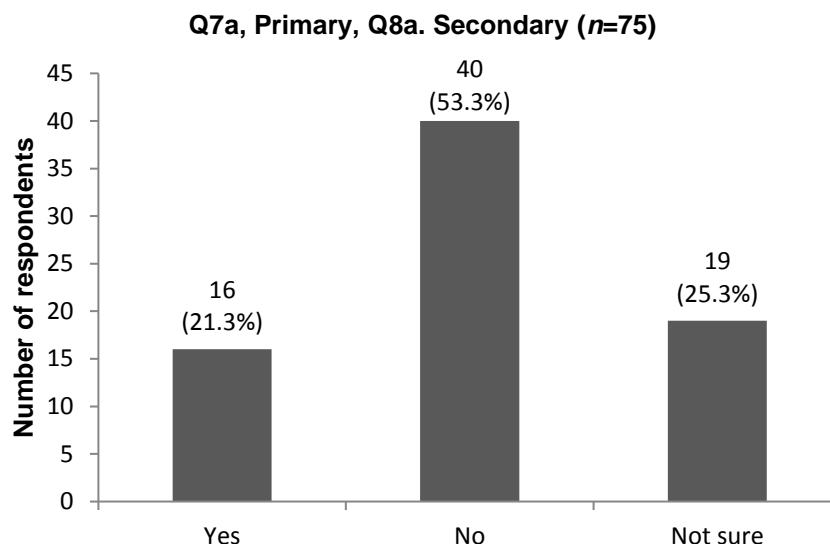
Figure 4.9 *Do you think that anything could be done to make things better for you at school?*

4.3.7.1 If yes, what would make things better for you at school? (Q7b. Primary, Q8b. Secondary)

Out of the 16 respondents who answered 'yes' to the last item, 14 offered suggestions about what would make things better for them at school. These suggestions were organised under four categories: awareness and understanding, cross-infection, staying well at school, and one person taking a lead. Table 4.3 on the next page presents the thematic organisation of these suggestions.

Thematic organisation of responses: 'If yes, what would make things better for you at school? (Q7b. Primary, Q8b. Secondary)	
Awareness and understanding	*"Children and teachers could be given more information about CF and why I take tablets and have IVs"* *"All teachers to understand CF"* *"Better understanding of what CF treatments are and how they make you feel"* *"For all staff to be aware"* *"I feel that people stare at me when coughing and the teachers tell me off for it"*
Cross-infection	*"For teachers not to make me sit next to people with coughs and colds"* *"There is another boy at school with CF. So at lunchtimes I can't sit near him which means sometimes I can't sit with my friends"* *"Letting me go home, sharing going into assembly with another child with CF, instead of never being able to go in when it's an all school assembly"*
Staying well at school	*"School dinners"* *"Food - on school dinners which are low in fat and calories and not appetising"* *"Cleaner toilets"* *"Change the school nurse. I feel awkward going to see him if I'm ill because he's an old man"* *"It would be helpful if I could be in charge of my Creon without having to rely on my dinner lady going to get them"*
One person taking a lead	*"Someone to talk to if I had a problem but I don't feel confident"*

Table 4.3 *Thematic organisation of responses: If yes, what would make things better for you at school?*

4.4   Section 2 – Managing treatments at school

4.4.1   In the last 12 months, which of these CF treatments have you had while at school? (Q4. Primary, Q6. Secondary)

Figure 4.10 shows the range of CF treatments required by the questionnaire respondents. The overwhelming majority of respondents indicated they have needed CF treatments at school in the last 12 months. Digestive enzymes capsules (such as Creon) represented the most common treatment required by children and young people at school (n=64). Participants also indicated that they have required more complex and time consuming treatments such as IV therapy (n=19) and

physiotherapy (*n*=12). Only 4 participants reported they received no CF treatments at school in the last 12 months. Generally, similar numbers of primary and secondary respondents had the CF treatments listed under this questionnaire item at school, although more primary respondents than secondary respondents indicated that they had taken oral antibiotics at school than secondary respondents.
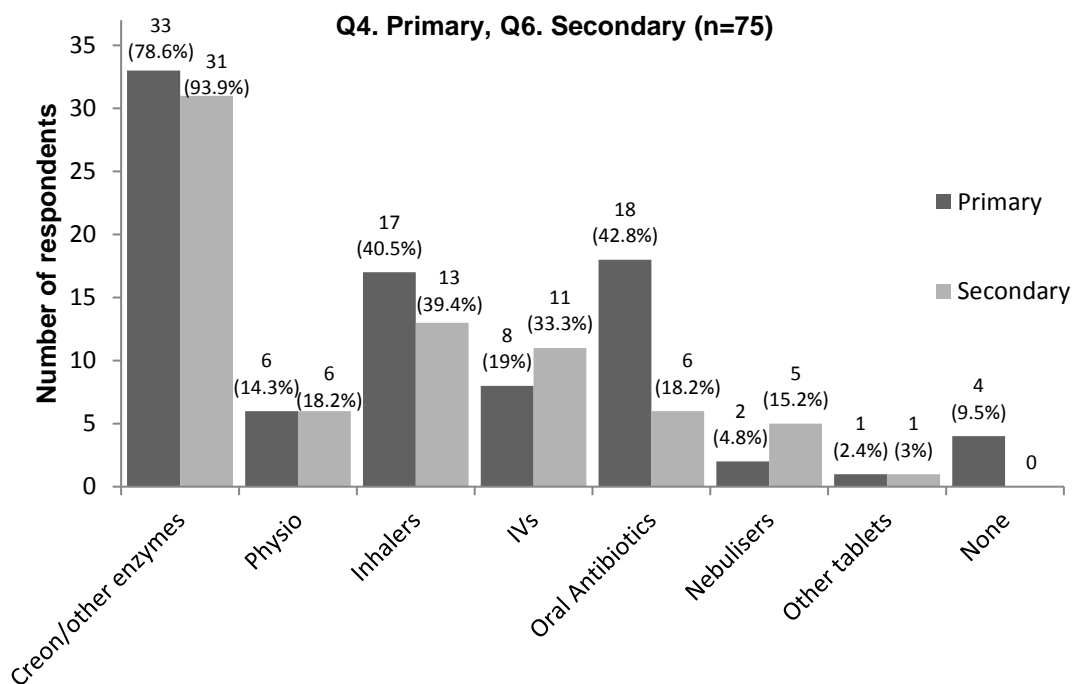
Figure 4.10 *In the last twelve months, which of these treatments have you had while at school?*

4.4.2 Are you happy with the arrangements in place for you to have your CF treatments at school? (Q5. Primary, Q7. Secondary)

Most children and young people (*n*=61) indicated that they were happy with the arrangements in place for them to have their CF treatments at school. Only 5 respondents answered 'no' to this question, while 8 stated they were 'not sure' (Figure 4.11). There was missing data for one respondent.

Q5. Primary, Q7. Secondary (*n*=74)
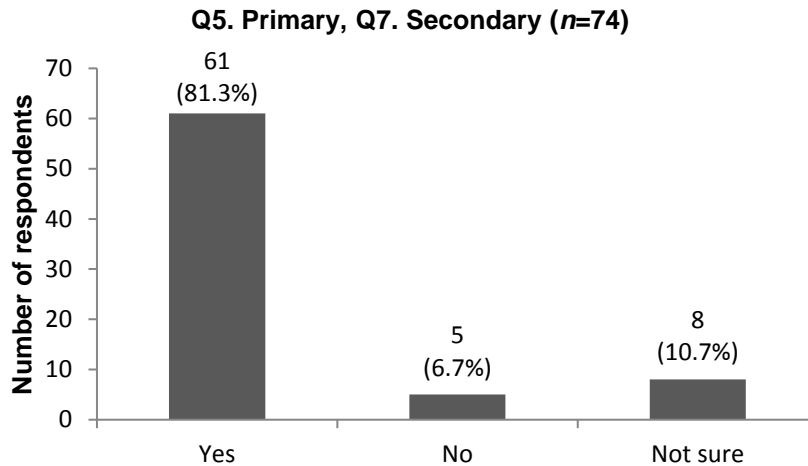
Figure 4.11 Are you happy with the arrangements in place for you to have your CF treatments at school?

4.5 Section 3 – Perceived impact of CF on education

4.5.1 When thinking about school, how difficult does CF make the following things? (Impact of CF on school activities scale: Q8. Primary Q9. Secondary)

Pupils were asked to rate the level of CF difficulty relating to twelve school related activities using a scale of 1 to 5, where 1 represents low level of CF difficulty and 5 represents high level of CF difficulty. Figure 4.12 illustrates a graphic representation of participant responses. School related activities with the largest number of respondents rating higher levels of difficulty were 'school trips' (*n*=18 rating 4 or 5), 'getting ready for school' (*n*=15 rating 4 or 5) and 'going to the toilet' (*n*=14 rating 4 or 5). Activities with the largest number of respondents rating lower levels of difficulty were 'getting on with others' (*n*=69 rating 1 or 2), 'break times' (*n*=66 rating 1 or 2) and 'getting around' (*n*=66 rating 1 or 2). There was missing data for 4 respondents on 3 of the scale items (Figure 4.12).

A Mann-Whitney U test was used to compare the median scores of groups of participants on the impact of CF on school activities scale, in order to determine if they differed in terms of the level of CF related difficulty. A Mann-Whitney U test revealed a highly significant difference in the level of CF related difficulty of those who had been in hospital in the last 12 months (median=25, *n*=31) and those who had not (median=17, *n*=40); r indicated a medium effect size (Cohen, 1988) (U = 309, z = -3.61, p = .001, r = .43). This demonstrates that respondents who had

been in hospital in the last 12 months were more likely to rate higher levels of CF related difficulty on the impact of CF on school activities scale. A Mann-Whitney U test also revealed a significant difference in the level of CF related difficulty of the respondents who had received home IV treatment in the last 12 months (median=24, n=28) and those who had not (median=18, n=43); r indicated a small to medium effect size (Cohen 1988) (U = 428, z = -2.05, p = .04, r = .2). Again this demonstrates that respondents who had received a course of IVs in the last 12 months were more likely to rate higher levels of CF related difficulty on the impact of CF on school activities scale. There was no significant difference in the level of CF related difficulty for primary respondents (median=19, n=41) and secondary respondents (median=20, n=30), U = 583, z = -.373, p = .71, r = .04.
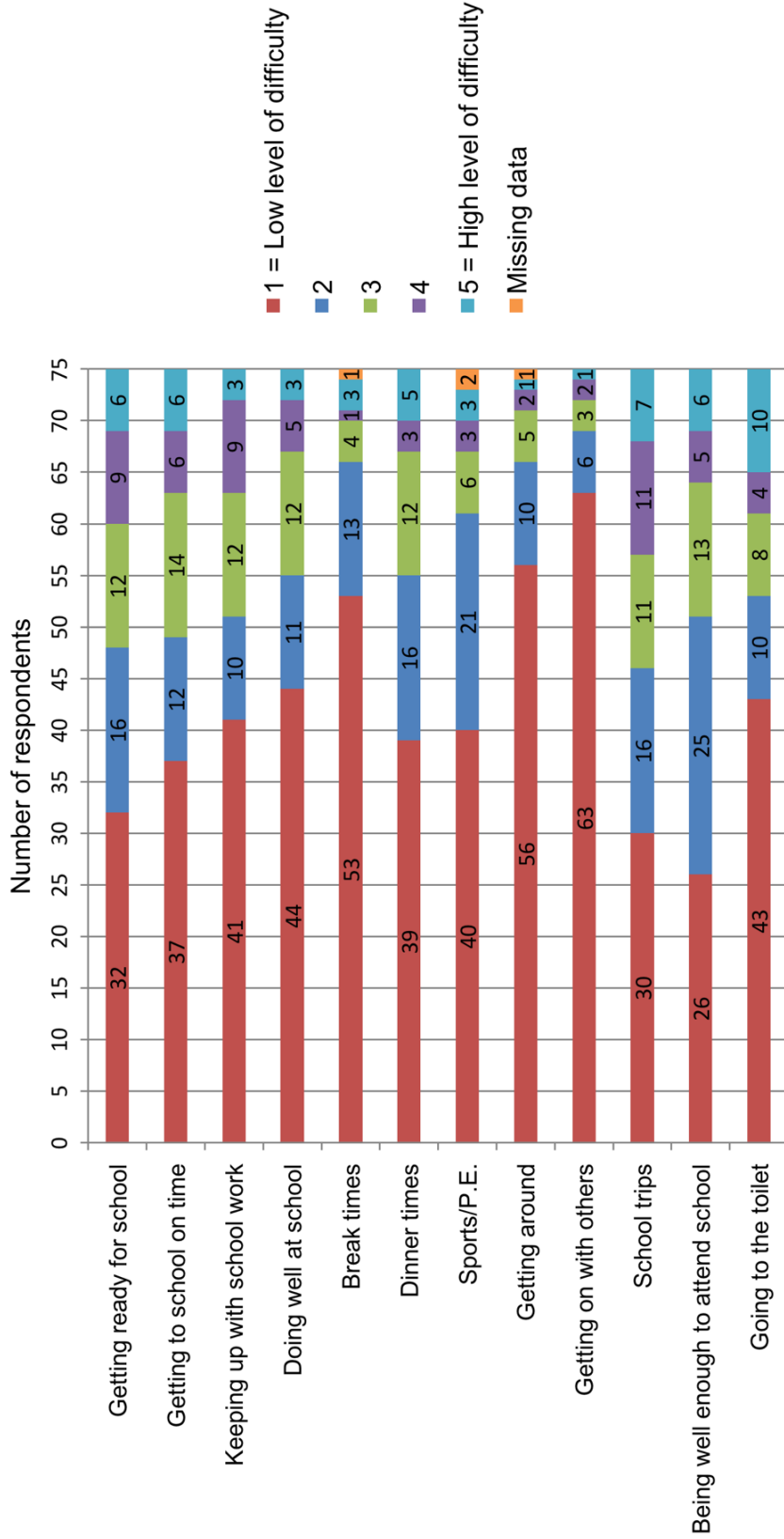
Figure 4.12 *When thinking about school, how difficult does CF make the following things?*

4.6　Section 4 – Future plans

4.6.1　What would you like to do when you leave school? (Q10. Secondary)

Out of the 33 secondary school respondents, 30 answered the question above. Six young people stated they were not sure what they wanted to do after they had left school. The remaining 24 respondents listed a range of educational and career aspirations, with some suggesting several possible options. The majority of participants stated that they wanted to go to college and/or university after they had left school (n=11). However, one young person expressed concerns about having limited job opportunities due to CF. The young person commented with the following:

> *'Preferably I would like to go to university and become a doctor, however that does not seem very likely as I am limited with certain job opportunities'.*
>
> (15 year old male who had received home IVs in the last 12 months)

This perspective demonstrates that decision making around career planning may be a significant area of concern to some young people with CF. It is possible that such concerns may not be adequately addressed by the careers advice that young people access through their schools.

Of the respondents who did not want to go to university, 13 young people named specific jobs or study areas that they wished to do after leaving school. The career or educational study areas most frequently stated by respondents were childcare (n=3), author (n=2) and information and communication technology (ICT) (n=2). Other career or educational study areas were stated once by individual respondents. The following word cloud provides a graphic representation of all the educational and career areas mentioned by the secondary questionnaire respondents. Educational or career areas cited most frequently are displayed with larger text in the word cloud, while the areas that were mentioned just once appear in the smaller text (Figure 4.13).

Figure 4.13 *What would you like to do when you leave school?*

4.6.2 Have you been given careers advice? (Q11a. Secondary)

The vast majority of secondary school respondents had either been given carers advice (*n*=18) or did not need this yet (*n*=8). Only six young people answered 'no' to this question. There was missing data for one respondent.
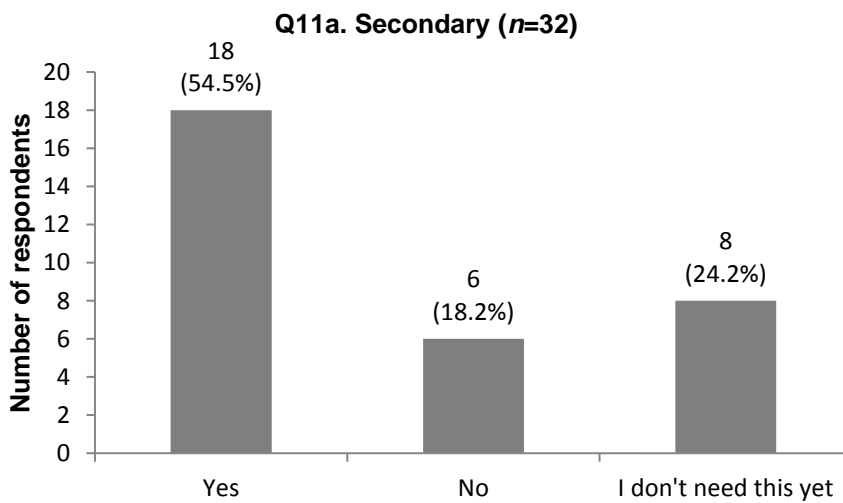
Figure 4.14 *Have you been given careers advice?*

4.6.2.1 If yes, how happy are you with the careers advice given? (Q11b. Secondary)

There were mixed responses to this question. Of the 18 respondents who answered yes to the previous item, half indicated they were either very happy (*n=5*) or mostly happy (*n=4*) with the careers advice given. Seven young people remained neutral, while two participants stated they were mostly unhappy with the careers advice given (Figure 4.15).

Q11b. Secondary (*n=18*)
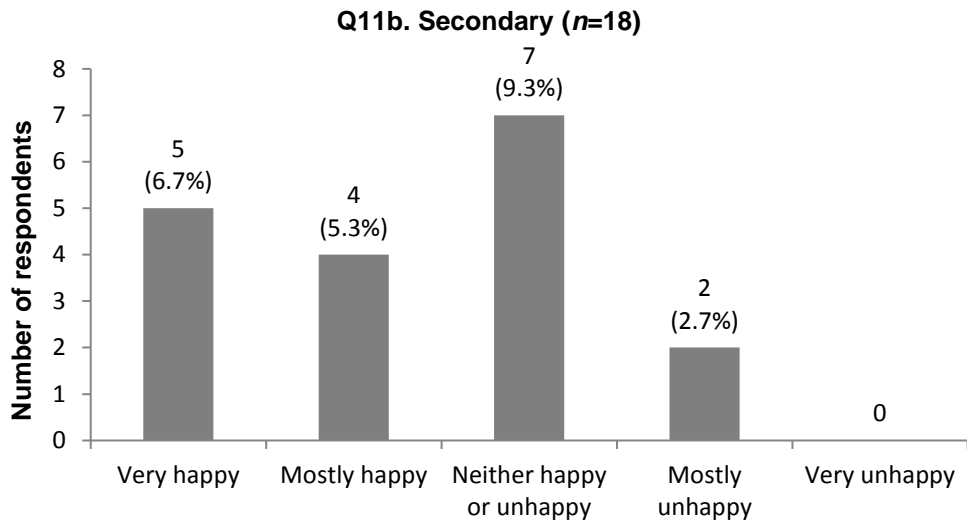
Figure 4.15 *If yes, how happy are you with the careers advice given?*

4.7   Section 5 – School absence and illness

4.7.1 In the last 12 months, have you been in hospital because of your CF/received home IVs; was this during term-time?

The results relating to two items in this section of the questionnaire are combined for illustrative purposes. Respondents were asked if they had been in hospital due to CF (Q9a. Primary, Q12a. Secondary) and if they had received home IVs in the last 12 months (Q10a. Primary, Q13a. Secondary). Where respondents answered yes to each of these questions, a follow up item asked them to indicate if this had occurred during term-time (Q9b. and Q10b. Primary, Q12b. and Q13b. Secondary*).* Almost half of the respondents had not received additional treatment during the last 12 months (*n=34*). Of the 41 remaining respondents, 26 indicated they had been in hospital during term time, with the same number of respondents indicating they had received home IV treatment during school term-time. As stated earlier (see section

4.2), a cross-tabulation revealed that 20 respondents had both been in hospital and received home IVs in the last 12 months. Figure 16 presents a combination of the data relating to the respective questionnaire items. A Chi Square test for association (with Yates Continuity Correction) indicated there was no significant association between the respondents' school type and the responses relating to being hospital due to CF (Chi Square = .446, df = 1, p = .50, Phi = .10) or having home IVs in the last 12 months (Chi Square = .000, df = 1, p = 1.00, Phi = .01). This suggests that primary and secondary students were no more likely than one another to have received more aggressive CF treatments in the last 12 months.

Q9a. & b., Q10a. & b. Primary,
Q12a. & b., Q13a. & b. Secondary (*n*=75)
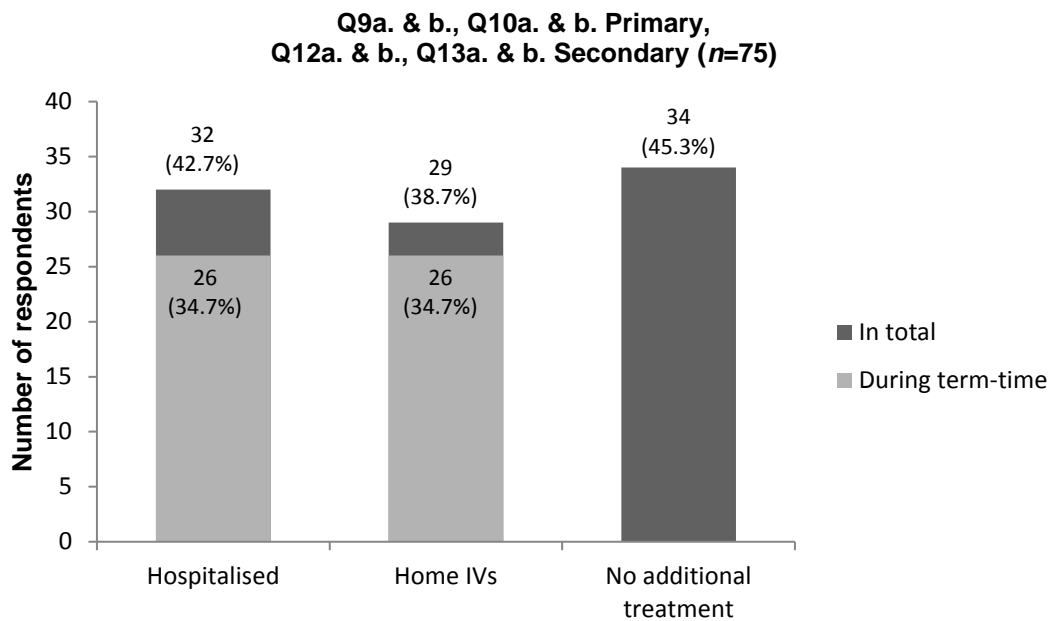
Figure 4.16 *Number of respondents having hospital or home IV treatment in the last 12 months during term time*

4.7.2 In the last 12 months, how much time have you taken off school due to CF? (Q11. Primary, Q14. Secondary)

Respondents were asked to indicate how much time they had taken off school in the last 12 months. The results should be considered to be an approximation of participants' school absence rates given the data was self-reported and not collected from official school attendance registers. Further, the results should be interpreted with caution. Participants were asked to indicate absence levels for the last 12 months rather than for the last academic school year. The 12 month time period was used to provide consistency throughout the questionnaire, particularly given the questionnaire ran for almost eight months. However, it is possible that this time period was inclusive of school days that occurred across two academic years.

Participants were not expected to provide information relating to the total number of school sessions missed during the last 12 months and therefore, the results cannot be compared with data available for the general school population.

The majority of respondents indicated they had 20 days absence or less due to CF (*n*=54). However, 20 children and young people stated they had 21 days absence or more (Figure 4.17). There were missing data for one respondent. The data suggests that school absence may not be as extensive a problem for school aged children with CF as first anticipated. However, school attendance may be a present a challenge for a subset of individuals. For example, a cross-tabulation revealed that of the 20 respondents who indicated they had taken 21 days or more off school, 14 had been in hospital in the last 12 months.

Q11. Primary, Q14. Secondary (*n*= 74)
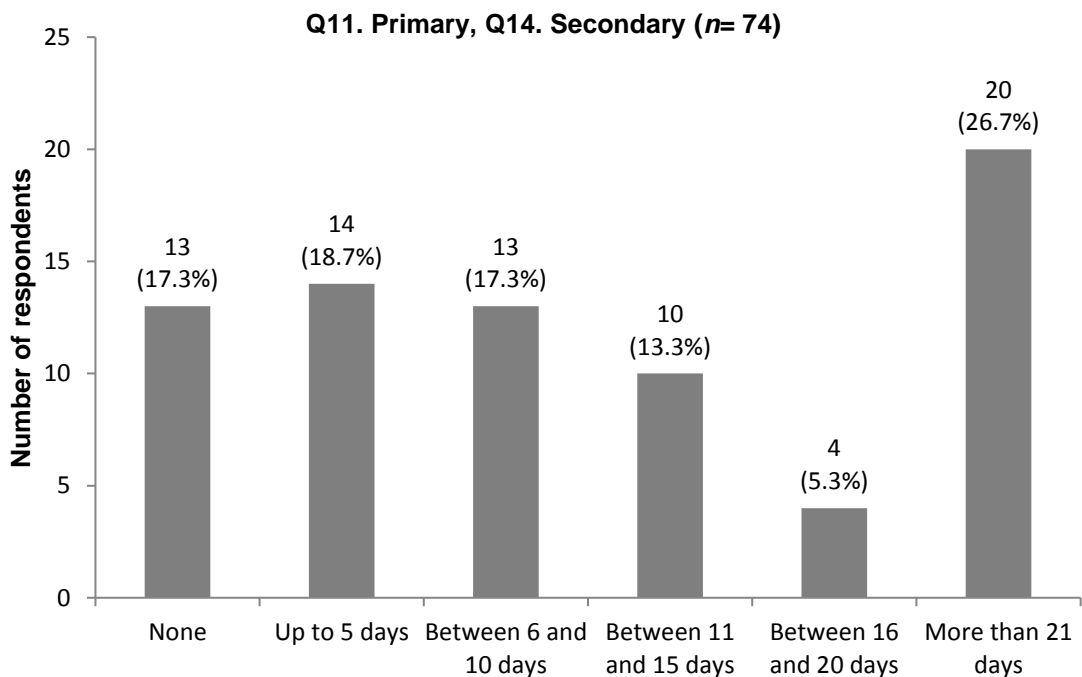
Figure 4.17 In the last 12 months, how many days have you taken off school due to CF?

4.8 Summary

The questionnaire analysis has begun to reveal the perspectives of children and young people on their educational experiences and needs, and the factors that they perceive to be helpful to them at school. A relatively diverse sample of children and young people with CF responded to the questionnaire in terms of their school type, gender, year group and the treatments that they undergo. The analysis conducted

on the data generated through the questionnaire showed that the vast majority of participants were happy at school, although a small proportion of children and young people stated some of the ways that school could be made better for them. The results suggested that teacher understanding of CF may be a particular problem for children and young people with the condition. It seemed that primary school participants were more likely to feel that their teachers understood CF than the secondary respondents. Similarly, the analysis suggested that primary school respondents were more likely to indicate that there was someone at school that they felt able to talk to if they needed to. These results demonstrate that there may be important differences between the educational experiences of primary and secondary students with CF, in terms of the extent that their needs are understood, identified and met in their education provision.

Where primary school respondents were asked about the extra help that they received at school, the analysis revealed this help was mainly focused on their medical needs, such as with their treatments or in relation to eating well. Some children did appear to receive help for their learning needs although it could not be established if this help was needed due to CF or in relation to any non-CF related educational difficulties. Secondary school participants were not asked about the support they received at school due to concerns that the idea of needing support might be rejected by some children and young people (see section 3.9.2). Indeed, ten respondents indicated they did not need any support at school. However, most suggested they were happy they would be able to get the support they needed if required. Analysis of the responses given in relation to the CF treatments that are needed at school suggested that a range of treatments may need to be administered within the school setting, despite the literature suggesting otherwise. A small proportion of children and young people were unhappy with the arrangements in place for them to have their treatments at school.

The impact of CF on school activities scale revealed that 'school trips', 'getting ready for school' and 'going to the toilet' were activities that may be more difficult for children and young people with CF. However, the vast majority of respondents rated lower levels of difficulty for all activities, which suggests that for most children and young people, the condition has a low impact on the school activities included within the scale. For a subset of individuals, such as those who have been admitted to hospital or required home IV treatment, higher levels of CF related difficulty on the impact of school activities scale may be experienced.

A range of career and educational study areas that secondary respondents wanted to do after they had left school were reported in the questionnaire. Most respondents had been given careers advice at school and were happy with this. However, one young person's response to an open-ended question suggested that CF could be a barrier to certain career opportunities in the future. Therefore, there may be a need for greater support in this area. Finally, the respondents' self-reported school absence rates indicated that most children and young people did not appear to spend extensive periods of time off school due to CF. However, a subset of individuals may be more likely to experience increased rates of school absence, such as those who have spent time in hospital.

The next chapter presents the findings from the analysis of the interviews conducted with children and young people, parents, and education and health personnel.

Chapter 5 Phase two: Interview findings

5.1   Introduction

This chapter presents the findings of the interview data analysis. Together with the results presented in the previous chapter, it addresses the following research questions and sub questions:

> RQ2. What are the perspectives of children and young people with CF on their educational experiences and needs?

> - To what extent do they feel their needs are understood, identified and met in their current educational provision?
> - What factors do they perceive to be helpful to their educational experiences?

> RQ3. What are the perspectives of other key stakeholders on the education of children and young people with CF?

This chapter describes seven overarching conceptual categories and the associated twenty-three themes constructed through the cycles of coding and analysis of the interview transcripts (see section 3.10.5). Conceptual categories are considered to be broader than a theme and are descriptive of a group of themes that are related in meaning. The transcript data is used throughout this chapter in an illustrative way via the use of participants' verbatim quotations alongside my own analytical narrative. Before I present the categories and themes, I first explain the purpose of and process for the inclusion of verbatim quotations within this chapter. Following this, I discuss the use of quotations when illustrating the interconnections between the themes. Then, I provide information about the presentation of verbatim quotations, including details of how quotations are edited for readability purposes. Next, I describe how the characteristics of each participant are summarised following any quotation via the use of a participant key. Before turning to the results of the interview analysis, I present a matrix table that provides details about the number of participants who contributed to each theme.

5.2   Purpose of using quotations

Verbatim quotations are not considered to be 'evidence', rather, they are presented to exemplify and illustrate the analytical narrative that concerns my own interpretation of the conceptual category and theme in which the quotation appears. Quotations are used illustratively to 'give voice' to those who took part in the interviews. The quotations demonstrate the perspectives of children and young people, and other key stakeholders on the educational experiences of children with CF and therefore, this chapter presents the data that will address the first two study aims along with research questions 2 and 3 (see section 3.3). A further purpose of including verbatim quotations is to illustrate the diversity of participant experiences within a given theme.

5.2.1   Process for the inclusion of quotations

I now turn to the criteria that I established for the inclusion of quotations throughout this chapter. In the interests of an inclusive approach, using some spoken words from all the interview participants was of high importance when reporting of the conceptual categories and themes. Quotations were generally selected for inclusion where these represented any differences in participants' views and experiences within a theme. Quotations that detailed any contrasting viewpoints were also included in order to represent the balance of feeling across the overall participant group (Corden and Sainsbury, 2006). However, there were three exceptions here.

Firstly, some participants were more communicative than others during the interviews. To this end, checks were made to avoid the overuse of quotes from particularly articulate participants. Where the less communicative had a similar point of view with more articulate participants within a theme, and they were in the same group of participants e.g. children, the quote from the less communicative participant was selected for inclusion. Consequently, more detailed and interesting participant quotations were sometimes excluded from the reporting. Secondly, where there was more than one participant with a similar perspective and they belonged to the same group, only one quotation was used and this is indicated in the narrative. The only exception to this would be where quotations portrayed similar perspectives, but with a slightly different nuance, in which case the words of each participant was included. Thirdly, where participants had a similar viewpoint or experience within a theme, and they were from different participant groups e.g. children and parents, quotations were included from each participant to demonstrate this similarity across the groups.

5.2.2 Thematic interconnections

In presenting the thematic analysis of the interview transcriptions, no single verbatim quotation is represented in more than one theme. However, the analysis that accompanies the participant quotations frequently demonstrates there are interconnections and/or relationships between two or more themes, with some themes influencing others. Where there are interconnections between the themes, this will be indicated in the narrative.

5.2.3 Presenting quotations

The quotations included throughout this chapter have received some editing in order to enhance readability. Firstly, the quotations have been re-punctuated and word repetitions and 'false starts' (Corden and Sainsbury, 2006) have been removed. Secondly, grammatical changes have been made where participant quotations contain words arising from regional dialects. For example 'nowt' has been changed to read 'nothing' and 'coz' has been changed to 'because'. Further, participant's sometimes used 'ums' and 'ers' while considering their responses to interview questions; these were taken out of the quotations. Thirdly, the use of three dots (…) is used to indicate long pauses or parts of a sentence being omitted at the beginning, middle, or end of a quotation, where something unrelated to the theme was being discussed. Lastly, brackets have been used around my own words in participant quotations where the meaning might otherwise be unclear.

5.3 Participant characteristics

Child participant characteristics are summarised following the quotations derived from the interviews used throughout this chapter. Detailed information relating to the summary of child participant characteristics can be found by referring to the participant key in Table 5.1.

Gender		Age	Year Group	Education Provision		Factor of Interest	
Male	♂	**A** (+ age given)	**Y** (+ year given)	*Primary*	**P**	*No IVS*	☒IVs
Female	♀			*Secondary*	**S**	*Home IVS*	🏠IVs
				Fee Paying	**fp**	*Hospital IVS*	✚IVs
				College	**C**		

Table 5.1 *Child participant characteristics key*

By way of example, Violet has the following characteristics; she is female, aged 9 years, in year 5, attends a primary school and has received home IV antibiotic treatment. Therefore, quotations from the interview with Violet are presented in the following way:

> *'Well, say if I forget something, which I probably won't, but if I did then they could like sort of remind me'.*

(Violet: ♀, A9, Y5, P, 🏠IVs)

Similarly, a summary of relevant children's characteristics are also included following any quotation from the interviews with parents and teachers who are directly connected to the children involved in the study. For example, a quote from Jackie who is Rachel's teacher is presented as follows:

> *'The school nurse is the first port of call really'.*

(Jackie, teacher of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

It should be noted that there is a difference between the summary of characteristics appearing after the quotations from the interviews with Joe and his parent Louise. At the time of the interview with Joe, he had never received IV antibiotic treatment and therefore the associated characteristics are presented accordingly following any quotation used from his interview. However, at the time of the interview with his mother Louise, which took place several weeks later, Joe had received IVs both at home and in hospital. Therefore, the characteristics that appear following quotations from Louise's interview are reflective of this change in circumstances.

Following any quotation from the interviews with adults who are not directly connected to child participants, such as the CF nurse specialists or the hospital school higher level teaching assistant, the participant's pseudonym and job title will be presented.

