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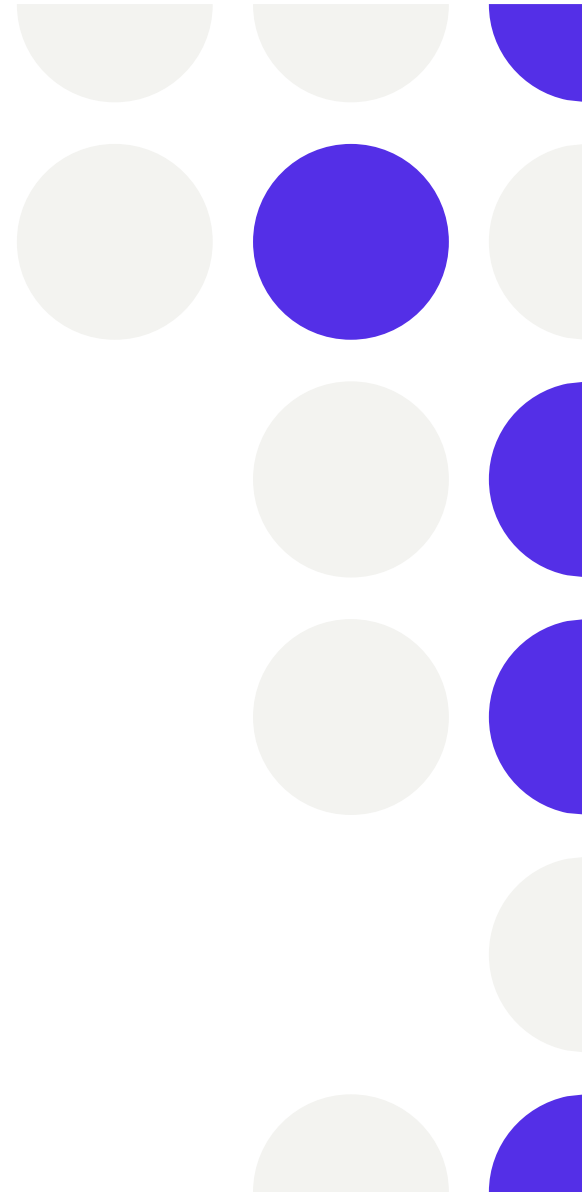
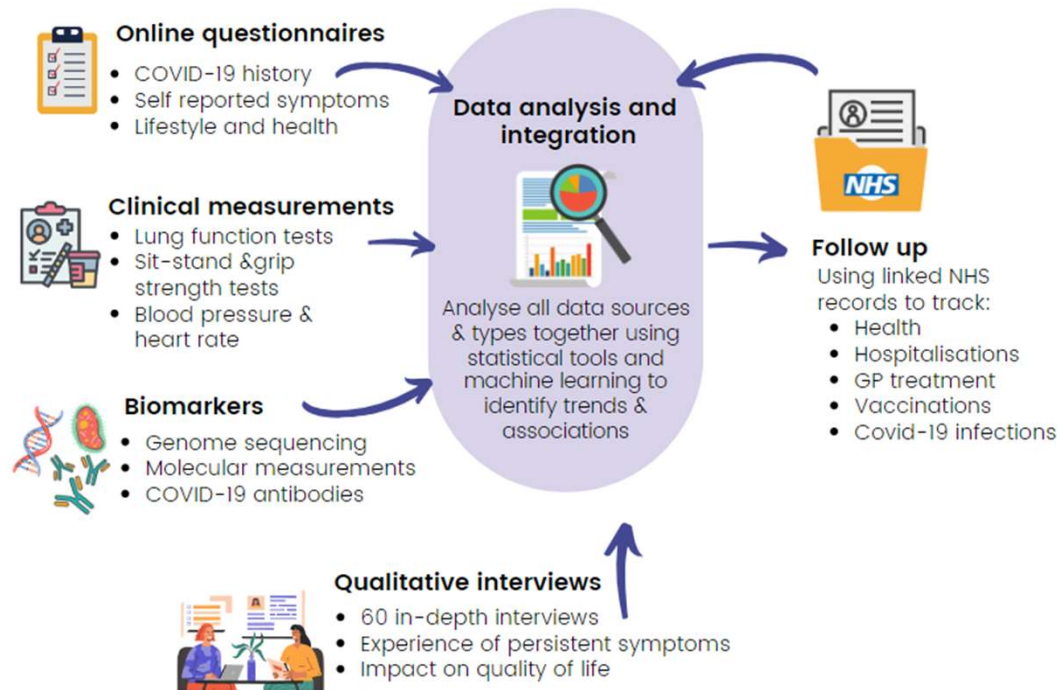
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REACT-Long Covid

