



International Collaboration for Participatory Health Research

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Participatory Health Research A Guide to Ethical Principles and Practice

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Participatory health research

A guide to ethical principles and practice

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¹ 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* was developed as part of a research project in the 'Connected Communities' programme funded by the Arts and Humanities Research Council in the UK. The work was coordinated by Sarah Banks, Durham University, UK. See <https://www.durham.ac.uk/media/durham-university/research/research-centres/social-justice-amp-community-action-centre-for/documents/toolkits-guides-and-case-studies/Ethics-Guide.pdf>

Introduction

The aims and purposes of the ethical principles and guidelines

This position paper outlines the central position of ethics in participatory health research (PHR), identifying the underlying ethical principles and offering guidance for putting the principles into practice. One of the main aims of producing this position paper in the form of a guide is to raise participatory health researchers' awareness of the ethical challenges that may arise, and to enhance 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 participatory health research. Taking account of the nuances of PHR may require institutions to change their ways of working and reconsider their values.

The ethical principles underpinning PHR emphasise democratic participation as having a key value in 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 the principles mean in their own contexts and work together to interpret, develop and implement them.

The ethical principles and guidelines are designed not to be too detailed or prescriptive (i.e. they do not take the form of rules). This would remove control and responsibility from researchers themselves, detract from democratic participation and assume a fixed model of what counts as good PHR. The ethical principles and guidelines thus cannot offer simple solutions to the inevitable and complex dilemmas and challenges that are part of the PHR process. Rather they provide a framework within which participatory researchers are encouraged to reflect together on the values they hold and the potential benefits and harms that may arise at each stage of the research.

In summary, this position paper in the form of a guide to ethical principles and practice has several purposes, including to:

1. Articulate clearly the ethical principles that underpin PHR.
2. Raise ethical awareness amongst all research partners and participants and encourage discussion about ethical issues that can arise in PHR.
3. Offer ethical guidance to partners and participants in PHR.
4. 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.
5. 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 patronising to practitioner and community researchers or partners.
6. Improve ethical practice in PHR.

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' in its broadest sense, as outlined by the World Health Organisation, 'is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'. 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.

What is ethics?

Ethics is a topic that covers questions relating to what kinds of lives we 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, justice and fair treatment; and the responsibilities of researchers to act with integrity.

Ethical 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 guidelines are offered in Part II. The guidelines suggest how the ethical principles can be put into practice when doing research. Under each heading there are some guidelines that give more detail of what might need to be considered or done to promote ethical research practice. The guidelines provide suggestions.

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, including codes of ethics for research and research ethics committees or institutional review boards (bodies that receive and approve research ethics applications on behalf of institutions such as universities or hospitals).

However, some kinds of research create specific challenges and opportunities, which may not be adequately addressed by traditional institutional frameworks for ethical conduct in research. This is particularly the case with participatory health research, when the distinction between researchers and people contributing research data may blur, as community-based researchers may also be research informants, and professional researchers may take on the role of social change activists. The topic of the research may be challenging and sensitive, and the benefits (e.g. power-sharing, the development of context-specific knowledge) may be long-term and relatively intangible.

There is a host of issues that need to be carefully negotiated in PHR, including the ways power and control are distributed, 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. Tips for preparing applications to research ethics committees can be found in Toolkits 1 and 2 in the Appendices.

Can one set of ethical principles apply internationally?

There is a question about whether one set of ethical principles can and should apply internationally and across cultures. Arguably, because principles are relatively general, they can be widely recognised and accepted. However, how the principles are applied in practice may vary according to contexts (for guidance on how to engage in discussion of ethical challenges and dilemmas see Toolkits 3 and 4 in the Appendices). Applying principles means thinking about what they mean and how to implement them in the most culturally sensitive ways. For example, the PHR principle of democratic participation does not entail that certain individuals, groups or numbers of people should

participate in decision-making in any particular research project, but that people should be enabled and encouraged to contribute according to their skills and interests. In practice this broad principle can be applied to research in which community members decide to do most of the research for themselves, as well as to research in which most people decide they do not want to participate, or only want to participate in specific activities such as choosing the research topic.

