

Lessons Learned in Using Community-Based Participatory Research to Build a National Diabetes Collaborative in Canada

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Submitted 10 August 2010, revised 2 November 2010, 8 November 2010. Funding for the CIRCLE study was generously provided in the form of a Contribution Agreement from the Aboriginal Diabetes Initiative (ADI), First Nations and Inuit Health Branch (FNIHB), Health Canada. The funding bodies had no role in the content of this study or in writing this article.

Abstract

Background: Using community-based participatory research (CBPR) principles, the Canadian First Nations Diabetes Clinical Management Epidemiologic (CIRCLE) study documents the current clinical management of type 2 diabetes (T2DM) and complications in 19 partnering First Nations (FN) communities.

Objectives: To outline the lessons learned in developing and fostering community health partnerships, and demonstrate the feasibility of using CBPR in multisite research at a national level.

Methods: Investigators developed investigator–FN community partnerships from seven Canadian provinces, and research assistants were hired from each community to facilitate data collection. Research assistants randomly selected patients from each community's diabetes registry, and audited the charts of consenting patients from 2006 to 2009 for diabetes indicators in accordance with national diabetes guidelines.

Lessons Learned: Lessons learned in using CBPR on a national scale are outlined by highlighting challenges and

facilitating factors associated with (1) building collaborative relationships, (2) culture and ethics, (3) collaboration and partnership, and (4) innovative avenues of data management and dissemination. Lessons learned include the need for a flexible research agenda, clear and mutually agreed upon roles, partnership from all community levels including Elders, regional coordinators managing several sites, and wide-scale dissemination methods.

Conclusion: The CIRCLE national CBPR multisite collaborative is unprecedented in Canada, and provides a feasible model for other studies. Using CBPR on a national scale exacerbates challenges commonly faced with single-site or multisite research, but the benefits provided in developing partnerships based on mutual trust and goals makes it of great importance.

Keywords

Community-based participatory research, multisite research, First Nations, diabetes, lessons learned, health, Aboriginal

T2DM has reached epidemic proportions in the Aboriginal* population of Canada with prevalence rates 2.5 to 5.0 times higher than those in the general population.¹ Morbidity and mortality rates associated with T2DM are also higher owing to an elevated burden of diabetes-related complications.² The rising incidence and prevalence of

T2DM and related complications among Aboriginal peoples presents a public health care crisis that will severely strain health care services in Canada.^{3,4} Corresponding with the heavy burden on the health care system is the high physical, financial, and emotional toll experienced by the individuals, families, and communities living with diabetes.

* Aboriginal is defined as First Nations, Inuit, and Métis.

CBPR is the accepted approach for working with Aboriginal communities, where a history of adverse experiences with academic institutions and health service agencies has led to a climate of mistrust between communities and researchers.⁵⁻⁷ CBPR promotes collaborative partnerships that value the active engagement of communities throughout the research process, encourages sharing of knowledge and skills, and facilitates capacity building while communities hold decision-making power as key stakeholders in the outcomes of a project.⁸⁻¹¹ CBPR is well-established in diabetes research with a limited number of Canadian FN communities, but has only been incorporated to varying degrees and with varying success in multisite research, and has never been used in a national study.¹²⁻¹⁹ The CIRCLE study was designed to provide a comprehensive understanding of the current clinical management and complications of T2DM in FN communities, while providing communities with their own data. With funding and policy partners from the Aboriginal Diabetes Initiative (ADI) at Health Canada,[†] CIRCLE built a national network partnering FN communities with academic investigators and experts in the fields of diabetes, participatory research, and knowledge translation. CIRCLE is the first Canadian study to use CBPR on a national scale. By developing strategies to overcome challenges for using CBPR with multiple geographically and culturally diverse communities, CIRCLE provides a model for all multisite CBPR research.

The lessons learned in CIRCLE are outlined by highlighting the challenges and facilitating factors associated with (1) building collaborative relationships, (2) culture and ethics, (3) collaboration and partnership, and (4) innovative avenues of data management and dissemination.

CIRCLE METHODS

Research Design and Setting

Research assistants performed cross-sectional chart audits in a purposive sample of communities. We designed community recruitment to ensure representation from seven Canadian

provinces (British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, and Newfoundland and Labrador) and the three isolation levels identified by Health Canada (isolated, non-isolated, and remote-isolated/semi-isolated). Selection criteria for FN communities were a minimum population of 500 adults aged 18 years and older, Band Council[‡] approval, health care facility agreement, and an existing relationship with investigators to facilitate collaborative partnerships. Investigators contacted communities that met all inclusion criteria for consultations. Community participation was confirmed by a research agreement or participation letter. Consenting FN community members living on reserve who were 18 years or older and diagnosed with T2DM were eligible to have their medical charts audited.

