



# Policy brief: identifying mental health support gaps for people living with Long COVID

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Project:



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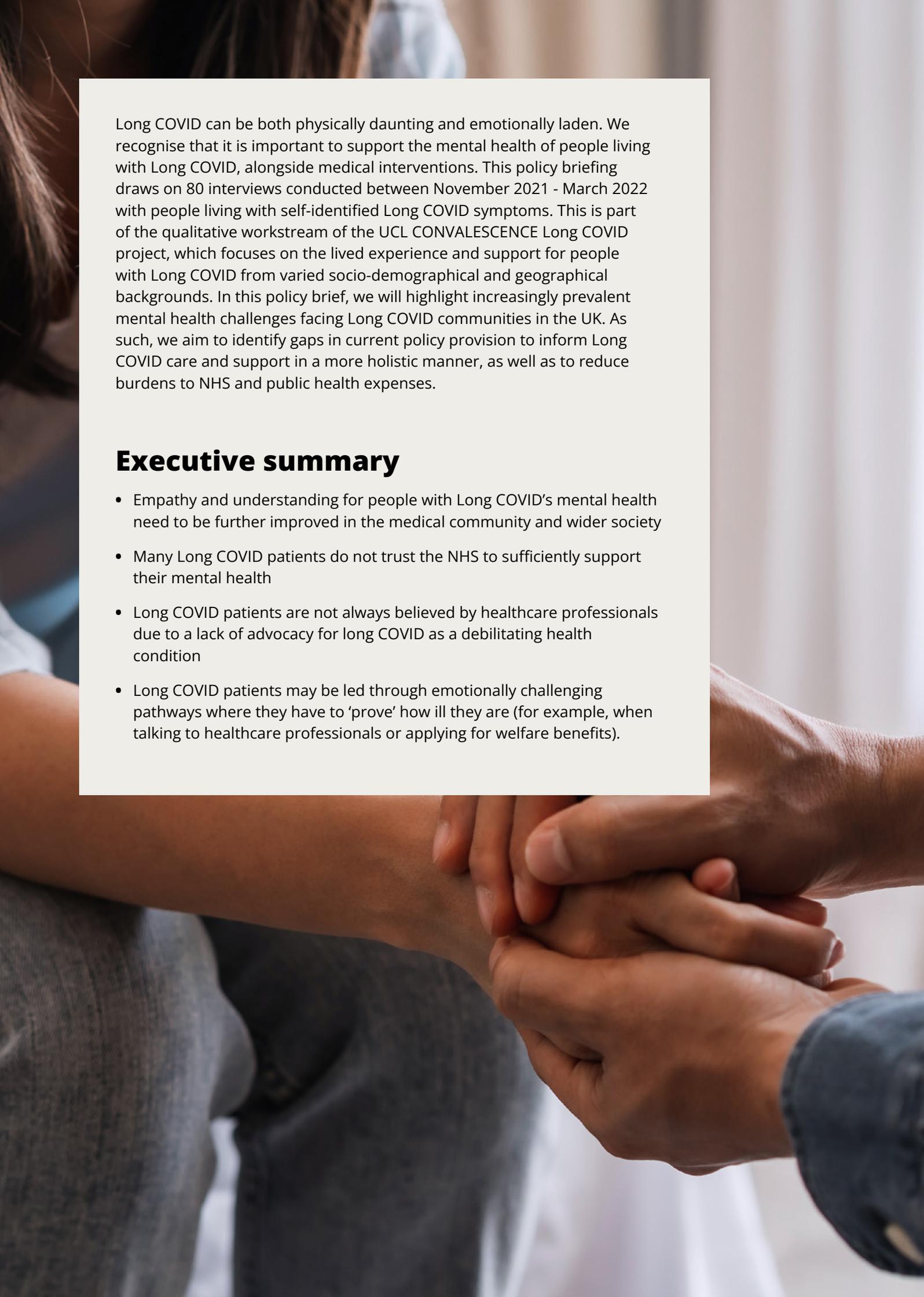


Coronavirus post-acute long-term effects: constructing an evidence base

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Long COVID can be both physically daunting and emotionally laden. We recognise that it is important to support the mental health of people living with Long COVID, alongside medical interventions. This policy briefing draws on 80 interviews conducted between November 2021 - March 2022 with people living with self-identified Long COVID symptoms. This is part of the qualitative workstream of the UCL CONVALESCENCE Long COVID project, which focuses on the lived experience and support for people with Long COVID from varied socio-demographical and geographical backgrounds. In this policy brief, we will highlight increasingly prevalent mental health challenges facing Long COVID communities in the UK. As such, we aim to identify gaps in current policy provision to inform Long COVID care and support in a more holistic manner, as well as to reduce burdens to NHS and public health expenses.

