

# 10

## **Issues in the Recruitment and Retention of Aboriginal Health Research Participants in Canada**

Victoria Nadalin, Marion Maar, Fred Ashbury,  
and John McLaughlin

### **Introduction**

Historically, health research within Aboriginal<sup>1</sup> communities was conducted by outsiders who, without appropriate oversight and understanding of the cultural differences, sometimes engaged in exploitive and even unethical behaviour. Over time, these practices considerably strained relations between researchers and Aboriginal peoples (First Nations Centre 2007). Historical examples of inappropriate behaviour by previous researchers are well-documented and include: individuals being pressured to participate in studies, the absence of informed consent, the collection and use of genetic material for inappropriate purposes, a general disregard of cultural norms and sensitivities, and the collection of information about traditional remedies for profit (Schnarch 2004). This situation was further exacerbated by studies with a purpose or implication inconsistent with the world view of Aboriginal peoples, the reporting of some harmful and misleading results, the conduct of studies with little or no positive impact, studies developed and conducted completely without community input, results that were not communicated to the participating community, and a suspicion that results could be used in ways that participants would not approve of (e.g., by the government for resource allocation). Further, research fatigue has been reported among Aboriginal peoples; in fact, some Aboriginal representatives have stated that their communities have been “researched to death” (Women’s Health Centre of Excellence 2005; Maar, Sutherland, and McGregor 2004). In light of these issues, it is not surprising that researchers frequently face skepticism and barriers when they attempt to study Aboriginal communities.

Despite strained relations between researchers and Aboriginal communities, there is a need for health research and interventions specific to Aboriginal peoples, for information that can be used to measure changes (positive and negative) in the health status of Aboriginal peoples and communities, and for information that will lead to a greater understanding of the underlying framework that perpetuates health inequality. Research that is specific to Aboriginal peoples is also needed because there are a number of important differences between these peoples and the general Canadian population. Policy-makers cannot assume that

the health status and needs of Aboriginal peoples is the same as that of the rest of the population. Among Aboriginal peoples, some chronic disease risk factors such as hypertension, cigarette smoking, and obesity are more common than in the wider population (Marret, Jones, and Wishart 2004); the pattern of various types of cancers is different (Marret, Jones, and Wishart 2004; Chen 2009); the rate of diabetes is three to five times higher (Health Canada, Diseases and Health Conditions 2006); the age-standardized prevalence of arthritis is 27%, compared to 16% in the non-Aboriginal population (Health Canada 2003); there is a higher frequency of cardiovascular disease and a higher burden of atherosclerosis (compared to Canadians of European descent), and the rate of heart disease is about one-and-one-half times that of the general Canadian population (Health Canada, Diseases and Health Conditions 2006). There is a need for ongoing research that will address these differences, and lead to a greater understanding of the circumstances that lead to poor health in these communities (Maar, Sutherland, and McGregor 2004).

Historically, research recognized by modern standards to be unethical occurred in many contexts, in both Aboriginal and non-Aboriginal settings (Sade 2003). Research ethics guidelines and the boards that enforce them emerged to protect all research participants. While clearly important, general research guidelines represent what the scientific community and broader society consider ethical; i.e., they were developed without the input or partnership of Aboriginal peoples (Schnarch 2004). Special efforts are needed in the conduct of research with Aboriginal peoples, who have logically developed distrust for researchers, have unique perspectives, and have an interest in ensuring accurate research regarding their heritage, community, and customs (Schnarch 2004). In recent years, improvements have been made in Canada, where ethical guidelines have been developed with special involvement of and attention paid to the special needs and interests of Aboriginal peoples.

A growing body of literature has emerged that suggests how research should be conducted with Aboriginal communities. New approaches have been described in peer-reviewed journals, e.g., the work of Maar et al. (Maar, Sutherland, and McGregor 2004) and Castellano (Castellano 2004), in the research guidelines of the Canadian Institutes of Health Research (CIHR), and in documents produced by representatives of Aboriginal peoples, e.g., the First Nations “Ethics Tool Kit” (National Aboriginal Health Organization 2003) Collectively, these documents present a general approach, elements of which include:

- Community consultation, participation and involvement. Some documents recommend community consent as a requirement, suspending the research if the community finds it to be unacceptable
- The usual ethical requirements for research (e.g., confidentiality, informed consent, monitoring and reporting of risks and benefits), in addition to others, specific to the context

- The explanation of all aspects of the research to the community or participants (e.g., purpose, methodology, sponsorship, risks and benefits, reporting plans, time frame, community involvement), on an ongoing basis, allowing communities to ask questions
  - The explanation of research results to participants/communities and assisting them in developing strategies for their use
  - The incorporation of traditional and local knowledge, with communities retaining their rights to this information
  - An understanding and respect on the part of researchers of the privacy, protocols, dignity, and rights of Indigenous people, and the involvement of Aboriginal culture and validation methods
  - Research that benefits both the community and the researchers, and supports the education and training of Aboriginal people and communities, while reducing or eliminating the risk of harm
  - Requiring that researchers learn the Aboriginal world view and apply relevant Aboriginal cultural protocols, ensuring ongoing communication, and, if possible, translating relevant materials
  - The understanding that Aboriginal peoples have the right to control and determine their interests in the use, collection, storage, and possible future use of the data, with biological samples considered “on loan” to researchers
  - Statement of the intellectual property rights of all parties in the research agreement
  - The option of participatory research, where participants have the opportunity to take part in the interpretation of results, and review the conclusions to ensure accuracy and cultural sensitivity
- (Schnarch 2004; Maar, Sutherland, and McGregor 2004; Canadian Institutes of Health Research 2007)

While it is promising that such guidelines have been developed, their documentation does not indicate their use. The present review provides a brief overview of current (past five years) peer-reviewed health research studies of Aboriginal peoples in Canada, describes the extent to which the principles outlined above are incorporated into these studies, and discusses some lessons learned from these, and considerations for future projects.<sup>2</sup>

## Materials and Methods

Recent English-language health research studies of Aboriginal peoples in Canada were surveyed using PubMed. Papers under consideration were those published between January 2004 and June 2008, included abstracts, and collected primary participant data. Although an important health issue, in order to minimize the number of articles included, those which focused exclusively on mental health were excluded.

Search terms used were risk factors, recruitment, chronic disease, Native, Inuit, Aboriginal, Métis, health, and epidemiology. Because the literature recommending research methods generally assumes rural, remote, or on-reserve residency, only studies that focused on these populations were considered (Caron 2005).

