

## ETHICS AND THE USE OF PARTICIPATORY ETHNOGRAPHIC EVALUATION AND RESEARCH (PEER)

This guide is in three parts. The first is an ethical statement that describes some basic minimum standards for using PEER. The second is a brief introduction to the ethical conduct of participatory research in resource poor settings. The third offers some practical guidance on applying these ethical standards to PEER.

### PART 1: ETHICAL STATEMENT<sup>1</sup>

1. This ethical statement provides a framework to which researchers and others implementing PEER will adhere.
  - 1.1. Implementers will maintain the highest professional and ethical standards in conducting PEER. Compliance with formal or informal guidance provided by the CDS-Options PEER Unit does not preclude the need to comply with other national and international standards.
  - 1.2. Implementers will ensure that the research conforms to the statutory and customary laws relating to ethical conduct of research involving human subjects, including guidance provided by the PEER Unit<sup>2</sup>.
2. As a minimum, implementers will follow an informed consent procedure consistent with international standards for participatory research and appropriate to the research context.
  - 2.1. Take all reasonable steps to ensure that participants collaborate freely and without coercion.
  - 2.2. Have a system of research governance adequate to ensure the highest standards of ethical conduct by researchers, other implementing partners and peer researchers.
  - 2.3. Take reasonable steps to assess and mitigate physical, social or psychological risks to which those participating or involved in the research may be exposed. This will require the collaboration of partners with detailed local knowledge and experience of working with similar communities.
  - 2.4. Where peer researchers are exposed to health related information that may put them at personal risk, such as misleading information regarding modes of transmission of HIV; implementers will take steps to provide correct information in an accessible format.
  - 2.5. Implementers will ensure that participants have a realistic understanding of what they can reasonably expect in terms of outcomes from research, both for themselves and their community.
  - 2.6. Implementers will ensure that all participants have the necessary support to participate as equals in the research process. They will ensure that participants are

<sup>1</sup> More information and resources can be found on the WHO Ethics and Health web site at <http://www.who.int/ethics/research/en/> accessed 22 June 2007. WHO's guidance on indigenous peoples and participatory health research is particularly relevant to the use of PEER and can be found at [http://www.who.int/ethics/indigenous\\_peoples/en/index.html](http://www.who.int/ethics/indigenous_peoples/en/index.html), accessed 22 June 2007.

<sup>2</sup> Ethics and the use of Participatory Ethnographic Evaluation and Research (PEER), available at [www.options.co.uk/PEER](http://www.options.co.uk/PEER)

not placed at material, social or psychological disadvantage by a decision to participate in the research. Where this requires material or financial compensation, it will be at a level appropriate to local circumstances and below that which could be considered coercive.

- 2.7. Implementers will take all reasonable steps to ensure that data collected are non-attributable. In-depth training in, and on going support for, the use of third person interviewing and the 'no names' rule is a prerequisite.
- 2.8. Implementers will ensure that channels of communication are clearly explained to participants and that they have access to representatives to address any concerns or questions related to the research. Implementers will take steps to facilitate access to a representative in a manner appropriate to the local context.

## **PART 2: RESEARCH IN RESOURCE POOR SETTINGS**

There are a number of specific issues that need to be considered by both local and international researchers when working with disadvantaged, marginalised or vulnerable groups. Many of these issues are founded in the inevitable inequalities of power between researcher and researched, wherein there is the possibility that researchers will unwittingly coerce individuals into participation or expose them to unacceptable burdens or risk. It follows that careful planning, involving those with a depth of understanding of potential respondents, is a minimum and essential prerequisite to the ethical conduct of research with vulnerable communities.

### **Governance**

Research is commonly a collaborative enterprise involving a number of actors, notably members of the community under study, field staff and a range of other technical and operational staff. Maintaining high standards requires careful management, as the individuals involved often come to the process from different organizations, disciplines and geographic locations. There must be clear agreement on the ethical responsibilities of all participants, and how these responsibilities are to be operationalised. A useful concept in this context is 'research governance'. Here it is used specifically to highlight the importance of having a clear operational structure to implement effectively the principles of ethical research.

