

REal-time Assessment of Community Transmission - Long COVID (REACT-LC)

QUALITATIVE INTERVIEWS

You are being invited to take part in a research study.

Whether you take part in the study is entirely up to you. Before you decide, it is important for you to understand why the research is being done and what it will involve.

Please take your time to read the following information carefully and discuss it with others if you wish.

INCLUDED IN THIS DOCUMENT

ABOUT YOUR ROLE

Why you have been chosen, what is involved and how it will help others

ABOUT THE STUDY

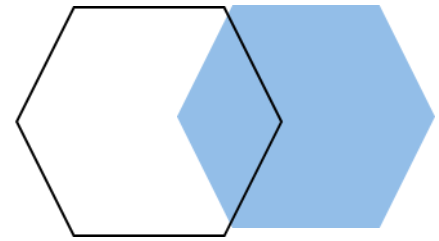
Who is carrying out this research, what will happen to the results

ABOUT YOUR DATA

What we will do with your data, how we protect your privacy and what information we share



YOUR ROLE



WHY HAVE I BEEN INVITED TO TAKE PART?

You have been invited to take part in this study because you have experienced new, unexplained, or persistent symptoms since contracting COVID-19 and you:

1. Took part in one of the REACT studies carried out by Imperial College London. This would have either been:
 - a. REACT-1 antigen (nose and throat swab) testing study;
 - b. REACT-2 antibody (finger-prick blood) testing study;
 - c. REACT-GE or REACT LC where you attended a clinical assessment center and follow up clinic

AND/OR

2. Have expressed an interest in taking part in REACT-LC research

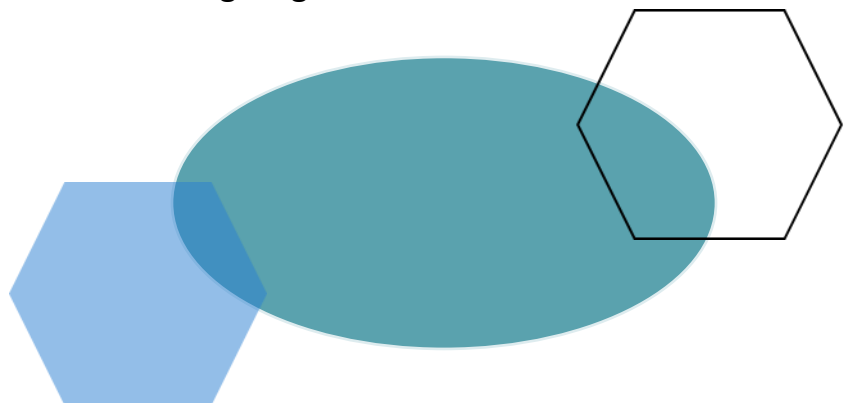


HOW DO I TAKE PART?

Click on the link in the email to complete a short online form to provide us with your details and consent.

A member of the research team will then be in touch to set up an interview at a time convenient to you.

Whether you take part in the study is entirely up to you. Even if you do decide to take part, you can change your mind at any time without giving a reason.



WHAT DOES THE INTERVIEW INVOLVE?

This interview will be carried out by a member of the research team over a virtual conference platform, such as Zoom, or by telephone, or face to face. If you are attending one of our REACT Long COVID research clinics, and an interviewer is available, the interview could be carried out while you are there.

The interview has no set time limit, we would ask you to talk for as long as you are comfortable. From our pilot study we find the interviews usually last approximately 20-40 minutes.

During the interview you will be asked a range of questions around your symptom experiences, health and wellbeing. Broad topics that may be covered are outlined below but these may vary depending on whether you have had COVID-19 and whether you have experience persistent symptoms:

- General background about yourself
- Your health prior to the pandemic
- Experience of contracting Covid-19
- Your new, unexplained or persistent symptoms and how they have affected you
- Your feelings about these symptoms and their cause
- How your symptoms, health and wellbeing has changed
- What treatment or support you have sought

CONTACT DETAILS

If you have any questions not covered here, you can contact a member of the imperial study team:

Emily Cooper, Research Assistant on the REACT-LC study

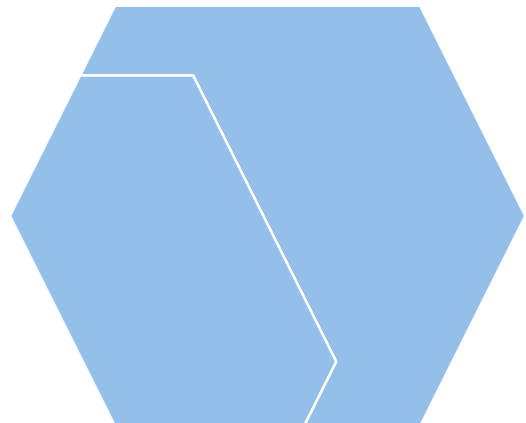
Email: react.lc.study@imperial.ac.uk

Address: Patient Experience Research Centre

St Mary's Campus

Norfolk Place

London, W2 1PG



THE STUDY

WHAT IS THE PURPOSE OF THE STUDY?

