III. Ethical Considerations in Surveys

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Introduction

These guidelines focus on ethical concerns with regard to cross-cultural surveys as human subject research. The World Health Organization defines human subject research as the "...systematic collection or analysis of data...in which human beings (i) are exposed to manipulation, intervention, observation, or other interaction with investigators either directly or through alteration of their environment, or (ii) become individually identifiable through investigators’ collection, preparation, or use of biological material or medical or other records" [25].

There is no lack of source material on ethical guidelines for human subject research (see [22], for a recent review). For example, the Declaration of Helsinki [26], originally adopted by the World Medical Association 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), the European Society for Market Research (ESOMAR), and the International Statistical Institute (ISI), 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 boards). 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. A compilation of laws, regulations and guidelines from 96 countries has been prepared by the US Office for Human Research Protections and can be found on the Internet [24].

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, including cross-national variation in laws and regulations relevant to human subject research and cultural differences that affect the conduct of ethical research across cultures. It is important to recognize that researchers may confront tradeoffs between ethical
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Figure 1. The Survey Lifecycle

Guidelines

**Goal**: To ensure that participating research teams follow widely accepted standards for ethical, professional, and scientific conduct from the design of the study through implementation, dissemination, 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 [26], and monitored by ethics review boards (in some countries). 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, any benefits being offered, and the purpose of the study).
  - 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 groups, by using special consent procedures (e.g., obtaining consent from a parent or family member) or other appropriate study modifications.
  - Keep respondent burden as low as possible [5].
    - Ensure that each question in the survey maps to a specific research goal.
    - Balance the need for information against the effort that is required to complete additional questions.
    - Ask questions in a way that is easy for respondents to answer (see [6], [7], and [9] 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.
    - Determine whether asking respondents to provide information on specific topics could bring harm or political repercussions to them and do not include questions on those topics.

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Consider carefully whether the requested information may be seen as private, threatening or embarrassing by the population interviewed, and implement techniques to minimize 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.

- Consider the sensitivity of the requested information and assess whether a person other than the respondent would be able to provide the information in order to determine whether a proxy interview may be appropriate.
- If proxy interviews are used, create and adhere to a clearly defined set of rules defining who can serve as a proxy respondent.
- If the target respondent has indicated any unwillingness to provide information, do not gather the information from the proxy instead. Take care not to affect the relationship between the proxy and the target respondent.

- Obtain voluntary informed consent [10]. In implementing the consent process, provide the following information and adhere to the following principles.
  - Information to provide (in oral or written form, as appropriate):
    - 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, including the expected duration of the respondent’s participation.
    - 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). It is important to note that in nearly all instances, respondents who are providing data to an interviewer cannot and should not be assured anonymity. In only rare instances generally involving self-administered surveys can respondents be promised that their data will be kept anonymous, that is, without any name or identifier ever associated with their response.
    - 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).
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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. 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 rights of individuals to refuse to be interviewed, to refuse part of the interview, and to terminate an interview in progress. Whether or not follow-up with individuals who initially refuse the survey request is appropriate may vary by culture, population, and study.
- Respect the right of individuals to refuse to answer any question in the interview.
- Obtain and document consent. Whether consent is obtained in oral or written form depends on a number of factors, including government laws and regulations, risk of harm for respondents revealing sensitive information, the mode of data collection, the type of information requested, and cultural norms. 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.
- Avoid making inaccurate or overly restrictive statements (e.g., the data will only be shared with the research team) if the data will be archived and shared with the research community [10].
  - Consent information should be conveyed in a format that is easy for respondents to understand. Written formats that may be appropriate include a document with narrative text, a list of Frequently Asked Questions (FAQs), and a brochure format. Samples of these formats can be found in Appendix A and [3].

- Protect rights to privacy of study participants. This should include a careful review of government privacy laws and regulations, which could vary on the type of data and persons that are covered and the definition of an “identifiable” case [4].
  - Obtain the permission of respondents before using electronic equipment (e.g., 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 (see Appendix B for an example of a pledge of confidentiality). It is important to note that preserving confidentiality takes on even greater significance if local interviewers are working in areas where they may be acquainted with sample members prior to the interview request.

