QUALITATIVE STUDY PROTOCOL
NIHR 135315
Version 2.2, Updated September 24, 2024

FUNDED TITLE

Improving Social Support and Recovery for Young People Affected by Long Covid: Qualitative Study

SHORT STUDY TITLE

Covid Made Long: Qualitative Study Among Young People

STUDY REFERENCE

National Institutes for Health and Care Research (NIHR) 135315

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NOTE ON THIS VERSION (Version 2.2, updated August 23, 2024)

We have marked in yellow the key revisions made to Version 2 of our original protocol. These revisions reflect changes in personnel (reflected above), as well as updates in light of fieldwork and to linked ethics approvals.

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SIGNATURES

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor.

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Date:

October 3, 2023

Noami Pentali
Research Facilitator, Research Governance, LSHTM

Chief Investigator:

Date:

October 3, 2023

Tim Rhodes, PhD
Professor of Public Health Sociology, LSHTM

QUALITATIVE STUDY PROTOCOL
NIHR 135315
Version 2.2, May 30, 2024

1 TITLE
Improving Social Support and Recovery for Young People Affected by Long Covid: Qualitative Study

2 SHORT TITLE
Covid Made Long: Qualitative Study Among Young People

3 INTRODUCING THE PROJECT
This is a UK-wide research project exploring how Covid is impacting young people's lives in the long-term, with a particular focus on how ‘Long Covid' illness intersects with precarity. Understanding how young people learn to live with the enduring effects of Covid-19 is critical. Long Covid in particular presents challenges to post-pandemic recovery efforts and young people’s futures. In consultations with young people, we have found that Long Covid is still in the making. This is because the uncertain and enduring debilitating effects of illness entangle with multiple forms of precarity, which are at times difficult to differentiate. This study is the first qualitative longitudinal project in the UK to focus on how younger generations adapt to the social and material effects of Covid and Long Covid, and how illness is ‘made long’ over time. The project is unique in learning how young people’s social networks act as sites of informal care and social support when living with the uncertainties of Covid and Long Covid and when adapting to futures that have become more precarious. The project produces outputs for use in social support and peer-based interventions.

4 PLAIN ENGLISH SUMMARY
In this project we seek to understand how the Covid-19 pandemic, and Long Covid specifically, intersect with various forms of precarity (such as inequality and uncertainty) in the lives of young people.

A key aim is to explore how illness is ‘made long’ through the social and material conditions in which young people live. Long Covid is of particular interest because such illness can alter young people’s lives at a time when they are making important life transitions. A second key aim is to explore social support, including peer support, among young people affected by Long Covid and by the effects of Covid in the long-term.

By learning directly from young people, qualitative research can help. In partnership with young people themselves, we will interview between 65 and 70 young people (15-25 years), of whom approximately half will be followed-up (6-9 months).[1] We will also generate interviews among the social and care networks of approximately half of those followed-up (approximately 30 network interviews).[1] We will sample young people who are experiencing precarity, and social and economic inequalities, in different ways. We will combine interviews with other methods in a participatory approach involving young people throughout.

This project is delivered in partnership with community organisations, including Long Covid Kids, and also Long Covid Support. The research aims to produce materials for use in participant-led, peer-based, and social support interventions as well as for use in training and advocacy.

5 EXTENDED PROJECT SUMMARY
Evidence of need
The UK has moved towards strategies of ‘living with’ Covid-19. Yet, Long Covid is an expanding problem [1], which makes futures more precarious [2]. Understanding how younger generations learn to live with illness that endures, and with illness that is ‘made long’ – that is, extended or entrenched – in its effects by social and material precarity is critical. The social and economic effects which intersect with, and flow from, lived experiences of Covid, and particularly Long Covid, offer an important case study for understanding how

illness is navigated in, as well as potentially extends, precarity [3-7]. Younger generations may be less frequently and severely impacted by Covid-19 infection itself, but are disproportionally affected by the social and material impacts of the pandemic [4, 8]. Long Covid has direct as well as indirect impacts on social, family and work life at a critical time of transition for younger generations. The social and material impacts of Long Covid, and of pandemics, not only alter the present but also the future, making lives more precarious, especially for the most vulnerable.

In this project, we study 'Long Covid' not only as the manifestation of multiple biomedical and post-acute illness effects of SARS-CoV-2 [9], but as an enduring social and material impact of illness. As we learn to live with Covid-19, it is critically important not to artificially separate Long Covid, the biomedical condition, from how persisting illness post SARS-CoV-2 is 'made long' through its social, material and everyday effects [10]. The Covid-19 pandemic has made visible how illness incorporates social, economic, ethnic, and material inequalities which pre-exist as well as extend the physical and medical effects of infections [11-13].

A major concern going forwards is how to provide social support and protection to young people affected by the long-term effects of Covid-19 – both pandemic generally, and Long Covid specifically – especially those who are made precarious in their 'transition years', and who are navigating uncertainties in education, employment, family and social life arrangements [14]. Illness effects are not only physical but social and psychological [15, 16], and intersect with broader insecurities in relation to future (for instance, cost of living, climate, environment). By learning directly from younger generations, qualitative research can build social support interventions as an adjunct to health and clinical care.

Practical relevance

Young people and their social networks can be inadequately covered by existing Covid and Long Covid services, especially regarding social and mental health support [17, 18]. This project learns from young people themselves about how their social networks can act as sites of care and social support through situations of pandemic precarity. Guided by young people, the project coproduces resources for training, advocacy and social support. The project will also improve how patient-led and community organisations can support young people affected by illness and living in precarious conditions.

Aim

To understand the social support needs of young people and their social networks as they adapt and recover in response to Covid and Long Covid.

Research questions

Q1 How is Covid and Long Covid navigated by young people and their social networks over time?
Q2 How are the lives and futures of younger generations who are living in contexts of vulnerability shaped by Long Covid and by the Covid pandemic?
Q3 What are the social support needs of younger generations affected by Long Covid, and how can young people's social networks and community-led initiatives help offer support and care?
Q4 How can partnerships be best developed between informal and formal services to deliver social support for young people whose lives are affected by Long Covid and the Covid pandemic?

Design

A qualitative longitudinal research design delivered through academic-community partnership. We combine qualitative interviews with other participant-driven methods to investigate young people's lived experiences over time, with the 'social network' a core unit of analysis. These findings feed into coproduced resources and action dialogues with, participants, peer researchers, participating projects, and local stakeholders.

Sample population

Young people, aged 15-25 years, with experience of Covid and Long Covid, and their social networks. Our purposive sampling concentrates on young people whose lives are precarious in different ways. Following initial consultations in the development of this project, this includes young people who are: living in unstable housing or home situations; living in economic constraint; recently transitioning from care; engaged in caring roles (including as new parents); and who may be navigating mental health or other chronic illness conditions. The project also purposively samples young people in relation to gender, ethnic diversity, neurodiversity, sexuality, socioeconomic status, and any other self-defined categories of precarity, marginality, or inequality.

Sample size

The originally proposed baseline sample for qualitative interviews was 80 young people, which has since been revised downwards to between 65 and 70 young people.[1] We will aim to follow-up (at 6-9 months) approximately half of the baseline (approximately 30 interviews). We will interview the social and care network contacts of approximately half of those followed-up (approximately 30 interviews).

Sites

Our sample is across the UK, recruited largely through collaborations with community partners and the NIHR REACT study which runs until 2024 (see below).

