

SCREENING FOR UNDIAGNOSED TYPE 2 DIABETES IN ABORIGINAL COMMUNITIES: WEIGHING THE ADVANTAGES AND DISADVANTAGES¹

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ABSTRACT

Many Aboriginal people worldwide share the experience of sociohistorical disempowerment. In Canada, the health system continues to build and rebuild subjugating structures that disenfranchise Aboriginal peoples. However, collaborative Aboriginal health research – research-related diabetes screening, in particular – has the potential to address Aboriginal disenfranchisement and create shared “ethical space” for Aboriginal communities and researchers. We describe Aboriginal disenfranchisement as it has been constructed via Canada’s health-care system. We discuss the

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advantages and disadvantages of conducting research-related screening for undiagnosed type 2 diabetes in Aboriginal communities, describing the potential for collaborative community-based participatory research (CBPR) to create trust relationships between community and researcher; define new ethical arrangements that emerge from community wisdom, tradition, practice, and commonsense; and take into account the sociohistorical realities experienced by Aboriginal peoples through generations. We assert that collaborative CBPR can be a blueprint for implementing new systemic structures, such as health care delivery, at a societal level, aimed at addressing Aboriginal disenfranchisement, and at creating shared ethical space to encourage the non-Aboriginal partner, situated in the dominant sphere, to relinquish power.

Keywords: diabetes, Aboriginal, Indigenous, screening, chronic disease care, ethics, community-based participatory research

This paper describes the potential for collaborative Aboriginal health research – community-based diabetes screening research, in particular – to address Aboriginal disenfranchisement and create shared “ethical space” for Aboriginal communities and researchers.

We describe Aboriginal disenfranchisement as it has been constructed historically and via Canada’s health-care system. We discuss the advantages and disadvantages of conducting research-related screening for undiagnosed type 2 diabetes in Aboriginal communities. Drawing on our experience collaborating with First Nations and Métis communities in northern Alberta, we describe the positive potential for collaborative community-based participatory research (CBPR) to create trust relationships between community and researcher; define new ethical arrangements that emerge from community wisdom, tradition, practice, and commonsense (Meara et al., 1996); and take into account the sociohistorical realities experienced by Aboriginal peoples through generations (Pels, 2000; Gold, 2001; Garvey et al., 2004; Quigley, 2006).

We assert that CBPR has the potential to address disenfranchisement by:

1. Empowering Aboriginal peoples through the generation of knowledge and health data about their communities, community-capacity development, and legitimizing Aboriginal tradition and history as a source for knowledge about health, healing, and prevention.
2. Creating shared ethical space to encourage the non-Aboriginal partner, situated in the dominant sphere, to relinquish power.

Therefore, a program of diabetes screening that incorporates CBPR principles (whether carried out via research or as part of publicly funded primary care at a community level) would be justified, with the advantages outweighing potential disadvantages.

ABORIGINAL DISENFRANCHISEMENT IN CANADA: THE HISTORICAL CONTEXT

Many Aboriginal peoples worldwide share the experience of systemic oppression and historic disempowerment (King et al., 2009). Despite some commonalities and overlap in Aboriginal and non-Aboriginal values (discussed below), medical and public health systems and institutions in former colonial countries continue to embody political structures of dominance vis-à-vis Aboriginal peoples (Van Reijen and Veerman, 1988; Garvey et al., 2004; Waldram et al., 2006).

For Aboriginal people in Canada,² experiences of disempowerment and dispossession began with postcontact depopulation largely due to infectious diseases³ transmitted by Europeans (Dobyns, 1983; Thornton, 1987; Dickason, 2002; Prat and de Souza, 2003; Waldram et al., 2006). Subsequent geographic confinement followed via Canada's Indian Act (1876) and the reserve system, accompanied by forced assimilation, cultural destruction, and abuse by means of the residential school system, contributing to the health disadvantages experienced by Canadian Aboriginal people today (Adelson, 2005).

The provision of medical services and health care remains problematic, with Aboriginal groups and the Canadian government and courts disagreeing on rights and obligations embodied in negotiated treaties (Indian Affairs and Northern Development, 1964; Waldram et al., 2006).⁴ Sadly, administra-

2. Individuals belonging to recognized Aboriginal groups in Canada's Constitution Act (1982), known as First Nations, Inuit, and Métis.

