

FOCUS GROUP INFORMATION SHEET

Central University Research Ethics Committee (CUREC) Approval Reference: R74960/RE001

n.b. An Easy Read version of this Information Sheet is available on request

Sensory Street: Autistic adults' experiences of sensory environments

1. Why is this research being conducted?

The aim of this study is to find out which sensory aspects of different environments most affect autistic people and who autistic people would most like to be informed about their sensory needs. We will use the results of this research to create a video that describes the impact of sensory processing on the lives of autistic people and design a multisensory experience ('Sensory Street') in collaboration with business owners to inform the general public about sensory processing in autism.

2. Why have I been invited to take part?

We are inviting autistic adults aged 18 years and over to participate in online focus groups. We are inviting participants who have a confirmed clinical diagnosis of an autism spectrum condition. We are not including people without a confirmed diagnosis for this part of the project because we can only see a relatively small group of people.

3. Who is conducting this research?

This research is being conducted by Dr Cathy Manning (Principal Researcher), Catherine Woolley (Research and Engagement Officer) and Keren MacLennan (Research Assistant) from the Department of Experimental Psychology at the University of Oxford. We are collaborating with Becky Lyddon (founder of Sensory Spectacle), Dr Brett Heasman (University of York St John), Emily (@21andsensory) and Jess Starns (founder of DyspraxicMe).

4. Do I have to take part?

No - it is up to you whether you would like to take part. Please read through this information before deciding whether to participate. You may ask any questions before you decide by contacting the research team (details below). If you later change your mind for any reason, you may withdraw before submitting your answers to the questionnaire by pressing the 'Exit' button/closing the browser, or you may withdraw before participating in a focus group by informing the research team. You can also leave the focus group at any point, without giving a reason. You can withdraw your data at any point up to seven days after the date of the focus group, without giving a reason, by contacting the research team. After 7 days from the date of the focus group, the transcript will be anonymised so that it will no longer be possible to remove your data.

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

You would be asked to fill in an online consent form and a brief questionnaire about your age, gender and diagnoses. If you are eligible, we will then contact you by email to ask you to complete a brief questionnaire about autistic traits and to schedule a time for you to join a small online focus group to discuss your sensory experiences of different environments (e.g., hairdressers, shops and restaurants). If we have a high response, we might not be able to see everyone who volunteers to take part. In this case we will aim to see a representative sample of people across ages and genders.

If you are invited to take part in a focus group, you will be sent the main questions beforehand. No background knowledge is required. Normally the focus group will consist of three or four autistic people and will be held on MS Teams, Zoom or Facebook. We expect the focus group to last about an hour. Towards the end of the focus group, you will be given the opportunity to provide a drawing to convey an example of an ideal sensory environment and to share this with the research team. You can share your drawing by sending a copy electronically by email or in the chat, or by holding a paper copy up to the camera. You may like to have a pen and paper to hand. We will take your preferences into account when scheduling focus groups. Information about the session (such as meeting passwords) will only be provided to people attending to prevent uninvited guests.

We will video/audio record the session and save the text in the chat box so that the information can be transcribed later by our research team and used for publicity materials (with your consent). You may participate however you feel most comfortable such as enabling your video and/or audio or communicating through the chat box.

After the focus groups are complete, we will be using the de-identified results to design a multisensory experience ('Sensory Street') to inform the public about sensory processing in autism. As part of the publicity materials for this event we would like to use video and audio clips from the focus groups to create a video help the public understand why the project is important. This is optional and you will be able to consent separately to providing your data for this on the consent form. Note that video and audio clips cannot be de-identified, due to their nature. We will keep you updated with the project's progress, if you agree.

6. Are there any potential disadvantages or risks in taking part?

There are very few risks to completing this study, however there is a possibility that you may find the session emotionally distressing due to your own personal experiences. If at any point you feel uncomfortable or upset during the focus group, you are welcome to leave the session (either for a short period or permanently), without giving an explanation. If you leave the session early, we will contact you afterwards to check that you are alright and will offer to discuss anything with you if you would like this.

When collecting online data there is always a risk of a confidentiality breach. If a data breach is suspected, the University's Information Compliance Team and Information Security Team will be contacted immediately. Following the session, your data will be de-identified within 7 days and therefore it will no longer be possible to identify you from the data itself unless you have given consent for us to keep short recordings for project outputs.

7. Are there any benefits in taking part?

While there are no immediate direct benefits for those participating in this project, it is hoped that the research will help shape our understanding of what sensory environments most affect autistic people and to increase public awareness of sensory processing differences.

8. Expenses and payments

You will receive a voucher of £20 as a thank you for your time and expertise.

9. How will my data be used?

The information you provide during the study is the **research data**. Any research data from which you can be identified is known as **personal data**. The data we will collect that could identify you will be:

- Contact details
- Audio/video recording
- Age Range
- Gender
- Diagnosis of Autism and any other conditions

Your IP address will not be stored. We will take all reasonable measures to ensure that data remains confidential. Your contact details will only be used to schedule the focus group with you, and optionally to update you on the progress of the 'Sensory Street' project if you indicate you would like to hear about this. Identifiable data will be stored on password-protected University servers and computers. The responses you provide in the focus groups will be written out (transcribed) and identifying data will be removed. Anonymised transcribed passages will be used on publicity materials and reports of the study results. We will only use clips of audio/video recordings if you provide your explicit consent. All other audio and video recordings will be deleted after transcription. De-identified research data and consent records will be stored for ten years after publication or public release.

10. Who will have access to my data?

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is used in the study. The University will process your personal data for the purpose of the research outlined above. Research is a task that we perform in the public interest. Further information about your rights with respect to your personal data is available from <https://compliance.admin.ox.ac.uk/individual-rights>. Authorised individuals from the University may look at your data for audit purposes.

De-identified data will be shared with our collaborative team to support the design of an immersive public engagement event ('Sensory Street') to inform the public about sensory processing in autism. We will also share de-identified data with other researchers through an online repository so that it can be of greater scientific benefit.

11. Will the research be published?

The research may be published with open access in an academic journal and presented at conferences. The findings will also be used to create an immersive public engagement event to inform people about how sensory processing differences affect autistic individuals. This research project has associated social media accounts (e.g. Twitter, Instagram and Facebook) and the results of the project will be broken down into a series of posts that can be delivered over a period of several weeks.

12. Who is funding the research?

This research is funded by a Wellcome Trust Enriching Engagement Grant KCD00230.

13. Who has reviewed this study?

This study has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committee (Reference number: R74960/RE001).

14. Who do I contact if I have a concern about the study or I wish to complain?

If you have a concern about any aspect of this study, please speak to Catherine Woolley (Catherine.woolley@psy.ox.ac.uk) or Dr Cathy Manning (Catherine.Manning@psy.ox.ac.uk) and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please

contact the Chair of the Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible: Medical Sciences Interdivisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD

15. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Principal Investigator: Dr Cathy Manning

PI Contact Details: catherine.manning@psy.ox.ac.uk; sensorystreet@psy.ox.ac.uk

Phone Number: 01865 271442

Department of Experimental Psychology, Anna Watts Building, Woodstock Rd, Oxford OX2 6GG

Research and Engagement Officer: Catherine Woolley

Researcher Contact details: catherine.woolley@psy.ox.ac.uk; sensorystreet@psy.ox.ac.uk

Department of Experimental Psychology, Anna Watts Building, Woodstock Rd, Oxford OX2 6GG

Research Assistant: Keren MacLennan

Researcher Contact details: [to insert when Keren has her Oxford email address]

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