

ADDITION Studies – Privacy notice

The information published here applies to the use of your information as part of the ADDITION studies, coordinated by the University of Cambridge. This study is being run by a research team based at the MRC Epidemiology Unit, School of Clinical Medicine, University of Cambridge.

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 is the data controller of any data that is collected as part of the ADDITION studies by the research team in Cambridge.

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/research-participant-data>

2. What information do we collect?

The research team collected information about you when you originally consented to take part in our studies, and again at our follow-up time points at 1, 5, 10 and 15 years. We link the data you gave us with other data sources to build up a picture of your health over the years.

We collect health information about you from a variety of sources including, but not limited to, records held by your GP, data provided by NHS Digital which includes Hospital Episode Statistics (HES) data and causes of death. We also check for any diagnoses of cardiovascular disease **as well as eye health**. This information comes from records held by your GP, data held in national audit projects (including the Sentinal Stroke National Audit Programme (SSNAP), the Myocardial Ischaemia National Audit Project (MINAP) and **Diabetic Eye Screening Programme Centres**.

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 by sharing identifiable information as outlined below.

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 ADDITION studies and to offer you the chance to either stop taking part or carry on helping us with our research.

The research data we collect from your medical records and the national audits as described above, is pseudonymised (in other words de-personalised, 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 us assess the long term effects on risk of cardiovascular diseases (CVD), such as heart attacks and strokes, of screening for diabetes and providing early treatment. In turn, this will help us understand how best to support people who are newly diagnosed in the future and their health practitioners.

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 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 that we have 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 pseudonymised data as widely available as possible whilst safeguarding the privacy of our volunteers. Your pseudonymised information and samples will be available only to bona fide researchers who have relevant scientific and ethical 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.

The Cambridge ADDITION studies also work closely with ADDITION Leicester, Holland and Denmark, and whilst some pseudonymised data is transferred between these studies, it does not include data from which you can be identified (such as your name or address) or any data provided by national audits or NHS Digital.

5. Keeping your data confidential and safe

Any personal data we hold is kept securely in a safe-haven that is part of the School of Clinical Medicine at the MRC Epidemiology Unit, University of Cambridge. Within the safe haven, personal data is on a secure research server within separate study databases. Access to the server and databases are controlled by the use of unique usernames and passwords which are not used to access other Unit systems. Access to the secure research server is further protected by two-factor authentication. All databases are encrypted. Physical access to the IT infrastructure and study offices are controlled by building card access and internal rooms where confidential paper information is stored and 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 pseudonymisation 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 so without providing a reason and without your medical care being affected) please contact us on:

ADDITION team

Email: addition@mrc-epid.cam.ac.uk

Or write to us at: ADDITION Study, MRC
Epidemiology Unit, University of Cambridge
School of Clinical Medicine, Box 285 Institute of
Metabolic Science, Cambridge Biomedical
Campus, Cambridge, CB2 0QQ

Tel: 01223 330315 (ask to speak to a member
of the ADDITION Study team)

University of Cambridge Data Protection team

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

Tel: 01223 764142