

# The intricate ethics of participatory research: Issues and challenges

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# Outline of presentation

- What is participatory research (PR) and why do it?
- Ethical issues in PR
- Everyday ethics and ethics work
- Exploring everyday ethics through case examples
- Cultivating the capacity of participatory researchers to do ethics work



## ETHICS IN PARTICIPATORY RESEARCH FOR HEALTH AND SOCIAL WELL-BEING

Cases and commentaries

Edited by Sarah Banks and Mary Brydon-Miller



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# Participatory research

# Community-based participatory research

# Participatory action research



# What is participatory research (PR)

**Participatory research** is a collaborative effort in which people whose lives might be affected by the issues being researched are partners in all, or some, of the processes of designing, undertaking and disseminating research, often with the aim of influencing socially just change.

**The process** aims to be democratic, participatory, empowering and educational.



# Examples of participatory research

- **Indebtedness in low-income households, Teesside, UK** – local community organisations and university research centre, with local mentor-researchers & campaigners
- **Suicide and well-being amongst Inuit people in the Arctic, Canada** – academic researcher & Inuit Steering Group, with some Inuit interviewers



# Degrees of community/resident/service user participation in research

1. **Community-controlled and -managed**, no professional researchers involved.
2. **Community-controlled with professional researchers** managed by and working for community groups.
3. **Co-production** – equal partnership between professional researchers and community members.
4. **Controlled by professional researchers** but with greater or lesser degrees of community partnership, e.g.
  - Advisory group involved in research design or dissemination.
  - Trained community researchers undertake some/all of data gathering, analysis, writing.
  - Professional researcher uses participatory methods (e.g. young people take photos).



# Why adopt a PR approach?

- An ideological commitment to participation
- To achieve social justice and social change
- Diverse perspectives enhance research design, interpretation
- Capacity building in communities
- To access to 'hard to reach' or 'easily ignored' people and groups
- To improve implementation of research into practice
- Public engagement and impact agendas in higher education & public services



# What about ethics?

**In the context of research with human subjects,** ethics traditionally covers topics such as the overall harms and benefits of research, the rights of participants to information, privacy, anonymity, and the responsibilities of researchers to act with integrity. It assumes a clear distinction between researcher and researched.

**In participatory research** this is different ...





# PR often involves:

- Partnerships between professional researchers and experts by experience
- An emergent design and research process, changing over time, 'messy'
- Community-based researchers as both informants and co-researchers
- Professional researchers as both co-researchers and activists.



This can create problems for Research Ethics Committees/Institutional Review Boards ....



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# Chair of Research Ethics Committee of Irish College of General Practitioners

Considering a participatory research project studying strategies for improving health care of migrants in European primary care settings:

*“We were used to randomised controlled designs, cohort studies and descriptive studies. This study was going to use a participatory approach and would involve action research and co-design with stakeholders. This was all very new to us and it was somewhat difficult for us to grasp what exactly all these terms meant. More troubling ...was the paucity of information on exactly who was going to participate in the study and what precisely was the intervention..”*

# Particular ethical challenges in PR

1. Partnership, collaboration and power
2. Blurring the boundaries between researcher and researched, academic and activist
3. Community rights, conflict and democratic representation
4. Ownership and dissemination of data, findings and publications
5. Anonymity, privacy and confidentiality
6. Institutional ethical review processes

(see Durham Community Research Team (2011) *Community-based participatory research: ethical challenges*,

[www.dur.ac.uk/resources/CCDiscussionPapertemplateCBPRBanksetal7Nov2011.pdf](http://www.dur.ac.uk/resources/CCDiscussionPapertemplateCBPRBanksetal7Nov2011.pdf)

also Banks et al, 2013, Banks and Brydon-Miller, 2019)

# Versions of ethics in research

- **Ethics as regulation** – codes, research ethics committees (following rules: *managerial ethics*)
- **Ethics as decision-making** – dilemmas, difficult choices (making choices drawing on principles/rules: *principle-based ethics*)
- **Ethics as embedded in everyday practice (everyday ethics/‘everywhere ethics’)** – situated in the research process: attitudes, ethos, ways of working, relationships (being a certain kind of person: *virtue ethics, ethics of care*). Requires ongoing effort, attention to context, ethical sensitivity, political awareness & reflexivity (‘ethics work’)





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28 case examples from around the world.