- Separate **personally identifiable information (PII)** from the respondent data. PII minimally includes name, address, phone number and identification number(s) (including an identification number assigned by a government agency such as a social security number in the United States or a driver’s license number), but may include other information including biometric data.

- 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, retention, and dissemination of survey data.

- If appropriate, obtain a certificate of confidentiality or other legal document for protection from the requirement to release the identity of a respondent in a legal proceeding. Make clear to respondents the extent to which confidentiality is protected.

- If disclosing survey data to outside parties, require all subcontractors, consultants, and third parties to enter into an agreement to maintain respondent confidentiality. This agreement should include an explicit statement that the outside party cannot use contact information or any other information to recontact the respondent for any reason not directly related to the study (e.g., data cannot be used to approach respondents for a different study or for marketing purposes).

- Report any breach of confidentiality according to [ethics review board](#) 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 [2].

- In 1974, psychologist Stanley Milgram conducted a study at Yale University [17]. 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 [10]. However, while attacked from an ethics perspective, the Milgram study 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.

- It is important to be truthful in describing the purpose of the study and the intended uses of study data.
  - 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 [2].
  - In the 1994 International Adult Literacy Survey (IALS), respondents in one country were told that they were participating in a pretest when in fact they were unknowingly providing data for the main study itself [12].

- Cross-cultural studies may involve the use of field research methods. Participant observation is a field research technique that involves becoming a trusted, yet temporary, participant in the community under study [23]. This temporary membership may lead to feelings of abandonment on the part of the participants. Possible solutions include maintaining honesty with the participants and community as well as providing the researched community with a final copy of the research results in the community’s native language [20].
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 [8].

- Regarding respondent burden and privacy, the duration and location of interviews has varied among established cross-cultural studies. Round 4 of the Afrobarometer Survey lasts approximately one hour and is usually administered in the respondent’s home, although other locations are sometimes used [27]. Similarly, the Asian Barometer interview is completed in the respondent's home or workplace [28]. The basic face-to-face portion of the European Social Survey (ESS), Round 5, takes approximately 60 minutes and is conducted in the respondent's home [29]. The International Social Survey Programme (ISSP) questionnaire consists of 60 questions, not including demographics, and takes approximately 15 minutes to complete [30]. The length of the Living Standard Measurement Study Survey (LSMS) varies across participating countries, depending upon the number of modules administered [15]. The Survey of Health, Ageing and Retirement in Europe (SHARE) is completed in the respondent's home; it takes approximately 80 minutes to administer to a single-family household, and 120 minutes to administer to a multi-family household [31]. The average length of the interview for the World Mental Health Survey varies across participating countries, ranging from 49 minutes as a computer-assisted interview in Italy to 210 minutes as a paper-and-pencil interview in South Africa; most interviews are administered in the respondent’s home, but in some countries, they are conducted in the respondent’s place of employment, group quarters, cafes, libraries, or the office of the research organization [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**

- Do not exclude minority groups, native populations, or aboriginal peoples in the sample, unless it is appropriate to do so.

- Identify ethnic or religious power structures in the areas in which data collection will occur and approach study participants in accordance with the cultural traditions and norms of the ethnic or religious groups (e.g., through the head of the family or a local leader).

- Involve other individuals or groups in the consent decision-making process as appropriate (e.g., older family members or local leaders).

- Observe local customs in planning for and conducting the interview (e.g., giving advance notice before arriving, dressing in a culturally appropriate manner, 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 elements (e.g., matching female interviewers with female respondents, if matching is culturally appropriate).

- Attempt to conduct interviews in settings that afford as much privacy as possible while still respecting cultural norms (see Guideline 3 in Data Collection).

- Identify the level or degree of sensitivity for different question topics during preliminary fieldwork, observations, and pretesting, since sensitive topics often vary among cultures and societies [14].

- Consider cultural traditions and norms when deciding whether to offer respondent incentives and determining what type of incentives would
be most appropriate (see Guideline 5 in Data Collection for more on incentives).