REACT-Long Covid (REACT-LC) is an extension study to the Real-time Assessment of Community Transmission (REACT) study. The main aim of the extension study is to better understand what causes some people to experience ongoing symptoms and ill health after having COVID-19 (commonly described as Long COVID), regardless of how severe the original infection was, whilst others recover quickly.

With this qualitative study we want to explore the **experiences of people living with any new, unexplained or persistent symptoms** since they contracted COVID-19. We want to hear people's experiences in their own words in order to understand how the symptoms differ between people and how those who have had COVID-19 are affected in the long term.

You can read more about the ongoing REACT testing programme at www.imperial.ac.uk/medicine/research-and-impact/groups/react-study/

WHO IS CARRYING OUT THIS RESEARCH?

This research is being run by doctors and researchers from Imperial College London in partnership with Genomics England. This research is funded by UK Research and Innovation.

Genomics England is a company set-up and owned by the Department of Health and Social Care. Genomics England is responsible for hosting the National Genomic Research Library. This contains the health data and genetic sequences of tens of thousands of NHS patients. They allow researchers to use their data to make discoveries and help develop new treatments.

Additional information about Genomics England is available:

<https://www.genomicsengland.co.uk/privacy-policy/>.

WHO HAS REVIEWED THE STUDY?

To protect your interests, all research at Imperial College London is reviewed by an independent group of people called a Research Ethics Committee. This study has been reviewed and granted approval by the South Central Berkshire B Research Ethics Committee.

WHAT WILL HAPPEN TO THE RESULTS OF THIS RESEARCH STUDY?

The results of this study may be shared in many different ways, such as being published in medical journals, presented at meetings of scientists and reported to both Imperial College, London and the Health Research Authority who oversee and review how research takes place in England. No personally identifiable information about you will be made available outside of the study team.



YOUR DATA

WHAT WILL YOU DO WITH MY DATA?

Your interview sign up information (personal details and contact information provided via the sign up form) will be temporarily held on our internal survey platform (the same platform used for registration for the clinics). This will be linked via your REACT study ID to previous information you have provided us with (e.g. demographic such as age or ethnicity) so that we don't have to ask for these again. The information relevant to the interviews will then be downloaded into folders on the secure servers at Imperial College London. The data from your interview (the digital recording) will be held separately to your personally identifiable information and be given a unique study code so that your identity remains confidential. The digital recording will be processed by the transcription service (UK Transcription) and the anonymised transcripts will be downloaded by the Imperial research team and saved in a separate folder to participant details, on the secure server.

Imperial College London and Genomics England will also need to use information from your medical records held by NHS Digital and other UK public health bodies for this research project. This information will be linked by your NHS number, name and contact details.

Investigators will use this information to monitor the long term health status of participants from this study. Unless they really need to know who you are, they will not be able to see your name or contact details. Your data will have a code number instead. The number of people who access this information will be kept to a minimum.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Imperial College and other research institutions both academic and commercial may continue to carry out research using the de-identified data collected during the study. The results of any research that is published, whether by Imperial College or anyone else, will never identify you. See 'Do you share my information with others' to learn more. From time to time we will inform you of other research studies that you might be interested in participating in. We will only share your contact details with other researchers if you give us consent to do so. Even if you receive invites to future studies, there is no obligation to take part.

The information you share with us as part of this study will **only be used for the purpose of health and care research or to contact you about future opportunities to participate in research**. It will not be used to make decisions about future services available to you, such as insurance.



HOW WILL YOU PROTECT MY PRIVACY?

Your name, address, email will be kept separate from your study data and only linkable by your unique study code. This is in case the Imperial College study team need to contact you about research that your data has been used in. Your contact details will never be passed to another organisation without your permission and will not be visible to the investigators performing the analysis. The results of any research that is published, whether by Imperial College or anyone else, will never identify you. See p6 'Do you share my information with others' to learn more.

