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“NO LONE PERSON:” THE ETHICS CONSENT PROCESS AS AN ETHICAL DILEMMA IN CARRYING OUT COMMUNITY-BASED PARTICIPATORY RESEARCH WITH A FIRST NATIONS COMMUNITY¹

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ABSTRACT

Carrying out informed consent is considered an essential aspect of ethical research practice. However, carrying out consent raises complex issues in Aboriginal communities where involvement in research has involved risk and where protocol for consent starts with the community. Based on our experience as explored in a focus group, we discuss challenges faced and lessons learned while obtaining informed consent from parents/guardians of

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community children for a school based, health intervention research project which took place at the request of the Alexis Nakota Sioux Nation located in western Canada. Ongoing ethical dilemmas and issues of consent as perceived by both the community and by the university ethics board were discussed along with possible solutions. Recommendations for managing ethical consent in research with Aboriginal communities are presented along with the need to find an “ethical space” (Ermine, 2007) where solutions can be developed.

Keywords: ethics, ethical dilemmas, informed consent, parental consent, First Nations, Aboriginal

Based on concern for justice, risk assessment, dignity, and autonomy of participation, academic research requires review by a University Research Ethics Board (REB) in Canada, or an Institutional Review Board (IRB) in the United States. REBs review potential harm as weighed against potential research benefit to individuals, communities, or the larger public and require researchers to attain informed consent from individual research participants (Beauchamp and Childress, 2001; Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council (NSERC) of Canada, and Social Sciences and Humanities Research Council (SSHRC) of Canada, 2010). The principles of both community-based participatory research (CBPR) and the guidelines for ethical research with Aboriginal² communities emphasize that the research process comply not only with academic standards but with the ethical values of the community where the research will be conducted (Brant Castellano, 2004; CIHR, 2007; Schnarch, 2004).

In this article we review the consent process in the context of a CBPR project carried out in collaboration with the Alexis Nakota Sioux Nation in western Canada. The research project involved the adaptation, pilot, and full implementation of an evidence-based substance use prevention program (Botvin and Griffin, 2004). The Life Skills Training (LST) program was culturally adapted by community research team members and Elders for use in this First Nation school setting. The ethical issues and strategies presented here are based upon ongoing discussions and a focus group where research team members gathered to discuss issues and challenges that developed as a result of needing to meet the ethical requirements from the University's

2. In Canada, the term Aboriginal is used to refer to First Nations, Métis, and Inuit peoples. We use First Nations to refer to specific indigenous nations. References from the United States include the use of the term Native American.

REB. Recommendations for different ways to deal with these challenges and issues were also discussed. These recommendations reflect the importance of conducting the research in a way that the community considers appropriate, or “a good way,” a way that respects community values and relationships.

INFORMED CONSENT IN RESEARCH

Current principles and practices regarding research ethics and consent are the result of an evolving process set in motion in the first half of the 20th century. Efforts to ensure ethical conduct in research were documented first in the Post WWII Nuremberg Code (1949); second, the Helsinki Declaration by the World Medical Association in 1964, and third, through the influential 1974 Belmont Report and related legislation in the United States (Flicker et al., 2007; Meaux and Bell, 2001; Nelson-Marten and Rich, 1999). Research ethics in Canada are guided by the Tri-Council Policy Statement Second Edition (TCPS-2), which is a document developed from three federal funding bodies for medical, scientific, and social science research (CIHR et al., 2010). Core principles of the TCPS-2 include respect for human dignity, respect for free and informed consent, respect for vulnerable persons, respect for privacy and confidentiality, respect for justice and inclusiveness, balancing harms and benefits, minimizing harm, and maximizing benefit.

Currently, the TCPS-2, along with the CIHR, make specific recommendations for research with Aboriginal communities (CIHR, 2007; CIHR et al., 2010). These guidelines present additional standards to ensure that the rights and interests of Aboriginal people and communities are respected. Additionally, some projects and communities have developed their own codes of ethics, notably the Kahnawake Diabetes Prevention Project (1997), the Mi'kmaw Ethics Watch Committee (2000), the Wikwemikong Unceded Indian Reserve (Jacklin and Kinoshameg, 2008), and Blue Quills First Nations College (2009). These codes address protocol, collective knowledge, building cultural capacity of researchers, benefit to the community, and dissemination (Battiste, 2008; Brant Castellano, 2004). Despite the development of ethics policies at the institutional and community levels, the principles of partnership, community control, mutual benefit, and holism are often applied inconsistently as seen in the decisions made by REBs or IRBs. Implementing the principle of informed consent in a respectful manner is particularly challenging in the context of Aboriginal research. Smith (1999) describes norms for how, who, and when consent should take place within

diverse worldviews, stressing that researchers need a thorough understanding of the historical and ongoing marginalization of Aboriginal people and the ways that research has been insensitive or served as an aspect of colonization.

