

SIREN

SARS-CoV2 Immunity & Reinfection Evaluation

PRIVACY INFORMATION

About the SIREN Study

The SIREN study aims to find out whether healthcare workers who have evidence of prior COVID-19, detected by antibody assays (positive antibody tests), are protected from future episodes of infection compared to those who do not have evidence of infection (negative antibody tests).

It is being conducted by Public Health England in collaboration with the Public Health Organisations in Northern Ireland, Scotland and Wales. The role of Public Health England, Public Health Agency Northern Ireland, Public Health Scotland and Public Health Wales is to protect and improve public health across the UK.

This privacy notice explains the personal information we collect, use and share for this purpose. It explains what your rights are if we hold your personal information and how you can find out more or raise a concern.

Data controller

Public Health England is an executive agency of the government, sponsored by the **Department of Health and Social Care**. We are listed under the **Department's registration** with the Information Commissioner's Office.

Public Health England is the data controller for the personal information collected for the SIREN study.

If you live in Northern Ireland, Scotland or Wales, Public Health England will also provide your personal information to the Public Health Organisation for your part of the UK. Public Health Agency Northern Ireland, Public Health Scotland and Public Health Wales are the data controllers for the personal data they receive from Public Health England for the SIREN study.

The information we collect

The types of personal information we will collect as a part of the SIREN study are:

- demographic information – name, date of birth, sex, ethnic group, NHS number, occupation and postcode, and contact details such as your phone number and email address
- health information – information about your symptoms, medical diagnoses and health risk factors related to coronavirus
- treatment information – information about your test results related to coronavirus

How we collect your information

We collect personal information in three main ways: directly from you when you complete the enrolment and follow-up questionnaires, from the research team at your healthcare organisation, and from tests undertaken on your samples (from your local laboratory and specialist laboratories who may receive your samples for additional testing).

The research team at your organisation will collect your personal data (e.g. name, date of birth) during recruitment, when they give you your study number and passcode. They are responsible for organising your enrolment and follow-up testing and will collect data for this purpose as required by the local booking process (such as your contact details, details on whether you attended your appointment). They will also monitor your results.

Your personal data and individual survey responses will be collected and analysed by Public Health England and by the relevant Devolved Administration public health organisation if you live in Northern Ireland, Scotland or Wales. Your test results will be shared with Public Health England and appropriate Devolved Administrations and will be linked to your questionnaire data. The SIREN team may wish to find out more detailed information about you and your results so we may discuss your results with the local research team, the occupational health team or the microbiology/virology team in your organisation.

If you have a positive swab test for SARS-COV-2, the laboratory who tested your sample will send the swab on to the COVID-19 Genomics UK Consortium (COG-UK) for genetic testing on the virus (sequencing). The PHE SIREN team will obtain sequencing results from COG-UK.

How we use your information

We will use your personal information (e.g. name, date of birth) to link your questionnaire data with any COVID-19 test results, including testing undertaken by specialist laboratories. We will link your questionnaire data on symptoms, exposures and any participation in vaccine/treatment trials with your testing data to help interpret your results.

The team working on the SIREN study at the site where you work will use your data to:

- contact you
- order tests and check results on your electronic record
- send your personal information and result to the relevant contact tracing service if required (positive SARS-COV-2 test)

- analyse and report data for local purposes (e.g. monitoring infections in staff over time)

Public Health England will use your data to:

- contact you and send your personalised survey links
- obtain test results
- request additional samples
- link your questionnaire and testing data to information about your health and care which is held centrally
- analyse information including to find out whether it is possible to get reinfected with SARS-COV-2
- monitor public health, for example to measure the proportion of frontline NHS staff exposed to SARS-COV-2 and how quickly it spreads
- report overall findings (these reports will be anonymous, and the findings will not identify any individuals)

If you live in Scotland, Northern Ireland and Wales, your Devolved Administration Public Health Organisation will use your data to:

- obtain test results
- request additional samples
- link your questionnaire and testing data to information about your health and care which is held centrally
- analyse information on participants in the relevant Devolved Administration, including trends in infections
- monitor public health in the relevant Devolved Administration, for example to measure the proportion of frontline NHS staff exposed to SARS-COV-2 and how quickly it spreads
- report findings on participants within the relevant Devolved Administration (these reports will be anonymous, and the findings will not identify any individuals)

Your data will be transferred securely between the team working on the SIREN study at the site where you work and Public Health England. If you live in Northern Ireland, Scotland or Wales, your data will also be transferred securely between the team working on the SIREN study at the site where you work, and with Public Health England and the appropriate Devolved Administration Public Health Organisation.

How we store and protect your information

Your personal information is protected by us in several ways.

It is stored on computer systems that are regularly tested to make sure they are secure, and which are kept up-to-date to protect them from viruses and hacking.

We store your personal information in the UK only.

Your information can only be seen by staff working on the study and who have been specially trained to protect your confidentiality. Strong controls are in place to make sure our staff can only see your personal information if they need it to do their job, and they are only provided with access to the minimum necessary amount of personal information.

Whenever possible, we only use your information in a form that does not directly identify you. For example, we replace your name and NHS number with study number and substitute your date of birth with your age in years to help protect your confidentiality.

No information that could identify you will ever be published by Public Health England, the Devolved Administration Public Health Organisations or any organisation involved as part of this SIREN study.

