

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)

The EPIC-Norfolk study is a partner in the UK Longitudinal Linkage Collaboration (UK LLC). UK LLC was created in 2020 as a resource to support researchers doing priority research to help understand the impacts of the COVID-19 pandemic and develop new treatments.

The UK LLC provides a Trusted Research Environment (TRE) where de-identified linked data can be securely analysed under strict safeguards. UK LLC have received additional funding from UK Research and Innovation, the Economic and Social Research Council, and the Medical Research Council to continue providing linked data for research.

UK LLC is now preparing to make data more widely available to researchers to perform their analysis within its TRE for purposes other than the impacts of COVID-19. By doing this, the UK LLC aims to enhance researchers' ability to address diverse and important issues that affect people's health and wellbeing.

To establish the linkage to health and wellbeing and other records, we provided a list of your personal identifiers only (e.g., name, NHS ID, address) to the NHS Wales Informatics Service (they never saw your study data). This NHS organisation sent identifiers to the groups conducting the linkages.

- The UK NHS authorities who share records with researchers (including NHS England in England, Public Health Scotland/eDRIS/National Records of Scotland in Scotland, SAIL databank in Wales, NHS Northern Ireland Business Development Organisation in NI);
- The UK statistical agencies (including the Office for National Statistics in England and Wales, eDRIS/National Records of Scotland in Scotland, Northern Ireland Statistics & Research Agency in NI);

The data is stored on secure servers controlled by the University of Bristol (the servers are located and run by the University of Swansea). The UK LLC will make available a full list of researchers using the UK LLC data and the purpose for this, which can be obtained by emailing project-ukllc@bristol.ac.uk. The UK Data Protection Act 2018 provides individuals with rights over how their data are used. The UK LLC supports these rights.

The EPIC-Norfolk team at the University of Cambridge remains the Data Controller for your data. At all times, we will determine whose records should be used in the UK LLC, which linkages can be established and which research teams can use your data and for which purposes. In this way, we make sure that all the principles of the EPIC-Norfolk study are upheld.

If you have any questions about the EPIC-Norfolk study participation in the UK LLC, please visit www.epic-norfolk.org.uk/for-participants/uk-llc/, or contact the study team if you would like to discuss the use of your data in this collaboration

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@mrc-epid.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: EPIC-Norfolk Study, MRC
Epidemiology Unit, University of Cambridge
School of Clinical Medicine, Box 285, Institute of
Metabolic Science, Cambridge Biomedical
Campus, Cambridge, CB2 0QQ