Non-relevant citations were removed, such as those that did not focus on rural, remote, or reserve populations, those that did not recruit participants, and those that did not focus specifically on Aboriginal populations (i.e., we excluded those that included Aboriginal peoples among a number of ethnic groups).

Next, we excluded those that did not describe the method used in the current publication, that is, we removed those that referred to an earlier paper (out of the years selected) for an explanation of the method.

The research methods of the selected citations were then examined for their overall attempts to incorporate design elements of the type outlined above, and the qualities of the study. Because the studies under consideration varied considerably in terminology, methodology, selected community (or communities), and sample size, quantifying the methods used was not logical or possible. Instead, these studies were examined for general trends in the use of appropriate methods. In order to have a sense of when research methods appropriate to Aboriginal populations were applied, we also considered the size of the study population, the initiator of the research (i.e., investigator or community initiated), where the study took place, and any lessons learned.

## Results and Discussion

Many studies were published on the health of Canadian Aboriginal peoples in the years selected. Before applying the selection criteria, the search terms yielded over two hundred articles. Using the criteria outlined above, fifty-three citations were selected for review.

Many of these citations dealt with single communities. Examples of these are cited here: Kaler et al. 2006; Bisset et al. 2004; Egeland et al. 2008; Bird et al. 2008; Daniel et al. 2004; Cook 2005; Skinner, Hanning, and Tsuji 2006; Sin et al. 2004; Pollex et al. 2006; Barton, Anderson, and Thommasen 2005; Reading et al. 2005; Macnab et al. 2008; Macnab et al. 2005; Thommasen et al. 2006; Thommasen and Zhang 2006; Thommasen et al. 2005; Charbonneau-Roberts, Young, and Egeland 2007. While many of the studies dealt with small groups, three of these studies were very small, with samples of fifteen people or less (Bird et al. 2008; Barton, Anderson, and Thommasen 2005; Crosato, Ward-Griffin, and Liepert 2007).

The citations that were examined all demonstrated currently accepted practices in their research methods, and most showed some awareness that special effort is needed for work with Aboriginal peoples. There were examples of authors who did not report a culturally based methodology who still demonstrated some awareness that research with Aboriginal communities requires respect for Aboriginal values,

**Table 10.1: Study Characteristics and Relevant Study Examples**

Methodological steps	Examples of studies
Steps taken to describe community input	Bird et al. 2008; Buxton et al. 2007; Cook 2005; Charbonneau-Roberts, Young, and Egeland 2007; Hamilton et al. 2004; Kaler et al. 2006; Nakano et al. 2005; Peressini et al. 2004, 382-382e; Peressini et al. 2004, 101-110; Reading et al. 2005; Sharma et al. 2008
Description of participatory research	Bisset et al. 2004; Charbonneau-Roberts, Young, and Egeland 2007; George et al. 2007; Hamilton et al. 2004; Minore et al. 2004; Peressini et al. 2004, 382-382e; Peressini et al. 2004, 101-110; Skinner, Hanning, and Tsuji 2006; Sharma et al. 2008; Pylypchuk et al. 2008; Rosecrans et al. 2008
Research of direct benefit to the community	Bird et al. 2008; Bisset et al. 2004; Panagiotopoulos et al. 2007; Reading et al. 2005
Translation (of materials, translators made available)	Bird et al. 2008; Charbonneau-Roberts, Young, and Egeland 2007; Cook 2005; Egeland et al. 2008; Hotson, Macdonald, and Martin 2004; Kovesi et al. 2007; Kuhnlein et al. 2004; Nakano et al. 2005; Skinner, Hanning, and Tsuji 2006; Pylypchuk et al. 2008; Stone et al. 2006
Community consent obtained	Bird et al. 2008; Buxton et al. 2007; Charbonneau-Roberts, Young, and Egeland 2007; Christofides, Schauer, and Zlotkin 2005; Egeland et al. 2008; Hamilton et al. 2004; Hotson, Macdonald, and Martin 2004; Kaler et al. 2006; King et al. 2007; Kovesi et al. 2007; Kuhnlein et al. 2004; Nakano et al. 2005; Peressini et al. 2004, 382-382e; Peressini et al. 2004; Pollex et al. 2006, 484-491; Pollex et al. 2006, 121-129; Receveur et al. 2008; Saksvig et al. 2005; Thommasen et al. 2006; Thommasen and Zhang 2006; Thommasen et al. 2005; Wardman et al. 2007

such as obtaining community consent (Christofides, Schauer, and Zlotkin 2005). More explicit attempts to incorporate an Aboriginal framework in their methodology were evidenced by authors who described steps they took to obtain community input, use participatory research, undertake research of benefit to the community, and ensure translation of relevant materials. Examples of studies that incorporate these elements can be found in **Table 10.1**.

Some specific examples of attempts to incorporate culturally sensitive study methods are described here. Cook (2005), in a study that surveyed patients attending a clinic in a First Nations community health centre to explore their use of Mi'kmaq medicine, designed the questionnaire in consultation with a

Mi'kmaq staff member, obtained study approval on behalf of the Band Chief of the community, and honoured the wishes of the community to remain anonymous (Cook 2005, 95–99). Kaler et al. (2006), who screened individuals in a single First Nation in Alberta for metabolic syndrome, cardiovascular risk, pre-diabetes, and diabetes, obtained study and manuscript approval, and authorship from the Chief and Council of the First Nation studied (Kaler et al. 2006). Bird et al. (2008), in a study of those living with diabetes on Baffin Island, conducted the project in response to the request of a community member and had a community member conduct and interpret study interviews (Bird et al. 2008). Other examples include the work of Gallo et al. (2007), who made use of Aboriginal recruiters and conducted their study in partnership with the Akwesasne Mohawk Nation (Gallo, Schell, and Akwesasne Task Force on the Environment 2007), and Sharma et al. (2008), who developed a quantitative food frequency intake questionnaire with five First Nations fieldworkers, who they trained, and then pilot tested the questionnaire on First Nations subjects (Sharma et al. 2008). Wardman et al. (2007), derived their questions from those raised by the British Columbia First Nations Tobacco Control community coalition and others, pretested their survey on four Aboriginal health programmers, and used an Aboriginal research assistant, although they did not demonstrate any further efforts to incorporate community input (Wardman et al. 2007). Other examples that demonstrate an awareness of the need for a special approach with Aboriginal communities can be found in the reference list of this paper (Thommasen et al. 2006; Charbonneau-Roberts, Young, and Egeland 2007; Kovesi et al. 2007; Nakano et al. 2005; Leslie et al. 2006; Iwasaki, Bartlett, and O'Neil 2004; Richmond 2007).

