UNIVERSITY OF ILLINOIS URBANA-CHAMPAIGN

Office of the Vice Chancellor for Research & Innovation

Office for the Protection of Research Subjects
805 W. Pennsylvania Ave., MC-095
Urbana, IL 61801-4822

Notice of Approval: New Submission

March 3, 2023

Principal Investigator	Mark Hasegawa-Johnson
CC	Heejin Kim
Protocol Title	*NOVA HABILITAS (NOVA H) Consortium*
Protocol Number	23183
Funding Source	Industry Consortium
Review Type	Expedited 6, 7
Status	Active
Risk Determination	No more than minimal risk
Approval Date	March 3, 2023
Expiration Date	March 2, 2028
Sites Approved:	University of Illinois Urbana-Champaign Davis Phinney Foundation LSVT Global

This letter authorizes the use of human subjects in the above protocol. The University of Illinois at Urbana-Champaign Institutional Review Board (IRB) has reviewed and approved the research study as described.

The Principal Investigator of this study is responsible for:

- Conducting research in a manner consistent with the requirements of the University and federal regulations found at 45 CFR 46.
- Using the approved consent documents, with the footer, from this approved package.
- Requesting approval from the IRB prior to implementing modifications.
- Notifying OPRS of any problems involving human subjects, including unanticipated events, participant complaints, or protocol deviations.
- Notifying OPRS of the completion of the study.

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Protocol Form

IRB Number: 23183

Human Subjects Research – Protocol Form

Guidelines for completing this research protocol:

- Please submit typed applications via email. Handwritten forms and hard copy forms will not be accepted.
- For items and questions that do not apply to the research, indicate as "not applicable."
- Provide information for all other items clearly and avoid using discipline specific jargon.
- Please only include text in the provided boxes. The text boxes will expand as they are typed in to accommodate large amounts of text.

Before submitting this application, ensure that the following have been completed.

- Protocol Form is complete.
- Relevant CITI modules have been completed for all members of the research team at www.citiprogram.org.
- Informed consent/assent/parental permission document(s) are provided.
- Relevant waivers and appendices are provided.
- Recruitment materials are provided.
- Research materials (e.g. surveys, interview guides, etc.) are provided.
- Any relevant letters of support are provided.

Instructions on the non-exempt review process and guidance to submitting applications, can be found on the OPRS website. You may also contact OPRS by email at irb@illinois.edu or phone at 217-333-2670.

Submit completed applications via email to: irb@illinois.edu.

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Protocol Form

Section 1: PRINCIPAL INVESTIGATOR (PI)

The Illinois Campus Administrative Manual allows assistant, associate, and full professors to act as PI. Other individuals may serve as PI after obtaining approval from the necessary party.			
Last Name: Hasegawa-Johnson	First Name: Mark	Degree(s): Ph.D.	
Dept. or Unit: Beckman Institute	Office Address: 2011 Beckman		
Street Address: 405 N Mathews Av	City: Urbana	State: IL	Zip Code: 61801
Phone: 217-333-0925	E-mail: jhasegaw@illinois.edu		
Urbana-Champaign Campus Status: Non-visiting member of (Mark One) ☒ Faculty ☐ Academic Professional/Staff (*Student Investigators cannot serve as PI*)			
Training ☒ Required CITI Training, Date of Completion (valid within the last 3 years), 3/19/22 ☐ Additional training, Date of Completion,			

Section 2. RESEARCH TEAM

2A. Are there other investigators engaged in the research?
☒ Yes (include a Research Team Form)
☐ No

2B. If yes, are any of the researchers not affiliated with Illinois?
☒ Yes
☐ No

Section 3. PROTOCOL TITLE

NOVA HABILITAS (NOVA H) Consortium

Section 4. FUNDING SOURCE

4A. Is the research funded?
☐ Research is **not funded** and is **not pending** a funding decision (Proceed to Section 5).
☒ Research is **funded** (funding decision has been made).
☐ Funding decision is **pending**. Funding proposal submission date:

4B. Indicate the source of the funding.
☐ University of Illinois Department, College or Campus, *please specify*:
☐ Federal, *please specify*:
☒ Commercial Sponsorship & Industry[1,2], *please specify*: Industry consortium MOU.

[1] Clarify whether or not sponsor requires specific language in the contractual agreement that impacts human subjects research
[2] Clarify whether or not the sponsor requires the protocol adhere to ICH GCP (E6) standards

Protocol Form

☐ State of Illinois Department or Agency, *please specify*: ☐ Other, *please specify*:
4C. Sponsor-assigned grant number, if known:
4D. A complete copy of the funding proposal or contract is attached. ☒ Attached, *please specify title*: Membership Agreement for Artificial Intelligence Accessibility Coalition
4E. Funding Agency Official To Be Notified of IRB Approval (if Applicable) **Name:** **Agency:** **E-mail:** **Phone:**

Section 5. CONFLICTS OF INTEREST

Please indicate below whether any investigators or members of their immediate families have any of the following. If the answer to any of the following items is yes, please submit the University of Illinois approved conflict management plan. If you have any questions about conflicts of interest, contact coi@illinois.edu.
5A. Financial interest or fiduciary relationship with the research sponsor (e.g. investigator is a consultant for the research sponsor). ☐ Yes ☒ No
5B. Financial interest or fiduciary relationship that is related to the research (e.g. investigator owns a startup company, and the intellectual property developed in this protocol may be useful to the company). ☐ Yes ☒ No
5C. Two or more members of the same family are acting as research team members on this protocol. ☐ Yes ☒ No

Section 6. SUMMARY & PURPOSE OF RESEARCH

6A. In lay language, briefly summarize the objective and significance of the research.
The goal of the Speech Accessibility Project at the UIUC Beckman Institute (https://speechaccessibilityproject.beckman.illinois.edu) is to collect, annotate, and curate a shared database of speech samples from people with atypical speech, and share this data set with researchers at other organizations. This two-year project plans to collect 1,200,000 speech samples from 2,000 people, each of whom will provide 600 samples. In Year 1, the initial focus will be people with Parkinson's. In Year 2, four more etiologies of interest will be recruited (such as ALS patients, stroke patients, etc.). UIUC will build an open-source software infrastructure to collect annotated speech samples and share these data in an appropriately secure fashion with researchers from our partner technology companies (and eventually, other organizations as well) so that they can use these data to improve their automatic speech recognition algorithms. This project promotes diversity, equity, and inclusion by helping technology companies to fully support all types of speech, and it is also more efficient and less burdensome for these specialized patient populations to have one centralized "collector" of speech samples.

Protocol Form

6B. Indicate if your research includes any of the following:
- ☐ Secondary data (use of data collected for purposes other than the current research project)
- ☐ Data collected internationally (include International Research Form)
- ☐ Translated documents (include Certificate of Translation Form and translated documents)
- ☐ Research activities will take place at Carle (include documentation (email or letter) from Carle stating that the review of your Research Services Request Form is complete)

6C. Letters of support from outside institutions or entities that are allowing recruitment, research, or record access at their site(s) are attached. ☒ Yes ☐ Not Applicable

Section 7. PROCEDURES

7A. Select all research methods and/or data sources that apply.
- ☐ Surveys or questionnaires, *select all that apply*: ☐ Paper ☐ Telephone ☐ Online
- ☐ Interviews
- ☐ Focus groups
- ☐ Field work or ethnography
- ☐ Standardized written, oral, or visual tests
- ☐ Taste or smell testing
- ☐ Intervention or experimental manipulation
- ☐ Exercise and muscular strength testing
- ☐ Noninvasive procedures to collect biological specimens (e.g., hair and nail clippings, saliva, etc.)
- ☐ Noninvasive procedures to collect physiological data (e.g., physical sensors, electrocardiography, etc.)
- ☐ Procedures involving radiation
- ☒ Recording audio and/or video and/or taking photographs: Yes
- ☐ Recording other imaging
- ☐ Materials that have already been collected or already exist, *specify source of data*:
- ☐ HIPAA-protected data
- ☐ FERPA-protected data
- ☐ GDPR-protected data
- ☐ Other, *please specify*:

7B. List all testing instruments, surveys, interview guides, etc. that will be used in this research. Drafts or final copies of all research materials are attached. ☒ Yes

7C. List approximate study dates. February 2023 – August 2024

7D. What is the duration of participants' involvement? Up to 5 hours, which is the time estimated to be trained on the system and then use it to provide 600 speech samples, where each sample is approximately 5 to 10 seconds of speech.

7E. How many times will participants engage in research activities? Multiple times as needed at their own pace and convenience to record speech samples.

7F. Narratively describe the research procedures in the order in which they will be conducted.

Protocol Form

The goal of our project is to collect 1,200,000 speech samples from 2,000 people with dysarthria, where we expect to collect data from 400 people each from five different patient populations. Each person would provide 600 speech samples.
(600 samples/person x 400 persons/etiology x 5 etiologies = 1,200,000 samples)

Our schedule of research procedures is:

1. February or March-August 2023: data collection of speech samples from 400 people with Parkinson's. Parkinson's Disease is "etiology 1".
2. August 2023-August 2024: data collection of speech samples from 1,600 people with other etiologies to be determined (i.e., voted on by our Advisory Committee). One of these etiologies will be ALS. The other three etiologies are to be determined.

In Year 1, we focus on people with Parkinson's and therefore, recruitment will be managed by our partner the Davis Phinney Foundation, a well-known non-profit advocacy group for people with Parkinson's. DPF will distribute our recruitment flyer (see **Attachment 3, recruitment for speech**) and engage in informational sessions with potential participants. (In Year 2, we will do the same procedure for other populations of interest, such as ALS patients. Therefore, in Year 2, we will add additional patient advocacy organizations to assist in recruitment, such as Team Gleason to recruit patients with
ALS.)

