

Democratizing research

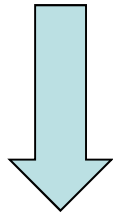
Issues of participation, social justice & ethical practice

Sarah Banks

s.j.banks@durham.ac.uk



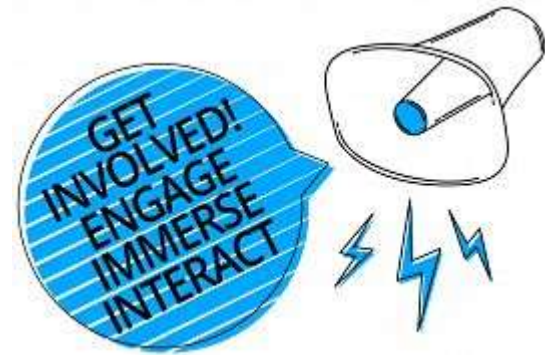
Democratizing caring, dying and grieving



Democratising research about caring, dying
and grieving
(participatory research)

Focus of today's presentation:

The participation of public/patients/service users/community groups as research partners with academics/professional researchers, and the ethical and practical issues this raises.



ETHICS IN PARTICIPATORY
RESEARCH FOR HEALTH
AND SOCIAL WELL-BEING

Cases and commentaries

Edited by Sarah Banks and Mary Brydon-Miller



What is participatory research (PR)

Participatory research (often called community-based participatory research in the health field) 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.



PR is not a research method – it is an orientation to the world

The participatory paradigm is based on:

- A 'radical' or 'extended epistemology', particularly valuing knowledge gained through experience (Heron and Reason);
- A commitment to principles of equality (valuing and respecting all contributions); participation (active engagement of all members in the group); and social justice (fair distribution of resources and power);
- A methodology based on cycles of reflection and action.



Examples of PR in health & social care

- **How people with intellectual disabilities feel at home in local neighbourhoods in the Netherlands** – partnership between a research institute & a self advocacy group, with some people with intellectual disabilities trained as researchers
- **Suicide and well-being amongst Inuit people in the Arctic, Canada** – academic researcher & Inuit Steering Group, with some Inuit interviewers
- **Sexual and reproductive health** among women with disabilities in the Philippines – Universities, NGOs, Participatory Action Groups
- **Strengthening community engagement with end of life issues** in Studio DöBra, Sweden - children, older people, design studio, artists, libraries



Degrees of community (public/patient/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 'seldom heard' or 'easily ignored' people and groups
- To improve implementation of research into practice
- Public engagement and impact agendas in higher education & public services



Challenges to PR

- ‘Scientific’ credibility – validity, reliability, generalisability
- Practical and ethical issues – ‘messiness’, emergence, boundary crossing



Scientific credibility

PR follows specific validity criteria (International Collaboration for participatory Health Research www.icphr.org)

- *participatory validity* – stakeholders take active part
- *intersubjective validity* – research meaningful to stakeholders
- *contextual validity* – relates to local situation
- *catalytic validity* – useful for social action
- *ethical validity* – processes and outcomes sound and just
- *empathic validity* – increased empathy among participants

As a consequence: The usual criteria for internal validity as found in other forms of research (methodological standards) may not be fulfilled!

Practical and ethical issues

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

Irish University Research Ethics Committee rejected proposed PR with people with advanced chronic respiratory disease

- A group of respiratory nurses in a hospital and an academic researcher wanted to study how basic palliative care might be embedded in everyday nursing and specifically in the care of people with advanced chronic respiratory disease.
- They proposed a [participatory] action research group of nurses and patients, who would co-design and carry out the research.
- The proposal was rejected by the University's Faculty Research Ethics Committee on grounds that:
 - a) Including patients with advanced disease in an action research group would be too onerous for them.
 - b) Asking patients to engage in a project the outcome of which was not pre-determined in terms of activities and time was unacceptable.

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)** – 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')

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
7. Collective social action

(see Durham Community Research Team, 2011, [Community-based participatory research: ethical challenges](#); also Banks et al, 2013; Banks & Brydon-Miller, 2019)

Everyday examples

1. **Irish nurses and an academic** had to work out how to redesign research on palliative care to include patients, sensitively and slowly.
2. **Dutch postdoctoral researcher** was asked by a community co-researcher with intellectual disabilities to 'correct' her writing.
3. **Research assistant with women's health NGO in Australia** considered how to respond to 'non-feminist' views of community co-researcher on violence against women.



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.
- question critically the currently accepted values and standards of research.
- 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.



Centre for Social Justice and
Community Action,
***Community-based participatory
research: A guide to ethical
principles and practice,***

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



International Collaboration for
Participatory Health Research,
Position Paper No. 2, ***Participatory
Health Research: A Guide to
Ethical Principles and Practice,***

www.icphr.org/position-papers--discussion-papers

Guide to ethical principles & practice: Principles

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



Guide to ethical principles & practice: Practice guidelines

1. Preparing and planning

- Why work together?
- Who should be involved?
- What are the aims and objectives of the research?

2. Doing the research

- How will the participants work together as research partners?
- How will researchers handle information and treat people who provide it?

3. Sharing and learning from the research

- How to analyse and interpret research data and findings?
- How to share the research?
- How to make an impact?



For more information and to download materials, Centre for Social Justice and Community Action, Durham University: www.durham.ac.uk/research/institutes-and-centres/social-justice-community-action/



ETHICS IN PARTICIPATORY RESEARCH FOR HEALTH AND SOCIAL WELL-BEING
Cases and commentaries

Edited by Sarah Banks and Mary Brydon-Miller



INTERNATIONAL COLLABORATION FOR PARTICIPATORY HEALTH RESEARCH

Promoting the science and enhancing the impact of participatory health research



Durham University

School of Applied Social Sciences

www.icphr.org/