The Alan Turing Institute

AutSPACEs: Participant information sheet

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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 data collection

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 platform is to enable research on sensory differences experienced by autistic people by collecting sensory processing experiences from autistic people in an ethical, participatory way using a citizen science approach.

"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 aged 18 or over and have capacity to give informed consent.

This project is based in the United Kingdom and is mainly interested in the perspectives of participants based in the United Kingdom.

Do I have to take part?

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

If you withdraw consent all your shared data will no longer be available for further research. But research projects that have already accessed your data are unlikely to be able to redact it form their datasets, this is particularly true if any publications have been made.

What will happen if I choose to take part in 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, and 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 its use for research and/or if you want to make it publicly accessible for others to read as well.

If you **choose to share your experience for research**, your story will be part of a research dataset alongside other people's experiences that have also agreed for those experiences to be used for research. Our research team at The Alan Turing Institute will then be able to use that experience to provide some initial analyses and improve how AutSPACEs collects new experiences based on such data.

In the future, the AutSPACEs team could want to share those data with additional researchers or for more in-depth research. In such cases, the AutSPACEs team would inform you of those plans via the Open Humans messaging system, allowing you to change your consent if you wish to do so. We encourage you to monitor those messages from Open Humans and to remain registered to our newsletter to ensure you are kept up to date with proposals for new analyses of your data.

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.

The table below describes the proposed data processing that the AutSPACEs team will conduct on different categories of data:

	Public	Private
Shared for research	- Number of experiences & participants - User demographics - Thematic analyses (incl. direct quotations)	- Number of experiences & participants - User demographics - Thematic analyses (excluding use of direct quotes)
Not shared for research	Number of experiences & participants	Number of experiences/participants

Managing your data as a participant

You remain in control of your data. You can change edit and delete individual stories or experiences at any time. You can also change your sharing settings for each story at any time (e.g. revoking permission for research use for a given story). Please be aware that changing those sharing permission only affects the future use of a story, meaning that already published research findings won't be modified to remove your story.

You can also delete your complete AutSPACEs account along with all of your data or use the Open Humans system to revoke AutSPACEs' permissions to access your data going forward. 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.

The use of Open Humans as third-party data storage provider

Additionally to take part you will need to create a profile in a web platform called Open Humans (https://www.openhumans.org/). This platform allows you to control your personal data and limits the data that you have to share with us (AutSPACEs), you will need to share an email account with Open Humans and select a user name, no other identifying information is required

but you may choose to include in your profile. Open Humans in turn only shares a random 8 digit identifier and the data you introduce directly via AutSPACEs with us, no username, email or password is shared.

Open Humans is run by the US-based non-profit *Open Humans Foundation* and their platform has its own information policy (https://www.openhumans.org/data-use/) and [Record of Personal Data Processing Activities (⬚Open Human policies⬚https://www.openhumans.org/data-processing-activities/).](#) We have reviewed Open Humans policies and are satisfied they comply with our best practices and all applicable laws, yet you are encouraged to decide on your own whether or not to create a profile on Open Humans.

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 randomised 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. If we are not able to contact you we will not quote your story in our research outputs.

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.

Posts that are not in line with our content moderation guidelines will not be made publicly available. Our moderators will always exclude stories that contain racial slurs and any stories that discriminate or belittle individual people.

We do allow publication of some difficult content as we want members of our community to share all their experiences including the difficult ones. By default content that is moderated as "Amber" are hidden unless you opt-in to seeing them. You can choose to see stories about:
- Abuse (physical, sexual, emotional and verbal)
- Violence and Assault
- Drug and/or Alcohol use
- Mental Health Issues
- Negative body image

The content warning labels for each publicly available story are added by our content moderators. Details of that process are available in our moderator guidelines.

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 reviewed The Alan Turing Institute's Ethics Panel, with reference number: 24041012 .

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.