

The Case Against Ethics Review in the Social Sciences

Zachary M. Schrag

Associate Professor

Department of History and Art History

George Mason University

zschrage@gmu.edu

When did scholars in the social sciences and humanities begin complaining about human subjects ethics committees? It was not in the 2000s, when public bodies in the United Kingdom and Australia expanded the reach of these committees, nor was it in the 1990s, when a series of harsh government enforcement actions in the United States led American universities to tighten controls on scholars in all disciplines, the social sciences included.

No, social scientists have been skeptical of ethics committees (variously called research ethics committees, research ethics boards, human research ethics committees, institutional review boards, or other terms, depending on the nation and the institution) since they were first proposed in the early 1960s. As early as 1966, they feared that

some institutions may be over-zealous to insure the strictest possible interpretation, that review committees might represent such a variety of intellectual fields that they would be unwieldy and incapable of reasonable judgment in specialized areas, and that faculty factions might subvert the purpose of review in the jealous pursuit of particular interests. There is also the danger that an institutional review committee might become a mere rubber stamp, giving the appearance of a solution, rather than the substance, for a serious problem of growing complexity which requires continuing discussion. Effective responsibility cannot be equated with a signature on a piece of paper. [1]

The author of these words, sociologist Gresham Sykes, was reporting apprehensions of what *could* happen. After decades of experience, today's scholars can complain about what *has* happened, to them and to their colleagues and students. Yet their grievances largely track those outlined by Sykes nearly half a century ago.

By 2007, sociologist Charles Bosk could write of a "chorus of complaint from ethnographers [about the] mismatch between the bureaucratic requirements that concern prospective review and the ethical dilemmas that are part of our lived experience." [2] His chorus metaphor is doubly apt, for it suggests both voices raised together to increase their volume, and also a sense of repetition that leaves the listener eager for the next verse.

If anything, the chorus is both louder and more repetitive than Bosk imagines, for it includes not only ethnographers, but action researchers, survey researchers, oral historians, political scientists, communication scholars, legal scholars, geographers, and others who cannot understand how they got caught up in regulations apparently designed for medical experimentation. As scholars loyal to their disciplines, they have largely published in their disciplinary journals and newsletters—anthropologists writing for anthropologists, political scientists for political scientists, and so on. (I am guilty of this myself, having published my first pieces on ethics review in periodicals read mostly by historians.) And as any fan of Gilbert and Sullivan knows, when the chorus sings in parts, many clever lines get lost amid the overall clamor.

In December 2006, I decided that one way to sort out the voices would be to start a blog that would gather relevant items as they were published, serving as a clipping service not just for me but for anyone else interested in the topic of ethics review of the social sciences. I find some items with Google alerts, some through tips from readers of the blog, and some through the old-fashioned method of following citations. I do not claim to have caught every relevant item, but I can say I haven't seen anyone with a more thorough bibliography on this subject than mine, though there are others as good. [3,4]

If nothing else, maintaining the Institutional Review Blog (institutionalreviewblog.com) has taught me that this question consistently interests scholars, so that I have had no trouble finding material about which to write. I was unpleasantly surprised to learn that writings about ethics review tend to cluster, so that after weeks of having nothing to say, I am often confronted with more than I can handle. On average, however, I have found something of note about once a week.

After four years, however, this weekly compilation has grown a bit unwieldy, especially for those new to the topic and unfamiliar with the most common assumptions of various players. And while I was able to synthesize some of the concerns in my 2010 book, *Ethical Imperialism: Institutional Review Boards and the Social Sciences, 1965-2009*, its goal was to explain the historical origins of the debate, rather than parse the anti-ethics review position as it now stands.

This essay, then, is designed to revisit some of my favorite writings on ethics committees, to organize the complaints thematically rather than by order of publication, and to serve as a brief restatement of the major critiques of ethics review.¹ I say critiques, plural, because the chorus consists of multiple, independent parts. One need not believe all of the parts to begin to doubt that social science and humanities research should be subject to review.

1

Longer comments on many of the items noted here can be found on the blog, Institutional Review Blog, www.institutionalreviewblog.com. In some cases I have repeated short passages from the blog here, rather than rewrite points I think I made well the first time. Bosk offers a helpful six-part taxonomy of the complaints in "New Bureaucracies of Virtue," 199-200. While adopting some of his categories, this essay omits some and seeks to add others.

I do not claim that only scholars in the social sciences and humanities have these complaints; medical and psychological researchers also complain about delays and restrictions that appear to be out of proportion to the risks faced by subjects. [5,6]. But the bulk of the work in those fields is of the quantitative, experimental sort that was envisioned by the creators of the ethics review system. Indeed, both medical and psychological researchers played important roles designing that system, which cannot be said for scholars in other social sciences and the humanities. [7]

Nor do I claim that all or even most scholars in the humanities and social sciences hold these positions, though what quantitative data exist suggest that a great many do. For example, a recent survey of ethnographers found that “only 8 percent believed that the proposed changes [recommended by their ethics committees] would protect informants, and 32 percent of the respondents actually believed that the modifications were “detrimental to the welfare of the informants or research participants.” [8] And policy makers—particularly in the United States and Canada—are beginning to pay attention. In late 2010, Canada revised its *Tri-Council Policy Statement* to address some of the concerns expressed here. And in July 2011, the U.S. government proposed reforms in part from the recognition that “Over-regulating social and behavioral research in general may serve to distract attention from attempts to identify those social and behavioral research studies that do pose threats to the welfare of subjects and thus do merit significant oversight.”[9]

Thus, though I do not expect readers of this essay to accept all of the charges against ethics review, I hope they will take them all seriously.

