Key ethical challenges in community-based participatory research

Sarah Banks, Andrea Armstrong, Kath Carter, Amelia Lee, Niamh Moore
Summary

1. *The Tackling Ethical Issues* project
2. What is CBPR?
3. Why use CBPR?
4. Advantages & disadvantages
5. Ethical challenges in CBPR
6. Ethical guidelines for CBPR
7. Ethics cases and reflections on learning

*Durham University*
*School of Applied Social Sciences*
The Tackling Ethical Issues project

- Funded by AHRC, Connected Communities programme
- Brought together 4 previous Connected Communities projects
- Aim to produce resources on ethics: guide and cases relevant to community-university partnerships and community-led research
The Tackling Ethical Issues team

- Andrea Armstrong, Durham University
- Sarah Banks, Durham University
- Kathleen Carter, Thrive, Thornaby
- Helen Graham, Leeds University
- Peter Hayward, Friends of Newport Ship
- Alex Henry, formerly Tyne & Wear Archives & Museums
- Tessa Holland, Energy Group, West End Housing Coop, Newcastle
- Claire Holmes, Young Women’s Project, Manchester
- Amelia Lee, Young Women’s Project, Manchester
- Ann McNulty, Health and Race Equality Forum, Newcastle
- Niamh Moore, University of Manchester
- Nigel Nayling, University of Wales, Trinity Saint David
- Ann Stokoe, Over the Waves, Aberteifi
- Aileen Strachan, Glasgow Museums/Glasgow Life
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).
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
• Public engagement and impact agendas in higher education
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).
<table>
<thead>
<tr>
<th>Elements of CBPR</th>
<th>Advantages</th>
<th>Disadvantages</th>
</tr>
</thead>
</table>
| **CB steering group (research design)** | • Relevant design  
• Facilitate access | • Time-consuming |
| **CB steering group (whole research process)** | • Facilitate implementation  
• Community credibility | • Complex partnership arrangements |
| **CB researchers (data collection)** | • Enhanced access  
• Enhanced information | • Training & support  
• Complex confidentiality/privacy |
| **CB researchers (data analysis & interpretation)** | • Range of perspectives  
• Ensure accessible & relevant language | • 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

• **Ethics as decision-making** – dilemmas, difficult choices

• **Everyday ethics** – embedded in the research process: attitudes, ethos, ways of working, relationships
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

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
Guide to ethical principles & practice: Ethical principles

1. Mutual respect
2. Equality and inclusion
3. Democratic participation
4. Active learning
5. Making a difference
6. Collective action
7. Personal integrity
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
Young women’s project case study - learning from reflecting on ethics

• Process of compiling the case study
• Process of working on the article together: ‘Everyday Ethics in CBPR’
Community researcher case example – learning

- Reflections on participation in the co-inquiry group on ethics
- Process of compiling the case example
- Publication of academic journal article: Kath Carter et al: ‘Issues of Disclosure and Intrusion - Ethical Challenges for a Community Researcher’ *Ethics and Social Welfare* journal
For more information and to download materials:

- www.publicengagement.ac.uk/how-we-help/our-publications
- www.durham.ac.uk/beacon/socialjustice/ethics_consultation

Join our follow-on project: socialjustice@durham.ac.uk