3. Emerging archaeological evidence suggests tubercular disease may have been endemic in the Americas prior to European contact, raising new questions about the evolution of tubercular disease and about animal-human relationships (Prat and de Souza, 2003).

4. Whether there exists a treaty right for Aboriginal peoples to free, comprehensive medical services has been debated publicly and challenged in Canadian courts. Only Treaty 6 (signed in 1876, comprising areas of Alberta, Saskatchewan, and Manitoba) includes a written clause pertaining to provision of medical services. However, there is evidence that provision of medicine was included in discussions/negotiations for the other 10 treaties signed between the Canadian government and Aboriginal groups. *R v Johnston* (1965) remains the leading interpretation in Canadian case law, wherein the Saskatchewan Court of Appeal interpreted the provisions in Treaty 6 to mean a first aid situation, rather than provision of full and comprehensive medical services (Indian Affairs and Northern Development, 1964; Waldram et al., 2006).

tive structures of health care foster continued inequity between Aboriginal groups in Canada, as health-care provision is different for on-reserve residents versus off reserve and urban Aboriginals, and treaty (registered) First Nations and Inuit people, versus nontreaty (unregistered) First Nations and Métis people.⁵ Of these groups, only treaty individuals receive supplementary⁶ noninsured health benefits through the federal First Nations and Inuit Health (FNIH) — Health Canada. These include dental, vision, pharmacy, medical supplies, equipment, transportation, crisis intervention, mental health services, and, in some regions, traditional healing (Bowen, 2000).

However, primary care services are administered as a patch work of federal health centres operating within First Nation reserves, Inuit communities, and provincial facilities. Availability of primary care services, such as diabetes screening, for instance, depends on the level of transfer a First Nations community has adopted via Health Canada's Indian Health Transfer Policy (Bowen, 2000).⁷

Health care for Aboriginal peoples has thus been constructed to be a matter of policy, rather than a legal/treaty obligation (Bowen, 2000). This has dramatically affected how health care has and continues to be delivered to Aboriginal citizens and communities. Because Aboriginal and Western concepts of health and healing differ (Toth et al., 2005), core objectives for care fundamentally differ. Physical health generally remains the primary outcome and measure for most health care that is offered or available, failing to incorporate traditional Aboriginal concepts of community/family/interconnectedness and the physical-mental-emotional-spirit construct. While geographic distance is a barrier to primary care as well as specialist services, cultural barriers are probably even more important, and despite the provision of transportation for some services, the requirement to spend

5. Registered Indian or Status Indian refers an individual recorded in the Indian Register, which thereby grants said individual greater benefits (such as reserve rights, tax exemptions, and hunting access) than unregistered Indians. The Indian Register is the official record of Status Indians in Canada.

6. Supplemental to Canada's publicly funded health-care system.

7. Centring on the concept of self-determination, health transfer policy provides a framework to facilitate transferring control of funded health programs (such as communicable disease control and treatment services) to First Nations community authorities. Levels of transfer adoption include health services transfer, integrated community-based health services, and self-government, representing graduated degrees of community autonomy in establishing and operating programs. At the self-government level, communities have the greatest flexibility over resource allocation and fewer reporting requirements; are able to provide a greater range of services; and are able to set their own priorities and develop programs. This self-government remains policy, not law, however, and has been negotiated through the structures of Canadian, not Aboriginal, society. Health transfer policy also fails to address many of the underlying socioeconomic conditions influencing health disparities (Bowen, 2000).

extended periods away from their communities is a problem both culturally and practically (e.g., child care is often not available to the patient who needs to travel).

Access to culturally appropriate, effective care is therefore very challenging for many Aboriginal people, which foments the experience of disenfranchisement and undermines efforts towards equity in health and health care. Having or being at risk for a chronic disease, such as diabetes, may require frequent and ongoing contact with the health-care system and daily self-care, and this requirement becomes an omnipresent challenge for an Aboriginal person, or is forsaken.

