

COMMUNITY BUILDING
FOR BETTER SCIENCE.

Citizen Science & Community.

TPS Community Managers Meeting

09/06/2022

About AutSPACEs

A **research collaboration** between
The Alan Turing Institute, Autistica, &
Open Humans.

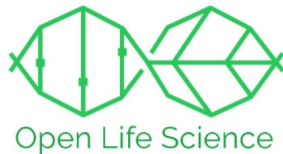
The
Alan Turing
Institute



About AutSPACEs

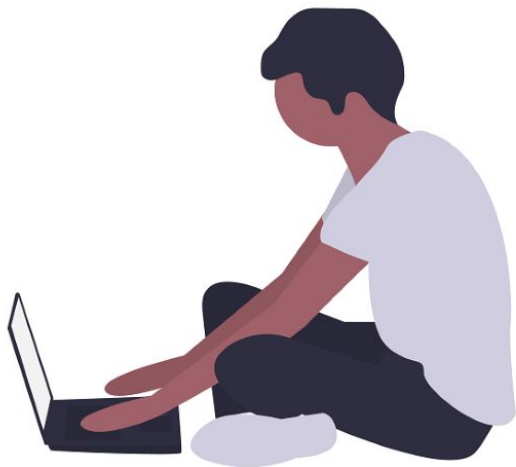
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About AutSPACEs

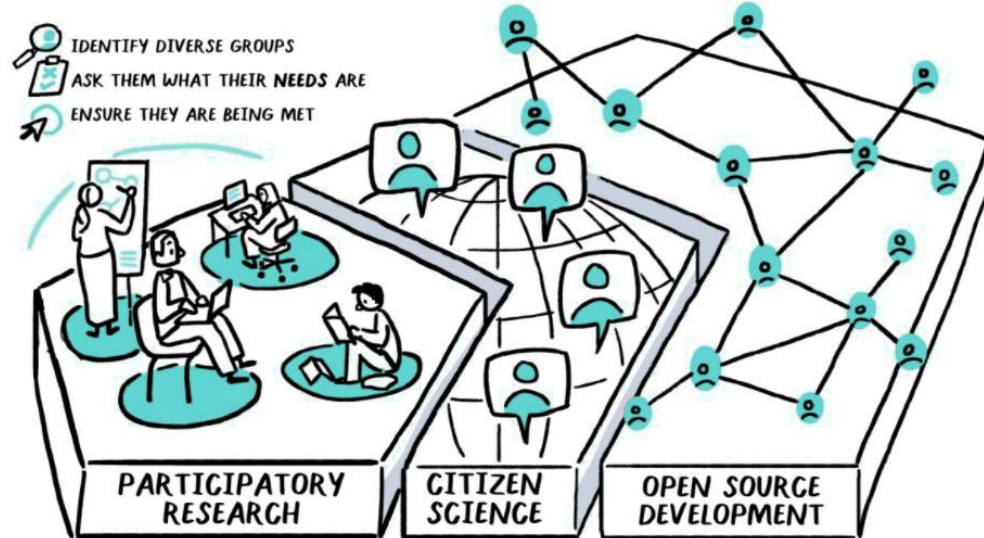
- A **research collaboration** between The Alan Turing Institute, Autistica, and Open Humans
- A **community** of autistic people, their supporters, researchers and open source developers
- A **citizen science platform** where autistic people and their supporters can share their stories of how they are affected by their senses in their daily lives



@AutSPACEs

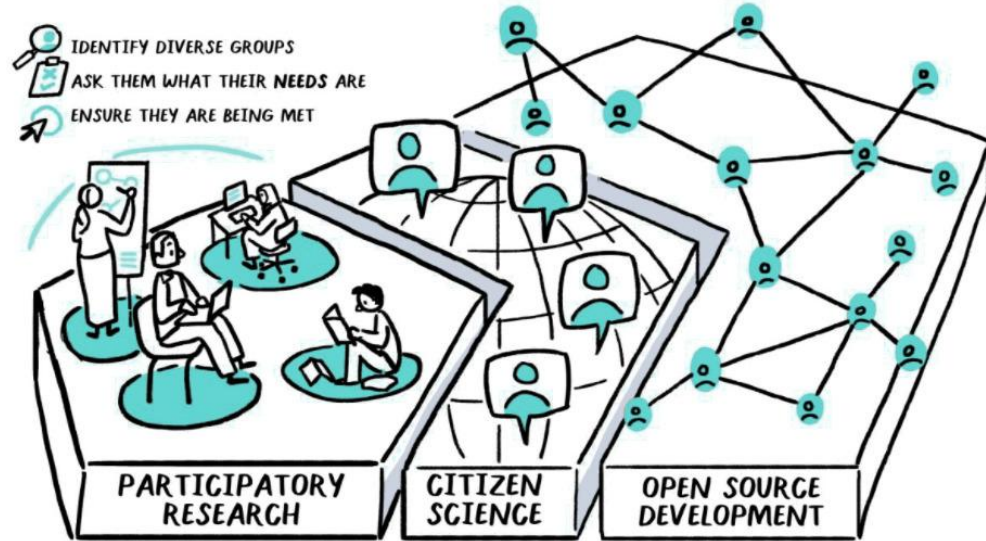
Collaborative Co-Creation.

- Built for autistic people by autistic people.
- Amplifies the experiences of autistic people.
- Mentorship and collaboration for co-creation.



Collaborative Co-Creation.

