International Collaboration for Participatory Health Research

Position Paper No. 2
Participatory Health Research
A Guide to Ethical Principles and Practice

Version: October 2013

Citation:
International Collaboration for Participatory Health Research (ICPHR) (2013) Position Paper 2: Participatory Health Research: A Guide to Ethical Principals and Practice. Version: October 2013. Berlin: International Collaboration for Participatory Health Research.

Editorial Group:

Sarah Banks Professor	Durham University	Durham, UK
Irma Brito Professor	Nursing School of Coimbra and Universidade de Cabo Verde	Coimbra, Portugal
Tina Cook Dr.	Northumbria University	Newcastle-Upon-Tyne, UK
Felix Gradinger Dr.	University of Exeter	Exeter, UK
Jane Springett Professor	University of Alberta	Edmonton, Canada
Hella von Unger Professor	Ludwig Maximilian University	Munich, Germany
Michael T. Wright Professor	Catholic University of Applied Sciences	Berlin, Germany

Acknowledgements

This paper draws heavily on a guide that was developed during 2012 entitled Community-based participatory research: A guide to ethical principles and practice[1] This paper is a revised version of that guide, developed by members of the ICPHR editorial group on ethics. It was circulated to all members of ICPHR during April/May 2013 for comments. This version incorporates the comments sent from members as far as is possible.

Contents

Introduction

1) What is participatory health research (PHR)?

Participatory health research (PHR) is a research paradigm (a set of underlying assumptions about the world and how it should be studied). As outlined in ICPHR Position Paper 1, *What is Participatory Health Research?* (May 2013, p. 5):

> For PHR the primary underlying assumption is that participation on the part of those whose lives or work are the subject of the study fundamentally affects all aspects of the research. The engagement of these people in the study is an end in itself and is the hallmark of PHR, recognizing the value of each person's contribution to the co-creation of knowledge in a process that is not only practical, but also collaborative and empowering...
>
> PHR is informed by a rich variety of participatory research traditions from different countries and time periods. All of these traditions have their basis in broad social movements striving for a more democratic and inclusive society.

In PHR, those engaged in the research as active partners may be patients or users of services, members of health-related interest groups or other communities of identity or place, health care or related practitioners, managers and policy-makers.

'Health' is understood in its broadest sense to include well-being and human flourishing. Hence PHR may cover a broad range of issues and topics, ranging from the spread of disease in populations to conditions for creating sustainable livelihoods in local neighbourhoods.

2) What is ethics?

Ethics is a topic that covers questions relating to what kinds of lives we lead, what counts as a good society, which 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.

3) Ethical principles, practice principles and guidelines

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 Part I of the document, some more detailed practice principles and guidelines are offered in Part II. The practice principles suggest how the ethical principles can be put into practice when doing 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.

4) Why do we need ethical principles and guidelines for PHR?

All research raises questions about ethics: about the rigour, responsibility and respect of the practices of researchers and those with whom they collaborate.

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 health research, where the boundaries between researchers and 'research subjects' begin to blur and the topic of the research may be challenging and sensitive.

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, particularly their health, these issues become more significant.

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.

5) Can one set of principles apply internationally?

There is a question about whether one set of ethical principles and guidelines can, or should, apply internationally and across cultures. This raises complex issues, which apply equally to international codes of ethics and the Declarations and Conventions on Human Rights of the United Nations.

Research needs to be culturally sensitive (for example, recognizing that in some contexts the aspiration to share power may be constrained), while not reinforcing harmful social divisions. For example, in some cultural contexts it is impossible for women to engage in research without the permission of men. Those organising research need to take this into account and work towards maximizing women's power in the research process, within the cultural constraints. These circumstances do not mean that principles of equality and democratic participation do not apply, but that they may conflict with the principle of mutual respect (including valuing diversity). Acting ethically is not straightforward, but involves complex processes of negotiation in situations where there may not be a clear 'right' course of action.

6) The aims and purposes of the ethical principles and guidelines

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

The ethical principles underpinning PHR emphasise democratic participation as one of the key values underpinning the research process. This means it is important that these principles are made explicit, in order to ensure everyone in the research process is 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:

1) raise ethical awareness amongst all research partners and participants and encourage discussion about ethical issues that can arise in PHR.
2) offer ethical guidance to partners and participants in PHR.
3) inform research institutions (including universities), research funders and sponsors about ethical issues that might come up so they can ensure PHR is conducted according to the highest standards.
4) inform research institutions, research funders and sponsors, journal editors and publishers about the complexities and nuances of PHR so they are less likely to impose ethical standards that are impractical or patronizing to practitioner and community researchers or partners.
5) improve ethical practice in PHR.