Conceptual framework

The project is unique in the NIHR portfolio because it brings together science and technology studies and medical sociology with implementation science and clinical expertise. We advance an ‘ecological’ understanding of illness and Long Covid as ‘embodied’ in young people’s lives, networks and contexts. Our overarching focus is ‘precarity’. We draw on the sociological concepts of ‘assemblage’ and ‘embodiment’.

Patient and public involvement (PPI)

The proposal was encouraged by patient-led organisation Long Covid Kids who coproduced the proposal. Long Covid Kids are Co-Applicants. Long Covid Support are also a PPI partner. The project incorporates PPI throughout, from design to implementation to dissemination, including through PPI workshops, PPI representation in the Project Advisory Group, a participatory research approach involving peer fieldworkers, and through intervention materials oriented to patient-led and peer-based engagement. The project will be coproduced in partnership with community organisations and initiatives linked to the targeted social networks of young people participating in the project.

Actionable findings

The project produces multiple resources for use in training, advocacy, and intervention. This is achieved through collaboration with Long Covid and participant-led organisations (including Long Covid Kids and Long Covid Support) and community organisations linked to the participating social networks of young people, who will also benefit from this research by improving efforts to support young people. Our creative partner PositiveNegatives has an excellent track record in turning qualitative evidence into intervention materials.

6 BACKGROUND AND RATIONALE

Living with Covid-19 demands responses which can build adaptation and resilience in the long-term [3, 4, 14, 17, 18]. In heavily affected societies, like the UK, the Covid-19 pandemic potentiates lasting effects via intersections with multiple forms of social and material vulnerability which extend beyond health. Covid-19 affects younger generations going forwards, making futures more precarious, through altering transitions in relation to work, home, education, health, social connections, and well-being, additionally patterned by structural vulnerabilities relating to age, race, ethnicity, and gender [10, 19-21]. It has been said that the pandemic is a “threat” to a “whole generation” of young people, sometimes termed “Generation Covid-19”, who some view as a generation “lost” and “scarred” because of the precarious conditions brought about by the pandemic [7, 22-24].

Long Covid, and enduring illness, presents particular challenges. The enduring debilitating effects of illness can deepen as well as extend social and material vulnerabilities in the lives of younger generations [18, 25]. Long Covid is largely becoming known through lived experience [26-30]. The condition has become clinically defined as a set of illness effects extending or recurring more than 4 weeks after acute Covid-19 and comprising an unpredictable trajectory of multiple symptoms; from organ damage, debilitating fatigue, psychological distress, post-viral inflammatory reactions, cognitive confusion, and psychological distress [30, 31]. While estimates of Long Covid are haphazard [32-34], with clinical measures subject to ongoing debate, recent data from the REACT-2 study had suggested that a third of symptomatic Covid-19 patients in England experience at least one symptom three months after diagnosis, almost a third of which described these symptoms as having a "significant effect on [their] daily life" [35]. National data in the UK has suggested that around 17% of diagnosed young people (17–24 years) have persistent symptoms at 5 weeks [36]. A US cohort study found that 46% of Covid-19 patients aged 10–21 years had features of Long Covid during the 6 months after diagnosis, with 40% of patients across the cohort not showing symptoms until after 90 [37]. Adolescents may have a higher risk of Long Covid than younger children [38]. As of January 2022, the Office of National Statistics estimated 1.5 million people in households in the UK (2.4% of the population) to self-report Long Covid, with 45% having had persistent symptoms for more than a year, 65% reporting severe everyday debilitating effects, and almost half having had no contact with NHS services [39]. Long Covid is one of the most critical and enduring impacts of Covid-19 that will be need to be managed through successive waves and new variants of infection [40, 41]. The latest NICE review of the long-term effects of Covid-19 calls for further research into the experience of Long Covid in young people, and social and community support interventions for managing Long Covid [42].

While evidence shows that Long Covid comprises unpredictable multiple symptoms (from post-viral inflammatory reactions, organ damage, debilitating fatigue, cognitive confusion, and psychological distress) [43], these combine with poorly described social and economic impacts affecting everyday life [4, 44, 45]. Among younger generations, the mental health and social effects of Long Covid entangle with altering education, employment and life transitions, and can therefore be profound and long-lasting [7, 17, 21, 46-48]. This project is unique because it does not simply investigate Long Covid as a biomedical condition with long-term clinical outcomes but considers how the effects of Covid-19 are '*made long*' through social and material vulnerabilities which affect young people's futures. As we detail below, there is no sociological research in the UK that is using qualitative methods longitudinally to explore how Covid, and Long Covid specifically, intersects with 'precarity' in young people's lives and how the social networks of young people adapt and cope in response.

Social support is critical

A major problem going forwards is how to provide social support to young people affected by the long-term effects of Covid, and Long Covid specifically, especially those who are in their 'transition years' regarding education, employment, family and social life [7, 17]. The challenge of providing social support is critical for young people living in precarious situations, such as those characterised by economic constraint, ethnic inequality, unstable housing and insecure work [7, 22, 23, 49]. As we note below, the mental health impacts of living with Long Covid, and of precarity linked to pandemic, are marked for young people [47, 48, 50]. Long Covid and the Covid-19 pandemic also entangle as ontological insecurities in relation to futures altered by 'big events' affecting everyday life, such as recessions, cost-of-living crisis, and climate change.

The NHS has established paediatric and adult Long Covid clinics to deliver physical, cognitive and psychological assessment and care. But it is unknown how well these cater to the social support needs of young people and their social networks [51]. In their study of people living with Long Covid in the UK, Rushforth et al. describe patients' attempts at navigating the NHS as a "lottery," where experiences of illness were "overlooked or dismissed by health professionals" [28]. Many people affected by Long Covid report a sense of dismissal as well as delay when seeking care [15, 52-56]. In common with other areas of health care, Long Covid services may be particularly inaccessible to those most socially disadvantaged, including ethnic minorities [57]. Long Covid clinics, especially adolescent services, are still new. By learning directly from lived experience, qualitative research can help build social support interventions which can work as an adjunct to, and enhancement of, existing clinical care [42].

Informal care, including peer support, offers a safety-net in the face of illness and uncertainty, especially when formal services are slow to develop, inaccessible, or overwhelmed [26]. Peer support, including in social networks beyond school and work, is an important resource of mental health and coping in response to Covid and Long Covid [58]. Patient expertise has driven knowledge, as well as responses, about adult Long Covid [26, 52, 59]. Yet the voices of young people, many of whom may not identify themselves as 'patients' of 'Long Covid', have been inadequately heard in participant-led initiatives. There is scope also, for read-across from peer-based interventions in other chronic conditions, including myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS) [60-63].

The capacity of young people's social networks to offer informal care, however, becomes fragile under pressure. For instance, families affected by Long Covid are juggling illness uncertainty, with the challenges of care-giving, and the effects of lockdowns, in the face of economic constraints [47, 50]. Young people themselves are sometimes juggling multiple care roles, including to family members affected by Long Covid, and alongside new parenting roles, while navigating uncertain transitions in work and education [21, 64]. In situations of precarity, Covid and Long Covid may not feature as primary concerns. Families have advocated hard for support, including via self-help groups [51, 65]. Despite emerging networks of informal care, there is little documented on how well they work for young people, the difference they make, and how precarious these efforts are, especially among the most disadvantaged, some of whom may feel socially isolated or detached from networks of informal support, or not identify as 'patients' or in need of care [66-68]. There is an opportunity to improve how patient-led initiatives cater for the needs of young people specifically.

