

## Participant Information Sheet

### A Multimodal Deep Learning Based Approach for the Early Detection of Neurodegenerative Diseases

You are invited to take part in research taking place at the Bristol Robotics Laboratory (Bay 17), University of the West of England, Bristol. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Your participation in this study is entirely voluntary. You may withdraw at any point, and this will not affect you in anyway.

Please take the time to read the following information carefully and if you have any queries or would like more information please contact **Gabriella Miles**, Faculty of Engineering and Technology, University of the West of England, Bristol ([gabriella2.miles@brl.ac.uk](mailto:gabriella2.miles@brl.ac.uk)).

#### Who is organising and funding this research?

This study is funded by the Engineering and Physical Sciences Research Council (EPSRC, Reference EP/L015293/1), as part of the FARSCOPE Centre for Doctoral Training (CDT). The director of studies for this research is Dr. Wenhao Zhang (UWE, Bristol Robotics Laboratory). Professor Melvyn Smith (UWE, Bristol Robotics Laboratory), Dr Nancy Zook (UWE), and Emma Gentry (UWE) are co-investigators.

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

Previous research has shown that eye movement characteristics change across our lifetimes. A decline in cognitive function due to Alzheimer's Disease has been shown to impair eye movement beyond that which is expected of healthy aging.

This study aims to gather eye movement data during different cognitive tasks. To do this, an experiment has been designed where you will complete some visual tasks (e.g. following a moving dot on a computer screen), while the movement of your eyes is recorded.

Collecting this data will allow us to investigate age- and cognitive task-related changes in eye movement using a machine learning approach. In future research, this work will be used to compare the differences between typical and atypical aging, and will potentially aid in the early detection of Alzheimer's Disease.

#### Why have I been invited to take part?

We need participants between the age of 18 and 75 years old, without sensory or respiratory impairment, who do not identify as a high-risk group for Covid-19 contraction.

As the focus of this study is on typical aging, participants cannot have a diagnosed neurological (i.e., stroke, dementia, etc.) or neuropsychiatric diagnosis (depression, bipolar, etc.) in the last 6 months as the focus of this study is healthy/typical development. Given the focus on vision, all participants must have normal or corrected 20/20 vision. If you do not have these health concerns, then you are an eligible participant.

## **What will happen to me if I take part and what do I have to do?**

Due to the current restrictions regarding interpersonal contact during Covid-19, the following experimental setup conforms with the regulations set out by UWE's Ethical Guidance to allow the experiment to take place during this period. These are further detailed in the "Covid-19 Precautions" section below – but please contact the researchers if you require any further information.

The study involves taking part in approximately one hour of testing. You will be asked to answer some questions about yourself (age, education, gender, health, etc.), and if you are happy to proceed with the experiment give consent to do so.

You will then complete the visual tasks, which will be displayed on a computer monitor. The visual tasks encompass a number of activities, including: watching a dot as it moves about the computer screen; looking at images of natural scenes (e.g. landscapes), or pairs of images side-by-side; and pressing the mouse or keyboard in response to certain images being displayed. You will be given time to familiarise yourself with and practice the task before completing each one.

During the tasks, your eye movements will be recorded with a camera on the desk – we will additionally ask you to use a chin rest to keep your head still during the tasks. Some of the tasks may be cognitively challenging, as they will require you to carry out additional problem-solving tasks (while also responding to the displayed visual stimuli. These problem-solving tasks include: mental arithmetics; word association; and tapping the mouse or keyboard keys in a particular rhythm.

While the tasks may be somewhat challenging, they are also quite short and you are welcome to take breaks between tasks. This is not a clinical evaluation and your data cannot be used for any diagnostic purposes.

## **Covid-19 Precautions**

In order to protect your safety and the safety of the researchers, social distancing will be practiced throughout the experiment where possible. Face masks and hand sanitiser will be provided for you, and used by the researcher. Any equipment will be thoroughly sanitised between participants. If you are feeling unwell in any way, or present with Covid-19 symptoms prior to the experiment, please inform the researcher using the contact details provided, at which point a new date for experimentation will be arranged.

## **What are the possible benefits of taking part?**

The overall goal of the project is to work towards the early detection of Alzheimer's Disease. Alzheimer's Disease leads to a significant reduction in quality of life, and is one of the largest contributors to elderly disability. In taking part in this experiment, you will be adding to scientific knowledge about aging and its effects on cognition and eye movements. Without volunteers like you research of this kind would not be possible. Your participation and contribution is, therefore, invaluable.

