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## **Title of Study: Sensory Activity in Preschoolers (SNAP)**

### **PARTICIPANT INFORMATION SHEET**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study 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.

#### **What will I be asked to do?**

Your child learns about the world and other people through their senses, like seeing, hearing and touching. Among all, touching has been guiding your child's curiosity in exploring the environment since the first years of life. But how can we understand how every single child senses the surrounding environment and which stimuli do they prefer? We will try to answer this question combining your child's responses to different touch stimuli: we will use both child-friendly neuroimaging techniques to measure their brain activity (e.g. how the brain responds to gentle vibrations) and behavioral observations to see their tactile reactions while having fun playing with some toys or with a tablet (e.g. reaction times touching things appearing on the tablet screen). Just as they normally do in their everyday life, we try to make the setting of this study as realistic as possible, and your child will be only asked to spontaneously play or to watch some videos while both their natural brain and touch responses will be recorded.

If you are happy that you and your child, take part in the study, you will be asked to sign a consent form, and you will be given a copy of the signed information sheet and consent forms to keep for your records. The assessment visit will include cognitive and clinical assessments, EEG, touchscreen and laptop tasks. Parents will also be asked to complete questionnaires and interviews about their child's behaviour, development, sensory function, and anxiety. Taking part in the study will take approximately 2 -3 hours total time (across home and lab completion). You can also withdraw from the study at any time without having to give a reason.

#### **Why have I been invited to participate in this study?**

You have been invited to take part because you have a child with a diagnosis of an Autism Spectrum Condition (ASC).

#### **Are there any benefits to taking part?**

Families will receive a £50 gift voucher for participation in their visit. If parents would like, we can also provide a brief summary of their child's results on some standardized tests of development. Children will also receive a small gift to thank them for participating.

### **What will happen to my data/how will it be protected?**

The results of this project will be written for a project/thesis or results will be presented at conferences and written up in journals. Results are normally presented in terms of groups of individuals. If any individual data is presented, the data will be totally anonymous, without any means of identifying the individuals involved.

### **Data Storage and Use**

All of your data will be kept confidential and securely stored, with only a number attached to each participant, and therefore it will not be possible to link any set of data with any individual. The University of Reading is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Reading will keep identifiable information about you for 5 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

If you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

If you agree to take part in this research study, you will also be asked whether you would like to be contacted in the future to potentially participate in other studies. If you consent then your contact details will be added to a secure database within the University of Reading's Centre for Autism. Information on the database can be found at [www.reading.ac.uk/autism/research/help-take-part/](http://www.reading.ac.uk/autism/research/help-take-part/).

### **Who can I contact about data privacy and storage?**

The organisation responsible for the protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at [imps@reading.ac.uk](mailto:imps@reading.ac.uk), or in writing to: University of Reading, Information Management & Policy Services, Whiteknights House, Pepper Lane, Whiteknights, Reading, RG6 6UR, UK.

The University of Reading collects, analyses, uses, shares and retains personal data for the purposes of research in the public interest. Under data protection law we are required to inform you that this use of the personal data we may hold about you is on the lawful basis of being a public task in the public interest and where it is necessary for scientific or historical research purposes. If you withdraw from a research study, which processes your personal data, dependant on the stage of withdrawal, we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your personal data.

If we have included any additional requests for use of your data, for example adding you to a registration list for the purposes of inviting you to take part in future studies, this will be done only with your consent where you have provided it to us and should you wish to be removed from the register at a later date, you should contact If you have any questions please contact Teresa Tavassoli by email at [t.tavassoli@reading.ac.uk](mailto:t.tavassoli@reading.ac.uk).

**You have certain rights under data protection law which are:**

- Withdraw your consent, for example if you opted in to be added to a participant register
- Access your personal data or ask for a copy
- Rectify inaccuracies in personal data that we hold about you
- Be forgotten, that is your details to be removed from systems that we use to process your personal data
- Restrict uses of your data
- Object to uses of your data, for example retention after you have

withdrawn from a study Some restrictions apply to the above rights where data is collected and used for research purposes.

You can find out more about your rights on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>

You also have a right to complain the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.

**Who has reviewed this study?**

This application has been reviewed by the School of Psychology and Clinical Language Sciences Research Ethics Committee and has been given a favorable ethical opinion for conduct (**SREC**)

**Where can I get more information/who I can contact about this study?**

If you have any questions or concerns about the research, please feel free to contact Teresa Tavassoli, [t.tavassoli@reading.ac.uk](mailto:t.tavassoli@reading.ac.uk).

Thank you for your help.