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Kathleen Carter , Sarah Banks , Andrea Armstrong , Sara Kindon & Ingrid Burkett

To cite this article: Kathleen Carter , Sarah Banks , Andrea Armstrong , Sara Kindon & Ingrid Burkett (2013) Issues of Disclosure and Intrusion: Ethical Challenges for a Community Researcher, Ethics and Social Welfare, 7:1, 92-100, DOI: [10.1080/17496535.2013.769344](https://doi.org/10.1080/17496535.2013.769344)

To link to this article: <http://dx.doi.org/10.1080/17496535.2013.769344>



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Published online: 18 Apr 2013.



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Case Study

Issues of Disclosure and Intrusion: Ethical Challenges for a Community Researcher

***Kathleen Carter, Sarah Banks,
Andrea Armstrong, Sara Kindon and
Ingrid Burkett***

This case study focuses on some of the ethical issues that arise in community-based participatory research, drawing on an example from practice in the UK. It comprises a case example written by a community researcher, followed by two commentaries, which analyse the case and offer different perspectives on the issues raised from the commentators' experiences in Aotearoa New Zealand and Australia. The case example highlights the challenges faced by volunteer action researchers undertaking research interviews and mentoring on sensitive topics in their local neighbourhoods. It raises questions about: the emotional effects of discussing matters of mental health, well-being and money management on both researchers and research participants; how much researchers should disclose about their own lives; and the nature of the support needs of volunteer community researchers.

Keywords Community-based Participatory Research; Peer Research; Researcher Disclosure; Emotions in Research

Kathleen Carter is lead community organiser and volunteer with Thrive, Teesside, UK. Sarah Banks is Co-director of the Centre for Social Justice and Community Action and School of Applied Social Sciences at Durham University. Andrea Armstrong is a researcher in the Centre for Social Justice and Community Action, Durham University, UK. Sara Kindon is Senior Lecturer in Human Geography and Development Studies in the School of Geography, Environment and Earth Sciences, Victoria University of Wellington, Wellington, Aotearoa New Zealand. Ingrid Burkett is an independent researcher and designer, based in Brisbane, Australia. She is also President of the International Association for Community Development, and part-time research fellow with the Centre for Social Impact at the University of New South Wales. Correspondence to: Sarah Banks, Centre for Social Justice and Community Action and School of Applied Social Sciences, Durham University, Elvert Riverside 2, Durham, UK. Email: s.j.banks@durham.ac.uk

Background

Kathleen Carter, Sarah Banks and Andrea Armstrong

This is a co-produced case study generated by a research project on the theme of ‘Tackling ethical issues and dilemmas in community-based participatory research’ funded by the Arts and Humanities Research Council in 2012. The project involved academics and community partners from different parts of the UK, who had experience of working together on participatory research projects, with support from an International Advisory Board. The group produced a set of ethical guidelines for community-based participatory research (Centre for Social Justice and Community Action and National Coordinating Centre for Public Engagement 2012) and a set of case studies, case examples and commentaries (Banks & Armstrong 2012). This case with its two commentaries is one of seven case studies/examples produced by the group.

Ethical issues in community-based participatory research (CBPR)

There is a growing literature on the theme of CBPR and related approaches such as participatory action research, co-production and co-inquiry and there are many different definitions of CBPR (Durham Community Research Team 2011). For the purposes of our research project we used a working definition of CBPR as follows:

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.’ By ‘communities’ we mean 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 more commonly, by community groups working alongside, or in partnership with, professional researchers (including academics and research students).

CBPR is an increasingly popular approach, especially in the field of health and in North America. However, its usage is developing across disciplines worldwide, for both ideological and practical reasons. It is part of a wider movement (including feminist and other forms of emancipatory research) that promotes greater equality in research relationships, and works towards social change and social justice outcomes. CBPR is also attractive as it can be particularly effective in reaching groups that might not otherwise participate in research—especially if people from those groups are involved as researchers.

