Connected Communities

Community-based Participatory Research: Ethical Challenges

Durham Community Research Team

Centre for Social Justice and Community Action, Durham University

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Executive Summary

This paper outlines the findings of a scoping study examining ethical issues in community-based participatory research (CBPR), based on a literature search and the deliberations of a co-inquiry action research group. The search indicated a range of research approaches claiming to be participatory and community-based, showing significant variation in degrees of participation and community control. Ethical challenges in CBPR include matters relating to: partnership, collaboration and power; community rights, conflict and representation; ownership and dissemination of data, findings and publications; anonymity, privacy and confidentiality; institutional ethical review processes; and blurred boundaries between researcher and researched, academic and activist. While many of these issues are common in qualitative social research, what is distinctive about CBPR is the openness, fluidity and unpredictability of the research process. It is often complicated by multi-layered partnerships based on the negotiation of power relations between diverse groups (with specific histories, politics, cultures and personalities), whilst also being constrained by rigid structures of research governance. Recommendations include: the adoption of specific ethical guidelines for CBPR by UK researchers, funders and sponsors; ethnographic research on the CBPR process; a search of grey literature for accounts of CBPR from community perspectives; and further longitudinal research on outcomes of CBPR.

Researchers and Project Partners

(for full details see Appendix 1)

Review Team: Andrea Armstrong (Research Associate), Maria Aznarez (Administrative Assistant), Sarah Banks (Principal Investigator), Thomas Henfrey (Workshop Facilitator), Helen Moore (Technical Associate) with Co-investigators Gary Craig, Rachel Pain and Carolyn Summerbell.

Co-inquiry Action Research Group: Kathleen Carter, Maurice Clarkson, Audley Genus, Rose Gilroy, Tessa Holland, Kate Hudson, Ann McNulty, Jenni Owen, Anna Wraith with Tom Henfrey, Maria Aznarez, Andrea Armstrong and Sarah Banks.

International Advisors: Harvinder Bedi, Ingrid Burkett, Michelle Fine, Angie Hart, Sara Kindon, Laura Saija.

Project partner: Beacon North East (Newcastle-Durham Beacon for Public Engagement)

Key words

Community-based research, participatory research, research ethics, research partnerships

Introduction and rationale

CBPR is increasingly popular, with a growing literature written mostly from an academic perspective. By 'community-based' we mean research that tackles issues relevant to people belonging to, or with interests in, a community of place, interest or identity (e.g. local residents, community activists, members of community groups, staff of NGOs or other service-providers). By 'participatory' we mean some degree of active involvement of a range of community stakeholders in research design, process and implementation (e.g. as research commissioners, advisory group members, co-researchers or peer researchers). In projects with 'deep participation', ownership lies with the community rather than outside researchers (see Box 1). Other terms such as 'community-based action research', 'participatory action research', 'co-inquiry' or 'co-production' are also sometimes used to refer to research that is community-based and participatory.

The popularity of CBPR stems partly from the fact that it is an approach that can be used to engage groups that are perceived as 'hard to access' by professional researchers (for example, minority ethnic and faith groups, indigenous communities, people with disabilities) and through this engagement more equitable and sustainable outcomes may be achieved for those groups/communities. There is also an ideological rationale for CBPR, often framed in terms of an explicit value position involving a commitment to sharing power with those usually the objects of research, and to working for progressive social change. In the UK, CBPR gained recent exposure through the Beacons for Public Engagement initiative in higher education (2008-2011) alongside a general growth of interest in community-university research engagement and research impact.

The main focus of this study is the nature and range of ethical issues in CBPR, taking a broad definition of 'ethics' as relating to matters of right and wrong conduct, good and bad qualities of character and responsibilities attached to relationships. The subject matter of ethics is often said to be human welfare, but the bigger picture includes the flourishing of the whole ecosystem. Initially a further topic for this scoping study was to explore the nature of the outcomes claimed for CBPR. However, due to the substantial number of articles generated by the search and time limitations, the main focus was ethical issues. A note on outcomes in CBPR is in Appendix 2. The aims of the part of the study reported here were to:

1. Provide a critical overview of literature on participatory approaches to community-based research, with a particular focus on ethical issues, drawing on national and international experience.

