



## **Ethics in community- based participatory research**

### **Case studies, cases examples and commentaries**

**Edited by  
Sarah Banks and Andrea Armstrong**

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# Contents

<b>Acknowledgements</b>	<b>4</b>
<b>Introduction</b>	<b>5</b>
Background to the materials	6
Reflections on compiling the materials	6
Use of the materials and suggested exercises	7
<b>Case studies</b>	<b>10</b>
Case study 1: A Co-inquiry Action Research Group	11
Case study 2: The Young Women's Group Allotment Research Project	14
Case study 3: The Newport Medieval Ship Project	17
Case study 4: The Polyveg Garden Project	21
<b>Case examples and commentaries</b>	<b>25</b>
<i>Case example 1</i>	25
<i>Issues of Disclosure and Intrusion: Challenges for a Community Researcher</i>	
Commentary 1, Sara Kindon	26
Commentary 2, Ingrid Burkett	27
Questions for discussion	29
<i>Case example 2</i>	30
<i>Guns and Gangs: Challenges in Supporting a Peer Research Project</i>	
Commentary 1, Laura Saija	32
Commentary 2, Michelle Fine	33
Questions for discussion	35
<i>Case example 3</i>	36
<i>Changing the Story: Issues of Copyright and Informed Consent in a Museum-Based Project</i>	
Commentary 1, Rachel Pain	37
Commentary 2, Helen Graham and Aileen Strachan	38
Questions for discussion	40

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# Introduction

## Sarah Banks

This compilation of case studies, examples and commentaries forms the third part of a set of materials relating to ethics in community-based participatory research (CBPR). Part I comprises a set of ethical principles, and part II is a set of practice principles and guidelines, published together as *Community-based participatory research: A guide to ethical principles and practice*.<sup>1</sup> The materials were developed during 2012 as part of a research project in the 'Connected Communities' programme funded by the Arts and Humanities Research Council: *Tackling ethical issues and dilemmas in community-based participatory research: a practical resource*.<sup>2</sup> These case materials are designed to be used in conjunction with the guide to ethical principles and practice, which discusses in more detail what we mean by community-based participatory research and ethics, as summarised below:

**Community-based participatory research** (CBPR) is 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).

**Ethics** is a topic that covers questions relating to what kinds of lives we should lead, what counts as a good society, what actions are right and wrong, what qualities of character we should develop and what responsibilities humans have for each other and the ecosystem. In the context of research, ethics as a subject area traditionally covers topics such as the overall harms and benefits of research, the rights of participants to information, privacy, anonymity, and the responsibilities of researchers to act with integrity.

<sup>1</sup>Centre for Social Justice and Community Action, Durham University and National Coordinating Centre for Public Engagement (2012) *Community-based participatory research: A guide to ethical principles and practice*, [www.publicengagement.ac.uk/how](http://www.publicengagement.ac.uk/how) and [www.durham.ac.uk/beacon/socialjustice](http://www.durham.ac.uk/beacon/socialjustice)

<sup>2</sup>The members of the research team (AHRC reference number AH/J006645/1) were: Sarah Banks & Andrea Armstrong, Durham University; Kath Carter, Thrive, Thornaby; Ann McNulty, Health and Race Equality Forum, Newcastle; Tessa Holland, W. End Housing Co-op, Newcastle; Niamh Moore, University of Manchester; Amelia Lee & Claire Holmes, Likt, Manchester; Helen Graham, University of Leeds; Alex Henry, formerly Tyne & Wear Archives & Museums, Newcastle; Aileen Strachan, Glasgow Museums/ Glasgow Life; Nigel Nayling, University of Wales, Trinity Saint David; Ann Stokoe, Over the Waves, Aberteifi; Peter Hayward, Friends of Newport Ship, Newport.

The international advisory group comprised: Harvinder Bedi, Development Support Team, Pune, India; Ingrid Burkett, independent researcher, Brisbane, Australia; Michelle Fine, City University of New York, USA; Sara Kindon, Victoria University of Wellington, Aotearoa New Zealand; Laura Saija, University of Catania, Italy.

## Background to the case materials

As indicated in the *Guide to ethical principles and practice*, CBPR often involves complex partnerships between organisations and individuals with different strengths, interests, power and influence. Frequently research relationships develop over time, and a research project may emerge organically. Ethical issues may not be anticipated in advance or be recognised as such when they do arise. Hence it was felt that detailed case studies and examples from real life practice would be helpful for researchers, funders and sponsors to enable them to reflect on and think through the kinds of ethical issues that tend to arise and how they might be tackled.

### *Case studies*

Each case study is designed to give an account of a research project or partnership, with a particular focus on ethical issues. The case studies were contributed by members of the *Tackling ethical issues* research team<sup>2</sup>, with the addition of one case study from the Permaculture Association. The reason for adding this case study was to include an account of a participatory science project, alongside studies from social sciences, arts and humanities. The first two case studies were compiled by groups of people involved in the research featured in the study. The second two case studies were compiled by the editors based on a mixture of written materials and interviews with the key participants. The case studies are not designed to be anonymous, and references are given to the research projects if the readers wish to follow them up.

Each case study starts with a brief description of the background to the research, covers ethical issues anticipated in planning and issues that emerged and developed, followed by an account of learning from the experience and a set of three questions for discussion. The questions were developed by the editors and are designed to be used by individual readers and groups of practitioners and students who are using the materials for discussion and learning.

### *Case examples and commentaries*

The case examples are written from the perspective of one individual and comprise accounts of particular ethical dilemmas, issues or situations experienced when undertaking CBPR. The authors of the case examples have not been named, as in some cases they discuss events and emotions that were sensitive for themselves or for others.

The first is written by a community researcher and raises issues about sharing personal information; the second is written by a youth worker and outlines some of the challenges of supporting young peer researchers; and the third example comes from a community outreach worker who encounters dilemmas relating to consent and copyright while working on a digital story telling project for a museum service.

Each of the case examples is then followed by two commentaries, written by people with an interest in the subject matter, who offer their comments and reflections on the ethical and practice issues in the example. While all the case examples are from CBPR undertaken in the UK, some of the commentators are from different countries across the world – hence offering wider perspectives on the nature of the issues and approaches to tackling them.

## Reflections on compiling the materials

In working with contributors to develop the case studies and examples, a number of interesting questions arose. One of the most challenging questions was: What counts as an ethical issue? Even if a definition can be given, everyone sees events and situations in different ways. Where some see ethical issues or dilemmas, others do not. There were differences between disciplines in understandings and awareness of the nature of ethical issues. In compiling the case studies, there was a process of dialogue amongst key participants involved in the projects studied to develop and refine the materials, and between key participants and the editors, who raised questions and suggested potential ethical issues for exploration. In relation to one case study, the key participants commented at first that there were no ethical issues, only political and legal ones. In another case, the material first presented focused on practical and technical matters, and the 'ethical' focus was developed in an iterative dialogue between the contributor and editors. This raised ethical questions for the editors: Who has the right to define what is an ethical issue and to frame a case study; and how much should the editors intervene? Ethical issues do not exist independently of situations and circumstances. They are intertwined with practical, legal, political and technical dimensions of life and are framed differently by different participants and observers.

For the case examples there was less editorial intervention – although questions were asked to prompt the authors to give sufficient information for readers to understand the situations described and the actions taken and many were revised several times. The case examples are written from the perspective of one person, who gives her/his own account of a situation, what happened and what she/he thought and felt. The challenge for the editors was to maintain the authenticity of the accounts, while ensuring clarity and sufficient background information for the reader.

In commissioning the commentaries on the case examples, we encouraged the commentators to offer their own reflections – comparing with their own experiences, if relevant. Although it is very easy to be critical as outsiders, the commentators help the readers to see the case examples from different angles and consider new ways of looking and acting.

In the process of writing the case materials, many of the contributors reported coming to see the situations and projects they described differently. They identified conflicts of rights and interests or matters of potential harm that they had not noticed previously, or certainly had not reflected upon in any depth. In writing, analysing and reflecting on ethical issues in their own cases and those of others, they were developing ethical sensitivity – the capacity to see the ethical dimensions of situations, actions and thoughts. They were also developing skills in ethical reflection and analysis as well as reasoning and argument. We hope these case materials will contribute in similar ways to the development of readers' awareness and competency. With this aim in mind, we suggest several exercises that can be used by individuals and groups to analyse and reflect on the issues raised.

### **Use of the materials and suggested exercises<sup>3</sup>**

We hope the case materials will be useful for people who are considering, planning and doing CBPR, in that the case studies and examples offer insights into how others have tackled issues and their reflections on how things might be done differently in future. In particular, the materials can be used in training sessions and group discussions for researchers and students, alongside the Guide to ethical principles and practice, which offers not only a set of ethical principles, but also practice principles and guidelines covering: preparing and planning research; doing the research; and sharing and learning from the research. The following exercises offer some simple ideas for using the materials.

#### **Exercise 1: Reflecting on a case study or example**

Read one of the case studies, or a case example plus its two accompanying commentaries, and answer (or discuss with colleagues) the three questions posed at the end.

#### **Exercise 2: Reflecting on your own analysis and learning**

Read one of the cases studies, or a case example plus its two accompanying commentaries, and consider the following questions:

1. What are the three most important ethical issues this case raises for you?
2. What, if anything, would you do differently if you were one of the key participants in the case study/example?
3. What lessons have you learnt from reading and reflecting on the case study/example about how to promote ethical practice in CBPR?

#### **Exercise 3: Writing a case study**

If you have been involved in CBPR, write your own case study about a particular project or partnership, using headings in the case studies published here as a guide:

1. *Brief description of the project* – an account of the background and history of the project/partnership: e.g. where it came from, who was involved, what its aims were, what happened, what was achieved and any other relevant information needed by readers as contextual background to understanding the ethical issues.

<sup>3</sup>Some of the exercises are adapted from those developed by Sarah Banks and included in Banks, S. and Nøhr, K. (2012) (eds) *Practising social work ethics around the world: cases and commentaries*, London: Routledge.



2. *Ethical issues anticipated in the project* - What ethical issues were anticipated in the planning of the project (e.g. the need to agree who would take responsibility for writing up the research and whose names would be on final report) or were embedded in the project (e.g. a partnership by its very nature entails agreements or assumptions - whether implicit or explicit - about roles, responsibilities, power, control).
3. *Ethical issues emerging and developing* - What ethical issues/challenges arose (some of which might have been anticipated, some unexpected or more complex than envisaged). How were these issues acknowledged, handled or worked with?
4. *Learning from the experience of working with these ethical issues* - reflections on what worked and what did not, what could have been done differently, what recommendations might be made to other similar projects.

