

## Ethical Issues Pertaining to Research in the Aftermath of Disaster

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In January 2003, The New York Academy of Medicine and the National Institute of Mental Health sponsored a meeting entitled “Ethical Issues Pertaining to Research in the Aftermath of Disaster.” The purpose of the meeting was to bring together various experts to examine evidence concerning the impact of research on trauma-exposed participants, review the applicable ethical principles and policies concerning protection of human subjects, and offer guidance to investigators, IRBs, public health and local officials, and others interested in assuring that research in the aftermath of a disaster is conducted in a safe and ethical manner. This article summarizes the group’s key findings and outlines potential considerations for those working in this field.

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**KEY WORDS:** IRB; disaster; research ethics; human subjects; research protections.

On January 13 and 14, 2003, The New York Academy of Medicine and the National Institute of Mental Health sponsored a meeting entitled “Ethical Issues Pertaining to Research in the Aftermath of Disaster.” The attendees included 37 mental health professionals, trauma researchers, public health officials, ethicists, Institutional Review Board (IRB) representatives, as well as family members and first responder representatives from the Oklahoma City and World Trade Center disasters (see Appendix). The purpose of the meeting was to examine evidence concerning the impact of research on trauma-exposed participants, review the applicable ethical principles and policies concerning protection of human subjects, and offer guidance to investigators, IRBs, public health and local officials, and others interested in assuring that research in the aftermath of a disaster is conducted in a safe and ethical manner.

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### Background

Disasters, whether unintentional acts of nature or human-made, can have profound effects on those who experience them. Although the physical dangers inherent in disasters are obvious, such events, including terrorism and bioterrorism, are a grave threat to mental health as well. Previous episodes of disaster have dramatically affected individuals, communities, and nations. In addition to affecting acute physical and mental health, disasters can have more chronic impacts creating social and economic hardship, loss of employment, the dissolution of personal relationships, and the long-term deterioration of physical and mental health (Canino, Bravo, Rubio-Stipec, & Woodbury, 1990). Research conducted after various types of disasters (Oklahoma City Bombing; Hurricane Andrew; Three Mile Island Disaster; 1989 San Francisco Bay Area earthquake; 1991/92 Iraqi missile attacks on Israeli civilians; and the terrorist attacks on New York City on 9/11/01) have demonstrated that adults and children who experience violent and traumatic events show a wide range of reactions. Some suffer distressing worries, difficulty sleeping and concentrating, and bad memories that while disturbing and impairing, most often fade with

good emotional support and the passage of time. Others are more deeply affected and experience long-term problems such as depression, posttraumatic stress disorder, and other anxiety disorders (Norris, Friedman, Watson, Byrne, et al., 2002; Norris, Friedman, & Watson, 2002). Terrorism is one of the most devastating types of disaster, the intentional creation of death and destruction in order to destabilize, instill fear and feelings of uncertainty, vulnerability, intimidation, demoralization, chaos and helplessness among those targeted. Because of its unique characteristics and the malice that motivates its aims, there are many important reasons to study the environmental, clinical, and psychosocial impacts of terror on individuals, families, and populations. Research focused on the effects of terrorism can provide important information that may: improve long-term survival (Lundin, 1984), help prepare for subsequent incidents (Murray Parkes, 1997), aid in assessing the physical and emotional needs of a population (Galea et al., 2002), impact on planning and provision of mental health services for victims and other disaster-affected persons (Canino et al., 1990), and increase understanding of the human response to trauma more broadly (Dreman & Cohen, 1990).

Prior studies involving trauma and disaster-affected populations have identified some of the special issues that exist for research in the unique circumstances of terror, but concerns about magnitude of risk to subjects of research postdisaster are largely undocumented. Some question whether witnesses to or victims of extreme trauma may be able to anticipate the degree of distress that will accompany research participation (Newman, Walker, & Gefland, 1999; Pope, 1999). The process of IRB review and approval is intended to insure that adequate procedures are in place to address this and other issues. However, beliefs and knowledge about the potential of these studies to traumatize or upset participants varies greatly among individual investigators and IRBs (Newman et al., 1999). This gap in knowledge and the challenges it represents were a major focus of this meeting.

Although the risks and benefits of participation in disaster-focused research are not fully understood, most would agree that there is a significant need for additional research in the aftermath of disaster. This tension points to the importance of balancing the potential benefits to society of activities that seek to enhance knowledge and provide effective services postdisaster and the necessity of protecting the rights of individual human research subjects.

