

Placing ethics in the centre: Negotiating new spaces for ethical research in conflict situations

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Abstract

Issues of power and consent, confidentiality, trust, and benefit, risks to researchers, and potential harm to participants, are all contested when working with different cultures and within environments marked by violence and insecurity. Difficulty resolving these dilemmas may paralyse ethics committees, may fail to give the guidance sought by researchers, and will not help populations who are among the world's most vulnerable. Even where efforts are made to respond to ethical guidelines and to improve practice, considerable impediments are present in many developing countries, including lack of formal ethical review structures in unstable settings, lack of required skills, limited political and institutional recognition of ethical issues, competing interests, and limitations in clinical and research practice (Elsayed 2004, Macklin 2004). In conflict settings, these limitations are more marked, and the responsibilities of the researcher for ethical practice are greater, but the mechanisms for oversight are weaker. Moreover, the constant focus on vulnerabilities and problems, and the often almost total lack of recognition of strengths and resilience, can further disempower already exploited groups and individuals. The capacity of refugees and communities in conflict to take an active role in the research process is seldom acknowledged, and undermines the potential for more innovative research which can help generate the evidence for better policy and practice.

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Introduction

Complex emergency settings are characterized by disrupted community and social networks, limited resources, multiple public health risks, extensive abuses of human rights, and intense competition for aid resources (Collinson 2002, Zwi et al. 2002). The compounded effects of persecution and erosion of capacity in protracted refugee situations are well documented (Harell-Bond 1986). These factors, and the associated marginalization and exclusion of populations, place communities at risk of exploitative and unethical research practices. At the same time, there is an urgent need to establish a rigorous evidence base for health initiatives in these contexts and to improve the delivery of services in emergencies. The fundamental challenge, therefore, is to develop models of research that respond to need, are cognisant of the practical difficulties of research in such environments, and minimize the risks.

Research can be understood as a systematic investigation designed to develop or contribute to generalizable knowledge. In complex emergency settings, most research is non-experimental (National Research Council 2002) and may focus on the collection of data regarding risks, exposures, and determinants of health on health status (including surveillance of morbidity or mortality), on service delivery and programme evaluation, or on new technologies, therapies, and interventions to address ill-health. The nature of ethical challenges will vary depending on the type of research being undertaken, the circumstances in which this takes place, the identified need, and the associated timescale for conduct of research and feedback of any relevant insights.

The need to find better ways of negotiating the ethical complexities of research in such settings is identified as a concern by many of those involved. Some refugee groups, for example, have voiced concern with the volume, quality, and management of research being undertaken. On the Thai-Burmese border, refugees drew attention to photographs and names of refugees being published without permission, thus placing refugees in danger, and the failure of researchers to provide promised copies of reports (Pittaway and Bartolemei 2003, Pittaway et al. 2004).

The conduct of social and health-related research in these and related settings is also under increasing scrutiny by bodies charged with ethical oversight, such as Human Research Ethics Committees (HRECs). In Australia, for example, HRECs conduct ethical reviews within the framework of guidelines set out in the National Statement on Ethical Conduct in Research Involving Humans (Commonwealth of Australia 1999). These guidelines are structured around a set of normative principles that are largely biomedical in their derivation; principles associated with minimizing harm, assuring respect and dignity for persons, promoting autonomy and justice, and drawing on researcher integrity. HRECs are increasingly recognizing that the interpretation and application of these principles must be fine-tuned to context and culture, especially in situations of significant power imbalance (Baker 1998, Macklin 1998, 1999, Zion et al. 2000).

Researchers themselves have identified a range of challenges faced in seeking to uphold principles of ethical conduct when doing research with vulnerable

populations (Goodhand 2000, Leaning 2001, Jacobsen and Landau 2003), in complex emergency settings (National Research Council 2002, Black 2003), and when delivering humanitarian assistance. Kottow (2002) highlights the particular responsibilities of researchers in resource poor settings, arguing that ‘investigators enter a special ethical relationship with research subjects’, and decries any measures which result in ‘tempting researchers to free themselves of commitments and responsibilities for the sole reason that they are operating in poor environments with precarious medical services’.

In conflict situations such challenges are amplified and those charged with ethical oversight of research are in a double-bind; they appreciate such situations of risk and potential exploitation, but often have little practical guidance to offer. This paper considers some of the limitations of existing review procedures and suggests a more interactive relationship between the key stakeholders involved with research in conflict-affected settings. It highlights some questions regarding whether research processes could be negotiated to ensure that public health and other forms of social research better serve conflict-affected communities.

