

Analysis of Wandering Patterns of Individuals with Alzheimer's

George Mason University

INFORMED CONSENT FORM (Caregivers – Informal/Family)

RESEARCH PROCEDURES

The purpose of the project is to collect GPS and medical data for people with Alzheimer's disease (AD). GPS trackers will be used to collect spatiotemporal data. Surveys of individuals with AD and caregivers will be used to establish AD stage, medical history, demographic, and socioeconomic status. The survey will be repeated every 3 months to establish changes in the individual's condition. Both survey and GPS data will be collected for one year. Caregivers will also be asked to record specific wandering incidents, so they can be linked to the geolocation data. Collected data will be used to test the feasibility of using machine learning algorithms to detect patterns of wandering. Spatiotemporal clustering will be used to detect normal locations where the participants typically are. The actual analysis will focus on anomalous locations that don't follow normal patterns of movement. These locations will be passed to machine learning algorithms in order to check for existence of patterns within the non-typical movements. This project will enable data collection for a long-term experiment to test if GPS data can be used to track progression of Alzheimer's disease. The project will result in the creation of protocols and the infrastructure needed for monitoring individuals with AD for several years

RISKS

Potential risks involve loss of privacy if security procedures are not strictly followed and individuals represented by the data are identified. The loss of privacy may result in distress, embarrassment, or discrimination. Strict procedures, personnel training, and implementation of appropriate physical, technical and administrative security measures during all aspects of the project will minimize the risk. While it is understood that no computer transmission can be perfectly secure, reasonable efforts will be made to protect the confidentiality of your transmission.

BENEFITS

The participants will receive free SmartSole devices and monitoring for one year. Because the participants will be recruited from among those who already have past history of wandering, such service may provide additional protection against being lost and pace of mind to families and caregivers.

CONFIDENTIALITY

The information collected in this study will be confidential. Your name or the name of your loved one will not be included on any information we collect. A number code will be assigned to both you and your loved one so that only the researchers will know the information you provide. Our team takes the highest possible precautions to protect human subjects. All project personnel receive human subject training and follow strict procedures. All data are stored and analyzed in secure environment within the GMU Center for Discovery Science and Health Informatics. For additional protection, the data will be stored on a dedicated virtual machine (rather than shared server) to provide additional layer of security. The environment consists of secure servers with double firewalls, strict user control and monitoring. They are physically located in GMU datacenter with restricted access. Data access will be limited only to direct project personnel. GPS data and survey data will be transferred in encrypted form using 2048 bit RSA encryption.

IRB: For Official Use Only



Institutional Review Board

Project Number: 1052716-6
Date Approved: 5/14/19
Approval Expiration Date: 5/13/20

PARTICIPATION

You and your loved one's participation is voluntary, and you and your loved one may withdraw from the study at any time and for any reason. If you or your loved one decides not to participate or if you withdraw from the study, there is no penalty or loss of benefits to which you are otherwise entitled. There are no costs to you or any other party.

Individuals with Alzheimer's Disease and good mobility, having at least 2 episodes of wandering in the past 3 months are eligible to participate. Caregivers will be asked to complete initial and periodical surveys, keep GPS devices charged, and report wandering incidents.

CONTACT

This research is being conducted by Dr. Janusz Wojtusiak, and Dr. Catherine Tompkins in the College of Health and Human Services at George Mason University. They may be reached at phone 703-993-4148 or email jwojtusi@gmu.edu for questions or to report a research-related problem. You may contact the George Mason University Institutional Review Board (IRB) Office at 703-993-4121 if you have questions or comments regarding your rights as a participant in the research.

This research has been reviewed according to George Mason University procedures governing your participation in this research.

CONSENT

I have read this form and agree to participate in this study.

Participant Name and Signature

Date

LAR Name and Signature
(in case Participant unable to consent)

Date

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