



SCIENCE FOR ALL



Involving People In DNA Research

Presented by Jack Nunn



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Learn more at:
ScienceForAll.World



Jack.Nunn@ScienceForAll.World



[@JackNunn](https://twitter.com/JackNunn)

Aims

The aim of this presentation and the accompanying resource is to **explore the concept of participatory action research** with real examples, and to **explain ways of planning, reporting and evaluating the process.**



Outcomes

After attending the presentation, participants will be able to:

1. Explain **the concept of participatory research**
2. Explain **the importance of evidence-informed methods of participatory research**
3. Summarise **how participatory research has been used in DNA research**
4. Explain **how participatory research can be planned, reported and evaluated** using for Standardised Data on Initiatives (STARDIT)
5. Summarise how **anyone can get involved in co-developing STARDIT**



Timings

- Introductions (defining participatory action research) – 10 min
- Summary of projects which have informed this presentation – 5 min
- Learnings from doing participatory research – 10 min
- Planning, reporting and evaluating participatory research – 5 minutes
- Open discussion (questions, thoughts, ideas) – 30 min



About the speaker – Jack Nunn

- **Founder and Director of the charity ‘Science for All’**, working to involve people in doing research by building partnerships between the public and researchers
- **A PhD researcher in the department of Public Health at La Trobe University** (Australia), where he is currently exploring genomic research and how people can be involved in shaping the future of this research.
- **Worked for over ten years to involve patients and the public in health and social care research**, including working on projects with Cochrane Australia, the World Health Organisation, the Australian Department of Health, the Poche Centre for Indigenous Health and the UK's National Institute of Health Research.
- A member of the Australian Federal Department of Health's **Medical Services Advisory Committee Evaluation Sub-committee**, on the editorial board for ‘Research Involvement and Engagement’, the ‘WikiJournal of Science’ and the ‘WikiJournal of Humanities’. He is the Strategy Liaison for the **WikiJournals** and a member of the **Cochrane Advocacy Advisory Group** and the **Royal Society of Victoria**.



Who's in the room?

- Please type how you'd describe yourself (researcher, citizen, someone planning a grant application etc)
- Please share anything in particular you are hoping to learn from this session



Defining participatory research

Participatory research is an umbrella term which describes a number of related approaches:

‘an approach to research where research is carried out “with” people rather than “on” them’

WikiData definition, 2020

Other related terms include community-based participatory research, co-design and forms of ‘public involvement’.

Here the term ‘**participatory research**’ will be used to refer to all variations of this method.



