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RESEARCH ARTICLE

The INSCHOOL project: Young people with long-term physical health conditions: An in-depth qualitative study of their needs at school

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Abstract

Introduction: The INSCHOOL project aimed to understand the school experiences and unmet needs of young people across a diversity of long-term physical health conditions.

Methods: Young people aged 11–18 years, in mainstream secondary school in the United Kingdom, with one of 11 physical health conditions were invited to unique participant-driven interviews, focus groups, or written activities. Creative preparation activities were provided to give participants increased control over the data collection and prioritize their voices. A needs analysis, in combination with participatory analysis sessions with young people, identified the common needs of participants in relation to their school lives.

Results: Eighty-nine young people participated from April 2022 to 2023. Analysis of their transcripts defined six common needs across all the health conditions: Need to safely manage my health at school; need for a flexible education pathway; need to be acknowledged and listened to in the right way; need to be included in and supported by the school community; need to build toward my future; need to develop attitudes and approaches to help me cope in school.

Conclusions: This study has generated new, actionable knowledge by identifying six major needs that young people have in relation to the intersection of their health condition and their school life. This paper shows that a commonalities approach to research and policy development is warranted given the similarities in experiences and needs. The common needs identified in the INSCHOOL project highlight six areas where future interventions could be targeted to begin making meaningful changes for all young people with long-term health conditions.

KEYWORDS

chronic conditions, needs, participatory research, qualitative research, schools

1 | INTRODUCTION

Although definitions vary (Bernell & Howard, 2016), chronic illness has been defined as "a disease of long duration and generally slow progression" (World Health Organization, 2014) or a condition requiring ongoing management over a period of years, which can be controlled, but not cured, with the use of medication and other therapies (Busse et al., 2010; National Health Service, 2019). Estimates in some countries have suggested that up to 30% of children and adolescents have a chronic health condition (Van Der Lee et al., 2007; Quach & Barnett, 2015), with 10% of those being a serious chronic illness (Van Cleave, 2010; Van Der Lee et al., 2007; Pittet et al., 2010). In the United Kingdom, this translates to approximately 1–1.7

million (All Party Parliamentary Group for Diabetes, 2018; Hagell et al., 2013; Lewis & Lenehan, 2012; National Institute for Health and Care Excellence, 2020).

In the United Kingdom, there is a legal duty for schools to look after children with medical conditions (Bainham & Gilmore, 2015; Department for Education, 2013, 2015; House of Commons, 2014; Parpworth & Thompson, 2010). However, the practical management of health conditions within school remains challenging for young people (Harries et al., 2019; Knight et al., 2018; Mukherjee et al., 2000; Sparapani et al., 2017; WellAtSchool, 2023). Young people with chronic health conditions have increased school absences and reduced academic attainment compared to their healthy peers (Austin et al., 1998; Eloi et al., 2019; Forrest et al., 2013; Jay et al., 2023; Knight et al., 2018; Moorthy et al., 2010; Oakley et al., 2020; WellAtSchool, 2023). Research into childhood epilepsy, diabetes and asthma all showed relative deficits in educational attendance or attainment (Flemming, Fitton, Steiner, McLay, Clark, King, Lindsay, et al., 2019; Flemming, 2019a, 2019b). These differences have been attributed to functional status (Forrest et al., 2013), severity of condition (Austin et al., 1998), frequency of health appointments (Eloi et al., 2019), sense of belonging in school (Tomberli & Ciucci, 2021), parent-perceived health-related quality of life (Emerson et al., 2016), and in-class challenges of pain, memory, and concentration (Moorthy et al., 2010). However, a 2023 review found limited evidence that school absence is a mediating factor in the attainment of young people with long-term health conditions (Jay et al., 2023). Therefore, policies focussing solely on reducing absence are unlikely to benefit this group (Jay et al., 2023; Lum et al., 2019).

