



**DIABETES MANAGEMENT AND PREVENTION:
ENVIRONMENTAL SCAN FOR THE NORTH WEST
LOCAL HEALTH INTEGRATION NETWORK**

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Thunder Bay, Ontario

Report prepared for the North West Local Health Integration Network

2009

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ACKNOWLEDGMENTS

The authors would like to acknowledge and thank the individuals who gave freely of their time to be interviewed for this study. While they must remain anonymous, as health care administrators and front-line care providers, the insights and ideas they shared about diabetes management and the challenges of delivering services across the North West LHIN region, in urban, rural and remote First Nations communities, represent a major contribution to this study.

As well, we wish to acknowledge the financial support provided by the North West Local Health Integration Network. We especially appreciate the time that the LHIN staff and members of the Diabetes Strategy Advisory Committee took to provide suggestions and feedback on preliminary findings. The interpretations and conclusions expressed in this study, however, are the authors' alone; no official endorsement by the NW LHIN is intended or should be inferred.

MAIN MESSAGES

- Diabetes in the NW LHIN is viewed as being poorly controlled due to a number of factors, principally difficulties accessing primary care, education and specialist services. Front-line health workers were reporting increased numbers of clients suffering from diabetes-related complications, which were in many cases resulting in amputations and renal failure. Difficulty accessing services was a particular problem for clients who resided in rural locations or remote First Nations. Travel for both clients and outreach care providers was a challenge, especially during the winter months when road-travel was hazardous.
- Nearly everyone interviewed reported their organizations and communities were in the process of developing or implementing diabetes management and prevention strategies. Informants were also active in diabetes health promotion and screening clinics. The nurses and physicians interviewed were very involved in the delivery of health services and were well attuned to their clients' needs. At the same time, many felt "overwhelmed" by the numbers of clients they saw on a daily basis.
- Human resources shortages, rural location and service gaps were identified as key barriers in the provision of diabetes care within the region, as evidenced by lengthy waiting periods for appointments, high complication rates and difficulties accessing specialist care. Organizations which provided outreach were especially challenged, given the demands for care in rural areas and isolated First Nations. Additionally, there was a noticeable lack of communication and coordination between organizations, which left some healthcare providers with the perception that they were working in "silos of care." Electronic medical records were also regarded as a benefit; however, many of the systems were incompatible.
- Those interviewed felt that the provision of additional resources to support enhanced communication and coordination of care between organizations would improve the status of existing diabetes management and prevention programs in the NW LHIN region. They identified needs for enhanced communication and coordination at both local and regional level. Ideally, they envisioned that collaboration, on "a community by community basis," would result in a regional network. Other respondents identified a need for regional consultations, "to get us all on the same page as to what this is, what it looks like, what is our vision of it when it is working well so that we can all be kind of working towards that."

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*Environmental Scan:
Diabetes Management and Prevention for the North West LHIN
Centre for Rural and Northern Health Research
Lakehead University*

EXECUTIVE SUMMARY

This study responds to the Northwest LHIN's interest in exploring the issue of diabetes prevention and management. Our research indicates that diabetes is a serious problem within Northwestern Ontario, particularly in Aboriginal communities. Given the prevalence of this disease, the development of an integrated diabetes management and intervention strategy is a planning priority for the region.

One of the goals of the study was to examine best practices with a particular focus upon diabetes management and prevention programs that had been developed for rural or remote settings. The scan examined models of care developed across Canada and internationally, with the objective of discovering effective strategies that might be applied in the NW LHIN. Given the high rates of diabetes among First Nations populations, the project also looked at culturally competent models of care developed for indigenous populations.

We also spoke to 23 health care professionals involved with the provision of diabetes care within their communities or regionally. They shared their observations regarding the effectiveness and availability of diabetes management and prevention programming and were given the opportunity to discuss and identify any barriers or service gaps that they felt had impacted the provision of care and delivery of health-care services within their communities.

Findings

- Across the region, providers reported that their communities were in the process of developing diabetes management and prevention strategies. The supports in place for diabetes care in Northwestern Ontario, commonly were provided by primary care practitioners, including family physicians, nurse practitioners and registered nurses. The larger communities also had diabetes education services and dietitians. Healthcare providers were very active within their community, in terms of health promotion activities and home visits. Some also delivered outreach services to isolated rural areas and First Nations. With the exception of some consultations via telehealth or outreach, endocrinology, nephrology and ophthalmology consultations were only available in Thunder Bay or Winnipeg.
- Electronic medical records were viewed as being beneficial to those involved in the day-to-day care of diabetic patients, as were supports, such as appointment reminders. Physicians, however, were sometimes reluctant to share patient data via the electronic medical records, which impeded communication between caregivers. Although the ideal was a single patient medical chart that "travelled with the patient," paper and fax based communications were the norm.

Barriers and Service Gaps

- Barriers such as limited funding, infrastructure and resources, human resources shortages, rural location and a lack of networking and coordination capabilities between organizations and service providers were identified as key factors which continued to hinder the development and implementation of diabetes prevention and management programming.
- A number of those interviewed in the study encountered difficulty in networking with other health-care organizations and expressed frustration as a result of this lack of coordination between health care providers, there was a general sentiment that although everybody was trying to accomplish the same goals, nobody was working together. On this issue, there was a need to ensure that both providers and clients were aware of the services provided locally.
- Difficulties associated with providing outreach care to isolated rural communities and First Nations, continued to be significant gaps in the provision of care. Shortages of primary care, limited outreach services, and difficulties accessing testing, education and other specialized care were believed to contribute to the high rates of diabetes complications, including amputations and renal failure, that occurred in these areas. These locations also experienced food security issues, specifically lack of affordable and nutritious fresh food, that affected clients ability to self-manage their condition.

Suggested Improvements

- When asked what they felt could improve or enhance existing diabetes management and prevention programs, the majority of the informants interviewed reported that increased funding to support communication and collaboration between organizations was priority. Two areas were of primary concern: the development of integrated EMR networks, to overcome current systems incompatibility, and development of regional networks, to enable closer collaboration between organizations providing diabetes care.
- Education also was touched upon by several informants as being an area for improvement. Some felt that health-care providers were not adequately educated on the intricacies of diabetes treatments, others saw a need for physicians and nurses to be given additional There was also acknowledgement that providers had difficulty teaching clients self-manage their diabetes was difficult to provide, when they were overwhelmed by care needs.

- When asked what could improve or enhance existing diabetes management and prevention programs, additional resources to support enhanced communication networks and coordination of care between organizations were priorities across the region. In terms of communication, the ability to share information between organizations through an integrated system of electronic medical records was needed, because current systems did not interface effectively. This problem contributed to “lack of communication between providers, between programs, between screening programs.”
- There also was a need for enhanced health intelligence, in the form of additional data on the needs of clients with diabetes in the NW LHIN. Although it was acknowledged that there is comparatively good information on prevalence and incidence in some organizations, there is no systemic way of gathering information on communities or population groups to identify clients at high risk of diabetes or complications. In the words of a primary care practitioner, “we just don’t have the system information to know what kind of problem is that, what kind of outcomes we are getting, who should be seeing who.”
- Other respondents emphasized the need for coordination of services among organizations. While there was a degree of collaboration at the local level, there was a noticeable lack of coordination between communities and more specialized services that were located in larger towns and the regional centre. There also was evidence that competitive program funding sometimes caused further fragmentation in care delivery. As an administrator remarked, when you have several organizations “all competing for the same money, that does cause an issue when you’re looking at the best uses for limited resources.”
- Rural location and transportation-related issues were a significant barrier negatively affecting access to diabetes care, particularly in isolated First Nations. On this issue, several informants spoke about the need to enhance outreach care. Addressing gaps in outreach primary care and services such as footcare and vision exams, would go along way towards reducing the complications seen in clients from these areas. Additional outreach, such as POCT, would also allow for more intensive management of clients who otherwise had difficulty accessing care.
- There was agreement that consultation and coordination around the delivery of diabetes services and supports needed to occur at both the regional and local levels. Several specifically suggested that the LHIN might take a role in this coordination, facilitating networking on “a community by community basis” towards the goal of developing an integrated diabetes care system for the region. Other respondents identified a need for regional consultations “to get us all on the same page as to what this is, what it looks like, what is our vision of it when it is working well so that we can all be kind of working towards that.”

INTRODUCTION

This research report responds to the North West LHIN's interest in conducting a literature review and environmental scan on diabetes prevention and management. Like other jurisdictions, Ontario's population has experienced significant increases in diabetes prevalence, particularly among younger age groups and women.¹

Ontario residents with diabetes who live in rural and Aboriginal communities, such as are found throughout the NW LHIN, are at greatest risk, experiencing complications twice as often as people who live elsewhere; those who reside in remote areas are almost three times more likely to have complications.² These facts, along with declining mortality among people diagnosed with diabetes, place increasing burdens on the health care system and have created demands for innovative ways to provide care.³

Across Canada and internationally, governments and local health authorities are now experimenting with new models of care to address these complex challenges. Best practice indicates that an evidence-based comprehensive approach to diabetes management and prevention produces improved clinical outcomes and enhanced quality of life. Specialized diabetes outreach programs for rural residents⁴ and Aboriginal populations,⁵ also address recognized gaps in care.

¹ Lipscombe, L. and Hux, J. Trends in diabetes prevalence, incidence and mortality in Ontario, Canada 1995-2005: a population-based study. *The Lancet*. 2007; 369 (9563); March 9: 750-756.

² Booth, G.L., Hux, J.E., Fang, J. and Chan, B.T. Time trends and geographic disparities in acute complications of diabetes in Ontario, Canada. *Diabetes Care*. 2005;28(5), 1045-50.

³ Lipscombe, L. The growing prevalence of diabetes in Ontario: Are we prepared? *Healthcare Quarterly*. 2007; 10(3): 23-25.

⁴ Siminerio, L., Piatt, G., and Zgibor, J.C. Implementing the chronic care model for improvements in diabetes care and education in a rural primary care practice. *Diabetes Educator*. 2005; 31(2):225-34.

⁵ Barton, S.S. Discovering the literature on Aboriginal diabetes in Canada: A focus on holistic methodologies. *Canadian Journal of Nursing Research*. 2008;40(4):26-54.

Through an exploration of policy frameworks and programming that have been adopted in different jurisdictions and an assessment of diabetes care in Northwestern Ontario, this study explores and identifies existing facilitators and barriers that could affect the development and implementation of a diabetes management and prevention strategy for the NW LHIN.

Research Questions and Objectives

This research project encompassed a literature review and environmental scan of key informant opinions on diabetes prevention and management, with a focus on issues of interest to the North West LHIN. It explored four major objectives:

1. Diabetes models of care, including management, self-management, prevention, health promotion and client supports, in Canada and other jurisdictions, including models used for Aboriginal populations.
2. Prevalence rates of diabetes and associated risk factors in Northwestern Ontario's urban, rural and remote regions (particularly in regards to incidence of diabetes in NW Ontario First Nations) and comparison with other northern, rural or remote areas.
3. Documentation of identified service gaps in NW Ontario with respect to existing diabetes management and prevention initiatives, including problems around screening, access to services and sustainability of care.
4. Issues affecting access to care for underserved populations (including residents of rural and remote communities, First Nations, and youth transitioning to adult care), were also examined.

Methods

The scan examined both health sector and non-health sector literature, national and international, using PubMed and Internet-based standard library search engines. Web-searches were enlisted to help identify the so-called grey literature, reports, policy papers, program descriptions and evaluations. Statistical information on the prevalence of diabetes and associated risk factors was summarized, with emphasis on the NW LHIN.

Open-ended interviews (Appendix A) were conducted over the telephone with 23 practitioners and health administrators in 14 communities across Northwestern Ontario, producing a sample size well beyond the recommended minimum of 8-12 interviews for achieve information saturation.⁶ Potential informants were identified by the NWLHIN staff, with additional respondents located through snowball sampling. All research procedures were approved by the Lakehead University Research Ethics Board. Participants were informed about confidentiality and informed consent procedures through a covering letter (Appendix B) and consent form (Appendix C).