Recognition, support and self-management in Long Covid:
Public involvement and qualitative findings from the REACT-
LC study

Emily Cooper, Research Assistant, Patient Experience Research
Centre, Imperial College London, UK

Background



Study methods

- Recruitment for the interview study was focused on people reporting persistent symptoms for 12 or more weeks following symptomatic COVID-19 who either (a) attended one of the REACT LC assessment clinics or (b) completed the REACT-LC Health and Wellbeing survey and consented to be approached for interview.
- 60 semi structured interviews were conducted on-line using MS Teams or Zoom by one of two interviewers (EC and AL) and audio recorded with permission. Interviews lasted around an hour.
- The topic guide used was initially developed for the pilot interview study (1). It was informed by existing literature and shaped by the REACT public advisory committee.
- Interviews were broad in scope. They focused on experience of acute and persistent symptoms, the impact of those symptoms, plus diagnosis and management as well as pre-pandemic life, self-management and 'recovery'

(1) Cooper E, Lound A, Atchison CJ, Whitaker M, Eccles C, Cooke GS, et al. Awareness and perceptions of Long COVID among people in the REACT programme: Early insights from a pilot interview study. PLoS One. 2023;18(1):e0280943.

Shaping the qualitative study research question

Our public advisory group helped to shift our research focus from experiences of 'recovery' to explore the ways people respond to their symptom in the context of uncertainty

Input from our public advisor group (PAG)



Including the PAG in deciding the research question



In March 2023 the research team held a quarterly meeting with the public advisory group to discuss a potential research question for the main qualitative study. The idea of a paper on 'recovery' had been suggested by some advisors



In the meeting a debate occurred about the appropriateness of the term 'recovery' in the context of persistent symptoms of Covid-19.



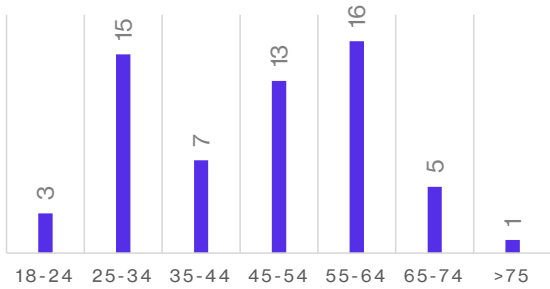
It became apparent that whilst the terminology used and the beliefs about the trajectory of the illness experience were different, there was a common ground where all individuals responded to and managed with their symptoms.

Some of the advisors felt 'recovery' was an **alienating** and **unachievable** concept for many, who were instead 'living with' the condition with little to no hope of getting better.

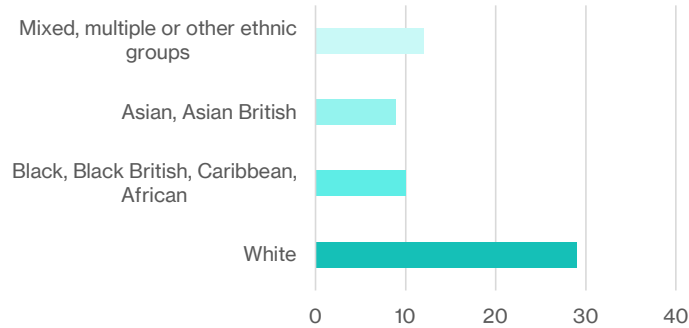
- For others in the group, recovery was the **only acceptable outcome** and 'living with' was an unacceptable term that suggested a permanency of their condition.

