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Study title: Flow: A live captioning system for dysarthric speech
Review ethic number: H22-03047-A001

Study Team

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Sponsor

Mitacs Accelerator Grant, Application Ref. IT32900

This form is for patient, caregiver, or advocate of a patient

Invitation and study purpose

You are being invited to take part in this research study to help build a future solution for people with communication difficulties . Part of this development requires collecting

Version 6.0 April 28th 2023

voice samples from people with Parkinson's Disease. The voice samples will be used to train a computer algorithm so that it can learn about communication difficulties, and develop a solution to predict any miss-spoken word.

Study procedures

To collect as many samples as possible, and follow any recommended pandemic precautions, a virtual voice collection method will be used. This will allow participants to record their voice samples remotely using a dedicated website.

The website will first prompt you to read and agree to a consent document. After providing consent, you will be prompted to click “record” and then read a few short sentences out loud. The website will stop recording when you are done reading, or when you select “stop”. The entire process should take less than 90 seconds to complete. You may choose to record more than one sample, if you would like. To best support the study, we recommend submitting at least 4 samples. No personal information will be collected, asked for, or used. All voice samples will be anonymous.

Study results

No final report, public, or internal report documentation is being produced from the direct collection of samples. There will be a report on the success of the project using the voice samples as test data. If parties are interested in knowing more about how these samples are being used in research and development, then please contact the Principal Investigator.

Potential risks of the study

There have been no risks identified with participating and submitting voice samples. No personally-identifying data will be collected or stored during this study.

Potential benefits of the study

As the population ages, the number of people with Parkinson’s disease is projected to double by 2030. There is no cure for Parkinson’s disease. Although research is ongoing, FDA drug approval often requires a decade to complete. In the meantime, upwards of 90% of people diagnosed with Parkinson’s disease will experience speech and communication issues. These issues can cause social isolation, safety concerns, loss of independence, and reduce a person's quality of life. Therefore, supporting people with speech issues through our technological solution will benefit many people, their families, their communities, and the healthcare system as a whole. Preventing social isolation due speech and communication difficulties is a key benefit of this research.

Confidentiality

Each participant will record their voice reading from a preset script. These recordings will be stored in a database that is encrypted and password protected. Each voice sample will have no personal identifiers, making each sample completely anonymous. Research findings will not be stored publicly or accessible publicly.

The only people who will have access to the data are all those listed in the study team on page one of this document.

The Website interface used to record the voice samples is stored on servers in the US and follows US privacy laws.

Data will be stored securely for five years after the publication of any research results stemming from these voice samples. The data will be stored securely on the Canadian server, which is located on Canadian soil, and the Principal investigator will remain responsible for its security throughout this five-year period.

Payment or Compensation

There will be no cost to participate in this study, and therefore no reimbursement for participants.

Contact for information about the study

If you have any questions or concerns about the study or procedures, then please contact the study leader or one of the study team. The names, emails, and phone numbers are listed at the top of the first page.

Conflict of Interest

There are no members of the research team who have a financial interest in the outcome of the research. This includes both academic supervisors and the research assistant. Neither are former employees of Skyline Inc.

Any Intellectual Property rights derived from the study are jointly shared between the Academic institution and Industrial Sponsor

The research project is currently funded by a Canadian Federal Grant from Mitacs.

Contact for Complaints

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598

Participant Consent

Taking part in this study is voluntary. As all voice samples are submitted anonymously and no personally-identifying markers are stored. Therefore, once voice samples are submitted, they are unable to be re-identified as yours and retrieved. As a result, please note that withdrawing previously-submitted voice samples is not possible.
For those people whom require a third party to represent the person volunteering to donate their voice samples, for example care giver or family member, they are also required to give consent.
After reading this consent form, and you wish to give consent, tick the box below to indicate and participate in the study.