



Investigating levels of anxiety and depression in children who stammer in the UK Information Sheet for Parents/Guardians

This project has been approved by the UCL Research Ethics Committee, Project ID#15535/001

We would like to invite you and your child to take part in a research study looking at anxiety and depression in children and young people who stammer in the UK.

Our study is funded by the Economic & Social Research Council (ESRC) and Action for Stammering Children Charity.

It is important that you understand the nature of the project and what it will involve for you and your child before agreeing to take part. Please take a look at the information below and do feel free to get in touch if you have any questions.

Thank you for reading.

Who are we and why are we doing this study?

We are researchers based at University College London (UCL), investigating the social, emotional and mental health profiles of children who stammer. We are interested in levels of anxiety and depression in English-speaking children who began to stammer in childhood. We will be asking boys and girls who stammer between eight and thirteen who live in the UK to take part.

Does my child have to take part? What if I change my mind?

It is up to you and your child whether you would like to take part or not. You can withdraw at any time during the study, including after it has begun. If you decide to withdraw from the study, we will discuss what you would like us to do with the data collected from you and your child.

What does the study involve?

If you wish to take part and are happy for your child to be part of the study, we will ask both you and your child to complete an online questionnaire. You will be able to access the questionnaire from home or any other computer with access to the internet.

The questionnaire that your child undertakes will ask them to:

- Rate their stammer
- Rate the frequency of experiencing different emotions
- Answer some questions about experiences of bullying

The questionnaire that you, as the parent/guardian, will be asked to complete includes:

- Rating the frequency of your child's experience of different emotions
- Answer some questions about your child to provide some background information

Each questionnaire should take around 15-20minutes to complete.

We will also collect email contact details so that we can send you information about the study results, unless you opt not to do so. You will be asked on the consent form whether you would be happy to be contacted about future studies. These details will be kept securely; they are not stored with the study data and not shared with anyone outside the study team.

What happens to my data?

Personal data (date of birth, postcode, diagnosis) will not be recorded next to the actual names of you or your child. All responses are identified by code numbers that are unique to the study. Personal data is encrypted and stored securely at UCL. We may share anonymised data (data that cannot identify you or your child) with Action for Stammering Children Charity. As we are publicly funded by the ESRC, we are required to donate anonymised data to the UK Data Archive, which will allow other research teams to access it. We will make every effort to ensure the data cannot be traced back to you. Once the data is passed to the Data Archive, it may be more difficult to withdraw it from future studies. You can read more about this here: <http://www.lilac-lab.org/scales/openscience/>. The data controller for this study is UCL. This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found [here](#).

Are there any risks to taking part?

It is highly unlikely that taking part in this study will pose any risk to you or your child. We will be asking your child about their feelings and emotions, which could result in some distress. We will also be asking him/her about how other children and adults treat them, which could potentially cause upset. However, your child can exit the questionnaire at any time – including after it has started.

Why should I take part: are there any direct benefits?

By taking part, you will be helping us to better understand stammering in children. Through understanding more about the emotions and mental health of children who stammer, we can feed this into development of future therapy approaches. Everyone who takes part will receive a small voucher (£5). This study will not offer any therapy/treatment for your child but we can tell you about organisations that you can get in touch with if you would like to do so.

I want to get in touch

If you would like more information or have a question, you can contact us here:

Ria Bernard, PhD student

Language & Cognition, Division of Psychology & Language Sciences, University College London, Chandler House, 2 Wakefield Street, London, WC1N 1PF

E: ria.bernard@ucl.ac.uk

Need to make a complaint

It is highly unlikely that this study will be cause for concern but if you are unhappy with any element of the project and want to make a complaint, you can contact:

- Principal Researcher, Professor Courtenay Norbury: c.norbury@ucl.ac.uk
- Chair of the Research Ethics Committee: ethics@ucl.ac.uk.

**Thank you for reading about our study.
If you would like to take part, please read and sign the consent form.**