### **Risk assessment**

Researchers have a responsibility to assess the level and nature of risk to which all collaborators in the research process may be exposed. These risks will vary with context and may include physical, social or psychological risks. Members of a researched community may, for example, be stigmatised by involvement with researchers on certain research topics. Involvement may impact on them in complex and unpredictable ways. It is important to note that part of effective governance entails working with all stakeholders, using local expertise to identify these risks and communicate them effectively to participants who should then be in a position to make a judgement about their level of participation.

## Overarching principles

There are usually considered to be three overarching moral and ethical principles that guide research: respect for autonomy, beneficence and justice.<sup>3</sup> These form the foundations of most other ethical guidance (Butler 2002). **Respect for autonomy** entails that individuals have intrinsic value, dignity, and the capacity to decide. Individuals should be given all the information needed to make good decisions, particularly relevant to informed consent discussed later (Rivera et al. 2004). **Beneficence** refers to an obligation that researchers not only work to protect individuals from harm, “but also by making efforts to secure their well being” (The Belmont Report 1979). Researchers should give forethought as to how the exercise will minimise harm *and* maximise benefits to the community in question. **Justice** entails that potential burdens, risks and benefits should not be distributed inequitably in a population, particularly on the basis of socioeconomic status or ethnicity without adequate justification. The most important implication is that it may be unethical to conduct research with the assistance of a population who are unlikely to benefit in some way from the results of that research (Rivera et al. 2002).

## Managing expectations

Researchers have a responsibility to ensure that all stakeholders have a realistic understanding about what they can reasonably expect in terms of outcomes from research, both for themselves and their community. In geographically isolated communities, or socially marginalised groups, the arrival of a researcher may be a significant event. Giving the opportunity for marginalised individuals or communities to express a voice can be an empowering experience for them, but can also lead to unrealistic expectations and ultimately disillusionment. Ideally, participatory research forms one part of a wider process; genuine participation can ensure that research is actually *responsive*, both to community needs and expectations (Rivera et al. 2004).

## Technical and material support

The disparity between the technical and financial capacity of different stakeholders in the research process can place individuals at a disadvantage and expose them to risk. Where participants who are poor, non-literate, less educated or do not share a common language are invited to collaborate with the research team, they will need support in order to participate effectively in the research and not be further marginalised by their involvement. Careful consideration should be given to the types of support participants may need at different stages of the work.

A practical implication is that stakeholders must also be adequately compensated for their involvement in research. Research can be time-consuming and costly for participants and researchers may not be well placed to understand the implications of time spent away from family, business or land. Monetary or other material compensation may be appropriate. There are a number of issues to consider:

- Researchers need to consider even extremely small costs borne by participants as potentially worthy of compensation. The cost of a short bus journey or telephone call may equate to many hours of work.

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<sup>3</sup> These were defined in the Declaration of Helsinki as a response to Nuremburg trials of those conducting research on concentration camp prisoners in the 1940s and also in the Belmont Report (1979), a response to *inter alia*, the Tuskegee Study of Untreated Syphilis in Black Males 1932-1972.

- Compensation may have a coercive effect in resource-poor communities. Individuals may not have a genuine choice to decline to participate when presented with financial incentives, whatever their misgivings.
- Power and exchange relationships in families and communities are complex. The recipient may not be able to keep for themselves the material compensation they receive for their participation.
- Inappropriate compensation may cause conflict and jealousy.
- Financial compensation, however welcomed in the short term, may not adequately compensate for the longer term implications of neglected crops or businesses.
- The individual involved may not have the authority within family or other power structures to negotiate spending time away from other responsibilities, whatever the remuneration.
- Compensation may influence the way in which the researched community responds to researchers, and this may impact on the objectivity of the research. It may also influence (positively or negatively) the longer term relationship between the community and the programme.