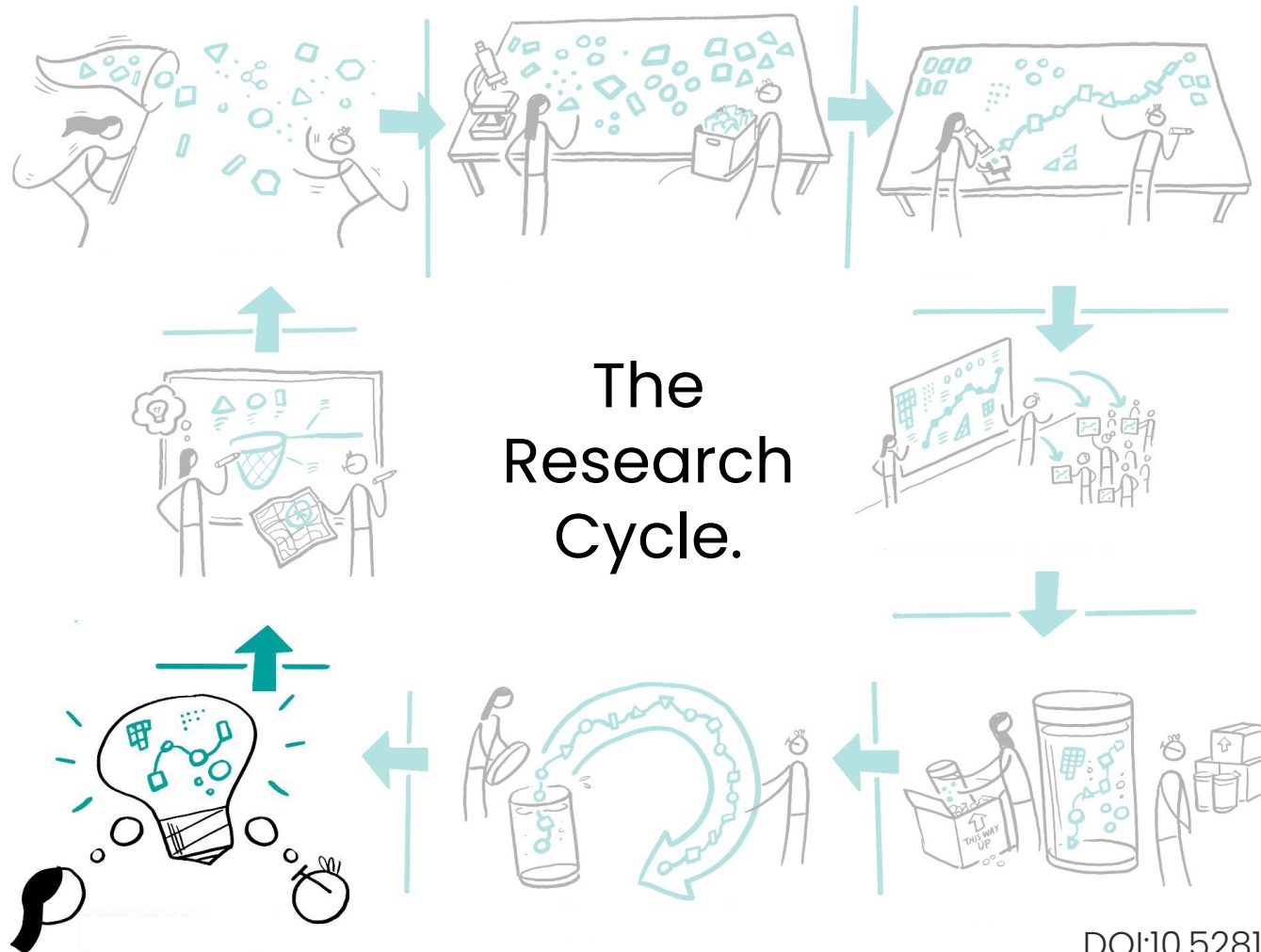
- Accessible and inclusive ways of working.
- Inclusive and community focused research.
- Active inclusion and coworking practices that support a neurodiverse community.