Data Collection Procedures

Community health care providers developed registries in each community identifying all adults with T2DM by combining lists of patients from the nursing stations with other programs such as foot care, home care, and diabetes prevention, and verifying diagnoses in the patient's chart. Research assistants were hired from each community through job advertisements. Interview candidates were selected from the submitted applications at the discretion of the communities. The University of Western Ontario (UWO) Program Manager conducted the interviews in collaboration with the community health center staff, typically the Health Director. In some cases, only the community health center staff conducted the interviews. The UWO coordinating staff trained all hired research assistants at two sessions in either Toronto or London, Ontario. The research assistants then randomly selected patients from each community's registry and contacted them for consent before auditing charts. This process was repeated until 50 patients consented in each community. Research assistants audited charts for diabetes health care information provided from January 1, 2002, to December 31, 2007, in accordance with national diabetes guidelines.²⁰ All data were entered into a laptop database using only study

[†] Health Canada is the federal department that represents the Canadian Government's Ministry of Health. The ADI is a department within Health Canada aimed at addressing the high rates of type 2 diabetes among Aboriginal peoples in Canada through health promotion, prevention, screening and treatment activities.

[‡] Band Councils are equivalent to Tribal Councils in the United States. Band Councils are elected every 2 years and provide political leadership over all community-related events and decisions.

identification numbers. Research assistants also distributed a survey to all consenting health care providers to gather data from their perspective on challenges to providing optimal diabetes care.²⁰

Ethics Approval and Principles of Participatory Research With FN Communities

We received approval for CIRCLE from Research Ethics Boards (REBs) at UWO, the University of Toronto, Health Canada, most of the investigators’ institutional REBs, and each community’s Band Council. Following the CBPR model, communities retained ownership of their data and held joint decision-making power throughout the study.

Statistical Analysis

Univariate analysis provided descriptive statistics. Analyses incorporated adjustments, where necessary, to account for the effects of patient clustering at the community level. Statistical tests were conducted using PASW Statistics version 18.0 (SPSS, Inc., Chicago, IL).

RESULTS

Demographics

Of the 19 communities recruited, 21% were non-isolated, 32% were semi-isolated, and 47% were isolated (Table 1). On-reserve community size ranged from 613 to over 10,000 people. In two communities, fewer than the target 50 patient consents were obtained owing to small numbers of people with T2DM. A total of 885 charts were audited. The cohort was predominantly female (63.3%) with mean age at audit of 54.9 years, and mean age at T2DM diagnosis of 43.7 years.

CIRCLE Lesson Learned 1: Building Collaborative Relationships

Challenge. Following CBPR principles, we initiated CIRCLE by promoting dialogue and developing trust between all partners, working with community leadership and health care providers, and hiring research assistants from each community (Table 2).²¹ Although these aspects of CBPR have successfully been implemented in single community studies, their simultaneous application in 19 FN communities presented a unique set of challenges, which added to the study timeline and complexity.^{12–14}

Resolution and Recommendations. Building on our previous experiences with CBPR and FN, additional time was invested in the initial stages of the project, including a flexible research agenda amendable to community timelines and priorities.^{4,12,13} We spent 8 to 12 months recruiting communities before initiating data collection.

CIRCLE first recruited investigators with established FN relationships and partnerships, because appropriate time and funding were lacking to develop new partnerships with multiple communities. Honoring the FN value of face-to-face communications, investigators travelled to meet with community leaders to describe the study and request formal participation. We put much effort into informing the communities of the study through radio announcements and posters throughout the community; after obtaining approval, study brochures were made available at the community health center(s).

CBPR typically includes a community advisory board (CAB) to partner with researchers in monitoring a project.^{12,21–23} However, FN communities are unique in that they elect a Band Council every 2 years, which provides leadership in all aspects of community life. In small communities, this also includes research. In one community, the investigators partnered with the community ethics board that was mandated by the Band Council to oversee research. Partnering with FN leadership eliminated the need to develop new CABs. It also reassured communities that CIRCLE had been approved by their elected leadership as each Band Council reviewed all research materials

Study Demographic	Value
Number of charts audited	885
Age, yrs, mean (SD)	54.9 (14.2)
Female, <i>n</i> (%)	560 (63.3)
Age at diagnosis, yrs, mean (SD)	43.7 (13.5)
Duration of diabetes, yrs, mean (SD)	11.2 (7.4)
Number of community partners	19
Non-isolated communities, <i>n</i> (%)	4 (21)
Semi-isolated communities, <i>n</i> (%)	6 (32)
Isolated communities, <i>n</i> (%)	9 (47)
On-reserve community population, min (max)	613 (10,000)

and methods and provided consent and/or feedback.