Ethics Committees Impose Silly Restrictions

The first thing to understand about the critique of ethics committees is that it is grounded in bitter, bitter experience. People who devote their lives to the study of others are often quite concerned with ethics, and when they learn that their universities maintain ethics committees, their first reaction is often eager cooperation. But that goodwill can evaporate quickly when a researcher loses an afternoon to online training that is obviously irrelevant to the ethical challenges she faces, or when a committee imposes reporting requirements or restrictions that make the work difficult or impossible.

Horror stories about ethics committees pop up on blogs, in scholarly publications, in reports by professional associations and faculty senates. I have collected a good number of them in my book and on my blog, and I will not try here to repeat them all. Rather, let three stories mark the boundaries of the problem. For sheer silliness, it may be hard to beat the case reported by Will van den Hoonard: “A member of a departmental ethics committee told a graduate student to turn her face the other way when she was doing participant observation in a group that had any human subjects who did not explicitly consent to the research.”[10]

The only rival could be the report of Irena Grugulis, who was “conducting an ethnography of a computer games company, watching the way people learned skills and the way they were managed. No under-18s, no members of vulnerable groups, no illegal

activities.” But her ethics committee “insisted on full written consent from every worker in the offices (about 250), every delivery person and – on the occasions I went off for a chat with informants – every barrista who served us coffee and waitress who brought us pizzas (no, seriously). An extensive correspondence later, since that would have effectively made an ethnography impossible, they grudgingly agreed to let me proceed and turned their attention to other social science projects.”[11]

At the other extreme—dead seriousness—is the case of Scott Atran, who wished to interview failed suicide bombers in an effort to understand the causes of terrorism, but was thwarted by an ethics committee that believed that prisoners cannot give free, informed consent to be studied, and interviews could put as-yet-uncaptured terrorists at risk of arrest. Atran recognizes the ethical challenges of his research, yet he wishes his ethics committee had placed more value on finding ways to avoid future murderous bombings. [12] In between the silly and the serious are countless other examples. Most go unreported, but enough make it into print to keep me busy.

In most of these cases, ethics committees seem to apply the standards of medical experimentation without thinking about the differences between that work and social science. If one cannot inject an experimental drug into people without their consent, one cannot—they reason—look at people without asking permission, or order coffee without a written consent form. And if society has abandoned the practice of using prisoners as convenient guinea pigs for medical experiments, then perhaps it is wrong to even talk to prisoners about their political beliefs.

Perhaps most damning, though, are not the stories of individual studies thwarted, but those that reveal wild inconsistency from one committee to the next. Any system of judgment—peer review, tenure review, figure-skating judging—will produce variation. And hard cases can be expected to be decided in one way by one committee, and in another way by another committee. [13] But researchers report a level of inconsistency so great that committees might as well be throwing darts at a board. Within universities, committees fail to explain the bases for their decisions, leaving researchers guessing about what kinds of research are acceptable. [14] In extreme cases, a committee may applaud part of an application as “eloquent and well-grounded in the literature,” only to fault the same section when the same application is reviewed after revisions. [15]

The variation is greater from one institution to the next. [16] For example, Australian scholars Greg Bamber and Jennifer Sappey found that James Cook University bans snowball sampling, a tool used widely by sociologists elsewhere, while the University of Newcastle idiosyncratically requires all research participants to be given the chance to edit or erase audio recordings. [17] Researchers who are required to seek permission from multiple ethics committees—for example, those who want to study students or faculty at more than one university—find that committees disagree wildly on what level of review or restrictions that project needs. [18–21] Likewise, an identical proposal sent to eighteen ethics committee chairs produced dramatically varied responses.[22] As Atran puts it, “Lack of inter-board reliability is a guarantee of lack of validity in judgment of facts and in judgment of values.”

Confronted by such restrictions, most scholars simply live within the system the best they can. One cannot work in a large institution like a university without some tolerance for silliness. But a vocal minority have turned their analytical talents to understanding why they are not free to conduct the research they were hired to do.