Everyday ethical issues:

- relationships
- power
- roles
- ownership
- ethics review



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# Ethics case examples

- Longer narratives of 2-3 pages
- Constructed by the authors as ‘ethics cases’ featuring difficulties, transgressions and/or dilemmas relating to rights, roles, responsibilities, power
- Descriptions of events & people involved; also accounts of emotions, reasoning and reflections
- Illustrative of some aspects of ethics work undertaken by the author.

# ‘Ethics work’ in a research context

‘**Work**’ – psychological and bodily processes of noticing, attending, thinking, interacting and performing, including the moves researchers make to perform or achieve a particular persona or state of mind (cf. ‘identity work’, ‘emotion work’ - social interactionism and constructionism, discourse analysis).

‘**Ethics work**’ - the effort researchers put into seeing ethical aspects of situations, developing themselves as good researchers, working out the right course of action & justifying who they are and what they have done (cf ‘phronesis’ - virtue & care ethics).



# Dimensions of ethics work

- **Framing work** – identifying and focusing on the ethically salient features of a situation; placing oneself and the situations encountered in political and social contexts (reflexivity and criticality).
- **Role work** – playing a role in relation to others (researcher, advocate, friend, critic); taking a position (partial/impartial; close/distant).
- **Emotion work** – being caring, compassionate, empathic; managing emotions.
- **Identity work** – working on one's ethical self; creating an identity as an ethically good researcher; maintaining researcher integrity.
- **Reason work** – making & justifying moral judgements and decisions.
- **Relationship work** – engaging in dialogue; working on relationships of trust and solidarity.
- **Performance work** – making visible aspects of this work to others; demonstrating oneself at work (accountability work).





# Everyday examples

1. **Dutch postdoctoral researcher** was asked by a community co-researcher with intellectual disabilities to 'correct' her writing.
2. **Research assistant with women's health NGO in Australia** considering how to respond to 'non-feminist' views of community co-researcher on violence against women.
3. **Community researcher in eSwatini** (formerly Swaziland) deciding not to follow protocols for interviews for health survey research so as not to hurt an interviewee from her village.



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# 1. Dutch postdoctoral researcher

*asked by a community co-researcher with intellectual disabilities to 'correct' her writing.*

- **Framing work** – people with intellectual disabilities as stigmatised in society
- **Role work**: seeing himself as co-researcher. 'I am not her Dutch language teacher'.
- **Reason work**: correcting language exerts 'cultural dominance', 'eradicates tension' in interactions between people/researchers with/without learning disabilities. Importance of 'authenticity'

## 2. Australian NGO researcher

*how to respond to 'non-feminist' views of community co-researcher on violence against women.*

- **Framing work:** feminist approach of NGO (Multi-cultural Women's Centre), belief in 'change being driven by people directly affected'
- **Relationship work:** building relationships with women experiencing violence; supporting groups
- **Role work:** considering whether to respond to the co-researcher's comments as a researcher (see her views as data), advocate (dispute her position) or woman driving a friend home ('gently questioning her'). [***Reflexive solidarity***]

### 3. Swazi community researcher

*deciding not to follow protocols for interviews for health survey research so as not to hurt an interviewee from her village.*

- **Framing work** – in scientific surveys asking the same questions is important to ensure high quality data; high prevalence of HIV in area.
- **Emotion work:** empathy – ‘he was the same age’, ‘lived in same community all our lives; ‘it might be offensive’; ‘I felt foolish’; ‘I would hurt the participant’; ‘I didn’t even think about breaking the data collection rules’.
- **Reason work** afterwards: ‘had I done the right thing?’