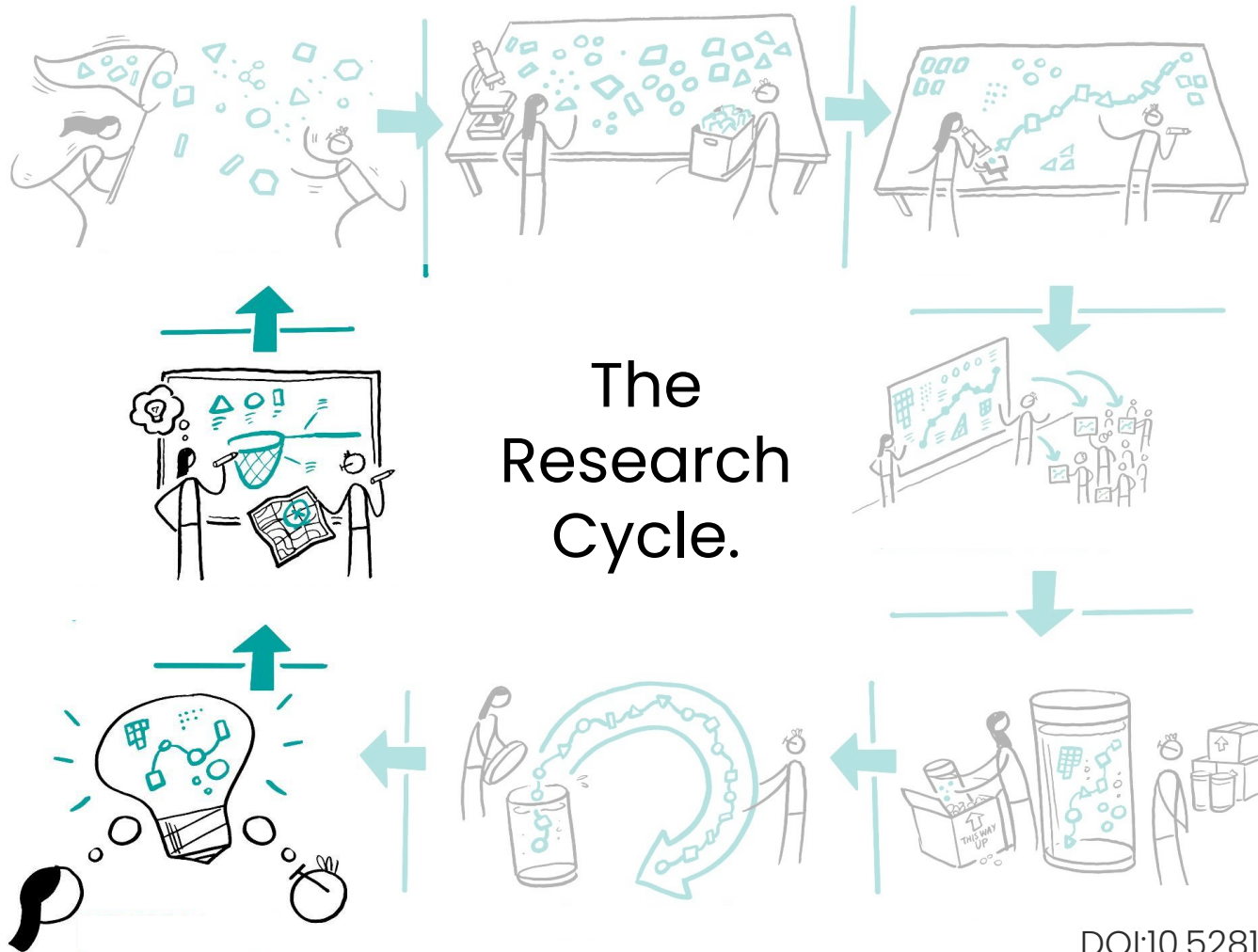
THERE'S MORE TO COLLABORATION

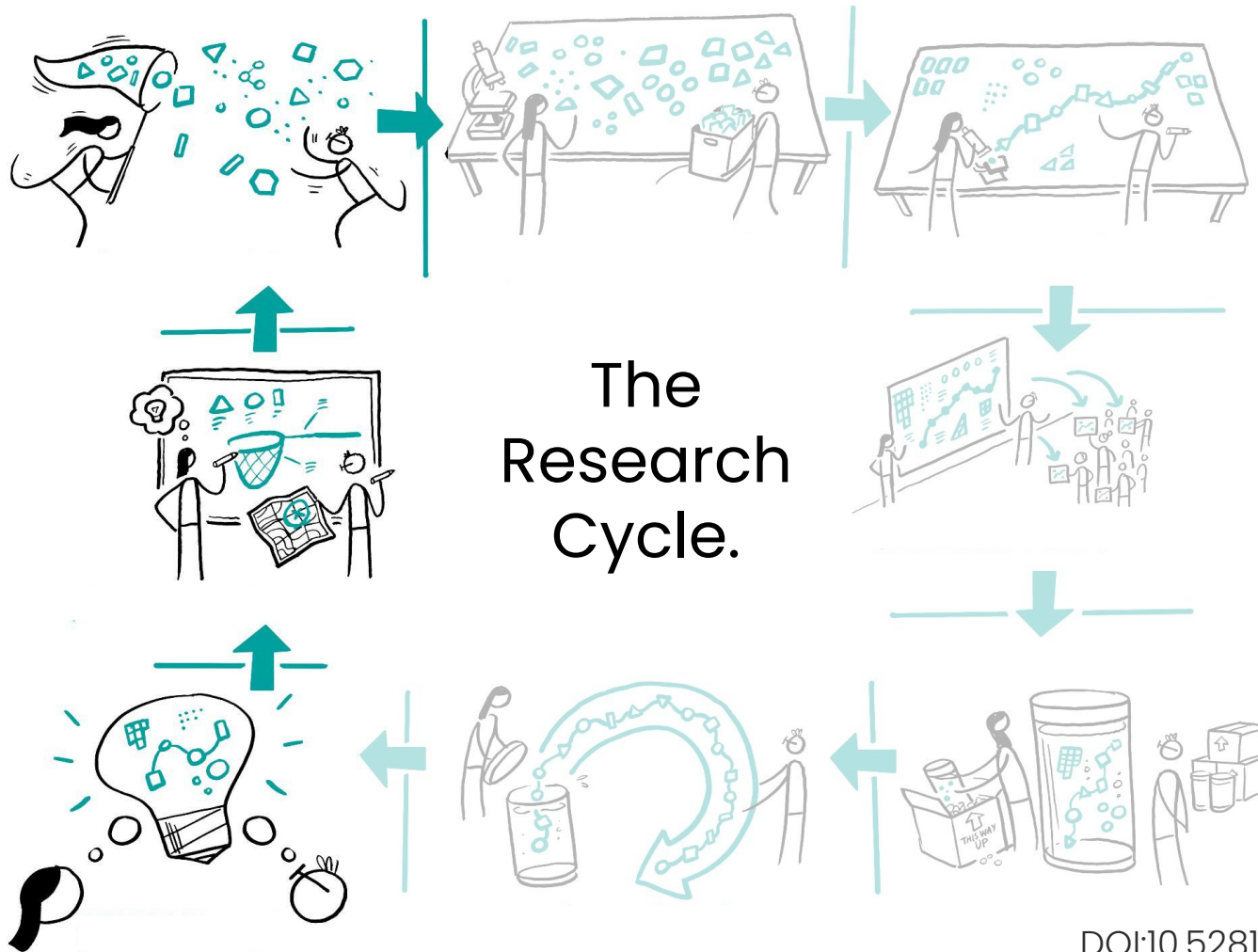
THAN YOU MIGHT THINK!



