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Department of Psychology

Sensory Profiles in Rare Genetic Syndromes

Participant Information Sheet

You are invited to take part in a research study about your child's sensory profile and behaviour. You have been invited to participate because your child has been diagnosed with one of the genetic syndromes involved in this research. Before you decide whether or not you would like to take part, it is important for you to understand why the research is being done and what will be involved. Please read the following information carefully and discuss it with others if you wish. You may ask for clarification of anything that is unclear or if you would like more information.

What is the purpose of the study?

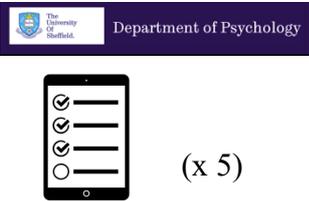
The aim of this research is to investigate the sensory profiles of children with Sotos syndrome, Tatton-Brown Rahman syndrome, 16p11.2 deletion syndrome and 16p11.2 duplication syndrome. A sensory profile is a measure of a child's response to everyday sensory events. This may relate to hearing, vision, touch, taste or smell, body movement, or how a child feels in certain situations. To take part, your child must be aged 3 to 14 years old. The study will also investigate relationships between sensory response and other behaviours, such as anxiety and autistic traits. This information will inform understanding of how children process sensory information and the impact that sensory issues may have on other aspects of behaviour.

Do I have to take part?

It is up to you to decide whether or not you would like to take part. If you do decide to take part, you will be asked to sign a consent form. Following this, you have the right to withdraw at any time and without giving a reason.



What will happen if I decide to take part?

1.	If you decide you would like to take part, the lead researcher will send you the questionnaires via email*.	
2.	You will be sent a link to complete the first set of questionnaires (five in total). The questionnaires will be completed on a secure website.	
3.	After you have completed the first set of questionnaires the lead researcher will send you an invitation to complete <u>two more</u> questionnaires on another secure website**.	
4.	When you have completed the questionnaires on both websites (seven questionnaires in total) your participation in the study will be complete.	
5.	After your participation, you will be sent an individualised summary report of your child's sensory profile.	

*If you would prefer to complete the questionnaires using pen and paper, let the lead researcher know and they will send them to you in the post.

** The questionnaires are completed on two different secure websites for licencing purposes.

Two of the questionnaires will be used to assess your child's sensory profile and the impact that sensory behaviours have on day-to-day life. An additional five questionnaires will be used to assess your child's behaviour and how certain behaviours may be related to sensory



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processing. The questionnaires can be completed in your own time and it will take approximately 1.5 to 2 hours in total.

What are the possible disadvantages and risks of taking part?

The only disadvantage is the fact that the study will take approximately 1.5 to 2 hours. No information that you provide will be shared with anyone else beyond the research team unless you choose to share this information yourself.

What are the benefits of taking part?

If you decide you would like to take part in the study, you will be given individualised feedback based on your responses to the questionnaires. This information will not be diagnostic but will provide an overview of your child's sensory profile. In addition, a summary of the findings from the study will be made available to everyone who takes part in the research. This will not contain any identifying information.

What if I wish to complain about the way in which this study was conducted?

If you have any complaints or concerns, please contact the project supervisors, Dr Megan Freeth or Dr. Elizabeth Milne:

E-mail: m.freeth@sheffield.ac.uk or e.milne@sheffield.ac.uk

Tel: (0114) 2226558

Postal address: Psychology Department, The University of Sheffield, Cathedral Court, 1 Vicar Lane, Sheffield. S1 2LT

What will happen to the information collected during the study?

Paper based personal information will be stored in a locked cabinet at the University of Sheffield and electronic personal information will be stored on a secure server space at the University of Sheffield in password protected documents. Anonymised research information will be stored securely for 10 years. Your personal information will only be accessible by members of the research team. If you would like to be contacted by the research team about



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relevant opportunities to participate in future research, your personal information will be stored for 3 years. If you would not like to be contacted about future research opportunities, your personal information will be deleted at the end of this study (September 2021).

Will my taking part in the study be kept confidential?

All information collected about your child during the research will be kept strictly confidential. Any information about your child that leaves the University will have your child's name removed so that they cannot be recognised from it. The results of the study will be analysed and prepared for publication in relevant scientific journals, following academic assessment. No identifying information about any individuals will be available in publications or conference presentations. Once published, you will be able to obtain a copy of the results and a summary of the findings from the research team.

This study has been reviewed by the Department of Psychology Ethics sub-committee at the University of Sheffield and conforms to the British Psychological Society “code of human research ethics”.

Thank you for taking the time to read this information sheet. If you would like to participate in the study or would like any further information, please contact:

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