Reciprocity and Constructions of Informed Consent: Researching with Indigenous Populations

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Abstract

In this article, the authors present a discussion of institutional review boards and potential challenges qualitative researchers may face when presenting human subjects research proposals to these boards for approval. In particular, they focus on issues of consent and reciprocity with Indigenous populations, whose culture and traditions might be quite different from those review boards typically see. After presenting these issues, the authors close with a framework that can be used as a guide for ethical considerations in research with Indigenous peoples.

Keywords: Indigenous peoples, First Nations, institutional review boards, human subjects research, research ethics, interview research
Our primary focus in this article is to place emphasis on the notion that researchers should attempt to employ culturally appropriate means, such as forms of symbolic reciprocity like offering asemaa (tobacco ties), in establishing consent when conducting research with Indigenous peoples. Institutional research boards (IRBs) need to be challenged in terms of their protocols and assumptions regarding the nature of qualitative research, especially in their reliance on signed informed consent as the only manner of establishing a consensual relationship built on trust in the observer-participant relationship. In this article, we question the positivistic colonial worldview of the composition of IRBs and draw lines of sight to the pitfalls of assumed neutrality in qualitative inquiry. The discussion concludes with a proposed theoretical framework based on Portman and Garrett’s (2005) work in the area of leadership and counseling in American Indian populations that might be adopted as a guide for ethical considerations in performing research with Indigenous populations. For the purpose of this article, American Indian, Native American, and Indigenous will be used synonymously. We realize the political and cultural implication of doing so, and by no means are we trying to represent any group as being more important than any other in the context of research. We attempt to argue that, as researchers, it is our responsibility to find culturally appropriate and acceptable means of building a research relationship constructed on the foundation of mutual respect and trust.

Introduction to the study

The first author conducted the study used as a backdrop for our discussion for his master’s thesis (Ellis, 2001). The thesis was about how Indigenous spiritual traditions affected the process of grieving after the death of a loved one. It was an interpretive study in which Ellis sought to understand the spiritual insights of five Indigenous individuals regarding loss and grief. It took seriously the nature of interpretation, particularly in relation to the researcher’s personal history and attempting to understand a complex phenomenon, such as Indigenous spirituality, in a culture foreign to the researcher. From this inquiry, findings suggested that spiritual practices such as prayer, song, the drum, and the offering of tobacco play important roles in the healing path, as does making peace with those who have crossed over to the spirit world. Findings also suggested that Indigenous individuals use both spiritual and scientific-based cognitive assimilation strategies to assimilate their loss.

An Overview of Institutional Review Boards and the Current Challenge to Researchers

The call for different approaches to how research is conducted has long been debated in American Indian communities (Manson, Garrouette, Goins, & Henders-son, 2004). This call has arisen out of research practices of the past having served the agenda of the colonization process in suppressing Indigenous knowledge (Wilson, 2004) and the objectification of Indigenous populations as portholes to the past (Vidich & Lyman, 1994). There is a movement to decolonize the knowledge-gathering process, but “decolonization ultimately requires the overturning of the colonial structure, [which] must be initiated by the colonized” (Wilson, 2004, p. 362). By working from a context of participatory, cooperative inquiry, this decolonization can begin; by entering into a reciprocal partnership, Indigenous and non-Indigenous researchers can work jointly toward this shared goal. The challenge comes from trying to do so with the current structures and parameters proposed by IRBs.

The origins of modern research ethics can be traced to the 1947 Nuremberg Military Tribunals following the experiments performed by Nazi doctors during World War II (Interagency Advisory Panel on Research Ethics, n.d.-a; Piquemal, 2001). The Nuremberg Tribunals condemned this research as a crime against humanity but, more important, “brought the issue of human experimentation to the forefront of public debate and influenced a series of international documents created to ensure that all countries respect adequate standards of human dignity” (Interagency Advisory Panel on Research Ethics, n.d.-a, para. 1). Of the documents created, the most relevant to American and Canadian research are the Universal Declaration of Human Rights (1948), the Declaration of Helsinki, the International
The Challenge of Presenting Qualitative Research to a Quantitative IRB