- Determine whether it is appropriate to follow up with persons who initially refuse the survey request and develop follow-up techniques in accordance with cultural traditions and norms.

**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 [2].
  - 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 [1].
  - 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 [8].

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.
**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, contracting**, and project management. These include the following:
  - Honestly describing the organization’s expertise in a bid.
  - Disclosing if a survey project is being carried out on behalf of multiple clients or is using subcontractors.
  - Meeting contractual obligations.
  - Ensuring agreement by both parties on any changes to contractual obligations.
  - Maintaining good relations between the coordinating center and research organizations involved in the study.
  For additional detail, see [Tenders, Bids, and Contracts](#).

- Disclose sources of financial support or relevant relationships that have the appearance of or potential to constitute a conflict of interest.

- Fulfill ethical responsibilities to employees (e.g., fair hiring practices, an objective performance 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).
  - Ensure that interviewers are aware of their ethical responsibilities, including their obligation to report evidence of child abuse and other observations.
  - Instruct interviewers on the limits of their ethical responsibilities (e.g., when they should provide information about local health resources or contact a clinical psychologist or social worker assigned to the project, rather than attempting to provide medical assistance or mental health support services themselves).

- 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](#).
• **Survey Quality.**

• **Tenders, Bids, and Contracts.**

• **Sample Design.**

• **Questionnaire Design.**

• **Adaptation of Survey Instruments.**

• **Translation.**

• **Instrument Technical Design.**

• **Interviewer Recruitment, Selection, and Training.**

• **Pretesting.**

• **Data Collection.**

• **Data Harmonization.**

• **Data Processing and Statistical Adjustment.**

• **Data Dissemination.**

• 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.

• When possible, 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. Most of the methodological research on ethics and other survey design considerations has been conducted in Western cultures. Additional research is needed in non-Western societies.

4. **Report research findings and methods and provide appropriate access to study data.**

*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. While the full reporting of results is an important ethical obligation, it is also important to consider the negative impact that reporting unfavorable findings about a specific ethnic, religious, or other social group may have on members of that group.

- 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, including de-identification of publicly available datasets to the greatest extent possible (see Data Dissemination for a detailed discussion).

- Provide a summary report of the study methodology and findings. See Appendix C for a checklist of items to include in the summary report.

- Provide a copy of the findings to all researchers and organizations that were involved in the study.

- Provide a copy of the de-identified dataset(s) and documentation to international data repositories such as the Inter-university Consortium for Political and Social Research (ICPSR) [11], Council for European Social Science Data Archives (CESSDA), UK Data Archive (UKDA), or the South African Data Archive (SADA).

- Provide safe, sustainable storage of the datasets and documentation.
• Adhere to government laws and agreements that address disclosure of survey data both within and across borders.

• 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 likely effect on study results, and provide an additional variable or other means along with appropriate documentation for analysts to identify the corrected value(s).

• Make an effort to respond to specific written requests for additional items pertaining to the publicly released findings [19].

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.

• It is important to be aware that some national standards require that raw and de-identified datasets be stored for a minimum time period (e.g., 10 years is the German National Science Foundation standard for empirical data).

5. Institute and follow appropriate quality control procedures.

Rationale

Development and implementation of quality control procedures is necessary to ensure that the procedures that have been developed to meet standards for ethical research are being carried out appropriately. If a failure to meet these standards is detected, protocols should be in place to remedy the failure. In addition, monitoring of procedures related to the ethical conduct of the study should inform efforts to improve quality and cost-effectiveness.

Procedural steps

• Pretest consent protocol and forms to ensure comprehension.
• Translate and adapt consent protocols and forms according to best practices (see Translation and Adaptation of Survey Instruments).

• Review recorded interviews and monitor live interviews to assure adherence to informed consent procedures.

• Monitor implementation of confidentiality protocols and procedures, including, but not limited to performing audits to determine adherence to these protocols and procedures.

• Securely store signed pledges of confidentiality and consent forms.

