

The European Prospective Investigation into Cancer in Norfolk study: Data privacy notice for participants.

The European Prospective Investigation into Cancer in Norfolk (EPIC-Norfolk) is a study of approximately 25,000 men and women resident in Norfolk who originally consented to participate in this long term study on lifestyle factors and health in 1993-1997 and who are being followed up for health outcomes. The information published here applies to the use of the personal information collected from participants as part of the EPIC-Norfolk Study.

The University of Cambridge is the sponsor for this study based in the United Kingdom. We will be using information from you and your medical records in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Cambridge will keep identifiable information about you for 15 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>

1. Who will process my personal information?

The University of Cambridge act as data controllers of any personal data that is collected by the research team as part of the EPIC-Norfolk Study.

Further information about the University's data protection policy, and about how the University uses your personal data as a research participant, can be found at: <https://www.information-compliance.admin.cam.ac.uk/data-protection>

2. What information do we collect?

The research team collected information about you when you originally consented to take part in Phase 1 of the EPIC-Norfolk study, and again at our follow-up time points (Phases 2, 3, 4, and 5). We also have support under S251 NHS Act 2006. Additional information has also been collected at various time points using postal questionnaires. We link the data you have provided with other data sources to build up a picture of your health over a number of years.

We collect health information about you from a variety of sources including, but not limited to, records held by your GP, data held in disease registers and data provided by NHS England which includes National Diabetes Audit (NDA) data, Mental Health Services data, Hospital Episode Statistics (HES) data, cancer registrations from cancer registries and causes of death from death certificates.

3. How we use the information we collect

We collect personal (identifiable) information about you so we can let you know what the next steps are in the EPIC-Norfolk Study and to offer you the chance to either stop taking part, or to carry on helping us with our research.

The research data we collect from your medical records and disease registers as described above, is pseudonymised (in other words de-identified, i.e. coded with a unique ID number, with the key to those ID numbers stored separately and securely) and linked with other data that you have provided in order to help gain a better understanding of the causes of chronic diseases and how to prevent them. We will use the information to identify patterns of ill health amongst EPIC-Norfolk participants and use this information to assess the risk of developing diseases such as (but not limited to) cancer, dementia, eye disease, osteoporosis, heart disease, stroke, and diabetes.

Collecting this data is necessary for the research we carry out in the public interest. We do not perform automated decision-making, including profiling.

4. Sharing your information

To be able to collect your latest health data, we will use personal information to link with NHS England, your GP, disease registers and hospital medical record departments. We always aim to limit the amount of information provided outside of the research team to the minimum needed to confirm we've got the right record for you. This includes your name, date of birth, address, NHS number and GP details.

We are committed to making our de-identified data as widely available as possible whilst safeguarding the privacy of our volunteers. Your de-identified information and samples will be available only to bona fide researchers who have relevant scientific and ethics approvals for their planned research. This could include researchers who are working in other countries and in commercial companies who are looking for new treatments or laboratory tests. Our [Data Access and Sharing Policy](#) defines the principles and processes for accessing and sharing our data.

5. Keeping your data confidential and safe

Any personal data we hold is kept securely at the University of Cambridge on a password protected network drive. This network is tightly controlled with restricted access only given to appropriate approved individuals. Physical access to the IT infrastructure and study offices are controlled by building card access and internal rooms where confidential paper information is stored are locked when not in use.

When sharing any personal data for specific purposes of record linkage, a secure file transfer protocol (SFTP) is used with encryption and data sharing agreements are in place to limit the use of our data further.

Data collected about you is coded with a unique identity number that is held separately from any personal data.

Your identifiable data will be kept for 15 years after the end of the study, in line with the Medical Research Council (MRC) policies. The need to keep holding your data after study formal closure will be reviewed regularly, as well as its **de-identification** processes to ensure they are in line with Data Protection requirements.

6. Newsletter distribution

In order to keep you updated with information about your participation in the EPIC-Norfolk study, as well as current study news, the study team send out regular newsletters. In such events, it may be necessary for the study team to use a company to manage this process. The company used will be UK based and GDPR compliant. Data will be transferred to the company under a data transfer

agreement, and files deleted on completion of the newsletter mailout. If you do not wish to receive study newsletters, please contact the study team EPIC-Norfolk@mrc-epid.cam.ac.uk who will update your mailout preferences accordingly.

