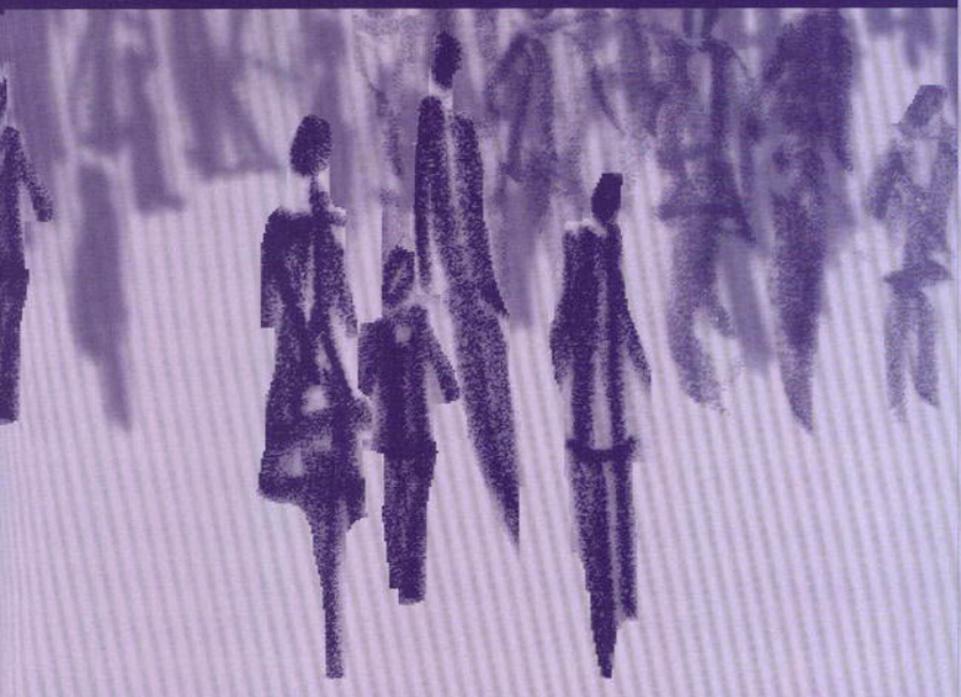


Research Ethics



in Complex Humanitarian Emergencies

SUMMARY OF A WORKSHOP

NATIONAL RESEARCH COUNCIL

Research Ethics in Complex Humanitarian Emergencies

SUMMARY OF A WORKSHOP

Holly Reed, Rapporteur

Roundtable on the Demography of Forced Migration

Committee on Population

National Research Council

NATIONAL ACADEMY PRESS
Washington, DC

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Preface

The Roundtable on the Demography of Forced Migration was established by the Committee on Population of the National Research Council in 1999. The roundtable is composed of experts from academia, government, philanthropy, and international organizations. The roundtable's purpose is to serve as an interdisciplinary, nonpartisan focal point for taking stock of what is known about demographic patterns in refugee situations, to apply this knowledge base to assist both policy makers and relief workers, and to stimulate new directions for innovation and scientific inquiry in this growing field of study. Charles B. Keely of Georgetown University serves as chair of the roundtable, and we thank him for his leadership and guidance of the group's activities.

The roundtable meets yearly and has also organized a series of workshops (held concurrently with roundtable meetings) on some of the specific aspects of the demography of refugee and refugee-like situations, including mortality patterns, demographic assessment techniques, and research ethics in complex humanitarian emergencies. For more information about the roundtable and its activities, please contact Holly Reed, program officer for the Committee on Population (202-334-3167; hreed@nas.edu).

This report to the Roundtable on the Demography of Forced Migration is the summary of one such workshop, which was held on October 18, 2001, under the auspices of the Committee on Population. The purpose of this meeting was to discuss whether it is ethical to do research among displaced populations. Participants explored the moral issues encountered

when conducting research among refugee and internally displaced populations during and in the aftermath of a complex humanitarian emergency. Although many types of research are becoming more common in these settings, specific ethical guidelines for such research do not exist. Research in crisis situations may entail special challenges in terms of ethics, and the workshop attempted to examine some of these challenges.