Data collection of speech samples in Year 1 will be a collaboration of UIUC and LSVT Global team members. Potential participants will be screened both with a questionnaire and by providing a short set of "quality control" speech samples (**Attachment 4**). If the participant does not pass screening, they will be thanked for their interest. Otherwise, the participant is eligible for the study and can do the informed consent process (**Attachment 5**) and then engage in contributing speech samples (**Attachment 7**).
Participants can do as many recordings as they wish at whatever time of day is convenient for them. Participants will be able to login to the system at any time, 24/7.

In Year 2, this procedure will be performed with patients from other etiologies with additional advocacy organizations as partners.

Participants also have the option to provide additional data about themselves, such as their age, race and ethnicity, year of their diagnosis, and other information as shown in **Attachment 9**. These "metadata tags" are completely optional but are helpful for analysis.

The collected speech samples will be stored securely in a custom database built by the UIUC Beckman Institute. All samples are stored with a unique participant ID code along with any of the optional

metadata tags. All samples are annotated by our UIUC research team with technical information about the acoustic waveform and other information.

The entire database of speech samples will be shared with our coalition partners (Amazon, Apple, Google, Meta, and Microsoft). Each partner has signed a data use agreement with UIUC that allows these deidentified data to be used for improvements in speech recognition technology and assures the privacy of participants and confidentiality of data. In the future, other partners may join this coalition, subject to a vote by the current members, and those future partners would also sign a data use agreement with the same terms and conditions.

Section 8. PERFORMANCE SITES TO INCLUDE INTERNATIONAL, SCHOOL, AND COLLABORATIVE STUDIES

8A. List all research sites for the protocol. For non-University of Illinois at Urbana-Champaign sites, describe their status of approval and provide contact information for the site. If the site has an IRB, note whether the IRB has approved the research or plans to defer review to the University of Illinois at Urbana-Champaign.

Performances Sites	
#1	University of Illinois Urbana-Champaign
#2	Davis Phinney Foundation, Colorado
#3	LVST Global, Colorado and Arizona

If there are additional performance sites, include them on an attachment and check here: ☐

8B. Is this a multi-center study in which the Illinois investigator is the lead investigator, or the University of Illinois at Urbana-Champaign is the lead site? ☒ Yes ☐ No
If yes, answer 8C and 8D. If no, proceed to Section 8E.

8C. Who is the prime recipient of funding, if funded? UIUC

8D. What is the management and communication plan for information that might be relevant to the protection of research subjects (e.g. unanticipated problems involving risks to subjects, interim results, and protocol modifications)? UIUC will issue subawards to DPF and LSVT Global. UIUC, DPF, and LSVT Global will establish a regular series of Zoom meetings with shared documents on Box or Teams. Any issues with participant engagement will be discussed regularly and remediated as appropriate. UIUC is responsible for monthly reports out to our founding partners, the Artificial Intelligence Accessibility Consortium.

8E. If subjects will be recruited from Illinois public or private elementary or secondary schools, additional deadlines and procedures may apply. Criminal background clearances might be required. Special consideration must be given to the exclusion of protected populations. Please contact the School University Research Relations (researchplacements@education.illinois.edu) for more information. Select one: ☐ Illinois schools **will** be used ☒ Illinois schools **will not** be used

Section 9. SUBJECT ENROLLMENT GOAL & EQUITABLE SELECTION OF SUBJECTS

Protocol Form

9A. For each performance site, indicate the estimated total number of participants.				
Performance Site		**# Male**	**# Female**	**Total**
#1	UIUC (20 for focus groups, 2000 for speech samples)	1010	1010	2020
#2	Davis Phinney Foundation collaborates with UIUC on recruitment	1000	1000	2000
#3	LVST Global collaborates with UIUC on focus groups, intake and collection of speech samples	1010	1010	2020
TOTALS		1010	1010	2020

If additional performance sites are included on an attachment, check here: ☐

9B. Select all participant populations that will be recruited.

Age:

☒ Adults (18+ years old)
☐ Minors (≤17 years old)
☐ Specific age range, *please specify*:

Gender:

☒ No targeted gender (both men and women will be recruited/included)
☐ Targeted gender, *please indicate*: ☐ Men/boys ☐ Women/girls ☐ Other, *please specify*:

Race/Ethnicity:

☒ No targeted race or ethnicity (all races and ethnicities will be recruited/included)
☐ Targeted race or ethnicity, *please specify*:

College Students:

☒ No targeted college population
☐ UIUC general student body
☐ Targeted UIUC student population, *provide the instructor or course information, name of the departmental subject pool, or other specific characteristics*:
☐ Students at institution(s) other than UIUC, *please specify*:

Any research with students on UIUC's campus needs to be registered with the Office of the Dean of Students.

Other:

☐ Inpatients
☒ Outpatients
☐ People who are illiterate or educationally disadvantaged
☐ People who are low-income or economically disadvantaged
☐ People with mental or cognitive disabilities or otherwise impaired decision-making capacities
☐ Adults with legal guardians
☐ People who are non-English speaking
☒ People with physical disabilities
☐ Pregnant or lactating women, human fetuses, and/or neonates

☐ Prisoners or people with otherwise limited civil freedoms
☒ Other, *please specify*: Adults with caregivers to help participants use computers

9C. Describe additional safeguards included in the protocol to protect the rights and welfare of the populations selected above.
We have designed the remuneration plan to include support for caregivers.

Our subawards with DPF and LSVT Global are meant to provide extra support for potential participants. DPF's recruitment activities include providing information and support as needed to potential participants to answer their questions. If a potential participant does not seem able to provide informed consent, they will not be recruited. LSVT Global will provide an intake coordinator and a number of mentors to support data collection. We anticipate that many participants will need advice and support during their attempts at data collection online, and so they will be able to schedule time with an LSVT Global mentor to get help.

Section 10. INCLUSION/EXCLUSION

10A. List specific criteria for inclusion and exclusion of subjects in the study, including treatment and control groups.

For the main study to collect speech samples, total n=2000 where Cohort 1 (n=400) etiology is Parkinson's Disease, and Cohort 2 etiologies are still to be decided (n=1600) for Year 2.

Inclusion criteria:

- Adult (age >= 18 years)
- Self-reported diagnosis of Parkinson's Disease or other etiology of interest
- Reads and speaks English
- Has a valid email address
- Ability to access web browser to participate in study

Exclusion criteria:

- Is a resident of the State of Washington, Texas, or Illinois (because these states have privacy laws that would not allow us to collect 'voice prints')
- If quality control screening of initial speech samples "fails" because of poor data quality (e.g., poor quality recording environment, or person's speech is "too typical" and not sufficiently interesting to continue collecting)

10B. Explain how the inclusion/exclusion criteria will be assessed and by whom. If special expertise is required to evaluate screening responses or data, list who will make this evaluation and describe their training and experience.

Assessing the inclusion/exclusion criteria will be in collaboration with patient advocacy organizations. In Year 1, that will be Davis Phinney Foundation and LSVT Global.

10C. Drafts or final copies of all screening materials are attached. ☒ Yes ☐ Not Applicable

10D. Describe procedures to assure equitable selection of subjects. Justify the use of the groups marked in Section 9B. Selection criteria that target one sex, race, or ethnic group require a clear scientific rationale.

We will offer participants the optional ability to provide demographic data, so that we can assess the diversity and equitable representation of our sample.

Section 11. RECRUITMENT

11A. Select all recruitment procedures that will be used.

☐ Student subject pool, *please specify*:
☒ Email distribution
☐ MTurk, Qualtrics Panel, or similar online population, *please specify*:
☐ US Mail
☒ Flyers/brochures
☒ Website ad, online announcement (e.g. eWeek), or other online recruitment, *please specify*:
newsletter announcements via organizations that advocate for and support people with disabilities.
☐ Newspaper ad
☐ Verbal announcement
☐ Other, *please specify*:
☐ Not applicable (secondary data only)

11B. Drafts or final copies of all recruitment materials (including verbal scripts) are attached.

☒ Yes ☐ Not Applicable

11C. For each group of participants, describe the details of the recruitment process.

In Year 1, Davis Phinney Foundation will include our recruitment flyer in their distribution channels, will also host optional information and Q&A sessions with potential participants, and will answer individual questions as needed from potential participants. The UIUC Speech Accessibility Project's website will remain as a public source of information, including an updated FAQ list that may be updated based on feedback from DPF.

Section 12. REMUNERATION AND PLAN FOR DISTRIBUTION

Refer to the University Business and Financial Policies and Procedures for further guidance on the compensation process and reporting requirements.

12A. Will subjects receive inducements or rewards before, during, or after participation?

☒ Yes ☐ No

If yes, complete the rest of Section 12. If no, proceed to Section 13.

12B. Select all forms of remuneration that apply.

☐ Cash*, please specify amount:*

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☐ Check, *please specify amount:*
☒ Gift Certificate, *please specify amount:* Amazon ecodes adding up to $180 per data contributor and up to $90 per caregiver.
☐ Lottery, *please specify amount:* *and odds:*
☐ Course Credit, *please specify amount:* *and specify equivalent alternative activity:*
☐ Other, *please specify*:

12C. Will payment be prorated before, during, or after participation?
☒ Yes, *please specify how:* prorated by number of recorded sentences uploaded to our system
☐ No

12D. For each group of participants, describe the details of the remuneration plan, including how, when and by whom they will be notified.
Our project plans to obtain a total of 600 recorded sentences per participant. Each participant will be compensated with up to $180: $60 after recording the 200th sentence, an additional $60 after recording their 400th sentence, and an additional $60 after recording their 600th sentence.

In addition to the participant compensation described above, participants will also be able to name a caregiver who is assisting them with performing the computer usage tasks in this study, and to specify additional compensation to the caregiver. Named caregivers will be compensated with up to $90: $30 after recording the 200th sentence, an additional $30 after recording their 400th sentence, and an additional $30 after recording their 600th sentence.

The NOVA H customized database system will track number of sentences per participant that are uploaded. The database will have a regular schedule of quality control checks and a built-in alert to remind the NOVA H project manager that payments are due as appropriate. The NOVA H project manager will then use the usual UIUC procedure to compensate the participants via automated email messages containing an appropriate Amazon ecode.

