



A SOCIAL, BEHAVIORAL, & EDUCATIONAL RESEARCH (SBER) CASE STUDY OF TERRORISM RESEARCH

ASSESSING FACTORS THAT INFLUENCE A REFUGEE POPULATION'S ASSOCIATIONS WITH TERRORIST GROUPS

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OVERVIEW

The social, behavioral, and educational research (SBER) case studies provide education and guidance on how to identify and mitigate risks associated with SBER. These studies may be used by both IRB administrators and investigators when reviewing and designing research studies that involved SBER components.

Case studies follow a standard format that includes: 1) a fact pattern, 2) regulatory, cultural, and ethical issues, and 3) a risk/benefit analysis and risk management options. This format was created to allow for flexibility in applying the case studies.

By identifying common themes, linking them directly to federal regulations and guidance, and outlining risk mitigation options, the case studies can be used in a variety of ways, which include: 1) as an education tool for training individuals in human subjects research, 2) as a basis for developing reviewer checklists/worksheets, and 3) as a tool in designing research projects.

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CASE STUDY

SCENARIO/FACT PATTERN:

A sociologist has teamed up with a psychologist to conduct a long-term study of mental health and social group formation among Latin American refugees to the US. The research cohort will be comprised of adults who have fled violent conflicts in countries where known terror groups are believed to be actively recruiting.

A specific aim of this project is to determine what factors influence whether or not refugees are likely to accept, engage, or align themselves with terrorist groups in their post-conflict lives. The researchers will look at the impact of social, personal, experiential, and psychological factors, at both the group and individual level.

The study involves taking personal histories from subjects, asking them to recount traumatic encounters, and tell their refugee story. Subjects will be asked to complete standardized psychological evaluations at specific time points throughout the study and will be followed as they settle in new homes and communities. Subjects will also be invited to focus groups in convenient clusters post-resettlement and their social networks will be mapped through periodic in-person interviews.

An important aspect of the follow-up interviews will be to gauge changes in opinion regarding certain negative social groups (terrorists or terror-related groups). The research team will also assess personal anecdotes regarding interactions with agents of negative groups within their community as well as with the authorities.

Subjects will not be told the specific aims of the research, only that the purpose of the study is to learn the long-term social and psychological outcomes of refugee resettlement on post-conflict groups.

The researchers will recruit through flyers at refugee/immigration service agencies, local community centers, churches, grocery stores, etc.

This research is funded through a grant from the United Nations. Participants will receive a \$25 gift card to a local supermarket chain at 12-month intervals for the duration of the research (based on continued engagement in the study).

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DISCUSSION

Questions/Comments for the researcher:

- Will all materials be written/evaluated in English? Or available in translation?
- Are members of the research team trained in screening for depression and PTSD? Specifically among this cultural group?
- Who will facilitate the focus groups? Who will conduct the interviews?
- How often will psychological screenings occur? Who will evaluate and in how timely a manner?
- What are the risks of triggering episodes of anxiety or depression when asking subjects to re-live and recount traumatic experiences? What measures can be put in place to ameliorate this risk and/or to address observed instances of distress?
- Will participants be informed of the results of their psychological evaluations? Will follow-up care be offered if such need is indicated? What is the protocol for indications of suicidality?
- Could the fact that participants will be asked about terrorist groups be added to the consent form among a list of discussion topics as a way to avoid deception? If not, will participants be debriefed about the full intent of the study?
- How will the data be protected from being used in such a way that brings harm to participants?
- If subjects are loosely affiliated with and/or in proximity to terrorist groups who see them cooperating with researchers, might they be at risk of harm from these groups?

REGULATORY, CULTURAL, & ETHICAL ISSUES:

45 CFR 46.116

An IRB may approve a consent procedure which does not include, or which alters, some or all of the elements of informed consent set forth in this section, or waive the requirements to obtain informed consent provided the IRB finds and documents that:

- (1) The research involves no more than minimal risk to the subjects;
- (2) The waiver or alteration will not adversely affect the rights and welfare of the subjects;
- (3) The research could not practicably be carried out without the waiver or alteration; and
- (4) Whenever appropriate, the subjects will be provided with additional pertinent information after participation.

American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct

§ 8.07 Deception in Research

- (a) Psychologists do not conduct a study involving deception unless they have determined that the use of deceptive techniques is justified by the study's significant prospective scientific, educational, or applied value and that effective non-deceptive alternative procedures are not feasible.
- (b) Psychologists do not deceive prospective participants about research that is reasonably expected to cause physical pain or severe emotional distress.

- (c) Psychologists explain any deception that is an integral feature of the design and conduct of an experiment to participants as early as is feasible, preferably at the conclusion of their participation, but no later than at the conclusion of the data collection, and permit participants to withdraw their data.

