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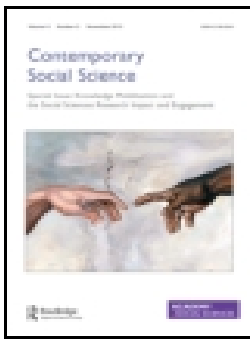
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Everyday ethics in community-based participatory research

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This article explores a range of ethical issues that arise in community-based participatory research (CBPR), drawing on literature and examples from practice. The experience of CBPR practitioners adds further weight to the growing critique by many other social researchers of regulatory approaches to research ethics (which focus on rule following in accordance with research governance frameworks, codes of conduct and ethics review procedures). Yet, whilst many of the ethical challenges in CBPR are common to social research generally (informed consent, anonymity, issues of ownership of data and findings), the dynamic, complex and value-based nature of CBPR gives them particular prominence. There are also specific issues relating to the ethics of partnership working, collaboration, blurring of boundaries between researchers and researched, community rights, community conflict and democratic participation that are more frequently encountered in CBPR. Four practice examples are used to demonstrate this argument. These are taken from a young women's community allotment, a community organisation researching poverty, a youth peer research project and a museum-based digital storytelling project. The article concludes that current institutional ethical codes, guidelines and ethical review procedures are not particularly well-suited to CBPR, in that they adopt principle-based and regulatory approaches to ethics; whereas character- and relationship-based approaches to ethics are also very important in CBPR, which is adopted by many researchers with a strong value commitment to social justice.

Keywords: community-based participatory research; ethics; institutional review; ethical guidelines

Introduction

This article draws on careful reflections on a range of ethical issues experienced in undertaking community-based participatory research (CBPR), demonstrating the challenges these pose to the standard ethical codes and institutional review processes for research. It considers ways of conceptualising these issues in terms of an approach we call 'everyday ethics', which stresses the situated nature of ethics, with a focus on qualities of character and responsibilities attaching to particular relationships (as opposed to the articulation and implementation of abstract principles and rules). This topic is particularly pertinent to the special issue theme of 'knowledge mobilisation' for several reasons. First, CBPR is an increasingly popular research methodology that aims

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to mobilise the local and indigenous knowledge of people based in communities of place, identity and interest. Second, its participatory nature contributes to enhancing the impact of research, as the process of CBPR promotes knowledge exchange within and between 'communities', universities and other research, policy-making or service delivery institutions. This can result in developing the skills, understandings and commitments of all parties in relation to the topic of the research and their abilities to work together in creating better designed policies and services, more effective campaigns and 'empowered' communities. Third, CBPR is a complex and challenging approach to research. It demands particular attention to the ethical issues arising from the dynamics of power relations between different parties. It also unsettles, along with other participatory and emancipatory approaches to research, the traditional framings of research ethics and procedures. So if it is to be effective in promoting knowledge mobilisation and generating impact on policy and practice, changes need to be made to the way we conceptualise, regulate and support research, so that CBPR can reach its full potential.

The article draws on two studies of ethical issues in CBPR, funded by the Arts and Humanities Research Council (AHRC) as part of the UK research councils 'connected communities' programme. The first is a scoping study based on a literature review and the deliberations of a co-inquiry action research group comprising community partners and academics from Durham and Newcastle Universities (Durham Community Research Team, 2011). The second is a study bringing together community and university partners from four previous projects to develop ethical principles and guidelines for CBPR and share and write up case studies and case examples of ethical issues (Centre for Social Justice and Community Action (CSJCA) and National Coordinating Centre for Public Engagement (NCCPE), 2012). Our brief description of the nature of CBPR and the key ethical issues identified in the literature draws on the first study. Our practice examples are taken from the second study in which the co-authors of this article were participants.

What is CBPR?

'CBPR' is an increasingly popular term, particularly in North America in the field of health research. While some definitions of CBPR have a focus on health, we are using the term in a broader sense to encompass research in a variety of fields that is 'community-based' and 'participatory'. 'Community' refers to a group of people with some (but not all) characteristics in common – for example, people who live in the same place (e.g. a housing estate, village or urban neighbourhood), or who share a common identity, interest or practice (e.g. a lesbian women's group, black young people's network and a football team). CBPR is research that entails some degree of active involvement of a range of community stakeholders and generally operates from a value base, derived from a commitment to sharing power and resources and working for beneficial outcomes for all participants. Indeed, Israel, Schultz, Parker, and Becker (1998), in an influential review, characterise CBPR as research that is based on a set of values that includes the promotion of equal partnerships and co-learning and an explicit commitment to ensuring research leads to, and is informed by, action.

