

### 3.2.7: Formal Protections for Research Participants

Different countries have slightly different protections. In the United States, the U.S. Department of Health and Human Services Office for the Protection from Research Risks issues regulations to protect research participants. Federal regulations follow a biomedical model and protect participants from physical harm. It is one federal government agency, and technically its rules apply only when federal money is involved, but in practice, all other government agencies and researchers follow its guidance. Local governments, hospitals, universities, and private companies model their internal policies on the federal rules. Other U.S. government rules require the creation of **institutional review boards (IRB)** at all research institutes, medical facilities, colleges, and universities where research with humans occurs. An institutional review board has a mix of researchers and nonresearchers. Its members review research procedures at a proposal or preliminary stage, making certain that ethical principles are upheld. Some forms of research are exempt from a formal, full review by the IRB. These include educational tests, normal educational practice, most nonsensitive survey questionnaires, observation of public behavior, and studies of existing public data in which individuals cannot be identified. Submitting a proposal to an IRB for review requires a little extra time and planning. IRB members are an “extra set of eyes” looking at a research design to ensure that research participants will be fully protected.

Most professionals (e.g., physicians, attorneys, family counselors, social workers, and others) have organizations that developed a written **code of ethics**, peer review boards, or licensing regulations. A code of ethics is a written statement of ethical rules that identify proper and improper behavior. Most professional social science associations have codes of ethics that represent a consensus of professionals on ethics. Although not all researchers may agree on every ethical issue, they uphold ethical

standards as members of a profession. These include the following:

- Ensure that participants have voluntarily consented to be in the study.
- Avoid unnecessary physical and mental suffering.
- Avoid any research where death or disabling injury to participants is likely.
- End a research study immediately if its continuation is likely to cause injury, disability, or death.
- Highly qualified people using the highest levels of skill and care should conduct research studies.
- Study results should be for the good of society and unattainable by any other method.

**MAKING IT PRACTICAL: CODES OF ETHICS** We can trace today’s codes of ethics for human research to the Nuremberg Code created after war crime trials in Germany at the end of World War II. The codes of most professional organizations, such as nursing, social work, public opinion research, psychology, or sociology are not identical but they do overlap a great deal. Professional associations create codes of ethics and hear about possible violations, but there is no formal policing of the codes. The penalty for a minor ethical violation rarely goes past public embarrassment and a letter of complaint. Those who commit a serious ethical violation, even if they violated no law, will face loss of reputation, loss of employment, a ban on the research findings being published, or restrictions from future jobs. Besides making explicit the beliefs of the research community and providing researchers with guidance, codes of ethics help universities and other institutions defend legitimate, ethical research against political or other pressures. If researchers receive unjustified demands to stop legitimate research or to reveal protected details about research participants, written codes of ethics that are widely endorsed within the research community provide an important line of defense.

## Ethics Code of the American Association for Public Opinion Research

We, the members of the American Association for Public Opinion Research, subscribe to the principles expressed in the following code. Our goals are to support sound and ethical practice in the conduct of public opinion research and in the use of such research for policy- and decision-making in the public and private sectors, as well as to improve public understanding of public opinion and survey research methods and the proper use of public opinion and survey research results.

We pledge ourselves to maintain high standards of scientific competence and integrity in conducting, analyzing, and reporting our work; in our relations with survey respondents; with our clients; with those who eventually use the research for decision-making purposes; and with the general public. We further pledge ourselves to reject all tasks or assignments that would require activities inconsistent with the principles of this code.