• Recontact a sample of cases for each interviewer to verify that screening and interview procedures were appropriately followed (see Guideline 7 of Data Collection).

• Use analyses of paradata (e.g., identification of question-level timings that are unusually short or long and identification of unusual variable distributions for one or more interviewers compared to the overall distribution [18] [21]).

• Conduct disclosure analysis (see Data Dissemination).

• Investigate any deviation from ethical protocols and take appropriate action to address the situation.

**Lessons learned**

• Sometimes a small group of interviewers can have a large impact on the quality of survey estimates. In a mental health survey of six European countries, the prevalence rates of mental health disorders were unusually low among German respondents. Experienced German interviewers were suspected of skipping screening questions that lead to a more extensive set of follow-up items in order to complete interviews more quickly. Even though only a small group of interviewers had prior interviewing experience, they conducted a sizeable percent of the total number of interviews and the responses that they solicited were very different. In general, positive responses screened respondents into more extensive sections on mental health disorders. Only 14.5% of screening questions administered by the interviewers with prior interviewing experience were positive, while 44.7% of screening questions administered by interviewers without prior experience were positive [16].
6. 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 board. 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 protocols.
  - Translated or adapted consent form templates and protocols.
  - Individual consent information for each respondent, stored in a safe environment separate from survey data.
  - Confidentiality procedures and protocols.
  - Pledge(s) of confidentiality completed by staff.
  - Records of completion of any specialized staff training on ethics.
  - Ethics review board original submission and requests for modification to study protocol (see Appendix D for a checklist of materials to include in an ethics review board submission).
  - Ethics review board correspondence (e.g., letters of approval).
  - Any correspondence between study staff or ethics review board members/staff and respondents regarding an ethical issue or concern.
  - Reports of quality control activities (e.g., documentation of verification activities).

- Provide a copy of the following documents to any central coordinating organization:
  - Translated or adapted consent form templates and protocols.
  - Ethics review board original submission and requests for modification to study protocol.
  - Ethics review board correspondence (e.g., letters of approval).
  - Reports of quality control activities (e.g., documentation of verification activities).
Appendix A

Study brochure

The following is a sample study brochure that can be mailed or handed to respondents to provide general information about the study purpose and protocol and to address frequently asked questions.
The Chicago Healthy Neighborhoods Study (CHNS) is a research study funded by the US National Office for Health to determine the impact of the quality of life in Chicago neighborhoods on the health of adults living there.

The information gathered from this study will help us better understand why there are social, economic, and racial/ethnic differences in the health of Chicagoans and how these differences affect Chicagoans' lives. With data from this study, effective approaches can be developed to improve the health and lives of all Chicagoans.

The CHNS is one of the largest surveys, done in a major American city, studying the relationship of the quality of people's lives and the neighborhood in which they live to their health. About 4,500 adults will participate in this important study.

Households are randomly selected using a scientific sampling procedure. Once a household is selected, an interviewer visits the house and makes a listing of all residents. One adult is randomly selected from all eligible residents. Only the selected individual may participate. Each person who is asked to participate has been carefully selected to represent fellow Chicagoans like them.

Interviews will be conducted in the participant's home or at another location by a professional University of West Chicago Survey Research Center interviewer. The interviewer will ask questions and record answers using a laptop computer. Participants will be provided with $20 as a token of appreciation for their participation in this project.

The interview includes a wide range of questions about work and family life, health, and social and physical characteristics of neighborhoods in which study participants live. There are no right or wrong answers. Most participants find the interview to be an enjoyable experience.

Funding for CHNS comes from the US National Office for Health (NOH).
The University of West Chicago’s Survey Research Center will conduct the interviews for this study. A University of West Chicago interviewer will greet you at your home. For security reasons, you may want to ask the interviewer to reveal his/her identification badge. UWC employees will gladly comply with your request.

We thank you for your interest in this project!

