Welcome!

AutSPACEs and Citizen Science.

Who we are.



Georgia Aitkenhead



Sophia Batchelor

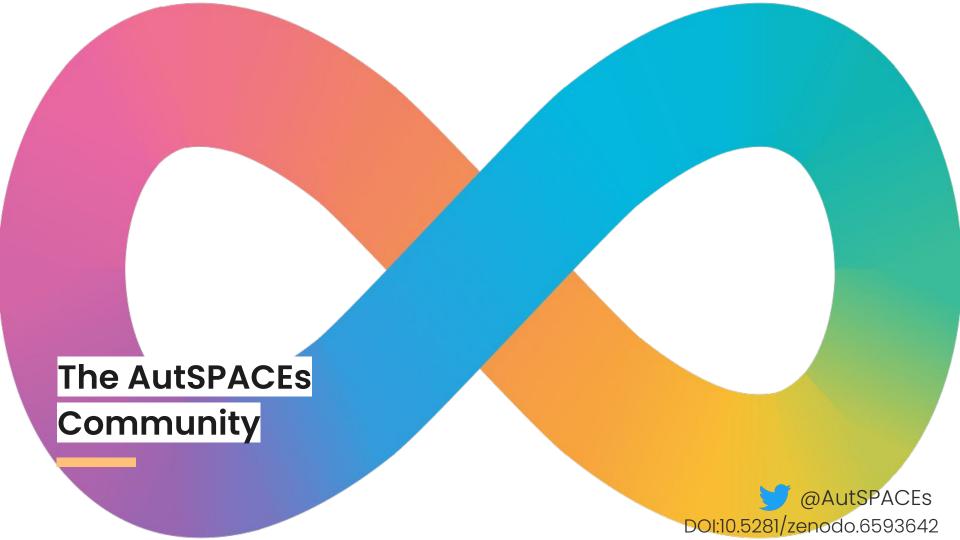


Susanna Fantoni



Otis Smith





What is AutSPACEs



The Alan Turing Institute

Research for real world Change.

AutSPACEs

Autism research into **S**ensory **P**rocessing for

Accessible Community Environments.

Research for real world Change.

AutSPACEs

Autism research into **S**ensory **P**rocessing for

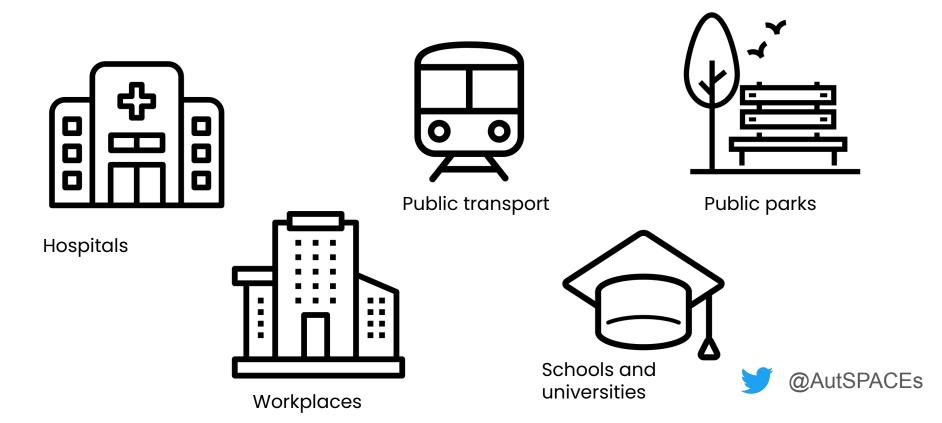
Accessible Community Environments.

