# Mental Health and Psychosocial Support in Crisis and Conflict: Report of the Mental Health Working Group

K. Allden, MD;[1] L. Jones, OBE, MRCPsych;[2] I. Weissbecker, PhD, MPH;[3] M. Wessells, PhD;[4]
P. Bolton, MBBS, MPH;[5] T.S. Betancourt, ScD, MA;[3] Z. Hijazi;[6] A. Galappatti, MSc;[7]
R. Yamout, MD, MPH;[8] P. Patel;[9] A. Sumathipala, MD, PhD, MBBS[10]

1. Department of Psychiatry, Dartmouth Medical School, Hanover, New Hampshire USA
2. International Medical Corps and Developmental Psychiatry Section, Cambridge University, UK
3. Harvard School of Public Health, Boston, Massachusetts USA
4. Columbia University, New York, New York USA
5. Center for Refugee and Disaster Response, Johns Hopkins Bloomberg School of Public Health, Baltimore, Maryland USA
6. International Medical Corps, Middle East Programs
7. Department of Social Anthropology, University of Edinburgh and the Institute for International Health and Development, Queen Margaret University, Edinburgh, UK
8. Faculty of Health Sciences, American University of Beirut, Beirut, Lebanon
9. Northeastern University School of Law/Tufts University School of Medicine, Boston, Massachusetts USA
10. Institute of Psychiatry Kings College, University of London, London, UK

Correspondence:
  Kathleen Allden, MD
  Health Care and Rehabilitation Services
  49 School Street
  Hartford, Vermont 05049 USA
  E-mail: kathleen.allden@dartmouth.edu

## Abstract

**Introduction:** The Working Group on Mental Health and Psychosocial Support was convened as part of the 2009 Harvard Humanitarian Action Summit. The Working Group chose to focus on ethical issues in mental health and psychosocial research and programming in humanitarian settings. The Working Group built on previous work and recommendations, such as the *Inter-Agency Standing Committee's Guidelines on Mental Health and Psychosocial Support in Emergency Settings*.

**Objectives:** The objective of this working group was to address one of the factors contributing to the deficiency of research and the need to develop the evidence base on mental health and psychosocial support interventions during complex emergencies by proposing ethical research guidelines. Outcomes research is vital for effective program development in emergency settings, but to date, no comprehensive ethical guidelines exist for guiding such research efforts.

**Methods:** Working Group members conducted literature reviews which included peer-reviewed publications, agency reports, and relevant guidelines on the following topics: general ethical principles in research, cross-cultural issues, research in resource-poor countries, and specific populations such as trauma and torture survivors, refugees, minorities, children and youth, and the mentally ill. Working Group members also shared key points regarding ethical issues encountered in their own research and fieldwork.

**Results:** The group adapted a broad definition of the term "research", which encompasses needs assessments and data gathering, as well as monitoring and evaluation. The guidelines are conceptualized as applying to formal and informal processes of assessment and evaluation in which researchers as well as most service providers engage. The group reached consensus that it would be unethical not to conduct research and evaluate outcomes of mental health and psychosocial interventions in emergency settings, given that there currently is very little good evidence base for such interventions. Overarching themes and issues generated by the group for further study and articulation included: purpose and benefits of research, issues of validity, neutrality, risk, subject selection and participation, confidentiality, consent, and dissemination of results.

**Conclusions:** The group outlined several key topics and recommendations that address ethical issues in conducting mental health and psychosocial research in humanitarian settings. The group views this set of recommendations as a living document to be further developed and refined based on input from colleagues representing different regions of the globe with an emphasis on input from colleagues from low-resource countries.

*Poverty is not being able to read and write while others write about you.*

-Author unknown

## Background
### Working Group Formation
The addition of the Working Group on Mental Health and Psychosocial Support at the 2009 Humanitarian Action Summit began with recognition by the Summit organizers of a need to address issues of mental health and psychosocial support in crisis settings. The two co-chairs were approached and, on acceptance, charged with the task of assembling a Working Group and setting an agenda based on current need. The mandate of the group was to:

1. Identify new and persistent field or policy-level challenges to humanitarian response, focusing on persistent, ongoing, unsolved problems;
2. Provide specific work products to advance policy and/or best practices;
3. Provide leadership-track professionals an opportunity to present original work; and
4. Improve collaboration between operational and multilateral agencies, research institutions, and donor agencies.

From the mandate, the Working Group chose to focus particularly on the issues of ongoing, unresolved problems, improving collaboration, and to produce a product that advances best practices. To facilitate collaboration of Working Group members from various geographic locations, Summit leaders provided the Working Group access to "Basecamp", an online forum to share messages, submit documents and written work products, and coordinate group work.

### Membership
The initial Working Group membership was drawn from personal connections and recommendations of the co-chairs, and included colleagues working in the field, as well as published authors. The group also received direct requests from individuals to join. The group aimed to form a geographically diverse group that included known and published writers in the field and younger unpublished humanitarian workers with pertinent experience, particularly from low income settings. Unfortunately, there were major constraints to membership. These included: (1) time; (2) online access to e-mail and the Basecamp forum; and (3) language barriers created by English-based communications. Furthermore, the representation of Working Group members at the Harvard Humanitarian Action Summit in March of 2009 was constrained by the absence of travel funds, which resulted in little representation of colleagues from the developing world. The Working Group is planning to integrate input from colleagues representing more diverse geographical regions and low-resource settings as the group moves forward after completion of the Summit.