§ 8.08 Debriefing

- (a) Psychologists provide a prompt opportunity for participants to obtain appropriate information about the nature, results, and conclusions of the research, and they take reasonable steps to correct any misconceptions that participants may have of which the psychologists are aware.
- (b) If scientific or humane values justify delaying or withholding this information, psychologists take reasonable measures to reduce the risk of harm.
- (c) When psychologists become aware that research procedures have harmed a participant, they take reasonable steps to minimize the harm.

Certificates of Confidentiality are issued by the National Institutes of Health (NIH) to protect identifiable research information from forced disclosure. They allow the investigator and others who have access to research records to refuse to disclose identifying information on research participants in any civil, criminal, administrative, legislative, or other proceeding, whether at the federal, state, or local level. By protecting researchers and institutions from being compelled to disclose information that would identify research subjects, Certificates of Confidentiality help achieve the research objectives and promote participation in studies by helping assure confidentiality and privacy to participants.

Questions for the IRB:

- Should individuals with signs of severe depression/PTSD be excluded from participation?
- What are the confidentiality risks? What risks are subjects exposing themselves to by opening up to the researchers?
 - Can a Certificate of Confidentiality be obtained to protect against compelled disclosure?
 - Does the use of focus groups introduce too much risk to individual privacy or safety?
- What are the reputational risks to the community?
- Does the partial disclosure of the research aims qualify as deception?
 - Does the research meet the criteria for a waiver of informed consent?
 - Is a waiver appropriate in this instance?
 - Would the information being withheld affect subjects' willingness to participate?
- Might some of the participants become incarcerated during their participation? If so, Subpart C protections would need to be invoked.
- Is coercion a factor here?
 - Does the compensation offered qualify as coercion or undue influence?
 - Might a refugee population feel compelled to cooperate with the host country and its researchers out of intense gratitude or a sense of obligation?

RESOLUTION & DISCUSSIONS:

Risk/Benefit Analysis:

- Is it ethical not to fully disclose the purpose of the research to subjects?
- What are the risks to the subject population as a group?

- What are the risks to individual subjects within family/community groups?
- Is there an obligation to provide psychological counseling or other treatment/services to this research population?
- How can potentially coercive aspects of the study design/compensation be addressed?
- What benefits are there, if any to participants? Can a benefit be built in to the study somehow?

Mitigation/Management of Risks:

- Engage a community member in the planning and/or conduct of the research.
- Utilize a bi-directional consent procedure or other method to help ensure participants understand that their participation in the research is voluntary, and that they clearly understand any risks and benefits before agreeing to participate.
- Ensure that data is coded such that accidental disclosure will not place participants at risk of harm, embarrassment, threat to social standing, liberty, employability, etc.
- Obtain a Certificate of Confidentiality to protect the data from compelled disclosure.
- Ensure that interviewers and focus group leaders are trained to detect anxiety or depression reaching levels requiring evaluation and/or treatment, and have a plan in place (counseling, referral, etc.) to address such situations if they arise.

Alternate Details:

- The study adds an intervention designed to aid resettlement and engages participants in psychologically advantageous activities, such as gainful employment at a local charity.
- The investigator receives significant additional funding but in order to receive it they have to create a documentary film about the participants and their settlement in the area. Half of the participants have to agree to allow camera crews and interviews in their homes and workplaces.

Other Events:

- The investigator discovers that the primary computer where they enter study data has been tampered with and a key-logging device installed. It is unclear who did it, when it was done, and what study data may have been siphoned off prior to encryption of the data.
- The investigator sees a news alert on television, which mentions a study participant who was just interviewed two days prior, who is suspected of being involved in a terror plot and is currently the subject of a manhunt in the vicinity. The news alert warns that the alleged attack remains an imminent possibility and that anyone who has information should contact authorities.
- A study participant tells you the only reason they are participating in the study is to obtain a visa. What ethical dilemma does the researcher face?

REFERENCE(S)

45CFR46.116, General requirements for informed consent:

<http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.116>

45CFR46, Subpart C, Additional Protections Pertaining to Biomedical and Behavioral Research Involving Prisoners as Subjects:

<http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#subpartc>

NIH Certificates of Confidentiality Kiosk:

<http://grants2.nih.gov/grants/policy/coc/>

HHS's IRB Guidebook, Chapter 3 (see section on "Deception and Incomplete Disclosure"):

http://www.hhs.gov/ohrp/archive/irb/irb_chapter3.htm#e2

Harvard Catalyst Community Engaged Research (CEnR) 101:

http://catalyst.harvard.edu/pdf/regulatory/CEnR_Webpage_101_Presentation.pdf

An Annotated Bibliography on Cultural Competence in Research

<http://catalyst.harvard.edu/pdf/diversity/CCR-annotated-bibliography-10-12-10ver2-FINAL.pdf>