Overview of sample

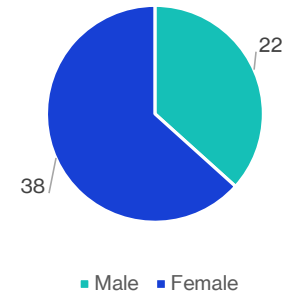
Age



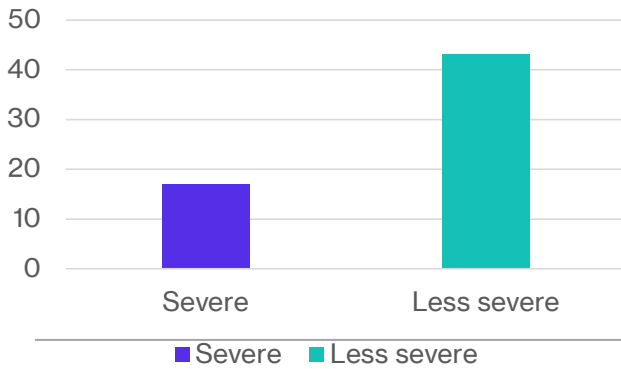
Ethnicity



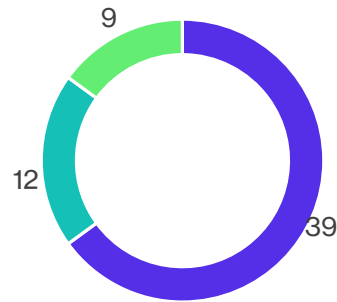
Gender



Severity of LC symptoms



Description of symptoms



FATIGUE
BREATHING ISSUES
COGNITIVE SYMPTOMS
LOSS OF TASTE AND SMELL

- Used term 'Long Covid'
- Did not use term 'Long Covid'
- Ambivalent

Not seeking clinical care

Reasons for not seeking help varied:

- Some did not attribute their ongoing symptoms to COVID-19,
- Offered alternative explanations such as ageing, menopause or deconditioning.
- Others felt that their symptoms were manageable without treatment
- Some did not want to burden the National Health Service (NHS)
- Some suggested that seeking treatment was futile since there was no available treatment.

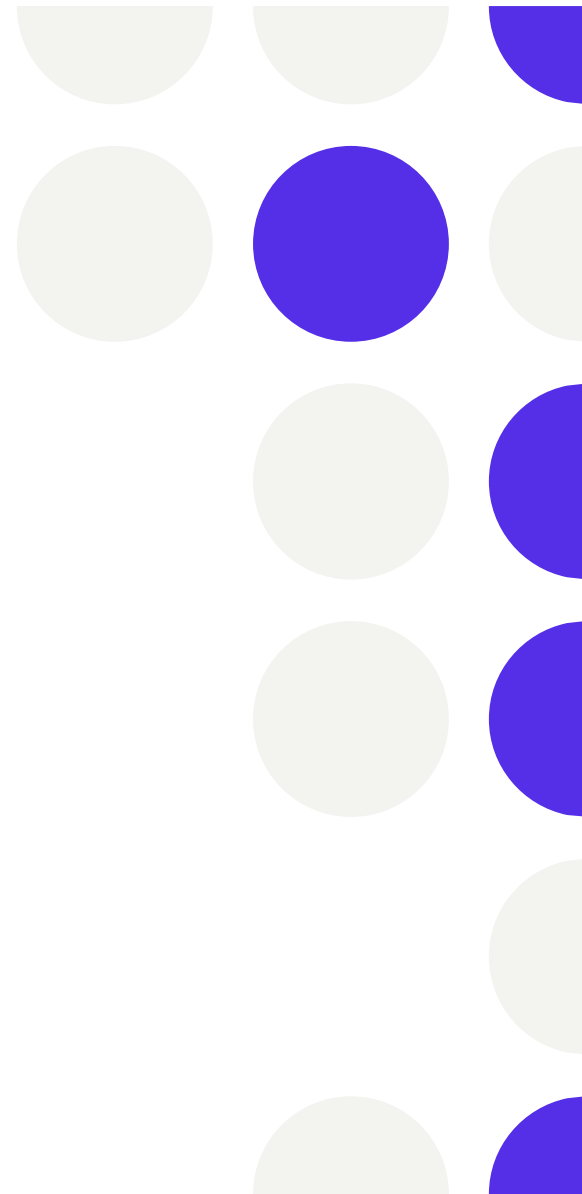
“I haven’t heard of anyone saying that they’ve got professional help for Long Covid and it’s helpful and a game changer”



