



Community-Based Research and Ethics: From Ethics Forms to Honouring Relations.

With Jeannie Kerr

Presented by the Community-Based Research Training Centre.

Description:

What is ethical in research and what are our responsibilities as researchers?

Unless you have designed a research project and completed ethics requirements yourself it may be difficult to know how the process works, especially in community-based research. As a Research Assistant on a project, you might not know what your own responsibilities are and why it might even matter to you. In this session, we will consider the ethical responsibilities of the research team when participating in community-based research projects. You'll see the big picture of the ethics requirements in research in Canada linked to Universities and communities. Through working through a case-study, we will think more specifically about what it means to recognize and honour our ethical responsibilities to research participants as a research team member.

Date of discussion:

March 31st, 2021. 12:00pm – 1:30pm. Zoom.

Note:

This transcription has been revised to remove filler words and points of confusion. Please direct any concerns, questions, or inaccuracies to Dagen Perrott at da.perrott@uwinnipeg.ca. The original video recording can be accessed through Winnspace at <https://winnspace.uwinnipeg.ca/>. As well the recording this is transcribed from begins a few minutes into the workshop.

Jeannie Kerr (00:19):

Okay, so pretty much everybody is here today. That's great and what we can do is during the presentation part of this, if you do have questions that come up, Dagen will be looking and monitoring and can interject with me so that I can respond to the questions. If you need more clarity on something just pop that in the chat and Dagen will let me know.

Here we are Community-Based Research and Ethics. What are we doing today? I am going to give you the big picture of what is ethics and what is the kind of framework that researchers work under in Canada. What is really required in terms of community-based research and what we need to think about. I'll give a little bit closer, like our picture, what is the process, what are these forms, what is that all about. What do you do when you're doing research connected through a university or an affiliated organization? Then the research team, what peoples responsibilities are. Then I am going to look a little bit at a case study and give you a chance to think about this and some questions or some things you can think through as we think about an actual case. This is a case study of something I didn't work on myself, it was just a project that's come across my desk a few times in terms of as a teacher and looking at some kind of developments in newcomer concerns in the Inner-City in Winnipeg. We will go over that and to participate in that part you'll be going into a breakout room and you'll have about, probably six or seven people in your breakout room. And you would be connecting with Mentee.com, so we will give you some instructions for how to do that, somebody in your group needs a cellphone, so we will make sure that happens and that we can figure that out.

I'll get started big picture-ish, there is a lot of things you may have heard and little names like SSHRC or NSERC and people aren't always explaining what these things are and how they relate to ethics etc. In Canada there is an inter-agency advisory panel on research ethics. It was created in 2001 and the inter-agency involves three agencies. Its CIHR which is related to health research, SSHRC, Social Sciences and Humanities, and NSERC is related to the natural science and engineering. Within those three organizations, that panel has people from each agency. What has been done is there is a thing called the Tri-Council Policy Statement, so people who are working on research in Canada should be following, for the most part, Tri-Council Policy. Its easy to find online, its had a few updates, but you'll notice that the dates aren't that long. You would think that research ethics would have been going back fifty, sixty years, but as most people can tell you that there is a lot of research that was done that really lacked ethics and was

very damaging to communities. You can see in this 2001 context, that there is this need to really think about how ethics is being approached and regulated in a Canadian context. That starts about twenty years ago and then there's been these few updates. But everybody for the most part in Canada, especially if you're affiliated with a university who works under Tri-Council Policy.

There is a great tutorial available and anybody whose working on research projects that have ethics review needs to have the core tutorial. It's free, it's advisable to use a university email because that then will connect you to the university. If you are not connected with a university you can still do the tutorial, at the end it will give you a certificate. Often an ethics board will ask you, when they are reviewing your project, will look at that and want to know if all the researchers and research assistants have completed the core tutorial and those certificates would be included. An interesting thing, and I'm not exactly sure why, is there is the core and if you look down it says module nine and ten. Research involving First Nations, Inuit, and Métis peoples of Canada, it's very advisable to do that tutorial because there's a lot of questions that come up around that. It's not clear to me why it's not included in the core, but I often ask people if they can have a look at that and get more familiarity. I will make sure to go over some of those aspects as well today.

So the idea, the big idea behind Tri-Council is based on respect for human dignity. A lot of people look at ethics sometimes as like oh I have to fill out these forms, and ugh it's like a barrier, or something like that. But because of the history of problematic research that's been done, that human dignity needs to be forefronted, and that what happens with the ethics application that anybody is looking at, is have you shown that you have really thought through all of the things that relate to maintaining human dignity for participants. In this sense they kind of frame it, in Tri-Council, on three pillars. So it's respect for persons, concern for their welfare, and concern for justice.

