

“A Glaring Gap”: Advancing the Outcomes for Adolescents with Health-Related Needs through Collaboration

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Declaration of own work

I, Erika Payne confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Erika Payne
May 2021

Impact statement

This research on the school support and outcomes of adolescents with health-related needs underpins a possible way forward for collaboration between schools and healthcare providers.

Long-term health conditions during adolescence can have a negative impact on education and employment outcomes. Addressing inequalities in education is a key target of the Millennium Development Goals, a commitment by the United Nations and its member states to tackle the major causes of global inequalities. Adolescents with health-related needs face significant barriers in achieving equal access to education. Holistic support should include the physical, learning and social, emotional and mental health needs of the adolescent. The research examined the barriers to support and outcomes and proposed solutions through the careful consideration of ecological systems surrounding individuals. Educational psychologists are well positioned to consider and propose structural changes that are aimed at improving equal access to education for all vulnerable student populations. The study found that schools and healthcare providers working with the same young people frequently do not communicate with each other and thus miss relevant information about the pupil's health, educational achievement, and attendance. Ways to improve communication between schools and healthcare professionals were highlighted. The study found that schools often lack the understanding of learning and mental health needs linked with physical needs where support is focused on physical barriers only. I am planning to design bespoke trainings and support schools to implement structural changes. These changes will enable them to understand and deconstruct some of the barriers faced by

adolescents with health needs. The study gained insight into the importance of self-advocacy, as a major protective factor to advance the outcomes of this population. Young people who are experts of their own condition are best placed to contribute to support planning procedures by communicating their views and desires. I am planning to work with schools on appropriate interventions; those aimed at improving the communication skills, the knowledge of one's rights and needs and the self-advocacy skills of the adolescent population. A major finding of the study concerned a lack of standardised approach and the minimal transparency of support systems within schools. I intend to organise meetings and other forms of knowledge exchange among relevant practitioners to share good practice and validate existing solutions. Additionally, I will advocate for increased monitoring of the support and outcomes of adolescents with health-related needs in order to ensure an equal access to education.

The knowledge produced through this research will be disseminated in relevant professional publications as well as at conferences aimed at both educational and healthcare professionals.

Abstract

This thesis presents an exploration of the experiences of adolescents with health-related needs in secondary schools, and of the parents and carers, school nurses and teachers supporting them. The health of adolescents is strongly affected by multiple factors at personal, family, school, and national levels. Safe and supportive families and schools, access to education and supportive teachers and peers are crucial to helping young people with health conditions to achieve their full potential. Improving adolescents' daily lives with families and peers, addressing risk

and protective factors in their schools, and focusing on points of intersection between their educational and healthcare providers are the structural changes needed to improve their educational and employment outcomes. For this study, an ecological model helped to understand the experience of adolescents with health-related needs and the factors that impact their support and outcomes. The research used mixed methods with a quantitative survey exploring the views of school nurses and qualitative semi-structured interviews exploring the views of adolescents, their parents and carers, school nurses and educational professionals. The interviews were analysed using thematic analysis. Findings included themes which described the views of the different participant groups from multiple angles. The central theme revolved around communication. Better and more transparent communication between all stakeholders and agencies can lead to necessary structural changes to improve the outcomes of adolescents with health-related needs. Further themes included invisible needs linked with health, training and awareness raising in schools, enhancing self-advocacy skills for adolescents, the lack of standardised support in schools as well as the need for scrutiny of the support and outcomes of this population. Recommendations for professionals and directions for future research are outlined.

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Chapter 1: Introduction

1.0 Overview of the Chapter

The aim of this research is to gain a better understanding of how support within secondary schools for pupils with health-related needs can be improved through more targeted collaboration between education and health services. The study provides an insight into the educational experiences of adolescents with health-related needs. It aims to identify any gaps in their support and provide examples of good contemporary practice. This chapter begins by outlining why research in this area is important. It then provides both a global and national context for the research. Next, the importance of knowledge exchange within educational settings is explored. It then argues why educational psychologists (EPs), through their expertise in research and educational interventions, may be well positioned to coordinate the different services working with adolescents. Finally, the researcher's own perspective and contribution to the research development is discussed.

1.1 The Importance of Research into the Relationship Between Health and Education Services Within School Settings

Recent advances in medical science, such as remote monitoring devices for certain conditions, have enabled many children and young people (CYP) with health-related needs to attend mainstream settings and independently manage their condition (Michaud et al., 2007; Mukherjee et al., 2000; nasen House et al., 2018).

Additionally, statutory (Department for Education (DfE), 2015) as well as non-statutory (nasen House, 2018) guidance to support pupils with medical needs aims to ensure that this population is not at a disadvantage compared to their peers in school settings. Despite these developments, ensuring that health conditions do not impact negatively on educational outcomes remains a challenge. There are currently 7,642,473 adolescents living in the United Kingdom (World Health Organization (WHO), 2020). The Office for National Statistics (ONS) (2019) estimates that approximately 1 in 5 adolescents live with a long-term health condition, such as epilepsy, asthma or diabetes. Several questions regarding those adolescents' wellbeing as well as school-based needs remain open. It is currently not clear how education professionals can support adolescents with health-related needs to ensure that their academic and vocational outcomes, as well as their social, emotional and mental health, are not impeded by their physical health. Recent research shows that despite growing rates of global school attendance and an increased recognition of schools as important platforms for enhancing student health (Alemán-Díaz et al., 2018), schools fail to support students with long-term health conditions (including disabilities) (Jourdan et al., 2021). The current research aims to explore the relationship between health and education services and how they interact within secondary schools. It is hoped that examples of good practice as well as areas for improvement can be identified.

1.3 Definitions and terminology

1.3.1 Terminology Relating to Medical Needs

Health-related needs in the context of this research are understood in their broad sense as chronic, life-threatening and life-shortening conditions. The UK government defines long-term medical conditions as “a health problem that can’t be cured but can be controlled by medication or other therapies” (Department of Health and Social Care (DoH), 2015, para 1). The National Health Service (NHS) uses the term *long term physical health conditions* for conditions “that require on-going management over a period of years and decades (...), cannot currently be cured but can be controlled with the use of medication and/or other therapies.” (NHS, n.d., Long Term Physical Health Condition, para 1).

Different terms, such as *long-term health conditions*, *long-term health problems* (Lowe, 2019), *chronic conditions* (NHS, n.d.) as well as *medical needs* (nasen House, 2018) are used throughout the literature. For the purpose of this research, the terminology of nasen House, UCL Centre of Inclusive Education and UCL Institute of Education will be adopted (nasen House, 2018) with a slight adaptation. Following the shift from a biomedical approach towards a more holistic understanding of health (Buchanan, 2006) the term *medical* condition will be replaced by *health-related* condition. It encompasses four types of conditions:

Acute conditions: Those that are sudden and severe in onset (e.g. broken bones).

Chronic conditions: Long-developing conditions which are persistent or lasting for more than three months (e.g. epilepsy).

Life-limiting/life-shortening conditions: Those for which there is no reasonable hope of cure and from which children's or young people's life will be shortened (e.g. cystic fibrosis).

Life-threatening conditions: Those for which curative treatment may be feasible but can fail (e.g. cancer).

1.3.1.1 Prevalence of Medical Conditions among Children and Adolescents.

Acute conditions: Most CYP in the UK consult a General Practitioner's office 3 to 6 times a year because of the onset of an acute illness. Less than 1% of all acute illnesses registered become a serious acute condition (Hippisley-Cox & Heaps, 2009; Saxena, 2010).

Chronic conditions: There are different estimates ranging from 15% to 31% of CYP living with chronic conditions (Dobbie & Mellor, 2008; ONS, 2019). Research consistently reports an on-going increase in the proportion of CYP as well as the general population with chronic conditions. It is assumed that chronic conditions will become the leading cause of death and disability in the global population by 2020 (Epping-Jordan et al., 2001; Michaud et al., 2007; WHO, 2002).

Life-limiting and life-threatening conditions: Together for Short Lives, (2018) estimates that 49,000 CYP between the ages of 0 and 18 and a further 13,000 young persons aged 18-25 in the UK live with a life-limiting or life-threatening condition.

1.3.2 Definitions of Adolescence and Youth

Adolescence is defined by the World Health Organisation as between the ages of 10 and 19 years (WHO, n.d.-a). The term *young people* refers to the 10–24-year-old age group. The UN Convention on the Rights of the Child (UN, 1990) defines a child as below the age of 18 years. Early adolescence refers to 10–14 years, late adolescence to 15–19 years, and young adulthood to 20–24 years. In this report, the experiences of young persons between the ages of 11 and 19, in the second decade of their lives, are explored. In the UK educational system, this corresponds to Year 7 through to Year 13 of secondary education. The terms young people and adolescents will be used interchangeably throughout the report referring to this particular age group.

1.4 Why Adolescent Health Matters

The World Health Organisation (2014) has recognised adolescent health as a primary focus for interventions. The report notes that adolescents living with chronic diseases and disabilities are among those who are particularly vulnerable and in need of targeted interventions to maximise their opportunities at school.

Furthermore, it highlights the need for a strategic collaboration among different sectors in order to coordinate important contributions to adolescent health. Young people between the ages of 10-24 have been identified as the “invisible generation” (AYPH, 2019 page 178) in terms of actions taken to target health promotion specific to their age group. Research around adolescent health (e.g. Michaud et al., 2007, Patton et al., 2016 and Suris et al., 2004) suggests that there is a close relationship between adolescent health and education. To optimise support initiatives and

interventions developed to meet the needs of this population should take this relationship into account. Physical and mental health during adolescence is key for educational and vocational achievement (Hale & Viner, 2018), while education and employment have long been recognised as important social determinants of health (Marmot et al., 2020; Wilkinson & Marmot, 2003).

During adolescence, individuals establish the physical, cognitive, emotional and social foundation for health and wellbeing during later life (Patton et al., 2016). These same resources define trajectories into the next generation, as adolescents are the next age group to parent. Health during adolescence has therefore far-reaching implications for generations to come. Although the link between adolescent health and education is well established, further research is needed to understand the outcomes of health-related interventions during adolescence on later stages of life (Hale et al., 2015).

1.5 Risks Associated with Health Needs during Adolescence

Theories about risk taking during adolescence are underpinned by multiple assumptions (France, 2000). These assumptions include that adolescence is a developmental phase linked with biological, intellectual and emotional changes that influence the way individuals develop their own sense of self. These changes are further influenced by social and cultural factors, such as socio-economic circumstances. Young people often deal with changes by paying attention to the most immediate issues. Not all aspects of health are prioritised during this transitional period, and it is particularly important to be aware of the risks linked with

poor adolescent health. The term *risk* in this context refers to undesired outcomes as a result of responses to responsibilities. The risk factors listed here can be seen as unknown harms that adolescents with health needs may need to prepare for (Zinn, 2009).

Psychosocial risks

The relationship between health needs and their associated impact is very complex (Hwu, 1995). Chronic illnesses can place significant strains on both the individuals and their families and have the potential to impact upon wider psychological adjustment (Dobbie & Mellor, 2008). Approximately 20% of CYP with chronic health conditions have been found to have behavioural and emotional needs, as opposed to 10% of CYP in the general population (Committee on Children With Disabilities and Committee on Psychosocial Aspects of Children and Family Health, 1993). The National Paediatric Diabetes Audit is (NPDA, 2018) annual reports from 2017-2018 note that nearly a third of CYP with Type One Diabetes (28.2%) with a recorded outcome of psychological support were assessed as requiring additional psychological support or support by the Children and Adolescent Mental Health Services (CAHMS) outside multidisciplinary clinics, with a higher proportion of girls than boys. A narrative review exploring school experiences among CYP with Type 1 Diabetes, Cystic Fibrosis and hearing loss using a socio-ecological approach found that mental health needs of the pupils were impacted by school absences potentially disrupting relationships; stigmatisation by teachers and peers; and gaps in teacher training reflecting a lack of knowledge and unsupportive attitudes (Runions et al, (2020).

School Absence

Health issues can result in school absence (Askeland et al., 2015) with illnesses being the most common reason for school absence. According to data published by the Department for Education (DfE, 2019), illnesses accounted for 57.6% of all absences across primary and secondary schools in England during the 2018-2019 academic year. Furthermore, illnesses presented the most common reason for persistent absences (pupils missing more than 10% of their sessions) with 10.5 per cent across all schools in England during the same period.

Pupils who meet the persistent absentee threshold present a particular problem. Due to the lack of clear data on CYP who are educated at home for medical reasons; have unexplained exits from the educational system; are enrolled in hospital schools at the same time as their local authority schools; or are missing from the educational system entirely, policy makers remain largely in the dark about the scale of the problem (No Isolation & Tomorrow Today, 2019).

Research into school absence linked to chronic conditions across 766,244 CYP in Scotland showed that all conditions under investigation (diabetes, asthma, epilepsy, attention deficit hyperactivity disorder and depression) were associated with increased school absence and periods of hospitalisation. Additionally, all conditions excluding diabetes were linked with poorer academic attainment and all conditions excluding ADHD with higher mortality rates (Fleming et al., 2019). Public

health data in England does not allow for a similar statistical breakdown of school absence by health condition.

School exclusions

A significant increase in secondary school exclusions has been identified as one of the key emerging trends impacting CYP's health (AYPH, 2019). A recent enquiry into school exclusions by the Department for Education (Graham et al., 2019) reported of CYP with medical conditions excluded from school, being taught separately, being banned from extra-curricular activities, having reduced access to the curriculum or being disadvantaged in other ways compared to their peers. Some CYP were also prevented from coming to school on the basis that "their needs could not be met" (page 41).

Educational outcomes

Recent research shows that health during adolescence is a key component of academic achievement as well as of the transition into employment at the end of schooling (Hale et al., 2015). Health issues can be associated with a change in educational attainment and risk *not in employment, education or training* (NEET) status regardless of previous attainment levels (Hale & Viner, 2018). Asthma and epilepsy (Fleming et al., 2019), Type One Diabetes (Fleming et al., 2019; Persson et al., 2019), and cystic fibrosis (Strawhacker & Wellendorf, 2004) are among the chronic conditions associated with reduced academic outcomes. Parsons et al. (2012) explored cognitive issues of cancer survivors after returning to school and

found that approximately 30% indicated having to deal with a wide array of issues, such as “forgetting’ and ‘keeping up” Poor health is a disproportionate problem in deprived households, therefore poor educational outcomes resulting from health issues may be a key barrier to social mobility (Power et al., 1996). The close relationship between health and learning highlights the importance of making health needs a “core business” of schools (Hale & Viner, 2018, p.469). Educational professionals incorporating health-related practice in their work can positively impact the determinants of health of their students and benefit them later in life (Jourdan et al., 2021).

Adolescents with chronic illnesses have been found to have significantly greater unmet school-based needs across all areas of academic, social and emotional needs and attendance than their peers without chronic illnesses. They are, however, not more likely than their peers to receive additional tutoring, or support from teaching assistants (Lum et al., 2019). They rate their relative health more poorly, are more likely to engage in health-risk behaviours (Suris et al., 2008) and they report feeling more unhappy and depressed than their peers (Pinquart & Shen, 2011). All these factors need to be key consideration points for educational settings, in particular during screening for social emotional wellbeing and planning of additional support. At the same time, education professionals feel under-trained in the area of chronic illnesses and express interest in receiving more training (Barracough & Machek, 2010).

Barriers between health and education

Health and education services are often seen as two separate worlds (Mukherjee et al., 2000) with conflicting priorities between illness management and learning requirements. Health and education services as well as policies are currently uncoordinated in England (Hale & Viner, 2018) without much consideration for how the two contribute to each other. In many schools, the notion of health is seen as an added task for education professionals, rather than the product of quality schooling that should be monitored alongside academic achievement (Jourdan et al., 2021). There is an enhanced awareness for education as a social determinant of health (Marmot et al., 2020) and how enhancing education improves population level health. Some health-promoting activities are occurring within educational settings, for instance to promote healthy diet. More could be done, however, to provide access to healthcare through school settings. Additionally, the role of interventions within healthcare settings to improve education and school-engagement of adolescents with long-term health needs should be highlighted (D. Hale, personal communication, February 4, 2020).

All pupils with health-related conditions should be supported so that they can fully access education inside and outside of the classroom, including physical education as well as extracurricular activities, such as school trips (*Equality Act 2010*). Research suggests that levels of awareness of health-related needs as well as support can vary greatly (Mukherjee et al., 2000). Some of the factors contributing to this include teachers' understanding of a child's condition and its visibility; communication problems identified between teachers and parents/carers; school and

health services; within school (staff to staff; school to new and supply teachers); and the transition from primary to secondary schools (Mukherjee et al., 2000). Barriers to effective communication between school and health services were identified both by teachers and healthcare practitioners. These consist of confusion about professional roles and responsibilities; lack of information from healthcare professionals; concerns of health professionals about confidentiality; and different agencies' unequal access to and understanding of information and its implications within school (Mukherjee et al., 2002). The lack of information flow proves particularly problematic for pupils, whose health condition is not registered within their school for instance through an Education, Health and Care Plan or an Individual Healthcare Plan. Unless a pupil with a health condition has an Educational and Healthcare Plan (EHCP) with multi-agency involvement, there is no system currently in place to draw attention to medical needs (Mukherjee et al., 2002). Even if a child is on the special educational needs and disabilities (SEND) register because of an EHCP, it is unclear to what extent the special educational needs coordinator (SENCO) can take on responsibilities relating to health needs (Mukherjee et al., 2000).

Vocational outcomes

Although employment outcomes of adolescents with medical conditions are beyond the scope of this research, it should be noted that the primary focus of all educational stages is the preparation of CYP for an independent life. Independence in adulthood is largely associated with employment opportunities. The SEND Code of Practice (2015) acknowledges the role of educational settings in the key transition point from education to employment in young people's life by ensuring their support

up to the age of 25. Therefore, educators need to be mindful that the difficulties adolescents with health-related needs experience in educational settings might present later during employment as well. Responses and interventions need to be preventative in nature and promote resiliency and self-care skills to increase future independence (Satariano, 2016).

Health issues can result in impaired educational and employment outcomes (Gledhill et al., 2000) and vocational impairments linked with restricted financial independence (Michaud et al., 2007). Previous research found that adolescents with chronic physical health problems are more likely to have subsequent reduced vocational outcomes and an adult income below the poverty line (Hale et al., 2015). Sixty-five per cent of parents/carers of paediatric brain tumour survivors reported that their children struggled to gain or sustain employment (Satariano, 2016). Research into social inequalities in health within the British Birth Cohort Study identified a relationship between health and social mobility, so that young adults with poor health were more likely to move downward (Power et al., 1996). Although adolescent mental rather than physical health was found to be a stronger factor in poor outcomes, adolescents with chronic physical conditions were found to be significantly disadvantaged compared to healthy control groups in terms of adult income and income below the poverty line.

The role of parents/carers in adolescent health

Parental advocacy and high expectations were found to be associated with enhanced educational achievement of adolescents with disabilities. Parents/carers

with high expectations provide more opportunities and practice in autonomy thereby enabling their children to develop a better understanding of their own abilities and practice self-advocacy and self-efficacy (Doren et al., 2012). Parental involvement in support planning procedures is key to ensure better outcomes. Research found that strengthening the collaboration between parents/carers and healthcare professionals has the potential to improve adolescent health outcomes (Ford et al., 2011), but parental interventions focusing on adolescent health in school do not typically include the contribution of healthcare professionals (Schuster et al., 2008).

Safe and supportive families and schools together with positive peer support are crucial to support adolescents to reach their full potential on the path to adulthood (Viner et al., 2012), focus on adolescents' daily life with families and peers in schools and addressing risk and protective factors on all social levels is a key consideration for enhanced health and improved educational and vocational outcomes.

1.6 Context for My Research

1.6.1 Global Context

The World Education Forum meeting in Dakar in 2000 (UNESCO, 2000) identified CYP with disabilities and illnesses among those who need a special focus to achieve the goals of Education for All. This was reaffirmed by the Policy Guidelines on Inclusion in Education (UNESCO, 2009) highlighting the rights for all CYP, including those with disabilities, illnesses and poor health to develop their

potential through education. Having clear strategies for the inclusion of these vulnerable groups is an important milestone to achieve the Education for All goals as well as the Millennium Development Goals. These strategies need to include novel approaches to teacher training programmes to provide teachers with the pedagogical tools to practise inclusive education with all children; as well as the training of all professionals responsible for ensuring inclusive education.

The rights for all children to receive education were set out in the *United Nations Convention on the Rights of the Child* (UN, 1990), the *Education for All by 2015* goals (Benavot & UNESCO, 2015) and Article 24 of the *Convention on the Rights of Persons with Disabilities 2006* (UN, 2006). Providing effective education for all by creating educational facilities that are inclusive and disability sensitive is one of the UN Global Goals (Sustainable Development Goals) (UN, n.d.). These link objectives related to schools and health explicitly and highlight the interconnected aspects of those goals. Goals for Good Health and Wellbeing (SDG3) and for Quality Education (SDG4) serve as underpinning for large-scale global initiatives to promote health through schools, such as the WHO's Health Promoting Schools (WHO, 2017) approach. The question of successful implementation of related practices in a wider global context with various local challenges requires on-going exploration. Some countries, such as Ireland, explicitly include pupils with chronic illness into their legal definitions of children with special educational needs and ensure support for this population by putting national policies in place. The on-going close collaboration between health services and schools is a particular focus of such policies (*Country Information for Ireland - Systems of Support and Specialist Provision | European Agency for Special Needs and Inclusive Education, 2010*)

1.6.2 National Context

In an international comparison of 19 countries (Shah et al., 2019), the UK was found to lag behind on some key health and wellbeing indicators. Some of these include: a high percentage of adolescents aged 15-19 not in education, employment or training (NEET); high rates of young people living with a long-standing health condition (ONS, 2019); the highest asthma death rate for young people aged 10-24 as well as a high burden of disease rate “in general” and in particular for Type One Diabetes. Burden of disease is a construct used by the World Health Organisation to describe death and loss of health due to illness (WHO, n.d.-b).

Relevant legislation relating to adolescents with medical needs in England¹

The *Equality Act 2010* came into force to ensure protection and equal rights for people with disabilities. The act details the duties of local authorities and all schools in England, Scotland and Wales towards CYP with health conditions that are treated as a disability (for instance Type One Diabetes). Furthermore, the act places the responsibility on governing bodies and proprietors of all schools to ensure that CYP with disabilities are not put at a substantial disadvantage compared with their peers. The act replaces the *Disability Discrimination Act 1995*. The responsibilities of schools to support children with medical needs are further outlined in the *Children and Families Act 2014*. These include arrangements to support pupils at schools with medical needs according to statutory guidance (DfE, 2015). The *SEND Code of*

¹ Various acts and guidance documents exist in the different nations of the UK. Because the dataset for this research was established in England, the relevant legislation in England will be referenced.

Practice 2015 provides guidance on supporting CYP with disabilities from the age of 0 to 25. It places a strong focus on the participation of CYP with special educational needs and disabilities in the decision-making processes (DfE & DoH, 2015).

Further legislation providing historical context:

Although currently there is no national standard or independent quality assurance for schools to follow, laws and policies have been in place for decades to ensure that CYP with health-related needs can access education either within or outside school settings.

Principles to promote the welfare of children with health-related needs have been part of the legislation since the introduction of the *Children Act 1989*. Section 3 placed a duty on local authorities to ensure that schools can meet their legal duties relating to CYP with a medical condition. Section 17 stated that Local Authorities should safeguard and promote the welfare of children 'in need' "In need' is defined by the lack of ability to achieve or maintain a reasonable standard of health; health being significantly impaired or being disabled. Section 19 of the *Education Act 1996* required local authorities to provide CYP who cannot attend school because of a health-related condition with 'suitable education' in hospitals or through home tuition. The education had to be suitable to the CYP's age, ability and aptitude and to any special educational needs they may have. Section 10 of the *Children Act 2004* required the local authority to promote cooperation between relevant partners in order to improve the wellbeing of CYP, including their physical and mental health. Section 21 of the *Education Act 2002* placed the statutory duty to promote and

safeguard the welfare of CYP on the governing body of maintained schools. Section 100 of the *Children and Families Act 2014* continued to place the duty on local authorities to support pupils with medical conditions at schools.

1.7 Health Promotion through Systems Thinking

1.7.1 The Medical Model and the Eco-Systemic Applied Model

According to the medical model paradigm, mental health and educational difficulties are frequently attributed to internal factors (Gutkin, 2012). This paradigm has led to a narrow definition of what is 'normal' in terms of behaviour and how society views those who do not fit in with this expectation. Increasingly, it has resulted in the medicalisation of several childhood behaviours (Hill & Turner, 2016), such as attention deficit hyperactivity disorder without taking the significant influence of a child's environment into consideration. Within the medical model, the goals are identified with the help of medical science, and individuals are expected to behave in accordance with these given goals, without detailed considerations of the circumstances (Buchanan, 2006). This view is progressively challenged by the eco-systemic applied model (Bronfenbrenner, 1992), whereby an ecological understanding of behaviour is promoted that considers the unique and specific needs of each individual child.

1.7.2 Socioecological Approach to Health

In the attempt to move away from the biomedical model, health must be seen as more than just an 'absence of disease'. Instead, the positive definition of health

introduced by the World Health Organisation (WHO, 1946) should be considered a state of wellbeing and not merely the absence of an illness. This concept leads to the socioecological approach to health (WHO, 1986) which links people's health with their environment. It conceptualises supportive environments so that they are based on this positive understanding of health. The socioecological approach to health highlights the importance of connectedness, mental wellbeing and psychological (e.g. isolation) as well as environmental (e.g. socioeconomic status) risk factors to health (Carroll & Hills, 2015). The key principle of this approach to health is personal empowerment as well as community development and a pre-requisite is a critical dialogue with supporting professionals and agencies.

The socioecological approach to health raises several questions regarding participation as well as the role of the specialists. We need to carefully consider whether we are creating supportive environments for health, especially for those whose health is negatively impacted by inequalities through multiple social and economic factors. The ways in which individuals are included in decision-making processes and the determination of goals, need to be explored. When we plan to create supportive environments without meaningful participation of those at the receiving end of the support, the voice of those who are the least empowered will not be heard or included.

1.7.3 Empowerment through Participation

A key goal of the educational model of health promotion (Buchanan, 2006) is providing support in a way that will improve people's own skills of practical

autonomy, rather than creating categories and pre-set formulas. For this, a participatory framework should be established that would allow individuals and communities to directly participate in the planning and implementation procedures that will have implications for their health. This approach of empowerment is consistent with the legislative requirements around including the voice of children and their families in decision making processes (DfE and DoH, 2015; *Children and Families Act, 2014*; *The United Nations Convention on the Rights of the Child, 1990*). Together with the impacted individuals and their communities, in this research adolescents with long-term health needs, it is important to carefully consider what they want to receive and how they want to receive it. Allowing people to participate in goal setting and determining strategies is a meaningful way to sustain change. It seems important to explore what personal skills need to be developed to empower individuals to participate in a meaningful way (Buchanan, 2006).

When considering adolescents with health-related needs, both the medical and the socio-ecological models have their limitations. While medical models of disability can foster stigmatisation of individuals, the focus on acceptance and inclusion might not suffice when trying to meet very specific needs of pupils with long-term health conditions in schools. A well-informed teacher with a good comprehension of the effects of symptoms and treatment regimens on learning, as well as the social-emotional aspects on a young person's life, can become a key person in advocating for that individual and supporting their relationship with peers and members of staff. Concurrently, research shows that educational support for teachers of students with health-related needs appears to be almost non-existent (Robinson & Summers, 2012). Educational psychologists, with their understanding of

the ecological systems surrounding the child (Bronfenbrenner, 1979, 1992, 1995), can work with teachers to consider how school environments and systems can be best adapted to meet individual students' needs. Furthermore, educational psychologists are well placed to raise awareness of the importance of physiological factors and how they can impact behavioural presentations. Ecological models that acknowledge the dynamics between medical and social models of illnesses and disabilities can fill the existing gap between educational and health services and show a way forward by continuous collaboration and exchange of knowledge. Identification and targeted preventative support for adolescents with health conditions may improve educational and vocational outcomes and therefore life chances in adulthood.

1.8 Health Promotion through Knowledge Exchange

There is growing interest in understanding how evidence-based social research is impacting upon policies (Boaz et al., 2009). Three models of collaboration between researchers and policy makers have been identified (Wehrens, 2014). *Linear models* represent a one-way transfer of knowledge from researchers to policy makers. *Relationship models* move on from the one-directional concept of knowledge transfer to a two-way exchange between researcher and policy maker in the form of a dialogue but does not highlight the co-production of knowledge. *Systems models* aim to incorporate the context in which the research question was established and promote interaction throughout the process from planning to policy writing. Although there is a clear development in terms of co-production of new knowledge, all of these models work with the assumption that knowledge producers and knowledge users are two separate communities with

conflicting goals and values (Caplan, 1979). Successful knowledge transfer between the two communities is mostly hindered by two factors: The perception of the knowledge's value on the micro-level on the one hand; and the way information is acquired for meta-level decisions on the other. This means that it is not guaranteed that only empirically based knowledge is included in the decision-making processes. At the same time, it may be difficult to ensure that all relevant knowledge is disseminated to decision makers. These factors draw attention to the importance of collaboration between “knowledge producers” and “knowledge users” involving a joint formulation of problems, shared understanding of gaps and collaborative implementation of newly produced knowledge.

Knowledge exchange in education

Murnaghan et al. (2013) identified knowledge exchange (KE) as an important tool to engage a variety of partners in a systemic approach to chronic conditions. Students, teachers, researchers, and policy makers should be brought together to facilitate interaction and build relationships. The goal is to better understand each other's knowledge base regardless of whether it is based on formal or informal learning (O'Neill, 2010). The research recognised the importance of positive working partnerships within the education sector in order to develop a shared understanding about health problems.

With the increasing rate of chronic conditions, it is urgent that relevant evidence is gathered to guide interventions and policies geared to youth. Systems thinking, to bridge the gap in support around CYP, is a key tool for integrating

knowledge and using it in a relevant school-context. KE can improve systems thinking by enhancing collaboration and partnership and using evidence base in a way that goes beyond data collection and report writing. Knowledge sharing activities between all stakeholders involved in adolescent health, as well as adolescent educational and employment outcomes, can lead to policy and practice initiatives that promote a better coordination of support within schools and narrow the achievement gap between adolescents with and without health conditions.

1.9 How can Educational Psychologists Contribute?

Educational psychologists are particularly well positioned to support children and young people with health-related needs. Educational Psychology Services remain involved with children and young people throughout their school life up to the age of 25 (*SEND Code of Practice 2015*) and are therefore key services to communicate information about them to current and future settings. They are well placed to separate health-related needs into physical, learning and mental health needs and address these needs in a way that can be applied in the school setting. They can also improve communication between professionals at key transition points, such as discharge from hospitals, or return to mainstream education after an extended absence (Ball & Howe, 2013; Kaffenberger, 2006). Furthermore, through their expertise with children and young people across the age range 0-25, they are well positioned to raise awareness for the changing needs of children with underlying health conditions, as they develop.

Educational psychologists need to be aware of common health conditions and the impact they can have on school success (Wodrich et al., 2006). They are able to liaise with those involved with CYP, such as family, school, healthcare and other professionals. They can monitor and influence school culture, share knowledge about the condition and its impact on learning, advise on approaches to support and, most importantly, listen to pupils and their families. By creating a compassionate school community, adolescents' need to fit in can be well balanced against any reasonable adjustments for their condition (Strawhacker & Wellendorf, 2004). Research suggests that this type of school-based liaison-role may be well suited to psychologists (Ball & Howe, 2013). There is a growing body of evidence showing that learning outcomes and social and emotional wellbeing are improved and health risk behaviours are reduced in response to holistic whole school approaches (Patton et al., 2006). Educational psychologists may be well placed to support schools to design and implement new approaches to health promotion taking into account the school culture, the overall constraints and available resources, leadership visions and general practices of staff. Additionally, they can support schools and teachers to develop practice-based evidence to complement the recommendations of health professionals (Jourdan et al., 2021).

Additional to the advocacy role, educational psychologists can play a key role in the implementation of evidence-based practices to meet the school-based needs of adolescents with health conditions. According to Kelly and Perkins (2012), educational psychologists can support implementation by working together with decision-makers, and contributing to the various stages of implementation. They can support schools on their path to create an inclusive environment, provide

stakeholders with data for decision-making and promote leadership approaches towards implementation. A first step towards this might be for educational psychologists to enhance their own knowledge of the impact of adolescent health-related needs on learning as well as educational outcomes.

1.10 Researcher Position

This research would not have been attempted without my strong interest in the area. Areas referring to researcher reflexivity will be discussed to clarify the researcher's position.

The decision to explore the collaboration between health and educational services came from my experience as a parent of an adolescent with a chronic condition, as well as an educational professional having worked with young people with various health conditions and disabilities. The appreciation of the impact of physical health on learning and social, emotional and mental health began during my career as a secondary school teacher. Once I acknowledged the various impacts health conditions could have, more disclosures of students' struggles came to light. At the same time, the experience as a parent having to advocate for a young person's rights highlighted the lack of understanding in schools surrounding the impact of a physical condition on social and emotional wellbeing as well as learning. My belief in the good intentions of schools to support all students equally resulted in the exploration of factors that might prevent them from providing equitable support to students with health-related needs. I have come to realise that physical health factors are taken routinely into consideration, particularly in the case of better-known conditions, such as childhood cancer or a physical disability. At the same time, I saw

much fewer attempts to reduce the barriers that might prevent adolescents with health needs from learning and fully participating in school life. As the parent of an adolescent who does not wish to share health-related information, I understand how difficult it can be for schools to gain a holistic picture. I believe that more awareness and a better integration of health in schools will improve individual support and enhance opportunities and outcomes.

Chapter 2: Methodology

2.1 Overview of the Chapter

This chapter focuses on the design and methodology of the present research, as well as the ontological and epistemological position of the researcher. Ethical considerations and steps taken to address those considerations will be discussed, followed by a description of research methods applied in the study, including recruitment of participants, quantitative and qualitative measures, and reflections on data analysis. Active voice will be used throughout the chapter in order to highlight the active role the researcher plays in the understanding and interpretation of the studied phenomenon (APA, n.d.). The constructivist paradigm assumes that the 'knower and the known are inseparable' (Tashakkori & Teddlie, 1998 page 23). I gained insight into related experiences prior to the research through personal experience. The influence of this pre-understanding needs to be acknowledged. Through the use of epistemological relativism, research questions can be studied both subjectively and objectively with the knower sometimes interacting with the known and other times standing apart from it. By using both qualitative and quantitative methodologies, I have embraced this dynamic relationship with the phenomenon under the lens.

2.2 Epistemological and Ontological Position

The present research adopts an ontological critical realist position and views knowledge as socially influenced. The study is based on the assumption that some

'authentic' (Braun & Clarke, 2013, page 85) reality exists and it is shaped by social and cultural factors, such as language and environment. There is truth to the existing diagnoses and support frameworks investigated in this study, but participants and schools construct their own reality of those, the elements of which are explored here.

The epistemological standpoint is social constructivism. This theory regards knowledge to be constructed through various discourses that are dynamic and related to specific social contexts. There is not one truth available to be explored (Braun & Clarke, 2013). Knowledge therefore is a product of how we understand it. Knowledge production is grounded in data (in this study in language) without a singular underlying reality providing the foundation for it.

2.3 Reflexivity in the Production of Knowledge

The assumption that the knowledge produced by this research is not a logical extrapolation from existing objective reality, but the product of social, cultural and individual processes makes it necessary to address the issue of reflexivity. Resemblances between actions can be "constructed and reconstructed by participants in diverse ways" (Woolgar, 1988). Additionally, the interpretative outcomes may be impacted by my personal experiences and my view of the existing reality. Therefore, I have tried to link knowledge generated within one participant group to knowledge within the other participant groups in order to create a triangulation process during production. By distancing my views from the voices in this text I attempted to not exercise "power" over those voices and maintain the distance that separates participants' views from my own reality.

2.4 Psychological Framework

Key concepts of Bronfenbrenner's theory of the ecological model of human development were used as a framework (Bronfenbrenner, 1979). Bronfenbrenner's theory evolved over time from the 1970s until his death in 2006 (Eriksson et al., 2018). For the purpose of this research, concepts from the final phase of the theory's development will be applied (1993-2006). Within the Process-Person-Context-Time (PPCT) model, proximal processes encompass the interaction between the individual and other persons, objects and symbols (Bronfenbrenner, 1995, page 620) within the microsystem, which is the individual's immediate environment. Processes entail regularly occurring activities and interactions with significant persons in the individual's life. For this research, parents/carers, school staff members as well as members of healthcare teams will be considered significant persons. Bronfenbrenner considered proximal processes within the microsystem as a powerful predictor of development. The model posits that individuals bring important characteristics to all processes (Liles & Juhnke, 2008). These characteristics build the Person. Context within the theory encompasses four interrelated systems: microsystem (the individual's immediate environment); mesosystem (interrelations between several microsystems), exosystem (contexts that have an indirect influence on the individual) and macrosystem (contexts with a shared culture and understanding). Aspects of Context could therefore be applied to evaluate the influences of different systems, such as schools or families surrounding the processes under investigation. Finally, aspects of Time need to be explored to gain an understanding of the way they influence Processes. The complex relationship between time and chronic illnesses is explored by Jowsey (2016). Some participants had to negotiate identity building with a timeline consisting of before and after the diagnosis. The considerable time spent

missing out on opportunities, the time constraints of health management as well as the implications that health holds for past, present, and future actions and opportunities, build part of the participants' narrative.

2.5 Conceptual Framework and Research Design

My ultimate goal is to bring about a positive change into the life of adolescents with health-related needs in secondary schools, therefore the research needed to adopt an advocacy approach. This approach is not a neutral stance, as the researcher hopes that the research will directly or indirectly result in a change of practice and attitudes. This transformative framework includes the researcher's worldview and implicit values (D. Mertens, 2003). Mertens posits that knowledge is not neutral, human interests influence it and it reflects social relationships and power within a society. The goal of knowledge construction is therefore to improve society. Perspectives of critical theory have an important place in research and include research around people with disabilities (Mertens, 2003).

Building on Mertens's work, (Sweetman et al., 2010) established a framework for transformative research that entails criteria for each step of the way throughout the research process. The building blocks of the framework include: (i) The open referencing of a problem in a vulnerable community; (ii) The open declaration of a theoretical lens; (iii) The inclusion of an advocacy stance in the research questions; (iv) A literature review that includes discussions of diversity and equal rights; (v) A discussion of appropriate labelling of the vulnerable population; (vi) Data collection and outcomes that benefit the community; (vii) Research initiated by members of the community and/or their direct engagement with research; (viii) Results shedding a

light on power relationships; (ix) Results facilitating social change; (x) The researcher's explicit statement about the use of a transformative framework. I attempted to explicitly follow the steps of a transformative framework.

The complexity of the topic necessitated an approach through multiple methods with the potential to address several aspects of an issue. Mertens (2003) and Sweetman et al. (2010) noted that mixed methods design fits well within the transformative framework reflecting the need for a qualitative dimension to gather perspectives as well as a quantitative dimension to demonstrate credible outcomes for community members and scholars. In order to explore important variables, emphasis was put mainly on the qualitative data collection and evaluation.

The voice of school nurses was accessed from the early stages of research - from the problem formulation and the drawing up of the research questions through the drafting of the survey questionnaires to the point of interpretation of the data. School nurses are well positioned to provide an insight into the link between young people with health-related needs, their schools and the healthcare services. Data gained from various stages of the research was integrated by connecting the results from the preliminary analysis to the data collection of the next procedure.

Qualitative and quantitative approaches yield a different type of data: open-ended data for qualitative methods and closed-ended data for quantitative methods (Creswell & Creswell, 2018). Health-related needs in a complex educational context is a nuanced and complicated topic with regards to the individual experiences as well as the patterns that emerge (Tashakkori & Teddlie, 1998). The research questions

had to be explored in a way that reflects their complexity. This complex picture reflects the experiences of the various participants and allows us access to a broader set of knowledge we may not have had otherwise (Dr. Ola Demkowicz '*Why Mixed-Method Research Matters*' – In Conversation, n.d.).

2.6 Purpose of the Research

The purpose of the research is to examine the support around adolescents with health-related needs in secondary schools by applying an explanatory sequential mixed method approach combining quantitative as well as qualitative data (Creswell & Creswell, 2018). In line with this approach, the quantitative form of data collection helped inform the qualitative form of data collection (D. M. Mertens, 2010; Sweetman et al., 2010). The study hopes to explore the support provided for students with health-related needs in secondary schools as well as to identify hidden gaps in practice and make sense of the concepts that might be associated with the reduced outcomes of the young people with long-term health conditions.

2.7 Research Questions

The overarching question being asked in the current research is:

How can health and education services work together to improve processes around adolescents with chronic, life-threatening and life-shortening health-related conditions?

There are several policies and pieces of legislation aimed at establishing good practice to meet the needs of CYP with health-related conditions in schools. For the purpose of this paper, I reviewed the following documents:

- 1) *Social and emotional wellbeing in secondary education* (National Institute for Health and Care Excellence (NICE), 2009) provides guidance to promote good social, emotional and physical health of CYP aged 11-19 years.
- 2) *The Equality Act 2010* ensures that schools and other educational provisions avoid discriminating against and promote equality for pupils whose medical conditions are seen as protected characteristics.
- 3) *Section 100 of the Children and Families Act 2014* requires arrangements to be made for supporting pupils at their school with medical conditions (*Children and Families Act, 2014*).
- 4) *Supporting pupils at school with medical conditions. Statutory guidance for governing bodies of maintained schools and proprietors of academies in England* (DfE, 2015) presents statutory and non-statutory advice based on good practice for making arrangements to support pupils with medical conditions at school and off site.
- 5) *Children with medical needs: What schools and settings need to know* (nasen House, 2018) provides guidance based on good practice for

schools on meeting the needs of children with medical needs in hospital schools as well as mainstream education.

6) *Health Conditions in Schools Alliance*

(www.medicalconditionsatschool.org.uk) provides guidance for schools to support children with medical conditions, including the preparation of Medical Conditions Policies as well as Individual Healthcare Plans.

Based on the guidelines identified within policies, I identified five subsidiary questions to the main research question. These address the various perspectives of the overarching research question:

1. Are policies, guidance and legislations surrounding young people with health-related needs effectively implemented in schools?
2. How is the transition and inclusion of young people with health-related needs managed by schools?
3. How can the awareness of educators be raised around the impact of health-related needs on young people's educational and social-emotional wellbeing?
4. How might different agencies interacting with a young person, such as schools and health services as well as parents/carers, work together better?
5. In what ways are social, emotional and mental health needs taken into account when planning support for pupils with medical needs in schools?

The research questions are aimed at identifying elements of good practice as well as gaps in five areas of policy; implementation; transition and inclusion; awareness; collaboration and social, emotional and mental health.

2.8 Procedures

2.8.1 Ethical Considerations

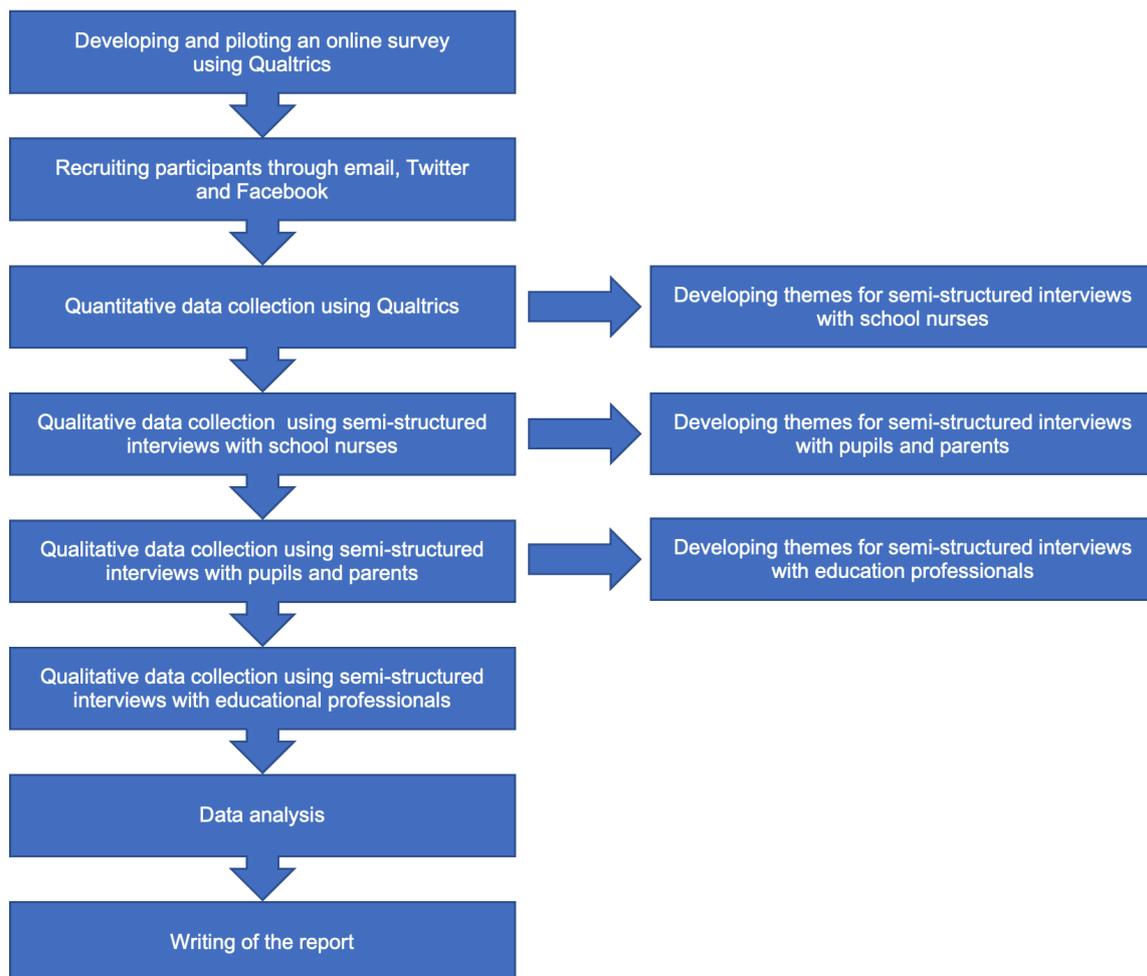
Ethical approval for the research was obtained through the Department of Psychology and Human Development at UCL Institute of Education in March 2020 (See Appendix I). Throughout all stages of the research, written informed consent was gained from all participants. Research information sheets were provided for school nurses, school staff, parents/carers as well as young people (see Appendix II). All participants were given the opportunity to contact me with any query and opt-in consent forms were issued to parents/carers. Once informed consent was obtained, I contacted the participants to arrange an interview time. All participants were informed that they were under no obligation to participate in the study; if they choose to participate, their data will remain anonymous and confidential, and they could choose to withdraw at any time without having to provide an explanation.

Once ethical approval was obtained, the quantitative survey designed for the first stage of the research was piloted with two school nurses. Based on their feedback, I made changes to the final version of the survey. The responses of the two school nurses were not included in the final analysis. At this time, a national lockdown commenced in the UK due to the Covid-19 pandemic and alternative

options had to be considered for participant recruitment and potentially a different research design. For an overview of the procedures see Figure 1.

Figure 1

Overview of Procedures



2.8.2 Recruitment and Participants

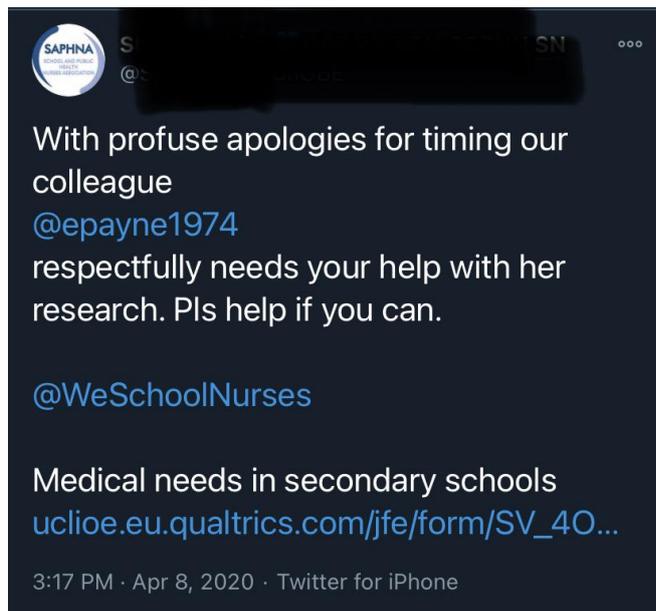
Stage 1: School nurses

Due to the lockdown, it was not possible to contact school nurses through schools. Therefore, I contacted the professional body of school nurses: School and

Public Health Nurses Association (SAPHNA). An invitation to complete the survey was shared through their social media sites (Facebook and Twitter).

Figure 2

Tweet Inviting School Nurses to Participate in Research During the Pandemic



Thirty-six school nurses completed the online survey and 23 of them indicated that they would be willing to participate in an interview. All 23 participants were contacted by email and eight interviews were conducted using either an online platform or by phone. School nurses were included in the research if they currently work or previously worked with a secondary school in England. All participants completed a consent form before they were able to proceed to the survey (see Appendix I). See Table 1 below for participant characteristics.

Table 1*Demographic Characteristics of School Nurse Participants in the Survey*

Place of work	State school	39%
	Independent school	17%
	Cluster of state and independent schools	44%
Number of schools covered	1 - 5	12%
	5 - 10	50%
	10 - 15	15%
	15 <	23%
Allocation	Working as the main nurse in allocated schools	69%
	Working in a team with shared responsibilities	31%
Employer	NHS	53%
	Local authority	8%
	Independent day or boarding school	17%
	Private sector provider	6%
	Other	17%
Length of time in the profession	Less than a year	6%
	1 - 5 years	31%
	5 - 10 years	17%
	10 years <	47%
Number of pupils responsible for	> 500	14%
	500 - 1000	17%
	1000 - 5000	50%
	5000 <	19%

Based on the school nurse survey, I was able to establish the main themes for the semi-structured interviews. These included: policies and systems in place; transitions (from primary to secondary school as well as from specialist to mainstream settings); inclusion; collaboration and social emotional mental health. See Table 2 below for the demographic information of the participants who agreed to be interviewed.

Table 2

Demographic Characteristics of School Nurse Participants in the Semi-Structured Interviews

Place of employment	
Participant 1N	In a nursing team providing drop-in service for one senior school and eight primary schools
Participant 2N	In a nursing team providing drop-in service for 64 mainstream schools
Participant 3N	In an NHS clinic-based school nursing team providing drop-in service for three secondary schools and six primary schools
Participant 4N	On site in an independent school
Participant 5N	Professional organisation for school nurses
Participant 6N	Previously in a nursing team providing drop-in service for schools, currently a safeguarding officer
Participant 7N	On site in a comprehensive state school
Participant 8N	On site in a special school

Stage 2: Pupils and parents/carers

For the next stage of my research, I needed to recruit young people and their parents/carers. All young people had to attend a secondary school in England and have a diagnosis of a chronic, life-threatening or life-shortening condition. As it was

not possible to recruit participants through schools, an alternative way was needed to approach young people and their families. Recruitment of parents and pupils seemed more challenging than finding participants for the first stage of the research, as I was not aware of any organisations that could help in reaching out to families. While reviewing available literature for the current study, I came across the organisation: Health Conditions in Schools Alliance (<http://medicalconditionsatschool.org.uk/>). Two of the participants interviewed were active members of that organisation and mentioned it during their interviews as well. This prompted me to reach out to the main organisation as well as to all the supporting charities to raise awareness about my research and ask for information to be shared with the families with whom they work. I received expressions of interest from nine families. I contacted them by email, introduced myself and forwarded the letters of information as well as contact forms for young people and their parents (see Appendix II). Three young people did not wish to be interviewed but agreed to complete an online questionnaire (see Appendix III for a sample of questions and responses). Six young people and their parents agreed to a semi-structured interview using an online platform. All interviews were conducted with the young person and their mother at the same time. See the table below for more information about the participants.

