

Tackling ethical challenges in community-based participatory research



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Summary

1. What is CBPR & why use it?
2. Approaches to ethics in research
3. Ethical challenges in CBPR – from Durham scoping study
4. The ethics guide, case examples, studies and films



What is CBPR

An approach to research that is based on a commitment to sharing power and resources and working towards beneficial outcomes for all participants, especially ‘communities.’

‘Communities’ are groups of people who share something in common – e.g. people living in a particular locality (a housing estate, village or urban neighbourhood), or groups based on common identity, interest or practice (such as a lesbian women’s group, a black young people’s network, an HIV support group or a netball team).

CBPR may be led and undertaken by members of community groups and organisations themselves, or by community groups working alongside professional researchers (including academics and research students).



CBPR & related approaches

- High proportion of literature from health field and N. America
- Term 'CBPR' used in health field to refer to community-based participatory health research
- Our use of the term CBPR is generic, covering all research that is community-based and participatory
- Overlap with participatory action research (PAR), but PAR is not always community-based

Why adopt a CBPR approach?

- An ideological commitment to participation
- Capacity building in communities
- Access to 'hard to reach' or 'easily ignored' participants
- New perspectives contribute to research design, interpretation
- Improved implementation of research into practice



Degrees of community participation in research

1. **Community-controlled and -managed**, no professional researchers involved.
2. **Community-controlled with professional researchers** managed by and working for the community.
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).



Elements of CBPR	Advantages	Disadvantages
CB steering group (research design)	<ul style="list-style-type: none"> •Relevant design •Facilitate access 	<ul style="list-style-type: none"> •Time-consuming
CB steering group (whole research process)	<ul style="list-style-type: none"> •Facilitate implementation •Community credibility 	<ul style="list-style-type: none"> •Complex partnership arrangements
CB researchers (data collection)	<ul style="list-style-type: none"> •Enhanced access •Enhanced information 	<ul style="list-style-type: none"> •Training & support •Complex confidentiality/privacy
CB researchers (data analysis & interpretation)	<ul style="list-style-type: none"> •Range of perspectives •Ensure accessible & relevant language 	<ul style="list-style-type: none"> •Time and training •May reduce credibility in some quarters

Ethics is a topic that covers questions relating to what kinds of lives we should lead, what counts as a good society, what actions are right and wrong, what qualities of character we should develop and what responsibilities humans have for each other and the ecosystem.

In the context of research, ethics as a subject area 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.



Versions of ethics in research

- **Ethics as regulation** – codes, research ethics committees/institutional review boards
- **Ethics as decision-making** – dilemmas, difficult choices
- **Everyday ethics** – embedded in the research process: attitudes, ethos, ways of working, relationships

The *Ethical Challenges in CBPR* project

- Funded by UK Arts & Humanities Research Council (AHRC) Connected Communities programme
- Comprised co-inquiry group of academics and researchers, a literature review and international advisors
- Aim to identify key ethical challenges from the literature and the experience of the co-inquiry group



The *Tackling Ethical Issues* project

- Funded by AHRC, Connected Communities programme
- Brought together 4 previous Connected Communities projects & international advisors
- Aim to produce resources on ethics: guide and cases relevant to community-university partnerships and community-led research



Ethical challenges in CBPR

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/beacon/CCDiscussionPapertemplateCBPRBanksetal7Nov2011.pdf)



Community-based participatory research:

A guide to ethical principles and practice



Guide to ethical principles & practice: Purpose



- raise ethical awareness amongst research partners and participants
- encourage discussion about ethical issues that can arise in CBPR
- offer ethical guidance to partners and participants in CBPR
- inform research institutions (including universities), research funders and sponsors about what ethical issues might come up so they can ensure CBPR is conducted according to the highest standards
- inform research institutions, research funders and sponsors about the complexities and nuances of CBPR to ensure they do not impose ethical standards that are impractical, patronising to community researchers or partners or inappropriate in other ways
- improve ethical practice in CBPR



Challenges in framing the guide

- How to give guidance without prescribing
- How to take account of ethics of research partnerships and ethics of researchers working with research participants
- How to highlight the need of those new to research for support/training without pushing into university/institutional mould
- How to value existing community-based ethics expertise



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?



Ethics in CBPR: Case studies, case examples and commentaries

Case studies – overviews of research projects

Case examples – accounts from individuals of ethical issues and challenges for them

Commentaries – on each case example from two different people



Challenges in framing cases

- What counts as research?
- What counts as an ethical issue?
- Seeing ethical issues – moral perception and sensitivity
- Anonymity of case authors or not?
- Exposure to commentators

Digital story-telling case example

- Museum-based project engaging with local people to create and accession their personal stories
- Although copyright assigned to museum, should people be able to withdraw/change their stories?
- Is a story fixed or dynamic?

Guns and gangs case example

- Youth peer research commissioned by local agencies
- Cooption and performance to agencies' agendas
- Disempowering of youth worker when she became a research trainer
- Honesty and credibility of the research

Young women's project case study – growing ethics film

www.publicengagement.ac.uk/about/ethics

<http://www.youtube.com/watch?v=gOGsSITMLf8>



For more information and to download materials:

www.durham.ac.uk/beacon/socialjustice/ethics_consultation

www.publicengagement.ac.uk/work-with-us/current-projects/ethics-cbpr

**Join our follow-on project:
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