This project was funded with a grant from the Andrew W. Mellon Foundation. We thank Carolyn Makinson, population program officer at the Mellon Foundation, for her support and enthusiasm for the roundtable's work.

Holly Reed authored the report. Christine Chen handled the arrangements for the workshop and Ana-Maria Ignat managed the manuscript during editing and review. This work was carried out under the general direction of Barney Cohen. We also thank Christine McShane, of the reports office of the Division of Behavioral, Social Sciences, and Education, for editing the report. Any opinions, findings, conclusions or recommendations expressed in this publication are solely those of the individual workshop participants and do not necessarily reflect the view of the organization that provided support for the project nor of the National Research Council (NRC).

This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the Report Review Committee of the National Research Council. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the charge. The review comments and draft manuscript remain confidential to protect the integrity of the process.

We thank the following individuals for their review of this report: Jonathan D. Moreno, Center for Biomedical Ethics, University of Virginia; Anne Petersen, W.K. Kellogg Foundation, Battle Creek, Michigan; and Robert Sprague, Department of Kinesiology, College of Applied Life Studies, University of Illinois (emeritus).

Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the content of the report nor did they see the final draft of the report before its release. The review of this report was overseen by David I. Kertzer, Department of Anthropology, Brown University. Appointed by the National Research

Council, he was responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the author and the institution.

Jane Menken, *Chair*
Committee on Population

Contents

Ethical Approaches	1
The Example of Liberia	3
Ethical Norms	4
Social and Demographic Categories	6
Informed Consent	8
Risks and Benefits	10
Summary and Final Discussion	11
Key Suggestions by Participants	11
Appendix: Workshop Agenda and Participants	13

Research Ethics in Complex Humanitarian Emergencies

Situations involving conflict and forced migration have become increasingly commonplace in today's world. The need to understand the causes, consequences, and characteristics of these situations is creating a burgeoning field of research. But given the nature of complex emergency settings, traditional research guidelines may be inappropriate. The research and policy community has recognized this problem and has begun to address issues surrounding the ethics of doing research in emergency settings and among conflict-affected and displaced populations. The Roundtable on the Demography of Forced Migration, under the aegis of the Committee on Population of the National Research Council, held a workshop to examine some of these issues. This report to the roundtable summarizes the workshop presentations and discussion but does not make any attempt to provide guidelines, conclusions, or recommendations for researchers or policy makers.

ETHICAL APPROACHES

The concept of research ethics is seeping slowly into the world of refugee research. For example, many countries are now requiring research projects among displaced persons to undergo ethical review (e.g., in Uganda and Tanzania). Some of the key questions facing researchers include: What is the ethical imperative of doing research at all? What amount and type of

research are permissible? And what are the ethics of doing research on interventions that are not sustainable after repatriation occurs?

Judith Lichtenberg of the University of Maryland, College Park, began the discussion of the ethical dilemmas that researchers face. One major ethical quandary has to do with the risks and benefits of research. Should an action be judged only by its ultimate effects, or should it be judged by its means and its end? In emergency settings, as in other settings, research may often benefit future populations of refugees but be of little immediate value to the research subjects themselves. Is it ethical to do research when the participants are not the immediate beneficiaries? Philosophically, this is a key issue in the current debate. Some researchers advocate that it is enough for a researcher to simply “do no harm,” while others argue that research must benefit participants or others. But if this is the case, who must the research benefit—individual research participants, the group of refugees at the research site, refugees everywhere? There are many other ethical concerns, including the process of informed consent, the sustainability of research, the security of data used for research, and the question of who owns and profits from the use of data and research.

