Understanding and supporting the long-term effects of COVID-19:
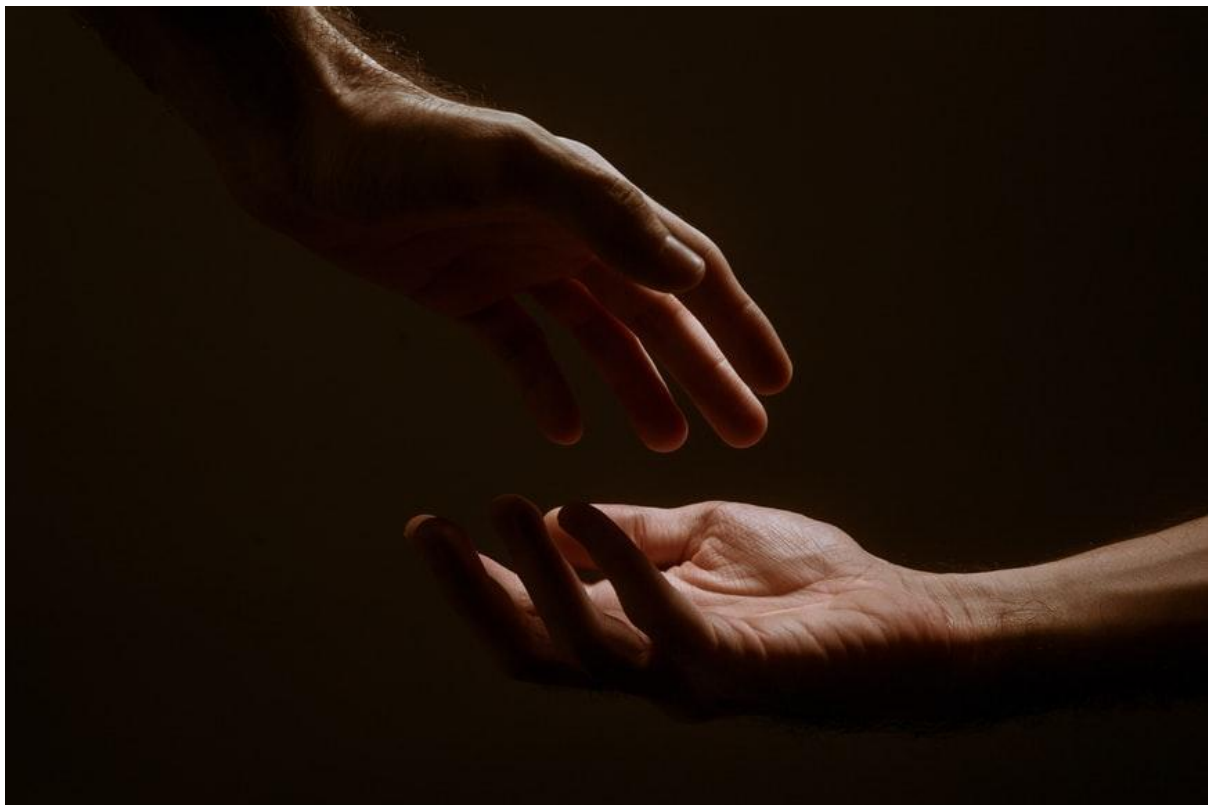