

PARTICIPANT INFORMATION SHEET

Title of Study: Sensory reactivity and mood in autism

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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 is the purpose of the study?

Autistic people often react differently to sensory inputs, such as being oversensitive to sounds or touch, and sensory reactivity has been linked to mental health symptoms, such as anxiety. We are hoping to investigate sensory perception and the link with other mental health symptoms, namely mood.

Why have I been asked to take part?

You have been asked to take part because you are an autistic adult, autistic teenager, or a parent/carer of an autistic adult or teenager.

Do I have to take part?

No. It is up to you to decide whether or not to take part. You are free to withdraw at any time and without giving a reason.

What will happen if I agree to take part, and what will I be asked to do?

If you are happy to take part, you will be asked to sign a consent form, and you will be given a copy of the information sheet to keep for your records. Taking part in the study will take approximately 1 hour. First, we will ask you to complete a survey online. Following this you will be invited to complete a short online interview asking about mood symptoms. Even though we say the study will take approximately 1 hour, you can take as much time as you need to complete the survey and the interview. You can also take as many breaks as you need.

Part of this study is looking at mood, and as such we also want you to know that there may be questions that you find uncomfortable, or that may trigger unwanted thoughts causing distress. If there are any topics that you find distressing, please let us know and we will endeavour not ask questions about those topics. Again, you can also withdraw from the study at any time without having to give a reason.

If the information you share with us during the research raises a significant concern about mental health we will consult with clinically qualified experts and, if they feel it is necessary, we will contact the General Practitioner or seek other medical assistance.

You will receive £10 for your participation, and will go into the draw to win an additional £50.

Can I have a support person with me?

Yes. You can have a support person with you during the interview. They will be able to sit with you throughout the interview, but they can't answer questions for you.

Will my information and responses be kept confidential?

Yes. In line with the UK's Data Protection Act, all data will be kept in a secure location and only accessed by the research team. Participants will be assigned individual ID numbers and these numbers will be used on all questionnaires, test forms and recordings, and in data sets for analysis. Identifiable data, containing the name-ID number associations, will be stored in a separate location managed by the chief investigator. Data files will be kept secured by being locked in an office in a secure cabinet file. Link-anonymised digital data will be stored securely on password protected computers.

What will happen to the results of the research study?

It is hoped that the results will be published in scientific journals. Again, no identifying details will be disclosed at any time. We intend to send a concise description of the interpretation of our results to all participants.

Data Storage and Use

All of your data will be kept confidential and securely stored, as described above.

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. Data will not be held longer than necessary for the specified purposes, and will schedule regular reviews of personal data holdings to determine whether they need to be retained or can be safely destroyed.

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 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/.

You can find out more about how we use your information by contacting Timothy Rossow or Teresa Tavassoli (contact details below).

Contact for further information

If you are interested in participating or you have any questions you can contact Timothy Rossow by email at t.w.l.rossow@pgr.reading.ac.uk or Teresa Tavassoli by email at t.tavassoli@reading.ac.uk or by phone +44(0)118 378 8100.

This application has been reviewed by the University Research Ethics Committee and has been given a favourable ethical opinion for conduct.

Thank you for considering taking part in this study.

Timothy Rossow