Table 3*Demographic Characteristics of Adolescent Participants*

	Method	Age	Gender	Condition	Diagnosed	Additional needs
Participant 1A	Questionnaire	15	F	Arthritis	No information	No
Participant 2A	Questionnaire	16	F	Asthma, Coeliac Disease, ventricular septal defect	No information	No
Participant 3A	Questionnaire	14	M	Type One Diabetes	No information	No
Participant 4A	Interview	15	F	Arthritis	Aged 7	No
Participant 5A	Interview	18	F	Cystic Fibrosis	Pre birth	No
Participant 6A	Interview	14	F	Cystic Fibrosis	Aged six months	No
Participant 7A	Interview	13	M	Epilepsy	Aged 7	Yes
Participant 8A	Interview	14	M	Type One Diabetes	Aged 13	No
Participant 9A	Interview	17	M	Narcolepsy, cataplexy	Aged 16	No

Stage 3: Educational professionals

After exploring the research questions from the point of view of school nurses as well as young people and their parents/carers, it was important to explore good practice and barriers experienced by educational professionals. The first lockdown during the Covid pandemic made it difficult to contact schools directly and I was hoping to be able to recruit participants after the summer. The challenging situation experienced by schools once they were able to open again for the 2020/21 academic

year, largely de-prioritised any involvement in research. Schools were busy providing a high-quality and safe educational experience for their students and school leaders were overwhelmed with the demands of these challenges (Hepburn, 2020). The pandemic undermined researchers' ability to conduct research in schools and the development of online resources and the introduction of digital platforms (Lancet, 2020) could not solve the lack of capacity school leaders experienced during these times. Snowball sampling was used to collect data from educational professionals (See Table 4). It was recommended to me to contact Participant 1E and participant 5E during the first stage of my research by school nurse participants. I was advised to contact Participants 2E, 3E and 4E by EPs familiar with my research topic. All participants at this stage of the research had to work with pupils with health-related conditions in an educational setting in England, either by completing pupil-facing work or by supporting schools to work with pupils with medical conditions.

Table 4

Demographic Characteristics of Educational Professional Participants

	Profession	Scope of work
Participant 1E	Head of a hospital school in England	Pupil facing work with children and young people (CYP) who are inpatients as well as outpatients (in schools as well as in their homes) Outreach work to provide training for schools in the county
Participant 2E	Advisory teacher for education support for	CYP with <50% attendance: pupil facing work CYP with 50%< attendance: guidance to schools

	medical absence	
Participant 3E	Advisory teacher for education support for medical absence	CYP with <50% attendance: pupil facing work CYP with 50%< attendance: guidance to schools
Participant 4E	Advisory teacher for physical and neurological impairment	Pupil facing work in schools County-wide training on certain conditions Guidance to schools
Participant 5E	Medical lead in a secondary school	2080 students, about 350 with Individual Health Care Plans

The table below shows the number of participants at each stage of the research:

Table 5

Number of participants

Stages of the research	Number of participants
1. Quantitative survey (school nurses)	36
2. Semi-structured interviews (school nurses)	8
3. Semi-structured interviews (pupils+parents)	6+6
4. Semi-structured interviews (educational professionals)	5

2.8.3 Quantitative Data Collection: Instrumentation of the Survey

The primary purpose of the quantitative survey of this study was to answer descriptive questions, such as what percentage of schools publish a medical needs policy on their website. The questions were developed based on the guidance and legislation referenced in 2.7 (Research Question). The design was adapted to provide a simple overview of areas of interest. The survey is cross-sectional with the data collected at one point in time. As this a sequential study, survey data were used to develop the qualitative semi-structured interviews. Data was collected using an online survey administered through the platform Qualtrics. Qualtrics is a web-based survey tool that can be distributed online via a link. I had access to the service via UCL Institute of Education's account.

The survey was built using the Qualtrics interface. The tool kept track of participation rates, actual time participants spent on the surveys, and other metadata useful to the research being conducted. The following three factors were considered for the use of an online survey (Ritter & Sue, 2007): (a) Participant factors: The participants are likely to have access to and ability to use the Internet and they are accessible through online recruitment. Furthermore, the advantage of the participants not being bound by a particular physical location was considered. Due to the Covid19 pandemic a web-based survey was the only option. (b) Questionnaire factors: Qualtrics allowed me to ask open- as well as close-ended questions. The anonymity of the participants could be maintained. The questionnaire was designed so that it could easily be completed on a smartphone. (c) Evaluator factors: Web-based surveys allow for a quick deployment. I had the level of technological

expertise required to use and evaluate the responses to the web-based questionnaire. For a sample of survey items for school nurses, see Appendix IV.

2.8.4 Data Collection: Semi Structured Interviews

I conducted semi-structured interviews using online platforms or the phone with the three different groups of participants. No face-to-face interviews were conducted due to Covid-related restrictions. Although I was initially concerned about missing non-verbal cues that could support the understanding of verbal responses, conducting interviews on an online platform allowed easy access to participants who were geographically dispersed. All the school nurses were interviewed individually. All pupils were interviewed together with a parent (the mother in each case). Participants 2E and 3E were interviewed together; the other educational professional participants were interviewed individually. Robson (2011) recommends having an interview guide with a checklist of topics as well as order and wording for the questions (see Appendix V for the interview guide with pupils and parents). Semi structured interviews allowed me to modify the flow of the interview when necessary and to follow up on topics mentioned by participants.

2.8.5 Quantitative Data Analysis: Summary and Display of Quantitative Data

The quantitative data collected during the first stage of my research was summarised and displayed using Excel. The small amount of quantitative data (n=36) required only frequency analysis. The spreadsheet software Excel was

recommended by Robson (2011) to produce charts based on the summary of data reported by Qualtrics.

2.8.6: Qualitative Data Analysis: Reflexive Thematic Analysis

All but one of the semi-structured interviews were recorded and transcribed verbatim. The recording quality of the interview with Participant 1N was poor and I had to rely largely on my notes when transcribing it. Using the cycles of coding described by (Saldaña, 2016) and the stages of reflexive thematic analysis (Braun & Clarke, 2006, 2013), I followed the steps outlined below for *eclectic coding* (Saldaña, 2016, p.226) of the interviews conducted with the three groups of participants: school nurses; pupils and parents; and educational professionals. Reflexive thematic analysis assumes “reflective and thoughtful engagement” (Braun & Clarke, 2019, page 14) with the data and the analytic process. It requires a considerable amount of work going into the analytic process whereby themes are *generated* rather than identified. Positioning and reflection on assumptions is a vital part of the process. Below the stages of the analysis:

- 1) During *familiarisation with the data* I transcribed the audio-recorded interviews. During this process, I took notes regarding initial thoughts and ideas about the data. The notes taken during familiarisation with the school nurse data, served as a starting point for themes for the semi-structured interviews with pupils and parents, and educational professionals.

2) Following the transcription, *initial codes were created* to organise the data into meaningful groups (nodes). Each interview was read and studied carefully with the help of a colour coding system in order to group segments. I first used *attribute coding* (Saldaña, 2016, p.101) to provide essential participant information and contexts. This was important as I interviewed multiple participants within various settings. The results of the attribute coding are represented in Tables 1, 2 and 3. Next, *structural coding* (p.110) was used to code and categorise data segments that relate to the specific subsidiary research questions. I chose structural coding for the first cycle of coding because my study employed multiple participants with semi-structured data gathering protocols. It is an exploratory investigation with the aim to gather themes of major categories. Using structural coding I attempted to ‘lump’ (page 40) segments of text on broad topics. These segments then formed to basis for an in-depth analysis within and across topics. Following the first cycle of structural coding, thematic analysis was used to explore themes and subthemes within the categories.

3) With the help of NVivo 12, data segments and codes were organised into potential main overarching themes and subthemes (*NVivo 12 Qualitative Data Analysis Software*, 2018). A combination of inductive and deductive approaches was used to generate themes. Although themes were generated based on the experiences of the participants, I had an analytical interest and sought to answer specific questions for the research purpose.

4) Themes and codes were *repeatedly reviewed and reconstructed* to ensure they formed a logical and consistent pattern, that there was enough data to support them and that they accurately reflected the whole dataset.

5) *Themes were defined and named* in order to identify the essence of each of them and their link to the narrative in relation to the research question.

6) The *research report* including the thematic analysis was written up.

This process was repeated three times for the different sets of interviews during the three stages of the research. Finally, thematic maps were created to link the three stages and visually present the overarching themes across the entire study (See Appendix V for a sample page with coding and Appendix VI for hierarchy of themes).

2.8.7 Triangulation of Themes

To increase the validity of my findings, I shared a Venn-Diagram of themes with one of the school nurse participants by email and asked for her feedback. She approved of the themes that were generated and asked for additional narrative explanations to be included. The themes based on the semi-structured interviews with the young people and their parents/carers were shared with two Trainee Educational Psychologists exploring a similar area of research in the course of an MS Teams meeting. The themes were largely in accordance.

Chapter 3: Findings

3.0 Aims

This chapter discusses the outcomes of the analysis conducted to answer the five individual subsidiary research questions. The overarching research question will be further addressed in the discussion section, as elements from various questions will be synthesised in an attempt to provide in-depth answers to it.

Subsidiary research questions

RQ1: Are policies, guidance and legislations surrounding young people with health-related needs effectively implemented in schools?

RQ2: How is the transition and inclusion of young people with health-related needs managed by schools?

RQ3: How can the awareness of educators be raised around the impact of health-related needs on young people's educational and social-emotional wellbeing?

RQ4: How might different agencies interacting with a young person, such as schools and health services as well as parents and carers, work together better?

RQ5: In what ways are social emotional and mental health needs taken into account when planning support for pupils with medical needs in schools?

The key findings of the survey conducted with school nurses are summarised and presented. The experiences and views shared by school nurses, adolescents, and their parents as well as educational professionals during semi-structured interviews were explored using reflexive thematic analysis which groups information according to the research questions to create a picture of current support of adolescents with health-related needs in secondary schools.

3.01 Key Findings of the Overarching Research Question

An overview of the findings of the overarching research question is provided before the subsidiary research questions are addressed individually. The overarching research question of this study is: *How can health and education services work together to improve processes around adolescents with chronic, life-threatening and life-shortening health-related conditions?* Below is an exploration of key areas where such collaboration can positively influence support and outcomes of this population based on the analysis of the quantitative and qualitative data provided by the participants. A further examination of potential collaboration and implications for the educational psychology practice will be provided in the next chapter.

Training

Participants' accounts show that more involvement of healthcare professionals in teacher training, as well as in training in schools around conditions that are present, may lead to an improved understanding of the impact of health-related conditions on learning, attendance and mental health needs. The training should go beyond physical implications of a condition or treatment regime and

explore how a condition might present in layman's terms, how it may impact learning, attendance and wellbeing, whether or not there are seasonal differences or crunch points in terms of mental health. Participants reported that training for teachers on medical conditions is often provided in technology-based e-learning format and can be very basic. Healthcare professionals' involvement in the creation and delivery of computer-based remote training programs may increase teachers' knowledge of the implications of health-related conditions in schools without adding too much pressure on the working hours of both professionals.

Information flow

Participants' accounts show that the information flow between schools and health services is limited. The reasons listed include lack of capacity, lack of transparency around contact persons and contact details, and professionals being unsure about how much information can be shared. Better collaboration may be ensured by both school and health services sharing relevant email addresses and details for easy contact. This highlights the necessity of a named person in school responsible for medical policies and implementation as required by the statutory guidance. Improved information flow between school and healthcare professionals seems particularly important at the time of transitions from primary to secondary school or from specialised settings to mainstream school, in case of extended absence as well as a drop in attendance or attainment. By sharing all relevant information, goals between different services can be better aligned and support systems can become more transparent. This is particularly pertinent for lesser known conditions (such as narcolepsy/cataplexy).

Involving schools in the creation of health-related resources

Participants noted that healthcare professionals create resources for schools without consulting educational professionals to improve the usefulness of such resources and to ensure that the language is accessible for school staff. Participants also pointed out that collaboration between schools and health services is enhanced when it is initiated by healthcare professionals. Perhaps by eliciting schools' views around the usefulness of resources created by health services, relationships can be started by individual professionals that may lead to long-term collaboration and a better understanding of each other's goals.

Collaborative working arrangements to produce Individual Healthcare Plans

Participants noted that better results can be achieved when all relevant professionals are in the same room. The pandemic showed that collaboration through tools such as MS Teams or Zoom can work well and is less time-consuming than traditional face-to-face meetings. By working together to produce IHP's, it can be ensured that all relevant information is included, and equal access to learning remains the focus of the plans, rather than the meeting of physical needs only. Additionally, by having personal contact with relevant professionals, opportunities for early intervention and improved information flow can be enhanced.

Relationships/trust

All but one family reported that they have a trusting relationship with their healthcare provider whereas no family reported that they currently have a person of trust in school. It was however noted by participants that processes are improved for the students when they experience a trusting relationship with a teacher in school.

Healthcare professionals together with schools may need to explore the reasons behind this finding so that together they can ensure that a similar level of trust is developed with an educational professional as with a healthcare professional. Furthermore, if that professional leaves school, it is important to ensure that this role is discussed with another member of staff and the pupil in order to ensure continuity.

Areas of collaboration between different services will be explored more in depth in the following sections. Further implications for reflection for schools and healthcare providers will be discussed in the next chapter.

3.1 RQ1: Are Policies, Guidance and Legislation Surrounding Young People with Health-Related Needs Effectively Implemented in Schools?

3.1.1 RQ1: Descriptive Statistics

Forty-one responses were recorded. Five responses were removed because of partial completion. An exploratory data analysis (Robson, 2011) using tools of descriptive statistics was conducted to represent relevant aspects of the set of quantitative data.

Participants completed 21 questions in the first section of the survey exploring the first subsidiary research question (see Appendix 1 for sample questions and a breakdown of responses). It emerged that there is a large variation among schools in terms of producing and publishing policies relevant for pupils with health-related conditions as well as how training is planned and conducted.

Table 6*Key Findings from the Quantitative Data Analysis (RQ1)*

Medical Lead and Policies
<ul style="list-style-type: none">• Eighty-six percent (31/36) of participants reported that schools have a designated staff member to support pupils with health-related needs.
<ul style="list-style-type: none">• A Medical Conditions Policy is published on the website of schools overseen by 24 participants with 21 policies reviewed annually.
<ul style="list-style-type: none">• Safeguarding concerns around health-related needs are included in the safeguarding policy in 86% (31/36) of schools.
<ul style="list-style-type: none">• Forty-seven percent (17/36) of participants reported that attendance policies are differentiated for pupils with medical needs.
Individual Healthcare Plans
<ul style="list-style-type: none">• Sixty seven percent (24/36) of participants reported that all students with a medical need have an Individual Health Care Plan and 19% (7/36) reported that students with the same condition (e.g. asthma, diabetes or epilepsy) have a shared care plan.
<ul style="list-style-type: none">• Eighty-one percent (29/36) of participants reported that Individual Health Care Plans are reviewed annually.
<ul style="list-style-type: none">• Sixty-one percent (22/36) care plans do not specify a plan of action for the event that a pupil refuses to take medication or carry out necessary procedures.
Training
<ul style="list-style-type: none">• Training on medical conditions for school staff is provided annually by 67% (24/36) of the participants.
<ul style="list-style-type: none">• Forty-three percent (15/36) of participants reported that pupils are never (29%) or rarely (14%) included in the training and 5% (2/36) always involved pupils.
<ul style="list-style-type: none">• Twenty-nine percent (10/36) participants never or rarely include parents/carers and 19% (7/36) always include parents/carers.

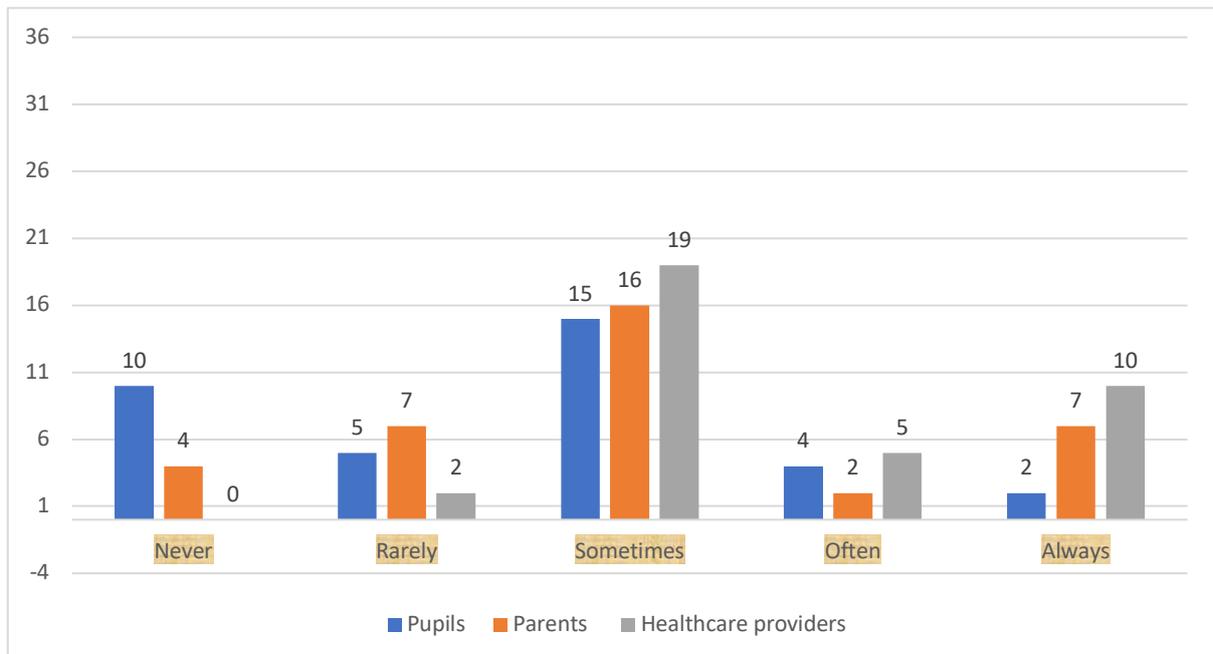
- Fifty-two percent (19/36) participants sometimes include healthcare professionals and 29% (10/36) always include them (See Figure 3).
- Supply teachers do not get briefed on medical conditions in one third of the schools and 53% of schools take staff turnover into consideration when planning training.

Pupils

- Forty-four percent (16/36) of the participants noted that students with medical needs are aware of where medications and devices are stored and can access storage facilities at all times.
- Eighty percent (29/36) participants reported that pupils who are unwell go to the medical room accompanied.

Figure 3

Involvement in Training

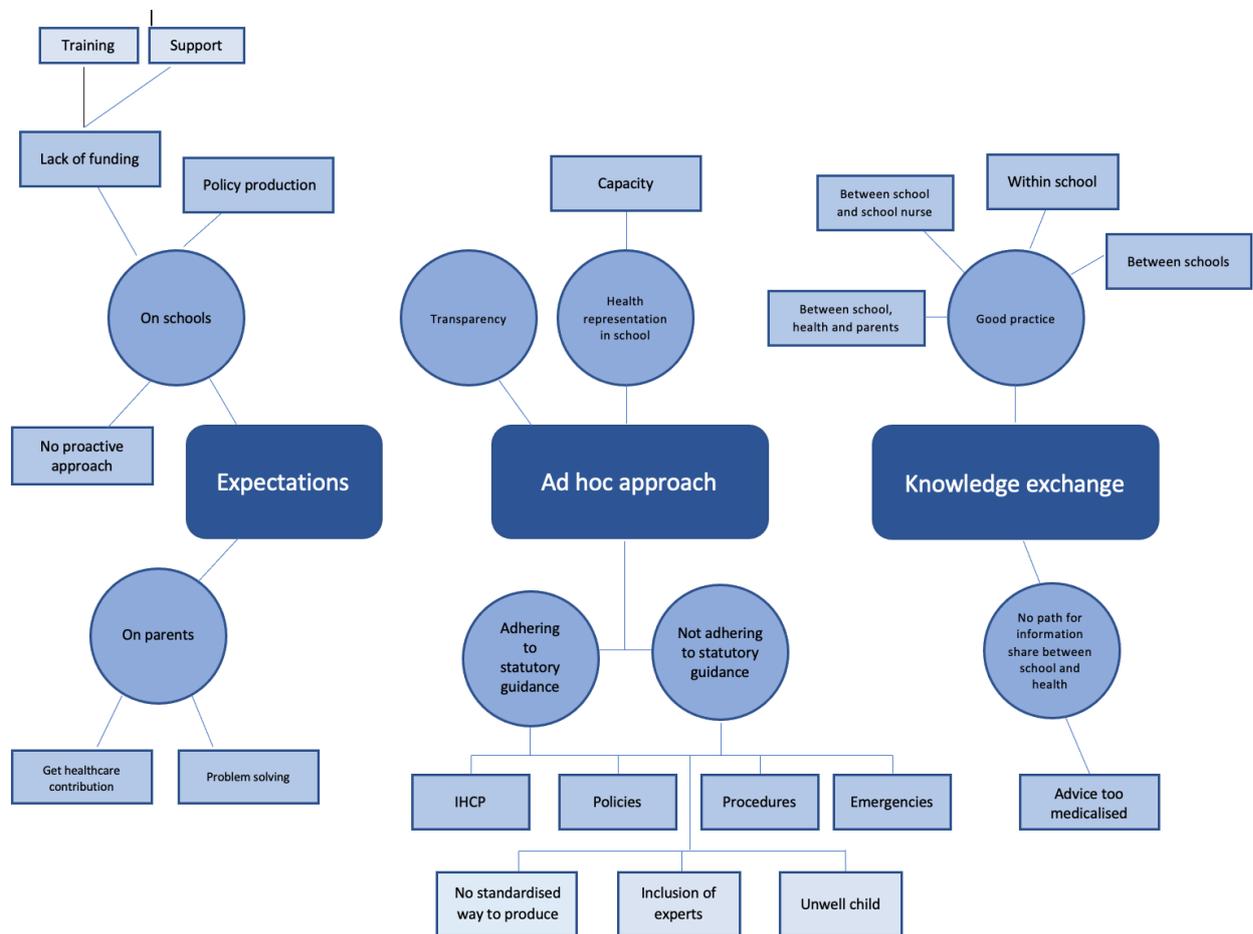


3.1.2 RQ1: Thematic Analysis of School Nurses' Views

Three superordinate themes were identified, each including themes and subthemes. Hierarchy of themes including with all the relevant participant quotes are shown in Appendix VI. A sample of the quotes is listed in this section.

Figure 4

Thematic Analysis of School Nurses' Views (RQ1)



3.1.2.1 Superordinate Theme 1: Expectations. This superordinate theme encapsulates the expectations posed on schools and parents/carers to implement relevant policies, guidance and legislation and the barriers to a successful implementation.

Table 7

Superordinate Theme 1 (SN RQ1)

Theme	Subtheme and participant quotes
<p>On schools</p> <p>School nurses commented on the various expectations placed on schools to provide support, engage in training and produce policies without receiving adequate funding. They also noted that schools often do not take a proactive approach to prevent absences or deteriorating progress of pupils with health-related needs.</p>	<p>Lack of funding for training and support</p> <p>“It is very tricky with funding, there is not a lot out there for these pupils.”</p>
	<p>Policy production</p> <p>“Obviously, the people who were dealing with it in school are not medically trained. So, it depends what school... some would really want you to take charge of it. But then we would also put the ownership back on school”</p>
	<p>No proactive approach</p> <p>“Maybe the child would get to a point where they would start having hospital admissions or something because things have deteriorated. Yeah. And that might be the trigger point at that point”</p>
<p>On parents</p>	<p>Get healthcare contribution</p> <p>“Put the onus on the parent to attend the annual or six-monthly asthma clinic reviews and get the symptoms and the triggers etcetera written down, so that it helps me look after them in school, but that is like fighting the biggest battle ever”</p>
<p>Parents are expected to engage with healthcare providers to get support for the individual health care plans. There is also the expectation that parents can problem solve in case of non-compliance of a pupil with medical procedures, or health-related</p>	<p>Problem solving</p> <p>“In case of non-compliance it is expected that parents are proactive, and problem solve”</p>

episodes in schools.	
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3.1.2.2 Superordinate Theme 2: Ad Hoc Approach. This superordinate theme gives a summary of the lack of standardised approach surrounding the support provided for pupils with health-related needs.

Table 8

Superordinate Theme 2 (SN RQ1)

Theme	Subtheme and participant quotes
<p>Health representation in school</p> <p>The support surrounding pupils with health-related needs is largely impacted by whether or not there is a school nurse on site. If there is no health representation in schools, support for these pupils can be deprioritised depending on the capacity of school nurse hubs.</p>	<p>Capacity</p> <p>“Health representation is not readily available anymore. You know, all newly diagnosed would have either a specialist nurse or the school nurse, I would say that is less the case these days. It is not... the capacity does not allow for it.”</p> <p>“Some schools have what they call a school nurse that is not a school nurse so they may actually take an unqualified person still”</p>
<p>Transparency</p> <p>School procedures, policies and key contacts are often not transparent.</p>	<p>“They do not ask for advice and they do not consult any healthcare professionals. They just do their own things with the governors.”</p>
<p>Adhering to statutory guidance Not adhering to statutory guidance</p> <p>There is a large variation between schools in their adherence to the statutory guidance. This encompasses IHCPs, policies, procedures and emergencies (subthemes). There are some examples of good practice and approaches that can be improved. Variation can impact the production of policies and healthcare plans, whether or not healthcare professionals, pupils and parents are consulted for documents and how schools deal with emergency situations, unwell or non-compliant pupils.</p>	<p>Adherence (Medical lead):</p> <p>“There is always somebody who's allocated as in charge of medical pupils”</p> <p>Adherence (Policies):</p> <p>“Anyone can access them”</p> <p>Non-adherence (IHCP):</p> <p>“Generally, they would have individual health care plans, but some schools would say this group of children have got asthma, therefore this is the plan. Generally, they would have</p>

	<p>individual but there are some who do not have best practice around that.”</p> <p>Non-adherence (Policies):</p> <p>“What sort of jumped out was the fact that their schools didn't have any policies”</p>
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3.1.2.3 Superordinate Theme 3: Knowledge Exchange. This superordinate theme encapsulates the information shared between parents, schools, and other relevant services. Although there are some examples of good practice, often there seems to be no clear pathway to share relevant information and contribute to the support.

Table 9

Superordinate Theme 3 (SN RQ1)

Theme	Subtheme and participant quotes
<p>Good practice</p> <p>Examples of good practice have a positive impact on support planning procedures. Good information flow can be within the school and between school, parents, and other services.</p>	<p>Between school, health and parents</p> <p>“If somebody came in with cystic fibrosis and hadn't had one for a while. They would update their policy and look into getting a health care plan by working with the school nurse, and with the hospital, and the parents.”</p> <p>Between school and school nurse</p> <p>“Normally, you may occasionally but in my experience, it has been very rare that they have not communicated with me”</p> <p>Between schools</p> <p>“You sort of help them devise specific policies, and then encourage them to share them with other schools as well so they do network between them. And they were very good in sort of sharing them and putting them online.”</p>

	<p>Within school</p> <p>“The health care plan would be shared with staff, probably at staff briefing, then would be pinned with some kind of alert flag to that pupil's folder. So, for example if you had that young person in your class and their attainment or achievement or attendance was floundering, then you could have a look in that folder and it will be flagged as a potential cause, but equally if that young person was on your watch in your lesson and they took unwell... you could very quickly access the emergency information”</p>
<p>No path for information share between school and health</p> <p>This can impact policy production, support for pupils with medical needs as well as advice for individual healthcare plans. It can result in IHCPs being too medicalised and difficult for school staff to follow and implement.</p>	<p>“In the past for right or wrong, school nurses would take on the main responsibility of that, but it is actually the governing body who called the legal responsibility. Nowadays, it is quite a mixed picture because that role is in such a grey area that schools struggle to get health professional support.”</p> <p>Advice too medicalised</p> <p>“A consultant will just write down the type of seizure that the child has, and they will expect the school staff to know what it means”</p>

Table 10

Key Findings (SN RQ1)

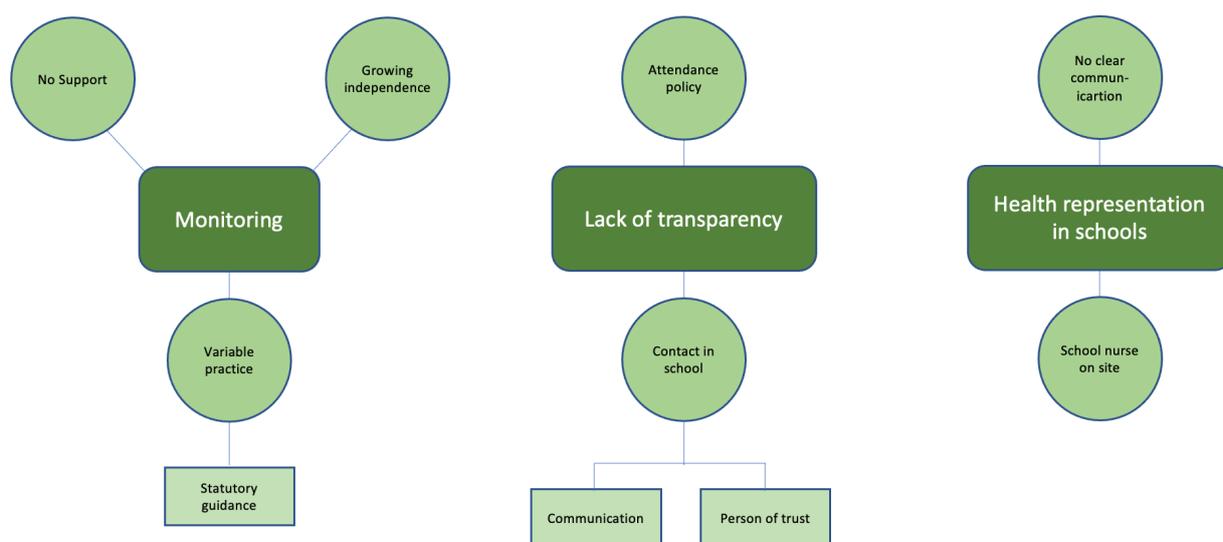
<p>Key findings: Thematic analysis of school nurses' views (RQ1)</p>
<ul style="list-style-type: none"> ● There is a large variation in schools' adherence to the statutory guidance, with some examples of good practice and several areas that can be improved.
<ul style="list-style-type: none"> ● There is no clear path for knowledge exchange between health services and schools.
<ul style="list-style-type: none"> ● There are many expectations placed on schools to meet the needs of pupils with health-related needs, often without adequate funding or training opportunities.
<ul style="list-style-type: none"> ● Schools have the expectation that parents can problem solve whenever issues arise.

3.1.3 RQ 1: Thematic Analysis of Pupils' and Parents' Views

Three superordinate themes were identified: lack of transparency, lack of monitoring and health representation in school. Additionally, the responses to four key questions around the statutory guidance are summarised below.

Figure 5

Thematic Analysis of Parents' and Pupils' Views (RQ 1)



3.1.3.1 Summary of Responses to Selected Key Questions Around Elements of the Statutory Guidance.

Individual Healthcare Plan (IHCP)

Pupils and parents were asked whether an IHCP detailing their needs and support was provided by school in accordance with the statutory guidance. The statutory guidance highlights the importance of the co-production of the IHCP by parent, child, healthcare professionals and key school staff. It specifies the necessity of the input from healthcare professionals (DfE, 2015 page 28)

Figure 6

Responses of Pupils and Parents About IHCPs

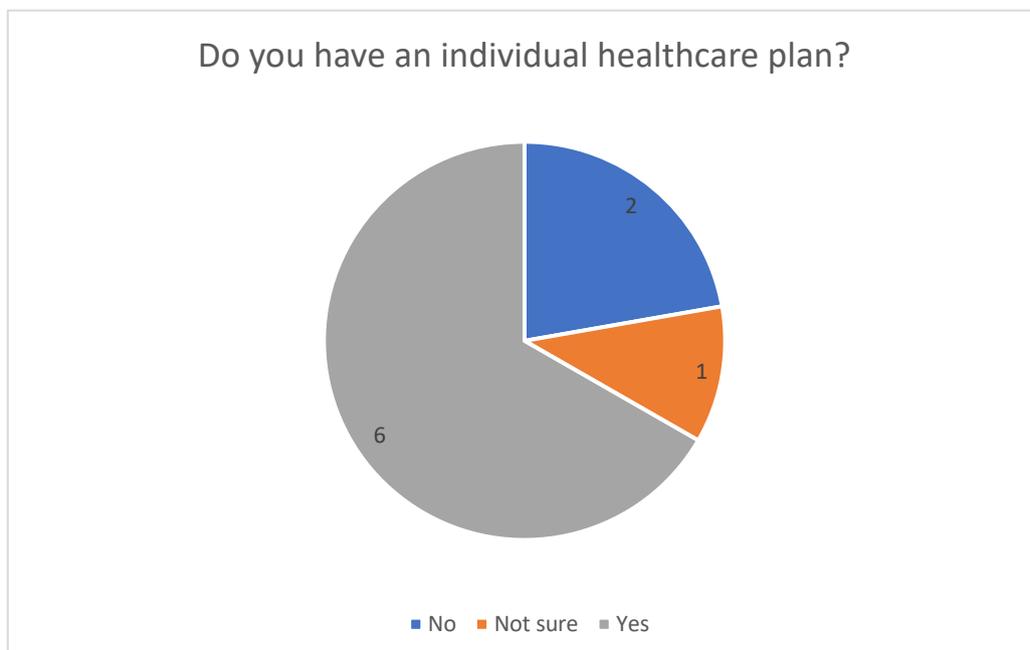


Figure 7

Responses of Pupils and Parents Regarding Contribution to IHCPs

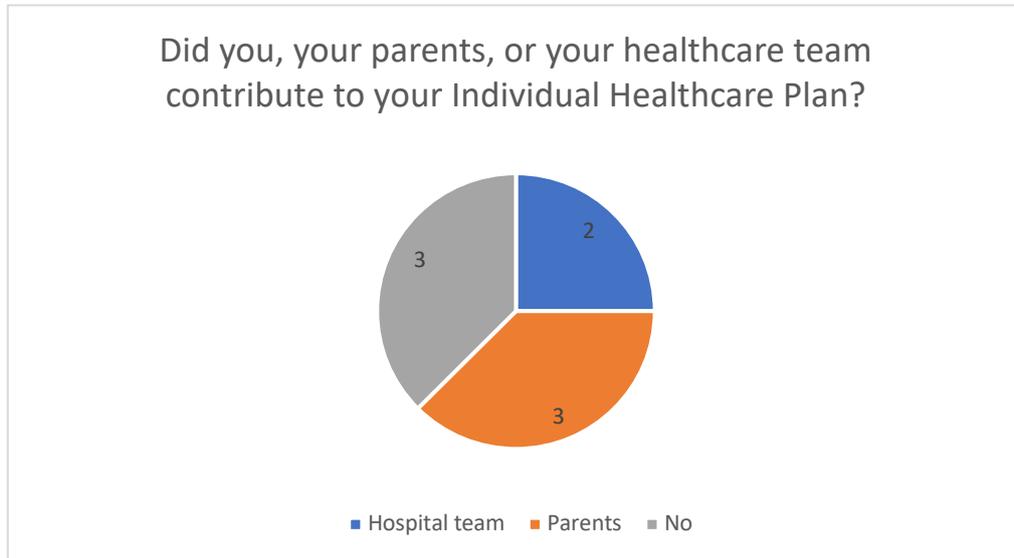


Figure 8

Awareness of Pupils and Parents of Their School's Medical Lead

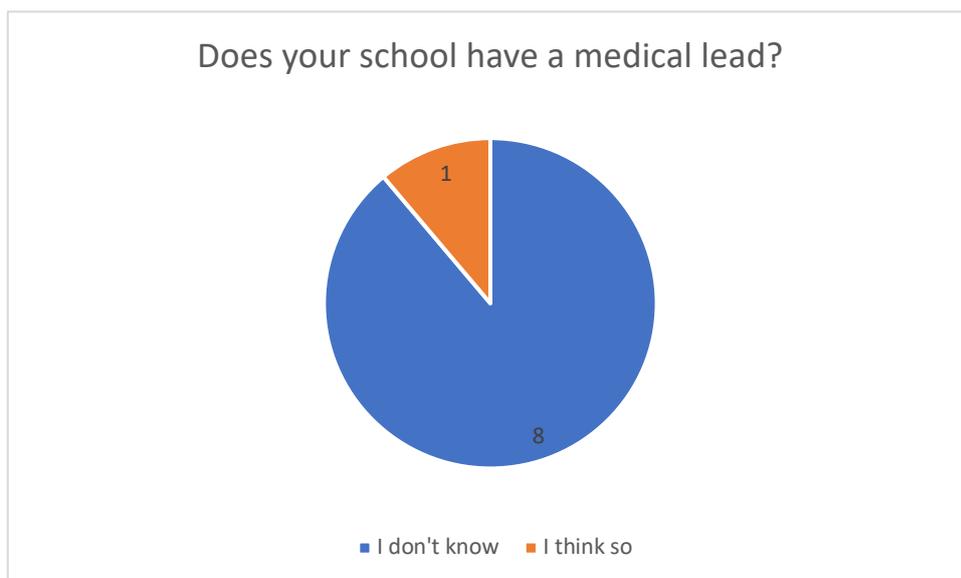
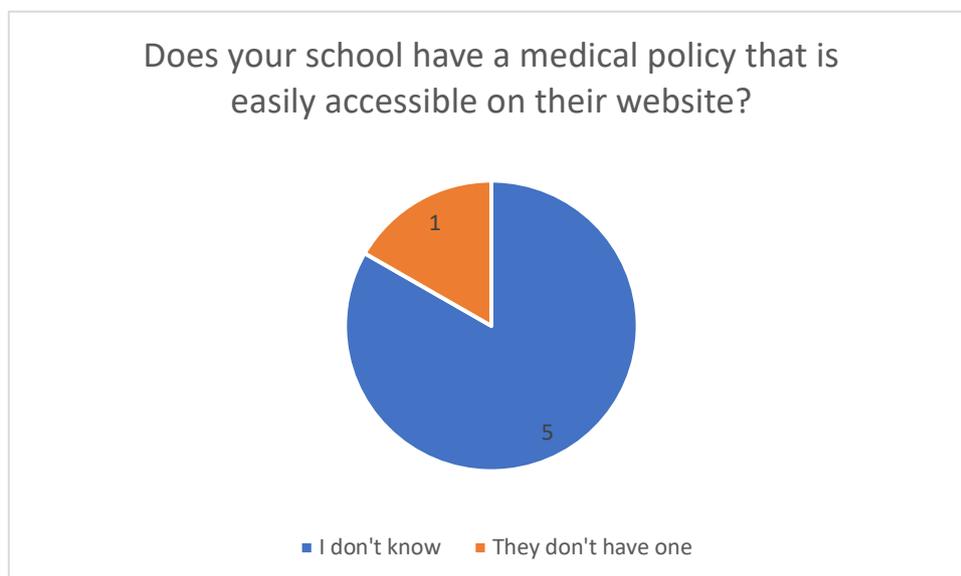


Figure 9

Awareness of Pupils and Parents of their School’s Medical Policy



3.1.3.2 Superordinate Theme 1: Lack of Transparency. This superordinate theme encompasses the difficulties that parents and their children reported regarding gaining insight into processes at schools.

Table 11

Superordinate Theme 1 (PP RQ1)

Theme	Subtheme and participant quotes
<p>Attendance policy</p> <p>Parents and pupils have noted that the attendance policy was applied in a way that permitted extensive absences without questioning the reason.</p>	<p>"It just kind of turned into this kind of permissive environment where they, you know, nobody was saying she had to be at school"</p>
<p>Contact in school</p> <p>Parents and pupils noted that it was unclear</p>	<p>Communication</p> <p>"There just seems a bit a lack of</p>

whom they needed to address with their questions and issues. Additionally, there was no person of trust for these students in their schools.	<p>communication because we do not actually know who to address with her problems"</p> <p>Person of trust</p> <p>"There should be somebody who she could have, maybe could have developed a relationship with to feel comfortable that she has had somebody to go there to speak to these things about these things, and there just really was not"</p>
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3.1.3.3 Superordinate Theme 2: Lack of Scrutiny. This superordinate theme encapsulates the lack of appropriate arrangements for monitoring as required by the statutory guidance.

Table 12
Superordinate Theme 2 (PP RQ1)

Theme	Subtheme and participant quotes
<p>Growing independence</p> <p>Adolescents are at a life stage where they require less monitoring and wish to become more independent.</p>	"I am just trusted"
<p>No support</p> <p>For certain conditions, monitoring medical procedures offers the support that enables pupils to remain in school and not miss learning.</p>	"The school are currently unable to follow up, even to check if he has had his medicine"
<p>Variable practice</p> <p>There is variation between schools in terms of adhering to the statutory guidance with regards to appropriate monitoring.</p>	<p>Adhering to the statutory guidance</p> <p>"Somebody is allowed to go to the medical room with you, he is allowed to be accompanied by somebody else"</p> <p>Not adhering to the statutory guidance</p> <p>"No, I just go by myself."</p>

3.2.3.4 Superordinate Theme 3: Health Representation in Schools. This superordinate theme summarises the participants’ experiences with and without on-site school nurses.

Table 13

Superordinate Theme 3 (PP RQ1)

Theme	Subtheme and participant quotes
<p>School nurse on site</p> <p>Participants value the presence of school nurses in schools.</p>	<p>“It is really valuable having a healthcare professional in the school because they can actually help to dispel some of the myths about health conditions, challenge when that is appropriate”</p>
<p>No school nurse on site</p> <p>Some participants have not had any contact with a school nurse. The statutory guidance clearly states that “A first-aid certificate does not constitute appropriate training in supporting children with medical conditions.” (Department for Education, 2015, p.18)</p>	<p>"We have a first aider but not, not, not a qualified nurse on site. There is an attached school nurse. And, in fact, we've never met her."</p>
<p>No clear communication</p> <p>Without a school nurse, participants are unsure whom to address with questions and issues.</p>	<p>"Hopefully as I said, there'll be a nurse or If not, I will probably have to, as mum said, go to my form tutor or Head of Year"</p>

Table 14

Key Findings (PP RQ1)

Key findings: Thematic analysis of the views of parents and pupils (RQ 1)
<ul style="list-style-type: none"> ● Key elements of the statutory guidance to support pupils with medical conditions are not in place. The guidance requires schools to support pupils with medical needs “properly, so that they have full access to education” (Department for Education, 2015, page 4).
<ul style="list-style-type: none"> ● Participants are often unsure about existing policies and procedures.

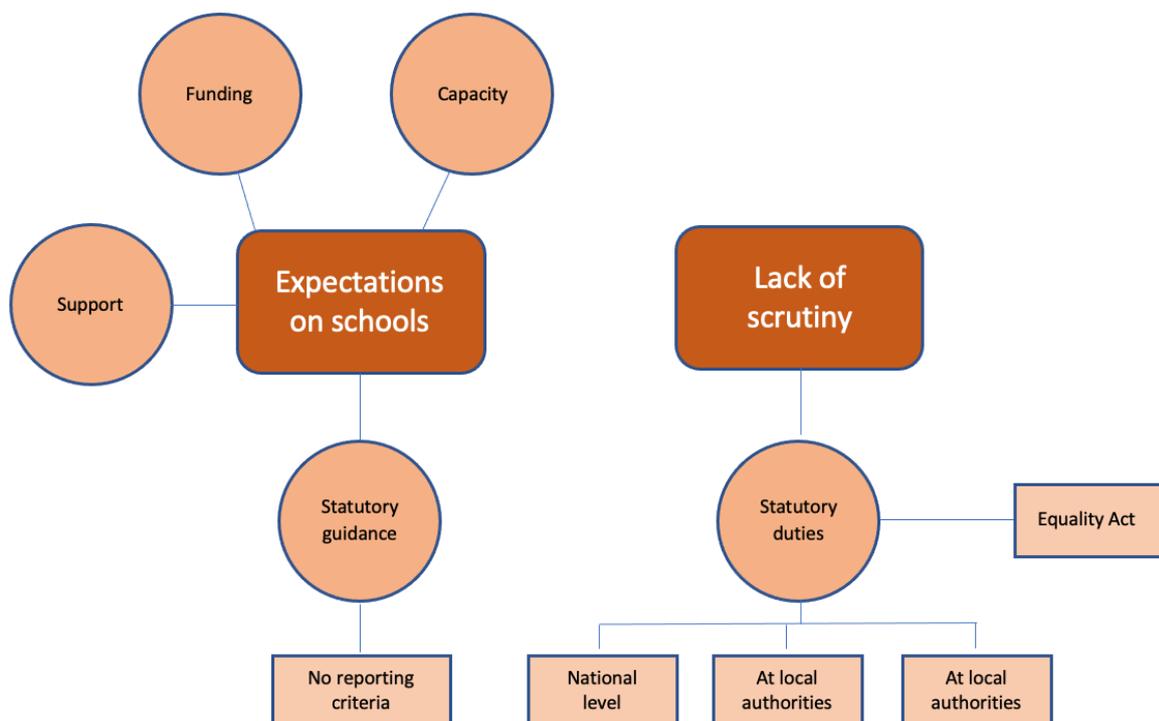
- In some schools, no appropriate arrangements are in place to monitor those pupils who self-manage their medical conditions.
- Attendance policies are more permissive with pupils with medical conditions without questioning the reason for their absences. This can lead to missed learning.

3.1.4 RQ1: Thematic Analysis of the Views of Educational Professionals

Two superordinate themes were identified: lack of scrutiny and expectations on schools.

Figure 10

Thematic Analysis of the Views of Educational Professionals (RQ1)



3.1.4.1 Superordinate Theme 1: Expectations on Schools. This

superordinate theme encompasses the expectations placed on schools to support pupils with medical needs as well as some of the barriers to providing that support.

Table 15

Superordinate Theme 1 (E RQ1)

Theme	Subtheme and participant quotes
<p>Support</p> <p>The statutory guidance requires schools to support pupils with medical needs so that they can fully access education (Department for Education, 2015).</p>	<p>"That number of those that we would support in some way, that might just range from making sure staff are trained, storing their medications, administering medications"</p>
<p>Funding</p> <p>Some participants have reported that there is not adequate funding available for the level of support required.</p>	<p>"Funding hasn't been looked at for years, they haven't changed its, its format, considering the numbers have increased significantly"</p>
<p>Capacity</p> <p>Capacity can be another barrier to the provision of adequate support.</p>	<p>"They were not obliged to have a named governor, but it was recommended. But that that is had to go there is no capacity for that work anymore"</p>
<p>Statutory guidance</p> <p>Although the statutory guidance clearly defines elements of the support schools are required to provide, there are no reporting criteria to monitor provision.</p>	<p>No reporting criteria</p> <p>"There is no requirement to report data"</p>

3.2.4.1 Superordinate Theme 1: Lack of Scrutiny. This superordinate

theme encompasses the lack of scrutiny of obligations imposed on local authorities and schools by statutory guidance as well as the Equality Act 2010.

Table 16

Superordinate Theme 2 (E RQ1)

Theme	Subtheme and participant quotes
<p>Statutory duties</p> <p>The statutory guidance requires schools to support pupils with medical needs so that they can fully access education (Department for Education, 2015). The elements of support are clearly defined within the guidance.</p>	<p>National level</p> <p>“There is nobody policing this area at all from a government perspective or from a local perspective, really, to say this is what you must, should be doing. Ofsted do not even have a look at policies, they do not scrutinise whether or not the schools are doing what they should be doing based on statutory guidance”</p> <p>“The government does not ask for any data about children with medical conditions”</p>
	<p>At Local Authorities</p> <p>“There are some local authorities that do not take their responsibilities seriously. And as a result of that a number a large number of young people do not get supported effectively”</p>
	<p>In schools</p> <p>“Schools obviously have their statutory duty to support young people who are at their school”</p> <p>“There is no scrutiny, generally, for pupils with medical needs”</p>
	<p>Equality Act</p> <p>“There are some significant needs around the Equality Act in particular that mean that more could and should and must be done to support these young people.”</p>

Table 17

Key Findings (E RQ1)

Key findings: Thematic analysis of the views of educational professionals (RQ 1)
<ul style="list-style-type: none">• The fulfilment of key elements of the statutory guidance to support pupils with medical conditions are not scrutinised on a national level, at Local Authorities or within schools. As a result, the statutory rights of many young people with health-related needs to access education remain unmet.
<ul style="list-style-type: none">• There are many statutory duties that schools must fulfil, and they often lack the funding or the capacity to support young people with health-related needs.

3.1.5. Key Findings from the First Subsidiary Research Question

Responses to the quantitative survey as well as the qualitative interviews show that there is a great variation in schools' adherence to the statutory guidance with some schools putting relevant policies and training in place and others not following all elements of the guidance. Processes prescribed by the statutory guidance are not monitored on any level. Lack of clarity around processes and policies is particularly problematic for parents and pupils with health-related needs. Participants largely agreed on the importance of health representation in schools and its role to improve processes and transparency. Participants noted that schools have a lot of expectations placed on them and often lack adequate funding to put policies and procedures in place.

3.2 RQ2: How is the Transition and Inclusion of Young People with Health-Related Needs Managed by Schools?

3.2.1 RQ2: Descriptive Statistics

Table 18

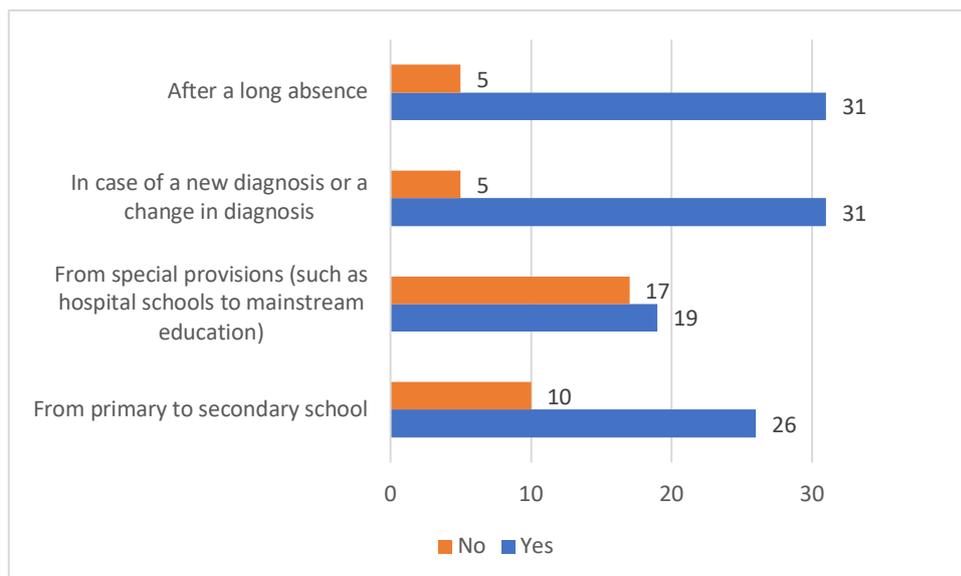
Key Findings from the Quantitative Data Analysis (RQ2)

Transitions
<ul style="list-style-type: none">• There is a plan in place to support the transition of students from primary to secondary school (72% or 26/36 participants), after a new diagnosis or a change in diagnosis (86% or 31/36 participants) or after a long absence (86% or 31/36 participants).• Fifty-three percent (19/36) of participants noted that schools have a plan for transition from a specialist provision to mainstream education (See Figure 11).• Thirty-nine percent (14/36) of participants noted that the plans for transition and reintegration are laid out in the Individual Healthcare Plans.

Figure 11

Plan in Place to Support Transition

Is there a plan in place to support transition?