#### **Exercise 4: Writing a case example**

If you have been involved in CBPR, write a case example based on your own experiences and reflections covering some of the ethical issues and challenges you faced or witnessed. The following points may be helpful:

1. *What is a case example?* A case example is a short description of the important features of a real situation, an event or a piece of work. The case example may describe everyday events and actions encountered in planning and doing research; or it may be a description of a situation that is constructed as problematic - involving a difficult decision, a dilemma, or a situation where 'mistakes' have been made.
2. *The art of writing a case example.* To ensure clarity, interest and sufficient (but not too much) information, the following checklist of points to bear in mind might be helpful:
  - Does the case example give a clear description of the situation?
  - Does the case example give the reader sufficient information to make it interesting and comprehensible, but not so many details that the reader may be confused?
  - Does the case example have a clear story-line (a 'main thread')?
  - Does the case example have the potential to generate discussion (does it raise challenging ethical questions, is it controversial, open ended)?
3. *Background information.* It is often helpful if the writer of a case can also preface it with a short introduction about the national, social, cultural and political context in which the case takes place. The writer of the case example should start with a short introduction about the context in which the case takes place - the type of project, any relevant background information.
4. *Description of events, thoughts, feelings.* The content should be mainly descriptive - what happened, including accounts of any thoughts or emotions ('I was worried ...', 'I couldn't decide what to do ....') and short reflections, if desired ('I felt I hadn't handled this well ...', 'On reflection this showed we should have been clearer at the start', 'This incident showed me how strongly I believe in equality ...').
5. *Anonymity.* Consider whether the names of people, organisations and places should be changed and any identifying features removed or changed, in order to protect the identity of the people and organisations involved. Sometimes the authors of cases may also wish to remain anonymous, in case their identities reveal the identities of other people or organisations, especially if the content of the case is personally or politically sensitive. It is important to think through whether or not you reveal identities and what harm might be caused if you do. If you have any doubts, then change the names.

#### **Exercise 5: Writing a commentary**

Using the commentaries given here as models, write your own commentary either on one of the case studies, or on a case study or case example written by a colleague. Consider the following points:

1. *Audience.* Consider who will be the audience for your commentary and ensure you write in language the audience will understand.
2. *Ethical issues.* Highlight what you think are the key ethical issues in the case - how can they be understood?



3. *Structure.* Use a logical structure – if you think headings would help the reader, then use headings to structure your commentary.
4. *Reflection on context.* If you are from a different country than the country of the case, or a different area of work, you might like to reflect on similar issues in your own country or area of work – to what extent are these universal/general questions in a particular context?
5. *Stick to the information given.* Be careful only to relate to information that is given in the case. You may wish to speculate about what might have happened or what might have caused a situation, but make it clear that you are speculating. Do not make assumptions about facts in the specific case.
6. *Think about how critical or judgmental you should be.* Think about how the author of the case, or other people who feature in the case, might respond to your comments. Whilst it is important that you write an honest commentary, from your own perspective, be careful how you phrase any judgements or criticisms in order to minimize unnecessary upset.
7. *Ending.* End the commentary with a conclusion which could be your own position statement ('My opinion about this particular case is ...' or 'at the heart of this problem lies ....') or a proposed solution to the problem or another suitable ending to the commentary.

## Case studies

### Case study 1: The co-inquiry action research group<sup>4</sup>

#### Brief description

A co-inquiry action research (CAR) group comprising community partners and university researchers was established as part of a small research project funded by a UK research council. The research was a scoping study to be undertaken over eight months on the theme of ethics in community-based participatory research. The project as a whole involved reviewing relevant academic literature on this topic (largely undertaken by an academic researcher) and the formation of a CAR group, which would meet three times to consider the themes generated by the literature review in the light of participants' own experience of ethical issues in community-based participatory research. The group comprised five community participants who had been involved with academics in various research projects; five academics from Durham and Newcastle Universities who had experience of community-based participatory research; and two administrative/development staff from a public engagement initiative that covered both universities. This group built on an earlier CAR group that had been convened to study the process of co-inquiry itself, and the first meeting of the new group was also the last meeting of the previous group. Three of the community partners were new members, whilst all the other participants had been in the previous group. The meetings took place at Durham University and were facilitated by an academic. The meetings were jointly planned by three core academics: the facilitator (responsible for the CAR group); the research associate (responsible for the literature review); and the principal investigator (who coordinated the whole project). These three academics were also part of a wider research team of Durham University academics and international advisors that focused mainly on the literature review.

#### Ethical issues anticipated in planning the group

Co-inquiry is an approach to research that involves a group of people working cooperatively to explore a topic or question. Whilst participants make different contributions, these are of equal value and it is vitally important that all participants show each other respect, are prepared to listen, build on the ideas of others and learn from each other. Part of the reason for forming such a group in this case was precisely to hear a range of perspectives and to value experiential knowledge (knowledge gained from doing) as much as theoretical knowledge. However, unlike the previous CAR group where the agenda was more open and group members could agree on how the work of the group developed, this group had a predefined purpose and needed to fit the prescribed timescale and outputs promised to the funding body. This invested more power and responsibility in the three core academics, as although all members had been consulted about the original funding application, it was the university staff who had written the funding bid and the university had gained the funding. For the core academics it was important to be clear about their responsibilities to the university and the funder, whilst at the same time maximising ownership and control by group members.

In order to create a participatory and respectful ethos, a number of preparations were made by the facilitator and principal investigator, examples of which are given below.

#### Ground rules

At the first meeting the group discussed and agreed some ground rules for how to work together. One learning point from the first CAR group was that it was easy for the university participants to use academic language or jargon, which community participants found off-putting and could exclude them from discussions. There was also an awareness that whilst it was desirable for all participants to talk freely, it would be important that information that people wished to remain confidential within the group

<sup>4</sup>Contributed and written by Sarah Banks, Andrea Armstrong, Kath Carter, Tessa Holland and Ann McNulty. For further details of this project see: Durham Community Research Team (2011) *Community-based participatory research: ethical challenges*, [www.dur.ac.uk/resources/beamon/CCDiscussionPapertemplateCBPRBanksetal7Nov2011.pdf](http://www.dur.ac.uk/resources/beamon/CCDiscussionPapertemplateCBPRBanksetal7Nov2011.pdf) and Beacon NE (2011b) *Coinquiry Toolkit: Community-university participatory research partnerships: co-inquiry and related approaches*, [www.beaconnortheast.org.uk/\\_assets/media/library-file/3.pdf](http://www.beaconnortheast.org.uk/_assets/media/library-file/3.pdf)

should not be revealed outside or written about without permission. These points formed the basis of two ground rules for the series of workshops, which involved an agreement from everyone to do the following:

- 1) Always use clear language – in particular, not to exclude anyone, especially non-academics, from conversations by using technical concepts or relying on expressions or idioms whose meaning would not be obvious to people unfamiliar with academic language.
- 2) Respect confidentiality, both in how we share experiences and in discussing any aspect of the workshops elsewhere.

#### *Payment of honoraria and provision of refreshments*

In recognition of the contribution of the community partners, funding for honoraria, travel expenses and lunches at meetings was built into the budget.

#### *Participatory framework for meetings*

In order to maximise participation a range of methods was used, including work in pairs and small groups. The facilitator and principal investigator attempted to model and develop an ethos of listening, questioning, reflecting and genuine interest in each person's contributions.

#### *Acknowledging the contributions of all in publications*

It was agreed that the report produced for the funder would acknowledge all participants, but given the group had only three meetings, it would be the core academics who took a lead in the writing up process.



### **Ethical issues emerging and developing**

Several ethical issues emerged during the course of the project and were tackled as they occurred.

#### *Balancing experiential with presentational and theoretical knowledge*

At the first meeting community partners from the previous CAR group presented details of the toolkit they were developing for community partners engaging in co-inquiry research with universities. The research associate, who was not present, had also sent a paper outlining a draft search framework for the literature review. This resulted in a great deal of information being presented, and due to shortage of time the small group exercises planned were not undertaken. This was discussed by the group at the end of the first meeting and the two subsequent meetings were deliberately planned to be as participatory as possible.

#### *Inclusion of new members*

It was also clear at the end of the first meeting that some new members who had not been part of the first CAR group were confused about the process and purpose of the group. If less time had been spent on presentations and more on getting to know each other and sharing experiences those feelings might have been reduced. It was also recognised that first meetings are often difficult and it takes time for people to feel comfortable and for mutual trust to develop.

#### *Whether and how to include community partners in the academic elements of the project*

A literature review on ethics in community-based participatory research was a major part of the whole project and the funding bid stated that the CAR group would be involved in developing the themes to guide the search framework and in commenting on the findings. Therefore the core academics felt it was important to share the process of the literature review with the CAR group. However, not only was the process of how to do a literature review using electronic databases of journal articles rather difficult to understand, but also the identification of key themes as search terms was not something to which non-academics, or even academics who were not social scientists or specialists in community-based research, felt they could contribute. Had there been more time, this might have been addressed over several meetings. But in the short timescale available, it was clear after the first meeting that it made sense for the research associate and academic team to take responsibility for framing and conducting the literature review. At the subsequent two meetings, some of ethical issues that were emerging from the review were discussed in the CAR group and linked to members' identification of key ethical issues based on their own experiences.

### *'Academic' ways of working*

Whilst the group had identified the avoidance of academic jargon as an important ground rule, this was only one part of the story about how academics could dominate the proceedings. Academics are also very used to analysing, critiquing, summarising and interpreting the comments of others. This was highlighted in an exchange between a community partner (Carol) and academic (Alan) at the third meeting, when Alan was feeding back to the whole group what Carol and Alan had been discussing in a pair relating to details of an ethical dilemma told by Carol to Alan. Carol commented: 'that is not what I told you!' Alan explained he was trying to summarise, to which Carol responded:

*Carol:* This is what we're getting down to: the judgement that you made upon my speech was not [my] judgement.

*Alan:* Probably not, I interpreted what you said.

*Carol:* Interpreted ... you interpreted my speech with your values, your speak, your understanding of the world.