## Previous Process
### Existing Guidelines
In setting an agenda, the Working Group built on previous work and recommendations, such as the *IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings*.[1] The Interagency Standing Committee (IASC) was created by the UN General Assembly Resolution 48/57 and consists of the heads of UN agencies (OCHA, UNFPA, UNHCR, UNICEF, WFP, UNICEF, WHO), the World Bank, the Red Cross Movement (IFRC and ICRC), and three large NGO consortia covering hundreds of international NGOs (e.g., Interaction, ICVA, and SCHR). Between 2004 and 2007, an IASC Mental Health and Psychosocial Support in a Emergency Settings Task Force of 28 member agencies began a three-year process to write guidelines for mental health and psychosocial support in emergency settings. Global consultation took place in four languages (English, French, Spanish, Arabic) and the Guidelines were published in September 2007. In total, the IASC Guidelines provide a "multi-sectoral, interagency framework that enables effective coordination, identifies useful practices and flags potentially harmful practices, and clarifies how different approaches to mental health and psychosocial support complement one another".[1] Developing best practices and guidelines continues to be an ongoing process through an IASC reference committee. The group decided that whatever focus would be adopted should be in consultation with the IASC group. Despite these important new guidelines, however, there is a general consensus among practitioners and scholars in the field of humanitarian assistance, that currently, there is an absence of a solid evidence base for mental health and psychosocial support interventions in emergency settings and an absence of ethical guidelines for conducting such research.[2]

### Initial Goals
Based on the experience and expertise of individual group members and consultation with the group that created the *IASC Guidelines Mental Health and Psychosocial Support in Emergency Settings*, the Working Group established seven initial goals:

*Goal 1—Build on the IASC Guidelines on Mental Health and Psychosocial Support (MHPSS) in Emergency Settings*. Complement the activities of the IASC Reference Committee by focusing on issues that are not covered and liaise with the Reference Committee for ongoing work.

*Goal 2*—Address the gap between emergency MHPSS and community mental health in the developing world. Adapt lessons learned in the developing world to complex emergencies and provide a forum to bridge the gap in between research and services in both areas.

*Goal 3*—Address the gap between emergency MHPSS and post-disaster/post-conflict community mental health. Examine best methods for transitioning psychosocial programs from short term emergency interventions to longer term development programs.

*Goal 4*—Address the deficiency of evidence-based research on MHPSS interventions during complex emergencies by proposing ethical research guidelines. Outcomes research is vital for effective program development but, to date, no

comprehensive ethical guidelines exist for guiding such research efforts.

*Goal 5*—Devise concrete methods to address the absence of an evidence base to aid providers of mental health and psychosocial programs in moving forward with rational plans for intervention.

*Goal 6*—Propose guidelines for training mental health and psychosocial emergency practitioners to address the current absence of formal guidelines, core competencies, and standardized curricula.

*Goal 7*—Utilize future leaders. Young academics and practitioners can contribute to innovative strategies for program development, research, and training.

*Focus on Ethical Guidelines*
The Working Group decided to focus primarily on Goal 4 and to propose ethical guidelines with the aim of addressing one of the reasons for the deficiency of evidence-based MHPSS research in emergency settings, which also connects to the other goals. The resulting deliverable product would contribute to addressing the gap between low-resource and emergency settings (Goals 2 and 3). Additionally, focusing on ethical frameworks can inform training curricula and engage future leaders in the field, as well as complement the work of other Working Groups, who are addressing the process of data collection in the field, but who have not discussed ethics.

## Objectives and Rationale

Ethical guidelines have the potential to address several unresolved issues that can act as barriers to conducting MHPSS research in humanitarian settings. First, although ethical guidelines and frameworks for the provision of services exist (Sphere/IASC Guidelines), there is little guidance on how to conduct ethical research in face of the need to develop an evidence base on effective interventions in emergencies. Such evidence is urgently needed to inform best practices in the field and to prevent harm. It has been noted that some mental health interventions that have been applied in the past, have proven to be damaging and unethical. This is the case for "single incident debriefing" for example, for which a mostly negative evidence base has emerged.[3] Second, standard research methods often are difficult to apply in humanitarian settings.[2,4,5] Researchers often sample from mobile and fragmented populations that can move before research is completed. Weather-related events or ongoing conflict and insecurity can make access to specific populations difficult if not dangerous. Furthermore, local humanitarian responder staff may have limited capacity to assist with research and evaluation projects. Third, donor and research institution attitudes have been a barrier. There is a donor-created divide between short- and long-term response, which also results in a divide between those working in a "development" context and an "emergency" context. The funding of research in humanitarian settings usually is constrained by short timeframes set by donors. Donors also may prioritize service provision while not being willing to fund research and evaluation

efforts. On the other hand, agencies that fund research may have a limited understanding of the emergency context. Finally, Institutional Review Boards (IRBs) often are not knowledgeable about field situations, and complexities of emergency situations including security threats and different cultures.[6,7] The legal protection of their institution can be seen as a priority over the needs of the human subjects involved in the research. Local IRBs often are not operational in many emergency settings or may approve of research because it is believed that such research may have advantages for their university or institution.[8]

Previous authors[6,9,10] have suggested ethical guidelines for conducting research in international, refugee, or low-resource settings. However, authors have not specifically addressed the ethical conduct of mental health and psychosocial support research in emergency settings.