Integration during absence

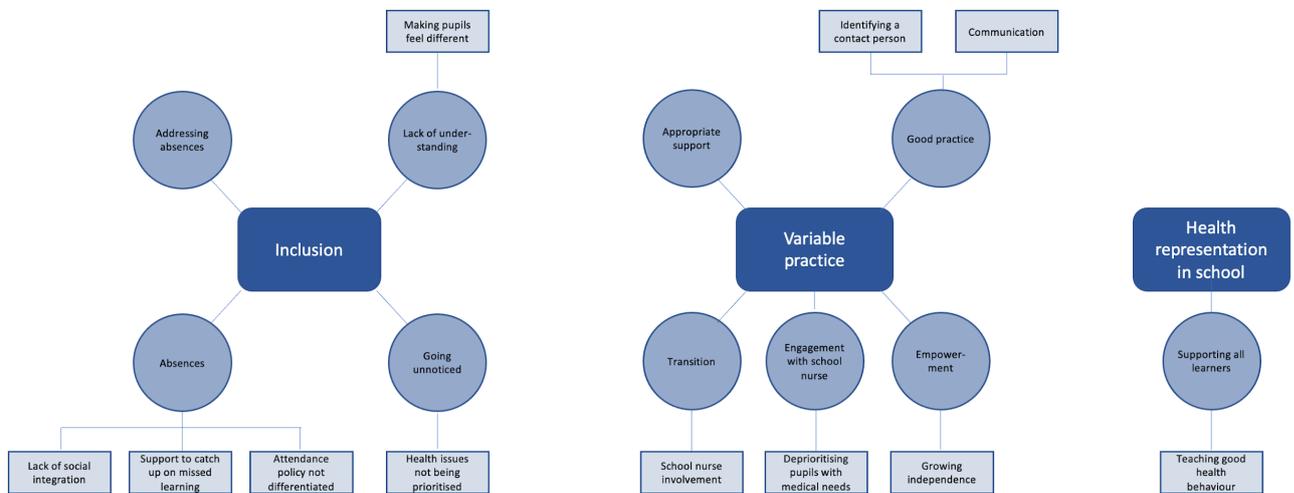
Thirty-three participants (92%) noted that pupils who cannot attend school because of a medical reason receive regular support to keep up with academic requirements. None of the participants listed any tools that schools use to ensure that pupils remain socially integrated during their medical absence.

3.2.2 RQ2: Thematic Analysis of the Views of School Nurses

Three superordinate themes were identified: Inclusion, variable practice, and health representation in schools.

Figure 12

Thematic Analysis of School Nurses' Views (RQ2)



3.3.2.1 Superordinate Theme 1: Inclusion. This superordinate theme encompasses the efforts to ensure that pupils with health-related needs have an equal access to education and opportunities.

Table 19

Superordinate Theme 1 (SN RQ2)

Theme	Subtheme and participant quotes
<p>Absences</p> <p>Some pupils can have extended absences. Others can be absent because of periods of health-related episodes, fatigue or doctor’s appointments.</p>	<p>Lack of social integration</p> <p>“Not really keeping them integrated. They do things like sending homework home and things like that (...) but in terms of socially, I do not really think they are.”</p>
	<p>Support to catch up on missed learning</p> <p>“If they are in hospital for a long time as well, schools would make sure that they are sent the same work. As far as they can. Within school they will try to get that homework and things to that child”</p>

	<p>Attendance policy not differentiated</p> <p>“Schools do not differentiate in terms of attendance for pupils with medical needs.”</p>
<p>Addressing absences</p> <p>Schools should address absences the same way they would for pupils without health-related needs. Often the absences are coded for medical reasons. However, when unpicking the reason behind the absence, it might emerge it does not warrant staying away from school.</p>	<p>“We had the best attendance, because you are teaching young people as well with minor ailments like headaches and stomach-ache. But that is not a reason to go home and miss your education!”</p>
<p>Lack of understanding</p> <p>In some schools there is a lack of understanding for the impact of feeling different on mental wellbeing.</p>	<p>Making pupils feel different</p> <p>“One school, they would make sure the child had it on them, which I used to be a bit debatable about that because I used to say is that not focusing the child from being different from other children and... but she wouldn't have the child in that school unless the child had that bum bag on them with the EpiPen in and so yeah so we do come across different practices in different schools”</p>

3.2.2.2 Superordinate Theme 2: Variable Practice. This superordinate theme summarises the lack of standardised approach to supporting pupils with health conditions.

Table 20

Superordinate Theme 2 (SN RQ2)

Theme	Subtheme and participant quotes
<p>Transition</p> <p>Four out of eight participants noted that secondary schools communicate with primary schools in order to ensure a smooth transition of pupils. This is often further improved with school nurse involvement.</p>	<p>School nurse involvement</p> <p>“Whether there was a verbal handover would be random. It would depend on the school. So, it tends to be there is a plan in place, but how robust that is , is another question so where it is known to school nurse, there'll be a good transition where it is not known, it relies on the parents and the school staff and that again, will be down to capacity.”</p>
<p>Engagement with school nurse</p> <p>There is a variation among schools in terms of their engagement with health services. Participants noted different approaches depending on the socio-economic status of the majority of pupils (with schools from deprived areas being more welcoming) as well as whether or not schools function as academies.</p>	<p>“Since the introduction of academies, and free schools that some of those are less welcoming to health services, because they do not have to. Yeah, and if it is going to interrupt the curriculum, and they do not necessarily have to be pleasant about any offer”</p> <p>De-prioritising pupils with medical needs</p> <p>“I think to be fair to schools I think the demands on them are very very high and actually you can when, when it is all about targets and results you can get away with kids who are, you can almost get a forgiveness for having children who are unwell who do not achieve. So actually, why would you put your energy into that?”</p>
<p>Good practice</p> <p>All participants noted pockets of good practice in terms of inclusion and transition of pupils with health needs.</p>	<p>Communication</p> <p>“Go through in detail with the parents and maybe the school nurse as well about, you know what, what extra support going to be needed to be in place so that when they do go in September, there is already a plan in place and everything's organised and, hopefully, less anxiety for the parent less</p>

	<p>anxiety for the child.”</p> <p>Identifying a contact person</p> <p>“Then we do transition training and everything before the child goes into, into secondary school, so we will identify the person who will be responsible for at school, so the teacher or the SENCO or the teaching assistant or receptionist, and we will get together, and we will do the training before the child goes into school.”</p>
<p>Appropriate support</p> <p>Schools that engage with processes and guidance are able to support pupils with health needs appropriately.</p>	<p>“We have mechanisms and processes in schools that, you know, have their eye on the ball.”</p>
<p>Empowerment</p> <p>Participants noted that a key aspect of their role is to empower young people to manage their condition independently and go on to live an independent life.</p>	<p>Growing independence</p> <p>“What we hope is that we're skilling, upskilling this young person, so they can become independent. Okay, and to self-manage.”</p>

3.2.2.3 Superordinate Theme 3: Health Representation in Schools. This superordinate theme highlights the importance of having health representation in schools noted by all participants. It is not only beneficial to pupils with health needs but to the entire student population as well as all school staff. A school nurse on site increases the likelihood of the support and progress of pupils with health needs being seen as a leadership priority.

Table 21

Superordinate Theme 3 (SN RQ2)

Theme	Subtheme and participant quotes
<p>Supporting all learners</p> <p>All learners benefit from available health representation in schools. Recent COVID</p>	<p>“I have tried my damndest to try and get people to listen that I truly believe that having a health care professional based on site is paramount. Not just to our children who have</p>

<p>related guidance highlights the importance of good health behaviour for instance for hygiene or coughing.</p>	<p>additional health needs. But for well children to teach good health behaviour. So, I call it health literacy and I am a great believer that if we want to grow, young children into healthy contributing adult society, then we need to teach first”</p> <p>Teaching good health behaviour</p> <p>“COVID being the golden opportunities and children, you know, need the same health teaching as they do education to learn the math and to do their English”</p>
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Table 22

Key Findings (SN RQ2)

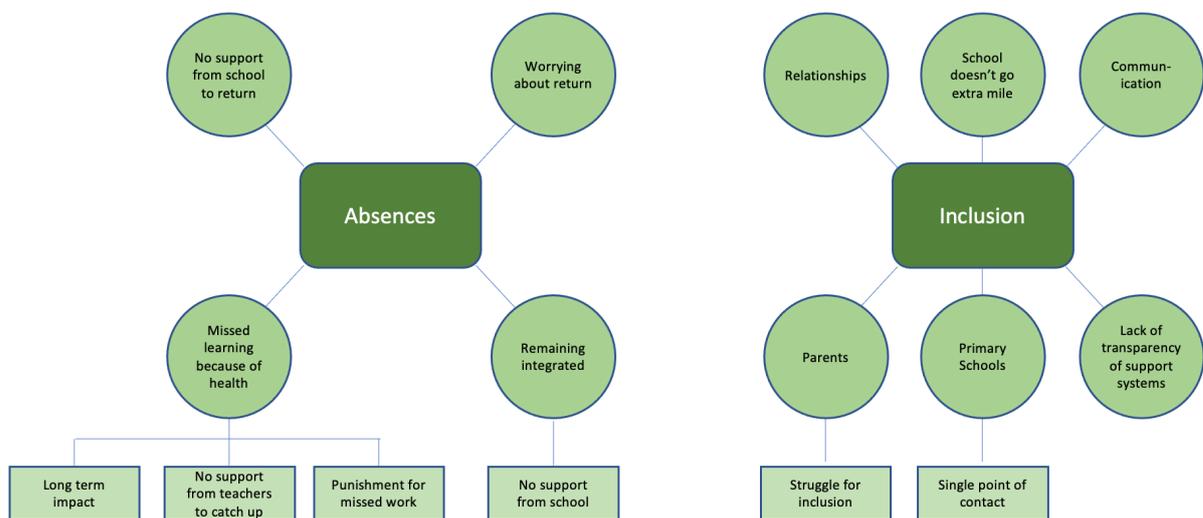
<p>Key findings: Thematic analysis of school nurses’ views (RQ2)</p>
<ul style="list-style-type: none"> ● Support is more likely to be offered for learning than for social inclusion during absences. ● There is a lot of variation in approaches to the provision of support to pupils with health-related needs in different schools with examples of good practice. ● Health representation in schools is key to the support of all learners.

3.2.3 RQ2: Thematic Analysis of the Views of Pupils and Parents

Two superordinate themes were identified: Absences and inclusion.

Figure 13

Thematic Analysis of Parents' and Pupils' Views (RQ2)



3.2.3.1 Superordinate Theme 1: Absences. This superordinate theme summarises the views of parents and pupils regarding absences. There are many concerns linked to absences, such as missed learning, missed opportunities, worries linked to remaining integrated and to returning to school after a period of absence.

Table 23

Superordinate Theme 1 (PP RQ2)

Theme	Subtheme and participant quotes
<p>Absences</p> <p>No participants felt that they had received adequate support during absences either for academic or for social integration. Several participants reported that they had received punishments for missed work during absences without appropriate support to catch up.</p>	<p>Missed learning because of health</p> <p>"She would put her hand up in classes to say she does not understand because she was not there last week. And she has been told to ask the person next to her. And she, you know, she has been told, or she has been told the other students will help her or show her what she has missed. Whereas I have challenged them at parents evening, I said, you know, that she is asking for help for a reason. Yeah, they are not great at helping her to catch up. No."</p> <p><i>Subthemes:</i></p> <p>Long term impact</p> <p>"She is quite academically able, the CF I suppose has impacted because of her absences. And, that kind of the adequate support to kind of fill in those gaps was not there. meant that kind of instead of doing something about it the school, sort of dropped her off a few GCSEs so that she took less GCSE than her peers"</p> <p>No support from teachers to catch up</p> <p>"She is trying to approach people, but it is like they are not interested. And (...) they haven't got the time to sit down and talk to M"</p> <p>Punishment for missed work</p> <p>"She returned to school and she got detentions for the work not being done"</p> <p>"We asked the school for like work from every lesson I would miss out on. But not every teacher gave me work. But then I would like get punishments for missing out"</p>
<p>Remaining integrated</p> <p>Participants noted that schools made minimal effort to ensure that students stay integrated</p>	<p>No support from school</p> <p>"School, from my perspective had the attitude of, I was being too pushy on M. And that kind,</p>

in the school community despite their absences.	'oh let her, leave her alone, she is you know, she is, she is ill, she is you know, she is, she is not gonna live forever, so let her be' ummm was the kind of like the overriding message that I kind of felt that they were, they were kind of putting out there really"
Worrying about return Participants noted the anxiety that can be linked to returning to school after extended periods of absence.	"She then decided to not go into school because of everything that has been going on. Yeah, I was having wrestles with her all morning trying to get her there and tried everything"
No support from school to return Participants noted the lack of support they were receiving to ensure a smooth transition back into school after periods of absence.	"Nothing happened within that whole system of trying to support, M or me and get helping M at all"

3.2.3.2 Superordinate Theme 2: Inclusion. This superordinate theme encompasses the efforts made to include pupils academically as well as socially, the importance of relationships and the barriers to inclusion.

Table 24

Superordinate Theme 2 (PP RQ2)

Theme	Subtheme and participant quotes
Primary schools Participants noted that inclusion worked better in primary school where communication flow was ensured by a single point of contact within the school.	Single point of contact "In primary school, you are, you have got a kind of a single point of contact"
Communication Participants found that there was communication between primary and secondary schools at the time of transition, but families were often not part of that communication.	"I do not know what conversations have gone on between the primary school and secondary school, and I was not some kind of party to any of those"
Schools do not go the extra mile	"I did contact school and they, I am not going

Participants noted that schools do not go out of their way to ensure inclusion and are reluctant to fulfil requests made by parents. This can lead to pupils missing out.	to say they were reluctant, but it was a hassle for them to give me the weekly menu with the carb values in. And, you know, you have to ask, because the menu changes. And it just seemed a lot of trouble."
Lack of transparency of support systems Participants noted the lack of clarity around the support schools offer. This refers to the person of contact, the processes in place as well as policies.	"I did ask the school, not that long ago I said do you know who is in charge of your inclusion? And they say, inclusion is everybody's job here."
Relationships Participants reported positively about individual teachers with whom they were able to form a trusting relationship.	"my biology teacher who I like a lot more than the rest of the teachers, because after lesson and things he will stay and talk me through the stuff that I missed exactly as you would in the lesson for everyone else so it is not patronising" "That relational thing that makes things happen."
Parents Parents reported about the difficult situation they find themselves in when trying to ensure their children access education while meeting their health-related needs.	"the people who have got the most to do to get through their daily lives, let's just chuck some more at them. To make it even more tricky" Struggle for inclusion "I have got thousands of emails where I have been trying to email the school to keep them in the loop. I think it was just to kind of all well, M's mum is taking care of it so we will just leave them to it. You know that is kind of the kind of felt the attitude that it was. It is such a really bizarre thing because it is a really high achieving school, and it is one of the top state schools in the country. But just, there is just this glaring gap in some kind of pastoral inclusion type care."

Table 25

Key Findings (PP RQ2)

Key findings: Thematic analysis of the views of parents and pupils (RQ2)

- Pupils with health-related needs miss out on learning because of absences. Often there is no support either to keep up or to catch up.

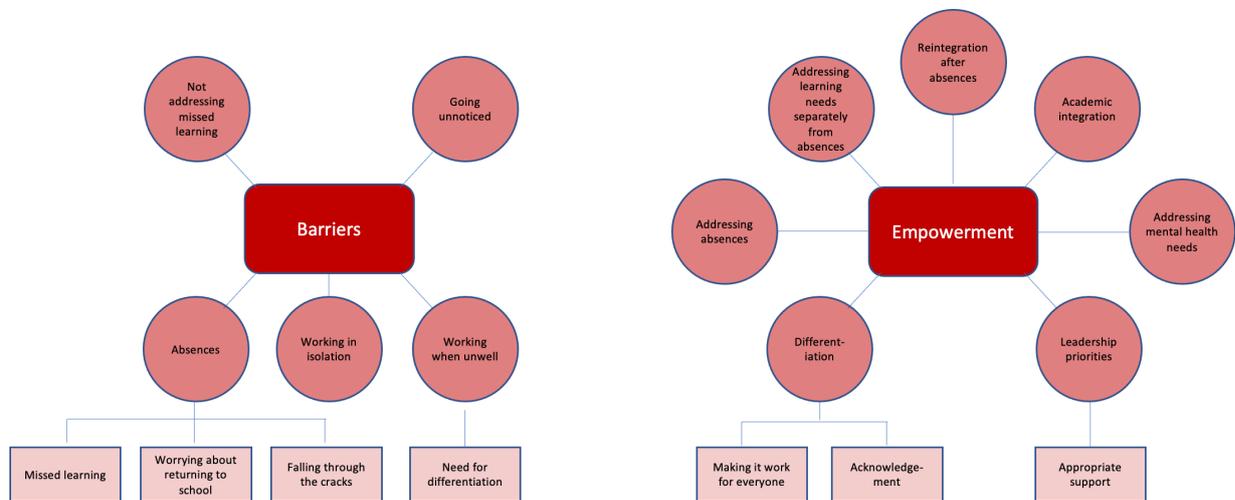
- Relationships with a person of trust in school can make a difference in terms of the wellbeing as well as the progress of the pupils.
- Parents who struggle to ensure their children are academically and socially integrated are often met with reluctance and lack of transparency from schools.

3.2.4 RQ2: Thematic Analysis of the Views of Educational Professionals

Two superordinate themes were identified: Barriers and empowerment.

Figure 14

Thematic Analysis of the Views of Educational Professionals (RQ2)



3.2.4.1 Superordinate Theme 1: Barriers. This superordinate theme

encompasses the difficulties identified by educational professionals that impact on the inclusion and support of pupils with health-related needs.

Table 26

Superordinate Theme 1 (E RQ2)

Theme	Subtheme and participant quotes
<p>Absences</p> <p>Absences are considered a key barrier to the progress and outcomes of pupils with medical needs.</p>	<p>"One of the big barriers is obviously attendance in school"</p> <p>Missed learning</p> <p>"They are having prolonged absences from school, and not accessing the lesson"</p> <p>Worrying about returning to school</p> <p>"They get very anxious about that return to school"</p> <p>Falling through the cracks</p> <p>"Generally, the children with health needs, they vote with their feet, they start to disappear, they start not attending"</p>
<p>Going unnoticed</p> <p>Participants noted that not all pupils feel empowered to request support.</p>	<p>"They are keeping their heads down in the classroom and they all do... they do not want to put their hand up asking for help. Yeah, so their needs are not being met."</p>
<p>Not addressing missed learning</p> <p>Participants reported that missed learning often does not get addressed by schools.</p>	<p>"They are not creating a problem for the school; they are impacting on themselves and that is the difficulty as well because it is not a problem for the school because our pupils are not there creating the problem."</p>
<p>Working in isolation</p> <p>Participants noted that accessing learning in isolation without interaction with the teacher does not lead to the same outcomes as classroom learning.</p>	<p>"The children are doing their work at home. But they are not, they are not having that interaction with the teacher or with other children in the class, so they are not, they are missing out..."</p>
<p>Working when unwell</p>	<p>Need for differentiation</p>

Participants noted that pupils who are absent for medical reasons can be too unwell to learn. If work sent home is not differentiated, they might struggle to access it the same way as their peers.	“They are not in a condition to do the work, because they are recovering from surgery, they are receiving treatment for the illness or their condition means that they just, they are not able to access the work at home”
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3.2.4.2 Superordinate Theme 2: Empowerment. This superordinate theme summarises strategies schools can embrace to ensure equitable access to education.

Table 27

Superordinate Theme 2 (E RQ2)

Theme	Subtheme and participant quotes
<p>Addressing absences</p> <p>Participants noted the importance of challenging absences and trying to unpick any underlying issues.</p>	<p>“Make sure that that is never an excuse, because sometimes we see absence, increasing, and you have diabetes, but it is not a reason for not being in school because if you are managing your condition, well, there is no reason for that absence.”</p> <p>“There is not enough challenge sometimes, there is an acceptance that, well, they are not doing so well in that subject because of their health condition,”</p>
<p>Addressing learning needs separately from absences</p> <p>Participants noted the importance of separating learning needs from absences. It requires a coordinated approach from different professionals.</p>	<p>“The school SENCO who would have an understanding of learning needs, and differentiation needs and the curriculum how that could be adjusted, and sometimes if it is if a young person's absence is actually picked up by the attendance team first rather than the SENCO, they might not be recognizing the learning needs attached to the absence, as much as. So, I think seeing attendance separate to learning in a school is where some gaps are created”</p>
<p>Reintegration after absences</p> <p>Participants reported the difficulties associated with return to school after prolonged periods of absences. These can be linked with learning as well as mental wellbeing. Reintegration requires targeted</p>	<p>“It is always been the most important part of the work that we undertake. Ours is to reintegrate young people back into their communities”</p>

support.	
<p>Academic integration</p> <p>Participants discussed the statutory obligation of schools to ensure that all pupils can access education.</p>	<p>“That responsibility in terms of statutory guidance is always the school's responsibility. They have to ensure that that young person is receiving a good education”</p>
<p>Differentiation</p> <p>The barriers that young people with health-related needs encounter, such as working in isolation, missing learning etc. require differentiation. The need for differentiation in most schools needs to be recognised and the planning should be part of a coordinated effort to support pupils.</p>	<p>Making it work for everyone</p> <p>“What kind of support, and it is interesting, the diabetes nurse thinks they need the child thinks they need, and the parent thinks they need”</p> <p>Acknowledgement</p> <p>“Every secondary school, certainly the largest secondary schools are going to have a number of young people with, with severe medical conditions that require some quite intensive support.”</p>
<p>Addressing mental health needs</p> <p>Participants discussed the importance of addressing the mental wellbeing of pupils during their absence and upon their return. Some participants noted the similarities to the problems encountered by all pupils during and after lockdown.</p>	<p>“They were really really subdued, and that you know, they would, they were very quiet, very wary of what was going on in the school, didn't talk to each other, let alone engage very much with the staff that were there. Yeah, and that, that is kind of a testament to the emotional challenges that young people are facing at the moment.”</p>
<p>Leadership priorities</p> <p>Participants discussed the differences between the attitudes of schools in terms of offering support to pupils with health-related needs. Whether or not appropriate support can be provided often depends on leadership priorities within the school.</p>	<p>“We work with some that are exceptional. We work with others that are good and willing, but do not have the processes in place and we work with others that actually are really quite negative as well.”</p> <p>Appropriate support</p> <p>“It is just reassurance that we've got you, we know what we're doing, this is what we can do. And we're with you for the journey, really, that is our plan. So, we work with them to really develop that.”</p>

Table 28

Key Findings (E RQ2)

Key findings: Thematic analysis of the views of educational professionals (RQ2)

- Some of the barriers encountered by pupils include prolonged absences, missed learning, working in isolation and working when unwell without receiving a differentiated workload.
- Schools need to acknowledge the necessity of a differentiated curriculum for students with prolonged absences and address learning needs separately from missed learning. The differentiation needs to be a coordinated effort of various professionals interacting with the pupil.
- More support needs to be provided for return after absences and to empower students to voice their needs.

3.2.5 Key Findings from the Second Subsidiary Research Question

Key findings from the quantitative and qualitative data analysis show that the majority of schools have a transition plan in place from primary to secondary schools, but they do not have similar plans for return from specialised settings or after a long absence. Although there is a lot of variation in terms of support provided to pupils during absences, typically, support would be limited to academic provision, rather than social integration. Academic work shared with students on long-term absences is commonly not differentiated. Parents of pupils with health-related needs reported of the difficulties that they encounter when trying to access support from school. They noted that there is little support available for reintegration after a prolonged absence and their children often lack the empowerment to voice their needs.

3.3 RQ3: How Can the Awareness of Educators Be Raised Around the Impact of Health-Related Needs on Young People’s Educational and Social-Emotional Wellbeing?

3.3.1 RQ3: Descriptive Statistics

Table 29

Key Findings from the Quantitative Data Analysis (RQ3)

Monitoring
<ul style="list-style-type: none">• Twenty five participants (70%) noted that students, who manage their condition independently, are monitored in school.• Thirteen participants (27%) reported that school staff (10) and pupils (3) are fully aware of emergency procedures (See Figure 15).
Impact on learning
<ul style="list-style-type: none">• None of the participants reported that school staff are fully aware of the impact of different medical conditions on a pupil’s ability to learn (See Figure 16).• Twenty-one participants (58%) noted that there are no procedures in place to make school staff aware of missed learning because of medical issues or tiredness.

Figure 15

Awareness of Medical Emergency Procedures

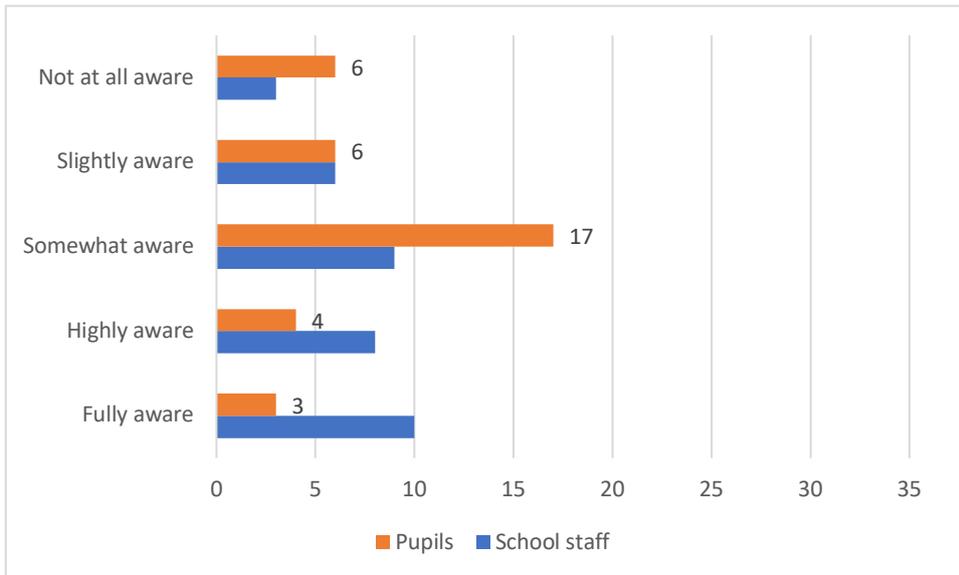
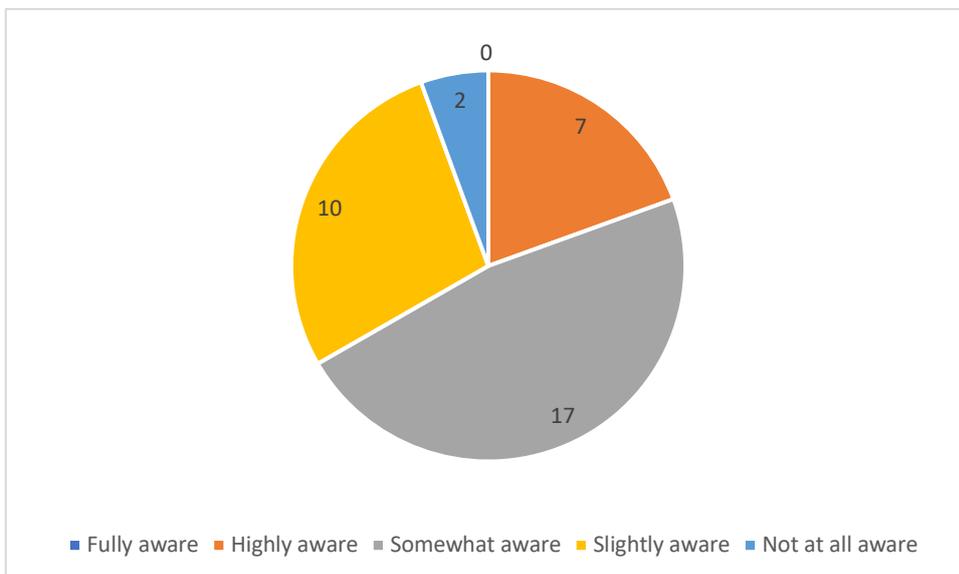


Figure 16

Awareness of Impact of Medical Conditions on Learning Among School Staff

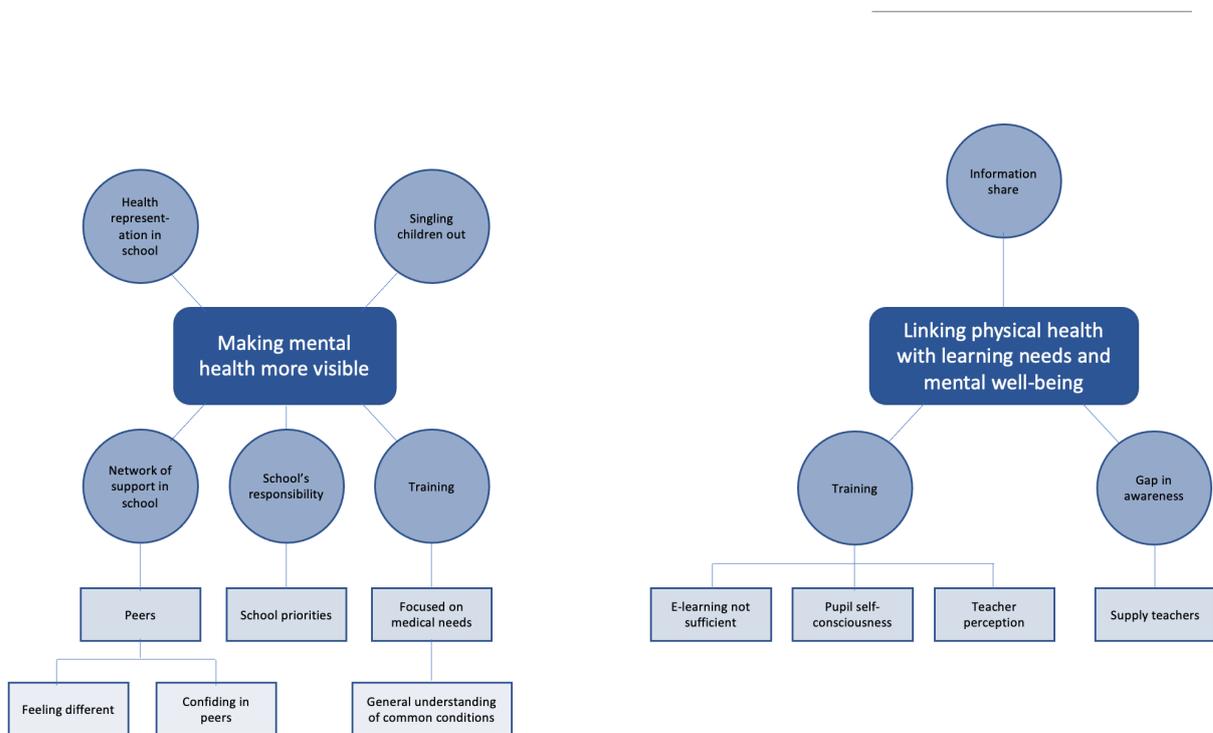


3.3.2 RQ3: Thematic Analysis of the Views of School Nurses

Two superordinate themes were identified: Making mental health more visible and linking physical needs with learning needs and mental wellbeing.

Figure 17

Thematic Analysis of the Views of School Nurses (RQ3)



4.3.2.1 Superordinate Theme 1: Making Mental Health More Visible. This superordinate theme summarises ways in which mental health needs in schools can gain a similar level of acknowledgement as physical needs.

Table 30

Superordinate Theme 1 (SN RQ3)

Theme	Subtheme and participant quotes
<p>Network of support in school</p> <p>Participants noted the necessity of a coordinated network to provide appropriate support in schools. Harnessing peer power and encouraging young people to confide in their peers was considered a priority. At the same time participants acknowledged that not all young people are comfortable sharing with their peers.</p>	<p>Peers</p> <p>“We do provide training to young people and their peers”</p> <p>Feeling different</p> <p>“Things you can’t do but your friends can do and not being quite the same way.”</p> <p>Confiding in peers</p> <p>“Being open and honest with the friends because in any emergency the closest people to them are going to be their friends. Yes, in any time spare of lessons and things like that. So I would always encourage that”</p>
<p>Health representation in school</p> <p>The importance of health representation in schools in their capacity to create awareness for mental health was highlighted.</p>	<p>“There is room, always to improve, I would say that I am very confident that due to the health roles in our school we do and are supportive.”</p>
<p>Training</p> <p>Issues around capacity and the availability of school staff has led to training being limited to awareness raising around common conditions with a focus on medical needs. Impact on learning and mental wellbeing is not regularly discussed.</p>	<p>Focused on medical needs</p> <p>“Generally, I do not think it is given second thought, to be honest”</p> <p>General understanding of common conditions</p> <p>I think it is that they feel that they can cope with it so we do not really get that many questions about things like asthma, I think it is very common, and there is a sort of sense of security around, understanding the condition.</p>
<p>School’s responsibility</p>	<p>“I do think they have a lot of responsibility</p>

It was acknowledged that schools have a lot of responsibilities and not all schools prioritise mental or physical health over academic progress.	schools now, I really do” School priorities “I do think it is a struggle with schools”
Singling children out Participants noted examples of poor practice, such as having the photos of pupils with health-related needs up on walls. One participant called this practice “the wall of shame”.	“I have seen poor practice around that, plastered all over the schools for everybody to see.”

3.3.2.2 Superordinate Theme 2: Linking Physical Health with Learning

Needs and Mental Wellbeing. This superordinate theme encompasses the impact physical needs make on learning and mental wellbeing.

Table 31

Superordinate Theme 2 (SN RQ3)

Theme	Subtheme and participant quotes
Information share Participants discussed how information can be best shared in order to ensure a general awareness.	“There is a very good point and maybe you have just got something I could do, maybe contact that particular teacher in that lesson and say, you know, or in the next lesson and say, you know, this young person has had a hypo today which is really helpful.”
Gap in awareness Participants noted the gap in awareness linked to teacher fluctuation as well as the role of supply teachers.	Supply teachers “No, they are not present, and they are not trained”
Training Training was highlighted as an essential tool for awareness raising. Participants discussed that teachers appreciate training but, in many schools,, it is only provided in the form of e-learning that does not suffice. Participants also noted that adolescents can be reluctant to participate in training to discuss their needs.	Teacher perception “I think training is definitely, you know, the biggest thing. Because usually teachers are very grateful. At the end of the training, and they do say actually you know I was not aware, and you have just opened my eyes to it.” Pupil self-consciousness

	<p>“With secondary schools. I do not, I would rate that quite low actually, possibly, and from experience of, even though you are involved in say residential with secondary schools, and you try, you do not want them to be labelled or anything like that, especially because they do become very self-conscious.”</p> <p>E-learning not sufficient</p> <p>“A lot of staff does online training, e-learning and it is not covered enough”</p>
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Table 32

Key Findings (SN RQ3)

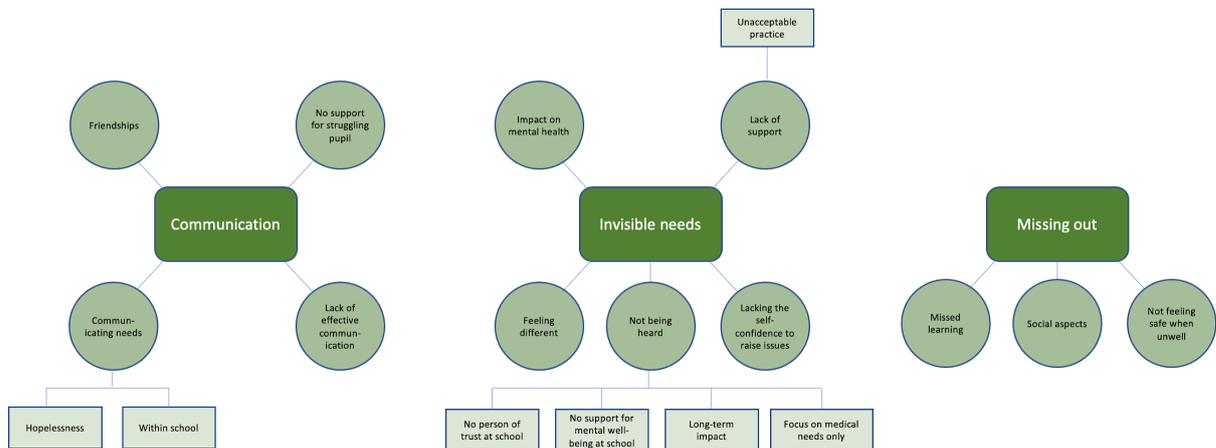
<p>Key findings: Thematic analysis of school nurses’ views (RQ3)</p>
<ul style="list-style-type: none"> ● It is essential to create a network of support in schools that includes different professionals from health and education as well as peers. ● Training is focused mostly on medical needs and does not discuss their impact on learning or mental health. In many schools, it is only provided in e-learning format and does not take teacher fluctuation or supply teachers into account.

3.3.3 RQ3: Thematic Analysis of the Views of Pupils and Parents

Three superordinate themes were identified: Communication, invisible needs and missing out.

Figure 18

Thematic Analysis of the Views of Pupils and Parents (RQ3)



3.3.3.1 Superordinate Theme 1: Communication. This superordinate theme encompasses the importance of information share as well as some of the barriers participants encountered when they tried to discuss their needs.

Table 33

Superordinate Theme 1 (PP RQ3)

Theme	Subtheme and participant quotes
<p>Communicating needs</p> <p>Participants reported that they often hit a wall when trying to communicate needs and access support within schools. It can be linked to teacher fluctuation.</p>	<p>Hopelessness</p> <p>“Well, we told them about it. I didn't really..... mean anything.”</p> <p>“I feel like we told them, but they didn't really take much interest in it, so they didn't really listen to us”</p> <p>Within school</p> <p>“There is an awful lot of teachers and staff that have left, new ones that have come in. So the people that did know about M in year 7 and 8 I have kind of moved on now”</p>
<p>Lack of effective communication</p> <p>Participants noted the lack of transparency around communication systems and people in charge within schools.</p>	<p>“There just seems a bit a lack of communication because we do not actually know who to address with her problems”</p>
<p>No support for struggling pupils</p> <p>Linked with the hopelessness mentioned above, several participants have expressed their exasperation over trying to get appropriate support.</p>	<p>“They do need to differentiate the work for him and the homework. And that is that. That does not happen regularly. Yeah, and it is not consistent. Erika, we had such a rough ride, getting the school to do anything.”</p> <p>“I think I am going to struggle this year, because let's say I am gonna be in pain again. I will be tired, and I have got to do a lot of extra work and things. So, I think I am going to struggle.”</p>
<p>Friendships</p> <p>Several participants highlighted the positive effect of friendships and awareness among their friends.</p>	<p>“It is just little things like if I am in school and like I need to cough, and people are like making a thing of it they will like tell people to just leave it and stuff. Or, like, if the teachers are, like, not getting that I need to leave to cough, they will, like, help me.”</p>
<p>Invisible needs</p> <p>The importance of highlighting invisible needs was discussed.</p>	<p>“It was just left to me to do a much more detailed plan for things like when she has IV antibiotics at home, it can, she can have a bad night's sleep. So therefore, she is not going to be the greatest at school, she can have headaches. It is probably a lot of little</p>

	things, although there is nothing medical they have to do for her.”
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3.3.3.2 Superordinate Theme 2: Invisible Needs. This superordinate theme encompasses the participants’ experiences around the impact of physical needs.

Table 34

Superordinate Theme 2 (PP RQ3)

Theme	Subtheme and participant quotes
<p>Lack of support</p> <p>There is a lack of support for needs that are not immediately noticeable. In some cases, it can lead to unacceptable practice, for instance, teachers not believing their students’ account.</p>	<p>Unacceptable practice</p> <p>“My teacher accused me saying that I do not even have CF and I am lying about it and stuff like that”</p>
<p>Impact on mental health</p> <p>Participants noted that the lack of acknowledgment of their needs and the lack of support can impact their mental wellbeing.</p>	<p>"Imagine the psychological impact on somebody who's always had a brilliant school record, is now fighting with a new medical condition, is sick in hospital and sees that he has got the first negative behaviour point of his whole life. And it is totally not in his control"</p>
<p>Not being heard</p> <p>Participants reported that their voices are not heard in schools, and it can have a long-term impact on wellbeing. This can be because of a lack of a person of trust or lack of support for needs that are not physical. Participants feel that it is easier to get support for more widely understood medical conditions.</p>	<p>No person of trust at school</p> <p>“I would have liked to talk someone, but I do not think there is anyone”</p> <p>No support for mental wellbeing at school</p> <p>“I would tell them that I am struggling, and they tell me that they just sort of, they do not listen either. It is like you tell them how you are feeling, and they are just not really helpful.”</p> <p>Long-term impact</p> <p>“When I look back on it now, I feel really angry about it because.... had I known, the kind of, you know, the massive effect, it was going to have on her”</p>

	<p>Focus on medical needs only</p> <p>“I think there is something about it being, I do not know, more acceptable, tangible, you know, knowledgeable and you know other people are touched by it. There is a kind of like an immediate life or death thing. That would kind of make their response different. Yeah, you know, I you know I think you know if. Yeah. Yeah. I can't explain it. It is still a mystery to me but...”</p>
<p>Feeling different</p> <p>Participants reported that young people sometimes struggle to use the strategies offered to them because they do not want to feel different from their peers.</p>	<p>“They did give me a queue jump card. But again, if you just jumped the queue, you get people shouting at you. I do not really like to see that. And then I have scenes where again, they say I can, when it is cold I get to wear my coat. Again, I am trying not to do that because it makes the whole class just go, because like, why is she wearing it?”</p>
<p>Lacking the self-confidence to raise awareness</p> <p>Participants noted that young people can lack the self-confidence to voice their needs.</p>	<p>“I do not enjoy drawing attention to myself”</p> <p>“She has, she has not really got the confidence to do that. I do not think”</p>

3.4.3.3 Superordinate Theme 3: Missing Out. This superordinate theme encompasses different opportunities that the participants felt they were missing out on. These include learning and social opportunities as well as the feeling of safety when they are unwell.

Table 35

Superordinate Theme 3 (PP RQ3)

Theme	Subtheme and participant quotes
<p>Missed learning</p> <p>Participants noted that they miss a lot of learning partially because of the lack of procedures in place within schools that would enable staff to provide support without asking the parent to pick their children up.</p>	<p>“A lot of missed learning”</p> <p>“They will phone me, and I will go and collect him”</p>

<p>Social aspects</p> <p>Participants highlighted that they miss out on social opportunities because of their health-related needs.</p>	<p>"CF would have undoubtedly impacted in terms of... she wouldn't have been able to do as much social engagements, through being unwell or in hospital"</p>
<p>Not feeling safe when unwell</p> <p>Participants noted that they often do not feel safe in school because of the lack of procedures in place.</p>	<p>"I have fallen asleep on that bed before and have people come in and out, whilst I am in there. Oh yeah. So, I was a lot in there because I have broken things, I have got things cut. And I have no idea... If any of them... Why, I have no idea what any of them did in the room at all."</p>

Table 36

Key Findings (E RQ3)

Key findings: Thematic analysis of the views of pupils and parents (RQ3)

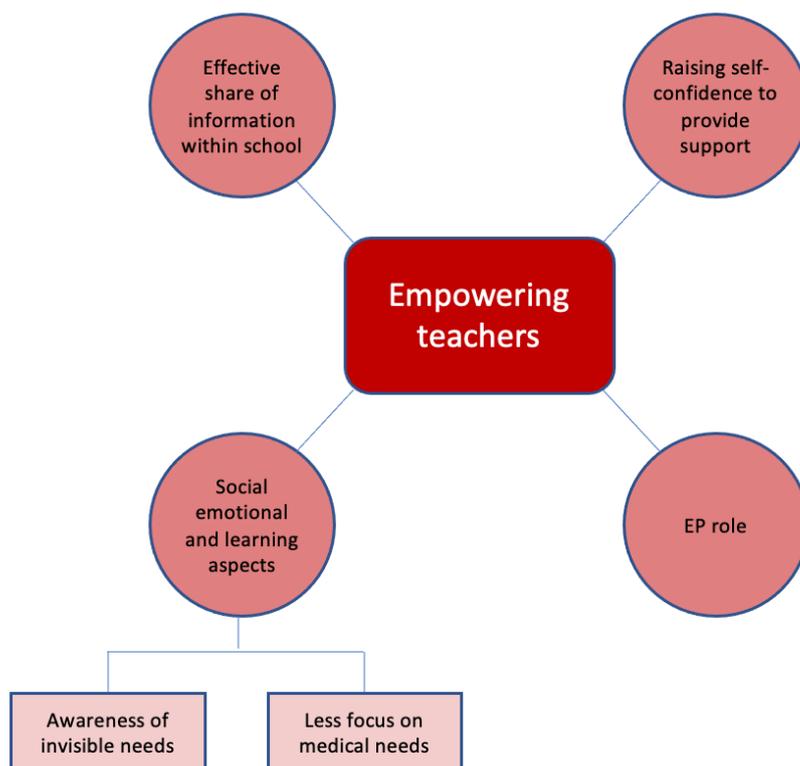
- Training and support are often focused on physical needs and can be lacking for other, less visible needs, such as needs associated with mental health and learning.
- Young people feel that their voice remains unheard when requesting support. It can discourage further disclosure and can lead to a feeling of hopelessness.
- Young people miss out on learning and social opportunities because of their health-related needs.

3.3.4 RQ3: Thematic Analysis of the Views of Educational Professionals

There was one superordinate theme identified: Empowering teachers.

Figure 19

Thematic Analysis of the Views of Educational Professionals (RQ3)



3.4.4.1 Superordinate Theme 1: Empowering Teachers. Empowering

teachers to have the self-confidence to provide support for pupils with health-related needs was considered key.

Table 37

Superordinate theme 1 (E RQ3)

Theme	Subtheme and participant quotes
<p>Raising self-confidence to provide support</p> <p>Participants noted that teaching staff's ability to provide support should be increased.</p>	<p>"It could be training to staff to make sure that they feel comfortable in supporting that young person"</p>
<p>Effective share of information within school</p> <p>Teachers' confidence to provide support can be increased through effective flow of easily accessible information.</p>	<p>"So, it would be class charts and provision maps as a way of making sure people can easily find information when they are faced with a student that they do not know."</p>
<p>Social-emotional and learning aspects</p> <p>Participants highlighted the importance of a successful information flow, so that individual teachers interacting with pupils with medical needs should be made aware of learning and social emotional needs. The focus should be shifted from the medical model to specific learning and SEMH needs of the pupils and appropriate support should be tailored.</p>	<p>Awareness of invisible needs</p> <p>"I have done so much work with pastoral members of staff in school, like Heads of Year and SENCOs, but we do not actually meet the math teacher who the child is terrified to go into the classroom with until much further down the line, and that we need to change that a little bit and then get the class teacher involved much earlier on."</p> <p>Less focus on medical needs</p> <p>"Make it objective that it is actually a valid special educational need, and create a support for them"</p>
<p>EP role</p> <p>The systemic role of Educational Psychologists in tailoring support and empowering staff to provide it was highlighted.</p>	<p>"Support our staff to think more carefully about that more deeply about how to overcome those barriers to learning"</p> <p>"She supports the staff as much as she does the young people directly actually within that teamwork"</p>

Table 38

Key findings (E RQ3)

Key findings: Thematic analysis of the views of educational professionals (RQ3)
<ul style="list-style-type: none">• Teachers need to be empowered through training, information sharing and systemic work of educational psychologists, so that they can offer appropriate support to pupils with health-related needs.
<ul style="list-style-type: none">• The focus needs to shift from medical needs to specific learning and social, emotional and mental needs and strategies should be designed accordingly.

3.3.5 Key Findings from the Third Subsidiary Research Question

The analysis of the survey responses and the semi-structured interviews show that there are significant gaps in teachers' understanding of the impact that health-related needs can have on learning and on social, emotional and mental health needs. Teacher training is often focused on physical health needs only. Young people feel that they are missing out on various opportunities because of their health, and they often feel discouraged to disclose their needs and request support. This can lead to feelings of hopelessness.

3.4 RQ4: How might Different Agencies Interacting with a Young Person, such as Schools and Health Services as well as Parents/Carers, Work Together Better?

3.4.1 RQ4: Descriptive Statistics

Table 39

Key Findings from the Quantitative Data Analysis (RQ4)

Collaboration
<ul style="list-style-type: none"> ● Twenty-seven participants (75%) reported that an initial meeting takes place between schools, parents/carers, healthcare professionals and other agencies to identify needs and make necessary adjustments. ● Twenty-eight participants (78%) reported that Individual Healthcare Plans identify collaborative working arrangements for all involved parties, including pupils, parents/carers, school and healthcare services. ● Sixty-four percent of parents (23) and 31% of pupils (11) are always involved in the production of the Individual Healthcare Plan (See Figure 20).
Risk assessment
<ul style="list-style-type: none"> ● Eleven participants (31%) reported that they always involve pupils, parents or healthcare professionals in the production of a risk assessment for school trips and other extracurricular activities (see Figure 21).

Figure 20

Involvement in the Production of Individual Healthcare Plans

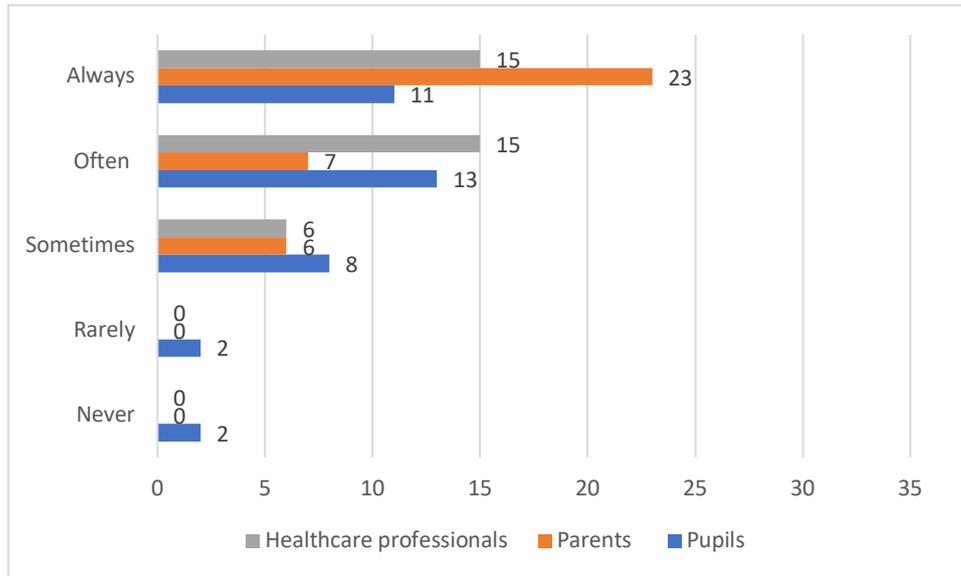
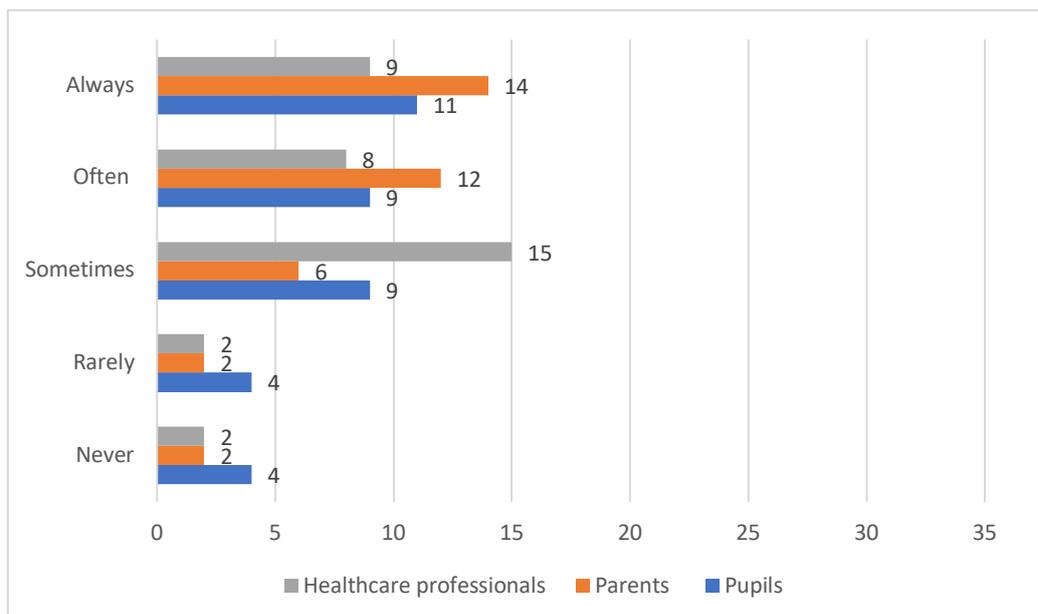


Figure 21

Risk Assessment

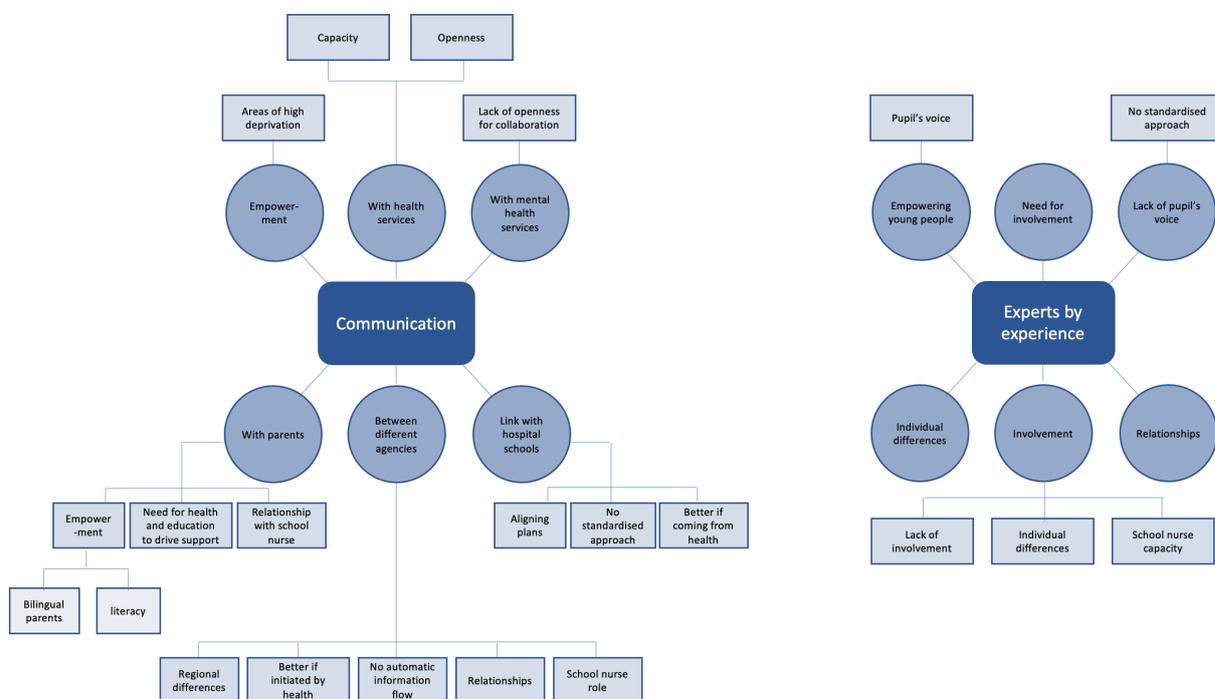


3.4.2 RQ4: Thematic Analysis of the Views of School Nurses

Two superordinate themes were identified: Communication and experts by experience. The term experts by experience refers to parents/carers and pupils, who have gained expertise in various aspects of health management through their experience of living with a health condition.