### **Informed consent**

This is a fundamental principle of research with human subjects, and all those involved in research need to have an understanding of the practical implications. Informed consent is a 'decision to participate in research, taken by a competent individual who has received the necessary information; who has adequately understood the information; and who, after considering the information, has arrived at a decision without having been subjected to coercion, undue influence or inducement, or intimidation' (COIMS/WHO2002). The process of informed consent requires researchers to:

- Describe the research and the role of the participant, clearly describing the commitment involved.
- Describe reasonably foreseeable risks.
- Describe expected benefits.
- Explain how information that may identify individuals or communities is managed, including the extent to which confidentiality and/or anonymity is guaranteed.
- Make clear whom the participant may contact if they have questions or concerns
- Explain that participation is voluntary, participants have a right to withdraw at any time and that no sanctions will be imposed for either non-participation or withdrawal.
- Adapted from Rivera et al. (2004)

As informed consent requires that potential participants understand the nature of the research, it is important to note that the concept of 'research' itself will often require some explanation. Furthermore in many cases participants may not initially be able to clearly distinguish research from other activity, for example the provision of healthcare (Molyneux et al. 2005). Thought will need to be given about how these issues are to be explained in a clear and accessible way.

The informed consent process may appear straightforward but researchers may not recognise where existing power structures are implicitly coercive. Coercion may be realised in terms of participants feeling unable to decline when their participation is requested by outsiders perceived as having high social status.

Alternatively, involvement of local authority figures such as village leaders or medical staff may lead to a real (and often justifiable) fear of future sanctions imposed for non-cooperation; for example denial of health services. Understanding local power structures is essential and failure to observe these, even where coercive or corrupt may have significant implications for both researchers and communities themselves, especially the disadvantaged and marginalised (Brown et al. 2004).

Informed consent is often explained and recorded in writing. However the focus must always be on the substance of the process rather than the means used to verify or record it. There are a number of factors to consider when deciding how to manage informed consent, particularly in non- or semi-literate communities:

- A written format may not be accessible to participants who are unwilling to disclose low levels of literacy.
- Official forms may be associated with specific institutions, such as the government. This may give the work inflated legitimacy, be inherently coercive or associate the work with others in undesirable ways.
- Lengthy forms using unfamiliar terms may be intimidating, cause anxiety and confuse rather than inform.
- Written consent may not ultimately lead to the verification that its use sought to provide. That a form is signed does not in itself mean that informed consent has taken place (Brown et al. 2004).
- There may be other stakeholders whose consent may need to be sought. These may include husbands, mother-in-laws or other official and unofficial gate keepers at village or district level.

In some cases researchers may wish to explore other methods for gaining informed consent, such as verbal consent using tape recorders or third party witnesses.

### **Right to information**

Those involved in research, and other relevant stakeholders should be given access to information about the research before, during and after the process. Making information available may allay local fears or help to prevent inaccurate rumours developing about the nature of the research. Following the study, findings should be shared with and among as many participants and community members as possible in an accessible format (Rivera et al. 2004).

### **Vulnerable groups**

It is important that asymmetries of power between external researchers and the community under study are acknowledged. The status that the respondent community occupies in wider society may mean that its members are unaware of their basic rights, or lack the power to exercise them. Vulnerable populations are particularly poorly placed to give informed

consent (Brown et al. 2004), and this issue should be discussed in some depth by the research team in the planning stage.

### **PART 3: THE ETHICAL USE OF PEER – SOME PRACTICAL GUIDANCE**

The issues discussed above relate in a generic way to social research in resource poor environments, including to the use of PEER. There are a number of specific ways in which PEER can be used to ensure high ethical standards when conducting research on sensitive topics among highly marginalised groups.

