IRB Boards and Qualitative Research: Bonus Handouts #4 Ethics, Confidentiality and Informed Consent

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Ethics, Confidentiality and Informed Consent

Summary for Student Researchers

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Students working on research projects need to follow the same guidelines of ethical behavior as their teachers and other professional researchers. This includes making sure that information collected remains confidential and that people whom you work with understand that they are part of a research project. This summary is meant as a short outline of ethical issues for Sociology and Anthropology. It is meant to accompany copies of the ethics statements for both disciplines.

What are the major points of ethics for sociologists and anthropologists?

Ethical statements set the standards of good conduct for a researcher. These principals come out of the experiences that researchers face when conducting studies. In general, social science researchers observe the following standards in their work:

Do no harm to the people, organizations or communities who participate in research projects

Get permission or informed consent from the people or organizations who are the subjects of the research before doing a study. This includes sharing the goals and procedures of the research that you intend to do with the people who will be the subjects of the research. If the project is funded by an agency looking for particular information, you also need to share those goals and objectives.

Maintain the privacy or confidentiality of the people and organizations participating in the research project.

Be honest about the limits of your training and what you can learn through a particular research project.

Not falsify or make up data on a research study. To report accurately and completely research findings-

Report your research findings to the communities involved in your study, the scientific community, and the general public as appropriate in ways that further the public good and scientific knowledge-

Develop and maintain a working relationship with the communities that you study so that you can benefit them and so that other researchers can continue work with these people.

In many cases, the right way to behave may not be obvious. When this happens, researchers should check with their teachers and, when appropriate, share their experience with their classmates or other students working on the same project. But this sharing must happen during a class or other structured context and maintain the privacy of the research participants.

What does "do no harm" mean?

Social scientists try to be neutral observers of the communities and people that they study. The goal is to understand the behaviors and attitudes of a research population or a community or agency involved in a study, not to judge the people in the research project or do anything which may hurt them in any way. For example, social scientists do not report criminal behavior in research settings to the police or try to change the behavior or values of their research subjects.

In some cases, the researcher may find situations which he or she clearly think require action. For example, an organization may run a program in a way that keeps some eligible people from getting benefits. In cases like this, the
researcher first must carefully document this information, understand the context for the behavior, and work with the agency to share those findings. He or she may report the research results to a wider audience or work with members of the community to advocate for change. In all cases, the researcher must maintain the privacy of those who participated in the research unless they give clear permission to use their names.

How do I get informed consent?

Informed consent means that the people and organizations involved in a research project understand that 1) they are voluntary participants in a study, 2) that their privacy will be maintained 3) how you plan to carry out your research, 4) why you are doing this project, and 5) how the information you gather will be used. The only time that you do not need to get informed consent is when you are observing a public place like a shopping mall or a public meeting. When the research project involves ongoing activity -like observing a school, the researcher needs to continue to make sure that people in the setting consent to be part of the project.

Researchers get informed consent through a written or oral statement which briefly outlines the answers to the five points above. For example, in a questionnaire study, the researcher might ask the participant to sign a consent form which states the person volunteers to participate in a research study. The next sentence in the consent form should state that all information given is completely voluntary, that the subject can refuse to answer any set of questions, and that the researcher will not reveal the person's name or the information given to anyone without the participant's permission. Then the researcher should briefly outline what is in the questionnaire, why he or she is doing the project and how that information will be used. For example:

I would like to ask you to answer a questionnaire that asks about your experience in school and some questions about your education and work experience. Participation is completely voluntary and you can refuse to answer any question. Your information will be combined with others and no-one will know your name or what you said. It should take about 15 minutes. I am doing this research because I am interested in how students like school. The information will be used for my class paper.

The researcher should ask if the potential participant has any questions before they sign

Qualitative studies often get consent orally. When a project involves studying an organization like a school or community based agency, permission to do the research is often obtained from the agency head, principal or teacher. In these cases, the researcher does not need to get permission from every student or person they meet in the agency. However, you need to tell everyone that you are doing a study and why. You also may not include someone if they do not want to be part of your research.

How do I maintain confidentiality?

In most cases, researchers keep the identities of the people and organizations they work with secret. Maintaining the privacy of research study participants is the main way that social scientists do no harm. In a questionnaire study, basic confidentiality procedures include making sure that the names of the study participants are kept separate from the data collected about them. Usually, researchers do this by assigning a number to identify research subjects on a questionnaire. These numbers may be put on the consent form signed by the study participant so that the researcher can find the person again if they need additional information. However, the consent forms and any list which links study participants to identifying numbers are kept separate from the data. This identifying information is often kept in a locked cabinet.

In qualitative studies, researchers usually make up names for participating agencies and people. Any public document or discussion of the fieldsite uses the false names. These pseudo sometimes used in fieldnotes if they are shared in a class or among members of a project. However, in most research projects which involve teams of researchers, other researchers know the identity of places and some of the participants. In these cases, the researcher must not share information in their research study with family, friends or outsiders in any way which could identify their study participants.
In a study of an agency, the researcher must also be careful to keep information gathered from one person or setting secret from others in the setting. For example, a teacher might interview with a student. Unless the researcher has permission to share information with the teacher from the student, or information on students is shared as part of more general findings and the identity of anyone student is kept confidential, the researcher should tell the teacher the information is confidential.

In some cases, agencies or individuals want their names used in research reports. When this happens, the researcher should check with the agency to make sure information is factually accurate.

**What does it mean to be honest about my training and the limits of the study?**

Since many people do not understand the methods and limitations of social science research, it is important to be clear about these limits. For example, a small study on why people like c can not solve the problems of the school system. The researcher must be clear about what he or she can learn in this project. A researcher who only knows how to do basic statistics can claim that he or she will do sophisticated multivariate analysis.

**Why is it important to collect accurate data and report all findings?**

The accuracy of the research findings depends on the quality of data. If students make up data, collect incomplete information or falsify information the findings will be useless. Likewise, research should seek to present all data on a particular topic. While most research reports support a particular point of view, the researcher can not deliberately leave something out because it contradicts his or her findings.

**Why is it important to share findings?**

While class papers might be seen only by the teacher, most research projects include a responsibility to share findings with the people who participated in the study and the scientific community. Social science research is meant to better the lives of people in the communities we study and add to general scientific knowledge about a given topic. Providing a fair and report on a research project is part of the service that social scientists offer to the wider community.

**Why must I maintain a working relationship with the community that I study?**

One of the hallmarks of ethical research is respecting the people, organizations and communities that you work with. Part of this process involves making sure that you maintain a working relationship with research subjects. This includes not judging them by your standards, maintaining confidentiality, and sharing research findings. Social science research should never aim to produce an expose on a particular subject. Research subjects or the agencies that commission a study may not always like your findings, and you may need to offer some truths in a report. However, this information can not be presented in a way that harms study participants and should try not to alienate them.

Maintaining a working relationship with a study community is also important so that others can continue to work with that community. Social science research is cumulative: no one study provides all the answers on a given topic. It is important to maintain a good working relationship with study participants so that future researchers can learn more about the topic or double check your findings.