Inspiring ethics

Exploring ethical models for participatory research

Community ethics boards

transparency
education
sustainability
community

Lambeth
proposed setting

Board is formed from a pool of people from a range of communities

ethics board offers
- bespoke ethics framework design
- opportunities to connect people
- training & education on ethical practice → plus accreditation for community participants
- ethics process facilitation for researchers

Model could sit within existing networks in Lambeth
- Black Thrive?
- Lambeth HEART?

Reviewers self-select the project(s) they want to work on via a portal

Lambeth has great infrastructure for & investment in this work

Who is & isn't allowed to be on a board?
- e.g. police? CEOs?
- + Open access publication to share frameworks developed through the project

Iterative approach

Funded! Who holds the funds?

An alternative or addition to uni boards?
What would incentivise people to seek out this board?

Older Latin community
imagined setting

in London

Separating out the roles between boards
- NHS & University boards retain technical focus, but defer to Community board
- Community board focuses on lived experience & community knowledge

Training for community board members

Paid for their time

A range of coordinating organisations would be responsible for recruiting bespoke boards for each project

Board has veto power over research projects

Developing standards for ethical research

What's to stop a researcher from seeking out another board after a veto?

Model requires substantial funding

Who owns the DATA?

Not a 'one & done' process
ongoing dialogue between researchers and boards

Is dividing out two streams viable?
& is it accessible to community researchers?

Dedicated participatory streams on uni ethics boards

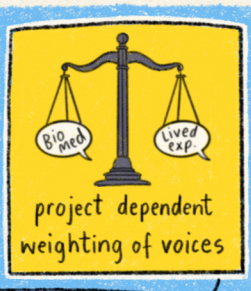
Uni participatory research project with neurodiverse youth
imagined setting

A relational and discursive approval process centred around ongoing communication

ethics process facilitator pool
- training & certification in research ethics
- renumerated for their time
- rotating panel of biomedical and/or lived experience

An approval system in two parts
1. Biomedically - informed
+
2. Participatory, lived experience

Both will collectively decide on research approval informed by their expertise



project dependent weighting of voices

with a facilitator to mediate

The stream would involve students & academics of all levels from undergrad upwards

collaboration
education
fair compensation

The stream would endorse researchers taking more personal accountability for the ethics of their work

BUT! HOWEVER!

This model doesn't challenge the power of the institution & means deferring to the university for ethical guidance

EXPENSIVE model

visual notes by tamara-jade Kaz