The biomedical approach treats type 2 diabetes management as an individual responsibility, with “noncompliance” perceived as the leading challenge (Sunday et al., 2001; Wade and Halligan, 2004). “Normal” correlates to the physical measurement of good blood glucose levels (Sunday et al., 2001). However, for Aboriginal peoples, achieving “normal” can mean transcending the loss of freedom type 2 diabetes imposes, with structural constraints and emotional consequences therefore being the most significant barriers to self-management. The inability to follow through on prescribed treatment, particularly lifestyle changes, may reinforce the feeling of loss of control, which in turn contributes to the overall experience of disempowerment.

DIABETES

While type 2 diabetes was almost unheard of in Aboriginal populations before the 1950s (Chase, 1937), rates in Canada are presently three to five times that of the general population (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee, 2008). Diabetes-related complications are similarly high for First Nations people (Mao et al., 1992; Harris et al., 1997; Young et al., 2000; Dean et al., 1998; Statistics Canada, 2003; Oster et al., 2009). Less is known about Métis and Inuit populations; however, Ralph-Campbell et al. (2009) have collaborated with Métis Settlement dwellers in Alberta to document their undiagnosed diabetes and prediabetes rates.

Prevention, or delay of onset of diabetes or complications, may be possible if people at risk are identified through screening (Harris, 1993; Harris and Eastman, 1996; Leiter et al., 2001; Young and Mustard, 2001; Edward et al., 2004; American Diabetes Association, 2008; Ginde et al., 2008). However, type 2 diabetes remains incurable, and preventive strategies studied to-date

have not been tested on a population basis nor within Aboriginal community settings, nor has prevention been shown to work long-term (Knowler et al., 2002; Togashi et al., 2002; Diabetes Prevention Program Research Group, 2003; Lindstrom et al., 2003). With respect to established type 2 diabetes, intensive therapy has been shown to reduce the rate of complications (Ohkubo et al., 1995; UK Prospective Diabetes Study Group (UKPDS), 1998a, 1998b; Herman, 2003), but this has not been demonstrated yet in Aboriginal communities with reduced or inconsistent access to health-care resources (Bowen, 2000).

While many Aboriginal and other organizations may find the concept of screening originally appealing, the logistics of applying screening programs can be daunting, the early benefits not immediately apparent, and the conceivable advantages offset by significant disadvantages (Panagiopoulou et al., 2007).

Negative perceptions, stigma, and labelling, and a magnified experience of loss of control are perhaps the most serious potential disadvantages of type 2 diabetes screening. These potential harms may be compounded for Aboriginal peoples because their experience of diabetes is situated within the ongoing sociohistorical context of disempowerment, including past abuses stemming from research (Bruyere and Garro, 2000). For instance, misuse of statistical data about Aboriginal communities, lack of reporting to the community, research providing no benefit to the community, imposed interventions, forced compliance — especially with non-Aboriginal structures and concepts — have historically threatened Aboriginal autonomy (Garvey et al., 2004; Schnarch, 2004; Canadian Institutes of Health Research et al., 2010). Additionally, diabetes screening may leave Aboriginal communities with a disease burden they are incapable of addressing via internal (community) or external (health-system) resources.

DIABETES SCREENING

Diabetes screening in Aboriginal communities in Canada has been undertaken mostly as part of research studies amongst First Nations in Quebec (James Bay Cree), Ontario (Sandy Lake Oji-Cree), Manitoba, and Alberta (Harris et al., 1997; Dannenbaum et al., 1999; Kaler et al., 2006; Bruce and Young, 2008), as well as Métis communities in Alberta (Ralph-Campbell et al., 2009).

Aboriginal communities have limited opportunities to undertake health research independent of an institution/university, or to receive or control

research funding. However, collaborative community-based participatory research initiatives may offer an opportunity for Aboriginal communities to access needed health services and resources not available to them via the public health system; to gain a degree of control over health resources available to their members; to generate health data about their communities; to develop health human resources and their own research capacity; and to engage in research relationships offering a partnership model that challenges the systemic structures and cultural barriers that contribute to ongoing disenfranchisement.

THE COMMUNITY-BASED PARTICIPATORY RESEARCH MODEL

In the past few decades, much has been written about community-based participatory research (CBPR). Cass et al. (2002) describe the approach as

a style of research in which the demarcation between 'researcher' and 'subject' is blurred, research design is negotiated, and the participants perceive the need to change and are willing to participate actively in the change process.