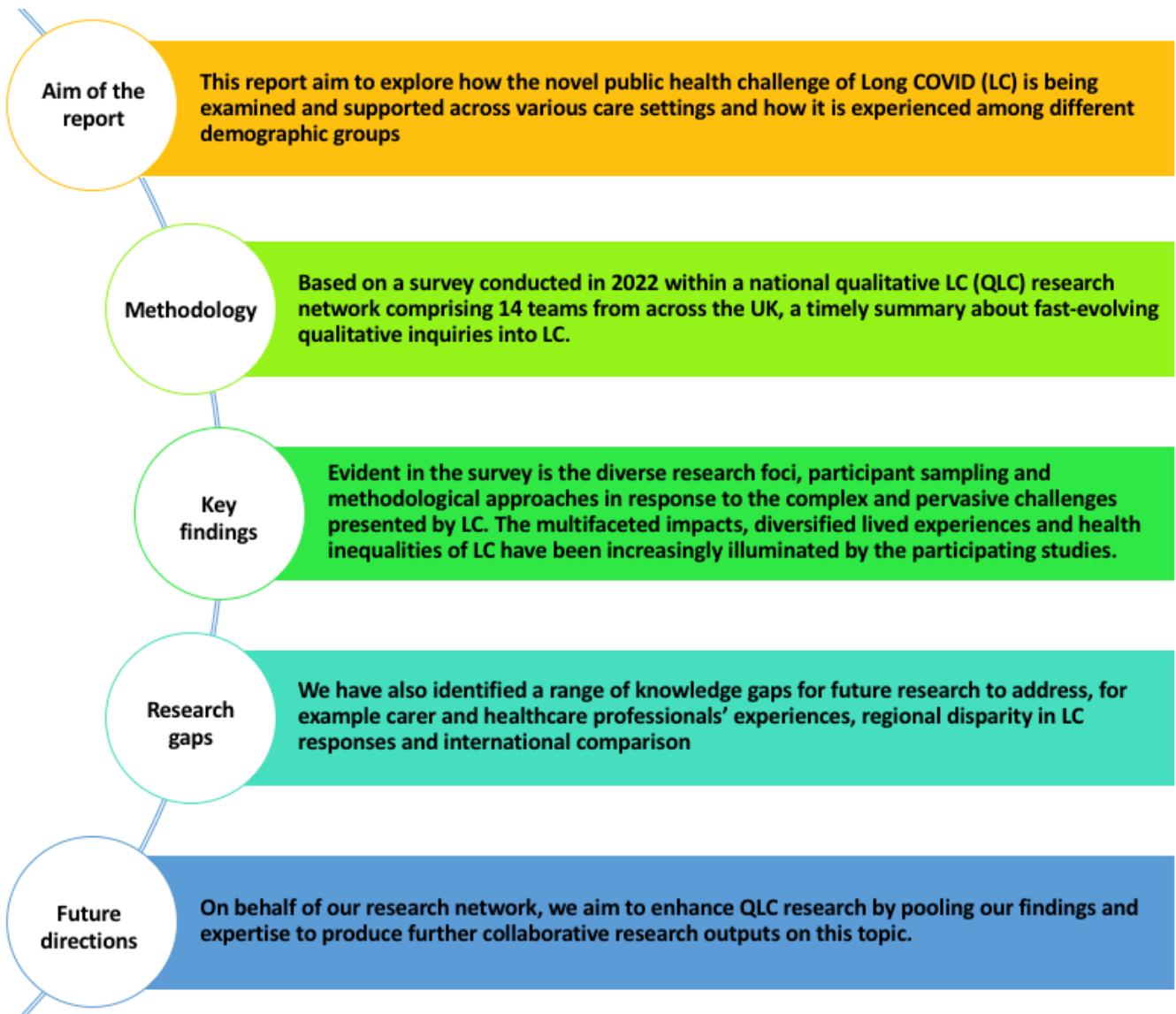## A report from the Qualitative Long COVID Research Network in the United Kingdom

