

## **Autistica/Turing citizen science project: Participant information sheet**

***Kirstie Whitaker, Georgia Aitkenhead, James Cusack & Bethan Davies***

*This document gives a brief overview of the project, including where to find more detailed information.*

### **Purpose of the study**

Autistic people have sensory processing sensitivities and differences when compared to neurotypical 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 taking 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 framework for ethical, participatory, citizen science.** We cannot build this tool 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 the online 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 everyone has a say 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.

If you received a specific invitation to contribute to the project, that may be because you have volunteered to be contacted by Autistica for the purposes of research via the Discover Network or Insight Group and have responded to our advertisement of this opportunity.

### **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 to me if I choose to contribute to the project?**

*In person*

If you take part in an **in-person session**, you will be part of a discussion group with up to 16 participants, including autistic adults and the relatives and carers of autistic people. There will be at least two facilitators from the research team present. You can ask them any questions at any time.

If you take part in a **user testing session**, you will meet with one of the members of the research team to give feedback on an example that they have created. These sessions may happen in person or online via video conferencing software such as Zoom or Skype.

You will be given a **consent form** to sign as well as an invoice form at the beginning of the session. For online user testing sessions we will ask you to sign and email back the form. For either session, you will be paid for your time as well as for reasonable travel expenses. For a half-day session we pay £75, for a 1 hour session we pay £20.

During the session we will ask for your opinions on questions related to building the online platform. We will record and transcribe these sessions and extract high level summary information. You can find more information about what we do with the data we collect in person in the attached **Data Management** document.

*Online*

You are also welcome to contribute to the project **online** at any time. You can complete an “always open” survey via Google Forms: <https://goo.gl/forms/dDu0CDCLiXOm32GH3>. Or you can contribute to the development of the project at our GitHub repository: <https://github.com/alan-turing-institute/AutisticaCitizenScience>.

In the google form we ask three questions:

1. What information would you like us to know about your needs, priorities, desires and concerns for the citizen science platform?
2. Do you have a personal connection to autism?
3. Can we use the information you have provided to inform how we design and build the platform?

All the information you submit online may be made publicly available. You can find more information about what we do with the data you submit online in the attached **Data Management** document.

**Will my taking part in this project be kept confidential?**

Yes. Only anonymous information will be made public by the research team. You can find more information about what we do with your data in the attached **Data Management** document.

If you would like to be identified as the contributor, please see the **process for acknowledging contributors** section in the attached **Building a Safe and Valued Community** document.

General information about how the University of Cambridge uses personal data can be found at <https://www.information-compliance.admin.cam.ac.uk/data-protection/research-participant-data>.

### **What are the possible benefits of taking part?**

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.

### **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. It may also be stressful to hear others share their stories. **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. You can read it [online](#) or in the attached **Code of Conduct** document. We are committed to ensuring that every member of our community is treated with respect. You can read more about our values in the attached **Values and Outcomes** document.

#### *In person*

You may also find it hard to attend an in-person discussion session. Some participants find the rooms noisy, too bright or distracting. We will have multiple facilitators available to ensure all participants' needs are met – such as providing you with additional food or water, a quiet space to decompress, or access to the bathroom. We will adjust light and sound levels as requested by the participants to ensure you are comfortable during the session.

**You can leave the room – and the discussion session itself – at any time without giving a justification.** You will still be paid for your time and travel expenses.

### **Who is organising and funding the research?**

The study is funded by Autistica and the Alan Turing Institute. The lead investigator is Dr Kirstie Whitaker.

### **Ethical review of the study**

The project has been reviewed by the University of Cambridge Psychology Research Ethics Committee.

### **Contact for further information**

You can contact Dr. Kirstie Whitaker by email at [kwhitaker@turing.ac.uk](mailto:kwhitaker@turing.ac.uk) for any further information.