

WORKING P A P E R

Ethical Principles in Social- Behavioral Research on Terrorism

Probing the Parameters

WORKSHOP PROCEEDINGS EDITORS:
TORA K. BIKSON, RICKY N. BLUTHENTHAL,
RICK EDEN, AND PATRICK P. GUNN

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PREFACE

This RAND working paper documents the proceedings of a daylong workshop, "Ethical Principles in Social-Behavioral Research on Terrorism: Probing the Parameters." The workshop was convened to initiate a public discussion of the parameters that should guide the ethical conduct of social and behavioral research on terrorism that is frequently carried out in countries or among groups hostile to the United States. The workshop was organized into three sessions on the topics of "Deception and Concealment vs. Autonomy," "Maximizing Beneficence and Maintaining Justice," and "Ensuring Confidentiality." Each session included a main speaker followed by short presentations from an expert panel, a plenary discussion, and a wrap-up by the session chair. All proceedings were taped and transcribed. The transcriptions of the presentations by the speakers and panelists have been lightly edited to improve readability, as have the introductory and wrap-up comments by the workshop organizers. The transcriptions of the plenary discussions have been summarized to highlight the main points.

Workshop attendees included a variety of individuals knowledgeable about and engaged with social and behavioral research in ways that are, or could become, relevant to terrorism research. Among the stakeholders represented were researchers on terrorism, research ethicists, professional societies with pertinent codes of ethics, major funders of social and behavioral research related to terrorism, institutional review boards (IRBs) that have dealt with such research, and the Office of Human Research Protection, Department of Health and Human Services (DHHS), which is charged with issuing guidance to all who are bound by the Common Rule (45 CFR [Code of Federal Regulations] 46).

These proceedings should be of interest to everyone who is concerned with understanding how social and behavioral research on terrorism can comply with core ethical principles for human subjects protection. In particular, the proceedings should be useful to social and behavioral science researchers as they design studies of terrorism that combine methodological rigor with an equally robust ethical concern

for protecting human subjects; to program officers in federal funding agencies and other sponsoring organizations who need to appreciate the ethical parameters that may inform the social-behavioral research they can expect to support; and to IRBs whose members are challenged to make project-specific ethical decisions about social-behavioral research on terrorism. Additionally, the workshop proceedings may interest human research ethicists in general, and may be of particular interest to those who endeavor to understand and interpret the application of the Belmont Report principles in international research arenas.

The workshop was held at the RAND Corporation's offices in Arlington, Virginia, on January 10, 2007. It was supported by grants from the National Science Foundation and the National Institute of Justice, with supplemental funding by RAND.

These workshop proceedings can be obtained by contacting Michael Woodward at 310.393.0411 x6595 or michaelw@rand.org. They are also available online at http://www.rand.org/pubs/working_papers/WR490-4/. Questions, suggestions, and comments should be directed to Dr. Tora Bikson (tora@rand.org).

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SUMMARY

As the word *probing* in the title suggests, the workshop addressed unresolved issues for which insights are needed from representative, knowledgeable experts. The goal was to arrive at well-grounded and consensual parameters for ethical decisionmaking in social-behavioral research on terrorism. Increasingly, RAND and other research institutions are being asked to help answer profoundly important policy questions about the antecedents, processes, and consequences of terrorist actions against civil society in the United States and abroad. What conditions influence individuals to undertake such actions? How do these individuals find like-minded others to engage in actions that require shared effort? How are such collaborations organized and supported? What are the scope and longevity of these social networks?

Questions like these are viably pursued with well-established social and behavioral theoretical frameworks plus research procedures that include, but are not limited to, interviews, surveys, and focus groups. However, unusual factors in this research environment raise ethical concerns not present in other contexts, particularly when the research is to be conducted outside the borders of the United States. These ethical concerns can be grouped into three categories: deception and concealment vs. autonomy, maximizing beneficence and maintaining justice, and ensuring confidentiality.

Deception and Concealment vs. Autonomy

Deception (misleading a subject concerning certain facts about a study) and concealment (withholding facts about a study) sometimes seem to be the only valid means for conducting certain behavioral research. For example, in conducting surveys or interviews to assess the prevalence of racial prejudice in a given population, researchers may not want to disclose the study's purpose, since doing so could prompt subjects to shade their responses, rendering results invalid. Likewise, researchers conducting focus groups or surveys to gauge attitudes and

beliefs among certain populations on issues related to terrorism may view some degree of deception and/or concealment as essential to their projects. For example, among some populations, antipathy toward the United States may be such that disclosure of who is sponsoring the research, who is conducting it, and/or its purpose could lead to high refusal rates, unrepresentative participants, and/or skewed responses.

There has been a long-standing debate among researchers and ethicists about the propriety of deception and concealment, with some arguing that such techniques are improper under all circumstances because they are inconsistent with a subject's right to make an autonomous, free decision about whether to participate. The Common Rule requires that subjects be given all information needed to make a fully informed and voluntary decision about whether to take part in research. However, the Common Rule also allows an institutional review board (IRB) to waive some or all elements of informed consent if certain conditions are met. Some IRBs have interpreted this waiver provision as permitting the use of deception or concealment in limited cases, provided the misstatements or omissions do not increase risk to subjects and do not relate to facts material to a subject's decision to participate. The lead agency charged with interpretation and oversight of the Common Rule, the Office for Human Research Protections, Department of Health and Human Services (DHHS), has issued no formal guidance on the use of deception and concealment in research. For these reasons, the proper parameters of deception and concealment under research covered by the Common Rule merit concerned and careful deliberation.

This session opened with a presentation by Dr. Franklin (Frank) G. Miller from the National Institutes of Health (he presented his own views, not those of the agency) titled, "Deception, Respect for Persons, and Informed Consent." Dr. Miller noted that deception takes many forms in research, including misleading disclosures, fake or rigged procedures, play-acting by the researcher and confederates, covert procedures, and undercover observation. He noted that the use of deception not only violates the autonomy of research subjects but may cause them distress when the deception is discovered or revealed. To make deceptive studies compatible with the spirit of informed consent,

Dr. Miller suggested consideration of "authorized deception," in which prospective subjects are informed of and consent to the fact that research will involve the use of deception. Dr. Miller proposed experiments to determine how authorized deception may affect scientific validity. In addition, Dr. Miller argued that when researchers publish deception research, they should have to justify the use of deception, and he proposed reporting standards. He concluded that deception should be limited to studies in which its use is necessary to answer a valuable research question and that, if used, it should be authorized.

Following the comments by the expert panel, an open plenary discussion focused on the following areas:

- The need to consider the basis for applying ethical restrictions on the use of deception in research vs. other activities in which deception may take place
- Common types of deception proposed for terrorism research
- Ethical vs. unethical uses of deception in research
- The ethics of conducting research within the context of groups in conflict
- The effects of deception on the value of scientific research on behavior
- IRB development and capacity building.

Maximizing Beneficence and Maintaining Justice

The Common Rule derives from many sources, including the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). One of the three core principles identified in the Belmont Report is "beneficence," which requires that research protocols maximize potential benefits to subjects and minimize harms. Although taking part in routine social/behavioral research procedures usually poses little risk, it is unclear what the risk exposure might be to subjects who express extremely violent or radically moderate views of terrorist activity. In addition, in certain situations, participation in U.S.-sponsored projects might in and of itself be a source of risk to subjects should persons outside the research context learn of it. Another core principle of the Belmont

Report, that of "justice," requires that researchers seek to ensure that those who bear the burdens of research share equally in its benefits. It would appear difficult to reconcile this principle with many studies of terrorism, particularly those that involve overseas populations. How researchers might approach these issues in such environments has received little attention in the literature.

Session two opened with "Assessing Risks, Minimizing Harms, and Promoting Justice for Participants in Research on Terrorism: An Ethical Conundrum of Restraint and Possibility," a presentation by Dr. Patricia Marshall from the Department of Bioethics in the School of Medicine at Case Western Reserve University. Dr. Marshall noted that terrorism research is conducted in a complex social context with many stakeholders, both national and international. Although perspectives among stakeholders vary, there is general agreement that research on terrorism can potentially present a number of harms to subjects, as well as to researchers themselves. Potential harms to subjects that need to be mitigated include physical harm, psychological harm, social harm, economic harm, legal harm, and dignitary harm (i.e., not treating a subject or the subject's value system with full respect). Drawing on her experience in conducting ethical research in low-resource settings, Dr. Marshall offered a framework for fostering trust among stakeholders in terrorism research so that conducting research will be less risky. The framework's key principles are collaborative partnerships, capacity building, and respect for persons and communities. She noted that transparent research (i.e., research that is not deceptive) helps to build trust among stakeholders and to create conditions favorable to sustaining research in a setting or population. She argued against treating research on terrorism as an exceptional case that requires new regulations. Rather, additional guidance is needed to help IRBs identify and balance harms, risks, and benefits of proposed studies on terrorism using the ethical framework of the Common Rule. As an example, she suggested that when an IRB evaluates benefits in terms of how a proposed study might contribute to existing knowledge, it should do so in the context of a full range of information from existing sources, including journalism and media.

Following the comments of the expert panel, an open plenary discussion focused on the following areas:

- Lessons learned from research on offenders and criminal behavior and possible relevance to research on terrorism
- Issues regarding dual use of terrorism research
- Potential inconsistencies in applying principles of beneficence and justice when researchers and participants represent avowed enemy groups
- Dignitary harm and paternalism.

Ensuring Confidentiality

The Common Rule obligates researchers to provide robust protection for the resulting data so that confidentiality is not breached either inadvertently (e.g., by a focus group member recognizing another participant) or intentionally (e.g., via data seizure). In the case of research on terrorism, researchers may face particular challenges in seeking to protect confidentiality. For instance, if project data were brought back to the United States, it is possible that they could be obtained by law enforcement without a search warrant and under certain provisions of the USA PATRIOT Act. Also, in cases where data are collected abroad, it may be unclear how local police, security agencies, or military organizations would regard compliance with confidentiality assurances provided to subjects. These are matters that warrant serious discussion.

Dr. Eleanor Singer of the University of Michigan opened the third session with a presentation titled, "Confidentiality in Terrorism Research: Can It Be Assured?" Dr. Singer noted that it is important to protect the confidentiality of subjects not only for ethical reasons but also for practical ones, because worries about confidentiality reduce research participation. Confidentiality is a salient concern in terrorism research because interest in the subjects and their information may be shared by many parties, including military, intelligence, law enforcement, and terrorist organizations. Breaches of confidentiality can arise not only from carelessness but also from illegal intrusions, legal requests, and statistical inference. The IRB

needs to consider how much risk it will permit potential participants to undergo. A breach of confidentiality in a study of terrorism may expose subjects to very severe harms, including imprisonment and death. Breaches of confidentiality can also harm the researchers, the study sponsor, and the research enterprise. Dr. Singer concluded by noting the need to develop and implement strong and perhaps additional protections against breaches of confidentiality. The strength of certificates of confidentiality issued by federal agencies has apparently never been tested against demands for disclosure under the USA PATRIOT Act.

Following the comments of the expert panel, an open plenary discussion focused on the following areas:

- Ethical guidelines for whether, when, and how terrorism researchers should violate participant confidentiality (e.g., to prevent imminent harm to the participant or others)
- Expansion of IRBs to include persons with international research experience or to include outside experts
- Strengthening the legal bases for assurances of confidentiality.

Conclusion

The ethical concerns examined in this workshop threaten to preclude meaningful social and behavioral research on issues of vital worldwide significance or to lead to its pursuit in ethically inconsistent, ad hoc, or even negligent ways. In the long run, it is unwise to handle such concerns on a project-by-project or institution-by-institution basis, since they will be faced by many research organizations and research sponsors across the country. Instead, a national dialogue aimed at responding to questions about how principles of research ethics are to be applied to this emerging new policy domain is urgently needed.

The workshop was designed and conducted on the assumption that, while reasonable people in diverse settings will disagree about the appropriate response to an ethical question in any particular research

context, it is possible to aim for consensus on the general parameters that should guide ethical decisionmaking across cases.

ACKNOWLEDGMENTS

The editors wish to thank the many individuals and organizations that contributed to the design, funding, execution, and documentation of the workshop on "Ethical Principles in Social-Behavioral Research on Terrorism: Probing the Parameters."

The workshop was supported by grants from the National Science Foundation and the National Institute of Justice, with supplemental support from RAND.

Dr. Patricia Marshall of Case Western Reserve University, Dr. Franklin G. Miller of the National Institutes of Health, and Dr. Eleanor Singer of the University of Michigan presented papers to open each session.

In each session, the main speakers were followed by presentations by an expert panel. Panelists included Mumtaz Ahmad, PhD (Hampton University), Sandra H. Berry, MA (RAND), Michael R. Cunningham, PhD (University of Louisville), C. Christine Fair, PhD (U.S. Institute of Peace), Jerrold D. Green, PhD (RAND), Shireen T. Hunter, PhD (Georgetown University), Brian A. Jackson, PhD (RAND), Robert J. Levine, MD (Yale University), Mary E. Losch, PhD (University of Northern Iowa), Ivor Pritchard, PhD (Office for Human Research Protections), James R. Sayer, PhD (University of Michigan), and Michael Traynor (Senior Counsel at Cooley Godward Kronish LLP and current president of the American Law Institute). Short biographies of all presenters appear in Appendix A.

The expert panels were followed by plenary discussions that elicited insightful comments from attendees, for whose contributions we are very grateful. Appendix B lists all attendees.

The editors extend a special thanks to Michael Woodward of RAND, who provided administrative support to the workshop and to the production of this working-paper documentation of the proceedings.

1. INTRODUCTION BY MICHAEL RICH

Good morning. My name is Michael Rich. For the last 14 years, I have served as the Executive Vice President of the RAND Corporation, which is the second ranking position at RAND. One of my duties is to serve as the Chief Institutional Officer overseeing our institutional review board, which is charged with ensuring that all human subjects research at RAND complies with the body of general regulations that have come to be known as the Common Rule.

Welcome to RAND this morning, and thank you all for participating in today's workshop on ethical principles in social-behavioral research on terrorism.

I want to begin by saying a few words about the RAND Corporation and the nature of the research we conduct, which includes a great deal of human subjects research and a long and important stream of research on terrorism and counterterrorism. Then I will tell you why I believed a workshop like this one was needed.

RAND is often called the original think tank, but we're actually quite different from the many organizations that use that term today. RAND is a stand-alone nonprofit organization that was created at the end of World War II, as were many scientific establishments in the United States. RAND was founded on the very simple proposition that rigorous objective analysis made for better policy and better policymaking. For reasons I won't go into now, we spent the first 20 years of our existence working exclusively for the Department of Defense, initially for the Air Force, and then, the rest of the Department of Defense. Much of our early reputation, mystique, and sometime notoriety was derived from our research for the Pentagon.

In the middle of the 1960s, now over 40 years ago, RAND recognized that all of the techniques and research methods that we were using to study issues relating to national security were just as applicable to problems of social and economic policy. That realization launched a diversification effort that was actually quite aggressive. By the time I arrived at RAND, which was in the mid-1970s, our work with the

Pentagon was only one-half of our total research activity. We had developed very active research programs in many areas of social policy, including health care, education, criminal justice, energy and the environment, infrastructure, and many more. In the same time frame, we established one of the first seven graduate schools in public policy. The Pardee RAND Graduate School is now the largest doctoral program in that field.

The difference today between RAND's national security research and what we term domestic research is probably not as distinct as it was in those years. Today, about 45 percent of RAND's research is conducted for clients and sponsors in the Department of Defense. In addition to that, we conduct over \$100 million of research annually for nondefense government agencies, for foundations, and for other clients, grantors, and donors on issues related to social and economic policy.

RAND's history of working with human subjects dates back to the beginning of our institution. Much of the early work at RAND in the late 1940s and early 1950s focused on the Soviet Union, a new adversary that was not understood well in the United States. There was precious little in the way of written information about the Soviet Union in those days. The ability of the United States to intercept communications was very crude, and in order to answer basic questions about how the politburo worked, how the economy was controlled, how the military operated, and how the Warsaw Pact Alliance was structured, the United States relied heavily on interviews of émigrés and defectors. RAND helped develop that research methodology and contributed heavily to that body of social and behavioral research.

RAND's programs of social and behavioral research grew markedly when we diversified in the 1960s and began addressing domestic questions of health care, education, crime, poverty, and so on. As a consequence, RAND has had a long history of grappling with a variety of tensions created by, on the one hand, an emphasis on methodological rigor and innovation and, on the other hand, stalwart respect for ethical principles guiding the protection of the human beings participating in our research projects.

I am proud to say that RAND instituted independent ethical review of its research projects well before such reviews were required by law. Like many of you who have played an active role in public commentary, RAND helped shape the evolution of those regulations.

That brings me to the origin and purpose of this workshop. About 18 months ago, in conversations with members of our institutional review board, I realized that current regulations and associated guidance were not adequate for helping our researchers and our IRB members grapple with the special circumstances they were encountering in the growing body of research that RAND was conducting on the antecedents, processes, and consequences of terrorism. The guidance we were getting from our usual sources was not adequate for these new kinds of research projects. For example, there was guidance about the appropriateness of deception and concealment, but it didn't seem to take account of some special circumstances present in certain kinds of research on terrorism. There was guidance on balancing the benefits and the risks to participants in research, but it didn't seem as helpful for a situation in which one group bore the risks and another group reaped the benefits. And there was the whole area of researchers' obligations to ensure confidentiality, where we needed to know whether assurances of confidentiality could still be given in an era of new intelligence and new law enforcement statutes and techniques, both in the United States and abroad, where we conduct much of the research. I concluded that there simply did not exist a coherent and accepted set of guidelines, a framework, for resolving any of these three sets of ethical issues. Additional guidance needed to be developed.

So, in November 2005, together with colleagues from the RAND IRB (whom I will introduce shortly), I spent several days talking to everyone we could think of in the U.S. government in a search for efforts under way to develop the kind of guidance that we thought we needed to address and resolve these issues. That is how I met many of you for the first time. Not only did we confirm there was insufficient formal guidance, but we learned that there wasn't any new draft guidance on the way, either.

The results of our search for guidance did serve to sharpen my concerns. I realized there were two potential bad outcomes of inadequate guidance. First, it was possible that research organizations like RAND might decline to do research that is vitally important, simply because they can't figure out, with confidence, how to address the protection of human subjects. Clearly, avoiding vital research is a very bad outcome. Second, and potentially just as bad, RAND and other research organizations might press ahead with research that is well intentioned, only to inadvertently commit important ethical mistakes that could harm the human subjects who participate in the research, and ultimately harm our organizations.

I believe it would be unwise for the research community to continue very long by handling these kinds of issues on a project-by-project or an institution-by-institution basis. The same issues are going to be confronting researchers and institutional review boards at many research organizations and universities across the nation. They need a common framework that can be used with confidence. That is why I initially conceived the idea of RAND organizing a workshop like this one, as a way of starting a discussion that will help develop the conceptual framework and the principles for resolving these questions so that human subjects research in this very important domain can proceed.

We found two generous cosponsors who provided funds for this workshop, and I want to acknowledge them: the National Science Foundation and the National Institute of Justice. Please join me in saluting them and thanking them for their leadership in this important activity.

I want to close by introducing two RAND colleagues who took what came from me as a rather inchoate idea for a workshop and made it something concrete: Dr. Tora Bikson and Mr. Patrick Gunn. Tora, whom many of you know, is a Senior Behavioral Scientist at RAND and the longtime chair of RAND's institutional review board. Patrick is a partner at Cooley Godward Kronish LLP, a San Francisco-based law firm, and also a member of RAND's institutional review board.

INTRODUCTION BY DR. TORA K. BIKSON

Good morning, everyone, and thank you for coming. It's my pleasure to report to Michael Rich, who is the responsible institution official for the IRB, and he takes that role very, very seriously. There is nothing like having someone at the top of the organization who really is concerned about human research participant protection programs to enhance their effectiveness and their influence on the ethical quality of its research.

As Michael Rich noted, RAND has been perplexed by problems of how to make decisions about the ethical quality of human subjects research involving terrorism. On the one hand, the research designs involve extremely ordinary behavioral research methods: surveys, focus groups, interviews. But they involve extraordinary problems because the researchers are in field settings that are unusual, posing risk both to the researchers and to the participants in the research. It, of course, occurred to us that RAND couldn't be the only institution with a Federalwide Assurance that was addressing research on the antecedents, processes, and consequences of terrorism with funding from agencies that are signatories to the Common Rule.

So we began to look for examples and precedents. What are other institutions doing? How are other IRBs responding? What are federal agencies saying about these issues? We looked in journal literature, we attended conferences, we searched online, and we found very little. Let me show you one case (see Fig. 1.1).

Post to irbforum.org
Date: 07-10-06 17:36

An investigator hopes to present fairly innocuous questions about dress to participant groups in the US and a country hostile to the US. Due to the dangers (to herself and to the participants seen cooperating with a US citizen), when in the hostile country, she plans to present herself as a citizen of the country (which she is, dual citizenship). Through a faculty member contact in the nation, she also plans to present herself as representative of a local university (which she is not). Again to protect the researcher and participants, no debriefing is planned.

This use of deception seems different from others I've seen as it is a misrepresentation of the researcher's identity rather than an aspect of the research methodology itself. It also seems like an unacceptable use of deception. It is quite likely that some participants would choose not to participate if fully informed about the investigator's true identity. Also, if the authorities somehow learned the truth (despite her safeguards), the participants might be placed at great risk.

So, my question is: Is there any way in which to conduct research such as this? I'm inclined to believe the investigator in her assertion that the research could not be carried out if her true backing was known, so fully informed consent appears infeasible, but the use of deception also sounds unacceptable. Any suggestions would be greatly appreciated.

Figure 1.1
Actual IRB Forum Posting

This is an IRB forum posting—it's the only actual example we were able to retrieve from the literature that seems to come close to the kinds of issues RAND was facing. I have removed the name of the poster because I'm not sure what the ethics are of presenting material that was aired in a venue where posters assume they are interacting with like-minded audiences. This was posted in July 2006, and the poster ends with a question very much like ours: "How can you do this kind of research ethically, or can you?" It looks as though it would be very difficult to apply the Common Rule principles in a context like this.

If we at RAND had been posting something, it might look like the following (see Fig. 1.2).

US researchers propose to study what Muslims in nonwestern countries think are "the greatest problems facing our religion today," what is the source of these problems, where do they go for what they regard as trustworthy information about them, and what do they think Muslims should do to address them. For this purpose the researchers plan to do neighborhood sampling in heavily Muslim-populated areas of a number of cities in countries that are generally hostile to the US; they will recruit men and women to participate (separately) in focus groups.

The researchers will employ in-country subcontractors to recruit participants and moderate focus groups. The US researchers will observe the focus groups through a one-way mirror, along with a simultaneous interpreter. The discussions will also be audiotaped for subsequent transcription and analysis. Because of likely participant antipathy to the US, the researchers do not plan to disclose that the study is funded by a US government agency or conducted by a US research institution; the real purpose of the research is also concealed. The researchers believe that if such information were provided, either no Muslims or only a highly unrepresentative sample would take part; additionally the researchers believe they and their subcontractors would be exposed to significant risk of harm.

Figure 1.2
Hypothetical RAND IRB Posting

I thought that, to spare you the entire research protocol, I should probably write up the project like the author of the previous posting and give you something quite short. This project proposes to conduct focus groups in countries where there is a significant amount of antipathy to the United States, particularly among Muslims, so it raises issues that are not unlike those addressed in the first posting. (I think both of these examples are included in your workshop packets.)

When we looked at these cases, we first asked ourselves, What if the design were changed? What if, for example, instead of focus groups, there were survey procedures? What if they were anonymous surveys? Could design changes like that significantly decrease the risk? What if sampling weren't neighborhood based? Or, what if neighborhood sampling were used mainly to assure that people from the same neighborhoods didn't end up in the same groups, if there were no good methodological substitutes for focus groups? More generally, we asked whether there are design parameters that, if changed, could alter the risk-benefit

ratio. We also asked ourselves, How could an IRB realistically assess the likely harms and likely benefits to participants in a diverse array of field settings? What kind of evidence would we want the researchers to bring to the IRB in a given case to convince us that there were benefits to participants that were at least equal to the risks? Further, assuming we could answer the questions about risks and benefits, how could an IRB justify the use of deception or concealment? As the author of the first posting suggested, the situations contemplated in research on terrorism are different from the standard sort of deception in which there is a particular hypothesis that the participants shouldn't know about because it might affect their responses.

We understood that the answers to these kinds of questions are highly dependent on the details of the specific research protocol, they're dependent on the very specific field context in which the research is being conducted, and they're dependent on the value commitments of the institution that's carrying out the research. So there is not going to be a simple, straightforward answer to any of the questions. On the other hand, we thought, as the title of this workshop suggests, that there are parameters to be probed. Possibly, a way of approaching the questions would be to say, What kinds of parameters should IRBs consider, should researchers consider, should funding agencies consider, when they're trying to make these kinds of ethical decisions? We assumed that, whereas there might not ever be a consistent agreement on answers to specific questions about specific research projects, we might, if we brought together varied stakeholders, come to some kinds of agreements on the parameters that merit consideration when ethical decisions about these kinds of research projects are being made.

Our charge to you today, therefore, is to please participate in all of the discussions. Everyone here wears multiple hats: you're researchers, you're funding agency people, you're people who are concerned with research ethics. Everyone is going to have opinions on many issues and experience with a number of them. We're hoping to identify, where we can, emerging themes or emerging areas of consensus

about the parameters for appropriate ethical decisionmaking. Where that's not forthcoming, we'd like to get a sense of whether there are sharp, well-defined value conflicts where we could conclude: "These are key issues where there is significant and serious disagreement." Or, potentially, we could identify areas that just require further scholarship and research, issues about which there's a great deal of uncertainty, but for which we might recommend either pilot projects or scholarly research that could further the deliberation in a given domain. These are our aims, and they constitute a big agenda.

Here are our plans for the next steps: We'll be taping all of the sessions and transcribing them. We'll give lead speakers back their own comments so that they can edit or revise them in light of the ensuing discussion. We'll do the same thing for each panelist. The workshop organizers will take responsibility for trying our best to summarize the discussion in the plenary sessions, and we will not identify specific individuals in our summaries of those discussions. Rather, our hope is to identify the common themes, conflicts, and uncertainties that emerge. We will try to get these workshop proceedings distributed back to everyone as soon as we reasonably can so that everyone here will have a copy and will be able to comment. We'll also ask for an external review of these proceedings. Our long-term aim is to look for a broader publication venue. We'll keep the distribution of proceedings limited so that we will subsequently be able to suggest that they become a special issue of a journal or some other more widely disseminated publication.

We have structured the workshop around three sessions, each addressing some of the most important questions that the RAND IRB raised in relation to this line of research on terrorism. In order to try to capture both depth and breadth, we've asked one lead speaker for each of the three main sessions to give us an in-depth picture of some of the key issues in the domain of concern. But in the interest of breadth, we've invited panelists to speak from their varying perspectives on the same issue domain. The panelists have not had the luxury of having an advance copy of the lead speakers' remarks; we knew that was unrealistic. So they will each be addressing the key concerns from

their own perspectives; they'll also have the first shot at raising questions in the ensuing plenary discussion, either to one another or to the lead speaker. I've asked Patrick Gunn, who is chairing the first session, to explain how the sessions are related to one another, and why they are organized as they are.

2. DECEPTION AND CONCEALMENT VS. AUTONOMY

- Moderator: Patrick P. Gunn, Partner, Cooley Godward Kronish LLP; Member, Institutional Review Board, RAND
- Presenter: Franklin G. Miller, PhD, Head, Unit on Clinical Research, Department of Clinical Bioethics, National Institutes of Health; Special Expert, National Institute of Mental Health Intramural Research Program, National Institute of Mental Health
- Panelists: Ivor Pritchard, PhD, Senior Fellow, Office for Human Research Protections, U.S. Department of Health and Human Services

Michael R. Cunningham, PhD, CIP, Professor of Psychology and Vice Chair, Social/Behavioral/Educational Institutional Review Board, University of Louisville

C. Christine Fair, PhD, Senior Research Associate, South Asia and Terrorism, Center for Conflict Analysis and Prevention, United States Institute of Peace

Sandra H. Berry, MA, Senior Behavioral Scientist; Professor, Pardee RAND Graduate School; Member, Institutional Review Board, RAND

INTRODUCTION BY PATRICK P. GUNN

Thank you, Tora. It has been my privilege for the past several years to work with a client like RAND, a client that's engaged in issues that really matter in a transcendent way, a way that's somewhat different from the typical matter that I deal with as a business lawyer

in a large law firm. And it's been a particular privilege, too, to work with Michael and Tora, and Rick and others at RAND, and to meet many of you over the past year in setting up this workshop. So, I wanted to start by thanking everyone for being here and being so committed and interested, and for participating in this important debate to try and move the ball forward and develop the guidance that Michael Rich had identified as being so lacking.

If you take a look at the agenda today, we've organized the discussion as follows: The first issue that we're going to be discussing is autonomy, with a specific focus on the proper parameters, if any, for the use of deception in the sorts of research on terrorism that are our focus. Second, we're going to discuss the Belmont principles of beneficence and justice, and how it is that we can be true to those in conducting this kind of research. Finally, we're going to talk about some methodological issues—specifically, ensuring confidentiality in this kind of research.

As Eleanor Singer and I were discussing just a few minutes ago, before we convened, there's a method behind that ordering. The discussion of autonomy and deception is, in many ways, a gateway issue. By that I mean that it introduces and touches upon the other issues that follow. The reason that's the case really flows from the principles and guidance that you find in both the Belmont Report and the Common Rule that govern an IRB's ability to waive elements of the informed consent requirement to allow deceptive protocols. I'm sure you're familiar with them, but just let me recap them now because I think they will illustrate how it is that beginning our discussion with autonomy leads us to and allows us to open up and discuss the other two issues.

First, an IRB can't approve a protocol that waives informed consent in a study that's other than minimal risk. Second, the IRB has to make a determination that there's no adverse effect on the rights or welfare of the subject. Third, the investigators have to demonstrate to the IRB that the research will not be practicable without some waiver of the informed consent process. And finally, if appropriate, there should be some provision that enables the subjects to be debriefed, post-

research, and apprised of the specific matter about which they were deceived.

Necessarily then, the IRB, in determining a request for a waiver of informed consent to allow some type of deception, has to do at least three things. First, the IRB has to identify the risks that are present. Second, the IRB has to assess or make an effort to assess the degree of risk that's present. And then, the IRB also then has to engage in a weighing process to evaluate the justification being advanced by the investigator for the waiver in the first place.

Anytime the IRB is engaged in considering issues of risk and potential harms that might befall the subject from a deceptive protocol, necessarily, the Belmont principle of beneficence is implicated. That's because beneficence, of course, focuses on maximizing benefits and minimizing potential harms.

Second, when there's any discussion about benefits and harms, we go back to the point that Michael Rich made earlier about justice. There necessarily are questions about the allocations of those benefits and harms, and one can understandably ask questions about the type of research we're discussing today as to whether there are certain populations—perhaps populations abroad that are poorly represented in the United States—who are bearing the burdens, ostensibly, at least, of research whose benefits might only flow to those people here in the United States.

Now, finally: confidentiality. There are many risks or potential risks that might be attendant on the type of research we're talking about today. But one risk that does seem to come up fairly consistently is the risk posed by breach of confidentiality. For the IRB to weigh and assess that risk, the IRB has to understand a few more things. It has to understand, first, something about the specific nature of the data being gathered. Second, the IRB has to have some understanding of the local context and conditions where those data are gathered, and also about where the data are going to be stored. And then, finally, the IRB has to understand something about the protocols that the investigator has in place to ensure confidentiality.

In referring to autonomy as a gateway, or threshold, issue, I, of course, don't intend to minimize the importance of autonomy on its own. I think, as some of you have observed to me, and I certainly agree, we could probably spend a day—indeed, we could probably spend a week—grappling with the issue of deception: both the propriety of deception as a philosophical matter and, if we concede that deception might be appropriate in certain circumstances, the proper parameters for deception.

There are many others in this room who have done a lot of thinking in a lot more depth than I have about this, and, thankfully, my role here is to pose questions rather than to answer them. We have some superb panelists and superb speakers who have devoted significant parts of their careers to addressing these issues. I will now introduce Frank Miller, who is going to be the first speaker. Frank is going to speak to the issue of deception and to the issue of autonomy. His presentation, as you'll see, is captioned "Deception, Respect for Persons, and Informed Consent."

Frank is the Head of Clinical Research in the Department of Clinical Bio-Ethics at NIH. He is also a Special Expert at NIH's Intramural Research Program. His principal current research interest is examination of the ethical issues in clinical research, including placebo-controlled trials, placebo surgery, use of deception in psychiatric research, and the ways in which clinical research differs from medical care. He serves on the IRB of the Intramural Research Program for NIH and the Ethics Committee for the Clinical Center at NIH. He also co-leads a seminar for psych research fellows on ethical issues in psychiatric research and coordinates bio-ethic seminars for first-year fellows at the Department of Clinical Bio-Ethics. From 1990 to 1998, he was on the faculty of UVA, where he taught courses in bio-ethics. He has published numerous articles in the area. He is a fellow at the Hastings Center, a faculty affiliate at the Kennedy Institute of Ethics, and an Associate Professor of Public Health in the Division of Medical Ethics at the Department of Public Health Medical College. He received his PhD in philosophy from Columbia. So with that, I'll turn it over to Frank.

PRESENTATION BY DR. FRANKLIN G. MILLER, "DECEPTION, RESPECT FOR PERSONS, AND INFORMED CONSENT"

It's a pleasure and a privilege to be here today to talk with you about deception. I'm going to be talking about deception in research mainly from the perspective of the principle of respect for persons or, more specifically, the tension between the need to promote scientific validity in research and respect for persons. I work for the federal government, so I need to tell you that these are my views, not the views of the government.

Disclaimer

- The views presented are mine and do not reflect the position or policy of the National Institutes of Health, the Public Health Service, or the Department of Health and Human Services.

Figure 2.1
Disclaimer

Overview

- Outline nature of deception
- Discuss why deception matters ethically
- Present “authorized deception” approach
- Pose queries about deceptive research
- Recommend standards for discussing deception and safeguards in published articles.

Figure 2.2
Overview

What I'm going to try to do this morning is to outline briefly the nature of deception in research, to discuss why deception matters from an ethical point of view, and to present what my colleagues and I call the Authorized Deception Approach to Deceptive Research. Then I'm going to pose a series of questions, hopefully to stimulate discussion about deceptive research. And then, finally, I'm going to touch briefly on some of the standards I think we need for discussing deception and the use of safeguards for deception in published articles.

Use of Deception

- Deception is frequent in psychology, neuroscience, and behavioral research.
- Purpose of deception is to promote scientific validity: obtain unbiased data about attitudes and behavior.

Figure 2.3
Use of Deception

Deception, as you all know, is quite frequent in psychological research, in neuroscience and social and behavioral research. And the purpose is to promote scientific validity, to obtain unbiased data about attitudes and behavior. In a wide range of aspects of human behavior, if subjects know the nature of the research, what the researchers are trying to find out, this could promote biased responses, which deviate from the truth. Hence, the use of deception. That sets up the basic conundrum of deceptive research, which is the tension between scientific validity and respect for persons.

What is Deception?

- Deliberately misleading communication about purpose or nature of research
- Deception in research needs to be seen against the background of a prima facie duty of truthful disclosure (transparency) and consent.

Figure 2.4
What is Deception?

It's not entirely clear exactly what deception is or, more specifically, what counts as deception and what doesn't. I propose, as a working definition, that deception is deliberately misleading communication about the purpose or the nature of research, where communication should be understood broadly, not just as verbal communication. Because we're talking about deception in research, we need to look at it against a background of an obligation of truthful disclosure or transparency, and of consent. I thought it might be helpful to suggest a typology that illustrates some of the various forms of deception that you find in research.