5.4   Conceptual category and theme table

Table 5.2 on the following page represents a quantitative indication of the spread of a theme across the overall group of participants. Participants who contributed to each conceptual category and theme are shown via a tick in the corresponding box. Boxes are left blank where participants did not contribute. The total number of sources relating to each theme is presented at the bottom of the table. A lower number of participant sources does not diminish the value of an idea contained within the perspectives of those took part in the interviews. Therefore, themes with both high and low numbers of sources are included in the analysis.

Conceptual category	Themes	Bob	Rachel	Joe	Luke	Violet	Linda	Louise	Nikki	Alice	Jackie	Jayne	Yvonne	Diane	Joanne	Total sources
		Children and young people					**Parents**				**Education personnel**			**Health personnel**		
1. Being me first	Being like everybody else	✓	✓		✓	✓	✓	✓	✓	✓		✓		✓	✓	11
	Being unhindered by CF	✓	✓	✓	✓	✓	✓	✓	✓			✓	✓			10
	Hiding visible differences	✓		✓			✓		✓			✓	✓			6
	Keeping CF private	✓	✓		✓	✓	✓		✓							6
2. Balancing treatments and school activities	Arranging treatments away from school	✓	✓	✓	✓		✓	✓	✓	✓			✓	✓		10
	Fitting everything in		✓	✓			✓	✓	✓	✓				✓		7
3. Staying well at school	Eating well			✓			✓	✓								3
	Using the toilet	✓		✓	✓	✓			✓			✓	✓			7
	Managing treatments at school	✓		✓		✓		✓		✓		✓	✓	✓		8
	Managing cross-infection	✓	✓				✓						✓	✓	✓	6
4. Knowing about CF	Informing CF	✓		✓	✓			✓	✓	✓	✓	✓		✓	✓	10
	Awareness & understanding	✓	✓	✓	✓	✓			✓	✓			✓			8
	One person taking the lead	✓		✓			✓	✓			✓		✓			6
5. CF impacting learning	School absence	✓	✓	✓		✓		✓	✓			✓	✓	✓	✓	10
	Falling behind & catching up	✓		✓	✓	✓	✓	✓	✓				✓	✓	✓	10
	Symptoms & side effects	✓		✓				✓	✓			✓	✓			6
6. Educational support	Continuity of education	✓			✓		✓	✓	✓				✓		✓	7
	Extensions & extra time	✓						✓							✓	3
	Significant school subjects & activities	✓	✓	✓	✓	✓		✓		✓	✓				✓	9
7. Negotiating CF alongside adolescence	Making sense of CF							✓		✓			✓	✓		4
	The importance of friendships			✓				✓	✓				✓			4
	Career aspirations	✓					✓	✓								3
	Body image	✓				✓						✓	✓			4

Table 5.2 *Participant contributions to conceptual categories and themes*

5.5   Conceptual category 1: Being me first

This conceptual category describes participant accounts that relate to the importance of children and young people being 'themselves' first at school, as opposed to CF being their immediate defining characteristic. There are four themes contained within this conceptual category; being like everybody else, being unhindered by CF, hiding visible differences, and keeping CF private.

5.5.1   Being like everybody else

Sources: *Children and young people: 4*

                 Other participants: 7

Participant perspectives relating to 'being like everybody else' were centred on the issue of difference at school. Four children and young people appeared to reject the idea of being different to other children. They saw themselves in the same way as their non-CF peers, as did parents and education and health professionals. Several participants, referred to children with CF as being 'normal' and children also described themselves in this way:

> *'I want to be seen as normal. I'm a normal person'.*

> (Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

> *'We like to think of things as, well she's normal, but needs a few extra things. I refuse to go down the sick role line. Like I say it's just not relevant at the moment'.*

> (Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs*)*

> *'These children are you know, normal children that just may need a little understanding at certain times, but certainly nothing to worry about at all'.*

> (Jayne, teacher of Violet: ♀, A9, Y5, P, 🏠IVs)

Despite these perspectives, two parents expressed there is also a 'seriousness' to CF, suggesting that this could have certain implications for children at school. However, the parents maintained that CF should not be a reason for their children to be treated differently. This appeared to be linked to fears and concerns relating

to the possibility that teachers may have different expectations of their children due to CF:

> *'I think she surprises the teachers. And I think is that in my mind? I'm maybe looking into it, but is it because they know she's got CF? And I remember in this meeting we had, they asked me "how do you want us to…" and I said I want you to treat her the same'.*

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

Conversely, the two specialist CF nurses suggested that treating children with CF in the same way as their non-CF peers could reinforce their difference. They explained that to avoid drawing attention to the child's medical condition, schools may need to make adjustments to certain practices, which they felt to be necessary for the inclusion of children with CF. One of the nurses gave the example of adapting practices during school trips:

> *'So, a favourite one is; they're going to the farm and you have certain situations where we'll say you know if they're in a barn and it's full of hay being swept about you've got all this risk of aspergillus and they're saying…Well, could it be that they do this outside? So all the children do it, and it's not just that one child left stood outside while everyone else is there because we don't want them not to go. It's looking at options as to how you could adapt things so that they don't feel picked on and pointed out. And as I say, not highlighting the fact that they're different from everybody else…we don't want to make them look different from other children, we want to make them feel included'.*

(Diane, CF nurse specialist)

Indeed, school trips may involve the provision of activities that are quite different to those typically provided at school, meaning that they may present additional barriers to participation for children with CF. Further, school trips can present changes to regular school routines which in turn may impact children's daily health regimes. One parent explained that her son felt unable to attend a school trip due to the changes this would impose to the management of his CF as a result of being away from home overnight for several days. She also stated he was concerned about doing his treatments while away from home, as this might draw attention to his CF and make him feel different. Therefore, this suggests a connection here to the themes 'hiding visible differences' and 'keeping CF private':

> *'I think he's quite worried about him being able to do his medicines and also Joe doesn't eat. His eating is absolutely dire. And he probably wouldn't eat what they would give him. You see as well, Joe won't take tablets. He's still on liquid so that would obviously make it harder as*

well. If he was on his tablets…like with Alex (brother), I just put his medicines in a planner and he just took them. Whereas Joe, he's still on liquid it would be drawing it up and keeping it in the fridge…I'd love for him to be able to and feel confident enough to go but…I can understand why he doesn't want to go, because it will make him a bit different won't it?'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

5.5.2 Being unhindered by CF

Sources: Children and young people: 5

Other participants: 5

Children and young people discussed the extent that they felt CF affects them from day-to-day. The overwhelming response from all children and young people was one of being unhindered by CF:

'Erm, it doesn't really affect me that much…not really. I do everything I want to do'.

(Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

'It never massively affected me like, I've never massively struggled where I've been ill for extended periods of time. So, it never stopped me doing anything I really wanted to do'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

Being unhindered by CF offers one explanation as to why children may reject the idea of being different to other children, therefore connecting this theme to the previous one; 'being like everybody else'. Parents and education and health professionals also discussed how children manage having CF in an educational context. They described children 'getting on with it' or not thinking or worrying about CF, therefore demonstrating the strategies that children use to manage living with a chronic medical condition while attending school:

'She just gets on with it; "this is my life and this is what we have to do". She had to do a RS project the other day and she had to circle the things that she agreed with…quotes from different religions. One of them was "I'm living now, so I'm not going to worry about what's happened in the past or what's happening in the future, I'll just get on with my life now". And she circled that green and that's just her totally'.

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

*'I think if they are getting into school and they're well, I think probably
it's managed really well. It's at the back of their mind'*

(Diane, CF nurse specialist)

5.5.3 Hiding visible differences

Sources: *Children and young people: 2*

               Other participants: 4

While there are few outwards signs of CF that are noticeable to other people,
participant accounts suggested that children and young people actively hide certain
aspects of having CF that could become visible to others at school. Avoiding taking
medication and supressing coughs were examples of 'hiding visible differences' that
were discussed by children and the CF specialist nurses during the interviews.
Participant perspectives within this theme also demonstrate a connection to the
next theme 'keeping CF private':

> *'They supress coughs all the time, I know they do it. They do it on the
> ward and I can understand you know you don't want…because you see
> people looking at them going "what is that horrible noise"…'.*
>
> (Diane, CF nurse specialist)

When children undergo IV antibiotic therapy, having CF may become more visible
to others due to the presence of an IV access line. Two parents talked about their
children hiding visible aspects of this treatment from their school friends:

> *'It was a rotten line and so she had to get it re-sited further down her
> wrist. So the bandage, the Tegaderm stuff, was over her hand and the
> bandage ended up over her palm. After she had it put in (the IV line),
> we went for some lunch and she ended up buying a pair of fingerless
> gloves and put them on and said, "right I'm going to wear these"…'.*
>
> (Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

> *'Even friends that would normally come to us, he won't let them come
> because he has IVs last thing at night and then in morning when he
> wakes up, so he doesn't want anyone to see what's happening'.*
>
> (Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

Children and young people also appeared to experience certain dilemmas as a
result of 'hiding visible differences' from others at school. For example, two

participants discussed scenarios where children decided to hide visible aspects of having CF, despite this being potentially detrimental to their health or education.

> *'We have one lad and they were saying, "well I don't want to be any different to the others". And I thought well yeah that's fair enough. He was getting in when he could get in. When he wasn't feeling well enough he didn't want to go in because he'd look different then, so he'd rather be at home and not bother going in at all'.*
>
> (Yvonne, hospital school HLTA)

> *'I went through a really stupid period where I didn't take my Creon at lunch because I didn't want anyone to know and I didn't want to take them in front of people…it was quite painful. It isn't the nicest feeling, you know a bad stomach and the runs and all that so'.*
>
> (Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

5.5.4 Keeping CF private

Sources: Children and young people: 4

           Other participants: 2

In the previous theme, participants discussed the actions taken by children to hide any visible differences arising from CF. During the interviews, it was also apparent that most children and young people preferred not to talk about CF to others at school and opted to keep it private, illustrating a relationship to the previous theme 'hiding visible differences':

> *'It's not really brought up between us'.*
>
> (Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

> *'I don't know, they don't really need to know so I don't really need to tell them. I just keep it to myself'.*
>
> (Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

When discussing the reasons why children and young people preferred to 'keep CF private', they raised concerns about being treated or viewed differently by others at school. This also offers an explanation as to why children may hide any visible differences, while illustrating the significance of being seen for 'themselves' first:

'I don't like people feeling sorry for me…that's why I don't tell people'.

(Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

"I don't want charity. I've never wanted charity from people. I don't want to be seen as different'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

The importance of 'keeping CF private' to children and young people was further demonstrated during an interview with one parent. She explained that a difficult situation arose for her son when in front of his peers, he refused to explain to a teacher that he was unable to attend a lesson for reasons relating to CF. This account suggests that 'keeping CF private' from adult figures may be regarded as counter to acceptable behaviour in the school setting:

> *'He doesn't want to tell her why he's not been in her class. "Where were you on Wednesday?" or something like that. I've had to go in a few times. I have seen her face-to-face a few times. She was like "well I'm asking him a question and he's just like laughing at me". And I'm like "because he doesn't want to say in front of the whole class where he's been"…'.*

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

Most of the children and young people interviewed explained that they had revealed their CF to other people at school on occasions. However, this was mainly when they felt they had little choice but to do so. One child explained that she felt she had to tell others about her CF due to CF related physical changes to her body being visible at times, therefore connecting this theme to 'body image':

> *'I don't really tell them because, unless like, you know when you're getting changed in like a girls changing room and you have to take your top off… but I've got this scar. Some people ask'.*

(Violet: ♀, A9, Y5, P, 🏠IVs)

> *'Well, when I had to tell my friends that I had CF because I was missing, I was having time off. People would ask like "oh where were you" and everything. Eventually you can't lie forever. You have to tell your mates, your best mates and everything you've got CF'.*

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

In contrast to the perspectives of the majority of participants within this theme, one parent explained that her son was happy to discuss aspects of life with CF with his friends. This suggests that opting to keep CF private may depend on individual personalities and circumstances:

> *'Joe isn't bothered who knows. He isn't bothered who knows about his Creon, his medicines, him going in hospital. When he was in hospital, his friends from school were ringing him up on his mobile and he were telling them all about his lines. He's quite OK I think when he's with his peers'.*

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

It is possible that where children and young people choose to keep CF private, the invisible nature of the condition enables them to do so. However, as a consequence the full extent of living with CF may go unnoticed by others at school. Therefore, this demonstrates a relationship with the theme 'awareness and understanding'.

5.6   Conceptual category 2: Balancing treatments and school activities

Children with CF must complete a vast amount of treatments every day in order to stay well. This conceptual category relates to how such medical treatments are balanced and managed alongside children's school experiences and activities. The conceptual category includes two themes relating to 'arranging CF treatments away from school' and 'fitting everything in'.

5.6.1   Arranging treatments away from School

Sources: Children and young people: 4

Other participants: 6

Despite the large treatment regime that children with CF must adhere to, participants discussed actively arranging and completing such treatments away from the school environment wherever possible. For the vast majority of children with CF, the main regular treatment required at school is a pancreatic enzyme replacement therapy such as Creon, which is needed when eating. The CF specialist nurses stated that school routines are specifically taken into consideration by the CF team when planning and prescribing the majority of day-to-day maintenance treatments. Indeed, all parents and the majority of children explained that they would purposely arrange and complete CF treatments to fit around the

school day. This suggests a commitment from parents, children and the CF team to minimise any disruption arising from medical treatments to the education of children with CF:

> *'Yeah I do everything in the morning when I'm at school, but on holiday I just do it any time'.*
>
> (Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

> *'He's never needed anything at school apart from Creon. The hospital have never ever even implied that he needs anything between 9 and 3. It's a doable time between 9 and 3 to not need anything'.*
>
> (Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

> *'Well, we consider education to be really important so anything that needs to be done we tend to get done before and after school. I mean we try to get children on twice daily Flucloxacillin when they start school, so they don't have to have them through the day at school…we advise things like if they're on Dnase, that they do it when they get in from school; if they're on twice daily Colomycin then to do it morning and evening'.*
>
> (Joanne, CF nurse specialist)

While maintenance treatment arrangements minimise disruption to education, when children required additional treatments, parents reported that balancing the demands of this alongside school activities could be problematic. One parent explained that her son was unable to attend school during a course of IVs, as one dose was needed during school hours. She discussed concerns about whether there would be anyone at school with sufficient training or knowledge to handle the demands of administering this treatment. The parent cited this as a reason for arranging such treatments away from school:

> *'I think the last time he had IVs he actually wanted to go to school but the thing is, he was on three times a day. I think if they were just twice a day we'd get him to school…I just know how I feel when I do them (IVs), I mean I was a nurse. I wouldn't want to give that responsibility to anyone else…And then you've also got to think he'd have to take all his anaphylaxis stuff to school and would they be capable of doing that? I don't know, I think it's a big responsibility to give to somebody else. I think I would prefer to do them at home'.*
>
> (Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

Similarly, the hospital school HLTA also suggested there may be certain CF treatments that children are unable to do in the school environment:

> *'I mean like this lad whose just come in today…I think well presumably he has certain pills that he has to take and I don't know if he has his physio before or after school so he doesn't have to do that in school. Fine. But there might be certain things he can't do in school and things like that you know'.*

(Yvonne, hospital school HLTA)

These perspectives raise issues around the resources needed to enable children and young people to have more complex CF treatments at school, which may offer one explanation as to why for most children with CF, the majority of treatments are arranged away from the school environment. The CF nurse specialists explained that they sometimes obtain funding to enable schools to administer physiotherapy. However, they stated that this is only needed by a small minority of children:

> *'We try and help schools obtain some funding for physio, but it's only a few children who have physio at school because there's no other way if they've got overnight feeds. It's like hectic for the family, they can't get things done in a morning. Then we would introduce physio into school'.*

(Joanne, CF nurse specialist)

Gaining funding for the administration of IV antibiotics at school was not discussed. It is possible that funding for support with IVs is not considered necessary, as the CF nurse specialists explained that these can typically be administered to fit around the school day. Yet, contrary to this view, two parents in the study spoke about their children needing IV antibiotics during school hours. Only one of these children continued to attend school throughout their course of IVs. However, she attended a fee paying school, and her parent explained that it was able to employ a full-time nurse who could support the administration of IVs. Therefore this demonstrates a connection to the theme managing treatments at school:

> *'They've been amazing really. The fact that they can do their IVs at lunchtime is worth its weight in gold…The nurse did all of the lunchtime doses for that fortnight that time. I went in the first time and sort of made sure she knew what to do…But usually we can manage them around school'.*

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

The two parental accounts illustrate that school resources may be influential in the arrangement of CF treatments and may promote or hinder school attendance. This demonstrates a connection between this theme, 'school absence' and 'managing treatments at school'.

5.6.2 Fitting everything in

Sources: *Children and young people: 2*

            Other participants: 5

Participants discussed CF treatments and school activities in terms of fitting everything in to the day. One of the CF nurse specialists commented on this issue and recognised that fitting everything in can be a challenge for children and parents:

> *'Before they come to school they've got all this treatment and when they get home from school they've got all this treatment to do and then at bedtime. In between that time, they've got to fit in a social life as well as doing all the homework'.*

(Joanne, CF nurse specialist)

During the interviews, parents explained a typical school day for their children, and gave details about CF related treatments and activities that must be completed. While parents and children appeared to have effective routines in place in order to balance CF treatments alongside school activities, one parent's account revealed the demands of this task:

> *'Well he gets up in a morning, he'll have his medicines, so he'll have his Flucloxacillin or any others, like at the moment he's on his Ciprofloxacin…If his chest is good I won't routinely do physio on him in a morning. He'll just do the PEP mask and then he'll have what nebulisers he needs. Like at the moment he's on Tobramycin, so he'll have that and he'll do his PEP mask before he does his Tobi and then he'll have his breakfast and then he'll toddle off to school. He has a packed lunch at school and then he'll come home at tea time and we'll have some more medicine and 'cause he's on his Fluclox three times a day he doesn't want to have it at school, so we just do it when he gets home. And then again before he goes to bed and then he'll do any homework, have his tea, have his Pulmozyme, and then usually he will do some activity when he gets home, whether it's running around the block or some boxing with his dad or wrestling and he'll do his PEP mask and then he'll have his Tobramycin again before he goes to bed. And that's really his day-to-day routine at school'.*

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

Two parents demonstrated the resourcefulness of themselves and their children when fitting in CF treatments around the school day:

> *'Like last night, she was doing her iNeb (nebuliser) whilst she was drying her hair'.*

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

> *'We do nebulisers in the car if she is on her own. Yeah we do a fair bit in the car'.*

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

In many cases parents and children explained that they must get up much earlier in order to complete CF treatments in time for the school day. Some children and parents stated that they felt this to be difficult, particularly when children were in receipt of additional medications for chest exacerbations. One parent stated that her son was often late to school as a result of trying to fit in his IV treatment around the school day:

> *'It's more a time management thing, you know trying to get everything done, because he sets off to school at twenty past seven so it's trying to… Because we do home IVs quite often so he can't get to school on time for that otherwise we'd be getting up at like 5'oclock in the morning'.*

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

> *'It (IV treatment) takes up more time to do stuff'.*

(Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

> *'It differs on a school day because my Cipro prevents me from having milk at different times. So if I want milk on a morning, because I get up at 7 for my breakfast, I have to wake up at 5 to have my medicine and then go back to sleep. And it's been like that for about a month now'.*

(Joe: ♂, A11, Y7, S, ☒IVs)

Some parents discussed fitting everything in to the school day as a dilemma. Two parents felt that they needed to make a choice between their children doing CF treatments or attending school in the usual way. In both cases, parents gave precedence to their child's participation at school, therefore illustrating the

strategies used to minimise any disruption to their children's education. It appeared that parents were keen for their children to participate in school life in the same way as other children without CF:

> *'But, they (the CF team) actually wanted him to have IVs in September because of his Pseudomonas and his coughing. He'd actually grown two different types of pseudomonas and we kinda like said, "oh he's just started at a new high school". So he actually didn't go in for IVs, he just had the three months oral. And I do feel bad about that now because he did need them (IVs) at Christmas'.*

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

> *'They would like him to do a nebuliser before school and we've kind of talked our way, that it isn't feasible because of the time thing again. So, ideally he would do one before school then one mid afternoon, then one when he got home…but they want to make it achievable and not want him to start dropping out of doing things…'.*

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

5.7 Conceptual category 3: Staying well at school

The previous category contained participant accounts that concerned balancing CF treatments and school activities. Participants discussed the management of CF away from school to enable children and young people to stay well. This conceptual category relates to the importance of children staying well while they attend school and details four themes that include; eating well, using the toilet, managing CF treatments and managing cross-infection.

5.7.1 Eating well

Sources: *Children and young people: 1*

                   Other participants: 2

Participants discussed the importance of children continuing to eat well while at school, which is necessary for maintaining their weight. One parent raised concerns about the potential for her child to miss eating lunch due to the school's lunch system. She suggested that consistent timings of lunch breaks were needed, which would allow enough time and opportunity for her daughter to eat well at school:

> *'They have a really complicated lunch system. It moves 20 minutes every week, so your lunchtime, one week it will start at 12:40pm and then the other week it will be 1pm and so on. And if you miss your slot,*

> *you need a pass to get in to the next slot…she could perhaps just do*
> *with having a pass that says I can come to any lunch slot…'.*

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

One young person and his parent also discussed concerns about the consumption of the typical 'CF diet' (consisting of high fat and high calorie meals and snacks) at school. They both explained that he had been reprimanded for having inappropriate foods in his lunch box. This suggests that the CF diet may be contrary to some schools' healthy eating policies, and therefore connecting this theme to 'awareness and understanding':

> *'In junior school, when I first went there I was eating my dinner and*
> *because it doesn't like you having stuff with chocolate in it, like in your*
> *packed lunch, one of the teachers came up and took my dinner off me'.*

(Joe: ♂, A11, Y7, S, ☒IVs)

> *'I'd gone in and explained everything about the diet, high fat and*
> *everything and he'd got chocolate in his lunch box as well as like*
> *yoghurts and stuff like that. But the teacher actually brought him out of*
> *the dining hall with his lunch box and said 'we have to phone his*
> *mother', that it wasn't a healthy meal, it wasn't appropriate'.*

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

5.7.2   Using the toilet

Sources: Children and young people: 4

Other participants: 3

Many participants discussed the importance of children being able to use the toilet when they needed to at school:

> *You need to make allowances for the fact that when they need to go to*
> *the toilet they need to go now, please don't make them hold it back…so*
> *we have to go in and say "please can you make allowances for them*
> *and don't make it obvious but if they need to go, they need to go"…'.*
> (Diane, CF nurse specialist)

The majority of children and parents stated that the school had made sure they were able to use the toilet when needed. One teacher expressed her understanding of the importance of this:

'I mean the staff members are made aware that you know, if she needs to go to the toilet, she has to go'.

(Jayne, teacher of Violet: ♀, A9, Y5, P, 🏠IVs)

'Most of the teachers just know, so say yes you can go. But to other people they won't let them go because they apparently should go at break time'.

(Violet: ♀, A9, Y5, P, 🏠IVs)

'He gets a toilet pass and he gets access to a separate toilet'.

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

However, it appeared that using the toilet during school time was a source of embarrassment for some children due to the unpleasant digestive symptoms of CF and the lack of privacy or appropriate facilities. One young person explained that he would prefer to use the toilet in quieter periods such as during lesson times. However, his teachers would not allow him to go:

'Sometimes if I need to go to the toilet and it's like…at my high school they don't let you go to the toilet during lessons'.

(Joe: ♂, A11, Y7, S, ☒IVs)

One young person said his school had organised separate toilet facilities for him, along with a toilet pass. However, he felt unable to take this up as he felt it drew attention to his digestive problems. He also talked about preferring to wait until he got home before using the toilet, as did another young person. This was the case even when waiting to use the toilet was a cause of discomfort for them. This demonstrates a relationship to the theme 'hiding visible differences':

'I had a toilet pass but I don't really use it because I wait until I get home'.

(Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

*'I can't think of a time when I went to the toilet at school. I would really
hold it in. I'm really good at holding it in. That is one of my skills. The
toilets at my school were pretty dire. Like I could be outside and you
could open the door. Some people would open the doors while people
were on the toilet…'.*

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

5.7.3 Managing treatments at school

Sources: Children and young people: 3

Other participants: 5

While participants explained that the majority of CF treatments are completed away
from school in the home environment (see conceptual category 'balancing
treatments and school activities), all children and young people reported taking
Creon at school. The CF nurse specialists explained that they would expect young
people to be responsible for administering their medication in the school
environment by the time they go to secondary school, suggesting that primary
students were more likely to require assistance with this:

*'By the high school age we'd be expecting them to be responsible for
their own Creon, whereas in primary school it tends to be the teachers'.*
(Joanne, CF nurse specialist)

However, according to the primary school teacher involved in the study, her student
was able to manage her own enzymes while at school, indicating that the self-
management of medication should be assessed on an individual basis:

*'She takes Creon and she does handle this herself, you know, she's
year five now and when she was in my class in year four, I started off by
reminding her but she's very good, she's very well organised'.*

(Jayne, teacher of Violet: ♀, A9, Y5, P, 🏠IVs)

Participants discussed the importance of children being in control of their
medication while at school. Some felt that children should not have to ask school
staff for access to their medication and felt that this might cause children to feel
different:

*'I would say things like Creon should not be locked in cupboards or
anything like that. I think they should be allowed on the person if that's
what the child wants…I do know that in some schools they are stricter
and how do you think that makes the children feel if they are starving*

and they have to go at lunchtime and wait for their Creon? That to me is not very good. So I'm mindful to say to the schools to let them be more independent'.

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

'And these things with pills…I know when my son was suffering with really painful knees and I just used to send him in with some Ibuprofen and if anyone saw him taking one they rang me, and they said all of the medication has to go to the office and he has to go to the office to take it. So I just thought, even the little things you take for having your meals, then in theory schools might say you have to go to the office to have them and I just think well it's making you different again is it'.

(Yvonne, hospital school HLTA)

Another parent felt that her son should be in control of his medication due to concerns that assistance with medication may not be available in the secondary school context:

'At primary school they wanted the Creon in the school office. He had to go and get it at lunchtime. Whereas at the end of year 6 I said to Joe "look I'm going to put your Creon in with your lunch because you need to be in control of it for when you go up to high school". So now he does all his medicine, you know, he has his Creon at school. The school don't have anything to do with that at all'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

It was clear that parents valued children's independence when considering the management of CF treatments in school. However, children and young people suggested some of the ways that schools can offer support with treatments while maintaining their independence at the same time:

'It would be more to ask them if there are places they can go or options they can use, if they want to, that will help them out. So, just stuff like say if they wanted to take their medication somewhere else, because that was offered to me and stuff like that will help them'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

'Well, say if I forget something (tablets), which I probably won't, but if I did then they could like sort of remind me'.

(Violet: ♀, A9, Y5, P, 🏠IVs)

Similarly, when Joe was asked the vignette question, he replied:

> *'If he runs out of medication during school, keep it in school, keep a spare bottle in student services or something'*

(Joe: ♂, A11, Y7, S, ☒IVs)

5.7.4 Managing cross-infection

Sources: *Children and young people: 2*

Other participants: 4

Participants discussed the issue of cross-infection, which is of significance where schools have more than one child with CF attending. While the CF nurse specialists explained that this scenario is rare, two young people involved in the study explained the risk of cross-infection needed to be managed at their schools, as they were not the only student with CF in attendance:

> *'At my school there was another boy with cystic fibrosis. And I remember he was the year above me and there was a big thing about classrooms. And there was one point where they tried to make me move schools because of him, because of cross infection. So yeah that was a big thing for the school'*

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

> *'Well, there's another person in our school, and when we like sit close, then I have to move'.*

(Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

Participant's suggested that the risk of cross-infection can be alarming to schools, suggesting there is a need for support and advice around this issue:

> *'They've been told they've got this child with a condition and the parents have obviously said, nobody else should have this condition in school and what have you, you know so they're a bit anxious about it and worry about things'.*

(Joanne, CF nurse specialist)

> *'We did have to go actually when she first joined. The staff got their knickers in a twist a bit about whether they could be together or not in the playground and across a distance and stuff and they were being a bit over zealous really'.*

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

Parents and young people reported some of the strategies used to minimise the risk of cross-infection at school. While some logistical difficulties were discussed, participant views suggested that schools were able to manage having more than one student with CF in attendance. In one case, the school rewarded the young person for actions that reduced the risk of cross-infection, suggesting that school recognised and reinforced the importance of avoiding this risk:

> They've given both of them a photograph of the other child with CF. And they say they shouldn't be in the same room as them for things like after school care or the library and they say "try and separate yourself and if you see you are in proximity with them, tell the teacher". And apparently last week it happened and she distanced herself and told a teacher. It resolved itself and then she was awarded some merits for doing that'.

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

> 'There was a thing that they tried to do where if he was in a classroom, I would have to wait an hour like after he'd left. There would have to be like an hour between those classrooms'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

The hospital school HLTA discussed the issue of cross-infection in a context of the education of children who are admitted to the CF ward for treatment. She explained that children with CF are not able to attend the hospital school classroom and therefore, educational provision would take place in patient's individual rooms. Her account suggests that a number of logistical difficulties are experienced by the hospital school staff when providing education to children with CF. This demonstrates a relationship to the theme 'continuity of education':

> 'Obviously we can't have anybody else in the school room at all…but the other thing is when we go down there (CF ward) we have to clean everything before we take it into the room. And we have to clean everything before we take it out of the room. And we're not supposed to go from one CF patient to another. We need to leave at least an hour between them. So, it can be a bit of a logistical nightmare, but once you know that it's not too bad. What you tend to do is if it's book work, you just photocopy it and then just throw it away or give it to the child to take home or whatever, we don't remove it out of the room…and then you don't have to spend all your time cleaning everything like that'.

(Yvonne, hospital school HLTA)

5.8   Conceptual category 4: Knowing about CF

This conceptual category captures the perspectives of participants that relate to others knowing about CF in the educational context. It contains three themes that detail informing CF, awareness and understanding about CF at school and one person taking the lead.

5.8.1   Informing CF

Sources: *Children and young people: 3*

                Other participants: 7

This category illustrates the processes by which schools were informed about CF. Therefore, this category also relates to 'awareness and understanding'. The CF nurses stated it was part of their role to provide information about CF to schools and nurseries, evidencing an inter-agency approach. Three children and one teacher discussed the involvement of the CF nurse specialists in informing the school about CF stating that they found this to be helpful:

> *'I remember we had the CF nurse from paediatrics unit, she had to come in and like speak to a load of my teachers and staff that I had it. So that helped a lot'.*

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

> *'Just before Violet just joined the school we had a meeting. It was very good and parents met with us and also brought in a CF nurse who talked to us…So we had a bit of information given and a question and answer session really to allay any fears'.*

(Jayne, teacher of Violet: ♀, A9, Y5, P, 🏠IVs)

The majority of participants reported that schools were informed about CF via a one off meeting, and usually at the point of children starting a new school placement. Participants suggested there were differences between schools in terms of who was present at initial information meetings. Those concerned with secondary provision explained that a few key members of staff were informed about CF who then passed information on to children's teachers at a later stage.

'We have a school nurse and so it (information) would have probably come directly through to the school nurse I imagine…We are informed about any medical issues and illnesses that we might need to be made aware of, almost like a staff briefing, at the start of the year'

(Jackie, teacher of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

'I think we had head of year, the matron, the science teacher and who was going to be his form teacher. And then we had the meeting and they passed the information on to the staff room to all Luke's teachers so all his teachers are aware'.

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

In contrast, a parent of a primary school student stated that all her daughter's teachers were able to attend an information meeting on CF, suggesting that CF was known about throughout the whole school. However, it is likely that this was due to the primary school being much smaller in size:

'I went in and the CF nurse came. She came to the school and when we knew we were going in, we *met and sat in a classroom with all the teachers of the junior school. The whole teachers, they took time out'.*

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

The level of children's involvement in such meetings was not widely discussed during the interviews. However, one parent said that her son had the opportunity to be involved in informing his secondary school about CF during a transition day:

'What they did was, they had some extra transition days. So all the children normally went for a visit but Joe actually went for a visit the week before everybody else went, along with some other children who they perhaps thought had other special needs as well. And there he met a deputy head of pastoral care and stuff. And he met her and he told her all about his CF and he also met the school nurse on that extra transition day too'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

Participants discussed the content of discussions when schools were initially informed about CF. There appeared to be a focus on the medical aspects of CF, demonstrating a relationship with 'keeping well at school'. This suggests that children's health at school was a priority for participants:

'I always start with, you know look, you're unlikely to come across a really urgent medical situation with a child with cystic fibrosis. It's not like a diabetes or an asthma, but what things are they're sort of slow and gradual. I think once you've spoken to staff and you've told them what CF is, they are much more relieved really'.

(Joanne, CF nurse specialist)

'The CF nurse went in and discussed it all…you know paper towels, and cleaning her hands after the toilet, you know, all that sort of stuff'.

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

Parents said they had not been involved in regular organised meetings with school beyond the initial information meeting. They stated that they tended to communicate with the school about any CF related issues as and when the need arose via email or the telephone:

'I've never done face-to-face apart from the first meeting'.

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

'We've only been once and then he was on his IVs…So what we find now is, if we've got problems with Joe, we email actual individual teachers, form teachers. Just as and when'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

These perspectives suggest there were no formal procedures in place to consider any changes to the health or treatment of children with CF and the possible implications for their educational experiences, such as meetings relating to Individual Healthcare Plans (IHP) (DfE, 2015) for example. Nevertheless, for the most part, parents appeared happy with the communication arrangements in place.

5.8.2 Awareness and understanding

Sources: Children and young people: 5

Other participants: 3

There were mixed responses from children and young people in regard to their teachers knowing about them having CF. Some thought the majority of their teachers were aware, although others said only certain teachers knew:

'Well some of them don't (know) but that's because they don't teach me in anything. But most teachers do'.

(Violet: ♀, A9, Y5, P, 🏠IVs)

'Not all of them know I have CF. My resistant materials teacher knows and I think he's the only one'.

(Joe: ♂, A11, Y7, S, ☒IVs)

Children and young people stated that while some people knew about their CF at school, this did not necessarily mean that they fully understood what having the condition entails. For example, when Rachel was asked if she thought her teachers had a good understanding of CF she replied:

'Not really. Just alright'.

(Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

One of the CF nurse specialists expressed the opinion that there is a lack of knowledge and awareness about CF more generally amongst the public, which could influence what is known about CF in the school context:

'You ask all your neighbours in the street and there'll be very few people who actually know anything about it'.

(Diane, CF nurse specialist)

However, many young people in the study felt it important that members of staff at their school were aware of and understood CF:

'School should probably know more about it (CF) and what it does'.

(Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

One young person expressed his frustration with the lack of awareness and understanding he experienced at school from his peers. He cited this as one of the reasons he preferred not to tell others about his CF, illustrating a connection here to the theme 'keeping CF private'. He also attributed a lack of understanding to the invisible nature of the condition. This perspective suggests that children and young people may experience a cyclic situation in which 'keeping CF private' perpetuates

a lack of understanding and awareness, which in turn reinforces their decision not to tell others about CF:

> 'The problem is, people don't really understand because you don't look ill. And I remember when I had my IVs in Year 10, and I came back, a guy came up to me and he said "I heard you've got CF, are you cured now?" and all this. And it's always aggravated me that people don't really understand it. Yeah, I've always felt that people don't really understand. When you have to tell people about it, they don't get that it's a serious thing'.
>
> (Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

Other participants also described a type of 'CF paradox' that can affect awareness and understanding of the condition, in that depictions of CF may not correspond with the child's visible presentation:

> '…But when the CF nurse did go in (to school) and do the presentation thing, what she told them was really serious and even I sat there and thought, well this doesn't really relate to Violet. I said it to Joanne (CF Nurse) when it finished and she said "well actually, you know, that is the condition"…'.
>
> (Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

Participant accounts demonstrated that limited awareness and understanding of CF in the school context could lead to problematic situations. Both children and parents discussed school experiences where a lack of awareness was potentially detrimental to children's health (see for example, Joe and Louise's perspectives, section 5.7.1). This demonstrates a relationship to the theme 'staying well at school'. One parent described a situation where a school nurse had misunderstood certain aspects of her son's home IV treatment and said he would not be allowed to attend school throughout this time. While her son was eventually allowed to attend after further advice was sought, this case illustrates that a lack of understanding about CF may also be detrimental to children's education:

> 'There was some confusion when he was on home IVs. They give you a letter from the hospital saying "Luke has a line in his left or right arm, he needs to stay out of PE, swimming and try not to get knocked in the corridor, but otherwise he's safe to be in school". But then the Matron was like "No, he can't, I'm not having him, we can't have it"…She just didn't know anything about it. She was scared…They were wanting him to stop off for two weeks. I'm like "no that's the whole point of home IVs, that he carries on with his normal routine". I said he might as well be in

hospital if he can't come to school. Anyway she just admitted "oh it's a lack of my knowledge" you know, she's quite an old school Matron'.

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

Another parent felt that children may find it difficult to explain important aspects of their condition to the adults they come across at school, again suggesting the significance of staff awareness and understanding. The parent gave the example of when a temporary teacher asked her daughter to take her jumper off while she was on a course of IVs, which risked damaging the IV access line placed in the back of her hand:

'For that situation, Violet needs to speak up and say "no because I've got my line in". And at the time she was just in her first year. Because it isn't like Violet to say. And we're expecting a lot to expect a little girl to say something to an adult teacher'.

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

5.8.3   One person taking the lead

Sources: Children and young people: 2

Other participants: 4

The interview participants discussed knowing about CF at school in terms of the usefulness of one person taking the lead. Parent's discussed the importance of having a contact in school who could take responsibility for knowing about CF and passing on information to relevant staff:

'I think the most valuable thing for us is to have one person who could kind of be a liaison between parents and the staff. Which is one of the fundamental things that the nurse does for us. You know I sort of email her and say would you let anybody who needs to know, know that…'.

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

'I think schools should have perhaps one named person who was able to look it (CF) up and research it. Or if you give them information, there be like one person there that knows about it and who's able to pass on that information to other people within the school environment. As long as there's like one person who knows a fairly decent amount about it and what the consequences are and about IVs and stuff like that and then they're able to like pass that on'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

Two children and young people also discussed one person taking a lead in a context of having someone at school that could look out for them and be an advocate:

> *'Not like all the time but some of the time, like for somebody to come in and see how I am and then leave. Someone should check on them (children with CF) from time-to-time'.*
>
> (Joe: ♂, A11, Y7, S, ☒IVs)

> *'My form teacher was the one that really pushed for me. Because she was really helpful my form teacher. She was probably the only really helpful teacher. Because she would always push for it to happen and then things would happen then. She would talk to the 'higher ups' – 'the suits'…'.*
>
> (Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

There were a number of different school roles that were discussed by participants in terms of one person taking a lead, suggesting that different schools have different approaches. Most children and young people stated their form tutor, class teacher or head of year tended to be a first point of contact for them in relation to any school issues. Both teachers involved in the study and some parents felt that the school nurse was an appropriate point of contact, again suggesting the health and medical aspects of CF in school were a priority for some participants:

> *'They do seem to communicate really well within school actually, through the nurse. She's the kind of, the channel'.*
>
> (Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

> *'The* school *nurse is the first port of call really'.*
>
> (Jackie, teacher of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

The hospital school HLTA referred to the school SENCo as a probable lead role in the school context. However, it is possible that children who are frequently admitted to hospital, and have regular contact with the hospital school, may experience greater difficulties in learning due to school absence and illness. Therefore, it is perhaps unsurprising that the HLTA was the only participant to suggest the SENCo as 'one person taking a lead' at school. However, subsequent discussion took place

about whether CF should be considered a SEN, demonstrating there is uncertainty around this issue:

> *'I'm not being cynical but what they usually do is they'll say "oh, that's the SENCo"…I think sometimes the SENCo gets lumped with all the medical needs whether there's a, you know…I suppose it's a special need, but is it a special educational need? I suppose it is, because you've got your treatments and this, that and the other'.*
>
> (Yvonne, hospital school HLTA)

5.9 Conceptual category 5: CF impacting learning

This conceptual category relates to participant's views that concern how CF can impact children's learning. It contains three themes that detail school absence, falling behind and catching up, and symptoms and side effects.

5.9.1 School absence

Sources: Children and young people: 4

Other participants: 6

Participants discussed children having to take time off school for reasons relating to CF. Some participants felt that school absence can be a key issue for children's education:

> *'I mean I think, the main issue it has is them missing school'.*
> (Yvonne, hospital school HLTA)
>
> *'I do know that attendance can be a bit of an issue'.*
> (Diane, CF nurse specialist)

In contrast, children and parents stated they would try to avoid school absence wherever possible in an attempt to avoid children falling behind in their school work. Therefore, these perspectives demonstrate a connection to the next theme; 'falling behind and catching up'. Some participants talked about children attending school despite experiencing undesirable CF symptoms. This suggests that maintaining good school attendance was important to children and parents involved in the study:

'On a morning sometimes Violet has said "oh I don't feel very well, I've got stomach ache" and I'll say "Violet get up" and she's tired and I'll say "well get yourself to school and if you're not feeling any better they will give us a ring and we'll come and get you". I do try to do that because I believe that the less school she misses, you know I don't want her to miss or get behind on anything'.

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

'I tend to try to get into school. If it's just a blocked nose I'll probably go into school. But if it's like a tummy bug then I'll stay off, well if it's a bad tummy bug'.

(Joe: ♂, A11, Y7, S, ☒IVs)

School absence affected the children and young people interviewed in different ways. Some stated that they only had time off school if they were admitted to hospital for treatment. Children that had home IVs were often able to attend school throughout their treatment, depending on the frequency of doses throughout the day. However, two children explained they would need time off school in order to start and finish home IVs as this would require a trip to the hospital:

'Sometimes, like you know when I had the IVs, I think I had to do something before I started the IVs…so I missed the whole day off school that day'.

(Violet: ♀, A9, Y5, P, 🏠IVs)

In addition to illness and having hospital treatment, there were other reasons why children and young people missed whole school days or parts of the school day due to having CF. Some parents and children reported that they would attend the CF centre for check-up appointments every 8 weeks, necessitating time off school. Others attended more frequently if children were unwell or when a regular medical procedure was required. The length of time taken off school to attend appointments differed for each child. This mostly depended on the distance travelled to the CF centre, which determined the amount of school missed:

'I'd say he has one day off a month for clinic because it's too hard to go, it takes the whole day up. That's purely because he needs his port (implanted IV access) flushing. He's got a port, he's only had that a year'.

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

'Well I mostly miss the morning because it's quite far away, it's like an hour and a half away, so when we go I miss about a morning and we get back at like lunchtime. So I get to play, and then I'm in (school) in the afternoon'.

(Violet: ♀, A9, Y5, P, 🏠IVs)

For the majority of children in the study, it appeared that they experienced short and sporadic periods of school absence as opposed to being off school for long durations, as exemplified by the following perspectives:

'So I never had any big chunks of time off. Well, obviously I had days when I didn't go in because I had to go to for my check ups and everything'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

'She does try to come in, but she does need to take time off school. It's not long lengths of time, you know, it's intermittent really. I wouldn't say it's lengthy periods of time off. Only slightly more than the average child, but not overly so'.

(Jayne, teacher of Violet: ♀, A9, Y5, P, 🏠IVs)

Some of the adult participants raised concerns that children can sometimes use CF as an excuse not to attend school or to leave lessons, particularly when children are struggling with other educational issues. The following perspectives suggest that having CF may compound other difficulties that children might experience in education, leading to an increased risk of school absence:

'Some people use it as an excuse to not go to school because they're having trouble at school, or just for other reasons that other children would have. Some kids use the CF as a bit of an excuse like that. You know, I've got a tummy ache or I'm not feeling well'.

(Diane, CF nurse specialist)

'One of the ones who doesn't get into school very often who's very low ability anyway and I have quite a bit of contact with her…her main contact at school will ring me. She said "she's refusing to come in saying she's poorly, then we'll see her in town later in the day". They seem to be trying their hardest to get her into school, but she's not been in here (the hospital)…'.

(Yvonne, hospital school HLTA)

The previous views also raise issues around attendance monitoring in schools. It would not be unreasonable for a school to accept a child is unwell if they are absent and have a chronic medical condition such as CF. However, it may be difficult to determine the legitimacy of school absences when a child with CF is absent for longer periods and/or is experiencing other difficulties at school. The hospital school HLTA suggested that themselves or the CF centre could be contacted to enable schools to check when children have been ill:

> *'I mean in theory some schools go for like 95% attendance on the books. And if it goes below that then it should be investigated. It would be like well "what's happening here? Oh it's CF well OK". We might understand a certain lowering of attendance. So I suppose, you know, find out from the ward or from us when they have been in (hospital). I've had enquires like this before. "Could you just tell us when they've been in hospital in the last 12 months and send that off", and they can map that up with what theirs (attendance monitoring) says'.*

(Yvonne, hospital school HLTA)

One of the CF nurse specialists also discussed the issue of attendance monitoring. She explained a situation in which a parent was concerned about her child having unauthorised absences when attending the hospital for clinic appointments. This account suggests there is the possibility that school absences may reflect negatively on children with CF where schools are not fully aware of the frequency of routine hospital appointments. Therefore, this demonstrates a relationship to the theme 'awareness and understanding' and again illustrates the importance of regular school attendance to parents and children with CF:

> *'Well, I had a mum phoning up saying she'd got a letter because her child had been marked absent and it correlated with when he was in clinic. I don't think it was understood that they can be recorded differently for different absences, and I don't think the school had been doing that. I don't think she knew that and so we've rectified that now'.*

(Joanne, CF nurse specialist)

5.9.2 Continuity of education

Sources: *Children and young people: 2*

Other participants: 5

Participants discussed the continuity of educational activities when children cannot attend school. Participants frequently referred to the importance of children being able to continue their school work, particularly when admitted to hospital, to allow

them to keep up with their peers. Therefore, this demonstrates a connection to the theme 'falling behind and catching up'. Many participants felt it important that schools were able to provide children with their current work schemes when they are absent:

> 'I think if schools had a really good robust system for making sure kids got work when they weren't in school…And they're seeing a lot of teachers, so some teachers are probably on the ball about getting work out to the kids and others maybe aren't. So I think if they can, if we could get that a bit better, that might help for the kids that are struggling'.
>
> (Joanne, CF nurse specialist)

Parents reported varying experiences of gaining access to current school work. One parent explained that there were arrangements in place that allowed school work to be immediately requested when her son was admitted to hospital and she found this to be helpful:

> 'Yeah, Richard (parent) went in to see them and he emailed his teachers to let them know and if they could give him a little bit of work to do while he was in hospital. So school have put that in place and when he was on IVs, they did send him some work home that he could do which I was quite pleased about. Because you still feel as though he is doing some form of learning'.
>
> (Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

However, one young person who had experienced several hospital admissions explained that school work was not sent during periods of school absence. His parent felt that teachers did not consider it necessary to provide work even when this had been requested. She said that school staff were unfamiliar with the need for recurrent hospital treatment and consequently, the cumulative effect of school absences as a result of such treatment were not taken into account:

> 'When I'm in hospital they don't really send any work to do while you're there. They could like send work when you ask for it so you don't fall behind'.
>
> (Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

> 'You know and I'm asking for work and they're looking at me confused, going "but he's only going in for two weeks". But he might go in again, two weeks here, and two weeks in three months' time and then another two weeks. I said really he's probably missed a couple of months of school. I don't think they quite grasp that it's a regular thing. You know

*'cause like if another child needed to go into hospital for two weeks
that's it; done and dusted and they don't go again'.*

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

The HLTA from the hospital school also experienced difficulties with gaining access
to children's current schemes of work. She explained that the hospital school did
not always receive school work in a timely manner when children were admitted to
hospital. Therefore, mechanisms were put in place at the start of the school year to
request this information for children who were frequently admitted to the CF ward.
However, these mechanisms were not always successful, as only a small number
of schools would respond to requests for information:

*'Every time they come in you have to ring them (school) or email, and
by the time they've sent it through, even if they're in for two weeks,
they've got two days and then they've gone home. Because then if
they're not actually in they'll say to you "but they're not in with you at the
moment" and you go like "yeah I know, but we are expecting them".
Because there are certain ones that we know come in every three
months and some that come in every four months. I've sent out what we
call a curriculum request in September…you know, what levels are they
working at the moment? What are you actually doing in school? And
two or three schools reply then nothing else'.*

(Yvonne, hospital school HLTA)

When school work was not provided when children were absent from school,
participants discussed making their own arrangements to ensure that children could
continue educational activities or catch up on the work they had missed:

*'If she misses the odd lesson, she'll chat to the girlies and they'll fill her
in'.*

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

*'He's just been off (school) for 3 weeks in February when he was in
hospital. And before we went I asked for work to take with us. None
materialised so I wasn't right happy with that but we just took all his
revision guides anyway because it's his GCSE year, so he just had
some practise papers to do'.*

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

Even where children with CF are provided with school work during times of
absence, some participants felt that this alone is insufficient to enable them to

continue their education. Two participants suggested that teaching input is also required, which illustrates the importance of the hospital school teaching service:

> *I've had a school recently where what they've decided to do is give the lad textbooks so he would know what was being studied. If he wasn't at school he could read it up on his book and everything. But then there's the problem…what if he doesn't interpret it very well, you still need that teaching input don't you?'.*
>
> (Joanne, CF nurse specialist)

> *'And say if they (children with CF) are falling behind in school work because of hospital, I think they probably would need extra help outside of college or school, you know where teachers will go through stuff with you'.*
>
> (Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

Indeed, parents of children that had spent time in hospital felt that teaching input from the hospital school was a positive experience for them:

> *'While he was in hospital, he had a science lesson as well. This guy came and taught him some science which was really good'.*
>
> (Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

> *'He had a couple of Maths lessons, he struggles with Maths anyway and he came out knowing things that he didn't know before. I said "if that helps you pass your GCSE you've had like a couple of hours private tuition there"… I said "use it". And they were really lovely'.*
>
> (Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

Two participants raised concerns about children's access to educational resources while in hospital, particularly as a result of them being unable attend the hospital school due to cross-infection risks. Therefore, this illustrates a connection to the theme 'managing cross-infection'. The hospital school HLTA explained that while there were computers in children's rooms on the CF ward, these did not have relevant software installed. Further, one of the CF nurse specialists felt that other children's wards had better educational facilities than those of the CF centre. These accounts suggest that accessing appropriate educational resources is important for children's continuity of education while in hospital:

> *'The NHS had paid for computers in every room on the ward that have got submersible keyboards and mice or whatever so that they can clean them. We know we can access the internet down there, so we were*

trying a few years ago to download Open Office, you know the free one with Word on it. Because they haven't got Microsoft Office on there, they hadn't paid for that. But, I was like actually that's what we needed. Because you know, using Powerpoint and Word and things like that are what we needed as well as the research'.

(Yvonne, hospital school HLTA)

'If you looked in that teenage cancer unit you would fall over with the facilities that they have and they seem to be doing it right but we don't have the resources'.

(Joanne, CF nurse specialist)

5.9.3 Falling behind and catching up

Sources: Children and young people: 4

Other participants: 6

Several participants felt that children with CF may encounter particular difficulties with falling behind in their school work and catching up on any work they may miss. Two young people involved in the study specifically discussed experiencing such difficulties:

'Sometimes, I get behind'.

(Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

'There were a few times where I'd miss, say, a load of key stuff…I suppose like getting behind, because I remember like when I went into hospital in year ten, it was in June when I was doing my GCSEs and I missed a load. So that can affect people, that affected a load of my work'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

Participants suggested different reasons why children might fall behind at school. Both the CF nurse specialists connected the issue of falling behind and catching up to children being ill and unable to attend school, therefore illustrating a relationship to the theme 'school absence':

'I think if everything is going fine and the kids are well, then I think it's not a problem. But I think when the kids are unwell and they miss school, it can be difficult because they're getting behind with their course work or with their lessons'.

(Joanne, CF nurse specialist)

One parent felt that her son had less time available to complete homework due to his CF treatment requirements and consequently this meant that keeping up with his school work was difficult. This suggests that some children with CF may be disadvantaged by time as they attempt to balance the demands of school work with their CF treatment commitments:

> 'I think probably keeping up with his work is quite hard because they get 9 hours of homework a fortnight. Which I think is quite a lot. And I think if you've got other things as well like Joe obviously, doing his nebulisers, because you think, when he comes home from school normally, he might just have his Pulmozyme to do, but then if he's on any extra treatment, like he'll have two nebulisers, he'll have his medicines, his physio or his pep mask or whatever activity we do for his physio and then meal times. When you've got to start sitting down and doing homework, I think sometimes probably he does find it, particularly for big projects to do and it's a set time, probably he does find that hard to keep up with'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

Some participants felt that the period during which children return to school after being ill can present a risk of falling further behind. The hospital school HLTA suggested that children could fall further behind if they do not understand what is being taught on returning to school and may become disengaged with learning:

> 'So we have one lad, and as I say he's not very low ability. But he'd miss great chunks and he'd go back in and not understand what's going on and would then mess about to cover up the fact that he didn't know what's going on and then get sent home because he was misbehaving. It's just a vicious circle…'.

(Yvonne, hospital school HLTA)

One parent of a young person who had received regular treatment in hospital explained that he could not get the help he needed to catch up on the work missed when returning to school. Consequently, he was unable to continue studying one school subject at GCSE level due to falling too far behind. Her account suggests that attempting to catch up after a return to school could be problematic. This illustrates the importance of children continuing their school work while in hospital, and therefore connects this theme to 'continuity of education':

> 'He wanted to do an IT GCSE in computing and the teacher was concerned that he'd missed too much (work) and she said "I'd advise him not to take it as a GCSE", and she kept going "because of your health, because you're off all the time"…kept looking at him. She said "if you miss too much, I can't come back and keep helping you catch

up"…If he's in hospital for two weeks, he's missing two weeks that she (the teacher) won't ever go back over and the class will have moved on. Basically she's saying it's too hard for her to do that…'.

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

However, other children involved in the study explained that they received additional teaching in the lessons where there was a risk of them falling behind if they were unable to attend school:

'Well, in maths we have this like group it's called a booster group and I'm in that booster group'.

(Violet: ♀, A9, Y5, P, 🏠IVs)

'They're giving me some extra lessons in English and Maths. It's given to people who struggle with them lessons. So lessons they do really well at they miss out on, and then they do the extra lessons to boost them in the lessons they don't do so well on'.

(Joe: ♂, A11, Y7, S, ☒IVs)

Other participants felt that falling behind at school could be circumvented where children and young people are more academically able:

'There's a lad that's just come in today and he's a really bright button. He's really focused and will work independently in his room, you know, a bright little thing. So if they're a bright one missing a bit more school than everybody else, it might not make that much difference'.

(Diane, CF nurse specialist)

'Well Rachel is bright. So yeah, she gets away with it (missing work)'.

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

5.9.4 Symptoms and side effects

Sources: Children and young people: 2

Other participants: 4

The symptoms of CF and the side effects of CF treatments were discussed by participants, along with the possible implications for children's educational experiences. Some parents and children discussed concerns about being tired, for

example through coughing which could disrupt sleep during the night or through waking early for treatment:

> *'Before he goes back (to school) I'll email his form tutor and just ask to pass around that he'll be getting up early for his treatment and he might be a tired'.*

> (Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

One young person suggested that tiredness could affect his academic performance as the school day went on:

> *'It does tire me out through the day so when I get to lesson 4, I'll be really tired and I wouldn't do as well as I would do in a morning. As I go throughout the day it gets harder and I just want to go home'.*

> (Joe: ♂, A11, Y7, S, ☒IVs)

Another young person explained that his cough was sometimes troublesome during lessons and he would need to leave the classroom to get relief. This suggests that while children are able to attend school, there remains the possibility of them missing parts of their lessons due to the symptoms of CF. Therefore, this theme has a relationship to 'falling behind and catching up':

> *'There were times when I would have to leave classrooms because I was coughing. But normally I'm not a big cougher, only when I've got something, if I've got a bug like Aspergillus or Pseudomonas. There has been a few times when I've had to leave the class to get some water and just have a drink'.*

> (Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

Participants discussed the issue of lateness as a result of children experiencing certain CF symptoms. One parent said that her son regularly experienced pain each morning due to CF related digestive issues. Consequently, these symptoms were sometimes making him late for school:

> *'…Belly ache he gets mostly, but come lunch time he's absolutely fine. But we can't get to the bottom of why he's got belly ache. It's every morning then it's relieved by going (to the toilet), but a few times, and that in itself is making him late for school'.*

> (Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

Two education professionals specifically mentioned observing mood changes in children while they were having IV antibiotic treatment. They felt that this IV treatment side effect could be distinguished from other adolescent emotional changes:

> 'There's a girl that was in last week, and she mentioned experiencing mood swings. I mean like OK yeah, she's 14. They all have mood swings at that age. But I thought that, I've never really talked to her about this…She'd never really said all of that and I think it's quite interesting'.
>
> (Yvonne, hospital school HLTA)

One teacher explained that her student's change in mood had affected the relationships she had with her peers:

> 'When she's on IVs, we have noticed she does become more moody and more emotional and it happened last year when she was in year four and I think it's happening now. There's more tendency to fall out with people. She was more unhappy, she fell out with more children and you know got angry with lots of people. And I did speak to her mum and whether it was to do with her medication'.
>
> (Jayne, teacher of Violet: ♀, A9, Y5, P, 🏠IVs)

5.10 Conceptual category 6: Educational support

This conceptual category details participant accounts that concern educational support for children with CF. Three themes are contained within this conceptual category; continuity of education, extensions and extra time, and significant school subjects.

5.10.1 Extensions and extra time

Sources: *Children and young people: 1*

                Other participants: 2

Participants referred to the provision of extensions and extra time for school activities as a helpful and supportive school response to some of the challenges faced by children with CF. Again, the following two perspectives demonstrate that some children may experience disadvantage at school due to the significant amount of time taken up by managing symptoms and treatments that might otherwise be spent on school activities. Therefore, the provision of extensions and/or extra time may serve to reduce this disadvantage:

'I mean I've also actually asked for things like extra time at exams and extensions for coursework if they've got a lot on and they're not very well and you know if they're not reaching what they should do purely because of their health'.

(Joanne, CF nurse specialist)

'But they have been really good, I mean like his Geography teacher, he had a project to do, and when he was on his Cipro last time before he went into hospital and he was really tired and it was a lot of work, and I just asked her if we could extend it and she let us. They've said he can have extra time with homework if he's needed it'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

Two participants specifically discussed GCSE examinations as a particular school activity where extra time may be of support to young people. One young person mentioned that while he received extra time during his GCSEs, he questioned his entitlement to such educational support. This suggests that some children with CF may not view the condition as a reason to receive educational support, perhaps through their concern with 'being like everybody else and rejecting the idea of being different to their non-CF peers. Therefore, this demonstrates a relationship between the two themes:

'I did get the extra time for my exams. I did get that as well for college. So I played (on) it (CF) a little bit there'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

5.10.2 Significant school subjects and activities

Sources: *Children and young people: 5*

           Other participants: 4

Participants frequently discussed specific school subjects and activities, suggesting these may be significant for the provision of educational support for children with CF. Two school subjects were discussed in particular. These were PE and science.

Two parents talked about the importance of their child's participation in sports, yet raised concerns that schools may have different expectations of children with CF and their physical capabilities. Again, the following perspectives also suggest that parents would like their children to participate in school activities in the same way as their peers, therefore connecting this theme 'being like everybody else':

'They had this cross-country thing and she came 4th and I said "what did the teacher say" and she said "oh wow Violet, we didn't expect that from you". So the sports side of it, I want her to do all the sports I want, I don't want her molly coddled, I don't want them to be thinking "oh she can't really do that"…'.

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

'And I think PE, they probably tend to treat him a little bit different. Richard (parent) has emailed the PE teacher because we just wanted to make sure that they don't really cut him much slack. We don't want him just going and not doing PE. We want him to contribute you know and he wants to join the Rugby team and everything. And I'd really like them not to make a difference for him for PE. Because at the moment he can keep up with everybody…Because I think at primary school he were a bit, they used to walk to church on a Friday and they used to say "oh we'll take Joe in the car". No he shouldn't go in the car, he can walk. We want him to take full part in PE and everything'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

While some parents have concerns about their children being treated differently while doing PE at school, one teacher's account suggests that CF is not always seen as a barrier to children's participation in sports. The teacher discussed actively encouraging her student's participation in PE and considered her to have a particular talent in this area:

'She achieves so much in PE. She's also very talented at it as well and she's a national windsurfer. She was in the national championships and came third, she skis, she mountain bikes and she'll be doing GCSE PE next year. She's in my sports teams at school so she plays, represents for the school and she's captain of the rounders team'.

(Jackie, teacher of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

Indeed, children and young people involved in the study described being very active, which is also an important part of CF treatment routines. When children were asked about their hobbies during the interviews, they all reported taking part in many sporting activities:

'Well, I'm just getting ready to go windsurfing'.

(Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

'I'm doing the village 10k with my dad. So, I run and I just started the gym'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

'Yeah I do quite a bit of running and a bit of boxing'.

(Joe: ♂, A11, Y7, S, ☒IVs)

'I do sports'.

(Violet: ♀, A9, Y5, P, 🏠IVs)

'I do weightlifting at the gym'.

(Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

However, aside from the physical capabilities of children with CF, one young person explained that he would frequently miss PE for an entirely separate reason, suggesting there may be other barriers to participating in this school subject. He explained that worries about his stature prevented him from getting changed in front of others. Therefore, his account demonstrates a relationship to the theme of 'body image':

> *'I always felt kind of a little bit inadequate for PE even though I wasn't. Like I'd say now, I'm probably fitter than most of the people I went to school with. But I didn't like to get changed in front of all the guys because I always felt like I was too thin. I used to get a few comments once in a while about my stature. So I used to always feel like I didn't want to do it. So sometimes I would just skive P.E. pretty much'.*
>
> (Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

Parents and children also specifically referred to IV treatment being a barrier to taking part in certain sporting activities. They raised concerns about the possibility of IV access lines becoming damaged during PE. Three children and young people expressed their disappointment at not being able to take part in sports they enjoy while having IVs:

> *'Well, because my arm is wrapped up in a bandage and because I really like gymnastics, I can't really do that so I have to like chat or do something else that doesn't involve hurting my arm'.*
>
> (Violet: ♀, A9, Y5, P, 🏠IVs)

In addition to PE, two participants also discussed school science as a significant school subject for the educational experiences of children with CF. CF often features within the secondary science curriculum to exemplify the inheritance patterns of genetic diseases. However, one of the CF nurse specialists felt that the curriculum could portray an inaccurate picture of life with the condition, which might be upsetting to children with CF:

> *'I think there's an issue with regard to things like biology when it's taught at GCSE level and then at A'level because CF is mentioned and it can be quite out dated and upsetting and what have you. It's really outdated and I know they can't change the curriculum. My daughter did A'level biology and she couldn't believe what was being told compared to what I used to say to her about it'.*

(Joanne, CF nurse specialist)

One young person felt that his science teacher avoided teaching a lesson in the usual way when it involved CF. Taking the previous account into consideration, it is possible that some teachers may have concerns about upsetting children with CF when teaching this aspect of the curriculum. However, changing the content of the lesson may also have the consequence of making young people feel different, again demonstrating a relationship to the theme 'being like everybody else'. The young person appeared frustrated when recalling the lesson about CF:

> *'In science, the biology teacher took me out and said they were teaching about CF in the lesson. But because I have CF they only did ten minutes on it and I know that there are five different classes where they did a one-hour lesson on it. They cut it short in mine. I don't know why, I'm not even bothered'.*

(Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

5.11 Conceptual category 7: Negotiating CF alongside adolescence

This conceptual category details participant's views that relate to negotiating CF alongside adolescence. The perspectives of those who took part in the research revealed that there are additional challenges that young people with CF must contend with during adolescence. The conceptual category contains four themes: making sense of CF; friendships; body image; and career aspirations.

5.11.1 Making sense of CF

Sources: *Children and young people: 0*

Other participants: 4

While the children who took part in the interviews did not refer to this theme, a small number of adult participants discussed some of the issues relating to children and young people making sense of and understanding CF. Two parents noted that children with CF must contend with many issues that other children do not. They referred to CF related issues that children may find difficult, such as when medical procedures do not go well:

> *'She's had IVs once and it didn't go very well. So at that point, you know, she went through a little bit of a stage where, because she had a needle phobia, every time we went to the CF unit and they tried to take her blood then she would sort of get upset'.*

(Alice, parent of Violet: ♀, A9, Y5, P, 🏠IVs)

It was also evident in the interviews that making sense of CF does not take place in isolation of children's educational experiences. One parent's account illustrated the interconnection between children's health and their school experiences when discussing her son's participation in a school activity:

> *I think the thing is with Joe is he's really deep and he doesn't let a lot slip. I think he thinks it, but I don't think he talks about it very much. Then at school when he was in year 6, they had a morning on what they had to be thankful to god for, and lots of children were saying "we're thankful for god because he looks after our grandma or granddad in heaven", and stuff like that. And Joe just turned around and said, "well if there was a god, why have I got cystic fibrosis?"…'.*

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

Periods of transition relating to health and education were also of significance during participant accounts. While transition to secondary school is a time of increased independence at school for many children, it is a time when children with CF are also encouraged to become more independent in the management of their health. One CF nurse specialist explained that the paediatric CF unit runs a specific programme that aims to increase children's knowledge of CF at the time of their transition to high school. This account therefore illustrates transition to high school as a doubly significant period of change in the lives of children with CF:

'We've got this moving to high school programme where we give children lots of information about CF and we do a questionnaire. And we start that when they're, just after they've done their SATs really in junior school. It's just basically to find out what they know and fill in any gaps and then they'll see like the physios and the dieticians and the psychologist and then we repeat that questionnaire a few months down the line when we know they've seen everybody. Just to find out, with a view to them beginning to understand what their condition is and it's sort of the first start of educating them really'.

(Diane, CF nurse specialist)

Another nurse explained that the teenage years are often a difficult time for those with CF who are beginning to make sense of their condition and also have the added pressure of achieving their GCSEs. She stated that this is a time when teenagers with CF can struggle to do their treatment, again evidencing an interconnection between education and health experiences:

I'm thinking maybe your teenagers you know when they're starting their GCSE course, just when not doing their treatment very well you know, maybe not as well as they could be. I think teenagers are difficult and that's the time when all this works being pushed on them at school isn't it. You must get your GCSEs and then you've got to stay on for two more years now don't you? And then there's "what if I don't get my results, I want to go to university, where should I go to university?"...It's difficult and there's an extra dimension when you've got CF I think...I would say it is a difficult time being a teenager'.

(Joanne, CF nurse specialist)

5.11.2 The importance of friendships

Sources: Children and young people: 1

*   Other participants: 3*

Participants discussed children's friendships during the interviews. Parents appeared to recognise the importance of friendships to children and young people with CF. One parent explained that her son's friendships sometimes took precedence over his CF treatments. Another parent stated that she would encourage her son to attend school on clinic appointment days in order maintain his relationships with friends, therefore linking this theme to 'school absence':

'I mean Friday afternoon he had to go and have a trial, a test dose of his Tobi. He said to me "oh mum I'll have all day off school". I said "no you're not Joe, you're going in the morning, you're having your dinner there and I'll pick you up after dinner"...Because it's social, "that's when you're seeing your friends". So yeah I am really conscious of him, I just

wanted him to have his friends, and I think that's so important when you go to high school'.

(Louise, parent of Joe: ♂, A11, Y7, S, ✚IVs, 🏠IVs)

'He wants to be on the bus with all his friends. He doesn't want me to take him and I'm like well if I took you, you could stay home a bit longer and do your medicine. "No, no I want to get on the bus with all my friends". So he's adamant he's leaving the house at twenty past seven'.

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

One young person also discussed the effect of CF treatment routines on his friendships. He appeared to experience a dilemma between completing his treatment and seeing his friends:

'I mean, sometimes I'm bothered (about doing treatment) because it means I don't get to see my friends. But then the other way, I know it's going to help me with my health'.

(Joe: ♂, A11, Y7, S, ☒IVs)

One of the CF nurse specialists recognised this dilemma. Consequently, she explained that during adolescence some young people do not complete their treatments as much as the CF team would like. This suggests that CF treatment routines can sometimes present a barrier to maintaining children's friendships:

'So I think we tend to find that teenage group do rebel a bit and try and withhold treatment because you know they can't go out with their friends, they can't meet up after school, they can't because they're sort of restricted with the treatment. They've got to come home for IVs, they've got to come home for their nebulisers…and I do think that a lot of them find it sort of restrictive'.

(Diane, CF nurse specialist)

5.11.3 Career aspirations

Sources: Children and young people: 2

*   Other participants: 1*

The career aspirations of young people with CF were discussed during the interviews:

'I chose film studies because I wanted to go into the film industry and I did Sociology because it sounded interesting. But I don't really want to go into the film industry anymore. I want to join the Police'.

(Bob: ♂, A17, Y12, C, ✚IVs, 🏠IVs)

'He wants to work in the sports industry. It's all he wants to do; running, weights, just anything sporty and that in turn helps his health anyway'.

(Nikki, parent of Luke: ♂, A16, Y11, S, ✚IVs, 🏠IVs)

However, one parent raised concerns about the provision of careers guidance for children with CF at school. She explained that certain careers could present a risk to the health of people with CF and noted a difficulty in gaining access to appropriate support and advice around this issue:

'Careers advice, I don't know where to go. There was a meeting at the hospital a couple of years ago where they tried to address it and it was interesting. The microbiologist was there to talk about what might be or might not be a good idea, like careers with animals or health care careers where there's infection, so that was quite helpful. It was useful, but where do you go beyond that? I just wouldn't even know where to start. I don't think it's kind of something that regular careers advisors at school will have any knowledge about'.