There were studies published in the selected years that demonstrate an incorporation of many of the elements outlined above. A review of the Diabetes Risk Evaluation and Microalbuminuria (DREAM) Studies project (the review that considers published and unpublished studies, and interviews with providers and participants) discusses the efforts researchers made to work under a structure that enables community ownership, control, access, and possession of the research, and to work within a collaborative, participatory research model (Pylypchuk et al. 2008; Tobe et al. 2006). Each project study team developed its research in response to a need identified by the community, and project results were fed into quality improvement in patient care, and the development of research expertise (Pylypchuk et al. 2008). Similarly, Macnab et al. (2005) describe their efforts to develop a truly collaborative, long-term research partnership with a remote First Nation's community, which resulted in a 100% study enrollment (Macnab et al. 2005). These researchers began their work by having the community identify health-care priorities for development, and study results were of direct benefit to the community, which continued to work with this research group. High response rates were reflected in some other projects that made significant use of methods appropriate for Aboriginal communities, such as that reported by Kuhnlein et al. (2004), and Nakano et al. (2005), who achieved participation rates between

75 % and 90% while studying dietary intake in the Far North (Kuhnlein et al. 2004; Nakano et al. 2005). Kuhnlein et al. attributed their response rate to study publicity, and encouragement from community leaders, who were in partnership with the researchers. The study by Nakano et al. was initiated by the community, which likely correlates with high response rates.

Other examples of studies that incorporate many of the recommended elements include those by Minore et al. (2004), who attempted to reflect the ideal of participatory research (Minore et al. 2004); Wardman et al. (2006), who consulted with community members at many points, provided training sessions to local contacts, and selected analyses through interactions with local research assistants (Wardman, Quantz, and Clement 2006); and George et al. (2007), who utilized local knowledge in a participatory action project that developed community-specific fetal alcohol intervention programs (George et al. 2007).

The work by Loppie (2007) provides a detailed account of the steps she took to employ Indigenous principles in her research on Aboriginal women in Nova Scotia. This author describes the development of a research partnership, and the experiences she had in trying to incorporate Western science with Indigenous cultures. This author then goes on to describe the need for researcher flexibility, humility, and the process of prolonged community engagement (Loppie 2007).

The work of Saksvig et al. (2005), describes the efforts these investigators made to develop a school-based diabetes prevention intervention in Sandy Lake that incorporated the learning styles of Indigenous peoples, including cooperative learning, with an emphasis on tradition and humour. The curriculum developed in the study made use of cultural traditions, and used storytelling as a way to introduce the main components of the lessons (Saksvig et al. 2005). Other examples of strong attempts to incorporate elements of the research methods described above can be found in the reference list of this paper (Bird et al. 2008, 17–21; Reading et al. 2005; Macnab et al. 2005; Buxton et al. 2007; Hamilton et al. 2004; Peressini et al. 2004, 382-382e; Peressini et al. 2004, 101-110; Panagiotopoulos et al. 2007; Stone et al. 2006; King et al. 2007; Smith et al. 2006; Wardman, Clement, and Quantz 2005).

Several studies described uneven attempts to incorporate research methods sensitive to Aboriginal peoples. Examples of these include studies by Christofides et al. (2005), Taylor et al. (2007), and Receveur et al. (2008). The study by Christofides et al. (2005) is described as a researcher-initiated prevalence study of iron deficiency anemia that did obtain approval from the communities and hospitals involved, yet the study questionnaire was based on information from Health Canada documents on Aboriginal foods and nutrition, validated by community nurses and fieldworkers, not community members. This study reported a 19% refusal rate (Christofides, Schauer, and Zlotkin 2005). Taylor et al. (2007) did not report obtaining community input, or the use of research methods specific to Aboriginal communities, beyond the presentation of study findings to the community, and used a previously validated (on off-reserve children) food

frequency questionnaire that had been pilot tested on Mi'kmaq children. This study obtained a response rate of 50% (Taylor et al. 2007). Receveur et al. (2008), in a study collecting dietary and anthropometric data, did obtain study approval by the Kahnawake Community Advisory Board, and presented results to the community. However, although reference is made to the Kahnawake School Diabetes Prevention Project (of which this study is a part), no other culturally sensitive research methods were described in the methods of this article (Receveur et al. 2008).

Among these studies, the themes of community data possession, intellectual property rights, and the use of traditional knowledge in the research agreement or ongoing explanation of aspects of the research were not usually described.

Thirteen of the studies were conducted in British Columbia, and nine were conducted in Ontario. A number of studies were conducted in multiple provinces, or in unidentified communities, with the rest split across the rest of the provinces, and the North. **Table 10.2** shows the location of studies.

Thirty-six of the studies were initiated by the researcher, and the rest were community initiated, or a joint project between the researcher and community.

Although ethics review from an external academic institution was almost always completed, in many cases, community consent was obtained. Translation was frequently offered to respondents in the form of a bilingual interviewer, a local interviewer, or by ensuring that an interpreter was available when needed. This information is contained in **Table 10.1**.

In terms of subject area, these studies commonly dealt with factors around diabetes (such as screening programs, its precursors, and issues around having the disease), the provision or utilization of health care, alcohol and tobacco (cessation and use), air quality and diet, and physical activity and weight.