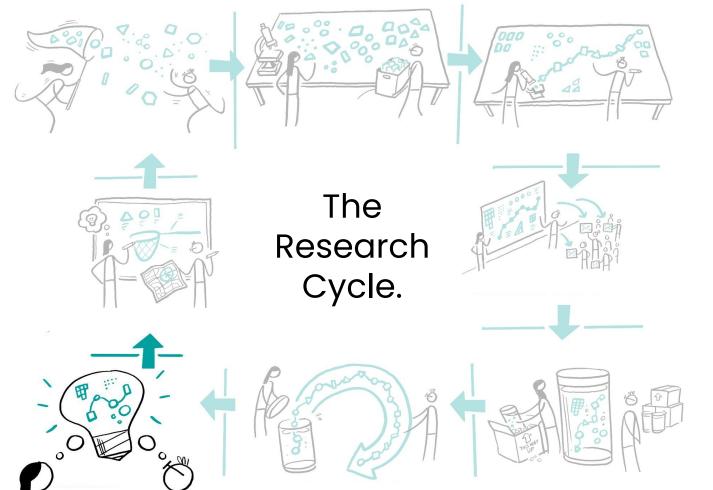
Participatory research to co-create an open

source, citizen science platform.

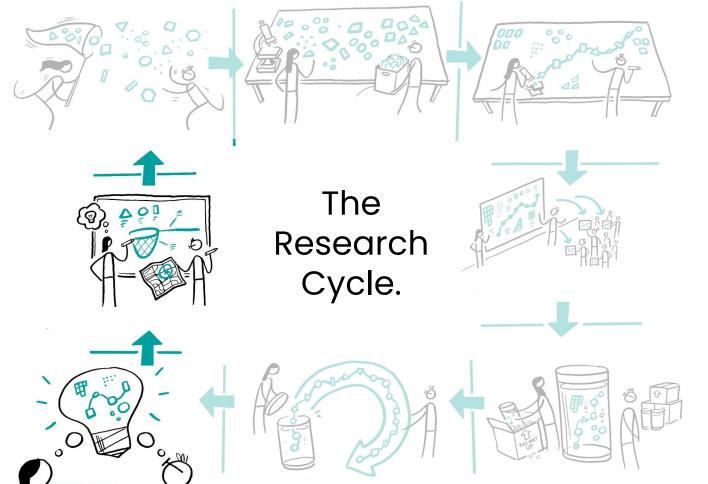


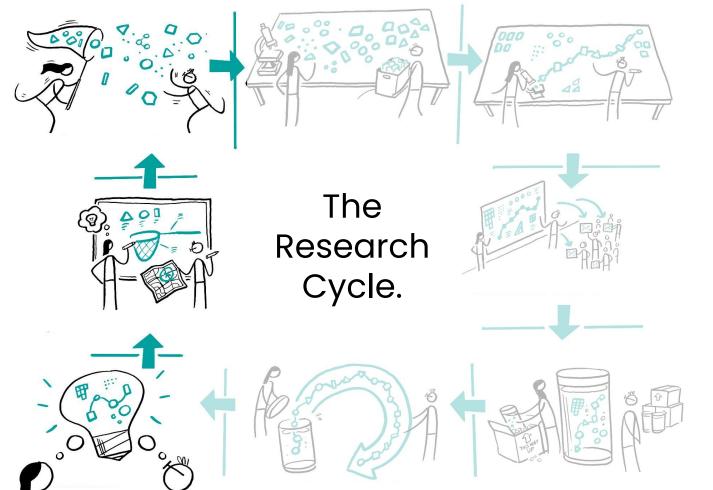
Research for real world change



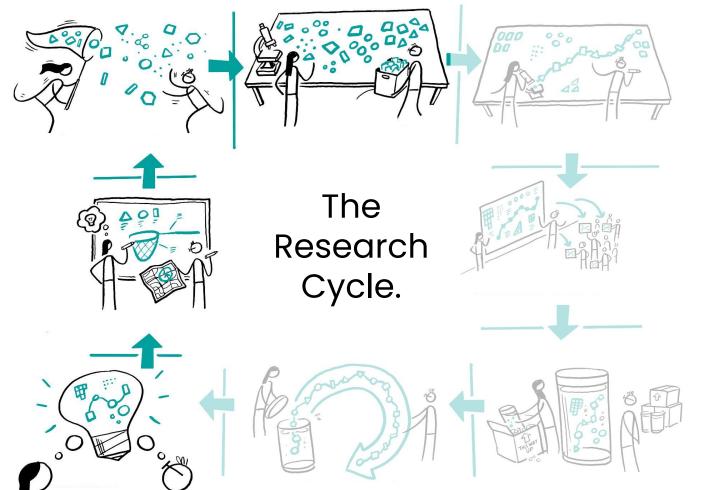


Scriberia

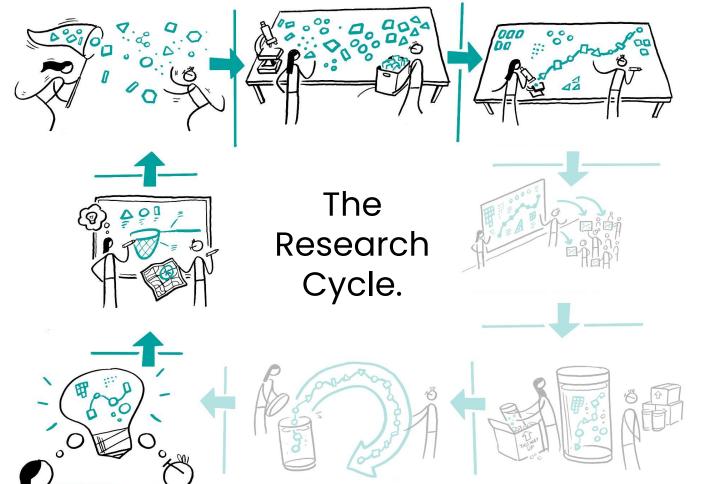


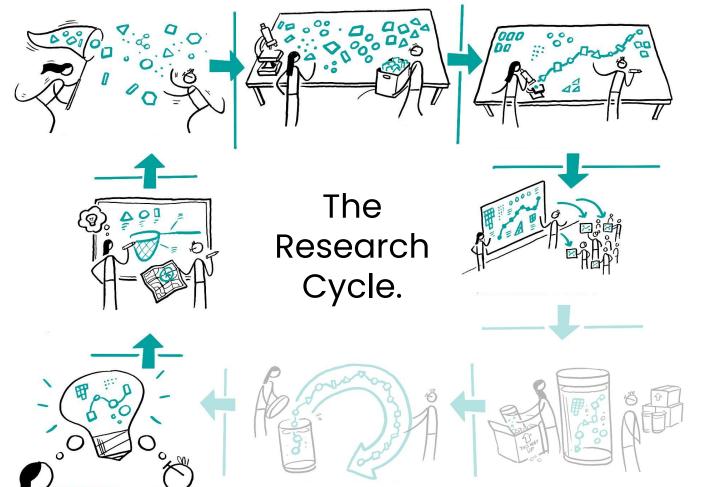


