Inspiring the future of research ethics, 2nd October 2023
Plain text version of Tamara-Jane Kaz's visual notes for screenreader users.

The visual notes have different sections in different colours mapping out the workshop's discussions. This alt-text starts at the top left and follows the sections round clockwise. Each set of bullet points under a heading is one coloured section of the notes.

A picture of a woman's face with question marks above it next to text: mapping ethical challenges in participatory research – a map collated on miro by inspiring ethics – broken down into themes.

Icebreakers
Illustrations of shoes, speech bubbles, a pronouns badge; text: braver spaces, counting and sounds game:

- The sounds of research ethics: Ker-ching! Urghh! Hmm…
- Some key words/questions: bureaucratic, extractive, colonial, rigid; where does the money come from; participants should be paid; doesn't align with my personal values; reminds me of power dynamics at school.

Challenges within the machine of ethics
- Inflexibility: tires to cover lots of research types but does not fit.
- Disconnect: paper process helps to think through processes but does not guarantee research will be ethical in practice.
- Whose 'ethics'? Who decides what is ethical?
- Implicit problematic framing of 'power' & 'vulnerability'.
- Dated: feels unprogressive, language doesn't fit.
- Accountability? Does not consider research positionality or protect participants sufficiently.

'Ideal' approaches to research ethics
- Lived experience represented in the process / lived experience panel.
- Ethics shape the project instead of being an afterthought.
- Considers data ownership & thinks about risk & protection differently: shared ownership.
    - Consent not a one-off tick box, but an ongoing process; engaging & accessible reporting.
    - Collaboration processes that enable co-production; resources for participants to self-identify 'vulnerability'; independent community ethics boards.
- Conversations to give participants & peer researchers a seat at the table.
    - Post-project plan that considers the impact of the research & how participants move on & project longevity.

Values
- Solidarity
- Transparency
- Accountability
- Inclusivity
- Collaboration
- Compassion

- Empowerment
- Capacity-building

Living statues: using tableaux to explore emotions

This section is illustrated with small silhouette figures in different positions representing the tableaux.

"Human subjects" – silhouettes of people standing flat against a wall with arms out, lying on the floor with limbs akimbo, standing with arms up in a surrender position and held anxiously in front of the chest. Captioned with "uncomfortable, disempowered?, observed".

"Researcher" – silhouettes of people kneeling down as though to patronise a child, sitting as though typing at a desk, and bending over pointing as though telling someone off. Captioned with "Comfortable, empowered? Unaccountable?"

Text in the same colour section reads: anthropological/impersonal/hierarchy/colonial dynamic.

Text underneath reads: but let's consider how most researchers are in junior positions with little guidance or support – how 'empowered' are they really?

Shifting power dynamics

Layers of precarity: illustrated with the silhouette figures from the section above: the telling-off figure is labelled "boss"; the person typing is underneath, labelled "junior research role – six month contract" and underneath them is a figure lying on the floor labelled "researched".

An arrow goes to an image labelled "less hierarchy / more equal footing" showing one silhouette figure crouching down and one lying down in a much more deliberate-looking pose. Arrows from this box read:

- Having advocate for participants
- A clear way out
- Guidance
- Paying for participation
- Human connection
- Travelling to participants
- Researcher identity reflecting participants'
- Options on how to participate.

Confronting the systems we work within

Illustration: a laptop with a ticked box saying "I confirm that this research is really, really ethical".

- "Human subjects" points to medical research – who qualifies for personhood?
- "Vulnerability" – who is defined as vulnerable and why? Who can consent?
- "Is the researcher competent in the methods?" Ambiguous question – how is this determined?
- "…ensure participants remain anonymous…" – implicit assumption that anonymity is ethical when it can mask pertinent information about participant identity.