



**AUT CENTRE FOR
PERSON CENTRED RESEARCH**


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Psychosocial experiences of Long Covid

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Long COVID: Journeying together through the fog symposium, May 2022



The making of
Long Covid:
from individual
to collective
narratives

“There are strong reasons to argue that Long Covid is the first illness to be made through patients finding one another on Twitter and other social media..”

Callard & Perego (2021)



Patient-Led Research Collaborative: embedding patients in the Long COVID narrative

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Abstract

A large subset of patients with coronavirus disease 2019 (COVID-19) are experiencing symptoms well beyond the claimed 2-week recovery period for mild cases. These long-term sequelae have come to be known as Long COVID. Originating out of a dedicated online support group, a team of patients formed the Patient-Led Research Collaborative and conducted the first research on Long COVID experience and symptoms. This article discusses the history and value of patient-centric and patient-led research; the formation of Patient-Led Research Collaborative as well as key findings to date; and calls for the following: the acknowledgement of Long COVID as an illness, an accurate estimate of the prevalence of Long COVID, publicly available basic symptom management, care, and research to not be limited to those with positive polymerase chain reaction and antibody tests, and aggressive research and investigation into the pathophysiology of symptoms.

Keywords: Long COVID, COVID-19, Patient-led research, Patient-centric, Long haulers, Post-acute sequelae of SARS-CoV-2 infection, Post COVID-19 syndrome, Patient-centered

