

Title of Project: Understanding perceptions of preventative healthcare in individuals with long-COVID in the UK.

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research project. Before you decide, it is important for you to understand why the project is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part.

1. What is the purpose of the project?

We want to understand how people with long-COVID feel about preventative healthcare and health-related risks. We will use what you tell us to develop recommendations to improve preventative healthcare strategies for people with long-COVID, to support their health.

2. Why have I been invited to take part?

You have been invited to participate because you may self-identify as having long-COVID, and because you have accessed this information through organisations or networks sharing details about this study.

You should only take part if the following conditions apply to you:

- Aged 18 years or older
- Live in the UK
- Self-identify as having long-COVID
- Willing to briefly appear on camera at the start of the meeting (this part will not be recorded); camera may be switched off afterwards.

We will be recruiting around 15-20 people in total to take part in this research study.

3. Do I have to take part?

No. It is up to you to decide whether to take part. You can ask questions before deciding. You can stop being part of the project at any time, without giving a reason. You may leave during an online interview by pressing the "Leave" button in Microsoft Teams. If you change your mind after taking part, you can ask us to withdraw your data up until May 2026.

4. What will happen to me if I take part?

We will ask you to read this information sheet. If you are happy to take part, you will sign a consent form, and send it to us by email. Please consider keeping a copy of the consent form for your future reference. We will meet online on Microsoft Teams. When we meet, we will first ask you to put your camera on briefly, while we check that you understand what the project involves, and are happy to take part. You can then turn your camera off if you wish, and we will begin recording the meeting through Microsoft Teams. We will ask your age, gender, ethnicity, religion, job title, long-term health conditions, what area you live in, and some questions about whether you have experienced stigma because of having long-COVID.

We will then talk to you about your views of preventative healthcare (such as cancer screening, vaccination programmes) and health-related risk. The meeting will take up to 60-minutes. You will be able to skip any questions you do not wish to answer, and can ask to pause or stop at any time, and we can reschedule if needed.

For those who agree, we may also reach out later in the study, to ask for feedback on our interpretation of what we learned, to help us be accurate. If you agree, we can discuss this over email, or if you'd prefer, we can schedule a 30-minute Teams meeting. We will appreciate any feedback.

5. Will I be recorded and how will the recorded media be used?

To take part in this project, you will need to give your consent for our conversation to be audio recorded via Microsoft Teams. The recording will only be used for this project and will not be shared outside the research team. You will also need to give your consent to appearing on video briefly at the start of the meeting (this part will not be recorded), while we check that you understand what the project involves and are happy to take part. You can then turn your camera off if you wish, and we will begin recording the meeting through Microsoft Teams. If you choose to leave your camera on, the recording will include both video and audio. The recording will only be used for analysis in this project, and will not be shared outside the research team.

6. Are there any possible disadvantages or risks in taking part?

During the study you will be asked about your experiences of preventative healthcare and long-COVID, and it is possible that this may cause you discomfort. You do not have to answer anything you do not want to. In addition, you can take a break or pause the meeting at any time if you need to, by letting the researcher know. If you find the meeting difficult, the researcher will be able to offer support, and if needed, can direct you to other sources of support, such as The Brain Charity (call: 0151 298 2999), for practical and emotional support on living with long-COVID.

7. Are there any benefits in taking part?

There will be no direct or personal benefit to you from taking part.

8. What personal data will be collected and what will happen to this?

The information you give us, or that we collect from you, from which you can be identified (e.g. from identifiers such as your name, audio recording etc.), is known as **personal data**. Taking part in this project will involve the collection/use of your personal data. We will keep all information about you safe and secure. The research team and other authorised university staff will have access to some or all of your personal data. You can object to our processing of your data and you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the project. If so, we will tell you why we cannot do this. The personal data collected will include:

- Contact details. With your agreement, we would like to store your contact details so that you may be contacted to give us feedback about our interpretation of the experiences shared with us. If you agree to this, you may be contacted to arrange this. We will delete your contact details when the project ends.
- A record of consent (which will include your name)
- Project data. We will use a code/pseudonym so that you cannot be directly identified from the data. The personal data collected/used will include more sensitive categories of personal data (special category personal data) such as your ethnicity and religion.

Identifiable project data will be stored securely for the duration of the project – unless there is no need for the data to be identifiable, at which point it will be made anonymous. Non-identifiable project data will then be stored in an open-access data library, and may be used for further research by our team or others. Other data (including consent forms) or project data that needs to be identifiable, will be stored securely at LJMU for three years after publication or public release of the work.

Limits to confidentiality

If you tell us that you or someone you know is in danger, we will have to tell someone (e.g., the emergency services). We will let you know first if we must do this.

9. Will the project be published? Could I be identified from any publications or other outputs?

We will share what we find at conferences, in journal articles, and with people who are interested, such as long-COVID charities, The Pandemic Institute, and the Wellcome Trust. If you would like, we can email you a copy of the study results.

We will write our reports in a way that no-one can work out that you took part in the project, and we would like your permission to use direct quotations but without identifying you in any outputs.

10. Data Protection

Liverpool John Moores University is the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University will process your personal data for the purpose of the project outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from:

- the LJMU [Privacy Notice for Research Participants](#)
- the LJMU Data Protection Officer: DPO@ljmu.ac.uk

Microsoft Teams may collect personal data (e.g. via the IP address, backups of project data). This makes them a data controller with respect to personal data and will determine how personal data is used. Please see their privacy notice here <https://privacy.microsoft.com/en-gb/privacystatement>

11. Who has reviewed this project?

This project has received ethical approval from an LJMU Research Ethics Committee.
Research Ethics Committee Reference number: 25/PSY/048

12. Who is funding the project?

This project is funded by The Wellcome Trust.

13. Whom do I contact if I have a concern about the project or I wish to complain?

If you are not happy with any part of this study, please contact Dr Anna Powell (A.Powell@ljmu.ac.uk). Anna should reply in 10 working days.

If you are still unhappy or wish to complain, please contact the Chair of the Liverpool John Moores University Research Ethics Committee, who will try to resolve the matter soon as possible:
Chair, Liverpool John Moores University Research Ethics Committee; Email:

FullReviewUREC@ljmu.ac.uk; Tel: 0151 231 2121; Research Innovation Services, Liverpool John Moores University, Exchange Station, Liverpool L2 2QP

14. Payments, reimbursements of expenses or any other benefit or incentive for taking part

You will receive a £25 Love2Shop voucher for taking part. Your contact details will not be recorded with the project data collected from you.

15. Further information and Contact details

If you want to take part or ask a question, you can contact:
Principal Investigator: Dr Anna Powell, member of LJMU staff
LJMU Email address: A.Powell1@ljmu.ac.uk
LJMU School/faculty: School of Psychology
LJMU Central telephone number: 0151 231 2121

Please consider keeping a copy of this information sheet for your future reference.