



# **Community-based participatory research**

## **A guide to ethical principles and practice**

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## Preface

### Why do we need ethical principles and guidelines for community-based participatory research (CBPR)?

All research raises questions about ethics: about the rigour, responsibility and respect of the practices of researchers. As a result, there are strict systems in place to encourage and enforce ethical practice. However, some kinds of research create specific challenges, which may not be adequately addressed by institutional frameworks for ethical conduct in research. This is particularly the case with participatory research, where the boundaries between researchers and 'research subjects' begin to blur.

There is a host of issues that need to be carefully negotiated in this kind of research, including the ways power and control are negotiated, how people's very personal experiences are shared and made public, and how the different needs and expectations of the participants are balanced in the design of the research process. When the research is closely related to people's everyday lives these issues become more significant. In what we call 'community-based participatory research,' that is research that is grounded in the lived experiences of communities, there can be significant challenges to ensure such research is ethically sound. Yet, there is some extraordinary research practice in this area, which reveals profound insights into people's lives.

This guide focuses on the lessons learned by people working intensively in this area- and provides a useful resource for anyone interested in developing more participatory approaches to their research.

### How were the principles and guidelines developed?

This guide was 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>1</sup> The work was begun by an earlier AHRC-funded project coordinated by Durham University's Centre for Social Justice and Community Action.<sup>2</sup> In addition to gathering feedback at several workshops, two rounds of national consultations took place on earlier drafts. Respondents included community researchers, academic, third sector and public sector researchers, research managers and funders. The majority of respondents felt that having a set of principles and guidelines for CBPR in the UK would be extremely valuable. Many very constructive and insightful comments and suggested revisions were received, which as far as possible have been incorporated. Since the majority of respondents felt that the statement should not be too long and detailed, we have not included all the suggestions made – as the statement could easily turn into a manual. We hope that we can refer readers to the many sources of information and guidance that already exist. We also hope that the final part of the project – which includes web-based case studies of CBPR research projects, case examples of ethical issues alongside commentaries from a range of different perspectives – will add some flesh to the framework offered by the principles and guidelines (see: [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)).

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<sup>1</sup>The participants in this project (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.

<sup>2</sup>Durham Community Research Team (2011) *Community-based participatory research: ethical challenges*, [www.ahrc.ac.uk/FundingOpportunities/Documents/CC%20scoping%20studies/CBbanks.pdf](http://www.ahrc.ac.uk/FundingOpportunities/Documents/CC%20scoping%20studies/CBbanks.pdf)

## Acknowledgements

We are very grateful to all those who responded to the consultation and have helped in developing this guide, particularly the members of the research project team listed on page 4, the international advisory group for the project, Beacon NE and members of the Centre for Social Justice and Community Action Steering Group, who commented on several draft versions. Without the funding of the AHRC this work would not have been possible and we would like to thank the Council for its support and encouragement. We are grateful to Beacon NE and the Centre for Social Justice and Community Action for the photos.

Development of ethical principles and guidelines is an on-going process. We expect that this first version will be updated over time and welcome comments and feedback on how this guide is being used and any suggestions for improvements (contact: [socialjustice@durham.ac.uk](mailto:socialjustice@durham.ac.uk)).



# Introduction

## What is community-based participatory research?

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). This entails a different approach from traditional research, which is generally led by professional researchers. In the case of social research, a clear distinction is often assumed between those who do the research and those who are researched. In CBPR, members of community groups and organisations may be engaged in research in many different ways: from providing data to designing and planning research, data collection and analysis, producing research outputs and determining whether and how to act upon findings. CBPR projects often evolve and change over time as partnerships grow, new people become involved and research participants become research partners.

Communities are not static, nor do they comprise people who are like-minded in all respects. Conflict may be already present or generated by the research process. CBPR often involves working with conflict, which needs to be acknowledged and can be creative. In particular, when CBPR involves a 'partnership' between professional researchers/research organisations and community researchers/community organisations, issues arise relating to the use of power and the tendency for professional researchers to dominate or 'colonise' the research.

## What is ethics?

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.

An 'ethical principle' is a general standard or norm that promotes what is regarded as worthy or valuable for the flourishing of humans and/or the whole ecosystem. Ethical principles may relate to right/wrong conduct, good/bad qualities of character and responsibilities attached to relationships. A principle does not tell us how to act in each situation we encounter, but is broad in scope, and needs interpreting in the light of particular circumstances.

