Participant Information Sheet

Version 3.1, Date: 20/07/2021

Study title: Are mild changes in how we see and perceive the world around us associated with changes in how we think?

Thank you for showing an interest in this project which has been funded by a grant from the Alzheimer's Research UK South West Network and by a donation to the University of Exeter by alumnus, Mr David Bays, class of 1964. Please read this information sheet carefully before deciding whether or not to participate.

Time commitment: this study takes 15 to 20 minutes to complete.

What is the purpose of the study?

We want to find out whether changes in how we feel and view the world around us are associated with changes in how we think, specifically how we make decisions and whether we take risks.

Why are we doing the study?

Some people experience mild changes in how they view the world (e.g. believing certain situations or people to be a threat when that wasn't the case before). They exist on a continuum in the general population. This means some people never or rarely experience them, while others experience them more often. We know some of these experiences are also associated with brain ageing, in this context they are known as symptoms of Mild Behavioural Impairment. Although they are associated with memory and thinking problems in some people they are not a cause for concern. This is because many people who have these experiences will report no problems with their memory or thinking.

We want to know whether these experiences influence risk taking and how we make decisions. We hope this will provide more detailed understanding of the role of these experiences as we age. If we achieve this we might be able to develop brain training games to help memory and thinking as we age.

Why have I been invited?

You have been invited to take part in this study because you are enrolled in the Platform for Research Online to investigate Cognition and Genetics in Ageing (PROTECT). As part of your participation in PROTECT you have completed some questionnaires which ask you about any changes in how you view the world. We are inviting a mix of people to take part in this study, some who have experienced some of the mild changes described above and others who have not.

What will I have to do?

You will be asked to complete a game called the Cambridge Gambling Task which measures decision making and risk taking. Before taking part, you will be asked to provide consent. After that you will receive an email with a link to the complete the Cambridge Gambling Task. All you have to do then is click on the link and complete the task. You will get to practice first.

Do I have to take part?

No. It is entirely up to you to decide whether or not to join the study. The purpose of this information sheet is to describe the study in detail and help you make your decision.

What are the possible benefits and risks of taking part?

There are no direct benefits to taking part in this study but you will be helping us learn more about how our thinking changes as we age.

Study and data management

The University of Exeter College of Medicine & Health Research Ethics Committee has approved this research (Ref: **RG/CB/19/11/231**) and the research will be covered by normal insurance policies at University of Exeter. The University of Exeter has overall responsibility for the research.

Your fully anonymous research data will be collected securely online through the Cambridge Cognition Ltd website. Cambridge Cognition Ltd is the organisation who developed the Cambridge Gambling Task. Cambridge Cognition Ltd will never be able to identify you.

Can I withdraw from the study?

Yes you can withdraw from the study at any time. You can do this by selecting 'Withdraw From Study' in the Manage Account section of your PROTECT study account. If you do decide to withdraw from the study we will not collect any further data from you for the purposes of this study and your data will be deleted. Withdrawing from this study will not affect your participation in PROTECT or other studies currently affiliated with PROTECT.

Will my taking part in this study be kept confidential?

All the data we collect will be stored strictly confidentially, according to the law. Data will be analysed anonymously so no participant can be identified. Your anonymised responses to the Cambridge Gambling Task will be stored by Cambridge Cognition Ltd until the end of the study. At the end of the study this data will be transferred to the University of Exeter and stored alongside you other PROTECT study data. Cambridge Cognition Ltd will not be able to access or know any personal information about you.If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing dataprotection@exeter.ac.uk or at www.exeter.ac.uk/dataprotection

What data or information// will be collected and what use will be made of it?

As part of this study we will collect cognitive test data. Cambridge Cognition is a cognitive test service provider and will only be able to view this data for the purposes of technical support. Cambridge Cognition Ltd will not at any point know your name, date of birth, or any of your contact details. They will also not be able to access any of this information.

What will happen at the end of the study?

At the end of the study we will contact you via the PROTECT study to let you know the study has ended. We will provide you with a summary of our findings in the form of a newsletter, again this will be communicated through your participation in the PROTECT study. The results of the study may be published in scientific journals or conferences. The information presented will be fully anonymous and no individuals will be identified in any reports/publications or presentations.

What if there is a problem?

If you have a question about any aspect of this study, you can contact Dr Byron Creese and the research team on mbi-study@exeter.ac.uk

If you have any complaints about the way in which this study has been carried out please contact the Chair of the University of Exeter Medical School College of Medicine & Health Research Ethics Committee:-

Ruth Garside, PhD
Chair of the College of Medicine & Health Research Ethics CommitteeEmail: cmhethics@exeter.ac.uk

This project has been reviewed and approved by theUniversity of Exeter College of Medicine & Health Research Ethics CommitteeCMH REC REFERENCE NUMBER: RG/CB/19/11/231

Consent to Take Part

- I confirm that I have read the information sheet dated 20/07/2021 version 3.1 for the above project. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.
- I understand that relevant sections of the data collected during the study may be looked at by members of the research team, individuals from the University of Exeter, PROTECT and regulatory authorities (for audit purposes), where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
- I understand that taking part involves anonymised completion of the Cambridge Gambling Task to be used for the purposes of:
  - Writing reports published in scientific publications
  - Presentation at scientific conferences
  - Sharing with other researchers for the purpose of future research
- I agree to take part in the above project.