Power, consent, and community representation

Power imbalances between researchers and research participants raise complex ethical issues, particularly in situations, such as refugee camps, where inhabitants are dependent on external bodies for meeting their basic needs and where some parties may have power over entire groups. Participation in research may be motivated by fear, desperation, or by unrealistic expectations of assistance, and autonomous decision-making may be compromised (Hyndman 2000).

The literature questions whether a ‘Western’ emphasis on individual autonomy and decision-making is appropriate where the family and community have decision-making authority (Barrett and Parker 2003, Molyneux et al. 2005). One response is to seek stepwise consent: engaging group community structures, then family, and, lastly, individuals. This response is not without its problems, however. Moreover, in periods of emergency, time and opportunity to negotiate stepwise consent is likely to be limited.

Researchers must also tread a careful path when community and individual consent conflict with one another. Community leaders may exert tight control through their ability to offer patronage and protection to some. Researchers must be mindful that their work does not privilege only the voices of those with the power to speak out, while silencing those already disempowered. Goodhand (2000) reminds us that conflict ‘manipulates information by promoting and suppressing voices’: researchers should ‘realize that research necessarily involves making political choices about which voices are heard and whose knowledge counts’.

Similar caution and sensitivity is required in seeking ethical approval or oversight. In conflict-affected areas, ethics committees may be absent, dysfunctional, or not trusted by the communities they are assumed to serve. Whether working with local ethical review bodies, or other gatekeepers, researchers should recognize that some members of society, often those better educated and more fluent in English, may

present themselves as reflecting the interests of the community when in fact, they do not. Community representation is complex: knowing who, if anybody, can 'speak' for the community requires a high level of contextual understanding (Fustukian and Zwi 2001), something which may be in short supply during crisis situations.

Confidentiality

Confidentiality is important in most research settings, for protecting both the information provided by research participants and their identities. In small communities, and especially in conflict and disaster-affected settings, confidentiality may be difficult to maintain. However the hazards of broken confidences may be extreme, resulting in serious harm to individuals and risks to the safety of individuals or entire communities (Leaning 2001).

Refugee women who participate in research following rape or sexual violence, for example, may face the additional risks of stigma, social exclusion, and violence from their own communities. This has been extensively documented in Kenyan refugee camps and among communities on the Thai-Burma border (Human Rights Watch 2002, Women's League of Burma 2002, Pittaway and Bartolomei 2003, KWO 2004). Where there is pressure from authorities to engage in research, maintaining confidentiality of those who do not consent or withdraw from a study, is equally important.

Some techniques used routinely in community-based research can be problematic in conflicted settings. Focus group discussions may lead to public disclosure of attitudes or practices which may pose risks to individuals and communities. For example, in highly contested environments, political affiliation and sympathies, or revelation of coping strategies, such as how to maximize access to resources available from NGOs or where people hide during militia raids, may expose individuals to danger. Interpreters and translators may gain access to information which is sensitive and may harm those providing such information if it is passed on to groups in conflict with one another. Researchers have a responsibility to ensure that confidentiality is respected by all members of the research team and to understand how and when this could be in jeopardy (Collinson 2002, Jacobsen and Landau 2003). This is itself a difficult task given that those collecting data or undertaking research may be reliant on local interpreters whose affiliation and positioning within the community may not be known.

Reciprocity, risk, and benefit

Reciprocity entails uncoerced giving in which things of relatively equal value are exchanged, and from which individuals have an expectation of fairly immediate return (Harrel-Bond 2002). In relation to research in complex emergency settings, reciprocity implies that the risks and costs associated with involvement in research are offset by the delivery of tangible benefits to participants. Turton (1996) asserts that research into the suffering of others can only be justified if alleviating their suffering is an explicit objective.

Negotiating reciprocity is rarely simple, and in conflict and disaster affected settings it has proved especially difficult. Researchers often strive to return to the community something of value. Such benefits, though, must not act as an excessive inducement, should be distributed in a way that maintains the confidentiality of participating communities and individuals, and must not in any way stimulate or exacerbate conflict.

There is little guidance for researchers on how to negotiate benefits with participants, and current funding arrangements neither provide the time nor the resources to effectively do so. Some of the ways in which researchers *do* seek to return benefit may be discouraged by ethics review structures: offering skills as health or community workers, or acting as advocates to assist participants with legal or health problems identified during the research, may be considered to be raising expectations of service delivery or may appear too advocacy-oriented.