7 WHY THIS RESEARCH IS NEEDED NOW

Absence of longitudinal research among young people

Despite strong investment in Covid and Long Covid research in the UK, there is an absence of qualitative longitudinal research focusing on young people. The NIHR has called for research and policy to "listen to the lived experience" and to include people affected by Long Covid as "partners" [45]. NICE has called for research on the care needs of young people and social and community support for managing the long-term effects of Covid and Long Covid [42]. The patient-led organisation Long Covid Kids has identified unmet need for social support among young people affected by Long Covid, and approached Prof Rhodes at LSHTM to develop this proposal.

Living with Covid-19 over time

Due to new variants and uneven vaccination coverage, Covid-19 may become a "disease of the young" [69]. With initially mild symptoms having the potential to become persistent or debilitating [70], and with prevalence estimates of Long Covid among young people haphazard [15], and often without formal diagnosis [51, 71], the long-term burden of Covid and Long Covid in younger generations is uncertain. This uncertainty, including in light of policies easing Covid-19 restrictions, exacerbates concern, including among families [42, 72]. Variable testing and diagnosis in relation to long-term illness can exacerbate anxiety, reinforcing needs for social support [71, 73-75].

Looking 'beyond the virus'

A key consideration going forwards, is that Long Covid specifically, and the Covid-19 pandemic generally, not only affect everyday life but also the future through creating precarious conditions in relation to work, education, social and family life, and by reproducing structural, ethnic and other vulnerabilities [7, 17, 18, 25, 44, 45, 76]. Because the social, material and mental health impacts of Covid and Long Covid for younger generations extend 'beyond the virus', so too must care and social protection responses [7, 18, 25, 44, 45, 47, 48, 50]. Box 1 below highlights how Long Covid specifically can precipitate longer-term 'generational' effects through 'precarity'.

BOX 1 THE ENDURING AND GENERATIONAL EFFECTS OF LONG-COVID AND PANDEMIC
Disrupted ***education*** affects the most disadvantaged through school closures, unequal access to remote learning, and competing carer and/or economic demands, which also sustain their effects through delayed return to education when post-pandemic societies seek to open-up [17, 78-80]. Over 90% of students worldwide have been affected by school closures, with 15% living under stay-at-home policies for most of 2020 [17, 81]. School closures risk a cascade of marginalisation effects beyond interrupted learning, through pressure on families, gaps in childcare and family earning, and weakened social support (such as school meals and safeguarding) [17]. The OECD estimates that a lost school year can equate to 10% loss of lifetime income [14]. Reduced or lost ***work*** opportunity, especially in lockdowns, potentiates lasting negative economic impacts and exacerbates already precarious labour markets and career prospects, especially among younger generations reliant upon insecure, informal, lower-paid, and less-skilled work, and especially in locations already characterised by poverty and higher levels of unemployment [7, 10, 14, 17, 82-86]. In the UK, young people aged between 16-24, and especially young Black workers, are most likely to have lost work and to have experienced reduced earnings as a result of pandemic, with those working in service and hospitality industries heavily affected [82, 83, 87]. Making the transition from education to first employment has become more precarious post-pandemic [87]. The first global rise in extreme ***poverty*** since the global recession of 1998 is anticipated as an effect of COVID-19, with anticipated increases in cost of living, child poverty and child labour, and decreases in school engagement, especially affecting girls [49, 80, 88, 89]. School closures and reduced access to work and income combine to produce ***food insecurity*** [90-94]. Much attention has focused on young people's vulnerability to the ***mental health*** effects of pandemic, associated with lockdown, social distancing, social isolation, altered home and work life, producing stress and anxiety [3, 47, 95, 96]. There is emerging evidence that problematic ***drug and alcohol use*** can coincide with Long Covid [97-99]. Pandemic precarity can also entangle with ***violence*** in the home [100, 101]. The capacity of ***helping systems*** to respond is also made precarious, including in the provision of mental health and social support to young people [17, 22, 102].

Need for systemic 'post-pandemic' responses

Adaptation and recovery to Covid-19 requires a systemic approach. The far-reaching effects of this pandemic affect whole social networks and generations [7, 17, 18, 25]. How Covid and Long Covid folds into, and extends, precarity in the lives and futures of younger generations is a critical policy question, which requires social science to offer a response [17, 77]. Providing younger generations with mechanisms of social protection and mental health support is critical in a future made more precarious [17, 69]. Critically, younger generations need to be incorporated as partners in research and post-pandemic responses [59]. The Covid-19 pandemic has been presented in global policy as "a historic opportunity to reimagine societies" to "initiate […] transformative changes" [17]. Policy narratives of 'post-pandemic' configure transition 'after' Covid-19 as a process of 'renewal' and 'recovery', potentiating 'resilience', and even as 'future-proofing' against 'crises' yet to happen [14, 17]. Yet there is an absence of qualitative research exploring what 'post-pandemic' actually means in the real worlds of affected younger generations.

Need to optimise informal care and social support

While UK funding has built an excellent foundation for clinical research in the long-term biomedical effects of Covid, there is an absence of research exploring how such illness is 'made long' and 'embodied' in social and material conditions and a lack of focus on patient-led and peer-based networks of social support among young people. These forms of social support are critical, yet themselves fragile, in situations of precarity [26, 47, 50, 60, 61]. In addition to structural interventions building less precarious environments through poverty alleviation, social security and whole-school interventions [5, 8, 17, 18], there is unrealised potential for building interventions to support informal mechanisms of peer-based and self-care within social networks, in partnership with clinical, patient-led, and local community responses.

8 WHAT THIS STUDY ADDS TO EXISTING RESEARCH

There is an absence of robust research on young people

The NIHR has called for an urgent need to learn, first-hand, from lived experiences of Long Covid [45]. A recent review of studies focused on young people experiencing Long Covid (including preprint and grey literature) found existing research to be limited, and the majority of poor quality [103]. We identified no such published qualitative studies among young people with Long Covid in the UK, but some focusing on adults [55, 56, 104-109]. One study focusing on adults in the UK [28] highlighted how in contrast to widespread difficulties in accessing clinical care, online communities and social networks were safe spaces in which experiences could be shared, where knowledge about recovery practices could be exchanged (especially self-help treatments, diet, and approaches to exercise and pacing), and where suggestions about how to mobilise informal care and support from family and friends could be made. This research highlights how social networks might be harnessed as sites of informal and peer-based care. There is ongoing qualitative research with a focus on adults with Long Covid in the UK outside of clinical settings (Ziebland, ESRC ES/V01603211; and in Scotland, Hunt, COV/LTE/20/04), but not among young people.

A focus on longitudinal research and peer-based social networks

The closest qualitative research to this proposal (NIHR COV-LT2-0005) is led by Ziebland et al. Ziebland's NIHR study focuses on how families are responding to Long Covid [110]. This study has concentrated on parents and carers thus far, and has included around 8-9 interviews with children at the time of writing. Our study offers added value by: focusing specifically on young people, 15 years and above; taking young people's 'social networks' as the unit of analysis and sampling; using a longitudinal approach; focusing on the potential of peer-based, patient-led and informal social support; focusing on 'precarity' (uniquely combining ideas from science and technology studies with medical sociology); and developing geographically and situationally targeted case studies as part of its approach.