Ethics Review Is a Solution in Search of a Problem

The first complaint of scholars is that policy makers justify ethics review by pointing to a proven record of abuses, and that no such record exists for the social sciences and humanities. Governments began requiring ethics review for medical experimentation only after a series of public, documented abuses. In the 1960s, Dr. Henry Beecher documented dozens of cases of unethical medical research. In the early 1970s, the Tuskegee Syphilis Study became the topic of a national debate in the United States in 1972 and 1973. [23] Such abuses continue, and scholars and journalists keep uncovering past studies that wronged their subjects. [24]

Policy makers have long used these stories to explain the restrictions placed on today's researchers. The *Belmont Report* in the United States, the *National Statement on Ethical Conduct in Human Research* in Australia, and the *Tri-Council Policy Statement* in Canada all allude to experiments in Nazi prison camps and other atrocities of medical research. Such allusions also appear when individual policy makers justify mandatory ethics review. For example, in July 2008, Jeffrey Botkin of the U.S. Secretary's Advisory Committee on Human Research Protections has explained that Beecher's "work illustrated that there were systematic problems with how research was conducted due to the lack of ethical standards, lack of peer review, and the lack of informed consent." Finding "no widespread systematic serious abuses of ethics occurring within our oversight system," Botkin judged the oversight system a success. In short, ethics committees were designed to fix *systemic* problems in the conduct of medical research.

No one has demonstrated such *systemic* problems in the conduct of social science, either before or after the imposition of ethics review. To claim that ethics committees protect participants from harm by social scientists is therefore akin to attributing the lack of tiger attacks in an American town to one's possession of a tiger-repellant rock. [25]

To be sure, social scientists—like tigers—occasionally hurt people. Ethicist Brian Schrag offers the example of anthropologist Nancy Scheper-Hughes, who, in 1974 and 1975, studied the residents in an Irish village. When she published her book in 1979, the villagers read it and took grave offense at some of its contents, such as the suggestion that adult brothers and sisters living together harbored "incestual preoccupations and anxieties." When she returned to the village twenty years later, they were still angry. "How *dare* you suggest that there is something not quite right with those God-fearing households of brothers and sisters?" one villager demanded. "What gave *you* the right to say those things?" [26] Troubled by such confrontations, Scheper-Hughes wrote in a revised edition that "I would now eat my words if I could." [27] Sociologist Sudhir Venkatesh was equally remorseful. While researching the underground earnings of the residents of a Chicago housing project, Venkatesh naively shared some of his notes with two powerful residents who used the information to extort additional money from their

neighbors. While his dissertation was progressing nicely, he realized that “other people were paying a price for my success.” [28]

But compared to the problems of medical research, serious social-science abuses are quite rare. As the human-subjects-research officer at the National Science Foundation from 1993 to 2006, anthropologist Stuart Plattner worked to mediate conflicts between ethics enforcers and social scientists, and he recalled receiving a proposal to conduct anthropology in a region of Mexico recently torn by violence, with no understanding of the risks such research could impose on respondents. Still, he noted, “in all the years I was responsible for human-subjects issues at NSF, I never learned of one case in which a respondent was actually harmed from participation in anthropological research.” He concluded, “although the possibility of harm to participants in ethnographic research is real, the probability of harm is very low.” [29]

Ethics Committees Lack Expertise

Despite the fairly clean record of social science, ethics committees are prone to overestimate the dangers. One study found that few research participants felt threatened or embarrassed by questions about sensitive topics, like illegal drug use. But ethics committees commonly require consent forms that warn participants about such feelings. [30] Committees often imagine that asking people about past trauma will “retraumatize” them, despite research showing that trauma victims benefit from having the chance to talk. [31]

A major reason committees ignore such empirical research is that, unlike peer review committees, ethics committees are not necessarily representative of the disciplines they govern. In many cases they oversee so wide a range of research they cannot possibly master it all. Historians may find themselves subject to the orders of boards that include no historians and are chaired by nutrition professors who see no ethical differences between interviewing an adult and building a DNA database. [32] Internet researchers complain of having their work reviewed by boards unfamiliar with the problems raised by their work, and unsure even whom to ask for advice. [33] Atran’s research on international terrorism was blocked by a board chaired by an expert in “the effects of hydrophobic and hydrophilic glass coatings, window tinting, and defrosters/defoggers on visual performance and driving behavior.” [34] “Back off,” one interview researcher imagined telling a board member. “You’re a chemist.” [35]

Qualitative researchers face a particularly tough time when their research is reviewed by committees that understand only quantitative data. “The numbers should come through in the paper,” shouted a hospital ethics committee member at Stefan Timmermans, an ethnographer who had come to observe the emergency room. “This is not systematic. What about statistics! . . . If you write something, we should know HOW MANY PEOPLE said WHAT, there should be NUMBERS in here. There is NO DATA in this paper.” [36]

Nor do ethics committee members appear eager to learn about the research they review. When University of California staffers tried to begin ethics committee meetings with “5

to 15 minutes of meeting time to developments in subject protection,” they found that the busy faculty members who made up the committees would skip that part of the session. [37] As Joan Sieber lamented in 2001, “There is now a literature of virtually hundreds of approaches to protecting privacy or assuring confidentiality. This literature is rarely sought out by IRBs, researchers, or teachers of research methods. Most are not even aware that it exists. . . . Many IRB chairs, members, and staff persons are not in a position to effectively guide or teach their clientele, or to gain the respect of their clientele.” [38] Indeed, such disrespect appears in the actions of scholars who game the system by deliberately withholding or shading information. Anthropologist Mary Gray wanted to be sure that her committee did not require her to get permission from the parents of the minors whose sexual identities she was studying, so she exaggerated the danger that such a requirement would pose, and won approval. [39]

For the most part, such researchers must guess at what happens to their applications behind closed doors. A few researchers have gained permission to watch ethics committees at work, and what they found is distressing. Maureen Fitzgerald noted that “the periods of greatest scrutiny and discussion occur at the very beginning, shortly before the end of the session and just before and after a break.” The last one or two applications will either get quickly approved or sent back to the applicant while committee members have their minds on other things. [40] But the beginnings of meetings are not always reliable either.

