

# Development of an integrated diabetes prevention program with First Nations in Canada

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## SUMMARY

*Type 2 diabetes mellitus is a major cause of morbidity and mortality among First Nations in Canada. We used multiple research methods to develop an integrated multi-institutional diabetes prevention program based on the successful Sandy Lake Health and Diabetes Project and Apache Healthy Stores programs. In-depth interviews, a structured survey, demonstration and feedback sessions, group activities, and meetings with key stakeholders were used to generate knowledge about the needs and resources for each community, and to obtain feedback on SLHDP interventions. First Nations communities were eager to address the increasing epidemic of diabetes. Educating*

*children through a school prevention program was the most popular proposed intervention. Remote communities had poorer access to healthy foods and more on-reserve media and services than the smaller semi-remote reserves. While the reserves shared similar risk factors for diabetes, variations in health beliefs and attitudes and environmental conditions required tailoring of programs to each reserve. In addition, it was necessary to balance community input with proven health promotion strategies. This study demonstrates the importance of formative research in developing integrated health promotion programs for multiple communities based on previously evaluated studies.*

*Key words:* diabetes; formative research; Native American

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## INTRODUCTION

Diabetes is a serious health problem in aboriginal populations (Young *et al.*, 2000). In Canada, the prevalence of diabetes is 3–5 times higher than that in the general Canadian population (Harris *et al.*, 1997; Young *et al.*, 2000). Studies of Native Americans and First Nations with diabetes have shown high rates of cardiovascular disease (National Steering Committee for the First Nations and Inuit Regional Health Survey, 1999), renal failure (Dyck and Tan, 1994; Narva, 2002) and retinopathy (Ross and Fick, 1991). Unfortunately, effective and widespread primary prevention programs are still lacking (Young *et al.*, 2000).

A number of studies have demonstrated the feasibility of implementing diabetes prevention programs in Native American communities, but

with mixed results and little expansion (Teufel and Ritenbaugh, 1998; Daniel *et al.*, 1999; Heffernan *et al.*, 1999; Himes *et al.*, 2003; Macaulay *et al.*, 2003). However, these studies leave many unanswered questions in how to scale up including how to ensure sufficient tailoring and community involvement when working with multiple sites, how to expand programs to intervene at multiple levels within communities and how to increase sustainability.

The failure of many community-based intervention trials to show significant impacts has been attributed in part to limitations of the interventions and theories used, and insufficient formative research (Merzel and D'Afflitti, 2003). Formative research is an important step in developing effective tailored interventions and evaluation instruments for targeted populations (Hohmann and Shear, 2002; Gittelsohn *et al.*, 2003). Some

interventions have not sufficiently targeted communities or risk groups within communities and multiple levels of intervention while others have not adequately incorporated local concepts and values into intervention (Daniel *et al.*, 1999). Another pitfall is that community-directed programs may select untested or less effective interventions resulting in the lack of significant behavioral changes (Daniel and Green, 1999; Daniel *et al.*, 1999).

This paper describes the process and results of formative research for a feasibility study to pilot a multi-institutional community-based diabetes prevention program in multiple First Nations communities in northwest Ontario, based on prior work with the Sandy Lake First Nation. The aims of the formative research were to (1) explore the needs and perceptions of community members surrounding health and diabetes; (2) assess the feasibility of adapting programs from Sandy Lake; and (3) engage the community in the development of an integrated intervention program through participatory activities.

### **The Sandy Lake Health and Diabetes Project (SLHDP)**

The SLHDP used extensive formative research and collaboration with the community to develop successful prevention programs. The partnership was conceived in 1991 when the Sandy Lake First Nation sought assistance from researchers in addressing their diabetes epidemic. Investigators and community leaders met regularly to plan all aspects of the project (Macaulay *et al.*, 2003).