There seems to be a discrepancy between the purpose of IRBs and their nature. Their basic purposes appear to be assessing the benefit-to-risk ratio of any given piece of research, independent of the proposed (qualitative or quantitative or mixed-methods) method and denying those studies whose perceived risks outweigh the benefits (Berg, 2004). There is concern, however, that IRBs might still challenge qualitative researchers because of “the divides between notions of good, ethical ethnography and qualitative research and the ethical frameworks and applications of basic ethical principles endorsed by local institutional review boards” (Hemmings, 2006, p. 12). Berg (2004) stated that even though IRB expansion has been continuous in its growth, it has not changed in terms of the composition of its membership. He discussed that “medical and behavioural scientists under the aegis of value free neutrality continue to dominate, and the changes in procedures generally have stayed within the biomedical model” (p. 147). Even researchers in the health fields, however, have run into challenges designing and conducting ethically sound research with Indigenous populations (Meadows, Lagendyk, Thurston, & Eisener, 2003). The U.S. Department of Heath and Human Services Code of Federal Regulations (1993) states, “each IRB shall have at least five members with varying backgrounds to promote complete and adequate review of research activities commonly conducted by the institution” (p. 7). Berg (2004) cited that IRBs should not have homogeneity in terms of gender, race, and profession, and that one member’s work should not primarily be the sciences or social sciences but further indicated that guidelines do not articulate what research skills the members
should have and concluded with the possibility that “members of the IRBs themselves may have never conducted research on human subjects or, for that matter, conducted any research” (Berg, 2004, p. 57).

The reach of IRBs seems to be more and more encompassing, as there are few exemptions and a small, rigid framework for the types of research that may undergo an expedited review process. In fact, “the specific exemptions for styles of research that can be expedited through IRBs largely are quantitative survey types, observation in public places, research involving educational tests, and archival research” (Berg, 2004).

What seems to be of central concern to IRBs is the nature of the relationship between the researcher and those being researched, especially in terms of informed consent. The Interagency Advisory Panel on Research Ethics (n.d.-b) Tri-Council Policy Statement (TCPS) states,

> The Nuremberg Code’s requirement for voluntary consent from human research subjects has been highly influential in the development of national research ethics policies. The TCPS defines free and informed consent as “the dialogue, information sharing and general process through which prospective subjects choose to participate in research” (TCPS p. 2.1). In most instances, researchers seek the free and informed consent of prospective research subjects or their authorized third party before participation in research begins. Consent should be maintained throughout the research subjects’ participation in the research. Consent is usually obtained in writing. (para. 1)

Bogdan and Biklen (1992) noted that the relationship between researcher and other in qualitative studies is vastly different from the relationships in quantitative approaches, in that most conventional procedures of obtaining informed consent and protection of human subjects amount to more than ritual. Manson (2002) further described some of the “thorny issues” involved with informed consent and American Indian tribes. Berg (2004) argued,

> The relationship between researcher and subject is frequently an ongoing and evolving one. Doing qualitative research with subjects is more like being permitted to observe or take part in the lives of these subjects. At best, it may be seen as a social contract. But, as in all contracts, both parties have some say about the contents of the agreement and in regulating the relationship. (p. 52)

Berg (2004) added culpability to this argument, in that because the relationship is such an evolving one, risks as well as benefits are hard to identify prior to the start of the study.

The latter possibility of unforeseen benefits can be discussed from the context in which the first author studied grief and loss issues with Anishnabe individuals. When he entered the researcher-researched relationship, he foresaw no real benefits to the participants coming out of the interview process; the payoff, he believed, would come in terms of providing more culturally sensitive counseling procedures for mental health providers dealing with Anishnabe individuals who self-identified as having the same or similar constructs of spirituality. He became aware of the individual benefits to the participants only when, 6 months after the conclusion of the research, one of the participants telephoned him and thanked him for being able to share his struggle to come to terms with his nephew’s death. He had benefited from being able to share his emotional upheaval in a focus group of individuals with similar stories, which provided him with a nonjudgmental forum in which to do the emotional “work,” as he termed it, which needed to be done as part of his grieving (Ellis, 2001).