Workshop participants benefited from a brief presentation by Jonathan Shay of Tufts University Medical School and the Department of Veterans Affairs Outpatient Clinic in Boston, Massachusetts. He addressed two issues; first, in conflict-affected settings, the researcher and the sponsoring organization have a duty to make a safety assessment: Are the research subjects still vulnerable to coercion or retribution? In many such settings, the confidentiality and security of the original research records cannot be ensured, despite the researcher’s good intentions. Second, psychosocial interventions are becoming more widespread in refugee camps, raising awareness of the mental health of refugees. However, the mental health of humanitarian field workers and researchers can be damaged by intense exposure to *both* the physical and psychological consequences of complex humanitarian emergencies. “Secondary” or “vicarious” trauma can damage the research and the researcher. Age, experience, or professional training may not provide adequate protection from secondary trauma. Shay discussed the dangerous phenomenon of “baseline creep,” which can occur when researchers become gradually habituated to and thus fail to protect themselves emotionally from the horrors and risks of working in dangerous settings with research subjects who have experienced atrocities. Both researchers and research subjects can become inured to violence, tending to minimize both its continued probability and its impact. Neither good

intentions nor an overconfident attitude can protect researchers. Without adequate self-care, working in these situations can cause psychological injury to everyone from medical doctors, to social workers, and even to data analysts located at a distance geographically. In Shay's opinion, there is an ethical "duty to warn" both humanitarian field workers and researchers of humanitarian emergencies about secondary trauma and a duty to provide protective resources, such as training in self-care and practices that reduce the frequency and severity of injury from this occupational hazard.

Another important question that participants discussed has to do with what types of activities constitute research. There are many reasons to collect data in an emergency setting (administrative data collection, physician interviews, surveillance, to name a few), but not all of these are considered research. However, they may still involve potential risks and benefits for research subjects, depending on the future use of such data.

The dangerous and extreme circumstances that accompany conflict and forced migration can make it very difficult to conduct ethical research. For example, W. Courtland Robinson of Johns Hopkins University recalled a situation in which ethnic Karen public health workers crossed the Thai border in Burma accompanied by armed insurgents as security guards in order to conduct public health surveys. Can one ethically make use of the data they collected? Many nongovernmental organizations (NGOs) collect program data that are meant to be internal, but are later used by researchers; is it ethical to use these found data? If they are individual case notes, is the answer different than if they are macro-level data? Also, it may not be known whether or not the data were collected in an ethical manner. All of these issues are real dilemmas in the field when data are precious but may be fraught with ethical concerns.

THE EXAMPLE OF LIBERIA

The general ethical principles may be the same in every emergency, but there are specific ethical challenges that researchers encounter in each setting. Participants heard a case study on the ethics of research and humanitarian practice in Liberia presented by Richard Black of the University of Sussex. This example focused on the development of ethical codes for humanitarian action and sought to draw lessons applicable to ethical codes for research in similar situations.

As Black explained, in Liberia, two humanitarian codes of conduct were developed during the emergency: the Principles and Protocols for

Humanitarian Operations (PPHO), which was a United Nations (UN) initiative, and the Joint Plan of Operations (JPO), which was initiated by the NGOs. The PPHO was focused on such issues as impartiality, neutrality, independence, informed consent, and the targeting of aid, because of a concern that aid was sustaining or legitimizing armed factions. The JPO was instituted after the April 1996 looting of aid and ransacking of NGO offices by armed factions; its focus was on minimum targeted lifesaving activities (MTLA).

The ethical codes tended to place limits on research and operations in Liberia, but Black argued that the very process of establishing codes was useful because it created a dialogue between donors and agencies about ethics. Yet even in this case there was poor coordination among agencies (six separate studies were commissioned to review the Liberian experience), so clearly even more discussion and harmonization are needed in the future. Redundancy and overlap are a common problem in emergency settings; there is a continuing accumulation of similar studies without any coordination among the research teams. Then if their findings are contradictory, it is unclear what the policy implications may be. Is it ethical to reapproach the same population to collect similar data if prior data remains unused?