## Methods

In order to gather background information and identify relevant issues regarding ethics of research in emergency settings, Working Group members conducted literature reviews and listed ethical concerns encountered in their own work. Each Working Group member reviewed different bodies of literature and subsequently generated annotated bibliographies. It should be noted that, due to time constraints, these were not systematic or comprehensive reviews. The Working Group welcomes pointers to additional key sources. The literature reviewed included peer-reviewed publications, agency reports, and relevant guidelines. Topics reviewed included general ethical principles in research, cross-cultural issues, conducting research in resource-poor countries, as well as working with specific populations such as trauma and torture survivors, refugees, minorities, children and youth, and the mentally ill. The Working Group members also shared lists of ethical issues encountered in their own research and fieldwork. The group scheduled bimonthly conference calls to coordinate the completion of tasks and to further discuss relevant issues.

## Findings, Conclusions, and Recommendations
*Historical Timeline of Ethical Considerations in Human Subjects Research*
A review of historical literature on human subjects research ethics resulted in a compilation of the following events as starting-point considerations for the Working Group's expansion into mental health and psychosocial support research in emergency settings, beginning with the Hippocratic Oath's mandate: "I will keep them [the sick] from harm and injustice. …I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect…"[11]

Specifically for the last century, the 1947 *Nuremberg Code* addressed the ethics of human subjects research. The Code was drafted by American judges at the Nuremberg Trials while assisted by three physicians, who merged the Hippocratic Oath and protection of human rights into one code. After deeming the Oath insufficient to protect subjects in medical experiments, they drafted 10 principles on research subjects, highlighting: (1) comprehensive, absolute informed consent of the subjects; and (2) the subject's right

to end the experiment. The Code aimed to prevent subordination of subject's rights to the researcher's will while retaining a view of physician/researcher beneficence (Shuster, 1998). The *Universal Declaration of Human Rights* later similarly stated: "No one shall be subjected to cruel, inhuman, or degrading treatment or punishment."[12]

The next important development in ethical research came with the *Helsinki Declaration* (amended in 1975, 1983, and 1989), a policy declaration on the ethics of human subjects research directed at clinical and non-clinical physician research. It comprises 31 principles aimed at "the duty of the [scientifically qualified] physician to promote and safeguard the health of the people," while prioritizing human subject well-being over scientific and societal interests (i.e., risks cannot outweigh benefits) and requiring informed consent.[13]

The 1974–1977 controversy surrounding the *Belmont Report* by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research directly resulted from public disclosure of the *Tuskegee Syphilis Study*: a 40-year US government denial of available treatment (and obstruction of efforts to obtain treatment) in order to study syphilis progression in 400 African-American men in rural Alabama. The report highlights three principles: (1) informed consent; (2) beneficence (with risk-benefit analysis for every protocol); and (3) justice requiring fairness in the selection of subjects.[14]

In the last 30 years, US ethics on human subject research has centered primarily around the *Common Rule* (proposed in 1986, codified in 1991), drafted by US Presidents' Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1980–1983). The Common Rule applies to human subjects research conducted by the US federal government or those receiving federal funding, and instructs IRBs on requirements for reviewing proposed research and highlights vulnerable groups whose ability to give informed consent is compromised (fetuses, *in vitro* embryos, pregnant women, prisoners, and children, but not the mentally ill).[14] The Common Rule was amended in 1999 because the original failed to address "voluntariness" or implications of "diminished capacity", instead only requiring that incompetent subjects have adequate third-party representation to safeguard their interests. The amendment, "*Research Involving Individuals with Questionable Capacity to Consent*," added considerations for work with individuals of diminished capacity, including the mentally ill.[15]

Most recently, the *International Ethical Guidelines for Biomedical Research Involving Human Subjects*, by the Council for International Organizations of Medical Sciences (CIOMS), updated their 1982 and 1993 guidelines. The CIOMS, founded under auspices of the WHO and UNESCO, issued 21 guidelines with commentaries based on ethical principles defined in the Helsinki Declaration. The guidelines help define national policies on biomedical research ethics, application of ethical standards in local circumstances, and establishment or redefinition of ethical review mechanisms for human subjects research. The 2002 edition aimed to reflect conditions and needs of low-resource countries, raise implications for multi-national guidelines, and

address new issues raised by HIV/AIDS clinical control trials in the 1990s (trials carried out by investigators in low-resource countries through external sponsors). The guidelines focus on: (1) respect for autonomy; and (2) protection of dependent or vulnerable persons and populations, while presuming respect for human rights of subjects and researchers.[16]

Using the lessons and language of these events and the reviewed literature as a starting-point, the Working Group set about identifying key themes and issues for discussion at the Summit. Of paramount concern was the need to apply accepted ethical principles in human subjects research to the unique environment of emergency settings.