**Reciprocity and informed consent**
Punch (1994) has taken the stance that professional codes of ethics are beneficial as guidelines but warned that the idea of informed consent is unworkable in some forms of research. Piquemal (2001) further argued that “ethical beliefs must be contextualized and grounded in particular cultures” (p. 70) and warned that current consent protocols might not conform with the ethical beliefs of Native communities. Punch stated that he is concerned that a strict application of codes will restrain and restrict a great deal of informal, innocuous research…that are unproblematic but where explicitly enforced rules concerning informed consent will make the research role simply unattainable. (p. 90)

Sin (2005) argued, getting respondents to sign a consent form or having secured approval from research ethics committees are, in themselves, insufficient to ensure that the process and products of research are conducted and wielded in ethical manners. (p. 281).

He further discussed the necessity of an ongoing negotiation with research participants regarding consent in rationing, in that constant renegotiation of consent is underlain by the understanding that the complexity of research demands different forms of consent, some more explicit than others, depending on the stage and nature of research at different points in time. (p. 281)

Reason (1994) submitted that from humanistic roots, like the argument stated in Sin (2005), have sprung cooperative inquiry methods. Cooperative inquiry challenges orthodox social inquiry methods, which hold as part of their rationale the intentional exclusion of participants from the “thinking and decision making that generates, designs, manages, and draws conclusions from the research” (Reason, 1994, p. 325). The nature of the observer-participant relationship in cooperative inquiry “rests on the high-quality, critical, self-aware, discriminating, and informed judgments of the co-researchers” (p. 327). The idea of reciprocal, coauthored research poses a possible solution to the problem that informed consent:

Cannot be entirely achieved at the beginning of the study, even if it is the intent of the researcher to do so, because the research context is constantly in flux and neither researcher nor anyone else really knows what is being consented to. (Erlandson, Harris, Skipper, & Allen, 1993, p. 155)

Integrating Sin’s (2005) and Erlander et al.’s (1993) notion of the constant renegotiation of informed consent furthers the nature of respectful reciprocity of those individuals choosing to participate in the research process. It is our hope that readers derive their own meaning of reciprocity in the observer-participant relationship, so that trust can be established through culturally sensitive approaches to qualitative inquiry.

**New directions of qualitative research in Indigenous populations**

Manson and colleagues (2004) indicated that the cultural values that are necessary for performing research with Indigenous populations revolve “around trust, respect, self-determination, mutuality of interests, perspective taking, full participation, reciprocity, collective benefit, and long-term commitment” (p. 605). In the University of Victoria’s Protocols and Principles for Conducting Research in an Indigenous Context (2003), the nature of the participatory relationship is made explicit:

Where Indigenous people are major participants in research or they have a major interest in the outcome of a research project focused on an issue of relevance to Indigenous people, then
working relationships based on collaboration and partnership should be established between the researcher and these participants. This would include the mutual sharing of research skills and research outcomes. (p. 3)

The University of Victoria’s Protocols (2003) detail the participatory approach in that research questions and methods should be designed cooperatively with Indigenous individuals or the groups being represented in the research. They further state that there should be an equal burden of the monitoring of the research process and sharing, and co-developing research skills should be an underlying premise of the partnership. Most important to the context of this article is the implication that the partnership should be one based on trust that does not prejudice anyone in the partnership and that is achieved by ensuring that Indigenous values are upheld at all times and that appropriate aspects of Indigenous peoples are understood, acknowledged, and upheld. We argue that by using cultural symbols of reciprocity, the integrity of what has been stated can be achieved. One example of such a cultural symbol is asemaa, discussed next.

Asemaa as a symbol of reciprocity

Traditionally, tobacco has played a central role of peace and healing for several Indigenous peoples of North America (Gill & Sullivan, 1992; Struthers & Hodge, 2004). Benton-Benai (1988) discussed Anishnabe ties of tobacco to both peace and the spirit world in writing:

Waynaboozhoo showed the people how to smoke tobacco in the Pipe and in so doing seal peace, brotherhood and sisterhood among bands, tribes and nations. Waynaboozhoo told the people that the smoke that came from the Pipe would carry their thoughts and prayers to the Creator just as their Tobacco offerings in the fire would do so. (p. 80)

Sacred uses of tobacco continue to define the culture of the Anishnabe (Ojibwe for from whence lowered the male of the species or original man) people (Benton-Benai, 1988). Struthers and Hodge (2004) described the cultural definition of tobacco “as a gift of the earth. It was burned, and the rising smoke was used to cleanse and heal” (p. 210). They further indicated that tobacco’s centrality to Anishnabe culture is indicated through its being “offered in every ceremony and in many other circumstances. Tobacco is used in funerals, weddings, for praying over and offering food, for picking medicines, for hunting, for thanking people, asking for help, praying for information, and sharing stories” (p. 217). Two of the listed uses of particular interest for this research are asking for help and sharing of stories. This aspect is detailed by recounting a narrative of research with Anishnabe individuals during the first author’s work on grief and loss issues. In the following sections, we highlight excerpts from his personal journal kept while conducting his thesis research, with thoughts about how these experiences informed his ideas about reciprocity and cultural sensitivity.