CONTEXT OF ETHICAL RESEARCH WITH INDIGENOUS COMMUNITIES

Mohawk Elder and scholar Dr. Brant Castellano (2004) states that Aboriginal worldview and way of life are foundational to ethical principles and practices. In fact, "Aboriginal conceptions of right behavior clash with norms prevailing in Western research" and rules located in other systems of thought will cause harm as a matter of course (Brant Castellano, 2004, p. 98). In the indigenous framework, risk applies not only to indigenous *individuals* but also to indigenous *communities* where "participants may be placed at risk when research design and data collection procedures [including informed consent] are inappropriate for the specific research context" (Tilley and Gormley, 2007, p. 373). Ermine et al. (2004) suggest moving towards more ethical, less "othering" research paradigms occurring as "a result of the decolonization agenda that has as a principal goal, the amelioration of disease and the recovery of health and wellness for Indigenous populations" (p. 9).

Canadian Aboriginal communities have reported feeling both over-researched and underrepresented in applied research that claims to respond to community-identified needs. Given concerns regarding past inaccurate and harmful misrepresentation, misuse of research, and failure to produce tangible benefits; "research is not a word that is taken lightly by Aboriginal peoples" (Pidgeon and Hardy Cox, 2002, p. 96). This research history perpetuates the historical failure of Western institutions to keep their word in signed agreements including treaty, medical, and other human rights (Ruttan, 2004). As a result, principles of respect, relationship, reciprocity, ownership, and collective self-determination cannot be overemphasized (Holkup et al., 2009; Kaufert and O'Neil, 1990; Pidgeon and Hardy Cox, 2002; Ruttan, 2004; Steinhauer, 2002; Weber-Pillwax, 1999).

SPECIFIC ISSUES IN GAINING INFORMED CONSENT IN INDIGENOUS COMMUNITIES

The development of community-based, action oriented, ethically sound, culturally relevant, and decolonized research models is difficult as it chal-

lenges IRB and REB practices grounded in Western philosophy and the medical model. Review board appraisals affect participants, researchers and other stakeholders by enforcing procedures that may not be appropriate in particular contexts or overlook “collective risks to members of specific geographic, racial, religious, or ethnic communities” (American Academy of Pediatrics, 2004, p. 148; McDonald and Cox, 2009). Further, ethics review occurs primarily at the outset of the research, is paper-based, and reflects a single snapshot-in-time approach reinforcing an emphasis on regulatory mechanics rather than ensuring the ethical conduct of the ongoing research process (McDonald and Cox, 2009). This approach does not accommodate the time and relationship factors involved, the nonlinear evolution of the research process, and the importance of equity, action, and capacity building essential to CBPR and indigenous research methodology (Flicker et al., 2007; Khanlou and Peter, 2005). It relies, for the most part, on signed informed consent as the only manner of establishing a consensual relationship. Typically, a series of questions are asked to ensure participant understanding, with the expectation that participants will respond to each question with a check mark, indicating agreement or disagreement. These questions concern and intimidate participants who may struggle due to literacy levels and the lack of plain English usage. They may also result in communicative, as well as cultural discrepancies, and be an affront to dignity (Piquemal, 2001; Smith, 1999). In response, researchers working with indigenous peoples are calling for culturally appropriate protocol and consent methods “even if this entails challenging the signed informed consent IRB protocol” (Ellis and Earley, 2006; Kaufert and O’Neil, 1990; Piquemal, 2001, p. 71).

RESEARCH CONTEXT

The Alexis Nakota Sioux Nation has 1660 registered members; a little over one third live off the reserve in nearby cities and towns. The community settlement is located in central Alberta approximately one hour’s drive from the metropolitan area of Edmonton, Alberta, Canada. The Alexis Nakota Sioux Nation is the northernmost nation of Sioux peoples in North America; their language is classified as one of the Siouan languages by linguists and is referred to as *Isga Ihabí* (Stoney) by the people. Strong family clan groups, along with collective identity and decision-making processes, are an aspect of community social and political life. Given the emphasis on the motto “One Nation, One Tribe, One Fire” (Alexis Nakota Sioux Nation, 2010) the vision statement of the Nation is as follows:

We, the Alexis Nakota Sioux Nation will protect and promote our cultural and spiritual values. We will strive to live in harmony and respect the Creator and all creation. We will commit to our I'sga beliefs and utilize every resource that the Creator has bestowed upon us to empower our people, spiritually, emotionally, physically and mentally.