Where researchers attempt to return benefits to communities in unstable settings, this may not always be possible. Communities may have moved by the time the research is completed, for example, or it may take too long to be of value to those involved. Benefits to future populations in similar circumstances are of value, but considerable care to identify current opportunities for reciprocal benefit should be taken.

There is a need for researchers to be realistic about the extent to which they will be able to follow-up at a later date, and a need to look for ways to provide some immediate benefits or feedback while researchers are with the community, rather than promising post-research dissemination, which may not be possible. Recognition of the range of benefits derived by researchers and their institutions from the conduct of research (publications, reputation, and funds) should be balanced by reciprocal benefits to those participating in such a study. One of the major complaints expressed by community groups concerns researchers who make promises which are not fulfilled, including the provision of training or project equipment (Pittaway and Bartolomei 2003, Pittaway et al. 2004).

Dangers of 're-traumatization' are present if sensitive issues are not handled appropriately and adequate supports made available. Such re-traumatization may follow 'intrusive' and 'invasive' questioning (Bäärnhielm and Ekblad 2002). Mass distribution of trauma surveys to affected populations raises serious ethical concerns, particularly when there are no follow-up support structures in place to assist those in need or those who may be re-traumatized by the research experience.

Researchers face their own risks and operate in an environment over which they have little effective control. They may need to engage with non-state authorities, including war-lords, for access to research populations or protection for themselves and research staff. Moral and ethical dilemmas arise when research exposes illegal activities such as sexual exploitation or trafficking of women or children or the recruitment of child soldiers. 'Traumatization' of researchers who are exposed through eliciting stories of torture or abuse, grief, and loss, and crimes against humanity, may occur (Jacobsen and Landau 2003).

Research relationships in conflict-affected settings

The World Health Organization (2004) has called for better preparation, prioritization, and coordination of responses to the health needs of those in crises. This requires that policy-makers be provided with data that are collected in a timely, scientific and ethically sound manner (Jacobsen and Landau 2003). An evidence-base is emerging, and being applied, for a number of health related interventions in humanitarian crises, especially in the areas of infection control, water, and sanitation, provision of nutrition, and shelter (Banatvala and Zwi 2000, Robertson et al. 2002). However, methodological challenges continue to limit the availability of evidence in general, as well as constraining the application of knowledge and evaluation of the effectiveness of interventions. Improving inter-agency lesson learning remains a challenge, although organizations like ALNAP (Active Learning Network for Accountability and Performance in Humanitarian Action; <http://www.alnap.org>) have made major strides in this respect.

The challenge

Solutions offered for these complex challenges, of ensuring more ethical research conduct, are often marginal; based on incremental changes to guidelines or slight modifications to methods, but they do not propose a more fundamental shift in current practice. We suggest that careful review of the research process, with a focus on the relationships between stakeholders, is required. One way of simplifying the considerations is through a diagram (see Figure 1) which identifies the parties involved and makes explicit some of their concerns.

Members of ethical review bodies, researchers, and those participating in research, all have their own set of interests (London 2002). Identifying and working with such interests more explicitly may help determine how shared objectives could be negotiated. We use a triangle to depict the space bounded by researchers, researched communities, and bodies charged with ethical oversight, such as HRECs. These actors all operate within a broader socio-political context, a context which Beyrer and Kass (2002) argue is central to the determination of risks and benefits, especially in situations in which violations of rights are frequent. Stakeholders seek to maximize the outcomes of interest to them, reinforcing tensions with other players.

Researchers often seek to maximize their autonomy and control of the research process, while HRECs seek to constrain this and manage risk. Cribb (2004) suggests that institutional review boards in general focus on protecting the researcher or institution, rather than the research subject, and view their task as 'more in legal than in ethical terms'. HRECs will make decisions in order to minimize risk of harm to vulnerable populations they 'protect', but also at times to avoid any risk of adverse publicity for the bodies they represent. On the other hand, researchers in conflicted environments may consider it critical to retain flexibility and the ability to respond on the spot to ethical or methodological