ETHICAL NORMS

Perhaps one place to start to understand research ethics is to examine the ethics codes for biomedical research, including the Declaration of Helsinki of the World Medical Association (Helsinki), the reports of the National Bioethics Advisory Commission (NBAC), and the proceedings of the Council for International Organizations of Medical Sciences (CIOMS). Kate MacQueen of Family Health International reviewed some basic tenets of these guidelines. All of these documents support the principles of respect for human beings and informed consent, beneficence (i.e., do no harm), and justice and the “fair” distribution of risks and benefits. Currently a lot of debate surrounds biomedical research ethics in the context of global and local inequities in access to medical care and preventive services. Access appears to be inversely related to need, and there are concerns that profit (rather than health goals) is driving biomedical research—particularly clinical trials—in developing countries and among vulnerable populations.

MacQueen noted that the type of research that was the focus of the workshop actually falls outside this realm; in most refugee settings, research

involves nonexperimental studies. Public health surveillance and outbreak investigations during the emergency phase are generally not considered to be research *per se*, but program evaluations, surveys, and observational research that occur in these settings are. For the public health researcher who is also a medical doctor, there may be many questions about ethical obligations. For example, is there an obligation to treat an ill research subject even if there is no access to care for the general population or there are great inequities in access to care? Or is a researcher obligated to disclose a health condition to a participant if the participant does not want to know or if no treatment is available locally (e.g., HIV/AIDS)?

Addressing these situations requires careful thought about consequences. The biomedical community has a common basis for ethical debate in its ethics codes. Participants were reminded by a presentation by William Seltzer of Fordham University on social science ethics codes, however, that the social sciences include a wide variety of disciplines (demography, economics, sociology, political science, etc.). Social scientists, unlike physicians, for example, are generally not licensed or legally regulated by a government. Ethical sanctions in the field of the social sciences are generally left to professional institutional review boards (IRBs), funding agencies, or professional societies. Although threats and risks can be thought of as either invasive or passive (merely gathering information), social science research may be more invasive than researchers think, especially in emergency settings.

Institutional review boards need to develop a different process for thinking about research ethics in refugee settings. Felice Levine of the American Sociological Association described various types of humanitarian emergencies—including natural disasters and state-sponsored, political oppression—and the range of harms, benefits, and risks associated with them. In each of these settings, the physical, political, and legal consequences for research participants may be more dangerous than in most research; the full range and types of risks may not be known; and the benefits may involve lowering the probability of harm for persons who have already been subjected to harm and are at great risk of further harm. Given these unique circumstances, IRBs and investigators should consider decision strategies for addressing ethical issues that are different from those used in “normal” settings. This is necessary because the legal recourse usually afforded research participants in other settings may be virtually nonexistent, despite the fact that many researchers are still bound by the ethical codes and laws of their home countries and institutions. Current ethical codes and guide-

lines, however, do not readily translate to research in challenging situations that are rapidly changing.

The circumstances of humanitarian emergencies essentially require a more flexible, dynamic process than is typical, Levine emphasized. New approaches could help to advance essential research done ethically and responsibly. Perhaps, in refugee settings, adjunctive mechanisms could be devised to address unanticipated ethical decisions or dilemmas as they present themselves. For example, peer advisory panels could be comprised of experts with social, cultural, political, or historical perspectives as well as local representatives or others with community knowledge, including local researchers. Such groups could provide advice and feedback to investigators regarding unanticipated ethical concerns as they arise in the field. The IRB role would be to evaluate protocols to ensure that investigators anticipate different types of events and unforeseen circumstances and have sufficient plans in place for protecting participants. IRBs would do their review aware that on-site panels can be drawn on in refugee settings to provide timely ethical guidance.

Also, as Ronald Waldman at Columbia University pointed out, group benefits and risks need to be carefully thought out before implementation of group or social consent as an alternative to individual consent. In all of these situations, the social context is rapidly changing, so researchers need to outline the types of emergencies and their potential ethical challenges beforehand. They need to indicate the range of types of research that are possible and the unique risks and benefits of research in each setting. NGOs and others need help and guidance on these issues.