The feeling of connectedness and belonging that any young person feels to their school, teachers, and peers is an important factor in their well-being, attendance, and attainment (Forrest et al., 2013; Knight et al., 2018; Kosola et al., 2018; Lum et al., 2019; Maslow et al., 2012; Pini et al., 2012, 2016; Pini, Hugh-Jones, et al., 2019). However, a young person's feeling of well-being at school has been shown (Pini, Gardner, et al., 2019) to be significantly lower for students with chronic health conditions, compared to healthy peers (Lum et al., 2019). Teachers with good understanding of the health condition and the time to attend to the needs of young people are an important factor in their feelings of safety and well-being in school (Mukherjee et al., 2000; Pini et al., 2012; Pini et al., 2013; Sparapani et al., 2017; WellAtSchool, 2023). Young people can find it challenging to explain their conditions to peers and for peers to respond in appropriate ways to support them (Mukherjee et al., 2000; Pini et al., 2016; Pini, Hugh-Jones, et al., 2019). In some cases, young people can experience bullying within school because of their health conditions (Ainsworth, 2021; Forrest et al., 2013; Holland et al., 2019; Stevens, 2009; Wakefield et al., 2022).

A 2018 All-Party Parliamentary report concluded supporting young people with health conditions in school *"demands a united front from all medical conditions"* (All Party Parliamentary Group for Diabetes, 2018). Individually each health condition is a small percentage of the secondary school population, but added together they represent a significant unmet need, resulting in a large cohort of young people with unmet and overlooked needs.

The INSCHOOL project is a 5-year program comprising four workstreams that aim to investigate and accurately document the holistic school experiences of secondary school students living with long-term health conditions. We have worked with young people and clinicians from 11 clinical groups to represent diversity of long-term conditions whilst acknowledging that this is not comprehensive coverage. The first workstream showed common themes in the evidence base, but also that there was little research focussing on school experiences for young people with long-term health conditions, with most research to date focussed on a single health condition (Spencer et al., 2022). This means we are not learning about the impact of chronic health conditions on young people's schools lives more widely. This paper details the INSCHOOL workstream that aims to understand the perspectives of young people with various long-term health conditions and their experiences of school life. The findings of these first two workstreams will inform the development of a school needs assessment tool for practice and research.

2 | RESEARCH QUESTIONS

1. What do secondary school pupils say about the impact their health condition has on their school lives?
2. What are the common needs of young people across clinical groups?

3 | MATERIALS AND METHODS

3.1 | Design

A pragmatic approach (Cornish & Gillespie, 2009) was taken to provide the best opportunity for young people to participate in this qualitative cross-sectional study. Throughout this workstream the pragmatic approach underpinned decisions made in relation to research questions, Patient Public Involvement and Engagement, data collection, analysis, and dissemination. The research team were guided by the "best fit" of the approaches taken in relation to the aims of the research, rather than being guided more specifically by theory or methodology. For example, the data analysis pivoted from a thematic analysis to a "needs-led" approach when it became clear that this was a better fit for the data we had collected. Engagement work with young people was integrated at every stage and detailed methods are available in an associated paper (Spencer et al., 2023). Young advisors were consulted at the inception of the project through a hospital-based youth forum and subsequently co-designed study documents, informed the recruitment process, developed creative approaches to data collection, participated in pilot interviews, co-analyzed the qualitative data, and co-presented results.

3.2 | Sampling strategy/recruitment

A variety of long-term health conditions were included in this project to address this knowledge gap and account for known risk factors (Pless & Nolan, 1991). Purposive sampling aimed to recruit a minimum of five participants from each clinic with diversity of age, gender, and ethnicity.

Eligibility criteria:

- 11–18 years.
- Enrolled in a mainstream secondary school in the United Kingdom.
- Free from a (self-reported) mental health condition that would make them too vulnerable to participate.
- Diagnosed with a condition from any of the following 11 health categories: oncology, cystic fibrosis, diabetes, asthma, rheumatology, neuromuscular, colorectal surgery, chronic pain, allergies, dermatology, and sickle-cell anemia.

Recruitment took place in pediatric outpatient clinics across a children's hospital in the north of England. Eligible young people were approached by a clinician and followed-up by the research team. Interested young people completed an online consent form (File S1) and a demographic form (File S2), in which they chose a one-to-one interview, focus group, or written task. Young people 16–18 years consented for themselves, whereas those 11–15 years assented alongside consent from a parent/carer.