This description of CBPR could fit equally well with much research that is characterised as 'participatory action research' (PAR). The term 'PAR' is used to refer to research that engages people usually regarded as 'subjects' of research in aspects of research design and/or process (participatory), with an explicit intention of generating practical changes (action). We have chosen to use the term 'CBPR' rather than 'PAR', as our interest is specifically in participatory research conducted by or with communities. While participants in PAR are frequently members of pre-existing communities, this is not a defining characteristic of PAR. Nevertheless PAR does work through creating 'participative research communities' during the course of the research and there is considerable overlap between PAR and CBPR. Hence much of our discussion applies equally to PAR and other participatory and collaborative approaches such as participatory inquiry, co-inquiry or

collaborative action research. Indeed, when discussing action research, Reason and Bradbury (2008, p. 6) describe it as a 'family of approaches'. This is an apt characterisation of a field of inquiry that they see as subscribing to a 'participatory worldview' and CBPR is certainly part of that family.

The growing popularity of CBPR

In the UK, research that is community based and participatory has gained recent exposure through national initiatives to promote stronger engagement between universities and a range of 'publics', including communities – for example, the Beacons for Public Engagement (2008–2011)[1] and Research Catalysts programme (starting in 2012).[2] Similar developments can be seen across other sectors – museums, local government and third sector organisations – and are linked to a number of related trends in society generally, and in public policy more specifically. These include a concern with challenging elitism and widening access to higher education, democratising the research process, demonstrating value for money, valuing of expertise by experience and developing local solutions to local problems (Benneworth, Conway, Charles, Humphrey, & Younger, 2009; Greenwood & Levin, 2001). For many academic researchers an important rationale is an ideological commitment to valuing different types of knowledge (particularly experiential knowing) and the redistribution of ownership and control away from universities and large research institutions (Heron & Reason, 2008; Pain, Kindon, & Kesby, 2007). Community-based groups and organisations also see the value in conducting research themselves, or in partnership with others, in order to gain evidence to satisfy funders, influence policy and practice and develop new skills, knowledge and confidence (Couzos, Culbong, Lea, & Murray, 2005; Hart, Maddison, & Wolff, 2007). However, CBPR may sometimes be instigated by professional researchers as an effective way of generating knowledge and creating impact, which would be hard to achieve without community engagement in the research design and/or process. It is often used to engage groups that are perceived as 'hard to access' by professional researchers, such as minority ethnic and faith groups, indigenous communities and people with disabilities (see Horn, McCracken, Dino, & Braybot, 2008; Johnson, Ali, & Shipp, 2009; Minkler et al., 2002). Hence it is seen as an important approach to knowledge mobilisation and exchange within this arena, but is also open to cooption by institutions and agencies for their own ends.

Indeed, research that is called 'CBPR' may exhibit varying degrees of community relevance and participation, ranging from projects where ownership lies with community-based groups, to those where outside researchers involve community participants in small parts of a professionally controlled project (see Box 1). Accounts of CBPR projects do not always specify how much power and control is held by community participants/partners. However, our review of the literature suggests that community control and equal partnership are much less common in practice than professional control with elements of community participation – although the balance of power may change over time and across different aspects of the research.

Box 1. Degrees of community participation in research
(taken from Durham Community Research Team, 2011, p. 6).

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

Ethics

In CBPR, the variety of stakeholders and the inherent commitment to some degree of power-sharing mean there is wide scope for complex ethical issues to arise. CBPR also provokes alternative understandings of the nature of ethics. The subject matter of ethics is often said to be human welfare, but the bigger picture includes the flourishing of the whole ecosystem. Debates in ethics cover questions relating to what counts as flourishing, right and wrong conduct, good and bad qualities of character, and what responsibilities humans have for each other and the ecosystem. In the context of social 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 and anonymity, and the responsibilities of researchers to act with integrity (Banks, 2012a). In recent years, there has been a growth of codes of ethics, statements of ethical practice and research governance frameworks for particular disciplines or types of research designed to regulate the conduct of research. It has also become standard practice that research involving human participants is subject to institutional ethical review and must be approved prior to commencement.