SOCIAL AND DEMOGRAPHIC CATEGORIES

One key component of social science research has to do with social and demographic categorization. Workshop participants listened to a presentation by Ruth Krulfeld of George Washington University about social categories and anthropological work among refugees. Social categories are often culturally determined, so finding the right recipients for aid depends on who determines vulnerability. The local population can be quite helpful in this process if they are not dismissed by researchers as “powerless” or victimized.

It is also important to recognize that definitions of harm vary from culture to culture, Krulfeld argued. For example, some Western researchers in Afghanistan thought of women being forced to wear a full veil as a

human rights abuse, but many Afghan women themselves did not. There can be great tension between cultural relativism and the universality of norms assumed by international human rights law. Ethics can help researchers to navigate this tension. Human rights codes are also a guide that can be used. The judgment of some researchers is that research can become more ethical by including the research subjects in the research process through the use of anthropological methods such as participant observation and focus groups. When researchers talked with the Afghan women about which of their rights they felt were being abused, they found them to be much more concerned about the lack of schooling for girls than the enforcement of veil wearing.

According to Krulfeld, including refugees as partners can often help to present or resolve ethical dilemmas. Understanding the community's cultural context also helps researchers to think about their role as benefactors in and risks to the community. Are local field staff treated equitably? Are they in danger because of their employment? What happens to the research when the expatriate researchers leave? Understanding the societal structure and relationships among groups can help researchers to avoid placing themselves or their local field staff in danger.

Children, due to their age and lack of societal influence, may be in a particularly vulnerable position in emergency settings. Kirk Felsman of Duke University discussed experiences conducting research with refugee children. With children, the first ethical question concerns the age at which one is no longer considered a child. This definition varies greatly among international conventions, researchers, aid agencies, communities, and children themselves. But it is important because it affects how and among whom research is conducted. Nevertheless, child refugees—just like other refugees—need to be able to tell their story for a variety of reasons. However, many potential risks are involved in this process when working with children. Children are of utmost concern to a variety of groups and therefore are subject to numerous possible abuses and exploitation. They may be put through multiple interviews, possibly with untrained or inexperienced interviewers. The interviews may not be private or confidential if parents or other relatives are involved. But researchers and ethical guidelines may differ about whether or not children can give their own informed consent, and their cognitive capacity to consent may also depend on a range of factors, including intellect, emotional maturity, and the degree of parental involvement or interference.

In addition, Felsman emphasized that many ethical implications sur-

round the issues of large databases and other materials (i.e., poems, drawings) collected from child refugees. For example, hard copy data collected from children in Sudan was moved a total of eight times between 1987 and 1996 and handled by multiple agencies. This created matching problems, lost data, and damaged data; this is not an uncommon occurrence. Because researchers have an ethical obligation to protect and secure their data archives, should research be conducted if security is an impossibility? Although family tracing databases for lost children (like the ones set up by the Red Cross) are meant for program purposes, they have research potential. But the ownership of the data is sometimes unclear; does it belong to the refugees or to the agency? Also, the identification of certain children as vulnerable can be harmful as well as helpful; it may cause tensions in a community.

Although it is important to recognize different cultural norms, Susan Martin of Georgetown University argued that cultural relativism can actually prevent agencies from defining people as refugees in order to protect and aid them. For example, if female genital mutilation is accepted as a cultural difference rather than a human rights abuse, then women who experience it may not be able to apply for protection under refugee status or asylum laws.

All of these problems are complex, but simple frameworks can help researchers to find solutions. Paula Reed Lynch of the U.S. Department of State listed four mantras for working in complex humanitarian emergencies. First, use local resources. Second, use global resources. Third, learn from previous research and program experiences. And fourth, you cannot easily change directions when a program has already begun. For example, if a feeding program has begun by giving food to men but discovers that it is better to give the food to women, it may be difficult to change the established routine. Therefore, research must be built into a program from the beginning, and programs must build on knowledge gained from research in previous emergencies.

