

PROPELS Study– Privacy notice

The information published here applies to the use of your information as part of the PROPELS Study coordinated by the University of Cambridge. This study is sponsored and led by the University of Leicester, based at the Leicester Diabetes Centre, University Hospitals of Leicester, Leicester General Hospital. The MRC Epidemiology Unit, School of Clinical Medicine, University of Cambridge are co-investigators and act as a recruiting centre.

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 PROPELS 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>

2. What information do we collect?

The research team collected information about you when you originally consented to take part in the study, and again at our follow-up time points at 12 and 48 months.

At these visits we collected health and personal information about you. This data included clinical measures, medical history and current medications. You would have also provided a blood and urine sample at these visits for analysis. We would have asked you to complete a questionnaire at each visit and to wear our physical activity monitors for a week after the visit.

Data collected in the questionnaires included social, economic, health, exercise and dietary information about you. The physical activity monitors collected data on your day-to-day physical activity in terms of 'steps' and sedentary time.

If you were in the 'walking away from diabetes plus' arm of the study, we would have also collected information about you during the intervention telephone calls and text message support. During the telephone calls we would have asked questions about your physical activity and noted your answers in our text message system. If you consented, these telephone calls would have been recorded. The data we received from text messages you sent to the study mainly consisted of a weekly (self-assessed) step count. The text systems also asked questions about your physical activity levels in order to assist the generation of further text message support.

3. How we use the information we collect

We collect personal (identifiable) information about you so we can invite you to study visits, let you know what the next steps are in the PROPELS study 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 you during the study 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). This data will be analysed along with the physical activity and questionnaire data collected (both of which are also pseudonymised) in order to assess the effectiveness of the study interventions.

Your blood and urine samples will be processed to help build a picture of your health status. If you consented to, your stored blood samples will be used for future genetic research relating to diabetes, and (if you consented to) will be transferred to a biobank if not used after 10 years.

The data collected from the intervention telephone calls and text message support is used in the text message system to generate the correct level of support for study participants. The recorded telephone calls are used for intervention fidelity (quality checks) which enables us to assess how the study intervention has been delivered to participants.

Collecting this data is necessary for the research we carry out in the public interest.

4. Sharing your information

When you joined the study you would have consent to your blood results and other clinical measures being shared with your registered general practitioner GP.

The Cambridge PROPELS team works closely with the Leicester PROPELS team 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).

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.

All other data collected about you (such as answers to questionnaires and clinical results) are entered on to a secure online database called MACRO. All data 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:

PROPELS team

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

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

University of Cambridge Data Protection team

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

Tel: 01223 764142

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