This statement holds within it the core reasons for engagement in research efforts on behalf of the health of the community and its children.

The Nakota Sioux signed an adhesion to Treaty 6 with the Canadian government in Edmonton in 1877. Treaty 6 (Indian and Northern Affairs Canada, 1964 [1876]) included clauses acknowledging the Crown's and later the federal government's responsibility to maintain schools for instruction and to provide a medicine chest or health care on each reserve. The First Nation is governed by a chief and seven counselors and organized with departments handling varying responsibilities. The impetus for this research came from the Nation's education and health departments and from community Elders in response to growing concerns about the impact of substance abuse in their community.

Elder involvement and endorsement of the project was very much a part of the entire research process. Elder approval initiated the project and is essential for all research involving Nakota Sioux children and culture. In this case the Chief at the time, Roderick Alexis, gathered a number of Elders to discuss the research project and to seek their approval and blessings. Following the receipt of the Elders' agreement, further support for the research collaboration between the University of Alberta and community was formalized in a Band Council Resolution (BCR)³ in 2005. As well, parents and other community members were invited to an orientation session where project goals were presented and where additional community input was obtained.

PROJECT BACKGROUND

Elders and community leaders believed that addressing substance use while also reasserting cultural strengths would be a successful strategy for decreasing substance abuse in their community. One Elder explained that cultural features were essential as, "I want these kids to be somebody. [If] they lost their language [and culture], they're nobody." In a letter of support for the project, former Chief Roderick Alexis stressed "we need to do something to

3. A numbered BCR is required by the Department of Aboriginal Affairs and Northern Development Canada (formerly INAC) to register and "legalize" band council decisions.

bring culture and tradition *back* into the community for our kids.” For the community education director, the goal was to “try to train the children at a younger age before they reach a certain life.” She spoke of community benefits in terms of “children being stronger in their mind and in their values, and their future.” The school principal believed that an effective substance abuse prevention program, that included helping the children feel valued for who they were, was essential to the school curriculum. Parents felt the program offered a “good thing for our children and their future.”

With these goals in mind, a collaborative community-university research team was set up. The research team explored possible evidence-based prevention programs for implementation at the school. The Botvin LST program was chosen for adaptation, delivery, and subsequent evaluation (Baydala et al., 2009). The LST program was chosen because of its high success rate and emphasis on building strengths (Botvin and Griffin, 2004; Botvin et al., 2003). Nation leaders and Elders agreed that culturally adapting the existing LST program to align it closer to the Nakota Sioux values was an important precursor to delivery and evaluation of the program (Baydala et al., 2009). Cultural adaptation has proven to be an effective method to enhance the fit of evidence-based programs (Botvin et al., 1995; Castro et al., 2004; Kumfer et al., 2002; Whitbeck, 2006). While informational and core approaches were maintained, a working committee of Elders and community education staff adapted the manuals to include extensive use of the Isga Ihaba language, Nakota values, and cultural activities. Appropriate images for the program manuals were created by local children and a community artist.

Bidirectional capacity building and co-learning amongst all members of the research team were important aspects of the project work (Fletcher et al., 2009). Elders were instrumental in providing guidance and direction to the research team. They also worked on language translation and supported delivery of the program in the classroom. Elders, as language and cultural knowledge holders, were essential to the adaptation process and their contributions ensured the establishment of community ownership and adherence to proper protocol. As one Elder emphasized “it will be *us* that put it together, that’s another good thing.”

APPROACH TO OBTAINING INFORMED CONSENT

Consent for the overall project was obtained from Elders and community leaders. Consent for the individual students’ participation was obtained

from parents or guardians and assent received from students. As guided by community-based team members, proper protocol was carried out including offering of tobacco to community leaders and tobacco and other offerings to Elders. The acceptance of the offerings by Elders and their oral consent at subsequent focus group meetings was acceptable to the REB. We received approval from the Health Research Ethics Board at the University of Alberta in September 2006 for completion of our pilot implementation. Ethics approval was renewed yearly and a new ethics submission was submitted and approved in April 2008 for the implementation of the full Nimi Icinohabi program. Subsequent amendments to the initial submission were approved as the project unfolded and new issues and queries arose.