While studies using questionnaires without community input, or those that made no (or limited) mention of methods specific for Aboriginal communities were uncommon, those that did use this approach often showed low response rates (Daniel et al. 2004; Sin et al. 2004; Christofides, Schauer, and Zlotkin 2005; Taylor et al. 2007; Valera, Dewailly, and Poirier 2008; Virani et al. 2006). For example, Taylor et al. (2007), in studying the nutritional concerns of on-reserve Aboriginal children in Prince Edward Island did not report the use of Aboriginal research principles, and reported a response rate of approximately 50%. These authors did, however, conduct a workshop with community members to discuss study findings and future interventions (Taylor et al. 2007). Virani (2006), in a screening project for diabetes complications, reported a follow-up rate of 26% of those who completed an initial assessment (which included a questionnaire with a response rate of 64%), 21% of whom completed the follow-up questionnaire (Virani et al. 2006). Although this study is part of an ongoing Alberta First Nations/Health Canada/University of Alberta initiative that provided translation when needed and staffed the project with First Nations or those trained for the community, in this study, no special steps were described in questionnaire

**Table 10.2: Geographic Location of Studies**

Location	Study
British Columbia	Barton, Anderson, and Thommasen 2005; Buxton et al. 2007; Daniel et al. 2004; Macnab et al. 2008; Macnab et al. 2005; Panagiotopoulos et al. 2007; Reading et al. 2005; Smith et al. 2006; Thommasen et al. 2006; Thommasen and Zhang 2006; Thommasen et al. 2005; Wardman, Quantz, and Clement 2006; Wardman, Clement, and Quantz 2005
Ontario	Minore et al. 2004; Saksvig et al. 2005; Sharma et al. 2008; Skinner, Hanning, and Tsuji 2006; Pollex et al. 2006, 484–491, Pollex et al. 2006, 121–129; Peressini et al. 2004, 382–382e, Peressini et al. 2004, 101–110; Rosecrans et al. 2008
Multiple provinces, unidentified communities	Christofides, Schauer, and Zlotkin 2005; Cook 2005; Crosato, Ward-Griffin, and Liepert 2007; Gallo, Schell, and Akwesasne Task Force on the Environment 2007; George et al. 2007; King et al. 2007; Masotti et al. 2006; Stone et al. 2006; Wardman et al. 2007; Richmond 2007
Rest of provinces and North	Bird et al. 2008; Bisset et al. 2004; Charbonneau-Roberts, Young, and Egeland 2007; Egeland et al. 2008; Hamilton et al. 2004; Hotson, Macdonald, and Martin 2004; Kaler et al. 2006; Kovesi et al. 2007; Kuhnlein et al. 2004; Leslie et al. 2006; Loppie 2007; Nakano et al. 2005a; Nakano et al. 2005b; Pylypchuk et al. 2008; Receveur et al. 2008; Sin et al. 2004; Taylor et al. 2007; Tobe et al. 2006; Valera, Dewailly, and Poirier 2008; Virani et al. 2006

development that engaged Aboriginal peoples. In contrast, some authors noted that when community members were hired and participation was encouraged among community members, response rates were higher (Peressini et al. 2004). King et al. (2007) echoed this finding in a study using mixed recruitment methods, wherein the most successful recruitment strategy was in a community where the trust of the community had been gained prior to recruitment (King et al. 2007). These results provide evidence that culturally appropriate research methods may increase participation rates in Aboriginal communities.

Incorporating research methods appropriate to Aboriginal communities did not however, necessarily lead to high response rates. Despite the use of participatory action research methodology and consultation with the Band Council, local health-care providers and community members, in two papers, Thommasen et al. (2006) obtained response rates of 38% and 39% (Thommasen et al. 2006; Thommasen

and Zhang 2006). One of these studies, which examined drinking habits, noted that the response rate is typically lower in studies of this type (quantitative mail-in surveys) (Thommasen et al. 2006). Another study by Charbonneau-Roberts et al. (2007) only recruited 7.2% of eligible participants in the selected community; however, recruitment was through radio announcements, pamphlets, and information sessions (Charbonneau-Roberts, Young, and Egeland 2007). Wardman (2006), in a study of HIV testing and risk behaviours, reported that community representatives were reluctant to include questions of HIV status in light of confidentiality concerns (Wardman, Quantz, and Clement 2006). Factors that influence recruitment and participation were therefore more complex and further research is needed to identify effective recruitment strategies and culturally appropriate methods of data collection.

Although qualitative approaches provided rich data in some cases, authors frequently described limited applicability of their study results to other communities as a limitation of their studies (Buxton et al. 2007; Hotson, Macdonald, and Martin 2004; King et al. 2007; Iwasaki, Bartlett, and O'Neil 2004; Wardman, Quantz, and Clement 2006). The work of Bisset et al. (2004) concludes with a quotation from an elder indicating that the results of their study can be used as a guideline for other communities, who must use the knowledge to guide their own work (Bisset et al. 2004).

## **Lessons Learned**

In reviewing the current literature conducted in these communities, a number of important lessons were learned:

### ***1. Following culturally sensitive research methods with Aboriginal peoples can improve response rates.***

Although these principles are not easily practiced, in some cases, their use results in interest, buy-in, high response, and retention rates, and increased effectiveness and efficiency of research (Peressini et al. 2004; Smylie et al. 2004). Some studies that made the effort to adapt questionnaires to the context reported impressive response rates (Wardman et al. 2007), or response rates higher than expected (Thommasen et al. 2006). The need to better link health research with the lives of the individual and community could apply to all research studies and other research contexts (Smylie et al. 2004).

### ***2. Those who wish to conduct research with Aboriginal peoples should have the long view and broader implications in mind.***

Conducting research on health with Aboriginal peoples has become a very complex task, requiring special knowledge and training in Aboriginal health, participatory research, and research ethics (Maar, Sutherland, and McGregor 2004). The historical context has had a profound impact on what is an acceptable

approach to Aboriginal community research and the ethics of Aboriginal research (Maar, Sutherland, and McGregor 2004).

Those citations expressing the most positive experiences, including requests from the community for further research and very high response rates, did make great efforts to establish groundwork supportive of continued work with these communities. The work of Macnab et al. (2005) best illustrates this, wherein their work became a starting point for ongoing work requested by the community. These authors described a “road map” of collective partnership that could be used in studies that address common health problems in Aboriginal children (Macnab et al. 2005). The work of Loppie (2007) is also instructive, and outlines the steps she took to establish trust, including socializing with participants before and after focus groups and tailoring her research approach to what was preferred by participants (Loppie 2007).

***3. Researchers who aim to include Aboriginal peoples in a study should undertake preparatory work to learn about the community, along with its history and culture, before starting the study.***

Researchers must understand that their world view is distinct and at times may even be in opposition to that of Aboriginal individuals and communities. This necessity is well described in the study by Bisset et al. (2004), who reported community shame and guilt around diabetes. These authors mention that it is important to understand how ready a community is to accept new information about a familiar problem (Bisset et al. 2004). Researchers need to get to know the communities they will be working with, which affirms the use of planning for a long-term relationship.