(Linda, parent of Rachel: ♀, A13, Y9, S(fp), 🏠IVs)

5.11.4 Body image

Sources: *Children and young people: 2*

                     Other participants: 2

Participants discussed CF specific physical changes that could affect young people's perceptions of body image while at school. One CF nurse specialist talked about the significance of body image to children and young people with CF and referred to the challenge of managing perceptions of body image alongside CF and keeping well:

'You know, you're more interested in how you look on the outside than the inside aren't you really? And there's things going on in school, there's girls, boys, you're body's changing, all these things that we all have to deal with but when you've got cystic fibrosis you've got to interpret that with your health as well don't you? If you've got a cough or I need to go to… or "I fancy that bloke but look at me, I'm coughing" or, do you know? And you get blokes who say they're a bit smaller…'.

(Diane, CF nurse specialist)

A teacher participant discussed a time when her student had experienced physical changes as a result of having steroid treatment. These changes were noticed by others at school and therefore, this illustrates how having CF might affect children's body image. The teacher explained that other children were supportive towards her student throughout her course of treatment, which demonstrates a connection here to the theme 'awareness and understanding':

> *'I know certainly last year, her face puffed up quite considerably…the children are a very good, very supportive year group so nothing was said. But the staff certainly noticed it and I noticed it because she was in my class'.*

(Jayne, teacher of Violet: ♀, A9, Y5, P, 🏠IVs)

As discussed in earlier themes such as 'significant school subjects' and 'keeping CF private', two children and young people explained that they had also experienced physical changes that had been noticed when getting changed in front of others. This suggests that there are specific situations where children's perceptions of body image may be highlighted at school.

5.12 Summary

The interview findings have further illuminated the perspectives of children and young people on their educational experiences and needs, along with the views of other key stakeholders on the education of individuals with CF. Seven overarching and interconnected conceptual categories and twenty-three associated themes were constructed through the analysis of the interview data. The health needs of children and young people with CF were explicitly identified within the perspectives of the interview participants, and other fundamental needs and challenges were also implicit in their responses.

Children and young people placed great importance on a need to be themselves first, as opposed to CF defining who they are. It appeared that they took action to maintain a 'normalised' persona by hiding any potentially visible differences or opting to keep CF private at times. Children and other stakeholders described the difficulties with balancing CF treatments alongside school activities and discussed some of the strategies they had developed in order to do this. Given the efforts made by children and parents to manage the huge regime of CF treatments at home, the health needs of children and young people remained a priority in the school setting. However, there were instances of children experiencing unmet

health needs at school in the stories told by the interviewees. A major finding form the interviews was that there appears to be a lack of awareness and understanding about CF in the school context, which may be compounded by the invisibility of the condition and the fact that many visible aspects of CF occur away from school. Participants reported a range of situations where a lack of awareness of CF was potentially detrimental to children's health or education. Consequently, the extent that children's needs were identified and met at school varied amongst those who took part in the interviews.

In addition to children and young people's health needs, the interview findings demonstrated that individuals with CF may also experience educationally related needs and challenges. Keeping up with school work may be particularly difficult for students with CF for a number of reasons, including school absence, the reduced time available for learning activities and due to CF symptoms and treatment side effects. It seemed as though children and young people experienced a lack of formal and robust support to prevent them from falling behind with their school work. However, possible areas of supportive practice were discussed, which included providing a continuity of education when children and unable to attend school and giving extensions and extra time for school work deadlines and examinations.

Two specific school subjects were significant to those with CF. PE was cited by participants as being beneficial to children's health. Science lessons on genetics may be potentially problematic where science teachers have outdated information about the condition. Finally, the interview findings demonstrated that young people with CF must contend with additional challenges during adolescence as they begin to make sense of CF. Participants recounted the importance of friendships during this time. The interviewee perspectives suggested that children and young people may experience future uncertainty, which could have implications for the plans they make after finishing statutory education, and in particular, any career plans they may make.

The next chapter considers the specific issues and challenges that arose throughout the research process, in terms of being a person with CF conducting research about CF, and involving children and young people in the study. Significantly, it reflects on the integration of the questionnaire and interview data sets in a context of the confirmatory, explanatory, and conflicting findings.

Chapter 6 Responding to specific methodological issues and challenges

6.1 Introduction

This chapter addresses the specific issues and challenges that arose when conducting the research. I present a reflexive account of the issues and challenges experienced in relation to three key contextual factors; being a person with CF conducting research about CF; involving children in the research; and conducting the research as a mixed methods study. Issues and challenges relating to the three key factors are discussed with reference to two or more aspects of the research process. Research question 4 is therefore addressed through the methodological reflections and discussion contained within this chapter:

RQ4. What issues and challenges arise in relation to the specific research context; namely:

   i.   A person with CF conducting research about CF?

   ii. Involving children in the research?

   iii. Conducting the research as a mixed methods study?

   • How can these issues and challenges be responded to?

The chapter begins by considering my 'insider' researcher positioning. In other words, I consider how being a researcher with CF, conducting research about CF, influenced the research process.

6.2 Being a person with CF conducting research about CF

As a person with CF investigating the educational experiences of children with the same condition, I have a personal closeness to the research topic and therefore can be considered to be an insider researcher. While being close to the 'inside' certainly brought many advantages to the study, there were also challenges arising from my insider researcher positioning that needed to be negotiated throughout the research. In this section, I discuss how I addressed some of the issues and challenges related to: avoiding cross-infection; subjectivity and insider research;

researcher positioning with children; researcher positioning with adult participants; and the personal impact of conducting research about CF.

6.2.1 Avoiding cross-infection

Perhaps one of the most important issues to consider in relation to being a researcher with CF conducting research about CF was the need to avoid cross-infection between myself and the child participants. The need to avoid cross-infection influenced all aspects of the research process and especially throughout the times that children and young people were involved in the study. During the questionnaire phase of the research I was unable to be present at the research site due to the risk of cross-infection. Therefore, I experienced concerns that I would not be available on hand to attend to any problems that might arise during the questionnaire administration. Further, I would not be able to immediately answer any questions about the research that were not addressed in the participant information sheets or through the information I passed on to the research nurse. While recruitment to the questionnaire phase of the study was unproblematic, there were some initial problems during the questionnaire administration that were compounded by me not being present at the research setting. For example, the decision to design two questionnaires (for primary and secondary students) caused uncertainty around administering the questionnaire to children who resided in LAs operating a three tier system of first, middle and upper schools. In response to this issue, the age range of the children that each questionnaire was intended for was provided for the research nurse. This ensured that the correct questionnaire was administered accordingly.

Additional aspects of the research involving other participants also required consideration of the risk of cross-infection. To this end, I did not meet with adults who were connected to children with CF in any spaces that children with CF might occupy. This issue had implications for the involvement of all adult stakeholders and in particular the parents of children with CF. The majority of parents chose to be interviewed face-to-face, with only one parent opting to be interviewed via the telephone. This meant that an alternative location to the family home needed to be identified for the interview to take place. A variety of locations were suggested by parents. One parent chose to be interviewed at her workplace, another asked to be interviewed at a supermarket café, while the other selected a pub restaurant. The interview locations chosen gave rise to a number of issues that perhaps would not have occurred had the interviews been held at the family home. The public nature of two of the locations presented a potential risk to the privacy of the interviews.

However, this in itself was not a problem as the timing of the interviews took place during quieter periods at the café and pub when other people were not in close proximity.

There was the further possibility of being interrupted during the interviews, which did occur with one parent who was interviewed in her work place. While this parent was self-employed and had the use of her own private office space, several disruptions occurred such as the telephone ringing and other employees requesting the parent's attention. Although the interview was halted during such times, the interruptions undoubtedly affected the flow of the conversation. On a number of occasions, the parent could not remember what she had been discussing prior to the interview being disrupted. In response to this issue I often needed to write down the current topic of discussion to ensure the continued exploration of any interesting viewpoints raised previously. Nevertheless, the challenges relating to privacy and disruption needed to be balanced against the ease and convenience of taking part in the research to the parents, along with removing the risk of cross-infection.

6.2.2   Subjectivity and insider research

My personal closeness to the research topic does inevitably raise the issue of subjectivity within the research process. Subjectivity is more often seen as something problematic that needs to be controlled when conducting research (Letherby et al., 2013). However, I have not viewed subjectivity as an unavoidable disadvantage of my research position or as a result of the methods chosen. On the contrary, I have valued the subjective experience of the research participants as well as my own experiences of living with CF. As Beresford (2007) argues, experiential knowledge based on first-hand experience has value like other forms of knowledge, and the fact that it is based on subjective understanding does not invalidate it. Indeed, my own personal experience has brought several advantages to the research process, as well as some challenges as I later discuss. That is not to say that objectivity was not also valued in the study. Given the pragmatic approach to the research, which encompassed a mixed methods design, there were elements of the questionnaire data generation that required less interaction with the participants and therefore, may be argued to be more objective than the qualitative data associated with the interviews. That being said, no research can be free from all values, interests and assumptions (Letherby et al., 2013). When developing the questionnaire, I selected the items based on the literature and my personal experience of life with CF, and therefore choosing these items represented a subjective decision (Onwuegbuzie and Leech, 2005). Consequently,

I recognised that a constant critical reflection of each phase of the research and the influences of my research positioning has been required throughout the entire study.

While there are undoubtedly advantages to having a close personal interest in the research topic, a significant challenge of being positioned as an insider researcher is the issue of insider blindness. As Delamont (2002) suggests, insiders may be familiar with the culture of the research participants in ways that outsiders could never be, but they can often experience a lack of distance and perspective on every day taken for granted events. This evidences why a reflexive approach was necessary in the study. To this end, I kept a research journal (see appendix 15), I analysed the journal entries, and I spoke to my research colleagues and my supervisors about my methodological reflections. These conversations were perhaps the most reflexively useful, as they allowed me to create some analytical distance between the familiarity of my own experiences of living with CF and those of the participants. For example, when discussing children's treatment regimes with one of my colleagues, she helped me to understand and appreciate that the day-to-day management of CF is considerably demanding. Gaining a frame of reference from someone without CF was important, as based on my general complacency of managing my own CF treatment, and the complacency of the parents and children involved in the study, I may have overlooked the demands this task. The reflexive process therefore allowed me to consider alternative interpretations during the data analysis.

It is important to note that my insider position was not fixed throughout all stages of the study. As I will come to discuss, in addition to being an insider, I adopted multiple positions within the research. My experience was consistent with research by Thomson and Gunter (2011), who recognised that the insider/outsider binary can be messily blurred in particular places and times. The multiple positions that I adopted in this study included; person with CF; adult; expert; service user; and empathic listener, to name a few. Each of these researcher positions meant that the relationship between myself and some of the participants altered at times. Despite being a person with CF conducting research about CF issues, an insider research position did not dominate the entire research process. Each of the researcher positions adopted had different influences on the study and my own subjective experiences.

6.2.3   Researcher positioning and children and young people

Nutbrown (2010) argues that in research involving children, researchers should be reflexive in order to examine their positionality and consider what they really think about children. Similarly, Punch (2002) has suggested ethical researchers should be reflexive about how to create conditions where children have agency and share power to the extent that is possible. Consequently, when I began this research, I was interested in how the children and young people I would interview might perceive me as another person with CF. A key concern in research involving children is that they are potentially more vulnerable to the unequal power relationships between adult researchers and child participants (Punch, 2002; Cappello, 2005; Phelan and Kinsella, 2013). I wondered if having CF might contribute to having a more equal power relationship with the child participants and whether this relationship might affect what they discussed during the interviews. As I saw it, issues of power and adult authority may have been connected to how children viewed my researcher position.

I considered that I had many similar and shared experiences with the children who took part. For example, we attend the same regional CF center, it is likely that some of the treatments and medications we take are the same, and it is possible that we undergo certain similar challenges when unwell. However, while there may be shared experiences between us, it is important to note that there are also major differences. Perhaps the most obvious is that as an adult, I am considerably different from the children in terms of age. This is significant, not just in relation to issues of adult authority, but also because when I was born in the late 1970s, CF was a very different condition and many children were not predicted to survive into adulthood. Back then, the management and treatment of CF was much more limited and my future was quite uncertain. Currently, more than half the CF population in the United Kingdom (UK) will live past 41 years and those born with CF today are expected to live even longer (CF Trust, 2016b). Therefore, it is likely that the CF experiences of the children involved in this study were quite different to the experiences that I had as a child. Consequently, I was uncertain as to whether having CF could in fact create a more equal power relationship with the children who took part.

The extent that children saw me as similar to them seemed to vary between the participants and therefore, having CF had different influences during each interview conducted. During the interview with Bob, who was the eldest of the children and young people that took part, I did not feel as though there was an unequal power

relationship and it seemed as though Bob did consider that, as an insider researcher, I may have had shared experiences with him. For example, when Bob discussed the issues of informing others about CF and keeping CF private, he said the following:

> *But the problem is, and I don't know if you ever experienced this, but people don't really understand because you don't look ill…*

In this excerpt, Bob regarded my CF as a commonality between us and it is possible that this helped to counter the potential challenges that may have arisen from any perceived position of authority that I may hold as an adult researcher. However, Bob's age, and the fact that I placed value on the advice he provided throughout the pilot interview process, might also have contributed a more equal power relationship during the interview with him. Bob did appear to be more open and eloquent about living with CF and his educational experiences than other child participants. However, a particular challenge that I needed to be alert to when Bob queried my own experiences was the potential for me to impose my own views onto him. As Phelan and Kinsella (2013) argue, the establishment of a relationship that elicits the child's own perspective is critical. Where participants saw me as an insider, I was aware of the possibility that they might ask me about my own experiences. I tried to avoid discussing these so not to influence participants responses. As Berger (2013) argues, using the researcher's experience as a lens to view and understand the experiences of the participants could invalidate their perspectives.

No other child participant attempted to make any comparisons between their CF experiences and my own. However, the majority of children did seem to recognise that I had an understanding of life with CF, as they freely discussed their treatment routines and medication names without needing to provide additional explanation. It is therefore possible that if the children and young people interviewed for the study assumed a shared experience with me, they may have felt a lesser need to provide fuller explanations about their experiences. A lack of participant expansion on their experiences appears to be a risk of conducting interviews as an 'insider' researcher.

There was one exception to the shared experience assumed by the children who took part, as early on in the interview with Violet, she seemed to describe some of her medication to me as though I had no knowledge of CF. It is possible that Violet might not have perceived me as an insider or someone who shared similar health

experiences with her and instead simply saw me as another adult. Alternatively, Violet might have recognised that we share the same medical condition, but still experienced uncertainties about the health experiences of other people with CF, particularly given her relatively young age. Nevertheless, Violet's perception of my researcher position suggests that my CF did not automatically contribute to establishing a more equal power relationship with her. Further, I feel it was unlikely that my CF was influential to the discussion during her interview.

It follows that the other children involved in the study also had varying interpretations of my position as a researcher with CF, and these interpretations undoubtedly affected the research relationship I had with them. My position as an adult may have influenced children's perceptions of me more strongly than my position as a person with CF. Therefore, having CF and being perceived as an insider researcher could not completely address any potential power imbalance between myself and the child participants. My experience demonstrates that issues of adult authority and power have implications for insider research with children. While adult researchers may assume an insider position and consider themselves to be closer to the inside, children may not necessarily perceive the researcher in this way. In this study, the degree of closeness to aspects of children's cultures only emerged during the data generation process with the child participants. Therefore, in some circumstances, the perceived benefits of insider research may not be as applicable to research involving children. The connections between researcher positioning and issues of adult authority and power needed to be negotiated throughout the data generation procedures used with the children who participated.

6.2.4   Researcher positioning with adult participants

My insider positioning had some advantages when it came to recruiting the adult participants for the study. When parents were approached about the research, my position as an adult with CF seemed to create a sense of 'connectedness' with them and this appeared to be a motivating factor in their decision to participate and the provision of consent for their children's involvement. This experience held similarities with Taylor's (2011) 'intimate insider' research, in that there was a quicker establishment of trust and rapport between myself and the research participants. When I met with the parents, some of them were interested in getting to know my own experiences of living with CF. One parent spoke of being 'inspired' at having met me, knowing my age, my reasonable level of health and the fact that I was pursuing PhD research. Parents also used these introductory meetings to talk about their children's health experiences, such as their treatments routines and

previous episodes of illness. Their personal stories were quickly shared with me upon first meeting them, suggesting that they also positioned me as an empathic and understanding listener. Therefore, the prior meetings certainly contributed to developing a connection between myself and the parents, and this connection was also advantageous when it came to the interviews with them.

During all the interviews, parents spoke to me with ease and candour. It certainly seemed as though parents were willing to share their experiences because they were confident that I would understand and be empathic with their situation. For example, I was able to offer experiential understanding when parents discussed CF symptoms and complications, treatment routines, the names of certain CF medications etc. Parents did not need to stop to provide further explanation around such conversational topics, which might not have been the case had the research been conducted by someone without CF. The interview conversations flowed well and it was as though the parents were talking to me as a friend. Given the parents were prepared to talk in depth about their experiences with me, it is possible that a greater volume of data was generated as a result of my multiple researcher positions.

My insider researcher position also appeared to influence the involvement of the two CF nurse specialists. Some of the issues that I experienced when recruiting parents to the study were also apparent when recruiting the nurses. For example, one of the nurses, who had several decades of experience in the care of children with CF, appeared excited that she might have looked after me as a child. This suggested that the nurse positioned me as a patient and experienced an emotional connection to both myself and the research. In the same way that parents appeared interested in my personal experiences of CF, this connection may have encouraged the nurses to take part. Given that I attend the same regional CF centre in which the study is based, my position as an adult patient may have influenced the responses provided by the nurses to the interview questions. For example, the nurses may have been more inclined to provide responses that were likely to depict a more favourable image of their role or the CF centre. It is also possible that the nurses omitted to mention anything that could have portrayed the CF centre in a negative light. As a patient who also attends the CF centre, the nurses may have been unlikely to discuss any issue that they perceived to cause concern; for example, issues relating to the level of service delivery. Therefore, I would argue that where an insider researcher is also situated as a service user within a study, and the participants include professionals from the same service, the potential for positive or socially desirable responding should not be discounted.

As an insider researcher, I also felt an emotional and personal attachment to the research topic and to the culture of many of the participants. It seemed that many of the participants, may have experienced a similar attachment to helping and supporting me, as an adult with CF. While this was a considerable benefit of conducting insider research, a challenge was to ensure that all participants fully understood what participation in the research would involve *before* making the decision to take part. My experience suggests, that in the insider research context, there is a risk that information relating to joining the study may be overlooked by any participant who experiences an emotional and personal connection to the topic or the researcher, which it turn could influence their decision to take part. To this end, I discussed each aspect of the study information sheet and consent form directly with all participants in advance of the interviews, as opposed to simply providing a paper copy for them to read independently. This allowed me to be certain that the process of informed consent had been correctly adhered to.

6.2.5 Personal impact of conducting research about CF

I have discussed how my researcher positioning has influenced the research. However, being a researcher with CF who conducted research about CF also had significant personal influences. When designing the methodological approach to this study, I took care to avoid an in depth exploration of factors relating to the more distressing aspects of living with CF, in an attempt to ensure that children did not become upset by taking part in the research. However, I was not prepared for my own emotional responses to some of the interview conversations with the participants, particularly those with the children and parents involved. Some of the stories told during the interviews did cause me to feel upset and at times, angry, especially when I felt that children and parents had encountered a poor understanding of CF or potentially discriminatory or exclusionary practices. I found myself thinking back and finding similarities between my own experiences of school and those described by parents and children. Indeed, my own school experiences were partly behind my personal motivation for the research. A challenge here though was not to react on my emotions and to try and remain objective so not to influence the participant's further responses. However, as an insider researcher, I found it hard to detach myself from the stories told by the participants. At times this was difficult because I was torn between trying to remaining objective without appearing aloof or insensitive; a challenge of doing research with children also reported by Jones and Tannock (2000). I found that keeping my feelings hidden meant that after I completed each interview, I needed a period of reflection, not only

for analytical purposes, but also to make sense of the emotions I had experienced. This was necessary to create sufficient distance between my own subjective experiences and those of the participants. Ultimately, I needed to make sense of my own experiences of life with CF in order to consider the various interpretations of the perspectives of the participants involved in the study. As I have often coped with my own challenges by not dwelling on them, critically reflecting on the possible interpretations to be gained from the participant's perspectives has been a difficult, though necessary task at times.

In the next section, consideration turns to the issues and challenges experienced as a result of involving children in the research.

6.3   Involving children in the research

The involvement of children in the research necessitated the use of methods that would avoid the risk of cross-infection. Had there been no risk of cross-infection, it is likely that face-to-face methods would have been preferable, resulting in a different approach to children's participation in the study. Nevertheless, many of the issues and challenges arising from the specific research context are applicable to involving children in research generally. I now discuss how I addressed some of these issues and challenges with reference to: involving children in the research design; recruiting children and young people; using online interviews with children; disruptions; building trust and rapport; engaging children in discussion; and socially desirable responding.

6.3.1   Children and young people's involvement in the research design

I had hoped to engage children with CF as advisers during the study design phase. Previous research has shown that this approach can enable the researcher to develop a greater understanding of the participants, which can subsequently support the development of appropriate methods (Sinclair Taylor, 2000; Connors and Stalker, 2007; Kellett, 2011). However, due to NHS research protocols, gaining access to children via the paediatric CF centre prior to the study being given NHS approval was not possible. At this stage, the methods selected for the study needed to be finalised and could not be changed without a reapplication to the NHS REC. All aspects of the research design were checked and tested through a series of iterative processes (see section 3.9.3 and section 3.10.2.1). The children and young people's interview schedule was piloted with Bob, the post-school aged

young person involved in the study. Regrettably, children and young people were not involved in the design of the questionnaire and this remains a limitation of the study.

Had children been involved in the design of the constructs this would have undoubtedly benefitted the questionnaire. Their involvement would have enabled the identification of issues that they felt to be significant to them at school, rather than what I considered to be relevant based on the available literature and my own subjective experiences of living with CF. The absence of children's involvement in identifying the school activities used in the questionnaire meant that it was difficult to know if the activities were appropriate or if there were pertinent activities that I had not considered. For example, the interview findings suggested that the completion of homework may be difficult as children attempt to balance the demands of this with their treatment commitments. However, I neglected to include 'homework' in the list of activities on the difficulty rating scale. It also follows that if children had been involved in the design of the impact of CF on school activities scale, it may have made it easier for child participants to indicate any negative effects of CF on school activities in the knowledge that these will have been raised by others, and may validate those experiences (Beresford, 1997).

6.3.2 Recruiting children and young people to the study

The recruitment of children and young people to the questionnaire phase of the research was quite straightforward given the support of the research nurse with this task. However, recruiting children and young people to the interview phase of the study resulted in a number of specific issues and challenges. Parents assisted with the process of recruiting children. As I discussed earlier, I experienced a sense of 'connectedness' with parents. I therefore questioned the possibility that some parents, with the intention of helping me with my research, may have inadvertently coerced their child into being interviewed by me. Although I attempted to ensure children were informed about the research before they consented/assented to being involved, it was difficult to know if some of the children I interviewed took part because their parents had asked them to, or because they wanted to participate as a result of being adequately informed about the study. Indeed, the potential disparity between child and parent consent and assent has been raised in research elsewhere (Warin, 2011; Phelan and Kinsella, 2013). This issue reinforced the importance of ensuring that children understood they did not have to take part in the study before the online interview took place and further, that they knew they had a

right to withdraw from the research at any time, without giving a reason even though consent from their parent had already been given.

A further issue that concerned the recruitment of children related to the potentially sensitive nature of the research. One parent appeared apprehensive about the involvement of her daughter when first approached about the study. While it was clear the parent wanted to be helpful towards me, she seemed to experience a dilemma about consenting to the participation of her daughter. The parent initially stated that she had concerns about the content of the interview questions. These concerns were specifically related to fears about the possible discussion of any CF related issues. The parent felt that her daughter did not fully understand what having CF might mean for her as she grows older and therefore wished to protect her from any such discussion during the interview. This was understandable, particularly given that her daughter was the youngest of the children to be approached about the interview phase of the study. At this point it was important to explain that careful consideration of the interview question wording had taken place to focus on the context of educational experience rather than any clinical or health issue relating to CF that might be upsetting to the child participants. However, I also acknowledged that children's health and educational experiences are not mutually exclusive and may influence each other, and therefore, some discussion about living with CF would occur. Subsequently, the children's interview schedules were shared with all parents so that they understood the areas of discussion that might take place which would help them decide if they wanted to consent to their child's participation in the research. All parents agreed that their child could take part following this approach.

6.3.3 Online interviews with children

Interviewing the children and young people using online equipment and software, as opposed to the uses of physical face-to-face methods, did not appear to be a barrier to gaining their perspectives on their educational experiences. The use of the iPad to enable children and young people to take part in the online interviews proved to be advantageous. While verbal and written instructions on how to use the iPad were provided, in most cases these were not required. As originally anticipated, the participants were already familiar with how to use the device, suggesting the iPad is an accessible tool for research involving children. Similarly, all children and young people were also able to access the Adobe Connect application via the iPad with no reported issues and with very little technical support. However, the online interviews were not without problems and some

technical issues were experienced. At times, the two participants encountered a long delay in the sound and video coming through. However, I did not experience the same delays. Despite trying to optimise the sound quality of Adobe Connect before the interviews took place, the delays remained throughout the interviews. This was incredibly disappointing as there was no doubt that the issues affected the flow of the conversation. There were a number of possible reasons for the delays, such as problems with the speed and capacity of the participants' or my own network.

It is conceivable that the technical problems encountered could have been off-putting to the participants and therefore these problems could have affected the richness of their responses to questions. Fortunately, the children in question did not lose interest in the interview and continued to share their perspectives, despite the conversation being interrupted at times. The technical issues that occurred in the two online interviews perhaps could have been prevented had I been aware of the potential for the problem. The issues had not been revealed during the pilot interview or during any other testing of the equipment and software. However, of particular interest here is that one of the children did not tell me there was a technical problem during the interview and it was only later that I found out when the child's parent informed me. It is possible that some children will rely on adults to identify such an occurrence. This demonstrates that in the children's online interview context it is vital that participants are provided with regular opportunities to inform the interviewer should any technical issues arise.

6.3.4 Disruptions

Children took part in the online interviews from their own family homes and unfortunately, disruptions were experienced that might not occur during other face-to-face approaches. Given that the family homes were likely to be busy environments, especially during the evening when other family members are around, I asked children and young people to find a quite space in their home when taking part in the interview to try and ensure relative privacy. This would be in line with Deakin and Wakefield's (2014) recommendation that online interviewees should be in a location free from controllable distractions. However, this was not always practical for the child participants and a number of disruptions to the interviews occurred, such as: family members coming into the interview space; doorbells and phones ringing; dogs barking; and parents shouting at the participant's siblings. It was difficult to see how I could overcome the disruptions given the parameters of the online interviews. However, in some ways, the

disruptive incidents provided another focus during the interviews, which at times were amusing, and this appeared to relax the participants.

6.3.5 Building trust and rapport

The photovoice activity was planned for use at the start of the interviews with the aim of building trust and rapport prior to administering the interview schedule. However, only two of the four school-aged children took part. Incidentally, both these participants were female. The male participants did not give any specific reason for not completing the activity other than that they just did not want to do it. There was no indication that the male participants felt the activity would be too difficult to complete or that the equipment/technology was not user friendly. However, it appeared that there was a general lack of interest in the photovoice activity and it is possible it was not perceived to be engaging or exciting to the male participants. Indeed, research with children elsewhere has had mixed success with photo elicitation techniques. For example, in Beresford's (2012) study, she found that success was partly dependent on the extent to which the young people remembered to use the camera, and whether or not parents supported the young person in the photo activity. While no specific criteria were given to the children and young people on what the images should contain in this research, as the intention was for the activity to be child centred and child led, this approach may have caused the two male participants to experience concerns about producing the 'wrong' kinds of images. Alternatively, they may have felt that the activity was too intrusive, which may have deterred them from taking part.

Nevertheless, the decision not to take part by the two male participants did not present any challenges. I did not wish to assume that rapport would be automatically established between myself and the child participants on the basis of a shared experience of living with CF. However, as with the parent participants, I did encounter a sense of 'connectedness' with some of the children and young people that enabled me to gain their trust without the use of the photovoice activity. This 'connectedness' facilitated a more candid discussion of participants' educational experiences. That is not to say that the use of photovoice was superfluous to the interviews with the two female students. Indeed, it was a useful icebreaker activity and seemed to put them at ease prior to the interviews. It is difficult to know whether the use of photovoice did in fact enable greater rapport between myself and the two female participants. However, it certainly gave me a glimpse into their lives through the synchronous viewing of images relating to their hobbies and interests. This formed a useful basis for discussion before I began the

interview. Clearly, the photovoice activity was not appealing to all the participants in the study. Therefore, the way in which researchers might attempt to build rapport may well depend on the characteristics of study participants (Hill, 1997; Barker and Weller, 2003; Fargas-Malet et al., 2010). Nevertheless, this study has illustrated the importance of allowing children to decide for themselves if they would like to participate in any of the methods selected for data generation.

6.3.6 Engaging children in discussion

Not all participants spoke to me with ease throughout the interviews, and this was perhaps one of the most difficult things that I encountered during this phase of the research. The ease of the discussion may have been related to the potential power imbalance between myself as the adult researcher and the children who took part. However, I found the vignette and fantasy wish interactive questions to be incredibly helpful in this regard, as used together these questions encouraged the majority of participants to offer more detailed perspectives about their educational experiences. The two forms of interactive questioning did have different levels of success for different participants, suggesting that a combination of these two approaches may work best. For example, during the interview with Rachel (13-year-old female), she was often silent after being asked a question, which led me to follow up with increasingly closed questions that generally produced "yes" or "no" responses. However, turning to an excerpt of this interview demonstrates how the vignette questions evoked a more detailed and interesting discussion. Using the vignette with Rachel led to her discuss the significance of being 'normal' to children with CF:

Interviewer: Imagine that you have a friend called Sam whose parent is a teacher at another school. Sam's parent has just found out that a young person with CF will be starting at their school very soon. Sam's parent knows you have CF and so comes to you to ask for advice. What advice would you give Sam's parent so that the young person with CF is happy at school?

Rachel: Err, just, like see if they know, like if they're alright with school and everything…if they want their teachers to know anything more. Then, yeah.

Interviewer: Oh okay, you think it's important that the young person is asked if they think their teachers should know about their CF? Is that what you mean?

Rachel: Yeah. Yeah…

Interviewer: Okay. Do you think it's important that young people with CF can keep CF to themselves and not tell anybody about it?

Rachel: Yeah if they want to

Interviewer: Yeah. Okay is there anything that you think might be helpful to the young person who is starting at your friend's mum's school?

Rachel: Err, I don't know really…

Interviewer: That's Okay, that's fine. Is there anything that you think the school shouldn't do?

Rachel: Be sending you to the school nurse all the time to see if you're okay

Interviewer: Oh okay. Does that happen at your school sometimes?

Rachel: No but… (long pause)

Interviewer: Why do you think that might be an issue then, being sent to the school nurse? How do you think that would make a young person feel?

Rachel: That they couldn't be like a normal person at school

Using the same vignette with Violet, who at aged 9 was the youngest participant to be interviewed, led me to believe that this form of questioning may be not be suitable for younger children. Violet did not appear to understand the vignette question, yet, she still attempted to answer it. This issue is exemplified by turning Violet's response after being read the vignette question during her interview:

Interviewer: (reads the vignette question)

Violet: Err, I don't know…

Interviewer: Is there anything you would like to say to Sam's parent? Would you like to give them any advice around what teachers should do? Or what they shouldn't do?

Violet: Yeah well they shouldn't forget to have their Creon because then they will get a tummy ache

Violet provided some excellent advice after being asked the vignette question, however, the advice was more applicable to a young person with CF at school rather than a teacher of someone with CF. Therefore, her response represented a misunderstanding of the question. This issue is consistent with Dockerell, Lewis and Lindsay's (2000) view that younger children may feel compelled to provide an answer to interview questions even if they do not know what they mean. Therefore,

it would seem the use of the vignette question, as presently worded, was not appropriate for the interview with Violet.

The fantasy wish question had mixed responses. Two young people said they did not have any wish to make school better or easier for them. This suggests that they were generally satisfied with their current educational provision or that they did not find the question useful for the discussion of additional viewpoints. However, the three remaining young people offered alternative perspectives and their responses to the fantasy wish question demonstrated that this type of interactive questioning can generate useful information. For some of the participants, the question facilitated additional discussion of issues previously raised in the interview, which helped them to clarify and corroborate their thoughts on certain topics of discussion. In other cases, the fantasy wish question enabled the discussion of new themes that had not been discussed elsewhere during the interview.

The ease of discussion with children during the interviews did not appear to relate to the age or gender of the participants, which is something I had not anticipated. It seemed to me that talking freely with the participants was more about the individual personalities of the children rather than something that was connected to their age or maturity. This finding parallels with research by Deakin and Wakefield (2014) who found that online rapport was only an issue when interviewing an individual who was particularly reserved or less responsive. Nevertheless, the combination of using both the vignette and fantasy wish questions certainly encouraged children and young people to discuss their views about their educational experiences. Significantly, the questions were particularly useful where children were less responsive to the other forms of interview questioning.

6.3.7 Socially desirable responses

When interviewing the children and young people, I expected that they would feel comfortable discussing the more challenging aspects of having CF with me, as I would be more likely to understand and empathise with them than an interviewer without the condition. At times I am sure that some children did feel able to talk to me about certain difficulties during the interviews. However, I was also struck by their positivity when discussing CF and their educational experiences and I wondered if this was a deliberate attempt by the child participants to be perceived in a positive light. Research elsewhere has suggested that when children are involved in research, they may focus on their strengths and capabilities and present themselves in a socially desirable and positive way (Begley, 2000; Greene and Hill, 2005; Fargas-Malet et al., 2010). As Greene and Hill (2005) argue, people are

prone to many biases in reporting their perspectives and experiences to others, and the impulse to present oneself in a way that is socially acceptable can influence the responses given in research.

During the interviews with children, there were a number of occasions where children's responses to questions could have been interpreted as socially desirable. For example, when children were asked how CF affects them and what it is like to live with the condition, all of their responses seemed to indicate that they did not feel affected by CF or were unhindered by the condition. It would not be unreasonable to consider these perspectives to be 'overly positive', given the treatment burden and periods of illness experienced by the children involved. There were also examples of children (and parents) using phrases that would suggest they believed CF is not a justifiable reason to need support or help. One young person used the phrase, 'playing it a little bit' when discussing the educational support he had received, suggesting he was using CF to his advantage. It is possible that the young person felt it more socially desirable to use such a phrase. One explanation for this response is apparent from the interview analysis. This revealed that children with CF are sometimes viewed by others as 'being like everybody else', and children also viewed themselves in this way (see section 5.5.1). It follows that the young person may have presented himself as he thought others might perceive him. Alternatively, he may not have felt that he should be entitled to the support he was offered.

