Working With Research Ethics:  
The Role of Advisory Committees in Community-Based Research

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ABSTRACT
Research confirms that the university ethics review process, the only formal ethics review process that most community-based researchers in Nova Scotia have experienced, is neither appropriate nor desirable for most community-based researchers. Instead, most community-based researchers conduct their own informal ethics review using an Advisory Committee. These committees facilitate and implement ethical considerations as they emerge out of the specific dynamics as the research progresses. This paper outlines how Advisory Committees are set up, how they attempt to include in decision-making as many voices as possible, especially those of the research participants, and how they monitor what researchers take from and give back to communities, including making sure that research participants' words are returned to them in an accessible form.

RESUME
La recherche confirme que le processus de l'examen de l'éthique mené par les universités, le seul processus formel de l'examen de l'éthique que la plupart des recherchistes de la Nouvelle-Écosse connaissent, n'est ni approprié ni désirable pour la majorité des recherchistes qui travaillent dans la communauté. Au contraire, la plupart des recherchistes qui travaillent dans la communauté mènent de façon informelle leur propre examen de l'éthique en se servant d'un comité consultatif. Ces comités facilitent et implantent les considérations éthiques au fur et à mesure qu'elles surgissent des dynamiques particulières au cours de la recherche. Cet article expose les grandes lignes de la façon dont on met sur pied les comités consultatifs, et comment ils essaient d'inclure dans la prise de décisions autant de voix que possible, surtout celles des participants à la recherche et comment ils surveillent ce que les recherchistes retirent des communautés et ce qu'ils leur redonnent, y compris s'assurer que ce que les participants à la recherche ont dit, leur soit retourné dans un format qui leur soit accessible.

For over a decade I have been involved in research in Nova Scotia that is community-based. By "community-based research" (CBR) I mean research that stems from a need identified by a group of people living and working at the community level and conducted by people close to the research problem in an attempt to find a practical solution to the need. The research I conduct has no university connection, and is, therefore, shaped in part by what funding I can find. By necessity, I've become something of an expert in obtaining and administering grants, and wording projects in such a way that service providers and other women can obtain money for workshops or pamphlets, or whatever it is they need.

My experience with community-based research ethics stems from a problem that arose when I was on the Board of the Maritime Centre of Excellence for Women's Health (MCEWH). Research projects funded by the MCEWH had to undergo the formal university ethics review process. Canadian academic research ethics are monitored by internal university committees, which review research proposals from students and faculty following prescribed guidelines that govern research involving humans in Canada: the Tri-Council Policy Statement. Ethics committees scrutinize the proposals to ensure the appropriate steps are planned for such things as confidentiality and that the participants in the research understand what is involved. They also ensure, as far as they can, that the research causes no unnecessary harm.
Once the committee gives the stamp of approval, the research can proceed. In this paper, I am not concerned with either the detailed working of this process nor whether it is an appropriate process for university-based research. What is my concern is that a number of community-based researchers have complained that the university-based review process is not suited to their needs. In response to this concern, the MCEWH partnered with CRIAW and the Dalhousie Health Law Institute to investigate the situation. We designed research to find out:

- in what ways the university ethics review process was not satisfying the needs of community-based researchers;
- how community-based researchers currently conduct ethics reviews;
- what process would better suit CBRs.

THE ETHICS REVIEW PROJECT

We did the research in three stages. First, we interviewed female community-based researchers in Atlantic Canada, then we surveyed the Chairs of all of the local research ethics boards, and finally we brought together a group of experienced community-based researchers to explore, in a Round Table format, the need for, and the best means to facilitate, ethical community-based research. The community-based researchers agreed that the university-based ethics review process is not appropriate to their needs, often finding it frustrating and demoralizing. The Round Table members were not convinced that a group of unknown professors, working in a different environment, really understood the methods and principles of the research the others were doing. People working at the community level usually like to meet face-to-face and discuss issues as equals with people we trust to understand the issue at hand. In contrast, the university ethics review process does not allow for any input on who makes up the Board, nor does it allow for any exchange of information or ideas. Some issues, for example the issue of confidentiality, are complex. Ethics review boards often insist that the research is confidential and respondents' identities are to be protected in a number of ways, but in the community context some people want to have their names linked to what they say. How confidentiality is handled works differently for different communities.

