Imperial College London

REACT Long COVID

Insights & progress so far

July 2022

Table of Contents

What is the REACT Long COVID study?

REACT Long COVID (REACT-LC) is a research project that aims to find out more about the reasons why some people experience long-term symptoms and health impacts after COVID-19 (commonly described as Long COVID) while others recover relatively quickly with no apparent ongoing ill health.

We are exploring people's varied experiences, and, through clinical studies, we are looking for biological and genetic factors that may explain these differences. Such insight will be used to improve the care of patients and hopefully will lead to new and more effective treatments.

REACT-LC is funded by UK Research and Innovation (UKRI) and the National Institute for Health Research (NIHR) and started in February 2021. The three-year project is being led by Imperial College London and builds on work of the REal-time Assessment of Community Transmission (REACT) programme of COVID-19 home testing. REACT-LC is being carried out in partnership with several other research institutions (including Queen Mary University of London, Charite University of Medicine, Berlin and the Universities of Leiden, Birmingham and Newcastle), patient groups and public advisors.
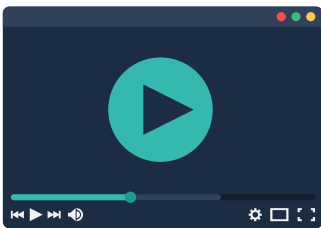
Watch a video introducing the REACT-LC Study here.
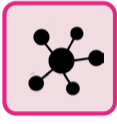
Genetic and Biological Factors

At the start of 2021, those who had taken part in the REACT study who had evidence of a positive test - either Lateral flow or PCR (polymerase chain reaction)- were invited to attend an assessment centre, where we obtained the following samples and measurements:

blood sample   urine sample   height, weight & waist circumference   grip strength   sit to stand test   blood pressure

To date, we have collected the above information and samples from 10,595 participants.

Three months after the first round of assessment centres, selected participants (1000 with persistent symptoms & 1000 without persistent symptoms)were invited to attend a follow up appointment, to fill out a questionnaire and collect a second set of samples. This will enable us to see if anything has changed over the 3 months (or more)since their first appointment.

The team have begun to analyse the blood and urine samples to better understand the role that the DNA, proteins, and molecules in the body may play in someone developing Long COVID, and how unwell they may become. The blood samples will also be analysed for diabetes, cholesterol and for COVID-19 antibodies.

Social & Environmental Factors

Gathering early insights into Long COVID

In March/April 2021 we started with a preliminary review of papers and reports that had explored Long COVID from the perspective of patients.

To further shape our understanding we conducted an analysis of 606,434 REACT participants self-reported persistent symptoms following COVID-19 during winter 2020–2021. 'We found:

- Proportion of people with one or more symptoms 12 weeks after onset was 37.7% in Sep 2020 – Feb 2021 and 21.6% in May 2021

- 'Long COVID' is likely to cover multiple overlapping syndromes

- We identified two main symptom clusters; one where tiredness was the most prominent symptom and the other where respiratory related symptoms were most common.

- Risk factors for persistent symptoms were: oider age, female sex, overweight/obesity, smoking, vaping, deprivation/income, hospitalisation with COVID-19, being a healthcare worker

Extending our understanding of experiences of Long COVID

Health and Wellbeing Questionnaire:

We are currently conducting a pilot for a large-scale survey of REACT participants who have had COVID-19 and those who haven't, to better understand differences in symptoms since the start of the pandemic. This questionnaire will include questions about the following:

medical history   current health & wellbeing   new or persistent symptoms   breathlessness   sleep & mood   impact on daily activities

In addition to the health and wellbeing questionnaire, participants will be invited to complete a cognitive test which includes a series of online activities and 'games'. At the end of the test they will be offered feedback on their performance. We aim to ask people to do a further survey after one year to see if their symptoms have changed, and they can check their cognitive function again.
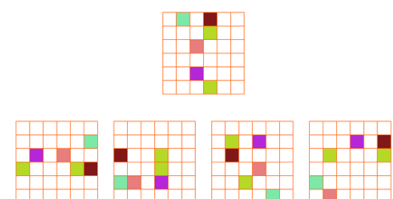
An example of a cognitive function task testing spatial reasoning

Qualitative interviews:

To help us understand the experiences of people with ongoing symptoms, we carried out a pilot study interviewing 13 people between the ages of 18 and 41 years in June and July 2021. We found:

- There are a wide variety of experiences of 'Long COVID' with different symptoms, durations and severity.

- People had different views on whether their new or persisting symptoms were due to COVID-19, or to other factors, and not everyone described themselves as having Long COVID.