Next, investigators, Band Councilors, research assistants, health care providers, ADI partners, and the coordinating center were invited to attend a 1-day startup meeting in Toronto, Ontario, to review draft study materials and initiate recommendations to ensure cultural relevance. As a result of discussions from this meeting, we revised study methods and instruments to incorporate local knowledge and better reflect community priorities, while ensuring academic rigor and policy significance (Table 3).

CIRCLE Lesson Learned 2: Culture and Ethics

Challenge. Before data collection, several community research assistants informed investigators that obtaining written consent would be challenging because of small communities with close relationships, communication barriers among participants who are not fluent in English, and negative perceptions of diabetes. In communities where diabetes holds a social stigma and where community size is small enough to allow for identification of the participant by the research assistant, the process of obtain-

Table 2. Roles and Responsibilities of Community Partners

Study Partner	Roles and Responsibilities
Band Council	<ul style="list-style-type: none"> Agreement and approval of study objectives, methods, outcomes, timelines and dissemination plans. Provides approval for community participation. Agreement on ownership of data collected and study outcomes. Assistance with administrative study tasks such as hiring of community research assistants. Open communication and input on study progress and outcomes. Participates in dissemination of study results.
Community Health Care Providers	<ul style="list-style-type: none"> Agreement to participate as partners in the study. Provides assistance to the community research assistant to perform chart audits. Provides guidance on study objectives, methods, outcomes, timelines and dissemination plans. Completes study survey (for those who provide consent) . Participates in dissemination of study results.
Community Research Assistant	<ul style="list-style-type: none"> Signs oath of confidentiality and maintains privacy of study participants when performing chart audits. Attends training session. Provides guidance on study objectives, methods, outcomes, timelines and dissemination plans. Completes data collection in the community and ensures study timelines are met. Primary contact person for study participants in the community. Participates in dissemination of study results.
Elders	<ul style="list-style-type: none"> Provides translation of study materials during informed consent process. Provides foundation of trust and comfort for study participants in the community. Assists in creating awareness of the study in the community and building relationships. Provides guidance on cultural relevance and ensures community priorities are met. Participates in dissemination of study results.

ing consent may lead to community and self-stigmatization, and may confer risks to participant confidentiality. Furthermore, asking community members for written consent may conflict with the oral traditions of FN peoples. A few research assistants also expressed discomfort in approaching community Elders, and others older than themselves, for written confirmation that they understood the consent form and study information as this can be considered disrespectful behavior.

Resolution and Recommendation. To obtain informed

consent in a culturally appropriate manner, CIRCLE employed Elders to accompany research assistants when requesting consent from community members to review their medical charts. We identified Elders through recommendations from the community research assistant or Band Council. The Elder helped in translation with patients who did not speak English and provided a foundation of trust and comfort. In addition, including Elders facilitated the process of building relationships in the community and creating awareness of CIRCLE.

Table 3. Incorporating Local Knowledge to Ensure Cultural Relevance in All First Nations Communities

Challenge	Initial Strategy	Community Input	Revised Strategy
Recruiting and obtaining consent from participants living in various geographical locations in a culturally appropriate manner	Letters of information and consent forms would be mailed to participants.	Mailings were identified as a barrier as concerns were raised about the literacy levels of some community members and the availability of a mailing service in more remote locations.	Although more costly and time consuming, door-to-door visits, posters, and radio announcements were used to reach a wide range of people who otherwise may not have heard of the study through other means. Elders helped with adapting and translating the recruitment materials and the informed consent forms.
Capacity building in the community	Hire local research assistants to gather informed consent, to conduct chart reviews, and to distribute and collect surveys.	Concerns were raised over ensuring confidentiality, particularly in smaller communities, where research assistants may know the participants they are obtaining consent from to review their medical charts.	Research assistants were hired as community health care employees and signed confidentiality agreements. Research assistants also received training on confidentiality and privacy protocols.
Chart audit procedures	Audits were to be carried out on paper forms or direct-entry into laptops.	Concerns were raised over the time needed to conduct the chart audits, the information collected and whether they would be conducted with a standard form or an electronic database, because many communities did not have access to fax machines.	To ensure the chart audits were conducted in a timely manner, the number of chart audits per community was reduced. An easy-to-use Access database with drop down menus was used to collect information.
Partnership characteristics	Research agreements with each stakeholder's roles and responsibilities were to be signed by each community.	Some communities preferred a letter of participation to the lengthy research agreements. Ownership, Control, Access, and Possession ²⁹ principles were highlighted and components of the partnership, such as ownership and decision-making power, were discussed and clarified.	All partners retain ownership of their community's data and received aggregate CIRCLE national data. Regular newsletters, teleconferences, and meetings were held to discuss and receive feedback. Joint investigator–research assistant dissemination occurred in each community.