Interview data was transcribed into machine-readable formats and analyzed using a qualitative data analysis program (NVivo). Members of the team analyzed the data independently, then compared and consensually validated findings. Written material from all sources was incorporated into this report. With permission of the LHIN, findings will be disseminated to stakeholders and decision-maker groups, through website posting, conferences and academic publications.

This Report

As a basis for enhancing diabetes management and prevention initiatives in the NW LHIN, this report presents a narrative synthesis of information from all materials reviewed for this scan. With a focus on diabetes management and prevention approaches designed for rural and remote populations and Aboriginal peoples, it includes information on chronic care models and programs, currently applied in Canada and internationally. The report also documents the opinions of health care providers who are actively involved in delivering diabetes care throughout the NW LHIN region. Their views on existing programs, gaps in services, barriers to accessing care, and areas for improvement are summarized.

⁶ Guest, B., Bunce, A. and Johnson, L. How many interviews are enough? An experiment with data saturation and variability. *Field Methods*. 2006; 18(1): 59-82

DIABETES PREVALENCE

Mirroring a pattern observed across the globe, the increase in diabetes across Ontario during the past decade far exceeds the rates which were projected even twenty years ago. Lipscombe and Hux (2007) noted that the provincial diabetes prevalence rose from 5.2% to 8.8% over the 1995-2005 period, producing an increase of 69% overall.⁷ Most of this increase can be attributed to higher rates of diabetes across all age groups, with especially higher rates occurring for younger individuals (under age 50) and women, and declining mortality rates among people with diabetes.

At the same time, the burden of diabetes is not evenly distributed throughout the province of Ontario. There is evidence that Aboriginal populations⁸ and some immigrant groups, such as Southeast Asians, have enhanced risk of developing diabetes.⁹ Serious complications of diabetes, such as amputations or renal disease occur twice as often in rural and Aboriginal communities and are three times more likely to occur among residents in remote areas of the province.¹⁰ As Hux (2007) has emphasized, these increasing burdens, experienced all across the province, will lead to demands for new and innovative ways to provide care for people with diabetes.¹¹

⁷ Lipscombe L., Hux J.E. Trends in diabetes prevalence, incidence, and mortality in Ontario, Canada 1995-2005: a population-based study. *Lancet*. 2007; 369:750-756.

⁸ Young, T., Reading, J., Elias, B., and O'Neil, J.D. Type 2 diabetes mellitus in Canada's First Nations: status of an epidemic in progress. *Canadian Medical Association Journal*. 2000; 163: 561-566.

⁹ Shah, B.R., Utilization of physician services for diabetic patients from ethnic minorities. *Journal of Public Health (Oxford)*. 2008; 30(3); 327-331.

¹⁰ Booth, G.L., Hux, J.E., Fang, J. and Chan, B.T. Time trends and geographic disparities in acute complications of diabetes in Ontario, Canada. *Diabetes Care*. 2005;28(5), 1045-50.

¹¹ Lipscombe, L. The growing prevalence of diabetes in Ontario: Are we prepared? *Healthcare Quarterly*. 2007; 10(3): 23-25.

Diabetes in the NW LHIN

As Bains and colleagues reported in *Chronic Conditions in the North West LHIN* (2007), Canadian Community Health Survey (CCHS) data indicates that the NW LHIN has a higher rate of diabetes than the province overall (6.1%, as compared to 4.8%).¹² As shown in *Table 1*, rates of mortality, hospital separations and emergency department care for diabetes within the LHIN are also above the provincial average. Rates of visits to family practitioners are lower than elsewhere in the province.

Bains notes, however, that these statistics may seriously under-estimate the true prevalence of diabetes and its effects in the region. Available data do not capture cross-border care, including that which is received by residents of Northwestern Ontario who go to Manitoba; the data may also not adequately capture the care by First Nations people, who received some of their care on-reserve, through federally-funded services.

Table 1
Diabetes - Mortality, Hospital Separations, Emergency Department Visits and GP/FP Visits, For North West LHIN and Ontario (from Bains 2007)

Diabetes (All Ages)	Rates	
	NW LHIN	ON
Mortality Rate (2001-03 Average)	39.4	25.8
Hospital Separation Rate (2005-06 Fiscal)	184	97
Emergency Department Visit Rate (2005-06 Fiscal)	431	186
GP/FP Visit Rate (2005-06 Fiscal)	10,712	12,176

Source: Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report*. Toronto, ON: Ministry of Health and Long-Term Care. (p. 10).

¹² Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report*. Toronto, ON: Ministry of Health and Long-Term Care. (p. 4).

The most recent estimates for the NW LHIN from the Institute for Clinical Evaluative Sciences (ICES),¹³ covering 2004-05, suggests that diabetes mortality rates for the region's population aged 20 and older remain higher than provincial rates (17.1 as compared to 13.8). The ratio between mortality rates in people with diabetes and without is largest in the NW LHIN (17.1 compared to 8.8); only in Hamilton Niagara-Haldiman Brent do rates approach this level. As shown in *Table 2*, prevalence of Type II diabetes in the Northwest LHIN is also somewhat higher than the provincial average (9.7% as compared to 8.5% for the province).

Table 2
Diabetes - Prevalence for North West LHIN /Ontario/ Males/Females
by Planning Areas (per 100 individuals, aged 20 or older) (2004-2005)

NW LHIN Planning Region	Males	Females	Overall
Dryden	7.7	8.1	7.9
Kenora	9.0	8.5	8.7
Kenora District (excluding Dryden and Kenora)	12.7	18.3	15.5
Rainy River District	9.5	9.1	9.3
North Shore	10.4	10.8	10.6
Nipigon, Red Rock, Greenstone	10.1	10.4	10.3
Thunder Bay City	8.3	7.8	8.1
NW LHIN	9.6	9.7	9.7
Ontario	9.0	8.1	8.5

Source: Institute for Clinical Evaluative Sciences (ICES), Intool, Diabetes. Age-adjusted prevalence rate of diabetes mellitus (DM per 100 Ontarians aged 20 years and older, by sex and planning area, 2004/05. LHIN 14 (NW) vs. Ontario. Found at: <http://intool.ices.on.ca> . Accessed March 15, 2009.

¹³ Source: Institute for Clinical Evaluative Sciences (ICES), Intool, Diabetes. Age and sex adjusted prevalence rate of diabetes mellitus (DM per 100 Ontarians aged 20 years and older, 2004/05. LHIN vs. Ontario. Found at: <http://intool.ices.on.ca> . Accessed January 28, 2009.

Although overall diabetes prevalence rates for the NW LHIN are high, significant variation is found among the LHIN planning districts. Lowest prevalence is found in the towns of Dryden, Kenora and the City of Thunder Bay, highest in Kenora District, the North Shore and Nipigon, Red Rock and Greenstone areas. Kenora District is most seriously affected, with almost one in six residents having a diabetes diagnosis. Women within Kenora District, at 18.3%, have the highest rate of diabetes documented across the province; men, at 12.7%, are also well above provincial rates.

As Young (2000) and other researchers have noted, such excessively high rates reflect the fact that Type II diabetes has reached epidemic proportions among Northwestern Ontario's First Nations people.¹⁴ Some First Nations, such as Sandy Lake north of Sioux Lookout, have rates of diagnosed diabetes and associated complications that are among the highest recorded anywhere in the world.¹⁵ Although Type II diabetes among children was formerly rare, Aboriginal children and youth in some First Nations are now developing the disease as young as age five.¹⁶ Aboriginal populations living off-reserve in Ontario are also seriously affected, with one in ten individuals having received a diagnosis of diabetes and an additional four in ten with elevated risks of developing the disease.¹⁷

(A later section of this report, *Diabetes and Aboriginal Peoples*, beginning on p. 34, provides more detailed information on diabetes prevalence, risk factors and programs for Aboriginal populations.)

¹⁴ Young, T., Reading, J., Elias, B., and O'Neil, J.D. Type 2 diabetes mellitus in Canada's First Nations: status of an epidemic in progress. *Canadian Medical Association Journal*. 2000; 163: 561-566.

¹⁵ Harris SB, Gittelsohn J, Hanley A, Barnie A, Wolever TM, Gao J, Logan A, Zinman B. The prevalence of NIDDM and associated risk factors in native Canadians. *Diabetes Care*. 1997; 20(2):185-187.

¹⁶ Harris, S.B., Perkins, B.A., and Whalen-Brough, E. Non-insulin-dependent diabetes mellitus among First Nations children. New entity among First Nation people of northwestern Ontario. *Canadian Family Physician*. 1996; 42: 869-876.

¹⁷ Statistics Canada. (2003). *Ontario (table). Aboriginal Peoples Survey 2001 – Initial Findings: Well-Being of the Non-Reserve Aboriginal Population: Supporting Tables*. Statistics Canada Catalogue no. 89-592. Ottawa, ON. Found at: <http://www.statcan.gc.ca/pub/89-595-x/pdf/4228621-eng.pdf> (PDF Version, 289 kb). Accessed March 15, 2009.

Table 2

Type II Diabetes - Risk Factors – Prevalence of common modifiable risk factors (prevalence per 100,000 population) (CCHS Cycle 3.1 data)

Factor	NW LHIN	ON
Poor diet (less than 5 servings of fruit or vegetables per day)*	59.9	53.8
Heavy drinking (more than 5 drinks x 12 occasions per year)**	28.6	22.1
Smoking (daily or occasional smoker)*	25.7	20.8
Physical inactivity**	41.1	46.0
Hypertension	18.5	15.4
Obesity (age 18+) (BMI 25.0 to 29.9 kg/m ²)**	22.3	15.2
Overweight (age 18+)(BMI greater than 30.0 kg/m ²)**	36.9	33.6

* Emerging evidence on association with diabetes.

** High likelihood of casual relationship.

Source: Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report*. Toronto, ON: Ministry of Health and Long-Term Care. (p. 28).

Risk Factors

The CCHS data analysed by Bains confirmed that residents of the NW LHIN were at increased risk of developing chronic diseases, including diabetes (Table 2). Although somewhat less likely to be physically inactive (41.4%), the majority were either overweight (36.9%) or obese (22.3%) and one-quarter reported heavy consumption of alcohol (28.6%) and smoking (25.7%). Given the level of risk, Bains recommended that chronic disease strategies underlying socio-economic conditions, such as poverty, education and employment, because such conditions are associated both with “risk factor prevalence and many chronic disease outcomes.”¹⁸

¹⁸ Bains, N., K. Dall, and J. Hohenadel. (2007). *Chronic Conditions in the North West LHIN. Health System Intelligence Project (HSIP) Report*. Toronto, ON: Ministry of Health and Long-Term Care. (pp. 29, 34).

CHRONIC DISEASE MANAGEMENT MODELS

A recent review of chronic disease management models suggested that “multi-pronged” strategies, including clinical care, education, enhanced information systems and other supports, are considered to be the most effective approaches.¹⁹ Some of the common elements of effective chronic care programs include: delivery systems designed to improve timely access to care; decision support based on clinical practice guidelines; clinical information systems, registries, reminders and feedback; and self-management supports for clients and their families.²⁰ Multidisciplinary care teams and effective patient-provider interactions are also emphasized as essential components of chronic disease care. In addition, some applications recognize the importance of culture and ethnicity in the provision of care.

As a basis for the discussion of specific diabetes management policies and programs that is presented later in this report, this section includes descriptions of three integrated chronic disease models, including a diabetes management and prevention model which has been proposed for Ontario, and examples of two self-management approaches developed for clients with chronic disease. Components of each of these models have potential application in the NW LHIN: (i) Chronic Care Model (CCM) (Wagner 1998); (ii) Expanded Chronic Care Model (Barr 2003); (iii) proposed Ontario Chronic Care Model (OCDPA 2006); (iv) Stanford Self-Management Model (Lorig 1997); and (v) Flinders Self-Management Model (Battersby 2001).