Local research team members stressed that any meaningful level of student participation would require respectful and informational visits to each child's home by a community-based research team member. Therefore, one of the community-based research team members delivered the program in the community school and visited each parent or guardian in their home. She provided parents and guardians with information about the adapted LST program, *Nimi Icinohabi*, the community approval process, and the research aspects of the project before asking for consent for their child's involvement in the research component of the program delivery. The information sheet and consent forms were left with the parents so they could consider the request before finalizing their signed consent or lack of consent, as required by the REB. The community-based research team member often revisited the parent or guardian homes a second time to answer any follow up questions and pick up the completed consent forms. In the context of the community's history with Western institutions, signing papers has often led to negative consequences. Therefore involving community members who are also active participants on the community-based research team was expected to aid in addressing issues of trust and to communicate community partnership (Ball and Janyst, 2008). The process of gaining informed consent proved to be time consuming and often frustrating to parents/guardians and research team members and complex issues required regular revisions to be sent to and approved by the REB.

METHODOLOGY

The research team gathered to explore lessons learned and to generate recommendations about how the informed consent process could be completed more effectively in the future. There were seven participants including

university and community-based research team members: three research team members from Alexis Nakota Sioux Nation School and four from the University of Alberta. Focus groups typically stimulate respondents to explore the subject more thoroughly and, through the conversation, generate deeper reflection (Fontana and Frey, 1994). They are also effective in cross-cultural contexts and with Native American participants in research conducted in the United States (Hughes and DuMont, 1993; Lowe and Struthers, 2004; Strickland, 1999). The focus group was clearly differentiated from ongoing team meetings and the goals were clearly articulated. Three central questions were developed and several sub-questions emerged from the discussion. The key questions included: (a) what were the challenges involved in obtaining consent; (b) if our purpose is to protect the children, what is the best method or form to ensure that this is being done; and (c) how could we better obtain consent from parents and community members and assent from participants.

DATA ANALYSIS

The focus group was recorded and transcribed. Following iterative readings of the transcript, the data was reduced and analyzed thematically by a research team member experienced in both qualitative data analysis and in working with indigenous communities. Responses related to each of the key focus group questions were coded and the overall transcript was analyzed to pick up additional themes and issues. As recommended by Dreachslin (1998), the context of cross-cultural communication, salience of communications, and intent were also kept in mind during the analysis. Transcripts, key themes, and ideas were shared with team members for review as is typical in CBPR projects (Israel et al., 1998; Macaulay et al., 1999). The paper was circulated electronically for review by all focus group participants followed by a formal review meeting. Subsequent revisions were made and again reviewed electronically before being submitted for publication.

RESULTS

CHALLENGES IN OBTAINING INFORMED CONSENT FROM PARENTS AND GUARDIANS

Time required for home visits

Participants reported that the process of obtaining consent in the manner expected by REBs presented a number of difficulties including challenges

of logistics and process. In retrospect, team members recognized the need to allocate more time and budget monies to the consent process. Delays in the implementation of the program and additional costs were a direct result of unexpected travel, number of visits in the home required, and the time it took to review the information sheet orally and carry out the process of building trust in a responsive manner. People were not always home or the children, in some cases, were found living with other family members; something that the community-based team researcher who visited the homes stressed was important to deal with in a sensitive matter. Additionally, several children were in child welfare placements which required obtaining consent from the appropriate guardian.

Challenges to completing informed consent documents

The informed consent document includes eight individual statements followed by yes/no check boxes that allow the parent or guardian to indicate an understanding of the project and issues related to risks, benefits, and confidentiality (Appendix A). A final statement indicates consent for the child to participate in the project. The most frustrating part of the informed consent process, for both parents and the researcher, was completion of the individual check boxes. Frequently, while the parent consented to their child's participation in the research, they either did not fill out the preceding check boxes or they responded "no" to the statements that indicated their understanding of the project and the risks/benefits and issues of confidentiality. This meant that another visit or a phone call to the home was necessary to obtain the required information. Two possible causes of the complications are: (a) concern on the part of the community researcher that correcting the inconsistencies could be perceived as interfering in the parents' or guardians' actions ("I don't want to stand over their shoulder because to me that's disrespectful"), and (b) that indicating "yes" by signing the document, particularly, in a setting where oral consent is considered more meaningful, should be sufficient ("yes, means yes to *everything*"). Requiring consent in this way and at this level of detail was offensive and, in some cases perceived as a lack of belief or trust between community and research team members. Reinforcing disrespectful relationships or mistrust is particularly problematic in this context.

Issues of language

The wording and length of the consent forms were also problematic. Medical and research terms that are not part of everyday language made

the document difficult to understand. Because the document was wordy and long, some parents did not read it completely and, truthfully, indicated they had not. Oral discussion and consent was recommended by several research team members as a more appropriate alternative, especially given the observation that the consent form “seemed to make them [the parents] feel threatened” and that the community-based researcher was also felt uneasy using the language and form. She described the words used on these documents as making not only the parents but, also, herself feel uneasy.