INFORMED CONSENT

To set the stage for a discussion of informed consent, Phillip Nieburg of the Centers for Disease Control and Prevention considered the different stages of an emergency as a sort of continuum of development. What one

really should be asking is: What kind of consent is necessary and feasible for different types of emergencies, at different stages and for different types of data collection or research? Informed consent needs to be seen as an ongoing process, not just a one-time event.

Nieburg noted that explicit consent is not necessary in surveillance or outbreak investigations. However, what about once a refugee camp is more established? Are refugee camps like institutions, since individuals lack autonomy? If so, then informed consent cannot create autonomy. But it is possible that there could be a waiver of consent granted by an IRB in a minimal risk situation. Or perhaps group consent or another form of surrogate consent could be implemented. However, this avenue may not recognize individual rights.

Individuals may want to opt out of research, but Nieburg argued that they might be just as likely to want to participate in it even if the community does not because there are benefits as well as risks to research. Yet the concept of individual consent may be misunderstood, particularly in chaotic settings. If “social trust” is destroyed, then what kind of informed consent are refugees truly capable of giving? Either because of cynicism or dependence, true informed consent may be impossible to obtain.

Many participants argued against the idea of consent waivers or the possibility of “triaging” research, stating that it could easily slip into human rights abuses by unethical practitioners. As Ron Bayer of Columbia University argued, protection has to take precedence over strict consent procedures in some cases. In a study of illegal North Korean migrants in China, only oral consent was obtained because of concern for the migrants’ security.

Despite the fact that informed consent may be more difficult to obtain in refugee camps, Richard Black of the University of Sussex advocated that it should not be abandoned even for research other than public health research. Social science research, such as studies of food distribution or livelihood strategies, can still be important in the postemergency phase and in fact helps communities to recover, because it is a normalizing activity. Ultimately, participants conceded that the informed consent model might be waived during the acute emergency phase for public data collection activities (surveillance, outbreak investigations), but only for a short period of time. Note that public health surveillance and outbreak investigations in the United States do not require informed consent procedures.

RISKS AND BENEFITS

In an extreme emergency situation, is there any type of research that is ethical? For example, one might contemplate testing new therapeutic feeding programs on severely malnourished children. In other words, that would be the equivalent of a clinical trial, but without informed consent. Does the possibility of reducing mortality among those children or among children in future emergencies justify research without informed consent?

Participants differed on this point. Ronald Waldman of Columbia University argued that most important in this setting is to perform triage. Triage allows some people to come to harm in an emergency because they require too many resources from a pool that is limited. The harm is already done and there are no good outcomes, but the focus must be on saving those who can be saved. Without testing the outcomes of a potential new therapy in an actual emergency situation, it is impossible to improve practices in order to limit the damage in future situations. Research is necessary. Of course, it must be carefully thought out and as much as possible should be done following the emergency phase, but research should be promoted to improve public health and perhaps other lifesaving practices (e.g., protection).

On the other side of the debate, Jennifer Leaning of Harvard University initially thought that no research could pass ethical muster for the emergency phase, but she now considers that it is possible that there are a few situations (such as the example of testing new therapies for malnourished children) that can be done in the acute emergency phase. Yet in practice it is very dangerous. There are a variety of issues surrounding informed consent and human rights that make it risky. For example, refugees are especially vulnerable because they are not completely protected by host country law and local culture and are essentially powerless and dependent on others for protection and care. Ethical codes may not be sufficient to protect populations in these straits. In addition, refugees must be treated with the utmost regard for their autonomy and human rights, so informed consent is essential. But it is likely to be impossible in many settings. A protective voice is needed which includes members of the affected community if possible, or at least individuals who are familiar with the culture and population—such as the advisory review panel suggested by Felice Levine (see below). Some researchers argue that research should be limited in all phases of emergencies. If research is deemed to be essential, then the refugees' capacity to give informed consent must first be taken into account.