Figure 22

Thematic Analysis of the Views of School Nurses (RQ4)



3.4.2.1: Superordinate Theme 1: Communication. This superordinate theme encompasses the factors that can influence communication between different services as well as the barriers that might prevent successful communication.

Table 40

Superordinate Theme 1 (SN RQ4)

Theme	Subtheme and participant quotes
<p>With health services</p> <p>Participants noted that capacity of health services as well as their lack of openness for collaboration can pose barriers.</p>	<p>Capacity</p> <p>“I do not think health professionals are much involved these days. They used to be. I would say, I do not know maybe 20-25%, maybe. But it is less than it used to be.”</p> <p>Openness</p> <p>“I have actually had GPs write letters to me personally and saying, stop giving me extra work to do (laughs). So that's, yeah, that is a barrier. That is only happened a couple of times but you know”</p>
<p>With mental health services</p> <p>Participants noted the difficulties around accessing mental health services.</p>	<p>Lack of openness for collaboration</p> <p>“I have been kind of involved with that because it is a physical health problem as well. But the school and I have both tried to contact Healthy Young Minds to get, to get more support for emotional, and we're just getting knocked back.”</p>
<p>With parents</p> <p>Participants gave account of the different factors that can influence communication with the parents and ultimately the level of support young people can access. Some of these factors encompass the empowerment, literacy and language skills of the parents, their relationship with the school nurse and the need for education and health services to drive support particularly for those parents, who may be less empowered.</p>	<p>Empowerment</p> <p>“And, you know, you will get very empowered parents and very empowered young people, and very driven people that will make sure it is in the plan.”</p> <p>Bilingual parents</p> <p>“A recent case with bilingual parents and anaphylactic child. School made no effort to reach out.”</p> <p>Literacy</p>

	<p>“I think that would be very much down to the health professional facilitating that and down to the literacy, the confidence, the vocabulary and the understanding of the parent and the young person.”</p> <p>Need for health and education to drive support</p> <p>“in your areas of high illiteracy (...) I would suggest that our children in the underserved populations, probably wouldn't be as easy for the parents to drive that, so there'll be a need for help on the health side, as well as the education side.”</p> <p>Relationship with school nurse</p> <p>“It is not until the parents sort of contact me and say for example, you know that their child is struggling at school or whatever, from, you know, and I have known them for some years like they have come through primary school, and you know they have transitioned into secondary school and parents have already got my number and they just call and say that they have got issues.”</p>
<p>Between different agencies</p> <p>Communication between different agencies can be improved through existing relationships, a proactive role of health services and the role of school nurse in a coordinating capacity. Some of the barriers noted by the participants are the lack of information flow between agencies as well as regional differences, in case services are accessed in different geographical areas.</p>	<p>Regional differences</p> <p>“We have had cross communication from out of areas sometimes when you do different procedures”</p> <p>Better if initiated by health</p> <p>“It is getting better, yes and tends to be better when it is coming from health to school.”</p> <p>No automatic information flow</p> <p>“We do not get informed, so if the GP is prescribed an EpiPen or inhaler or whatever we will not get told about that”</p> <p>Relationships</p> <p>“We have good contact with our local GP to come to school and they are a good source of contact for anything as well”</p> <p>School nurse role</p> <p>“If we didn't know the answers and we, didn't</p>

	we were not aware of the situation, or the condition, we would liaise, help to liaise and coordinate with the hospital as well”
<p>Link with hospital schools</p> <p>Participants reported that there is a lack of standardised approach to link with hospital schools, but communication tends to be better if it is initiated by health services.</p>	<p>No standardised approach</p> <p>“If it is from a specialist provision, chances are, I am not involved in that.”</p> <p>Better if coming from health</p> <p>“It is getting better, yes and tends to be better when it is coming from health to school.”</p> <p>Aligning plans</p> <p>“We do have some good practice for example, I know a (...) who sends the plan that they drop in the hospital, a copy goes straight to school with permission obviously of the parents, of the child, so that everybody sharing the same plan, so there are pockets of good practice.”</p>
<p>Empowerment</p> <p>Participants noted that collaboration between health and educational services seems to work better in areas of high deprivation.</p>	<p>Areas of high deprivation</p> <p>“We find that areas of highest deprivation are probably more welcoming.”</p>

3.4.2.2: Superordinate Theme 2: Experts by Experience. This

superordinate theme summarises the importance of involving parents and young people in support planning procedures and the barriers that might limit involvement.

Table 41

Superordinate Theme 2 (SN RQ4)

Theme	Subtheme and participant quotes
<p>Relationships</p> <p>Participants highlighted the importance of relationships for successful support planning.</p>	<p>“Relationships are key with families and children, and your staff to make sure you have got rounded children”</p>

<p>Need for involvement</p> <p>Participants noted that parents are included in meetings surrounding their children's needs, for instance, for risk assessments for school trips.</p>	<p>"The parents should always be at those meetings. And, yeah, it would be between school usually health and the parent and pupils. It depends on age of the pupil"</p> <p>"I would say that parents are always included."</p>
<p>Lack of pupils' voice</p> <p>Participants noted the lack of standardised approach to include young people's voice in the support planning.</p>	<p>"I do not think so, they do not think about this from the child's perspective."</p> <p>No standardised approach</p> <p>"It is not routinely done with adolescents, it is up to the individual"</p>
<p>Empowering young people</p> <p>Several participants highlighted the positive impact of including young people in support planning and listening to their voice.</p>	<p>Pupil's voice</p> <p>"We've got them to come along to the training session as well, as part of their.... sort of progress, yeah, and that worked really really well, that young person was really grateful for it, and took on the ownership of it all as well and really appreciated what was done so I think that was, that was a good job"</p> <p>"I think we need to involve the young people and not just the teachers with saying: This is normal. This is normal for me. And this is what we do, and this is how I deal with my medical condition"</p>
<p>Individual differences</p> <p>Participants noted that not all young people wish to be included in support planning procedures.</p>	<p>"So, to be fair, a lot of adolescents would want to be left alone, and not singled out."</p>
<p>Training</p> <p>Participants gave largely differing accounts of the involvement of parents and young people in training. Several participants highlighted the importance of the contribution they could make to training, in terms of creating an awareness for individual differences and experiences.</p>	<p>Lack of involvement</p> <p>"I have seen it a long time ago, but I haven't in my recent job. It is not something I have seen recently."</p> <p>"We get the parents to come in and discuss the exact signs and symptoms of the, you know, the child or young person will have, we get the children..."</p> <p>Individual differences</p> <p>"We could use the experts by experience much more, so we find where young people</p>

	<p>and our parents share their stories that has a much greater impact than all of us trying to pontificate from afar. Yes, use experts by experience much more.”</p> <p>School nurse capacity</p> <p>“Always parents and the child / young person got to be involved in that kind of planning, and in, in the training as appropriate. That happens less because we haven't got the capacity”</p>
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Table 42

Key Findings (SN RQ4)

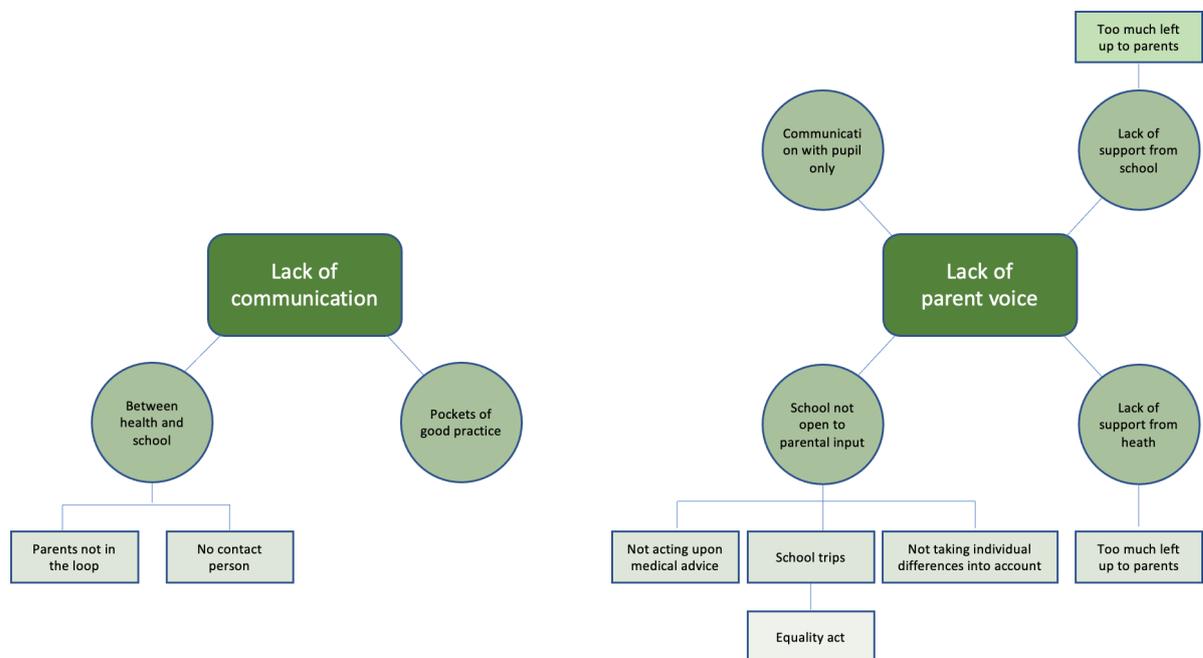
<p>Key findings: Thematic analysis of the views of school nurses (RQ4)</p>
<ul style="list-style-type: none"> ● Communication between different agencies is influenced by many factors, such as openness, capacity and parental empowerment. There is no standardised system to involve all agencies in support planning procedures. ● There is no standardised approach to include experts by experience, such as pupils and parents/carers in support planning procedures, although there is a recognition of the importance of their voice.

3.4.3 RQ4: Thematic Analysis of the Views of Pupils and Parents

Two superordinate themes were identified: Lack of communication and lack of parent voice.

Figure 23

Thematic Analysis of the Views of Parents and Pupils (RQ4)



3.4.3.1 Superordinate Theme 1: Lack of Communication. This

superordinate theme encompasses the barriers limiting successful communication between school and families and some examples of good practice.

Table 43

Superordinate Theme 1 (PP RQ4)

Theme	Subtheme and participant quotes
<p>Between health and school</p> <p>Participants noted that parents are not kept up to date with regards to communication between school and health services. Not having a contact person in school seems like another barrier that prevents successful communication.</p>	<p>Parents not in the loop</p> <p>"As far as I am aware, school have not contacted the hospital, and the hospital have not contacted the school"</p> <p>"They haven't been in touch with his other doctors, not that I am aware of anyway."</p> <p>No contact person</p> <p>"This feels like there is nowhere to turn to and I thought well maybe actually what needs to happen is that they should be, you know, much like outreach work with kids"</p>
<p>Pockets of good practice</p> <p>Participants noted that there are examples of good practice.</p>	<p>"I think in Year 7, she sat down and spoke to me about it, and, and what sort of things she could put in place for me. And then we just went through all different things that I struggle with and things that I need help with and just little things like that"</p>

3.4.3.2 Superordinate Theme 2: Lack of Parent Voice. This superordinate theme highlights that parents often feel not heard when requesting support for their children.

Table 44

Superordinate Theme 2 (PP RQ4)

Theme	Subtheme and participant quotes
<p>Communication with pupil only</p> <p>Participants noted that they are not always kept in the loop by schools who only communicate with the pupils rather than the parents.</p>	<p>“They haven’t contacted me, but they spoke with T.”</p>
<p>Lack of support from school</p> <p>Participants noted that there is an expectation for parents to push for support. Parents noted that their efforts are not always backed by school.</p>	<p>Too much left up to parents</p> <p>“I felt I was becoming the irate, the irrational parent because I was getting onto the school saying you have got to do something to get M back in, you got to do something and you know they were kind of like, oh well, you have got to get her here and did nothing to try and support me”</p> <p>“If you haven’t got parents who were pushy and stubborn”</p>
<p>Schools not open to parental input</p> <p>Participants noted that some schools seemed reluctant to accept parental input. This can endanger their children’s safety in schools or on school trips, and therefore infringe their rights enshrined in the Equality Act. Additionally, in some schools, individual differences are not taken into account when planning support for pupils with the same condition.</p>	<p>Not acting upon medical advice</p> <p>“I do not know whether the SENCO thought he was all knowing when he is not medically trained. I do not know why. They ask for medical diagnosis documents, and then do not act upon them.”</p> <p>School trips/Equality Act</p> <p>“There is a school trip coming up, and they haven’t talked to us at all. And I doubt there is going to be anything in there about me.”</p> <p>Not taking individual differences into account</p> <p>“We do not have no meetings”</p> <p>“We were met with a bizarre, kind of response</p>

	from the school, whereby the leader of the special needs said, well we've had a child in the school before, you see, so we know what we're doing. Okay, which, you know, completely undermined M as an individual”
<p>Lack of support from health services</p> <p>Some participants noted that they struggle to access support from health services. This was exacerbated by the Covid-related lockdown.</p>	<p>Too much left up to parents</p> <p>“I had a phone call with the hospital in Oxford and she will not see him yet, she just wants me to video link. Which is not much help because I am not leaving my son fit into video”</p>

Table 45

Key Findings (PP RQ4)

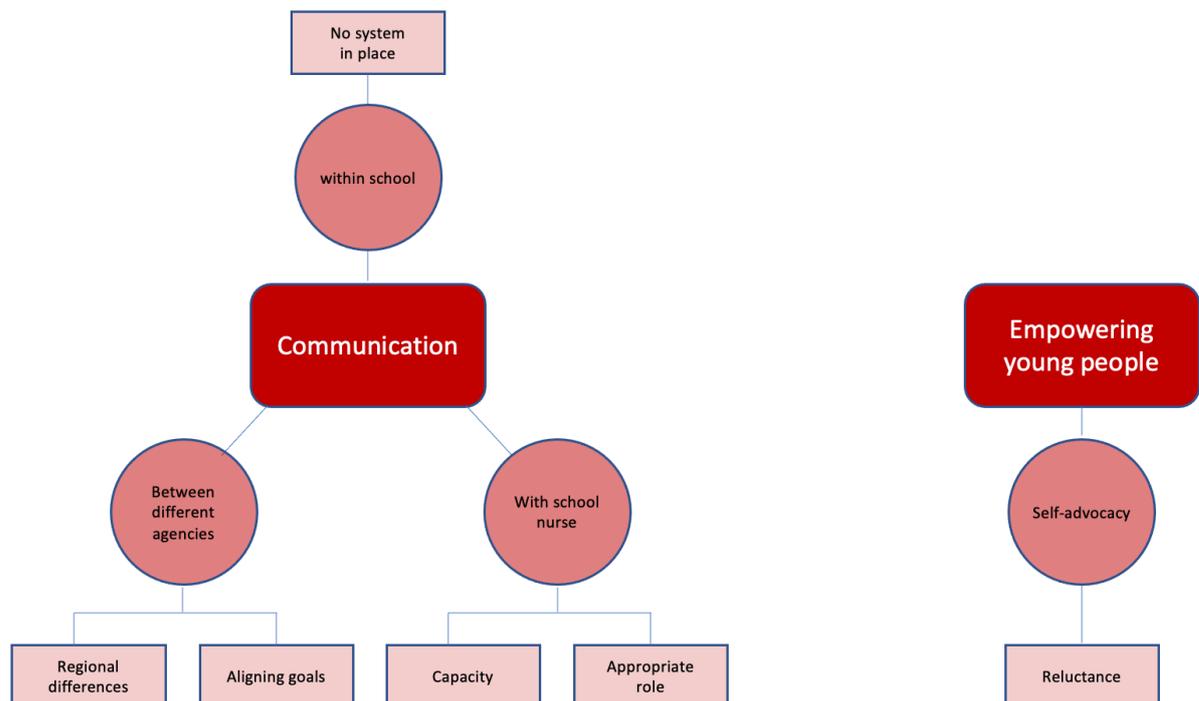
<p>Key findings: Thematic analysis of the views of pupils and parents (RQ4)</p>
<ul style="list-style-type: none"> ● Communication between school and parents can be limited, although there are examples of good practice. ● Parents often feel that their voice is not heard when trying to access support for their children.

3.4.4 RQ4: Thematic Analysis of the Views of Educational Professionals

Two superordinate themes were identified: Communication and empowering young people.

Figure 24

Thematic Analysis of the Views of Educational Professionals (RQ4)



3.4.4.1: Superordinate Theme 1: Communication. This superordinate

theme encompasses communication between different agencies and within schools as well as the barriers that can limit it.

Table 46

Superordinate Theme 1 (E RQ4)

Theme	Subtheme and participant quotes
<p>Between different agencies</p> <p>Participants mentioned the difficulty linked with coordination of support when health services are from different areas. They also noted that the goals of different services do not always seem aligned but appropriate communication can improve this.</p>	<p>Regional differences</p> <p>“It depends which agency they have gone to, and whether the health support is in the local area, or they gone to London for example”</p> <p>Aligning goals</p> <p>“CAHMS will often say to me, it is not our remit to get this child back into school. Our remit is to keep this child healthy and well and safe.”</p> <p>“I tend to find that when we are all in one group, if we are all in the room at the same time, there is a lot more that can be done”</p>
<p>With school nurse</p> <p>Participants noted that school nurses can improve collaboration between different agencies, but because of their limited capacity, their involvement is often not requested.</p>	<p>Capacity</p> <p>“The school nurse team, bless them, are very small. And so, I think because they are because of their small capacity to provide support they are sometimes missed out in the link”</p> <p>Appropriate role</p> <p>“If a school had an initial concern regarding medical, we would probably say contact the school nurse first, see what they say and then the school nurse will pass it on to whoever is right for you”</p>
<p>Within school</p> <p>Participants noted that not all schools have an effective flow of information.</p>	<p>No system in place</p> <p>“The matrons are not passing the information on to these school staff so it is not feeding into the educational targets and direction at all”</p>

3.4.4.2: Superordinate Theme 2: Empowering Young People. This

superordinate theme highlights the importance of self-advocacy among young people.

Table 47

Superordinate Theme 2 (E RQ4)

Theme	Subtheme and participant quotes
<p>Self-advocacy</p> <p>Participants acknowledged the importance of self-advocacy for young people but noted that some might be reluctant to engage.</p>	<p>“There is a lot of work about emotional literacy is not there about a young person being able to explain the difficulties that they are having rather than masking it”</p> <p>Reluctance</p> <p>“We would encourage it because it is quite nice to talk to somebody who might be having a similar experience, but actually it happens very rarely that the young person wants to. It almost makes it a little bit too real. I would rather have friends that do not have anything wrong with them”</p>

Table 48

Key Findings (E RQ4)

Key findings: Thematic analysis of the views of educational professionals (RQ4)
<ul style="list-style-type: none"> ● Communication between agencies and within schools can be limited and goals are not always aligned. ● Young people benefit from the ability to self-advocate, but some may be reluctant to engage.

3.4.5 Key Findings from the Fourth Subsidiary Research Question

The findings of the quantitative and qualitative analysis show that communication between different agencies is influenced by many factors, such as openness, regional differences, and parental input. There is, however, no standardised approach to automatically involve relevant agencies in support planning procedures and this can lead to limited communication and goals that are not aligned. Although there is recognition of the importance of the voice of parents/carers and pupils, they are not routinely included in decision-making processes. This can result in parents/carers feeling not heard when trying to access support for their children. Young people with health-related needs would benefit from the ability to self-advocate but some may be reluctant to engage.

3.5 RQ5: In What Ways are Social, Emotional and Mental Health Needs Taken into Account When Planning Support for Pupils with Medical Needs in Schools?

3.5.1 RQ5: Descriptive Statistics

Table 49

Key findings from the Quantitative Analysis (RQ5)

Key findings: SEMH support
<ul style="list-style-type: none">• Sixteen participants (44%) reported that they are moderately confident in schools' ability to provide effective support for the social-emotional wellbeing of pupils with health-related conditions (see Figure 25).
<ul style="list-style-type: none">• Eleven participants (30%) reported that Individual Healthcare Plans outline support for pupils' social and emotional as well as educational needs (see Figure 26).
<ul style="list-style-type: none">• Nine participants (25%) noted that plans include additional support to catch up and keep up, 12 participants (34%) reported of rest breaks and six participants (17%) reported of counselling sessions.

Figure 25

Confidence in SEMH Support

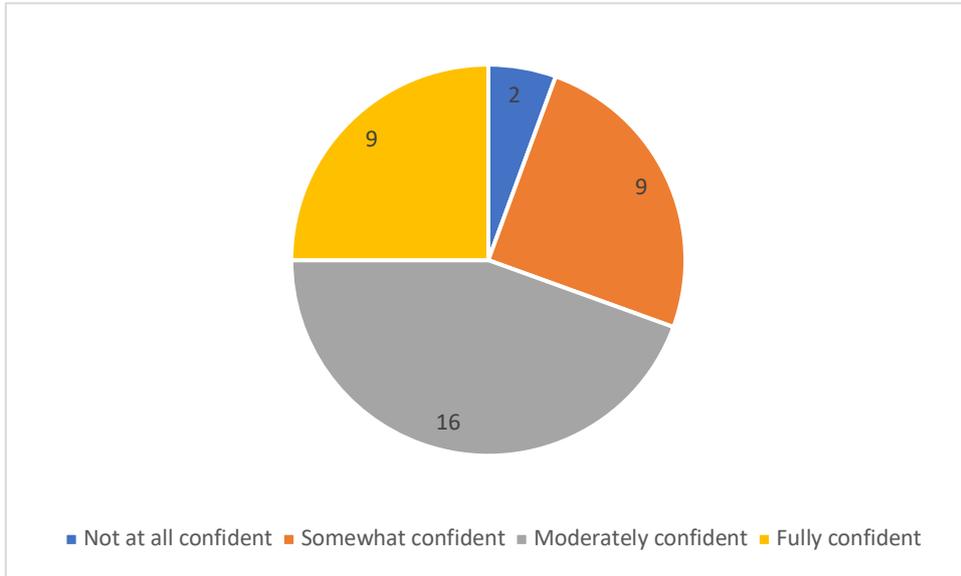
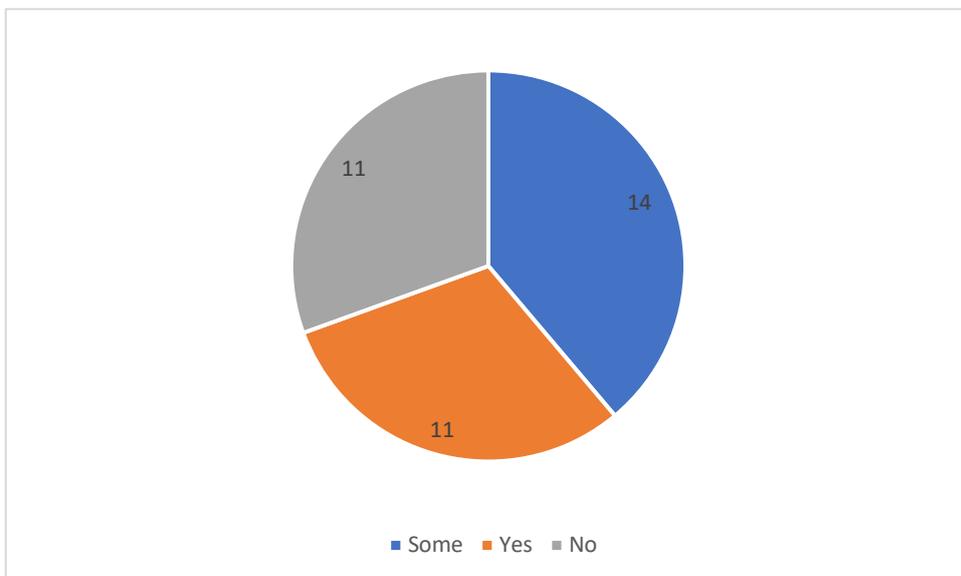


Figure 26

SEHM and Educational Support Outlined in Individual Healthcare Plan

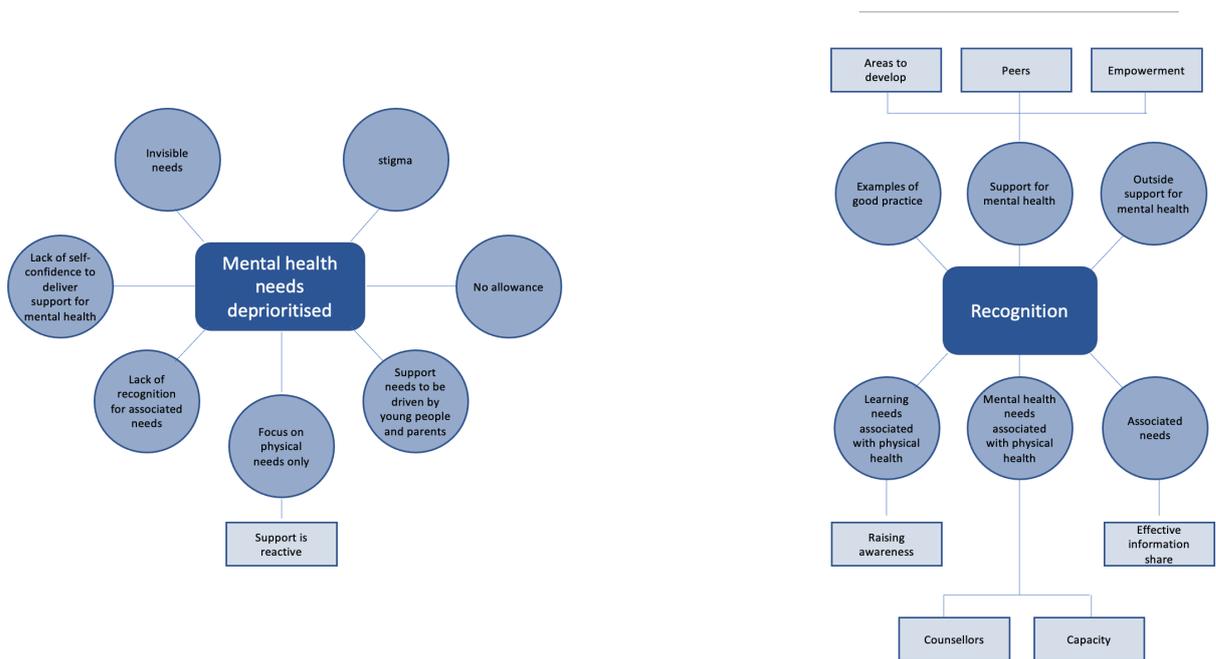


3.5.2 RQ5: Thematic Analysis of the Views of School Nurses

Two superordinate themes were identified: *Mental health needs deprioritised* and *recognition*.

Figure 27

Thematic Analysis of the Views of School Nurses (RQ5)



3.5.2.1: Superordinate Theme 1: Mental Health Needs Deprioritised. This superordinate theme highlights the barriers that limit the availability of appropriate support for mental health needs within schools.

Table 50

Superordinate Theme 1 (SN RQ5)

Theme	Subtheme and participant quotes
<p>Invisible needs</p> <p>Mental health needs are deprioritised compared to physical needs.</p>	<p>“Wish they could provide so much more emotional support to children. They try their best. But I think there is so much need around mental health anyway, that sometimes children with medical needs to get sort of forgotten, if that makes sense, because, because it is visual, and it is not a mental thing, it is put in a different bracket. So, I find yeah.... Sometimes it is completely invisible as well..”</p>
<p>Stigma</p> <p>Participants noted that mental health needs can be stigmatised in some schools.</p>	<p>“I get told by the students that they are not very sympathetic towards certain health conditions or, particularly if it is anxiety or something like that but they often do not get back into the classroom they will be in the corridors or whatever.”</p>
<p>No allowance</p> <p>Participants noted that schools lack the capacity to create an awareness or provide support for needs associated with health-related conditions.</p>	<p>“I think there is a willingness, but there are huge barriers to doing so because of the way schools are inspected and judged. So, I think, to be fair to school staff they probably want to, but actually I do not think it is given that much thought or understanding.”</p>
<p>Support needs to be driven by young person or parents</p> <p>Participants highlighted the importance of the role of parents and pupils in driving support.</p>	<p>“it is on a school-by-school basis. And it is often down to the parents and the young person to drive that”</p>
<p>Focus on physical needs only</p> <p>Participants noted that training and communication is often focused on physical needs only and support can be reactive.</p>	<p>“There has never been any sort of social or emotional bits in there, it is very much sort of their symptoms and signs what you do, and, you know, that sort of stuff.”</p> <p>Support is reactive</p> <p>“We do not tend to talk about that in our training, unless there is an emergency.”</p>
<p>Lack of recognition for associated needs</p> <p>Participants noted that some schools lack awareness for mental health needs</p>	<p>“Schools do not understand that chronic conditions often come with psychological conditions, and pupils do not want to be different from peers, and they do not want to</p>

associated with physical conditions.	worry about their condition all the time. Unless you spell it out for schools, they do not get that. They just want you to fix it but it is more complex than that”
<p>Lack of self-confidence to deliver support for mental health</p> <p>Participants highlighted that they lack self-confidence as well as appropriate training to deliver support for mental health.</p>	<p>“Because we go on with evidence base sort of professionals and I do not know how much evidence there is to..... we sort of know.... but, what's the proof? Where's the evidence? And it is just not that is not something that we..... yeah..... sort of.... it is probably down, down the priority list to be honest because..... it shouldn't be. And I guess a lack of training or lack of, I do not feel, I wouldn't feel confident enough to say for sure.”</p>

3.5.2.2: Superordinate Theme 2: Recognition. This superordinate theme indicates that there is a recognition of mental health needs associated with physical health but there are barriers to delivering effective support within schools.

Table 51

Superordinate Theme 2 (SN RQ5)

Theme	Subtheme and participant quotes
<p>Mental health needs associated with physical health</p> <p>Participants highlighted the complexity of mental health needs associated with medical needs. The lack of capacity is a barrier to delivering effective support. Some participants mentioned that schools employ onsite counsellors.</p>	<p>“I think one of the problems you have got with children with long term medical conditions is things become more complex their relationships with people become more complex and their relationship with their own mental health becomes more complex and so there is always a bit. Lots of different strands. Yeah. Yeah, that is part, that is part of why you can't, you can't get a straight answer because some of it is about the child's own resilience.”</p> <p>Counsellors</p> <p>“They are very lucky here because mostly we do have very good counsellors”</p> <p>Capacity</p> <p>“There is no specialist guidance, and you just</p>

	<p>have to do what you can. We cover a hell of a lot and we are not experts.”</p>
<p>Learning needs associated with physical health</p> <p>Some participants noted their role in raising awareness for learning needs associated with medical needs.</p>	<p>Raising awareness</p> <p>“If someone's having lots of small seizures, or absences then obviously they are missing chunks of their day so that we sort of, just go over that again, sort of remind staff”</p>
<p>Associated needs</p> <p>Participants noted that there is an increased recognition of mental health needs that are associated with medical needs. Mental health needs also have to be part of an effective information share in order to provide appropriate support.</p>	<p>“There was a huge part about mental health, obviously because we had to be very mindful that this was a huge situation for her, not just physically but emotionally and mentally and, as you say with her friends, so I think there has been many, I would have many examples I think have been very mindful that it is not, it is the whole person, you know it is not just the condition.”</p> <p>Effective information share</p> <p>“We have a thing they have developed, called a pupil passport. So, children who have particularly errrrr needs that you know are either emotional or social issues. They have a pupil passport which is written by one of our wellbeing team, and that is shared with staff so that might have information about you know: I get angry. And when I get angry, I need to do this. Please give me time, so it is written with the young person so yes we do have that.”</p>
<p>Support for mental health</p> <p>Support for mental health can include interventions that include peers and interventions that are aimed at empowering young people to describe their needs. It is an area that is seen by participants in need of further development.</p>	<p>Area to develop</p> <p>“Maybe it is something that we could, that we need to, sort of work on to be honest. It is something that we do not..... I think it is that we, you know, it is understood that there is an impact but it is not something that we use evidence to say.....you know, no. We do need to.”</p> <p>Peers</p> <p>“Nurses would provide a circle of friends training, for instance, if kids are anxious about having a fit or so. They can train up their friends”</p> <p>Empowerment</p>

	<p>“The young person would say: I might not seem interested, I might be a pain in the neck, I might be rude. Just think about this before you judge me.”</p>
<p>Examples of good practice</p> <p>Participants highlighted examples of effective support.</p>	<p>“Sometimes we use things like tree houses, or we've got a health mentor he has got (...) of self-esteem tools and, yeah, you know, looks at healthy eating and things and exercise and those sorts of things that can make you feel better.”</p>
<p>Outside support for mental health</p> <p>Participants referred to the availability of external support in some cases.</p>	<p>“It would just be discussing with other people and just trying to get them extra support (...) outside (...) we generally have a good take up on everything. It works well.”</p>

Table 52

Key Findings (SN RQ5)

<p>Key findings: Thematic analysis of the views of school nurses (RQ5)</p>
<ul style="list-style-type: none"> • Support for mental health needs within schools is limited by capacity, training and self-confidence of school nurses as well as by too strong focus on physical needs. • Although there is a recognition of needs associated with health-related conditions, delivering effective support for those needs remains an area to develop.

3.5.3 RQ5: Thematic Analysis of the Views of Parents and Pupils.

Two superordinate themes were identified: Lack of support and support.

Figure 28

Thematic Analysis of the Views of Parents and Pupils (RQ5)



3.5.3.1: Superordinate Theme 1: Lack of Support. The impact of the lack of support, particularly for mental health needs was highlighted. To many participants this lack of support seemed to indicate that schools have no interest in the wellbeing of the pupils in their care.

Table 53

Superordinate Theme 1 (PP RQ5)

Theme	Subtheme and participant quotes
Long term impact Participants discussed the long-term effect of missing out on schooling and not receiving sufficient support for integration.	"The long-term impact that kind of missing out on that schooling and falling into that bad pattern has had"
For SEMH needs	"I didn't really feel very supported through any

Participants highlighted the lack of support for SEMH needs.	of it, really."
<p>Parent perception</p> <p>Participants noted that it seemed like schools showed no interest in offering support to pupils with health-related needs.</p>	<p>"I think I got, you know a fairly standard 'oh really sorry to hear that I hope she is feeling better soon'. Very helpful. Well yeah, I mean, what you come to expect."</p> <p>School shows no interest</p> <p>"This was last term, we asked for this. And the school was supposed to ask the individuals that he has identified but we've, we've not heard..."</p>

3.5.3.2: Superordinate Theme 2: Support. Examples of good practice were highlighted.

Table 54

Superordinate Theme 2 (PP RQ5)

Theme	Subtheme and participant quotes
<p>Mental wellbeing</p> <p>Some participants were offered counselling for their mental health needs.</p>	<p>Counselling</p> <p>"They offered counselling."</p>
<p>For physical needs</p> <p>Participants reported that there was support available for physical needs.</p>	<p>"They did give me a queue jump card"</p> <p>"The evac chair at every stair"</p>

Table 55

Key Findings (PP RQ5)

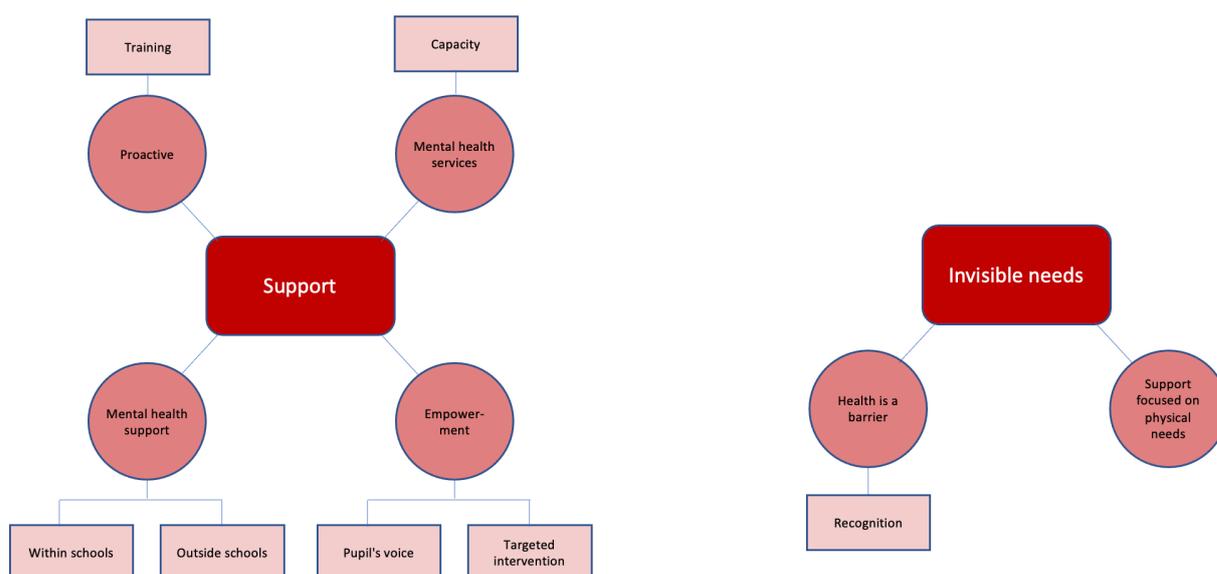
<p>Key findings: Thematic analysis of the views of parents and pupils (RQ5)</p>
<ul style="list-style-type: none"> • The lack of available support for SEMH needs has a long-term impact.
<ul style="list-style-type: none"> • There is more support available for physical needs than for mental health needs.

3.5.4 RQ5: Thematic Analysis of the Views of Educational Professionals

Two superordinate themes were identified: *Support* and *invisible needs*.

Figure 29

Thematic analysis of the views of educational professionals (RQ5)



3.5.4.1 Superordinate Theme 1: Support. The positive impact that proactive support can have on young people’s mental wellbeing was highlighted together with strategies that schools can implement.

Table 56

Superordinate Theme 1 (E RQ5)

Theme	Subtheme and participant quotes
<p>Proactive</p> <p>Participants noted that some schools are proactive in accessing training to provide targeted support.</p>	<p>Training</p> <p>“We do do modelling in schools it; it is always been really successful and effective and staff would take it on board”</p>
<p>Mental health support</p> <p>Participants discussed ways to support mental wellbeing within schools and acknowledged the difficulties around accessing mental health services outside schools.</p>	<p>Within schools</p> <p>“Setting up a buddy system and talk about different ways that would work”</p> <p>Outside schools</p> <p>“Often it is easier to have a link with a medical service, than one that supports emotional wellbeing”</p>
<p>Mental health services</p> <p>Participants acknowledged the limited capacity of mental health services and the difficulties around accessing support.</p>	<p>Capacity</p> <p>“It is a real struggle to find services that are willing to engage with schools and a lot of it is due to their workload, but they are the harder services to access because of the demands on their time. But often they are the most critical.”</p>
<p>Empowerment</p> <p>Participants highlighted the importance of empowering young people through involving them in support planning and interventions targeted at increasing their self-confidence. Outreach services can support schools with similar interventions.</p>	<p>Pupil’s voice</p> <p>“Talking about our adolescent children and we would involve them in a conversation”</p> <p>Targeted intervention</p> <p>“Loric, each of the letters l o r i c stands for different words that are considered to be social programme has been developed to focus very much on employability skills so that the letters of loric stand for L is for leadership, o for organisation, r is for</p>

	resilience, i is for independence and c for communication. So, within that programme. We've developed some teaching strategies and activities that develop those five skills in the young people. And we've seen some really significant developments in confidence around those young people”
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3.5.4.2 Superordinate Theme 2: Invisible Needs. The use of the medical model makes it difficult to raise awareness for needs that are not physical.

Table 57

Superordinate theme 2 (E RQ5)

Theme	Subtheme and participant quotes
<p>Health is a barrier</p> <p>Participants highlighted the importance of recognising that a health-related condition can be a barrier to educational achievement.</p>	<p>“The young person is just too unwell, too ill. They have been coping and struggling, and they reach a point where they just can’t do it anymore. So, the referral is for the mental health, but underlying is a physical health condition”</p> <p>Recognition</p> <p>“Some students we have to actually argue, their educational progress is fine, but they could be doing better. And actually, their health needs are a barrier. The progress would seem fine, they are green across the board, but actually we still need to challenge that because they should be doing better than that”</p>
<p>Support focused on physical needs</p> <p>Participants discussed the reasons why more support might be available for physical needs in schools.</p>	<p>“The actual physical disability school seem to, to show, they seem to understand it better because they can see it, they can see the difficulty the child's having.”</p>

Table 58

Key Findings (E RQ5)

Key findings: Thematic analysis of the views of educational professionals (RQ5)
<ul style="list-style-type: none">• Schools need to consider ways for offering support for mental wellbeing because of the limited capacity of mental health services.• There needs to be an improved recognition for mental health needs linked with health-related conditions and focus needs to shift from offering support for physical needs only.

3.5.5 Key Findings from the Fifth Subsidiary Research Question

Findings from the quantitative and qualitative data analysis show that in spite of the improved recognition for social, emotional and mental health needs associated with physical health conditions, support for those needs remains an area to develop. This can be linked to limited capacity, insufficient training and lack of self-confidence of school staff to deliver appropriate support. However, limited capacity of external mental health services and the long-term impact of unmet mental health needs necessitate enhanced mental health support within schools. The focus of support offered to pupils with health conditions needs to shift from physical needs only towards effective support for social, emotional and mental health needs.

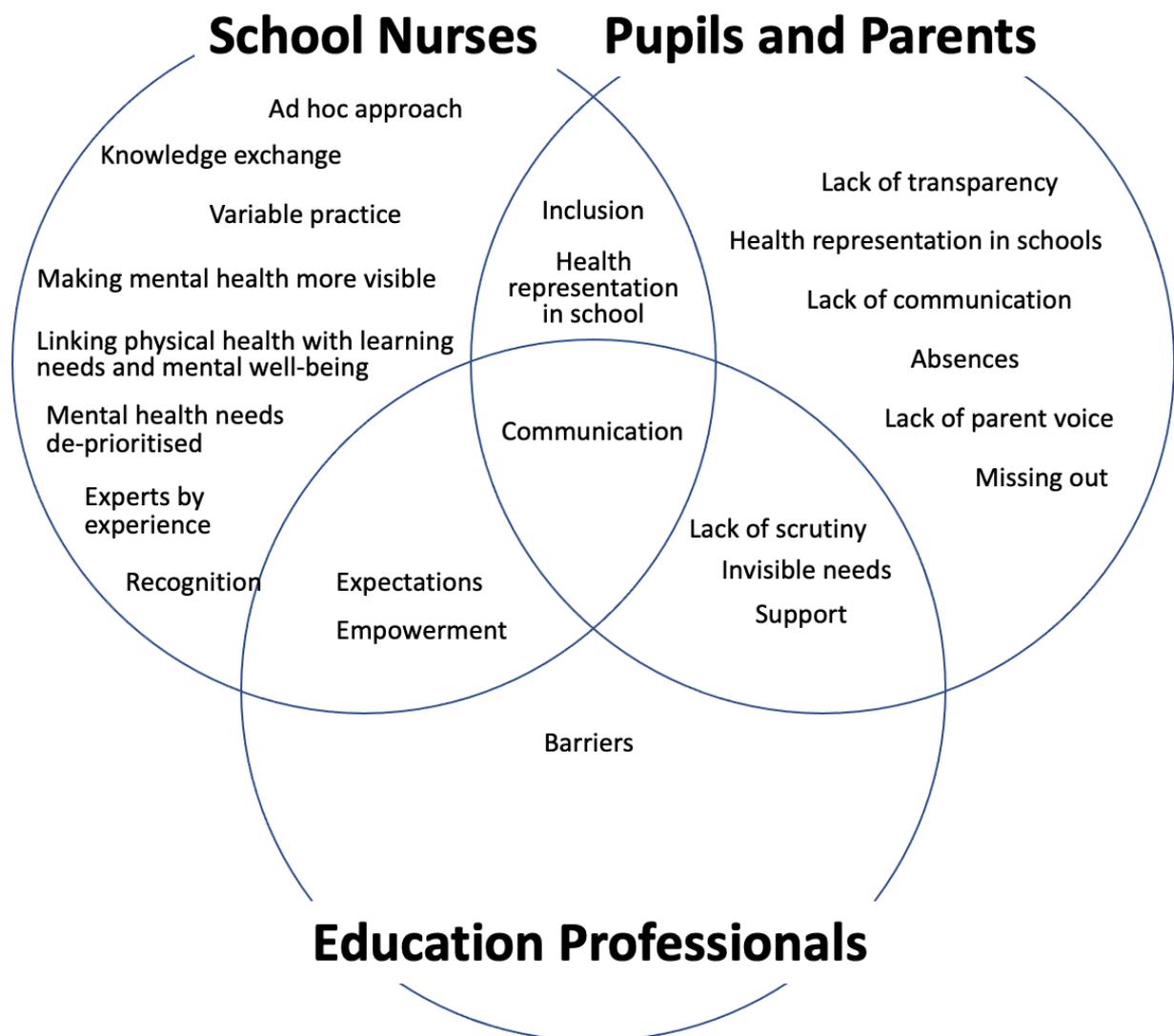
3.6 Conclusion

The data provided by the three groups of participants are generally in accordance. The themes complement each other or offer differing views on the same subject. Figure 30 represents superordinate themes referenced. There are no major

disparities between the participant groups, suggesting that there is a general awareness around the issues addressed. These will be explored in depth in the subsequent section.

Figure 30

Venn Diagram of Participant Views to Meeting the Needs of Pupils with Health-Related Conditions in Schools



4. Key Findings and Discussion

4.0 Aims

This chapter includes a discussion of the key findings in relation to the overarching research question and the literature review. The risk and protective factors that play a role in the overall support and outcomes of pupils with health-related needs are considered. Specific examples will be provided throughout the chapter. Recommendations are listed for schools and healthcare professionals. The implications of the Covid-19 pandemic are discussed.

4.1 Factors Influencing the Processes Around Adolescents with Health-Related Needs in Schools

This research explored the current practice in a sample of secondary schools regarding adolescents with health-related needs; what barriers they encounter and how their support could be enhanced. A holistic view was sought to answer the overarching research question: *How do health and education services work together to improve processes around adolescents with chronic, life-threatening and life-shortening health conditions?* The study attempted to provide a balanced account by engaging with the views of school nurses, adolescents, and their parents/carers, as well as educational professionals working in various roles. The information elicited enabled me to focus on key systems around adolescents with health conditions, as well as the protective and risk factors that influence the support and outcome of this population (Eriksson et al., 2018). Similar themes in many areas were raised by all three participant groups, such as the lack of awareness for learning and mental health needs associated with physical health, and the importance of communication

between different agencies and families to ensure an appropriate flow of information. Other issues experienced by schools and school nurses include limited resources and the lack of health representation in many schools. Approaches for schools and healthcare providers to enhance support through multi-agency work, and to empower adolescents with health-related needs will be discussed, and more specific examples of recommendations will be provided throughout this chapter.

4.1.1 Protective Factors

On the basis of this investigation, I was able to identify a range of protective and risk factors that can impact the outcomes of adolescents with health-related needs. Protective factors refer to the individual characteristics as well as environmental factors that enhance successful functioning within the context of an adversity, whereas the term risk factors have the potential to disrupt the development of positive outcomes (Martinez-Torteya et al., 2009).

Protective factors discussed by the different participant groups include:

Environmental factors

- Health representation in school with a school nurse on site. Nursing hubs looking after a large number of schools often lack the capacity to provide sufficient input for pupils with varying degrees of health-related needs. In contrast, full-time school nurses on site can contribute to leadership priorities that emphasise the support of pupils with health-related needs.

- Support for physical needs, such as evacuation chairs, lunch passes and time-out cards to allow time for the management of a medical condition (for instance, blood glucose measurement for CYP with Type One Diabetes).

Relationships

- Positive relationship with a school nurse. School nurses can be a person of trust for the entire family. A positive relationship with an approachable school nurse that involves regular updates on a student's condition can lead to early intervention and tailored support.
- The role of the medical lead within a school. This role should be executed by a named member of staff who has overall responsibility for the implementation of the medical policy, the coordination of information share and relevant training in collaboration with healthcare services. The role should clearly establish a person of trust within school, a port of information and a single point of contact for families as well as healthcare professionals. The role is particularly important if there is no health representation on site. Schools should have a clear job description for the role of the medical lead according to the statutory guidance (DfE, 2015).
- Person of trust in school. This can be a teacher or any other member of staff with whom the pupil has a positive and trusting relationship.
- Parental involvement and parental advocacy are identified as main factors that can drive support and outcomes. This is consistent with previous research by Doren et al. (2012). It is beyond the capacity of this research to study ways to improve parental involvement in schools but there is extensive

literature exploring this topic (Arias & Morillo-Campbell, 2008; Hess et al., 2006; Hornby & Blackwell, 2018).

Communication and collaboration

- Individual Healthcare Plans for all pupils with health-related needs. There should be no shared healthcare plan for the same condition for multiple pupils, as it would disregard individual experiences and the individual presentation of a health condition. This research shows that even severe physical conditions, such as cystic fibrosis or narcolepsy, might not warrant an EHCP. Therefore, it is important to ensure that health needs are registered elsewhere within the school, so relevant information is easily accessible for teachers and other members of school staff.
- Pupils' views about their individual experiences and needs are elicited and respected. Pupils and their families are included in trainings, the creation of risk assessment, Individual Healthcare Plans and any other support planning procedures.
- Healthcare professionals are actively involved in training teachers and other school staff related to medical needs.
- Effective information flow between healthcare professionals, school, and parents/carers.
- Well-planned transition from primary to secondary school and from special provisions to mainstream schools. Participants generally reported positive experiences regarding transition into secondary school, but a standardised approach is still lacking and much of it is up to individual capacity and

commitment. Transition from specialised provisions (such as hospital schools) into mainstream education was reported to be much more problematic, with no collaboration between the different settings.

