University of Southampton

Faculty of Environmental and Life Sciences

School of Psychology

Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families

by

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Abstract

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Long COVID is a debilitating, long-term health condition that was officially recognised in 2020 and has affected millions of people worldwide. Characterised by a wide range of fluctuating symptoms including tiredness, shortness of breath, problems with memory and concentration, muscle aches and pains, it has a significant impact on the lives of both adults and young people. Since the end of the pandemic, those suffering from the long-term effects of COVID-19 have often felt invisible, unheard, and forgotten within health and education systems. Chapter 1 sets the context for understanding Long COVID, highlighting the lack of representation of affected individuals in public discourse and emphasizing the need for further qualitative exploration of their experiences. This chapter also reflects on the personal and professional motivations of the researcher. Chapter 2 presents a systematic review of existing qualitative literature on the experiences of young people with Long COVID, analysing six papers published in recent years. Each paper was critically appraised for quality, and a thematic synthesis (Thomas & Harden, 2008) identified four main themes: facing disbelief and stigma, disruptions to school experiences, healthcare challenges, and navigating ongoing struggles. The review summarises key findings, discusses strengths and limitations, and offers suggestions for future clinical and research developments. Chapter 3 describes an empirical study exploring the experiences of young people with Long COVID and their parents, using semi-structured interviews and photovoice. Eleven participants shared their stories and reflected on the impact of Long COVID. The interviews were analysed using reflexive thematic analysis (Braun & Clarke, 2022), revealing four themes: disrupted childhood, changes in family life, the debilitating nature of a hidden illness, and healthcare journeys. The chapter discusses the implications of the study and provides recommendations for future research and clinical practice.

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Declaration

I acknowledge the use of Perplexity AI,

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to support the process of checking spelling and grammar, as well as proofreading parts of my thesis.

Research Thesis: Declaration of Authorship

Print name: JULIA DOMANSKA

Title of thesis: Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
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6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: Date: 15/02/2026

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Definitions and Abbreviations

LC.................................... Long COVID, a syndrome characterised by the persistence or development of symptoms attributed to Covid-19 (typically including extreme fatigue, breathlessness, and muscle weakness) more than twelve weeks after initial infection

ME/CFS............................ Myalgic encephalomyelitis, also called chronic fatigue syndrome or ME/CFS, is a condition that causes extreme tiredness and a range of other symptoms.

PPIE .... Patient and Public Involvement and Engagement

RTA .... Reflexive Thematic Analysis

Chapter 1

Contextualising the challenge of Long COVID

Long COVID term

The term Long COVID (LC) received official recognition in 2020, in response to international bodies such as the World Health Organisation officially acknowledging the condition: “*COVID-19 can lead to serious long-term effects, known as post COVID-19 condition (PCC). It is also commonly referred to as Long COVID”* (WHO, 2025, para.1). Prior to official recognition, efforts were seen from patient-led initiatives, alongside a small group of researchers, who collectively highlighted the need for more research, information, and medical acknowledgment, while raising awareness and increasing collaboration between patients, researchers, and healthcare professionals (Miyake & Martin, 2021).

Narratives about Long COVID

People suffering from Long COVID have largely remained invisible in society, with the condition absent from public discourse. For a variety of reasons - including prioritisation of other conditions, lack of understanding and difficulties with diagnosis and treatment (The Lancet, 2023, Wild et al., 2024) - Long COVID has received little attention in policy priorities, which has subsequently affected the lived experiences of those affected. Many individuals with Long COVID have reported feeling invisible, shamed, or ignored (Wild et al., 2024), indicating the need to explore narratives of those suffering from this condition.

Long COVID narratives differ from linear stories that start from crisis and lead to cure (Howell, 2022). With the fluctuating nature of symptoms and no clear overview of progression, Long COVID does not fit with general expectations of recovery (Wild et al., 2024). Societal and cultural norms set up examples of what health narratives are acceptable, which are socially valued and appreciated while others are silenced. This can lead to the experience of stigma, both internal and external (Husain et al., 2020), discouraging people from sharing their experiences. Reports from the ME/CFS community describe difficulties in receiving adequate support and attention from others (Dumit, 2006), with ME/CFS classified as stigmatised illnesses (Baken et al., 2018) and existing similarities in lived experience between those with Long COVID and those with ME/CFS (Jason & Dorri, 2023). With illness narratives, there seems to be a certain hierarchy in what narratives are well seen and received, and those that are excluded and unsupported. Arthur Frank (1995) theorised that those with chronic illnesses whose experience does not lead to happy endings are prevented from telling their stories, and in the context of Long COVID, the stories of ongoing struggle could negatively influence public perception.

Narrative coherence is based on the interrelationships between story, characters, themes and values and in an illness narrative, the patient, family and medical professionals equally play a part (Weingarten, 2001). Rushforth (2021) described Long COVID narratives as unique, in that they lack a professional witness due to pandemic-related reasons. Rather than having discussions with clinicians, people with Long COVID struggled to have their voices heard, outside of the online community. Patient-led organisations worked intensively to provide a space for those with lived experience to have a voice, connect with others, free from judgment and discrimination while advocating for better recognition, treatment and management of Long COVID. Rushforth (2021) argued that it was only through collective sharing and listening that Long COVID narratives began to offer more appropriate descriptions of the diverse presentations of this new illness. This research aims to explore these narratives and to deepen understanding of the unique circumstances of individuals affected by Long COVID.

Need for further Long COVID research

While research into Long COVID has increased over the last couple of years, it has not led to significant improvements in people’s quality of life (Long COVID Kids, 2025). Further research, as well as training and education of the healthcare and research workforce - has been highlighted as needing improvement (Davis et al., 2023). Researchers argue that building on knowledge about existing post-viral conditions will ensure a better understanding of the mechanisms and overlaps between Long COVID and other conditions. Existing research demonstrates the need for further research that includes the populations of those who are developing Long COVID at high rates, particularly people from ethnic minorities (Jacobs et al., 2023). Medical research has typically under-represented these populations and privileged those coming from white and higher socio-economic backgrounds. To improve the quality of research, working with people of colour, LGBTQ+ and low-income communities can strengthen evidence (Davis et al., 2023). Long COVID Kids (2025) emphasised that patient involvement should be central and seen throughout the research process.

Aims of Chapter 2

Chapter 2 aims to summarise the qualitative literature exploring Long COVID among children and young people's lives. It provides a structured, systematic review of the evidence base and considers what is known about lived experiences of Long COVID amongst young people. By reviewing and summarising the literature, the paper provides a thematic synthesis (Thomas & Harden, 2008) of people's experiences and seeks to distinguish meanings in themes identified from the literature. It shows that across all six papers, four main themes were identified: *facing the disbelief and stigma, disruptions to school experiences, healthcare challenges and navigating the struggle*. The paper advocates for further change in society, through raising awareness and education. It offers ideas on positive changes in schools and education system by for example, establishing good communication between teaching staff and families, working on individualised adaptations, and being person centred. It also suggests changes within healthcare systems, suggesting changes to staff training, raising awareness among healthcare staff and overcoming existing barriers within services. Furthermore, it encourages strengthening positive coping skills for those who are managing Long COVID. Chapter 2 also discusses the limitations and need for further research to improve the quality of people's lives.

Aims of Chapter 3

Chapter 3 documents the experiences of eleven participants affected by Long COVID; young people and their parents using semi-structured interviews and photovoice. By applying qualitative methodology, the researcher examined the collaborative experience of meaning-making through the process of photography and interviews. The chapter aims to explore the extent to which Long COVID affects young people's lives and understand this in the context of their development using Bronfenbrenner's ecological systems theory (1979). Reflexive thematic analysis (Braun & Clarke, 2019; Braun & Clarke, 2022) led to identification of four themes: *disrupted childhoods, affected family lives, the debilitating nature of hidden lives, and healthcare* *journeys*. Chapter 3 reflects on the strengths and limitations of the research study and provides a list of recommendations for further development in this area.

Ontology and Epistemology

Ontology can be viewed as a set of beliefs that define how someone, depending on their social and political stance, perceives the world and their individual place in it (Guba & Lincoln, 1994). Realist ontology is based on the idea that there are objective truths that exist, regardless of how humans think or talk about them; relativist ontology, on the other hand, proposes that the same situation can be described in many different ways, giving rise to different perspectives and understandings (Burr, 1995). This qualitative study was grounded within a social constructionist approach, with a primary focus on how the realities of those living with Long COVID are constructed, described, and experienced, as well as how narratives about Long COVID are shaped during the research process (Tashakkori et al., 2021). Constructionism is a relativist epistemological position which advocates that knowledge and reality are created through perception and social experience (Tesch, 1990). Social constructionism proposes that our understanding of the world is mediated through language and shaped by temporal and cultural contexts (Burr & Dick, 2017). The researcher focused on how meaning is collaboratively constructed through consultations with Experts by Experience, which enabled the researcher to learn about the realities faced by those with Long COVID and to adapt the research process to better suit their needs and experiences of those participating. Reflections on meaning continued throughout the research process, as the researcher considered participants' journeys with Long COVID (Braun & Clarke, 2019; Braun & Clarke, 2022).

Accordingly, the project was less concerned with establishing objective facts about Long COVID and more with how knowledge is shaped and what is collectively agreed upon, both individually and within the Long COVID community, regarding the reality of the illness. This was explored through an inductive qualitative methodology, specifically reflexive thematic analysis (Braun & Clarke, 2019; Braun & Clarke, 2022) which involved collecting and familiarising with the data, reflecting on its meaning, systematically reviewing it, and identifying themes both within individual accounts and across the participant cohort.

The researcher also recognised their active role in the construction of knowledge and the completion of the research (Grossoehme, 2014), engaging in reflexive practice by documenting personal experiences and assumptions in a reflexive journal, reflecting on the process of conducting research, participating in Long COVID community events, and attending the qualitative researchers network groups. Additionally, the researcher considered how personal and professional attitudes and experiences contributed to the research process.

Reflexivity

Sullivan (2002) argued that reflexivity is an important element of qualitative research, and Braun and Clarke (2022) indicated the essential role of reflexivity in thematic analysis. This thesis examines a long-term health condition characterised by uncertainty, invisibility, and many unknowns. Although the author does not have personal experience with Long COVID, the context surrounding the condition, including the lack of public narratives, experiences of silencing, and the importance of community responses, carries personal significance. Through their own experiences of ill health, the author can relate to the pain described by Long COVID sufferers and their ongoing struggle to secure safe, informative treatment options and maintain hope for recovery.

Recognising that Long COVID has received little attention in public discourse, the author was particularly motivated to reflect on, acknowledge, and give voice to those with lived experience - individuals whose perspectives have primarily been heard through organised community initiatives, rather than through enabled public discourse. Promoting a voice of those with lived experience is in line with personal values and commitment to social justice. The motivation and resilience demonstrated by interview participants highlighted the profound determination and impact individuals can have on their own lives, which the author found deeply inspiring.

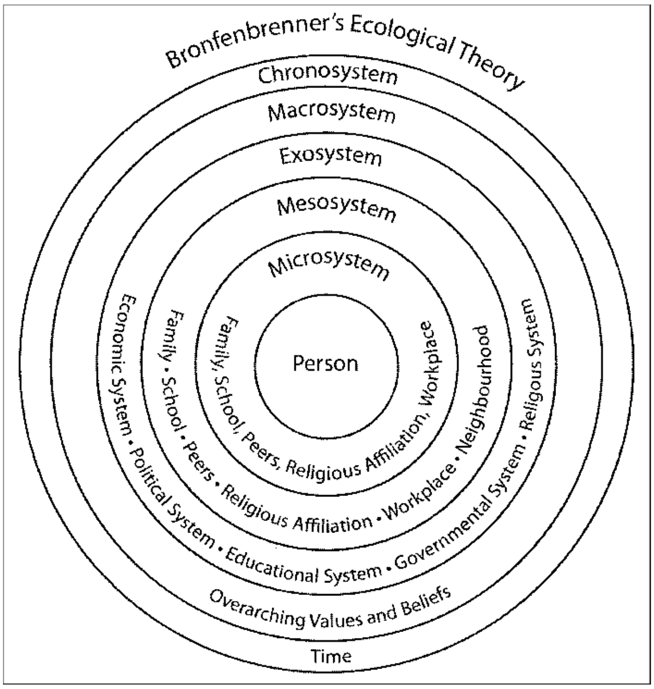
Additionally, through reflecting on Long COVID, the author recognised the significant burden of an illness that remains poorly understood and under-researched, contributing to ongoing uncertainty and complexity about the future for those affected and their families. The experiences shared by people with lived experience have illuminated broader societal issues, particularly the tendency to stigmatise conditions that are not well understood. These narratives also highlight the human need for control and predictability; in a world unsettled by the pandemic, experiences that lack easy explanation can be frightening and, as a result, marginalised. This marginalisation appears to be evident in relation to Long COVID - a condition that has been largely silenced in public discourse, as societies move forward under the assumption that the pandemic, and all related challenges, are now behind us. While the pandemic period was profoundly challenging for many, there has been a strong collective desire to return to normality. For some individuals, however, the burden of the pandemic persists, with its effects continuing to shape daily life.

Theoretical underpinnings

In this study, Bronfenbrenner's ecological systems theory (1979) guides exploration of young people's experiences living with Long COVID. The ecological theory focuses on how humans' experiences are shaped by the conditions and systems surrounding the person comprising the microsystem, mesosystem, exosystem, macrosystem and the chronosystem. All systems are interlinked (Bronfenbrenner, 1979) and affect the child's development.

Figure 1

Bronfenbrenner's Ecological Theory



The child is positioned at the centre, with all surrounding systems, providing a context for their experiences. The framework guides exploration of individuals' circumstances, focusing on unique experiences, coping strategies, and personal beliefs about Long COVID. On the microsystem level, it explored the immediate environments of the young person, considering relationships with family, friends, support groups, health and education providers. On a mesosystem level, it explores interconnections with organisations, such as the school and health. On an exosystem level, it considers how broader social systems, that indirectly impact on individuals, have contributed to their experiences of Long COVID, thinking about healthcare or education policies, community resources. On a macrosystem level, the research aims to understand how cultural values, norms, and attitudes, about health and illness, and how public discourse affects individual experiences. It also looks at how the impact of time, and shifting, developing knowledge and changing attitudes changed the experiences. By looking at all these systems, the research aims to understand all contributing factors, shaping the experiences of living with Long COVID.

Ethical considerations

Research into Long COVID highlights the need for greater integration of marginalised voices and more inclusive practices involving those from ethnic minorities, people from lower socioeconomic backgrounds and young people (Davis et al., 2023; Wild et al., 2024). This research seeks to include a diverse range of participants from various social, cultural, and ethnic backgrounds in order to explore Long COVID from multiple perspectives. To enhance the quality of the study and ensure it addressed the needs of those affected, including participants under 16 years old, careful planning and preparation proved essential, particularly considering additional challenges that young people faced. This approach ensured that all necessary adaptations were made and that the health and well-being of children and young people remained a top priority (MRS, 2012; MRC, 2021). To minimise distress, thorough preparation took place, adapting resources to make them age-appropriate, minimising distress through careful consideration and providing a supportive environment. All participants were offered information about the study and provided with the opportunity to ask questions before signing a consent form. All adult participants signed the form, confirming their participation, including a consent form allowing their children to participate. Young people were also asked to confirm their participation by signing an assent form.

Dissemination plans

The author intends to disseminate the papers by publishing them in journals such as *Qualitative Health Research*, an international, interdisciplinary forum dedicated to advancing health, health care, and the development of qualitative health research. The papers adhere to the journal's guidelines. As an open-access publication, *Qualitative Health Research* offers increased visibility and the opportunity to reach a broader, multidisciplinary audience that may find the findings relevant. Furthermore, the author plans to present the results at conferences specifically focused on Long COVID and young people, which address the health and well-being of this population. This approach will help reach a wide audience of individuals impacted by these issues.

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Chapter 2

Living with Long COVID: A Qualitative Systematic Review of Children and Young People's Experience

Abstract

Long COVID affects approximately 2 million people in the UK and over 65 million people worldwide, impacting individuals' ability to work, study, and engage in social activities. The main symptoms include fatigue, shortness of breath, muscle aches, difficulty concentrating, and joint pain, with many individuals unable to carry out daily activities. Long COVID has been studied primarily in adults, and research has shown that many people feel unheard or invisible - partly due to the narrative that COVID-19 is over and that few people are still affected. There has been less exploration of young people's experiences with Long COVID; however, in recent years, more research has emerged in this area. This systematic review examined experiences of young people living with Long COVID. A stepped review process was conducted, assessing studies that met the inclusion criteria. Six papers were identified and critically appraised for quality, and a thematic synthesis was performed. This analysis led to the identification of four main themes in the existing qualitative literature: facing disbelief and stigma, disruptions to school experiences, healthcare challenges, and navigating ongoing struggles. The review summarizes the findings, including strengths and limitations, and offers suggestions for further clinical and research development.

Introduction

Following the COVID-19 pandemic, substantial numbers of people continued to experience high levels of symptoms, leading to disability, decreased quality of life and associated problems (Goodridge et al., 2023). Data indicated that approximately 1.9 million people living in the UK reported symptoms of Long COVID (2.9% of the population) as of 5 March 2023, alongside 65 million globally (ONS, 2024). These numbers likely underestimated prevalence due to the nature of illness and changes in policy around monitoring and testing COVID infections (Wild, 2024). Individuals with Long COVID typically struggled for more than four weeks after the initial COVID-19 infection (ONS, 2023), with fatigue being the most often reported symptom. Other symptoms commonly experienced by people with Long COVID included shortness of breath, muscle aches, difficulty concentrating and joint pain. Most people expressed that their day-to-day activities were adversely affected by Long COVID symptoms, with 20 per cent reporting that their ability to undertake those activities had been limited a lot (ONS, 2023).

Long COVID research has focused predominantly on adults, with numerous qualitative studies and systematic reviews exploring their lived experiences. Early pandemic studies reported adults feeling unheard and invisible (MacLean et al., 2023), experienced changes to their abilities and self-identity (Goodridge et al., 2023) and faced ongoing fears about long-term symptom impacts - exacerbated by healthcare shortcomings and limited evidence. Eberhardt et al.'s (2024) systematic review highlighted key themes, including profound physical, economic, and social debilitation with pervasive uncertainty about illness. Scepticism from others further fuelled anxiety. The review showed a role of peer-led support groups providing reassurance and predominantly negative healthcare encounters involving dismissal of symptoms. Complementing this, Macpherson et al. (2021) emphasised emotional disruptions to self-identity, relationships, and sense of self.
Patients themselves reportedly undertook advocacy work to secure diagnoses and treatment, calling for more informed and supportive healthcare systems (Long COVID Kids, 2021). Those at greatest risk of significant impact - and the most vulnerable in society- experienced disproportionate effects from COVID-19 and Long COVID, influenced by social determinants such as poverty and structural inequalities (Berger et al., 2021).

Experiences of children and young people living with Long COVID were initially overlooked, due to the existing belief that young people do not suffer badly from infection. Over the last couple of years (2023-2025), more papers examining the experiences and needs of young people with long-term health illnesses have been published. These findings have not been systematically analysed or described, which provides a foundation for this study. Given the new publications over the last couple of years, this systematic review aims to summarise the most up-to-date findings, provide a helpful overview of established research, synthesise experiences of young people living with this condition, and contribute to the understanding and awareness of challenges, experiences, and barriers faced by this population, while also advancing the development of knowledge in this area and support creation of much needed well-being provision in education, community and health settings.

The systematic review was designed to comprehensively identify, evaluate and summarise all available research, answer specific questions and identify gaps in the literature. By using a transparent and structured approach, the review set steps to minimise bias and identify gaps in order to provide a comprehensive overview of current evidence (CASP, 2018).

In this thematic synthesis, existing literature was explored in a systematic way to address the question: *What are the experiences of young people living with Long COVID?* This research was completed with the four objectives below:

1. Search for papers on children and young people with Long COVID
2. Review and appraise the quality of evidence.
3. Provide a thematic synthesis of the evidence.
4. Consider implications and propose areas for future research.

Methods

Aims

This systematic review aimed to answer the research question concerning young people's experiences of Long COVID and provide a structured critique of the research papers which address this area.

Search strategy

The search of existing literature was carried out between 16th and 26th of September 2024 using CINAHL, PsychInfo, Medline, Web of Science databases. The search strategy was developed using the SPIDER framework (Cooke et al., 2012). This strategy included consideration of the sample, phenomenon of interest, design, evaluation and research type. The keywords were developed over time, with some initial searches completed in one of the databases. The words used in searches: “Post COVID-19” OR “Long-COVID” AND “experiences” OR “qualitative” OR “perspective” AND “child*” OR “adolescent*” OR “youth*” or “teen*”. The research terms were derived from the research question: *What are the experiences of young people with Long COVID*?

Inclusion/exclusion criteria

Several inclusion and exclusion criteria were applied to guide the selection of the papers in response to the research question. The following studies were excluded: studies which applied quantitative methodologies, as they did not align with the narrative focus of the systematic review. Additionally, studies which did not constitute original research, as they did not contribute primary data. Medical case studies were excluded as they had a different focus. Furthermore, studies covering broader experiences of the pandemic and the older age group were excluded as these did not meet the parameters of the research question.

