Digital Voice (dVoice): Optional UDSv4 instrument

Sudeshna Das, PhD

Thursday, October 17, 2024

2024 Fall ADRC Meeting

Why dVoice?

- As cognitive abilities evolve, subtle shifts in vocal expression can reveal underlying changes. These shifts may include alterations in word choice, sentence structure, and speech patterns, reflecting potential compromises in memory, attention, executive, and/or motor function.
- **Early detection:** A growing body of literature indicates that analyzing digital voice recordings holds promise as a method for differentiating individuals with and without cognitive impairments. (Rhoda Au at BU, Jeff Kaye at OHSU)
- **Differential Diagnosis**, voice recordings can serve as biomarkers of clinical syndromes and etiological diagnoses, e.g., PPA, PD, ALS (Brad Dickerson at MGH)

Benefits of dVoice Biomarkers

- **Low cost and inclusive:** Penetration of recording devices allows for easy, low-cost collection of voice data that can be done in the person's native language.
- **Minimal participant burden:** NP tests are already being conducted; digital voice collection allows for scientific enablement at no additional burden to participant.
- **Quality control (QC):** Digitally recorded voice tasks can act as a QC tool to determine natural drift in standardization in any longitudinal study.
- **Novel analytics:** Natural Language Processing (NLP) and other advanced AI offer unprecedented opportunities to explore acoustic and semantic features in novel forms

Digital Voice is Not New – Lots of Precedence

- **ADRC Technology Survey from Fall 2023 ADRC:**
  - 18 ADRC's were collecting digital voice data during cognitive assessments as of Fall 2023
  - 8 ADRC's said "No, but we plan to collect this data in the future"
  - 8 ADRC's said "No, we do not plan to collect this data"
- **Framingham Study**
- **LEADS**
- **ADNI-4**
- **Dementia Bank**

Tools and Resources for ADRC's: IRB Protocol

- **Objective:** Clearly state the purpose of the study and the role of audio recordings in achieving the study objectives.
- **Recording Procedure:**
  - Specify what will be recorded
  - Specify the setting and method for audio recording (e.g., office or virtual visits).
  - Detail the equipment to be used for recording**.**
- **Storage:** Describe measures to protect participant confidentiality
- **Data Sharing:** Specify who will have access to the recordings and who will the data be shared with.

Example: LEADS Study

7.3.3 Audio Recording

- The administration of select language and memory tests will be audio recorded for every participant, at every visit. This data will be collected to allow for additional analyses. A recording device, such as the Olympus VN-722PC digital voice recorder or a similar digital recording device, will be used.

15.4 Audio Recording Storage

- The audio files acquired in this study will be securely transmitted and stored in databases being used for the study. The audio recorded during the administration of select assessments should not contain PHI. Sites will be responsible for ensuring that no PHI is included in the recordings prior to upload.

Example: I-CONECT Study

Audio/Video Recording

The I-CONECT video chat system is a secure, scalable, and cost-effective video chat platform for conducting in-home telehealth with geriatric populations. It enables researchers, clinicians and older participants (age 75+) easy access to private meeting spaces at the touch of a button. I-CONECT uses highly modified 2-in-1 style Chromebooks with functional touchscreens and webcams. The devices are folded to hide the keyboard, leaving only the touchscreen usable. The device is customized with Google G-Suite Enterprise, to enable remote management, updates, restricted access, and automatically load up the I-CONECT video chat app. They are installed with needed peripherals, several audio options, and a cover. The I-CONECT video chat app is a javascript interface built to run on top of commercial video chat software which uses a Web RTC interface. Essentially, it facilitates joining video-chat services by automatically entering required join commands for the subject with one click. Users have two UI options: “Join” or “Restart”. Researchers and clinicians join video chats through the commercial platform interface on their personal computers, which allows them to record chat audio using installed software. I-CONECT uses MacBook Air’s, with Audio Hijack installed, which allows individual channels to be isolated, recording input and outputs separately.

Audio/Video Recording Storage

All the recordings are stored in the HIPAA-compliant institution-supported cloud sources.

Tools and Resources for ADRCs: Informed Consent

- **Purpose:** Clearly explain the reason for the audio recording and how it will be used.
- **Confidentiality:** Describe how the recordings will be kept confidential and the measures in place to protect the participant's privacy.
- **Data Sharing:** Specify who will have access to the recordings and who will the data be shared with.
- **Benefits and Risks:** Explain any potential benefits and risks associated with the audio recording.