The growing interest in ethics in research has quite a strong focus on both the development and discussion of sets of principles, rules and guidelines for the regulation of researcher conduct (UK Research Integrity Office, 2009) and on difficult decision-making and ethical dilemmas faced by researchers (Iphofen, 2011). These approaches to ethics could be categorised as *ethics as regulation* and *ethics as decision-making*. The regulatory approach requires awareness of, and confirmity to, codified ethical rules on the part of researchers; whilst the decision-making approach is premised on the idea of researchers as active moral agents tackling conflicts between ethical principles (such as, 'do no harm' versus 'respect confidentiality'), often framed as dilemmatic choices between two courses of action that have equally unwelcome outcomes. The moral agent facing a dilemma is often constructed as an impartial decision-maker, engaging in moral reasoning based on abstract principles. These approaches to ethics can be characterised as 'principle-based', drawing on principles relating to the promotion of utility or well-being (consequentialist ethics, see Mill, 1863/1972; Singer, 2011) or respect for freedom of choice and human dignity (duty-based ethics, see Baron, 1997; Kant, 1785/1964).

Rather than simply considering occasions when codified ethical rules may be in danger of being infringed, or difficult decisions have to be made, here we explore what we call 'everyday ethics' – the daily practice of negotiating the ethical issues and challenges that arise through the life of CBPR projects. This way of constructing the 'ethical' is to see the moral agent not just as an impartial deliberator, but also as an embedded participant with situated and partial relationships, responsibilities, values and commitments that frame and constrain ways of seeing, judging and acting in particular situations. Thus the 'ethical' is present in ways of being as well as acting, and in relationships and emotions, as well as conduct. The key qualities of a researcher include ethical sensitivity (a capacity to see the ethically salient features of situations) and relational virtues, such as trustworthiness (reliability and not letting others down). This approach to ethics draws on virtue ethics, which places primacy on qualities of character (see Aristotle, 350 BCE/1954; Banks & Gallagher, 2009) and the ethics of care, which focuses on responsibilities attached to particular relationships (see Held, 2006; Tronto, 1993).

Ethical challenges in CBPR

Our literature review identified six broad themes relating to ethical challenges in CBPR (Durham Community Research Team, 2011), outlined briefly below. We follow this with four case examples that illustrate some of these challenges. The majority of the literature on which we

drew did not focus on ethical issues *per se*, but contained brief sections on ethics, or more commonly, described various practical and political challenges that we identified as relevant to our conception of everyday ethics.

Partnership, collaboration and power

All participatory research involves some degree of collaboration – whether between professional researchers and community partners or a range of different community researchers. This means, it is necessary to pay attention to how partnerships are established, power is distributed and control exerted. Some of the ethical issues and dilemmas noted in the literature include: tackling the mismatch between timelines and expectations of community organisations, funders and academics (Love, 2011); awareness that closer research relationships also bring greater potential for exploitation (Dodson, Piatelli, & Schmalzbauer, 2007, p. 823); and taking account of the fact that co-researchers may experience moments of inclusion and exclusion in the research process (Ponic & Frisby, 2010). Partnerships also evolve over time as trust is built, which means that partnership agreements and norms need to be constantly under review, as demonstrated in Example 1 (in the next section) about changing relationships between partners in a community allotment research project.

Blurring the boundaries between researcher and researched, academic and activist

Insofar as CBPR involves some degree of co-production of research and an action-orientation, this means that community members take on roles of researchers, and professional researchers may take on roles commonly associated with community development or community action work. Tensions may arise for people who find themselves in the role of both researcher and community advocate (Horn et al., 2008) or academic and activist (Cancian, 1993). Community researchers studying their own communities or peer groups may find themselves in the roles of both researcher and researched, and have to consider whether and where to draw the lines between being researcher and friend or neighbour, as Example 2 about dilemmas experienced by a community researcher illustrates.