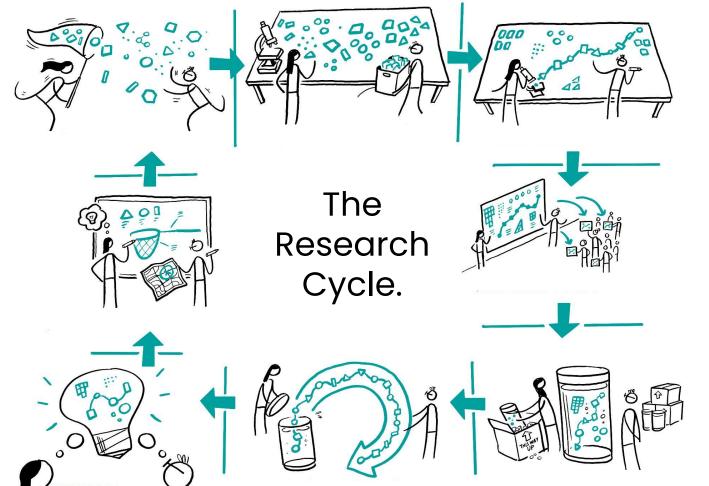
Scriberia



Scriberia &













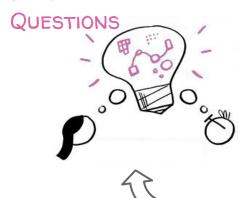




DRIVEN

CO- CREATION

CITIZEN SCIENCE









FAIR DATA **MANAGEMENT**









CO- CREATION

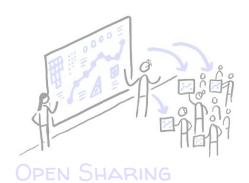




COMMUNITY

DRIVEN







MANAGEMENT





DOI:10.5281/zenodo.6593642

Community Needs.

