Information sheet: Data collection, processing, and holding

This document outlines how the research team, led by Dr Kirstie Whitaker, will manage our participants' and contributors' data as contributions to the Autistica/Turing Citizen Science community. It details the data we collect, what we do with it and why we collect it.

<u>In Person</u>

We recruit for our in-person sessions from Autistica's Insight Group and Discover Network (https://www.autistica.org.uk/get-involved/take-part-in-research). Individuals can voluntarily sign up and there is a brief application process. They are given an application form to fill out and our Discover Network Co-Ordinator, Bethan Davies, contacts them once she has received the application.

The personal and contact details as well as some demographic information from the application form are held securely by Autistica. Autistica use the contact details provided to contact the participant with project updates and opportunities from across Autistica's research network. We use this information to invite a diverse and representative group of participants to the participatory science sessions. For example, we make sure that autistic people are well represented at these sessions using the reported "autism diagnosis" field on the form. Members of the Discover Network or Insight Group may ask to be removed from the database at any point by contacting Bethan Davies at discover@autistica.org.uk.

We use the contact details to send joining instructions for in-person sessions, including location, directions, and what to expect on the day. The in-person sessions are groups of up to 16 participants and researchers to discuss topics relevant to the Citizen Science Project. Participants are given a consent form to sign and return to the researchers, as well as an invoicing form. We use the details provided on this form to pay participants for their time after the session has finished. They are paid directly into the participant's bank account. The consent form and invoice form are filed securely in Autistica's London offices.

Recordings are made of the sessions. They are shared with the core researchers of the project and are destroyed after they have been transcribed. This will be a maximum of 3 months after the recordings have been made. Verbatim transcripts are made by either researchers or transcribers, with the names and any explicitly identifying details (such as address, child's school, or employer) redacted. The anonymised transcripts are kept on Autistica and The Alan Turing Institute servers and only shared with the core research team. These transcripts will be deleted at the end of the research collaboration period between the Turing Institute and Autistica (currently March 31 2021).

High-level themes from the transcripts, including some quotes, are sent to all session participants and the core research team. Participants have two weeks to request comments be redacted or rephrased. Our goal is to make sure that all participants are comfortable with the publicly released summary document. After two weeks the summary document is made public at the project's dedicated GitHub repository (https://github.com/alan-turing-institute/AutisticaCitizenScience). The information is used to design and build the

participatory science platform, and the themes along with selected quotes may be used in published research papers. 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

Contributions to the project can be made via GitHub at the project's dedicated repository (https://github.com/alan-turing-institute/AutisticaCitizenScience). Participants must have a GitHub account. GitHub's privacy statement can be found at https://help.github.com/en/articles/github-privacy-statement. Contributions to the project repository are public and associated with the GitHub account of the contributor.

Our designated moderator will redact any comments which contravene our code of conduct. This includes undermining, prejudicial, or abusive comments. If participants would like comments made by others to be redacted or removed they can contact the moderator directly, who will make an assessment based on our code of conduct and act accordingly. All other contributions remain publicly available. All information within the GitHub repository is publicly available, and licensed for reuse by anyone, so long as they credit the Autistica/Turing citizen science community.

Contributions may also be made via Google Form (https://goo.gl/forms/dDu0CDCLiXOm32GH3). Google's privacy statement can be found at https://policies.google.com/privacy. Consent is sought for the information provided to be made public before any data is collected. We do not elicit any identifying information or ask for contact details via Google Form. The data is stored in Google Drive cloud servers and will be accessible by the core research team. A member of the research team will personally assess all submissions and redact any names or locations to ensure the text is as anonymous as possible. They will also redact any content which contravenes our code of conduct (for example, sharing personally identifying information about someone else). The submitted, assessed information is made publicly available in our GitHub repository. Information within the GitHub repository will remain publicly available, and is licensed for reuse by anyone, so long as they credit the Autistica/Turing citizen science community.