Table 1

Inclusion and exclusion criteria

Inclusion criteria	**Exclusion criteria**
Studies using qualitative methodologies, **including mixed methods studies, where** the **qualitative component can be extracted.**	Quantitative research.
Studies presenting original research with primary data.	Non-original research.
Studies focused on experiences of living with Long COVID in children and young people aged 5-18 years old.	Medical case studies.
Studies reporting CYP perspectives directly and/or via parents/caregivers about experiences, impacts, or care needs related to Long COVID	Studies on broader experiences of the pandemic, acute COVID-19 without Long COVID or experiences of adults/older population.

Study selection process

All studies were reviewed and screened using the inclusion and exclusion criteria. Studies included in the analysis included worldwide qualitative studies which focused on experiences of children and young people aged 5 to 18 years old who met the criteria for Long COVID, at least twelve weeks since initial infection. Exclusion criteria involved people older than 18 years old, quantitative papers, or medical case studies which did not provide sufficient data for thematic synthesis.

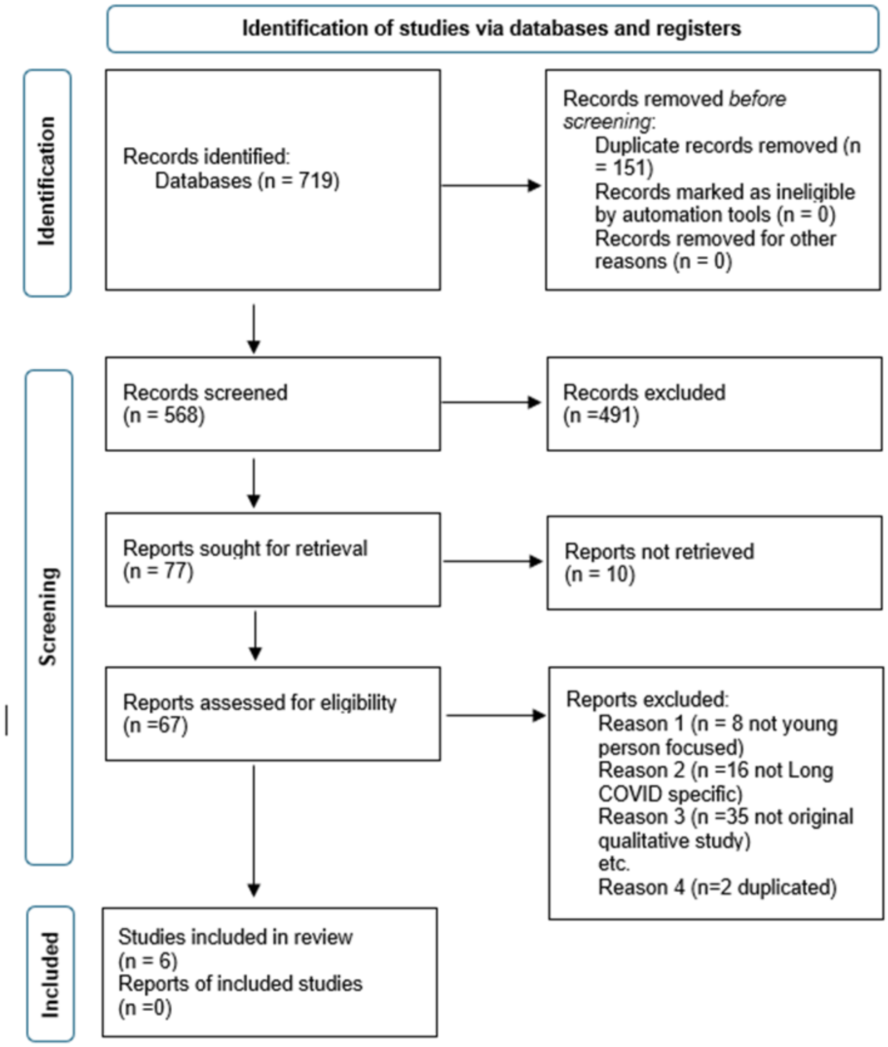
Screening, data extraction and review were conducted by the lead researcher with oversight from the team to reduce bias. The study has been registered with PROSPERO, nr CRD42024607831. Researchers found 719 articles in all four databases (Table 2) using search strategy and 151 duplicates were removed using EndNote. Next, 568 searches were screened using the title and abstract applying inclusion and exclusion criteria. 497 records were removed as not meeting the criteria of this review with 77 studies sought for retrieval. All papers which were retrieved (67) were screened using full text and with consideration of the inclusion and exclusion criteria. Of all 67 papers some studies were removed owing to exclusion criteria, more specifically study being a medical intervention, case study, reflecting on pandemic experiences rather than Long COVID, or not relating to young people. This led to 6 papers matching inclusion criteria and being included in this review. Reference lists of all six papers, all 202 papers were screened using title and considered for the review but not included in final analysis. Grey literature has been searched using adjusted search criteria, but no papers have been found to meet the criteria for this systematic review.

Quality appraisal strategy

In order to ensure a quality assessment, the lead researcher maintained a detailed record of all decisions made throughout the review process. A database was created for the 67 papers that were reviewed in full, systematically recording key study characteristics and summarising the relevant information. To enhance reliability, a second researcher independently reviewed just over 10% of the papers (ten articles selected at random) in full, to verify that inclusion criteria were applied consistently and that exclusion criteria were appropriately considered, with good agreement. Papers where eligibility remained uncertain were flagged and discussed in team meetings until consensus was reached, and no unresolved disagreements arose regarding study inclusion or exclusion. Critical appraisal checklists were used systematically to assess the quality of evidence in the included studies (Table 3) and the outcomes of this appraisal informed decisions were reported alongside the interpretation of findings.

Table 2

Identification of studies via databases and registers (flow diagram)



Data analysis

Thematic synthesis

The focus of data synthesis was the lived experiences of children and young people living with Long COVID using Thomas and Harden’s thematic synthesis (2008). As per the protocol, which proposes a structured approach to synthesizing qualitative research findings, data analysis involved three stages. Firstly, all data from all six primary studies were extracted using results sections and carefully, systematically coded line for line. Each paragraph was given a descriptive code, based on its meanings and content. The process was inductive and data-driven with no previous preconceptions about results; this meant that all findings were analysed and constructed according to identified ideas (Thomas & Harden, 2008). Codes were initially descriptive, and as they were reviewed, they were grouped together to descriptive themes which summarised findings with more analytical themes conceptualised as the synthesis progressed. The synthesis process was finalised with the thematic map and the results are presented in the descriptions below. A summary of all analytical themes and their emergence across studies has been presented in Appendix B.

Quality assessment

All six papers analysed in this review have been analysed using CASP Qualitative Studies Checklist (CASP, 2018) by the lead researcher to account for the strengths and weakness of each study using a 10-item scale. Aspects which were considered included how the studies defined their aims, how good was the design and methodology, recruitment, data collection and analysis, how they considered ethical issues and how important the study was overall. All studies have been analysed in ten sections using 0-2 scores for each out of the items, where 0 meant not meeting the criteria, 1-partially and 2 -meeting the criteria. Where necessary, the lead researcher consulted the team to ensure objective scoring decisions.

Findings

Six qualitative studies analysed in this review (appendix A) explore the experiences of children, young people (aged approximately 5–18), and their parents/carers living with Long COVID. These studies, using methods such as thematic analysis, content analysis, and mind-mapping, consistently identified key themes including symptom severity and diagnostic uncertainty, impact on identity, mental health, education, and social connections, challenges in accessing healthcare and support services, and mixed school responses combined with a lack of awareness among professionals. The studies consisted of populations ranging from small samples of 4 to 39 participants (primarily White females), focusing on areas such as family dynamics, resilience, and public narratives that minimise paediatric Long COVID. Strengths of the studies included PPI involvement and diverse recruitment in some, while common limitations were small or homogeneous samples, lack of saturation, absence of researcher reflexivity or ethical details.

Quality assessment

Out of six papers two were written with high quality, with the remaining four with moderate quality. Most papers clearly defined the aims of the research, used appropriate methodology, and design, and collected data in an appropriate way (Table 3). Each study stated their ethical stance, providing information about ethical approval, some only vaguely referring to approval like Torres and others (2024), or MacLean (2023) but some, more extensively introducing ideas like informed consent with young people, or ethical considerations of working with young people below 16 years old e.g. Newlands (2024), or Nightingale-Faux (2023). Studies by Nightingale-Faux (2023) and Wild (2024) accounted for Public and Patient Involvement, reflecting how co-investigators contributed to different stages of the research process whereas Messiah (2023) clearly stated that there was no PPIE involvement in the study. Other papers do not mention anything about PPIE. Some studies missed on opportunities to reflect on relationship between participants and researchers and didn't account for the impact it might have had on their relationship and approach to data analysis. Faux-Nightingale (2023) reflected on their positionality, recognising backgrounds of researchers and their relationship to Long COVID and how it influenced their focus and interpretation of the data. Similarly, Newlands and others (2024) recognised the position of the lead researcher and their approach to study. All studies appeared to rigorously analyse results, with some presenting their data in both narrative and visual way, using tables like MacLean (2023) or a theme map like Messiah (2023) with all papers clearly sharing participants quotes alongside interpretations of the researchers. All studies appeared to bring new information and understanding, particularly considering that this remains under research area, and voice of those with Long COVID still remain unheard. By quoting participants, all studies provided a reflection of experiences of young people with Long COVID.

Table 3

Quality assessment

Study	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	Overall score
The double invisibility of Long Covid in children	0	2	2	2	2	0	0	2	2	2	14
Experiences and care needs of children with long Covid: a qualitative study	2	2	2	2	2	2	2	2	2	2	20
Understanding Experiences of Youth with Long COVID: A Qualitative Approach	2	2	2	2	2	0	1	2	2	2	17
Impact of Long Covid on the school experiences of children and young people: a qualitative study	0	2	2	2	2	0	2	2	2	2	16
People don't have answers: A qualitative exploration of the experiences of young people with	2	2	2	2	2	2	1	2	2	2	19

Long COVID										
Persistent symptoms and conditions among children and adolescents hospitalised with COVID-19 illness: a qualitative study	2	2	2	2	2	0	1	2	2	2	17

Thematic synthesis

The completed thematic synthesis identified four main themes across all analysed studies: facing disbelief and stigma, disruptions to school experiences, healthcare challenges, and navigating the struggle and - 12 subthemes.

Figure 2

Thematic synthesis – main themes and subthemes

Main Theme 1: Facing disbelief and stigma

The studies portrayed experiences of disbelief and stigma (Wild et al., 2024), capturing ongoing invalidation experienced by children and young people with Long COVID from peers, schools, families, and healthcare professionals. Subthemes included lack of understanding, where participants struggled to receive support amid scepticism and jokes; lack of evidence, exacerbated by absent biomarkers leading to gaslighting and delayed care (Torres et al., 2024; Faux-Nightingale et al., 2023); and stigma, prompting many to hide symptoms to avoid judgment and strained relationships (Newlands et al., 2024).

Lack of understanding

Almost all papers reflected on difficulty related to some level of disbelief surrounding Long COVID which affected the way people with this condition were perceived and treated by others. Starting from relationship with friends, to school and health professionals, participants expressed how difficult it has been to receive appropriate understanding or support in response to existing problems. Lack of appropriate social response received by participants correspondents with beliefs commonly held in a society and outlined by Wild and others (2024) that “Covid-19 is mild and (almost) everyone recovers after a short illness” (p.2*)*. This among other narratives that COVID is finished, and only very unwell people suffer from consequences undermined the experiences of interviewees who suffered with prolonged difficulties and struggled to have their needs met. Many participants reflected on experiences of being questioned, being challenged by others, whether that is by others doing jokes or professionals being sceptical about their complaints. Researchers also recognised that participants could struggle to communicate the severity of the extent of their illness (Wild et al., 2024). As suggested in Wild’s research (2024), compared to other long term health conditions and more visible illnesses, Long COVID has not been socially understood or culturally perceived as serious and is not existing in public narratives. This led to what researchers described as a lack of social currency, which resulted in many suffering from Long COVID to be invisible in society. Young people admitted they do not find talking to friends or peers about their illness helpful, as feel they would not understand.

> even if ... even if they tried to, and a lot of the times they’ll just like make a joke out of me not being able to taste things. (Wild et. al., 2024, p. 4)

This resulted in many relationships being estranged or tested (Faux- Nightingale et al., 2023) with some reports that people do not really know what to say to others (Newlands et al., 2024).

Lack of evidence and stigma

One of the factors contributing to disbelief was the lack of biomarkers and diagnostic tests for Long COVID. With this challenge some patients felt unable to provide evidence to support their narratives, which led to their illness being questioned or dismissed. Some described experiences of gaslighting by professionals. A lack of understanding further contributed to an unsupportive diagnostic process and, at times, delays in receiving appropriate care (Torres et al., 2024). Some participants also noted that when they appeared well, it was even harder for others to believe they were ill. This affected their experience of healthcare and relationship with healthcare providers.

> When [children are] really ill sometimes, they're just accused of being difficult if [healthcare professionals] can't measure what's going on. (Wild et al., 2024, p.4)

To avoid negative responses, some children and young people reported refraining from talking about Long COVID, with belief that they will not be trusted by others, including healthcare professionals.

> [I'm] scared it will be all my fault for pressing the [ECG test] button and no-one will believe me. (Faux-Nightingale et al.,2023, p.6)

Lack of awareness and its impact were also affecting young people through experiences of judgment and stigma, including situations at school and with other members of the public.

> The school and then just general people, like even now, mum is like, some people you can clearly tell that they think you're putting it on, I was like, I am really not. (Faux-Nightingale et al, 2023, p.7)

Main theme 2: Disruptions to school experiences

Studies showed that children and young people with Long COVID valued education as central to their identity development, future aspirations, and sense of normality, yet faced profound barriers, including difficulty with attendance due to fatigue, brain fog, and medical appointments (MacLean et al., 2023; Torres et al., 2024). Participants discussed experiences such as being mislabelled as "lazy" despite motivation, academic setbacks like lower grades and delayed progress (Faux-Nightingale et al., 2023), alongside social isolation from peers leading to loneliness and strained friendships upon inconsistent returns to school (Newlands et al., 2024). Despite mixed school responses, participants expressed hope for full reintegration, highlighting the emotional toll of compensatory efforts and lost opportunities (MacLean et al., 2023).

Education as a valued activity

Young people and parents recognised that due to their illness they can be sometimes labelled as lazy, or difficult, not wanting to engage in daily school (Wild et al, 2024, MacLean, 2023). However, interviews showed that young people value school and view education as important for their future (MacLean et al.,2023).

> [The hardest part is] not being able to go to school or like see people my age, socialise and everything. It's all like online for me now over like social media or messages(...)seeing other people(...)my age that are going out in school or doing all their exams [and] doing lots of things throughout the summer that I would like to be able to do, but I just can't. I think is that's quite hard. (MacLean et al., 2023, p.3)

Young people reported that not attending school affects their relationships with peers, goes against the sense of "normality" typically expected for people their age, and that long periods of absence can be isolating, leading to feelings of being left out (MacLean, et al., 2023). Others reported a sense of loss of self-identity as Long COVID distanced them from their previous lives, with school being a big part of everyday life.

> We used to go on a lot of walks and I used to do a lot of running at school with my friends, but I don't do that that much anymore because it's really tiring. (Faux-Nightingale, et al., 2023, p.6)

Friendships, or social life, which often relates to school-based activities has been reported by Newlands et al. (2024) and others as something impacted by Long Covid with many young people reporting they feel isolated and lonely.

> In form like there's like no-one that I'm friends with in it so I'm always just like sitting there on my own. (Faux-Nightingale et al., 2023, p.6)

Disruptions to academic progress

Participants recognised that Long COVID affected them academically, resulting in lower grades or worse results before prolonged symptoms (Faux-Nightingale et al., 2023). Many required healthcare appointments which affected their ability to participate in school-based activities. Some difficulties in school experienced by young people with Long COVID mentioned by Torres et al. (2024) included trouble keeping up with coursework, delay in academic progress, and stress related to school difficulties.

> My teachers have always been really good when I was too sick to do anything for a while there. (Torres, et al., 2024, p.6)

Other problems described by participants included extreme fatigue, crashes, cognitive impairment or navigating school buildings (McLean et al.,2023) due to lack of energy.

> I just feel like ever since I've got [Covid), I've just lost a lot of my drive [for school] just because I'm always in such pain(...)constantly taking breaks and being in pain and you can't really concentrate if you were just, like, burning inside. (McLean et al., 2023, p.3)

These noted problems with academic engagement linked to widespread symptoms that many reported due to Long COVID.

Problematic attendance

The majority of young people reported some difficulty with school attendance or trouble undertaking online learning with some not being able to engage with studying at all (McLean et al., 2023).

> [For my son] online learning at home wasn't an option either because he has quite a lot of brain fog so has a lot of difficulty with concentration and was finding learning new things seems to be really difficult, short-term memory, all sorts of things like that were really hard. (MacLean, et al., 2023, p.3)

Research by McLean and colleagues (2023) showed that attending school was difficult, particularly as school responses were often mixed. While it was not always possible, some participants reflected on how schools required a letter from a healthcare professional to approve certain adjustments. This requirement was often challenging for healthcare professionals to meet in the absence of clear evidence. However, it was reported that once the letter was obtained, schools were generally supportive in making changes for the child.

> (...) [Once] I'd managed to get a letter from a paediatrician then [the school] said, 'Yes, you know, how many hours can he do? What can he do? (MacLean et al.,2023, p.4)

Despite missing time at school, young people reported feeling hopeful about their return to school full time, as that was seen as a key part of regaining "normal life".

> I would give so much to go back to school full-time. I miss it a lot. (McLean et al., 2023, p.3)

There were reports of social and emotional challenges upon returning to school with some reporting that they found it upsetting to see they felt behind their peers, and how their absence affected their friendships. Sometimes despite being well to go to school, young people missed classes because of GP or hospital appointments (Newlands et al.,2024) Furthermore, on their return, they had to compensate for their school attendance, with the cost to other areas of their lives.

> after school, I would come home [and] sleep for ages [and] I've never done that before. (McLean et al., 2023, p.4)

Others were unable to reintegrate back to school life, and families had to make difficult decision to refrain from school attendance and instead, focus on at-home education, or changing schools (Torres et al., 2024).

Main theme 3: Healthcare challenges

Participants of the studies described predominantly negative healthcare experiences marked by diagnostic difficulties due to absent biomarkers, fluctuating symptoms, and professional disbelief or even gaslighting, often framing the condition as psychosomatic or less serious (Wild et al., 2024; Torres et al., 2024). Subthemes included misunderstanding and patronising attitudes and low awareness (MacLean et al., 2023; Faux-Nightingale et al., 2023), barriers to access healthcare such as transport, funding shortages, and insurance issues (Faux-Nightingale et al., 2023; Messiah et al., 2024). Among mostly negative, difficult experiences, there were rare reports of positive encounters, mostly later in the journey with empathetic, knowledgeable providers who facilitated validation and support (Torres et al., 2024; Newlands et al., 2024).

Difficulty with diagnosing

Young people described difficulties with being diagnosed and during interactions with healthcare professionals (Torres et al., 2024). This was partially due to lack of understanding, but also due to disbelief, and what some researchers described as difficulties with signalling the severity of their problems. Unpredictability and episodic nature of illness meant that their experiences were not always considered as legitimate (Wild et al., 2024) and many professionals also did not know enough about the condition to be able to offer meaningful help (Faux-Nightingale et al., 2023). Faux-Nightingale (2023) described in their research that the impact of the condition on lives of young people and their families is not well understood in healthcare settings, yet acknowledgment during early consultations is vital for their sense of well-being. Wild (2024) explained how lack of social currency, and ongoing stereotypes means that children who are unwell, don't gain appropriate attention from public. Some participants struggled because on paper there was nothing wrong with them, with no biomarkers or tests showing any significant changes yet experiencing severe impact on their lives.

> When [children are] really ill sometimes, they're just accused of being difficult if [healthcare professionals] can't measure what's going on. I think that's the problem as Covid is throwing up immeasurable things. (Wild et al., 2024, p.4)

Not as serious as other long-term health conditions

One mother in her interviews, compared how a cancer diagnosis is widely understood to be significant and evoke appropriate response, whereas discourse around Long COVID has been rather dismissive, with the condition not perceived as socially or culturally serious. Remaining unwell for an extended period was perceived by professionals as disappointing (Wild et al., 2024), reflecting a general expectation that individuals should recover. Interviews showed that sometimes young people were patronised, treated as difficult, or problematic, exaggerating their symptoms or feeling that others believed they are making it up, which some referred to as gaslighting (Wild et al.,2024).

> Well, you know, and he's an 11-year-old, 12-year-old, they're not going to be hypochondriacs and making things up like that when [he is] mega fit. (Wild et al., 2024, p.6)

Misunderstood condition

Young people reported difficulties communicating with healthcare professionals and a lack of awareness of Long COVID (MacLean et al., 2023). Experiences of hospitalisations were largely negative with one participant describing the doctors as the most mentally damaging part (Torres et al., 2024, p.5).

