



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

Study Team

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Sponsor

Mitacs Accelerator Grant, Application Ref. IT32900

Invitation and study purpose

You are being invited to take part in this research study to help build a future communication solution. Part of this development requires collecting voice samples from people with Parkinson's Disease. The voice samples are to be used to train an algorithm

Study procedures

To collect as many samples as possible and follow any Covid restrictions still in place. A Web Application seemed the best solution, this would allow people to remotely record their voice samples in their settings.

The website will first prompt you to read the consent document. After giving consent you would read a short few sentences while recording this voice sample, then submit. You can record more than one sample.



No personnel information will be collected, asked for, or used. All voice samples will be anonymous.

The process of recording a single sample takes less than 90 seconds. Multiple samples will assist with the quality of the research and 4 samples would be recommended to support the study.

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. Contact the Study team list on the first page.

Potential risks of the study

There have been no risks identified with participating and submitting voice samples. No personnel-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 is going to double by 2030. Unless a cure is discovered very soon, a drug for the masses takes typically over a decade to pass FDA approval. Supporting people with speech issues with a technological solution will benefit many people, not only friends and family but also healthcare workers. Preventing Social Isolation is the main key benefit to this problem.

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 with 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 what we are asking of you, 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.

Contact for Complaints

About your rights as a research participant, 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 personnel identifying marks are stored, therefore withdrawing after submitting voice samples is not possible.

After reading this consent form, and you wish to give consent, tick the box below to indicate and participate in the study.