

III. Ethical Considerations in Surveys

Introduction

These guidelines focus on ethical concerns with regard to human subject research. Human subject research is “a systematic investigation...designed to develop or contribute to generalizable knowledge” with “a living individual about whom an investigator ...conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information” [32]. Although this definition is drawn from a U.S. source, these elements are widely accepted on an international level as definitive of human subject research.

There is no lack of source material on ethical guidelines for human subject research (see [28], for a recent review). For example, the Declaration of Helsinki [39], originally adopted by the World Medical Assembly in 1964 and most recently revised in 2004, defines the ethical responsibilities of physicians to their patients and to the subjects of biomedical research. The principles in the Declaration of Helsinki have been extended to include social science human subject research. Professional organizations, such as the American Association for Public Opinion Research (AAPOR), the World Association for Public Opinion Research (WAPOR), and the European Society for Market Research (ESOMAR), have also developed ethical codes and guidelines for their members.

In addition to these self-regulatory measures, many countries have legislation in place that affects human subject research (e.g., data protection legislation and requirements for [ethics review committees](#)). Whether working in familiar surroundings or in new contexts, researchers must make sure they are informed about, and comply with, relevant legislation. When working in other countries or locations, researchers may need to comply not only with local requirements, pertaining to the place where they are collecting data, but also with their own country's requirements.

As might be expected, there is considerable overlap in the principles contained in the various ethics codes, professional association guidelines, and government regulations. This section attempts to consolidate their common elements, as well as to highlight concerns particular to cross-cultural studies. It is important to recognize that researchers may confront tradeoffs between ethical principles. For example, maintaining sensitivity to cultural differences by having other family members present during the interview may conflict with ethical obligations to protect confidentiality and to minimize error in respondent reporting. For further information on the ethical principles presented here, please see the listing of ethics codes, declarations, guidelines, and other resources for researchers conducting cross-cultural human subject research that is provided in the [References](#) section.

Guidelines

Goal: To ensure that participating research teams follow widely accepted standards for ethical and scientific conduct from the design of the study through implementation and reporting.

- 1. Protect the rights of free will, privacy, [confidentiality](#) and well-being of research participants, and minimize the burden of study participation to the greatest extent possible.**

Rationale

The social researcher's responsibility to protect the human rights of study participants is universally prescribed in ethics codes and guidelines, such as the Declaration of Helsinki [39], and monitored by ethics review committees. In addition, the collection of accurate data depends upon the cooperation of respondents: individuals are more likely to agree to participate in a study and to give complete, accurate information if they feel that they can trust the research organization. Finally, a positive experience with regard to the research interaction encourages participation in future research.

Procedural steps

- Avoid undue intrusion.
 - Use existing data whenever possible; do not collect new data unnecessarily.
 - Encourage participation in the research study only in ways that avoid personal harassment. This may include limiting the number of times that an interviewer visits a household to attempt to obtain sample member participation.
 - Be respectful and honest with survey respondents (e.g., be honest about the length of the interview).
 - Adapt the study protocol as needed to protect the rights of participants from vulnerable populations, such as children, pregnant women, the elderly, prisoners, the mentally impaired, and members of economically and otherwise disadvantaged or pressured groups, by using special [consent](#) procedures (e.g., obtaining consent from a parent or family member) or other appropriate study modifications.
 - Keep the survey burden as low as possible.
 - Ensure that each question in the survey addresses a specific measurement goal.
 - Balance the need for information against the effort that is required to complete additional questions in a survey instrument.