The original goals of the project were to determine the prevalence and risk factors for diabetes in order to prevent it and its complications. Extensive formative research was conducted to explore the sociocultural context and beliefs that affect diet and physical activity (Gittelsohn *et al.*, 1996). The objective of the community programs was to prevent diabetes by improving diet and increasing physical activity. The SLHDP met these goals through a survey of risk factors, community-wide screening for diabetes, and a community-based diabetes prevention program that included a weekly radio show, community events, and school, food store and home visit programs (Macaulay *et al.*, 2003; Saksvig *et al.*, 2005).

The initial survey and screening helped determine the areas on which to focus prevention activities (Harris *et al.*, 1997; Wolever *et al.*, 1997; Gittelsohn *et al.*, 1998; Hegele *et al.*,

1999). Based on survey findings and additional formative research, the community diabetes program was developed. The Sandy Lake School Diabetes Prevention Program demonstrated increases in dietary knowledge, self-efficacy and intention, and decreases in television watching associated with the program as well as decreases in dietary fat and increases in dietary fiber intake (Saksvig *et al.*, 2005). The local Northern grocery store cooperated in a program to identify and increase the sales of foods that were low in sugar, low in fat and high in fiber using shelf labels. Results showed positive trends in the sales of soda, diet soda, butter, lard, milk and canned meat (SLHDP, unpublished data). A home visit program brought individualized teaching on nutrition, health and physical activity to interested families but did not result in significant changes in behavior (SLHDP, unpublished data). In addition, the SLHDP broadcasted a weekly radio show on topics related to diabetes. These programs were developed in response to emerging community needs and did not always run concurrently.

### **Scaling up and integrating community-based diabetes prevention activities**

Although the SLHDP interventions showed some impact, they were not integrated, and targeted only one community (Macaulay *et al.*, 2003; Saksvig *et al.*, 2005). Merzel and D'Afflitti emphasize the importance of a comprehensive ecological model for intervention and sufficient reach into targeted populations (Merzel and D'Afflitti, 2003). Integration of multiple intervention strategies can help ensure that there is adequate tailoring and reach of programs while addressing both individual and environmental change. Therefore, the next step was to see if the SLHDP programs could be scaled up to other First Nations reserves in the region with integrated delivery rather than as a series of separate programs.

While reserves in Northwest Ontario share many characteristics, each is unique. Among the over 60 First Nations in the area, at least three different languages are spoken (Cree, Oji-Cree and Ojibwe). On reserve populations range from ~60 to over 2000. Attitudes and beliefs toward health as well as access to resources also vary between reserves. Some reserves have their own schools, while others send their children to public schools in non-Native communities. On reserves

there are both chain stores and locally owned stores. Health infrastructure also varies as well between larger and smaller reserves, remote and semi-remote reserves. These variations need to be considered when developing a community-based program for multiple reserves.

## METHODS

### Study setting

All three communities are located in Northwest Ontario (Table 1). In the semi-remote area where there are several small reserves (Communities A and B), most health-related services have been transferred to the local Tribal Health Authority or directly to the bands. Owing to the small size of the bands, per capita funding is sometimes consolidated by the Health Authority and delivered to the reserves from the central Health Access Centre located in a nearby town.

In contrast, the large population and remoteness of Community C resembles Sandy Lake, where there are on-reserve staff for many health programs. A community physician comes to the reserve for a week every month.

All reserves also have traditional healers who conduct ceremonies or make traditional medicines. In all communities the schools had obtained independent funding for supplemental nutrition programs although none of the schools

had formal health curricula, and only the on-reserve school had a physical education teacher.

Communities were selected from those that responded to invitations to participate. Our sampling goals were to include both semi-remote and remote communities that expressed interest in participating in the study.

### Procedures

Our study employed qualitative and quantitative methods, drawn from both participatory research and ethnography (Table 2). This blend allowed in-depth investigation with direction from community members. We conducted in-depth interviews, group activities, demonstrations, observations and discussions with participants. During in-depth interviews, participants were asked about community history, activities, causes of diabetes, ways to manage diabetes, resources for health care and education, foods, community issues, and recommendations.

