

## **Privacy Policy**

### **Purpose of Study:**

The ultimate aim of our study is to help diagnose Alzheimer's disease (AD) at an early stage. Changes in spatial navigation occur at the beginning of AD, before people develop symptoms of dementia. The availability of personal devices such as smartphones now provides an opportunity to measure real life navigation. The future use of apps as diagnostic tools is particularly important in the light of the Covid-19 pandemic which emphasises the need for remote testing in place of traditional face-to-face clinic visits.

However, prior to using the app in patients, we need to collect navigation data in healthy people without memory problems, to help us test the robustness of our location data collection app and start developing the analysis pipeline. Modelling navigation information obtained from healthy volunteers is a necessary first step before we can model the information from patients.

Taking part in this study will involve installation of the navigation app on your smartphone. We will provide a unique ID for registering the app with the server. We will ask you to select your age group from a list of options (18-40, 41-60, 61-80, and 81+) too. Upon completing the registration, as you undertake your normal daily activities the app will collect your location every 15 minutes while the phone is stationary and every minute otherwise. The collected data would include the date and time of collection, latitude and longitude. The collected data will be periodically transmitted via a secure communication channel to a secure server at the Department of Computer Science, University of Cambridge where the data will be stored. The data will only be used for academic research purposes.

### **User Declaration**

I understand that the data to be recorded is highly sensitive personal data, which will identify me personally (by the location of my home address, my workplace, and any other locations that I regularly visit), and that it will record every place I travel and every location that I visit, even briefly, 24 hours a day and 7 days a week, wherever I carry my phone for a period of six months.

Because this data is highly sensitive, I understand that it will be stored securely, on an encrypted disk drive. I understand that any temporary decrypted copies made in the process of research analysis will be securely deleted immediately after each analysis session. I

understand that a permanent record will be kept of the individuals who are given access to the decryption passwords, and that I can request a copy of that list at any time.

You can control recording by enabling or disabling the location service in the phone; Opt out of the study by uninstalling the app; and request to delete your own data by emailing the provided ID. Upon delete request we shall delete all the traces of your data. We acknowledge that the location data can be engineered to infer sensitive information, but we will not derive any such information from the collected data. Moreover, we will keep your personal identities (name and email addresses) separate from the collected data all the time.

In future, for research purposes a derived version of the location traces shall be shared with other research institutions under legal agreements to be drafted at the appropriate time. The derived data shall contain statistical and topological features extracted from the traces or suitably chosen parts of the traces so that the personal features become fuzzy. Example features would include the number of times you turned more than 90 degrees in a day, etc. Although the exact features to include depends on the result of the analysis and will be decided later, we shall refrain from including any geometric feature (such as a time series of turn angles) that could lead to revealing locations in the map.

For further general information about the University of Cambridge's use of your personal data as a participant in a research study, please see <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>. Please note that the legal basis for processing any personal data collected by this project is to perform a task in the public interest, namely academic research.

## **Consent**

I have had the opportunity to discuss this study with an investigator, and I am satisfied that my questions have been answered. I voluntarily consent to participate in this study with the understanding that I can withdraw at any time.

**Participant Signature:**

**Investigator Signature:**

**Date:**