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on behalf of the UK Qualitative Long COVID Research Network**

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Report summary

Aim of the report	This report aim to explore how the novel public health challenge of Long COVID (LC) is being examined and supported across various care settings and how it is experienced among different demographic groups
Methodology	Based on a survey conducted in 2022 within a national qualitative LC (QLC) research network comprising 14 teams from across the UK, a timely summary about fast-evolving qualitative inquiries into LC.
Key findings	Evident in the survey is the diverse research foci, participant sampling and methodological approaches in response to the complex and pervasive challenges presented by LC. The multifaceted impacts, diversified lived experiences and health inequalities of LC have been increasingly illuminated by the participating studies.
Research gaps	We have also identified a range of knowledge gaps for future research to address, for example carer and healthcare professionals' experiences, regional disparity in LC responses and international comparison
Future directions	On behalf of our research network, we aim to enhance QLC research by pooling our findings and expertise to produce further collaborative research outputs on this topic.

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Data availability

The data collected from the network survey that support the findings of this article are available on request from the corresponding author.

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1. Introduction

Long COVID (LC) has become a major public health issue worldwide. A broad range of persisting and fluctuating respiratory, cognitive, cardiovascular and other multisystemic symptoms have been reported, impacting patients' health, wellbeing and everyday lives.[1] The LC challenge faced in the United Kingdom (UK) is particularly significant due to the high and still increasing number of people experiencing self-reported LC symptoms (around 3.5% of the population in October 2022), as well as the increased pressure placed on already over-stretched health and social care systems.[2] The prevalence of LC has further highlighted gender, socioeconomic, ethnic and occupational inequalities, raising urgent questions about how to address LC as both a health and socio-economic crisis.[3]

The UK has provided a major contribution to LC research. Quantitative studies have played a leading role in exploring epidemiological mechanisms and pathological 'casualties' of LC using large-scale samples.[4] Despite this, understanding of the varying estimates of LC prevalence at a population level alone cannot fully capture the complexity of LC as a highly unique and embodied experience and its pervasive impacts on patients, families, carers, clinicians and service providers. A wide range of qualitative studies have been and are being conducted in the UK to develop deeper and more nuanced understandings of how LC is experienced, understood and supported in varied care and societal settings (see **Figure 1**, **Table 1**). People living with LC were among the first to identify and shape the medical and social discourses of it.[5] The bottom-up approach of focusing on people's experience and care provision adopted by these qualitative studies can provide further insights into individual experiences, complementing quantitative studies to provide better understandings about the contexts, mechanisms, development and treatment for LC.

A national Qualitative Long COVID (QLC) network was formed in September 2021 bringing together UK-based qualitative studies. The main aim of this network is to maximise mutual learning and support for LC across varied socio-demographic groups and settings. The group was formed following meetings between lead investigators of NIHR funded LC studies.[6] The network was subsequently expanded through existing members' research networks. It currently consists of over 50 members across 11 UK-based research institutions. Frequent research seminars have been held to share results, facilitate communication and mutual learning. By summarising studies in our network, we intend to provide a focused overview of the types and value of qualitative approaches to understand the complexities of LC in the UK. As such, we seek to use this article to 1) attract more national and international qualitative researchers to join the network, 2) pool expertise and findings across diverse qualitative studies, 3) feedback up-to-date research outcomes to people with LC and wider society. We acknowledge that there are other qualitative LC studies being conducted outside our network.

2. Methodology

To capture the qualitative studies within the QLC network, a survey was sent to the network members in April 2022 via email communication. The survey asked for project teams to provide descriptive details of their study, including study aim(s), research design, methodology, sample, place of care for acute COVID-19, areas of interest and current progress. Altogether, 14 teams responded and provided details of their study. All studies are taking place in the UK. **Table 1** summarises each study. **Figure 1** depicts the duration of the studies and the years during which they are running.
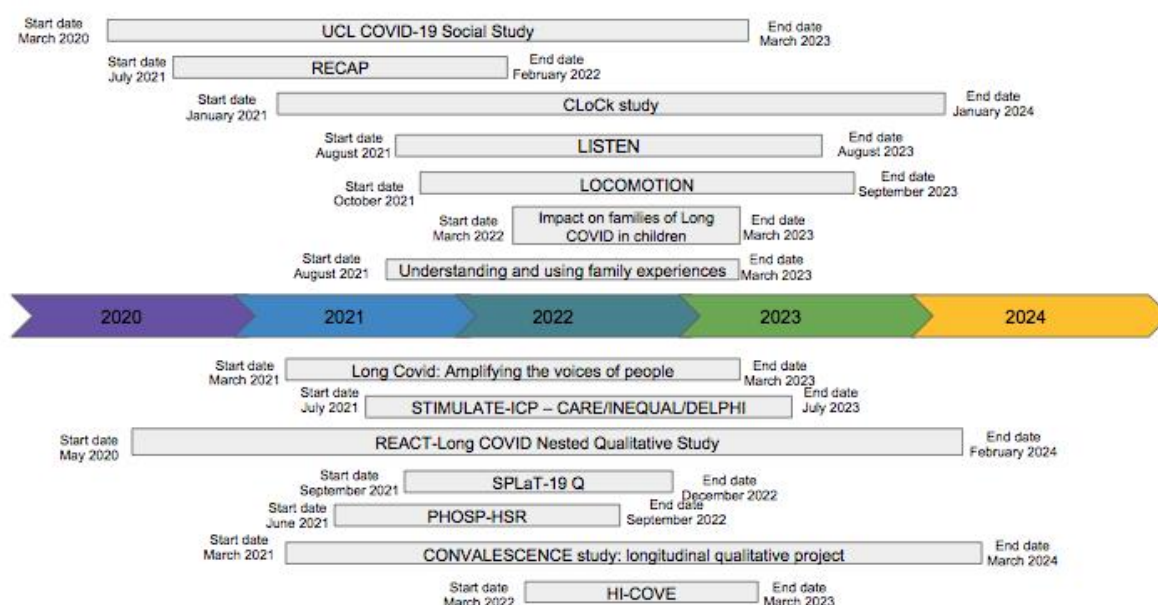