A structured survey adapted from the SLHDP with input from local research assistants asked randomly selected adult band members about sociodemographics, health history, food preparation and consumption, physical activity, and preferences for intervention methods. Twenty-eight (93%), 19 (73%) and 25 (63%) of the selected respondents from Communities A, B and C, respectively, agreed to participate ( $n = 72$  total).

Direct observations were conducted at stores and of students at schools to note eating,

**Table 1:** Characteristics of communities

|  | Community A<br>(semi-remote) | Community B<br>(semi-remote)                  | Community C<br>(remote)                          | Sandy Lake<br>(remote)                           |
|--|------------------------------|---|--|--|
| No. of band members <sup>a</sup>                   | 336                          | 249   | 2084   | 2198   |
| Percentage of band members on reserve <sup>a</sup> | 71                           | 49  | 53   | 84   |
| Languages spoken                                   | Ojibwe, English              | Ojibwe, English                               | Ojibwe, English                                  | Oji-Cree, English                                |
| Syllabics used                                     | No                           | No  | Yes  | Yes  |
| Road access to reserve                             | Year-round                   | Year-round                                    | 6–8 weeks in winter                              | 6–8 weeks in winter                              |
| Schools serving communities                        | Public, off reserve (K-12)   | Public off reserve (K-12)                     | Independent, on reserve (K-10)                   | Independent, on reserve (K-10)                   |
| Local media  | Daily newsletter             | Twice weekly newsletter                       | Local radio, local cable access, bulletin boards | Local radio, local cable access, bulletin boards |
| Food stores on reserve                             | Convenience store            | None (reopening of convenience store pending) | Two small grocery stores, two convenience stores | One large supermarket, two convenience stores    |

<sup>a</sup>INAC (2003).

**Table 2:** Methods used to learn about diabetes and lifestyles and to pilot potential interventions

| Method  | Number conducted<br>(no. of participants) | Types of participants   |
|---|---|---|
| Interviews: semi-structured in-depth interviews   | 81 (78)                                   | Adult community members, health care providers, school and food store staff |
| Observation: informal direct  | 6   | Students in class, lunch, recess and stores                                 |
| Group sessions: included seasonal calendars, voting, social mapping, problem trees, Venn diagrams, discussion, etc. | 7 (143)                                   | Community members   |
| Demonstrations: school lessons, cooking, slide show, radio/TV call-in programs, home visit, store promotions, etc.  | 13  | Community members, school and health staff                                  |
| Survey: on risk factors and attitudes   | 72  | Randomly selected band members over 18 living on reserve                    |

purchasing and activity patterns as well as available food selection. At schools, observations were conducted during snack time, lunchtime, classes (including physical education) and recess.

The researchers planned and facilitated meetings to provide a forum for community members to discuss their health concerns and resources. We also visited existing activities such as an elders' exercise class and elders' luncheon to work with targeted groups. Group activities were used to explore issues and understand what intervention strategies would be appropriate. We conducted 3–6 group activities per reserve. On average 5–7 people participated. Women attended more frequently than men.

Piloting of potential intervention strategies included the demonstration of SLHDP interventions and other methods to groups and in public places. Impressions of group sessions were also discussed with the local research assistants and teachers who observed sessions. Group participants at the audio drama and home visit lesson sessions completed written feedback forms.

All qualitative and some quantitative data were collected by a public health faculty member and a master's of health science student/registered nurse. Local Ojibwe-speaking research assistants were trained to carry out the survey and organize activities. A few elders preferred to conduct interviews or surveys in Ojibwe rather than English.

Written consent was obtained from all respondents. The study was approved by the Ethics Review Board of the University of Western Ontario and the Committee on Human Research

of the Johns Hopkins Bloomberg School of Public Health.