Following the ethical principles in Section I of the document, some more detailed practice principles and guidelines are offered in Section II. The practice principles suggest how the ethical principles can be put into practice in the doing of research. Under each practice principle there are some guidelines that give more detail of what might need to be thought about or done to promote ethical research practice. The guidelines provide suggestions or advice.

## The aims and purposes of the ethical principles and guidelines

One of the main aims of producing this guide is to enhance the awareness of ethical challenges on the part of research partners and their ability to tackle these challenges. Another aim is to encourage research funders, academic and other institutions and research ethics committees to understand the complexities of CBPR and modify some of their existing requirements to fit CBPR contexts. Taking account of the nuances and complexities of CBPR may require institutions to change their ways of working and reconsider their values.

The ethical principles underpinning CBPR emphasise democratic participation in the research process. This means it is important that these principles are made explicit, in order to ensure all participants are aware of them, and able to discuss what they mean in their own contexts and work together to interpret, develop and implement them.

In summary, the guide to ethical principles and practice has a number of purposes, including to:

- raise ethical awareness amongst all research partners and participants
- encourage discussion about ethical issues that can arise in CBPR
- offer ethical guidance to partners and participants in CBPR

- inform research institutions (including universities), research funders and sponsors about what ethical issues might come up so they can ensure CBPR is conducted according to the highest standards
- inform research institutions, research funders and sponsors about the complexities and nuances of CBPR to ensure they do not impose ethical standards that are impractical, patronising to community researchers or partners or inappropriate in other ways
- improve ethical practice in CBPR

The ethical principles and guidelines are designed not to be too detailed or prescriptive (i.e. they do not take the form of rules) as this removes control and responsibility from the research partners themselves and assumes a fixed model of what counts as good research. The ethical principles and guidelines cannot offer simple solutions to the inevitable dilemmas and challenges that are part of the CBPR process.

## Relationship to other ethical principles, guidance and codes

In drafting the guide we have taken note of the kinds of ethical challenges reported by community partners and academics that have participated in our two AHRC-funded research projects, reports in the literature and the comments received from the consultations. We have also taken account of other relevant sets of ethical principles and guidelines for research.

These principles and guidelines should be read in conjunction with, and regarded as complementary to, subject specific ethical principles and codes of conduct, institutional research ethics guidance and research governance frameworks developed by research councils and research funders. Although many of these are relevant and useful, they may not contain specific guidance relating to CBPR and may make assumptions that do not fit with a CBPR approach. Useful examples that researchers may wish, or be required, to consult are included at the end of Section II.

There are also several sets of guidelines and principles produced for specific research contexts in the USA (e.g. Community Alliance for Research and Engagement, 2009; Community-Campus Partnerships for Health, 2006 - see list of websites, p. 13). However, the principles and guidelines produced here are designed to be generic (across all disciplines), to include community-led as well as community partnership research, and for use in the UK. Although the ethical principles are transferable internationally, the practice principles and detailed guidance are designed with UK research governance structures and processes in mind.

## How to use the guide and supporting materials

This guide is aimed at a wide audience and can be used in many ways, for example:

**In training, teaching and learning** about research ethics in general and community-based participatory research in particular, the guide and case studies and examples can be used to encourage greater awareness about ethical issues likely to arise in CBPR and as a focus for group discussion and learning.

**In preparing to undertake research**, professional and lay researchers and other stakeholders might familiarise themselves with the guide, discuss the ethical principles and use the practice principles and guidelines as the basis for preparing a working agreement and as a reference point throughout the research process.

**In undertaking institutional research ethics reviews**, research institutions can use the guide as a benchmark against which to judge applications that involve community-based participatory research. They might consider revising their policies and procedures to make them more amenable to CBPR and/or make reference to this guide.

**In drawing up research funding guidance** and considering funding applications, research funders might also consider revising their policies and procedures to make them more amenable to CBPR and/or make reference to this guide.

The materials are in three parts:

**Section I** – Ethical principles, which outline briefly the underpinning values and ethical principles of CBPR.

**Section II** – Practice principles and guidelines, which give more detail on how to put the ethical principles into practice.

**Section III** – Case studies of CBPR research projects and case examples of ethical issues and dilemmas in CBPR followed by commentaries. This is available as a separate document to download.

