

PARTICIPANT INFORMATION SHEET

INVESTIGATING VARIATIONS TO ADULT STUTTERING TREATMENT PROCEDURES

UTS HREC REF NO. ETH25-10859

WHO IS CONDUCTING THIS RESEARCH?

This research is being conducted by:

Associate Professor Susan O'Brian (University of Technology Sydney, NSW)

Associate Professor Robyn Lowe (University of Technology Sydney, NSW)

Associate Professor Mark Jones (Bond University, QLD).

WHAT IS THE RESEARCH ABOUT?

The purpose of this research is to investigate variations to the way current speech treatments are taught to adults who wish to control their stuttering. The overall aim of this study is to improve speech treatment for adults who stutter so that the benefits of treatment are maintained long term.

WHY HAVE I BEEN INVITED?

You have been invited to participate because you are an adult who stutters, and you would like to learn methods to control your stuttering.

Before you decide to participate in this research study, please check the selection criteria:

- Your stuttering developed before you turned 12 years of age.
- You have not received speech or psychological treatment for your stuttering in the last 6 months.
- You are able to understand, read, and speak English well.
- You can attend 16 regular, 1-hour speech-training sessions over Zoom, followed by one final group meeting over Zoom.
- You have access to a regular and stable internet connection.

FUNDING

Funding for this project has been received from the National Health and Medical Research Council (APP 2036439).

WHAT DOES MY PARTICIPATION INVOLVE?

If you are interested in participating in this study, we will first determine your eligibility. There are two-stages to determine eligibility: (a) we will invite you to discuss your initial eligibility with one of the researchers, then (b) the next stage will be to complete some questionnaires. The questionnaires will take approximately 10 minutes to complete.

If you are not eligible, a researcher will discuss this with you.

If you are eligible, we will ask you complete some further questionnaires. This set of questionnaires will take approximately 30 minutes to complete. Some of these questionnaires will be directly related to this

study, and some will not be directly related. The questionnaires not directly related to this study explore various aspects of your personality, psychological, and emotional wellbeing. These questionnaires will be used in future research to continue developing our understanding about stuttering, for which we will seek separate ethics approval. You don't have to complete all the questionnaires in one sitting. You can complete some and return later to complete the rest.

After you have completed the questionnaires, you will be randomly assigned to one of two speech-training groups. The speech-training procedures for both groups are based on established evidence-based techniques.

We will ask you to attend 16 speech-training sessions with a speech pathologist over Zoom. These sessions will be (mostly) weekly and will be approximately 1 hour long. You will attend these speech-training sessions individually. These sessions will be audio recorded to ensure the speech pathologist adheres to the treatment procedures.

After the 16 speech-training sessions have been completed, we will ask you to complete another set of questionnaires, which will take approximately 10 minutes. You will then be asked to attend a group meeting over Zoom. Six other people will also attend this meeting and you will be asked some questions. This meeting will take approximately 30 minutes, and it will be video recorded. These final questionnaires and group meeting form part of the study outcomes. After you have completed all research commitments and all data has been collected, you will be compensated with a \$100 voucher.

ARE THERE ANY RISKS/INCONVENIENCES?

Yes, there are some risks associated with this study.

The speech-training procedures, although based on well-established evidence-based procedures, may not be effective for all adults who stutter. In addition, the speech-training procedures used in this study are only offered for 16 sessions, which may not constitute a complete treatment program for some people. Therefore, you may not receive as much treatment as you might ultimately need to reduce your stuttering to a level you are happy with.

However, this number of sessions is based on clinical and research evidence and is sufficient for most adults to be able to learn the techniques and see some reduction in stuttering in some situations.

If further treatment for your stuttering is required or desired after your participation in this study, we will provide relevant referrals. Please note that we will not be able to offer you additional speech-training sessions at the end of your participation in this study.

DO I HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is entirely voluntary. It is your decision whether or not you would like to participate in this research.

If you decide not to participate, or choose to withdraw from the study, it will not affect your relationship with the researchers or the University of Technology Sydney or Bond University.

WHAT IF I WITHDRAW FROM THIS RESEARCH PROJECT?

If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason by contacting Associate Professor Robyn Lowe (robyn.lowe@uts.edu.au) or Dr Anna Hearne

(anna.hearne@uts.edu.au). This will not affect your current or future relationship with the researchers or the University of Technology Sydney.

If you decide to leave the research project, the information already collected about you will be retained to ensure that the results of the research project can be measured properly, and to comply with law. You should be aware that all research data collected up until the time you withdraw will form part of the research project results. If you do not want us to do this, you must tell us before you join the research project.

WHAT WILL HAPPEN TO INFORMATION ABOUT ME?

By signing the consent form, you agree to the research team collecting and using personal information about you for this research project. Your information will be treated confidentially. To maintain your privacy, upon entry into this study, you will be assigned a unique identifying code. All the information we collect about you will be de-identified, where possible, using this code. The de-identified information will be stored and used for analysis. Any identifying information about you, such as your name and date of birth, will be stored separately from the information we will collect during this research. The audio and video recordings will be kept separate from any personal information about you and any data we collect from you during this research. The information will be stored on a secure server at the University of Technology Sydney.

Only the researchers directly involved with this research study will have access to your information, including the audio and video recordings.

We would like to store your information for future use in research projects that are an extension of this research project. In all instances, your information will be treated as confidential and stored securely. You can accept or decline this on the consent page.

It is anticipated that the results of this research project will be published and/or presented in a variety of scientific forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified. We will only ever present group data or de-identified data from the results of our analysis. We will not use audio or video recordings of you in any such publications and/or presentations.

The results of this research may also be shared through open access (public) scientific databases, including internet databases. This will enable other researchers to use the data to investigate other important research questions. Results shared in this way will always be de-identified by removing all personal information (e.g., name, address, date of birth, etc.). No audio or video recordings will ever be shared in any data sharing arrangement.

In accordance with relevant Australian and/or NSW Privacy laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

WHAT IF I HAVE ANY QUERIES OR CONCERNS?

If you have any queries or concerns about the research that you think we can help you with, please feel free to contact us.

You will be given a copy of this form to keep.

NOTE:

This study has been approved in line with the University of Technology Sydney Human Research Ethics Committee (UTS HREC) guidelines. If you have any concerns or complaints about any aspect of the conduct of this research that you wish to raise independently of the research team, please contact the Ethics Secretariat by phone: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au, and quote the UTS HREC reference number (ETH25-10859). Any matter raised will be treated confidentially, investigated, and you will be informed of the outcome.