### Key Definitions and Consensus
#### Definition of Research
*Research* has been defined by the US Federal Guidelines as "a systematic investigation, including research development, testing, and evaluation, designed to develop or contribute to generalizable knowledge".[15] Most actors conducting MHPSS interventions are engaged in prior assessments and continuing monitoring and evaluation, which may not fall under the umbrella of "research". Therefore, they may not be subject to IRB approval. As the results often are used only for internal or donor consumption, NGOs providing services and assessing outcomes may not view themselves as "researchers". Yet, the activities in which they engage raise the same ethical questions. Therefore, the group wished to clarify that these proposed ethical guidelines also should be viewed as applying to these *formal and informal processes of assessment and evaluation in which most service providers engage.*

#### Definition of an Emergency
The Working Group decided to adapt the UN Office for the Coordination of Humanitarian Affairs (OCHA) definition of a *complex emergency*. According to the OCHA definition, a *complex emergency* is characterized by extensive violence and loss of life, massive displacement of people, widespread damage to societies and economies, the need for large-scale, multi-faceted humanitarian assistance, as well as obstructions to such assistance by political and military constraints including security risks for the relief workers themselves.[17] The shorthand of "emergency" will be used throughout this article.

### Consensus: The absence of relevant research on mental health and psychosocial support in emergency settings is unethical.

Currently, research must be approved by IRBs that review study design and methods to ensure the safeguarding of ethical principles. The underlying assumption appears to be that the default position of no research being done is the ethical one, and that those wishing to conduct research must provide an ethical justification. This is not surprising given some of the abuses cited above. However, given that specific past mental health and psychosocial interventions have had negative effects, the Working Group has challenged this assumption, noting that service provision without a proper evaluation component is unethical. Therefore, the Working Group agreed on the principle that *the absence of relevant research on mental health and psychosocial support in emergency settings is unethical.* The word "rel-

evant" refers to the notion that research should be based on the existing evidence base of best practices for the intervention, as well as on culturally relevant assessment methods. Interventions that have not empirically proven effective in other settings should not be "tried out" in humanitarian settings; service provision should be based on existing data. At the same time, the collection of data and evaluation of services should be built into programming efforts and service provision.

The Working Group reached agreement on the point that research in humanitarian settings should not be conducted without benefit to the community being studied.[6,18] Therefore, the Working Group reached consensus on the principle that *conducting research without ensuring appropriate services available to those researched also is unethical.* These positions can be summed up in the statement "no survey without service and no service without survey." (The word *survey* is meant to refer to research in general). A shorter version of this statement is attributed to Archibald Cochrane of the Welsh National School of Medicine, who taught it to his students, including a medical school instructor of one of the Working Group members (PB). This constitutes a departure from the default position that research cannot be conducted in emergencies.

### Key Themes and Issues
The Working Group discussed overarching themes and issues that arose during literature reviews and summaries of field experiences. From these reviews and discussions, the group generated 10 different, interconnected topics for further study and articulation: research purpose and benefits, validity, neutrality, risk, subject selection and participation, confidentiality, consent, and dissemination. The preliminary discussions around most of these themes are elaborated further below. During the course of the conference, the Working Group generated several preliminary recommendations, which begin to address these key issues. However these recommendations are a work in progress and should be seen as a stimulus to further discussion.

### Purpose and Benefits
An important question to consider is what the primary purpose of the research is and who will benefit.[19] Research may be useful to the subjects, the researchers, or the wider community that is being studied. In the experience of the Working Group, the research often is useful primarily to the researcher who is designing the study, with possible implications for general theory and practice. Ideally, there should be some benefit to the research subjects being studied.[19] However, in emergency situations, researchers must consider the realities that mobile populations may not benefit directly from the eventual results of the research. Often, it is a challenge to give back data or implement programs in the community after the research is completed. Analyzing results can take a long time, and it is difficult to conduct research that can benefit those suffering in the here-and-now. Furthermore, subjects may participate because they hope for a potential benefit, even if the researcher communicates that no direct benefit can be expected.[20] It can be argued that there may be potential benefits to subjects from participating, such as occupying their time, a sense of being

heard, as well as finding meaning in knowing the research may benefit others in the future.[9,21] An important question is whether those benefits are sufficient to justify the research. Some initiatives (e.g., the Psychosocial Working Group that the Mellon Foundation had convened) have taken a position asserting that there should be no research without aid. Local needs and priorities also should be considered.

*Recommendations*—Researchers should consider the following when assessing the purpose and benefits of their research:
1. Research should provide a benefit to the local population;
2. If the primary purpose is to assist those being studied, research should:
   a. address important unknowns that affect the nature of humanitarian assistance (program design and planning); and
   b. evaluate benefits/risks of interventions when these are also unknown;
3. Research also may facilitate progress in the field of humanitarian assistance (i.e., improved services after future disasters); and
4. There should be a generalizable benefit, if possible.

If the research is determined to be of *no* benefit to the local population, then it should not be carried out.

