Supporting Children and Young People with Chronic Illness in their educational setting: Considering the role of the Educational Psychologist

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Abstract

It is well documented that the prevalence of chronic conditions among children and young people (CYP) is rising (NICE, 2019). In addition, poor educational outcomes of children with chronic illness (CI) are documented in research (Fleming et al., 2019; Lum et al., 2019). The overall aim of this research is to further understand how Educational Psychologists (EPs) can support children and young people with chronic illnesses. The unique contribution of this research is to consider the work that EPs are already doing and what practices and approaches they are taking. Additionally, I aim to understand the distinctive contribution of EPs and the barriers that they may face in providing additional support.

The first phase of this project involved conducting a survey using mixed methods (*n*= 100). Through this survey, I aimed to understand how EPs interact with children who have chronic illnesses. It included a quantitative section that used closed questions, which were mostly in the form of multiple-choice or binary items. This section measured how often EPs see children with CI, how they become involved, and what they do when they become involved. In the survey's qualitative section, the EPs were able to share their thoughts, perspectives, and experiences regarding working with children with CI and their role in providing support. The first phase of data collection influenced my research questions and exploration in the second phase. For the second phase of the project, focus group interviews were conducted to gain a better understanding of how some EPs work with children who have CI (*n*= 14). The aim was to explore the views and perspectives of EPs in their role of supporting and working with these children.

The synthesized results from each phase indicated that the EPs who participated in this study currently work with a diverse range of children with CI, but this work is inconsistent and often comes about through statutory assessment. I found that EPs work with children with CI

in similar ways to that suggested by SEED (2002) and Cameron (2006). Possible distinct contributions of the EP's role were indicated by participants and included their ability to 'bring' psychology, support multi-agency work, take a holistic approach, understand the child's perspective, and be a supportive professional. Barriers to supporting children with CI were considered and included: the EP's scope of practice, misunderstandings of the EP's role, their capacity and time, socio-political influences, and difficulties in collaboration between health and education.

This study has provided valuable insights into how EPs can support children with CI and indicates some potential opportunities for EPs in this endeavour. It contributes additional knowledge concerning the role that EPs have in supporting children with CI in a context where they experience poor educational outcomes (Fleming et al., 2019; Lum et al. 2019; Musgrave & Levy, 2020). I conclude with some implications for EPs' practice and research.

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List of Abbreviations

AEP	The Association of Educational Psychology
BPS	The British Psychological Society
CFS	Chronic Fatigue Syndrome
CI	Chronic Illness
CYP	Children and Yong People
CR	Critical realism
DFE	Department of Education
DFEE	Department of Education and Employment
DoHSC	Department of Health and Social Care
EHCNA	Education Health and Care Needs Assessment
EHCP	Education, Health and Care Plan
EP	Educational Psychologist
EPS	Educational Psychology Service
HCPC	The Health and Care Professionals Council
IHP	Individual Healthcare Plan
LA	Local Authority
NHS	National Health Service
NICE	The National Institutes for Health and Care Excellence
PE	Physical Education
SEED	Scottish Executive Education Department
SEN	Special Educational Needs
SENCo	Special Educational Needs Coordinators
SEND	Special Educational Needs and Disability
SEND CoP	SEND Code of Practice

SP	School Psychologist
TEP	Trainee Educational Psychologist

1. Introduction

In this chapter, I outline the rationale for this research and the context in which it resides. I first highlight the background of the research topic and provide a brief rationale. Following this, I consider the social-cultural context and the personal context that led me to explore this research topic. I conclude by briefly introducing the research focus and aims, although these will be explored in more detail in Chapter three. Finally, I conclude this section with a brief outline of the thesis structure to provide a broad understanding and overview of the research project.

1.1 Background

Before the COVID-19 pandemic, it was well documented that the prevalence of chronic conditions among children and young people (CYP) was rising. NICE (2019) highlighted that, in 2019, 1.7 million CYP in England were experiencing one or multiple long-term health conditions such as epilepsy, asthma or diabetes. The number of children with life-limiting conditions in England alone had risen from 26.7 to 66.4 per 10,000 between 2001/2 and 2016/17 (Fraser et al., 2021). The increase in prevalence was greatest in the under-one age group and was related to mainly congenital disorders, followed by perinatal disorders. The prevalence of children with a life-limiting condition was predicted to continue to rise until 2023 (Fraser et al., 2021). The rise in these conditions has been attributed to increased levels of deprivation, electronic recording of diagnosis, and improved levels of survival (Fraser et al., 2021).

Throughout the pandemic, alongside the threat of a COVID-19 infection, children with CI also experienced some failures in disease management (Lignou et al., 2022). The quarantine period and unsafe hospitals (due to the risk of infection) caused many illnesses to hide in the background. A crowded healthcare service and extended quarantine periods made it extremely challenging for doctors to work in their usual way. This exacerbated the existing difficulties experienced by children with CI. It has been speculated that, due to the lack of access to care at this time, missed or delayed diagnoses were experienced (Lignou et al., 2022). Additionally, an increase in disease severity for many children and young people was believed to have taken place (Greenwood, 2022). The significance of these effects of the pandemic is difficult to determine.

Thanks to medical advances, children with CI are living longer lives than ever before. The proportion of children whose illness ends in early fatality is decreasing (Fraser et al., 2021) and there are fewer emergency admissions of children with long-term health conditions (NICE, 2019). This implies a growing population of CYP living with and managing chronic conditions. Many of these young people manage their conditions successfully and live fulfilling lives. However, living with a chronic condition can have a negative impact on quality of life, including the need for daily adjustments to manage a lifelong condition. This experience can be especially challenging for young people and it has the potential to exclude children from aspects of a ‘normal’ life (Musgrave & Levy, 2020).

In some cases, CYP diagnosed with CI experience difficulties accessing education. It is well known that sufficient school attendance supports good health outcomes and reduces inequality (Jourdan et al., 2021). Nevertheless, children with chronic conditions are at risk of being excluded from a full educational experience as a consequence of their ongoing health difficulties (Musgrave & Levy, 2020). Previous studies have documented poor educational outcomes of children with CI (Fleming et al., 2019; Lum et al., 2019) and these will be further evidenced in Chapter 2. Poor educational outcomes suggest a potential need for professional support. In this research, I will consider whether the EP’s role is appropriate to support this population of children.

1.2 Socio-cultural context

The evolution of the EP's role has been documented over many years. In particular, significant developments in EPs' practices have been widely noted since the DfEE (2000) report and the Every Child Matters (2004) initiative. These reports actively placed the EP's role within a community context (Farrell, 2006). In turn, this supported multi-agency work in a 'team around the child' approach, requiring changes in service structure around more multi-agency teams (Farrell, 2006). As a result, EPs encounter more diverse work within a community setting (Farrell, 2006).

Although there has been an increase in diversity within EPs' work, this has also been impacted by recent and significant changes in the socioeconomic and political environment in the UK. The education sector has been negatively affected by more than a decade of austerity measures (Hargreaves, 2021). As a result, local authorities (LAs) have been forced to reduce expenditure due to budget cuts, whilst still being expected to deliver high-quality services (Hanley et al., 2020). Changes to taxes and benefit systems have also put greater pressure on families. This has increased poverty and rates of mental health difficulties, among other negative implications (Hanley et al., 2019).

Subsequently, the field of Special Educational Needs and Disability (SEND), in which EPs work, has faced significant challenges. Since the SEND reform in 2014, there has been a consistent rise in the number of Education Health and Care Plans (EHCPs) (GOV.UK, 2022), which has resulted in increased demands on LAs to deliver these plans. Consequently, EPs also experience significant pressure, as their workload is redirected towards fulfilling their statutory duties. Lyonette et al. (2019) evidenced this in a review of the EP workforce. Principal EPs mentioned that the most common demand placed on the service was an increase in statutory assessments. As a result, EPs experienced a decrease in work variety (Lyonette et al., 2019). Further exemplifying the difficulties, LAs have also experienced obstacles in recruiting EPs, often because there are attractive job opportunities elsewhere. Additionally, only a limited number of new EPs are trained each year (Lyonette et al., 2019). LAs have continually struggled at this time and, thus, only 58% of EHCPs were issued within the twenty-week deadline in 2020 (DoE, 2022). Children and families have consequently experienced difficult situations. These challenges have been acknowledged in the recent government green paper, which sets out a mission to fulfil children's potential, build parents' trust, and provide financial sustainability (DfE, 2023).

In summary, this context has put additional pressure on EPs to focus their time on statutory assessments. My experience has been that EPs are currently experiencing less traded work and more statutory work. Some services are experiencing a 'pause to trading' to focus on their statutory duties. This current climate may impact EPs' potential ability to support children with CI, as well as many other CYP.

1.3 Personal context

Before embarking on this research, I had a career as a primary school teacher in an all-through school. Early on, I took an opportunity to work as the primary school Special Educational Needs Coordinator (SENCo). I had some idea of what to expect in my new role, but the aspect I was most surprised about, rather naively, was the varied nature of the students and families I was supporting. Of course, this role was not just about SEN but also focused on areas of safeguarding, whole-school interventions, quality first teaching, and many more.

Another aspect of the role that I was not expecting was the support I gave to two students in the school who were diagnosed with CI. I will not elaborate too much to maintain confidentiality, but one child had a life-limiting condition and the other a condition that had to be carefully managed. Both students were vulnerable, and their illness was often seen as a deficit by other professionals. In my work with these children, I felt out of my depth. I spoke with medical professionals and clinical psychologists, and I attended hospital schools. I sought and received training about these conditions, but throughout these interactions and experiences, I did not get to the bottom of how I should support these children in school. I wondered about gaining expert advice on how the child's school day might look, what should their expectations be and, most importantly, how to make school a fun and enjoyable place. Other members of staff looked to me for advice on topics such as school attendance, reasonable adjustments, and inclusion. I did my best to support and answer. I wanted to ensure that the students felt that they belonged, that they knew they were capable, and that they were cared for.

In hindsight, I realise that I would have liked to have the opportunity to discuss these questions with an educational professional such as an EP. In my opinion, EPs play a crucial role in listening, validating, problem-solving, and planning. These are all skills that I believe would have helped to support me. When I started working in a LA, I became interested in the work that EPs did when they were given cases of children with CI. I shadowed these interactions, and it reminded me of the experiences I had had as a SENCo. In this research, I endeavour to explore EPs' views on this topic and to understand whether EPs have a consistent role to play in supporting children with CI.

1.4 Research focus and aims

This piece of research aims to explore the potential role of EPs in supporting children and young people who experience CI. It considers the work that EPs are already doing, what approaches they are taking, and the impact of their work. Additionally, it explores the potential contribution of EPs' work in the future: what approaches and practices they could potentially bring to support children and young people with CI. It will also highlight the barriers that EPs may face in providing additional support, and whether this area of work is included in their scope of practice.

To address these aims, this study used a mixed method, two-stage design to capture both the depth and breadth of EPs' views. The quantitative data aims to provide breadth, gaining an understanding of views across a large sample size. The qualitative data provides more depth in understanding experiences of supporting children with CI and captures complex and nuanced discussion about this work. The methodologies will be introduced and discussed in more detail in Chapter 3.

1.5 Outline of the research project

The thesis is organised into six chapters that document this two-phase research project. Following this first chapter, Chapter 2 comprises a review of the current relevant literature, exploring the definition of CI, the influence of policy, CI and educational outcomes, and the EP's role. The research aims and questions emerge from the literature review and are presented in Chapter 3, which considers the context of the study and its philosophical underpinnings. It will also discuss the rationale of the research design and provide further detail about the design. Following this, Chapter 4 describes the findings for both phases of the research separately, focusing on the research questions. Chapter 5 presents a discussion of both phases of the research, comparing key themes and relating this to relevant research. Finally, Chapter 6 presents a conclusion that considers the limitations of the study, implications for practice, and suggestions for further research.

2. Literature review

I begin this chapter by describing the search strategy used to complete this literature review. I move on to provide a discussion around the definition of CI. This is followed by an exploration of how children with CI may receive additional educational support. Next, I address why consideration for CYP with CI is so important in education. Within this, the links between CI and poor educational outcomes are examined. I then formulate the problem that has led to the focus of this research. Finally, I consider the EP's role and possible contribution to supporting children with CI. I review the literature in this area and identify a current gap in the research. Throughout this section, I present an argument that EPs may be in a good position to provide additional support to children with CI. Finally, I consider barriers to support and the potential future for the EP's role before presenting concluding thoughts.

2.1 Search strategy

I reviewed the literature using the following search engines: ERIC, PsychNet, APA Psychinfo, Jstor, and Taylor and Francis. After these searches, I expanded my search using Google Scholar. I also searched government and Department of Education websites. Finally, I reviewed articles, charities, and websites concerning CI; I used this information when I considered it to be particularly important. Initially, the search took place between December 2021 and June 2022, but an additional search was undertaken between January and April 2023 to consider more recently published data.

The literature search comprised two phases. First, an overview and preliminary search of the literature was needed and thus the search considered CI and educational outcomes. Initially, I searched for the key term 'chronic illness AND educational outcomes.' This search yielded valuable literature and helped me identify additional key terms. With this knowledge, I was able to broaden my search for relevant literature. Initially, I set a research parameter of the last 5 years. In response to this search, other relevant terms that I incorporated into my search strategy included:

- Chronic illness, chronic disease, medical conditions, long-term health problems, life-limiting conditions, life-threatening conditions.
- Children, child, childhood, young person.
- Educational outcomes, education, school, learning.

Only these key terms were used to search for relevant literature. To obtain a wider range of literature and research related to the topic, I extended the time frames of my search to 15 years. The search returned literature that focused on educational outcomes for children with CI, including some interesting research that considered the school experiences of children and families. Some of the articles had been published by charities supporting certain conditions, e.g. Asthma UK. It is recognised that these papers may entail greater potential for bias and lack of information regarding methodology, on this basis, the use of information from these sources was carefully considered.

The second phase of the search focused on the role of EPs in supporting children with CI. During my initial search I used the keywords 'educational psychologist AND chronic illness' and specifically searched for studies conducted in the UK over the past five years. Unfortunately, I found very limited literature, so I decided to broaden my search terms to ‘educational psychologist AND long-term health problems’; and ‘educational psychologist AND medical condition’. Due to the lack of research, I removed the time parameter and searched for international research. Many of the results found were valuable to understand the context of children with CI in education and further informed the first part of this literature review. However, only two articles specifically considered the role of the EP in relation to chronic illness.

Therefore, I expanded my search terms to include ‘school psychologist AND chronic illness’; ‘school psychologist AND long-term health problems’ and ‘school psychologist AND medical condition’. I used the term ‘school psychologist’ (SP) to expand my search internationally since other countries refer to a role similar to EPs as SPs (although the role is not precisely the same, as SPs tend to work directly with individual students while EPs work at three different levels, namely the child, the school and the community). I felt it was important to consider international research to obtain a comprehensive understanding of the existing knowledge around my topic. As there seems to be a lack of research from the UK, it is important to consider the strategies adopted by other countries that could be useful for the UK to comprehend in this context. I hoped that these results would highlight some key contributions that psychologists working in education could bring to children with CI.

This led to a few more results that specifically mentioned the role of the EP or SP. Altogether, the 11 results that I found were written in the USA (8), Australia (1), or the UK (2). The main focus of these results was children with CI, but they all mentioned the role of the EP or SP. They covered a range of topics including knowledge and beliefs, school re-entry, collaboration with other professionals, therapeutic support, teachers’ confidence, and risk assessments. I carefully considered these studies and highlighted some key literature themes. When doing this, I considered the key contribution of the EP or SP that the work had highlighted, and grouped themes based on this.

Finally, I expanded the search once again and used a list of the most common CIs in the UK to support my search (DEWIS Wales, 2023; NICE, 2019; RCPCH, 2022). These included: arthritis, asthma, cancer, chronic fatigue syndrome, cystic fibrosis, diabetes type 1, diabetes type 2, eczema, epilepsy, and heart disease. Within this, I searched the literature for discussion about the EP’s role specifically. I searched for ‘educational psychologist AND xxx’, where ‘xxx’ represented a specific illness. I did not add a parameter of time or location on this search. Relevant articles were found concerning arthritis (1), chronic fatigue syndrome (1) and epilepsy (5). A discussion of this literature is found later in this chapter, where I reflect on the EP's role (section 2.8).

2.2 Defining chronic illness

I now turn to the definition of CI and how it is currently defined both in research articles and policy documents. Understanding and clearly defining a concept such as chronic illness is vital. How professionals use key terms, such as CI, may have a direct impact on the possible support that CYP have access to.

The National Health Service (NHS) in the UK defines CI as 'a health problem that requires ongoing management over a period of years and decades' (NHS, n.d). The term CI is not commonly used in government documentation, which instead uses other similar terms. For example, the Department of Health and Social Care (DoHSC, 2015, para 1) uses the term 'long term medical conditions' and defines this as 'a health problem that can't be cured but can be controlled by medication or other therapies'. In the context of education, the Department of Education (DoE) uses the term 'medical conditions'.

In the statutory guidance 'Supporting Children with Medical Conditions' the DoE (2014) posits that the term 'medical conditions' can apply to both mental and physical health. This term seems broad, but no clearer and more specific definition of the term is included. Additionally, no clear definition of the term is evidenced in any recent government documentation, including the SEND Code of Practice (2015).

In contrast, the term CI is commonly used in the research literature. When defining CI, it seemed that three consistent themes are most prevalent. The first theme highlights that, for an illness to be chronic, it requires medical attention from a professional (Bell et al., 2016; Lum et al., 2019). The second theme proposed that the illness must last for a long time; many papers suggested a minimum of three to six months (Barnett et al., 2018; Berger et al., 2018;

Lum et al., 2019; Musgrave & Levy, 2020). The third theme highlighted that most CIs had a poor prognosis. This tended to include either a reduced lifespan or a negative influence on the child's development (Bally et al., 2018; Barnett et al., 2018; Bell et al., 2006; Musgrave & Levy, 2020). A poor prognosis was described as one of three differing conditions:

- A condition that was severe and interfered with the child's usual activity (Musgrave & Levy, 2021).
- A life-limiting condition (LLC) whereby a young person's life was shortened due to the illness (Fraser et al., 2021).
- A life-threatening condition (LTC) whereby treatment to cure the illness was possible but had the potential to fail (Fraser et al., 2021).

Following these considerations, I use the following definition in this thesis: a chronic illness is a health problem that is long-term (must last over 3 months), requires ongoing management and the support of a professional, and has a poor prognosis.

This definition would usually allow for both physical and mental illness. However, due to the scope of this research, this project limits the definition to a physical chronic illness, such as asthma, diabetes, or cancer. The relationship between mental and physical health conditions is recognised, so the complete separation of these constructs is challenging.

2.3 Difficulties with definition

Within the political context, definitions and labels are often nuanced and their use is inconsistent. Norwich (2014) highlighted the inconsistency in the use and definition of the term SEND. This inconsistency is present across key legislation, policy, and models. Despite this, these same documents and political structures result in the continuation of the labelling of students: instead of focusing on their strengths and potential, students are often labelled based on their deficits (Rolfe, 2019). This takes a medical model perspective, whereby the deficit lies within a child and successful support comes from an accurate assessment of the child’s ‘impairment’ (Rolfe, 2019).

Conversely, labels are seen as an important way to ensure that children gain additional support through the correct statutory guidelines, particularly by concerned parents (Rolfe, 2019). Labels can be a useful strategy if they lead to appropriate and specific interventions that support CYP (Lauchlan & Boyle, 2007). Labels can offer a broad view of the child’s needs, perhaps leading to an intervention, but they may fail to focus on the child’s individualised and specific strengths and difficulties. One might argue that an individualised intervention programme may be more supportive (Lauchlan & Boyle, 2007). The label does not accurately provide intervention support for an individual child (Lauchlan & Boyle, 2007).

Guidelines and documents that might support children with CI will be discussed in the following section. To support children with CI, it is crucial to identify the key terms within the legislation that may apply to them. It could be argued that, in some circumstances, the terms ‘SEN’ or ‘disability’ may apply to children with CI. Although this topic is nuanced, it identifies where support for children with CI is currently documented. This will now be explored further.

2.4 CI and its relation to SEN

The Children and Family Act (2014) states that a child has an SEN if they have a ‘learning difficulty or disability which calls for special educational provision to be made’. CYP must have a ‘significantly greater difficulty in learning than the majority of others their age’ or ‘have a disability which hinders them from use of facilities of a kind generally provided for others the same age’ (Section 20).

2.4.1 Disability

It should, therefore, be considered if a child with a chronic condition could be classified as ‘disabled’ to access additional educational support. Under the Equality Act

(2010), a disability is defined as ‘a physical or mental impairment that has a “substantial” and “long-term” negative effect on your ability to do normal daily activities’ (Section 6). Certainly, some CIs can fit within this definition. For example, Neo et al. (2017) found that people living with cancer often report limitations in normal activities that make them unable to live independently. In addition, children with epilepsy can find normal activities difficult due to the constant risk of seizures (Aguiar et al., 2007). However, as CI is so varied, some forms of illness may not be sufficiently severe to fit into this definition.

Milder forms of chronic conditions may not significantly affect normal daily activities. For example, Bever et al. (2014) argued that 90% of eczema cases are moderate to mild and can be managed without significantly impacting daily life. Thus, chronic illnesses do not always classify as a disability.

2.4.2 Learning difficulties

Additional support should be considered if a child with a chronic condition can be classified as having a ‘learning difficulty’. A learning difficulty is when a child ‘has significantly greater difficulty in learning than the majority of others their age’ (Children & Families Act, 2014, p. 20). Factors that could suggest that children with CI have significantly greater difficulty in learning (such as school absences, social difficulties, and decreased physical functioning) are considered later in this chapter.

On a day-to-day basis, it may be argued that some children with CI face significant challenges in their education. Isik and Isik (2017) highlight that asthma can often be controlled and managed with the right care and medication but, despite this, it can have a large impact on children’s lives. Having asthma can come with exacerbating factors, such as restrictions on school activities (particularly before and after school clubs and PE), nocturnal coughing, negative self-confidence, and visits to hospitals. All of these may impact the child’s learning ability (Isik & Isik, 2017).

Children with epilepsy can experience direct symptoms that affect their learning abilities. Reilly et al. (2014) conducted a study whereby 85 children with active epilepsy (defined as having had a seizure in the last year) underwent psychometric assessment of word reading, sentence comprehension, spelling, and maths computation. Seventy-two per cent of the children tested displayed low achievement (1 standard deviation below the test mean) in a minimum of one subtest. This result could be due to many factors, including seizures at early ages, lack of school attendance, and the effects of medication (Reilly et al., 2014). As highlighted previously, CI variations are vast and unknown, but these accounts highlight that children with CI could find learning more difficult than their peers. Therefore, it could be argued that some children with CI could be supported on the basis that they have learning difficulties.

2.4.3 Presenting nuance

With the evidence I have presented above, it can be argued that there may be an overlap in the needs and definitions of having a CI, SEN, and a disability. But the relationship is clearly complex and nuanced. Certainly, it can be argued that children who have CI are likely to be a vulnerable population that needs to be noticed and supported when appropriate. Despite this, as I have highlighted, it is challenging to understand where children with CI ‘fit’ in terms of legislation and receiving support in school. This will now be further considered.

2.5 Receiving support in school

Within the UK, there are several key documents and legislation related to children who experience chronic conditions. This includes the Children and Family Act (2014) and the Supporting Children with Medical Conditions document (2014). Within the former, children with medical conditions are only briefly mentioned: the Act simply highlights the responsibility of schools to support children with medical conditions and act in accordance with statutory guidance.

In contrast, the Supporting Children with Medical Conditions (2014) document discusses appropriate support in more depth. The document suggests that children with CI should have an individual healthcare plan (IHP). The plan should include:

- A description of the condition and resulting needs. This includes medication, practical reasonable adjustments, management of the condition and any dietary needs.
- Support surrounding social, emotional, and educational needs. This includes how school absences might be managed, exam arrangements, and additional support.
- Supporting inclusion for activities and trips.
- Emergency responses.

The Supporting Children with Medical Conditions document encourages schools to set out these aspects clearly, to ensure that parents are comfortable with their child's needs being met in school.

Despite this, there appears to be limited research that assesses the effectiveness and use of IHPs. Some studies highlight that these documents have the potential to be extremely supportive. At least two studies have shown them to increase teacher awareness and improve children's experiences (Boisclair-Fahey, 2009; Singleton, 2015). In both studies, the support of a multi-disciplinary team, including both healthcare professionals and educators, was used to support the creation of the IHP. These teams also reviewed its effectiveness. This ensured that the plan was both effective and supportive (Boisclair-Fahey, 2019; Singleton, 2015). Without this level of intervention, the general effectiveness of these plans is unknown due to the lack of research in this area, and this is an important consideration for future research. Many children with chronic conditions might well be supported by this documentation, but the IHP does not set out any specific learning provision or needs unless the child also has recognised additional SEN.

After a review of the literature and documentation, it appears that the Supporting Children with Medical Conditions (2014) document is the only legislation that sets out supportive measures specifically for children with chronic conditions. Other legislation is focused on children with disabilities and SEN, which, as discussed previously, could in some cases be supportive for children with CI. An example is the SEND Code of Practice (2015) (SEND CoP), which is statutory guidance aimed at supporting children with disabilities and SEN. Additionally, the Equality Act (2010) provides guidance that protects people from ‘harassment, victimisation, and discrimination’, and campaigns for the equal rights of people with disabilities. It advocates for equal educational opportunities for all.

Although, at first glance, these documents do not seem relevant to children with CI. As highlighted previously, it could be argued that the terms ‘SEN’ or ‘disability’ may apply in some circumstances. Despite this, it is challenging to understand where children with CI ‘fit’ in terms of legislation, outside of the Supporting Children with Medical Conditions (2014) document.

Musgrave and Levy (2020) highlighted that the definitions set out by the government (that I presented in section 2.2) may disqualify a student from receiving special educational services due to a lack of clarity around the terms. Currently, children with CI often have a health plan but not SEN support (Musgrave & Levy, 2020). Socially, we often perceive a SEN as something related to a particular learning difference, such as dyslexia, and not something related to vulnerable populations (Musgrave & Levy, 2020). Therefore, this often means that children with CI do not access the educational support they may need (Musgrave & Levy, 2020). It is important to highlight that, due to the vastly variable nature of CI, not all children will need educational support. However, students that do have needs may struggle to access the necessary resources due to a lack of support from current legislation. The following section will consider the relationship between CI and poor educational outcomes.

2.6 Chronic illness and poor educational outcomes

As highlighted in Chapter 1, the poor educational outcomes of children with CI are well documented in research (Fleming et al., 2019; Lum et al., 2019; Musgrave & Levy, 2020). Key literature was presented by Lum et al. (2017, 2019). Lum et al. (2017) conducted a meta-review of eighteen systematic literature reviews, covering 172 studies, to consider the relationship between CI, school experiences, and outcomes. In 2019, Lum et al. conducted a quantitative study that compared students with chronic illness and students without chronic illness to assess school experiences. The findings highlight the difficulties that children with CI can experience:

> Compared with students without chronic illness, students with chronic illness have significantly greater school-based needs. Nonetheless, students with chronic illness were no more likely to receive additional home- or school-based tutoring, or assistance from a teacher’s aide or school psychologist, than children without illness. Our study suggests that students with chronic illness have significant unmet school needs across academic, social, emotional, and attendance domains of school. (p. 632)

Although Lum et al.'s (2017, 2019) studies were conducted in Australia, they still offered valuable insights that can be applied to the UK. Looking at research from other countries helps us identify common trends and issues that might also be present in our own context. It also provides an opportunity to explore potential solutions that have been successful elsewhere. Given the current lack of research and findings related to the UK, this section will consider international and UK research. Much of the international research discussed derives from Australia, USA and Europe, these are particularly relevant to the UK due to the similarities in cultural context and education systems that come from a western society.

However, it's crucial to acknowledge that there are still differences. This emphasizes the importance of conducting further research in the UK regarding this topic. I have made note of international studies when it is important to understand the context of the research.

In this section, I will highlight the key contributory factors in the literature that influence poor educational outcomes for children with CI. I will discuss levels of attainment, school absenteeism, social impacts, physical functioning, communication between education and health, poverty, and the effects of COVID-19. It should be considered that the studies presented in this section contain limitations due to variations in their terminology and definitions of CI. It is also important to note that many of these factors and their effects may be interrelated.

2.6.1 Levels of attainment

Students in Australia who experience CI are reported to underperform compared to their peers (Lum et al., 2019). Lum et al. (2019) found that students with CI were 3.8 times more likely to repeat a year and 4.9 times more likely to have illness-related school absenteeism. Moreover, Fleming et al. (2019), focusing on children in the UK with asthma, found that they experience lower attainment in exam results, had higher absences, and were more likely to be on the SEN register than their peers. Furthermore, it was found that a significantly higher number of children with CI were rated as ‘below’ their age-related expectations in both numeracy and reading in Australia (Nasuuna et al., 2016).

2.6.2 School absenteeism

A key determining factor for low educational outcomes in children with CI is greater school absence (Lum et al., 2019). Lum et al. (2019) highlighted that in an Australian context, 55% of CYP with CI experienced at least a day of absence over ten days of school, compared to just 24% of their peers. In the USA, many of these absences are due to illness, diminished physical functioning, or diminished social functioning (Emerson et al., 2016). In the Netherlands, medical absenteeism is found across many different CIs (Vanneste et al., 2015). In the UK, chronic fatigue syndrome is a CI that can significantly influence school attendance. Sankey et al. (2006) found that, of 28 students with chronic fatigue syndrome 22 took up to three months to achieve full-time education following a gradual return to school. Six students were either in school part-time or at home.

Frequent absence due to illness is an experience shared by many children. The Department for Education (DfE, 2022) highlighted that in 2018/2019 (the last year uninterrupted by COVID-19), illness accounted for 52.6% of all absences. Furthermore, at a conference on adolescent medicine and child psychology, Eves (2017) reported that children who were absent for more than 20 days were more likely to have a CI than those who missed less than 5 days.

In addition to diminishing physical or social functioning, Emerson et al. (2016) also highlighted that in the USA parental anxiety about the illness may contribute to missed school days. They suggest that parents feel apprehensive about the child returning to school. Kish and Haslam (2018) support this, suggesting that Australian parents worry that children will not get the same care at school compared with at home, and often report that the child's health gets worse when they are at school or nursery. In the UK statutory guidance Supporting Children with Medical Conditions (2014), the DfE shows an awareness of parental anxiety by stating that a health plan should be put in place to support parents in trusting the school to meet the child's health needs.

2.6.3 Social impacts

Lum et al. (2019) found that Australian children with CI were 4.6 times more likely to have low social confidence compared to peers who did not experience CI. Children with CI often experience mental health difficulties alongside the physical health challenges that they face. One possible reason for this, is the social challenges that they may experience (Runions et al., 2019). This can involve feeling different, being stigmatised, discrimination, bullying, and lack of teacher understanding (Runions et al., 2019). Emerson et al. (2016) explained that children with CI in the USA can feel ‘undesirably different’ (p. 3). Runions et al. (2021) found that Australian children with asthma were more likely to be involved in bullying, either as the bully or the victim, compared to their healthy peers. These bullying interactions elevated peer problems for the child. Such factors can be challenging to navigate when children with CI want to ‘conform’ and feel as if they are no different from others (Jackson, 2013).

Additionally, these social difficulties can then become a factor in poor school outcomes. Australian children who experience these social difficulties are more likely to take more absences from school and experience school exclusions (Runions, 2021). Lack of school attendance can further lead to disruption of relationships with friends and increased stigmatisation (Jackson, 2013) which, in turn, lead to more school absences (Runions, 2021). This cyclical experience can lead children to feel that they don’t ‘fit in’ with their peers when re-entering school after a period at home (Janin et al., 2018).

2.6.4 Emotional impacts

Bergmans & Smith (2022) found that in the USA CI in CYP is linked to the experience of mental illness and poor mental health. Despite vastly different experiences depending on the type and severity of the illness, commonalities are also noticeable. This can include undergoing treatment, daily management, and disruption (Bergmans & Smith, 2022). Children with CI have a higher chance of experiencing insecure parent attachment, anxiety, poor self-esteem, and depressive symptoms (Bergmans & Smith, 2022; Feeney, 2001; Pinquart, 2013). Bergmans and Smith (2022) found that having a variety of different health problems in childhood for more than six months (including disability, allergies, epilepsy, heart difficulties, hearing or visual impairment, respiratory illness, severe headaches, and stomach difficulties) was associated with depression in later life. Experiencing poor mental health has been linked to lower educational outcomes, which exemplifies the difficulties that children with CI may experience (Brännlund et al., 2017).

2.6.5 Physical functioning

Diminished physical functioning can impact school outcomes for children who have CI. One example of such a decline is a possible negative impact on general brain development. Stunted or damaged brain development will have a detrimental influence on a child’s development and school outcomes. Children who have survived brain cancer can experience deterioration in academic attainment due to the treatment and their illness. For example, Vanclooster et al. (2019) suggested that children often demonstrate reduced performance due to brain dysfunction. This can affect ‘concentration, executive functioning, memory, and visuospatial abilities, affecting academic progress in mathematics, spelling, and reading’ (p. 1). They found that children reported finding it hard to listen and write at the same time (Vanclooster et al., 2019). This type of decline in academic attainment can also be seen in children with epilepsy, which may be due to continuous and prolonged seizures and dysfunction in the brain (Aguiar et al., 2007).

In addition to stunted brain development, some CIs can cause diminished physical functioning with the onset of extreme fatigue. Nunes et al. (2018) highlight that fatigue is the most common symptom associated with chronic conditions. They show that children with cancer often experience high levels of fatigue, which is often exacerbated by chemotherapy treatment. This fatigue can influence their psychological, physical, and cognitive health (Nunes et al., 2018).

Many other illnesses also cause significant fatigue in children and, for some, it is the primary and most significant symptom. For example, children with chronic fatigue syndrome may not experience lessened fatigue even after significant rest (Rowe, 2019). They can also experience cognitive difficulties, flu-like symptoms and pain (e.g. headaches or muscle aches) (Rowe, 2019). The symptom of fatigue brought on by many CIs can affect all parts of the child's life, including their education. Rowe (2019) posits that children with chronic fatigue syndrome experience significantly reduced time at school, with a detrimental impact on educational functioning. It can be argued that any significant long-term fatigue will have an impact on a child's education.