2. Offer guidance and recommendations to the Connected Communities programme on tackling ethical challenges in CBPR.

Methodology

The study was undertaken during March-October 2011, comprising:

1) A literature search.
2) Three Review Team meetings.
3) Three Co-inquiry Action Research (CAR) group workshops.
4) Three consultations with International Advisors.

A search framework (Appendix 3) was applied to three databases that index published journal articles. Initially the search was wide – relating to research that was community-based, participatory and involving so-called 'hard to reach' groups. This generated the following results: Applied Social Science Index and Abstracts (ASSIA), 3094 articles; Web of Science (WoS), 9578; and Medline, 3948. We focused on ASSIA results, as articles could be ordered by relevance. A further search for 'ethics' or ethical' in the title/abstract resulted in 28 articles from ASSIA and a further 15 from hand-searching WoS. Of these, 15 were rejected as not meeting the criteria of being community-based and/or participatory and/or having any substantive content relating to ethics.

The Review Team comprised seven academics from Durham University with expertise in participatory research, community development and literature reviews. The team discussed results from database searches, recommended key literature and planned next steps. The CAR group comprised academics from Newcastle and Durham Universities and community research partners, who discussed ethical issues in workshops using a range of participatory techniques. The International Advisory Board comprised six expert academics and/or community development practitioners from India, Australia, USA, UK, New Zealand and Italy, consulted following team meetings and workshops.

Types of CBPR

The initial database searches generated articles in a variety of formats, the most common being case studies of particular research projects or interventions. CBPR is noticeably popular in health research in the USA. Not all articles were explicit about the degree to which the reported research was community-based and/or participatory. If we assess studies along a continuum of community participation (Box 1), the majority of research falls into the fourth category (controlled by professional researchers, with some degree of community participation). This is unsurprising, given the searches focussed more on academic articles than professional or 'grey' literature. However, it also reflects the way research sponsors allocate funding and the requirements of universities for publication. Many accounts of research that are framed in terms of co-production betray moderate degrees of professional researcher control. Some articles include community partners as co-authors, but very few are written from a community partner perspective.

Box 1: Degrees of community participation in research

1. Community-controlled and -managed research, 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 design, dissemination.
   - Trained community researchers undertake some/all of data gathering, analysis, writing.
   - Professional researcher uses participatory methods (e.g. young people take photos).

CBPR and ethics

There are two main ways that issues of ethics in CBPR are framed in the literature:

1) **CBPR is often claimed to be inherently more 'ethical'** (meaning ethically good) than so-called 'traditional' research in which there is alleged to be a clearer distinction between researchers and researched. Examples are often given of scientific/health research that has harmed/exploited vulnerable participants, including indigenous or ethnic communities or people with disabilities. While these assumptions can be questioned, especially when CBPR is academic-led, it is presented as an inherently ethical model in that it is:

   a) more ethically-aware because it takes greater account of issues of power, rights and responsibilities and the roles of all stakeholders.

   b) more egalitarian and democratic, based on respect for and partnership with community members.

2) **CBPR entails complex relationships of power and accountability** and hence raises distinctive ethical challenges relating to developing/maintaining partnerships, difficulties in maintaining anonymity and blurred boundaries between researcher and researched (e.g. community researchers researching their own communities). Some ethical issues identified in the literature and by the CAR group relate more to the research topic and/or group/neighbourhood that is the focus of the research (i.e. sensitive issues or disadvantaged groups) than specifically to the fact that the

approach is CBPR. But it is hard to disentangle approach, methods and topics, as CBPR often focuses on disadvantaged groups/neighbourhoods and sensitive topics. It may also be undertaken by researchers who are politically committed and wish to use the results for campaigning.

Examples of ethical challenges in CBPR

The most common explicit coverage of ethics in the literature relates to the operation of Research Ethics Committees or Institutional Review Boards and issues of confidentiality, informed consent, representation, anonymity and ownership of data. These issues are common to qualitative research, but take on specific dimensions in CBPR. Implicit ethical issues are often embedded in discussions of research methodology and process, even if not named as such, particularly in relation to power, partnership and participation. The deliberations of the CAR group complemented the findings from the literature review, building on many of the key issues, providing more nuanced understandings or alternative perspectives and raising new issues less prominent in the literature (Appendix 4). A selection of the main ethical challenges covered in the literature and discussed in the CAR group is outlined below.

