HERITAGE Research: Understanding Long Covid (LC) and Myalgic Encephalomyelitis (ME/CFS): Improving Care After Infection

Patient Information Sheet: Patient/Public Interview

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Research on Long COVID and ME/CFS

Thank you for expressing an interest in the HERITAGE study. We would like to invite you to take part in this research project and are providing this information sheet so that you can learn more about the study and what participation would involve.

HERITAGE is a UK-wide health services research study funded by the National Institute for Health and Care Research (NIHR). The study aims to improve understanding of the experiences of people living with Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and to help inform the future design and delivery of NHS services for these conditions. The study has been reviewed and approved by the London-Surrey Research Ethics Committee.

We are inviting people with Long COVID and/or ME/CFS, carers, and healthcare professionals to take part in different parts of the study. Please take time to read the following information carefully and discuss it with others if you wish. If you decide to take part or have any questions, please contact the research team using the details provided at the end of this information sheet.

Why are we doing this research?

- People with Long COVID and/or ME/CFS want to have better quality of life and better quality of healthcare.
- The information you provide will help researchers understand the impact of long COVID and ME/CFS on people's lives and how the NHS cares for them.
- This research aims to help the NHS design better healthcare for people living with Long COVID and/or ME/CFS.

How are people with Long COVID and/or ME/CFS involved?

- People with Long COVID and/or ME/CFS are taking part in this research, by providing information about their health and their health care.
- People with these conditions have been involved in the project from the very start.
- They helped design the research and get funding.
- They helped write this document and will be involved in all stages of the research.
- We are also involving staff who provide support and health care to patients with Long COVID and/or ME/CFS.

What will I be doing?

- You will be asked to take part in an interview with one of the researchers from the University Leicester.
- Questions will be asked about your experiences and perspectives of Long COVID and/or ME/CFS services.
- We will also ask you for some demographic information at the end of the interview (e.g., gender, age, ethnicity, the region you're based in etc)

Who will be interviewed?

We will interview patients and non-patients:

- Are aged 18 or over
- Able to provide informed consent
- Able to communicate in English
- Have received a GP diagnosis or you self-report LC/ME/CFS symptoms
- Have not received any specialist LC/ME/CFS services in the last 3 years OR
- Those currently using, have been referred to, or were recently discharged from NHS specialist LC/ME/CFS services at HERITAGE study sites (Leeds, Leicester, Hertfordshire, Cornwall)
- For those living with LC, have had LC symptoms for >2 years (persistent LC)
- We will also interview staff working in Long COVID and/or ME/CFS services

We will also spend time in specialist Long COVID and ME/CFS services to understand how those services are run.

How will the interview be arranged?

- We will arrange the interview at a time that works for you.
- We will do the interview either by phone or video/audio internet call, you can choose which works best for you.
- If you would prefer an in-person interview, we can discuss this with you.
- If you choose phone, we will call you on the number you give us.
- If you choose video/audio internet call, we will email a Microsoft Teams link to an email address you give us.

Do I need to prepare for the interview?

- You do not have to prepare for the interview.
- You can see the list of topics that will be covered if you like.

How will you accommodate Long Covid and ME/CFS?

- We know that people with Long Covid and ME/CFS may experience difficulties in taking part in interviews and may have increased symptoms afterwards.
- We want to try and make it easier for people to participate in the interviews.

How long will the interview last?

- We expect that the interview will take up to an hour.
- We will ask you if you would like a break during the interview.
- You can ask to take a break at any time.
- If you do take a break, we won't rush the rest of the interview.
- You're free to stop the interview whenever you need, with the option to reschedule if you'd like.
- If you prefer, you can split the interview into several short sessions—up to five in total. It's completely up to you how you'd like to split them up.
- You can add any additional information by emailing the researcher who interviews you at any time during the research until 30th June 2027.

Will the interview be recorded?

With your permission, the researcher would like to audio record the interview.

Can I have someone with me?

- You are welcome to have someone with you for support.
- They can help answer questions for you and help you recall events during your interview.
- We will ask this person to read this document and to consent to take part as well.

Do I have to take part?

- No, taking part in this research is up to you.
- You can stop at any time, without giving a reason.
- If you don't take part, or you decide to stop, this won't affect your care by the NHS or any health professional, now or in the future.

What should I consider?

The main thing to consider is whether you are comfortable with researchers asking you questions about:

- Your experience of NHS specialist services for Long COVID and/or ME/CFS
- Your health

Will I benefit from taking part?

- There are no direct benefits to you from taking part, but we hope that it will improve the care of people with Long COVID and/or ME/CFS in the future.

Are there any potential risks from taking part?

- You may find taking part in the interview fatiguing or sometimes upsetting.
- If you are fatigued or upset, you can take a break or ask to stop the interview.
- The fatigue and/or upset you experience can lead to the worsening of symptoms.
- Planning the interview into your day will help with pacing.
- You may also find it helpful to build some time into rest after your interview.
- If you find the research is too much for you, then you can stop. You can do this at any time. You do not have to give us a reason.

- Remember, you do not need to take part, particularly if you think your health might suffer.

Will I get paid for taking part?

No, there is no payment for taking part in this research.

How do I agree to take part?

- We have provided you with a research consent form along with this information sheet.
- If you decide to take part, we will ask you to email us your completed consent form.
- If you prefer, we can post out a paper consent form for you to sign and return to us.
- Alternatively, we can audio record your verbal consent before we begin the interview. If you decide to take part in a face-to-face interview, you can complete a paper consent form before the interview starts.