PEER is a participatory qualitative research method derived from the anthropological approach, which holds that building a relationship of trust with the community<sup>4</sup> is essential for researching social life (see Price and Hawkins 2002; Hawkins, Price & Mussá in press; for full details of the PEER method). Peer researchers recruited from the community under study conduct a series of interviews with their peers following participatory training, during which they identify key research themes and develop 'prompts' to guide their interviews.

Using peer researchers presents a number of opportunities in terms of creating a more equitable and collaborative relationship between researchers, programmes and communities. Working together for a common purpose can help develop a stronger relationship of trust between programme and target group. Giving voice to often marginalised communities, and fostering a sense of ownership over both the process and data, together represents a less extractive model of research while offering a starting point for genuine dialogue.

#### **Supporting peer researchers**

Those involved in field research may require support in a number of ways whilst conducting PEER. Here they are discussed in the order in which they occur in the research process.

#### **Informed consent**

Those using PEER will need to design an informed consent process tailored to local requirements. This will need to satisfy the requirements of local ethics committees, collaborators, legislation and the communities themselves. In many cases agencies will be more familiar with requirements for biomedical research than participatory, qualitative methods like PEER. Where witnessed verbal consent is deemed most appropriate, researchers may need to explain the rationale of the research in some detail; the literature detailed in the ethical statement may prove useful (eg Bhutta 2004). For witnessed verbal consent to be effective it should be explained and practised during the peer researcher training. Role play should be observed to ensure the procedure is fully understood.

#### **Travel**

Once recruited, researchers may be required to travel to a training venue. Thought should be given to how they are to make and finance this and other journeys. Long journeys, particularly on foot will be difficult for women with babies or children. Travel using public transport may be expensive, and researchers should not be expected to pay transport costs

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<sup>4</sup> By 'community' we mean a group of people with common or shared characteristics, such as occupational, cultural, ethnic, or socioeconomic similarities, rather than simply geographical proximity.



up-front, even when they are to be reimbursed later. Participants should also have been given some indication of the nature of the work before the training commences.

### **Creating a comfortable environment**

A first and vital step in conducting the peer researcher training is to create an informal and comfortable environment. The venue should reflect as much as possible familiar surroundings for the peer researchers. Hotels or health centres are often least appropriate. A social environment where participants feel free to voice concerns is a pre-requisite for ethical conduct and there are a number of practical ways to facilitate this:

- The early use of ice-breaking games with the full participation of all present
- Informal dress code and seating arrangements, with formal opening ceremonies avoided or kept to a minimum.
- The sensitive selection of researchers who are to work together, for example a wide age-range or mixed sex group may inhibit full participation.

### **Clarifying objectives**

Peer researchers may come to the training with anxieties about what is required of them. Following basic introductions these can be tackled as the first exercise during the peer researcher training. Participants are first asked why they think they have been invited, and any misunderstandings clarified. Explaining in an accessible way the value of their 'lay expertise' can be a good introduction to the process. It must be made clear to potential peer researchers that they are free to stop participating at any time.

### **Clarifying time commitments and remuneration**

It is important that facilitators clarify the likely time commitment involved and how peer researchers are to be compensated. Clarifying these issues early on helps to prevent misunderstandings developing later, and is a vital part of informed consent.

### **Payments and incentives**

How the research team should compensate participants is highly context-specific. The time of all participants must be valued, and as a general rule peer researchers should be compensated for lost earnings, particularly during the initial training. Local advice should be sought on what is appropriate and care taken to ensure that payments are not at a level that may be coercive. As interviews are usually conducted opportunistically over an extended period, research teams may feel that financial compensation for this part of the work is less important. Experience indicates that money for a snack and drink for peer researchers and respondents at each interview is usually sufficient.

### **Research with traumatised populations**

The direct involvement of members of the researched community at the design stage will work to limit the discussion of issues that are uncomfortable or likely to revive traumatic memories. The narratives are locally-owned, non-personal and volunteered in a private sphere. However, in environments such as post-conflict settings, provision may need to be made for access to support during and after the research (Goodhand 2000).