Challenge. Some communities requested to advertise that remuneration would be given on the recruitment posters displayed in the community. Most REBs considered this to be unethical and coercive. In contrast, remuneration is viewed as a gift in respect of the time and sharing of information and is a common tradition among some FN.

Resolution and Recommendation. In communities where remuneration was requested, and once REB approval was received, we provided participants with a small gift after consent was obtained or at the dissemination meeting. Gifts included messenger bags, gift certificates to the community grocery store, T-shirts, and long distance phone cards (approximately \$30 each). When evaluating the balance of risk and benefits, REBs should recognize that remuneration should be offered when culturally appropriate.

CIRCLE Lesson Learned 3: Collaboration and Partnership

Challenge. We experienced challenges in developing strategies for recruiting and obtaining consent from participants, capacity building in the community, and chart audit procedures that reflect the local cultures of 19 distinct FN communities.

Resolution and Recommendation. Involving community partners in all aspects of research ensures that the results will be meaningful to the community, and promotes capacity building and sustainability past the end of funding. We planned CIRCLE collaboratively with research assistants to incorporate local cultures and knowledge into study materials and methods (Table 3).²¹ As each community is unique, the actions we took were not necessarily applied in all communities.

Challenge. Although the strategy of having investigators with established FN relationships facilitated community recruitment, it did not prove as successful in study implementation. The original study design relied on all investigators actively working with and problem solving in the communities they recruited—a task that was time consuming and required front-line presence. This approach was too demanding and the coordinating center at UWO had to undertake much of this work.

Resolution and Recommendation. For future projects, we recommend hiring regional coordinators responsible for several sites to work with investigators and a central coordinating center. This approach has been successful in other multisite research.²⁴ The center would not function as an advisory body, but rather as a hub to ensure standardized methods and mes-

sages are relayed to all partners.

Challenge. Building capacity in 19 geographically dispersed communities, including training community research assistants with varying degrees of diabetes and research knowledge, was particularly challenging. In addition, because many communities were small with close relationships, we sought to minimize the personal impact research assistants might experience in obtaining consent and conducting chart reviews.

Resolution and Recommendation. Capacity building was an on-going and bi-directional process, with both the communities and research team learning from one another. All research assistants attended one of two initial 3-day training sessions in either Toronto or London, Ontario. One of the co-investigators provided the research assistants with an introduction to diabetes. The UWO Program Manager provided a review of privacy, confidentiality, and protocol methods, a chart audit training manual, and audit training. We also gave research assistants a laptop computer for direct entry from charts to a database, and devoted time to briefing research assistants about the personal impact they might experience when obtaining consent and reviewing the charts of fellow community members. Given the diverse research and medical backgrounds of the research assistants, future approaches will include tiered training that may prove more efficient.

The central coordinating site continued to provide support throughout the project, with regular newsletters on study progress and regular teleconference calls wherein research assistants shared experiences, concerns, and strategies. The teleconference calls, along with the training sessions, were extremely beneficial, allowing research assistants to build relationships not only with the coordinating center but also with one another. It was not uncommon for discussions to expand to personal circumstances. A strong need for support—research, administrative, and emotional—was present throughout the study. Multisite CBPR must be amendable to such community needs.

CIRCLE Lesson Learned 4: Innovative Avenues of Data Management and Dissemination

Challenge. We encountered challenges in developing an approach for disseminating research findings to each community in a culturally appropriate manner. We were also committed to disseminating national data while ensuring that

each community's results remained confidential.

Resolution and Recommendation. In CBPR, community partners play an integral role in interpreting and disseminating research results.²¹ In CIRCLE, each community held joint decision-making power and ownership of all data collected from their own community, and all communities had access to the anonymous aggregated dataset created to provide a national snapshot of diabetes care in all CIRCLE communities.

At no time were results from one community compared with those from another. This recommendation was made in the initial stages of the study, and all the communities agreed that this was a key decision.

For each community, research assistants and investigators reviewed individualized draft diabetes report cards tailored with their results and the national aggregated data (Figure 1). We developed two versions of the draft report cards: (1)