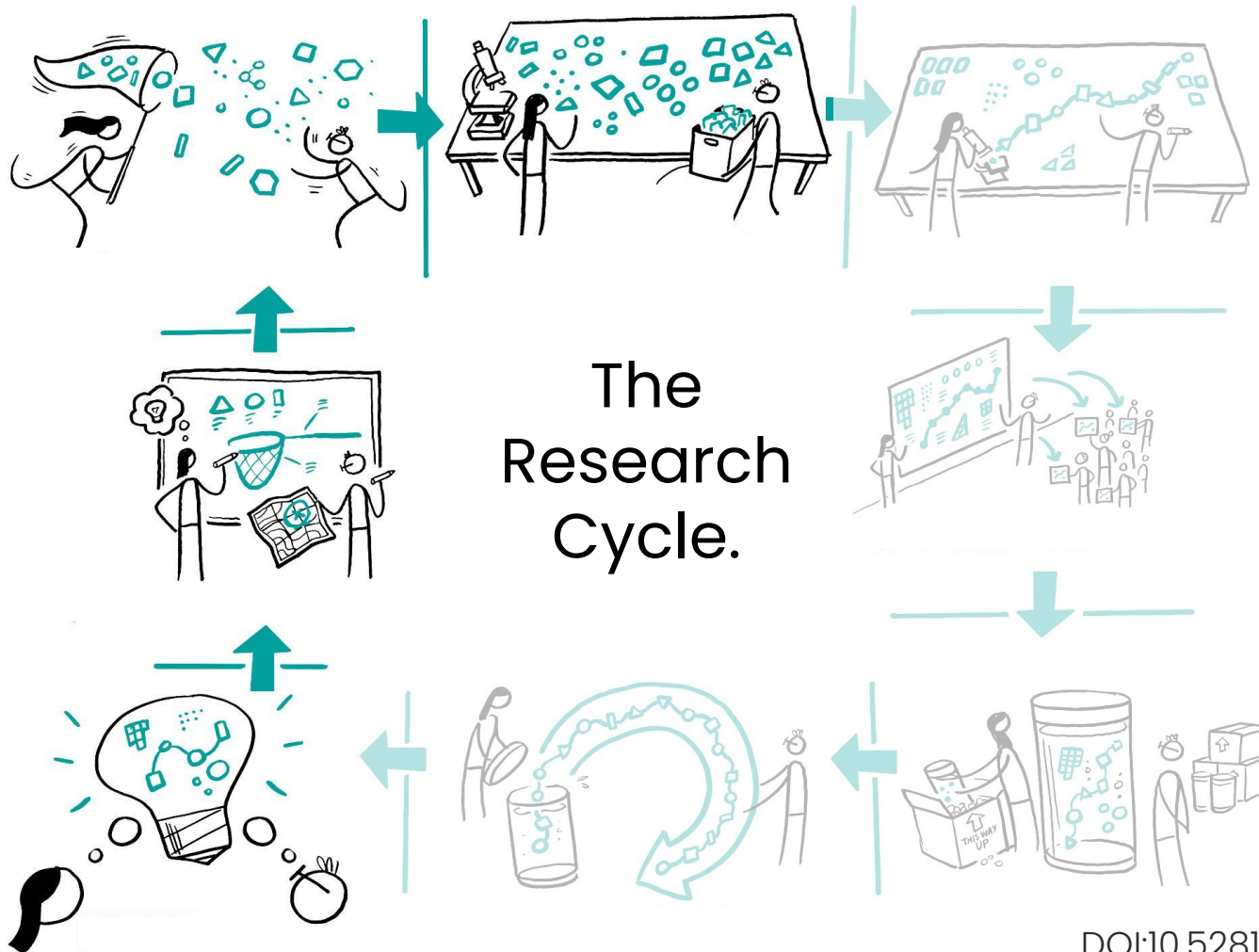


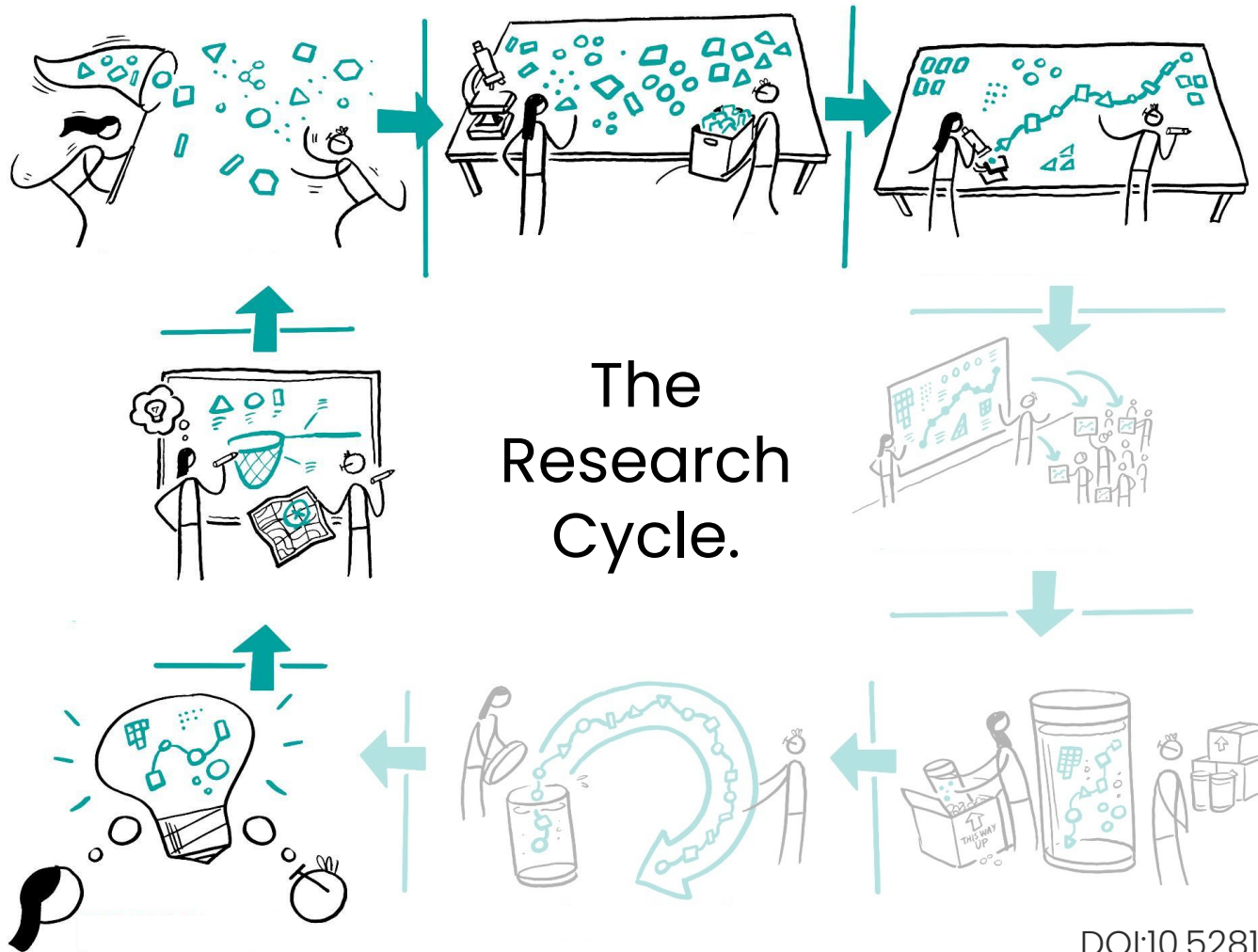
The Research Cycle.

