



Jo Farmer Consulting
POLICY AND EVALUATION

Empowerment or exploitation: the ethics of engaging people with lived and living experience in evaluation

AES Conference, Brisbane, 28 September 2023



Acknowledgement of country

We recognise the diversity of Aboriginal and Torres Strait Islander peoples across this country and acknowledge their sovereignty was never ceded.

We pay our respects to Elders past and present, and acknowledge their continued custodianship and care for the many lands and waterways that support life.

We acknowledge the untold histories and the injustices of the past and the present. We respect the value and ongoing contribution that Aboriginal and Torres Strait Islander people make to our communities and to wider Australia.

Content flag



- We'll be talking about LE concepts. We acknowledge there will be people here in the room with personal experiences. We trust you to manage your experiences - please take a break if you need to and there is no expectation to share anything personal in this space.

Art: Eliry Art "The Healing Power of Sharing"

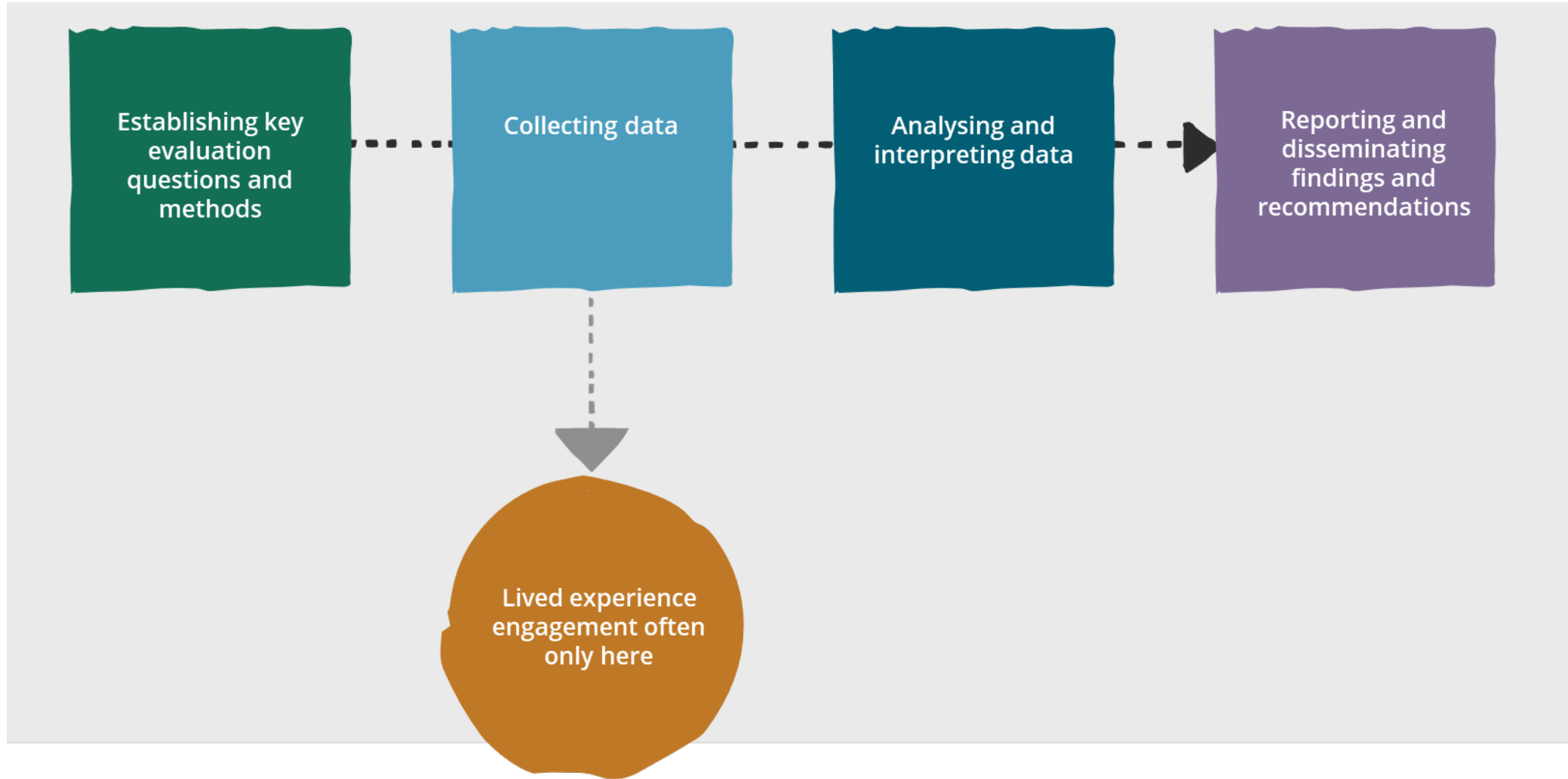
What is lived experience?



Experiences of a social issue where “the experiences were so significant they caused the individual to reassess and often change their lives, their future plans, and their view of themselves.”

- National Lived Experience (Peer) Workforce Development Guidelines

Involving people with lived experience



Why involve people with lived experience?



Image: *Disabled and Here*

- Hearing lived experience perspectives
- Asking the right questions in the right way
- Safety and comfort for participants
- Building rapport with participants
- Understanding the participant experience
- Translating lived experience

Can people with lived experience participate in evaluation safely?

Yes!