The Beckman Institute is fully aware of OBFS guidance on potential IRS tax implications of human subject payments. The NOVA H project manager will assure that the team follows OBFS guidance and will work closely with the Beckman business affairs office to ensure that tax implications are addressed.

12E. The information listed above is provided on the relevant consent forms.
☒ Yes

Section 13. RISKS & BENEFITS

13A. Describe all known risks to the participants for the activities proposed, such as risks to the participants' physical well-being, privacy, dignity, self-respect, psyche, emotions, reputation, employability, and criminal and legal status. Risks must be described on consent forms.
Risks include (1) the risk of loss of privacy in case any research institution that has been granted data access violates their data use agreement by releasing participant speech samples to people not covered by the agreement, and (2) the risk that subjects may get tired while recording sentences.

13B. Describe the steps that will be taken to minimize the risks listed above.

(1) The risk of loss of privacy will be minimized in two ways. First, we recognize that speech audio recordings are considered to be personally identifiable information, but no other personally identifiable information will be stored in the same database with the speech audio recordings. Personally identifiable information other than the speech audio recordings will be stored securely in a database at the Beckman Institute, which will only be accessible to personnel named in this IRB application. Second, before any research institution is permitted to receive any speech audio recordings, they will be required to sign a data use agreement. Key terms of the data use agreement will include commitments that the research institution (a) is an organization or individual with the legal status necessary to sign a contract, (b) will not make the speech audio recordings available to any individual who is not bound by the member's signature on the data use agreement, (c) will store the data in a secure fashion to prevent data theft, and (d) will not seek to identify any of the participants.

(2) The risk of tiredness will be minimized by designing our user interface so it will allow participants to log in to the system at their convenient time and location. They will be allowed to record at their own pace. They can log out at any time, then log in again to continue recording as they wish.

13C. Indicate the risk level.

☒ **No more than minimal risk**

(The probability and magnitude of harm or discomfort anticipated for participation in the proposed research are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests).

☐ **More than minimal risk** (answer 13D)

13D. If you checked that the research is <u>more than minimal risk</u>, describe the provisions for monitoring the data to ensure the safety of subjects, such as who will monitor data and how often, what criteria will be used to stop the research, etc.

13E. Describe the expected benefits of the research to the subjects and/or to society.

There is no immediate benefit of the proposed research to the participants, but participants may eventually benefit from improved communication tools that will be developed based on the outcome of the proposed research. Potential benefits to society and people with speech disorders include automatic speech recognition (ASR) technologies of which accuracy will outperform any existing ASR tools applied to disordered speech.

13F. Weigh the risks with regard to the benefits. Provide evidence that benefits outweigh risks.

The benefit to society of the proposed research is the development of improved communication tools for people with speech disorders, while no more than minimal risk is anticipated for participation in the proposed research. Thus, the potential benefits outweigh the minimal risks.

Section 14. INFORMED CONSENT PROCESS TO INCLUDE: WAIVERS, ASSENTS, ALTERATIONS, ETC.

Protocol Form

14A. Indicate all that apply for the consent/assent/parental permission process.

☐ Written informed consent (assent) with a document signed by
☐ adult subjects ☐ parent(s) or guardian(s) ☐ adolescents aged 8–17 years

☒ Waiver of Documentation (signature) of Informed Consent *(include the relevant Waiver Form)*
☒ adult subjects ☐ parent(s) or guardian(s) ☐ adolescents aged 8–17 years

☐ Waiver of Informed Consent *(include the relevant Waiver Form)*
☐ adult subjects ☐ parent(s) or guardian(s) ☐ adolescents aged 8–17 years

☐ Alteration of Informed Consent *(include the relevant Alteration Form)*
☐ adult subjects ☐ parent(s) or guardian(s) ☐ adolescents aged 8–17 years

14B. List all researchers who will obtain consent/assent/parental permission from participants.
DPF personnel will publicize the opportunity to their clients and offer support as needed, such as group information sessions and one-on-one dialog.

14C. Describe the method for obtaining consent/assent/parental permission.
The consent procedure will be conducted online with optional support as needed. DPF will generate many referrals of potential participants who self-report that they meet initial inclusion criteria. These referrals will be kept as a list of names and email addresses that are shared with LSVT Global and UIUC. LSVT Global's intake coordinator will contact each potential participant to verify their information and ensure that they provide the quality control samples of their speech in the online UIUC system. UIUC personnel will assess these two pre-screening data sources (initial questionnaire and quality control samples) and decide whether or not the participant is eligible. If not, then the participant is thanked for their interest. If the person is eligible, then the person's information is confirmed with LVST Global and the person is directed to the online informed consent document with the option to get help. While it is possible for the person to read and sign the online informed consent document and immediately begin data collection through the UIUC online system all by themselves, it is more likely that the LVST Global intake coordinator will schedule time with an LVST Global mentor or UIUC research team member to talk the person through the informed consent document and help them with the first few sessions of data collection.

14D. Describe when consent/assent/parental permission will be obtained. A pre-screening procedure will happen first, and once a participant is deemed eligible, then they will be offered the opportunity to review and sign the informed consent document.

14E. Will participants receive a copy of the consent form for their records?
☒ Yes ☐ No, *if no, explain*:

14F. Indicate factors that may interfere or influence the collection of voluntary informed consent/assent/parental permission.

☒ No known factors
☐ Research will involve students enrolled in a course or program taught by a member of the research team
☐ Research will involve employees whose supervisor(s) is/are recruiting participants
☐ Participants have a close relationship to the research team
☐ Other, *specify any relationship that exists between the research team and participants*:

If applicable, describe the procedures to mitigate the above factors.
14G. Copies of the consent form(s) are attached. ☒ Yes ☐ Not applicable
14H. Will this project be registered as a clinical trial? ☒ Yes ☐ No If yes, effective January 21, 2019, an informed consent form must be posted on the Federal Web site after the clinical trial is closed to recruitment, and no later than 60 days after the last study visit. LSVT Global has told us that in order for the Michael J. Fox Foundation to become an additional future recruitment partner for this project, that we must register our study as a clinical trial. Therefore, we intend to do this registration after we receive UIUC IRB approval.

Section 15. DEVICES & DRUGS

Indicate if your research includes any of the following. ☐ Equipment [Researchers collecting physiological data, not testing the device] (*include Appendix A, the Research Equipment Form*) ☐ Devices [Researchers planning to test devices on human subjects] (*include Appendix B, the Device Form*) ☐ Materials of Human Origin (*include Appendix C, the Biological Materials Form*) ☐ Drugs and Biologics (*include Appendix D, the Drug and Chemical Usage Form*)
☐ MRI AT BIC To use the Beckman Institute Biomedical Imaging Center (BIC) in human subject's research, you must obtain prior approval from the BIC (217.244.0446; ryambert@illinois.edu) and use BIC-approved screening and consent forms. Attach: ☐ BIC approval ☐ BIC screening form ☐ BIC consent form

Section 16. CONFIDENTIALITY OF DATA & PRIVACY OF PARTICIPATION

16A. How is participant data, records, or specimens identified when received or collected by researchers? Identifiers include, but are not limited to, name, date of birth, email address, street address, phone number, audio or video recordings, and SSN. ☐ No identifiers are collected ☒ Direct identifiers are collected ☐ Indirect identifiers (e.g. a code or pseudonym used to track participants); Does the research team have access to the identity key? ☐ Yes ☐ No
16B. Select all methods used to safeguard research records during storage: ☒ Written consent, assent, or parental permission forms are stored separately from the data ☒ Data is collected or given to research team without identifiers ☐ Data is recorded by research team without identifiers

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☐ Direct identifiers are removed from collected data as soon as possible ☐ Direct identifiers are deleted and no identity key exists as soon as possible ☒ Participant codes or pseudonyms are used on all data and the existing identity key is stored separately from the data ☒ Electronic data is stored in a secure, UIUC-approved location, *please specify* Beckman Institute Dell/EMC Isolon storage system that is fully encrypted ☐ Hard-copy data is stored in a secure location on UIUC's campus, *please specify* ☐ Other, *please specify*:
16C. How long will identifiable data be kept? In perpetuity according to the terms of the industry consortium agreement. The identity key linking participant data to their identity will be destroyed no less than three years after the date of the participant's last speech recording, by deleting the corresponding entry in the participant identity database.
16D. Describe provisions to protect the privacy interests of subjects. Separation of identifiable information from speech samples in the database. Participant's recorded speech samples are stored on a virtual machine that contains no other information contributed by the participant; on this virtual machine, the participant's identity is coded using a participant code that consists of a randomly generated sequence of letters and numbers. Participant contact information, and any other information contributed by the participant, are stored in a separate database, on a separate virtual machine, accessible only by University of Illinois employees with administrative access to the server. Both virtual machines are implemented on the Beckman Institute Dell EMC Isilon/PowerScale encrypted storage array. The Isilon system currently has storage to accommodate approximately 1 PB of data, with over 300 TB of open space available. We can add additional storage, up to a maximum of 64 PB, by adding additional nodes to the array. The primary system is in a secure server room in the Beckman Institute building, and the disaster recovery (DR) system is in a secure data center on the Illinois State University campus. Both systems are fully encrypted and connected on the University of Illinois WAN. The data is synchronized from the production site to the DR site 3 times a day. Snapshots of the data are taken 3 times a day, and each is retained for 4 weeks. In addition, a monthly snapshot is taken and retained for 12 months. Participant speech data, and text transcripts created by University of Illinois annotators, will be distributed to coalition partners approximately once per month during the period of data collection and annotation. Each data distribution will consist of a single archive file, compressed and encrypted using a secure key technology such as RSA or DSA, so that it can only be decompressed by individual researchers who have been authorized by the coalition partner company under the terms of the data use agreement. Data distributions to coalition partners will never contain any information contributed by a participant other than their recorded speech samples.
16E. Describe the training and experience of all persons who will collect or have access to the data. The team members are up to date on CITI modules and Research IT trainings on data privacy and security.