Feeling excluded from support

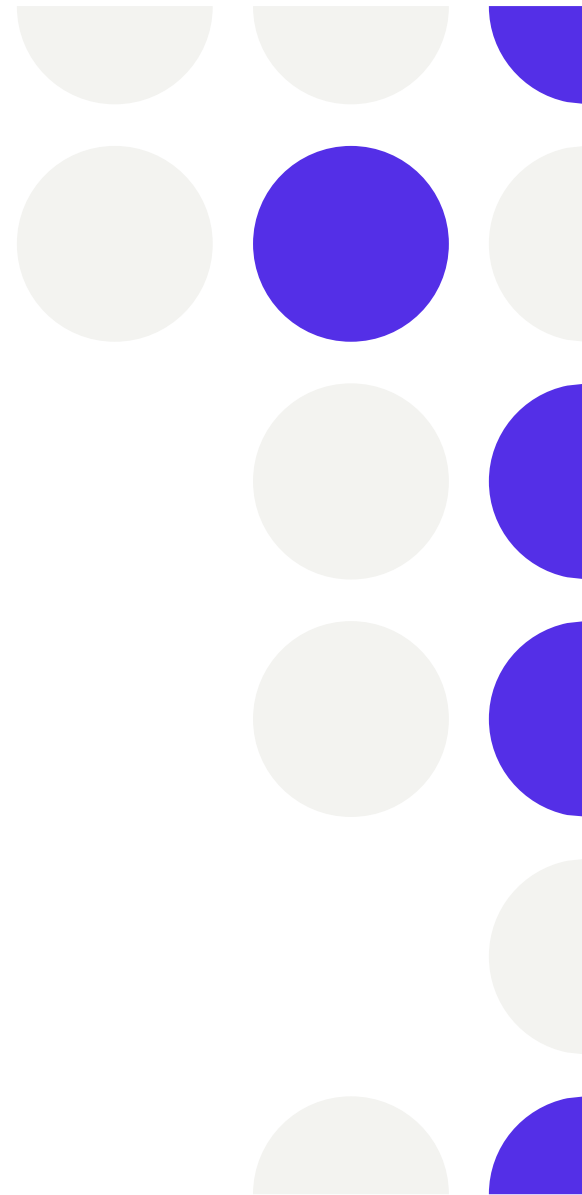
“Because everything I’ve come across feels very geared for people who I feel are more poorly than I am. I feel as if there isn’t a sort of, ‘not extreme’ support group. It always feels as if everyone else has very extreme symptoms, and I feel like an imposter in a group”

““Because they were getting treatments, people were seeing neurologists, they were seeing cardiologists, I was thinking, “How did you get access to that?””



