

Participant Information Sheet for Williams and Down Syndrome

UCL Research Ethics Committee Approval ID Number: Z6364106/2018/11/61

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

Title of Study: How does anxiety and poor motor ability impact daily living skills in Williams and Down Syndrome?

Department: UCL Institute of Education, Department of Psychology and Human Development

**Name and Contact Details of the Principal Researcher: Leighanne Mayall;
leighanne.mayall.14@ucl.ac.uk**

Name and Contact Details of other researcher(s): Emily Farran; e.farran@surrey.ac.uk

1. Invitation Paragraph

We are psychology researchers based at the Institute of Education, University College London. We are writing to invite your son/daughter to take part in a research study. Before you decided it is important for you to understand why the research us being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

2. What is the project's purpose?

We are interested in finding out about motor ability and how this is related to daily living skills and anxiety in Williams syndrome and in Downs Syndrome. It has been found in previous research that individuals with Williams Syndrome and Down Syndrome often show motor difficulties and high levels of anxiety, and we would like to find out more about how this low motor ability and high level of anxiety is impacting these individuals ability to take part in activities of daily living, such as getting dressed, cooking and personal hygiene.

3. Why have I been chosen?

You are being asked to take part as you are a parent of an individual with Williams Syndrome or Down Syndrome, have been contacted by phone by the researcher, and have expressed interest in taking part in the study.

4. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep, and be asked to sign a consent form. You or your son or daughter can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

5. What will happen to me if I take part?

If you and your son or daughter agree to take part, we will ask you to fill in a few questionnaires about your son or daughter's motor development, their daily living ability

and their anxiety. These questionnaires can be accessed online via the following link, and will take around 45 minutes to complete:

https://uclioe.eu.qualtrics.com/jfe/form/SV_1Gmg068ncs3TGzr

The questionnaires' do not have to be completed all at once, and you can save what you have done and come back to it later.

Each participant will also carry out a few motor tasks to measure skills such as fine-motor skills, balance, and throwing and catching skills. The participant will also be asked to do some daily living activities, such as putting on shoes, doing up buttons, making a sandwich, etc. While the participant is taking part in these tasks, they will be asked to wear an activity monitor (a FitBit wrist watch) to monitor their heart rate. The participant will also complete several brief measures of verbal and nonverbal ability. Participants with Down Syndrome will also be asked to complete a task where they will make patterns out of blocks, and a computer task where they will be asked to mentally rotate pictures. These assessments will take place in one session, which will take no longer than two and a half hours. There is no time limit and it would be fine to work at whatever pace is suitable, with breaks where needed.

6. What are the possible benefits of taking part?

Whilst there are no immediate benefits for those people participating in the project, it is hoped that this work will help to shape future research and will help to inform intervention to improve daily living skills and independence for individuals with Williams Syndrome and Down Syndrome.

7. What if something goes wrong?

Should you wish to lodge a complaint or concern at any time during or after the research, you can contact the principal researcher, Leighanne Mayall at Leighanne.mayall.14@ucl.ac.uk. Alternatively, you can contact the principal researcher's supervisor, Professor Emily Farran at e.farran@surrey.ac.uk. Any and all complaints and concerns will be handled swiftly and carefully.

Should you feel that your complaint has not been reasonably handled, you would be welcome to contact the Chair of the UCL Research Ethics Committee at ethics@ucl.ac.uk.

8. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications. Please be assured that all personal details and data collected will be treated with confidentiality, stored safely and disposed of safely after five years, in line with the General Data Protection Regulation (2018).

9. Limits to confidentiality

Confidentiality will be respected subject to legal constraints and professional guidelines. Confidentiality will be respected unless there are compelling and legitimate reasons for this to be breached. If this was the case we would inform you of any decisions that might limit your confidentiality.

10. What will happen to the results of the research project?

Data from this research will be used as part of a PhD thesis, will be written up for publication in scientific journals and the general group findings will be shared with the Williams Syndrome Foundation UK magazine and will be provided to any interested participants. All personal details and data collected will be stored safely and disposed of safely after five years, in line with the General Data Protection Regulation (2018).

11. Data Protection Privacy Notice

Notice:

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk.

Further information on how UCL uses participant information can be found here:

www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice

Your personal data will be used for the purposes outlined in this notice. The categories of personal data used will be as follows:

Name
Address
Contact details
Presence of a neurodevelopmental disorder (i.e. Williams Syndrome or Down Syndrome)
Age
Gender

The legal basis that would be used to process your *personal data* will be performance of a task in the public interest.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

You have certain rights under data protection legislation in relation to the personal information that we hold about you. These rights apply only in particular circumstances and are subject to certain exemptions such as public interest (for example the prevention of crime). They include:

- The right to access your personal information;

- The right to rectification of your personal information;
- The right to erasure of your personal data;
- The right to restrict or object to the processing of your personal data;
- The right to object to the use of your data for direct marketing purposes;
- The right to data portability;
- Where the justification for processing is based on your consent, the right to withdraw such consent at any time; and
- The right to complain to the Information Commissioner’s Office (ICO) about the use of your personal data.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

If you remain unsatisfied, you may wish to contact the ICO. Contact details, and further details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

12. Who is organising and funding the research?

Research is funded by the ESRC and the Williams Syndrome Foundation UK.

16. Contact for further information

For further information, you can contact Leighanne Mayall at Leighanne.mayall.14@ucl.ac.uk, or Emily Farran at e.farran@surrey.ac.uk.

Thank you for reading this information sheet and for considering to take part in this research study.