9 FORMATIVE RESEARCH

Qualitative longitudinal research among adults with Long Covid

Since mid-2020, Principal Investigator TR has collaborated with Co-Investigator KL in qualitative longitudinal research with adults in Australia as part of a prospective observational cohort study investigating patient experiences and outcomes linked to Long Covid, adaptation and recovery [27, 111]. The ongoing interdisciplinary work of this study – now at two-year follow-up, with three waves of qualitative interviews – provides an empirical and conceptual foundation for this study, and demonstrates the feasibility of a longitudinal approach. This work has highlighted the multiple social effects of Covid and Long Covid, and how uncertainty is navigated through informal care, often hidden from view. Participants described "invisible" effects of long-term illness effects and highlighted the need for collective knowledge-generation and social support: "everyone who has had the disease going forward now will be in the same boat and we are not going to know the long-term effects". Our ongoing qualitative research with adults has demonstrated the need for different forms of social support at various stages of recovery, as participants adapted and adjusted their lives: "the social aspect of these sorts of events are as important as the health and medical aspects […] I think that's where people need a lot of support and probably we don't do all that well as a community." Moving away from online support groups when feeling overwhelmed, participants emphasised existing networks of friends and family as sites of everyday care, around mundane but essential practices such as food shopping, child care and home life. This social support and care reshaped how participants saw themselves and their place in the world, reduced loneliness, and enhanced connection. The longitudinal approach has highlighted the value of studying the fluctuating effects of illness related to Covid over time. The study also demonstrates how long-term illness materially and socially affects whole households, and how informal care is provided in these networks, often with little support and in the face of uncertain futures: "nobody asked the carer, how they are dealing with all this because it was very, very stressful". The study highlights the need for support that extends beyond the individual, and beyond the biomedical: "If my story and a few other stories can all be put together in some sort of form that someone that was going through a similar thing was able to read, and understand they're not alone; [that says] this is how you're going to feel and expect these emotions and feelings and uncertainty." Our proposal builds on this expertise.

Pilot qualitative research among young adults with Long Covid

Linked to the NIHR REACT study (see below), Co-Investigator HW has undertaken pilot qualitative research among 13 adults aged 18-34 years. This work shows the multiplicity, ambiguity and unpredictability of reported symptoms. Although this is a small pilot, key findings are that symptoms are related to living conditions, including to the "effects of the pandemic and lockdowns" which link with "psychological stress" and a sense of “lack of control”. Moreover, the variability and uncertainty of experienced symptoms also means that not all participants identify with the biomedical condition of “Long Covid” or feel that they “do not fit the diagnosis”. Our project builds up on these pilot findings by exploring how ‘Long Covid’ is not merely a biomedical condition but an effect of social conditions, including ‘pandemic precarity’, and by sampling people with a diversity of illness experience, including those undiagnosed.

Network of qualitative research in Long Covid

We are members of a network of public health researchers engaged in qualitative research in Covid and Long Covid. This network meets bi-monthly, and includes NIHR funded qualitative research among healthcare workers, adults and families. Our project is unique in its longitudinal focus on young people.

10 AIM

To understand the social support needs of young people and their social networks as they adapt and recover in response to Covid and Long Covid.

11 RESEARCH QUESTIONS

Q1 How is Covid and Long Covid navigated by young people and their social networks over time?
Q2 How are the lives and futures of younger generations who are living in contexts of vulnerability shaped by Long Covid and by the Covid pandemic?
Q3 What are the social support needs of younger generations affected by Long Covid, and how can young people’s social networks and community-led initiatives help offer support and care?
Q4 How can partnerships be best developed between informal and formal services to deliver social support for young people whose lives are affected by Long Covid and the Covid pandemic?

12 PATIENT AND PUBLIC INVOLVEMENT

Professor Rhodes at LSHTM was encouraged by the patient-led organisation Long Covid Kids to develop this proposal. Long Covid Kids has identified an unmet need to carefully document lived experiences of the long-term effects of Covid among young people to inform service delivery. This proposal has had direct input from patient-led organisations. Our methods foster participation throughout, including data generation with trained peer interviewers, and coproduced materials with young people, also designed to facilitate community-led advocacy and peer-based social support. We will foster wider impact through public engagement enabled via the development of accessible materials. The project is guided through PPI workshops at all stagesp. Our PPI partners, including Long Covid Kids, co-host PPI workshops. Our Advisory Group has PPI representation. Our creative partner PositiveNegatives has an excellent track record in turning qualitative evidence into actionable materials, including for public engagement. Our community and patient-led partners will feed findings directly into their efforts to improve support for young people.

13 PROJECT DESIGN

A qualitative longitudinal design delivered through academic-community partnership. We combine qualitative interviews with other participant-driven methods to investigate young people’s lived experiences over time, with the ‘social network’ a core unit of analysis.

14 THEORETICAL FRAMEWORK

Our project infuses thinking from science and technology studies with medical sociology and implementation science. We advance an ‘ecological’ understanding of Covid and Long Covid as ‘embodied’ in young people’s lives, social networks and social contexts. Our overarching conceptual interest is ‘precarity’. We also draw on the sociological concepts of ‘assemblage’ and ‘embodiment’. Below we say more about how we conceptualise ‘Long Covid’ and ‘social support’ as these are core to the study.

Long Covid

We conceptualise Long Covid as not only encompassing biomedical and post-acute illness effects of SARS-CoV-2 [9], but as the embodiment of social and material effects of illness. An ecological understanding of

Long Covid and the Covid pandemic does not artificially separate Covid, the biomedical condition, from how such illness is 'made long' through its social and material effects [10, 112-114].

Precarity

Precarity usually denotes forms of insecurity that are brought about through modernisation, development and other Big Events that intersect with structural vulnerabilities [115-117]. We pose the notion of 'pandemic precarity' as a means to investigate the generational effects of Covid. Younger generations in the UK have been configured in some sociological studies as the 'new normal' of 'post-crisis' precarity, wherein precarious conditions flowing from recent global recessions become internalised as normal [118, 119]. The disturbance from pandemics and other Big Events (for instance, economic recession, cost-of-living crisis, climate change, Brexit) can be conceptualised to entangle with this 'new normal' of precarity. Yet, at the same time, younger generations are not passive agents 'lost' to their situations of constraint (despite often being projected as such), but actively negotiate liminality as well as demand difference rather than a 'return to normal' [14, 22]. Younger generations can create social change in their everyday responses to precarious conditions, including those exacerbated by Covid. How Long Covid, itself uncertain, folds into, as well as extends, precarity – what we conceptualise as 'pandemic precarity' – is also locally variable, contingent upon young people's social networks of informal care, protection and recovery. To study how the effects of illness and Covid-19 are 'made long', it is necessary to trace the extending chains of relations which entangle Covid and Long Covid as elements of social and material precarity [120]. This is why it is important to draw attention to pre-pandemic conditions that shape how Covid entangles with longer social, political and environmental trajectories. The focus on precarity advances an 'ecological' understanding by investigating how viruses, young people and their environments adapt together [121, 122].

Assemblage

A key analytical concept for this project is the assemblage [120, 123]. Drawing on work from science and technology studies, we are interested in the assemblages or networks of care and recovery which create capacity in the lives of younger generations as they navigate the effects of Covid, Long Covid and pandemic. By assemblage, we refer to the multiple actors and elements in a network which *become together* to bring about practices of care [123]. Assemblage thinking has increasingly shaped the social sciences in health [124], including our own work on 'evidence-making interventions' [125, 126]. Assemblage theory shifts attention from overly 'deterministic' models of causality to 'relational' models of 'emergent causation' [127]. Focus shifts also from "presumed objects" (approaching viruses, pandemics, illness, people, networks, and environments as if separate, stable and immutable) to the "relations involved in their becoming" (approaching these as mutable, entangled and relational) [128]. We therefore trace how adapting to Covid *comes to life* as effects of assemblage and network relations. We hone our specific attention on how the assemblages and networks, of which young people are a part, afford potential for adaptation, care and recovery. Recent work on 'family assemblages' is particularly relevant [129]. Our Logic Model illustrates how the 'care assemblage' fits in an ecological understanding of Covid and Long Covid (See below).