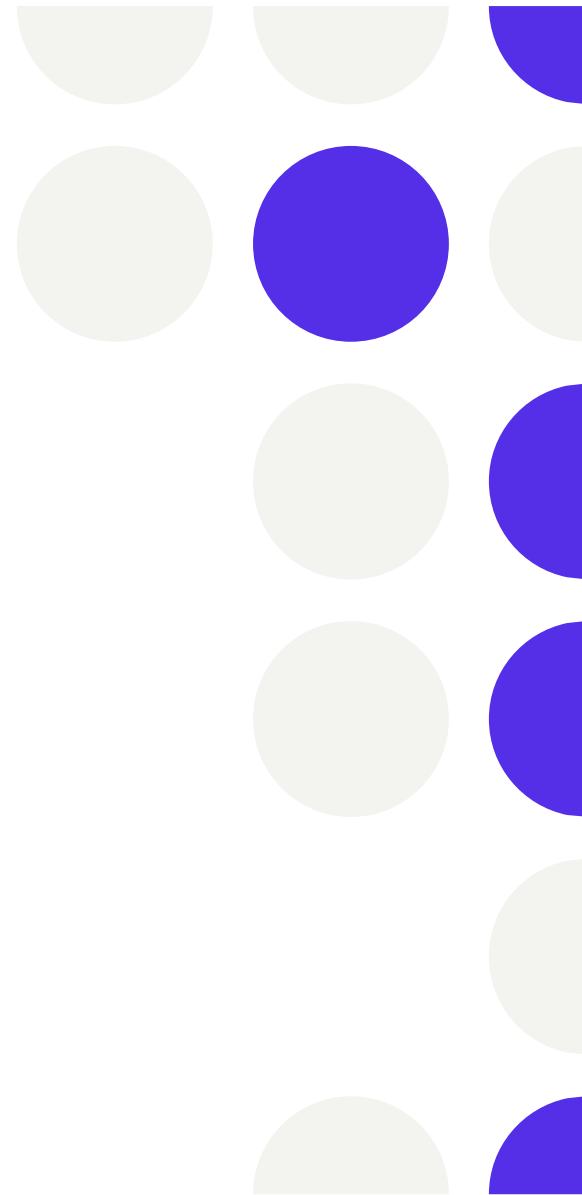
Reacting to and working around symptoms

“Because you knew you were going to run out of energy, towards the end, you'd start to feel the fatigue coming...If I still had three things, whatever it was, I wanted to get done that day, I'd be going faster and faster to try to achieve what I wanted to achieve that day.”



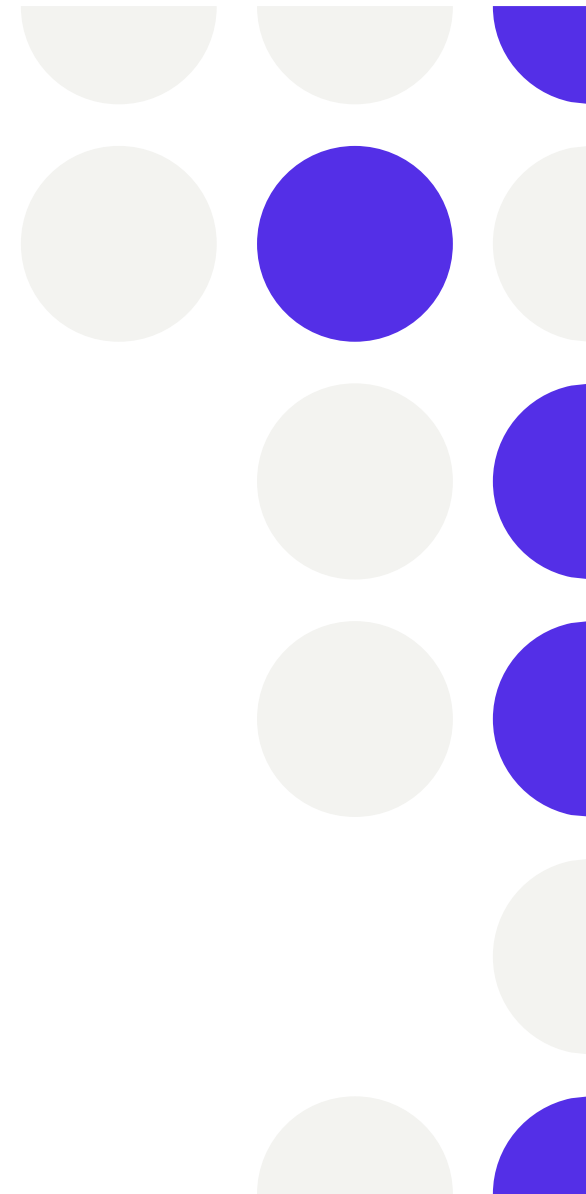
Trying to treat symptoms for themselves

- *“We have a forum where we talk about what we are eating, the diet. We talk about health. We talk about the symptoms, manifestations...”*
 - *“I’ve met a doctor, consultant, researcher who said the way they treat Long Covid is just give people high doses of vitamin D. Well, that’s what I did. I went and bought high doses of vitamin D”*
-



Support needed to ‘help me manage’

“I think it’s that subtle difference in expectations that hasn’t got rid of the fatigue, it hasn’t got rid of the insomnia. It has, however, made things more manageable...If I need to stop and take a two-hour nap, I can work until later in the evening. It’s those nuances in the, “We still expect you to do what you’re expected to do, but you can do it at your own pace.”