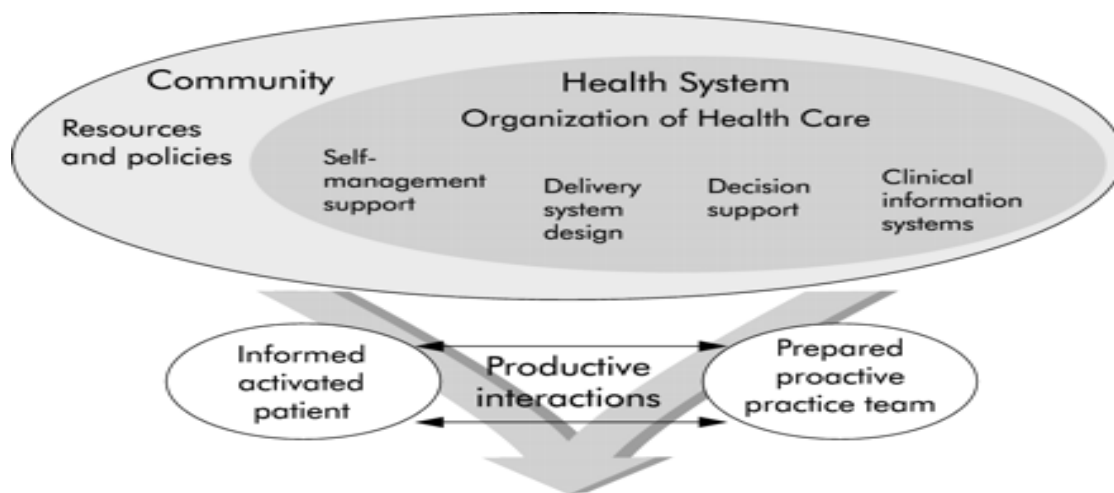
¹⁹Barr, V., S. Robinson, B. Marin-Link, L. Underhill, A. Dotts, D. Ravensdale, and S. Salivaras. The Expanded Chronic Care Model: An integration of concepts and strategies from Population Health Promotion and the Chronic Care Model. *Hospital Quarterly*. 2003; 7(1): 73-82.

²⁰Brodheimer, T., Wagner, E.H., and Grumbach, K. Improving primary care for patients with chronic illness. *Journal of the American Medical Association*. 2002; 288(14):1775-1779.

(1) The Chronic Care Model (Wagner)

The initial formulation of the Chronic Disease Management Model (Wagner, 1998)²¹ offered six different types of support to promote effective healthcare delivery to individuals with chronic disease: organizational support, clinical informational systems, delivery system design, decision support, self-management support and community resources. Chronic disease management or practice improvement strategies can be based on each of the concepts separately or on the model as a whole.

Figure 1: The Chronic Care Model (Adapted from Wagner)



As Fiandt emphasizes, full implementation of the chronic care model requires that each of the components is fully supported and resourced.²² She specifically recommends supports in six areas: (i) leadership, to support organizational changes designed to improve quality; (ii) clinical information systems, incorporating disease registries, guidelines, and performance indicators; (iii) delivery system redesign, emphasizing team-based care, case management and client follow-up; (iv) practice guidelines, including prompts, reminders

²¹ Wagner, E.H. Chronic disease management: What will it take to improve care for chronic illness? *Effective Clinical Practice*. 1998;1:2-4.

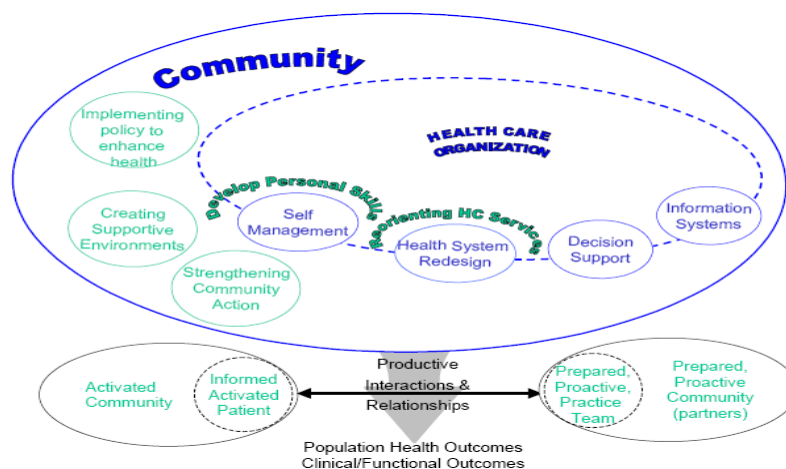
²² Fiandt, K. The chronic care model: description and application for practice. *Topics in Advanced Practice Nursing eJournal*. 2006;6(4). [Online]. Found at: <http://www.medscape.com>.

and access to specialist consultation; (v) self-management, educational and psychosocial resources, enhancing each client's abilities to monitor and manage her or his condition; and (vi) community resources, providing extra assistance for seniors, low-income families and minority populations.

(2) The Expanded Chronic Care Model (Barr)

Going beyond the clinical focus of the Wagner Chronic Care Model, the Expanded Model adds extra supports to enable populations to follow healthy lifestyles. As Barr and colleagues note (2003), "this strategy requires action on the determinants of health as well as delivery of high quality healthcare services."²³

Figure 2 -- The Expanded Chronic Care Model (Barr 2003)



The model, *Figure 2*, includes: (i) self-management resources, located in community centres and schools; (ii) consultation, with volunteer and citizen groups, to ensure that all available supports are utilized; (ii) collaborative decision-making, between professionals and clients, to encourage clients to become full partners in their care; (iii) e-health systems,

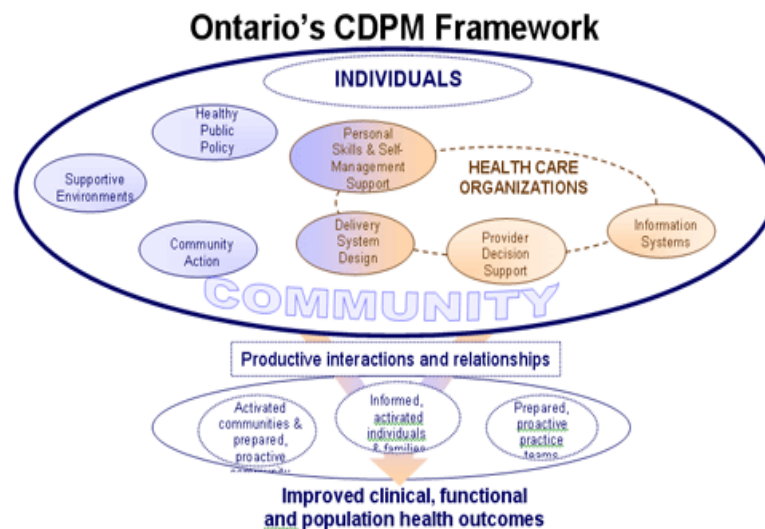
²³ Barr, V., S. Robinson, B. Marin-Link, L. Underhill, A. Dotts, D. Ravensdale, and S. Salivaras. The Expanded Chronic Care Model: An integration of concepts and strategies from Population Health Promotion and the Chronic Care Model. *Hospital Quarterly*. 2003; 7(1): 73-82. (p. 76).

permitting health care providers to track and analyze client outcomes, as well as community information on determinants of health; (iv) public policies, improving access to necessities of life, specifically affordable and healthy foods; (v) housing and recreational policies, promoting safety and activity; and (vi) public participation, encouraging citizens to become in identification of community health needs and solutions.

(3) Ontario's Proposed Chronic Disease and Prevention Model (OCDPA)

The draft Ontario Chronic Disease Prevention and Management Framework (2005), was designed to assist Ontario in the shift from an acute care focused health system, to an integrated system that seeks to improve clinical and functional health outcomes.²⁴

Figure 3: The Proposed Ontario's CDPM Framework (2006)



²⁴ Ontario Chronic Disease Prevention Alliance. *Thinking like a system: the way forward to prevent chronic disease in Ontario*. March 2006. Found at: http://www.ocdpa.on.ca/docs/SystemPlan2005_06FinalJune2006.pdf. Accessed October 22, 2008.

As shown in *Figure 3*, the framework builds on central aspects of the Expanded Chronic Care Model developed by Barr, integrating preventive and population health initiatives into the chronic disease management system. The model's unique features include integrated community-based health strategies and the use of multidisciplinary health teams that deliver primary and specialist care outside clinical settings, both features designed to support comprehensive approaches to chronic disease management and prevention. The model also recognizes the importance of public policy supports, including specific actions designed to address health inequalities and determinants of health.

A scan commissioned by the OCDP Alliance,²⁵ however, identified significant barriers to implementation of this type of comprehensive chronic disease model, considering the current health care system and policy structures. These included: (a) an emphasis on disease management and acute care, which left comparatively few resources devoted to disease prevention or population health promotion initiatives; (b) an absence of integrated messages about common risk factors associated with a number of chronic diseases; (c) inconsistent inclusion of strategies designed to address determinants of health; and (d) a lack of networking and knowledge translation among the various provincial disease-specific strategies.

Developing integrated chronic disease management and prevention strategies, furthermore, was constrained by several features of the Ontario health care system, including the numbers of organizations involved in the planning and delivery of services; the complexity of public/private/not-for-profit sector relationships; an absence of continuity in policy and program development; competition around disease-linked research strategies. Resources to support the transition to an integrated chronic disease management and prevention model were also unavailable.

²⁵ Lyons, C. and Kungl, A. *Informing Directions for Chronic Disease Prevention and Management in Ontario: Environmental Scan of Chronic Disease Prevention and Management Strategies in Ontario and Collaboration Efforts of the Ontario Chronic Disease Prevention Alliance*. Final Report. September 2005. Found at: <http://www.ocdpa.on.ca>. Accessed on November 10, 2008.

(4) Stanford Self-Management Model (United States)

Patient education and self-management supports have long been recognized as an important component of diabetes management programs, because “day-to-day care responsibilities fall most heavily on patients and their families.”²⁶ Developed in 1996, one of the most widely-known chronic disease self-management initiatives is the Stanford Self-Management Model. This commercial education program, delivered through a licensing system, is used throughout the United States, Canada, and internationally.²⁷ As well as a generic chronic disease self-management program, Stanford has developed two diabetes-specific programs, one delivered through community-based workshops and the other through the Internet. Both programs should be available later in 2009.

The community-based Stanford diabetes program follows the same model used in its chronic disease self-management training.²⁸ Two trained leaders, at least one of whom has diabetes, deliver six weekly 2.5 hour workshops to groups of 12-16 participants in community settings such as churches, libraries and hospitals. Workshops are topic-focussed, giving participants the opportunity to learn about coping with symptoms, exercising to maintain strength, eating healthy foods, using medication properly, and communicating with health care providers. Discussions, peer to peer support and goal setting are facilitated using structured manuals, including a book, *Healthier Living with Chronic Conditions*, audio relaxation and exercise tapes.

The Internet version, *Healthier Living With Diabetes*, follows the same format, with facilitators delivering six weekly lessons to on-line groups of up to 24 participants, using the same manuals and resources for community workshops. Participants expected to log-on to

²⁶ Von Korff, M., Gruman, J., Schaefer, J., Curry, S.J., and Wagner, E.H. Collaborative management of chronic illness. *Annals of Internal Medicine*. 1997; 127(12): 1097-1102. (p. 1097).

²⁷ In the NW LHIN, Dryden Area Family Health Team, Fort William Family Health Team, Sunset Country Family Health Team, and Thunder Bay Regional Health Sciences Centre have received training in use of the Stanford system for generic chronic disease management.