Who we share your information with

Your healthcare organisation

All your study data may be shared between ourselves and the research team at your healthcare organisation. We may discuss your data (particularly your contact information and personal data) and results with appropriate individuals within your organisation, including the local research team, the occupational health team or the microbiology/virology team.

SIREN study teams in Devolved Administration Public Health Organisations

The SIREN team at PHE is working in partnership with SIREN teams in Public Health Organisations in the Devolved Administrations (Public Health Agency Northern Ireland, Public Health Scotland and Public Health Wales) to deliver SIREN across the UK. If you live in Scotland, Northern Ireland or Wales, all your study data will be shared between PHE and your appropriate Public Health Organisation.

As there are different laws in the Devolved Administrations, the different public health organisations may have different approval processes for the use of data in research. These include many of the same robust controls in place to safeguard your information. If you live in Northern Ireland, Scotland or Wales you may therefore wish to visit the website of these organisations to view their individual privacy notices for full details on how they handle personal information (links provided below).

COVID-19 Genomics UK Consortium (COG-UK)

If your swab is positive, then it will be sent to the COVID-19 Genomics UK Consortium <https://www.cogconsortium.uk/> by the laboratory used by your healthcare organisation, under the arrangement between the NHS and the COG-UK Consortium. COG-UK will not receive your information in a form that identifies you and your sample will be pseudoanonymised. This pseudoanonymised data will be held securely by COG-UK and the results made available to the PHE SIREN study team and the relevant Devolved Administration Public Health Organisation.

With researchers

We may share your personal information with university and other researchers, for example so they can help us model the spread and impact of coronavirus on public health. The information we share is provided in a form that means the researchers cannot identify

you. For example, we replace your name and NHS number with pseudonyms and substitute your date of birth with your age in years to help protect your confidentiality.

If we share your information in a form that directly identifies you we will only do this with researchers who have approval from a medical ethics committee and special permission from the Health Research Authority's Confidentiality Advisory Group. This group provides independent advice to the Secretary of State for Health & Social Care on whether the use of confidential information is in the interests of patients and the public. This is known as 'section 251' approval. The part of the law that applies here is section 251 of the National Health Service Act 2006 and the associated Health Service (Control of Patient Information) Regulations 2002. Public Health England never shares personal information with researchers without these approvals.

A register providing details of the information that Public Health England has shared with other researchers is published [here](#).

How long we keep your information

We will only keep your personal data for as long as the study is running. At the end of the study your data will be anonymised and archived to be retained for a period of five years. Throughout the study, the SIREN Study Management Group will regularly review whether we need to continue to store your personal data.

Your rights over your information

Under data protection law, you have several rights over your personal information.

- you have the right to ask for a copy of any information about you that we use
- you have the right to ask for any information we hold about you that you think is inaccurate to be changed
- you have the right to ask for the use of your information by us to be restricted, for example, where you think this information is inaccurate
- you have the right to object to any information held about you being used by us, although this is not an absolute right and we may need to continue to use your information – we will tell you why if this is the case
- you can ask for information held about you to be deleted by us although this is not an absolute right and we may need to continue to use your information – we will tell you why if this is the case
- you can ask for a copy of your information to be provided to you in a commonly used electronic format
- you can object to your personal information being used to make a significant decision that affects you based solely on automated processing, including profiling – although the SIREN study does not use your personal information

You can exercise any of your rights by contacting us at:

Public Information Access Office

Public Health England
Wellington House
133-155 Waterloo Road
London SE1 8UG
Email: FOI@phe.gov.uk

You will be asked to provide proof of your identity so that we can be sure we only provide you with your personal information.

You will not be asked to pay any charge for exercising your rights. If you make a request, we will respond to you within one month.

For information on how you can exercise your rights for any of the devolved administration Public Health agencies, please visit their respective privacy notices:

Public Health Scotland

<https://publichealthscotland.scot/our-privacy-notice/>

Public Health Wales

<https://phw.nhs.wales/use-of-site/privacy-notice/>

Public Health Agency Northern Ireland

<https://www.publichealth.hscni.net/privacy-notice>

Our legal basis to use your information

The law on protecting personal information, known as the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, allows us to use your personal information in this study.

We process both personal data and special categories of personal data, particularly data about your health, for this purpose. The sections of the GDPR and the Data Protection Act that apply are:

- GDPR Article 6(1)(e) - processing is necessary for the performance of a task carried out in the public interest
- GDPR Article 9(2)(i) - processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health
- GDPR Article 9(2)(j) - processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes
- Data Protection Act Schedule 1 Part 1 (3) - public health
- Data Protection Act Schedule 1 Part 1 (4) - research

How to find out more or raise a concern

If you would like to find out more about the use of your personal information for this study, you can contact SIREN team in Public Health England at phe.siren.participants@phe.gov.uk.

If you have any concerns about how we use and protect your personal information, you can contact our Data Protection Officer at dataprotectionofficer@phe.gov.uk or by writing to:

Data Protection Officer
c/o Public Information Access Office
Public Health England
4th Floor, Wellington House
133-155 Waterloo Road
London SE1 8UG

You also have the right to contact the Information Commissioner's Office if you have any concerns about how we use and protect your personal information. You can do so by calling the ICO's helpline on 0303 123 1113, visiting the ICO's website at www.ico.org.uk or writing to the ICO at:

Customer Contact
Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
SK9 5AF

About this privacy information

In the event of changes to the data collection and processing requirements in this study we may need to revise this notice. If we do, the date and version number will change.