Public involvement and engagement

Throughout the REACT-LC study we have sought to engage with members of the public, to share our ideas and shape our understanding. We have especially tried to include those with lived experience of persistent symptoms of Covid-19 .

We have held online events, attended community events and produced update reports about our research as well as sharing findings and updates via our website and social media.

Imperial College
London

REACT Long COVID

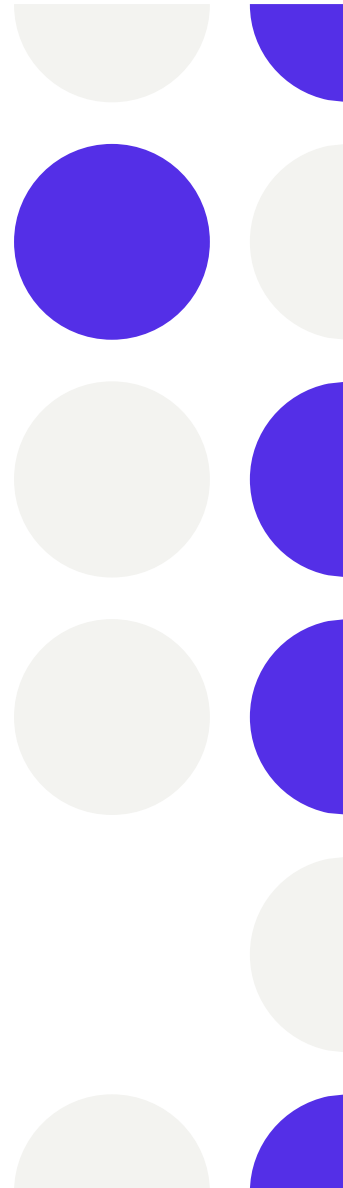
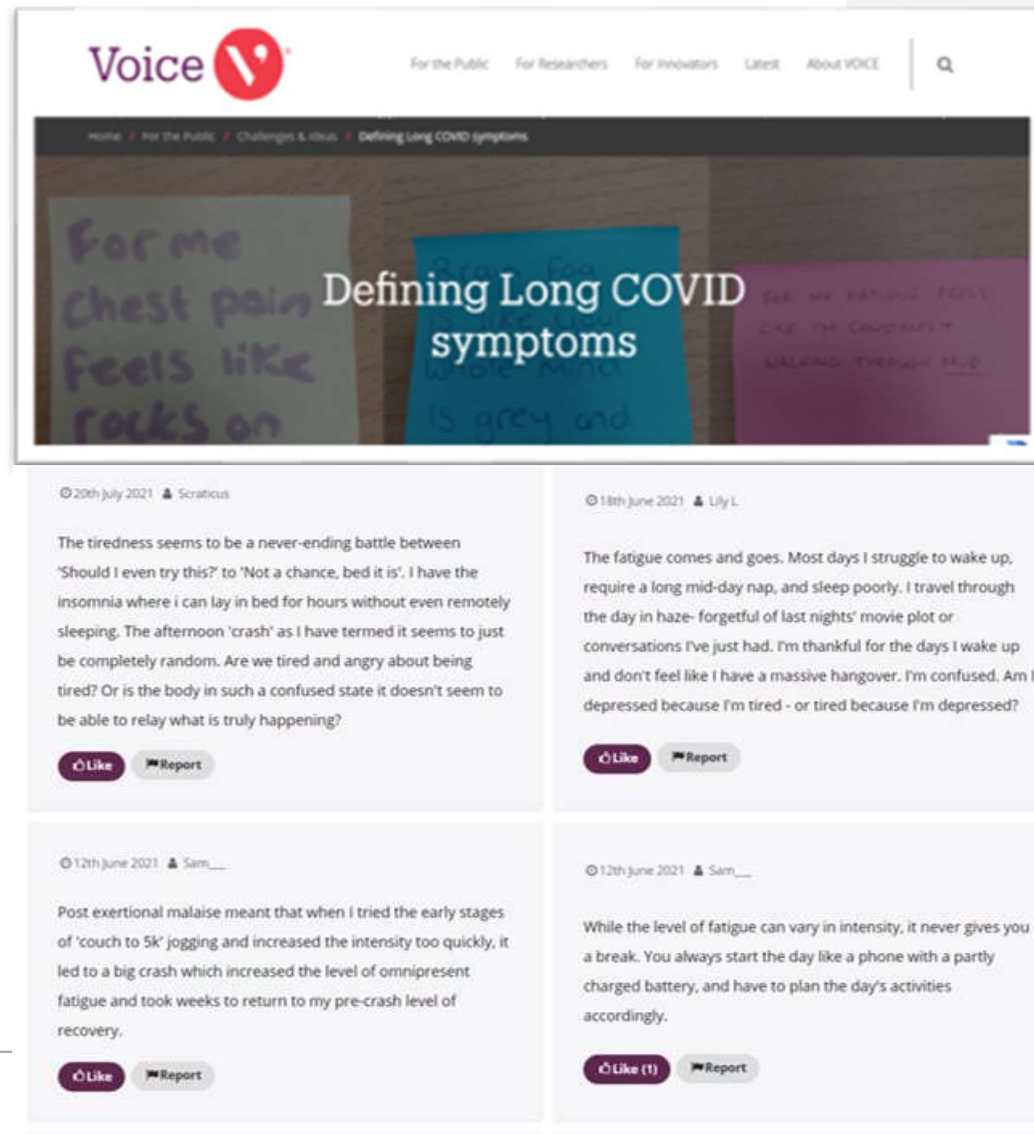
Continuing progress