Some young people could not get meaningful help and their symptoms were interpreted as psychosomatic due to the lack of evidence (Wild et al., 2024). Where the condition was understood as psychological, parents reported that professionals were less likely to believe them (Torres et al.,2024). Professionals explained in interviews, that Long COVID symptoms were difficult to distinguish from other factors, including low mood, anxiety of neurodiversity, which were also identified in this population (Faux-Nightingale et al., 2023). Those who were able to provide some proof of some of their symptoms, were met with more appropriate response. Parents reported that they walked a thin line between presenting themselves as responsible and concerned for their child, and being seen as anxious, or unstable (Wild et al., 2024). The way they were perceived and judged was important for receiving appropriate care.

Difficulty accessing healthcare

Where young people accessed medical care, they struggled with getting to appointments and navigating public transport, which sometimes led to cancellations and prevented them from using available services.

> We went to the Long Covid clinic in [place] in August [...] It took quite a while to wake, and we ended up by getting a taxi all the way there [because] I don't drive. (Faux-Nightingale et al., p.8)

Sometimes distance to the clinic created barriers. Access to services was also recognised as a problem by professionals mostly due to funding, and recruitment of healthcare staff.

> As far as the government is concerned, Covid is over [...] there is going to be no funding after next year, but post Covid isn't going anywhere. (Faux-Nightingale et al., p.8)

When unable to access public help, participants discussed seeking treatment themselves, privately accessing the care, or visiting Long COVID fora for emotional support (Faux-Nightingale et al., 2023). Additionally, participants in some countries experienced difficulties securing health insurance to pay for their medication and found accessing treatment to not be affordable (Messiah et al., 2024).

Positive experiences of healthcare

While the majority of papers reflected on negative and frustrating early interactions with healthcare professionals, there were some accounts of positive medical experiences. Torres and others (2024) recognised that some families reported more positive experiences later on their medical journey, and having access to professionals who were more aware of the illness. It was recognised that having knowledge of the healthcare helped families to overcome some early difficulties and more promptly receive diagnosis (Torres et al.,2024). Parents described feeling grateful to those healthcare professionals who supported them and advocated for Long Covid testing (Newlands et al., 2024).

Main theme 4: Navigating the struggle

Participants reflected on the struggle of living with the multifaceted daily burden of Long COVID, including a wide range of physical symptoms that disrupt routines, relationships, and self-perception (Newlands et al., 2024; Torres et al., 2024). The impact on mental health included anxiety, depression, sleep issues, and PTSD-like symptoms triggered by losses in socialising, hobbies, and identity (Faux-Nightingale et al., 2023; Messiah et al., 2023). Despite the challenges, positive coping skills emerged through family/friend support, peer connections, resilience, and adaptive strategies like gaming or sports, fostering periods of improvement and hope (Messiah et al., 2023; Torres et al., 2024).

Wide range of symptoms

Participants talked about much wider impact of Long COVID affecting the way they spend their time, related to others and felt in themselves (Newlands et al.,2024). Participants reflected on a variety of symptoms and ways in which they coped and managed them. Some of the symptoms reported by young people living with Long COVID included brain fog, cognitive issues, cardiovascular and respiratory symptoms, loss or altered smell/taste, pain, change in appetite, and dermatological symptoms (Torres et al., 2024; Newlands et al., 2024). Interviews showed that participants were initially experiencing problems making sense of their experiences, understanding what triggers or causes their symptoms, which can be a case for many with other long term health conditions, but particularly is a case in Long COVID since it is a condition surrounded by a lot of unknowns. Accordingly, to severity of symptoms, participants described their experiences as horrible with more severe presentation or annoying (Faux-Nightingale et al., 2023). The reality of living with a novel condition was surrounded by uncertainty related to unknown nature and progression of Long COVID (Newlands, 2024), particularly affecting people with questions.

> why is it still here? [...] why can’t it just go away?” (Newlands et al., 2024, p. 789)

Mental health

Some young people discussed their mental health during research with both positive and negative experiences. Interviewees talked about involvement in mental health treatment (Torress et al., 2024). Many described difficulties including depression and anxiety (Messiah et al.,2023). Some talked about problems with sleep (Torres et. al, 2024) and some participants had more long-lasting difficulties similar to the symptoms of PTSD (Messiah et al., 2023). Some of the reasons that contributed to feelings of anxiety were the inability to engage in previously enjoyed activities, including socialising with friends and education, as well as new health worries (Newlands et al., 2024). Faux-Nightingale and others (2023) described the difficulties young people faced in maintaining hobbies, as well as the loss of friendships and identity, as Long COVID distanced them from their former lives. These encompassed all activities that had contributed to their sense of wellbeing and provided a sense of normality.

Positive coping

There were also discussions about positive coping by those infected by COVID-19. Participants talked about helpful social support networks, periods of feeling better, recovery from symptoms and positive family interactions.

> …a lot of support from my family and the friends I have… (Messiah, et al., 2023, p.3)

Participants appreciated opportunities to build relationships with those who have similar experiences (Torress et al., 2024) but also drew on other support systems, and coping skills like sports, video games, and other sources of help (Messiah et al., 2023). The combination of resilience and support systems led to better recovery results (Messiah et al., 2023).

Discussion

This results summary shows the four main themes identified by researchers completing studies into young people experiences of Long COVID. In six analysed papers, experiences of *facing disbelief and stigma, disruptions to school experiences, healthcare challenges and navigating the struggle* summarised research in the area of young people who were suffering from chronic presentation of Long COVID.

Experiences of disbelief revealed widespread reports of young people struggling to be understood and taken seriously by others. Existing public narratives undermined COVID-19, shaping perceptions of those with the condition and the care they received. Researchers highlighted that Long COVID carried low social currency, eliciting weaker social responses compared to other long-term health conditions. Although school remained a valued activity for participants, many grappled with declining grades, attendance issues, and diminished capacity to engage in school-based activities. Participants missed school, and those who attended often prioritised it over other pursuits, unable to complete them due to debilitating exhaustion and fatigue; consequently, many shifted to online learning or home schooling. Participants reported feeling misunderstood by professionals who lacked knowledge of Long COVID. Young people struggled to articulate their difficulties amid absent objective evidence, often facing dismissal of their concerns. Challenges in accessing care - sometimes compounded by judgement - hindered receipt of appropriate support. Participants described coping with these struggles as horrible or annoying, with some drawing on peer support networks, positive family relationships, and experiences of recovery. Navigating profound uncertainty surrounding the condition proved challenging. Discussions of mental health acknowledged adaptive coping alongside difficulties such as anxiety and depression. Despite extensive accounts, Long COVID remained shrouded in uncertainties, complicating navigation for those with lived experience and professionals alike. nature.

Looking at the systematic reviews capturing experiences of adults with Long COVID (Eberhardt et al., 2024; Macpherson et al., 2022) and comparing them with the themes identified in this review of six papers focused on experiences of young people with Long COVID, the results reveal similarities and shared experiences between the two populations. Participants in both groups report profound physical and social debilitation, ongoing uncertainty about symptom trajectories, heightened anxiety from external scepticism and invalidation, negative healthcare encounters marked by symptom minimisation and diagnostic delays, and disruptions to sense of self and isolation. Peer and family support emerges as a vital coping mechanism in both groups, providing validation not available in formal systems. However, differences are notable: adults face pronounced economic challenges (Eberhardt et al., 2024), while children grapple with school-specific disruption - such as mislabelling as "lazy," academic regression, peer isolation, and reintegration struggles - that threaten developmental normality (MacLean et al., 2023). Paediatric stigma carries age-related narratives dismissing COVID as "mild in kids," resulting in what Wild has described as double invisibility of children with Long COVID (Wild et al., 2024).

Strengths and limitations

This systematic review offers focused qualitative synthesis of experiences of young people with Long COVID. By analysing qualitative studies, it provides a rich overview of personal experiences of those with Long COVID. It preserves individual stories while identifying cross-studies themes, balancing personal contexts and patterns that emerged across research. As it prioritises lived experiences, it makes findings relevant for developing specific, person-centred support services and clinical guidelines providing the overview of under researched experiences in understudied demographic.

In terms of limitations, with only six studies being analysed, generalisability may be limited. It is possible that with such a small pool of studies, and with all being published in English, the reviewremains vulnerable to over-representation of specific individuals and missing out on other important voices. Furthermore, variations in study design, with some being interviews, other focus groups, some young people only, other drawing on experiences of parents and professionals, it affects direct comparison. While the search was completed using worldwide search, only English studies were considered in this systematic review, limiting access to experiences of people from non-English speaking countries.

Future recommendations

In order to improve the overall experience of young people with Long COVID and to overcome disbelief, raising awareness and educating society remains important. This can be achieved through awareness campaigns, speaking up about the problem and using schools and healthcare provision to raise awareness. It is important to include voices of those with lived experience and ensure that those voices are heard within public domain. By overcoming unhelpful narratives around COVID, experiences of stigma and judgment can be minimalised. Key recommendations include modelling appropriate care and understanding for those reporting Long Covid symptoms, improving testing provision and offering responsive care with management of the condition.

To increase engagement in schools, raising understanding among teaching staff and support staff who can show their care and support – remains essential. Collaborating with young people to find appropriate solutions allowing them to engage in school-based activities in a sustainable way proves critical. In order to support young people to reintegrate successfully, school should establish good communication with parents and young people. Offering a range of personalised adaptations, tailored to individual needs may support young people managing Long COVID in the context of school; with some adaptations including reduced, adapted timetables, rest/time out card, lift access, additional time for study, preparation support, and understanding for healthcare appointments (McLean et al., 2023)

To support effective engagement with healthcare professionals, it is important to raise awareness and provide staff training about Long COVID. Overcoming barriers such as limited access to services and specialists can lead to positive outcomes for young people. In situations where a lack of evidence is an issue, further medical studies aimed at understanding the mechanisms behind existing symptoms would be beneficial.

Participants spoke about challenges and severity of symptoms, and the impact of these on them, but also positive ways of coping. Strengthening ways of coping and supporting people to further develop ways of managing symptoms can be positive and promote better wellbeing.

In this review, six papers were summarised, reflecting on experiences of young people with Long COVID. This is a helpful overview of existing qualitative literature in this subject, providing good opportunity for reflection, raising awareness and providing a good foundation for further research in this area. On the other hand, there is still more to be known in understanding mechanisms of Long COVID and further medical studies would be helpful to underpin future healthcare provision.

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Chapter 3

Experiences of Young People with Long COVID and their parents: qualitative study

Abstract

Long COVID is a debilitating condition that causes persistent symptoms after the initial COVID-19 infection. Common symptoms include fatigue, aches, breathlessness, headaches, and difficulty concentrating. Early research overlooked the experiences of young people due to the belief that Long COVID does not affect children. However, recent studies, although still incomplete showed that young people were also at risk of developing persistent symptoms, which significantly affected their social and educational activities. This study aimed to explore the experiences of young people with Long COVID and their parents using Bronfenbrenner's ecological theory, focusing on their experiences of diagnosis, interconnections with the systems around and to understand the overall impact of Long COVID on their lives. Eleven participants- four children and seven parents - took part in semi-structured qualitative interviews with two young people contributing photographs portraying their experiences. A qualitative, inductive approach was applied, using reflexive thematic analysis to organise, analyse, and identify recurring themes in data. The analysis revealed four themes identified in participants' narratives: disrupted childhood, changed family life, debilitating nature of a hidden illness and healthcare journeys. This study accessed rich personal perspectives of those living with a marginalised illness, providing an opportunity for greater understanding and acknowledgment, building evidence base including experiences of individuals coming from ethnic minority background. However, the study was limited in its use of photovoice, which could have further enhanced understanding of this long-term health condition. Further clinical and research developments are needed to improve the quality of lives of young people with Long COVID.

Introduction

Long COVID, sometimes called Post-COVID Syndrome, is characterised by the persistence of physical, psychological, and neurological symptoms (Goodridge et al., 2023) lasting for 12 weeks after COVID-19 and unexplained by other diagnoses (NHS England, 2024). Research showed that approximately 10-20% of people following an acute infection developed mid- and long-term persistent symptoms (WHO, 2023), and according to the UK's Office for National Statistics, an estimated 2 million people in England and Scotland had experienced self-reported symptoms (ONS, 2024).

While it had not been clear why these symptoms persisted over time (Han et al., 2022), the majority of people experienced symptoms for months or years after initial infection (UoM, 2023). Individuals with lived experience reported challenges associated with debilitating symptoms, feelings of powerlessness, and concerns about the future. Qualitative studies revealed themes such as the burden of living with Long COVID symptoms, the complex nature of symptom management, lack of trust in the healthcare system, and the challenging process of adaptation (Goodridge et al., 2023). The complexity of this condition contributed to fear and uncertainty about the implications of long-term symptoms for individuals' futures (Goodridge et al., 2023).

While early research had minimised the experiences of young people with Long COVID - owing largely to the initial belief that it did not affect children - later research showed that young people were indeed affected. Although prevalence was highest among people aged 35-50 (Wild et al., 2024), Long COVID affected children, impairing their ability to participate in education-based activities, sports, and social pursuits (NIHR, 2024). However, compared to adults, the condition in children had not been as well characterised (Ford, 2025), making it difficult to establish treatment approaches for this population (Fainardi et al., 2022); adolescents, women, and individuals with underlying health problems - including mental health issues - were particularly at risk (Fainardi et al., 2022).

Charities warned that obtaining an official diagnosis had been difficult, with many denied opportunities due to the fluctuating nature of symptoms, lack of clear biomarkers, or definitive tests for Long COVID (Wild et al., 2024). Furthermore, many professionals remained ill-informed about Long COVID in children and young people. Reports indicated that young people's experiences accessing healthcare (Wild et al., 2024) or education (MacLean et al., 2023) had been challenging. Long COVID has been characterised by low social recognition, and children and young people experienced what researchers termed "double invisibility" (Wild et al., 2024) - a lack of acknowledgment stemming both from the general underestimation of Long COVID's severity and from the perception that children were unlikely to be affected. This double invisibility led to missed opportunities for validation and support (Wild et al., 2024). Reports suggested that people with Long COVID had experienced social stigma and embarrassment related to a lack of awareness and disbelief in its impact (Faux-Nightingale et al., 2023).

Long COVID had been underrepresented in health policy, despite growing attention to evolving COVID-19 symptoms over the years (Wild et al., 2024). To address the needs of young people and families affected by Long COVID, specialist services had operated in the UK in recent years (NICE guideline, 2020), but with the end of funding for these services (Long COVID Kids, 2025), many clinics had now closed.The condition has been known to place a huge burden on the families of survivors (Cardiff University, 2021). Research showed that partners and family members of COVID-19 survivors report feeling worried and frustrated, with many experiencing sadness (Shah et al., 2021). Some parents reported the emotional toll of the uncertainty related to this condition and guilt over whether their actions caused or exacerbated their child's condition (Faux-Nightingale et al., 2024). Qualitative research by Messiah et al. (2023) showed that apart from fear of COVID-19 unknowns, parents of children with Long COVID discuss their experiences of mixed messages from health system and find schools to be both helpful and hindering the progress.

Not much is known about the process of recovery and how long it may take. Research by Great Ormond Street Hospital and University College London Great Ormond Street Institute of Child Health (2024) has found that 70% of children and young people will likely recover over a two-year period, but older teenagers and people from more disadvantaged backgrounds are less likely to recover. Economic barriers, geographic barriers, problems with housing have been identified as potential contributions to health inequity in Long COVID (Berget et al., 2021).

Considering that children and young people undergo significant psychological, physical and social changes affecting their development, additional difficulties caused by Long COVID can impact key developmental milestones (Batra, 2013). This study aimed to explore the developmental experiences of living with Long COVID using Bronfenbrenner's theory (1979). Bronfenbrenner's ecological systems theory (1979) proposes that human development and experiences are shaped by interconnected systems surrounding the individual: the microsystem (immediate settings like family, peers, school); mesosystem (interactions between microsystems, e.g., home-school links); exosystem (indirect influences like policies); macrosystem (cultural values, societal norms); and chronosystem (changes over time, such as evolving knowledge). In this study, the theory positioned young people's Long COVID experiences as influenced by these interlinked systems - from personal relationships and healthcare access to public narratives. Understanding interactions between young people and various systems was used to determine how the child is experiencing and perceiving Long COVID, and how the system around them affected their functioning (Chachar et al., 2021), considering equally the interactions with the near systems around them, and wider systemic impact.

Long COVID remained an under researched condition, therefore, understanding people's experiences through the collaborative exploration of meanings, and use of creative means has been used to develop new understandings, support development of new approaches and advance care pathways to suit the needs of young people with long term health conditions. This study was conducted with the hope that findings can contribute to raising awareness in society, creation of improved healthcare systems, and offer more evidence-base to existing research, improving the quality of lives of children living with long-term health conditions.

Methods

Research aim

To better understand the effects on children, young people, and their parents, a qualitative, in-depth social constructionist approach (Santos, 2015) was applied with the aim to explore how life with Long COVID was experienced by young people and parents. The approach was based on the understanding that there is no one truth and knowledge is socially constructed - individually and within the social and cultural context in which it exists (Burr, 2015). It was hoped that through co-created interactions, new meanings about the experiences of young people with Long COVID would be acquired. The qualitative design provided a framework for collating and analysing narratives and visual data allowing for studying and understanding participants lived experiences from different perspectives using a photo elicitation and semi-structured interview method using reflexive thematic analysis (Braun & Clarke, 2022). The study aimed to answer the question: *What is the impact of Long COVID on the lives of children and young people aged 10 to 18 years old and their parents/carers?*

Patient and Public Involvement and Engagement

Experts by Experience were consulted at various stages of the project. Beginning in the planning phase, discussions with an adult living with Long COVID contributed to the formulation of the research question and the development of the initial interview guide. The conversations highlighted the varied nature of symptoms and the severe impact Long COVID can have on daily life, as well as the influence of systems around (Bronfenbrenner, 1979) – including cultural and social messages prompting reflection on the prevailing social perception that COVID-19 was over once the pandemic officially ended with recognition that it was a shared global trauma for the majority (Hughes Hall, 2025).

Further consultations with clinicians working in this field provided insights into the functioning of Long COVID clinics, the clinical interventions currently in use, and the challenges faced by professionals in this under-researched area. Just before recruitment began, two young people (aged 16 and 18) with lived experience of Long COVID, along with their mother, were consulted to review the research methods, and to discuss the recruitment strategy. A draft of the topic guide was shared for feedback and updated accordingly. Additionally, the consultation led to discussions about necessary adjustments to accommodate the needs of young people with Long COVID during interviews. It became clear that, due to fatigue, interviews needed to be adapted to allow participants to choose how they engaged with the research. Discussions about photovoice revealed that, while young people generally found photography to be a potentially valuable means of expressing their experiences, anxiety about completing the task could limit their participation.

Positionality

All aspects of the research process can be influenced by researcher positionality (Holmes & Darwin, 2020). The main researcher is a clinical psychology doctoral student living in the UK. While the lead researcher lacked personal experience of Long COVID, the context surrounding the condition, particularly marginalisation of human experience and stigma surrounding unheard, unvoiced narratives, hold personal interest. All data collection, coding and analysis was conducted by the main researcher under the oversight of three supervisors, Psychology Teaching Fellows at the University of Southampton. To maintain self-awareness throughout the research process, the researcher kept a reflective journal to record their experiences. (Braun and Clarke, 2013)

Ethical considerations

Before commencing the research, ethical approval was obtained from the University of Southampton (ERGO: 91849). Ethical considerations included protecting participants from distress and ensuring safe practices, particularly as the research involved children and young people, some below 16 years old. Guidelines for research involving children and young people were adhered to (MRS, 2012; MRC, 2021). Informed choice was particularly important, considering the vulnerability and young age of some participants. The consent was obtained from all participants, with children below 16 years old providing assent and parents signing the consent form.

Participants

There were a number of inclusion and exclusion criteria used during recruitment. People who were invited to participate in the study included children and young people aged 10 and over, but no more than 18 years old, or a parent looking after a child of this age. Furthermore, a confirmed diagnosis of Long COVID was essential either through GP, involvement with Long COVID service or self-identified ongoing symptoms twelve weeks after the initial COVID-19 infection. Additionally, the ability to communicate effectively in English or willingness to work with an interpreter; access to a mobile phone or laptop allowing to connect for online meeting, and physical and mental capacity to allow for up to one hour conversation were included. Young people below 10 years old or above 18 years old, or their parents, were excluded from the study. Also, people who had acute presentation of COVID-19 (NICE guideline, 2025) or any other paediatric illness explaining their symptoms were excluded. Considering that people with Long COVID can experience significant fatigue, it was discussed at the early stages, ensuring the participants were able to undertake the interview.