3.3 | Data collection

An overview of the data collection methods are presented here with Supporting Information files, but for more detailed information please see (Spencer et al., 2023). A participant-led approach was used throughout data collection to gather first-hand experiential accounts from young people. A participant-led approach to data collection was a pragmatic choice in keeping with the aim to facilitate first-hand accounts from young people about the impact of health on school life. In collaboration with our young advisors the research team designed data collection methods to encourage a participant-led dynamic in interviews and focus groups. This participant-led approach aimed to address, as far as possible, the power dynamics of the data collection process and offer participants the best opportunity to steer the content and direction of conversation. The research team were committed to the value of this approach and debriefed after each interview and focus group to reflect on content and any challenges in maintaining participant-led dynamics. Participants chose between an interview, a small focus group, or an alternative written task and could have a family member present if they wished. Interviews and focus groups were held online via Zoom or telephone. For those who preferred not to speak to researchers, a written task was offered (File S3).

Participants were sent a choice of four creative preparation activities in advance, which were co-created with young advisors (File S4). Participants selected one activity to complete and bring to the interview/focus group. Activities gave participants an opportunity to reflect on their school experiences and arrive at the data collection with some control over the topics they introduced, and the priority placed on each topic.

In the interviews, participants initially described their health condition in their own words, followed by a brief description of where they attended school. The remainder of the interview was led by the participant talking through their preparation activity. The researcher did not use a topic guide, and instead asked follow-up questions based on what the participant described.

For the focus groups, participants completed the "bullseye" activity in advance, which they then discussed and completed together during the group. Before the focus group participants were told the demographic makeup of the group to ensure they were comfortable attending.

The preparation activities were combined with the transcripts or written task to produce a uniquely rich and diverse qualitative data set.

3.4 | Data analysis

A pragmatic and iterative approach was taken to analysis of the large volume of qualitative data generated, and through several participatory analysis meetings with young people (Spencer et al., 2023). All transcripts were annotated by B. S., with a 20% sample annotated by S. P. and supervision from S. H. J. Initially a thematic analysis (Braun & Clarke, 2006) was conducted through a process of familiarization and development of broad themes following the first 10 interviews. Analysis and concurrent data collection continued throughout the first 6 months of the project, with weekly discussions of emerging themes and fit with the data. During analysis we identified that underpinning the data corpus was a narrative (both implicit and explicit) of the needs (met and unmet) of the young people. We tested the fit and value of adopting a lens of met/unmet needs and confirmed it was sufficiently broad and flexible to capture almost all elements of young people's accounts. We therefore moved to a needs-based analysis (McKenna & Doward, 2004), which was also favored by patient advisors.

The needs-led approach involved extracting all segments of text relating to positive and negative experiences at school. Extracts were inductively coded to capture the nature of the experience, returning to the interview to enhance understanding of context. The research team (S. P. and B. S.) approached each extract by asking: “What need is being impacted here?.” This resulted in a framework of needs, which was refined through iterative application to transcripts, supervision meetings (S. H. J.), and three participatory analysis meetings with young advisors (Spencer et al., 2023).

4 | RESULTS

4.1 | Participant details

From April 2022 to March 2023, clinical collaborators referred 111 eligible participants. Ten declined, nine were uncontactable, and three were ineligible, resulting in 89 participants. Targets were met for a minimum of five from each clinical group and diversity of characteristics (Table 1).

TABLE 1 Participant details.

Age	11–13	39
	14–15	26
	16–18	24
Gender	Female	48
	Male	41
	Nonbinary	0
Ethnicity	White	53
	Asian	22
	Black	11
	Mixed White/Asian	2
	Other	1
Health condition	Allergies	7
	Asthma	9
	Cystic fibrosis	10
	Chronic pain	8
	Colorectal surgery	8
	Dermatology	9
	Diabetes	10
	Neuromuscular	5
	Oncology	9
	Rheumatology	9
	Sickle-cell anemia	5

4.2 | Needs analysis

Detailed analysis of the transcripts, including three participatory analysis sessions with young advisors (Spencer et al., 2023), resulted in identification of six fundamental needs for young people in relation to attending school with a long-term health condition:

1. Need to safely manage my health at school.
2. Need for a flexible education pathway.
3. Need to be acknowledged and listened to in the right way.
4. Need to be included in and supported by the school community.
5. Need to build toward my future.
6. Need to develop attitudes and approaches to help me cope in school.

These needs are described below and exemplified by participant extracts. Files S5 & S6 show where each participant/focus group provided examples related to each need, and an expanded quotes table.

4.2.1 | Need to safely manage my health at school

Participants described how they managed practical and medical aspects of their health conditions within school. These experiences reflected the adjustments needed to engage with school life, their ability to attend to their symptoms and manage medications, and how they responded to feeling unwell at school.