These are just two examples of possible diminished physical functioning that experiencing CI could create. However, it is important to note that, due to the vast nature and differences in CIs, many other examples of diminished physical functioning exist and can affect a child or young person's educational outcomes.

2.6.6 Communication between education and health

Jourdan et al. (2021) highlight the importance of education and health professionals working together effectively and cohesively to obtain the best outcomes for young people. Currently, the UK's education and health systems are separate and communication between the two can be challenging to facilitate (Jackson, 2013). Multi-professional collaboration, with a variety of different professionals, can be challenging to navigate due to a multitude of factors including lack of resources (time and money), lack of ownership, conflicts of interest, and communication difficulties (Solomon, 2019).

However, the need for multi-agency work is key in complex cases (Solomon, 2019). It is essential to consider that the experience of a CI can differ greatly, making it difficult for teachers to feel prepared to support each child (Mukherjee et al., 2010). When surveying some teachers in the USA, Berger et al. (2018) found that they were not aware that children with CI may need additional learning support in their classrooms. Teachers were not fully aware that these children may experience additional barriers to educational achievement. Furthermore, they had not considered the possible social implications that a CI can have. This survey was small and cannot be generalised across all teachers, but the findings do highlight that some professionals may not have recognised that there may be a connection between physical illness and poor educational outcomes (Berger et al., 2018). Additionally, in the UK Mukherjee et al. (2010) found that the support offered by teachers for children with CI was highly variable across different classrooms.

Both studies highlighted a real need for teachers to have more direct discussions with health professionals who support children with chronic conditions (Berger et al., 2018; Mukherjee et al., 2010). It appears that clear supportive collaborative dialogue is needed for educational support. If this is not provided, poor communication between education and health systems could be described as a contributory factor for poor educational outcomes for children with CI.

2.6.7 Poverty

It is well documented in the literature that being brought up in poverty is associated with poor health outcomes (Browning & Rigolon, 2019). The UK Government Chief Medical Officer’s Annual Report (2020) highlighted that people on lower incomes were more likely to have poor health, with those in the most deprived areas spending a larger proportion of their life experiencing poor health. Sadly, the report suggested that the overall gap in life expectancy, when comparing the most deprived populations to the least, is 9.5 years for men and 7.5 for women.

Additionally, living in poverty can mean that managing a CI is more challenging. Umaretiya et al. (2021) highlighted that, in the US, children diagnosed with cancer and living in poverty had a decreased survival rate and were more likely to relapse, compared to children not exposed to poverty. Asthma UK (2018) argues that asthma is more widespread, and people are more likely to visit hospital due to asthma, in deprived areas. Living in poverty can include a lack of food, housing, funds, and transportation (Umaretiya et al., 2021), all of which support the management of illness or recovery. Those communities in poverty are also more likely to be exposed to an environment that increases poor health; for example, be exposed to smoking or air pollution for children with asthma (Asthma UK, 2018).

The correlation between poverty and poor health is important to note when considering school outcomes of children with CI, as this population is also more likely to experience poor educational outcomes (Green et al., 2018). Children living in poverty, who are chronically ill, are therefore an especially vulnerable group when it comes to managing their health and educational needs.

2.6.8 Effects of COVID-19

In addition to the aforementioned factors, the impact of the COVID-19 pandemic has had an additional negative effect on children who have CI, and on their education in the UK. As highlighted by Hamilton et al. (2021), many children with CI may not have returned to school during the pandemic, even when their peers chose to do so. This may be due to the weakened immunity that some CIs create, and a lack of research on the safety of those with CIs in the context of COVID-19 (Hamilton et al., 2021).

Along with the concern surrounding the threat of a COVID-19 infection, children with CI have also experienced some difficulties in disease management (Lignou et al., 2022). A busy healthcare service and long quarantine periods meant that doctors were unable to work in their usual way. For example, in the middle of the pandemic, Ashton et al. (2020) wrote that ‘those of us working in paediatric gastroenterology now lack the ability to provide the same level of diagnostic care and ongoing management to our patients’ (p. 706). Additionally, some patients experienced delayed routine follow-up visits that are vital to the maintenance of their illness (Lignou et al., 2022).

Despite this, the pandemic also offered a unique chance to raise awareness of factors that affect children with CI, and of potential solutions to support them. As highlighted by Ashton et al. (2020), doctors became very familiar with alternative methods of working, including over the telephone or via video calls. Teachers also became used to adapting their classrooms to online delivery. These alternative procedures, which have now become a regular occurrence, may be able to support children with CI in the future when they have periods where they need to be at home or in the hospital.

2.7 Formulating the problem

When formulating the problem for my research project, I can summarise that children with CI are more likely to have poor developmental and educational outcomes (Barnett et al., 2018), but they may not be recognised as a vulnerable population who could require additional specific educational support in certain circumstances. Therefore, this highlights the need for additional support and attention for this population of children. It could be argued that, in this context, there could be a role for EPs in supporting children with CI. I will now consider the role of the EP and whether this fits within their scope of practice.

2.8 The EP's role

The Association of Educational Psychologists (AEP), the professional body and trade union for EPs, described Educational Psychology as 'the application of psychological theory, research and techniques to support children, young people, their families and schools to promote the emotional and social wellbeing of young people' (AEP, n.d). The AEP adds that EPs support students with SEN to reach their best potential. EPs do this by considered assessment, reviews, and monitoring. EPs work with those aged 0–25 and consider a variety of factors, including student development, social skills, emotional skills, behaviour, and education. The AEP proposes that the main work of EPs is through consultation with families and a variety of professionals, including doctors.

The British Psychological Society (BPS), an organisation that promotes and represents psychology in the UK, describes EPs as professionals who ‘look at how children and young people experience life within the context of their school and home environment and how different factors in these environments interact with each other’ (BPS, n.d). The BPS acknowledges that the work of an EP can often take place in educational settings, LAs and sometimes in the child’s home.

Although these descriptions of the EP’s role appear simple and consistent, there has been long discussion and debate about it (Farrell et al., 2006; Hill, 2013; Jimerson et al., 2007; Lee & Woods; 2017; Love, 2009; Stobie, 2002). As highlighted in Chapter 1, the EP’s role is ever-changing and EPs work in a variety of ways. The addition of a traded service has further diversified opportunities for EPs (Lee & Woods, 2017).

The role and contribution of EPs has also been considered by SEED (2002), which suggests five key strands that describe general EPs’ work: consultation, assessment, intervention, training, and research. These all occur at the levels of the local authority, the school, and the child (Boyle & Lauchlan, 2009; Cameron, 2006). I will now consider these core constructs and the additional distinct contributions that EPs can offer.

2.8.1 Consultation

The use of consultation is often documented as an essential part of the EP’s role, as highlighted in the AEP description. However, different models and forms of consultation are widely used. Leadbetter (2006) posits that, at that time, there had been little clear development around the use, description, and skills of consultation approaches.

Wagner (2000, 2008) most notably described and conceptualised consultation concerning the EP’s role and service delivery. Wagner (2000) posits that consultation is collaborative and voluntary, allowing for the opportunity to use and explore different approaches and practices within it. Wagner (2000) describes consultation as ‘a process in which concerns are raised, and a collaborative and recursive process is initiated that combines joint exploration, assessment, intervention and review' (p. 11). This is a supportive process, that can consider the child's strengths and needs and provide early intervention (Nolan & Moreland, 2014). In addition, Leadbetter (2006) suggests that consultation can be used with multi-agency professionals when the outcomes of the meeting are specific actions that are taken with the child in mind. EPs' joint problem-solving skills may be supportive in these meetings.

2.8.2 Assessment

Assessment has consistently been a prominent feature of the EP's role. In the 1950s, the primary role of the EP was to assess IQ and provide results that determine a child's 'disability' (Love, 2009). Within this context, it was thought that medical officers were using IQ testing unreliably, so psychologists developed psychometric testing to support the accurate assessment of a child and their needs. Love (2009) highlights that, indeed, this is the original view of schools and parents: they assumed that child psychologists were cognition 'testers'. This view may persist somewhat even today. Lee and Woods (2017) highlighted that some SENCo's in the research viewed EPs as specialists who provide professional cognitive assessment.

Despite this, assessment appears considerably different from testing, and the use of psychometric assessment can be contentious in the current context. In recent decades, psychometric assessment has been viewed not so much to provide IQ scores, but as a tool to be used in conjunction with other assessments to provide a fuller understanding of a child's specific strengths and needs (Boyle & Lauchlan, 2009). This provides supportive evidence to enable intervention and provision in support of the young person (Cameron, 2006). EPs also have a specific role in communicating the limitations of psychometric testing (Boyle & Lauchlan, 2009; Love, 2009).

2.8.3 Intervention

As discussed through consultation and assessment, intervention is a vital aspect of the EP's role. Within their conceptualisation of a problem, psychologists use evidence-based practice to consider the bigger picture and to gain an understanding of the problem. From this, they provide an intervention plan to support CYP (Cameron, 2006). The development of a specific intervention is focused on the understanding of the child, their experience, and their circumstance. Psychological theory is used in this instance to both understand the child's reality and inform evidence-based intervention (Black & Allen, 2019).

2.8.4 Training

Training has become an important aspect of the EPs' role. As this role broadened from simply being 'testers', EPs began to support, not just the child, but the teachers and educators within school settings (Love, 2009). In the current context, EPs can provide support and training to schools in a variety of ways. At times, this could be in support of teacher education, either as part of initial teacher training (Lohse-Bossenz et al., 2013) or ongoing professional development (Poulou, 2006). EPs can also support training in other contexts. One example is contributing to training through charity-funded projects such as the Timpson Project. Alternatively, in my own experience, EPs have provided training to parents, designated safeguarding leads, senior leadership teams, teaching assistants, and more.

2.8.5 Research

With changes to EP training, resulting in the establishment of a doctoral training programme seventeen years ago, there has been a continuing discussion about the promotion of the EP's role in research (Campbell & Green, 2022). This should support links between research and practice, strengthening outcomes for students (Campbell & Green, 2022). This is particularly pertinent now, as the link between research and practice is often not well developed. Campbell and Green (2002) argued that EPs are in a suitable place to develop this link, due to their dual knowledge of research and education.

2.9 Distinctive contributions of EPs

Alongside the key areas of work that EPs carry out, Cameron (2006, p. 293) proposes five distinctive contributions of EPs. These will be considered in the following sections.

2.9.1 'Adopting a psychological perspective'

Cameron (2006) highlighted that EPs add something that others cannot: a distinctive psychological perspective that is inspired by scientific enquiry and 'evidence-based practice'. Others have also commented on the application of psychology as being distinctive to the EP's role. Birch et al. (2015) argue that EPs use applied psychology throughout each interaction, in support of children, parents, teachers, and other professionals. In this perspective, rather than taking a singular view, psychologists often carefully consider how multiple factors can integrate into the child's experiences (Cameron, 2006). EPs also consider the multiple layers of a problem and collate everyone's views to support a solution (Cameron, 2006).

2.9.2 'Drawing on the knowledge of psychology to uncover mediating variables'

Just as psychologists consider multiple factors, they must also consider alternative explanations for complex situations. By discovering mediating variables, EPs offer a hypothesis that others may not have considered and that may not be the most obvious one (Cameron, 2006). For example, a teacher may consider a child to be disturbing the class due to low motivation, but an EP may offer an alternative hypothesis, such as an SEMH need. The EP provides a possible alternative reality that may support change for that young person.

2.9.3 'Unravelling problem dimensions'

Many situations presented to EPs are complex and not clear-cut. These situations need careful consideration and to be unpicked. EPs use problem analysis to support this. Problem analysis is a systematic process whereby information is collected and analysed in a structured way (Cameron, 2006). The use of psychological models can support understanding the problem’s dimensions, and EPs use a variety of models to support their work. Such examples include the Monsen Model, COMOIRA, and the interactive factors framework, among many others.

As an example, the Monsen Model is a framework that supports problem analysis. It ensures that complex and nuanced problems can be structured so that evidence-based analysis can be completed (Kelly, 2006). The problem analysis framework was created in support of trainee educational psychologists (TEPs) to encourage their understanding and ability to solve problems created by complex real-life situations (Monsen & Frederickson, 2008) The idea is that an accurate psychological analysis leads to more specific and successful intervention (Kelly, 2006). The COMOIRA model has a similar but more flexible approach, with a particular focus on promoting effective change (Sedgwick, 2019).

2.9.4 ‘Using evidence-based strategies for change’

EPs are required to use evidence-based strategies throughout their support of a young person (Cameron, 2006). Each stage of support should be carefully considered, including the initial consideration of approaches that they might work with, the assessment they might use, the models they might consider, and the interventions they might suggest. This supports EPs to be up to date with relevant research and supportive interventions (Cameron, 2006).

2.9.5 ‘Promoting big ideas’

Finally, EPs have a role in promoting ‘big ideas’ when working with schools, families, and children. Giving clients autonomy and providing empowerment about the things that can be achieved can be extremely supportive for all parties (Cameron, 2006). This provides a contrast to pointing out deficits and instead focuses on a positive future.

2.9.6 Additional possible contributions

It can be argued the EP's role may even go further than Cameron's (2006) suggestions, with other contributions being present across differing areas of research. A discussion of all these additional contributions is beyond the scope of this chapter. However, one key aspect of the EP's role that has not been explicitly mentioned is their ability to effectively gather the views of the child (Farrell et al., 2006). It can be argued that EPs are well-placed to use a variety of techniques and theories to support their ability to do this. Smillie and Newton (2020) investigated how EPs obtained and represented CYP's views, finding that EPs often use a selection of techniques in meetings, including self-report scales, solution-focused questioning, therapeutic approaches, person-centred planning, and other indirect methods (Smillie & Newton, 2020). These techniques are supported by psychological theory, particularly solution-focused theory, and personal construct psychology (Smillie & Newton, 2020).

This section has highlighted the EP's role and possible contribution; however, it has not considered whether this may be supportive of children with CI. The following section will address this, as well as considering the current context, barriers, and future practice.

2.10 Potential EP's role in supporting children with CI

As presented in the previous section, it can be argued that the distinctive contributions that EPs bring could have great potential to support children with CI. As already highlighted, cases of children with CI can be complex and the vast nature of the different diagnoses emphasises this complexity. Cameron (2006) argues that EPs can discover mediating factors and unravel problems to get to the root of a child's needs, whilst at the same time validating the real-life complexities. It could be argued that this can offer much to the lives of children with CI. The contribution of EPs in bringing insights from psychology and evidence-based practices is an additional quality that is of value and that is distinctive to EPs (Cameron, 2006). It can be argued that this supports the involvement of EPs for children with CI, as it is unlikely that other professionals can bring the same support.

Some might argue that working with children who have CI could be beyond EPs' scope of practice. This is an important consideration throughout this research. The Health Care Professional Council's (2010) standard of proficiencies for EPs states that EPs should 'be able to practise safely and effectively within their scope of practice' (p.7). This includes understanding the limits of their knowledge and practices and seeking support from alternative professionals when needed. There might be particular emphasis on this aspect of the EP's scope when working with children who have CI, although it seems that there is certainly room for a contribution from EPs.

Despite this, there seems to be very little research that considers the EP's role in supporting children who have CI. More specifically, there seems to be a significant gap in research on the current work of EPs and the support they offer. I discovered this when conducting my literature search (section 2.1). I was unable to locate literature that commented on the current support that EPs bring to CYP with CI in the UK, and on the potential for future practice. This could either reveal a gap in the literature or it could suggest that EPs are not often involved with children with CI. This will be the focus of one of my research questions. The literature discussed in the previous section highlights the contributions that EPs may be able to bring to this vulnerable population; the next section will present the literature themes that were found when conducting a literature review for EPs and CI.

2.11 Key literature themes

The literature tended to focus on recommendations for educational or school psychologists and their contribution when supporting children with CI. For the purpose of this research, although US and Australian focused literature considers SPs, I will describe this literature using the terms ‘EP’ for consistency with the rest of the thesis. Although the roles have differences, ‘EP’ will refer to psychologists working in education. Many of the research was focused on the US. I was unable to find literature that discussed what EPs in the UK were doing in the current context and the implications of this. However, the literature does call for EPs to be available to support children with CI. Lum et al. (2019) suggest that psychologists are in a position to support students with CI by supporting teachers, communicating between health and education, and delivering evidence-based intervention. EPs were involved with children with CI at about the same rate as working with students who do not have CI. Other key literature themes found will now be discussed.

2.11.1 Types of CI

In the literature search, I found results that discussed the support of the EP for specific types of CI. For example, several articles focused on children with epilepsy. Reilly and Fenton (2013) specifically considered the role of the EP in supporting these children. Epilepsy may be a particular focus due to its relationship with learning difficulties and its association with cognitive assessments (Johnson & Parkinson, 2002; Papavasiliou, 2005; Petropoulos, 2019). Reilly and Fenton (2013) highlight that, alongside cognitive assessment, EPs can support in understanding needs, multi-agency work, and interventions.

The support of an EP was also mentioned in an article about arthritis, but no further comment was made about their specific role (Ansell, 1981). However, Brown and Cox (1999) considered children with chronic fatigue syndrome and highlighted the potential role of the EP in listening and believing the young person, collecting their views using personal construct psychology, having an empathic view, sharing knowledge with others, supporting families, completing assessments, and recommending appropriate provision. Additional literature highlighted other contributions of EPs within the context of CI, which will now be discussed.

2.11.2 Multi-agency working

A key theme that considered the contribution of EPs was the support that they could bring when working within multi-disciplinary teams alongside medical professionals and school staff, as well as with family members (Barraclough & Machek, 2010; Berger et al., 2018). In this process, EPs could support the translation of jargon (Ball & Howe, 2013; Schilling, 2018). EPs could also consult with school staff to support the child or young person (Schilling, 2018). Singleton (2019) found that school nurses valued the support of EPs for problem-solving, communication with parents, sharing resources, assessing student progress, improving outcomes, and avoiding duplication of services. However, despite this, the school nurses suggested that they had very little collaboration with EPs. Additionally, Arora et al. (2019) highlighted that EPs often feel ill-equipped to have multi-disciplinary meetings with medical professionals and may value more training on this. This form of contribution can be linked to that of consultation and unravelling problem dimensions discussed in the previous section.

2.11.3 School re-entry

Schilling (2018) stated that EPs are well-equipped to liaise with medical staff, school staff, and family to facilitate the re-entry to school by children with CI after time spent in hospital. Ball and Howe (2013) emphasise that EPs would be valuable at the discharge meeting at the hospital so that they can document what is said to support the child’s reintegration into school life. The documented discharge meeting could also be filed and used to understand the impact of the illness on the child and their future education, as well as on their possible social, emotional, and mental health needs. This draws on the EP’s ability to apply psychology and detect mediating variables as presented in section 2.9.2.

2.11.4 Intervention

The literature highlighted inventions as a supportive contribution of the EP, just as highlighted by SEED (2002) in the previous section. EPs could develop and implement differing interventions for children with CI. Kay (2019) highlighted that EPs could support children's self-advocacy concerning their CI, specifically supporting them to decide how, when and who form their future decisions concerning their CI (Kay, 2019). Alternatively, Jones and Salamon (2020) discuss the need for EPs to implement evidence-based interventions aimed at improving academic, mental, and behavioural health. Jones and Salamon (2020) suggest (in the context of children with chronic pain) that interventions could address self-regulation of the perception of pain and the management of emotional regulation. Some EPs are well-placed to support the delivery of these interventions (Jones & Salamon, 2020).

2.11.5 School policy and practice

Nabors et al. (2008) suggest that EPs could have a role in supporting, coordinating, and implementing school policies that would support children and young people with CI. EPs can aid this process by helping to write the policy, appointing a named contact in school, reintegration planning, contributing to the referral procedure, communicating and collaborating with parents and pupils, and being involved in effective multi-agency work with school staff, medical professionals, and training for children with CI (Nabors et al., 2008). This suggests a diverse range of supportive contributions.

2.12 Barriers to support

The reviewed literature points out that EPs may be well-placed to bring value to supporting children and young people with CI. However, some studies have highlighted the importance of additional training for EPs so that they feel equipped to offer appropriate support (Arora et al., 2019; Barraclough & Machek, 2010). Barraclough and Machek (2010) suggested a training course that covers common CI conditions in children that could be taken as a continuing professional development activity.

In addition to this, other barriers to EPs support may be present. As highlighted in Chapter 1, the additional pressure and rise of statutory assessments due to the current political context is limiting the work of EPs. MacKay (2020) argues that EPs have been undertaking fewer cases of early intervention work as a result of the rising number of statutory assessments. Increasing workload and demands for statutory assessment have not only taken EPs from supportive alternative work, but the quality of statutory reports are now also a concern (Capper & Soan, 2022). This may affect EPs' ability to take on further work, such as working with children with CI.

2.13 Future practices in educational psychology

As previously highlighted, the EP's role is evolving, much like the context in which it resides. The future of EPs' practice rests on the abilities of EPs to understand the challenges they face and to embrace the changes that might come. To maintain relevance, Gersch (2009) argued that EPs must be able to provide solutions and support to people with complex problems. This can be applied to supporting children with experience of CI.

Additionally, Norwich (2013) suggested that a distinctive future for EPs includes a need to be innovative; this might come about through the collaboration of research through universities and educational services, creating a cycle or exchange of knowledge and practice. One need for innovation that Norwich (2013) mentioned was in the definition of disability and SEN. Although this research will not fully address this, I hope that it might display the complexity of working with such fixed definitions of terms as presented in this literature review.

2.14 Concluding thoughts

In this literature review, I have considered the topic of chronically ill children in education and the current national context. I have highlighted the potential difficulties with definitions and the importance of this for CYP when gaining access to additional support. I have formulated the problem that is at the core of the research. This is that children with CI are more likely to have poor developmental and educational outcomes (Barnett et al., 2018), but may not receive as much specific educational support as they potentially require. This highlights the need for additional support and attention for this population of children. The literature emphasises the possible distinctive contributions that EPs could make to support CYP with CI. However, there is a gap in the literature when considering what EPs in the UK are currently doing in this regard.

The overall aim of the remainder of this thesis is to further understand how EPs can support CYP with CI. I consider the work that EPs are already doing, what approaches they are taking, and the impact of their work. Additionally, I consider the contribution of the EP's work in the future: what approaches and practices they bring to support children and young people and the barriers they may face.

3. Methodology

In this chapter, I outline my research questions and aims for each phase of the research. I then focus on the methodology and design of the research, and its aligning ontological and epistemological assumptions. I will present my own positionality to provide an understanding of my influence on the project.

3.1 Research aims and questions

3.1.1 Phase 1 research aims

In the first phase of the study, the aim was to gather information to provide an overview of the topic and the EP's general work, views and understanding. Specifically, I aimed to determine whether EPs currently work with children with CI and, if so, how often. I also aimed to explore how EPs received the work; for example, did their contact with children with CI come about through EHCP applications, casework from the school, or other sources? A further objective was to investigate the type of work that is completed by EPs to support children with CI. Finally, I aimed to clarify how EPs might define CI, and collect their opinions regarding children with CI and the interaction this has with SEN.

3.1.2 Phase 1 research questions

1. How often do EPs work with children who have a CI, and in what context?
2. What type of CIs do EPs often work with, and what type of work do EPs carry out?
3. What do EPs regard as a CI, and how does this relate to SEN?

3.1.3 Phase 2 research aims

In the second phase, the aim was to gain a deeper insight into how a sample of EPs worked with children who had CI. The aim was to examine EPs' views and explore their perspectives on their role while working with children who have CI. I used the first phase data to influence the questions and exploration in the second phase, although the main aim remained the same. I wanted to investigate the context and conversations concerning children with CI, what practices EPs might carry out, and their thoughts about provision and intervention. The significance of this phase was to highlight the value of EPs' involvement, and to capture the reflections of EPs on their current practice when they worked with children who had experienced CI.

3.1.4 Phase 2 research questions

3. (Continued from Phase 1) What do EPs regard as CI, and how does this relate to SEN? Does practice change based on this?
4. How do EPs respond to differing cases of children with CI?

5a. What practices, approaches, and perspectives do they take to a realistic case?

5b. What do EPs believe they can contribute that is distinctive?

6. To what extent do EPs feel equipped, without further training, to support children with CI? What are the barriers to practice?

3.2 Study design

This project used mixed methods to answer these research questions. Mixed methods can be broadly understood as research that incorporates both qualitative and quantitative methods to 'collect and analyse data, integrate the findings, and draw inferences' (Tashakkori & Creswell, 2007, p. 4). Integration of methods is imperative when completing a mixed methods study; the data from one set of methods should be integrated with the other. Further discussion regarding the integration of methods is explained in the methods section.

Phase 1 consisted of a mixed methods survey to describe the interactions between the role of the EP and chronically ill children. The quantitative section of the survey used closed questions, these were mostly binary or multiple choice in order to produce numerical data. The qualitative section of the survey gave the EPs a chance to comment on their experiences, perspectives, and views. The first phase of data influenced my questions and exploration in the second phase. Phase 2 of the project consisted of a focus group interview design to gain a deeper insight into how some EPs were working with children who had CI. A full description of the mixed methods used in this research is also included in the methods section.

A mixed methods design fits with my ontological and epistemological positioning. In bringing qualitative and quantitative methods together, it supports a holistic picture of the phenomenon (Zachariadis et al., 2013). In addition, it is a design that is often used to support social inquiry (Greene, 2008). Mixed methods offer an opportunity to engage deeply with the data, and to listen to and understand different perspectives and voices (Greene, 2008). As my topic is situated in an educational context and discusses children's CI, it deals with a complex and nuanced phenomenon. The mixed method design captures some understanding of both the breadth and depth of the participants' experiences and views, which should be valuable in understanding the EP's role in supporting children with CI.

3.3 Ontological position

For this research, I adopted a critical realist ontology. Critical realism is based on the work of Bhaskar (2016) and focuses on the complex nature of the social world. In traditional positivist science, empiricism is based on observing and measuring variables and examining their statistical relationships (Robson & McCartan, 2016). My viewpoint is that the social world is more complex than this; in the social world there exists entities that are intractable and unobservable. One such entity could be discrimination or human rights (Haigh et al., 2019). As humans, we may witness the effect of the entity but not the entity itself. The social world is layered, complex, and open (Haigh et al., 2019). Critical realism suggests that reality exists independently of our thoughts about it, and we all interact with this reality (Maxwell & Mittapalli, 2010). We construct knowledge about this reality, but our knowledge is situated and incomplete (Robson & McCartan, 2016). The knowledge that each of us possesses captures only a small section of this reality (Fletcher, 2016).

Reality in critical reality is seen to be made up of three domains: the empirical, the actual, and the real (Figure 1). In the ‘empirical’ domain, events can be experienced and observed (Haigh et al., 2019). The ‘actual’ domain considers the events we experience and the effects they have (Haigh et al., 2019). It recognises that these events and effects would have been activated by mechanisms which are associated with the ‘real’ domain (Haigh et al., 2019).

3.4 Epistemological position

Whilst taking a critical realist position, flexibility is required in my epistemological positioning. Due to this, when considering my viewpoint on how knowledge is created, I take a fallibilistic approach. In this view, knowledge is always fallible; human observations, methods, and reason are inconclusive and contain intrinsic errors (Yucel, 2018). This aligns with the critical realist’s perspective. To put it another way: there is an existing truth, but science is unable to determine this with complete accuracy. Instead, knowledge is socially constructed and refers to reality, but fallible (Yucel, 2018). A mixed method design is supportive in understanding such knowledge. It serves the purpose of providing an understanding of a complex, nuanced phenomenon (Shannon-Baker, 2015).

3.5 Own positionality

Reflexivity involves being able to reflect on the role one holds as a researcher and the research practice and process that one takes (Braun & Clarke, 2022). When critically reflecting on our own practice, the researcher should consider how the research was designed. Wilkinson (1988) talks about functional reflexivity as the research itself, heavily linked with personal reflexivity, which considers how the research is formed. The research and methods are formed through our values, role in society, and life experiences. I understand that my view of the complexities of the social world comes from my study of psychology. I have an understanding that my reality is not a clear truth about the world, but rather my meaning and perception of it.

Personal reflexivity has a bi-directional impact on functional reflexivity. It considers the researcher’s identity (Wilkinson, 1988). Often research can be a personal expression or interest of the researcher, as topics of choice can often derive from personal concerns (Wilkinson, 1988). In this case, I have a strong interest in supporting children with CI. I experienced children with CIs in my classroom when I was a teacher. I often did not know where to turn for support and help. I became aware of the various impacts that CIs can have, ranging from their impact on learning, social interaction, mental health, and time away from school.

I think it is important to highlight that I am unable to remove my personal experience, and thus my influence, from the research. To minimise the impact of my worldview, I have carefully chosen methods that support the triangulation of the data (Figure 1) in the quantitative and qualitative aspects of the survey, and the qualitative focus groups. Using these methods, I designed questions to enable participants to give their full views and experiences independently of my own.

3.6 Methods

Following on from the theoretical assumptions, research questions, and research aims this section will move on to present the methods used to collect and analyse the data, including recruitment of participants, quantitative and qualitative methods and presenting the data analysis. This will be done for both phases of the research in turn.

3.6.1 Phase 1 research design

To support the research questions and research aims this phase used a survey design for data collection. In support of the integration between both quantitative and qualitative methods, the survey took a convergent parallel mixed methods approach (Creswell, 2014). The survey focused on gathering information from anonymous EPs at one point in time.

A survey was used to describe the interactions between the role of the EP and chronically ill children. In the quantitative section of the survey, I wanted to consider how often EPs see children with CI, how they become involved, and what they do when they become involved. Quantitative methods within a critical realism approach are often considered descriptive and document the prevalence of something. This type of data is unable to explain the reasons why the event happened, nor can it predict what may happen in the future (Zachariadis et al., 2013).

Therefore, within the qualitative section of the survey, I wanted to give the EPs a chance to comment on their experiences, perspectives, and views regarding working with children with CI, and their role in supporting this. When using qualitative methods, the researcher is more able to explain the intricacies of why an event may have occurred and how it occurred (Zachariadis et al., 2013).

A cross-sectional survey was used which takes an assessment at one point in time and is used to document the prevalence of something (Visser, 2013). This could be a behaviour, attitude, or opinion (Connelly, 2016). The advantages of cross-sectional surveys are that they are flexible and easily distributed, enabling the capture of a large sample size (Connelly, 2016).

3.6.2 Phase 1 materials

A 16-item survey was designed with a mixture of both closed, direct questions (using a quantitative method) and more open-ended questions (using a qualitative method). Table 1 provides the research questions and associated closed and open questions. The full version of the survey can be found in Appendix A.

Table 1

Research questions and their relation to the questionnaire

Research Questions	Closed direct questions	Open Questions
How often do EP's work with children who have a chronic illness and in what context?	3) Do you have a particular specialism that brings you into contact with children who have chronic illness? 4) How often do you work with chronically ill children? 5) I work with children with chronic illness when writing statutory advice. Y/N 6) I work with children with chronic illness as part of a medical, early support or multi-disciplinary panel. Y/N 7) I work with children with chronic illness from individual school referrals. Y/N 8) I discuss children with chronic illness in planning and review meetings. Y/N	3a) If 'yes' what is your specialism? 9) Is there anything else you would like to say about contact you have had with/about children with chronic illness?
What type of chronic illness do EPs often work with and what type of work do EPs carry out?	10) Please select the types of CI you have come across in your work and the type of involvement you have had… 10a) Have you had involvement with the following CI? Y/N 10b) Was involvement part of an EHCNA? Y/N 10c) Select type of involvement…	10d) Please elaborate on the type of work you completed. 12) Is there anything else you would like to say about the type of CI you have come into contact within your professional role?
What do EP's regard as CI and how does this relate to SEN?	14) Please highlight the statement you most agree with: (Participants given statements about the definition of CI and its relation to SEN)	14) Please explain your answer (This question was presented after each statement choice)

Please see Appendix A for full Survey Questions

3.6.2.1 Direct questioning. According to Peterson (2000), closed questions are appropriate when the answer options are comprehensive. Throughout this survey, closed questions were used when asking for an answer of yes/no or selecting from a small number of multiple choices.

The direct questions were first used to ask for demographic data. Then, the questions focused on the understanding of the contact that EPs were having with children with CI, how often this contact was, and through what means. Participants were asked yes/no questions in response to whether they had encountered children with CI through statutory advice, school referrals, panels, and planning meetings. Ashton and Roberts' (2007) work on the unique role of the EP influenced the type of work that was presented to participants in the direct questioning. In addition, my own experiences of working in an LA supported this. However, I recognise that by using direct questioning at this point I may have lost an opportunity for EPs to share other experiences of interacting with children with CI. This direct style of questioning focused on answering the research question: How often do EP's work with children who have a CI, and in what context? (see Table 1).

3.6.2.2 Direct and open questioning. Peterson (2000) highlighted that the addition of open questions can support the 'richness' of the results, and can supplement direct questions. In the next section of the survey, closed and open questioning styles were used to complement one another. Participants chose CI from a comprehensive list and were asked direct questions. What CI they had worked with? Was it part of a statutory assessment? Who did they have contact with (individual child, family, school)? Several sources were used to determine the list of CI conditions presented to the EPs. First, the most common CIs in the UK were considered (DEWIS Wales, 2023; NICE, 2019; RCPCH, 2022). Furthermore, conversations with several EPs regarding their encounters helped me to compile a list of conditions that they had encountered.

Direct questions were followed by open questions (Table 1). This allowed participants to elaborate on the answers to the direct questions. They were able to state if they had worked with a CI that was not previously mentioned and to elaborate on the work they had completed. A deeper understanding of their involvement was therefore obtained.

This mixed style of questioning was also used to explore working with healthcare professionals, the definition of CI, and its relationship to SEN. Peterson (2000) highlights that the use of open questions may deter participants from completing a survey, but I hoped that the mixed style of questioning might avoid this. Participants were not required to answer the open questions, only the closed ones. However, some missing data were apparent nearer the end of the survey. This mixed style of questioning was used to answer two of the research questions for this phase: What do EPs regard as a CI and how does this relate to SEN? What types of CI do EPs often work with and what type of work do EPs carry out? (Table 1).

