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SOCIAL MEDIA POSTS - 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 public about sensory processing in autism.

2. Why have I been invited to take part?

We are inviting autistic people above the age of 18 years to take part to respond to posts on social media regarding sensory experiences. Autistic people without a formal diagnosis of an autism spectrum diagnosis are welcome to take part.

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. You can ask questions about the research before deciding whether or not to take part. If you do decide to participate by responding to posts on social media, you are free to delete comments and likes at any point. Once two months after the date of the original social media post has passed, we will collect the comments and remove your name so that it will no longer be possible to remove your data from our dataset.

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

You will be invited to comment on social media posts generated and produced across a range of channels including Twitter, Instagram and Facebook. These posts will be phrased as questions or statements for you to interact with (such as adding your own experiences of an environment or activity).

We will collect the activity generated from these posts such as likes, comments and shares of these posts and remove identifying information. By interacting with the post, you consent to us collecting your responses to the information and using this for future materials associated with the research project. You

will be able to delete your posts or unlike comments if you do not wish for these to be used in the project for up to two months from the date of the original post (when the data will be collected and identifying information removed).

After the social media campaign is complete, we will be using the 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 may use your anonymised quotes from the social media posts as part of a video to help the public understand why the project is important.

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

There are very few risks to completing this study beyond those normally involved in social media use. All data will be de-identified after collection, however, when collecting online data there is always a risk of a confidentiality breach. If a data breach is suspected, the Information Compliance Team and Information Security Team will be contacted immediately.

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. What happens to the data provided?

Personal information such as your username or IP address will not be stored. We will take all reasonable measures to ensure that data remain confidential. The responses you provide will be stored in a password-protected electronic file and may be used in academic publications. Identifiable information will be deleted when written out. De-identified research data will be stored for ten years after publication or public release.

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.

9. Will the research be published?

The research will 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.

10. Who is funding the research?

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

11. 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).

12. 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 contact Catherine Woolley or Cathy Manning (sensorystreet@psy.ox.ac.uk / catherine.woolley@psy.ox.ac.uk / 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

13. Data Protection

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 is performed 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>.

14. Further Information and Contact Details

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

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