

Participant Information Sheet

Study Title: *Exploring the nature of facial recognition impairments in early onset and late onset Alzheimer's Disease*

We would like to invite you to take part in our research study. Before making an informed decision, it is important to understand the aims of the study and what it will involve. Please take your time to thoroughly read the following information and feel free to ask us any questions if there is something that is not clear.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

What is the purpose of the study?

Alzheimer's Disease is defined by a decline in memory and thinking, which accounts for 70% of all dementia cases. Alzheimer's Disease can present more typically in individuals aged 65 years and above but in rare cases, symptoms can appear in younger individuals below 65 years of age. This is characterised as early-onset Alzheimer's Disease and late-onset Alzheimer's Disease. Recent research has shown there to be differences in how people with early- and late-onset Alzheimer's Disease perceive faces. The ability to recognise faces is useful in every-day life as it helps improve social interaction and overall well-being. Therefore, it is important to understand why facial recognition challenges can occur in Alzheimer's Disease. To do this, we have selected a range of questionnaires, thinking tests and famous face recognition tests for you to complete in order to explore your facial recognition performance.

Who can take part in this study?

You can take part in the study if:

- You are aged 50-90.
- You have a clinical diagnosis of Alzheimer's Disease

What does participation in this research involve?

If you decide to take part in this study, you will be either invited to the Harry Pitt Building, located in the Psychology and Clinical Languages department at the University of Reading or a local dementia community group setting. This is where the study will take place. The study will last approximately 2-3 hours and will include:

1. Questionnaires about your self-reported facial recognition ability.

2. Memory and thinking tests looking at how well you can remember words, use of language, your attention to detail and drawing skills.
3. Facial recognition tests assessing how well you can remember familiar and nonfamiliar famous faces.

Do I have to take part in this research study?

Participation is voluntary so if you wish to withdraw at any point, you can do so freely without a given reason.

What are the possible benefits of taking part?

Whilst there are no direct benefits from taking part, we hope that the information gathered will improve our understanding regarding why facial recognition impairments can occur in Alzheimer's Disease. In turn, this could help improve the accuracy of current Alzheimer's diagnostic assessments and enable more specific interventions to be developed.

What are the possible risks of taking part?

There are no known risks associated with taking part in this study. Some of the tests and questionnaires that assess your thinking, memory and recognition may raise concerns about your cognitive health. We cannot give medical advice so we would encourage you to take any concerns to your GP. Also, any concerns regarding your participation can be discussed with the research lead, Dr Samrah Ahmed, in person or by emailing samrah.ahmed@reading.ac.uk.

Expenses and payments

Travel expenses will be reimbursed. Please pass on your receipts or, if you travelled in your own car, let us know how many miles you travelled.

Will my taking part in this study be kept confidential?

All data that is obtained will be kept confidential and managed according to the University Compliance Policies. Raw data will be kept securely locked in the GS18 lab with restricted access to the named researchers only. After 10 years the data will be destroyed.

Identifiable information will be pseudo-anonymised through providing you with a unique ID number. This pseudo-anonymised data will be digitally transferred to a secure master excel spreadsheet file. This will be accessible by the main researchers only through a PI password coded one drive account. After that point, we will not be able to link any data to you. Hence, if for any reason you wish to withdraw your data from the study, you must do it before this point. Pseudo-anonymised de-identifiable data will be made available on a public repository for future research, as specified on the participant consent form.

Some tasks involve being audio or video recorded. This is because, performance on these tasks involves personal judgements by researchers completing assessments. Your data will be transcribed as soon as possible after your visit, and then will be deleted. You will be told which tasks are video or audio recorded.

The organisation responsible for protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at imps@reading.ac.uk, or in writing to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading , RG6 6UR, UK.

Contact for Further Information

You should contact PhD student Rachel Corrigan for further information. You can contact her via email at brainhealth@reading.ac.uk.

Thank you for your participation.

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