Participants needed adjustments to comfortably engage with school life. The most common adjustments were being able to use toilets, lifts, phones (predominantly for blood sugars), and take time out of classes, often facilitated by carrying a pass or wearing a badge/lanyard. These adjustments were often insufficient to fully meet participants' needs. Many participants faced inconsistency and disbelief from staff in relation to reasonable adjustments, especially with temporary staff, which could lead to conflict between staff and young people. Participants spoke of receiving unwanted attention when making use of adjustments in front of others and difficulties with asserting their agency in these situations:

> “I asked if I could go to the toilet. So I showed her the pass and she told me to wait… but it just really annoyed me because I'd showed her the pass…and it says that I'm allowed to go to the toilet even five minutes before the end of the lesson and she didn't let me go which I don't understand.” – 12 y Colorectal Surgery

Safely managing medication or treatment, physically navigating the school, and addressing symptoms and side effects were a common need within school. Support from a trusted member of staff, such as the school nurse who could store medication and assist with treatment, was valuable but not always available. Moving between lessons, negotiating stairs, and carrying bags or books could be challenging, and was often supported by peers. Participants highlighted secondary school as a time for developing independence in managing their health condition and the importance of having a private space to administer treatment. Taking medication and using devices were sometimes inconvenient in the school setting due to lack of understanding from peers and teachers, lack of privacy, and further difficulties with asserting their agency.

> “Basically my phone beeps whenever my blood sugars go high, and I was trying to look, and [my teacher] said, ‘No, you can't’, and I told her, like it's probably urgent, and out of nowhere she got like super angry, she kicked me out of the class” – 14 y Diabetes

Participants often felt unwell in school, which would cause discomfort or distress. Usually this meant asking for time out, going to the nurse or reception and/or contacting parents. Participants needed to feel comfortable asking to leave, which was facilitated when staff were aware of their health condition and responded without unnecessary attention or conflict. Participants described having to balance their need for support with their desire to avoid conflict, attention, or disbelief. Several participants recalled being sent back to class whilst still unwell and reluctance from staff to send them home due to disbelief or the impact on attendance. Many participants knew how they would like these situations to be managed:

> “If my bloods are high, I like to be left alone, just by myself in a quiet room, so obviously I don't want to be angry at anyone, shout at them, I don't want that to happen, but sometimes they don't leave me alone or don't let me leave school at the end of the day, it can really get on my nerves…once I walked out of school at the end of the day when they weren't letting me going…I couldn't really control it because of my bloods, and they just weren't letting me go” – 14 y Diabetes

Participants required a supportive structure at school to safely attend to their specific health needs related to medication, devices, symptoms, and side-effects. However, the majority of participants described multiple examples of where this supportive structure was missing or inadequate at meeting their health needs.

4.2.2 | Need for a flexible education pathway

It was common for participants to find the school system was not sufficiently flexible and supportive to accommodate their fluctuating needs in relation to keeping pace with their education.

Absences, appointments, and leaving lessons meant many participants missed lesson content and faced challenges in catching up. Peers and teachers could be supportive in providing materials and recapping lessons, but many participants thought this was unstructured and felt personal responsibility to initiate this process. The move to online resources during COVID-19 was often cited as an improvement in meeting these needs, which, for some, was reduced when schools returned in person. Some participants developed strategies for independently keeping up with work, such as prioritizing subjects, breaking down tasks, and revising in their spare time. However, the stress of managing work alongside health often meant sacrificing free time and social life. Some felt unsupported by schools, with teachers doubting their effort or ability, and that they were significantly disadvantaged or *"pushed behind."* For those most impacted, this meant changing educational, career and life goals, or taking a break from education altogether.

> "I hate being that person that complains and who was kind of using what I went through to get longer deadlines and everything, so I kind of just do the work and hand it in, but I'd be so tired from it all." – 18 y Oncology

Participants found that their health condition affected them in class. Some talked about persistent difficulty concentrating, *"brain fog"* and fatigue because of symptoms, medication/treatment side effects, and disrupted sleep. They spoke of being distracted by pain and monitoring symptoms. Their ability to focus was linked with their motivation to learn and enjoyment of lessons.