This discussion highlighted why understanding the stages and phases of emergencies is crucial. However, the phases are not always clear, stable, or progressive. Most importantly, the capacity of the population to give informed consent for and participate in research must be carefully analyzed before any research is done.

SUMMARY AND FINAL DISCUSSION

The dialogue at the workshop barely grazed the myriad ethical issues surrounding research among displaced and conflict-affected populations. Participants agreed that a great deal of discussion is needed. There are several ongoing projects on research ethics in emergencies at the World Health Organization, the Harvard School of Public Health, and the American Public Health Association, among others. Given that ethics questions differ depending on the type of emergency, the development of a comprehensive taxonomy of types of complex humanitarian emergencies would be useful. Researchers, policy makers, NGOs, and international agencies must be careful to think about the ethical implications of their actions and continue to discuss and debate these questions both within and outside the field.

KEY SUGGESTIONS BY PARTICIPANTS

- Warn both humanitarian field workers and researchers in humanitarian emergencies about secondary trauma and provide protective resources, such as training in self-care and practices that reduce secondary trauma and its effects (Shay).
- The very process of establishing ethical codes can be useful because it creates a dialogue between donors and agencies about ethics (Black).
- Institutional review boards need help with thinking about research ethics in refugee settings; peer advisory panels could be comprised of experts with social, cultural, political, or historical perspectives as well as local representatives or others with community knowledge, including local researchers. These panels could provide advice and feedback to investigators regarding unanticipated ethical dilemmas in the field (Levine).
- Researchers should outline types of emergencies and their potential ethical challenges before beginning research, indicating the range of types of research that are possible and the unique risks and benefits of research in each setting (Waldman).

- The use of anthropological methods, such as participant observation and focus groups that include the research participants in the research process can help research become more ethical and prevent researchers and local field staff from placing themselves in dangerous situations (Krulfeld).
- Build research into a program from the beginning and build on knowledge gained from research in previous emergencies when designing programs (Lynch).
- Informed consent should be an ongoing and reflexive process, not just a one-time event (Nieburg).
- Protection of refugees must take precedence over strict consent procedures in some cases (Bayer).
- “Triaging” research in emergencies under some circumstances is needed; by testing the outcomes of a potential new therapy or procedure in an actual emergency situation, it may be possible to improve public health or protection practices in order to limit damage in future situations (Waldman).

Appendix

Workshop Agenda and Participants

October 18, 2001

AGENDA

Welcome and Introductions

Barney Cohen, National Research Council
Charles Keely (*Chair*), Georgetown University

Session 1: Ethical Approaches to Research in Emergencies

Presenter: Judith Lichtenberg, University of Maryland
Comments: Jonathan Shay, Tufts University and Department of
Veterans Affairs Outpatient Clinic, Boston

Session 2: Research Ethics in Practice: Case Study of Liberia

Presenter: Richard Black, University of Sussex
Comments: Frederick Ahearn, Catholic University of America

Session 3: Issues Related to Ethical Norms in Biomedical and Social Research

Biomedical Sciences: Kate MacQueen, Family Health International
Social Sciences: William Seltzer, Fordham University
Comments: Felice Levine, American Sociological Association

Session 4: Social & Demographic Categories in Research in Emergencies
 Race, Ethnicity, and Gender: Ruth Krulfeld, George Washington
 University

Children: Kirk Felsman, Duke University

Session 5: Informed Consent Issues for Conflict-Affected Populations
 Presenter: Phillip Nieburg, Centers for Disease Control and
 Prevention

Comments: Ron Bayer, Columbia University

Session 6: Potential Long- and Short-Term Risks and Benefits of Research
 in Emergencies

Presenter: Ronald Waldman, Columbia University

Presenter: Jennifer Leaning, Harvard University

Final Discussion and Wrap-up

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