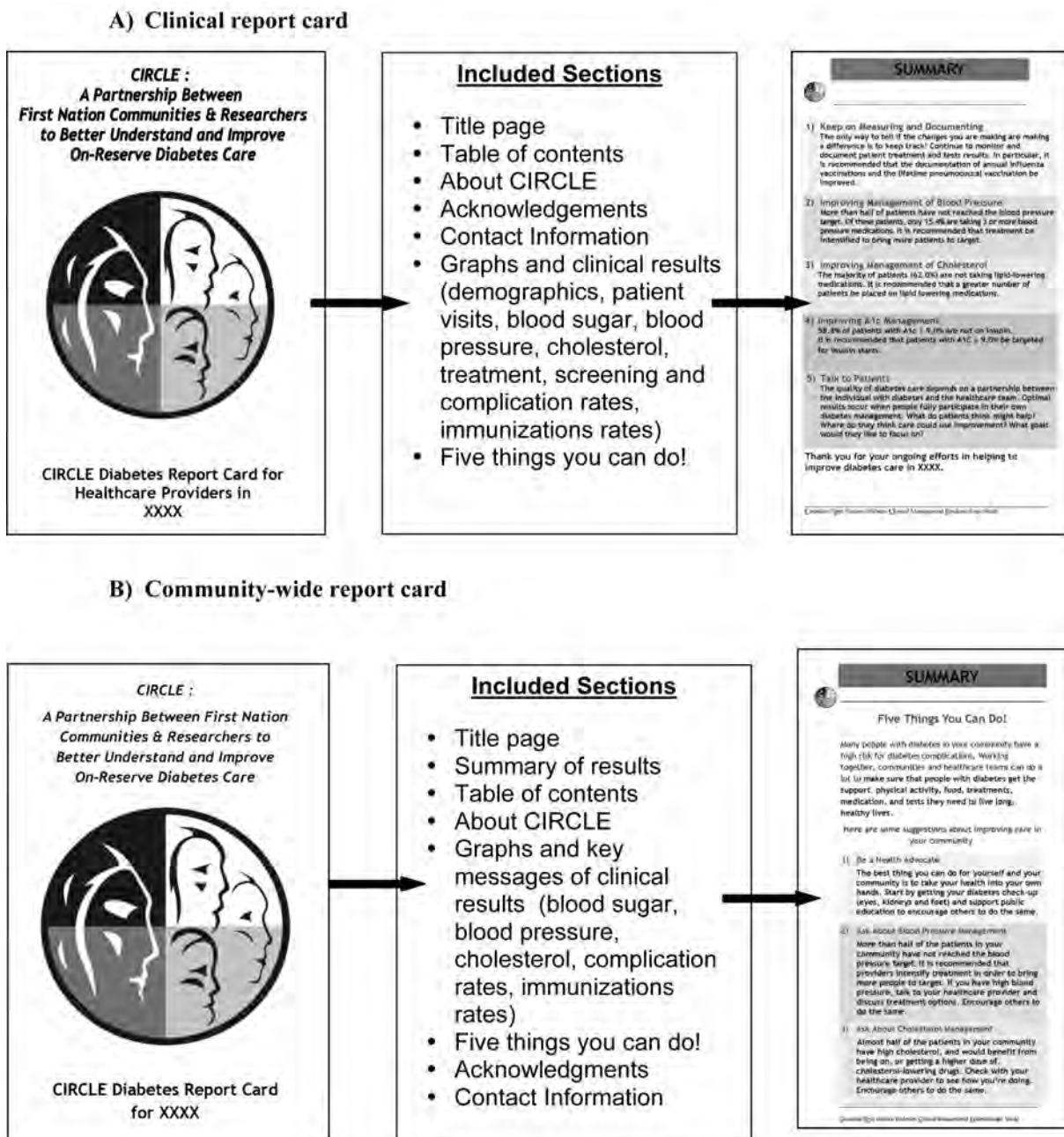


Figure 1. Example of an Individualized Community Diabetes Report Card

(A) Clinical report card. (B) Community-wide report card.

A clinical version targeted to health care providers, and (2) a community-wide version geared to community members and leaders. For communities located in Quebec or when requested, we provided report cards in both English and French.

With feedback from the communities and investigators, the final report cards were used to (1) develop posters for display in health care facilities, food stores, Band Councils and other community buildings, (2) deliver numerous interactive community presentations by investigators and research assistants, and (3) deliver interactive presentations and clinical teaching to health care providers highlighting care gaps identified by CIRCLE and recommendations for improved diabetes care.

In an effort to reach a wide audience and encourage the active involvement of community members, we developed innovative ways of sharing information. Community radio shows incorporating contests with prizes for callers providing correct answers to questions based on the community presentations were broadcast.

Challenges and Recommendations for Sustaining the CIRCLE Collaborative

Before releasing CIRCLE results to national and international audiences, the coordinating center held a 1-day wrap-up meeting to review and discuss the results with all key stakeholders including investigators, research assistants, community health care providers, Band Council members, and ADI policy advisors. Discussions centered on lessons learned and strategies for sustaining the national CIRCLE network. Community health care providers and research assistants were recognized as being invaluable for participant recruitment and community engagement, but concerns were raised over lack of funding and resources to sustain this new national network, which could offer continued expertise for future T2DM research. Lack of funding has been widely identified as undermining the progress of research networks.^{25,26} Accordingly, identifying the value and productive components of research for both participants and funding agencies is critical to achieving sustainability.