3.6.2.3 Open questioning. The final section of the survey aimed to explore EPs' views concerning their confidence about working with children with CI and the barriers they perceive. These questions were purely open, to encourage participants to give their perspectives, additional experiences, and some contextual information. This section aimed to inform the design and questioning in the second phase of the study.

3.6.2.4 Piloting The questionnaire was piloted with a small group, consisting of two EPs and two TEPs, to estimate how long it would take to complete the questionnaire, to ensure it was a reasonable commitment for participants. The survey took about 20 minutes for the pilot group to complete. They carefully considered whether the survey was easy to access, use, and understand. After this phase, the survey was refined to clarify the definition of CI to ensure that the language used was accessible and the meaning conveyed was understood. The final version of the survey is available in Appendix A.

3.6.3 Phase 1 participants

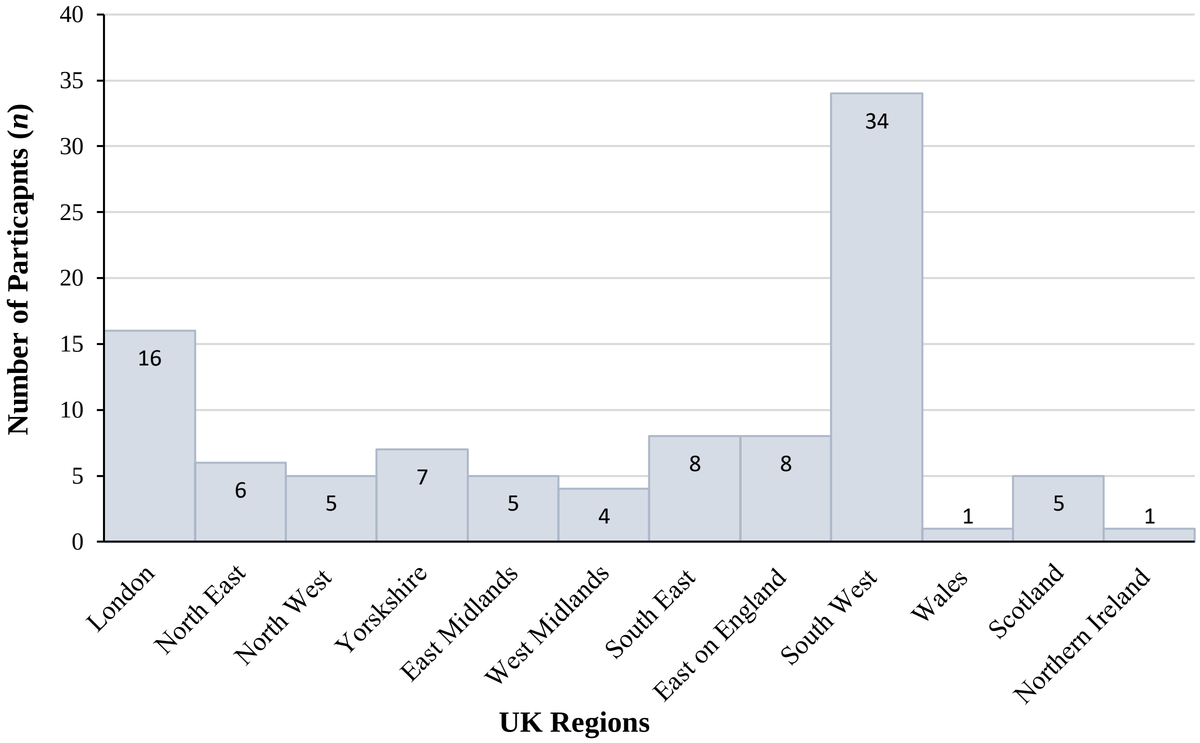
For Phase 1, participants were recruited through email and social media posts. Initially, recruitment materials (Appendix B), with an accompanying link to the survey, were sent across several EPs' email services, including EPNET and SEPNET. The recruitment material was also posted on Twitter with relevant hashtags to attract participants. Several EPs' websites that advertised research projects were identified: the Association of Educational Psychology (AEP) newsletter and the edpsy website. Both forums were contacted and agreed to post the recruitment material. Finally, EP services across the UK were contacted and asked to share the recruitment material with their EPs.

For Phase 1, I used convenience sampling, a nonprobability way of sampling (Battaglia, 2008) that recruits people who choose to participate (Sousa et al., 2004). The benefit of this method is that everyone interested in the study can provide their views. However, it is also subject to the potential bias that those who responded may have a particular interest in the topic and possibly, therefore, strong feelings about it. However, the study took a non-representative design to sampling, so gaining a generalisable population was not the aim.

In total, 112 EPs and TEPs took part in the online survey, 12 participants were removed due to high levels of missed data (n=100). The data that was collected varied from very little experience (e.g. still completing doctoral study) to significant experience (up to 46 years of experience as a qualified EP). In years of experience, the average was almost 6 years (M = 5.98, SD = 8.55). The distribution was positively skewed (2.10, SE = 0.241), meaning that more EPs who are earlier in their career seem to complete the survey. Although participants were from a wide range of regions across the UK, they were not evenly distributed across the regions, with a third based in the South West (Figure 2).

Figure 2

Distribution of phase 1 participants across the UK regions



3.6.4 Phase 1 data analysis

When completing the analysis of the survey I held in mind the convergent parallel mixed methods approach and considered the importance of integration of the two methods. For research questions where both closed and open questions were relevant, I analysed the qualitative and quantitative data at the same time to ensure a full and rich picture of the data.

The closed questions produced numerical data which was analysed using IBM SPSS. The data were checked for missing entries and participants' responses were removed from the sample if a considerable proportion of their data was incomplete. Descriptive statistics functions were used to obtain the measure of central tendency, the central point of the scores, as well as the dispersion of the scores (Fisher & Marshall, 2009). As there were many multiple-choice and binary questions in the questionnaires, much of the data collected was nominal. The descriptive statistics allowed for a general summary of the data, which aligned with the aim of this phase of the research. For example, it highlighted the frequency of EPs that worked with children with CI through statutory assessment.

The open questions produced qualitative data that was analysed using reflexive thematic analysis. Thematic analysis is a method of ‘identifying, analysing and preforming patterns with data’ (Braun & Clarke, 2006, p. 79). Thematic analysis is widely used in psychology and education as an explorative approach (Gavin, 2008). It is flexible in nature and is not tied to a given epistemological or theoretical position (Braun & Clarke, 2006). Thus, it fits well with the critical realist approach taken in this project. In the ‘Phase 2: Focus Group’ section of this chapter, each stage of thematic analysis will be outlined.

In this first phase, data were coded using an inductive orientation, where the codes emerged through the data. Data were coded for each question asked on the survey and subsequent themes were developed. This approach was taken to ensure that the coding was optimised for the survey’s purpose and so that the qualitative data were analysed in conjunction with the quantitative data from each question. The codes produced were then considered in relation to the research questions in Phase 1 and preparation for Phase 2. This highlighted some overall meaning produced from the survey.

3.6.5 Phase 1 ethical considerations

All data collection was carried out in accordance with the Health and Care Professionals Council’s code of practice (HCPC, 2016) and the British Psychological Society’s Code of Ethics and Conduct (BPS, 2018). Before beginning the research, ethical approval was obtained from the University of Exeter’s College of Social Sciences and International Studies (SSIS) Ethics Committee. A copy of the ethical approval can be found in Appendix C.

Crucial ethical considerations for this project across both phases were the processes of ensuring confidentiality and gaining informed consent. All data collected for this research will be deleted on the completion of the doctorate. In Phase 1, consent was gained via a consent statement as the first question of the survey. As well as this statement, an information page was included which documented participants’ right to withdraw, their anonymity, and information regarding the study. Participants were required to acknowledge that they had understood the information before being allowed to proceed to the survey (see Appendix D). At the start of the survey, participants were asked not to provide any personal data so that they would remain anonymous. Participants were asked if they would like to share their email addresses at the end of the survey, if either they would like to take part in Phase 2 or wanted information about the results of the study. Participants were informed that these data were securely downloaded, stored on the university OneDrive system, and that their information would be treated confidentially.

As the survey was centred on a conversation about CI, the project carried a small risk to participants. There was an awareness that the survey contents might provoke some emotional distress. To ensure participants' emotional well-being, I provided information sheets at the start of the survey that documented the nature of the study and its focus on CI (see Appendix D). Participants were informed that they could withdraw at any point and for any reason before submitting their responses.

3.6.6 Phase 2 research design

In Phase 2, focus group interviews were used to gain a deeper insight into how some EPs were working with children who had CI. The objective was to examine EPs’ views and explore their perspectives on their role in working with children who have CI, and to gain an understanding of what practices, approaches, and perspectives they took in such cases. Phase 1 responses influenced the questions and exploration in Phase 2. In Phase 1, the research highlighted a variety of experiences and views on how to support children with CI and the EP’s role. This led me to want to understand how EPs interact in group discussions about these topics and what conclusions, if any, they might come to as a group. The method was an online focus group, within which I acted as both researcher and moderator. This will be further discussed in section 3.6.7.2.

3.6.7 Phase 2 materials

In Phase 2, I used a focus group interview. Although the structure and purpose of focus groups are debated, for this project it is understood that focus groups take place in the middle ground between an unstructured conversation and a highly structured meeting (Sim & Waterfield, 2019), and thus in the middle of a continuum between spontaneity and structure (Barbour, 2010). Topics and questions are often outlined carefully, but participants have a large degree of freedom in their contributions (Sim & Waterfield, 2019).

Focus groups have the advantage of using interaction as a way of generating data (McLafferty, 2004). Barbour (2010) argues that focus groups are best used when the research wants to consider a ‘group process’ (p. 10). Being in a group allows participants to use discussion to consider their position and respond to the given problem (Barbour, 2010). A group format can also encourage participation and truthfulness. This is known as the ‘loosening effect’, whereby participants are more likely to express their opinion by being in a relaxed group setting (Vaughn et al., 1996).

When considering how EPs may support children with CI, the objective was to explore how they interact in group discussions and what conclusions they come to. Focus group interactions can involve an exchange of reactions, personal and collective experiences, and opinions (Vaughn et al., 1996), aiding an understanding of EPs’ views and experiences. To promote discussions, an interview schedule and stimulus materials were used.

3.6.7.1 Stimulus materials. Within qualitative research designs, stimulus material can be used as a method for encouraging participants to focus on and discuss the research topic (Törrönen, 2002). Stimulus materials can take a variety of forms, including text, photography, videos, and audio (Stacey & Vincent, 2011). Törrönen (2002) suggests that researchers should consider three points when using stimulus materials:

1. That the stimulus material refers to a narrative or description that is more extensive and highlights a wider context than a question.
2. The stimulus material is understood as a generation of meaning.
3. The role of the stimulus material must be considered within the interview design.

In Phase 2, participants were presented with realistic but fictional referral forms for EP involvement, as a stimulus text. The referral forms were written as if to represent a fictional child's situation. To create the stimulus material, I researched cases of children with CI that have been referred for EPs' support, attended medical panel meetings, and talked to EPs about referrals they had received. Different aspects of this research were combined to create fictional forms. For example, in Phase 1 of this research, participants highlighted that a CI was not often the primary reason for the referral. Thus, within the stimulus text, the CI was presented in, amongst, and equal to other additional needs that the child experienced.

As Törrönen (2002) highlighted, the stimulus material refers to a narrative or description that is more extensive and highlights a wider context than a question. The fictional referral forms were based on the complexities of EPs' involvement with children with CI. The referrals involved cases where interaction between SEN and CI was possible but nuanced. An attempt to represent the varying complex nature of CI was made. Across the three referral forms, varying illnesses of differing complexities and longevity were included. One case was included in which the side effects of medication may have had a negative influence on the child's cognitive functioning (see Table 2). The reason for the referrals (that cognitive needs were a primary concern) was kept the same for all three stimulus materials. This was because within the Phase 1 data participants highlighted that cases like these are often referred to EPs. Across all the referral forms, just as in real cases, there were no clear and correct answers.

Table 2

Characterisation of stimulus materials

	Stimulus Material 1	Stimulus Material 2	Stimulus Material 3
Pseudonym	Mia Smith	Bertie Jefferson	Katie Brown
Age	7 yr 6 m	15 yr 3 m	5 yr 3 m
Year group	Yr 2	Yr 10	Yr R
Gender	Female	Male	Female
Reason for Request	▪ To further understand child's cognitive strengths and needs, ▪ We would also like some advice on provision that may support ---'s needs at school.		
Background:	▪ 3 years behind ARE in math, reading and writing. ▪ Finds friendships challenging. ▪ Medication being trialled.	▪ Accessing lessons at around a Yr 7 level ▪ Finds the understanding and expression of language challenging. ▪ Finds making friends challenging.	▪ Below expected level attainment ▪ Finds it hard to enter school. ▪ Find it hard to play with others. ▪ Attends hospital school.
Chronic Illness	▪ Epilepsy ▪ Regular seizures at school, every 20-30 mins	▪ Type 1 Diabetes- injecting insulin to manage blood glucose levels	▪ Stage four neuroblastoma (Cancer) ▪ Low school attendance
Assigned Focus group	1 & 3	1 & 2	2 & 3

Thus, the stimulus materials acted to provoke the generation of meaning and knowledge on the topic (Törrönen, 2002). Törrönen (2002) suggests that the 'provoker' material aims to produce knowledge around the research focus that creates discourse concerning established practices. The referral forms allowed participants to discuss their reactions and views about how they might support the fictional referral.

Two referral forms were presented, in advance, to the EPs involved in the focus groups. Each group received two of the three stimulus texts, such that each text was used twice. This design was actioned to answer research question four: How do EPs respond to differing cases of children with CI? It allowed for a comparison of TEP's and EPs' reactions to differing referral forms. Table 2 outlines the allocation of stimulus material to each focus group.

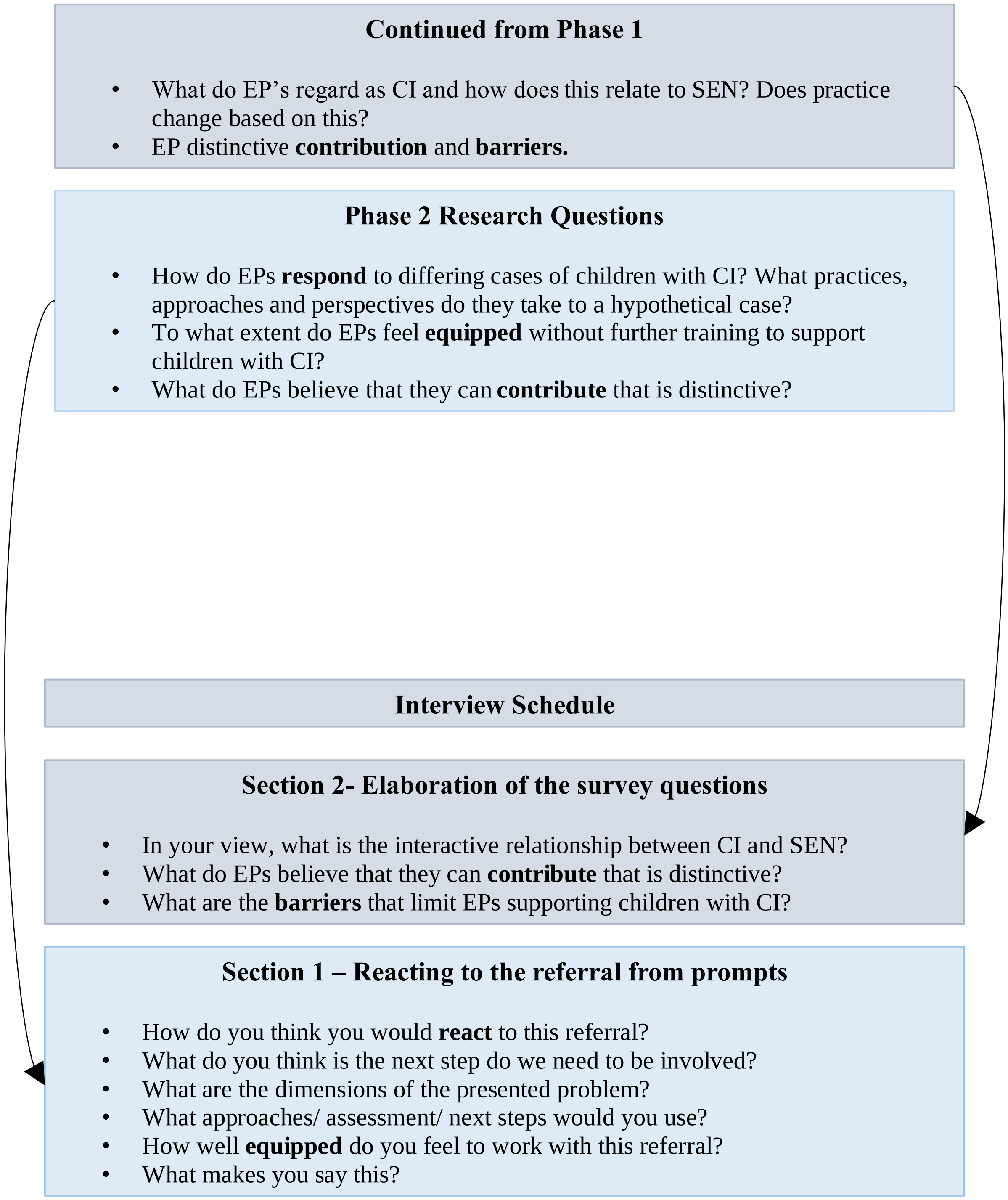
3.6.7.2 Interview schedule. For the focus group interviews in Phase 2, a 'topic guide' was created, as suggested by Barbour (2010) (see Appendix E). This was derived from two strands (Figure 3).

First, the Phase 1 data were considered to determine what had been found, what was missing, what needed refining, and what further information was required. Within the Phase 1 data, it was determined that more views would be valuable in considering the interaction between SEN and CI, particularly whether practice changed based on this interaction. Furthermore, discourse surrounding change in practice was not captured by Phase 1. Further consideration was also needed concerning EPs' views on their contribution and potential barriers to practice.

Second, the research questions for Phase 2 were considered. Interview topics were carefully considered to ensure that they would effectively answer the research questions, as previously explained.

Figure 3

Interview schedule and its derivation section



Continued from Phase 1

- What do EP’s regard as CI and how does this relate to SEN? Does practice change based on this?
- EP distinctive **contribution** and **barriers.**

Phase 2 Research Questions

- How do EPs **respond** to differing cases of children with CI? What practices, approaches and perspectives do they take to a hypothetical case?
- To what extent do EPs feel **equipped** without further training to support children with CI?
- What do EPs believe that they can **contribute** that is distinctive?

Interview Schedule

Section 2- Elaboration of the survey questions

- In your view, what is the interactive relationship between CI and SEN?
- What do EPs believe that they can **contribute** that is distinctive?
- What are the **barriers** that limit EPs supporting children with CI?

Section 1 – Reacting to the referral from prompts

- How do you think you would **react** to this referral?
- What do you think is the next step do we need to be involved?
- What are the dimensions of the presented problem?
- What approaches/ assessment/ next steps would you use?
- How well **equipped** do you feel to work with this referral?
- What makes you say this?

Within the focus group interviews, I acted as the moderator. The moderator and researcher as a dual role was also considered in the interview schedule. The researcher takes an active role in supporting the group's discussion (McLafferty, 2004). It is key to be flexible in the approach and know when to let the discussion develop. At times in the interview, it can seem that participants might have gone off-topic; however, this can often lead to interesting and valuable discussions (Barbour, 2010). Allowing flexible questioning using the interview schedule as a guide, rather than using it verbatim, is important.

Additionally, a strength of the focus group method is the interaction between participants that continues throughout the interviews; however, this is equally a limitation of the approach (Femdal & Solbjor, 2018). Within the focus group, there is often a power dynamic between the researcher and the participants. Power dynamics exist in all social relationships (Cyr, 2019), so there may also be a power dynamic between participants. Power dynamics can be further exemplified by the focus group occurring online, as the use of microphones can be difficult and make it hard to find space to talk. Group composition is key to supporting a successful focus group interview (Femdal & Solbjor, 2018). The interview schedule incorporated some measures to reduce power imbalances. Cyr (2019) highlights that the moderator should be attentive but also interject as little as possible, letting control of the conversation be governed by the participants. Thus, the interview schedule included some prompts to support this, such as that the moderator should create a warm environment, support a naturally developing conversation, and attempt to avoid interjection (see Appendix E).

3.6.8 Phase 2 participants

In Phase 2, participants were recruited through opportunistic sampling. The participants who completed the online questionnaires were asked if they would be interested in taking part in the focus groups at the end of the survey. In all, 15 EPs and five TEPs expressed interest. As in Phase 1, this is a form of convenience sampling, meaning that the participants are self-selecting (Sousa et al., 2004).

All 20 participants who expressed interest were contacted to take part, and 11 qualified EPs and five TEPs accepted to take part in the focus group interviews. The participants' characteristics are outlined in Table 3. This project aimed to recruit psychologists with varying levels of experience, including TEPs. This was important to gain a better understanding of their perspectives on working with children who have CI. It was also important to consider whether the current doctoral training adequately prepares psychologists to work with these cases. I endeavoured to recruit psychologists from various regions in the country to gain a better understanding of the different practices of different local authorities. As participants were recruited through the survey, this was a challenging aspect to control for. EPs from seven different LAs across four different regions of the UK were recruited. As with the survey data, many of the participants were from several different LAs across the South West region. Thus, the data were not evenly distributed across the UK.

Three focus groups were conducted online, using Microsoft Teams video conferencing. These took place between 24th November 2022 and 8th December 2022. Guest et al. (2016) highlighted that three focus groups were sufficient to identify the most prevalent themes within a data set in the analysis stage. TEPs were grouped together in the first focus group. They were separated from the EPs to gain an understanding of the views of TEPs without the influence of more experienced EPs. Furthermore, it would make an interesting point of comparison if TEPs' perspectives differed from the more experienced EPs. The TEPs within this group worked across three local authorities.

Table 3

Participants' demographic characteristics and focus group placement

Participant	Region currently working in	Role	Focus Group
1	South West	TEP (2nd year)	1
2	South West	TEP (3rd year)	
3	South West	TEP (3rd year)	
4	South West	TEP (3rd year)	
5	South West	TEP (3rd year)	
6	London	Private EP	2
7	North East	LA EP	
8	South West	LA EP	
9	South West	LA EP	
10	South West	LA EP	3
11	South West	LA EP	
12	South West	LA EP	
13	South West	LA EP	
14	South East	LA EP	

The composition of the other two focus groups was created based on the participants' location (Table 3). In total, they worked across six differing localities. Although many were from the Southwest, most worked in differing LAs. Two participants were not able to continue with the study at this time, one participant did not attend the virtual meeting and the other discontinued from the study. Fourteen participants completed the focus group interviews.

3.6.9 Phase 2 data analysis

All data collected in Phase 2 were gathered through three focus group interviews that took place using video conferencing. When participants were ready and had provided their informed consent, the call was recorded (ethical considerations are discussed in the next section). Throughout the process of data analysis, I kept a reflexive journal to be continuously reflective, questioning my initial thoughts and noting my responses (Braun &

Clarke, 2022). I found this a useful process where I was able to note any developing themes that I found surprising or interesting (see Appendix F).

The three interviews were first transcribed through the transcription function of the Microsoft Teams application. After each interview, I reviewed and cross-checked the pre-created transcription, re-formatted it, and corrected any mistakes (Greenwood et al., 2017). I did this during the day following each interview, as it is beneficial to perform transcription soon after the original interview (Morrison-Beedy et al., 2001). I attempted to create a transcription that was as verbatim as possible; however, I did find that spoken words were not always clear. Greenwood et al. (2017) suggest that verbatim transcripts are not always the priority and that listening to the audio of the focus group data can provide a purer way to approach the analysis. Transcripts can miss important aspects of the interview, such as group dynamics, body language, and use of voice intonation. Thus, I used both the transcription and the video recording to support data analysis.

I used Braun and Clarke's (2022) six-phase approach to reflexive thematic analysis to analyse the data (Figure 4). Cross-checking the transcript with the video recording acted as a start to familiarisation, the first step of reflexive thematic analysis. As outlined by Braun and Clarke (2013, 2022), this is a step where one is immersed in the data. In this phase, the transcripts were read and re-read, and the videos were watched several times. Notes and ideas were documented in the reflexive journal and mind maps were created regarding thoughts around possible key themes and concepts (see Appendix G).

In the second phase, coding, the transcripts were uploaded to Nvivo transcript software and code labels were given to segments of meaningful data (Braun & Clarke, 2013, 2022). I carefully and systematically worked through the data set and codes with accompanying segments of the data were collected (Appendix H). Each code was aimed to capture a single concept at differing levels from semantic to conceptual meanings (Braun &

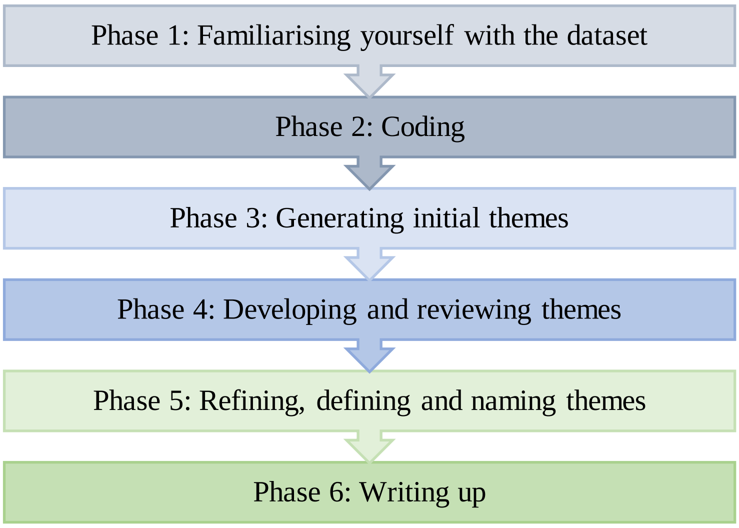
Clarke, 2022). A selection of the codes was sent to my supervisors to monitor their consistency.

In the third phase of the process, initial themes were developed. Collections of codes were created that shared the same concept and that related to my research questions. Themes should be based on the data, the research questions, and the researcher’s insight, being actively constructed by the researcher (Braun & Clarke, 2022). Themes provide and capture a broader combined meaning across the data set (Braun & Clarke, 2013, 2022). In this phase, candidate themes were created and coded data were collated.

After the creation of candidate themes, the themes were then developed and reviewed in phase four. The data set was reviewed, and themes were assessed to ensure that they encompassed important shared meaning represented by the coded extracted and full dataset (Braun & Clarke, 2022). At this time, revisions took place and concept mapping supported the process of reviewing themes and considering the relationship between them (see Appendices I). After this process, in phase five, themes were defined and given concise and meaningful names (Braun & Clarke, 2013, 2022). An example of themes and coded transcripts are included in Appendices K. The sixth phase was then completed: the data were written up in the results section of this thesis (Section 5). Documentation of the research narrative had started earlier than this point, through the reflexive journal and concept maps that I used throughout the process.

Figure 4

Braun and Clarke's (2022) six phases of reflexive thematic analysis.



As highlighted previously, focus group data has an advantage in gaining an understanding of group dynamics and interactions (Grønkjær et al., 2011). While methods for the analysis of group interaction data are debated, Duggleby (2005) suggests that the analysis of focus group interaction data can be based on the methodological approach taken by the researcher, so in this case thematic analysis was used. I analysed the group interaction data separately and compared it to the coded data. While analysing the group interaction data, I read back the transcripts that included commentary of key interactions of participants (such as 'EP5 nodded') and simultaneously watched the recorded interviews. Afterward, I coded and created themes based on the interaction data. For example, when an EP or several EPs nodded and expressed 'yes' I coded this interaction as 'agreement in the group'. I considered how the group interaction data compared to the focus group data and noticed that the integration data supported certain themes. I have included this consideration in the results section where appropriate.

3.6.10 Phase 2 ethical considerations

As presented in the section 3.6.5 of this chapter, all data collection was carried out in accordance with the Health and Care Professionals Council's code of practice (HCPC, 2016) and the British Psychological Society's Code of Ethics and Conduct (BPS, 2018).

Ethical consideration across both phases was centred on ensuring confidentiality and gaining informed consent. In Phase 2, a consent form and information sheet were emailed to those participants who had registered interest before the focus groups commenced. The participants were required to complete the consent form before the interviews took place. The consent form and information sheet documented their right to withdraw, information regarding research, confidentiality, and information regarding the video recordings. Participants were informed that their data would be securely stored on a password-protected university OneDrive account and transcribed confidentially. The data would be destroyed upon the completion of the doctorate. When the interviews began, I summarised some of the key information in the consent forms and confirmed explicit consent for me to obtain and use the video recordings. I outlined the importance of ensuring confidentiality between the group participants. A copy of the information sheets and consent forms are found in Appendix L.

As in Phase 1, the focus groups centred on a conversation about CI. The project, therefore, held a small risk to participants since the interviews might provoke some emotional distress. To ensure participants' emotional well-being, I provided information sheets at the start of the focus groups that documented the nature of the study and its focus on CI. At the beginning of the focus group, I reminded the participants that they have the right to withdraw and refuse to answer questions at any stage.

4. Results: Phase 1

This section will analyse the survey results in connection with the three research questions it sought to answer. Within each research question, both the relevant qualitative and quantitative data are presented. The section then considers data taken from the Phase 1 survey that supported the creation of the interview schedule and research questions in Phase 2. As highlighted in the methodology section, some qualitative data was missing towards the end of the survey. Despite this, participants who answered the open-ended questions provided detailed and sometimes passionate responses that described their views on the topic. This resulted in rich qualitative data, which complemented the quantitative data collected.

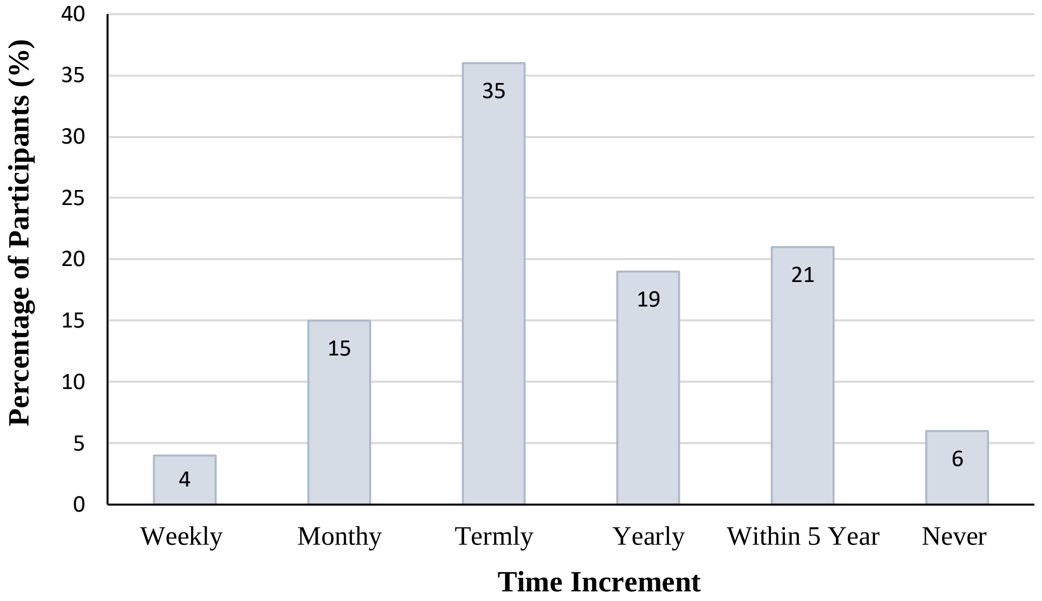
4.1 Research Question 1 – How often do EPs work with children who have a CI and in what context?

4.1.1 Quantitative data

Within the survey, most participants indicated that they had worked with children who have CI. However, some reported that they had not yet worked with a child with CI (6%). Around half of the participants (54%) reported that they worked with children with CI on a termly basis, or more frequently than that. Other participants (40%) indicated that they worked with children with CI less frequently: either yearly (19%;) or within 5 years (21%). The overall distribution of the data is presented in (Figure 5).

Figure 5

Percentage of participants stating how often they worked with CYP with CI (n=100)



Many participants indicated that they had worked with children with CI when completing statutory assessments (78%). Participants also received school referrals to request EP involvement (71%) and indicated that they discussed children with CI in planning and review meetings (73%). Fewer participants indicated that they attended or discussed children with CI in panel meetings (18%). The overall response for frequencies is presented in Table 4.

Table 4

Frequency of participants completing different types of work

	Statutory advice		Panel Meetings		School referrals		Planning and Review meetings	
	Frequency	Valid Percent	Frequency	Valid percent	Frequency	Valid Percent	Frequency	Valid Percent
Yes	78	78	18	18	71	71	73	73
No	22	22	82	82	29	29	27	27
Total	99	100	100	100	100	100	100	100

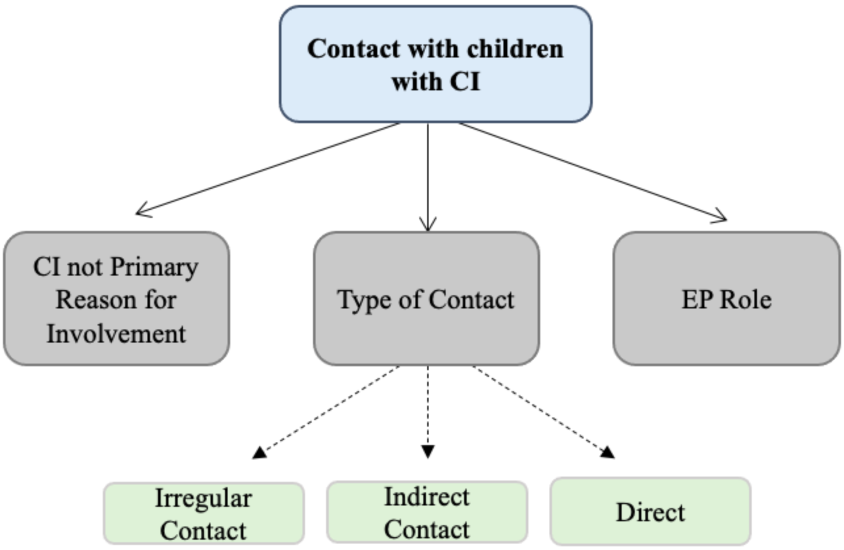
A high number of participants (93%) did not have a specialism that brought them into contact with children who had CI. Those who did have a specialism (7%) mentioned roles such as: ‘EP in a special school’; ‘participation in medical panels’; ‘linked EP for hospital school’; specialism in ‘autism’ and ‘selective mutism’.