Typology of Deception

- Misleading disclosure
 - Lack of accurate disclosure by withholding specific information about research
 - Misinforming subjects about the research
 - Distinct from disclosed concealment in double-blind placebo-controlled trials
- Fake or rigged instruments or procedures

Figure 2.5
Typology of Deception

First, and probably foremost, is misleading disclosure. The most benign form would be the lack of accurate disclosure about the research by withholding specific information about it. Very often there will be a vague description of the purpose of the research, say in an informed consent document, which doesn't state specifically what the research is about. Somewhat more problematically, there can be deliberate misinforming of subjects about the nature of the research. I think it's helpful to see that these two forms are distinct from the type of disclosed concealment that you have in the double-blind controlled trial. Because there, subjects are told that neither they nor the investigators will know what treatment a subject receives. Thus, there's concealment, but there isn't deception, at least in the sense of misleading communication about what's going to go on in the research.

Secondly, there can be faked or rigged instruments or procedures; going back to the famous Milgram experiment, the fake shock generator would be an example of that.

Typology of Deception

- Misleading play-acting in experimental design: researcher, confederates
- Covert procedures: e.g. observation behind one-way mirror
- Covert research
 - Undercover observation
 - Staged experiment in public place

Figure 2.6
Typology of Deception (cont'd)

Thirdly, the researchers or other members of the research team can play misleading roles. Play-acting is a part of experimental design. Fourthly, there could be covert procedures—for example, observation behind a one-way mirror. Actually, both of these forms were also present in the Milgram experiment. And, then, there can be more purely covert research, undercover observation, or a staged experiment in a public place.

Irony of Deception in Science

- Science aims to learn and communicate the truth.
- Research may require deception to learn the truth about attitudes, motivations, and beliefs and their effects on behavior.
- If so, then the end of learning the truth is pursued by the means of untruth.

Figure 2.7
Irony of Deception in Science

I think there's a certain irony about deception in science because science aims to learn and communicate the truth, whereas research may require deception to learn the truth about attitudes or motivations or beliefs and their effects on behavior. If so, then this aim of learning the truth is going to be pursued by the means of untruth. And I think scientists should be given pause by the use of deception given their commitment to the truth.

Does Deception Matter?

- Deception is prevalent in ordinary life and often considered justified to be polite and not hurt others' feelings.
- Why, then, should we care about deception in research?
 - In research subjects are not being deceived for their own benefit.
 - They are deceived for the purpose of developing socially valuable knowledge.

Figure 2.8
Does Deception Matter?

Does deception really matter? What's the big deal? Deception is quite prevalent in ordinary life. It is often considered to be justified, to be polite, not to hurt other people's feelings. We often don't tell the truth about how we feel or how we think in ordinary communication. We even are quite comfortable with very elaborate deceptions like surprise parties. Why, then, should we be concerned about deception in research?

Ethical Problems with Deceptive Research

- Violates respect for persons
 - Manipulates people to do something that they otherwise might not want to do.
 - Violates right to choose what to do based on relevant information.
- Deception may cause distress when discovered.
- If use is not disclosed in advance, it violates informed consent.

Figure 2.9
Ethical Problems with Deceptive Research

First of all, research subjects are not being deceived for their own benefit. So unlike ordinary deception, which we think is justified for other people's benefit, this is not coming into play here. They're being deceived for the purpose of generating knowledge. And clearly, deception, on its face, violates the principle of respect for persons. It can manipulate people to do something that they otherwise might not want to do, and therefore violates their right to choose what to do with their life based on relevant information. It may cause distress when it's discovered. And if its use is not disclosed in advance to subjects, it violates informed consent. It also may promote distrust in science.

Ethical Problems

- Deception can be corrupting
 - Moral character depends on habits of conduct.
 - Practice of deception in research may interfere with the disposition not to lie or deceive.
 - This is a matter of concern both for those who do the deceiving and other professionals or students who witness deception.

Figure 2.10
Ethical Problems

Furthermore, there's some reason to be concerned that deception is potentially corrupting. According to an old tradition in moral philosophy, character depends on habits of conduct. And so, the practice of deception in research may interfere with norms not to lie, or to deceive; and I think we should be concerned about this, not only for those who do the deceiving, but for others who may be witnessing it.

Is Deception Necessary?

- Deception should not be used if non-deceptive alternatives are available.
- Deception should not be used unless research has adequate potential value sufficient to justify risks associated with deception.

Figure 2.11
Is Deception Necessary?

So given these ethical concerns about deception, a basic question in thinking about any research project is, Is deception really necessary? There is a consensus that deception should not be used if a nondeceptive alternative is available. Therefore, it is important to be confident that, in order to answer the scientific question, you need to use deception; and that the research has sufficient value to justify any risk of a study, in general, and risk specifically associated with deception.

Does Debriefing Neutralize Deception?

- Debriefing mitigates the harm and wrong of deception by explaining the rationale for the deception.
- It does not cancel the violation of respect for persons.
- Retrospective endorsement by deceived subjects is not the same as prospective informed consent.

Figure 2.12
Does Debriefing Neutralize Deception?

Debriefing is a very common procedure in deceptive research, which is to tell subjects, at the end of their participation, the nature of the research and the exact procedures—in a sense, to undo the deception which was going on. It certainly can mitigate the harm and wrong of deception by making subsequently transparent what was going on in research. But I don't think that cancels the violation of respect for persons, just as restitution for a crime doesn't cancel the wrong. And even if there's some sort of retrospective endorsement by deceived subjects that comes through the debriefing process, that's certainly not the same as prospective informed consent.

Can There Be Informed Consent to Deceptive Research?

- Subjects can be told that an experiment will not be described accurately or that some procedures will be deceptive.
- Soliciting prior authorization for deception is key to making deception compatible with spirit of informed consent.
- Prospective subjects can decide whether or not they want to participate in research involving deception.

Figure 2.13

Can There Be Informed Consent to Deceptive Research?

Can there be informed consent to deceptive research? Well, it's fair to say there can't be fully informed consent because, typically, informed consent involves informing people accurately about the nature of the research and the procedures—something that can't be done in deceptive research. But subjects can be told that an experiment will not be described accurately or that some of the procedures will be deceptive. And soliciting this prior authorization for deception is, I think, a key to making deception compatible with at least the spirit of informed consent. And, then, subjects can decide whether or not they want to participate in research involving deception.

Suggested Consent Language

- “You should be aware that the investigators have intentionally misdescribed certain aspects of the study. This use of deception is necessary to conduct the study. However, an independent ethics committee has determined that this consent form accurately describes the major risks and benefits of the study. The investigator will explain the misdescribed aspects of the study to you at the end of your participation.”

Figure 2.14
Suggested Consent Language

I will now present some suggested generic language that can be used, obviously with modification, depending on the nature of the protocol. “You should be aware that investigators have intentionally mis-described certain aspects of the study. The use of deception is necessary to conduct the study; however, an IRB has determined the consent form accurately describes the major risks and benefits of the study, and the investigator will explain the mis-described aspects of the study to you at the end of your participation.”

Virtues of Authorized Deception

- Authorized deception (AD) makes process of deceptive research transparent.
- Subjects informed that:
 - They will be misled or deceived
 - No important risks have been concealed
 - Independent committee has approved
 - Debriefing will occur.

Figure 2.15
Virtues of Authorized Deception

There are certain virtues to this approach of authorized deception. It makes the process of deceptive research transparent, because subjects are told that they will or may be misled or deceived, that no important risks have been concealed, that there has been an independent ethics committee which has approved the research, and that there will be some sort of process of debriefing at the end.

Limitations of AD

- Telling subjects that deception will/might occur may make them suspicious, thus possibly leading to biased data.
- Using the AD approach in current research reduces the comparability to previous research.

Figure 2.16
Limits of Authorized Deception

But there are also some limitations of the authorized deception approach. The key one is that there's concern that telling subjects that deception will or may occur might make them suspicious about what's going on. This may lead to biased data. Also, using the authorized deception approach in current research may reduce the comparability to previous research which did not use that method. Most deceptive research does not use the authorized deception method. If the authorized deception method doesn't bias the data, then we don't really have to be concerned about the comparability. And I think there's still the issue of whether comparability itself is a sufficient concern to perpetuate an ethically problematic practice.

Limitations

- Disclosure of deception may lead to reduced subject enrollment.
- AD is impossible in covert research that cannot be conducted with consent.
- Does AD compromise scientific validity?

Figure 2.17
Limitations

Disclosure of deception to prospective subjects may reduce enrollment. We don't really know whether this would occur; but if it would occur, I think it tells us that people don't want to be deceived. I think that it's important to give people the chance to make their views felt. Finally, there are some kinds of research, particularly covert research, where it may be impossible or not feasible to use authorized deception because there isn't any consent process whatsoever, and also no debriefing. So the scope of authorized deception has some limitations, and they may be particularly relevant to some research involving terrorism. But the basic question is whether the authorized deception approach compromises scientific validity.

“Prebriefing” Experiment

- Study of attribution of responsibility for rape based on trial transcripts Weiner R, Erker P. J of Psychology 1986;120:397-410
 - 68 college psych students either correctly informed or misinformed about jury verdict.
 - Half received consent document stating that “you may be purposefully misinformed.”
 - No differences on attribution of responsibility depending on whether or not subjects alerted to possibility of deception.

Figure 2.18
“Prebriefing” Experiment

There have been some interesting data on this. I was able to find one psychology experiment from the mid-1980s which involves a test of this authorized deception approach under the label of “prebriefing.” It’s a study of the attribution of responsibility for rape based on trial transcripts. The subjects were given summaries of transcripts of a trial; they were informed or misinformed about the jury’s verdict. And they were asked to make their own judgments about whether the defendant was innocent or guilty. It involved 68 college psychology students who were either correctly informed about the jury verdict or misinformed. That is, half of them received a consent form that told them that you may be purposefully misinformed. Half of them got the authorized deception approach, the other half got a disclosure typical of deceptive research—they were told nothing about the deception. The investigators found that there weren't any differences on the main outcome measure of attribution of responsibility depending on whether or not the subjects were alerted to the possibility of deception. There

are some questions about the generalizability of a study like this, particularly because, as in much psychology research, it involves psychology students, many of whom probably are aware that there is deception used in psychology research. And so that, in itself, may interfere with, or contaminate, the basic question about whether the authorized deception approach biases data.

Proposed Methodological Experiment

- Study of attitudinal/behavioral research on terrorism in volunteers recruited by advertisements.
 - Half of subjects not informed of deception
 - Half receive authorized deception approach
 - Investigate any differences in study outcomes depending on informed consent disclosure.

Figure 2.19
Proposed Methodological Experiment

I think we need to conduct further methodological experiments to see whether this approach—which makes it possible to use deception and at least be consistent with the spirit of informed consent—is consistent with scientific validity. You may want to consider, as part of your research portfolio here, doing a study that involves terrorism in which half of the subjects are not informed about the deception, and half of them do receive this authorized deception approach, and seeing if there's any difference in the study outcomes depending on the disclosure. I, myself, am in the process of planning a study with some

colleagues at Harvard in which we're going to test the authorized deception approach in research on the placebo effect in migraine using a fairly extensive deceptive study design. In this project, half the subjects will be told beforehand that some of what they are going to be told will not be the truth, and the other half will get the standard disclosure. And we're going to see whether that makes any difference in terms of people's expectations and responses to a drug.

Queries about AD

- If AD is necessary to justify deceptive research can it be ethical to conduct a methodological experiment comparing AD with the standard approach to deception?
- If AD is thought or found to compromise scientific validity, can deception be justified?

Figure 2.20
Queries About Authorized Deception

There are some basic queries one can raise about this authorized deception approach. If it's believed to be necessary to justify deceptive research, can it be ethical to conduct a methodological experiment that compares authorized deception with a standard approach? If one thinks that this is the only way you can ethically do deceptive research, the very experiment that I'm proposing involves at least half of people not getting it. So that, in itself, might be seen as a problem. But there isn't consensus in the ethics world about what the

requirements are for research involving deception, and getting some data on this authorized deception approach—or more data—would be quite useful. Therefore, I think that a methodological experiment of this sort could be justified. However, the authorized deception approach may be thought, or may even be found empirically, to compromise scientific validity, raising the basic question, Can deception be justified? And I can see people going two different ways. Some perhaps would say, “Well, if we can’t do deception via the authorized deception approach, we really should abandon deception entirely because it violates respect for persons and informed consent.” Others may say, “Well, there really is no alternative; there’s valuable research to be done. We should continue to do deception in the usual way without alerting people to the fact that deception will be involved.”

Queries about Deception and Consent

- Is complete lack of consent, as in much covert research, better or worse than distorted consent in research involving deceptive disclosure?
- Is withholding of accurate information about research less problematic than misleading disclosure about purpose or nature of research?

Figure 2.21
Queries About Deception and Consent

I want to raise a series of other queries for our consideration in thinking about deception and consent. First, Is complete lack of

consent, as in much covert research, better or worse than the partial consent that's typical in research involving deceptive disclosure? One might go both ways on this. No effort to get consent whatsoever seems deeply problematic. On the other hand, to invite people into a study under false pretenses is quite manipulative. Second, Is withholding accurate information about research, which may be the most common form of deception, less problematic than misleading disclosure about the purpose or the nature of research? It would seem that it's worse to lie than to not tell the exact truth; but this is a context in which there is an affirmative duty to disclose accurate information to subjects, so the distinction between omission and commission may not have that much force.

Queries about Debriefing

- Can debriefing be waived?
 - In much covert research debriefing may be impossible.
- Should investigators apologize or express regret for use of deception?
- Should debriefed subjects be given the option of withdrawing their data?

Figure 2.22
Queries About Debriefing

What about debriefing—is it a general requirement? Is it always necessary? Or are there situations under which it can be waived for a variety of reasons? When we're talking about covert research, it really

may not be possible or feasible to have a debriefing process. And that, in itself, raises some further concerns. When debriefing is done, should investigators apologize or express regret for the use of deception? If deception's wrong, it would seem reasonable to have that as part of the purpose of the debriefing process. A tricky question, but one that I think deserves serious consideration, is whether debriefed subjects should be given the right of withdrawing their data. They didn't have the opportunity truly to give informed consent up front; should they be able once they know what's going on to say, "Well, I'm sorry, I don't approve; you can't use my data"? There was some debate about this in the literature approximately 20 years ago.

Deceptive Research and Public Accountability

- Published articles represent the public face of science.
- Published articles should satisfy public accountability for violating respect for persons and informed consent by discussing the use of deception.

Figure 2.23
Deceptive Research and Public Accountability

Now, I'd like to shift gears for a couple minutes to talk about how to handle deceptive research in published articles, because I think that's an area that deserves more attention. I see the published literature as the public face of science. Therefore, the literature

should satisfy public accountability for the violation of respect for persons and informed consent that's involved in deceptive research by explicitly discussing the use of deception.

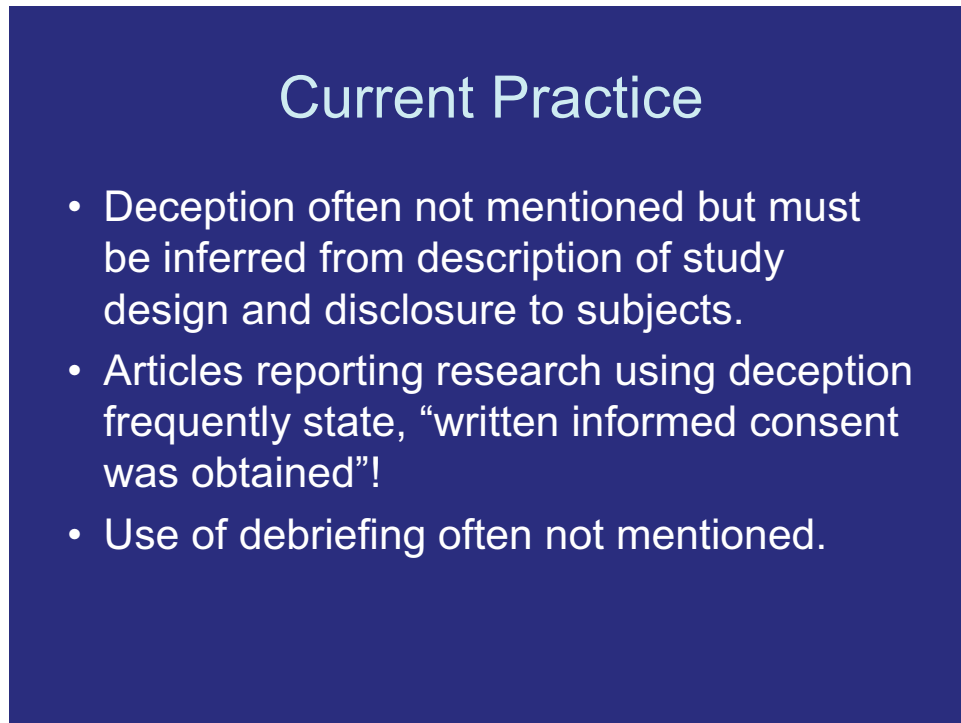


Figure 2.24
Current Practice

The current practice leaves a great deal to be desired. When one is looking for examples in the literature of deceptive research, it rarely comes labeled as deceptive. One needs to read the report and to infer from the description of the methods that there was deception going on. And in these articles, it's curious, but typical, that one sees this boilerplate statement: "Written informed consent was obtained." Now, what does that mean—if the research involved deception—that written informed consent was obtained? The concern is particularly strong if the research did not involve the authorized deception approach, which it typically does not. If you see informed consent merely as a signing of a consent document, then this statement is true; otherwise, it seems to be quite misleading. And so, in a sense, the published literature that

involves research using deception is perpetuating deception in the way that it's being presented to the research community. Also, debriefing, sometimes but not always, is mentioned.



Figure 2.25
Discussing Ethical Issues

I propose that articles discuss these key aspects of deception in order to promote public moral accountability. Such a standard for publishing deceptive research would be analogous to the recognized responsibility to discuss the methods of research, which promotes scientific accountability.

Reporting Standards

- Highlight Deception
- Explain rationale for deception/lack of non-deceptive alternatives
- Describe deviation from informed consent and whether authorized deception used
- Describe use and nature of debriefing
- Detailed discussion on journal website

Figure 2.26
Reporting Standards

Here are some of the points that I would recommend that research employing deception should highlight: First, make it clear that deception was involved. Then, there should be some effort to explain the rationale for the deception and the lack of nondeceptive alternatives. Also, make clear what the deviation from informed consent was in the informed consent process; explain whether or not the authorized deception approach was used; and describe something about the debriefing process. Journals have a lot of concern about space, but in the contemporary world, one has unlimited space on the Web, so there's an opportunity to have a more detailed description, if needed, put on the Web.

Conclusions

- Deceptive research pits scientific validity vs. respect for persons.
 - Burden of proof rests on justifying deception.
- Stringent safeguards, are required, which may include authorized deception.
- Deception should be minimized and used only when necessary in studies having considerable value.

Figure 2.27
Conclusions

In conclusion, deceptive research pits scientific validity against respect for persons. Given the range of moral problems with deception, I think the burden of proof clearly rests on justifying deception in research. Stringent safeguards are needed, which may include the authorized deception approach; and deception should be minimized and used only when necessary for studies that have considerable social value. Thank you very much.

PANEL INTRODUCTION BY PATRICK P. GUNN

Let me begin by introducing the panel, from left to right, starting with Ivor Pritchard. He's a Senior Fellow at OHRP with specific research interests in issues of autonomy. Next on the panel we have Michael Cunningham, who is a Professor of Psychology and Vice Chair of the University of Louisville. He's also a member of its IRB. Next we have Christine Fair. Chris was formerly at RAND and is now a Senior Research Associate at USIP Center for Conflict Analysis and Prevention. Her specialty is South Asian political and military affairs. And then we go over to Sandy Berry, who serves on RAND's IRB. She's a Senior Behavioral Scientist, a Professor at the Pardee RAND Graduate School, and has been a member of the Institutional Review Board for several years.

Panel Remarks by Dr. Ivor Pritchard

Before I get into the substance of what I'm going to say, there are a couple of comments that I want to make as preface, particularly given that we're talking about autonomy and deception. I don't want to deceive you. I should tell you that I'm speaking autonomously, for myself. I'm not obeying the orders of the Department of Health and Human Services or the Department of Education in what I say. So if I say something wrong, you have to hold me responsible and not the people that I work for. Second, I noticed that there was a comment in the materials for this workshop that said OHRP has not provided guidance on this issue. Out of respect for my brother or sister agencies, I want to point out that with respect to regulatory matters, if a research study raises ethical concerns for which some federal guidance is needed, it's important to turn first to the particular agency that funded the research for whatever guidance or help it can provide about the ethical qualities of its research study that are related to the federal regulations, rather than to OHRP.

Now let me talk about the content of what I have to say about deception in research. I want to make basically three points. The first point is to distinguish between doing wrong and doing harm. This is going to put me at odds with all of the utilitarians in the room. I

do not believe that whether research is unethical or not is entirely a function of the balance or proportion of benefits or achieved goods over harms to which the activity will contribute, which is the basic premise of the utilitarian perspective. To make the distinction between wrong and harm clear, imagine two circumstances. First, imagine a circumstance in which I've gotten Patrick Gunn to promise to help me with a practical joke that I plan to pull on the rest of you, and Patrick reneges on his promise—he breaks it. Even if no harm results from his breaking his promise, Patrick has wronged me in that instance. He should have kept his promise, regardless of anything that has to do with harm or benefit. Consider a second example: At the end of my comments, in his remarks, Patrick tears my reasoning to shreds. Particularly since these comments are going to be circulated in the public, this may do me a tremendous amount of harm. It may ruin my career. But Patrick will have done no wrong by harming me in this way. So it's important to notice that whether something is wrong or unethical is not necessarily a function of whether there is harm or benefit involved.

Now this is where I think the notion of consent comes into play in research. Consent makes a great deal of difference in research, as to whether a particular research activity is or isn't wrong. In this society, our working assumption is that participation in research is a voluntary matter. You don't have to do it. You can do it if you choose to. And so, if I need people to participate in research, and I invite them to participate, they get to decide whether they're interested in participating in that activity with me or not, and they are free not to do it if they don't want to. If they never get asked to participate, they never have a chance to make that decision. So, for example, in the kind of research that I look at on a daily basis at the Office for Human Research Protections, if somebody wants to give somebody else a drug, and that drug is being given to a healthy volunteer, only harm can result to the subject. There's no possibility of benefit. Why is that ethical? Why is that morally okay? It's only morally okay if the healthy subjects are volunteers, if they agree to do it. And by virtue of their deciding to agree, they make that research ethical. In

thinking about Frank Miller's experiment involving authorized deception and medication for migraines, I would have much more trouble if he went up to Harvard and proposed a third arm to his study in which the study drug was surreptitiously given to undergraduates who didn't even know that they were being made to participate in research. I would consider that to be wrong, regardless of the benefits that accrue in the analysis of the outcomes.

The second point that I want to make is that I think the research purpose matters a whole lot. Tora already referred to this a bit, but let me elaborate the idea. Earlier, I was wondering where Christine Fair was, because the seat with her name card was unoccupied here. What I imagined—turns out I'm wrong in what I imagined—was that Christine was out in the field, as an ethnographer, interviewing potential suicide bombers. Now imagine that she comes back to report on her findings. We ask her, "Did you tell the people you were interviewing what you were doing and why?" And she says, "No. For a variety of reasons I can explain to you, I didn't do that." But it also seems to me important to answer the question of why she was doing this work. It seems to me there are at least three possible explanations she could give of the research purpose that bear in a crucial way on whether the research is ethical or not. The first explanation she could give is, "I think suicide bombers are really interesting people. I wanted to understand just what it is, what kind of personality characteristics, what kind of life experiences, what kind of general social circumstances, social environment, and reasoning behind their actions lead these people to do such a striking thing. I just want to understand them." The second explanation she could give is, "The reason why I was doing this study is that I'm interested in helping suicide bombers. I'd like to help them develop a personality profile and the characteristics of potential suicide bombers who actually go through with it, in order to make the suicide bombing efforts of the group to which these participants belong more efficient and effective." The third explanation that she might give is, "I was studying these people because I want to develop an understanding of how to stop people from becoming suicide bombers, of

how to discourage this from happening, how to prevent these people from actually going through with it."

It seems to me that we ought to look at these three kinds of research purposes and recognize that even if the interview questions were exactly the same, our judgment about whether the research study is or is not ethical ought to vary depending on which one of these three purposes is actually true. I would say that by and large, the first two are easier to justify than the third, because of a feature of the activity which is analogous to, but not the same as, something that Dr. Miller was talking about concerning debriefing. Imagine what would have happened had Dr. Fair gone back and debriefed the suicide bombers after she interviewed them. We can imagine that the initial decision to agree or not to agree to participate in the research, or, if we offered it to them in the debriefing session, that the decision of whether or not to withdraw the data from the study would vary with each of these three explanations. I think it's pretty safe to assume that the participants under the first and second scenarios would be more likely to agree to participate in the research than the participants under the third scenario. I recognize that debriefing is not the same as initial consent, but I think it does show a parallel respect for persons, in so far as it revisits the opportunity of the participant to elect to contribute or not contribute to the research. Now if it is the case that participants would not elect to contribute to the research under the third scenario, it is particularly problematic, I guess. I suspect that the people in this room are most interested in the kind of research that I think is the most difficult to justify of those three sorts of research purposes.

Now I come to the third point that I want to make. Is it ever ethically acceptable to conduct covert research with people who, it would be reasonable to expect, would not want to participate in the research? I think the answer to that question, unfortunately, is "sometimes." I think that there is some covert research with unwilling participants that is wrong, period, regardless of the benefits that result. At the same time, I think I can give at least one example of a type of research for which I would be willing to argue that covert

research would be ethical—recognizing it would be research that does not accept the assumption I referred to before, that participation in research always has to be voluntary.

Let's imagine that I go out to do some research and I'm interested in burglars. I go out and observe burglars covertly. I think it would be ethical to carry out some such research, observing the burgling behavior of burglars. I don't think it would matter at all, ethically, whether or not, after the burglars went out the second-storey window and came down to the ground, I tapped them on the shoulder and said, "By the way, I've been watching you, and I was wondering if it would be okay with you if I kept the data about you, so long as I promise you confidentiality." I don't think this would be relevant to deciding whether the study was ethical. Whether or not the ethical quality of such research extends to the kind of research that Tora presented us with at the beginning of today's presentation, I'm not so sure. I guess that's why we're going to talk for the rest of the day. So I'll stop there.

Panel Remarks by Dr. Michael R. Cunningham

My remarks center around PowerPoint® slides created in immediate response to the opening comments of Patrick Gunn and the presentation of Dr. Franklin Miller. Other disclaimers should include the fact that I am not only a vice chair of the Social, Behavioral, and Educational IRB Committee of the University of Louisville, but also an active social psychology and communication researcher. I do research that has in the past involved the use of deception, and I do research now that involves the use of deception. Therefore, I have fairly strong feelings on this topic, based on trying to avoid deception but sometimes finding it necessary in order to obtain accurate results.

Common Rule

- **1) I support 45 CFR 46, that subjects have an absolute right to be fully informed about a scientific experiment that involves invasive, potentially personally harmful treatment.**
- **Social science experiments are, usually, not invasive. They usually hinge on obtaining access to information or behavior that subjects often conceal due to complex psychological motives. Experimenters often have to create situations where subjects choose to reveal themselves.**
- **Consent is not binary, it is an ongoing process. At any point in time, subjects can discontinue participation. They can do so when they discover that research is deviating from expectations.**

Figure 2.28
Common Rule

We all recognize 45 CFR 46, which says that subjects have a right to fully informed consent. But related discussion usually focuses on scientific experiments that involve invasive, potentially personally harmful treatment. Social science experiments are a little different from medical experiments (I work on medical research teams, as well as social science teams). The difference in social science is that we are not truly invasive in the sense of penetrating the body with anything that is potentially toxic. The social science studies usually hinge on obtaining access to information or behavior that subjects often wish to conceal because of their own, complex psychological motives. In the best of all possible worlds, we could simply ask people questions and they would tell us the truth. But that is not the world in which most social scientists find themselves. So we often have to create situations where subjects choose to reveal themselves.

This is the important element that I want to stress: Informed

consent is not a binary process. Experimenters do not give informed consent forms once and then the experimenter and research participants forever hold their peace. Researchers inform subjects about an experiment and then subjects learn about that experiment as they participate in it. The informed consent documents that everyone looks at and signs involve the notion of a withdrawal without loss of benefits to which signers are otherwise entitled. At any point, a subject can stop. At any point, a subject can leave. So if experimenters do not fully inform subjects about everything that is happening, subjects can bail out whenever they find something that is a little bit problematic for them, if they choose. This was true in the Milgram (1962) experiment, although the experimenter made it challenging for subjects to exercise that option. That option still existed, and 35 percent, even under the worst of circumstances, chose to discontinue their participation. That is an important thing to know: It is not a matter of giving people informed consent forms or not; it is a revelation process. A subject chooses to participate in the first five minutes and then, implicitly, there is a continued choice to continue.

Levels of Deception

- **Deception is not an absolute. Levels of Deception similar to OHRP categories of Research involving children**
- **a) Withheld intention of PI**
 - Lack of accurate disclosure by withholding specific information about goals of research
- **b) Withheld meaning of procedure**
- **Fake or rigged instruments or procedures**
- **Misleading play-acting in experimental design; researcher, confederates**
- **c) Withheld PI or funding source identity**
- **d) Withheld procedures**
- **Covert procedures: e.g., observation behind one-way mirror**
- **Covert research**
 - Undercover observation
 - Staged experiment in public place
- **e) Withheld side-effect of likely consequences**

Figure 2.29
Levels of Deception

A second point I would like to make is that there are levels of deception, and it is important to distinguish among them. Dr. Miller alluded to this to some degree, but I think we can make further distinctions. I have not yet made all of them to my heart's content. But I suggest that, similar to OHRP categories of research involving children, we can evaluate levels of deception. This is a very nuanced process, similar to the IRB process in place for evaluating research involving mentally incapacitated individuals or prisoners.

In my view, a low level of deception is involved in withholding the full intentions or scope of interest of the investigator while fully telling the subject everything that will happen. For example, an experimenter might tell subjects, "We're going to have you take a test; the test is going to be difficult; we're going to watch you take that test; we're going to measure your reactions. People respond positively or negatively depending on how they perform." That may fully inform the subjects about what will happen. What the experimenter may not tell

them is: "The test is almost impossible; nobody's ever gotten more than half of the answers right; you may be upset by your apparent failure." While we withhold some of the information, we tell them everything about the procedure. I regard that as the lowest level of withholding information, or misinformation. Withholding the meaning of a procedure is similar to that. "We're having you interact with someone; we're going to measure and videotape your reactions." What we don't tell you is: "The person is a confederate who is working for us." The subject knows he or she will be interacting with another person and that the interaction is videotaped. The subject does not know that the other person's behavior is scripted and rehearsed rather than spontaneous. That is a little bit more deceptive, but I submit that is not bad in terms of research ethics.

Withholding the principal investigator's identity or funding support is a little bit more problematic, because it has a direct bearing on the subject's willingness to participate in the research. But I submit that an IRB can, and should, evaluate the risks that a subject will incur through participation in a research project sponsored by a foreign government or its contractor. Specifically, an IRB should evaluate the risks to the subject's physical safety, and feelings of autonomy and dignity, that may occur when the subject is asked to participate in a study in which the identity of the study sponsor remains concealed or if sponsorship should happen to be revealed in the near future. If such risks are minimal, they might be balanced by the value of the knowledge to be gained. Such risk/benefit calculations are predicated on the goal of acquiring knowledge that is intended to benefit all humankind rather than a narrow partisan or military interest. Ironically, research that is intended for parochial ends generally does not qualify as likely to produce "generalizable knowledge" and consequently is not reviewed by U.S. IRBs.

A little more problematic than withholding information about sponsorship is withholding information about some important element of the procedure. A covert procedure is one in which a stimulus or experience is planned to be delivered to the subject, but the experimenter does not forewarn the subject about it, such as in an

informed consent document. The classic Darley and Latane bystander intervention studies exposed subjects to strangers who appeared to sustain an injury and were in need of aid. That experience could be unsettling to some subjects, but the subterfuge probably was necessary to obtain authentic reactions.

Finally, withholding information about a side effect, or a likely adverse consequence of being involved in the research, would probably be the most deceptive of all. That seems difficult to justify under current ethics. The larger point is that we should start thinking about withheld information and deception in terms of levels of informativeness rather than framing the issue as “fully informed versus deceptive.” We have to start parsing our shades of gray to some degree.

Scientific and Other Merit

- **Deception is a threat to the Belmont principle of Autonomy, Respect for Persons, and Beneficence.**
- **But, the Scientific Merit and other benefits of the study can partially balance the risk, although there are limits to the extent to which Scientific Merit balances Respect & Beneficence.**
- **Justify more deception if there is more social value. Calibration will be difficult, and using the term “national security” to justify anything, will not stand.**
- **John Irving said that “Self-insight is never good news.” Subjects may benefit from an experience that is initially experienced as unpleasant. Ph.D. oral examination.**

Figure 2.30
Scientific and Other Merit

On the flip side, we have to also look at the levels of merit. That was already alluded to, to some degree. Recognizing that deception is a threat to Belmont principles of autonomy, respect, and beneficence does not settle the issue. To some degree, under some circumstances,

scientific merit might balance those threats. The level of scientific merit will vary from an undergraduate research project for extra credit, through dissertations, faculty theory-supported investigations, to research that actually focuses on national security. I do not believe that national security interests can necessarily counterbalance anything that a scientist may wish to know or do. Accepting that kind of rationale can lead to Nazi Dr. Mengele's experiments on freezing to death, which were conducted on unwilling prisoners but intended to benefit German pilots downed in the North Atlantic. National security interest is not a rationale that trumps all other ethical considerations, but it may contribute some additional merit to justify some increased risk to the subjects. Determining such trade-offs will require continued discussion; certainly I am not going to settle that issue today. I want to simply suggest that as the potential merit of a study goes up, the justification for some small level of risk also may go up.

We can also talk about long-term, as well as short-term, benefits of a study to the individual subject. Novelist John Irving once said that "self-insight is never good news." I think that also might be said with respect to what subjects learn about themselves in research. Subjects may not welcome embarrassing facts about themselves, such as their willingness to obey destructive authority figures or their unwillingness to help a stranger, but they may actually benefit from such experiences in the long run. Similarly, suppose that interview research on the motivations of terrorists, conducted without disclosing sponsorship, leads to insights that lead to the cooption and dissolution of a terrorist movement. In the short term, a participant in the movement might feel outrage at being undermined. In the long term, the participant might end up leading a more satisfactory life than if the movement had not been undermined, likely a better life than if it had ended prematurely in a suicide bombing.

I recognize that the suggestion that a long and peaceful life is better than one that ends in a suicide bombing is predicated on Western cultural values. But a radical Islamist position that argues the opposite, or a cultural relativist position that argues for the

equivalency of the two perspectives, seems unconvincing. In addition, American history provides a parallel. Many Confederates who were defeated in the American Civil War ultimately recognized that the loss of their cause produced a better outcome than if they had succeeded.

I also recognize that it is a slippery slope to suggest that subjects do not always recognize their long-term interests and that researchers can withhold information from them based on that rationale. Currently, IRB committees have justifiable reservations about adopting the role of guardian *ad litem* for reluctant subjects. But I am suggesting that those kinds of considerations should come into play, at least to some degree, in our discussion. Again, there are many things we go through that we later recognize as more beneficial than we thought at the time. I mentioned, in the slide, that the PhD oral examination is something that few would choose to go through if given the opportunity to decline. But many students look back on it and say, "That was actually kind of interesting, and it was more educational and valuable than I thought." People look back on it as not that bad of an experience. The mind rationalizes that way, of course.