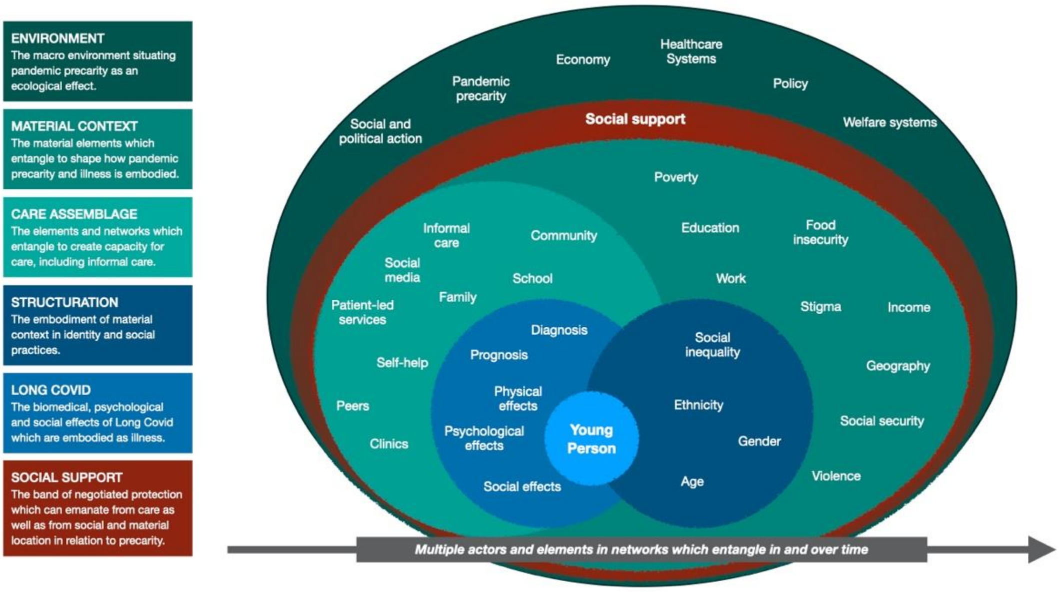
Embodiment

Another key area of theory for us is embodiment. We are guided by the work of Marsha Rosengarten (an advisor to this project) on 'emergent bodies' [130]. We also draw on the work of Nikolas Rose on 'ecological niche' in relation to mental health [131]. An ecological niche is a bio-social locality in which illness and precarity is embodied. Our project will map the multiple embodied effects of Covid and Long Covid, from physical illness and symptomology to pandemic precarity. The analysis of embodied Covid will thus 'jump scale', by connecting accounts of illness in individual bodies to materialisations of localised precarity [132].

Social support

As illustrated in our Logic Model, we conceptualise social support as an effect of young people's 'assemblage relations', which themselves are situated ecologically. This is precisely why our approach to data generation accentuates sampling in relation to young people's social networks (see Sampling below). We operate an inductively grounded definition of social support as a resource [133, 134], tracing this as it is described by young people themselves. Of significance, is our orientation to exploring how social support emanates through everyday informal practices of care. This means that our study is not only concerned with the potential afforded by formalised or outside-supported interventions of social support that have emerged in response to Covid and chronic illness – such as structured peer-based, patient-led and psychosocial initiatives [42, 54] – but is also attuned to capturing the contribution made by everyday social interactions of care that are often hidden from view. Such informal care need not arise specifically as 'intervention' in relation to 'illness' or a sense of 'patient' identity or citizenship, may orientate as much to the indirect social effects of illness than its biomedical or physical manifestations, and may go unrecognised as care, but nonetheless contributes to recovery [135, 136]. Conceptualising social support as situated in a network of extending relations also allows us to attend to the fragility and costs of such care, recognising the need to generate research which better understands how to support those who do this caring labour and how to bridge or connect-up such informal care with formal support services.

The conditions and effects of Long Covid as a dynamic network of ecologically situated 'assemblage relations'



15 SAMPLING

The baseline sample is between 65 and 70 young people (15-25 years), of whom approximately half are followed-up (at 6-9 months).[1] The social and care network contacts of approximately half of those followed-up will be interviewed, generating approximately 30 network interviews.[1] In keeping with an iterative approach to developing grounded hypotheses and analysis [137], we sample purposefully across carefully selected networks of affected young people which afford grounded comparisons in relation to different forms of precarity and practices of informal care. The sampling and recruitment process is summarised below.

Purposive sampling at baseline

Our sample is young people, aged 15-25 years, and their social networks. We focus on the ten year age range of 15-25 years as 'transition years' in relation to education, employment, family and social life.

Our purposive sampling concentrates on young people whose lives are precarious in different ways. Following initial consultations in the development of this project, this includes young people who are: living in unstable housing or home situations; living in economic constraint; recently transitioning from care; engaged in caring roles; and who may be navigating mental health or other chronic illness conditions. The project also purposively samples young people in relation to gender, ethnic diversity, neurodiversity, sexuality, socioeconomic status, and any other self-defined categories of precarity, marginality, or inequality. This is as well as sampling in relation to illness/diagnosis, symptom persistence/occurrence, and care needs (including informal). Our study makes particular efforts to recruit into networks most socially and materially disadvantaged.

We define Long Covid as experiencing symptoms of SARS-CoV-2 for at least twelve weeks [42]. Our baseline sample seeks to include young people with a clinical and/or test positive diagnosis linked to experiences of Long Covid, as well as the lived experiences of those with long-term or persistent illness who are undiagnosed, as well as initially testing PCR or Lateral Flow negative. This variation is necessary given the emergent and uncertain symptoms of Long Covid, the diversity of illness experiences linked to the long-term illness effects of Covid, and increasingly variable access to testing among younger generations. Because our study includes young people with undiagnosed as well as diagnosed long-term illness linked to Covid, we will be including participants whose experiences of Long Covid may not necessarily align with prevailing clinical definitions, including for instance those experiencing long-term effects linked to Covid who may not necessarily see these as Long Covid.

Given that the variability as well as uncertainty in young people's accounts of Long Covid and of the long-term effects of Covid are key areas of concern to investigate, the study incorporates young people with experiences of long-term effects linked to Covid who may not necessarily identify or define themselves as 'patients' of Long Covid. A learning point of consultations with young people, and of evolving baseline interviews, is that young people may experience long-term effects of Covid without necessarily tracing or linking these to Long Covid, which itself is variably understood. The ways in which the illness effects of Covid are 'made long' through experiences of the pandemic and of precarity in the lives of young people is highly variable. A sufficiently diverse baseline sample enables analytical comparisons across varied lived experiences of Long Covid and of how covid is 'made long' in social and material conditions. Though we will be sampling iteratively throughout, and in keeping with our original design, we envisage the baseline sample will target of up to 50% (40) with a clinical and/or test positive diagnosis linked to experiences of Long Covid. The vast majority of our sample will be recruited via community networks of people identifying themselves as people experiencing Long Covid and/or via the NIHR REACT study of people reporting persistent illness symptoms linked to Covid (see below).

Sites

Our sample is across the UK. We will young people in relation to social, material and ethnic diversity [39]. It is important to note that we do not see location as merely 'geographical' but also 'social' with regards to how young people's networks 'locate' in relation to precarity (See Theoretical Framework).