The IT system developers are all professional full-time employees of the Beckman Institute's IT services department.

Section 17. DISSEMINATION OF RESULTS

17A. List proposed forms of dissemination (e.g. journal articles, thesis, academic paper, conference presentation, sharing within industry, etc.).
The de-identified data repository is accessible only to institutions who sign a data use agreement with UIUC. In addition, we expect this project to lead to the usual forms of research dissemination (journal articles, conference presentations and papers).

17B. Will any identifiers be published, shared, or otherwise disseminated? ☒ Yes ☐ No
If yes, does the consent form explicitly ask consent for such dissemination, or otherwise inform participants that it is required in order to participate in the study? ☒ Yes, optionally, participants may also consent to allow the use of their voice recordings in research settings such as professional conference presentations or journal publications. This is completely optional and not required for participation.

17C. Do you intend to put de-identified data in a data repository? ☒ Yes ☐ No
If yes, explain how data will be de-identified. We will assign a unique universal ID number to each participant. The Beckman Institute will host this private data repository and only share its contents with partner organizations who have signed the data use agreement.

Section 18. INVESTIGATOR & DEPARTMENTAL ASSURANCES

- I certify that the information provided in this application is complete and correct.
- I certify that I will follow my IRB Approved Protocol.
- I accept ultimate responsibility for the conduct of this study, the ethical performance of the project, and the protection of the rights and welfare of the human subjects who are directly or indirectly involved in this project.
- I will comply with all applicable federal, state and local laws regarding the protection of human subjects in research.
- I will ensure that the personnel performing this study are qualified and adhere to the provisions of this IRB-certified protocol.

2023 February 10

Principal Investigator Date

If the PI is not eligible to serve as PI under the Campus Administrative Manual, the applicable academic dean, institute director, or campus administrative officer indicates their approval of the researcher to act as Principal Investigator. Please note that departmental assurance only needs to be provided in the initial application.

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Protocol Form

Name of Authorizing Individual
Signature of Authorizing Individual Date

NOVA H IRB PROTOCOL ATTACHMENT 2:

This is EXHIBIT C from the MOU signed by the five founding partners of the coalition. “Organization” here refers to the University of Illinois Urbana-Champaign.

LICENSED SPEECH SIGNAL DATA
DATA USE TERMS AND CONDITIONS

The licenses to Licensed Speech Signal Data granted to each Member pursuant to Section 9.b. of the Agreement are subject to the following Terms and Conditions. Each Member receiving such a license is referred to herein as the “**Data User**”. Any capitalized terms used but not otherwise defined in this Exhibit C shall have the meanings given to them elsewhere in the Agreement.

1. Provision and Use of Data

1.1 Effective as of the Effective Date, Data User may make, have made, use, load, access, store, copy, reproduce, destroy, modify, transmit, display, make derivative works of and otherwise use the Data made available to it by Organization under the Agreement on a non-exclusive, non-assignable, non-sublicensable (except as provided in Section 2.1 below) basis solely for the Permitted Purpose subject to the terms of this Exhibit C and the Agreement. Any such modifications or derivative works made by Data User are “**Modification(s)**”.

1.2 This Agreement does not restrict Data User’s use or modification of any portions of the Data that Organization makes publicly available under a more permissive license, if applicable, to the extent Data User uses or modifies the Data under the terms of such public license, or that otherwise become public.

1.3 The rights and restrictions set forth in this Exhibit C as it relates to the use, modification, distribution, disclosure, and privacy of the Data may only be modified by a written agreement between Data User and Organization specifically indicating it is amending these Terms and Conditions, e.g., these Terms and Conditions may not be amended by or superseded by any general terms and conditions that are presented or included as part of access to or use of data storage, data processing, platform, or computing resources.

2. Restrictions

2.1 Data User may not sell, rent, lease, lend, transfer or otherwise redistribute the Data or any Modification of the Data, in whole or in part, except that Data User may disclose or provide access to the Data (including any Modifications) to its employees, Affiliates, contractors, and consultants working on behalf of Data User for the Permitted Purpose (collectively “**Representatives**”).

2.2 This Agreement (including without limitation Section 2.1) does not impose any restriction with respect to the development, use, modification, or distribution of Results.

2.3 All costs and expenses incurred by Data User to exercise its rights and comply with its obligations under this Exhibit C shall be paid by Data User, and Data User shall not be entitled to reimbursement from Organization for such costs and expenses.

3. Confidentiality of Data, Privacy

3.1 Data User may not disclose or provide access to the Data (including any Modifications) to any third party, except that Data User may disclose or provide access to the Data (including any Modifications) to its Representatives, and may allow such Representatives to use and modify the Data (including any Modifications) solely to the extent needed for the Permitted Purpose, provided that such Representatives are bound by the terms and conditions of this Agreement (including Sections 3.2 and 3.3) or have entered into a written agreement with the Data User that (i) requires the Representative to process the Data on behalf of Data User and only in accordance with Data User's documented instruction, and (ii) contains data protection obligations not less protective than those imposed on Data User in this Agreement with respect to the protection of the Data processed by the Representative on behalf of Data User for the Permitted Purpose. Data User is responsible for its Representatives' compliance with the applicable terms of this Exhibit C.

3.2 Data User agrees to implement and maintain reasonable physical, administrative, and technical safeguards to protect the Data from inadvertent or unauthorized access, disclosure, or use, and shall comply with applicable privacy laws relating to its possession and use of the Data or any Modification of the Data, including any biometric laws.

3.3 Data User will not attempt to identify any natural person from any anonymized, pseudonymized, or otherwise de-identified personal data included in the Data.

4. Representations and Certifications

4.1 Organization represents and certifies that (i) it will provide Data composed solely of anonymized, pseudonymized, or otherwise de-identified data; (ii) it will provide Data to the Data User that does not violate any laws, rules, standards, or regulations governing the use of personal data, including but not limited to United States privacy laws and biometric laws; (iii) it will obtain all consents, waivers and clearances required to provide the Data to the Data User and for the Data User to process the Data for the Permitted Purpose, subject to the terms of this Exhibit C and the Agreement; and (iv) it will promptly delete any Data from the centralized repository following a data contributor's withdrawal of consent and/or request for data deletion and promptly notify Data User of the same.

4.2 EXCEPT AS PROVIDED IN SECTION 4.1 ABOVE, THE DATA IS PROVIDED ON AN "AS IS" BASIS, WITHOUT WARRANTIES, CERTIFICATIONS, OR CONDITIONS OF ANY KIND, EITHER EXPRESS OR IMPLIED INCLUDING, WITHOUT LIMITATION, ANY WARRANTIES, CERTIFICATIONS, OR CONDITIONS OF TITLE, NON-INFRINGEMENT, MERCHANTABILITY OR FITNESS FOR A PARTICULAR PURPOSE.

5. Termination, Terms and Conditions, Notices

5.1 Organization may terminate Data User's license to the Data upon written notice if Data User does not follow the terms of this Exhibit C, including the limitations set forth in Section 2, and does not fully cure such failure within thirty (30) days of receiving written notice from Organization. In the event Data User's license is terminated under this Section 5.1, Data User shall cease use of the Data and any Modifications and use reasonable efforts to delete any copies of the Data, but shall not be restricted from continued use of any Results.

5.2 Data User may terminate its license to the Data upon written notice to Organization. In the event Data User's license is terminated under this Section 5.2, Data User shall not receive access to additional Data following termination, but shall not be restricted from continued use of the Data to which Data User was previously granted access pursuant to this Exhibit C or to any Modifications.

5.3 The terms and conditions of the Agreement (including but not limited to Sections 11, 13.d., and 13.f. of the Agreement) shall continue to apply with respect to Data User's exercise of its license rights pursuant to Section 9.b and this Exhibit C; provided, however, in the event of a conflict between the terms and conditions of this Exhibit C and the terms and conditions elsewhere in the Agreement, the terms and conditions of this Exhibit C shall prevail.

5.4 Any notices provided under this Exhibit C shall be provided pursuant to Section 13.e. of the Agreement using the applicable party contact information listed in the Agreement.

6. Definitions

6.1 "Data" means the Licensed Speech Signal Data (as defined in the Agreement) that Data User receives under the Agreement during the Term while such Data User is a party to the Agreement, in modified or unmodified form. Data does not include Results.

6.2 "Permitted Purpose" means research by or on behalf of Data User to advance understanding of machine learning-related data variances associated with atypical speech variations, and the development of products, technologies, and services by or on behalf of Data User to improve communications and increase access to technology, including computational use, processing of Biometric Data, and the creation and training of machine learning solutions and artificial intelligence models including for research and for commercial purposes.

6.3 "Result" means anything that Data User develops or improves for the Permitted Purpose that does not include more than a de minimis portion of the Data (e.g., summary statistics such as the number of speakers, and the gender, age range, etiology, ethnicity, and similar characteristics of speakers) on which the use is based. Results may include de minimis portions of the Data necessary to report on or explain use that has been conducted with the Data, such as figures in scientific papers, but do not include more. For example, machine learning and artificial intelligence models trained on Data (and which do not include more than a

de minimis portion of Data) are Results to the extent they are developed by or onbehalf of Data User pursuant to the terms of the Agreement and this Exhibit C.

6.4 "Biometric Data" means data relating to an individual's physical and/or behavioral characteristics that could be used for identification, including without limitation information relating to an individual's DNA, fingerprints, face, hand, retina,gestures, voiceprint, typing rhythm, and gait.

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University of Illinois Urbana-Champaign
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Speech Accessibility Project: Individuals with disabilities helping researchers to improve technology

You are being asked to participate in a voluntary research study that is called the "Speech Accessibility Project." The purpose of this study is to help researchers at universities and companies to develop spoken-language user interfaces that work for people with atypical speech. Software programs that understand speech are developed using machine learning. Machine learning is a software development method that imitates the way humans learn, by testing the software repeatedly, and changing its behavior whenever it makes a mistake. In this way, the software learns to reduce the risk of similar mistakes in the future. By providing examples of the sounds of atypical speech, this study will make it possible for the software to learn how to make fewer mistakes when it encounters atypical speech in the future. Participating in this study is all online and will involve recording sentences and uploading your audio recordings to a secure encrypted storage system. We ask you to provide up to 600 speech samples or about 5 hours of your time which you can do any time online, at your own pace and convenience. Risks associated with this study are no greater than those in everyday life. There is no expected benefit of this research to you personally; the expected benefit to society is that companies and organizations using your speech recordings will be able to train better speech technology for people with speech and motor disabilities, which will make technology more accessible for everyone.