March 2024



Defining Long Covid activity

We worked with our public advisor and illustrator [Monique Jackson](#) to develop illustrations which visually capture the range and impact of Long COVID symptoms shared on our online involvement platform



Shortness of Breath

'...lower ribcage has a tight band round so I can't inflate my lungs'



Loss of taste or smell



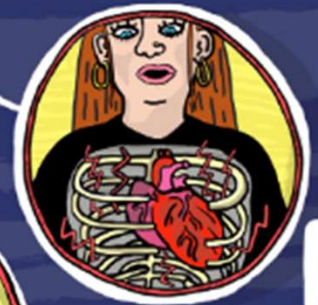
Reflection of impact of symptoms on life:

'I feel like I'm trapped in a body that I don't recognise. I used to run 5k 3-4 times per week, was very sociable and a high achiever at work.'



Palpitations

'...like my heart is hitting ribcage and is going to jump out of my chest'



Gastric issues, bloated stomach and nausea

'I have episodes anything from a few weeks to a couple of months apart with the same - onset whilst eating or immediately on finishing - severe lower lower abdominal pain, cramp & diarrhoea for 24hrs to a week.'

Brain Fog

'My head feels as if it is full of cotton wool. I'm unable to read effectively, miss word order & forget what I'm saying'



Joint Pain

'my body feels as though my joints have been smashed with a sledge hammer'



'While the level of fatigue can vary in intensity, it never gives you a break. You always start the day like a phone with a partly charged battery, and have to plan the day's activities accordingly'

Fatigue

'it encompasses my entire being, it floods in uncontrollably like a



Tinnitus



Headaches

'The brain fog is often preceded by a vice that connects to



Body Buzz

Buzzy or restless legs feels





Grid sequences of the 'Impact of Long Covid' cartoons shared via @imperial_perc on Instagram

Thank you

Email: emily.cooper@imperial.ac.uk

Instagram: @Imperial_PERC

Website: <https://www.imperial.ac.uk/medicine/research-and-impact/groups/react-study>