- Ask questions in a way that is easy for respondents to answer (see [Questionnaire Design](#) for guidance).
- If sensitive or otherwise demanding information is required, devise ways to help respondents provide it without undue burden. For example, part of the interview could be self-administered if there is concern that respondents might be uncomfortable providing responses to an interviewer.
- Consider carefully whether the information requested may be seen as private, threatening or embarrassing by the population interviewed, and implement techniques to minimize respondent unease. In mental health studies, provisions are often made to provide suitable support for respondents or interviewers who experience emotional distress (for example, some form of emotional or psychological support service). In addition, interviewers in these studies complete specialized training on how to handle interviewing on sensitive topics. Also, recognize that cultures differ in what topics can be discussed and how they can be discussed.
- If [proxy interviews](#) are used, take care not to affect the relationship between the proxy and the target respondent. If the target respondent has indicated any unwillingness to provide information, do not gather the information from the proxy instead.
- Obtain voluntary [informed consent](#). In implementing the consent process, provide the following information and adhere to the following principles.
 - Information to provide:
 - A clear identification of the research firm affiliation
 - A brief description of the survey
 - A description of the role of the respondent in the study
 - An explanation of how the respondent was selected for the study
 - A clear indication that participation is voluntary and that the information provided will be held [confidential](#) to the extent allowed by law (unless there are special circumstances in which respondents have waived confidentiality)
 - A clear description of any benefits and risks associated with participation
 - Contact information for a study investigator or other research team member whom respondents can contact (provided or available on request)
 - If the study has been reviewed by an [ethics review board](#), contact information for a review board member whom respondents can contact (provided or available on request)

- Principles to follow:
 - Do not use coercion in any form. Whether a practice is defined as coercive or not may vary by culture, population, and study. Large monetary payments that are given to participants may be considered coercive in some studies.
 - Respect the right of individuals to refuse to be interviewed or to terminate an interview in progress.
 - Obtain and document consent. Whether consent is obtained in oral or written form depends on a number of factors, including the mode of data collection, the type of information requested, cultural norms, and government laws and regulations. In mail surveys, [consent](#) may be implied (that is, not explicitly obtained in oral or written form) if the respondent chooses to fill out the questionnaire and mail it back.
 - Obtain informed consent from a parent or responsible adult before interviewing children or young people.
- Protect rights to privacy of study participants. This should include a careful review of government privacy laws and regulations, which vary on the type of data and persons that are covered and the definition of an “identifiable” case [\[7\]](#).
 - Obtain the permission of respondents before using electronic equipment (taping, recording, photographing) and one-way viewing rooms.
 - To the extent allowed by law or regulations, train staff to keep confidential both identifying material (e.g., respondent names, addresses, and phone numbers) and all information given by respondents.
 - Require staff to sign a pledge of confidentiality or to provide assurance in some form that they will maintain confidentiality.
 - Store documents with personal information (e.g., [coversheets](#)) separately from survey data and, if applicable, questionnaires.
 - Keep secure and confidential any data source which links survey responses to identifiable respondents.
 - Limit access to confidential data to project staff members who have pledged to maintain confidentiality and have been trained on appropriate use of study data.
 - Use information gained through the research activity for study-related purposes only.
 - Adhere to government laws and regulations on storage and retention of survey data.
 - If appropriate, obtain a certificate of confidentiality or other legal document for protection from being required to release the identity of a respondent in a legal proceeding.
 - Report any breach of confidentiality according to ethics committee policies and government regulations.

Lessons learned

- The manner in which research is conducted can shape a community's views positively or negatively on research topics, research institutions, and assumed or actual funders of the research.
 - Project Camelot was a U.S. Department of Defense research study designed to evaluate the Chilean masses' potential for revolutionary political action, and to determine the most effective means of counteracting that action. Participating Chilean social scientists were not told that the U.S. Department of Defense was funding the project and would ultimately receive the data. When Chilean researchers learned the facts, the study was cancelled. The image of the U.S. funders and U.S. research suffered greatly [5].
 - In 1974, psychologist Stanley Milgram conducted a study at Yale University. Test subjects were told that they were part of an experiment on punishment and memory, and that they would act as "teachers." The "teacher" subjects were instructed by the experimenter to administer an electric shock to a "learner" if the latter failed to perform as required. Unbeknownst to the subject, the "learner" was one of the research team and deliberately gave many incorrect answers. The subject was ordered by the experimenter to give higher and higher intensity shocks to correct this poor performance. Although in fact no shocks were administered, the majority of subjects believed that they were actually administering electric shocks to the "learner." As a result, subjects experienced distress and tension during the experiment; several even had seizures. The unethical Milgram study was highly criticized after the event, and became a landmark in the effort to develop ethical guidelines for social science research [28]. However, while attacked from an ethics perspective, the Milgram study nevertheless made a major contribution to research on obedience in social psychology. This study illustrates how it can be a challenge to balance the goals of science and ethical considerations [21].
- It is important not to create false expectations and to correct those that may arise. For example, respondents may mistakenly assume that researchers/ interviewers have access to important information or can use the data collected to directly leverage change or provide benefits.
 - In a study in India, dishonest interviewers were believed when they told respondents that survey participation would result in new schools, roads, and an electricity supply [5].
- Proper, ethical conduct may be simple and straightforward in one location but require multiple steps in another.