In a university ethics review there is no mechanism for revisiting the proposal. If, after the research is approved, we realize the consent form is not adequate to our needs, or we want to change the interview questions, or we think individual interviews will be more useful than the focus groups we had planned, we have to go back to square one, revise the proposal, get in the line-up and wait again for the committee's approval. We often don't know all the questions we need to ask until we've talked to the participants. We rarely know how we are going to present our findings until we've consulted with people in the field. For these reasons, community-based researchers need the freedom to change our methods as we discover ways we can do things better.

Another problem community-based researchers encounter with the university process is the lack of accountability. We have experienced instances when hired researchers working on projects funded through the university are not even aware that the project underwent a university ethics review. A researcher working on a university reviewed project recently told me, "I have no clue about whether any project I've ever done (including the one I'm working on now) has ever gone through an ethics review. In fact, the words 'ethics review' have never graced a meeting, as far as I know." She was not even aware of the existence of any approved consent forms. So, going through the university review process can be merely a formality. This researcher also complained that the lack of accountability had put her in an unethical position. She had promised the women she interviewed that she would bring back to them the final report of the research so they could see how their words had been used. Two years after the interviews, no such report had materialized. For these reasons, among others, using the academic ethics review is often inappropriate for community-based research. But it is the only formal ethics review process available to community-based researchers, although whether they would choose to use it outside university funded research is doubtful.

THE INFORMAL RESEARCH ETHICS REVIEW PROCESS

Community-based projects are seldom
required to undergo an ethical review, and some projects are conducted with little, if any, conscious consideration of ethics. However, most researchers agree that it is dangerous to go it alone without any ethics review at all because an ethics review process helps us to keep in mind our need to be accountable. The process we need at the community level is something more personal, more interactive and more immediate than the academic model, and we need to know that the members of our committees understand the issue at hand. Although there are excellent tools available, such as the CRIAW/ICREF, Feminist Research Ethics: A Process, 2d ed., (Ottawa: CRIAW/ICREF, 1996), the researchers who attended the Roundtable agreed that a body which would offer ethical guidance, and with whom they could consult, as well as more directive printed guidelines and tools, would be helpful. We do have to be very careful, though, that we don't create a monster. An "ethics police" could be a creation even worse than the university process - or worse than nothing at all. Lack of monies available to fund ethics reviews also presents a problem. Some funding agencies require an ethics review to be submitted with research proposals, and Roundtable participants expressed their concern that the time required for this was not funded.

The fact is that typically community-based research projects do put in place an informal research ethics review process. When a project begins, the sponsoring organization usually sets up an advisory or steering committee and, although it is seldom identified as such, it is this committee that performs the work of informal ethics review. The committee also performs other functions, but for the purposes of this paper, I will focus on their ethics review work. It is this committee that helps the researcher develop the research method, test the research tools and make sure the appropriate participants are included. Committee members keep their ears and eyes open for ways that the collection and use of data could do harm, so that in doing our research we don't inadvertently contribute to people's problems. Researchers use advisory committees to find out what would and would not be helpful to the community we are working with, and to keep reminding us of this throughout our work.

FOUR PROJECTS

To illustrate some of the ways advisory committees function in the ethics review process, I will describe my experiences with advisory committees in four research projects I have coordinated. All of the projects involved qualitative research and in each case, I was responsible for designing the research process. Information was obtained by interviewing in person, and encouraging participants to speak from their own experience. Usually the questions were open-ended and, within reason, participants were encouraged to tell us whatever they wanted to.

In the "Liberty Project" I was the paid research manager and project coordinator. I listened to women who had left abusive partners and who had attended a series of eleven facilitated workshops. The aim of this project was to produce a manual for group leaders and survivors of woman abuse so they could run the workshops.

In the Parent Abuse Project a colleague and I interviewed parents, teenagers, service providers and academics about the abuse of parents by their adolescent children. A pamphlet, short guide, and report detailing our findings about why the abuse occurs, who the perpetrators and victims are, and how parents and service providers deal with the issue, were produced. Again, I was the paid research manager and project coordinator.

In the Women Down Prospect Health Project a group of women from a small Nova Scotia coastal community learned the basics of social research and interviewed each other about our health needs, and a variety of people about women's health projects in Nova Scotia. The women organized a series of workshops on various health topics in response to their findings. My role in this project was as a volunteer team member, and I wrote my master's thesis about my struggle to relinquish leadership and facilitate the empowerment of the women involved.