The gatekeeper calls

I’ve got a tight schedule with travel from one end of the province to the other. Home base is at Dad’s in central Ontario. It’s late afternoon, my papers are spread out all over my father’s glass dining room table as I frantically hammer out the protocol for my interviews. My mind oscillates between the task at hand and what my kids are doing with their grandparents. The phone rings. It could be important; it could be Alvin, the man who had previously offered to assist with entry. I pick it up, fumbling, but getting a hold of it and finally placing it to my ear. “Hello,” I say, out of great anticipation. “Hi Jason it’s Alvin. I needed to talk to you before I see you at the Powwow tomorrow.” “OK,” I say, “what’s up?” “Well you need to prepare something before you go.” I think to myself, what, my questions need to be rephrased, my consent form needs to be redone, oh my God my IRB will never let it go if I need to make an impromptu change, my heart beats faster, I think I’m screwed. “You need to get some red broadcloth and rip it into
six inch squares,” he continues. “Don’t cut it, they need to be ripped so start a little with the scissors and then rip away. You also need to rip some one inch strips so that you can use them as ties. Go to a corner store and buy a package of pipe tobacco, take about the size of a large gum ball and place it in the middle of the broadcloth you ripped then tie it tight with one of the strips. When you go to speak with someone and ask them to do your interview, you need to reach out with the asemia in your hand. If you don’t do it they won’t talk to you.” I thank Alvin for the tip as I continue to make notations in my journal and try to decode what needs to be done next. By late evening I purchase and prepare the broadcloth and tobacco into tight little ties. (Excerpt from field notes and reflexive journal)

The author’s original reaction to this key informant’s suggestion for gaining access was one of disbelief and a general lack of understanding. He had no idea of the significance of tobacco in terms of culture and wondered how he would be received in trying to perform a cultural practice specific to Indigenous peoples while being of non-Indigenous roots.
The interview that never happened

I step out of my car not quite knowing where I need to go. I check to make sure I have my two recorders and extra batteries and tapes. “Nothing like overcompensating,” I think to myself. My nerves are on edge, I fear how I will be received. The last thing I want to do is offend anyone, but I think no matter how well I am prepared, you never know what life can throw your way. Here we go. I walk with reluctant intentionality into the large grassy area. There are clusters of people dressed in ceremonial clothes but mostly jeans and tees like I am wearing. I wander around slowly for a few minutes to get a feel for what is around me. A few large tented overhangs, like you would see at an outdoor wedding a large food truck offering traditional foods and lots of cars parked to the sides. The drum doesn’t stop. There is a constant rhythmic pulse in the background that I can almost feel in tune with my own heartbeat. My attention focuses back on task; I scan around for Alvin and after some searching find him. He is an athletic man in his forties, graying with salt and peppered hair, both facially and on his head. He greets me and says, “hey, you made it, great, walk with me for a second I need to put something in my truck.” We walk and he seems to be familiar with all who cross his path, he hurriedly greets them as we make small talk about finding the location and the condition of the roads in an instant he diverts me in another direction and tells me that he has somebody he wants me to meet. He takes me over to a where there is a moderate sized open fire burning and introduces me to the keeper of the fire. Alvin makes his exit after the introductions and the research begins. I introduce myself and hold out one of the tobacco ties I had prepared the previous evening. The keeper of the fire looks at me sternly and tells me I am offering it with the wrong hand. I switch hands as I internally submit to abusive self-talk—“I am an idiot.” He accepts my offering and tells me that “he’ll see what he can do.” I cognitize, “he is offering me a response, but I did not ask a question.” There is something symbolic in the offering of the tobacco tie alone; the understanding that if I can help you I will, if not, I’ll return your tie to you. I take out my recorder but never start it; I fumble with initiating my questions. In a moment I am swept up in the discourse and not what it means to multicultural counseling or even just getting the research done; I become fixated on how the knowledge transforms me. He tells me about the sacred fire and how one goes about praying. He describes the embodiment of directions, the herbs used in the offering and offers to take me to the fire rationing that one can only know through the experience itself. I go and I am transformed. The nature of their culture has in someway merged with my own. I return to him and make reference to the fact that I never turned the recorder on. He looks at me like we are old friends and smiling says, “I know Jason, if you had turned it on I never would have talked to you at all.” (Excerpt from field notes and reflexive journal)