Time for cultural process

The need to engage in a process of visiting and talking with the parents more than once and often for an hour or two on each occasion proved time consuming but essential to the successful completion of informed consent. The informed consent process needed to proceed in this manner not only to share information about the research project, but perhaps more importantly, to reaffirm kinship and relationship with the community researcher. The visit and conversation moved the provision of consent into a relationship context which is more familiar and appropriate for this community. As one community-based team member explained, “everybody’s trust in authority has been so shattered that they’re not going to give that [consent] without thoughtful judgment.” This meant that, as a process of establishing confidence in the project, two and sometimes three visits by a community-based researcher were required. The information was introduced, conversation engaged in, and the form was left for parents or guardians to review with further discussion and consent signing on the second visit. In a few instances a third visit was required. Many parents also took this opportunity to discuss how they personally were connected to the sensitive issue of substance use. This is much different than the typical 10–15 minute process used to obtain informed consent in mainstream settings.

Ensuring researcher safety

Safety, in physical, cultural, and relational terms, was an important issue for the community research team member who went out to meet in parents’ or guardians’ homes to discuss the project and to ask for signed consent for children’s participation. Challenges to physical safety included being bitten by a dog twice at one home. More importantly, the community-based researcher indicated that initially she felt anxious regarding the legitimacy of the informed consent process, although not the research project itself. Her

discomfort was a response to her own values and experience, as a member of the community, with past research efforts. As well, she indicated that asking community members, who were her relations, to sign papers where complex wording made her unsure of the implications, made her feel at times like a “sales lady” or even “a betrayer.” As she put it, “I really felt torn, part of me would stand and was protecting, protecting them [parents/guardians], you know, we don’t want to be used again.” Another community team member described the ongoing risk from requests for assistance from outside institutions, “your guard goes up for protection because we’re so used to giving, giving, giving and by [researchers] writing it [inaccurately] that made you leery.”

THE CONTEXT OF RISK AND COMMUNITY

The meaning of “risk”

The use of the word “risk” in the consent forms was problematic. Risk is a term with multiple meanings even in standard English and “mainstream” contexts; language, place, and identity inform its understanding (Jardine et al., 2008). One research team member pointed out that it can be an especially threatening word when placed in conjunction with activities involving one’s children. Risk was described by community-based team members as a word that scares people given that there was significant risk in past research projects and in relationships with government and educational institutions. They believed the use of the word risk raised concerns among parents. Does it indicate lack of integrity, could their children or community be placed at risk by signing something they don’t completely understand? “Signing a paper,” in and of itself, was described as potentially risky in a way that giving one’s word orally, accompanied by personal knowledge of the integrity of the researcher, was not. At the same time, research team members noted that any risk associated with the project is more likely a collective than personal risk and thus not, in fact, accounted for through the current informed consent process which focuses on individuals. For example, as one university-based researcher explained, it “is a form of consent that doesn’t necessarily provide the best protection for the children because it’s out of context and because it’s not the way that it’s done [in this community].” It was agreed that the use of the specific word “risk” was an unnecessary challenge in the consent process. Unfortunately, our request to the REB to use another term was turned down.

Collective risk

Given collective identity and the possibility of collective risks, community-based team members indicated that “decision making is always with the collective in the background if you are from the community.” This means that “no lone person can make a decision that affects the rest of the community.” As one of the community-based team members made clear, when you are going to make a decision you must think about whether it is yours to make. You must, “think about it when you do it. What you’re doing affects the family, and eventually affects the rest of the community.” Given these dynamics, all of the focus group participants reiterated the concern that the current process is not meeting the stated objectives of safety and informed consent as typically envisioned by REBs. The community-based researcher who obtained the consents from the parents and guardian summed it up by commenting that “it’s like trying to fit a circle into a square. It [the existing consent form and process] just does not work.”

Community ownership

Finally, community-based team members stressed their control and ownership of the cultural adaptation of the program. The program is informed by Nakota Sioux values, language, and concepts, and was developed by Elders using community language and education specialists to prevent substance abuse while immersing children and youth in cultural concepts and practices. While careful to articulate the difference between the program and the research, the issue of ownership including ownership of the community-based ethical processes remained. “If this research takes place within activities and approaches based in our culture then why do we have to go through the university’s informed consent process rather than using our own protocols for consent?”