Community rights, conflict and democratic representation

While most ethical codes and guidelines for research are concerned with the rights of individual 'human subjects' (to safety, privacy, freedom of choice to participate or withdraw), CBPR raises the challenge of extending rights to communities or groups (Quigley, 2006). This creates issues in defining 'community', taking account of conflict within and between communities and groups and deciding who represents a group or community interest (Wallwork, 2003). If the topic of research is controversial (e.g. attitudes towards assisted suicide amongst disabled people, see Minkler et al., 2002) there are complex matters relating to democracy and community relations to be considered. Example 3 about peer research on guns and gangs raises issues about the role of research in reinforcing stereotyping and stigmatisation of black young people and particular neighbourhoods, and what responsibilities an adult trainer has to challenge young researchers' approaches.

Ownership and dissemination of data, findings and publications

If multiple partners are involved in research, there may be conflicts of interest in terms of who takes credit for the findings and what channels are used for dissemination (Love, 2011;

Maddocks, 1992; Quigley, 2006). These may manifest themselves in decisions about co-authorship, publicity and claims for research impact, particularly as academic pressures to publish and give evidence for impact on policy and practice increase. Example 4 about ownership of digital stories raises issues about control over archived data.

Anonymity, privacy and confidentiality

Whilst these matters are common concerns in all social research, the close relationships developed in CBPR preclude straightforward solutions. If community or peer researchers are involved, and wide dissemination is planned within the community, identities of research participants may be hard to conceal. Some participants may wish to be named and credited, others may not. There may be matters that some representatives of a community or group wish not to be revealed, such as survival strategies of asylum seekers, sex workers or families in poverty (Dodson et al., 2007). The role of community researchers in Example 2, which involves engaging with people in their own homes on very personal matters, has the potential to raise questions of intrusion and confidentiality.

Institutional ethical review processes

A noticeable theme in some of the literature is the difficulty of fitting CBPR into the process and procedures for institutional ethical review (Flicker & Guta, 2008; Love, 2011; Manzo & Brightbill, 2007). Whilst many of the assumptions underlying the ethical review process – including the predictability of research trajectories – are problematic for all social research, they pose specific challenges for CBPR. Ethical guidelines for research and forms to be completed are often premised on a clear distinction between researchers and subjects of research; require individual consent to participate; and make assumptions that an academic or professional researcher ('principal investigator') has primary control over and responsibility for the research. Example 1 shows how the research process transformed relationships in a CBPR project in ways that were not predicted at the start.

Examples from practice

We now illustrate some of the ethical issues in CBPR through four examples from practice contributed by several of the article's authors. These are based on real experiences and are summaries of longer accounts collected as part of the second AHRC project. The examples are designed to be largely descriptive, including some reflective comments from key participants, with the aim of illustrating the nuances and complexities of the ethical issues. We have chosen to use longer, more detailed and contextualised accounts from research practice, as we believe this format is more useful for raising ethical awareness and taking account of the qualities of character and relationships of those involved, rather than just their actions or conduct, as is often the case in short, de-contextualised ethics cases used in textbooks (Banks, 2012b). All names have been changed.

Evolving partnerships

In CBPR, the nature of the relationships between various stakeholders is critical, and the importance of making an agreement at the start regarding roles, responsibilities and ownership of outputs is frequently stressed (Cargo et al., 2008; Horn et al., 2008; Johnson et al., 2009; Minkler et al., 2002). Yet often a 'research partnership' develops slowly – perhaps arising

from a pre-existing non-research relationship – and may evolve as trust develops and circumstances change, as this example illustrates.

Example 1: Participatory research with young women at an allotment project

A young women's group runs an allotment in a UK city. The allotment was transferred to the group several years ago, and provides opportunities for lesbian, bisexual and transgender young women aged 14–25 years old to learn about growing and cooking together and to socialise outside their youth centre. Several youth workers work with the young women at the project. An older woman, Polly, who was involved with a previous community group at the allotment, stayed on as a member of the new group. Polly is also a university researcher and after a couple of years suggested that the group might get involved in a participatory research project documenting the work they were doing at the allotment as part of a wider research project with other groups. After discussion, the young women decided they would interview each other and make videos. Polly worked with the group to submit a successful grant application, for which the funding went to her university, with Polly named as the person responsible for coordinating the research, in partnership with the young women's group.