- In Western cultures, simple parental consent may suffice when studying minors. In Mali, on the other hand, a medical research team that wanted to study children under 9 years of age who had been exposed to malaria first discussed the study with a group of village elders. Next, they convened focus group discussions with the heads of extended families. Then they held similar discussions with mothers whose children might become part of the malaria study. Finally, they obtained the consent of the individual families involved [13].

2. Maintain sensitivity to cultural and social differences.

Rationale

Designing study protocols that are sensitive to cultural traditions and norms is vital to building trust and gaining cooperation. Being respectful of cultural norms and customs also leaves individual participants with a positive impression of the research community. Beyond the individual level, it may forestall negative political and social consequences. Finally, participation in social science and health studies may promote awareness of research issues in the community.

Procedural steps

- Include minority groups and native or aboriginal peoples in the sample, when appropriate.
- Approach study participants in accordance with cultural traditions and norms (e.g., through the head of the family or a local leader).
- Involve other individuals or groups in the [consent](#) decision-making as appropriate (e.g., family members or community leaders).
- Observe local customs in planning for and conducting the interview (e.g., giving advance notice before arriving, removing one's shoes inside the house, partaking of refreshment, sending a thank-you note).
- Be flexible when implementing consent procedures (e.g., accepting oral consent in place of a written form, if literacy is an issue).
- Present study materials in a form that can be understood by the respondent (e.g., in the respondent's native language or orally rather than written if literacy is an issue). Avoid the use of technical language or jargon.

- Observe cultural norms when assigning interviewers to sample cases (e.g., matching female interviewers with female respondents, if matching is culturally appropriate).
- Consider cultural traditions and norms when deciding whether to offer respondent incentives and determining what type of incentives would be most appropriate.

Lessons learned

- As with other aspects of research, we cannot assume that “one size fits all” when implementing a study protocol with regard to ethics.
 - There may be different levels of requirements for privacy in different cultures.
 - In a study involving 11-year-old boys in India, in-home interviews tended to include relatives and neighbors. At times the interviewers had to use considerable tact to discourage members of the audience from interjecting their own answers to the questions being asked [5].
 - In some cultures, it may be necessary to gain approval from authority figures within a community (gatekeepers).
 - In a fertility study in Guatemala, interviewers were effectively barred from a rural municipality by the single act of a local priest. The priest warned his parishioners against the “red urbanites who would prevent women from having children,” as he described the researchers [35].
 - Respondents in some cultures may be reluctant to provide [written consent](#).
 - Researchers in Mali found that documenting the consent process with a signed paper was a challenge. At first, villagers were opposed to signing any document, because they strongly believed that their word should be sufficient. In addition, participants found the legal language difficult to understand. It took very careful explanation and patience to overcome this resistance [13].

3. Observe professional standards for managing and conducting scientifically-rigorous research at all stages of the study.

Rationale

Researchers have a responsibility not only to protect participants but also to adhere to ethical management practices and to conduct research that meets the scientific standards of their field. The reader is referred here to other chapters which provide useful guidance on meeting scientific standards for the design, implementation, analysis, and documentation of

cross-cultural surveys. See all chapters, as listed in the Procedural Steps below.

