



Bureacratizing Ethics: Institutional Review Boards and Participatory Research

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Abstract

This paper provides a brief history of regulatory research ethics, as embodied in Institutional Review Boards in the United States. The purpose is to foster common disciplinary understanding of the origin and purpose of IRBs, and to identify the core conflict between the philosophies of participatory action research and regulatory ethics. That conflict centers on the contradictory language and associated understandings of research “subjects” and “participants”. I suggest a need for more disciplinary engagements around this conflict, to foster more open ethical debates and competencies among geographers.

Introduction

To accept passively an unjust system is to cooperate with that system; thereby the oppressed become as evil as the oppressor. Noncooperation with evil is as much a moral obligation as cooperation with good. (Paraphrased from Martin Luther King Jr. 1986[1958], 51)

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The purpose of this paper is to consider participatory action research (PAR) in light of the history and goals of what I want to call “bureaucratized research ethics”, or what are known (in the United States) as Institutional Review Boards (IRBs) and their associated human subjects committees (for a thorough and more international review, see Israel and Hay 2006).² I juxtapose this topic in light of the opening quote from Martin Luther King, Jr., to provoke debate and discussion about the role of IRBs in geographical research in general and philosophies about participatory research in particular. To truly create action research that challenges existing power relations and structures, we as geographers need to explicitly engage our institutions, as well as our research participants, over questions of justice in research practice. IRBs represent an institutional power structure that may be at odds with action research, thus, we need to ask how geographers should conceptualize and carry out research in light of regulatory frameworks that oversee such activity? Arguing that it is not enough to ignore IRBs—a luxury perhaps afforded only those with security of tenure—I call for engagement with the purpose and scope of IRBs, with a goal of better disciplinary understanding and greater opportunity for open discussion of IRBs and their role in and impacts on our research and agendas.

In general, a few scholars openly recognize tensions between making judgments about ethical behavior in research, and the codified ethics in government and institutional “regulatory regimes” of review boards (IRBs) (Hay 1998, 73; Israel and Hay 2006). We have not been explicit as a discipline about understanding the goals and rationales behind the existence of IRBs and human subjects committees (except Israel and Hay 2006). I first became aware of human subjects committees as a graduate student, and was struck then as now by how little geographers seemed to discuss them and their impacts on research. Hay (1998) described the need for geographers to be more engaged in debates about research ethics requirements and guidelines; this paper is an attempt to establish some common ground in terms of understanding why and where the formal legal guidelines exist, so that geographers can be better informed about such requirements when they debate research ethics. I hope to promote not just understanding, but informed dialogue with and about regulatory regimes and how they should impact research. I examine the history and goals of IRB guidelines in the United States, and consider how researchers might approach these committees in order to conceptualize and realize their participatory research goals. Although I

² This paper evolved from a panel discussion at the Chicago (2006) Association of American Geographers Annual Meeting on “The Politics of Participation 1: Negotiating Ethics” (thanks to Rachel Pain and Caitlin Cahill for organizing!). At the time, I had not seen any systematic discussion in geography or by geographers of the ethical dilemmas posed by IRBs. Israel and Hay (2006) fills that gap, although it does not discuss participatory research specifically. Nonetheless, it provides a much more thorough treatment of the intricacies and histories of regulatory review of research ethics (and in international perspective) than I can do here.

refer to the context in the United States, the basic history and rationale of IRBs extends to other countries as well, despite differences in bureaucratic structures.

Ethics, IRBs, Human Subjects ... Complicity and Resistance in Research and the Academy

Participatory research may include many goals and methods, but broadly, such research aims to include the participants (often called “subjects” in conventional or traditional social research) in the design, analysis, interpretation, and subsequent applications of the research (Kindon 2005). Participatory Action Research (PAR) is an extension of PR that seeks social change, or social action, as the name suggests. The degree of participant involvement at each stage of participatory research varies with the goals of the project and the researcher. PR and PAR explicitly recognize power relations within the research process, and seek to empower social groups who may be marginalized within society and especially in social research (Kindon 2005). They do not see the researcher as able to “give” power to participants per se, but view research as inherently power-laden, needing negotiation between researchers and participants. PAR extends this concern with power farther than PR, by demanding that the researcher take on political causes or stances that reflect the needs and goals of research participants. By working to interrupt power relations and to change them, PR/PAR bring an explicitly normative component to the research process. Interpretations of what is “right” in research will of course be subject to considerable debate, however, and such controversy extends to how to work within, or challenge, bureaucratic norms that seek to ensure ethical practices in research (Hay 1998).

The simplest and broadest meaning of ethics is that it “is a branch of philosophy and theology . . . Ethics is the study of ‘right behavior’” (Singleton and Straits, 2005, 515). Applying ethics to research, then, involves figuring out what is the ‘right’ research approach for a given project. Drawing on Reese and Fremouw (1984), Singleton and Straits (2005, 515) identify three distinct areas of research ethics: in “data collection and analysis ... treatment of participants, and ... responsibility to society.” Focusing on human subjects, Hay (2003, 40-1) suggest that three principles guide most human subjects committees in their evaluation of research projects: justice, beneficence, and respect. These echo the 1979 *Belmont Report* of the United States National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979) (hereafter, “Belmont Report, 1979”).