- 5. Which environments/supports are most appropriate in terms of achieving the best life outcomes in autistic people?
- 9. How can sensory processing in autism be better understood?





"Nothing about us, without us."

- Disability Rights Movement

Online Citizen Science Platform.

Engaging people who are not professional scientists in scientific **research** *at scale*.

- Research design driven by a community.
- More reflective of the wider population.
- Real world experiences.
- Research results support the community.



• From Focus Groups...

"just one thing or question or visual per page, and then...press next"

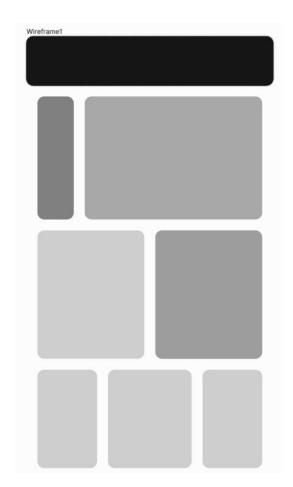
"one thing up at a time"

"you don't want too many things on the page at the same time, because it's just too much"

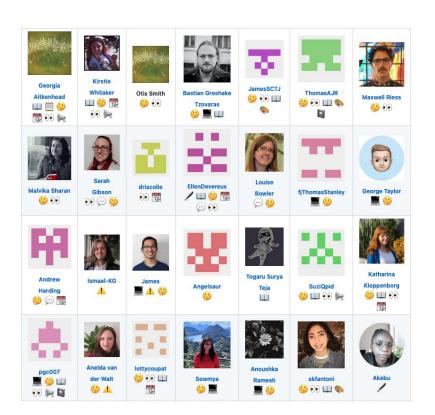
"I've always been better if there's less information on one page"

@AutSPACEs

- From Focus Groups...
- ...to Design Decisions...



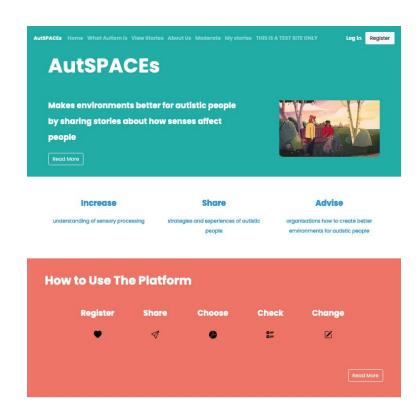
- From Focus Groups...
- ...to Design Decisions...
- Co-working and Meet up Groups...



- From Focus Groups...
- ...to Design Decisions...
- Co-working and Meet up Groups...
- ... supported design iterations...

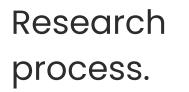


- From Focus Groups...
- ...to Design Decisions...
- Co-working and Meet up Groups...
- ...supported design iterations...
- To a platform built by the community for the community.



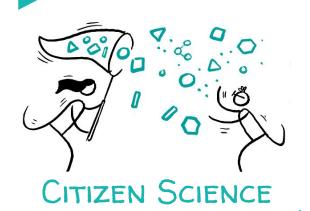
"...it's not just expert advice, everyone is...coming from their life experience, from their relative's experience, and they're saying, 'it helped someone, I'm sure it would help others'..."

Autistic parent of an autistic person



Data gathering.

Research process.



Data gathering.



Otis Smith: my take on citizen science.

Data and Agency.

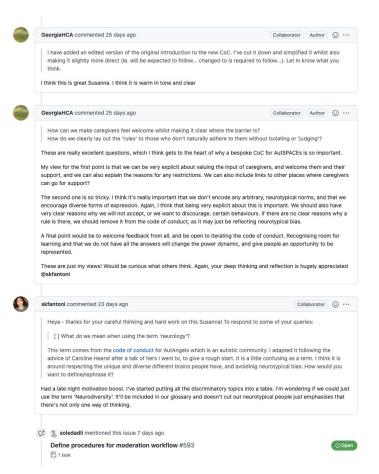
- Co-created data management and moderation
- Highest standards of data protection
- Consent that is dynamic and informed
- Genuinely open means safe and inclusive (Sharan 2021)





Open Source tools for Collaboration.