This gave an opportunity for all members of the group to acknowledge what had happened and what they could learn from it. The fact that it was handled amicably and discussed openly by Carol, Alan and the other participants was testimony to the levels of trust in the group by this point. Reflecting on this exchange later, Carol commented that the issue for her was that Alan took her story and 'made it his own'.

### **Learning from the experience of working with these ethical issues**

Some of the key learning points in relation to anticipating ethical issues, creating an ethical climate and tackling ethical problems and dilemmas as they arise include:

- 1) *Clarity about power and responsibility* - It is important to be clear about where power and responsibility lie in relation to different aspects of a research project. If there are parts that require specific academic skills or certain outputs for funders then this should be acknowledged. Equally, thought should be given as to whether some academic processes can be demystified or adapted for use by community participants (e.g. a participatory literature review).
- 2) *Questioning and adapting traditional research methods* - Translation, sharing and reworking of academic purposes and processes (such as a literature review) take time and effort. If more thought had been given at stage of designing the research, perhaps a different type of scoping study could have been undertaken without an academic literature review.
- 3) *Setting the tone at the first meeting* - The first meeting of a collaborative research group is important in setting a non-threatening tone and participatory ethos. It is vital to hear from everyone, allowing people to start from their own experiences and to feel respected and valued.
- 4) *Questioning traditional academic ways of working* - Academics need not only to avoid academic jargon, but also to modify their styles of critical analysis and interpretation.
- 5) *Time for building trust* - It takes time to build a group and generate good working relationships. In this group, by the third meeting people were more relaxed and able to speak out and challenge each other.
- 6) *Reimbursement* - Payment of honoraria as well as travel expenses for community partners is important, especially in the current economic climate. Participants valued this and one of the community partners commented: 'I found the first meeting quite daunting. I might not have come back if there had not been an honorarium. Payment indicated that my participation was valued by the group'.
- 7) *Writing up as a learning process* - Even if a few people take a lead in writing up, the iterative process of developing drafts, incorporating new insights and amendments from all participants is an important part of the learning experience. Writing up may continue after a research project has ended and it is important to allow time to continue to involve people in the process. The authorship of the final report was attributed to 'Durham Community Research Team', with all participants listed at the start of the report.



- 8) *Genuine co-production is time-consuming and challenging* - In an ideal world, community partners would co-design the research project; the CAR group would be co-facilitated by an academic and community partner; and more work would be done by the group on creating the agenda and co-writing the outputs. For this particular research project, that ideal was not possible. But in future projects, with the levels of confidence, expertise and trust developed by community partners from working in this CAR group and an increasing awareness on the part of funders of the crucial role of community co-researchers, some further steps might be taken towards this ideal. But the time and commitment this would take should not be under-estimated.

### Questions for discussion

1. One of the issues raised in this case study is the inaccessibility of academic literature reviews. How might it be possible to conduct more participatory reviews, whilst still covering academic journal articles?
2. Under the heading 'academic ways of working', Carol objects to Alan taking her story and making it his own. What do you think is going on here and how would you carry on the conversation if you were either Carol or Alan?
3. What is the most important lesson for you from this case study?



## Case study 2: The young women's group allotment research project<sup>5</sup>

### Brief description

This case study is based on a participatory research project undertaken by a young women's group in partnership with a university researcher. The group is for lesbian, bisexual and transgender women aged 14-25 years, and organises a range of activities and projects across a major UK city. The focus of the research was on the allotment that the young women's group runs through the summer months. The allotment allows young women to meet, learn to grow fruit and vegetables, cook together and socialise in a safe space. Unusually for the group, which is generally for younger women, and partly because of the way the allotment was formed, it welcomes women aged over 25 and so often runs as an intergenerational space. The allotment plot had been transferred to the young women's group by Pride Sports, which had been supporting it subsequent to the folding of the community group that had originally been running it. One member of the original group, who worked as a university researcher, remained and ended up becoming actively involved in the young women's group as a result.



The research project emerged out of a meeting between this university researcher and another researcher at a national conference run by a funding body. They discovered they were both involved in food-growing community groups. Out of this encounter arose the ideas for a project and a successful funding application, initiated by the other researcher, which ultimately involved three academics and members of three community groups in different parts of the UK. The aim of the research project was for each group to work to find ways of documenting their histories and practices, and for the groups to participate in community exchange events, where both the process of the research, and the final products, would be shared. The allotment group decided to make YouTube videos; the other groups made a talking quilt and story boards.

With the exception of the two university researchers who were involved in two of the community groups, the individuals and groups were not known to each other in advance of the project. With this in mind, and the possibility of various logistical, administrative and ethical issues that might arise as a result, the project was planned with a fairly open remit: that the groups were to find ways to document their histories and practices. The intention was that there would be multiple outputs, including formats which would be directly useful to the groups - that is, not only conventional academic papers.

In the allotment project, the university researcher worked with the young women to develop skills in interviewing and the group collectively generated a list of questions that they would use. Neither the university researcher nor anyone in the young women's group had extensive video skills. However a video camera was borrowed from the university and the young women's group arranged for someone with video skills to come along to the allotment and give some basic training.

### Ethical issues anticipated in the project

The three 'action research projects' were very much seen as extensions of the work of the existing activities of the community groups, with the university researchers 'fitting in' to the groups' own norms and procedures for ethical practice. In part because two of the university researchers were already involved in two of the groups, and hence were aware of the groups' own practices and procedures for dealing with ethics, the university researchers were happy to let the community groups take a lead on ethical practice. In the allotment project, it was also the case that the youth group often carried out peer research projects and so had experience of research and ethics. Thus, for instance, the decision was taken use the youth group's own consent forms for the project.

<sup>5</sup>Compiled and written by Niamh Moore, Claire Holmes and Amelia Lee. For further details of this project see: [www.lik.org.uk/activities/allotment/](http://www.lik.org.uk/activities/allotment/)

However, the university researcher was aware that while YouTube videos might be familiar to the participants, they may be less familiar with more traditional academic outputs such as journal articles. Furthermore, the participatory and unfolding nature of the project meant that academic publications were not defined upfront. This meant that issues around consent in relation to academic publishing would need to be addressed separately and later as publications emerged, although with the added complication that the transitory nature of some of the people in the groups might add further complications to the process of consent.

## **Ethical issues emerging and developing**

### *The distribution of ethical awareness and responsibility amongst the project partners*

One example of an ethical issue that arose, and was professionally handled as a matter of course by one of the youth workers in the project, related to the question of consent in relation to the making of the YouTube videos. A first cut was shown in the youth centre, with the youth worker and the university researcher present, to see what the young women thought of the film, and to see if any changes were required by them. A few changes were suggested and were passed on to the video editor to implement. However, the youth worker also noticed that one of the young women watching seemed uncomfortable about being in the video, and checked in with her privately about this. Subsequently the video editor was asked to take any images of her out of the final cut. It is unlikely that the university researcher would have had enough knowledge of the young women to pick up this, initially unspoken, discomfort. However, it was part of the everyday in-depth knowledges the youth worker had of the young women and part of her own daily practices to be attuned to, and responsive to, these signs.

At the same time, it is also worth noting that some young women would likely have already intentionally avoided the sessions where videoing was taking place, or made sure that they did not appear in the video, if they did not want to. This serves as a reminder that arguably these young women have been living with, and needing to address, issues of risk, harm and ethics, throughout their daily lives, in multiple contexts, and have developed competencies around assessing risk and harm. Thus ethical practice in the project was actually distributed across the group, even if unevenly. This does not necessarily mean that young women are always in a position to be able to bring about the best outcomes for themselves, and this recognition is not intended to suggest that the university researcher should be absolved of responsibility. Rather it is a reminder that the university researcher is not always in a position to recognise all the ethical issues, and may not always be best placed to address them. Here issues around participation and consent were not only addressed by the university researcher, but also, and sometimes much better, by the youth worker, and at other times were managed by the young women themselves.

### *How much information to give the university researcher about young people's personal lives?*

Relatedly, the university researcher's lack of detailed knowledge can also contribute to situations where she is possibly made vulnerable, and to situations where youth workers are forced to make ethical decisions around this. To expand on this, the youth workers on the project are aware of young people's issues, from their behaviour in the wider group to incidences of current or past abuse in the young people's lives. As a volunteer on the allotment sessions, however, the university researcher had limited contact with the young people and so did not attend staff/volunteer meetings and was not included in child protection briefings. As the project developed, 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.

An example of this was when the youth worker was informed that one of the young women had fabricated a relationship with a teacher, and subsequently made allegations that they were in a romantic relationship with each other, resulting in the teacher being suspended pending investigation. The youth worker had already suspected that the young woman 'had attachment issues and stretched the truth', but the youth worker had not disclosed this to the researcher. The youth worker then gained information that led her to believe that the young person was attracted to her (the youth worker) and there was a fear the young person would make allegations about her or another member of staff. As the young person was attending a residential weekend for one of the community exchange events with the university researcher, there was a need to inform the researcher of this issue. This was judged necessary in order to protect all parties, including the young woman, by ensuring that the young woman was not left alone with either the youth worker or the university researcher.



## Learning from the experience of working with these ethical issues

Some of the key ethical issues raised in this project are around questions of who does ethics and who has responsibility for ethics. What this project makes clear is the multiplicity of ethical frameworks, approaches and professional guidelines across the project. In academic research, related disciplinary ethical guidelines and ethical review practices within universities, there is often an assumption that responsibility for ethics lies only in the hands of university researchers. There are often related assumptions that the university researcher is in a powerful position in relation to community researchers and research participants, who are thus more vulnerable in the research process. Yet in this case the youth worker and young woman are also 'co-researchers' and the young women's group is located in its own ethical contexts, of youth work, even if youth work ethics is not necessarily always as codified as some of those of academic disciplines, or as academic ethical review boards. At the same time, youth work also negotiates more explicitly legal frameworks, around working with those under the age of 16, and with child protection issues for example (so that the university researcher had to have a Criminal Records Bureau check). Arguably the professionalization, or bureaucratisation, of ethics in university research has tended to produce an account of ethics, that does not correspond well with the complex operation of ethics in community-based participatory research. Here a more dynamic account of how power moves and shifts in the process of a participatory research project, as well as a recognition of the multiplicity of ethical frameworks in play, might be more appropriate for understanding how and when ethical issues might arise, and how they might be appropriately addressed.

