

# Title of Study: Sensory Activity in Preschoolers (SNAP) PARTICIPANT INFORMATION SHEET

# What is the study about?

Autism Spectrum Conditions (ASC) is a term used to characterise the diverse presentations of Autism. Autistic individuals excessively-or-under experience sounds, touch, lights, taste or temperatures. These differences occur in 70-95 per cent of individuals, leading to physical and emotional pain which can be highly distracting, especially during social interactions. As a result, it negatively impacts their mental and physical health, causing profound difficulties in daily functioning. These sensory differences appear to manifest from early childhood to adolescence, with touch-related issues affecting 60 per cent of children and exacerbate mental health issues like anxiety. Critically, every autistic individual senses their environment very differently; likewise, how they interact socially, and their behaviors vary hugely. Thus, autism occurs on a continuum. Given the vast differences in autistic individuals' experiences it is vital to understand how these occur, what similarities and differences are based on specific features that are so common.

To understand these differences in touch and how social difficulties occur in ASC, the brain features underpinning them need to be studied during the developmental window corresponding to the age of diagnosis and onset of core difficulties, which is between 3 - 6. Using reliable tools that measure behavior (perception) and the underlying brain features. Additionally, using methods which do not just rely on parent reports makes them more reliable and inclusive.

The SNAP study will address these issues in several ways with different methods. In the university laboratory, we will look at the brain activity of children aged between 2.5 years to 6 years and 11 months and another group between the ages of 3- 6 years using a device called electroencephalography (EEG), which is a pain-free and non-intrusive way to measure how the brain produces electrical activity. We will use EEG equipment, and the vibrating device taped to the child's index finger, delivering pain-free vibrations akin to a vibrating phone while the child watches Peppa Pig or Octonauts on the tablet. We will also study how the child responds to vibrations on a custom-made story-based task. A fully trained research team member will also interact with children to assess IQ, ASC and

responsiveness toward different sensory toys (sound makers, bells). Parents or Care givers of children will be asked to fill out several questionnaires asking questions regarding how the child copes with new situations, sensory experiences and social needs. This will help us understand the biological mechanisms underpinning differences in ASC children's sensory and social experiences. We will be able to identify groups of children with similar difficulties. In turn, these can potentially be used as therapeutic targets to develop interventions to better help autistic people.

#### **Study Location**

Centre for Integrative Neuroscience and Neurodynamcis School of Psychology and Clinical Language Sciences University of Reading, **Reading, Berkshire RG6 6AL** 

cinn@reading.ac.uk | @UniRdg CINN

CINN is located near the Earley Gate entrance of Whiteknights Campus, on the ground floor of the Harry Pitt Building (north entrance). See a <u>full map</u> of the Whiteknights Campus.

For Sat Nav use: RG6 6ES what3words: <u>https://w3w.co/hang.foster.icon</u>

**By bus: Number 17** (frequent) or Numbers 19a, 19b,19c (3 per hour). Numbers 21 and 21a (let you of across campus by the main entrance, and you need to walk across to Earley Gate.

**By taxi from Reading Station:** Ask for "Earley Gate, University of Reading." On having entered the campus direct the driver toward the large brick building on the left after the first roundabout. This is the Harry Pitt Building

# What does participate in this study involve?

We will try to answer these questions by measuring how your child's behavioural and brain respond to different touch stimuli. We will use pain-free and child friendly way to measure brain activity, Electroencephalography (EEG). We will also attach a small vibrating sensor at the same time as the EEG while your child watches child friendly movies on the PC screen and tablet. The little sensor, named tactor, vibrates like a mobile phone device. Your child will also be asked to play on two short tablet games which include vibrations and animals. After a lunch break, we will ask your child to take part in some interactive games and mini interview like tasks with our trained Research Assistant. These tasks include puzzles, dolls, cars, pictures and sensory toys. During these tasks we will record (pen and paper) your child's natural responses to questions and behaviours. We aim to make the environment as comfortable and the study setting as realistic as everyday life.

If you decide to take part, and sign consent, we will also ask parent/legal guardian to fill out some questionnaires about your child's behaviours via an online link to

a highly secure questionnaire set. Every single element of this study has already been carried out at Birkbeck University of London by the SNAP research team.