4.1.2 Qualitative data

In the survey, participants were asked for comments about the contact they had with children with CI. Figure 6 demonstrates themes and subthemes that arose from these comments. One notable theme was that the child's illness was not always the main factor for EPs’ involvement or referral. An EP commented ‘the chronic illness is most often not the reason I am working with the child, but usually their progress’. In these cases, the child was described as having other difficulties or needs. The illness was either not mentioned in the referral or mentioned as a secondary priority. One participant wrote that CI was ‘not always mentioned by the SENCo on referral forms but information arises during consultation’.

Figure 6

Themes and subthemes related to contact with children with CI.



A second theme documented the type of contact that participants had with children with CI. Participants noted that they had some direct contact. There was a strong feeling that this direct contact was mostly through completing statutory assessments. A participant wrote ‘usually it’s for an EHCP assessment’. Participants indicated that they also completed indirect work with children with CI. This included having informal conversations with schools to support them and being involved in research that supported children with CI. A participant wrote ‘I worked with a chronically ill young person as part of research that was commissioned by the local authority’. Participants indicated that contact with children with CI was often irregular. The EPs noted that they could experience several cases in short succession, followed by no cases for long periods.

A third theme focused on the EP’s role. Participants noted that their personal role brought them into contact with children with CI more than their colleagues. Some participants had a special interest in CI or had a CI themselves. These participants noted that they actively sought to work with children with CI. An EP wrote ‘I think maybe I am more tuned into this type of work as my family members have CI.’ Others had a specific specialism (as mentioned previously) that enabled a higher level of contact time.

4.2 Research Question 2 – What type of CI do EPs often work with and what type of work do EPs carry out?

4.2.1 Quantitative data

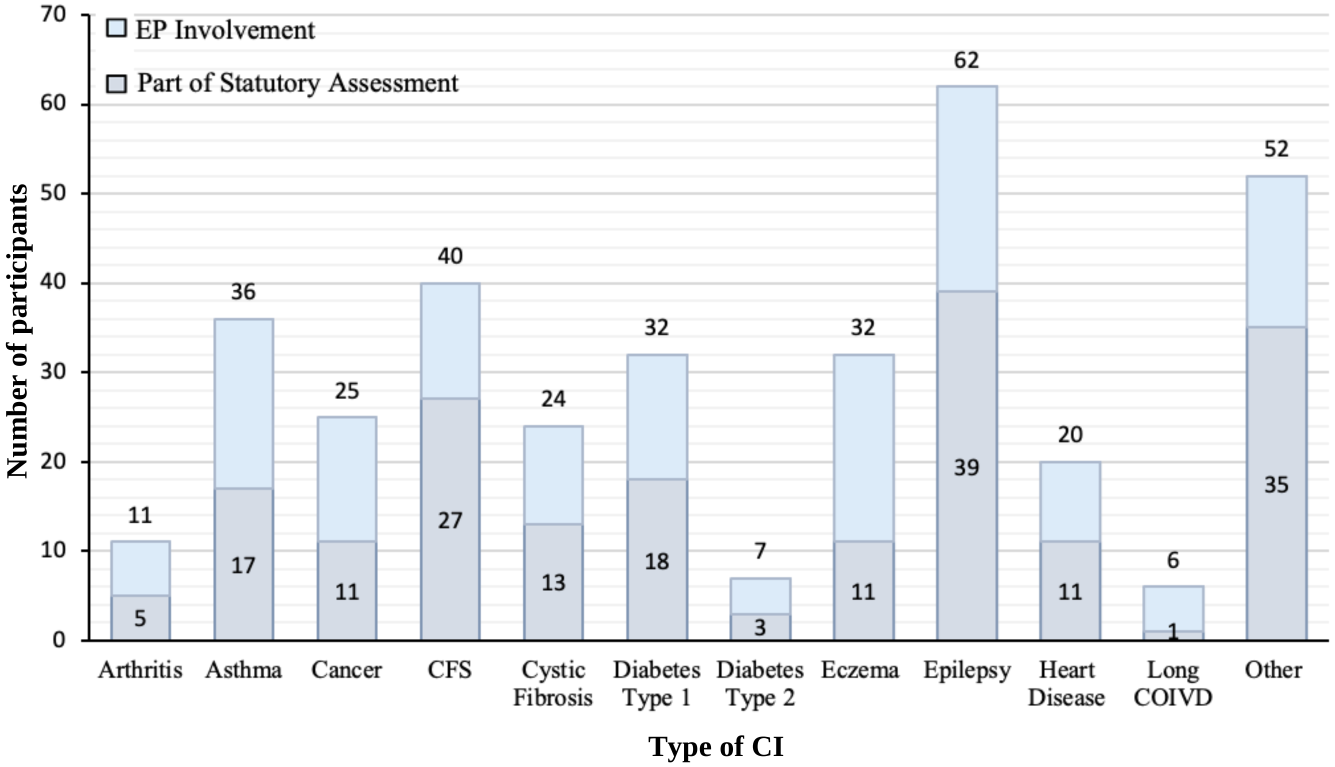
Participants indicated that they had worked with children who experienced a range of CIs. Figure 7 highlights the number of participants who indicated that they had involvement with a certain CI. The numerical label at the top of each bar indicates the overall number of participants that had experienced involvement with that specific illness. Interestingly, many participants indicated that they had worked with children who had epilepsy. Participants had the least contact with children who experienced arthritis, type 2 diabetes and long COVID.

Participants had also worked with ‘other’ CIs that were not included in the survey. They reported working with CYP with Ehlers-Danlos syndrome, hypermobility, inflammatory bowel disease, Duchenne muscular dystrophy, cerebral palsy, lung disease, spina bifida, genetic conditions, and other rare conditions. Participants also mentioned that they had worked with young people who experienced mental illness.

In the survey, the participants were asked if the work they had completed was part of a statutory assessment. The inner bar and central numerical label of Figure 7 indicate the number of participants who indicated involvements that were part of statutory assessment work for each category of CI. Overall, the data indicated that participants’ involvement was part of a statutory assessment 55% of the time reported.

Figure 7

The number of participants who indicated involvement with each category of CI.



Participants indicated the type of work they had completed to support children who had differing CIs. Figure 8 displays the overall distribution of the data collected. The totals for the overall scores related to type of involvement are shown in Table 5. Table 5 shows the number of times participants indicated that they had completed an 'individual assessment', 'work with the family', and 'work with school' across all listed CI's. Results indicate that across all CIs, participants favoured completing individual assessment work with the child (39%). This was closely followed by work with the school (34%) and then work with the family (27%).

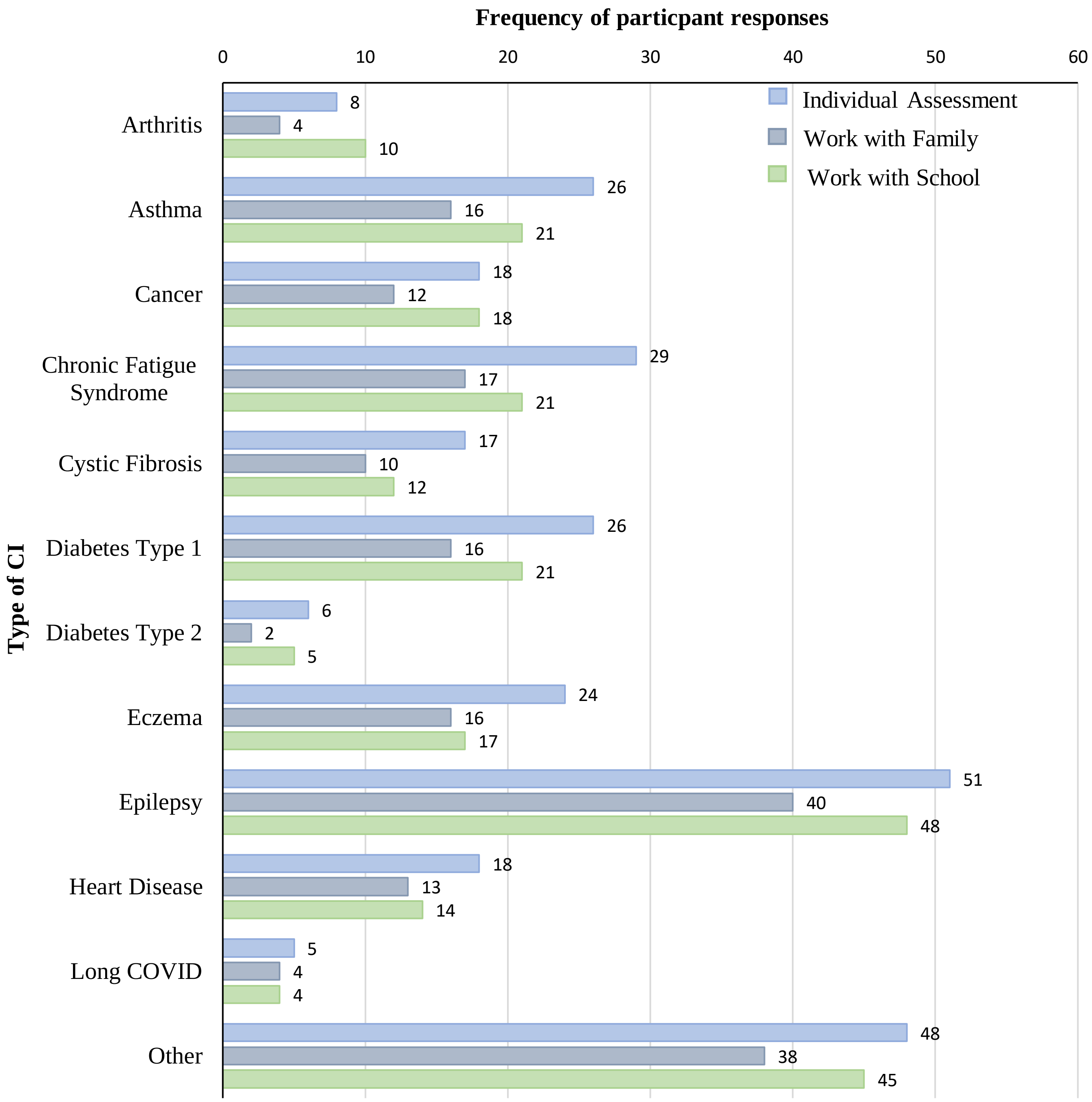
Table 5

Number of responses related to type of involvement across all CIs.

EP Involvement	Individual Assessment	Work with Family	Work with School
Number of Responses	276	188	236
Percentage Equivalent	39	27	34

Figure 8

Number of responses regarding different types of work with each category of CI

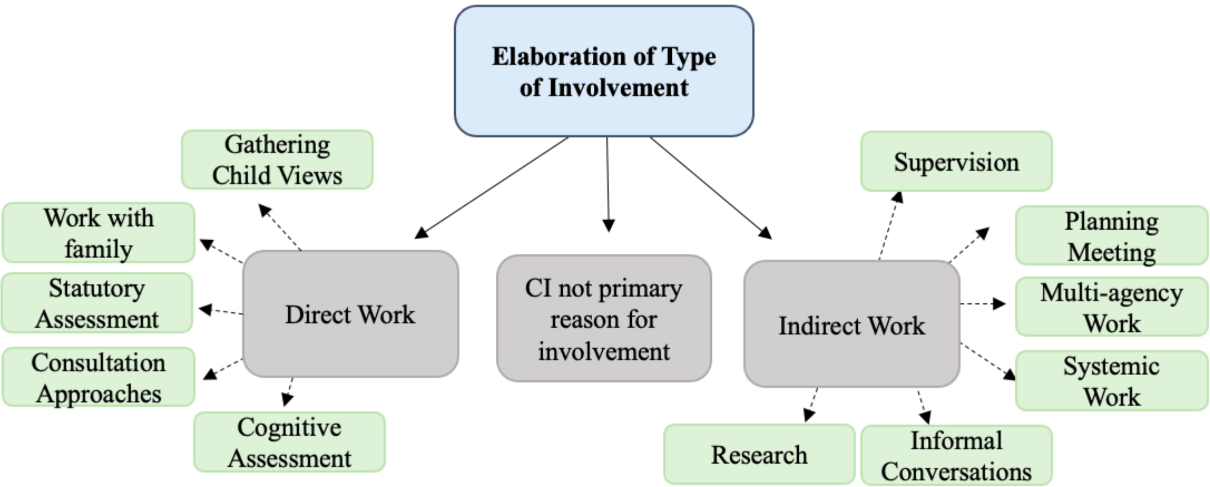


4.2.2 Qualitative data

Participants were asked to elaborate on the type of involvement that they had with children with CI. Similar themes developed when compared to the participants' comments regarding Research Question 1 (Figure 9). Notably, participants again described that CI was not the primary reason for which the child was referred to them or the service.

Figure 9

Themes and subthemes related to elaboration of type of involvement.



Participants described a variety of direct work that they had been engaged with. The completion of statutory assessments was mentioned as the main source of contact with children with CI. However, participants also noted alternative types of direct involvement, such as 'cognitive assessment', 'consultations', 'gathering the child's views', and 'supporting the family'.

Participants described that they engaged in some indirect work to support children with CI. This included communication about cases in supervision with staff and engagement in related topics of research. Participants expressed that they engaged in systemic work and multi-agency work that supported children with CI. Participants wrote it was key to 'liaison with lots of professionals'. They also described that they had 'informal' conversations with schools and discussed cases of chronically ill children in planning and review meetings.

4.3 Research Question 3 – What do EPs regard as CI and how does this relate to SEN?

4.3.1 Quantitative data

Around half of the participants (52%) indicated that a child or young person had been referred to them primarily due to their CI. Subsequently, 48% of the participants indicated that CI is not a major focus or is not at all considered when being referred for EPs' involvement. This finding supported the creation of the stimulus text for Phase 2, as described in Chapter 3.

Participants were asked to indicate if they agreed with the definition of CI (a health problem, that last more than 3 months, and requires medical professionals and ongoing management). In the survey, 87% of participants indicated that they agreed that a CI lasts for more than 3 months; 62% felt that a medical professional based in an educational setting (e.g. school nurses) must be involved; and 75% agreed that children with a CI always require ongoing management. The overall response frequencies are presented in Table 6.

Table 6

Frequency of participants who agreed with the statements related to the definition of CI.

Definition of CI	Last more than three months		Requires Medical Professionals		Ongoing management	
	Frequency	Valid Percent	Frequency	Valid percent	Frequency	Valid Percent
Agree	73	87	53	62	64	75
Disagree	11	13	33	38	21	25
Total	84	100	86	100	85	100

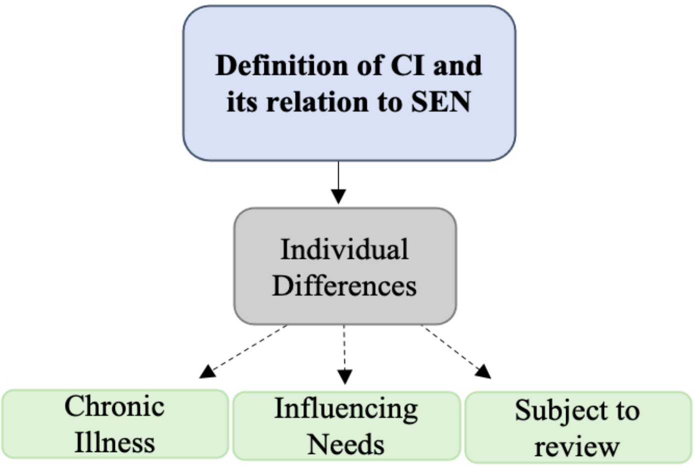
The relationship between CI and SEN was explored. Most participants felt that there were times when CI and SEN may become synonymous (83%). However, 17% of participants disagreed, suggesting that CI is different from having an SEN. Most of the participants (95%) agreed that CI can sometimes lead to an SEN, with only 5% indicating that CI always leads to an SEN.

4.3.2 Qualitative Data

Themes and subthemes that considered the definition of CI and its relationship with SEN are shown in Figure 10. The notable theme of ‘individual differences’ became clear in the comments. This is related to the first subtheme of CI. The data suggested that the definition of CI was highly related to the child’s situation. The definition can change depending on an individual’s experience. A participant wrote ‘individual experience of CI can be highly variable, and they are likely to need different types and levels of support at different times.’ Participants commented that the child’s illness, its severity, and the strengths and needs associated with it, can influence what CI might mean for that young person. A participant reflected ‘if a chronic illness is well-managed it may not present a barrier to learning. But I would have thought that more often than not a chronic illness will have an impact upon a CYPs ability to access learning.’

Figure 10

Themes and subthemes related to the definition of CI and its relationship to SEN.



The subtheme of ‘influencing needs’ was developed, as participants noted the additional influence of other factors or needs that might also be affecting the child. For example, the child might experience needs related to cognition, language, or mental health, which can each also have a bidirectional impact on the child’s general daily experience and their experience of the CI. A participant wrote ‘illness may impact on all aspects of development- attendance at school (impacting on belonging and academic achievement) cognition, social, communication and SEMH’. Participants also highlighted the importance of reviews to assess the child’s changing situation over time, developing the subtheme ‘subject to review’.

This theme of individual differences appeared in participants’ comments across all questions that related to the definition of CI. Participants indicated that the involvement of medical professionals, the duration of the illness, and ongoing management all depended on the individual circumstances of the child.

Additionally, there was a strong feeling that the relationship between CI and SEN was related to the individual’s situation and personal experience. A participant wrote ‘it genuinely depends upon the illness and the child involved’. Participants suggested that, for certain children, there may be no interaction between CI and SEN. In other cases, it was proposed that CI could be seen as an SEN when additional educational support is required.

4.4 Preparation for Phase 2 - Working in collaboration with health care professionals

4.4.1 Quantitative data

Around half of the participants (49.5%) indicated that they had experienced working in collaboration with health care professionals to support a child or young person with CI. This meant that 50.5% of participants highlighted that they had not worked in collaboration with health care professionals (see Table 7).

Table 7

Frequency of participants who worked in collaboration with health care professionals.

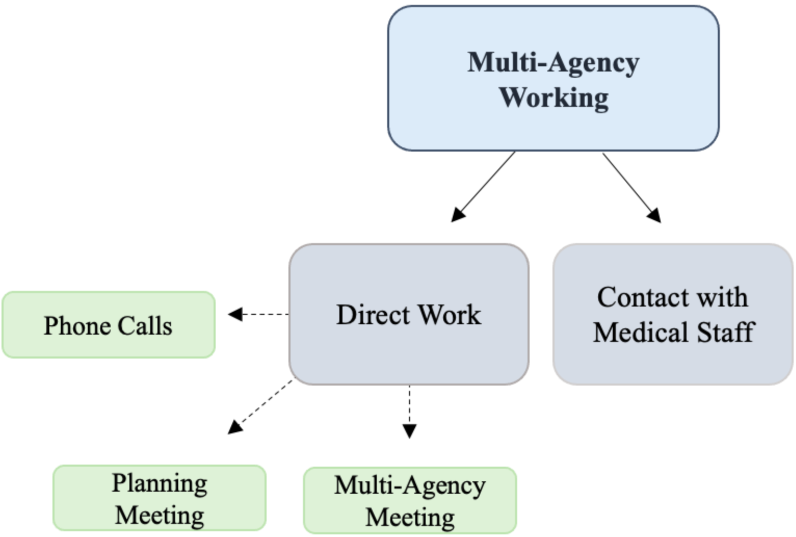
Collaboration with health professionals	Frequency	Valid Percent
Yes	45	49.5
No	46	50.5
Total	91	100

4.4.2 Qualitative Data

Participants who indicated that they had worked with health care professionals were asked to elaborate on this matter. They were asked about the role of the professionals they had worked with and the types of experience they had. Themes and subthemes related to multi-agency work are presented in Figure 11.

Figure 11

Themes and subthemes related to multi-agency working.



Participants indicated that their direct work with medical professionals included collaboration in ‘planning meetings’, collaborative ‘multi-disciplinary meetings’, and individual ‘phone calls’ to medical staff. Participants noted the contact with medical staff and the varied members they had worked with. This included working with Children and Adolescent Mental Health Services (CAMHS), Speech and Language Therapists (SALT), school nurses, specialist health teams, clinical psychologists, and paediatricians. Participants also indicated that they had worked with specialist teams related to cancer and cystic fibrosis. In these cases, participants took an active role as members of a multi-agency team supporting the child.

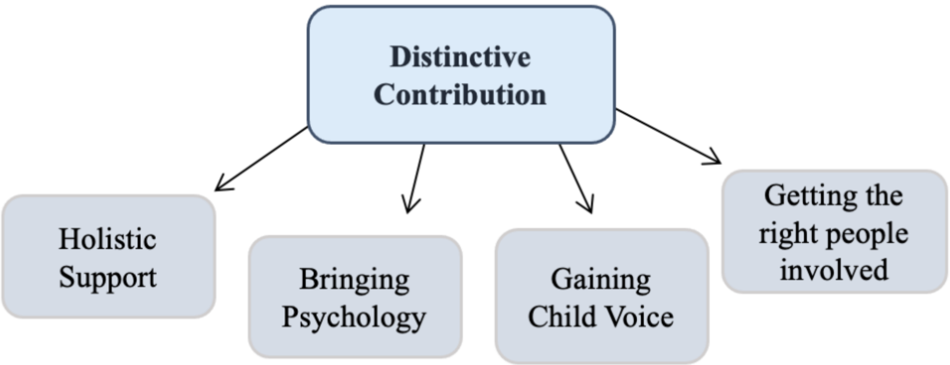
4.5 Preparation for Phase 2 – The EP's distinctive contribution and barriers to work

4.5.1 Contributions

The participants were asked to share their thoughts on the distinctive role that EPs play when working with children who have CI (Figure 12). A strong theme of 'holistic support' was developed from their comments. An EP commented that 'understanding the impact from a holistic picture' was important. Another stated, 'bringing together the puzzle pieces to form a whole picture that has a positive impact'. Participants noted their role focused on understanding the child, their world, their experience, and the systems around them. Participants discussed supporting the whole child and their individual strengths and needs.

Figure 12

Themes and subthemes related to the distinctive contribution of EPs.



Participants emphasised the importance of getting the right people involved to understand the full picture of a given child’s case. They noted that they collaborated with the child’s family and professionals to provide the best possible support for the child. A participant commented that ‘bringing together key role partners with the child at the centre’ was their contribution. Another wrote that ‘multi-disciplinary work, supporting with a different perspective within teams around children’ was important.

Additionally, bringing psychology to the case was a theme that developed from the participants' comments on the distinctive contributions of EPs. Participants discussed the importance of applying psychological theory and frameworks to support the child, their family, and school. One participant wrote ‘I think it’s to do with applying psychology and looking at the systems around the child’. There was a strong feeling that using consultation approaches was beneficial and provided support.

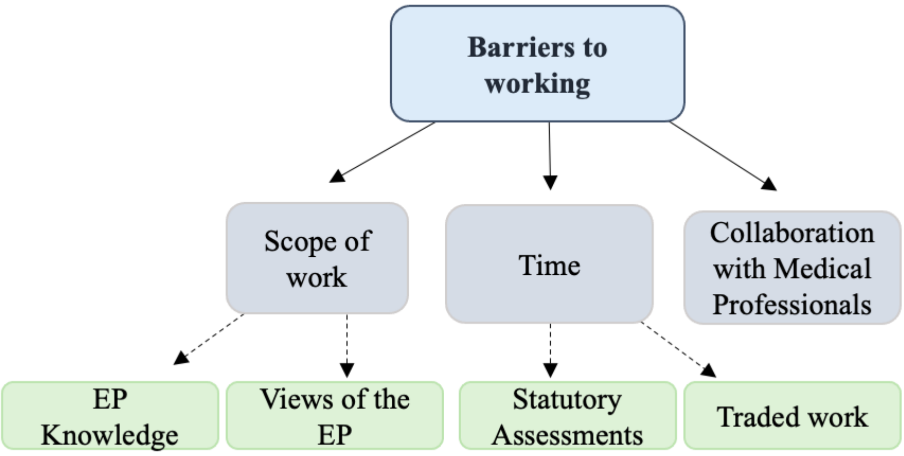
Participants noted the importance of collecting and taking account of the child’s voice to understand their own perspective of the situation. The importance of advocating for the child or young person was also mentioned.

4.5.2 Barriers

The participants were asked to provide feedback on the obstacles they faced or perceived when working with children with CI (Figure 13). Participants noted the importance of understanding the scope of the EP’s role and potentially recognising the limits to this. A participant commented ‘I do fear that this is potentially beyond the remit of EPs and strays into the domains of paediatricians and clinical psychologists’. Alternatively, participants also mentioned that schools and medical professionals may not understand the full scope of the EP’s role and therefore do not refer to EPs.

Figure 13

Themes and subthemes related to the barriers to working for EPs.



Many participants mentioned time and capacity as a barrier to working. Some participants expanded on this, describing their current high workload of statutory assessment. A participant commented ‘workload of statutory involvement taking up space’. Building upon this, participants also mentioned the difficulties with collaborating with medical professionals and the additional time that this can take. A participant noted ‘the continued difficulties with finding time to collaborate with health professionals’ and ‘working with other teams – not everyone communicates their information’.

5. Results: Phase 2

This section presents the focus group results in connection with the four research questions it intended to answer. For each research question, the thematic concept map, the structure of the themes, and appropriate quotes from participants will be presented to answer the question.

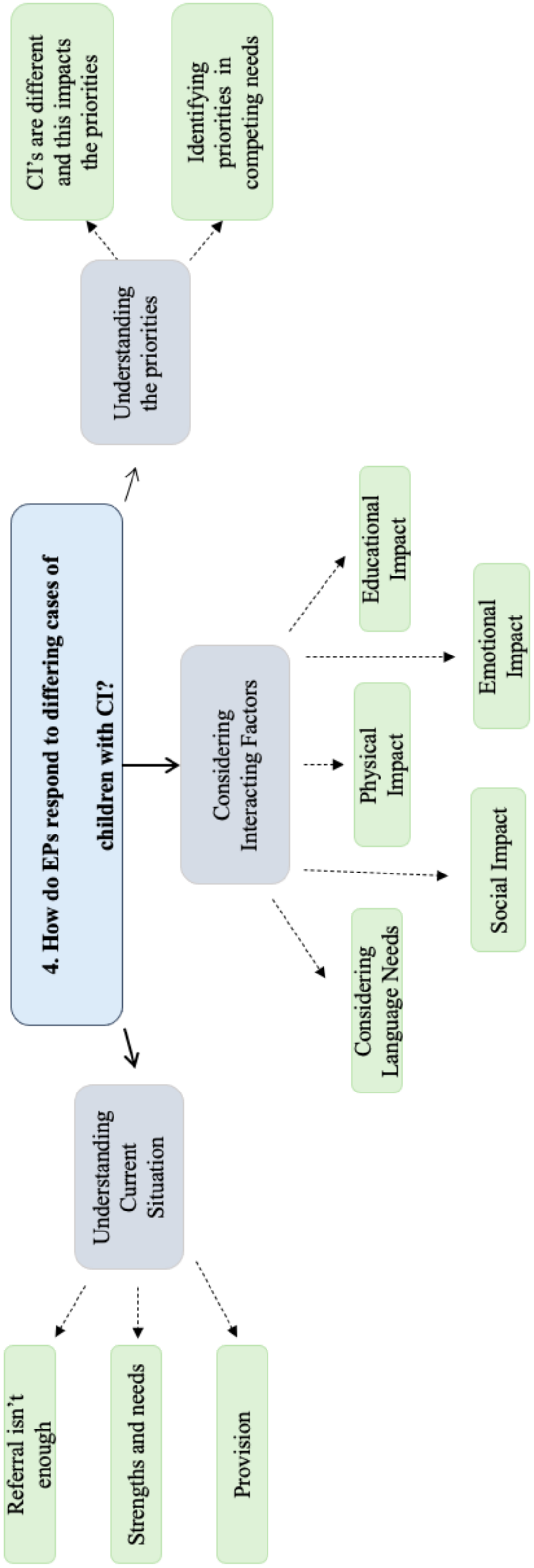
A discussion of group interaction will be presented throughout this chapter when considered relevant to the theme. Within most of the interactions, there was significant discussion that was coded under ‘agreement in group’ or ‘expressing support’. These coded items appeared when EPs behaved in ways such as nodding, smiling and saying yes when others were speaking. There was some coding of ‘disagreement in the group’, that highlighted opposition and discussion. In these rare cases, EPs made facial expressions that appeared confused, thoughtful or shook their head. These coded interactions were compared to the codes that developed through the verbal transcripts as suggested by Duggleby (2005). At times the interaction codes and interview codes complemented each other, and these will be the focus of the discussion about participant interaction throughout this chapter.

5.1 Research Question 4 – How do EPs respond to differing cases of children with CI?

Three themes were developed relevant to this research question. These were ‘understanding current situation’, ‘considering interacting factors’ and ‘understanding the priority’. Themes and subthemes are presented in Figure 14.

Figure 14

Themes and subthemes related to Research Question 4



5.1.1 Understanding the current situation

Participants' initial reaction to the cases presented in the stimulus text was often a desire to understand the situation further. The subtheme 'referral isn't enough' was developed. There was a strong feeling that the referral alone would not be enough information to understand the situation. A participant (EP 3) stated 'I guess there isn't much information', while another (EP 4) noted 'I think it would be helpful to have more information'. EP 4 highlighted that it was hard to consider any interaction between factors based on the referral, saying 'I think it comes back to there being very discreet bits of information in that referral, but actually we need to think about how those factors interact?'.

Following this, a subtheme developed that focused on a child's 'strengths and needs.' There was a feeling that understanding strengths and needs could make a difference in supporting the child. A participant (TEP 1) stated, 'we should unpick the strengths and needs to find out what she really needs to support her'. Participants stressed how important it was to understand that these strengths and needs were not fixed and might change. This was particularly important when a CI was involved. A participant (TEP 4) stated: 'Support her strengths and needs as she is, but just bearing in mind that that might change over time because of early epilepsy'.

Participants also wanted to know more about the current and past provision for the child and a further subtheme was developed. Participants felt that this added to the bigger picture. It supported an understanding of what had previously worked to support the young person and what was not so successful. EP 2 noted:

> I would want to look at what was happening in primary school because they would have known him very well. And I would want to know what they've done at secondary school so far to help him and what has been successful.

5.1.2 Understanding the priorities

Within this theme, there was a strong feeling that participants wanted to understand more about current priorities for the young person. There was a lot of group interaction and discussion within this theme; participants engaged with and discussed what the competing priorities might be for each young person depending on their situation. There was agreement and support in the group. There was a strong feeling that well-being is a priority over education. A participant (EP 1) stated ‘You know, just exactly going back to getting priorities right here and it’s well-being isn’t it’. As a result of putting well-being first, education might occasionally be reduced for a short time. For some children, school attendance may not always be the biggest priority. This was mentioned most concerning the stimulus text in which the referral mentioned a cancer diagnosis. A participant (EP 4) highlighted: ‘It feels like it is almost causing more harm than good you know, every time she’s coming into school that’s potentially traumatic for her’. When children are still able to attend school, a participant (EP 8) mentioned the possibility to ‘step back academic challenge’.

However, there was a unique point that highlighted that every child has ‘a right to education’ (EP 6) and that a reduction in time at school may be unsupportive. This view also considered the importance of normality. It was mentioned that not attending school may feel ‘abnormal’. In this case, the importance of having a conversation with all parties was noted. In particular, there was a strong sense that the family should be consulted to ensure their voice was heard and the main focus of the decision. EP 6 stated:

> I would take my lead from parents with that, it's like, what do they need to hear? What do they want? You know? Would it hurt them to know what we were thinking? Because obviously we wouldn't be taking away any experiences for her. And I totally think that obviously her emotional and social development, I would prioritize that. But also I think you'd have to be quite sensitive with the messaging, because what

> would it sound like if your child was really ill with cancer and we sort of said, ohh, you know, we're gonna pull back the school. You know, I think you'd have to tread really carefully.

Within the ‘identifying priorities in competing needs’ subtheme, participants discussed the possible competing needs coming from school. From the stimulus text, participants had a sense that cognition was possibly a primary focus for the school. There was a feeling that EPs might want to have a conversation with schools about this and they noted that they would want to explore more than cognition. A participant (TEP 2) highlighted:

> Everything is about cognitive strengths and needs and around kind of being below ARE etc. And then you see this kind of diagnosis of epilepsy, which maybe adds to the picture a little bit, so I guess. I do wonder a bit about what the schools, um, priorities are with that. Is it around supporting understanding her cognitive abilities or is it around that broader picture of how she can be supported in school.

Participants did highlight some differing views here. Some were particularly concerned about the school’s focus on cognition needs and did not view this as the main priority. Others considered that the cognition needs are important to explore in each case, whether a child has a CI or not. This discussion led to the subtheme ‘CIs are different and this impacts the priorities’.

In the ‘CIs are different and this impacts the priorities’ subtheme, participants felt that each situation, child, family, and illness needs to be considered separately. Participants noted that some CI cases can seem more vulnerable than others and that this can lead to changing priorities. This can become particularly prominent in children who have life-limiting conditions. One participant (EP 4) stated:

> Having conversations around outcomes, are we talking about, you know, in a year’s time we want this child to have made this much progress in the assessment brackets

> within reading writing and in maths or are we saying actually this is a conversation about maintaining and optimizing quality of life?'

Participants mentioned that some CIs can feel more stable than others. There was a sense that the stimulus material that included a child with type 1 diabetes seemed like a more stable situation than other referrals and that the priorities might thus be different.