> "What happens is I just kind of focus on what I'm supposed to do and try and forget what I'm feeling like and what I'm thinking, just like I've got this task to do, let's get on with it instead of being like, oh I feel sick…I just need to get on with the work." – 11 y Rheumatology

Participants also faced challenges sitting exams and revising. Some reported that brain fog and exhaustion affected their chances in exams, and managing health could be disruptive to themselves and others. Exams could be more challenging due to missed lessons resulting in gaps in their learning. They often felt they did not achieve as highly as they could have done and were conscious of how this would affect their future. Reasonable adjustments were helpful, including extra time, separate rooms, a scribe, a laptop, scheduled breaks, or nurses monitoring health. However, this could lead to feelings of separation, unwanted attention, disruption to focus, or lack of practice in using these adjustments. Participants were often unaware of the possibility of reasonable adjustments and had to reach out, rather than being offered options. This could make them feel overlooked and disadvantaged.

> "When my mock exams came around I'd had no experience with using a scribe before and they'd given me three exams to do in one day…obviously when you're writing you can think at the same time as writing and you can hold things in your mind better, when you're having to try and tell someone else at the same time it's quite difficult to keep your train of thought going. So I didn't do as well." – 16 y Chronic Pain

Participants described many examples of their school system not being flexible enough to adjust for and support the additional needs presented by their health conditions. In their accounts there was clear evidence of a lack of systematic approaches offered by schools, with many participants feeling like it was their own responsibility to catch up with missed work or to make the best out of the adjustments that were on offer to them in classes or exams.

4.2.3 | Need to be acknowledged and listened to in the right way

Underpinning most participant accounts was the feeling they were not acknowledged and listened to within school in a way that would make them feel safe, supported, and able to comfortably engage in school life. Participants reported receiving significant attention due to their health condition. When it was a trusted individual, or questions were asked out of a desire to understand, participants were generally comfortable with attention and happy to briefly describe their condition. When this was absent some participants expressed a desire for more interest from friends and teachers. However, it was common for participants to experience persistent or insensitive questions, causing discomfort, upset, or concealment. Many had negative experiences of unwanted attention from teachers or in front of a class, unpleasant comments or harmful misconceptions from peers and staff, and verbal or physical bullying. Sometimes, this had a profound impact on school life, with some experiencing feelings of fear and dread in relation to school, school avoidance, and in some instances changing schools as a result.

> "I think it's like the difference between wrong attention and right attention, like you want to inform people about it but you don't want to be asked like, do you need anything to eat all the time" – 17 y Diabetes

Some participants had visible signs of their condition, such as scars, hair loss, weight changes, rashes, boils or spots, wheelchairs, crutches, boots, or bandages. Participants also spoke of looking unwell, and how they could be defined as *"the ill kid."* Visibility could make school daunting for participants due to unwanted attention, unpleasant comments, bullying, and being highlighted as different. Participants highlighted that significant value is placed on appearance during adolescence, exacerbated by social media. This could lead to concealing visible elements of their condition to counter the negative impact of appearing different and to hide "*weakness*" or that "*something's wrong.*"

Invisible aspects of health conditions could be similarly impactful for young people. In these cases, participants often felt disbelieved and overlooked, and stated this affected the level of support they received from school. Visibility and appearance significantly affected participants' well-being, with some mourning the loss of a previous self or wanting to not be seen altogether.

> "I definitely feel the urge to be like 'can you stop looking at my rashes' and be like 'I get that it's not something that you've seen before but you looking at them and staring at them whilst I'm trying to have a normal conversation is quite intimidating for me because it makes me feel like you're kind of looking at me and judging me for what's happened to me and what I am.'" – 14 y Dermatology

When teachers and peers listened to, believed, and understood the needs of participants, it was positive for their well-being in school. Disbelief from both peers and staff was a significant challenge for participants. Peers sometimes thought participants were *"faking"* or exaggerating, leading to challenges in peer relationships. Participants mentioned staff disbelieving or minimizing their needs, which could result in conflict and subsequent punishment for arguing. This was invalidating and upsetting for participants and difficult for them to manage. Participants felt staff often displayed a lack of emotional understanding and awareness of their health needs, even when plans and information were available.

