

The European Prospective Investigation into Cancer in Norfolk study: Website 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.medschl.cam.ac.uk/research/privacy-notice-how-we-use-your-research-data/>

1. Who will process my personal information?

The University of Cambridge act as data controllers and data processors 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 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 Digital which includes Hospital Episode Statistics (HES) data, cancer registrations from cancer registries and causes of death from death certificates.

We also request and receive recent address and GP information from NHS Digital to enable us to keep in touch as people move over the years.

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 health data we collect from your medical records and disease registers as described above, is anonymised and combined 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 our EPIC-Norfolk participants and use this information to assess the risk of developing particular diseases such as 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.

4. Sharing your information

To be able to collect your latest health data, we may use specific personal information to link with NHS Digital, 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 can include your name, date of birth, and NHS number.

The EPIC-Norfolk Study also works closely with scientific collaborators in other centres both nationally and internationally, and this may include commercial companies. Whilst some anonymised data is transferred between organisations, it does not include data from which you can be identified (such as your name or address) or any identifiable data provided by NHS Digital.

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 including the study team.

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

Your data will be kept for a minimum of 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 anonymization in line with Data Protection requirements.

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@srl.cam.ac.uk

Freephone number: **0800 616911**

University of Cambridge Data Protection team

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

Or write to us at: EPIC-Norfolk Study,
Department Public Health and Primary Care,
Strangeways Research Laboratory
Worts Causeway, CB1 8RN