5.1.3 Considering interactive factors

The 'considering interactive factors' theme developed as participants noted several factors that could interact and impact the child. There was a strong sense that it was key to consider the emotional impact that a CI might have on the child, developing the subtheme 'emotional impact'. This factor was mentioned as a response to all three stimulus texts and there was agreement in the group. To illustrate, one dialogue from the transcripts went as follows:

> EP 7: I guess a hypothesis might be that her emotional needs or her emotional well-being is presenting as a barrier to her progress in learning or her emotional well-being associated with her epilepsy is a potential barrier for learning.
>
> EP 6: It's difficult, isn't it as well, because I wonder, like her, I suppose her reflections would probably be quite concrete, like her experience of having a seizure is a very concrete thing, but her understanding of the relationship between that seizure and what it makes her think, how it makes her feel, her confidence, her focus, like those are very abstract concepts, aren't they? For a year two child. So yeah.

There was a sense that different aspects of mental health could be impacted. Participants noted the potential for trauma and attachment needs, particularly surrounding the referral that mentioned a cancer diagnosis. A participant (EP 6) noted 'I think I'd want to be thinking about trauma.' There were concerns about the potential for difficulties with self-confidence and self-esteem. A sense of belonging was also considered by the participants, particularly for children who might have had some time away from school. A participant (EP 5) asked ‘How can we help her to feel really safe and have a sense of belonging in the school?’

The subtheme of the potential ‘physical impact’ of a CI was developed. The impact that a CI can have on fine motor and gross motor skills was considered. But there was a strong sense that the presence of a CI may impact a child’s fatigue. A participant (EP 8) noted:

> Oh yeah, and obviously seizures, and they, drain you. She's really fatigued as well. And so I was thinking about, rest breaks and things, but it is really hard with the seizures being so frequent. But like, you just wonder is there a decline across the day? How are they giving her, you know, breaks and yeah, just in terms of her processing, like you said, that cognitive fog.

A subtheme around the ‘social impact’ for the child was also developed. There was a particular focus on building friendships at school. As a response to the stimulus text that mentioned cancer, participants concluded that the young person would have spent some time out of school and in hospitals. The ability to build friendships was therefore a concern that they participants had for her. One (TEP 4) stated: ‘thinking about the social impact of that as well in terms of how she makes friends and how she feels possibly isolated from her friendship groups’. Concern about friendship-building was also mentioned regarding the other two stimulus texts. Within these cases, participants noted the potential impact of poor self-esteem and how this might affect socialising.

The ‘considering language needs’ subtheme was developed from the data. There was a sense that possible language needs could act as an interacting factor for the child. Language needs were not talked about as a potential result of the CI but rather as an existing need. One participant (EP 4) hypothesised: ‘there are lots of things that could be going on and I’m thinking if that’s combined with some underlying speech and language difficulties.’

The ‘impact on education’ subtheme developed as participants indicated that interactive factors and needs may have a negative impact on education. The direct impact on education that a CI might bring was also considered. Participants mentioned the effect on cognition that medication could potentially have. A participant (EP 5) noted that a child could be ‘in a sort of cognitive fog due to the medication’. The influence of a CI on concentration and attention was also considered: ‘so concentration levels will be different, energy levels will be different’ (EP 1).

5.2 Research Question 5 – a. What practices, approaches and perspectives do EPs take to a realistic case? b. What do EPs believe they can contribute that is distinctive?

Many of the themes concerning research questions 5a and 5b were linked and reoccurring, as was expected when creating two parts to this research question (see Figure 15). However, some of the themes were separated and related only to one part of the question. Thus, to simplify the discussion, themes related to research question 5a are considered first, followed by themes related to research question 5b. Finally, themes that were present for both aspects of the questions are discussed.

5.2.1 Research Question 5a

5.2.1.1 EP as a supportive role. Figure 16 demonstrates the themes and subthemes solely related to research question 5a. In the first theme ‘EP as a supportive role’, participants explicitly mentioned and agreed that EPs take a supportive role in working with children with CI. In particular, they spoke about supporting families. Participants noted ‘often our role is around signposting and considering the whole of the family’ (EP 7).

Figure 15

Themes and subthemes related to Research Questions 5a and 5b.

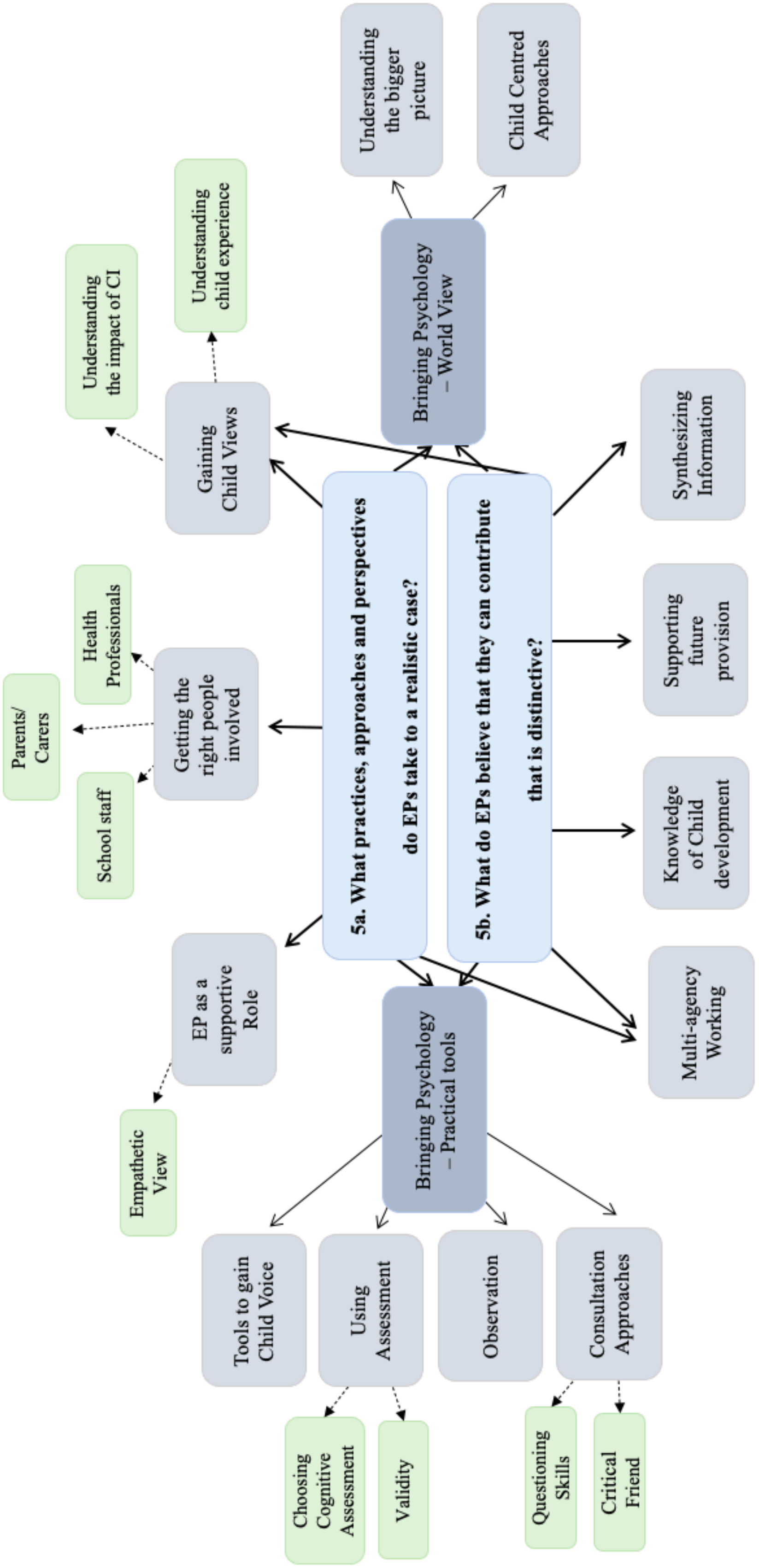
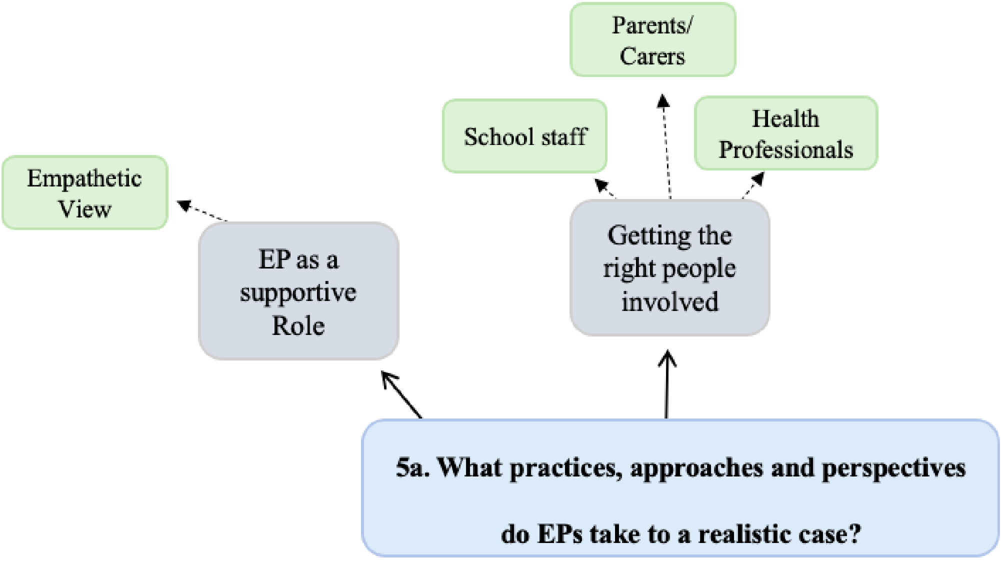


Figure 16

Themes and subthemes related to Research Question 5a.



Participants also discussed supporting teachers, particularly when they might have to make a 'brave' decision, such as reducing academic challenge. A participant (EP 8) commented: 'I think sometimes it is a really useful part of our role to give teachers permission to step back academic challenge'.

A subtheme of 'empathic view' was developed from the implicit meaning of what participants had discussed. When carefully reading the transcripts, I noticed a recurring theme of empathy emanating from participants when they discussed the stimulus text. They expressed statements such as: 'I felt an emotional pang when I read that and just saw, you know, what a tough time she must be having' (EP 1). And 'how difficult that must be for her and for her mum and I kind of want to wrap them both up in a really sort of snuggly blanket' (EP 5). In these instances of empathy, the group dynamic was often one of solidarity: the group were often nodding and agreeing that a situation was difficult.

Following this, in the 'empathic view' subtheme, participants also mentioned having careful and considered conversations with parents. They discussed being 'sensitive with the messaging' and the possibility of having a 'pre-conversation' or check-in call with families before a visit or consultation takes place. Participants mentioned providing a safe space where families can talk about the situation openly.

5.2.1.2 Getting the right people involved. In their approach to the case, participants noted the importance of trying to get the right people involved in that conversation, developing this theme. Participants suggested that this would be different in each situation. A participant (EP 1) highlighted that when choosing the right people, it must be 'people who know and can tell us about a situation and with real honesty'.

Participants discussed a range of people that could be involved with each case. A subtheme developed about getting parents involved in the conversation. There was a strong feeling that parents were in the best position to talk about their child and their CI. EP 6 reflected:

> I think that sometimes school staff don't understand the full extent of the child's medical experience, and I think that parents are really good at it, they really intimately understand how a medical need impacts the child. I don't know. I just feel like they tend to know that really, really well. And it's really useful to have them and have that conversation in the room, isn't it?

Participants noted the importance of school staff being involved and a subtheme was developed. Staff working in a variety of roles were mentioned as valuable. A conversation with a teaching assistant was mentioned, as they often have a secure relationship with the child. It was suggested that the SENCo and other senior leaders should be involved, to ensure that actions come from the meeting. The class teachers' view was also desired, as they often understand the current situation. EP 5 stated:

> I might try and go through the class teacher if I could, but sometimes I think in early years if there's a TA that's working really closely with her, that can actually be more

> beneficial. Maybe someone from SLG [Senior Leadership Group] at school as well.

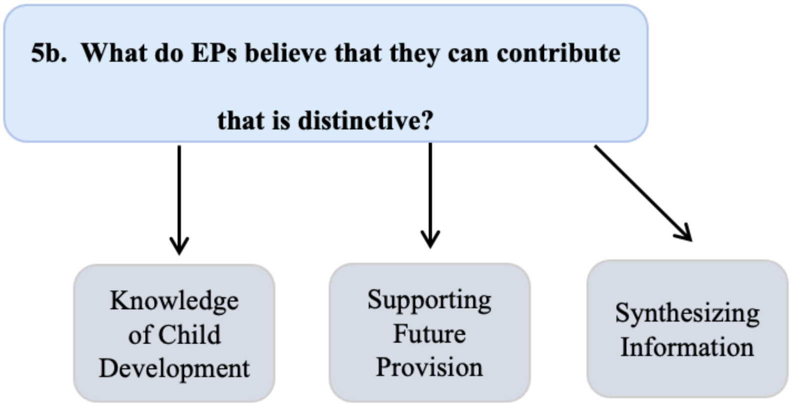
Finally, in the subtheme ‘health professionals’, participants talked about possible involvement of health professionals; general healthcare professionals were mentioned and, more specifically, clinical psychologists, doctors and hospital teachers were discussed. A participant (TEP 3) reflected ‘I would just see who the doctor was and make contact. And gather information in that way.’

5.2.2 Research Question 5b

Participants mentioned many ways in which they could be distinctive in their contribution towards supporting children with CI. Many of these will be discussed in the following section 5.2.3 ‘Research Question 5a and b’. Three themes were derived from the data that answered specifically research question 5b (Figure 17).

Figure 17

Themes and subthemes related to Research Question 5b.



First, in the theme ‘knowledge of child development’, participants highlighted that they had a full knowledge of child development that is supportive. Sometimes this was mentioned explicitly; one participant (EP 4) stated, ‘I think as an EP our contribution is coming to this with what we know about child development’. Elsewhere this was more implicit, and development was mentioned consistently throughout the discussions.

Participants used phrases such as ‘that makes sense in terms of what we know about psychological development’ (EP 4) and ‘I'm just thinking of other case work with children at a similar developmental stage’ (EP 8).

In the theme ‘supporting future provision’, participants felt that supporting the development of appropriate provision was a distinctive contribution that they make. One participant stated: ‘Supporting provision, I think that's the unique place that we hold’ (TEP 3). Mentions of provision were present throughout the EPs’ discussions. For example:

> EP 5: And I mean, I don't know very much about cancer, so stage 4 neuroblastoma. Does that mean that's very likely to be terminal? What are her needs right now?
>
> EP 8: and how much should that influence us? I think I would still be looking at what the appropriate provision was at that time, regardless of the prognosis.

Finally, the theme ‘synthesizing information’ was developed. Participants felt their ability to synthesize information was a contribution that they could bring to a case. A participant stated: ‘I think the unique contribution which is vital is the sort of synthesis of everything and what that means’ (TEP 3). In their interaction, participants showed agreement within the group on this theme, and there was much nodding of heads as people spoke. Participants mentioned the importance of listening to all parties involved and bringing those views and expertise together. This led to understanding the information. TEP 4 reflected:

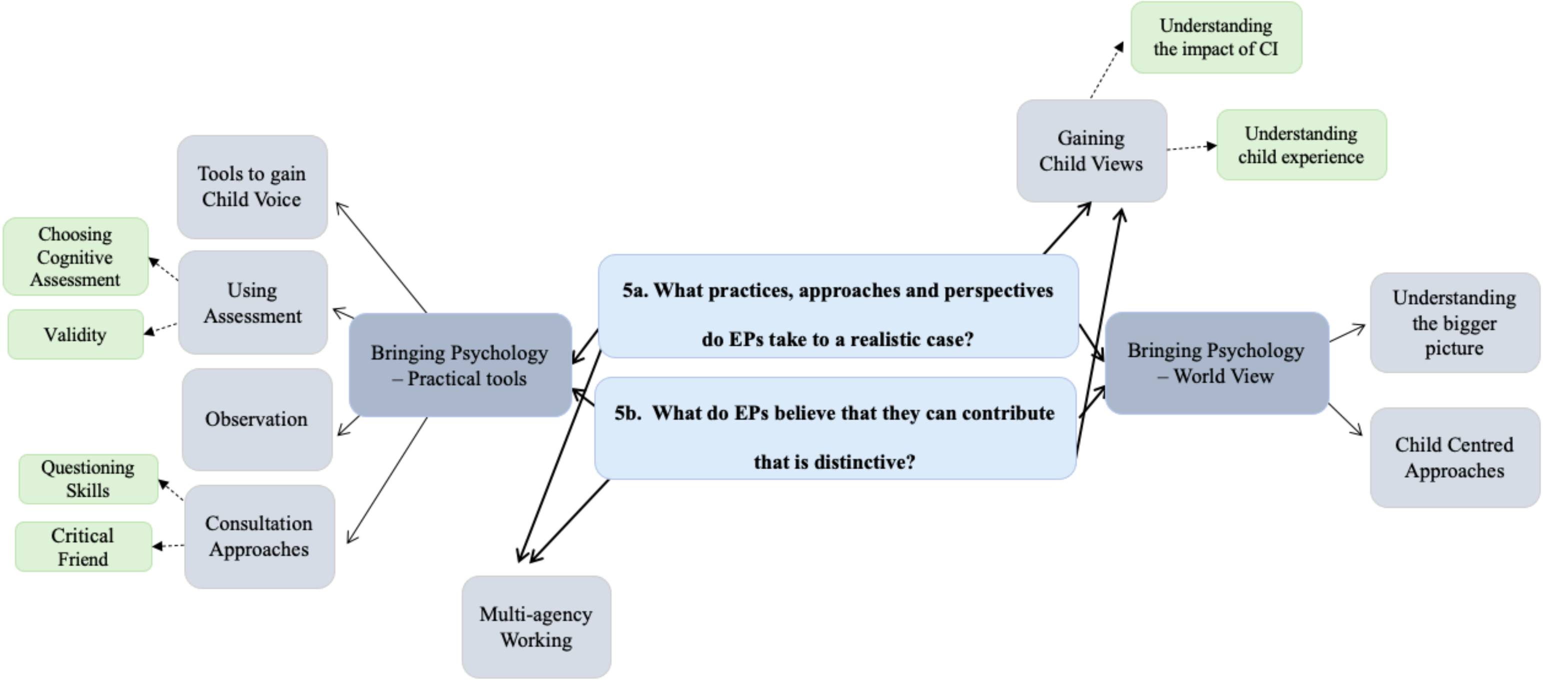
> ‘If we’re using a consultation framework, we’re using all the knowledge that everybody else has. So in that, we don’t need to know everything, we’re just bringing those views together, and it’s about asking the right questions and the right way, and then piercing other people’s expertise together.’

5.2.3 Research Questions 5a and 5b

As highlighted previously many themes and subthemes related to both research questions 5a and 5b. These are summarised in Figure 18.

Figure 18

Themes and subthemes related to Research Question 5a and b.



EPs' approach to the cases revealed two overarching themes in the data: 'bringing psychology-practical tools' and 'bringing psychology-world view'. These themes described both their approaches and their views of their distinctive contributions. These overarching themes became obvious as participants repeatedly mentioned psychological theory, approaches, and tools, both explicitly and implicitly. Within their discussion, their interactions were coded expressing support and agreement in the group regarding these topics.

5.2.3.1 Bringing psychology – world view. The theme 'world view' was developed as participants noted their approaches and perspective to each case. There was a feeling the participants used a child-centred approach throughout their work more generally and in the cases of children with CI in particular. This developed the theme 'child-centred approaches.' EP 3 reflected:

> And my experience is almost been that sometimes when it gets to the statutory level decision it can get a bit political between whether these interventions, whether this extra support is funded by health or whether it's funded by education. And my experience has been that sometimes that discussion that's happening has kind of almost overshadowed the fact that what we need to bring it back to is a child-focused model about how that young person feels and how that child and how that family is feeling about this situation, what support they need.

Within the 'child-centred approaches' subtheme, participants emphasised the importance of individual differences throughout the cases. They stressed that no situation is ever the same, particularly when working with children with CI. Participants stated, 'My experience has been that it can vary a lot between different children in terms of how much they're having to be monitored' (EP 3), and 'people's experiences of a medical condition is gonna be different. And so, it's just being really open-minded about that as well' (EP 1). When considering a child at the centre approach, participants highlighted approaches and models that they would use. They emphasised the use of a social model of disability. This view is captured in this quote:

> I just really liked the fact that we work from a social model rather than a medical model because, you know, over the years I've worked with so many parents who've had sort of devastating meetings with medical professionals and sort of negative diagnosis and prognosis and actually it can be so much more positive. (EP 5)

Participants referred to and compared their use of the social model to health colleagues' use of a more medical model. This suggested that the use of a social model and child-centred view could be a contribution to the EP's role. Within these conversations, participants also referred to a strengths-based approach, mentioning phrases such as: 'I'd be perhaps thinking about a strength-based approach' (EP 4) and 'It'd be interesting to look for strengths' (EP 7).

The theme of ‘understanding the bigger picture’ also came from the conversations. Participants referred to holistic working as an approach they used to understand the child, their situation, and the interactive factors around them. There was a feeling that having a holistic view was their unique contribution, compared to how other professionals were involved. Participants’ interaction was coded as agreement and expressive support throughout this theme. EP 2 reflected:

> Yeah. I think just to add to the holistic thing, if I could pick one area it’s this that we alone have the experience. Yes, across the areas, but within education and knowing that education isn't something that only happens between 9:00 and 3:30 and between the ages of five and 16. Umm, so we can actually look at how we can help children and families provide education for children.

Within this approach, participants applied psychological models and approaches to support their understanding of the whole picture. This included the use of a biopsychosocial model, the interactive factors framework, and an open-minded approach. These approaches allowed participants to consider multiple factors and their interactions.

> I think it's about being able to take a sort of biopsychosocial approach where you look at all aspects of the problem. I think that it's that systemic focus and also I think that as I said earlier, I think it's about us being able to interpret the impact on the experience [participants nod and smile in agreement] (EP 6)

5.2.3.2 Bringing psychology - practical tools. Participants mentioned tools and procedures that they would use in their approach to working with children with CI. The ‘observation’ theme was developed as participants mentioned that they would like to complete an observation of the child to better understand the child’s situation. For example, a dialogue from the transcripts went as follows:

> EP 7: Be interesting to do some observation at playtime as well as in lessons at

> different times of day.
>
> EP 5: And do they even go out to play? Do they keep her in to keep her safe? You know, so there might be a sort of lack of opportunity for some. I mean they may not be doing that of course, but you know.

The ‘tools to gain child voice’ theme developed as participants noted the tools that they might use to support the acquisition of child views. Personal construct psychology was noted as a support to them with this activity. TEP 4 noted ‘So yeah, I'd be wanting to get her point of view I think. Doing some personal construct stuff.’

There was agreement that consultation was a method that they would often use, which developed the theme ‘consultation approaches’. It was thought that EPs’ consultation skills were an integral part of their role, enabling them to make valuable contributions. In particular, participants saw skill in their ability to ask considered questions. A participant (EP 3) reflected:

> We’re able to ask the questions and be mindful of when we don’t know, you know, and actually we’re part of a profession that is, hopefully, open to asking the questions and recognising the aspects that we're aware of and that we're not aware of. Being open to having those kinds of discussions and sometimes challenging discussions when there is different views.

Within this, participants also noted their role in sometimes being a critical friend. They mentioned ‘challenging views’ and ‘gentle challenge’ to support the child and their family.

Finally, the theme ‘using assessment’ was developed. There was some discussion and slight disagreement in the focus groups on this topic. This concerned the use and focus on cognitive assessment. Some participants felt that a cognitive assessment was important, as the school was asking for it. It could contribute to the understanding of the bigger picture and the young person’s learning needs. Others felt that it was important to understand what the schools' priorities were, before conducting cognitive assessment. This dialogue represents some of this discussion:

> TEP 4: My feeling was a little bit that epilepsy could be a distraction from what you're being asked to do, and they're… actually you're trying to assess where she's at at the moment and so you could still do a cognitive assessment. Kind of picking up parts where she is at the moment and having discussions around that and how to support her strengths and needs as she is, but just bearing in mind that that might change over time because of early epilepsy.
>
> TEP 2: I guess I wondered a bit, just building on what TEP 4 said, about what the school's priorities were. So I guess until you get to that last paragraph where they talk about epilepsy. Everything is about cognitive strengths and needs and around kind of being below ARE etc. And then you kind of see this diagnosis. This kind of diagnosis of epilepsy, which may be adds to the picture a little bit. So I guess, I do wonder a bit about what the schools, um, priorities are with that. Is it around supporting understanding her cognitive abilities, or is it around that broader picture of how she can be supported in school? Cause I guess to me they feel like two slightly different things, depending on how you look at the kind of impact of epilepsy on that.

Other participants noted their concerns surrounding the validity of completing a psychometric assessment. Participants talked about the impact a CI might have on the validity of an assessment – for example, if a child was experiencing regular seizures or was under the influence of medication.

Although it might be argued that the psychological tools that EPs bring can be a distinctive contribution to children with CI. Interestingly, participants did not mention explicitly using many tools as a distinctive contribution. Participants tended to talk about their approaches or worldview as a distinctive contribution, compared to the practical tools that they used.

5.2.3.3 Gaining child views. EPs considered two main areas within this theme, when looking to gain the child's voice. First, they wanted to get the child's view about the impact the CI is having on them and their school experience. EP 8 reflected, 'What does she think she's doing well at and what she's finding difficult and maybe you know, how is epilepsy for her?' Additionally, participants wanted to gain a further understanding of the child's experience, through the child's eyes, in many different areas, such as their school experiences, friendships, and school provision. EP 5 noted 'Yeah, she's in year two, but I'm sure she still has feelings about, you know, being separated from her friendship groups'.

5.2.3.4 Multi-agency work. In the 'multi-agency work' theme, there was a feeling that multi-agency work was a key contribution that EPs could bring to cases of children with CI. In particular, they felt a role in bringing everyone together. Participants felt that they were able to support the joined-up thinking of different professionals and to work in such a team.

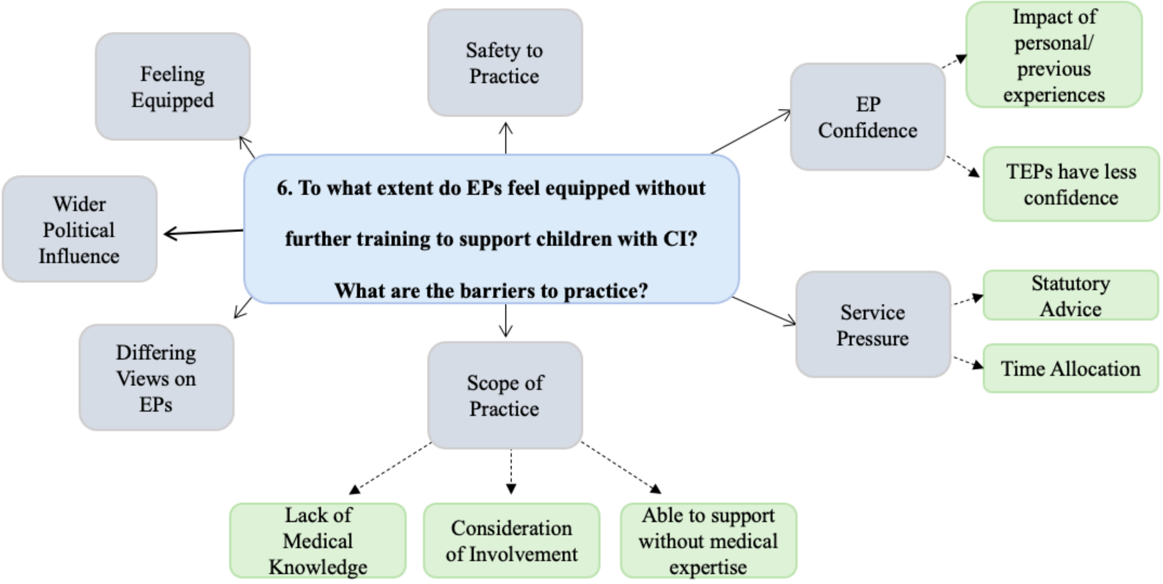
> EP 1: I think I'm equipped at working with others in a team. For this, but I wouldn't want to be trying to tackle it alone. Well I think I'd be quite good at asking some questions that we need to explore. Umm. Like you know, some things we've talked about and who needs to be there. You could best help us with understanding this medical condition. But no I mean… I just... I wouldn't feel like I could talk about diabetes or cancer or anything like that. Not only from the medical point of view, but it's all like you said, EP 4. It's different for everybody, isn't it?

5.3 Research Question 6 – To what extent do EPs feel equipped without further training to support children with CI? What are the barriers to practice?

It is clear from the themes I have demonstrated previously in this chapter that participants felt equipped to use many approaches, perspectives, and tools in their support of children with CI. In this section, I will focus on participants' answers that specifically related to how they felt equipped. I will also comment on their concerns about barriers to providing support.

Figure 19

Themes and subthemes related to Research Question 6



5.3.1 Feeling equipped

Within the theme 'feeling equipped', there was a general feeling that participants would feel equipped to work with cases of children with CI and to support them in school. A participant highlighted 'There's nothing in it that makes me worried that, that would be out of my expertise' (EP 8).

Some participants mentioned specific aspects of the work that they felt equipped in. As previously mentioned, participants felt that they would be equipped to work as part of a multi-agency team and at asking questions. Participants felt that they were equipped at seeing ‘the bigger picture’ as demonstrated in the ‘understanding the bigger picture’ theme presented earlier in this chapter.

5.3.2 EPs’ confidence

Within the data so far there has not been a substantial difference between the EPs’ focus groups and the TEP focus group. However, when discussing feeling equipped, it was clear that the TEP group felt less confident in supporting children with CI than more experienced EPs. They noted ‘I have to go back to like my lecture notes and see what we did on chronic illness’ (TEP 5) and ‘I think there’d be a certain element where I would just want to make sure that I clued myself up on things a little bit’ (TEP 2). TEP 2 expanded on this:

> It would definitely be one of those kinds of situations where I think I would need to go away and think about this and research this a bit for myself before I can make any decisions or start this process.

In their group interaction, there was some disagreement with this conclusion, with other TEPs highlighting that they would feel adequately equipped to provide support. TEP 3 stated:

> I'd be really happy to have it, but I think that comes from working in health previously. I would be happy to consult and talk as part of the work. That's just something that we do all the time, and so I think I am used to it.

The more experienced EPs mostly expressed that they would feel confident, particularly when working in support of other professionals. Participants felt most confident when they had experience with a CI themselves or when they had worked in the health industry in a past career. A participant reflected:

> I think for me personally, I live with a chronic health condition, and I think that that’s given me insight and into certain elements of it. That if I just had the doctoral training alone that would be different, and I think perhaps I wouldn’t feel as well equipped.

5.3.3 Differing views of EPs

The conversations in the focus groups led to the theme ‘differing views of EPs’. Participants felt that EPs’ individual views may either lead them to feel equipped to work with children with CI or may act as a barrier. A participant reflected: ‘There are gonna be EPs who have a very strong ‘I am not a medical professional and therefore I don’t even touch a case where a child has a chronic illness’ view’ (TEP 2).

Participants also noted that different services may have differing views about working with cases of children with CI. A unique conversation took place in the TEP focus group. Participants discussed the physical and sensory section of the Education, Health and Care Plan (EHCP) assessments. TEP 3 noted:

> There's been a lot of discussion that I've had with people recently about our role in writing about physical and sensory because I think some people feel that it's not our role at all, because we don't have that sort of medical expertise, if you like. However, I think the unique contribution which is vital is. The sort of synthesis of everything and what that means.

5.3.4 Scope of practice

Participants reflected on their ‘scope of practice’ as a potential barrier to working with children with CI, and a theme was developed. There was a feeling that EPs need to be careful about their ‘boundary’. An EP reflected that ‘at some point we recognise the limits of our competence’ (EP 4). Some participants considered working alongside health colleagues to support them. However, there was some disagreement here, as other participants suggested that medical professionals may not always be needed to support the child. They reflected that it can be difficult to get in contact with health professionals and to work in a multi-agency way. They suggested that sometimes reports and parents may be enough to support the child in their education. Participants considered that their role would not be on the medical side of the child’s needs but rather considering the interactive factors. They also highlighted that it would be important to be clear about their scope of practice. This quote highlights the thought pattern of a participant:

> That would feel like something that wouldn't obviously be within my skill set. But as you both said, sort of the going in, then the asking questions and also thinking about the questions at the moment, the schools are very focusing on is for both the cognition and learning. And I think wandering around that and that feels familiar territory. But I think the intricacies of the wider impacts of the health condition – that would be something that I'd want to be quite tentative about. My… you know …my experience and…. You know, you'd need to work collaboratively. (EP 3)

Participants also highlighted that they thought EPs may not be included in these cases because they are not medical professionals. Participants considered that, if there was no learning need, EPs may not be consulted to support a child with CI. A TEP reflected:

> I do wonder whether there will be some instances where, if a child is doing okay at school, if there's, kind of, no major concerns related to learning and attainment, I do wonder whether we would be involved or whether people would be seeking advice from medical professionals instead, and perhaps aren't recognising our contribution in the sense of being able to kind of assimilate all of that information and thinking about ways in which that chronic illness might impact a child psychologically, socially, emotionally. (TEP 2)

As highlighted in the quote, participants hypothesised that clients may not know what the contribution of EPs would be to these cases. These aspects were also mentioned in Phase 1 of the research, which further evidences these views.

5.3.5 Service pressure

As in Phase 1, ‘service pressure’ was developed as a theme, as participants mentioned this as a barrier to working with children with CI. This aspect was mutually agreed on in each of the focus groups. A participant reflected ‘I think it’s just again the problem with time and the referral and the service pressure’ (TEP 3). ‘Statutory assessments’ was developed as a subtheme as there was a strong feeling that the rise in statutory assessment work is making it hard to work with any other referrals. It was described as a barrier:

> At the moment I would just say statutory work, like I would not unfortunately …probably be able to pick up maybe the odd case, but like it's really difficult to kind of do anything that's not EHCP at the moment. So I think from a realistic point of view that is the main challenge. (EP 8)

‘Time allocation’ was also developed as a subtheme as there was a feeling that this was currently an additional barrier to working with children with CI.