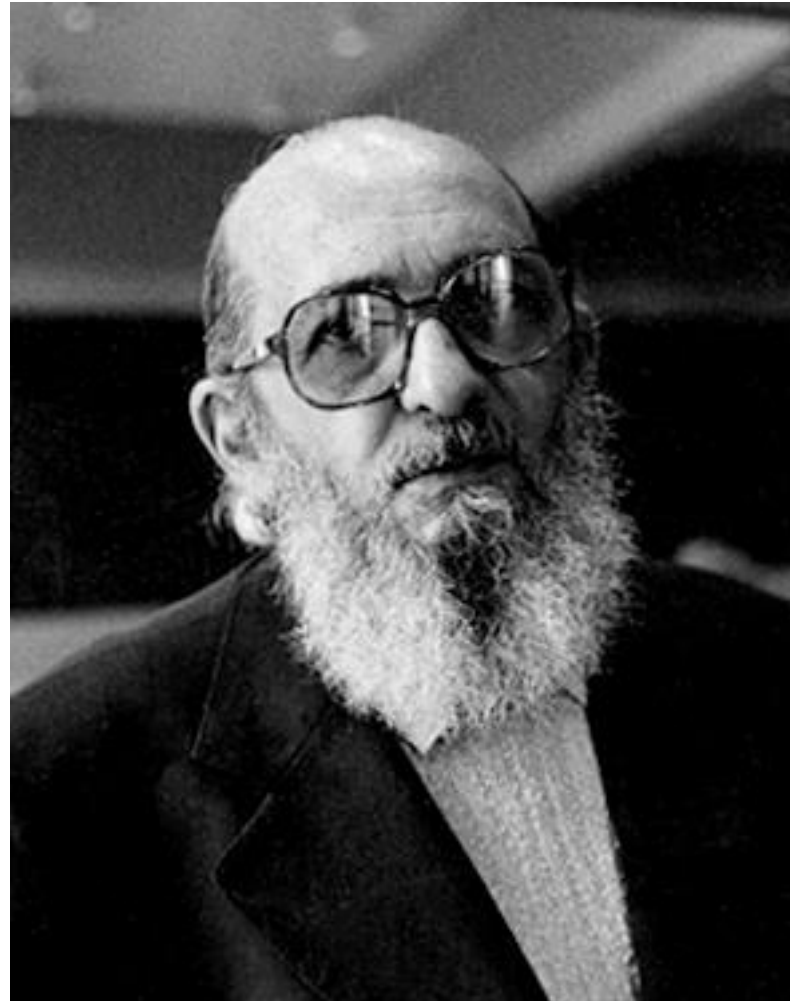
Defining participatory research

- An approach to **research with communities** that emphasises **participation and action**.
- It seeks to **understand the world by trying to change it, collaboratively** and following reflection.
- Emphasizes **collective inquiry and experimentation** grounded in experience and social history.
- "**communities of inquiry and action** evolve and address questions and issues that are significant for those who participate as co-researchers"

[Wikipedia.org/wiki/Participatory_action_research](https://en.wikipedia.org/wiki/Participatory_action_research)



**“to see the world
not as a static
reality, but as a
reality in process,
in transformation”**



Paulo Freire

Photo: https://en.wikipedia.org/wiki/Paulo_Freire#/media/File:Paulo_Freire_1977.jpg

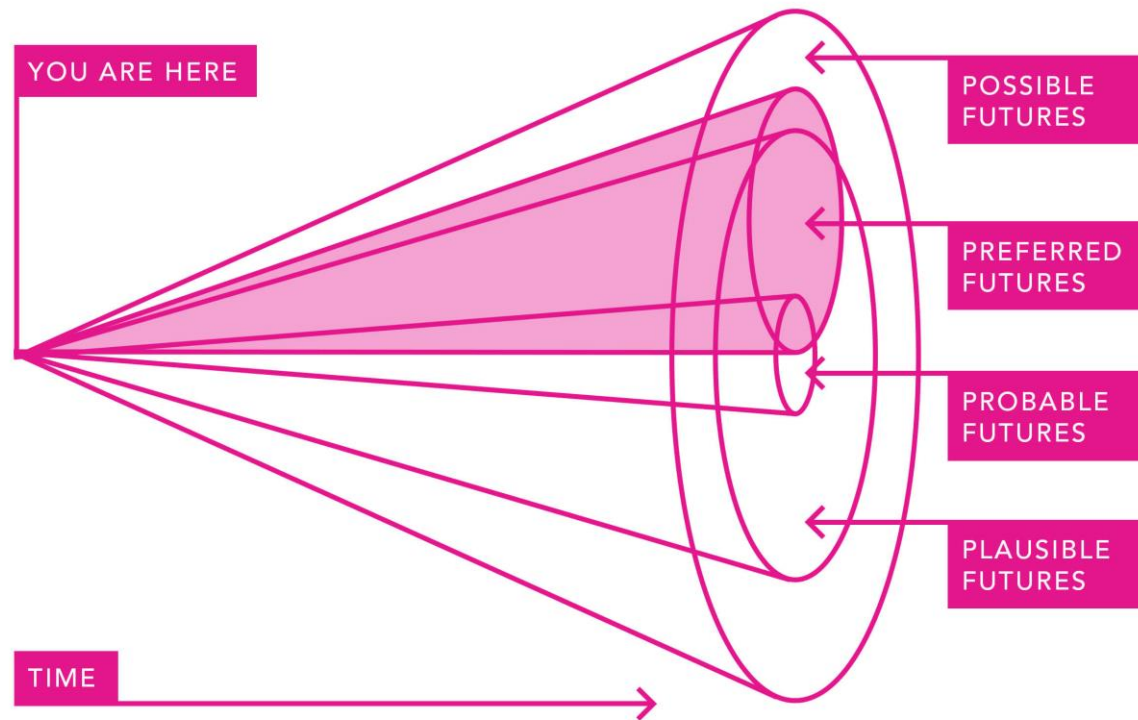
Critical pedagogy:

Advocates of critical pedagogy view teaching as an inherently political act, reject the neutrality of knowledge, and insist that issues of social justice and democracy itself are not distinct from acts of teaching and learning

[Wikipedia.org/wiki/Critical_pedagogy](https://en.wikipedia.org/wiki/Critical_pedagogy)



THE CONE OF POSSIBILITIES



Source: Joseph Voros, "A Generic Foresight Process Framework," 2003



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Jack.Nunn@ScienceForAll.World



@JackNunn

Evidence-informed participatory research?