***4. Aboriginal communities need to know about quantitative studies, and to develop guidelines for researchers in their conduct.***

There is a need to expand on Aboriginal health research in Canada and to develop innovative ways of doing this. Much of the recent health research conducted in these communities that made use of methods appropriate to Aboriginal communities was done on only a small scale. Quantitative data have merit and can provide information that helps leaders and policy-makers make informed decisions. There is an opportunity here to develop unique methodologies that bridge research gaps (Smylie et al. 2004).

Culturally competent research approaches have been successfully applied, particularly in individual communities for qualitative studies, whereas there have been more challenges in applying such methods to quantitative and anthropometric data collection. It has been suggested that a combination of quantitative and qualitative information provides a holistic picture of the research context (Kenny 2004). Some of the projects reviewed have achieved success in a mixed-methods

approach (Reading et al. 2005; Minore et al. 2004). While it may not always be possible to incorporate all of the approaches considered appropriate to Aboriginal communities, it is important that their intent be understood, even if it is not always possible for them to be fully applied.

***5. Appropriate research methods in Aboriginal communities present challenges to researchers, who must plan for known challenges from the conception of the study forward.***

Some of those researchers who attempted to conduct studies with Aboriginal communities experienced challenges in their execution. Issues of shifting timelines, difficulties in obtaining a representative sample (transient/seasonal population) and in meeting funding deadlines, and high turnover of community staff were all described (Kaler et al. 2006; Minore et al. 2004). CIHR has noted that researchers should make no assumptions and determine who has the authority in a community on a case-by-case basis as a joint responsibility between the community and researcher (Canadian Institutes of Health Research 2007). Recent work by Maar and colleagues (2009) suggests that Aboriginal communities would prefer researchers to be strategic in ways that prevent the duplication of research, and avoid repeated requests to communities to participate in similar research studies (Maar, Lightfoot, et al. 2009)

***6. These principles are applicable to studies of other marginalized groups, and to the wider research context.***

To some extent, the principles outlined here might be adapted to the wider health research context, where new privacy laws have limited researchers' access to health data. Recent restrictions on access to cancer data, for example, have left researchers in a position of needing to develop a relationship with their participants, acknowledge the personal nature of much of the information in health records, and treat this information with great privacy and reverence. In order to obtain and retain the participation of research participants, researchers might consider adopting a greater focus on qualitative research methods that involve participatory action. They might also attempt to attract research participants by directly engaging them in their communities, such as by offering employment to members of the target community, and by making a greater effort to develop research of direct benefit to individuals and their communities.

***7. Funding agencies need to appreciate the intricacies of research with Aboriginal peoples when these guidelines are followed.***

While the Canadian Institutes of Health Research (CIHR) has released guidelines for health research involving Aboriginal peoples, to be assumed by researchers funded by CIHR (Canadian Institutes of Health Research 2007), and in some cases (e.g., the Northwest Territories' *Scientists Act*) legislatures have enacted

research requirements for work with Aboriginal peoples (Canadian Institutes of Health Research 2007), this trend needs to continue so that large-scale studies can be carried out that incorporate culturally specific research principles with Aboriginal people, and are supported by the agencies that fund them.

### ***8. Research methods need to be developed for the off-reserve population.***

Although historically most research was conducted in a rural/reserve setting, the off-reserve and urban Aboriginal peoples also have health-related inequities on which research is warranted. It has been suggested that there are significant gaps in how health-care providers have been trained in relation to, and in their knowledge of, how to best serve urban Aboriginal patients (Levin and Herbert 2004). Therefore, there is a need for health research on the off-reserve and urban populations, and for the development of health research methods unique to these people (Bartlett et al. 2007).

## **Conclusion**

Research approaches specific to Aboriginal peoples have become more clearly developed and better known, though their use is not universally applied. We can only speculate as to why this is the case. Issues of cost and timeliness are likely considerations, but more importantly, the traditional scientific education of researchers has not generally included training in cross-cultural collaboration. Researchers must acknowledge, explore, and resolve differences in world views and values that might exist between them and participating communities (Lightfoot et al. 2008). The recent development of ethical guidelines, such as those adopted by CIHR and other agencies, underscores the importance of this approach now and in the future.

We examined the broad methodological patterns in recently published literature related to Aboriginal health research over a defined period of time, as found in PubMed. Our findings show that authors who have published in peer-reviewed journals over the past five years have generally taken steps to incorporate elements of appropriate research methods, and that those who have used this approach have often achieved higher levels of participation. As has been reported, in order to conduct respectful research in Aboriginal communities, extra time, money, and cross-cultural training are needed on the part of researchers, who continue to be pressured to complete their work on time, publish, and help their students graduate (Schnarch 2004).

While researchers are challenged to work collaboratively with Aboriginal communities, at the same time, Aboriginal communities are challenged to build local research capacity to monitor and improve community health (Masotti et al. 2006). Respectful collaboration and blending of the knowledge of both researchers and communities appears promising. However, challenges remain; it is often

unclear how to best incorporate these principles, particularly in large-scale and quantitative studies.

This review has demonstrated that there have been many promising research developments, and attempts by researchers to incorporate some or most of these principles into their research projects. It is now clear that in order to enhance the relevance, quality, and impact of their findings, investigators must plan ahead and incorporate these principles and methods into the design and conduct of health research.

There is a need to dramatically expand the scope of Aboriginal research in Canada, and to develop new research frameworks, protocols, and dissemination activities in collaboration with Aboriginal peoples. There is important work to be done to address the health-related disparities suffered by Aboriginal peoples in Canada, and for this to succeed, there is an urgent need for solid research that applies the principles reviewed.

## **Acknowledgements**

Thanks to Melissa Pirrie, who assisted with the collection of articles for this document.

Thanks also to Ms. Caroline Lidstone-Jones, Dr. Nancy Kreiger, Dr. Greg Ross, Mr. John Gagnon, and Ms. Gail Maiangowi, who provided input on this paper. Cancer Care Ontario's Aboriginal Cancer Care Unit is also acknowledged for the development of principles and strategies for both research and cancer care.

## Endnotes

- 1 The authors acknowledge that the word “Aboriginal” has limitations. It is used here to refer to all of Canada’s Indigenous peoples, including on-reserve and off-reserve peoples, plus Inuit and Métis.
- 2 It is important to note that each study is unique; there are differences in the extent to which all elements of the guidelines *can* be applied, which is related to the type of study and community. For example, some communities may choose not to be involved in the level of detail implied by the full set of guidelines, or may find some topics or results (e.g., quantitative and anthropometric measures) to be less relevant to the community.