Significantly, some researchers have argued that socially desirable responding may have implications for the validity of research (Begley, 2000; Greene and Hill, 2005). Taking this view suggests that when children are presenting themselves in an overly positive manner they are not portraying an entirely accurate picture of their experiences or self-perceptions. However, in the qualitative research context, I would argue that what appears to be a socially desirable response may not always present a risk to validity. Consideration must be given to potential explanations for positive or socially desirable responses during the data analysis, as these can be of value to the findings. An explanatory approach can be exemplified by returning to the instance of children suggesting they were unhindered by CF during the interviews. Such perspectives might be interpreted as socially acceptable responses because children are viewing their life with CF in what seems to be a positive way. While this may be true, other viewpoints were given elsewhere in the interviews that could explain why children presented such positive perspectives. For example, children stated that CF did not prevent them from doing the things that they wanted to do, and other participants suggested that children did not think or

worry about having the condition. It is possible that certain positive responses from the children involved in the study may in fact reflect how they perceived themselves and are therefore not a validity issue.

It is also important to consider what might influence researcher perceptions about socially desirable responses. This is particularly significant for research that involves children with an impairment or disability. If socially desirable responses are a matter of interpretation by the researcher, whether or not researchers have an impairment or disability is likely to influence the interpretation that researchers make. Taking the example of Bailey and Barton's (1999) study that considered the impact of hospitalisation on two young people with CF; the authors concluded that the young people were not coping as well as their responses would suggest and their positive outlook during the interviews was a coping strategy that allowed them to deny the existence of their illness. Bailey and Barton (1999) have inferred that the young people's positivity could not be reflective of their actual experiences. This position views CF as inherently negative and therefore aligns itself with a 'disability as tragedy' model (Oliver, 1996). However, a personal, non-tragedy view of impairment and disability can take many forms and be expressed in a variety of ways (French and Swain, 2004). It is possible that what might appear to be an overly positive perspective could be interpreted as a socially desirable response by a researcher without experience of the participant's impairment. While many of the children involved in this study did appear to give certain positive responses, I do not consider these perspectives to be an inaccurate reflection of their experiences. It is of course possible that the children and young people simply did not wanted to talk about the more difficult or distressing aspects of CF. Further, I believe it is less likely that the children painted an 'overly' positive picture of life with CF during the interviews, due to them knowing that as an adult with CF, I understand and experience my own challenges of living with the condition.

The next section considers the methodological issues arising from the decision to conduct the research as a mixed methods study.

6.4   The mixed methods approach

Having considered the issues and challenges related to being a researcher with CF conducting research about CF, and involving children in the research, I now turn to the issues and challenges arising from the mixed methods approach adopted. A key reason for using a mixed methods approach was that one data source was deemed insufficient to gain both an in depth understanding of the perspectives of

individuals connected to CF, and the views of a relatively large group of participants who could represent the varied lived experiences of children with CF. Nevertheless, the use of this methodological approach was not without challenge, particularly when it came to integrating the data from the two distinct phases of research. Indeed, the difficulties associated with integrating quantitative and qualitative data sets have been raised in other research studies (see for example Morgan, 1998; Bryman, 2007; Woolley, 2009). Much of the discussion in this section concerns the issues and challenges relating to the process of integrating the data sets, and what might be learned from the combined results. Before discussing the integration of the datasets, I first consider one particular advantage of the mixed methods approach that relates to weakness minimisation, in that the limitations of one method were offset by the other.

6.4.1   The value of each method

A major advantage of adopting a mixed methods research design was that the limitations of one method were compensated by another. For example, a particular weaknesses associated with the questionnaire was that it measured children's educational experiences based on a number of mostly closed variables that were constructed with reference to the literature and my own subjective experiences. The questionnaire mainly employed the use of closed questions, and so generally, participants did not have many opportunities to self-identify any factors that they felt to be salient to their own educational experiences. The use of the interviews offset this particular weakness of the questionnaire, and by fostering a participant led discussion, this enabled an in-depth exploration of issues in education relevant to children with CF. In other words, the interviews compensated for the limited exploratory and explanatory potential associated with the questionnaire approach (Cohen et al., 2011). The interview findings also added meaning, context and explanation to some of the questionnaire results, as I discuss later when reflecting on confirmatory and explanatory findings. Therefore, greater insights and understandings could be gained about the educational experiences of children with CF which would not have been possible had the questionnaire been used alone. Similarly, a weakness of the interview approach was also offset by the use of the questionnaire. Only a small proportion of the population of children with CF in attendance at the regional CF centre were involved in the interviews. While the interview sample was designed to be sensitive to the varied lived experiences of children with CF, the small sample employed could not reflect the range of individual and unique ways that CF can impact children's lives. However, the

questionnaire enabled a larger number of children with CF to take part in the research, and the sample was inclusive of a group of children with more diverse health experiences than that of the interviews. This was useful when it came to comparing the findings from each phase of data generation, as the comparable aspects of the questionnaire and interview data therefore encompassed a broader and more varied range of perspectives.

6.4.2 Integrating the data

While being able to compare the findings of the questionnaire and interviews was initially thought to be a major advantage of conducting a mixed methods study (Gorard and Taylor, 2004), in practice integrating the two data sets was much more difficult than first anticipated. At the research design phase, the two phases of research were linked in several ways (see section 3.5.1). One particular factor that connected the two methods was the eight constructs used to inform the questionnaire items and interview questions. I considered that using the same constructs within each method would aid with the integration of the data sets at a later stage. However, the process of linking the findings, through the constructs, was not straightforward. The analysis of the interview data resulted in the construction of many new, a posteriori themes and conceptual categories. It was unclear how some of the new themes directly related to the 'fixed' nature of the constructs used within the questionnaire items. Consequently, some of the interview findings did not appear to be fully comparable with the questionnaire results.

The difficulties experienced when comparing the data sets were partly related to the decisions taken around the thematic analysis of the interview data, in that this process was mainly inductive and not exclusively driven by the a priori constructs. Had the interview data analysis been exclusively driven by the a priori constructs, the findings would have been more comparable with the questionnaire results, leading to a greater integration of the two data sets. However, this approach would have led to any non-comparable aspects of the interview data being discarded; data that may have contained exploratory meaning or important insights that would further understanding of the educational experiences of children with CF. At the onset of the study, I expected that the questionnaire and interviews would play an equally important role in answering the research questions and initially I did not prioritise one methodological approach over another. However, after the two phases of data generation were complete, and the data analysed, I found the interview data to be more inherently interesting and compelling than the

questionnaire results. The option of discarding aspects of the interview data in favour of a more fully integrated mixed method study seemed counterproductive to answering the research questions. Therefore, a partial integration of the two data sets was favoured as a result of the challenges I have discussed here.

Despite the challenges with achieving maximum integration of the data associated with each phase of research, there were certain aspects of the data sets that were comparable. Consequently, my understanding of the educational experiences of children with CF has been enhanced by the availability of both the questionnaire results and interview findings. The partial integration of the two data sets revealed that some of the results and findings appeared to be confirmatory or explanatory of each other. However, there were also conflicting results. Reflecting on where the data sets were confirmatory, explanatory or conflicting has offered additional insights into children's educational experiences. Consequently, the comparing the two data sets has brought additional value to the study.

6.4.3   Reflecting on confirmatory findings

Both the questionnaire and interviews showed that not all children felt that their teachers understood CF. While the issue of teacher understanding was an a priori construct used to inform some of the questionnaire items and interview questions, three aspects of the data sets suggested that this was indeed a salient issue to children with the condition. Firstly, the issue of teacher understanding was widely discussed during the interviews along with some of the associated difficulties that children had experienced (see section 5.8.2). Secondly, results relating to an open question included in the questionnaire showed that several children cited teacher understanding as something that would make things better for them at school (see section 4.3.9.1). Thirdly, a closed item included in the questionnaire, revealed that the majority of children either felt their teachers did not understand CF or were not sure (see section 4.3.3). Therefore, taking both data sets into consideration would suggest that teacher understanding of CF is not only important for the education of children with the condition, but is also an area that may require improvement.

Results from the questionnaires and interviews also appeared confirmatory in relation to the subject of children's involvement in discussions about CF at school. Almost half of the children who responded to one questionnaire item (for secondary students only), indicated that that no one from their school had talked to them about CF or they were not sure if anyone had (see section 4.3.2). The interview findings seemed to confirm this result. Only one young person was mentioned to have formally been given the opportunity to discuss CF with the staff at his school.

Generally, the level of children's involvement in school discussions about CF was not directly discussed during the interviews. However, while parents tended to inform schools about CF related issues through one initial meeting, no participants mentioned that children were also invited to attend. Combining the questionnaire and interview results therefore implies that children may have limited opportunities to have their perspectives about CF and their educational experiences taken into account in the school context.

Another example of a confirmatory finding relates to the issue of school absence. Both the questionnaire results and interview findings demonstrated that school absence may not be as extensive a problem for children with CF as the literature might suggest. In the questionnaire, only a quarter of children indicated they had taken more than 21 days off school in the last 12 months (see section 4.5.2). Equally, the interviews revealed that many children and parents would attempt to avoid school absence wherever possible. Participants did discuss children needing short and sporadic periods of school as opposed to long durations. However, of note here is that the questionnaire results and interview findings relating to school attendance are based on participant self-reported measures which may not accurately reflect formal school attendance monitoring. Nevertheless, the combined results demonstrated that many children (and parents) involved in the study did not appear to suggest that persistent school absence was problem for their educational experiences. This inference may be better explained by further research.

6.4.4 Reflecting on explanatory findings

Returning to the issue of teacher understanding, combining the two data sets suggests there may be a number of factors that could explain why the majority of children indicated in the questionnaire that their teachers did not understand CF or were not sure if they did (see section 4.3.3). These possible explanations would not be clear from the questionnaire data alone. During the interviews, participant views contained within the conceptual category 'being me first' demonstrated that children and young people actively hid any visible differences from others at school, and regularly chose to keep their CF private. Other perspectives within the same conceptual category also suggested that children adopted a normalised persona at school and valued being seen in the same way as their peers. Consequently, integrating the data suggests that the opportunities available for teachers to gain an understanding of CF and consider the implications of the condition in the school context may be significantly reduced. While the two data sets revealed teacher understanding to be an area of importance to children and parents, it is possible

that children and young people placed a greater value on being able to adopt a normalised persona while at school. Therefore, some children may have been willing to forsake teacher understanding in order to avoid being seen or treated differently to their peers.

In addition, participant perspectives that were discussed during the interviews contained within the conceptual category 'knowing about CF' offer other explanatory factors pertaining to the level of teacher understanding indicated in the questionnaire. It is reasonable to assume that the way schools are informed about CF may contribute to teacher awareness understanding of the condition. The interviews revealed that detailed information about CF is usually conveyed through one initial meeting when a child begins a new school. Having one formal meeting in which to discuss CF may again limit the opportunities available for teachers to learn about the implications of the condition for children's education. Further, a lack of children's involvement in such meetings, and opportunity to put their own views forward, may also explain why some children felt that their teachers do not understand the condition.

There were other aspects of the interview data that might explain certain questionnaire results. For example, where participants were asked to rate the level of CF difficulty for 12 school related activities in the questionnaire, 'school trips' was one activity with the largest number of respondents rating higher levels of difficulty (see section 4.4.1). Again, interview responses contained within the conceptual category 'being me first', provided both confirmatory and explanatory factors as to why school trips may present particular difficulties for children with CF. One participant suggested that school trips may be a school activity where CF is more likely to be revealed to others, therefore drawing attention to potential differences between children with CF and their non-CF peers. However, as mentioned earlier, the interviews revealed that being able to keep CF private was of importance to some children with CF. Therefore, school trips may present situations in which children feel unable to do this. An additional explanation for the difficulty rating of school trips in the questionnaire can also be inferred from one parent's perspective during the interviews. The parent suggested that her son felt unable to attend a school trip due to the associated changes to the typical school routine and the impact of such changes on his daily CF treatment requirements. Combining the two data sets suggests that the 'school trip' is a school activity that children with CF may have difficulties accessing. The interviews provided additional explanatory information for this finding, therefore increasing my understanding of the reasons behind the related questionnaire result.

6.4.5 Reflecting on conflicting findings

There was one specific area in which the questionnaire results and interview findings appeared to be conflicting. This was in relation to the management of CF treatments in the school context. The perspectives gained through the interviews suggested that the majority of CF treatments can be managed away from the school environment, with the exception of enzymes that are needed with food (Creon). However, the questionnaire results revealed that additional CF treatments were needed by some children whilst at school (see section 4.3.7). A quarter of the questionnaire respondents (*n*=19) indicated they had received IVs at school. Children also reported needing oral antibiotics (*n=24*), nebulisers (*n=7*) and physiotherapy (*n=12*) in addition to Creon at school. While the number of children indicating that they required such treatments at school was relatively small in the questionnaire, in contrast to the interview findings, this suggests the that some children do in fact require a range of treatments for CF in the school setting. This conflicting finding could also be related to differences between the children who took part in each phase of the research. For example, there were more primary students than secondary students who completed the questionnaire and all but one of the children's interviews took place with secondary students. Therefore, the extent that CF treatments are managed at school may be related to the child's school type. However, it was not clear from the questionnaire results or interview findings why this might be the case. One explanation might be related to the differences between the sizes and systems of primary and secondary settings, as these could influence the support structures in place for managing medical treatments at school. Alternatively, secondary school children may be less willing to complete CF treatments at school, as this might cause them to feel different to their peers. Despite the uncertainty relating to this conflicting result, integrating the questionnaire and interview findings in this conflicting area has revealed that the management of CF treatments in the school setting may be an important area for further research.

6.5 Summary

My reflections contained in this chapter have highlighted some of the issues and challenges experienced throughout the research in terms of: being a person with CF conducting research about CF; involving children in the research; and conducting the research as a mixed methods study.

I have shown that being close to the subject of the research brought about both advantages and challenges. There were challenges relating to the issue of cross-infection. I was not physically available to deal with any problems that arose with the questionnaire administration at the CF centre. The risk of cross-infection also affected the choice of location for the interviews with many of the participants, and this led to disruptive incidents during the interviews which sometimes hindered the conversations that took place. The issue of subjectivity was raised and I argued that subjective experience was something to be valued throughout the research. However, I also acknowledged that being close to the research required a reflexive approach in order to gain analytical distance from my own subjective experiences of living with CF. I discussed some of the advantages of the researcher positions adopted, such as being able to develop trust and rapport with some of the participants more quickly, and having a 'connectedness' with parents, which facilitated the flow of conversation during the interviews. My researcher positions when interviewing children and young people were also discussed. In particular, I considered the extent that children saw me as similar to them, through being another person with CF, along with the possible influence on power dynamics during the online interviews with them. I found that child participants had varying interpretations of my position as a researcher and that my CF did not necessarily lead to a more equal power relationship with all the children who took part. I argued that the advantages of being an insider may not be entirely applicable to research involving children. A final issue discussed in relation to being a person with CF conducting research about CF related to the personal impact of conducting the research. I stated that reflecting on the interpretations to be gained from participant perspectives sometimes evoked an emotional response that I had not been prepared for prior to the study.

In this chapter, I also reflected on the involvement of children in the research, which concerned the use of methods that would avoid the risk of cross-infection. I discussed one of the limitations of the study, in that I was unable to gain access to children with CF before the NHS had given approval for the research to go ahead, and this meant I was unable to consult them on the suitability and design of the methods chosen. I considered some of the ethical issues relating to the recruitment of children to the study. One issue concerned the possibility that children may be inadvertently coerced by their parents to take part in research. A further issue related to parental unease around their children's participation in research, which may necessitate revealing the content of children's interview schedules to allay any fears. I also discussed the online interviews in practice and argued that while these

can be a useful approach for research involving children, they are not without problem. Technical issues and disruptions were encountered which affected the flow of conversation at times. I suggested that children may not always feel able to inform the interviewer that a technical problem has occurred, and that it is important to ensure children are able to report such issues at regular intervals throughout the interview. I considered the use of interactive interview techniques, such as photovoice and the vignette and fantasy wish questions. I found that the techniques had mixed results and argued that a combination of approaches may work best for some children and young people. Lastly, I discussed the issue of socially desirable responding in research with children. I stated that potentially socially desirable responses might be a matter of interpretation by the researcher, and the researcher's characteristics may affect the interpretation made by them.

A final consideration in this chapter concerned the decision to conduct the research as a mixed methods study. I discussed the value of using two methods, and argued that the limitations of each method were compensated by the other. I discussed the challenges experienced when combining the two data sets, opting for a partial integration of the data. I reflected on the confirmatory, explanatory and conflicting findings as a result of integrating the data sets and demonstrated that my understanding of the educational experiences of children with CF had been enhanced by the availability of both the questionnaire and interview data.

In the next chapter I draw together and discuss the main findings of the research with a particular focus on the fundamental needs and challenges experienced by children and young people with CF, and possible areas of supportive practice, in a context of the existing literature.

Chapter 7 The educational experiences of children and young people with CF: a discussion

7.1   Introduction

The main aim of this research has been to explore issues in education related to children and young people with CF. As I discussed in Chapter 1, there has been a dearth of research into CF and education specifically, and consequently the educational experiences of individuals with CF have remained largely unknown. This study has begun to address the gap in the research. I utilised questionnaires and online interviews to explore and analyse children and young people's perspectives on their educational experiences. Interviews were also used to explore and analyse the perspectives of additional stakeholders involved in the care and education of children and young people with CF, such as parents, teachers and members of the CF clinical team. The findings and analysis relating to the questionnaires and interviews contained in Chapters 4 and 5 respectively, addressed the following research questions (see section 1.3 for all research aims and questions):

RQ2. What are the perspectives of children and young people with CF on their educational experiences and needs?

i.   To what extent do they feel their needs are understood, identified and met in their current educational provision?
ii.   What factors do they perceive to be helpful to their educational experiences?

RQ3. What are the perspectives of other key stakeholders on the education of children and young people with CF?

In Chapter 2, empirical evidence and literature relating to the education of children with medical conditions was reviewed and I presented an ecological and interactional approach for understanding children's educational experiences through the biopsychosocial model (see section 2.8.3). In this chapter, I discuss the findings of the research in light of the literature discussed in Chapter 2. Particular attention is made to the findings related to the educational needs and challenges experienced by children and young people with CF, and associated areas of supportive practice that is likely to be beneficial to them at school. The discussion contained within this chapter therefore addresses the fifth and final research question:

RQ5. How can the study data inform developments in the education of children and young people with CF?

Towards the end of this chapter, the implications of the research for policy and practice are discussed, followed by the biopsychosocial implications of the research.

7.2   Fundamental needs and challenges

This section synthesises the research findings and the existing literature in order to consider the fundamental school related needs and challenges experienced by the children and young people with CF involved in the research.

7.2.1   'Being me first' – a need for normality

It is clear from the study findings that the children and young people with CF involved in the research valued school as a place in which they could be 'normal', in that the more difficult aspects of managing and living with the condition that may instil possible feelings of difference, for the most part did not occur in this environment. This seemed to be a factor that demonstrated the importance of school to those with CF. The interview findings revealed that children and young people took action to maintain a sense of normality at school, by hiding any visible aspects of the condition or opting to keep CF private (see section 5.5.3 and section 5.5.4). Previous research has claimed that 'normalisation' signifies that children are denying the existence of their illness (Bailey and Barton, 1999; Taylor et al., 2008), or downplaying the major difference that their life represents (Ferguson and Walker, 2012). Earlier in Chapter 2, I posited that individuals with CF may therefore reject the idea of needing support at school (see section 2.7.1). However, in contrast to other studies, this research would suggest that the actions taken by children and young people to normalise CF did not necessarily indicate they were downplaying or denying their condition to staff at school, nor did this seem to constitute an outright rejection of needing support. It seemed as though they normalised CF out of a concern that their school peers might perceive any noticeable difference as something inherently negative. However, children and young people wanted their teachers to understand what having CF might mean to them (see section 5.8.2), although maintaining a normalised persona was important around their school friends.

Yates et al (2010) argue that institutional policy and practices relating to the provision of support can fail by being too focused on what is not 'normal' about a

young person. In this respect, the normalised personas adopted by individuals with CF may obscure any educational challenges they experience, which could create tensions around the identification of appropriate school related support. At the same time though, the findings demonstrated that children and young people with CF do have to contend with circumstances arising from their condition that their non-CF school peers do not. Therefore, this study does not support the position that it is most helpful for children with CF to be treated as 'ordinary' as possible at school (Puckey et al., 2006). In much the same way as Yates et al (2010) have suggested, there needs to be a better understanding of the way that being both 'normal *and* vulnerable' are intertwined in the identities of young people with medical conditions. Indeed, a similar identity dynamic was experienced by those with CF involved in the study. Yet, the research findings suggest that children and young people may more often be seen as 'normal' at school rather than being in any vulnerable educational circumstances, and therefore without additional educational needs (see section 5.5.1). The situation may well be compounded by the relative invisibility of CF and the mistaken view that there are no cognitive difficulties associated with the condition (see Chadwick et al., 2015).

A key concern of children and young people in their need for normality was that having CF could be a cause for others to see them as different at school, or for teachers to treat them differently. It follows that schools may interpret a child's need for normality as a reason not to implement different school practices or provisions for the child. However, the perspectives of the research participants revealed a number of scenarios where it was apparent that children and young people experienced a heightened sense of difference because school practices were not adapted. For example, Luke's mother Nikki discussed a situation in which he was reprimanded in front of his peers for being absent from school on the previous day due to his CF. This finding is consistent with research by Asprey and Nash (2006b) who found that children with CF often experienced unexpected incidents at school that drew attention to them and their medical condition. The findings suggest, somewhat paradoxically, that children and young people with CF may need to be treated differently to other students in certain situations in order to avoid them feeling a sense of difference at school.

7.2.2 Keeping up with school work

The findings clearly demonstrated that a number of CF related factors were experienced by children and young people with CF that could make keeping up with school work a challenge. However, the questionnaire results seemed to indicate

that not all children and young people undergo difficulties with keeping up at school (see section 4.5.1). Participant perspectives within the interviews suggested that falling behind at school could be circumvented by more academically able students with CF (see section 5.9.2). Nevertheless, potential sources of difficulty with keeping up at school appeared to affect many of the children and young people interviewed for the study. The literature on the education of children with medical conditions has tended to cite school absence and illness as key reasons for the difficulties associated with keeping up at school (Bolton, 1997; Lightfoot et al., 1998; Closs, 2000). While the study findings would corroborate this view, potential difficulties with keeping up with school work were also associated other additional factors, suggesting that such difficulties may be specific to individuals with the condition.

Before these other factors are discussed, it is necessary to consider how children and young people with CF experience school absence. Previous research has not yet considered the specific school attendance rates of individuals with CF and the possible implications for keeping up with school work. Yet, some studies have surmised that the attendance rates of children with CF may be poor (Bailey and Barton, 1999; Closs, 2000; Puckey et al., 2006). While the efforts made to prioritise education and ensure regular school attendance were evident in the perspectives of the study participants, the questionnaire results revealed that nearly a third of respondents had been absent from school for 16 days or more in the last 12 months (see section 4.7). However, it seemed that the children and young people with CF involved in the study experienced multiple short and sporadic periods of absence as opposed to being off school for extended durations (see section 4.7 and section 5.9.1). This finding is significant, because the more lengthy periods of absence associated with different medical conditions may be handled differently to the sporadic absences experienced by individuals with CF, by schools and LAs. Children with one-off long periods of absence may be more likely to receive alternative education provision in line with DfE (2013) guidance, because the cumulative effects of this absence is more obvious. The issue of alternative education provision is discussed further in section 7.4.4.

There are other CF specific factors that may impact on a child's ability to keep up with school work. Asprey and Nash (2000a) have noted that for individuals with CF school absence is not always related to illness, as was the case in this study. Certainly, the children and young people involved were required to attend frequent hospital appointments that necessitated time off school for parts of the school day, or even a whole day, depending on the distance travelled to the regional CF centre

(see section 5.9.1). As will be discussed later, it also seems that for a small minority of children, certain complex CF treatments may also impede their school attendance (see section 7.3.1). This demonstrates that children and young people may miss several days of schooling in any school year, irrespective of any periods of illness or the severity of their condition. The participants also indicated that even when children and young people attend school, the symptoms of CF could potentially cause them to miss out on further learning in class, due to tiredness and coughing for example (see section 5.9.3).

It is possible that the huge treatment regime that children and young people with CF undergo reduces the time available for home based education activities, which may also lead to difficulties with keeping up at school. During the interviews, the issue of completing homework was discussed by several participants, particularly in a context of the difficulties with fitting this in alongside the CF treatment routine after the school day (see section 5.6.2, section 5.9.2 and section 5.10.2). Given that the majority of daily CF maintenance treatments take place away from school, it is possible that teachers may be unfamiliar with the extent of the treatments that individuals with CF must complete, or the time that must be devoted to managing CF on a daily basis. Consequently, teaching staff may not make allowances for incomplete homework. Indeed, this issue was reflected in research involving children with CF by Asprey and Nash (2006a). They found that teachers were reportedly unaware of the repercussions of treatment routines upon children's school work and further, that difficulties with completing homework were also compounded by a return to school following a period of absence (Asprey and Nash, 2006a).

In summary, it would seem that children and young people with CF are educationally disadvantaged because they are at risk of experiencing difficulties with keeping up at school, not only due to illness related school absence, but also for reasons that extend beyond this. The need for children and young people to attend hospital appointments, the complex treatments they undergo, along with the symptoms of CF culminate in recurrent, restricted opportunities for learning, and uneven learning profiles that may lead to them falling behind at school. The situation may also be compounded by an apparent absence of additional help and support to allow children to catch up on any school work they may miss and a lack of educational continuity when they are unable to attend school (see section 7.4.4).

7.2.3 Balancing health and education

The research has highlighted the commitment made by parents, children and health professionals to minimise any potential disruption to school life arising from CF treatment regimes. Participants reported the efforts made to organise treatments to fit around school in order to avoid the need for medications to be administered within the school setting (see section 5.6.1 and section 5.6.2). A factor that appeared influential when organising treatments in this way was the belief that it would enable children and young people with CF to take part in school life in the same way as their non-CF peers. While there were examples of resourcefulness in balancing CF treatment demands alongside school, fitting both health and education obligations into the day was sometimes a challenge for children and their parents. Indeed, treatments and education are not the only dimensions involved in the lives of children and young people with CF. The experiences of the participants demonstrated that as a consequence of CF treatment demands, disruptions to school life were sometimes unavoidable. This was particularly apparent when new or additional treatments were introduced into a child's routine.

Previous research has not addressed such challenges and has concentrated on issues relating to the administration of medication during school hours (Closs and Burnett, 1995; Bolton, 1997; Mukherjee et al., 2000; Farrell and Harris, 2003). A finding of interest was that it seemed as though the potential disruptive effects of treatments led parents and children to circumvent or negotiate alternative treatment options as they wanted to protect and prioritise school time. During the interviews, Luke's mother Nikki explained that it was not feasible for Luke to complete a nebulised treatment before school as recommended by his CF team, because it would have made him late. Similarly, Joe's mother Louise negotiated a less time consuming treatment option when his CF team suggested he needed a course of IVs when joining his new secondary school, which may have prevented him forming a new friendship group. In these two instances, a choice needed to be made between the child either having the CF treatment or attending school in the usual way, with both parents opting to prioritise their child's schooling.

However, it seemed it was not always possible to prioritise school over and above the administration of CF treatments, particularly when the child was ill, in which case the treatments took precedence. Nevertheless, the possible interruptions to school life arising from CF treatments have not been considered in wider clinical debates concerning children and young people's treatment compliance and adherence (Abbott et al., 1994; Modi et al., 2006; Modi and Quittner, 2006). The

reported challenges with balancing the demands of CF treatment regimes alongside school activities therefore broadens understanding in this area. The findings indicate there is a need for further research to better understand the implications and effects of managing CF treatments together with children's education.

7.2.4 Negotiating CF alongside adolescence

Adolescence is a time of rapid social, psychological and biological change (Ferguson and Walker, 2012) and young people with CF must negotiate adolescence together with the experiences of living with a chronic medical condition. The research findings suggested that young people with CF must contend with many additional issues and challenges throughout adolescence. The interview participants pointed out that during adolescence individuals with CF begin to start making sense of their condition, which has a number of repercussions for their schooling. Parents explained that certain CF procedures or uncertainty about the future may increase their children's anxiety, which has the potential to pass over into school time and affect their educational experiences (see section 5.11.1). The CF related physical changes that could affect children and young people's perceptions of body image were also discussed, for example through steroid treatment or being smaller in stature (see section 5.11.4). As Eiser (2000) has suggested, these changes can be a constant reminder of a health problem which may be highlighted at school due to their visibility.

Future uncertainty may also be a cause for concern in regard to career planning as young people with CF become closer to school leaving age. Young people and their parents discussed the subject of career aspirations, and a range of career and educational possibilities were mentioned within the questionnaire. Rachel's mother Linda pointed out there is a distinct lack of support in the area of career planning (see section 5.11.3), which corroborates the view of the CF Trust (2007) and Demars et al (2011). Indeed, one questionnaire respondent felt his CF to be barrier to certain job opportunities. However, the questionnaire results indicated that of the respondents that had needed careers advice at school, the majority of respondents had received this, although there were mixed responses in relation to how happy they were with the advice given (see section 4.4.2 and section 4.4.3).

The CF nurse specialists stated that adolescence is a time that young people are educated about their condition from their health team, and are encouraged to become more independent with looking after themselves (see section 5.11.1). However, as will be discussed later (see section 7.3.1.3), the CF team's aim of fostering independence may be hampered by apparent variations in school policy

relating to children and young people's control of their medications while in the school setting. This issue suggests a need for schools to understand the importance of encouraging 'self-care' in the CF context (Puckey et al., 2006). Certainly, other research has demonstrated that independence needs to be encouraged from an early age so that young people have autonomy when they move to adult CF services (Lloyd et al., 2012; Gladwell et al., 2015; Massey-Chase et al., 2015).

The importance of friendships to children and young people with CF were recounted in the perspectives of the research participants (see section 5.11.2). A number of studies have claimed that children with medical needs may experience disconnected peer relationships at school (Bolton, 1997; Lightfoot et al., 1999; Closs, 2000; Yates et al., 2010). While no specific peer relationship difficulties, such as bullying, were reported by the children and young people with CF in the study, many participants felt that CF could restrict opportunities to see their friends or to maintain friendships (see section 5.11.2). Closs (2000) has also recognised the restrictiveness of children's medical conditions upon friendships. She argues that the time available to form friendships, and to establish the kind of confiding, more intimate friendships, may be limited for children who need to follow medical treatment regimes (Closs, 2000). Similar concerns were evident in the perspectives of some of the parent participants. For example, one parent talked about persuading her son to remain at school over lunchtime even though he had a CF clinic appointment in the afternoon, so that he would see his friends during this time. There were other instances of parents worrying about their child missing out while other children are forming and consolidating friendships, which would fit with the findings reported by Bolton (1997).

The issues discussed in relation to adolescence clearly do not take place in isolation of young people's educational experiences. Therefore understanding of these issues in a context of children's schooling is important in terms of finding ways to work with and support the strategies used by young people as they attempt to negotiate adolescence alongside living with a chronic illness (Ferguson and Walker, 2012).

7.3   Distinctive health needs within the school setting

Those involved in the research described the distinctive health needs of children and young people with CF in education, and it was clear that maintaining their health while at school was of high importance to those who took part. When

participants explicitly identified any additional help that children and young people had needed or received at school, this was mainly orientated towards their medically related needs, such as using the toilet (see section 5.7.2), the CF diet (see section 4.3.1 and section 5.7.1), support with medication (see section 4.3.4.1 and section 5.7.3), and cross-infection prevention (see section 4.3.9.1 and section 5.7.4). That is not to say that the health needs of children and young people were always recognised and met at school, as participants discussed instances where this was not the case. While other studies have discussed the potential health needs of children with CF in the school setting (Lightfoot et al., 1998; Bailey and Barton, 1999; Asprey and Nash, 2006b; Puckey et al., 2006), there is a dearth of research that considers children and young people's experiences of such needs at school. The research therefore extends understanding of the specific health related challenges and issues encountered by individuals with CF in the school context.

7.3.1.1   Using the toilet

The need to use the toilet urgently at school appeared to be problematic health need. In contrast to the Asprey and Nash (2006b) study, most children and young people reported they were allowed to go to the toilet when they needed to, suggesting that their schools did recognise this area of need. However, the interview findings demonstrated that despite offers of support, such as the provision of a toilet pass and access to separate toilet facilities, some individuals with CF choose to forgo these provisions, due to embarrassment or concerns about revealing their condition to others (see section 5.7.2). This may explain why a small proportion of questionnaire respondents rated 'going to the toilet' as a school activity with higher levels of difficulty for them at school (see section 4.4.1). For example, both Luke and Bob felt that the support offered to them drew too much attention to their digestive problems. Consequently, they chose not to use the toilet at all in the school setting, as was the case for some of the participants in the Asprey and Nash (2006b) study.

Luke and Bob's experiences indicate that a young person's need for normality at school may surpass any health need they may have, leading to them to relinquish the adaptations and provisions made available to them. This fits with Ferguson and Walker's (2012) view that a young person's desire for normality can at times inhibit the effectiveness of school support frameworks and intentions, as the young people actively work to become less visible. The research further suggests that a young person's need for normality may not only hinder the supportive intentions of the school, but may also have repercussions for children's health in the school setting.

In Luke and Bob's case, waiting to use the toilet until they arrived home may have caused them discomfort and pain, with implications for their digestive health. A key challenge therefore lies in how schools can provide support to individuals with CF that is least likely to draw attention to their condition. The findings suggest that for more visible health needs, there may be no obvious resolution to this challenge. Nevertheless, the research points to a need for schools to be sensitive to children and young people's need for normality in the school setting, alongside the other health and education needs they may have. Therefore, one possible solution to the need to use the toilet might be to allow all children within a school to go when they need to.

7.3.1.2   The CF Diet

Access to the CF diet at school, which involves the consumption of high fat, high calorie foods, appeared to be of concern to the children and young people, and parents involved in the research. For example, they stated that gaining access to the CF diet could be problematic where high calorie foods were not available or not allowed in the school setting. Others indicated that school systems were not set up to allow children and young people to consume enough of the foods needed throughout the school day (see section 4.3.9.1 and section 5.7.1). The findings mirror the experiences of the Royal Brompton Hospital reported by Puckey et al (2006), that parents often have anxieties around their children eating enough at school, and the findings of Asprey and Nash (2006b) demonstrating that the CF diet is likely to be counter to many school's healthy eating policies.

Puckey et al (2006) have surmised that students with CF may be unfairly stigmatised for eating what is perceived to be an unhealthy diet at school. The perspectives of some of the study participants would appear to confirm this viewpoint. For example, Joe and his mother Louise explained that he was challenged by a teacher about his high calorie lunch and was told it was inappropriate (see section 5.7.1). The suggestion by Asprey and Nash (2006b) that there is a general lack of awareness of the need for individuals with CF to eat enough and at regular intervals throughout the school day, paints a similar picture to the data within this study. However, as Puckey et al (2006) have argued, the political pressure upon schools to encourage healthy eating appears to compound the lack of awareness of this hidden health need. Subsequently, it is possible that reasonable adjustments to relevant school policy in line with the DDA (2005) and the Equality Act (2010) may not be made, meaning that children and young people with CF may experience challenges with consuming a typical CF diet in the school

setting. This raises issues around the identification of CF as a disability, which will be discussed in further detail later (see section 7.5.1).