> "…Because I'm only a child, I'm not an adult, they think I can just instantly trust someone. I feel like, so like even though I want them to think of me as a child, they think of me as an adult" – 12 y Neuromuscular

Not being able to control the ways in which information was shared was distressing for participants. Forced disclosure was a negative experience, usually the result of rumors, or teachers/peers talking openly about their health in front of others. When participants limited how much they shared, this was usually due to a desire to keep their personal life private and protect themselves from the negative impact of disclosure. Sometimes participants opted not to share as it was too difficult to convey to others in a way they would be happy with. When participants did disclose aspects of their health, it was important to control who was told and the nature of the telling. Typically, this meant telling trusted friends or teachers. Many stated they would be comfortable to tell people in their own way, especially if it was to improve understanding, make them feel safer and reduce stigma, but often did not perceive there to be the opportunity or interest for this to happen.

> "The reason why I didn't want people at my school to find out because they gossip a lot, so [laughs] like it just, like spreads everywhere…this one girl was like telling everybody about it…one of my friends came up to me and she was like, 'Oh you know this girl, she's spoken about you having cancer and everything, like did you know that?'" – 13 y Oncology

Being seen and understood in the right way, at the right time and by the right people was fundamentally important for how participants felt about their school lives. How their health condition appeared to others in school, how those people responded and the resulting practical and emotional consequences of those responses, was a sequence of events that could be very challenging for participants, peers, and teachers to "get right."

4.2.4 | Need to be included in and supported by the school community

The challenges presented above often resulted in participants feeling devalued in the school community and that their needs were an obstacle to inclusion in school activities and social groups. Many participants cited being included within peer groups as a key factor in a happy and welcoming school community. When friends were supportive, this involved being treated the same as others, providing opportunities to talk, supporting their health needs and simply "*checking in*." For some, social life and peer relationships were challenging due to the demands of living with a health condition and/or negative experiences with other students. Friendship was transitory for those absent for significant periods of time and participants saw peers *"move on"* in their absence. Participants often felt different or excluded from peers because of absence, exhaustion, needing to choose work over friendship, lack of understanding, and bullying. Some participants described finding the *"right"* friends who were supportive, consistent, and sincere.

> "They like forget about you because you just started talking and then you left and then you come back, so you don't really want to disturb their new friendship, so you just kind of leave them alone…it's still like a hi and bye situation" – 15 y Sickle-cell anemia

Many participants felt school staff did not care about them or make them feel like a valued part of the school community. They emphasized the importance of a support network in school who acknowledged their needs, often comprised of a small number of supportive teachers. Many participants felt unsupported and described their relationship with the school and staff as conflictual. They said staff lacked understanding of their health and how it affected school, which reduced their willingness to engage with teachers or ask for help. This occasionally had a profound impact on participants' trust in the school and made them look forward to leaving. This could be exacerbated by feeling they and their families were *"hounded"* for explanations about any absences, rather than being shown concern.

> "Teachers very much made me feel like the inconvenience" – 16 y Dermatology

Missing school activities, trips, and outdoor activities, was described as significant to many participants. Though some could take part and were included wherever possible, many felt overlooked or marginalized because of adjustments not being made to accommodate their health needs on trips or in physical education lessons. A common example was being excluded from attendance reward activities or prizes due to low attendance, despite these absences being unavoidably linked to their health. Participants said this made them feel marginalized and like their condition was an inconvenience, as well as exacerbating distance in their friendships and social life.

> "I feel like it really clarifies like your disability doesn't it? It's like 'oh are you going on the trip?', 'No, I can't go'… they're quite light subjects but I feel like they mean quite a lot to me." – 16 y Chronic Pain

Inclusion in the school community for participants was partly practical and partly about care and belonging. Effort made by peers and school staff to overcome and support with practical obstacles to engaging in trips or activities was well received when it was present and made clear to participants. The feeling that the school community cared about the needs they had as young people with health conditions was vitally important to their feeling of belonging. This could be demonstrated through overcoming practical obstacles, checking in with them and their families, and recognizing and understanding their needs and the efforts they make to overcome health difficulties. However, it could be significantly negatively impacted by participants feeling they were unnecessarily excluded from school activities or that school staff interacted with them or their family in a way that demonstrated a lack of understanding, care, or sympathy about their needs.

4.2.5 | Need to build toward my future

Participants described how living with their health conditions influenced the way in which they approached their futures. There was a need to think ahead to transition points and the challenges of establishing new safety measures and support networks.