5.3.6 Wider political influence

The theme of ‘wider political influence’ developed. Participants talked about how the current systemic context can limit their ability to provide support. They again mentioned that there has been an increase in the level of statutory work. Additionally, they expressed difficulties in securing necessary provisions for children, due to funding constraints. A participant reflected: ‘It's a really uphill struggle to get the funding to look at the best ways of education’ (EP 2).

There was a feeling that there is currently intense pressure on schools to secure good exam results. Participants noted that a focus on educational outcomes can reduce focus on provisions for vulnerable children. A participant made this comment concerning schools:

> They do feel under a hell of a lot of pressure, and so does schools where children don't meet the requisite standards if they're only at school, part-time or something like that. And it, you know, it affects their results and league tables and everything else.

This led to a discussion that was unique to one focus group, which noted the potential negative influence of labelling development, and how little it can mean for a young person.

5.3.7 Safety to practice

Participants also reflected that these cases have the potential to be emotionally difficult for the EP, and the theme of 'safety to practice' was developed. EPs highlighted the importance of being in a good emotional place themselves, where they felt safe to practice. In potentially difficult cases, it may be appropriate to not complete a referral, if the EP feels it could be upsetting for them. A quotation that highlights this point states:

> Sometimes there may be a referral where you're not the best person, and somebody in your team might be better to take that referral because it might be really difficult for you to contain other people's strong emotions when you're experiencing your own bereavement'. (EP 7)

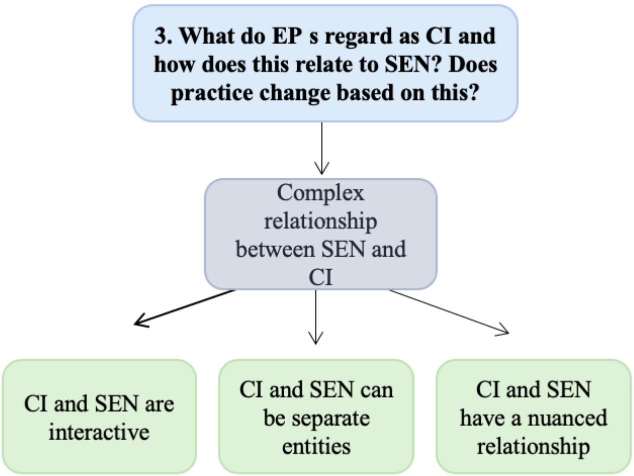
Following on from this conversation, participants discussed the importance of supervision and of seeking it after a difficult conversation or case, to gain support.

5.4 Research Question 3 (continued from Phase 1) – What do EPs regard as CI and how does this relate to SEN? Does practice change based on this?

This research question was a continuation from Phase 1. An amalgamated discussion of the work in both phases will be presented in Chapter 6. Here, I focus on the discussion from the focus group interviews and present the emerging themes (see Figure 20).

Figure 20

Themes and subthemes related to Research Question 3



5.4.1 Complex relationship between SEN and CI

The theme that emerged from the data was that there is a ‘complex and nuanced relationship between SEN and CI’, which is dependent on the individual’s situation. The definition of CI, much like in the first phase of the research, was dependent on the individual. Three subthemes emerged. In the first, ‘CI and SEN are interactive’, participants recognised that CI and SEN can interact, and often do. Participants made comments such as, ‘That’s really gonna interact with each other’ (TEP 3), ‘those two things, they can be a bi-directional’ (TEP 1) and ‘there’s a kind of bidirectional influence’ (EP 6).

However, there was some disagreement here in the interactions between participants, developing the second subtheme, ‘CI and SEN can be separate entities’. There was a unique feeling within the TEP group of the two as being distinct and separate. One TEP reflected, ‘I definitely saw the two as being separate’ (TEP 2).

But as the discussions continued, the subtheme ‘CI and SEN have a nuanced relationship’ was established. Participants shifted their view and highlighted that there are cases where the two can interact. At the conclusion of the discussions, there was a strong feeling that CI and SEN can be both interactive in some instances and separate in others, depending on the individual circumstances. This quotation summarises this perspective:

> The first one was sort of in and of itself, and then the second one is as a result of interacting things that a secondary to the sort of the chronic illness. So yeah, I guess it would be both in equal measure maybe. (TEP 2)

The second part of Research Question 4 asks ‘Does practice change based on this?’ Participants emphasised throughout these focus groups that practice does not change based on having a certain SEN or CI. Throughout this chapter, I have highlighted the participants’ approaches and perspectives on each case study. Often the focus was on a child-centred holistic approach. The only difference noted was that in some cases (such as cancer or epilepsy), participants had a more empathetic, careful response. They were more concerned about carefully considering the priorities in these cases, as highlighted in the priorities section of this chapter.

6. Discussion

In this chapter, the research questions are considered in turn. For each question, the results are discussed with reference to relevant literature. Data and findings from both phases have been incorporated to answer the research questions. The contribution to knowledge and the implications for EPs' practice are also discussed.

6.1 Research Question 1 – How often do EPs work with children who have a CI and in what context?

6.1.1 Frequency of work

Lum et al. (2019) found that, in Australia, EPs were working consistently with children who had CI at the same rate as those who did not. Lum et al.'s (2019) study supported a consideration that EPs in the UK might be doing the same. In Phase 1 of my study, EPs reported that they were also working with children who experience CI, although this aspect of their work was variable and irregular. Around half of EPs worked with children with CI on a termly basis, or more frequently, whereas around a quarter reported being involved less than yearly. This seems less frequent than in Lum et al.'s (2019) study, but it highlights that EPs in the UK are already working with children who experience CI. In particular, some participants highlighted specific roles or interests that ensure that they work with children with CI more regularly.

6.1.2 Context of work

In Phase 1, participants highlighted that they worked with children with CI in a variety of contexts. Notably, they identified that they had the most direct contact with such children through statutory assessment work. This is understandable, due to the continued increase in demand for statutory assessment work that has been placed on EPs (Capper & Soan, 2022; Lyonette et al., 2019). Additionally, EPs demonstrated that they worked with students with CI in the context of individual casework, research, and planning and review meetings. These related to the expected role of the EP, as discussed by SEED (2002). Perhaps unexpectedly, EPs reported having informal conversations with school staff to support them. These informal conversations were not previously considered, as prior literature considers the EPs' contribution only in a more formal multi-agency meeting context (Barraclough & Machek, 2010; Berger et al., 2018).

The findings of this study (in both phases) indicate that CI might not be the primary reason for the referral for EPs' support. EPs felt that students referred to them often had other learning needs, which was the reason for the referral. Previous literature highlights a possible lack of understanding of the EP's role in the community (Lee & Woods, 2017). The EP's role is often perceived through its contribution to cognition and testing (Lee & Woods, 2017; Love, 2019). This perception perhaps, supports this finding, although further research is needed in this area.

6.1.3 Research Question 1: Key conclusions

Participants indicated that they do have workloads that include children with CI, although this can be experienced irregularly and inconsistently. They identified that some of their work with children with CI was in the realm of an EP's role as highlighted by SEED (2002), including individual casework and research. However, participants perceived that much of this work was coming through statutory assessments or when CI was not the primary reason for the referral. This has wider implications regarding the EP's role in a context where statutory assessment is a key focus (Lyonette et al., 2019) and where the role may be understood as one focused on cognition (Lee & Woods, 2017; Love, 2019).

6.2 Research Question 2 – What types of CI do EPs often work with and what type of work do EPs carry out?

6.2.1 Type of CI

EPs demonstrated that they work with a diverse range and types of CI. The poor educational outcomes of children with many differing CIs are well documented in the literature (Fleming et al., 2019; Lum et al., 2019; Musgrave & Levy, 2020). Poor educational outcomes are not related to a specific illness. Instead, they are an increased risk factor when experiencing a diverse range of illnesses (Lum et al., 2019). EPs working with a range of different CIs reflected this finding.

In Phase 1, the most reported CI that EPs work with was epilepsy. The relationship between epilepsy and the support offered by EPs is demonstrated in previous literature. Reilly and Fenton (2013) highlighted the considerable support that EPs can provide to students with epilepsy, including understanding their needs, multi-agency work, and supporting interventions. Epilepsy was perhaps documented as the most prevalent CI in EPs' work due to its relationship with the experience of learning difficulties. Previous studies have highlighted this link and called for EPs' support to provide a cognitive assessment (Johnson & Parkinson, 2002; Papavasiliou, 2005; Petropoulos, 2019). In addition, EPs play a role in explaining the assessment result in the context of learning needs (Reilly & Fenton, 2013).

Moreover, working with children with chronic fatigue syndrome was the second most reported illness that EPs worked with. Brown and Cox (1999) highlighted the potential positive support that EPs can bring to this population of children. This included but was not limited to, supporting with an empathic view, acquisition of child views, supporting the school, and supporting families.

6.2.2 Type of work

The type of work that EPs conducted was similar across all the differing conditions. In Phase 1, EPs identified that they completed individual assessment work with the child, followed closely by working with the school and then the family. Participants noted specific types of direct work they were involved in. This included conducting cognitive assessments and consultations. This type of work has been documented as a key aspect of the EP's role in contexts other than working with children with CI. Consultation and assessment are identified as two of five aspects of the EP's role mentioned by SEED (2002). Participants also mentioned that they gathered child views and worked to support the family. Brown and Cox (1999) documented the support that EPs can offer to families in the context of chronic fatigue syndrome, while Smillie and Newton (2020) highlighted the key role that EPs have in gathering child views. Thus, these results appear consistent with the literature surrounding the EP's role. In Phase 2, EPs provided further insights into the type of work they carry out, which will be presented in the following sections, addressing other research questions.

The potential support that EPs could bring to multi-agency work is documented in the literature (Barraclough & Machek, 2010; Berger et al., 2018). In both phases of the research, participants expressed that they engaged in systemic and multi-agency work that supported children with CI.

6.2.3 Research Question 2: Key conclusions

EPs demonstrated working with a diverse range of CI, although working with children with epilepsy was identified as most prominent. This was perhaps due to its links to learning difficulties and a call to support with cognitive assessment (Reilly & Fenton, 2013). As highlighted previously, providing cognitive assessments and understanding learning needs is seen as a primary contribution of EPs' work (Lee & Woods, 2017). Despite this, EPs identified many different types of work conducted outside of assessment. This included consultation methods, collecting child views, supporting families, working with the school, supervision, research, and multi-agency work. This supports the premise that the EP's role is far more supportive than just that of cognitive assessment, as highlighted by Farrell et al. (2006).

6.3 Research Question 3 – What do EPs regard as CI and how does this relate to SEN? Does practice change based on this?

6.3.1 CI and its relation to SEN

To answer this research question, results from both phases were considered. In Phase 1, participants indicated their agreement with most of the CI definition presented in this study. However, participants also noted that the definition can change depending on an individual's experience. Participants commented that the child's illness, its severity, and the strengths and needs associated with it, can shape what CI might mean for that young person. This highlighted the importance of individual differences.

In Phase 1, most participants (82.6%) felt that there were times at which CI and SEN may become synonymous. The majority of the participants (95.3%) agreed that CI sometimes leads to an SEN. Notably, participants indicated that the relationship between CI and SEN was heavily related to the individual's situation. The themes that developed from the data from Phase 2 were consistent with Phase 1. Participants highlighted a nuanced relationship between CI and SEN which was dependent on the individual's situation. Many participants recognised that CI and SEN can be, and often are, somewhat interactive.

The views of participants were consistent with the complex understanding of labelling. Although labels can be viewed as an important way to ensure that children gain the additional support they need (Rolfe, 2019), and can offer a broad view of the child's needs leading to intervention, they may fail to focus on the child's individualised and specific strengths and difficulties (Lauchlan & Boyle, 2007). The EPs in this study had a similar view to Lauchlan and Boyle (2007) and highlighted the importance of focusing on the individual as this is the best way to create and recommend personalised and appropriate individualised intervention plans.

Research Question 3 was originally posed to understand where children with CI ‘fit’ in terms of legislation about receiving educational support. However, as each child has individual circumstances, this is nuanced and complex. Unfortunately, there is no definite solution here. This displays the complexity of working with such fixed term definitions as presented in the literature review. Despite this, EPs could have a role here, as they can focus on an individual, unravel problem dimensions, and support individualised interventions for CYP with CI (Cameron, 2006; SEED, 2002). Additionally, in future practice, they may also have a role in the innovation of definitions of disability and SEN (Norwich, 2013).

6.3.2 Change of practice

The second part of Research Question 3 asks ‘Does practice change based on this?’ In Phase 2, the only difference noted was that in some cases (such as cancer or epilepsy), participants had a more empathetic and careful response. However, participants highlighted that practice does not change based on having a certain CI. Participants emphasised a focus on a child-centred holistic approach to everyone. As highlighted throughout this discussion, participants aimed to understand the situation for each child, understand the problem, and move forward to support intervention for everyone. This was as expected within the EP’s role, as highlighted by Cameron (2006).

6.3.3 Research Question 3: Key conclusions

Participants indicated that they agreed with much of the definition of CI presented in this study, but noted that the definition may change depending on an individual’s experience. Additionally, participants considered that there can be a relationship between CI and SEN; however, again this is dependent on the individual’s situation and circumstance. EPs did not change their general approach to cases based on need but instead focused on unravelling the problem and moving forward positively, as highlighted by Cameron (2006).

6.4 Research Question 4 – How do EPs respond to different cases of children with CI?

6.4.1 Understanding the current situation and priorities

In Phase 2, upon reading the stimulus text, participants' initial response highlighted a desire to obtain a better understanding of the current situation, beyond what was initially presented to them. Participants wanted to have a clearer indication of the child's strengths and needs. Additionally, they wanted to understand the child's current and previous provision, to indicate supportive strategies. This search for further knowledge is consistent with Cameron's (2006) proposal that EPs use problem analysis to support their understanding of a complex situation. This process of acquiring knowledge is seen in many problem analysis models in psychology, such as the Monsen Model (Monsen & Frederickson, 2008).

Following this, EPs wanted to understand the current priorities for the child from different perspectives, particularly those of the child, school, and family. This further supports the use of problem analysis, as the EP collects further information to form a hypothesis (Kelly, 2007). In addition, EPs look to gain further knowledge to understand the priorities and the problem they are presented with (Kelly, 2007).

In the second phase of the research, participants indicated that they began to consider what priorities might be important with the information they were given in the referral. This could have been in the context of a continued attempt to form a guiding hypothesis (Kelly, 2007). EPs highlighted that well-being was a priority which led to them considering some reduction in school demand and attendance, although there was some disagreement in the group. Brown and Cox's (1999) paper about children with chronic fatigue syndrome that EPs were in a good position to support the decisions about school provision. EPs can support families and schools to understand the child's position and recommend appropriate provision to support them (Brown & Cox, 1999). Brown and Cox (1999) further highlight that, in some cases, this may be in the form of reduced school attendance and home education, as discussed by the participants in this study.

6.4.2 Considering interactive factors

During both phases of the study, participants emphasised the importance of assessing each situation, child, family, and illness on a case-by-case basis. In Phase 2, to understand each case, participants considered multiple interactive factors relating to the young person and their circumstances. Participants mentioned a variety of factors that they would like to explore and consider when reacting to the referral text stimulus. Considering interactive factors is documented as a key part of the EP's role, as demonstrated in the BPS definition of EPs' practice. This states that 'EPs look at how children and young people experience life within the context of their school and home environment and how different factors in these environments interact with each other' (BPS, n.d). Additionally, Cameron (2006) highlighted that EPs adopt a 'psychological perspective', whereby they often adopt an interactive factors view rather than a singular one. EPs consider how multiple factors can integrate with the child's experience (Cameron, 2006).

In Phase 2, participants indicated several possible interactive factors that could be affecting the young person with CI. Many of these factors mentioned were also highlighted in prior literature, as discussed in Chapter 2. Participants indicated that they would consider the emotional impact of having a CI. CI in CYP is linked to the experience of mental illness and poor mental health (Bergmans & Smith, 2022). Additionally, participants indicated concern about possible trauma, attachment needs, and low self-esteem. These concerns are documented by Bergmans and Smith (2022), Feeney (2001) and Pinquart (2013), who all note that children with CI have a higher chance of experiencing insecure parent attachment, anxiety, and poor self-esteem.

Participants also discussed the potential impact that CI might have on the child’s social life, such as possible difficulties with the initiation and maintenance of friendships. This is consistent with Runions et al.’s (2021) study, which found that children with asthma were more likely to be involved in bullying compared to their healthy peers. Moreover, participants discussed concerns about a child’s sense of belonging, particularly if that child had experienced school absences. Increased school absences due to CI have been documented in prior research (Emerson et al., 2016; Eves, 2017; Lum et al., 2019; Vanneste et al., 2015). Additionally, Runions et al. (2009) found that, in their study, students with CI felt that they were different, and experienced discrimination and stigmatisation at school (Runions et al., 2019).

Participants indicated that they would consider the child’s physical functioning and whether this might be impacting them at school. They specifically mentioned the impact that fatigue can have on functioning and concentration at school. Nunes et al. (2018) highlight that fatigue is the most common symptom associated with chronic conditions and it can influence students’ psychological, physical, and cognitive health.

Participants indicated that they would be concerned about the educational impact of experiencing a CI. Consistent with this view, Lum et al. (2019) found that students who experience CI are reported to be more likely to experience lower attainment compared to their peers.

6.4.3 Research Question 4: Key conclusions

EPs in the study responded to different cases of CI in similar ways. Initially, they wanted to discover more about the situation and understand key priorities that influenced their involvement. This was in line with the steps of problem analysis (Cameron, 2006). EPs recognised that each case was unique to the child and had to be fully understood without preconceptions.

Furthermore, the EPs indicated that to fully understand a situation, they must consider all interactive factors. This is also regarded as a key aspect of the EP's role (BPS. n.d; Cameron, 2006). The participants noted important factors that they perceived to have an impact on the child, based on the referral information. EPs were able to recognise and discuss key impacting factors for children with CI, as evidenced in prior literature. This provides evidence that EPs could be supportive professionals when working with children who experience CI.

6.5 Research Question 5 – a. What practices, approaches and perspectives do they take to a realistic case? b. What do EPs believe that they can contribute that is distinctive?

A key contribution of EPs' practice, as documented in the literature, is their ability to use and apply psychology to approach each situation (AEP, n.d; Cameron, 2006; Lee & Woods, 2017; Norwich, 2013). EPs emphasised this as a key approach and contribution in both Phase 1 and 2. EPs indicated how they would use psychological approaches to support children with CI.

6.5.1 Bringing psychology - world view

In both phases, EPs considered a child-centred approach as one that would be supportive of children with CI. EPs indicated a particular focus on individual differences and understanding each situation separately. In Phase 2, there was a feeling that participants would endeavour to take a social model of disability to support the young person they were working with. In contrast to the medical model of disability discussed in Chapter 2, where the deficit sits within the child, the social model focuses on removing barriers to support children to reach their full potential (Rolfe, 2019). Although not previously examined in this study, the social model utilized by EPs could be a supportive approach. According to Goering (2015), individuals with CI may not view their condition as a weakness. Therefore, a social model can provide effective support.

Additionally, EPs used psychological approaches to consider the bigger picture for the young person. Participants in both phases considered a holistic approach to supporting a child with CI, agreeing that this was a potential contribution they could offer. Within this, the use of a biopsychosocial model and interactive framework model was mentioned to support their work. The use of models to support problem analysis is, again, consistent with Cameron's (2006) proposal that EPs use problem analysis to support their understanding of a complex situation. Additionally, the holistic view offered by EPs can be supportive of children with CI. This was previously highlighted in the 'considering interactive factors' section, that considering the whole child and their bigger picture is important. In addition to previous research presented, Piko and Bak's (2006) study highlighted that children saw their health holistically, with some children commenting that health was about the body, mind, and happiness. EPs who take a similar approach may be supportive of the young person.

6.5.2 Bringing psychology – practical tools

In addition to the application of psychology as an overall approach, EPs in this study demonstrated key psychological tools that they would use to support children with CI. This was present in both phases of the study. Many of these tools were parallel to the literature presented in Chapter 2.

In Phase 2, participants noted that they would use observation of the child to further understand their current situation. Conducting an observation supports EPs to continue to gather information in support of forming an initial hypothesis. This further supports the use of problem analysis, as EPs collect further information to form a hypothesis (Kelly, 2007).

In both phases, EPs highlighted the positive use of consultation to support children with CI, understand everyone's views, and move forward to a more positive future. The use of consultation is often documented as an essential part of the EP's role, including the AEP and SEED's (2002) description of the role. Wagner (2000) points out that consultation is collaborative, and voluntary, and allows for the opportunity to use and explore different approaches and practices within it. This is a supportive process that can consider the child’s strengths and needs, and provide early intervention (Nolan & Moreland, 2014). In addition, Leadbetter (2006) notes that consultation can be used with multi-agency professionals when the outcomes of the meeting are specific actions that are taken with the child in mind. Participants indicated that their consultations often led to future provisions and interventions. Providing intervention support is also previously documented as a vital contribution of EPs (Black & Allen, 2019; SEED, 2002).

Further to this, in Phase 2, participants highlighted that in consultations they felt their contribution was to ask skilful questions. These questions were supported by psychological theories, such as solution-focused theory and a strengths-based approach. This links back to Cameron's (2006) theory which suggested that EPs use evidence-based strategies in their work with CYP. In addition, EPs discussed being a critical friend in their consultations, challenging possible views or preconceptions. This has previously been documented as a distinctive aspect of the role (Lee & Woods, 2017) and is supported by Cameron's (2006) view that EPs discover mediating variables. Within this approach, EPs offer a hypothesis that others may not have considered (Cameron, 2006). The EP provides a possible alternative reality that may support change for that young person, but that might challenge others’ views.

Moreover, participants highlighted their role in using assessment to support children with CI. In both phases, participants referred to cognitive assessment in conjunction with other tools to offer support. In Phase 2, participants specifically referred to psychometric assessment, but there were also a few mentions of dynamic assessment. As highlighted previously, assessment has always been a prominent feature of the EP’s role (Love, 2009). More recently, psychometric assessment has been viewed not simply as the provision of IQ scores, but as a tool to be used in conjunction with other assessments to provide a better understanding of a child’s specific strengths and needs at that time (Boyle & Lauchlan, 2009). Participants highlight this in their discussions throughout the focus groups. A cognitive assessment can provide supportive evidence to enable appropriate intervention and provision for the young person (Cameron, 2006).

Cognitive assessments and their use have been a contentious issue. This view was equally shared by participants in Phase 2. Participants were concerned about the validity of the assessment, particularly because children with CI have medication or physical impairments that can affect cognition. This was an important distinction for EPs to make. The validity of assessments and assessment profiles have been considered for population differences, such as regarding neurodivergence (Mayes & Colhoun, 2008). The validity of the performance of some students with CI might also need to be considered.

6.5.3 Additional knowledge

In Phase 2, participants indicated that their knowledge of child development was both supportive to children with CI and a distinctive contribution compared to other professionals. In this instance, EPs used their knowledge of child development to support their understanding of the situation and appropriate interventions. This is linked to Cameron's (2006) suggestions highlighting that EPs adopt a psychological perspective and apply evidence-based thinking in their work.

6.5.4 Acquisition of child views

Within both phases of the study, participants emphasised their role in acquiring the child’s voice and view. During Phase 2, participants indicated that they would want to gather information about the child's overall school experience, their experience with a CI, and how it impacts their daily life. Participants noted that using techniques such as personal construct psychology was helpful for this. In support of this, Farrell et al. (2006) highlighted that EPs are well-placed to use a variety of techniques and theories to support their ability to collect the views of the child. Smillie and Newton (2020) found that EPs often use a selection of techniques to collect these views. The techniques were supported by psychological theories such as solution-focused theory and personal construct psychology, among others (Smillie & Newton, 2020). Brown and Cox (1999) emphasise the importance of EPs gaining the child's view in their experience of chronic fatigue syndrome. They suggested that EPs should use techniques such as personal construct psychology to gain an understanding of the child's perceptions of the illness and their identity. This can provide autonomy and support the empowerment of the young person, as highlighted by Cameron (2006).

6.5.5 Supportive role

In Phase 2, participants took a supportive approach to the referral forms and indicated that this is their approach to all cases of children with CI in their practice. They identified that it was particularly important to support the family and school staff in their work. The EPs took an empathic approach to the stimulus texts, demonstrating empathy for the families in difficult situations. Participants commented that they would want to have carefully considered conversations with parents to communicate information sensitively and clearly. Additionally, the coded interactions of the EPs in the focus groups showed considerable supportiveness to each other, further exemplifying their ability to support others.

Lum et al. (2019) and Cameron (2006) highlight the role that EPs have in supporting school staff, and Love (2009) suggested that EPs are well-placed to support families. However, it seems that the empathic support that EPs suggest they can offer is not directly mentioned in these papers as a distinctive contribution of the EP. Despite this, EPs themselves see this as an important quality that they bring to their role. Brown and Cox (2007) emphasise the importance of an empathic view when supporting children with chronic fatigue syndrome, suggesting that often students and families feel they are not believed or listened to. The ability of EPs to carefully listen and validate others is important in these cases. This could be a key approach that is supportive for many students with a CI.

6.5.6 Multi-agency work

In both phases, participants indicated that their ability to support multi-agency work was an aspect of their work that they felt was distinctive and supportive of children with CI. This finding was consistent with the prior literature. Barraclough and Machek (2010) and Berger et al. (2018) indicate that a contribution of psychologists is working with a multi-disciplinary team of medical professionals and school staff. Participants indicated their ability to support the understanding of complex situations and relaying this to families. These papers discussed that EPs could support consulting with medical staff and liaison with family members. In this process, EPs could support the translation of jargon (Ball & Howe, 2013; Schilling, 2018).

In Phase 2, participants indicated that, when working in a multi-agency setting, they often considered who might be the right people to get involved in the case, including medical professionals and school staff. EPs also wanted to include the family in their conversations. These aspects were in support of gathering information as a means of offering support in a problem analysis approach (Kelly, 2007).

Additionally, in Phase 2, the ability to synthesize key information in support of change was another key theme that EPs felt was distinctive to their role. They indicated that they can collate information from differing agencies, understand it, and unravel the problem. This is in line with the distinctive contributions described by Cameron (2006). Psychologists can draw on their knowledge to consider vast amounts of information and identify mediating variables. They can then move forward to unravel the dimensions of the problem (Cameron, 2006). This is in line with their role as a ‘collaborative problem solver’, as highlighted by Lee and Woods (2017).

6.5.7 Supporting future provision

In Phase 2, participants noted their role in supporting provision and intervention as a vital aspect of the EP's role. Within their conceptualisation of problems, psychologists use evidence-based practice to consider the bigger picture and gain an understanding of the problem. From this, they provide an intervention plan to support CYP (Cameron, 2006). Psychological theory is used in this instance to both understand the child's reality and inform evidence-based intervention (Black & Allen, 2019).

6.5.8 Research Question 5: Key conclusions

Within this section, participants highlighted some key approaches and contributions that they could bring to support CYP with CI. As highlighted previously, a key contribution of EPs' practice is their ability to use and apply psychological theory to approach each situation (AEP, n.d; Cameron, 2006; Lee & Woods, 2017; Norwich, 2013). This was evident throughout the study; participants brought psychology to all aspects of the work in supporting children with CI and named specific theories and approaches. This included theories such as the social model of disability and a holistic view. They also highlighted key tools that they would use, such as assessment, consultation, and supporting provision.

Many aspects of an EP's work that were identified concerning working with children with CI were consistent with SEED (2002). In this section, participants mentioned three of the five ways of working that SEED (2002) suggested: assessment, consultation, and intervention. This study found that EPs also alluded to many of Cameron's (2006) suggested distinctive contributions, such as 'adopting a psychological perspective', 'uncovering mediating variables', 'unravelling problem dimensions', 'using evidence-based strategies', and 'promoting empowerment'.

In the context of children with CI, participants also mentioned some unique contributions that they considered important. Although these are alluded to in Cameron's

(2006) paper, they were not mentioned as specific contributions. Participants mentioned their key role in multi-agency work, which is supported by prior literature (Ball & Howe, 2013; Barraclough & Machek, 2010; Berger et al., 2018; Schilling, 2018). In addition, EPs discussed their contribution to be acquiring child views, which is seen as a part of their role (Farrell et al., 2006) and is emphasised as being important in this context (Brown & Cox, 1999). They also noted their role in being a supportive professional, which again, is seen as a key contribution in the support of children with CI (Brown & Cox, 1999).

6.6 Research Question 6 – To what extent do EPs feel equipped without further training to support children with CI? What are the barriers to practice?

6.6.1 Feeling equipped

It is clear from the focus discussions in Phase 2 that participants felt equipped to add many approaches, perspectives, and tools to support children with CI. Participants indicated that they did feel equipped to support children with CI in some way. They noted feeling this particularly if they have the support of additional professionals. This may often be the case, as EPs indicated that when supporting children with CI, they would take a very similar approach to supporting any other students.

However, the participants did differ in levels of confidence. TEPs, in particular, noted that they felt that they would need additional support. Although this finding was not previously considered, it is an understandable feeling. Hill et al. (2015) highlight that TEPs go on a journey with their confidence across their three years and sometimes experience a lack of confidence, at which time their supervisor is needed for support. When comparing the data in Phase 2, this was the main difference between TEPs and EPs.

6.6.2 Barriers

In both phases, participants were asked to comment on the potential barriers to working and supporting children with CI. Within both phases, participants indicated concerns regarding their scope of practice. Participants indicated it was important to understand the scope of the EP’s role and recognise its limits. Participants noted that some EPs may not feel that EPs’ work should edge into the realm of CI. This is an appropriate concern, as highlighted by the Health Care Professional Council’s (2010) standard of proficiencies. It states that EPs should ‘be able to practise safely and effectively within their scope of practice’ (p. 7), but it also refers to understanding the need to refer to other professionals. Participants suggested that, with the right knowledge and support from other professionals, working with children with CI is within their scope to practice.

In both phases, participants also mentioned that schools and medical professionals may not understand the full scope of their role and therefore not refer children with CI to EPs. As highlighted previously, there is a possible lack of understanding of the EP's role in the community (Lee & Woods, 2017). The role can be perceived in terms of its contribution to cognitive testing and focus on learning (Lee & Woods, 2017; Love, 2019). Thus, other professionals may not consider EPs when thinking about support for children with CI.

As expected, participants across both phases noted their time and capacity as a barrier to working. In Phase 2, participants expanded on this, mentioning their current high workloads of statutory assessment. The total number of EHCPs has continued to increase since the SEND reform in 2014 (DoE, 2022). As a result, the work of EPs is being redirected to support statutory work and away from other work. Lyonette et al. (2019) evidenced this in their review of the EP workforce.

Additionally, in Phase 2, participants indicated the government pressure that has increased the focus on educational outcomes. This has had an impact on schools’ ability to both focus on and put correct provision in place for children with CI as, in some cases, this would mean reducing academic expectations. Although this can be a barrier to support and can entail some difficult conversations, Brown and Cox (1999) highlight that it is appropriate for the EP's role to encourage supportive provision.

Jackson (2013) highlighted that the professional collaboration between health and education can be challenging to navigate. This is due to many contributing factors such as lack of resources, lack of ownership, conflicts of interest, and communication difficulties (Solomon, 2019). Participants indicated that this was a barrier that they face. They mentioned the difficulties in collaborating with medical professionals and the additional time that this can take.

6.6.3 Research Question 6: Key conclusions

This study indicated that participants felt equipped in their ability to support students with CI. The findings suggested that EPs seemed to approach a case of a child with CI in much the same way as any other case. As highlighted in Research Question 3, the approaches and tools that they used were ones that they used regularly in their practice. The approaches are known as key contributions to EPs' practice, as highlighted in prior literature (Cameron, 2006; Farrell et al., 2006).

Participants identified expected barriers to supporting children with CI. The wider political influence of increased time spent completing statutory assessments and focus on educational outcomes are important barriers to note. Without a change to these aspects, additional support for children with CI, and other CYP, will not be as well supported. MacKay (2020) argues that EPs are carrying out less vital early intervention work at the expense of writing statutory assessments. This additional pressure has also not only taken EPs from supportive alternative work, but now the quality of the statutory reports is also a concern (Capper & Soan, 2022). Additionally, understanding the role of the EP and their scope to practice is a barrier to their work. To be able to access children with CI, some work on how an EP can support may be helpful to schools. EPs must also have a professional duty to seek supportive professionals when they feel a case is out of their scope to practice, even though this could be challenging, as the professional collaboration between health and education can be difficult to navigate (Jackson, 2013).

6.7 Overall discussion

The poor educational outcomes of children with CI are well documented in research (Fleming et al., 2019; Lum et al., 2019; Musgrave & Levy, 2020), highlighting the need for additional support and attention for this population of children. This study aims to consider supporting CYP with CI, and the role of the EP in doing this. Despite concerns about the scope of practice of EPs, this study has found that EPs work to support children with CI, although this can be experienced irregularly, inconsistently, and often through statutory assessment work. EPs are working with a diverse range of CI, with epilepsy being identified as the most prominent.

6.7.1 The EP's role in supporting children with CI

This study found that the contribution that EPs can bring to support children with CI is similar to the support they bring to all students, supporting them in a holistic way and as a whole person. In this study, many aspects of the role that EPs highlighted as being important in their work to support children with CI, have already been mentioned in prior literature. Furthermore, the findings were broadly consistent with SEED (2002), which suggested five key areas of work for EPs: assessment, consultation, intervention, training, and research. Participants mentioned that assessment, consultation, intervention, and research were all part of their work in support of CYP with CI. However, they did not mention the use of training in this context.

Consideration of the EP's role was also consistent with Cameron's (2006) views on the distinctive contribution of EPs. Cameron proposed five distinctive contributions to EPs' practice: 'adopting a psychological perspective', 'uncovering mediating variables', ‘unravelling problem dimensions’, ‘using evidence-based strategies’, and ‘promoting big change’. Many of these aspects were highlighted in the key themes drawn out in this study, such as gathering information, considering interactive factors, and bringing psychology.

This study also highlighted some aspects of the EP’s role that has been previously mentioned in work considering the EP’s role and CI. EPs in this study discussed their contribution to multi-agency work to support the child. A key contribution mentioned in previous literature was the support that EPs could bring when working in multi-disciplinary teams, including medical professionals and school staff (Barraclough & Machek, 2010; Berger et al., 2018).

