

## PARENT INFORMATION SHEET AND CONSENT FORM FOR ONLINE SURVEYS

UTS HREC Approval number: ETH20-4897  
Unhelpful thoughts of school age children who stutter:  
The development of a measure

**What is the research study about?**

Children who stutter are at risk of experiencing speech related anxiety. Negative thoughts play a role in the development and maintenance of anxiety.

Your child is invited to take part in a research study looking at the thoughts of school age children who stutter.

The results of this study will assist speech pathologists and researchers in developing a clinical tool to identify children who:

- Hold negative thoughts about their stutter
- May benefit from mental health support to manage negative thinking patterns about their stutter

**Who is conducting this research?**

Monique Jones, Speech Pathologist and PhD student, is conducting this study at the Australian Stuttering Research Centre, the University of Technology Sydney. This project is being supervised by Professor Ross Menzies ([Ross.Menzies@uts.edu.au](mailto:Ross.Menzies@uts.edu.au)) and co-supervised by Professor Mark Onslow and Associate Professor Robyn Lowe.

**Inclusion/Exclusion criteria**

Children eligible to participate include those:

- Aged between 7 and 12 years
- With a confirmed diagnosis of stuttering by a speech pathologist
- With functional English (includes basic speaking, reading and writing)
- Who have access to a computer, tablet or smartphone with internet connection

Children ineligible to participate include:

- Children with an intellectual disability, autism spectrum disorder, Down Syndrome or a neurological disorder.
- Children who are currently receiving or have received treatment from a psychologist for anxiety or depression within the last 6 months.
- Those whose stutter began after a sudden traumatic head injury or neurological event.

**What will the study involve?**

The study involves your child completing five online questionnaires and then one final questionnaire, two weeks later.

The first questionnaire is designed to give us a clear understanding of the thoughts of school age children who stutter. In particular, the researchers are interested in whether or not children have unhelpful thoughts about their speech. Subsequently, the children will be presented with a list of thoughts (for example, "I can't do speeches"; "I'll stutter more if I'm talking to a scary person"; "everyone thinks I'm dumb because I avoid using difficult words" etc.) and then asked to decide how often they have each thought, if at all. The remaining questionnaires include two about communication and two related to psychological well-being. Specifically, there is an anxiety scale and mood inventory.

Responses to these questionnaires will provide valuable information about the the thoughts and feelings of

school age children who stutter. Furthermore, information gained will assist the researchers in developing a new means of identifying children with unhealthy thinking patterns about their stutter. If clinicians have a way to identify such problems the appropriate supports can be put in place during the school age years.

It is advised that parents sit with their children whilst they complete the questionnaires.

We ask however that parents don't discuss or influence their child's responses in any way and that they let their child complete the questionnaires independently.

The questionnaires can be completed from home in one or multiple sittings and in total may take up to 60 minutes to finish. The final questionnaire, which will be sent to you two weeks later, should only take 10 to 15 minutes (total time commitment of 75 minutes). To compensate your child for their time to participate in the study, they will receive a \$30 gift voucher (choice of Apple, LEGO or KIDS Gift Card) upon completion of the final questionnaire.

**If you wish to participate in this research, simply complete the brief eligibility and consent sections of [this online form](#) and then the survey link will take you to a short section about your child's stuttering history followed by the questionnaires.**

If you or your child have any questions about the study, please feel free to contact the Australian Stuttering Research Centre and ask to speak to Monique Jones (phone: 02 9514 5314 or email [Monique.L.Jones@student.uts.edu.au](mailto:Monique.L.Jones@student.uts.edu.au)).

You do not need to contact the researchers before beginning the questionnaires, unless you have any questions about this study and you would like further information.

#### **Does my child have to take part in this research study? Can they withdraw from the study once they've started?**

Being in this study is completely voluntary and your child does not have to take part. Your decision whether to let them participate will not affect your/their relationship with the researchers or anyone else at the University of Technology Sydney, now or in the future.

If you decide to let your child take part in the study and then change your mind later (or they no longer wish to take part), they are free to withdraw from the study at any time.

If your child withdraws from the study, we will not collect any more information from them. Please let us know at the time of withdrawal what you would like us to do with the information we have collected up to that point. If you wish, the information will be removed from our study records.

#### **Are there any risks or costs associated with being in the study?**

Aside from the time involved to complete the questionnaires, we do not expect that there will be any risks or costs associated with taking part in this study.

It is recommended that parents supervise their child whilst they complete the questionnaires.

In the unlikely event that your child experiences emotional distress when responding to the questionnaires, you are advised to contact the psychologist and chief investigator, Ross Menzies, or your GP or local community health service for information and professional guidance. Please refer to the additional advice sheet at the start of the questionnaires for further details on supervising your child's participation in this research.

#### **What will happen to information that is collected during the study?**

Your child's information will be stored securely on a UTS password protected server and their identity and information will be kept strictly confidential, except as required by law. Only the researchers involved in this study will have access to the data.

Study findings may be published, but neither you nor your child will be individually identifiable in these publications.

By providing your consent, you are agreeing to us collecting personal information about your child for the purposes of this research study. Their personal information will only be used for the purposes outlined in this Parent Information Sheet. In the future, if we wish to use your child's data for any other research, your

consent will be sought.

### What if we have concerns or a complaint about the study?

If you have concerns about the research that you think we can help you with, please feel free to contact Ross Menzies by email: [Ross.Menzies@uts.edu.au](mailto:Ross.Menzies@uts.edu.au) or by phone: +61 2 9514 5314. This information sheet is for you to keep.

NOTE: This study has been approved by the University of Technology Sydney Human Research Ethics Committee. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat by phone: +61 2 9514 2478 or email: [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au), and quote the UTS HREC reference number (ETH20- 4897). Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.