As the research developed, relationships across the project changed. Polly's role shifted from 'adult volunteer' in the youth project, to being both a co-researcher and a research participant (being interviewed by the young women as part of the research). At first this shift was not specifically discussed or defined, but it came to the fore when a specific situation caused the youth workers to rethink their view of Polly's role. As a volunteer, Polly mainly participated in the allotment sessions, and not those in the youth centre. Thus, she did not attend team meetings or training around child protection. The youth workers were particularly careful not to reveal to Polly any details about young people's private lives – issues at home or at school – which they regarded as confidential. However, as one of the youth workers reflected:

> The researcher [Polly] began to spend more time on the project and build deeper relationships with the young people. Decisions about what and how much information to disclose about members of the group to the researcher needed to be taken. This was both to protect the young women in the group and in some cases the researcher.

A particular situation arose in relation to a young woman who had accused one of her teachers of having a romantic relationship with her, resulting in the suspension of the teacher. The youth worker discovered that the young woman was also attracted to her and was concerned that the young woman would make allegations about her or other staff members. Prior to a residential weekend in which Polly was to participate as part of the research, the youth worker decided to tell Polly about this situation, so Polly could protect both the youth worker and the young woman by ensuring they were not left alone together and in order to alert Polly to the possibility that she too might be subject to allegations.

This example illustrates how an initial non-research-based relationship evolved over time and notions of youth workers' responsibility for maintaining professional boundaries between the academic researcher and young people had to be reconsidered. This is just one very specific example among many that could have been chosen from this research project to demonstrate that any agreement about roles and responsibilities needs to be continually reviewed and renegotiated.

It also demonstrates the limits of university-based ethical review processes, which assume a monopoly on academics ensuring ethical standards in research, when community organisations also have their own ethical frameworks and youth workers and young people may have heightened ethical sensitivities and competences in everyday situations in familiar settings.

Blurring boundaries: ethics, emotions and what counts as professional practice

Qualitative research on people's everyday lives inevitably brings up emotions, some of which may be around difficult life experiences. Ethical guidelines often stress the potential of harm to research participants, while assuming the invulnerability of researchers. Yet these clear distinctions between researcher and research participant become untenable in the context of 'peer research' – that is, research undertaken by people who have similar experiences or are part of the same peer group as those researched, and where researchers may be known to participants and do not always leave 'the research field' when the project is over. Peer research is often a component of CBPR projects, as community partners act as gatherers of data (as in the allotment project in Example 1). Example 2 is a summary of an account given by a community researcher.

Example 2: The community research and mentoring project

Eileen is a volunteer community activist with a community organisation near where she lives. The organisation focuses on poverty and injustice and has undertaken action research on issues such as household debt and health. Eileen got involved with the organisation after having been interviewed herself as a research participant and encouraged to take part in community action and further research. She undertook training in community organising, research and mentoring offered by the community organisation. She then became a researcher/mentor with another action research project that involved collecting data on household debt and offering mentoring support to households experiencing debt and related problems.

Eileen reported that on one occasion she and another (female) mentor had called on a woman who was isolated, depressed and experiencing suicidal thoughts. Eileen reported:

> To console her, the other mentor who was with me revealed details from her own personal life. She did this as she had experienced very similar issues. The two women opened up to each other and both cried … I sat listening and watching unable to do anything – an outsider with no power to intervene as each sentence meant something to them. I thought to myself: 'Who am I to interfere? What damage will I do if I call a halt? What damage will I do if I let things calm down and take their course?' When things settled we left on good terms with arrangements for financial information on benefits to be given to the woman we had visited.

The situation was reported to the manager of the community organisation, who advised them that they should not have intervened and were 'out of their depth'. He arranged for professional help for the woman. Afterwards Eileen said she felt 'drained and emotional' and reflected on the experience as follows:

This situation made me think about several issues around whether it is ethical to intrude in people's personal lives and in the process to disclose details of your own life. I became aware of the responsibilities of this and wondered whether this would happen if as researcher/mentor you have not experienced similar life circumstances to the people being visited. When going into people's homes as part of research there is an element of the unexpected – by this I mean you cannot always plan and prepare for what people will say. How they will respond? How they will feel? How will you as the community researcher/mentor feel?

