

Building a participatory citizen science platform to improve the lives of autistic people

Autistica/Turing citizen science project: Study protocol

Kirstie Whitaker, Georgia Aitkenhead, James Cusack & Bethan Davies

This document gives a brief overview of the project and is intended as a guide for the research team, including where to find detailed information in supplementary documentation.

Purpose of the study

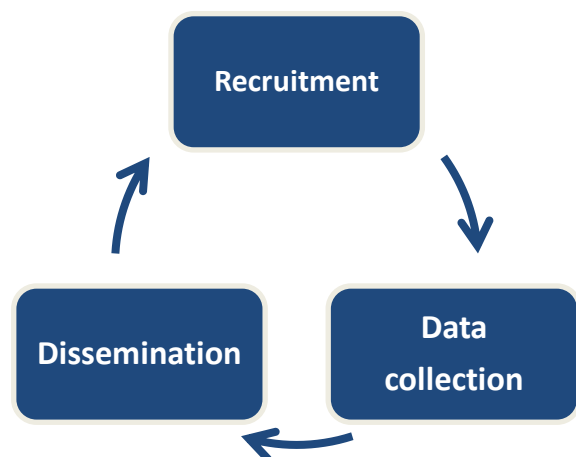
Autistic people have sensory processing sensitivities and differences when compared to neurotypical people. These differences can make it difficult to navigate environments that were not built with autistic people in mind. For example, it can be stressful to take a busy train during rush hour, or to 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 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 autistic people and their relatives and carers about their experiences, priorities, needs and wants to co-design the online platform.

Participatory science and using, creating and developing this protocol

Participatory science means that we will continually recruit autistic people, their relatives and carers, to collaborate on the project and make decisions about how it unfolds. We will be in continual communication with this community of people to collect feedback and disseminate results. The protocol is therefore not a linear process, it is circular and iterative, and will be adapted as we receive community input. This protocol should be considered a living document. All recommendations and changes will be tracked and incorporated in line with the project's findings.



Recruiting Contributors

Who is invited to contribute 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. That means anyone can choose to be part of the study – but for this project to be successful we will need to recruit three (potentially overlapping) groups:

1. Autistic people, their relatives and carers

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. For this project we will recruit autistic people, their relatives and carers, into decision-making and direction-setting positions as well as asking them about their experiences and testing our work with them. All outputs from the project should include an autistic co-author.

2. Developers

Because the platform is being built entirely open source, developers from anywhere in the world and of any background are free to contribute to the code via the project's dedicated [GitHub repository](#), providing they follow our code of conduct (**A2_CodeOfConduct.pdf**).

3. People able to directly implement social change

This includes, for instance, policy workers in government, managers of public services, commissioners, local authorities, public research funders, employers, head teachers, and architects.

Entry points to joining the community

To invite people to join the community of contributors, you should encourage them to:

- Join the dedicated project mailing list:
<https://tinyletter.com/AutisticaTuringCitizenScience>.
- If they are autistic, or the relative or carer of an autistic person, and over the age of 18, invite them to join Autistica's Discover Network or Insight Group.
<https://www.autistica.org.uk/get-involved/take-part-in-research>. More information about recruitment can be found on Autistica's webpages:
<https://www.autistica.org.uk/get-involved/take-part-in-research> and their insight Group Recruitment Form: **A5_AutismInsightGroupRecruitmentForm.pdf**
- Give feedback via the online google form: <https://forms.gle/3eUs9p39SNNcHgXy9>.
- If they feel comfortable, contribute directly via the GitHub repository:
<https://github.com/alan-turing-institute/AutisticaCitizenScience>.

Recruiting contributors for in-person sessions

The following steps outline the process for recruiting contributors for in person sessions.