²⁸ Stanford University. “Patient Education Programs.” Found at: <http://patienteducation.stanford.edu>. Accessed: January 15, 2009.

the sessions two or three times each week at their convenience, for about one to two hours each week total. Once logged on, they can complete the lessons and exchange information and mutual support with other participants via email and bulletin boards. They can also post questions, which are answered by facilitators. The Internet version includes a sub-study for American Indians and Alaska Natives, which is currently underway.²⁹

(5) The Flinders Model of Self-Management Support (Australia)

The Flinders Model of Self-Management Support has been developed to improve chronic disease self-management through creating individualized care plans.³⁰ It consists of three tools: (i) *Partners in Health Scale*, a thirteen-part questionnaire, determines clients' knowledge and their ability to manage symptoms and illness impacts; (ii) *Cue and Response Interview*, an open-ended motivational interview, explores clients' perceptions of self-management and barriers; and (iii) *Problem and Goals Assessment*, a checklist, allows health care providers and clients to examine problems and goals.

Each of the instruments covers a wide range of self-management issues, to assess a client's knowledge of their condition and treatment; ability to take medicine, make decisions, and attend appointments; understanding of monitoring and recording their condition; understanding of symptoms and their management; ability to manage the physical, emotional and social impacts of their condition; and their progress towards adopting a healthy lifestyle. The three tools can be used individually, for stand-alone assessments, or can be used in conjunction with one another, to support development of individualized care plans. Culturally competent versions of the tools also are being developed for use with Aboriginal populations.

²⁹ Stanford University. "Patient Education: Healthier Living for Diabetes." Found at: <http://patienteducation.stanford.edu/internet/diabetesol.htm>. Accessed March 15, 2009.

³⁰ Flinders University. "School of Medicine: The 'Flinders Model' of Chronic Condition Self-Management." Found at: http://som.flinders.edu.au/FUSA/CCTU/self_management.htm#Flinders_Model. Accessed March 15, 2009.

CANADIAN DIABETES MANAGEMENT PROGRAMS

As noted in a review of diabetes education and management approaches, large numbers of interventions to manage diabetes have been developed and tested; however, there is little substantive evidence on process improvements or client outcomes to guide the choice of management models.³¹ Few guidelines exist to assist policy and decision-makers in developing specific screening,³² patient education,³³ or cultural programs.³⁴ Assessments on innovations in diabetes primary care, involving specialists,³⁵ pharmacists,³⁶ and nurses³⁷ are equally inconclusive.

For the purpose of the present scan, we chose eight Canadian programs, all of which have components that might be applied in the NW LHIN: (i) Capital Health's Regional Diabetes Program (Edmonton, AB); (ii) Diabetes Education Centres (BC); (iii) Chronic Disease Management Collaborative (SK); (iv) Maestro Project (Winnipeg, MB); (v) Côte-des-neiges Diabetes Program (Montreal, QU); (vi) Group Health Centre's Diabetes Initiative (Sault Ste. Marie, ON); (vii) Latin American Diabetes Program (London, ON); and (viii) MicroHealth Internet Diabetes Program (Kitchener, ON).

³¹ Renders, C.M., Valk, G.D., Griffin, S., Wagner, E.H., Eijk, J.T. and Assendelft, W.J. Interventions to improve the management of diabetes mellitus in primary care, outpatient and community settings. *Cochrane Database Systemic Review*. 2001;(1):CD001481. Rev. 2009

³²Norris, S.L., Kansagara, D., Matsos, C., Fu, R.; U.S. Preventive Services Task Force. Screening adults for type 2 diabetes: a review of the evidence for the U.S. Preventive Services Task Force. *Annals of Internal Medicine*. 2008;148(11): 855-868.

³³ Duke, S.A., Colagiuri, S., and Colagiuri, R. Individual patient education for people with type 2 diabetes mellitus. *Cochrane Database Systemic Review*. 2009;(1):CD005268.

³⁴ Hawthorne, K., Robles, Y., Cannings-John, R., and Edwards, A.G. Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups. *Cochrane Database Systemic Review*. 2008 (3):CD006424.

³⁵ Smith, S.M., Allwright, S., and O'Dowd, T. Effectiveness of shared care across the interface between primary and specialty care in chronic disease management. *Cochrane Database Systemic Review*. 2007;(3):CD004910.

³⁶ Wubgben, D.P., and Vivian, E.M. Effects of pharmacist outpatient interventions on adults with diabetes mellitus: a systematic Review. *Pharmacotherapy*. 2008; 28(4): 421-435.

³⁷ Loveman, E., Royle, P. and Waugh, N. Specialist nurses in diabetes mellitus. *Cochrane Database Systemic Review*. 2003;(2):CD003286.

(1) Capital Health's Regional Diabetes Program (Edmonton, Alberta)

In 2003, Capital Health, which serves Edmonton, nearby small towns and their surrounding rural areas, introduced a Regional Diabetes Program to address delays in accessing services.³⁸ Specialized supports included a central booking office, which manages referrals to education, assessments or specialists; a central disease registry, which permits monitoring of high risk patients; and a fax and telephone-based Diabetes Information and Advice Line (DIAL) which links providers with diabetes nurses, dieticians and diabetologists. The system also allows people with diabetes to self-register for group education sessions.

In 2005, Diabetes Care Teams were added to Capital Health's newly organized Primary Care Networks (PCNs). The teams include family physicians and nurse practitioners, who act as care managers, and registered nurses, who follow standard protocols for monitoring client's glucose, blood pressure and lipid levels, maintain a diabetes disease registry, follow client referrals to vision and foot-care services and deliver ongoing education. Each PCN is responsible for providing specialized diabetes training to family physicians and nurses.

Although evaluations suggest that the Regional Diabetes Program has produced good results, including higher screening rates, reduced wait times, and improved glucose control, there have been some challenges. Barriers include a shortage of space in primary care clinics to accommodate additional staff; absence of electronic records in some clinics; and difficulty in making organizational changes required to integrate nurse practitioners into each network's family practices.

³⁸ Every, B., Better for ourselves and better for our patients: chronic disease management in primary care networks. *Healthcare Quarterly*. 2007;10(3):70-74.

(2) Diabetes Education Centres (British Columbia)

Using a program originally developed in the Capital Health Region of Victoria,³⁹ the province of British Columbia now funds 80 Diabetes Education Centres (DEC). Most of the centres are affiliated with hospitals, but centres may be located either in a hospital or community health centre.⁴⁰ The DECs offer comprehensive diabetes education and services to people with diabetes and their families and train staff and volunteers that work with community agencies.

The centres are staffed by nurses and dietitians, with social workers, podiatrists, pharmacists and physiotherapists in some locations. Staff deliver individual and group education to people with diabetes and their family caregivers, on referral from family physicians. Education is offered both as one-on-one counselling or group learning sessions, with the target group being newly-diagnosed individuals. Depending on individual needs, educational support may extend over several days, weeks or months. Topics covered include healthy eating, glucose goals, monitoring, medication, exercise, healthy lifestyles and coping with the stress.

Some of the DECs also sponsor two-and-a-half hour specialized Stanford model self-management education sessions, which are delivered by pairs of trained clinicians and lay leaders, to give patients confidence and encouragement to improve their self-management skills and coping abilities.⁴¹

³⁹ Closson, T.R. The Capital Health Region's Early Experiences: Moving Towards Integrated Healthcare. *Healthcare Papers*, 1(2) 2000: 88-95

⁴⁰ British Columbia Ministry of Health. "Chronic Disease Management: Diabetes Education Centres." Found at: <http://www.health.gov.bc.ca/cdm/patients/diabetes/dec.html>. Accessed March 28, 2009.

⁴¹ McGowan, P. "British Columbia Evaluation of the 2003-06 Implementation of the Chronic Disease Self-Management Program." Found at: <http://www.coag.uvic.ca/cdsmp/documents/CDSMP%20Evaluation%20BC%202003-2006.pdf>. Accessed March 28, 2009.

(3) Chronic Disease Management Collaborative (Saskatchewan)

In 2005, Saskatchewan introduced its Chronic Disease Management Collaborative as part of its provincial health quality improvement strategies.⁴² The primary mechanism for improving care is the *Chronic Disease Management Toolkit*, a web-based disease registry and support tool originally developed in British Columbia. The toolkit lets primary care teams, including doctors, nurses, dieticians and other health care professionals use the system to track patient progress and remind care providers of required tests, services or medications. The software produces paper flow sheets, which are uploaded on a monthly basis and can import data from some clinic EMR systems, eliminating the need for double-entry.⁴³

The system also produces quarterly reports for the province's 13 Regional Health Authorities (RHAs) that identify improvements in care, gaps in services and populations with special needs. Each RHA has established a quality-improvement team, which works with physicians, nurse practitioners, nurses, educators, pharmacists, dieticians and First Nations and Métis groups, to ensure more timely care.

Overall evaluations of the first two years of operation indicated that the system has significantly reduced waiting times for clients with diabetes, with most clients being seen by primary care providers on their day of choice. The system also increased numbers of patients receiving annual kidney screening and improved percentages of patients receiving recommended cholesterol and anti-platelet medications. In addition, physicians were seeing increased numbers of patients with good control of blood sugar.⁴⁴

⁴² Canadian Health Services Research Foundation. Turning the Tide on Chronic Disease: How a province is using evidence to build Quality Improvement Capacity. *Health Policy*. 2007; 3(2): 67-70.

⁴³ Kermode-Smith, B. Saskatchewan promotes quality chronic disease management care. *The Medical Post*. 2007; 3rd quarter: 44-47.

⁴⁴ Ehman, A. Saskatchewan successfully implementing best practices. *Canadian Medical Association Journal*. 2007; 176(8): 1072.

(4) Maestro Project (Winnipeg, Manitoba)

Launched in 2002, the Maestro Project is an innovative community resource and transition service for young adults 18 to 25 years of age with type 1 and type 2 diabetes.⁴⁵ Its goal is to help teens and young adults make the transition from pediatric to adult diabetes services, to ensure that they don't drop out of care. The project team includes: adult endocrinologists and diabetologists, diabetes educators, optometrists and family physicians, who can assist in managing diabetes. The goal is to keep youth with diabetes within the care system, to help reduce potentially life-threatening crises and complications.

As of January 2008, there were 472 young adults (aged 16-25) living with type 1 diabetes in Manitoba and of those people, 91% were participating in the program. The majority are referred to the program by a diabetes education centre, general practitioner, or endocrinologist. Information is collected upon referral to the Maestro Project as well as in follow up calls and emails twice a year. Demographics, medical and diabetes education visits, health status, and diabetes-related concerns are tracked.

The program offers a number of specialized resources, including newsletters and a 72 page booklet *Building Connections: A Resource Book for Young Adults With Type I Diabetes* that emphasizes the importance of avoiding complications and keeping in touch with physicians and diabetes educators. The project also has a *Cultural Broker* who via workshops, the web and email offers culturally-appropriate information designed specifically to address the needs of Aboriginal young adults with diabetes.

Evaluations, which compared outcomes for youth enrolled in the program with preceding cohorts of youth who received usual care, documented that the program was successful in retaining young people with diabetes under care and keeping them in connection with physicians and educators. Overall, the program produced a 75% reduction in the fall-out rate in the first year of transfer.

⁴⁵ The Maestro Project. Found at: <http://www.maestroproject.com/>. Accessed March 10, 2008.

(5) Côte-des-Neiges Diabetes Program (Montreal, Quebec)

The Côte-des -Neiges area of Montreal is the second most-populated area within the province of Quebec and one of the most ethnically diverse areas of the province. Significant variations in socioeconomic status exist in the Côte-des-Neiges area and certain communities have the lowest income levels anywhere within the city of Montreal. The Côte-des-neiges-health care system is composed of 12 medical clinics, more than 50 practitioners' offices, three acute care hospitals, and one CLSC (an integrated health and social services system).⁴⁶ Prior to this initiative, most people with diabetes had received most of their treatment and educational services from family physicians. Specialized supports, such as nutrition counselling or footcare, had wait-lists that were several months long.