Even if not acknowledged in formal ethical guidelines, this kind of situation is not uncommon in qualitative research, and is much discussed in feminist research where the ideas of reciprocity and disclosure (mutual sharing between researcher and researched) have been both valued (Oakley, 1981) and problematised (Stacey, 1988). In action-oriented research, researchers often have an explicit combined research and action role (in this case, mentoring) and may also be volunteers from the same communities as research participants. Rather than relying on traditional notions of who has power and responsibility, and who is made vulnerable by research, Eileen recognised that these assumptions are unsettled in the process of the research. Hence she poses questions about: her own assumptions and those of others; what others were experiencing in the process; and how to be a responsible and accountable researcher, community member and colleague. These do not have easy 'off-the-peg' answers. With little by way of appropriate ethical guidance or other support, as in many instances of ethical difficulties in CBPR, the researcher is left to work through the issues herself.

Issues of stereotyping and research integrity

The next example also relates to a peer research project, based on an account given by a youth worker/trainer whose role was to support young people in carrying out research. When experienced researchers or trainers are involved in supporting peer research, and the aim is for peer researchers not only to collect data but also to be involved in analysing and presenting findings, issues can arise about how much influence a professional researcher/trainer should have on how the peer researchers conduct the research and present their findings. This example is complex and raises issues about how research can reinforce stigmatisation and about research integrity (honesty and transparency in the research process).

Example 3: The gangs and guns peer research project

A young people's peer research project was initiated by a local authority and a housing association, in partnership with several other agencies, in an urban area with high levels of gang-related and gun crime. A youth worker from a local youth project was employed to lead the training of the young people, who were recruited by another partner organisation. The young people were aged 14–25 years old and were largely black young men. The plan was that they would design a piece of research based on gaining information from other young people from the area – both those involved and those not involved in gangs. The results would be presented to a conference of 100 professionals later in the year, with the aim of helping tackle some of the issues relating to gun- and gang-related crime.

The work was very challenging for the youth worker/trainer – a white lesbian woman, who was not 'out' to the group. There was a lot of sexism and homophobia, which the trainer did not tackle – as she was afraid it might turn attention onto herself and away from the young people as researchers. She did work with them on issues of racism and stereotyping – though she felt that sometimes they were presenting themselves as 'victims' of racism in cases where by their own accounts this label did not really fit. Although the young researchers were not themselves involved directly in gangs or gun crime, they tended to tell stories presenting themselves in this way. The trainer and her colleagues decided not to challenge the young people on this, as they knew that at the conference the professionals attending would want to hear young people's stories. A group of younger peer researchers also decided to present a play at the conference depicting a scene showing how gang violence was sparked by a particular incident, which the youth worker felt was a misrepresentation of the long-standing feuds between rival gangs.

When the young people presented their findings at the conference, the professionals (from social work, probation, youth justice and other related agencies) quizzed them about gang membership rather than looking at protective factors that had influenced why they were not members of gangs. The young people presented findings of their research showing the impact of closure of a play scheme meaning that children from opposing neighbourhoods no longer met in a social context; the need for the satellite job centre to open more than one day a week in an area of very high unemployment; and the importance of the local authority encouraging building contractors in the area to employ local apprentices. However, the professionals did not seem to listen carefully or respond to what the young people had to say on these matters. They went on to talk about policing, 'hot spots' and reducing 'silo working' – terminology not understood by the young people.

Reflecting afterwards, the youth worker/trainer commented:

> This research project made me think about several ethical issues around the sometimes conflicting priorities or motivations of the different stakeholders involved in a CBPR project. In this case, the funders seemed to want the research to fit with their existing agenda rather than really to listen, whereas the young people hoped to be able to educate and influence policy-makers. I also wondered whether as a trainer I could have used my own gender or sexual orientation in a more disruptive way to help the group analyse their own situation. Finally, reflecting afterwards, I considered whether the young researchers should have been more detached from the research as an outside researcher would have been, or have been more honest about their identities when they had not come from a gun- or gang-related background.

This example raises several ethical issues. First, it shows how easy it is for CBPR to be used by institutions for their own ends – with the terms of reference for 'participation' being managed by funding and service delivery agencies. This account calls into question the integrity of the commissioners of the research in that they did not seem willing to respect the young people or listen to their findings. Second, the young researchers were not entirely honest about their own relationships with gang and gun crime – therefore while some of the research findings may have been honestly and carefully derived from interviews and fact finding in the area, the credibility of their research as a whole was undermined by elements of their presentation at the conference. Third, we hear about the dilemmas faced by the youth worker, who took account of what she thought the interests of the funders were, and judged that although her role was to 'train' the young people in how to do research, there was a limit to which she could challenge their attitudes and presentation of their stories. This example demonstrates that participatory research is not necessarily a good in itself, and although it places value on experiential knowing and alternative ways of conceptualising validity, these do not outweigh the value of honesty.