## References

- Bartlett, J.G., Y. Iwasaki, B. Gottlieb, D. Hall, and R. Mannell. 2007. “Framework for Aboriginal-guided decolonizing research involving Metis and First Nations persons with diabetes.” In *Social Science & Medicine* (1982) 65, (11) (Dec): 2371–82.
- Barton, S.S., N. Anderson, and H.V. Thommasen. 2005. “The diabetes experiences of Aboriginal people living in a rural Canadian community.” In *The Australian Journal of Rural Health* 13, (4) (Aug): 242–6.
- Bird, S.M., J.L. Wiles, L. Okalik, J. Kilabuk, and G.M. Egeland. 2008. “Living with diabetes on Baffin Island: Inuit storytellers share their experiences.” In *Canadian Journal of Public Health* 99, (1) (Jan-Feb): 17–21.
- Bisset, S., M. Cargo, T. Delormier, A.C. Macaulay, and L. Potvin. 2004. “Legitimizing diabetes as a community health issue: A case analysis of an aboriginal community in Canada.” In *Health Promotion International* 19, (3) (Sep): 317–26.
- Buxton, J.A., V. Ouellette, A. Brazier, C. Whiteside, R. Mathias, M. Dawar, and A. Mulkins. 2007. “Bridging the gap in population health for rural and Aboriginal communities: A needs assessment of public health training for rural primary care physicians.” In *Canadian Journal of Rural Medicine* 12, (2): 81–8.
- Canadian Institutes of Health Research. 2007. *CIHR guidelines for health research involving Aboriginal people*. Ottawa: Government of Canada .
- Caron, N.R. 2005. “Getting to the root of trauma in Canada’s Aboriginal population.” In *CMAJ : Canadian Medical Association Journal* 172, (8) (Apr 12): 1023-4.
- Castellano, M.B. 2004. “Ethics of Aboriginal research.” In *Journal of Aboriginal Health* January, (January 2004): 98.
- Charbonneau-Roberts, G., T.K. Young, and G.M. Egeland. 2007. “Inuit anthropometry and insulin resistance.” In *International Journal of Circumpolar Health* 66, (2) (Apr): 129–34.
- Chen, Y. 2009. *Cancer incidence in Fort Chipewyan, Alberta: 1995–2006*. Division of Population Health and Information Surveillance: Alberta Cancer Board.
- Christofides, A., C. Schauer, and S.H. Zlotkin. 2005. “Iron deficiency and anemia prevalence and associated etiologic risk factors in First Nations and Inuit communities in Northern Ontario and Nunavut.” In *Canadian Journal of Public Health* 96, (4) (Jul-Aug): 304–7.
- Cook, S.J. 2005. “Use of traditional Mi’kmaq medicine among patients at a First Nations community health centre.” In *Canadian Journal of Rural Medicine* 10, (2) (Spring): 95–9.
- Crosato, K.E., C. Ward-Griffin, and B. Liepert. 2007. “Aboriginal women caregivers of the elderly in geographically isolated communities.” In *Rural and Remote Health* 7, (Online): 1–12.
- Daniel, M., M.D. Cargo, J. Lifshay, and L.W. Green. 2004. “Cigarette smoking, mental health and social support: Data from a northwestern First Nation.” In *Canadian Journal of Public Health* 95, (1) (Jan-Feb): 45–9.
- Egeland, G.M., D. Denomme, P. Lejeune, and D. Pereg. 2008. “Concurrent validity of the International Physical Activity Questionnaire (IPAQ) in an Liyiyiu Aschii (Cree) community.” In *Canadian Journal of Public Health* 99, (4) (Jul-Aug): 307–10.
- First Nations Centre. 2007. *OCAP: Ownership, Control, Access and Possession. First Nations Information Governance Committee, Assembly of First Nations*. Ottawa: National Aboriginal Health Organization.