In the first part you will often hear about consent forms, so that process is really about making sure that people feel that they are free and not being forced to participate in something that they don't feel comfortable. That they fully understand what the nature of the project is, in a language that makes sense to them. That's the free and informed consent, and it can be digital, or it can be verbal, or it could be in paper, there's lots of ways to do it, but it has to make sense for the participants involved. And again, they need a voice in it to be able to say that they can walk away at any time, that they are not going to have an adverse event because of walking away from

a project. That a concern for their vulnerability is present. In this sense, vulnerability refers to people who perhaps are incarcerated, and have less ability to make their own destination for what they want to do because of constraints on them. Sometimes with young people under 16 its often considered because they're required to be in certain structures, that they may be a little bit more vulnerable, they may be in a classroom and being forced to participate in a research study that they are not even aware of. Vulnerability is a big thing when we are looking at research projects.

Concern for welfare, do you know the risks, and these are psychological, emotional, physical, that participants may be exposed to. How is that balanced off the benefits for that person and to society at large. So those are very careful balance obviously and its done from the participants perspective as well. How would they feel about it, not just how everybody else feels. As well as confidentiality in terms of is the anonymity of the participant being honoured and respected and guaranteed in some way.

Concern for justice is a good one because its really about thinking about whose been invited or not invited to participate and have their voice put in to research. This is a big thing about inclusion, appropriateness, and awareness of what the project is. Justice is important, and especially, obviously in the context of Indigenous peoples of Canada that have not experienced justice within research or within a Canadian settler-colonial context. What does that mean for thinking about how your study engages Indigenous peoples and their knowledges and perspectives.

There is a full chapter in Tri-Council policy, chapter nine, that really gets into the specifics of what researchers need to think about. A lot of people, so when I see some of the forms that come through, say oh well I'm not doing this research on reserve lands, so its nothing that I have to think about right now. But literally if you look through, these different points are the questions you need to ask yourself: is the research being conducted on Indigenous land, that's one. Is recruitment even including criteria as Aboriginal identity for even a subgroup. The third one, research that seeks input from participants regarding a community's cultural heritage, artifacts, a lot of people would recognize that one that they should respond to. But the fourth one there, a lot of people don't realize, so if you're doing research in which Indigenous identity or membership in an Indigenous community is used as a variable for analysis, that's research that has to respond completely to chapter nine. I will give you an example after but its something that people aren't always aware of. If you're thinking about the experience of Indigenous peoples,

even within a larger study of say studying the outcomes of educational results or something like that, you still really need to think all through chapter nine. If we have more questions about that for sure I can discuss that more.

If you are responding to chapter nine, if there's something with Indigenous research that you need to attend to, you need to engage community and have advice. Even Tri-Council recognizes that it really has to be specific to the community and their needs and what's going on. Its impossible to just generalize and have one set of standards. but there are, you can go online and there's lots of interpretations and advice as to the appropriate sort of engagement that would be suited to different studies. And you can always check with the research ethics board as well and check-in with the community or the people that you're engaging with.

In this example, so if its research and it's focusing on a large community and its known to include Indigenous people, regardless if even a few, if you are going to make any Indigenous specific conclusions, then this would be an example. A study of student retention in high schools in Sault Ste. Marie in Ontario, and you are going to look at one of the variables as Indigenous participation or what's going on in terms of retention. Their suggestion is put together a little committee with organizations, Indigenous organizations, urban Indigenous people whose children may be affected by that study and the conclusions. That they can give advice to you and your research. You can go through and we can always discuss that more, but its one of the things that probably has the most questions, like how do I engage? In what ways? Especially if its not based in community, if it is based in community it's a lot more straightforward of engaging with the people that you're working with.

The documents you need to think about including, so this is another question that comes up quite a bit. People will say okay well what's your process? What is the agreement that has gone on between you and the community in terms of how you are going to conduct the research? And you have to document it, so that its clear, what is that agreement. But if the community itself doesn't do formal agreements in that way and they have meetings and oral understandings. Then you need to follow what the community does, you don't make ethics dictate to communities. But the ethics board may just ask you, okay well what is your agreement, what do you understand, and you would clarify in a document that we have an oral agreement, I attend meetings at these times, this is how I do it, and this is the substance as to what has been agreed to

in that. Its really the researcher that has to do the work, shouldn't be downloading that off to the community.