Procedural steps

- Clearly and objectively lay out the study's major research questions.
- Ensure that a survey is the most appropriate method to use to answer the research questions.
- Adhere to ethical business practices in bidding, contract development, and project management. These include honestly describing the organization's expertise in a bid, disclosing if a survey project is being carried out on behalf of multiple clients, meeting contractual obligations, and maintaining good relations between the coordinating center and research organizations involved in the study. For additional detail, see [Tenders, Bids, and Contracts](#).
- Fulfill ethical responsibilities to employees, e.g., fair hiring practices, an objective evaluation process, and a commitment to employee safety. See Guideline 3 of the [Data Collection](#) chapter for guidance on the survey organization's responsibility to protect the well-being and safety of its interviewing staff.
- Train staff on the importance of ethics and scientific rigor in research involving human subjects (see [other Guidelines](#) in this chapter).
- Equip staff involved in design, data collection, and analysis with appropriate skills to perform scientifically rigorous research.
- Follow best practices in survey design, data collection, and post-survey processing as described in the following chapters:
 - [Study, Organizational, and Operational Structure](#)
 - [Sample Design](#)
 - [Questionnaire Design](#)
 - [Translation](#)
 - [Adaptation](#)
 - [Survey Instrument Design](#)
 - [Pretesting](#)
 - [Interviewer Recruitment, Selection, and Training](#)
 - [Data Collection](#)
 - [Harmonization of Survey and Statistical Data](#)
 - [Data Processing and Statistical Adjustment](#)
 - [Dissemination of Survey and Statistical Data](#)
- Employ appropriate tools and methods of analysis.

- Make interpretations of research results that are consistent with the data.
- Be clear and honest about how much confidence can be placed in the conclusions drawn from the data.
- Report research findings, even if they are not in line with the researcher's hypothesis.
- Monitor possible ethics violations such as interviewer falsification or plagiarism during the design, data collection, and analysis phases.
- Consider both cost and error implications of decisions that are made in the design, implementation, and analysis phases of the research study.
- Conduct methodological studies to inform understanding of the cost and quality implications of survey design decisions for the benefit of future studies and the scientific research community.

4. Report research findings and methods.

Rationale

Professional social science organizations generally agree that their members should report findings to benefit the widest possible community. From this it follows that data collection agencies should provide full information to allow readers and data users to assess both methodology and results. Dissemination of results and research reports also increases public confidence and alerts potential users to limits of accuracy and reliability, avoiding misinterpretation of findings. In addition, sharing documentation on study methods can assist other researchers in making informed choices about research design and implementation in future studies. While providing access to study data and methods is advantageous for the reasons outlined here, researchers must also assess the risk of a breach of confidentiality and address this concern when preparing data for dissemination.

Procedural steps

- Report findings as completely, widely and objectively as possible, while also protecting participants' [confidentiality](#).
- Make available as much of the study's methods, results, and raw data as possible, within the bounds of protecting participants' confidentiality,

in order to permit others to evaluate the study and to replicate the findings.

- Evaluate the risk of a breach of confidentiality and implement appropriate techniques to protect the confidentiality of the data (see Guidelines 2 and 3 of the [Dissemination of Survey and Statistical Data](#) chapter for a detailed discussion of these methods).
- Provide a summary report of the study methodology and findings, including:
 - The purpose of the study
 - Who sponsored the survey and who conducted it
 - A copy of ethics review committee approval (if appropriate)
 - A copy of the informed consent form or script
 - A definition of the population under study and a description of the sampling frame
 - A description of the sampling and survey designs
 - Sample sizes and, where appropriate, eligibility criteria, screening procedures, and response rates. A summary of the disposition of sample cases should be included, in order for the user to calculate a response rate should one not be included in the report or a different one desired.
 - Method, location, and dates of data collection
 - A copy of questionnaire, interviewer instructions, and any visual aids used in the interview
 - A detailed description of results that are based on anything less than the total sample, including the size of the sample and inclusion/exclusion criteria
 - A full description of the weighting (if appropriate) and estimation procedures used for all results that are reported
 - The major findings
 - A description of the precision of the findings, including estimates of sampling error
- Provide a copy of the findings to all researchers and organizations that were involved in the study.
- Provide a copy of the dataset(s) and documentation to international data repositories such as the Interuniversity Consortium for Political and Social Science Research (ICPSR), Council for European Social Science Data Archive (CESSDA), UK Data Archive (UKDA), or the South African Data Archive (SADA).
- Adhere to government laws and agreements that address disclosure of survey data both within and across borders. These laws may require that some types of information that respondents provide be disclosed