- An easily accessible reporting system including information about health needs. Information about health needs must form part of the transition documentation including contact details of relevant healthcare professionals.
- Respect for growing independence of the young person but appropriate monitoring as advised in statutory guidelines. *Appropriate support* must be clearly defined together with the adolescents and their family and documented in the individual healthcare plans.
- Pupils and their parents/carers are experts of their respective health condition. Their expertise needs to be recognised and they should be included in all stages of support planning. This entails a strong collaboration between school and parents/carers. Parents/carers can problem solve, keep school informed about upcoming absences, any changes in condition and any necessary arrangements. In turn, schools work with parents, accept their expertise and respond to requests for support and adjustments.
- If attendance or academic progress deteriorates, school staff need to raise health needs as a potential contributing factor and information about potential changes in health must be sought.

Individual factors

- Recognition of the individual experiences of pupils with health-related needs.

- CYP's ability to self-advocate. This includes the knowledge of self; of one's rights, communication skills and leadership (Test et al., 2005). A good understanding of rights and needs alongside assertive communication skills are the tools necessary for self-advocacy.

4.1.2 Risk Factors

The following risk factors that might pose barriers to the support and outcomes of adolescents with health-related needs were identified by the participants:

Environmental factors

- Lack of awareness of an underlying medical condition and its associated impact on learning and emotional wellbeing.
- Lack of a standardised approach to support pupils with health-related needs. Reports concur with findings by Mukherjee et al. (2000) and show that often there are no standardised pathways for communication and support planning around pupils with health-related needs. This can lead to some teachers not receiving relevant information about extended absences or the impact of a health condition. Support planning is therefore not optimised, and pupils miss out on important learning opportunities, such as school trips.
- There is little preventative support available in schools for health-related needs. Participants noted that referrals to various services are made only

when children and young people already exhibit major difficulties. A trigger for referrals is often a hospital admission.

School Absence

Consistent with previous research (DfE, 2019), participants report that school absence poses a large barrier to educational outcomes. This barrier can be broken down into four dimensions: registration of absences; missed learning and social opportunities; lack of information flow between different provisions and within the mainstream school; lack of support to return to school.

There is a lack of guidance and no specific code for recording absences due to mental ill health or long-term health needs. All illnesses are coded “I” (for illness) without the school being under any obligation to consider the veracity or the severity of an illness (DfE, 2020). Because of this relative ease of reporting, schools are under no obligation to seek advice from other professionals (such as medical professionals, Educational Welfare Officers or educational psychologists) to put appropriate multi-agency plans and interventions in place that are aimed at increasing attendance. A poorly managed medical condition leading to unnecessarily increased absences, or an episode of emotional-based school avoidance of an adolescent with a health-related condition may not lead to any action if it is reported as ‘Illness’ by school. This issue can lead to an extensive drop in attendance, from which it may be difficult for a pupil to recover. A further problem of the reporting system revolves around dual coding. If a pupil has an extended hospital stay for instance, schools may be inclined to code the pupil’s absence accordingly, without any further investigation around the actual length of the hospital stay, whether or not the pupil is attending hospital school, and what the provision of the hospital school

may look like. This can lead to pupils becoming invisible within the educational system or pupils exiting the system altogether. As previously discussed, because of this lack of clarity around attendance data, it is currently unclear how many children and young people are missing from the educational system due to health reasons (No Isolation & Tomorrow Today, 2019) and how many of those pupils would be able to manage their condition within school with multi-agency support.

No parent/carer or pupil participant reported that their school offered opportunities to remain socially included during extended absences despite clear guidance around such provision (nasen House et al., 2018). No support was provided to return to school after extended absences. Participants reported poor academic support to keep up and catch up during and after absences, with parents having to do a lot of chasing up and pupils receiving punishments upon return for missed academic work. Educational professionals reported that mainstream schools do not liaise with hospital schools to optimise academic support during absences. Information flow within schools can also be lacking. Participants noted that information shared about extended absences does not always trickle down to individual teachers. In terms of academic support, participants reported that teachers often only share a PowerPoint Presentation of the missed lesson with the pupils without any explanation or reasonable adjustment of the workload for pupils who work in isolation and while being physically unwell.

Communication and collaboration

Insufficient communication with healthcare professionals might lead to a reduced understanding of a young person's needs. Participants' accounts are consistent with previous findings by Mukherjee et al. (2000) and show that there are only limited attempts to align conflicting priorities of educational and healthcare professionals. Schools may be unaware of how a condition might impact learning and mental health and wellbeing. At the same time, healthcare professionals may lack awareness of an adolescent's school attendance and academic progress and therefore no preventative measures can be put in place. Coordinated early intervention with sufficient input from both educational and healthcare professionals may lead to improved outcomes.

Individual factors/mental health

Concurrent with previous findings, participants reported a lack of awareness around mental health needs linked with physical health conditions. Support in schools is mostly focused around physical barriers and there is reduced recognition of needs that remain invisible. Wellbeing is an essential prerequisite for learning (Hale & Viner, 2018) and previous research found poor mental health, rather than physical health to be a strong factor in reduced outcomes (Power et al., 1996). Participants recognised that limited support for mental health is a particular barrier to outcomes but consistent with existing research, neither school nurses nor educational professionals reported that they feel confident to deliver support for mental health. This significant gap in mental health provision within schools is well documented (Crenna-Jennings & Hutchinson, 2018). Curtis (2019) found that school

staff lack the confidence to meet social emotional mental health needs, while Child and Adolescent Mental Health Professionals were found to lack the training and expertise to support children and young people with learning needs (Vostanis et al., 2011, 2013). There does not seem to be any joined up training for educational and mental health professionals (Vostanis et al., 2011) and added to this problem, schools were found not to use evidence-based interventions to support children and young people with mental health needs (Curtis, 2019).

Participants noted that pupils with medical needs often lacked empowerment to request support. Worrying about being different, they tend to keep their head down and miss out on important learning opportunities with their teachers. This can result in further deterioration of their achievement. Barriers to parental advocacy can be exacerbated by a lack of parental empowerment, for instance, through level of parental education or socio-economic factors (Hornby & Lafaele, 2011).

4.2 Key Themes for Reflection by Schools

Based on this investigation and considering the participant sample size, some key themes were generated that may need further exploration. These themes are focused on five main areas: awareness, early intervention and self-advocacy, transparency, and absences.

Awareness

Schools may consider ways to improve their understanding of mental health needs and learning needs connected with physical needs. This might entail more training for individual teachers and for school leadership, as well as a systemic approach to embed new practices including appropriate monitoring and evaluation to support and sustain practice.

Schools need to separate learning needs from health-related needs. If a child or a young person misses a lot of school, it is likely that a learning need will develop, and support must be provided. In a multi-agency collaboration with the appropriate medical professionals, a good understanding needs to be gained around what can reasonably be expected of the pupil. It is essential to set expectations high with appropriate support, rather than lowering the bar for pupils with health-related needs. Information about differentiation and reasonable adjustments need to form part of individual healthcare plans and need to be monitored and regularly reviewed in collaboration with the pupils and their parents. Maintaining appropriate educational

progress needs to be the focus of individual healthcare plans. The plan should highlight a positive view of future professional and educational outcomes.

Early intervention and self-advocacy

Participants highlighted the importance of a proactive approach. If achievement or attendance deteriorates, it is of utmost important that existing health-related needs are flagged up and investigated. Early contact with families may shed light on any change in health that may lead to a drop in educational outcomes.

Targeted interventions should be developed to improve self-advocacy skills of young people, with and without special educational needs and disabilities. This will require a scaffolded approach (Rogoff, 1990) with the guidance of a competent adult and consistent with the UNCRC principles (UN, 1990). A key factor in achieving positive educational outcomes is awareness of one's needs or disability (Pocock et al., 2002). Self-awareness and self-knowledge are critical skills needed in all aspects of self-advocacy (Paradiz et al., 2018). Engaging in self-advocacy is important throughout every child and young person's life. Individuals must know and understand themselves enough to be able to judge when unsettling events occur, or when events take a turn that does not match their goals and desires. If that happens, they need to speak up and share their experiences. At the same time, it is crucial that children and young people develop a good comprehension of the laws and entitlements designed to regulate and improve their life (Paradiz et al., 2018).

Transparency

A medical lead with an appropriate job description should be appointed and assigned a medical-lead@school... email address. Similar to admin@ and senco@ email addresses, this can lead to improved communication targeted at the relevant practitioner within school. The email address should be included in all communication with parents around health-related needs.

Schools may benefit from a transparent system, with a single point of contact (medical lead) within school. The communication pathways outside school with parents and healthcare professionals as well as within school among individual teachers need to be transparent with a good flow of relevant information. To further enhance transparency, it would be important to have a registration system that allows pupils with health-related needs to be easily recognisable with a one-page profile for easy access. When discussing changes in achievement and attendance, health-related needs should be flagged up and considered as a contributing factor.

Experts by experience, such as pupils and their families as well as healthcare professionals, should be included in goal setting and support planning procedures, such as training and the production of individual healthcare plans and risk assessments.

Absences

Some further implications for practice concern missed learning because of tiredness or being unwell. Following the guidance by nasen House (2018), support for keep-up and catch-up should be provided for short-term and long-term absences.

Schools might consider taking a proactive approach and maintaining contact with young people during medical absences. Students should be encouraged to participate in social life during graduated return by including assemblies, clubs and lunchtimes in any part-time table, rather than just academic lessons.

For any pupil with health-related needs, procedures should be in place to make staff aware of missed learning because of tiredness or being unwell. Even if the pupil is in school, learning might be impacted by an enhanced need for sleep as reported by a participant with narcolepsy, or a seasonal change in the medical condition (such as with cystic fibrosis).

4.3 Themes for consideration for Healthcare Professionals

Working with Adolescents with Health-Related Needs

Based on participants' reports, healthcare professionals working with children and young people may consider aligning plans and goals with schools. It was noted that joined up plans for multi-agency work "*tend to be better when it is coming from health to school*" (SN5, 17:48). Some recommendations based on participants' accounts are listed below:

Healthcare professionals may reflect upon opportunities to advocate for inclusion and equity in school policies and practices, while recognising schools' expertise in promoting health and supporting students with health-related needs. They could consider validating school health promotion and prevention programmes

and encourage schools to move on from typical lecture-like sessions on health topics towards an approach to positive health that is incorporated in all teaching.

Upon a new or changed diagnosis, healthcare professionals may consider routinely reaching out to school to discuss potential reasonable adjustments and staff training needs, as well as the impact of the condition on the learning and wellbeing needs of the child or young person. Both schools and healthcare professionals may consider the implications of gaining consent from families for joined up multi-agency work. For a seamless collaboration, healthcare professionals may establish a link with the school medical lead in order to ensure that appropriate advice can be shared with schools if they notice a drop in achievement or attendance of the child or young person. Healthcare professionals can raise awareness for education as an important social determinant of health. They may consider contributing to an improved understanding of health-related needs among teachers by building motivation and agency of teachers through multi-agency work, formal and informal training and the validation of medical policies and Individual Healthcare Plans.

Initiatives aimed at enhancing awareness and support around the needs of children and young people, such as the Epilepsy Passport (RCPCH, n.d.), need input from educational professionals for maximising the usefulness of the resource. According to the description of the Epilepsy Passport, it was created to improve communication with “healthcare and other professionals”, but input for the development was requested only from “epilepsy professionals, parents, children and young people”. The Epilepsy Passport could be used to create a better awareness

around the individual needs of pupils in schools, yet participants noted that it is overly medicalised, focuses exclusively on medical needs without any consideration given to mental wellbeing, learning needs or individual experiences.

4.4 Health in Schools and the Covid-19 Pandemic

Several participants pointed out that all pupils during the current Covid-19 pandemic encountered problems that are similar to the experiences of CYP with long-term health conditions. These include an extended absence from their educational setting, working in isolation, a phased return connected with a lot of insecurity, missing out on learning and social opportunities, concerns about physical and mental health and many emotional challenges around engagement and reintegration. Plans around the recovery curriculum (Carpenter & Carpenter, 2020) and reintegration post-lockdown should show a way forward for the future for pupils after extended medical absences. Experts agree that any recovery curriculum post-lockdown needs to creatively respond to wellbeing needs, acknowledge the disruption caused by the pandemic and manage higher than usual stress and anxiety levels (BBC, 2021; O'Connor, 2021). Schools may consider the same themes when planning for the return of students after an extended absence for health-related reasons.

The Covid-19 pandemic highlighted the importance of health education in schools. Going forward, basic safety measures during the pandemic, such as hand washing, social distancing and staying at home while unwell must form the base of health education for all pupils. Additionally, risk factors of Covid-19, such as obesity,

poverty and other community health risk factors should be addressed in schools from an early age. In the course of a rounded health education, schools may consider raising awareness for different medical conditions as well as responses to emergency situations. This may lead to a reduction in stigma and perhaps to more inclusive school communities and workplaces.

The pandemic increased the levels of social, environmental and economic inequality in society thereby damaging health and wellbeing (Marmot et al., 2021). Recommendations to fight health inequity exacerbated by the pandemic include the commitment to better engage and communicate with young people; development of early response to improve mental and physical health (children 0-5); addressing the social determinants of health and improving educational attainment.

The Covid-19 pandemic created unexpected challenges for schools around the world. At the same time, it showed the importance of prioritising health. In a school, this can mean having an involved school nurse on site, setting leadership priorities, and raising awareness for health-related needs. It is my hope that those measures will benefit future pupils with health-related needs in a way that will make their support and integration better structured and more easily accessible.

5. The Implications of this Research for Educational Psychology Applied Practice

5.0 Aims

For the purpose of this section, key themes that emerged from the data were combined with implications for the EP practice. The resulting general recommendations were included in one integrated section. The chapter discusses the ways in which EPs can work with adolescents with health-related needs on an individual, organisational and national level. The limited participant base does not allow for wide-ranging recommendations but the themes that were generated may serve as a base for further explorations. Strengths and limitations of the current research as well as implications for future research are considered.

5.1 The Role of the EPs

There are key themes emerging from this research that may be considered in the EP profession as well as by wider stakeholders, for instance schools, local educational authorities, and national organisations, such as the Office for Standards in Education, Children's Services and Skills (Ofsted). These messages include the many invisible needs associated with health-related needs, the lack of monitoring of the support and outcomes of pupils with health-related needs, the frequent lack of adherence to statutory guidance, the implications of the Equality Act for this population, and the importance of self-advocacy skills for adolescents with and without health conditions. Recommendations for educational psychologists are listed below for actions on individual, organisational and at a national level.

5.1.1 Individual Level

Consultation

Educational psychologists are in the right position to gain insight into health-related needs that may remain invisible to the wider school community by means of joint school-family consultations involving parents/carers (Wagner, 2017).

Educational psychologists can explore learning needs that require differentiation and reasonable adjustments as well as mental health needs that may require further support. Educational psychologists can also model good examples by including adolescents and their families in goal setting and decision making. The statutory guidance (DfE, 2015) requires schools to provide “appropriate support” (p.5) and “appropriate monitoring” (p.11). In consultation with school staff and parents/carers as well as the adolescents, the term *appropriate* needs to be clearly defined and well documented.

Although a consultation starts at the individual level, its ultimate goal is to enhance systems thinking within the school and to enable school staff to notice patterns that occur over time and in wider contexts. For instance, if adolescents with health conditions struggle to discuss their needs, schools may assume that all adolescents are at some point reluctant to talk about their views or needs and they will all benefit from working together on this area. Research shows for example that pupils experiencing mental health problems, such as anxiety or depression find it very difficult to communicate about their experiences (Dunsmuir and Cobbald, 2017). Educational psychologists can work with teachers on bespoke activities and interventions that will help all students.

5.1.2 Organisational Level

Support for school staff

Educational psychologists may have the skills to alert schools to the need of organisational-level work and then deliver such work effectively and in a time-efficient way that is appropriate for the school ethos (Richards, 2017). When planning interventions for pupils with health-related needs, EPs can support staff in exploring any barriers to learning and how to overcome those. Schools may wish to invite EPs to pupil progress meetings and discuss generic support for this vulnerable population as well as specific interventions in some circumstances where a young person faces particular challenges. Together with staff, EPs can unpick learning and social, emotional and mental health needs from physical needs and develop a better understanding of how pupils can be supported in the school context. A trusting relationship with staff members and a sharp insight into school structures may enhance EPs' ability to upskill school staff. As part of their termly review, EPs may consider a set of questions to ask schools about the number of CYP presenting with health-related needs in a similar way they ask about looked after CYP or CYP with safeguarding concerns. If this becomes a standing item for review meetings, together with schools EPs can monitor what, if any, direct action is required. On these occasions EPs may consider reminding schools of the importance of having a medical lead. Additionally, this may give EPs the opportunity to raise awareness for pupils' rights enshrined in the *Equality Act 2010* and other legislation, such as the

Statutory Guidance for Supporting Pupils at School with Medical Conditions (DfE, 2015).

Knowledge exchange

Educational psychologists may consider opportunities for knowledge exchange among schools in a geographical area or a cluster, similarly to initiatives that are in place for SEND/SENCo's. This may enable medical leads to share best practice. EPs can offer proactive support for the organisation of such meetings and ensure that healthcare professionals, such as school nurses or GPs are invited in order to enhance seamless collaboration and to gain a better picture of opportunities and systems within an area.

Raising awareness

Pupils attending schools with long-term and complex health-conditions may need ongoing support while in school to manage their health condition and stay safe and well. Some pupils may need monitoring or emergency interventions. Others may have unpredictable changes in their condition over time, which can result in extended absences. All of these factors may impact on these pupils' access to learning. It is important for schools to have systems in place for identifying pupils whose access to learning is impeded by their physical health. One of the ways that this can be achieved is by improving teacher awareness about the impact of physical health on mental health and learning needs.

To ensure equal opportunities for pupils with health-related needs, EPs may consider highlighting the individual experiences of pupils and the systems around them that can enable them. This should include an emphasis on the burden experienced by parents of children and young people with long-term health conditions. Educational psychologists can remind schools to include all associated needs in support planning procedures and trainings. By offering training, EPs can work with teachers to tailor support specific to learning needs and barriers to learning, and to think about how to overcome those.

5.1.2.1 Levels of advocacy. Both self- and parental advocacy play a major role in enhanced support and outcomes. Educational psychologists are well positioned to advocate for adolescents, whose parents/carers may not be in a strong position to provide this kind of support. Advocacy might include highlighting the rights of an individual as well as their needs and ways in which these can be communicated. Often it can be difficult for adolescents to challenge schools or to advocate for themselves, or they might simply not want to do that. Educational psychologists can create an awareness around their rights and needs and ensure that there are transparent systems in place in school to provide support. With the consent of the individual, EPs may reflect upon opportunities to harness peer power and include peers in the support network. Interventions that focus on communication and self-advocacy can then target peer groups without singling out individual pupils.

Self-advocacy and independence

This research shows that pupils' self-advocacy skills can be an important protective factor. At the same time, several pupils expressed their reluctance to advocate for themselves. EPs are well placed to plan targeted interventions to enhance self-advocacy skills for this age group, make it part of their preparation for independence and empower adolescents through improved communication and self-advocacy skills. Educational psychologists can examine research around targeted intervention programmes aimed to improve self-advocacy skills of young people and ensure that school interventions are informed by evidence base. Educational psychologists can model these interventions for schools and encourage them to tailor and optimise them. Throughout individual and organisational work, EPs should highlight the importance of participation in support planning both in schools as well as to families.

Ladder of participation

Research shows that parents (Coyne, 2006) as well as their children are keen to ensure that children and young people have the right to speak for themselves and challenge the traditional advocacy role of parents. This may enhance their understanding of their needs and rights and promote their self-esteem and positive self-regard (Phillips, 1990). Meaningful participation, however, remains a challenge. A ladder of participation entailing eight levels of pupil engagement in decision making processes was constructed by Hart (1992). The rungs of the ladder range from three levels of non-participation (manipulation, decoration and tokenism) to five different degrees of participation based on a number of important requirements for meaningful participation in processes. These requirements concern children and

young people's understanding of the intentions behind plans; their knowledge about why their involvement is important and who decided to involve them; whether or not they have a meaningful role; whether or not their participation is informed and voluntary. It was concluded that schools are essential venues to develop children and young people's sense of democratic engagement. Additionally, families should be seen as primary influencers of their children's sense of social responsibility and competence. Therefore, a joint home-school approach should be encouraged to develop the framework to foster informed participation of young people in decision making.

5.1.3 Systemic (Local Authority and National) Level

Training

Educational psychology services often hold training around guidance and policy, inclusion according to the *Equality Act 2010* and statutory duties. In the course of such training, EPs may consider highlighting the population of pupils with long-term health conditions. Research estimates that nearly 25% of 11-15 year olds have a long-term illness or disability and one in ten of 10-24 year olds report a disability that prevents them from completing normal daily activities (AYPH, 2019). This means, every school is likely to have pupils with long-term health conditions of varying degrees of severity. Training around this population can highlight the link between mental and physical health, advocate for support that goes beyond physical barriers, work with schools to improve mental health provision and to develop appropriate interventions. Educational psychologists may explore training opportunities to work with school nurses on recognising mental health needs, and

screening pupils with medical conditions for mental health needs. Educational psychologists may also explore avenues to work with teacher training providers to highlight the ways medical conditions can impact learning and mental wellbeing and how support can be developed for CYP with health conditions.

Research on implementation science (Kelly, 2017) shows that initial training alone is generally not enough to support the development of practitioners' skills and confidence. Follow up coaching and consultation to support and sustain practice as well as continuous assessment of practice and outcomes are essential to achieve wide systemic change. Quality of leadership and consideration of the school ethos when planning training are further key components of an effective implementation of interventions.

Mental health support

All participant groups addressed the issue of mental health needs associated with health conditions. Educational psychologists and professional bodies, such as the Association of Educational Psychologists or the Division of Educational and Child Psychology of the British Psychology Society, may reflect upon advocating for counsellors in every school, to provide a service that is accessible, child-friendly and proactive. This is consistent with the plan of Anne Longfield, the former Children's Commissioner for England (Children's Commissioner, 2018). Having mental health provision on site may encourage a more proactive approach towards supporting the pupil population with health-related needs.

Emerging data from across the globe show the deteriorating patterns in pupil mental health due to the current pandemic (Fazel & Hoagwood, 2021). At the same time, access to mental health services is disrupted (Newlove-Delgado et al., 2021; Thomas, 2020) and many pupils who were previously able to access services can no longer do so. This places the onus on schools to identify mental health needs and provide support to their pupils. Structured and unstructured opportunities within the school environment to improve self-esteem, self-acceptance and sense of belonging will contribute to improved outcomes for all pupils, not only those with additional needs. For a paradigm shift in mental health support in schools, the voice of young people needs to be in the forefront when interventions are being developed and evaluated. Recent research shows that pupils have little confidence that their views make a difference (Mansfield et al., 2020). A major challenge for mental health support in schools will be to shape it in a way that will seem accessible and desirable for young people.

5.2 Implications for Future Research

It was beyond the capacity of this research to analyse and understand any socio-economic differences in terms of providing support for adolescents with health-related needs. It was however discussed by participants that schools in areas of highest deprivation are more welcoming towards health-services than other areas. It might be valuable for future researchers to gain insight into the reasons behind this trend and apply this knowledge to engage harder to reach schools.

Another trend discussed by the participants relates to the engagement of parents and carers and their children. Participants have noted that the Covid-19 pandemic brought a U-Turn in the relationship of school nurses with harder to engage families. It may be linked to the use of virtual methods with reduced face-to-face contact, but more research is needed to understand it. As discussed previously, parental engagement is a major protective factor in terms of support and outcome of adolescents with health-related needs.

This research found that currently there are no standardised reporting criteria in place to monitor the support for pupils with health-related needs at a school level, within Local Authorities or on national level. Future explorations may consider ways to enhance scrutiny for the support and outcomes of this population, for instance by including those in Ofsted education inspection framework criteria.

5.3 Limitations of the Current Research

An evaluation of the current study to identify limitations and weaknesses gave me an opportunity to critically reflect on the various aspects and evaluate those. This reflection aims to highlight the researchers embedded role, as discussed by Pellegrini (2009).

I started exploring this research area during Year 1 of my doctoral training. I was committed to the topic and it may have led to a strong enthusiasm to touch upon as many angles as possible. In hindsight, it may have been better to reduce the research questions and explore fewer aspects more in depth. The survey may have contained too many questions. On reflection, I wonder whether the survey was able

to capture the complexity of the participants' experiences and practices. Some of the questions started with phrases such as 'To what extent' or 'How confident'. This may be open to interpretation and therefore influence the validity of the results.

Recruiting participants for educational research during a global pandemic was challenging. The use of online platforms made participation possible and, in fact, enhanced the geographical dispersion of participants. However, recruitment occurred largely through self-selection and this created issues that need to be acknowledged. Professionals, such as school nurses or advisory teachers who participated in this research, may have been driven by their intention to demonstrate their good practice. Pupils and parents on the other hand, may have participated because they wanted to share their poor experience. I hoped to reconcile this by highlighting the different angles of themes emphasised by the different participant groups. Focusing on one participant group only may have led to a greater understanding of their experiences. All but one family were recruited through charities, which excludes any potential participants who fulfil the inclusion criteria but are not members of any charities or registered advocacy groups. Being members of such charities also implies a level of advocacy and potentially literacy, and this research may not have fully addressed the concerns of families who do not have that level of agency. There was little diversity in terms of ethnicity among the participants. It is possible that families and professionals of different ethnic minorities have different experiences within the educational and healthcare system. A more comprehensive look at geographical representation may have highlighted different experiences and practice between different regions of the country, such as the North

and the South of England or urban and rural areas. It was beyond the capacity of this research to further examine those differences.

The limited participant base will not allow for any generalisation of the findings. However, the themes that have emerged may provide a valuable starting point for further explorations. The large number of themes identified by the participants did not allow for a more critical in-depth analysis. I hoped to increase the validity of the findings by asking some of my participants to read through the themes that were identified. I also liaised with two fellow Trainee Educational Psychologists with similar research interests from the Universities of Sheffield and Nottingham to compare themes around pupil experiences.

5.4 Contribution to Knowledge and Dissemination

Throughout this research it became apparent that the overarching research topic of the current study was under-explored. Furthermore, the research questions addressed several gaps, including identifying any learning and social, emotional and mental health needs associated with long-term health conditions, lack of transparency of support systems within schools both from the families' and from school nurses' perspective and lack of pathways of communication for healthcare professionals and schools supporting the same pupils. Educational psychologists are well placed to provide input through the use of their skillset (for instance, consultation, training and systemic work). I hope that the findings of this study will contribute to an increased understanding of the support currently provided for this vulnerable group of pupils and, in my future practice, I can contribute to facilitating change through engaging constructively with stakeholders.

I have a strong intention to disseminate the key messages of this research to wider stakeholders involved in the support and outcomes of pupils with health-related needs. I will pursue this line of research in the years to come. I will seek opportunities to publish the findings in relevant professional journals. Together with another trainee educational psychologist with similar research interests, we are planning training for schools and healthcare professionals to highlight some of our key findings and recommendations. There has been interest from children's hospitals around the country in such training. I have also considered creating a Webinar and an accompanying small booklet offering bespoke advice on how schools can meet the needs of pupils with health conditions. I am hoping to present to EPs within the Local Authority where I am currently completing my placement, as well as the TEP Annual Conference 2022 and other relevant conferences. I am also seeking to provide training for school nurses around the impact of medical conditions on mental health as well as learning and have been in conversations with the School and Public Health Nurses Association about such opportunities.

5.5 Conclusion

This study sought to investigate the ways health and education services collaborate to improve the support and outcomes of adolescents with health-related needs in schools. The research was composed of three parts: The first stage entailed a quantitative survey as well as qualitative semi-structured interviews conducted with school nurses; the second stage sought the views of pupils and their parents through semi-structured interviews; and the third stage explored the views of educational professionals. In summary, all participant groups felt that support can be

enhanced and identified gaps in practice and methods to rectify this. The main theme identified by all participants revolves around communication. Communication flow (Blase et al. 2012) between health and education services, between schools and healthcare professionals, between families and schools and between individual pupils and individual teachers can be improved. The findings suggest that EPs could have a role in supporting schools working with pupils with health-related needs and their families. Educational psychologists can address some of the concerns identified by this research by providing support on an individual, organisational and national level.

Throughout this study, the Covid-19 global pandemic was mentioned as a barrier to research. As we are slowly recovering from the impact of the pandemic, we need to consider opportunities to rethink and “build back better” (Biden, 2020). The pandemic shed light on the experiences of those working and learning in isolation with health concerns and we now have a better understanding of mental health and learning issues surrounding this. I remain hopeful that this improved understanding will enhance the support and experiences of adolescents living with long-term health needs and ultimately contribute to their outcomes in a positive way.

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7. APPENDICES

Appendix I: Ethics Application Form

Doctoral Student Ethics Application Form

Institute of Education



Anyone conducting research under the auspices of the Institute of Education (staff, students or visitors) where the research involves human participants or the use of data collected from human participants, is required to gain ethical approval before starting. This includes preliminary and pilot studies. Please answer all relevant questions in simple terms that can be understood by a lay person and note that your form may be returned if incomplete.

Registering your study with the UCL Data Protection Officer as part of the UCL Research Ethics Review Process

If you are proposing to collect personal data i.e. data from which a living individual can be identified **you must be registered with the UCL Data Protection Office before you submit your ethics application for review.** To do this, email the complete ethics form to the [UCL Data Protection Office](#). Once your registration number is received, add it to the form* and submit it to your supervisor for approval. If the Data Protection Office advises you to make changes to the way in which you propose to collect and store the data this should be reflected in your ethics application form.

Please note that the completion of the [UCL GDPR online training](#) is mandatory for all PhD students.

Section 1 – Project details

- | | |
|--|---|
| a. Project title | Supporting students with medical conditions in secondary schools. |
| b. Student name and ID number (e.g. ABC12345678) | Erika Payne , 18098882 |
| c. *UCL Data Protection Registration Number | Z6364106/2020/03/06 |
| a. Date Issued: 02/03/2020 | |
| d. Supervisor/Personal Tutor | Dr Zachary Walker/Dr Jeremy Monsen |
| e. Department | UCL IOE Professional Educational, |

Child and Adolescent Psychology

- f. Course category (Tick one) PhD
EdD
DEdPsy

g. **If applicable**, state who the funder is and if funding has been confirmed.

h. Intended research start date 01/04/2020

i. Intended research end date 01/04/2021

j. Country fieldwork will be conducted in **UK**

k. If research to be conducted abroad please check the [Foreign and Commonwealth Office \(FCO\)](#) and submit a completed travel risk assessment form (see guidelines). If the FCO advice is against travel this will be required before ethical approval can be granted: [UCL travel advice webpage](#)

l. Has this project been considered by another (external) Research Ethics Committee?

Yes External Committee Name:

Date of Approval:

No **go to Section 2**

If yes:

- Submit a copy of the approval letter with this application.
- Proceed to Section 10 Attachments.

Note: Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the [National Research Ethics Service \(NRES\)](#) or [Social Care Research Ethics Committee \(SCREC\)](#). In addition, if your research is based in another institution then you may be required to apply to their research ethics committee.

Section 2 - Research methods summary (tick all that apply)

- Interviews
- Focus Groups
- Questionnaires
- Action Research
- Observation
- Literature Review
- Controlled trial/other intervention study
- Use of personal records
- Systematic review – **if only method used go to Section 5**
- Secondary data analysis – **if secondary analysis used go to Section 6**
- Advisory/consultation/collaborative groups
- Other, give details:

Please provide an overview of the project, focusing on your methodology. This should include some or all of the following: purpose of the research, aims, main research

questions, research design, participants, sampling, data collection (including justifications for methods chosen and description of topics/questions to be asked), reporting and dissemination. Please focus on your methodology; the theory, policy, or literary background of your work can be provided in an attached document (i.e. a full research proposal or case for support document). *Minimum 150 words required.*

The project aims to explore current practice of secondary schools in Hertfordshire to support students with medical needs. Based on current legislation and guidance, five areas of interest were developed for further exploration: 1) Policies, plans, procedures, systems; 2) Transition/integration; 3) Inclusion; 4) Collaboration; 5) Social emotional wellbeing.

The research aims to explore the factors that are potentially preventing students with medical conditions from succeeding in schools. Furthermore, it aims to identify aspects of support that are working well, areas of difficulty and ideas to improve support to enable pupils with medical conditions to succeed academically and socially.

The research question is: How can educational psychologists empower schools to take responsibility for enabling children with medical conditions to succeed?

The first phase of the project will entail a quantitative Qualtrics survey with open and closed questions sent to all secondary schools in Hertfordshire to the attention of the school nurse, the staff member in charge of students with medical needs or the safeguarding lead. The second phase of the project will entail a quantitative Qualtrics survey with open and closed questions sent to students with medical needs identified by their schools. Based on the results of the first survey, I am interested to explore how they see the support they receive from their school and whether their views differ from the schools' views. The results of both surveys will be analysed using quantitative frequency count.

Finally, in the last phase of the project I aim to conduct three focus group interviews: one with school nurses, one with students with medical needs and one with parents and carers of students with medical needs. The goal of the focus group interviews is to gain a rich insight into the lived experiences of these groups and further explore specific areas of interest that are highlighted through the surveys. The data from the surveys will be analysed through descriptive statistics methods. The focus group interviews will be recorded, transcribed and analysed through thematic analysis.

The findings will be reported to UCL Institute of Education in the format of a doctoral thesis. Furthermore, the findings will also be reported to stakeholders and secondary schools within the local authority. This can take place in form of a training or professional development event.

Section 3 – research Participants (tick all that apply)

- Early years/pre-school
- Ages 5-11
- Ages 12-16
- Young people aged 17-18
- Adults please specify below
- Unknown – specify below
- No participants

School nurses or other members of staff in charge of students with medical needs; parents and carers of students with medical needs

Note: Ensure that you check the guidelines carefully as research with some participants will require ethical approval from a different ethics committee such as the [National Research Ethics Service](#) (NRES) or [Social Care Research Ethics Committee](#) (SCREC).

Section 4 - Security-sensitive material (only complete if applicable)

Security sensitive research includes: commissioned by the military; commissioned under an EU security call; involves the acquisition of security clearances; concerns terrorist or extreme groups.

- a. Will your project consider or encounter security-sensitive material?
Yes* No
- b. Will you be visiting websites associated with extreme or terrorist organisations?
Yes* No
- c. Will you be storing or transmitting any materials that could be interpreted as promoting or endorsing terrorist acts?
Yes* No

** Give further details in **Section 8 Ethical Issues***

Section 5 – Systematic reviews of research (only complete if applicable)

- a. Will you be collecting any new data from participants?
Yes* No
- b. Will you be analysing any secondary data?
Yes* No

** Give further details in **Section 8 Ethical Issues***

*If your methods do not involve engagement with participants (e.g. systematic review, literature review) **and** if you have answered **No** to both questions, please go to **Section 8 Attachments**.*

Section 6 - Secondary data analysis (only complete if applicable)

- a. Name of dataset/s
- b. Owner of dataset/s
- c. Are the data in the public domain?
Yes No
If no, do you have the owner's permission/license?
Yes No*
- d. Are the data special category personal data (i.e. personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation)?
Yes* No
- e. Will you be conducting analysis within the remit it was originally collected for?
Yes No*
- f. **If no**, was consent gained from participants for subsequent/future analysis?
Yes No*

g. **If no**, was data collected prior to ethics approval process?

Yes No*

* Give further details in **Section 8 Ethical Issues**

*If secondary analysis is only method used **and** no answers with asterisks are ticked, go to **Section 9 Attachments**.*

Section 7 – Data Storage and Security

Please ensure that you include all hard and electronic data when completing this section.

a. Data subjects - Who will the data be collected from?

Schools, young persons and parents

b. What data will be collected? Please provide details of the type of personal data to be collected

Quantitative data through survey regarding school's practice to support students with medical needs, qualitative data through focus group interviews with school staff, students and parents about lived experience

Data will be collected on the students' age, gender and medical condition

Is the data anonymised? Yes No*

Do you plan to anonymise the data? Yes* No

Do you plan to use individual level data? Yes* No

Do you plan to pseudonymise the data? Yes* No

* Give further details in **Section 8 Ethical Issues**

c. **Disclosure** – Who will the results of your project be disclosed to?

UCL Institute of Education in the course of my completion of the DEdPsy, Hertfordshire Local Authority and perhaps later on publication will be considered

Disclosure – Will personal data be disclosed as part of your project?

no

d. Data storage – Please provide details on how and where the data will be stored i.e.

UCL network, encrypted USB stick**, encrypted laptop** etc. encrypted laptop

** Advanced Encryption Standard 256 bit encryption which has been made a security standard within the NHS

e. **Data Safe Haven (Identifiable Data Handling Solution)** – Will the personal identifiable data collected and processed as part of this research be stored in the UCL Data Safe Haven (mainly used by SLMS divisions, institutes and departments)?

Yes No

f. How long will the data and records be kept for and in what format?

Electronic format for 10 years

Will personal data be processed or be sent outside the European Economic Area? (If yes, please confirm that there are adequate levels of protections in compliance with GDPR and state what these arrangements are)

no

Will data be archived for use by other researchers? (If yes, please provide details.)

no

- g. If personal data is used as part of your project, describe what measures you have in place to ensure that the data is only used for the research purpose e.g. pseudonymisation and short retention period of data'.

N/A

** Give further details in **Section 8 Ethical Issues***

Section 8 – Ethical Issues

Please state clearly the ethical issues which may arise in the course of this research and how will they be addressed.

All issues that may apply should be addressed. Some examples are given below, further information can be found in the guidelines. *Minimum 150 words required.*

Electronic survey sent to secondary schools in Hertfordshire as well as to students with medical needs identified by their school. Informed consent will be needed for members of staff as well as students. For all students under the age of 16 parental consent will be needed.

In the course of the focus group interviews potentially sensitive topics may be discussed (e.g. bullying). The debrief will need to include advice or guidance on how to proceed and stay safe in case a sensitive topic caused emotional distress.

All data will remain confidential and will be anonymised. No individual schools, members of staff or students will be named. Data will be stored securely on a password protected laptop in an encrypted folder.

All data will be reported in a collated form and all details will remain confidential.

The findings of the report will be shared with the UCL Institute of Education. Furthermore, the findings will be shared within the Local Authority. Eventual publication of the report is planned.

Please confirm that the processing of the data is not likely to cause substantial damage or distress to an individual

Yes

Section 9 – Attachments. *Please attach the following items to this form, or explain if not attached*

- a. Information sheets, consent forms and other materials to be used to inform potential participants about the research (List attachments below)

Yes No

[Adult consent form](#)

[Student consent form](#)

[Consent form for parents and carers](#)

[Information sheets for parents and carers, school staff and students](#)

- b. Approval letter from external Research Ethics Committee Yes
- c. The proposal ('case for support') for the project Yes

Section 10 – Declaration

I confirm that to the best of my knowledge the information in this form is correct and that this is a full description of the ethical issues that may arise in the course of this project.

I have discussed the ethical issues relating to my research with my supervisor.

Yes No

I have attended the appropriate ethics training provided by my course.

Yes No

I confirm that to the best of my knowledge:

The above information is correct and that this is a full description of the ethics issues that may arise in the course of this project.

Name [Erika Payne](#)

Date [12/02/2020](#)

Please submit your completed ethics forms to your supervisor for review.

Notes and references

Professional code of ethics

You should read and understand relevant ethics guidelines, for example:

[British Psychological Society](#) (2018) *Code of Ethics and Conduct*

Or

[British Educational Research Association](#) (2018) *Ethical Guidelines*

Or

[British Sociological Association](#) (2017) *Statement of Ethical Practice*

Please see the respective websites for these or later versions; direct links to the latest versions are available on the [Institute of Education Research Ethics website](#).

Disclosure and Barring Service checks

If you are planning to carry out research in regulated Education environments such as Schools, or if your research will bring you into contact with children and young people (under the age of 18), you will need to have a Disclosure and Barring Service (DBS) CHECK, before you start. The DBS was previously known as the Criminal Records Bureau (CRB). If you do not already hold a current DBS check, and have not registered with the DBS update service, you will need to obtain one through at IOE.

Ensure that you apply for the DBS check in plenty of time as will take around 4 weeks, though can take longer depending on the circumstances.

Further references

The www.ethicsguidebook.ac.uk website is very useful for assisting you to think through the ethical issues arising from your project.

Robson, Colin (2011). *Real world research: a resource for social scientists and practitioner researchers* (3rd edition). Oxford: Blackwell.

This text has a helpful section on ethical considerations.

Alderson, P. and Morrow, V. (2011) *The Ethics of Research with Children and Young People: A Practical Handbook*. London: Sage.

This text has useful suggestions if you are conducting research with children and young people.

Wiles, R. (2013) *What are Qualitative Research Ethics?* Bloomsbury.

A useful and short text covering areas including informed consent, approaches to research ethics including examples of ethical dilemmas.

Departmental use	
If a project raises particularly challenging ethics issues, or a more detailed review would be appropriate, the supervisor must refer the application to the Research Development Administrator via email so that it can be submitted to the IOE Research Ethics Committee for consideration. A departmental research ethics coordinator or representative can advise you, either to support your review process, or help decide whether an application should be referred to the REC. If unsure please refer to the guidelines explaining when to refer the ethics application to the IOE Research Ethics Committee, posted on the committee's website.	
Student name	Erika Payne
Student department	Institute of Education
Course	Doctorate in Educational, Child and Adolescent Psychology
Project title	Supporting students with medical conditions in secondary schools
Reviewer 1	
Supervisor/first reviewer name	Zachary Walker
Do you foresee any ethical difficulties with this research?	No- it looks like it will meet all requirements.
Supervisor/first reviewer signature	
Date	02/02/2020
Reviewer 2	
Second reviewer name	Jeremy J. Monsen
Do you foresee any ethical difficulties with this research?	No – it looks like it will all requirements and is low in intrusiveness.

Supervisor/second reviewer signature	
Date	2 nd of March 2020
Decision on behalf of reviews	
Decision	Approved <input type="checkbox"/>
	Approved subject to the following additional measures <input type="checkbox"/>
	Not approved for the reasons given below <input type="checkbox"/>
	Referred to REC for review <input type="checkbox"/>
Points to be noted by other reviewers and in report to REC	
Comments from reviewers for the applicant	
<i>Once it is approved by both reviewers, students should submit their ethics application form to the Centre for Doctoral Education team: IOE.CDE@ucl.ac.uk.</i>	

Appendix II: Consent Form

Institute of Education



UCL

Supporting students with medical conditions in secondary schools Consent form

If you are happy to participate in this study, please complete this consent form.

	Yes	No
I have read and understood the information leaflet about the research	<input type="checkbox"/>	<input type="checkbox"/>
I agree to be filmed during the focus group interview	<input type="checkbox"/>	<input type="checkbox"/>
I understand that if any of my words are used in reports or presentations, they will not be attributed to me	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can withdraw from the project at any time, and that if I choose to do this, any data I have contributed will not be used.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that I can contact Erika Payne at any time and request for my data to be removed from the project database.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the results will be shared in research publications and presentations.	<input type="checkbox"/>	<input type="checkbox"/>
I agree for the data I provide to be archived at the UK Data Service. I understand that other authenticated researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that the other genuine researchers may use my words I n publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	<input type="checkbox"/>	<input type="checkbox"/>

Name:

Signed:

Date:

Erika Payne
UCL Institute of Education
20 Bedford Way London WC1H 0AL
erika.payne@ucl.ac.uk

Appendix III: Letter of Information

Institute of Education



Supporting students with medical needs in secondary schools

Information sheet for students

My name is Erika Payne and I am inviting you to take part in my research project titled “Supporting students with medical needs in secondary schools”.

I am hoping to find out about secondary schools’ current practices to empower their students with medical needs to succeed. I am particularly interested in exploring what policies are in place, how students’ transition into secondary school and their inclusion is ensured, how schools collaborate with parents and medical professionals and what measures they take to enhance the social emotional wellbeing of students with medical needs. This information sheet will try and answer any questions you might have about the project, but please do not hesitate to contact me if there is anything else you would like to know.

Who is carrying out the research?

Erika Payne Trainee Educational Psychologist at UCL Institute of Education
Erika.payne@ucl.ac.uk

Why are we doing this research?

Currently, the educational outcomes of students with medical needs are not as good as the outcomes of other students. Adolescents with a health condition are more likely to end up not in employment, education or training after the age of 19. I would like to find out how schools can better help their students succeed. I would also like to find out what currently works well and what areas could be improved.

Why am I being invited to take part?

Your participation will inform schools about practices that are currently working and support that could be improved. I will be talking to school nurses and other members of school staff, parents and carers as well as students. Some participants will only be invited to complete a survey. Others will be invited to participate in a group discussion after completing the survey.

What will happen if I choose to take part?

First, you will be asked to complete an online survey. This will take approximately 15 minutes. If you wish to participate in a focus group interview, subsequently you may get an invitation. Not all participants who complete the survey will be invited, only approximately six school nurses or other members of school staff, six parents and six students. I am interested to find out whether schools and students view current practices the same way.

The focus group interview will take approximately 40 or 50 minutes. The location, the date and the time will be agreed on with the participants. The interviews will be recorded, so they can later be transcribed. Nobody other than the researcher will see the videos. They will be stored in an encrypted folder on a password protected computer and deleted according to the GDPR regulations.

Will anyone know I have been involved?

All data will be confidential. If I may have to disclose information, for example if I have concerns about the welfare of a participant, then my obligation to do so will be made clear. All contributions will be anonymised, although specific medical conditions may be mentioned. This will be done while ensuring that no participants can be identified. For instance: *Boy, aged 16, Type One Diabetes*

Could there be problems for me if I take part?

No. If at any point you feel uncomfortable to continue, you can stop. If difficult subjects are discussed (for instance bullying), it will be ensured that all participants remain safe and guidance will be provided to manage potential emotional distress.

What will happen to the results of the research?

The findings of the research will be presented in the form of a doctoral dissertation to UCL Institute of Education. The findings will also be shared with all participating schools as well as other schools in Hertfordshire. Additionally, the findings may be presented at trainings for educational professionals and perhaps will be published in a professional journal. The data gathered for this research will be stored securely for 10 years.

Do I have to take part?

It is entirely up to you whether or not you choose to take part. We hope that if you do choose to be involved, then you will find it a valuable experience. If you decide not to take part, there will be absolutely no consequences for you.

Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in research studies, click [here](#)

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Appendix IV: Sample Questions from the Qualtrics Survey for Young People with Responses

Q7. Do you know if supply teachers are briefed on your medical condition?

#	Answer	%	Count
1	Yes	0%	0
2	No	33%	1
3	Not sure	67%	2
	Total	100%	3

Q8. Have you ever been rewarded for your attendance, even if it was below a 100% due to medical appointments etc?

#	Answer	%	Count
1	Yes	33%	1
2	No	67%	2
	Total	100%	3

Q9. Is there a designated staff member in your school to support pupils with medical needs?

#	Answer	%	Count
1	Yes	0%	0
2	No	0%	0
3	Not sure	100%	3
	Total	100%	3

Q10. If yes, does that person liaise with your parents as well as healthcare professionals to optimise your support?

#	Answer	%	Count
1	Yes	0%	0
2	No	33%	1
3	Not sure	67%	2
	Total	100%	3

Q11. Do you know where medications and/or medical devices are kept in your school and are you able to access storage facilities at all times?

#	Answer	%	Count
1	Yes	33%	1
2	No	67%	2
	Total	100%	3

Q12. If you are unwell, is there a protocol in place to ensure that you are not sent to the medical room unaccompanied?

#	Answer	%	Count
1	Yes	67%	2
2	No	33%	1
	Total	100%	3

Q13. Does your school have a school nurse on site?

#	Answer	%	Count
4	Yes	33%	1
5	No	67%	2
	Total	100%	3

Q14. If you are unwell or have concerns, who you can talk to?

14. If you are unwell or have concerns, who you can talk to?

Parents, Friends, teachers, school nurse

Parents

Whoever is on duty

Q15. During your transition to secondary school were you and/or your parents invited to discuss your support?

#	Answer	%	Count
1	Yes	33%	1
2	No	33%	1
3	Not sure	33%	1
	Total	100%	3

Q16. Do you have any experience with any of the following?

#	Question	Yes		No		Total
1	Special provisions (such as hospital schools)	0%	0	100%	3	3
2	A new diagnosis or a change in diagnosis during secondary school?	67%	2	33%	1	3
3	An extended absence due to medical reasons during secondary school?	33%	1	67%	2	3

Q17. If you answered yes to any item in question 2, can you provide some more details below?

3a. If you answered yes to any item in question 2, can you provide some more details below?

I got diagnosed with coeliac in year 11.

Diagnosed at secondary school in holidays

I had a lot of time off with appointments and operations

Q18. If you answered yes to any item in question 2, did a meeting take place between you and/or your parents, your school and your healthcare professionals to support your re-entry into your secondary school?

#	Answer	%	Count
1	Yes	33%	1
2	No	33%	1
3	Not sure	33%	1
	Total	100%	3

Students with medical needs in secondary schools

Start of Block: Information page

Q68 Thank you for taking part in this research project.

For the purpose of this survey, medical needs will be defined according to the nasen House terminology:

Acute conditions Those that are sudden and severe in onset (e.g. broken bones)

Chronic conditions Long-developing conditions which are persistent or lasting for more than three months (e.g. epilepsy)

Life-limiting/life-shortening conditions Those for which there is no reasonable hope of cure and from which children's or young people's life will be shortened (e.g. cystic fibrosis)

Life-threatening conditions Those for which curative treatment may be feasible but can fail (e.g. cancer)

If you are happy to participate in the study, please complete the consent form on the next page.

End of Block: Information page

Start of Block: Consent

Q1 I have read and understood the information about the research

Yes (1)

No (2)

Q2 I agree to be contacted for the focus group interview

Yes (1)

No (2)

Q3 I understand that if any of my words are used in reports or presentations, they will not be attributed to me

Yes (1)

No (2)

Q4 I understand that I can withdraw from the project at any time, and that if I choose to do this, any data I have contributed will not be used.

Yes (1)

No (2)

Q5 I understand that I can contact Erika Payne (erika.payne@ucl.ac.uk) at any time and request for my data to be removed from the project database.

Yes (1)

No (2)

Q6 I understand that the results will be shared in research publications and presentations.

Yes (1)

No (3)

Q7 I agree for the data I provide to be archived at the UK Data Service. I understand that other authenticated researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.

Yes (1)

No (2)

Q8 I understand that the other genuine researchers may use my words in publications, reports, web pages and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.

Yes (1)

No (3)

Q9 If you agree to be contacted for a focus group discussion that will probably take place in the autumn of 2020, please enter your email here.

End of Block: Consent

Start of Block: About yourself

Q69 Please tell me about yourself:

Q10 1. Do you work in a

- State school? (1)
 - Independent school? (2)
 - Cluster of state and independent schools? (3)
-

Q11 2. If you work in a cluster of schools, how many schools do you cover?

- 1-5 (1)
 - 5-10 (2)
 - 10-15 (3)
 - More than 15 (4)
 - N/A (5)
-

Q12 3. About your allocation...

- Are you allocated to a specific school in which you are the main school nurse? (1)
 - Does the school nursing team share responsibility for all the schools in your area (you do not have your 'own' schools)? (4)
-

Q13 4. What is your job title?

- School nurse (1)
 - School matron/sister (2)
 - Special needs school nurse (3)
 - Team leader/coordinator/clinical lead (4)
 - School health nurse/advisor (5)
 - Practice teacher (6)
 - Community staff nurse (7)
 - Specialist advisor (8)
 - Other (9)
-

Q14 5. If you answered 'other', please elaborate further

Q15 6. Is your employer

- The NHS (1)
 - The Local Authority (2)
 - An independent day and/or boarding school (3)
 - Private sector provider organisation (4)
 - Other (5)
-

Q16 7. If your responded "other", please explain here

Q17 8. How long have you been working in school nursing?

