Introduction:
Anxious borders between work and life in a time of bureaucratic ethics regulation

Over the past few decades, anthropologists have reassessed the value of fieldwork “at home,” in particular, and reviewed the disciplinary status of field practice, in general—in both cases from various angles—in light of the shifting contemporary circumstances and opportunities for ethnographic work. The articles in this AE Forum extend that scrutiny by focusing attention on informality in ethnographic fieldwork both at home and away. Informality here refers to the un-demarcated moments of ethnographic practice when “research” and “daily life” are inextricable. Informality is a prominent feature of partly or wholly unfunded (self-funded) research pursued part-time at home; it is also evident, if less notable, perhaps, in funded research anywhere, insofar as “doing fieldwork” is all about embedding oneself in ongoing social situations not designed by the investigator. Although informality is a long-standing, acknowledged fact in ethnographic sociology—in which unfunded research at home is the norm—it is as yet largely unremarked in anthropology despite being a common corollary of the trend to home-based fieldwork.

In both disciplines, informality demands explicit attention because it has recently become problematized in new ways in the United States. For over three decades, institutional review boards (IRBs) have overseen researchers’ compliance with U.S. federal regulations concerning ethical “human subjects” research. During the past five or six years, however, federal regulators have been on high alert, a stance passed along to local IRBs as an increasing fear of legal and financial consequences to their home institutions should they slacken efforts to fulfill their internal monitoring responsibilities. Federal regulations presuppose a research process whose locations, time frames, personnel, and protocols are all clearly demarcated (in funding proposals, typically) such that research may be clearly distinguished from a scholar’s “ordinary life,” in which other ethical guarantees and constraints (like the First Amendment and libel laws) apply. Against this presumption of clearly bracketed research, informal fieldwork blurs the work–life distinction.

Consequently, ethnographers working informally in the United States have encountered ethical, political, and regulatory ambiguities,
administrative frustrations, and, occasionally, serious trouble. The articles in this AE Forum provide several case studies; explore some of the historical, structural, and political contexts; and offer suggestions for action—as openings for discussion of the regulatory problems associated with informal research. They take a sounding of anthropological and sociological experience with research that flies under the radar, and with researcher identities that slide among subject positions, along the way identifying some if its contradictory ethical-political entailments and raising both epistemological and practical questions.

Background

Although the articles that follow provide important background and offer guidance for further reading, an initial historical overview may help. A response to revelations concerning Nazi medical experimentation, the Nuremberg Code is arguably the foundational text for subsequent international agreements concerning research involving human beings, notably, the 1964 Declaration of Helsinki (World Medical Association 2002). The Helsinki declaration elaborated a set of universalistic ethical principles concerning the treatment of medical-research participants—including informed consent, confidentiality, and protection from harm—that have been integrated into many national and funding-agency research ethics codes.

The history of the current human-subject protections system in the United States is well documented (see the history module of the National Institutes of Health [NIH] online ethics-certification course [National Cancer Institute n.d.], which has links to the major national and international documents; and see, e.g., Faden and Beauchamp 1986 and citations elsewhere in this AE Forum). Although it was not the first such exposition (McCarthy 2001), Henry Beecher’s 1966 New England Journal of Medicine article documenting scores of horrifying U.S. medical-research abuses prompted the NIH to develop its Policies for the Protection of Human Subjects that year. In 1972, media exposure of the Public Health Service’s Tuskegee syphilis study—which had been regularly reapproved over its 40-year duration (Jones 1993)—led to passage of the National Research Act of 1974. This act raised the NIH guidelines to federal regulatory status when they were adopted by the Department of Health, Education, and Welfare (now the Department of Health and Human Services [DHHS], of which NIH is part) as “Code of Federal Regulations, Title 45 ‘Public Welfare,’ Part 46 ‘Protection of Human Subjects’ ” (DHHS 2005). The 45 CFR 46 regulations became known as the “Common Rule” in 1991, when 16 other federal agencies that fund human-subjects research signed on (each using its own regulatory reference code).

As specified in 45 CFR 46.103, each institution that plans to accept federal research funding must file an “assurance” with the federal agency providing the funds or else have a Federalwide Assurance (FWA) on file with the NIH–DHHS Office for the Protection from Research Risks (see, esp., Shweder this issue). This document obligates those institutions to set up one or more IRBs (often referred to as “human-subjects committees”), and has several other procedural provisions (DHHS 2005:103[b]). Notably, IRBs are mandated to perform prospective reviews of research plans, and their judgments are final (there is no appeal process).

