

## Participant Information Sheet

### Cambridge Centre for Ageing and Neuroscience (Cam-CAN) Study

We would like to invite you to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

#### What is the purpose of the study?

There is a revolution underway in our understanding of the development of brain and cognition as we progress through adult life. As greater numbers of us are living longer, it is increasingly important to understand how we can age healthily. The purpose of this study is to understand the development of the brain across the entire adult age span. Using state of the art cognitive testing and imaging techniques, a detailed investigation of the brain across all ages will be undertaken. Questions about differences and similarities across all ages will be addressed.

#### Why have I been chosen?

You have been randomly selected to represent your age group from people registered at GP surgeries in the Cambridge city area. The only information provided to us is your name, address, sex, and your month and year of birth. All of this information has been processed by us in accordance with the Data Protection Act 1998. We do not know anything else about you, and have not seen your medical records. If you agree to take part in this study we will ask for your written consent to look at them.

#### Do I have to take part?

No, there is no obligation to take part and you can withdraw at any stage, without giving any reason. The study is for research only and will not affect your medical care or legal rights.

#### What will happen if I decide to take part?

There are two main stages of Cam-CAN:

##### 1. *Initial home visit*

If you should decide to take part or want to hear more about the study, a research interviewer will visit you at your home (or your preferred location). If the time is not convenient they will return at a more convenient time for you. In advance of their visit they will send you a short questionnaire to complete which asks you about your lifetime experiences and physical activity. When they visit they will go through the information sheet with you and answer any questions you may have about the study. You will then be asked to sign a consent form to say you have read the information sheet, have had the opportunity to ask questions, and would like to take part in the study.

Following this you will be asked some simple questions on your background, health, contact with friends and family and day to day activities; there will also be a section on memory and concentration and some standard health measurements. They will also collect the short questionnaire that you completed before they arrived. The home interview will take approximately 1½-2 hours.

## **2. Imaging and further cognitive testing**

Following this home interview a selection of participants across all age ranges will be asked to become involved in more detailed measurements about the brain and to undertake some brain imaging investigations and further cognitive testing. These individuals will receive £7/hour for their time and effort. They will be asked to visit the MRC Cognition and Brain Sciences Unit (MRC-CBSU) in Cambridge where they will have brain scans using MRI (Magnetic Resonance Imaging) and MEG (Magnetoencephalography) technology. They will also have their height, weight and blood pressure measured and complete more simple tasks at the MRC-CBSU or the University of Cambridge which are designed to look at attention, emotional response, memory, language and motor skills. This testing will take place over three 2¼-hour sessions.

Some participants may then be invited to return to the MRC-CBSU for three further sessions, lasting 2-2½ hours, where we would collect detailed measurements of the brain using MRI, MEG and EEG (Electroencephalography). These individuals will receive £10/hour for their time and effort.

During one of these sessions participants will also be asked if they would consent to supply a saliva sample by depositing a small amount of saliva into a container which will be stored for research related to genetic influences on the brain.

You do not need to take part in any aspects of the study in which you do not want to be involved. The more you are involved the better, but even participation in just the initial home interview is of enormous benefit to our work. It is important that all types of people join Cam-CAN. We would like you to take part regardless of your current health status.

### **Who will have access to my information?**

Data collected by the study will only be analysed by approved researchers and results will be published in scientific journals, presented at scientific meetings or in talks at scientific meetings. Results will always be presented in such a way that data from individuals cannot be identified. All the information collected by the study is completely confidential and it is stored without personal details on secure systems in compliance with the Data Protection Act 1998. Contact information is stored separately to research data. Occasionally we may ask to tape record an interview. Audio tapes are anonymised and used for training and quality control purposes only and will be destroyed when no longer required.

### **Are there any risks for me in joining Cam-CAN?**

Taking part in Cam-CAN should not cause you any harm. It is not intended to change directly what happens to people who take part: in particular the home visit is not a "health check". It is possible that you may feel slightly uncomfortable with some of the questions asked. You will be able to skip such questions if you wish.

For the later imaging parts of the study there are reasons why people cannot be measured safely using imaging techniques. These exclusions will be detailed during the interview and repeated before each session. For example, if you have a pacemaker or metal implants, or if you have difficulty in enclosed spaces (claustrophobia), then this scan would not be suitable. Exclusion from imaging does not mean you cannot take part in the home interview. MRI is a painless and safe technique that can obtain detailed pictures of the brain using radio waves in a magnetic field. MEG and EEG are complementary techniques used for measuring the electrical and magnetic fields naturally generated by the brain. All three techniques are non-invasive and involve no exposure to hazardous radiation such as X-rays. When undertaken in appropriate and safe conditions, there are no known short or long-term effects on health. We will do whatever we can to help you relax before and during the scan. Our Radiographers and Operators are very experienced in making the scans as comfortable as possible.

## **What happens if I have an abnormal result?**

A consultant radiologist will review all the scans. In the event of a clinically relevant brain abnormality being detected, your GP would be informed so that they can arrange any appropriate further investigation, treatment and/or referral for further assessment. Such early detection has the benefit of starting treatment early but, in a small number of cases, may have implications for future employment and insurance. We will also check all blood pressure results and report any readings that may require further investigation to your GP.

## **Will my GP be informed?**

Your GP knows you were invited to take part in the Cam-CAN study, but not whether you participated. Like faces, brains come in all shapes and sizes, so that there are many normal variations of what the scan shows. Even for a healthy person, however, there is a small chance that your scan may show a significant abnormality of which you are unaware. In the event of a clinically relevant brain abnormality being detected during neuroimaging (after review by a consultant radiologist), your GP would be informed so that they can arrange any appropriate further investigation, treatment and/or referral for further assessment. We will also inform your GP if the blood pressure reading is at a level where further investigation may be required. This would not mean that you have high blood pressure, merely that your blood pressure needs to be considered or checked again by your GP.

## **Who is organising and funding Cam-CAN?**

The study is organised by a collaborative group of scientists based in Cambridge, led by Professor LK Tyler in the Department of Experimental Psychology, University of Cambridge. This study has been reviewed and given a favourable ethical opinion by the Cambridgeshire 2 Research Ethics Committee and by an independent group of international scientists before funding. The study is funded by the BBSRC.

## **Further information**

If the addressee is unable to respond, we would be grateful if a relative or carer could discuss with us whether an interview can take place or whether the relative/carers would be willing to be interviewed instead.

If you have any concerns or complaints about anything to do with the study please contact us on 01223 766458 and ask to speak to the Study Coordinator who if unable to help you will direct you to the appropriate person. Indemnity arrangements for the study are provided by the University of Cambridge.

If you wish to discuss participating in Cam-CAN with an independent contact who is not involved in the study, you can contact Linda Barnes, MRC-CFAS Study Co-ordinator, Institute of Public Health, University Forvie Site, Robinson Way, Cambridge, CB2 0SR, Tel: 01223 330311, e-mail: [leb22@medschl.cam.ac.uk](mailto:leb22@medschl.cam.ac.uk).

If you would like any further information or have any questions please contact us on 01223 766458, email [admin@cam-can.com](mailto:admin@cam-can.com) or look at our website [www.cam-can.com](http://www.cam-can.com)

***Thank you for taking the time to consider being part of Cam-CAN***