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 research partners themselves and assumes a fixed model of what counts as good participatory health research. The ethical principles and guidelines cannot offer simple solutions to the inevitable dilemmas and challenges that are part of the PHR process.

Rather they provide a framework within which research partners are encouraged to reflect together on the values they hold and the potential benefits and harms at each stage of the research.

7) Relationship to other ethical principles, guidance and codes

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 funders. Useful examples that researchers may wish, or be required, to consult are included at the end of this document. However, it is important to bear in mind that while many of these are relevant and useful, they may not contain specific guidance relating to PHR and may make assumptions that do not fit with a PHR approach.

There are also several sets of useful guidelines and principles produced for specific research contexts in the USA (e.g. Community Alliance for Research and Engagement, 2009[2], Community-Campus Partnerships for Health, 2006[3]).

8) 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 PHR in particular, the guide can be used to encourage greater awareness about ethical issues likely to arise in PHR 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 participatory health research. They might consider revising their policies and procedures to make them more amenable to PHR and/or make reference to this guide.

---

[2] Community Alliance for Research and Engagement (2009) *Principles and Guidelines for Community-University Research Partnerships*, Yale Center for Clinical Investigation, USA, http://ycci.yale.edu/care/resources.aspx
[3] Community-Campus Partnerships for Health (2006) *Principles of Good Community-Campus Partnerships,* http://depts.washington.edu/ccph/principles.html#principles

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 PHR and/or make reference to this guide.

In evaluating research projects, the ethical principles in Section I might be used as a framework within which to assess the research process and outcomes.

In publishing, authors, editors and publishers can use the guide as a benchmark against which to ensure that the research that is reported upon has been conducted according to sound ethical principles and that co-authorship and the acknowledgement of contributions is discussed and agreed.

The document is in two parts:

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

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

I.   ETHICAL PRINCIPLES

This section outlines some general ethical principles to bear in mind for those who are conducting or supporting participatory health 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 people have diverse perspectives, different forms of expertise and ways of knowing that may be equally valuable in the research process.

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 in language everyone can understand, including arranging translation or interpretation if required.
   - using participatory research methods that build on, share and develop different skills and expertise.

4) **Active learning:** seeing research collaboration and the process of research as providing opportunities to learn from each other, including a commitment to:

   - ensuring there is time to identify and reflect on learning during the research, and 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 change 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 a 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.
- recognizing and working with conflicting rights and interests expressed by different interest groups, communities of practice or place .

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

- working within the principles of participatory health research.
- ensuring accurate and honest analysis and reporting of research.
- being open to challenge and change, being flexible 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 designed as an outline of some of the ethical issues that those involved need to think about.

1. Preparing and planning

Before starting out to do research together, it is helpful if those 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. When children or people with learning disabilities, cognitive or sensory impairments are to be involved as research partners, particular attention needs to be paid to the way communications are conducted and whether/how to involve carers or other supporters/interpretors.

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, who should be involved in the collaboration? Are there certain people or groups with expertise, experience or interest in the topic who should be invited and what might be barriers to their participation? Is there a group of people that deliberately or unintentionally excludes others? Some people may have the capacity and desire to be heavily involved whereas others may dip in and out. How might this be constructed as a positive choice? 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 – 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 on a set of aims and objectives, it may be useful to develop a 'working agreement' about how to work together. This would normally be a written document,

unless culturally inappropriate or explicitly not wanted by the partners. The agreement need not be regarded as fixed or unchangeable – as participatory health research may develop in unexpected ways. For this reason, the working agreement may be used as a framework to be reviewed and revised on an ongoing basis. The working agreement 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. The process of developing the written research agreement is as important as the end product. The discussions needed to develop a written agreement allow all partners to understand better everyone's needs and concerns. This helps to build openness and trust - both essential for good partnerships.

When the research partners include children or people with learning disabilities or cognitive impairments, particular attention needs to be paid to the form, content and communication of the agreement and how sharing of power can be achieved, whilst also protecting both researchers and researched.

