Tackling Ethical Challenges in Community-based Participatory Research

Holgate Conference Centre, Grey College, Durham University, UK

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CONFERENCE REPORT

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Introduction

The *Tackling Ethical Challenges in Community-Based Participatory Research* conference brought together over 90 people, with the aim of sharing experiences and ways of tackling ethical challenges in community-based participatory research (CBPR). Participants included members of community organisations, third sector and government researchers, academics, university research administrators and researcher funders. Whilst many of the ethical challenges are common to social research generally (informed consent, anonymity, issues of ownership of data and findings), there are many distinctive ethical challenges when communities and universities work together on research projects. These include the use and abuse of power, co-authorship of publications, ownership of findings and institutional ethical reviews processes.

The conference saw the launch of a newly developed guide, *Community-based Participatory Research: A Guide to Ethical Principles and Practice*, and a set of case materials and exercises. These materials were produced by a group of community partners and academics, coordinated by Durham University's Centre for Social Justice and Community Action, published by National Coordinating Centre for Public Engagement (NCCPE) and funded by the Arts and Humanities Research Council under the Connected Communities programme.

A series of workshops, co-facilitated by community partners and academics, provided the opportunity to share and learn about ethical issues and challenges in CBPR in the areas of:

- Health
- Museums and heritage
- Science and engineering
- Arts and culture
- Social justice
- Environment

Professor Sarah Banks, the Principal Investigator for the AHRC Connected Communities *Tackling ethical issues in community-based participatory research* project opened the conference. This was followed by a welcome from Professor Ray Hudson, Deputy Vice Chancellor, Durham University who spoke about *Issues for community-university partnerships in a climate of austerity.*
Morning Plenary: Key Ethical Challenges in CBPR

The morning plenary involved an overview and discussion of the Tackling ethical challenges in CBPR project. *Community-based Participatory Research: A Guide to Ethical Principles and Practice* was introduced by Professor Sarah Banks and some of the project team (academics and community partners), along with the accompanying case studies, case examples, commentaries and exercises. Amelia Lee from the young women’s allotment group and Niamh Moore from Manchester University shared their experiences of the research. This included ethical challenges, such as how much information the university researchers should be given, or might need, about the young people involved in the project and the potential effect of this on their relationships with those young people. Kath Carter from Thrive, Teesside, discussed how she became involved in the project and gave a perspective as a community partner. She raised the issue of power imbalances. For example, if vulnerable community members feel powerless and excluded from decision making processes about their lives, how might community-based researchers address these concerns?

Morning Workshops

The morning plenary was followed by the first three workshops – ethical issues in participatory *health, museum and heritage* and *science* research. Each workshop was facilitated by community partners and academics and chaired by academics or community partners with experience in the field.

1A Participation in participatory health research: legislation, bureaucracy and access

This workshop was facilitated by Tina Cook and Helen Atkin (Northumbria University), Andrew Stafford (Lawnmowers Independent Theatre Company) and Nicola Armstrong (Northumberland Tyne and Wear NHS Foundation Trust) and drew on the experience of three research projects. The first took place in a medium secure unit for men with a learning disability; the second involved a case study of the impact of inclusive practice
in Neuro Rehabilitation/Neuro Psychiatry Services; and the third is currently exploring whether there is a pathway to mental health recovery through care coordination. The main aim of the projects was to enable people who have experience of the topic and might otherwise belong to the group known as ‘seldom heard’ to be active researchers and participants.

A number of ethical issues were discussed during the workshop, many of which had been experienced by the three projects. This included how people with experience gained access to the project, both as researchers and participants. Having explained some of the barriers to participation, the discussion focused on how to enable the right to participate in practice. Andrew Stafford showed a DVD of the project undertaken through the Lawnmowers Independent Theatre Company, which highlighted the key themes to be explored.

1B Ethical issues in participatory museum and heritage research: ownership and informed consent in perpetuity

This workshop was facilitated by Helen Graham (Leeds University), Alex Henry, (formerly with Tyne and Wear Archives and Museums) and Aileen Strachan (Glasgow Museums/Glasgow Life), who shared their experiences of two recent museum-based participatory projects: Culture Shock! (based at Tyne & Wear Archives & Museums) and Curious (based at St Mungo Museum of Art and Religious Life, Glasgow Life) and an interlinked AHRC-funded research project ‘Partnership and Participation: Intellectual Property and Informed Consent’. Both museum projects were involved in recording, displaying and collecting personal testimony and responses and explored the ethical challenges that this had brought, in particular the issue of the ‘transfer of ownership’ of the stories collected. The group considered the complexity of accountability to both individuals and the wider public within the context of personal donations, which are treated as historical evidence. This also led to an in-depth debate about ethical issues that may arise in the future, such as the historical context of consent for materials collected through research projects.