Project Name: The Speech Accessibility Project, which has the website: https://speechaccessibilityproject.beckman.illinois.edu/

Principal Investigator Name and Title: Professor Mark Hasegawa-Johnson, University of Illinois Urbana-Champaign ("UIUC"), Beckman Institute and Department of Electrical and Computer Engineering.
Contact Information: speechaccessibility@beckman.illinois.edu is the team email address.
Organizations that will perform this study: University of Illinois Urbana-Champaign (UIUC) is the lead organization that will perform this study and has partnered with the Davis Phinney Foundation and LSVT Global, two non-profit advocacy organizations.
Sponsor: The Speech Accessibility Project is funded by a consortium that currently includes five companies: Amazon, Apple, Google, Microsoft, and Meta (parent company of Facebook). In the future, other companies, universities, and organizations may join this consortium as well.

Why am I being asked?
You are being asked to participate in this study because you are an adult who is part of a community of people who may have atypical or non-standard speech, and you have already qualified to be in the study by successfully answering our pre-screening questions and providing a set of speech samples.

We plan to recruit more than 1,000 people to be in this study. Because the purpose of this study is to help organizations develop better speech interfaces for technologies, our team needs to gather many different types of speech samples from many types of voices.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois Urbana-Champaign, its partners, or its sponsors of this project. If you decide to participate, you are free to withdraw at any time without affecting that relationship.

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What procedures are involved?

We will provide you with access to a website where you can record up to 600 speech samples by either reading the text prompt aloud, or by speaking the answer to a question. You can do these recordings at any time, 24/7, at whatever pace you wish. We encourage you to record at different times of day so that we can learn how your speech might change throughout the day. And don't worry about giving us "bad" samples – all data are really helpful. The more diverse our data set is, the better!

You have the option to work with our partner organization, LSVT Global, to get help. LSVT Global can provide you with a mentor to help you do your recordings, give you advice about your microphone settings, and give you tips for when and where to do your recordings.

You may take up to three months to finish recording the 600 speech samples. If you will need more than three months, please contact the research team at UIUC at speechaccessibility@beckman.illinois.edu.

We will also ask you to provide optional data about yourself, such as your age, racial and ethnic identity, and questions about how your speech ability may have impacted your everyday life. You are not required to answer any of these questions. This information will only be used to confirm diverse representation in this data collection, and, if provided, will not be shared outside of the UIUC research team.

The UIUC research team will review all of your speech samples, and we will edit them to protect your privacy by removing any references to personally identifiable information about you or others that you might have said in your answers to our question prompts. We will also annotate your samples with "tags" that refer to technical aspects of the acoustic signals in your samples. We will not attach your name or email address to these samples; instead, we will assign a unique participant identification code to you and will annotate your samples with that code. Only the UIUC research team will know the "identity key" that relates your email address to your participant identification code.

The UIUC Speech Accessibility Project research team has established a secure, fully encrypted storage system at the UIUC Beckman Institute to store your samples. We will separately store your identifiable information in a separate secure database. We have also established a secure data sharing mechanism with the partners in our consortium. Right now, our partners are the five company sponsors of this project: Amazon, Apple, Google, Meta, and Microsoft. UIUC researchers and researchers at each of the partners will use the collected speech samples to train machine learning algorithms to perform better on speech recognition tasks. These partners will only have access to your speech samples and to no other data about you.

The five corporate sponsors of this research at UIUC have signed a legal agreement with the University that sets forth the permitted purposes of the speech data collected from this research project. These permitted purposes are only for research and technology development as stated here:

- Your samples will be kept forever, to assist in research and technology development in perpetuity.
- Your samples are not identified with your name or email address, but only with a unique participant code that is only known to the UIUC research team.
- Your samples will be analyzed by the UIUC research team to verify that the study is being done properly and to provide advice to other researchers about how to design or improve future studies.

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- Your samples will be analyzed and combined with other people's samples to create aggregate results that will be published in the research literature.
- Your samples will be used to advance understanding of machine learning-related data variances associated with atypical speech variations, and eventually to develop products, technologies, and services by or on behalf of our sponsors to improve communications and increase access to technology, including the creation and training of machine learning solutions and artificial intelligence models for both research and commercial purposes.

In the future, any additional partner organizations in this consortium will sign data use agreements with the same terms and conditions. For these future uses of your data, we will not ask you to consent again. In other words, the future use of your de-identified data could happen without additional informed consent.

In summary, your speech samples will help researchers at UIUC and its partner organizations to develop better speech recognition technology algorithms and may eventually help commercial products perform more effectively for people with atypical speech.

What are the potential risks and discomforts?
In general, we believe that the risks of your participation in this research study are no more than you would encounter in everyday life. However, we do recognize two issues that may be risks in this study, and we also have designed measures to minimize these risks.

First, you may get tired. To minimize your tiredness, we have arranged to let you record your speech samples over multiple sessions. You can log in to the system at a time and location convenient to you, and record at your own pace. You can also log out at any time, then log in again to continue recording as you wish. We hope that this flexibility and convenience will minimize any fatigue that you may experience.

Second, as is true for almost any online data collection research study, there is a risk that your speech samples could be released for purposes and to other individuals, companies, and organizations beyond the purposes to which you have given consent. Please know that the UIUC team has designed measures to minimize the possibility of unauthorized data release include the following:

- Participant code numbers will be used to annotate all speech recordings; your name and email address are not attached to any speech samples directly.
- All organizations using your speech recordings are required to sign a data use agreement, in which they agree that they will store the data securely, that they will prevent unauthorized access, and that they will not attempt to identify you or obtain any other identifying information about you.
- Researchers from outside UIUC will not know your name, e-mail address, state of residence, or any other identifying information about you. Identifying information will be stored separately from your speech recordings, in a database accessible only to UIUC research team members. In addition, as stated above, the UIUC team will edit and annotate your speech samples to protect your privacy.
- You are allowed to withdraw your voluntary consent at any time and request that all of your data be destroyed. When you notify the UIUC team that you wish to have all of your speech samples destroyed, UIUC will ensure that your speech recordings are removed from the UIUC secure system and will direct our partners that you wish your data to be removed from any copies they have as well.

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Are there benefits to participating in the research?
There is no immediate benefit of this research to you personally.

Information obtained from you in this research may help in the development of commercial products by UIUC, its research partners, or members of the consortium. There are no plans to provide financial compensation to you should this occur.

The expected benefit to society is that companies and organizations will be able to develop better spoken-language user interfaces so that people with atypical speech can be as easily understood as other people with typical speech.

What other options are there?
You have the option to not participate in this study. This study is entirely voluntary.

Will my study-related information be kept confidential?
The UIUC research team has made every effort to protect the audio records of your speech samples. The UIUC team will edit out identifying information from your speech samples (such as your name) and will only store your audio files with a participant code number. This participant code number is stored with your identifiable information on a secure server at the UIUC Beckman Institute, and this "identity key" information is only accessible by the UIUC research team. This information is necessary in order to pay you for your participation in this project.

As described previously, the UIUC team will also listen to all of your speech samples and edit out any personaly identifiable information.

Faculty, staff, students, and others with permission or authority to see your study information (such as University auditors) will maintain its confidentiality to the extent permitted and required by laws and university policies.

Speech recordings will be distributed only to companies and organizations that have signed a data use agreement, agreeing to confidentiality terms specified above. No other personally identifiable information will be published or presented.

Because this is a research project, we do expect to publish research papers as a result of this study. These papers may be in the public domain. Research papers will never state your name or any identifying information about you. Optionally, you may choose to allow the university to share anonymized samples of your voice as part of research publications or presentations, but this is not required.

Will I be reimbursed for any expenses or paid for my participation in this research?
You will be compensated up to $180 as follows: $60 after recording the 200th sample, an additional $60 after recording the 400th sample, and an additional $60 after recording the 600th sample.

In addition to your own payment, if you require the help of a caregiver to use a web browser, please contact the UIUC research team at speechaccessibilityproject@beckman.illinois.edu to validate that your caregiver may also receive compensation for helping you. Named caregivers will be compensated with up to $90 as

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follows: $30 after recording the 200th sentence, an additional $30 after recording the 400th sentence, and an additional $30 after recording the 600th sentence.

Payments will be made through email using Amazon ecodes.

Can I withdraw or be removed from the study?
Yes. You are free to withdraw your consent and discontinue participation at any time by notifying the UIUC research team by email or phone. The UIUC research team also have the right to stop your participation in this study without your consent if they believe it is in your best interests. If you withdraw consent, the UIUC research team will remove your speech recordings from the UIUC database and will notify the sponsors and partners that they should also remove your data from their own databases using only your anonymized participant code number. If you withdraw consent, your data will not be used for any future research. If the data you previously provided has been used to inform or create computer code or machine learning algorithms it may not be possible for your data to be removed from them.

Will data collected from me be used for any other research?
As stated above, UIUC and its partners in the Speech Accessibility Project consortium will use your speech samples to advance understanding of machine learning-related data variances associated with atypical speech variations, and to develop products, technologies, and services to improve communications and increase access to technology, including computational use, and the creation and training of machine learning solutions and artificial intelligence models including for research and for commercial purposes.

It is possible that, in the future, other organizations will be granted access to the data, in addition to the founding consortium partners that are Amazon, Apple, Google, Meta, and Microsoft. These other organizations may be other universities or other companies. All organizations seeking access to the data will be required to sign data use agreements that specify the same terms as above: that your speech samples will only be used for research and technology development, that your data will be stored securely, and that you may withdraw consent at any time. You may not be asked to provide additional consent for these future uses of your data.