Sociologist Laura Stark observed misbehavior in three university ethics committees, one in a medical school and two at universities without medical schools. Committee members attempted to judge projects based on poor understanding of the methods involved, an overestimation of risks, and a reliance on personal experience rather than scholarly research. All three committees judged proposals based on the proportion of spelling and typographical errors in the proposal. [22] Such behavior, I believe, represents what Sir James George Frazer called the practice of “homeopathic magic.” As Frazer put it in *The Golden Bough*, “the magician infers that he can produce any effect he desires merely by imitating it.” [41] In this case, the proposal serves as a magic charm, and a tidy proposal guarantees an ethical research project. That ethics committees would resort to such practices is strong evidence that they lack the expertise to judge proposals on their merits.

Ethics Committees Apply Inappropriate Principles

Many social scientists charge ethics committees with misunderstanding not only research methods, but also research ethics. In the United States, at least, committees treat the Belmont Report as a guide to all research ethics, rather than a codification of medical research ethics as they existed in 1978. “Extending [the Belmont Report] principles to other, non-experimental research settings without making the underlying mode of science and its methodology explicit and without exploring their suitability to non-experimental scientific modes and methodologies has resulted in a hodgepodge of ethical guidance that is confused and confusing,” complain Dvora Yanow and Peregrine Schwartz-Shea. “Those guidelines do not give the many serious ethical problems of field research design and methodologies the sustained attention they deserve.”[42]

Particularly important is the charge that ethics review precludes research that could harm research participants, even when such harm is appropriate. Typically, such charges imagine a researcher who is studying powerful people and institutions and may want to expose their wrongdoing. Bamber and Sappey offer the example of Huw Benyon who, without permission, observed a Ford factory where he witnessed such scenes as managers' demanding that workers keep producing despite the presence of their co-worker's corpse. Such research, they suggest, may well do harm to the corporation, but that is no reason for it to be restricted.[17] Similarly, Peter Moskos, a sociologist who served as a police officer, argues that ethics committees' standard requirements of confidentiality should not prevent a researcher from reporting a serious act of police brutality.[43] And public health researchers complained of being forbidden to purchase individual cigarettes to determine which stores sold these "loosies" in defiance of laws intended to discourage youth smoking.[44]

Even rules that seem to protect vulnerable groups may threaten vulnerable individuals. For example, Canada's 1998 *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* required researchers to get approval from Band Councils before interviewing Aboriginal peoples. But that meant that dissidents within Aboriginal communities would need their opponents' permission to speak with an outside researcher. [45]

To be sure, some social scientists hold themselves to the medical admonition, "do no harm." In 2010, the American Anthropological Association's ethics task force sparked a spirited debate when it proposed that the association's Code of Ethics state that "Anthropologists share a primary ethical obligation to avoid doing harm to the lives, communities or environments they study or that may be impacted by their work." Some respondents embraced the idea, and others complained that it did not go far enough—anthropologists had a duty to do positive good.

But some anthropologists pointed out that what is good for some people may inevitably harm others. "I work," wrote Bryan Bruns, "in conjunction with communities and a government agency, to design and support a process in which communities are likely to, in a reasonably democratic way, act to restrain the behavior and thereby (harm) reduce the benefits of a few people (upstream irrigators, large landowners) who currently take advantage of others, it's not clear how a principle of 'do no harm' would allow any practical engagement." James Dow similarly rejected the medical borrowing from medical ethics. "'Do no harm' is an good ethical principle to be applied to individual social relationships, which we hope that we understand," he wrote. "However, there is a problem when applying it to larger societies and cultures." [46]

In other words, ethics review may be bad for ethics. "The most serious defect of the current regulatory system," writes Charles Bosk, "is that the requirements of policy reduce and trivialize the domain of research ethics. In the process, our ability to conceptualize, discuss, and make sense of the ethical problems of ethnographic work is dulled. As we do our work, we face ethical dilemmas aplenty, almost none of which have to do with the dual mandate of prospective research review—the adequacy of the consent

process, which is invariably reduced to concern about a ‘formal document’ or potential risks to subjects.”[2]

Ethics Review Harms the Innocent

Even as it shields wrongdoers from accountability, ethics review hurts those who have done no wrong. Obviously, it imposes burdens on university-based researchers, whether they abandon promising projects, get less work done, make do with lower response rates, or leave ethics-committee meetings in tears.[47,48] Student researchers lose the most. Since they are often on tight schedules, they may be the most likely to abandon projects in the face of ethics-committee sluggishness.[49–51]