Issues of ownership and recognition

Informed consent is generally regarded as a central ethical issue in any research involving human participants. This entails researchers giving potential participants relevant information about the research, ensuring that they understand the implications of being involved, and seeking their agreement (often in writing). This is a far from simple process (it requires decisions about how much information to give and whether consent is meaningful). In CBPR, where the aim is to encourage co-production and co-ownership of data and findings, it becomes even more complex. Issues of community consent, and how this is gained, particularly in relation to topics on which there are divided opinions, are particularly challenging. This example, however, relates to individuals' rights to change or remove their digital stories after they had been accessioned by a museum.

Example 4: Issues of copyright and informed consent in a museum-based project

Louise was a project manager, employed by a museum service, for a large-scale participatory research project that took place over a three-year period. The project was designed to work with members of the public living in a particular region of the UK to tell and make their own digital stories. These would then be displayed across the region and formally accessioned as part of the museum's collections. By adding these stories to the collections, the project aimed to demonstrate that people's stories were valued by the museum. This also meant that the stories would be available for future display after the end of the project.

The project team discussed how to support participants on the issue of informed consent – that is, obtaining people's agreement for the stories to be used for a short-term display and long-term public access through the museum's collection. As Louise commented:

> It was felt that we needed to make people aware of what was happening to their story at the beginning so that they would create a story they would be happy to share. We decided that we would take an 'upfront' approach to consent and copyright. Getting a clear assignment of copyright to the museum at the start was seen as important, because the museum did not want to have to go back and seek permission every time they wanted to re-use the story. Once copyright has been assigned and the stories are accessioned into the collection they become 'fixed' – or so we thought.

However, two participants made requests after the project had ended that challenged the notion of 'fixity'. These participants had told stories about partners from whom they had since split up. The first participant wanted their story removed from public display and the other wanted their story changed. In the first case, this was relatively straightforward and simply involved removing the digital story from the website and adding new notes to the collections management records for that particular story, so museum staff were aware of these restrictions. The second example was more complicated, as it raised issues about whether these digital stories should be treated in the same way as 'regular' museum objects. As an accessioned object, should the master copy of this digital story be changed to take into account the wishes of the story creator? As Louise reflected:

> Both these situations certainly made me feel conflicted – there were the understandable wishes and feelings of the story creator on one side versus the official procedures of museum collecting on the other. This example clearly demonstrates that the ethical issues of accessioning 'digitally born' material that has been produced by the public needs further thought and debate.

This example is clearly framed as an ethical dilemma requiring a difficult decision in a situation where the museum worker judged there was no obvious right course of action. Some readers may judge that, given careful attention was paid to informed consent, the participants knew their stories were to be accessioned for posterity and they had assigned copyright, then legally and ethically they had no rights to change or remove 'their' stories. If we regard the museum workers as impartial deliberators interpreting and implementing abstract ethical principles relating to rights and duties (principle-based ethics), this is the ethical judgement we might make. Yet in a participatory project, where the worker was very conscious of the institutional power of the museum and wished to work according to principles of co-production, she took the issue seriously, saw it as a learning opportunity and chose to reconsider the issues of copyright and consent in a museum

context. This is a good example of an approach to ethical questions focusing more on particular relationships and responsibilities (relationship-based ethics).

Conclusions: towards an ethical framework for CBPR

Our review of the literature and discussion of detailed and reflective examples from practice have several implications for the way we conceptualise, negotiate and manage issues of ethics in CBPR, and in social research and knowledge mobilisation more generally. Here, we suggest three important implications.