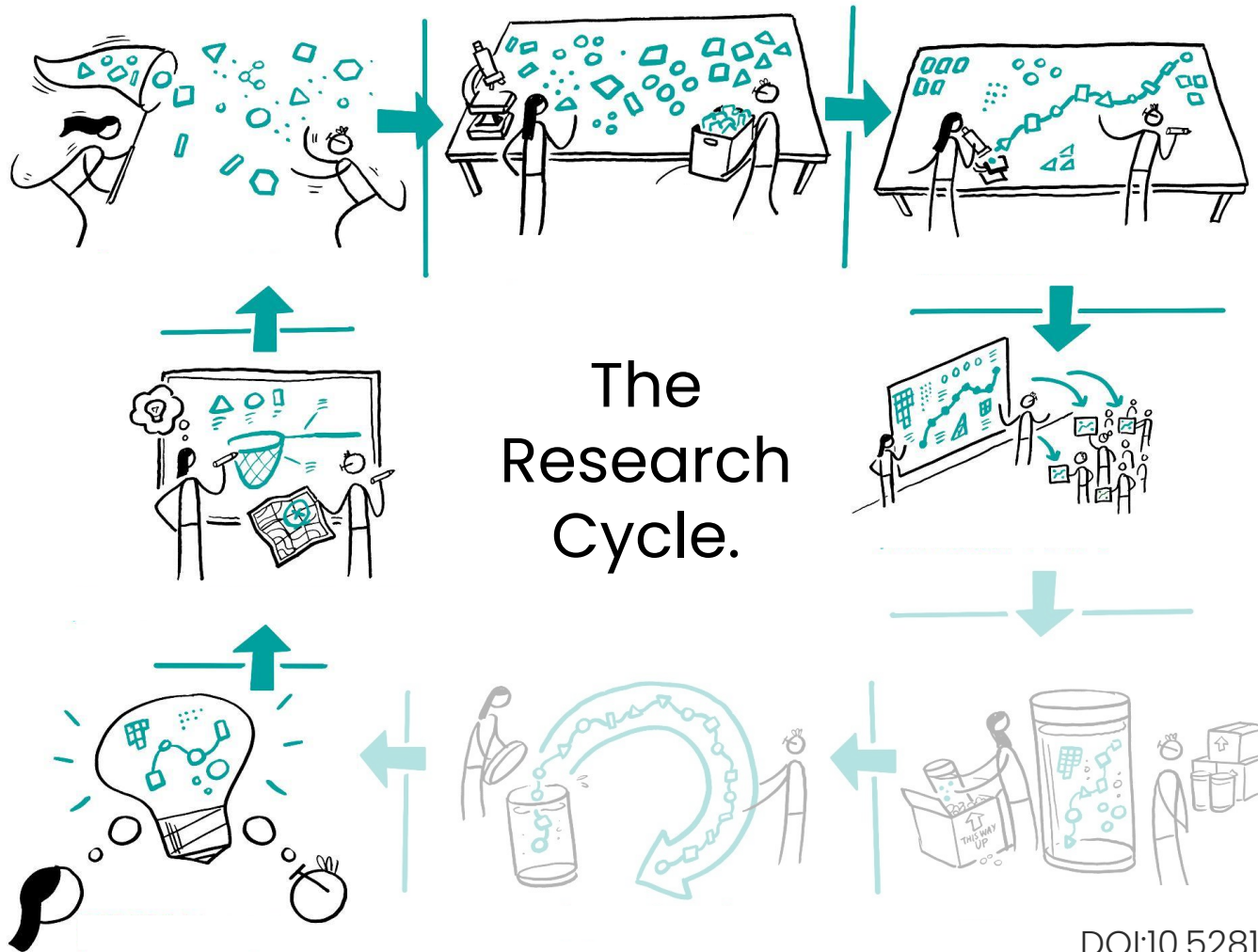


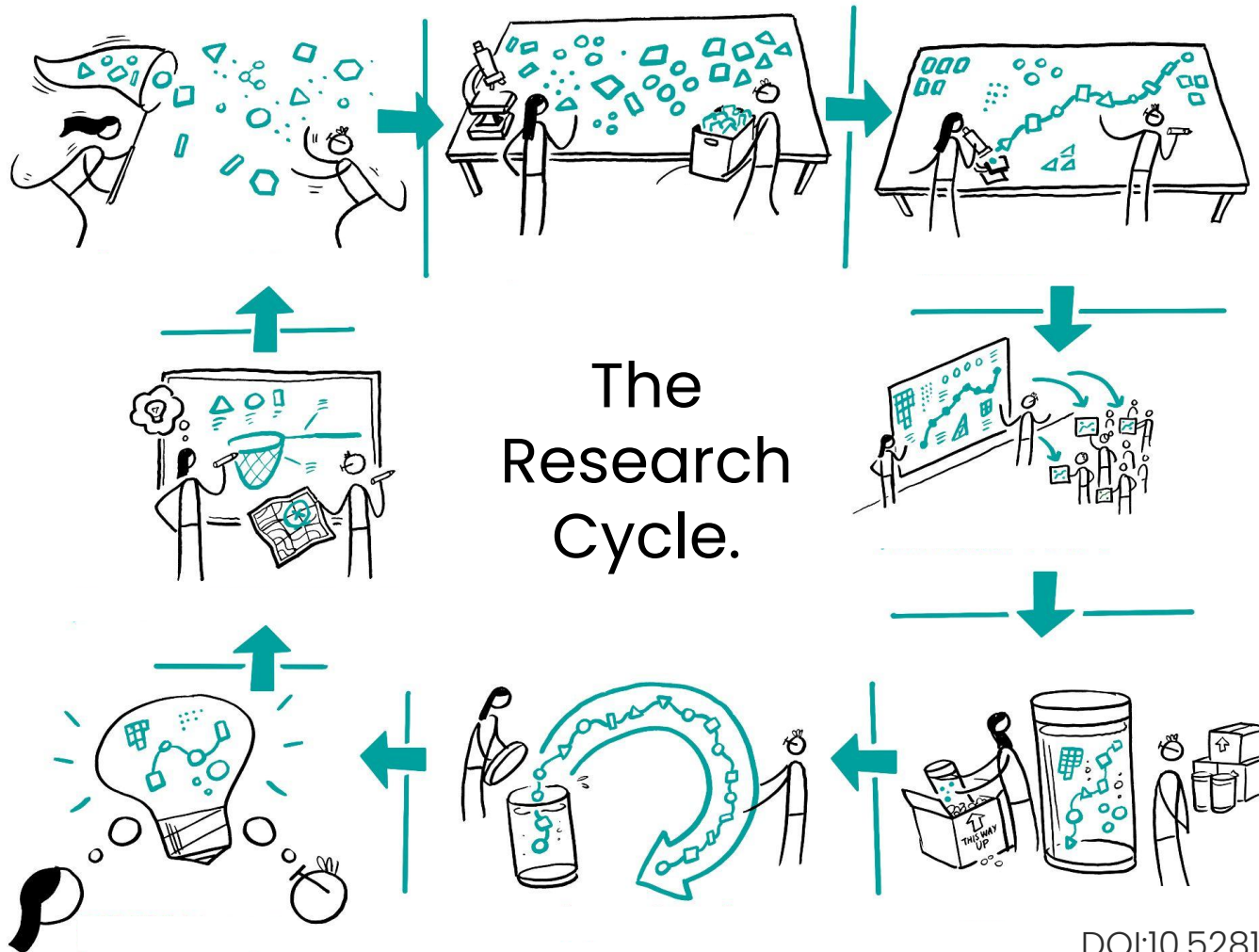


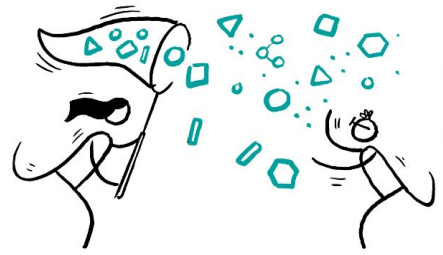
The Research Cycle.







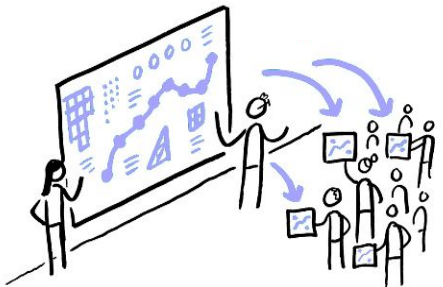




COMMUNITY
DRIVEN
QUESTIONS

COLLABORATIVE
CO-CREATION

CITIZEN SCIENCE



OPEN SHARING
& PUBLISHING

FAIR DATA
MANAGEMENT



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.