CBPR and principles of CBPR are not exclusive to research involving Aboriginal communities. LaVeaux and Christopher (2009) explore the eight gold-standard CBPR principles described by Israel et al. (1998), contextualizing these for Aboriginal community settings (see Table 1). Through this contextualization exercise, LaVeaux and Christopher identified additional principles for carrying out CBPR with Aboriginal communities (see Table 2). They contend that understanding and applying CBPR principles in context is critical to the success of CBPR in Aboriginal communities.

The National Aboriginal Health Organization's (NAHO's) OCAP principles also embody CBPR values: collective ownership of data; First Nations control over research and information; First Nations management of access to data; and physical possession of the data (Schnarch, 2005). NAHO contends that adhering to these OCAP principles results in more participatory research methods, helps rebuild community trust, contributes to community empowerment and encourages meaningful capacity development (Schnarch, 2004).

CBPR/OCAP principles are additionally embodied in Canada's Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (Canadian Institutes of Health Research et al., 2010), wherein three core values are interpreted within Aboriginal contexts as follows (summarized):

Table 1. Community-based Participatory Action Research (CBPR) Principles, and CBPR Principles Contextualized for Aboriginal Community Settings

<i>CBPR Principles Israel et al. (1998)</i>	<i>Aboriginal Contextualization of CBPR Principles LaVeaux and Christopher (2009)</i>
The research process should:	
Recognize community as a unit of identity	The shared experience of colonization, and the shared experience of living in a bicultural world are powerful means of identification for Aboriginal communities.
Build on strengths and resources of the community	Culture and traditions can provide useful resources for research methodology.
Facilitate collaborative partnerships in all phases of the research	Equality in the relationship between community and university partners establishes trust and shared research goals; partnering also helps the researcher avoid inadvertent mistakes and culturally inappropriate actions.
Integrate knowledge and action for mutual benefit of all partners	Many communities are dealing with imminent issues such as poverty, and are looking for immediate assistance and tangible benefits to help alleviate these conditions.
Promote a co-learning and empowering process that attends to social inequalities	Researchers have the ability to provide Aboriginal communities with resources, training, skills, et cetera.; Aboriginal communities have the ability to provide researchers with an appreciation of Aboriginal ways of knowing, methodologies, and the sociopolitical dimensions of Aboriginal health.
Involve a cyclical and iterative process	Though time-consuming, each voice in the community is important, and consensus may be required for important community decisions if trust is to be developed/maintained.
Address health from both positive and ecological perspectives	Changing history involves focus on both assets and negative issues in a community; by identifying barriers within the system, and identifying and developing capacities to overcome these barriers, research can empower communities towards change.
Disseminate findings and knowledge gained to all partners.	Distribution of research findings should occur through relevant community channels and in appropriate languages; agreements should be in place to determine who controls dissemination of information, including what cultural knowledge is taken out of the community.

Table 2. Additional CBPR Principles for Aboriginal Settings LaVeaux and Christopher (2009)

- The research process should:
1. Acknowledge historical experience with research and with health issues and work to overcome the negative image of research;
 2. Recognize tribal sovereignty;
 3. Differentiate between tribal and community membership;
 4. Understand tribal diversity and its implications;
 5. Plan for extended timelines;
 6. Recognize key gatekeepers (e.g., Elders; knowledge holders in the community; individuals with influence);
 7. Prepare for leadership turnover;
 8. Interpret data within the cultural context; and,
 9. Utilize Aboriginal ways of knowing

1. Respect for Persons (expressed through free and informed consent) extends beyond the protection of individuals to include the interconnection between humans and the natural world, and the obligations to maintain and pass on knowledge received from ancestors and generated through present innovations.
2. Concern for Welfare (considering participants and prospective participants in their physical, social, economic, and cultural environments) extends not only to individuals but to the community to which they belong, acknowledging the role of the community in negotiating collective rights, interests, and responsibilities that also serve the welfare of individuals.
3. Justice (preventing an imbalance of power between researcher and participants) prescribes relationship-building and engagement between the community and researchers prior to initiating recruitment, aimed at defining the collaborative partnership, facilitating the development of mutually beneficial research goals, and ensuring reciprocal understanding of what constitutes respect for persons and concern for welfare. Efforts such as these acknowledge and seek to prevent repeat of abuses that have occurred in the past, such as inappropriate use of human tissue, misappropriation of cultural goods (artifacts, stories, songs), and failure to share data with the host community.