Research ethics regulation in the United States may be unique for its relatively long history compared with that at the national (government or funding-agency) level in other countries. The United States is not unique for orienting its research ethics regulations around biomedicine, however. A cursory review of position papers from the European Union (e.g., see Lewis et al. [2004] on European Codes of Practice 2002), the United Kingdom (see, e.g., University of York and Oxford Brookes University 2003–05 for Economic and Social Research Council documents and many useful links), Canada (Jorgensen n.d.; Panel on Research Ethics [PRE] 2004), Australia (Chalmers 2001), and elsewhere suggest that biomedical research risks in the context of global inequalities have been the main motive and focus for the development of ethics codes and guidelines by funders, professional associations, and national agencies. On account of this widespread original motive and focus, developing ethical rubrics appropriate to social-science and humanities work is a pervasive contemporary concern. Needless to say, the structural and political challenges faced by social researchers around the world are not monolithic.

For example, there is wide variation in the European Union (such that a key contemporary project aims for “the harmonization” of diverse funding-agency, professional association, and national research ethics codes); however, at the same time, “there are no formal ethics approval procedures and issues such as informed consent, confidentiality, and dissemination of information to research participants are not reviewed at the funding stage” (Lewis et al. 2004:5). Canada’s recently published advisory guidelines for social research (PRE 2004)—aimed at changing the provisions of the Tri-Council Policy Statement that governs the practices of Canada’s three main funding agencies—are exemplary in their recognition of the “spectrum” of disciplinary methodologies and ethical frameworks; their sensitivity to the needs of fields that, as those advisory guidelines put it, do not adopt “paradigmatic/positivist/experimentalist assumptions”; and their acknowledgment of the importance of protecting both academic freedom and human research participants. Still, “there is no national accreditation or compliance, surveillance or oversight system in place” (Lewis et al. 2004) for research ethics boards (the Canadian equivalent of U.S. IRBs).

Against this background, one may consider the U.S. situation. It is important to note the strikingly accidental quality of the U.S. system of human-subjects protection regulations,
in particular its origin as an incremental reworking of narrowly medical NIH guidelines rather than as a more deliberately designed system developed on the basis of systematic, broad-based consultations with representatives of the disciplines to be regulated (see, e.g., Pattullo 1982, 1984). Because of this particular history, the code has been a problem for social researchers from inception (i.e., the present hue and cry recapitulates protests that were already sharp and sophisticated in the 1970s). Inconsistencies in the U.S. regulations likely reflect their cut-and-paste history, whereas, elsewhere, human-research ethics codes may have emerged from more apparently systematic processes without necessarily happier results. In Britain, for example, one needs to take account of the generally fraught situation of universities and research bodies, in which reductive accountability standards, modeled on the financial audit, have to be continually accommodated or resisted (Strathern 2000).

For U.S. social research, a defining moment came in 1979, when a national commission, established by the National Research Act of 1974 to develop policy and procedures, published a statement of general ethical principles known as the “Belmont Report” (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1979). The Belmont principles—“justice,” “beneficence,” and “respect for persons”—still guide the federal system and inform basic IRB procedures: respectively, the scrutiny of research-subject selection; harm–benefit calculi; and informed consent and provisions for preserving confidentiality. Nevertheless, regulatory revisions also issued in 1979—which expanded 45 CFR 46 application to all research regardless of funding—provoked months of heated criticism by social scientists, and new revisions were published in 1981 (see, esp., Pattullo 1982; Tropp 1982). Confusion over the resulting tangle of rulings prompted the writing of a book-length IRB Guidebook in the early 1980s (Penman with Porter 1993), to no effect.