But we should not think that professors and students are the only victims. People who participate in research have interests too. Some scholarly endeavors, termed participatory research or action research, seek to include members of a community as full collaborators in a project. When ethics committees insist on anonymity for such participants, they may be stripping co-authors of the credit that is due to them.[52,53] And even when participants do expect their identities to be concealed, they have an interest in having a project proceed unhindered. When upper-middle income families agreed to talk to a researcher about their children’s educations, perhaps they did so for the few hundred dollars they received in compensation for their time. More likely, however, they were motivated in large part by the wish to advance human knowledge. When such a project is blocked, their efforts are squandered.[54]

Overregulation can also endanger research participants. It can provoke researchers to lie to their ethics committees, perhaps discrediting the very idea of research ethics.[55] Moreover, ethics committee attention to low-risk studies can endanger participants in higher-risk studies. As Jerry Menikoff, director of the U.S. Office for Human Research Protections, recently noted, ethics committees “always have constraints on their time and resources, and any time they spend reviewing one protocol takes away time from reviewing others.” Taking advantage of regulatory exceptions for less risky research—which includes a great deal of social science research—“therefore frees up resources for reviewing riskier research.”[56]

Finally, ethics committees that hamper research hurt the potential beneficiaries of that research. Critics of biomedical ethics committees have begun trying to count the cost, in lives, of delays in valuable research due to needless meddling.[57,58] It would be harder to make the case that the restrictions on social science kill people, but I don’t think it is out of the question. Had Scott Atran been allowed to interview more failed suicide bombers, might he not have helped avert a bombing, saving dozens or hundreds of lives? Had Robert Dingwall had an easier time studying the reuse of single-use surgical and anaesthetic devices, might he not have prevented more deaths from post-operative infections?[59]

Better Options Exist

Most critics of the current system of ethics review acknowledge the dangers of unethical research in the social sciences and humanities, but they see the current system of ethics review as a poor way to address those dangers. Embedded in their criticism are a number of potential alternatives to the status quo.

One set of proposals focuses on the possibility of retaining the basic forms of ethics review while liberating social scientists from the assumptions of medical ethics. Martin Tolich and Maureen H. Fitzgerald, for example, think that ethics committees tend to ask the wrong questions of qualitative researchers. Demands for information “on such matters as sampling size, how the results generalize to the population, and general bias” only antagonize researchers by suggesting that “ethics committee members reviewing qualitative research assume the research project should emulate quantitative research.” Instead, Tolich and Fitzgerald suggest that committees ask four open-ended questions:

1. What is the research project about?
2. What ethical issues does the researcher believe are raised by this project?
3. How does the researcher plan to address these ethical problems? . . .
- [4.] What contingencies are in place if the research project changes its focus after the research has been approved and has begun?[60]

By contrast, Lisa Rasmussen suggests that researchers and scholarly organizations craft “a variety of research templates” describing low-risk research. Researchers adhering to these templates would gain “automatic exemption” from committee review.[61]

These proposals are designed to allow existing committees—composed of non-experts—to review varied forms of research more efficiently. Other suggest that it might be easier have the research reviewed by experts, the way that peer review works. Such expert review could take the form of decentralization, if most ethics review were done by individual university departments rather than university-wide committees. Or it could result from greater centralization, if national or even international committees were formed, or even if committees were required to communicate with each other.[62,63] It is the current structure—in which the most powerful bodies are composed of researchers haphazardly chosen from a variety of disparate fields and isolated from other committees—that leads to the wildest misunderstandings.

A second stream of criticism contends that the cure—ethics review—is often worse than the disease. Some critics challenge the timing of review, arguing that prospective review of protocols makes less sense for exploratory methods like ethnography than it does for laboratory experiments. They seek to instill ethics at other points, starting with methodological and ethical training. In the United States at least, hundreds of universities put ethics training in the hands of compliance officers, who in turn require researchers of all stripes to complete training designed for biomedical researchers. But what researchers, especially graduate students, really need is training in their own disciplines, emphasizing

the kinds of ethical problems they—not medical researchers—are likely to encounter. A few scholars have begun the work of assembling curricula along these lines.[64,65] At the University of Pennsylvania, researchers who complete “documented discipline-appropriate education regarding human subject protection” are relieved from the burden of spelling out “the details of a dynamic research protocol” for some forms of research. [66]

This policy is premised on the fact that qualitative researchers often begin their work not knowing what they will find, or even what questions they will form. The ethical problems they do encounter may be equally surprising, so that ethics review prior to fieldwork both wastes their time and fails to address the challenges that do emerge. Perhaps, then, the proper moment for much ethics review comes not before the start of fieldwork, but prior to publication. When the researcher has drafted a report, an outside reader could go through and catch passages that could harm an identifiable individual.[60,67]

Nor should we overlook that time-honored response to misconduct: grievance. People who feel wronged by researchers have a number of options open to them, from public criticism of researchers to lawsuits. This is how we fight other forms of research misconduct, such as plagiarism. Of course, research participants may lack the knowledge, means, or time to challenge the person who wronged them. Still, waiting for the complaints would provide a better understanding of what wrongs and harms social scientists are committing, compared to the current guesswork.