Table 3

Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Child or Young person of age 10 and over, but no more than 18 years old; or a parent/carer caring for a child or young person in this age.	Children and Young people younger aged 10 years old, or more than 18 years old.
Must have experience accessing Long Covid services and/or received a diagnosis of Long Covid or self-identified with ongoing symptoms 12+ weeks after initial Covid-19 infection or act in a caring capacity for someone with this experience as a parent or carer	Acute Covid-19 presentation or diagnosis of other paediatric diagnosis explaining symptoms
Must continue to experience symptoms for a duration of 12 weeks after the initial diagnosis of Covid-19 (confirmed with one or more positive Covid tests), or be a carer for someone with these characteristics.	Physical or mental health too poor to manage a photography task and 1hr interview.
Communicative English or willingness to work with an interpreter	Difficulty communicating in English
Access to the Internet, laptop and/or a mobile phone with a camera	No access to the Internet, or mobile phone
Ability to engage mentally/physically in a photography task and 1h interview without this being too detrimental to someone's health.	Acutely distressed by discussing health-related problems.
Cognitive ability to understand a task and ability to express verbally thoughts, feelings and ability to describe experiences.	Cognitive difficulties, severe learning disability impacting on one's ability to effectively engage with the task and interview.

In total, eleven participants were interviewed during the study (Table 4), comprising seven parents (all mothers) and four children aged 11–17 years (including both genders). Despite recruitment efforts, no fathers participated. Participants were geographically diverse across counties in England (cities, towns, and rural areas). Ethnically, most (seven) were White British, with three British Asian and one Asian participant. All had direct Long COVID experience - either as affected young people or carers of children with the condition. Interviews were conducted via Microsoft Teams. All mothers were interviewed separately from their children; two children (Owly, Pickle) participated independently, while two (Frogo, Thor) had their mothers present due to participant-identified needs.

Table 4

List of participants

No	Pseudonym	Parent/child	Gender	Ethnicity	Age	Area in the UK
1	Maria	Parent	Female	British Asian	51	East Midlands
2	Owly	Young Person	Male	British Asian	17	East Midlands
3	Helen	Parent	Female	British	50	Norfolk
4	Karen	Parent	Female	Asian	58	Essex
5	Frogo	Young Person	Male	British Asian	11	Essex
6	Ivy	Parent	Female	British	48	West Midlands
7	Thor	Young Person	Female	British	17	West Midlands
8	Lily	Parent	Female	British	57	Hampshire
9	Ava	Parent	Female	British	53	Leicestershire
10	Pickle	Young Person	Female	British	11	Leicestershire
11	Eveline	Parent	Female	British	57	Dorset

Recruitment

Research aimed to reach a variety of people, with diversity in age, gender, ethnicity, location and socioeconomic status across the United Kingdom to represent experiences of a wider group of people affected by this condition. Recruitment started in April 2024 (Appendix D, E) and finished in September 2024 and included several routes, including social media platforms, online Long COVID community groups and contacting schools with most participants recruited from the online Long COVID group. The most effective sampling technique was snowballing, which allows to reach hidden and hard to reach populations (Atkinson & Flint, 2001). Upon showing interest, participants were provided with information about the study via email i.e. Participant Information Sheet (Appendix F, G), Debrief Form (Appendix J, F), Consent Form (Appendix J, I) and had the opportunity to ask questions, before giving written consent for the interview. Young people under 16 years old were also asked to provide their parent's consent.

Methods

Following receipt of consent forms, the date and time for the interview was agreed accommodating the needs and preferences of participants. Young people were asked to prepare photographs portraying their life with Long COVID and send those before the interview.

Photovoice, a participatory research method, was established by Wang and Burris in 1997 as a means of generating knowledge by inviting participants to caption their own photographs, discuss their meanings, document the strengths and concerns of their communities, promote critical dialogue, and engage policymakers. As a highly flexible approach, it can be adapted to the needs of specific communities and public health contexts. Over the past fifteen years, it has been increasingly employed in healthcare research, including studies involving young people living with pain (Donovan et al., 2022), people living with diabetes (Tang et al., 2025), adolescents vulnerable to HIV (Short, 2006). Research has found participants considered the photovoice approach acceptable and beneficial, suggesting its potential value for future research applications (Donovan, et al., 2022).

In the present study exploring the experiences of young people with Long COVID, photovoice was employed in an adapted form. Participants were invited to caption and discuss their photographs individually rather than in group settings and did not receive formal camera training. These adaptations were made to minimise participant burden and to acknowledge existing challenges such as physical and cognitive fatigue.

The interviews were conducted and recorded online over the Teams platform, lasting between 45-60 minutes with some shorter due to experienced fatigue. The interviews began by asking firstly about experiences of diagnosis and subsequently followed by questions about the impact of Long COVID including experiences of education, social life, healthcare and general public culture (Bronfenbrenner, 1979) (Appendix L, M). Where young people collated their photographs showing the life with Long COVID, they were asked initially to comment on what they chose to photograph and why, and how that linked with their daily experiences of living with Long COVID. Parents were encouraged to reflect on their own experiences, including their own wellbeing and parenting style, recognising changes to their own lifestyle following their child getting unwell. Families were emailed a £20 voucher for their participation. Interviews were transcribed verbatim by the main researcher removing identifiable data and pseudonymised transcripts were uploaded to NVivo software for coding.

Analysis

Data from both parents and young people were analysed using reflexive thematic analysis (Braun & Clarke, 2019) (Appendix N). Reflexive thematic analysis is a method used to identify, analyse, and organise data by developing themes that capture meanings relevant to the research questions. The analysis followed a six-stage process: first, the main researcher familiarised themselves with the data by reading and re-reading the material, noting initial impressions and systematically highlighting interesting elements across the dataset. Using an inductive approach, key ideas identified in the data were grouped into concise descriptions (codes) using both semantic and latent coding. These codes were then examined in relation to the research question and organised into main themes and subthemes. The themes were reviewed and summarised in a table, which included corresponding subthemes and codes. Finally, the themes were visually presented in a map to illustrate their relationship to the research question (Figure 3) and were described in detail with supporting quotations to answer the research question.

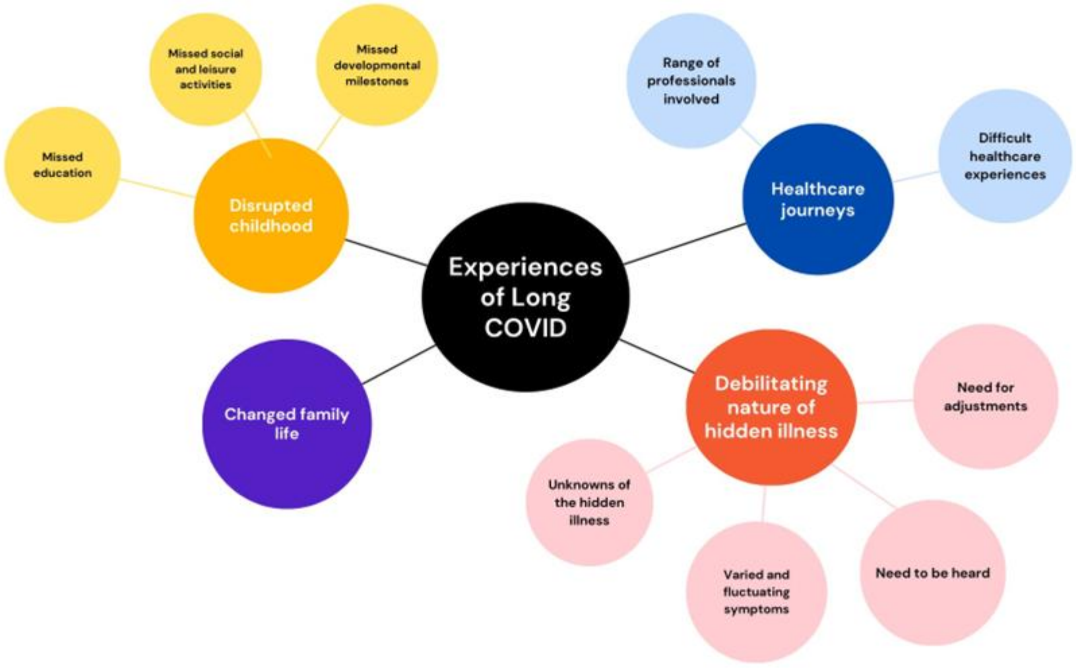
Results

Researcher completed 11 interviews, either alone with a young person or a parent, or in dyads with a young person and their parent, with the parent being available for emotional support. Out of four young people, two completed a photography task before the interview, collecting photographs to show their experience of Long COVID, which were shared and discussed at the beginning of the interview. All young people were encouraged to participate in photovoice as a way of empowering them to share their voices (Fountain et al., 2021). However, some declined, explaining that they were either unsure what photographs to take or did not feel this was an appropriate way for them to express themselves. Nevertheless, they were invited to participate in interviews, with the hope that this would allow them to engage meaningfully in the research.

Interviews exploring the experiences of young people living with Long COVID and their parents revealed a multilayered and complex picture of navigating the illness. Due to its varied symptoms, Long COVID was reported to have a significant impact on individuals, families, and their communities. Participants described complicated relationships with institutions such as education and healthcare, highlighting ongoing challenges and the need for advocacy to sustain care and support. Many struggled to have their difficulties validated over extended periods. Experiences of ill health influenced how young people related to themselves, their families, and others, often encompassing fears of being judged or not believed. The main themes emerging from the interviews were *disrupted childhood, changed family life, the debilitating nature of a hidden illness, and healthcare journeys*.

Figure 3

Thematic map



Main theme 1: Disrupted childhood

Participants described how Long COVID interrupts young people's developmental trajectories, particularly through missed education, missed social/leisure activities (e.g., family outings, colouring, cycling) and delayed milestones (e.g., school trips, dating, creating "teenage" moments). Despite recognising school's normative value, participants faced limited responsiveness from schools, accusations of avoidance, and ongoing systemic barriers, affecting their experiences and ways they were able to navigate their illness.

Missed education

Participants talked about experiences of Long COVID and disruption to their childhoods, which was evidently affecting different areas of their lives, with one of them being school life documenting the relation between individual's experiences and microsystem (Bronfenbrenner, 1979). While young people recognised a positive role of school, particularly in maintaining relationships with their peers and giving them a sense of normality, the reality was that participants felt a sense of disappointment from their limited ability to participate and perform as they used to. Lily spoke about her daughter's cognitive difficulties and how it impacted on her academic performance.

> She used to be highly organised but now faces some executive functioning challenges. Academically, she was doing very well before COVID at a competitive grammar school, scoring highly in her GCSEs. However, she has found school increasingly difficult and achieved much lower grades than predicted due to the mental effort required and the concentration and memory problems. (Lily)

Interviewees talked about limited empathy shown towards the impact of the condition on their lives. This led to feeling unsupported, having to look for alternative education solutions and at some cases, moving into home schooling.

> My son was basically out of education for two and half years (...) And he had almost no education (...) Devastating beyond belief, my son's school asked us to leave. They asked us to leave without giving us anywhere else to go because they didn't want him. And they did nothing to support us. (Karen)

Alongside other parents, she talked about anxiety caused by education, particularly with messages regarding school attendance. Due to low attendance, schools tried to keep parents accountable causing parents to worry about potential consequences.

> Because they've got complications from Long COVID and the reason that attendance at schools has dropped and the levels of anxiety are so high. (Karen)

Some parents spoke about accusations coming from professionals that their child may be exaggerating symptoms, and their school avoidance was intentional, showing how the culture of the systems may disturb experiences of individuals (Bronfenbrenner, 1979).

> Maybe it's school avoidance. Maybe he doesn't want to go to school, despite the fact that he had a diagnosis of post viral fatigue. (Eveline)

Maria, and other parents, talked about their children's needs not being met at school and their attempts to apply for Educational Healthcare Plans with the hope to have their children's needs recognised with special adjustments applied. Often these applications were unsuccessful, leaving parents to look for other solutions.

> Umm we tried. Well tried again for educational healthcare plan, but umm they said no. (Maria)

Ava realised that the education system was no longer able to respond to their child's needs and with no significant improvements to their child's condition, they decided to give home education a try.

> We're so relieved to be out, that we've deregistered. We're home educating now, way more education than she was before. (Ava)

She recognised that her daughter would be better off being educated at home, admitting that she was receiving more education than before. On the other hand, there were examples given by participants where school was supportive and responsive despite challenges surrounding Long COVID. Maria talked about how her son, who has interest in science, after having previous difficult experiences at school, started lessons in college that inspired his curiosity.

> But now, because he's in science, this course is all sciency, so he is quite happy. Well it has only been the first week, but, he said I like the lessons so, so that's like a plus and you see like a tiny spark of how he used, you know, because he loves learning. (Maria)

Missed social and leisure activities

Participants shared experiences of loss and how they were no longer able to engage in activities that were meaningful for them, describing sense of loss and disappointment with how Long COVID impacted on them. Eveline spoke about how her son missed out on opportunities to participate in family-based activities.

> And he really wanted to do it because we've missed out. He's missed out on three birthdays, Christmases, family stuff, you know, and actually it's affected the wider family because, you know, we're quite a close, close knit family. (Eveline)

Pickle shared a photograph showing her shopping trip with her family and reflected on how Long COVID affected her energy levels, impacting on her getting easily tired, and having to shorten their outing, reflecting on her changed experiences of family time. She also spoke about her creative endeavours, and how Long COVID made it difficult for her to continue colouring.

> I used to love doing colouring like a lot (...) And it's harder for me now, because like you do something wrong and the whole thing's ruined. And you have to do something new. It's just too stressful. Like I've been struggling a lot with stress cause of long COVID. (Pickle)

Lily spoke about her daughter’s process of recovery and how over time she regained some of her physical stamina and was able to cycle more, but importantly, continuously needed to remember doctors' advice about pacing and listening to her body.

> She found it very hard to pace herself, but certainly she's, you know, physically she can go for cycling for hours at a time and the days where she has confined to bed are sort of less frequent and for shorter. (Lily)

Missed developmental milestones

Participants reflected on various developmental milestones, highlighting the impact of Long COVID on young people’s growth. By missing out on opportunities to participate in activities alongside their peers, young people with Long COVID missed on developmentally crucial experiences. Owley, for example, spoke about missing out on doing things with friends as a teenager. While he recognised that there would be opportunities to engage in these activities in the future, he was acutely aware that these experiences would not be the same as they would have been during this time.

> As a result, I never got the chance to do a lot of, I mean, obviously I'm still I'm only 17, so I still have time to do like, teenage stuff. But because I never got the chance to really go out and do stuff with friends or just on a whim, go out to a shop or something and there's a probably experiences I'll never get back again, because when I am able to do them, I won't be the same age as when you sort of have a different mind about it, if that makes sense. (Owley)

Helen talked about how common experiences like school trips, which are expected activities undertaken by children of school age, were resulting in significant fatigue in her child, leading to long recovery and hesitation towards participating in similar activities in the future.

> She had one exam and then the next day she had a school trip where she had to stand for five hours and she was just completely and utterly wiped out. (Helen)

She also spoke about her daughter missing out on the opportunity to date, which other peers were able to do. This linked with Helen's fear about how her daughter will mature, and whether she will be able to create and maintain relationships with partners in the future.

> She didn't want to date whilst doing GCSEs. Now, she says it's just not fair. I'm too ill. (Helen)

Participants described how their children missed the experience of school life, particularly missing out on social and cultural opportunities that come with being part of a school community, contributing to them missing out on opportunities for development (Bronfenbrenner, 1979).

> And over the last year, she wasn't in school at all. So she's lost all her friends like, lost them all a year ago, really from school and they don't come and visit, there's been no continuation. (Ava)

Main theme 2: Changed family life

Parents reflected on the impact that having a child with Long COVID had on their own lives, influencing how they were perceived by others, how they spent their time, and the overall shape of their daily experiences, which consequently, affected young people. Parents recognised mostly more closely attuned relationships they developed over these experiences (Bronfenbrenner, 1979).

Ivy shared that she and other parents were sometimes viewed negatively, often being portrayed as neurotic or irrational, particularly in interactions with healthcare professionals. This frequently led to feelings of being misunderstood or judged.

> I've been in touch with some of the parents off the [support network] who have had, you know, whose children [...] have gone through, similar horrendous journeys of, people thinking that you're a neurotic mad parent. (Ivy)

Some parents were questioned to the extent that concerns about their parenting were escalated to social services. Being required to undergo assessments of their parenting skills reinforced their worries about judgment and how they were perceived by others.

> We had to have people around my home to make sure that I was looking after [removed] properly and it wasn't myself that I got the issue and that that was mind-blowingly difficult. (Ivy)

Having a child with Long COVID also affected parent's lifestyle; Eveline talked about becoming the main carer for her child with Long COVID.

> It's been a sentence for me as well because I've had to kind of give up life really because I'm I've been house bound with him, you know, as the main carer. (Eveline)

Likewise, relationships within the family changed, holiday arrangement differed and overall, how family members spend time together had to change due to the child's needs.

> And then myself as a person or me and my husband as a couple having more time for ourselves and each other, and now have less time, it's like having your young child back again. (Ivy)

Some parents spoke about the need to adapt their working lives, such as adjusting their hours or transitioning to remote work. One participant shared that she had to give up her job entirely in order to care for her child at home, which resulted in significant financial pressures and debt.

> I've had to give up my job. You know, financially, God, I'm just, I'm going to be in debt for years by what we've gone through. (Eveline)

Main theme 3: Debilitating nature of hidden illness

In all accounts, interviewees identified the debilitating nature of Long COVID, highlighting its invisible nature, which undermined validation. The fluctuating symptoms (e.g., brain fog, fatigue, dizziness) appear invisible to others and, with significant impact, prompt questions about recovery and trajectory. Participants reflected on the need for adjustments, including wheelchairs, walking aids, blue badges, home modifications, and flexible schooling to sustain some quality of life. Many spoke about the need for validation, for understanding, and to be heard, urging systems to listen to lived experiences over rigid protocols. For many affected by these experiences, finding safety in peer community groups was critical for maintaining some sense of well-being.

Unknown of the hidden illness

Participants recognised that Long COVID is an invisible condition, making it difficult for others to understand. While people with Long COVID may appear outwardly fine, others can struggle to grasp the challenges they are facing, affecting sense of validation and understanding that young people receive. The impact of the systems around the child, can have a powerful role in providing support and messages of positive regard (Bronfenbrenner, 1979).

> It's harder than it looks, and just because we don't show, because you can't see it physically it doesn't mean we are not ill. (Owley)

Owley explained that illnesses with clear physical symptoms are easier for people to recognise and understand compared to conditions like Long COVID, portraying the impact of social and cultural perceptions over the invisible illnesses.

> With invisible illnesses, I mean, even with mental health, people aren't as receptive to that because you can't see it manifest physically (...) people are better with physical manifestation of illness. (Owley)

Participants spoke about challenges being understood by those without the lived experience.

> But I think for everybody to fully understand the difficulties, you'd have to actually be like living it. (Ivy)

One of the questions that participants wondered about was what recovery looks like in the case of Long COVID. With so much unknown it is hard to understand how quickly and what the process of recovery may look like for those affected by Long COVID.

> So what's recovery look like? That's scary because you just want your children to be, happy and healthy, don't you? (Ivy)

Varied and fluctuating symptoms

As research has shown, and as discussed in the interviews, Long COVID has been characterised by numerous symptoms affecting multiple organ systems and leading to debilitating effects.

> Her symptoms have always been dizziness, severe brain fog, severe fatigue, umm. She hasn't had breathing difficulties or, you know, she's not had anything that you would think had affected her, her lungs or a heart or... It's been more chronic fatigue like symptoms for her. (Helen)

Eveline talked about the fluctuating nature of Long COVID and how different symptoms appear and change over time.

> He just started off with a variety of different symptoms, but it was just a very slow burn. So one week, you know, he was like, on and off for a few days. Not great. And then the next week, it was kind of like a layering of then something else came out in him, and then the next week, something else. (Eveline)

Some participants recognised the impact of Long COVID as so debilitating that it had stopped them from being able to participate in any of their daily activities, and some considered their experience as disability.

Need for adjustments

In interviews, participants discussed needs around adjustments and advocating for improved accessibility to allow them to have a better quality of life:

> He's had to use a wheelchair for outside use. He can't get to school(...) He can't walk. (Karen)

A use of wheelchair is just one of the examples mentioned by families with experience of Long COVID. Frogo shared a photograph portraying him on a wheelchair in a park, recognising that's the only way for him to enjoy outdoors. Other participants spoke about how the aids have improved their children's daily life.

> All these like devices and aids, you know, wheelchair in the house now walking frame in the house. (Eveline)

Other arrangements included applying for Personal Independence Payment and supporting young people with the application. Parents felt that having a blue badge could make their life more manageable too, showing the role of exosystem in supporting individuals with long-term health conditions (Bronfenbrenner, 1979).

> I will try and get if he can get personal independent payment for him (...) We'll try that and then you can have a blue badge which will help you put other stuff as well. (Maria)

Owley spoke about experiences of running late for classes and being penalised for not turning up on time. He spoke about his limitations to how quick he can walk, and difficulty explaining it to others.

> Please don't mark me late because I physically can't go any quicker than I can, so I find that you have to really for people with power, you have to really explain it to them. Because I think they don't understand how bad it can actually be (Owley)

One parent spoke about changes to their bathroom and how acquired funding contributed to adjustments made which improved their child's quality of life.