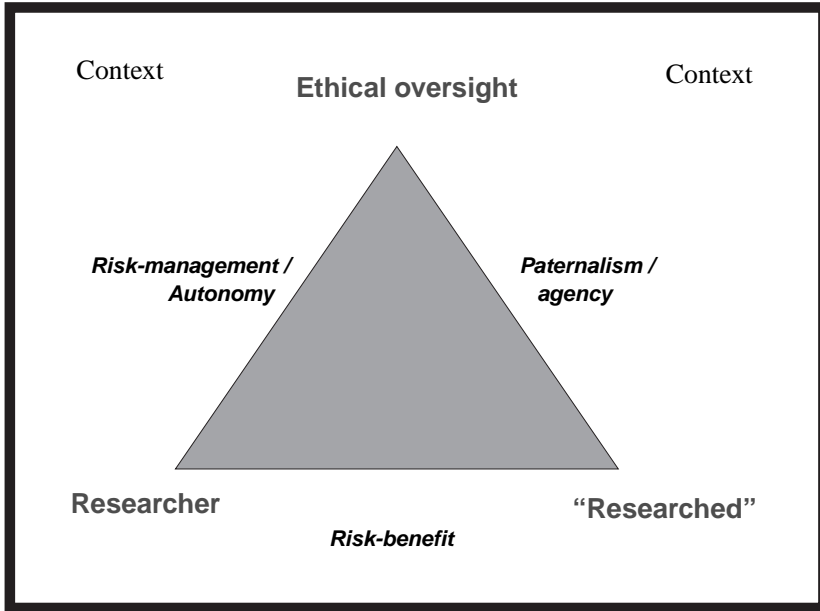


Figure 1. Tensions between key players operating to ensure ethical oversight of research activity in conflict settings.

challenges in order to retain relationships with populations under stress in a fast-changing environment.

Tensions may also arise between researchers and researched groups as the latter weigh personal risks and benefits of participation. Researchers may consider what data are available, how much it will ‘cost’ in time and resources to collect, and what their value may be to generating knowledge. Researched communities may see aspects of the process as extractive and exploitative; the response may be to block access, or to lie, or to direct researchers away from their communities and towards other sites or to otherwise refuse to engage in the research process (Pittaway et al. 2004). Barriers could potentially be removed in return for certain compensations, benefits or rewards, thus establishing a new ‘contract’ between those involved.

However, where these situations arise, the risk is that those with least power (sometimes minorities within affected communities) are unable to negotiate effectively, that research proceeds without adequate ethical oversight, or that researchers, unaware of these dynamics, may misrepresent, minimize, or deny important community issues in their findings. The complexities of negotiating these relationships may prevent valuable research from taking place at all.

Towards improved research relationships with conflict-affected populations

In conceptualizing these research processes, we suggest that more effort be focused on developing the shared spaces in the middle, where communities, researchers, and HRECs all have, potentially, opportunities to participate, both conceptually

and practically, in the research. Opening out this 'space' facilitates opportunities to collaborate on identifying key questions, the methods and mechanisms through which to address them, and the analysis, interpretation, and dissemination of results which may be of value in addressing important health and social issues.

Mutual interest and commitment from each stakeholder is necessary, and experience and levels of trust between the different stakeholders take time to develop, especially if they are to be based upon shared values and motivation. The subjects of research must place sufficient value on the potential outcomes of the project in order to engage, the HRECs must be motivated to negotiate solutions with researchers, and researchers must be prepared to adopt a more participatory and consultative approach to their agendas. The funders of research, perhaps the most powerful stakeholder, sitting above the triangle and with influence over all participants, must be prepared to make resources available which facilitate the delivery of reciprocal benefits.

Developing a shared approach to research needs entails a shift away from a primary emphasis on the researcher–HREC link, where much decision-making is currently concentrated, and towards an environment in which 'researched communities' and their representatives might begin to exercise a greater degree of agency and to influence the terms of engagement and the research process itself.

Given the vulnerability of communities in conflict situations, more equitable approaches might give consideration to the following matters.

Are there mechanisms through which rethinking research methodologies may promote greater engagement and control by participants?

Participatory action research provides some insights to potential benefit and reciprocity, although Gold (2001) rightly cautions against seeing participatory research as an antidote to 'all that is wrong in the skewed power structure of social scientific and development projects'. Participatory action research recognizes the links between knowledge and power, and aims to 'produce understanding' that is useful for, and empowers, the group involved (Green and Thorogood 2004). Participatory and other forms of action research must be rigorous if they are to be ethical; despite enhanced rigor, ethics committees often struggle with the review process for action research even outside of conflict settings (Khanlou and Peter 2005).

