

Privacy Notice

PHOSP COVID 19 sub-study - UK evaluation of NHS support post-hospitalisation for COVID19 to inform service development and achieve holistic, integrated, equitable and cost-effective services

Information you need to know:

The **University of Leicester (Leicester)** and **The London School of Hygiene and Tropical Medicine (LSHTM)** are jointly conducting research to *Understand NHS care pathways for survivors of a Covid 19 hospital admission (the Study)*.

This Study is part of the national Post-hospitalisation COVID-19 Research Study (PHOSP COVID 19) which aims to identify whether there are longer-term health problems of COVID-19 for those who were admitted to hospital. **Leicester** is the sponsor for the PHOSP-COVID 19 Research.

Leicester and LSHTM are Joint Data Controllers for your information for the purposes of the Data Protection Act 2018 and the UK General Data Protection Regulation (UK GDPR). Leicester and LSHTM undertake to treat all your personal data in accordance with these data privacy laws.

Further information about Leicester can be found here: <https://le.ac.uk/> , and information about LSHTM can be found here <https://www.lshtm.ac.uk>.

Personal data and privacy enquiries relating to this Study should be directed to **Leicester's Data Protection Officer** Parmjit Singh Gill Information Assurance Services Manager who can be contacted by post addressed to the Data Protection Officer, The University of Leicester, University Road, Leicester, LE1 7RH or by email: dpo@leicester.ac.uk.

This privacy notice is supplemental to the main PHOSP-COVID 19 privacy notice and explains what information we are collecting, how we will use your personal information in this Study and what rights you have in relation to your information.

What information are we collecting or using?

This Study comprises 4 work packages as follows:

Work package 1 lead by Leicester: An online survey of clinicians about their organisations' post-hospitalisation pathway services

Work package 2 lead by Leicester: a) Interviews with clinicians and healthcare managers about designing and delivering post-hospitalisation care pathways and b) Interviews with patients about their experiences of post-discharge care.

Work package 3 lead by LSHTM: Focusing on remote analysis of the PHOSP-COVID data set held within a trusted research environment at Public Health Scotland in Edinburgh with

respect to quality of life, health care resource use and productivity losses for subjects in the 12-months after hospital discharge.

Work package 4 lead by LSHTM: Bringing together the previous three work packages in order to project the quality adjusted life year and health care burden over the long term, separately estimated by different levels of post-hospitalisation pathway services.

In **Work packages 1 and 2** we will be collecting information from existing PHOSP COVID 19 participants and other people aged 16 and over and who are either:

- Clinicians working in healthcare settings providing healthcare pathways or
- Healthcare staff responsible for developing and implementing post hospitalisation healthcare pathways for Covid 19 patients in their organisations or
- Covid 19 patients who have experienced these healthcare pathways.

We will only collect and use your information in this research if you have voluntarily agreed to participate in this Study and have given verbal consent in accordance with ethical requirements and to meet legal obligations relating to confidentiality.

The personal information we will collect directly from you in agreeing to participate and in consent forms includes:

For Clinicians and Healthcare staff

- First and last name and contact information including email address

For Patients

- First and last name and contact information including your email address
- Health/healthcare information you share in the interviews

For Clinicians only, your responses to the Online Survey (JISC) about your organisation's post-hospitalisation pathway services.

For all participants invited to an interview with one of our researchers, the information we may document from your views expressed during interviews includes the following:

- For clinicians, healthcare professionals and managers' your experiences of designing and delivering post-hospitalisation pathway services; or
- For patients, your experiences of post discharge care following a hospital stay with COVID-19.

In **Work packages 3 and 4**, we will be accessing and using research datasets from the national PHOSP COVID 19 Study and the outputs from work packages 1 and 2 of this Study. **LSHTM** will not have access to your personal contact or other identifiable information held by **Leicester**. In addition none of these datasets will contain personal identifiable information so it will not be possible for **LSHTM** researchers to tell that you took part in this Study.

Why are we collecting your data for this Study?

As COVID-19 is a new disease, the main purpose of this Study is to explore healthcare staff and managers' experiences of designing and delivering post-hospitalisation services and patients' experiences of post discharge care following a hospital stay with COVID-19. The data will be used to inform the National Institute for Health Research funded evaluation of support in post-hospitalisation for COVID19. The data will also inform service development to help achieve holistic, integrated, equitable and cost effective services.

The aim of research is to understand:

- The range of care pathways implemented for COVID-19 patients after discharge from hospital.
- The experiences of healthcare professionals and managers of implementing such pathways, including barriers and facilitators and lessons learned.
- The experiences patients have of care pathways post hospitalisation with COVID-19, including how such care pathways are integrated with other healthcare they may be receiving.

How we will use this data?

We will use your information to enable us to answer the research questions for this Study we have set out above.

In **Work packages 1 and 2** we will do this in a way that protects your identity as follows:

- Data collected from interviews these will only be recorded with participants' permission.
- Where we have your permission to record, the recordings will be professionally transcribed by a third party with whom we have a contract and any information from which you could be identified will be removed upon transcription. Original recordings will be deleted once they have been transcribed.
- Any views or opinions used in our research findings or publications will be anonymised so it will not be possible to identify you from those comments.

Leicester has technical and organisational measures in place to ensure that your information used in this Study is securely stored and only used for the purposes of this study, as described in this notice. **LSHTM** also has technical and organisational measures in place to protect the data it uses for this Study.

Individuals from regulatory authorities may look at data collected during the study; these bodies have their own technical and organisational measures in place to comply with Data Protection Legislation.

