

AutSPACEs: Participant information sheet

Dr Bastian Greshake Tzovaras, Dr. Kirstie Whitaker, Georgia Aitkenhead, David Sarmiento and Sophia Batchelor

This document gives a brief overview of the project, including where to find more detailed information, as well as an outline of what to expect from contributing to AutSPACEs.

Purpose of the study

Many autistic people have sensory processing sensitivities and differences when compared to non-autistic people. These differences can make it difficult to navigate environments that were not built with autistic people in mind. For example, it can be stressful to take a busy train during rush hour, or to attend an appointment in a brightly lit hospital waiting room.

Every person is different. We want to gather many autistic people's stories together. Our goal is to 1) share them with people who have similar experiences, 2) educate neurotypical people on how they can better support autistic people, and 3) advise people on how they can design and adapt spaces to improve autistic people's lives.

The purpose of this study is to investigate sensory differences experienced by autistic people by collecting sensory processing experiences from autistic people in an ethical, participatory, citizen science-way.

"Citizen-science" is when non-professional scientists directly contribute to scientific research and are involved in the research process. This could be, for example, by performing tasks, analysing data, or contributing data.

An online "platform" is a way of collecting and sharing data from people.

Who is invited to contribute to the project?

The best research about autism is done in close collaboration with autistic people. Participatory citizen science is a way of doing research that involves many people contributing to the project. Citizen scientists do not have to be paid academic researchers (in fact most are not) and

participatory means that we will include a large and broad range of people, including non-professional scientists in the direction and design of the work.

We particularly invite autistic people and the carers and relatives of autistic people to contribute to the project. The eligibility criteria to be part of this study are that participants are over the age of 18 and have capacity to give informed consent.

Do I have to take part?

Taking part is entirely voluntary. You can withdraw at any time without having to give a reason.

What will happen if I choose to take part in a AutSPACES?

If you join AutSPACES you will be able to contribute your own stories around sensory processing experiences in text form, alongside recommendations of what would have made that experience better. Additionally, we ask you to fill in a small profile with demographic information (age, gender, whether you identify as autistic).

Entering any of these data is optional and participation more broadly is voluntary. For each story or experience you share you can choose whether you want to allow researchers to use this story for their research and/or if you want to make it publicly accessible for others to read as well.

If you choose to share your story for research, your story will be part of a research dataset alongside other people's experiences, and our research team at The Alan Turing Institute will be able to use that experience to learn about shared sensory processing challenges.

If you choose to make your experience public, your experience will first be checked over by a moderator to make sure it follows our content moderation guidelines. If you opt-in to receive notifications, we will let you know when a moderator has decided about your experience. If your story follows our code of conduct, it will be published anonymously on this website. Anyone will be able to view your story, but your name will be kept private. You can make this choice by checking the box 'share online with everyone'.

Both sharing for research and making stories are optional, you can also choose neither, in which case you can personally see your stories, but they won't be publicly listed or used for research.

For each of your stories you can always change your mind and edit/rewrite it, delete it or change your sharing settings at any time.

All your data and information will be handled according to The Alan Turing Institute Information Policy that you can read here <https://www.turing.ac.uk/data-protection-policy>

Will my taking part in this project be kept confidential?

Yes. Your email address and username are only stored on the Open Humans system, the AutSPACES team will not have access to it. Instead, the AutSPACES project only receives a randomized identifier that allows us to read & write your experiences into Open Humans, without receiving personal identifiable information.

If you decide to make a story publicly accessible, a moderator from our research team will review it in accordance to our content moderation guidelines, to amongst other things avoid that it contains personal identifiable information.

For stories that you select to be usable for research, we will not use direct quotations from it, unless the stories are also publicly shared. For non-public stories that are consented for research use, we will use the anonymous contact feature of AutSPACES to request your individual consent with the possibility to redact personal information before using any quotes.

What are the possible benefits of taking part?

By taking part in AutSPACES, you will be able to share your sensory processing experiences both for research and publicly. Writing up these stories can be a way to process past experiences to personally learn from them.

Regardless of whether you are taking part in AutSPACES by contributing stories, you will also be able to read publicly shared stories, which has the potential to be beneficial by learning from other contributors' adaptive techniques.

Are there possible disadvantages and/or risks in taking part?

Our goal is to learn from autistic people's experiences of challenges they have navigating environments that were not designed by or for autistic people. You may find it stressful or upsetting to remember and share these difficult experiences although this is not a necessary required. **If you do not wish to participate in any parts of AutSPACES, you do not have to.**

We have a [code of conduct](#) that applies to all online and in person interactions during the project. We are committed to ensuring that every member of our community is treated with respect.

Who is organising and funding the research?

The study is funded by Autistica and The Alan Turing Institute. The lead investigators are Dr. Kirstie Whitaker and Dr. Bastian Greshake Tzovaras.

Ethical review of the study

The project has been previously reviewed by the University of Cambridge Psychology Research Ethics Committee and subsequently by The Alan Turing Institute's Ethics Committee.

Contact for further information

You can contact Georgia Aitkenhead by email at gaitkenhead@turing.ac.uk for any further information.

If you feel that your query has not been properly addressed you may contact the project lead investigators: Dr. Kirstie Whitaker at kwhitaker@turing.ac.uk or Dr. Bastian Greshake Tzovaras at bgreshaketzovaras@turing.ac.uk.

If you have any concerns about how your data and information has been handled you can also get in contact with our Data Protection team at dataprotection@turing.ac.uk.