However, this kind of research raises quite challenging ethical issues that do not necessarily fit with institutional approaches to research ethics. It often involves complex partnerships between organisations and individuals with different strengths, interests, power and influence. Research relationships may develop slowly over time, and a research project may evolve organically. Ethical

issues may not be anticipated in advance or be recognised as such when they do arise. Furthermore, as this case example illustrates, boundaries between the researcher and researched may not be clear-cut, more complex issues of confidentiality and anonymity may arise if researchers collect data from people they know, and the closeness and often personal nature of relationships may leave participants vulnerable to exploitation, and researchers taking on a burden of responsibility for intruding into people's lives. Many of these ethical issues arise in qualitative research more generally, especially research on sensitive topics. But the challenges are compounded and intensified in CBPR, with its dynamic partnerships and closeness to the communities that form the focus of the research (for further discussion of ethical issues in CBPR see Durham Community Research Team 2011 and Banks and Armstrong et al. 2013).

Introduction to the case

This case example was written by a volunteer community activist with a community organisation that focuses on issues of injustice and poverty in an urban neighbourhood. She has recently been involved in several community-based action research projects as a community researcher and mentor for households in poverty. These projects have been undertaken by the community organisation with which she is involved, and also latterly by the community organisation in partnership with a local university. She started off as a participant in a research project, then became a community researcher/mentor and community activist involved in campaigning work. The research was action research and involved community researchers/mentors who would support householders in making changes to their lives, whilst also collecting details of finances, debt and well-being as data for research and campaigns. This example focuses on two related dilemmas that came about during the transition from 'research subject' to 'community researcher/mentor'. These relate to the issue of intruding into people's personal lives for the purposes of research and the responsibilities felt by the community researcher/mentor for the emotions and feelings generated by asking questions about difficult or sensitive topics.

The Case

Written by a community researcher

I started off as a participant in a research project. I became involved after there was a knock on the door from two people from a local community organisation asking if I would like to take part in a research project. They were collecting details of household income, debts, employment, strengths, weaknesses, and so on. As there was nothing on the television I asked them in. The visit lasted two and a half hours as there was a long questionnaire to fill in. At the end I was asked to fill in a 'happiness line' [Warwick Edinburgh Mental Well-being Scale] to assess

on a score of 1–8 the various different aspects of my life. I scored 8 as I was quite happy at the time.

Speaking to other people on the estate where I lived who were also research participants I found that they couldn't handle the 'happiness' scoring because it made them look at their lives. The accounts of people's lives as shown by the research—lives controlled by debt, drugs and family dynamics—were sometimes very different from their own views of their lives. One woman broke down in tears when she was talking to me as she realised she was supporting her daughter but not helping her. Another said she wondered what use it was to place herself on the well-being scale as nobody listened, understood or cared.

Over time I became more involved with the community organisation and became a community researcher and mentor myself on another related project that was focussing on household finance linked with a local university. I reflected on the feedback from the happiness score and worried about the disruption to people's lives that had been reported to me. This was very personal to me as during a meeting at the University when relating my experience, I realised my original score was wrong. Working with the community organisation and the University, using my brain to think about other things, had lifted my depression and I felt immensely different to when I filled that happiness score in. It should have read a 4 then, because now I was an 8. Apathy had ruled my life and I was co-dependant on the family to fulfil my needs and for my life to have a purpose. Now I had my own personal purpose in life, and not dependant on anyone, I had choice.

The happiness score was not used in later projects, but the idea of community mentors who would both collect research data and provide support to households over a period of time was introduced. It was during this time that a situation arose that made me think again about issues of intruding and disrupting people's lives as part of the research process. In this instance, I and another mentor (who was male) visited a household where a woman lived alone in a flat. On the first visit she didn't open up very much so on the second visit I went with a female mentor. On this occasion the participant opened up to us and revealed some very personal details and became very emotional and started to cry. She was very depressed and experiencing suicidal thoughts due to what had happened in her personal life. 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 was there but mainly observing by now. The mentor offered friendship to the woman and other help. The woman was very pleased to meet someone who had similar experiences and did not just show empathy, but had a shared experience. What was exchanged between these two women was very personal and private—including feelings and emotions rising to surface that had been hidden by shame and fear. Both these women bared their souls to each other as only shared experiences can. 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, and 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.