- Less than a year (1)
 - 1-5 years (2)
 - 5-10 years (3)
 - More than 10 years (4)
-

Q18 9. Approximately how many pupils are you responsible for?

- Less than 500 (1)
- 500-1000 (2)
- 1000-5000 (3)
- More than 5000 (4)

End of Block: About yourself

Start of Block: I. Policies, plans, procedures, systems

Q19 I. Policies, plans, procedures, systems

Q20 1. Does your school have a Medical Conditions Policy that is published on your website for current and future pupils?

- Yes (1)
 - No (2)
-

Q21 2. How often is it reviewed?

- Once a year (1)
 - Less frequently than once a year (2)
 - More frequently than once a year (3)
 - Never (4)
-

Q22 3. Do all students with medical needs have an Individual Healthcare Plan in your school?

- Yes (1)
 - No (2)
-

Q23 4. Do students with the same condition (e.g. asthma) share an emergency care plan or do they have individualised care plans?

- Shared emergency care plan (1)
 - Individualised care plan (2)
-

Q24 5. What medical conditions would warrant a shared emergency plan in your school?

Q25 6. Who is responsible for developing and monitoring the plans?

Q26 7. How often are they reviewed?

- Once a year (1)
 - Less frequently than once a year (2)
 - More frequently than once a year (3)
 - Never (4)
-

Q27 8. How often is staff training provided on medical conditions present in your school?

- a) Once a year (1)
 - b) Less frequently than once a year (2)
 - c) More frequently than once a year (3)
 - Never (4)
-

Q28 9. Whose responsibility is it to ensure that staff are trained?

Q29 10. Are parents, pupils and healthcare professionals involved in the training?

	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)
Pupils (1)	<input type="radio"/>				
Parents (2)	<input type="radio"/>				
Healthcare professionals (3)	<input type="radio"/>				

Q30 11. Are supply teachers briefed on medical conditions?

Yes (1)

No (2)

Q31 12. If your answer was yes on question 11, can you tell us what that briefing contains? For instance, do just tell supply staff that it is their responsibility to familiarise themselves with any medical conditions of those they teach by looking them up on the school's electronic system? Or do they receive more detailed information?

Q32 13. Is staff turnover/staff absence taken into account when planning training?

Yes (1)

No (2)

Q33 14. Does the attendance policy differentiate for pupils with medical needs?

Yes (1)

No (2)

Q34 15. Does the policy recognise and reward attendance of children with medical needs, even if it is below 100%?

Yes (1)

No (2)

Q35 16. Is there a designated staff member to support pupils with medical needs?

Yes (1)

No (2)

Q36 17. If yes, does that person liaise with parents as well as healthcare professionals to optimise support?

Yes (1)

No (2)

Q37 18. Do the Individual Healthcare Plans specify a procedure in the event that a child with medical conditions refuses to take medication or carry out the necessary procedures?

Yes (1)

No (2)

Q38 19. Are emergency drugs kept accessible, easy reach and not in a lockable cupboard?

Yes (1)

No (3)

Q39 20. Are emergency medication action plans for adrenaline auto injectors, Salbutamol and Buccolam kept with the device to follow in the event of an emergency?

Yes (1)

No (2)

Q40 19. Please think about the pupils you support and how aware they are about where their medications and devices are kept. You can divide up the pupils into different categories:

By fully aware, we mean they can access their own medication and could help others by sharing useful information with them. By highly aware, they can access their own medication and devices but can't help others. By somewhat aware, they are generally informed about where their medications are kept but they might occasionally forget how to access them. By slightly aware, they might forget where medications are kept but they know what staff members to ask. By not at all aware, they can't access their medication independently without members of staff telling them what the procedures are. For example, if you think that 10% of the pupils can't access their medication independently, please write 10 in 'not at all aware'

Are pupils with medical conditions aware of where the medications and devices are kept and how they can access storage facilities at all times?

Fully aware : _____ (1)

Highly aware : _____ (2)

Somewhat aware : _____ (3)

Slightly aware : _____ (4)

Not at all aware : _____ (5)

Total : _____

Q41 19. Is there a protocol in place to ensure that pupils with medical needs are not sent to the medical room unaccompanied?

Yes (1)

No (2)

Q42 20. If you regularly dispense medication in school - what policy does the school use for that?

Q43 21. Are safeguarding concerns around a pupils' medical needs included in the safeguarding policy?

Yes (1)

No (3)

End of Block: I. Policies, plans, procedures, systems

Q44 II. Transition/integration

Q45 1. Is there a plan in place to support the transition and integration of pupils with medical needs:

	Response	
	Yes (1)	No (2)
From primary to secondary school? (1)	<input type="radio"/>	<input type="radio"/>
From special provisions (such as hospital schools) to mainstream education? (2)	<input type="radio"/>	<input type="radio"/>
In case of a new diagnosis or a change in diagnosis? (3)	<input type="radio"/>	<input type="radio"/>
After a long absence? (4)	<input type="radio"/>	<input type="radio"/>

Q246 2. Are steps for reintegration laid out in the Individual Healthcare Plans?

Yes (1)

No (2)

Q47 3a. Are steps taken to ensure that pupils who cannot attend school because of their medical needs remain academically and socially integrated?

	Response	
	Yes (1)	No (2)
	<input type="radio"/>	<input type="radio"/>

Do they receive regular support to keep up with academic requirements? (1)

Does school liaise with hospital schools and/or tutors to better support pupils? (2)

Are video chats and other means of communication used to ensure that pupils who temporarily cannot attend school remain visible? (3)

Q48 3b. Are any other steps taken to ensure that pupils who cannot attend school because of their medical needs remain academically and socially integrated?

End of Block: II. Transition/integration

Start of Block: III. Inclusion

Q49 III. Inclusion

Q50 1. If a student is self-managing his/her medical condition (for instance diabetes through an insulin pump), is the management monitored?

Yes (1)

No (2)

Q51 2. Who is responsible for monitoring?

Q52 3. How would you rate the awareness of all staff interacting with pupils with medical needs of procedures in an emergency?

Please think about members of staff in your school/s and how aware they are of medical emergency procedures. You can divide up the staff members into different categories:

By fully aware, we mean they know what to do in case of a medical emergency and could share practice usefully with others. By highly aware, we mean they are good at following emergency procedures and they can explain them to others. By somewhat aware, we mean they are generally informed about what to do in case of a medical emergency but would need another member of staff to support them. By slightly aware, we mean they have been informed about procedures in case of a medical emergency. By not at all aware, we mean they have not been informed about procedures in case of a medical emergency.

For example, if you think that 10% of the staff did not receive training on medical emergency procedures, please write 10 in 'not at all aware'.

How would you rate the awareness of all staff interacting with pupils with medical needs of procedures in an emergency?

Fully aware : _____ (1)
Highly aware : _____ (2)
Somewhat aware : _____ (3)
Slightly aware : _____ (4)
Not at all aware : _____ (5)
Total : _____

Q53 4. Are other pupils aware of what to do in an emergency?

Please rate pupil awareness of medical emergency procedures according to the guidance in Question 3.

Fully aware : _____ (1)
Highly aware : _____ (2)
Somewhat aware : _____ (3)
Slightly aware : _____ (4)
Not at all aware : _____ (5)
Total : _____

Q54 5. How does the school ensure that the individual needs of different pupils with the same medical condition are differentiated? For instance, is it highlighted that that some children with Type One Diabetes might use a pump-therapy and some might use injections?

Q55 6. Are all staff interacting with a pupil with medical needs aware of the procedures to follow if a child is unwell?

Yes (1)

No (2)

Q56 7. How would you rate staff awareness regarding the impact of different medical conditions on a child's ability to learn?

Please rate how aware staff members are of the cognitive as well as social emotional impact of medical conditions on learning.

By fully aware, we mean they are aware of relevant research and could share practice usefully with others. By highly aware, we mean they are aware of relevant research and can explain it to others. By somewhat aware, we mean they are generally informed about the impact of medical conditions on learning and specifically of the impact of medical conditions of pupils they interact with. By slightly aware, we mean they have received information in a staff training for instance but did not follow up on the impact of specific condition of pupils they interact with. By not at all aware, we mean they have not been informed that medical conditions might have a cognitive or social-emotional impact on learning.

How would you rate staff awareness regarding the impact of different medical conditions on a child's ability to learn?

Fully aware (1)

Highly aware (2)

Somewhat aware (3)

Slightly aware (4)

Not at all aware (5)

Q57 8. What methods do you use to increase awareness?

Q58 9. Is there a procedure to make staff aware of missed learning because of medical issues or tiredness?

Yes (1)

No (2)

End of Block: III. Inclusion

Start of Block: IV. Collaboration

Q59 IV. Collaboration

Q60 1. Did an initial planning meeting take place between school, parents, pupils, healthcare professionals and other agencies to identify needs and necessary adjustments?

Yes (1)

No (2)

Q61 2. Did an agreement take place regarding what information the pupil and the parents wanted shared and with whom?

Yes (1)

No (2)

Q62 3. To what extent are pupils, parents and healthcare professionals involved in the making of Individualised Healthcare Plans?

	Always (1)	Often (2)	Sometimes (3)	Rarely (4)	Never (5)
Pupils (1)	<input type="radio"/>				
Parents (2)	<input type="radio"/>				
Healthcare professionals (3)	<input type="radio"/>				

Q63 4. Do Individual Healthcare Plans identify protocols for collaborative working arrangements between *all* involved parties (pupils, parents, school, healthcare services etc.)?

Yes (1)

No (2)

Q64 5. Do they include information on working in partnership to ensure that the needs of pupils with medical needs are met effectively?

Yes (1)

No (2)

Q65 6. How frequently do you involve children/parents/external healthcare professionals in the creation of risk assessments for school trips and other extracurricular activities?

	Always (1)	Often (2)	Sometimes (3)	Rarely (4)	Never (5)
Pupils (8)	<input type="radio"/>				
Parents (9)	<input type="radio"/>				
Healthcare professionals (10)	<input type="radio"/>				

End of Block: IV. Collaboration

Start of Block: Social Emotional Mental Health

Q66 V. Social Emotional Mental Health

Q67 1. How confident are you in your school's ability to provide effective support for the social-emotional wellbeing of pupils with medical needs?

- Fully confident (1)
 - Moderately confident (2)
 - Somewhat confident (3)
 - Slightly confident (4)
 - Not at all confident (5)
-

Q68 2a. What specialised support do you provide for social emotional mental health issues for pupils with medical needs?

- Circle of Friends (1)
 - Circle of Support (2)
 - Buddy network (3)
 - Other (4)
-

Q69 2b. If you responded 'other' in the previous question, can you describe the support you provide?

Q70 3. Does school promote self-care for adolescents with health issues?

- Yes (1)
 - No (2)
-

Q71 4. In what form?

Q72 5a. Do Individualised Healthcare Plans outline support for pupils' social and emotional as well as educational needs?

- Yes (1)
- No (2)
- Some (3)

Q73 5.b If you responded 'some' to Question 5.a - in your experience, what specific conditions require Individualised Healthcare Plans, where support for social, emotional and educational needs is outlined?

Q74 5c. For instance, do the Individualised Healthcare Plans include

- Rest breaks (1)
- Additional support to catch up and keep up (2)
- Counselling sessions and alternative plans if the child is unwell (3)
- Other arrangements (4)

Q75 5d. If you responded 'other arrangements' to the previous question, can you describe these?

Appendix VI: Interview Guide with Pupils and Parents

1. Demographics

1. Can you tell me your age?
2. Are you his/her mum?
3. What medical condition do you have? When were you diagnosed?
4. Can you tell me how it impacts your daily life?
5. Are there any procedures you regularly have to complete in school?
6. Do you complete these independently or do you get support?
7. Is it in any way monitored by your school?

2. Plans and policies

1. Does your school have a school nurse on site?
2. Does your school have a medical policy on their website?
3. Do you have an individual healthcare plan? Who wrote it?
4. Can you tell me about any special adjustments that your school put in place for you?
5. Were you or your parents ever invited to share information about your condition with school staff?
6. Does your school have a medical lead?
7. Has that person ever been in contact with your medical team?
8. If you are unwell in school, what's the protocol?

3. Transition / inclusion

1. Before you started secondary school – did your school reach out to discuss what support you might need to be in place?
2. Have you ever had an extended absence due to medical reasons?
3. If yes: In what way did your school help you to remain visible to your community?
4. After your diagnosis/during your absences, did your school do anything

memorable to make things easier for you?

5. In case of an emergency, do your teachers know what to do? Your peers? Who told them?
6. Are there other pupils in your school with your condition? If yes, has your school linked you with them?
7. Does anyone in your school reach out if you are underperforming academically to see if you are OK?
8. In what way would you say that your condition impacts your learning? Your friendships?
9. Do you ever miss learning because of tiredness or being unwell?
10. Do you communicate that?
11. Can you tell me about any awareness raising you did in your school?

4. Collaboration

1. Can you tell me about any link between your school and your healthcare consultant? Are there any regular meetings, information exchange etc?
2. Is your contribution sought for risk assessments?
3. With regards to your peers – are they in any way involved in your support? Have they participated in any training?

5. SEMH

1. Has your school ever reached out in relation to your mental wellbeing, e.g. regarding stress or sadness?
2. Have you ever received any support for that?
3. Have you been encouraged to inform them if things are not going well for you?
4. How well supported do you feel on a scale of 1-10 with 1 being not at all and 10 being extremely well supported?
5. Have there been any particular episodes that you think are worth mentioning? Anything particularly positive or anything that you perceived as a barrier?

Appendix VII: Interview Sample with Coding

Erika Payne 9:27

Yeah, so I want to know what what they have put in place for you,

Young person H 9:43

Next to nothing.

Erika Payne 9:44

So, so what is the "next"?

Physical support

Young person H 9:49

They'll open the window for me. Well, I have to go and open the window if I get too hot. Some of the teachers will let me stay after lesson for a bit, try and catch up. Other ones don't, because they're not as professional as the others. What else do they do?

Parent G 10:19

They did buy a chair eventually. An evac chair.

Physical support

Young person H 10:23

Oh my God, the evac chair at every stair. Okay, so that should have been. That is a requirement that they are meant to have anyway but they only had one in the PE block, and they still only have two wheelchairs. Okay.

Erika Payne 10:43

Anything. Yeah, anything else?

Parent G 10:47

As in what they've actually done?

Erika Payne 10:49

Put in place, yeah...

Young person H 10:54

I've tried to inform my teachers...

Information share

Parent G 10:56

I believe. Teachers are supposed to have been informed of his condition and his requirements. And I don't, I don't know any of them so I just have to take their word that that that information has been shared. Then, what else do we know?

Erika Payne 11:25

Okay, that's, that's fine.

Long-term impact

Parent G 11:27

They are supposed to give Heath extra time in exams and in the test conditions. I don't know if that's going to be in place with your summer exams... it was supposed to be for tests that he's been doing recently which would feed into his predicted grades for UCAS. They've not done that they've not given him any extra time they've not turned the clock off when he's had fallen asleep in the test. They've just. They, they say he's got really poor results at the moment. And he might you might have got a few extra points.

Appendix VIII: Hierarchy of Themes

Superordinate themes, themes and subthemes are shown using the fading of a particular colour.



Subsidiary Research Question 1

Parents and teens

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Attendance policy	"school put out this, like, really staunch attendance policy for the masses, and then seem to kind of back right off when it came to M, even though it had been explained to them that she, you know, had 90 something percent attendance at primary school and she is perfectly able to partake in everything"	Differentiation	Lack of clarity regarding attendance policy	Attendance policy	Lack of transparency	Attendance policy	Lack of transparency
	"It just kind of turned into this kind of permissive environment where they, you know, nobody was saying she had to be at school"	Not questioning absence	Lack of transparency regarding attendance policy	Attendance policy	Lack of transparency	Attendance policy	Lack of transparency
Not knowing whom to talk to	"There just seems a bit a lack of communication because we do not actually know who to address with her problems"	No clear communication from school	Contact in school	Communication/contact in school	Lack of transparency	Contact in school/communication	Lack of transparency
	"I was really struggling. And she was around there and she rang mum. But obviously she will not do that. It is not her job now."	Not knowing whom to talk to	Lack of transparency within school	Communication/contact in school	Lack of transparency	Contact in school/communication	Lack of transparency
	"they are more than happy to contact the school when M goes back (...) But we didn't know who to go to at that point"	Not knowing whom to talk to	Lack of transparency within school	Communication/contact in school	Lack of transparency	Contact in school/communication	Lack of transparency
	"There should be somebody who she could have, maybe could have developed a relationship with to feel comfortable that she has had somebody to go there to speak to these things about these things, and there just really was not"	Not knowing whom to talk to	No person of trust within school	Communication/contact/person of trust	Lack of transparency	Contact in school/person of trust	Lack of transparency

Monitoring	"I am just trusted"	Growing independence	Monitoring	Growing independence	Monitoring	Growing independence	Lack of monitoring
Monitoring of medical procedures	"No support in school"	Growing independence/ Individual Healthcare Plans/Statutory guidance	Monitoring	Growing independence/ Individual Healthcare Plans/Statutory guidance	Monitoring	No support	Lack of monitoring
	"they do not always remind me"	Lack of monitoring	Lack of monitoring/Not adhering to statutory guidance	Not adhering to statutory guidance	Monitoring	No support	Lack of monitoring
	"the school are currently unable to follow up, even to check if he has had his medicine"	Lack of monitoring	Lack of monitoring/Not adhering to statutory guidance	Not adhering to statutory guidance	Monitoring	No support	Lack of monitoring
	"they should monitor it"	Statutory guidance	Statutory guidance	Statutory guidance	Monitoring	No support	Lack of monitoring
	"The school, honestly, just can't be bothered"	Pupil perception	Lack of monitoring/Not adhering to statutory guidance	Growing in dependence but need for support	Monitoring	No support	Lack of monitoring
Accompanied to health centre	"No I just go by myself."	Unacceptable practice/Statutory guidance	Lack of monitoring/Not adhering to statutory guidance	Not adhering to statutory guidance	Monitoring	Variable practice/ Not adhering to statutory guidance	Lack of monitoring
	"somebody is allowed to go to the medical room with you, he is allowed to be accompanied by somebody else"	Adhering to statutory guidance	Statutory guidance	Adhering to statutory guidance / support varies from school to school	Monitoring	Variable practice/ Adhering to statutory guidance	Lack of monitoring

On site school nurse	"We have a first aider but not, not, not a qualified nurse on site. There is an attached school nurse. And, in fact, we've never met her."	No school nurse on site	Healthcare in school	No school nurse on site	Health representation in school	No school nurse on site	Health representation in school
	"There was a really nice nurse. But unfortunately, just before lockdown, she left and then no one replaced her. And so I do not know if they are gonna replace her because they didn't seem like they were going to. So I am not too sure if we're gonna have a new one."	No school nurse on site	Healthcare in school	No school nurse on site/No clear communication/lack of transparency	Health representation in school	No clear communication	Health representation in school
	"No, they do not"	No school nurse on site	Healthcare in school	No school nurse on site	Health representation in school	No school nurse on site	Health representation in school
	it is really valuable having a healthcare professional in the school because they can actually help to dispel some of the myths about health conditions, challenge when that is appropriate	On site school nurse	Challengng when appropriate	Health representation challenging school practice	Health representation in school	School nurse on site	Health representation in school
Hoping for an onsite school nurse	"If we have people within our medical team that are actually medically trained. That might help."	Hoping for a school nurse	Healthcare in school	Need more support	Health representation in school	No school nurse on site	Health representation in school
	"hopefully as I said, there'll be a nurse or If not, I will probably have to, as mum said, go to my form tutor or Head of Year"	Hoping for a school nurse	Healthcare in school	No school nurse on site/No clear communication/lack of transparency	Health representation in school	No clear communication	Health representation in school

Educational Professionals

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Lack of monitoring for schools	"There is no formal monitoring process"	No scrutiny of support for pupils with medical	Monitoring whether statutory duties are met	Monitoring whether statutory duties are met in school	Scrutiny	Statutory duties/In schools	Lack of scrutiny

	needs					
"There is no scrutiny"	No scrutiny of support for pupils with medical needs	Monitoring whether statutory duties are met	Monitoring whether statutory duties are met in school	Scrutiny	Statutory duties/In schools	Lack of scrutiny
"There is no scrutiny, generally, for pupils with medical needs"	No scrutiny of support for pupils with medical needs	Monitoring whether statutory duties are met	Monitoring whether statutory duties are met in school	Scrutiny	Statutory duties/In schools	Lack of scrutiny
"Nobody ever asks me for any data."	No scrutiny of support for pupils with medical needs	Monitoring whether statutory duties are met	Monitoring whether statutory duties are met at local authority	Scrutiny	Statutory duties/at local authorities	Lack of scrutiny
"There is nobody policing this area at all from a government perspective or from a local perspective, really, to say this is what you must, should be doing. Ofsted do not even have a look at policies, they do not scrutinise whether or not the schools are doing what they should be doing based on statutory guidance"	No scrutiny of support for pupils with medical needs	Statutory duties not met	No monitoring processes on national level	Scrutiny	Statutory duties/on national level	Lack of scrutiny
there are not sufficient monitoring processes in place for schools and on schools to ensure they are fulfilling their statutory duties	No scrutiny of support for pupils with medical needs	Statutory duties not met	Monitoring whether statutory duties are met in school	Scrutiny	Statutory duties/In schools	Lack of scrutiny

	<p>"There is a lot more that could, should be done and a lot around the national structure and organisation of how the statutory guidance is actually monitored, that there is no formal monitoring process. There is a duty for local authorities to ensure that the statutory guidance are actually fulfilled"</p>	No scrutiny of support for pupils with medical needs	Statutory rights not met	Monitoring whether statutory duties are met at local authority	Scrutiny	Statutory duties/at local authorities	Lack of scrutiny
	so many young people are missing out on their education, and their statutory rights and needs are not being met at the moment	No scrutiny of support for pupils with medical needs	Statutory rights not met	Statutory rights not met/Equality Act	Scrutiny	Statutory duties/Equality Act	Lack of scrutiny
Equality Act	"There are some significant needs around the Equality Act in particular that mean that more could and should and must be done to support these young people."	Lack of support	Equality Act	Statutory rights not met/Equality Act	Scrutiny	Statutory duties/Equality Act	Lack of scrutiny
Local Authority duty	"There are some local authorities that do not take their responsibilities seriously. And as a result of that a number a large number of young people do not get supported effectively"	Lack of support	Equality Act	Statutory rights not met/Equality Act	Scrutiny	Statutory duties/Equality Act	Lack of scrutiny
	"capacity is a big issue"	Lack of support	Capacity	Capacity	Scrutiny	Capacity	Lack of scrutiny
	"It does not scrutinize on progress it scrutinizes on attendance."	Attendance rather than progress	Scrutiny	Attendance rather than progress	Scrutiny	Attendance rather than progress	Lack of scrutiny
	"every local authority should have something in place"	Duty to monitor	Local authority	Monitoring whether statutory duties are met at local authority	Scrutiny	Statutory duties/at local authorities	Lack of scrutiny
	"statutory guidance needs to provide more clarity and be more specific around what the expectations of local authorities are at the local level"	Clarity of expectations	Local authority	Monitoring whether statutory duties are met at local authority	Scrutiny	Statutory duties/at local authorities	Lack of scrutiny

	"the statutory guidance, but (...) they are not adhering to it because nobody's got administration of medicines training in the school"	Statutory guidance	Schools not adhering to statutory guidance	Schools not adhering	Statutory guidance	Statutory guidance	Expectations on schools
Statutory guidance	"There has to be. It is statutory to have a school policy and a named person."	Statutory guidance	Statutory guidance	Expectation on schools	Statutory guidance	Statutory guidance	Expectations on schools
	"There is no reporting criterion nationally"	No reporting criteria	No monitoring on national level	No reporting criteria nationally	Scrutiny	Statutory duties/No reporting criteria	Lack of scrutiny
	"There is no requirement to report data"	No reporting criteria	No monitoring on national level	No reporting criteria nationally	Scrutiny	Statutory duties/No reporting criteria	Lack of scrutiny
	"funding hasn't been looked at for years, they haven't changed its, its format, considering the numbers have increased significantly"	Lack of funding	Capacity	Funding	Scrutiny	No increase in funding	Expectations on schools
	"the government does not ask for any data about children with medical conditions"	No reporting criteria	No monitoring on national level	No reporting criteria nationally	Scrutiny	Statutory duties/No reporting criteria	Lack of scrutiny
National level	"We have a government policy now, but it is not enforced."	Statutory guidance not enforced	No monitoring on national level	No monitoring on national level/statutory guidance not enforced	Scrutiny	Statutory guidance/on national level	Lack of scrutiny

	"because every local authority, they, they take their responsibilities very differently, although there are statutory guidance, every local authority deploys in a way which they see best locally, their responsibilities and their duties to either schools or to an organisation within their authority, an organisation like us to actually meet the needs of statutory guidance, and it really is a bit of a lottery, there are some that do it exceptionally well, there are others that it is really difficult to understand and get under the skin of what they are doing at all. So it is a very, very mixed picture across the country"	Statutory guidance not enforced	No monitoring on national level	No monitoring on national level/statutory guidance not enforced	Scrutiny	Statutory guidance/on national level	Lack of scrutiny
	"the guidance needs to change, to provide a national model of what should be expected in every local authority"	Statutory guidance not enforced	No monitoring on national level	No monitoring on national level/statutory guidance not enforced	Scrutiny	Statutory guidance/on national level	Lack of scrutiny
School duty	"at all points, it is the school that is the lead educator and leading the program"	Statutory duty of schools	Statutory duty of schools	Statutory duty of schools	Statutory duty of schools	Statutory duties/In schools	Lack of scrutiny
	"it is a case of the school, establishing the right reasonable adjustments, being flexible and monitoring them, you know regularly"	Statutory duty of schools	Statutory duty of schools	Statutory duty of schools	Statutory duty of schools	Statutory duties/In schools	Lack of scrutiny
	"schools obviously have their statutory duty to support young people who are at their school"	Statutory duty of schools	Statutory duty of schools	Statutory duty of schools	Statutory duty of schools	Statutory duties/In schools	Lack of scrutiny
	"every school should have a named person for supporting medical medical conditions as per the statutory guidance. Yeah, because there is no monitoring of their statutory guidance, not all schools are doing it"	Statutory duty of schools	No monitoring of statutory guidance	Statutory duty of schools	Statutory duty of schools	Statutory duties/In schools	Lack of scrutiny

	"Sometimes they are just saying well of course that is the SENCO's responsibility or that is the designated safeguarding lead's responsibility, but actually nobody knows what it is. Yeah, so I think that there should be a standardised job description as much as there is for actually the designated safeguarding lead. There should be a standardised job description for the person that takes responsibility in every school across the country for supporting people with medical conditions"	Statutory duty of schools	No standard monitoring of statutory guidance	No monitoring of statutory guidance/schools	Scrutiny	Statutory duties/In schools	Lack of scrutiny
Governors	"they were not obliged to have a named governor but it was recommended. But that that is had to go there is no capacity for that work anymore"	Capacity	Inclusion	Capacity	Expectations on schools	Capacity	Expectations on schools
Monitoring within school	"We would encourage schools to have individual health care plans for children with chronic conditions. And again, again, it'd be interesting from school to school to see whether that individual health care plan is monitored by the Senco or whether it is monitored by somebody else"	IHCP	Monitoring	Monitoring within school	Statutory duty of schools	Statutory duties/In schools	Lack of scrutiny
Safeguarding	sometimes we have students and their families who are not adhering to medical advice""	Not following HC advice	Safeguarding	School role/support	Expectations on schools	School role/support	Expectations on schools
	"a safeguarding situation because you are not following healthcare advice, you are not meeting your child's needs"	Safeguarding	School role	School role/support	Expectations on schools	School role/support	Expectations on schools
Writing policy	"So we write them but then seek out local specialist and specialist oversight"	Policy writing	School role	School role/support	Expectations on schools	School role/support	Expectations on schools
School role	"we are part of that then structure moving forward that support, but almost from a, with better understanding"	Support	School role	School role/support	Expectations on schools	School role/support	Expectations on schools

	"that number of those that we would support in some way, that might just range from making sure staff are trained, storing their medications, administering medications"	Support	School role	School role/support	Statutory duty of schools	School role/support	Expectations on schools
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School nurses

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Different school types	private and state school nurses work very differently	Private/state schools	Lack of standardised approach	Private/state schools	Lack of standardised approach	Private/state schools	Ad hoc approach
	if you look at schools, in the private sector, then I think they are very good at doing their policies and having things up to date, as opposed to state education.	Private/state schools	Lack of standardised approach	Private/state schools	Lack of standardised approach	Private/state schools	Ad hoc approach
Funding	Nurses link with local hospital to discuss training but it is often linked with funding issues. Schools need to pay for training but they say they do not have the money.	Lack of funding	Training	Training	Expectations on schools	Expectations on schools/lack of funding/training	Expectations
	It is very tricky with funding, there is not a lot out there for these pupils.	Lack of funding	Support	Support/no funding	Expectations on schools	Expectations on schools/lack of funding/support	Expectations

	<p>And unless somebody provides that training to them, then they may or they may not have that knowledge, and it depends on the school and how proactive the school is in engaging and sending their staff, because obviously by, you know, by sending their staff on to training it incorporates you know a couple of hours, so they are still having to pay them for a couple of hours, they are having to get supply teachers to cover, things like that so it is all financial thing as well as to how much, how many people are actually informed or not.</p>	Lack of funding	Training	Support/no funding	Expectations on schools	Expectations on schools/lack of funding/support	Expectations
	<p>it is a poor show, really.</p>	Lack of funding	Support	Support/no funding	Expectations on schools	Expectations on schools/lack of funding/support	Expectations
	<p>It is so much more than that and it is about money</p>	Lack of funding	Support	Support/no funding	Expectations on schools	Expectations on schools/lack of funding/support	Expectations
IHCP	<p>we are not responsible for their individual health care plans but we encourage the schools to follow in line with things like Asthma UK or on Anaphylaxis UK who have their own individual health care plans. And if they haven't got one already established within their medical needs policy, then we will encourage them to have to seek out those individual health care plans from Asthma UK, you know, simple ones.</p>	???	Guidance through Individual Healthcare Plans	Policy production	Expectations on schools	Expectation on schools/policy production	Expectations

It is very medicalised	Too medicalised	Guidance through Individual Healthcare Plans	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange
They are very just for medical aspects of individual health care plans	Too medicalised	Guidance through Individual Healthcare Plans	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange
a consultant will just write down the type of seizure that the child has, and they will expect the school staff to know what it means.	Too medicalised	Guidance through Individual Healthcare Plans	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange
simple things the school staff can understand or the layperson can understand	Too medicalised	Guidance through Individual Healthcare Plans	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange

No, there has never been any sort of social or emotional bits in there, it is very much sort of their symptoms and signs what you do, and, you know, that sort of stuff.	Too medicalised/No consideration for SEMH or other needs	Guidance through Individual Healthcare Plans	Problems around IHCP/no consideration of individual differences	Knowledge exchange	No clear path for knowledge exchange between school and health/IHCP too medicalised	Knowledge exchange
We do have health care plans if there is any need for them. Asthma and that sort of thing. Anaphylaxis and anything else that comes across,	Health-related needs	Guidance through Individual Healthcare Plans	Adhering/IHCP	Statutory guidance	Adhering to statutory guidance/individual healthcare plans	Ad hoc approach
Generally they would have individual health care plans, but some schools would do that but say this group of children have got asthma therefore this is the plan. Generally, they would have individual but there are some who do not have best practice around that.	No individual differences /based on medical need	Guidance through Individual Healthcare Plans	Problems around IHCP/no consideration of individual differences	Lack of standardised approach	No standardised way to produce individual healthcare plans	Ad hoc approach
Some schools have really good links with the child's consultant, and the connected children's nurse or the specialist nurse for that condition. Others do not have any links at home rely on the parents and therefore it would fall at the feet of a pastoral lead in school, or, or even a teaching assistant who was, you know, named for that child.	Production/ Written by non-experts	Lack of standardised approach	Production of policies and individual health care plans/no clear path	Lack of standardised approach	No standardised way to produce individual healthcare plans/Inclusion of experts	Ad hoc approach
Some will but very few will. It is normally in partnership with the parent and the young person and it is just a thing that they do.	Production/ Sometimes written with experts	Lack of standardised approach	Production of policies and individual health care plans/no clear path	Lack of standardised approach	No standardised way to produce individual healthcare plans/inclusion of experts	Ad hoc approach

Yes. Every student with a medical need. Yeah, yeah. From what from my experience and that is that has been, and we as school nurses used to help if needed.	According to Statutory Guidance	IHCP	Adhering/IHCP	Statutory guidance	Adhering to statutory guidance/individual healthcare plans	Ad hoc approach
I would say the templates are national, but the plans themselves. Personally I think they should. They should all be individual, which I think more or less they were.	According to Statutory Guidance	IHCP	Adhering/IHCP	Statutory guidance	Adhering to statutory guidance/individual healthcare plans	Ad hoc approach
they would have the educational need, they would have their social needs, they would have emotion need, mental health. So yeah, these would be included in the form.	According to Statutory Guidance	IHCP	Adhering/IHCP	Statutory guidance	Adhering to statutory guidance/individual healthcare plans	Ad hoc approach
it would be individual, every child has their own.	According to Statutory Guidance	IHCP	Adhering/IHCP	Statutory guidance	Adhering to statutory guidance/individual healthcare plans	Ad hoc approach
I think every child's an individual so they should have their own care plan.	According to Statutory Guidance	IHCP	Adhering/IHCP	Statutory guidance	Adhering to statutory guidance/individual healthcare plans	Ad hoc approach
I do struggle with getting any care plan, so I have had to write one for epilepsy myself because I haven't been able to get their, initially, that help	Difficulties around production	IHCP	Production of policies and individual health care plans/no clear path	Lack of standardised approach	No standardised way to produce individual healthcare plans	Ad hoc approach
put the onus on the parent to attend the annual or six monthly asthma clinic reviews and get the symptoms and the triggers etcetera written down, so that it helps me look after them in school, but that is like fighting the biggest battle ever	Onus on parents	IHCP	Production of policies and individual health care plans/no clear path	Expectations on parents	Expectations on parents/Get healthcare contribution	Expectations

	the parents would complete health care plan individual health care planning, in collaboration with the parents to establish their specific needs. So it is very much individual to that particular child or young person.	According to Statutory Guidance	IHCP	Adhering/IHCP	Statutory guidance	Adhering to statutory guidance/individual healthcare plans	Ad hoc approach
Information share	school does what they do, they are not upfront about the information they share	Between school and health	No clear path for information share	No clear path for knowledge exchange between school and health	Knowledge exchange	No clear path for knowledge exchange between school and health	Knowledge exchange
	Sometimes they will go to the GP and never reach the school, so you are relying on the GP to contact the school. Some do some do not.	Between school and health	No clear path for information share	No clear path for knowledge exchange between school and health	Knowledge exchange	No clear path for knowledge exchange between school and health	Knowledge exchange
	the health care plan would be shared with staff, probably at staff briefing, then would be pinned with some kind of alert flag to that pupil's folder. So for example if you had that young person in your class and their attainment or achievement or attendance was floundering, then you could have a look in that folder and it will be flagged as a potential cause, but equally if that young person was on your watch in your lesson and they took unwell... you could very quickly access the emergency information.	Within school	Information share	Good practice	Knowledge exchange	Good practice/within schools	Knowledge exchange
	safeguarding... and normally, normally, you may occasionally but I in my experience, it has been very rare that they have not communicated with me.	Between school and health	No clear path for information share	No clear path for knowledge exchange between	Knowledge exchange	Good practice/between school and school nurse	Knowledge exchange

				school and health			
	they would have one sheet, if they have care plan so it is easy and quick to look at, especially in any time of an emergency. And then they would have additional information, kept probably in the same folder for that pupil	Within school	Information share	Good practice	Knowledge exchange	Good practice/within schools	Knowledge exchange
	we would be sent a copy on our records as well. So we will have that. So say for instance every year I would know how many were to transition into a new school, and I would know who to look at, and who to find so fingers crossed. Nobody would get missed.	Between school and health	Information share	Good practice	Knowledge exchange	Good practice/Collaboration between school and school nurse	Knowledge exchange
Medical lead	there is always somebody who's allocated as in charge of medical pupils	Medical lead	Adhering to statutory guidance	Adhering/medical lead	Statutory guidance	Good practice/adhering to statutory guidance/medical lead	Ad hoc approach
	they would probably also have a number of other responsibilities tagged on to their title, so they are probably designated teacher for pastoral care, or safeguarding or special needs	Medical lead	Adhering to statutory guidance	Adhering/medical lead	Statutory guidance	Good practice/adhering to statutory guidance/medical lead	Ad hoc approach
	Every single school that I have worked with.	Medical lead	Adhering to statutory guidance	Adhering/medical lead	Statutory guidance	Good practice/adhering to statutory guidance/medical lead	Ad hoc approach

	school is responsible for medical policy, not the nurse	Expectations on schools	Policy production	Production of policies and individual health care plans/no clear path	Lack of standardised approach	No clear path for knowledge exchange between school and health	Ad hoc approach
	They do not ask for advice and they do not consult any healthcare professionals. They just do their own things with the governors.	Between school and health	No clear path for information share	No clear path for knowledge exchange between school and health	Knowledge exchange	No clear path for knowledge exchange between school and health	Ad hoc approach
	It is probably reviewed yearly, but again, no nurse is involved with that.	Between school and health	No clear path for information share	No clear path for knowledge exchange between school and health	Knowledge exchange	No clear path for knowledge exchange between school and health	Ad hoc approach
	what sort of jumped out was the fact that their schools didn't have any policies.	Policies	Not adhering to statutory guidance	Not adhering / policies	Statutory guidance	Not adhering to statutory guidance	Ad hoc approach
Medical policy	I sort of encouraged them to devise a specific medical needs policy, and some schools are really good in sharing them. So, you sort of help them devise specific policies, and then encourage them to share them with other schools as well so they do network between them. And they were very good in sort of, yeah, sharing them and putting them online.	Between schools	Knowledge exchange	Between schools	Knowledge exchange	Good practice/between schools	Knowledge exchange

<p>in the past for right or wrong, school nurses would take in the main take on the responsibility of that, but it is actually the governing body who called the legal responsibility. Nowadays, it is quite a mixture mixed picture because that role is in such a gray area that school struggled to get health professional support.</p>	<p>Between school and health</p>	<p>No clear path for information share</p>	<p>No clear path for knowledge exchange between school and health</p>	<p>Knowledge exchange</p>	<p>No clear path for knowledge exchange between school and health</p>	<p>Knowledge exchange</p>
<p>from experience, yes, and that is in mainstream schools. And that is also been done in independent public schools where they have had the policy as well, in all the schools I have worked in,</p>	<p>Policies</p>	<p>Adhering to statutory guidance</p>	<p>Adhering / policies</p>	<p>Statutory guidance</p>	<p>Adhering to statutory guidance/policies</p>	<p>Ad hoc approach</p>
<p>I think that they have to be by law. I think they are available for everybody because parents are very interested in seeing that before any child, especially if they have got a medical need in the school, and they want them on the websites. So, from my experience, all the schools that I have worked in had the policy on the website.</p>	<p>Policies</p>	<p>Adhering to statutory guidance</p>	<p>Adhering / policies</p>	<p>Statutory guidance</p>	<p>Adhering to statutory guidance/policies</p>	<p>Ad hoc approach</p>
<p>I would say, annually and / or whenever there is a change or a new condition with a child, say, if somebody came in with cystic fibrosis and hadn't had one for a while. They would update their policy and look into getting health care plan by working with the school nurse, and with the hospital, and the parents.</p>	<p>Between health, schools and parents</p>	<p>Knowledge exchange</p>	<p>Good practice</p>	<p>Knowledge exchange</p>	<p>Good practice/between school, health and parents</p>	<p>Knowledge exchange</p>

	I would say, joined, because obviously, the people who were dealing with it in school are not medically trained. So it depends what school.. some would really want you to take charge of it. But then we would also put the ownership back on school	Policy production	Expectations on schools	Policy production	Expectations on schools	On schools/policy production	Expectations
	In my role because my, my school value health, it is me. Along with parents and the professionals, and health service, so the clinical nurse specialists and hospital doctors, consultants and specialists.	Policy production/nurse on site	Expectations on schools	Policy production	Expectations on schools	On schools/policy production	Expectations
	Yes, I hope so. Anyone can access them	Policies	Adhering to statutory guidance	Adhering/policies	Statutory guidance	Good practice/Adhering to statutory guidance/policies	Ad hoc approach
	Annually at least we, the nurses are responsible for a few of them and then the education staff are responsible for others.	Policy production/nurse on site	Expectations on schools	Policy production	Expectations on schools	On schools/policy production	Expectations
Procedures for an unwell child	i hope they follow the care plan but they probably just call the parents.	Unwell child	Expectations on parents	Problem solving	Expectations on parents	On parents/problem solving	Expectations
	I think they might know generally how to deal with an unwell child though most of them would send them to the school secretary or to the office.	Unwell child	Lack of standardised approach	unwell child	Lack of standardised approach	Transparency	Ad hoc approach
	it is to go to the school office, and there will be whether they have got their own school nurse or whether it is the first aid for that school.	Unwell child	Good practice	Good practice	Standardised approach	Good practice/Transparent procedures for unwell child	Ad hoc approach
	we try to not at every cost for a young person to go home or for the parent having to come in.	Unwell child	Good practice	Good practice	Standardised approach	Good practice/Transparent procedures for unwell child/transparency	Ad hoc approach

	we rely on the parents to be honest to make the decision	Unwell child	Expectations on parents	Problem solving	Expectations on parents	On parents/problem solving	Expectations
	In case of non-compliance it is expected that parents are proactive and problem solve	Problem solving	Expectations on parents	Problem solving	Expectations on parents	On parents/problem solving	Expectations
	I do not know, to be quite honest, because I did see that on your, on your questionnaire before and I thought that is a really good point, because I do not think it is.	Non-compliant child	??	Policy production	Expectations on schools	On schools/policy production	Expectations
	We have had one or two problems with students, but they usually come around to it.	Non-compliant child	??	Policy production	Expectations on schools	On schools/policy production	Expectations
	When the school nurses were more involved, they probably would have had that conversation. But I wouldn't have thought it would be the norm, and you have added quite a valid point actually, so no I do not think so.	Non-compliant child	Lack of standardised approach	Policy production	Lack of standardised approach	No clear procedures for unwell child/non-compliance	Ad hoc approach
	he kept getting admitted to hospital, but with regard to that ended up becoming a safeguarding issue. Yes, because he was non compliant and we had to really get with the parents to get them involved and everybody,	Problem solving	Expectations on parents	Problem solving	Expectations on parents	On parents/problem solving	Expectations
	if you are not compliant, then that is also mentioned within the policy that we would contact the parent	Problem solving	Expectations on parents	Problem solving	Expectations on parents	On parents/problem solving	Expectations
Procedures for non-compliance	all I could do was, speak to the mother, and inform her so we would never force a child to have something they do not want	Problem solving	Expectations on parents	Problem solving	Expectations on parents	On parents/problem solving	Expectations
Safeguarding	In the better schools, yes. I would say it is probably 50/50	Policy	Adhering to statutory guidance	Not adhering / policies	Statutory guidance	No standardised way to produce policies	Ad hoc approach

	we really encourage that the cupboards are unlocked. You know, because when I first started in school nursing 10 years ago. All the cupboards would be locked because they were frightened other children would go in to get the pens, and it was a real battle to say you have to have those cupboards unlocked, and they do,	Procedures	Adhering to statutory guidance	Not adhering / policies	Statutory guidance	Not adhering to statutory guidance/policies	Ad hoc approach
School nurse on site	Some schools have what they call a school nurse that is not a school nurse so they may actually take an unqualified person still.	???	No health representation in schools	??	Lack of standardised approach	No health representation in schools/capacity	Ad hoc approach
	health representation to that is not readily available anymore. You know, all newly diagnosed would have either a specialist nurse or the school nurse, I would say that is less the case these days. It is not..... the capacity does not allow for it.	Capacity	No health representation in schools	No health representation in schools/capacity	Knowledge exchange	No health representation in schools/capacity	Ad hoc approach
Support requested too late	Although we are early help, I think we are early help a little bit too late, so....	No early intervention	Support	Early intervention	Expectations on schools	On schools/no proactive approach	Expectations
	maybe the child would get to a point where they would start having hospital admissions or something because things have deteriorated. Yeah. And that might be the trigger point at that point.	No early intervention	Support	Early intervention	Expectations on schools	On schools/no proactive approach	Expectations
Unaccompanied children	We, we say in our training that they shouldn't go alone. Whether it is in the policy, I do not know.	Unaccompanied child	Not adhering to statutory guidance	Practice/unaccompanied child	Not adhering to statutory guidance	Unwell child/Not adhering to statutory guidance/Unaccompanied to medical room	Ad hoc approach

	Some, some but not the norm.	Unaccompanied child	Not adhering to statutory guidance	Practice/unaccompanied child	Not adhering to statutory guidance	Unwell child/Not adhering to statutory guidance/Unaccompanied to medical room	Ad hoc approach
	It does state that but that is a constant battle that I have with teachers who've sent diabetic children who are hypoglycemic to me without calling me to them but it is not (...) to trying to change their behavior but the next day it seems to happen, but it is documented it is just a historical that teachers will send children to the medical room.	Unaccompanied child	Not adhering to statutory guidance	Practice/unaccompanied child	Not adhering to statutory guidance	Unwell child/Not adhering to statutory guidance/Unaccompanied to medical room	Ad hoc approach
	I do think the children themselves come on their own. and I do not think they are accompanied.	Unaccompanied child	Not adhering to statutory guidance	Practice/unaccompanied child	Not adhering to statutory guidance	Unwell child/Not adhering to statutory guidance/Unaccompanied to medical room	Ad hoc approach
Emergencies	Only emergency medical needs would require nurse involvement, for example anaphylaxis or allergies	Dealing with emergencies	Expectations on schools	Dealing with emergencies	Expectations on schools	On schools/dealing with emergencies	Expectations
	I think there will be appointed teachers who will be but as a whole school, no.	Not dealing with emergencies	Expectations on schools	Dealing with emergencies	Expectations on schools	On schools/dealing with emergencies	Expectations
	I think they would kind of get rid of the problem.	Not dealing with emergencies	Expectations on schools	Dealing with emergencies	Expectations on schools	On schools/dealing with emergencies	Expectations

	I think basic first aid and basic general awareness yes but not specific, and I think they would kind of get rid of the issue rather than deal with it any further.	Not dealing with emergencies	Expectations on schools	Dealing with emergencies	Expectations on schools	On schools/dealing with emergencies	Expectations
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Subsidiary research question 2

Parents and teens

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Long term impact on achievement	"She is quite academically able, the CF I suppose has impacted because of her absences. And, that kind of the adequate support to kind of fill in those gaps was not there. meant that kind of instead of doing something about it the school, sort of dropped her off a few GCSEs so that she took less GCSE than her peers"	Long term impact	Absences	Long term impact	Absences	Missed learning because of health/long term impact	Absences
	"They have not done that they have not given him any extra time they have not turned the clock off when he has had fallen asleep in the test. They have just. They, they say he has got really poor results at the moment."	Long term impact	Missed learning because of health	Long term impact	Missed learning because of health	Missed learning because of health/long term impact	Absences
	"it is changed the way that M has learned, I suppose or has applied herself in an academic environment"	Long term impact	Missed learning because of health	Long term impact	Missed learning because of health	Missed learning because of health/long term impact	Absences
Lack of academic support during absences	"I and my husband was endlessly emailing the teachers, that seems to be the way it works. You can't speak to a teacher, you have got to email them, and some teachers were great, they emailed work to us. We would print it off at home and take it into hospital with us. There was quite a few subjects. We were getting nothing... no reply."	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
	"mum would email them saying, Can you send me some work to catch up? And they never would. And I have quite a lot of gaps of missed learning. Yeah, they never really sent things to catch up"	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences

"They did acknowledge the email, but they never did anything to help M catch up"	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
"she would put her hand up in classes to say she does not understand because she was not there last week. And she has been told to ask the person next to her. And she, you know, she has been told or she has been told the other students will help her or show her what she has missed. Whereas I have challenged them at parents evening, I said, you know, that she is asking for help for a reason. Yeah, they are not great at helping her to catch up. No."	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
"I said to her, like, I have missed the last two weeks of this book, and I, what you want me to do, she said, just read it"	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
"when M was not at school, you know she was not getting works sent home, there was , you know even if she did, if we we managed to get work from them, they were not checking in, when she was in hospital"	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
"it was not always sent through and so their hospital school would do a lot of chasing, I would do a lot of chasing. And we might get a few drabs and drabs, but that was...."	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
"And then, within a couple of weeks she was in hospital and then so she fell behind, and then that was kind of, you know, never, never real clear way of kind of catching up"	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences

	"in terms of the work set they didn't send us anything"	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
	"he had been given a negative behaviour point, because he hadn't completed some work that have been set in class. (...) I have informed you you know where he is he is in high dependency he is very sick. I have let school know."	Punishment for missed work	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/Punishment for missed work	Absences
	"They wouldn't actually tell me or give me the missed work. And so they never really helped me catch up with anything"	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
Punishment for missed work due to absences	"We asked the school for like work from every lesson I would miss out on. But not every teacher gave me work. But then I would like get punishments for missing out"	Punishment for missed work	Missed learning because of health	Missed learning because of health/Punishment for missed work	Absences	Missed learning because of health/Punishment for missed work	Absences
	"No, no, they did not. I mean, if anything, it was me that was keeping them in the loop. I was mailing them but I was not getting much of a response back"	No attempt from school to remain in touch	Absences	No attempt from school to remain in touch	Absences	Remaining integrated/No support from school	Absences
	"school, from my perspective had the attitude of, I was being too pushy on M. And that kind, 'oh let her, leave her alone, she is you know she is, she is ill, , she is you know she is, she is not gonna live forever, so let her be' ummm was the kind of like the overriding message that I kind of felt that they were, they were kind of putting out there really"	No support from school to remain integrated	Absences	No support from school to remain integrated	Absences	Remaining integrated/No support from school	Absences
Lack of SEMH support during absences	"I think she may have got once or twice, she might have got a card from her form. And with all of them saying that we missed you, can't wait for you to come back."	Reaching out	Absences	Reaching out	Absences	Relationships	Inclusion

	"They only reached out to us, because I reached out to them and had to make a complaint. Whilst T was in hospital"	No support from school to remain integrated	Absences	No support from school to remain integrated	Absences	Remaining integrated/No support from school	Absences
	"she returned to school and she got detentions for the work not being done"	Punishment for missed work	Missed learning because of health	Missed learning because of health/Punishment for missed work	Absences	Missed learning because of health/Punishment for missed work	Absences
	"I said to her, so what would happen with another child who has this level of attendance and they said, Well, the education welfare officer get called. And I said, well, should shouldn't we be calling them? And they were like, Oh, well I will check with somebody, I will check with somebody, and they didn't do anything because then I would explained you know this was not about it was not about her CF..."	No support from school to return	Absences	No support from school to return	Absences	No support from school to return	Absences
	"I am glad you called me because M's name has come up several times but the school have told me all the time it is because she has CF"	No support from school to return	Absences	No support from school to return	Absences	No support from school to return	Absences
	"nothing happened within that whole system of trying to support, M or me and get helping M at all"	No support from school to remain integrated	Absences	Remaining integrated/No support from school	Absences	Remaining integrated/No support from school	Absences
Lack of support to reintegrate after absences	"she was she just was not turning up to come to school and, you know, we were not, we didn't get phone calls. And, you know, lo and behold they were just marking it down as CF all the time. And, you know, not checking in"	No support from school to remain integrated	Absences	Remaining integrated/No support from school	Absences	No support from school to return	Absences
	I am sort of nervous about going back in a few days because I actually do not know what's happening	Worry about return	Absences	Worry about return	Absences	Worry about return	Absences
Going back to school after absences	"she then decided to not go into school because of everything that has been going on. Yeah, I was having wrestles with her all morning trying to get her there and tried everything"	Worry about return	Absences	Worry about return	Absences	Worry about return	Absences
Impact on parents	"the people who have got the most to do to get through their daily lives, let's just chuck some more at them. To make it even more tricky"	Struggle for inclusion	Parents	Parents/struggle for inclusion	Inclusion	Parents/ struggle for inclusion	Inclusion