Finally, some harms from research are best avoided not by policing the researchers, but by targeting other actors. Since the 1970s, scholars have noted that a major threat to the confidentiality of research is the subpoena power of prosecutors. Were governments serious about protecting the human subjects of research, they might better pass shield laws protecting research notes rather than human subjects regulations that burden researchers.

Ethics Review Has Few Success Stories

The criticisms of ethics review would be less important if ethics committees had a proven record of protecting research participants. They do not. As bioethicist Christine Grady acknowledged in late 2010, American regulators lacked compelling evidence that their national system of institutional review boards were doing their job. “Protection from unnecessary or excessive risk of harm is an important measure of IRB effectiveness,” she noted, “yet no systematic collection of data on research risks, no system for aggregating risks across studies, and no reliable denominator of annual research participants exist. Even if aggregate risk data were easily available, it may be difficult to quantify the specific contribution of IRB review to reducing risk because protection of research participants is not limited to the IRB.”[68]

The current system does have its occasional successes, both in preventing unwanted behavior and in holding unethical researchers to account. One prominent, recent example concerns Professor Gilbert Burnham of the Johns Hopkins Bloomberg School of Public Health, who published a controversial study of mortality rates in Iraq following the

United States invasion. Burnham told his ethics committee that this team would not collect the names of the people they surveyed, but the data collection forms included space for those names. Because it had required Burnham to submit a protocol, Johns Hopkins was able to hold him to account by suspending his privileges to serve as a principal investigator on projects involving human subjects research.[69] If social scientists were regularly misbehaving in this way, and if ethics committees were regularly catching them, it would be easier to forgive the committees' own missteps. As it stands, however, I cannot think of a case not involving some kind of health research in which the ethics-committee system performed such service.

Supporters of committee review tend to assume or assert its benefits, rather than offering specific examples. And most advocates of moderate reform—rather than a wholesale rethinking—claim only that committee review can be made less burdensome on social scientists, not that researchers at any particular institution are happy with the practice or that any committee has a good record of heading off abuses. Given the coercive nature of ethics review and its long record interference with legitimate research, I would suggest that the burden of proof for its continuation rests on its defenders.

1. Sykes GM. Feeling our way: A report on a conference on ethical issues in the social sciences. *American Behavioral Scientist*. 1967 Jun 1;10(10):8–11.
2. Bosk CL. The new bureaucracies of virtue or when form fails to follow function. *PoLAR: Political and Legal Anthropology Review*. 2007 Nov 1;30(2):192–209.
3. Heimer CA, Petty J. Bureaucratic ethics: IRBs and the legal regulation of human subjects research. *Annual Review of Law and Social Science*. 2010 Dec;6:601–26.
4. Hoonaard WC van den. *Seduction of ethics: Transforming the social sciences*. University of Toronto Press; 2011.
5. Fost N, Levine RJ. The dysregulation of human subjects research. *JAMA: The Journal of the American Medical Association*. 2007 Nov 14;298(18):2196–8.
6. Kim S, Ubel P, De Vries R. Pruning the regulatory tree. *Nature*. 2009 Jan 29;457(7229):534–5.
7. Schrag ZM. *Ethical imperialism: Institutional review boards and the social sciences, 1965-2009*. Johns Hopkins University Press; 2010.
8. L. L. Wynn. Ethnographers' experiences of institutional ethics oversight: results from a quantitative and qualitative survey. *Journal of Policy History*. 2011;23(1):94–114.
9. U.S. Department of Health and Human Services. Human subjects research protections: Enhancing protections for research subjects and reducing burden, delay, and ambiguity for investigators. *Federal Register*. 2011 Jul 26;76:44512–31.
10. Hoonaard WC van den. Introduction: Ethical norming and qualitative research. In: Hoonaard WC van den, editor. *Walking the Tightrope: Ethical Issues for Qualitative Researchers*. University of Toronto Press, Scholarly Publishing Division; 2002.
11. Grugulis I. Research ethics and James Bond [Internet]. social science space. 2011 Jan 6 [cited 2011 Sep 15]; Available from: <http://www.socialsciencespace.com/2011/01/research-ethics-and-james-bond/>
12. Institutional Review Blog: Scott Atran, “Research police – how a university IRB thwarts understanding of terrorism” [Internet]. [cited 2011 Sep 1]; Available from: <http://www.institutionalreviewblog.com/2007/05/scott-atran-research-police-how.html>
13. Edwards SJL, Ashcroft R, Kirchin S. Research ethics committees: Differences and moral judgement. *Bioethics*. 2004 Sep 1;18(5):408–27.
14. Jacobs SP. Stern lessons for terrorism expert. *Harvard Crimson*. 2007 Mar 23;