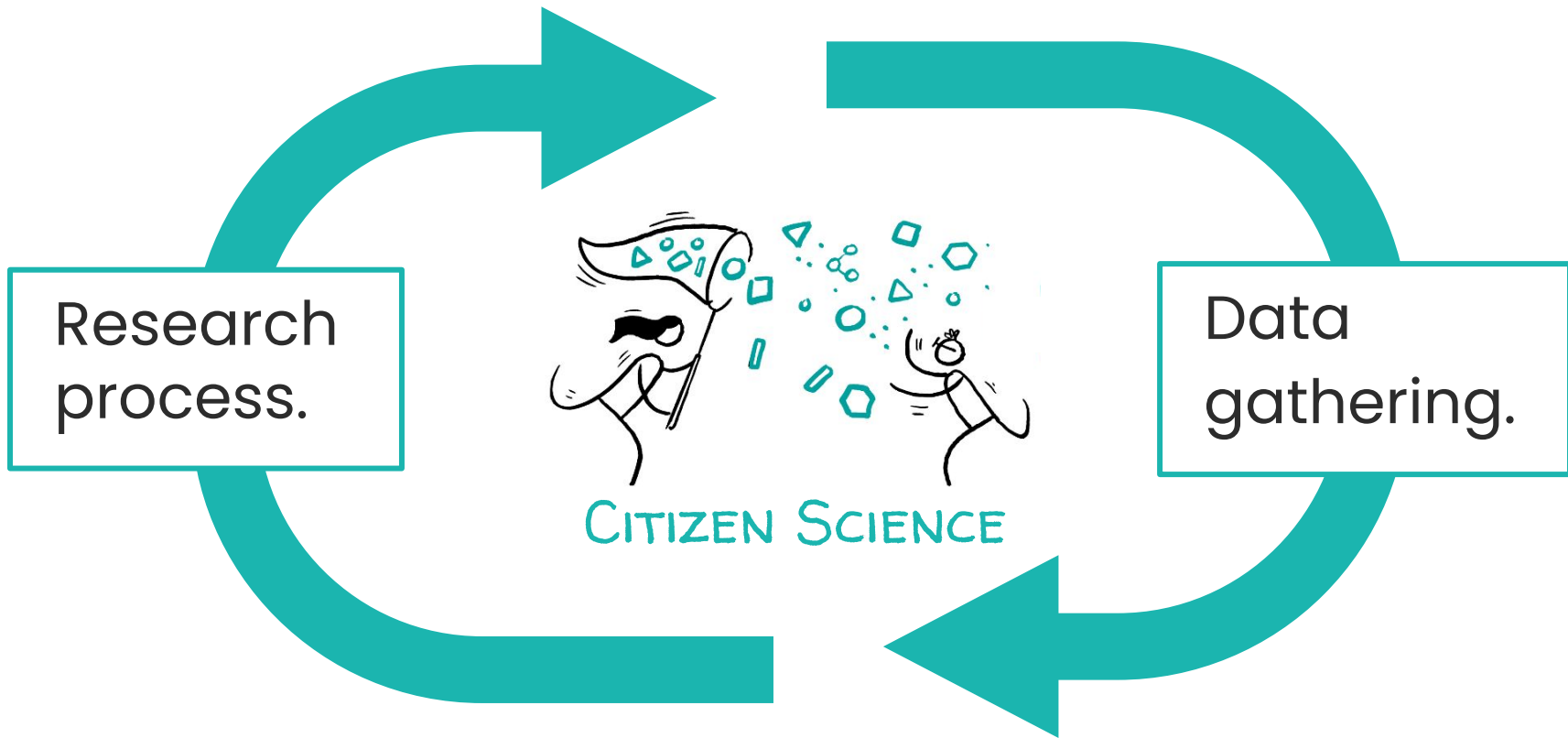


COLLABORATIVE
CO-CREATION



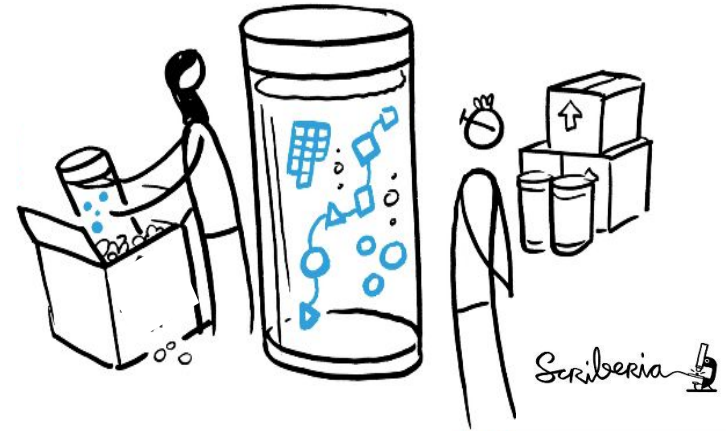
@AutSPACES

DOI:10.5281/zenodo.6593642



Data and Agency.

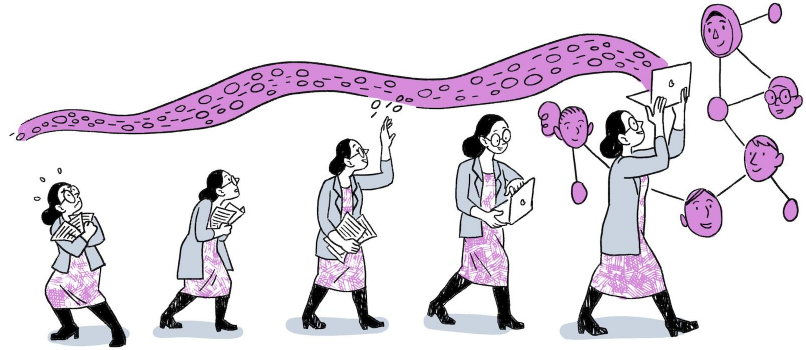
- Co-created data management and moderation
- Highest standards of data protection
- Consent that is dynamic and informed
- Genuinely open means safe and inclusive (Sharan 2021)



FAIR DATA MANAGEMENT

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



EVOLVING TOWARDS AN
ERA OF
OPEN RESEARCH

Scriberia 



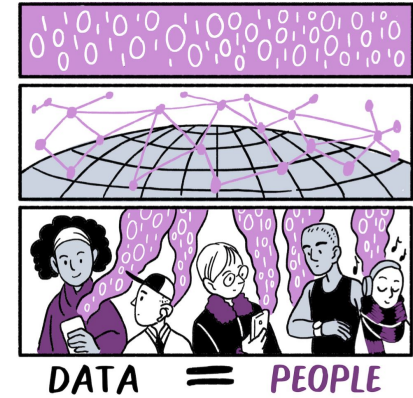
@AutSPACES

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Let's get
(inter)Active!