Additionally, this study did draw out some key themes that were particularly important parts of the EP's role in supporting children with CI. These have been mentioned in previous literature about the EP’s role but have not previously been considered as distinctive contributions that can be supportive specifically for the population of children who have CI. EPs considered that taking a holistic approach to support children with CI was a distinctive contribution. Within this, EPs talked about gathering information, getting the right people involved, multi-agency work, considering interactive factors, asking skilful questions, and understanding priorities. Of course, this is linked to unravelling problem dimensions as discussed in Cameron (2006). However, this feels particularly important when considering children with CI. The communication between health and education has been documented as particularly difficult to navigate and facilitate (Jackson, 2013). Despite this, children with CI have greater school-based needs compared to children without CI (Lum et al., 2019). Thus, the EP’s role – understanding a holistic view of the situation and bringing everything together to facilitate change and support provision – seems a positive and distinctive contribution that they indicate they can make.

Building on this, this study indicated that EPs have a role in understanding and gaining children's views, to fully understand the situation and problem. Participants emphasised their role in gaining the child's voice and view. They noted that using techniques such as personal construct psychology was helpful for this. EPs are in a good place to gain children's views and can use a variety of psychology and evidence-based techniques to support this (Farrell et al., 2006; Smillie and Newton, 2020).

Furthermore, the ability of EPs to be supportive professionals to families can be seen as a key part of their role. EPs took an empathic approach to working with and considering cases of children with CI. This empathic view is not previously considered a clear contribution of the EP's role, although Brown and Cox (2007) emphasise the importance of an empathic view when supporting children with chronic fatigue syndrome because students and families often feel they are not believed or listened to. EPs' ability to accept a situation as genuine is important in these cases and could be a key approach that is supportive for many students with a CI.

This study highlighted that EPs and the EP's role could be supportive in working with CYP with CI in their educational setting. Some might argue that it is possible for other professionals to provide the support that has been discussed above. However, as the poor educational outcomes of children with CI are well documented in research (Fleming et al., 2019; Lum et al., 2019; Musgrave & Levy, 2020), a call for support from a variety of professionals working together seems appropriate.

6.8 Contribution to knowledge

This study aimed to provide a unique contribution to knowledge when considering the role of the EP in supporting children with CI. A gap in the literature was identified, namely an understanding of EPs' views about what they already do and what support they could offer to CYP with CI. I aimed to consider the work that EPs are already doing and the practices and approaches they take. Additionally, I aimed to understand the distinctive contribution of EPs and the barriers that they may face in providing additional support. The findings of the study indicate that:

- EPs are working to support children with CI, although this can be experienced irregularly, inconsistently, and often through statutory assessment work.
- EPs are working with a diverse range of CIs, although working with children with epilepsy was the most prominent.
- They were working in four of the five ways noted by SEED (2002): assessment, consultation, intervention, and research, to support children with CI.
- They were contributing in ways similar to that explained by Cameron (2006). Many of these aspects were highlighted in key themes drawn out in this study, including gathering information, considering interactive factors, and bringing psychology.
- They have some distinct contributions to make in supporting children with CI. These were highlighted in key themes collected from the data and included: multi-agency work, taking a holistic approach, gaining child views, and being a supportive professional.
- There are some barriers to working with children with CI, including the scope of practice, misunderstandings of the EP's role, capacity and time, socio-political influences, and less than optimal collaboration between health and education systems.
- There is a complex and nuanced influence of labelling and definitions when considering their application to children and the support they are offered.

This study has presented some exciting opportunities for EPs' practice in supporting children with CI. It is hoped that it contributes thought-provoking insights into the additional contributions that EPs can make to support children with CI in a context where they are experiencing poor educational outcomes (Fleming et al., 2019; Lum et al., 2019; Musgrave & Levy, 2020). I now proceed to consider the implications for EPs.

6.9 Implications for EPs' practice

This study has several implications for EPs' practice. First, it highlights that EPs are already working with and supporting children who have CI. With this in mind, it is hoped that this study highlights the positive contribution that they can have, just as others have shed light on it (Brown & Cox, 1999). In the study, EPs reflected and indicated several useful and supportive strategies and approaches in working with children with CI. It is hoped that this study can be used as a source of support to ensure EPs know what their role is with children with CI and feel equipped to work within their scope of practice.

Additionally, this study has also identified other areas that EPs can work within to support children with CI. It indicated that CI might not be the primary reason for the referral for an EP's support. EPs felt that students were primarily referred to them because of other learning needs. Likewise, EPs reported working most often with children with epilepsy, who often experience learning needs that are directly related to their condition. The previous literature highlights a possible lack of understanding of the EP's role in the community, where it is sometimes perceived through its contribution to cognitive testing (Lee & Woods, 2017; Love, 2019). Although this cannot be determined with certainty without further research, perhaps cases of CI are not being referred to EPs due to alternative professionals not considering this as part of the EP's scope of practice. Participants highlighted that they thought that schools would not refer these cases to them. In this case, EPs have a role in promoting their potential contribution to schools, to ensure they are considered as a supportive professional.

Moreover, this study has highlighted some difficulties surrounding definitions and labelling when accessing additional support. Although labels can be viewed as an important way to ensure children gain the additional support they need (Rolfe, 2019), they can also provide a general overview of the child’s needs and not focus on the child’s lived experience. Participants highlighted the importance of focusing on the individual. They indicated that they felt definitions, such as that of CI, can change based on individual circumstances. Lauchlan and Boyle (2007) highlighted the importance of focusing on the individual as the best way to create and recommend appropriate individualised intervention plans. In this study, there has been consideration of where children with CI ‘fit’, in terms of legislation on educational support. However, this study has highlighted that this is nuanced and displays the complexity of working with such fixed term definitions. It has demonstrated the difficulties in the medical model versus social model debate. Norwich (2013) called for EPs to be innovative, suggesting that they should connect with university-based research groups and alternative professionals to support knowledge and evidence-based growth, and relating this to policy and service support. One of the suggestions is ‘greater involvement in the definition of disability and special educational needs that goes beyond the dualism of the social and medical models’ (p. 51). It could be considered that findings in this study support this implication for future practice, where EPs can influence support for children with CI at a systemic level.

Although this study has presented some exciting opportunities for EPs’ practice, it must be noted that the current context may not support the prospects that have been highlighted. As discussed here, the influence of austerity measures has had a detrimental impact on education (Hargreaves, 2021). As a result, LAs have reduced their expenses, whilst delivering the same services (Hanley et al., 2019). The total number of EHCPs has continued to rise since the SEND reform in 2014 (DoE, 2022), putting further pressure on EPs (Lyonette et al., 2019). Participants highlighted this as a real barrier to working with and supporting children with CI; they felt that they did not have sufficient time or allocation to support this population. Unfortunately, until a systemic change has been delivered, the possibility for additional support of EPs in this area will be challenging to implement. This is currently a considerable barrier that EPs face in supporting CYP with CI, as well as in many other areas of their role.

7. Conclusion

This chapter aims to bring together the information gathered from this study in a conclusion. It will consider how it may influence future research and present the limitations of the current research. Finally, it will conclude by discussing how the project has influenced my practice, and present concluding comments summarising the aims, methodology, and main findings of this project.

7.1 Implications for future research

As identified, there is a lack of research that considers the EP's role in supporting children with CI. Although this study has added to this, further research in the area would be appropriate. First, such future research could include a more representative group of EPs, as the majority of responses I received were from EPs in the South West of England. It might also be useful to consider a representative sample, as different LAs take different stances on working and supporting children. The study may have missed important views and experiences due to its limited sample distribution.

Additionally, it would be supportive to involve the views of parents, children, health professionals, and educational professionals. This study has identified aspects of the EP's role that could be supportive, but it has not analysed if it is supportive to the children involved. Talking to families and professionals about their experiences of working with EPs would support an understanding of the EP's contribution, and perhaps areas to work on.

Building upon this, this study suggested that some educational professionals might have an incomplete view of the EP's role. It found that EPs have a perception that children with CI were not often to them unless there was an existing learning need. Consistent with this, prior research has suggested that the EP's role is sometimes perceived as existing to provide cognitive testing (Lee & Woods, 2017; Love, 2019). Further research that aims to understand the societal perception of the EP’s role may be useful. This could be in direct relation to whether professionals consider supporting children with CI as part of the EP’s role.

Additionally, participants indicated that professional collaboration between health and education systems can be challenging to navigate. They mentioned the difficulties experienced in collaborating with medical professionals and the considerable time that this can take. Additional research to improve multi-agency work in the current socio-political climate would be supportive. Research about the inclusion of EPs in multi-agency work in support of children with CI would be particularly useful.

7.2 Limitations of research

7.2.1 Sampling

This section presents and identifies the potential limitations of the current research. In both phases of the study, I used convenience sampling as a way of gaining participants. Convenience sampling recruits individuals who choose to participate and who are thus self-selecting (Sousa et al., 2004). The benefit of this method is that everyone interested in the study can discuss their views. However, it also assumes that those who responded may have a particular interest in the topic and, thus, may have strong and specific feelings about it. Some of the participants in the focus groups, for example, had a specialist interest in CI or had experienced a CI themselves. It could be that the positive views expressed here by EPs working with children with CI were due to this bias.

The distribution and sample size of participants could also be perceived as a limitation. In all, 100 EPs and TEPs completed the online survey. These participants tended to be early in their careers, and a third of participants came from the South West of England, rather than being evenly distributed across the UK regions. In the focus group, nine qualified EPs and five TEPs took part in the interviews. EPs from seven different LAs across four different regions of the UK were recruited. As with the survey data, many of the participants were from several different LAs across the South West region and the data were not evenly distributed across the UK region. In one sense, this is not a critical issue, as the study took a non-representative design to sampling and generalising to the UK population was not the aim. However, it should be acknowledged that the sample distribution and size may have limited the production of codes in the study and that with a wider sample more novel codes may have been produced.

Building upon the limitation of sample size, Peterson (2000) highlights that the use of open questions can deter participants from completing the survey. I noticed missing data nearer the end of the survey and, perhaps, the use of opening questions here influenced this.

7.2.2 Focus group dynamics

The use of focus groups presents potential limitations to the research. Focus groups were used due to the advantage of using interactions as a way of generating data (McLafferty, 2004). Being in a group allowed participants to use the discussions to consider their position and respond to the given problem (Barbour, 2010). However, this interaction is equally a limitation of the approach (Femdal & Solbjor, 2018), particularly when there are dominant voices (Smithson, 2000) or power imbalances in the group. First, group composition is key to supporting a successful focus group (Femdal & Solbjor, 2018). The way of creating successful group composition is to ensure a balance between the group's homogeneity and diversity. It is important to consider aspects such as age, education, and gender (Smithson, 2000). In this research, the focus groups were carefully designed to support this. For example, TEPs were in one focus group to support homogeneity, but were from several different LAs or universities, to create some diversity. Second, the moderator supports group cohesion, reduces power imbalances, and supports equal voices of participants. On the other hand, Cyr (2019) highlights that the moderator should interject as little as possible, letting the conversation be governed by the participants.

When reflecting on the focus groups, I sense that group composition was not fully accomplished in one focus group. Within this group, a few participants were from the same LA and had an existing relationship. This did not support the diversity of the group. This was further exacerbated by technical difficulties. My internet connection was poor and some of the conversations I had with other groups, regarding hearing differing viewpoints and supporting everyone's voice, were lost. Due to this, in the first five minutes of the first focus group, one participant left the Teams call and withdrew from the study. When contacted afterwards to ensure they were supported, the participants disclosed that they felt there were dominant voices and they were unable to say what they wanted. This instance highlighted that, without a supportive group composition and a moderator to support the group, the interactions can limit participation. In future, I would perhaps end conversations if the internet connection is inadequate or instead hold face-to-face focus groups. I would also aim for a more diverse group of participants. This was a limitation of the approach and could have restricted voices and experiences in this study.

7.2.3 Research bias

When completing thematic analysis as a single researcher, research bias is hard to avoid. However, by using a reflexive thematic analysis approach in this study, it is hoped that readers understand that it aimed to embrace the subjectivity of the researcher (Braun & Clarke, 2022). As highlighted by Braun and Clarke (2022), the approach of thematic analysis is based on intersubjective judgement, and it highlights that coding cannot produce perfectly accurate themes. The process can be described as interpretative.

7.2.4 Conferencing software

Finally, using video conferencing to conduct my focus groups could be a potential limitation of this research. Although the use of this software has several advantages, including representation and accessibility (Keemink et al., 2022), there are also limitations to using this approach, notably that social interaction online is different to that offline. Participants are unable to perceive all paralinguistic behaviours, notably eye contact (Keemink et al., 2022). In my view, this exemplified the difficulties in group composition in one group. The use of the microphone was difficult and there were some internet difficulties. One participant felt that they were unable to voice their view. Despite this, other group members provided feedback suggesting they enjoyed the video conferencing and discussion with other EPs. The method appears to be preferred by some and not by others. In the future, I would consider using a ‘hands-up system’, so that the moderator is better able to see when participants wish to speak. In a face-to-face interaction, this would be more obvious due to participants’ paralinguistic behaviours.

7.3 Implications for personal practice

Personally, completing this research project has had some important implications for my practice as a TEP and becoming an EP. First, and more generally, the project has stimulated a large amount of reading and reflective time concerning the role of the EP. This has enabled me to consider the type of EP I wish to be and the work I want to do in my future practice. It has emphasised my affiliation with humanist psychology but also highlighted the limitations of this approach at a wider system level. I have used and considered different theories, models of working, and approaches that I might not have considered if I had not completed this project.

Additionally, my passion for working with children with CI has grown stronger. I feel that this research has put me in a good place to talk about children with CI, and their potential strengths and difficulties, as well as to talk about the EP’s role and how we can support these young people. I endeavour to share the knowledge I have gained with the EPs’ community, starting with the service I work within and then reaching out to other services and EPs.

In addition, as I highlighted in the implications of EPs’ practice, I endeavour to reach out to the schools I work in and discuss the variety of the EP’s role. I will outline the support I can offer to many children, including those with CIs. I want to encourage schools to bring children who have CI and who are struggling to planning and review meetings, in the same way that we discuss children in care or with learning needs. I have recently worked with two children who experience a CI, as well as their family and school, and I feel that completing this project has enabled me to feel better equipped in what I can offer. I feel I understand my role and limits to practice.

When starting this project, a few EPs commented ‘Is that relevant to educational psychology?’ They would often ponder it, and then the same reaction happened: they would state something like ‘Oh, actually I recently had a case with a child that has…’ and name a CI. It is my view that EPs do not always recognise the support that they are bringing to such a varied population of children, because it is what they do on a daily basis. That is an exciting prospect and a vital contribution to the role, in my view.

7.4 Concluding comments

The overall aim of this research was to further understand how EPs can support children and young people with CI. The unique contribution of the research was to consider the work that EPs are already doing and what practices and approaches they are taking. Additionally, it aimed to understand the distinctive contribution of EPs and the barriers that EPs may face in providing additional support. The study used a mixed methods survey to describe the interactions between EPs and chronically ill children and to understand the breadth of EPs’ experiences and views. I also set up three focus group interviews with a total of 14 participants, to gain a deeper understanding of these issues. Through synthesising the findings, I gathered views from EPs about the practices and approaches they use and their thoughts about their distinctive contributions and barriers as they support children with CI.

In Phase 1, through surveying EPs nationally, data were collected regarding their current practices. It was found that EPs are working to support children with CI, although this can be experienced irregularly, inconsistently, and often through statutory assessment work. EPs work with a wide range of CIs, although working with children with epilepsy was identified as the most prominent. Building upon this, by conducting focus group interviews in Phase 2 and integrating the results from both phases, further data were gathered to understand the current practice of EPs. This indicated that EPs work with children with CI in four of the five ways noted by SEED (2002), including assessment, consultation, intervention, and research, and contribute in ways similar to that set out by Cameron (2006). Many of these aspects were highlighted in key themes drawn out in this study, such as gathering information, considering interactive factors, and bringing psychology.

When integrating findings from both phases, some distinct contributions were found in the ways that EPs support children with CI. These included multi-agency work, taking a holistic approach, gaining the child's views, and being a supportive professional. Some barriers to working were also indicated, including the scope of practice, misunderstandings of the EP's role, limited capacity and time, socio-political influences, and poor levels of collaboration between health and education systems.

This study has presented key opportunities for EPs' practices in supporting children with CI. It is hoped that this study contributes thought-provoking insights into the additional contribution that EPs can bring to supporting children with CI, in a context where they are experiencing poor educational outcomes (Fleming et al., 2019; Lum et al., 2019; Musgrave & Levy, 2020). However, it must be noted that the socio-political context, and views of the EP's role, may need to adapt and change to ensure that EPs can work with children who experience CI and who are finding education challenging.

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Appendix A

Online survey

1. What area of the UK are you currently working in?

○ London (1)

○ North East (2)

○ North West (3)

○ Yorkshire (4)

○ East Midlands (5)

○ West Midlands (6)

○ South East (7)

○ East of England (8)

○ South West (9)

○ Wales (10)

○ Scotland (11)

○ Northern Ireland (12)

○ Other (13) ____

2. How long have you worked as an EP?

I am a TEP

	0	10	20	30	40	50	60	70
Years ()								

<u>Definition</u> For the purpose of this survey chronic illness will be defined as:
A health problem that is long term (over 3 months), requires the support of a professional, ongoing management and has a poor prognosis.

For example conditions such as: Asthma, Cancer, Diabetes, Chronic Fatigue etc

3. Do you have a particular specialism that brings you into contact with children who have chronic illness? (e.g. participation in a medical panel)

○ Yes (1)

○ No (2)

If 'yes' what is your specialism?

____

4. How often do you work with chronically ill children?

'Work' refers to any contact you have had with/about a child who has a chronic illness - this may include even a brief conversation with a school about a child or young person.

Weekly Monthly Termly Yearly Within 5 Years Never

	0	1	2	3	4	5	6
Frequency ()							

5. I work with children with chronic illness when writing statutory advice

○ Yes (1)

○ No (2)

6. I work with children with chronic illness as part of a medical, early support or multi-disciplinary panel.

○ Yes (1)

○ No (2)

7. I work with children with chronic illness from individual school referrals.

○ Yes (1)

○ No (2)

8. I discuss children with chronic illness in planning and review meetings.

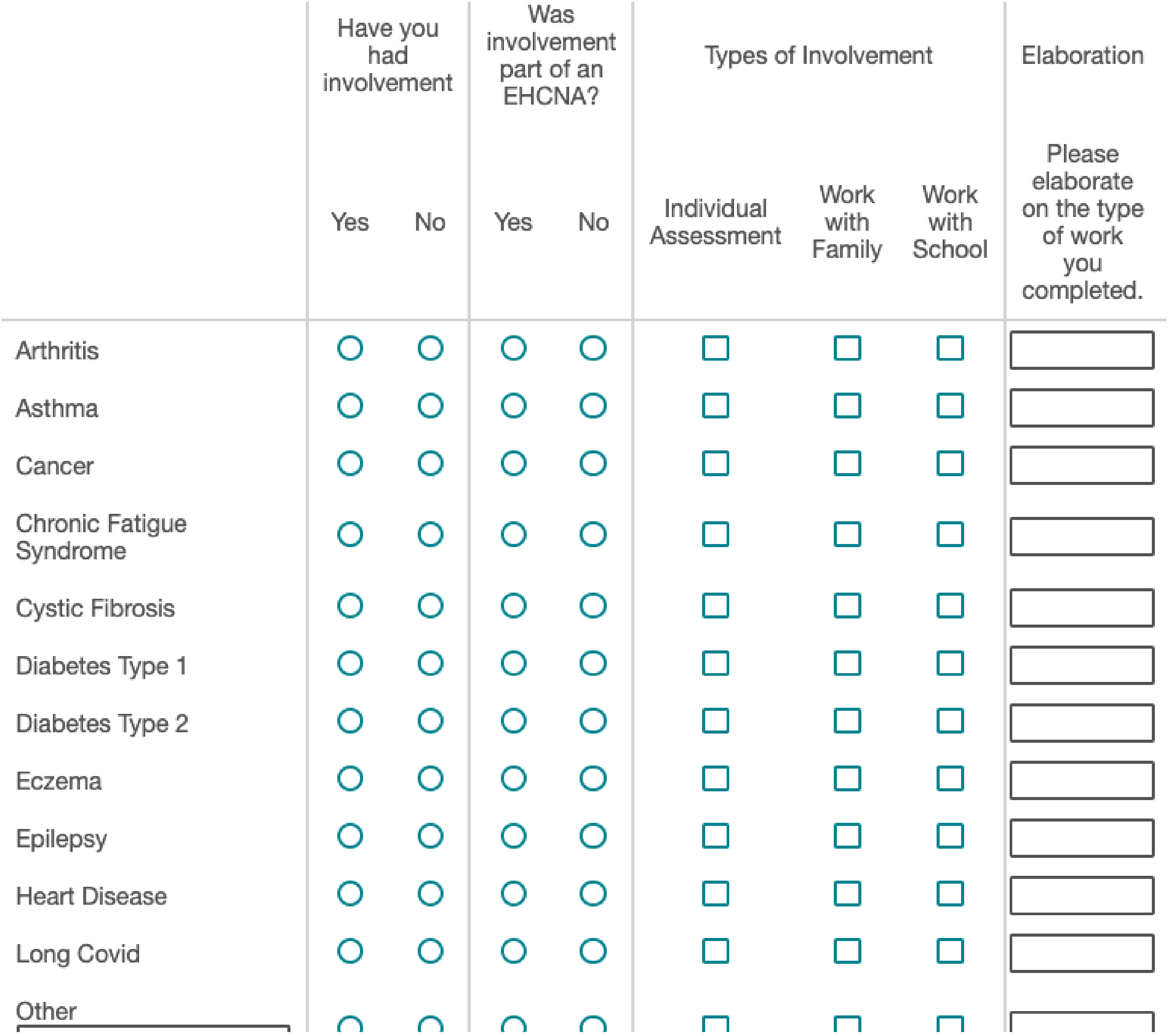
○ Yes (1)

○ No (2)

9. Is there anything else you would like to say about contact you have had with/about children with chronic illness?

____

10. Please select the types of chronic illness you have come across in your work and the type of involvement you have had.



	Have you had involvement		Was involvement part of an EHCNA?		Types of Involvement			Elaboration
	Yes	No	Yes	No	Individual Assessment	Work with Family	Work with School	Please elaborate on the type of work you completed.
Arthritis	○	○	○	○	☐	☐	☐	
Asthma	○	○	○	○	☐	☐	☐	
Cancer	○	○	○	○	☐	☐	☐	
Chronic Fatigue Syndrome	○	○	○	○	☐	☐	☐	
Cystic Fibrosis	○	○	○	○	☐	☐	☐	
Diabetes Type 1	○	○	○	○	☐	☐	☐	
Diabetes Type 2	○	○	○	○	☐	☐	☐	
Eczema	○	○	○	○	☐	☐	☐	
Epilepsy	○	○	○	○	☐	☐	☐	
Heart Disease	○	○	○	○	☐	☐	☐	
Long Covid	○	○	○	○	☐	☐	☐	
Other	○	○	○	○	☐	☐	☐	

11. Have you had experience of working in collaboration with health care professionals to support a child or young person with chronic illness?

○ Yes (1)

○ No (2)

11a. If 'yes', please elaborate on the role of this professional and your experience of the collaboration

____

12. Is there anything else you would like to say about types of chronic illness you have come in contact within your professional role?

____

13. Have you been referred a child or young person primarily due to their chronic illness?

○ Yes (1)

○ No (2)

14a. Please highlight the statement you most agree with:

○ Medical professionals based in educational settings (e.g. school nurses) must be involved with children who have chronic illness (1)

○ There are times where medical professionals in educational settings do not need to be involved. (2)

Please explain your answer

____

14b. Please highlight the statement you most agree with:

○ To have a chronic illness it must last for a long period of time (more than three months) (1)

○ You can have a chronic illness for a short period of time (less than three months). (2)

Please explain your answer

____

14c. Please highlight the statement you most agree with:

○ Children who have a chronic illness always require ongoing management, for example this could be anything from daily medication or a periodic review with a medical professional. (1)

○ You can have a chronic illness and not need any sort of ongoing management. (2)

Please explain your answer

____

14d. Please highlight the statement you most agree with:

○ Having a chronic illness is different from having a special education need. (1)

○ There are times whereby chronic illness and special educational needs may become synonymous with each other (2)

Please explain your answer

____

14e. Please highlight the statement you most agree with:

○ A chronic illness always leads to a SEN (1)

○ A chronic illness sometimes leads to a SEN (2)

○ A chronic illness is a medical matter and does not influence a child’s learning and development at school. (3)

Please explain your answer

____

15. What additional or distinctive contribution do you think that educational psychologists 'currently' bring to supporting students with chronic illness?

____

---

16. What barriers to EP contribution do you feel 'currently' exist?

____

I am looking for qualified EPs to take part in focus groups to explore supporting children with chronic illness further. The focus groups will take place on zoom/teams with approx. 3 other EPs from your service. The main questions will focus on what practices, approaches and perspectives that EPs take in case work with children who have chronic illness.

If you would like to take part, **please register your interest in the box below by providing your email address** (all information will be kept confidentiality and securely on my university one drive account):

____

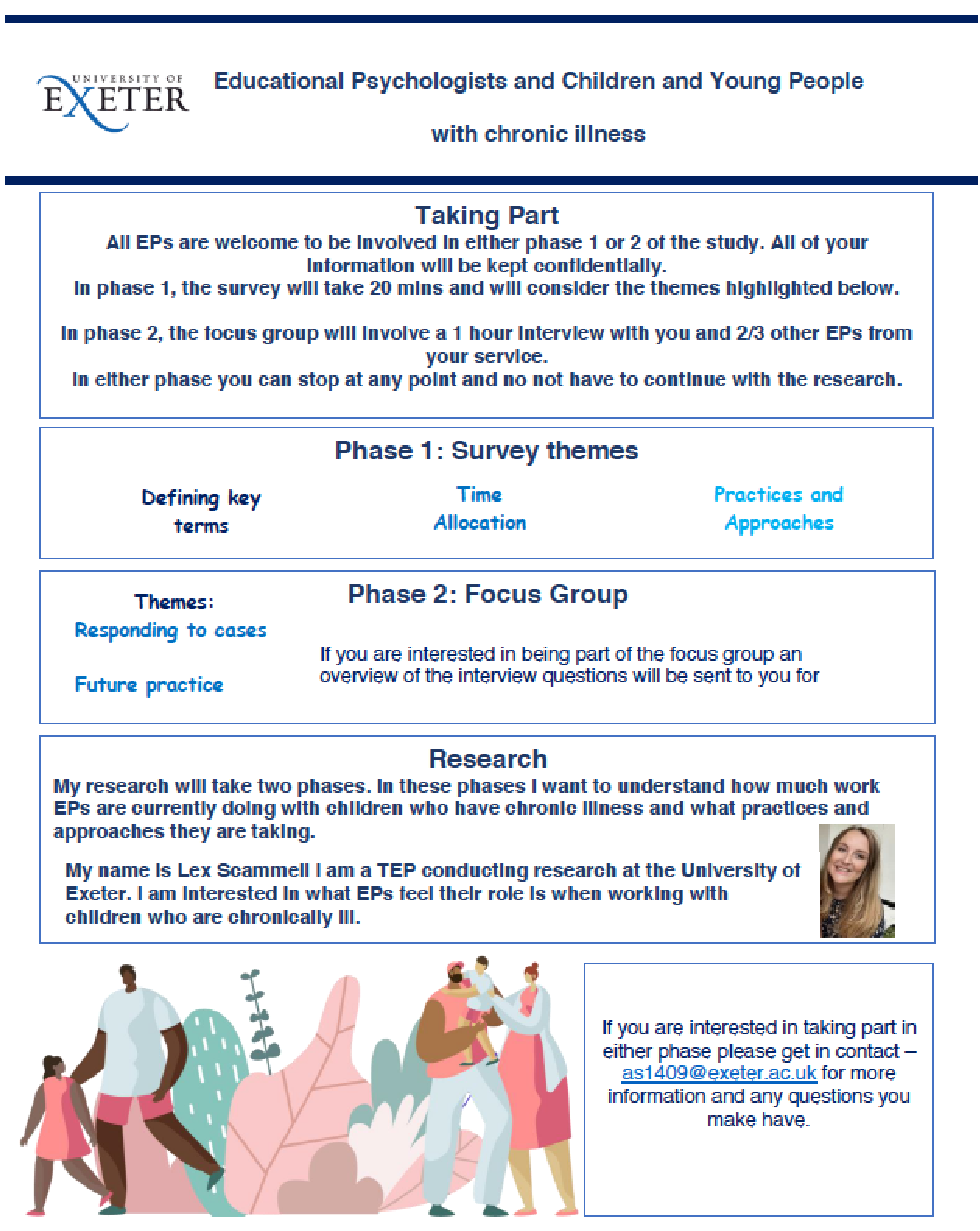
Would you like to be updated about the results of the research?
This would mean keeping contact details on record

○ Yes (1)

○ No (2)

Appendix B

Research advertisement



Educational Psychologists and Children and Young People with chronic illness

Taking Part

All EPs are welcome to be involved in either phase 1 or 2 of the study. All of your information will be kept confidentially.
In phase 1, the survey will take 20 mins and will consider the themes highlighted below.

In phase 2, the focus group will involve a 1 hour interview with you and 2/3 other EPs from your service.
In either phase you can stop at any point and no not have to continue with the research.

Phase 1: Survey themes

Defining key terms

Time Allocation

Practices and Approaches

Phase 2: Focus Group

Themes:
Responding to cases

Future practice

If you are interested in being part of the focus group an overview of the interview questions will be sent to you for

Research

My research will take two phases. In these phases I want to understand how much work EPs are currently doing with children who have chronic illness and what practices and approaches they are taking.

My name is Lex Scammell I am a TEP conducting research at the University of Exeter. I am interested in what EPs feel their role is when working with children who are chronically ill.

If you are interested in taking part in either phase please get in contact – as1409@exeter.ac.uk for more information and any questions you make have.

Appendix C

Ethical approval

Research Ethics Committee Review Outcome

Dear ALEXANDRA JEFFERY

Ethics Application ID: 493112
Title: To understand how Educational Psychologists can support Children and Young People with chronic illness in their Educational Setting.
(Version: 1.0)
Proposed Project Duration: 7 Mar 2022 - 31 Aug 2023

Your research study ethics application submitted above on 28 Jan 2022, 14:01 has been reviewed by the FHASS Social Sciences and International Studies Ethics Committee.

Outcome decision by Research Ethics committee: Approved

Dear Lex

This study is now approved and you are free to commence research. Please be aware that any significant changes to the study should be reviewed by proposing an amendment for review and receiving a favourable opinion prior to implementation.

If during the course of the research process you encounter issues or events that significantly change the level of anticipated risks of the research, you should contact the Research Ethics Committee for advice. Please remain aware of any UK government guidance or advice if appropriate.

Feel free to get in touch if you have any queries. Best wishes for a successful study.

Regards
Mark Slater
Research Ethics Officer

Decision Date: 7 Mar 2022, 05:22*

Italic note:

You can only start your research once you have received an* ***Approved* *outcome. The start date of your research will be no sooner than the Ethics Committee Approval decision date above.*

Research Ethics Committee Approval End Date: 31 Aug 2023

Regards

FHASS Social Sciences and International Studies Ethics Committee

Appendix D

Online survey consent form and information sheet

General Information

The purpose of this research project is to understand how educational psychologists are currently working with chronic illness and to what frequency. Additionally, what practices, approaches and perspectives do they take in case work with children who have chronic illness.

Thank you for participating in this questionnaire/online survey. Please read through all of the information before agreeing to participate (if you wish to) by ticking the ‘yes’ box at the bottom. You may ask any questions before deciding to take part by contacting the researcher (details below).

The Principal Researcher is Lex Jeffery, who is attached to the Humanities Department at the University of Exeter. This project is being completed under the supervision of Brahm Norwich and Margie Tunbridge.

In this survey you will be asked a series of questions related to any work you may have completed with chronically ill children. This should take about 20 minutes. No background knowledge is required. The collect data will be analysed to further understanding the scope of current EP work and its relation to children with chronic illness. Only Lex Jeffery, Brahm Norwich and Margie Tunbridge will have access to this data.

Do I have to take part?

No. Your participation is entirely voluntary. If you do decide to take part, you may withdraw at any point for any reason before submitting your answers by pressing the ‘Exit’ button/ closing the browser. All questions are optional.

How will my data be used?

We will not collect any data that could directly identify you. Your IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential.

The responses you provide will be stored in a password-protected electronic file and may be used in academic publications. Research data (including consent records) will be stored for until the completion of the doctorate December 2024.

If you choose to provide your email address at the completion of the survey, your data will be securely downloaded and stored on a password protected University one drive system. Data will be reported to ensure confidentiality at all times.

Who will have access to my data?

Qualtrics is the data controller with respect to your personal data and, as such, will determine how your personal data is used. Please see their privacy notice here https://www.qualtrics.com/privacy-statement/. Qualtrics will share only de-identified data with the University of Exeter, for the purposes of research.

This survey project will be written up for a Doctoral degree.

Who has reviewed this study?

This project has been granted a favourable ethics review by the University of Exeter College of Social Sciences and International Studies (SSIS) Research Ethics Committee (REC) [reference number].

Who do I contact if I have a concern or I wish to complain?

If you have a concern about any aspect of this study, please speak to Lex Scammell at as1409@exeter.ac.uk and we will do our best to answer your query. I will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chairs of the SSIS REC at the University of Oxford who will seek to resolve the matter as soon as possible by emailing ssis-ethics@exeter.ac.uk

Please note that you may only participate in this survey if you are 18 years of age or over.

☐ I certify that I am 18 years of age or over

If you have read the information above and agree to participate with the understanding that the data (including any personal data) you submit will be processed accordingly, please check the relevant box below to get started.

☐ Yes, I agree to take part

Appendix E

Focus group topic guide

Characteristics of Focus Group Interviews

Overview

- 3 focus groups of 4- 6 people.
- 3 referral forms – each focus group has two allocated.
- EP’s from different LA’s and private companies.
- All participants to have referral prompts prior to interview.

