Health Effects fRom Infection sequelae: Tailoring services and Advancing GuidancE

HERITAGE Long COVID and ME/CFS

FUNDED BY NIHR | National Institute for Health and Care Research

Participant Information Sheet

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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 (LC) 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 LC 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.

Please take the time to read and understand this information sheet, so you can decide if you want to take part or not. You can ask us questions using the contact details 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 will 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 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.

How can I help the research?

- By telling us about your experience of Long COVID and/or ME/CFS.
- You could have one or both conditions.
- You could be under the care of a GP. You could be under the care of a clinic. You might not be using healthcare for these conditions.
- Your experiences will help us understand what healthcare services you need, when, where and how.

What will I be doing?

- You will be asked to fill in 4 surveys and 2 questionnaires when you join the research and then repeat them at months 3, 6, 9 and 12 (i.e., 5 times in total).

- When you complete the surveys and questionnaires, you will be able to take breaks and spread them out over one or two days if that is more comfortable for you. They will take about 60 minutes in total to complete.

The surveys and questionnaires will ask about:

- Your symptoms and how they affect you
- How your finances have changed
- About your use of healthcare (both NHS and private).

You can fill these surveys and questionnaires in a way that works for you, either:

- A smartphone or tablet using a free App
- Using a free website over the internet
- Or you can fill out a paper version
- You can ask for help filling in the surveys and questionnaires from family, friends, carers, or healthcare staff.
- If you are severely ill, you can ask someone to complete the forms for you, using your answers.

If you cannot complete consent or questionnaires digitally using the ELAROS app, you may choose to complete them on paper.

- Clinic participants: paper consent forms and paper questionnaires will be provided by your NHS clinical team or Clinical Research Fellow. You will still be registered on the ELAROS system by the NHS team so that you can be given a study ID number. Your completed paper forms will be returned to the NHS research team and entered into ELAROS securely by authorised staff.
- Public (non-clinic) participants: if you require paper consent or questionnaires, these will be sent to you directly by the University of Leeds research team. Completed forms can be returned by post. We will enter your answers into ELAROS so they can be included in the study.

We will use your information for the purpose of the study. This information may come from:

- The surveys and questionnaires you complete
- Your medical records (only if you are seen by, or on the waiting list for, a participating NHS clinic)
- The information you provide through the ELAROS app or website
- None of the survey or questionnaire information you provide will be shared with clinicians or services unless it forms part of your usual care within those services.

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.

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.

- You might find it helps to track your symptoms over time using the app or website we provide for the research. You can also show the information you have collected to your GP or other healthcare staff.
- The app also links to useful information from the NHS and charities helping people with Long COVID and/or ME/CFS, however note that these are not associated with our research project.

Are there any potential risks from taking part?

- You may find completing the survey tiring or sometimes upsetting.
- If you are tired or upset, you can take a break or ask for help from family, friends, or carers.
- 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.

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?

- You will need to sign a consent form in order to take part.
- You can fill in the consent form when you have read this patient information sheet and have got all your questions answered.
- The consent form can be accessed via the ELAROS app or website or we can provide you with a paper copy.
- If you are not under the care of a participating HERITAGE clinic, you will provide your consent through the public version of the ELAROS app or website. You will be shown this information sheet and then asked to complete the consent form before you begin any surveys.

Can I change my mind later?

- Yes, you can change your mind and stop at any time, without giving a reason. If you decide to withdraw from the study, you can contact the research team using the details at the end of this information sheet. You can withdraw from completing further questionnaires and surveys at any time. You may also request that identifiable information already collected about you is deleted where possible, though data that has already been anonymised or included in analyses may not be removable.

Data Protection

How will we use information about you?

- We need to use information from you for this research project.
- This information will include your:
    - Name
    - Date of birth
    - Contact details
    - NHS number (for clinic cohort participants)
- People will use this information to do the research or to check your records 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 number instead.
- University of Leeds is the sponsor of this research.
- University of Leeds is responsible for looking after your 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)
- 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 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?

- This study has been reviewed and approved by the London – Surrey Research Ethics Committee.
- 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-studyteam@leeds.ac.uk
- by sending an email to the University of Leeds Data Protection Officer: dpo@leeds.ac.uk
- by ringing us on 0113 3924 734
- Health Research Authority: Patient data and research leaflet: www.hra.nhs.uk/patientdataandresearch

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.

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

More details about this process are available on the research website (https://heritage.leeds.ac.uk/).

If you have any worries or complaints about this research, please contact the HERITAGE research team first:

- **Chief Investigator:** Professor Manoj Sivan
  Clinical Professor in Rehabilitation Medicine
  Leeds Institute of Rheumatic and Musculoskeletal Medicine
  The University of Leeds
  Chapel Allerton Hospital
  Leeds
  West Yorkshire
  LS7 4SA
  Email: m.sivan@leeds.ac.uk
  Phone: 0113 3924 734

If you prefer to speak to someone independent of the research team, please contact the University of Leeds Research Governance Office:

- Email: governance-ethics@leeds.ac.uk

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

You can also contact the Information Commissioner's Office (ICO) if you are unhappy with how your information is being used:

- Web: www.ico.org.uk

- Phone: 0303 123 1113

Thank you for considering taking part in HERITAGE