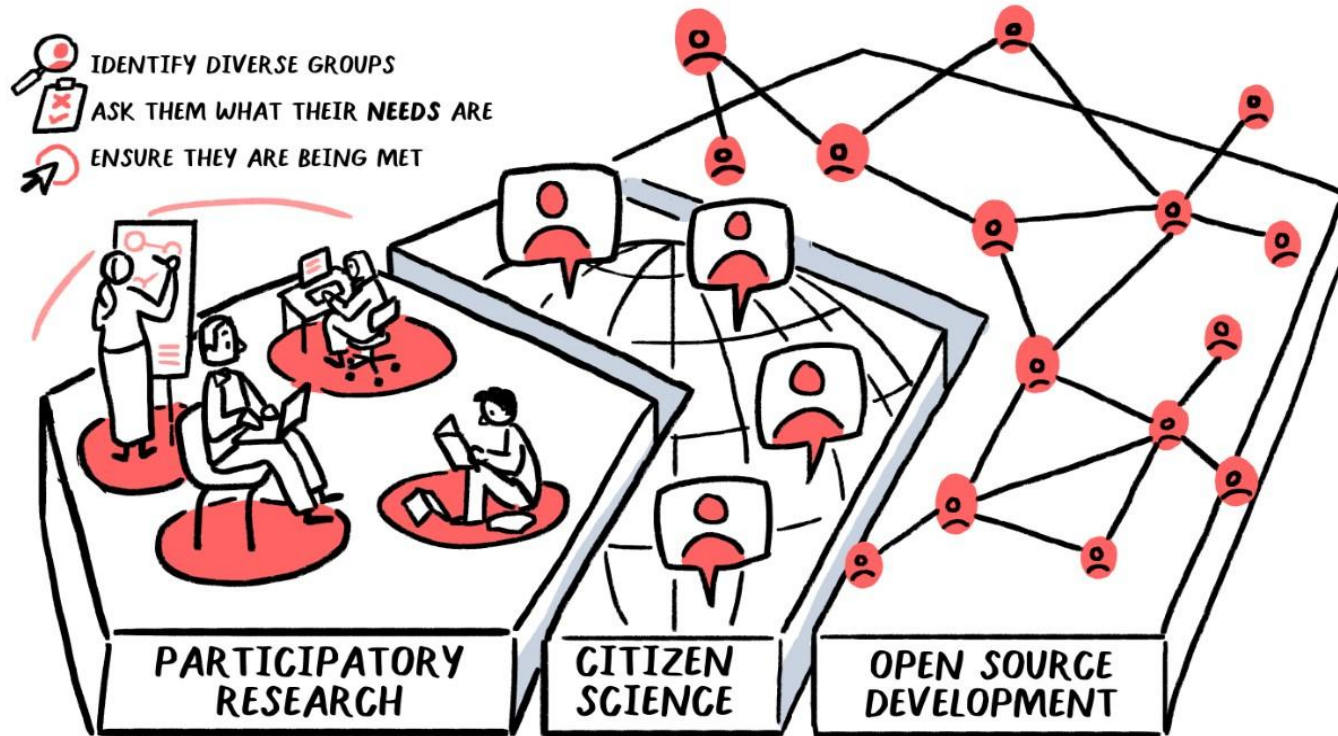
How are citizens/ members of the public impacted by your projects?



Scriberia



Where are members of the public involved in your projects?



Definitions.

- Citizen Science
- PPIE
- Participatory Research
- Community of Practice

Citizen Science is the practice of public participation and **collaboration** in scientific research*.

Citizens take an **active role** in the scientific process in collaboration with researchers; from forming research questions and methods, to curating data and disseminating findings.

Definitions.

- Citizen Science
- **PPIE**
- Participatory Research
- Community of Practice

Patient and Public **Involvement** means that activities and research are carried out 'with' or 'by' members of the public or patients, rather than 'to', 'about' or 'for' them.

Patient and Public **Engagement** is about ensuring that information and research outputs reach patients and the public.*

Definitions.

- Citizen Science
- PPIE
- **Participatory Research**
- Community of Practice

Strives to close the gap between “researcher” and research subject, giving **power to people** who ultimately stand to gain or lose most.

Definitions.

- Citizen Science
- PPIE
- Participatory Research
- **Community of Practice**

A community of practice (CoP) is a group of people who **share** a common concern, a set of problems, or an interest in a topic and who come together to fulfill both individual and group goals.

Everyone
can cook .

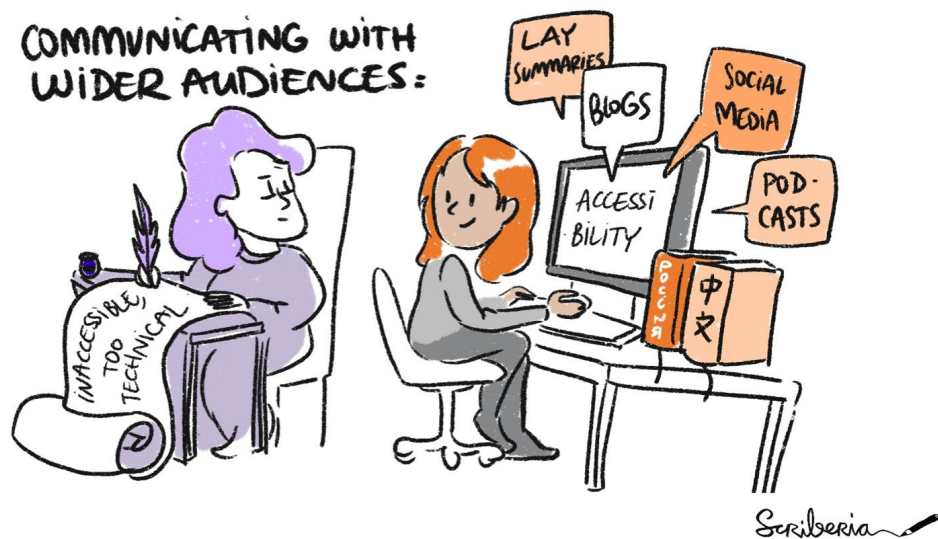


Everyone *Do*
~~can cook.~~ *SCIENCE.*



Community & SciComm.


- **FAIR Data**
 - Findable
 - Accessible
 - Interoperable
 - Reusable
- Highest standards of data protection.
- Fine-grained consent that is dynamic, and informed.



@AutSPACES

Inclusion with Open Source.

- Public GitHub Repositories as a form of “living” documentation.




GeorgiaHCA commented 25 days ago

Collaborator Author ...

I have added an edited version of the original introduction to the new CoC. I've cut it down and simplified it whilst also making it slightly more direct (ie. will be expected to follow... changed to is required to follow...). Let me know what you think.

I think this is great Susanna. I think it is warm in tone and clear



GeorgiaHCA commented 25 days ago

Collaborator Author ...

