

PREVENT

Research Programme



Welcome to the Spring edition of the PREVENT Research Programme newsletter. We have seen a few changes in the Research Programme over the past few months with our London participants returning for their Year 2 study visits and also the launch of our Membership scheme. We're really excited for what is in store throughout 2016 and as always we thank you for your continued support which has allowed us to continue to grow the programme.

Study Results: Approaches to the Communication of Alzheimer's disease Risk (ACAR) study:



Research like PREVENT aims to detect changes in the brain before people start developing typical symptoms, like memory loss. This would allow doctors to identify the disease at an early stage and prevent or delay the disease from developing into dementia. However, it also means that in the future, research and clinical care, might involve telling people they have an increased chance of developing Alzheimer's disease.

The aim of the Approaches to the communication of Alzheimer's disease risk (ACAR) study was to build our understanding of the potential consequences of this risk disclosure, and to contribute to guidance on whether and how to communicate risk in Alzheimer's research. Four focus group discussions were held with PREVENT participants in London and four more were held with participants in a similar study in Barcelona.

Most people in the groups said they would be interested in learning their risk status. They felt that this information would help them plan for the future, try to reduce their risk, and potentially even help receive a diagnosis if they were to develop symptoms that could be related to dementia. However, participants felt that at the moment information about Alzheimer's risk is uncertain and of limited value, particularly given the lack of any definite course of action to reduce risk or delay the onset of dementia.

The research produced recommendations about the communication of Alzheimer's risk. These will inform the development of approaches to risk disclosure within projects like the European Prevention of Alzheimer's Dementia (EPAD) study. A huge thanks again to all those PREVENT participants who came to take part in the focus groups.

PREVENT London—Year 2 Follow-up assessments:

We have recently started inviting our London participants back for the Year 2 assessments. The team have enjoyed seeing them again and are highly appreciative for them taking the time to carry out the assessments again. It is critical for the study that we capture data across time so we really can't overestimate how grateful we are for you returning for follow-up assessments. Currently 25 participants have completed the Year 2 assessments and we will be running these through to September 2017 which will mark the end of the pilot phase of the study.

For more information about the ACAR study, contact Dr Richard Milne at the University of Cambridge: rjm231@cam.ac.uk



Open day for International Clinical Trials day:

The Clinical trials unit which runs the London PREVENT site is holding an open day on Friday 20th May. The unit will be showcasing all the current research studies that they are working on and there will be a number of presentations throughout the day from researchers and academics working within the unit. Anyone is welcome to attend, for more information please contact Katie Wells: Katie.wells@imperial.ac.uk

European Prevention of Alzheimer's Dementia project (EPAD):

The EPAD project has now officially been opened at our Edinburgh site is already inviting participants from PREVENT to take part. EPAD is also led by Professor Ritchie who as you know also leads to PREVENT project. Recruitment for EPAD will be different to how it was for PREVENT as only people who are involved in cohort studies like PREVENT can become an EPAD participant. Initially the recruitment will only be based in Edinburgh but later in the year we anticipate that we will also be opening EPAD in London at which point our London participants will also be invited to take part. The EPAD project aims to:

- Create a new cohort of participants eligible to take part in clinical trials.
- Trial multiple treatments for the prevention of Alzheimer's dementia at the same time.
- Provide data for researchers globally to use to help understand pre-symptomatic Alzheimer's disease.

For further information about EPAD you can visit the project website www.ep-ad.org. If you would be interested in taking part in the EPAD project and you have been a participant at the Edinburgh PREVENT site please contact Natalie Jenkins: njenkins2@exceed.ed.ac.uk for further information. You can also follow the study on Twitter via [@IMI_EPAD](https://twitter.com/IMI_EPAD).



Prof Simon Lovestone: Professor of Translational Neuroscience

Oxford University



Prof Lovestone is Professor of Translational Neuroscience at Oxford University and Lead for the NIHR Translational Research Collaboration in Dementia which is a network of six Research Units and Centres in England focused on dementia. Prof Lovestone is also informatics lead in the Dementias Platform UK and co-coordinator of the European Medical Information Framework, which aims to develop data platforms for biological marker discovery in Dementia and Diabetes.

Prof Lovestone has research interests in seeking new targets for therapy in Alzheimer's disease in disease modification trials and experimental medicine in the search for biological markers for early diagnosis.

Prof Lovestone is the Biological markers lead in the PREVENT Programme and will be working with the PREVENT Steering group committee to devise the most appropriate way to analyse the biological samples collected as part of the study.

Follow [@AD_PREVENT](https://twitter.com/AD_PREVENT) on Twitter for study updates and relevant Dementia Prevention news.