The Côte-des-neiges Diabetes Initiative, developed through needs assessments, resource inventories, and consultation with primary care providers, delivered interdisciplinary team care to clients with diabetes. Nurses assumed principal roles in coordinating care and client education, with supports from a dietician, foot care technician, community organizer, social worker, and exercise consultant. The initiative also developed multilingual patient education resources and primary care practice supports (computer, software, flowcharts, referral sheets, CME and CD-rom practice guidelines).

Evaluations confirmed that both physicians and patients believed the program improved access to services. Uptake of practice supports, however, was variable and effects on practice uncertain. Many physicians found the computer system too time-consuming to integrate into their daily practice and did not use the software or CD-rom resources, preferring to manage clients using hard-copy flow charts and referral sheets.

⁴⁶ Nasmith, L., Coté, B., Cox, J., Inkell, D., Rubenstein, H., Jimenez, V., Rodriguez, R., Larouche, D., Contandriopoulos, A.P., and Côte-des-Neiges Diabetes Project Team. The challenge of promoting integration: conceptualization, implementation, and assessment of a pilot care delivery model for patients with type 2 diabetes. *Family Medicine*. 2004;36(1):40-5.

(6) Group Health Centre's Diabetes Initiative (Sault Ste. Marie, Ontario)

The Group Health Centre (GHC) of Sault Ste. Marie is a multi-specialty, interdisciplinary, ambulatory care facility with diagnostic services staffed by 180 primary care physicians, specialists and allied health professionals, serving Sault Ste. Marie and surrounding rural areas. The GHC developed the Algoma Diabetes Education and Care Program in 2000. This initiative uses an e-health record template to monitor 12 process and clinical outcomes for over 3,500 patients identified as having diabetes.⁴⁷

The EMR system, which is also connected to pharmacies throughout the city, automatically flags the charts of clients with diabetes to indicate to primary care providers when regular blood tests are needed, dates on which the patient should be recalled, and reminders if specialty care, such as referrals for vision care, is required. Physicians routinely use the diabetes template to deliver orders to the diabetes clinic regarding medication and insulin adjustments and make referrals to dietitians, counsellors or other programs. The EMR also includes a patient portal, which permits clients and their family caregivers to access their own health records and review test results.

Between 2000 and 2005, use of the system was associated with better implementation of medical directives for insulin and oral diabetes medication and closer adherence to best practice guidelines, with over 60% of patients enrolled reaching target glucose levels.⁴⁸ The same evaluation produced evidence of cost effectiveness, largely because the intensive case management and monitoring in the diabetes program prevented complications, resulting in fewer hospitalizations for patients who were enrolled in the program.

⁴⁷ Crookston, D. Group Health Centre Sault Ste. Marie, Ontario. Presentation at the National Chronic Disease Management Conference. Toronto, ON; April 7, 2006. Found at: <http://www.colloquematadieschroniques.com/Archives/docs/ConferencesMagistrales/Dr%20David%20Crookston%20-%20%20Sault%20Ste.%20Marie.pdf> . Accessed March 10, 2009.

⁴⁸ O'Reilly, D., Hopkins, R., Blackhouse, G., Clarke, P., Hux, J. Tarride, J-E., Dolovich, L. and Goeree, R. Long-term cost-utility analysis of a multidisciplinary primary care diabetes management program in Ontario. *Canadian Journal of Diabetes*. 2007; 31(3): 205-214.

(7) Latin American Diabetes Program (London, Ontario)

The Latin American Diabetes Program (LADP) was established by the London Intercommunity Health Centre (LIHC) in 1999 and is an example of an integrated systems approach to chronic disease prevention and management (CDPM) in practice. Although Latinos represented only about 5% of London's population, they had a 10% incidence rate and a 40% lifetime prevalence rate for diabetes, nearly four times the rates for Canadians in general.⁴⁹ Needs assessments confirmed that Latino residents had difficulties accessing existing diabetes programs and that programs failed to take into account unique determinants of health for Latinos.

Patients are seen by an interdisciplinary team consisting of a nurse practitioner, dietician, and foot nurse. It uses software to track client outcomes, case management, and follow-up for clients requiring primary prevention or complication prevention. Services are culturally and linguistically appropriate, with innovative use of volunteer health professionals from Latino backgrounds. Families are also given fruit and vegetable vouchers, interpreters, English as a second language classes and paid YMCA memberships for families with obese children.

Outcome evaluations suggest that the program is successful,⁵⁰ with 50 per cent of clients achieving optimal glucose control, as compared to only 37 per cent of clients in private practices. The program is also cost-effective, delivering annual care at an average cost per client that is about two-thirds of the cost of delivering similar care in family physician practices.

⁴⁹ Peter Drucker Award. "Latin American Diabetes Program." Found at: <http://www.innovation-award.ca/storya5dd.html?IdeabookID=746>. Accessed October 31, 2008.

⁵⁰ Association of Ontario Community Health Centres. "Fact Sheet: Highly Effective Disease Management: Case Study: How CHCs Enhance Diabetes Care and Save Public Health System Resources." Found at: <http://www.aohc.org>. Accessed March 28, 2009.

(8) MicroHealth Internet Diabetes Program (Kitchener, Ontario)

The MicroHealth Internet Diabetes Management Program developed by the University of Waterloo, uses MedManager software and an Internet portal system.⁵¹ It supports a range of educational, planning, data collection, graphing, and communication tools to promote improved self-management of diabetes. The objectives include: improving glycemic control, disease management behaviours, health status and patient satisfaction. Two clinical trials of the program both showed positive results among clients who were current users of the program.⁵²

The system includes a central data repository that patients and healthcare providers can access via a confidential password. Patients are able to enter data on blood glucose measurements, diet, exercise, insulin and oral medications. A diabetes nurse monitors the data, gives feedback, makes recommendations about treatment and provides individualized patient education. The Internet portal supports a chatting or communication module, which enables patient-to-patient discussions, and bulletin boards, which allow patients to post questions and helpful information on managing lifestyle factors.

Patients found the Micronet interface easy to understand and believed it helped them manage their diabetes and communicate better with providers. The online wellness education component is being pilot tested by the Northern Diabetes Health Network in three locations, with programs in Geraldton and Kapuskasing implemented in March 2008 and launched in Sioux Lookout in February 2009.

⁵¹ Medmanager Canada. "Solutions: Medmanager Software Innovations." Found at: <http://www.medmanager.ca/solutions.cfm>. Accessed March 28, 2009.

⁵² Canadian Diabetes Association "Leading Initiatives in the prevention of the complications of diabetes" National Policy Summit on the seriousness of complications of Diabetes in Canada. Found at: <http://www.diabetes.ca/Files/nationapolicysummit/Materials/Leading-initiatives-in-prevention-of-DC.pdf> Accessed November 10, 2008

INTERNATIONAL DIABETES MANAGEMENT PROGRAMS

This section describes seven integrated diabetes management and education programs, including examples from the United States, Great Britain, Australia and Israel. As with the Canadian models described in the preceding section, the models were selected based on their comprehensiveness and ability to serve high-risk populations. Some of the models also address the needs of rural populations or ethnic populations with high risks of diabetes. Several provide descriptions of innovative technologies, including Point of Care testing and Web-based delivery systems.

(1) Kaiser Permanente Diabetes Programs (United States)

Since 1997, Kaiser-Permanente Health Care in northern California has been recognized as a leader in the development of diabetes management and prevention models and has made considerable progress towards the goal of creating nationally standardized, evidence-based approaches to care that would in time produce cost savings through fewer hospitalizations and emergency department visits. The Kaiser Diabetes Initiative supports multidisciplinary care which is organized around a computer risk registry, with on-line access to data and, for high-risk clients, intensive management by specialty team.⁵³

All individuals with diabetes are scheduled for regular monitoring, medication adjustments, eye screening and group health education. Those with any risk factors, including high HbA1c, ACR, high blood pressure, retinopathy or foot problems, are given a six-month program of intensive case management, with nurse managers continually monitoring their care and providing follow-up via telephone. Clients with established cardiovascular disease, end-stage renal disease, advanced retinopathy or amputations receive

⁵³ Mirkin, R., Solomon, N. and Pettay, H. The Care Management Institute's Integrated Diabetes Care Program: A collaborative approach to improving patient care and outcomes. *The Permanente Journal*. 1998; 2(4): 45-53.

specialty care, with continuous monitoring by cardiologists, nephrologists and endocrinologists.

Core supports include clinical practice guidelines, interactive patient education curricula, and a sophisticated computer-based clinical information system that allows continuous assessment of care processes and outcomes. Clients also are offered self-management education, including a 3-hour *Introductory Diabetes* course and a multi-session *Living Well With Diabetes* program; both teach glucose monitoring, medication management, nutrition and exercise basics; the multi-session classes include information on complications and footcare.⁵⁴ Spanish-language and culturally-modified versions of the educational programs have been developed to meet the needs of Latino clients with diabetes.

Long-term outcome assessments demonstrate that the Kaiser model's intensive nurse-lead management of high risk clients produces better glucose control; however, good results seen in the six months of intensive case management are not sustained when clients return to usual care.⁵⁵ More recent evaluations indicate that Kaiser clients also have lower rates of foot and retinal complications and shorter hospital stays.⁵⁶

Subsequent analyses reveal that the lower rates of complication are directly related to the Kaiser diabetes management system's ability to give providers timely feedback on client outcomes, prompting providers to order scheduled testing, and when complications occur, make appropriate referrals to specialists.⁵⁷

⁵⁴ Kaiser Permanente. Found at: <http://kp.org.healthyliving> Accessed April 10, 2009.

⁵⁵ Domurat, E.S. Diabetes managed care and clinical outcomes: the Harbor City, California Kaiser Permanente diabetes care system. *American Journal of Managed Care*. 1999;5(10): 1299-1307.

⁵⁶ Taylor, C.B., Miller, N.H., Reilly, K.R., Greenwald, G., Cuning, D., Deeter, A., and Abascal, L. Evaluation of a nurse-care management system to improve outcomes in patients with complicated diabetes. *Diabetes Care*. 2003;26(4):1058-63.

⁵⁷ Mangione, C.M., Gerzoff, R.B., Williamson, D.F., Steers, W.N., Kerr, E.A., Brown, A.F, Waitzfelder, B.E., Marrero, D.G., Dudley, R.A., Kim, C., Herman, W., Thompson, T.J., Safford, M.M., and Selby, J.V. The association between quality of care and the intensity of diabetes disease management programs. *Annals of Internal Medicine*. 2006;145(2):107-116.

(2) Veteran's Health Administration Model (United States)

The Veteran's Health Administration (VHA) is the largest integrated health care system in the United States, designed to deliver publicly funded health care to veterans of the military services and their families, through a system of primary care clinics, hospitals and long-term care facilities. The system uses a sophisticated information management system, including patient registries, linked with Medicare data, which allow tracking of changes in individual patient's conditions over time.

The VA system has piloted two unique models of diabetes care, involving shared medical appointments and telemedicine. In the shared medical appointments model, nurse practitioners perform a lead role in care of patients with diabetes, working with physicians and pharmacists to adjust medications, educate clients, and, through motivational interviewing, encourage lifestyle changes.⁵⁸ The VA has also employed the *Health Hero* in-home telephone-based message system that prompts clients to input information about their glucose levels, diet and activity levels, which is then forward to nurse managers, who provide real-time monitoring of high risk clients, with beneficial results.⁵⁹

Overall evaluations of VA programs suggest that the most effective care is multidisciplinary; delivered by teams of nurse practitioners and part-time physicians; uses electronic health information systems, including registries, to improve access to care; and is flexibility, permitting team managers to adjust staffing and services to meet clients' needs.⁶⁰

⁵⁸ Watts, S.A., Gee, J., O'Day, M.E., Schaub, K., Lawrence, R., Aron, D., and Kirsh, S. Nurse practitioner-led multidisciplinary teams to improve chronic illness care: the unique strengths of nurse practitioner applied to shared medical appointments and group visits. *Journal of American Academy of Nurse Practitioners*. 2009;21(3):167-172.