From time to time we will inform you of other research studies that you might be interested in participating in. We will only share your contact details with other researchers if you give us consent to do so. Even if you receive invites to future studies, there is no obligation to take part. And if you do agree to take part, you can drop out at any time

WHAT WILL HAPPEN TO THE INFORMATION I PROVIDE?

Imperial College London is the sponsor for this study and will act as joint data controller for this study along with Genomics England. This means that we are responsible for looking after your information and ensuring that the processing complies with the General Data Protection Regulation (GDPR). You can access Genomic England's Privacy Notice at: <https://www.genomicsengland.co.uk/privacy-policy/>

Imperial College London will keep your personal data for 20 years after the study has finished.

Imperial College London has regular internal and external audits of their information security controls and working practices and are accredited to the International Standard for Information Security, ISO 27001.

DO YOU SHARE MY INFORMATION WITH OTHERS?

So that the maximum information can be obtained from your participation in this study we may make the deidentified data available to other researchers.

It is important that researchers understand as broadly as possible the factors concerning your health now, and in the future to identify as accurately as possible what puts people at greater risk of developing COVID-19, experiencing severe illness or suffering from ongoing ill health. We therefore require your consent for Imperial College London to link data (such as your GP health records) held by NHS Digital and other UK public health bodies to the REACT study data. This will provide information on the long term health status of the participants. An example of the use of this information would be to enable the monitoring of the longer term effects of COVID-19 on health. You can withdraw this consent at any point.

Researchers in the UK and overseas who wish to access the data from this study and/or to contact participants about future research will have to apply to a Data Access Committee composed of at least three of the study investigators and at least one public representative.

WHERE CAN I FIND OUT MORE ABOUT HOW MY INFORMATION IS USED?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to react.lc.study@imperial.ac.uk

CONFIDENTIALITY

If you consent to take part in the research your name or other identifying information will not be shared outside the research team. Your personal data will never be available to the general public in any circumstances. The results of this research are likely to be published but will not contain personal information which could identify you such as name, age, gender, ethnicity. Please keep this information sheet for reference.

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the United Kingdom (for example, to a research partner). Where this information contains your personal data, Imperial College London and Genomics England will ensure that it is transferred in accordance with data protection legislation

SHARING YOUR INFORMATION WITH OTHERS

For the purposes referred to in participant information sheet and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

- Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies and they are required to delete the data when no longer needed to provide the service.

LEGAL BASIS

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research

Our legal basis for using your information under General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:

- Imperial College London- “performance of a task carried out in the public interest” (Article 6(1)(e) in the GDPR);
- Genomics England Ltd – “legitimate interests pursued by the controller or a third party” (Article 6(1)(f) in the GDPR);
- Where special category personal information is involved, both organisations rely on “scientific or historical research purposes or statistical purposes (Article 9(2)(j) in accordance with Article 89(1) in the GDPR”.

Your usual statutory rights to be able to access, change or move your information are limited, because of exceptions applicable to some types of research, and also because we need to manage your information in specific, lawful ways in order for the research to be reliable and accurate.

CAN I CLAIM COMPENSATION IF I AM HARMED DURING THE STUDY?

Imperial College London holds insurance policies which apply to this study. If you experience harm or injury as a result of taking part in this study, you will be eligible to claim compensation without having to prove that Imperial College is at fault. This does not affect your legal rights to seek compensation. If you are harmed due to someone’s negligence, then you may have grounds for a legal action. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this study then you should immediately inform the Principal Investigator Professor Paul Elliott at p.elliott@imperial.ac.uk. The normal National Health Service complaints mechanisms are also available to you. . If you are still not satisfied with the response, you may contact the Imperial College [Research Governance and Integrity Team](#) at rgitcoordinator@imperial.ac.uk.

HOW TO MAKE A COMPLAINT

If you wish to raise a complaint on how we have handled your personal data, please contact:

- The REACT-LC Study Team on react.lc.study@imperial.ac.uk
- Imperial College London’s Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.
- Genomics England’s Data Protection Officer via email at dataprotection@genomicsengland.co.uk and/or by post to REACT-LC Data Protection Officer, Genomics England, Dawson Hall, Charterhouse Square, London, EC1M 6BQ

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (Imperial College London and Genomics England) first before involving the regulator. You can find details about how to contact the Information Commissioner's Office at <https://ico.org.uk/global/contact-us/> or by sending an email to: casework@ico.org.uk