The hermeneutic context from which this researcher was working is noted. He clearly believed that in doing ethnography, there is a merging of horizons; this merging is the transformation referred to in the narrative. The aim in the research experience can be defined as to understand differently, not better (Koch, 1993). The researcher doing this study did comply with IRB protocol in having the fire keeper sign the informed consent form but consciously chose to exclude the specific details of the sacred fire in both his master’s work and in this article, because the participant’s intentions were clear that only through experience can one truly know that knowledge is transformational. This is the basic premise to the idea of reciprocity being discussed in this paper.

By the IRB book: Well, except for the tobacco, smudging, etc.

I’ve got to get psyched up; my game has to be on. I’m nervous as hell, the sweat is already pooling under my arms and I’m not even at the interview site yet. Why the hell am I doing this, do I really need a Master’s degree? I’m in the downtown core of a moderately small city. I pull into the parking lot bordering where my next interview will take place. This time I’m running it
as a focus group with three individuals, two Anishnabe and one Métis. When I asked for the interview initially Jerry, who was the point of access for this research site, seemed reluctant but I know that this will be the most important group. Two healers are willing to speak with me about grief and loss in terms of spirituality; I need to conquer my fear. The secretary seats me in a large formal board room. One female and two males come in and seat themselves on the other side of the table. I sense confrontation is coming by the set-up. Jerry says that we should probable smudge first. He produces a shell and a long braid of sweet grass. He proceeds to light it up and they individually usher the smoke around their eyes, ears, mouths and the tops of their heads. He offers me to do the same and I do. He explains to me that the process is to ask the Creator to help them see, hear, speak, and think with good intentions. I take a deep breath and walk around the table to offer my tobacco ties. Both men accept; the woman tells me that the man adjacent to her will accept it for her. I sit myself back down on the other side of the table. Jerry opens our discussion by asking me what my intentions are. I hesitate for a moment; formulating my thoughts and utter something unintelligible. The female in our group turns to me and makes the observation that I seem nervous. I tell her that I don’t want to screw this up or be offensive in any way. I tell them that I am looking for information on their construct of spirituality and how this affects the way they grieve the loss of a loved one. Jerry says in a soft voice, yet full of determination, “Jason, you have shown us respect for our ways by offering tobacco and smudging. Your intentions seem to be good ones, let’s see how we can help you.” (Excerpt from field notes and reflexive journal)

The author melted into his chair at that statement. Trust and rapport were no longer an issue; they were now a given. There was an understanding of respect for each other in this forum. He was of the opinion at this point in his academic career that he was to be an impartial party; observing and being the neutral instrument in the research process. This did not happen. He was drawn into his participants’ lives, their pain. He walked their journey through grief and shared their joy in hope. The relationship can only be defined as reciprocal, not just in terms of symbolic reciprocation as an exchange of tobacco for stories but on a deeper level of empathy and emotional giving. He too was drawn into sharing his own stories and clarifying their stories to make meaning from his Eurocentric perspective.

Neutrality in qualitative research, or in any situation where there is direct human contact, is a fallacy. Christians (2005) confirmed this idea by stating, “a positivistic philosophy of social inquiry insists on neutrality regarding definitions of the good, and this worldview has been discredited” (p. 148). There is a parallel with Struthers and Hodge’s (2004) findings, in that “without offering tobacco, you just end up with empty words” (p. 216). We would submit that, as researchers, without offering culturally sensitive means of building reciprocity, researchers end up with empty findings. We further suggest that we, as researchers, must attempt to find the most culturally relevant modes of establishing consent, even if this entails challenging the signed informed consent IRB protocol. This idea of reciprocity is integral to mending the ethical wounds left by research performed with Indigenous populations through orthodox positivistic scientific inquiry.