Figure 1: Timeline of Long COVID qualitative studies involved in the QLC network

3. Research summary

The QLC network survey results have captured 14 qualitative studies being conducted across the UK. The earliest study, UCL COVID-19 Social Study, can be traced back to March 2020, whilst most studies commenced in 2021. By focusing on the long-term and often multifaceted effects of living with LC, the studies in our network have paid attention to a wide range of areas, including symptoms and recovery experiences, access to healthcare, impacts on family, social, working and education lives, wellbeing, mental health, social and ethnic inequalities, as well as care and support development. As such, a rich body of evidence is being collected to illustrate the diverse experiences and needs of those living with or caring for people with LC in varied healthcare and societal settings. These understandings can help further characterise the specifics of LC and inform future practical support. In conducting qualitative

research to develop academic understandings of LC and practical support mechanisms, the studies illustrate the importance of empowering, working with and putting people with LC and their social support networks at the heart of research.[7]

All of these 14 qualitative projects have adopted semi-structured interviews as a primary data collection method, while some (e.g., RECAP, LOCOMOTION, LISTEN, STIMULATE-ICP) have used additional focus groups as an interactive platform to gain insights into LC related challenges and support gaps. Creative and multimedia data, such as photographs, drawings, diaries and theatre-based workshops, have also been collected from a few studies, including the 'impact on families of LC in children' study, SPLaT-19 Q and HI-COVE. These participatory approaches aim to utilise creative means to work with participants to promote public engagement in their findings and holistically incorporate individual experiences into the research process. Some studies in our network use mixed-methods approaches. For instance, CLoCk, LOCOMOTION, PHOSP-HSR and STIMULATE-ICP aim to combine macro quantitative data and micro qualitative data (including individual interviews and focus groups) to seek both depth and breadth of the issues and explore interventions and treatments for LC. Given the persisting and often fluctuating nature of LC symptoms and the fast-evolving LC care provision in the UK, LOCOMOTION and the qualitative workstream of the CONVALESCENCE study have adopted a longitudinal approach conducting multiple sweeps of interviews over time. They aim to capture the ongoing experiences and changes over time of living with LC and identify resources and mechanisms to support people's changing needs in the longer term. Some studies are also making people's experiences of LC readily accessible via setting up online websites (see Healthtalks website, COv-VOICES project).

A strength of the qualitative studies in our QLC network is the focus on diverse research participants, including people with LC from different age groups (both children and adults), socio-economic backgrounds, ages, ethnicities, as well as their family members, support professionals, health and social care practitioners. Such a diverse focus is key to LC research as complexities around LC do not only entail physical/cognitive symptoms, but also cause multifaceted challenges to people's everyday lives and amplify long-standing issues prior to LC (e.g., socioeconomic inequalities and racism). In doing so, it is useful to identify both unique and shared challenges faced by people with LC from varied backgrounds, to help better develop adequate and person-centred care and support. Preliminary findings from LOCOMOTION suggest that even shared challenges can have greater impact on disadvantaged groups as a result of their more limited capacity and resources. Another strength of our network's collective work is to capture experiences from different pathways and places of care, including those initially hospitalised for acute COVID-19 and non-hospitalised people 'hidden' in the community. Such a sampling approach is particularly useful to include people with LC who have not been formally diagnosed with LC, and who could not or are unable to access healthcare. Healthcare inaccessibility is commonly reported by people with LC in the UK.[8] This inclusive approach is further evidenced by Patient and Public Involvement (PPI) in

various stages of the research process.[7] For example, CONVALESCENCE has worked closely with its PPI group to co-design the interview topic guide and shape data analysis frameworks. This process mirrors the PPI activities adopted by many other studies included here. Finally, a unique strength of these studies lies in the collaborative nature of our QLC network, by which mutual learning has been facilitated to thoroughly inform the research design and progress to maximise the diversity and productivity of qualitative understandings of LC in the UK.