There are some situations in which two or more ethical principles (or other universal principles such as human rights, or the rights of women, children or indigenous people) may be in conflict. For example, in some contexts, women who engage in research without a man's permission might be put at risk (for how this was handled in one particular PHR study, see Case Example 1 in the Appendices). Those organising research need to take this into account and work towards maximising women's power in the research process, within the cultural constraints. These circumstances do not mean that principles of equity, inclusion 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.

Relationship to other ethical principles, guidance and codes

These principles and guidelines should be read in conjunction with, and regarded as complementary to, generic ethical principles for all research, subject-specific ethical principles and codes of conduct, institutional research ethics guidance and research governance frameworks developed by research funders. In all research, the principle of researcher integrity (including honesty in presentation of findings) is important, while in research involving animals and people, principles relating to balancing benefits and harms are also paramount. Ethical principles for research involving 'human subjects' or 'participants' are well-developed across disciplines and usually include the following:

1. *Respect for research participants* - enabling participants or their representatives to make considered choices about whether and how to engage; treating them respectfully throughout the research process.
2. *Protection of research participants/communities* - ensuring participants or the communities being researched are not harmed, and/or minimising the risk of harm during the research.
3. *Justice and fair treatment* – ensuring that the costs and benefits of the research are distributed fairly, including enabling research participants to access the benefits of the research.
4. *Public and professional responsibility of researchers* - being clear about what information gained during research may be disclosed to third parties; being prepared to act on serious matters relating to the welfare or safety of participants/the public.
5. *Honesty in communication* – being as open as possible about the purpose of research and honest in analysis, presentation and publication of findings.

6. *Research should be of benefit to society* – ensuring the research contributes to human knowledge and well-being.

While these broad sentiments also apply in participatory research, it is important to note that they are based on the assumption that a research project involves ‘professional researchers’ (who design research, collect data and disseminate findings); and ‘research participants’ or ‘informants’ (who agree to take part in the study and provide data for the researchers). In this form of ‘traditional’ research, it is the responsibility of the researchers to respect and protect the participants. However, as noted earlier, in PHR these boundaries may be blurred, as people affected by an issue being studied may also act as researchers (often called ‘community researchers’). Hence the ethical principles for PHR focus on the relationship between the different people involved as ‘co-researchers’ (community researchers and ‘professional researchers’ working together), while also acknowledging that co-researchers may collect data from other people who are regarded as ‘research participants’.

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 committee reviews, research institutions can use the guide as a benchmark against which to judge applications that involve PHR. They might consider revising their policies and procedures to make them more amenable to PHR 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 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 all partners’ 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 guidelines, which give more detail on how to put the ethical principles into practice.

I. Ethical Principles for PHR

This section outlines some ethical principles to bear in mind (in addition to the generic ethical principles that apply to all research) for those who are conducting or supporting PHR. 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 guidelines 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) **Equity 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 by:
- 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.
 - recognising 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 PHR.
 - ensuring accurate and honest analysis and reporting of research.
 - being open to challenge and change, recognising and reflecting on one's own privileges and prejudices and being flexible and prepared to work with conflict.

II. Guidelines for Ethical Practice in PHR

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 key 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. A 'research partnership' refers to a group of people and/or organisations, who have come together in order to conduct research (e.g. members of a community organisation and university academics).

Consideration should be given to what forms of communication might be used. 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 their caregivers or other supporters/interpreters. When the research group includes people who speak different languages, provisions for translation may need to be made. When the group includes people whose voices are typically silenced (e.g. children or women in patriarchal societies, people from minority ethnic groups), particular attention needs to be paid to developing approaches that maximise their opportunities to share their opinions, without putting them at risk.