## **Debriefing**

In addition to regular support to peer researchers in conducting research, provision may need to be made for researchers after the work to dispel any incorrect beliefs that are revealed during the process. For example, where researchers and respondents have discussed incorrect modes of transmission of HIV, a mechanism should be put in place where they are given access to correct information at the end of the process. Often a short session on HIV is integrated into the final workshop.

## **Identifying risks**

As with all research with vulnerable groups, participation may carry risks to the participants. Research focusing, for example, on commercial sex work or intravenous drug use, may inadvertently label participants and further marginalise them within their communities. In-depth local knowledge is essential to understand and mitigate these risks and researchers who do not have an established relationship with the community under study will need to make specific arrangements. This may involve developing a partnership with organisations already working with these communities or with experience of working with similar groups, usually for the duration of the work.

## **Ensuring confidentiality**

The use of PEER offers a comfortable non-public space for respondents to talk about sensitive issues, promoting research that is both scientifically rigorous (Price & Hawkins 2002) and ethically sound. Interviewees are asked to talk about 'what other people like them do or say' and relate stories they have heard. A clear implication is that care needs to be taken to ensure that specific individuals are not identified in the narratives or stories collected by the peer researchers. Both the 'no names' rule, and third person interviewing are used to ensure confidentiality.

## **Third person interviewing**

The use of the third person enables respondents to talk about sensitive issues in their social networks without personal attribution. Throughout the training of peer researchers, facilitators continually re-affirm the importance of, and develop skills in the use of 'third person' interviewing. Role play and practice can be used to develop this skill, explaining that as peer researchers we are interested in the stories and experiences of 'our friend's friends'.

## **'No Names'**

Similarly, the 'no names' rule is referred to throughout the training period. This can be turned into a game with researchers trying to catch each other out by deliberately using names and testing their partner's response. Researchers are taught to inform their respondents that names are not to be used; where a name is inadvertently used, they are to remind the respondent and move the interview on.



## References

Belmont Report, The (1979) *Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. The National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, USA

Bhutta Z (2004) Beyond informed consent. *Bulletin of the World Health Organisation*, 82:10, 771-777.

Brown N, Boulton M, Lewis G, Webster, A (2004) *ESRC Research Ethics Framework: Social Science Research Ethics in Developing Countries and Contexts*. ESRC Discussion Paper 3. Science and Technology Studies Unit (SATSU), Department of Sociology, University of York; and School of Social Studies and Law, Oxford Brookes University.

Butler I (2002) A Code of ethics for social work and social care research. *British Journal of Social Work*. 32:2, 239-248.

Council for International Organizations of Medical Sciences (CIOMS)/ World Health Organization (2002). *International Ethical Guidelines for Biomedical Research Involving Human Subjects*. Geneva.

Goodhand J (2000) Research in conflict zones: ethics and accountability. *Forced Migration Review*. 8:12-15.

Hawkins K, Price N, Mussá F (in press) Milking the cow: Young women's constructions of identity, power and risk in transactional age-asymmetric sexual relationships in Maputo, Mozambique. forthcoming in *Global Public Health*

Molyneux C, Wassenaar D, Peshu N, Marsh K (2005) 'Even if they ask you to stand by a tree all day, you will have to do it (laughter)' Community voices on the notion and practice of informed consent for biomedical research in developing countries. *Social Science & Medicine*. 61:2, 443-454.

Nuffield Council on Bioethics (2002) *The Ethics of Research Related to Healthcare in Developing Countries*. London.

Price N & Hawkins K (2002), "Researching sexual and reproductive behaviour: a peer ethnographic approach". *Social Science & Medicine*. 55:8, 1325-1336.

Rivera R, Borasky D, Carayon F, Rice R, Kirkendale S, Wilson W, Woodsong C. (2004) *Research Ethics Training Curriculum for Community Representatives*. Family Health International.

Rivera R, Borasky D, Rice R, Carayon, F (2002) *Research Ethics Training Curriculum*. Family Health International.

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