



AFS Position Statement on Research With Human Subjects

1. American Folklore Society Comments on Proposed Changes to the Common Rule (76 FR 44512)

Submitted electronically to the US Department of Health and Human Services on October 25, 2011

Like our sister learned societies in the humanities and social sciences, the American Folklore Society welcomes the joint initiative by DHHS and OSTP to reconsider the Common Rule. We are eager to see the revision of the human subjects review process so that it does not produce unintended consequences for the well-being of subjects or the ethical conduct of research.

We strongly endorse the detailed and carefully considered statement submitted by the American Anthropological Association. We are writing here also to add a few general comments from the perspective of folklore studies, a discipline in which scholars often work in close collaboration with community members on projects of mutual interest. Folklorists do not speak of their collaborators as "human subjects" but tend to consider them rather as knowledgeable partners in dialogue and as resources for exploring cultural forms and performances: these cultural practices, not their practitioners, are typically the object of our research.

Human subjects review of qualitative interpretive research commits a category error. OHRP regulations and individual IRBs have developed their procedures taking the controlled lab experiment as the paradigm of all research, but most humanistic research is framed as documentation, interpretation, or conversation.

Interactionist and interpretive research approach generalization differently from the interventionist research that is the appropriate object of human subjects review. The immediate object of ethnographic participant observation and interviewing is to gain knowledge of particulars: the specific complexities of a concrete situation. Interpretation and theory-building mostly come later, in the process of writing up. The researcher does not know beforehand the full parameters of what she will find on the ground. The methodology is therefore based on listening, observation, and conversation in the normal environment of the activity being studied. The ethics of such research demand that the researcher learn and follow the community's rules of conduct and take the community's lead in the direction of the research. This emergent process, with its continual negotiation of consent, is very different from the top-down "systematic investigation, including research development, testing and evaluation" defined by the Common Rule.

Naturally the researcher's presence changes things, in the way that any new entrant to a social setting changes things. When people of different backgrounds, agendas, and resources interact, there are social risks, and where representation and publication are taking place, these risks are exacerbated, in research as in journalism, art, education, politics, social activism, and many other realms of civic life.

We stress again the different center of gravity in interactionist and interpretive research. While humanistic research mimics the procedures of ordinary social life, scientific or interventionist research resembles the functioning of the modern state. The abuses possible in science are roughly comparable to those possible in government: the violation of personal autonomy and physical integrity. The ethical concerns characteristic of humanistic research—respect, reputation, and recognition—are those of civil society. Just as regulation maintains transparency and prevents abuses in government, so it can in



interventionist research. But the regulation of civic life is viewed with justified suspicion by democracies, and regulation raises comparable problems for humanistic research. Indeed, legal historian Philip Hamburger has made the case that federal human subjects regulations violate the First Amendment, inasmuch as they place a prior restraint upon speech, requiring that it be licensed before the fact. His argument is strongest in the case of research in which speech is the primary method.

The risks of humanistic research constitute a special case of the risks inherent in civil society. But just as we protect the freedoms of speech and association in the interest of democracy, so we should protect them in the interest of creating public knowledge. In civic life, social risks are managed not through regulation but through social control and public opinion. By the same token, social control, professional socialization, and peer review have long interacted to critique and improve the ethical conduct of humanistic research. The consensus emerging from these processes is formalized in disciplinary codes of ethics (such as those our own Society has adopted for our field), lapses from which are subject to serious social and professional sanctions.

While appreciating the concern displayed for privacy rights, the American Folklore Society strongly rejects the appropriateness of HIPAA-style standards for cultural and social research. Folklorists have historically studied marginalized or disempowered populations: minorities, women, workers, and rural people. Over our century and a half of disciplinary existence, we have learned to stop treating people as generic members of a social category or as passive "tradition-bearers." Individuals typically want credit for their knowledge, experience, and creativity. It would be absurd to strip individual identifiers from a study of Plácido Domingo's vocal technique or an intellectual history of the counterinsurgency strategy in the Iraq war. It is equally nonsensical to strip such identifiers from a study of gospel singers or grassroots activists: no intellectual sense can be made of their practices without the surrounding context. More importantly, to demand the suppression of individual identities denies these people the dignity and respect conferred on more powerful individuals.

To be sure, anonymity is often necessary: some research topics are sensitive or dangerous and many actors are vulnerable in their local contexts. Ethnographic researchers are trained to make case-appropriate judgments and to hold frank discussions with their community collaborators (i.e. research subjects) about the positive and negative ramifications of publicity.

