Automated vehicle Services for People with disabilities – Involved Responsive Engineering (ASPIRE Center)

Topic: Implications of Accessible Automated Vehicles and Mobility Services for People with Disabilities

Data Management Plan

Data sharing and preservation enable validation of results by allowing others to have the opportunity to further analyze the results and have the opportunity to potentially merge similar and/or related data sets collected by other sites nationwide.

1. Types of data

I. Literature Review: Data collected will include peer-reviewed articles and studies, articles published in a scholarly journal, or grey literature of high quality. Important information about the design and conduct of the systematic review will be available on an open access electronic database (PROSPERO). Key features from the review protocol will be recorded and maintained as a permanent record.

II. Voice of Consumer – Provider: Data resulting from focus groups and journey mapping will include secure web meeting recordings which will be transcribed along with their sociodemographic characteristics (e.g. age, gender, disability type, etc.) Surveys may have optional fields to capture additional open-ended comments. The survey will be developed in multiple formats (web-based, interview, paper). The web-based survey will be developed using either Redcap or Qualtrics.

III. Modeling – Simulation: Data collected from the systematic review and surveys will be synthesized into sets of 3D solid models. To maximize the value for all stakeholders, these models will be used to illustrate key design and usage parameters which will be made publicly available. The American Community Survey (ACS) data will be download and stored onto our secure research servers. Software such as SAS 9.4 will be used to merge the 2 data sets (ACS and survey response) by census tract to create a single data file.

2. Data format and metadata standards

We will use the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. PRISMA is an evidence-based set of items for reporting in systematic reviews and meta-analyses.

A de-identified, anonymized dataset will be created and shared. No identifiable information will be provided. The minimum amount of information necessary to achieve the objectives of the research proposed will be collected and shared.

3. Data access policies

Every effort will be made to protect personal privacy and the confidentiality of private information collected for research purposes. This dataset will be de-identified and the minimum amount of information necessary to achieve the objectives of the research proposed will be shared. Any paper-based research records will be kept in a secured file room with restricted access within the

research facility (Human Engineering Research Laboratories). Any records that contain direct participant identifiers will be stored separately from data collection forms that will only be labeled with a case number. The information linking subject identity with case number will be kept separately. Digital or computer-based files will be stored on a university affiliated FISMA Compliant and secured server. Access to both the electronic and paper-based files will be restricted to the associated research staff.

4. Data management and ethical compliance

University of Pittsburgh Institutional Review Board (IRB) approval will be obtained for projects that involve human subjects and investigators will adhere to IRB policies and procedures during research activities, ensuring compliance. Clinical coordinators will periodically review study documentation to ensure that participant's confidentiality is maintained. Investigators and the clinical coordinators will meet at least quarterly during periods of study development and active recruitment or more frequently, if needed, to discuss the study and review recruitment efforts and enrollment rates to ensure goals are being met.

5. Data archiving and preservation

Data will be submitted to Inter-university Consortium for Political and Social Research (ICPSR) https://www.icpsr.umich.edu/web/pages/deposit/index.html

The final data sets will be maintained locally until enterprise-level resources become available for long-term storage and access. Guidance on request and distribution processes will be provided by the University of Pittsburgh Office of Research & Development.

Information collected as a result of this research will be retained a minimum of 7 years following study completion as per University of Pittsburgh policy. Given the nature of this research, linkage code information will be retained indefinitely to not duplicate enrollment.

6. Public access and sharing

Participants will be informed about the possibility of publishing their de-identified dataset during the consent process. Manuscripts will be submitted at the end of every phase of the project. The initial drafts will be reviewed by the Advisory Board. Their input will be used to revise the manuscript, which will then be submitted for peer review to a scientific journal.

Publications from this research will be made available to the public through the National Library of Medicine PubMed Central website within one year after the date of publication. We will ensure they are open access.

The ASPIRE Center will have a website linked to the HERL website. HERL maintains a traditional website that acts as an archive for important news items, publications, State of the Science symposia dating back to 2011, newsletters dating back to 2002, videos, recruitment and volunteering information, and links to other affiliated websites.