If you have any questions, please contact the project team toll-free at:

1-800-733-7373

University of West Chicago Survey Research Center

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Chicago Healthy Neighborhoods Study

Project Leader
- Christopher Antoun, Ph.D., Survey Research Center (SRC) & Department of Urban Health, University of West Chicago

Senior Investigators
- Benjamin Duffey, Ph.D., Department of Urban Health, University of West Chicago
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- Emily Blasczyk, Ph.D., Department of Psychology & SRC, University of West Chicago
- Mason Flounder, Ph.D., Department of Sociology, Northwestern University
- Yuchieh Lin, M.D., Mental Health Research Institute & Department of Psychiatry, University of West Chicago
- William Jones, M.D., Department of Psychiatry, University of West Chicago

Consultants
- Robert Kessenheimer, M.D., Department of Psychiatry, Loyola University (Chicago)
- Sara Neighbors, Ph.D., Department of Psychology, University of Pennsylvania
Appendix B

Pledge to safeguard respondent privacy

This pledge to maintain respondent privacy is used by the Institute for Social Research at the University of Michigan. The form is signed by all staff members, and fulfillment of the pledge is a requirement of employment.

I have read the Institute for Social Research Policy on Safeguarding Respondent Privacy, and pledge that I will strictly comply with that Policy. Specifically:

- I will not reveal the name, address, telephone number, or other identifying information of any respondent (or family member of a respondent or other informant) to any person other than an employee directly connected to the study in which the respondent is participating.

- I will not reveal the contents or substance of the responses of any identifiable respondent or informant to any person other than an employee directly connected to the study in which the respondent is participating, except as authorized by the project director or authorized designate.

- I will not contact any respondent (or family member, employer, other person connected to a respondent or informant) except as authorized by the project director or authorized designate.

- I will not release a dataset (including for unrestricted public use or for other unrestricted uses) except in accordance with authorization, policies and procedures established by ISR and the Center with which I am affiliated.

- I will take all necessary precautions to avoid unintended disclosure of confidential information, including securing of paper and electronic records, computers, user IDs and passwords.

I agree that compliance with this Pledge and the underlying Policy is: 1) a condition of my employment (if I am an employee of ISR), and 2) a condition of continuing collaboration and association with ISR (if I am an affiliate of ISR). I understand that violation of this Policy and Pledge may result in disciplinary action, up to and including termination of employment or severance of any relationship with ISR and the applicable research project.

If I supervise affiliates who have access to ISR respondent data (other than unrestricted public release datasets), I will ensure that those affiliates adhere to the same standards of protection of ISR respondent privacy, anonymity, and confidentiality, as required by this Pledge and the associated Policy.

Signature: ___________________________________ Date: __________________

Typed or printed name: _____________________________________________
## Appendix C

Checklist of items to include in summary report of study methodology and findings

- The purpose of the study
- Who sponsored the survey and who conducted it
- A copy of ethics review board 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 elements 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

Appendix D

Checklist of materials to be provided to an ethics review board

<table>
<thead>
<tr>
<th>General Study Information, including:</th>
<th></th>
</tr>
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<tbody>
<tr>
<td>• Financial sponsorship</td>
<td></td>
</tr>
<tr>
<td>• Key personnel</td>
<td></td>
</tr>
<tr>
<td>• Performance sites</td>
<td></td>
</tr>
<tr>
<td>• Study dates</td>
<td></td>
</tr>
<tr>
<td>• Study abstract/summary</td>
<td></td>
</tr>
<tr>
<td>• Research design (including specific aims, background/prior research, methodology, analysis plan, etc.)</td>
<td></td>
</tr>
<tr>
<td>• Benefits to subjects from participation</td>
<td></td>
</tr>
<tr>
<td>• Risks to subjects</td>
<td></td>
</tr>
<tr>
<td>• Recruitment methods and description of subject population</td>
<td></td>
</tr>
<tr>
<td>• Informed consent procedures</td>
<td></td>
</tr>
<tr>
<td>• Data confidentiality provisions</td>
<td></td>
</tr>
<tr>
<td>• Conflicts of interest</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Discussion of Special Considerations, for example:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Procedures used to obtain consent to interview minors or other populations that require special consent (e.g., if interviewing minors, describe procedures for obtaining parental consent and include child assent and parental consent forms/oral protocols).</td>
<td></td>
</tr>
<tr>
<td>• Compensation and costs involved in participation for study subjects</td>
<td></td>
</tr>
<tr>
<td>• Procedures for handling biological samples, such as blood or saliva</td>
<td></td>
</tr>
<tr>
<td>• Proposal to conduct genetic typing/analysis from biological samples</td>
<td></td>
</tr>
<tr>
<td>• Considerations in conducting epidemiological or public health research</td>
<td></td>
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<tr>
<td>• Use of deception</td>
<td></td>
</tr>
<tr>
<td>• Use of internet/email for research</td>
<td></td>
</tr>
</tbody>
</table>
Ethical Considerations in Surveys