There is another point regarding the concern about existing research data being turned to secondary purposes to which the subjects had not consented (4.v.). Again, the nature of humanistic data is different. We don't destroy the plays of Shakespeare because they have already been studied. We understand that these are cultural texts with ongoing power to speak to us, and are not exhausted by a single set of questions asked of them in a given moment. In the same way, the narratives recorded by oral historians and the performances documented by folklorists are cultural texts, primary documents of richness and complexity inaccessible to a single observer or historical perspective. Almost always, these texts are not pure artifacts of the research process itself, but have existed in multiple performances and venues long before that research began. Even the content of a directed interview has often been long-rehearsed in more intimate community conversations: sometimes we find that informants have just been waiting for an occasion to speak to a broader audience. Both researchers and interviewees/practitioners typically assume that their testimony or practices are important in their own right rather than merely as contributions to a specific research project. This mutual recognition is part of what is considered in the ongoing negotiation of consent, identification, and appropriate venues for publication.



We believe strongly that IRBs and DHHS need to conserve their resources to concentrate on the serious abuses possible in interventionist and particularly in biomedical research. We see the value of university-based peer review of interactive and interpretive research involving living people; such review can be especially useful with the growth of interdisciplinary projects where researchers may not have been trained in codes of ethics. But, as the AAA statement insists, such review needs to operate according to discipline-specific and locally-specific standards if it is not to do more harm than good, both to the quality of the knowledge produced and to the well-being of the individuals and communities involved.

We applaud DHHS and OSTP for the careful thought put into the Advance Notice of Proposed Rulemaking, and look forward to seeing the draft revised regulations.

2. AFS Position Statement on Research With Human Subjects

Approved by the AFS Executive Board in 2006

Preamble

The American Folklore Society: The American Folklore Society, founded in 1888, is an association of people who create and communicate knowledge about folklore. The more than 1,200 members of the Society today are scholars and teachers at colleges and universities, professionals in arts and cultural organizations, and community members involved in folklore work. The purposes of the Society are to stimulate and encourage interest and research in folklore in all its aspects; to aid in the dissemination of the results of such research; to promote responsible application of such research in the broad variety of settings in which folklorists work; to publish and distribute publications, reports and journals; and to serve as a bond among those interested in the study of folklore.

Folklore and folklorists: Folklore is the body of traditional art, literature, knowledge, and practice that is disseminated largely through oral communication and behavioral example. Every group with a sense of its own identity possesses and shares such a body of traditions which may be called folklore. Folklorists are trained scholars who undertake to record, describe, catalog, analyze, and explain such traditional knowledge and expression and to disseminate the products of this research in books, articles, films, recordings, museum exhibitions, and display events.

Folklore research: Most folklore research should be exempt from IRB review.

Folklore research is conducted to record and describe traditional art, literature, belief, material objects, and custom. Folklore research is ethnographic and participatory. Folklorists are instructed in traditional culture by the members of ethnic, occupational, religious, and other groups. The folklore being studied may be relatively public (festival, community dance, musical performance) or relatively private (family story, quilt making, home recipe or remedy).

In either case, the folklorist needs to build rapport with community members in order to describe the traditions and to learn how and why they are created and maintained and how and under what conditions they are performed and transmitted. Such fieldwork takes time and depends upon the development of a trusting relationship between folklorists and community members.



Folklore research is not conducted in laboratories or offices. Folklore research is not carried out with testing instruments, standardized questionnaires, or "control groups." Folklorists are not experimentalists or clinicians. The people with whom folklorists work are not selected from a pool, are not randomly chosen, and they are not subordinate to some experimental design. Folklore fieldwork is conducted in the public and private spaces of a community. Folklorists are guests in such communities. They can only work successfully at the invitation of and with the collaboration of the members of that community.

Bio-medical clinical and experimental models are inappropriate models for folklore research. Folklorists build relationships with people in order to learn about their ways of life and art. Not infrequently, these relationships last a lifetime. The people with whom folklorists work are not "human subjects"; they are artists, performers, hosts, teachers, and often, over time, they come to be friends. They help the folklorist understand their culture and its expressive forms.