There was consensus among the team that the consent process should be grounded in and reinforce culturally based ethical norms and consent practices rather than negotiated as an add-on to academic institutional practices. In response to these concerns, community-based team members said that an ideal approach to obtaining consent would be during a community activity that takes place “on the land.” The consent process would then reinforce the values stressed in the culturally adapted LST program. Consent would be obtained in a meaningful setting “connected with Mother Earth” so that “it’ll have a little bit more strength” and “people will be more receptive to what we’re trying to offer to the children.” This ideal approach, a “com-

munity campout,” would include university and community-based team members participating in cultural activities in order to build relationships and trust and create opportunities to discuss the program. Community and individual consent could then be obtained through a process of consensus.

COMMUNICATION AND CO-LEARNING AS ETHICS

Ongoing co-learning

Several other issues of interest emerged during discussions and are worth noting, particularly with regard to issues of communication and meaning. First, both university and community-based team members used the focus group as an opportunity continue educating each other cross-culturally as they had throughout the project (Fletcher et al., 2009). One university-based team member, a graduate student, mentioned several times during the discussion that she had “never thought about it that way before” indicating growth in listening to and learning from community-based team members. A senior university-based researcher explained the reasoning behind Western research philosophy and REB requirements to the team, thus helping to explore the challenges even where she personally believed a different approach was necessary in this research context.

At the same time, community members continued to make good use of the opportunity to share teachings related to values and worldviews, to interpret protocol at deeper levels of meaning, and to interpret other culturally based responses to the university researchers. For instance, as one of the community-based team members explained in reference to protocol,

each time we invite Elders to any meeting we offer tobacco; it doesn't matter what it's for. That's like the written, you know, it's like the invitation. You know, there's memos sent out or there's formal, you know, 'you are invited.' Well, that's *our* way of doing things.

Another community-based team member added to this by stressing the depth of meaning and significance of this protocol:

The other thing too is that when you accept that [tobacco], you're accepting it in the presence of God; they're accepting it in [the presence of] the Creator. Even if nobody sees you, you're already in your mind, consciously [thinking], 'I took that. I have an obligation.'

In other words, tobacco is given not simply as a form of polite practice, it indicates of the seriousness of the issue and, if accepted, of a spiritual commitment in response to the request made.

Not speaking for others

University researchers also saw community-based team members consistently demonstrate their respect for the traditional value of not speaking as they answered direct questions about other community members' opinions indirectly. During the focus group, when asked what they thought other community members felt about an issue, they repeatedly qualified themselves in their responses ("that's just how I think about it," "I wonder if those were their thoughts," "I don't know, that's just my idea, that's what I think"). The principle of not replying on behalf of others was also present in the community-based team members' careful reminders that they were speaking only for what worked in their own nation and that these issues would have to be addressed from the start in each nation.

Role of relationship

Issues of culturally based language and meaning were apparent during discussion of the issue of coercion in research and the nature of "relationship." One of the university-based researchers described how the REB views its work as protecting research participants and that the questions asked on consent forms are viewed as an important aspect of that protection. Community-based team members described how indigenous communities have their own "systems of security" and of ethics approval. They indicated that in this case, the involvement and approval of both Elders and community leaders from the start allowed them to feel protected (i.e., spiritually, politically, and from potential community jealousy) in implementing the project.

Differing understandings of the role and importance of "relationship" were also problematic. One university-based researcher explained that REBs are concerned that "if you know the people and you have a relationship with them, perhaps you are influencing their decision ... to agree to participate." Another university-based researcher with extensive experience in communal consent, maintained that it is important to distinguish between coercion and the act of respecting the importance of relationships, "we're not coercing, we're building a relationship." Struggling with the question of how to respond to REBs regarding this issue, the first researcher asked "how do you know [that you are not being coercive]?" This query led to further discussion of the term "relationship" and how that term is used differently in the context of both university and community located ethical principles. From the REB's perspective, previous or ongoing relationships could lead to either direct or indirect coercion, raising concerns about whether consent is voluntary

and suspicions regarding the research results. From the community's perspective, without relationships you cannot ethically begin or sustain research with community. By engaging in proper protocol, community researchers believed in the university researchers' commitment to a relational and ethical process. As a result, community-based researchers said they felt comfortable presenting the project to community members and encouraging their participation; community members "would have more trust in you."

