Participant Information Statement

Research Study: An evidence-based dysphagia telerehabilitation program for stroke survivors

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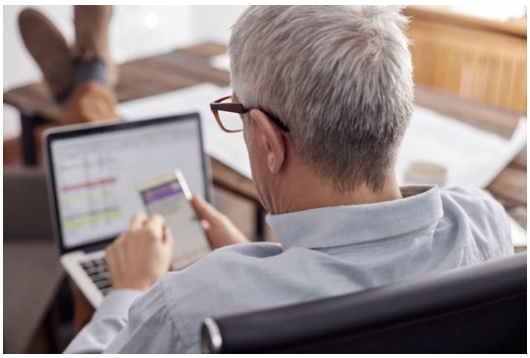
1. What is this study about?



We are conducting a research study about **dysphagia telerehabilitation**. Taking part in this study is voluntary.

Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

2. Who is running the study?

The study is being carried out by:
Dr Emma Wallace, Discipline of Speech Pathology, School of Health Sciences, Faculty of Medicine and Health.

The researcher has no conflicts of interest or financial benefits from the study.

3. Who can take part in the study?

We are inviting stroke survivors, > 6 months post stroke, with swallowing impairment (dysphagia) who are living in the community to participate in the study.

4. What will the study involve for me?

If you decide to take part in this study, you will be asked to:

1. **Express interest:** You will need to contact the research team (call, text or email) to express interest in the study. You may have someone call or email on your behalf. **We will provide you with information about the study.**

2. **Screening:** A questionnaire will be completed with you via telehealth (phone or videoconferencing) to determine your eligibility for the study.

3. **Provide verbal and written consent.**
   You will be asked to sign a consent form.
   You will be asked to provide verbal consent at the beginning of every telehealth session.

4. **Complete questionnaires.**
   You will need to complete some questionnaires at the start and end of the study.
   Some questionnaires will be completed via telehealth.
   Others are completed independently on the computer anonymously.
   You can ask someone to help you to complete the questionnaires if needed.
   The questionnaires will take approximately 30 minutes each to complete. You don't have to complete them all at once.

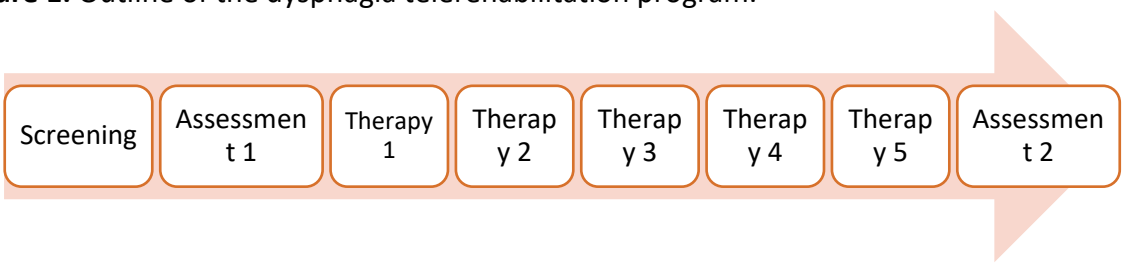
5. **Use your mobile phone to attend two assessment sessions via telehealth.**
   Sessions will occur at the start and end of the program at a mutually convenient time.
   They will last 1 hour in each.
   You will be sent a link to access the telehealth sessions in advance.
   Audio and video recordings may be used if internet speed is too slow to do live telehealth sessions. In such cases, you can send a video of tasks to the researchers and the session can be conducted via phone.

6. **Use your mobile phone to attend weekly telerehabilitation.**
   Sessions will last 40-minutes or less.
   Sessions will occur at a mutually convenient time.
   There will be 5 sessions in total.
   All sessions will be with the same speech pathologist.
   You will be sent a link to access the telehealth sessions in advance.
   Telehealth session will be recorded. This is to allow the researchers to check the accuracy and reliability of the data. You can position your camera so that only your mouth is visible in the recording if you wish.
   Audio and video recordings may be used if internet speed is too slow to do live telehealth sessions. In such cases, you can send a video of tasks to the researchers and the session can be conducted via phone.

7. **Complete daily training exercises.**
   The training can be done in your own time.
   A device will be sent to you in advance, free of charge.
   The training will last 20 minutes daily.
   A record sheet will be provided to you to help monitor the progress your training.

8. **Where will sessions take place:** All sessions will be conducted via telehealth (phone or videoconferencing). You will not have any face-to-face contact with the research team.

Figure 1: Outline of the dysphagia telerehabilitation program.



5. Can I withdraw once I've started?

Being in this study is completely voluntary and you do not have to take part. Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

If you decide to take part in the study and then change your mind you can withdraw by calling, e-mailing, or texting anyone on the research team. You can have someone contact the research team on your behalf if you prefer.

If you choose to withdraw, we will not collect any more information from you. Your decision to withdraw will not affect your current or future relationship with the researchers or anyone else at The University of Sydney. Please let us know at the time you withdraw what you would like us to do with the information we have collected about you up to that point.

6. Are there any risks or costs?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

7. Are there any benefits?

You will not receive any direct benefits from being in the study. The knowledge generated form this study will help the research team develop a dysphagia telerehabilitation program for stroke survivors living in the community.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you for the purposes of this study.

Any information you provide us will be stored securely and we will only disclose it with your permission, unless we are required by law to release information. We are planning for the study findings to be published. You will not be individually identifiable in these publications.

The only information that we collect will be provided by you. We will not collect any information from other individuals.

You name will not appear on any information that we collect. You will be assigned a number at the start of the study that will be used on any documentation that is collected and stored.

All data that we collect will be stored on a password protected computer on the University of Sydney server. The data will be deleted from the server after 5 years.

9. Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. Please provide you email address on the consent form if you wish to receive this feedback. This feedback will be in the form of a brief lay summary.

10. What if I would like further information?

When you have read this information, the following researcher/s will be available to discuss it with you further and answer any questions you may have:

Dharshini | Phone: 02 86275737| Email: dharshini.m@sydney.edu.au

11. What if I have a complaint or any concerns?

The ethical aspects of this study (Project Number: 2021/75) have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney according to the *National Statement on Ethical Conduct in Human Research (2007).*

If you are concerned about the way this study is being conducted or wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

This information sheet is for you to keep