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. It can also help to build trust between all potential team members

1.2 Who should be involved and how? – 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? Are all the parties aware of the different opportunities to participate, for example in designing the study, collecting and analysing the data and preparing and sharing the results? What is the process for deciding democratically who should do

what? 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, or may only apply to some of the partners. For example, a student researcher may aim to write up the results as a thesis and this could be a legitimate aim even if it does not apply to the entire group (although co-interpretation of the findings would be important). Since PHR is often initiated by academic researchers, it is particularly important that potential community co-researchers engage in creative thinking about what they want to get out of it. At the same time, academic co-researchers need to be wary of being dominant, and sometimes patronising.

2. Developing a working agreement

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 PHR 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. Conversations before, during and after developing the working agreement should include considering power relationships and how to share power, control and responsibilities and how to maximise democratic participation in decision-making and in various parts of the study.

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

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.
- *mandatory requirements* that the group must adhere to, for example institutional or national ethical guidelines, laws regarding working with vulnerable people or disclosing certain types of information (e.g. about illegal behaviour), and or organisational or community rules.
- *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.
- *how recognition will be shared*, for example through co-authorship of research outputs or sharing any financial rewards that may result from the research.

2.2 How will researchers handle and store 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 PHR 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. Consider any tensions that asking (or not asking) certain groups for consent may cause (see Case Example 1: Developing a culturally appropriate (gender discriminatory) survey consent procedure in the Appendices). 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 PHR 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, Instagram, Twitter or WhatsApp) 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. Sometimes a limit is placed on confidentiality (i.e. researchers are allowed to disclose confidential information) 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 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 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. This needs to be discussed fully and consideration given to the implications of naming one person for the anonymity of others. Given the implications are often impossible to predict at the beginning of the research, it may be useful to keep identities confidential until the results of the research are available.

- *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 (including audio-visual material). Ownership’ means the right to access and use data and pass them on. If the data are 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 (e.g. if knowledge of traditional remedies is commercialised or funding is available to travel and present results). 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). Universities often assume by default that they are the sole owners of the data generated, therefore academic researchers may need to state explicitly in their intellectual property agreements details of joint ownership and use with communities.

3. Designing the research

Sometimes a research project is designed by professional researchers and funding is gained prior to inviting people with lived experience to play a role in doing the research. However, in PHR ideally at least some people with experience of the issue being studied should be involved in the research design – either at the initial stage, or in developing the design, so it reflects their knowledge and priorities. Because there is such a variety of types of research partnership, it is hard to give detailed guidance regarding the ethical issues arising in the design phase, but it is important to think about how to put the principles of equity, inclusion and democratic participation into practice here.

3.1 Creating space to engage a range of people in sharing what matters to them – it is important to create space and time for people to share their experiences of the issue to be studied and what their priorities might be for making change. This will help in identifying possible conflicting values and priorities and will aid in the process of formulating agreed aims and objectives. Creating a welcoming atmosphere, using non-technical language and holding listening exercises can be very productive.

3.2 Allowing time and resources to consider carefully possible methods – some people will have experience of doing research and using particular methods, while others will not. It is important to allow time to reflect on the advantages and disadvantages of different methods, and to leave space for creative adaptation or invention of new approaches.

3.3 Building in regular reviews of the research design - as the research proceeds, it may make sense to revise the design. It is important that all members of the research team are involved in this process and feel able to feed in their ideas and experiences.

4. Generating and analysing data

A PHR study may take many forms, sometimes using ‘traditional’ methods (eg surveys, interviews) as well as participatory methods (eg participatory arts or appreciative inquiry). Members of the PHR team or group of active researchers may share their own experiences of the issue being studied, and/or may ‘collect’ information from others. This is a complex process and needs to be planned carefully and reflected upon throughout.

4.1 Deciding on methods – it is important that the methods of generating or collecting data fit with the aims and objectives of the research, will generate the type and quality of data needed and can be used reliably by the research team. The quality of the data and methods influence the credibility of the research.

4.2 Deciding how to analyse 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, involving 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.

4.3 Supporting members of the research team – learning opportunities and support may be required for community-based researchers, who may face stress and demands

from their own communities generated by the research. Some of the challenges community-based researchers may face are discussed in Case Example 2 in the Appendices.