1. Bethan Davies, Autistica's Discover Co-Ordinator, will send specific invitations to members of Autistica's Discover Network or Insight Group. The eligibility criteria are that participants must be over the age of 18 and must be either autistic or the carer or relative of an autistic person. You can invite people who meet these criteria to join by directing them to Autistica's webpages: <https://www.autistica.org.uk/get-involved/take-part-in-research>, or to the Insight Group recruitment form (**A5_AutismInsightGroupRecruitmentForm.pdf**). The initial email communications will be sent by Bethan Davies. This is our preferred route to recruitment for in-person sessions for the project. Members of the Discover Network or Insight Group may ask to be removed from the database at any point by contacting Bethan Davis at discover@autism.org.uk.
2. People can also become collaborators by responding to invitations sent through our dedicated project mailing list (<https://tinyletter.com/AutisticaTuringCitizenScience>). The mailing list is managed by MailChimp, and their privacy policy can be found at <https://mailchimp.com/legal/privacy>. Members of the mailing list are asked to confirm their subscription through a two-stage process and may remove themselves at any time. The contact information provided may be accessed by members of the research team. It is never removed from the MailChimp platform. We expect to send one mailing list update per month.
3. Invite a diverse and representative group to sessions. Effort should be made to be inclusive of a diverse population. This includes representing ethnic and socio-economic diversity, diversity of gender identification and sexual orientation, representing people from across the autistic spectrum, and being inclusive of people with caring responsibilities and people with disabilities. Groups should include a mixture of autistic people and families and carers of autistic people. Make sure that autistic people are well represented by using the reported "autism diagnosis" field in the Discover Network form.

Recruiting contributors for online participation

1. For online recruitment, you can encourage people to openly share their feedback and suggestions via social media, our GitHub repository or the "always open" the google form as listed above.
2. Regularly remind participants that their contributions via the online google form is anonymous and to contact Georgia Aitkenhead by email (gaitkenhead@autistica.ac.uk) if they wish to be publicly acknowledged for their contribution.
3. Invite participants to sign up to the [project mailing list](#) for regular updates.

Collecting community recommendations and feedback

In-person discussion sessions

The following section outlines the steps that the team should take before, during and after an in-person discussion session. For more information about how to manage data collected from in person sessions please see **A8_DataManagement.pdf**.

Before

1. Find a location for the discussion session. Pay particular attention to making sure that it can be accessed outside of peak travel hours. In addition to the main area where the session will be held, make sure that there is a designated private, quiet space where participants can go if they need a break from the session.
2. Make sure that the lead researcher at any focus group has a current disclosure or barring service (DBS) or Disclosure Scotland certificate, and that there is at least one additional facilitator who can be present for the session.
3. Select a diverse group of participants, as described above. Keep the groups for discussion sessions small: ideally no more than 7 and up to a maximum of 16.
4. Email a copy of the consent form (**A6_ConsentForm.pdf**) and the following appendices to the session participants:
 - Participant information sheet (**A7_ParticipantInformationSheet.pdf**),
 - Code of conduct (**A2_CodeOfConduct.pdf**)
 - Guidelines for building a safe community (**A4_BuildingASafeCommunity.pdf**)
 - Data management guidelines (**A8_DataManagement.pdf**)
 - Payment form

Include in the email an outline of the schedule for the day as well as clear directions to the venue and to the specific meeting area within the venue. If possible, include images to guide participants.

5. Print out physical copies of the consent form (**A6_ConsentForm.pdf**), Participant information sheet (**A7_ParticipantInformationSheet.pdf**) and payment forms for every participant.
6. Print out 5-10 copies of each of the other documents (**A2_CodeOfConduct.pdf**, **A4_BuildingASafeCommunity.pdf** & **A8_DataManagement.pdf**) to give to participants for their reference on request.

During

1. Make sure all participants are offered a glass of water and shown where the toilets are before the sessions begins.
2. Give a physical copy of the consent form (**A6_ConsentForm.pdf**), participant information sheet (**A7_ParticipantInformationSheet.pdf**) and payment forms to every participant as they arrive.

3. Give every participant post-it notes and writing materials.
4. Ask participants what you can do to make them more comfortable in the session, such as adjusting temperature, light, or sound levels, and follow their requests where possible.
5. Explain to all participants what the session will involve and remind them that they can end the session at any time without having to give a reason. Explain that they do not need to answer any questions which they do not want to answer.
6. Tell participants that if they have something they want to share but don't want to do so out loud, they can write it down on the post-it notes available and the researchers will collect in the information and include it after the sessions ends.
7. Explain that they have the option of emailing one of the facilitators if they have any additional points that they would like to share after the session ends.
8. Let them know that there is a space available if they need to go somewhere private, and that they can go there themselves or ask to be escorted there at any time. Tell them that they can ask the facilitators questions or raise issues with them at any time.
9. Explain to participants that if they have a concern or a complaint, they can speak privately to one of the researchers, and that if they have a complaint about one of the researchers they can contact Autistica's Director of Science, Dr. James Cusack, directly. If they need more information, refer them to the safeguarding section of **A4_BuildingASafeCommunity.pdf**.
10. Ask the participants to read the participant information sheet and complete the consent form and payment form. Let them know that you have printed copies of the other documents if they would like one. Make clear that they can ask any questions.
11. Explain that the session will be recorded from this point onwards, and that the content of the recording will be deleted after it has been transcribed by either a professional transcriber or a member of the research team. Remind participants that they do not need to continue to if they do not feel comfortable with a recording being made of the session.
12. After the session has finished, gather together the handwritten notes and all forms and invoices.