Federal regulations (The Common Rule – 45 CFR 46, subpart A) provide the framework for the protection of the human subjects of research. These regulations and additional subparts B through D define the standards for

the ethical conduct of research, including the process for proposal review through IRBs. They describe the process of voluntary informed consent and note that additional protections should be afforded vulnerable subjects such as children, prisoners, fetuses, the decisionally impaired, and the economically and educationally disadvantaged (Federal Policy for the Protection of Human Subjects, 45 CFR §46.111, 1991). IRBs are also charged with consideration of the overall burden to specific individuals or populations created by research participation. The burden of research may be additive to other nonresearch burdens being experienced by subjects or it may occur directly as a result of the research, such as when an individual is asked to participate in multiple or redundant studies (Office for Human Research Protections [OHRP], 2001).

Research involving victims and survivors of all too common acts of violence such as rape and sexual assault, community violence, domestic violence, and child abuse has helped to establish safeguards for the protection of research participants that are useful for IRBs. The most significant intentional human-caused disaster that took place in the recent history of the United States prior to the events of September 11, 2001, was the bomb explosion at the Alfred P. Murrah Federal Building in Oklahoma City on April 19, 1995. Much research was undertaken in Oklahoma, and a good deal of it was centrally reviewed and approved through a special process put in place by the University of Oklahoma Health Sciences Center (UOHSC) with the imprimatur of the Governor (North, Pfefferbaum, & Tucker, 2002). The result was that the University's IRB became the single body approving research involving the population affected by the bombing as captured by a registry of victims. The goals of this approach were to protect the survivors of the disaster, maximize the knowledge obtained from the investigations, coordinate the numerous studies, minimize the burden on research subjects, and attend to simultaneous needs for acquiring new knowledge and clinical treatment in this population (North et al., 2002).

In the case of the World Trade Center disaster of September 11, 2001, investigators with interest and expertise from all over the country and internationally wanted to study these events and the aftermath. In the absence of clear recommendations about coordination of research, concern arose about assuring that victims of terror and their families not be subjected to inordinate burdens. Given the massive scope of the disaster and the research that took place afterwards, extensive coordination on the scale of Oklahoma City did not take place. The result is two very different examples of oversight of research following terror.

### Purpose and Structure

The purpose of this meeting was to examine the evidence concerning the impact of research on trauma-exposed participants, review the applicable ethical principles and regulations that govern research, and offer guidance where possible to investigators, IRBs, regulators, public health and local officials, and others concerned with scientific and clinical endeavors as well as those charged with protecting the interests of human subjects.

Participants in the meeting were invited for their leadership and experience in the areas of mental health, disaster-focused research, public health, and research ethics, or for their personal knowledge and involvement as family members of victims or first responders to the Oklahoma City and the World Trade Center disasters.

Four areas of critical importance to development, evaluation, and conduct of research protocols postdisaster were identified by the planners of the meeting: decisional capacity of potential participants, vulnerability of research subjects, risks and benefits of research participation, and informed consent. Each topic was the subject of a discussion at the meeting. The moderators of each discussion were asked to review the literature in the field, examine evidence directly related to research postdisaster, and define those areas that required further study.

After each discussion, and in a summation session, the group attempted to formulate summaries that might be of help in the future to investigators, IRBs, and public health and local officials faced with a natural or human-caused disaster.

### Decisional Capacity

The discussion of decisional capacity focused primarily on what is known about the factors that impact on an individual's ability to make decisions in the face of acute stress (Rosenstein, 2004). In order to shed light on the decision-making capacity of individuals in the aftermath of a disaster, the general literature on decision making in clinical treatment and research was reviewed. In the clinical setting, adult patients are assumed to have the capacity to make decisions concerning clinical care unless physicians have a reason to question that ability. Even for those with questionable capacity, experience shows that decision-making capacity varies depending on the nature of the question posed and the complexity of the choice. Decision-making capacity can also be improved through intensive educational efforts (Carpenter et al., 2000). Capacity to make decisions is not viewed as a bimodal, yes or no, phenomenon and even varies in the same individual

over brief periods of time. Applebaum has identified four components of decisional capacity (factual knowledge, ability to communicate a choice, appreciation of information, and ability to manipulate information) that should be considered in evaluating the individual prospective research participant's competence to provide informed consent (Applebaum & Roth, 1982).