1. **Partnership, collaboration and power**. CBPR promises a move away from the 'outside expert' and tokenistic involvement, placing emphasis on negotiating and developing relationships in specific cultural/spatial/political/historical contexts. Dodson et al. (2007:822) warn that "researchers must grapple with power and vulnerability – both those of other people as well as their own". Many articles refer to work with a social justice focus, including ethical issues relating to 'race', ethnicity and cultural difference. However, it is important to recognise that all CBPR involves navigating social difference. A range of articles provide reflections on relationships between professional researchers and community partners, echoing the comments of Dodson et al. (2007:823) that 'collaboration and the conventions of research methodology are uneasy partners'. The time taken to build trusting relationships (Love, 2011) and the mis-match between academic calendars, funding timelines and community needs and expectations also create challenges. Several articles discuss the importance of ongoing dialogue in building relationships of trust, relieving group tensions and planning outcomes (Johnson et al, 2009; Love, 2011; Mohatt et al, 2004; Springgate et al, 2009). Experiences of participation may not be universal and those involved may experience moments of exclusion and inclusion (Ponic and Frisby, 2010). Direct personal accounts shared in the CAR group illuminated the importance of relationships based on mutual understanding and respect for difference, and how these can develop into effective partnerships that address the needs and interests of academics and community partners. The focus of CBPR on relationships also suggests that theoretical approaches to ethics that emphasise responsibilities and relationships (ethics of care) might be helpful in providing alternative/complementary framings to rights-based approaches (ethics of justice) (Charles, 2011).

2.   Community rights, conflict and democratic representation.   Despite the plethora of ethical codes for research, most are concerned with the individual rights of human subjects. CBPR raises the challenge of extending rights to groups or communities (Quigley, 2006). This creates problems, including defining what counts as a 'community'; the potential for conflict between individual and group interests; how to modify informed consent to take account of group characteristics; and issues of who best represents a group or community (Wallwork, 2003). Further complexity is added if the topic is controversial and opinions are divided within a 'community'/group. Interesting examples include research on female genital cutting in the Somali community (Johnson et al., 2009) and attitudes of people with disabilities to physician-assisted suicide/death with dignity (Minkler et al., 2002). However, other articles demonstrate the unifying potential of research that identifies and examines a common issue or problem. For example, Horn et al. (2008) report how internal conflicts were avoided in Native American communities by ensuring diverse groups unified around a common theme, emphasising consensus-building rather than division and difference. Traditional conceptions of representation may be difficult to apply in some settings, such as multi-ethnic neighbourhoods or amongst stigmatised and marginalised groups, where there may be a lack of pre-existing structures for representation (Shagi et al, 2008). Furthermore, as the CAR group deliberations indicated, communities may have their own ethical codes/framings that differ from or conflict with those of external researchers (see Kindon and Latham, 2002; Sanderson and Kindon, 2004).

3. Ownership and dissemination of data, findings and publications.   Group and/or community involvement as research partners adds complexity when considering ownership of data and results. According to Quigley (2006:142):

> The most problematic areas of research ethics in communities are about data control, confidentiality, interpretation of results, ownership, publication of results and dissemination procedures.

Many community research partners may not anticipate these issues and hence, in the view of the CAR group, it is particularly important to negotiate before research starts. To avoid the academic exploitation of community data, stigmatisation of communities and violation of privacy, some CBPR projects develop agreements relating to data ownership and publication (Quigley, 2006; Maddocks, 1992). Several articles highlight the difference between 'traditional' ways of disseminating research amongst professional peers and CBPR, involving dissemination to communities and wider publics (Love, 2011). Community members of the CAR group stressed the importance of using plain language in community dissemination.

4.   Anonymity, privacy and confidentiality. These issues are common in all social research, but distinctive questions in CBPR include:

1) How can communal as well as individual consent be negotiated?

2) What rights should a community have to demand confidentiality in relation to certain types of information?

3) Can anonymity of participants in CBPR be secured, especially if community researchers are involved and there is wide dissemination within the community that is the focus of the research?

4) Is the preoccupation with anonymity always desirable, as community participants may wish the community and individuals to be given credit and/or to be named in order to publicise specific issues and improve longer-term outcomes?

To tackle these questions, many CBPR projects establish community-based agreements to ensure participants understand the research, that there is an awareness and explanation of community risks and benefits and issues of anonymity, coercion and voluntariness are discussed (Quigley, 2006).

