



Negotiating Participatory Ethics in the Midst of Institutional Ethics

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Abstract

This paper proposes participatory ethics as a framework from which we might begin to proactively engage some of the contradictions and gaps inherent in institutional ethical frameworks. A growing number of researchers negotiate ethical dilemmas encountered in research or expectations for what constitutes ethical research practice in collaborative dialogue with research participants. I show how participatory ethics are premised on very different assumptions, practices and subjectivities than those of institutional ethics, but create a forum for dialogue and reflective practice that is essential for engaging some of the shortcomings of institutional ethics.

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This collection of short papers exploring participatory ethics contributes to a growing call by geographers for research practices that more actively promote social and political change, theorize and practice geographies of care and responsibility, and re-examine the ethical and moral commitments that shape what we do as researchers and how we do it (see for example, Cloke 2002, Massey 2004,

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Valentine 2005, Lawson 2007). In this issue, Cahill, Sultana and Pain's framing of participatory ethics as a way of negotiating ethical practices with our research participants seems to me to be one means of practicing what Lawson (2007) terms 'care ethics'. She writes, 'We can engage care ethics through open dialogue that itself manifests mutual relations of care.' (p. 9). For me, it is this practice of reflective dialogue with research participants that lies at the heart of participatory ethics, as we try to anticipate, understand, and respond together to the inevitable ethical quandaries, difficult decisions, and interpersonal struggles that are part of any research project.

The collective deliberation, reflection, and action that we are calling participatory ethics are of course not new. Many geographers have been practicing them for years, especially those who work with feminist or participatory methodologies. But increasingly we are faced with the challenges of practicing participatory ethics in addition to what I will refer to here as institutional ethics. Most of us are required to adhere to ethics rules and protocols designed by universities, professional associations, and policy makers, ethics committees, institutional review boards (IRBs), and other structures.² Here I focus primarily on university boards and committees that define and review ethical practices in research. However, it is imperative to keep in mind that the institutionalization of ethics in research occurs at many other sites. These include ethical codes from professional associations; university insurance officers or safety boards; editors, reviewers, and policies of the journals where we publish our work; laws and public policy; and for those who intersect participatory research with our teaching, curriculum committees and university teaching guidelines. Institutional ethics tend to operate top-down, through fixed codes and rules defining everything from what to say (and not say) in recruiting research participants, to when and how to conceal participants' identities, who may or may not participate, and what activities can or cannot be undertaken. The institutionalization of a commitment to ethical research practice and to protecting research participants from harm is tremendously important. But in practice, negotiating the requirements and processes of institutional ethics can be frustrating and difficult. Here I suggest that there is a broader context that informs these frustrations. Negotiating institutional and participatory ethics is inherently contradictory because of their different guiding assumptions, practices, and subjectivities. In this paper I explore contradictions that can occur before, during, or after research, drawing on examples from my own

² Deborah Martin (this issue) provides a detailed description of the history and functioning of IRBs in the U.S. By federal law, all research conducted with federal funding must be reviewed by an IRB, so nearly all universities and colleges now have an office or staff members responsible for administering rules regarding the protection of humans and animals in research. While the rules and procedures of IRBs are federally mandated, there is a great deal of variation in the actual practices at any given university. Some institutions, for example, require all research to undergo IRB review, while others only require federally funded research to be reviewed.

research experiences. I suggest ways that we might negotiate these contradictions, both in our daily research practices and at broader institutional levels.

On one level, institutional ethics and participatory ethics are both guided by a shared commitment that research practices and interactions should protect and respect participants' health, safety, privacy, and physical and emotional wellbeing. But beyond this shared principle, they are quite different. Institutional ethics assume that ethical problems and risks can be identified before they occur, can be identified outside the context of the research situation, and that rules for ethical practices can be universal. Within these frameworks, the 'subject' who is to be protected from harm (or who might benefit from participation) is envisioned as an individual, constructed as inherently vulnerable and not an active agent in identifying and responding to ethical dilemmas in research. The core practices through which institutional ethics seek to minimize harm and avoid or respond to ethical challenges tend to be fixed standards, rules, and codes; and the main actors involved in these processes are the researcher(s) and institutional participants such as IRB members.

