Citizen science platform with Autistica Impact Report – December 2020

Contents

Purpose

To present progress to date of the support of the Citizen Science Platform

Background

Fujitsu selected a new charity partner from January 2019 for a 2-year relationship. This opportunity was specifically for a small charity to provide them with step changing support that enables them to have a transformational impact. Collaborating with a great charity partner helps bring a powerful dimension to our community pillar within our Responsible Business Framework. The benefits back to the company drive employee engagement, support employee wellness and help us learn more about a specific issue.

We want Autistica to help Fujitsu deliver on this commitment by learning more about autism and how we can support employees who have autistic family members as well as enabling more people with autism to work.

Autistica has four main strategic priorities:

To gather information to help understand how autistic people's sensory differences affect how they navigate different environments.

To offer support for autistic people and their families and carers to help them navigate different environments and understand responses to different sensory stimuli.

To raise the visibility of Autistica, promote the need for research and encourage sign up to the Discover Network and to encourage wider empathy for autistic people's experiences.

To provide an opportunity for autistic people to connect with others with similar experiences. To build a community where experiences and ideas can be shared.

Numerous studies have confirmed that autistic people experience sensory processing differences, and that this can significantly impact their lives. One aspect, which is not yet fully understood, is how these differences affect the ways in which autistic people navigate different environments. Using participatory methods, this project will build a citizen scientist platform, which will collect rich information about people's experiences navigating the world. The data can be used to improve public and private spaces for autistic people, educate the public, and help create strategies to cope with, and remove, barriers autistic people may face.

Explaining the science

Autism

Autism is a spectrum of developmental conditions. Around 1/100 people in the UK are autistic. More information is available at **Autistica's website**.

Citizen science

Citizen Science is when non-professional scientists contribute directly to scientific research. This could be, for instance, by contributing data or performing tasks.

Participatory science

Participatory science means that members of the affected community are directly involved in research as more than research subjects: they are active contributors on a number of levels, for instance by setting direction, having influence over critical decisions, or designing the procedures and modes of the study itself.

Open source

Open source refers to software which is released under an Open Source License, meaning that anyone is free to reuse, modify, share, and build upon the code. The code is often built collaboratively and openly with a range of volunteers.

The project is split into two separate Open Source, Public Github repositories:

- AutisticaCitizenScience (https://github.com/alan-turing-institute/AutisticaCitizenScience): Holds project management documentation.
- AutisticaPlatformPrototype (https://github.com/alan-turing-institute/AutisticaPlatformPrototype): Stores the technical source code to the platform prototype.

We are also using Open Humans https://www.openhumans.org

Project aims

Understanding sensory processing differences in autism was one of the autistic community's top ten research priorities, identified in the **2016 James Lind Alliance priority-setting partnership led by Autistica**.

To help investigate this issue, an online, citizen science platform will be built to gather information at scale on experiences of sensory processing and navigating different environments. This will increase understanding of sensory processing in a way, which improves the daily lives of autistic people. The project will be participatory from the ground up. All aspects of the project will be designed and developed in collaboration with members of the autistic community.

The platform will be developed under a free and open source license and all software, and design and process documents, will be made open. Integral to the project will be building and providing citizen scientists with a fine-grained consent model that supports individual contributor's personal preferences on how their data is used on the platform. The project aims to empower everyone in supporting autistic people and their families in living long, healthy, happy lives.

Ultimately, the platform, the fine-grained consent model, and the participatory practice developed, will be able to be adapted for subsequent research. The aspiration is to be at the forefront of change in creating the groundwork for more thoroughly participatory and empowering science.

Applications

This work has a number of directly impactful applications. The data collected can be used to better modify public and private spaces, such as workplaces, schools, hospitals, and public transport, so that they are more accessible (and enjoyable) for autistic people and their families. It can also be used to educate non-autistic people about the experiences of autistic people, so that they can modify their own behaviour, respond to autistic people with greater understanding, and are more able to offer support. Additionally, it can be used to create personalised recommendations and strategies for coping with different environments based on connecting people with others who have had similar experiences.

The platform created will be easy to modify to answer other research questions. The fine-grained consent model can also be adapted for other research projects, allowing for a more individually nuanced and empowering way of collecting data for scientific research. The project will result in a framework for doing science in a way which is open and participatory, and the experiences and learning from carrying it out will be used to help guide fellow and future practitioners.

Fujitsu Support

Fujitsu helped in designing the "front-end" interface for the platform, and Open Humans will be used for the "back end of the platform.

Fujitsu designed using open source using GitHub.

Fujitsu adopted an 'Agile' methodology for managing our part of the project: this involved building the interface in lots of stages, starting with the minimum requirements, testing, and improving on the basis of repeated feedback.

Fujitsu provided a checkpoint and update every 3 weeks – which included a short demo video a sprint Report.