The materials are available on the following websites:

National Co-ordinating Centre for Public Engagement  
(<http://www.publicengagement.ac.uk/how-we-help/our-publications>)

Centre for Social Justice and Community Action,  
Durham University  
([www.durham.ac.uk/beacon/socialjustice](http://www.durham.ac.uk/beacon/socialjustice))

# I. Ethical Principles

This section outlines some general ethical principles to bear in mind for those who are conducting or supporting community-based participatory research. The principles are at a relatively general level, with the bullet points offering brief illustrations of what each principle might include. The bullet points are not meant to be an exhaustive list. More detailed practical principles and guidance are offered in Section II.

**1. Mutual respect:** developing research relationships based on mutual respect, including a commitment to:

- agreeing what counts as mutual respect in particular contexts
- everyone involved being prepared to listen to the voices of others
- accepting that there are diverse perspectives

**2. Equality and inclusion:** encouraging and enabling people from a range of backgrounds and identities (e.g. ethnicity, faith, class, education, gender, sexual orientation, (dis)ability, age) to lead, design and take part in the research, including a commitment to:

- seeking actively to include people whose voices are often ignored
- challenging discriminatory and oppressive attitudes and behaviours
- ensuring information, venues and formats for meetings are accessible to all

**3. Democratic participation:** encouraging and enabling all participants to contribute meaningfully to decision-making and other aspects of the research process according to skill, interest and collective need, including a commitment to:

- acknowledging and discussing differences in the status and power of research participants, and working towards sharing power more equally
- communicating clearly using language everyone can understand
- using participatory research methods that build on, share and develop different skills and expertise

**4. Active learning:** viewing research collaboration and the process of research as an opportunity to learn from each other, including a commitment to:

- ensuring there is time to identify and reflect on learning during the research, and the on ways people learn, both together and individually
- offering all participants the chance to learn from each other and share their learning with wider audiences

- sharing responsibility for interpreting the research findings and their implications for practice

**5. Making a difference:** promoting research that creates positive changes for communities of place, interest or identity, including:

- engaging in debates about what counts as 'positive' change, including broader environmental sustainability as well as human needs or spiritual development, and being open to the possibility of not knowing in advance what making a 'positive difference' might mean
- valuing the learning and other benefits for individuals and groups from the research process as well as the outputs and outcomes of the research
- building the goal of positive change into every stage of the research

**6. Collective action:** individuals and groups working together to achieve change, including a commitment to:

- identifying common and complementary goals that meet partners' differing needs for the research
- working for agreed visions of how to share knowledge and power more equitably and promote social change and social justice
- recognising and working with conflicting rights and interests expressed by different sections of communities or by different communities

**7. Personal integrity:** participants behaving reliably, honestly and in a trustworthy fashion, including a commitment to:

- working within the principles of community-based participatory research
- ensuring accurate and honest analysis and reporting of research
- being open to challenge and change and prepared to work with conflict



## II. Practice Principles and Guidelines

This section focuses on how to put the ethical principles presented in Section I into practice and offers some brief guidance. It is not designed to offer comprehensive practical guidance about how to conduct a community-based participatory research project, but rather to outline some of the ethical issues that those involved should think about.

### 1. Preparing and planning

Before starting out to do research together, it is usually helpful if the parties involved go through a preliminary phase of checking out expectations, including considering whether the proposed research project and/or research partnership is a good idea at all.

**1.1 Why work together?** At the start, it is a good idea for everyone involved to get to know each other, discuss their hopes and fears for the research and share what they want to get out of it. What are the commonalities and differences? Is it going to be practical and productive to work together? At this point it might be decided that the research or proposed partnership is not going to work or that some expectations need to be changed. Sharing experiences and stories can be a useful part of the process to find out common values and aspirations.

**1.2 Who should be involved?** Given the purpose of the proposed research, are there certain people or groups with expertise, experience or interest in the topic who should be invited and what might be the barriers to their participation? Is there a group of people that deliberately or unintentionally excludes others for no good reason? Some people may have the capacity and desire to be heavily involved whereas others may dip in and out. Anticipating and managing the different levels of involvement is important to ensure nobody feels either pressured to contribute, or deliberately excluded.

**1.3 What are the aims and objectives of the research?** Are all parties clear about why they want to do the research and what they want to get out of it? It is important to involve as many people as possible in the process of designing the research and to take account of different expectations of the purpose of the research – being clear which aims and objectives can be agreed by all and which may need to be modified or changed.

### 2. Doing the research

Having established that there is potential to work together, decided who to involve and agreed a set of aims and objectives, it may be useful to develop a 'working agreement' about how to work together. This need not be regarded as fixed or unchangeable – as community-based

participatory research is not always controllable and may develop in unexpected ways. For this reason, it may help to provide a framework that can be reviewed and revised on an ongoing basis. This may include practical details of working relationships, as well as an outline of how to ensure that people who provide research data are protected and credited.