Sampling young people at follow-up

We will follow-up approximately hald of those interviewed at baseline, at 6-9 months.[1] This period is sufficient to capture evolving change in Covid and Long Covid and how such illness connects with life transitions and material situation. Follow-ups are sampled according to emerging hypotheses on precarity, social support and informal care [137], and for diversity across young people's social networks.

Sampling the networks of young people

Our sampling of social and care networks is informed by the analysis of baseline interviews in combination with the nominated social and care network contacts of those followed-up (for example, friends, family, work colleagues). We will discuss with those followed-up the nomination of 2-3 others linked to their networks (generating approximately 30 network members overall). Participants for network interviews will be selected on the basis of people with whom those at follow-up have social or informal care connection and/or people they would like "to help them tell their story". Participants for network interviews need not have Covid or Long Covid themselves. Sampled networks represent a diversity, including on account of socio-material situation, and according to the kinds of social support and informal care provided. We therefore include diverse social networks according to how young people perceive these. The Principal

Investigator has experience in using these methods in qualitative studies with young people and families [129, 138].

16 RECRUITMENT

We use a combination of recruitment methods to sample purposively (see above), given our focus on 'precarity', social and material vulnerability, and investigating young people's multiple interpretations of Covid and Long Covid.

REACT

A primary point of departure is the existing infrastructure and cohort of the NIHR REACT-1 study which runs until 2024 [139], and the newly funded REACT-CYP study, which is exploring cognitive impacts of Covid-19 in children and young people [140]. REACT-1 has generated repeated community-based population surveys of SARS-CoV-2 prevalence, estimating perhaps 2 million people with Long Covid nationally [35]. At the time of writing, REACT-1 has 364,594 people within our sample age range of 15-25 years, of whom 3% have symptoms of over 4 weeks. Engagement among those already consented to REACT-1 will be enabled through an ethics amendment.

Participant-led networks

We also recruit purposively through the networks linked to our PPI partners, especially Long Covid Kids (LCK), as well as Long Covid Support (LCS). LCK has 3,000 members. The online patient group of LCS has approximately 45,000 members, and around 14,000 followers to its public Facebook and Twitter accounts. Both initiatives have collaborated in research, including with the REACT study. Recruitment at LCS will be managed via their Covid-19 Research Involvement Group, and via the online networks of LCK and LCS with links to our study infographic and website (see below), as well as via chain referral. Young people may also be introduced to the study via their parents or carers, for instance in the case of interest generated through LCK.

Community initiatives

In our consultations to develop this project we have made a variety of connections with community organisations and initiatives working with young people living in precarity in different ways. These include community-based initiatives working with young people affected by gang violence, unstable housing and homelessness, drug use and alcohol, family disruption, and those transitioning from care. These initiatives offer potential collaborations as we move into the targeted sampling of young people's networks.

Young people's social and informal care networks

Our sub-sample of network members are selected on the basis of analysis of baseline interview data and those nominated by young people at follow-up, and then contacted directly.

Local services

We also have the potential, if needed, to supplement community-based recruitment through adult and paediatric Long Covid services.[2] In the development of this proposal the following NHS Trusts have expressed interest, for instance: Imperial Healthcare; Birmingham University Hospital; and Manchester University Hospital. These clinics also have links with community services catering to young people with Long Covid and/or persisting symptoms who have not been hospitalised or reached by NHS services.

Recruitment process

Those purposively selected and eligible will be approached to gauge their interest. Once introduced to the research team, young people will have opportunity to learn more about the study as well as to make contact with peers assisting with recruitment. Our involvement of peers in our recruitment assists in recruiting those hardest-to-reach, including those not in contact with services. The study develops accessible materials to assist engagement, including an accessible information sheet (in relevant languages). We will be careful to assess that all participation is voluntary and that young people have competency to consent (See also Ethics).

17 DATA GENERATION

Qualitative interviews

Interviews will be face-to-face if feasible (see below), otherwise via Zoom or Teams. Interviews focus on Long Covid and informal care experience, triangulated through the perspectives of young people and their network members. All interviews are audio recorded and transcribed verbatim for analysis, with informed consent. Interviews with young people will be undertaken by the research team and, where appropriate, by trained peer interviewers (young people, with experience of Long Covid and/or indigenous to the communities of interest, including local languages). Interview conversations are facilitated by a topic guide, the content of which is finalised in consultation with young people and via the first of three PPI workshops. The key areas of investigation which form the basis for topic guides are summarised below.

Key areas of content to form the basis of interview topic guides	
ILLNESS EXPERIENCE	testing, diagnosis, treatment, symptoms, effects
UNDERSTANDING COVID	interpretations of pandemic, SARS-CoV-2, Covid-19, Long Covid
LONG COVID EFFECTS	manifestation of physical, psychological, social and material effects (including regarding school, work, home, family and social life)
SELF-CARE	strategies of self-care when navigating illness, risk, uncertainty and social interactions (in the context of school, work, home, family and social life)
SOCIAL NETWORKS	accounts of social, peer, family and patient-led networks, and social support, interaction and informal care within these
INTERVENTION EXPERIENCE	accounts of formalised Long Covid care/service experience
LONG COVID ADAPTATION	accounts of self and bodily adaptation and recovery over time
MATERIAL CONTEXTS	accounts of social and material factors and contexts shaping life transitions
FUTURE	accounts of anticipated illness trajectory, life transition, and future

Interviews, which will last around an hour, are loosely structured and coproduced conversations, designed to explore participants' narratives and stories of their experiences [141]. Interviews will take place at participant's preferred location, and if not online via Teams or Zoom and restrictions related to Covid-19 allowing, will take place in participant's homes, in an alternative private space, or in a private room at collaborating services. All interview participants will receive reimbursement to the value of £20 for their participation in the study. Our original ethics approval (July 10, 2023) enabled reimbursement by non-cash vouchers, but following stakeholder consultations we requested (as of October 9, 2023), and had granted (as of December 9, 2023), an ethics amendment to enable receipted cash reimbursement (See also Ethics below).[3] TR and KL have extensive experience in narrative interviewing, including among young people, on sensitive topics, and on Long Covid specifically [27, 135, 138, 142].

Time-lines and network maps

Linked to baseline interviews, we will co-produce time-lines [143]. These trace biographical trajectories in time across health, illness, home, family, work, and social life. Time-lines graphically represent connections across biographical 'life-lines', also acting as an elicitation device for interview talk, once shared, as part of follow-ups. As part of interviews, participants will also be invited to map their social networks. When interviews are conducted face-to-face, time-lines and networks maps will be coproduced (using supplied materials), and in the case of remote interviews these will be generated through conversation with the participants also invited to generate their own visualisations post-interview. Time-lines and network maps generate data for triangulated analysis as well as for dissemination and intervention materials. We have generated time-lines in qualitative research before [see 143].

Following initial interviews, we gave less emphasis to the co-production of time-lines as originally proposed above. This is because the creation of time-lines was acting as a barrier to unfolding conversation in interviews, especially given that these have been undertaken remotely as per the preference of young people. We will alternatively, following consultation with young people, enable participating young people to input creatively to 'map their covid', after their baseline interview, which can include the creation of time-lines and/or other forms of visualisation. This can then be used as a prompt for further discussion in follow up interviews. We were granted ethics approvals for this (as of April 14, 2024 and August 8, 2024).

