

Utah State University

DigitalCommons@USU

Funded Research Records

Data Services

Fall 9-19-2024

Listener Training for Improved Intelligibility of People with Parkinson's Disease

Stephanie Anna Borrie

Utah State University, stephanie.borrie@usu.edu

Follow this and additional works at: https://digitalcommons.usu.edu/funded_research_data



Part of the [Communication Commons](#), [Disability Studies Commons](#), and the [Rehabilitation and Therapy Commons](#)

Recommended Citation

Borrie, Stephanie Anna, "Listener Training for Improved Intelligibility of People with Parkinson's Disease" (2024). *Funded Research Records*. Paper 258.

https://digitalcommons.usu.edu/funded_research_data/258

This Grant Record is brought to you for free and open access by the Data Services at DigitalCommons@USU. It has been accepted for inclusion in Funded Research Records by an authorized administrator of DigitalCommons@USU. For more information, please contact digitalcommons@usu.edu.



DATA MANAGEMENT AND SHARING PLAN

Element 1: Data Type

A. Types and amount of scientific data expected to be generated in the project:

- Patient participant profiles (de-identified): Demographic information, including biological sex, age, and race/ethnicity data, will be collected from 90 patient participants with Parkinson's disease.
- Partner participant profiles (de-identified): Demographic information, including biological sex, age, and race/ethnicity data, and test results, including hearing and cognition, will be collected from ~270 communication partners.
- Raw audio recordings (preserved): A total of 140 testing phrases and eight training passages will be audio recorded for aim 1. Another 150 sentences and 10 short stories will be audio recorded for aim 2. Quantitative interviews from 45 dyads (patient-partner pairs) will be audio recorded for aim 3.
- Intelligibility scores (de-identified): Intelligibility scores will be obtained from each of the 270 partners at three different time points.
- Listener effort and comprehension scores (de-identified): Listener effort and comprehension scores will also be obtained. each of the 270 partners at three different time points.
- Communicative participation scores (de-identified): Communicative participation scores will be obtained from each of the 90 patients and 270 partners at two different time points.

Data collection will be performed at Utah State University and Florida State University with adults with Parkinson's disease and adult communication partners.

B. Scientific data that will be preserved and shared, and the rationale for doing so:

All de-identified data produced in the course of the project will be preserved and shared to enable the replication of the proposed study. We will share de-identified individual-participant level (IPD) data. Appropriate measures such as assigning alphanumeric codes and removing identifiable information will be used for data de-identification and sharing, and informed consent forms will reflect those plans. Given the risks to privacy from sharing audio-recorded data (i.e., cannot be de-identified without degrading the integrity of the acoustic signal), audio recordings will not be shared publicly. We also plan to share our data through conventional channels, namely the timely publication of multiple research articles in scientific journals and presentation of the material at scientific conferences.

C. Metadata, other relevant data, and associated documentation:

To facilitate interpretation of data, lab standard operating procedures and manuals detailing the way in which the data was collected and analyzed will be created, shared, and associated with the relevant datasets.

Element 2: Related Tools, Software and/or Code:

All data will be made available in PDF, HTML, or CSV files and will not require the use of specialized tools to be accessed or manipulated. Open-sourced statistical programs such as R can be used to analyze the raw data present in CSV files. R is a free software environment for statistical computing and graphics. RStudio is a free R development environment that runs on most operating systems. R Scripts produced through the course of the research will be made publicly available on the PI's OSF account and will be provided as supplementary files for any publications through an OSF link. Code will be available no later than when a publication has been submitted.

Element 3: Standards:

In accordance with FAIR Principles for data, we will use open file formats (e.g. CSV, TXT, PDF, HTML, etc.) and persistent unique identifiers (PIDs). Formal standards for perceptual data have not yet been widely adopted. However, our data and other materials will be structured and described clearly and transparently to facilitate ease of use.

Element 4: Data Preservation, Access, and Associated Timelines

A. Repository where scientific data and metadata will be archived:

The derived data supporting all publications associated with this project will be available for public access via the Open Science Framework (housed by the Center for Open Science).

B. How scientific data will be findable and identifiable:

The data will be findable in the Open Science Framework by standard indexing tools (keywords, including entrainment, autism, conversation, etc.). For all publications, a digital object identifier (DOI) will be assigned. This data DOI will be referenced in the publication to allow the research community easy access to the exact data used in the publication.

C. When and how long the scientific data will be made available:

All scientific data generated from this project will be made available as soon as possible and no later than the time of publication or the end of the funding period, whichever comes first. The duration of preservation and sharing of the data will be a minimum of 10 years after the funding period.

Element 5: Access, Distribution, or Reuse Considerations

A. Factors affecting subsequent access, distribution, or reuse of scientific data:

There are no anticipated factors or limitations that will affect the access, distribution, or reuse of the deidentified scientific data generated by the proposal.

B. Whether access to scientific data will be controlled:

Controlled access will not be used. The data that is shared will be shared by unrestricted download.

C. Protections for privacy, rights, and confidentiality of human research participants:

In order to ensure participant consent for data sharing, IRB paperwork and informed consent documents will include language describing plans for data management and sharing of data, describing the motivation for sharing, and explaining that personal identifying information will be removed.

Element 6: Oversight of Data Management and Sharing:

Drs. Borrie and Lansford (M-PIs) will be responsible for the day-to-day oversight of team data management activities and data sharing. Broader issues of DMS Plan compliance oversight and reporting will be handled by the M-PI as part of general USU and FSU stewardship, reporting, and compliance processes.