7.3.1.3 CF treatments

The research revealed mixed results relating to the management of CF treatments in the school setting. The interview findings suggested that for the majority of children and young people with CF, most treatments can take place away from school (see section 5.6.1), consistent with the position of Puckey et al (2006). However, a small number of questionnaire respondents indicated that they needed more complex treatments at school, such as IVs, nebulisers and physiotherapy (see section 4.3.7). It was not clear why there were conflicting results in relation to this issue, however, possible explanations were considered earlier in Chapter 6 (see section 6.4.5). Previous literature has not yet considered the management of more complex CF treatments, such as the administration of IVs, in the school setting, and the study findings reveal new information in relation to this issue. While many interview participants stated that the majority of CF treatments were not needed throughout the school day, two individuals with CF involved in the study; Rachel and Joe, did in fact require IV antibiotic doses during school hours, due to the nature of the course prescribed (three daily doses, six to eight hours apart) (see section 5.6.1).

In the case of Rachel and Joe, school responses to this health need were quite different. No health provision was available at Joe's school, while the other school arranged nursing support with Rachel's lunchtime IV doses. The nursing support enabled Rachel to continue attending school throughout her course of IVs, while Joe remained absent throughout this period. However, it must be noted that Rachel attended a fee-paying private school, which suggests that financial resources may play a part in the support available to meet CF related health needs in the school setting. In the case of Joe, there was no mention of the provision of any home education throughout his IV treatment. While perhaps an unusual scenario, which may only apply to a small proportion of individuals with CF, the possibility therefore remains that some children and young people could be inadvertently excluded from educational activities when having home-based IV therapy requiring three or more doses per day.

It is possible that some CF health needs may be perceived to be too complex for mainstream schools to manage, preventing children and young people with CF from attending school when undergoing such treatments, even when they feel well enough to do so. This may be especially true where there is a lack of school access

to nursing support or where CF treatments are needed infrequently or at short notice, making the provision of appropriate support difficult to organise in a timely manner. Due to the complexity of certain CF treatments, it is also conceivable that parents and individuals with CF would find it preferable to remain absent from school in order to suitably manage such treatments at home, forgoing education throughout this period. This approach would fit with the 'balancing act' described by Bolton (1997), in which children's health and education needs may shift in priority at different times. However, it would appear that there is a lack of educational provision throughout such periods, and managing treatments in this way would require a parent to abstain from working. Mukherjee et al (2000) raised similar concerns as parents in the study commented they were only able to carry out medical tasks during school hours because they did not work, and wondered how other parents coped who were employed. Certainly, this approach would seem contrary to DfE (2013) guidance.

The findings in relation to the administration of more regular treatments at school, such as Creon for example, suggested that the majority of children and young people were in control of their own medication (see section 5.7.3), in line with the advice given in current government policy (DfE, 2015). However, a small number of individuals who completed the questionnaire indicated they were unhappy with the arrangements in place for them to have their treatments at school, with one respondent suggesting that they had to ask a member of staff to give them their Creon (see section 4.3.8 and section 4.3.9.1). The study findings are therefore consistent with the experiences of Puckey et al (2006), in that schools may vary widely in the level of self-medication which they allow a child to do. Other research has reported that where Creon is kept away from the child, this can cause them distress as it could make them late for lunch, prevent them from eating, or getting enough to eat (Asprey and Nash, 2006b). This demonstrates the negative implications of moderating children and young people's independence with their treatments in the school setting.

7.3.1.4 Cross-infection

The risk of cross-infection in children's education and the subsequent need to avoid this risk is an issue that is unique to CF. Given that CF is a relatively rare condition, the possibility of two children with CF attending the same school is low. There is a dearth of research that addresses the implications of the risk of cross-infection upon the education of children and young people with CF. Respondents to the questionnaire and the interview participants suggested that schools were able to

implement specific measures to reduce cross-infection risks (see section 4.3.9.1 and section 5.7.4). Helpful practices reported by the participants included; giving the students with CF a photograph of one another, so both could recognise the other student and move away; ensuring sufficient time had passed between each student with CF using the same classroom; and rewarding students for finding a teacher when a possible cross-infection risk presented itself. That such practices were implemented would appear to contrast with findings by Asprey and Nash (2006b) showing that schools may not appreciate the consequences of cross-infection risks in the school environment.

Nevertheless, it seemed as though some of the children and young people involved in the study were not always happy with the measures put in place by their schools, as they felt these excluded them from certain school activities. For example, one questionnaire respondent claimed he was never allowed to take part in the whole school assembly while another student with CF always was. Another respondent felt excluded from sitting with his friends at lunchtime if another boy with CF was close by. These experiences demonstrate the importance of consulting with children and young people when planning the arrangements to reduce cross-infection risks at school, to ensure fairness and equality of access to school activities for the individuals with CF concerned.

Earlier in Chapter 2, I suggested that the issue of cross-infection may have repercussions for the education provided to children who are admitted to hospital, since previous research has shown that children with CF are not usually permitted to attend the hospital school (MacKay, 2011). The findings suggested that cross-infection risks not only prohibited children's use of the hospital school classroom, but also inhibited children's access to fundamental educational resources. Overcoming the barriers to accessing the hospital school arising from the risk of cross-infection, were attempted through the provision of one-to-one teaching in children's hospital rooms on the CF ward. While children had access to an internet enabled computer in their rooms, the hospital school HLTA reported that appropriate word processing software had not been installed on them (see section 5.10.1). This suggests that children and young people with CF may not be able to complete certain aspects of their school work when they are admitted to hospital, and contributes to additional challenges around keeping up or catching up with school work.

7.4 Supporting the education of children and young people with CF

This section discusses some of the factors identified within the analysis of the study data that participants perceived to be helpful and supportive to children and young people's educational experiences. It considers the extent that these areas support were taking place for the individuals with CF involved in the research.

7.4.1 Informing schools about CF

When children, young people and their parents discussed the subject of informing schools about CF during in the interviews, many recounted how helpful it was to have the involvement of the CF nurse specialists in any meetings with the school. School based participants also appreciated the support of the CF team when being informed about CF. The findings suggested that participants were happy with the level of health service involvement in liaising with the schools of individuals with CF. This would appear contrary to other research finding that schools often experience difficulties with engaging health care providers in planning the support needed for children with medical conditions (Bolton, 1997; Lightfoot et al., 1998; Hopkins et al., 2014). One possible explanation for this might be that this body of research focused on the education of children with a number of different medical conditions, with varying health providers. Yet, the CF nurse specialists involved in this study stated that working with children's schools was directly built into their role.

The interview participants discussed the information about CF that was provided to children's schools and it seemed as though this was mainly focused on CF symptoms and treatments and any resulting medically orientated needs (see section 5.8.1). In other words, the information was based on there being a unidirectional relationship between CF and education, with concerns that were focused upon what children's schooling might mean for their health. In addition, two participants felt that the school nurse should take the lead role in coordinating support for the child with CF at school, again suggesting that potential health implications took priority (see section 5.8.3). There appeared to be less consideration of a possible bidirectional or interactional relationship between CF and education, such as what having CF might mean for children's education or the possible educational implications that could arise. Certainly, some of the literature specifically relating to CF and education emphasises the biological influences on children and young people's educational experiences rather than the possible environmental influences that occur. This medical emphasis is well exemplified in

the article by Puckey et al (2006), who only briefly discuss the issue of falling behind due to school absence as one educationally orientated impact of CF on children's schooling, yet the authors predominantly refer to children's education in the context of specific health concerns (see section 2.6). In practice, the situation may mirror that of research into CF more generally, which is dominated by clinical understandings of the condition.

It is possible that individuals with CF are not seen as being at any overt risk of educational difficulty, beyond that of the effects of school absence, leading to a medical, rather than an educational focus within the information given to schools about CF. Indeed, this would confirm the positions of Bailey and Barton (1999) and Asprey and Nash (2006) when they state that children and young people with CF are less likely to be seen as having additional educational needs than students with more visible disabilities. However, as was discussed earlier (see section 7.2.2), students with CF do appear to be educationally disadvantaged, as the study has shown they may experience recurrent, restricted opportunities for learning, and uneven learning profiles that could lead to difficulties with keeping up at school. Yet, it would seem there is a failure to be proactive in considering the *educational* needs of students with CF (Bailey and Barton, 1999).

Identifying appropriate educational support for children and young people with CF may be a challenge for schools, particularly when there are no overt difficulties in learning associated with the condition. Similar challenges were reported in the Mukherjee et al (2000) research, who found that teachers were concerned they could not get access to advice and information about the specific educational implications of a child's condition. Ultimately, recognising and meeting the educational needs of children and young people with CF not only requires awareness and understanding of how CF affects them, but also knowledge of the educational requirements upon them. In this respect, inter-agency advice and information is necessary, although the findings suggest this must move beyond a unidirectional health needs focused approach to consider the bidirectional interactions that exist between CF and education.

7.4.2 Awareness and understanding

The questionnaire results and interview findings showed that teacher awareness and understanding of CF was of great importance to children and young people with the condition. Yet, it seemed that for many participants, the level of awareness and understanding of CF at school was sometimes low (see section 4.3.3, section 4.3.9.1 and section 5.8.2) which would support the findings of Asprey and Nash

(2006a). In some cases, a lack of understanding of CF seemed to have been detrimental to the health and education of some of the children and young people involved. For example, Luke's mother Nikki reported that he was not allowed to attend school temporarily when having some home IV treatment due to a misunderstanding on the part of the school about what the treatment involved. Taylor et al (2008) reported similar problems in that teachers often imposed unnecessary restrictions upon children because of safety concerns as they did not know enough about the medical condition. Several other difficulties relating to there being a low awareness of CF at school were implicit in the perspectives of the study participants such as; a young person being reprimanded for school absence in front of his peers, a lack of adaptations to school policies, and teachers drawing attention to CF symptoms such as coughing for example. Certainly, several other studies point to a need for teachers to be aware of and understand the medical conditions of their students and the impact of these on their school life, in order to avoid such difficulties occurring (Bolton, 1997; Lightfoot et al., 1999; Closs, 2000; Asprey and Nash, 2006a; Taylor et al., 2008).

The research findings suggest that there may be a number of contributory factors as to why children and young people with CF might experience low awareness and understanding of their condition at school. In the last section, I posited that the information given to schools about CF is predominantly medically focused. However, because the majority of CF treatments usually take place away from the school setting, and due to the relative invisibility of the condition, schools may be led to believe that the needs of children and young people with CF are inherently medical and do not need to be addressed in school. Indeed, both Bailey and Barton (1999) and Asprey and Nash (2006a) have suggested that a medicalised view of CF could encourage a distanced attitude in teachers who may feel that the condition is being handled by other professionals and is unrelated to education. In addition, a child's need for normality at school may serve to obscure any particular challenges they experience from their teachers, leading to further problems with awareness and understanding. Bailey and Barton's (1999, p81) view that students with invisible conditions may 'languish largely unnoticed in the education system' certainly parallels with the experiences of some of the children and young people involved in this study.

The findings demonstrate that issues of awareness and understanding must also be considered in a context of child-adult power relations. Children are in a multitude of ways subject to sets of power relations at home and at school (James et al., 1998). Conceptualisations of childhood as a time of vulnerability and dependency on

adults may mean that children and young people with CF place a great deal of trust in their teachers to understand their condition and the resulting difficulties they may incur. Younger children more so may be positioned as 'powerless dependents' (James et al., 1998). This may explain why primary school respondents to the questionnaire appeared more likely to feel that their teachers understood CF, although primary schools commonly have a relatively smaller student population, which may facilitate the awareness and understanding of a child's medical condition.

The positioning of children and young people with CF as vulnerable or dependent also raises issues about adult views of children's competency and capability. The research has demonstrated that the children and young people who took part were experts in their own lives and significantly, their experiences of living with CF. However, it has been argued that adults have a 'framework' within which children are seen and treated as not capable, and in turn this influences how children may see themselves (Jones, 2009). Indeed, due to the existence of such a framework it seemed as though some participants with CF felt unable to contest teacher decisions, arising from a low awareness of their condition, that were unhelpful to their health. For example, in the case of Violet, when she was asked to remove her jumper at school, she did so despite knowing the risk of damaging the IV access line placed in the back of her hand (see section 5.8.2). Parent participants were keen for teachers to understand CF due to concerns that their children may not be able to 'stand up' to any unsuitable requests or decisions. Similar challenges in relation to adult views of children with CF as 'incapable' were reported in the Asprey and Nash (2006b) study. One parent participant said a teacher had telephoned her because she did not believe her son when he said he was in pain as a result of being required to sit on the floor for long periods. As Beresford (1997) argues, children and young people appear to be very aware of adults' reluctance to place any credence on their views and opinions.

The research has shown that a good level of teacher awareness and understanding of CF in the school context is not only of great support to children and young people with CF, but is also vital in order to reduce the potential for school practices that may be detrimental to their health and education. From a legal perspective, awareness and understanding of CF is needed to ensure that schools identify children's needs, and are able to meet their obligations under the DDA (2005), the Equality Act (2010) and the Children and Families Act (2014). The consequences of low awareness and understanding of CF may be far-reaching in relation to the likelihood of individuals with CF gaining access to the support they require

(Lightfoot et al., 1999), and in terms of making the adjustments needed to practice and policy that will reduce any potential disadvantage in the school setting.

7.4.3   One person taking a lead

Several research studies point out the importance of identifying a key person within the school setting who can liaise and communicate with children, parents and other stakeholders in relation to a child's medical condition (Bolton, 1997; Lightfoot et al., 1998; Asprey and Nash, 2006a; Dixon, 2012). A similar theme was reflected in the findings of this study, with both children and young people, and their parents discussing the usefulness of having one person at school who could take the lead (see section 5.8.3). Despite this finding, government guidance on supporting pupils with medical conditions at school states that this 'is not the sole responsibility of one person' (DfE, 2015, p.12). There is no requirement upon schools to identify a specific member of staff who should take responsibility for ensuring that children and young people with medical conditions (or disabilities) are adequately supported and are able to achieve their educational potential. Yet, for other students who experience vulnerable educational circumstances, the importance of a lead role is well recognised, such as the designated teacher for looked after children (DfE, 2014), or the SENCo for those with SEN (DfE and DoH, 2015), for example.

The absence of a requirement for a key person at school for students with medical conditions would again suggest that as a group they are not considered to experience educational difficulty. Nevertheless, the perspectives of the participants demonstrated why having someone take a lead role at school was important to them. Some school staff, such as form tutors, heads of year and a school nurse in one case, took it upon themselves to be an advocate for the children and young people involved in the study, which is in contrast to other research that identifies the school SENCo as a suitable lead role (Bolton, 1997; Lightfoot et al., 1998; Asprey and Nash, 2006a). It is certainly the case that some individuals with CF experience additional issues and challenges as they negotiate life with a chronic medical condition alongside adolescence which demonstrates a need for emotional or pastoral support from a key person in the school setting, in addition to educational or learning support. However, it would appear that without the good will of certain school staff, children and young people with CF may fall under the radar of the school support systems that could be of benefit to their education.

7.4.4 Ensuring education continuity

Earlier in section 7.2.2, I discussed some of the factors that can make keeping up with school work a challenge for children and young people with CF. This section considers the extent that children and young people were able to continue educational activities when they were unable to attend school. The study data clearly demonstrated that being able to continue with school work was crucial to enable individuals with CF to keep up with their peers or prevent them from falling behind. However, the extent that children and young people were able to continue their school work during periods of absence varied amongst those involved in the research.

The hospital HLTA reported that despite the proactive measures taken to anticipate children's admissions to the CF ward, many schools would not send through the relevant schemes of work needed for children to continue their subject work (see section 5.10.1). This often meant that the focus of hospital teaching was not synonymous with the precise stage of learning in the curriculum areas studied by the child at school. A similar picture was reported in the hospital education case studies presented by Landy and Colburn (1995), which identified specific problems in relation to curriculum planning and delivery, arising from a lack of information exchanges between schools and hospitals. Some of the participants felt that schools did not always understand the need for some children to be admitted to hospital for IV treatment on a regular basis, and not as a single one-off event. This is perhaps not so surprising since the findings also illustrated that the visible presentation of a child or young person with CF may not correspond to teacher perceptions of illness, or the complexity of the condition. As Pinder (1996, p138) puts it; 'there are difficulties involved in despatching impairment and disability into neat, watertight compartments'. In this sense, a child's outwardly 'healthy' appearance may fool teachers into thinking that they are medically well even when they are in need of aggressive treatments to prevent damage to the lungs. Consequently, the potential cumulative effect of regular hospital admissions or school absences upon children and young people's education may not be given the pre-emptive action and attention it deserves. Indeed, Yates et al (2010) found that the long-term needs and interests of the young people with ongoing medical conditions involved in the study were often not considered by their schools.

Arrangements for continuing and catching up on school work tended to lie with the parents and children themselves who would ask their friends what work they had missed. It appeared from the interview findings that many schools did not maintain

a high profile during children's hospital admissions. This would be contrary to Harris and Farrell's (2004, p.15) concept of 'mainstream ownership', which they argue is needed to deliver services and provision in line with government policy on the education of children with medical conditions. The picture that emerged was similar to that of the findings of other research in which the students themselves accepted responsibility for coping with their absence from school (Bolton, 1997; Bailey and Barton, 1999; Asprey and Nash, 2006a; Dixon, 2012). The importance of providing children and young people with their current school work throughout school absences did not seem to be recognised by the teachers of children and young people with CF in this study.

In the case of children and young people who had not been in hospital, no participant suggested that they had been provided with alternative education while absent from school. By this I mean that no formal education provision appeared to have been given to children who were ill but not in hospital, such as those on home IV treatment. This is despite DfE (2013) guidance stating that 'alternative education' must be provided for children who experience consecutive *or* cumulative periods of school absence of 15 days or more. Both Closs (2006) and Lightfoot et al (1998) have reported similar problems in relation to ambiguity around children's entitlement to home tuition. This research suggests that the practical application of the guidance on providing education to those who cannot attend school for health reasons (DfE, 2013) is not straightforward in the CF context. One possible explanation might be that predicting the illnesses and potential school absences of children and young people with CF is particularly challenging due to the variability of the condition. Consequently, there may be uncertainty as to the pattern, and possible extent of a child's absence in any school year, leading to ambiguity around the entitlement to alternative education provision when children are unable to attend school. A lack of formal education provision throughout school absences has obvious effects upon children being able to keep up with their school work. As Closs (2000) has argued, sometimes even legislation and guidance is insufficient to establish adequate and efficient education for children who experience school absence due to their medical needs.

In much the same way as Bailey and Barton's (1999) research has found, there seemed to be few efforts made by teachers to include the children and young people involved in this study in their school work when they were unable to attend school. There were acute consequences of this for the interviewee Luke, who due to falling too far behind in a school subject that he enjoyed, was told he would not be allowed to continue studying it at GCSE level (see section 5.9.2). In this case,

the teacher did not appear to take account of the disadvantage experienced by Luke, through his CF and a lack of support throughout his school absences, and this served to emphasise his difference from his peers. The situation resonates with that of another young person's experience reported in the Yates (2010) research. The scarcity of school responses to prevent children and young people from falling behind, combined with a lack of educational continuity and mainstream ownership throughout school absences, therefore supports the view that students with CF may be subjected to 'an involuntary form of exclusion by neglect' (Bailey and Barton, 1999, p.95).

7.4.5   Extensions and extra time

A simple yet effective supportive school practice put forward by some of the interview participants was the provision of extensions to school work deadlines, and extra time for examinations. However, there were examples of children and young people who seemed to question their entitlement to such support (e.g. Bob, see section 5.10.1), which may connect with their need for 'normality' at school. This may be indicative of the resilience of children and young people with CF in that they are used to 'getting on with life' (Ferguson and Walker, 2012) and as such do not know a life without CF (see section 5.5.2). Therefore, some children and young people may not grasp the possible extent of learning time lost to CF care activities, through their treatments, hospital appointments and periods of illness for example. However, as Yates et al (2010) point out, disadvantage in school examinations is not simply about the amount of learning time missed, but also relates to the likelihood of there being gaps in subject knowledge. Offers of extra time in examinations and extensions to the deadlines involved with class work therefore demonstrate how schools can acknowledge and respond to the disadvantage experienced by children and young people with CF in their education.

7.4.6   Physical education, science and school trips

The findings demonstrated that there are school subjects and activities that are likely to be of significance to children and young people with CF, which suggests these should be taken into account in terms of their support. PE in particular was cited in the literature as being an area of the curriculum that students with CF may find challenging (Lightfoot et al., 1998; Bailey and Barton, 1999; Asprey and Nash, 2006b). Since CF causes repeated chest infections and breathing difficulties, it would not be unusual for those with limited knowledge of the condition to expect that children and young people should refrain from intensive physical activity. However, this is not the case and the findings have shown it is important that PE

teachers are aware of the benefits of exercise to individuals with CF. Indeed, the children and young people interviewed for the research all revealed that their hobbies and interests all related to sporting activities, and some of the participants were particularly talented in this area. Nevertheless, the participants suggested that there may be certain CF related barriers to taking part in PE, such as when children and young people have IV access in place for courses of treatment, or due to CF related body image concerns arising from being smaller in stature for example. The findings suggest it is important that teachers consider these barriers to ensure children and young people are included in PE activities.

School science lessons that use CF to exemplify the inheritance patterns of genetic conditions have been raised elsewhere as potentially problematic for students with CF and the science teachers involved (Asprey and Nash, 2006b). The research would confirm that such lessons may be an uncomfortable or distressing experience for both students with CF and their science teachers. One of the CF nurses specialists felt that the information given about CF during science lessons is often outdated. One young person involved in the study also explained that his science lesson on CF was noticeably shortened. While the young person was unsure of the reason for this, it is possible that his teacher experienced uncertainty about relaying any outdated information on CF to the students (see section 5.10.2). The research therefore illustrates a vital need for science teachers to be adequately informed about CF well in advance of any lesson planning. Further, there may be an opportunity to support students with CF to be involved in the delivery of teaching about genetic inheritance patterns, although this must be balanced against a need for children and young people to feel 'normal' at school.

School trips appeared to be another significant school activity for children and young people with CF in that there may be barriers to their participation in them. During the interviews, Joe's mother Louise talked about him feeling unable to participate in a school trip due to concerns about managing his treatments while away from his parents overnight, and the treatments drawing attention to his CF (see section 5.5.1). As explained previously in Chapter 6, this offers a possible explanation as to why 'school trips' was a school activity with the largest number of respondents rating higher levels of difficulty in the questionnaire. That there are treatment related barriers to children's participation in school trips would support the findings of other research on the education of children medical conditions (Bolton, 1997; Lightfoot et al., 1998). Certainly, Asprey and Nash (2006b) found that several CF treatments, along with the consequences of the condition, restricted children's participation in school trips and especially residential ones. The findings in relation

to school trips illustrate that deviations from the typical school day could disrupt the careful balance that is maintained in relation to managing CF treatment regimes alongside children's education. Such disruptions therefore have implications for children's participation in non-typical school activities, and may call for more health focused support during these activities, such as providing help with administering treatments or adapting activities to reduce any barriers to participation.

7.5 Implications of the research for the education of children and young people with CF

7.5.1 Implications for policy and practice

The previous sections have discussed the findings of the research in a context of the needs of children and young people with CF, and the practical strategies that are likely to be of support to them in their education. There is a need for interdisciplinary working between health and education providers to consider both the implications of school upon children and young people's health, *and* the implications of CF upon their education. Yet, the findings suggest that interdisciplinary practice has so far been too focused on the first. Therefore, support has mainly been directed at meeting the health needs of children and young people with CF, as opposed to the other fundamental needs they may have at school (see section 7.2). The analysis of the study data has revealed a number of useful suggestions of where schools and the CF clinical team might direct their efforts to better support the education of those with CF.

Earlier in Chapter 2, I pointed out that several studies discuss the educational needs of children and young people with medical conditions with a particular emphasis on the support available through SEN policy. While there is uncertainty surrounding the application of the SEN framework to students with medical conditions, many authors argue that it is necessary to 'place them on the SEN register' to ensure that they gain access to the support they may need at school (Lightfoot et al., 1998; Thies, 1999; Closs, 2000; Asprey and Nash, 2006a; Jackson, 2012). However, the findings of this study suggest otherwise. No questionnaire or interview participant appeared to consider the needs of children and young people with CF in a context of SEN policy or procedures, except for the hospital school HLTA. It would seem possible, as Ferguson and Walker (2012) found, that an external construct such as SEN did not merge with children and young people's descriptions of their own identities and educational experiences.

I would argue the factors that participants perceived to be helpful and supportive to children and young people's educational experiences do not require them to be deemed to have SEN to access such support. That is not to say that students with CF do not have SEN. The possibility remains that some children and young people may experience 'significantly greater difficulties in learning than the majority of others of the same age' (DfE and DoH, 2015, p.16). However, the supportive and helpful practices suggested by the research participants may be considered as part of the responsibilities of schools and other relevant agencies under the Supporting Pupils at School with Medical Conditions guidance (DfE, 2015), rather than the SEN Code of Practice (DfE and DoH, 2015), or indeed as part of an 'inclusive' school ethos.

While the supporting children with medical conditions duty (Children and Families Act, 2014) was active throughout the interview phase of the research, it appeared from the research findings that application of this duty was limited within the schools of the children and young people who took part, which would corroborate the conclusions made by the HCSA (2016) investigation. For example, a key feature of the guidance (DfE, 2015) is the option to develop an IHP to formally record children's health, educational, social and emotional needs at school. Although the CF nurse specialists seemed to suggest a form of care planning takes place during initial information meetings with schools, no other participant mentioned being involved in the development of an IHP. Further, there appeared to be no formal arrangements in place, which are associated with an IHP, to frequently review the potentially changing needs of children and young people with CF. Parents stated that they communicated new information with their child's school on an ad hoc basis (see section 5.8.1). This supports the view of Closs (2000) that some schools do not respond to the needs of children with medical conditions in any comprehensive or sustained way. However, it must be noted that the supporting children with medical conditions duty (Children and Families Act, 2014) was in its infancy at the time of the research and may not have begun to influence practice at every level.

Closs's (2000) position offers one explanation as to why some authors have argued for the SEN framework to be applied to children with medical conditions, as regular monitoring and review of children's needs would be required through the 'graduated approach' described in the SEN Code of Practice (DfE and DoH, 2015). The complexity and variability of the needs and challenges experienced by the individuals with CF involved in the research, coupled with a low awareness and understanding of the condition, demonstrate that regular formal opportunities to

discuss and identify children's needs with the school are likely to be beneficial. As Yates et al (2010) has argued, educational support for children with medical conditions should take account of their situation as a process over time, and not just as an assessment of needs at one point in time.

Of further significance is that children and young people with CF may be considered to be disabled under disability legislation (DDA, 2004; The Equality Act, 2010) , even if they do not associate themselves with this term. Therefore, the supportive practices raised by the research participants could also be thought of as reasonable adjustment provisions that reduce the difficulties experienced by children with CF, which may arise from any structural barriers within their education. However, a particular challenge facing schools in meeting their duties under disability legislation, is how to develop reliable and manageable approaches for identifying pupils with disabilities (Feiler et al., 2012). The research findings would suggest that children and young people with CF may not always be considered to be disabled by their schools, and consequently they may not be afforded to the same rights as other children with more overt disabilities. This echoes other research claiming that a significant proportion of children with medical needs, but with no SEN, experience difficulties that are unknown to schools and LAs (Porter et al., 2009). In my study the overwhelming picture was that policy and legislation aiming to support the education of children with medical conditions or disabilities, did not appear to be influencing practice for all of the children and young people who took part. Consequently, it seemed that some of the individuals with CF involved in the research had not been picked up by formal school support systems in response to the needs and challenges they had experienced.

A further implication for practice lies in the role of health professionals in supporting the schools attended by students with CF. The findings suggest that inter-agency working requires greater consideration of how CF might impact children's education and opportunities for learning, so that appropriate support can be put in place by the school where necessary. To this end, the information about CF provided to schools by health professionals should extend beyond the health needs of children with the condition to take into account the factors that may create educationally vulnerable circumstances. In other words, the information given should emphasise that children with CF may experience difficulties with keeping up at school due to a number of factors such as: school absence; CF symptoms and treatment side effects; the need to attend frequent hospital appointments; and due to the extensive and considerably demanding treatment regime that restricts opportunities for learning.

7.5.2   Biopsychosocial implications

The insights from different stakeholders across education and health disciplines and the involvement of children and young people, and their parents in the research, has facilitated richer understandings of the multiple interacting factors involved in the education of individuals with CF. Consideration of the research findings in light of the biopsychosocial model reveals both the biological and environmental interacting influences upon children and young people and their educational experiences, some of which are illustrated in Figure 7.1. In much the same way as Close (2000, p.3) has argued, the biopsychosocial model illustrates that children with CF experience a 'constellation of factors' that may place their education at risk. The factors that may present a risk to the education of children and young people with CF not only reside at the biological level, but also at the environmental level.

Figure 7.1 *Biopsychosocial interactions in the educational experiences of children and young people with CF*

A key implication of the biopsychosocial approach for education has been raised by Cooper (2008) in his work on Attention Deficit Hyperactivity Disorder (ADHD), which also has relevance in the CF context. He argues that the more we understand about the biological and psychosocial connections of a condition, the better placed we will be to provide educational environments that avoid exacerbating any difficulties that children experience (Cooper, 2008). In this respect, the model facilitates deeper understanding of the challenges that children and young people with CF may experience, which is vital given that many research participants felt that awareness and understanding of CF amongst school staff was low. Using the example of the need to use the toilet, biopsychosocial understandings of this health need demonstrate there are various biological and structural factors at work that may make this a challenge for some children and young people. At the biological level are the embarrassing CF related digestive symptoms which interact with an environmental influence of support that may highlight difference (such as a toilet pass or separate toilet facilities). At the level of children's educational experiences is the desire for normality. These interacting influences may therefore lead a young person with CF to refuse to use the toilet at school or forgo any support provided. Understanding such difficulties from a biopsychosocial perspective therefore provides greater insights into children's educational experiences.

Understanding the educational experiences of children and young people with CF within the ecological context afforded by the biopsychosocial model also provides useful information in terms of planning the possible responses to any particular challenges they may encounter. For example, the findings demonstrated that some children may experience difficulties with keeping up at school. Such difficulties may be construed as a problem directly related to CF itself, as it may seem that there is less time available for learning or study because the child has a great deal of daily treatments to administer, or that the child has fallen behind due to illness. Therefore, responses may be directed at the biological level, such as adapting the treatment regime or offering additional treatments with the aim of boosting health and encouraging school attendance. However, the findings have shown there are also environmental influences involved with children experiencing difficulties with being able to keep up at school. One such example reported by the participants was that schools did not appear to provide support to allow children to continue their education when absent or to catch up on any work they may have missed. Responses to challenges with keeping up at school at the environmental level might therefore include the provision of school work during school absences and additional teaching time when the child is in attendance. Certainly, there are both

biological and environmental interactions involved in the challenges relating to keeping up at school or falling behind with school work.

Where biological and structural influences interact and cause undesirable educational experiences, Cooper (2013) argues that these influences almost always have implications that must be addressed at the social-environmental level. Yet, this study suggests that responses to the implications of these influences are more often directed at the biological or medical level rather than at the school level, likely due to the belief that CF has not previously been associated with particular difficulties in learning. Subsequently, the findings appeared to show that there is less consideration of any possible environmental or structural barriers in place within the education system. Biopsychosocial understandings of the study findings therefore support the position of Closs (2000, p.4) when she states that:

> *It is actually a lack of focused thought on the part of education providers and a lack of preparedness to ensure quality education, rather than the actual medical conditions that put children's education most at risk.*

Given the dominance of medicalised research into CF, there has been a failure to consider how biology and environment interact to cause challenges in the lives of individuals with the condition. The use of the biopsychosocial model in relation to CF demonstrates that the educational experiences of children and young people with the condition are best understood from a biopsychosocial perspective. This is because the model reveals what initially may have been thought of as a biological problem related to CF, may in fact also be derived from an environmental issue. The biopsychosocial approach unveils the complexity of children's educational experiences which can help to inform developments in the education of children and young people with CF. In other words, the model promotes understanding of the challenges and issues experienced by individuals with CF at school and aids the formulation of appropriate responses to their needs. Indeed, using biopsychosocial insights in the development of educational provision is likely to lead us closer to a genuinely inclusive education system (Cooper, 2008).

7.6   Summary

This chapter has discussed the findings of the research in light of the existing literature on the education of children with medical conditions, with a particular focus on the needs and challenges experienced by children and young people with CF and possible supportive responses. In this respect, the chapter has shown how

the study data might inform developments in the education of children and young people with CF. In the same way as Yates et al (2010) have suggested, I argued for a greater understanding of children's need for normality at school, yet also recognition of the specific vulnerable educational circumstances they may experience. I demonstrated that these vulnerable circumstances arise from both biological and environmental interacting factors. The findings of the study corroborated those of other research that suggests keeping up with school work may present a challenge for individuals with CF. While much of the literature has suggested school absence is a key contributory factor to this challenge (Bailey and Barton, 1999; Closs, 2000; Puckey et al., 2006), this research has shown other specific factors are also involved, such as children's treatment regimes, CF symptoms, and the need to attend frequent hospital appointments. Consequently, children and young people may experience recurrent, restricted opportunities for learning, culminating in difficulties with keeping up at school.

The study revealed novel findings in terms of how CF treatments are balanced alongside school activities, and demonstrated the commitments made by children and parents to protect and prioritise school time where possible. Adolescence appeared to be a particularly significant time period for individuals with CF. As this study and other research has shown, there may be a lack of support for young people's needs and challenges throughout this time such as with career planning, fostering treatment independence and forming and maintaining friendships (Closs, 2000; Puckey et al., 2006; Demars et al., 2011; Ferguson and Walker, 2012). Findings from previous studies in relation to the potential health needs of children and young people with CF were confirmed by this research and extended understanding of their experiences of these needs in the school setting, such as using the toilet, the CF diet, CF treatments, and cross-infection. Barriers to meeting such needs appeared to reside in a low awareness and understanding of CF, support that had a tendency to draw attention to a child's condition, a failure to adjust school policy to incorporate children's needs and an apparent absence of appropriate health based resources in the school setting.

Possible areas of supportive practice were identified in the study findings. I argued for greater consideration of the educational implications of having CF in addition to the medically orientated needs of individuals with CF, when informing schools about the condition. This was considered to be necessary in order to move away from a problem identified in other studies, in that schools may believe that children's needs are predominantly medical and are unrelated to education (Bailey and Barton, 1999; Asprey and Nash, 2006b). Certainly, there needs to be better teacher

awareness and understanding of CF. The study findings suggest this is vital to reduce the potential for school practices that are potentially detrimental to children's health and education. In contrast to the advice given in government guidance, the research illustrated the importance of having one person who could take the lead at school. Parents and children valued this supportive approach which they found to be necessary for effective communication between the school and other key stakeholders. Harris and Farrell's (2004) concept of 'mainstream ownership' appears to be greatly needed by children and young people with CF, as in the same way as other research has identified, children and parents often took it upon themselves to catch up on the school work missed when children were unable to attend.