Informed Consent Example: LEADS Study

Memory and thinking tests: You will be asked to do activities which include remembering information, naming and drawing pictures, connecting symbols, and other similar tasks. The tests will be a combination of written, verbal, and computerized tests using a device like an iPad. The tests will take up to 5 hours to complete and can be split over multiple days. You can skip any questions you do not want to answer and take breaks if needed. We will audio record your responses to some of the memory and language tests. Recording your responses will allow researchers to write out (transcribe) your responses exactly as they were spoken. These audio recordings and transcriptions will allow researchers to analyze your responses in order to answer important questions about (such as) behavioral markers of speech, language and cognitive decline. Your recordings will be maintained on secure servers used for this study and only those with privacy training and permission from the study team will have access to them. While your voice can identify you, all other information which might identify you will be removed to protect you.

Informed Consent Example: LEADS Study

Memory and thinking tests: You will be asked to do activities which include remembering information, naming and drawing pictures, connecting symbols, and other similar tasks. The tests will be a combination of written, verbal, and computerized tests using a device like an iPad. The tests will take up to 5 hours to complete and can be split over multiple days. You can skip any questions you do not want to answer and take breaks if needed. We will audio record your responses to some of the memory and language tests. Recording your responses will allow researchers to write out (transcribe) your responses exactly as they were spoken. These audio recordings and transcriptions will allow researchers to analyze your responses in order to answer important questions about behavioral markers of speech, language and cognitive decline. Your recordings will be maintained on secure servers used for this study and only those with privacy training and permission from the study team will have access to them. While your voice can identify you, all other information which might identify you will be removed to protect you.

Informed Consent Example: I-CONECT Study

Informed Consent Form Extract:

All video chats in this study will be video and audio recorded. Parts of the testing calls will be audio recorded. The weekly phone call will also be audio recorded. We will use these recordings for educational materials and research analysis.

In the future, your saliva and information and recordings may be given to researchers for other research studies. These studies may include genetic research.

We will protect your privacy when sharing audio recordings by only sharing the recordings with approved researchers. We will not share any parts of the audio recordings that contain identifying information like your name, telephone number, or other information we think could be used to tell your identity. However, because everyone's voice is unique, it's possible that someone listening to the recording could identify you from the sound or pattern of your voice.

Tools and Resources for ADRCs: Additional Consent

Do you give us permission to audio record your responses to some of the memory and language tests?

☑ Yes, you have my permission
☐ No, you do not have my permission:

Additional consent is required if the audio recording is not an essential part of the study

How to collect dVoice? Preferred method

- **Step 1:** Turn on Zoom recorder. Power the Zoom H4N recorder by sliding down power button.
- **Step 2:** Record staff name/initials, participant NACC ID, visit information (visit date and number), neuropsych test name. Ensure there is limited background noise.
- **Step 3:** Record participant response. Press record button, administer test, and press pause once the participant has finished.
- **Step 4**: End the recording. Press the square symbol to end the recording.
- **Step 5:** Store and upload data to NACC.

How to Process, Store, and Submit dVoice?

Processing

- Splice PII from the recording to the extent possible.
- De-identification tools are in process for voice masking and PII splicing.
- NACC will not share any vocal data until such de-identification processes are validated and complete on all vocal recordings.

Storage

- Use NACC naming conventions: NACCID_DATE_TESTNAME
- Store in WAV format (preferable)

Submission

- Enter meta-data of the test in UDSv4 dVoice form

UDSv4 Digital Voice Metadata Recommendations

NACC and the **CTF Technology Workgroup** are collaborating with digital voice data leaders across the field to develop a metadata form to accompany digital voice data upon submission to NACC. This form will capture key metadata variables that will aid in the storage, processing, analysis, and sharing of digital voice data in the future.

Key fields included:

- NACCID and/or PTID
- VISIT DATE
- NACC VISIT NUMBER
- COGNITIVE TEST
- TIME STAMPS (if more than 1 cogtest present in recording)
- INTERVIEWER INITIALS
- MASK (whether interviewer and/or participant had a mask)
- VISIT LOCATION/SETTING
- MICROPHONE LOCATION
- DEVICE MANUFACTURER
- DEVICE MODEL
- NUMBER OF RECORDING SUBJECTS

Helpful Tips

1. Keep purpose and details of study procedure general and non-specific to avoid limiting yourself in the future
   - Use examples, with "such as", as opposed to blanket statements
2. Privacy and security of data should be protected in the same manner as other data types (e.g., imaging, genotyping)
   - Locally stored in HIPAA compliant storage solutions
   - Access limited to IRB-approved study-staff
   - Transmitted securely to NACC (NIH certificate of confidentiality)

NACC will establish a governance structure designed to protect participant privacy and confidentiality while also ensuring the proper handling and sharing of any proprietary or copyrighted information.

View available resources:

bit.ly/UDSv4_DigitalVoice

Thank you!