One wonders nowadays whether history is repeating itself. Ever since 45 CFR 46 became the “Common Rule” in 1979, various national and presidential study commissions have been convened, hearings held, and reports filed in efforts to rework the system. The most notable of the commissions, the National Bioethics Advisory Commission (NBAC), held hearings over a six-year period and, just a few years go, issued its final policy recommendations for an overhaul of the federal system (NBAC 2001). As the NBAC was completing its work, however, a series of medical research tragedies at major research universities, such as the University of Pennsylvania and Johns Hopkins University, provoked an upsurge of regulatory hypervigilance, both nationally and by local IRBs, and a reactive growth of regulatory oversight—IRB “mission creep”—into new research areas decidedly distant from those for which the regulations were designed. All of this has reawakened concern along a wide spectrum of affected parties—including not only social scientists but also literature professors, oral historians, lawyers, and journalists—and prompted a round of meetings and position papers by individuals and professional associations (e.g., American Association of University Professors 2001, 2002; Gunsalus et al. 2005) and the beginnings of a major rethinking of the legal basis for the regulatory system as a whole (e.g., Hamburger 2005).

**AE Forum articles**

The collective focus of the articles in this *AE Forum* is relatively narrow, concerned with the U.S. situation, in general, and with problems regarding IRB oversight of ethnography, in particular.

First, although the set of articles does not address the issue directly, there is no doubt about the importance of attending to differences, similarities, and mutual influences among cross-national discourses on ethics codes, regulation, and accountability. Anthropological and other kinds of social research crosses national borders, of course, and may involve cross-national collaborations, all of which necessitates an awareness of the politics of diverse national regulatory situations. The *AE Forum* commentary accompanying these articles provides a glimpse of that global canvas.

A comparative framework would help clarify the specificity of the U.S. case. Along with a better understanding of the political dynamics of funding, access, and corporatization in U.S. educational institutions, a comparative perspective might both sharpen and nuance the rapidly emerging national debate about conflicts between the present system for ensuring ethical human-research practice, on the one hand, and, on the other hand, First Amendment rights of social researchers as citizens and related principles of academic freedom that protect critical research so central to the mission of the nation’s colleges and universities. This is an important focus most especially of the articles by Jack Katz and Richard A. Shweder. Useful comparisons may be drawn between this emergent U.S. discourse and parallel Canadian arguments over academic freedom in the regulation of social and humanistic research.

Second, these articles pay special attention to qualities of ethnographic fieldwork that set it apart from other kinds of social research. Without question, fieldworkers in anthropology, sociology, nursing, education, and other fields also conduct systematic surveys and formal interviews: structured interactions in which the researcher works to control contextual factors like topical frames and sequences. But participant-observation is distinctive for placing contextual control into the hands of research participants, a characteristic that makes it uniquely problematic for IRB regulation (as even regulatory insiders have long recognized). Exaggerating the point, the articles zero in on partly or wholly self-funded research “at home,” in which the fieldwork–everyday life distinction is maximally blurred.
All of the anthropologists represented in this set of articles have previously done funded fieldwork outside the United States—Daniel Bradburd in Iran, Rena Lederman in Papua New Guinea, and Shweder in India—as well as the work described here; sociologist Katz has conducted ethnographic work on urban neighborhoods, law, crime, emotions, and other topics in the United States. Reviewing the regulatory situation to introduce our collective concerns, Lederman reports the results of a comparative investigation into disciplinary knowledge-making for which IRB discourse is both content and context. She locates the grounds for ethical–methodological miscommunication among practitioners from related disciplines and identifies presuppositions in the federal regulations that weigh particularly heavily on ethnographers. Bradburd provides contrastive cases involving studies both of everyday attitudes and behavior and of marginally legal practices. He uses these illustrative examples of informal ethnographic work as opportunities to reflect on the process of deciding whether, when, and how to make the work known to his IRB.

Lederman and Bradburd suspect that their circumstances, experiences, and choices working with elites and ordinary people of various sorts are not idiosyncratic. With cases like these in mind, Katz offers an ambitious, detailed analysis and critique of the impact of federal regulation on fieldwork, paying particular attention to ethnographic sociology. Arguing that ethnographers have been driven underground by the ways that IRBs have come to interpret federal regulations, he outlines a strategy of practical responses that will enable researchers to be both ethical and aboveboard.

The articles’ emphases complement one another. We hope that, together with AE Forum commentary, they productively inform, provoke, and refresh anthropological discussion.

[institutional review boards (IRB), mission creep, ethnography, fieldwork, research ethics, audit, unfunded research, informality]

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Introduction: Anxious borders between work and life

American Ethnologist


Panel on Research Ethics


Pattullo, E. L.


Penslar, Robin Levin, with Joan P. Porter


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