Impact of Deception

- **I am not sure that deception always undermines subject's feelings of respect.**
- **(cf. slide 13).**
- **The assertion that debriefing does not erase a violation of respect for persons is an empirical question (p. 13).**
- **Berscheid, Baron, Dermer, Libman (1974). Anticipating informed consent: an empirical approach. Am Psychol. 1973 Oct; 28(10):913-25.**

Figure 2.31
Impact of Deception

Another issue is the impact of deception. It remains an open question, as Dr. Miller suggested, whether deception undermines people's feeling of respect. I believe this is an empirical question on which we need more data. There was also the assertion that debriefing does not erase a violation of respect for persons. I think that, also, is an empirical question that deserves more research. However, some research has been done on those topics, dating back at least to Berscheid, Baron, Dermer, and Libman in 1973. That research was done at University of Minnesota while I was still a graduate student, so it shows how old it is. But it looked forward to how subjects respond to various configurations of experiments in which researchers tell them how likely they are to behave in a positive or a negative way—the nature of the debriefing. So there is a long tradition of interest in this issue. We probably need to do a meta-analysis and summarize all of it. But we

should not necessarily make assumptions about how subjects are going to react.

At the University of Louisville, when I was supervising the subject pool in the Psychology Department, we asked for subject comment cards on each experiment. It was routinely the case that experiments involving deception were among those rated the most interesting and most educationally valuable by the subjects. We trained the experimenters to be really polite and really nice and effective in their debriefing, because the consequences were so high. And the training paid off in terms of the subjects' positive evaluations of the experimental experience. It was the case that we misled them somewhat, and we tricked them a little bit, and we got them to reveal things that they would not otherwise disclose. But subjects thought that is really what a psych experiment is all about. So although there is a threat to autonomy of and respect for persons involved in a deception experiment that does not mean the experiment will be perceived negatively in the end. We should not make assumptions about how people are going to react to experimental treatments; we should measure those reactions.

Authorized Deception

- **Authorized Deception meets the stipulation that research should display the “epitome of rectitude” (Shulman & Berman, 1974). But, I’m not convinced that Authorized Deception will enhance subject’s feelings of respect.**
- **We need a manipulation check on studies using AD to see if it is noticed, and if it enhances feelings of respect. Null effects on Weiner & Erker (1986) on n=68 subjects in scenario study.**

Figure 2.32
Authorized Deception

Authorized deception, which Dr. Miller is proposing, does meet the stipulation recommended by Shulman and Berman that research should display the epitome of rectitude. But I am not convinced that authorized deception will enhance subjects’ feelings of being respected. We need a manipulation check on studies using authorized deception, first of all to see if it is noticed. One of the interesting things is that subjects may not read everything in an informed consent. So it is easy to support authorized deception from the standpoint that if nobody notices the disclosure, it will not hurt research results. But if people do notice and read the authorized deception stipulation, does it make them feel more respected? Does it produce equal quality data? Dr. Miller is proposing to do such research, and I am eager to see the results. I am not as excited about the null results obtained in a prior

study on authorized deception with 68 subjects being seen as definitive on this topic. I support the notion that further research is needed.

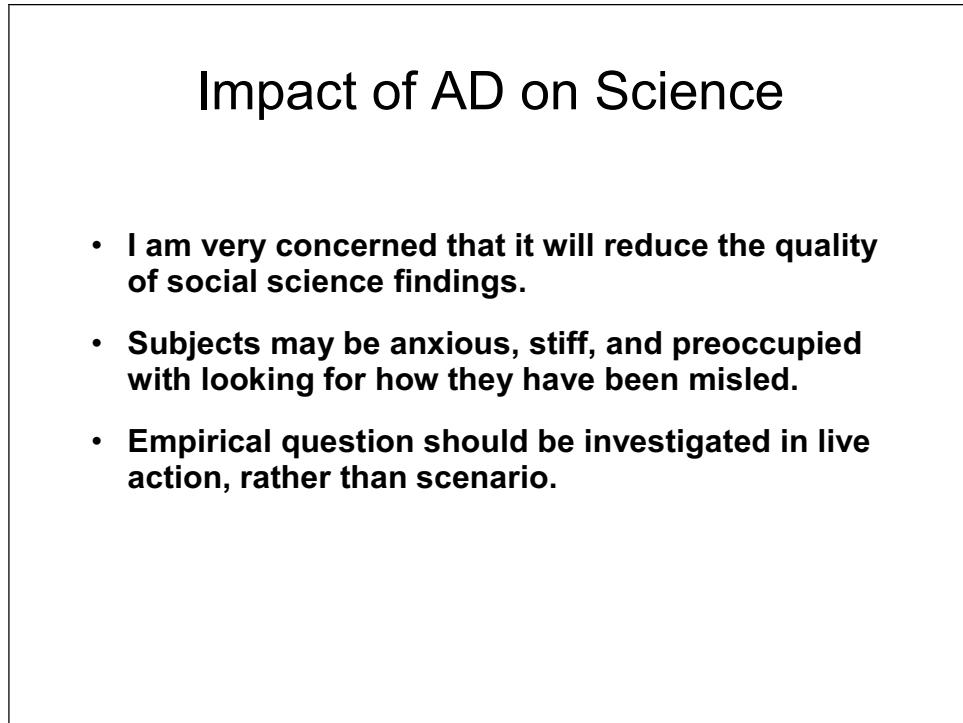


Figure 2.33
Impact of AD on Science

I am concerned that if authorized deception is noticed by subjects in an informed consent, it often will reduce the quality of social science findings, simply because subjects may be anxious, stiff, and preoccupied with looking for how they may be misled. If that is the case, and if deception becomes subjects' preoccupation, then subjects are not cognitively and emotionally involved in our experiment—they are involved in a different experiment, on the impact of being misled. I suspect that will only be the case with a small fraction of subjects, those who actually pay attention to every word on the informed consent and those who are prone to be suspicious and distrustful. Nonetheless, it is going to change the results. But I support the idea of further research on authorized deception. One thing I suggest is a need to do it

in live action studies rather than scenario designs. In other words, inform people in a situation where they will actually be thinking and behaving, as opposed to just processing scenarios presented to them on paper. I think that is a different dynamic. And the impact of being misled by something they read is a little different than being misled through overt interaction. It would be more serious in the live action.

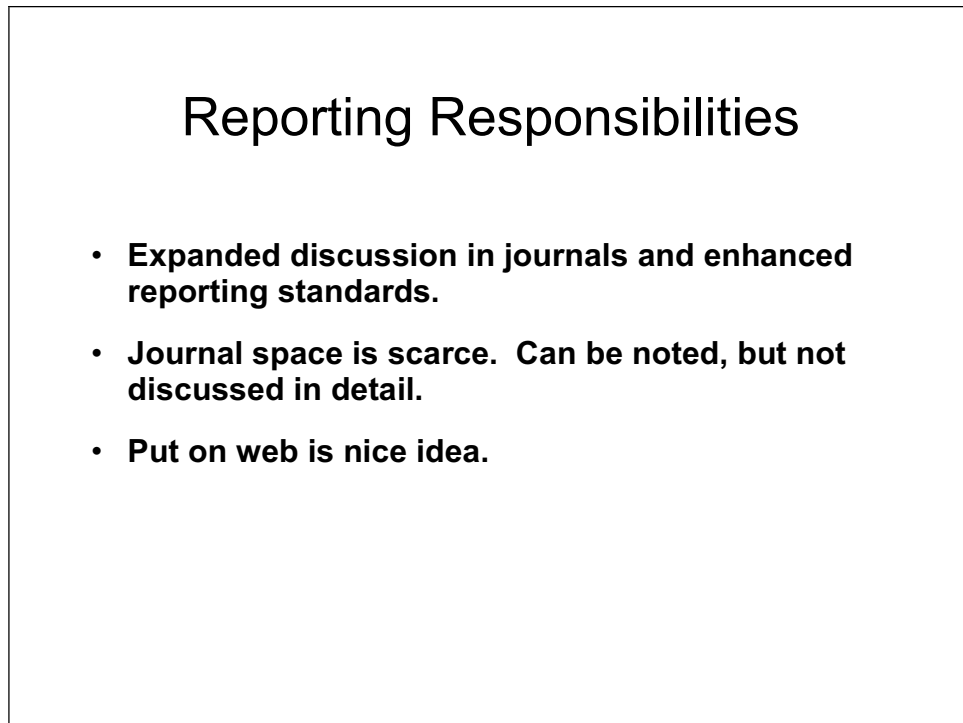


Figure 2.34
Reporting Responsibilities

In principle, I am in favor of expanded discussion of deception and debriefing in journals and of enhanced reporting standards, but that will be an uphill battle. Dr. Miller alluded to the fact that journal space is scarce. As a consequence, I do not think that every investigator will be able to discuss the ethics of his or her study in detail. Usually, in psychology experiments, we have to indicate that we acted with IRB approval and in accord with the ethics code of the American Psychological Association, which requires informed consent. That is usually enough to express the minimum, but not the maximum, of

exactly what was stated in the informed consent. Putting materials on the Web, I think, is a great idea. And archiving all the additional details of the experiment will be really helpful for future meta-analysis and for anyone interested in a clearer picture of the procedures of a study. Quite frankly, most of the informed consent and debriefing procedures, and the manipulation checks that we run to make sure that everything is working, are never reported in the journals. Nobody cares about them except the experimenter and a few meta-analysts in the future; but if someone wants the information, most investigators will be happy to make it available. These are my initial thoughts in reaction to Dr. Miller's very stimulating presentation, but I look forward to continued discussion of the issues in the literature and at professional conferences.

I want to conclude by returning to the broader question, concerning how the rights of the human subject should be handled by investigators. Certainly, treatment of human subjects should be governed by the Belmont principles of autonomy, respect, and beneficence. Certainly, subjects have the absolute right to participate or not participate in a research study. Yet if a subject has freely consented to participate in a study but is likely to provide false answers, current research ethics allow the experimenter to design procedures in which the subject is led to unwittingly disclose his or her true thoughts, feelings, and behaviors, provided such disclosure entails minimal risk to the subject. I submit that a similar situation exists if a study poses minimal risk to a subject, but the subject is likely to refuse to participate based solely on misinformation, inaccurate stereotypes, or irrational prejudice against the procedures, the investigators, or the sponsors.

If a subject from a nonindustrial culture superstitiously believes that having a photograph taken steals his soul, then an investigator might respect that belief by covert photography, which avoids all overt action that might cause the subject distress, rather than by never taking a documentary image (note that additional issues arise concerning the publication of such images). Similarly, if a group of subjects holds the prejudicial belief that women should not be investigators, then the survey team should ensure that a man conducts interviews with

such subjects and reports only investigators' initials and surnames, rather than gender-identifying first names, on the informed consent. Prejudicial subjects should not be able to dictate that women must be precluded from any involvement in the research. Finally, if a subject from an adversarial culture incorrectly believes that any research conducted by any U.S. organization contributes to the Great Satan, then it is reasonable to discuss whether such beliefs must be respected by disclosing a fact that activates a prejudice or can be respected by avoiding mention of, or concealing, the inflammatory fact. In my view, IRBs should evaluate on a case-by-case basis whether the scientific merit of the research justifies the nondisclosure of information that activates inflammatory evaluations by research subjects.

Panel Remarks by Dr. C. Christine Fair

I'm with the United States Institute of Peace. My views, or what I'm going to say today, are my own and do not reflect the views of USIP. I think I am on this panel because I actually spend a lot of time in the field doing work that has human subjects implications. But I think it's important for you to understand a little bit about USIP. At USIP, we don't have an IRB, and we have no formal protocol adopting human subjects requirements and spelling out researchers' obligations—and we have well-intended, but inadequate, resources to execute those obligations, whatever they may be. So as a researcher who does this research, it's actually very difficult to navigate my way around the obligation without the resources to execute the obligation.

The study I'm going to talk about today is a survey—actually, it was the first project I did once I left RAND—and it was sort of engrained in me, "Okay, we have to do a human subjects review." But no one at USIP, including my boss, could provide guidance on how to do it. The study involved interviewing 140 families of militants whose sons died fighting in Kashmir and Afghanistan. I did not interview active or aspiring or otherwise living militants for a number of reasons, including safety and ethical issues—obviously, conflict of interest. Dealing with families of slain militants seemed relatively safe in terms of the human subjects issues.

However, getting this thing through human subjects review was actually very challenging. Obviously, the lack of organizational clarity at USIP was a big hurdle. Organizations like USIP that don't have an IRB are really struggling with this. In the case of my militant survey, I think everyone agreed, we had to do it; we just didn't know how. For another survey that I fielded in Iran with another partner, it was decided that because we were collecting no personal information, it didn't require human subjects review. But when I look at that instrument and my current instrument, I really don't see why one study required it and one didn't. So there is an enormous problem for institutions like USIP that don't have these IRB resources.

A second problem is that when you do need human subjects review, where do you have to go? You have to go to a commercial IRB. And I would prefer not to go through this process again. Not that these reviewers were bad, not that they were incompetent; but they were completely incapable of dealing with this kind of research. This was an organization set up to do pharmaceutical trials. It was very much oriented toward biological and biomedical research. It just didn't have staff or core competency to deal with some of the social issues inhering in this study. This was a very consistent problem throughout the IRB process.

To give you a little more background, I did not conduct the actual survey—which is unusual because, with the exception of this survey, I do my own fieldwork. It was a decision undertaken with my team that, in the post-911 environment and the post-Indo-Pakistan crisis, my being there would cause more problems than it would lend credibility to the study. So we made a group decision that I was going to go out and do the training, make a few field visits to collect the data, but largely stay remote. We also set up a number of electronic means by which they could convey coded data back to me in the event that some agency should have a problem with the study and take our data and run. So we built a fairly elaborate structure to insure that data were flowing in my direction at all points and that the likelihood of compromising the whole study was minimized. We were interested in getting very detailed household information: household composition, education, work

experience, socioeconomic information. We were also interested in collecting very detailed human capital information about the militant—that was really the objective.

Going back to the commercial IRB, the reviewers certainly were not capable of really assessing the benefits and the potential harms of this study. There is an element of risk to the human subjects, but there are risks to the researchers as well. (The political views of one of the IRB reviewers even seemed to me to be hostile to the "intelligence community," and that person was less inclined to see the benefits of the study. This is obviously my impression based only upon the IRB's written communications and upon discussions with my point of contact with the IRB, and I hope I have not mischaracterized this person's positions.) My objectives were: I want to be ethical and I want to be transparent, subject to a minimum of what I'll call "safety constraints" for my team. But this idea of risk to researchers was really not something that the IRB was prepared to deal with, nor did the reviewers think it germane. And, I suppose, from a narrow technical perspective they were right.

In the consent form that I used, the first part concerns the nature of the study. Now, in the nature of the study, I did not seek approval for the use of deception for a number of reasons I'm going to explain. I was very transparent about who I am and my organization. I said, very clearly, that I am here to understand why families support Jihad in Kashmir and Afghanistan. I felt that this was adequate. The IRB insisted that I say that USIP is government funded. This funding issue, for me, was the single most problematic issue. Again, it comes back to this cultural lens with which the IRB was generally unfamiliar. When you say "U.S. government," that means one thing: "CIA." So in its effort to make consent fully informed, the IRB actually introduced a scope for misinterpretation of the study. The consequences, I don't think, were apparent to them. But on a couple of occasions, my surveyors were actually put in physical harm's way. One individual was nearly beaten over that statement, and he was cast out summarily. So the IRB's intention may have been reasonable. But it clearly did not appreciate what "USG" means in other parts of the world. But I think it introduced grounds for misunderstanding. Had a family said, "Oh, by the

way, who does fund USIP?" (I doubt the question would have ever arisen), then, I think, that would have been an appropriate time to deal with the issue of USIP's funding. But this was not anything that the IRB was willing to negotiate.

On the other hand, with literacy rates being very low, the consent statement was oral. If people were literate and they wanted to read it, they certainly had the option. The IRB agreed that having a signed consent form floating around where agencies could grab it actually compromised the identity of the person. So the IRB was reasonable about that issue. But on the issue of government funding, is it a question of deception or is it a question of need to know this? For somebody who does work in the field, it's a huge problem to be linked with the CIA when in fact you have no association whatsoever.

The risk of participation was, I think, another issue where my commercial IRB was really ill prepared. You could say that militant families are an at-risk or difficult-to-reach population. But unlike individuals that are engaging in criminal activity, the militant groups in Pakistan in which we were interested are (or in some cases were) actually state sponsored. It is rare to have an organization that does not enjoy some form of state patronage, because the groups are used to prosecute Pakistan's foreign policy in Kashmir, for example. (We were not looking at—nor did we find—families that directly supported illegal groups like Al Qaeda.) With respect to the militants, families are proud of their sons. Our evidence suggests that some (not many) of them got better marital alliances, better social alliances, because of the social standing enjoyed from this status. There is no stigma. They talk about it freely. It's not a criminal activity. So where does that put the vector of risk? It points the vector of risk at the researchers, because we are obtaining information that no one is really supposed to know. This was something that was very difficult to communicate to the IRB.

Another problem with the IRB was the individual (mentioned above) who appeared to me to have issues with the Global War on Terrorism, which is fine except that, in my opinion, it affected his/her views of this study. For example, the reviewer was concerned that the CIA was

going to get the study. Well, everything is going to be published; it's going to be public. So the CIA is going to be able to access it if the CIA has folks that do lit reviews. But in the end, they judged that I could not, for example, make a publicly available data set, even though we were collecting no personal identifiers. This has meant there's impact for the scientific distribution. My colleagues and I can't publish the analysis in journals that require replication data sets. So there were a number of implications of my having to rely upon a commercial IRB that just didn't understand this kind of work.

As I look back, I think we were probably on solid ground in being clear about the nature of the study and my personal identity or organizational affiliation—albeit not with the funding source so prominently displayed. But if you looked at the consent form, you might ask the question, Why in the world would anyone participate in your survey? I have to ask myself the same question. I think they were generally proud of their sons' accomplishments. I actually think they wanted to share their enthusiasm about what their sons did. It was seen as an opportunity to communicate their sons' valor.

Now I want to talk about the issue of sample bias. I have no doubt that the consent form certainly conditioned the participation. Given that some of my surveyors were physically ousted from the home, I know that it did. But from my point of view, this study was never going to be something that could claim to have any sort of scientific validity in terms of its sample. It was always going to be a convenience sample. It could never claim to represent a distribution of militants in Pakistan generally. So if I can put it this way, the cost, ethical and otherwise, imposed by using deception didn't seem to be greater than the benefit that could be garnered in terms of improvement of the sample. So in the end, I really didn't see a sampling argument to try to use deception.

Now, even though I'm saying I don't think there was a need for deception for this study, I would be remiss if I were not to address some of the other general comments raised by the speakers before me. Let's take the example of debriefing—there is just too much risk with that suggestion. We tried to be as transparent as possible in the

consent form, because we wanted to be as brief as possible. My families and my interviewers were most at risk during the time they were in the same room. If the family decided to talk about the interview once the interviewer left, maybe there could be some subsequent risk. But they were most at risk during the actual interview, because if a police officer came by, or an intelligence operative, everyone is going to be in trouble—just because the family is talking to this journalist, not because what the person did was wrong. So we were always trying to minimize the survey instrument and to get as much out of it as possible in a limited time. My sense was: Let's be as honest as possible; let's be as brief as possible; read the consent statement orally; field questions to make sure participants got the main issues; let's get on to the main part of the survey and wrap up.

There's another advantage of avoiding deception, about which I felt strongly going in, and I even feel more committed to now. By saying, "Here's my objective. I'm Christine Fair. This is my institute. We're doing the study. The embassy knows me"—then, if various agencies got the protocol, it would be a lot harder to abuse my interviewers, and even the subjects. They can't ever come back to me and say, "Oh, you lied about it. So my feeling was that, in addition to not compromising subject autonomy any more or worse than it would have been otherwise, openness also conveyed a general kind of safety net. I want to minimize deception because I want to maintain my credibility. I don't want anyone to ever say, "We caught you lying on this." And this, to me, is very important. I think it's been important to maintain my reputation within the countries I work, and I want them to feel okay that I'm a data-driven person, not an ideology-driven person. Deception would have undermined that goal.

There are a couple points I'd like to conclude with. Cultural bias doesn't adequately capture the problems that I had with the IRB. For example, the notion of privacy, which was a big issue because that IRB has a very U.S.-centric understanding of privacy. There is, I think, a very engrained, culturally biased notion of what privacy is in this country. In the case of my survey, the IRB was obsessed with the questions I was asking about the militants' education, where they were

recruited, what organization they served with, where they died, whether they were married, what they did the year before they joined. They thought that these questions were so outrageous that they would never get answered and thus did not deserve to be asked given the low likelihood of obtaining data that would be useful for scientific purposes. They, on the other hand, raised very few questions about general household roster economic background. I knew immediately, going in, that they were dead wrong. As I said, these folks are very proud of what their sons did, whereas they were very hesitant to talk about economic issues because of economic prestige. And because of "honor constraints," many were hesitant to even tell us how many daughters they have in their household, much less talk about their education. But the point is that the IRB really obsessed about somethings because of inadequate understanding of the cultural situation and what is considered "private" or inappropriate questioning.

My biggest fear going into this work is, for lack of a better term, a conflict of interest between the respondent's privacy and the benefits of public security. My fieldwork before this survey had suggested that where there's one militant, there are two. In other words, militant families often don't just stop with one. So there was a high probability that in any given family we went to, there would be another militant, either active or aspiring. And, in fact, that was the case— not in all or even most families, but in many nonetheless. Some families had five sons that they sent to the Jihad in Kashmir and Afghanistan. My worst nightmare was, What happens if, in the course of the interview, actionable intelligence is presented about an imminent attack? We did talk about this in the IRB: "What would you do if...?" The IRB's final rule was that family sanctity, informed consent, and protection of confidentiality trump public safety. I am not sure I agree with that. I don't know. I'm not an ethicist, but I do suspect strongly that there are parts of our society where personal confidentiality does not trump the benefits of public safety. Now, in my study, this issue did not arise. But since this is the kind of work I do, I can't be guaranteed that in the future this isn't going to arise. So this is one of the kinds of issues that we need to really

wrestle with: At what point do we have to really be cognizant of these personal risks versus public safety? I don't have an answer.

Panel Remarks by Sandra H. Berry

I'm going to keep it very brief, because I think Chris has covered much of what I wanted to say. Although I personally don't do this kind of work involving terrorism, I do survey research all the time, and do a lot of wrestling with human subjects issues. I see this specific line of work as having problems with human subjects issues that have the potential to shove it outside the tent. In a recent article in *The New Yorker*, a social science researcher talks about the fact that she has become a renegade because she does work on terrorism. I really don't think that we want our research in these areas to be renegade research. Nor do I think such work has to be renegade research. We need to think through what the issues are and come to grips with them in a way that we can pursue work that's in our national, and probably international, interest, and still stay within reasonable ethical guidelines that are appropriate for the situation.

We have talked about terrorism research as though it is all one thing, and it's certainly not. There are lots of different concerns involved. There's talking with detained accused terrorists who are currently imprisoned; with admitted suicide bombers and their families; with reformed terrorists who are not incarcerated; with citizens in countries that we are currently occupying or in which we have substantial military presence. There are general populations in countries where we have interests in avoiding development of terrorist activities. And there are immigrant populations in the United States, legal/illegal, citizen/noncitizen. So we're talking about lots of different kinds of work, which would have very different implications and run into different kinds of ethical issues. We have to unbundle this thing and think about it in a more specific way.

The notion that we want to conduct work to promote general and contextual cultural understanding and communication is important. If we have military in a country, the military needs to understand how to behave and what the implications are of the way they are behaving. If

we're going to attempt to help groups that we think are contrary to terrorism, we need to understand (a) whether that's true and (b) whether we're helping them in ways that are actually helpful or not.

We have several options here. Our IRB has thought through these options, and one of them, which Christine Fair has exemplified, is that people are overly afraid of full disclosure. It means simply coming out and saying who you are. There are lots of people who are quite happy to talk to you if they know who you are. In fact, they may want to talk to you because of who you are. They have a message to convey. There's also partial disclosure, where you have a U.S. connection, but you may not be completely explicit about the full nature of your U.S. connection. Exactly what is the money trail? And, as Chris points out, even if you explained the money trail to them, not everyone would actually understand what that meant. Then there's the notion of concealment of a U.S. connection, in the sense that it appears that the work is being carried out by local researchers. It is introduced in this way: We (the researchers) are carrying out work. There is no offer made of who the client is or where the money is coming from.

Now I have to point out that in a great deal of the research carried out in the United States—on marketing issues, on political issues, on message testing, on candidate strength—there is no statement made about who is sponsoring the research. You don't know if it's the Republicans or the Democrats, or the Bush camp, or whoever. There simply is no statement made about that. And (as I have done many times when I've been called on the phone) if you ask the interviewer or whomever you speak to, that person simply says, "I really don't know. They don't tell us that." And if you go to the supervisor, the supervisor says, "I really don't know. They don't tell us that." And you participate or not on the basis of whether you are willing to undertake participation in something that you are not able to fully explore. In my case, I don't.

The issue of disclosure is complicated, though. If you disclose fully, then you have full informed consent. But then it's not possible for respondents to participate without acknowledging exactly what they're doing. There may be situations where ambiguity is a positive

for all concerned—some people may wish to convey their message to the United States without explicitly having done so. They may wish to preserve some deniability. It may be safer for all concerned not to make the issue too explicit. I think that's a kind of ambiguity that's very uncomfortable to deal with. In many people's eyes, this is a slippery slope, and may be well down on that slope. But there is a function to ambiguity that often is important. And the disclosure may, in fact, endanger the participants far more than the ambiguity ever would, as well as endangering the researchers.

I think people believe that nondisclosure allows you to do two things: One, to engage people who would not otherwise engage with you, from whom you are going to gain valuable information; and, two, to make it possible for people to tell you things that they would not otherwise tell you. I don't know that that's well proven. It's something that's stated, that's put out there. But I have not seen the research behind it that indicates there is this kind of bias that's produced unless you are actively deceptive.

Now if you attempt to work your way through deception in the Belmont Report, in the Common Rule, it is complicated to do, although it's possible. And as we attempted to do it (and I'm the one who tried to work my way through this and make the plausible case for deception, which I persuaded myself of on some days, but not on others), first of all you'd have to say that you're taking the standard of a reasonable volunteer. So somehow the members of the IRB have to be able to put themselves in the mindset of a reasonable volunteer in the cultural context in which this future research subject is operating—no small matter. You need to convince yourself that incomplete disclosure is necessary—again, very hard to assess. But the really scary one to me is that you have to convince yourselves, as an IRB, that there are no undisclosed risks to subjects, which means that the IRB is making the judgment—on behalf of the participant who is not being allowed that possibility—that the research is low risk. That's where our IRB had considerable difficulties, because, you really don't know exactly what will happen. Chris Fair alluded to some of the issues that come up, of what kinds of risk subjects might face and researchers might face. But

the IRB is explicitly taking on the responsibility of making the judgment of risks when it approves deception.

Then there is the issue of debriefing, "as appropriate," which does not necessarily, to me, mean always debriefing. It's debriefing as appropriate. If you think that it's the debriefing, as much as, say, the signature on the consent form, that puts people at risk, you might ask yourself whether that debriefing is, in fact, appropriate. However, in any case, the IRB must require truthful answers to direct questions, and that's extremely difficult to evade. So the question that you ask yourself, if you try to skate your way through the Common Rule on this issue of deception is, Is it possible? Can you balance the benefits and risks to justify doing this? Can an IRB make an assessment of risk that's appropriate? If so, how does it actually do that? And then, How do we protect the subjects if we assume that we can undertake the risks, on their behalf, from the dangers of association with this kind of research, and the risks to confidentiality that Chris Fair alluded to? I don't think we have fully resolved these questions to our own satisfaction.

Those are the kinds of problems that we have faced. But my overall goal is to figure out a way that we can resolve these problems without sending the people who do such studies outside the bounds of what we normally consider to be ethically conducted human subjects research.

SYNOPSIS OF FIRST PLENARY DISCUSSION

Workshop participants discussed parameters for approving the use of concealment or deception in social and behavioral research on terrorism. In addition to deceptive research, participants sometimes discussed covert research.

Revisiting the Ethical Bases for Research

To understand the ethical parameters for conducting deceptive research, the social and behavioral research community and its regulators need to think broadly about how, as a society, we justify

doing things that may affect other people without their approval or awareness.

We do not have consistent principles guiding us in research and nonresearch domains. In the 1940s, research was identified as a special case. Rules and regulations were developed to apply to research that apply nowhere else in our society. In research, for example, it is considered disrespectful to observe people without making them aware that you are doing so. Yet outside research, there are many surreptitious activities that we may accept as ethical. What about the way our credit ratings are developed? No one ever asked whether you want your decisions about whether or not to pay off your American Express card on time to be put in a file that anybody can access. Law enforcement and intelligence agents conduct surreptitious observation whenever they infiltrate drug-abusing cultures, terrorist groups, and so on. The police are routinely allowed to use deception, saying such things as, "Lefty confessed. If you don't confess, you're doing all the time. If you want to split the deal and you confess also, then you both get three years. Otherwise you get seven." That kind of deception is often seen as legitimate. The press, protected by the Bill of Rights, is also held to a different standard of ethics. If you're working as an investigator for the press, you don't have to do the things routinely required of researchers, such as obtain informed consent, saying to the potential subject that he or she has the right to refuse participation at any time or to withdraw data they've provided once debriefed.

In some activities where deception is accepted (e.g., poker, football), a common feature is that the deception is agreed to by the people who decide to participate. In this sense, because they authorize the deception, their autonomy as participants is respected.

The concept of authorized deception was introduced in the 1970s and early 1980s, though it was called by a different name. The term *authorized deception* applies to research in which there are undisclosed purposes, particularly the purpose of specific interventions. For example, sometimes when researchers study compliance monitoring, they don't tell the subjects that the pill bottle or inhaler they are getting has a little gadget inside that measures how often the item is used.

The concept of authorized deception does not apply to most of the rest of the research based on deceptive strategies, particularly those in which the participants cannot be debriefed.

Debriefing is usually part of authorized deception; in fact, the researcher might well include in the final sentence of a consent form the promise to debrief. This resolution may not be useful in proposed deceptive research with terrorists as subjects. It might put the researcher in extreme danger to debrief a terrorist subject on his or her true identity or purpose.

Some deceptive activities outside research are not authorized, of course. Spying is an appropriate analogous activity to look at because to some extent, social and behavioral research on terrorism is like scientific spying, if you will. As with research, there's ethical spying and unethical spying, as there is ethical and unethical investigative journalism. The ethicality of the activity is not merely a function of the deception; it's also a function of other features of the particular activity and its context.

As we examine the ethical bases for deceptive research, it is important to ask what the specific ethical requirements are of different activities and whether there should be specific ethical requirements that are distinct to research. Currently, researchers are governed by the Common Rule and other regulations. Those are the guidelines that IRBs and researchers need to follow, but it may be that after careful consideration of their ethical bases, we can amend them in ways that will facilitate the ethical conduct of needed research on terrorism. If we do not, there is the danger that some social and behavioral research on terrorism will be conducted outside the purview of IRBs, rendering it "renegade research."

Common Deceptions Proposed for Terrorism Research

In social and behavioral research on terrorism, IRBs are usually faced with projects that propose to use partial deception or to conceal certain information from the prospective participants, especially during the consent process. The piece of information that terrorism researchers particularly want to conceal is sponsorship by the U.S.

government or its agencies and military services. Researchers may wish to conceal sponsorship simply because of the antipathy that prospective subjects may have toward the culture, religion, or politics of the sponsor. For instance, an American researcher might want to withhold sponsorship information just because subjects are believed to hate all things American and will not want to associate with or participate in American research, irrespective of the purpose of the research. Assumptions of such hostility may, however, not always be warranted; and even if such hostility exists, populations in some countries may still participate in research because of their desire to communicate their perspectives to America.

Under the Common Rule, sponsorship is not a required element of consent, but participants are supposed to have all information that might be material to their decision. In the case of terrorism, sponsorship appears to be strongly material. In fact, the source of funding is almost always the most sensitive element.

Workshop participants inferred that this was true because potential subjects are using sponsorship of a study as a proxy for its purpose, including dual purpose. It is worth noting that under the Common Rule, purpose is among the elements required for full consent. Potential subjects seem to use sponsorship as a proxy for the real purpose of getting their information. There particularly seems to be concern among potential participants about sponsors that are American intelligence agencies and military services conducting activities in the potential participants' countries. They may even believe that the research, while beneficial to the sponsoring agency's country, will prove to be detrimental to their own country and thus pose a risk rather than a benefit to them.

When it becomes known or suspected that an agency such as the CIA is distributing funds in a region to study elements of its culture, such as its education and information systems (and so on), potential subjects of research may suspect that the CIA is behind any study for which they are approached, regardless of what they are told or what the truth is. If they know the research is being conducted or sponsored by the U.S. government, they will assume there is CIA involvement. Often,

regardless of how innocuous the sponsoring agency might be in terms of having any capability to inflict harm on subjects or their groups, the potential participants infer that the research is actually being conducted by an intelligence agency. The potential subjects and other community members may infer falsely that the CIA is involved and they are at risk for that reason. Accurate disclosure of sponsorship (e.g., a domestic U.S. agency or foundation) can sometimes lead to unexpected problems, namely, mistaken assumptions by subjects about study purpose.

Sometimes researchers wish to conceal the fact that any research is being conducted at all ("covert" research). They may attempt to justify a proposal to use such complete deception by claiming that valuable research could not otherwise be conducted. For example, some populations of interest may not consent to research because they really do not value it. For instance, some groups of interest may not read or be able to read books and reports, and they may not want others to read them either. Such groups would not be open to research that involved informed consent to study them. So a researcher might propose a participant observer protocol that involved joining the group in order to study it, and the researcher might propose doing so in a way that concealed the purpose of his or her activity. This would be complete deception.

Ethical vs. Unethical Deceptive Research

Workshop participants noted that within current guidelines, some deceptive research would be regarded as ethical and some would, if approved and conducted, be viewed as unethical. However, the distinction can be a gray one, and there is a slippery slope, since there are many behaviors that test the acceptable bounds of what is or is not socially destructive.

As a hypothetical ethical case, consider a researcher who proposes to study covertly the interactions between spouses and children in the privacy of their homes. Suppose the population is lower socioeconomic class parents and their very young children. Let's say the reason is to determine whether there is anything in the parenting practices of this group that contributes to the well-established research finding that

children of this population come to school already behind their age peers in terms of their ability to succeed academically. The proposed research is to be covert because the researchers claim they need to observe what the parents are doing without knowledge that they are being watched to capture normal interaction styles. The benefits of such research might turn out to be tremendous. Yet there is the ethical problem that such a study, if approved, would be invading and violating the privacy of those people. As recognized by the principle of autonomy, these people have a right to the protection of their privacy in a way that research cannot, and should not, violate.

Consider, by contrast, a hypothetical case of proposed covert research that lies somewhere else on the slippery slope. Suppose a researcher wants to study burglars committing burglaries. Burglars are engaged in an activity that violates accepted standards for ethical behavior in our society. Some might argue that burglars have violated a social contract and do not have a right to privacy in their illegal activities, even though their behavior suggests they have an expectation of privacy. But others might argue that they retain their rights as research subjects.

Another example of covert research that might be less problematic ethically is this. Suppose someone proposed a study of soccer hooligans. It would be infeasible to collect consent from all the fans at a soccer game who might engage in hooligan behavior. Moreover, the participants are probably not identifiable. Researchers could also argue that their observation of public hooligan behavior is ethical because there is no expectation of privacy in a sports stadium.