Who should I contact if I have questions?
Contact the UIUC research team leader, Professor Mark Hasegawa-Johnson (jhasegaw@illinois.edu), if you have any questions about this study or your part in it, or if you have concerns or complaints about the research.

What are my rights as a research subject?
If you have any questions about your rights as a research subject, including concerns, complaints, or to offer input, you may call the UIUC Office for the Protection of Research Subjects (OPRS) at 217-333-2670 or e-mail OPRS at irb@illinois.edu. If you would like to complete a brief survey to provide OPRS feedback about your experiences as a research participant, please follow the link here or through a link on the OPRS website: https://oprs.research.illinois.edu/. You will have the option to provide feedback or concerns anonymously or you may provide your name and contact information for follow-up purposes.

Please print this consent form if you would like to retain a copy for your records.

Please read each item carefully and check each box to indicate your agreement.

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☐ I have read and understand the above consent form.

☐ I understand that my speech samples are collected for the purpose of improving speech recognition technology and are protected by a legal agreement between UIUC and the current members of the Speech Accessibility Project coalition, and that future members of the data coalition and any future data licensees will also be bound by similar legal agreements.

☐ I certify that I am 18 years old or older.

☐ I understand that I must maintain a valid email address in order to participate in this study and to be paid for my participation.

☐ I certify that I and I alone will use my login to record speech samples. I will not allow other people to record speech samples on my behalf.

☐ I understand that the only financial compensation that I will receive for participating in this study is the payment for contributing speech samples, which will be $60 for every batch of 200 samples I provide.

☐ I understand that my goal is to provide 600 samples total, and that therefore my maximum payment will be $180.

☐ I understand that if I need the help of a caregiver to contribute speech samples, that I must notify the UIUC team and have my caregiver approved to be paid in addition to myself.

☐ I understand that at any time, I can end my participation and withdraw my consent. When I do so, the UIUC research team will remove all of my speech samples from the UIUC secure system. I also understand that it is UIUC's responsibility to ask all sponsors and partners to remove any copies of my speech samples from their own databases as well.

***Optional checkbox**: By checking the box below, you may also specifically grant your consent for the research team to play or provide audio files of your voice in a public research setting or publication.*
☐ *I consent to have my voice samples shared in public at research conferences and similar professional meetings, and to have digital audio files of my voice be shared as part of professional research publications.*

***Optional checkbox**: By checking the box below, you may also specifically grant your consent to share your contact information with other research teams, so that they may contact you to be a potential participant in their own research studies.*
☐ *I consent to have my email address and phone number be shared with other research teams, who may contact me to participate in their studies.*

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By clicking the "I CONSENT" button below, I indicate my willingness to voluntarily take part in this study.

I CONSENT

ILLINOIS
Office for the Protection of Research Subjects

Waiver of Documentation of Informed Consent

For Requesting a Waiver of the Documentation of Informed Consent

All forms must be typewritten and submitted via email to irb@illinois.edu.

Section 1. PROTOCOL INFORMATION

1A. Primary Investigator: Mark Hasegawa-Johnson
1B. Protocol Number: 23183
1C. Project Title: Consortium NOVA HABILITAS (NOVA H)
1D. Is this research regulated by the US Food and Drug Administration? ☐ Yes ☒ No

Section 2. REQUEST FOR WAIVER OF DOCUMENTATION

A consent procedure which does not document obtained consent through a physical signature may be approved by the IRB under certain conditions. To request IRB approval of a consent procedure which does not document consent through a physical signature, provide a response to **only one** of the following. Note that the IRB may require the investigator to provide subjects with a written statement regarding the research, even though the documentation requirement may be waived.
2A. The only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern. (Note: A waiver of documentation of informed consent is not permissible under this category if the research is subject to FDA regulations.)
2B. The research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside the consent. This research will be conducted entirely online with adult volunteer participants from all states in the USA except those that have laws restricting the use of "voice print" technologies (WA, IL, TX). Each participant will set up a login and password to the NOVA H Data Repository, will be assigned a unique user ID number, and will periodically upload speech samples via our website by speaking into their local computer's microphone and having the resulting audio file stored in our system. They will be compensated for their participation through the emailing of Amazon ecodes. After pre-screening, they will do the informed consent process online and check a series of checkboxes and a final button to provide consent to participate in the study.
2C. The subjects or legally authorized representatives are members of a distinct cultural group or community in which signing forms is not the norm, the research presents no more than minimal risk of harm to subjects, and there is an appropriate alternative mechanism for documenting that informed consent was obtained.

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Research Team

For Listing Additional Researchers who are Involved in the Project

All forms must be typewritten and submitted via email to irb@illinois.edu.

When to use this form: If there are collaborating researchers participating in a research study, including those from other institutions, complete this form by listing all collaborating researchers. Include all persons who will be: 1) directly responsible for project oversight and implementation, 2) recruitment, 3) obtaining informed consent, or 4) involved in data collection, analysis of identifiable data, and/or follow-up. **Please copy and paste text fields to add additional research team members.**

Note:

- Changes made to the Principal Investigator require a revised Protocol Form and an Amendment Form.
- A complete Research Team form with all research team members included needs to be submitted every time the research team is updated.

Section 1. PROTOCOL INFORMATION

1A. Principal Investigator: Mark Hasegawa-Johnson
1B. Protocol Number: 23183
1C. Project Title: NOVA HABILITAS (NOVA H) Consortium

Section 2. ADDITIONAL INVESTIGATORS

Full Name: Heejin Kim	**Degree:** Ph.D.	**Dept. or Unit:** Linguistics
Professional Email: hkim17@illinois.edu		**Phone:** 244-4972
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☒ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 04/12/22 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☒ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☒ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 2/17/22	**Date removed from research team:**	

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Full Name: Clarion Mendes	**Degree:** M.A.	**Dept. or Unit:** Speech and Hearing Science
Professional Email: cmendes2@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☒ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 06/13/22 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☒ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:		
If administering biomedical study procedure (e.g., blood draws, scans, depression index, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 2/17/22	**Date removed from research team:**	

Full Name: Meg Dickinson	**Degree:** M.S.	**Dept. or Unit:** Beckman Institute
Professional Email: megd@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☒ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 02/28/22 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☒ Recruiting ☐ Consenting ☒ Administering study procedures ☐ Handling identifiable data ☒ Other, *please specify*: engaging with advocacy groups to share recruiting materials		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 2/22/22	**Date removed from research team:**	

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Research Team

Full Name: Erik Hege	**Degree:** B.S.	**Dept. or Unit:** Beckman Institute
Professional Email: hege@illinois.edu		**Phone:** 333-0636
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☒ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 7/22/2022 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☒ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: develop and maintain IT infrastructure for collection of speech samples from participants		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 2/22/22	**Date removed from research team:**	

Full Name: Jose Villamizar Valero	**Degree:** B.S.	**Dept. or Unit:** Beckman Institute
Professional Email: josev2@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☒ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 06/14/22 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: develop and maintain IT infrastructure for collection of speech samples from participants		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		

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☐ **This researcher is no longer an active research team member.**	
Date added to research team: 2/22/22	**Date removed from research team:**

Full Name: Dean Karres	**Degree:** B.S.	**Dept. or Unit:** Beckman Institute
Professional Email: karres@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☒ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 06/13/22 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: develop and maintain IT infrastructure for collection of speech samples from participants		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 2/22/22		**Date removed from research team:**

Full Name: Ngoc-Bic Le	**Degree:** B.S.	**Dept. or Unit:** Beckman
Professional Email: nle@illinois.edu		**Phone:** 265-5237
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☒ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 06/13/22 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☐ Handling identifiable data ☒ Other, *please specify*: develop and maintain IT infrastructure for collection of speech samples from participants		

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If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):
☐ **This researcher should be copied on OPRS and IRB correspondence.**
☐ **This researcher is no longer an active research team member.**
Date added to research team: 6/13/22 **Date removed from research team:**

Full Name: Kayla Ferguson	**Degree:** M.S.	**Dept. or Unit:** Davis Phinney Foundation
Professional Email: kferguson@dpf.org		**Phone:** 720.457.0211
Campus Affiliation: ☐ University of Illinois at Urbana-Champaign ☒ Other, *please specify*: Davis Phinney Foundation 357 S McCaslin Blvd, Ste 105, Louisville, CO 80027, 1-866-358-0285, contact@dpf.org **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☒ Other, *please specify*: Subaward receipient to UIUC		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☒ Recruiting ☐ Consenting ☐ Administering study procedures ☐ Handling identifiable data ☐ Other, *please specify*:		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 11/17/22 **Date removed from research team:**		

Full Name: Lorraine Ramig	**Degree: PhD**	**Dept. or Unit:** LSVT Global
Professional Email: ramig@colorado.edu and lori.ramig@gmail.com		**Phone:** 1-888-438-5788
Campus Affiliation: ☐ University of Illinois at Urbana-Champaign ☒ Other, *please specify*: LSVT Global Research and Development Office, Speer Blvd. Denver, CO 80204, info@lsvtglobal.com and is also professor emerita of speech, language, and hearing science at University of Colorado (https://experts.colorado.edu/display/fisid_102662) **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student		

Research Team

☐ Visiting Scholar ☒ Other, *please specify*: Subaward recipient to UIUC
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 10/28/22 ☐ Additional training, **Date of Completion:**
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☒ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):
☐ **This researcher should be copied on OPRS and IRB correspondence.**
☐ **This researcher is no longer an active research team member.**
Date added to research team: 11/30/22 **Date removed from research team:**

Full Name: Kristen McManus	**Degree:** M.M.	**Dept. or Unit:** Speech and Hearing Science
Professional Email: knm6@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☒ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 01/16/23 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☒ Consenting ☒ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:		
If administering biomedical study procedure (e.g., blood draws, scans, depression index, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 1/27/2023 **Date removed from research team:**		