Some of the main learning points include:

- 1) All project partners and participants can be a resource when identifying and addressing ethical issues - Knowledge, experience and practice of ethics are not only in the hands of the university researcher; everyone in any project will have their own experience of dealing with ethical issues. This does not absolve university researchers of responsibility for dealing with ethical issues, but rather acts as reminder that university researchers are neither always in control, nor always the best placed, to identify and address ethical issues.
- 2) All research partners face ethical issues - It is necessary to recognise that all research partners may face ethical questions and dilemmas in research projects, not only the university researchers; community partners and community-based researchers also face and address ethical dilemmas.
- 3) All research partners may be vulnerable - The need to address complex ethical issues may itself be understood as a site of vulnerability in research. All researchers, university and community-based, may be left in positions of vulnerability during the process of research. As well as paying attention to the possible vulnerabilities of community researchers and research participants, in community-based research (and perhaps all research) the vulnerability of the university researcher needs to be considered. This is rarely fully recognised in university and discipline-based ethical procedures.

## Questions for discussion

1. This research project worked within the ethical and procedural norms of the youth group (based on youth work ethics). These did not explicitly cover matters relating to academic publications, which might include permission to use quotations and findings, as well as questions of how to credit contributions and attribute authorship. What might be the advantages and disadvantages of developing a specific 'ethical agreement' at the start of the research that addressed matters of academic publication, as well as making explicit the youth work norms regarding confidentiality, child protection and so on?
2. A dilemma for one of the youth workers was how much personal information to disclose to the university researcher about a young woman in the project. Do you think she was right to tell the university researcher about the allegations made by the young woman and about the youth worker's other 'suspicions'?
3. One of the learning points relates to the importance of recognising the vulnerability of all research partners and participants, including the university researcher. What might be the implications of this for how research is supported and conducted?

## Case study 3: The Newport medieval ship project<sup>7</sup>

### Brief description

This case study is based on what happened after the unexpected discovery in 2002 of a medieval ship in Newport, Wales (the Newport Medieval Ship) during the construction of a new performing arts centre for Newport City Council. Finding artefacts during building developments is not that unusual in the heritage sector and a find is occasionally the starting point of an archaeological project. However, finding a medieval ship is a rare and important occurrence. The Newport Medieval Ship project was unplanned and did not start out as a community-based participatory research project. What this case study shows is how a heritage project grew and evolved in unexpected



ways as the nature of community engagement changed over time. It shows how ethical issues emerged and how participants in the project adapted and resolved challenges. The process was complicated because a wide range of parties was involved, including professional archaeologists, builders, public authorities and grant-giving bodies. Community engagement is now a notable feature of the project and this shifted over time from local action (the Save Our Ship group, initially involved in campaigning and petitioning) to the establishment of a support charity (the Friends of Newport Ship) concerned to promote understanding, conservation and the eventual display of an extraordinary heritage asset.

### Ethical issues anticipated in planning

The Newport Medieval Ship was a fortuitous find. This meant that rather than being able to plan the research and anticipate ethical issues, everyone involved and/or interested in the ship had to react, especially in the first few months. The future of the ship at this time was uncertain and it was not at this stage identified as a research project even though archaeologists were involved. The archaeologists (including a nautical archaeologist brought in as a specialist) were working in the role of contractors, employed by the developer (Newport City Council).

### Ethical issues emerging and developing

*Conflicts between the rights and interests of archaeologists, developers, local authorities and the public*

One of the first ethical issues to arise was around who had the right, and indeed the power, to decide on the ship's future and on what grounds? Should it be destroyed because it was stalling a £12 million development scheme? Was it important enough to save? And how would it be saved? In this situation the archaeologists – especially the nautical specialist – had a huge responsibility. They are the experts able to identify it as a ship (from exposed timbers) and importantly as a medieval ship, making it a rare and important find. This strengthened the 'save' rather than 'destroy' argument and meant that the new development had to be stalled. During this period, the building site was not open to the public and the discovery was kept confidential. Nonetheless, news of the discovery leaked out. The prospect of the ship's imminent destruction led to increasing local disquiet and the formation of the Save Our Ship campaign, which petitioned, protested and appealed for the ship to be saved as a heritage asset for the people of Newport. The ship was seen by the local community as public property. At this early stage, during the period two to three months immediately after the find, relationships between the local authority, developer, archaeologists and local community were tense.

<sup>7</sup>Based on materials contributed by Nigel Nayling and Peter Hayward, compiled by Andrea Armstrong and Sarah Banks. For further details of this project see: [www.trinitysaintdavid.ac.uk/en/newportship/](http://www.trinitysaintdavid.ac.uk/en/newportship/), <http://newportship.org/> and [www.newport.gov.uk/\\_dc/index.cfm?fuseaction=mediaevalship.homepage](http://www.newport.gov.uk/_dc/index.cfm?fuseaction=mediaevalship.homepage)

Tensions were eventually alleviated once the announcement was made by the Welsh Assembly Government that £3.5 million had been secured to conserve, research and display the ship. This changed the relationships between the different parties, who from then on began working more closely together. The Newport Ship Project was born and participation and community engagement became the approach used in what was now becoming a more community-based action research project. This allowed the focus of the local community group to change from campaigning to supporting. Thus, as a registered charity, its main activities are providing practical and financial help and raising awareness of the ship and its importance.

*Disclosing confidential information: reconciling different aspects of a professional code of conduct*

Another ethical issue emerged for the archaeologists whilst working in those early stages in their role as contractors employed by the developer (Newport City Council). Archaeologists who are members of the Institute for Archaeologists (IfA) agree to abide by its code of conduct<sup>8</sup>. The object of this code is 'to promote those standards of conduct and self-discipline required of a member in the interests of the public and in the pursuit of archaeological research', with guidance provided within five principles. These principles stress the need for members to adhere to high standards of ethical behaviour, to uphold their responsibility to the conservation of the historic environment, to properly record and disseminate their research and to take due regard of the aspirations of employees, colleagues and helpers.

The archaeologists found that even when working within the professional code, the issue of disclosing confidential information was problematic. The archaeologists were, of course, interested in the ship as a source and site of research and new information; but they also had to balance this academic interest with their role and responsibilities as contract archaeologists. The code makes clear that members have an obligation to prevent the release of confidential information (as defined by an employer or client), yet also should 'accept the responsibility of informing the public of the purpose and results of his/her work and shall accede to reasonable requests for information dispersal to the general public'. This proved a challenge during the early stages of the ship's discovery and excavation, when contractual agreements constrained the archaeologists from being able to communicate openly with the community campaigners. The archaeologists spoke to the local campaigners informally as the nautical specialist archaeologist explained:

The group (Save Our Ship) start a 24 hour vigil outside the site with signs, taxi drivers sounding horns, lorry drivers threatening to block roads – campaigning. So archaeologists are turning up at the site on a daily basis and talking to the group informally. Then shutting the gates. The relationship between the archaeologists and the group was very friendly, but we were not disclosing information from meetings with the local authority; we could only say things about the finds. But we would get some difficult questions from the campaigners about the future plans.

The ethical challenge here stems from the fact that according to the code it is the employer/client who defines what is 'confidential information', not archaeologists. However, in this case, it was the archaeologists who met the local campaigners on a daily basis and who had to decide what was reasonable disclosure and what was not. These tensions were resolved once the find had been officially made public and information exchange became less problematic.

*Co-producing a book: acknowledging the limitations and benefits of different knowledge and expertise within a partnership*

Another ethical issue came later in the project. Over time, once the ship's future was secured, the project became more like a community-based participatory research project and a number of local partners were involved – archaeologists, the Friends of Newport Ship, Newport City Council and Newport Museums and Heritage Service. Public interest in the ship was high and there was increasing pressure to produce a book about the ship. The archaeologists were initially reluctant because they were a long way from finishing their research. However, it was decided to write the book and that the first draft should be written by the curator of the ship and the specialist nautical archaeologist (a heritage practitioner and an academic). It is not unusual in CBPR (involving a community-university research partnership) for one of lead authors to be an academic, especially if the article or book is for an academic audience. However, in this case the audience was the 'public' and as the nautical archaeologist commented: 'the first attempt was too technical for the intended audience, it was far too specialist'. Instead the Friends of Newport Ship took on editorial control and turned the draft into something more suitable.

<sup>8</sup>Institute for Archaeologists (IfA) (2010) *By-Laws: Code of Conduct*, [www.archaeologists.net/codes/ifa](http://www.archaeologists.net/codes/ifa)

One member of the Friends was vital in acting as a bridge between academic content and public accessibility, aided by the fact that he had experience as a professional researcher. The archaeologists checked it, and the Council allowed the Friends to use whatever photographs they needed. The Friends then took on responsibility for publishing and selling it, with the Council printing it at cost price. The end result has been a best seller which has benefitted the Friends, the archaeologists and the Council alike. As the nautical archaeologist commented:

The guidebook, now in its third edition, is an example of knowledge exchange and co-production. We wanted it to be accessible and popular. So with the involvement of the Friends the balance shifted to what the public found interesting. We realised that there are different ways of doing things for different markets and audiences.

The ethical issue here was about co-production and who should lead the interpretation and writing. Academics may write more frequently than other members of the project and sometimes assume they are best placed to handle certain aspects, without recognising the potential benefits of bringing in others.

### **Lessons from the experience**

This project came about because of an unexpected archaeological find and, from a situation of conflict at the start, a community-based participatory research project eventually emerged. There are many lessons from the experience:

1. *Evolving relationships – roles, identities and becoming a partnership* - When the ship was found the archaeologists' role was that of 'contract archaeologists' with responsibilities to the employer/client but also working within a professional code of conduct. However, as the ethical challenges discussed above reveal, the archaeologists were also mediators because of their daily contact with the local community. They disclosed and exchanged what information they could but felt a conflict of loyalties, brought about because of their responsibilities to their employer/client. At this time members of the local community group were campaigners. When the ship became public and funding for its preservation was secured these roles and identities changed and from this the partnership emerged. The archaeologists and the Friends of Newport Ship became more closely involved in community engagement and worked together as educators. The archaeologists focused on academic research throughout the project, but increasingly through the partnership with the Friends they came together in various dissemination efforts. This is where the strength of working with different knowledges and experiences became apparent. As the Vice-Chair of the Friends group commented:

Over the last few years in particular, the degree of cooperation between the parties has been an object lesson in how disparate parties can work together for mutual benefit. Of course that doesn't mean the future will be a bed of roses. There are still some tensions and probably always will be, but because the parties have shown they can cope with difficulties and find ways of working round them, the future of the project is much brighter than it would otherwise be.