- There were different levels of recognition and awareness of Long COVID, with mixed opinions on the term 'Long COVID

Following the pilot we plan to interview 60 more people in the main qualitative component of the REACT-LC study. So far (July 2022) we have interviewed 30

people, and hope to complete this part of the study by Autumn 2022. We are recruiting people from a range of ages, ethnicities and socio-economic backgrounds to ensure that we gain an understanding of the variety of experiences of persistent symptoms following COVID-19.

The study invitations and participant information sheet focus on 'experiences of new or persistent symptoms. This will enable us to recruit people who may not recognise the term 'Long COVID' or who feel the term doesn't apply to them.

Working with our public advisors

We are involving the public, including people with Long COVID, in all aspects of our research. In April 2021 we held a collaborative public engagement event called 'Let's talk about Long COVID' to talk about the study and answer questions relating to the REACT-LC project .

Let's Talk About Long COVID Research - Zoom recording 29.04.21
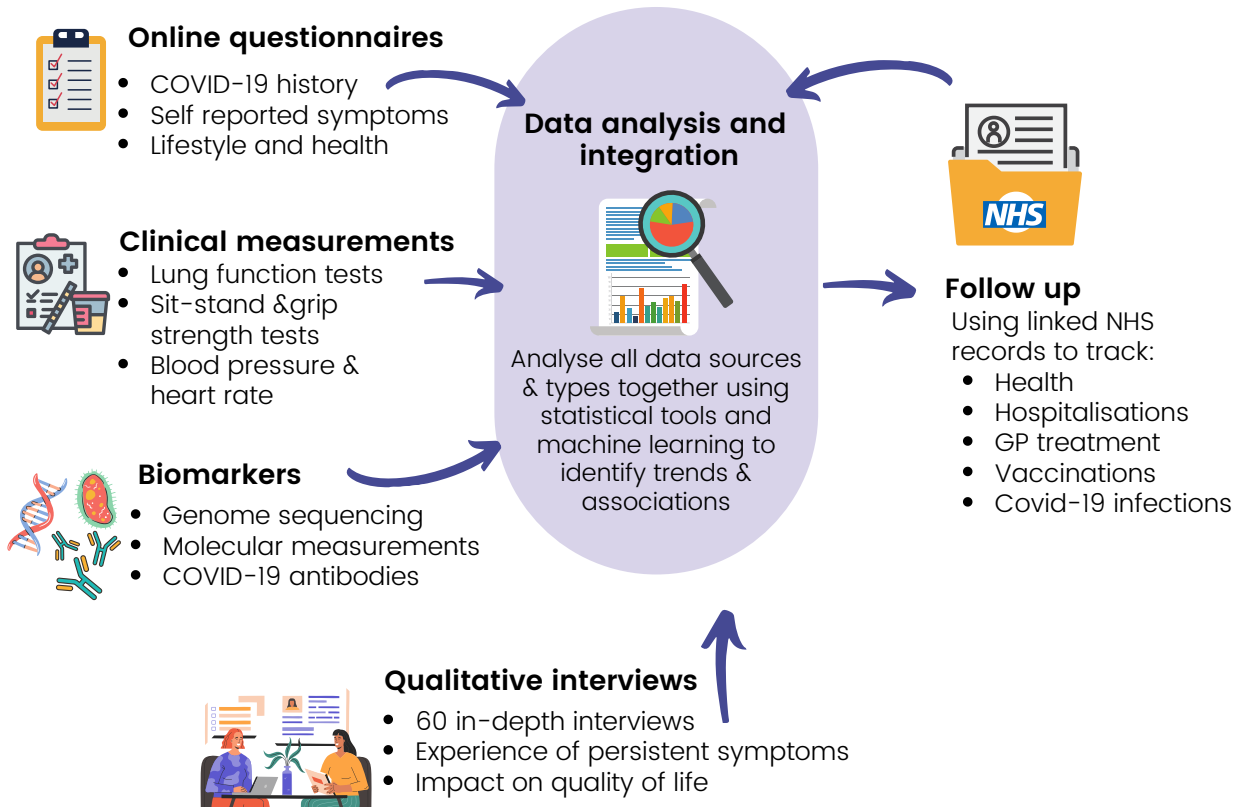
We have worked closely with our Public Advisory Group (PAG) who have provided input on several key areas, including:

- Shaping the topic guide for the qualitative interview pilot study and advising us on our analysis of the findings

- Helping design the health and wellbeing questionnaire and advising us on the recruitment documents and strategy for this part of the study

Data Analysis & Integration

The wider risk factors for Long COVID will be identified by linking the study data which has been collected (including samples, measurements and questionnaire responses) to people's medical records held by NHS Digital and other UK public health bodies.