Object analysis

Participants selected for follow-up may be invited to bring (where feasible) to their follow-up interview an object. Objects can include any item deemed relevant as a means of reflecting lived experience and story-telling by participants [144]. This is entirely optional. Objects have proved excellent elicitation devices for talk about everyday illness experience and recovery in our ongoing qualitative longitudinal work with adults experiencing Long Covid in Australia. Objects have included, for instance, photographs, documents, books, music, paintings, hand-crafted objects, pets and animals, furniture, and aspects of built home or hospital environment. In addition to triangulating these data as part of the analyses of interviews, we will produce analytical reflection on the method of object analysis, as well as incorporate elements of the objects analysis into discussion at our dissemination event (See below).

Visual data and documents

We will also create opportunity for young people in baseline interviews to contribute written and visual data, should they wish. In our consultations, some young people have said that they might prefer writing down their experiences as a way of creating a story or account. Submitting written or visual materials as data, as with objects, is entirely optional, with participants being invited to consider this option at the end of their baseline interviews, including as a talking point during follow-up interviews. We are open to treating multiple forms of written and visual material as data, and will triangulate these data as part of young people's story-telling. Examples of written and visual data may include: accounts written in the form of letters; short statements submitted in response to a question for inclusion as part of curated blog communications; accounts written in the form of short stories; and visualisations. Subject to preserving anonymity, we will incorporate examples of written material into data analysis and as an element of dissemination (See below).

Participant driven and creative methods

We will consult with young people about the use of the different methods of data generation during consultation and PPI workshops (which focus on project design and emerging findings). It is important to note that the balance and incorporation of methods listed above – including timelines, the mapping of networks and object oriented interviews – is contingent upon our consultations with young people and on how the project is coproduced. We may therefore incorporate alternative additional creative methods as a supplement to interviews.

18 DATA ANALYSIS

Analysis of the dynamics of social support

We combine qualitative thematic and narrative analysis, which we will triangulate with time-lines and other materials (see above). Through triangulating multiple forms of data – interview account, written material, visualisations, objects and their description, time-lines – the study seeks to 'story' lived experience both in context and in time. A unique focus is that we are generating situated accounts of experience in time, with specific attention to how enactments of Covid and Long Covid unfold, how young people adapt iteratively, and how social networks evolve as 'assemblages' of social support [129]. This offers a situated analysis of Covid and Long Covid as matter 'in-the-making' and as materialised in unfolding everyday practices [27, 125]. As outlined in our Theoretical Framework (see above), our prime focus of analysis is how assemblages of social support and informal care adapt to their situation, and how alterations to the make-up of such assemblages potentiate social networks as resources of support and protection [125, 129]. Our analysis informs future models and practices of care enabled through peer-based, patient-led, and social network interventions, including as an adjunct to existing Covid and Long Covid services. An interview sample of 65-

70 baseline accounts with follow-ups of approximately half of these is sufficiently rich, and in keeping with our previous longitudinal studies [136, 145, 146].[1]

Analysis for actionable outputs

We will use our data analysis to co-produce, in collaboration with young people, materials for use in the delivery of training as well as patient-led advocacy and intervention. A list of intervention materials is given below (See Section 19). Young people will be consulted in relation to data analysis through the second and third of our PPI workshops (which focus on emerging findings and intervention development respectively), as well as through consultations hosted by our creative partner PositiveNegatives when designing-up project outputs. The narratives of lived experience generated by interviews, and supplemented by other materials (objects, time-lines, documents, visualisations), create the evidence base for designing-up materials for use in training, advocacy and intervention (see below). In addition to coproducing output with young people, we bring the analysis of findings into deliberative conversations with providers and stakeholders to coproduce actionable strategies locally.

19 DISSEMINATION, OUTPUTS AND ANTICIPATED IMPACT

We maximise impact in relation to research, policy and action through coproduced activity with our PPI partners (especially Long Covid Kids), creative partner PositiveNegatives, local collaborators and stakeholders, and multi-expert Project Advisory Group. It is important to note that project outputs are contingent on what is coproduced with young people and project partners throughout the project, with the list below acting as a guide.

What do we intend to produce from our research?

1 Project Report. This is coproduced between the research team, our creative partner PositiveNegatives and through collaboration with our PPI partners and workshops. Our project report, of no more than 30 pages, is a mix of accessibly synthesised findings, presented in a narrative form which is engaging, illustrated throughout, and incorporates colour. It is designed for dissemination via online networks and in printable PDF format. The Report fosters patient and public and not only academic and policy engagement.

2 A Young Person's Guide. An option is for us to produce a short, accessible and illustrated guide to living through the long-term effects of Covid that is coproduced with young people and PPI groups. Our PPI partners and our creative partner PositveNegatives will engage participants in the design and format of such output through our PPI intervention materials workshop. This ouput will be disseminated via online networks, and will be suitable for use in training (for instance, schools) as well as a platform for discussion and/or intervention.

3 Comic Strips. Our creative partner PositiveNegatives have established expertise in turning qualitative findings into animated and illustrated output for participant and public engagement, including for young people via comic formats. One option we will consider is a comic series or series of comic strips. If young people wish to coproduce such an output, we have the budget to work with participants to select and storyboard material to form the foundation for three themed comics. If this approach is taken, each comic will be 4-6 pages, and distributed online, including for use in training and advocacy. An example produced by PositiveNegatives is here: https://positivenegatives.org/story/born-julius-and-julia/comics/. It is important to note that the creative materials we coproduce with young people will be contingent on their participation in PPI and creative workshops.

4 Action dialogues. These involve deliberative consultations with small groups of people across the different sites of research among those who have a stake in developing or delivering services and/or a role in social protection, welfare and care in the lives of young people (including those involved in: clinical care; mental health; adolescent health; drugs and addictions; education; employment; social care; family services; and youth work). These consultations, undertaken in close collaboration with our local partners, invite dialogue in response to specific study findings, and will also engage young people themselves. They can be audio

recorded, subject to consent, thus generating additional data on the process of moving from research to actionable strategy. They are designed to cut across different networks of care relevant to young people and vulnerability, since many young people may not define themselves as 'patients' of 'Long Covid' and 'precarity' extends beyond illness experience. They generate dialogue on: (a) how best to action joined-up approaches across services and young people ('bridging'); and (b) how best to support informal and peer-based care within young people's networks ('bonding') [147].

5 Policy Briefs. We will produce two short themed Policy Briefs designed to engage policy experts.

6 Project Infographic. This assists in recruitment and representing the project in a simple and accessible way to participants and publics. This will also feature on the project website.

7 Peer reviewed publication. We will publish a study protocol (through NIHR), as well as analyses as peer reviewed journal papers, including open access, and in high ranking journals (such as the *BMJ*, *BMJ Open*, *Social Science and Medicine*, *Sociology of Health and Illness*). We target a minimum of 4 high ranking peer reviewed journal publications (we envisage more; see publication track record of the Co-Investigators).

8 A Dissemination Event. To pull these outputs together, we plan a dissemination event, ideally face-to-face, to which study participants, patient-led organisations as well as researchers and policy experts will be invited. We will plan this as a multi-media event, including for instance representing selected outputs (such as the comic strips, above). In addition to show-casing or launching the project outputs, the event can include roundtable discussion and short presentations.

9 Project Website. We will design an accessible project website.

10 Social Science Contribution. The analyses will contribute theoretical development on the social science of 'pandemic precarity', and specifically, how Long Covid becomes 'embodied' (See Theoretical Framework). This will lead to new theorising in relation to ecologies of social support, and how the networks of which young people are a part affect capacity or agency for recovery (See Data Analysis).

How will we inform and engage patients, service users, NHS and wider population?