To compensate you for your time, you will receive a £10 Amazon voucher or one credit towards your research requirement participation (where applicable).

## **What are the possible disadvantages of taking part?**

We do not feel that there are many disadvantages to taking part. If, for any reason, you feel distressed during or after taking part in the research then please let the researcher know and they will be able to help. You can withdraw at any time. You can also contact any of the researchers whose details are at the bottom of this sheet.

### **Who will be informed of my participation?**

If you decide to take part in the study, then all of the data from the study will be kept confidentially, and nobody will be told about your participation.

### **Who has ethically approved this research?**

This study has been approved by a Faculty Research Ethics Committee (UREC) at the Univ. of the West of England (UWE REC REF No: FET.21.01.028). Any comments, questions or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at: [Researchethics@uwe.ac.uk](mailto:Researchethics@uwe.ac.uk), quoting the title of the study and the reference number FET.21.01.028.

### **What will happen to my data?**

All the information we receive from you will be treated in the strictest confidence.

All the information that you give will be kept confidential and demographic/test data will be anonymised immediately. The only circumstance where we may not be able to keep your information confidential is the videos that will contain images of your face (focused on the eyes).

These images will be stored securely for up to 10 years. You will be asked to identify if you are willing for us to securely store these images, if you are willing to allow us to share these with other researchers, if we can use them for journal publications, and to sign a consent form stating as such. Hard copy research material will be kept in a locked and secure setting to which only the researchers will have access in accordance with the University's and the Data Protection Act 2018 and General Data Protection Regulation requirements. All data collected as part of this study will be archived securely for a period of up to ten years after the end of the study and may be used as a comparison group in future studies.

The results of this study will be published in peer-reviewed journals in the relevant subject field (e.g. robotics/mathematics/machine learning). If you decide you would like to come to an event or be sent a copy of published papers, then please let the researcher know.

With your consent, anonymised research data and images will be shared with other researchers via a Research Data Repository, e.g. UWE's Research Data Repository <https://www1.uwe.ac.uk/library/searchforthingsa-z/researchdatarepository.aspx>.

### **What if something goes wrong?**

Any concerns, queries and/or complaints can be addressed by contacting either the lead researcher, Gabriella Miles ([gabriella2.miles@brl.ac.uk](mailto:gabriella2.miles@brl.ac.uk)) or the Director of Studies, Dr. Wenhao Zhang ([Wenhao.Zhang@uwe.ac.uk](mailto:Wenhao.Zhang@uwe.ac.uk)).

### **Further information**

**If you do decide to take part we will ask you to sign a consent form and we will give you a copy of this information sheet and the consent form to keep. If you wish to withdraw any time during the study simply tell the researcher, you do not need to give a reason. If you decide to withdraw after you have participated please get in touch with the researcher, Gabriella Miles, ([gabriella2.miles@brl.ac.uk](mailto:gabriella2.miles@brl.ac.uk)) within 15 days.**

If you would like to find out more information about the study, then please do get in touch with Gabriella Miles (contact details below).

### **What do I do now?**

If you are happy to take part, **please contact Gabriella Miles ([gabriella2.miles@brl.ac.uk](mailto:gabriella2.miles@brl.ac.uk)) and an appointment will be arranged at a convenient time and date for you** to come to the Bristol Robotics Laboratory, Frenchay Campus, University of the West of England, Bristol. On arrival, a researcher will be on hand to answer any questions you may have about the study. Your appointment will last approximately one hour, after which your participation in the study will be complete.

This sheet will hopefully provide you with enough information about the study to allow you to make an informed decision about whether you would like to take part. However, if you have any questions or would like to discuss anything please contact any of the researchers listed below. If you are happy to take part in this study, please read and sign the consent form on the following page.

Thank you for your time!

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Co-Investigators: Wenhao Zhang ([wenhao.zhang@uwe.ac.uk](mailto:wenhao.zhang@uwe.ac.uk)); Nancy Zook ([nancy.zook@uwe.ac.uk](mailto:nancy.zook@uwe.ac.uk)); Melvyn Smith ([melvyn.smith@uwe.ac.uk](mailto:melvyn.smith@uwe.ac.uk)); Emma Gentry ([emma2.gentry@live.uwe.ac.uk](mailto:emma2.gentry@live.uwe.ac.uk)).