DISCUSSION

In indigenous communities today, ethical research practice requires consent at the individual and community level to prevent replicating historical and colonizing practices. Consent processes should engage proper protocol and build relationships based on respect, integrity, reciprocity, and ongoing cross-cultural co-learning. As this paper illustrates, the ethics consent process and procedures mandated by REBs present an ethical dilemma in themselves. Even when consent for research is obtained without major difficulty, ethical quandaries in obtaining consent raised by issues of power, justice, beneficence, protocol, and cultural safety must be addressed. As we experienced, obtaining informed consent in this context involves challenges in a variety of areas: logistics, process, relations, culture, and systems. Given the historical harms to indigenous communities and the strength of collective identity and decision-making processes in many communities, communication of intent, negotiation, and decision-making power must lie with the collective, allowing individuals to opt in or out. The processes of obtaining informed consent need to be based in culture and cultural protocol throughout the entire project. Community consent requires trust that is founded on whether researchers are deemed trustworthy to engage in this type of relationship with community: "they have to get to know you to be able to trust ... especially in First Nations because they have so much mistrust, for so long and I think they're really watchful of that, what your intentions are."

The multiple meanings of risk, relationship, ethics, and consent are complicated by the fact that these terms are understood within historical and cultural contexts. Managing risk is not always found in individual decision making but in culturally significant collective processes. Further, focusing so strongly on Western principles of autonomy, rather than on the value of self-determination as collective communities, is a risk, in itself, by contributing to assimilation to Western values though the rules-based approach of REBs (Kaufert, 1999; Smith-Morris, 2007).

Cultural safety is the basis of good research partnerships. We realized through our discussions that, although safety and relationship building were identified as ongoing priorities, there were still areas of concern as described by a community-based researcher:

Part of me was also — I felt like a traitor. Or not so much a traitor but somebody on the opposite side — like the them/us. I *really* was torn, because trying to, like explaining the consent forms to them, you know talking about research — it just really felt weird, you know. If I could [only] take out those words, research and project.

While she supported the project, the shared history of past research abuses, the feeling of joining outsiders, and the connotations and use of particular words were deeply troubling for her. Given that one of her roles was to gather consent in people's homes, looking back, she suspected her own initial lack of comfort affected her success in her early efforts.

We were also concerned about being responsive to the issues of greater safety for the community as a whole. Since we were asking individuals to provide consent on behalf of the community, the team questioned whether or not the process of individual consent was meeting the stated objectives of informed consent. Those objectives include fully informed, voluntary, and competent to give consent within principles of dignity and justice, minimizing harm, and maximizing benefit. The process, in many instances, contravened community norms about who should be involved when decisions are being made that could affect the community as whole. A number of researchers recommend alternatives including oral and audio-taped methods or being given a choice between written or oral formats (American Academy of Pediatrics Policy Statement, 2004; Ball and Janyst, 2008; Gordon, 2000). While we obtained REB approval to use oral consents with community Elders, several focus group participants stressed that the use of oral consent for everyone involved would be preferable to the use of written consent. If written consents are used they should be much shorter and use plain language so that the "words" themselves do not make it difficult to understand or become reminiscent of historical abuses.

RECOMMENDATIONS FOR BEST PRACTICES

The current processes mandated by REBs, despite good intentions and attempts to be respectful of CBPR and research in indigenous communities, do not protect community, family, or child participants in a way that is truly

informed, autonomous, or culturally respectful. Institutional protocol for informed consent does not respect or attend to decision-making processes that are grounded in indigenous ways at the community or individual level. As a result, institutional REBs lack responsiveness to cultural knowledge and indigenous ethical protocols and fail to empower or add dignity to the research experience. In thinking about how to obtain consent more respectfully and effectively, one focus group participant stated that “you probably wouldn’t show up at their door with a form. You would probably show up in a very different way or gather in a very different way.” The following suggestions for improving the consent process were offered:

1. Use oral or written consents in either the English (plain language) or Stoney language as participants choose.
2. Use written forms, when necessary, that allow greater flexibility in language and length.
3. When possible, obtain consent through a community gathering, preferably on the land in a “campout” setting, where relationships could be built and where the meaning of the process and ability to listen calmly and think deeply about what you say is strengthened by the connection with Mother Earth.
4. Eliminate the term “risk” as inappropriate in this context.
5. Acknowledge that the beginning stages of research, including the ethics review and consent process require more time for building the research relationship. This relationship requires that university researchers respect and be willing to learn about community on the community’s ground so that the community has an opportunity to assess the researcher’s character as an aspect of the initial and ongoing consent process.
6. Identify and incorporate strategies for the physical, emotional, and spiritual protection of community members involved in asking for consent. This may be accomplished through training and ensuring cultural safety through culturally appropriate ethical procedures at both the REB and community level.
7. Participate in building REB board members’ capacity to review CBPR research with indigenous communities and encourage the use of consultants or cultural advisors to REBs to provide assistance to clarify procedures.
8. Community involvement in establishing ethical principles and proced-

ures to safeguard community and individuals should proceed from the outset.