In contrast, participatory ethics is rooted in assumptions that ethical problems and dilemmas are situational, specific to the relationships and interactions of a particular research context. From this perspective, preemptive proscription of fixed ethical codes, values, and practices is impossible, and the expectation that such codes may be universally applied is unrealistic. Instead, these assumptions suggest a very different set of practices through which participatory ethics might be negotiated, such as shared dialogue among a wide range of research participants (potentially university researchers, community researchers, and people affected by the research), before, during, and after research. A wider range of subjectivities are imagined in participatory ethics, moving beyond the notion of an atomistic individual who assesses risks and benefits to determine participation in a research project. As many of the contributors to this collection will illustrate, participatory ethics tries to speak to the ways that identities, group membership (or exclusion), and power relations can shape ethical practices and challenges in the social situations of research.

In practice, many of us find that institutional ethics are incomplete and problematic on their own, and that participatory ethics offer a stronger basis for ethical practice in our research. But for university-based researchers, it is increasingly not a matter of choosing one or the other, but developing ways of practicing both simultaneously in spite of their contradictions. We experience these contradictions most directly in the day-to-day interactions and decisions of a research process, from designing a research project and gaining IRB or ethics committee approval, to conducting the research and publishing from it. In the next several paragraphs I will offer some examples of institutional-participatory ethics contradictions from my own research, and how I and my research partners have

sought to address them. Of course these examples are limited, shaped by the particular contexts in which I have conducted research and the kinds of research questions I tend to ask.

One of the basic contradictions I encounter most frequently are the sharp differences between ethical concerns raised within an institutional ethics framework, such as an IRB review, and the concerns voiced by research participants in a participatory setting. In ethnographic research studying lesbian households' residential choices and mobility, the research participants and I were concerned about ways of ensuring the confidentiality of their home locations in later analysis and writing from the project. To our surprise, the IRB raised no concerns whatsoever about this element. Rather, it was concerned that participants might experience psychological distress speaking about life decisions made when they were coming out as lesbians. None of us discounted this concern as unimportant, and we agreed wholeheartedly from our own experiences that the coming out process can be painful and difficult. But we found it somewhat disturbing that the IRB was more concerned about an event long past than the participants' present concerns about keeping their home locations confidential.

In the end, the IRB insisted on an additional caution in the informed consent process alerting participants that the interview would include questions about their coming out experiences and reminding them that they were free to withdraw at any time. While we were not wholly comfortable with the 'warning' tone of this additional text, the process of negotiating this solution was important. Discussing how to address the IRB's concerns forced us to consider more specifically how the research process might affect participants whose experiences might differ dramatically from our own. In describing how a care ethics framework might inform research design, Lawson (2007) emphasizes the practice of building connection and working toward relationships, institutions, and actions that prioritize mutuality. These are precisely the commitments and practices that should inform the process of our engagement with the contradictions of institutional ethics.

Differences between institutional understandings of ethical practices and those of research participants are also cropping up in my current work, a participatory GIS project. As part of this project, community organization staff members are creating GIS-based maps for use in their community development and neighborhood revitalization activities.³ But the maps also function as archival documents informing our research questions. We occasionally publish them in neighborhood newspapers and academic journal articles, and the community map makers and their colleagues circulate them widely as part of their activities. The

³ For more detailed discussion of this project, see Elwood (2006a) and Elwood (2006b).

IRBs reviewing this project have strongly urged that the names and identities of my research 'subjects' be concealed. Within this framework of expectations, the community map makers are research subjects and by extension, their names and organizational affiliations ought not to appear on the maps. However the community map makers feel strongly that these identifications must appear on their maps.

Situated in a context in which community-based organizations must compete for funding, influence, and the legitimacy to 'represent' a community's needs and conditions, the map makers argue that claiming these cartographic representations as their own is an essential component in securing a place for their ideas and priorities in urban planning and revitalization. As well, some of the map makers wanted their names on the maps because they felt their own skills and contributions overlooked and undervalued by other people in their organizations. In the end, we decided to include individual and organization names on the maps for community use, but to remove individual names when the maps are reproduced in academic publications. The process of creating this practice was crucial. Among other things, our discussions around this question revealed some of the reasons why individual and organization identifications are so power-laden in this particular social and political context. Here again I would emphasize the linkage of this participatory process as one possible enactment of a care ethic in research practice, because this process involves being attentive to how the social and political are constituted through unequal power relations. In the situation described above, addressing contradictions around anonymity and identification required us to engage directly with some of the unequal power relations in the local politics of community development and in workplace relations, both closely intersecting with inequalities along lines of gender, race, and class.

