Severity of Childhood Stuttering

PARENTAL INFORMATION STATEMENT

(1) What is this study about?

Your child is invited to take part in a research study investigating the measurement of stuttering severity in children. The results of this study will assist speech pathologists and researchers to evaluate evidence based treatment services for people who stutter in the future by answering the following questions:

i. How do parent ratings of their child’s stuttering severity, without any training, compare with those of a speech pathologist?

ii. How do parent ratings of their child’s stuttering severity, after training, compare with those of a speech pathologist?

iii. How does the stuttering severity rating of a 10 minute sample of a child’s speech compare to the rating of a whole day?

iv. What is the variability of a child’s stuttering throughout the day?

The most researched and widely used stuttering treatment approach, the Lidcombe Program, relies on parent/caregiver daily severity ratings. The results of this research project will show the accuracy of parent severity ratings as well as the importance of parent training. Currently, there is no evidence of the potential variability of a child’s stuttering. This study may provide evidence of variability which would be important for clinical decision making.

Your child has been invited to participate in this study because:

- He/she has a noticeable stutter
- He/she is between 3 years and 6 years of age
- He/she speaks English at home
- He/she has not been assessed or exposed to the stuttering severity scale
This Participant Information Statement tells you about the research study. Knowing what is involved will help you decide if you want to let your child take part in the research. Please read this sheet carefully and ask questions about anything that you don’t understand or want to know more about.

Participation in this research study is voluntary. So it’s up to you whether you wish to let your child take part or not.

By giving your consent you are telling us that you:
- Understand what you have read
- Agree for your child to take part in the research study as outlined below
- Agree to the use of your child’s personal information as described.

You will be given a copy of this Parental Information Statement to keep.

(2) Who is running the study?

The study is being carried out by the following researchers:
- Professor Mark Onslow – Director, Australian Stuttering Research Centre, The University of Sydney
- Dr Susan O’Brien – Senior Researcher, Australian Stuttering Research Centre, The University of Sydney
- Dr Robyn Lowe – Speech Pathologist/Researcher, Australian Stuttering Research Centre, The University of Sydney
- Jessica Thambyaiyah – Honours student, Australian Stuttering Research Centre, The University of Sydney
- Amanda Chan – Honours student, Australian Stuttering Research Centre, The University of Sydney

Amanda Chan and Jessica Thambyaiyah are conducting this study as the basis for the degree of Bachelor of Applied Science (Speech Pathology) at The University of Sydney. This will take place under the supervision of Dr Robyn Lowe, Researcher at the ASRC, University of Sydney.

(3) What will the study involve?

The purpose of this study is to measure your child’s stuttering throughout the day. Hence, this study will involve your child’s speech being audio recorded for approximately 8 hours. The researchers will provide a t-shirt with a small recording device attached. Once it is turned on, you will be encouraged to go about your day as normal. At some point in the day, the researcher will call you in order to get a 10-minute random sample of your child’s speech. The details of this activity will be explained to you before consenting to the study.

Neither you nor your child will need to alter your ordinary routine in any way. We only ask that you remain at home for confidentiality purposes. At the end of the recording time, the researcher will come by your house to pick up the recording device. At this time, you will be asked a few questions about your child’s speech throughout the day. This should take about half an hour.

(4) How much time will the study take?

Your involvement in this study will take approximately 9 to 10 hours over one day. The entire research project will be completed within 2 years.

(5) Who can take part in the study?
For this study, we are looking for children between 3 years and 6 years of age, who stutter. The child should be developing normally in all other respects as this will ensure that the measurements are purely representative of the stutter. The child and family must speak English at home. The child must not have been assessed or treated for stuttering at the time of the study, nor should any other children in the family have been treated for stuttering. However, at the conclusion of the day, the researchers would be happy to answer any questions about stuttering that you may have.

(6) Does my child have to be in the 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 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 him/her. 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, you can request that the information be removed from our study records.

(7) Are there any risks or costs associated with being in the study?

Participation in this study may involve some inconvenience to your child as he/she will be required to wear the recording device for the duration of the day. In order to minimise any discomfort, a small, lightweight recording device will be used which will fit into the pocket of a shirt. A microphone will be attached to the recorder. The whole device will measure approximately 15cm x 3cm. There will be no financial costs associated with being in the study.

(8) Are there any benefits associated with being in the study?

The training and information provided to you at the end of the day will be useful when your child is further assessed or treated for his stuttering. The information obtained from this study will contribute significantly to the knowledge base of childhood stuttering. The results will have implications for future research and inform clinical practice. Also, in order to offset any inconvenience caused by your participation in the study, you will be offered a $50 Coles-Meyer gift card at the end of the day.

(9) What will happen to information that is collected during the study?

This study will involve the collection of audio recordings. These recordings will be analysed and used to determine your child’s stuttering severity and variability over the day. Your child’s information will be stored securely and their identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but your child will not be individually identifiable in these publications. Instead, identification numbers will be used for you and your child when data and documents are being labelled and stored. Any other identifying information about you or your child will be removed.

For the duration of the study, audio recordings will be stored on a password protected computer at the Australian Stuttering Research Centre and after the study, the recording and any other digital information will be stored in our Australian Stuttering Research Centre university-protected database. We will keep the information we collect for this study, and we may use it in future projects. We don’t know at this stage what these other projects will involve. We will seek ethical approval before using the information in these future projects.
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 Participant Information Statement, unless you consent otherwise.

(10) Can I or my child tell other people about the study?

Yes, you are welcome to tell other people about the study.

(11) What if we would like further information about the study?

When you have read this information, Dr Robyn Lowe will be available to discuss it with you further and answer any questions you may have. If you or your child would like to know more at any stage during the study, please feel free to contact Robyn or any of the researchers named above (phone: 9351 9061).
Email: robyn.lowe@sydney.edu.au

(12) Will we be told the results of the study?

You and your child have a right to receive feedback about you individual results at the time of your participation. You also have the choice to receive feedback and results after the study is finished.

(13) What if we have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney [protocol number, 2014/588]. As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect people who agree to take part in research studies.

If you (or your child) 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 using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:
- Telephone: +61 2 8627 8176
- Email: ro.humanethics@sydney.edu.au
- Fax: +61 2 8627 8177 (Facsimile)

This information sheet is for you to keep