DISCUSSION

CIRCLE is the first CBPR multisite study to collaborate with 19 geographically and culturally diverse FN communities

across Canada. Our primary goals were to collect national data on current diabetes care in Canadian FN communities and to provide individual communities with their own data. Using CBPR brought key national stakeholders to the partnership, including policy makers who funded the project (ADI, Health Canada), academic investigators, FN leadership, community research assistants, and health care providers. CIRCLE is an excellent example of CBPR that promotes empowerment, co-governance, capacity building, and hopefully sustainability. The national data are essential for developing T2DM policies, and local data are critical for increasing community knowledge and designing health care quality improvement initiatives.

We encountered many challenges that are common to multisite research, such as increased costs and time, working with multiple REBs, and writing manuscripts in collaboration with multiple partners.^{18,19,25–28} We also faced a number of unique challenges and developed unique strategies to overcome them. This included incorporating 19 very diverse FN cultures, and creating an investigator–CAB team for each community where members were involved in the overall joint decision making throughout the study.

Community research assistants raised many concerns, such as ensuring both community leadership and health care providers were approached for approval to maximize community participation, the potential risk of stigmatization when obtaining consent in small communities, the cultural inappropriateness of asking for consent from Elders, and the incompatibility of remuneration policies with community traditions. Despite such challenges, the benefits of using CBPR were clear. Collaborating with community members increased cultural relevance, enhanced recruitment and participation, and proved to be efficient and effective. Furthermore, community participation in data interpretation and dissemination ensured the results were relevant to the community, the primary goal of CBPR.²⁴

In Canada, CBPR is well-established in diabetes research with a limited number of communities.^{12–16} In other multisite CBPR, one central CAB works in partnership with the researchers to oversee the data collected across multiple sites.²⁴ The SLICK project is a diabetes screening initiative that partnered one academic institution with 44 FN communities in Alberta, Canada, and was coordinated by Health Canada. Although community co-governance, joint decision making, and com-

munity dissemination were noted during the design and implementation stages of the project, this was limited to one province with one CAB.¹⁷ In contrast, CIRCLE was carried out across 3,000 miles in full collaboration with multiple FN partners (19 investigator–community partnerships), who all played an integral role in designing and implementing the study, interpreting and disseminating the data, and where the individual communities retain ownership of the data collected.

CIRCLE presents a feasible model for multisite CBPR research and offers a number of lessons learned that can be used to inform other multisite studies (Table 4):

1. A flexible research agenda is required for the lengthy process of developing strong relationships, culturally appropriate materials and data collection methods in partnership with different communities, and with ethical approval from institutional REBs and each individual community. Recruiting investigators with preexisting community relationships reduces the time and funding needed to build new partnerships.
2. Partnerships with elected FN Band Councils that provide leadership in all aspects of community life, including research, eliminated the need to develop new CABS to oversee the study, and supported the capacity building of FN leadership in diabetes research.
3. Significant funding was necessary to support several face-to-face meetings with the coordinating center, all key stakeholders, and over 20 research assistants.
4. The inclusion of Elders minimized risks and increased the cultural acceptability and awareness of the study. Offering gifts was a culturally appropriate way of thanking participants for their time. This required discussions and approval from REBs who were concerned that offering gifts would be coercive.
5. Solving day-to-day issues proved very time consuming for investigators. Including regional coordinators responsible for several sites in addition to a central coordinating center might improve the flow of communication between all partners.
6. Important data management decisions were made at the onset of CIRCLE. This included anonymous aggregated data for the overall project, anonymous data for each individual community, and agreement that no comparisons would be made between communities. We developed the individualized data in partnership with each community to ensure it would be relevant and

easily understood by community members and health professionals.

7. Results were returned to the community in many formats, including posters and interactive sessions with the research team. The results were broadcast on interactive radio shows to reach a wider audience, and included contests and prizes to encourage community members' active involvement.
8. Continued or increased support of this national team for future research and follow-up of this study would facilitate the overall goal to improve diabetes care for FN communities. Sustainability of community–investigator networks requires on-going funding.

CONCLUSION

The CIRCLE national multisite CBPR collaborative is unprecedented in Canada, and provides a viable model for other studies. We certainly hope that the CIRCLE national collaborative will be sustained and expanded to provide an expert group for future T2DM research, by developing, implementing and evaluating diabetes quality improvement programs, and always in partnership with FN communities.

ACKNOWLEDGMENTS

The authors acknowledge all the site investigators, Aboriginal communities, Band Councils, and community research assistants who participated in the CIRCLE study.