### Validity
The issue of validity is particularly salient when working in diverse cultural settings.[5,22] Which methods are being used and how validity is assessed and by whom must be considered. Measures that have been developed in Western settings are often inappropriate for use among different cultures and settings. The Working Group has pointed out that mere translation and back translation of instruments into the local language may not be sufficient, if specific cultural contexts and meanings are not considered. Additionally, bilingual research staff may be part of a different culture or of higher socio-economic status (and thus, different life experiences and word usage) than are the research participants, which can lead to invalid translation. Such Western instruments also may have limited validity when used among oral cultures.[22] At times, the creation of new or modified research instruments, which are tailored to specific settings and cultures, is warranted.[9,23] The gathering of poor quality data can lead to misleading conclusions that can impact programming and policy decisions.[24]

*Recommendations*—When conducting assessments in different cultural contexts, researchers should consider the following:
1. Translations with back translations of pre-existing questionnaires that have been validated in different cultural contexts rarely are sufficient;
2. Utilize participants' own wording and conceptions of psychosocial and mental health problems;
3. Employ both qualitative/ethnographic and quantitative methods;
4. Learn about the local context through proceeding with qualitative data collection as a point of departure in new settings; avoid closed-ended and leading questions;
5. Test the cross-cultural validity of any instruments developed among the population to be researched;

6. Raise awareness among donors, that adhering to those recommendations is likely to be more time- and cost-intensive, but crucial for arriving at outcomes that have cultural validity; and
7. No data are better than invalid and misleading data.

*Neutrality*

The concept of neutrality deals with the issue of the subject's perception of the researcher and the impact that this perception has on the subject's participation in a research project. It has become increasingly clear among researchers that the researcher's personal characteristics have a significant influence on the research process and outcomes. As described by Boyden, "the personal manner and characteristics of researchers, and particularly social attributes like gender, generation, and ethnicity, are regarded as critically influencing research outcomes. Hence, it is now accepted that the researcher's social status can have a major impact even on participation in research".[20] In other words, it is not possible for the researcher to be a neutral factor in the research process or outcome. The power imbalance caused by the differences in social status of the researcher and the individuals that may be the subjects of the research project, will have reverberating influences on consent, motivation, validity of responses, and outcomes. An emergency context, where the population is vulnerable, usually impoverished, and possibly in danger, serves to further heighten the impact of the power imbalance between researcher and subjects of the research. In addition, the giving of aid is not divorced from donor's political agendas. Thus, the actual presence of humanitarian workers in a particular emergency setting may be driven by political considerations rather than any measure of need.[25] Therefore, the implications for power dynamics' influence on research outcomes are vast. While the Working Group recognized the significance of the topic of neutrality and power imbalances, there was insufficient time during the Summit to expand and explore all of the nuances to the extent that is due to a matter of such importance. The group plans to continue to work on this topic and make relevant recommendations.

*Do No Harm/Risks*

Research can have various positive or negative unintended, or unforeseeable consequences.[2,4,19,26] Many forms of harms and risk, however, are foreseeable, and therefore, can become preventable or manageable. The following types of risk should be considered:

*Protection Risks*

1. *Stigmatization and recrimination risks*: Interviewing vulnerable groups (e.g., rape survivors, children) may put them at risk for being targeted or stigmatized by the community. Working Group case examples on Iraqi refugees in Jordan highlighted that even locally recruited interviewers may show discomfort discussing mental health issues due to the culturally-specific stigma associated with mental health.
2. *Sexual exploitation and abuse*: Researchers may need to ensure that codes of conduct are followed by all national staff. One Working Group member recounted an example in which researchers gave great attention to ethics and staff behavior only to learn subsequently that the research group's driver, who stayed with the research staff in the village where research was being conducted, engaged in transactional sex with girls <18 years of age.
3. *Discrimination*: In some cases, local governments may suggest not interviewing marginalized groups, in which case, the research itself may support social injustice.[9] One Working Group member recounted a situation where the local government told researchers not to "bother" interviewing certain lower status residents. Another Working Group member provided an example of research in Beirut, Lebanon where various NGOs carried out assessments on Sunni, but not Allawi, neighborhoods, thus underscoring the tensions between the city's Sunni and Allawi religious communities.
4. *Participation*: In some contexts, participation in research can be viewed by subjects as a basic right, a pathway to having one's voice heard, or a means of recovery and regaining dignity. However, participation also can lead to the targeting of subjects for violence or other repercussions.[20] Participation by one group also can evoke jealousies over a program to which others do not have access. The issue of participation is fundamental in particular kinds of research such as participatory action research, which tries to maximize participation while minimizing risk.[22,27]
5. *The "Blame Game"*: The misuse of research data can result in data on the most "damaged" and overwhelmed groups being used by governments as a political weapon to assign blame.[20]
6. *Breaches in confidentiality*: Protecting the identity of subjects can be challenging in emergency settings. In the past, media sensationalism has resulted in inappropriate disclosures of identity and breaches of confidentiality. For example, a journalist's desire to tell a compelling story could endanger the subjects if their photographs are printed in major news sources without prior consideration for their safety.
7. *Security*: Research activities can compromise the security of research subjects as well as of the researchers themselves. Security risks are particularly significant for children who could be targeted for recruitment by groups that could exploit them as a result of research and program activities. Convening groups of youth for discussions or to respond to survey questions could also spark fears of military activity and generate reprisal or detentions. The presence of western researchers in itself, could present a danger in targeting of local civilians, as well as to the researchers themselves. Many researchers willing to place themselves in harm's way may see this as an individual risk, but such risks can have much wider implications. If an expatriate researcher gets killed in a particular area, aid can be shut down and the level of armed conflict can increase.

*Psychological Risks*

1. *Raised expectations*: Researchers may be viewed as wealthy westerners and as a lifeline to aid and money.