**2.1 How will the participants work together as research partners?** The working agreement might include:

- **agreed ethical principles**, such as those listed on the previous page
- **protocol for communications**, including preferred ways of communicating (e-mail, skype, face-to-face meetings), expected frequency of communications and meetings, how to ensure that a few participants do not dominate and that people speak in plain language
- **protocol for safety**, including procedures for researchers working on their own
- **protocol for handling difficulties and conflict**, including ways to sort things out if people disagree, fall out and things go wrong
- **agreed aims and objectives** of the research
- **methods to be used**, including how these will reflect a commitment to participation
- **management of research**, whether by a research team, partnership, steering group or other means, including acknowledgement that leadership roles may change throughout the research process
- **what funding is available** to whom, for what, and who will allocate and be accountable for the budget. If some researchers are volunteers, it will be important to agree payment for time and expenses
- **any training required** for the research partners (e.g. professional researchers needing training in the specialist field of the community partner or community partners in specialist research methods)
- **practical details** of who will take responsibility for what, e.g. research design, data collection, analysis, interpretation and dissemination

- **when and where** meetings will be held
- **processes for reflection, evaluation and learning** from each other and from the research throughout the process

## **2.2 How will researchers handle information and treat people who provide it?**

The working agreement might include more details about handling and using information of the kind usually required by research ethics committees (indeed, the following might provide the basis for a submission to a research ethics committee):

**Informed consent:** Ensuring as far as possible that people who provide information or allow access to aspects of their lives as part of the research are given information about the purpose and uses of the research data. They need to know enough about it to be able to decide whether to participate (or for their parent/guardian/consultee to agree). In CBPR those who may need to give consent might include community and professional researchers (who may be both collectors of information from others and providers of information themselves), as well as people who are invited to participate in information-collection aspects of the research only. Sometimes it is not only the consent of individual people that is required, but also collective consent (e.g. of a community, group or organisation). It is also important to acknowledge that the purpose and uses of the research may change and develop over time, so consent may need to be continually reviewed and renegotiated, especially as specific plans for publication and dissemination are developed.

**Handling personal information:** In all research, it is important to ensure that identifying information (e.g. names and addresses) is stored separately from other personal information collected as part of the research (e.g. interview transcripts, questionnaire responses) and securely (e.g. in a locked filing cabinet, password protected computer). In CBPR it is vital that researchers who are also community members, neighbours or relatives take particular care in safeguarding personal data that may be stored in community centres or neighbourhood projects.

**Confidentiality:** When community researchers are collecting data from and about people they know, or live near, it is advisable to be very careful about confidentiality. If someone tells a researcher something that is personally compromising or that they do not wish to be passed on to others, it is important to honour this. It may mean that information cannot be directly used

in the research, and should not even be passed on to other members of the research team. Alternatively, it might mean the information can be used, but people's names and other identifying features of the situation should be removed. At an early stage it is worth discussing the ways in which using social media (e.g. Facebook or Twitter) affects issues of confidentiality. It is important to be as clear as possible about how confidentiality will be handled in order to avoid causing harm or embarrassment to people. Usually, in social research, a limit is placed on confidentiality in circumstances where researchers get to hear about unlawful or risky behaviour, suspected child/adult abuse and/or where there may be a risk of serious harm to other people. The circumstances of disclosure should be made clear to those participating in the research in advance.

**Anonymity:** It is a good idea to discuss in the research team and with others involved in the research the advantages and disadvantages of identifying people, places and organisations (by their real names, appearances or voices in written, visual or audio records or social media) – whether this is in team discussions or dissemination of the research. If research relates to sensitive topics or contexts (e.g. household debt, mental health, domestic violence, public protest, crime), it is often important not to name or give identifying features of individuals. It may also be advisable to give organisations and places different names, as using real names may help identify people. However, in some cases, individuals and organisations may wish to be named, to have their opinions, achievements or challenges credited or highlighted. Yet naming some people needs to be discussed fully and consideration given to the implications for the anonymity of others.

**Ownership, control and use of the research data and findings:** When research is a collaboration between several people or partner organisations it is important to be clear who 'owns' any data, new knowledge or collaborative outputs that have been produced. 'Ownership' in this context means the right to use it and pass it on. If it is jointly owned, then it is important to decide what rights each partner has to use the data to inform their work or produce publications and whether the permission of all partners is required. Sometimes a funder may control the use of data and findings, and all parties need to be clear about the implications of this from the outset. It is particularly important that recognition is given to new knowledge made by communities and that when appropriate they receive financial rewards and have the right to own and use it.