The CIRCLE Study Group

British Columbia: Site Investigator: Dr. Keith Dawson. Research Assistants: Sue Gladstone, Laurel deGoeij, Kelly Legere.

Alberta: Site Investigator: Dr. Ellen Toth. Research Assistants: Natalie White Quills, Darci Healy, Theresa Campiou, Brenda Laboucan, Pam Cooke, Daniel Wildcat.

Saskatchewan: Site Investigator: Dr. Roland Dyck. Research Assistants: Wendy McKenzie, Teresa McLeod.

Manitoba: Site Investigator: Dr. Nichole Riese. Research Assistants: George Flett, Cheyanne Harper.

Ontario: Site Investigators: Dr. Bernard Zinman, Dr. Onil Bhattacharyya, Dr. Michael Green, Dr. Anthony Hanley. Coordinating Centre: Dr. Stewart Harris, Mariam Naqshbandi, Jim Esler, Marnie Orcutt. Research Assistants: Elizabeth Estey, Peggy Sugarhead, Denise Troutlake, Linda

Nakogee, Tom McLeod, Tina McLeod, Sharon Dockstater, Vikki Tran, Laverne Fiddler, Marie-Elaine Delvin.

Quebec: Site Investigators: Dr. David Dannenbaum, Ms. Joceline Piché, Dr. Darlene Kitty, Dr. Laura MacLaren, Dr Ann

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Newfoundland and Labrador: Site Investigator: Ms. Kayla Collins. Research Assistant: Maggie Organ.

Table 4. Challenges and Facilitating Factors Associated With Implementing Multisite CBPR Research With First Nations (FN)

CBPR Component	Challenges	Facilitating Factors
Building Collaborative Relationships	Lack of time and funding to build new relationships and develop research advisory boards	<p>Incorporate extra time and a flexible research agenda.</p> <p>Recruit investigators with preexisting community relationships and with communities identifying T2DM to be a priority.</p> <p>Work with FN community leadership to oversee the research process.</p>
Culture and Ethics	<p>Obtaining informed consent in a culturally appropriate manner, while minimizing community and self-stigmatization as well as respecting the oral traditions of FN peoples</p> <p>Advertising remuneration for participation in recruitment materials when REBs did not allow it due to the possibility of coercion</p>	<p>Hire Elders to accompany research assistants when obtaining consent to provide a foundation of trust and comfort, and to help in translation with participants who are not fluent in English.</p> <p>After obtaining REB approval, participants were provided with a small gift once consent was obtained or at the dissemination meetings.</p>
Collaboration and Partnership	Time and effort required by investigators to work closely and problem solve with multiple communities	<p>Hire regional coordinators responsible for several sites working with investigators, communities and an organized central coordinating center.</p> <p>Regular and frequent teleconference calls to problem solve.</p> <p>Newsletters to update on study progress.</p>
Innovative Avenues of Data Management and Dissemination	Developing an approach to disseminating individualized research findings to 19 diverse communities and varying audiences in an appropriate, meaningful, and culturally relevant manner	<p>No comparisons made between communities.</p> <p>Joint interpretation of data by each community research team.</p> <p>Joint dissemination of diabetes results by each community research team.</p> <p>Diabetes report cards targeted to (1) health care providers, (2) community leadership, and (3) the community-at-large.</p> <p>Broadcasting the results on the interactive radio allowed for results to reach a wide audience, create interest, and encourage the active involvement of community members.</p>
Sustainability	Sustaining the national network that was created	Identifying the value and productive components of research for participants and funding agencies is critical to achieving sustainability.

Abbreviations. T2DM = type 2 diabetes mellitus; REB = Research Ethics Boards.