These research principles/processes have been incorporated in the Kahnawake Schools Diabetes Prevention Project (KDSPP), with KSDPP investigators proposing similar principles for CBPR and OCAP in Aboriginal communities (Potvin et al., 2003). Use of the CBPR model allowed for capacity building (including Aboriginal health human resources development) and community ownership over the project and collected data, and enabled sustainability of the KSDPP project within the community for a number of years. Several successful initiatives involving Australian Aborigines have similarly incorporated CBPR principles (Henderson et al., 2002; Weston et al., 2009). We are undertaking two screening projects involving Aboriginal communities in Alberta, Canada, similarly incorporating CBPR and OCAP principles.

The Mobile Diabetes Screening Initiative (MDSi) identifies undiagnosed type 2 diabetes, prediabetes, and cardiovascular risk in Métis communities. MDSi is ongoing since 2003 and encompasses mobile units that take diagnostic equipment, a testing lab, counselling, and education (for

both patients and community health workers) into the community setting. MDSi partially fills the gap in health-care delivery to Métis communities. Follow-up protocols include patient referral to local physicians, with patients' screening results copied to their family physician or nurse.

The BRAID (*Believing we can Reduce Aboriginal Incidence of Diabetes*) project is a longitudinal screening study being carried out in a single First Nation community in northern Alberta, with similar protocols, except lab equipment is permanently present in the community at the health centre.

Both projects provide health services in conjunction with research activities. Both were initiated at community request, with community consent given prior to commencement of recruitment, facilitated through existing community approval structures, such as First Nation Chief and Council.

Project staff receive cultural competence training, and when possible Aboriginal staff, who may speak Cree, are recruited. Traditional Aboriginal concepts of health and wellbeing are incorporated into the lifestyle counselling provided, including traditional medicines, foods, and activities. Personal, family, and community histories and experiences are incorporated into counselling, and diabetes and diabetes risk are discussed within this context.

Locally engaged community representatives provide support to the projects and participants, and in turn receive training and skills development from the researchers. To mediate external cultural barriers, the project staff liaise with the primary physicians and health-care workers serving these communities. Additionally, the projects conduct lab analyses on site rather than taking blood samples out of the community, and results and counselling are provided to the client on the same day as screening.

MDSi and BRAID follow a model of shared care entailing ongoing communication among all members of the health-care team, which is known to increase commitment and self-care of the patient (Hoskins et al., 1993; Greenhalgh, 1994). This enhances local/community capacity for dealing with the disease burden that our screening activities may produce.

Collaborative relationships are fostered through the research team making repeated visits to the communities, interacting with community leadership, Elders, and members, and, upon invitation, participating in community cultural events such as conferences and pow wows.

Local knowledge about community organizing has been utilized to enhance project implementation. For instance, MDSi hires local appointment bookers, who draw on their community knowledge and relationships in their

outreach to research participants. BRAID integrates with other programs in the community, such as a girls' club, the community school, and the community's Diabetes Program which provides traditional healing and teaching.

Two project evaluations have been completed for MDSi, for which community members were extensively consulted. The second of these evaluations was conducted by an Aboriginal consultant.

Communications strategies for knowledge translation incorporate avenues that speak to the different population segments in the community, such as Elders and youth, and include direct conversations with community knowledge-keepers, community presentations, community newsletters, a projects web site, and utilization of online social networking tools. BRAID project information is also posted on the host community's web site. A clinical database with analysis and reporting capabilities has been developed by E.L. Toth and her research team, with the long-term goal of enabling community health staff to use the projects' web site to generate community-specific reports for themselves.

Where not prohibited by submission guidelines, the research team has striven to share abstract and manuscript authorship with the communities. Data is not reported in newsletters, manuscripts, or conference abstracts without community vetting and approval.