When we went back to the community organisation office we explained to the project manager what had happened. He said we shouldn't have done what we did, as we were out of our depth and not capable of looking after the woman. The project manager intervened and arranged for professional help. I was left feeling drained and emotional. To witness first hand people laying their lives bare about a situation I cannot really comprehend left me with many questions. We met to mentor this woman about her financial situation and signpost her to help. She had not received help in the past due to self-imposed isolation caused by her life experiences. How is anybody to know how life has treated the people we are mentoring until we start to talk? Many can hide these problems, but some cannot and they come rushing out when somebody takes the time to listen to them for whatever reason. To stop the interview in such a highly charged emotional atmosphere should have been my responsibility. Why I didn't is still a question I have not answered. Was I inexperienced, caught up in the moment, or just listening to woman unburden herself as to why she lived as she did and apologising for herself? Everybody likes to be heard and are you out of your depth if you listen and then arrange for help?

This situation made me think about several ethical 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 this happen if 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?

Commentary 1

Sara Kindon

This is a thought-provoking description of events associated with the involvement of a community participant turned researcher in sensitive research into injustice and poverty within an urban neighbourhood. I was drawn to the concepts of 'intrusion' and 'responsibility' within the author's key questions: (a) is it appropriate to 'intrude' into people's personal lives for the purposes of research? and (b) how should a researcher best respond to the feelings or emotions generated in participants/respondents as the result of asking questions about difficult or sensitive topics?

From my experience, research is only likely to become intrusive when consent is not fully informed consent. If participants/respondents are given adequate information, then research should not feel like an intrusion into their lives, but rather a welcome opportunity to reflect and learn in a supportive process. The types of information would be about the nature and orientation (perhaps

even copies) of research questions, the likely length of time an interview may take and how the material they provide will be used and protected. They also need the opportunity to ask questions about the research, the time to think about how or when they can be involved. Having this kind of information is power and enables choice. Feelings of intrusion result when people do not feel they have choice, or realise that they have shared more than they were emotionally ready to at that point in their lives with little recourse to act on this 'new' knowledge. I therefore wonder how the initial information/consent procedures given to the community researchers were designed and carried out. Were they framed within an awareness of the wider issues they may raise for participants? How different might outcomes have been had support structures been put in place to scaffold people into support services through which they could act constructively on their 'new' knowledge?

Furthermore, it is important that responsibility is clearly accepted within any social research process in order to minimise harm, enhance reliability of information generated and hopefully, afford participants/recipients some benefits as a result of their participation. In this case, it was heartening to read that over time community researchers/mentors were appointed to 'collect research data and provide support to households'. However, the community researcher then found herself in a position where her decision to 'listen and watch... with no power to intervene' (letting the cathartic interaction between an interviewee and her co-researcher reach its calm and productive conclusion) does not appear to have been supported by her project manager. In this instance, she was the one left confused and emotionally drained by the research process, not just her participant/respondent. The ethical focus on 'doing no harm' and being responsible to research participants/respondents is sound, but what of the potential harm being done to community researchers through a research process, especially if they have little or no formal research training through which to make sense of their experiences and feelings?

From my own experience being involved in sensitive research with former refugees in Aotearoa New Zealand, the ethical imperative to 'stay present' and 'bear witness' as participants/respondents process painful aspects of their lives within a research interaction, rather than shutting them down, is essential if further trauma is not to result. Sometimes this may also involve the disclosure of personal information because it reduces feelings of isolation and can help a participant move towards engagement with appropriate services after the interview. I see parallels in these experiences with the community researcher's involvement in sensitive research into money and poverty. In this kind of work then, when research is known to be sensitive, and where non-formally trained community researchers are at the front-line, it is also important to ask what ethical responsibility project managers and funding agencies have to provide post-interview professional supervision for them.

In conclusion, both questions raised by the community researcher have value and both speak to larger ethical concerns about the design of community-based research projects, and the extent of ethical responsibilities, which community

organisations and universities have to support non-formally trained frontline staff. I would welcome more discussion about these less well-represented aspects of our collective practice.

Commentary 2

Ingrid Burkett

Introduction

This case example highlights many common issues facing community-based researchers. The researcher has been both a participant in community-based research and a researcher—a position that offers extraordinary insights into the complex nature of community research.