The need to be protective of an individual with questionable capacity to make decisions also varies with what is at stake. The level of risk of the decision and the irreversibility of the choice are important factors in creation of safeguards to protect the interests of individuals who may have varying or questionable capacity. In the clinical context, physicians are ethically obligated to recommend treatment options deemed to be in the best interests of their patient. The patient evaluates that recommendation and decides whether to proceed based on his or her own values and assessment of the risks and benefits while knowing that the physician believes this course of action is consistent with benefiting the patient. This is not always the case in the context of deciding about research participation. There may be no intended direct benefit to the individual subject participating in research or the potential benefits may be uncertain or unknown. Risk of participation in research may be minimal or vary widely depending on the specific investigation. Thus, the capacity required for participation in research may vary with the level of risk.

There has been a great deal of research in the field of mental health on the assessment of decision-making capacity in both clinical and research settings (Rosenstein, 2004). There are data to support the notion that some potential research participants postdisaster will have impaired decision-making capacity as a result of their traumatic experience (Marmar, Weiss, & Pynoos, 1995). It would, however, be inaccurate and potentially stigmatizing to assume that all persons who have experienced terror or other disasters are decisionally impaired and unable to make choices for themselves. Although it is reasonable to presumptively accept that potential research subjects postdisaster will have the capacity to make decisions, given the significant impact of experiencing such trauma, the process of informed consent should consider the prospective research participants' ability to provide meaningful and voluntary consent. It is reasonable to consider whether more individuals with impaired decision-making capacity will be encountered in this context than in the general population. However, there is little empirical evidence regarding decision-making capacity in disaster-affected populations. Related evidence from studies of patients with acute stress disorder and posttraumatic stress disorder offer evidence that decisional ability in these individuals, as a group, is not significantly compromised. Even

individuals who are extremely upset and under significant stress in general are able to make rational decisions about clinical care and research participation (Rosenstein, 2004). Numerous factors have been identified as influencing decision-making capacity under stress, but the extent of the effect of these factors is unclear, and each of these factors is affected by the antecedent mental health of the individual participant, the characteristics of the study, and contextual variables such as research site, experience of the investigator, etc.

### Vulnerability

The discussion of vulnerability focused on the importance of this concept in the history of protection of human subjects of research and its relevance as a descriptor of the population of those who have experienced disaster (Levine, 2004). The term “vulnerable” is generally applied to groups that are “more likely than others to be misled, mistreated, or otherwise taken advantage of as participants in research studies” (Levine, 2004). In the decades after World War II, in response to the Nazi experiments and various research scandals in the United States, research was viewed as a risky and burdensome enterprise from which individuals needed protection. In 1978, a national commission was convened by Congress to address this problem. It published *The Belmont Report*, the ethical justification for the regulatory structure for the protection of human subjects that exists to this day (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978). The Report defined vulnerable populations as those groups that might “bear unequal burdens in research” due to their “ready availability in settings where research is conducted,” such as prisons, hospitals, and institutions, and it called for extra protections for these groups.

The Code of Federal Regulations, developed as a result of the recommendations of the national commission, does not specifically define vulnerability but creates specific protections for four “particularly vulnerable populations”: children, prisoners, pregnant women, and fetuses (§46.201, 1991; §46.301, 1991). In addition, there is reference to other populations whose ability to make voluntary and uncoerced decisions about research participation may be impaired. These include adults who are cognitively impaired or mentally disordered, and those who are economically or educationally disadvantaged (§46.111, 1991). When individuals from these groups are potential subjects of research, there may be limits on the permissible levels of risk to which the subjects may be exposed without compensating benefit, and the IRB may impose procedural

safeguards to protect the interests of the subjects. In recent years, the concept of vulnerability has been expanded to include even more groups. These include populations with insufficient power to protect their own interests or those at risk for being “wronged” or treated in ways that assault their dignity (Levine, 2004).

The concept of vulnerability appears to have become extraordinarily elastic, capable of being stretched to cover almost any person, group, or situation (Levine, 2004). It gathers people of widely varying characteristics and capacities under one large umbrella without accounting for critical differences among individuals. Some have argued that vulnerability ought not be conceived as a characteristic of a group at all, but rather that certain individual characteristics may render persons vulnerable in certain situations (DeBruin, 2001).