2. *Limitations of professional codes* - Values articulated through professional codes or standards can produce tensions for researchers bound by these whilst working in community settings. This project highlights the need for such codes to recognise that there can be conflict between different aspects and that there is a need for guidance as to how the professionals and other parties may go about resolving the conflicts and tensions.
3. *Tapping the strengths of different participants* - As the issues relating to the production of the book illustrate, there are challenges around the issue of co-production that once worked through can lead to mutual benefits for the partnership. By thinking about the different knowledges and experiences within the partnership and tapping into these strengths, this can lead to a mutually supportive partnership and help ensure its sustainability. The two key lessons related to this are:
  - a) A project like this needs to tap grants from a number of sources. Whilst initially that seemed to be solely the Council's responsibility as owners of the Ship, the archaeologists and conservators working for the Council then recognised that charities had access to a number of grants that were not available to public bodies. The approach then changed, to one where both the Council and the Friends were involved in seeking grants for different aspects of the project, opening up more resources than would have been available to the Council alone.
  - b) Educating the public and maintaining their interest are crucial to the success of the project. The archaeologists and conservators, the Council and the Friends now recognise that they can achieve more by working together than by trying to work independently. Thus the Council organises



open days, but the Friends provide guides and other support. Similarly, the Council employs an outreach worker for schools and the professional team of archaeologists; Newport Museum and Heritage employees such as the curator, project officer, project assistant and conservator give talks to local groups; while the Friends provide Newsletters, a website and promotional leaflets. But for all these activities members of both groups help each other.

4. *Building on commonalities* - Overall, the Newport Ship project has continued to succeed in challenging circumstances. This is in part because all the institutions and groups involved have recognised that:
- they have a common goal (the conservation and display of the ship for the benefit of the people of Newport and beyond).
  - there is value in bringing the diverse skills and enthusiasm of all together to achieve it.
  - they need to understand and accommodate the perspectives and objectives of other participants.

As the Vice-Chair of the Friends of Newport Ship commented:

When all participants adopt this attitude, ethical issues become much easier to handle, and that is probably the most important lesson from the Newport Ship Project.

### Questions for discussion

1. Apart from the code of ethics of the Institute for Archaeologists and the fact that the archaeologists were contracted by the City Council, no mention is made of protocols, agreements or procedures to support the relationship between the various parties involved in this project. If you were involved in the project, do you think some kind of agreement(s) might be useful and if so at what stage in the developing process would you introduce them and why?
2. Try putting yourself in the shoes of some of the parties at the start of the project – the archaeologists, community campaigners, city council politicians, museum and heritage employees, local residents or employees of the building construction company. What interests do you think you would have and what rights would you want to assert?
3. Whilst the City Council and Friends Group are reported as getting along well at the time that the case study was written, what might rock the boat in the future and how would you plan for handling new tensions and conflicts?



## Case study 4: The polyveg garden project<sup>9</sup>

### Brief description

This case study describes a 'community science' project involving a university-based researcher (plant ecologist), an interest group (Permaculture Association, PA) and volunteer researchers (gardeners, members of the PA). The majority of the issues that were anticipated and emerged were generally seen by participants as being practical and scientific (how best to communicate or how to achieve reliable data) rather than ethical (relating to conflicts of interest, rights and responsibilities of different parties). Therefore, in addition to discussing several ethical tensions identified by the plant ecologist, this case study also draws out some of the potential or latent ethical issues.



The polyveg garden project was a 'one year trial' participatory research project that involved 50 gardeners across the UK growing annual mixed vegetables using a polyculture approach. Polyculture involves growing a mix of vegetables, herbs, flowers or fruit. Common examples include the English Cottage Garden, Caribbean kitchen gardens and allotments of Bangladeshi communities in London<sup>10</sup>. It differs from conventional vegetable gardening, where each crop is grown in rows or patches, in that a mixed crop is grown together in the same space. In conventional gardening the same species (e.g. peas or brassicas) may be grouped together, which means they compete for the same nutrients and become attractive to pests.

The key question for this project was: Can growing food plants in communities rather than monocultures also be more productive (and better for the environment)? The aim of the study was to compare low and high density mixes to answer two questions: 1) Are more diverse (12 species) vegetable mixes more productive than less diverse (three species) mixes?; and 2) How easy do gardeners find these systems to use?

The idea for the project emerged from informal discussions between members of the Permaculture Association (PA), one of whom was a plant ecologist based in the National School of Forestry, University of Cumbria. As the plant ecologist explained: 'The Permaculture Association was keen to develop the research side and move towards "academic" research to complement and enhance their existing body of practitioner research'. The plant ecologist's academic work had involved forest gardening, but as a keen vegetable grower and plant ecologist the opportunity to work with PA on a vegetable growing project was interesting. A working group, comprising the plant ecologist and three other members of PA discussed how to run a member trial, seeking insights from Garden Organic<sup>11</sup>, a national charity for organic growing.

The project started in January 2011. The Permaculture Association's contact database was used to recruit participants. Once 50 were recruited the trial began in earnest during the growing season of March to October 2011. The project was managed by the Polyculture research team comprising the plant ecologist from the University of Cumbria and four people from the Permaculture Association Mixed Vegetable team. Each team member was responsible for managing different aspects of the trial and their expertise/experience determined who would manage what. The plant ecologist, in liaison with the Mixed Vegetable Team, managed the scientific aspects, such as seed densities and what to plant. Her remit was to ensure the scientific aspect was 'clear and rigorous'. The PA members of the team were responsible for data and administrative management and it was an intern who coordinated the trials, sent out the seeds, was the

<sup>9</sup>Based on materials contributed by Naomi van der Velden and the Permaculture Association, compiled by Andrea Armstrong and Sarah Banks. For further details of the project see: van der Velden, N. (2012) *Mixed vegetable polycultures trials: the results*, The Permaculture Association/University of Cumbria, [www.cumbria.ac.uk/Public/SNRO/Documents/Research/NKVeldon2012MixedVegResultst.pdf](http://www.cumbria.ac.uk/Public/SNRO/Documents/Research/NKVeldon2012MixedVegResultst.pdf)

<sup>10</sup> [www.permaculture.org.uk/sites/default/files/page/MixedVegGarden\\_A4\\_blacknwhite.pdf](http://www.permaculture.org.uk/sites/default/files/page/MixedVegGarden_A4_blacknwhite.pdf)

<sup>11</sup> [www.gardenorganic.org.uk/](http://www.gardenorganic.org.uk/)

first point of contact and collected all the data. Often the emails were written by the plant ecologist and then the intern made them user-friendly. As the plant ecologist explained: 'there was not a hard and fast structure. At any point anyone could feed in about the choice of species, range of plant families and niches'. Funding was provided either in-kind or through donations - for example, four seed companies provided free seed for the trial.

Each participant was sent seeds and asked to create two plots – one for the low diversity plants (peas, radish and beet) and one for high diversity plants (peas, radish, beet, onions, lettuce, beetroot, sweet corn, coriander, runner beans, kale, marigolds and rocket). They were asked to record when they visited the plots, how long they spent there and to weigh each species each time it was harvested.

In the end 24 of the participants completed the trial and returned useable data. The plant ecologist analysed the data and wrote up the results, which were presented to the PA and made available in an accessible report.<sup>12</sup>

## **Ethical issues anticipated in the project**

### *Consent and anonymity of volunteer researchers*

As the project was seen as scientific research based on the study of plants (rather than the study of humans or animals) it was not submitted for institutional ethical review at the University. However, the plant ecologist did pay attention to the rights and interests of the volunteer researchers, ensuring that they were properly briefed and their privacy was assured. As the ecologist explained:

A common sense approach to ethics was taken drawing on years of research project experience and taking into account the most likely/common ethical issues such as anonymity, confidentiality, informed consent and handling of personal data.

A letter was sent initially to each participant providing information about the project and detailing what participation meant: to grow the vegetables according to the specifications; record information as required; and complete questionnaires. Informed consent was gained from participants once they had read, understood and agreed to the project terms. Anonymity and privacy were considered important because in a previous research project involving forest gardens, the plant ecologist had learnt that: 'some people wanted to be more private. They wanted to know who would have the information, where would it be publicly available and they wanted assurances that it would not be personally identifiable'. For the polyveg trial these potential concerns were anticipated and privacy of participants was assured in that the team promised that no personal information would be shared outside of the PA and University. Furthermore, e-mail addresses would only be used to contact participants in relation to the trial. The team also checked that participants would be happy to share data findings within the network and more widely.

Personal anonymity was assured and the data were aggregated to such an extent that participants would not be personally identifiable. When the plant ecologist produced a map (publicly available on a website) showing where the plots were, this was circulated to participants. There were no objections because the dots on the map covered such a large area, it was impossible to identify specific gardens or even towns. Permission was sought to use photographs that were shared on Flickr.

### *Ownership of data and findings*

It was made clear from the outset that the data would be used by both PA and the University of Cumbria. The research team knew and trusted each other and did not feel it was necessary to produce a written agreement regarding intellectual property, whose names would appear on publications or how to credit the volunteer researchers.

<sup>12</sup> van der Velden, N. (2012) *Mixed vegetable polycultures trials: the results*, The Permaculture Association/University of Cumbria, [www.cumbria.ac.uk/Public/SNRO/Documents/Research/NKVeldon2012MixedVegResultst.pdf](http://www.cumbria.ac.uk/Public/SNRO/Documents/Research/NKVeldon2012MixedVegResultst.pdf)



### *Credibility of findings*

The research team anticipated a high drop-out rate of volunteer researchers and wanted to ensure findings were reliable and credible. Hence they recruited 50 people, with the aim of gaining data from 20. The fact that they used data from 24 plots was regarded as satisfactory as far as this study was concerned.

### **Ethical issues emerging and developing**

#### *What is research? Negotiations between research partners about what is practical and scientific*

Even though the two research partners (PA and the University of Cumbria's plant ecologist) shared an interest in gardening and in particular vegetable growing it emerged early on that what each thought counted as research was very different. Discussions at the early stage revealed very different ideas about how to approach the research project. These differences were interesting (i.e. hearing other perspectives) and challenging (i.e. how to negotiate and move forward). One member of the PA thought that everyone in the trial could grow what they wanted, but the plant ecologist thought that this was not scientific as it would not produce data that could be subject to rigorous analysis. The plant ecologist was concerned with replicability and control, and initially wanted a much larger scale trial. In the end, a balance was reached whereby the trial was practical and scientific. They asked the questions – what can we ask people to do that is not too demanding, but will yield results that are both relevant to the participants and scientifically meaningful? And 'how much science can we ask people to do?'