#### Data management and analysis

In-depth interviews (IDIs), group activities and observations were taped or recorded in notebooks, transcribed and coded for different topics using N5 (QSR International, 2000). All but four IDIs were conducted in English. The four IDIs in Ojibwe were conducted through a translator and transcribed in English. Member checking was used to direct further activities and confirm or refine ongoing content analysis. Quantitative analysis was performed using the Statistical Package for Social Sciences (SPSSPC, 1995) and Stata (2002).

## RESULTS

### Changing concepts of diet and disease

While each community emphasized different concerns, all perceived an increase in illnesses in recent years:

During the time that I remember, my childhood, there was very little, almost no sickness...[youth and children] are probably going to experience much more of these problems, an increase in illness or disease that develop from our adopting a different diet.

Increases in chronic illnesses were often attributed to decreased activity, decreased intake of traditional foods, increased intake of fried or processed foods, and increased emotional stress from

communal living and breakdown of traditional family structures that had occurred in the past 50 years. Diabetes was noted to be affecting more Native people at a younger age. In the words of one community health representative,

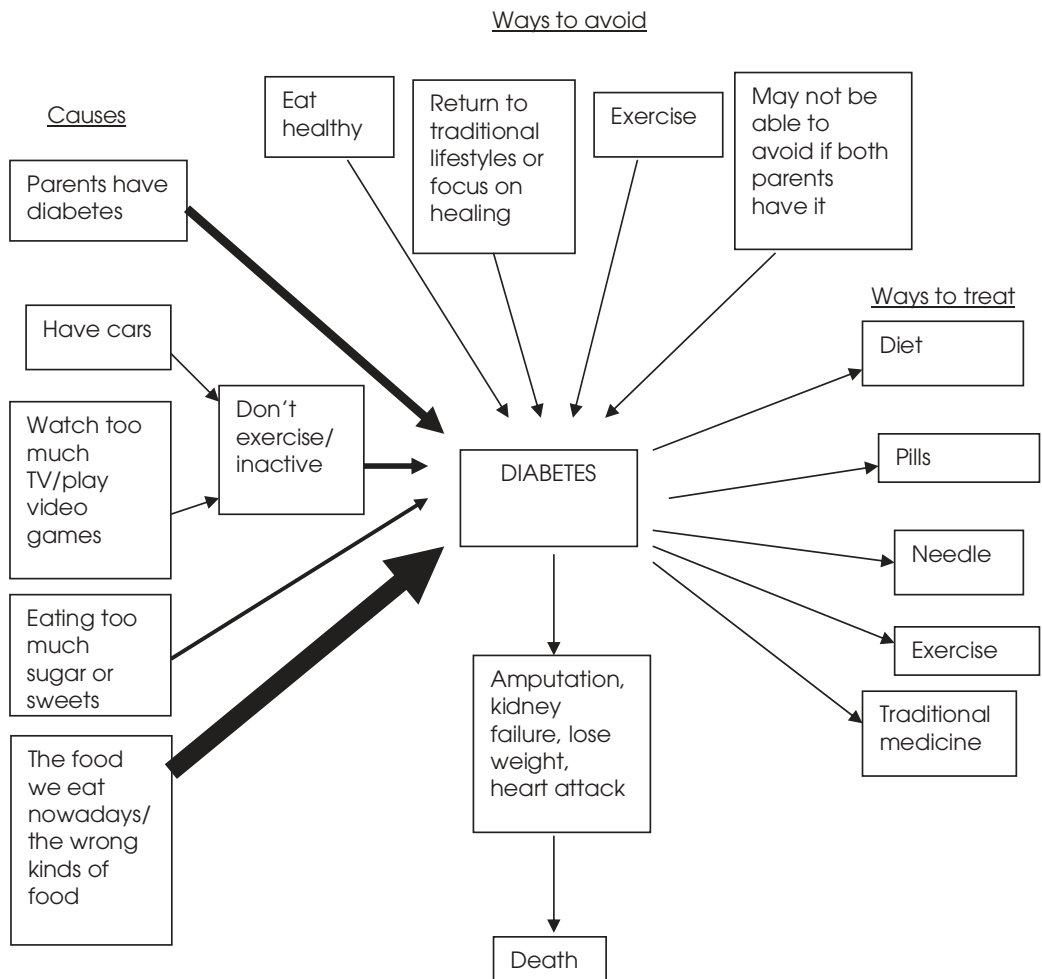
‘... when I first started off [over 20 years ago] we didn’t have very many people with diabetes. It was mainly our elders that ... had this diabetes. But now ... it’s getting younger and younger.’