15. Mustanski B. Ethical and regulatory issues with conducting sexuality research with LGBT adolescents: A call to action for a scientifically informed approach. *Archives of Sexual Behavior*. 2011 Apr 29;40:673–86.
16. Green LA, Lowery JC, Kowalski CP, Wyszewianski L. Impact of institutional review board practice variation on observational health services research. *Health Serv Res*. 2006 Feb;41(1):214–30.
17. Bamber GJ, Sappey J. Unintended consequences of human research ethics committees: au revoir workplace studies? *Monash Bioeth Rev*. 2007 Jul;26(3):26–36.
18. Charbonneau L. Ethics boards harming survey research, says York professor. *University Affairs*. 2005 Jun 6;
19. Purcell JM. Another case for the review of IRB review [Internet]. *Academic Exchange Extra*. [cited 2011 Sep 15]; Available from: <http://www.unco.edu/AE-Extra/2008/7/purcell.html>
20. Thornton LC. The role of IRBs in music education research. In: Thompson LK, Campbell MR, editors. *Diverse methodologies in the study of music teaching and learning*. Charlotte, N.C.: Information Age; 2008.
21. Vander Putten J. Wanted: Consistency in social and behavioral science institutional review board practices. *Teachers College Record* [Internet]. 2009 Sep 14 [cited 2011 Sep 15]; Available from: <http://www.tcrecord.org/Content.asp?ContentID=15767>
22. Stark L. Morality in science : how research is evaluated in the age of human subjects regulation. 2006;
23. Reverby S. *Examining Tuskegee: the infamous syphilis study and its legacy*. UNC Press Books; 2009.
24. Stobbe M. AP IMPACT: Past medical testing on humans revealed. *Washington Post*. 2011 Feb 27;
25. Lisa Simpson's tiger-repellant rock [Internet]. *Critical Thinking*. [cited 2011 Sep 15]; Available from: <http://www.criticalthinking.org.uk/tigerrepellantrock/>
26. Schrag B. Piercing the veil: Ethical issues in ethnographic research. *Science and Engineering Ethics*. 2008 Nov 26;15:135–60.
27. Scheper-Hughes N. *Saints, scholars, and schizophrenics: mental illness in rural Ireland*. University of California Press; 2001.
28. Venkatesh SA. *Gang leader for a day: A rogue sociologist takes to the streets*. Penguin; 2009.

29. Plattner S. Comment on IRB regulation of ethnographic research. *American Ethnologist*. 2006 Nov 1;33(4):525–8.
30. Fendrich M, Lippert AM, Johnson TP. Respondent reactions to sensitive questions. *J Empir Res Hum Res Ethics*. 2007 Sep;2(3):31–7.
31. Sieber JE. Protecting the vulnerable: Who are they? *Journal of Empirical Research on Human Research Ethics: An International Journal*. 2008 Mar 1;3(1):1–2.
32. Howard J. Oral history under review [Internet]. *The Chronicle of Higher Education*. 2006 Nov 10 [cited 2011 Sep 16]; Available from: <http://chronicle.com/article/Oral-History-Under-Review/6566>
33. Buchanan EA, Ess CM. Internet research ethics and the institutional review board. *ACM SIGCAS Computers and Society*. 2009 Dec 1;39:43–9.
34. Schrag ZM. The dormant right to expertise [Internet]. *Institutional Review Blog*. 2007 Oct 7 [cited 2011 Sep 15]; Available from: www.institutionalreviewblog.com
35. kohelet. comment on topic, “Do IRB’s go overboard?” [Internet]. *Chronicle Forums*. 2010 Apr 10; Available from: chronicle.com/forums/index.php?topic=68012.0 (
36. Timmermans S. Cui bono? Institutional review board ethics and ethnographic research. *Studies in Symbolic Interaction*. 1995;19:153–73.
37. University of California. University Committee on Research Policy (UCORP). Institutional review boards at UC: IRB operations and the researcher’s experience [Internet]. 2007 [cited 2011 Sep 16]. Available from: www.universityofcalifornia.edu/senate/committees/council/ac.irb.0507.pdf
38. Sieber JE. Privacy and confidentiality: As related to human research in social and behavioral science. In: National Bioethics Advisory Commission, editor. *Ethical and Policy Issues in Research Involving Human Participants*. 2001.
39. Jaschik S. Who’s afraid of incestuous gay monkey sex? [Internet]. *Inside Higher Ed*. 2007 Aug 14 [cited 2011 Sep 16]; Available from: <http://www.insidehighered.com/news/2007/08/14/soc>
40. Fitzgerald MH. Punctuated equilibrium, moral panics and the ethics review process. *Journal of Academic Ethics*. 2005 Nov 30;2:315–38.
41. Frazer SJG. *The golden bough*. Courier Dover Publications; 2002.
42. Yanow D, Schwartz-Shea P. Reforming institutional review board policy: issues in implementation and field research. *PS: Political Science & Politics*. 2008;41(03):483–94.