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- Consent procedures for audio or video recording of interviews
- International research considerations
- Protocols for viewing of images or listening to recorded material
- Secondary data analysis

**Forms, including:**

- Copy of the grant/contract application
- Consent protocols/scripts/forms
- Copy of the questionnaire

**Other forms (as appropriate):**

- Cognitive interview protocol
- Focus group moderator guide
- Recruitment flyers or emails
- Study brochure/fact sheet
- Letter(s) to be sent to respondents
- Data use agreement (for use of secondary data from third party sources)
- Documentation of review from other ethics review boards
- Documentation of training in research ethics for study staff

Glossary

**Accuracy**  The degree of closeness an estimate has to the true value.

**Adaptation**  Changing existing materials (e.g., management plans, contracts, training manuals, questionnaires, etc.) by deliberately altering some content or design component to make the resulting materials more suitable for another socio-cultural context or a particular population.

**Anonymity**  Recording or storing information without name or identifier, so the respondent cannot be identified in any way by anyone. No one can link an individual person to the responses of that person, including the investigator or the interviewer. Face-to-face interviews are never anonymous since the interviewer knows the address (and likely, the name) of the respondent.

**Audit trail**  An electronic file in which computer-assisted and Web survey software captures paradata about survey questions and computer user actions, including times spent on questions and in sections of a survey (timestamps) and interviewer or respondent actions while proceeding through a survey. The file may contain a record of keystrokes and function keys pressed, as well as mouse actions.

**Auxiliary data**  Data from an external source, such as census data, that is incorporated or linked in some way to the data collected by the study. Auxiliary data is sometimes used to supplement collected data, for creating weights, or in imputation techniques.

**Bias**  The systematic difference over all conceptual trials between the expected value of the survey estimate of a population parameter and the true value of that parameter in the target population.

**Bid**  A complete proposal (submitted in competition with other bidders) to execute specified jobs within prescribed time and budget, and not exceeding a proposed amount.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cluster</td>
<td>A grouping of units on the sampling frame that is similar on one or more variables, typically geographic. For example, an interviewer for an in person study will typically only visit only households in a certain geographic area. The geographic area is the cluster.</td>
</tr>
<tr>
<td>Cognitive interview</td>
<td>A pretesting method designed to uncover problems in survey items by having respondents think out loud while answering a question or retrospectively.</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>Securing the identity of, as well as any information provided by, the respondent, in order to ensure to that public identification of an individual participating in the study and/or his individual responses does not occur.</td>
</tr>
<tr>
<td>Consent (informed consent)</td>
<td>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 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. In some cases, consent must be given by someone other than the respondent (e.g., an adult when interviewing children).</td>
</tr>
<tr>
<td>Contract</td>
<td>A legally binding exchange of promises or an agreement creating and defining the obligations between two of more parties (for example, a survey organization and the coordinating center) written and enforceable by law.</td>
</tr>
<tr>
<td>Coordinating center</td>
<td>A research center that facilitates and organizes cross-cultural or multi-site research activities.</td>
</tr>
<tr>
<td>Coverage</td>
<td>The proportion of the target population that is accounted for on the sampling frame.</td>
</tr>
<tr>
<td>De-identification</td>
<td>Separating personally identifiable information (PII) from the survey data to prevent a breach of confidentiality.</td>
</tr>
</tbody>
</table>
Disclosure analysis and avoidance

The process of identifying and protecting the confidentiality of data. It involves limiting the amount of detailed information disseminated and/or masking data via noise addition, data swapping, generation of simulated or synthetic data, etc. For any proposed release of tabulations or microdata, the level of risk of disclosure should be evaluated.