The changing diet is part of the issue for these communities. Survey respondents reported frequent intake of high fat, high sugar and low fiber foods. Many elders noted the shift from

traditional to store bought foods and possible negative effects:

Nowadays a lot of the stuff that we buy from the local store, especially the meat, we don’t know how long ago, it was processed, or packaged ... A lot of times [that] could be one of the things that could make you sick. And [it] could be also, a result of why today people get diabetes.

Some pointed out that wild foods were traditionally boiled or roasted rather than fried, as is common today. Many teachers and parents also commented on children’s frequent consumption of pop, chips and candy. On semi-remote reserves



**Fig. 1:** Ethnomedical model of diabetes for three First Nations reserves. Thickness of lines represents relative strength of association.

parents were concerned that students attending high school in town were eating fast food on a daily basis.

When asked about physical activity and diet, people expressed concern over children spending too much time watching television and eating too much 'junk food'. Excessive consumption of sugar was associated with diabetes. The most commonly suggested causes of diabetes were not eating the right foods or eating too many sweets or junk foods (Figure 1).

Community A had the greatest concern surrounding obesity and the lack of physical activity although they did not always identify a connection between these issues and diabetes. On all reserves people complained about the lack of safe walking or exercise areas due to various concerns such as dusty roads, cars, unleashed dogs and lack of equipment.

Women were usually more interested than men in learning about health issues, issues concerning children, nutrition and healthy foods. Men and elders seemed to note more often the decline in their own level of physical activity. A group of women suggested that this might be because many women still spent considerable time doing housework and walking places while men used vehicles more and participated in sports less often nowadays. Men seemed more interested in issues such as housing, economic development and healing, than in how to eat healthy or manage an illness. Both were in agreement about the need to provide resources to children and to increase parental involvement.

### **Changing concepts of healing and treatment**

Elders noted that when they were young it was only with minor illnesses that were treated with traditional medicines from the bush. An older respondent recalled:

... my mother used to make medicine for us when I was sick. That's why I never seen a doctor when I was little ... And that's how we survived, didn't go to the doctor. Just used Indian medicine ...

Today, going to an allopathic healthcare provider is generally the first action in seeking health care, especially in semi-remote areas where they are more easily accessible. People also seek additional information from books, magazines, pamphlets, the Internet and occasionally friends or family. In addition, some people consult traditional healers.

### **Perceptions of diabetes**

Overall, 22% of survey respondents reported having diabetes. Many community members felt that diabetes was a major concern because while they knew people with diabetes, they personally knew little about the disease itself. Even people with diabetes admitted that they did not know much until they were diagnosed. As one remarked,

'I was never aware of the disease before I had it. I knew there were some people who were diabetics who were around. But I was not aware of the disease itself, until I got it.'

A person without diabetes expressed it this way: 'Everybody knows we have a problem, but what are the symptoms? ... I don't know if you can protect yourself from diabetes or if it's hereditary ...' This lack of awareness of the signs and risk factors for diabetes among First Nations contrast with a strong sense of inevitability about diabetes. Thirty-nine percent of respondents agreed with the statement, 'If my parents have diabetes, I will definitely get diabetes too.'