In the Youth Health Centre Project young people and people who work with youth were interviewed to ascertain in what ways youth are involved in youth health centres, and whether involvement at all levels is essential. I co-managed the Youth Health Centre Project with a colleague.
IN THE BEGINNING

The ethics of research starts with why we are doing the research in the first place. Ideas for these projects, as with most community-based research, came, not from researchers, governments or the universities, but from the organisations or groups in the communities who needed the data. Community-based research is conducted because some group needs the data for very practical purposes. A small Halifax group called the Committee Against Woman Abuse (CAWA), has sponsored a number of research projects in response to a need expressed by group members. Membership in CAWA is open to anyone who wants to join and who has an interest in anti-violence work. The Committee includes people from the local community - women who have successfully survived family violence and want to do something to help others, and/or professionals such as social workers, therapists, community-developers and activists, and police. The Liberty Project, for example, is a CAWA project. One of the members, Diane Kays, a counsellor, saw a client who realized that she always returned, if not to the same abusive man, to one who was similar. The client approached Diane and said she thought it would be helpful to her if she could join a discussion group of women who were having similar experiences. As they couldn't find such a group, they decided to form one. The group was so successful they had a long waiting list and received many requests to set up groups in other communities. Demand increased at such a rate that after a couple of years, the two group leaders were exhausted. They brought their problem to CAWA, which subsequently secured a grant to produce a manual so that other women could form and run groups. The contents of the manual were based on interviews with the two group leaders and with many of the women who had been through the group sessions.

The Parent Abuse study began in a similar way. One of the members approached CAWA with a request for information. In her work she was seeing more and more evidence of the problem of parents being abused by their adolescent children, but could find nothing about the topic. A literature search came up with very little, and Health Canada had no information available, so CAWA organized a one-day session on the topic and invited parents, service providers such as police and social workers, and high school students, and asked them to share what they knew about the issue. We particularly wanted to know if parent abuse was a problem in our community, what people were doing about it and what they would like to see done about it. About fifty people turned out to the meeting, and the consensus was that parent abuse was a problem but people were unsure how best to handle it and wanted more information. Health Canada agreed to fund a small research project so we could begin to define some of the parameters of this form of family violence.

The Youth Health Centre Project also came from that group, and was conducted in response to request by a director of the local teen health centre's for ideas for how she could get the centre evaluated. She felt she would be in a stronger position to apply for core funding if she had an arm's length report that documented the work of her organization. We asked Health Canada for money. They refused, but said that if we were interested in doing a piece of work they needed, the evaluation could be carried out as part of that research. Apparently, when youth health organizations approach the government for money, they usually declare that they are "youth-driven." The government wanted a document that would help these organizations define what they meant by "youth-driven" and help them assess how much involvement and at what levels, youth actually had in the organization. To write this document, we conducted interviews with youth who did and did not use health centres, and with professionals who were in some way connected with centres.

The Women Down Prospect Health Project had a very different, but no less community-based origin. Lower Prospect is a small fishing village outside Halifax where I lived for ten years. The women in the village struggle constantly with the stress of lack of money. Knowing where we could get a small health research grant, I asked a group of women if they'd like to do a research project about their health needs so they could access a little money. Interestingly enough, the women, many of whom had less than seven years formal education and no research experience, were more enthusiastic about doing the research than about the money.
The Women Down Prospect Project was conducted by a team of women who acted both as researchers and as the steering committee. In the other three projects, the first thing the sponsoring organizations did, in consultation with me as the researcher, was to set up an advisory committee. The committee accepted control and responsibility for the research and was invaluable in keeping the research on the right track.

SETTING UP AN ADVISORY COMMITTEE

It is not always easy to get people to join these committees because most people are already over-extended, but being on an advisory committee is useful to the members because it helps them keep abreast of current work in their field, and is an excellent place for networking. For each project we managed to gather a group of five to ten people who worked in the field of family violence or teen health or were experienced with group work, research or manual writing, and who agreed to act as consultants on demand and to meet once or twice a fortnight, at least in the early stages, to oversee the project.