Full Name: Emma Mueller	**Degree:** High school diploma	**Dept. or Unit:** Speech and Hearing Science
Professional Email: emmam4@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☒ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		

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Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 9/29/2020 ☐ Additional training, **Date of Completion:**
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:
If administering biomedical study procedure (e.g., blood draws, scans, depression index, etc.), please specify the procedure(s):
☐ **This researcher should be copied on OPRS and IRB correspondence.**
☐ **This researcher is no longer an active research team member.**
Date added to research team: 2/17/2023 **Date removed from research team:**

Full Name: Monika Surowiec	**Degree:** High school diploma	**Dept. or Unit:** Speech and Hearing Science
Professional Email: monikas2@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☒ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 02/08/2023 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:		
If administering biomedical study procedure (e.g., blood draws, scans, depression index, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 2/17/2023 **Date removed from research team:**		

Full Name: Citlali Guzman	**Degree:** High school diploma	**Dept. or Unit:** Speech and Hearing Science
Professional Email: cguzm3@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☒ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		

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Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 02/13/2023 ☐ Additional training, **Date of Completion:**
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:
If administering biomedical study procedure (e.g., blood draws, scans, depression index, etc.), please specify the procedure(s):
☐ **This researcher should be copied on OPRS and IRB correspondence.**
☐ **This researcher is no longer an active research team member.**
Date added to research team: 2/17/2023 **Date removed from research team:**

Full Name: Corrie Penrod	**Degree:** High school diploma	**Dept. or Unit:** Speech and Hearing Science
Professional Email: cpenrod2@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☒ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 08/12/2021 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:		
If administering biomedical study procedure (e.g., blood draws, scans, depression index, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 2/17/2023 **Date removed from research team:**		

Full Name: Lauren Stec	**Degree:** High school diploma	**Dept. or Unit:** Speech and Hearing Science
Professional Email: lgstec2@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☒ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		

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Research Team

Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 02/01/2023 ☐ Additional training, **Date of Completion:**
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:
If administering biomedical study procedure (e.g., blood draws, scans, depression index, etc.), please specify the procedure(s):
☐ **This researcher should be copied on OPRS and IRB correspondence.**
☐ **This researcher is no longer an active research team member.**
Date added to research team: 2/17/2023 **Date removed from research team:**

Full Name: Donna Mulchrone	**Degree:** High school diploma	**Dept. or Unit:** Speech and Hearing Science
Professional Email: donnagm2@illinois.edu		**Phone:**
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☒ Undergraduate Student ☐ Visiting Scholar ☐ Other, *please specify*:		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 01/31/2023 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☐ Recruiting ☐ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☐ Other, *please specify*:		
If administering biomedical study procedure (e.g., blood draws, scans, depression index, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 2/17/2023 **Date removed from research team:**		

Full Name: Heather Hodges	**Degree:** MA	**Dept. or Unit:**
Professional Email: heather.hodges@lsvtglobal.com		**Phone:** 303-929-9028
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student		

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Research Team

☐ Visiting Scholar ☒ Other, *please specify*: Community member Research Support
Training: ☐ Required CITI Training, **Date of Completion** (valid within last 3 years): ☒ Additional training, **Date of Completion:** 2/23/2023
Role on Research Team (check all that apply): ☒ Recruiting ☒ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: Participant Education/Training on Software
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):
☐ **This researcher should be copied on OPRS and IRB correspondence.**
☐ **This researcher is no longer an active research team member.**
Date added to research team: 3/2/23 **Date removed from research team:**

Full Name: Ona Reed	**Degree:** MA	**Dept. or Unit:**
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Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☒ Other, *please specify*: Community member Research Support		
Training: ☒ Required CITI Training, **Date of Completion** (valid within last 3 years): 9/25/18 ☐ Additional training, **Date of Completion:**		
Role on Research Team (check all that apply): ☒ Recruiting ☒ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: Participant Education/Training on Software		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 3/2/23 **Date removed from research team:**		

Full Name: Emily Nauman	**Degree:** MA	**Dept. or Unit:**
Professional Email: emily.nauman @lsvtglobal.com		**Phone:** 303-653-2685
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☒ Other, *please specify*: Community member Research Support		
Training:		

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Research Team

☐ Required CITI Training, **Date of Completion** (valid within last 3 years): ☒ Additional training, **Date of Completion:** 2/28/2023
Role on Research Team (check all that apply): ☒ Recruiting ☒ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: Participant Education/Training on Software
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):
☐ **This researcher should be copied on OPRS and IRB correspondence.**
☐ **This researcher is no longer an active research team member.**
Date added to research team: 3/2/23 **Date removed from research team:**

Full Name: Carly Bergey	**Degree:** MA	**Dept. or Unit:**
Professional Email: carly.bergey@lsvtglobal.com		**Phone:** 720-475-0660
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☒ Other, *please specify*: Community member Research Support		
Training: ☐ Required CITI Training, **Date of Completion** (valid within last 3 years): ☒ Additional training, **Date of Completion:** 2/27/2023		
Role on Research Team (check all that apply): ☒ Recruiting ☒ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: Participant Education/Training on Software		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 3/2/23 **Date removed from research team:**		

Full Name: Julie Bergquist	**Degree:** MA	**Dept. or Unit:**
Professional Email: julie.bergquist@lsvtglobal.com		**Phone:** 303-709-5557
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☒ Other, *please specify*: Community member Research Support		
Training: ☐ Required CITI Training, **Date of Completion** (valid within last 3 years):		

Research Team

☒ Additional training, **Date of Completion:** 3/1/2023
Role on Research Team (check all that apply): ☒ Recruiting ☒ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: Participant Education/Training on Software
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):
☐ **This researcher should be copied on OPRS and IRB correspondence.**
☐ **This researcher is no longer an active research team member.**
Date added to research team: 3/2/23 **Date removed from research team:**

Full Name: Fiona Briggs	**Degree:** MA	**Dept. or Unit:**
Professional Email: fiona.briggs@lsvtglobal.com		**Phone:** 563-214-6829
Campus Affiliation: ☒ University of Illinois at Urbana-Champaign ☐ Other, *please specify*: **Campus Status:** ☐ Faculty ☐ Academic Professional/Staff ☐ Graduate Student ☐ Undergraduate Student ☐ Visiting Scholar ☒ Other, *please specify*: Community member Research Support		
Training: ☐ Required CITI Training, **Date of Completion** (valid within last 3 years): ☒ Additional training, **Date of Completion:** 2/28/2023		
Role on Research Team (check all that apply): ☒ Recruiting ☒ Consenting ☐ Administering study procedures ☒ Handling identifiable data ☒ Other, *please specify*: Participant Education/Training on Software		
If administering biomedical study procedure (e.g., blood draws, scans, etc.), please specify the procedure(s):		
☐ **This researcher should be copied on OPRS and IRB correspondence.**		
☐ **This researcher is no longer an active research team member.**		
Date added to research team: 3/2/23 **Date removed from research team:**		

LSVT GLOBAL

Professor Mark Hasegawa-Johnson

Beckman Institute for Advanced Science and Technology

University of Illinois Urbana-Champaign

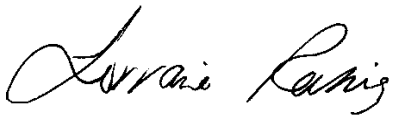
405 N. Mathews Ave, Urbana IL 61801

November 30, 2022

Dear Professor Hasegawa-Johnson,

LSVT Global, Inc. is delighted to be a partner with UIUC in the Speech Accessibility Project. We look forward to collaborating on research procedures.

Sincerely,



Lorraine A. Ramig, PhD, CCC-SLP

Chief Scientific Officer, LSVT Global, Inc.

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Tucson, AZ 85705
www.lsvtglobal.com

520-867-8838 Office
888-438-5788 Toll Free
info@lsvtglobal.com Email

DAVIS PHINNEY
Foundation For Parkinson's
every victory counts®

December 8, 2022

Mark Hasegawa-Johnson, PhD
University of Illinois Urbana Champaign (UIUC)
Address

R**e: Support for *Speech Accessibility Project***

Dear Professor Hasegawa-Johnson,

The Davis Phinney Foundation is delighted to partner with UIUC on the *Speech Accessibility Project*. We look forward to working with you to recruit people with Parkinson's to provide speech samples for the University's data repository and ultimately to make voice recognition technology more accessible for people living with Parkinson's. This will be a giant step forward in improving the quality of life for our Parkinson's community.

After your team at UIUC receives IRB approval and the software is functional and available, the Davis Phinney Foundation will assist in recruiting 200-300 adult volunteers living with Parkinson's to participate by providing speech samples.

We are looking forward to the opportunity to collaborate with you and your team.

Sincerely,

Polly Dawkins

Executive Director
720-259-0906
pdawkins@dpf.org

NOVA H Attachment 3.2.
Recruitment flyer for participants to contribute data

Your voice is needed to improve speech technology!

Intelligent devices can understand spoken commands because they've been trained using millions of hours of audiobooks and radio broadcasts. If you have a speech impairment, though, your devices probably don't understand you so well. The Speech Accessibility Project wants to record examples of your speech, so that researchers and companies can improve their devices so that they work better for you.

Mission Statement: The goal of the Speech Accessibility Project is to improve speech technologies for all people, by collecting speech data and sharing it with technology partners.

How it works: You use a web browser to access our system 24/7, where you will be prompted to provide audio samples of your speech, either by reading a sentence or answering a question. You can provide speech samples at your own pace and on your own schedule.

Compensation: You can earn up to $180 for contributing 600 verified samples to the system. If you need a caregiver to help you participate, your caregiver can earn up to $90 as well.

About us: The Speech Accessibility Project is managed at the University of Illinois Urbana-Champaign, is funded by a consortium of technology companies (currently Amazon, Apple, Google, Meta, and Microsoft), and is partnered with the Davis Phinney Foundation and LSVT Global advocacy organizations. The leader of the Speech Accessibility Project is Professor Mark Hasegawa-Johnson at UIUC.

How to get started: You can sign up at our website (https://speechaccessibilityproject.beckman.illinois.edu) or contact our recruitment team at the Davis Phinney Foundation at (xxx@dpf.org).