## **Executive summary**

- Empathy and understanding for people with Long COVID's mental health need to be further improved in the medical community and wider society
- Many Long COVID patients do not trust the NHS to sufficiently support their mental health
- Long COVID patients are not always believed by healthcare professionals due to a lack of advocacy for long COVID as a debilitating health condition
- Long COVID patients may be led through emotionally challenging pathways where they have to 'prove' how ill they are (for example, when talking to healthcare professionals or applying for welfare benefits).

## What is Long COVID?

Long COVID may refer to patients who experience COVID-19 symptoms 5 to 12 weeks after onset (ongoing symptomatic COVID-19), as well as those who continue to experience signs and symptoms after 12 or more weeks from onset (Post-COVID-19 Syndrome). According to [NHS](#), these symptoms impact patients' physical, psychological and cognitive health, including but not limited to:



**Fatigue**



**Mood disorders**  
(depression, anxiety, PTSD)



**Insomnia**



**Brain fog**  
(impaired attention,  
concentration, and memory)



**Muscle pain**

In February 2023, the [Office for National Statistics](#) estimated there to be 2 million individuals (3% of the population) living with Long COVID in the UK. Although there are NHS support clinics for Long COVID patients, access to these clinics is inconsistent across the UK; England has 89 Long COVID clinics since July 2021, Northern Ireland currently has one, and Wales and Scotland have yet to set up long COVID clinics.

GPs are able to provide some support, medication or referral for further testing for those struggling with Long COVID symptoms. Yet, there is no specific protocol for individuals with Long COVID and some individuals find that doctors do not believe their symptoms are real or feel they are exaggerated or prioritise severe respiratory related symptoms.



# Our Approach and Aims

The following policy briefing draws its recommendations from data collected through a series of qualitative interviews with individuals who self-identified as Long COVID patients. Our approach to this policy briefing is evidence-based as we draw on the lived experiences of individuals with Long COVID.

## Aims

- To highlight mental health challenges faced by Long COVID patients
- To identify the current gaps in mental health care for individuals suffering from Long COVID drawing on qualitative evidence
- To provide evidence-based policy recommendations to improve Long COVID mental health care both in healthcare and community settings.

## Methods

This policy briefing draws from research conducted through the CONVALESCENCE Long COVID project, particularly a longitudinal qualitative study, in which 3 rounds of interviews are being conducted over time (2021-2023) with 80 individuals with self-identified Long COVID symptoms across the UK. Participants were recruited five nationally and one regionally representative cohort studies and wider community. These cohort studies are National Survey of Health and Development (born in 1946), National Child Development Study (born in 1958), British Cohort Study (born in 1970), Next Steps (born in 1989-90) and Millennium Cohort Study (born in 2000-02), and Born in Bradford Cohort Study (parents of children born in Bradford Royal Infirmary between March 2007 and December 2010). This study has a specific focus on representing individuals from diverse backgrounds and has also oversampled individuals from ethnic minority and low socioeconomic backgrounds. It explores the lived experiences of 80 people (aged 18-75 with LC) and regional differences in LC service provision.

## Our findings

Improvements in quality of life and mental health can be incremental and non-linear, but experiences within the NHS for chronic conditions feel overwhelmingly deficient. It must be noted services that are available for chronic conditions are focused largely on 'symptom management'. There appears to be a focus and prioritisation towards respiratory issues and physical health and less support for mental health in the case of Long COVID patients.

Problems with current provisions of care mean that advocacy, trust and disability affect Long COVID patients' mental health. Here we present three findings in relation to mental health: a need for advocacy, lack of trust in current offerings of care and struggles to navigate through care systems.



# 1



## Burden of advocacy

A lack of knowledge and understanding of Long COVID patients' experiences and limited resources in NHS could create serious barriers to accessing mental health care and treatment. It is crucial to remember that these are patients who are already fatigued and suffering ill health who are having to do the 'hard and heavy work' of understanding and managing the illness and trying to navigate and obtain healthcare support (Baz, et al., 2023; Kingstone et al 2020). Long COVID forces individuals to redefine their roles, interests and passions. Many individuals experience changes and losses in identity as they now see themselves as a chronically ill person.