Are there benefits from extending ethical oversight to include local bodies?

Hurst (2001, quoted by London 2002) suggests that institutional review processes 'need to develop new ways to recognize and strengthen the agency of individuals, groups and communities, whom institutional review has thus far only viewed as candidates for protection'. Kottow (2002), in relation to research in developing country settings more generally, argues also that the potential benefits of research should not hinge on 'benevolent paternalism' but should draw on the perspectives of local professionals and practitioners.

It remains unclear how best to ensure that researched communities or their representatives can interact with HRECs to articulate their needs or desires for the outcome of the research. Currently HRECs are distant from those they seek to protect, making it difficult to contextualize decisions, and posing the risk of paternalistic attitudes to research participants. Requiring researchers to obtain ethics approval from multiple committees, institutional and local, may not provide the best solution to this difficulty. In such situations, the review process tends to be regarded by researchers as a bureaucratic hurdle that must be overcome, rather than an opportunity to engage seriously with the ethical issues raised by the research.

An alternative solution might be that where foreign researchers are operating in conflict zones, ethical clearance by home institutes could be made contingent on engaging one or more local advisors to help provide feedback and offer guidance in the field. This may be based around models of iterative ethical approval, where an initial phase of research is approved with subsequent stages dependant on meeting reporting obligations, demonstrating appropriate research behaviour, and responding sensitively to ongoing ethical challenges. Peer advisory panels comprised of experts with social, cultural, political, historical, and community knowledge and insights, have also been proposed for complex emergency settings (National Research Council 2002).

In conflict settings, the responsibilities of the researcher for ethical practice are greater, but the mechanisms for oversight, weaker. In the future, incentives for developing and practising new ethical models may require engagement by external agencies; funding bodies may be in a position to influence more ethical and accountable research practices. Journal editors can also encourage and promote better descriptions of the ethical challenges in such research and can promote debate regarding emerging responses. Community advocates may seek support and identify mechanisms through which communities might more actively participate in shaping the research process.

Key questions arising

Highlighting the issues and challenges does not translate into simple actions, and numerous questions remain. Articulating these issues does, however, seek to engage the stakeholder communities in exploring the weaknesses of current frameworks, deepening the debate, reflecting on experience, and identifying potential solutions.

In what ways can communities play a greater role? Are HRECs in a position to work more closely with communities? How can local bodies be supported to undertake a more active role in ethical oversight?

The most disempowered and vulnerable are least able to forge more equitable relationships with researchers. What can be done to develop their role? Might training of community members be of value? Is this impractical in most refugee

settings or, given the chronicity of an increasing number of contexts, might it be possible? How might community advocates retain accountability to their communities while voicing their concerns among research-oriented peers? What changes to HREC composition, engagement with key stakeholders in conflict-affected settings, discourse, approach, and processes, might facilitate greater engagement with local community concerns? When the 'terms and conditions' for research are set in the home country of the researcher, how can perspectives from the research site be more clearly heard?

London (2002) offers some suggestions, notably about holding review processes more openly, establishing independent mechanisms for monitoring the conduct of research, protecting whistle-blowers who identify system failures, and expanding HREC membership, including the recruitment of lay members, as is already the case in some countries, such as Australia. He also argues passionately for strengthening the role of civil society in promoting ethical oversight.

If a wider range of groups is to be actively involved, careful examination of experience and lessons learned will increase their value. Researchers themselves may, however, be poorly skilled for more effective engagement with communities, and not all researchers working in these environments will be sensitive to the needs identified.

Where there is a vacuum in research governance, how might the international community respond?

In complex humanitarian emergencies, it is most likely that there is no local ethical oversight body present and often no capacity available. The short time frame in which research is undertaken may preclude capacity building, such as circumstances in which an urgent health situation analysis is required. If there is to be a surrogate ethical oversight body in such situations, who should take responsibility for establishing it? In refugee situations, UNHCR may act as surrogate authority, as might the UN in situations where a transitional authority, as in East Timor, was in place. However, in most cases no agency has a specific mandate to step in when national structures have collapsed or are non-existent, an issue of particular concern in relation to internally displaced people or marginalized indigenous populations. What then should be the options to provide ethical oversight to research at a time when populations are at the height of their vulnerability?

What lessons may be derived from research with other marginalized groups?