> ….In my home country of Sri Lanka, for example, the 2004 tsunami was followed by a huge influx of foreign organizations and individuals offering humanitarian aid, including counseling. Some advocated compulsory counseling for survivors, though this runs against recommendations from the WHO and the Cochrane Collaboration — a not-for-profit organization that provides information on the effects of health care.
>
> …In parallel to these 'services', doctoral students from developed countries acquired data to finish their theses, harassed survivors with numerous questionnaires and even collected blood to research neurobiological stress markers. In the rush to provide assistance, a lack of familiarity with local customs caused cultural insensitivities. For example, many people would prefer to seek help from a temple rather than a therapist.

<div style="text-align: right">Allden © 2009 Prehospital and Disaster Medicine</div>

Quote by Athula Sumathipala, Senior Lecturer at the Institute of Psychiatry in Kings College London, UK, and Honorary Director of the Institute of Research and Development in Sri Lanka[32]

The asymmetric power dynamics create divergent perceptions and hopes for aid in the eyes of subjects.[4,8,20] Subjects hoping for aid may feel let down when researchers leave without giving back to the community.

2. *Recounting stressful stories*: Using aggressive methods of questioning and recounting of stories with little support for distressed individuals can put subjects at risk for psychological harm.[19,28] While research suggests that there is typically no harm after participation in psychiatric research and that subjects tend to feel positive about participation,[21,29] those with mental disorders, previous traumatic experiences, and low social support may be at a higher risk for experiencing distress during interviews.[29,30] Furthermore, research often does not include baseline assessments of distress, control groups, and long-term follow-up, and negative effects of research may not be documented.[29]

3. *Labeling*: Western research methods may use psychological labels or categories that medicalize complex and multidimensional (e.g., political, historical, social) problems, which can stigmatize individuals and which may be inappropriate in different sociocultural settings. Some researchers argue for example, that apparently straightforward notion of 'childhood' is a cultural construct and using the label inappropriately may have unintended consequences.[31]

4. *Power Dynamics*: Power asymmetries occur between international and national researchers, and between researchers and local NGOs and communities.[20] Local participants may be eager to 'please' outsiders in hopes of getting aid or cash. Compensation also can undermine parental desire to encourage children to participate in research altruistically,[9,27] or produce adverse effects when "reasonable compensation" is defined differently for separate economic classes.[9] Alternately, local people may silence their own beliefs and practices in hopes that western science will make their lives better. Local groups also may have their own internal power asymmetries; therefore, attempts to hold community meetings or to enter the community through particular gatekeepers can augment the power of local elites or exacerbate sensitive, within group differences.[9] Imposing categories and labels on local populations, can silence local voices and marginalize indigenous understandings. Outsider actions also can serve to weaken or undermine existing supports.

6. *IRBs*: Traditional IRBs often do not have the background and expertise to determine risks and benefits in crisis and conflict settings.[7,21] Traditional IRBs even may reject research in socially sensitive settings based on concern for harming subjects, even in cases in which subjects feel they benefit from the research. There are many reasons for these problems, such as great physical distance between the research university and the location of the research, as well as lack of familiarity of IRB members with the social, cultural or political context of the region where the research is to be conducted. To remedy this problem and to a make an IRB review more meaningful and relevant to the local context, some researchers have suggested creating local advisory boards and local IRBs to judge the acceptability, benefits, and risks of the research.[6,22] However, such a process poses challenges as well. For example, one Working Group member described her experience working with clan based Somali communities where every selection and creation of a committee created conflict with those not selected.

*Recommendations*

In advance of any research project, possible risks should be identified and addressed and risk management and mitigation plans should be created. Critical elements that must be addressed during the planning phase should include team preparation, participant selection, informed consent, confidentiality, expectation management and rapid response, protection, and managing psychological risks. The following steps should be taken to protect subjects and minimize harm:

1. Consider whether your presence and/or the research process can cause harm;
2. Ensure that data collection staff and ancillary support staff are well-trained in ethical codes of conduct;
3. To mitigate risks, identify and have available culturally and politically acceptable support mechanisms;
4. Avoid labeling or stigmatizing participants;
5. Be aware of the risks of gathering large groups together in insecure and conflict areas because these groups may become targets;
6. Recognize changing circumstances;
7. Monitor risks and adjust research plans and procedures accordingly;
8. State and repeat the purpose and benefits of research to help avoid false expectations. A story might aid in clarification;
9. If feasible, create an inclusive advisory board from the refugee or local community to review proposals and judge the social value of the research; and

10. Create a fast-track, independent IRB from a consortium of agencies (i.e., engaged academic networks) that include former-refugees.