# Cultivating the capacity of participatory researchers to do 'ethics work':

- see the ethical issues at stake from multiple perspectives, including reflexive awareness of the position of self, organisation and social & political context.
- be prepared to engage in reflexive solidarity
- manage and engender emotions;
- work on ethical identity (e.g. becoming and being a respectful/honest person);
- work on relationships with research participants and other stakeholders;
- undertake practical reasoning, including working out how to act;
- take action;
- question critically the currently accepted values and standards of research.



# Chair of Research Ethics Committee of Irish College of General Practitioners

“In the end, we recognised that we had to trust the integrity and expertise of the research group. We came to realise that the very fact of using a participatory approach showed a high degree of sensitivity to the vulnerability of the group that was the focus of the research. We also had to accept that not all the information we were used to having at the outset of a study would be available until the study group commenced their work. We did ask for some clarification of the methods of participant recruitment and we sought some assurance about the availability of translators/cultural mediators. We asked that the participant information be simplified. It was a bit too jargonistic even for us, never mind for potential research participants.”

**IS THIS ENOUGH?**



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# **“ ... we had to trust the integrity and expertise of the research group”**

- Can we trust the integrity & expertise of the academic (and community) researchers doing PR?
- What do they have to do to convince the Research Ethics Committee? Show awareness of ethical issues and give clear outline of kinds of processes they will use to ensure ethical research?
- But the forms often do not encourage/allow this

# Community-based participatory research: A guide to ethical principles and practice, 2<sup>nd</sup> edition

## Community-based participatory research A guide to ethical principles and practice (2nd edition)

Centre for Social Justice and Community Action, Durham University  
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# Section I - Principles



1. Mutual respect
2. Equity and inclusion
3. Democratic participation
4. Active learning
5. Making a difference
6. Collective action
7. Personal integrity



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# Section II: Guidelines for ethical practice

1. Preparing and planning
2. Developing a working agreement
3. Designing the research
4. Generating and analysing data
5. Sharing and making impact from the research
6. Engaging in ongoing dialogue and ethical reflection



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# Appendix: Toolkits & cases

Tips for managing institutional research ethics committee processes in participatory research

Imagining the institutional ethical review process

Applying ethical principles in participatory research: Using ethical case discussions to promote ethical reflection and decision-making

Dilemmas cafés: Promoting ethical dialogue in participatory research

Developing a culturally appropriate (gender discriminatory) survey consent procedure

Issues of disclosure and intrusion: challenges for a community researcher

Establishing community-led ethical review boards in India



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# Cultivating the capacity of participatory researchers to do ethics work

- Working with longer, real life cases in class/training
- Supervision and critical dialogue with peers in a research team
- Ethics consultation
- Moral case deliberation
- Neo-Socratic dialogue
- Dilemmas cafés
- Forum theatre



# Everyday ethics & ethics work

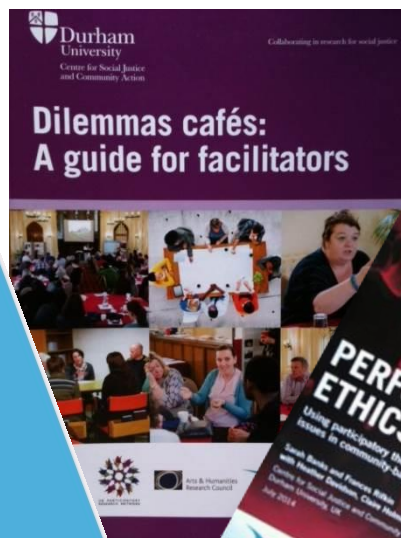
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Banks, S. (2016). [Everyday ethics in professional life: social work as ethics work](#). *Ethics and Social Welfare* **10**(1): 35-52.

Banks, S. and Brydon-Miller, M. (2019) (eds) [Ethics in participatory research for health and social well-being: Cases and commentaries](#), London: Routledge.

For more information and to download materials, Centre for Social Justice and Community Action, Durham University:

<https://www.durham.ac.uk/research/institutes-and-centres/social-justice-community-action/research-areas/ethics-consultation/>



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