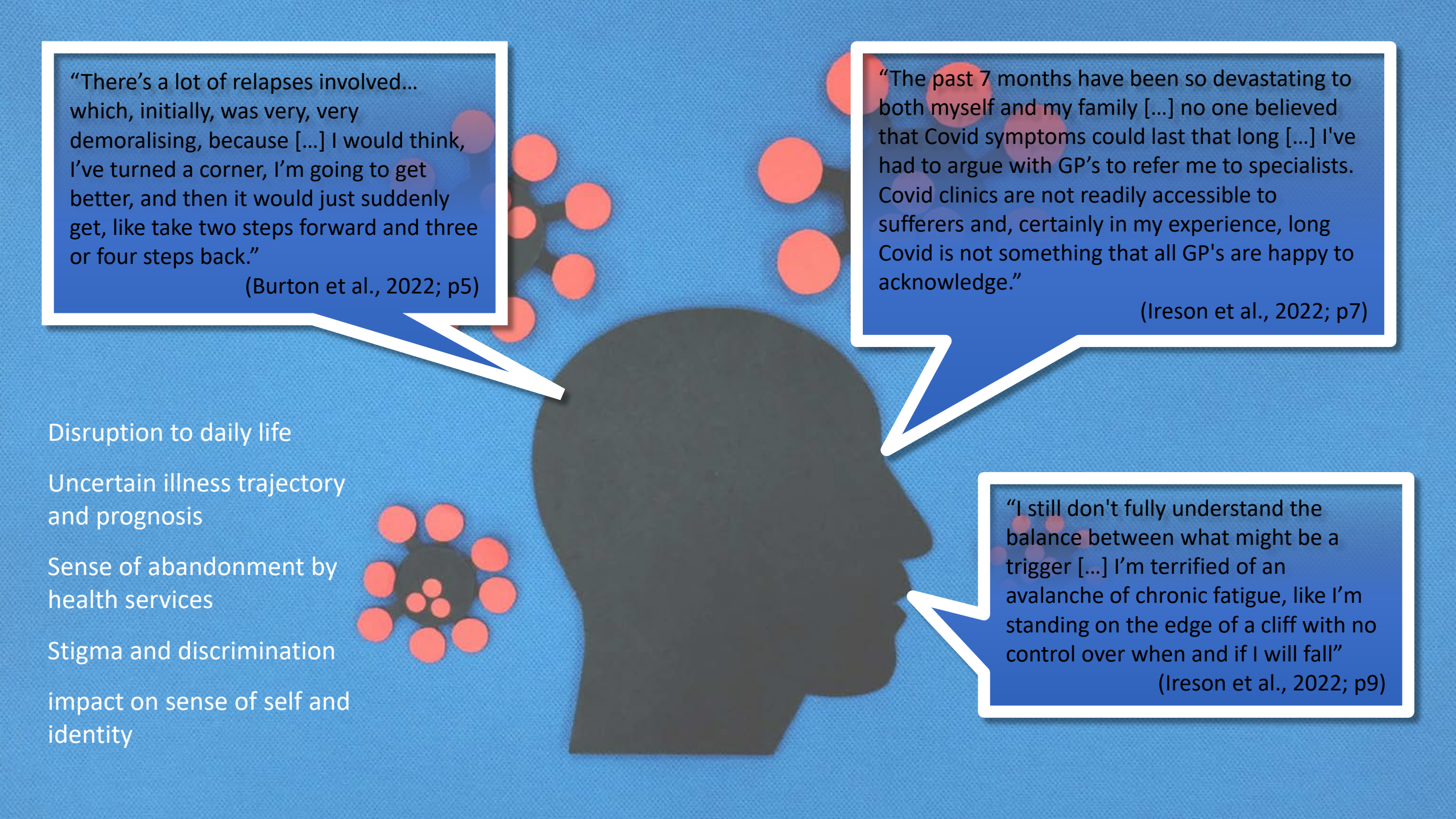
PATIENT-LED RESEARCH COLLABORATIVE

HOME RESEARCH TEAM RESOURCES CONTACT US SITE MAP

About the Patient-Led Research Collaborative

About

The Patient-Led Research Collaborative is a group of Long Covid patients who are also researchers. We were born out of the [Body Politic Slack support group](#) and did the first research on Long Covid in April 2020. We are all researchers in relevant fields – biomedical research, participatory research, neuroscience, cognitive science, public policy, machine learning, human-centered design, health activism – in addition to having intimate knowledge of COVID-19.



“There’s a lot of relapses involved... which, initially, was very, very demoralising, because [...] I would think, I’ve turned a corner, I’m going to get better, and then it would just suddenly get, like take two steps forward and three or four steps back.”

(Burton et al., 2022; p5)

“The past 7 months have been so devastating to both myself and my family [...] no one believed that Covid symptoms could last that long [...] I've had to argue with GP's to refer me to specialists. Covid clinics are not readily accessible to sufferers and, certainly in my experience, long Covid is not something that all GP's are happy to acknowledge.”

(Ireson et al., 2022; p7)

Disruption to daily life

Uncertain illness trajectory and prognosis

Sense of abandonment by health services

Stigma and discrimination

impact on sense of self and identity

“I still don't fully understand the balance between what might be a trigger [...] I’m terrified of an avalanche of chronic fatigue, like I’m standing on the edge of a cliff with no control over when and if I will fall”

(Ireson et al., 2022; p9)

The background features a dark blue field with several red, spiky virus-like particles. There are also abstract orange and grey shapes, including zig-zag lines and a tangled grey line. The overall theme is related to health and the impact of a virus.

“Nobody is listening. I feel
debilitated and so depressed.”

“When patients were not listened to, it created a plethora of **missed learning and service delivery opportunities for the healthcare profession**. It also had a **significant impact on the care received** by the participants. By not listening or hearing their concerns, **the healthcare system left them vulnerable** to both the physical and mental impact of the virus, the emotional impact of being left to cope alone and the psychological impact of not being taken seriously.”

(Ireson et al., 2022; p7)



HOW MIGHT WE MOVE...

FROM...

A health and social system which contributes to and exacerbates the psychosocial trauma experienced by people living with long Covid

TO...

A health and social system which listens to and values lived experience and which bolsters psychosocial resources for navigating life in the context of long Covid



A starting point might be to...

1 Listen to and acknowledge the lived experience of people living with long Covid

2 Co-design clear flexible, and accessible pathways of care for long Covid

3 Treat every encounter with the health system as inherently psychosocial

4 Pay explicit attention to psychosocial experience and outcome

5 Practice humility and 'intellectual candour'

6 Remain emotionally aware and reflexive

In summary

- Navigating life in the context of long Covid is as an inherently psychosocial process which has a profound impact on peoples lives
- Interactions with health services have so far exacerbated peoples trauma
- We need to get to know, understand and value
 - The unique and specific experience of individuals
 - The collective experience of the long Covid community
- An opportunity to design for positive psychosocial experiences and outcomes from the outset