Disposition code

A code that indicates the result of a specific contact attempt or the outcome assigned to a sample element at the end of data collection (e.g., noncontact, refusal, ineligible, complete interview).

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.

Fitness for intended use

The degree to which products conform to essential requirements and meet the needs of users for which they are intended. In literature on quality, this is also known as "fitness for use" and "fitness for purpose."

Focus group

Small group discussions under the guidance of a moderator, often used in qualitative research that can also be used to test survey questionnaires and survey protocols.

Imputation

A computation method that, using some protocol, assigns one or more replacement answers for each missing, incomplete, or implausible data item.
Informant

The person who supplies a list of the eligible elements within the selected unit. For example, many in-person surveys select a sample of housing units at the penultimate stage of selection. Interviewers then contact the housing unit with the aim of convincing the member of the housing unit who responded to the contact attempt to provide a list of housing unit members who are eligible for the study. The housing unit member who provides a list of all eligible housing unit members is called the informant. Informants can also be selected respondents as well, if they are eligible for the study and are chosen as the respondent during the within household stage of selection.

Interviewer falsification

Intentionally departing from the designed interviewer guidelines that could result in the contamination of the data. Falsification includes: 1) Fabricating all or part of an interview—the recording of data that are not provided by a designated survey respondent, and reporting them as answers of that respondent; 2) Deliberately misreporting disposition codes and falsifying process data (e.g., the recording of a respondent refusal as ineligible for the sample; reporting a fictitious contact attempt); 3) Deliberately miscoding the answer to a question in order to avoid follow-up questions; 4) Deliberately interviewing a nonsampled person in order to reduce effort required to complete an interview; or intentionally misrepresenting the data collection process to the survey management.

Item nonresponse, item missing data

The lack of information on individual data items for a sample element where other data items were successfully obtained.

Mean Square Error (MSE)

The total error of a survey estimate; specifically, the sum of the variance and the bias squared.

Microdata

Nonaggregated data that concern individual records for sampled units, such as households, respondents, organizations, administrators, schools, classrooms, students, etc. Microdata may come from auxiliary sources (e.g., census or geographical data) as well as surveys. They are contrasted with macrodata, such as variable means and frequencies, gained through the aggregation of microdata.

Mode

Method of data collection.
<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Noncontact</strong></td>
<td>Sampling units that were potentially eligible but could not be reached.</td>
</tr>
<tr>
<td><strong>Nonresponse</strong></td>
<td>The failure to obtain measurement on sampled units or items. See unit nonresponse and item nonresponse.</td>
</tr>
<tr>
<td><strong>Paradata</strong></td>
<td>Empirical measurements about the process of creating survey data themselves. They consist of visual observations of interviewers, administrative records about the data collection process, computer-generated measures about the process of the data collection, external supplementary data about sample units, and observations of respondents themselves about the data collection. Examples include timestamps, keystrokes, and interviewer observations about individual contact attempts.</td>
</tr>
<tr>
<td><strong>Personally Identifiable Information (PII)</strong></td>
<td>Information that can be used to identify a respondent that minimally includes name, address, telephone number and identification number (such as social security number or driver's license number), but may include other information including biometric data.</td>
</tr>
<tr>
<td><strong>Pledge of confidentiality</strong></td>
<td>An agreement (typically in written or electronic form) to maintain the confidentiality of survey data that is signed by persons who have any form of access to confidential information.</td>
</tr>
<tr>
<td><strong>Post-survey adjustments</strong></td>
<td>Adjustments to reduce the impact of error on estimates.</td>
</tr>
<tr>
<td><strong>Precision</strong></td>
<td>A measure of how close an estimator is expected to be to the true value of a parameter, which is usually expressed in terms of imprecision and related to the variance of the estimator. Less precision is reflected by a larger variance.</td>
</tr>
<tr>
<td><strong>Pretesting</strong></td>
<td>A collection of techniques and activities that allow researchers to evaluate survey questions, questionnaires and/or other survey procedures before data collection begins.</td>
</tr>
<tr>
<td><strong>Primary Sampling Unit (PSU)</strong></td>
<td>A cluster of elements sampled at the first stage of selection.</td>
</tr>
</tbody>
</table>
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Proxy interview

An interview with someone (e.g., parent, spouse) other than the person about whom information is being sought. There should be a set of rules specific to each survey that define who can serve as a proxy respondent.