We also sought out people who lived the issue at hand. These were women who had attended the Liberty group, or were abused parents, or youth who were interested in youth health centres. I believe it is important to include in these committees not only professionals involved with the issue but also people who can offer an alternative voice. Researchers can point out patterns in the data, but to get solid, reliable data we also need the people who know the topic at a hands-on experiential level. People who have lived the problem can help to ensure that the questions we ask are grounded in people's experience, rather than academic surmise. They can help make sure our interpretations are not missing the obvious, and that the way we present our findings is attractive and accessible. Having people on our advisory committee who have experienced the problem or the issue we are researching, and people from minority groups, provides a series of checks and balances, and helps to avoid the pitfalls of arrogance, racism, sexism and ageism in our method design.

We do not expect these people to represent entire groups. A woman who has left an abusive relationship cannot talk about the experience of all women who have done so, a Mi'kmaq person cannot represent all aboriginal people, or even all Mi'kmaq people, but she can talk from her own experiences, they can tell us how our questions offend or exclude them, or if they find them demeaning or threatening, or are inadequate to address their experience. There is a fine line here. One of my Black friends told me she finds it embarrassing when people ask her in the abstract if something is racist or not. She says, "How come I'm supposed to be the authority on that topic?" We also work to avoid tokenism. One woman who has been abused, or one person from the Mi'kmaq or Black community, often feels isolated and self-conscious in a group, and sometimes cannot find his or her voice. Ideally we would make sure there are two or more members of a minority as this takes the pressure off an individual, and supports someone who feels like the "lone voice." When people feel safe, which is often when another member of their community or a person who has had similar experiences is nearby, they will tell us when they experience something as offensive or inadequate to their needs. When the committees include people who can speak with alternate voices, we all have to take the time to work out differences and find ways to work together. This is not always easy and often tensions and difficulties arise, but ultimately this process enriches our research. If we have women, Blacks, and Mi'kmaqs on our committees, we are not likely to forget to include these groups in our research and to use language they can relate to, and our data is enriched and, therefore, more useful. The task of finding people who are willing to represent minority voices is time consuming, and often we fail. To be more successful, we must find ways for the work of advisory committees to be of some benefit to the women, so we are not always demanding generous donations of their time, and thereby falling guilty of taking and not giving - the very thing we are trying to avoid in our research.

Advisory committees usually inform and shape our research in an invaluable way because they represent many years of experience. In the Women Down Prospect Group, many of the group members were women from the community. We discovered that in one living room we had the voices of more than a hundred years of experience of living in poverty in a fishing village, and
consequently that became the focus of our project. Advisory committee members represent a variety of experiences. In the parent abuse project we had widely different perspectives on the issue that we wanted to collect, including parents who had experienced abuse and different types of professionals who try to work with families; in the youth health study the research design was influenced by people who work in the field, by people who work in the community and in government, and by the youth themselves. This wide range of experiences can be very helpful in problem solving: researchers can ask for legal or ethical advice or information, and someone usually has the answer or knows where we can find it. For example, one mother I interviewed was in terrible distress and disclosed her despair to me. I was able to go back to the committee and ask if anyone had any suggestions for how I could handle this. Some of the committee had suggestions which I was able to take back to the woman, including how she could get to see a counsellor without having to pay and without having to wait for months.

Many complex ethical issues arise in research that researchers are not sure how to handle. For instance, I discovered that a number of youth who were abusive towards their parents were later diagnosed as having serious mental disorders such as schizophrenia. In all cases, the parents had taken the children to doctor after doctor, counsellor after counsellor, trying to find some help. When the diagnosis was finally made, the parents were relieved to know the cause of the behaviour, and angry it had taken so long for the mental health profession to offer help. I described this finding to the Parent Abuse Project Advisory Committee. One mental health practitioner was concerned that parents would feel relieved by a "sick" label (because it makes the problem easier to understand in the short term), and it would send a message to parents that they should seek a "sick" diagnosis. I needed to write up this experience in my report, but I did not want to confuse the issue for parents who were already in a state of despair about what is happening in their families, or encourage them to seek a medical diagnosis. The Advisory Committee took the issue seriously, took time to discuss it and made some practical suggestions for how it should be handled. They gave me the support I needed.