We will not be using the data to record, learn or decide something about you.

This Study does not involve automated decision-making or profiling.

What is the legal basis for processing the data?

The legal basis for processing your information that we are collecting and using for this Study is for the *performance of a task in the public interest* (Public Task) as set out in the

Data Protection Act 2018 and UK GDPR Article 6.1(e). Research is a public task that the Leicester and LSHTM perform in the public interest, and is part of their core functions.

Our additional legal basis for processing special category health information you provide in interviews is that processing is *necessary for scientific research* as set out in the Data Protection Act 2018 and GDPR Article 9.2.j.

If we are sharing your data with others, who are we sharing it with?

Access to original transcripts or any files containing identifiable special category health and/or potentially sensitive information will be limited to members of the research team at **Leicester**.

We will be sharing information with:

- Our third party provider who will transcribe and anonymise information from the audio recording of interviews. We have a contract with the third party for these services that includes terms relating to confidentiality to protect your privacy.
- Online Surveys (JISC) who are our third party processor contracted to administer the surveys to be carried out with participating Clinicians.
- The University of Edinburgh who are providing the main data centre services for PHOSP COVID 19 studies and are a Joint Data Controller (with Leicester) for the data held in the data centre.
- Other third party providers of technology we use to support recruitment, communications and virtual interviews for e.g. Microsoft Teams and related back-up systems.
- Bona Fide researchers outside the Study team who successfully apply to our PHOSP COVID 19 access committee. They will only have access to research data that does not identify individuals.
- Participant information may be required to be disclosed to regulatory authorities and public health agencies though most will only require anonymised information.
- Direct access will be granted to authorised representatives from Leicester and LSHTM as sponsor, host institution, and the regulatory authorities to permit monitoring, audits and inspections.

We are also required to provide progress reports and summarised, anonymised research information to our grant funders the National Institute for Health Research UK for their related research purpose as described in this notice but this will not include any information about individual participants.

We will only share with all these parties the minimum information that is necessary for them to undertake the task they are performing. We will not share information that identifies participants such as their name and contact information with people who do not need to know this.

Anonymised information means that a person can no longer be identified from the information and it is not *personal information* for the purposes of Data Protection Legislation.

How long will we process your data for?

All the identifiable information being collected from you in this Study will be processed and unless otherwise stated, the information will be held for and deleted after 5 years:

- Your verbal consent to participate forms;
- Anonymised transcripts of audio recordings, held in our Research File store;
- Encrypted original audio recordings which will be deleted as soon as they have been transcribed;

Anonymised and summarised research data, analysis, outcomes and reports will be kept indefinitely and are not considered to be *personal data* so they are not covered by the Data Protection legislation.

What are your rights and how can you enforce them?

Under UK Data Protection legislation, you normally have rights in relation to the personal information we hold about you. For the purposes of research, where such individual rights would seriously impair research outcomes, your rights are limited.

In this Study, and specifically in respect of patient health and healthcare information we need to limit your rights and are relying on the exemptions in Schedule 2 Part 6 paragraph 27 of the Data Protection Act 2018 because we are processing this information for scientific research in accordance with UK GDPR Art. 89(1) and Approved Medical Research covered by s19 Data Protection Act 2018.

Prior to applying these exemptions, we have carried out a Data Protection Impact Assessment and taken into account:

- That this scientific research is of public interest and national significance because it relates to COVID -19, a new disease classed as a pandemic because it has affected people in many countries;
- That the results of our research will only be published in an anonymised or summarised basis;
- We have taken appropriate measures to safeguard participant information we collect or receive and to protect the rights and freedoms of all participants including patients whose information we will be using in our research by use of anonymisation techniques in respect of the identifiable personal or pseudonymised information from the survey questionnaires and transcripts of interviews;
- We, our partners and data processors are under an obligation to maintain confidentiality in our handling of your identifiable and pseudonymised information;
- We are making information about our research and use of information available to you and the public through this privacy notice which is available on the PHOSP COVID 19 website phosp.org , **Leicester's** and **LSHTM's** main website.
- We have concluded that the exercise of rights by participants would seriously impair the achievement of the Study objectives and the exemptions are necessary to enable us to fulfil our scientific research purposes.

How will this affect your rights as a participant?

Whilst you and other participants involved in this research may withdraw from the study at any time you will not be able to exercise your rights to access your personal information, to request correction of inaccurate information or erasure of your information, to restrict processing of information or to object to our processing of your information even if you leave the study. These rights, which are set out in the UK GDPR (Articles 15,16,17,18 and 21) will not apply.

If you withdraw from the project, we will keep the information we have already obtained but we will protect your rights in our research analysis since this will only involve processing information and the use of transcripts which do not identify you.

If you wish to ask questions about our research please contact Dr Charlotte Overton, one of the researchers at **Leicester**, by email charlotte.overton@leicester.ac.uk

What right do you have to complain to the Information Commissioner's Office?

If you have concerns or wish to complain about our use of your data in this Study or your rights, please contact Information Assurance Services by email at ias@leicester.ac.uk or **Leicester's** Data Protection Officer by email at dpo@leicester.ac.uk. In any communication, please provide the project title ("NHS Care Pathways COVID -19 Study") and detail the nature of your concern or complaint.

Anyone can raise concerns about how their information has been processed with the Information Commissioner's Office (ICO).

The ICO may be contacted:

By Post addressed to: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF.

By Email: contact can be made by accessing www.ico.org.uk