⁵⁹ Dang, S., Ma, F., Nedd, N., Florez, H., Aguilar, E., and Roos, B.A. Care coordination and telemedicine improves glycemic control in ethnically diverse veterans with diabetes. *Journal of Telemedicine and Telecare*. 2007;13(5):263-267.

⁶⁰ Jackson, G.L., Yano, E.M., Edelman, D., Krein, S.L., Ibrahim, M.A., Carey, T.S., Lee, S.Y., Hartmann, K.E., Dudley, T.K., and Weinberger, M. Veterans Affairs primary care organizational characteristics associated with better diabetes control. *Journal of Managed Care*. 2005;11(4):225-237.

(3) University of Pittsburgh Integrated Diabetes Initiative (United States)

Beginning in 2000, the University of Pittsburgh Medical Centre (UPMC) introduced a system-wide integrated diabetes program based on Wagner's chronic care model.⁶¹ The 27-site UPMC system covers five urban and rural counties, spanning a region 400 km across. The program is supported by a registry, which delivers quarterly physician-specific reports over a rolling 12-month period, flags risk factors and provides reminders for scheduled tests. Overall, more than one-half of clients reach acceptable HbA1c levels.

In 2007, the UPMC expanded the system to integrate certified diabetes educators into primary care practices to deliver group and individual education and self-management training to people with pre-diabetes, those who were newly-diagnosed and established diabetes.⁶² It also uses the *HealthTrak* web portal which lets patients view their medical records, communicate via email with their primary care physician's office, and access self-management tools, tracking medication, diet and physical activity.⁶³ Use of the patient web-portal has been variable, because many patients have no interest in monitoring their care.

While primarily designed for urban settings, the UPMC model was tested in a six-physician rural practice in Appalachia.⁶⁴ Rural results were disappointing, as many clients missed appointments and dropped out of the education sessions. Providers felt that poor attendance by rural clients was largely due to external factors, including lack of public transportation, financial issues, and mobility challenges experienced by people with diabetes and physical disabilities.

⁶¹ Siminerio, L., Zgibor, J., and Solano, F.X. Implementing the chronic care model for improvements in diabetes practice and outcomes in primary care: the University of Pittsburgh Medical Centre Experience. *Clinical Diabetes*. 2004; 22(2): 54-58.

⁶² Pittsburgh Regional Initiative for Diabetes Education. "PRIDE Program." Found at: <http://prideofpa.org>.

⁶³ Hess, R., Bryce, C.L., Paone, S., Fischer, G., McTigue, K., Olshansky, E., Zickmund, S., Fitzgerald, K., and Siminerio, L. Exploring challenges and potentials of personal health records in diabetes self-management. *Telemedicine and e-Health*. 2007; (13)5: 509-517.

⁶⁴ Siminerio L, Piatt G, Zgibor JC. Implementing the chronic care model for improving diabetes care and education in a rural primary care practice. *Diabetes Educator*. 2005;31:225-234.

(4) Ten City Challenge: Pharmacist Diabetes Coaching (United States)

Given the many challenges associated with the management of diabetes, the American Pharmacists Association introduced the Ten Cities Challenge Program in 2005.⁶⁵ Building on earlier pharmacist-delivered education programs, this initiative trained community pharmacists as “coaches” to improve diabetes self-management skills. Working in partnership with collaborative care teams, pharmacists offer clients instruction around setting goals, correct use of medications, and the importance of having regularly scheduled blood pressure, cholesterol, foot and eye exams. Costs are covered by employee benefit plans, with employers covering co-payments as an incentive for workers to participate.

The program is currently offered in the cities of Charleston, Chicago, Colorado Springs, Honolulu, Los Angeles, Milwaukee, Pittsburgh, Tampa, and in small towns and rural areas of Northern Georgia and Western Maryland. Activities are coordinated through collaborative care teams, including pharmacists, diabetes educators and physicians, who are compensated for their time. Each client is assigned a pharmacist coach, who provides education around medication, goal setting, and reinforcement of each individualized care plan. Additionally, pharmacists give regular feedback to physicians on patient status, progress towards self-management goals, and needs.

Initial evaluations of the program indicated that over a year, clients received an average of 6 educational sessions with pharmacist coaches, with each session lasting approximately 51 minutes.⁶⁶ Compared to patients receiving usual care, enrolled clients showed significant improvements in glucose, cholesterol, blood pressure and BMI measures, with generally closer adherence to recommended plans of care.

⁶⁵ American Pharmacists Association. Diabetes Ten City Challenge. Found at: http://www.aphafoundation.org/programs/diabetes_ten_city_challenge/330.cfm. Accessed March 18, 2009.

⁶⁶ Fera, T., Bluml, B.M., Ellis, W.M., Schaller, C.W. and Garrett, D.G. Diabetes Ten City Challenge. *Journal of the American Pharmacy Association*. 2009;49:e52-e60

(5) Ozark Rural Self-Management Education Telemedicine (United States)

Diabetes self-management education has been shown to be effective when delivered through group visits in medical and community settings. There have been few studies, however, which have focused specifically upon DSME in rural communities. Ozark Health, a hospital situated in Clinton, Arkansas was selected as the pilot site, for testing the implementation of a DSME telemedicine system to deliver services to a predominantly rural county that did not have any standard diabetes education available.⁶⁷

The DSME-T program included six bi-weekly group sessions (two one-hour sessions and four two-hour sessions) delivered via web-cam telehealth technology, with a registered nurse available on-site for additional information and support during each class. The sessions involved presentation, demonstration and interactive discussion using an American Diabetes Association recommended diabetes curriculum.

Delivering diabetes education via telemedicine posed a number of challenges, however, related to technical issues and adopting the curriculum to distance-education formats. Class sizes, for example, had to be kept small, to ensure that all participants were in range of the web-cam and monitor. Some activities, such as demonstrations of food portions or footcare techniques, could not be translated to an Internet format. Similarly, suggestions for further study using on-line resources could not be implemented, because most participants did not have Internet in their homes. Results, however, indicated that the web-based program achieved the goal of improving patients' confidence about managing diabetes. Patients' self-efficacy measures rose post-program and the percentage of patients who monitored their blood on a daily basis increased, as did the number of participants who received professional foot examinations.

⁶⁷ Balamurugan, A., Hall-Barrow, J., Blevins, M.A., Brech, D., Phillips, M., Holley, E., and Bittle, K. A pilot study of diabetes education via telemedicine in a rural underserved community. Opportunities and challenges: a continuous quality improvement process. *The Diabetes Educator*. 2009; 35(1): 147-154.

(6) The DESMOND Program (United Kingdom)

The DESMOND program (Diabetes Education and Self-Management for Ongoing Clients with Newly-Diagnosed Diabetes) was initially piloted in 2003 in 207 general practices throughout 17 primary care sites within England and Scotland.⁶⁸ Delivered either as a full-day 6-hours session or over two half-days, to maximum of 10 people with newly-diagnosed Type II diabetes and family caregivers, the program is delivered by teams of two trained educators, usually practice nurses, diabetes nurses or dieticians, who support participants in learning about risk factors, healthy eating, physical activity and medication options.

A controlled trial comparing DESMOND to usual one-on-one or group diabetes education sessions demonstrated that, 12 months after diagnoses, participants were more successful in stopping smoking and reducing weight. DESMOND patients also had increased confidence in their ability to control the disease and less depression; however, there were no significant differences in clinical outcomes, including glucose levels, blood pressure or complications.⁶⁹

Three new programs based on DESMOND are currently under development: one addresses the needs of people with Type II diabetes who are 2 to 10 years post-diagnosis; another version will be culturally adapted to meet the needs of Southeast Asian populations, who are at high risk of developing the disease; and the third, will assist patients in improving their knowledge and skills around monitoring blood and urine glucose levels.

⁶⁸ Desmond Program. "About the Program." Found at: <http://www.desmondproject.org.uk/about.html>. Accessed March 31, 2009.

⁶⁹ Davies, M.J., Heller, S., Skinner, T.C., Campbell, M.J., Carey, M.E., Craddock, S., Dallosso, H.M., Daly, H., Doherty, Y., Eaton, S., Fox, C., Oliver, L., Rantell, K., Rayman, G., and Khunti, K. Effectiveness of the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed type 2 diabetes: cluster randomised controlled trial. *British Medical Journal*. 2008 ;336(7642):491-4955.

(7) Mallee Track Point-of-Care Diabetes Management (Australia)

In 2003, seven communities in the rural ‘Mallee Track’ region of South Australia collaborated to establish a multidisciplinary diabetes management and prevention service. The goal was to improve access to care, by providing outreach risk assessment and management services, thereby eliminating the need for residents to travel two hours or more for testing and other specialized services.⁷⁰

Risk assessments, offered by community nurses at schools, social and recreational events, used point-of-care technology (POCT) to assess blood glucose, total cholesterol and blood pressures. Other diabetes and cardiovascular risks were assessed through a questionnaire documenting age, family history of diabetes, smoking, weight and exercise. Multiple sessions were offered in each location and clients who tested out of range were referred to community health centres for follow-up.

Along with risk assessments, the service offered “one stop” management to people diagnosed with diabetes.⁷¹ Appointments, scheduled on a quarterly basis, combined a physician assessment and nurse-managed POCT testing (HbA1C, ACR, total cholesterol, HDL, LDL and glucose), with visits to a diabetes educator and podiatrist. Results from POCT were available in 15 minutes, permitting physicians to make immediate adjustments in medication and treatment plans. Data from the registry established to record results revealed that about 20% of the region’s adult population had been screened and 75% of those diagnosed with diabetes had taken part in the management program. Two-thirds of clients achieved good glycemic control, improved lipid levels and lowered their blood pressure readings.

⁷⁰ Ouyen Victoria. “Overview: Diabetes Management Along the Mallee Track.” Found at: <http://www.mannet.com.au/camh/research>. Accessed March 28, 2009.

⁷¹ Shephard, M.D., Mazzachi, B.C., Shephard, A.K., McLaughlin, K.J., Denner, B., and Barnes, G. The impact of point of care testing on diabetes services along Victoria's Mallee Track: results of a community-based diabetes risk assessment and management program. *Rural and Remote Health*. 2005;5(3):371.

(8) Western Negev Mobile Diabetes Care Program (Israel)

In 1996, Israel's major health care organizations established urban multidisciplinary diabetes intervention teams, comprised of family physicians, primary care nurses, diabetologists, dieticians, and health educators.⁷² Supported by a computerized registry that generates reminders and continuous feedback on indicators of care, the system provides integrated clinical care and patient education, with corresponding improvements in access.

When it became apparent in 2000 that rural residents had poor access to the integrated chronic disease system, the Western Negev Mobile Diabetes Clinic was developed.⁷³ The multidisciplinary team includes a physician who specializes in diabetes care, a diabetes nurse educator and a dietician, who respectively deliver physical assessments, client education and nutritional information, who regularly travel to the region's primary care clinics to deliver diabetes management and education. The nurses are responsible for the coordination of the program activities, educational sessions and staff meetings with local primary care providers.

The results of a program assessment demonstrated that the Negev mobile clinic achieved its goal of providing specialized care to rural patients with diabetes at locations closer to their residences. Glucose levels were reduced significantly and blood pressure was reduced to levels deemed to be satisfactory.⁷⁴

More than 70% of patients with poorly controlled diabetes showed improvements. Patients with poor compliance and those with other serious chronic conditions or mobility limitations, however, were less likely to benefit, due to irregular attendance at the outreach clinics.