As I collected the data for the parent abuse project, I began to realize that parents were telling me that they felt blamed and not helped when they went to see counsellors. Counsellors, on the other hand, were finding that if they mentioned parenting skills, parents heard that as "blame." Not sure how to make sense of this, I took it to the advisory committee. Two counsellors on the committee discussed the issue at length, and this discussion became a constructive part of our report. All committee members read the final reports on the data and offer suggestions. This, of course, leads to some complications, especially when there are disagreements between the researcher's conclusions and the views of the committee, but it is still a wonderful resource. When we have all these experiences in one group, a synergy happens. All the different minds spark off each other and we have the benefit of a creative energy which one person alone cannot produce.

TIME AND RESOURCES

Often our discussions are long and difficult, but ultimately they enrich the data and are, therefore, time and energy well spent. The committee also saves the researcher time because committee members all hear about the project at the same time, and keep current with project developments and so the researcher does not have to explain the research every time we want some help or advice. On the other hand, advisory committees do take up time and energy, and as ethics reviews are rarely factored into the research design, they are rarely a funded part of the research.

OPEN AGENDAS

With a committee of up to ten people from a variety of backgrounds, there are many different goals and agendas and it is difficult for them to remain hidden. In my experience, personal agendas can be more destructive when they are not aired and dealt with in a way that leaves the self-respect of all players intact. When the issues are out in the open, difficulties and tensions surface and have to be handled carefully. But if it is recognized that everyone has an agenda when a group of people is scrutinizing the research, then an individual committee member's personal motives and goals are very quickly brought to light. And when they are
out in the open, they often form the basis for interesting discussion, and again, enrich the end result.

For instance, in the youth health organizations project two people on the advisory committee had opposing goals for the research. The representative from the funding agency wanted a document that would show that many youth organizations did not involve youth in any decision making. A committee member who is a community development worker believed that if people who work with youth do not include them in decision making, it must be for good reason; that they work with youth while the government representative does not, and, therefore, the document should not present youth involvement in decision making as a necessary component of working with youth. She felt it was essential that the document neither criticised nor shamed organizations that did not involve youth in all decision making. At first, neither of these committee members actually stated the way they were trying to bias the report, but it did not take long for tensions to surface and ultimately everything was out on the table. We had many long, often tense, discussions about the issue, and eventually resolved it to everyone's satisfaction. In the end, we did not simply find out who involves youth in decision making and who does not, but included the debate over youth involvement. Had the research been conducted without the committee, I suspect the funders' bias would have influenced the outcome.

**AVOIDING HARM**

Above all, the advisory committee helps researchers avoid contributing to participants' problems. Researchers are often dealing with painful and difficult aspects of people's lives and, as community-based researchers, we don't want our research to add to their pain. Rather, we want to be helpful. To do this, we must be aware of what those problems are or could be. For example, during an advisory group discussion when I outline how I intend to set up and conduct interviews, it is not unusual for someone to remind me that there is no confidentiality in groups and that I should suggest to group interview participants that they should not say anything they want kept secret. In smaller communities, where the families are often intertwined, this was invaluable advice. The women in many small fishing communities are, for example, sometimes married to each other's relatives, a fact they sometimes dangerously forget in the intimacy of a group discussion. In the advisory committee we discuss, as a group, alternative ways of handling these situations and ways to inform participants of the dangers and how to avoid giving them a false sense of security. Together we try to work out ways the research can be less threatening. They make suggestions for ways to give participants options so they can meet with me in a place where they'll feel comfortable. This may all seem quite obvious, but it is valuable to a researcher to be reminded of it. During the Women Down Prospect research project, a meeting took place shortly after the New Year. I planned to open the session by inviting the women to share something that had happened over the holiday. I will always be grateful to the participant who reminded me that Christmas is a difficult time for some people. Armed with that warning, I was prepared for the tales of pain and depression that the group shared, and ready with some exercises we could do together so as not to leave them on a negative and miserable note.

**GIVING BACK**

I believe that one of the most important ethical considerations is to remember that once researchers go into communities to get information, we need to find ways to give to communities as well as take from them. We are takers, and we need to repay. The Mi'kmaq people in Nova Scotia get so weary of researchers coming in to their communities, taking their time, asking questions and leaving nothing behind. Directors of organizations are extremely busy people, often trying to find the funds just to survive; parents who are being abused are usually exhausted and in despair. It is, I believe, unethical just to take from these people. The advisory committee is a group of people who live and work the issues, and, unlike academics who come, do their research and go, the advisory committee members are a part of the community. It is even more imperative for them to be ethical, fair and appropriate since they are answerable for their actions in a day-to-day and ongoing manner. Their connection to the
community puts them in a good position to help find ways to give back to the community.

