

American Anthropological Association Statement on Ethnography and Institutional Review Boards

Adopted by AAA Executive Board June 4, 2004

Background to the AAA Statement on Ethnography and Institutional Review Boards

Universities and research organizations in the US are required to follow a set of regulations known as "the Common Rule" (technically, "Federal Policy for the Protection of Human Subjects," DHHS' 45 CFR 46 or the equivalent regulations for other federal agencies) when they receive federal support. The Common Rule specifies how Institutional Review Boards (IRBs) are to function. This statement aims to interpret for policymakers, IRBs and ethnographers the Common Rule in its application to ethnographic research.

The American Anthropological Association (AAA) advocates that all ethnographic researchers should cultivate a strong foundation for the ethical conduct of research with human populations. This means that the risks of harm must be considered in relation to the potential benefits of ethnographic research. This process should actively involve the researcher and the IRB, the researcher and participants, and finally the IRB, the researcher and stakeholders.

Cultivating an ethical climate for ethnographic research requires trust among all involved in the process of implementing a research project. Because the ethnographer often resides in the participants' community or geographical area and participates in community life, trust develops between the ethnographer and participants as a result of ongoing relationships. In some cases, ethnographers return to the same community or area over time, for instance over 20 years or more. Therefore IRBs should view informed consent in this context as an ongoing and dynamic process.

1) What is ethnography?

Ethnography involves the researcher's study of human behavior in the natural settings in which people live. Specifically, ethnography refers to the description of cultural systems or an aspect of culture based on fieldwork in which the investigator is immersed in the ongoing everyday activities of the designated community for the purpose of describing the social context, relationships and processes relevant to the topic under consideration. Ethnographic inquiry focuses attention on beliefs, values, rituals, customs, and behaviors of individuals interacting within socioeconomic, religious, political and geographic environments. Ethnographic analysis is inductive and builds upon the perspectives of the people studied. Ethnography emphasizes the study of persons and communities, in both international and domestic arenas, and involves short or long-term relationships between the researcher and research participants.

Multiple methods are used in ethnographic research. These include but are not limited to the following: unobtrusive direct observation, participant observation, structured and unstructured interviewing, focused

discussions with individuals and community members, analysis of texts, and audio-visual records. Ethnographic methods can be employed in non-traditional ways in interdisciplinary projects that bridge the sciences and humanities.

The complexity and length of ethnographic research engenders an approach to ethics that is both dynamic and flexible. The process of obtaining informed consent may be continuous and incremental throughout the course of the research, and review of consent obtained may be periodic.

2) Is ethnography subject to review by IRBs?

Ethnographic research is subject to the Common Rule ("Federal Policy for the Protection of Human Subjects", DHHS 45 CFR 46; <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm>) because it involves "a systematic investigation...designed to develop or contribute to generalizeable knowledge." Although ethnographic research takes place in natural settings and differs significantly from clinical research, ethnographic research projects are subject to review by an Institutional Review Board (IRB) to ensure that the participants in the proposed research are not harmed. Because of its complexity, variable contexts, and duration of different ethnographic research projects, ethnographic research should be reviewed on a case-by-case basis.

3) What are the risks and benefits of ethnographic research?

Review of ethnographic research should be commensurate with the level of risk of harm vs the potential benefits of each specific research project. The review should consider the likelihood or probability of harm, the severity of harm, and the duration of harm. Each project should be examined on its own merit.

Unlike experiments and trials in clinical settings, which have clear beginnings and endings, ethnographic research generally is ongoing, at times sporadic, and takes place in dynamic, natural settings, often where participants are able to decline to participate at any point in the process. Just as in daily life, in these natural settings of research there may be a high probability of risk, but the magnitude of such harm, like uncertainty, mild embarrassment or boredom, is usually low. There are, however, instances where the possible magnitude of harm could be high, often in conflictive environments. IRBs should consider the social and cultural environment of each research project, the physical, psychological and political status of the research participants, and the complex power relationships between researchers and participants in particular situations.

Ethnographic research may involve significant risks of harm-for example, discrimination, disruption of personal and family relationships, loss of rights or claims, civil or criminal prosecution-usually as the result of disclosure of private, identifiable information such as data gathered in interviews, filmed on video, or recorded on tape or field notes. Ethnographers should inform IRBs and participants how they plan to use and protect data from disclosure and if personal identifiers and other data will be preserved or destroyed. Ethnographers should inform participants of the possible benefits and risks of providing identifiable information (e.g., data collected during the course of a study could be subpoenaed). Ethnographers should also respect participants' wishes if the participants would like to be identified and/

or credited.

The AAA supports the sharing of research data and encourages ethnographers to consider preserving field notes, tapes, videos, etc. as a resource accessible to others for future study. Ethnographers should inform participants of the intent to preserve the data and make it accessible as well as the precautions to be undertaken in the handling of the data.

The benefits of ethnographic research may be long-term and far-reaching. Examples range from helping people record their ways of life as part of their heritage, to gaining recognition of their needs and rights, or understanding institutions and processes of change through time, as well as assessing particular challenges institutions and societies face. Often the interview itself affirms the value of the respondent's experience and is a rewarding experience. Ethnographers should inform IRBs and prospective participants about the possible benefits of ethnographic research so that they can make a determination of the relative balance between benefits and harms.

4) Is ethnography exempt from IRB review?