The rules, codes, and expectations of institutional ethics may also contradict other institutional expectations that are a part of the research process, or put us in difficult positions in our interactions with research participants. This is especially true in participatory research. In this context, research 'subjects' are understood as active participants with agency, voice, and control in the research process. 'Data' and other outputs are created and used by many participants in different ways. Here again, the case of the community-produced maps described previously provides an illustrative example. To publish one of these maps as part of a paper, journals require copyright permission from the person who made the map, and yet at the same time, the IRBs I have worked with require breaking identifying links between participants' names and project 'data' they have produced. What is the responsible choice in this instance, for the conflicting rules and for the research participants themselves? In these situations I tend to focus on a process of dialogue, trying to discuss the conflicting rules with both the community participants and managing editors. I usually ask managing editors for a statement that the community participants' copyright permission will be kept confidential. But whatever the

specific solution (and there are no doubt several), practicing care through discussion of conflicting institutional requirements opens the possibility for broader institutional change, beginning by making individuals aware of these contradictions.

In another instance, a journal editor insisted on cartographic changes to a community-produced map, a seemingly simple request that is fraught with ethical dilemmas. Amending a map I did not make felt inappropriate, even if these changes might be construed as cosmetic rather than substantive. But asking the community map makers to alter the map felt equally wrong – a tacit suggestion to them that their map, quite useful and important for their own work in its original form, was not good enough. I explained my concerns to the editor, who continued to insist that altering the map was the only acceptable solution. Then I sought assistance from another editor, who recognized my concerns but could not alter the decision of the other. So I opened discussion with one of the map makers, and we considered several possible actions: asking that our concerns be reviewed by the journal's editorial board, withdrawing the already-accepted manuscript, or implementing the changes but noting them explicitly in the paper and stating why they were made.

In the end, we chose the third course, though neither of us was entirely comfortable with the decision. Perhaps most troubling to me was a question raised by the map maker which highlighted the challenges of balancing competing needs in our research relationships. What would be the professional consequences for me of withdrawing the paper, he wondered, 'Doesn't it help you for that tenure thing?' He went on to suggest that because his community had benefited from our research project, it might be wrong to insist we do something with negative consequences for me. Grateful as I was for this act of care toward me and my interests, I also continue to wonder whether he accepted an uncomfortable course of action because he felt the community somehow owed me. In part, my point is that practicing participatory ethics is by no means a guarantee of resolving such intellectual, interpersonal and political challenges in research, or even negotiating them in a way that we can feel confident is the best or right set of actions. As well, these examples illustrate the extent to which researchers, data, and disseminated results can never be detached from the social and interpersonal situations of research, in spite of the ways that institutional ethics understand them as such.

The complex social interactions of research also mean that institutional ethical frameworks are inevitably incomplete. In practice, research interactions always present us with dilemmas that are not recognized or addressed by institutional rules and practices for ethical behavior in research. IRBs, in their design and purpose, are primarily concerned with ensuring that researchers behave ethically, and that our practices prevent harm to individual research 'subjects'. But I suspect many of us have been in situations where we, our research assistants, or

our students were either targets or witnesses to inappropriate behavior from research participants. In a previous project, I worked with an organization whose leader was verbally and emotionally abusive to staff members, something I discovered only after a student was employed by the agency. In participatory research projects that also involve my undergraduate students, I occasionally encounter community partners who are not responsible to the students working with them, failing to share the workload or to give timely and constructive feedback.

Institutional ethics protocols have little to offer in the way of guidance through such difficulties, precisely because of their constrained view of the subjectivities and relationships through which ethical and unethical practices occur in research. Such situations fall outside an IRB's notion of 'adverse events' (harm to research subjects based on their participation in the research). Furthermore, these situations cannot necessarily be prevented in the future through the review and revision of research study procedures, which take place in response to an adverse event being reported to the IRB. Meanwhile, participatory ethics may also not prevent these situations from happening, nor ensure that participants will behave responsibly and ethically toward one another. Nevertheless, by beginning from an assumption that all participants are involved in creating ethical research practices, participatory ethics creates a space for constructive dialogue when problems occur.

Given their basic differences, I suspect that responding to the demands of institutional ethics structures will always be challenging for those of us who seek to engage more participatory approaches to research ethics. The question is less how to prevent conflicts between the two, but instead how to productively engage the contradictions. Approaches that have worked for me include trying to accommodate the requirements of institutional ethics in a way that promotes broader dialogue with research participants, or trying to create other forums to work out the issues that might go unrecognized or unaddressed within these frameworks.

