Technology for Swallowing Exercises in Parkinson's Disease: A Usability Study

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PURPOSE OF PROJECT

This is a usability study, aiming to test a non-invasive technology that is designed to help with swallowing therapy.

The main objective of this study is to gain insights into the usability of the technology by people with Parkinson's Disease by testing the effectiveness and efficacy of their interaction with the technology.

We also aim to explore users' satisfaction, specific needs, and issues (if any) around their use of the technology.

SIGNIFICANCE OF THE WORK AND THE NEED FOR THE STUDY

This study will help the researchers identify the specific features needed and/or issues of using and interacting with technology for swallowing therapy by people with Parkinson's Disease, by examining their interaction with the technology.

This information will help in improving the technology to be best implemented for people with a history of Parkinson's Disease and will eventually be considered for future patients with dysphagia (swallowing difficulty) and Parkinson's Disease.

WHO IS ELIGIBLE TO PARTICIPATE IN THE STUDY

You are being invited to participate in a research study because you are an individual who has Parkinson's Disease.

- 18 years or older.
- Diagnosed with Parkinson's Disease.
- Living or willing to travel to Edmonton, Alberta.
- This study does not cover Parkinson-plus syndromes:
    - Progressive supranuclear palsy (PSP)

- Multiple system atrophy (MSA)
- Cortical-basal ganglionic degeneration (CBGD)
- Dementia with Lewy bodies (DLB).

- Please do not participate in this study if you were diagnosed with one of the Parkinson-plus syndromes on the list above.
- This study does not cover people with Parkinson's Disease who have dementia or severe cognitive impairment.

WHAT WILL I BE ASKED TO DO?

Taking part in this study is voluntary. You may choose whether or not you take part. If you choose to participate, you may leave the study at any time without giving reasons. Deciding not to take part or deciding to leave the study early will not result in any penalty or affect your current or future care or employment.

If you choose to participate in this study, you will be expected to:

- Attend one session in Edmonton, Alberta.
- Provide written informed consent at the beginning of the session.
- The session will consist of an introductory part that will include collecting demographic information about you and completing two questionnaires.
- After the introductory part, you will be asked to complete seven tasks to assess the usability of the device.
- During the session, your performance will be video and audio recorded by a camera.
- At the end of the session, a usability questionnaire will be completed to explore your satisfaction.

If you are interested in participating in this study, kindly send an email to the student investigator alolayan@ualberta.ca to indicate your interest and book a time for the session.

HOW MUCH TIME WILL THIS SESSION TAKE?

The session is expected to last for approximately 60-90 minutes.

WHAT ARE THE POTENTIAL BENEFITS ASSOCIATED WITH MY PARTICIPATION?

There may not be any direct benefit to you from participating in this study.
However, this study will help the researchers learn more about the effectiveness, efficiency, and satisfaction of using this technology.
Hopefully, this information will help in improving the technology to be best implemented for people with a history of Parkinson's Disease and can eventually be considered for future patients with dysphagia (swallowing difficulty) and Parkinson's Disease like yours.

ARE THERE ANY RISKS ASSOCIATED WITH MY PARTICIPATION?

There are no known or anticipated risks associated with participating in this study.

WHAT HAPPENS IF I WANT TO WITHDRAW FROM THE STUDY?

You can choose to end your participation in this research study at any time without providing a reason.

The research team can withdraw your data up to the point of complete analysis. After the analysis is completed, it will not be possible to find and delete data because all data are anonymized at that point and the researcher will not know which data are yours.

WHAT PROCEDURES ARE IN PLACE TO ENSURE CONFIDENTIALITY?

- All data collected in this study will be kept confidential.
- Only the members of the research team will have access to the information of the study.
- Members of the research team do not have any access to participants' health records. All they will learn about the participants is what they choose to say in their responses.
- Any publications or reports that result from this study will present group data and your information will not be identifiable.

WILL I BE PAID FOR PARTICIPATING IN THE PROJECT?

Participants will not be paid for their participation in the study.

HOW WILL I LEARN ABOUT THE RESULTS OF THE PROJECT?

You have the right to be informed of the results of this study once the entire study is complete. The results of this study will be available publically. Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected.

WHO CAN I CONTACT IF I HAVE QUESTIONS?

If you have any questions about the research now or later, please contact Dr.Jana Rieger (Principal Investigator, University of Alberta) at any time **(780-492-4992)** or **jana.rieger@ualebrta.ca**

If you have any questions regarding your rights as a research participant, you may contact the University of Alberta Research Ethics Office at reoffice@ualberta.ca. This office has no affiliation with the study investigators.