As for reconciling deception with autonomy, it is clear that the regulations already permit some kinds of human subjects research that is not truly voluntary, thereby compromising the principle of full autonomy. Research is commonly conducted where the subjects don't know anything about it: medical records research, the whole field of quality improvement, disease outbreak investigations, surveillance, and so on. So we ought to be considering, more generally, what are our justifications for doing things without consent.

Research in the Context of Group Conflict

IRBs reviewing proposals for social and behavioral research on terrorists have the additional ethical difficulty that the research team, its sponsors, and potentially the IRB are all taking sides in a conflict whose conduct, progress, and outcome the research is designed to influence.

When research is conducted within an active conflict, however, every minute that the researcher is in an "opponent" country and/or interacting with its residents or constituents, one could say that he or she is conducting research and is subject to suspicious inferences regarding identity and purpose and sponsorship. Some countries may not have a strong tradition of social and behavioral research that is objective and ethical; there may be a history of research being conducted primarily for political and strategic ends. For Americans conducting research abroad, full disclosure can begin in practice much earlier than the creation of a consenting process. It begins when they fill in their visa applications. They ask for religion. They ask your profession. Do you say "political scientist," which creates all sorts of problems? Do you say "social scientist"? Do you say "researcher"? Answering these simple questions on the visa application can create problems.

Research may not be perceived as a neutral activity, and rightly so. There may be a strong intersection of research and politics, and this may be particularly true in a research area such as terrorism. Terrorists may choose to participate in research precisely because they see a benefit to sending a message about their political struggle. This might be the key benefit they balance against the risk of participation. Consider, too, that researchers may be manipulated in the political struggle. For instance, they may find it valuable to maintain a dual citizenship: Funding sources in the country sponsoring the research may fund them to do research in the host country in part because they have this dual citizenship. The research may be innocent but have not so innocent uses. There may be a process of constant manipulation going on.

It is an open question whether any research whose objective is to help advance the fortunes of one side in a military or political conflict between groups—such as a nation and a terrorist group—can be conducted ethically within the current regulations. It may be that when research is sponsored, conducted, and used in the context of such a conflict, it must be deceptive or covert. This is particularly true when the research is applied, i.e., when it is designed and conducted in order to inform policymakers on one side of the conflict. In such a situation, potential participants in the research from the other side of the conflict are likely to object to the research. The question arises whether it is ever justifiable to try to carry out that research and sidestep the answering of questions regarding purpose and sponsorship.

The Effects of Deception on Scientific Value

Deception in social and behavioral research is problematic on scientific grounds, and this bears on the research's ethicality because the benefits of conducting the research are related to its scientific value. Margaret Mead noted that when we're attempting to deceive subjects, we're often unsuccessful. They can read right through it. This observation has been repeated and expanded by researchers such as Joan Sieber, who has noted that when subjects discover or suspect that you are deceiving them, they think it's fair game to deceive you right back, and give you the sorts of answers they think will either shock you or please you. So deception can compromise the quality of the research results.

Some have argued that the deception genie is out of the bottle and there's no way to get it back in. So many persons have either been in deceptive studies or been exposed to famous or infamous instances of research deception that participants in nondeceptive studies commonly ask, upon the conclusion of the procedure, "What are you really studying?" The participants are trying to find out the hidden question. This means that by permitting the use of deception in research, the research community can change the base of the research population in terms of its sophistication and expectations. Perhaps this has already happened in the populations studied by researchers in terrorism.

If the population has been changed by the practice of deceptive research, that raises the question of how the value of the research itself is affected. The data collected from such a population may be skewed or contaminated, diminishing its scientific value and the potential benefit of any study.

It may be that in populations in which there is the greatest suspicion that research may be deceptive, there is also the greatest likelihood that subjects aren't going to tell the truth. This diminishes the benefit to be balanced against risks.

IRBs cannot be expected to take into consideration the long-term effects on research quality when they are assessing the use of deception or partial deception in a specific study. But regulators might wish to do so.

IRB Development

Workshop participants expressed a concern that American IRBs are generally not well prepared to review social and behavioral research on terrorism, even though many of them have experience with other forms of international research and with other forms of offender research, such as research on criminal gangs. This lack of preparation may be even more characteristic of commercial IRBs than of the IRBs in major research universities and institutions.

A new IRB capability may need to be developed in the social and behavioral research community. There is an analog in the medical community for this sort of development. The Council for International Organizations of Medical Sciences, CIOMS, has developed international ethical guidelines. CIOMS recognized that American IRBs sometimes cannot even determine what is considered private information in some other countries. So these guidelines require that when research is carried out in a country and the investigators and sponsors are from a different country (and they have particularly in mind the case in which the different country is a wealthy industrialized country and the host country is a low resource country), the researcher must be reviewed both by the IRB in the country of the sponsor and by a local IRB in the host country.

The option of using local IRBs is sometimes open to social and behavioral researchers on terrorism, depending on the country. However, their use may be limited precisely because of the kinds of activities that are being studied. In some cases, they may be of too much interest to the governments in the host countries, specifically to their legal, military, intelligence, and security agencies. The IRBs themselves may be compromised in those countries because they reside in universities and research institutions that are controlled by the government. In such cases, ironically, submitting a protocol to a host country IRB may actually increase the risk to subjects, as well as to the researchers proposing to conduct the research.

Perhaps a way can be found to establish capable, independent IRBs for social and behavioral research in host countries where there are presently none. There are models for how to do so in epidemiological and biomedical research. Another option is the use of outside experts by regularly constituted IRBs to complement the IRB's knowledge with greater contextual understanding.

RAPID WRAP-UP BY PATRICK P. GUNN

A rapid wrap-up of the wide-ranging discussion we had on the issues of autonomy and deception, I think, really, is impossible to do. What I will try to do is identify some specific issues that I felt were interesting and relevant. I think perhaps the easiest way for me to organize this is to follow the scheme that Sandy Berry outlined, because, as you may recall, at the end of our session, she took a stab at some sum-up. That scheme looked at the continuum of approaches we might have with respect to the use of deception.

The first approach would be to adopt a policy of full disclosure. The working assumption we made from the outset here was that if you adopted a policy of full disclosure, you would be effectively precluded from conducting much of this research because the subjects would elect not to participate. As we heard from Christine Fair, that may or may not be true in all circumstances. It may also be the case that full disclosure might reduce risks, both for the participant and for the research team. I was particularly taken by Christine's comment that

during the course of her research in Pakistan, she felt much better and slept better at night knowing that the facts and circumstances of that research had been fully disclosed. However, as Christine did note, the particular research that she was doing in Pakistan might be quite different from research in other cases. I've had discussions with Kim Cragin and Audra Grant of RAND, both of whom have considerable experience conducting terrorism research overseas and who have explained that disclosing U.S. sponsorship—indeed, even disclosing the connection of the United States (not the United States government, but the mere connection of Americans in any way with the study)—might effectively preclude research from going forward because subjects just won't participate. Such is the level of antipathy toward and distrust of the United States in those communities.

The next approach would be partial disclosure. To what extent it is permissible to withhold certain details about the research? Someone, I think Ivor Pritchard of OHRP, raised the question of whether there was a meaningful ethical distinction between actively misleading a subject about research and simply not disclosing everything about research. Christine Fair made the point that if you were to disclose the connection of the U.S. government with the research, in many countries: (1) the conclusion drawn by the subject might actually be inaccurate (namely, that the CIA was behind the whole thing); (2) you might place the researcher at risk; and (3), the responses might be skewed, even if you could get subjects to participate. So, again, with respect to partial disclosure, there might be circumstances under which you might need to do it in order to recruit. And it might promote beneficence and respect for persons because you wouldn't be introducing an additional level of mistrust based on misperceptions and incorrect conclusions about what was really going on with the research.

The third approach we talked about is authorized deception. I think Dave Wendler calls it "second-order consent." That's the notion of disclosing to the subjects that there's going to be something about a research protocol that is deceptive. Various views were expressed on that. Bob Levine observed that authorized deception will not work in a context where you can't debrief the subject afterwards. There was a

reference to potential reactive throat-slitting from an unhappy debriefed subject, which I remember very keenly. It struck me that if you are in a context where you are forced to disclose because of a debriefing obligation and are going to get violence as a result, maybe you are better off eliminating all deception or, failing that, not engaging in the research at all.

The fourth approach, of course, would be to allow some degree of deception in research. Several commentators observed that deception has been allowed for a long time in all sorts of research, and that there are persons who are doing activities essentially similar to what other research institutions do but who don't feel themselves to be bound by these ethical obligations. There is a legitimate question from researchers engaged in this type of research, and legitimate frustration as to the issue of why us and not them. In addition, when considering deception, I wonder whether there is a distinction between (1) misleading a subject about the research itself (maybe about the research's aims—about facts that you don't believe, as an investigator, would be material to the subject's decision to participate), and (2) misleading the subject about facts that you know—or have very good reason to believe from inception—that if disclosed would cause the subject to make a decision not to participate. When you look back at the 1992 APA ethical principles that govern psychologists, there is a pretty clear statement with respect to the use of deception. I believe the APA has said that researchers should never mislead subjects about facts that are material to their participation. We should ask whether that might be a line that could be drawn, or should be drawn, by researchers on terrorism when they're conducting these sorts of protocols.

Further—and this was a point made again and again with respect to justification for deception—there is the importance of assessment of risks. If there was one nugget of consensus that seemed to emerge today on that topic—and, in fact, it appears to be dictated, as Ivor Pritchard reminded us, by the Common Rule—an IRB can't make informed judgments about risks unless it has some participation on the IRB by people who have knowledge that's relevant and specific to the research context.

Whether we address that requirement by constituting a local IRB, as I think Bob Levine has suggested, with that specific focus, or, alternatively, by getting some area experts involved on the remote institution's regular IRB, is a matter for discussion. But the bottom line is, the IRB can't make credible judgments about those risks without having that kind of participation.

That will conclude my efforts to sum up quickly. I have a suspicion that we're going to be meeting again and again, or at least discussing a lot of these issues further. That's because largely what we've done is turn up many questions rather than answers.

3. MAXIMIZING BENEFICENCE AND MAINTAINING JUSTICE

- Moderator: Ricky N. Bluthenthal, PhD, Senior Social Scientist and Member, Institutional Review Board, RAND; Professor of Sociology and Director of the Urban Community Research Center, California State University Dominguez Hills
- Presenter: Patricia Marshall, PhD, Professor of Bioethics and Anthropology, Department of Bioethics, School of Medicine, Case Western Reserve University
- Panelists: Robert J. Levine, MD, Professor of Medicine and Lecturer in Pharmacology, Yale University School of Medicine; Director of the Law, Policy and Ethics Core, Yale University Center for Interdisciplinary Research on AIDS; Co-Chair, Executive Committee, Yale University Interdisciplinary Bioethics Project

James R. Sayer, PhD, Assistant Research Scientist, Human Factors Division, University of Michigan Transportation Research Institute; Chair, University of Michigan Behavioral Sciences Institutional Review Board

Brian A. Jackson, PhD, Physical Scientist; Associate Director, Homeland Security Program; Member, Institutional Review Board, RAND

Shireen T. Hunter, PhD, Visiting Fellow, Center for Muslim-Christian Understanding; Adjunct Professor, Georgetown University

INTRODUCTION BY DR. RICKY N. BLUTHENTHAL

One of the core principles of the Belmont Report is beneficence, which requires that researchers maximize benefits and minimize risks for research subjects. Within the context of terrorism research, this can be very challenging, as the ultimate beneficiaries are likely to be in the U.S. while likely harms fall almost exclusively upon potential research participants and others who might support terrorist activities.

I'm delighted to be able to introduce Dr. Patricia Marshall to speak on this topic. Aside from being a friend of mine and a former collaborator on a very interesting three-city study of HIV risk among drug users, Dr. Marshall is also Professor of Bioethics and Anthropology in the Department of Bioethics at the School of Medicine at Case Western University. In 1999, Dr. Marshall served as a consultant to the President's National Bioethics Advisory Commission on its project examining ethical issues in international health research. In 2000, she was a consultant to the World Health Organization's Council for International Organization of Medical Societies on its revision of ethical guidelines for international research. Dr. Marshall was appointed to the National Academy of Sciences study panel on IRBs, surveys, and social science research in 2001. In 2007, she was appointed to the Secretary's Advisory Committee for Human Research Protection (SACHRP) for the Office of Human Research Protection (OHRP). So Dr. Marshall is exceptionally well qualified to speak on this topic.

PRESENTATION BY DR. PATRICIA MARSHALL, "ASSESSING RISKS, MINIMIZING HARMS, AND PROMOTING JUSTICE FOR PARTICIPANTS IN RESEARCH ON TERRORISM: AN ETHICAL CONUNDRUM OF RESTRAINT AND POSSIBILITY"

Thank you very much. You can see from the title of my talk that I'm concerned about risks and benefits as an ethical conundrum in the context of research on terrorism—an ethical conundrum of restraint and possibility. What I'd like to do today is consider some of the issues that surround notions of harm and potential risk and benefits for those of us who are involved in and concerned about research on terrorism.

Every day in the media we are inundated with images of terrorism. Some of the photographs that you are going to see in my presentation

come just from this year. Whatever direction we are moving in, we cannot get far from this literal and symbolic representation of terrorism in our life, and the consequences of terrorism in our life.

Terrorism

“Political violence: violence or the threat of violence, especially bombing, kidnapping, and assassination, carried out for political purposes.” *Encarta Dictionary*

Terror: “...violence (as bomb-throwing) committed by groups in order to intimidate a population or government into granting their demands”
Websters Dictionary

Bombs in Bangkok Kill 2 and Wound More Than 30

A Thai police officer
Examines the area where
A bomb exploded Sunday in
Kon Toey market in Bangkok.
Seth Mydans
New York Times January 1, 2007



Figure 3.1
Terrorism

In my talk today, I want to call attention to the importance of recognizing the existing sources of information that we have about terrorism on a range of different concerns. Also I want to end my talk with a template that might help us begin systematically to consider questions that we might want to raise about harms, risk and benefits.

I think it's very important for all of us to recognize the complex set of relationships that exist any time you think about research on terrorism. Christine Fair, I was so happy that you mentioned your role as a researcher and some of the risks that you are under, because here, in this rendering of the stakeholders who are involved in research on terrorism (see Fig. 3.2), I've got not just the individuals who are participating in this research or their communities and the nations where they live—I've got three very important stakeholders here: investigators, institutional sponsors/funders, and a group of people, the population that is participating in or is affected by the research

and by terrorism. And it all happens within a local and a global context.



Figure 3.2
Stakeholders in Research on Terrorism

So we've got this social context within which research occurs and within which the terrorist acts occur. Researchers, all of us, have to deal with the national and international ethical guidelines. All of you are familiar with the ethical guidelines that we have to address in our work, including informed consent processes and so on. There are a number of stakeholders involved, and this relationship is very complex, partly because it always involves the negotiation of power.

An Ethical Conundrum

Conundrum defined:

- "something puzzling, confusing, or mysterious" *Encarta Dictionary*
- "... an intricate and difficult problem *syn see* mystery.: *Websters Dictionary*
- Why? Because research on terrorism raises complex questions about risks for participants, investigators, and sponsors.

Figure 3.3
An Ethical Conundrum

Why is it a conundrum? What is a conundrum? It's something puzzling, a confusion, or mysterious. Why is it mysterious? Why is it problematic? Because research on terrorism raises complex, very difficult problems about risks for everybody involved. I think it's important for us to sort out what we mean by harm and risk. They answer different kinds of questions.

If you think about harm, then you're focusing on the nature or the form of the negative impact of either conducting or participating in research. You're focusing on the "what" question. What is the harm?

Risk and Harms in Research on Terrorism involving Human Participants

- **Harm:** the nature/form of harm from conducting or participating in research. *What is the harm?*
- **Risk:** the likelihood that harm may occur. *How likely is it that this will happen?*
- Potential harms and potential risk for **both** participants and researchers need to be considered.

Figure 3.4
Risks and Harms in Research on Terrorism Involving Human Participants

Whereas, when you think about risks associated with conducting or participating in research, here, the question is frequency of occurrence or likelihood of occurrence. How likely is it that this will happen? How likely is it that any of us here might be the victim of a bombing on the streets of Washington? Well, theoretically it could happen, it has happened. The likelihood of that occurrence is going to be not so frequent as you might find if you're in Jerusalem or if you're in Baghdad, and so on. The potential harms and the potential risks for both participants and researchers absolutely, of course, have to be considered.

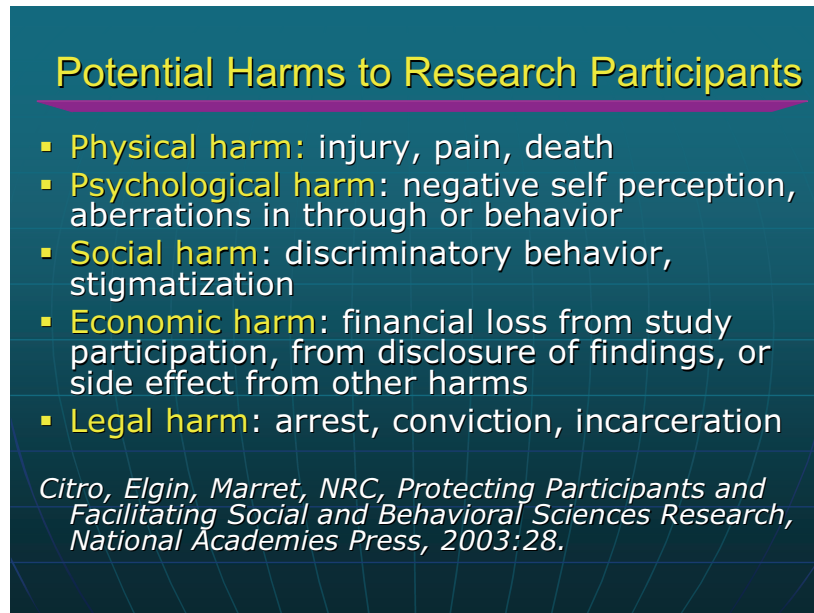


Figure 3.5
Potential Harms to Human Participants

What are some of the potential harms? In other words, what can happen as a result of participating in, conducting, or sponsoring research on terrorism? These are some of the harms that were identified by the National Academy of Sciences panel that Tora Bikson and Eleanor Singer participated in; I was involved in that also (see Fig. 3.5). We were looking at IRBs and social science research, and some of the concerns that we all face as behavioral scientists. Physical harm is an obvious one, including the potential for death threats. Christine, you mentioned that one of your researchers was nearly beaten. I think that's the way that you framed it. So physical harm is a reality for people who are in the field doing research on terrorism. Psychological harm, including negative self-perceptions, discomfort, anxiety, is another possibility. In some cases, mental illness and social harm. All of these are fairly obvious, as is legal harm.

Potential Harms to Research Participants

- **Dignitary harm:** "can result when individuals are treated as means to an end and not as people deserving respect for their own values and preferences. Such harm can happen in studies that do not appropriately obtain informed consent."

Citro, Elgin, Marret, NRC, Protecting Participants and Facilitating Social and Behavioral Sciences Research, National Academies Press, 2003:28.

Figure 3.6
Potential Harms to Human Participants (cont'd)

Finally, we have to consider relevance of deception for potential dignitary harm. This can result when individuals are treated as a means to an end, and not as people who are deserving of respect for their own values and preferences. This kind of harm can happen in studies that do not obtain informed consent. So I think this has implications for how we use deception in research on terrorism.

Victim of terrorist attack: 1994, woman shot on street, bullet remains near spine

Asked if she would participate in research:

“People who are diagnosed with PTSD ...talking brings it back to life...it’s not helpful, and that’s from a victim’s point of view. I would not be interested...[but some people might]”



Figure 3.7

Victim of Terrorist Attack: 1994, Woman Shot on Street, Bullet Remains near Spine

I spoke with an individual who was the victim of a terrorist attack. In this case, it’s someone who was shot while she was on the street in front of a restaurant. It was a random shooting that was part of a bigger event. This happened in 1994; she still has the bullet in her back. I asked her a number of questions about research on terrorism and her willingness to be involved. I asked her if she would participate in a set of interviews about her experience as a victim. She was diagnosed with Post-Traumatic Stress Disorder. She said that people who are diagnosed with Post-Traumatic Stress Disorder—in her case—talking about it brings it back to life. And when she talks with other people who have been through this kind of thing, she said, it’s not very helpful. From her perspective—it’s a victim’s point of view—she wouldn’t be interested; but, she said, some people might. And she also said, “Well, if you are going to be interviewing suicide bombers . . .”—they are at the other end of the continuum here—. . . what kind of incentive are you going to give them to participate in a study?” For her, I couldn’t offer an incentive that would be meaningful, and she questioned whether or not it would be possible for anyone to really

participate in a meaningful way. But I disagree with her on this. She was not interested, but I think some people would be. Right now, what are our sources of information about terrorism?

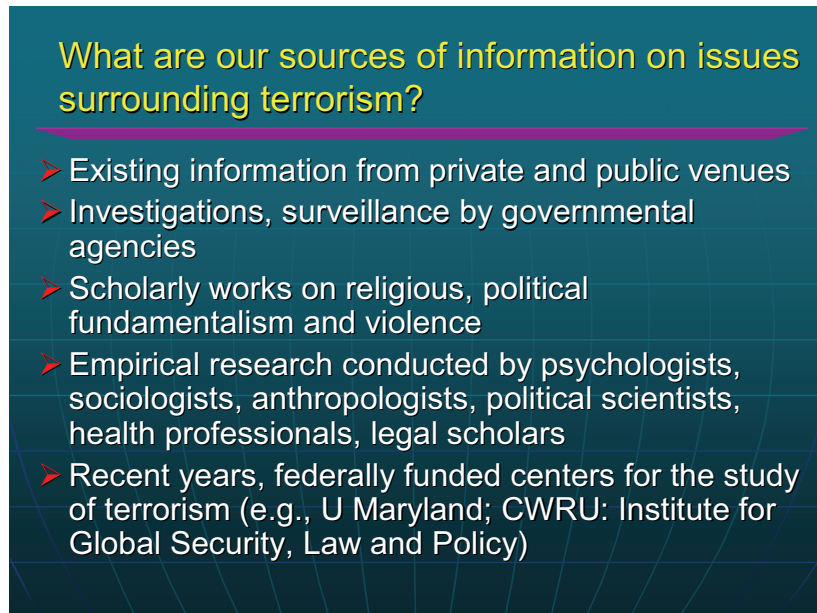


Figure 3.8

What Are Our Sources of Information on Issues Surrounding Terrorism?

There is, in fact, a large body of data that we can draw on right now. There have been investigations, covert research operations by governmental agencies, scholarly works on religious fundamentalism and violence. So, there's an existing body of literature about ideological and political fundamentalism and social violence. Work has been conducted by psychologists, sociologists, anthropologists, political scientists, health professionals, and legal scholars. We're not starting from scratch. People have experience doing this kind of work, and they have dealt with some of the issues we are discussing today. In recent years, we've had centers developed specifically for the study of terrorism. I didn't know this, but we have a center on the Case Western Reserve University campus. The center is called the Institute for Global Security, Law and Policy. There's a center at the University of Maryland, and there's one in California. Their goal is to help us get

more information about the causes of terrorism, the impact, and so on.
What are other sources of information?

Other sources of information

- Investigative journalism
- Fiction, Film

Paradise Now
(Hany Abu-Assad 2005)
Two childhood friends
are recruited for a
suicide bombing in
Tel Aviv.


A movie poster for the film 'Paradise Now'. The poster features two men in dark suits seen from behind, looking out over a bright blue sky. The title 'PARADISE NOW' is at the top in white capital letters. Below the title, there is a line of smaller text: 'THE FILM THAT INSPIRED THE TV SERIES'. At the bottom, there are some credits in Arabic and English.

Figure 3.9
Other Sources of Information

Investigative journalism, which is not research, as well as fiction and film are other sources. This is an advertisement for a film that was produced by a Palestinian last year, and it's gotten very good reviews. I haven't seen it, but I had heard it was excellent. It follows two childhood friends who are recruited for a suicide bombing in Tel Aviv. This is another source of information that we might use to help us understand the factors that contribute to a willingness to participate, in this case, in suicide bombing.

Is it possible to conduct “less risky” research on terrorism?

Context is key: *Steven Erlanger NY Times, 1/6/07*

- What is nature of study?
- Who is being studied?
- Who is collecting the data?
- Who is funding the study?
- How are results published,
- applied?




Figure 3.10
Is It Possible to Conduct “Less Risky” Research on Terrorism?

Is it possible to conduct “less risky” research on terrorism? And I put that phrase in quotes, because we don’t have time to deconstruct the notion of risk here; but I think that when we consider risk, context is absolutely essential. The context is going to be the key issue here. So it’s a little bit difficult to consider risk and harm apart from an actual study. You’re always going to be considering factors like the goal of the study. What is the purpose of this research? Ivor Pritchard, right at the very end of our first session this morning, went straight to the heart of it. Why are the data being collected and how are they going to be used? Why do the funding agencies want this information? Who is collecting the data? Who is funding the study? How are their results published or applied?

“..Perceptions of Terrorism Among Israelis and Palestinians”

Shamir, Jacob, Shikaki, Khalil *Political Psychology* 23, 2002. p
Abstract: ...two surveys, 2001, *Israeli Jews, Israeli Arabs and Palestinians* asked if 11 local/international incidents were acts of terrorism in their view, and whether they were considered acts of terrorism by the international community. *Israeli Arabs judged all acts of violence as terrorism in high percentages. Israeli Jews and Palestinians' definitions present a mirror image; however, they did not project these definitions to the international community.* Instead, they perceived an international norm divergent from own viewpoint, inflating world judgment of own acts of violence as terrorism and underestimating world judgment of the other side's violence, in what amounts to a hostile-world phenomenon.

Figure 3.11
“Perceptions of Terrorism Among Israelis and Palestinians”

Here are some examples of research that has been conducted. In this case (see Fig. 3.11), the study is published in *Political Psychology*. These were surveys conducted in 2001 with Israeli Jews, Israeli Arabs, and Palestinians. They were asked about their response to 9/11 and to local and international incidents of terrorism. The Israeli Arabs in high percentages judged all acts of violence as terrorism. Israeli Jews and Palestinians' definitions presented a mirror image of the Israeli Arabs', but they did not project these definitions onto the international community. Instead, they perceived an international norm that diverged markedly from their own viewpoint. The approach was a survey with a mixed group of respondents.

Impact of Terrorism: Adolescent Violence

Even-Chen, Merav Solomon, Itzhaky, Haya
Journal of Community Psychology 2007, Vol.
35 Issue 1, p4

Abstract: Two hundred and fifty-four Israeli adolescents residing in areas with different levels of exposure to terrorism completed questionnaires. *The findings confirm that exposure to terrorism contributes significantly to violent behavior....* findings emphasize impact of...prolonged exposure to terrorism on manifestations of violence.

Figure 3.12

Impact of Terrorism: Adolescent Violence

Here's another one, the impact of terrorism on adolescent violence (see Fig. 3.12). Two hundred and fifty-four Israeli adolescents completed questionnaires. The findings confirmed that—and this is not rocket science—the more you are exposed to violence, the more violent your behavior might be.

Response of British Muslims to 9/11

Ahmad, Fauzia *J Ethnic & Migration Studies* 06

Small sample, self-identified British Muslims, variety of ethnic backgrounds and age groups, response to reporting of the events of 11 September 2001. Detailed semi-structured interviews, supplemented by e-mailed responses to a related questionnaire, revealed varied terrestrial and satellite viewing patterns. **There were distinct perceptions of Eurocentric and US bias in the Western media.** 24-hour rolling news programmes were criticised for failing to provide in-depth analysis of world events and the motives for the attacks, and for failing to attach equal significance to other 'ground zeros'... profound belief that negative stereotyping, ...sensationalism in early stages...contributed significantly to increase in anti-Muslim attacks and resulted in infringements upon civil liberties. **Representation of Islam as 'violent' and abusive to women was a commonly expressed concern. Many felt that the 'clash of civilisations' hypothesis was perpetuated by the media.**

Figure 3.13

Response of British Muslims to 9/11

Here is another example of the kind of study that is being done on terrorism (see Fig. 3.13). And in this case, British Muslims were interviewed about their response to 9/11. You can see they were very concerned about the representation of Islam as violent and abusive to women. That was a common concern that was expressed. Many felt that the clash of civilizations—that kind of paradigm—was perpetuated by the media after 9/11. The reason I'm going through these examples is just to give you a sense of the existing and varied types of information that we have.

"Study into suicide bombing curtailed"

NY Times 9/29/06, Ed Supp, p11

Riaz Hassan, a professor of sociology at Flinders University in...South Australia ... *cancel plans to interview international terrorist leaders after he was intervened by the anti-terrorism laws of the country.* Hassan has planned to approach several organizations, including Hezbollah in Lebanon, Hamas in the Palestinian territories, Islamic Jihad in Egypt and Jemaah Islamiah in Indonesia.

Figure 3.14

"Study into Suicide Bombing Curtailed," *NY Times* 9/29/06, Ed Supp, p. 11

How does risk impact the investigator who is doing the survey? In one case, Dr. Hassan, a sociologist in South Australia, had to cancel his plans to interview international terrorist leaders after he was intervened by the anti-terrorism laws of his country (see Fig. 3.14). This was a *New York Times* article in the educational supplement from last year. There was a much longer article in the *Chronicle of Higher Education*, that some of you may have seen, about terrorism. Dr. Hassan was mentioned in that article. Here is a case where the researcher had to stop his project because of the risk. I wanted to share this with you, and I'm going to end in just a minute, because I think it will be good to move on and have a fuller discussion of this issue of risk and benefit in terrorism research.



Figure 3.15
Trust Framework: Ethical Research in Low-Resource Settings

This is the way that I think about conducting ethical research in low-resource settings (see Fig. 3.15). I do a lot of research on informed consent, and I call this the “trust framework.” It builds on the work of Zeke Emanuel and his associates, as well as other guidelines that have been available for a long time—the CIOMS Guidelines, the Belmont Report, and so on.

I think about the trust framework in this way. There are three underlying principles: collaborative partnerships, capacity building, respect for persons and community. Those three underlying ethical principles allow you to ask questions about how they become articulated in behavior. What does transparency mean if you think about collaborative partnerships? Well, for example, it means being clear about the purpose of the research, the results of the research, any financial gain, and so on. How does relevance come into play in relation to respect for persons? That would obviously be associated with something like informed consent practices. If you think about this kind of trust framework in the context of research on terrorism, where does it get you? In terms of capacity building—I’m not sure how we talk

about capacity building with research on terrorism. But for myself, I wanted to begin to try to connect this framework to risk and harm.

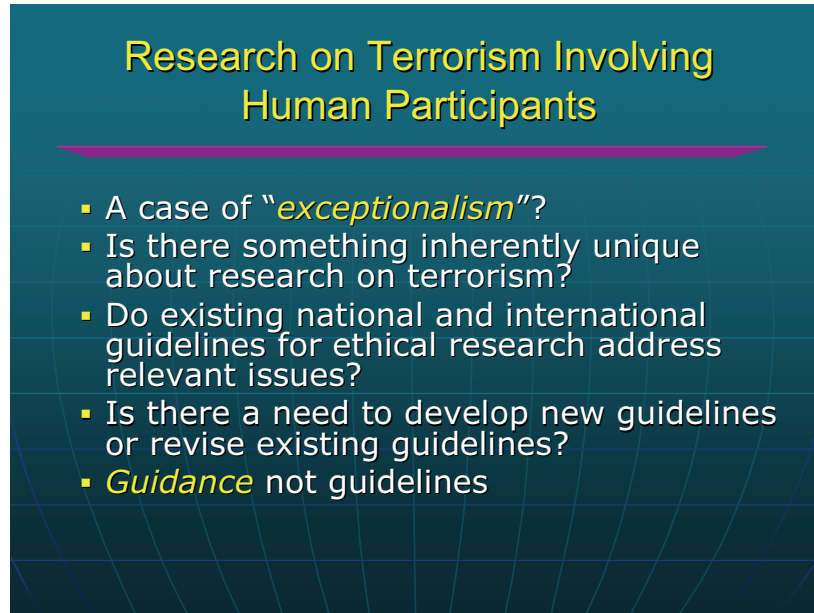


Figure 3.16
Research on Terrorism Involving Human Participants

What it made me think about is the question of exceptionalism. Is research on terrorism that involves human participants—do we have a case of exceptionalism here? Some people have said, of genetics research: Is there something unique about doing that kind of research? You might say that's analogous to raising the question in this context. Do existing national and international guidelines address the relevant issues in research on terrorism? Is there a need to develop new guidelines? I would say no. I don't think we need new guidelines, and I don't think that we need to revise the guidelines that we have.

But perhaps we need more guidance about the application of the national and international guidelines. There are a number of very specific issues that need to be considered when you're talking about minimizing harms, reducing risks, and promoting justice for everyone involved in research on terrorism. The key points of consideration have to do with, first, the significance and relevance of the particular study. Here, you want to ask the question, Why are we doing this?

What's the relevance? How important is this information that we are going to get?

**Minimizing Harms, Reducing Risks,
Promoting Justice: Research on Terrorism**

Points for Consideration: **Bomb's Lasting Toll: Lost Laughter and Broken Lives**
Sabrina Tavernise *NY Times* 1/7/07

- Study significance and relevance of study
- Existing knowledge
- Research Design
- Sample population
- Recruitment strategies
- Incentives
- Dissemination of results



Figure 3.17
Minimizing Harms, Reducing Risks, Promoting Justice:
Research on Terrorism

The next thing I think you have to ask is, What information do we already have? Do we need to be putting people at risk if we already have information that's out there that we can draw on? What do we know before we talk to people? The third point is research design. Of course, this has a whole range of issues, including the method that you are going to use. Is it like participant observation, is it doing semi-structured interviews? Is it doing a randomized survey? Is it doing something that perhaps involves people indirectly, so that you're talking with key informants, but you are doing an analysis of policies that might be related to terrorism? So the design issue is important. Further, who is the sample population, and how vulnerable are these people to potential risks and potential harms? How are they being recruited? The issue of incentives is very important, of course, and the dissemination of results. I want to highlight these particular points: significance and relevance, existing knowledge, design, the

population and their vulnerability. People can, of course, be vulnerable for a whole range of reasons, including their gender, their political or religious association. How are we identifying the population as researchers?

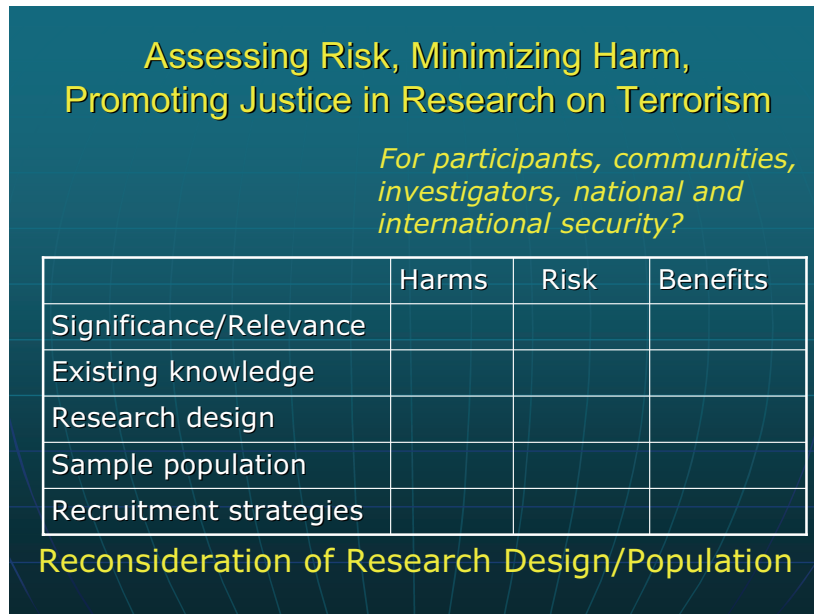


Figure 3.18
Assessing Risk, Minimizing Harm, Promoting Justice in Research on Terrorism

One way to think about this is as a template (see Fig. 3.18). For each of these points for consideration, you ask the question, What is the harm for all of the stakeholders? What are the harms that might result from designing, conducting, or sponsoring this research? What's the harm for participants, communities, investigators, and for national and international security? What are the risks? What is the likelihood of risk associated with the harms in relation to population identification? What are the benefits—immediate, intermediate, and long term? For individual participants, there may be none; for communities, there may be some; for investigators, well, yes, we'll have benefits, too.