For more information, visit https://speechaccessibilityproject.beckman.illinois.edu/about-the-project.

NOVA H Attachment 4: Participant Pre-Screening for Speech Samples

Initial pre-screening will be conducted with a combination of online and live engagement with potential participants. There are two parts to the pre-screening: Step 1 is a short questionnaire and Step 2 is providing a set of quality control speech samples. The questionnaire may be answered online by the potential participants directly (via a URL that is shared with them via email and is not public) or may be conducted as a telephone or Zoom interview with a member of the research team. Therefore, the Step 1 Pre-Screening Questionnaire shown below will be implemented both as an interactive web page and as an interview script.

Step 1: Pre-Screening Questionnaire

Thank you for your interest in the Speech Accessibility Project! To help us determine whether we can record your voice, please answer a few questions about yourself.

The information provided in these pre-screening questions will only be used to confirm your eligibility in the study and will remain confidential. This information will not be shared outside of the UIUC research team.

1. **Do people or devices (e.g., Alexa, Siri) have a hard time understanding your speech?**
   <Answer field: Menu options Yes or No>
2. **Have you been diagnosed with Parkinson's Disease?**
   <Answer field: Menu options Yes or No>
3. **Are you 18 years of age or older?**
   <Answer field: Menu options Yes or No>
4. **What state do you live in?**

<Answer field: Drop-down menu listing all U.S. states, and the option "None of the above">

5. **Do you have a valid email address?**
   <Answer field: Menu options Yes or No>
6. **Do you have regular access to a web browser?**
   <Answer field: Menu options Yes or No>
7. **Do you have the ability to read and speak English?**
   <Answer field: Menu options Yes or No>

Note: ANSWER 1 and ANSWER 2 can be any answer; this is useful information but not screening criteria.

IF ALL OF THE FOLLOWING CONDITIONS ARE TRUE:

ANSWER 3 = Yes
ANSWER 4 = any state except IL, TX, WA, "none of the above"
ANSWER 5 = Yes
ANSWER 6 = Yes
ANSWER 7 = Yes

THEN CONTINUING: "Thank you! So far it looks like you are eligible to be in the study."
ELSE FAILED PRE-SCREENING: "We're sorry. It looks like you are not eligible to be in our study. Thank you for your interest. Please stay in touch with us at https://speechaccessibilityproject.beckman.illinois.edu"

IF CONTINUING, go to STEP 2 below. The text below is both on a web page and used as telephone/Zoom script by a member of the research team.

Step 2: Quality Control Speech Samples

Thank you! So far, it looks like you are eligible to be in our study. To confirm your final eligibility, the next step is for you to provide us some examples of your speech. We will give you access to a website where you will be prompted to record a small number of sentences (about 20 sentences). After you establish a login and password, the website will present you with a text prompt and the capability to record and save your speech samples. Your task is to make a set of voice recordings. The system will prompt you to read some text, and you will record yourself reading that text aloud. You can quit at any time and come back to this task later.

This task is performed entirely online at your own convenience. You may stop this task and restart it at any time at your own convenience, 24/7. You do not need to make all the recordings in one session; you can feel free to perform this task for just a minute or two each day spread over one week. We estimate that this task will take about 10 minutes of your time in total.

After you have submitted the full set of speech samples, the UIUC research team will evaluate the quality of your recordings. Within one week, the UIUC research team will contact you to either confirm that you may continue to participate in the study, to work with you to improve your recording environment, or to let you know that you will not be asked to participate any further in this study.

If you **are not** eligible to be in the study based on your speech samples, we will delete all of your data including your email address.

If you **are** eligible to participate in the study based on your speech samples, the speech samples provided for pre-screening will only be used to confirm your eligibility in the study, will remain confidential, and will not be shared outside of the UIUC research team.

Go to **this website (<insert URL here>).** If you need help to provide these samples or have any questions, please contact (<insert name, email, telephone number of research team member>).

"This website" will include the following text:

Welcome to the Speech Accessibility Project pre-screening website! At this site, you will be prompted to record a small number of sentences (about 20 sentences) that our research team will analyze in order to make sure that you are eligible to participate in our study.

First, please establish a login and password.
<Login and password process>

Thank you! Now, you can start recording your samples at any time. You may do these recordings at any time at your own convenience. We estimate that providing the full set of samples will take about 10 minutes total of your time. After you have submitted the full set of speech samples, the UIUC research team will evaluate the quality of your recordings. Within one week, the UIUC research team will contact you to either confirm that you may continue to participate in the study, to work with you to improve your recording environment, or to let you know that you will not be asked to participate any further in

this study. If you are not eligible to be in the study based on your speech samples, we will delete all of your data including your email address. If you have questions, please contact <*Insert name, telephone number, email address of research team member*>.

NOVA H Attachment 7

Examples of research materials for speech sample data collection

- You will be speaking many different sentences and phrases.
- Our goal is to get many different types of speech from many different people.
- Sometimes, you will be reading aloud digital assistant commands. These are common phrases that people may ask their phone or smart speaker to help them with.
  - Example: What is the weather today?

- Sometimes, you will read aloud sentences that have been randomly selected from novels.
  - Example: You would never have believed that one small elbow could make such a big hole
  - Some of the sentences may seem silly, or not make much sense. Please just read it as automatically as you can.

- Lastly, sometimes you will speak a little longer by answering some conversational questions.
  - Example: What is a favorite tv show of yours and why?

- In summary, there are 3 sections.
  1. 30 digital assistant commands
  2. 10 sentences from novels
  3. 5 open questions

Block One

Section 1:

Digital Assistant Commands

What song is this?

Pause the music.

Resume.

Play music.

Stop.

Play some Beatles music.

Play my dance playlist.

Set the volume to 5.

Turn up the sound.

Skip backward
2 minutes.

Play hip hop music.

Skip forward 30 seconds.

Decrease volume.

Skip this track.

Brighten the office lamp.

Turn on all switches.

Dim the living room lights.

Raise the temperature.

Set the heat to 68.

Turn off cooling.

Answer the door.

Lock the front door.

Broadcast
‘I’m home.’

What’s the weather like today?

Do I need an umbrella today?

What’s today’s news?

Who won the NFL game yesterday?

What movies came out last week?

Answer the call.

Hang up.

End of Section 1.

Thank You!

Block One

Section 2: Sentences Selected from Novels

Block One

<u>Reminder</u>: Some of these sentences might not make sense. Read them as naturally as you can! It's OK to make mistakes!

I'm sure I don't know how it happened.

You would never have believed that one small elbow could make such a big hole.

But it is too late.

It's not more than half an hour since Uncle George and Aunt Bella went.

I'll have you ready in a twinkling.

But the fire and the children!

Father says that this was very wrong of him, and I suppose it was, since he says so.

But I don't see how Father could do anything wrong.

Anyway, he had a sister Esther whom he loved very much.

We had to hurry to fix the kite if we wanted to send it up before the wind fell.

End of Section 2.

Thank You!

Section 3:

Open Questions

Block One

Answer each question using one or more sentences.

Don't read the question out loud – just speak your answer!

Tell us about one of your favorite bands or singers.

Tell us about one of your favorite TV shows.

What kind of music do you dislike, and why?

Tell us how to make your favorite sandwich.

Tell me all the steps involved in withdrawing money from a bank account, as if I had never done it before.

End of Section 3, and

End of Block One!

Thank You!

NOVA H Attachment 9 optional metadata

You have the option of providing extra information to help researchers interpret your speech recordings. Providing answers to such questions is not a requirement for participation in this study; if you prefer not to answer, you will be able to choose the option "Prefer not to answer."

This information will only be used to confirm diverse representation in this data collection, and, if provided, will not be shared outside of the UIUC research team.

1. **Do you consider yourself to be a member of one of the following racial groups?**
    a. Answers: choose from
        i. American Indian or Alaska Native,
        ii. Asian,
        iii. Black or African American,
        iv. White,
        v. Some other race (text box to allow description),
        vi. Prefer not to answer

2. **Do you consider yourself to be Hispanic or Latino/a?**
    a. Answers: choose from Yes, No, Prefer not to answer

3. **What is your gender?**
    a. Answers: Male, Female, Non-binary, Prefer not to answer

4. **How old are you?**
    a. Answers: Age range in years (scroll menu), or Prefer not to answer

5. **What state do you live in?**
    a. Answers: Menu of US states (scroll menu), or Prefer not to answer

6. **Did you regularly converse in a language other than English before your 12th birthday?**
    Answer: Yes, No, Prefer not to answer
    If Yes: **what was/were the language(s)?**
        Answer: Textbox
    If Yes: **at what age did you start conversing in English?**
        Answer: Age in years (scroll menu), or Prefer not to answer

7. **The next questions ask how easy or difficult it is for you to do certain things when you speak. Please answer as best you can. There are no wrong or right answers. It's just your opinion.**

For each item, please rate how easy or difficult it is for you to do.

	Very Easy	Somewhat Easy	Neither easy nor difficult	Somewhat Difficult	Very difficult	Prefer not to answer

Speak with a few familiar people at home (e.g. friends or family)?						
Speak with an unfamiliar person (e.g. waitstaff, store clerk)?						
Speak with a familiar person on the phone?						
Speak with a stranger over the phone?						
Speak in a noisy environment (e.g. a social gathering)?						
Speak while traveling in a car?						
Have a long conversation, an hour or longer?						
Speak when you're upset or angry?						

8. **How much do you agree or disagree with the statements below? Please answer as best you can. There are no wrong or right answers. It's just your opinion.**

	Strongly Agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Prefer not to answer
I am frustrated by my speech.						
I rely on others to help me communicate.						
I have to repeat myself often.						
Other people have difficulty hearing me.						
I avoid speaking when I am tired.						
My speech has impacted how often I participate in social activities.						

9. **Does your speech change throughout the day?**
    a. Answers: Yes, no unsure, prefer not to answer.
    b. If yes, please describe:
        i. Answers: textbox