Despite perceptions of their own high risk, 79% of respondents agreed that diabetes can be prevented. When asked what could be done to prevent diabetes, recurring answers were to increase awareness and have more workshops. People with diabetes also stressed that educating people without diabetes would give support to people with diabetes. In particular, they felt education for family members would be useful. One respondent reported,

'So I was taught what not to eat, you know, not eat this, not eat that, stuff. So my wife never got anything like that, to be told what she should be feeding me ... I have to teach her that.'

For some people with diabetes making diet changes was the most difficult part of their illness, especially when people around them did not alter their habits:

It's the diet, what to eat, what not to eat. It's that when I am cooking for my family, that's what's hard for me. Because they're not diabetics yet, ... because, what they eat, I usually don't eat what they eat, ... And I'm the one that's cooking for them. That's what's hard.

The way diabetes education was delivered was itself a concern for some people with diabetes.

**Table 3:** Relative ranking of potential intervention strategies

| Intervention          | A+B+C<br>(n = 72) | A (n = 28)<br>Semi-remote | B (n = 19)<br>Semi-remote | C (n = 26)<br>Remote |
|-----------------------|-------------------|---------------------------|---------------------------|----------------------|
| School health program | 1                 | 1                         | 1                         | 1                    |
| Renal education       | 2                 | 2                         | 3                         | 4                    |
| Pamphlets             | 3                 | 3                         | 5                         | 3                    |
| Grocery store         | 4                 | 5                         | 2                         | 6                    |
| Home visits           | 5                 | 4                         | 3                         | 5                    |
| Radio shows           | 6                 | 6                         | 6                         | 2                    |

They reported that it was difficult to understand all the explanations they were getting about their illness. One suggested, ‘... what I’d like to see myself provided to diabetics, is a diabetic dictionary. Like what is cholesterol, what does it really mean?’ In addition, it was often difficult to explain things to older family members in Ojibwe when no translations of medical terms existed or a translator was not available.

Non-Native health providers who work with First Nations people with diabetes expressed concern with the apparent resignation or ‘denial’ that people experienced with their diagnoses. This was viewed as a major barrier to maintaining blood glucose control and preventing complications. One provider reported that many patients felt ‘doomed’ by the diagnosis. Another provider identified additional barriers as lack of time spent on primary prevention and teaching for diabetes management.

### Responses to the SLHDP interventions

Elements of SLHDP intervention components were piloted in community settings. In the survey, respondents were asked to rank potential intervention activities (Table 3). Inclusion of a school prevention program was rated as the top choice by survey participants. Teachers and students exposed to the Sandy Lake curriculum gave very positive feedback and suggestions for modifications such as more visually oriented and interactive lessons. Parents felt that education at an early age could be an effective way to prevent diabetes and appreciated that the Sandy Lake curriculum was targeted specifically toward Native populations.

Radio shows had the lowest overall relative rank, but placed second in Community C, which was the only reserve with its own radio station. A culturally appropriate audio drama on renal education with Native characters originally intended for radio broadcast was played

for groups on all reserves and was well received. In Community C, where local access cable was available, a live television show on diabetes generated calls and comments from community members. Several Community C members suggested cable television and radio as a good way to reach a wide audience.

Although a grocery store intervention did not rank highly in Community C, testing of shelf labeling and concurrent flyer and radio promotion of 1% milk at one store resulted in much interest and steady sales of the specially ordered product. A demonstration of cooking methods and tips for healthier shopping at a large supermarket in a non-Native town serving Communities A and B and other semi-remote reserves did not attract a wide audience. Home visits had a low relative rank, although a sample lesson demonstration with a group of young women in Community A garnered positive responses. In the survey, younger women tended to rank this intervention higher than men and older women.

### DISCUSSION

This study used formative research to scale up community-based diabetes prevention interventions. Previous literature reinforce the need for culturally appropriate diabetes prevention interventions that utilize community input and formative research (Daniel *et al.*, 1999; Potvin *et al.*, 2003). We determined the acceptability of many components of the SLHDP, identified key challenges and target groups. These findings are being used to develop a multi-institutional diabetes prevention program for a feasibility study with seven First Nations.