- At the moment, **there's no standardised way to describe how people have been involved in participatory research, or to report the impacts of involving people.**
- In a 2019 scoping review about public involvement in genomics research, we concluded:

“there would be significant value in developing a more systematic method of both reporting and evaluating how people are involved in human genomics research. Data from such reporting could provide the evidence required to inform future policy around involvement of the public, as human genomics research continues to grow”

- We created Standardised Data on Initiatives (STARDIT) to try and solve this issue.





We need to know the **‘who’**, **‘how’**, **‘what’** and **‘why’** of initiatives such as **research**, **education**, **policy** and international **development**.

STARDIT is designed to be useful across **all disciplines**, including health, environment, basic science, policy, education and international development.

It will share **open access data**, **reporting impacts** across **multiple human languages**.

STARDIT can report:

- Who is involved in which tasks?
- Who is funding what?
- Why do this?
- What are the outcomes?
- How will data be shared?

Get involved in helping
develop **Standardised Data**
on **Initiatives (STARDIT)**

This project supported by:



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MOVEMENT AFFILIATES



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Learn more at:
ScienceForAll.World/STARDIT



Jack.Nunn@ScienceForAll.World

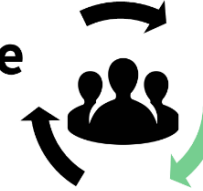


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INVOLVING PEOPLE IN GENOMICS RESEARCH

1. Global review of genomics research projects

A **third** of initiatives **reported involving people**



2. Learning applied to four projects

Australia's largest trial



Planning multi-generational study

Half-siblings who share the same donor father, from an **international group** of 40+



Aboriginal personalised medicine project



People affected by a **rare disease**, working with charity ausEE



3. Standardised reporting of involvement in research

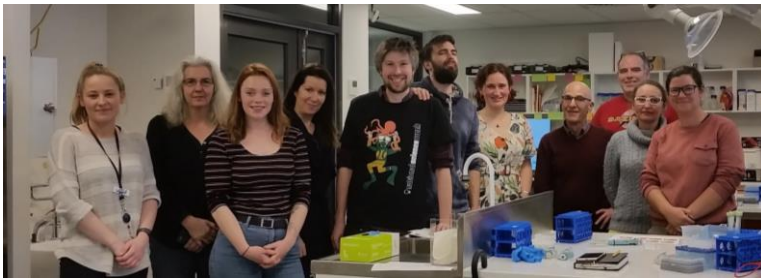


We can all be involved in shaping the future of genomics research

✉ Jack.Nunn@Latrobe.edu.au  @JackNunn

Jack Nunn, PhD Candidate, School of Psychology and Public Health, La Trobe University





Wild DNA

**Citizen scientists using
environmental DNA to
identify critically
endangered species**



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Wild dna



This photo shows the youngest member of our survey, Ziggy, reporting a 'Sugar Glider' sighting as part of the 'Wild DNA' project



CAMPFIRES & SCIENCE



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Learnings from doing participatory research

‘Who is involving who?’

- Words like ‘participation’ and ‘involvement’ can mean different things and can imply very different power relationships.
- While it is important to ask ‘who is involving who’, a more helpful question can be ‘who is working with who, how and why?’.
- Who is not involved, and why?
- Who is a ‘stakeholder’ – someone who has a stake in the research outcome – and who is not?



Photo published by the Poche Centre for Indigenous Health

Learnings from doing participatory research

Motivation and values

‘First, **check your ego and your motives**. Why are you doing this? Second, you **don’t need to be an expert** to understand the knowledge processes of people from other cultures and enter into dialogues with them...**Understanding your own culture and the way it interacts with others, particularly the power dynamics of it**, is far more appreciated’

From ‘Sand Talk: How Indigenous Thinking Can Save the World’, by Tyson Yunkaporta²⁵



Learnings from doing participatory research

Valuing people

- How are people being valued? How is their time or expertise valued?
- Are some people involved paid and others not?
- Is it clear how these decisions are made?
- Are people supported in other ways, such as with training or emotional support?



This photo shows the youngest member of our survey, Ziggy, reporting a 'Sugar Glider' sighting as part of the 'Wild DNA' project. On the table is a box of toffee.

Learnings from doing participatory research

Boundaries

Agreeing the following can help ensure everyone knows who is doing what, feels safe and is supported.

- Who is doing which tasks?
- Why? (are certain skills, knowledge or values required?)
- What isn't being done? (define what is 'out of scope')
- What support is there? What isn't supported? (is there money to pay for people's time, is there practical or emotional support? Who is accountable for providing this?)
- How much time? (what are the time scales, what is the expected commitment?)