Other things you would need to include with your ethics as an application would be how you are going to recruit people, examples of that posters and emails. Consent documents or formats you would have to include, so even if its going to be an oral consent process, you as the researcher would need to document what you are going to be saying and how you are going to clarify that you have that consent. The protocols, so step by step, like how are you going to do interviews, or whatever it is, how are you going to as you sit down, how are you going to ask for consent, what's the process for you. How are you going to document it, how are you going to hold on to it, and then how are you going to start your interview, what are the questions you are going to be asking, you have to really do all that and submit those documents with your ethics but also attach the core tutorial certificates for anybody who is on your project.

Interesting update. Tri-Council just updated in 2019, so this is really relevant for community-based research ethics. I think you are picking up that there's been quite a process going on with Tri-Council about how to engage more respectfully and meaningfully with Indigenous communities. In their recent update, 2018, they said that we should be working towards this with all communities that may be impacted by research. I guess originally, and this is my view, Tri-Council is very much a western document that sees individuals as not imbedded in communities, and that's been the kind of way they've gone. And now you can see their edging towards it with this latest update that we should probably be doing more of what has been doing with Indigenous communities, with all communities. If there is a community of interest, or geographic community, and we could even see this within the north end of Winnipeg as a community, that we should really be thinking about exactly how we do this kind of work that respects the community and not just sees people as disconnected from communities.

A big and important organization that's kind of leading in these conversations is also Community-Based Research Canada, which is a national non-profit and they have lots of resources for community-based researchers as well. But for them they're trying to also kind of bring to the forefront the need to respect and engage community more fully then just as people, individuals who happen to be part of a community. That you should really be able to understand the community, you should respect their processes and protocols and engage with them, but they should be right from the beginning helping to shape the research and the questions. The

relationships should be coming first in terms of being involved and understanding what the community sees as significant for them and important for what they want to do and that you as a researcher are more responsive than telling them what they should be doing or presenting a fully formed project.

In terms of community-based research it's really, it's research that attempts to understand and challenge societal inequalities and problems. It's not just any just general I was interested in this today, it's really social justice focused, often about research that is responsive and understands that it's not research that just with individuals, it's in a community context. The type of engagements can be really interesting and different, and it all depends on what the community wants, what the researcher is doing. The, sometimes it's been framed as capacity building for within community about research, but I've really appreciated some more recent documents where I've seen it called bridging expertise. That we're looking at that community has a certain amount of expertise about what it is their priorities are, what they do, what the real nature of their priorities are, and that the researchers who are based in universities have a certain level of expertise about how to do research, and so it's bridging these two things together rather than building capacity. It's sort of a more strength-based understanding for both people involved I think as well.

A weird thing that is coming up, that's very unusual and it's mostly to Manitoba, is that health based research is going to move out of being approved in universities, and they're putting together a completely separate research board for Manitoba called RITHIM, well the board is not called RITHIM it's called CHIPER, but the organization that's being responsible for it is called RITHIM, so Research Improvements Through Harmonization in Manitoba. If you are doing any kind of health research, so as we think about the humanities, health, and NSERC for natural sciences, if it's in health it's not going to be approved in the university anymore through a university level board, it will be a Manitoba board. Which is meant to, anybody who has done health research knows that there's a mass of approvals that has to happen, so it's meant to shrink that. So that you're just going one stop. We will see how that develops, but you should just kind of have it on your awareness if you're in health research that it may look different.

What do we do at University of Winnipeg, so I chair that research ethics board. I review all of the applications that come in just to see in terms of risk level and that it's complete. In terms of most projects that are minimal risk, meaning that it's, yaknow, any participant in your research

project would not encounter any kind of risks beyond what their regular life would look like. I look at that, I determine and if its greater than minimal risk the whole board reviews it, but if its minimal risk then that goes out to a few delegated reviewers and that they take a look and then they give you that feedback. Before you are submitting an application definitely do the core tutorial, it'll give you a good sense and preparation for being ready. Students can be, its always the principal investigator that submits the application, but if its your project as a student you are the PI, you would do it, but you'll have to make sure you're naming a faculty supervisor. If you're a community-based organization that's always a place to figure that out, there are approval boards that will do reviews for you. The easiest and probably the most straightforward way is to collaborate with a university researcher so that you can access the ethics board. Usually, the funding source determines what kind of ethics review you need and what kind of approvals you need.

With us, the Community-Based Research Training Centre is sponsored by Manitoba Research Alliance as part of their SSHRC grant. So that's a lot of acronyms, but if anything that goes through SSHRC has to have university review and so that way if you collaborate with university researchers you automatically get the universities reviews. Usually, its often funding that will determine what kind of review you need. You should probably just assume every project needs review and then figure out how you are going to get it.

