

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 your user testing session.

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 co-design and build a citizen science platform to investigate sensory differences experienced by autistic people, and to uncover the best research practices for ethical, participatory, citizen science.

"Co-design" means that the platform and framework will be designed in collaboration with project participants, such as yourself. The framework will lay out how the project will be managed and how the platform will be designed going forwards.

We cannot build this framework without the input of a diverse community of autistic people and their relatives and carers. In this study we will ask you about your experiences, priorities, needs and wants to co-design an online platform.

"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. This could be as simple as an online survey which asks questions and stores responses, or it could be much more

complex. The exact nature of the platform will depend on input from participants. That is why you are involved at the stage of designing and testing the platform.

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 User Testing Session?

User testing is a process where researchers will share a piece of technology with a person to gather their feedback and to observe their behaviour and see how easy or hard tasks are to perform.

For AutSPACES, user testing sessions will be in the form of an online video call via Zoom which we will schedule with you at a time that suits you. The session will be approximately one hour long, and we will record the session with your permission.

Before the session, you will be emailed this participant information sheet so you know what to expect as a participant, a consent form to sign, and details on how to join the session using Zoom. You will also be given the email address of two researchers so you can contact us if you have any questions, concerns or requests. We will always be flexible and try to help and support you to take part as best we can, and handle any complaints promptly and sensitively. During the session, a researcher will share the AutSPACES website with you. You will be asked some questions about the website and asked to do some tasks. The researcher will also take notes. This isn't to assess your ability to do the tasks, but to work out how easy the website is to use and how it can be improved. There are no wrong answers or actions.

We will give you £25 for your time in the form of a voucher. You can stop the session at any time without giving a reason if at any point you don't wish to continue, and you will still receive the vouchers.

We will deliberately select a diverse group of autistic people so that we can check how the platform works for a range of different people. This includes having a mix of ages, genders, and testing with people who have a variety of co-occurring conditions and accessibility requirements.

AutSPACES is an open community and everyone is welcome to contribute to the design of the website. You are always welcome to get in touch with the team to join in with the platform design even if you're not invited to do user testing.

After the session, if you give us permission, we will publish notes from the session on the project's dedicated GitHub repository, which is a public online tool we are using to build the AutSPACES website together and share information about the project. We will use these notes to make changes to the AutSPACES website to improve it for users like you. We will also give you the option to stay informed about the project by signing up to our newsletter or by joining our mailing list to be invited to our monthly open community meet-up sessions. We will also deliver your voucher using the details you gave us.

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. Only anonymized information will be made public by the research team, unless you explicitly request to be acknowledged.

What are the possible benefits of taking part?

You will be taking part in the **design phase** of the project in which we will consult with you on how to best design the platform to collect data and conduct the project going forwards. We will also ask you to use the platform and give us comments about what you like and dislike, and note any challenges you might have. We will only begin to collect data on sensory processing using the platform when it has been publicly launched.

By taking part, you will be able to directly influence the research process and elements of the design of the platform itself, so that they can be better suited to your needs. You will also be able to influence the participatory science research, which investigates best practice for conducting scientific research in a participatory way, and which could influence how other studies are conducted.

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 part of the user testing sessions. **If you do not wish to participate in any parts of the discussion, 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.

You can leave the meeting – and the discussion session itself – at any time without giving a justification. In case of online sessions, you may simply hang up, or switch off your video, microphone and/or audio if you need a break.

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.