In relation to both HIV-affected and indigenous populations, it has been recognized that the needs of affected communities have not been well served by the practices of many researchers or by standard ethical review procedures (Donovan and Spark 1997, Kaufert and Kaufert 1998, Humphery 2001). In voicing their concerns, indigenous communities have been instrumental in

renegotiating the frameworks and approaches to research. This has led to the development of alternative or supplementary guidelines, which emphasize respect for indigenous understandings of community, acknowledge the vulnerability of indigenous groups due to historical injustice, and demand genuine reciprocity in the research process (Henderson et al. 2002). In some cases this may include rights to intellectual property emerging from the research (Rigney 2001, National Health and Medical Research Council (NHMRC) 2003).

Strong advocacy by and for people with HIV/AIDS has redefined aspects of the interaction with researchers and the ethical bases for ensuring opportunities to benefit from available treatments (Zion 2005). Lessons may also be learned from the ethical challenges inherent in research with prisoners, where voluntary consent is constrained by total dependence on those providing care and services (Kalmbach et al. 2003). Researchers working with conflict-affected communities should study these experiences of community engagement and agency in the research process to determine what transferable or adaptable lessons may be present.

What role can funding bodies play in ensuring more ethical conduct?

Funding bodies have the power to stimulate new relationships among key stakeholders, are able to monitor how interactions proceed, and can ensure that standards of research conduct are appropriate. Most importantly, they can provide the additional funds required to support processes to facilitate consultation, and enable agreement and delivery of key forms of reciprocity to be offered through the research. Whether or not they will rise to this important role, or will find it in conflict with their other priorities and agendas, remains to be seen. We propose that progressive funding bodies explicitly identify and respond to this agenda.

The discussion above highlights a scope for a more empowering research environment, one where those 'researched', or their advocates, take greater control of negotiating the questions, the design, the analysis, interpretation, and communication of results. A more community-led approach is essentially about a redistribution of power, and as such is likely to be resisted by some.

A particular challenge arises when one or another of the stakeholders does not participate or negotiate. Does the project fall apart, move to another area and work with other groups, or is the hand of one party forced to ensure cooperation? Can the entire research project be renegotiated to ensure win-win outcomes for all involved, or is this idealistic fantasy? Callahan and Jennings cite 'critical ethics' in asserting that discussion of ethics and public health policy should be 'genuinely public or civic endeavours'; not the advocacy efforts of a well intentioned elite on behalf of needy clients, but a search for meaningful participation, open deliberation, and civic problem-solving and community building (Callahan and Jennings 2002).

Conclusion

This paper highlights the key stakeholders in research in conflict-affected settings. It outlines the motives, incentives, and relationships that exist, and reflects on some of the challenges of negotiating more ethical research in these environments. Research that frames and seeks to answer important questions is of value: it builds the evidence upon which enhanced policy and practice may be based. Critiquing ourselves should not undermine opportunities to conduct valuable research; but it should challenge all involved to be more explicit, more realistic, and more honest about what can and cannot be done, how, with whom, and to what effect.

Seeking to promote opportunities for greater engagement by all parties and to support the development of a shared values-base ultimately reduces risks to all involved. We reflect on these issues to encourage debate on what better health research might look like in conflict-affected settings. Time, resources, skills, preparation, support, and supervision (in short, appropriate funding) are necessary. Building capacity is valuable. So too is a commitment to ensure that it builds the evidence with which to inform better policy and practice.

The model presented seeks to be a stimulus for further exploration. Are aspects of it unrealistic and unattainable? Perhaps. However, presenting it at an early conceptual stage allows an opportunity for refinement and debate, and prompts deeper thinking about relationships and reciprocity.

Much remains to be done: HRECs must move beyond harm minimization to emphasize the importance of negotiated reciprocal benefit; researchers must justify their projects in terms of their value to conflict-affected communities; participants must help shape the research process and assure benefit; and funding agencies should set new terms and conditions for grant awards so that better practice is promoted.

We welcome reflection and sharing of ethical challenges and responses in research in conflict-affected settings. More fundamental critiques of how research is negotiated and proposals for how this can be done better are of great value in ensuring that those most marginalized will benefit.

‘Vulnerable groups, vulnerable communities, and vulnerable countries will remain passively “in need of protection” until they gain the type of agency . . . that locates organized and active communities at the centre as initiators and managers of their own health’ (Macfarlane et al. 2000, London 2002). Negotiating a range of reciprocal benefits from stakeholders committed to undertaking research will provide one modest, but potentially important, means of gaining visibility and other benefits for communities affected by violence and instability.

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