

PARTICIPANT INFORMATION SHEET

EVALUATING A SIMPLE TREATMENT FOR YOUNG CHILDREN WHO STUTTER ETH23-8378

WHO IS CONDUCTING THIS RESEARCH?

This research is being conducted by the following researchers at the Australian Stuttering Research Centre, The University of Technology Sydney: Professor Mark Onslow, Professor Ann Packman, Professor Ross Menzies, Associate Professor Susan O'Brian, and Associate Professor Robyn Lowe

WHAT IS THIS RESEARCH ABOUT?

Researchers at the Australian Stuttering Research Centre are developing a new simple treatment for young children who stutter. The treatment is based on research evidence that has shown two simple procedures may reduce stuttering.

The treatment involves parents meeting with a speech pathologist weekly. During these consultations, parents will first learn how to identify and measure stuttering. Parents then learn how to implement the two procedures: 1. slowing their rate of speech, and 2. pausing between sentences when talking with their child. A speech pathologist will guide parents as to when and how often to use these two procedures.

The purpose of this research is to test whether these two simple procedures can reduce or eliminate stuttering with very young children.

WHY HAVE I BEEN ASKED?

You and your child have been invited to participate because:

- you are the parent of a child who stutters.
- your child is younger than 3 years.
- your child is not currently receiving stuttering treatment.
- your child has not had treatment for stuttering.

FUNDING

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

WHAT WILL MY PARTICIPATION INVOLVE?

If you decide to participate you will be asked to:

- upload a video of your child talking so we can confirm that your child stutters and is eligible to participate in this study.
- complete a set of questionnaires online. This will take approximately 15 minutes.
- consult with a speech pathologist weekly for up to one hour.
- consult with the speech pathologist using video conferencing, for example, Zoom or another videoconferencing software. These treatment sessions will be video recorded.
- complete a 5-minute questionnaire each fortnight. Based on your responses to this questionnaire, you may be asked to complete another questionnaire that will take a minimum of 15 minutes and a maximum of 60 minutes.

- discontinue treatment after three months. A researcher will then contact you to determine if your child requires further treatment. It is anticipated that additional treatment will be required for some children. If further treatment is required, service options will be discussed with you. Any additional treatment services that may be required will be at your own expense.
- complete a final 5-minute survey upon completion of the study.

ARE THERE ANY RISKS/INCONVENIENCE?

Yes. It is possible that your child may respond only minimally or not at all to this treatment.

To minimise this risk, the following safeguards will be implemented:

- You will consult with a speech pathologist weekly. The speech pathologist will monitor your child's stuttering over the three-month period and make recommendations during that time.
- You will complete fortnightly questionnaires that have been designed to monitor your child's reactions to the treatment and to determine if further guidance is needed.
- You are encouraged to contact the researchers if you have any concerns about your child's progress during the study.

DO WE HAVE TO TAKE PART IN THIS RESEARCH PROJECT?

Participation in this study is totally voluntary. If you decide not to participate in this study, neither your current nor future relationships with the researchers or the University of Technology Sydney will not be affected.

WHAT IF WE 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 by email: asrc.research@uts.edu.au or phone: 9514 5314.

Withdrawal will affect neither your current nor future relationships with the researchers or the University of Technology Sydney. If you decide to leave the research project, we will not collect additional personal information from you; however, personal information already collected will be retained to ensure that the results of the research project can be measured properly, and to comply with law.

Please be aware that any data collected up until the time you withdraw your child will form part of the research project results. If you do not want us to do this, you must inform us before consenting to join this research project.

WHAT WILL HAPPEN TO OUR INFORMATION?

By signing the consent form, you agree to the research team collecting and using personal information about you and your child for the research project. All information will be treated confidentially. The following steps are taken to ensure your privacy and confidentiality:

- You and your child will be assigned a unique identifier that will only be known to the researchers in this study.
- All information obtained from you will be de-identified, where relevant, for data storage and analysis.
- All data, including those that cannot be de-identified, for example, the audio and video recordings, will be stored securely on a University server and saved in a different location from any personal information about you and your child.

- We plan to use the video recordings of your treatment sessions to evaluate the quality and consistency of the treatment procedures used by the treating clinician. For any future clinical trials or change in treatment procedures we may also use the video recordings for the training of research speech pathologists.
- Only researchers directly involved with the research will have access to your information.

We would like to store the information you provide about you and your child for future use in research projects that are an extension of this research. In all instances, your information (a) will be treated as confidential, (b) will be stored in a de-identified format where possible, and (c) will be stored on secure University servers. In the event that we wish to use your information for a future research project, we will seek ethical approval to access your data, and only researchers involved with the research will have access to your information.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that neither you nor your child can be identified, except where you give explicit permission.

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 where appropriate. Please inform one of the research team members 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 concerns about the research, please feel free to contact one of the following researchers below:

Professor Mark Onslow or Associate Professor Robyn Lowe
Email: asrc.research@uts.edu.au
Phone: 9514 5314

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 on ph.: +61 2 9514 2478 or email: Research.Ethics@uts.edu.au], and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated, and you will be informed of the outcome.