Direction and priorities for the projects are determined in consultation with the communities. Where opportunities have presented, community representatives have served as co-investigators on funding applications.

Some communities have utilized their community data to secure funding for diabetes-related prevention programs, such as the Eastern Métis Settlements Diabetes Prevention Project (EMSDPP). The community hosting BRAID has secured multiyear funding that supports the community's Diabetes Program, including a full-time Diabetes Coordinator who is a community member. Assisting the communities in developing these resources, as well as the development of health human resources within the community, speaks to the principle of justice as it relates to shared benefit and resource sustainability in the communities.

The work has not been without challenges. Preparing for leadership turnover is one of the principles identified by LaVeaux and Christopher (2009). This has been a significant challenge, for the BRAID project in particular. We have navigated these challenges by trusting that each community has the capacity to decide for itself what is best, and to address these internal issues on its own terms.

Another important challenge has been the amalgamation of health services in Alberta from a regionally to a centrally based model. This process included the dissolution of Community Health Councils, which served the Métis communities, and gave MDSi a critical site for community engagement.

The most recent MDSi project evaluation highlighted requests by community members that MDSi move from a biomedical model towards a more holistic Aboriginal health model. In response to this, MDSi has hired an Aboriginal Community Liaison who is currently facilitating development of a healing model incorporating tradition-based concepts and methodology, with the goal of addressing sociohistorical trauma (the residential school legacy, in particular) in the Métis communities. This process will enable the researchers to produce more dynamic data interpretations, situated within the communities' cultural contexts and incorporating biopsychosocial factors.

Diabetes screening, carried out through collaborative CBPR, can therefore satisfy the ethical norms embodied by the CIHR and OCAP guidelines, with the potential to mediate Aboriginal disenfranchisement in a number of ways:

1. Addressing a "new" epidemic threatening Aboriginal communities with further depopulation and dispossession;
2. Providing needed health services and resources to Aboriginal communities, within a community setting (thereby mediating barriers such as distance and absence from family/community);
3. Identifying individuals needing prevention/treatment, and facilitating follow-up by communicating with local health workers (including community health representatives and nurses) and primary care providers;
4. Incorporating traditional knowledge in effective prevention/treatment, towards facilitating outcomes consistent with both Aboriginal and Western health models;
5. Incorporating traditional knowledge and practices into lifestyle counselling, making recommendations more relevant for clients and thereby more meaningful to work towards;
6. Contextualizing the experience of diabetes, to avoid amplifying the experience of loss of control;
7. Developing community capacity for providing health services, and undertaking health data collection and analysis (enhancing capacity for communities to undertake their own health research independently);

8. Providing health information to support the communities in making evidence-based requests to authorities for health services and resources (whether external or internal to the community);
9. Resituating power with the community, in terms of consenting to allow research, negotiating terms, identifying desired research outcomes, and so on;
10. Experiencing equality in developing research agreements and ethical codes that address Aboriginal values and cultural norms;
11. Enhancing the research community's ability to conduct culturally relevant research (Canadian Institutes of Health Research et al., 2010), including supporting skills development for Aboriginal students and researchers;
12. Demonstrating an effective, alternative partnership structure, and community-based service/care model, in juxtaposition to the health system's currently problematic patchwork, inconsistent, and culturally insensitive policy and service delivery for Aboriginal people.

CREATING SHARED "ETHICAL SPACE"

While the literature generally paints a dichotomous picture of Aboriginal and non-Aboriginal views on health and healing as holistic versus reductionist, respectively, significant overlap and commonality exist between the viewpoints. For instance, many Aboriginal people engage in non-Aboriginal religious traditions; and holistic healing is gaining a wider role in Western medicine (Garvey et al., 2004). As well, the CIHR guidelines, interpreted within an Aboriginal context to prioritize community and cultural integrity, clearly demonstrate the primary principles of respect for persons, concern for welfare, and justice are commonly held values in both Aboriginal and Western worldviews.