Online questionnaires
- COVID-19 history
- Self reported symptoms
- Lifestyle and health

Clinical measurements
- Lung function tests
- Sit-stand &grip strength tests
- Blood pressure & heart rate

Biomarkers
- Genome sequencing
- Molecular measurements
- COVID-19 antibodies

Qualitative interviews
- 60 in-depth interviews
- Experience of persistent symptoms
- Impact on quality of life

Data analysis and integration

Analyse all data sources & types together using statistical tools and machine learning to identify trends & associations

Follow up
Using linked NHS records to track:
- Health
- Hospitalisations
- GP treatment
- Vaccinations
- Covid-19 infections

Note: As part of this activity, participant data will have a study code that will not allow researchers to know who the person is. A small number of people will have access to the code linking to the person but this will be very tightly controlled.

Linking the data will help us understand the short term determinants of susceptibility (who is at risk) and severity (how ill they become) as well as long term health outcomes. The data linkage will help us achieve our aim to better understand the biological, social, and environment risk factors for Long COVID and its long-term health consequences and to inform the provision of healthcare services and support .

Public Involvement & Engagement Opportunities

Join the Long COVID Research Involvement Hub
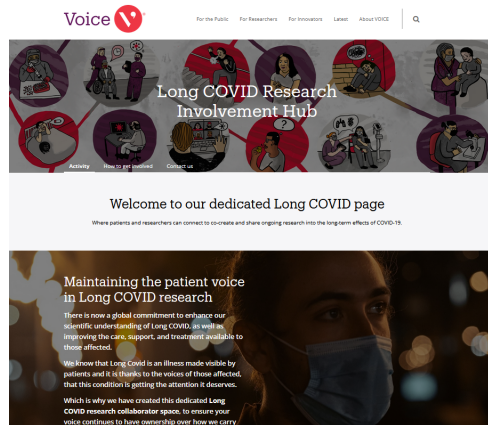
As part of our wider involvement work, we have recently launched the 'Long Covid Research Involvement Hub' on the VOICE online platform. The hub is open to Long COVID researchers & members of the public with experience of, or interest in, Long COVID and aims to bring together opportunities for involvement, events & updates related to Long COVID research in the UK.

Click here to post on the hub: share an involvement opportunity, news item, research update, event or case study of being involved, or involving people in Long COVID research

Help us to 'define Long COVID'

For the last year we have been collecting experiences of long COVID symptoms as part of our 'Defining Long COVID' challenge on the VOICE platform. We have begun working with an illustrator, Monique Jackson, (who is also one of our public advisors) to create some images based on the submitted experiences. We showcased these images for the first time at the Great Exhibition Road Festival in London in June 2022.

Sharing experiences of ongoing symptoms after COVID-19 will help us understand the varied experience of Long COVID and improve the way we conduct the REACT-LC study

We are continuing to invite responses as part of this challenge.

Click here to share how your ongoing symptoms feel in your own words or pictures and/or read what others have shared.

Keep up to date & get involved

If you would like to stay up to date with our latest research findings and updates, as well upcoming public involvement and engagement opportunities please join our online REACT: COVID-19 Community Network on the VOICE platform.

Further information and Outputs

Publications:

- [Persistent symptoms following SARS-CoV-2 infection in a random community sample of 508,707 people](#) (pre-print article; 2021)

- [Global surveillance, research, and collaboration needed to improve understanding and management of long COVID.](#) (Ward et al. The Lancet 2021.)

- [Persistent COVID-19 symptoms in a community study of 606,434 people in England](#) (Whittaker, M et al. Nature Communications, 2022)

- [Understanding and tracking the impact of Long COVID in the United Kingdom](#) (O'Mahoney L, et al Nature Medicine, 2022)

News items:

- Feb 2021 - [REACT study expanded to help better understand Long COVID](#)

Webinars & presentations:

- Apr 2021 - [Let's Talk About 'Long COVID'](#) (REACT-LC team)

- June 2021 - Shared Patient Experience International Colloquium 2021. Long COVID: a new condition shaped by shared experience and patient activism (Helen Ward, Keynote)

- July 2021 - Royal Society of Medicine Panel Discussion on Spotlight on Long COVID, chaired by Professor Sir Simon Wessely (Paul Elliot)

- Nov 2021 - Imperial College, London Academic Health Science Centre Seminar, [Understanding and Treating Long COVID' Seminar. 'Researching Long COVID: an investigator view'](#) (Helen Ward)

- Nov 2021 - Robert Koch Institute Web-seminar. **Lessons from SARS-CoV-2 antibody testing at scale: the REACT-2 study** (Helen Ward)

- Dec 2021 - European Congress on Neurorehabilitation. Understanding and management of Long Covid in session Long-COVID: Chimera or reality? (Helen Ward)

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