43. Moskos P. More on IRBs [Internet]. Cop in the hood. 2008 Feb 15 [cited 2011 Sep 21];Available from: <http://www.copinthehood.com/2008/02/more-on-irbs.html>
44. Malone RE, Yerger VB, McGruder C, Froelicher E. "It's like Tuskegee in reverse": A case study of ethical tensions in institutional review board review of community-based participatory research. *Am J Public Health*. 2006 Nov;96(11):1914–9.
45. Janovicek N. Oral history and ethical practice: Towards effective policies and procedures. *Journal of Academic Ethics*. 2006 Nov 18;4:157–74.
46. American Anthropological Association. Ethics Task Force – Draft principle: do no harm « American Anthropological Association [Internet]. 2010 [cited 2011 Sep 21];Available from: <http://blog.aaanet.org/ethics-task-force/ethics-task-force-first-principle/>
47. Viadero D. Security checks of U.S. education contractors to change. *Education Week* [Internet]. 2008 Apr 2 [cited 2011 Sep 21];Available from: <http://www.edweek.org/ew/articles/2008/04/02/31townhall.h27.html>
48. Johnson TS. Qualitative research in question. *Qualitative Inquiry*. 2008 Mar 1;14(2):212–32.
49. White RF. Institutional review board mission creep: The common rule, social science, and the nanny state: The Independent Review: The Independent Institute. *Independent Review*. 2007 Spring;11:547–64.
50. Dasgupta P. Students seek approval to do human research [Internet]. *Daily Princetonian*. 2009 Nov 9 [cited 2011 Sep 21];Available from: <http://www.dailyprincetonian.com/2009/11/09/24347/>
51. Schrag ZM. ANPRM comments: oral historians call for exclusion from common rule [Internet]. *Institutional Review Blog*. 2011 Sep 26;Available from: <http://www.institutionalreviewblog.com/2011/09/anprm-comments-oral-historians-call-for.html>
52. Elwood S. Negotiating participatory ethics in the midst of institutional ethics. *Ethics*. 2007;6(3):329–38.
53. Bradley M. Silenced for their own protection: how the IRB marginalizes those it feigns to protect. *ACME: An International E-Journal for Critical Geographies* [Internet]. 2007;6. Available from: www.acme-journal.org
54. Berrett D. IRB overreach? [Internet]. *Inside Higher Ed*. 2011 Mar 18;Available from: http://www.insidehighered.com/news/2011/03/18/brown_professor_sues_university_f_or_barring_her_from_using_her_research
55. Keith-Spiegel P, Koocher GP. The IRB paradox: could the protectors also encourage deceit? *Ethics Behav*. 2005;15(4):339–49.

56. Millum J, Menikoff J. Streamlining ethical review. *Annals of Internal Medicine*. 2010 Nov 16;153(10):655–7.
57. Roberts I, Prieto-Merino D, Shakur H, Chalmers I, Nicholl J. Effect of consent rituals on mortality in emergency care research. *The Lancet*. 2011 Mar;377:1071–2.
58. Whitney SN, Schneider CE. Viewpoint: A method to estimate the cost in lives of ethics board review of biomedical research. *Journal of Internal Medicine*. 2011 Apr 1;269(4):396–402.
59. Dingwall R. The ethical case against ethical regulation in humanities and social science research. *Twenty-First Century Society*. 2008 Feb;3:1–12.
60. Tolich M, Fitzgerald MH. If ethics committees were designed for ethnography. *J Empir Res Hum Res Ethics*. 2006 Jun;1(2):71–8.
61. Rasmussen LM. Not all research is equal: taking social science research into account. *Am J Bioeth*. 2008 Nov;8(11):17–8.
62. Stark L. Gaps in medical research ethics. *Los Angeles Times*. 2010 Oct 8;
63. Dreger A. Nationalizing IRBs for biomedical research – and for justice [Internet]. Bioethics Forum. 2010 Oct 22; Available from: <http://www.thehastingscenter.org/Bioethicsforum/Post.aspx?id=4939&blogid=140#ixzz1ZDMQqrph>
64. Wynn LL, Mason PH, Everett K. Human research ethics for the social sciences and humanities [Internet]. Available from: http://www.mq.edu.au/ethics_training/
65. Creager A, Haldon J. Responsible conduct of research workshop, June 14-15, 2010 [Internet]. Available from: www.princeton.edu/gradschool/about/docs/academics/HIS-HOS_503_RCR_syllabus_Final.pdf
66. University of Pennsylvania. Policy regarding human subject research in the sociobehavioral sciences [Internet]. 2006 Oct 3; Available from: www.upenn.edu/almanac/volumes/v53/n06/or-hsresearch.html
67. Johnson CG. Risks in the publication of fieldwork. In: Sieber JE, editor. *The ethics of social research: fieldwork, regulation, and publication*. New York: Springer-Verlag; 1982.
68. Grady C. Do IRBs protect human research participants? *JAMA: The Journal of the American Medical Association*. 2010;304(10):1122–3.
69. Johns Hopkins Bloomberg School of Public Health. Review completed of 2006 Iraq mortality study [Internet]. 2009. Available from: http://www.jhsph.edu/publichealthnews/press_releases/2009/iraq_review.html