Although the CIHR guidelines are a leap forward in facilitating culturally appropriate research, they nonetheless represent an externally imposed non-Aboriginal structure. Humphrey (2001) suggests the imposition of guidelines such as these "encourage the procedural observance of rules rather than a more dynamic movement towards fully reconceptualising research practice." Indeed, CBPR as described in the literature seems to involve a much more formal process, rather than a relational process (relationship-based) as it may be experienced by the community and the researcher. Most health research involving Aboriginal people and communities is currently

carried out in a bicultural context, and protocols must speak to the needs of both partners, Aboriginal and non-Aboriginal. Henderson et al. (2002) highlight the need for written protocols to guide and protect both partners, with the temporal capacity to supervise non-Aboriginal researchers as they engage with Aboriginal communities. In the non-Aboriginal context, guidelines in writing have greater weight as a promise; this social meaning of written rules for non-Aboriginal Western researchers (Sahlins, 1976), makes them an important ingredient to include in the trust-building process between researcher and community. From an Aboriginal viewpoint, Humphrey (2001) states that

[Aboriginal] researchers have sought to move debate beyond the notion of research guidelines by seeking to treat ‘Western’ research traditions as a ‘tool box’ from which they can take whatever methods are deemed appropriate to Aboriginal knowledge production, and insisting on the development of new paradigms for research governed by ‘Aboriginal Terms of Reference.’

Several Aboriginal groups/communities/stakeholders in Canada have developed their own ethics codes — a process recommended in the CIHR guidelines as an important element of CBPR — implemented them at the local level, and facilitated a degree of control over the research process (Kahnawake Schools Diabetes Prevention Project, 1996; First Nations and Inuit Regional Health Survey National Steering Committee, 1999; Battiste and Youngblood Henderson, 2000). Table 3 outlines themes and objectives common to these, identified by Schnarch (2004). These efforts represent a practical application of shared values (which guidelines such as CIHR’s embody) in a bicultural context, expressed in a way that meaningfully addresses the ethical and process norms of both worldviews.

Table 3. Common Themes and Objectives in Ethics Policy Documents Prepared by Aboriginal Communities (Schnarch 2004)

Research should provide clear benefits to First Nations Peoples and communities.
Research should help develop capacity in meaningful ways.
Research should increase First Nations control of information and research processes.
Research should respect sovereignty/jurisdiction/ rights of First Nations.
Research should support self-determination.
Research should support cultural preservation and development.

If a collaborative framework can serve as a means for equalization, dismantling structures of domination, and moving Aboriginal empowerment forward in a bicultural society, the real value of research is this potential for creating shared ethical space, wherein Aboriginal and non-Aboriginal views overlap, without undermining each other (Turner, 1999), and wherein the

ethical requirements of both partners are satisfied. In this shared ethical space, the forging of trust relationships can be maximized, and the non-Aboriginal partner, situated in the dominant sphere, encouraged to relinquish power.

CBPR principles, as a practical expression of shared values, can therefore serve as a blueprint. Applied at a societal level, CBPR principles would ideally translate into replacing the systemic structures that maintain Aboriginal disempowerment and disenfranchisement — such as health transfer policy, negotiated via non-Aboriginal structures and terms of reference, which, as Bowen (2000) notes, fail to address many of the underlying socioeconomic conditions influencing health disparities — with structures that equitably incorporate needs and interests and terms of reference of both partners — such as publicly funded health care administered and delivered locally by and under the control and direction of Aboriginal communities, towards satisfying ethical norms and the health outcomes identified as shared goals by both the communities and the health-system partners. In other words, health-system authorities would trust that Aboriginal communities best know what they need and how to address these needs.

The diabetes screening efforts described above provide an example of the potential benefits of collaborative, community-based initiatives. While most diabetes screening in Canada has been research related, these benefits would be easily transferrable to the public health care system with the adoption of a more collaborative framework.

DISCUSSION

LaVeaux and Christopher (2009), the CIHR guidelines (2010), and NAHO guidelines (Schnarch, 2005) suggest that a community- and participatory-based model situating control within the Aboriginal community has the potential to provide additional benefits further justifying an intervention, such as health promotion, education, and training for community members. MDSi, BRAID, and other Canadian projects (such as KSDPP in Quebec and the Sandy Lake Health and Diabetes Project [SLHDP] in Ontario) (Harris et al., 1997; Potvin et al., 2003) are successful examples of innovations towards this community-based, community-controlled model.