Re-conceptualising research ethics

CBPR is often undertaken by mixed groups of researchers comprising academics, paid and volunteer staff of third sector organisations and other professionals and activists. Hence particular attention needs to be paid to building relationships, generating trust and negotiating power. Relationship-based ethics, including the ethics of care (which focuses on responsibilities attached to particular relationships) is as important as principle-based ethics (which focuses on individual rights and duties) in conceptualising and understanding the ethical dimensions of the research. Furthermore, CBPR frequently has a focus on social justice outcomes. Hence researchers may be involved in some kind of action and have a commitment to bringing about social change. This means they are not detached and neutral in relation to the impact of the research, although they do need to ensure rigour and honesty in the research process. Fine, Weis, Weseen, and Wong (2000, p. 128) speak of a 'retreat from the stance of dispassion'. This does not necessarily entail that principle-based ethics is irrelevant (impartial principles of fairness and justice are important), but rather that we need to acknowledge the dialectical tension between impartial principles and rules and the responsibilities that arise from relationships of trust and care and a commitment to working for a better world. These tensions are clearly illustrated in the youth worker's reflections on the guns and gangs example (honesty in research versus respect for young researchers' own ways of working) and the museum example (the rights of the museum to copyright freely assigned versus care and empathy for the creators of the stories). Whilst there are no easy answers or sets of rules that provide definitive prescriptions for action, an awareness of the potential complexities and conflicts and a willingness and ability amongst research collaborators to reflect together on such issues throughout the planning and conduct of CBPR are very important.

Research governance

Institutional codes of ethics and research governance frameworks generally pay little attention to participatory research. They assume that researchers from research institutions are in control of projects and have complete responsibility for ensuring ethical practice. They assume predictability rather than flexibility in the research process, tend to be 'risk averse' and may categorise community researchers in the same way as research participants who are simply informants. Policies, frameworks and forms need to be re-thought to take account of these complexities – both to support CBPR and to take account of other forms of knowledge mobilisation and exchange that do not fit existing categories.

Researcher reflexivity, education and training

By its very nature, CBPR requires a high degree of researcher reflexivity – that is, all researchers need to reflect critically on their positionality and power in the research process and constantly bear in mind the group dynamics of the research team, its inclusiveness and barriers to participation. This needs to be built into research methods education and training in universities

and training for community researchers. This point also highlights the value of joint training and research workshops with a range of participants in order to develop mutual understanding and share different assumptions, experiences, knowledge and skills.

Whilst our discussion of CBPR throws these issues into sharp focus, many are common to other forms of participatory research, action research, feminist research and social research in general – where research relationships are important, sensitive topics may be covered and participants include groups experiencing marginalisation and disadvantage. The growth in CBPR and related participatory approaches in the context of an increasing focus on knowledge exchange and mobilisation and research impact means that the time has come for a radical rethinking of research ethics in theory and practice. This means acknowledging that researchers may be embedded in the communities they are researching and are committed not just to preventing harm in the course of research, but also to promoting social justice and developing caring relationships.

Arguably there is an often unstated contradiction between the social justice value base of CPBR and the drive of research institutions to capitalise upon and own the impact of CBPR, with researchers caught in this nexus. CBPR is a particularly potent site where competing demands are currently playing out between requirements for increasing regulation and accountability and the desire of research institutions (especially universities) to promote the impact and engagement agendas. If CBPR is to be effective and achieve its full potential, institutions need to address this tension between an increased demand for engagement and impact, and the increasingly bureaucratised nature of ethics procedures, unsuited to the nuances of this work.

To this end, one of the products of the two research projects described at the start of the article is a guide to ethics in CBPR, designed as a *framework* to be used by researchers engaging in CBPR, research funders and ethics committees, alongside case studies and examples of ethical issues in practice to encourage critical reflection and discussion (CSJCA & NCCPE, 2012). The guide is a unique product of an 18-month collaboration between academic and community partners. It is designed to cover CBPR across disciplines and across the spectrum of research, from community-led partnerships to professionally controlled participatory research. The aim is not to offer prescriptive rules (regulatory ethics), nor to present ethics as simply about the dilemmas faced by individual researchers at crucial points in the research process (ethics as decision-making). Rather it is to see ethics as embodied in researchers and embedded in everyday practice (everyday ethics), with a scope that includes the nature of relationships and qualities of character (such as trustworthiness and integrity), as well as impartial decision-making and principled rule following.

Acknowledgements

Notes

1. www.publicengagement.ac.uk/about/beacons
2. www.rcuk.ac.uk/per/pages/catalysts.aspx

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