The knowledge that results from folklore research is not quantitative but overwhelmingly qualitative. On occasion, a folklorist may employ a questionnaire or other survey instrument at the initial stages of research, but these are rapidly abandoned in favor of close conversation, careful observation, and prolonged participation. Folklorists seek to be educated by the people with whom they work. Consequently, folklorists seek instructions, demonstrations, explanations, commentaries, reflections, and reminiscences.

There is almost no folklore research that can be conducted using a pre-formulated set of questions. As folklorists learn more about the traditions that are the focus of their research, the kinds of questions they ask will necessarily change. Each response provokes new and unanticipated questions, each question leads to new areas of inquiry. In folklore and other ethnographic research, the questions to be asked cannot be known or formulated in advance. In many respects, folklore research is a type of investigative journalism; but it is deeper, longer lasting, and more responsible: the bonds established between the researchers and community members are more personal and enduring.

Folklore Research and the Protection of Human Subjects

Documentation of informed consent: Folklorists inform their consultants about the aims and methods of research. The nature of the relationships that folklorists build with their consultants, however, is such that a written, signed, legally effective document would be inimical to the relationship upon which folklore research is based. Folklorists cannot go as guests into people's home communities, build trust and friendships, and then present a legal document for signature. Nor can they ask for signatures to be witnessed.

Informed consent is given orally, and possibly can be recorded on audio- or videotape, but introducing a written legal document into the folklorist-consultant relationship would generally prove an insult to the consultant and bring folklore research to a halt. Institutional review boards should alter or waive the requirements for written informed consent in the case of folklore and other forms of ethnographically based research

There is clear justification for this position as well in the Federal regulations: "An IRB may approve a consent procedure which does not include, or which alters, some or all of the elements of informed consent ... or waive the requirement to obtain informed consent provided that ... the research could not



practicably be carried out without the waiver or alteration" (45 CFR § 46.116). "An IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds ... that the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside the research context" (45 CFR § 46.117)

Confidentiality: Folklorists document folk traditions. They do not destroy such documentation but preserve it in their own files, in archives, and make it known through publications and exhibitions. Folklorists inform consultants of identifiable materials prior to publication and exhibition and obtain written consent for the placement of materials in public archives. Folklorists guard the confidentiality of their consultants when such confidentiality is requested. In most, instances, however, consultants want their contributions to research to be made known. They want to be acknowledged for their contributions and be recognized as community artists and experts in local traditions.

In such cases, the folklorist acknowledges their contributions in books, articles, exhibition catalogs, and displays. However, the folklorist would keep confidential such information as might place the consultant "at risk of criminal or civil liability or be damaging to the subject's financial standing, employability, or reputation" and would forewarn the consultant that such information might not be kept confidential were records subpoenaed as part of some legal action.

Student class projects: Folklore courses in universities often require students to establish relationships, collect folklore, and interview consultants as part of the instruction in the theories and methods of folklore research. Such classroom assignments are educational and are not intended to result in a "systematic investigation, including research development, testing and evaluation, designed to contribute to generalizable knowledge." They do not constitute "research" in any sense intended by the section of 45 CFR § 46.102 just cited, and should be exempted from institutional review. It should be left to class instructors to inform the students of their ethical responsibilities and oversee the assignments that are a part of course curricula.

Statement on Ethics of the American Folklore Society: The American Folklore Society has its own code of ethics that spells out the responsibilities of folklorists to those studied, to the public, to the discipline, to students, and to sponsoring organizations and governments. What follows is the American Folklore Society's statement on folklorists' responsibilities to those whom they study:

- In research, folklorists' primary responsibility is to those they study. When there is a conflict of interest, these individuals must come first. Folklorists must do everything in their power to protect the physical, social, and psychological welfare of their consultants and to honor the dignity and privacy of those studied.
- Where research involves the acquisition of materials and information transferred on the assumption of trust between persons, the rights, interests, and sensitivities of those studied must be safeguarded.
- The aims of the investigation should be communicated as much as is possible to the informant.
- Consultants have the right to have their identities remain confidential. The right should be respected both where it has been promised explicitly and, as much as possible, where no clear understanding to the contrary has been reached. These strictures apply to the collection of data by means of cameras, tape recorders, and other data-collecting devices, as well as to data collected in interviews.



AMERICAN
FOLKLORE
SOCIETY

- There shall be no exploitation of individual informants for personal gain. Fair return should be given them for all services.
- There is an obligation to reflect on the foreseeable repercussions of research and publication on the general population being studied.
- The anticipated consequences of the research should be communicated as fully as possible to the individuals and groups likely to be affected.