Mailing list

Members of the Autistica/Turing citizen science community may join a mailing list to receive monthly updates from the project at 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.
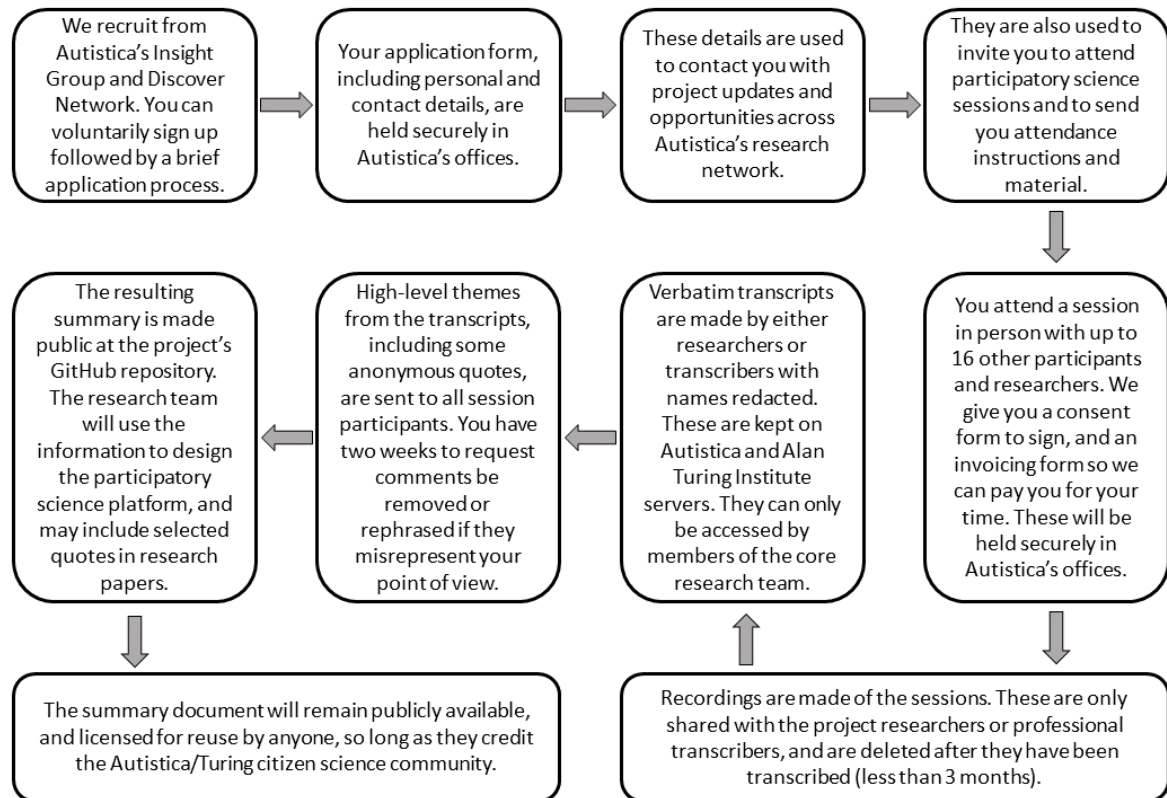
We recruit from Autistica's Insight Group and Discover Network. You can voluntarily sign up followed by a brief application process.

→ Your application form, including personal and contact details, are held securely in Autistica's offices.

→ These details are used to contact you with project updates and opportunities across Autistica's research network.

→ They are also used to invite you to attend participatory science sessions and to send you attendance instructions and material.

The resulting summary is made public at the project's GitHub repository. The research team will use the information to design the participatory science platform, and may include selected quotes in research papers.

← High-level themes from the transcripts, including some anonymous quotes, are sent to all session participants. You have two weeks to request comments be removed or rephrased if they misrepresent your point of view.

← Verbatim transcripts are made by either researchers or transcribers with names redacted. These are kept on Autistica and Alan Turing Institute servers. They can only be accessed by members of the core research team.

You attend a session in person with up to 16 other participants and researchers. We give you a consent form to sign, and an invoicing form so we can pay you for your time. These will be held securely in Autistica's offices.

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

Recordings are made of the sessions. These are only shared with the project researchers or professional transcribers, and are deleted after they have been transcribed (less than 3 months).

Figure 1 Data collection, processing and holding pathway for in-person events

Contribute Directly via GitHub

You create a GitHub Account and make contributions via the project's dedicated GitHub repository.