Sprint Reports

https://github.com/alan-turing-institute/AutisticaCitizenScience/tree/master/project-management/sprint-reports

Autistica CSP Sprint 1 Demo Video

https://www.youtube.com/watch?v=4f6kn5HLysc

Autistica CSP Sprint 2 Demo Video

https://www.youtube.com/watch?v=A_6uOwFZRfo

Autistica CSP Sprint 3 Demo Video

https://www.youtube.com/watch?v=IG-Vq8m8ELA

Autistica CSP Sprint 4 Demo Video

https://www.youtube.com/watch?v=oN9zw1tBJRE

Autistica CSP Sprint 5 Demo Video

https://www.youtube.com/watch?v=GWvf1KbF5GE

Autistica CSP Learn More Promo

https://www.youtube.com/watch?v=T4SPTKijxqw

Autistica CSP Sprint 6 Demo Video

https://www.youtube.com/watch?v=UAon_KHBaMM

Autistica CSP Sprint 7 Demo Video

https://www.youtube.com/watch?v=3a3A1BxFBUU

Autistica Presentation August 2020

https://www.youtube.com/watch?v=lysFtD7XAFo

Autistica CSP Sprint 6 1to1 Feedback Demo Video

https://www.youtube.com/watch?v=kRBXYbqVbgE

Autistica CSP Sprints 1 - 8 Review

https://www.youtube.com/watch?v=pX66xqRZYW4

Autistica CSP Sprint 9 Demo Video

https://www.youtube.com/watch?v=ZWH8ZGvZFTc

Autistica CSP Sprint 10 Demo Video

https://www.youtube.com/watch?v=Hz2gfEf5YkU

Following on from the Demo's Fujitsu received feedback from the community.

Sprints 1- 6 User Feedback

Wireframes

https://github.com/alan-turing-institute/AutisticaCitizenScience/issues/359

Tom A Feedback

https://github.com/alan-turing-institute/AutisticaCitizenScience/pull/138

Sprints 1 - 3 User Feedback Questions

https://github.com/alan-turing-institute/AutisticaCitizenScience/issues/204

To help improve the process a Community *Wireframe Feedback Mechanism was developed.*

Feedback Mechanism

https://github.com/fjAutisticaCitizenScience/AutisticaCitizenScience/blob/documentation/project-management/wireframes/feedback-mechanism.md

Also including

Community Questions

https://github.com/fjAutisticaCitizenScience/AutisticaCitizenScience/blob/communityquestions/project-management/wireframes/updated-questions.md

On the basis of all the feedback and community insight the following were produced.

Platform Designs

https://github.com/alan-turing-institute/AutisticaCitizenScience/tree/master/platform-designs

Sept Platform Wireframes

https://c6q95y.axshare.com/

Wireframe Upload

https://github.com/alan-turing-institute/AutisticaCitizenScience/tree/master/platform-designs/wireframes

Throughout the project, Tasks were kept as GitHub issues and anyone was able to access code via. GitHub.

In order to have Respectful and Inclusive Environment for all Participants we followed this approach.

- Being listened to really important.
- Sense of respect and inclusivity must emerge organically through interactions.
- Reporting pathways have been defined and were presented to the group– but these are for when something goes wrong not how to make environment best it can be.
- Best to have feasible but not overly ideal goals, which can definitely be met, rather than presenting an ideal to strive towards which might never be met: better to under-promise and over-deliver than over-promise and under-deliver.
- Language should be as literal and clear as possible – minimal use of metaphor.

- Some differences in preference of language used, for instance ‘autistic person’ compared to ‘person with autism’ – sensitivity needed around this.
- Some autistic people have an immediate focus on detail.
- Good to have information in small bites.
- Useful to have things precisely timed out.
- Sensitivity needed around whether people ‘suffer’ from autism – some autistic people feel that they do and some feel they don’t.
- Recognising multiple points of view important.
- Feedback important and admitting when you get things wrong.
- Rigidity around expectations.
- Some environmental considerations, such as turning down the lights or the fan (from previous focus group) important – need to ask people and not just assume. Everyone is different and what will be preferred by some not the same for others.
- Face to face direct questions can be difficult.
- Ask for feedback after the fact.
- Send initial summary and plan of meetings in advance.

Component Design Decisions

https://github.com/alan-turing-institute/AutisticaPlatformPrototype/blob/documentation/documentation/COMPONENT_DESIGN_DECISIONS.md

Accessibility Design

https://github.com/alan-turing-institute/AutisticaPlatformPrototype/blob/documentation/documentation/ACCESSIBILITY.md

Platform Styling Locations

https://github.com/alan-turing-institute/AutisticaPlatformPrototype/blob/documentation/documentation/CLASSLOCATION.md