Many participants wanted to do well in exams and make the most of their futures and had additional motivation from overcoming obstacles presented by their health. Sometimes participants found thinking ahead to grades a source of motivation, but also pressure. In some cases, participants described frustration with the perception other people had about their limitations in relation to their health.

> "Those have been my goals for so long, I'm not going to stop now because of one thing that happened in my life." – 17 y Oncology

Participants had a variety of career aspirations, with some inspired to work in healthcare due to their experiences. Having career goals helped some participants with motivation and focus, influencing their approach to learning and their expectations of themselves. Having a health condition sometimes meant factoring management and treatment into career goals and wondering if some careers would be difficult for them to aspire to. A few participants expressed concern about the future and saw thinking ahead as stressful due to change, pressures, and expectations.

> “As someone whose life expectancy isn't as long as a normal, or a person without CF, a job or like a good job where you need to get, you need to go to university for isn't as important to me.” – 13 y Cystic Fibrosis

Transitions within school life were an important part of future planning for participants that could produce anxiety and challenges. Moving to new schools, further education or new year groups could result in uncertainty regarding how their health needs would be met in new environments. For those who had experienced challenges at one stage of schooling, transitions could also offer a chance for new beginnings.

> “I'm nervous to start sixth form. I'm also really excited because it's a new start, a new beginning.” – 16 y Chronic pain

Participants particularly reflected on their transition into secondary school and having to re-explain needs, establish new support mechanisms and ensure they could manage their health in the way they wanted to. For some, secondary school was more challenging because of their perception of less support and being overlooked amongst a larger school population. Development of increased self-management and independence in secondary school could be positive for individuals, but also increase the likelihood of being overlooked in this environment.

> “Then in terms of secondary…it's like impossible to discuss with literally every single teacher how to deal with it…it sort of turns out to me having to tell them in the situation which you know isn't obviously great because I can't exactly tell them if I'm mid-asthma attack.” – 13 y Asthma

Short term and long term future planning were important to many participants and something they required much more support with from school and healthcare staff. However, there were a variety of positive and negative influences that living with a health condition had on future aspirations of participants, with some using it as motivation and others as a source of anxiety or limitation.

4.2.6 | Need to develop attitudes and approaches to help me cope in school

Participants spoke of general approaches that helped them in their school life. Some of these were related to personal development, such as building themselves up in the face of challenges, striving academically, and having an altruistic approach. Several participants discussed not having an active approach, but a general need to “*press on*” or forget about challenging periods.

> “I just sort of wanted to get on with it and that was my attitude a lot of the time really, it was just get on with it, which was like sometimes a good thing but sometimes a bad thing.” – 17 y Oncology

The most common characteristic that participants discussed was a high level of independence in relation to practical aspects of school life such as work or managing health, but also in more social/emotional ways, such as not wanting to need support or finding friendships and social connections challenging. Being mature was raised as both a positive and a negative characteristic, and there was a sense of having missed out on parts of childhood. Some participants had or hoped for a level of self-awareness, confidence, and comfort in relation to their health and education that would empower. For example, the challenge of dealing with increased attention from peers often resulted in developing empathy for those peers and finding ways to *“rise above”* negative attention. In some cases, participants described wanting to be a *“good role model”* for other young people with health conditions or other challenges.

> “I think it just made me grow up quite a lot, in a way… faster than everyone else, which, I guess, in some ways is good, but in other ways it's just nice to be young and care about less serious things” – 18 y Rheumatology

Some participants wanted more support in developing proactive and affective attitudes and approaches. However, many felt they had developed these on their own through their experiences and just wanted to have this acknowledged and respected by those around them.

5 | DISCUSSION

The INSCHOOL project addressed a significant knowledge gap by providing first-hand accounts of school life from young people with a diversity of long-term physical health conditions. The data demonstrated that, regardless of health condition, many young people share common needs in school. These accounts from young people provide compelling evidence that uniting long-term conditions for research, practice, and policy action has merit. Our data support the evidence showing this group have unmet needs at school beyond attendance and attainment (Jay et al., 2023; Pini et al., 2012; Pini, Hugh-Jones, et al., 2019) and add significant richness and detail about the nuanced nature of these needs. Indeed, the emphasis on attendance targets can be actively harmful for this group. These unmet needs represent significant impacts and risks to emotional, physical, and educational outcomes. In keeping with previous literature, participants described increased absences from school because of their conditions (Austin et al., 1998; Eloi et al., 2019; Forrest et al., 2013; Jay et al., 2023; Knight et al., 2018; Moorthy et al., 2010; Oakley et al., 2020; WellAtSchool, 2023). However, our data illustrate absences are only one element in young people's holistic experience of school life, and, given the opportunity to share what is important to them, young people described fundamental school needs for safe health management, maintaining their education pathway, being understood, feeling part of the school community, preparing for the future, and being able to cope in school.