After

1. File the consent forms and invoice forms securely in Autistica's London offices.
2. Pay participants for their time directly into the participants bank account, using the invoicing details they provided in the session.
3. Do not share recordings of the session or the handwritten notes beyond the core researchers of the project (other than with professional transcribers).
4. Either make a complete transcript of the session, redacting any explicitly identifying details (such as address, child's school, or employer), or anything participants have specifically asked to be discounted, or send the recording to professional transcribers

for transcription. Include in the initial transcript the proportion of autistic and non-autistic members of the group. Identify in the transcript speaking participants as autistic or the relative or carer of an autistic person, but do not identify them by name.

5. As soon as the transcription has been made, destroy the original recordings. Do this within 3 months of making the recordings.
6. Keep the anonymised transcripts on Autistica and The Alan Turing Institute's servers and do not share beyond the core research team.
7. Extract high-level themes from the transcripts and incorporate the handwritten notes and any emailed feedback from participants. This can include quotes.
8. Send high-level themes to all session participants and the core research team. Make clear in the email that participants have two weeks to request comments are redacted or rephrased.
9. Redact or rephrase the summary document according to the participants request and in line with the code of conduct (**A2_CodeOfConduct.pdf**).
10. After four weeks make the summary document public at the project's dedicated [GitHub repository](#). The summary document will remain publicly available, and licensed for reuse by anyone, so long as they credit the Autistica/Turing citizen science community.

In-person and video conferencing for 1:1 user testing

The following section outlines the steps that the team should take before, during and after an in-person or video conferencing 1:1 user testing session. For more information about how to manage data collected from in person sessions please see **A8_DataManagement.pdf**.

Before

1. Select your participant as described above. Be as considerate as possible about making sure that the participants represent the diversity of the autistic community and their family and carers. Be as flexible as possible in meeting the participant's preferred time as this will aid in building diversity in the user testing cohort.
2. Email a copy of the consent form (**A6_ConsentForm.pdf**) and the following appendices to the session participants.
 - Participant information sheet (**A7_ParticipantInformationSheet.pdf**),
 - Code of conduct (**A2_CodeOfConduct.pdf**)
 - Guidelines for building a safe community (**A4_BuildingASafeCommunity.pdf**)
 - Data management guidelines (**A8_DataManagement.pdf**)
 - Payment form

Include in the email an outline of the schedule for the 1:1 session as well as clear directions to the venue or connection details for online sessions. If possible, include images to guide participants, for example on how to find the specific location or how to use the video conferencing software.

3. If the session is in person, print out physical copies of the consent form (**A6_ConsentForm.pdf**), Participant information sheet (**A7_ParticipantInformationSheet.pdf**) and payment forms.

During

1. If the interview is in person, make sure the user tester is offered a glass of water and is shown where the toilets are before the sessions begins.
2. If the interview is in person, give a physical copy of the consent form (**A6_ConsentForm.pdf**), participant information sheet (**A7_ParticipantInformationSheet.pdf**) and payment form to the user tester.
If the interview is via video conferencing, talk the user tester through how to sign these documents virtually.
3. Ask the user tester to read the participant information sheet and complete the consent form and payment form. Let them know that you have printed copies of the other documents if they would like one. Make clear that they can ask any questions or raise concerns at any time.
4. Ask the user tester what you can do to make them more comfortable in the session, such as (for in person sessions) adjusting temperature, light, or sound levels, and follow their requests where possible.
5. Explain what the session will involve and remind the user tester that they can end the session at any time without having to give a reason. Explain that they do not need to answer any questions which they do not want to answer.
6. Explain that if they have a complaint with the interviewer they can contact Autistica's Director of Science, Dr. James Cusack, directly. If they need more information, refer them to the safeguarding section of **A4_BuildingASafeCommunity.pdf**.
7. Explain that they have the option of emailing one of the facilitators if they have any additional points that they would like to share after the session ends.

After

1. File the consent forms and invoice forms securely in Autistica's London offices.
2. Pay participants for their time directly into the participants bank account, using the invoicing details they provided in the session.
3. Make notes on insights gathered from the session ensuring that they do not contain any personally identifying information.
4. Send summarised insights from sessions to the user tester and the core research team.
5. Allow the user tester two weeks to request comments be redacted or rephrased.
6. Redact or rephrase the summary document according to the participants request and in line with the code of conduct (**A2_CodeOfConduct.pdf**).

