GLoW Study– Privacy notice

The information published here applies to the use of your information as part of the GLoW Study 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 and the Cambridgeshire and Peterborough Clinical Commissioning Group are co-sponsors 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 20 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-noticehow-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 GLoW study 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

This study is part of the University of Cambridge and as such the legal basis to hold and use personal data is covered under the General Data Protection Regulation "Article 6(1) (e) processing is necessary for the performance of a task carried out in the public interest". To hold special categories of personal data our lawful basis is for pursuing scientific research under "Article 9(2)(j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.".

2. What information do we collect?

The research team collected your contact details when you first registered your interest in taking part. Information about you was also collected when you visited a GLoW clinic appointment or remotely via online data capture at a number of timepoints throughout the study. This included information about your activity levels, diet and body measurements. We also collected blood samples, some of which were analysed straight away and others that are stored for future research.

We link the data you give 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 may 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 arrange study visits, let you know what the next steps are in the GLoW study, inform you of any results and 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. We do not perform automated decision-making, including profiling.

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.

As part of this study, you will be randomised to one of two programmes. One is a diabetes education programme called DESMOND and the other is a diabetes and weight management programme called "Live Well With Diabetes". So that both of the programmes can provide you with the study intervention, we will need to share some of your information with each provider.

With your permission, we will share your clinically relevant results (which can include blood results and other measurements taken at clinic appointments) with your GP. This will also contain personal information as described above so it can be matched to your medical records.

To be able to collect your latest health data, we will share your information with NHS Digital, your GP, hospital medical record departments, Sentinal Stroke National Audit Programme (SSNAP), and the Myocardial Ischaemia National Audit Project (MINAP). Sections of your medical notes may be looked at by members of the study team, regulatory authorities or by the NHS Trust where it is relevant to you taking part in the study.

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 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 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 are locked when not in use.

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 your 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 20 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:

GLoW Team	**University of Cambridge Data Protection officer**
Email: glow.study@mrc-epid.cam.ac.uk	Email: data.protection@admin.cam.ac.uk
Or write to us at: GLoW Study, MRC Epidemiology Unit, University of Cambridge School of Clinical Medicine, Box 285 Institute of Metabolic Science, Cambridge Biomedical Campus, Cambridge, CB2 0QQ	Address: Information Compliance Office Registrary's Office University of Cambridge The Old Schools Trinity Lane Cambridge CB2 1TN
Tel: 0800 783 4611 (direct GLoW phone number)	Tel: +44 (0) 1223 764142