The central conflict between bureaucratized ethics and PR philosophies is that the former conceptualize research participants as “subjects” who face potential harm and exploitation in the research process. The calls for justice, beneficence, and respect in the Belmont Report and elsewhere translate, as I describe below, into a codified set of procedures that assumes a standardized, researcher-driven model

of scholarship. PR, however, seeks to redefine the researcher-subject model, conceptualizing research as a collaborative, negotiated process in which the direction and benefits of the research are as much a product of the participants' involvement as the researcher's (Kitchin and Hubbard 1999; Kondon 2005). These two conflicting approaches do not explicitly come into tension in geographical writing, however (or rarely; see Hay 1998; Israel and Hay 2006). Understanding the origins and frameworks of the regulatory regime, however, may offer means to challenge those frameworks, creating a truly more activity and empowering model of participant—and researcher—subjectivity.

Origins of Ethical Codes/Principles for Research

The Belmont Report drew upon existing principles in research such as those first codified in the 1947 Nuremberg Code, which delineated appropriate treatment of human subjects in medical research (Mitscherlich and Mielke, 1949; Belmont Report, 1979; United States Holocaust Memorial Museum (USHMM), 2007a; 2007b). It set out ten principles, focusing first on informed consent, and laying out expectations of benefits to humanity of experimentation, as weighed against possible harm to participants. The Code's influence on behavioral (or social) scientific research resulted from public and scholarly debates about appropriate research ethics from the end of World War Two into the 1970s (Belmont Report, 1979). The "prison experiment" research of Zimbardo (Haney, Banks and Zimbardo, 1973, in Schutt, 2004; Zimbardo 1973, in Singleton and Straits, 2005), for example, which caused psychological distress among volunteer participants, highlighted the importance of formal research ethics for behavioral as well as biomedical research (Schutt, 2004; Singleton and Straits, 2005).

United States' Federal laws governing research through IRBs were revised from 1974 to 1991 in a number of Departments and Agencies, most notably, the Department of Health and Human Services (DHHS). These culminated in the "Common Rule" Code of Federal Regulations (CFR) Title 45 Part 46 (known as 45 CFR 46) (Israel and Hay 2006), which are followed not only by DHHS but also, for example, the National Science Foundation, Departments of Energy, Transportation, Veteran's Affairs, and others (DHHS 2005; Israel and Hay 2006). Although each agency has its own set of Federal Codes (laws), the DHHS 45 CFR 46 encompasses the United States' government policies on human subjects protection. The laws apply to any research "... supported or otherwise subject to regulation by any federal department or agency..." (DHHS, 45 CFR 46.101.b, 2005). Initially interpreted to mean any research *directly* funded by a government agency, 45 CFR 46 did not immediately impact geography and related social and humanistic sciences when adopted in 1991.

Regulation in Practice: Dilemmas and Conflicts

After the 1991 Common Rule, however, IRBs increasingly expanded their purview to all research conducted in universities and colleges or in any federal agency, regardless of whether they were directly federally funded or not (Cohen 2007). One reason for the broadening of the scope of IRBs is the seemingly disconnected ethics of requiring one set of processes and research standards for some (federally funded) research, while allowing other research to proceed without any oversight (Alexander 2001). The Common Rule sets out a series of guidelines which, as in practice today, affect nearly all research undertaken by students and faculty in U.S. colleges, universities, and federal agencies (Gunsalus 2004; Israel and Hay 2006; Cohen 2007). Nonetheless, note of these restrictions and guidelines is rarely made in methodological discussions in geography.

The guidelines of 45 CFR 46 require that all research ensure full anonymity *or* confidentiality to human participants (who are always referred to throughout the laws as “human *subjects*”). Further, all research should ensure full informed consent of participants through the use of consent forms. However, there are important exemptions to these requirements. Any research that involves “use of educational tests ... survey procedures, interview procedures or observation of public behavior” is fully exempt from IRB review according to the 45 CFR 46.101(b)(2), as long as data are gathered in a way that ensures the anonymity of all human participants. If data are gathered such that participants could be identified in some way, or would be harmed – “at risk of criminal or civil liability ... damage[e] to ... financial standing, employability, or reputation” (DHHS 2005: 45 CFR 46.101(b)(2)(i)), then the research is not exempt *unless* the participants potentially exposed or harmed are “elected or appointed public officials or candidates for public office” (DHHS 2005: 45 CFR 46.101.(b)(3)(i)). There are many other qualifications to these general guidelines, but a key tenet of the exemption sections is that IRBs themselves are the bodies empowered to determine exemptions, leaving researchers subject to the sole judgment and discretion of their institutions’ IRBs regardless of exemption category (Gunsalus 2004; Cohen 2007). This institutional arrangement has the odd effect of undermining the presumed empowered status of researchers, thereby also potentially limiting their abilities to actively work for social justice and the empowerment of others.