> And I've sorted out a wet room for her so she can sit in the shower because she was only showering once every three weeks, and that's the field I work in. So I applied for funding for her to have a walk in shower, which she's now got. She's never wanted me to physically help her shower or wash and dress. (Helen)

Some young people talked about adjustments to their lifestyle and activities, including online based activities which allowed them for some interactions with peers while not putting a strain of having to leave the house.

> One thing I found, I find comforting… Well, there are two things really. One is like YouTube videos. I found like a community of Minecraft Youtubers that are really nice. (Pickle)

Need to be heard

The interviews highlighted the importance of listening to lived experiences. Both young people and parents emphasised the value of understanding what Long COVID feels like firsthand.

> But because the parents know the child more than the medical people; medical people know medical stuff, obviously. But we know the child as a person, as a whole person, not just that bit when they see them. So they need to listen to us I think. (Maria)

Some people spoke about desperation for advice and information.

> You just feel like you're in a desperate situation when this just comes out of the blue from nowhere your child can't get out of bed, you know, it's like the a major life disruptor. And you don't know what to do to help or make them better, you know. So just desperate for some kind of like proper guidance and advice. (Eveline)

Some spoke about not fitting in, and being a problem for the mainstream system, which doesn’t account for people with Long COVID difficulties. Owley portrayed how inflexible the system has been in his experience:

> I think it's that they're sort of designed to keep the system moving and when they find someone or something that doesn't fit into that system, rather than trying to adapt the system, they try and sort of push the square peg into the circle hole (…). (Owley)

Pickle spoke about feelings of safety in her community of people living with Long COVID.

> It's partly because on Minecraft I can make things like, but I can never make in real life and like, do things and it's also partly just being able to show that it's like if I feel safe around them because they understand what it's like to have Long COVID I don't have to hide things from them. (Pickle)

Main theme 4: Healthcare journeys

Participants described lengthy and challenging journeys in accessing the healthcare system and particularly, more specialised services. From the initial recognition of symptoms to obtaining a diagnosis and finally reaching specialised care, families often spent months consulting multiple doctors before receiving appropriate support, showing the role of the exosystem in supporting timely diagnosis and treatment of young people with long-term health conditions (Bronfenbrenner, 1979).

Range of professionals involved

All participants described their experiences navigating the healthcare system and recognising a range of professionals involved in their own or their children's care, starting with GPs and extending to paediatricians, multidisciplinary teams, and Long COVID services. Reflecting on the number of professionals involved, participants discussed both the helpful and less helpful aspects of their interactions with multidisciplinary teams.

> And that was a good, they were a good team. We saw an MDT, a multidisciplinary team and they were all very good, very knowledgeable and experienced about long COVID and fatigue related illnesses, they knew what they were talking about, they were very sympathetic actually. (Ava)

> So I think multidisciplinary is good if it's the right thing, but you can have too many people involved (Eveline).

Difficult Healthcare experiences

Participants described a range of experiences with the healthcare system, some of which were particularly difficult. From not being believed, to being dismissed, with some parents reflecting that their experiences with the public healthcare system were so disappointing that they began searching for answers wherever they could. Owley noted that healthcare professionals often relied on a checklist approach, which was of limited help especially when dealing with a condition as poorly understood as Long COVID.

> Think mainly it's from the doctors that sort of follow a textbook thing, which is usually fine. But I think for a lot of experiences and conditions, you can't just follow a checklist so I would say mainly it's like GPs and people like I saw a neurologist as well so those kinds of ones where they look for symptoms and stuff like specific signs and things like that, I think them the most likely to dismiss it. (Owley)

Eveline talked about difficulty with getting diagnosed and the long time it took her to finally be understood.

> I've had my suspicions on long COVID for some time, and I kept raising it. But I'll be honest with you, it's like not on anybody's radar. Nobody really wants to know. (Eveline)

Participants talked about the problem with attitudes and behaviours among healthcare professionals; Ava noted the problem of burnout affecting motivation and interest in helping to meet their needs.

> The lack of interest really, I think the first paediatrician just didn't want to... they're all burned out. I totally get it, they don't want to do more work. He was just like, there's no point me doing anything. Well at the long term clinic, they will do it. (Ava)

And even, as highlighted by some, more specialist teams were disappointing at times. Eveline described her experience with a specialised team that lacked knowledge about Long COVID, resulting in inadequate treatment.

> Actually I don't know how even to verbalise this, if I'm really honest with you, [removed] because I'm so disgusted with the treatment that we had, the complete lack of I would say knowledge within that team. (Eveline)

For some, difficulties they experienced with healthcare system, meant they had to search for help privately, often at the cost to their household budget.

Overall, all interviews highlighted the challenging experiences of navigating Long COVID, with participants reflecting on various systemic influences that impacted their experiences of living with a long-term health condition. Drawing on Bronfenbrenner's Ecological Theory (1979), many interactions at different systemic levels were identified as influential in shaping how young people and their families experienced Long COVID.

Discussion

This study presents the experiences of eleven individuals affected by Long COVID, either directly as young people living with the condition or as parents of those affected. All participants chose to take part in the study because they believed that raising awareness about Long COVID is important and hoped that sharing their experiences might lead to changes in how others respond to the illness.

Drawing on Bronfenbrenner's Ecological Systems Theory (1979), the experiences of young people with Long COVID can be understood as shaped by multiple, interacting levels. At the microsystem level, their immediate environments - such as family, school, and peer relationships - were profoundly disrupted. Young people described missing out on typical experiences of childhood such as attending school, spending time with friends, or engaging in leisure activities and early relationships (Faux-Nightingale et al., 2023). Their families adapted lifestyles often resigning or withdrawing from participation in typical family events like holiday trips. These disruptions represented a loss of developmental opportunities and milestones that would ordinarily support identity development and social growth, like dating, or social shopping trips. Within the mesosystem, which reflects the interconnections between these environments, families played a crucial role in mediating young people's experiences. Parents often made significant adjustments, including modifying work schedules, resigning from jobs, or seeking remote-working arrangements to support their child's health needs. Family routines and dynamics changed considerably, with some parents describing a reversion to caretaking roles resembling those of early childhood. These adaptations, while necessary, altered family relationships, and while many families reported they felt closer as a result of their experiences of Long COVID, they also shared a sense of loss over lost developmental opportunities. At the exosystem level, institutional systems such as healthcare and education heavily influenced families' experiences. Participants highlighted variability in institutional understanding and responsiveness to Long COVID, pointing to enduring challenges in accessing recognition, support, and appropriate care with some examples of more helpful interventions accessed through specialised services. The macrosystem, encompassing wider societal attitudes and policies, also shaped experiences of validation and dismissal. As a largely invisible illness, Long COVID often lacked social recognition, contributing to feelings of invalidation and stigma (Wild et al., 2024) with some examples shared about how difficult it has been to remaind others about the severity of symptoms experienced by the child. Participants emphasised the need for greater societal awareness and more responsive healthcare structures that acknowledge the legitimacy and long-term impact of this condition. Finally, the chronosystem provides a perspective to understand how the ongoing and fluctuating nature of Long COVID influenced development, access to and experience of treatment and social awareness of Long COVID across months and years. The illness's unpredictable nature generated anxiety, uncertainty, and shifting identities, with some young people beginning to view themselves as disabled and making practical adjustments such as using wheelchairs or lift passes at school.

Strengths and limitations

This study demonstrates the voices of 11 participants with experience of Long COVID, allowing for in-depth exploration of experiences of this marginalised illness and consideration of meaning that people create from living with it. It captures a broad range of narratives, and contexts of people who have firsthand experience, giving those with lived experience a voice, in expressing themselves and exploring their experiences, recognising the impact of systemic influences on experiences of illness (Chachar et al., 2021; Batra, 2013; Bronfenbrenner, 1979). Furthermore, a number of participants identified as coming from Asian background, allowing for culturally richer reflections surrounding the experiences of Long COVID within ethnic minorities underrepresented in Long-COVID specialist clinics and Long-COVID lived experience research (Smyth et al., 2024). Considering limited research in this area, this study provides an insightful description of what it looks like to live with a hidden illness. The study has been enriched by accounts of experts with lived experience, who contributed to the study, and shared their insights, influencing the focus and the format of the research.

As for limitations, given the qualitative nature of the study, the sample size was small. While triangulation was achieved and the recommendations may be transferable to other populations with long-term health conditions, further accounts and experiences would be valuable to explore. The study applied an adapted form of the photovoice method drawing on other examples of photovoice projects used with youths (Fountain et al., 2021) aiming to empower young people to share their experiences of living with Long COVID (Wang, Burris, 1997). The photovoice approach was modified to suit participants' needs and the constraints of the research context. Young people were invited to caption and discuss their photographs in individual interviews rather than group settings, and no formal camera training was provided. These adaptations aimed to reduce participant burden and accommodate challenges such as fatigue and cognitive difficulties, which were common among those experiencing Long COVID. However, these methodological adjustments also introduced limitations. With only two participants submitting photographs, the study did not fully realise the potential of photovoice as a participatory and visual method. The limited number of visual contributions reduced the depth and diversity of multimodal data that could have complemented the interview findings. Consequently, the study's capacity to explore how young people construct and communicate their experiences through visual and narrative means was constrained. Furthermore, the absence of group discussion - a core component of traditional photovoice - meant that opportunities for shared reflection, collective meaning-making, and empowerment through dialogue were restricted. Despite these limitations, incorporating an adapted photovoice element still demonstrated the method's potential, highlighting both the value and the challenges of participatory and creative methods in research with young people managing complex, fluctuating health conditions. Future studies might benefit from offering flexible opportunities for participation including hybrid approaches that consider participants needs.

Another challenge encountered in the study related to recruitment strategies. A sample bias was likely present, as all participants were actively engaged in a Long COVID community group and demonstrated a relatively high level of understanding of healthcare and research. It is possible that individuals who were less engaged or not part of such networks may have had different experiences of navigating Long COVID.

Implications

The study has implications for education, healthcare, social policy, and public attitudes towards young people with Long COVID. At the microsystem level, the study's findings reveal disruptions to young people's daily routines. Interruptions to schooling show the need for more personalised and flexible learning approaches - including practical adaptations - as well as enhanced emotional and academic support around cognitive and other difficulties; supported by Education Health Plans. Training for teachers and school staff to recognise and accommodate invisible illnesses such as Long COVID could strengthen these immediate environments and promote inclusion enabling school to provide an understanding, validating experiences. At the mesosystem, which considers the interactions between home, school, and healthcare settings, stronger collaboration is needed to ensure continuity of care and educational engagement with minimal disruptions. Coordinated communication between families, educators, and health professionals could facilitate more consistent support, enabling young people to manage symptoms while maintaining educational and social participation - which is key for their health and future prospects. Within the exosystem, encompassing wider institutional structures that indirectly influence young people's lives, implications arise for healthcare systems and social welfare policies. The study highlights the need for clearer diagnostic and management guidelines within healthcare, alongside practical support such as access to Personal Independence Payments or flexible workplace arrangements for parents caring for children with Long COVID. Ongoing funding for Long COVID clinics or alternative arrangements is important to ensure access to specialised services. At the macrosystem level, societal attitudes and policy frameworks shape how Long COVID is recognised and responded to, affecting directly experiences of those with lived experience. Findings from this study demonstrate the importance of increasing public awareness and professional understanding of Long COVID as a significant, potentially disabling condition - through active media involvement, public awareness campaigns or other means enabling wider public to learn about the condition. Formal recognition of Long COVID as a disability would help ensure that affected children and families receive appropriate legal protections and access to necessary educational and social resources, supporting their daily living. Finally, the chronosystem draws attention to how these experiences and systemic responses evolve over time. As knowledge of Long COVID continues to develop, sustained efforts including ongoing clinical research are needed to adapt support systems, reduce stigma, and foster understanding across all societal levels.

Future recommendations

As demonstrated, children and young people with Long COVID often struggled to have their illness validated and understood (Wild, 2023). Future recommendations should therefore address the interrelated systems that shape their experiences, drawing on Bronfenbrenner's Ecological Systems Theory (1979). At the microsystem level, it is essential to strengthen direct support by creating safe, supportive environments that validate experiences of young people. This includes empowering and enabling parents as primary carers, and fostering meaningful, responsive interactions within schools, and healthcare settings, and where possible, creating better community responses. At the mesosystem level, stronger collaboration between home, school, and healthcare contexts is crucial. Developing in collaboration with young people and families tailored, person-centred plans that address individual needs, challenges, and coping strategies across education and health systems can help improve outcomes and overall wellbeing. Within the exosystem, policy and service structures should prioritise equitable access to healthcare, educational adaptations, and financial assistance, this includes access to Personal Independence Payments and flexible workplace arrangements for parents who may benefit from practical adaptations and alleviate financial pressures associated with caring for young people affected by Long COVID. Further training for educators and healthcare professionals on invisible chronic illnesses would further strengthen the understanding and improve responsiveness. At the macrosystem level, raising societal awareness of Long COVID as a legitimate diagnosis could reduce stigma and enhance understanding, addressing feelings of invisibility and frustration among those affected. By promoting inclusion and equality, these broader cultural and policy shifts can help reduce inequalities and improve social participation. Finally, from the chronosystem perspective, ongoing investment in research is important. Future studies should continue to expand the evidence base on Long COVID, focusing on the development of effective interventions, refinement of clinical guidance, and improvement in symptom management and rehabilitation; developing understanding about trajectory and recovery. Importantly, research should include the firsthand perspectives of children and young people and their parents, as well as those from underrepresented or higher-risk groups, to ensure that evolving policies and services remain inclusive and responsive to diverse experiences.

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Appendix A Descriptive summary of findings

Table 5

Descriptive summary of findings

Reference	**Design**	**Population**	**Aim**	**Results**	**Strengths**	**Limitations**
Wild et al., 2024	Qualitative; mind-mapping technique (Ziebland & McPherson, 2006)	39 participants, 22 adolescents and 17 parents/carers	To identify narratives around COVID	Three main public narratives were proposed: *"Covid-19 is mild and (almost) everyone recovers after a short illness", "Children don't get Covid-19", "Covid-19 is over"*	Representation of under researched group of adolescents with Long COVID. Consideration about public narratives surrounding Long COVID. Good sample of participants. PPI involvement.	No consideration of ethical issues. No mention of researcher's relationship to Long COVID.

Faux-Nightingale et al., 2023	Qualitative; Thematic analysis	4 young people, 3 parents, two focused groups with 7 professionals	To understand participants' views and experiences of having Long Covid	Three main themes were identified: *"Living with Long COVID", "Uncertainty around Long COVID", "Seeking help for symptoms",*	Good, holistic overview of experiences of young people having Long COVID and experiences of professionals. Good description of PPIE involvement. Ethical considerations of working with younger people considered. Relation to the subject by researchers described.	Heterogeneous population could affect the analysis Researchers did not achieve saturation in data Low sample
Torres et al., 2024	Qualitative; conventional content analysis	6 children, 5 parents	To explore the lived experiences of paediatric Long COVID	There were 8 themes that were identified: "severity of illness/symptomatology" "difficulty surrounding the diagnostic process/not being believed", "impact on family and social connections", "poor	Discussed impact of Long COVID on several areas, highlighting severity of Long COVID. Good description of further research that is required in this area.	Relied on self-reporting of symptoms by participants. Small, racially and ethnically homogeneous sample size.

				school functioning”, “positive coping”, “subsequent positive medical experiences”, “ mental health”, and “knowledge of medical field/healthcare experience”		
MacLean et al., 2023	Qualitative; Thematic analysis	22 young people and 15 parents	To explore the impact of Long Covid (LC) on the school experiences of children and young people (CYP).	Three key findings were highlighted: “Going to school is a valued part of CYP’s lives and participants viewed educational attainment as important for their future trajectories”, “Attending school (in-person or online) with LC is extremely difficult”, “School responses to CYP with LC were reported to be mixed and hampered by difficulties communicating with healthcare professionals	First qualitative study exploring the impact of Long COVID on school experiences. Draws on rich accounts from a diverse sample of children and young people with LC.	It does not include the perspectives of education professionals on their experiences of engaging with CYP with LC and the support they need to do this.

				during the pandemic and a lack of awareness of LC among healthcare and education professionals”		
Newlands et al., 2024	Qualitative; Thematic analysis	11 young people and 6 parents	To understand the experiences of young people living with Long COVID	Four themes were identified: “Unravelling Long COVID: Exploring Symptom Journeys and Diagnostic Dilemmas”; “Identity Disruption and Adjustment”; “Long COVID’s Ripple Effect: the impact on Mental Health, Connections, and Education”; and “Navigating Long COVID: barriers to support and accessing services.”	One of the first studies looking at experiences of people living with Long COVID. PPI involvement.	Most participants are white, and female; which means it may not be representative of ethnic minority group’s voice.
Messiah et al., 2023	Qualitative; Thematic analysis	25 parents	To interview parents who had a child who was hospitalised with COVID-19	Seven themes were highlighted: “Post-traumatic stress disorder”, “Social anxiety”, “Severe	Racially diverse sample. Good sample size.	Lack of PPI Involvement.

			illness among a sample of ethnically and socioeconomically diverse children.	symptoms on reinfection”, “Worsened pre-existing conditions”, “Lack of insurance coverage for costly treatments”, “Access and utilisation of support systems”, “Overall resilience and recovery” and four parent-specific themes were identified: “Fear of COVID-19 unknowns”, “Mixed messaging from health information sources”, “Schools being both a support system and a hindrance” and “Desire for and access to support systems”.		Participants recruited from main study, hence possible selection or participation bias. Possible limitations related to generalisability given the sample recruited from one large paediatric healthcare system in one large urban area of the USA.

Appendix B Themes summary – systematic review

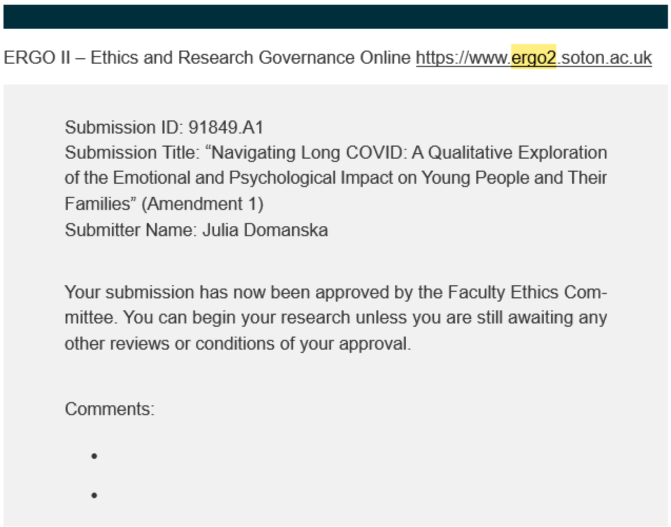
Table 6

Themes summary

Study	Facing disbelief and stigma		Disruptions to school experiences			Healthcare challenges				Navigating the struggle	
	Lack of understanding	Lack of evidence and stigma	Education as valued activity	Disruptions to academic progress	Problematic attendance	Difficulty with diagnosing	Misunderstood condition	Difficulty accessing healthcare	Positive experience of healthcare	Mental health	Positive coping
Wild et al., 2024	Y	Y				Y	Y	Y			
Faux-Nightingale et al., 2023	Y	Y		Y	Y	Y	Y	Y			Y
Torres et al., 2024	Y	Y		Y	Y	Y	Y	Y	Y	Y	Y

MacLean et al., 2023	Y		Y	Y	Y	Y	Y				Y
Newlands et al., 2024	Y			Y	Y	Y	Y	Y	Y	Y	Y
Messiah et al., 2023	Y		Y	Y			Y	Y		Y	Y

Appendix C Ethical approval



ERGO II – Ethics and Research Governance Online https://www.ergo2.soton.ac.uk

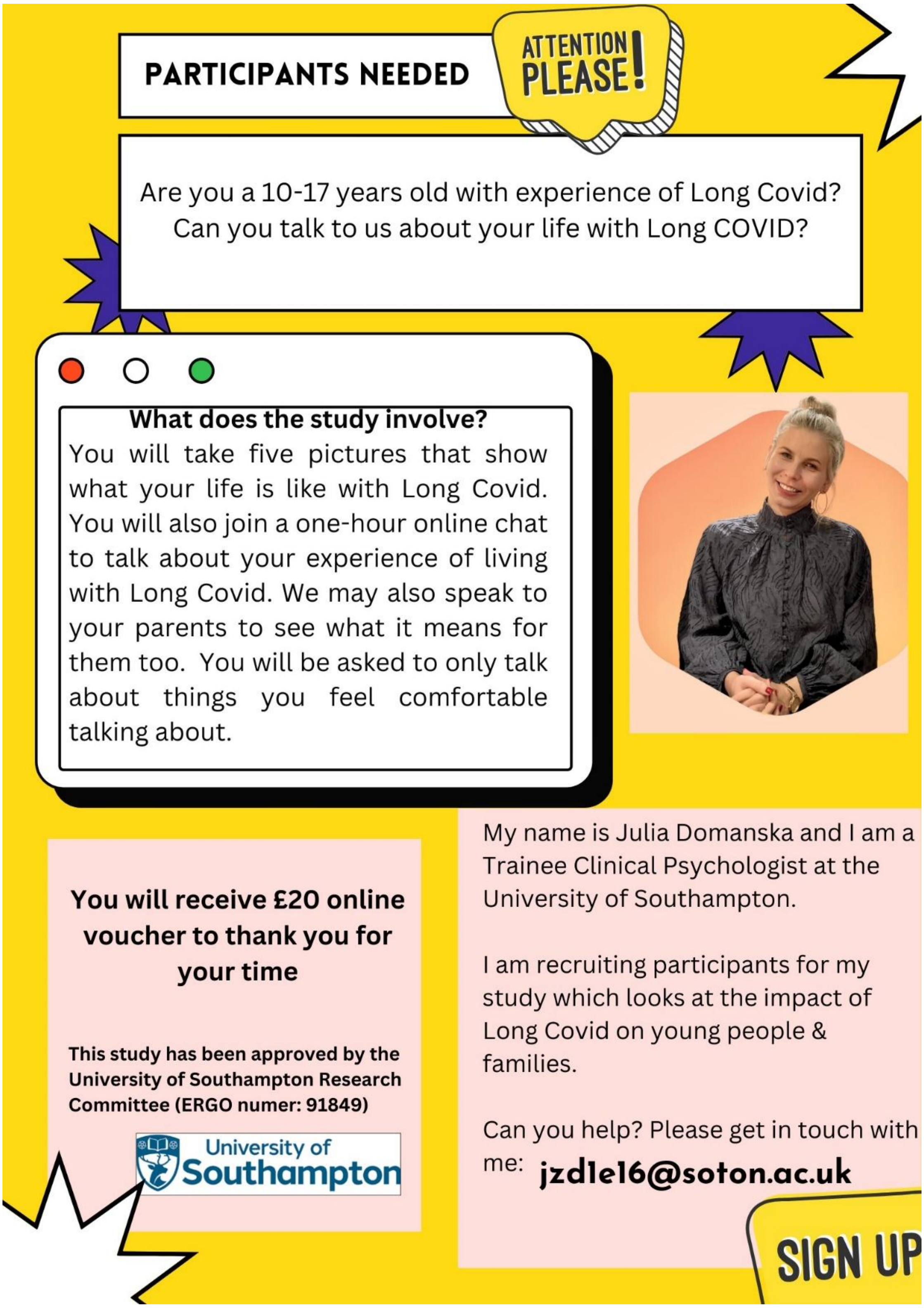
Submission ID: 91849.A1
Submission Title: "Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families" (Amendment 1)
Submitter Name: Julia Domanska

Your submission has now been approved by the Faculty Ethics Committee. You can begin your research unless you are still awaiting any other reviews or conditions of your approval.