⁷² Godfracht, M., Levin, D., Peled, O., Poraz, I. Stern, E., Weissl, D. and Lieberman, L. "Diabetes in the Community: 12 years of chronic disease management program." Presentation at Changing Diabetes Barometer: International Seminar. Oxford: UK; December 8-9, 2008.

⁷³ Maislos M. Western Negev Mobile Diabetes Care Program: A model for interdisciplinary diabetes care in a semi-rural setting. *Acta Diabetologia*. (2002) 39:49-53.

⁷⁴ Maislos, M. and Weisman, D. Multidisciplinary approach to patients with poorly controlled type 2 diabetes mellitus: a prospective, randomized study. *Acta Diabetologia*. 2004;41(2): 44-48.

DIABETES AND ABORIGINAL PEOPLES

Although diabetes was comparatively unknown among Aboriginal peoples several generations ago, the disease emerged in epidemic proportions during the 1970s.⁷⁵ Available statistics suggest that diabetes occurs in Indigenous communities at rates 3 to 5 times higher than among the general population, with corresponding increases in diabetes-related complications.⁷⁶ As a further indicator of the seriousness of the disease, Aboriginal peoples often develop Type II diabetes at a much younger age than would otherwise be expected. Aboriginal women also are at particular risk of developing gestational diabetes.⁷⁷ Among the First Nations communities studied, Sandy Lake, north of Sioux Lookout, has a prevalence rate of 26.1%, which is among the highest rates for Type II diabetes ever documented.⁷⁸

National Survey Data

Nationally, the best estimates on the effects of diabetes among Aboriginal peoples are found in two self-report surveys: the First Nations Regional Health Survey (FNRHS) (2002-03), for on-reserve populations, and the Aboriginal Peoples Survey (2001), for off-reserve populations (See *Table 3*). Overall, the FNRHS confirmed that 19.7% of First Nations adults had been diagnosed with diabetes.⁷⁹ Type II diabetes predominated, with only 9.9% reporting Type I diagnoses. Prevalence rates were highest for older First Nations women,

⁷⁵ Young, T., Reading, J., Elias, B., and O'Neil, J.D. Type 2 diabetes mellitus in Canada's First Nations: status of an epidemic in progress. *Canadian Medical Association Journal*. 2000; 163: 561-566.

⁷⁶ Naqshbandi, M., Harris, S.B., Esler, J.G., and Antwi-Nsiah, F. Global complication rates of type 2 diabetes in Indigenous peoples: A comprehensive review. *Diabetes Research and Clinical Practice*. 2008;82(1):1-17.

⁷⁷ Kelly, C., and Booth, G.L. Diabetes in Canadian Women. *BMC Womens Health*. 2004; 4(S1): S16.

⁷⁸ Harris SB, Gittelsohn J, Hanley A, Barnie A, Wolever TM, Gao J, Logan A, Zinman B. The prevalence of NIDDM and associated risk factors in native Canadians. *Diabetes Care*. 1997; 20(2):185-187.

⁷⁹ First Nations Centre. *First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities*. Ottawa: November 2005. (pp. 70-76). Ontario data not available.

with rates for ages 55-64 (36.7%) and 65 or older (40.2%) about four times higher than equivalent national age groups.

The Aboriginal People's Survey (APS) conducted in 2001 showed 7% of Ontario's Aboriginal-identity population had diabetes, compared with 4.3% of the general population. Rates were highest for individuals identifying as North American Indian (11.0%) and lower for those in Métis and Inuit populations (6.0% and 2.3%, respectively).⁸⁰

Table 3
Diabetes - Prevalence Rates for Aboriginal Populations (Self-Reported Survey Data) (Canada) (Rate per 100 individuals)

National Data - Diabetes (All Ages)	Category	Rate
Canadian Community Health Survey (2001)	General adult population	4.3
First Nations Regional Health Survey (2002-03)	On-reserve	19.7
Aboriginal Peoples Survey (2001)	Off-reserve	7.0

Sources:

Statistics Canada. (2003) *Canadian Community Health Survey, Cycle 3.1. (2002-03)* Ottawa, ON.

First Nations Centre. *First Nations Regional Longitudinal Health Survey (RHS) 2002/03: Results for Adults, Youth and Children Living in First Nations Communities.* Ottawa, ON: November 2005.

Statistics Canada. (2003). *Aboriginal Peoples Survey 2001: Initial Findings.* Ottawa, ON: Statistics Canada, Catalogue no. 89-589.

⁸⁰ Statistics Canada. (2003). *Aboriginal Peoples Survey 2001: Initial Findings.* Ottawa, ON: Statistics Canada, Catalogue no. 89-589.

Ontario Data

Because Ontario's administrative health databases do not contain ethnic identifiers, provincial estimates on the prevalence of diabetes among Aboriginal populations are only available through analyses of self-report data, such as those published in the Aboriginal People's Survey (2001), or through geographical analyses of administrative data, as was done in the *ICES Practice Atlas on Diabetes* (2003).

The Aboriginal People's Survey revealed that 12,610 of Ontario's 134,220 Aboriginal identity population (9.4%) had diabetes, which is approximately double the rate reported for the Ontario population overall.⁸¹ Within the Aboriginal population, there is some variation in the extent to which specific groups experience diabetes. Diabetes was more commonly reported among people identifying as First Nations (11.0%), than among those who identified as Métis (6.0%).

The *ICES Atlas* analysis of 1994 and 1998 Ontario Diabetes Registry data (Shah et al. 2003) showed even higher rates of prevalence. This analysis found that 13% of adults living in geographically-distinct First Nations reserves and settlements had been diagnosed with diabetes, a rate three times higher than found in the rest of Ontario.⁸² First Nations people with diabetes who lived in these communities were more likely to experience complications and hospitalization for cardiovascular or cerebrovascular diseases than people with diabetes who lived elsewhere. Those who resided in the most remote communities were at greatest risk of avoidable complications.⁸³

⁸¹ Statistics Canada. (2003). *Aboriginal Peoples Survey 2001: Supporting Tables*. Ottawa, ON: Statistics Canada, Catalogue no. 89-592. (pp. 15, 38, 58).

⁸² Shah, B., Anand, S., Zinman, B. & Duong-Hua, M. (2003). "Diabetes and First Nations People." Pp. 231-248. In *Diabetes in Ontario: An ICES Practice Atlas*. Hux, J., Booth, G., Slaughter, P., Laupacis, A. (Eds). Toronto, ON: Institute for Clinical Evaluative Sciences, pp. 231-248.

⁸³ Booth, G., Hux, J., Fang, J., & Chan, B. (2005). Time trends and geographic disparities in acute complications of diabetes in Ontario, Canada. *Diabetes Care*, 28(5), 1045-1050.

These estimates are believed to be low, however, as they do not capture First Nations people living off-reserve, nor do they address cross-border care. As Shah and others have commented, the actual numbers of First Nations people affected by diabetes may be much higher, with up to 50% of residents in northern Oji-Cree communities showing evidence of glucose abnormalities.⁸⁴ Incidence of gestational diabetes is equally high, with between 8% and 13% of women affected.⁸⁵

Risk Factors

Although the evidence is limited, it has been suggested that the high rates of diabetes among Aboriginal populations and associated cardiovascular complications have occurred because of dramatic changes in lifestyle and environment over a few generations.⁸⁶ The associations between socioeconomic transitions and the development of diabetes among Aboriginal peoples are particularly evident in the studies of Northwestern Ontario's Sandy Lake First Nation, which has tracked changes in diabetes prevalence over a period of more than twenty years.⁸⁷

First Nations communities have also undergone changes in food consumption and activity patterns, with associated increases in the proportions of the population who are overweight, a primary risk factor for diabetes. The most recent studies,⁸⁸ from Sandy Lake and eight other First Nations confirmed that 8 of every 10 in remote and semi-remote communities were overweight or obese. Although younger individuals who lived in less

⁸⁴ Shah, B., Anand, S., Zinman, B. & Duong-Hua, M. (2003). "Diabetes and First Nations People." Pp. 231-248. In *Diabetes in Ontario: An ICES Practice Atlas*. Hux, J., Booth, G., Slaughter, P., Laupacis, A. (Eds). Toronto, ON: Institute for Clinical Evaluative Sciences, pp. 231-248. (p. 234).

⁸⁵ Harris, S.B., Caulfield, L.E., Sugamori, M.E., Whalen, E.A. and Henning, B. The epidemiology of diabetes in pregnant Native Canadians: A risk profile. *Diabetes Care*. 1997; 20(9): 1422-1435. .

⁸⁶ Young, T.K. Are subarctic Indians undergoing the epidemiologic transition? *Social Science and Medicine*. 1988;26(6): 659-671.

⁸⁷ Harris, S.B., Gittelsohn, J. and Hanley, A. The prevalence of NIDDM and associated risk factors in Native Canadians. *Diabetes Care*. 1997; 20(1): 185-187.

⁸⁸ Ho, L., Gittelsohn, J., Sharma, S., Cao, X., Treuth, M., Rimal, R., Ford, E., and Harris, S. Food-related behavior, physical activity, and dietary intake in First Nations - a population at high risk for diabetes. *Ethnicity and Health*. 2008;13(4):335-49.

isolated communities had better awareness of healthy food alternatives, there was no difference in food consumption patterns between remote and semi-remote communities. Foods eaten were high in energy, fat and sugar and low in fibre in all locations. As might be expected, residents of the communities who were overweight were also more likely to have diabetes.

Other environmental factors, including food security issues, sedentary lifestyles and hazardous environments for recreation, are believed to contribute to the high levels of diabetes observed among Aboriginal populations. In the Sandy Lake studies, lack of affordable and healthy food choices was cited as a primary contributor to obesity and, by extension, to diabetes.⁸⁹ Food security and safety issues also negatively affect the health of off-reserve Aboriginal people, with three times as many Aboriginal households as non-Aboriginal reporting that they could not afford food for themselves or had days on which they did not have food for their children.⁹⁰

Aboriginal families in remote, rural and urban communities also lack access to affordable and safe recreation. In many communities, even walking is not feasible, due to lack of sidewalks, concerns about crime, or in remote communities, worry about unique hazards such as dogs on the loose and bears in the neighbourhood.⁹¹ Similar concerns have been cited as contributing to lack of physical activity among Aboriginal people living in Northwestern Ontario.⁹²

⁸⁹ Ho, L.S., Gittelsohn, J., Harris, S.B. and Ford, E. Development of an integrated diabetes prevention program with First Nations in Canada. *Health Promotion International*. 2006; 21(2): 88-97.

⁹⁰ Willows, N.D., Veugelers, P., Raine, and Kuhle, S. Prevalence and sociodemographic risk factors related to household food security in Aboriginal peoples in Canada. *Public Health Nutrition*. 2008;24: 1-7.

⁹¹ Kirby, A., Levesque, L., Wabano, V. and Robertson-Wilson, J. Perceived community environment and physical activity involvement in a northern rural Aboriginal community. *International Journal of Behavioral Nutrition and Physical Activity*. 2007; 4(4): 63.

⁹² Northern Diabetes Health Network. *Aboriginal Diabetes Needs Assessment in Northern Ontario. Report prepared for the Ministry of Health and Long-Term Care*. Thunder Bay, ON; November 2006.

ABORIGINAL DIABETES PROGRAMS

At the present time, a range of screening, prevention and management programs have been developed in Canada to address the high rates of diabetes and complications among Aboriginal peoples.⁹³ Most are funded through Health Canada's Aboriginal Diabetes Initiative, which supports diabetes treatment and lifestyle preventions.⁹⁴ The ADI includes two programs: the First Nations On-Reserve and Inuit Communities Program; and the Métis, Off-Reserve Aboriginal and Urban Inuit Prevention and Promotion Program, which delivers off-reserve services through Aboriginal organizations. The United States, Australia and New Zealand have similar diabetes strategies and programs, with the most successful delivered in partnership with indigenous communities.