The principal investigator submits the ethics application, at University of Winnipeg its called webgrants. You would need to obviously do the tutorial, you need to think through all of the stuff we have been talking about in terms of what's the relationship, what have you agreed to, do a literature review, methods, risk-benefit analysis, have all that sort of clear and then you can proceed with looking at these application forms and they basically mirror a lot of the tri-council policy in terms of the ethics process. And then I would review it if it's a UofW project, if it's put through there, and then its either expedited to reviewers or it gets a full board review if its more than minimum risk.

Relationships, community-based research, the key. A lot of times people look at ethics as a hurdle. Right so oh I have to get through this, and it can be kind of onerous, but its all related to human dignity. Human dignity I feel like its expressed through the way we honour our relationships with the participants and the research and the communities that we are affiliated with. All of this stuff is just meant to make sure that this is being done in the best way possible.

A lot of researchers have great intentions but have done irresponsible research not quite realizing all of the implications. The ethics process is really meant, if you look at it more in terms of support, as like okay you have done your absolute best to maintain the dignity and respect for the community that you are working with and the participants and that this is a way to get somebody's feedback. Like do you see anything else? And you are being asked to be really really clear, okay what are you doing? Have you thought about all of this? Then you get that kind of feedback in the way, in my experience on the board I feel like most of the board members or all of them as far as I have been able in my experience these last couple of years, they really just want to see the best research, cover all the angles, make sure that everybody is not going to have an adverse event from the research project. Its to help you in that way. At the heart of it is about honouring relationships and helping you think through that.

When you've got the research team, these are the kind of people. The principal investigator is the person who is in charge of documenting all of this stuff, making the plans. Research is always better with more people, so hopefully you are not all by yourself as the PI. But the PI is responsible for everything. The Co-Investigators are pretty much anybody that you want to work with but you always have to have pretty much one principal investigator. But Co-Investigators are people that are really involved in the research and that would think through all of these things with you. Then the Research supporters can be co-investigators, so supporters may be people on those advisory boards you put forward, organizations that are really supporting the research and are actively interested in the results to inform the work that they do. They can all depending on the involvement, they can also be co-investigators, but the Supporters are important especially for community-based research. If you don't have supporters then its hard to document how you understand and are being responsible, if you are not really involved with anybody at the community level. Research assistants are often, especially for funded projects, are great opportunities for students to figure out how research works and to get that experience. And in terms of the MRA, all of this, we're really giving this funding for the CBRTC is about helping people figure out how they are gonna manage as and learn how to be research assistants. And there will be opportunities from that larger MRA grant for research assistants. Collaborators are people who maybe can't be involved but could give you good advice, they may have similar interests, but a collaborator would probably be less involved. When you are putting in an ethics application, you'd really have to specify all of these people as kind of part of the research team.

You want to be as clear as possible about how you are going to do this and how the members are working.

That's a lot of me talking. I hope I was trying to balance it with what you may be interested in, the broader picture, and all that kind of thing. What I was thinking we could do is a case study. I don't know the researchers, this is public documents, they may even be here we don't know, but it is a great example of a case. What we can do is just think about, now okay we have talked about a lot of stuff, but say you've been hired as a research assistant or you have been invited as a co-investigator on a community-based project. And the next slide it'll have a little more details of the project, but you're asked to conduct interviews.

What we want to think about is what are your responsibilities and what questions do you need to ask the PI before you get going on what you're going to do. I'm not sure how familiar anybody is with Menti.com, but what we will do is we will go into breakout rooms, you'll have probably about six people in your breakout room. The idea would be that you introduce yourselves, so that you all know each other and that you can then discuss and maybe pick one person who could help to make sure everybody's included. When you respond to the, on the next slide you will see, you can go on Menti.com and everybody in your group can type stuff in or you can have one person, its up to you.

I am just going to go to the next slide. Now that you can see it, this is a specific research project. It's already been done, it's been documented, but we are going to do an imaginative exercise where we think about you as a PI - not as a PI, as being invited by a PI. What do you need to ask before you get started and what are your ethical responsibilities? What we will do, you will see on Menti.com and I think Dagen is going to put the code in. You'll go in your group and you'll have that introduce each other, have that discussion, and when you put things in we can actually, we will all be able to see it. Everybody will be doing this within their groups and then what we'll do is we'll get back together, and we will talk about all of these things people are thinking about. And then have an opportunity to ask more questions as well if that is where it needs to go.