Can I change my mind later?

Yes, you can change your mind and stop your participation in HERITAGE at any time, without giving a reason. If you choose to leave the study, we will ask you what you want to do with the information you have already given us. You will have up to two weeks from the date of your participation to withdraw your data. You can email us to let us know and we will destroy all of your associated data immediately. After two weeks, it may no longer be possible to destroy your data as it may have been integrated into the broader dataset. More details on this can be found on the research website (https://heritage.leeds.ac.uk/).

How will we use information about you?

We will need to use information from you for this research project.

This information will include your:

- Name
- Contact details

People will use this information to do the research or to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code (pseudonym) instead.

University of Leeds is the sponsor of this research.

The University of Leicester will be responsible for looking after your identifiable information, and the University of Leeds will be responsible for looking after your anonymised information. We will share your information related to this research project with the following types of organisations:

- The University of Leeds (research sponsor)
- The University of Oxford (research partner)
- The University of Leicester (research partner)
- ELAROS 24/7 Ltd (approved data processor providing the app and secure platform)
- NHS staff at participating clinics (only where relevant to your care and to the study)

- University of Leicester-approved transcription service

We will keep all information about you safe and secure by:

- using secure systems to store your data
- limiting access only to people who need it
- replacing your name and contact details with a study code (pseudonym) wherever possible
- keeping audit trails to show who has accessed your data and why

International transfers

Your data will not be shared outside the UK.

How will we use information about you after the study ends?

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.

We will keep your study data for a maximum of five years. The study data will then be fully anonymised and securely archived or destroyed.

What are your choices about how your information is used?

- you can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have
- you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- our website www.heritage.leeds.ac.uk
- by asking one of the research team
- by sending an email to Heritage@leeds.ac.uk
- by sending an email to the University of Leeds Data Protection Officer: dpo@leeds.ac.uk
- by ringing us on 0113 243 1751
- HRA link: www.hra.nhs.uk/patientdataandresearch.

How will information from my interview be included in project reports?

We are audio recording our interviews. This is so we can accurately remember what interviewees and researchers have said. Recordings will be typed up word-for-word using Microsoft Teams for online and telephone interviews, and a university-approved transcription service for face-to-face interviews. The transcription service will protect your information in the same way we do. Transcripts will be anonymised, removing names and other identifying information. This anonymisation process will help

us ensure that your identity is protected. Audio recordings will be deleted immediately after transcripts have been anonymised, checked and verified.

Anonymised interview transcripts will be retained for a maximum of 5 years. This will enable us to:

- Analyse the anonymised interview data
- Write reports for our funders and the NHS
- Write academic and practice publications
- Present findings at conferences and other public events
- Draw on findings for the purposes of teaching and educating (e.g., health professionals, researchers, Doctoral or master's students)
- Produce summaries of our findings for patients/members of the public
    - We will ask you if you would like a summary of findings to be shared with you.

With consent, we will include participants' anonymised quotes in our publications. You will not be named or identifiable in any of our publication activities.

How will I be safeguarded during this research?

In the rare event that you disclose information which indicates that you or someone else may be at risk of harm, we may need to take appropriate action to ensure safety. This may include breaching confidentiality and sharing relevant information with appropriate health or social care professionals or safeguarding services.

Where possible, we would seek to discuss this with you before taking any action. However, if there is a serious concern or an immediate risk of harm, we may need to act without your consent.

If we have concerns about your wellbeing or care needs during the study that do not indicate immediate risk, we may signpost you to relevant support services or other sources of help.

Who is conducting this research?

- The HERITAGE research is funded by the National Institute for Health and Care Research.
- The Chief Investigator is Professor Manoj Sivan from the University of Leeds.
- Dr Gemma Hughes is leading on the qualitative work including interviews from the University of Leicester.
- Only approved researchers from the University of Leeds, University of Oxford, University of Leicester and NHS staff will have access to the information you give us.
- This study has been reviewed and approved by the London – Surrey Research Ethics Committee.

How do I ask questions?

For questions about the interviews, you can contact Dr Gemma Hughes on gemma.hughes@leicester.ac.uk or 0116 373 6741 or Dr Joanne Alexander on joanne.alexander@leicester.ac.uk 0116 252 2673

For questions about the research, you can contact the Chief Investigator. He will arrange for someone to get back to you quickly.

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If I have worries or complaints during the research, what I do?

If you have any worries or complaints about this research, please contact the University of Leeds Research Governance office:
Email: governance-ethics@leeds.ac.uk
Phone: 0113 343 7587

If you are worried about your care, the Patient Advice and Liaison Service can be contacted via the NHS Choices website:
Web: https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/
Phone: 0113 206 6261

If you are worried about the use of your information, please contact the University of Leeds Data Protection Officer:
Email: dpo@leeds.ac.uk
Phone: 0113 243 1751

If you are unhappy with the response from the University of Leeds Data Protection Officer, you can contact the Information Commissioner's Office (ICO):
Web: https://ico.org.uk/make-a-complaint/
Phone: 0303 123 1113

More details about this process are available on the research website (https://heritage.leeds.ac.uk/). This includes a plain English Patient Data and Research leaflet, from the NHS Health Research Authority which explains how health and care researchers use information from patients, service users and other participants in research.

Thank you for considering taking part in HERITAGE