5.   Institutional ethical review processes. The context-dependent nature of CBPR makes it difficult to fit within institutional review frameworks, which are generally not established with CBPR in mind (Flicker and Guta, 2008; Love, 2011). They tend to assume: a clear distinction between researchers and researched; a requirement for individual consent to participate; predictability of process and outcomes; and control by professional researchers. Malone et al. (2006: 1915) argue that the current culture of academia often protects institutional power at the expense of community empowerment. In judging the overall merit of research proposals, Fundación Sabiduría Indígena and Kothari (1997) argue that benefits for local people should be given as much weight as theoretical and methodological aspects. As interest grows in participatory approaches, Moore (2004:145) suggests universities need to adapt to alternative research methodologies. Academic CAR group members offered examples of difficulties in gaining institutional recognition and ethical approval. Effective partnership was regarded as vital in highlighting institutional constraints experienced by academics, generally invisible to community partners, and enabling their negotiation in ways that allow representation of diverse viewpoints and needs. The value of a set of ethical principles for CBPR to be used in institutional ethical review processes was highlighted by the CAR group and initial ideas are in Appendix 5.

6. Blurring the boundaries between researcher and researched, academic and activist. CBPR often makes high demands on emotional and intellectual energy and may disrupt participants' personal lives (Moore, 2004). Tensions may emerge between the roles of academic and activist (Cancian, 1993); outcomes may be unexpected and painful (Miller, 1994). Transformation is often both an aim and outcome of CBPR - personal transformation as well as transforming social structures (Maguire, 1993; Carson and Sumara, 1997). Moore (2004:155) warns that 'transformation can be a difficult pathway filled with anxiety, self-critique and heightened awareness', so supportive institutional structures are required. CAR group members emphasised that community researchers interviewing or conducting focus groups in their own communities, or social welfare or health practitioners adopting a research role, need high degrees of self-awareness to ensure that privacy and confidentiality are not breached and professional and personal issues do not become damagingly blurred.

Recommendations for future research

1. Adoption and promotion of a set of ethical principles and guidelines for CBPR in the UK by researchers, research councils, research charities, universities and other research funders and commissioners.

2. Ethnographic research on the process of CBPR to provide detailed and nuanced accounts of ethical challenges and how these are tackled.

3. A review specifically focussing on grey literature to source accounts of CBPR from community perspectives.

4. Longitudinal studies of communities engaged in CBPR to trace longer-term outcomes in relation to the research and examine approaches to evaluation.

References and external links

(For the full bibliography, see Appendix 6)

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Websites

These websites offer a wealth of information and guides to those interested in CBPR, related participatory approaches and ethical issues.

Community-Campus Partnerships for Health, USA
http://www.ccph.info/

Community-University Partnership Programme (CUPP), University of Brighton, UK
http://www.brighton.ac.uk/cupp/

Development Support Team, Pune, India
http://dstpune.org/index.aspx

Institute of Development Studies: Knowledge Services, UK
http://www.ids.ac.uk/go/knowledge-services

Involve: making participation count, UK
http://www.involve.org.uk/

Involve: supporting public involvement in NHS, public health & social care research, UK
http://www.invo.org.uk/

National Coordinating Centre for Public Engagement, UK
http://www.publicengagement.ac.uk/

Public Science Project website, UK
http://www.publicscienceproject.org/resources/

Appendices

A copy of the appendices to this report can be downloaded from:
http://www.durham.ac.uk/beacon/socialjustice/researchprojects/ OR
http://www.dur.ac.uk/sass/research/archive/

Appendix 1: Project participants
Appendix 2: A note on outcomes of CBPR
Appendix 3: Details of the literature search
Appendix 4: Preliminary report on Co-inquiry Action Research group workshops
Appendix 5: Towards draft ethical principles for CBPR
Appendix 6: Bibliography

The results of additional work on this topic will be added to the websites.
For further details contact: s.j.banks@durham.ac.uk

The Connected Communities

Connected Communities is a cross-Council Programme being led by the AHRC in partnership with the EPSRC, ESRC, MRC and NERC and a range of external partners. The current vision for the Programme is:

> "*to mobilise the potential for increasingly inter-connected, culturally diverse, communities to enhance participation, prosperity, sustainability, health & well-being by better connecting research, stakeholders and communities*."

Further details about the Programme can be found on the AHRC's Connected Communities web pages at:

www.ahrc.ac.uk/FundingOpportunities/Pages/connectedcommunities.aspx