Resonant with existing studies, connectedness and well-being were important in the school lives of our participants (Forrest et al., 2013; Knight et al., 2018; Kosola et al., 2018; Lum et al., 2019; Maslow et al., 2012; Pini et al., 2012, 2016; Pini, Hugh-Jones, et al., 2019; Tomberli & Ciucci, 2021). Regardless of the specific need in question, an underlying factor toward positive connection to school was feeling that school staff recognized the young person's needs, made reasonable and sensitive adjustments, and demonstrated a desire to include them in school activities. The overall quality of life for these young people depended to a large extent on being listened to and believed about the needs they had in relation to their health and seeing schools' efforts to make reasonable adjustments as needed, but otherwise to include them in the school community.

The accounts of participants revealed cycles that young people with health conditions experienced in their school life. These cycles were present in many participant accounts and occurred regularly throughout their time at school providing frustrating and repetitive experiences. One of these cycles was struggling to manage their condition within the confines of the school environment, which has been previously described to some extent (Harries et al., 2019). Young people often described knowing how they needed their health to be managed, but when this was not met in school, they could become frustrated, which in turn resulted in either withdrawing or challenging teachers. Withdrawing could mean having to accept uncomfortable situations and challenging could result in conflict. Either option resulted in their needs not being met in the short-term, and less chance of seeking adjustments and help in the future. This cycle often repeated itself every time they had health needs at school and had a cumulative draining effect on young people. A second cycle present in the data was of falling behind in schoolwork or peer group interactions because of absences or health symptoms, and then having to catch up, before falling behind again. Intervening in these cycles provides an opportunity to address some of the unmet needs of this group and improve their lives at school.

The common needs identified in the INSCHOOL project highlight six areas where future interventions could be targeted to begin making meaningful changes for all young people with long-term health conditions. Improving safety, flexibility, understanding, inclusion, future planning, and approaches to coping within school will likely result in associated improvements in attendance and attainment outcomes for this group and be more effective than attempting to address these outcomes directly. The next phase of the INSCHOOL project will move toward actioning the knowledge acquired from this qualitative project by developing a school needs assessment for use as a data collection and evaluation tool in research and a screening tool to identify young people with unmet needs in school.

6 | STRENGTHS AND LIMITATIONS

A key strength of this study was the strongly participant-driven approach that prioritized young people's accounts as a valuable form of knowledge. The needs-based approach to the analysis provided a framework to describe the unmet needs of this group in a form of actionable knowledge. A further strength is the large sample size and diversity of health conditions represented.

However, each condition was represented by a small sample and is therefore not representative of all subconditions. Future research should assess transferability of findings to different long-term health conditions and educational contexts, such as alternative provision, colleges, and universities. Additionally, whilst diversity was monitored by the research team to provide equitable coverage of ethnicity, age, and gender across the sample, the specific intersectionality of demographic data was not analyzed in depth within this workstream. Our future workstreams will assess this in more detail through larger sample quantitative data collection.

7 | CONCLUSION

Young people with long-term health conditions have unmet health, academic, psychological, and social needs within school. There are clear and common needs across all long-term conditions and this combined group represent a significant percentage of the school population with unmet needs. This paper shows that a commonalities approach to research and policy development to support this group of young people is warranted given the similarities in experiences and needs. Using the findings of this qualitative project as a starting point, the development of a new school needs assessment will allow schools and clinical services to screen for young people with unmet needs and provide future research with a tool appropriate for gathering holistic school experience data and evaluating school-based interventions.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request. Details of coding generated during the current study is available from the corresponding author on reasonable request.

ETHICS STATEMENT

Ethical approval was granted by East Midlands-Nottingham Research Ethics Committee in January 2022. All participants in this study provided informed consent, along with parental/guardian consent for 11–15 year olds.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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