Learnings from doing participatory research

Communication

- There's no magic tool or trick to communication. It's hard work, trial and error (and evaluation!).
- Sticking to boundaries helps create safe, inclusive and supportive communication spaces - everything else will follow.
- Creating spaces for support and confidential discussion is also important.



Learnings from doing participatory research

Transparent power structures

- Who is accountable? Who isn't
- If there is power in decision making, label it
- Distributing decision making can work, however often only certain people can be accountable
- **Who decides who decides what is ethical?**
- Using tasks, not 'roles' to describe what needs to be done can help keep things focussed



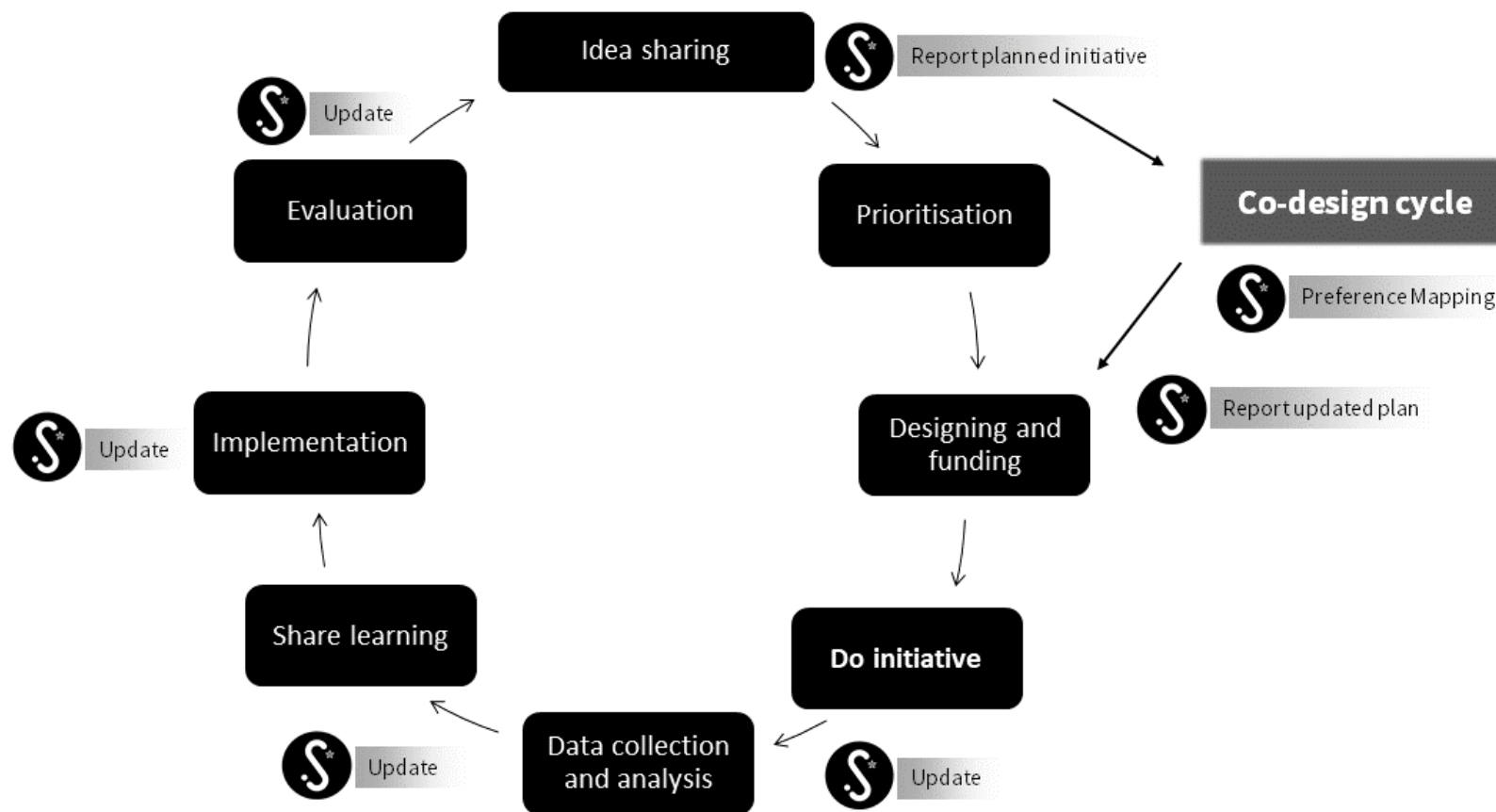
Knowing who is accountable for safety in a community lab space is very important!

