

## **ADDITION Studies – Privacy notice**

The information published here applies to the use of your information as part of the ADDITION studies, (ADDITION Plus, & ADDITION 10 Year) 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.

### **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> and <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 and 10 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, including your most recent weight and blood pressure measures, and blood test results. We also check for any diagnoses of cardiovascular disease. 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 data provided by NHS Digital which includes hospital admissions and causes of death.

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 health 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.

### **4. Sharing your information**

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.

To be able to collect your latest health data, we will share your information with NHS Digital, your GP, hospital medical record departments, Sentinel Stroke National Audit Programme (SSNAP), and the Myocardial Ischaemia National Audit Project (MINAP).

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 at the MRC Epidemiology Unit on a password protected isolated network drive, in other words not connected to the internet or outside world. This network is tightly controlled with access only given to appropriate approved individuals including the study team.

When sharing any identifiable data 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.

All other data collected about you (such as answers to questionnaires) is coded with a unique identity number that is held separately from any identifiable data we hold.

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 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](mailto: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)