Comments:

-
-

Appendix D Advertisement poster (Young Person)



PARTICIPANTS NEEDED

ATTENTION PLEASE!

Are you a 10-17 years old with experience of Long Covid?
Can you talk to us about your life with Long COVID?

What does the study involve?

You will take five pictures that show what your life is like with Long Covid. You will also join a one-hour online chat to talk about your experience of living with Long Covid. We may also speak to your parents to see what it means for them too. You will be asked to only talk about things you feel comfortable talking about.

My name is Julia Domanska and I am a Trainee Clinical Psychologist at the University of Southampton.

I am recruiting participants for my study which looks at the impact of Long Covid on young people & families.

Can you help? Please get in touch with me: **jzd1e16@soton.ac.uk**

You will receive £20 online voucher to thank you for your time

This study has been approved by the University of Southampton Research Committee (ERGO numer: 91849)

University of Southampton

SIGN UP

Appendix E Advertisement poster (Parent)

University of Southampton

NAVIGATING LONG COVID EXPERIENCES

Are you a parent of a child with Long COVID?
Can you help us understand your experiences better?

What this study is about?

This study explores the experiences of children and young people with Long COVID, as well as their parents. **If you are a parent caring for a child with Long COVID, we would like to hear from you.**

You will be invited to participate in an online 30-45 minutes interview sharing your perspectives and experiences and offered a £20 online voucher for your time.

If possible, we would like to speak to your child too, but this is not required.

If you want to take part, please email me at: jzd1e16@soton.ac.uk

This research has been approved by the University of Southampton Ethics Committee (ERGO number: 91849)

Appendix F Participant Information Sheet (Young Person)

Participant Information Sheet (Young Person)

Study Title: "Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families"

Researcher: Julia Domanska

ERGO number: 91849

You have been invited to take part in a research study about Long Covid. This is a condition that can affect people after they have had Covid-19. The study wants to understand how Long Covid affects the lives of young people and their families, and what kind of help might be useful.

Please read information about this study to help you decide whether you want to take part or not. You will need to sign a form to confirm you are happy to participate.

What is the research about?

The aim of this project is to get a better understanding of people's experiences. We want to hear from young people and their families how it is to have experience of Long Covid. We hope this may help us to think about how to better support people who may have this experience.

This study is a final project completed by the end of Doctoral Programme in Clinical Psychology at the University of Southampton.

Why Me?

You have been invited because you have experience with Long Covid. This means you have either had been diagnosed or self-diagnosed as someone suffering from Long Covid. The study is looking for people who have been affected by Long Covid for at least 12 weeks.

What Will I Do?

If you decide to take part, you will be asked to take five pictures that show what your life is like with Long Covid (using a camera, e.g. on your phone). Don't worry if you don't have a camera, we can find a way around it. You will also be asked to have an online interview with Julia. The interview will be about your experiences of living with Long Covid. You may be asked things like "What your day looks like? What a good day is like? What a bad day looks like? How is Long Covid affecting your school, friendships and hobbies? We also want to hear about what you think is important for us to know!

Do I Have to Take Part?

No, it's completely up to you. Taking part is your choice, and you can decide not to take part at any time. Even if you start the study, you can stop at any time without giving a reason.

What Will I Get?

You will receive a £20 shopping voucher for taking part in the study. This is to thank you for your time and help.

Will My Information Be Kept Private?

Yes, your information will be kept private. Only the research team and people who are allowed to check the study will see your information. Your name and personal details will be kept separate from your answers. If you have any questions or want more information, you can ask Julia Domanska or her research supervisors at the University of Southampton.

What Will I Be Asked to Do if I Do Decide to Take Part?

Once you have confirmed you are happy to take part, you will need to take five photos showing your life with Long Covid and have a one-time video chat with the researcher. Your parents can join you. They may also be interviewed separately.

What Will Happen if I Don’t Want to Carry on with the Study?

You can leave the study at any time, even after saying yes. You don't have to answer all the questions in the interview. If you start the interview but change your mind, you can stop without giving a reason. If you leave the study early, all your information will be deleted. But there are some rules about deleting your information after the interview. You can ask to delete your information up to two weeks after the interview by emailing Julia. After two weeks, your information can't be deleted because it will be used for the study. If you leave the study after the interview or during it, you will still get the shopping voucher. But if you leave before the interview, you won't get the voucher.

Possible Advantages and Disadvantages of Taking Part

The study wants to understand what it's like for young people and families living with Long Covid. This will help them know what kind of help is needed. But talking about hard things might make you feel upset. If this happens, the researcher will ask if you want to stop or take a break. There are also details of organizations that can help if you feel upset after the interview.

What's Happening with the Study?

The things we find in the study will be written in a paper called a "doctoral thesis" which is something that doctoral students are expected to do by the end of their studies. It might also be put in science magazines or talked about at meetings. This is to make sure that relevant people and organisations can learn from this study. If you want, we can send you a short version of the study when it's all written up.

Who's in Charge?

The study is being looked after by the School of Psychology at the University of Southampton. This it to make sure everything is done the right way.

Got a Problem?

If you're not happy with something in the study, you can tell the University of Southampton Research Integrity and Governance Manager. They'll help sort it out. Contact details: (023 8059 5058, rgoinfo@soton.ac.uk).

Thanks!

We're really happy you joined in on the study. Thanks for being part of the team!

Appendix G Participant Information Sheet (Parent)

Participant Information Sheet (Parent)

Study Title: "Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families"

Researcher: Julia Domanska

ERGO number: 91849

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This study aims to explore experiences of children, young people and families with experience of Long Covid and to develop an understanding about how Long Covid impacts on people's well-being and what psychological help could be helpful. Previous research focused on experiences of adults with Long Covid, showing that the impact of Long Covid can affect people's identity, sense of belonging and cause sometimes difficult emotions. Furthermore, some people talked about confusion around diagnosis and limited support. This project will explore what are the experiences of young people, and their parents and think about unique challenges of young people living with Long Covid with the aim of developing better understanding around needs and support.

Why have I been asked to participate?

You have been invited because you have lived experience of Long COVID either as a person directly affected by the virus or caring for someone with Long COVID. Potential participants must have

- experience accessing Long Covid services and/or
- have received a diagnosis of Long Covid and/or
- self-identified with ongoing symptoms 12+ weeks after initial Covid-19 infection or
- act in a caring capacity for someone with the above experiences as a parent or carer.

For the purposes of this study, participants must continue to experience symptoms for a duration of 12 weeks after the initial diagnosis of Covid-19 (confirmed with one or more positive Covid tests), impacting their physical, mental or social well-being and interfering with some aspects of their living (GOSH, 2020) or be a carer for someone with these characteristics. This will be confirmed by researcher requesting the evidence showing this diagnosis.

What will happen to me if I take part?

You have been invited because you have lived experience of Long COVID either as a person directly affected by the virus or caring for someone with Long COVID. Potential participants must have experience accessing Long Covid services and/or have received a diagnosis of Long Covid or self-identified with ongoing symptoms 12+ weeks after initial Covid-19 infection or act in a caring capacity for someone with this experience as a parent or carer. For the purposes of this study, participants must continue to experience symptoms for a duration of 12 weeks after the initial diagnosis of Covid-19 (confirmed with one or more positive Covid tests), impacting their physical, mental or social well-being and interfering with some aspects of their living (GOSH, 2020) or be a carer for someone with these characteristics.

Unfortunately, you cannot take part if you are experiencing or caring for someone with an acute COVID infection or other health conditions which explain the symptoms. Also if you are feeling too unwell to complete the interview, or feel that this could be too distressing for you, you should not take part. We are looking for around 10 participants including children, young people and parents across the country to share their experiences with us.

Young people will be asked to collate five pictures portraying their live with Long Covid and attend one hour online interview with the main researcher either on their own or accompanied by their parents. Parents will be invited for the interview separately.

Are there any benefits in my taking part?

You will be offered a £20 shopping voucher as a family for your participation. One family will receive one voucher only. No other incentives or expenses will be provided for participation. You will still receive a voucher if you withdraw your participation during or after the interview. You will not receive a voucher if you cancel your participation prior to starting the interview.

Are there any risks involved?

It is hoped that the study will contribute to an understanding of the lived experiences of children, young people and families who have lived experience of Long COVID. As for the disadvantages, you might experience emotional distress during the interview due to the discussion of difficult and potentially sensitive experiences and the impact of ill health. If this happens, the researcher will ask you if you want to take a break from the interview, stop the interview or withdraw from the study. You will receive details of organisations that may be able to help you if the interview causes any distress in the debrief form.

What data will be collected?

If you decide to take part, you will be asked to sign an electronic consent either via email or via Qualtrics.

This study will require young people to take five photographs picturing their life with Long Covid and sending this to the main researcher through the secure platform and completing a one-off online interview with the researcher. Parents will be invited to take part in the interview separately. You will be asked about your experiences of caring for someone with Long Covid which may include discussing how Long Covid has affected your everyday life, what does it look like to care for someone with Long Covid, any support have you received from healthcare services. The interview will be semi-structured and while the researcher will have a general list of topics for discussion, you will also have the opportunity to speak about anything you feel is relevant or important to the topic area. We will collect some basic demographic questions, such as your age, gender, and ethnicity to help us understand how diverse the group of participants is.

The online interview will be conducted over Microsoft Teams and will be arranged at a time and date that is convenient for you. This will be done through emailing you an individual Microsoft Teams link. The interview will last approximately an hour and may be shorter or longer than this, depending on what you decide to talk about. If you do agree to participate, it is advised that you arrange to be in a quiet location where the interview will not be overheard, such as a room where you are able to be alone. If there are any interruptions during the interview and you are disturbed by someone coming into the room, the interview will be paused and resumed when you are alone, or we can re-arrange the interview for another time. The interview will be recorded using the Microsoft Teams recording function. Following the interviews, a word for word transcript of your interview will be produced for data analysis.

All information collected about you during the study will be kept confidential and will be stored securely on the University of Southampton's Data Research Store for up to 10 years after the study has ended. Only members of the research team will have access to your data, and they will abide by all legal requirements of current General Data Protection Regulations (GDPR). This means that the audio files of your transcript will be deleted as soon as data transcription has taken place and only anonymised interview transcripts will be stored securely on the University of Southampton's laptop. This will ensure that any quotations from your transcript that may be used in publications will be anonymous and cannot be linked back to you.

Will my participation be confidential?

Your participation and the information we collect about you during the course of the research will be kept strictly confidential.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Only your consent forms and the audio recordings will be personally identifiable to you. The audio recordings will be securely deleted as soon as they have been transcribed. The consent forms will be stored in a separate password protected file to all other information. The email address you provide to receive your participation voucher will be detached from all your other personal information. It will only be possible to connect your interview data to you via a special code. I have a duty of care to discuss any serious concerns and/or risks related to your safety, or the safety of others during the interviews, with my research supervisors. I may need to take further action. I will inform you at the interview if I feel I need to discuss any concerns with my supervisors. If the information disclosed indicates a serious risk, we may need to break your confidentiality to safeguard you and contact relevant authorities, such as the Police.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part. If you decide to take part, you are still free to leave the study at any time and without giving a reason.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. You are asked to contact the main researcher up to two weeks following the interview to withdraw your consent. Even after you have given consent, you are free to leave the study at any time. You do not have to answer all the questions in the interview if you do not want to. If you begin an interview but change your mind, you do not have to continue or give a reason why you want to stop. If you withdraw from the study early, all your data will be securely erased. It is important to note that there are some limits on withdrawal of your data once the interviews have been conducted. You can email the researcher to remove your data from the study up to two weeks after the date of the interview. After two weeks, it will not be possible to withdraw your data from the study as data transcription will have been completed and analysis may start. If you withdraw from the study after the interview or at any time during the interview, you will still receive the shopping voucher. Vouchers will not be provided to participants who withdraw prior to the interview.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent.

The results of the study will be written up in a doctoral thesis. A copy will be stored at the University of Southampton. The findings may also be published in academic journals and/ or the findings presented at conferences. If you choose to, you will be emailed a summary of the study after it has been written up.

Where can I get more information?

You can contact the lead researcher for any further information regarding this study

Julia Domanska, Trainee Clinical Psychologist, E-mail: jzd1e16@soton.ac.uk

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

Julia Domanska, Trainee Clinical Psychologist, E-mail: jzd1e16@soton.ac.uk

Dr Judith Bruce-Golding, Senior Teaching Fellow in EMHP at the University of Southampton, e-mail: j.m.bruce-goldingsoton.ac.uk

Dr Melanie Hodkinson, Senior Teaching Fellow/Clinical Tutor at the University of Southampton, e-mail: m.j.hodkinson@soton.ac.uk

Dr Becky Ward, Teaching Fellow and Research Director at the Centre for Homelessness Research and Practice at the University of Southampton, e-mail: r.j.ward@soton.ac.uk

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Head of Research Ethics and Clinical Governance (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking time to read the information sheet and consider taking part in the research.

Appendix H Consent Form (Young Person)

CONSENT FORM (YOUNG PERSON)

Study Title: “Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families"

Ethics/ERGO number: 91849

Version and date: 1.1; 05.04.2024

Hey there! We're glad you're interested in our study. We want to make sure we do things the right way, so this form is all about asking if you're okay with joining our study. Take a look at the points below, and if you're ok with it, just put your initials and signature to show you're on board with being part of this research.

Please put your initials in these boxes if you agree with what's written.

I agree…	**Your Initials**
I read the Participant Information Sheet (Young Person) version 1.1, dated 05.04.2024 explaining the study and know what I need to do.	
I had the chance to ask questions and got all the answers I needed.	

I'm ok with being part of this study and know that the data collected is just for this research.	
I know I can choose to leave the study whenever I want without having to explain why.	

I understand…	**Your initials**
I know that to take part in this study I need to take five pictures showing what it is like for me to live with Long Covid and send the pictures to the main researcher. I agree for these pictures to be analysed by researchers and be summarised as a part of this research project.	
I agree for my pictures to be shown to others and be published if this could be helpful for others to see, e.g. on conferences, workshops, exhibitions or in a book.	
I know that my meeting on Microsoft Teams will be recorded on video, and I'm okay with that. The video will be deleted right after it's turned into text.	
If I decide to leave the study, I can ask for my information to be removed from the project within 2 weeks after I take part.	

I am happy…	**Your initials**

I feel ok to share with the researcher some basic health record to show that they can confirm my experience of Long Covid and I know this won’t be used anywhere.	

______________________________ ________________________ __________________

Name of participant **Signature** **Date**

______________________________ ________________________ __________________

Name of person taking consent **Signature** **Date**

Appendix I Consent Form (Parent)

CONSENT FORM (PARENT)

Study Title: “Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families"

Ethics/ERGO number: 91849

Version and date: 1.1; 05.04.2024

Thank you for your interest in helping with this study. It is very important to us to conduct our studies in line with ethics principles, and this Consent Form asks you to confirm if you agree for your child to take part in the above study. Please carefully consider the statements below and add your initials and signature only if you agree for your child to participate in this research and understand what this will mean for them and you.

Please add your initials to the boxes below if you agree with the statements:

Mandatory Consent Statements	**Participant Initials**
I confirm that I read the Participant Information Sheet (Parent) version 1.1 and/or the Participation Information Sheet (Young Person) version 1.1, dated 05.04.2024 explaining the study above and I understand what is expected of my child.	
I was given the opportunity to consider the information, ask questions about the study, and all my questions have been answered to my satisfaction.	

I agree for my child to take part in this study and understand that data collected during this research project will be used for the purpose of this study.	
I understand that my child's participation is voluntary and that they are free to withdraw from this study at any time without giving a reason.	

Additional Statements - please add your initials in the boxes below you to agree to:

Additional Consent Statements	**Participant Initials**
I understand that taking part in this study involves video recording. I am happy for my child's interview to be video recorded and understand that the video recording will be transcribed and deleted immediately once transcription is completed.	
I understand that I/they can withdraw data from the use in this study within 2 weeks following their participation.	

Child/Young Person Participation – Parent Consent Statements	**Participant Initials**
By providing my consent, I authorise my child to partake in this study. I understand that I will be asked to provide a confirmation of my child's health problem to confirm their eligibility for this project. I understand that my child will be required to capture five photographs using their mobile phone portraying their experience with Long Covid, which will be shared and analysed with the researcher and where appropriate for research purposes, may be shared more widely. Additionally, they will engage in an one-hour interview with the main researcher using Microsoft Teams, where a note taking programme will be used. Whilst every effort has been made to reduce the likelihood of causing distress to my child, it is acknowledged that discussions about health issues may occasionally lead to emotional upset.	

____________________	____________________	________________
Name of participant	**Signature**	**Date**
____________________	____________________	________________
Name of person taking consent	**Signature**	**Date**

Appendix J Debriefing Form (Young Person)

Debriefing Form (Young Person)

Study Title: "Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families"

Ethics/ERGO number: 91849

Researcher(s): Julia Domanska, Dr Judith Bruce-Golding, Dr Melanie Hodkinson, Dr Becky Ward

University email(s): jzd1e16@soton.ac.uk, m.j.hodkinson@soton.ac.uk, r.j.ward@soton.ac.uk

Version and date: Version 1.0; 25.02.2024

Hey there! Thanks for being part of our research project! Your help means a lot to us and we really appreciate it.

What's this study about

What we're trying to figure out is how Long Covid affects young people and families. We want to understand how it makes people feel and what kind of help could make things better.

Privacy

Don't worry, your information will be kept secret. We won't use your name or anything that would make others know who you are. Do you remember when we created your "nickname" when we met over the Teams? This is what will be used in the report.

Study results

If you want to know what we find out from our interviews, just drop a message to our main researcher Julia Domanska at jzd1e16@soton.ac.uk. She'll send you a summary of the results when we're done.

Thanks again for being awesome!

Where can I find more information and help?