According to the Common Rule (section 46.101(b)), certain categories of research may be exempt. "Exempt" means that research is not subject to the requirements of the Common Rule, including IRB review. Individual researchers are not free to exclude or exempt themselves from regulatory oversight. A researcher has a conflict of interest in this decision, and to avoid the possibility of biased decisions on whether or not an activity is exempt, such decisions should be made by one or more people not directly involved in the conduct of the research. Many institutions have policies and procedures that make the IRB responsible for making exemption decisions, but there is no regulatory requirement that such decisions be made by the IRB. The federal regulation is silent on whom makes the decision, and an institution may designate the head of sponsored research, a dean, department chair, the IRB, etc. to make the decision.

Research that may be exempt from the Common Rule includes research that involves only procedures within the exempt categories. The exempt categories include research

- "conducted in established or commonly accepted educational settings, involving normal educational practices."
- "involving the use of educational tests...survey procedures, interview procedures or observation of public behavior" unless the information recorded is individually identifiable and such research poses a risk to participants.
- "involving the use of educational tests...surveys procedures, interview procedures or observation of public behavior" where the participants are elected or appointed public officials or candidates for public office, or federal statute requires confidentiality of identifiable information.
- "involving the collection or study of existing data, documents, records" if these sources are public or information is recorded by the investigator in such a manner that the participants cannot be identified, directly or through identifiers linked to the subjects."

5) Does ethnography qualify for expedited review?

Expedited review means that the research poses minimal risk and the research is reviewed by only a subset of the IRB's members rather than by the full board. Much ethnographic research may qualify for expedited review because it is among the categories of research identified for expedited review in category 7 of guidance issued under the Common Rule (Section 46.110), and normally it involves minimal risk (<http://www.hhs.gov/ohrp/humansubjects/guidance/expedited98.htm>). Most ethnographic research involves the observation and interaction of the researcher with adult participants in ordinary life and poses risks not greater in and of themselves than those ordinarily encountered in daily life.

Although most ethnographic research involves minimal risk, IRBs cannot presume that all ethnographic research involves no more than minimal risk. Ethnographic research can involve significant risks. Although ethnographers often observe and record public behavior that involves minimal risk to participants, if, for example, the public event is videotaped and used by the researcher or others for purposes that may harm the participant(s) and the identity of the participant(s) can be ascertained, the research involves higher risk. This is particularly true in research that involves working with vulnerable populations, such as those with a potentially stigmatizing illness (e.g., HIV/AIDS), individuals engaged in illegal activities (e.g., sex work, drug use), or those whose civil rights have been compromised.

6) How is informed consent obtained and documented in ethnography?

Informed consent includes three key components: communication of information, comprehension of information, and voluntary participation. Informed consent is an interactive process that involves the researcher informing potential participants of the purposes and procedures of the research, the risks and benefits associated with the study, and how the data provided by the participant will be protected and stored. The ethnographer bears the responsibility of ensuring that the participants are fully informed of the intent of the ethnographic research, how the participants' information contributes to the research, and the anticipated risks and benefits the participants may expect to occur as a result of their agreement to participate in the research.

One of the most contentious areas of disagreement between IRBs and ethnographers is the documentation of informed consent. Some IRBs assume that all research resembles clinical, biomedical research and involves a clinician and client/patient in the US, an English-speaking and literate country where individuals, and only individuals, have the right to determine whether or not to participate in research. Yet, much ethnographic research takes place outside of the US, often in developing countries and among populations that may not be literate, and where the group or another individual may determine the right of an individual to participate in research.

At issue is the question of whether written informed consent is required to document participants' consent. It is often not appropriate to obtain consent through a signed form—for example, where people are illiterate or where there is a legacy of human rights abuses creating an atmosphere of fear, or where the act of signing one's name converts a friendly discussion into a hostile circumstance. In these and in other cases, IRBs should consider granting ethnographers waivers to written informed consent, and other appropriate means of obtaining informed consent should be utilized.

The Common Rule clearly allows IRBs to authorize oral informed consent. Section 46.117(c) of the regulations permits the waiver of written consent, either if the consent document would be the only form linking the subject and the research and if the risk of harm would derive from the breach of confidentiality or if the research is of minimal risk and signing a consent document would be culturally inappropriate in that context. Section 46.116(d) authorizes the IRB to waive informed consent or approve a consent procedure that alters or eliminates some or all of the elements of informed consent if four conditions are met: (1) the research is of no more than minimal risk; (2) the change in consent procedures will not harm the respondents; (3) the research could not "practicably be carried out without the waiver or alteration;" and (4) whenever appropriate, additional information will be provided to subjects after participation.

These regulations can be interpreted to provide alternative means of obtaining consent. Consent can be assumed in instances where the respondent is free to converse or not with the researcher and is free to determine the level and nature of the interaction between participant and researcher. This in no way absolves the anthropologist from clearly informing participants about the purpose and procedures of the study, its potential risks and benefits, and plans for the use and protection of ethnographic materials gathered during the study.

There are also situations in which some community authority must approve the research before any individual community member is asked to participate. In some communities an individual would be put at risk of community sanction if he or she agreed to participate in a research project without the formal approval by community authorities. In some cultural settings, a spouse or male household-head, rather than an individual person, may be the culturally or legally appropriate agent to provide consent.

In reviewing particular cases posing complex ethical questions, an IRB that does not have an ethnographer on its panel should consult an outside expert with knowledge of ethnographic research and/or the particular context in which the research will take place.

Relevant Codes and Documents:

American Anthropological Association

Code of Ethics

www.aaanet.org/committees/ethics/ethcode.htm

Office for Human Research Protections (OHRP)

Federal Policy for the Protection of Human Subjects ("the Common Rule") <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.htm>

Category 7 of Guidance Issued Under the Common Rule

<http://www.hhs.gov/ohrp/humansubjects/guidance/expedited98.htm>

United Nations *Universal Declaration of Human Rights*

www.un.org/Overview/rights.html

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