



**Health Effects fRom Infection
sequelae: Tailoring services and
Advancing Guidance**

FUNDED BY
NIHR | National Institute for
Health and Care Research

Privacy Notice for Research Participants

About this notice

This privacy notice explains how the University of Leeds collects and uses your personal information when you take part in the HERITAGE research project. Please also read the Participant Information Sheet, which gives more details about the study and what information will be collected.

Who is conducting this research?

The HERITAGE study is funded by the National Institute for Health and Care Research (NIHR).

The Chief Investigator is Professor Manoj Sivan, University of Leeds.

Only approved researchers from:

- University of Leeds
- University of Oxford
- University of Leicester
- NHS staff

will have access to the information you provide.

The digital health technology company ELAROS 24/7 Ltd providing the digital apps will also have access to any data collected digitally only for technical service provision and maintenance of the system used in the study. They will not access your information other than for technical support requests made by you or clinics providing you with care. ELAROS' privacy notice can be found at: <https://c19-yrs.com/legal/privacy-policy/>

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 minimum 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:
 - o our website www.heritage.leeds.ac.uk
 - o by asking one of the research team
 - o by sending an email to heritage-studyteam@leeds.ac.uk
 - o by sending an email to the University of Leeds Data Protection Officer: dpo@leeds.ac.uk
 - o by ringing us on **0113 243 1751**
 - o 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.

How to ask questions or raise concerns

- **Study questions:**
Prof Manoj Sivan
Clinical Professor in Rehabilitation Medicine
University of Leeds
Email: m.sivan@leeds.ac.uk
Phone: **0113 392 2647**
- **Concerns or complaints about the study:**
University of Leeds Research Governance Office
Email: governance-ethics@leeds.ac.uk



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- **Concerns about your care:**

Patient Advice and Liaison Service (PALS)

Web: <https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/>

Phone: **0113 206 6261**

- **Concerns about your data:**

University of Leeds Data Protection Officer

Email: dpo@leeds.ac.uk

Phone: **0113 243 1751**

- **National regulator (ICO):**

Web: <https://ico.org.uk/make-a-complaint/>

Phone: **0303 123 1113**

More details are available on the study website: [<https://heritage.leeds.ac.uk/>]

This includes a plain English leaflet from the NHS Health Research Authority about how researchers use patient information.

<https://dataprotection.leeds.ac.uk/research-participant-privacy-notice/>