4. Knowledge gaps and implications

Despite the above strengths, further qualitative inquiries are needed to better understand LC experiences and to support the management of the condition. Firstly, whilst the lived experiences of people with LC have been significantly explored in our network, there has been less exploration of the concerns and needs of their support networks, particularly carers, family members and healthcare professionals. This can be further incorporated into research to holistically inform LC support. Secondly, the studies in our network have been carried out predominantly in English and Scottish settings (while some studies have included samples from Wales and/or North Ireland, such as CONVALESCENCE, LOCOMOTION and PHOSP-HSR). Therefore, future qualitative studies may wish to pay further attention to people with LC living outside England and Scotland. Thirdly, given unevenly distributed healthcare resources across the UK, it is important to further explore and reduce regional disparities in healthcare access and provision to avoid the "postcode [geographical] lottery of care" faced by many people with LC.[8] Finally, whilst the focus of this article is on UK-based LC studies, we also recognise the importance of comparing experiences of LC and accessing healthcare services more internationally (e.g., the ADAPT study based in Australia)[9], to afford unique opportunities to examine LC both as a universal healthcare challenge and a unique socio-culturally constructed experience. This international lens can further serve to tackle LC as a global health challenge.

5. Conclusion

This article provides a snapshot of the qualitative LC studies currently taking place in the UK and illustrates the strengths of qualitative research in contributing towards this rapidly evolving field of research. The studies across the network are contributing towards developing a more holistic understanding of the experiences of and support for people with LC in the long term. The QLC network members aim to add value to each other's work, share research findings, enhance qualitative LC research and forge further research collaborations, ultimately improving the experience of living with LC. So far, the network has held regular seminars enabling research teams to share their progress and study findings. We will continue to develop the network as a platform for communication, dissemination and a pool of information for mutual learning to improve the lives of people with LC, via meetings, seminars, conferences and symposia. We invite other QLC researchers to join the network, pooling our findings and expertise, with the aim to collaboratively enhance QLC research and outputs.

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Table 1 | Summary of Long COVID qualitative studies involved in the QLC network						
Title and Funder	**Institutions & Principal investigator/Co-authors**	**Aim**	**Methodology**	**Sample**	**Place of Care for Acute COVID-19**	**Areas of Interest**
UCL COVID-19 Social Study (Nuffield Foundation, Wellcome Trust)	UCL; Alexandra Burton, Daisy Fancourt	To explore social and mental health impacts of COVID-19 on a wide range of populations, including people living with LC.	Quantitative surveys and qualitative interviews	21 LC participants in qualitative interviews (started in November 2020) and 1190 LC participants in quantitative surveys	Community	Mental health and wellbeing, identity, healthcare, lived experience
RECAP: Remote Covid Assessment in Primary Care (UKRI, Wellcome Trust)	University of Oxford; Trisha Greenhalgh	To explore remote consultations in primary care and the impact on people living with continuing COVID-19 symptoms	Individual interviews and focus groups	People who had, or believed they had, LC	Non-hospitalised	Defining LC, mental health and wellbeing, identity, healthcare and lived experience
CLoCk PhD study: Long COVID in Children and Young People - Qualitative investigation of mental health PhD Studentship (Beryl Alexander Charity)	UCL; Roz Shafran, Fiona Newlands	To understand the health of children and young people LC and their parents	Interviews with linked quantitative data	Non hospitalised children and young people aged 11-17	Non-hospitalised	Mental health and wellbeing, children, parent-child relationships
LISTEN: Long COVID Personalised Self-managemenT support - co-design and EvaluatioN (NIHR)	Kingston University, St George's, University of London; Fiona Jones, Fiona Leggat	To explore everyday experiences of living with LC and the impacts of the LISTEN intervention	Interviews and focus groups	Over 1chils living with LC; healthcare professionals	Non-hospitalised	Mental health and wellbeing, identity, healthcare, lived experience, health professionals experience of LC; recovery, treatment and

						self-management strategies, care pathways
LOCOMOTION: LOng COvid Multidisciplinary consortium Optimising Treatments and services across the NHS (NIHR)	Leeds University; Trish Greenhalgh, Ghazala Mir, Jordan Mullard	To understand health inequalities and the needs of marginalised communities with regards to LC.	Qualitative interviews	15 healthcare professionals and 30 people living with LC without support from LC clinics	People with persistent COVID symptoms	Defining LC, mental health and wellbeing, identity, healthcare, inequalities, diversity, family, employment, lived experience, health professionals
A qualitative exploration of the **impact on families of LC in children** (Middlesex University)	Middlesex University; Camille Alexis-Garsee, Dr Nicola Payne	To explore the impact of LC on child and their families to further inform healthcare practice and policy	Interviews in combination with children's drawings or photographs	Children with LC and their mothers	Non-hospitalised	Defining LC, mental health and wellbeing, identity, healthcare, inequalities, family, children, employment and lived experience
Understanding and using family experiences of managing Long Covid to support self-care and timely access to services (NIHR)	University of Oxford, Stirling, Aberdeen, Bristol, Edinburgh and The Open University; Sue Ziebland, Cervantée Wild	To explore the impact of LC on families from diverse socio-economic and ethnic minority backgrounds	In-depth narrative interviews	Children, adolescents, young people and parents experiencing LC in the family context	Non-hospitalised	Mental health and wellbeing, healthcare, inequalities, family, children, lived experience and health professionals