For example, at the outset of a research project that involves organizations of any kind, IRB rules typically require documentation such as formal letters of commitment from organizations that will participate. Typically these letters must include a description of what services, material resources, or activities will be provided by the collaborating organization. But simultaneously, I work with research participants to develop our own parallel document that frames our goals, concerns, activities, and what we hope to gain from the project. This document also includes a description of what I and other academic partners will do and contribute as part of the project. Thus, the document can incorporate the concerns or contributions of any participants, not just organizational representatives. In most cases, we go through several iterations of reviewing, discussing, and changing this project summary. This process provides a forum for us to engage some (but not

necessarily all) of the hopes, concerns, benefits, and potential problems that go unrecognized in IRB reviews.

Similarly, I try to work with IRB-mandated consent forms in a way that creates broader discussion. I have always found it awkward to begin an interview conversation with the legalistic and formal language of a consent form, which I find tends to distance ‘researcher’ and ‘subject’ at a moment when it is especially important to foster connection and interrelation. For interviewees who are uncertain or anxious, the consent form usually seems to heighten these feelings. So I usually begin the process by trying to initiate discussion about the history and politics of informed consent in research, reasons why universities require researchers to follow certain protocols, or what the process recognizes and what it might leave out. This approach is certainly not appropriate to all situations or participants. But I find that directly highlighting the broader context and potential silences of consent forms is one way of using these documents to build interaction and connection, and encourage participants to voice concerns that may otherwise go unrecognized.

Beyond the day to day activities of our own research, I also believe it is critically important to engage with the structures of institutional ethics to push for more flexibility in rules, codes, and procedures, to accommodate a more diverse range of research topics and approaches. For US-based researchers, this might mean serving on IRBs or on department- and college-level local review boards that provide initial feedback on IRB protocols. It could involve providing clear and constructive feedback to these institutional structures about how they might revise their documentation and requirements to better include social science research that is neither experimental in design, nor medical and psychological in content. Simply put, IRBs and ethics committees are people. If these institutional structures are ever going to address the contradictions experienced by researchers who practice participatory ethics, we need to actively and constructively engage them. Such efforts toward institutional change are, I would argue, an act of care toward our students and colleagues who will interact with these structures in the future, and toward the individuals and communities touched by our research. We also have the opportunity and responsibility to constructively engage these participatory and institutional ethics contradictions in our professional service. In addition to being researchers, we are also reviewers, editors, members of editorial boards, and curriculum committee members. In these capacities, we need to be aware of and sensitive to the ways in which the different rules and structures of these institutions can create practical problems and ethical contradictions for researchers. As I have negotiated the situations described here, I have been inspired by the thoughtful ways that many of our colleagues, near and far, are already doing so.

Given the different motivations, priorities, and processes of institutional ethics and participatory ethics, we will inevitably encounter some discontinuities and difficult decisions. In negotiating these contradictions, I believe our main

responsibility is to foster dialogue with research participants and thoughtful mutual engagement with these dilemmas when they occur. If we take seriously the commitment from participatory research methodologies that no single participant has a complete perspective on the research process, this implies that we as researchers will not necessarily be able to identify and address all ethical dilemmas in our research interactions. This is a difficult lesson to live out in practice. IRBs conceptualize us as individually accountable for ethical practice in research. I suspect most of us tend to think of ourselves as ultimately responsible for what happens in our research relationships. But at the end of the day, there is a great deal about these interactions that is not under our control and that we cannot resolve individually. This is why a participatory approach to ethical research practice is so important.

Though I have written at length here about the shortcomings of institutional ethical structures and the tensions that can arise in trying to accommodate their rules and codes in tandem with a participatory approach to ethical practice, I want to end by underscoring the importance of institutional ethics. I do so because I have heard a surprising number of researchers suggest that institutional ethical structures such as IRBs are not relevant or useful, citing contradictions such as those I have discussed here. As Martin (this issue) details, the institutionalization of rules about ethical research practice occurred in response to appalling violations of individuals and communities that have been carried out under the auspices of 'research'. Institutional rules for ethical practice in research and systematic oversight of researchers, however partial and frustrating they may be, ensure that all university-based research has at least one forum where the ethics and human impacts of its activities must be considered. This institutional commitment is tremendously important for all of us, everywhere. Participatory ethics offers us the opportunity to extend this commitment to ethical research practice in ways that may be more mutually inclusive and responsive to the concerns, experiences and subjectivities of all research participants.

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