5. Sharing and making impact from the research

During the course of the research, and/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, as well as community organisations, policy makers, politicians, academics and others. They need to decide how to do this, and how best to make the impact they desire from the research.

5.1 Deciding how to share the research - in PHR 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 or newspaper articles, radio or television interviews, 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. Remember that making results accessible to the study community is usually considered important in PHR. It can be achieved through local meetings or events, word of mouth and potentially many other media.
- *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 recognised.

- *Who should disseminate and to whom?* – it is also very important to consider ‘who is the messenger?’ and ‘to what audiences are we speaking?’ when planning dissemination of the research. Dissemination may be planned for a range of different audiences (policy-makers, practitioners, service users, community members and academics) 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.

5.2 Making an impact – Many changes happen during/after a PHR project – including changes in the attitudes, skills, knowledge and actions of co-researchers (‘participatory impact’), as well as the thinking and actions of professionals, policy-makers and fellow citizens (See [Position Paper 3: Impact in Participatory Health Research](#)). This means it is important to be aware throughout the research process of the impact of doing the research on co-researchers, as well as the impact of the research findings on others. It is also important to remember that once a particular research project is written up, or when the funding runs out, this is not necessarily the end of the process. Considerations to bear in mind include:

- *Changes in co-researchers through doing the research* – all research partners need to be aware of the changes that doing research on a topic close to their hearts may bring in attitudes, thinking and actions, and consider the benefits and harms for individuals and the group.
- *Implementation of findings* - 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.

- *Reflecting on the limitations of evidence* - the PHR group may be unable to ensure the implementation of changes recommended by their research findings. This is an important check in the era of evidence-based practice, which implies that creating evidence alone is sufficient to create change. Often political will, economic factors, social norms and other factors prevent change, despite evidence.
- *Good endings* – at some point the relationships that were formed around the research may have to end (funding ends, people move on). Therefore 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.

6. Engaging in ongoing dialogue and ethical reflection during the research process

At all stages of the research process it is important that the researchers reflect together on what they are doing and why, and what may be the ethical impact of their decisions and actions. This requires a space for open dialogue, where all voices are heard and respected, generating a spirit of inclusion and curiosity, and a willingness to challenge each other constructively, yet critically (see Toolkit 3 on ethical case discussion and Toolkit 4 on dilemmas cafés in the Appendices). The creation of such an open and inclusive space, based on the ethical principles outlined in this guide, may not always be easy to achieve. It requires on-going work and a commitment by everyone to:

- A shared search for knowledge, with a focus on themes and topics that matter to all those involved.
- A valuing of diverse contributions and avoidance of dominance by some people at the expense of others.
- An openness to new possibilities and being prepared to let go of limits and rethink what might be feasible.
- An attitude of curiosity, and a willingness to be both playful and reflective.

Further reading

References quickly date and are often very time- and culture-specific. We have cross-referenced other ICPHR working papers, but have not cited other texts in this position paper.

An edited book published under the auspices of ICPHR, which covers many relevant topics and includes ethics case examples and commentaries from around the world is:

Banks, S. and Brydon-Miller, M. (eds) (2019) *Ethics in Participatory Research for Health and Social Well-Being*, London: Routledge.

Appendices: Toolkits and Cases

(see separate document on ICPHR website)

<i>Toolkit 1</i>	Tips for managing institutional research ethics committee processes in participatory health research
<i>Toolkit 2</i>	Imagining the institutional ethical review process
<i>Toolkit 3</i>	Applying ethical principles in PHR practice: Using ethical case discussions to promote ethical reflection and decision-making
<i>Toolkit 4</i>	Dilemmas cafés: Promoting ethical dialogue in participatory research
<i>Case example 1</i>	Developing a culturally appropriate (gender discriminatory) survey consent procedure
<i>Case example 2</i>	Issues of disclosure and intrusion: challenges for a community researcher
<i>Case example 3</i>	Establishing community-led ethical review boards in India