Common-sense usage of the term vulnerability must be differentiated from the technical meaning of the term in the context of human research protection. Victims of violence and disasters are of course vulnerable in the sense of sometimes requiring additional care and attention, as they have often suffered trauma and loss. However, available evidence does not indicate that as a class, they are unable to participate knowingly and voluntarily in decision making. Protocols that present novel or high risk or have uncertain risk-benefit ratios should be examined carefully before being approved. Specific protocols with the possibility of increased risks faced by individual participants should be scrutinized on a case-by-case basis. IRBs must determine whether, on balance, the benefits of any particular research endeavor outweigh the cumulative risks to individual subjects. Investigators must also be sensitive to the fact that individuals in this group have suffered injury and loss and may be more inclined to conflate clinical services and research.

### Risks and Benefits

The discussion on the risks and benefits of participation in research postdisaster focused on the evidence of the impact of research on participants and the perceptions of subjects about their experience of participating in research (Newman & Kaloupek, 2004). There are clearly risks and benefits associated with participation in disaster-focused research, but there has been little empirical research in this area. There are about a dozen published studies that examine the risks and benefits of research postdisaster (Newman & Kaloupek, 2004).

A number of benefits to participation in research postdisaster have been identified. Such benefits include: enhanced awareness of material resources, medical and

mental health services, empowerment, learning and insight, altruism, kinship with others, feeling of satisfaction or value after participating, and favorable attention from investigators. However, while there is evidence that benefits exist for at least some research participants, these benefits have not been examined in detail, and it is not known which kinds of participants are most likely to gain from what type of research involvement. In addition, it has been observed that disaster-affected individuals seem to receive greater benefit from interview-based research over questionnaire-based research or studies that are more biologic in nature (Newman et al., 1999).

There are risks associated with participation in disaster-focused research. Such risks include physical harm, inconvenience, legal action, economic hardship, psychological discomfort, loss of dignity, breach of confidentiality, and unwanted media attention. Unlike findings on the benefits of research participation, researchers have identified several characteristics of participants and protocols that may enhance their potential for risks while taking part in disaster-focused research studies. These characteristics include preexisting distress or mental illness, age (both young and old), history of multiple trauma exposures, social vulnerability, and physical injury. Furthermore, there is evidence to suggest that repetitive research involving the same participants carries a potential for risk. Because disaster-affected persons are limited in number and are of interest to numerous investigators, the potential for overburdening these individuals with multiple or repetitive studies should be considered a risk in this type of research (Newman & Kaloupek, 2004).

Perhaps the most frequently discussed risk is that of emotional distress. Emotional distress is a risk of disaster-focused research participation, but it is not unique to trauma studies, and it varies greatly in degree depending on the individual participant and study. Often, it may be difficult to identify, because the research may not necessarily cause emotional distress but rather may make the subject aware of distress caused by the antecedent trauma (Newman & Kaloupek, 2004). Furthermore, an individual noted to be upset during participation in research might not necessarily regret participation. It is often the act of remembering the past that can induce distress, but at the same time, in the appropriate context, this act can aid individuals in achieving insight into their experiences.

Emotional distress caused by remembering events has sometimes been referred to as "retraumatization." Re-activation or exacerbation of residual stress-related symptoms precipitated by stimuli after the original exposure to a traumatic stressor may be an appropriate component of clinical care in a controlled and safe setting and should not be confused with the actual occurrence of traumatic

exposure. Research participation may upset subjects but it does not traumatize them as a disastrous event would. Trauma-inducing events involve unpredictable and uncontrollable experiences, while disaster-focused research should be both predictable and highly controlled. The use of the term retraumatization is often inappropriate in the disaster-research context and may lead to exaggerating the risk involved in participation. Thus, investigators and IRBs must take special care in assessing the risk-benefit ratio of a research protocol so as not to over or underestimate risk (Newman & Kaloupek, 2004).

Available evidence demonstrates that negative emotions are experienced by at least some individuals during research posttrauma. Acknowledging that this occurs does not address how such emotional upset compares to the magnitude and frequency of distress that these individuals confront in their daily lives. There are no clear data to define whether research-related upset reflects new symptoms, acute intensification of typical symptoms, or emotional responses that are commonly experienced by the subject. In addition, the majority of subjects who experience strong emotional reactions do not regret or negatively appraise research participation, suggesting that distress may be understood as an indicator of emotional involvement in the research project rather than as an indicator of harm (Kassam-Adams & Newman, 2003; Newman et al., 1999; Ruzek & Zatzick, 2000; Walker, Newman, Koss, & Bernstein, 1997).