↓ Your contributions are immediately public and associated with your GitHub account.

↓ Our designated moderator will redact any comments which contravene our code of conduct. This includes undermining, prejudicial, or abusive comments.

↓ If you would like comments made by others to be redacted or removed you can contact the moderator directly, who will make an assessment based on our code of conduct and act accordingly.

Contribute via Anonymous Google Form

We ask for your consent for the information you provide to be made public before any data is collected. We will not elicit any identifying information or ask for contact details.

↓ The data is stored in Google Drive cloud servers and can only be accessed by members of the core research team.

↓ A member of the research team will personally read all submissions and redact any names or locations to better anonymise the text. They will also redact any content that violates our code of conduct (for example, sharing personally identifying information about someone else).

↓ The reviewed information is made publicly available in our GitHub repository.

Information within the GitHub repository will remain publicly available, and licensed for reuse by anyone, so long as they credit the Autistica/Turing citizen science community.
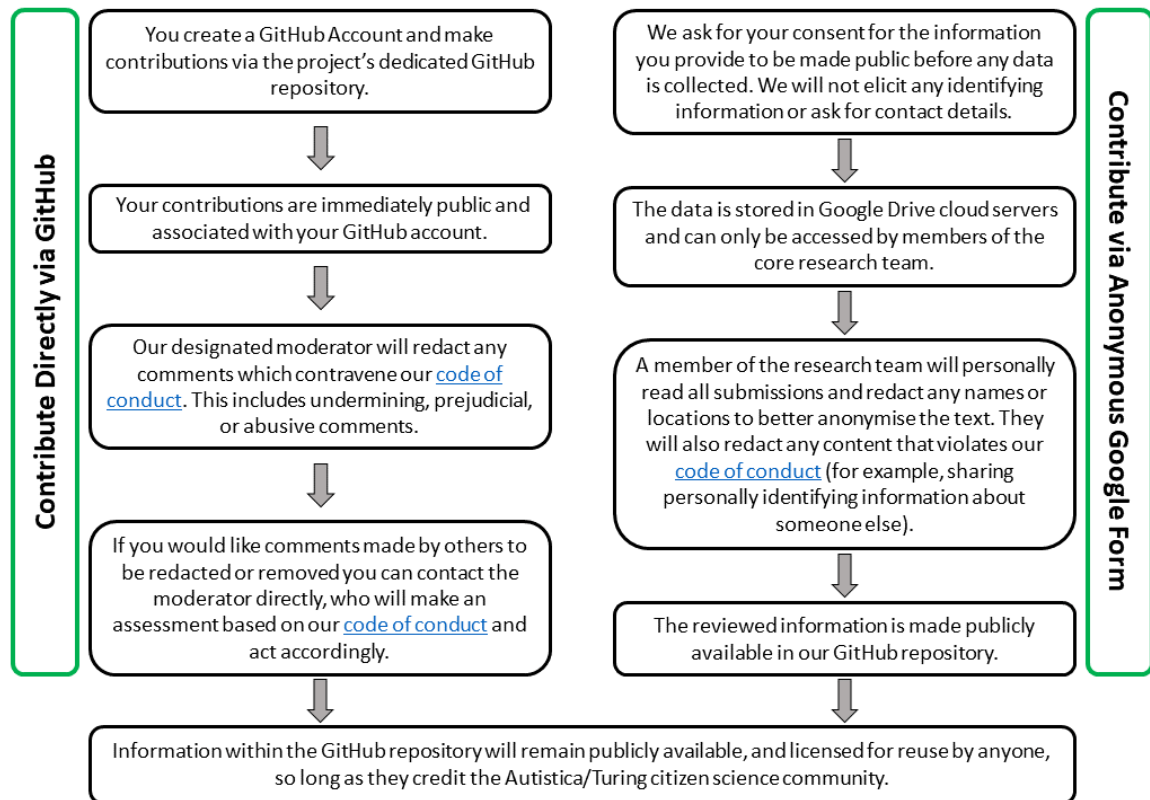
Figure 2 Data collection, processing and holding pathway for online contributions