#### *Communications between the research team and volunteers*

Another issue, related to language, came about when writing the project instructions. The 50 participants came from a variety of backgrounds, with wide ranging levels of education, knowledge and experience of gardening. However, they were not particularly knowledgeable about the polyveg approach and the science underpinning it. The challenge was to write clear and intelligible instructions that were not too prescriptive so as to appear patronising. Despite efforts to write the instructions clearly the project team were surprised at the various interpretations. For example, some people wanted detailed information on where to place each seed, whereas others were happy to do what they usually did. Also, even though the instructions said how to record the information people interpreted this differently. In some situations the geographical location influenced decisions to deviate from the instructions because planting seeds in April (as per the instructions) may not be appropriate due to variations in weather between the North and South of the UK. The issues raised about how to communicate and negotiate the instructions were both practical (what would work best) and ethical (not being patronising and respecting local knowledge).

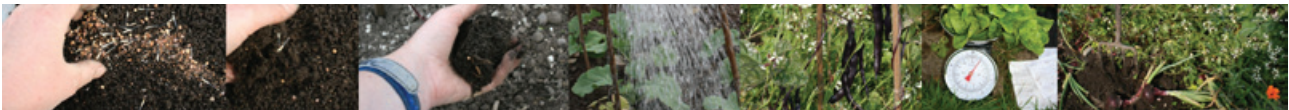
### **Learning from the experience of working with these ethical issues and reflections on potential ethical issues**

1. *The advantages and disadvantages of institutional ethical review* – The plant ecologist discussed the project with the Head of the Ethics Committee at the University and was advised that it was not necessary to go through a full approval process. This was because the research was not seen as involving experiments on humans or animals and did not involve using personal data from the volunteers. However, if the research had gone through some kind of institutional review process it might have raised the fact that the research was a partnership between University and the PA and its members. So some kind of agreement might have been made between the parties regarding intellectual property, including the use of findings and data. The advantages of ethical review are that it can trigger deeper thinking in advance about ethical, practical and scientific matters. The disadvantages are that the review procedures are not geared up for CBPR, can force a fixed research design, may hamper an emergent research process and turn a complex relationship of trust between people into a simple written contract between organisations.
2. *Credibility and use of volunteer researchers* – an issue that might have come up, but did not, was what to do if some of the data from the volunteer researchers seemed unreliable and there was a dispute between the plant ecologist and a volunteer. Family members of the ecologist were part of the trial, as were members of the PA research team.

3. *The status of the volunteer researchers* – there was an issue regarding the extent to which the volunteers were 'co-researchers' or simply 'providers of data'. Their names and locations were kept anonymous. This meant they could not gain credit for their part in the research. In future projects it will be important to have discussions with volunteer researchers about the advantages and disadvantages of anonymity and whether some might wish to be named.
4. *Agreements regarding authorship and ownership of data* - Although no conflicts occurred in this case, some discussion and a working agreement at the start regarding who would be able to use the data might be useful.
5. *Seeing ethical issues* - In planning and carrying out the project, the team did not see it as involving ethical issues (apart from consent and anonymity of the volunteer researchers). There can be some value in viewing a research project through an 'ethical lens', but this is not easy if 'ethics' is not part of the normal discourse. Having a set of principles and guidelines for scientists to use when doing 'member trials' or other forms of CBPR in science will help this process.

### Questions for discussion

1. One of the main ethical issues anticipated was the need for volunteer researchers to remain anonymous. Might there be other ways of ensuring privacy of those who desire it, without requiring 'blanket anonymity' for everyone?
2. This research project was not subject to formal ethical review in the University. Do you think it should have been reviewed? What are the challenges of subjecting CBPR projects to institutional ethical review?
3. This research project did not receive external funding, but did receive some donations in kind, such as seed from seed companies. In this case accepting donated seeds is a very small contribution and there is no indication that seed companies would have any influence on the research. However, in some cases donations may be larger, or research may be fully funded by a private company. What criteria should a CBPR partnership use in deciding whether to accept donations towards its work?



## Case examples and commentaries

### Case example 1

#### Issues of disclosure and intrusion: challenges for a community researcher

##### Introduction

This case example was written by someone who is now 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

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 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 that 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.

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## **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.

**Ingrid Burkett** is an independent researcher and designer, based in Brisbane, Australia. Her research centres particularly on community economic development. She is also President of the International Association for Community Development, and is a part-time research fellow with the Centre for Social Impact at the University of New South Wales.



### **Questions for discussion**

1. When community researchers are undertaking research interviews with people in similar circumstances to themselves, what are the positive and negatives outcomes of researchers sharing personal information and feelings?
2. This was an action research project, with local community researchers involved in collecting data on household circumstances as well as offering mentoring. If you were offering training to community researchers/mentors, how would you cover the 'boundary' issues between being a fellow resident, a researcher and a mentor?
3. What system of support do you think should be in place for community researchers/mentors in projects like this?



## Case example 2

### Guns and gangs: challenges in supporting a peer research project

#### Introduction

This case example was written by a youth worker, who was involved in taking a lead role in training young people involved in a peer research project on guns and gangs. 'Peer research' is an approach to research that entails people acting as researchers with their own 'peer' groups (e.g. young people researching other young people; people with experience of a particular issue researching others with similar experiences). Peer research is increasingly popular in a youth work context, as it not only enables information and opinions to be collected that adult researchers might not be able to access, it is also a way of young people gaining new skills and generating evidence that they can use to try to influence policy and practice.

#### The case

The research project was initiated by a Housing Association and a Local Authority, to investigate how to address gun and gang issues in a particular area of a UK city. They were concerned about the high level of gun and gang crime and the perception of this area as a crime 'hot spot'. They contacted the organisation where I work (a youth organisation) to see if we could research the issue with the help of young people. It was agreed that we would take on this piece of work as a peer research project, supporting young people to undertake the research themselves. It was agreed that I would lead the training, with a co-trainer. The project was a partnership between the Housing Association, Local Authority, a University researcher, a local Christian community work project and a voluntary sector environmental and youth work charity. The project entailed working with local young people from a specific ward (small administrative area) with the highest gun-related crime, according to police statistics. The young people were recruited by one of the project partners. When the project first began, the partner organisation had brought together a group of young people aged from 12 up to 25 years old. They were all black young men, except for one black young woman (who only came once or twice to the group) and one white young man. There was a mixture of young people who had experienced gun or gang violence and those who had not. I, the lead trainer, am a white woman, who is a lesbian, but I was not 'out' to the group.

My role was to train the young people during weekly sessions to enable them to gain an understanding of the nature of research, to explore and evaluate different research methods and to look at issues of risk and ethics. The young people would then work on developing an action plan, and would undertake and document a piece of peer research. The research was to be carried out with young people from the area, both those who had been involved with gangs and those who had no connection with gangs. The findings were to be presented at a conference for 100 professionals later in the year.

The group was challenging to work with as their attitudes and behaviour could be quite sexist and homophobic. For example, during the first session it became clear that there was a lot of machismo in the group and stereotyped behaviours around masculinity. As was the custom within the sessions, we started with an ice breaker or cooperative game. In one session, after a few weeks, the game involved holding hands and sending a pulse down a line of people by squeezing the hand of the person next to them. The young people reacted to this quite strongly and refused to play the game, saying they did not want to be seen as being gay. However, I never explicitly addressed issues of gender, homophobia, why they were a male group, what issues women faced, nor why there was such a macho culture (of which they may not even have been aware). The general implicit consensus seemed to be that women were not really important to the issue of gang violence or gun culture. This caused me some difficulties since, as a youth worker, I would normally address these issues. In some ways I was scared to do this, because I did not have the mandate to do youth work as such with the young people, and there was limited time to tackle these issues in depth. In addition, the other workers were all men and I did not know how much 'back up' I would get from them on these issues, given that one had directly challenged me before when I trained young people on anti-oppressive practice. I also did not want the sessions to become about me and my life instead of about the research.

However, I did discuss racism with the group, acknowledging my own position as a white woman. The young people recognised through our conversations that some of the issues relating to the stereotyping and treatment of gang members had racist elements, especially when they were recounting their own personal stories. During some of these personal stories, however, it appeared that they were as much at fault as the police or gang in question, but positioned themselves as victims of racism. I felt a bit uncomfortable with this as I was not sure whether they were adopting a victim stance and whether this was because of how they felt they had to position themselves in relation to the issue.

As the project progressed the young people designed ways to find out about how to address gun and gang violence through doing semi-structured interviews and questionnaires. Because the peer researchers were from the same area they were researching, they would often start talking about their own experiences, or interpret what other people were saying in relation to their immediate situation. One issue that arose was whether they were stuck in their own stories and if this would cloud their judgement as researchers. This was never addressed head-on because we knew we would present the findings at a conference being run by the local authority's gun and gang strategy team, and a big part of that would be the young researchers telling their own personal stories too. So it served the funders' priorities to keep them focussed on their own experiences.

The younger people in the group decided to create a play to perform at the conference, as a way of showing how gang violence develops. These young members of the group had not had any involvement in gang crime, and did not particularly base the play on the findings of their research. Instead, they came up with a plausible issue about someone stealing something from another person and that sparking a gang feud. However, this scenario did not recognise the fact that most of the gang violence in the area was carried out by two main gangs, based on longstanding hostility dating back to the 1970s. They did have some training about the origins of the gang violence, but they did not seem to have taken this in. As they were engaging in the project that had been dominated by the older ones, I hung back and let them develop this play, although I did feel a bit compromised in terms of mixed messages this would send to the conference.

When the young people performed their play, and the rest of the group presented the findings and shared their stories, the conference participants treated them as if they were all very close to gang violence and all had connections to it. The conference participants (from a variety of professional disciplines in local authorities, along with social work and criminal justice organisations), seemed as if they were reinforcing the idea that being a gang member gave young people status. It felt like the young people would only be listened to by the professionals if they, in effect, pretended they were in a gang. The professionals quizzed the young people about gang membership rather than looking at why it was that members of this group were not involved with gangs-- that is, what protective factors had positively changed their lives in a ways that meant they were less inclined to fall into gang culture.