Long Covid: Amplifying the voices of people with lived experience to improve understanding, support, treatment and education. (Chief Scientist Office)	University of Stirling, University of Aberdeen, University of Oxford; Kate Hunt, Alice MacLean	To understand and publicly disseminate people's lived experiences throughout their LC illness trajectories and across different healthcare systems	Qualitative interviews	Adults with LC	Non-hospitalised	Defining LC, mental health and wellbeing, identity, healthcare, inequalities, diversity, family, employment and lived experience
STIMULATE-ICP – CARE/INEQUAL/DELPHI: Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways (NIHR)	UCL, University College Hospital, University of Southampton, Brighton and Sussex Medical School, University of York; Mel Ramasawmy, Amitava Banerjee	To understand how experiences and challenges of developing LC healthcare can be integrated to health systems to reinforce existing integrated care pathways	Mixed methods: surveys, interviews and focus groups, a Delphi study with patients and health professionals	1) Patients with LC (n=120) and health professionals (n=24) from six LC services involved in the STIMULATE-ICP trial; 2) people across the UK living with or supporting LC and other long-term conditions	All settings	Healthcare, inequalities, ethnicity, employment, lived experience, healthcare professionals, care pathways and resource utilisation
REACT-Long COVID Nested Qualitative Study (NIHR)	Imperial College London; Emily Cooper, Adam Lound	To explore variations in experiences of people with new and persistent COVID-19 symptoms to clarify LC determinants alongside clinical and quantitative findings	Semi-structured interviews	Up to 60 participants sampled through invitations to: 1) selected adults attending REACT-LC assessment clinics (n=10,500), 2) selected people taking part in a follow-up survey	Community	Defining LC, mental health and wellbeing, identity, healthcare, inequalities, diversity, lived experience, awareness of LC, recovery, treatment and self-management strategies

Study	Institution & Investigators	Aim	Method	Participants	Setting	Themes
SPLaT-19 Q: Symptom Patterns and Life with Longer Term COVID-19 in Children and Young People (NIHR School for Primary Care Research))	Keele University; Benjamin Saunders; Alice Faux-Nightingale	To explore the impact of LC on the lives of children and young people and their families (including personal, family, social and educational effects)	Semi-structured interviews; diary study; focus groups	1) Children young people with LC and their parents/carers, identified through General Practices, 2) professionals involved in the care of young people	Community	Children, lived experience
PHOSP-HSR: UK evaluation of NHS support post-hospitalisation for COVID-19 (NIHR)	University of Leicester; Natalie Armstrong, Rachael Evans, Charlotte Overton	To explore experiences of post COVID-19 hospitalisation care pathways from views of healthcare providers and patients	Comparative case study involving staff and patient interviews	Healthcare professionals, services managers and patients from hospital sites participating in PHOSP-COVID study	Hospitalised	Healthcare, lived experience and health professionals
CONVALESCENCE study qualitative workstream: longitudinal qualitative project (NIHR)	UCL, University of York; JD Carpentieri, Laura Sheard, Chao Fang, Sarah Baz	To understand lived experiences and engagements with healthcare of people with LC	Three waves of longitudinal qualitative interviews	1) 80 self-identified LC patients (aged between 20s to 70s) across the UK, oversampled on socio-economic disadvantages, 2) 15 healthcare professionals in Bradford	Non-hospitalised	Defining LC, mental health and wellbeing, identity, healthcare inequalities, diversity, family, employment, lived experience, health processionals
HI-COVE: Hearing from the unheard: impact of Long-COVID in black and minority ethnic groups in the UK (NIHR)	University of Westminster, Keele University, Queen Mary University of London, and the University of Southampton; Nina Smyth, Damien Ridge, Carolyn Chew-Graham	1) To understand and illuminate health inequalities of people living with LC from minority backgrounds.	Interviews and development of artwork (co-created with participants)	Adults self-reporting LC from ethnic minority groups	All (in community)	Defining LC, mental health and wellbeing, identity, healthcare, inequalities, ethnicity and lived experience