to the appropriate authorities. As appropriate, make clear to respondents the extent to which confidentiality is protected.

- If an error is discovered after publication of the results, make an effort to correct the error using an erratum document that describes the error and its impact on study results, and provide an additional variable or other means along with appropriate documentation for analysts to identify the corrected value(s).

Lessons learned

- There are useful examples of efforts to fully document study methods and provide survey data from cross-cultural studies to a wide community of users. In part or whole, their approach and templates can serve as models for other studies.
 - The European Social Survey website provides comprehensive information on study methodology and access to data for any registered user. Registration is free and easy to complete.
 - The World Mental Health Survey Initiative used a standardized web-based survey instrument to collect information on study methodology from participating countries.

5. Document materials and procedures related to the ethical conduct of the study and ethics committee reviews.

Rationale

In research that involves human subjects, it is critical to maintain documentation of materials that were used to inform potential participants about study participation and subsequently record [consent](#), in case there is ever a question of ethics violations or a request for additional information from an [ethics review committee](#). In addition, documentation of all survey procedures including those related to the ethical conduct of the study is a key element of high-quality scientific research.

Procedural steps

- Maintain a copy of the following documents:
 - Scripts, letters, [fact sheets](#), and any other materials provided to respondents to give them information they need to make an informed decision about participation
 - Consent form templates and/or protocols
 - [Confidentiality](#) procedures and protocols
 - [Pledge\(s\) of confidentiality](#) completed by staff
 - Records of completion of any specialized staff training on ethics

- Ethics review committee submissions (e.g., original submissions, requests for modifications to study protocol, etc.)
- Ethics review committee correspondence (e.g., letters of approval)
- Provide a copy of the following documents to any central coordinating organization:
 - Translated consent form templates and/or protocols
 - Ethics review committee submissions (e.g., original submissions, requests for modifications to study protocol, etc.)
 - Ethics review committee correspondence (e.g., letters of approval)

Glossary

Confidential, confidentiality	Securing the identity of and any information provided by the respondent to ensure to the greatest extent possible that public identification of an individual participating in the study and/or his or her individual responses does not occur.
Consent, informed consent, written consent, oral consent	A process by which a sample member voluntarily confirms his or her willingness to participate in a study, after having been informed of all aspects of the study that are relevant to the sample member's decision to participate. Informed consent can be obtained with a written consent form or orally (or implied if the respondent returns a mail survey), depending on the study protocol.
Coversheet	Electronic or printed materials associated with each case that identify information about the case, e.g., the sample address, the unique identification number associated with a case, and the interviewer to whom a case is assigned. The coversheet often also contains an introduction to the study, instructions on how to screen sample members and randomly select the respondent, and space to record the date, time, outcome, and notes for every attempt.
Ethics review committee or human subjects review board	A group or committee that is given the responsibility by an institution to review that institution's research projects involving human subjects. The primary purpose of the review is to assure the protection of the safety, rights, and welfare of the human subjects.
Fact sheet	A sheet, pamphlet, or brochure that provides important information about the study to assist respondents in making an informed decision about participation. Elements of a fact sheet may include the following: the purpose of the study, sponsorship, uses of the data, role of the respondent, sample selection procedures, benefits and risks of participation, and confidentiality .
Pledge of confidentiality	An agreement (typically in written form) to maintain the confidentiality of survey data that is signed by persons involved in data collection, post-survey processing or analysis.
Proxy interview	An interview with anyone other than the person about whom information is being sought (e.g., parent, spouse).

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