7. After four weeks make the summary document public at the project's dedicated GitHub repository (<https://github.com/alan-turing-institute/AutisticaCitizenScience>).
8. The summary document will remain publicly available, and licensed for reuse by anyone, so long as they credit the Autistica/Turing citizen science community.

Online via Google forms

The following section outlines the steps that the team should take before, during and after collecting information via the “always open” google form online. For more information about how to manage data collected online please see **A8_DataManagement.pdf**.

Before

Note that as this form is “always open” this should only need to be done once unless the form is being updated.

1. Anyone is welcome to contribute to the project **online** at any time by completing an “always open” survey via Google Forms: <https://goo.gl/forms/dDu0CDCLiXOm32GH3>
2. Seek consent for the information provided to be made public before any data is collected (this a prerequisite question and the final question in the google form).
3. The google form asks three questions:
 - What information would you like us to know about your needs, priorities, desires and concerns for the citizen science platform?
 - Do you have a personal connection to autism?
 - Can we use the information you have provided to inform how we design and build the platform?
4. Ensure that the online environment where the survey is accessed includes prominent links to:
 - **A2_ValuesAndOutcomes.pdf**
 - **A3_CodeOfConduct.pdf**
 - **A4_BuildingASafeCommunity.pdf**

After

1. The data is stored in Google Drive cloud servers. Only members of the core research team should access it.
2. Check the data from Google Forms at least twice a week.
3. Download the data and read all new contributions.
4. Redact publicly identifying information, such as names and locations. If any contributor submits personally identifying information about another person this should also be redacted.

5. After they have been read and redacted, publish the data collected at the project's [GitHub repository](#).
6. When requests are received via email to de-anonymise contributions, update the project's [contributors.md](#) page within one week of receiving the request.
7. The data will remain publicly available, and licensed for reuse by anyone, so long as they credit the Autistica/Turing citizen science community.

Online via GitHub

The following section outlines the steps that the team should take before, during and after collecting information via GitHub. For more information about how to manage data collected online please see **A8_DataManagement.pdf**.

Before

1. Anyone is welcome to contribute to the project online via our [GitHub repository](#). GitHub's privacy statement can be found at <https://help.github.com/en/articles/github-privacy-statement>. Contributions to the repository are public and associated with the GitHub account of the contributor.
2. Ensure that the project's GitHub repository includes prominent links to:
 - a. **A2_ValuesAndOutcomes.pdf**
 - b. **A3_CodeOfConduct.pdf**
 - c. **A4_BuildingASafeCommunity.pdf**

During

1. Check GitHub at least twice a week and respond to comments, questions, and requests from the community.
2. Refer to: **A4_BuildingASafeCommunity.pdf** and **A3_CodeOfConduct.pdf** to decide if any comments need to be removed or redacted, and refer to the safeguarding procedures in **A4_BuildingASafeCommunity.pdf** for handling concerns and complaints about behaviour in the GitHub community.
3. Redact any comments which contravene our code of conduct (**A3_CodeOfConduct.pdf**). This includes undermining, prejudicial, or abusive comments.
4. Contributors can directly submit a request on GitHub to the repository's moderators if they want to be acknowledged on the [contributors.md](#) file.
5. Direct contributors to the safeguarding procedures in **A4_BuildingASafeCommunity.pdf** if they wish to raise concerns themselves.

After

1. The data will remain publicly available, and licensed for reuse by anyone, so long as they credit the Autistica/Turing citizen science community.

Dissemination of findings and ongoing communication with contributors

The following section outlines the steps that the team should take to disseminate findings and maintain strong multi-directional communication with our contributors.

- Approximately once per month, email regular updates in the form of a newsletter to:
 - Everyone who has subscribed to the project's mailbox
 - Anyone from the Discover or Insight Group who has been previously involved in the project, unless they have requested not to be contacted for this purpose.

These newsletters should be developed openly on GitHub, archived regularly, and make easy to re-read for new contributors to the project.

- Openly publish important documentation relating to the project on the project's GitHub repository and keep the documents updated.

Encourage comments (in line with our code of conduct, **A3_CodeOfConduct.pdf**) on all documentation.

- Updates can also be shared on social media, our GitHub repository, and via project pages on the Turing Institute and [Autistica's](#) webpages. If appropriate, capture these updates in the GitHub repository for long term curation.