1C Ethical issues in participatory science research

This workshop was facilitated by Erinma Ochu (MOSI, Manchester), Mandy Naylor (Latent Promise) and Rebecca Ellis (Lancaster University), with preparatory input from Jonathan Swinton (independent researcher working with University of Manchester), who was unable to attend. The facilitators discussed their experiences of undertaking participatory science research. The first example given, Turing's Sunflowers, explored mathematical patterns in sunflowers; and the second, Catalyst - Citizens Transforming Society Tools for Change! explored how and why citizens might create digital tools to facilitate social change. A number of ethical issues were discussed, such as ownership and intellectual property rights. In particular, the need to build community capacity before and after the project and the challenge of ensuring that the research partnership is mutually beneficial were considered.
Afternoon Workshops

The three afternoon workshops offered academic and community partner perspectives on the ethical issues encountered in participatory arts and cultural, social justice and environmental research.

2A Ethical issues in participatory arts and cultural research

This workshop drew on contributions from two projects working with vulnerable people, one with people with learning disabilities and one with asylum seekers and refugees. Facilitated by Christine Atkinson, Phillip Walton (Gateshead People), Se Kwang Hwang (Northumbria University) and Helen Charnley (Durham University), the first project, *Fulfilling Lives*, explored the use of leisure time by adults with learning disabilities. A number of ethical challenges were discussed by the group, including power relations between people with learning difficulties, practitioners, researchers and funders; and how the work undertaken can have an on-going impact.

Maggie O'Neill (Durham University) and Susan Mansaray (Purple Rose, Stockton), discussed an arts-based biographical research project they had developed, which focused on women, well-being and the community. A clip from a film produced as part of the project was shown, which provided a starting point for discussing visual methods. The potential of visual methods was explored by both projects, including their role in reducing power differentials and providing an alternative means of expression. However, this also raised other related ethical challenges, including what is and is not represented in the final film produced.
2B Ethical issues in participatory research for social justice

This workshop also involved two projects. Andrew Russell (Durham University) and Brian Pringle (ASH – Scotland) shared their experiences of *Don't Get Me Started*, a project on the use and potential of science education centres for tobacco control. The project involved taking a group of young activists (W-West) to Uruguay to learn about a unique interactive exhibition, designed to discourage young people from smoking. A number of ethical issues were discussed, including participation by a wide age-range of young people and the differences between the concerns of the Health Board and the reality of taking young people to South America.

Jan Flaherty (Durham University) and Tracey Herrington (Thrive, Thornaby-on-Tees) introduced the project *Debt on Teesside*, which worked with low income households experiencing unmanageable debt. One of the key questions they raised was in whose interest does such research take place? One ethical challenge that emerged during the project was that a number of participants were clearly experiencing mental health problems. The group thus discussed how to provide support to participants and how to ensure that consent is fully ‘informed’ in such circumstances.

2C Ethical issues in participatory environmental research

This workshop was facilitated by Rachel Pain (Durham University), Tom Henfrey (Durham University) and Wilf Richards (Transition Durham/North East Permaculture Network). Rachel drew on the project *Building Adaptive Strategies for Environmental Change with Rural Land Managers*, a participatory action research project in river catchment management, which aimed for academics to act as facilitators as opposed to researchers in land management issues. A key challenge that emerged and was discussed by the group, was how to influence policy-making through a bottom-up project approach.