Sometimes talking about ill health can be upsetting. This is understandable and normal. It may be good to talk to people you trust, read things that can help, or get professional help from your GP. Here is a list of some places that may be good to check out:

Organisation	Contact Details
GP	Please contact your GP if you are not feeling good.
111	The NHS 111 number (option 2) is available 24 hours / 7 days a week for more pressing issues and help.
MIND - charity providing mental health support	Call Infoline for information for further support: 0300 123 3393 or email: info@mind.org.uk

	MIND Website has links to further resources for emotional support: https://www.mind.org.uk/information-support/
Long Covid Kids	For information around Long Covid & support you can check this organisation: Children & Young People | Long Covid Kids
Your COVID Recovery	Here you can find more info on COVID and getting better: - Children and young people with COVID - Your COVID Recovery
Aneurin Bevan University Health Board	This is a good recovery guide for people with experienced of Long Covid: abuhb.nhs.wales/files/mental-health/paediatric-psychology/recovery-from-illness-top-tips/
SAMARITANS - charity providing mental health support	Call 116 123 to talk to Samaritans or email jo@samaritans.org for a private talk with someone.
PAPYRUS -charity providing mental health support	PAPYRUS helps young people who may be feeling in crisis. Call 0800 068 41 41 for support if you are under the age of 35. www.papyrus-uk.org
NHS Talking Therapies Service	From age 16 you can refer to local talking therapies services. https://www.nhs.uk/service-search/mental-health/find-an-NHStalking-therapies-service/
NHS Every Mind Matters	There are some self-help resources and well-being information on the NHS Every Mind Matters website: https://www.nhs.uk/every-mindmatters

Appendix K Debriefing Form (Parent)

Debriefing Form (Parent)

Study Title: "Navigating Long COVID: A Qualitative Exploration of the Emotional and Psychological Impact on Young People and Their Families"

Ethics/ERGO number: 91849

Researcher(s): Julia Domanska, Dr Judith Bruce-Golding, Dr Melanie Hodkinson, Dr Becky Ward

University email(s): jzd1e16@soton.ac.uk, m.j.hodkinson@soton.ac.uk, r.j.ward@soton.ac.uk

Version and date: Version 1.0; 25.02.2024

Thank you for taking part in our research project. Your contribution is very valuable and greatly appreciated.

Purpose of the study

The aim of this research was to explore experiences of children, young people and families with experience of Long Covid and to develop an understanding about how Long Covid impacts on people's well-being and what psychological help could be helpful.

It is expected that living with Long Covid will impact on people's emotional and mental well-being. Your data will help our understanding of what the impact of Long Covid is on people's lives and what psychological help would be most beneficial.

Confidentiality

Results of this study will not include your name or any other identifying characteristics.

Study results

If you would like to receive a copy of the summary of the research findings when it is completed, please let us know by contacting the main researcher Julia Domanska at jzd1e16@soton.ac.uk

Further support

If taking part in this study has caused you discomfort or distress, you can contact the following organisations for support:

Organisation	Contact Details
GP	Please contact your GP if you are experiencing distress.
111	The NHS 111 number (option 2) is available 24 hours / 7 days a week for urgent mental health support/ referral to local crisis teams.
MIND - charity providing mental health support	Call Infoline for information and signposting for further support 9am to 6pm Monday to Friday on: 0300 123 3393 or email: info@mind.org.uk MIND Website has links to further resources for emotional support: https://www.mind.org.uk/information-support/
Long Covid Kids	For information & support visit the website: Children & Young People | Long Covid Kids
Your COVID Recovery	Information and resources on COVID: - Children and young people with COVID - Your COVID Recovery
Aneurin Bevan University Health Board	Getting better after illness guide abuhb.nhs.wales/files/mental-health/paediatric-psychology/recovery-from-illness-top-tips/
SAMARITANS - charity providing mental health support	Call 116 123 to talk to Samaritans or email jo@samaritans.org for a reply within 24 hours www.samaritans.org
SHOUT - charity providing mental health support	Text SHOUT to 85258 to contact the SHOUT Crisis Text Line. SHOUT also provide 24/7 text support for

	emergency services staff. You can text BLUELIGHT to 85258 to speak to a trained crisis volunteer. Website: https://giveusashout.org
PAPYRUS -charity providing mental health support	Call 0800 068 41 41 for support if you are under the age of 35. www.papyrus-uk.org
NHS Talking Therapies Service	Self-referral information is available here for longer-term support in your local area: https://www.nhs.uk/service-search/mental-health/find-an-NHStalking-therapies-service/
NHS Every Mind Matters	There are self-help resources and well-being information on the NHS Every Mind Matters website: https://www.nhs.uk/every-mindmatters

Further reading

If you would like to learn more about this area of research, you can refer to the following resources:

Goodridge, D., Lowe, T. N., Cai, S., Herriot, F. N., Silverberg, R. V., Heynen, M., Hall, K. C., Peters, J., Butcher, S., & Oyedokun, T. (2023). "We're drowning and we're alone": a qualitative study of the lived experience of people experiencing persistent post-COVID-19 symptoms. CMAJ Open, 11(3), E504–E515. doi: 10.9778/cmajo.20220205

“We're drowning and we're alone”: a qualitative study of the lived experience of people experiencing persistent post-COVID-19 symptoms - PMC (nih.gov)

Further information

If you have any concerns or questions about this study, please contact Julia Domanska at jzd1e16@soton.ac.uk who will do their best to help.

If you remain unhappy or would like to make a formal complaint, please contact the Head of Research Integrity and Governance, University of Southampton, by emailing:

rgoinfo@soton.ac.uk, or calling: + 44 2380 595058. Please quote the Ethics/ERGO number which can be found at the top of this form. Please note that if you participated in an anonymous survey, by making a complaint, you might be no longer anonymous.

Thank you again for your participation in this research.

Appendix L Interview guide (Young Person)

Opening statement

Hey, thanks for being part of this study!

Before we start, I just want to remind you of a few things. Our chat will be recorded on Microsoft Teams, but don't worry, only me and my research team will listen to it, and we'll delete it once we've written everything down. As I mentioned in the letter I sent you, we're going to talk about your experiences with Long COVID, which can be tough. If it gets too much, just tell me, and we can take a break or stop and talk another time. You can tell me as much or as little as you're comfortable with.

With all this in mind, are you still okay with being part of this research and having our chat recorded? (*Gain verbal consent)*

Setting interview & Padlet

Let me first send you a link to Padlet that we will be using throughout. Have you got any experience using Padlet? Let me show you how it works *(send the email link and shows the platform)*.

Here is a quick reminder of what this study is about and who the researchers are *(shows the quick reminder about the study and procedure of the study and & introduces the team using Padlet*)

Photo based interview

Here we can see five pictures you sent me earlier *(shows photographs displayed in Padlet).* The idea was to show what your life looks like with “Long COVID”. Thank you so much for sharing this with me, that’s great. I wonder whether you could tell me more about these pictures.

What can we see here?
What made you decide to choose these photo shoots? (Anything that has inspired you?)
What does it feel like looking at these pictures?
What did it feel like taking these photos?

How was it for you taking these pictures? (Anything helped? Anything that was difficult?)
Have you had any strategy when choosing these pictures?
Is there anything else that fits with the theme of your "Life with LONG COVID" that we can't see here? What would this photo look like?

Continuation - Interview Guide

Can you tell me about your experience of being diagnosed with Long COVID? What was your experience with doctors?

What has changed in your life since Long COVID?? (e.g. school, hobbies, friendships)?

What does it look like when you have a good day and coping well?

Is there anything that help you feel better?

What does it look like when you are not doing well?

Is there anything that makes you feel worse?

What do you need right now that you don't currently have?

What is your experience of other people reactions to your difficulties?

What has it been like with your education?

In what ways do the people/services around you help you to understand and cope with your health problems?

What would you like others to know about living with Long COVID?

Is there anything else you want to say that we haven't talked about?

Closing statement

Thanks for talking to me today. Before we finish, is there anything else you want to tell me? If you ever feel really down, you can get always get help from Papyrus and other organisations that I have put together in the document I have sent you. Also, if you want updates on the research, I am happy to share them once we have finished the project. Thanks again!

Appendix M Interview Guide (Parent)

Opening Statement

Thank you for taking part in this study. Before we start, I just want to remind you of a few things. I will be recording our conversation on the Microsoft Teams. As mentioned in the letter I sent you, we will discuss your experiences of caring for someone with Long Covid and this can be at times difficult to talk about. If this is a case, please let me know and we can take a break or stop and rearrange the interview. You are invited to share as much with me as you feel comfortable to do.

With all this in mind, are you still happy to take part in this research and have our conversation recorded? *(Gain verbal consent)*

Interview Guide

How has caring for your child with Long Covid impacted your daily life and routine?

How experiences of Long Covid affected your parenting style, if at all?

What are the biggest challenges you face in supporting your child's needs?

What kind of support do you feel is most helpful for you and your child?

How do you navigate the healthcare and educational systems to ensure your child receives the best care and support?

What are your hopes and concerns for your child's future?

How do you take care of your own well-being while caring for your child?

What would you like others to know about living with Long COVID?

Do you have anything you would like to share that we didn't discuss?

Closing Statement

Thank you for participating in this interview and sharing your experiences with me. Is there anything you would like to share with me before we end today's interview? If you find yourself feeling distressed you can access support organisations I have listed in the debrief form. We plan for that this research to be completed in 2025, if you would like to receive updates please let me know.

Appendix N Reflexive thematic analysis process

Thematic analysis step	Description
Step 1: familiarisation with the data	Researcher viewed and read all transcriptions completed from the interviews at least a couple of times, familiarising themselves with the content and highlighting ideas and areas discussed during interviews that answer the research question looking for similarities and differences in the data. Completed reflective journal highlighting the key ideas.
Step 2: generation of codes	Researcher viewed all transcripts and manually through the use of NVivo software and paper notes used inductive approach to identify concise descriptions of appearing ideas (codes). Researcher reviewed all wide range of codes, identifying codes which appeared across the data. Attended an interest group for research conducting qualitative health research, maintaining a reflexive approach to work.
Step 3: identifying themes	Researcher reflected on the main codes appearing across the data and grouped them into distinctive themes; identifying the four themes and subthemes resulting from the codes, based on their frequency, distinctiveness and similarity.
Step 4: reviewing themes and creating a summary table	All codes, subthemes and themes were reviewed and combined in the summary table.
Step 5: defining and naming themes	All themes and subthemes were describing what each theme means, and integrated in

	pictorial representation highlighting experiences of young people with Long COVID and their parents.
Step 6: presenting the research findings	This step involved producing the paper which highlighted the research findings explaining how the themes relate to the research questions and the research literature.

Appendix O

Appendix O

Transcripts excerpts – interview with Maria (mum)	Initial thoughts/reflections	Code
53-67 And you know, I'm concerned. So he sort of said, (umm) he wasn't sure that, the GP wasn't sure themselves. We were back and forth of the GP's a lot. So we saw one GP that said is post viral (umm) fatigue or something and somebody else said needed emergency bloods, but I couldn't get in, (umm) like 2 weeks later, I couldn't get in, so that wasn't really emergency blood. So they weren't sure what they were looking for or what was going on. And… to be honest, they didn't really believe me that was to do with the vaccine.	Understandable anxiety in the family/mum which arise from concerning symptoms, that couldn't be easily understood. It required some initial advocating and chasing in order to reach the right help. There is an element of disbelief due to context in which the illness started.	Anxious mother Asking for help
90-100 So he got the referral and it's like a big MDT meeting. We'll do it a couple of months, I think and it's where MDT meeting where we had the consultant and I think we had the physio and OT that were meant to be there. And psychology team described his symptoms and everything, said oh, not to worry, children tend to recovery, so we took it from there really.	Long COVID requires multiagency involvement.	Asking for help
106- 117	It's important to see that young person had a useful advice	Access Adaptations

And they just sat with him and they discussed things how to make things easy for him, like pacing yourself and etcetera. They also were very good in the sense that went into his school and had a meeting with a year head, (umm) try to make things easy for him, because at the school had a lift so, you know, if he can use the lift, let him a lift Pass and talked about reduction of his timetable, which we did do.	allowing them to structure their lives and think about adaptations they require to lead a fulfilling live.	Pacing
152-156 We got permission from the school where you could attend the actual exam, but I can bring him home and not stay in school because it would have tired him out.	The level of tiredness described by Maria shows that many daily activities wouldn't be possible for her son.	Loss Adaptations Rarely made it through a day
157-160 But in the middle of the missed all of this, we got the attendance officer because it's attendance was really low even though	One of topics that was mentioned in other interviews, some parents felt threatened by schools and attendance officers. It shows that there has been lack of understanding and perhaps inflexible structures in place, which although had good intentions in ensuring young people attend school, in this case, have been harmful.	Lack of understanding
168-171	Emotional reactions seem to be understandable given stressful	Anxious mother

I still have to go to a meeting at school and I did break down then I was quite cross as well	context. Here, Maria talks about her frustrations related to school meetings.	
181-189 it's a struggle for him to stay because for example, I’ll take him at 9:00 after waking up and struggling to get up and have to dress him to get him into school. You get there about 9:00, half nine have to go pick him up. But the attendant officer couldn't quite understand.	Maria’s son required quite a lot of her involvement in order to be able to meet his daily routines. She described in a lot of detail, how they structure their days and actions she needs to undertake to support him. It shows that her son’s independence was affected by Long COVID and he required different adaptations, which haven’t been always well received by others.	Lack of independence Lack of understanding Adaptations
289-291 They're checking him out on that. So the people are there and he's on various waiting list	Maria talked about her son’s condition developing and different symptoms that were emerging and were investigated through different professionals. At this point, it was unclear whether it was all Long COVID-related.	Constantly changing

318-322 So that sounds is good, and he started college this week. So, umm, he's in bed now he's shattered. But umm, has to retake his GCSE's because he got two and he's very disappointed.	The reality if of failing GSCE shows the broken young people's dreams and hopes; especially as for this young person, academic performance was important. It also links with cognitive/memory issues described by Maria, and symptoms identified within Long COVID.	Broken young people hopes Cognitive issues
346-352 Cause he is so young and he won't, umm, he struggles sometimes to walk and he doesn't want any walking aids or anything 'cause it's, you know, 17 and he.. But he... I asked him yesterday, does he see himself disabled?	That's really meaningful conversation that Maria had with her son. It shows that she has been attuned to his struggles and wanted to understand his perception of disability. It highlights issues of being incapable of doing something and affect on his independence.	Lack of independence Incapable Access
480-483 I can't walk a little bit. I can't do this. I can't do that, I said you are allowed to cry and be upset of what you've you know, at the minute what you've lost.	Maria named experiences of her son, where he is unable to do things he wishes to do. It shows devastation he could be experiencing, but also his broken dreams.	Devastation Broken young people hopes

511-514 But then I have to give him his tablets in bed because he can't sit and it's in a glass in a straw, it never used to be that.	Maria talks about evolving nature of Long COVID and changes they have to make to accommodate changing needs of her son.	Lack of independence Constantly changing
522-527 so I have to do that and then and then I just then I go. We've got sort of like a middle routines sort of thing, so I give him his meds and I go lay there for a minute. I'll be back in a minute, like in a couple of minutes.	Maria although gracefully recognised her role as a carer for her 17-years old son.	So, I am a carer
667-670 I probably won't have had as much maybe then I have now, but I'd rather him being out and about then be at home	Here, she has highlighted how her son's hasn't been able to follow a normal path for teenagers, and is restricted in things he can do	Broken family expectations
676-680 Running in different way and I think I worry I worry more. But I've had to tell myself to step back because some of the stuff is… some of the stuff he'll do is a teenager stuff…	Maria talked about some worries related to being a mother of growing teenager, but also anxiety related to him having Long COVID.	Anxious mother
1001-1003 Well tried again for educational healthcare plan, but umm they said no.	Maria recognised a need for adaptations and thought EHCP plan could support him in accessing education more.	EHCP Adaptations

1059-1061 I will try and get if he can get personal independent payment for him	Here, Maria was again thinking about adaptations and ways to enable her son; here she was considering PIP plan, thinking about his future and means that he might require to function more effectively	Financial aspect
1068-1071 We'll try that and then you can have a blue badge which will help you put other stuff as well.	Maria talked about the role of a blue badge in her own life as someone with experience of long-term condition, and saw a role of how this adjustment could make her son's life easier	Access Incapable
1168-1172 But I think sometimes I don't know because he looks outwardly, obviously because it's hidden, isn't it? He looks fine. I think he's only 17. He'll get better. And he hasn't.	This highlights an issue with Long COVID as an invisible illness, that's hard to understand and can be invalidated due to its invisible character.	Looks fine
1205-1209 I think that's good, but I think I'll be me personally, I'll be a mess. I'll be worried (laughs). I'll be thinking, is he up? [Inaudible]	Maria here talks about her anxiety which is an understandable reaction of a parent thinking about her child moving out the house; however in her situation, she has	Anxious mother

	additional concerns to consider given the impact of Long COVID on her son	
1235-1248 And he gave, umm, like he gave us consent for his GP, written consent for myself and husband to contact the GP if we need, you know, for appointments and stuff like that because. He's so exhausted, he probably won't be able to do. R: Yeah. P: And then, because he has brain fog, he won't remember. But he's.	Maria and her husband appear to be very caring and supporting parents, providing their son with help that they may require in order to keep up with their appointments. It also highlights difficulty with managing independence by their son and their memory issues in remembering about their appointments.	Cognitive issues Lack of independence
1346-1351 he worries more about me then cause couple of times with the first time with the psychology session he went I think my mum needs counselling. Think she needs? I said look, I’m fine.	It appears as Maria’s son recognised the impact of ill health on her mother’s anxiety too.	Anxious mother
1428-1433 Initially, I think people didn't quite get it because, umm, they say, oh if he just rests he’ll be he’ll be okay. And, umm, and him forgetting things, I think they say always but he's, you know, he's young.	Maria talks about invalidating experiences and lack of understanding in others, who may not appreciate the full impact of Long COVID on her son.	Looks fine Lack of understanding

1515-1520 So we used to say, oh, we can't do this and, umm, I think cause she's a teacher, teach.. well the next English teacher thing. I think this teacher's mentality. And I went. No, we can't. He can't do this.	Maria talks about the need for educating others, and making them understand how Long COVID affects her son.	Lack of understanding
1564-1570 But in the mornings I do it, but it's just that, saying actually this is a normal, you know, I shouldn't be caring for 17 doing this sort of stuff and dressing him because I said to him… you know I made a joke about I shouldn't be dressing you anymore.	Maria although gracefully attend to her son's needs, recognised that developmentally he should be able to care with daily routines for himself, perhaps despite joking about it, experiencing some level of disappointment.	Disappointing motherhood
1643-1647 … COVID has disappeared. Sort or it hasn't and I think, but no one's thinking about millions of people that have been affected and that lives of change. But no one talks about it.	Long COVID has been not spoken about, and many people who are left to experience Long COVID can feel isolated and marginalised.	COVID is not over

Transcripts excerpts – interview with Owley (young person)	Initial thoughts/reflections	Code
35-43 Researcher: Hmm. And have you found this process of I guess getting diagnosed kind of helpful in making sense of that experience at all? Participant: Yes, because now if I'm asked, rather than explaining a vague set of symptoms, I can sort of give a more accurate idea of what I struggle with.	Owley touches on important issue of getting diagnosed and having a chance to explain their experiences to others. Owley recognised that he has been experiencing a vague set of symptoms, that could be misunderstood and invalidated, if left without the context. Long COVID or other invisible illness, can be hard to understand.	Difficult to understand
89-93 I think initially I had missed a couple months of school because I just wasn't able to move and whenever I tried to go in to school, I'd be wiped out for like 2 weeks.	Here he talks about the severity of Long COVID and the impact it has been having on him and his life. It shows how severe the condition can affect people's lives, leaving them incapable to attend to their daily activities and losing on some opportunities to be active.	Loss Incapable
141-144 See if you haven't experienced long COVID, it's harder for you to fully grasp what it is like; it's like with anything.	Long COVID, perhaps similarly to other conditions, can be difficult to understand without the first hand experience, that's why discussions like this, add value and are	Difficult to understand

	important representation of what the lived experience of condition looks like.	
171-177 I think it's a very variable illness. I think the thing people grasp is being tired and being in pain but I think the thing that most people struggle with, if you haven't experienced is the amount of pain or fatigue that you experience.	While pain or tiredness are experiences that are relatable, Owley makes a point, that Long COVID's experiences vary in severity and can be hard to capture.	Difficult to understand Constantly changing
184-203 I can't walk very far, or very quickly. I'm not showing up at school meant I didn't see my friends very often, so by the time school ended basically, I didn't really speak to them very much and now I don't really have much contact with them. So in a way, it kind of caused me to lose a lot of my people who I thought were very good friends. And also as a result of missing a lot of school, I failed most of my GCSE as well. And I wasn't a particularly active person but I did like running and moving around a lot because of I got energy and stuff like that. But now I can't really do much of that, I used to walk around my garden a lot and yeah, my main thing was that I liked running, but now I can't really do that.	Owley lists a number of things he has lost and been unable to do as a result of Long COVID. It's sad to hear the constraints that young people can be experiencing in response to this debilitating condition, and how much losses they encounter.	Loss Broken young people hopes
258-262 … learning to pace myself and understand my pain and fatigue makes it so that I can do the best I can with what I've been given.	Owley talks about need for adaptations, learning about his abilities and limitations, which appear critical for good management of any long term health condition.	Adaptations
305-310	It's great to hear about the progress Owley has made, and it is very important to hear those	COVID is not over Loss