# **E**rain activity

In this study we will measure how children's brain recognises touch. To do this, we will be using a brain activity measurement called Electroencephalography (EEG), a completely pain free and safe approach which detects the brain activity.

In the lab at the Centre for Integrative Neuroscience and Neurodynamics . We will put a cap on your child's head which includes the sensors and gel suitable for sensitive skin types. These sensors pick up the naturally occurring electrical activity produced by the brain. We will also attach a very small sensor to the child's finger with non-adhesive medical tape. This sensor will deliver very gentle vibrations akin to a vibrating mobile phone. Both the EEG cap and sensor will be attached your child's finger secured with non-adhesive compression tape at the same time. Your child will be sitting on a chair while watching cartoon on a PC monitor. During this time, the gentle vibrations will be applied to your child's finger through the mini-sensor device.

# Touch games

Your child will also take part in a number of fun and engaging activities such as playing with different toys and with a tablet, which we've found children really enjoying doing! The first task for your child will be one of the two tablet tasks. For this task your child will be asked to press the animal as fast as they can when they feel it vibrating. In the second tablet task your child will be asked to decide which animal vibrates the most.

# Interactive games and mini-interviews

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We will ask your child to play with us using a variety of toys and solving different tricky tasks (e.g. building a big tower with blocks). These games are designed to understand how your child understands, learns and interacts with others. Do not worry if you child will not be able to do something because some of the items will be for older children and it is fine if your child will find them too difficult!

# Parent/legal guardian questionnaires

Before your study visit will ask you to complete some questionnaires about your child's behaviours and personality. You will have the opportunity to complete the questionnaires online in your own time via a highly secure link and your child will be given a unique code making them unidentifiable.

# **Possible side effects?**

Every aspect of this study has been tried and tested in children of the same age range and behavioural profile. All the measures are entirely safe, and we do not expect any risk or side-effects. The testing schedule is around 4.5-5 hours including breaks, therefore if your child becomes tired or wishes not to take part, the study will be terminated. You will still receive full compensation with  $\pounds$ 50.00 voucher and up to  $\pounds$ 25.00 for travel costs.

#### What are the benefits?

You will receive a £50 gift voucher for your participation and be compensated up to £25.00 for travel. We can also arrange over-night accommodation for you and your child if required; the cost will be covered for the research team. We will require receipts to be shown to the team.

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

The results of this project will be written for a project/thesis and results will be presented at conferences and written up in scientific journals. Results are normally presented in terms of groups of individuals for out-reach purposes and scientific conferences. If any individual information such as feedback quotes is presented, all information will be strictly anonymised.

#### Data Storage and Use

All your data and child's will be kept confidential and securely stored at University of Reading secure database as an anonymised dataset with a unique code. This grants the data unidentifiable. The University of Reading is the sponsor for this study based in the United Kingdom We will be using information from you 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 for the research to be reliable and accurate. Unless, if you decide to withdraw from the study, you have the right to ask for your data to be removed. To safeguard your rights, your child's data do not contain any personal information deeming them identifiable. Information and collected data 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. The only instance in which your anonymity will be breached is if there is a serious safeguarding concern regarding the child.

If you agree to take part in the SNAP study, the information about your health and care may be provided to researchers running other research studies in the University of Reading and will be shared with King's College London. Other UK based organisations and or companies involved in health and care research in this country or abroad may also be provided with the data. 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 and under no circumstances will the Ethical regulations and General Data Protection Regulations (2018) be breeched. Please see the universities Research Data Management Policy here: <u>University of Reading Research Data Management Policy</u> and the University of Readings code of good practice here <u>UCOGPR (reading.ac.uk)</u>

We will also ask parents and legal guardians' permission to take photographs of your child during the study on the studies tablet, which is stored away in locked facilities at the University Site. We also re-confirm permission on the day of the study.

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 <u>www.reading.ac.uk/autism/research/help-take-part/</u>.

# 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, <u>t.tavassoli@reading.ac.uk</u>.

# Who can I contact if I have any concerns about this study?

If you have any concerns about how this study is conduced, then please feel free to contact the Research & Ethics Committee by email on **<u>urec@reading.ac.uk</u>**