### Confidentiality

When working in emergency settings, a researcher must consider how private information will be kept confidential, who can access the data, how the information will be stored, and what happens with data after completion of the research. Different cultures may have varied attitudes about confidentiality and about sharing information from the research with community members.[9] It may be logistically difficult or culturally unacceptable in emergency settings to interview someone in private, as no private space may be available. Privacy also may be compromised by cultural norms such as not being able to have a woman participate in an interview without her husband being present. Issues of confidentiality also will affect the dissemination of information, especially when reporting back to funding research institutions or publishing in peer-reviewed journals. One Summit participant noted a recent case in which a researcher was reprimanded by his IRB for including names of places to which researchers needed to return in order to complete the research, stating that this information constituted a "patient identifier." Institutional research boards may not have the expertise to understand, in a particular cultural context, the information that is necessary or not sufficient to identify a particular individual.[7,21] In settings in which there may not be an IRB substitute available, a researcher must be able to convey the requirements necessary to maintain confidentiality without compromising the research.[33]

### Recommendations:

1. Utilize a fluid set of principles adapted to the context rather than rigid set of rules;
2. There may be no way of obtaining confidential/private interviews at times due to cultural and safety considerations;
3. Obtain consent from participants if they could be identified by products of the research such as photographs;
4. Weigh the costs and benefits of making participants identifiable (e.g., attention and benefits vs. possible stigma, humiliation, and safety concerns); and
5. The individual subjects' safety and security must be the top priority.

### Selection of Subjects and Topics

There are several key points to consider when selecting who and what requires study. The Working Group noted that particular groups are studied more frequently than others. This may be more of a reflection of the interest of the researcher than of the actual need in the community. Groups, such as children including child soldiers, victims of violence, and women are studied more frequently than other groups such as the elderly, men, individuals suffering from learning disabilities or severe mental disorders, or perpetrators of violence. Post-traumatic stress disorder is one of the most researched mental health topics in emergency settings while the impact of epilepsy and developmental disorders, although arguably as common,[34] remains under-researched. Research frequent-

ly focuses on deficiencies and problems. There is a lack of inquiry into resilience and strengths; this lack of information can further disempower groups and individuals.[35]

The process of subject selection and whether specific groups in the community are excluded requires attention before the research begins. In the experience of the Working Group members, those not selected may feel that their views are not being heard and that others are being privileged, which can lead to tension and conflict in the community. Selecting certain groups also may confer unwarranted legitimacy and importance on them. In general, it appears that those selected tend to respond positively to having their views heard and communicating their needs. One of the Working Group members reported working with a NGO conducting research in Sunni as well as Allawi neighborhoods after a ceasefire agreement in Lebanon. This ensured that an inclusive approach of subject selection was taken. Specific groups also may exclude themselves.[22] For example, in family research, women and children may defer to men in their family; therefore, specific selection strategies may need to be devised to hear from them.

One way of addressing the concerns over subject and topic selection is to ensure a more participatory process. Various authors have made a case for community-based participatory research, which aims to include participants in all phases of the research process and can empower communities.[9,22,27,36,37] Researchers also have established community collaborations and coalitions.[38] However, such research also should take into account the local context, including power dynamics, cultural factors, and risks associated with participation.[27]

### Recommendations:

1. Engage affected communities in partnerships to discuss their priorities, and with them, define the service and research agenda. Explore participatory research methods to engage communities in designing and shaping the research and interpreting outcomes;
2. Try to ensure that communal and non-pathological processes, such as resilience, receive as much attention as mental and behavioral disorders;
3. Include marginalized and vulnerable members of the community and those with little access to power (e.g., different ethnic groups) in subject selection;
4. Make research reflective and responsive to a changing agenda; and
5. Establish partnerships that foster local agency while remaining open to new ideas.

### Consent

The Working Group defined "informed" as meaning that an individual has an understanding of a study's purpose, who are the targeted beneficiaries, and the implications of involvement. Also, to be "informed" means that information is communicated in a form appropriate to the culture, age, and educational level of that individual. "Consent" refers to an active agreement for participation in research, with the understanding that the participant has the right to refuse any question and to stop participation or withdraw at any time. However, obtaining true informed consent in crisis and conflict set-

> ....One of the team members, a medical practitioner, conducted interviews whilst attending patients at impromptu clinics set up in villages and homes...

JB, discussing research in Burma

> It was only during the course of the interview, as they experienced the content and the range of questions being asked that they seemed to comprehend the nature and implications of the evaluation study. In effect, any consent respondents provided prior to undergoing the interview was largely meaningless, and so it became necessary to again request their consent to utilize their survey responses after the completion of the interview...

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tings can be challenging.[8,18] There are several aspects of the consent process that require particular attention.

Communities may have different concepts of adulthood, and thus, a different idea of whom exactly must or can provide consent.[6,9,20,21] Communities may see individuals who are 14- and 15-year-olds as adults who do not need parental consent to participate in research. How researchers negotiate this setting without imposing outsider views is a significant challenge.[27]

Concepts of individual autonomy may have different meaning in collectively oriented cultures. Individuals may seek to do what is best for community rather than themselves. An individual may consent to research because their community, husband, or parent consented, or because there was tacit pressure from a community leader.[9,22] A distinction also can be made between explaining the research and obtaining consent from participants versus explaining the research to the wider community.[9]

Genuine consent also may be hindered by unequal power relationships and raised expectations of benefits. During emergencies, researchers hold more power than participants, especially in cultures where the subjects of the research traditionally hold lower status.[20] There may be benefits to participation that are provided as part of the research or are perceived by participants. Research participants also may feel coerced into participating if they worry that refusal may compromise support or access to services.[9,22] Additionally, the use of compensation in return for participation could be a coercive factor for economically distressed families.[9] One case study discussed by the Working Group indicated that volunteers recruited to conduct interviews did not understand the importance of consent, especially when compensation was involved. Even if research and service provision are separate, participants may not perceive a clear distinction between the two. Also, it may be the case that a refusal would be perceived as violating local norms of hospitality. Furthermore, communities may have their own internal power imbalances where certain groups could be excluded or coerced to participate.[9]

The above quotation by JB concerning medical practitioner conducting research interviews while providing clinical care illustrates an interesting dilemma posed in insecure settings when the role of service provider and researcher is combined. This method of interviewing ensured the security of the interviewee and avoided the scrutiny of security services, but arguably, a patient being attended by a physician is unlikely to refuse to answer any question because of his dependence on that physician in that situation. The patient may hold the belief that refusal to cooperate in a research interview will compromise the medical attention they receive.