A further supportive practice demonstrated by the study, and confirmed the findings of other research, was the provision of extensions and extra time of school work or examinations (Yates et al., 2010) which may compensate to a certain extent for the learning time lost to CF care activities. The research also highlighted school subjects that are of significance to individuals with CF and must be taken into account when planning any support for them. In considering how the study data can inform developments in the education of children and young people with CF, the discussion contained within this chapter also discussed the policy implications of the study. In contrast to other research (Lightfoot et al., 1998; Thies, 1999; Closs, 2000; Asprey and Nash, 2006a; Jackson, 2012), this study suggested that individuals with CF should not need to be identified as having SEN in order to receive appropriate support. Application of the duty to support children with medical conditions (Children and Families Act, 2014) or indeed the provisions made within the DDA (2004) and the Equality Act (2010) should afford children and young people with CF the right to access the support they need in education. Finally, the biopsychosocial model facilitated deeper understanding of the interacting issues and challenges that children and young people with CF experience in education, and revealed the need to mainly address these at the environmental or school level.

The next chapter concludes this research and highlights the contributions and further implications of the study. In addition, I discuss the proposed dissemination activities, the study limitations and possible areas of further research, and finally, reflections on my personal research journey.

Chapter 8 Conclusion

8.1 Introduction

The broad aim of this research was to explore issues in education related to children and young people with CF. The aim was broad because there has been a dearth of research exclusively on CF and education and consequently, I set out to enable children and young people to self-identify the issues that are important to them at school. The educational experiences of children and young people with CF were explored and analysed through the use of questionnaires and interviews. The research recognised the heterogeneity of individuals with CF and the sample chosen for the study reflected the different experiences of life with the condition through the varied treatment regimes that children and young people undergo. The ecological and interacting influences in the lives of individuals with CF were also acknowledged and these influences justified the involvement of other stakeholders in the research, such as parents, teachers and health care personnel.

This final chapter begins by summarising the study in a context of the research aims and questions that were addressed throughout the thesis. Next, the chapter demonstrates the original contribution the study makes to understanding the educational experiences of children and young people with CF. The methodological contribution of the study is also highlighted in terms of the novel methods used, the insider research context and in relation to conducting educational research in a clinical setting. Following this, I discuss dissemination of the study findings and other aspects of the research process to relevant audiences. I go on to consider the limitations of the study and possible areas for further research. Finally, the chapter provides a reflection on my personal research journey.

8.2 Summary of the study

While there is a body of literature on the education of children with medical conditions, there has been a dearth of studies that consider issues in education specifically related to children and young people with CF. CF is distinctive from other medical conditions because it is invisible, variable, and a huge regime of time consuming and complex treatments must be completed on a daily basis. A review of the existing literature demonstrated the need for an exploratory approach to the research, because it could not be established if the conclusions made by more general studies on the education of children with medical conditions were applicable to all children and young people with CF, even where such studies

included those with the condition. Consequently, in addition to the broad aim of the study, which was to explore issues in education related to children and young people with CF, four further research aims were identified:

- To explore and analyse the perspectives of children and young people with CF about their educational experiences
- To explore and analyse other key stakeholder understandings of the needs of children and young people with CF in education
- To make recommendations for appropriate educational provision for children and young people with CF

Given the unique study context, a methodologically related aim was also devised:

- To contribute to methodological knowledge by developing an appropriate method for research involving children when the proximity of the researcher and/or other participants is problematic.

The aims of the study were met through addressing the five research questions and sub-questions (see section 1.3) throughout this thesis. Chapter 2, addressed **RQ1**: What is the current research evidence about the links between CF and Education? The chapter demonstrated that children and young people with CF may experience vulnerable educational circumstances, yet the specific vulnerabilities were unclear in the existing research evidence context. Some of the themes arising in the body of research reviewed in Chapter 2 appeared relevant to children and young people with CF, and therefore helped to inform areas of exploration within this study. Chapter 3 presented the study methodology and provided the rationale for a further methodologically orientated research question, as will be discussed later.

The data analysis contained in Chapter 4 together with that of Chapter 5, addressed the following research question and sub-questions:

RQ2. What are the perspectives of children and young people with CF on their educational experiences and needs?

- To what extent do they feel their needs are understood, identified and met in their current educational provision?
- What factors do they perceive to be helpful to their educational experiences?

Chapter 5 also addressed **RQ3**: What are the perspectives of other key stakeholders on the education of children and young people with CF? The analysis

contained in Chapters 4 and 5 revealed that children and young people place great importance on being 'normal' at school and did not want CF to be their immediate defining characteristic. A key finding in the analysis was that there seemed to be low awareness and understanding of CF in the school context and of children and young people's subsequent needs. Yet, there may be differences in the educational experiences of primary and secondary students with CF in regard to the extent that their needs are understood, identified and met at school. Participants reported situations in which low awareness and understanding may have been detrimental to children's health and education. Where extra help or support was provided, this was mainly targeted at children and young people's health related needs. However, children and young people also implicitly discussed their educationally orientated needs and challenges, particularly in relation to keeping up with school work. Indeed, there were a number of specific school subjects and activities that presented a challenge to them. It seemed that there was an absence of formal systems in place to support their needs and challenges. Nevertheless, the participants discussed possible areas of support that might be of help to the education of children and young people with CF.

Chapter 6 addressed the methodologically related research question and sub-questions:

> **RQ4**. What issues and challenges arise in relation to the specific research context; namely:
>
> > i.   A person with CF conducting research about CF?
> >
> > ii.   Involving children in the research?
> >
> > iii.   Conducting the research as a mixed methods study?
>
> - How can these issues and challenges be responded to?

In this chapter I discussed the issue of researcher 'closeness' to the research topic and argued that this brought both advantages and challenges to the study context. I argued that subjective experience or experiential knowledge was of value to the research and not a limitation, although this required a reflexive approach. I also reflected on the involvement of children and young people in the research, and expressed my disappointment at being unable to consult them about the research design due to access difficulties prior to gaining NHS approvals. I recounted the use of online interviews with children, along with interactive interview techniques such as photovoice and the vignette and fantasy wish questions. I argued that these had

mixed results, and a combination of approaches may work best. Finally, in Chapter 6, I considered the use of mixed methods in the research and explained some of the challenges I experienced when attempting to integrate the questionnaire and interview data. I reflected on the confirmatory, explanatory and conflicting research findings.

Chapter 7 discussed the findings of the research in light of the existing literature on the education of children with medical conditions, including those with CF. Particular attention was made to the findings in relation to the needs and challenges experienced by children and young people with CF, and possible supportive responses that are likely to be helpful to them in education in order to address the final research question: **RQ5** How can the study data inform developments in the education of children and young people with CF?

I demonstrated that the vulnerable educational circumstances experienced by individuals with CF arise from both biological and environmental interacting factors within a biopsychosocial framework. However, it was argued that support should more often be directed at the social-environmental level. Finally, the policy implications of the research were discussed and I suggested that children and young people with CF should not need to be deemed to have SEN in order to access the factors that participants perceived to be helpful and supportive to their educational experiences. While the new duty to support children with medical conditions (Children and Families Act, 2014) strengthens the children's rights to access the support they may need at school, it was claimed it may not yet be influencing practice in the context of the education of children and young people with CF.

8.3   Contributions of the study

This study contributes to the wider literature on CF, which typically focuses on clinical understandings of the condition, by considering the perspectives of patients on their lived experiences. Through adopting an ecological, biopsychosocial perspective, the research has increased understanding of the interacting biological and structural influences upon children's education. This has revealed that children and young people's educational experiences are not only influenced by biological or health related factors, as are the dominant concern of the medical literature, but also by environmental and structural factors. The environmental influences involved in the educational experiences of children and young people with CF, as identified

by the study, represent new information that is likely to be helpful to education and health agencies when planning and providing appropriate educational support.

This study findings support several studies claiming that children with medical conditions may experience vulnerable educational circumstances (Lightfoot et al., 1998; Bailey and Barton, 1999; Closs, 2000; Harris and Farrell, 2004; Porter et al., 2008). However, the significance of this study lies in the increased understanding of why and how children and young people with CF specifically experience vulnerable educational circumstances. It is the first study of its kind to identify the particular needs of children with CF in relation to their education, as identified by children and young people themselves. Other research that concerns the education of children with medical conditions has regarded them as a homogeneous group. While this body of research is useful, it fails to account for the unique aspects of CF that make it distinctive from other conditions. The research has demonstrated that the distinctive features of CF may obscure the challenges and issues faced by children and young people with the condition, which might not be the case for children with other more visible and familiar medical conditions.

In much the same way as Bailey and Barton (1999) have argued, the findings suggest that children and young people with CF may go unnoticed in the education system. This issue is of significance to those working in schools who must meet their obligations under various legislation such as the DDA (2005) and the Equality Act (2010) in supporting students with disabilities. While schools are required to identify children with SEN, this process will not necessarily identify children with disabilities (Feiler et al., 2012) and especially invisible disabilities such as CF. Given that research has demonstrated that schools and LAs may not distinguish effectively between SEN and disability (Porter et al., 2008; Porter et al., 2011; Feiler et al., 2012), and this study has shown that the needs of children with CF are not typically considered within the SEN framework, the research highlights the needs of a group of children who may be especially vulnerable to falling beneath the radar in terms of gaining access to school support systems. The research therefore further demonstrates the importance of differentiating between children with SEN and children with disabilities in schools and LAs. This is not just an issue that is of academic interest to researchers, but is also a challenge the schools and LAs must address (Feiler et al., 2012). The study therefore also contributes to wider debates on inclusive education, and in particular, debates on 'full inclusion' (Lindsay, 2007) that see inclusive principles as being relevant to all students and not just those with SEN (Booth and Ainscow, 2011).

This study also has a methodological contribution to make in terms of the novel methods used; the insider research context; and the cross-disciplinary approach to the study by conducting educational research within a clinical setting. I now turn to each of these contributions in turn.

The study has shown the possibilities of non-physical, face-to-face research methods through the use of online interviews, which in this research context surmounted the risk of cross-infection and enabled more than one person with CF to participate in the research at the same time (in this case the researcher and the participant). The methods chosen not only have applications to studies where the proximity of the researcher is an issue, but also to research where potential participants are difficult to reach, such as people with disabilities. The approaches used in the study may therefore enable people to take part in research and share their views where this would not otherwise have been possible. In addition, the study has also demonstrated the potential of the online interview approach with children and young people. While, there is a need for further research that examines the use of online methods with children, since the majority of studies taking such an approach have done so with adult participants (Hanna, 2012; Deakin and Wakefield, 2014; Weller, 2015b), my experience suggests that children's technical abilities should not be underestimated and do not present a barrier to gaining their views. Rather, it is the technical skills of adult researchers that may limit the success of online approaches. Reflections on the use of online interviews with children are considered in detail elsewhere (Gathercole, 2017). In summary, the research points to a need to use a range of interactive interviewing techniques, which may compensate in part for the 'virtual' context of online methods.

My study suggests that insider research or studies conducted by individuals with CF about issues related to life with the condition has a definite contribution to make. My subjective experiences of living with CF and my professional background has allowed me to identify a potential problem that might not have been recognised or given attention by the clinical community. Therefore, I would question whether certain social research issues relating to CF would gain the attention they deserve without patient involvement in directing the research agenda or studies that are conducted by and for people with CF. As Beresford (2007) claims, insider research can not only help in the development of new knowledge but can also make possible the creation of knowledge in areas that might otherwise be overlooked, and engage a wider range of perspectives and analysis than might otherwise be the case. Certainly, the development and identification of new and relevant research issues is not the only objective of insider research, as influencing and making

recommendations for change also remains an important aim. I hope that this study marks a step towards thoughtful discussion, not only about CF patient involvement in research, but also CF patient led research and the role of insider knowledge in improving services for people with the condition.

A final contribution of the study relates to what can be learned from my (challenging) experience of conducting educational research within the NHS. Given that this research took place within a clinical setting, it was necessary to seek ethical approval via the NHS governance system. As a researcher in the field of education, I was unfamiliar with NHS procedures for gaining ethical approval and in particular, the additional permissions I would require. I experienced many challenges with locating relevant knowledge and information about negotiating the approvals process. Much of the information available was targeted directly at NHS employees and those involved in clinical research such as drug trials. For social research, the NHS governance system remains excessively bureaucratic and time consuming because a philosophical framework intended for clinical studies is imposed throughout the application process. In this sense, there is an attempt to assert medical dominance on research that may stem from paradigms outside the traditional REC remit (Williams-Jones and Holm, 2005; Dyer and Demeritt, 2009; McDonach et al., 2009). The time taken to understand and negotiate the system correctly and complete the necessary paperwork for the approval of this study made for an even more extended process.

Proportionate review, which is an expedited system of ethical review for low risk research, may go some way to resolving some of the challenges experienced by social researchers. Social research projects are often conceptualised as relatively 'low risk' (van Teijlingen et al., 2008; Wilkinson, 2008). However, my experience suggests that the Proportionate Review Service (PRS) is unable to review all types of social research because the concept of 'low risk' is difficult to quantify (Edwards and Omar, 2008). This was the case in my study and led to a more lengthy full REC review, which meant that my research ultimately received the same level of ethical scrutiny as a complex clinical drug trial. The time taken to complete all the NHS approvals process was well over three months. This placed me at a substantial disadvantage to other students conducting social research projects in non-clinical settings who were able to gain necessary approvals more swiftly via university procedures. Nevertheless, the involvement of the NHS was deemed vital to the recruitment of a relatively large sample of children and young people with CF that would enable a broad range of voices to be explored and analysed.

Perhaps an unintended consequence of the NHS governance framework is that rather than protecting potentially vulnerable research participants, it represents a significant barrier to certain relatively low-risk research projects (van Teijlingen et al., 2008). Locating my experience of the process within the wider context demonstrates that there are particular difficulties in gaining access to children and young people in NHS settings, as has been the case for other social researchers (Noyes, 1999; Miller, 2000; Stalker et al., 2004). However, as Alderson and Morrow (2004) argue, the risk of harm from research should always be balanced against the risk of harm caused by a failure to seek children's views.

8.4   Dissemination

Outputs from this research will be targeted at multiple, relevant audiences to share and inform research and to promote best practice. Aspects of the research process and the study findings will be disseminated through peer reviewed journals with an international readership and at research conferences. Articles and conference papers will focus on the findings related to the needs of children and young people with CF in education and areas of supportive practice, for audiences such as those researching and working in inclusive education, and CF clinical care. Articles and conference papers on further aspects of the research will include; the use of online methods with children, researcher 'closeness' to the study topic and issues of insider research.

Dissemination activities will take place with those who are interested in the research but may not have access to peer reviewed materials. The research participants will be provided with a report containing the findings of the study. They will also be provided with a copy of the thesis where this has been requested. The research findings will be presented during an information evening for patients and parents at the regional paediatric CF centre in which the study took place. In order to disseminate the research to the wider CF community, the findings will be shared on social media in partnership with the organisation @CFAware, which is run for and by parents and people with CF. @CFAware has a wide social media presence with over 11,500 global followers from the CF community on Twitter and Facebook. The findings of the research will also be shared with the CF Trust charity in their development of a new resource for children, parents and those involved in the secondary education of children and young people with CF.

8.5   Limitations

The study has revealed some important insights into the educational experiences of children and young people with CF. However, a significant limitation of the study is that children and young people were not involved in the research design. While children and young people were encouraged to self-identify issues in education that were of significance to them, their perspectives were influenced by the constructs used in the research instruments, which were informed by the existing literature and my own subjective experiences of living with CF. I considered that children's involvement in the design of the study would have brought many advantages to the research, such as development of more relevant constructs that could inform the questionnaire items and interview questions, or the use of interactive questioning techniques that may have been more interesting and engaging to all of the study participants. Despite this limitation, the questionnaire received a number of quality checks before being approved for use in the study, and the interview schedules were developed in partnership with an 'expert' group in order to reduce the possible influence of my own unhelpful subjectivities (see section 3.9.3 and section 3.10.2.1).

Since the study involved only one regional paediatric CF centre inclusive of both rural and urban areas, the questionnaire sample size was smaller than what might have been possible had a second CF centre been involved (see section 3.6.1). In addition, only five children and young people were interviewed for the second phase of the research. While the study took account of the heterogeneity of children with CF through their varied treatment regimens, the sample chosen cannot be representative of all children and young people with the condition. In other words, there are limitations in terms of the wider generalisation of the findings, although this was not my intention in conducting the study. Despite this limitation, the findings of the research do reveal the needs and challenges experienced by children and young people with CF in one large paediatric CF centre, along with possible helpful and supportive responses, which may be of relevance to other children and young people with the condition.

It must also be noted that the study data was generated at a particular 'snapshot' in time for each research participant. This is significant in terms of conducting research about CF because of the changeable nature of the condition. More specifically, children and young people's educational experiences, or needs and challenges, are not static and may alter in line with their different experiences of life with CF. In this sense, a longitudinal study may better take account of how

variations in the experiences of living with CF might have different implications for education.

The presupposition that some young people with medical conditions may reject the idea of having support at school due to having a strong desire to appear normal, appeared to be mistaken for some of the school-aged study participants (see section 3.9.2 and section 7.2.1). In this study, it seemed that children and young people 'normalised' CF out of a primary concern that their peers might view them differently. Subsequently, the research missed an opportunity to enable secondary school questionnaire respondents to expand on any school related help or support they may have needed or received. This was a limitation of the study, since a questionnaire item that allowed primary respondents to do this yelled interesting information about their educational experiences.

8.6   Areas for further research

There is a need for a shift in the dominance of positivist and objective clinical research about CF, to research that also considers the lived experiences of people with the condition. There is a paucity of studies, not only on the education of children and young people with CF but also in relation to other relevant social research issues. This study has begun to fill a gap in the body of literature, but has demonstrated there is an absence of the voices of people with CF in research generally. This issue has very recently started to be addressed by organisations such as the James Lind Alliance by involving individuals with CF in prioritising research possibilities (McPhee, 2016). The study has demonstrated the possibilities of using online methods in future research involving individuals with CF, to overcome any potential risk of cross-infection. The methods adopted for this study are not just an alternative to face-to-face methods but are indeed a viable option for any research where the proximity of the researcher or participants is an issue. The online tools adopted in this study are certainly transferrable to other CF research contexts, and are of particular value to individual and group interview studies.

This research illustrates that children and young people with CF do experience specific needs and challenges in their education. However, the study raises further questions as to whether CF has negative implications for children's educational outcomes, such as their Key Stage or GSCE attainment levels. It is not known if children and young people with CF are able to circumvent any needs and challenges they may have that reside in interacting biological and structural

systems, in order to achieve in line with their non-CF peers. Therefore, further research is required in this regard.

There are a number of issues raised by the study that would benefit from additional research to improve contextual understanding of the educational experiences of children and young people with CF. For example, children's experiences of school absence were based on self-reported measures in the research and may not accurately reflect official school attendance monitoring that would take account of school absences beyond reasons of illness (see section 4.7.2 and section 5.9.1). Further research in this area would reveal new insights into the extent of school time missed by individuals with CF. In addition, the questionnaire and interviews revealed conflicting information as to the range of CF treatments that might be needed in the school setting by children with the condition (see section 6.4.5). More research is required in relation to the potential effect of CF treatments upon children's education, as these are likely to have a range of implications for issues such as the provision of health support at school, school absence, treatment independence and the support needed by school personnel.

8.7   Final reflections

I arrived at conducting this study from a number of contexts that have included working in schools and LAs, returning to higher education after several years as an education practitioner to be a student, and finally a researcher. I have learned a great deal throughout this time, and have become concerned with ensuring that good quality research evidence informs practice. Throughout this PhD study I have become equipped with research skills such as systematically reviewing existing literature, designing methodological tools, and carrying out quantitative and qualitative data analysis techniques. I have broadened my understanding of the cross-disciplinary research context and different research paradigms, through conducting educational research in a clinical setting. I have developed a sincere interest in social research issues relating to CF and I remain passionate about the value of involving people with CF in every level of the research process. It is a privilege to have been allowed a glimpse into the lives of the children and young people with CF and their parents who took part in the study.

Throughout the research I have undertaken my own personal journey not only in terms of my development as a researcher but also in terms of reflecting on my own experiences of living with CF. Ultimately, by doing this study, I have enriched my experiences both as a researcher and as a person with CF. The combination of this

positioning has enabled me to participate in and influence the wider CF research agenda, through membership of clinical steering groups, as an 'expert' patient advisor to various projects, and in terms of ensuring patient experience informs training and practice in the area of CF.

When I first broached the idea of conducting this study, I experienced great uncertainty about the need for such a research project. Part of this uncertainty was influenced by other people who held the view that CF must have no bearing upon children's education, which appeared to be based on their perceptions of my own education level as an adult researcher with the condition. I found myself looking back to my personal schooling experiences and thinking about how wrong such uninformed opinions were. But, I also found it difficult to challenge these views with clear reasons and evidence of why CF might impact education. It was at this point that I understood the necessity of the study. I realised, if I could not respond to unhelpful beliefs about CF as an adult with the condition who also has a professional grounding within education, then it followed that children and young people may also struggle to articulate how CF might directly or indirectly impact their schooling.

In conducting the research, I wanted to identify the implications of CF for education and any practices that might be helpful to children and young people at school. Yet, at the same time, I did not want to give the research participants the impression the study was being conducted out of a concern that CF is a definitive reason for children and young people to do poorly at school. I was mindful not to offend the resilient and determined mind-sets of many people with CF that I had encountered through my own membership of the CF community, and I wanted my research questions to be sensitive to children and young people's approaches to life with CF. The research questions have not directly focused on the potentially negative implications of CF that children and young people may not identify with. This has enabled and encouraged children and young people to articulate their educational experiences from their own perspectives and in their own words. My intention has been for the analysis of the perspectives of those who took part in the research to inform developments in the education of children and young people with CF. As a pragmatic researcher, I hope that through the dissemination activities to be undertaken, this study will bring about improved understanding of the fundamental needs and challenges experienced by children and young people with CF, and inform practical support that will be of benefit to them in education.

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Glossary

Aspergillus A chest infection caused by an allergic response to the spores of the aspergillus fungus.

Anaphylaxis/Anaphylactic kit During intravenous antibiotic therapy a rare but serious allergic reaction remains a possibility. An anaphylactic kit must be available at all times during the administration of home intravenous antibiotic drugs. The kit comprises of an insulin pen, high dose steroids and antihistamines which must be administered in the case of a severe reaction.

Carrier testing Potential parents can be screened for the faulty gene that causes cystic fibrosis to determine the risk of having a child with the condition.

CF diet see high calorie diet.

CF related diabetes A unique type of diabetes that is common in people with cystic fibrosis. Damage to the pancreas can hinder the production of insulin. It shares some of the features of both type 1 and type 2 diabetes.

Chest exacerbation An increase in lung symptoms such as productive coughing, breathlessness and wheezing, due to the presence of a chest infection.

Colomycin An antibiotic that is often nebulised (inhaled) by people with CF and may also be given intravenously.

Cipro See Ciprofloxacin.

Ciprofloxacin An oral antibiotic that is often prescribed for pseudomonas infections. The calcium in milk interferes with the absorption of the antibiotic which can prevent it from working correctly.

Creon A pancreatic enzyme replacement therapy used to treat people with CF who cannot digest food normally because their pancreas does not function correctly. Almost all people with CF must take some form of pancreatic enzyme replacement therapy with every meal and snack.

Cross-infection People with CF are at particular risk of spreading certain germs amongst others with the condition.

Dnase See Pulmozyme.

Exacerbation See chest exacerbation.

Enzymes See Creon.

Fluclox See Flucloxacillin.

Flucloxicillin A preventative oral antibiotic that may be part of a daily maintenance treatment routine.

Gastrostomy A tube directly inserted into the stomach in order to deliver nutrition. It may be used to provide extra calories to children and young people with CF overnight.

High calorie diet A diet high in energy and rich in fats and protein to compensate for the food wasted through inadequate digestion, and to meet the additional energy requirements needed to improve the chances of fighting off infections.

IVs Intravenous antibiotic therapy that usually takes place for a minimum of two weeks either at home or in hospital. Courses of intravenous antibiotic therapy can take place multiple times a year. A typical course may involve the administration of two or more intravenous antibiotic drugs, two to three times per day throughout the course. Each individual dose may take between half an hour and one hour to administer.

Intravenous access line A thin tube inserted into a vein to administer intravenous medication, such as a cannula or long line.

iNeb See nebuliser.

Line See Intravenous access line.

Nasogastric feeding A tube fed through the nose to carry food directly into the stomach. It may be used to provide extra calories to children and young people with CF overnight.

Nebuliser A device used to administer medication in the form of a mist that can be inhaled directly into the lungs.

Overnight feed Used to provide extra calories to children and young people with CF overnight via a nasogastric tube or a gastrostomy.

PEP mask A form of chest physiotherapy using positive expiratory pressure (PEP) via a mask or handheld mouthpiece to help clear the lungs of mucus.

Port A device implanted beneath the skin that provides central venous access and enables intravenous drugs to be delivered into the person. It is also possible to draw blood from a port, with less discomfort than a more typical needle. Ports are sometimes favourable when years of intravenous drugs and blood tests have weakened existing veins, making conventional intravenous access more troublesome.

Pulmozyme A nebulised medication designed to break down the thick secretions in the lungs.

Physiotherapy Airway clearance techniques to move secretions out of the lungs and reduce chest symptoms. The traditional use of percussion during which a caregiver 'pats' the child's chest is perhaps a more recognisable feature of CF to others with little knowledge of the condition. However, several other physiotherapy techniques are now used (see PEP mask).

Pseudomonas A bacteria that is a major cause of lung infections in people with CF.

Sprinkles/Springles A type of Creon enzyme medication for younger children that is 'sprinkled' onto fruit purée or yoghurt and swallowed prior to them eating a meal, so that the food can digested.

Tegaderm A transparent medical dressing used to cover intravenous access sites during a course of intravenous antibiotics.

Tobi See Tobramycin

Tobramycin An antibiotic that is often nebulised (inhaled) by people with CF and may also be given intravenously.

Appendices

Appendix 1 Literature Search Flow Chart

Review Question
RQ1: What is the current research evidence about the links between CF and Education?

Search Terms
Children and young people
AND
combinations and variations of:

Cystic Fibrosis (AND)	Education
Medical needs OR Medical conditions OR Chronic illness OR Health OR Sick OR Life limiting OR AND Hospital (Hospit*) OR Disabled (Disab*) OR Invisible OR Identification (Identif*)	School (Scho*) OR Inclusion (Inclus*) OR Special Educational Needs OR Learning OR Cognition OR Achievement OR Attainment OR Academic

Sources
UoL Library Catalogue, British Education Index, ERIC, ASSIA, Social Sciences Citation Index, Sociological Abstracts, Google Scholar, Web of Science, Index to Thesis, PsycINFO, White Rose eTheses Online, Case Law
Manual check of individual relevant journals

Total papers for inclusion = 69
24 empirical research papers and review articles that specifically involve/ relate to children with CF and education (of which 2 articles solely concerned children with CF)
9 clinical CF papers with a theme that has relevance for education (e.g. cognition, quality of life etc)
2 PhD Theses with a theme of CF and education
8 Empirical research papers and articles re education of children with a disability arising from a long term or hidden condition
17 Relevant government policy/guidance and associated research/review papers, case law , charity sector communications
5 Articles relating to connections between Disability and Illness
4 Articles re inclusive education definition

Exclusionary criteria
- Published beyond previous 25 years.
- Children with CF not participants in the research where study relates to children with medical conditions and education.
- Clinical articles with no educationally relevant theme.
- Not related to children of statutory school age

Appendix 2 Example Participant Information Sheets

UNIVERSITY OF LEEDS

The Leeds Teaching Hospitals NHS
NHS Trust

St JAMES'S & SEACROFT

Information Sheet for secondary school children and young people
(phase one)
(ages 11 to 16)
Version 3: 31-10-13

Study Title: The educational experiences of children and young people with Cystic Fibrosis (CF)

What is this study about?
We are asking you if you would like to join in a research project to find out the experiences of children and young people with CF at school. Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your parent/carer, nurse or doctor if you want to.

Why are we doing this research?
We do not know very much about the experiences of children and young people with CF in their education and what it is like for them at school. We would like to know more about this.

Why have I been invited to take part?
You have been chosen to take part in this study because you are a young person of school-age and you have CF. The study will involve about 100 other children of school-age who attend the Leeds Regional Paediatric CF centre.

Do I have to take part?
You do not have to take part in this study. It is up to you. We will ask your parent/carer if it is OK for you to take part. We will give you a copy of this information sheet to keep.

What if I change my mind about taking part?
If you no longer wish to be involved in this project you are free to stop taking part at any time and you do not need to say why. You just need to let us know and we will not contact you again about the study. If you decide to stop this will not affect the care you receive from your CF team.

What will happen to me if I take part?
You will be asked to fill in a short questionnaire about having CF and what it is like for you at school. This should take around 10 minutes to complete. You and your parent/carer will also be

You will be given more information about this part of the study later to help you decide if you want to take part.

What are the possible benefits of taking part?
We cannot promise the study will help you directly. We hope that you taking part in the study and sharing your experiences will help us to learn about what it is like to be at school with CF. The information received will help us to identify what is helpful to children and young people with CF at school.

What if there is a problem?
If you are worried about anything to do with this study, you or your parent/carer should speak to the researcher who will do their best to answer any questions. Alternatively, you or your parent/carer can speak to the CF Clinical Nurse or Research Supervisor. Contact information is available at the end of the information sheet.

Will anyone else know I am doing this study?
We will not tell your school anything about the information you give us. We will keep your information in confidence. This means that we will only tell those who have a need or a right to know. Direct quotes from your answers to questions will be used in reports in an anonymised form. This means that what you write in the questionnaire may be written down in reports, although you will not be identifiable. The questionnaire will not ask for any of your personal details. None of your personal information will be included in the final report.

What will happen to the results?
The results of the study will be published in research journals and may be presented at conferences. You will not be identified in any way in the published reports.

Who is organising and funding the research?
The main researcher for this study is Katie Gathercole. The study is being run by the School of Education at the University of Leeds. The study is funded by a research bursary from the Economic and Social Research Council (ESRC).

Did anyone else check the study is OK to do?
All research in the NHS is looked at by a group of people called a Research Ethics Committee to protect your interests. This study has been reviewed and given a favourable opinion by Yorkshire and The Humber – Bradford Leeds Research Ethics Committee.

Is there anything else I need to know?
The main researcher on this study is an Adult with Cystic Fibrosis. Therefore, the study has been designed to make sure that there are no cross-infection risks to either the participants or the researcher.

Further information and contact details
If you or your parent/carer would like any further information about this study, please contact:

Katie Gathercole   Research Supervisor:
School of Education   Dr Susan Pearson
E.C. Stoner 9.91   School of Education
University of Leeds   University of Leeds
Leeds   Leeds
LS2 9JT   LS2 9JT
Tel. 07773 328761   Tel. 0113 3433227
Email: ed09kag@leeds.ac.uk   Email. s.e.pearson@leeds.ac.uk

General information about participating in research can be obtained from the following
website INVOLVE (www.invo.org.uk).

Thank you for reading this information leaflet.

The Leeds Teaching Hospitals **NHS**
NHS Trust

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S⁺ JAMES'S & SEACROFT

Phase two information sheet for primary school children
(ages 5 to 11)
Version 3: 29-10-13

This research is about children with Cystic Fibrosis and what they think about things to do with school.

Thank you for carrying on to the next part of the study.

What is research? Why is it being done?

Research is a way we try to find out the answers to questions that we do not know the answers to. We want to find out what it is like to go to school when children have CF.

Why have I been asked to take part?

You have been chosen to do the next part of this study because you are a child with CF who goes to school and you filled in the questionnaire in the first part of the study. Three children with CF will take part.

Did anyone else check the study is OK to do?

Before any research is allowed to happen, it must be checked by a group of people called a Research Ethics Committee. They make sure that the research is fair. This project has been checked by the Yorkshire and The Humber – Bradford Leeds Research Ethics Committee.

Do I have to take part?

You do not have to do this part of the study if you don't want to. It is up to you. We will ask your parent/carer if it is OK for you to take part too.

What will happen to me if I take part?

First you will be asked to take some pictures that will help to show the researcher what it is like to have CF and go to school.

After this, you will have a chat with the researcher about the pictures you have taken and what it is like for you at school. The chat will happen by using a computer and a special camera so that you will be able to see and hear the researcher.

The researcher will give you and your parents more information about this later.

Will joining help me?

We cannot promise that this part of the study will help you. We hope that you taking part will help us to learn about what it is like to be at school with CF and to find out what is helpful to children with CF at school.

What happens when the research stops?

The result of the study will be published in journals and presented at conferences.

What if something goes wrong during the study?

If you are worried about anything to do with this study you can ask your parent/carer to speak to the researcher or the CF clinical nurse who will do their best to answer any questions.

School of Education
Faculty of Education, Social Sciences and Law (ESSL)

Will anyone else know I am doing this?

We will keep your information private. This means that we will only tell those who have a need or a right to know. We will not tell your school anything about what you say.

What if I don't want to do the research anymore?

It is OK if you don't want to do the study anymore. You can just tell your parents who will let the researcher know.

Appendix 3 Primary Questionnaire

The Leeds Teaching Hospitals **NHS**
NHS Trust

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Patient Identification Number

S¹ JAMES'S & SEACROFT

Children with Cystic Fibrosis
CF and School Questionnaire
Version 2: 29-10-13

Questions about school (please circle your answer)

1. How do you feel about being at school?

| I am always happy at school | I am mostly happy at school | I am sometimes happy at school / I am sometimes unhappy at school | I am mostly unhappy at school | I am always unhappy at school |
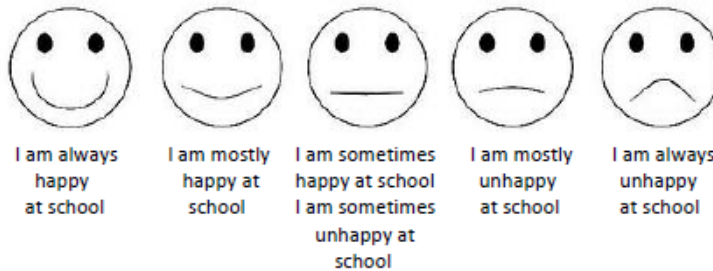
2. Do you think your teachers understand what Cystic Fibrosis is? (please circle your answer)

Yes   No   Not sure

3a. Do you get any extra help with anything at school? (please circle your answer)

Yes   No   Not sure

3b. If yes, what do you get extra help with?