It also felt like the professionals were putting the young people on a pedestal and expecting them to have all the answers, rather than seeing this research in combination with longstanding academic research on the topic based on the same geographical area. In the afternoon session the young people worked in small groups with the adults, with the hope that they could get the professionals to pledge help from their organisations. Instead, the professionals focussed on a crime and punishment model and 'passed the buck', rather than really listening to what the young people had to say. For example, the research findings showed that cutting the playscheme in the local area some 10 years before had meant that young people from opposing neighbourhoods no longer mixed with each other as children, and therefore were not building up positive allegiances with each other. The young people also said that unemployment was high in the area, but that the satellite job centre only opened one afternoon a week; and that even though lots of building work was happening in the area, there was no pressure from the planning department to recruit local apprentices as part of its contracting requirements. Professionals said that was a shame, but then went on to talk about policing, 'hot spots' and 'reducing silo working', which was a lot of terminology that the young people did not understand.

This research project made me think about several ethical issues around the sometimes conflicting priorities or motivations of the different stakeholders involved in a community-based participatory research 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.

## **Commentary 1**

### **Laura Saija**

As indicated by the author of this case example, the choice of 'peer research' as an approach to exploring gang violence reflects the belief that only insiders can really know what happens in very difficult contexts. This assumption reflects what is often the main argument in favor of CBPR, against traditional research: CBPR is a way to know 'better'. Is it true? If so, what does 'better' mean?

In the case example, the author raises doubts in relation to the three dimensions through which CBPR is usually evaluated:

- Knowledge outcomes - how 'good' is the knowledge produced on gang violence? The author shares her feeling that young researchers have not been 'objective' enough.
- Participants' learning outcomes - how beneficial are the outcomes for both young researchers and conference participants?
- Practical outcomes - have there been 'good' impacts, especially in relation to policies on gangs?

Why did this happen? Could things have been done differently? Answers might be very subjective, but I would like to answer in the light of what I believe is the ethical framework that differentiates CBPR from other traditional approaches.

According to ethical theories that are the foundations of traditional approaches to research, 'true' or rigorous knowledge of what is good or right is meant to precede and then guide human and social actions. On the other hand, ethical theories that are the foundation of CBPR are based upon the assumption that:

- not only do individuals and communities (including professional researchers) in different places and times have different legitimate value systems, but also
- they can change their minds, building a common ethical perspective through common experiences.

CBPR is, in fact, conceived to be a common experience between individuals with very different backgrounds and values, in which 'knowing' is the mechanism through which people explore their ethical understanding of the world, and have the opportunity to modify it through interaction, in order to 'improve' (according to this new perception) reality. As a consequence, moral judgments do not precede the research process itself, since they do not have a universal value; they can be modified along the way, converging and having a 'positive' effect on reality. It is the convergence itself that allows participants to act, establishing whether or not a certain effect on reality is or is not 'positive'.

The author describes the differences between her ethical understanding of the world (negative ethical judgment of machismo and racism) compared with those of the others involved in the project (young researchers, research conference participants). Within the ethical framework described in the previous paragraph, we are not expected to wonder who is right or wrong: this would make sense only with predefined criteria to define what is good or right. The main concerns, from a CBPR point of view, are:

- Whether or not the research process itself allows different values systems to contaminate each other, and
- More importantly, whether or not such a convergence opens up possibilities for action (policies and initiatives against gang violence).

In relation to these points, the author shares with us her negative evaluation: young researchers and research conference participants have not learnt from each other, nor have they converged in looking at (which also means evaluating) the gang issue differently than before the research project. Neither have they agreed to act collectively to work on this issue.

In the story, the issue of gang violence and the need to address it with urgency, was pretty much identified before and outside the research process itself. Therefore it does not come as a surprise that, during the research, other issues (such as lack of jobs) came out, since the involvement of 'insiders'

helped in reframing the problem in a more holistic and complex way. However the reframing was allowed only within certain boundaries:

- Within the goal of the research itself (to understand the nature of, and how to address, gang violence);
- Within a predefined research structure;
- Within the activities of 'selected' youth with the trainer, excluding other youth (that I guess have only been asked questions by the peer researchers);
- With a limited interaction (within a research conference) with key actors in terms of opportunities for future actions.

A crucial question arises: would it have been better to enlarge those boundaries, in order to facilitate the contamination of different value systems?

**Laura Saija** works as Research Fellow at Department of Architecture, University of Catania, Italy. She is currently on leave, and is a visiting faculty member in the Graduate Division in City and Regional Planning at the University of Memphis, USA.

## Commentary 2

### Michelle Fine

This is a beautifully written case example, on a critical social issue, crafted with intellectual and aesthetic care. A group of marginalized young men have been invited by the government to engage in peer research on an incredibly hot and dangerous topic. The state offers support (lite) and surveillance (heavy). These young Black men (w)rap themselves in a protective discursive layer of machismo and homophobia when narrating lives steeped in poverty and structural abandonment. A politically savvy, culturally sensitive and methodologically astute researcher is hired to facilitate the research; she is well educated, white and lesbian. In the end, some of the young men perform a play for an audience that chooses not to hear the story of racism or structural inequality. They prefer to learn why some boys do, and don't, make good choices.

On a sea of neo-liberal dispossession, the global dynamics of immigration, political economy, racism, budget cuts, criminalization and inequality gaps are stuffed into a bottle. A single research question etched on a small ripped piece of paper floats above the water, asking why some boys decide to join gangs and play with guns. I fear that participatory researchers are being recruited into this theatre of structural disinvestment to produce a fig leaf of community-based research doubling as 'voice' and, if we are not careful, co-optation.

What's distinct and refreshing about this short essay is the honesty, clarity and the sobering reflective details the author shares with readers. I am hoping we can slow down the research story and map points where critical participatory researchers might challenge the official script rather than watch it unfold, with us caught in the under-tow.

#### *1. Re-framing the shape of the problem*

After three decades of work on/for/with/by structurally marginalized youth, and lots of mistakes, I worry that community-based researchers are today being invited to 'make science' with marginalized youth in order to create narratives 'in their own voices,' that legitimate a very narrow question about 'risk' while whitening out histories of structural violence and the collateral damage of global capitalism, racism, sexism, heterosexism, xenophobia, Islamophobia, ableism...

When the Housing Authority, Department of Education or Health, Juvenile Justice Unit, a foundation or school next contacts us, what if we explicitly initiated a re-framing, or re-negotiation of the research question:

Before we agree to take up this work, can we talk about the working assumptions of the project? What is your organizational theory of why this problem is occurring, and are you open to generating evidence that might widen the scope of the problem? So, for instance, might your [organization] be willing to subsidize a project in which we study and document with youth, educators, elders, activists and researchers the long history of guns in the UK, the systematic and disproportionate budget cuts to our communities and our playgrounds, the racialized unemployment rates, and the well funded criminalization of poor and working class youth, and then interrogate why some young people use guns and join gangs?

CBPR can trouble neo-liberal shrinkage, shine an empirical light on history, economics and politics, complicate the commonsense attribution of blame onto the bodies of the young men and women living in poverty, and still examine the original question of responsibility, agency, ambivalence, desire and risk – but in context.

## 2. Design an intentionally diverse research team: building 'contact zones'

The dynamics on the research team of 'guns and gangs' are also quite familiar: low income, marginalized youth of colour (in this case boys) and a lone woman, often White, facilitating the group. If, as I tried to suggest above, we insist on widening and historicizing the shape of the problem, then we need a research team much broader than boys with (or without) arms.

At the Public Science Project at the Graduate Center, City University of New York, we design most of our research spaces with an ethic and aesthetic of intentional diversity, what Maria Elena Torre (2005) describes as a contact zone. Cross generational research groups, dynamically diverse by race, ethnicity, gender, class and sexuality, come together to share their distinct knowledges, challenge one another, learn with and from, and generate new frameworks for understanding problems that seem individual and but are indeed structural.

As an example: The Morris Justice Project studies racialized policing/stop and frisk practices in the South Bronx of New York City. Brett Stoudt and Maria Torre facilitate a research team of young men (who are most likely to be targeted by policing practices) and young women, elders from the community, researchers, lawyers and a former corrections officer who have finalized the research questions, determined the sample, developed methods and instruments, and will be creating scholarly as well as community-friendly products. This intentionally diverse research team widens the recognition of who holds knowledge, troubles the overly simplified binaries of researcher and researched and broadens the scope of who is responsible for social change.

## 3. Theorizing audience: working against judgment and empathy or solidarity

Finally, we have also witnessed, the scene when an audience is emotionally moved by and drawn to the stories of the young people. Firmly unwilling to engage the tougher questions of political economy and racism, audience members are entranced instead by their own fantasies of who is in a gang, who is homeless, in foster care, has an incarcerated parent, who is undocumented. We now believe we have an ethical responsibility to rechannel judgments of and empathy for, into a sense of responsibility to and solidarity *with*. After our performances, youth researchers/performers turn to the audience to say, 'Now what you are going to do about this?' (Fox & Fine, 2012)

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I thank the author of Guns and Gangs for inspiring me to think aloud about our political and ethical debt to marginalized communities and consider how three pivotal moments in participatory work – negotiating the research question, building the research team and challenging the audience – can be re-imagined to provoke a more ethical set of possibilities for CBPR.

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### Questions for discussion

1. The author of this case example is very honest about the difficulties encountered in the research project. Drawing on the insights of the commentators, how would you go about setting up and conducting a peer research project on guns and gangs to ensure it was ethical and effective, from the perspectives of: the research commissioners; the youth workers; the young people?
2. What do you think are some of the main ethical issues associated with peer research?
3. The youth worker/trainer seemed to take off her 'youth work hat' (youth workers are traditionally regarded as informal educators, with responsibility to challenge received ideas and promote anti-discriminatory practice). Why do you think this happened? Do you think she could/should have retained her professional identity as a youth worker in this work?



## Case example 3

### Changing the story: issues of copyright and informed consent in a museum-based project

#### Introduction

This case example was contributed by a community outreach worker with a large local authority based museum service in the UK. The role of the community outreach team at this museum service is to engage excluded audiences and community groups in the collections and venues of the museum service through creative heritage projects, which are developed and delivered in partnership with the group. This reflects a growing trend for museums to develop their engagement with local communities. Outreach staff work in partnership with community groups and voluntary organisations to develop and deliver a range of different creative heritage projects, which can include reminiscence projects, arts and crafts, oral history projects, film and photography, object handling sessions, or one-off visits behind the scenes or museums visits. The case example offers an account of some of the ethical challenges of working with local people on a digital storytelling project, particularly the issue of informed consent.