As a community-based researcher myself, the case example highlights for me the importance of ensuring that there is space for reflection in the research process, and opportunities for changes in direction when issues arise that warrant such changes. For me this is fundamental to the nature of action research—when issues arise that provide important insights into either the context or the content, the research process and the researchers immersed in the process need to be able to respond to the situation.

From my perspective the major ethical issues raised in the case study are three-fold:

- (1) The impact of particular methods on participants, and the space for following up on this impact.
- (2) The appropriateness of disclosure and the nature of boundaries in the context of community-based research.
- (3) The need for support and reflective space for researchers, particularly when they are or have been community participants.

Impact of Methods

The very nature of community-based research means that, despite our best efforts, our research methods sometimes have unintended consequences in certain communities with which we work. Sometimes methods we think should be relatively benign, can evoke all sorts of reactions—especially if they ask participants to reflect on their own vulnerabilities or their experiences of living in challenging situations.

Sometimes piloting methods can pick up these issues, but other times the issues may only be raised in the course of the research itself. And sometimes, unfortunately, researchers do not even realise that the methods have had a detrimental impact. This can occur particularly if we do not build into the

process ways to ‘check-in’ with participants after we have spent what is often very intense time with them, to see how they are travelling, or to ask about any reflections they have had since the last meeting (either on content or process).

In this case example it seems that there was a realisation of the impact one particular method had on participants, and that this led to a change in the process, ensuring that there was support and follow-up for participants. This highlights the importance of using the learnings from the research to change the process of the research where it is needed. In community-based research this is a critical part of the process, both from the perspective of ethics, but also in research terms, as reflection *on* the research is a key part *of* the research.

Disclosure and Boundaries

The case highlights a particular example of where a member of the research team responded to the distress of a participant by disclosing her own difficult experiences. This is a very delicate and difficult situation. In theory I would always say that a researcher should be very mindful of highlighting to participants that the process may raise some responses and feelings that will require follow-up and that, if this happens, the researcher would organise for professional support for the participant. In practice, however, community-based researchers are often in a position where they experience the messy realities of people’s lives, and it is not always possible to strictly apply distance and implement the wonderful theories we have all learnt.

From my perspective it has always been important in research to respond to people at a human level—participation does not have neat boundaries, and if we want to engage in participatory research then we will, no doubt about it, be exposed to the messiness of our common humanity. It is absolutely essential to be able to draw boundaries between our roles as researchers and the people participating with us. But the boundaries are inevitably fuzzy and contextual rather than being strict, neat and always easily discernable. The important thing is for us to be able to develop insight into how we engage with people as part of the research, and to be open to receiving feedback about this—both from colleagues and from participants. It is only through this reflection and seeing ourselves in the process that we are able to work on what the boundaries in a particular context should be.

Support and Reflection in the Process

As I read this case study I recognised the insightful questions the researcher was asking her/himself, and I hoped that there were opportunities for this researcher to reflect on these difficult questions within the research process. The intensity of community-based research often necessitates formalised reflection processes where researchers can not just reflect, but also debrief about their experiences

in a supportive environment. This, from my perspective, is a critical part of a community-based research project—there needs to be ‘community’ built into the research process itself so we are not just studying ‘the community out there’.

Concluding Remarks

Community-based research is not for the faint-hearted—it involves learning as much about ourselves as it does about ‘the other’, and this case example highlights some of the heartfelt struggles that are often involved in the process, particularly when the ‘content’ of the research is close to our own journeys. From my perspective it is very helpful to hear about and reflect on some of these struggles as we design our research processes, as this can help us to ensure that we have built in opportunities and structures for reflecting and supporting all those involved.

Acknowledgements

We are grateful to the Arts and Humanities Research Council for funding the research project from which this case study is drawn: Tackling ethical issues and dilemmas in community-based participatory research: a practical resource. The research team for this project (AHRC reference number AH/J006645/1) was: Sarah Banks, Andrea Armstrong, Kath Carter, Ann McNulty, Tessa Holland, Niamh Moore, Helen Graham, Alex Henry, Aileen Strachan, Nigel Nayling, Ann Stokoe, and Peter Hayward. International advisors were: Harvinder Bedi, Ingrid Burkett, Michelle Fine, Sara Kindon, Laura Saija.

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