## The Code

- I. Principles of Professional Practice in the Conduct of Our Work**
- A.** We shall exercise due care in developing research designs and survey instruments, and in collecting, processing, and analyzing data, taking all reasonable steps to assure the reliability and validity of results.
    - 1. We shall recommend and employ only those tools and methods of analysis that, in our professional judgment, are well suited to the research problem at hand.
    - 2. We shall not knowingly select research tools and methods of analysis that yield misleading conclusions.
    - 3. We shall not knowingly make interpretations of research results that are inconsistent with the data available, nor shall we tacitly permit such interpretations.
    - 4. We shall not knowingly imply that interpretations should be accorded greater confidence than the data actually warrant.
  - B.** We shall describe our methods and findings accurately and in appropriate detail in all research reports, adhering to the standards for minimal disclosure specified in Section III.
  - C.** If any of our work becomes the subject of a formal investigation of an alleged violation of this Code, undertaken with the approval of the AAPOR Executive Council, we shall provide additional information on the survey in such detail that a fellow survey practitioner would be able to conduct a professional evaluation of the survey.
- II. Principles of Professional Responsibility in Our Dealings with People**
- A. The Public:**
    - 1. When preparing a report for public release we shall ensure that the findings are a balanced and accurate portrayal of the survey results.
    - 2. If we become aware of the appearance in public of serious inaccuracies or distortions regarding our research, we shall publicly disclose what is required to correct these inaccuracies or distortions, including, as appropriate, a statement to the public media, legislative body, regulatory agency, or other appropriate group, to which the inaccuracies or distortions were presented.
    - 3. We shall inform those for whom we conduct publicly released surveys that AAPOR standards require members to release minimal information about such surveys, and we shall make all reasonable efforts to encourage clients to subscribe to our standards for minimal disclosure in their releases.
  - B. Clients or Sponsors:**
    - 1. When undertaking work for a private client, we shall hold confidential all proprietary information obtained about the client and about the conduct and findings of the research undertaken for the client, except when the dissemination of the information is expressly authorized by the client, or when disclosure becomes necessary under the terms of Section I-C or II-A of this Code.
    - 2. We shall be mindful of the limitations of our techniques and capabilities and shall accept only those research assignments that we can reasonably expect to accomplish within these limitations.
  - C. The Profession:**
    - 1. We recognize our responsibility to the science of survey research to disseminate as freely as possible the ideas and findings that emerge from our research.
    - 2. We shall not cite our membership in the Association as evidence of professional competence, since the Association does not so certify any persons or organizations.
  - D. The Respondent:**
    - 1. We shall avoid practices or methods that may harm, humiliate, or seriously mislead survey respondents.
    - 2. We shall respect respondents' concerns about their privacy.
    - 3. Aside from the decennial census and a few other surveys, participation in surveys is voluntary. We shall provide all persons selected for inclusion with a description of the survey sufficient to permit them to make an informed and free decision about their participation.
    - 4. We shall not misrepresent our research or conduct other activities (such as sales, fund raising, or political campaigning) under the guise of conducting research.
    - 5. Unless the respondent waives confidentiality for specified uses, we shall hold as privileged and confidential all information that might identify a respondent with his or her responses. We also shall not disclose or use the names of respondents for nonresearch purposes unless the respondents grant us permission to do so.
    - 6. We understand that the use of our survey results in a legal proceeding does not relieve us of our ethical obligation to keep confidential all respondent identifiable information or lessen the importance of respondent anonymity.
- III. Standards for Minimal Disclosure**
- Good professional practice imposes the obligation upon all public opinion researchers to include, in any report of research results, or to make available when that report is released, certain essential information about how the research was conducted. At a minimum, the following items should be disclosed.
- 1. Who sponsored the survey, and who conducted it
  - 2. The exact wording of questions asked, including the text of any preceding instruction or explanation to the interviewer or respondents that might reasonably be expected to affect the response
  - 3. A definition of the population under study, and a description of the sampling frame used to identify this population
  - 4. A description of the sample design, giving a clear indication of the method by which the respondents were selected by the researcher, or whether the respondents were entirely self-selected

5. Sample sizes and, where appropriate, eligibility criteria, screening procedures, and response rates computed according to AAPOR Standard Definitions. At a minimum, a summary of disposition of sample cases should be provided so that response rates could be computed.
6. A discussion of the precision of the findings, including estimates of sampling error, and a description of any weighting or estimating procedures used
7. Which results are based on parts of the sample, rather than on the total sample, and the size of such parts
8. Method, location, and dates of data collection.

From time to time, AAPOR Council may issue guidelines and recommendations on best practices with regard to the release, design, and conduct of surveys.

## Summary Review

### Basic Principles of Ethical Research

- Accept responsibility for all ethical decisions and the protection of research participants.
- Use the research techniques that are most appropriate for a topic or situation.
- Follow accepted methodological standards and strive for high accuracy.
- Detect and remove any threats of harm to research participants.
- Never exploit research participants for personal gain.
- Get informed consent from the research participants before beginning.
- Treat the research participants with dignity and respect at all times.
- Only use deception if absolutely needed, and always debrief participants afterward.
- Honor all guarantees of privacy, confidentiality, and anonymity you make to participants.
- Be candid and honest when interpreting and reporting study results.
- Identify the sponsors of funded research to participants and to the public.
- Release all details of the study procedures with the results.
- Act with integrity and adhere to the behaviors outlined in professional codes of ethics.

## 3.3: How Do Sponsors Affect Research Ethics?

### 3.3 Identify some of the tactics used by research sponsors to aid their causes

You might find a job in which you are assigned to conduct research for a *sponsor*—an employer, a government agency, or a private firm. Special ethical issues can arise when a sponsor pays for research, especially applied research. Some

sponsors believe that because they are paying, they can ask researchers to compromise ethical research standards as a condition of employment or part of a contract for research. While few would ask a medical doctor to prescribe medications unethically or a lawyer to violate professional ethics in a court of law, some sponsors are not aware of or are unconcerned about professional ethics in social research.

If a sponsor makes an illegitimate demand, you have three basic choices: be loyal to an organization and cave in to the sponsor, exit from the situation by quitting, or voice opposition and become a **whistle-blower**. You need to set ethical boundaries beyond which you refuse a sponsor's demands and choose your own course of action. Whatever the case, it is best to consider ethical issues early in a relationship with a sponsor and to express concerns up front.

While sponsors often provide essential funding for research, and most allow great autonomy to professional researchers, some interfere with the research process in unethical ways. This occurs in three main ways: to require certain research findings, to restrict how research is done, and to suppress unwanted results.

### Tips for the Wise Consumer Who Paid for a Study?

It is unethical to hide the identity of a research sponsor. You should tell study participants who the sponsor is and inform the readers of research reports. Participants in a study have a right to know the sponsor. Telling participants is rarely controversial, but it becomes tricky in a few instances. For example, a pro-choice organization sponsors a study to look at the attitudes of members of religious groups opposed to abortion. The organization asks that you not reveal the sponsor to participants. You must balance the ethical rule to reveal a sponsor's identity against the sponsor's desire for confidentiality and possible bias or reduced cooperation by study participants. In general, unless you have a very clear, strong methodological reason for not doing so (such as reduced cooperation and strong bias), tell participants of the sponsor of a study. If telling participants of the sponsor will create a bias or noncooperation, then wait until after you have gathered the data. When reporting study results, the ethical mandate is unambiguous: You must always reveal sponsors who fund a study.