9. Develop a process and documentation of protocol for oral and group consent processes. Protocols vary amongst different peoples and traditions; information on proper protocol should be sought and followed, as shared by community team members.
10. Be prepared for the fact that activities related to consent cannot always be anticipated. Within the context of CBPR and indigenous research paradigms, opportunities to reflect, respond, and revise consent protocols need to be acknowledged as an ongoing part of the project.
11. Conduct research activities and processes, including working with REB boards, in a relational space of integrity between two worldviews that Cree scholar Willie Ermine refers to as “the ethical space” (Ermine, 2006; 2007).

We found that team members engaged in an ongoing process of teaching and learning from each other. Community consent requires trust that is founded on whether researchers are deemed personally trustworthy to engage in this type of relationship with community. This trust building must occur at the university level through REB and researcher awareness, education, and training including the involvement of community knowledge holders with REBs. This makes continual engagement within the ethical space more likely. As one of the community researchers concluded, “there has to be some compromise between the University REB and their proposals [procedural requirements] need to go through the ethical space. Take the university ethics, the community ethics and find where’s the overlap?”

IMPLICATIONS FOR EDUCATION AND RESEARCH AGENDAS

University-based researchers were reminded by community-based team members that they could not speak for other communities and pointed to the need for a nation by nation approach that respects differences in priorities, values, and protocols. Negotiating consent, nation by nation, has the potential to move individuals and communities beyond the ethical wounds left by previous research projects (Ball and Janyst, 2008; Smith, 1999; Whitbeck, 2006). The National Aboriginal Health Organization’s (NAHO) Community Research Ethics Toolkit is a starting point or template for sup-

porting the building of research ethics guidelines and consent documents that respects the needs of individual communities (NAHO, 2003).

Research is not just a scientific activity; it is understood by many indigenous people to occur in the context of relationships past, present, and future. This includes harm experienced as a result of past research engagement, increasing self-determination in current research, and the expectation of benefit for future generations. These relationships have important implications for research with indigenous people and must be stressed with students and beginning researchers. When working with Elders and children, an understanding of the impact of colonial history and its ongoing presence in First Nations communities may avoid replicating cultural harm and reinforce traditional values.

We found that the current approach to informed consent does not fully inform, protect dignity, or serve justice. The principles of CBPR and indigenous knowledge and teaching processes, where work is based in relationship and learning occurs through proper behaviour, are key components of ethical research in indigenous communities. Researchers may rightly ask, as one of the focus group participants did, why university ethics rather than community ethics has so much weight. As Marshall (2006) points out, the moral rendering of respect for persons may have different meanings for individuals living in different social and political environments. While REBs have increasingly attempted to acknowledge this issue they do so within their own normative reference which frames questions in ways that may perpetuate this dilemma. Additional research engaging REBs and the community in a more in-depth examination of the ethical dilemmas in existing procedures for attaining ethical consent is required. These same learning opportunities would be valuable to students planning to work with indigenous communities and could be integrated into requirements for research ethics training.

The ethical dilemmas caused by different worldviews regarding the ethics of the research relationship and the ramifications of the maintenance of dominant perspectives by university REBs and IRBs warrants more critical analysis and discussion. How do we show respect for the ethical concepts of two worldviews in a process that promotes respect for both? How can the university process allow for research that is responsive to noninstitutional norms and processes? What factors, personal, institutional, and community-based, affect researcher's decisions and behaviour in this research environment?

It is the responsibility of each individual working in and with diverse communities to practice in an ethical space where actions reflect a respect for each others' knowledge and experience. Bidirectional capacity building and, ultimately, respect for each other's understanding of ethics and ethical behaviour, depends on ongoing dialogue and practice in the ethical space generated by respectful, responsible, accountable relationships.

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APPENDIX A

	<i>Yes</i>	<i>No</i>
Do you understand that your child has been asked to be in a re-search study?	☐	☐
Have you read and reviewed the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions about the study?	☐	☐
Do you understand that you and your child are free to withdraw from the study at any time, without having to give a reason?	☐	☐
Do you understand who will have access to your child's study re-cords?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you know that the information that you provide will be used for written reports, presentations and recommendations for future research?	☐	☐

I agree that my child may take part in this project: Yes ☐ No ☐

Child's Name: _____ Grade: _____

Signature of Parent or Guardian: _____ Date: _____

Printed Name: _____