#### The case

I was project manager for a large-scale partnership digital storytelling project that took place between 2008-2011. The project was designed to work with members of the public living across the region to tell and make their own digital stories, which would then be displayed across the region and formally accessioned as part of the museum's collections. By adding these stories to the museum collections, the project demonstrated 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.

My role was to manage the project from initiation to completion. I was responsible for managing the extensive project team from across the four regional partners, who were facilitating workshops with a range of community groups and organisations across the region. In addition to running workshops where stories were produced, there was also a public screening programme of these stories, which included a website that is still active, a festival of events, a museum exhibition and the opening of an empty shop in a busy city centre shopping centre. In total nearly 600 people created digital stories and a further 40,000 people engaged with the stories through the public screening programme.

I was aware from the beginning that what we were asking people to do was no small thing. We were asking people to share their personal stories and to consent for them to be not only displayed in the short term, but to be accessioned into the museum's collections for perpetuity. The project team discussed how to make sure we were supporting those involved to give their informed consent for these uses of their stories. By 'consent' we meant getting people's agreement for the stories to be used for particular purposes. The project was directly linked to short term display and long term public access through the museum's collection. Because of this it was felt that the project 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 also seen as important, because the museum did not want to have to go back and seek permission every time they wanted to reuse the story. This was not just a practical point, rather it was linked to questions of public value and the need not to focus resources disproportionately on a small group of people. 'Copyright' is the exclusive right to produce copies and to control an original literary or artistic work, granted by law for a specified number of years.

There were many moments that made it obvious how difficult it was for anyone to give informed consent and the particular difficulties of informed consent that come from signing over copyright. The project was very public – for example, the stories were shown on a big screen in a neighbouring town. However, a more unimaginable dimension to consent in terms of signing over copyright was that of future use.



One example of this arose approximately eight months after the project had officially ended. One of the effects of assigning copyright and then of the stories being accessioned into the collection was that they became fixed. In theory, they could not be changed. Yet two participants had told their 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 remaining and future museum staff were aware of these new restrictions placed on this story. The second example was slightly 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, and in the same way someone cannot change the content of the oral history, should the master copy of this digital story be changed to take into account the wishes of the story creator, even though the museum 'owns' the story? This caused a dilemma as I wanted to respect the wishes of the participant, but I was unsure about what the appropriate action should be. This situation had not arisen before as the museum service had not used digital storytelling as a community engagement tool before this. A solution has yet to be found by the museum service due to current changes with the collections management system. Perhaps a compromise in this situation would be to adapt the public version of the story while leaving the master copy as it is.

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.

It might seem like the answer to all this is to negotiate in each case, taking account of particular circumstances. Although this does work in many cases, the question of accessioning of objects does make this more difficult and raises questions of whether it is ethically right that a personal story and a digital object should be 'fixed' in this way.

The issues raised by this project led to further work being undertaken on the issue of informed consent in the museums sector. In a focus group held with participants twelve months after the project ended, most people said they were fine with signing over copyright. However, they wanted to be told if their story was going to be re-used and said they would like to be invited to the exhibition opening. They repeatedly described this as being shown 'courtesy'.

## **Commentary 1**

### **Rachel Pain**

This case example comes from outside of academic research in a museum context, but the core issue it discusses is familiar to us all. Public engagement and participation are now encouraged in areas of the public and voluntary sectors as well as universities. Indeed, museums have a long history of attempting different approaches to involve people in producing collections and exhibitions. In such institutional contexts, the ethical issues and dilemmas that face all researchers can be amplified. When we try to engage a participatory ethics, the conflicts with institutional ethics and practices are often the key struggle. The author highlights important issues of copyright and consent in her discussion. I would like to add to these some comments on participatory/institutional ethics, and the impact and relative visibility of cultural context.

#### *Participatory/institutional ethics*

The case study describes some of the ethical issues in a digital storytelling project, which engaged local people as knowledge producers. From this particular project, it brings to the fore a much more widely felt conflict between participatory and institutional ethics.

The former involves a 'retreat from the stance of dispassion' (Fine et al., 2000, 128) that traditionally characterises relations between institutions and individuals who are 'engaged' in their activities, such as research or in this case, developing a museum collection. The principles of participatory ethics commonly include forefronting of people's representation, accountability, social responsiveness, agency and reflexivity (Manzo and Brightbill, 2007). Institutional ethics, on the other hand, are ethical protocols developed by particular institutions such as the museum or the university, ostensibly to 'cause no harm' and to treat publics with respect, but also serving to protect the institution and having foundations in particular traditions and understandings about knowledge generation, outputs and ownership.

By their nature, participatory ethics suggest an emergent process of negotiating ethics with participants based on their positions and concerns, and this rarely sits easily with inflexible institutional traditions and procedures.

In this case example, a careful and sensitive approach was taken to ethical issues over people's stories. The major issue that surfaced was about the ownership of stories once they were recorded. Here personal ethics and wishes about making changes to or withdrawing 'my' story might potentially collide with the accessioning of objects in curation practice (here the story becomes the object and thus the 'museum's' to own and to take curatorial decisions about). The project made great efforts to respect people's rights to make decisions about what happened to their stories. I was fascinated by the dilemma over one participant's wish to change their story. The traditional assumption would be that the story is 'fixed'; that there is an authenticity to a story even when the person who told it wants it to change. And yet if the story no longer reflects what the participant desires and wants it to project, does it not become meaningless? This dilemma reflects those of many other researchers: who does data belong to, and who should make decisions about what happens to it? In whose interests is the frequent practice of asking participants to sign away their rights to deciding on this? Participatory research, in contrast, has as an ethical priority joint ownership of whole research processes/projects, ownership of data always remaining with the person who produced it.

#### *Cultural context*

We are not told here, but I understand that a diverse range of social groups contributed stories to the digital storytelling project. This raises other dilemmas, which the author has not chosen to reflect on in the case example, about cultural context. Every story is produced from and enters a historicised cultural context where there are already great imbalances in the representation/voice of people of different social classes, genders and ethnicities. Museums in this region have tended to tell the stories of more powerful groups, or of white working class men; women and black and minority ethnic populations have been far less visible. So I wondered if there were ethical issues here about representing the stories of the less visible. There may be additional pressure on invisible minorities through the inclusion of their stories, and a bind of being held to 'represent' particular communities, as well as issues of reception among the wider audience. In other countries where working alongside excluded indigenous communities has a long history, practice is rarely perfect but there tend to be better developed existing precedents and protocols on which to draw.

Overall, this is an interesting and well-considered discussion of an ethical issue. Such examples from different areas of practice have much to inform and stimulate in thinking about ethical orientations in other forms of research.

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## **Commentary 2**

### **Helen Graham and Aileen Strachan**

The case example outlines a very innovative piece of museum practice. The project pushed participation in museums to a new level by not only displaying the project's outcomes but also accessioning them into the museum's collections for perpetuity. In doing so the project reveals and questions some of the logics of museum practice, each of which have ethical implications.

The ethical dilemmas may seem specific to 'digitally born' objects, but the quandaries outlined flow from the inherent oddness of museums as institutions. Museums collect material culture perceived as being valuable for perpetuity – whether that is a painting by Monet or a commemorative mug – with the aim of keeping it safe and making it available for display and research to everyone now and everybody in the future.

Our first aim in responding to the case example is to relativise the dilemma by highlighting parallels with collecting non-digital objects. One interesting issue raised by the case example is the perceived link between accessioning and 'fixing', or 'freezing' the digital object. The museum's hope in accessioning the stories was to demonstrate their value and for them to be looked after for display and research forever. However, the process of accessioning the digital story appears to have assumed a fixity and therefore raised the dilemma of whether participants have a right to change their story. Yet preserving objects is never about fixity as such. While it might seem that preserving an object is about keeping it the same, in reality the attempt to keep something forever requires intervention to stabilize the object and indeed, in some cases, active restoration work is undertaken. In other words, across museum collections, members of museum staff continually make negotiations and compromises, with political and personal dimensions. So while these questions are more apparent in the context of 'changing' a digital story, the fundamental idea of objects as subject to change as a means of securing their permanence exists across collections. That would suggest the possibility and even desirability of similar compromises with digitally born and co-created objects.

Traditionally, the argument for why the museum has to own – and therefore control – objects is that to preserve material culture requires large amounts of public money. In this way, it has been argued (for example in the Museums Association *Code of Ethics for Museums*, 2008) that an individual donors' interests must be balanced against interests of the public as a whole. This means that objects cannot simply be returned to donors if they change their minds. However, one of the big differences flagged by the case example is the very personal nature of the stories. The case example suggests that when the stories are personal, even if the form is signed and the story is accessioned, then the museum still finds itself having to respond. In other words, when it comes to personal stories the same rules can no longer apply.

The case example quite rightly draws attention to the difficulty of aiming not simply for consent but informed consent. Informed consent in the context of museums is a difficult business. As is suggested by the compromises in the case study, participants find it hard to imagine a museum keeping a story 'forever.' In the case example, it is suggested that participants who wished to alter their stories could be accommodated with changes only to the currently public versions of their stories. Yet this raises questions about whether participants/story authors really are giving informed consent for the future use of the unadapted story.

The idea of public record is fundamental to museums and archives. It is clear that records such as council committee minutes or newspaper articles cannot be changed or expunged on request. Yet when museums work with people to produce personal testimony (not simply collect testimony that exists anyway) we wonder whether that changes the requirement to maintain unaltered records. Might it be possible to see that-which-is-collected not as a specific object or specific story, but the very *idea of an authored and controlled contribution itself*? If imagined that way, then the compromise suggested would not be necessary and the stories can evolve. All objects evolve so they can be kept, perhaps we need to accept that personal stories will do the same?

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### Questions for discussion

1. This case study gives an account of an issue that is framed as an unresolved dilemma for the community outreach worker and the museum service: whether to change the woman's story or not. What are the arguments on both sides?
2. In Commentary 2, it is suggested that one response to the dilemma might be to see the testimony not as a fixed object or story, the ownership of which is taken from its author by the museum, but as an 'authored or controlled contribution' that might be changed by the author over time. What are the practical and ethical implications of this?
3. All research involving interviews raises similar issues about interviewees' rights to modify and control the use of records of the interview. If this project is framed in terms of 'co-production' (i.e. people researching themselves in partnership with the museum) does this make a difference to how we view the rights and responsibilities of the contributors of the stories?

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