Autistica/Turing citizen science project: Values and projected outputs

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This document outlines the values for the project and the projected outputs.

Values

Impact: We will strive towards increasing knowledge and providing solutions which will help to create longer, healthier, and happier lives for autistic people and their families. We will aspire to maximise the impact that we have on the lives of autistic people, both immediately and in the long term. We will ensure that our solutions are sustainable, appropriately resourced, and underpinned by outstanding science. We will pursue opportunities and innovations which will allow us to maximise impact.

Participatory Science: Community involvement will be integral to the conception and evolution of the project as well as the iterative design of the platform we create. We will involve members of the autistic community as co-collaborators and strive to diminish distance between researcher and researched. We will partner with members of the autistic community in designing the content, form, direction, and methodologies of the project throughout. We will continuously collect feedback on the project and implement changes to our policies to ensure we follow the standards of best practice as they adapt and evolve.

Transparency: We will be transparent about the aims of the project, its priorities, and its ongoing progress. We will be upfront with all participants about our intentions for the project when they are first involved and will also keep participants continually updated as the project progresses, as long as they agree to be contacted again for this purpose. We will also publicly publish updates and results on an ongoing basis.

Protection and Consent: We will rigorously uphold high standards of data protection. We will ensure that consent is always actively sought when we are requesting input from participants, and that we remind them of their right to withdraw from future participation at any point. We will develop, create, and maintain fine-grained consent models which will allow participants to have control over how their data is used and how it is shared. Unless the participant has provided explicit permission, all sensitive information and identities will be kept secure.

Open Source: All source code that we generate during the project will be made available under a free and open source license, and will be available to be used, changed, or shared by anyone free of charge. We believe that open source working will encourage more rapid innovation, collaboration, and community support.

Diversity and Inclusion: We are dedicated to diversity and inclusion. We will endeavour both to remove barriers to inclusion wherever we encounter them, whether they be direct or indirect, and to proactively support the inclusion of diverse groups. This includes creating and maintaining an environment which is supportive of difference. We will neither

discriminate nor tolerate any discrimination on the basis of race, gender identification, neurodiversity, or sexual orientation. We are committed to equity for all.

Respectful Conduct: We will treat each other with mutual respect and acceptance. We will strive to be empathic towards one another and will not undermine each other or belittle opinions which differ from our own. We will not tolerate any forms of bullying or harassment. We will ensure people have the means to raise any problems or concerns they may have and will make sure they are not either directly or indirectly prevented from reporting bullying or harassment. Any member of the community – including citizen scientists, developers, researchers, and members of Autistica or the Alan Turing Institute – will be asked to end their participation in the project if they persist in bullying or harassing behaviour. We will conduct ourselves with care for others and professionalism.

Outputs

Platform: an online platform where citizen scientists can upload their experiences of navigating the environment. It will be open source and openly developed from the start of the project. The platform will be scalable to accommodate at least 1000 active users (hopefully more). It will be collaboratively developed to include a user-friendly interface interacting with a structured and secure database. Our timeline projects a minimum viable product available in autumn 2019, with the main platform launched in January 2020. The platform will be iteratively improved based on user feedback.

Dataset: a curated dataset that has informed consent from participants of the citizen science project that can be shared with researchers for future work. The data will be kept secure and only made available under managed access. The consent model that will be developed in early 2019 will ensure that contributors to the project are able to control which research partners are able to access their data and for what purpose.

Community: two – hopefully overlapping – communities will be built and supported over the course of the project. One will focus on communicating shared experiences between autistic citizen scientists and readers of the experiences on the platform. The other will consist of contributors to the open source platform, building a community of designers, software developers and data scientists in conversation with autistic collaborators.

Publications:

- **Position paper:** a peer-reviewed academic article laying out the values, incentives, structures, and requirements of a platform to conduct citizen science on autistic people's experiences navigating their environment. This will also include a fine-grained consent model based on input from the autistic community. Our timeline projects submission of this paper by 31 May 2019.
- **Presentation paper**: a peer-reviewed academic article presenting the final platform and reporting on lessons learned in building a citizen science project to share autistic people's experiences navigating their environment. This will cover the successes and challenges of a fine-grained consent model, a report on the communities built over the course of the project and the open source software developed to support the platform. Our timeline projects submission of this paper in summer 2020.

- **Research paper**: a peer-reviewed academic article presenting the outcome of results of an analysis to understand and communicate how autistic people navigate their environment. This will be conducted in collaboration with other research groups. Our timeline projects that this project will start in autumn 2020 and be submitted for publication in winter 2021.