	"I did contact school and they; I am not going to say they were reluctant, but it was a hassle for them to give me the weekly menu with the carb values in. And, you know, to have to ask, because the menu changes. And it just seemed a lot of trouble."	Schools do not go the extra mile	Inclusion	Schools do not go the extra mile	Inclusion	Schools do not go the extra mile	Inclusion
Lack of inclusion efforts	"I have got thousands of emails where I have been trying to email the school to keep them in the loop. I think it was just to kind of all well, M's mum is taking care of it so we will just leave them to it. You know that is kind of the kind of felt the attitude that it was. It is so really bizarre thing because it is a really high achieving school, and it is one of the top state schools in the country. But just, there is just this glaring gap in some kind of pastoral inclusion type care."	Struggle for inclusion	Parents	Parents/struggle for inclusion	Inclusion	Parents/struggle for inclusion	Inclusion
Integration at primary school	"in primary school, you are, you have got a kind of a single point of contact"	Clearer path	Primary school	Better support	Appropriate support	Primary schools/single point of contact	Inclusion
	There is always a way that any member of staff can log on to the system and kind of look up an issue or you know the basic care plan of any child.	Clearer path	Primary school	Better support	Primary schools	Primary schools/single point of contact	Inclusion
	"the school was quite good with my condition. And I had a good teacher who used to help me a lot. And I think we had the Senco there as well, and she put things in place."	Clearer path	Primary school	Better support	Primary schools	Primary schools/single point of contact	Inclusion
Support for transition	"You know, actually. it is about forming the kind of the relationship with somebody who they can trust and who feels that they have got a vested interest in them, to help them move forward"	Support for transition/person of trust	Primary school to secondary school	Support for transition/person of trust	Primary school to secondary school	Relationships	Inclusion
	they kind of went through the basics. You know, what would be required from the school.	Support for transition	Primary school to secondary school	Support for transition/person of trust	Primary school to secondary school	Relationships	Inclusion
	"from that perspective the initial, the first initial bit after diagnosis was maybe challenging"	???	Difficult transition	??	Inclusion	??	Inclusion
Transition from primary to secondary school	"I do not know what what conversations have gone on between the primary school and secondary school, and I was not some kind of party to any of those"	Communication between schools	Primary school to secondary school	Communication between schools	Primary school to secondary school	Communication	Inclusion

	"I think one of the ladies went in there to speak to them before he went to secondary school"	Communication between schools	Primary school to secondary school	Communication between schools	Primary school to secondary school	Communication	Inclusion
	"She is trying to approach people, but it is like they are not interested. And (...) they haven't got the time to sit down and talk to M"	No support from teachers to catch up	Missed learning because of health	Missed learning because of health/No support from teachers to catch up	Absences	Missed learning because of health/No support from teachers to catch up	Absences
	"it probably is quite disappointing that there is, there is some really good teachers. But you haven't gone that extra mile, maybe"	Going the extra mile	Missed learning because of health	Individual teachers/going the extra mile	Inclusion	Relationships	Inclusion
	"My math teacher is very good. She is the one who gave me a little bit of catching up time and she is very good. She usually asks me how I am before lesson and she knows"	Going the extra mile/individual teachers	Missed learning because of health	Remaining integrated/going the extra mile	Inclusion	Relationships	Inclusion
	"I mean, she is nice, but I just wouldn't want to really sort of put her in that position because it is not her job, sort of thing."	Going the extra mile/individual teachers	Missed learning because of health	Going the extra mile/individual teachers	Missed learning because of health	Relationships	Inclusion
	"I know one teacher contacted Narcolepsy UK and spoke to their schools liaison person, that is H's former tutor. And the reason was that she wanted the information, and she did not agree with things, then Senco's policy"	Going the extra mile/individual teachers	Missed learning because of health	Going the extra mile/individual teachers	Missed learning because of health	Relationships	Inclusion
	"my biology teacher who I like a lot more than the rest of the teachers, because after lesson and things he will stay and talk me through the stuff that I missed exactly as you would in the lesson for everyone else so it is not patronising"	Going the extra mile/individual teachers	Missed learning because of health	Going the extra mile/individual teachers	Missed learning because of health	Relationships	Inclusion
	"I was on IVs. And one of my, my language teacher was emailing me asking how things are. And my old college manager was really good. And if like, I didn't feel well she would just let me sit in her office until I start feeling better."	Going the extra mile/individual teachers	Missed learning because of health	Going the extra mile/individual teachers	Missed learning because of health	Relationships	Inclusion
Support from individual teachers	"I say two teachers stand out for me"	Going the extra mile/individual teachers	Missed learning because of health	Going the extra mile/individual teachers	Missed learning because of health	Relationships	Inclusion

	"There were a couple of teachers and in fact her year 11 teacher... was particularly good with her. And she, you know she was she was more, more interested in social and emotional, mental well being. And that made, that did make a massive difference"	Going the extra mile/individual teachers	SEMH	Going the extra mile/individual teachers	SEMH	Relationships	Inclusion
	"she felt that she was more recognised and valued as an individual. And you know it is what everybody wants, is not it? So, yeah, M felt that she could speak to her as well."	Going the extra mile/individual teachers	SEMH	Going the extra mile/individual teachers	SEMH	Relationships	Inclusion
	"That relational thing that makes things happen."	Going the extra mile/individual teachers	Relationships	Relationships	Inclusion	Relationships	Inclusion
Transparency of support systems within school	"I did ask the school, not that long ago I said do you know who is in charge of your inclusion? And they say, inclusion is everybody's job here."	Lack of transparency of support systems	Inclusion	Lack of transparency of support systems	Inclusion	Lack of transparency of support systems	Inclusion
	"I do not know what information there was passed on, and we never..... the secondary school didn't reach out to us as a family"	Lack of transparency of support systems	Inclusion	Lack of transparency of support systems	Inclusion	Lack of transparency of support systems	Inclusion
	"the reason we applied to this year is that no one had even mentioned it to us until we had a meeting at college at the beginning of this year about reintegrating M back in"	Lack of transparency of support systems	Inclusion	Lack of transparency of support systems	Inclusion	Lack of transparency of support systems	Inclusion

Educational Professionals

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Absences	"one of the big barriers is obviously attendance in school"	Missed learning	Absences	Missed learning	Absences	Absences/missed learning	Barriers
	"they are having prolonged absences from school, and not accessing the lesson"	Missed learning	Absences	Missed learning	Absences	Absences/missed learning	Barriers
Addressing the absence	it sounds very positive in a meeting where the teachers are saying, why do not you focus on your health. And when you feel better come back to school and we will sort things out, but actually really they are just pushing it under the carpet, they are not addressing the needs.	Missed learning/not addressing	Absences	Not addressing missed learning	Absences	Not addressing missed learning	Barriers

	make sure that that is never an excuse, because sometimes we see absence, increasing, and you have diabetes, but it is not a reason for not being in school because if you are managing your condition Well, there is no reason for that absence.	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
	sometimes we're on a sterner supportive pathway, helping young people who are struggling.	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
	no, asthma is not an excuse to be out of school, five days every month because your asthma is bad. Well controlled asthma is not like that.	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
	this is unauthorised absence because if you are managing your condition and working with your healthcare professional appropriately, there is a good chance that this wouldn't happen. So then we have to go down a safeguarding route.	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
	A little bit more critical of when, when a parent might like to write a letter excusing a child for something, then we would challenge that.	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
	they have had a couple of conversations that worried them about attendance so they will flag that up to us as well	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
	No, check, there is not enough challenge sometimes, there is an acceptance that, well, they are not doing so well in that subject because of their health condition,	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
	if people are not attending. If you code it differently, they can disappear in the numbers. So part of it is making sure that the absences are coded right, so it still raises the red flags, but not many people will know how significant coding attendance is. If you keep it the right code, the red flags are flying, which is where you get the most intense support. If somebody's going oh well, authorise them since they are just unwell for x y and zed... But it's knowing that level of detail.	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
Managing absences separately from learning issues	there is also an issue between schools managing attendance separately to learning issues and the Senco	Separating absences from learning needs	Absences	Differentiation/ separating learning needs from absences	Empowerment	Addressing learning needs separately from absences	Empowerment

	the school Senco who would have an understanding of learning needs, and differentiation needs and the curriculum how that could be adjusted, and sometimes if it is if a young person's absence is actually picked up by the attendance team first rather than the Senco they might not be recognizing the learning needs attached to the absence, as much as. So I think seeing attendance separate to learning in a school is where some gaps are created.	Separating absences from learning needs	Absences	Differentiation/ separating learning needs from absences	Empowerment	Addressing learning needs separately from absences	Empowerment
The need to reintegrate	it has always been the most important part of the work that we undertake. Ours is to reintegrate young people back into their communities	Reintegration	Absences	Reintegration	Empowerment	Reintegration	Empowerment
Return to school	they get very anxious about that return to school	Worrying about returning to school	Absences	Absences/worrying about returning to school	Empowerment	Absences/worrying about returning to school	Barriers
Support role of mainstream school	it is going to be the mainstream school that has got that ongoing level of support and if, health dips, if attendance then regresses a little bit. It is going to be them that needs to make sure that they have got that high level of support on ongoing basis.	Reintegration	Absences	Absences/worrying about returning to school	Empowerment	Absences/worrying about returning to school	Barriers
	making sure that they get that they do not just focus on filling those academic gaps in a young person's learning, but they actually think about really carefully, looking at and considering the social emotional challenges that our young people have in coming back to school. And that is a really, it is a very real set of challenges those young people have got.	SEMH/worrying about returning to school	Absences	Absences/worrying about returning to school	Empowerment	Absences/worrying about returning to school	Barriers
	that responsibility in terms of statutory guidance is always the homeschool's responsibility. They have to ensure that that young person is receiving a good education.	Academic integration	Absences	Academic integration	Empowerment	Academic integration	Empowerment

	the home school of the young person that we're working with should be asking us questions about the quality of our education, what are we doing with that young person because they are still responsible for that young person's education. I mean they might be delegating that responsibility to us for a period of time for a short period of time, but they should be challenging us around the quality of delivery.	Academic integration	Absences	Academic integration	Empowerment	Academic integration	Empowerment
	It should be more about the schools quizzing us and questioning us on what we're doing on a regular basis,	Academic integration	Absences	Academic integration	Empowerment	Academic integration	Empowerment
	it will be down to the school to maintain contact	Academic integration	Absences	Academic integration	Empowerment	Academic integration	Empowerment
Barriers to learning	one barrier, is how, how they access the learning when they are home.	Academic integration	Absences	Academic integration	Empowerment	Academic integration	Empowerment
Children stop going to school	generally the children with health needs, they vote with their feet, they start to disappear, they start not attending	Not returning to education	Absences	Falling through the crack	Absences	Absences/falling through the crack	Barriers
Concerns about other children	we get a response regarding safeguarding, and it can pick up on the children in the class, or that the child could effectively record the lesson from home, and then the teachers are concerned that they do not know what's going to be used, how that footage is going to be used.	Safeguarding concerns	Support	Differentiation/making it work for everyone	Empowerment	Differentiation/making it work for everyone	Empowerment
Expectations	what kind of support, and it is interesting, the diabetes nurse thinks they need the child thinks they need, and the parent thinks they need	Differing expectations	Support	Differing expectations	Empowerment	Differentiation/making it work for everyone	Empowerment
Initial meeting for transition	we'd meet with the parent, the student and a member of the pastoral support team at school. And then what we would do is facilitate that first discussion which is the creation of the care plan really, then we can look at the specifics of the school day routine, where they might want to store medication, administer insulin and get a sense of what kind of support	In school	Support	Problem solving together	Empowerment	Problem solving together	Empowerment

	school staff may have the understanding and the skill set to support young person after they have had a seizure, or, you know, if there is a particular medication or if they are hyperglycaemic, like you say, I should imagine the reality of that is the child is not in the classroom. And then they are missing learning.	Missed learning	Support	Not addressing missed learning	Absences	Absences/not addressing missed learning	Barriers
	Even if work's been sent home.... they are not getting that direct teaching...	Working in isolation	Absences	Working in isolation	Absences	Working in isolation	Barriers
Missed learning	they are always working in isolation at home.	Working in isolation	Absences	Working in isolation	Absences	Working in isolation	Barriers
Covering missed content	he curriculum is not very forgiving. (...) If you have any absence from school. That is where the gap comes in their outcomes versus what they could achieve really.	Missed learning	Absences	Not addressing missed learning	Absences	Absences/not addressing missed learning	Barriers
Differentiation	what they do not do necessarily is differentiate the work to take into account that the child has actually been absent for a month or two months, or that the child has got, you know compromised cognition or learning needs at the time. And so I think there needs to be a lot more differentiation of the work.	Missed learning/lack of differentiation	Absences	Not addressing missed learning/differentiation	Absences	Absences/not addressing missed learning	Barriers
	they are not creating a problem for the school, they are impacting on themselves and that is the difficulty as well because it is not a problem for the school because our pupils are not there creating the problem.	Falling through cracks	Absences	Not addressing missed learning	Absences	Absences/not addressing missed learning	Barriers
	by the time we pick up a young person they could have missed two terms. Yes, and if that is your key stage four curriculum that is where your outcomes are then significantly reduced.	Missed learning	Absences	Not addressing missed learning	Absences	Absences/not addressing missed learning	Barriers
Impact of missed learning	the children are doing their work at home. But they are not, they are not having that interaction with the teacher or with other children in the class, so they are not, they are missing out...	Working in isolation/needed for differentiated work	Absences	Working in isolation	Absences	Working in isolation	Barriers
Missed learning because of being unwell	they are not in a condition to do the work, because they are recovering from surgery, they are receiving treatment for the illness or their condition means that they just, they are not able to access the work at home	Missed learning/needed for differentiated work	Absences	Accessing work from home	Need for differentiation	Working when unwell/need for differentiation	Barriers

	Every secondary school, certainly the largest secondary schools are going to have a number of young people with, with severe medical conditions that require some quite intensive support.	Differentiation	Differentiation	Differentiation	Empowerment	Differentiation/acknowledgement	Empowerment
Need for inclusion	if you think of an ordinary secondary classrooms, there is a lot of children with a lot of different needs.	Differentiation	Differentiation	Differentiation	Empowerment	Differentiation/acknowledgement	Empowerment
Pupils do not have the confidence to ask for support	They are keeping their heads down in the classroom and they all do... they do not want to put their hand up asking for help. Yeah, so their needs are not being met.	Going unnoticed	Pupil's voice	Going unnoticed	Empowerment	Going unnoticed	Barriers
	the student who might not feel as an empowered (...) then at least they have got a system going.	Going unnoticed	Pupil's voice	Going unnoticed	Empowerment	Going unnoticed	Barriers
	They do not want to be a hindrance to their peers because they think they might slow that pace down because they can't go as fast in their wheelchair.	Going unnoticed	Differentiation	Going unnoticed	Empowerment	Going unnoticed	Barriers
	the individual does not want to impact on the game.	Going unnoticed	Differentiation	Going unnoticed	Empowerment	Going unnoticed	Barriers
Reintegration	How do you respond when a young person says something to you that you do not like, which inevitably in a large school setting is going to happen from time to time? So, we talk an awful lot about that sort of thing	Mental wellbeing	Empowerment	Addressing mental health needs	Empowerment	Addressing mental health needs	Empowerment
Role of SENCO	with the best will in the world. That is not the most appropriate role to be supporting it.	Appropriate support	Leadership priorities	Leadership priorities/appropriate support	Empowerment	Leadership priorities/appropriate support	Empowerment
	You need a sufficient position within the school to be working with the right leadership team as well.	Appropriate support	Leadership priorities	Leadership priorities/appropriate support	Empowerment	Leadership priorities/appropriate support	Empowerment
Role of teacher	You do not, you can't just forget that child you have to think well what have they missed. And how am I going to help reintegrate them back in because, really, they are fundamental in their re-integration	Reintegration	Absences	Reintegration after absences	Empowerment	Reintegration after absences	Empowerment

	I have done so much work with pastoral members of staff in school, like Heads of Year and Sencos, but we do not actually meet the math teacher who the child is terrified to go into the classroom with until much further down the line, and that we need to change that a little bit and then get the class teacher involved much earlier on.	Worrying about returning	Absences	Worrying about returning	Absences	Absences/worrying about returning to school	Barriers
Risk assessment	You can easily see the list of students that are going to have medical needs, so that they can begin to address that before they even plan where they are going, what they are doing, how they are going to get there, because all that can be affected by what the medical needs are of the students.	Inclusion	Empowerment	Problem solving together	Empowerment	Problem solving together	Empowerment
School attitudes	We work with some that are exceptional. We work with others that are good and willing, but do not have the processes in place and we work with others that actually are really quite negative as well.	Appropriate support/school attitudes	Leadership priorities	Leadership priorities/appropriate support	Empowerment	Leadership priorities/appropriate support	Empowerment
	some of them are really good and kind of really, really show that they understand it and doing everything and above what they possibly could to, to support the child into, to make it work.	Appropriate support/school attitudes	Leadership priorities	Leadership priorities/appropriate support	Empowerment	Leadership priorities/appropriate support	Empowerment
	Other schools...we think they have understood it, and then we go in. I realize that they haven't understood it.	Appropriate support	Empowerment	Leadership priorities/appropriate support	Empowerment	Leadership priorities/appropriate support	Empowerment
	it is just reassurance that we've got you, we know what we're doing, this is what we can do. And we're with you for the journey, really, that is our plan. So we work with them to really develop that.	Appropriate support	Empowerment	Leadership priorities/appropriate support	Empowerment	Leadership priorities/appropriate support	Empowerment
	you often find that primary schools are more inclusive	Primary schools	Inclusion	Inclusion	Empowerment	Leadership priorities/appropriate support	Empowerment
Similarities with lockdown	at the moment, all children in lockdown, they are all experiencing the same... and they are not progressing.	Lack of progress	Missed learning	Lockdown/misused learning	Absences	Working in isolation	Barriers

	They were really really subdued, and that you know, they would they were very quiet very wary of what was going on in the school didn't talk to each other, let alone engage very much with the staff that were there. Yeah, and that, that is kind of a testament to the emotional challenges that young people are facing at the moment.	Emotional challenges	Empowerment	Addressing mental health needs	Empowerment	Addressing mental health needs	Empowerment
Social inclusion for unwell children	just because they can't attend school does not mean they can't attend an after school activity or a lunchtime club that they like	Mental health/social inclusion	Empowerment	Addressing mental health needs	Empowerment	Addressing mental health needs	Empowerment
	The parents are often so so sure that they have got to keep up to date with work and we've got to keep them from falling behind and actually sometimes it is about helping them relax a little bit about, they will catch up, they will. But let's just make sure they are well first because they will catch up quicker if they are well.	Mental health	Empowerment	Addressing mental health needs	Empowerment	Addressing mental health needs	Empowerment
Underexpectations	the barriers would be preconceived held ideas by parents as well sometimes as to what they expect of their child. "Oh they have got that then. They are not doing well, are they?' Why? Who said that? So it is the underexpectation from parents, underexpectation from child, "I have got this now, I am never going to do as well". Underexpectations for performance of teachers.	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment
	"Oh you have really not been well so of course, stay home, oh yeah quite understand you can stay home."	Addressing absences	Absences	Addressing absences	Empowerment	Addressing absences	Empowerment

School nurses

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Academic integration during absences	Not really keeping them integrated they do things like sending homework home and things like that (...) but in terms of socially, I do not really think they are.	Academic integration / lack of social integration	Absences	support to catch up / lack of social integration	Absences	Absences/lack of social integration	Inclusion
	actually, it wouldn't necessarily be a school nurse, I think she would be an educator, so the child does not miss out on education	Support to catch up	Absences	Support to catch up	Absences	Absences/support to catch up on missed learning	Inclusion

	if they are in hospital for a long time as well, schools would make sure that they are sent the same work. As far as they can. Within school they will try to get that homework and things to that child	Support to catch up	Absences	Support to catch up	Absences	Absences/support to catch up on missed learning	Inclusion
Academic support	I do know that they are aware of, are they meeting their targets and if they are not meeting the targets they will put support in place for that.	Support to catch up	Absences	Support to catch up	Absences	Absences/support to catch up on missed learning	Inclusion
	Schools do not differentiate in terms of attendance for pupils with medical needs. This is a big problem. They tell the school every single time but it does not actually happen. They have no way to confirm whether what school says is true.	No differentiation	Attendance	No differentiation of the attendance policy	Absences	Absences/attendance policy not differentiated	Inclusion
	Sometimes, usually not, I think, unless there is any of the issues	???	????				
	I think to be fair to schools I think the demands on them are very very high and actually you can when, when it is all about targets and results you can get away with kids who are, you can almost get a forgiveness for having children who are unwell who do not achieve. So actually, why would you put your energy into that?	Going unnoticed/not being prioritised because of health issues	Progress	Going unnoticed/not being prioritised because of health issues	Inclusion	Going unnoticed/not being prioritised because of health issues	Inclusion
	We do, we do not discriminate any child I am just updating as our school is a new, new school. I am updating our medical policy, and within that there it clearly states that you will not penalize a child who has a medical condition if they can't access school, we will do everything we can to ensure that they are supported in order to access their education.	Support in place	Integration	Differentiation of the attendance policy	Variable practice/Absences	Absences/attendance policy not differentiated	Inclusion
	we had the best attendance, because you are teaching young people as well with minor ailments like headaches and stomachache. But that is not a reason to go home and miss your education!	Addressing absences	Integration	Addressing absences	Integration	Addressing absences	Inclusion
Being different	he didn't bring the epipen back in. Couldn't get hold of mom and they just said, they just ended up saying 'Right, you are not coming to school', which obviously got a result, it is not obvious but it did get a result. Because the child is in school.	Communication with parents/punishment for child	Inclusion	Communication with parents/punishment for child	Being different	Lack of understanding/making pupils feel different	Inclusion

	one school, they would make sure the child had it on them, which I used to be a bit debatable about that because I used to say is that not focusing the child from being different from other children and.. but she wouldn't have the child in that school unless the child had that bumbag on them with the epipens in and so yeah so we do come across different practices in different schools,	Punishment for child/being different	Inclusion	Lack of understanding	Being different	Lack of understanding/making pupils feel different	Inclusion
	There is no planning for transitions, often the nursing team gets a panic call from a school on the first of September because they are not prepared to integrate a pupil with a certain condition. Nurses try to skill schools up but it is a wild goose chase and it is often met with reluctance.	Need to prepare for transition	Integration	Transition/integration	Variable practice	Transitions/school nurse involvement	Variable practice
	Nursing team is not involved with transition and they are aware that it is a problem, they are looking at ways to be better involved, it is definitely an area they are looking to improve. They have never been asked by school to provide support.	Need to prepare for transition	Integration	Transition/integration	Variable practice	Transitions/school nurse involvement	Variable practice
	Then we do transition training and everything before the child goes into, into secondary school, so we will identify the person who will be responsible for at school, so the teacher or the Senco or the teaching assistant or receptionist, and we will get together and we will do the training before the child goes into school.	Nursing team involvement	Variable practice	Good practice / Identifying a contact person	Variable practice	Good practice / Identifying a contact person	Variable practice
Transition from primary to secondary	they work out that that child needs extra support at primary school is quite a big part to play in this, because they will identify it as an issue that needs that support with regards to transition to high school. And then obviously the high schools got to respond to that appropriately as well. So some of it is about the communication between the two schools, and then the high school will, you know, you do have a couple of days where you go to high school as a primary child anyway,	Communication between schools/support for transition	Variable practice	Good practice / Communication	Variable practice	Good practice / Communication	Variable practice

	go through in detail with the parents and maybe the school nurse as well about, you know what, what extra support going to be needed to be in place so that when they do go in September, there is already a plan in place and everything's organized and, hopefully, less anxiety for the parent less anxiety for the child.	Communication between schools/support for transition	Variable practice	Good practice / communication	Variable practice	Good practice / communication	Variable practice
	It would come from the previous school. I would see if they can send any information about what happened there and how it was treated. So it comes over with them.	Communication between schools/support for transition	Variable practice	Good practice / communication	Variable practice	Good practice / communication	Variable practice
	whether there was a verbal handover would be random. It would depend on the school. So, it tends to be there is a plan in place, but how robust that is, is another question so where it is known to school nurse, there'll be a good transition where it is not known, it relies on the parents and the school staff and that again, will be down to capacity. Yeah, they are pretty good at raising it down.	School nurse involvement for transition	Variable practice	School nurse involvement for transition	Variable practice	Transitions/school nurse involvement	Variable practice
	we used to always liaise with the pupils we'd find out which new school they were going to, and we would liaise with that new school and make sure that have a care plan that is ready with that treatment, all on the first day of starting a new school.	School nurse involvement for transition	Variable practice	School nurse involvement for transition	Variable practice	Transitions/school nurse involvement	Variable practice
	the secondary schools' school nurses are the primary schools' of school nurses also	School nurse involvement for transition	Variable practice	School nurse involvement for transition	Variable practice	Transitions/school nurse involvement	Variable practice
Difference between schools	it is up to the school whether they reach out for advice, it does not happen consistently.	Need to prepare for transition	Variable practice	Transition	Variable practice	Transitions/school nurse involvement	Variable practice
	I have got three high schools and I would say, different in the different schools. Some schools are really good at doing that transition and other school is a little bit more hectic.	Need to prepare for transition	Variable practice	Transition	Variable practice	Transitions	Variable practice

	since the introduction of academies, and free schools that some of those are less welcoming to health services, because they do not have to. Yeah, and if it is going to interrupt the curriculum, and they do not necessarily have to be pleasant about any offer. And so there is something about the changes in legislation and the introduction of academies and free schools.	Prioritising academic progress/not welcoming health/school attitudes	Variable practice	Collaboration with health services / prioritising academic progress	Variable practice	Engagement with school nurse / Deprioritising pupils with health-related needs	Variable practice
	we have mechanisms and processes in schools that, you know, have their eye on the ball	Support in place	Variable practice	Appropriate support	Variable practice	Appropriate support	Variable practice
	we're not based in schools, we're based elsewhere, and different schools, some schools have more anxiety than other schools, some just take it as, you know, really easy and, but I presume that depends	School attitudes	Variable practice	Appropriate support	Variable practice	Appropriate support	Variable practice
	if they are over 16 for example we would look at, you know, transferring that responsibility onto the child as well so that they are expert patients and they feel more empowered to deal with that medical condition too	Growing independence	Empowerment	Empowerment/growing independence	Variable practice	Empowerment/growing independence	Variable practice
	to try and encourage them to manage the situation themselves, which is what we want. But I can liaise with the parent and keep them informed, but if I do not feel that we are managing it then I can ring.	Growing independence	Empowerment	Empowerment/growing independence	Variable practice	Empowerment/growing independence	Variable practice
	what we hope is that we're skilling, upskilling this young person, so they can become independent. Okay, and to self manage.	Growing independence	Empowerment	Empowerment/growing independence	Variable practice	Empowerment/growing independence	Variable practice
Growing independence	my role as a public health nurse is to empower to become independent. For the child and the family. Yeah, you know, and that young person managing that condition to go on to live an independent healthy life you know, making decisions for themselves.	Growing independence	Empowerment	Empowerment/growing independence	Variable practice	Empowerment/growing independence	Variable practice
Health representation	Nursing team is not involved with transition and they are aware that it is a problem, they are looking at ways to be better involved, it is definitely an area they are looking to improve. They have never been asked by school to provide support.	School nurse involvement for transition	Variable practice	Transition/school nurse involvement	Variable practice	Transition/school nurse involvement	Variable practice

So it is thinking ahead as well, so it is sort of saying actually you should have somebody in school who is able to manage medical issues if a child is on roll and needs to have something specific done to them it is not waiting until that child comes along and then thinking what are we going to do because nobody's happy to deal with encopresis for example or, or stuff like that so.	Need to prepare for transition	Variable practice	Transition	Variable practice	Transition/school nurse involvement	Variable practice
When there is health representation, yes. If you have got a specialist nurse there or it comes from hospital direct to schools then I think yes, and less so if health representation is absent or weak.	School nurse involvement for transition	Variable practice	Transition/school nurse involvement	Variable practice	Transition/school nurse involvement	Variable practice
we've been unable to secure any training for staff. But my headteacher is not as concerned because obviously I am on site.	School nurse involvement for transition	Variable practice	Transition/school nurse involvement	Variable practice	Transition/school nurse involvement	Variable practice
she was able to come to school because I am a nurse and I was on site so her parents were very confident and so was she, the teachers were terrified because obviously they didn't understand that I know what to do	School nurse involvement for transition	Variable practice	Transition/school nurse involvement	Variable practice	Transition/school nurse involvement	Variable practice
I have tried my damndest to try and get people to listen that I truly believe that having a health care professional based on site is paramount. Not just to our children who have additional health needs. But for well children to teach good health behavior. So I call it health literacy and I am a great believer that if we want to grow, young children into healthy contributing adults society, then we need to teach first	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools
COVID being the golden opportunities and children, you know, need the same health teaching as they do education to learn the math and to do their English	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools

I think we fundamentally miss that if you are not at school, when you are not visible, and you are not accessible to children, to get the children having a voice, forget the peer and forget, you know, teaching have, like I said health literacy and independence. It just does not happen, you can't, you can't just dip in and out of these schools for an hour and have a drop in, you know, kids, will not come to you if they do not know you.	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools
it is more than that, it is about knowing the child, knowing the family, the child being able to come to you throughout the day.	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools
I so believe it is essential to have health care in school	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools
they will be safe and looked after, because there is a nurse on site	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools	Supporting all children/teaching good health behaviour	Health representation in schools

Subsidiary research question 3

Parents and teens							
Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Awareness within school	"I feel like we told them but they didn't really take much interest in it, so they didn't really listen to us"	Within schools	Awareness	Hopelessness	Trying to raise awareness	Communicating needs / Hopelessness	Communication
	my teacher accused me saying that I do not even have CF and I am lying about it and stuff like that.	Within schools/penalising pupils/unacceptable practice	Lack of awareness	Lack of support/unacceptable practice	Invisible needs	Lack of support/unacceptable practice	Invisible needs

	in terms of her peers, you know I have I have you know I have done the kind of the one to one contact with year heads and senior leadership team and, you know, explain things, I have brought professionals in and... Yeah, that is as much as I as I knew I was able to do at the time, I suppose.	Parents work on raising awareness	Raising awareness	Within schools	Trying to raise awareness	Communicating needs / within school	Communication
	Well, we told them about it. I didn't really..... mean anything.	Losing hope	Raising awareness	Hopelessness	Trying to raise awareness	Communicating needs / Hopelessness	Communication
	it was just left to me to do a much more detailed plan for things like when she has IV antibiotics at home, it can, she can have a bad night's sleep. So therefore, she is not going to be the greatest at school, she can have headaches. It is probably a lot of little things, although there is nothing medical they have to do for her.	SEMH needs, impact on learning	Raising awareness	Invisible needs	Trying to raise awareness	Invisible needs	Communication
Communication within school	"There is an awful lot of teachers and staff that have left, new ones that have come in. So the people that did know about M in year 7 and 8 I have kind of moved on now"	Within schools	Communication	Within schools	Lack of effective communication	Communicating needs / within school	Communication
	here just seems a bit a lack of communication because we do not actually know who to address with her problems.	Lack of communication/lack of contact person	Awareness	Within schools/lack of contact person	Lack of effective communication	Lack of effective communication	Communication
	I think it was an internal communications thing in school. So, I would certainly let school reception know and I had let the head of year know. I just do not think that message had in time got filtered down to the rest of school	Lack of communication within school	Lack of awareness	Within schools/lack of contact person	Lack of effective communication	Lack of effective communication	Communication
Mental health	"imagine the psychological impact on somebody who's always had a brilliant school record, is now fighting with a new medical condition, is sick in hospital and sees that he has got the first negative behaviour point of his whole life. And it is totally not in his control!"	Impact on mental health	Awareness	Impact on mental health	Lack awareness	Impact on mental health	Invisible needs
	when I get in pain, I usually get or a bit moody and I sort of go a bit quiet and when I am really tired, so I think it does affect me..	Impact on mental health	Impact on mental health	Impact on mental health	Invisible needs	Impact on mental health	Invisible needs

	"I would tell them that I am struggling and they tell me that they just sort of, they do not listen either. It is like you tell them how you are feeling and they are just not really helpful"	Lack of support for mental health	Lack of support	Lack of support	Not being heard	Not being heard	Invisible needs
	there was one time my teacher accused me saying that I do not even have CF and I am lying about it and stuff like that. Like, then I would have liked to talk someone but I do not think there is anyone.	Impact on mental health	Lack of support	Lack of support / impact on mental wellbeing	Not being heard	Not being heard/no person of trust in school	Invisible needs
	my school is not really that good when it comes to things like that.	Lack of support for mental health	Lack of support	Lack of support / impact on mental wellbeing	Not being heard	Not being heard/no support for mental wellbeing in school	Invisible needs
	I find it hard to talk to them because I go to them. I say like, can I have work? What I have missed? They say.... I do not know, they just do not really seem to care. Even if I did tell them, I do not really think they are interested.	Lack of support for missed learning	Lack of support/not being understood	Lack of support / impact on mental wellbeing	Not being heard	Not being heard/no support for mental wellbeing in school	Invisible needs
	I would tell them that I am struggling and they tell me that they just sort of, they do not listen either. It is like you tell them how you are feeling and they are just not really helpful.	Lack of support	Not being understood/not being heard	Lack of support / impact on mental wellbeing	Not being heard	Not being heard/no support for mental wellbeing in school	Invisible needs
	just listen to me. That is all really, just listen. And it is like, you tell them something, and they will tell you the opposite, or just things like that.	Lack of support	Not being understood/not being heard	Lack of support / impact on mental wellbeing	Not being heard	Not being heard/no support for mental wellbeing in school	Invisible needs
	when I look back on it now I feel really angry about it because.... had I known, the kind of, you know, the massive effect, it was going to have on her.	Long term impact	Lack of support	Lack of support / long term impact	Invisible needs	Not being heard/long-term impact	Invisible needs
Lack of support for mental health	I suppose that they are more focused on the psychology around the medical needs than the social emotional needs	Medical needs prioritised over SEMH needs	Awareness	Focus on medical needs only	Invisible needs	Focus on medical needs only	Invisible needs

	I think there is something about it being, I do not know, more acceptable, tangible, you know, knowledgeable and you know other people are touched by it. There is a kind of like an immediate life or death thing. That would kind of made their response different. Yeah, you know, I you know I think you know if. Yeah. Yeah. I can't explain it. It is still a mystery to me but....	Invisible needs	Lack of awareness	Focus on medical needs only	Invisible needs	Focus on medical needs only	Invisible needs
Missed learning	"a lot of missed learning"	Missed learning	Missing out	Missed learning	Invisible needs	Missed learning	Missing out
	there is definitely a lot of tiredness. But the main thing is that hospital admissions and appointments, and sometimes treatment at home.	Impact on learning/imp act on wellbeing	Impact of health-related needs	Missed learning	Lack of awareness	Missed learning	Missing out
	if I was in the middle of a lesson and I had to go to the medical room.	Missed learning	Impact of health-related needs	Missed learning	Missing out	Missed learning	Missing out
Friendships	I only have a couple of friends that I can say are like proper friends. I mean, it is hard. Like when you as I said, if I have prolonged periods off, you sort of go back and you definitely feel like a new sort of person and yeah, it is hard.	Missing out on social aspects	Missing out	Social aspects	Missing out	Social aspects	Missing out
	"CF would have undoubtedly impacted in terms of... she wouldn't have been able to do as much social engagements, through being unwell or in hospital"	Missed opportunities	Missing out	Missed opportunities	Missing out	Social aspects	Missing out
	it is just little things like if I am in school and like I need to cough, and people are like making a thing of it they will like tell people to just leave it and stuff. Or like if the teachers are like not getting that I need to leave to cough, they will like help me.	Friendships	Friendships	Friendships	Friendships	Trying to raise awareness	Friendships
Peer awareness	"The minute he came out of hospital, he had the lads over and he educated them exactly what to do"	Peer awareness	Independence/self confidence/rasising awareness	Friendships	Trying to raise awareness	Friendships	Communication
	I get some support, like the girls in my biology class they pat me on the back and keep me awake if I fall asleep.	Peer support	Friendships	Friendships	Trying to raise awareness	Friendships	Communication
	No, they do not know. I think they all did know, in Year 7 when I had to go in my wheelchair. I stopped doing that because I didn't like, didn't like it. So I think many of them do not know, only a few people know.	Invisible needs	Lack of awareness	Feeling different	Invisible needs	Feeling different	Invisible needs

	they did give me a queue jump card. But again, if you just jumped the queue, you get people shouting at you. I do not really like to see that. And then I have scenes where again, they say I can, when it is cold I get to wear my coat. Again, I am trying not to do that because it makes the whole class just go, because like, Why is she wearing it?	Invisible needs	Lack of awareness	Feeling different	Invisible needs	Feeling different	Invisible needs
	when they were covering genetics, in secondary school that you know all of her friends were like, you know, very sensitive towards M about how they were doing that.	Peer awareness	Friendships	Friendships	Trying to raise awareness	Friendships	Communication
	as a kind of a preteen and teenager she wouldn't have wanted in her class or assembly to do anything like that. And she, you know, she would have felt uncomfortable with me going and doing that, as well.	Not wanting to seem different	Awareness	Feeling different	Invisible needs	Feeling different	Invisible needs
Procedures for unwell child	"they would call me to come and collect her from school"	Asking parents to pick up children from school/no procedures for unwell child/missed learning	Absences	Missed learning	Missing out	Missed learning	Missing out
	they will ring my mom and ask her what to do. .	Parental involvement	Parents	???	???		
	there really was not an actual protocol because it would end up that M would text me or phone me and say that she was not feeling well and I willturn up at the office, she will turn up there and then I willtake her home.	Asking parents to pick up children from school/no procedures for unwell child/missed learning	Absences	Missed learning	Missing out	Missed learning	Missing out
	they will phone me and I willgo and collect him	Asking parents to pick up children from school/no procedures	Absences	Missed learning	Missing out	Missed learning	Missing out

		for unwell child/missed learning					
	"she is not really got the confidence to do that. I do not think"	Pupil's voice	Independence/self confidence/raising awareness	Lacking self confidence	Trying to raise awareness	Lacking the self-confidence to raise awareness	Invisible needs
	I have fallen asleep on that bed before and have people come in and out, whilst I am in there. Oh yeah. So i was a lot in there because I have broken things I have got things cut. And I have no idea... If any of them... Why I have no idea what any of them did in the room at all.	Not feeling safe when being unwell	Lack of awareness for associated needs	Not feeling safe when unwell	Missing out	Not feeling safe when unwell	Missing out
	I do not enjoy drawing attention to myself. So that might be like the one odd person	Not having confidence to raise awareness	Lack of awareness	Lacking self confidence	Trying to raise awareness	Lacking the self-confidence to raise awareness	Invisible needs
	I kind of have to encourage K, she has got to have the voice because there is obviously a lot that is not in place that I would like in place, but with it being secondary I have just got to really encourage, K you have got to speak up or otherwise something else happens, stay behind after the class and say you know that is not right or are you aware of this, so it does not happen again. But it is not always that easy, is it?	Not having confidence to raise awareness	Lack of awareness	Not having confidence to raise awareness	Lack of awareness	Lacking the self-confidence to raise awareness	Invisible needs
	i do not really want people to be knowing, to be honest.	Not wanting to seem different	Invisible needs	Feeling different	Invisible needs	Feeling different	Invisible needs
	She has, she has not really got the confidence to do that. I do not think,	Not having confidence to raise awareness	Lack of awareness/invisible needs	Not having confidence to raise awareness	Lack of awareness	Lacking the self-confidence to raise awareness	Invisible needs
Pupil's voice	he was prepared to do it, and he then, he did his presentation to the peer group	Raising awareness	Awareness	Friendships	Trying to raise awareness	Friendships	Communication
Struggling pupil	"I just do not know why there is the barrier between ... I do not understand it. I do not understand why it is there. It shouldn't be... If you have a child who's got a diagnosis"	Struggling pupil	Lack of support	Struggling pupil	lack of awareness	No support for struggling pupil	Communication

	They do need to differentiate the work for him and the homework. And that is that. That does not happen regularly. Yeah, and it is not consistent. Erika, we had such a rough ride, getting the school to do anything.	Struggling pupil	Lack of support	Struggling pupil	lack of awareness	No support for struggling pupil	Communication
	I think I am going to struggle this year, because let's say I am gonna be in pain again. I will be tired, and I have got to do a lot of extra work and things. So I think I am going to struggle.	Struggling pupil	Invisible needs	Struggling pupil	lack of awareness	No support for struggling pupil	Communication

Educational Professionals

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Awareness raising	We raise general awareness at the beginning of the year with inset training and flag up the Big Four,	Focus on medical needs	Communication	Effective share of information within school	Empowering teachers	Effective share of information within school	Empowering teachers
	what medical information for the students is stored individually under their student name, but obviously unmanageable from a day to day basis when a teacher's got a query.	Effective share of information within school	Communication	Effective share of information within school	Communication	Effective share of information within school	Empowering teachers
	raise awareness with the parents as well not to dismiss that bit of a cough or with hay fever and so it is only hay fever.	With parents	Communication	??	??	??	??
	It could be training to staff to make sure that they feel comfortable in supporting that young person	Empowering staff to provide support	Communication	Raising staff self confidence to provide support	Empowering teachers	Raising staff self confidence to provide support	Empowering teachers
Databases	So it would be class charts and provision maps as a way of making sure people can easily find information when their faced with a student that they do not know.	Effective share of information within school	Communication	Effective share of information within school	Empowering teachers	Effective share of information within school	Empowering teachers
	what medical information for the students is stored individually under their student name, but obviously unmanageable from a day to day basis when a teacher's got a query.	Effective share of information within school	Communication	Effective share of information within school	Empowering teachers	Effective share of information within school	Empowering teachers
EP role	with us to kind of get more ideas I guess and strategies on how we can support the child	Empowering staff to provide support/EP role	Communication	EP role	Empowering teachers	EP role	Empowering teachers

	provides training for our staff on particular aspects of the work from time to time as well. And so yeah so her role has been really valuable in helping us to move forward in terms of education psychology services.	Empowering staff to provide support/EP role	Communication	EP role	Empowering teachers	EP role	Empowering teachers
	she is providing some of the training modules that we use with some of the schools	Empowering staff to provide support/EP role	Communication	EP role	Empowering teachers	EP role	Empowering teachers
	her role is very much about the psychological impact of a medical condition, physical medical condition, on the young person.	Empowering staff to provide support/EP role	Communication	EP role	Empowering teachers	EP role	Empowering teachers
	support our staff to think more carefully about that more deeply about how to overcome those barriers to learning.	Empowering staff to provide support/EP role	Communication	EP role	Empowering teachers	EP role	Empowering teachers
	she she supports the staff as much as she does the young people directly actually within that team work.	Empowering staff to provide support/EP role	Communication	EP role	Empowering teachers	EP role	Empowering teachers
Lack of confidence to support SEMH needs	it is something that we're looking to try and develop further because it is not an area that I am particularly confident, it is an area that I haven't had a huge amount of training on myself. So it yeah it is trying to work out what's going to work and what we can do with our knowledge in the social emotional aspect.	Empowering staff to provide support/social emotional aspect	Communication	Social emotional aspects	Empowering teachers	Social emotional aspects	Empowering teachers
	We touch on it but no, we do not do a huge amount on that aspect.	Need to empower staff to provide support/social emotional aspect	Communication	Social emotional aspects	Empowering teachers	Social emotional aspects	Empowering teachers
Role of pastoral care	we often find young people with long term health conditions need that additional pastoral support.	Need to empower staff to provide support/social emotional aspect	Communication	Social emotional aspects	Empowering teachers	Social emotional aspects	Empowering teachers

	I have done so much work with pastoral members of staff in school, like Heads of Year and Sencos, but we do not actually meet the math teacher who the child is terrified to go into the classroom with until much further down the line, and that we need to change that a little bit and then get the class teacher involved much earlier on.	Need to empower staff to provide support/social emotional aspect/raising awareness for invisible needs	Communication	Social emotional aspects / awareness of invisible needs	Empowering teachers	Social emotional aspects / awareness of invisible needs	Empowering teachers
	Do those classroom teachers know how to support that young person? They may have an awareness, but I bet their go to response is to send them to the pastoral member of staff	Need to empower staff to provide support/social emotional aspect	Communication	Social emotional aspects	Empowering teachers	Social emotional aspects	Empowering teachers
	You have got your pastoral staff who might take responsibility for managing the young person's condition and situation and put adjustments and things in place and then you have got your curriculum, your maths teacher, your history teacher, your geography teacher.	Need to empower staff to provide support/social emotional aspect	Communication	Social emotional aspects	Empowering teachers	Social emotional aspects	Empowering teachers
SEMH impact	It is a big part of our children's lives	Need to empower staff to provide support/social emotional aspect	Communication	Social emotional aspects	Empowering teachers	Social emotional aspects	Empowering teachers
Understanding	Understanding generally in terms of what healthcare conditions can mean for a young person, and that can be understanding from teachers, or from parents, the student themselves.	Addressing learning and SEMH needs/less focus on medical aspects	Understanding needs associated with health	Social emotional and learning aspects/less focus on medical needs	Empowering teachers	Social emotional and learning aspects/less focus on medical needs	Empowering teachers
	make it objective that it is actually a valid special educational need, and create a support for them.	Addressing learning and SEMH needs/less focus on medical aspects	Understanding needs associated with health	Social emotional and learning aspects/less focus on medical needs	Empowering teachers	Social emotional and learning aspects/less focus on medical needs	Empowering teachers

School nurses

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Creating a network of support in school	the dinner ladies if anything are the best port of call, because it is 'well, we're not meant to have our phones switched on... However, we have our mobile phone in our pinny, and it is on silent' and the majority would say that and the heads, Headmistress/ masters used to just turn a blind eye basically because they have to have.	Network of support in school	Support	Making medical conditions more visible	Network of support in school	Network of support in school	Making health more visible
	in one school they ended up getting the walkie talkies which I know a lot of schools have now	Network of support in school	Support	Making medical conditions more visible	Network of support in school	Network of support in school	Making health more visible
Impact on learning	sometimes they do need to understand, because they haven't got that medical knowledge, they do not always understand how a medical condition can affect a child so for example with with epilepsy you know if they have nocturnal epilepsy, it is going to have a huge impact on their learning on them being at school on them being tired on them getting in late, you know, especially if they have a seizure at night. So all those things they become aware of when we're doing the training as well.	Impact on learning	Training	Linking medical conditions with learning needs	Network of support in school	Training	Linking physical health with learning needs and mental wellbeing
	with epilepsy and you can have like absent seizures and so many staff, sometimes go "oh I never knew you could get absent seizures, but that makes so much sense because I can see, you know, a few that might have that in class"	Impact on learning	Training	Linking medical conditions with learning needs	Network of support in school	Training	Linking physical health with learning needs and mental wellbeing
	Not particularly.	??	??				
	they do not perhaps realize that a young person say with a hypoglycemic attack is a couple of hours, and well prior to the actual, the reading, and then it is a couple of hours after, so they do not really realize the impact, I do not believe, of that event on that young person's performance or behaviour,	Impact on learning	Lack of understanding	Linking medical conditions with learning needs	Training	Training	Linking physical health with learning needs and mental wellbeing

	They do not consider the impact of any need on learning	Impact on learning	Lack of understanding	Linking medical conditions with learning needs	Training	Training	Linking physical health with learning needs and mental wellbeing
	even if they speak to the parent they do not always understand the impact	Impact on learning	Lack of understanding	Linking medical conditions with mental wellbeing	Training	Training	Linking physical health with learning needs and mental wellbeing
	I suppose not in the broad sense of mental health, and it is good idea probably will from now on.	Impact on mental health	Training	Linking medical conditions with mental wellbeing	Training	Training	Linking physical health with learning needs and mental wellbeing
	a lot of staff do online training, elearning and it is not covered enough...	Elearning / Not sufficient	Training	Elearning / Not sufficient	Training	Training / elearning not sufficient	Linking physical health with learning needs and mental wellbeing
	generally, I do not think it is given second thought, to be honest.	Impact on SEMH	Not taken into account	Linking medical conditions with mental wellbeing	Training	Training	Linking physical health with learning needs and mental wellbeing
	I do think they have a lot of responsibility schools now, I really do	School responsibility	School responsibility	School responsibility	Network of support in school	School responsibility	Making health more visible
Impact on SEMH	With secondary schools. I do not, I would rate that quite low actually, possibly, and from experience of, even though you are involved in say residential with secondary schools, and you try, you do not want them to be labeled or anything like that, especially because they do become very self conscious.	Impact on SEMH	Invisible needs	Linking medical conditions with mental wellbeing/invisible needs	Training	Training/pupil self-consciousness	Linking physical health with learning needs and mental wellbeing
	we do provide training to young people and their peers	Peers	Training	Peers	Network of support in school	Network of support in school/peers	Making health more visible
	Things you can't do but your friends can do and, not being quite the same way.	Peers	Feeling different	Peers / feeling different	Network of support in school	Network of support in school/peers/feeling different	Making health more visible
Peers	there is young people who have said, I need my friends to know, or we think it'd be a good idea if my friends knew	Peers	Training	Peers	Network of support in school	Network of support in school/peers	Making health more visible

	Yeah, if they wanted to. Yeah, absolutely, especially secondary school pupils. I always advise that they liaise and tell their friends how	Peers	To confide in peers	Peers / confiding in peers	Network of support in school	Network of support in school/peers/confiding in peers	Making health more visible
	And being open and honest with the friends because in any emergency the closest people to them are going to be their friends. Yes, in any in any time spare of lessons and things like that. So I would always encourage that.	To confide in peers	Peers	Peers / confiding in peers	Network of support in school	Network of support in school/peers/confiding in peers	Making health more visible
	She said that it is her friends or monitor her really rather than anyone actually go up to her and said: Have you got your epi pens on you?	To confide in peers	Peers	Peers / confiding in peers	Network of support in school	Network of support in school/peers/confiding in peers	Making health more visible
	I always recommend the parents and the young person that they confine in a couple of their close friends, so that they are aware of the condition	To confide in peers	Peers	Peers / confiding in peers	Network of support in school	Network of support in school/peers/confiding in peers	Making health more visible
Role of school nurse on site	when school nurses have their role in this they would have just been able to be encourage and support this.	Training for peers	Peers	Peers / confiding in peers	Network of support in school	Network of support in school/peers/confiding in peers	Making health more visible
	when school nurses delivered that, this would have been an essential part of the training,	Training for peers	Peers	Peers / confiding in peers	Network of support in school	Network of support in school/peers/confiding in peers	Making health more visible
	Our staff are because of me again because I have a big role within the school as a health care professional. So they are all aware that they have two registered nurses on site. And, and, you know, we're the all day every day and they come for advice for themselves, for the pupils. So yes, they are aware.	To confide in peers/encouragement	Peers	Making health more visible	Health representation	Health representation in schools	Making health more visible
	I think there is an awareness because of my role within the school, and I am very visible and "doable"	Making medical needs more visible	Health representation	Making health more visible	Health representation	Health representation in schools	Making health more visible
	they can't get, you know, medical advice so you know I think I think it becomes embedded within the school, that is because this role has become this	Making medical needs more visible	Health representation	Making health more visible	Health representation	Health representation in schools	Making health more visible
	I can't see how we will ever change anything for young people with medical conditions unless we have health professionals based on sites	Making medical needs more visible	Health representation	Making health more visible	Health representation	Health representation in schools	Making health more visible