Quality

The degree to which product characteristics conform to requirements as agreed upon by producers and clients.

Quality assurance

A planned system of procedures, performance checks, quality audits, and corrective actions to ensure that the products produced throughout the survey lifecycle are of the highest achievable quality. Quality assurance planning involves identification of key indicators of quality used in quality assurance.

Quality audit

The process of the systematic examination of the quality system of an organization by an internal or external quality auditor or team. It assesses whether the quality management plan has clearly outlined quality assurance, quality control, corrective actions to be taken, etc., and whether they have been effectively carried out.

Quality control

A planned system of process monitoring, verification, and analysis of indicators of quality, and updates to quality assurance procedures, to ensure that quality assurance works.

Quality management plan

A document that describes the quality system an organization will use, including quality assurance and quality control techniques and procedures, and requirements for documenting the results of those procedures, corrective actions taken, and process improvements made.

Recontact

To have someone other than the interviewer (often a supervisor) attempt to speak with the sample member after a screener or interview is conducted, in order to verify that it was completed according to the specified protocol or to edit potentially erroneous responses.

Reliability

The consistency of a measurement, or the degree to which an instrument measures the same way each time it is used under the same condition with the same subjects.
Response rate: The number of complete interviews with reporting units divided by the number of eligible reporting units in the sample.

Sample element: A selected unit of the target population that may be eligible or ineligible.

Sampling error: Survey error (variance and bias) due to observing a sample of the population rather than the entire population.

Sampling frame: A list or group of materials used to identify all elements (e.g., persons, households, establishments) of a survey population from which the sample will be selected. This list or group of materials can include maps of areas in which the elements can be found, lists of members of a professional association, and registries of addresses or persons.

Sampling units: Elements or clusters of elements considered for selection in some stage of sampling. For a sample with only one stage of selection, the sampling units are the same as the elements. In multi-stage samples (e.g., enumeration areas, then households within selected enumeration areas, and finally adults within selected households), different sampling units exist, while only the last is an element. The term primary sampling units (PSUs) refers to the sampling units chosen in the first stage of selection. The term secondary sampling units (SSUs) refers to sampling units within the PSUs that are chosen in the second stage of selection.

Secondary Sampling Unit (SSU): A cluster of elements sampled at the second stage of selection.

Survey lifecycle: The lifecycle of a survey research study, from design to data dissemination.

Survey population: The actual population from which the survey data are collected, given the restrictions from data collection operations.

Target population: The finite population for which the survey sponsor wants to make inferences using the sample statistics.
**Timestamps**

Timestamps are time and date data recorded with survey data, indicated dates and times of responses, at the question level and questionnaire section level. They also appear in audit trails, recording times questions are asked, responses recorded, and so on.

**Total Survey Error (TSE)**

Total survey error provides a conceptual framework for evaluating survey quality. It defines quality as the estimation and reduction of the mean square error (MSE) of statistics of interest.

**Unit nonresponse**

An eligible sampling unit that has little or no information because the unit did not participate in the survey.

**Variance**

A measure of how much a statistic varies around its mean over all conceptual trials.

**Weighting**

A post-survey adjustment that may account for differential coverage, sampling, and/or nonresponse processes.
References


Ethical Considerations in Surveys

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Internet Links


Further Reading


Ethical Considerations in Surveys


Warwick, D. P. (1983). The politics and ethics of field research. In M. Bulmer & D. P. Warwick (Eds.), Social research in developing countries (pp. 315-