_____

_____

4. **In the last 12 months, which of these CF treatments have you had whilst at school? (circle all that you've had)**

Creon or other enzymes   Physiotherapy   Inhalers

Insulin   Oral antibiotics   Nebuliser   IVs

None of these   Anything else? (Please say what this is)

_____

5. **Are you happy with the arrangements in place for you to have your CF treatments at school?** (please circle your answer)

Yes   No   Not sure

6. **Is there somebody at school that you feel you can talk to if you need help with anything?** (please circle your answer)

Yes   No   Not sure

7a. Do you think that anything could be done to make things better for you at school? (please circle your answer)

Yes   No   Not sure

7b. If yes, what would make things better for you at school?

_____

_____

_____

_____

_____

Questions about CF and school activities

The next questions on the following page are going to ask you if you think CF makes things difficult when thinking about school. You can answer the questions by circling the number on the scale. The scale starts at number 1 and goes up to number 5. As the number goes up, the amount that CF makes things difficult goes up too. So, number 1 means that CF does not make things difficult at all and number 5 means that CF makes things difficult a lot.

8. When thinking about school, how difficult does CF make the following things?	1 Not at all	2	3	4	5 Lots
Getting ready for school	1	2	3	4	5
Getting to school on time	1	2	3	4	5
Keeping up with school work	1	2	3	4	5
Doing well at school	1	2	3	4	5
Playtime/breaks	1	2	3	4	5
Dinner time	1	2	3	4	5
Sports/P.E.	1	2	3	4	5
Getting around	1	2	3	4	5
Getting on with others	1	2	3	4	5
School trips	1	2	3	4	5
Being well enough to go to school	1	2	3	4	5
Going to the toilet at school	1	2	3	4	5

Questions about being poorly (please circle your answer)

9a. In the last 12 months have you been in hospital because of your CF?

Yes   No

9b. Was this during term-time? (please circle your answer)

Yes   No

10a. In the last 12 months have you had home IVs? (please circle your answer)

Yes   No

10b. Was this during term-time? (please circle your answer)

Yes   No

11. In the last 12 months, how much time have you taken off school due to CF?
(please circle your answer)

None   up to 5 days   between 6 and 10 days   between 11 and 15 days

Between 16 and 20 days   more than 21 days

Questions about you (please circle your answer)

12. I am a…?

Boy   Girl

13. How old are you? (please circle your answer)

5   6   7   8   9   10   11

14. What year group are you in at school? (please circle your answer)

Reception   Year 1   Year 2   Year 3

Year 4   Year 5   Year 6

15a. As well as having CF, do you have any other difficulties or disabilities? (please
circle your answer)

Yes   No

15b. If yes would you like to say what other difficulties or disabilities you have?

_____

_____

_____

Thank you very much for completing this questionnaire!

Appendix 4 Secondary Questionnaire

The Leeds Teaching Hospitals **NHS**
NHS Trust

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St JAMES'S & SEACROFT

Patient Identification Number

Young People with Cystic Fibrosis
CF and School Questionnaire
Version 2: 29-10-13

Questions about school

1. **On a scale of 1 to 5, how do you feel about school?** (please circle a number)

I am always happy at school	I am mostly happy at school	I am sometimes happy at school / I am sometimes unhappy at school	I am mostly unhappy at school	I am always unhappy at school
1	**2**	**3**	**4**	**5**

2. **Has anyone from school ever talked to you and/or your parents about your Cystic Fibrosis?** (please circle your answer)

   Yes   No   Not sure

3. **Do you think your teachers have a good understanding of Cystic Fibrosis?** (please circle your answer)

   Yes   No   Not sure

4. **Is there somebody at school who you feel you can talk to if you need to?** (please circle your answer)

   Yes   No   Not sure

5. **If you ever needed help or support with anything at school, are you happy that you would get what you need?** (please circle your answer)

Yes I am happy I would get what what I need	No I am not happy I would get what I need	Not sure	I do not need any help or support at school

6. **In the last 12 months, which of the following CF treatments have you had whilst being at school?** (circle all that you've had)

Creon or other enzymes   Physiotherapy   Inhalers   Insulin   IVs

Oral antibiotics   Nebuliser   None of these

Anything else? (Please say what this is)

_____

_____

7. **Are you happy with the arrangements in place for you to have your CF treatments at school?** (please circle your answer)

Yes   No   Not sure

8a. Do you think anything could be done to make things better for you at school?
(please circle your answer)

Yes   No   Not sure

8b. If yes what would make things better for you at school?

_____

_____

_____

_____

Questions about CF and school activites

The next questions on the following page are going to ask you if you think CF makes things difficult when thinking about school. You can answer the questions by circling the number on the scale. The scale starts at number 1 and goes up to number 5. As the number goes up, the amount that CF makes things difficult goes up too. So, number 1 means that CF does not make things difficult at all and number 5 means that CF makes things difficult a lot.

9. When thinking about school, how difficult does CF make the following things?	cf 1 not at all	cf 2	cf 3	cf 4	cf 5 a lot
Getting ready for school	1	2	3	4	5
Getting to school on time	1	2	3	4	5
Keeping up with school work	1	2	3	4	5
Doing well at school	1	2	3	4	5
Breaks	1	2	3	4	5
Dinner time	1	2	3	4	5
Sports/P.E.	1	2	3	4	5
Getting around	1	2	3	4	5
Getting on with others	1	2	3	4	5
School trips	1	2	3	4	5
Being well enough to go to school	1	2	3	4	5
Going to the toilet at school	1	2	3	4	5

Questions about when you leave school

10. What would you like to do when you leave school?

_____

_____

11a. Have you been given careers advice? (please circle your answer)

Yes   No   I don't need this yet

11b. If yes, how happy are you with the careers advice given? (please circle a number)

Very Happy	Mostly Happy	Neither Happy or Unhappy	Mostly Unhappy	Very Unhappy
1	**2**	**3**	**4**	**5**

Questions about being poorly (please circle your answer)

12a. In the last 12 months have you been in hospital because of your CF?

Yes   No

12b. If yes, was this during term-time?

Yes   No

13a. In the last 12 months have you had home IVs?

Yes   No

13b. If yes was this during term-time?

Yes   No

14. How much time have you taken off school due to CF?

None   up to 5 days   between 6 and 10 days   between 11 and 15 days

Between 16 and 20 days   more than 21 days

Questions about you (please circle your answer)

15. Are you...?

Male   Female

16. How old are you?   11   12   13   14   15   16   17

17. What year group are you in at school?

Year 7   Year 8   Year 9

Year 10   Year 11   Year 12

18a. As well as having CF, do you have any other difficulties or disabilities?

Yes   No

18b. If yes, would you like to say what other difficulties or disabilities you have?

_____

_____

_____

Thank you very much for completing this questionnaire!

Appendix 5 REC Provisional Opinion Letter

NHS

Health Research Authority

NRES Committee Yorkshire & The Humber - Leeds Bradford

North East REC Centre
Room 002
TEDCO Business Centre
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 4283545

23 October 2013

Mrs Katie Gathercole
PGR Student
University of Leeds
School of Education
University of Leeds
Leeds
LS2 9JT

Dear Mrs Gathercole

Study Title:	**The Educational Experiences of Children and Young people with the Medical Condition Cystic Fibrosis**
REC reference:	**13/YH/0342**
Protocol number:	**1**
IRAS project ID:	**132623**

The Research Ethics Committee reviewed the above application at the meeting held on 15 October 2013. Thank you for attending to discuss the application.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Covering Letter	Letter from Katie Gathercole	17 September 2013
Investigator CV	Katie Gathercole	17 September 2013
Other: CV-Supervisor 1	Dr Sue Pearson	13 September 2013
Other: CV-Supervisor 2	Professor David Sugden	
Other: Certificate of Insurance		29 September 2012
Other: Letter from Funder	Letter from Jean Uniacke	10 September 2013
Other: Peer Review	1	11 August 2004
Other: Protocol Flowchart	1	17 September 2013

A Research Ethics Committee established by the Health Research Authority

Other: Interview Schedules	1	17 September 2013
Other: Hospital School Semi Structured Interview	1	01 September 2013
Other: Cross Infection Policy		
Participant Consent Form: Phase 1- Parent	1	16 September 2013
Participant Consent Form: Phase 2- Parent	1	16 September 2013
Participant Consent Form: Phase 2- Parent Participant	1	16 September 2013
Participant Consent Form: Phase 2- School Children	1	16 September 2013
Participant Consent Form: Phase 2- Post School Age	1	16 September 2013
Participant Consent Form: Phase 2- Education and Health	1	16 September 2013
Participant Consent Form: Assent- Phase 2- Young Children	1	16 September 2013
Participant Information Sheet: Phase One- Parents	1	16 September 2013
Participant Information Sheet: Phase One- Primary	1	16 September 2013
Participant Information Sheet: Phase One-Secondary	1	16 September 2013
Participant Information Sheet: Phase Two- Parent Participants	1	16 September 2013
Participant Information Sheet: Phase Two-Parents	1	16 September 2013
Participant Information Sheet: Phase 2- Primary	1	16 September 2013
Participant Information Sheet: Phase 2- Secondary	1	16 September 2013
Participant Information Sheet: Phase 2- Post School Age YP	1	16 September 2013
Participant Information Sheet: Phase 2- Ed & Health	1	16 September 2013
Protocol	1	13 September 2013
Questionnaire: Primary	1	16 September 2013
Questionnaire: Secondary	1	16 September 2013
Questionnaire: Cover Sheet	1	16 September 2013
REC application	132623/504026/1/967	18 September 2013

The Committee reviewed the above study.

Ethical issues raised by the Committee in private discussion, together with responses given by the researcher when invited into the meeting.

You and Dr Sue Pearson attended the meeting to discuss the application.

1. The Committee discussed matters which were identified by the PR Committee and informed the researchers that this Committee did not feel it necessary for the participants GP to be contacted about the study.

2. The Committee also noted that the addition information provided with reference to the PR Committee response had been received and this will be considered alongside the application. Any correspondence will relate to the Participant Information Sheet submitted since that review.

3. The Committee queried the tear off section on the questionnaire for participants to indicate their willingness to participate in the interviews.

   You clarified that only a small number of participants will be selected to undergo the interview and the Committee agreed that this should be made clear.

   You agreed to make this clear.

4. It is documented that the nominated teacher would be first contacted about the study via telephone and the Committee queried whether this could be deemed cold calling.

   You informed the Committee that you would first write to the head teacher to inform them of the study and the student involved and that you will also inform them that the participant is required to nominate a teacher. You will also seek advice about the potential for photos to be taken within the school and will gain their consent to allow the participant to do this.

5. The Committee queried whether the nominated teacher will be aware that they will be contacted.

   You stated that the information could be given to the participant to then forward on to their nominee and sought the Committees advice on whether this would be more appropriate than a telephone call.

   The Committee agreed that this appeared to be a more satisfactory approach.

6. The study documents that direct quotes will be used within the report and the Committee raised their concerns surrounding anonymity. This should be made more explicit within the Consent form.

   You informed the Committee that you initially wanted to carry out the questionnaire within two paediatric CF centres but due to time constraints was only able to do this within the one centre. You explained that you wanted to allow the children involved to identify their own pseudonym and will involve them in the discussion regarding anonymity.

   You informed the Committee that you will reword the Consent form and Participant Information Sheet to document that direct quotes will be included and that anonymity will be protected at all times.

7. Question 9 of the School Questionnaire was noted to be confusing as this didn't provide information on whether the answers given will reflect a positive or negative opinion and should be re worded.

You *agreed to re word this section.*

You left the meeting at this stage.

Decision – Provisional Opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Further information or clarification required

1. The Participant Information Sheet for participants of primary school age needs to be rewritten in a more appropriate language age i.e. possibly incorporate the use of pictures.

2. To include a statement about the use of direct quotes in the Participant Information Sheet and Consent form.

3. The tear off slip to be re written to explain not all participants will go onto interview stage.

4. Question 9 of the School Questionnaire to be amended.

5. To amend the grammatical errors discussed during the meeting.

6. The Participant Information Sheet for phase 2 of study is written as if the participant is just being introduced to the study however they are actually being reintroduced to the study. The Committee asked that consideration be given to amend the wording to read 'thank you for continuing in the next stage of the study....'

The Committee nominated the coordinator to be the point of contact should further clarification be sought by the applicant upon receipt of the decision letter.

The Committee nominated the Chair to be the point of contact for the Co-ordinator for further information.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact the REC Manager Hayley Jeffries at nrescommittee.yorkandhumber-leedsbradford@nhs.net

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application

A Research Ethics Committee established by the Health Research Authority

form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 22 November 2013.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

13/YH/0342	Please quote this number on all correspondence

Yours sincerely

pp H J p h

Dr Janet Holt
Chair

Email: nrescommittee.yorkandhumber-leedsbradford@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Clare Skinner, University of Leeds

                      Dr Derek Norfolk, R, G & M Manager - LTHT R&D

Appendix 6 Children and Young People's Interview Schedule

**School-age children and young people
semi-structured interview schedule**

- Describe the study
- Ask if participant has any questions
- Ask participant to sign consent form
- Ask the participant to choose a pseudonym
- Press record

Ice Breaker

Tell me a bit about yourself.
What year are you in at school?
What do you like doing when you are not at school?
Photograph discussion

Getting to know you and your CF

As you know I have CF myself so I know quite a bit about it. But I would like to know more about how your CF affects you and your experiences of living with CF.

1. What's it like, having CF?

2. Can you tell me a little about how your CF affects you from day to day?

3. Are there any particular times when you struggle because of your CF?
   Does CF ever stop you doing anything you want to do?

4. Can you tell me about a time that you have needed to describe or explain your CF to someone who didn't know you have it?
   What happened?
   How did you feel about telling them?

CF routine and CF treatments

Everyone has different experiences of CF, so I would like to know more about your CF treatment routine and what you have to do each day in order to stay well.

5. Can you tell me about what your daily CF routine is like?
   What treatments do you have to do?
   Are there any particular times when you struggle with your treatments?

6. Would your daily CF routine be any different on a school day?
   Tell me about how you manage your CF routine on a school day?

7. How do you feel about having to do your CF treatments on a school day?

Communication, awareness and understanding

I would like to know more about what other people know about your CF at your school.

8. Do staff and teachers at your school know you have CF?
   Which ones?

9. How were school told about you having CF?
   What did this involve?

10. What are your thoughts about your school's understanding of your CF and how it affects you?

11. What about your friends understanding?

12. Do you think it is important that your friends and teachers know about your CF?
    Why/Why not?

Impact of CF on school related activities

I would like to move on to thinking about being at school and how CF might affect things there.

13. What CF treatments have you needed to do whilst at school? (Prompts: Enzymes, Antibiotics IV/Oral, Physio, Insulin).
    Can you tell me about the times when you do your treatments in school? (Prompts: when, where, how).
    What do you think about having to do your CF treatments at school?

14. Do you think that any part of having CF makes a difference to you at school?

15. Do you think any part of having CF makes things harder for you at school?

Help and support

I would like to move on to thinking about things at school that are helpful to you.

16. Do you get any extra help or support at school because you have CF? (Prompt: Toilet pass, early lunch, extra time in exams, modified timetable, stay indoors at break etc).
    Who put this in place?
    Do you find this helpful? Why/Why not?
    Do you think you need any extra help or support with anything at school?

17. **Fantasy wishes**: If you could make some wishes about things that would make school better or easier for you what would they be?

Illness and school absence

So thinking about the times when you might not be able to get into school because of CF:

18. Has having CF ever meant you needed to miss any school? If yes, why was that? (Prompts: Illness, hospital appointments, admission).

19. What happens about your school work when you can't go to school? (Prompts: Education in hospital, access to school work).
    Are these arrangements helpful?

20. What are your thoughts about needing to take time off school? How does that affect you?

Closing questions (happiness at school, help and support)

21. **Vignette:** Imagine that you have a friend called Sam whose parent is a teacher at another school. This teacher has just found out that a young person with CF is going to be starting at their school very soon. Sam's parent knows you have CF and so comes to you to ask for some advice.

    - What advice would you give to her so that the young person is happy at school?
    - What do you think would be helpful for this young person at school?
    - Is there anything that the school should/shouldn't do?

22. Is there anything else that you think may be important or useful for me to know about?

23. Do you have any questions?

Appendix 7 Parent Interview Schedule

Parents/Carers semi-structured interview schedule

1. **How would you say your child's CF affects them from day to day?** What is the CF routine like at home? (prompts: day-to-day medication and treatments, illness: IVs, nebs, impact on family life).

2. **How do you think your child deals with having CF?** Are there any particular times that they might struggle more than others?

3. **What was the process of telling your child's school about CF?** What information was given to the school about CF? (Prompt: meetings, CF nurse, phone calls, responsible person at school). **What about updating school on any CF issues – how is this managed?**

4. **How have things been at school since they were told? Any anecdotes about school practices?** (Prompts: what's been helpful, any concerns, keeping in touch) **What does your child think about school being told?**

5. **Are any CF treatments needed during the school day? How are CF treatments managed alongside school activities?** (Prompts: meds/physio at school, any help with meds at school – who?, fitting treatments around school, treatments in addition to usual routine, IV access)

6. **How would you say CF affects things at school? Do you think any part of CF makes any difference to things?** (Prompts: treatments, absence, how the child is treated, healthy eating, sports, keeping up with work)

7. **Can you tell me about any additional support or help your child gets with anything at school?** (prompts: stay in at lunchtime, help with meds, toilet pass, extra time in exams)

8. **Has your child ever needed to take time off school?** (prompts: hospital stay, on IVs, illness, hospital appointments) **What impact does taking time off/or not taking time off have?** (Prompts: falling behind, friendships, keeping up with work, fitting everything in).

9. **What advice would you give to schools that have a student with CF attending?**

10. **Is there anything else you think might be important or useful for me to know about?**

Appendix 8 Education Personnel Interview Schedule

Education Personnel Semi-Structured Interview Schedule

1. **Can you tell me about your role in school?** The young person with CF nominated you to be interviewed for this study. **Why do you think they chose you?**

2. **What was the process of being informed about** *name of child's* **CF?** (Prompt: Meetings with parent, CF team help, school plans – IEP, HCP)

3. **Do you think that you (and other members of the school staff) gained the information/support needed about CF at this time?** What was helpful? Did you have any concerns?

4. **What about gaining updates on any CF issues – how is this managed?** (Prompts: periods of illness, new CF difficulties/problems, gaining information, being supported)

5. **How would you say CF affects** *name of child* **at school? Do you think any part of CF makes any difference to things?** (Prompts: treatments, absence, how the child is treated, healthy eating, sports, keeping up with work, friendships)

6. **Are any CF treatments needed during the school day? How are CF treatments managed alongside school activities?**

7. **How are** *name of child's* **CF treatments managed at school? What support/training have you been given with this?**

8. **Can you tell me if any additional support or help is needed for** *name of child* **at school? If yes what does this involve?** (prompts: stay in at lunchtime, help with meds, toilet pass, extra time in exams)

9. **Does** *name of child* **ever need to take time off school?** (prompts: hospital stay, on IVs, illness, hospital appointments) **What impact does taking time off/or not taking time off have?** (Prompts: falling behind, friendships, keeping up with work, fitting everything in).

10. **What advice would you give to schools that have a student with CF attending?**

11. **Is there anything else you think might be important or useful for me to know about?**

Appendix 9 Health Personnel Interview Schedule

CF Clinical Team Interview Schedule

1. Can you tell me about your role in the CF team?

2. What are some of the situations where you might be involved in the education/schooling side of children with CF?

3. What is the usual process of informing a child's school about their CF? (Prompt: Meetings with parent, CF team help, school plans – IEP, HCP) **What advice/information do you give to schools that have a student with CF attending?**

4. How do things usually go once a school has been informed about CF? Any stories or anecdotes?

5. Children and young people with CF have quite a lot of treatments and therapies to do everyday. How would you say these are managed alongside school activities?

6. Many young people and their parents have talked about fitting the CF treatment routine around the school day. Would you say this is also a particular aim of the CF unit?

7. Do you know of any patients who might need CF treatments other than enzymes during the school day and if so how are these managed?

8. How would you say CF affects children in their education? Do you think any part of CF makes any difference to things? (Prompts: treatments, illness and absence, how the child is treated, healthy eating, sports, keeping up with work, friendships)

9. In general, do you think children with CF need any additional support or help at school? (prompts: stay in at lunchtime, help with meds, toilet pass, extra time in exams)

10. Is there anything else you think might be important or useful for me to know about?

Appendix 10 Code Book

	Conceptual Category (code)	Definition	Examples
1.	**Being me first**	Comments relating to children with CF having a 'normalised' identity, including references to issues of difference.	**Bob (post school-age young person):** I don't want to be seen as different. I don't want to be seen as disabled. I want to be seen as normal. I'm a normal person. I know that a lot of people…..I, I don't want charity. I've never wanted charity from people. I don't want to be seen as different, I just want to be seen as normal. **Violet (Primary school-aged young person**): I don't really tell them because, unless like you know when you're getting changed in like a girls changing room and you have to take your top off… but I've got this scar. Some people ask.
	Sub category: Keeping CF private	References to preferring not to tell others about having CF	**Luke (Secondary school-aged young person):** I haven't really told anyone so I don't really describe it to people… I don't know, they don't really need to know so I don't really need to tell them. I just keep it to myself.
	Sub category: Being unhindered by CF	References to children being unaffected by CF, not thinking about it and 'getting on with it'.	**Louise (Parent):** I wouldn't particularly say that it affects him as in, he just gets on with everything. Yeah I would just say that he just gets on with it and I don't think he lets it affect him and what he's doing.
2.	**Staying well at school**	References to issues that may affect the health of children with CF at school and the practices that maintain the health and wellbeing of children with CF at school.	**Diane (CF Nurse):** …you need to make allowances for the fact that when he needs to go to the toilet he needs to go now, please don't make him hold it back. Because a lot of primary schools, they're not allowed to leave assembly and so we have to go in and say please can you make allowances for them and don't make it

		obvious but if they need to go, they need to go. **Louise (Parent):** We'd gone in and explained everything about the diet, high fat and everything and he'd got chocolate in his lunch box as well as like yoghurts and stuff like that. But the teacher actually brought him out of the dining hall with his lunch box and said we have to phone his mother, that it wasn't a healthy meal, it wasn't appropriate.
3. **Balancing treatments and school experiences**	References to managing CF treatment routines alongside school experiences.	**Nikki (Parent):** They would like him to do a nebuliser before school and we've kind of talked our way,…that it isn't feasible because of the time thing again. So, ideally he would do one before school then one mid-afternoon then one when he got home and it was just making him late for school all the time.
4. **CF impacting learning**	Comments relating to direct and indirect aspects of CF that negatively impact learning.	**Joanne (CF Nurse):** We do inform the school that they are likely to be coming to clinic 8 weekly, more frequently if they are not very well. **Luke (Secondary school-aged young person):** Err, probably when I'm in hospital 'cause they don't really send any work to do while you're there. So I've got to catch up on some stuff.
5. **Support for learning**	References to the strategies and practices needed for educational support of children with CF, including specific areas of the curriculum that are significant for them.	**Louise (Parent):** But they have been really good, I mean like his Geography teacher, he had a project to do, and when he was on his Cipro last time before he went into hospital and he was really tired and it was a lot of work, and I just asked her if we could extend it and she let us.
6. **Knowing about CF**	Comments about the knowledge, awareness and understanding of CF at school.	**Alice (Parent):** She had a jumper on and a blazer and she'd gone in and I said "Violet, make sure you keep your jumper on and don't take it off while

		you're in there because I wouldn't want it to get damaged (the IV access line)" you've got to be so careful when you take it off. And the swimming teacher said to her "take your jumper off" and Violet said "no" because she was like quite timid. And the teacher made her take it off and sort of helped her but took it off. And Violet told me, so I went, I was really mad, I went into the school and spoke to the headteacher. **Joanne (CF Nurse):** Well we do a lot of visits to nurseries and to schools. So when children are starting in the school, we go into schools and we basically do a brief discussion about what CF is, what to expect in school…
7. **Negotiating adolescence alongside CF**	Comments referring to aspects of adolescence that are important to all young people yet must be negotiated alongside having CF for those with the condition.	**Bob (post school-age young person):** I didn't like to get changed in front of all the guys because I always felt like I was too thin. People always made like (inaudible), I used to get a few comments once in a while about my stature. So I used to always feel like I don't want to do it. So sometimes I would just skive P.E. pretty much.

Appendix 11 REC Favourable Opinion Letter

NHS
Health Research Authority

NRES Committee Yorkshire & The Humber - Bradford Leeds

North East REC Centre
Room 002
TEDCO Business Centre
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 428 3387

18 November 2013

Mrs Katie Gathercole
PGR Student
University of Leeds
School of Education
University of Leeds
Leeds
LS2 9JT

Dear Mrs Gathercole

Study title:	**The Educational Experiences of Children and Young people with the Medical Condition Cystic Fibrosis**
REC reference:	**13/YH/0342**
Protocol number:	**1**
IRAS project ID:	**132623**

Thank you for your letter of 31 October 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the REC Manager Miss Sarah Grimshaw, nrescommittee.yorkandhumber-bradfordleeds@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

A Research Ethics Committee established by the Health Research Authority

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter	Letter from Katie Gathercole	17 September 2013
Investigator CV	Katie Gathercole	17 September 2013
Other: CV-Supervisor 1	Dr Sue Pearson	13 September 2013
Other: CV-Supervisor 2	Professor David Sugden	
Other: Certificate of Insurance		29 September 2012

Other: Letter from Funder	Letter from Jean Uniacke	10 September 2013
Other: Peer Review	1	11 August 2004
Other: Protocol Flowchart	1	17 September 2013
Other: Interview Schedules	1	17 September 2013
Other: Hospital School Semi Structured Interview	1	01 September 2013
Other: Cross Infection Policy		
Participant Consent Form: Phase 2- Post School Age	1	16 September 2013
Participant Consent Form: Phase one - parents	3	31 October 2013
Participant Consent Form: Phase two - Parents	3	31 October 2013
Participant Consent Form: Phase two - Children and Young people	3	31 October 2013
Participant Consent Form: Phase two - post school age	3	31 October 2013
Participant Consent Form: Phase two - Parent participants	3	
Participant Consent Form: Phase two - Parent participants	3	31 October 2013
Participant Consent Form: Phase two - Education and health personnel	3	31 October 2013
Participant Information Sheet: Phase 1 - Parents	3	31 October 2013
Participant Information Sheet: Phase 1 - primary children	3	29 October 2013
Participant Information Sheet: Phase one - secondary children	3	31 October 2013
Participant Information Sheet: Phase two - parents	3	31 October 2013
Participant Information Sheet: Phase two - parent participants	2	31 October 2013
Participant Information Sheet: Phase two - primary	3	31 October 2013
Participant Information Sheet: Phase two - secondary	3	31 October 2013
Participant Information Sheet: Phase two - post-school age	3	31 October 2013
Participant Information Sheet: Phase two - Education and Health	2	31 October 2013
Protocol	1	13 September 2013
Questionnaire: Cover Sheet	1	16 September 2013
Questionnaire: Cover sheet - phase 1	2	30 October 2013
Questionnaire: Questionnaire primary	2	30 October 2013
Questionnaire: Questionnaire secondary	2	30 October 2013
REC application	132623/5040 26/1/967	18 September 2013
Response to Request for Further Information		31 October 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

<u>Reporting requirements</u>

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

<u>Feedback</u>

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/YH/0342	**Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

pp
Dr Janet Holt
Chair

Email:nrescommittee.yorkandhumber-bradfordleeds@nhs.net

Enclosures: "After ethical review – guidance for researchers" *SL-AR2*

Copy to: *Clare Skinner, University of Leeds*
      Dr Derek Norfolk, R, G & M Manager - LTHT R&D

Appendix 12 Research and Development Approval Letter

The Leeds Teaching Hospitals NHS
NHS Trust

Rosie Underwood

19/12/2013

Katie Gathercole
School of Education
Hilary Place
Leeds
LS2 9JT

Research & Development

Leeds Teaching Hospitals NHS Trust
34 Hyde Terrace
Leeds
LS2 9LN

Tel: 0113 392 2878
Fax: 0113 392 6397

r&d@leedsth.nhs.uk
www.leedsth.nhs.uk

Dear Katie Gathercole

Re: NHS Permission at LTHT for: The Educational Experiences of Children and Young People with the Medical Condition Cystic Fibrosis: An Explaoratory Study
LTHT R&D Number: RM13/10873
REC: 13/YH/0342

I confirm that *NHS Permission for research* has been granted for this project at The Leeds Teaching Hospitals NHS Trust (LTHT). NHS Permission is granted based on the information provided in the documents listed below. All amendments (including changes to the research team) must be submitted in accordance with guidance in IRAS. Any change to the status of the project must be notified to the R&D Department.

Permission is granted on the understanding that the study is conducted in accordance with the *Research Governance Framework for Health and Social Care*, ICH GCP (if applicable) and NHS Trust policies and procedures available at http://www.leedsth.nhs.uk/academic/research-development/

This permission is granted only on the understanding that you comply with the requirements of the *Framework* as listed in the attached sheet "Conditions of Approval".

If you have any queries about this approval please do not hesitate to contact the R&D Department on telephone 0113 392 2878.

Indemnity Arrangements

The Leeds Teaching Hospitals NHS Trust participates in the NHS risk pooling scheme administered by the NHS Litigation Authority 'Clinical Negligence Scheme for NHS Trusts' for: (i) medical professional and/or medical malpractice liability; and (ii) general liability. NHS Indemnity for negligent harm is extended to researchers with an employment contract (substantive or honorary) with the Trust. The Trust

Chairman Mike Collier CBE Chief Executive Maggie Boyle

The Leeds Teaching Hospitals incorporating:
Chapel Allerton Hospital   Leeds Dental Institute   Seacroft Hospital
St James's University Hospital   The General Infirmary at Leeds   Wharfedale Hospital

use the NHS Number
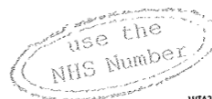
WTA280

only accepts liability for research activity that has been managerially approved by the R&D Department.

The Trust therefore accepts liability for the above research project and extends indemnity for negligent harm to cover you as investigator and the researchers listed on the Site Specific Information form. Should there be any changes to the research team please ensure that you inform the R&D Department and that s/he obtains an appropriate contract, or letter of access, with the Trust if required.

Yours sincerely

[signature]

pp **Dr D R Norfolk**
Associate Director of R&D

Approved documents
The documents reviewed and approved are listed as follows

Document	Version	Date of document
NHS R&D Form	3.5	18 November 13
SSI Form	3.5	18 November 13
Directorate Approval		29 August 2013
REC Letter confirming favourable opinion		18 November 13
Certificate of Insurance		19 September 13
Letter from sponsor	Letter from Jean Uniacke	10 September 13
Peer review	1	11 August 04
Protocol Flow Chart	1	17 September 13
Interview Schedules	1	17 September 13
Hospital School Semi-structured interview	1	September 13
Consent Form: Phase one: Parents	3	30 October 13
Consent Form: Phase two: Parents	3	31 October 13
Consent Form: Phase two: Children and young	3	31 October 13
Consent Form: Phase two: Post school age	3	31 October 13
Consent Form: Phase two: Parent Participants	3	31 October 13
Consent Form: Phase two: Education and health personnel	3	31 October 13
Participant Information Sheet: Phase one: Parents	3	30 October 13
Participant Information Sheet: Phase one: Primary children	3	29 October 13
Participant Information Sheet: Phase one: Secondary children	3	31 October 13
Participant Information Sheet: Phase two: Parents	3	31 October 13
Participant Information Sheet: Phase two: Parent Participants	2	31 October 13
Participant Information Sheet: Phase two: Primary	3	29 October 13
Participant Information Sheet: Phase two: Secondary	3	31 October 13
Participant Information Sheet: Phase two: Post school age	3	31 October 13

Appendix 13 Example Consent Form

The Leeds Teaching Hospitals **NHS**
NHS Trust

UNIVERSITY OF LEEDS
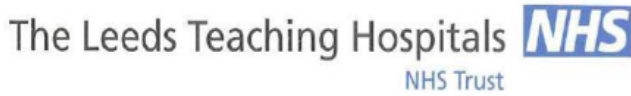
St JAMES'S & SEACROFT

Centre Number:
Study Number:
Patient Identification Number:

CONSENT FORM: Children and Young People – Phase Two (Version 3: 31-10-13)
Title of Project: The educational experiences of children and young people with cystic fibrosis
Name of Researcher: Katie Gathercole

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated **31st October 2013, version 3** for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that data collected during the study may be looked at by individuals from the research team at the University of Leeds, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

4. I agree to the online interview being recorded and transcribed.

5. I understand that direct quotes from my answers to interview questions will be used in written reports. I agree to quotes being used on the understanding that my anonymity is maintained.

6. I agree to take part in the above research study.

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of person   Date   Signature
taking consent.

Version 3: 31-10-13

Appendix 14 Example Assent Form

The Leeds Teaching Hospitals **NHS**
NHS Trust

UNIVERSITY OF LEEDS

Patient identification Number

St JAMES'S & SEACROFT

Assent form for children & young people – Phase one questionnaire
(to be completed by the child and their parent/guardian)
Version 1: 07-10-13

Study Title: The educational experiences of children and young people with Cystic Fibrosis

Child (or if unable, parent on their behalf) /young person to circle all they agree with:

Has somebody else explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have you had your questions answered in a way you understand?	Yes/No
Do you understand it's OK to stop taking part at any time?	Yes/No
Are you happy to take part?	Yes/No

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Your name:

Date:

The researcher needs to sign too:

Print Name:

Sign:

Date:

Thank you!

Version 1: 07-10-13

Appendix 15 Reflexive Diary Excerpt

Meeting with Parent for pilot interview

I met with a parent of a young person with CF today. This was in preparation for a pilot interview that I will be conducting with the post 16 school age person. I came to thinking that this meeting raised a number of ethical issues that I had not previously considered and hadn't been picked up by the three different ethical review panel that have reviewed the study. Of course, it is possible that some of these ethical issues may be unique to CF social research.

Firstly, it was clear that the parent was very moved by meeting with me because she felt that I looked really well and I was obviously older that her two children who have CF. She asked my age, and when I told her I will be 36 next month she seemed overwhelmed and happy that I could be so well and so old with CF. She said she was glad to have met me. This emotional response raises some ethical concerns. She may feel an emotional attachment and could potentially coerce her son into taking part in the research because of this. This is a potential issue for all pwcf doing research in the CF community because there is a very special community of people who all share an experience of CF in one way or another.

Having said this, does this mean that this ethical issue is the same for clinical drug trials in CF medicine for example? There is much hope for a 'cure' or life saving treatment for CF so do pwcf (or their parents) take part in drug trails because researchers are able to tap in to this 'hope'. Is this any different to the emotional attachment and potential coercing of any participant in CF research? Do researchers ever take advantage of the special shared experience in the CF community?

How can researchers be sure to avoid taking advantage of the special CF community and their good will to make advancements in research?

Secondly, how can I be certain that meeting with parents before conducting interviews with children does not influence children's assent/consent to take part? By ensuring that children are able to say they do not want to take part even if parents say they should.

- -

Posted by Katie at 17:37   No comments:
Labels: children, coerce, Ethics, parents, phase two

A few thoughts on reflexivity

It is becoming quite clear that I need to start a reflective diary to be kept throughout the data collection process. I am already well into this so I need to start one asap. A reflective diary can