What I am trying to do here is set up a framework where there is an overlay of questions and concerns. Then, as researchers or IRB members,

we could focus specifically on these different research concerns and ask ourselves a set of questions about harms, risks, and benefits related to each. I think that the answers are going to be determined on a case-by-case basis. I'm going to stop there.

PANEL INTRODUCTION BY DR. RICKY N. BLUTHENTHAL

I'll just start with brief introductions. Dr. Robert Levine is a Professor of Medicine and Lecturer in Pharmacology at the Yale University School of Medicine, and is Director of the Law, Policy and Ethics Core of the Yale University Center for Interdisciplinary Research on AIDS, and, lastly, is Co-Director of the Executive Committee of the Yale University Interdisciplinary Bioethics Project. Dr. James Sayer—he's already self-introduced—is the Chair of the University of Michigan IRB and an Assistant Research Scientist at the University of Michigan. Dr. Brian Jackson has been a member of the research staff at RAND since 2000, and his research activities focus on homeland security and terrorism preparedness. And Dr. Shireen Hunter is a Visiting Fellow at the Center for Muslim-Christian Understanding at Georgetown University, and is also an Adjunct Professor there. So, Dr. Levine, if you could start; and limit yourself to ten minutes, please.

Panel Remarks by Dr. Robert J. Levine

Thank you. I often say, at the beginning of a talk in a place I haven't visited before, how grateful I am to those who invited me. This time it has special meaning. I have been invited into a world that's utterly novel to me. And I will come out of this changed in significant respects in my understanding of the varieties of problems that can be presented in the course of doing research on human subjects, so thank you very much.

I'm going to stick to what I was asked to do, and that is to talk about risk justification and the protection of vulnerable subjects. My news won't be very good for you. I'm going to conclude that if you follow the federal regulations meticulously, there is no way you can

justify most of the work you do; therefore, we're going to have to do something else.

Beneficial vs non-beneficial research

- Synonyms: therapeutic research; clinical research
- An incoherent concept.
 - Rejected by National Commission in 1977.
- A source of error in ethical codes and regulations.
- Current codes and regulations have lingering traces of the term.
 - All research has at least some components that are not beneficial to the individual research subject.

Figure 3.19
Beneficial vs. Nonbeneficial Research

It's all too common to distinguish between beneficial and nonbeneficial research. Synonyms for "beneficial research" are "therapeutic research" and "clinical research." It's common but erroneous to do this. Therapeutic research (beneficial research) is an incoherent concept. It was rejected by the National Commission for the Protection of Human Research Subjects in the 1970s. And yet current ethical codes and regulations have lingering traces of the term.

COMPONENT ANALYSIS

- Replaces the concept of ‘beneficial research’.
- “...interventions or procedures that [do or do not] hold out the prospect of direct benefit for the individual subject.”

Nat'l Commission: [Research Involving Children](#)

Figure 3.20
Component Analysis

It's important to bear in mind that all research has at least some components that are not beneficial to the individual research subject. Component analysis replaced the concept of distinguishing beneficial and nonbeneficial research. This calls upon us to evaluate each intervention, or procedure, in the research in terms of whether it does or does not hold out the prospect of direct benefit for the individual subject.

BENEFICIAL PROCEDURES

- Justification as in medical practice
 - Risk justified by anticipated benefit
 - Relation of anticipated benefit to risk is at least as favorable as that of alternatives

Figure 3.21
Beneficial Procedures

This is something recognized in the code of federal regulations. It is expressed most clearly in the "special protections" for research involving children: "With beneficial procedures, the justification is just as it is in medical practice; the risk is justified by anticipated benefit to the individual. And the anticipated balance of harms and benefits should be at least as favorable as that of any available alternative."

RISK JUSTIFICATION

- Procedure or intervention:
 - Beneficial: limited *only* by personal benefit
 - Nonbeneficial: limits and thresholds

Figure 3.22
Risk Justification

As I mentioned, with beneficial procedures the limits are only in terms of personal benefit. With nonbeneficial procedures—that is, procedures that are done to produce benefits for society, or the collective—there are limits and thresholds.

Minor increase over minimal risk

- Reasonably commensurate with those in actual or expected situation
- Anticipated knowledge of vital importance to understanding *the subject's* disorder or condition
- *Problem:* Terrorists do not have a relevant disorder or condition.
 - Analogous to prisoners?

Figure 3.23
Minor Increase over Minimal Risk

For example, going back to the children's regulations, if there is a minor increase over minimal risk, the procedure must be reasonably commensurate with those in the actual or expected situation of that child subject. Furthermore, the anticipated knowledge must be of vital importance to understanding the subject's disorder or condition.

This, then, presents us with a problem: Terrorists (or suspected terrorists and their associates) don't have a relevant disorder or condition. There is no way we can say that our research findings will be of vital importance to understanding their disorder. They don't have a disorder. Or, at least, not a disorder in the usual sense of the term, the sense that was used by the National Commission.

I see these issues as somewhat analogous to the justification of research involving prisoners. In the 1960s, research involving prisoners was widely practiced. They were a convenient group of people who weren't going anywhere, so you didn't have to track them around as you tried to do your phase 1 drug studies on them. But then the National Commission came along and said, "If you're dealing with people who might have limited abilities to consent, you must be doing things that are relevant to their condition or disorder." And that's why we came out with such very restrictive regulations for research involving prisoners—regulations that only now, 30 years later, are beginning to get sorted out and rationalized.

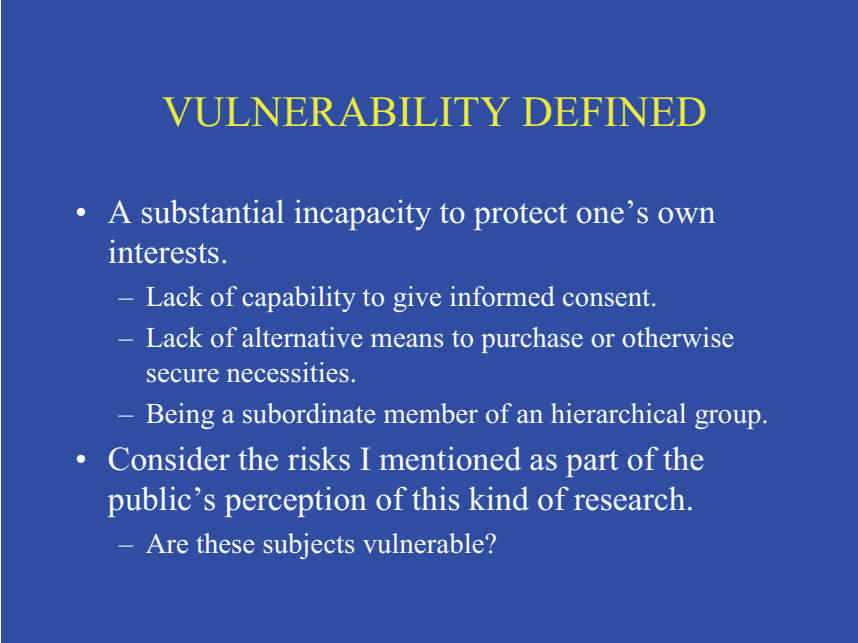
PUBLIC PERCEPTION OF RISK

- Researchers will collect data that could be construed as evidence that a subject has 'terrorist connections'.
- There could be a breach in confidentiality.
 - Inadvertent.
 - Federal government demands access to confidential information.
- Would confidentiality certificates be honored when national security interests are at stake?
- Grave consequences of confidentiality breach
 - Stigmatization at the least.
 - Incarceration without due process (etc).

Figure 3.24
Public Perception of Risk

The public perception of risk in this case is that the researcher will collect data that could be construed as evidence that a subject has terrorist connections. There could be a breach of confidentiality. It could be inadvertent. Or it could be that the federal government demands access to confidential information. Would confidentiality certificates be honored when national security interests are at stake?

I am not sure they would. And there are grave consequences over breach of confidentiality. At the very least, there might be stigmatization. And at the worst, there could be incarceration without due process. We already have some experience with that.



VULNERABILITY DEFINED

- A substantial incapacity to protect one's own interests.
 - Lack of capability to give informed consent.
 - Lack of alternative means to purchase or otherwise secure necessities.
 - Being a subordinate member of an hierarchical group.
- Consider the risks I mentioned as part of the public's perception of this kind of research.
 - Are these subjects vulnerable?

Figure 3.25
Vulnerability Defined

Now I'm turning to the vulnerability part of my talk. Here's a proposed definition for *vulnerability*: a substantial incapacity to protect one's own interests; for example, by lack of capability to give informed consent, by lack of alternative means to purchase or otherwise secure necessities, or by being a subordinate member of a hierarchical group. Now consider the risks I mentioned as part of a public perception of this kind of research. Then I would propose that you ask yourselves whether the subjects we're talking about could be considered vulnerable.

I think many would conclude that in relevant respects they are vulnerable, particularly in the face of the grave consequences of a breach of confidentiality.

ETHICAL JUSTIFICATION

- a) Research could not be carried out with less vulnerable subjects—eg, no other population has the disease.
- Children: polio vaccine.
 - Schizophrenics: antipsychotic drugs.

Figure 3.26
Ethical Justification

Ethical justification for involving vulnerable persons as subjects includes the requirement that the research could not be carried out with less vulnerable subjects—for example, no other population has the disease of interest. I'm using these medical analogies because this is largely what we were given by the National Commission, as well as by the federal regulation writers who based their writing on what the National Commission had recommended. So, for example, if you're developing a polio vaccine, it might be appropriate to involve children as subjects. And in the development of antipsychotic drugs, it may be appropriate to involve schizophrenic patients as subjects.

ETHICAL JUSTIFICATION cont'd

- b) Research intended to obtain knowledge that will lead to improved diagnosis, prevention or treatment of conditions characteristic of or unique to the class of vulnerable subjects (not necessarily the actual subjects).
- c) Subjects and other members of their class will ordinarily be assured reasonable access to products developed as a consequence of the research.

Problem: Terrorists have no relevant 'condition'.

Figure 3.27
Ethical Justification (cont'd)

Ethical justification further requires that the research should be intended to obtain knowledge that will lead to improved diagnosis, prevention, or treatment of conditions characteristic of, or unique to, the class of vulnerable subjects.

Lastly, subjects and other members of their class should ordinarily be assured reasonable access to products developed as a consequence of this research. Please note, as I go through these, how utterly irrelevant they are to all the research we are discussing at this meeting. The problem? Once again, the problem is that terrorists have no relevant condition.

ETHICAL JUSTIFICATION cont'd

- d) Risks of interventions not intended to benefit individual subjects will be minimal unless an ethical review committee authorizes a slight increase in risk.
 - Vital importance.
 - Commensurate with actual or expected medical experiences.
 - More knowledgeable agreements.

Figure 3.28
Ethical Justification (cont'd)

The risks of interventions not intended to be of benefit to individual subjects must be minimal, unless an ethical review committee authorizes a slight increase, or a minor increase, over minimal risk. The research must also pass the standards I mentioned earlier, of being of vital importance to understanding or ameliorating the subject's condition, and the interventions must be commensurate with actual or expected medical experiences of the subjects.

THE CENTRAL PROBLEM?

- If terrorists (e.g.) and other intended subjects of the research we are here to discuss are considered **vulnerable**, and
- If the proposed research presents **more than minimal risk**, then
- There is no way to satisfy the requirements of US Federal regulations for research on this population.

Figure 3.29
The Central Problem?

The central problem is this: If, for example, terrorists, and other intended subjects of the research we are here to discuss, are considered vulnerable, and if the proposed research presents more than minimal risk, then there is no way to satisfy the requirements of U.S. federal regulations for research on this vulnerable population.

Recommendations

- o Attempt to develop fail-safe systems for maintaining confidentiality.
 - o Lowers the risk to 'minimal risk'.
- o Consider the possibility that the risks of participation in this research are commensurate with those encountered in their everyday lives.
- o Explore the possibility of adding this category of research to the list of exemptions from coverage by the common rule.

Figure 3.30
Recommendations

My recommendations are as follows: We must attempt to develop fail-safe mechanisms for maintaining confidentiality. This would lower the risk to the minimal risk level. We must consider the possibility that the risks of participation in this research are commensurate with those encountered in the subjects' everyday lives—this is from the federal definition of minimal risk—and we must explore the possibility of adding research in this category to the list of exemptions from coverage by the Common Rule. There are some other very risky categories of research already in the exempted class, so it's worth considering that.

There is another thing I want to add to this slide, based upon what I've heard at this meeting. We probably ought to be looking carefully at our society's level of tolerance for all deceptive or surreptitious practices and what it takes to justify such behavior ethically. In the 1960s and 1970s, we, as a society, singled out research as the one area

in which deception is, if not unacceptable, at least very difficult to justify. But at the time we reached this decision, we were not thinking about research of the types discussed at this meeting.

I want to offer one final note of caution. When researchers find in our ethical codes, guidelines, or regulations an obstacle to doing the kind of research they consider necessary, they often attempt to have the rules revised in a way that will enable or facilitate the conduct of their research. Often such revisions can and should be made, particularly when the new research presents issues that were not anticipated by the policymakers and regulation writers. What concerns me is that people who are not involved in this process will notice that every time researchers encounter an obstacle to their aspirations, the policymakers revise the guidelines a little to let a new category of research in. I've called this problem "the perception of infinite malleability." We have to do what we can to maintain rational policy, but we also have to make sure that the public understands that we don't see our system of regulations and ethical codes as infinitely malleable. There are some ethical limits to research that all participants—scientists and policymakers alike—consider inviolable. Thank you very much.

Panel Remarks by Dr. James R. Sayer

I don't have a presentation, per se—I have notes. The notes I want to share with you are from the perspective of an IRB chair and long-term IRB member, specifically at a public academic institution. We've heard a lot today. I can't begin to pretend that I know a great deal about the area of terrorism, but I know a great deal about the struggles of trying to maintain an IRB that must review terrorism—or close to terrorism—types of research. A lot of discussion has, thus far today, surrounded certain assumptions with regard to risks and benefits. And I think there are many instances where the assumptions do not hold.

About two years ago the University of Michigan got its most recent, modern-time baptism in the area of terrorism research. A lot of what I have to say has come out of that and subsequent applications that we've seen. It was a real eye-opening event for us. We struggled a great

deal, and Eleanor Singer, who's on the board, remembers many of the lengthy discussions, late into the night, that the board struggled with. I think, in the end, it was to the satisfaction of no one.

The one assumption I want to raise, particularly coming from an academic institution, is the assumption that most of the people doing this work are trying to field experienced professionals. At the University of Michigan, we have approximately 45,000 students, graduate and undergraduate. Not unlike a lot of other major research institutions, we attract students from all over the world; currently, we have students who are doing research on every continent of the globe. A lot of times these students like to go back home and do research. They do research over the holidays, when they go back to visit their families.

But often times, we find situations where students want to go some place out of the blue. They've never been there before. They don't know anybody in country. They have no support once they get there. And their advisor is, in fact, not particularly well versed in the culture of the location where the student is going. So we often are faced with trying to assess the benefit of allowing a certain research protocol to be conducted that may be appropriate for a seasoned professional, but is not appropriate for an undergraduate honors thesis in psychology student. This is important, because I think the community as a whole needs to be concerned about the well being tainted—the well being tainted by people that might go out and do work that is going to make it more difficult for tried and true professionals.

We also often make the assumption that the work that is going to be done is going to be groundbreaking. This is new territory—nobody's ever investigated this question before. In fact, a lot of student research that comes to our board, involving some high-risk scenarios—including interviewing freedom fighters in the West Bank, Sudan, rural provinces of China, and Indonesia—isn't necessarily groundbreaking. When we point this out to the student and the advisor, often what we hear back is, "Well, yeah, but this is just a student. And, you know, a student needs to learn and this is a good learning experience. So, you should let it go because, if you don't approve it, you're infringing upon my academic

freedom." If I had a dime for every time I've heard "you're infringing upon my academic freedom," I'd be sitting in Maui right now, not here. So I think we have to be careful about who is conducting the work and make an assessment about whether or not it's appropriate to be conducted.

We heard a lot about reporting the funding agency that is funding the research. I can tell you, there's a lot of our work that gets done that's not funded. People will use their own funds. You know the parents will pay for the ticket to Cuba. And off they go. This is not necessarily a situation where the research has been approved by some larger body that's going to provide oversight and determine whether or not the research design is appropriate. That, therefore, is left up to the IRB. Oftentimes we see people going into situations—faculty and students—where we know that they are putting themselves at risk.

I can remember one situation where a young woman was going to Cuba and was going to take several hundred dollars with her so she could pay her participants. Well, federal law dictates you can't take more than a hundred dollars in cash. But certain members of the IRB were not willing to require a stipulation that she could not pay Cubans in American dollars.

Perhaps one of the most contentious issues we've had is the issue of security, and specifically electronic security. All students now walk around campus with laptops. Their entire lives are on their laptops. I remember that when I was a graduate student, my now-wife used to harass me and make fun of me because I carried a copy of my dissertation on a CD in my jacket pocket, for fear that the apartment and the building where I did my graduate work would burn down at the same time. But today, everything is on a laptop. And laptops get stolen. I'm worried about the confiscation of the laptop of some very green, naïve undergraduate student trying to get out of Israel after just having been in the West Bank doing a bunch of research on some very delicate topics. The idea that some of these things will just simply be confiscated is not at all beyond the realm of expectation. It's even to the point where one of the members in one full Board discussion that I recall suggested to me, regarding this early baptism in terrorism

research, that the researcher should consider putting the data on a USB memory stick and hiding it in a body cavity. Certainly cavity searches aren't unheard of either. And relative to the security issue, what we often hear, particularly in the social behavior analysis domain, is a reluctance to stipulate things, like encryption of the data. Or there are instances where our board has recommended the daily uploading of the data and hosting it on a server back at the University of Michigan so that the data aren't on the laptop in the event that the laptop gets confiscated. That's not possible if you're in the jungles of Indonesia. What do you do in that kind of a situation? We really struggled with the security issue.

Lastly, we've struggled with expertise, or rather the lack of expertise. Two years ago we sought assistance from a number of academic and private institutions to get reviewers to assist us in the evaluation of one particular protocol. And we found nobody. Maybe that's because people really don't want to assume that risk themselves. Maybe it's because, from an academic standard perspective, I'm sure those of you who review IRB applications don't get many really big feathers in your cap for doing it. And you're certainly not going to get them for reviewing somebody outside of your institution. It's gotten to the point that at the University of Michigan we are seriously considering putting together another board. That board would deal exclusively with international research. There's enough of it going on that we could easily keep that board busy on a monthly basis. But we will still struggle with trying to find somebody that understands what the culture is like in rural provinces of China, in the Sudan. And as hard as we try, we can't always adhere to what is the intent of the federal regulations in having the necessary expertise. Thank you.

Panel Remarks by Dr. Brian A. Jackson

As many of the comments we've heard already suggest, the terrorism research field is an interdisciplinary one. For instance, my academic training was in the biomedical sciences, and I had some formal ethics training. However, I'm not here as an ethics expert, because I'm not one, but as a terrorism researcher. I am involved in helping to manage

one of the programs where research is conducted in terrorism here at RAND.

That said, the usual disclaimer applies: The things that I'm going to say are my own opinions, not those of RAND or any of our research sponsors. I do have some prepared remarks that have been heavily annotated in response to earlier panelists' comments. But what I'm going to try to do is bridge the language of the biomedical sciences that we've been hearing with some of the issues associated with terrorism research. From that perspective, terrorism research seems to strain, or even break through, some of the fundamental bedrock assumptions that underlie human subjects protections and the design of the regulations that implement them. As a result, as we've seen in some of the earlier comments, a standard application of those requirements across all terrorism research may risk producing some rather perverse outcomes—some of which, one might even argue, go against the fundamental intent of the regulations themselves. In the remainder of my remarks I'm going to examine three fundamental assumptions regarding human subjects protection and talk about why I think terrorism research is problematic with respect to each assumption.

The first assumption I want to look at is justice—the idea that “all subjects should be treated as equally and as justly as possible, both during the research and in the use of the products of the research.” We've heard this earlier, but in the context of medical research, the appropriateness of these principles is obvious. It's easy to understand. No group is inherently less worthy than any other for protection, and one shouldn't be exploited for the benefit of another. Obviously, as many of the folks here on IRBs probably know, putting those principles into effect on any given research project can be relatively difficult in some cases. But the goals are clear. And what you want to do is apply them as faithfully as possible in the way that you design and implement your research. But applying them across terrorism research is problematic. Because terrorism is fundamentally about two groups that are in conflict with one another, you can make reasonable and ethical arguments for treating different populations of research very differently. And for some populations, the principle of

maintaining justice, with respect to individual research subjects, may have less or even no applicability.

To explore this, it is useful to go back to the idea of a spectrum of potential research populations, which has appeared in some of the discussion earlier. The spectrum has, at one end, the actual active terrorist; at the other end of that spectrum are members of a general population, in an area where you might want to ask questions that are of interest to terrorism researchers. This idea of a spectrum is useful because it lets us ask questions at the ends of the spectrum and then go to the more complex, and probably more common, research problems in the center of the spectrum, which are harder to make judgments about.

In thinking about research involving actual members of terrorist groups, it's obvious why we would want to do that. But as others have said, when you look at it from the perspective of beneficence, doing that research looks ethically questionable or even prohibited. Supporting research on terrorist groups is frequently part of targeted states' efforts to defend themselves. As a result, it seems the conflicting interests between the terrorist groups and the states that are targeting them would violate the principles that have been outlined. In earlier presentations, we've heard people talk about incarceration as a potential outcome of research. In counterterrorism research, one of the goals is to affect negatively the well-being of the terrorist groups that you're looking at. The downsides can go beyond incarceration to actual physical harm, not unlike the physical harms that regulation of medical research is intended to prevent. The benefits of counterterrorism research, almost by definition, accrue to one group at the expense of another. So this makes the results of terrorism research different from the outcomes in medical research, which generally we assume not to have this zero sum character. That is, the benefit of the research when it's applied won't have to impose a cost on someone else in order to be beneficial. I would put more broadly a statement we heard earlier, that unless a researcher really believes that his or her research is never going to be applied in any way to inform counterterrorism, the idea that you can do such research while

maintaining beneficence for the population and protecting all the individuals involved seems absolutely impossible.

Of course, as a good practical policy analyst, one could then ask the question, If you think that your research is never going to be used for anything, why are you doing it in the first place? That might be my bias, coming from my institution. Another point I'd want to make is that it's important to note that these issues come from the conflict that exists between the two groups. It's not a terrorism-specific problem. So it doesn't depend on your making a judgment about the validity of what the terrorist group is trying to do, or the legitimacy of terrorism. It's the fact that there's a difference in interest between the funder of the work and people that are being studied.

At the other end of the spectrum, we have more general populations, as shown in some of the examples we have heard about of opinion surveys in countries to assess support for violence. In these cases, the application of traditional human subjects protection makes a lot more sense. And unlike research directly on terrorist organizations, it's less likely that the results are going to be directly applied to "targeting" those individuals, if you will. It is possible that applying the results will not "hurt" the people involved. However, and even so, when you think about a broad definition of just distribution of benefits, even studies that appear on their face to be benign could be utilized in ways that the participants would legitimately see as undermining their interests. If the research is used by one country against—from its perspective—the other country's interest, that could undermine the well-being of the participants. This is so even if there aren't immediate risks to the people for participating. So even in this case, it seems that the application of any research results by one party against another has the potential to produce quite a few of the harms that we heard in the opening lecture, from dignitary harm to economic harm, to others. And this makes it seem that any research, not just on terrorism, that involves parties who are in a current or potential conflict would be ethically problematic based on a strict reading of the regulations. It could even be one country studying another country that

it's currently in tension with, or may potentially have tensions with in the future.

So, coming from RAND, I would argue these questions could affect a lot more of our research agenda than just research on terrorism. As a result, in order to make any research on conflict ethically pass muster, it seems like you have to make a rather legalistic distinction that today we're protecting these people as human subjects, even though tomorrow perhaps we'll apply the results of the research itself, and they're then going to be targeted as adversaries, whether targeted means them personally or their interests.

It is also true that while the principle of beneficence makes sense where the focus is definitely on the safety and rights of the individual participants, there are potential harms it does not consider; in the case of terrorism research, it doesn't weigh potential outcomes for people who might be injured or killed in future terrorist events. A reason for human subjects protections being established in the first place was researchers justifying harming one population to help another in medical research. But given the nature of the problems that we're studying here, it's impossible to ignore the fundamental reality that this is about research on one group of individuals that are actively seeking to, knowingly and purposely, harm other groups of individuals. As a result, treating that research population unequally isn't the same, or isn't ethically equivalent to, exploiting one population in a medical study that's intended to help other populations.

This isn't to say that principles of ethical research don't apply. But it seems that ethics associated with armed conflict—and there is an ethics associated with armed conflict—apply as well. We might be able to get some sort of consensus at the extremes of the spectrum that if you had a confessed terrorist who was willing to kill again tomorrow you might be able to treat that person differently, or markedly differently, than someone from the general population. Then, obviously, the hard questions concern the middle of that spectrum—which is, of course, occupied by everyone from active supporters of the terrorist group all the way up to people who might agree with their aims but not their methods. If one does buy that there are two sets of ethics that might

apply here, deciding where the boundary is between those two—or where the gradient starts to change—changes based on how close they are to violent action or other criteria, is obviously difficult. And that's a question that I pose rather than try to get to an answer for.

The second fundamental assumption I want to look at is that there is a significant one-directional power asymmetry between researcher and research subject. We heard earlier that an underlying assumption in a lot of the human subjects protections is that researchers, as is certainly the case in biomedical studies, are in privileged and potentially powerful positions over their subjects. A central reason for human subjects protections is to address that asymmetry. As we also heard earlier, terrorism research, particularly field research that's on or close to actual terrorist organizations, actually has the potential to turn that fundamental assumption upside down. With respect to researchers—particularly when they're operating in a foreign country, away from their support system, potentially where local authorities may be unsympathetic to them or simply ineffective—there's an issue with researchers potentially coming to physical harm as a result of the work that they're doing. So, even though the researcher's actions may cause harm to the studied group, this is a case where that potential for harm is much more symmetrical. Obviously the researchers in a medical research situation are very unlikely to come to harm as a result of their participation in the research. We've already talked, to some extent, about how the requirements to disclose where your funding comes from, which make perfect sense for medical research, may actually increase those risks and change that power asymmetry even further away from the researcher.

The third and last fundamental assumption underlying human subjects protections that I want to examine—which is a little bit different, and one that we haven't heard earlier—is that the researcher is best positioned to assess risks and explain them to potential subjects. In standard applications of human subjects protection, this risk assessment is something that's done at the beginning, so it can be described during informed consent to potential subjects. Again, this makes perfect sense in biomedical research, where you need specialized knowledge to even

think through all the risks. However, in the case of terrorism research, this is another assumption which could be wrong.

A straightforward example is drawn from my own research, which involves contact with counterterrorism or intelligence practitioners, doing interviews about terrorist groups and how they do what they do. In this case, individuals who are directly involved in counterterrorism activities have access to more specific intelligence information than you do as a researcher. They usually reside in the area where they work and where these groups are active. And, as a result, they're actually in a much better position to assess their own risks of participating in your research than you are. While you can certainly think through these issues beforehand, it's unlikely that your assessment is going to materially affect or inform their decision. To a lesser extent, you could make similar arguments about other individuals, who aren't counterterrorism professionals. Given a reasonable presentation of what you're planning on doing, individuals who are from the local area may be in a better position to make a risk assessment than you are.

This comes down to issues of local knowledge. We've heard earlier how important local knowledge is in assessing many of these risks, because the risks are essentially second-order risks—what happens if people find out that you participated in this research. The potential consequences of that kind of a breach are very "local situation dependent." In some conflicts, disclosure of a policeman's identity or revealing participation in this kind of research might have absolutely no consequences at all, whereas, in other cases, it might result in that person being targeted for assassination. It will really depend on the specific details of the conflict that you might be looking at, and even the evolution of that conflict over time. In some conflicts, that might be something that's exceedingly dangerous; in others, as things have changed and moved over time, maybe not.

In my remarks I've tried to explore a few areas where the nature of terrorism research seems at odds with fundamental bedrock assumptions about the ethics of human subjects research. In conclusion, I'll return briefly to the difficult case that everyone has been referring to—research with actual members of terrorist groups—which seemed ethically

problematic at best and perhaps ethically unacceptable. I have suggested that one way at cutting that knot would be to look through both the lenses of the ethics of armed conflict and the ethics of research. I want to close by asking the practical question, Well, what if we don't? What if we just apply the principles that we have now to this research and, as a result, put certain areas out of bounds, "out of the tent," as we heard earlier? Echoing some of the earlier speakers, what one might call research on terrorism in this case will continue, in spite of ethical prohibitions, for the fundamental reason that nations that are attacked by terrorist organizations have a right to defend themselves. And learning about your adversary is an integral and legitimate part of any effort to do so. So, as a result, the questions that terrorism researchers tend to ask will be asked. But they'll be asked by individuals who don't consider—or call—themselves researchers.

For purposes of discussion, I'll focus on two groups who would continue to explore this area. One I'll call "intelligence professionals," by which I don't just mean people who are government employees working for intelligence agencies, but other people who are contracted by them, etc.; the other I'll call "journalists." The questions being asked and the data being gathered are similar among terrorism researchers, intelligence professionals, and investigative reporters. However, it's only terrorism researchers who would ever describe what they're doing as research involving human subjects. Reporters frequently make the same promises of confidentiality that researchers do. For intelligence professionals, there are certain things they can and cannot do. So this isn't to say that there aren't ethics and codes of behavior that regulate those activities. However, the practices of these other learners do differ considerably from those required by research regulations. My glib example is that it's unlikely that recruitment of a clandestine intelligence source ever involves anything even remotely close to formal fully informed consent. So in spite of any ethical concerns about this research, both journalists and intelligence professionals will continue to work in these areas. And you can make solid and ethical arguments why they should. As a result, an ethical prohibition of terrorism research may affect only some of the

individuals who do this type of work, to the extent that these people are different, or could just result in semantic distinctions about what individuals call themselves when they're doing the work. So even a single university faculty member might be a "terrorism researcher" on a time-shared basis, if you will. In the morning, when doing grant-funded research, everything is covered by these ethical requirements; on the other hand, as a consultant to an intelligence agency in the afternoon, on a classified national security contract doing similar work, the faculty-member consultant may be bound by national security regulations not to even disclose who the work is for or why it's being done.

In medical research, the fact that all participants consider themselves researchers, and are commonly recognizable as such by what they do, means it's possible to shape their behavior through application of a common set of ethical principles for research. However, in the area of terrorism research, that's just not the case. A variety of individuals, from a number of different professions, will use similar techniques in pursuit of similar answers; they don't have a common set of principles that they're going to rely on to shape their efforts. One reaction to this may be simply to concede that, okay, the work will go on, but it won't be considered research. That is another semantic distinction that we could make that would, again, cut the knot. But I would argue that there's a price for conceding that way.

While intelligence professionals, investigative reporters, and researchers may all ask similar questions, I believe there are important differences in the way those different professions approach their work. Though I may be somewhat biased, I think there is a value to having the people who consider themselves researchers doing this kind of work. Given the nature of terrorism, there is a need to study with a high level of detail, to look for causative relationships, things which the practical pressures and timelines of journalism often don't allow. And there's also a need to disseminate research results as broadly as you can to inform other researchers and the public, which are things that are frequently impossible or not even desired by intelligence professionals. And given that the discussions of the causes of terrorism, future behavior, and appropriate ways of addressing the

terrorism threat are invariably politically charged—going all the way back to the definition of what terrorism is—I believe it’s important to facilitate rather than limit that kind of research. This isn’t to say that anything that you call research on terrorism should have an ethical blank check—far from it—since one distinction we draw between us and terrorists is that they are ignoring some of the commonly held ethical principles about how you wage armed conflict. But research on terrorism should be done.

As a result, I believe that we have to ask these questions and wrestle with them over time. Not doing so isn’t attractive either, since the work will go on. It just won’t produce the more global benefits that having it be *research* and done by *researchers* would yield. However, doing that for terrorism research requires that you have individuals from many disciplines involved in the ethical consideration as well: people who are experts coming from the ethics of research field, who know what the regulations are trying to do; and people on the ground doing the terrorism research that can work through what the actual impacts of the ethical principles are when they’re implemented across the spectrum of different types of terrorism research.

Panel Remarks by Dr. Shireen T. Hunter

Thank you very much. I must say that I feel overwhelmed by all the very specific knowledge that has been presented by distinguished scholars in this field. I am not an expert on ethics in research, by any means. When I first talked to Tora a few months ago, we chatted on the phone and I told her some things based on my experience, and she thought those insights were interesting. So that’s why I’m here. Also, I didn’t realize this workshop is specifically regarding research on terrorism. In general, I took the focus to be research that involves nationals of certain countries that live either under particular political and legal conditions or under constraints for which association with certain governments or research institutions might cause them a range of problems. Basically, the question was, How best can one minimize the potential harm?

Obviously, one cannot predict the exact amount of harm that may occur. I know that philosophers, ethicists, and others often talk in absolute terms, and "relativism" is a dirty word sometimes. But I think it is important to consider the balance of harm and benefit—how many people harm comes to, and how many people may benefit as a result of that particular harm—and the willingness of the person to get involved in a particular project even if it may include some harm to him.

I want to bring a kind of value-added to this discussion. Professor Marshall said that she wanted to deconstruct the concept of terrorism but didn't have time in her excellent presentation to do so. So I would like not to deconstruct "terrorism," because I am not a terrorism expert, but to address it. In the 1980s, I did address it and wrote about what terrorism exactly means. So far, we haven't established here any definition of terrorism.

First of all, we have to say what aspect of terrorism we want to do research on. For example, I've heard people say let's look at the root causes of terrorism. Sometime this means—it has been interpreted this way recently—that you are soft on terrorism. By the time you find the roots, then the terrorists have already achieved their goal and you've nothing. This is true. But I believe that we can actually, very soberly and practically, divide studies regarding terrorism into basically what I call two categories.

One is the contextual analysis of terrorism. In other words, what kinds of conditions are associated with terrorism? There could be, for example, studies of the socioeconomic conditions of upper Egypt or, for instance, of parts of Sinai that have been major centers of militant Islam, and so on. If somebody participates in this type of research—particularly if it is funded by reputable foundations, and even if it has some element of U.S. government funding—it might not be problematic. I don't think that the people, the local experts that participate in those types of studies necessarily will become stigmatized or risk other, greater harms.

For example, in the research that I am doing (it's not that kind of research, but it is on the Muslim reformists' thinking), there is in Egypt currently a group whose members call themselves the Repentants.

These were terrorists, if you want to call them terrorists. I'm hesitant to use the word "terrorists" because, again, it's very loaded and judgmental; nevertheless, they were involved in acts of violence against the government and then went to jail. These people went through an analysis of their strategies and their philosophies, and checked those philosophies and strategies against the results that they had achieved. They came to the conclusion that their approach—trying to establish Islam—actually ended up harming them. So they have come up with different methods. If an American researcher (even with some U.S. government funding) or an institution that gets a lot of its funding, but not necessarily its entire funding, from the U.S. government wants to do research on ex-militants, I don't think that existing terrorist groups are going to harm them. Or if an Egyptian participant gets involved in this sort of study, I don't think he's going to lose his job. Most probably, in the current Egyptian context, an Egyptian who participates in a study on the Egyptian government's crackdown on political dissent would be more likely to lose his job or go to jail than would an Egyptian who participates in research on ex-militants. The harm all depends on the circumstances under which you are doing the project. It seems to me that if we want to look basically at what I call the context of terrorism, this first category does not represent a research area that poses very tremendous ethical problems. We could easily be very transparent, be open to people.