Sometimes the research process itself has more impact on the research participants than the final research report. One mother came to see me a few months after my interview with her about the abuse she was experiencing at the hands of her 16 year old daughter. She said that the interview had helped her sort through what was going on, and questions like, "and what did you do then?" helped her see that instead of remaining adult and in control, she had responded to her daughter with all the fear and distress that she was experiencing. Since the interview, she had taken control of the situation and things were going much better for them both. She found the data we produced informative, but it was the research process that was most useful to her. The benefit of the interview had little to do with my skill. I am not a counsellor or a social worker, nor do I try to be, it was simply the process of talking about her problem to someone who was not in any way judgmental that was, to her, a gift.

We began the Women Down Prospect project by exploring whether any other groups in Nova Scotia were doing similar research on health issues. I gave the women a list of contacts they could telephone. At the next meeting I suggested we share the results of our research. One of the women laughed and said, "Wow, I can't believe I'm doing this. I always thought you had to have a college degree to do research." The pride the women felt, and the self-confidence it generated, were every bit as important as the data we collected. One of the women, Carolyn, had telephoned the head of a university department. The department head treated Carolyn with the respect she deserved, and though she did not know of any similar projects, she encouraged Carolyn to describe the project to her and told her how valuable she thought the project was. Shortly after this, she came to me and said that there was a job opening as a teacher's aid at the local school and for the first time in her life she realized that she could do something other than housework or working on the fish plant assembly line. She credited her conversation with the department head with helping her come to that realization. I talked with Carolyn recently, and she told me that the job had changed her life. With an independent income, and with the respect she gets at work, her own self respect grew and she now feels she can hold her own with her husband and teenage children in a way she was never able to before. This shows how research does not have to be a mysterious, inaccessible process that only a few can do. Research is about teaching us to learn about ourselves in a systematic way, and the research process can be a gift we can share.

I sometimes give the people I interview information about resources in the community and much of that information comes from the advisory committee. Because they have followed the research carefully as it is being conducted, advisory committee members are well positioned to answer requests for talks and workshops on parent abuse. It is the least we can do. It's also ethical to make sure the participants' words are returned to them, in a form that is accessible to most, if not all, of the community. This means it has to be readable, it has to be cheap or free, and distribution has to be built into the research design. The advisory committees are the groups who advise whether the material is readable and how and where it should be distributed. They are the people who take boxes of pamphlets containing a summary of our findings to their meetings to make sure it reaches as many people as possible.

**CONCLUSION**

Implicit in what I have been saying is the distinction between the review and the implementation of ethical considerations. Research Ethics Boards, as their name suggests, scrutinize proposals to determine whether standard ethical considerations, such as confidentiality and minimum harm, have been included in the proposal. They serve a useful and necessary function in this respect. However, in community-based research, ethical issues are not standard. The important factor for us is the facilitation and implementation of ethical considerations as they emerge out of the specific dynamics of the work. For this, an ongoing advisory committee is crucial.

In this paper, I have attempted to give some insight into the ways advisory committees have acted as ethical review bodies and enhanced my research in the community. Working with such committees is not always easy, but I hope I never have to work without them. In my experience, both
university and community-based researchers are concerned about how we do research in terms of accountability to the people we are studying and the groups we are working with. We all know the need to examine how we get direction on framing the research method and questions we ask, and on who owns the research and how it is used. We need to continually examine what we give back to the community, and to realize that research can be political and can hurt or help the communities involved. The university ethics review process is currently under review itself, and in many universities is only now being developed. With the increasing emphasis on university, government and community partnering in research projects, this may be the right time to try to understand the different ways we do our work, and to explore if there are ways we could in fact learn from each other. Then, perhaps, we could be more of a resource to each other, even though the different organizational contexts and the issues of power and authority that are inherent in this relationship mean that working together is, at times, difficult.

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**ENDNOTE**

1. For the purposes of this paper, I will assume that by "ethics," we mean the ways in which we make sure our research is sensitive to the needs of the people we are researching and the communities in which we work.