A repeated sentiment throughout interviews when asked about previous knowledge of Long COVID is:

"This is a significant illness for me that lasted, and I still have symptoms. And you don't know those symptoms, and nobody can tell you."

**(White British, male, 63, London)**

These patients are still dealing with the reality of living with a chronic illness and should not be using limited energy to justify their symptoms.

Across our interviews, there appeared to be a common narrative that people with Long COVID experiences and mental health issues were not well understood or even dismissed by healthcare professionals. One patient, when describing

seeking medical help for neuropathy (pins and needles which may cause weakness, numbness, and/or pain), recalled:

"I mean when I went into hospital, I had a terrible experience [...] they'd been quite excited, I think really, because they thought I had Guillain-Barré Syndrome, [...] which is a life-threatening syndrome, and that of course got them all excited. And then the next day I was seen by a whole team of people, ITU and neurologists and everything. And the neurologist said, 'no, this is not Guillain-Barré, this is functional'. This is in her head, basically."

**(White British, female, 51, South East)**

Not only does this attitude exacerbate existing mental health issues, but also erodes trust in healthcare and may prevent people from seeking out help in the future. This patient ended up seeing a neurologist six months later, who confirmed the neuropathy was likely caused by the COVID infection. Additionally, patients are often left to research and demand access to resources themselves.

# 2



## Mistrust

Our research has evidenced a lack of trust between individuals and the NHS. Many Long COVID sufferers do not seek help for physical or mental illness citing previous trauma from past experiences and belief that the NHS would be unable or not want to help them. For example, one participant stated:

“I was terrified, I was really scared and I just thought that there’s nothing the doctor can do to help me anyway. So that’s why I didn’t seek any help.”

**(British Pakistani, female, 33, East Midlands)**

Another participant (British Pakistani, female, 24, Bradford) discussed how their previous experiences with their GP lead them to feel that their ‘doctors aren’t really that good in that sense anyway, so I wouldn’t even go to them for help’. This lack of trust and confidence in their healthcare can lead to poorer recovery. Furthermore, this causes individuals to alienate themselves from other avenues of mental health support. Confidence in healthcare can also be eroded due to difficult experiences and the fragmentation of care. Fragmentation in care makes it difficult for individuals to receive the quality support they need and creates additional pressures (such as, using having to use their energy to understand how the healthcare system works or to find out what to do next) that may exacerbate mental health issues such as anxiety and depression.

# 3



## Struggles to navigate through care systems

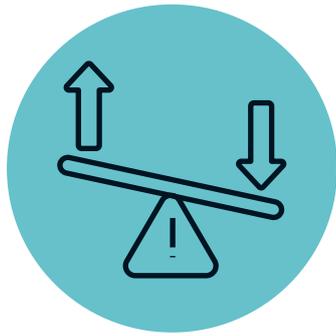
We found that people with Long COVID had to negotiate access and eligibility for care with healthcare professionals. This issue can be addressed by offering advocacy and education more widely about Long COVID to make more mental health support available for the condition. One patient described:

“So they wouldn’t believe me at first. They, they were basically very resistant to refer me to anyone’...you [are], probably faking it, which was, you know, not great seeing as I’d fought so hard to get that referral.”

**(Mixed race, female, 21, London)**

This participant had fought hard for their referral and had repeatedly identified themselves as a candidate for care. However, the participant was continually denied the help they required. This could have been possibly due to a lack of information available to healthcare professionals about Long COVID.

# 4



## Addressing current gaps

In light of these findings, we argue for the following gaps in services to be addressed:

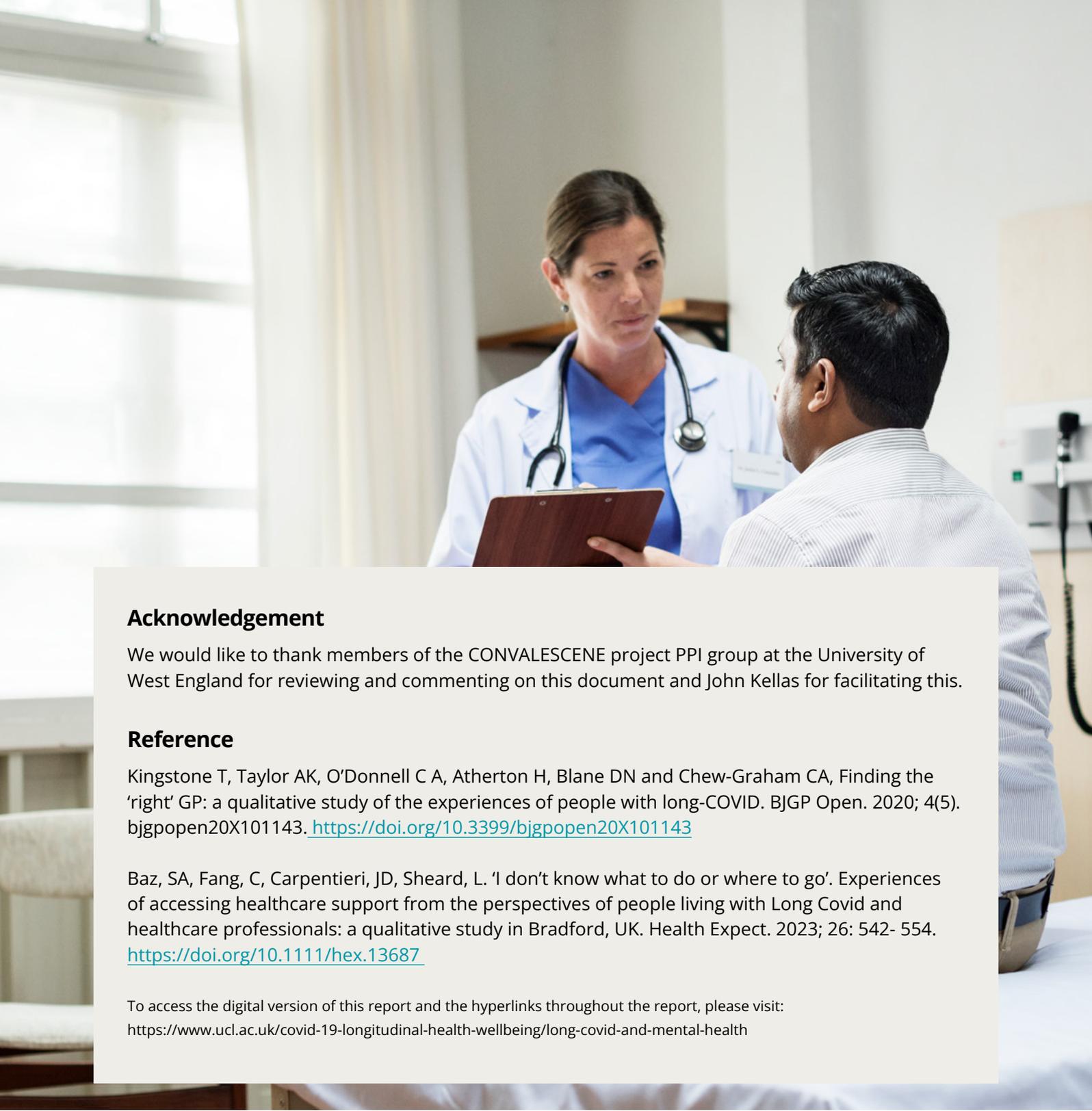
- Regional disparities in mental health services must be addressed
- The evidence shows a lack of understanding from healthcare professionals. Improved service provision that provides continuity in care and support for people with LC needs to be more apparent
- We need to take into account the differential experiences which can be influenced by social background and social inequalities
- The difficulties accessing mental health care must be addressed to better support people with LC.



## Conclusion and recommendations

It is well acknowledged that there is an ongoing mental health service crisis (e.g., long waiting times) and thus it is essential to provide timely mental health support to people with Long COVID. The experiences of individuals with Long COVID reveal gaps in current mental health services offered by the NHS for those with chronic conditions. Long waits between referrals, negative and invalidating experiences with healthcare professionals, and a lack of understanding of Long COVID prevent individuals from accessing the care they need in the UK.

- Specialist mental health support for Long COVID patients to be consistently available throughout the UK
- Educational training for GPs/healthcare providers informed by Long COVID patients' experiences
- Long-term continuing support for chronic conditions beyond just "symptom management"
- Public community awareness about experiences of Long COVID and hidden disabilities.



## Acknowledgement

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## Reference

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To access the digital version of this report and the hyperlinks throughout the report, please visit: <https://www.ucl.ac.uk/covid-19-longitudinal-health-wellbeing/long-covid-and-mental-health>

Cohort studies