- Gallo, M., L.M. Schell, and Akwesasne Task Force on the Environment. 2007. "Selected anthropometric measurements of Akwesasne Mohawk youth: Skinfold, circumferences, and breadths." In *American Journal of Human Biology* 19: 525–36.
- George, M.A., P. Masotti, S. MacLeod, M. Van Bibber, C. Loock, M. Fleming, T. McDiarmid, et al. 2007. "Bridging the research gap: Aboriginal and academic collaboration in FASD prevention. The healthy communities, mothers and children project." In *Alaska Medicine* 49, (2 Suppl): 139–41.
- Hamilton, S., J. Martin, M. Guyot, M. Trifonopoulos, A. Caughey, and H.M. Chan. 2004. "Healthy living in Nunavut: An on-line nutrition course for Inuit communities in the Canadian arctic." In *International Journal of Circumpolar Health* 63, (3) (Sep): 243–50.
- Health Canada. 2003. *Arthritis in Canada. An ongoing challenge*. Ottawa: Health Canada.
- . 2006. Diseases and Health Conditions. *First Nations and Inuit Health*.
- Hotson, K.E., S.M. Macdonald, and B.D. Martin. 2004. "Understanding death and dying in select First Nations communities in Northern Manitoba: Issues of culture and remote service delivery in palliative care." In *International Journal of Circumpolar Health* 63, (1) (Mar): 25–38.
- Iwasaki, Y., J. Bartlett, and J. O'Neil. 2004. "An examination of stress among Aboriginal women and men with diabetes in Manitoba, Canada." In *Ethnicity & Health* 9, (2) (May): 189–212.
- Kaler, S.N., K. Ralph-Campbell, S. Pohar, M. King, C.R. Laboucan, and E.L. Toth. 2006. "High rates of the metabolic syndrome in a First Nations community in Western Canada: Prevalence and determinants in adults and children." In *International Journal of Circumpolar Health* 65, (5) (Dec): 389–402.
- Kenny, C. 2004. *A holistic framework for Aboriginal policy research*.
- King, K.M., J. Sanguins, L. McGregor, and P. LeBlanc. 2007. "First Nations people's challenge in managing coronary artery disease risk." In *Qualitative Health Research* 17, (8) (Oct): 1074–87.
- Kovesi, T., N.L. Gilbert, C. Stocco, D. Fugler, R.E. Dales, M. Guay, and J.D. Miller. 2007. "Indoor air quality and the risk of lower respiratory tract infections in young Canadian Inuit children." In *CMAJ: Canadian Medical Association Journal* 177, (2) (Jul 17): 155–60.
- Kuhnlein, H.V., O. Receveur, R. Soueida, and G.M. Egeland. 2004. "Arctic Indigenous Peoples experience the nutrition transition with changing dietary patterns and obesity." In *The Journal of Nutrition* 134, (6) (Jun): 1447–53.
- Leslie, W.D., C.J. Metge, H.A. Weiler, M. Doupe, P. Wood Stiemann, and J.D. O'Neil. 2006. "Bone density and bone area in Canadian Aboriginal women: The First Nations bone health study." In *Osteoporosis International* 17: 1755–62.
- Levin, R., and M. Herbert. 2004. "The experience of urban Aboriginals with health care services in Canada: Implications for social work practice." In *Social Work in Health Care* 39, (1/2): 165–79.
- Lightfoot, N., R. Strasser, M. Maar, and K. Jacklin. 2008. "Challenges and rewards of health research in Northern, Rural, and Remote Communities." In *Annals of Epidemiology* 18, (6) (Jun): 507–14.
- Loppie, C. 2007. "Learning from the grandmothers: Incorporating indigenous principles into qualitative research." In *Qualitative Health Research* 17, (2): 276–84.
- Maar, A.M., M. Sutherland, and L. McGregor. 2007. "A regional model for ethical engagement: The First Nations Research Ethics Committee on Manitoulin Island." In *Aboriginal Policy Research Volume IV: Moving Forward, Making a Difference*. Toronto: Thompson Educational Publishing.
- Maar, M., N. Lightfoot, M. Sutherland, R. Strasser, and K. Wilson. 2009. *Research priorities and research strategies for collaborative Aboriginal Cancer Study. Results of the 'Go to the People' Consultations*. Toronto: Cancer Care Ontario.
- Macnab, A., R. Rassekh, Y. Hon Lai, D. Benton, D. Duffy, F. Gagnon, and R. Harrison. 2005. "Development of a symbiotic relationship with a remote First Nations community leading to a collaborative school-based oral health program." In *The IHS Provider* (September 2005).
- Macnab, A.J., J. Rozmus, D. Benton, and F.A. Gagnon. 2008. "3-year results of a collaborative school-based oral health program in a remote First Nations community." In *Rural and Remote Health* 8, (2) (Apr-Jun): 882.
- Marret, L., C.R. Jones, and K. Wishart. 2004. *First Nations Cancer Research and Surveillance priorities for Canada. Workshop Report, September 23–24*. Cancer Care Ontario.
- Masotti, P., M.A. George, K. Szala-Meneok, A.M. Morton, C. Loock, M. Van Bibber, J. Ranford, M. Fleming, and S. MacLeod. 2006. "Preventing Fetal Alcohol Spectrum Disorder in Aboriginal communities: A methods development project." In *PLoS Medicine* 3, (1) (Jan): e8.

- Minore, B., M. Boone, M. Katt, P. Kinch, and S. Birch. 2004. "Addressing the realities of health care in Northern Aboriginal Communities through Participatory Action Research." In *Journal of Interprofessional Care* 18, (4) (Nov): 360–8.
- Nakano, T., K. Fediuk, N. Kassi, G.M. Egeland, and H.V. Kuhnlein. 2005. "Dietary nutrients and anthropometry of Dene/Metis and Yukon children." In *International Journal of Circumpolar Health* 64, (2) (Apr): 147–56.
- Nakano, T., K. Fediuk, N. Kassi, and H.V. Kuhnlein. 2005. "Food use of Dene/Metis and Yukon children." In *International Journal of Circumpolar Health* 64, (2) (Apr): 137–46.
- National Aboriginal Health Organization. 2003. *Ethics tool kit*. Ottawa: NAHO.
- Panagiotopoulos, C., J. Rozmus, R.E. Gagnon, and A.J. Macnab. 2007. "Diabetes screening of children in a remote First Nations Community on the West Coast of Canada: Challenges and solutions." In *Rural and Remote Health* 7, (3) (Jul-Sep): 771.
- Peressini, S., J.L. Leake, J.T. Mayhall, M. Maar, and R. Trudeau. 2004. "Prevalence of dental caries among 7- and 13-year-old First Nations children, District of Nanitoulin, Ontario." In *Journal of the Canadian Dental Association* 70, (6): 382–382e.
- Peressini, S., J.L. Leake, J.T. Mayhall, M. Maar, and R. Trudeau. 2004. "Prevalence of early childhood caries among First Nations children, District of Manitoulin, Ontario." In *International Journal of Paediatric Dentistry / the British Paedodontic Society [and] the International Association of Dentistry for Children* 14, (2) (Mar): 101–10.
- Pollex, R.L., A.J. Hanley, B. Zinman, S.B. Harris, and R.A. Hegele. 2006. "Clinical and genetic associations with hypertriglyceridemic waist in a Canadian Aboriginal Population." In *International Journal of Obesity* 30, (3) (Mar): 484–91.
- Pollex, R.L., A.J. Hanley, B. Zinman, S.B. Harris, H.M. Khan, and R.A. Hegele. 2006. "Metabolic syndrome in Aboriginal Canadians: Prevalence and genetic associations." In *Atherosclerosis* 184, (1) (Jan): 121–9.
- Pylypchuk, G., L. Vincent, J. Wentworth, A. Kiss, N. Perkins, S. Hartman, L. Ironstand, J. Hoppe, and S.W. Tobe. 2008. "Diabetes Risk Evaluation And Microalbuminuria (DREAM) studies: Ten years of participatory research with a First Nation's home and community model for type 2 Diabetes care in Northern Saskatchewan." In *International Journal of Circumpolar Health* 67, (2–3) (Jun): 190–202.
- Reading, J., A.J. Ritchie, J.C. Victor, and E. Wilson. 2005. "Implementing empowering Health Promotion Programmes for aboriginal youth in two Distinct communities in British Columbia, Canada." In *Promotion & Education* 12, (2): 62–5.
- Receveur, O., K. Morou, K. Gray-Donald, and A.C. Macaulay. 2008. "Consumption of key food items is associated with excess weight among elementary-school-aged children in a Canadian First Nations community." In *Journal of the American Dietetic Association* 108, (2) (Feb): 362–6.
- Richmond, C.A.M. 2007. "Narratives of social support and health in Aboriginal communities." In *Canadian Journal of Public Health* 98, (4) (July-August): 347–51.
- Rosecrans, A.M., J. Gittelsohn, L.S. Ho, S.B. Harris, M. Naqshbandi, and S. Sharma. 2008. "Process evaluation of a multi-institutional community-based program for Diabetes prevention among First Nations." In *Health Education Research* 23, (2) (Apr): 272–86.
- Sade, R.M. 2003. "Publication of unethical research studies: The importance of informed consent." In *The Annals of Thoracic Surgery* 75, (2) (Feb): 325–8.
- Saksvig, B.I., J. Gittelsohn, S.B. Harris, A.J.G. Hanley, T.W. Valente, and B. Zinman. 2005. "A pilot school-based healthy eating and physical activity intervention improves diet, food knowledge, and self-efficacy for Native Canadian Children." In *The Journal of Nutrition* 135, (July): 2392–8.
- Schnarch, B. 2004. "Ownership, Control, Access and Possession (OCAP) or self-determination applied to research: A critical analysis of contemporary First Nations research and some options for First Nations communities." In *Journal of Aboriginal Health* (January): 80–95.
- Sharma, S., X. Cao, J. Gittelsohn, L.S. Ho, E. Ford, A. Rosecrans, S. Harris, A.J. Hanley, and B. Zinman. 2008. "Dietary intake and development of a quantitative food-frequency questionnaire for a lifestyle intervention to reduce the risk of chronic diseases in Canadian First Nations in North-western Ontario." In *Public Health Nutrition* 11, (8) (Aug): 831–40.
- Sin, D.D., H.M. Sharpe, R.L. Cowie, S.F. Man, and Alberta Strategy to Help Manage Asthma Executive Committee. 2004. "Spirometric findings among school-aged First Nations children on a reserve: A pilot study." In *Canadian Respiratory Journal: Journal of the Canadian Thoracic Society* 11, (1) (Jan-Feb): 45–8.