Now I'll turn to the other category of terrorism research, which, frankly, I think is very difficult for researchers to do, because it really, truly moves into intelligence work. And that is not really research. An academic may want to be involved in it. If you are a very adventurous academic—and occasionally there have been some—you may want to engage in that sort of activity. But I don't believe that you can, for example, go and interview Al Qaeda members and come out safe and sound, unless you are a local hire. So it seems to me, there, the element of fairness is clear, because locals are being recruited. I would identify this type of research as the kind that relies on what we used to call "local sources." And somebody who wants to act as a local source understands the risk.

The ethical responsibility, therefore, of the country or the government that uses those human resources is, to the extent possible, to protect them and, if their cover is blown, to try to get them out of harm's way. But that element of risk is there, and it's going to be there all the time. This is really what I'm trying to get at.

One of the problems that I basically have with so-called terrorism studies is epistemological. I don't really get the meaning of terrorism studies. What is it about "terrorism studies" that is so qualitatively different, beyond the technicalities? For example, how do you penetrate a terrorist cell? And how do you intercept—which is a technical issue—their communications? How do you prevent them from conducting cyber attacks?

These are very technical, intelligence-related issues. What are terrorism studies? I have seen references to certain studies, like "Psychology of Bin Laden." How can we know? We haven't met Bin Laden. Even people who go to therapy for ten years—I don't think their psychiatrist can give them their profile or explain what they are saying. So basically, we should be very concerned about epistemology, as well as ethical restrictions. RAND should be applauded that it is always very concerned with these things. I don't think that RAND wants researchers to feel crippled, because most terrorism studies are likely to be doable in that broader first category, even if they include people who might be on the margins of or who have previously been involved in terrorism.

For example, if you want to find out what prompts somebody to join a terrorist group, consider ex-members of the Islamic Jihad in Algeria who now have repented. You can go there and conduct a very good study. I'd like to get a grant and do that study. Or there are groups in Egypt, or in other places. You don't have to go into the lion's den, actually. Some professionals may have to go into the lion's den, but that is not the business of the think-tank researcher, or an academic researcher for that matter. Academics might provide backup in the sense of making intelligence operatives aware, when in those environments, of how to behave expertly in that culture or society. They have to go through classes like the spies used to attend in the Cold War days. But

that goes beyond, in my opinion, academic or even policy-related research. It really straddles, it seems to me, the realm of intelligence and operations. Research institutes are not in that business—at least according to my very limited understanding.

Thank you, very much.

SYNOPSIS OF SECOND PLENARY DISCUSSION

Lessons Learned from Research on Offenders and Criminal Behavior

Workshop participants noted that some research on terrorism resembles research on individuals engaged in other undesirable, unethical, and/or illegal behavior, including violent criminal behavior. Many violent terrorist acts are criminal actions as well, and terrorists can be viewed, from one perspective, as a class of criminals. The closest analogy to terrorism research may be the research on crime gangs in the United States. A potentially important difference between terrorists and other offenders is that terrorism research occurs within the context of a conflict between groups, with researchers and IRBs aligned with one side and the terrorists with another. Another, related difference is that terrorists may have quite different values than the research community has, including different understandings of the ethical principles of autonomy, beneficence, and justice. For instance, criminals may share a researcher's perspective that their actions are criminal, but terrorists may view themselves as engaged in noble causes. It may be that the conditions of justice and beneficence can never be satisfactorily met when the participants represent groups with which the researchers and sponsors are in avowed ideological conflict.

Despite these differences, IRB experience with offender research might provide lessons for reviewing social and behavioral research on terrorism. A general lesson is that the risks for human subjects in these types of research can be quite high, even with the best efforts to mitigate them, so the IRB must assure that the research also has potential benefits that are high enough to justify its approval and conduct.

Workshop participants acknowledged that there is no such thing as risk-free research. In social and behavioral research, subjects are typically asked to express their opinions, nominally a safe act. Yet even in the most liberal and tolerant societies, when one takes positions on issues, one risks antagonizing some people. In international research, the risk may even be of incurring bodily harm or imprisonment. Research subjects risk incurring some form of harm because of the views they express to researchers or simply because they are observed talking with outsiders, and this risk may or may not be sufficiently balanced by the benefits they receive from participation.

Because terrorists are by definition members of organized groups (albeit, perhaps, small ones), the IRB must also consider the risk of potential group harms. That is, terrorists who participate in a study may put not only themselves at risk, but also the members of their group. Of course, this is a concern in other research settings as well, such as research on a racial minority, a stigmatized profession, or any number of other groups.

Because the risks and harms associated with social and behavioral research on terrorism can be so high, IRBs must examine the associated benefits very closely. Research on criminal offenders has challenged the way IRBs think about benefits, both proximal and distal. First, the likely benefit of such research for actual and potential victims of such offenses is salient. This consideration of benefits for victims of offenders under study also raises the principle of justice, because the IRB would need to balance the benefits of the research to subjects with its benefits to others. Often, criminal justice researchers believe their efforts to prevent or decrease offender behavior will benefit current and prospective offenders themselves. In contrast, the beneficial effects of research on terrorists may fall mostly to countries other than where the research was conducted—the countries to which terrorists may export their attacks—and not to their own populations.

Dual Use

The consideration of indirect benefits opened a wide-ranging discussion among workshop participants regarding dual use of terrorism research. Dual use of terrorism research is a special concern because of the power of governments under some circumstances to subpoena information otherwise protected by assurances or certificates of confidentiality. The social behavioral researcher on terrorism acquires information that might be utilized for intelligence purposes.

The potential for dual use is familiar from other areas of social and behavioral research. For instance, psychology research can be applied to marketing. In such a case, the IRB may ask (in terms of fully informed consent) whether the researcher needs to tell the subject that the study may be applied to find out how to better manipulate people to buy carbonated colored sugar water, which may not be in their health interests over time. For instance, the American Anthropological Association, in its ethical standards, expects that anthropologists will not conduct research that is going to be to the detriment of the people they're studying.

The Common Rule prohibits IRBs from taking into account possible long-term harms that might result from applying the results of research: "The IRB should not consider possible long-range effects of applying knowledge gained in the research, for example, the possible effects of research on public policy, as among those research risks that fall within the purview of its responsibility." However, the Common Rule is silent with respect to whether IRBs can take into account long-term benefits that might result from applying the results of research. This silence may be interpreted as permission to do so.

On the other hand, at the time the Common Rule was developed, almost all of the justifications in the field of drug development research were based on predictions of what long-range consequences this would have. If IRBs did not consider the benefits of those long-range consequences, they would be left without justification for approving any such studies. The commission heard that protest and did not respond to it. So that inconsistency remains in the Common Rule to this day.

Dual use of social and behavioral research on terrorism may involve law enforcement or intelligence agencies or military services that have an interest in gaining access to additional information about terrorism in general, as well as about specific individuals and groups. Breach of confidentiality is always an important violation of ethical principles, but the resulting harm can be especially great in matters concerning terrorism.

The potential for dual use may be increased by the blurry boundary that exists between academic researchers and strategic analysts working in government intelligence, law enforcement, and military agencies. Some of the same researchers may be involved in intelligence research and in academic research on terrorism. The analytic sections of intelligence agencies employ PhD's just as do academic departments of research universities. And the nature of the investigations in the two work settings is truly similar, focused on broad trends and questions.

Dignitary Harm

Workshop participants discussed at length the risks for dignitary harm in social and behavioral research on terrorism. Dignitary harms are of several sorts. The first set is prima facie harms connected with what are commonly agreed to be violations of rational action guides: breaking a promise, telling a lie, treating somebody as a despised minority person. All of these are considered dignitary harms, apart from whether or not they have any other consequences. Dignitary harm compromises the principles of both beneficence and autonomy. Sometimes dignitary harm can also be a group harm in that the research has the potential to discredit not just the participants, but also the group they represent.

Another category of dignitary harms is strong paternalism—that is, repudiation of a person's considered judgments. Researchers sometimes contend that research on offending populations may benefit those human subjects by tacitly motivating them to reevaluate and perhaps desist from their offending activities. Research that has an explicit purpose of helping its subjects to change their behavior is sometimes called advocacy research. A researcher may wish to interview prostitutes and

talk to them about their life experiences with the goal of getting them to give up being prostitutes because the researcher doesn't think it is good for the prostitutes to be prostitutes. The human subjects in such research may have a different perspective on their activities. A prostitute may counter, "Wait a minute, I'm pretty careful about what I do. It's pretty good money. There are a lot worse things that I could be doing. And, yes, it does involve legal risks; but I choose to take those risks along with the risks of sexually transmitted diseases, which I try to be careful about. But given the calculation of where I am, what my education is, and what my possible options are, I choose to live this life as a prostitute." Certainly, in the case of research on terrorism, the participants are unlikely to believe that the researchers are doing them a favor if the research helps them get out of the targeted activities. They might think the research actually opposes their interests.

A paternalistic perspective tacitly devalues the judgments of the research participants and presumes that the researchers (and perhaps the IRB) know better than the subjects themselves what is good for them. IRBs should take care not to adopt a paternalistic view of the prospective subjects without careful evaluation of its merits. It is difficult to find grounds for saying, "I know better than you whether your devout dedication to a political cause is or is not really the goal of your life." Yet sometimes, the IRB may judge that the participants' defense is unfounded. For instance, research has shown that gang membership really is bad for gang members. So research that tries to improve our understanding of gang activity with the goal of getting people out of gangs is to the benefit of the research subjects.

It may be difficult for an IRB to decide whether or not participation in a group, even a terrorist group, is genuinely in an individual's interests. No member of the IRB may have the background and expertise to make that decision with confidence; outside experts may need to be consulted. To take the extreme case of a suicide bomber, it may seem self-evident from one perspective that a suicidal act cannot possibly be in one's own interest because it ends one's life. But it is certainly possible to find people who believe that suicide bombing is in

the bomber's self-interest. Ultimately, an IRB may not be able rationally to choose one perspective over another without an a priori judgment about the superiority of one system of values over another.

Dignitary harm can occur in much more subtle forms than strong paternalism or advocacy research. Consider the case in which the researcher conducting a study on terrorism interviews a person who has been previously involved in or favored certain violent activities. In the course of the interview, the researcher probes for rationales for violence and says something akin to, "How would you convince someone that that your world view has some justification?" This line of questioning may be truly objective, or it may reflect the researcher's own ideological biases and values. Regardless, the effect may be to create some doubt in the subject's mind regarding the justifications for what he or she espouses. One could argue that this effect of participating in the research procedure is a harm, a dignitary harm. Specifically, one could argue that participation in this type of research erodes participants' faith in themselves and diminishes their sense of self-worth as ethical agents in the world.

Another source of dignitary harm that may arise in research on terrorism is the use of deception, the topic of session one. Deception in research speaks directly to respect for persons, respect for individuals. Of course, much research on terrorism does not use deception, and this is true of research on criminal offenders, as well. For example, much of the research on gangs is not deceptive. Many people are surprised to learn that some criminals are willing to participate in research studies when accorded full and open consent. This is also true in the case of terrorists. Precisely because they have strong positive feelings about their actions—they may view themselves as freedom fighters—they are willing to speak about them. Also, terrorists traditionally view media as an important forum for spreading their views, and they may treat researchers as they do journalists, risking the danger associated with being interviewed because of the perceived benefit of having their views broadcast widely.

It appears there will always be individuals throughout terrorist organizations—leaders, activists, operatives, middle managers, and members—who are willing to talk to researchers.

It is interesting to contrast the way in which deception is typically used in medical research with the way in which it is typically used in social and behavioral research on terrorism. In medical research, the interests of the researchers and subjects are usually closely allied: There's a common enemy, a disease or a virus, that they both want to defeat. By contrast, in offender research—research on prostitution, for instance, or gangs or drug addiction—the researcher and the subject might well have quite different interests. This difference may be even more pronounced in terrorism research. The presence of orthogonal interests and potentially opposing values raises the question of what perspective the IRB should take as it reviews the research. How should it use and balance perspectives when it makes judgments regarding the value of the research, the risks associated with it, and the benefits? If an IRB permits a study to use deception in order to induce subjects to act in ways that they otherwise would not—including agreeing to participate in the study at all—then the subjects' own perspectives have clearly been discounted.

To understand conditions under which this discounting might occur, IRBs may find it useful to look at terrorism research within a historical framework of research on group conflicts. One way to characterize terrorists is that they are groups taking violent actions in an effort to influence other groups. One could argue that a country is also a group that is devoting its resources and activities to achieving its interests, sometimes through violence. Much of the social and behavioral research that the United States conducted on the Soviet Union involved human subjects, including refugees and ex-patriots, for instance. Some of this research was conducted deceptively. Without careful IRB review, deceptive research on members of an opposing group moves very close to the boundary with espionage, which is governed by principles other than autonomy, beneficence, or justice.

RAPID WRAP-UP BY DR. RICKY N. BLUTHENTHAL

Let me first apologize for the violence I'm about to do to other people's ideas. And let me take this a little out of chronological order. It seems to me that Shireen Hunter started out with really good questions—both for research in the United States and with these international studies related to terrorism—which are, How do we understand the cultural context in which the research is going on, and then how do we evaluate whether any benefit is happening or whether risks are indeed being minimized? It wasn't clear to me from the discussion that we actually came to any agreement about how we safely do that, other than to acknowledge that our best effort would probably entail trying to get other area experts—similar to the way we deal with domestic issues in the United States.

That leads to the question about whether we can regard terrorism as a special research activity, distinct from other kinds of research that might be related to criminology, or anything having to do with stigmatized or disadvantaged populations. It seems that there was some agreement, at least at the macro level, that research on terrorism has to be contextualized and, once understood in context, probably can be done safely within the existing framework that we've already been provided.

On a different but related note, I thought both Dr. Levine and Dr. Jackson raised in some ways oppositional but very interesting points about understanding the real dynamics that are involved in terrorism research that are probably distinct from the domestic situations that someone like me, who's a drug researcher, confronts. When I go into a "shooting gallery" or I'm dealing with drug dealers, the truth is, I do have more power than they do. Outside of some very rare circumstances, I have more resources available to me: If they happen to have a gun and they want to shoot me, I'm out of luck. But in the broader scheme of things, we both understand that I'm going to leave, and that if something happened to me, there are resources that I could bring there into the situation that would be very negative for them. There's a big element of coercion, obviously, in these kinds of interactions. But there is that big difference.

One of the things I really appreciated about what Dr. Jackson was pointing out is that the truth is—and this came up again and again—in these situations with terrorism research, the power dynamics are not always clear. So he raises questions about whether terrorists are in immediate harm or researchers are in immediate harm—or both—because of government interests, both in the United States and elsewhere. Because of the immediate circumstances where this work occurs, the research participants, to the extent that they are active terrorists, do have a great deal of power. In terms of the evaluation of risk, people who work in the intelligence agencies are going to have a much better, much keener awareness of their own risk than people back in the United States or professionals from fields other than intelligence.

I put this point, probably unfairly, in opposition to what Dr. Levine pointed out, because I thought it was also a useful rubric for talking about terrorists as vulnerable subjects. They may be people who might be incarcerated, people who probably have been in the criminal justice system. As we look at the existing regulations and acknowledge that they do provide some guidance, there probably is a need for some special consideration for the populations of interest in terrorism research, particularly with respect to protecting confidentiality. A re-evaluation of "risk" is needed. I think Dr. Levine was the only one who brought up the question of what are "ordinary" risks in these circumstances. In the drug research area, we deal with this issue a little bit, but it probably hasn't surfaced enough, and it has to do, again, with cultural context. If Chris Fair is right—and I'm guessing she is—a family that produces one terrorist may produce another. And that truth is probably widely known. These are not secrets to people who are interested in doing something about it, such as local police and other security forces. As a result, research on these activities may not be adding additional risk if we are prudent in the way that we handle issues related to confidentiality, coding our data, protecting laptops, and what have you.

Lastly, Dr. Marshall brought up a framework that resonates with me personally, but that might be difficult to apply in some of these circumstances. The framework involves—in the terminology I would use—

participatory action research. There's an attempt to engage a community to develop a dialogue that results in trust. It involves identification of both divergent needs and common cause, so that the research activities are not seen as distinct from the community's own goals. But in most terrorism research, framing what you are trying to do as something that helps the community will be difficult. That's obviously an ideal that I think we actually don't practice very much even in the United States. It's hard to see how that approach might be implemented in the kinds of studies we're discussing here. But it leads to what Dr. Marshall pointed out as a useful path for understanding and maybe evaluating these research protocols from a distance. That is, to put on the table the things that we care about. What is the significance of the research? How is it going to contribute to existing knowledge? What is the research design? Where are the sample populations? What are the recruitment strategies? And then we need to systematically go through these protocols and identify harms, risks, benefits, and attempts to minimize the risks. We don't have a good handle on how to deal with these things, and it would be helpful to begin to apply rigorously some framework—and I think Dr. Marshall provides us with a good start on that—for systematically going through these issues. The framework may not be comfortable, but at least we will have some idea about how to evaluate the protocols we confront and how to protect the researchers and their research subjects.

4. ENSURING CONFIDENTIALITY

- Moderator: Tora K. Bikson, PhD, Senior Behavioral Scientist and Chair, Institutional Review Board, RAND
- Presenter: Eleanor Singer, PhD, Research Professor Emerita, Institute for Social Research, University of Michigan
- Panelists: Mumtaz Ahmad, PhD, Professor of Political Science, Hampton University; Editorial Board, American Journal of Islamic Social Sciences

Jerrold D. Green, PhD, Senior Advisor, Middle East/South Asia, and Acting Director, Middle East Development Council, RAND

Mary E. Losch, PhD, Assistant Director and Associate Professor, Center for Social and Behavioral Research and Department of Psychology, University of Northern Iowa

Michael Traynor, Senior Counsel, Cooley Godward Kronish LLP; President, American Law Institute

INTRODUCTION BY DR. TORA K. BIKSON

Welcome to the third workshop session on ensuring confidentiality. By now, this subject matter has received so much attention that I don't need to introduce it. Confidentiality is an issue that gets raised in relation to research on terrorism—whether it's in relation to fully informed consent (see session one) or in relation to assessing risks and benefits and maintaining justice (see session two), or simply satisfying the ethical condition that research participants have the right to keep their opinions private. I probably don't even need to introduce the lead speaker either, because Eleanor Singer is well known to everyone in

social and behavioral research. She recently became Research Professor Emerita at the University of Michigan's Institute for Social Research, Survey Research Center. She is especially well known for her work on the interplay between ethical and methodological issues, which is why we have asked her to address this topic today. Her contributions to this field are too numerous to mention without using up all of her floor time, so I'll just cite two of them that are particularly important to RAND. We have used her work on levels of incentives versus coercion for participation in survey research to guide our own judgments; we have asked her, on several occasions, to serve as an outside expert and give us guidance on reviewing fairly tricky research protocols. And as Patricia Marshall mentioned, Eleanor was a major contributor to the National Academies report on protecting participants and facilitating research in the social, behavioral and economic sciences, which we treat as a definitive resource. So, Dr. Singer, I'm just going to give you the floor.

PRESENTATION BY DR. ELEANOR SINGER, "CONFIDENTIALITY IN TERRORISM RESEARCH: CAN IT BE ASSURED?"

Tora refrained from defining confidentiality, but I'm not going to do that. Basically, what I'm going to talk about is confidentiality and its relation to terrorism research.

Why Protect Confidentiality?

- Breaches of confidentiality, and their potential consequences, are arguably greatest source of harm to individual subjects in much social research, especially survey research
- It thus violates the ethical injunction to exercise beneficence, as well as the legal requirement to maximize benefits and minimize harms
- Confidentiality breaches also have practical consequences, whether or not they harm individuals: Much research indicates that concerns about confidentiality reduce survey participation —e.g., National Research Council, 1979; Singer, Mathiowetz and Couper, 1993; Singer, Neugebauer and Van Hoewyk, 2003; Hylligus et al., 2006

Figure 4.1
Why Protect Confidentiality?

What do I mean when I say I'm going to keep information about you confidential? I mean that I am not going to disclose information that you have given to me under a promise of confidentiality in such a way that other people are going to be able to identify you with the answers that you have given. It's identifiable transmission of information that's at issue when we talk about confidentiality. The way it fits in here is that in social science research—behavioral research, more generally, including research on terrorism—a breach of confidentiality is probably the biggest harm that can be done to a participant, a subject in research. And I don't just mean a dignitary harm, I mean the consequences of a breach of confidentiality for that participant. So

confidentiality breaches violate both ethical and legal principles for the protection of human subjects, and they also have practical consequences. I want to emphasize those because I think they haven't been really much touched on yet today.

There is a fair amount of research on the fact that concerns about confidentiality and breaches of confidentiality reduce peoples' willingness to participate in research. Much of that research has been done by and for the U.S. Census Bureau, and I won't go into the details of it here. But that is a way in which breaches of confidentiality harm not only the subjects of research, but also the research enterprise itself.

Déjà Vu All Over Again

- Government-sponsored research on "terrorism" is not new
- Preoccupation with communism and the Cold War in the sixties spawned Project Camelot
 - Social scientists were recruited to conduct basic research on conflict and social change in modern societies
 - Project was located in the Special Operations Research Office (SORO) of the Army
 - SORO justified the project on grounds of counter-insurgency; social scientists, as basic research on social change
 - Publicity about the project in Chile led to violent denunciations of it as well as of US policy generally; project was aborted before it began (cf. Horowitz 1967; Wax and Cassell, 1979, ch. 4)
- In seventies, Vietnam War and civil rights movement gave rise to research on protest movements in the US; issues of protecting confidentiality were paramount for researchers
 - Some researchers sent identified data files to Canada for safe-keeping
 - Others anonymized data

Figure 4.2
Déjà Vu All Over Again

And there is another way in which these breaches of confidentiality, and the perception that they are likely to occur, harm the research enterprise. That's what I've called here déjà vu all over again. This is certainly not the first time that social scientists are confronting the issue of whether or not to engage in research that is

not only ultimately and theoretically dual use, but quite explicitly has different parties interested in different aspects of the research.

There was a so-called Project Camelot, conceived in the 1960s. The Department of Defense was very much involved in it. The Defense Department was interested in research on counterinsurgency—how to counteract communist revolutions and particularly leftist activist movements in South America. Social scientists were interested in studying social change. It was, in a way, a marriage of convenience—mutual interests. The project was located in the Special Operations Research Office of the Army, and it was justified in different ways by the different groups with different interests and stakes in it. The project never got started because publicity about it was leaked. In particular, it became known in Chile—the first country which was proposed for the research. So the project was abandoned, so far as is known. And I don't know any more than that. We say that it was abandoned; but honestly, I don't know, and that's the point I want to make, ultimately.

The point was made earlier today, in connection with deception research, that if you don't tell people what you're doing, they will make up their own stories. And Aronson showed this about 40 years ago (Aronson and Carlsmith, 1968). In psychological experiments, he points out, whatever story you tell, people will assume that there's a different story you're not telling them. The other point of this is that when social science research becomes identified with or confused with intelligence research, there is the danger that you can't disentangle the two after that.

So social science research, in general, becomes suspect as it did after this episode of Project Camelot. Not only the specific social scientists involved with that project, but social science in general and sociology and anthropology in particular were in bad repute for many years after this episode. This is, I think, why anthropology has adopted certain ethical guidelines for the kinds of research that may be done. It is a harm that comes not to individual subjects of research, but that comes to the enterprise of social science research in general, and I don't think it can be entirely ignored. That's not the kind of

thing that can be considered by an IRB—it shouldn't be considered by an IRB—but it is an issue that needs to be thought about by individuals and institutions in connection with whether or not to undertake particular types of research.

Is Terrorism Research Different?

- Methods don't necessarily differ from those of other research
- But motivation to identify subjects is much greater
- Temptation exists for government to use research to target specific individuals, not just the causes of terrorism, radicalization, etc.
- Statutory protections against confidentiality breaches may be inadequate in US, nonexistent in other countries
- Potential for harm to subjects is therefore greater
- Even if they are fully informed
- Question: How much potential harm may subjects be permitted to consent to? I.e., can informed consent be used as a substitute for protecting subjects from harm? Should it be so used? Under what circumstances?

Figure 4.3
Is Terrorism Research Different?

So the question is, Is terrorism research different from other kinds of social science research? Is it different from research on deviant behavior—for example, drug use, sex work, and so on?

The way in which I think it differs is not in terms of the methods that it uses, but in terms of the motivation to identify subjects. Recently, I chaired a National Academies panel on access to research data (National Research Council, 2006). The issue there is, we collect social science data, at great public expense; and the push is to disseminate, to make those data available for use by other people, other social scientists, private organizations. It's been paid for at public expense, so it ought to be available for public analysis and use. The concern is that the wider dissemination is going to result in the potential for breaches of confidentiality. The argument that's often

made against these concerns and for wider dissemination is, Who wants to breach confidentiality in those data sets? It's much easier to get the information about individual subjects in other ways. But in research on terrorism, there is a temptation for governments—both our government and the governments in the countries where the research is done—to use the information about the individual subjects of research. In other words, there is much more motivation to breach confidentiality in this kind of research, I would argue, than in other kinds of social science research. It's hard to get information about individual terrorists or potential terrorists in other ways, harder than most other kinds of data that social scientists collect. And so, the protections against breaches of confidentiality that exist in the United States, in particular, may not be adequate; they may not hold in a situation where the motivation to breach confidentiality is much greater.

Another point I'm trying to make here is, even if you tell subjects fully (which is what Sandy Berry was arguing earlier) about the fact that you may not be able to protect confidentiality—in a situation like the focus groups, for example—how much harm is it permissible for a subject to expose herself to, even if she is fully informed? I don't have the answer to this, but I think it's a question that IRBs do confront and maybe it goes to the issue of paternalism. Sometimes the argument is made that everything is permissible; informed consent bears the full brunt of this ethical obligation. As long as people know what they're in for, what they may be in for, you don't have the right to prevent their participation. In general, I have argued in the context of the work I did on incentives and coercion (Singer and Bossarte, 2006) that one shouldn't try to make informed consent do all the work of protecting people against harm. So you may allow people to participate in very risky drug trials, but not usually if they're healthy volunteers. Usually you permit this only if the person is, in fact, very ill and there's no alternative treatment. There are limits on the extent to which you permit people to expose themselves to harm, but I don't know that those limits have been spelled out, either in ethical or regulatory ways. So I'm just going to raise this issue.

How Do Confidentiality Breaches Arise?

- Carelessness
 - Not removing identifiers from questionnaires or electronic files
 - Leaving cabinets unlocked
 - Not encrypting files containing identifiers
 - Talking about respondents with others not authorized to have information
 - ↳ Because of motivation to breach confidentiality in terrorism research, retaining identifiers increases likelihood of breaches through carelessness
- Illegal intrusions
 - E.g., “identity theft”; theft of Social Security numbers (often with connivance of employees bribed to commit theft)
 - Research on terrorism offers additional opportunities:
 - ↳ Members of focus group may inform on other members
 - ↳ Interviewers may inform on respondents
 - ↳ Guards may inform on/coerce prisoners interviewed in non-US countries
 - ↳ Unlike “ordinary” social research, where lack of motive for breaching confidentiality is often alleged, many people and organizations have a motive for breaching confidentiality in terrorism research

Figure 4.4
How Do Confidentiality Breaches Arise?

How do confidentiality breaches arise? Carelessness, illegal intrusions—we’ve mentioned some of these before, so I don’t think I have to spend too much time on them. But research on terrorism, I would say, first of all, offers some additional motivation to breach confidentiality, so you have to be more careful to remove identifiers, not to keep identifiers, and so on. Also, in relation to certain methods that are used in social research—like focus groups, like surveys or interviews—in all those situations, you don’t worry so much about breaches of confidentiality in ordinary kinds of social science research. People do worry about it in research on illegal activities in general. And, like other kinds of illegal activities, I think, you worry about it more in connection with research on terrorism because there are greater incentives for people to act as informants to breach confidentiality. It’s not so much of a hypothetical in those situations.

How Do Confidentiality Breaches Arise? (ctd)

- Legal Intrusions and Law Enforcement
 - Subpoenas
 - FOIA's
 - Requests from law enforcement agencies
 - Patriot Act specifically provides for access by US Attorney General to identifiable records of the NCES
- Statistical (deductive) disclosure
 - Possible even when identifiers have been removed
 - Involves using data available outside the survey to match unidentified data file with one containing identifiers
 - Facilitated by detailed geography, date of birth, multiple waves of data, small populations
 - Impeded by measurement error and other errors, by coding that blurs detail, and by multiple imputation
 - ↳ Given motivation for breaching disclosure in terrorism research, particular care must be taken to protect against statistical disclosure

Figure 4.5
How Do Confidentiality Breaches Arise? (cont'd)

There are legal intrusions that are feared in all kinds of social research: subpoenas, FOIAs, requests from law enforcement agencies, the PATRIOT Act, and, finally, statistical disclosure—the matching of unidentified or de-identified files with data files that have identifiers, which permits you to match the people with records in both sets of files on certain characteristics in order to obtain the names and addresses and so on for the previously unidentified file.

Protections against Confidentiality Breaches

- Anonymization of data (direct and indirect identifiers removed)
- Certificates of confidentiality (HHS; Justice Department)
- CIPSEA (federal statistical agencies or their agents only)
 - Neither CIPSEA nor confidentiality certificates have been tested in courts of law
 - Precedents exist for breaches when confidentiality conflicts with national security:
 - ↳ In 1917, personal information from 1910 census was released to courts, draft boards, and the Justice Department for several hundred young men suspected of not complying with the draft (Barabba, 1975; cited in Seltzer and Anderson, 2003). Other instances cited in Anderson and Seltzer, 2004.
 - ↳ In WWII, senior Census Bureau staff cooperated with Japanese internment by making census tabulations available to law enforcement agencies (Prewitt, 2000)
 - ↳ In 2004, Census Bureau provided information about the residences of Arab Americans to the Customs and Border Protection agency of the U.S. Department of Homeland Security (perceived as violation of law, which it was not, as well as of trust)

Figure 4.6
Protections against Confidentiality Breaches

These are the characteristic ways of confidentiality being breached that one is concerned about in all kinds of research. There are protections that can be used for all of them. You can anonymize the data; you can obtain a certificate of confidentiality, either from HHS or from the Justice Department; there is now the Confidential Information Protection and Statistical Efficiency Act (CIPSE), which was finally passed in 2002 and which protects the records obtained under a promise of confidentiality for exclusively statistical uses by the Federal statistical agencies or their agents. I believed that neither of these had been tested in the courts. However, Sandy Berry corrected me earlier, saying that, in fact, a case involving a certificate of confidentiality had reached the appellate court and was upheld, and the Supreme Court declined to hear it on appeal. So the certificate of confidentiality has been upheld once, but CIPSE certainly has not been tested. And the concern is that when there is a very high degree of interest on the part of the government in obtaining the data, these guarantees may, in fact, not be adequate. There exist a number of

documented instances of breaches of confidentiality under conditions where national security interests conflicted with the Census Bureau's promise of confidentiality. I'm not going to take the time to give them to you, but they are available in various papers by Margo Anderson and Bill Seltzer (Anderson and Seltzer, 2004, 2005; Seltzer and Anderson, 2007).

Harms Arising from Breaches of Confidentiality

- Life, liberty, employment, reputation all may be threatened by violations of confidentiality in connection with terrorism research
- Ethically, subjects of research must be protected whether they are terrorists or not
- Harm is compounded if subjects are not terrorists and are treated as if they were
- As already noted, research enterprise as a whole is threatened if trust and willingness to participate is further eroded as a result of breaches

Figure 4.7
Harms Arising from Breaches of Confidentiality

We've already considered to some extent the harms that can arise from these breaches, and I won't repeat them. Ethically, the subjects of research must be protected, whether they are terrorists or not. But the harm, it seems to me, is compounded if the subjects, in fact, aren't terrorists but are treated as if they are. And as I've already noted, the research enterprise as a whole may be threatened if trust and willingness to participate are further eroded as a result of confidentiality breaches.

Illustrations of Potential for Confidentiality Breaches and Harms

- E.g., in Case 1 a USG agency funds interviews with subjects in nonwestern country on perceived legitimacy of suicide attacks:
 - Identifiable data are kept in host country and the US, and can be stolen or subpoenaed (could be avoided by collecting anonymous data and de-identifying data set)
 - Subjects are known to interviewers and local agency, and their names can be turned over to government of host country for questioning (no way to protect against this)
 - Police agencies of host country may be very interested in subjects' knowledge of potential suicide bombers
 - US has no way of protecting subjects against interrogation, imprisonment, or worse (no way to protect against this)

Figure 4.8

Illustrations of Potential for Confidentiality Breaches and Harms

Some of us got a few illustrative cases ahead of today's workshop. So I decided to look at them and see what risks to confidentiality arise in connection with these cases.

In the first case, a U.S. government agency funds interviews with subjects in a non-Western country on the perceived legitimacy of suicide attacks, and identifiable data are kept both in the host country and in the United States. Such data can be stolen or subpoenaed. (That isn't part of the protocol, but that's my interpretation.) If they exist, they can be stolen and they can be subpoenaed. Researchers could avoid both of these by collecting anonymous data or de-identifying the data set as soon as possible. A second risk is that subjects are known to interviewers and the local interviewing agency and their names could, in principle, be turned over to the U.S. government or the host country for questioning. As far as I know, there's really no way to protect against this. Again, the issue of motivation arises. There is presumably more motivation to do this in terrorism research than in other kinds of research. The police agencies of that host country may be very interested in subjects' knowledge of potential suicide bombers.

Earlier today, Christine Fair said that if there's one activist militant, then there's another one—most likely, in the same family or else known to the family. So that is a matter of interest. And if the names are known, then that family and that person become a matter of interest. And the U.S. has really no way of protecting subjects against interrogation/imprisonment in the host country.

Illustrations of Potential for Confidentiality Breaches and Harms (ctd)

- Case 2 proposes to evaluate the extent to which Muslims in US prisons are becoming radicalized, and to identify factors leading to radicalization, by interviewing former prisoners. Names will be kept for recontact.
 - Names will be kept and can be subpoenaed. CIPSEA and/or CoC may protect, or may not.
 - Data files may also be subpoenaed—see above. If so, acquaintances still in prison may be subject to questioning. Risk and potential harm to them is unclear.
 - (Design is not very informative—no control group)

Figure 4.9
Illustrations of Potential for Confidentiality Breaches and Harms
(cont'd)

The second case also provides illustrations of the potential for confidentiality breaches and harms. Case 2 proposes to evaluate the extent to which Muslims in U.S. prisons are becoming radicalized and to identify factors leading to radicalization by interviewing former prisoners. Names will be kept for re-contact purposes. Again, if names will be kept, they can be subpoenaed. CIPSE and certificates of confidentiality may protect against this or they may not. That's the problem—it's an unresolved issue. Data files could also be subpoenaed. Presumably, as former prisoners, the subjects themselves are not considered a vulnerable population. But if you get their names and get to their acquaintances in prison, those people clearly are still

vulnerable and may be at risk. It's not known what kinds of questioning practices and so on they may be subjected to. The design of this particular study, by the way, I didn't think was very informative, and that is a legitimate issue to raise if there is potential harm to subjects.