Interventions such as these can empower communities to take forward-looking precautionary/preventive actions to protect the next generations, an essential Aboriginal way of maximizing the potential for community integrity.

Screening for undiagnosed diabetes and diabetes risk in Aboriginal communities speaks to prevention/precaution in two ways: 1. To reduce burden of complications by means of early detection and treatment; and, 2. To provide alternatives to conventional health care as a means of improving accessibility to care. These represent potential social benefits of empowerment for Aboriginal communities when screening is done on site under Aboriginal control.

The *Ottawa Charter for Health Promotion* defined health as the process of enabling people to increase control over, and improve their health (World Health Organization, 1986). In accordance with this, and with CIHR and NAHO guidelines for health research involving Aboriginal peoples, diabetes screening should be undertaken when possible as long as it offers control to Aboriginal individuals and communities (including control over their health), and provides a means for reclaiming power within a colonial socio-historical context that has undermined Aboriginal peoples' political power.

Studies of Pima Indians suggest the risk of developing type 2 diabetes may be reduced by maintaining traditional food choices and lifestyle (Ravussin et al., 1988; Williams et al., 2001). If relegitimization of Aboriginal culture, connecting health with tradition, is viewed as an alternative solution for diabetes when biomedicine offers no cure (or no treatment that appropriately addresses Aboriginal needs), we believe the potential advantages of screening outweigh the potential harms for Aboriginal peoples. Particularly since the social benefits, such as capacity-building, empowerment, and a return to traditional culture, could lead to beneficial lifestyle modifications.

The divergence between the biomedical perspective and the Aboriginal perspective is clear. But the examples of community-based collaborative programs described in this paper point to shared values as the starting point for incorporating the two perspectives in a way that undermines neither perspective, maximizes the benefits for Aboriginal peoples, and outweighs the potential harms of diabetes screening. Protocols that develop from CBPR offer a blueprint for processes aimed at negotiating more equitable and effective systemic structures (such as the health care system) that meaningfully incorporate Aboriginal terms of reference and address socio-historical and cultural barriers.

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Dr. Sharona Supernault Kaler is a family doctor in Halifax, Nova Scotia and is balancing work and family life. Dr. Kaler is an Aboriginal physician who hopes to increase awareness of Aboriginal health to both the Aboriginal and non-Aboriginal populations. Dr. Kaler has been involved with ACADRE (Aboriginal Capacity and Developmental Research Environments; funded by the CIHR – Institute of Aboriginal Peoples Health) since its inception. While attending medical school, Dr. Kaler gained experience in community research by undertaking field work for the BRAID Study. She hopes to continue to have an involvement with type 2 diabetes and the metabolic syndrome in her practise with a focus on preventative medicine.

Sharndeeep (Norry) Kaler completed his MSc in Medicine in 2005, with the BRAID Study as the topic of his thesis. He is currently studying medicine at Dalhousie University. He continues to be passionate about Aboriginal health. Norry has been involved with various Aboriginal organizations and has published work on type 2 diabetes, the metabolic syndrome, and screening for type 2 diabetes in Aboriginal communities. He hopes to continue his work in Aboriginal health research in the upcoming years.

Ellen L. Toth, MD, collaborated with Alberta First Nations and Health Canada (First Nations and Inuit Health Branch) to establish SLICK, a health services research project from 2001–2007, exploring an alternative model of diabetes service delivery. Since 2003, she has been principal investigator of MDSi, in partnership with Alberta Health Services zones (regions) and stakeholder communities. Similar to SLICK, MDSi serves Métis and First Nations off-reserve communities. Dr. Toth is principal investigator of the BRAID Study, screening for diabetes and diabetes risk within a single First

Nation, since 2002. She is principal investigator of BRAID-Kids, underway in this community since 2008, aimed at reducing obesity and diabetes risk amongst children via families and an in-school prevention curriculum. She was Alberta Site Investigator for CIRCLE (Canadian First Nations Diabetes Clinical Management Evaluation), a nation-wide study funded by Health Canada, looking at diabetes-related health service usage and rates of diabetes-related complications in communities, and an initial co-investigator on Alberta ACADRE.