I think that long COVID never goes away, I don't think I'll ever be back to what I was before, but I think I could get to maybe 50% with a lot of work and effort because I've definitely made progress and to get from that 3 to 5% to the 20%	positive. Of course, Owley recognised that he doesn't believe he will reach his previous levels, which is a bitter sweet reflection on his progress.	
328-336 And so having to learn to constantly think about every action I'm doing and what how it all affect me takes a lot of effort of constantly doing something and not thinking about it and then feeling the consequences and having to learn it again and just doing that over and over again.	Owley speaks about the constant need for reviewing and noticing how he is doing, and thinking about potential consequences. Here, it appears important that he has been able to learn about pacing that he is able to practice.	Pacing
378-382 Yeah, like we said earlier, with long COVID, it's very variable between people and then in people themselves, it's also constantly changing. It does feel random.	Interesting that Owley described Long COVID changes as random. Based on his description, Long COVID is evolving and constantly changing, and although he didn't go into mentioning how his symptoms evolved over the time, other people spoke about their condition changing quite a lot.	Constantly changing Difficult to understand
441-454 I find that because you're tired and everything you do makes you tired and in pain, it's hard to find the motivation to keep going because you think, oh, there's no point in trying because, I'm just going to end up being tired in pain anyway by the end of it and progress is very slow.	While Owley presented as generally very hopeful, and motivated person focused on his progress, there were moments, which highlighted the devastating nature of the condition.	Devastation
502-504	Owley spoke about adaptations that he welcomed in his life; one of which was a lift	Access

I have a lift pass and there are lifts that I don't have to go down steps, except for on fire drills	pass that enabled him to avoid walking up and down the stairs.	
509-515 Even sitting can be tiring when you have long COVID, because it's just the situation you're in and also being sat up is surprisingly tiring because you're putting a lot of, I guess, energy into holding your body upwards	Long COVID can be draining for people experiencing it, despite not being active. Even, passive sitting can be exhausting as what Owley, described, holding body upwards can be a challenging task. Here, Owley highlighted once again the need for pacing and for understanding ones' limitations and finding ways to have meaningful breaks.	Pacing
546-550 but a lot of the time I do just sit there and think, oh, I don't want to anymore, I'm tired and it hurts, I want to not bother anymore but I'm not particularly sure what keeps me going	Owley painted a picture of pain and tiredness he has been experiencing, showing the devastating nature of Long COVID.	Devastation
605-612 but they don't fully understand it and I don't use any aids like walking sticks or frames or wheelchair so people don't notice it until I tell them. So they don't think about how fast they're walking or if they go down the stairs, I have to leave them and just sit and wait for a lift	Here, he discussed the reality of invisible illness that can be hard to understand for those who don't know the reality of living with it. A lot of experiences can go unnoticed, if they are not shared.	Difficult to understand Looks fine
645-652 Just sort of the little things that you don't they take for granted when you're able bodied, I would like them back.	It can be easy to assume things, when able-bodied, forgetting how much effort it can cost someone to participate in some activities, and	Broken young people hope

	appreciating potential consequences the impact of them can have on someone.	
678-689 I think at my at my secondary school, you had to have a sit down meeting with the attendance officer and tell him that I physically can't and you can't expect me to be in as much as I was before because I'm I have no control over whether I can come in as much. And you have to really hammer in because I think they underestimate how bad it can be, and then again when I went to a place to do my retakes, I had to tell them, “I can't”.	School can be challenging for people who don’t suffer from long-term health conditions; due to pressures and expectations from the educational system; however understandably for someone with health problems, it can be particularly challenging. Here, Owley spoke about the issue of attendance, which seem to be a problem for many children with Long COVID and how it can be misunderstood by attendance officers.	Lack of understanding Loss
692-694 so I find that you have to really for people with power, you have to really explain it to them.	The power imbalance can make it difficult to advocate for marginalised individuals and groups, who are not being attended to. Owley raised an important issue, about need for those holding power to have more understanding and for taking an active stance in explaining the situation to them	You have to fight for
697-699 I think some people might think that you're playing it up to some degree as well.	With lack of understanding, some people may be more prone to judge, and invalidate experiences.	Being judged

746-752 so I think a lot of those in power can marginalise, because either they're can't be bothered to accommodate because it's a lot of effort to accommodate for small things that are small for them, but not small for us.	Again, he raised an issue of advocacy and changes that are required to accommodate people with various needs.	You have to fight for
859-865 I would say mainly it's like GPS and people like I saw a neurologist as well so those kind of ones where they look for symptoms and stuff like specific signs and things like that, I think them the most likely to dismiss it	Some issues raised regarding professionals, involved not having enough training or understanding, or simply following the textbook, and not listening to people with lived experiences	Not being heard
883-890 It's harder than it look, and just because we don't show, because you can't see it physically it doesn't mean we are not ill. We are still ill and we are really trying anything we do, we have to try much harder than the average person and please be a bit more receptive.	Despite looking fine, and "normal" Owley like others with invisible illness, can struggle a lot, and would appreciated being recognised for his efforts.	Difficult to understand Looks fine
910-913 The only time you can see my long COVID physically is if I'd stumble or have to cling onto a rail or something like that.	There aren't many visual representations of the impact of Long COVID in how Owley experiences it; but there are those moments he identified, when perhaps others could notice. There are times when he might be less capable to do things, other teenagers can do easily.	Incapable
937-940	Research shows that a percentage of people with COVID will develop persisting	COVID is not over

Cause there's not many of us. There's more than people think, but out of the general population was still a small group.	symptoms; but like Owley said, it's still a relatively small group and perhaps with that in mind, and with the lack of public awareness, many would not appreciate that these experiences continue to affect people and that while many don't think about COVID anymore, for some COVID-related issues continue to exist.	
965-966 I think with mine, with my illness, there's a certain tragedy	The circumstances in which Owley developed his illness, and lack of control he had felt, has meant he felt some level of tragedy, and devastation around his circumstances	Devastation
1011-1015 Yeah, because this was, it's sort of the age [15] where like you at your physical prime and I never got the chance to experience that. As a result, I never got the chance to do a lot of…	It's saddening to think about losses he encountered; and many other young people experienced.	Loss
1018-1027 But because I never got the chance to really go out and do stuff with friends or just on a whim, go out to a shop or something and there's a probably experiences I'll never get back again, because when I'm when I am able to do them, I won't be the same age as when you sort of have a different mind about it, if that makes sense.	It shows how critically important are some experiences are for one's development. With the time passing, Owley won't be able to catch missed opportunities, and perhaps he might have regrets in the future	Loss Broken young people's hope

1051-1052 And I never got those experiences, that I probably would have benefited from.	Long COVID impacted on Owley ability to engage in various activities, which other of his colleagues have been able to participate in. This is understandably saddening and important to recognise in understanding how this condition affects young people.	Loss

Appendix P Reflective journal – excerpts

October 2023

Expert by experience discussion

It was interesting to reflect on the reactions of others in response to Long COVID. Anna (name changed) noted that people tend to be sympathetic during the first few weeks; however, as time goes on, there is a general expectation that you should recover. This expectation can particularly affect young people, as assumptions are often made about their health, youth, and energy.

“You are young and healthy; you should be fit within a couple of weeks.”

Anna reflected on what happens if you do not get better. If you are not meeting these expectations, not recovering, and not feeling like you are improving, it can lead to a sense of shame, stigma, and guilt.

“If you feel pain or fatigue, what does it say about you?”

The range of symptoms people can experience is broad, which can make diagnosis and treatment challenging:

“My energy levels, fatigue, and my ability to process information were affected.”

The changing landscape around COVID-19 - with less media coverage and less interest or investment in this condition - has also had an impact, leaving people feeling left out.

“You feel pressure - more pressure - to get on with life because everyone else is.”

Anna described her experience as confusing, especially when you are supposed to be getting better after a period of illness, yet continue to question yourself:

“I couldn’t trust myself to rely on my resilience.”

It made me wonder about potential hypotheses to explore in my interviews; including how is living with Covid-19 affecting young people’s mental and emotional wellbeing, peer relationships and identity development? How cultural and societal expectations are impacting on the experiences of living with Long Covid in young people. How living with Long Covid is contributing to the development of shame and stigma amongst young people.

August 2024

Experts by Experience discussion

When discussing the idea of taking photographs to portray life with Long COVID, Anna and John found it challenging. They were unsure what kinds of images would help them make sense of their experiences and felt overwhelmed by the choices. Anna decided to photograph a broken cable to symbolise how broken and exhausted she felt. Another chose a picture of a calendar, feeling it represented how time seemed to have stopped for them. Family suggested that, in future projects, providing examples of possible photo subjects—such as feelings of happiness, sunshine, or everyday objects—could help participants get started. They also discussed the difficulty of engaging with lengthy advertisements or information due to brain fog. It was agreed that simplifying recruitment materials and creating shorter, parent-focused adverts would be beneficial.

Family described the early days of Long COVID as frightening and confusing, saying, “We didn’t know what was happening.” At first, there was little understanding or support, and unhelpful suggestions like “it’s all in your head, just exercise and go back to school” were common. Receiving a formal diagnosis and more information brought relief. The journey often included visits to the GP, thyroid tests, discussions about depression, and limited access to specialists, as no dedicated clinics existed at the time. After about six months, some were referred to a Fatigue Clinic, where, for the first time, they felt heard and reassured: “You will get better.” The uncertainty was one of the hardest aspects to cope with.

They described their lives as being “on hold.” Activities that were once enjoyable became impossible, and daily routines revolved around conserving energy and resting. They withdrew from social media, finding it unhelpful. Activities that provided comfort included seeing friends, spending time with pets, engaging in crafts like crochet, and enjoying warmer weather. Unhelpful comments, such as “They’re typical teenagers” or “Just push through it,” were common. Family often felt they had to fight to be believed, expending precious energy to advocate for themselves and adjust to a new “normal.”

August 2024

Reflections on recruitment

Reaching out to families has been challenging. What has proven most effective is collaborating with non-profit organizations and leveraging word of mouth from those with lived experience—these connections have enabled the study to reach individuals directly affected by Long COVID. Previous strategies, such as using social media more broadly or contacting schools, were largely unsuccessful. I wonder if families dealing with severe symptoms become marginalised within mainstream channels, possibly because they must conserve their limited energy and be selective about the initiatives they participate in.

When speaking with parents about involving their children in research, it becomes clear that symptoms like brain fog and low energy make participation extremely difficult, if not impossible. Families report that their children are often completely out of education, or, if they are able to access education, it is in a very limited form—such as just two hours per week of tailored, adapted home schooling, which itself presents significant challenges.

While people generally express a willingness to engage, the realities of living with Long COVID are often too demanding. From my perspective as a researcher, it is difficult to accommodate these needs, as the usual practical adaptations and support mechanisms do not seem sufficient for this population.

September 2024

Listening to stories of people with Lived Experience during Paediatric Long Covid: Call for research, Kid's experience, parents and caretakers organised by Long COVID Moonshot (Twitter)

Previously, discussing COVID often resulted in "blank looks," as many people seemed unfamiliar or dismissive of its ongoing impact. However, this appears to be changing, especially with recent spikes in COVID cases and increased challenges with school attendance across many households. Non-governmental organizations (NGOs) such as Long COVID Families and Long COVID Kids now provide valuable advice and resources to help families and parents navigate the education system. While everyone has the right to free and safe education, accessing this right can still be difficult for those affected by Long COVID.

Individuals living with Long COVID frequently report symptoms such as brain fog and difficulties with working memory. Despite their best efforts to engage in conversations and daily activities, these cognitive challenges can make participation exhausting. There is widespread appreciation for advocacy efforts that raise awareness about Long COVID and help connect people to support.

Navigating the education system remains a significant hurdle. For example, certificates of attendance are often celebrated as “badges of honour,” reinforcing a culture of presenteeism. This practice can inadvertently penalise students who face health challenges, adding to feelings of shame and stigma associated with chronic illness. Schools are under pressure to reduce absenteeism, which is often linked to funding, further complicating the situation for students with Long COVID.

There are also ongoing debates within some governing bodies about the legitimacy of Long COVID, despite increased awareness efforts such as Paediatric Awareness Week. While some people struggle with the Long COVID label, others face related diagnoses like POTS or ME/CFS, which also carry stigma and misunderstanding.

These challenges reflect deeper societal problems, such as ableism and the marginalization of those with chronic illnesses. Cultural expectations around productivity and a lack of recognition for the need to rest contribute to these issues. The COVID pandemic and growing recognition of Long COVID present an opportunity for broader reflection on ableism and the persistent marginalization of people with disabilities.

There have been some positive policy developments. For instance, the Biden administration in the United States has officially recognised Long COVID as a disability, which has implications for disability law in schools. However, practical challenges remain, such as the expectation that symptoms must persist for 12 months to qualify for support, even as routine testing has declined.

Advocacy efforts are taking place at multiple levels. Some individuals focus on grassroots, local-level advocacy, which has led to meaningful changes in their communities. Others are working to influence government policies and decision-makers from the top down. Both approaches are essential for driving systemic change and ensuring that the needs of those living with Long COVID are recognised and addressed.

September 2024

Interview with Maria

It was a pleasure to speak with Maria. Her gentle and thoughtful manner brought to life her experiences as the parent of a 17-year-old son living with Long COVID. Maria conveyed the daily struggles of managing a chronic illness, yet she also highlighted her son's abilities and strengths, maintaining a hopeful and future-oriented perspective.

Maria expressed deep gratitude for the support she and her son have received from professionals, while also acknowledging the significant challenges they have faced along the way. Her reflections resonated with my own experiences as a healthcare professional working in paediatric services and supporting families managing long-term health conditions.

One particularly meaningful moment Maria shared was a recent conversation with her son about the meaning of disability. This intimate parent-child exchange illustrated the realities of living with a long-term health condition—recognizing one's limitations while still appreciating life's possibilities. It prompted me to reflect on what it means to acknowledge a disability, especially at a young age, and to consider the social model of disability, which emphasises that it is often societal attitudes and barriers, rather than individual differences, that create disability. I also wondered about the potential impact of these experiences on a young person's developing identity.

Maria's own experience with a long-term condition has given her a unique perspective, enabling her to look beyond illness and envision a positive future for her son as well. Her story underscored the importance of parents being heard, listened to, and believed. It left me reflecting on our professional attitudes and responses to families' concerns, and reinforced the need for open-mindedness and empathy in healthcare.

Interview with Owly

Owly, presented as a confident, well-spoken and very considerate 17-years old male, who talked about his experiences in a way that made me feel hopeful for him. He was aware of challenges but also hopeful looking at his recent progress and changes that were taking place, allowing him to reconnect with his interests and educational aspirations.

Interview with Helen

Helen brought a wealth of experience to our conversation—not only as a mother and carer for two children with additional needs (one with Long COVID and another with autism), but also as a professional familiar with navigating the healthcare system. Her knowledge and understanding of support pathways enabled her to effectively advocate for her children and secure the help they needed. Helen acknowledged the privileges that allowed her to access private treatments and manage the competing demands of her family, recognizing how these advantages made a significant difference in her ability to support her children.

Both Helen and I agreed that a parent's ability to engage with services and advocate for their child is often crucial in accessing appropriate support. However, not all families have the same resources or knowledge, highlighting an important area of inequality.

A recurring theme in our conversation was loss—missed holidays, special occasions, and hopes for the future. These losses brought raw emotions to the surface, underscoring the profound impact of living with a limiting illness and the things that are so easily taken for granted. Despite these challenges, Helen held onto hope that, in the long term, things would improve and her child would have the opportunity to build greater independence.

We also reflected on how chronic physical health issues can affect young people's confidence—not just in their bodies, but in their ability to interact with others, try new things, and give themselves permission to make mistakes. We wondered whether a loss of confidence in one's body might ultimately lead to a broader loss of self-confidence, affecting social skills and self-esteem.

Interview with Karen

The resilience, strength, and resourcefulness of parents caring for children with Long COVID have far surpassed my expectations when I began this study, leaving me genuinely humbled. My meeting with Karen—a passionate, determined, and fiercely devoted mother—truly exemplified the themes emerging from my interviews: the extraordinary power of motherhood and the almost superhuman determination to forge a path forward for their children.

Karen was exceptionally well-informed and had done extensive research, drawing from her own firsthand experiences. She was prepared to fight for her child's needs, and even during our conversation, she was emotionally processing the years of advocacy—naming both her victories and her defeats, and allowing herself to express the deep pain that comes with mothering a child through chronic illness. Like many mothers in similar situations, Karen had been labelled “anxious”—perhaps too articulate, too knowledgeable, and not always willing to accept the limitations of the current system. Her story, like those of others, did not fit neatly within dominant narratives, leading to a sense of being “othered.”

I found myself reflecting: can a mother ever be “too anxious” when her child is suffering from debilitating symptoms? Karen did not choose this path; it was not the motherhood she had envisioned or prepared for. Our conversation revealed another layer of loss—the loss of the motherhood she had imagined. I felt her pain deeply.

We also spoke about families who, unlike Karen, may not have the resources or skills to navigate the system as effectively, highlighting the privilege that comes with certain forms of knowledge and ability. This research journey has taken me to unexpected places, revealing remarkable stories and profound insights. As my work continues—listening, summarizing, and finding ways to share these experiences—I am left with one pressing question: will I be able to do justice to this project and the voices it represents?

Interview with Frogo

The interview provided a vivid illustration of what living with Long COVID can be like for a young person—marked by debilitating symptoms and significant impacts on daily life. Despite Frogo’s willingness to participate, he needed support from his mother and found it difficult to engage without lying down and resting throughout the conversation. This experience was eye-opening for me, prompting deeper reflection on the daily realities and challenges faced by young people living with Long COVID

Interview with Thor

Witnessing Thor, a 17-year-old, struggle to access appropriate medical care made me reflect on the many young people who go undiagnosed for extended periods, forced to endure their symptoms without understanding the cause. Thor’s experience—having to leave school and being unable to attend college—paints a poignant picture of a teenager missing out on crucial developmental milestones and opportunities during these formative years.

Interview with Lily

Lily remained hopeful that her daughter could recover, despite ongoing challenges with brain fog and memory problems. She described the fluctuating nature of her daughter’s illness and the difficulties they faced in accessing support through the NHS. After seeking private care, her daughter received an ADHD diagnosis, and medication for ADHD has since helped her concentrate much better.

Lily recognised that her daughter often struggled to follow advice from professionals, such as pacing herself or taking breaks—her teenage drive and desire to do more frequently took precedence. Lily also reflected on the complexities and disagreements surrounding a diagnosis of COVID or Long COVID. For her daughter, acknowledging a Long COVID diagnosis would mean accepting that there is no clear treatment and that she might be facing a long-term, chronic condition - something she is reluctant to do. This seems to be a coping mechanism: by not naming the condition, it feels less real and less overwhelming.

While for many people, receiving a diagnosis is crucial for understanding and managing their health challenges, for others - like Lily's daughter - avoiding a formal label may be a way to cope and continue moving forward despite the difficulties. This highlights the diverse ways individuals and families navigate the experience of chronic illness.

Interview with Ivy

During our interview, Ivy shared her experiences of how others have responded to her daughter's illness. She described a journey marked by disbelief, scepticism, and, at times, dismissive attitudes from medical professionals - one even told her, "You're too complex a case, and we don't know what to do." Ivy acknowledged how unhelpful and disheartening these responses have been.

I found myself reflecting on the potential impact such messages could have on a young person's development. What does it mean for a teenager to be labelled "too complex"? How might this affect their sense of identity, their expectations for recovery, and their trust in the healthcare system? It seems clear that these experiences can be profoundly influential.

Ivy and I discussed her perceptions and trust in professionals, and she noted the advantages they found in seeking private care. Her story underscores the importance of being believed and supported, especially for young people navigating complex health challenges.

Interview with Ava

Ava spoke about the profound sense of isolation that comes with chronic illness, describing how living with Long COVID can leave individuals feeling left in the shadows of society - unable to meet certain expectations or follow the usual rules. She reflected on how growing up in a capitalist society often means that those who cannot “deliver” are pushed to the margins, further compounding feelings of exclusion.

Ava noted that a lack of understanding is a common experience among people with Long COVID. However, she also shared that her choice to embrace an alternative lifestyle has allowed her to build a community of more understanding and supportive individuals.

Our conversation also touched on neurodiversity, as Ava, like other parents, noticed potential links between the onset of Long COVID and emerging signs of autism or ADHD. This intersection raised important questions about how chronic illness and neurodiversity may overlap and influence each other in the lives of young people.

Interview with Pickle

Pickle appeared energetic and engaged during our conversation, even as she lay on the sofa. She described how living with both Long COVID and ADHD creates a unique tension in her daily life—on one hand, she feels a strong urge to be active and often experiences restlessness; on the other, she is frequently held back by overwhelming fatigue. Pickle shared some photographs that vividly captured these contrasting experiences and spoke with optimism about the support she receives from her family.

Interview with Eveline

Eveline reflected on the significant impact Long COVID has had on her family, including financial pressures, the need for home adjustments, and the purchase of various devices to help manage the condition. She spoke about the substantial costs involved in acquiring these resources and how this has added further stress to their lives. This theme emerged in other interviews as well, highlighting not only the need for better accessibility and support but also the wide range of pressures - financial and otherwise - that families affected by Long COVID often face.