7. EPIC-Norfolk's involvement with the UK Longitudinal Linkage Collaboration (UK LLC)

A new way of working with longitudinal data is by combining data from many Longitudinal Population Studies to allow researchers to look at more people across diverse population groups, occupations and other factors to improve health and wellbeing and service provision. To do this, many studies need to put relevant data into a highly secure computing environment, known as either a Trusted Research Environment (TRE) or a Safe Data Haven (SDH) or a Secure Data Environment (SDE).

The EPIC-Norfolk study is a partner with UK Longitudinal Linkage Collaboration, a Trusted Research Environment set up to bring data together for research in the public good.

Who is UK Longitudinal Linkage Collaboration (UK LLC)?

UK LLC is the national Trusted Research Environment for data linkage in longitudinal research. It is run by the Universities of Bristol and Edinburgh, in collaboration with [University College London \(UCL\)](#), [Swansea University](#), [University of Leicester](#) and [City St George's, University of London](#). Their purpose is to bring together data about Longitudinal Population Study (LPS) participants that has been collected by their LPS or as part of their wider care and support and link it to participants' health and other data.

The University of Bristol is the Data Controller for UK LLC and SeRP UK at Swansea University is the contracted Data Processor to University of Bristol for UK LLC. SeRP UK is a leader in providing this type of secure research server in the UK and internationally.

How does this work?

The EPIC-Norfolk study provides UK LLC with de-identified copies of selected data. We remain the owner and Data Controller and retain control of how the data is used in the UK LLC Trusted Research Environment. This makes sure the principles of the EPIC-Norfolk study are upheld.

The EPIC-Norfolk study provides a list of personal data (e.g. name, date of birth, address) to NHS Digital Health and Care Wales (DHCW). They are a NHS Trusted Third Party, which means they have the official approvals in place to handle data in this way. They do not see your study data. They then facilitate linkages by sending your personal identifiers to linked data owners and UK LLC's place-based (e.g. air pollution, noise pollution) modellers for processing. These organisations extract and send de-identified datasets to SeRP UK who bring them together with your survey datasets. They then deposit your de-identified data into the UK LLC TRE. Through this split process, NHS Digital Health and Care Wales can only see your personal identifiers and SeRP UK and UK LLC can only see de-identified data about you.

Linked data owners

- NHS England
- Public Health Scotland/eDRIS/National Records of Scotland in Scotland*
- Office for National Statistics in England and Wales
- SAIL databank
- NHS Northern Ireland Business Development Organisation*
- Northern Ireland Statistics & Research Agency*

*not yet approved, no data has flowed

Where and how is study name data stored at UK LLC?

The EPIC-Norfolk study data is stored on secure servers at [SeRP UK](#), which are controlled by the University of Bristol and physically located at Swansea University. The servers are managed to information security best practice standards (including ISO 27001) and are regularly audited by external experts in information security.

Can I find out if the EPIC-Norfolk study data held in the UK LLC Trusted Research environment has been approved for a research project?

UK LLC has a Data Use Register - <https://ukllc.ac.uk/data-use-register> where you can view all approved and declined applications, with project summaries that provides a list of the UK LLC partner Longitudinal Population Studies that have been approved as part of each project and the aims of the research question.

The UK Data Protection Act 2018 provides individuals with rights over how their data are used. The UK LLC supports these rights. If you would like to find out more, read the full UK LLC privacy notice - <https://ukllc.ac.uk/privacy-policy>

Opting out of UK LLC

If you do not want your identifiers to be used for linkage into the UK Longitudinal Linkage Collaboration (UK LLC), please contact the study team.

Choosing to opt out of UK LLC will not affect your participation in EPIC-Norfolk.

8. How to contact us

If you have any questions about the study, the information we hold about you, or if you would like to opt out of the study (which you can do without providing a reason and without your medical care being affected) please contact us on:

EPIC-Norfolk Study Team

Email: EPIC-Norfolk@ims.cam.ac.uk

Freephone number: **0800 616 911**

University of Cambridge Data Protection team

Email: data.protection@admin.cam.ac.uk

Tel: [01223 764 142](tel:01223764142)

Or write to us at: Institute of Metabolic Science
(IMS) Epidemiology, University of Cambridge
School of Clinical Medicine, Box 285, Institute of
Metabolic Science, Cambridge Biomedical
Campus, Cambridge, CB2 0QQ