Applying the participatory action research method

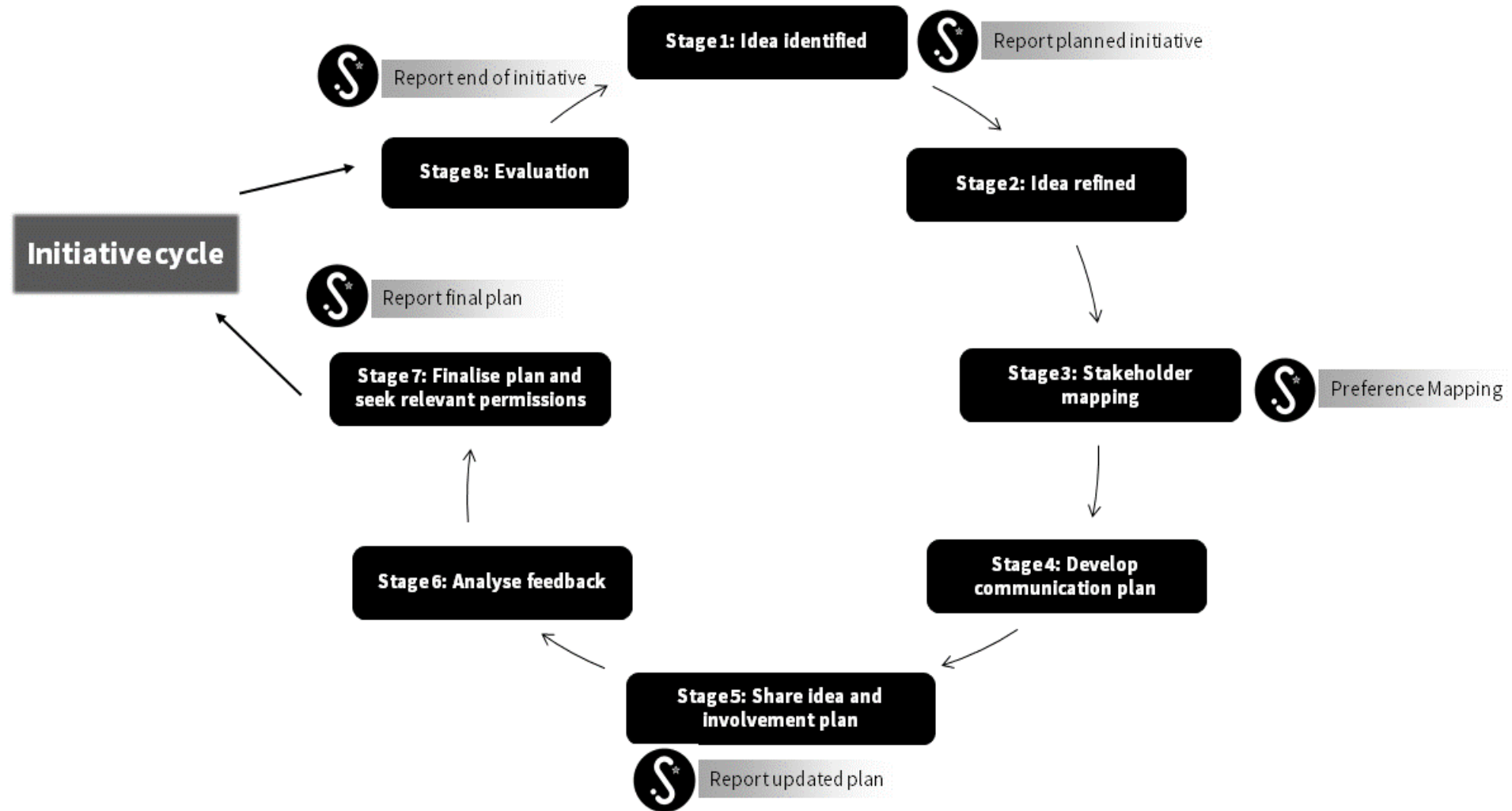
- There are lots of ways of applying the values, principles and philosophy of participatory action research, and the main point is that the methods **must be co-created with the people you are working with.**
- Importance of safe online spaces is important. More so than ever in the time of pandemic.
- The 'Idea Vortex' in the additional material is a simplified way of applying participatory methods



Planning and reporting participatory research using STARDIT



Planning and reporting the participation using STARDIT



Time for some participatory action research

Do you have any thoughts or ideas about Standardised Data on Initiatives (STARDIT)?

We will share some links in the chat for you to share feedback and to get involved!