### 3. Sharing and learning from the research

During the course of the research, or once the findings have been drawn together, the research team will usually want to share the research with others – people in the locality, community organisations, policy makers, politicians, academics and others.

**3.1 How to analyse and interpret research data and findings?** There is often a tendency for professional researchers or more experienced community members to take responsibility for analysis and interpretation of the research data. However, involvement of a range of people in analysis and interpretation of findings can be an opportunity for the development of new skills. It may require more time, training and creative thinking about inclusive processes, but may add valuable alternative perspectives on what some of the findings mean and contribute to the thinking about problems and solutions.

**3.2 How to share the research?** In CBPR the process and findings may be shared with others as the research progresses, and there may be a wide range of different audiences and research users to consider.

**What to share?:** Sharing research findings can have both positive and negative effects on communities. For example, sharing accounts and analyses of social problems of particular groups or neighbourhoods might be expected in a report to research funders or service providers, and may result in heightened awareness of inequalities and/or improved services. But this may have a negative effect on the self-esteem of community members. Open, honest discussions and negotiations about what to share, how to share it, desired outcomes and possible negative impacts should be an ongoing part of the research process.

**Formats for dissemination:** If a range of different audiences is anticipated, it is important to consider the most accessible format to reach people, e.g. visual materials including film, art, cartoons and photos; performance arts including theatre and music; written reports, magazine articles, academic papers and books; conferences, workshops and celebratory learning events; or web-based materials. It is also important

to consider what formats may suit the skills of different members of the research team, and several different types of outputs geared to different audiences might be produced.

**Authorship and credits:** It is a good idea to discuss in advance who will be responsible for compiling or writing the outputs, when decisions will be made about the nature and formats of outputs and how the responsibility can be shared and skills developed by those who are not used to doing this. Although it may be time-consuming, holding writing, editing, film or photography workshops, where people work and learn together, can be an empowering and satisfying process for all concerned. Agreeing who will be credited and how is also important – ensuring that the variety of contributions is recognised.

**3.3 How to make an impact?** Once a particular research project has been written up or when the funding runs out, this is not necessarily the end of the process.

**Implementation:** It can be useful to think about how to use or implement the findings and follow-up any recommendations for change in practice, policy and ways of working.

**Producing useful outputs:** Consideration should be given to ensuring that any reports or other products of the research are made accessible to other researchers, policy-makers, service providers, community members and organisations for future use. Additionally it is important to ensure that the skills and knowledge gained by all of the partners is capitalised upon in further research or action projects.

**Learning from the research:** It can be very productive for the research partners to reflect on what they have learnt. Not just from the research findings, but also from the process of doing the research and working together. If the relationship has gone well, or has potential to go well, then a longer term research partnership may develop.

**Good endings:** At some point the relationships that were formed around the research may have to end (funding ends, people move on). So it is worth thinking about how endings should be negotiated to ensure the benefits of the research can continue into the future and some participants do not feel let down.

## A Selection of Useful Websites and Web-based Resources

### Guidance from UK Research Councils

Economic and Social Research Council (2010) *Framework for research ethics*,  
[www.esrc.ac.uk/about-esrc/information/research-ethics.aspx](http://www.esrc.ac.uk/about-esrc/information/research-ethics.aspx)

Medical Research Council, *Ethics and Research Guidance*,  
[www.mrc.ac.uk/Ourresearch/Ethicsresearchguidance/index.htm](http://www.mrc.ac.uk/Ourresearch/Ethicsresearchguidance/index.htm)

Research Councils UK (2009) *Policy and Code of Conduct on the Governance of Good Research Conduct*,  
[www.rcuk.ac.uk/Publications/researchers/Pages/grc.aspx](http://www.rcuk.ac.uk/Publications/researchers/Pages/grc.aspx)

### Some codes of ethics and ethical guidance from professional associations and other bodies (UK and international)

Association of Internet Researchers (2002) *Ethics Guide*,  
<http://aoir.org/reports/ethics.pdf>

British Educational Research Association (BERA) (2011) *Ethical guidelines*,  
[www.bera.ac.uk/publications/ethical-guidelines](http://www.bera.ac.uk/publications/ethical-guidelines)