This formative work suggests multiple strategies for scaling up health interventions:

- *Change social norms by intervening in multiple institutions:* The challenges some respondents

reported in the absence of social support is consistent with other studies that have shown the importance of social support in changing physical activity and diet behavior (Sallis *et al.*, 1992; Eyster *et al.*, 1999; Thrasher *et al.*, 2004). Studies suggest that parental involvement in child-targeted health programs strengthens positive behaviors in both parents and children (Crockett *et al.*, 1989; Nader *et al.*, 1996; Borys and Lafay, 2000; Rasanen *et al.*, 2003). The limited scope of influence that individuals reported having on what children or family members ate demonstrates the need for intervention strategies that target at risk persons in multiple settings and at multiple levels so that social norms are modified to support individual changes (Merzel and D'Afflitti, 2003). It is unlikely that individually targeted interventions alone will be effective. Working with schools, stores and band administration may provide the opportunity to address environmental and policy issues such as healthy food availability.

- *Address salient concerns:* Respondents had many questions about how to prevent diabetes and eat healthy. Although it will be essential to address environmental barriers to sustain behavior change there is evidence that education may be needed to create demand for policy changes.
- *Balance community learning preferences with proven strategies:* Survey results showing a preference for a school program, culturally appropriate renal education program, and pamphlets may reflect high valuation of children, culturally specific programs and learning by observation rather than didactic approaches such as home visits were supported by qualitative data. We felt it was important to evaluate acceptability of intervention methods because of the evidence that strategies that incorporate local logic and beliefs may increase the acceptance and impact of an intervention (Daniel *et al.*, 1999). On the other hand, there is also evidence of the failure of purely informational interventions such as pamphlets in sustaining behavior change. Finding a balance between theoretically sound intervention methods and strategies that are suited to local context will be essential.
- *Emphasize active community participation:* While it has been difficult to quantify the importance of community participation on

intervention outcomes (Merzel and D'Afflitti, 2003), it is evident that active partnership with First Nation communities enhances acceptability and sustainability of programs (Daniel and Green, 1999; Macaulay *et al.*, 2003).

- *Tailor programs to individual communities:* Modifications needed would vary by community (Merzel and D'Afflitti, 2003). To elicit these differences we deliberately worked in a diverse set of study sites in order to maximize variation. We included both large and small, remote and semi-remote, and reserves from different treaty areas and tribal councils. In general, data on health concerns, diet behaviors and social changes from this study are similar to those found in Sandy Lake, especially for Community C (Gittelsohn *et al.*, 1994). Nevertheless, there was regional variation. For instance, semi-remote community members utilized cars and fast food restaurants more frequently while remote community members were more likely to engage in activities such as chopping wood and walking to the store. Unemployment and the high cost of groceries, especially fresh produce, were a complaint on all reserves, but the limitations were more extreme in Community C. These differences highlight the need for a flexible approach (Potvin *et al.*, 2003). For instance, without community radio listenership in the semi-remote reserves, a community-wide health promotion component may have to rely on newsletters, pamphlets and posters.

Based on these findings and piloting experiences, it is most likely that a combination of a school-based, store-based and community-wide health promotion programs would reach the largest audience and be the most acceptable and sustainable for similar Native communities. This approach would allow for targeting of multiple levels of intervention, integration of the theoretical framework with local cultural concepts and active involvement of different types of community members, which have been cited as important factors in the success of community-based programs with First Nations (Daniel *et al.*, 1999; Gittelsohn *et al.*, 2003; Macaulay *et al.*, 2003; Potvin *et al.*, 2003). The continued participation of these communities in a feasibility study based on this research demonstrates the success of an approach that engages community members in the scaling up process.



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