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

- *an agreed set of ethical principles* (such as those listed on the previous page).
- *a 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.
- *a protocol for safety,* including procedures for researchers working on their own.
- *a protocol for handling difficulties and conflict,* including ways to sort things out if people disagree, fall out or if things go wrong.
- *the agreed aims and objectives* of the research.
- *the methods to be used,* including how these will reflect a commitment to participation.
- *the 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.
- *whether training is needed* for any of the research partners (e.g. professional researchers needing training in the specialist field of the practitioners/community partners or practitioners/community partners in specialist research methods) and how the training will be provided.
- *Descriptions of each person's role*, including 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 during the process of doing it.

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 participatory health research those who may need to give consent might include practitioner, 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 develop.

- *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 or questionnaire responses) and securely (e.g. in a locked filing cabinet or password protected computer). In participatory health research it is vital that researchers who are also community members, neighbours or relatives take particular care in safeguarding personal data that could be stored in community centres or neighbourhood projects.

- *Confidentiality* – when practitioner or community researchers are collecting data from and about people they know, work with or live near, it is advisable to be very careful about confidentiality and written confidentiality agreements might be useful. 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 need to 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 behavior, 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 organizations (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. mental health, domestic violence, drug use), it is often important not to name or give identifying features of individuals. In some situations, participatory research may be conducted in the workplace of practitioner researchers - for example, in a hospital. In such cases, the nature of the research (open, dialogic, participatory) may mean that although researchers make every effort to ensure anonymity, it cannot be assured. In such cases it may also be advisable to give organizations 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. This needs to be discussed fully and consideration given to the implications of naming one person 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 organizations it is important to be clear who 'owns' any data, new knowledge or collaborative outputs that have been produced. By 'ownership' is meant 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, that they have the right to own and use it and that when appropriate they receive financial rewards. It is important also to decide who has the right to have the data generated in their possession (e.g. to hold copies of transcripts or data files) and to access the data (which may be held by one organisation).

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 – individuals and groups with an interest in the research, community organizations, policy makers, politicians, academics and others.

3.1 Deciding how to analyze and interpret research data and findings – there is often a tendency for professional researchers or more experienced practitioners/community researchers 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

thinking about problems and solutions. If it is not possible to include all research partners in data analysis, it is valuable to discuss together the nature of the information collected and the findings. This provides an opportunity for everyone to take account of their own contexts and add their interpretations.

3.2 Deciding how to share the research - in participatory health research 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 practitioner groups and communities. For example, sharing accounts and analyses of health and 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 what is 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 (including literacy levels) 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 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 recognized.

- *Who should disseminate*? – it is also very important to consider 'who is the messenger?' when planning dissemination of the research. Dissemination may be planned for a range of different audiences (policy-makers, practitioners, service users, community members) and it is worth bearing in mind that people often learn best from their peers. There also may be good opportunities for researcher-practitioner/community member teams to disseminate findings jointly. Joint presentations at conferences to policy makers and in the community are powerful ways to demonstrate role models of research partnerships.

3.3 Making 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. It is useful if researchers can commit to follow-up actions and even follow-up research projects.

- *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, health practitioners, community members and organisations for future use; and that the skills and knowledge gained by all partners is capitalised upon in further research or action projects.

- *Learning from the research* - it can be very productive for research partners to reflect on what they have learnt - not just from the research findings, but also from the process of doing 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 can be negotiated to ensure the benefits of the research continue into the future and participants do not feel let down.

A selection of web-based resources

Some codes of ethics and ethical guidance from professional associations and other bodies:

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

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/about/ethics/resources

Committee on Publication Ethics (COPE)
http://publicationethics.org/

Community Alliance for Research and Engagement (2009) *Principles and Guidelines for Community-University Research Partnerships*, Yale Center for Clinical Investigation, USA,
http://www.yale.edu/hrpp/resources/docs/PrinciplesandGuidelinesforCommunityResearchPartnerships10-27-11.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*,
http://www.esf.org/fileadmin/Public_documents/Publications/Code_Conduct_ResearchIntegrity.pdf

International Federation of Social Workers (2004) *Ethics in Social Work. Statement of Principles*.
URL: www.ifsw.org

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

Social Research Association (2003) *Ethical 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/

Ressources in German

Deutsche Forschungs Gemeinschaft (German Research Society) (1998) Vorschläge zur Sicherung guter wissenschaftlicher Praxis: Empfehlungen der Kommission „Selbstkontrolle in der Wissenschaft"(Proposals for safeguarding good scientific practice) Deutsche Forschungsgemeinschaft:
http://www.dfg.de/download/pdf/dfg_im_profil/reden_stellungnahmen/download/empfehlung_wiss_praxis_0198.pdf