British Sociological Association (BSA) (2002) *Statement of Ethical Practice*,  
[www.britisoc.co.uk/about/equality/statement-of-ethical-practice.aspx](http://www.britisoc.co.uk/about/equality/statement-of-ethical-practice.aspx)

Committee on Publication Ethics (COPE), Guidelines and codes,  
<http://publicationethics.org/resources>

Community Alliance for Research and Engagement (2009) *Principles and Guidelines for Community-University Research Partnerships*, Yale Center for Clinical Investigation, USA,  
[http://medicine.yale.edu/ycci/nethaven/memberresources/464\\_55486\\_PrinciplesforU-CPs\\_001.pdf](http://medicine.yale.edu/ycci/nethaven/memberresources/464_55486_PrinciplesforU-CPs_001.pdf)





Community-Campus Partnerships for Health (2006) *Principles of Good Community-Campus Partnerships*, <http://depts.washington.edu/ccph/principles.html#principles>

European Science Foundation (2011) *The European Code of Conduct for Research Integrity*, [www.esf.org/activities/mo-fora/research-integrity.html](http://www.esf.org/activities/mo-fora/research-integrity.html)

Government Office for Science (2007) *Rigour, Respect and Responsibility: A Universal Ethical Code for Scientists*, [www.bis.gov.uk/policies/science/science-and-society/communication-and-engagement/universal-ethical-code](http://www.bis.gov.uk/policies/science/science-and-society/communication-and-engagement/universal-ethical-code)

Museum Association, Ethical guidelines, [www.museumsassociation.org/ethics/ethical-guidelines](http://www.museumsassociation.org/ethics/ethical-guidelines)

National Disability Authority (2009) *Ethical guidance for research with people with disabilities*, [www.nda.ie/cntmgmtnew.nsf/0/232F61AE5397A93D802576650052B3B9/\\$File/ethicsfootnotes.html](http://www.nda.ie/cntmgmtnew.nsf/0/232F61AE5397A93D802576650052B3B9/$File/ethicsfootnotes.html)

National Research Ethics Service (NRES)  
<http://www.nres.nhs.uk/>

National Children's Bureau (NCB) (2011) *Guidelines for research with children and young people* (Shaw, C., Brady, L-M. and Davey, C.), [www.ncb.org.uk/media/434791/guidelines\\_for\\_research\\_with\\_cyp.pdf](http://www.ncb.org.uk/media/434791/guidelines_for_research_with_cyp.pdf)

Oral History Society, Ethics, [www.ohs.org.uk/ethics/](http://www.ohs.org.uk/ethics/)

Social Research Association (2003) *Ethical Guidelines*, [http://the-sra.org.uk/sra\\_resources/research-ethics/ethics-guidelines/](http://the-sra.org.uk/sra_resources/research-ethics/ethics-guidelines/)

World Health Organisation, *Ethical standards and procedures for research with human beings*, [www.who.int/ethics/research/en/](http://www.who.int/ethics/research/en/)

### Useful guidance or information published by other UK organisations

Data Protection Act (1998)  
<http://www.legislation.gov.uk/ukpga/1998/29/contents>

INVOLVE (NIHR) *Public involvement in research: impact on ethical aspects of research*, [www.invo.org.uk/wp-content/uploads/2012/06/INVOLVEevidenceresource.pdf](http://www.invo.org.uk/wp-content/uploads/2012/06/INVOLVEevidenceresource.pdf)

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### **Centre for Social Justice and Community Action**

The Centre for Social Justice and Community Action is a research centre at Durham University, made up of academic researchers from a number of departments and disciplines and community partners. Our aim is to promote and develop research, teaching, public/community engagement and staff development (both within and outside the university) around the broad theme of social justice in local and international settings, with a specific focus on participatory action research.

[www.durham.ac.uk/beacon/socialjustice](http://www.durham.ac.uk/beacon/socialjustice)

### **National Co-ordinating Centre for Public Engagement**

The National Co-ordinating Centre for Public Engagement's vision of a higher education sector making a vital, strategic and valued contribution to 21st-century society through its public engagement activity. We are working to help support universities to improve, value and increase the quantity and quality of their public engagement and embed it into their core practice.

The NCCPE is part of the National Beacons for Public Engagement initiative, funded by the UK Higher Education Councils, Research Councils UK and the Wellcome Trust.

The six Beacons are university-based collaborative centres that help support, recognise, reward and build capacity for public engagement work, based in: Newcastle and Durham, Manchester, CUE East UEA, UCL, Wales and Edinburgh.