The second area discussed was the experiences of several collaborations over the past few years on permaculture and its applications in community development, such as the Transition Towns movement. In particular they discussed how ethical processes have become embedded within their work, in particular as permaculture is a design approach rooted in three overlapping ethics: earth care, people care and fair share. This also raised ethical issues in terms of how to balance environmental protection and social justice with institutional ethics.
Afternoon Plenary: Issues arising and to take forward for action

The afternoon workshops were followed by the afternoon plenary, chaired by Professor Tom McLeish (Pro Vice Chancellor for Research, Durham University). The aim of the plenary was to examine issues arising from the discussions and to develop some plans to take forward for action. The four panel members offered different perspectives:

1. A **Community Partner** perspective from Susanne Martikke (Greater Manchester Centre for Voluntary Organisations and UK Community Partner Network);
2. A **University perspective** on Research Governance from Sophie Welch (Durham University Research Office);
3. A **Research Funding Council** perspective from Gary Grubb (Arts and Humanities Research Council);
4. A **Charitable Research Funder** perspective from Sian Aggett (Wellcome Trust)
Sue Shaw (Chair, Action with Communities in Rural England) and Professor Sue Hyatt (Indiana University-Purdue University, Indianapolis) closed the event with some final reflections. They praised the projects that had taken part in the conference and said they were inspired by the commitment to take forward community based participatory research. They identified some of most complex ethical challenges discussed during the conference and the innovative ways these are tackled. During her closing comments, Sue Hyatt reflected on:

“the complexity of doing community-based research and the complexity of the kinds of relationships that we develop with our community based partners. They span a whole spectrum of human possibilities …How to behave ethically when you’re dealing with somebody in such a multi-stranded way, and not just as an object of research, is a very complicated problem. I think we’ve had tremendously deep conversations about that today.”

In particular, Sue Hyatt and Sue Shaw thought the conference had highlighted the value of ‘slow ethics’. This term was introduced by Sarah Banks in response to discussions in one of the workshops that had highlighted the importance of research partners taking time to build relationships and listening carefully to each other. In a short report, written after the conference, Sue Hyatt and Sue Shaw gave their thoughts on this:

“Among the closing reflections offered by delegates in the final discussion were ideas about re-thinking research ethics as what we called “slow ethics”—that is, an ethical stance that understands ethical considerations as gradual and emergent, a constant evolution that shifts and requires re-thinking and re-adjustment as the research project goes on. We all agreed that research ethics was most important not at the beginning of the project when all of the required ethical forms are filled in and filed, but as part of a process that continues throughout the life of the research. We talked about cases in which people who had consented to be part of projects changed their minds and decided they didn’t want to be named or portrayed or to have their remarks included even with the protection sometimes offered by anonymity. We agreed that ethical considerations must constantly be responsive to the needs and concerns of the interviewees, clients and collaborators who are involved in the research, and that it is a constant negotiation among participants. There was consensus that with the shift toward more participatory models for research, ethics is an idea whose time has come. These considerations are not merely bureaucratic or peripheral but should be at the heart of any research practice.”
Evaluating the Conference

Almost half of the participants attending the conference completed evaluation forms at the end and the feedback was overwhelmingly positive. Participants found the diverse range of voices and viewpoints from different projects and backgrounds inspiring and beneficial, providing a creative and informative milieu of different, and sometimes new, perspectives. The case studies and workshops were considered to be an excellent platform for participants to meet others and reflect upon their own practice, research and experiences. In particular, positively focusing on identifying a range of actions to address the ethical challenges raised provided participants with ideas to take forward in their own practice and research. The overwhelming majority agreed that what they listened to in the plenary sessions or the workshops will influence the way they practice and in particular, reaffirmed the importance of ethics as an on-going process.

However, a number of participants commented that they would have liked longer workshops with more opportunity for discussion and some felt the event could have run over two days. As the conference was so well attended, some groups were quite large, which some found difficult for discussion. Overall, the final plenary panel received positive reviews although a few participants suggested that it could have been longer and some shorter, questioning how they could relate some of the discussion to their own experiences.

The response to the CBPR Guide to Ethical Principles and Practice and the booklet of case studies and examples was extremely positive, and both documents were regarded as useful frames of reference. Praise was given for the value of the guide and how informative it is for a diverse range of people engaged in CBPR, including trustees, community projects and researchers. In particular, participants expected the case studies, examples and activities for teaching about the various ethical issues discussed during the conference to be a constructive tool to use back within their own organisations, both community and research institutions. The reflections contained within the cases was cited as especially useful for giving insight into, and developing understanding of, ethical issues that participants may not yet have encountered.
Ethics in Community-Based Participatory Research

Resources

ETHICS IN CBPR GUIDE:
http://www.durham.ac.uk/resources/beacon/CBPREthicsGuidewebNovember20121.pdf

VIDEO: Introducing the ethics guidelines
This video of Sarah Banks and Heather Davidson introducing the ethics guidelines was made at the Connected Communities Showcase, 12 March 2013 in London.
http://www.youtube.com/watch?v=GGubkxsO7cQ

ETHICS IN CBPR – CASES AND COMMENTARIES:

ETHICS IN CBPR – PODCASTS
To accompany the commentaries on the three case examples of ethics in CBPR (see above Banks and Armstrong, 2012), Alex Henry interviewed academics and community partners at the Ethics Conference in Durham to produce these podcasts.