How can we make caregivers feel welcome whilst making it clear where the barrier is?
How do we clearly lay out the 'rules' to those who don't naturally adhere to them without isolating or 'judging'?


These are really excellent questions, which I think gets to the heart of why a bespoke CoC for AutSPACES is so important.

My view for the first point is that we can be very explicit about valuing the input of caregivers, and welcome them and their support, and we can also explain the reasons for any restrictions. We can also include links to other places where caregivers can go for support?

The second one is so tricky. I think it's really important that we don't encode any arbitrary, neurotypical norms, and that we encourage diverse forms of expression. Again, I think that being very explicit about this is important. We should also have very clear reasons why we will not accept, or we want to discourage, certain behaviours. If there are no clear reasons why a rule is there, we should remove it from the code of conduct, as it may just be reflecting neurotypical bias.

A final point would be to welcome feedback from all, and be open to iterating the code of conduct. Recognising room for learning and that we do not have all the answers will change the power dynamic, and give people an opportunity to be represented.

These are just my views! Would be curious what others think. Again, your deep thinking and reflection is hugely appreciated @skfantoni



skfantoni commented 23 days ago


Collaborator ...

Heya - thanks for your careful thinking and hard work on this Susanna! To respond to some of your queries:

[] What do we mean when using the term 'neurology'?

This term comes from the [code of conduct](#) for AutAngels which is an autistic community. I adapted it following the advice of Caroline Hearst after a talk of hers I went to, to give a rough start. It is a little confusing as a term. I think it is around respecting the unique and diverse different brains people have, and avoiding neurotypical bias. How would you want to define/rephrase it?

Had a late night motivation boost. I've started putting all the discriminatory topics into a table. I'm wondering if we could just use the term 'Neurodiversity'. It'll be included in our glossary and doesn't cut out neurotypical people just emphasises that there's not only one way of thinking.




soledadli mentioned this issue 7 days ago

Open

Define procedures for moderation workflow #593

1 task



skfantoni commented 5 days ago

Collaborator ...

How do we intend to respond to stories that include comparisons?

- Comparing your experiences to someone you know
- Comparing your experiences to another story

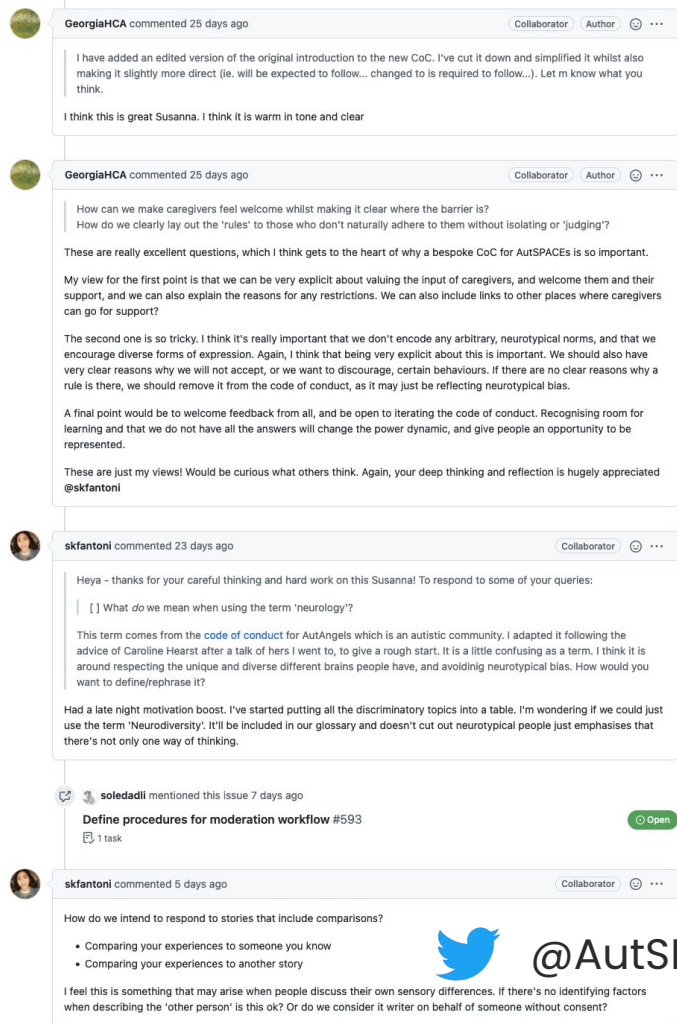
I feel this is something that may arise when people discuss their own sensory differences. If there's no identifying factors when describing the 'other person' is this ok? Or do we consider it writer on behalf of someone without consent?



@AutSPACES

Inclusion with Open Source.

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



The screenshot displays a series of GitHub discussions. The top discussion by GeorgiaHCA, 25 days ago, shows a comment where the author has revised the introduction to the new Code of Conduct (CoC), making it more direct and simplified. The author expresses appreciation for the feedback and mentions the new CoC is warm in tone and clear.

The second discussion, also by GeorgiaHCA and 25 days ago, is a more detailed response to questions about the CoC. It addresses how to make caregivers feel welcome while being clear about the barrier, how to lay out 'rules' for those who don't naturally adhere to them, and the importance of valuing the input of caregivers. It also discusses the removal of neurotypical norms and the importance of being explicit about the reasons for restrictions.

The third discussion, by skfantoni 23 days ago, is a response to queries about the term 'neurology'. It explains that the term comes from the 'code of conduct' for AutAngels, an autistic community, and that it was adapted following the advice of Caroline Hearst. It also mentions the author's motivation to create a table of discriminatory topics and the inclusion of the term 'Neurodiversity' in the glossary.

The fourth discussion, by soledadli 7 days ago, is a mention of a task titled 'Define procedures for moderation workflow #593'.

The fifth discussion, by skfantoni 5 days ago, is a response to a question about how to respond to stories that include comparisons. It lists two points: 'Comparing your experiences to someone you know' and 'Comparing your experiences to another story'. It also mentions the author's feeling that it is something that may arise when people discuss their own sensory differences and the importance of not identifying factors when describing the 'other person'.

In the bottom right corner, there is a Twitter logo and the handle @AutSPACES.

Explain it Like I'm 5!

"Re-write" your assigned excerpt as either 3 tweets **or** a blurb less than 150 words so that a member of the public with no background knowledge could understand it.

Rejoin the main room and share out your tweets/blurbs.

Explain it like I'm 5!



“Re-write” your assigned excerpt as either 3 tweets **or** a blurb less than 150 words so that a member of the public with no background knowledge could understand it.

Emma & Eirini: [Link](#)

Vicky & Sarah: [Link](#)

Achintya & Malvika: [Link](#)

What questions
do you have?