DGfE (Deutsche Gesellschaft für Erziehungswissenschaft – German Society for Science in Education) (2010): Ethik-Kodex. URL:
www.dgfe.de

DGS (Deutsche Gesellschaft für Soziologie – German Sociological Society) (1993): Ethik Kodex der Deutschen Gesellschaft für Soziologie und des Berufsverbands Deutscher Soziologen. URL: http://www.bdssoz.de/content/view/551/226/

Other useful guidance or information

Canadian Institutes of Health Research (CIHR) (2007) *CIHR Guidelines for Health Research Involving Aboriginal People*, http://www.cihr-irsc.gc.ca/e/29134.html

Faulkner A. (2004) *The ethics of survivor research. Guidelines for the ethical conduct of research carried out by mental health service users and survivors*, Joseph Rowntree Foundation, Bristol,
http://www.jrf.org.uk/sites/files/jrf/1861346662.pdf

Flicker, S.,Travers, R., Guta, A., McDonald, S., Meagher, A. (2007) Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards. *Journal of Urban Health*, 86 (4), 478-493.

INVOLVE (NIHR). The INVOLVE website has a range of resources on public involvement in research http://www.invo.org.uk/. Selected resources include:

Public involvement in research: impact on ethical aspects of research,
www.invo.org.uk/wp-content/uploads/2012/06/INVOLVEevidenceresource.pdf

Turner, M. and Beresford, P. (2005) *What User Controlled Research means, and what it can do*, http://www.invo.org.uk/posttypepublication/user-controlled-research-its-meanings-and-potential/

Resources for researchers – includes ten briefing notes on how to involve members of the public in research. There are also supplements, case studies and templates. Downloadable at: http://www.invo.org.uk/resource-centre/resource-for-researchers/

McKenzie, A. and Hanley B. (2009) *Consumer and Community Participation in Health and Medical Research. A practical guide for health and medical research organisation*s, The University of Western Australia and The Telethon Institute for Child Health Research, Australia.
http://www.involvingpeopleinresearch.org/index.php/resources/green-book

Mental Health Research Network (MHRN) UK, *Guidance and policy publications*, http://www.mhrn.info/pages/guidance-and-policy-publications.html

National Children's Bureau (2011), *Young People in Research: How to involve us, Guidance for researchers from the PEAR young people's public health group*, www.ncb.org.uk/media/111093/pear_guidelines.pdf

National Coordinating Centre for Public Engagement (NCCPE), *Ethics in Community-based Participatory Research*, web resources
www.publicengagement.ac.uk/about/ethics

National Health & Medical Research Council (NHMRC) Australia /Consumers' Health Forum of Australia Inc (CHF) (2002) *Statement on Consumer and Community Participation in Health and Medical Research*,
www.nhmrc.gov.au/guidelines/publications/r22-r23-r33-r34

Parry, D., Salsberg, J. and Macaulay, A. (2009) *A Guide to Researcher and Knowledge-user Collaboration in Health Research*, Canadian Institutes of Health Research (CIHR), http://www.cihr-irsc.gc.ca/e/44954.html

Participants United, *Ethics*, http://participantsunited.ageofwe.org/ethical-dilemmas/

Repper, J., Simpson, A. and Grimshaw, G. (2012) *Good practice guidance for involving carers, family members and close friends of service users in research*, http://www.mhrn.info/data/files/MHRN_PUBLICATIONS/REPORTS/Carer_good_practice_guidance_-_complete.pdf

The Research Ethics Guidebook: a resource for social scientists,
http://www.ethicsguidebook.ac.uk/

Strauss, R.P., Sengupta, S., Quinn, S.C., Goeppinger, J., Spaulding, C., Kegeles, S., Millet, G.(2001) The Role of Community Advisory Boards: Involving Communities in the Informed Consent Process. *American Journal of Public Health* 91 (12), 1938-1943 .

Williamson, G.R. (2002). Illustrating the ethical dimensions of action research. *Nurse Researcher*, 10(2).

Williamson, G.R. & Prossner, S. (2002). Action research, ethics and participation. *Journal of Advanced Nursing*, 40(5).

Ressources in German

von Unger, H; Narimani, P (2012) *Ethische Reflexivität im Forschungsprozess: Herausforderungen in der Partizipativen Forschung*. Discussion Paper. Berlin: Wissenschaftszentrum Berlin für Sozialforschung:
http://bibliothek.wzb.eu/pdf/2012/i12-304.pdf