1 Prior consultation to develop the proposal, revise the protocol, and design-up the project, including with community organisations working directly with young people and people affected by Long Covid and Covid Made Long.

2 Incorporating PPI partners, including Long Covid Kids and Long Covid Support, in an academic-community partnership approach.

3 Undertaking PPI consultations and workshops at key stages of the project to guide its methods and development, including through workshops on design, emerging findings, and developing intervention materials.

4 Incorporating input from PPI linked to the REACT study as part of PPI workshops, feedback and dissemination.

5 Implementing a participatory approach to research through the training and involvement of peer fieldworkers as part of the research team.

6 Generating coproduced deliberative dialogue with multiple stakeholders to turn research findings into actionable strategies locally.

7 Implementing and disseminating research in close collaboration with local community organisations and services.

8 Incorporating a creative partner, PositiveNegatives, as a collaborator in the coproduction of training, advocacy and intervention materials resulting from the research, including dissemination online and through an event which orientates towards public as well as patient engagement, and through outputs accessible to young people and to interested publics more broadly.

How will we share with study participants the progress and findings of our research?

Our project engages young people and stakeholders throughout, including through follow-up, participation in PPI workshops (including on findings and intervention), invitation to comment on draft materials, and via dissemination of output. Our mechanisms to ensure ongoing updates on project progress also include the project website, which will be designed to foster (anonymised) engagement among study participants, including through targeted activity (such as blogs and comments) and through quarterly project updates and/or infographics. Our recruitment partners will also keep study participants in touch with project output.

20 TIMETABLE

	0-3	4-6	7-9	10-12	13-15	16-18	19-21	22-24
Establish collaborations, appoint staff	■							
PPI Workshop 1 – design		■						
Clarify design and methods		■						
Secure ethics and R&D approvals	■	■						
Build website		■						
Synthesise existing qualitative data		■	■					
Advisory Group meeting 1		■						
Generate baseline interview data			■	■				
Undertake preliminary analysis				■	■			
Generate follow-up sampling				■	■			
Generate follow-up interview data					■			
Undertake preliminary analysis					■	■		
PPI Workshop 2 – emerging findings					■			
Advisory group meeting 2					■			
Generate network interview data						■		
Undertake iterative analysis				■	■	■	■	
Generate hypotheses				■	■	■	■	
Code data for intervention materials						■	■	
PPI Workshop 3 -- intervention							■	
Advisory Group meeting 3							■	
Produce intervention materials						■	■	
Disseminate findings							■	■
Action dialogues with stakeholders						■	■	■
Undertake evaluative interviews								■

21 PROJECT MANAGEMENT

Project leadership is provided by the Principal Investigator, in collaboration with Co-Investigators and collaborators, supported by the Project Advisory Group. The Project Advisory Group gives guidance at all key stages, including design, analysis and output. There are a minimum of three such meetings. Our Project Advisory Group involves leading relevant academics, clinicians, patient-led researchers, and patient-led and community-based organisations, as well as young people themselves. In addition to the Project Advisory Group we will establish a Youth Advisory Group to foster young people's engagement and coproduction in the project.

22 ETHICS

This project has ethics approval from the LSHTM Research Ethics Committee (Ref 28635, July 10, 2023). Additional NHS local ethics approval will be sought should the project seek to recruit via NHS services (as currently proposed, and given the community focus of the project, we do not envisage this being necessary). All participants will consent (written and verbal) to their participation in the study. Consent to interview includes conversations being audio-recorded. The research team will assess competency and autonomy to consent carefully, especially among younger participants (where carer or parental consent may additionally be sought for those 15 years). Participants have the option to withdraw, at any time, without reason. All young people participating in the research will receive £20 to reimburse for their time and as a token of gratitude for their participation. Our current ethics approval (Ref 28635, July 10, 2023) enables reimbursement by non-cash vouchers. Following stakeholder consultations, we requested (October 9, 2023), and had granted (December 9, 2023), an ethics amendment to enable receipted cash reimbursement.[3] Young people engaging in initial consultations and PPI workshops will have their time and costs reimbursed (as per budget justification) in non-cash equivalents in the form of a voucher, with those engaging as peer collaborators also having the option of cash payment for their time in keeping with our amended ethics (as of December 9). In the case of creative and visual materials young people have the option of these not being anonymised, with this option being discussed as part of consenting procedures (as per ethics approvals of August 8, 2024). Participants have the option of commenting on project materials. All participants can be linked to young people's support services, including linked to partnering community organisations.

23 EXPERTISE

Our investigator team comprises a PPI Lead (Long Covid Kids, McFarland) collaborating with lead social scientists at LSHTM (Professor Rhodes, Associate Professor Lancaster) and leading academics and clinicians in Long Covid and young people's health (Professor Ward, Imperial). The LSHTM team have extensive expertise in the proposed qualitative methods. We also work with young people as peer interviewers, and with creative partners in the coproduction of intervention materials.

TR, Professor of Public Health Sociology, extensive experience in qualitative methods and mixed-methods applied to health and in delivering social science research among socially marginalised populations, including young people. Tim has been working with KL on one of the longest standing qualitative longitudinal studies of adults with Long Covid, which started in May 2020, and which so far includes three waves of interviews. Tim is also delivering qualitative research with health care workers in response to Covid-19 (in Sydney and Colombia).

KL, Professor, senior qualitative social researcher, working in science and technology studies, public health sociology, and policy studies. Since May 2020, Kari has led one of the best established qualitative longitudinal studies on Long Covid among a cohort of adults linked to a clinical trial. She has experience of using participatory approaches with socially marginalised populations. Kari is also delivering qualitative research with health care workers in response to Covid-19 (in Sydney). Kari ceased contributing to the project as a Co-Investigator as of August 16, 2024.

HW, Clinical Professor of Public Health at Imperial College and NIHR Senior Investigator, with three decades of experience in research, education and applied public health. Currently leading on the implementation of the REACT study, and directing the Patient Experience Research Centre at Imperial. Helen has also developed pilot qualitative work, linked to the REACT study, among young people with Long Covid aged 18-34 (see above), and is involved in longitudinal clinical research among young people and children affected by Covid-19.

SM, Founding member of Long Covid Kids, a patient-led organisation advocating for social support and services for children and young people with Long Covid and their families. Sammie has been an active advocate on behalf of families, children and young people affected by Long Covid in the UK.

24 ENDNOTES ON PROTOCOL REVISIONS

1 In our Project Steering Group, of May 2024, it was noted that the original proposed sample of 80 baseline, 40 follow-ups, and 40-60 network interviews, was a very large sample for a qualitative study, and likely larger than it needs to be. At this point (May 2024) the project had recruited 45 young people into the baseline. Following discussion at the Project Steering Group, and ongoing reviews of transcribed interviews since, we revised our target samples downwards to between 65 and 70 baseline interviews, from which we will aim to follow-up approximately half, with approximately half of these also generating social and care network interviews. At the time of writing, the project has generated over 60 baseline interviews and ongoing iterative coding of data has indicated sufficient saturation in relation to key emergent themes, including that can be investigated further in follow-up interviews. In consultation with NIHR we will re-visit the target sample size of follow-up and network interviews 3-5 months from now (ie. between December 2024-February 2025) in light of ongoing coding and iterative analysis.

2 In practice, and as noted as part of project progress reports to NIHR, we have not recruited via NHS services but through community-recruitment methods largely through collaborations with community partners and the NIHR REACT study (see above).

3 In practice, we have used non-cash reimbursements for baseline interviews given that all of these have been online rather than in-person.