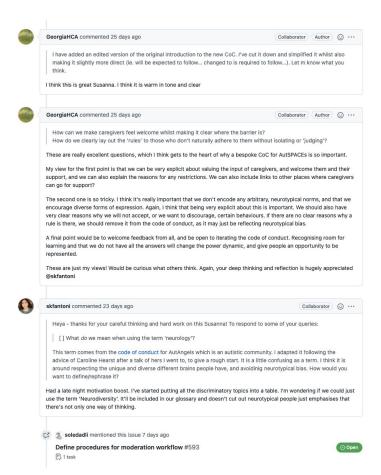
Public GitHub
 Repositories as a form of "living" documentation.





Open Source tools for Collaboration.

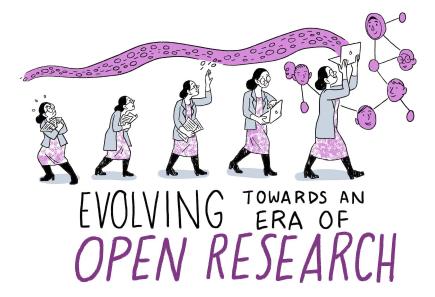
- Public GitHub
 Repositories as a form of "living" documentation.
- Supporting
 asynchronous, open, and
 viewable
 communication.





Making research open

- We want to move towards a world where research is:
- Openly licensed and widely available
- Collaboratively created and shared
- Sustainable
- Reproducible
- Accessible





Moderation and code of conduct

To develop our moderation strategy and draft code of conduct we:

- Held focus groups
- Built user personas
- Reviewed and consolidated existing frameworks
- Engaged with the wider Autspace's community for feedback
- Reviewed academic literature and moderation best practice.

Based on these activities we developed a draft code of conduct and bespoke moderation and content solutions.

Challenges when co-creating a moderation system.

- How can we meet users freedom of expression whilst adhering to the project's ethos of a safe and inclusive environment?
- Finding balance between inclusivity and authenticity; to ensure and accurate research evidence base.

Sharing stories for others?

- Contentious and important topic
- Held session specifically to work on this area
- Guidelines for sharing respectful accounts for others
- Co-written with autistic people
- Explicitly autistic-voice first (reflected in moderation decisions)

"...we don't want it to be about neurotypical people talking about non-neurotypical people."

Autistic person

Solutions & Innovations: Story Categorisation

Red, Green and Amber

• Red = Breaks CoC and will not be approved for public sharing

• **Green**= Meets all requirements

 Amber = Doesn't break CoC but contains potentially triggering content so will be flagged

2.A New TV

My family recently got a new TV. It's much larger than our previous one and has limited screen settings.

Autistic Person

Read Full Story

3. Lack of Spatial Awareness

Autistic Parent

Includes triggering contents

Read Full Story

Report Triggering Contents

Co-creation for impact at scale.

share people's stories and adaptive techniques with others who have similar experiences

Educate

neurotypical people to better support their friends, family and colleagues

Advise

organisations on how they can design and adapt spaces to improve people's lives

Co-creation for impact at scale.

share people's
stories and
adaptive
techniques with
others who have
similar experiences

Educate

neurotypical people to better support their friends, family and colleagues

Advise

organisations on how they can design and adapt spaces to improve people's lives

Openly licensed code that can be adapted to answer other research questions, and resources that can support other participatory projects.

Longer, healthier, happier lives for autistic people...

Longer, healthier, happier lives for autistic people...

...a more accessible, diverse, and inclusive **science**, **world** and **web**.

Thank you to the project team and thank you for listening!

KIRSTIE WHITAKER

JAMES CUSACK

BETHAN DAVIES

BASTIAN GRESHAKE TZVORAS

OTIS SMITH

SUZANNE IWAI

JAMES KIM

ROBIN TAYLOR

SOWMYA RAJAN

MALVIKA SHARAN

TOM AUGUR

LOTTY COUPAT

SOLEDAD LI

ANOUSHKA RAMESH

OPEN LIFE SCIENCES

SUSANNA FANTONI

JAMES SCOTT

The AutSPACEs Open Source

Community

...and all of our amazing autistic

collaborators!!



The Alan Turing Institute







DOI:10.5281/zenodo.6593642