There is room, always to improve, I would say that I am very confident that due to the health roles in our school we do, and are supportive.	Making medical needs more visible	Health representation	Making health more visible	Health representation	Health representation in schools	Making health more visible
I would go further than that, I would say, why do not we have healthcare professionals in schools?	Making medical needs more visible	Health representation	Making health more visible	Health representation	Health representation in schools	Making health more visible
so it is fundamental to me to have healthcare professionals in schools.	Making medical needs more visible	Health representation	Making health more visible	Health representation	Health representation in schools	Making health more visible
Not very many are fully aware. she encourages them to go on websites of certain conditions but she thinks it is unlikely that they do that unless there is a pupil they need to be aware of or there is an emergency	Making medical needs more visible	Health representation	Making health more visible	Health representation	Health representation in schools	Making health more visible
if the staff were aware of the problem and something wouldn't be done, then it would start making a noise about it being a problem. I think the problems, probably, possibly come in, where they are not aware that the problem and all this something is not being done properly.	Making medical needs more visible	Health representation	Making health more visible	Health representation	Health representation in schools	Making health more visible
with the best will in the world, teachers can be fantastic and caring, but they do not understand. They do not have the medical knowledge.	Making medical needs more visible	Network of support in school	Making health more visible	Health representation	Health representation in schools	Making health more visible
teaching staff they are not taught about medical conditions when they are doing their training, they are taught about education so they have no idea.	Making medical needs more visible	Teacher training	Making health more visible	Health representation	Health representation in schools	Making health more visible
I think generally schools have a better understanding of cognitive development and adolescent neurodevelopment so I think certainly teachers that have been trained in the past five years, it is included in their curriculum.	Making medical needs more visible	Teacher training	Making health more visible	Teacher training	Health representation in schools	Making health more visible

	<p>teaching staff are always changing. It is incredible how quickly they change if you have got a teacher who's been there for years and years, they know, they you know they have come across it, they know where their difficulties they have had our training. They have talked to us a lot about that. But if you have got young teachers, who are constantly rotating and moving on and new teachers are coming. I do not think they do have the awareness</p>	Making medical needs more visible	Teacher training	Making health more visible	Teacher training	Health representation in schools	Making health more visible
Teacher turnover	<p>I have developed for all relief, or supply staff on the back of the cover sheet to have a list of all of the children with diabetes, anaphylaxis and epilepsy. So, they have a name, so hopefully they, you know, they would be prompt in their actions or maybe notice a diabetic child is not performing, and they might ask themselves the question, you know, this child has a diabetes, or you know maybe they are having a hypo or something so.</p>	Linking medical needs to learning needs	Teacher awareness	Linking medical needs to learning needs	Teacher training	Teacher training	Linking physical health with learning needs and mental wellbeing
	<p>No, I do not think they are to be honest. Cuz I do not know what the process is for their employment. And I know that it is usually the regular teachers who attend our training so they come to our training on anyway. But supply teachers unless the school sends them along. Then, we do not know whether they get informed or not, although we do during our training we do, explain things like like supply teachers not having that correct information, or even things like, you know, going on school trips overnight trips those sorts of things and how important it is to have somebody who is aware of that child to have to be on those trips as well</p>	Supply teachers	Gap in awareness	Gap in awareness / Supply teachers	Network of support in school	Gap in awareness/supply teachers	Linking physical health with learning needs and mental wellbeing
Training for supply teachers	<p>no they are not present, and they are not trained.</p>	Supply teachers	Gap in awareness	Gap in awareness / Supply teachers	Network of support in school	Gap in awareness/supply teachers	Linking physical health with learning needs and mental wellbeing

	I think training is definitely you know the biggest thing. Because usually teachers are very grateful. At the end of the training, and they do say actually you know I was not aware and you have just opened my eyes to it so.	Linking medical needs to learning needs	Teacher awareness	Linking medical needs to learning needs	Training	Teacher training	Linking physical health with learning needs and mental wellbeing
	sometimes we only find out that they have been given Baccolum when the teacher comes to one of our centralized trainings and says, "we've got that in school". And then obviously at that point we do collaborate with them.	Making medical needs more visible	Teacher awareness	Making health more visible	Training	Training	Making health more visible
	I touched on it, but it is more like, if you have. If you are a child with asthma, then they are not going to have as much oxygen go into their brain when they are going through start of an asthma attack or whatever. So then they have limited concentration. Same with a child with diabetes in that blood sugar's low they are just not going to be a 100%.	Linking medical needs to learning needs	Teacher awareness	Linking medical needs to learning needs	Training	Training	Linking physical health with learning needs and mental wellbeing
	I do talk about things like, you know, if a child's going into anaphylactic shock, they will feel really anxious about it, do not leave the child on their own because that is going to make it more scary for them, that sort of thing. So, in a specific way yeah I do but not more general overall.	Linking medical needs to learning needs	Teacher awareness	Linking medical needs to learning needs	Training	Training	Linking physical health with learning needs and mental wellbeing
	Yes, that could probably go on the seat plans..... (inaudible) with safeguarding. Another would probably be able to read that...	???	???				
	I have seen poor practice around that, plastered all over the schools for everybody to see.	Poor practice	Information share/singling children out	Poor practice/singling children out	Network of support in school	Singling children out	Making health more visible
	it depends very much on the training they get and when you are doing a whole cluster of schools now not, you know what, you know, that the training is different. It will cover it but it will not cover it in depth.	Linking medical needs to learning needs	Teacher awareness	Linking medical needs to learning needs	Training	Training	Linking physical health with learning needs and mental wellbeing
Trying to raise awareness	let's get all the pupils in to say, this is normal, this is, some people suffer with this condition. How can we all help together in this school community?	Making medical needs more visible	Network of support in school	Making health more visible	Network of support in school	Network of support in school	Making health more visible

	I do think it is a struggle with schools	School attitudes	School responsibility	School attitudes	School responsibility	School responsibility/school priorities	Making health more visible
	there is a very good point and maybe you have just got something I could do, maybe contact that particular teacher in that lesson and say, you know, or in the next lesson and say, you know, this young person has had a hypo today which is really helpful.	Linking medical needs to learning needs	Teacher awareness	Linking medical needs to learning needs	Information share	Information share	Linking physical health with learning needs and mental wellbeing
Understanding a condition	I think it is that they feel that they can cope with it so we do not really get that many questions about things like asthma, I think it is very common, and there is a sort of sense of security around, understanding the condition.	Making medical needs more visible / general understanding of common conditions	Teacher awareness	Making medical needs more visible / general understanding of common conditions	Training	Training/general understanding of common conditions	Making health more visible
	They were very well controlled the ones we had so there were no problems	Making medical needs more visible / general understanding of common conditions	General understanding of common conditions from the medical perspective	Making medical needs more visible / general understanding of common conditions	Training	Training/general understanding of common conditions	Making health more visible
	I think is very, very misunderstood misunderstood condition you know the severity of it. Yeah, especially within schools.	Making medical needs more visible / general understanding of common conditions	General understanding of common conditions from the medical perspective	Making medical needs more visible / general understanding of common conditions	Training	Training/general understanding of common conditions	Making health more visible

Subsidiary research question 4

Parents and teens

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Collaboration with medical consultant	"as far as I am aware, school have not contacted the hospital, and the hospital have not contacted the school"	With health services	Collaboration	Between health and school	Lack of communication	Between health and school	Lack of communication

	I know that they have liaised in the past again with that nurse, the one that is left and so I know she has spoken to them once or twice. Apart from that, I am not sure. I think physio got involved as well at one point. Apart from that, no.	Lack of communication	Lack of communication between health and school/parents do not know if they have linked	Between health and school/parents unaware	Lack of communication	Between health and school/parents not in the loop	Lack of communication
	the information exchange level is between us and school	Between health and school/communication through parent	Lack of communication	Between health and school/communication through parent	Lack of communication	Between health and school	Lack of communication
	They haven't been in touch with his other doctors, not that I am aware of anyway.	Between health and school	Lack of communication	Between health and school	Lack of communication	Between health and school	Lack of communication
	This feels like there is nowhere to turn to and I thought well maybe actually what needs to happen is that they should be, you know, much like outreach work with kids	Between health and school/nobody seems to be in charge	Lack of communication	Between health and school/nobody seems to be in charge	Lack of communication	Between health and school/no contact person	Lack of communication
	there would have been some collaboration between the hospital school and M's school.	"some collaboration"	"some collaboration"	"some collaboration"	"some collaboration"	Pockets of good practice	Lack of communication
Lack of support for parents	"I felt I was becoming the irate, the irrational parent because I was getting onto the school saying you have got to do something to get M back in, you got to do something and you know they were kind of like, Oh well, you have got to get her here and did nothing to try and support me"	Lack of support for parents as they are supporting the pupil/lack of collaboration with parents/not listening to parents voice	Too much left up to parents	Lack of support from school/too much left up to parents	Lack of parent voice	Lack of support from school/too much left up to parents	Lack of parent voice
	it was such a battle that in the, you know, we waited and we waited, and we waited. And we said that he is entitled to all of these things. And we got nothing back from the school.	Lack of support from school	uncertainty about getting support	Lack of support from school	Lack of parent voice	Lack of support from school	Lack of parent voice
	They usually send me a copy of it. But they do not go, do not really sit down and go through it.	Explaining support/clarifying issues/uncertainty	Too much left up to parents	Lack of support from school/too much left up to parents	Lack of parent voice	Lack of support from school/too much left up to parents	Lack of parent voice

	I had a phone call with the hospital in Oxford and she will not see him yet she just wants me to video link. Which is not much help cuz I am not leaving my son fit into video	Little support from health	Too much left up to parents	Lack of support from health/too much left up to parents	Lack of parent voice	Lack of support from health/too much left up to parents	Lack of parent voice
Communication with parents	"if you haven't got parents who were pushy and stubborn"	Parents having to push for support	Parents	Parents having to push for support	Lack of parent voice	Lack of support from school/too much left up to parents	Lack of parent voice
Parental expertise	"I have not been invited to share information I have requested that I could (...) also offered to go in and talk to the school. Both of these were rejected by the Senco, who said he knew everything, and it was all okay"	Parents having to push for support/parental expertise/not listening to parents voice	Parents	Parents having to push for support	Lack of parent voice	School not open to parental input	Lack of parent voice
	I have got a home school book so school writes in everything that is happened during the day and I write in what happens during the night?	Communication between home and school	Communication between home and school	Communication between home and school	Communication between home and school	Pockets of good practice	Lack of communication
Pupil's expertise	we were met with a bizarre, kind of response from the school, whereby the leader of the special needs said, well we've had a child in the school before, you see, so we know what we're doing. Okay, which, you know, completely undermined M as an individual.	School thinks they know it all	Not listening to expert by experience, lack of pupil's voice	School not open to parental input/not taking individual differences into account	Lack of parent voice	School not open to parental input/not taking individual differences into account	Lack of parent voice
	They haven't contacted me but they spoke with Tom.	With parent	Lack of communication	Communication with pupil only	Lack of parent voice	Communication with pupil only	Lack of parent voice
	I do not know whether the Senco thought he was all knowing when he is not medically trained. I do not know why. They ask for medical diagnosis documents, and then do not act upon them.	School thinks they know it all	Not listening to expert by experience, lack of pupil's voice, lack of parent voice	School not open to parental input/not acting upon medical advice	Lack of parent voice	School not open to parental input/not acting upon medical advice	Lack of parent voice
	"I think in Year 7, she sat down and spoke to me about it, and, and what sort of things she could put in place for me. And then we just went through all different things that I struggle with and things that I need help with and just little things like that"	Pupils expertise	Pupils voice	Explaining support	Pupil's voice	Pockets of good practice	Lack of communication

	"There is a school trip coming up, and they haven't talked to us at all. And I doubt there is going to be anything in there about me."	Risk assessment	Parents voice/pupils voice	School not open to parental input/school trips/Equality Act	Lack of parent voice	School not open to parental input/school trips/Equality Act	Lack of parent voice
	no I have never been contacted about the trips.	School thinks they know it all	Lack of parent voice	School not open to parental input/school trips/Equality Act	Lack of parent voice	School not open to parental input/school trips/Equality Act	Lack of parent voice
Risk assessment	I am not aware of a formal risk assessment. So I again contacted the head of year that M, you know, obviously needs to do her treatments and take tablets and, you know, but if so, in fact I am. I had a whole conversation, and you know handed over all the medication everything. And, and they were all in dosed boxes and things so but when it came back half of them haven't been done.	School not listening/trip s/putting pupils in danger	Lack of parent voice	School not open to parental input/school trips/Equality Act	Lack of parent voice	School not open to parental input/school trips/Equality Act	Lack of parent voice
	"Maybe when she first joined the school, it would have been beneficial"	Parents expertise/pupils expertise	Parents voice/pupils voice	School not open to parental input	Lack of parent voice	School not open to parental input	Lack of parent voice
Invitation to staff training	we do not have no meetings	School thinks they know it all	Lack of parent voice	School not open to parental input	Lack of parent voice	School not open to parental input	Lack of parent voice

Educational Professionals

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
	the difference between having those conversations and understanding it and then it happening on a regular basis from one math lesson to the next math lesson to the next, you know it is the communication within the system is not it?.	Standardised approach	Communication within school	No system in place	Communication within the school	Within school/no system in place	Communication
Communication within school	the matrons are not passing the information on to these school staff so it is not feeding into the educational targets and direction at all	Not happening	Communication within school	No system in place	Communication within the school	Within school/no system in place	Communication
Linking health and education	It depends which agency they have gone to, and whether the health support is in the local area, or they gone to London for example	Regional differences	Communication between different agencies	Regional differences	Communication between different	Between different agencies/regional differences	Communication

					agencies		
	CAHMS will often say to me, it is not our remit to get this child back into school. Our remit is to keep this child healthy and well and safe.	Different goals not linked to each other	Communication between different agencies	Aligning goals	Communication between different agencies	Between different agencies/aligning goals	Communication
	We have quite good close relationships with our local hospitals and their diabetes nurse specialists, because of the area that we cover with	Regional differences	Communication between different agencies	Regional differences	Communication between different agencies	Between different agencies/regional differences	Communication
	I tend to find that when we are all in one group, if we are all in the room at the same time, there is a lot more that can be done	Aligning goals	Communication between different agencies	Aligning goals	Communication between different agencies	Between different agencies/aligning goals	Communication
	How many times in a year schools will contact.. bear in mind we're teaching in any given year we're teaching over thousand children in our school in a year. I could probably, probably count on the fingers of one hand the number of times a year, but schools will be contacting us directly to challenge us on what it is that we do, it is very very rare. Very rarity.	Aligning goals	Communication between different agencies	Aligning goals	Communication between different agencies	Between different agencies/aligning goals	Communication
Pupil's voice	we would encourage it because it is quite nice to talk to somebody who might be having a similar experience, but actually it happens very rarely that the young person wants to. It almost makes it a little bit too real. I would rather have friends that do not have anything wrong with them.	Young person might be reluctant	Exchanging experiences	Importance of self advocacy/reluctance	Empowering young people to explain their difficulties	Self-advocacy/reluctance	Empowering young people
	a lot of the young people. They are keeping their heads down in the classroom and they all do... they do not want to put their hand up asking for help. Yeah, so their needs are not being met.	Importance of self advocacy	Empowering young people to explain their difficulties	Importance of self advocacy	Empowering young people to explain their difficulties	Importance of self advocacy	Empowering young people to explain their difficulties
	there is a lot of work about emotional literacy is not there about a young person being able to explain the difficulties that they are having rather than masking it.	Importance of self advocacy	Empowering young people to explain their difficulties	Importance of self advocacy	Empowering young people to explain their difficulties	Importance of self advocacy	Empowering young people to explain their difficulties

Review meetings ran by ESMA	We do review meetings every six weeks and the child's voice is central to any planning and it is a sort of very multi agency where the health professional we listen to their recommendations about going into school, the school teacher, and then obviously, our team as well if we're involved and any other agency.	Aligning goals	Communication between different agencies	Aligning goals	Communication between different agencies	Between different agencies/aligning goals	Communication
School nurse capacity	the school nurse team, bless them, are very small. And so I think because they are because of their small capacity to provide support they are sometimes missed out in the link.	School nurses missed out	Communication between different agencies	School nurses/capacity	Communication between different agencies	With school nurse/capacity	Communication
	sometimes even if a school do refer to the school nurse team, because their capacity is so limited it does not meet that criteria sometimes.	School nurses missed out	Communication between different agencies	School nurses/capacity	Communication between different agencies	With school nurse/capacity	Communication
	Our school health, we have half a day a fortnight for all 2080 students and with the best will in the world, that is never going to even touch the tip of the iceberg	School nurses missed out	Communication between different agencies	School nurses/capacity	Communication between different agencies	With school nurse/capacity	Communication
	if a school had an initial concern regarding medical, we would probably say contact the school nurse first, see what they say and then the school nurse will pass it on to whoever is right for you.	School nurses	Communication between different agencies	School nurses/role	Communication between different agencies	With school nurse/appropriate role	Communication

School nurses

Initial codes Phase 1	Participants quotes	Theme/Sub themes Phase 1	Superordinate Themes Phase 1	Theme/Sub themes Phase 2	Superordinate Themes Phase 2	Theme/Sub themes Phase 3	Superordinate Themes Phase 3
Collaboration out of area	It is very difficult to, if another area has different policies and procedures to how you would deal with it in your area	Between different agencies/regional differences	Communication	Between different agencies/regional differences	Communication	Between different agencies/regional differences	Communication
	we have had cross communication from out of areas sometimes when you do different procedures.	Between different agencies/regional differences	Communication	Between different agencies/regional differences	Communication	Between different agencies/regional differences	Communication

	if you manage to get a really sympathetic school nurse, who has a keen interest on medical needs. Yeah, they should be able to support you as well and make sure that, you know, they get the training that they need and things and access. It is such a shame though, it depends on the area you see	Between different agencies/regional differences	Communication	Between different agencies/regional differences	Communication	Between different agencies/regional differences	Communication
	But I do know that even in the surrounding areas, that they haven't got that sort of support in place. It is not top of their agenda.	Between different agencies/regional differences	Communication	Between different agencies/regional differences	Communication	Between different agencies/regional differences	Communication
Different areas	We find that areas of highest deprivation, are probably more welcoming.	Difference in school attitudes	Areas of high deprivation	Empowerment/areas of high deprivation	Communication	Empowerment/areas of high deprivation	Communication
	No kids or parents are involved in the training. Parents do training sometimes but kids never.	Training/lack of involvement	Parent voice/pupils voice	Training/lack of involvement	Experts by experience	Training/lack of involvement	Experts by experience
	We get the parents to come in and discuss the exact signs and symptoms of the, you know, the child or young person will have, we get the children...	Training/individual differences	Parent voice/pupils voice	Training/individual differences	Experts by experience	Training/individual differences	Experts by experience
	I have seen it a long time ago but I haven't in my recent job. It is not something I have seen recently.	Training/lack of involvement	Parent voice/pupils voice	Training/lack of involvement	Experts by experience	Training/lack of involvement	Experts by experience
	always parents and the child / young person got to be involved in that kind of planning, and in, in our and or the training as appropriate. That happens less because we haven't got the capacity	Training/lack of involvement/school nurse capacity	Parent voice/pupils voice	Training/lack of involvement/school nurse capacity	Experts by experience	Training/school nurse capacity	Experts by experience
	we could use the experts by experience much more, so we find where young people and our parents share their stories that has a much greater impact than all of us trying to pontificate from afar. Yes, use experts by experience much more.	Training/individual differences	Parent voice/pupils voice	Training/individual differences	Experts by experience	Training/individual differences	Experts by experience
	there are examples of schools, you know, working with the expert by experience and allowing that young person to tell the school about their condition. If they are brave enough. Or for them to do it on their behalf, and then to put in strategies around that	Training/individual differences	Parent voice/pupils voice	Training/individual differences	Experts by experience	Training/individual differences	Experts by experience
Experts by experience	I would always encourage parents to come to the session as well because I think it is very important to have anybody	Training/individual differences	Parent voice/pupils voice	Training/individual differences	Experts by experience	Training/individual differences	Experts by experience

	Um, no, these all staff training. I have never known children or parents being involved on a school level.	Training/lack of involvement	Parent voice/pupils voice	Training/lack of involvement	Experts by experience	Training/lack of involvement	Experts by experience
	Oh no, no.	Training/lack of involvement	Parent voice/pupils voice	Training/lack of involvement	Experts by experience	Training/lack of involvement	Experts by experience
Link with hospital schools	We do not tend to get involved with children who are like in hospital or being hospital schooled.	Hospitalised children/lack of communication	Communication between different agencies	Link with hospital schools/no standardised approach	Communication	Link with hospital schools/no standardised approach	Communication
	they will be the ones that the school will liaise with and they are very very good as well so their needs are well met.	Hospitalised children	Communication between different agencies	Link with hospital schools/no standardised approach	Communication	Link with hospital schools/no standardised approach	Communication
	if it is from a specialist provision, chances are, I am not involved in that.	Hospitalised children/lack of communication	Communication between different agencies	Link with hospital schools/no standardised approach	Communication	Link with hospital schools/no standardised approach	Communication
	It is getting better yes and tends to be better when it is coming from health to school.	Works better if initiated by health	Communication between different agencies	Link with hospital schools/works if coming from health	Communication	Link with hospital schools/works if coming from health	Communication
	we do have some good practice for example, I know a (...) who sends the plan that they drop in the hospital, a copy go straight to school with permission obviously at the parents of the child, so that everybody sharing the same plan so there are pockets of good practice.	Hospitalised children	Communication between different agencies	Link with hospital schools/aligning plans	Communication	Link with hospital schools/aligning plans	Communication
	hospital schools are very good with liaising and and are much better at liaising with schools, school nursing GPN's. I think that is much better and they are much more established in that processes. Yeah, and, but not always. Not always.	Works better if initiated by health	Communication between different agencies	Link with hospital schools/no standardised approach	Communication	Link with hospital schools/no standardised approach	Communication
	they would work with the nurses in the hospital. So there wouldn't, it wouldn't be necessarily a school nurse, however we normally are made aware, or sometimes the school might liaise with us and say: Oh, we've had some (..) that has been off for a long time, could you just get some information with us. So we will work together and it is good communication.	Works better if initiated by health	Communication between different agencies	Between different agencies/works better if initiated by health	Communication	Between different agencies/works better if initiated by health	Communication

	I have not come across where the hospital nurses or specialist nurses have not liaised with those over any.	Hospitalised children	Communication between different agencies	Link with hospital school	Communication	Link with hospital school	Communication
	it is very rare that I have had children in a special provision coming back into mainstream, and certainly I can't think of any with medical needs.	????	Communication between different agencies	Link with hospital schools/no standardised approach	Communication	Link with hospital schools/no standardised approach	Communication
Links with medical professionals	we do not get informed, so if the GP is prescribed an epipen or inhaler or whatever we will not get told about that	Not automatic info share	Communication between different agencies	Between different agencies/no automatic info share	Communication	Between different agencies/no automatic info share	Communication
	I think, you know, having that link is really really important to maintain, you know, good working relationships and ensure all the children are well cared for.	Relationships	Communication between different agencies	Between different agencies/relationships	Communication	Between different agencies/relationships	Communication
	it depends how well they know the children	Relationships	Communication between different agencies	Between different agencies/relationships	Communication	Between different agencies/relationships	Communication
	we have good contact with our local GP to come to school and they are a good source of contact for anything as well.	Relationships	Communication between different agencies	Between different agencies/relationships	Communication	Between different agencies/relationships	Communication
	I do not think health professionals are much involved these days. They used to be. I would say, I do not know maybe 20-25%, maybe. But it is less than it used to be.	Health to school/capacity	Communication between different agencies	With health services/capacity	Communication	With health services/capacity	Communication
	much of that is down to school nurse involvement. Or decent health care professional involvement so where we have specialist nurses, and our GPN that have got that capacity in that culture then, you know, those kinds of things are always much better.	School nurse/capacity	Communication between different agencies	With health services/capacity	Communication	With health services/capacity	Communication
	if we didn't know the answers and we didn't we were not aware of the situation, or the condition, we would liaise, help to liaise and coordinate with the hospital as well.	School nurse role	Communication between different agencies	Between different agencies/school nurse role	Communication	Between different agencies/school nurse role	Communication
	if the parents didn't get back to me. I would work with other health professionals	School nurse role	Communication between different agencies	Between different agencies/school nurse role	Communication	Between different agencies/school nurse role	Communication

	normally, you may occasionally but I in my experience, it has been very rare that they have not communicated with me.	School nurse role	Communication between different agencies	Between different agencies/school nurse role	Communication	Between different agencies/school nurse role	Communication
	I have actually had GPs, write letters to me personally and saying, stop giving me extra work to do (laughs). So that's, yeah, that is a barrier. That is only happened a couple of times but you know	Health to school/openness	Communication between different agencies	With health services/openness	Communication	With health services/openness	Communication
	I would definitely involve medical professionals, I wouldn't just do that you know I would want them in	Health to school	Communication between different agencies	Between different agencies/school nurse role	Communication	Between different agencies/school nurse role	Communication
Link with mental health services	We are not involved, we only get involved if there are emergencies or problems. Education is so in control of what they do.	Education not liaising with mental health services	Communication between different agencies	With mental health services/lack of openness for collaboration	Communication	With mental health services/lack of openness for collaboration	Communication
	You have told us, she has got agoraphobia, you have noticed that so why, why can't you go to her house. We're not asking you to go to everybody's house, but for her particularly, why can't you go to her house? No, sorry we can't do that. So I am quite involved in that one because it feels like there is a lot of cracks.	Mental health services/openness for collaboration	Communication between different agencies	With mental health services/lack of openness for collaboration	Communication	With mental health services/lack of openness for collaboration	Communication
	I have been in kind of involved with that because it is a physical health problem as well. But the school and I have both tried of contact Healthy Young Minds to get to get more support for emotionally, and we're just getting knocked back.	Mental health services/openness for collaboration	Communication between different agencies	With mental health services/lack of openness for collaboration	Communication	With mental health services/lack of openness for collaboration	Communication
	a recent case with bilingual parents and anaphylactic child. School made no effort to reach out.	Bilingual parents/school does not reach out	Communication with parents	With parents/empowerment/bilingual parents	Communication	With parents/empowerment/bilingual parents	Communication
Links with parents	it depends on child and on how proactive the parent is. Parents can say that school puts child at risk by not engaging but schools can be resistant, often there is no resolution	Lack of collaboration at the expense of the young people	Communication with parents	With parents/empowerment	Communication	With parents/empowerment	Communication
	I do not know if. if they involve the children or the parents...	????	Communication with parents	Lack of involvement	Experts by experience	Lack of involvement	Experts by experience

<p>it is not until the parents sort of contact me and say for example, you know that their child is struggling at school or whatever, from, you know, and I have known them for some years like they have come through primary school, and you know they have transitioned into secondary school and parents have already got my number and they just call and say that they have got issues.</p>	<p>Relationships/with school nurse</p>	<p>Communication with parents</p>	<p>With parents/relationship with school nurse</p>	<p>Communication</p>	<p>With parents/relationship with school nurse</p>	<p>Communication</p>
<p>They expect the parents to come back to school and say, actually, this has changed... which does not always happen.</p>	<p>Parents need to be proactive</p>	<p>Communication with parents</p>	<p>With parents/empowerment</p>	<p>Communication</p>	<p>With parents/empowerment</p>	<p>Communication</p>
<p>get the impression from the schools that they do a good job of trying to get hold of parents but sometimes they have difficulty with parents, getting back to them, or updating them or, you know, so whether or not, I have got a true idea of what goes on because I am not in there all the time. I do not know, but my view as a visitor seems to be that they try, but they do not always succeed.</p>	<p>Parents need to be proactive</p>	<p>Communication with parents</p>	<p>With parents/empowerment</p>	<p>Communication</p>	<p>With parents/empowerment</p>	<p>Communication</p>
<p>And sometimes you just rely on the parent which is completely unfair and depends on the parents really and the young person. And when there is a change in diagnosis it often relies on the parent. Yeah, and that depends on the parents' literacy and empowerment. And, you know, English skills. Yeah, their literacy and their English. Absolutely. And the relationship with the school, because you know some parents do not have great relationships with the school so it is dependent on multiple factors and I would say it is not a standard approach.</p>	<p>Parents need to be proactive/no standard approach/depends on how empowered parents are</p>	<p>Communication with parents</p>	<p>With parents/empowerment/literacy</p>	<p>Communication</p>	<p>With parents/empowerment/literacy</p>	<p>Communication</p>
<p>I think that would be very much down to the health professional facilitating that and down to the literacy, the confidence, the vocabulary and the understanding of the parent and the young person.</p>	<p>Parents need to be proactive/no standard approach/depends on how empowered parents are</p>	<p>Communication with parents</p>	<p>With parents/empowerment/literacy</p>	<p>Communication</p>	<p>With parents/empowerment/literacy</p>	<p>Communication</p>

	in your areas of high illiteracy. And, you know, you will get very empowered parents and very empowered young people, and very driven people that will make sure it is in the plan. I would suggest that our children in the underserved populations, probably wouldn't be as easy for the parents to drive that, so there'll be a need for help on the health side, as well as the education side.	Parents need to be proactive/no standard approach/depends on how empowered parents are / need for support from both education and health	Communication with parents	With parents/empowerment/literacy/need for education and health services to drive support	Communication	With parents/empowerment/literacy/need for education and health services to drive support	Communication
	the parents should always be at those meetings. And, yeah, it would be between school usually health and the parent and pupils. It depends on age of the pupil.	Need for involvement	Communication with parents	Need for involvement	Experts by experience	Need for involvement	Experts by experience
	They should always be included in the risk assessment.	Need for involvement	Communication with parents	Need for involvement/school trips	Experts by experience	Need for involvement/school trips	Experts by experience
	I would say that parents are always included.	Need for involvement	Communication with parents	Need for involvement	Experts by experience	Need for involvement	Experts by experience
	I contact the parent, and then we discuss how we can support that young person and what that is going to look like for them.	Need for involvement/school nurse involvement	Communication with parents	Need for involvement/school nurse role	Experts by experience	Need for involvement/school nurse role	Experts by experience
	try and encourage them to manage the situation themselves, which is what we want. But I can liaise with the parent and keep them informed, but if I do not feel that we are managing it then I can ring.	Empowering young people/school nurse role	Communication with parents	Empowering young people	Experts by experience	Empowering young people	Experts by experience
Pupil's voice	it would be very important to listen to adolescent voices and she tries to include them in planning but it is up to the individual	Empowering young people/school nurse role	Communication	Empowering young people	Experts by experience	Empowering young people/pupil's voice	Experts by experience
	I do not think so, they do not think about this from the child's perspective.	Lack of pupil's voice	Communication	Lack of pupil's voice	Experts by experience	Lack of pupil's voice	Experts by experience
	it is not routinely done with adolescents, it is up to the individual	Lack of pupil's voice/no standardised approach	Communication	Lack of pupil's voice/no standardised approach	Experts by experience	Lack of pupil's voice/no standardised approach	Experts by experience
	i do not know a 100% but they offer support if it is driven by the young person	Support	Empowering young people	Pupil's voice/self advocacy/empowerment	Experts by experience	Empowering young people/pupil's voice	Experts by experience

we've got them to come along to the training session as well, as part of their.... sort of progress, yeah, and that worked really really well, that young person was really grateful for it, and took on the ownership of it all as well and really appreciated what was done so I think that was, that was a good job	Support	Empowering young people	Pupil's voice/self advocacy/empowerment	Experts by experience	Empowering young people/pupil's voice	Experts by experience
it depends on the individual child. And what's going on for that child in terms of the support they were already getting.	Support	Pupil's voice	Pupil's voice	Experts by experience	Individual differences	Experts by experience
So, to be fair, a lot of adolescents would want to be left alone, and not singled out.	Pupil's voice/reluctance to engage	Communication	Pupil's voice/reluctance to engage	Experts by experience	Individual differences	Experts by experience
we had a period I would say up to about five years ago where this was gathering momentum, I would say that lessened unfortunately.	Empowering young people/school nurse role	Empowering young people/school nurse role	Pupil's voice/not happening	Experts by experience	Lack of pupil's voice/no standardised approach	Experts by experience
she has always been open and honest and, and this is why I think we need to involve the young people and not just the teachers with saying: This is normal. This is normal for me. And this is what we do and this is how I deal with my medical condition	Empowering young people/self-advocacy	Communication	Pupil's voice/empowerment	Experts by experience	Empowering young people/pupil's voice	Experts by experience
that is from my experience also, I think they do put a lot of trust in the secondary school pupils especially	Empowering young people/self-advocacy	Communication	Pupil's voice/empowerment	Experts by experience	Empowering young people/pupil's voice	Experts by experience
So the parents consent, I, I also want to develop that that young person give as an pupil voice young person gives that consent as well. And that is something I would like to add to my consent form. Yeah, because at the moment it is the guardian or the parent.	Empowering young people/listening to pupil's voice	Communication	Pupil's voice/empowerment	Experts by experience	Empowering young people/pupil's voice	Experts by experience
I just had a mess of experience with a young person who refused to come to school with diabetes, and we now have 100% attendance and he is going off to college now, so I I came into the school two years ago, and he communicated to me and his mom that he was made, nobody understood, he was made to test the sugars outside the main office, there was no understanding of, you know, giving him any privacy or understanding about what it means	Empowering young people/listening to pupil's voice	Communication	Pupil's voice/empowerment	Experts by experience	Empowering young people/pupil's voice	Experts by experience

Relationships	relationships are key with families and children, and your staff to make sure you have got rounded children.	Relationships	Communication	Relationships	Experts by experience	Relationships	Experts by experience
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Subsidiary research question 5

Parents and teens

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Long term impact of missed learning	"the long-term impact that kind of missing out on that schooling and falling into that bad pattern has had"	Long term impact of lack of support	Lack of support	Long term impact of lack of support	Lack of support	Long term impact of lack of support	Lack of support
	we were told, it is not a big deal. It is just seeing what you are doing. And in the end, it changed people's predicted UCAS grades over this one test, which was 90. Well, 80% multiple, multiple choice. And we were told it is not a big deal, but that is a huge deal.	Long term impact of lack of support	Lack of support	Long term impact of lack of support	Lack of support	Long term impact of lack of support	Lack of support
	"I have got lift keys"	Support for physical things	Support	Support for physical things	Support	Support for physical things	Support
	they gave me passes to leave lessons early,	Support for physical needs	Support	Support for physical needs	Support	Support for physical needs	Support
	they did give me a queue jump card	Support for physical needs	Support	Support for physical needs	Support	Support for physical needs	Support
Physical support	the evac chair at every stair.	Support for physical needs	Support	Support for physical needs	Support	Support for physical needs	Support
	"I didn't really feel very supported through any of it, really."	Lack of support for SEMH	Support	Lack of support for SEMH	Support	Lack of support for SEMH	Support
	this was last term, we asked for this. And the school was supposed to ask the individuals that he has identified but we've, we've not heard...	Parent perception/school shows no interest	Lack of support	Parent perception/school shows no interest	Lack of support	Parent perception/school shows no interest	Lack of support
	It is not happened.... which is disappointing.	Parent perception/school shows no interest	Lack of support	Parent perception/school shows no interest	Lack of support	Parent perception/school shows no interest	Lack of support
SEMH support	They offered counselling.	Mental wellbeing/counselling	Support	Mental wellbeing/counselling	Support	Mental wellbeing/counselling	Support

	I think I got, you know a fairly standard 'oh really sorry to hear that I hope she is feeling better soon'. Very helpful. Well yeah I mean, what you come to expect.	Parent perception/school shows no interest	Lack of support	Parent perception/school shows no interest	Lack of support	Parent perception/school shows no interest	Lack of support
	the head of year, his office is right next to our classrooms and he said if I need anything to go straight to his office.	Person of trust	Support	Person of trust	Support	Person of trust	Support

Educational Professionals

Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
	setting up a buddy system and talk about different ways that would work	Support for mental health	Peers	Mental health/within schools/peers	Support	Mental health support/within schools/peers	Support
	talking about our adolescent children and we would involve them in a conversation	Pupil's voice	Empowerment	Pupil's voice/empowerment	Support	Empowerment/pupil's voice	Support
	Loric, each of the letters l o r i c stands for different words that are considered to be social programme has been developed to focus very much on employability skills so that the letters of loric stand for L is for leadership, o for organisation, r is for resilience, i is for independence and c for communication. So within that programme. We've developed some teaching strategies and activities that develop those five skills in the young people. And we've seen some really significant developments in confidence around those young people	Targeted intervention	Empowerment	Targeted intervention/empowerment	Support	Empowerment/targeted intervention	Support
Building confidence	they are talking to the group that they are working with about how they could best do it, and they are actually developing those skills, without even thinking about it.	Targeted intervention	Empowerment	Targeted intervention/empowerment	Support	Empowerment/targeted intervention	Support
	we have a facility in school a resource called a wellbeing hub	Within school	Mental health support	Mental health/within schools	Support	Mental health/within schools	Support
Good school model	if that child has any health related needs. Then my colleague and I are part of the solution is to looking at why. Is it health that is the barrier, is it not?	Associated needs/health a barrier	Support	Health is a barrier	Invisible needs	Health is a barrier	Invisible needs

	some students we have to actually argue, their educational progress is fine, but they could be doing better. And actually, their health needs are a barrier. The progress would seem fine, they are green across the board, but actually we still need to challenge that because they should be doing better than that.	Associated needs/health a barrier	Support	Health is a barrier	Invisible needs	Health is a barrier	Invisible needs
	Follow all the strategies that we give, get in contact when they need to.	Proactive	Support	Proactive	Support	Proactive/training	Support
	we do do modeling in schools it, it is always been really successful and effective and staff would take it on board,	Training	Support	Proactive/training	Support	Proactive/training	Support
Lack of capacity to support wellbeing	It is a real struggle to find services that are willing to engage with schools and a lot of it is due to their workload but they are the harder services to access because of the demands on their time. But often they are the most critical.	Mental health services/capacity	Support	Mental health services/capacity	Support	Mental health services/capacity	Support
No support until it is too late	the young person is just too unwell, too ill. They have been coping and struggling, and they reach a point where they just can't do it anymore. So the referral is for the mental health, but underlying is a physical health condition.	Associated needs/health a barrier	Support	Health is a barrier	Invisible needs	Health is a barrier	Invisible needs
Peers	peer mentor, or somebody in the sixth form of our school who has expressed an interest in helping a different person, a younger person with any kind of emotional wellbeing issues, and they have an opportunity to meet once a week, once a fortnight.	Within school/peers	Support	Mental health/within schools/peers	Support	Mental health/within schools/peers	Support
	we do some kind of peer support training to.	Within school/peers	Support	Mental health/within schools/peers	Support	Mental health/within schools/peers	Support
	the class group, rather than the whole school because I do not think it works.	Within school/peers	Support	Mental health/within schools/peers	Support	Mental health/within schools/peers	Support
Support	It could be managing symptoms of anxiety during the day, facilitating some lessons which are trickier because of their health condition, and we just need to help them be able to access so it could be physical access if it is a moving and handling issue, ability issue	Associated needs	Support	Health is a barrier	Invisible needs	Health is a barrier	Invisible needs

	where we struggle is with the hidden disabilities like the memory and the processing and the fatigue aspect the schools just..... some of them, some of them understand it and others	Associated needs/invisible needs	Needs	Health is a barrier/recognition	Invisible needs	Health is a barrier/recognition	Invisible needs
	schools are more flexible with their reasonable adjustments for children with physical and health issues, rather than mental health issues.	More support for physical needs	Invisible needs	More support for physical needs	Invisible needs	More support for physical needs	Invisible needs
	the actual physical disability school seem to, to show, they seem to understand it better because they can see it, they can see the difficulty the child's having.	More support for physical needs	Invisible needs	More support for physical needs	Invisible needs	More support for physical needs	Invisible needs
MH support	We have youth workers that come in from externally so they have an opportunity to have one to one sessions with them so they are trained counsellors. We also have a trained CAHMS counsellor, the child and adolescent mental health counsellor, who comes in once a week	Outside	Mental health support	Mental health/outside schools	Support	Mental health/outside schools	Support
	Often it is easier to have a link with a medical service, than one that supports emotional wellbeing	Outside/capacity	Mental health support	Mental health/outside schools	Support	Mental health services/capacity	Support
School nurses							
Initial codes Phase 1	Participants quotes	Theme/Subthemes Phase 1	Superordinate Themes Phase 1	Theme/Subthemes Phase 2	Superordinate Themes Phase 2	Theme/Subthemes Phase 3	Superordinate Themes Phase 3
Awareness of SEMH impact in schools	We do not tend to talk about that in our training, unless there is an emergency.	No recognition of mental health needs/focused on medical needs only	Training	Training focused on physical needs/reactive	Lack of recognition of mental health needs	Focus on physical needs only/support is reactive	Mental health needs deprioritised
	Schools do not understand that chronic conditions often come with psychological conditions, and pupils do not want to be different from peers, and they do not want to worry about their condition all the time. Unless you spell it out for schools, they do not get that. They just want you to fix it but it is more complex than that	No recognition of mental health needs/focused on medical needs only	Training	Training focused on physical needs/reactive	Lack of recognition of mental health needs	Lack of recognition of associated needs	Mental health needs deprioritised

	I think one of the problems you have got with children with long term medical conditions is things become more complex their relationships with people become more complex and their relationship with their own mental health becomes more complex and so there is always a bit. Lots of different strands. Yeah. Yeah, that is part that is part of why you can't you can't get a straight answer because some of it is about the child's own resilience.	Individual differences	Mental health needs	Individual differences/resilience	Mental health needs	Mental health needs associated with physical health	Recognition
	if someone's having lots of small seizures, or absences then obviously they are missing chunks of their day so that we sort of, just go over that again, sort of remind staff.	Missed learning/learning needs	Training	Learning needs/raising awareness for them	Recognition	Learning needs associated with health/raising awareness	Recognition
Counsellors	We have counsellors and they also talk about that.	Counsellors	Mental health support	Mental health needs / Counsellors	Recognition	Mental health needs / Counsellors	Recognition
	And we discuss it with the counsellors as well.	Counsellors	Mental health support	Mental health needs / Counsellors	Recognition	Mental health needs / Counsellors	Recognition
	they are very lucky here because mostly we do have very good counsellors.	Counsellors	Mental health support	Mental health needs / Counsellors	Recognition	Mental health needs / Counsellors	Recognition
	They come into the medical center, and chat generally so we're always aware of what's going on around the school.	Counsellors	Mental health support	Mental health needs / Counsellors	Recognition	Mental health needs / Counsellors	Recognition
	we have two school based counsellors who I work very closely with	Counsellors	Mental health support	Mental health needs / Counsellors	Recognition	Mental health needs / Counsellors	Recognition
Feeling competent to provide SEMH support	There is no specialist guidance, and you just have to do what you can. We cover a hell of a lot and we are not experts.	Capacity	Mental health support	Mental health needs/capacity	Recognition	Mental health needs/capacity	Recognition
	Because we go on with evidence base sort of professionals and I do not know how much evidence there is to..... we sort of know....but what's the proof? Where's the evidence? And it is just not that is not something that we..... yeah..... sort of..... it is probably down, down the priority list to be honest because..... it shouldn't be. And I guess a lack of training or lack of, I do not feel, I wouldn't feel confident enough to say for sure.	No recognition of mental health needs/focused on medical needs only	Mental health support	Focus on medical needs only	Lack of recognition of associated needs	Not having the self-confidence to deliver support for mental health	Mental health needs deprioritised

Information share	we have a thing they have developed called pupil passport. So children who have particularly errrrr needs that you know are either emotional or social issues. They have a pupil passport which is written by one of our wellbeing team, and that is shared with staff so that might have information about you know: I get angry. And when I get angry, I need to do this. Please give me time, so it is written with the young person so yes we do have that.	Information share/pupil's voice	Recognition of needs linked with health	Associated needs/information share	Recognition	Associated needs/effective information share	Recognition
	it does not really happen	???	???				
	wish they could provide so much more emotional support to children. They try their best. But I think there is so much need around mental health anyway, that sometimes children with medical needs to get sort of forgotten, if that makes sense, because, because it is visual, and it is not a mental thing, it is put in a different bracket. So, I find yeah....Sometimes it is completely invisible as well..	Invisible needs	Lack of support	Associated needs / invisible	Lack of recognition	Invisible needs	Mental health needs deprioritised
	there has never been any sort of social or emotional bits in there, it is very much sort of their symptoms and signs what you do, and, you know, that sort of stuff.	Invisible needs/focus on medical needs only	Lack of support	Invisible needs/focus on medical needs only	Lack of recognition	Focus on medical needs	Mental health needs deprioritised
	I get told by the students that they are not very sympathetic towards certain health conditions or, particularly if it is anxiety or something like that but they often do not get back into the classroom they will be in the corridors or whatever.	Mental health needs	Lack of support	Mental health needs/lack of support	Lack of recognition	Stigma	Mental health needs deprioritised
	I do not think we do focus on the mental health side of long term conditions, probably anywhere near enough.	Mental health needs	Lack of support	Mental health needs/area to develop	Recognition	Focus on medical needs	Mental health needs deprioritised
Lack of support for mental health	In ours it wouldn't be it would be something that we see sort of as a problem here, or there is a gap that needs to be met.	Mental health needs/recognition of area to develop	Lack of support	Mental health needs/area to develop	Recognition	Mental health needs/area to develop	Recognition

<p>And then we wonder, because you know, our adolescents, take risks anywhere because that is part of adolescent behavior. And then we wonder why we have this whole cohort of children that struggle to comply and in fact, almost self neglect. Yes, you know it is hard enough being an adolescent Never mind, throw it into the pot. A lot of them are newly diagnosed at that age, particularly with diabetes. And then, you know tell them the need to inject themselves, or take blood sugar or not have chocolate bars at lunch and they are just going to kick back, so. Yeah, we could do a lot better. It is awful.</p>	<p>No recognition of mental health needs/focused on medical needs only</p>	<p>Mental health support</p>	<p>Mental health needs/area to develop</p>	<p>Recognition</p>	<p>Mental health needs/area to develop</p>	<p>Recognition</p>
<p>they told them you know of the difficult times that they are having. And although the school understood they were very still very quick to reprimand the boys when they didn't have the homework in or were late. So, I think they have an understanding, but I do not think they are always allowed for it.</p>	<p>Mental health needs</p>	<p>Lack of support</p>	<p>Mental health needs</p>	<p>Lack of recognition</p>	<p>No allowance</p>	<p>Mental health needs deprioritised</p>
<p>I think there is a willingness, but there are huge barriers to doing so because of the way schools are inspected and judged. So, I think, to be fair to school staff they probably want to, but actually I do not think it is given that much thought or understanding.</p>	<p>Mental health needs/recognition of area to develop</p>	<p>Lack of support</p>	<p>Mental health needs/area to develop</p>	<p>Recognition</p>	<p>Mental health needs/area to develop</p>	<p>Recognition</p>
<p>Maybe it is something that we could, that we need to, sort of work on to be honest. It is something that we do not..... I think it is that we, you know, it is understood that there is an impact but it is not something that we use evidence to say.....you know, no. We do need to.</p>	<p>Mental health needs/recognition of area to develop</p>	<p>Lack of support</p>	<p>Mental health needs/area to develop</p>	<p>Recognition</p>	<p>Mental health needs/area to develop</p>	<p>Recognition</p>
<p>it is probably down, down the priority list to be honest because..... it shouldn't be. And I guess a lack of training or lack of, I do not feel, I wouldn't feel confident enough to say for sure</p>	<p>Mental health needs deprioritised / recognition of area to develop</p>	<p>Lack of support</p>	<p>Mental health needs deprioritised/area to develop</p>	<p>Recognition</p>	<p>Not having the self-confidence to deliver support for mental health</p>	<p>Mental health needs deprioritised</p>
<p>.it is something that we really need to be sort of focusing on more for sure.</p>	<p>Mental health needs deprioritised / recognition of area to develop</p>	<p>Mental health needs deprioritised / recognition of area to develop</p>	<p>Mental health needs deprioritised/area to develop</p>	<p>Recognition</p>	<p>Mental health needs/area to develop</p>	<p>Recognition</p>

	it is on a school by school basis. And it is often down to the parents and the young person to drive that	Up to parents and young people to drive it	Lack of support	Support needs to be driven by young people and parents	Mental health needs are not a priority	Support needs to be driven by young people and parents	Mental health needs deprioritised
	that there are some examples I think that is getting better, but it is down to the parents and the child to drive that	Up to parents and young people to drive it	Lack of support	Support needs to be driven by young people and parents	Mental health needs are not a priority	Support needs to be driven by young people and parents	Mental health needs deprioritised
Parents	the responsibility lies on the parents and young person's shoulders	Up to parents and young people to drive it	Lack of support	Support needs to be driven by young people and parents	Mental health needs are not a priority	Support needs to be driven by young people and parents	Mental health needs deprioritised
	With regards to the epilepsy, we do encourage them to maintain a journal between house and school that they know what's happened, the previous night, or so mum knows or dad knows or a parent knows what's happened in school as well. And obviously you know if they have spent some time in the medical room. Recovering or anything that the things are put into place so that they do not miss out on the education that was given to them. So, yeah. Okay. All that is encouraged, whether it sort of gets put into place very well I do not know. Yeah. Yeah, that is a different story	Recognition of need but do not know if support gets put into place	Recognition of need but do not know if support gets put into place	Recogniton of need/not following up on support in place	Mental health needs are not a priority	Associated needs/unsure whether support is in place	Recognition
	Sometimes, I can come up with suggestions that will make a difference, like the toilet pass or something and then there are other times when it is more difficult and you are not getting any progress.	More support for physical needs	Lack of support	Focus on physical needs only	Mental health needs are not a priority	Focus on physical needs only	Mental health needs deprioritised
	I would be asked to become involved and particularly if there has been a medical issue, because obviously what my experience would see different issues you know it is not education it is health so i would i would be more aware of how that can impact the, you know, attending school so that might be wheelchairs that might be access to toilets, to the medical room might be issuing them with a card to give them permission to leave class without having to explain anything, etc etc.	More support for physical needs	Lack of support	Focus on physical needs only	Mental health needs are not a priority	Focus on physical needs only	Mental health needs deprioritised

	Nurses would provide circle of friends training, for instance, if kids are anxious about having a fit or so. They can train up their friends	Peers	Support for mental health	Support for mental health/peers	Recognition	Support for mental health/peers	Recognition
	if they do have a medical condition, they tend to get passed over to us but they also get passed on directly to the wellbeing team for example who can provide them that emotional support. But that is more children who already exhibiting real difficulties.	Reactive	Support for mental health	Support is reactive	Mental health needs are not a priority	Support is reactive	Mental health needs deprioritised
	Sometimes we use things like tree houses, or, we've got a health mentor he has got (...) of self esteem tools and, yeah, you know, looks at healthy eating and things and exercise and those sorts of things that can make you feel better.	Support / examples of good practice	Support for mental health	Examples of good practice	Recognition	Examples of good practice	Recognition
	Chat with people just do things that can help them and that sort of thing. And we can direct them over there, the counsellors can direct them. You know, staff will let us know if they are not happy with somebody. And so we do encourage them to do a lot themselves and we will put them in touch with somebody that might be able to help them similar problems, and they might be able to buddy with.	Peers	Support for mental health	Support for mental health/peers	Recognition	Support for mental health/peers	Recognition
	It would just be discussing with other people and just trying to get them extra support (...) outside (...) we generally have a good take up on everything. It works well.	???	Outside support/collaboration between agencies/communication	Outside support for mental health	Recognition	Outside support for mental health	Recognition
	there are always good examples. Always. So we do have schools that would work very hard with the young person and their parents and the health services to gain a better understanding, who would offer some kind of support to that child and family as needed. That might be school counseling sessions or buddying up with another pupil, or a mentor or something... So we do have some really good examples.	Examples of good practice	Support for mental health	Examples of good practice	Recognition	Examples of good practice	Recognition
Support for MH	the young person would say: I might not seem interested, I might be a pain in the neck, I might be rude. Just think about this before you judge me.	Empowerment/self-advocacy	Recognition of mental health needs	Mental health needs/empowerment	Recognition	Mental health needs/empowerment	Recognition

	<p>I would be trying to look at encouraging a buddy system because I think that is an amazing idea in schools. And, yes, so yeah. Yeah, I think that is brilliant, I and I really try to encourage that in the schools I was in especially</p>	<p>Buddy system/peers</p>	<p>Support for mental health</p>	<p>Support for mental health/peers</p>	<p>Recognition</p>	<p>Support for mental health/peers</p>	<p>Recognition</p>
	<p>there was a huge part about mental health, obviously because we had to be very mindful that this was a huge situation for her, not just physically but emotionally and mentally and, as you say with her friends, so I think there has been many, I would have many examples I think have been very mindful that it is not, it is the whole person, you know it is not just the condition</p>	<p>Recognition of mental health needs</p>	<p>Recognition of mental health needs</p>	<p>Associated needs</p>	<p>Recognition</p>	<p>Associated needs</p>	<p>Recognition</p>