

## LE Summer Lab Session 3: Wednesday:

### Accountability and Ethics

*This session seeks to allow us to appreciate, analyse, criticise and correct how power plays out in our moral principles and commitments during research so that we can review how we work with research participants during Participatory Action Research (PAR). Doing no harm during PAR should be centred on the understanding that the research process is a collective, non-hierarchical research approach in which participants are also the researchers, and seek to deconstruct and shift power in our knowledge system. Therefore, accountability in PAR should look into how our own histories/herstories, internalised oppressions, privileges and prejudices may inform what we consider as doing good or doing no harm, and how the power that we hold has some bearing on how we respond to, and what we consider as ethical conduct during research. In PAR, those who are impacted by a particular phenomenon define the research problem and articulate it in their own way. After the end of this session, we are hoping that we can all be able to think through how we can put in place ways of ensuring that all research participants feel safe, and are by all means safe throughout the PAR processes, that research participants' well-being is at the centre and goes beyond ensuring the safety of research participants but that we also create spaces for care and well-being.*

**Time keeper for today: Sukti**

**Note taker for today: Emese**

**Recording:** Ask group if we can record for learning purposes only; explain that--as an example of our relation of care and rejection of "one-off" consent--we can delete if a discussion is captured that make folks feel uncomfortable

### Agenda

#### Opening Music

<https://www.youtube.com/watch?v=jST8hP9is-E>

9:00 Open with Meditation: Meg

#### 9:10 - 9:20 BREAKOUT INTO PAIRS/ open ended questions

Ten Minute Tea Time - breakout rooms for random pairs

Power conversations (in research processes), one on one.

Conversation guide:

*Have you ever been involved in a research process?*

*Who did you feel had more power? How did it feel?*

*If you would change one thing in the research process, what would you change?*

9:20 - 9:35

Mela - Opening Circle

Getting grounded for the day - A reflective "Walk" into a photo gallery

What do we see in the pictures?

What is the story that each picture is telling us (participants can be allowed to pick one picture that stands out for them and tell us what they think)?

What is the untold story emerging from the picture(s)?

What are the pictures telling us about ethics?

(can we allow for questioning who owns the knowledge that is produced in research as an ethics issue, and centre the power of knowledge?)

Centering community-centered ethics, accountability, care

Demystifying language and processes around ethics

### 9.35 -10.00 Ethics in PAR: Consent, Confidentiality, Safety and Care

Meg--slides/notes

Opening Question: What comes to mind when you hear the phrase “research ethics”? [type in the chat—read some out]

Historically, “research ethics” have been bound up in extractive forms of research

Research institutions have been the home of some of the worst forms of extractive and exploitative research, in which oppressed communities were used as research “subjects” with the benefits going to oppressors

- Research on enslaved people and colonized populations was at heart of US and European medical and social science for centuries
  - In US, enslaved people were used for racist medical experiments
  - In US, abuses continued in different forms as research on incarcerated people, unhoused persons, children in institutionalized settings
- Settler colonialists experimented on Native American/First Nations communities and continued unjust experiments through the Indian Health Service
- Colonial medicine often entailed forced examinations and experimental treatments

→ “the origin stories of research ethics enact a form of “colonial unknowing,” an active erasure of academia’s complicity in producing ongoing contexts of racialized social injustice” (Sheeva Sabati)

Calls for Accountability Led to Changes in Research Ethics

Following WWII, decolonial struggles, and the civil rights movement, there was a push to reexamine research ethics

- German Nazi science

- Used concentration camp prisoners as research subjects
- led to Nuremberg War Crime Trials
  - Nuremberg code was drafted as a set of standards for judging physicians and scientists who had conducted biomedical experiments on concentration camp prisoners
- U.S. Public Health Service syphilis study at Tuskegee used deception and withheld treatment from Black men over decades until it was exposed in 1972
  - In the US, the US Public Health Service studied Black men, some of whom it knew has syphilis, without their consent, using deception (lying about what they were studying and telling them they were receiving treatment) and withholding effective treatment (1932-1972—ended only because it was exposed; 1997, President Clinton offered official apology)
- led to Belmont Report and IRBs in US—identified core principles to protect research subjects; similar to formulations used globally [see next slide]

### **But the background power dynamics and forces of oppression remain**

- Core Elements of Modern Research Ethics
  - Respect for persons
    - § Respect for autonomy
    - § Protection for those with diminished autonomy
  - Beneficence
    - § Do no harm
    - § Maximize benefits
    - § Minimize harms
  - Justice
    - § Who enjoys the benefits of research?
- Informed Consent
  - Information
  - Comprehension
  - Voluntariness

How might Research Ethics be different in the context of PAR? [type into chat]

- No “research subjects”—all are co-researchers or partners in research
- Research is aimed directly at benefiting those conducting the research—it’s not only about knowledge, but also about change and justice
- Ethics are important for community as a whole, not only individuals

- Ethics are woven throughout the PAR process
  - From designing the questions a PAR will ask, to designing the research itself, ethical issues are always central
- PAR begins with the ethics the community already has
  - Starting by asking questions about how the community works best, how it takes care of its members, what care looks like in the community, can prompt discussions of how to conduct research in the most ethical way in this community
  - Shared commitment that no one will harm the other
  - Part of the process of critical consciousness and unpacking what harm is in any given context
  - An Ethical Protocol can be built in this way, from the ground up, as the research is designed

In text box: Unique Features of PAR Relevant for Ethics  
 Modified from Israel et al. (1998)

1. PAR involves a long-term commitment.
2. PAR recognizes community as part of identity.
3. PAR builds on strengths within the community.
4. PAR facilitates collaborative, equitable partnerships in all phases of the research, involving an empowering and power-sharing process.
5. PAR promotes co-learning and capacity-building.
6. PAR integrates and achieves a balance between research and action.
7. PAR emphasizes the local relevance of the many broad causes of injustice.
9. PAR makes its findings and knowledge gained available to all.