Environment

- Online
- Recorded
- Comfortable

Moderator

- Create warm and friendly environment
- my aim to have some suggested questions
- also some naturally occurring questions
- support a naturally developing conversation
- interject as little as possible

Focus Group Topic Guide

Introduction -Welcome, overview of topic and ground rules

Section 1 – Reacting to the referral form prompts

Suggested Questions

- How do you think you would react to this referral?

- What do you think is the next step do we need to be involved?

- What would be your initial guiding hypothesis?

- What are the dimensions of the presented problem?

- What approaches/ assessment/ next steps would you use?

- How well equipped do you feel to work with this referral?
    - What makes you say this?

Section 2 – Reacting to the referral form prompts

Suggested Questions – elaboration of the survey questions

- In your view, what is the interactive relationship between CI and SEN?

- What do EPs believe that they can contribute that is distinctive?
    - Does it matter if their contribution is not distinctive but shared with other professions?

- What are the barriers that limit EPs supporting children with CI?

Pauses and Probes throughout the focus groups

- Would you explain further?

- Would you give an example?

- Is there anything else?

- What popped into your head when you saw/heard?

Ending

- As we come to an end is there anything else you would like to comment on?

- Provide a brief summary of what was said – do you think that’s an adequate summary?

- Have we missed anything?

- Thank you so much for coming today – it has been a really interesting conversation and I have really enjoyed hearing your views.

Appendix F

Reflexive journal extract

Reflective Journal - February 2nd.

As having an experience with working with children with CI and reading the comments from phase 1. I expected the conversations around CI to maybe be slightly negative. I perceived that EP's may have views that its is not in the scope of our role. Something quite different happened:

- EPs have varied and interesting conversations about the referrals and potential for support.
- They came with more questions about the referrals and what they might to know, than answers about what is going of for that child.
- They can with an empathic, holistic view and argued for the child at the centre of everything.

Reflective Journal - February 3rd

As I continued to look at the data more closely today, I found a few interesting views and assumptions that I possible was not expected:

- Most EPs took a social model approach but some spoke in a most medical model way of thinking.
- All EPs felt like the CI would impact the child in some way.
- EPs talked about the limits of practice but all agreed that they could support children in some way.
- Much of the conversation focused more on consultation skills and collecting child views. – not many EPs talked about any assessment at first visit.
- It seemed most viewed CI and SEN as bi-directionally and distinction – one EP summarised a complex interaction relationships. One can influence the other, but also they could have no effect on each other at all.

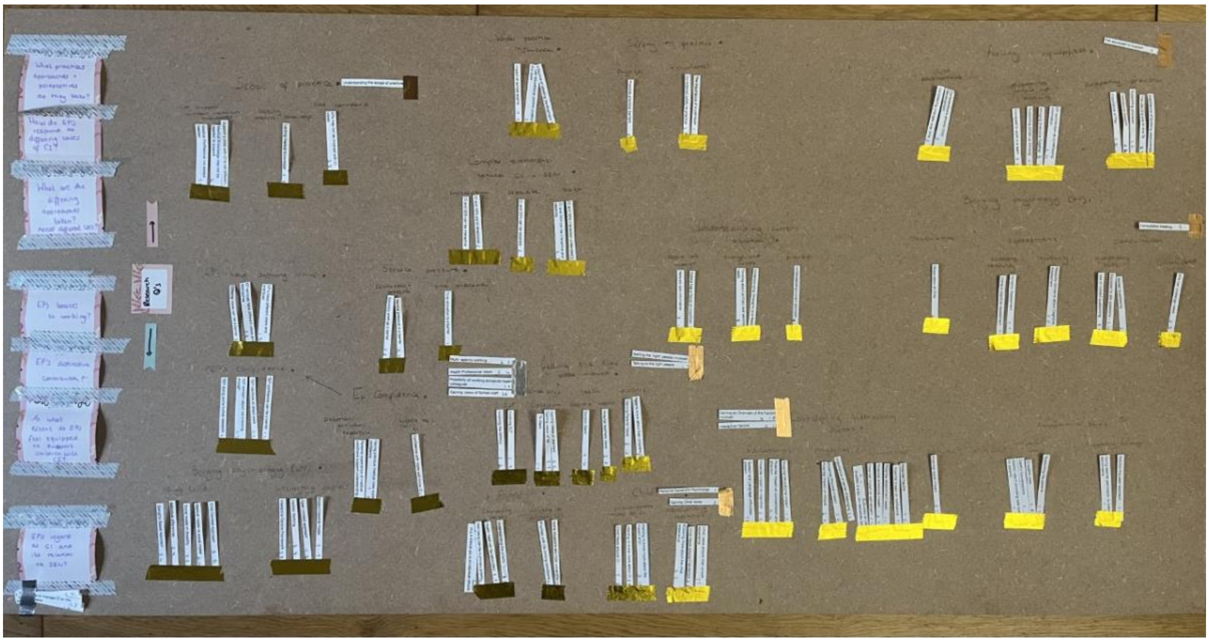
I wonder how being in a group dynamic impacted people willingness to give there honest views, but EPs were agreeable to each other.

Appendix G

Familiarisation word map – created pre-coding

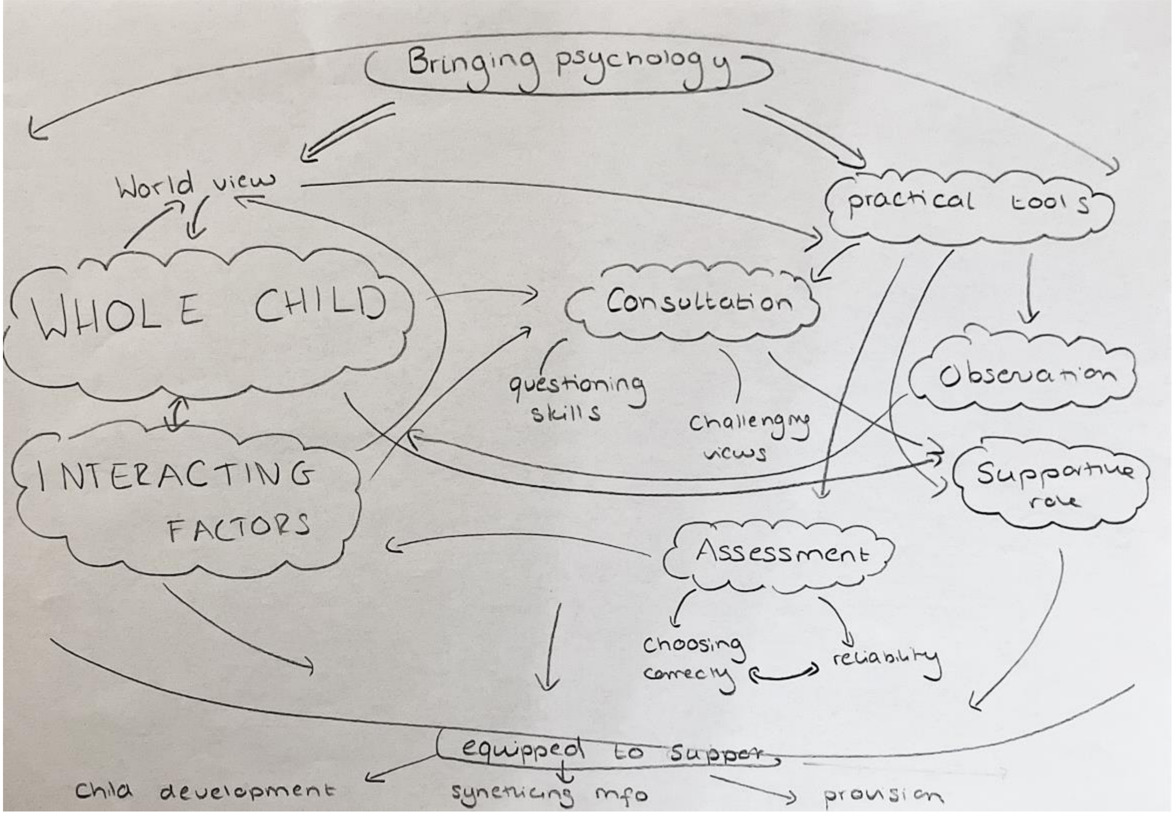
Appendix H

Process of reviewing themes



Appendix I

Coding concept map example



Appendix J

Table presenting final themes

Overarching themes	Themes	Subordinate themes	Codes
	Considering Interacting factors	Educational Impact	Impact on concentration and attention
			Impact on cognition
		Considering Language needs	Speech and Language needs present
		Physical Impact	Impact of fatigue
			General physical impact
		Emotional Impact	Potential Trauma
			Potential attachment needs
			Impact on self-confidence and self-esteem
			Impact on sense of belonging
			Impact on general emotional needs
		Social Impact	Impact on friendships
Bringing Psychology - Practical Tools	Observation		Observation of Child
	Using Assessment	Choosing Cognitive Assessment	Using Dynamic Assessment
			Using Psychometric Assessment
		Reliability	Reliability concerns surrounding Psychometric Assessment
	Consultation Approaches	Questioning Skills	Skilled Questioning
			Equipped to ask questions
		Critical Friend	EPs can challenge views
	Tools to gain Child Voice		Personal Construct Psychology
			Use of Visual resources

Bringing Psychology – World View	Child Centred Approaches		Child Centred Approach
			Social Model of Disability
			Social Model vs Medical Model
			Individual Differences
			Strength based approach
	Understanding the bigger picture		Interactive Factors Framework
			Holistic Working
			Open minded approach
			Biopsychosocial model
	Understanding Current Situation	Referral isn’t enough	Referral lacks information
			Referral has a focus on cognition
		Strengths and Needs	Understanding strengths and needs
			Understanding primary and secondary needs
		Provision	Understanding current provision
	Getting the right people involved	School staff	Involving SLT
			Involving SENCo
			TA Views
			Gaining views of Teacher
		Health Professionals	Clinical Psychologists
			Doctors Views
			Health professionals views
			Hospital Teacher
		Parents/Carers	Gaining Parents views
			Parents Know about their Childrens CI
	Gaining Child Views	Understanding the Impact of CI	Knowing more about the impact of CI
			Child Views about CI

		Understanding Child Experience	Child views around their school experience
			Child view around friendships
			Knowing more about child experience
	EP as a Supportive Role	Empathic View	Supporting Parents
			Careful Conversations
			Providing a safe space
			Expressing Support
			Giving teachers permission to make adjustments
	Knowledge of Child Development		Considering change over time
			Considering Child development
	Synthesizing information		EP contribution as synthesizing information
	Multi-Agency Working		Bringing everyone together
			Supporting joined up thinking
			Equipped to work in a team.
	Supporting future provision		Negative us of one to one TA
			Transitional Support
			Importance of Play
			Supporting provision
	Understanding the Priorities	Identifying priorities in competing needs	Understanding if school attendance is a priority
			Understand what the priority is
			Health needs can be secondary
			Well-being can be the primary priority
			Some situations are more vulnerable

		CIs are different and this impacts priorities	Priorities might differ with life-limited conditions
	Scope of Practice	Lack of medical knowledge	EPs do not have medical expertise
			Careful to understand scope of practice
		Consideration for involvement	EPs may not be considered for involvement in CI cases
		Able to support without medical expertise	Approach a CI case as any other
			Medical knowledge may not be needed to support
			Medical professional may not always be needed
	Feeling Equipped		EPs felt equipped generally
			Equipped to work in a team
			Equipped to ask questions
			Equipped to understand the bigger picture
	Safety to Practice		Considering emotional impact on EPs
			The importance of supervision
	Wider Political Influence		Impact of labelling attainment
			Wider educational policy underpins this work
			Impact of school exams
	Service Pressure	Statutory Advice	Service pressure for EHCP is a barrier
			Statutory Work as a Barrier
		Time Allocation	Time Allocation in is a barrier
	Differing Views of EPs		EPs have differing views and practices

			EP services have different views and practices
			Differing views can be a barrier
			Disagreement in group
	EP Confidence	Impact of personal/previous experiences	Having a pervious medical role supported confidence
			Personal experience of a CI supported understanding
		TEP’s have less confidence	TEP confidence as a barrier
			TEP cautious of direct work
			TEP concern around not knowing enough
			TEP wanting to do further research
	Complex relationship between SEN and CI	CI and SEN are Interactive	CI and SEN are bi-directional
			CI and SEN can interact
		CI and SEN can be separate entities	CI and SEN can be separated
		CI and SEN have a nuanced relationship	CI and SEN can interact and also separate
			CI and SEN interaction undecided

Appendix K

Example transcription and coding from NVivo

Transcription

Focus Group 3

Number of speakers: 5

1 Interviewer: OK, I think that's started.

2 EP 5: Excellent, well done.

3 Interviewer: If I, if I share the first referral, So if you just have a little read through that and while you're reading through it, I just want to think about what your first reaction is really.

4 EP 5: You ready for reaction?

5 Interviewer: Yes, go for it.

6 EP 5: I think my first reaction I think if I got a referral like this, I think my first reaction would be, gosh. I'm not so concerned about her cognitive strengths and needs, but I'm really concerned about how she's doing emotionally and about friendship and how she's feeling and how her family are coping and how she's coping with this epilepsy that seems, you know, very, very regular, isn't it? And that must be quite scary. I should think, for her and for her family, and probably for her teachers and support staff as well. So I think they sort of cognitive strengths and needs, whilst I wouldn't want to totally overlook that and and not sort of. You know, under assume I would that be there be so much more that I want to explore. [nodding from EP 6]

7 EP 6: Yeah, I was just thinking. It's just linking to what you were saying there about her, like emotional needs and how bewildering it must be for her. It says she she's confused when she comes around and then she's having a seizure every 20 minutes. I suppose. I was wondering, like, how long is she confused for and actually could she be spending like every you know, is there actually gap between feeling confused and it happening again and is it just this constant?

8 EP 5: It's not much of a gap of that, no. And the medication is very strong probably and is often changing. So they haven't got it right yet, you know, so they're still trying to experimenting and on poor Mia and yeah, so she's maybe in a in a in a sort of cognitive fog due to the medication really. [nodding from EP 6,7 & 8]

9 EP 7: That's what I was thinking. I was wondering about the impact the medication like you were saying, EP 5, and that if I did want to go ahead and do any cognitive work, I'd be quite cautious about any conclusions that I would reach around deficits in cognitive function because it might be

a side effect of the meds. It'd be interesting to look for strengths if there were any areas of cognitive ability which, in spite of everything, were areas of strength. But if if I came across a weakness, I'd want to. Yeah. Be very careful about conclusions drawn.

10 EP 8: Oh yeah, And obviously seizures. And yeah, drain you. And it's like that. She's really fatigued as well. And so I was thinking about like, rest breaks and things, but we really hard with it being so frequent. But like, she would you just wonder like is there a decline across the day? How are they giving her, you know, breaks and yeah, just in terms of her processing, like you said, that cognitive fog, I think someone just said. But yeah, that kind of. And I would be I would be thinking about, yeah, how we can take some of the demands away to enable her to process things without doing perhaps too much assessment really be looking at the kind of structure today really.

11 Interviewer: Yeah, wondering if anyone else had any thoughts about what they might want to, you know, approaches, they might take?

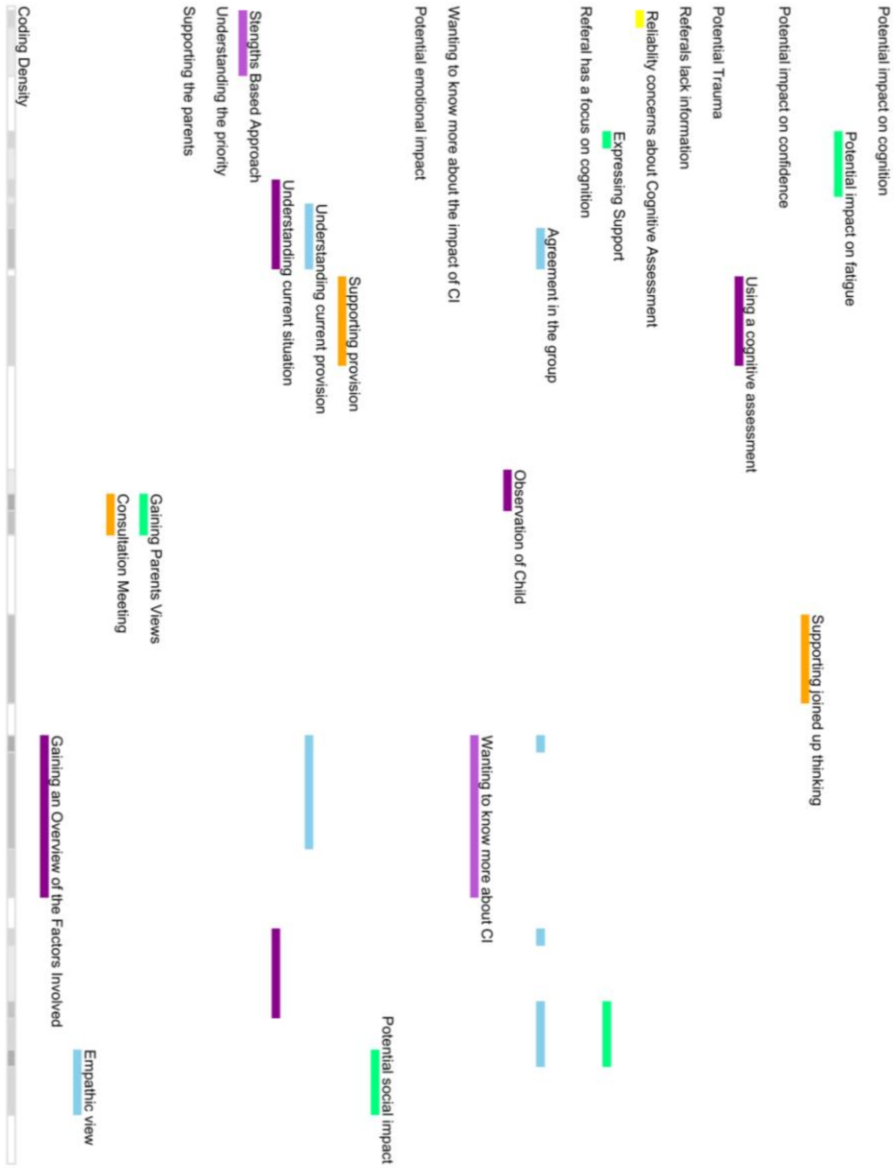
12 EP 5: I think I I think I don't want to do a kind of a mixture of of of observation of of Mia to have a real sense of her and how she's sort of coping. But I really want to do consultation and and bring in parents and all carers and.

13 Interviewer: Yes. Yeah.

14 EP 5: And staff that are key staff working with her to just kind of make sure everybody's really understanding and on the same page and sort of supporting each other really. And this. You know. [Group members nod

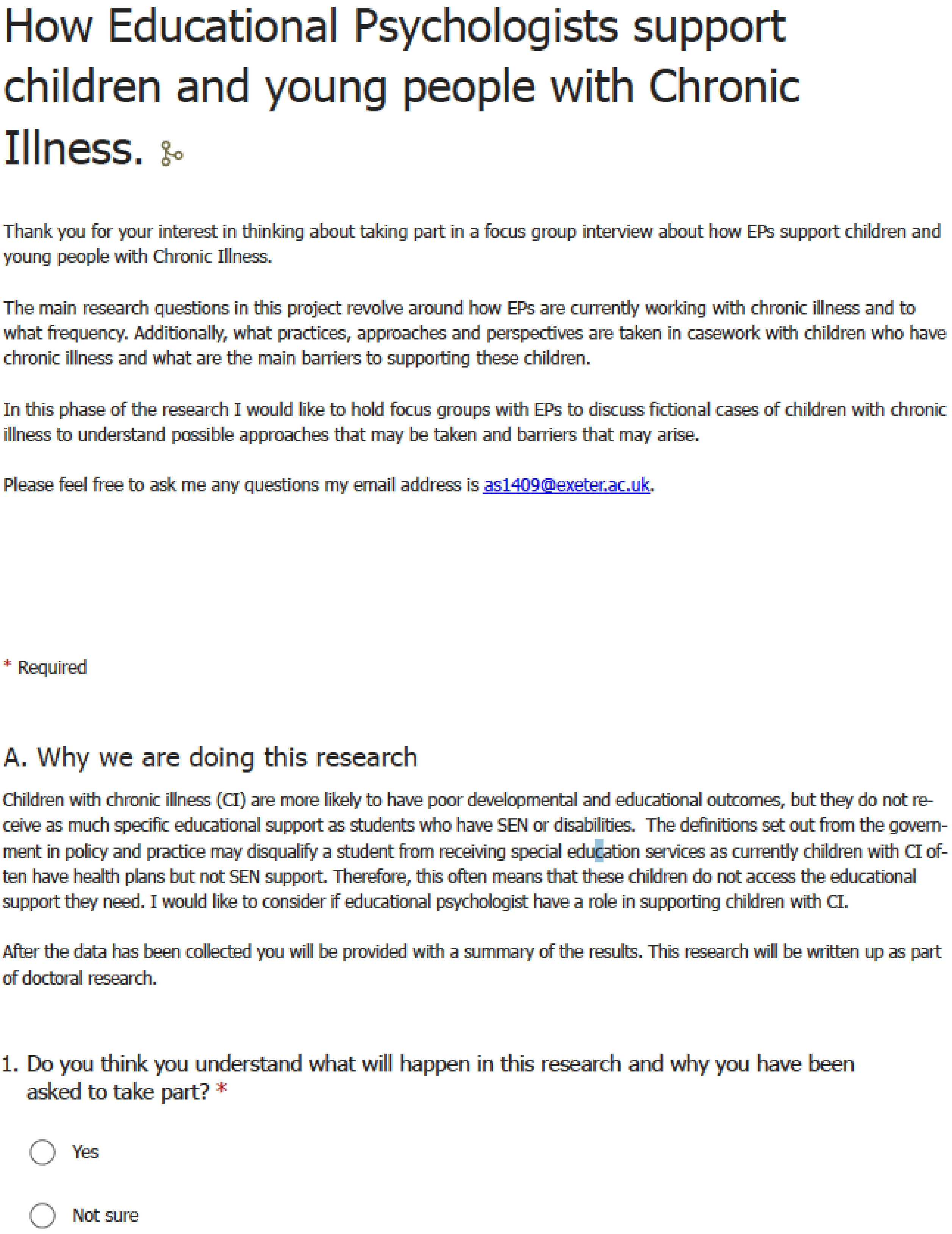
15 EP 7: Yes, I'd have some more questions to ask about her history. I'd like to know when she was diagnosed because with absences rather than any other kind of seizures, they can, they can be misinterpreted or confused by people that may have thought in the past that perhaps she just wasn't listening. Or perhaps she had an attention deficit difficulty. So I'd want to know when the epilepsy was diagnosed to get a sense of what her early school experiences might have felt like for her in reception and year one.

16 EP 5: Yeah, if she's in year two, I wonder whether she was. I mean, it could be that she was diagnosed very early, couldn't it? And they've known this for a long time where it could be that she hasn't been diagnosed until recently. And as you say, EP 7, I mean, maybe there was a lot of assumptions made about that. It might be other things that were that were causing her to be struggling so much. I just feel really sad about the friendship thing actually as well. Just think. I would really think, gosh. That that could be all sorts of things, couldn't it? That could be kind of



Appendix L

Focus group consent form and information sheet



How Educational Psychologists support children and young people with Chronic Illness.

Thank you for your interest in thinking about taking part in a focus group interview about how EPs support children and young people with Chronic Illness.

The main research questions in this project revolve around how EPs are currently working with chronic illness and to what frequency. Additionally, what practices, approaches and perspectives are taken in casework with children who have chronic illness and what are the main barriers to supporting these children.

In this phase of the research I would like to hold focus groups with EPs to discuss fictional cases of children with chronic illness to understand possible approaches that may be taken and barriers that may arise.

Please feel free to ask me any questions my email address is as1409@exeter.ac.uk.

* Required

A. Why we are doing this research

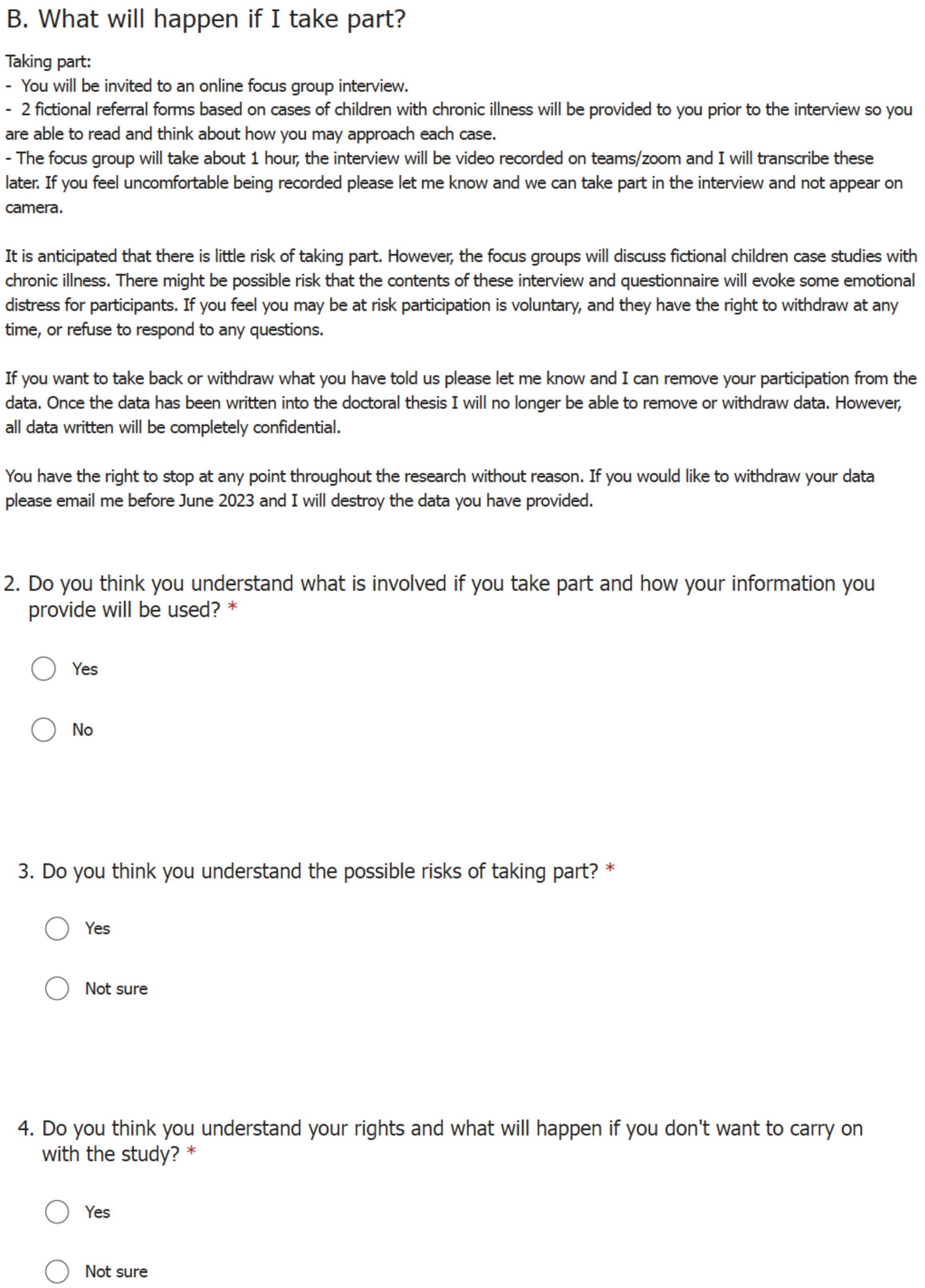
Children with chronic illness (CI) are more likely to have poor developmental and educational outcomes, but they do not receive as much specific educational support as students who have SEN or disabilities. The definitions set out from the government in policy and practice may disqualify a student from receiving special education services as currently children with CI often have health plans but not SEN support. Therefore, this often means that these children do not access the educational support they need. I would like to consider if educational psychologist have a role in supporting children with CI.

After the data has been collected you will be provided with a summary of the results. This research will be written up as part of doctoral research.

1. Do you think you understand what will happen in this research and why you have been asked to take part? *

○ Yes

○ Not sure



B. What will happen if I take part?

Taking part:
- You will be invited to an online focus group interview.
- 2 fictional referral forms based on cases of children with chronic illness will be provided to you prior to the interview so you are able to read and think about how you may approach each case.
- The focus group will take about 1 hour, the interview will be video recorded on teams/zoom and I will transcribe these later. If you feel uncomfortable being recorded please let me know and we can take part in the interview and not appear on camera.

It is anticipated that there is little risk of taking part. However, the focus groups will discuss fictional children case studies with chronic illness. There might be possible risk that the contents of these interview and questionnaire will evoke some emotional distress for participants. If you feel you may be at risk participation is voluntary, and they have the right to withdraw at any time, or refuse to respond to any questions.

If you want to take back or withdraw what you have told us please let me know and I can remove your participation from the data. Once the data has been written into the doctoral thesis I will no longer be able to remove or withdraw data. However, all data written will be completely confidential.

You have the right to stop at any point throughout the research without reason. If you would like to withdraw your data please email me before June 2023 and I will destroy the data you have provided.

2. Do you think you understand what is involved if you take part and how your information you provide will be used? *

○ Yes

○ No

3. Do you think you understand the possible risks of taking part? *

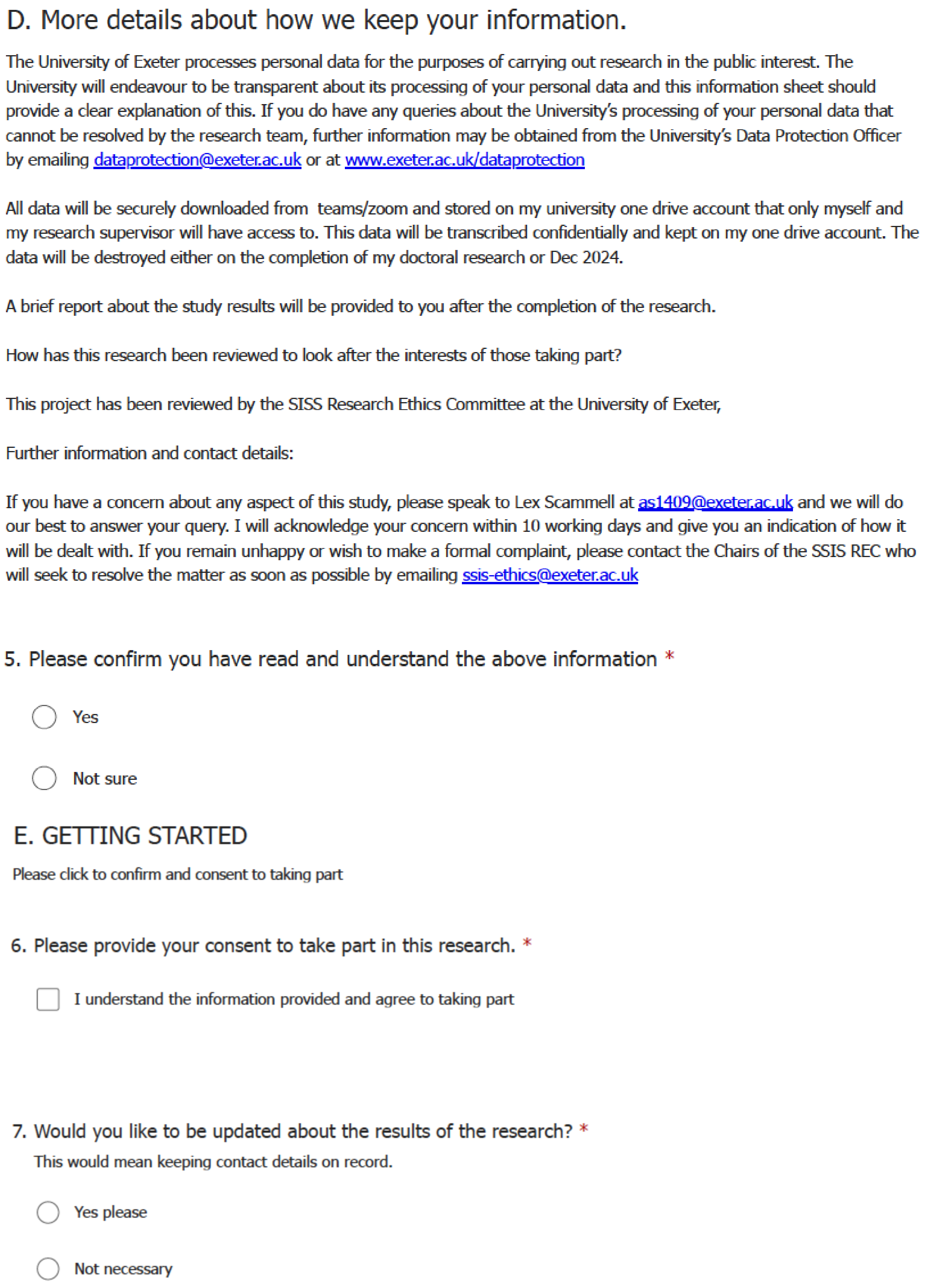
○ Yes

○ Not sure

4. Do you think you understand your rights and what will happen if you don't want to carry on with the study? *

○ Yes

○ Not sure



D. More details about how we keep your information.

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection

All data will be securely downloaded from teams/zoom and stored on my university one drive account that only myself and my research supervisor will have access to. This data will be transcribed confidentially and kept on my one drive account. The data will be destroyed either on the completion of my doctoral research or Dec 2024.

A brief report about the study results will be provided to you after the completion of the research.

How has this research been reviewed to look after the interests of those taking part?

This project has been reviewed by the SISS Research Ethics Committee at the University of Exeter,

Further information and contact details:

If you have a concern about any aspect of this study, please speak to Lex Scammell at as1409@exeter.ac.uk and we will do our best to answer your query. I will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chairs of the SSIS REC who will seek to resolve the matter as soon as possible by emailing ssis-ethics@exeter.ac.uk

5. Please confirm you have read and understand the above information *

○ Yes

○ Not sure

E. GETTING STARTED

Please click to confirm and consent to taking part

6. Please provide your consent to take part in this research. *

☐ I understand the information provided and agree to taking part

7. Would you like to be updated about the results of the research? *

This would mean keeping contact details on record.

○ Yes please

○ Not necessary