### **Informed Consent**

The discussion of informed consent focused on what is known about the process and effectiveness of informed consent in postdisaster research. Informed consent became the cornerstone of the protection of human subjects of research in the United States after a number of highly publicized research scandals in the 1960s and early 1970s raised public awareness of the risks of research and questioned the motives of investigators. Informed consent is the operationalization of the principle of respect for persons described in the Belmont Report (DHEW, 1978). Although many have focused on the document that is signed by the research participant as the "informed consent," informed consent is a much broader process which includes informing the potential subject of the procedures, potential risks, benefits, and alternatives to the research and then obtaining documentation of authorization to proceed.

The history of voluntary and informed participation in research dates back at least to the beginning of the twentieth century and the experiments of Walter Reed who recruited American soldiers to determine the vector

of Yellow Fever (Moreno, 2000). During the twentieth century, healthy persons who became experimental medical participants were routinely referred to as volunteers, a term suggesting altruism and praiseworthiness. Patients who became the subjects of research were less likely to be viewed as altruistic volunteers and more likely to be seen as deriving benefit from participation. Some maintain that informed consent procedures were less rigorous in these circumstances and sometimes were ignored (Advisory Committee on Human Radiation Experiments [ACHRE], 1996).

There has been a great deal of interest in research involving human subjects in the area of public health and prevention of the physical and mental health consequences of war. Members of the armed forces have been exposed to biologic, chemical, and nuclear substances to measure effects and determine appropriate responses in the face of attack and have been vaccinated without consent. Other public experiments without consent have subjected whole cities or communities to biologic exposures and various measurements and calculations of impact (Moreno, 2000).

Public health research, research in the military, and research postdisaster may all occur in an atmosphere of enhanced patriotism and a sense of civil duty to participate in research in response to public health and national security threats. Given the increased concern for biological warfare and outbreaks of smallpox and anthrax, as well as the greater likelihood for future terrorist attacks, research in these areas may be perceived as a way to lessen the threat to public safety (Lombardo, 2003).

This perception is an important factor for investigators and IRBs to consider in order to ensure the voluntary and informed consent of participants in disaster-focused research. Individuals, particularly those directly affected by disaster, may feel pressured to consent to research participation out of a desire not to appear unpatriotic or unhelpful in a time of national need. Such individuals might include firefighters, police officers, and emergency services workers who respond to disaster. These workers, because of historic tradition and media portrayal as strong, brave, and heroic, may feel pressured to contribute to research efforts so as not to appear weak or disappoint their peers or supervisors.

Considering the circumstances of obtaining informed consent in the aftermath of disaster and the substantial need of victims, survivors and their families for care and comfort, the problem of what has been called the therapeutic misconception is very important in this context. Although research participants may very well benefit from research participation, as mentioned earlier, it is easy for both the potential participant in the research and the researcher to confuse the purpose of the research,

increasing knowledge, with the purpose of clinical care, direct benefit to an individual. Much research postdisaster is not explicitly therapeutic in intent and the informed consent process must make the purposes of the research clear and not exaggerate the benefits of interacting with the investigators when treatment is not an intended part of the research and potential benefits may be less predictable (Appelbaum, Roth, Lidz, Benson, & Winslade, 1987).

## Conclusions

Attendees at this meeting agreed that research postdisaster is extremely important and that it can be performed in an ethical manner. They concluded that there is a need for investigators, IRBs, and public health and government officials to have access to discussions of this type in the event of future disasters in order to assure that important research can be expeditiously reviewed and conducted in a manner that protects the interests of the participants. Survivors of the disaster, families of victims, and others who are potential participants of research should play a role in the development and implementation of research projects assuring adequate provisions for confidentiality of the data and sensitivity to the broad range of needs of those affected by the disaster.

Survivors and families are often in need of clinical, legal, and social services. Research should in no way interfere with the delivery of needed services with respect to the needs of individuals who are grieving and suffering. Research participation should be voluntary, and the decision whether or not to participate must not affect access to other services or treatments. Researchers must be particularly vigilant in ensuring that prospective study participants do not confuse research procedures with clinical care and evaluation and thus fall prey to the so-called therapeutic misconception.