While there is logic to requiring that IRBs, not individual researchers, ensure that a given research project is exempt from the Common Rule, there are several undesirable effects.³ First, the entire system places a tremendous burden on individual IRBs, stressing the structure and providing potentially little opportunity

³ Israel and Hay (2006) provide a thorough discussion of the dilemmas and contradictions of ethical regulations and ethical practice.

for dialogue with researchers, stifling creativity about the ethics—as opposed to regulation—of the research and its goals (Gunsalus 2004; Cohen 2007). Second, the entire structure of the system positions researchers as *a priori* guilty of potential unethical behavior—or at least, of not following the regulations—until they can prove otherwise to their IRB (Mueller 2003; Cohen 2007). Third, by imposing a codified set of actions to ensure “ethical” behavior, the system limits alternative conceptualizations of human “subjects”.

In practice, researchers cannot conduct any research within the auspices of their college/university without some overview of the IRB, within these rather narrow frameworks of what constitutes research and a researcher-*subject* relationship. Indeed, one of the main criticisms of the federal laws in 45 CFR 46 is that they were written primarily for a biomedical model of research. This model fails to conceptualize the potential participants of research as individuals with understandings, agencies, and competencies in their own lives, and who can, therefore, identify potential risks of research to themselves at least as well if not better than any IRB. Such individuals are quite capable of restricting or rejecting interactions with researchers (Gunsalus 2004). Ironically, among those individuals who might be harmed in some way by research, the consent forms required under the auspices of the Common Rule might fail to actually protect against anxieties produced by a legalistic research relationship implied by the consent process (Gunsalus 2004). Indeed, I have faced the disempowering effects of IRBs, when I have been unable as a researcher to claim that my research—conversational interviews about neighborhood activism—posed no greater harm than the average journalistic encounter. Further, my “subjects” were disempowered when clearly uncomfortable when faced with a legalistic document that I was asking them to sign before our interview. (It is extremely difficult to write an informal consent form because of the requirements of IRBs that they explain “risks” and “benefits” explicitly to research participants.)

The frustrations and limitations of the IRB system in the United States, and its parallel regimes in other countries, may be well known within geography. Yet we as a discipline exercise little open acknowledgement or debate about these constraints. In the lengthy professional ethics statement of the Association of American Geographers, for example, there is little guidance for scholars whose research does not fit the dominant researcher-subject paradigm. Rather, the statement includes affirmation of the importance of regulatory regimes: “geographers should comply with government requirements for the protection of researchers, human subjects, the public, and the environments in which they work” (AAG 2005). While the entire ethics statement itself includes many dimensions, the idea that geographical research can at all times and in all places unproblematically conform to regulatory regimes fails to acknowledge or provide guidance for ethical decision-making, especially when institutional regulations may violate participatory goals of empowerment for research “subjects”. At the same

time, however, the AAG statement explicitly recognizes that “any statement [on professional ethics] that seeks to be comprehensive will inevitably fail”. Thus, the statement openly acknowledges the paradoxes of a “code” of ethics, while seeking simultaneously to affirm that the AAG does have ethical standards and goals. Rather than open debate about IRBs, I have found that individual researchers discuss them very little in formal settings, or in hushed tones in personal conversations, perhaps a testament to the silencing power of IRBs to reprimand individual scholars by denying them their rights to publish. Creating more space for open discussion are Israel and Hay (2006), who suggest active engagement with regulatory bodies and open debate about appropriate ethics and research procedures.

Conclusion: Philosophies of participatory research and the possibility for dialogue with regulatory regimes

Martin Luther King, Jr.’s provocative words about complicity with oppression may seem out of place or even strident in the context of a paper about the dilemmas of ethical regulations in participatory research philosophies. But a core principle of PR/PAR is social change or challenge to power (Kendon 2005). The regulatory regimes of research ethics as practiced by IRBs represent a codified set of power relations and assumptions about agency and abilities to produce knowledge that, however inadvertently, disenfranchise both researchers and the potential participants of any social research. Researchers who seek to interrupt those power relations are faced with the dilemma of (a) ignoring an IRB – a bureaucratic wrong that may also indicate a lack of concern for one’s institution, students, and even research participants, by closing off insights from other colleagues; (b) acceding to the demands of an IRB, but in doing so, diluting the participatory component of a research project – a second wrong for a PR researcher; or (c) trying to navigate a middle ground, without firm assurance of the IRB’s willingness to engage alternative visions of ethical research. Israel and Hay (2006) suggest that the final option is the most desirable from an ethical standpoint – one which sees both institutional regulation and concerns of PR as equally legitimate frameworks. Certainly it is not enough to complain about the limitations of regulatory regimes – we ought to engage with a goal of change. Negotiating between PR goals and IRB regimes may seem impossible, given their competing normative stances (but Elwood (this issue) provides a discussion of how one might do so). This paper’s discussion about the history and goals of IRBs offers a starting point for a truly participatory approach to research; in which greater knowledge of and engagement with IRBs forms a basis for instituting more equitable and socially just research.

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