REFERENCES

1. National Diabetes Surveillance System. Responding to the challenge of diabetes in Canada: First report of the national diabetes surveillance system (NDSS). Ottawa, Ontario, Canada: NDSS; 2003.
2. Naqshbandi M, Harris SB, Esler JG, Antwi-Nsiah F. Global complication rates of type 2 diabetes in Indigenous peoples: A comprehensive review. *Diabetes Res Clin Pract.* 2008;82:1-17.
3. Young TK, Reading J, Elias B, O'Neil JD. Type 2 diabetes mellitus in Canada's First Nations: Status of an epidemic in progress. *CMAJ.* 2000;163:561-6.
4. Hanley AJG, Harris SB, Mamakeesick M, Goodwin K, Fiddler E, Hegele RA, et al. Complications of type 2 diabetes among Aboriginal Canadians: Increasing the understanding of prevalence and risk factors. *Canadian Journal of Diabetes.* 2003;27:455.
5. Fletcher C. Community-based participatory research relationships with Aboriginal communities in Canada: An overview of context and process. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health.* 2003;1:27-62.
6. Christopher S, Watts V, McCormick A, Young S. Building and maintaining trust in a community-based participatory research partnership. *Am J Public Health.* 2008;98:1398-406.
7. Brant-Castellano MB. Ethics of Aboriginal research. *Journal of Aboriginal Health.* 2004;98-114.
8. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: Assessing partnership approaches to improve public health. *Annu Rev Public Health.* 1998;19:173-202.
9. Fletcher F, McKennitt D, Baydala L. Community capacity building: An Aboriginal exploratory case study. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health.* 2006;5:27-60.
10. Green LW, George MA, Daniel M, Frankish CJ, Herbert CJ, Bowie WR, et al. Study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada. Ottawa: The Royal Society of Canada; 1995.
11. Macaulay AC, Commanda LE, Freeman WL, Gibson N, McCabe ML, Robbins CM, et al. Participatory research maximises community and lay involvement. *Br Med J.* 1999;319:774-8.
12. Potvin L, Cargo M, McComber AM, Delormier T, Macaulay AC. Implementing participatory intervention and research in communities: Lessons from the Kahnawake schools diabetes prevention project in Canada. *Soc Sci Med.* 2003;56:1295-305.
13. Hanley AJG, Harris SB, Barnie A, Gittelsohn J, Wolever TMS, Logan A, et al. The Sandy Lake health and diabetes project: Design, methods and lessons learned. *Chronic Dis Can.* 1995;16:149-56.
14. Heffernan CM. Diabetes and aboriginal peoples: The Haida Gwaii diabetes project in a global perspective. In Stephenson PH, Elliot SJ, Foster LT, Harris J, editors. *A persistent spirit: Towards understanding Aboriginal health in British Columbia.* Victoria, Alberta: Department of Geography, University of Victoria; 1995. p. 261-92.
15. Herbert CP. Community-based research as a tool for empowerment: The Haida Gwaii diabetes project example. *Can J Public Health.* 1996;87:109-12.
16. Kaler SS, King M, Toth EL. The BRAID study design: Believing we can reduce the Aboriginal incidence of diabetes. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health.* 2006;4:95-104.
17. Virani S, Strong D, Tennant M, Greve M, Young H, Shade S, et al. 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. *Canadian Journal of Public Health.* 2006;97:241-7.
18. Macaulay AC, Nutting PA. Moving the frontiers forward: Incorporating community-based participatory research into practice-based research networks. *Ann Fam Med.* 2006;4:4-7.
19. Westfall JM, VanVorst RF, Main DS, Herbert C. Community-based participatory research in practice-based research networks. *Ann Fam Med.* 2006;4:8-14.
20. Canadian Diabetes Association. Clinical practice guidelines for the prevention and management of diabetes in Canada. *Canadian Journal of Diabetes.* 2003;27:S1-S152.
21. Baldwin JA, Johnson JL, Benally CC. Building partnerships between Indigenous communities and universities: Lessons learned in HIV/AIDS and substance abuse prevention research. *Am J Public Health.* 2009;99(Suppl 1):S77-82.
22. Shirey LA, Griffith DM, Brady J, Kruger DJ, Morrel-Samuels S, Greene-Moton E. Challenges and lessons learned in developing a community-based health survey. *Prog Community Health Partnersh.* 2008;2:99-104.
23. Wallerstein NB, Duran B. Using community-based participatory research to address health disparities. *Health Promot Pract.* 2006;7:312-23.
24. Williams RL, Shelley BM, Sussman AL; RIOS Net clinicians. The marriage of community-based participatory research and practice-based research networks: Can it work? A research involving outpatient settings network (RIOS net) study. *J Am Board Fam Med.* 2009;22:428-35.
25. Nutting PA. Practice-based research networks: Building the infrastructure of primary care research. *J Fam Pract.* 1996;42:199-203.
26. Bodenheimer T, Young DM, MacGregor K, Holtrop JS. Practice-based research in primary care: Facilitator of, or barrier to, practice improvement? *Ann Fam Med.* 2005;3(Suppl 2):S28-32.
27. Graham DG, Spano MS, Stewart TV, Staton EW, Meers A, Pace WD. Strategies for planning and launching PBRN research studies: A project of the academy of family physicians national research network (AAFP NRN). *J Am Board Fam Med.* 2007;20:220-8.
28. Mold JW, Peterson KA. Primary care practice-based research networks: Working at the interface between research and quality improvement. *Ann Fam Med.* 2005;3(Suppl 1):S12-20.
29. National Aboriginal Health Organization. OCAP: Ownership, control, access and possession. Ottawa, Ontario: National Aboriginal Health Organization; 2007.