Research by investigators who support the importance of the work may be benefited by thoughtful concern for subjects who may exhibit emotional or mental health problems that could impair decision-making or increase risk. Since research postdisaster is not always intended to benefit present participants, researchers must remember that subjects bear the burdens and risks of research in order to benefit future persons who will experience a disaster. Any information gathering activities in this context must acknowledge and adhere to the imperatives of doing no harm, placing the care and safety of victims and survivors above all else, and coordinating with assistance efforts. Where relevant, this realization should impact on research design and IRB review and be reflected in the informed consent process.

Administrators and IRB members who are charged with protecting the interests of human participants in research may be benefited in their considerations by having access to data on the low likelihood of significant risk of research postdisaster when conducted in appropriate settings with sensitivity to the needs of the participants. Realizing that remembering and describing events in the research context, while potentially distressing to some, is quite different from experiencing the original trauma may help reviewers place this type of research in the proper context. Evidence of the important benefits that disaster-focused research participants experience may also be useful to reviewers when weighing the risk-benefit ratio of participation. The degree to which additional protection is afforded should be proportional to the potential risks to which participants are exposed.

Collaboration among investigators and coordination of research in order to decrease redundancy and burden on individual participants is an important goal. There are several ways in which this cooperation could take place. First, investigators and funders could seek to increase collaboration and decrease redundancy of research as much as possible. Second, local academic or governmental authorities might work with IRBs and researchers on a voluntary basis to assist in coordination and decrease redundancy and participant burden in research. Third, options for a more formalized central structure for protocol review and approval could be considered, as was done in Oklahoma. Whatever approach is taken to address this potential risk, important research should not be delayed by increasing the bureaucracy of the review process.

Finally, careful review of the extant literature in disaster-focused research reveals that there has been insufficient study of specific benefits and risks of research participation, rates and reasons for refusal, recruitment procedures, methods for involvement of members of affected communities, approaches to integrating provision of clinical and human services with research investigation, and creative and sensitive ways of obtaining informed consent. This is true for virtually all social science, mental health, and health services research and not merely related to research after trauma.

The attendees concluded that the following guidance could be offered as points to be considered in research postdisaster:

1. It should be assumed that, as a group, those affected by a disaster have the capacity to provide meaningful and voluntary informed consent to participation in research. When questions arise, individual assessments should be conducted. The decision to participate or not participate in re-

search is entirely the purview of the competent prospective participant.

2. Capacity assessment tools exist and should be utilized and capacity might need to be monitored over time; the level of risk of the research should determine the level of concern about capacity. One capacity assessment available to investigators is the MacArthur Competence Assessment Tool for Clinical Research (McCAT-CR) (Appelbaum & Grisso, 2001).
3. Disaster-affected populations should not necessarily be considered “vulnerable” in the regulatory sense. However, research proposals should address the individual psychological state of potential participants and have explicit mechanisms available for timely referral of subjects in need of mental health consultation, including training of investigators and research staff to recognize emotional problems in research participants.
4. Specific research proposals should be scrutinized based on the level of risk, the novel nature of the research, and the uncertainty of the risk-benefit ratio; such scrutiny may result in the need for additional procedural safeguards for that specific proposal.
5. There is a critical need for additional research on the risks and benefits of participation in disaster-related research. It is important to study the effect of the research itself on participants and whether their experience of participation was what they had expected based on the enrollment process.
6. Ideally, representatives of the community who will be participants of the research should have some level of involvement in the planning and implementation of the research.
7. Information for potential participants about a research project should make clear whether there is therapeutic intent. Informed consent procedures should reduce the likelihood of participants mistaking research for clinical services (the therapeutic misconception).
8. The setting for the explanation of the research should be a safe, controlled environment conducive to making an informed decision about participation.
9. Provisions for confidentiality of the data and protection of the privacy of the subjects should be an explicit part of the research plan.
10. Proposals should have explicit plans for the training and support of research staff who will be exposed to the emotional challenges faced by research participants.

11. Participants in research postdisaster should be informed of the results of studies in which they have participated.
12. Coordination and collaboration among researchers and IRBs may help minimize redundant research and participant burden; various models should be considered to facilitate such coordination without unduly impeding research.

The research community that has focused its attention on assessing and minimizing the impact of terror and disaster on affected individuals and communities has made major contributions to enhancing knowledge, services, and outcomes for countless victims and their families. This community can continue to serve victims and survivors of traumatic events by maintaining sensitivity to the needs of this population and striving to understand more about the effects of trauma and trauma-focused research participation while continuing with their important work.

#### **Appendix: Meeting Attendees**

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