Case Example 1: Issues of disclosure and intrusion
Mary Brydon Miller (University of Cincinnati, Ohio, USA)
https://www.publicengagement.ac.uk/sites/default/files/Case%20Example%201%20Mary%20Brydon-Miller%20Second%20Cut.mp3

Susanne Martikke (Greater Manchester Centre for Voluntary Organisations)
https://www.publicengagement.ac.uk/sites/default/files/Case%20Example%201%20Susanne%20Martikke%20First%20Cut.mp3
Case Example 2: Guns and gangs: challenges in supporting a peer research project

Felicity Shenton (Investing in Children and PhD researcher)
https://www.publicengagement.ac.uk/sites/default/files/Case%20Example%202%20Felicity%20Shenton%20second%20cut.mp3

Graeme Tiffany (Freelance Researcher)
https://www.publicengagement.ac.uk/sites/default/files/Case%20Example%202%20Graeme%20Tiffany%20Second%20Cut.mp3

Case Example 3: Changing the story: issues of copyright and informed consent in a museum-based project

Rachel Pain (Durham University)
https://www.publicengagement.ac.uk/sites/default/files/Case%20Example%203%20Rachel%20Pain%20First%20Cut.mp3

Aileen Strachan (Glasgow Museums/Glasgow Life) and Helen Graham (University of Leeds)
https://www.publicengagement.ac.uk/sites/default/files/Case%20Example%203%20Aileen%20and%20Helen%20First%20Cut.mp3

ETHICS IN CBPR – FILMS

Four short films linked to the ethics case studies and the ethics conference
https://www.durham.ac.uk/beacon/socialjustice/ethics_consultation/films/

ETHICS IN CBPR – EASY READ VERSIONS

Centre for Social Justice and Community Action (CSJCA) and National Coordinating Centre for Public Engagement (NCCPE) (2013) *Doing research together: How to make sure things are fair and no one is harmed* (an EasyRead version of the ethics guide). Downloadable pdf available at:
http://www.dur.ac.uk/resources/beacon/Easyreadbookletethicsguideforweb7.3.13.PDF

Centre for Social Justice and Community Action (CSJCA) and National Coordinating Centre for Public Engagement (NCCPE) (2013) *What is doing research together?* (an EasyRead introduction to CBPR). Downloadable pdf available at:
http://www.dur.ac.uk/resources/beacon/ISL31812DoingResearchTogetherleafletEasyReadLWRESFINAL08Apr2013.pdf
ETHICS IN CBPR – JOURNAL ARTICLES


AHRC CONNECTED COMMUNITIES SUMMARY REPORT – CBPR: ETHICAL CHALLENGES


WEBSITES

These resources are also available on the following websites (which are always being updated with new ethics in CBPR materials):

Centre for Social Justice and Community Action
https://www.durham.ac.uk/beacon/socialjustice/ethics_consultation/

National Coordinating Centre for Public Engagement
http://www.publicengagement.ac.uk/about/ethics
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Sue Shaw (Chair, Action with Communities in Rural England)
Helen Graham (Leeds University)
Alex Henry, (formerly with Tyne and Wear Archives and Museums)
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Phillip Walton (Gateshead People)
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Helen Charnley (Durham University)
Jen Wingate (Durham University)
Andrew Russell (Durham University)
Brian Pringle (ASH – Scotland)
Jan Flaherty (formerly Durham University)
Tracey Herrington (Thrive, Thornaby-on-Tees)
Gary Craig (Durham University)
Rachel Pain (Durham University)
Tom Henfrey (formerly Durham University)
Wilf Richards (Transition Durham/North East Permaculture Network)
Tom McLeish (Pro Vice Chancellor for Research, Durham University)
Susanne Martikke (Greater Manchester Centre for Voluntary Organisation (GMCVO) and UK Community Partner Network)
Sophie Welch (Durham University Research Office)
Gary Grubb (Arts and Humanities Research Council)
Sian Aggett (Wellcome Trust)
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