Illustrations of Potential for Confidentiality Breaches and Harms (ctd)

- **Case 3: A USG agency wants to assess anti-American sentiment among Muslims in western and non-western countries by convening focus groups in several countries. Names and addresses are kept and groups are videotaped. Identifiable data are kept in US and host country pending completion of study.**
 - Focus group members are known to each other, and may inform on each other
 - Identifiable data are kept in host country and the US, and can be stolen or subpoenaed (could be avoided by collecting anonymous data and de-identifying data set, but see below on videotapes)
 - Subjects are known to moderators and local agency, and their names can be turned over to government of host country for questioning (no way to protect against this)
 - Police agencies of host country may be very interested in subjects' knowledge of those with anti-Western sentiments, and US has no way of protecting subjects against interrogation, imprisonment, or worse (no way to protect against this)
 - Aside from names, videotapes of group discussion will identify members and their attitudes; this may lead to interrogation by security agencies, etc. (No way to protect against this?)

Figure 4.10
Illustrations of Potential for Confidentiality Breaches and Harms
(cont'd)

In Case 3, a U.S. government agency wants to assess anti-American sentiment among Muslims in Western and non-Western countries by convening focus groups in several countries. Names and addresses are kept, and groups are videotaped; identifiable data are kept in the U.S. and host country pending the completion of the study. So, again, we see the same kind of concerns as in Case 2. You're keeping the names; you could avoid those risks by destroying them. You can't really protect against other members of the focus groups who may be persuaded to act as informants. You're keeping a videotape; the videotape in itself is potentially more identifiable than an unidentified transcript. Again, you have very little control over the police agencies in the various

countries where you're doing the research, and you haven't really tested the certificate of confidentiality in such circumstances, even in the U.S.

Conclusions

- Proposal to use "research" for national security purposes is not new
- Some evidence exists that such attempts have ended badly in the past
- Maintenance of confidentiality in such research is difficult because high motivation exists for intrusion by US as well as foreign governments
- Breaches of confidentiality potentially harm subjects, researchers, sponsoring agency, and research enterprise as a whole
- Is such research appropriate for social scientists to undertake? If so, what additional protections are needed?

Figure 4.11
Conclusions

What do I want to say in conclusion? The proposal to use research for national security purposes is not new; we've been here before. Evidence exists that some such attempts in the past have ended badly. The maintenance of confidentiality in this kind of research is difficult because there is a lot of motivation for intrusion by the U.S., as well as by foreign governments, in ways that aren't true of other kinds of social research. Breaches of confidentiality potentially harm the subjects, the researchers, the sponsoring agency, and the research enterprise as a whole. What I want to emphasize is that by fostering confusion between research and other kinds of purposes, broad classes of potential harms arise. The question that I would raise is the question that Bob Levine raised earlier: Is this kind of research appropriate for social scientists to undertake? And if so, what additional

protections do we need to put in place in order to permit that to happen?

PANEL INTRODUCTION BY DR. TORA K. BIKSON

You've had a chance to hear from some of these people in discussions earlier today, but I'm going to briefly introduce them.

The first panelist will be Dr. Mumtaz Ahmad, who is Professor of Political Science at Hampton University and Editorial Board Member for the American Journal of Islamic Social Sciences. He's a member of the American Academy of Arts and Sciences' Fundamentalism Project, and a former research fellow at the Brookings Institution.

Next is Dr. Jerrold Green, a RAND Senior Advisor for Middle East/South Asia and Acting Director of RAND's Middle East Development Council. Jerry is also a member of the Council on Foreign Relations and the International Institute of Strategic Studies. His research languages are Arabic, French, Hebrew, and Persian, and I think you'll find his English is pretty good, too.

Dr. Mary Losch is Associate Professor of Psychology at the University of Northern Iowa and Assistant Director of its Center for Social and Behavioral Research. She chaired the University of Northern Iowa's IRB from 2001 to 2006 and is still serving as a member of it. She, since 2002, has chaired the American Association for Public Opinion Research IRB Task Force and serves on its Standards Committee.

Michael Traynor is Senior Council in the law firm of Cooley Godward Kronish and current President of the American Law Institute. He is a fellow of both the American Academy of Arts and Sciences and the American Academy for Advancement of Science. We're proud to say he was a RAND IRB member from 1986 to 2002 and currently still serves as an alternate member for us.

Panel Remarks by Dr. Mumtaz Ahmad

Thank you very much. I really enjoyed the presentation by Dr. Eleanor Singer. At first, I was wondering why I was invited. I wasn't sure whether I was invited as a social scientist who happens to have

done some work on Islamic extremism and Islamic militancy, or I was invited as a Muslim to present some "special insights" on terrorism research. When I came here and I saw Jerry Green, then it occurred to me it was neither. Actually, I was invited as a result of tribalism of the University of Chicago alumni.

In social science research, we begin with the assumption that the primary obligation of a researcher is to meet the demand for truth and for the internal quality standards that the research community has developed for its own profession. Within this context, the social science research community has also developed certain ethical rules when it comes to human subjects. Freely obtained and informed consent is one, about which we talked in the earlier panel. Not to expose the research subjects to injury and pain is another; we discussed this concern in the previous panel. Maintenance of confidentiality is yet another among the most important ethical considerations. And it seems to me—at least this was my understanding before I came to attend this workshop—that the assumption behind organizing this workshop was that social science research on terrorism represents some special ethical dilemmas. I think that was confirmed by some of the remarks made in earlier discussions. I think no one will disagree that there are some special dilemmas that are located at the intersection of law, politics, and ethics, especially when it comes to the issues related to confidentiality of research subjects.

It was in this context that I talked with my son, who is a law student at William and Mary, and asked him whether there is an analogy between attorney/client confidentiality and researcher/subject confidentiality. His first reaction was, "Well, an attorney is supposed to represent his client and defend him, while the researcher is not defending and representing the subject." But then he added that the ethics of confidentiality should apply in both cases; if an attorney can lose his license to practice law for violating the attorney-client confidentiality, so should a researcher be stripped of his research privileges for compromising the confidentiality of his/her subject.

But the more serious concern that we shared during our discussion was that the mere fact that a workshop was being held on ethics of

social science research on terrorism indicates that social scientists who are engaged in research on terrorism are probably looking for some exceptions to the ethical norms of research. Does the fact that we are holding such a workshop mean that we are not satisfied with the paradigmatic social science research ethics? Are we looking for some loopholes and exceptions?

And this reminded me of a similar debate that is taking place among the legal theorists in America today on what Carl Schmitt once called "the state of exception"—that is, the harsh and provisional and exceptional measures to restrict individual liberties in special circumstances (for example, threats to national security). The Italian philosopher Giorgio Agamben talks about the biopolitical significance of this state of exception in which law encompasses living beings by means of its own suspension. My hope—and it was confirmed by listening to the earlier discussions—is that this is not the case, and it was, indeed, very reassuring for me. I didn't want us to sit down and formulate or replicate the USA PATRIOT Act for the social sciences. As in law, exceptions to norms have a tendency to become working paradigms, even in the social sciences. You make one exception, then another exception, then another exception; and in no time, these exceptions become the accepted paradigm. This is what we are seeing in the increasing erosion of civil liberties in the United States and in other Western democracies as well. And all this is happening within the framework of "the state of exception," which, I am afraid, will eventually become the working paradigm of the technique of government in "liberal" democracies.

I have already mentioned some questions I had about why I was invited. My invitation letter suggested that we want to hear Muslim perspectives, if I'm not mistaken; and I was also asked to contact some other Muslims who could be invited here as participants. Now, as for the question of Muslim perspectives on social science research on terrorism, I'm afraid there is no such thing as Islamic ethics of social science research on terrorism. There are no special insights Muslims can offer to which non-Muslims do not have access. But there could be, I believe, two underlying assumptions that can make some sense of Muslim perspectives on social science research on terrorism. One is the idea

that since the majority of the research subjects would be Muslims—we all know about that, let's not pretend—therefore, a Muslim voice from the researcher or consultant side would be of considerable significance and usefulness. And the second assumption could be the idea that a Muslim researcher just may be more objective and committed to ethics of social science research in comparison with someone who has preconceived notions of Islam as a terrorist religion or Muslims as congenital, blood-thirsty terrorists. So in a way, a Muslim perspective on research on terrorism may be more objective in the sense of being more empathetic, without any preconceived notions or without having any agenda, let's say.

So these are my preliminary remarks. But now I will talk about confidentiality, and I will illustrate my points by mentioning a couple of personal experiences. One experience which is relevant here is the incident that occurred at the Tel Aviv Airport some years ago. I was in Israel attending a conference. Afterwards, I stayed a few more days in Jerusalem, during which a contact arranged a meeting with some senior leaders of Hamas in Gaza. Then I went to Amman and, there again, another contact arranged a meeting with two other senior leaders of Hamas. The Israeli intelligence agents probably knew what we were doing, but they were not sure. When I was returning to the United States, they stopped me at the airport and started asking questions. And the questions were, "Who did you meet when you were in Gaza and when you went to Amman? Why did you go to Gaza?" My answer was that actually, I had very fruitful meetings. They asked again, "Who did you see? Give us the names." And my answer was, "I can only tell you that, as a political science student, as a researcher, I meet all kinds of people. I met some of the Israeli leaders, I met one Israeli cabinet minister, and I met some members of Hamas and members of Islamic Jihad in Gaza. But I'm not going to give you the names." They insisted and said, "You are going to miss your flight." I said, "Fine, I'll miss my flight, but I'm not going to give you the names." I tried to render anonymously the information they were looking for. They said, "What did you talk about?" I said, "I can give you the general idea. I asked my respondents about their views about terrorism, Islamic justification of suicide bombing—how can they justify it in accordance with Islamic law.

These were the general questions. And if you want, I can give you their answers because I'm going to publish those answers anyway. However, I'm not going to give you the names." Ultimately, when they realized that I wasn't going to give them any names, they just let me go. One thing I should mention was that they looked into my bag, although they didn't search it thoroughly. My notes were in the Urdu language but I had written my notes in what we call Shakasta script (broken Urdu script), which I don't think anyone in Israel could read, not even Yohannan Friedman, a fine Israeli scholar of South Asian Islam who knows and reads the Urdu language very well.

But lo and behold, while the Israelis were considerate enough not to subject me to a body search or to look into my baggage and search my papers, the Homeland Security Department of my own country was not so considerate. It so happens that I share my last name Ahmad with at least 150 million other Muslims, including someone who is on a suspect list of the Homeland Security Department. So during the last two years, whenever I return from my overseas travels at any port of entry—whether it's Chicago, Los Angeles, or JFK—I am picked up by an immigration officer, escorted by him/her to some back room at the airport, and interrogated by the Homeland Security people. The first time it happened to me, I was returning from a research trip to Pakistan and Bangladesh, and I was carrying extensive notes of my interviews with all kinds of Islamic leaders and activists with me. And this time, the notes were not in broken script; they were in regular, legible script in Urdu. And I know that FBI and Homeland Security have hired many people since 9/11 who can read Urdu. Anyway, they asked me some questions and then, without my permission, opened my suitcase. Then they started opening my files, taking out sheets of papers, making photocopies of all the papers that I had with me, including the newspaper clippings. And—you guessed it right—all my newspaper clippings were on terrorism, on militancy, on radicalism. They were so excited that they had got their man. Everything they were looking for was right there—screaming headlines of suicide bombings, vociferous anti-American statements of Islamic militants, roaring calls for Jihad, it was all there! Then they asked for my wallet, and they took my credit cards and photocopied them.

But then they started photocopying the entire deck of the visiting cards that they had earlier taken from my suitcase. That made me very upset. I had met so many people in Pakistan and Bangladesh who were not even my research subjects; they were people I met casually at some reception, or in a meeting, or at a dinner, and with whom I'd exchanged cards as people usually do when they meet for the first time. To give you an idea: there was this one visiting card in my collection that a Bangladeshi cook had given me (printed on the back side of the card was a long list of his satisfied customers) after a wonderful feast that was prepared under his professional supervision at a wedding party in Dhaka. And I thought, My God, all their names are now going to be on the list of the Homeland Security and FBI, and they will curse me for the rest of their lives! Every time they apply for a U.S. visa or enter the United States, their names will be there. The problem was that all my research notes—my interviews with some of the "radical leaders" in Bangladesh—were photocopied, and now they are probably with the Homeland Security Anti-Terrorism Task Force. If there is anyone from that agency present here, please return my notes.

Since then, I have realized that I probably cannot maintain confidentiality as long as I am not cleared from the Homeland Security Department. Now I have started writing my notes in Punjabi—and not even in Punjabi, but in a dialect of Punjabi that only I and my mother speak. So this for me is the safest way to maintain confidentiality of my research subjects. Confidentiality is very, very difficult in terrorism research, particularly in the United States, where laws have been passed that can compel disclosure of any information that the government wants. And if I refuse to comply, then I am in trouble. Of course, as in legal practice, I will have no qualms about disregarding the confidentiality principle if a law is going to be broken or when human lives are at stake. But that's where the line should be drawn.

Panel Remarks by Dr. Jerrold D. Green

One thing I want to add—although I'm big on tribalism—is that it is important to remember that Mumtaz is also a member of an organization composed of Muslim social scientists.

I really enjoyed Professor Singer's talk. I started my academic career at Michigan, so I find it hard to be objective about Michigan professors. Dr. Singer asked two questions, which I think are really important. One is, Should social scientists do this type of research? And second, Are extra protections required? And my answer to both of these would be yes. I'll talk a little bit from my own career, as did Mumtaz, and I'll give three very quick examples.

First, I did my PhD dissertation research in Iran during the Iranian Revolution. And although I don't speak Punjabi as does Mumtaz, I crafted my research notes in precisely the way that Mumtaz did, trying to encode them so as to protect the identity of my respondents. The codes were so complicated, I had trouble making sense of them! I would mail them out from Iran during the Revolution, I would misnumber them, I would send different interviews in different mailings—I took all sorts of precautions, which I thought were very amateurish. These measures highlight the fact that a lot of us are sensitive to confidentiality issues because our respondents are people that we know, and they trust us. There's not only a moral dimension, there's also a practical dimension: we want to be able to keep talking to these people. Eventually they grow up to be somebody. What Mumtaz did not mention is that a third member of our class at the University of Chicago is the new United States Ambassador to the United Nations. If you go through our class at the University of Chicago, another classmate heads the opposition in Indonesia. We generally try to interview significant people, so it's important to preserve these relationships and to guarantee confidentiality for a whole variety of reasons.

The second example occurred more than 20 years ago. It involved a very distinguished professor of political science at Harvard University (some of you may remember this) who convened a conference at Harvard on the Middle East. The conference was funded by the CIA; he invited people from the Middle East but neglected to tell them that it was being funded by the CIA. When some of the Middle East participants arrived at Logan Airport, the *Harvard Crimson* had broken the story about CIA sponsorship, and a good number of them turned around and went back to

the Middle East. The professor eventually resigned from Harvard. Who was at fault here, the professor, Harvard, or the CIA?

My third example is as follows. I was invited to Tehran several years ago by a friend who is a senior government official in Tehran. We went through all sorts of steps to get me there and to get a visa. At our meeting, he told me that he had a message he wanted me to bring back to Washington. I said, "All right, what's the message?" He told me what he wanted to convey. I responded by saying that I would convey the message but that "in Washington they will insist that I reveal your identity. If I don't say who you are, they're not going to take it seriously. Do you want me to do that?" He said, "Yes." I said, "I will do it, but I think you're making a mistake." And I explained to him why I felt that his trust in me would be abused if I revealed his identity. Basically, I talked him out of it, largely because I thought his identity would be far more interesting to the powers that be than would the substance of the message—in part, because he was exceeding his brief.

These experiences suggest there's a kind of jerry-rigged quality to such multipurpose research interactions. I'm telling you these things to show that the systems we put in place really are very, very important. Although Tora oversees a lot of the things we do, and we may at times find it kind of annoying, at the end of the day, if we're smart, it's important for us to be annoyed by IRBs, because we could otherwise make mistakes and never know it. And the implications for the people we talk to could be profound. So I think we should all be supportive of these efforts. I'm sort of a mixed-breed here: I've done research as a Fulbright professor as well as with support by the Social Science Research Council; I've also done work for the CIA and the DIA, as a RAND analyst. So I can speak to both sides of the research picture. My research as a Fulbright professor and the work I've done for the CIA are actually remarkably similar. The people that I have dealt with at the National Intelligence Council, which is sort of the think tank of the CIA, are generally too smart to ask me for names, because they know they're not going to get them. And in a sense, they're tasking is much deeper and much more profound. They are

interested in trends, interpretations, insights. I suppose if I offered names and phone numbers, they'd be happy to pass them on to somebody else. But at the end of the day, they were chiefly interested in the research I was doing; they're like us, at RAND—analysts. The spooks are there as well, but they're elsewhere in the building, and they don't usually talk to researchers like us.

In general, there are lots of parties interested not only in substantive research in these areas but also in who you talk to and why. So it's important to build in the safeguards that we have been talking about, that Tora oversees for us at RAND, along with Michael Rich and others. It's a complicated oversight structure for people with my training. People like me and my classmates, colleagues, and students need to be involved in social research on terrorism, but there's got to be a way in which we create the types of ethical protections in general and confidentiality assurances in particular that you're talking about. I also think it's really important to distinguish intelligence analysis from espionage information collection and the like. When I travel internationally, I am extraordinarily sensitive and attentive to the kind of things that I want to ask people and to discuss with them, and to how I impart the information I get to others. There are lots of participants here who can address the difference between intelligence and espionage. I encourage people in the audience to speak up and help make distinctions about the information needs of the intelligence community that do not violate the kinds of confidentiality concerns that Professor Singer has articulated.

Panel Remarks by Dr. Mary E. Losch

I won't be talking about the intelligence community, but I have learned a great deal today within this intelligent community. I think most of the big issues have already been brought to the table, between when we started this morning and when we arrived at this point. I don't think I can throw out any specific conundrum, quandary, or otherwise sticky wicket that has not crossed the minds of most of you all. But what I did note most of the day is that the big conceptual issues come out, but there is not as much grappling with the practical issues. For

me as an IRB member, and certainly for many years as a Chair, what happened was that I could identify an ethical issue for investigators, and then they would say, "So what could I do about this?" I could say, "This is my concern about your protocol," and sometimes they would say, "Oh, I understand. Well, how about I change this?" But most of the time it was, "So what do I do about it?" And that's where I want to go.

With regard to confidentiality, I see two very different areas of problems related to concerns and risks. Most of what I see in the literature and discussions has to do with the transfer and maintenance of data once we have the data. That's true across the board—irrespective of the kind of research, breach of confidentiality is often an issue. In this particular context, obviously, that can be an even more significant risk, a more severe risk. I think that Eleanor Singer talked briefly on one of her slides about some of the practical things that can be done. I would be interested in knowing whether it is in fact standard practice, for example, to remove all identifying information from data sets immediately or as soon as possible; whether or not noise is inserted statistically to protect the identities of respondents in these sorts of projects; whether or not, if you have what you might call a panel study that needs follow-up, there are mechanisms in place currently to utilize codes rather than identifying information. A project may have identifying information somewhere, but is it four times removed so that anyone getting the list wouldn't know what it was for, for example? These are the kinds of things that we recommend for studies that are far less high risk than the kinds of studies that are being discussed here. I heard some specifics about these studies this morning, but not really in the kind of detail that allowed me to judge whether or not there are reasonable sorts of confidentiality protections already in place. Are we looking for something far beyond that, or are there some fairly standard sorts of safeguards that are not routinely being carried out that could be?

Then there's the distinction between the transfer and maintenance of data versus the recruiting and data collection procedures. Concern for confidentiality protection in these earlier phases of a study is not unique to terrorism research, but it certainly places an additional risk

that is not typical of most research. We have definitely looked at protocols that I would deem very similar, in that if participants are seen talking to researchers, that's going to increase the risk to them. Certainly these are issues in crime research, issues in gang research. Domestic violence is another area that would provide some relevant and useful paradigms. So my recommendation is to look for examples in the numerous studies that deal specifically with protection of the identity of individuals during recruitment and data collection. I would hope there might be insights to be gained from looking at these relevant areas of research.

Along these same lines, another confidentiality question should be raised. Under what circumstances will confidentiality be breached intentionally by either the interviewer or the researcher? To me, that would be very central in the cases we're discussing here. While different, mandatory reporting is what comes to mind as the model that I'm more used to. So what does happen if researchers or co-participants hear what they think is reportable information? Earlier this was alluded to, but there were no specifics. Is there, in fact, training for what to do in such a circumstance? This is an area in which I'm doing some work for AAPOR, in fact. A question came up about whether there are standards and guidelines and training with regard to intentional breach of confidentiality. Suppose an interviewer on the telephone is not discussing high-risk content—we're not talking about specific studies of suicidal ideation here—but it happens in the course of the more general interview that the respondent says he or she is going to end his or her life. That has happened. So what does that interviewer do? Is there a specific protocol that should be followed?

It seems to me in the case of terrorism research, this is even more important. If someone says to the researcher, "Yes, I'm proud of what my son did, and my other son plans to do something similar tomorrow," what does the researcher do with that information? That's one issue. But what guidelines does the researcher have ahead of time? To me, that gets to the confidentiality point. And does the consent provide some sort of framework for having participants understand the limits to their confidentiality? We can talk about the importance of

maintaining confidentiality, but I don't think we should lose sight of the other issue that comes with that, in terms of situations under which confidentiality will, in fact, be breached intentionally. That's an important issue as well.

Continuing with practical steps, I think focus groups are particularly risky with regard to knowing who's where and who's talking about what. Researchers can provide some control if they are doing one-on-one interviews. Is it possible—and again, I'm just spinning ideas here—is it possible to maintain a resource, a facility for focus groups where there is no visual contact among participants, only voice contact? It seems to me that's possible, although resource intensive, perhaps. People could be brought in so that they don't see one another, and participate in cubicles where they can hear one another but cannot see one another. If the focus group format is critical, the vocal quality and the interactive dynamic may be needed, but is the maintenance of the visual contact absolutely necessary? Perhaps not, perhaps that's a way to make a practical change in the venue that increases the confidentiality protection, even in that research context.

I, again, get back to the question of how do I solve the problem, how do I mitigate the risk? If the interviewer does not know who the interviewee is, then there's more protection. If you're doing face-to-face interviews in a home, that's very difficult. Because you might even be compelled by state authorities, if you didn't have a list of identifiers, to tell where you went to get this information. Again, I'm just spinning out scenarios of potential coercion to breach confidentiality. If you have a central facility or central location in a community, and the individuals come to you, you don't have to know who they are. If you have multiple individuals involved in the recruitment, these recruiters know who's scheduled to come on this day, but they don't know who actually came or didn't; then, as an investigator, I can't tell who showed up or said what. These kinds of strategies, it seems to me, are where we need to look. We can debate the overarching questions of whether we should or whether we shouldn't conduct this type of research, and I think that's a worthy debate. It's been started today, and it probably won't end in my lifetime. But in the meantime,

it seems to me, we also have to focus on the practical issues. I think it's important not to ignore the extant body of research on areas that are similar—not identical, but similar to terrorism research—where the actual participation per se presents additional and perhaps very significant risks for those individuals. A formal review of that literature—plus informal conversations with people who have done such research for many years—might yield some very important practical strategies for what we can do today and tomorrow in the field to try to deal with some of these issues that are front and center.

Panel Remarks by Michael Traynor

In accepting the George F. Kennan award last month, John Negroponte commented on Kennan's philosophy and research approach. He said his wisest decisions and conclusions were reached from studying life in the streets of Moscow, from talking to Russians in their own language, and from studying the culture and history of the country. In this month's *New York Review of Books*, Christian Carl describes the Iraqis today. He refers to what we all now know is the monumental failure of intelligence about weapons of mass destruction. But he also refers to the equally scandalous failure of the Bush administration to form any clear picture of Iraqi public opinion, and its reluctance to engage in sound research about the culture and history and behavior of people in that country. This kind of research that we've been talking about today is of vital importance to our country, not only for our national security, but also to help us frame what should be a responsible position for our country and the world. And confidentiality is of corresponding importance. I'm very proud of the record that RAND has had over all the decades that I've been involved with it of never compromising confidentiality in the sense that Dr. Singer mentioned—revealing identifiable confidential information. I don't know of a single instance in which RAND has voluntarily, or under compulsion of subpoena or otherwise, disclosed that kind of data. And that's an important record.

In this context, I see confidentiality as a special challenge—not just to provide confidentiality in the usual sense in which we are used

to it as researchers, but to see whether there's any way of enhancing and strengthening confidentiality to meet the enhanced risks and harms that Dr. Singer mentioned. Enhancing and strengthening confidentiality could also help to make up for compromises that might be made in the other two domains of our discussion, autonomy and beneficence. Can we, through enhanced confidentiality, end up not causing harm, but increasing the protection for the research subjects that are involved?

Here I think we need to have a dose of reality about our own country's legal background. I won't speak to the law of other countries, which I assume is no better; but we have, in our country now, the PATRIOT Act and associated statutes. I'm talking not about the constitutional challenges that have not yet been completed, but what both Congress and the executive branch have done. It's now possible, proceeding in accordance with these statutes and orders, although not necessarily constitutionally, to search for records, to enter computer databases, to do that in secret without prior notice, and to do that with or without, in some cases, a court order. And when a national security letter is issued or a court order is issued, it will be frequently accompanied by a gag order so that you're not even permitted to talk about the situation. At one point, I had a case—not for RAND, but another client—where the gag order said, on its face, that you couldn't talk to anybody, not even your attorney. The Justice Department now, I think, is interpreting that to allow you to talk to your lawyer when you have a gag order. So that's the situation in our country when the government is proceeding in accordance with the statutory authority that it claims. But we now also have a record of lawlessness on the part of our government at the highest levels in terms of warrantless surveillance, violation of the Geneva Conventions, deportation of people, and so forth. So we are in an atmosphere where the challenges to protecting confidentiality are very severe.

So what can we do about it? In addition to data safeguarding plans, let me take a look at aggregation. We're accustomed to reporting data in statistical aggregates. Is a new look required for the reporting of data in the aggregate? Are new levels of abstraction required to protect confidentiality in a way that will still yield a

meaningful report? Will the IRB take a look at how the reporting is going to take place with respect to the level of aggregation? In terms of security, are any special coding requirements required? Are any special protections needed against the identification of people or links to the identifiers? Should there be greater distribution of relevant information so that if government orders are sought or subpoenas are brought, the people pursuing those will run into half a dozen dead ends before they get any useful information? It seems imperative to me that all of this be done with a coherent legal strategy by the research institution involved, such as RAND or others.

The legal strategy, in part, starts with the funding contract. Significant mention has been made here today about the problems of the source of funding in this research and whether the funding comes from government. In the context of a legal proceeding before a judge, recognize that there's only going to be one party present before that judge, and that's going to be the government. The researcher is not going to be a party, in most cases, before the judge. The judge is going to be leaned on with a statement by the government that it is in the utmost interest of national security that we breach confidentiality. Even if there's a one percent chance—in Cheney's terms, for example—of finding out the identity of a proposed suicide bomber, it's purportedly worth breaking a whole sequence of research and confidentiality assurances to get that information. The judge is likely to be quite responsive to those contentions. And if the additional contention is made that the research and data collection were funded by the United States government, that is going to be another factor tilting in favor of a court order compelling the disclosure and production of those records. So in the negotiation of the funding contract, if the government is going to fund the research, maybe some special protections can be sought. For example, is there some assurance the government can give that before any kind of effort is made to get the data, there will have to be some high-level clearance through a person who would be friendly to the research organization? There may be additional protections that can be sought, but I am urging that we think in terms

of the hurdles that need to be set up, legally and practically, to the disclosure of sensitive confidential information.

There's an additional point I'd like to raise, related to the question of destruction of data. Mention was made this morning of the importance to the scientific community of having data and analyses that can be replicated by others, to insure that a study was done with integrity and competence and professional skill. That presents a special issue, it seems to me, in the area of terrorism research. Are there ways of protecting the data, short of destruction, given our understanding of the consequences of destruction? It may be that more consideration will have to be given to locating some of the data offshore, distributing data, and setting up physical as well as legal barriers to eventual production.

SYNOPSIS OF THIRD PLENARY DISCUSSION

Ethical Guidelines for Whether, When, and How Terrorism Researchers Should Violate Participant Confidentiality

Workshop participants noted that social and behavioral researchers studying terrorism may collect a variety of information about imminent harm that they may feel ethically obligated to report to military organizations, intelligence agencies, or law enforcement authorities, even though there appears to be no legal or professional reporting requirement. This information may be useful for averting very dangerous actions (i.e., "actionable intelligence"). The collection of such information may create an ethical dilemma for the researcher, who, on one hand, has promised participants confidentiality and desires to protect the integrity of the research process, and, on the other hand, also wants to protect the safety of other persons who may be at risk of harm.

In other research settings, there are analogous situations in which a research participant reports a plan or intent to do harm to oneself or to another (and, in the case of so-called suicide bombers, to both). For instance, some professionals are mandated reporters of child abuse and elder abuse. Others are obligated to intervene when there is

a clear danger of suicide or homicide. However, terrorists' actions may take forms that lie outside current legal requirements or professional/regulatory guidance but still create ethical concerns.

Assuming the decision could be made that under certain conditions it is ethical to violate confidentiality, social and behavioral researchers studying terrorism and the IRBs that review their activities need guidelines that answer at least these questions:

- What are the criteria for determining when harm is "imminent"?
- When is the information "actionable"? Does the information need to represent a viable plan plus means? Is the information likely to be reliable? Is the plan or method feasible?
- How should researchers determine whether a threat is real enough to breach confidentiality?

They need to understand whether the obligations should vary according to the discipline of the research team member (e.g., does a sociologist have different obligations from a historian or psychologist?). They also need to know whether their obligations vary according to which country they are conducting the research in; what is illegal, unethical, or nonreportable in one country may have a quite different status in another. Researchers conducting a single study in more than one country need guidance on how differentially to manage discrepant regulations and value norms in multiple sites.

Such guidelines would provide the basis for developing procedures that could then inform the training of research staff in the field who are collecting data via interviews, surveys, focus groups, and other methodologies. Interviewers could also be trained to ward off the sorts of disclosures that might be reportable when they can anticipate them.

The training would include within-study procedures for communicating and analyzing potentially reportable information. Field staff need to understand when and how to communicate such information to a supervisor or to other people who may then examine it and analyze its credibility. They should not be left in the position of using their individual judgment on a case-by-case basis to report the information directly to a law enforcement or investigative agency or other authority.

A clear stipulation of the conditions for breaking confidentiality and the types of information that characterize them would also aid in the modification of research designs and protocols to reduce the risk that such conditions will be created and such information will be elicited unintentionally. IRBs could advise researchers regarding modifications to planned studies that would help ameliorate the risks to participants (as well as to researchers, whose openness may preclude untoward disclosures or perceptions of betrayal if confidentiality is broken in the specified circumstances).

To the extent that the conditions for violating confidentiality can be stipulated, the question also arises of whether these conditions must be communicated to all research participants and, when they are communicated, in what manner. There are precedents for such communications. For instance, it is common for psychologists studying family environments to warn research participants that they are mandated to report instances of child abuse. A related question is whether and how to communicate the fact of reporting to the participant, as this could create great risk for the research staff.

More specifically, guidance is also needed on how to communicate in consent statements the conditions under which confidentiality might be intentionally violated. Everyone agrees that there should never be absolute guarantees of confidentiality. An argument for including such conditions in the consent protocol is that they can be presumed to be material to the decision to participate. Also, the explicit inclusion of these conditions may act as a warning, reducing the chance that a participant will share such information and therefore reducing the chances that the researcher would have to report it.

When researchers include exceptions to the assurance of confidentiality in consent statements, they avoid the potential for creating an ethical dilemma for themselves later if one of the conditions is met and they feel obligated to report confidential information. If the conditions are made explicit from the outset, then the researcher can proceed to report with confidence that no promise to the participant has been broken.

Because of the nature of social and behavioral methodologies, participants can quickly develop a trust and openness with research staff that permits them to disclose information that has not been requested and may even have been explicitly warned against. For this reason, communicating the conditions under which confidentiality may have to be violated probably cannot safely end with an explanation in the consent protocol. The conditions may need to be underscored during the course of an interview, survey, or focus group, particularly as topic areas of seemingly high risk are about to be broached. IRBs may need to develop additional guidance to help research teams communicate with participants in ways that augment the information provided at the outset by the consent procedure.

Because of the moral dilemma involved in deciding whether to live up to the promise of confidentiality or fail to live up to the obligation to protect the well-being of the participant and/or society, the research should be of sufficient value to make coming to terms with that dilemma in any case worth the effort.

Expansion of IRBs to Include Persons with International Research Experience or to Include Outside Experts

Workshop participants noted that IRBs reviewing social and behavioral research on terrorism may find it difficult to meet the regulatory requirement that "[t]he IRB shall be sufficiently qualified through the experience and expertise of its members and the diversity of its members, including consideration of race, gender, and cultural backgrounds, and sensitivity to such issues as community attitudes, to promote respect for its advice and counsel in safeguarding the rights and welfare of human subjects." This regulation is intended to assure that the IRB can make its judgments and decisions based on accurate answers to such basic questions as these: What are the dangers of research participation in that culture? Do the potential benefits of the proposed research justify the risks that would be involved for the subjects? How is privacy defined and regarded in the culture of the subject population? What data would be of great interest to local authorities and might occasion their efforts to obtain them?

In order for the IRB to comply with the Common Rule, it must either have the apposite experience, expertise, and diversity represented among its members, or it must have access to external persons who possess the required characteristics in addition to being experienced in the conduct and/or review of human subjects research. In the case of terrorism research, this requirement can be challenging because of the number of countries and cultures involved. And the situation is worsened by the circumstance that individuals with the needed international expertise might not have the appropriate background to understand and apply the ethical regulations.

It is safe to say that most IRBs in the United States today lack sufficient members who have the needed expertise and experience to evaluate much of the proposed social and behavioral research on terrorism. In order to assess with confidence the risks of participation in particular studies—given the subject population, the information to be collected, the proposed research methodologies, and the locale—IRBs may need to draw on outside experts who can provide an informed background for understanding how the ethical principles of autonomy, beneficence, and justice should be applied in the context of the country where the research is to be conducted.

At most U.S. research institutions, IRB members' competencies for reviewing studies with vulnerable subjects appear predominantly to concern domestic issues in the United States: child abuse, drug abuse, suicidality, criminal behavior, and so forth. For the most part, they lack significant international research experience with the sorts of vulnerable populations envisioned by this workshop.

IRBs at major universities may have ready access on campus to a large number of international researchers who may be qualified to act as external experts in the review of specific studies. Nevertheless, the need for truly global expertise, experience, and diversity makes the process of accessing appropriate external experts very challenging. There are a couple hundred countries in the world, and within many countries there are multiple languages and cultures. For research that proposes to involve human subjects in studies of terrorism in several countries, the IRB may require several external experts for assistance.

It will also be helpful for those in the social and behavioral research communities who study terrorism to take steps to engage and educate their IRBs. They can become regular or alternate members. The sharing of expertise will then run two ways, as their research community will become familiar with human subjects regulations and IRB processes.

Some institutions have proposed establishing specialized IRBs to deal solely with international research, to include social and behavioral research on terrorism conducted outside the U.S. However, other institutions are wary of specialized IRBs because they reduce transparency into the research domain and may promote isolation. This danger is recognized for IRBs formed solely to review narrow classes of research other than terrorism: for example, research in particular fields, such as epidemiology, or of a special character, such as classified research or quality improvement activities.

Strengthening the Legal Bases for Assurances of Confidentiality

Information collected about terrorism and terrorists is of interest to many communities other than the research community, including military organizations, intelligence agencies, and law enforcement personnel. In fact, strategic intelligence analyses to inform policy conducted by such agencies can resemble studies conducted by academic researchers: It is a blurry line between the two research groups, particularly as their professionals are graduated from the same schools and departments, may use similar methods, may know each other as colleagues, and may move between academic and government employers during their careers. These communities may include academics, research professionals, and government officials in countries where the data are collected, as well as in countries where the research is sponsored.