Obtaining consent only once may not be appropriate in crisis and conflict settings. Even if participants provide their consent at the outset, they may not sufficiently understand the research procedures until they engage in them, and they may not anticipate the impact of their participation.[8,19] An individual's right to refuse to answer a question or to withdraw at any time should hold true throughout the research period, even after the interview has ended.[8,19,27] It may not be until after the research interviews are over that the participant understands the risks of participation. He/she may wish, at that time, to withdraw his/her consent. This may pose difficulties to the researcher, who may lose valuable data. However, the practice of requesting consent at different points in the research has been promoted by various authors as well as by the Working Group.[18,19,22,27]

Written consent may have no perceived meaning to illiterate individuals and even may undermine their trust in settings where participants are illiterate and the government has violated human rights by asking people to sign their names to forms they did not understand, thereby forcing or tricking people into pledging or relinquishing something such as property or rights, or some other matter.[22] Researchers who use written forms may be perceived as government collaborators or collectors of information that will be used against the potential participants. In such situations, recording oral consent may be more appropriate.[4]

Researchers should determine whether individuals have the capacity of giving full informed consent. The severely mentally ill may lack the capacity to give consent, or may give consent that they may ultimately regret (e.g., allowing the use of pictures). In such circumstances, obtaining consent from caregivers may be the appropriate course of action, but this depends on the context.[9]

*Recommendations:*
1. Obtain consent that is informed by giving a full explanation of why the research is being conducted, what it is for, why this subject is selected, and what it will involve on their part;
2. Explain fully the costs and benefits of participation including potential negative impact;
3. Explain how the results will be stored and disseminated.
4. Explain how confidentiality will be maintained;
5. Be aware of power differentials between the researcher and respondent that may increase their likelihood of participation;

6. Utilize flexible consent procedures such as informed oral consent instead of written;

7. Avoid incentives that could be coercive or inappropriate;

8. Understand that there may be false expectations from participants about the outcomes of the research;

9. Take consent at multiple times during the research process, including at the end of data collection; and

10. Take consent from multiple agencies including community, parents, and partners as appropriate.

*Dissemination*

When examining issues of dissemination, researchers should consider who owns the data, how data will be prescribed and distributed, whether participants will learn about the results, and whether there could be unintended consequences of dissemination.[22] Dissemination of information collected in the field (e.g., pictures), can inform the outside world and mobilize support. However, photographs also can bring humiliation or stigma, and violate the rights to privacy. Images may reinforce the image of the subjects as victims, rather than as resilient individuals. Even in the case in which consent to publish or use a picture is given, subjects may not fully understand the number of people who would see their picture, in what context their picture might be viewed, or the implications for themselves.

Furthermore, findings from research often are not disseminated appropriately among other NGOs or groups conducting work in the same area, which leads to a duplication of efforts and undue burden on research subjects. One of the Working Group members recounted speaking to an Iraqi refugee in Jordan. Upon asking the participant if she would be willing to provide information for research, the woman returned from her house with a stack of surveys filled out for prior researchers and replied "Take your pick." Participants may experience "burnout" from prior research, which may be compounded by a lack of involvement of participants and no tangible benefits.

*Recommendations:*

1. Weigh costs and benefits of dissemination of pictures as well as the vulnerability of participants. Researchers must be able to ask themselves: How would I feel if it was me in the picture?;

2. If feasible, arrange feedback meetings after completion of the research and share findings with participants;

3. Coordinate data collection and share findings with other NGOs and organizations; and

4. Develop an open-source system that can track data collection efforts and locations to facilitate coordination and data sharing.

## Conclusions

Based on a review of the literature and experience in the field, the Working Group identified several key ethical issues that should be addressed when conducting research in crisis and conflict settings. The reached consensus that it would be unethical not to conduct research and evaluate outcomes of mental health and psychosocial interventions in emergency settings, given that there is no good evidence base for such interventions. On the other hand, the Working Group also agreed that it would be unethical to conduct research without any intended benefit or service to the community. The Working Group outlined several issues and recommendations pertaining to the topics of purpose and benefits, validity, neutrality, risk, subject selection and participation, confidentiality, consent, and dissemination. However, the group views this set of recommendations as "a work in progress". They plan to further develop and refine the recommendations based on input from colleagues representing different regions of the globe with an emphasis on input from colleagues from low-resource countries. It is hoped that this body of ethical guidelines will be a living document of benefit to researchers and the NGO community alike, and that this community of humanitarians and researchers together will amend and clarify the steps necessary for conducting much needed ethical research, assessments, and evaluations of psychosocial and mental health interventions during the extreme conditions of complex emergencies.

## Acknowledgements

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