Institute of Public Health
University of Cambridge, Forvie Site
School of Clinical Medicine
Cambridge Biomedical Campus
Cambridge CB2 0SR

Tel: 01223 330312
W: www.cfas.ac.uk

CAMBRIDGESHIRE PROJECT FOR LATER LIFE STUDY II
PARTICIPANT INFORMATION SHEET

The Cambridgeshire Project for Later Life II is part of a large and important survey into the health and wellbeing of the older population. More than 7,500 people from Cambridgeshire as well as Newcastle and Nottingham have taken part in this study so far. This phase of the study is being funded by Alzheimer's Research UK (ARUK)

Why have I been chosen to take part?

You are being invited to take part because you have conducted two previous interviews with our study researchers in your own home in the periods 2008-2010 and 2011-2013.

The aim of the study continues to be to examine how health and well-being varies and changes with age. The longer the study continues the more valuable each contribution becomes. From this study we hope that we will be able to suggest ways in which the health of the older people can be improved in the future. Your contribution, if you are willing to be re-interviewed, will help us with this.

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 and talk with others if you wish.

The purpose of the study

Ageing is now recognised as one of the major challenges facing the world's populations. It presents challenges to national and local policy makers and service providers in planning and providing for the needs of the older population.

Over the past decades there has been an increase in life expectancy with improved health generally, screening, diagnosis and treatment of many chronic disorders. The aim of this study is to find out how health (including brain health) and well-being change as people grow older. Some people experience difficulties as they get older while others remain fit and active. We are interested in the full range of experiences so that we can get a true picture of ageing in the population.

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 medical research only and will not affect your medical care or legal rights.

What would taking part involve?

A named interviewer will visit you at your own home to see if you would like to take part in the study and to arrange, if you agree, an appointment time to suit you. They will explain the study in more detail and will answer any questions you may have. At the interview you will be asked to sign a consent form to say you have read this information sheet, have had the opportunity to ask questions, and would like to continue to take part in the study.

Following this you will again be asked questions on: your health since we last visited you; contact with friends and family and your social and day to day activities. There will also be a section on memory and concentration. As in previous waves you will be invited to take part in a small number of physical measurements such as a hearing test, completing a short walk and standing up from a chair. We would also like to add a few new measurements all of which are detailed below. The interview will take approximately 1½ hours to conduct.

At the end of the interview a small number of participants may be invited to take part in a short online pilot study (12 weeks) which will aim to provide information on lifestyle choices such as diet, smoking, and exercise via an online format. The purpose of the pilot is to see if this way of delivering health advice is acceptable to an older age group and if successful could potentially be rolled out to a much wider audience.

We will ask everyone who participates in the interview if they would agree to a 12 week follow up interview, this interview would take approximately 50 minutes to conduct.

Data Linkage/access to medical records:

We have previously asked for your consent to access your GP and medical records and permission to flag your name at the NHS Information Centre (now NHS Digital). We would like to update this permission to reflect this name change. We would also like to ask your permission to allow us to link your interview data with your medical and social care records – we enclose a separate information sheet about this.

What are the possible benefits of taking part?

Whilst there are no immediate direct benefits to participants, the information we collect will be used to provide more detailed information on how it will be possible to improve health and to deliver targeted services to the older population in our communities.

What are the possible disadvantages and risks of taking part?

We foresee no disadvantages or risks involved in taking part. If the participant or interviewer feel it would be unsafe to do some elements of the study such as chair stands or timed walk because of possible mobility problems these elements would be missed out.

How will my information be kept confidential?

All the information collected by the study is completely confidential, it is stored on secure systems at the Clinical School, University of Cambridge in compliance with the EU General Data Protection Regulations, (GDPR), which came into force on 25/05/2018 and the Data Protection Act. Cambridge University is the sponsor for this study based in the UK. We will be using information from you (and/or your medical records) in order to undertake this study and will act as the data controller for this. Cambridge University 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 at
https://www.medschl.cam.ac.uk/research/privacy-notice-how-we-use-your-research-data/

Occasionally we may ask to record an interview, personal information will be erased and recordings only used for training and quality control purposes and will be destroyed when no longer required.

What will happen to the results of this study?

Data collected by the study will only be analysed by approved researchers. No personally identifiable data is ever shared or presented in publications, conferences or meetings.

How have the patients and public been involved in this study?

We currently have two lay members on the CFAS Management Committee from the Alzheimer's Society and the Hospital Chaplaincy. We have received advice and input into the proposed research from two groups of current CFAS participant's based in Cambridgeshire and Nottingham and have discussed the planned research with Voice North (Newcastle) and the Public Involvement in Research into Ageing and Dementia (PIRAD) group (Cambridge) who have provided advice to the study from a patient/public/carer perspective.

Who has reviewed this study?

The study has been considered by the Wales 7 Research Ethics Committee and the Health Research Authority (HRA). Ethical approval, REC Ref: 18/WA/0120.

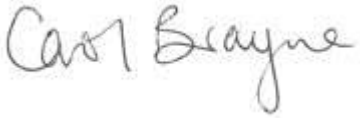
Further information and contact details:

If you would like any further information or have any questions please contact us on 01223 330312 or have a look at our website www.cfas.ac.uk

If you have any concerns or complaints about anything to do with the study please contact us on 01223 330312 and ask to speak to the National 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.

You can find independent information on research in general by contacting INVOLVE, the national advisory group of the National Institute for Health Research (telephone: 02380 651088, email: admin@invo.org.uk, website: www.invo.org.uk).

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/carer would be willing to be interviewed instead.



Professor Carol Brayne
Local Principal Investigator

Linda Barnes
National Coordinator MRC CFAS II

Information about physical measurements

All of the measurements will be carried out within your own home. They will involve minimal inconvenience and should not cause undue discomfort. The research team are very experienced in collecting this information and understand that not everyone has the same level of ability. All the following tests will only be carried out with your permission and conducted to your level of ability.

Chair stands: The interviewer will ask you to stand from a sitting position to assess the strength in your legs

Timed Walk: The interviewer will ask you to walk a short distance in your own home at your usual pace.

Hearing Test: The interviewer will conduct a hearing test by placing a small device over your ear which plays a short series of tones.

Weight: The interviewer will weigh you in your own clothes (without shoes or slippers) using scales.

Height: The interviewer will ask you to stand against a portable height frame which will allow us to calculate your height.

Blood Pressure: The interviewer will measure your blood pressure three times during the interview twice whilst sitting and once whilst standing using an automatic blood pressure machine by placing an inflatable cuff on the top of your arm.

Cholesterol Measurement: We will ask your permission to take a small pin prick sample of blood (from your finger) to test your blood cholesterol levels – results will be fed back to you at the 12 week re- interview.