Terrorism researchers in the United States should be aware that the USA PATRIOT Act has greatly expanded the power of the executive branch to search for records and to enter computer databases without prior notice and, in some cases, without a prior court order. In many parts of government, there is considerable motivation to obtain identifiable information about terrorist activities from researchers who have acquired it under assurances of confidentiality. It would be

useful, therefore, to develop ways in which researchers could strengthen the practical legal bases for the assurances of confidentiality that they often wish to provide to human subjects.

Researchers can modify their research practices to strengthen confidentiality in a number of ways. They can address intense potential interest on the part of authorities by heightened data safeguarding procedures, including aggregating data, destroying data immediately after analysis (recognizing that this may make it hard for others to conduct follow-up research or verify findings), distributing data so that they are stored in various remote locations, and even using dummy data storage sites so that government actors have to run down blind alleys.

One legal strategy might be for the researcher to require the research sponsor to enter into contractual assurances that provide protections somewhat similar to those of a confidentiality certificate. Such assurances might be particularly helpful if the government is funding the study. In such a case, the contractual assurance might obligate the government sponsor to act as a "friend in court" with the researcher to actively resist disclosure. Alternatively, it might obligate the sponsor to alert the research team immediately upon receiving a request or legal process compelling the disclosure of research data so that there is a chance to resist disclosure.

This strategy could be implemented with a change in contract procedures, and there is some precedent for it. For instance, especially in the case of law enforcement research, where RAND's IRB thought that there might be some interest on the part of the funding agency in getting identifiable data back about people in the justice system, the IRB requested that the study obtain letter agreements with funders (state criminal justice agencies) stipulating that they will not ask for identifiable data and will not try to use any de-identified data sets to reverse-engineer identity and/or to make individual decisions about individual persons. More than one study has obtained such agreements successfully. The strength of these agreements has never been tested in court, however.

RAPID WRAP-UP BY DR. TORA K. BIKSON

I'm going to be extremely brief wrapping up, partly because, of course, it's late in the day, and the last session is still quite fresh in our minds. Dr. Eleanor Singer argued persuasively, I think, that the issue of confidentiality is different in terrorism research than it is in other kinds of research, simply because there are a lot of incentives outside of the research team to get identifiable data and possibly use them to inform decisionmaking. Dr. Ahmad and Dr. Green provided us with some first-hand examples of people attempting to get such information from them. So this, in turn, results in the need to create very strong protections for confidentiality of data—starting with Eleanor Singer's suggestions. Couldn't these studies be anonymous? That is, are there ways that researchers can collect their data without getting any direct identifiers? Or can they anonymize what information they do get? Mike Traynor suggested maybe aggregating data upward to higher levels of abstraction would be a solution in some cases.

Nonetheless, everyone did agree that there is nonnegligible risk of harm from breaches of confidentiality, which might be either inadvertent (through careless data handling) or intentional (when outside agencies attempt to acquire identifiable research data). This brings us back to Bob Levine's point that one of the strongest ways of protecting human subjects is reducing the risk of research participation by producing really very robust confidentiality safeguards when anonymity is not possible.

We also dealt with an interesting issue that came up first in the initial session and then again this last session: What guides should be applied to make decisions about intentionally breaching confidentiality if a researcher obtains information that, if revealed, may protect others from imminent terrorism-related harm. This situation would be analogous to those that invoke Tarasoff, or Good Samaritan, duties. What's a researcher to do if the researcher elicits that kind of information from participants in the course of conducting social-behavioral research on terrorism?

There were three suggestions. One was to provide informed consent protocols that clearly outline for participants the conditions under

which confidentiality might be breached. A second was to provide explicit instructions to respondents that their comments should not include names or other detailed information that could associate identifiable individuals with specific events; researchers should also anticipate and head off such disclosures before they are made in interviews or focus groups. The third was to make sure that researchers in the field are well trained procedurally so they turn potentially reportable information over to a senior researcher or analyst who is in a position to make a sound judgment about whether the information is reliable enough, and the problem imminent enough, to make it worth the breach of confidentiality. Discussion of the need for such protocols and procedures, in part, was occasioned by the concern that if trust is established between the researcher and the research participant, inadvertent disclosures might be made even when the researcher had no intention of asking about future behaviors or specific planned events. So even though such questions aren't included in the research protocol, it doesn't necessarily mean the researcher isn't going to end up with what one workshop participant referred to as "actionable intelligence."

In the end, both Dr. Losch and Mr. Traynor gave us some strong requests to develop practical methods: Address questions of what to do now to reduce risks of breaches of confidentiality even while we are deliberating the ethical issues raised. Mary Losch gave us some practical guides that her IRB puts in place to try to reduce risks of inadvertent confidentially breach. Mike Traynor gave us some examples of approaches that could be used with funding agencies—letters of agreement which, while perhaps not foolproof, would give the researcher some ground to stand on in arguing that neither the sponsor nor the courts should try to compel release of identifiable information from the study.

I believe we're going to spend quite a lot of time reading and thinking about the material that we've gotten from people at this workshop today. I want to thank everybody for contributing. I was hoping, at the beginning, that all attendees would actively contribute, not just those who were asked to speak to get the conversations going. This hope was more than fulfilled by your participation.

5. CLOSING SESSION

REMARKS BY MICHAEL RICH

I'd like to close with a very few words. I certainly enjoyed my time here today, and I learned a great deal. This workshop has turned out to be just what I had in mind when I first conceived it: a solid starting point for a dialogue aimed at addressing ethical issues that arise in certain human subjects research on the antecedents, processes, and consequences of terrorism. I hope and believe you will agree with me that the workshop was very successful in identifying not only many of the major ethical issues, but also some approaches that could help funders, researchers, and IRBs to promote the conduct of specific studies in a more ethical manner.

As I mentioned in my opening remarks, I have seen more and more instances in which our principal investigators in terrorism are proposing innovative projects involving novel research designs on very important issues. Frequently, it seemed to me, the proposed studies in this area were bedeviling our IRB. By bedeviling, I mean they raised ethical issues regarding basic principles of autonomy, beneficence, and justice that were gray, murky, and complex. And this was a diverse and experienced IRB that has grappled with innovative projects on children, prisoners, prostitutes, gang members, and other challenging populations to study.

This created a dilemma for me that I am sure is similar to that faced by provosts and chancellors at the universities where some of you work. As the Executive Vice President of RAND, as well as the Chief Institutional Officer overseeing the IRB, I was faced with a situation in which two important streams of interest were on a collision course: On the one hand was RAND's mission of conducting important research in areas critical to our nation's well-being; while on the other hand was RAND's commitment to upholding the ethical standards for human subjects research. It is important to me to enable these interests to converge, not to collide.

I am hoping that the thoughtful presentations and rich discussions we have shared here today will help RAND's IRB work with researchers in

the coming months to devise plans and designs that enable them to carry their work forward in this important research domain. My side conversations during the workshop today make me optimistic on that score. We may not have answered all the questions that have been raised, but it seems to me we made substantial progress.

We will also follow up with you all to find avenues for disseminating today's proceedings and for continuing the dialogue with other stakeholders. There are a variety of stakeholder communities that we might wish to engage. Among these are federal funding agencies, interested IRBs, research ethics scholars, terrorism researchers, the Office of Human Research Protection, and the concerned public. Most of these stakeholder communities are international in scope. We have identified a preliminary list of communication vehicles that we might use to reach these communities.

It only remains for me to thank everybody for their participation and contributions. I particularly want to thank again the two institutions that helped pull this workshop together and provided funding to support it: the National Science Foundation and the National Institute of Justice. Both agencies stepped forward very, very quickly when we approached them with the idea of a workshop, and we deeply appreciate their leadership and support.

A. SHORT PROFILES OF WORKSHOP PARTICIPANTS

Mumtaz Ahmad, PhD, is a professor in Hampton University's Department of Political Science. He has been a senior research associate at MRM, Inc., a social science research and consulting firm focusing on contemporary South Asian and Middle Eastern developments, and an associate professor at the National Institute of Public Administration in Karachi, Pakistan. He is a member of the American Academy of Arts and Sciences' "Fundamentalism Project," and has been a research fellow at the Brookings Institution, a fellow of the American Institute of Pakistan Studies and the International Institute of Islamic Thought, a Fulbright professor in Bangladesh and Pakistan, and a visiting professor at International Islamic University, Kuala Lumpur.

Dr. Ahmad holds a PhD in political science from the University of Chicago, and other degrees from the American University of Beirut, Lebanon, and the University of Karachi, Pakistan. His main areas of academic interest are the comparative politics of South Asia and the Middle East, Islamic political thought and institutions, and the comparative politics of contemporary Islamic revivalism. Dr. Ahmad has published seven books and numerous papers and articles on the politics of Islamic resurgence and Islamic developments in South Asia and the Middle East.

Sandra H. Berry, MA, is a sociologist who has been managing and conducting research for 30 years. She is a senior behavioral scientist at the RAND Corporation and an adjunct member of the RAND Human Subjects Protection Committee. She directed the RAND Survey Research Group for 15 years and teaches research methods at the Pardee RAND Graduate School PhD program in public policy.

Ms. Berry managed instrument development and data collection for the Medical Outcomes Study, which developed many of the quality-of-life measures (such as the SF-36) that are most widely used today. She served as senior project director and directed the instrument design and data collection for the landmark HIV Cost and Services Utilization Study (HCSUS) that collected the first national probability sample survey data on HIV+ U.S. adults in care. She served as co-principal investigator on a recent National Cancer Institute-funded study on the cost of cancer treatment associated with clinical trial participation, a study that required enlisting the participation of 55 cancer treatment centers to identify and enroll 1,500 of their patients as treatment and control subjects. She is currently the principal investigator of a multiyear National Institutes of Health-funded study of bladder disease in women, and co-principal investigator of the Coordinating Center for a National Institute of Drug Abuse cooperative agreement on the diffusion of HIV among drug users and from drug users to the general population. She chairs the field committee for the Healthy Passages Study, a longitudinal panel survey starting with fifth graders. She has extensive experience working with clinical experts, measurement experts, statisticians, patient advocates, and survey researchers to conduct innovative and challenging studies. She has worked with hundreds of IRBs to obtain clearance to conduct complex studies involving sensitive populations and topics, as well as the collection of survey, biomedical, and other kinds of data.

Tora K. Bikson, PhD, has been a senior scientist in behavioral science research at the RAND Corporation from 1976 to the present. Dr. Bikson received BA (1962), MA (1964), and PhD (1969) degrees in philosophy from the University of Missouri-Columbia, and MA (1970) and PhD (1974)

degrees in psychology from the University of California, Los Angeles. She has chaired RAND's IRB since 1986 and has taught graduate-level courses on ethical issues in human subjects research at both UCLA and the Pardee RAND Graduate School. Additionally, she participated as an expert contributor to a National Institutes of Medicine workshop on privacy protection for human research participants. Recently, she completed serving as a member of a National Research Council (CNSTAT) panel on institutional review boards, surveys and social science research; the panel produced a report aimed at improving and streamlining the procedures for protecting the well-being, autonomy, and privacy of participants in social, behavioral, and economic sciences research. She was also appointed to the Subcommittee on Accreditation, Secretary's Advisory Committee on Human Research Participant Protection (DHHS).

Dr. Bikson's own research focuses on identifying and understanding the factors that explain the successful introduction of innovative digital technologies into varied user settings. To this end, her work applies and extends sociotechnical systems theory. At present, she is working on a project that applies this framework to understanding the properties of wireless mobile information and communication technologies that act as boosters and barriers to their broad implementation for enhancing the performance of diverse work teams. Previously, she led projects aimed at exploiting the capabilities of networked digital technologies for improving communication and decisionmaking while capturing and making widely available information that should be in the public domain (funded by varied U.S. state and federal government agencies, as well as the European Commission and a number of UN organizations). Dr. Bikson is also a scientific member of Data for Development, a UN Secretariat providing guidance on the implementation of information systems in developing countries.

Ricky N. Bluthenthal, PhD, is a senior social scientist at the RAND Corporation and a professor of policy analysis at the Pardee RAND Graduate School. He received his PhD in sociology from the University of California, Berkeley, in 1998. Dr. Bluthenthal is currently involved in several studies. He is the principal investigator on a National Institute on Drug Abuse-funded study comparing the effectiveness of different models of syringe exchange programs. In addition, he is co-leading a study on the impact of business improvement districts (BID) on adolescent violence and victimization in Los Angeles County that is funded by the Centers for Disease Control and Prevention (CDC). He is co-investigator on a number of other studies, including one that examines alcohol marketing and promotion and alcohol morbidity and mortality in California and Louisiana (funded by the National Institute on Alcohol Abuse and Alcoholism [NIAAA]) and one addressing the role of urban religious congregations in efforts to prevent HIV and provide care for those who are infected (funded by the National Institute of Child Health and Human Development). Dr. Bluthenthal recently concluded three studies: one on alcohol consumption patterns and consequences among low-income drinkers in South Los Angeles and one on community characteristics associated with alcohol treatment outcomes in Los Angeles County (both funded by NIAAA), and a CDC-funded study on the impact of a state law that permits local jurisdictions to legalize syringe and needle exchange programs in California.

Dr. Bluthenthal is an internationally known expert on HIV risk and infection among injection drug users; he has author and co-authored more than 50 articles in peer-reviewed scientific journals such as the *American Journal of Public Health*, *Social Science and Medicine*, *AIDS*, *Addiction*, and *Alcoholism: Clinical and Experimental Research*. Dr. Bluthenthal is also a professor in the Department of Sociology and

Director of the Urban Community Research Center at California State University, Dominguez Hills.

Michael R. Cunningham, PhD, received a BA at Carleton College and a PhD in psychology at the University of Minnesota. His current positions include professor in the Department of Communication, University of Louisville; Senior Industrial-Organizational Psychologist for Pearson Performance Solutions; and secretary-treasurer for the International Association for Relationship Research. He is a certified IRB professional and serves as vice chair for the Social/Behavioral/Educational Committee of the AAHRPP-accredited IRB of the University of Louisville. He is currently working on an NIH grant to study mate selection dynamics and is collaborating with a team of University of Louisville engineers in an effort to assess the nonverbal indicators of violent intention. His research has been featured in the *New York Times* and *Washington Post*, and he has been on "Dateline," Discovery programs, BBC programs, "Oprah," "CBS News," and other media.

C. Christine Fair, PhD, is a senior research associate in the United States Institute of Peace (USIP) Center for Conflict Analysis and Prevention, where she specializes in South Asian political and military affairs. Prior to joining USIP in April 2004, she was an associate political scientist at the RAND Corporation. Much of her research has concerned security competition between India and Pakistan, Pakistan's internal security, analyses of the causes of terrorism, and U.S. strategic relations with India and Pakistan. She conducted several analyses for the U.S. government, including an assessment of Indo-U.S. army-to-army relations; an examination of political Islam and its recent developments in Pakistan and Iran; and a comparative study of urban terrorism and state responses in Sri Lanka, Pakistan, and India.

Dr. Fair is a graduate of the University of Chicago, where she earned a master's from the Harris School of Public Policy and a PhD in South Asian languages and civilizations.

Jerrold D. Green, PhD, is Senior Advisor for Middle East/South Asia and acting director of the Middle East Development Council at the RAND Corporation. He has responsibility for broadly expanding the work of the Doha-based RAND-Qatar Policy Institute throughout the Middle East and South Asia. Prior to working at RAND in his current positions, he served as a partner and Executive Vice President for International Operations at Best Associates in Dallas, Texas, where he was also Executive Vice President for Academic Affairs of Whitney International University System. Before that, he was the director of International Programs and Development and of the Center for Middle East Public Policy at RAND. He has also served as a visiting professor in the School of International Relations at the University of Southern California and in the Department of Political Science at the University of California, Los Angeles. He has a BA (summa cum laude) from the University of Massachusetts/Boston, and an MA and PhD in political science from the University of Chicago, where he specialized in the politics of the Middle East. Dr. Green's career began at the University of Michigan, where he was a faculty member in the Department of Political Science and the Center for Near Eastern and North African Studies. He subsequently joined the University of Arizona, where he became a professor of political science and sociology as well as Director of the Center for Middle Eastern Studies.

Dr. Green uses Arabic, French, Hebrew, and Persian in his work and has lived and worked in Egypt, Iran, and Israel with support by such organizations as the Fulbright Foundation, Social Science Research Council, and American Research Center in Egypt. He travels frequently

to the Middle East and has lectured extensively on six continents. He has been a visiting fellow at the Chinese Academy of Social Science's West Asian Studies Center in Beijing, a visiting lecturer at the Havana-based Center for African and Middle East Studies (CEAMO), and a fellow at the Australian Defense College; and he has delivered papers at international conferences sponsored by the Iranian Institute of International Affairs in Tehran. At Best Associates, he was engaged in business activities in a range of countries, including Argentina, Brazil, China, Colombia, Costa Rica, Liberia, Mexico, Panama, and Philippines. He is a member of the Council on Foreign Relations and the International Institute of Strategic Studies (London), and has served on the advisory committee of the Asia Society of Southern California. Dr. Green is a Specialist Reserve Police Officer with the Los Angeles Police Department, where he advises the Anti-Terrorism Division on Middle East issues. He also serves as a member of the advisory board of Columbia University's Middle East Institute in New York, as well on the international advisory board of the Whitney International University System.

Dr. Green has written widely on Middle East themes focusing on American Middle East policy, the role of religion in the region, inter-Arab relations, Iranian politics, and the Arab-Israeli conflict. His work has appeared in such publications as *World Politics*, *Comparative Politics*, *Ethics and International Affairs*, *Survival*, *Middle East Insight*, *Politique Etrangere*, *The World Today*, *RAND Review*, *Harvard Journal of World Affairs*, and *Iranian Journal of International Relations*.

Patrick P. Gunn is a partner in the San Francisco office of the law firm of Cooley Godward Kronish LLP. His areas of practice include (among others) privacy, information security, and bioethics. Since 2002, he has been a member of the RAND Human Subjects Protection Committee, and he is a member of the American Bar Association's Committee on Electronic Privacy. Mr. Gunn recently co-authored (with others at RAND) an assessment of the Health Insurance Portability and Accountability Act (HIPAA) privacy rule on research access to data. Mr. Gunn received his JD in 1994 from Boston University.

Shireen T. Hunter, PhD, has been a visiting fellow at the Center for Muslim-Christian Understanding at Georgetown University since September 2005 and is an adjunct professor. She is also a Distinguished Scholar at the Center for Strategic and International Studies (CSIS) in Washington, DC, with which she has been associated since 1983, most recently as the director of the Islam Program. Additionally, Dr. Hunter is a consultant to the RAND Corporation and was an academic fellow at Carnegie Corporation from 2000 to 2002. From 1993 to 1997, Dr. Hunter was a visiting senior fellow at the Centre for European Policy Studies (CEPS) in Brussels, where she directed the CEPS Mediterranean Programme.

Dr. Hunter was educated at Teheran University (BA in international law), the London School of Economics (MSc in international relations), and the Institut Universitaire de Hautes Etudes Internationales in Geneva (PhD in international relations). Among her major publications relevant to the workshop are the following: *Islam and Human Rights: Advancing a US-Muslim Dialogue* (editor), forthcoming, CSIS Press, 2005; *Modernization, Democracy and Islam* (co-editor and contributor), Praeger, 2005; *Islam in Russia: The Politics of Identity and Security*, M. E. Sharpe, 2004; *Islam: Europe's Second Religion* (editor), Praeger, 2002; *The Future of Islam-West Relations: Clash of Civilizations or Peaceful Coexistence?* CSIS/Praeger, 1998; *Central Asia Since Independence*, CSIS/Praeger, 1996; *The Transcaucasus in Transition: Nation-Building and Conflict*, CSIS/Westview Press, 1994; *Iran After Khomeini*, Praeger, 1992; *Iran and*

the World: Continuity in a Revolutionary Decade, Indiana University Press, 1990; *The Politics of Islamic Revivalism* (editor), Indiana University Press, 1988; and *OPEC and the Third World: Politics of Aid*, Indiana University Press, 1984.

Dr. Hunter has testified before congressional committees and the Helsinki Commission and has traveled extensively in Europe, the Middle East, the former Soviet Union (Russia, Caucasus, Central Asia), China, and Japan. Dr. Hunter belongs to the Council on Foreign Relations. She is fluent in English, French, Persian, and Azeri Turkish, and has a working knowledge of Italian and Arabic.

Brian A. Jackson, PhD, is a physical scientist and associate director of the Homeland Security Program at RAND. He holds a BS in chemistry from Haverford College, a master's in science, technology, and public policy from George Washington University, and a PhD in chemistry from the California Institute of Technology. His research activities at RAND have focused on homeland security and terrorism preparedness. Recently, he co-lead a study examining how emergency responder safety and security needs can be better incorporated into incident management during responses to major disasters and large-scale terrorist attacks. He has also participated in studies addressing emergency responders' equipment and technology needs, adoption of technology by law enforcement organizations, critical infrastructure protection, and cybersecurity. Dr. Jackson has also been involved in and managed a variety of research efforts examining terrorist tactics and adaptive/learning behaviors.

Robert J. Levine, MD, is a professor of medicine and lecturer in pharmacology at the Yale University School of Medicine; director of the Law, Policy and Ethics Core of Yale University's Center for Interdisciplinary Research on AIDS; and co-chair of the Executive Committee of Yale University's Interdisciplinary Bioethics Center. He is a fellow of the Hastings Center, American College of Physicians, and American Association for the Advancement of Science; a member of the American Society for Clinical Investigation and American Society for Pharmacology and Experimental Therapeutics; a past president of the American Society of Law, Medicine & Ethics; a past chairman of the Connecticut Humanities Council; and a director of Public Responsibility in Medicine and Research. Dr. Levine also has served as chair of the IRB at the Yale-New Haven Medical Center (1969-2000), chief of the Section on Clinical Pharmacology at Yale University, chair of the Section on Medico-Legal Matters and R&D Administration of the American Society for Clinical Pharmacology and Therapeutics, associate editor of *Biochemical Pharmacology*, and editor of *Clinical Research*. He is the founding editor of *IRB: A Review of Human Subjects Research* (editor from 1979 to 2000 and current chair of editorial board) and has served as a consultant to several federal and international agencies involved in the development of policy for the protection of human subjects. Dr. Levine is the author of numerous publications and is preparing the third edition of his book *Ethics and Regulation of Clinical Research*. In the past 30 years, most of Dr. Levine's research, teaching, and publications have been in the field of medical ethics, with particular concentration on the ethics of research involving human subjects.

Recent human subjects protection activities include membership in the Council of International Organizations of Medical Sciences; chairperson of the Steering Committee for Revision of *International Ethical Guidelines for Biomedical Research*; chair of the World Medical Association's Working Group for Revision of the *Declaration of Helsinki*; consultant with the Joint United Nations Programme on HIV/AIDS, Project on Ethics in HIV Vaccine Trials (assigned to develop the Guidance Document for trials of preventive HIV vaccines); member of the U.S.

Department of Health and Human Services National Human Research Protections Advisory Committee; member of the National Institute of Mental Health's Human Subjects Research Council Workgroup; member of the Pan American Health Organization's International Bioethics Advisory Board; and member of the Ethics Committee of the U.S. Centers for Disease Control and Prevention.

Mary E. Losch, PhD, is an associate professor of psychology and the assistant director of the Center for Social and Behavioral Research at the University of Northern Iowa. Dr. Losch worked in the private sector as a research analyst for a national survey research firm before joining the University of Iowa as program director at the newly established Iowa Social Science Institute in 1988. In 1998, she became the assistant director of the university's Center for Social and Behavioral Research. She teaches psychology of gender differences and graduate research methods. In addition to her administrative and teaching duties, she has collaborated with more than 75 investigators in the planning and oversight of a host of survey and evaluation projects, including a number in the areas of public policy issues and health care. She has published research in survey methods, social science and health disciplines generally, and in maternal and child health. Her own funded research efforts have focused on the relationship between attitudes and infant feeding decisions, determinants of unintended pregnancy, and women's access to prenatal care.

Dr. Losch has been actively involved in the protection of human research participants for over 12 years. She served as vice-chair of the social science IRB at the University of Iowa from 1994 to 1998 and as chair of the University of Northern Iowa IRB from 2001 to 2006; she currently serves on the University of Northern Iowa IRB. Since 2002, she has been the chair of the American Association for Public Opinion Research (AAPOR) IRB Task Force. She is a member of the AAPOR Standards Committee.

Patricia Marshall, PhD, is a professor of bioethics and anthropology in the Department of Bioethics at the School of Medicine, Case Western Reserve University. Her research interests and publications focus on multiculturalism and the application of bioethics practices, research ethics, and informed consent in international settings, and on HIV prevention among injection drug users. Dr. Marshall's current research includes National Institutes of Health (NIH) funding to study informed consent to genetic epidemiological research in the U.S. and Nigeria. She is a member of the investigative team in Nigeria and Kenya for the development of a haplotype map for the human genome. She is also investigating informed consent to hepatitis B vaccine among injection drug users in the U.S.

Dr. Marshall is a past member of the executive boards of the American Society for Bioethics and Humanities, the Society for Medical Anthropology, and the Society for Bioethics Consultation. She also served on the advisory board for the Fogarty International Center at NIH. In 1999, Dr. Marshall served as a consultant to the President's National Bioethics Advisory Commission on its project examining ethical issues in international health research. In 2000, she was a consultant to the World Health Organization's Council for International Organization of Medical Societies on its revision of ethical guidelines for international research. Dr. Marshall was appointed to the National Academy of Sciences study panel on IRBs, surveys, and social science research in 2001. She has been on the editorial boards of *Medical Anthropology Quarterly*, *Journal of Immigrant Health*, and *Cambridge Quarterly of Healthcare Ethics*. In 1991, Dr. Marshall was awarded the

highly competitive Kellogg Foundation National Fellowship for innovative leadership.

Franklin G. Miller, PhD, is head of the Unit on Clinical Research, Department of Clinical Bioethics, National Institutes of Health, and Special Expert, National Institute of Mental Health Intramural Research Program. His principal current research interest is examination of ethical issues in clinical research, including placebo-controlled trials, placebo surgery, use of deception, psychiatric research, and the ways in which clinical research differs from medical care. He serves on the IRB of the Intramural Research Program of the National Institute of Mental Health and the ethics committee for the Clinical Center, National Institutes of Health. Dr. Miller co-leads a seminar for psychiatric research fellows on ethical issues in psychiatric research and coordinates the bioethics seminar for first-year fellows in the Department of Clinical Bioethics.

From 1990 through 1998, Dr. Miller was on the faculty of the University of Virginia, where he taught various courses in bioethics. Dr. Miller has written numerous published articles in medical and bioethics journals on the ethics of clinical research, ethical issues concerning death and dying, professional integrity, and pragmatism and bioethics. Dr. Miller is a fellow of the Hastings Center, a faculty affiliate at the Kennedy Institute of Ethics, and an associate professor of public health in the Division of Medical Ethics, Department of Public Health, Weill Medical College. He received his PhD in philosophy from Columbia University.

Ivor Pritchard, PhD, is a senior fellow in the Office for Human Research Protections (OHRP), U.S. Department of Health and Human Services. He came to OHRP from the Institute for Education Sciences at the U.S. Department of Education, where he was a senior research analyst. He joined the U.S. Department of Education in 1986. He has a PhD in philosophy from Boston University. His research interests are research ethics and federal policy, moral and civic education research and practice, and education policy.

Michael D. Rich is the executive vice president of the RAND Corporation. He is also co-chair, with Her Highness Sheikha Mozah Nasser Al-Misnad, of the board of overseers of the RAND-Qatar Policy Institute. Mr. Rich was formerly vice president in charge of RAND's National Security Research Division and director of the National Defense Research Institute. He has published numerous RAND reports on many topics, including the B-2 acquisition strategy and trends in weapons acquisition. Before becoming a vice president, he served at RAND as Deputy Vice President, Director of the Defense Resource Management Program. He chairs the admissions committee of the Pardee RAND Graduate School.

Mr. Rich is chairman of the board of both the International Institute for Strategic Studies-U.S. and the Communications Institute. He serves on the Santa Monica-UCLA Medical Center Board of Advisors, the board of directors of WISE Senior Services, the Blue Ribbon Committee of the WISE/Los Angeles Long-Term Care Ombudsman Program, the UCLA Foundation board of councillors, and the advisory board of the Everychild Foundation.

Mr. Rich received a BA from the University of California, Berkeley, and a JD from the University of California, Los Angeles.

James R. Sayer, PhD, is an assistant research scientist at the University of Michigan Transportation Research Institute (UMTRI), where he has conducted research since 1993. His research interests include the development of driver safety systems, understanding driver behavior, and driver vision with an emphasis on pedestrian safety. He has overseen the conduct of several large field operational tests of driver safety systems involving several hundred drivers and accumulating over 300,000 miles of naturalistic driving data. Dr. Sayer currently serves as project director for the Intelligent Vehicle-Based Safety Systems Field Operational Test (IVBSS FOT) and as chair of the University of Michigan's Behavioral Sciences IRB.

Eleanor Singer, PhD, is a research professor emerita at the Survey Research Center of the Institute for Social Research at the University of Michigan. Her research focuses on motivation for survey participation and has touched on many of the important issues in survey methodology, such as informed consent, incentives, interviewer effects, and nonresponse bias. Two of her major studies examined the role of privacy and confidentiality concerns as factors in response to the 1990 and 2000 decennial censuses. She was a member of the National Academies panel that produced *Private Lives and Public Policies: Confidentiality and Accessibility of Government Statistics*, and she chaired the panel whose report, *Expanding Access to Research Data*, appeared in 2006. She is most recently a co-author (with Robert M. Groves and others) of *Survey Methodology* and a co-editor (with Stanley Presser and others) of *Methods for Testing and Evaluating Survey Questionnaires*. She is the editor of a special issue of *Public Opinion Quarterly* on nonresponse bias, published in 2006. She is also a former president of the American Association for Public Opinion Research, as well as a recipient of its award for distinguished lifetime achievement.

Michael Traynor, a former member and now an alternate member of the RAND Human Subjects Protection Committee, is a former partner (1969-2004) and now senior counsel in the San Francisco office of Cooley Godward Kronish LLP. He is the president of the American Law Institute, which has begun work on a project on government access to personal information, and a fellow of the American Academy of Arts and Sciences, the American Academy of Appellate Lawyers, and the American Association for the Advancement of Science. He received the U.S. Court of Appeals for the Ninth Circuit's outstanding lawyer award in 2004.

B. LIST OF WORKSHOP PARTICIPANTS

Mumtaz Ahmad, PhD

Professor, Department of Political Science, Hampton University

Farhana Ali

Associate International Policy Analyst, RAND

Elliot Avidan

Presidential Management Fellow (Attorney-Advisor), Science and Technology Directorate, Department of Homeland Security

Edward Balkovich, PhD

Associate Director, Transportation, Space, and Technology Program of RAND Infrastructure, Safety, and Environment, and Senior Information Scientist, RAND

Peg (Marguerite) Barratt, PhD

Deputy Director, Clinical Research Policy Analysis and Coordination (CRpac), Office of Biotechnology Activities, Office of Science Policy, Office of the Director, National Institutes of Health

Sandra H. Berry, MA

Senior Behavioral Scientist; Professor, Pardee RAND Graduate School; and Member, Institutional Review Board, RAND

Tora K. Bikson, PhD

Senior Behavioral Scientist and Chair, Institutional Review Board, RAND

Ricky Bluthenthal, PhD

Senior Social Scientist and Member, Institutional Review Board, RAND; Professor of Sociology and Director of the Urban Community Research Center, California State University, Dominguez Hills

Kim Cragin, MPP

International Policy Analyst and Member, Institutional Review Board, RAND

Kellina Craig-Henderson, PhD

Program Director and Human Subjects Protections Officer, Social Psychology Program, Division of Behavioral and Cognitive Sciences, Directorate for Social, Behavioral and Economic Sciences (SBE), National Science Foundation

Cheryl Crawford-Watson, JD

Human Subjects Protection Officer, National Institute of Justice

Michael R. Cunningham, PhD

Professor of Psychology and Vice Chair, Social/Behavioral/Educational Institutional Review Board, Human Subjects Protection Program Office, University of Louisville

Patty Decot

Assistant Director, Regulatory Affairs and International Programs, Department of Defense

Rick Eden, PhD

Associate Director and Research Quality Assurance Coordinator, Military Logistics Program, Army Research Division; Associate Director of Research Quality Assurance; Senior Defense Research Analyst; and Member, Institutional Review Board, RAND

C. Christine Fair, PhD

Senior Research Associate, South Asia and Terrorism, Center for Conflict Analysis and Prevention, United States Institute of Peace

Thomas E. Feucht, PhD

Deputy Director for Research and Evaluation, National Institute of Justice

Jerrold D. Green, PhD

Senior Advisor, Middle East/South Asia, and Acting Director, Middle East Development Council, RAND

Audra Grant, PhD

Political Scientist, RAND

Stephen B. Greenbaum, PhD

Senior Analyst, BAI, Inc., Regulatory Compliance Office, Directorate of Science and Technology, Department of Homeland Security

Mary E. Groesch, PhD

Senior Advisor for Science Policy, Office of Biotechnology Activities, Office of Science Policy, Office of the Director, National Institutes of Health

Patrick P. Gunn, JD

Partner, Cooley Godward Kronish LLP; Member, Institutional Review Board, RAND

Felix Khin-Maung-Gyi, PharmD, MBA, CIP

Chief Executive Officer, Chesapeake Research Review, Inc.

Hilary G. Harding

Division of Social and Economic Sciences, National Science Foundation

Shireen T. Hunter, PhD

Visiting Fellow, Center for Muslim-Christian Understanding, and Adjunct Professor, Georgetown University

Brian A. Jackson, PhD

Physical Scientist; Associate Director, Homeland Security Program; and Member, Institutional Review Board, RAND

Ellen Laipson

President and CEO, Henry L. Stimson Center; former Vice Chair, National Intelligence Council

Robert J. Levine, MD

Professor of Medicine and Lecturer in Pharmacology, Yale University School of Medicine; Director of Law, Policy and Ethics Core, Yale University's Center for Interdisciplinary Research on AIDS; and Co-Chair of Executive Committee, Yale University's Interdisciplinary Bioethics Project

Mary E. Losch, PhD

Associate Professor, Department of Psychology, and Assistant Director, Center for Social and Behavioral Research, University of Northern Iowa

Patricia Marshall, PhD

Professor of Bioethics and Anthropology, Department of Bioethics, School of Medicine, Case Western Reserve University

Franklin G. Miller, PhD

Head, Unit on Clinical Research, Department of Clinical Bioethics, National Institutes of Health; Special Expert, National Institute of Mental Health Intramural Research Program

Andrew Morral, PhD

Director, RAND Safety and Justice Program, and Senior Behavioral Scientist, RAND

Ivor Pritchard, PhD

Senior Fellow, Office for Human Research Protections, U.S. Department of Health and Human Services

Michael D. Rich

Executive Vice President, RAND

Mark Rosen

Deputy Associate General Counsel, Directorate for Science and Technology, U.S. Department of Homeland Security

James R. Sayer, PhD

Assistant Research Scientist, Human Factors Division, University of Michigan Transportation Research Institute; and Chair, University of Michigan Behavioral Sciences Institutional Review Board

Eleanor Singer, PhD

Research Professor Emerita, Institute for Social Research, University of Michigan

Cindy Smith, PhD

Director, International Center, National Institute of Justice

Amber L. Story, PhD

Program Director, Social Psychology, Division of Behavioral and Cognitive Sciences, National Science Foundation

Michael Traynor, JD

Senior Counsel, Cooley Godward Kronish LLP; President, American Law Institute

Carol J. Weil, JD

Public Health Analyst, Office for Human Research Protections, U.S. Department of Health and Human Services

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