- Skinner, K., R.M. Hanning, and L.J. Tsuji. 2006. "Barriers and supports for healthy eating and physical activity for First Nation youths in Northern Canada." In *International Journal of Circumpolar Health* 65, (2) (Apr): 148-61.
- Smith, D., N. Edwards, C. Varcoe, P.J. Martens, and B. Davies. 2006. "Bringing safety and responsiveness into the forefront of care for pregnant and parenting Aboriginal people." In *ANS. Advances in Nursing Science* 29, (2) (Apr-Jun): E27-44.
- Smylie, J., N. Kaplan-Myrth, C. Tait, C.M. Martin, L. Chartrand, W. Hogg, P. Tugwell, G. Valaskakis, and A.C. Macaulay. 2004. "Health sciences research and Aboriginal communities: Pathway or pitfall?" In *Journal of Obstetrics and Gynaecology Canada*, (3) (Mar): 211-6.
- Stone, R.A., L.B. Whitbeck, X. Chen, K. Johnson, and D. M. Olson. 2006. "Traditional practices, traditional spirituality, and alcohol cessation among American Indians." In *Journal of Studies on Alcohol* 67, (2) (Mar): 236-44.
- Taylor, J.P., V. Timmons, R. Larsen, F. Walton, J. Bryanton, K. Critchley, and M.J. McCarthy. 2007. "Nutritional concerns in Aboriginal children are similar to those in non-Aboriginal children in Prince Edward Island, Canada." In *Journal of the American Dietetic Association* 107, (6) (Jun): 951-5.
- Thommasen, H.V., J. Berkowitz, A.T. Thommasen, and A.C. Michalos. 2005. "Understanding relationships between diabetes mellitus and health-related quality of life in a rural community." In *Rural and Remote Health* 5, (3) (Jul-Sep): 441.
- Thommasen, H.V., N. Hanlon, C. Thommasen, and W. Zhang. 2006. "Alcohol drinking habits and community perspectives on alcohol abuse in the Bella Coola Valley." In *Canadian Journal of Rural Medicine : The Official Journal of the Society of Rural Physicians of Canada*, 11, (1) (Winter): 15-22.
- Thommasen, H.V., and W. Zhang. 2006. "Impact of chronic disease on quality of life in the Bella Coola valley." In *Rural and Remote Health* 6, (2) (Apr-Jun): 528.
- Tobe, S.W., G. Pylpynchuk, J. Wentworth, A. Kiss, J.P. Szalai, N. Perkins, S. Hartman, L. Ironstand, and J. Hoppe. 2006. "Effect of nurse-directed hypertension treatment among First Nations people with existing hypertension and Diabetes mellitus: The Diabetes Risk Evaluation And Microalbuminuria (DREAM 3) randomized controlled trial." In *Canadian Medical Association Journal* 174, (9) (April 4).
- Valera, B., E. Dewailly, and P. Poirier. 2008. "Cardiac autonomic activity and blood pressure among Nunavik Inuit adults exposed to environmental mercury: A cross-sectional study." In *Environmental Health: A Global Access Science Source* 7, (Jun 6): 29.
- Virani, S., D. Strong, M. Tennant, M. Greve, H. Young, S. Shade, M. Kanji, E. Toth, and Implementation Committee of the Aboriginal Diabetes Initiative. 2006. "Rationale and implementation of the SLICK project: Screening for Limb, I-eye, Cardiovascular and Kidney (SLICK) complications in individuals with type 2 Diabetes in Alberta's First Nations communities." In *Canadian Journal of Public Health* 97, (3) (May-Jun): 241-7.
- Wardman, D., D. Quantz, J. Tootoosis, and N. Khan. 2007. "Tobacco cessation drug therapy among Canada's Aboriginal People." In *Nicotine & Tobacco Research* 9, (5) (May): 607-11.
- Wardman, D., K. Clement, and D. Quantz. 2005. "Access and utilization of health services by British Columbia's Rural Aboriginal Population." In *International Journal of Health Care Quality Assurance Incorporating Leadership in Health Services* 18, (2-3): xxvi-xi.
- Wardman, D., D. Quantz, and K. Clement. 2006. "HIV/AIDS: Testing and risk behaviors among British Columbia's Rural Aboriginal Population." In *International Journal of Circumpolar Health* 65, (4) (Sep): 313-21.
- Women's Health Centre of Excellence. 2005. *A Winnipeg Workshop with Kim Anderson: Community based research and Aboriginal Women's Health and Healing*. 133.