- Several studies have found that research is not distressing for most people, and that any distress is not extreme and is short-lived (Weiss, 2023; Appollis, et al., 2015; Jaffe, et al., 2015; Legerski and Bunnell, 2010)
- Participation may lead to small benefits (Blades, et al., 2018)

But, there is some evidence that suggests risks are higher among people with a history of trauma/lived experience

So it is vital to design safe and ethical evaluation:

- In collaboration with people with lived experience
- Understanding context and strengths
- Not assuming vulnerability and lack of capacity

Readiness - individual



- Emotional readiness
 - Anxiety about the process
 - Capacity to take on the work
 - Your own wellbeing
- Skills and knowledge
 - Trauma informed
 - Role of LE evaluators
- Biases



Readiness - organisational

1

Leadership support

- Commitment to centre views of people with lived experience

2

Purpose and values

- Clarity of purpose and scope
- Clear shared values (including with client/funder)
- Considered approach
- Terms of reference/ position descriptions

3

Operational

- Infrastructure in place
- Time and budget
- Training for team members

What are our ethical responsibilities and values?



Readiness from the LE perspective



- Clear understanding of what lived experience is
- Clear sense of purpose and benefits
- Think through how to manage the dignity of risk
- Consider how to provide people with the support they will need (and how you will know what they need)

Involving LE team members – key principles

Flexible

- People can move in and out as they need to
- Accommodating with needs of project balanced

Inclusive

- People can be part of any part of the project work
- Include in BAU, so people are there when decisions are being made

Communicative

- Keeping people updated
- Feedback loops

Transparent

- Clear about what is possible and not possible

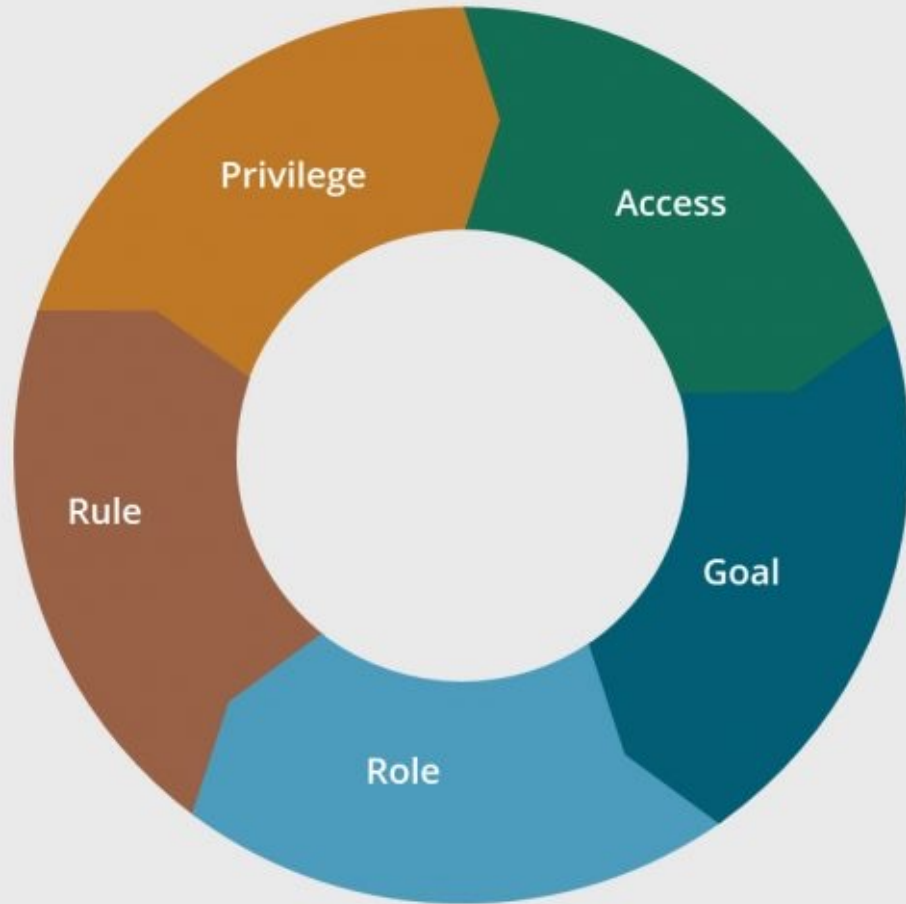
Supportive and empowering

- Considering power dynamics
- Providing people with what they need to be successful

Fairness

- Remuneration
- Training and support
- Opportunities for growth

Power



Privilege: Power from social groups.

Access: Power to influence who is included in the process.

Goal: Power to influence decisions.

Role: Power from role and to influence roles.

Rule: Power to influence how stakeholders work

Reference: Goodwill (2020). 'A Social Designer's Field Guide to Power Literacy'

What does this mean for ethics processes?



Section 4 of the National Statement is under revision.

Key considerations:

- Who to involve and how
- Dignity of risk and the ethics of *not* involving people
- How to demonstrate capacity to participate

How to engage with HRECs on these issues



- Build good relationships (especially with the Secretariat!) and have open discussions
- Educate HRECs about the context, the evidence and precedents
- Challenge decisions you disagree with – provide constructive advocacy

Working through ethical dilemmas

What's feasible? What are the challenges? What are the limitations? Where can it go wrong?

Pick one or more scenarios to work through. Use Table 5 if there are other scenarios you'd like to discuss!

<p>Table 1 (Jo)</p> <p>An HREC questions the experience of the LE researchers leading your team, suggests they have a conflict of interest (given personal experiences), and questions their ability to assess participants' capacity.</p>	<p>Table 2 (Alex)</p> <p>You plan to engage lived experience researchers in a project, but you have a really short delivery timeline for the project specified by the client.</p>
<p>Table 3 (Sharon)</p> <p>Your project is full of power dynamics that you have little control over! The project has been commissioned by a powerful entity, and there are multiple power dynamics within your stakeholders.</p>	<p>Table 4 (Jade)</p> <p>You've found that lived and non-lived experience perspectives on your topic are very different, but you need to bring them together in a way that is respectful and meaningful.</p>

How did we navigate these dilemmas?



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