#### Creating an Ethics Protocol

- What is it?
- Should it be written?
- Some communities already have protocols
  - Indigenous Communities—e.g. principles of Ownership, Control, Access and Possession (OCAP) in First Nations in Canada; IRBs in Tribal Nations in the US
  - Some refugee communities
  - Places that have been subjected to over-research
- What are some elements to include? [How might the core principles be expressed differently in PAR, drawing from your experience and Mela's short article; Many consider the core principles a floor upon which to build]
  - Respect for persons

§ Respect for autonomy [But PAR is community-focused; not only about individuals; FPAR about both individual autonomy and collective good]

§ Protection for those with diminished autonomy

§ Mela:

- Free, prior, informed and continuous consent
- Group consensus for FPAR process
- Individual consent to publish individual stories, quotes and photographs
- Respect for traditional knowledge

○ Beneficence

§ Do no harm

§ Maximize benefits

§ Minimize harms

§ Mela: all co-researchers must do good and do no harm; protection of identities; care for one another

○ Justice

§ Who enjoys the benefits of research?

§ Mela: recognition of vulnerabilities; no exploitation; no abuse

○ Safety and security

§ Mela: co-researchers must carefully consider safety and the potential for PAR to make co-researchers more vulnerable

○ Deception and Exaggeration

§ Mela: no deception, fabrication, exaggeration or plagiarism

○ Feminist ethics of wellbeing and care

§ Mela: care for self and others—especially important since questions at heart of PAR are often fraught and emotionally laden for all co-researchers

§ Mela: FPAR embraces attachment to the research since it's about core issues that impact self + community

§ Mela: Representation as an Ethics Issue—will discuss later in the week

§ Mela: need to reflexively examine hidden power in PAR; build in space for self-reflection on situatedness + privilege [segue into next session]

**10:00 - 10:05 BREAK --music**

**10:05 - 10:50 Large group discussion**

Mela - Spider Web

Forces that trap us during PAR: Faces of Power

The story of a poor marginalised woman who died from gender-based violence. We will assume the woman's name is Amina. Amina goes to the well to fetch water, the well is dry and she goes to another well, further up to get water for her family. Her partner comes back home and finds that Amina has not finished preparing food and beats her up. Amina dies. What killed Amina? Let us connect the dots and discuss how this forms a web of injustices and systemic violence.

Can we use this picture of Amina (not her real name).



Instructions for Small Groups [10 mins in groups--10:15-10:25]

- Identify the different forces that caused Amina's death and write them in the "type here" tags
- Add strands of the web using the "line" tool showing the connections among these forces
- Discuss: How do we investigate, research into cases like Amina's without doing further harm?
- Examine the elements of ethics and look underneath/below them to ask
  - Consent: Amina is no doubt a traumatized person--how can we understand "consent" in this context?
  - Individualistic approaches to research will do more harm to her than good

Post-Small Group: Reporting Back and Delving Deeper [10:25-10:50]

Debrief:

--If we are carrying out research and we focus on only of the strings, are we able to understand the experience and situation of women like Amina?

-- Mela shares examples of PAR that were not designed with the community--these end up examining issues that are not relevant to the community--or worse, they can backfire (Oxfam example)

Connecting this to Ethics:

--If we have a Research Protocol that is approved by an Ethics Board, would that be enough to protect research participants who are trapped inside this web of injustice?

--How best can we carry out research without causing more harm to Amina?

What should we throw into our burning pot of privileges so that our research practices do not cause further harm to Amina?

-- If we look only at research ethics--consent, beneficence, justice--will these principles ensure your PAR responds to the hidden web of systemic violence?

-- Might the standard ethics principles also blind you to the ongoing harms that the research may be causing

-- CONSENT: When people are traumatized, "consent" takes on new meanings → must look beyond consent to examine wellbeing holistically

-- BENEFICENCE:

-- JUSTICE:

-- PAR is so beneficial because we are not dealing only with one individual, but the whole group--when the lead researcher is not there, the whole group can provide care, decide not to conduct research that day, etc.

Reflective Questions for Discussion

1. How do we deal with consent as a collective and individuals, given that the activist researchers are co-researchers, and researching into their own challenges and experiences?
2. Dealing with confidentiality – this is a collective process and how do we maintain confidentiality, our stories and experience are supposed to inform action?
3. How do we mainstream safety throughout the research process? Safety as an ethics issue for PAR carried out in hostile environments, and for groups living outside of the protection of the law? (e.g. security plans)
4. Wellbeing security / care

How do we:

- question the gender (and other) biases in individualistic approaches to ethics
- create a collective commitment based on thorough and impassioned consideration of care for self and others
- provide a starting point for understanding and addressing the material, emotional and psychological conditions that create insecurity for research participants
- look at care ethics and security as inextricably linked during the PAR process.

- build relationships of care and support
- challenge the dichotomy underlying the separation of thought from emotion, of reason from intuition conventional ethics
- refine and elaborate our ethics to suit our particular situations and contexts
- committed to flourishing and growth of individuals whilst acknowledging our interconnectedness and interdependence

10:50-11

Closing Circle: [Tom--body movement and optional sound]

11.

Sukti: One word from each person.