A possible ethical guide to research with Indigenous peoples

By using what Portman and Garrett (2005) have suggested as the embodiment of the American Indian worldview involving collectivism, collaboration, compassion, and courage, we as researchers can move to approach Indigenous populations in a culturally sensitive manner. We briefly describe these notions next.

Collectivism

Portman and Garrett (2005) discussed collectivism in terms of Native American cultural identity as being rooted in tribal or band affiliation, community, and heritage. Hence, “American Indian people judge
themselves and their actions according to whether or not they are benefiting the tribal community and its continued harmonious functioning” (p. 287). They contrasted this notion with mainstream American society as worth and status being equivocal to occupation and achievement. As researchers, we must ensure that the research is a reflection of the people who are the focus of the inquiry. If we do not, we are not serving what they value in terms of their worldview but, rather, our own selfish research agendas based on individual achievement. This is not a suggestion to “go native,” as Lincoln and Guba (1985) caution researchers to avoid, but, rather, to empathize with the culture one studies enough to represent their worldview as truly as possible through your inquiry.

Collaboration

Returning to the idea of seeking group harmony, Portman and Garrett (2005) suggested that American Indians seek this through sharing and the protection of each other. They described generosity as being “a central value among American Indian traditionalists and acts as a sign of a person who is willing and able to consider others above herself within that cultural context” (p. 288). In seeking to perform qualitative inquiry with Indigenous populations, the researcher must ensure an ongoing renegotiation of consent, as discussed previously in Sin (2005). In doing so, those being researched are placed in a continual role of power in forming the limits of the research. During the research that has been described, participants could have returned the tobacco ties, signaling the removal of consent and terminating the research; the power always remained literally in their hands. In moving to a reciprocal, participatory mode of inquiry, such as those described in the University of Victoria’s research protocol (2003), the idea of collaborative partnership is furthered in terms of the participant’s or group’s role in the direction of the inquiry. In the research process, the empowerment of the participant in the decision making process is equivalent to considering the other (participant) above self (researcher). Portman and Garrett (2005) summed up this idea by stating, “empowering others in relationships establishes a context that emphasizes harmony and balance” (p. 288).

Compassion

Portman and Garrett (2005) described the American Indian value of compassion as related to the idea that all within a community are part of a Circle of Life. The individual in this circle comes to realize that all actions that he or she takes affect the entire circle, and as such, he or she must consider how his or her actions might affect the collective prior to committing them. Portman and Garrett (2005) defined this act as mutual empathy dictating mutual respect and, again, returning to the underlying premise of valuing the other over oneself. We, as researchers, require the same level of empathy when performing inquiry inside or outside of our cultural context. We have discussed the use of asemaa, not as suggested by Fontana and Frey (2005) as “merely being a technique to persuade the interviewee to reveal more and be more honest in his or her responses” (p. 696) but, rather, as a culturally relevant means of establishing consent in the context of empathizing with a worldview other than our own.

Courage

Portman and Garrett (2005) discussed authenticity as aligning well with the concept of courage, in that one must have strength to be who one is and to seek one’s vision. They further defined authenticity as “a genuineness or honesty of self in the relationship. This genuineness means a sense of belonging in and experiencing fully in relationship to others” (p. 289). The premise here is that as researchers, we must strive to be authentic in our relationships with participants in the inquiry. By implication, understanding one’s vision for the outcome of the research and inherent biases in worldview requires courage. This courage is even more evident when the researcher gives up total control over the process and empowers those who are participants in the process to provide direction for the inquiry.
Conclusion

The main argument in this article is that not only must researchers remain culturally sensitive when conducting research with Indigenous populations, they might also have to challenge traditional IRB processes as part of this cultural sensitivity. Under the notion that IRBs are still constructed under colonial notions of research, we argue that IRBs might have under-representation in relation to individuals who are aware of the many nuances of qualitative research and research with Indigenous peoples. The asemaaprocess the first author encountered during his thesis research is just one example of possible methods through which qualitative researchers build reciprocal participatory relationships with participants in the inquiry process, a method incompatible with the traditional IRB-prescribed signed informed consent practice. Portman and Garrett’s (2005) work incorporating the values of collectivism, collaboration, compassion, and courage can serve as a guide for researchers as they design, and potentially explain to IRBs, research with Indigenous populations.

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