The following section describes seven examples of innovative and integrated Aboriginal diabetes programs, four models from Canada and one each from the United States, Australia and New Zealand. Although strategies vary in each jurisdiction, the examples chosen all represent innovative and community-based diabetes programming, which recognizes and respects Aboriginal peoples' preferences for holistic and culturally resonant diabetes programs.^{95 96 97}

⁹³ Ship, S.J. and Jacobs, J. First Nations Diabetes Programs. Found at: <http://www.niichro.com/Diabetes/Dia6.html>.

⁹⁴ Health Canada. Aboriginal Diabetes Initiative (Evaluatory Framework) Found at: http://www.hc-sc.gc.ca/fnih-spnia/pubs/diseases-maladies/_diabete/2002_frame-cadre-eval/info-eng.php. Accessed: February 13, 2009.

⁹⁵ Pegler, J., DeBruyn, L., Burrows, N.R., Gilbert, E.D., and Thompson, J.L. Sharing a vision of hope for diabetes care and prevention among American Indian and Alaska Native Communities: the National Diabetes Prevention Centre. *Journal of Public Health Management Practice*. 2003; (Suppl):S26-9.

⁹⁶ O'Dea, K., Rowley, K.G. and Brown, A. Diabetes in Indigenous Australians: possible ways forward. *Medical Journal of Australia*. 2007; 186(10): 494-70.

⁹⁷ Potvin, L., Cargo, M., McComber, A.M., Delormier, T., and Macaulway, A.C. Implementing participatory intervention and research in communities: lessons from the Kahnawake Schools Diabetes Prevention Project in Canada. *Social Science and Medicine*. 2003;56(6):1295-1230

(1) First Nations Mobile Telemedicine Diabetes Clinic (British Columbia)

Supported by funding from Health Canada and developed in partnership with UBC and the Carrier-Sekani Health Authority, the First Nations Mobile Diabetes Telemedicine Clinic was developed in 2002 to improve care for an estimated 22,000 Aboriginal people residing in 22 remote reserve communities situated in British Columbia's Northern Interior Region.⁹⁸

The mobile clinic, staffed by two half-time registered nurses certified as a diabetes educator and a half-time eye care technician, offers POCT testing (HbA1C, ACR, total cholesterol, HDL, LDL and triglycerides); screening for retinopathy and glaucoma; blood pressure, height and weight measurement; footcare examinations and individual management advice. The diabetes educator also offers group education sessions on diabetes prevention and risk management, delivered in collaboration with Community Health Nurses and Community Health Representatives. Reports are forwarded to primary care physicians, who refer clients for specialist care when complications are detected.

A full-time project coordinator, based in Prince George, schedules two visits annually to each of the communities. Assessments revealed that First Nations clients and their family caregivers believed that the mobile clinic was a satisfactory means of delivering care, because it eliminated the necessity of travelling outside their communities to access testing, footcare services or specialist care. As well, the cost of the van and service delivery, over the first year of operation, was lower than the costs that would be incurred if the First Nations clients had to go outside their communities for care.⁹⁹

⁹⁸ Carrier Sekani Family Services. Mobile Diabetes Clinic. Found at: <http://www.csfs.org>. Accessed March 28, 2009.

⁹⁹ Jin, A.J., Martin, D., Maberley, D., Dawson, K.G., Secombe, D.W. and Beattie, J. Evaluation of a mobile diabetes care telemedicine clinic serving Aboriginal communities in northern British Columbia, Canada. *Circumpolar Health*. 2004;63(S2): 124-128.

(2) First Nations Diabetes Integration Project (Manitoba)

The Manitoba First Nations Diabetes Integration Project (DIP), a mobile diabetes care and treatment service designed to improve access to care for rural and remote First Nations, was piloted in 2007.¹⁰⁰ Programs were developed to address known gaps in care, specifically lack of follow-up care and difficulties accessing “off reserve” diabetes education, footcare and other speciality services. Travel for health education purposes is not covered by Health Canada’s Non-Insured Health Benefits, and travel for footcare is covered in remote northern First Nations but not in southern locations.

Each van is staffed by two specially trained nurses, an RN and LPN, who screen for cardiovascular, retinal, kidney, limb and mental health complications and provide self-management education, including nutrition and physical activity counselling. Vans are equipped with retinal screening and POCT equipment (HbA1C, ACR, total cholesterol, HDL, LDL and triglycerides).¹⁰¹ When complications are found, nurses use care pathways to guide referrals to family physicians, diabetologists, endocrinologists, infectious disease specialists, dieticians, mental health counsellors and footcare services.¹⁰²

Currently, the project delivers services to three southern and three northern First Nations. Full implementation will see 11 mobile diabetes teams located throughout the province, six in the south, including one team based in Winnipeg, and five in the north. The goal is to improve access to comprehensive diabetes care, to residents of all of the province’s urban, rural and remote First Nations.

¹⁰⁰ Government of Manitoba. “Diabetes Integration Project: RDP Share and Learn Workshop Care and Support.” January 17, 2008. Found at: www.gov.mb.ca/health/diabetes/rdp/dip.pdf. Accessed April 10, 2009.

¹⁰¹ Four Arrows Regional Health Authority. Diabetes Integration Project. Found at: <http://www.fourarrowsrha.ca/web/about-dip.html>. Accessed March 28, 2009.

¹⁰² Diabetes Integration Project. DIP Team Nurse Referral Pathway. Found at: <http://www.diabetesintegrationproject.ca/about-nrp.html>. Accessed April 10, 2009.

(3) Kahnawake School Diabetes Prevention Project (Quebec)

The Kahnawake Schools Diabetes Prevention Project (KSDPP), established in 1994, introduced physical activity and nutrition programs within community schools and the promoted healthy family lifestyles outside of school.¹⁰³ Community-based interventions were directed at both the children and the parents and it was anticipated that the parents would reinforce the healthy lifestyle practices learned in school. The project also partnered with community-based groups to improve access to affordable recreational activities, developing resources such as bicycle and walking paths.

Although initial assessments of KDSPP outcomes showed mixed results,¹⁰⁴ recent evaluations suggest that, contrary to the trends in many other First Nations, Kahnawake diabetes prevalence rates are levelling off and approaching the Canadian population rates.¹⁰⁵ Its innovations, including development of grade 1-6 health curriculums, no-junk food school health policies, partnerships with local grocery stores to promote healthy and affordable food choices, and creation of a training centre to teach other Aboriginal communities about the model, have been widely adapted.¹⁰⁶ Additionally, the model is frequently cited a successful example of an ecological approach to diabetes prevention, which uses multiple strategies to reduce risk at both the individual and environmental levels.¹⁰⁷

¹⁰³ Kahnawake School Diabetes Prevention Project. About Us. Found at:

<http://www.ksdpp.org/elder/intervention.html>. Accessed: April 7, 2009

¹⁰⁴ Paradis, G., Lévesque, L., Macaulay, A.C., Cargo, M., McComber, A., Kirby, R., and Receveur, O. " Impact of a diabetes prevention program on body size, physical activity, and diet: Kanien'keha:ka (Mohawk) children 6 to 11 years old: 8-year results from the Kahnawake Schools Diabetes Prevention Project." *Pediatrics*. 2005;115(2):333-9.

¹⁰⁵ Horn, O.K., Jacobs-Whyte, H., Ing, A., Bruegl, A., Paradis, G., and Macaulay, A.C. Incidence and prevalence of Type 2 diabetes in the First Nation Community of Kahnawake, Quebec, Canada, 1986-2003. *Canadian Journal of Public Health*. 2007; 98(6): 438-443.

¹⁰⁶ Kahawake Schools Diabetes Prevention Project. KDSPP Training Program. Found at: <http://www.ksdpp.org/elder/intervention.html>. Accessed: April 7, 2009

¹⁰⁷ Levesque, L., Guilbault, G., Delormier, T. and Potvin, L. Unpacking the black box: a deconstruction of the programming approach and physical activity interventions implemented in the Kanawake Schools Diabetes Prevention Project. *Health Promotion Practice*. 2005;6(1); 64-71.

(4) Sandy Lake First Nation Health and Diabetes Project (Ontario)

The Sandy Lake First Nation Health and Diabetes Project (SLHDP), an integrated prevention program that links clinical research and community-based interventions, was instituted in 1991. The project, which has produced over 80 published articles, has documented that residents of the communities have 3 to 5 times greater risk of developing diabetes and cardiovascular complications.¹⁰⁸ Current clinical activities are focussed assessing risks of developing kidney, eye and nerve damage, using POCT testing (ACR, Hb1AC), retinal cameras and neuropathy screening methods.

The SLHDP diabetes project¹⁰⁹ now includes six preventive interventions: First Nations School Curriculum on Diabetes (grades 3 to 6), Community Radio Shows, Home Visit Programs, Healthy Food Choices Program, Morning School Snack Program, and Community Walking Trails. Initial evaluations suggested that the SLDHP improved knowledge and encouraged families to make healthy food choices, although no significant changes occurred in weight or physical activity.

The Zhiiwapenewin Akino'maagewin Program (ZATB), which tested the Sandy Lake model in eight remote and semi-remote NWO First Nations, demonstrated that the program could be adapted to address the needs, health beliefs, cultural traditions, activity patterns and resources of different First Nations communities.¹¹⁰ Results from the ZATB showed that the model was equally successful in these locations, producing measurable improvements in knowledge about food and healthy food choices. Over time, it is anticipated that residents of participating First Nations will improve weight and physical activity, thereby eliminating significant risk factors for diabetes.

¹⁰⁸ Harris SB, Gittelsohn J, Hanley A, Barnie A, Wolever TM, Gao J, Logan A, Zinman B. The prevalence of NIDDM and associated risk factors in native Canadians. *Diabetes Care*. 1997; 20(2):185-187.

¹⁰⁹ Sandy Lake. "Sandy Lake Diabetes Project". Found at: <http://www.sandylakediabetes.com>. Accessed April 10, 2009.

¹¹⁰ Ho, L.S., Gittelsohn, J., Harris, S.B. and Ford, E. Development of an integrated diabetes prevention program with First Nations in Canada. *Health Promotion International*. 2006; 21(2): 88-97.

(5) Diabetes Healthy Heart Program (United States)

In 1997, the American federal government established the Special Diabetes Program for Indians (SDPI), to support treatment and prevention services in tribal and urban areas. The IHS DPP supports over 333 community-based diabetes programs, 66 demonstration projects, and development of a diabetes data electronic medical record infrastructure. Current demonstration projects target two areas: (i) preventing the development of diabetes in at-risk individuals and (ii) preventing diabetic cardiovascular complications through lifestyle change.

The Diabetes Healthy Heart Program of the Albuquerque Indian Health Centre,¹¹¹ for example, supports Native Americans with diabetes who reside in the urban area and three rural Pueblos. Services are delivered by a multidisciplinary team, including a supervising physician, a social worker, personal trainer, and four nurses, pharmacists and nutritionists, who collaborate on care management and conduct outreach activities.

The team teaches practical lifestyle modifications, using two cultural curricula, *Balancing Your Life and Diabetes* and *Honoring the Gift of Heart Health*. To encourage increased physical activities, participants in the program have access to the *Healthy Heart Centre*, a community recreational facility, that offers the use of exercise equipment and personal trainer supports, with exercises supervised by medical personnel, if necessary. Overall evaluation of the IHS programs confirmed that better outcomes are found among these types of integrated diabetes programs, which offer coordinated screening, treatment and education, use multidisciplinary care teams, and have registries to track clinical outcomes and complications.¹¹²

¹¹¹ Department of Health and Human Services. Indian Health Services. Division of Diabetes Treatment and Prevention: Featured Demonstration Projects. Found at: <http://www.diabetes.ihs.gov> . Accessed March 15, 2009.

¹¹² Roubideaux, Y., Noonan, C., Goldberg, J., Valdez, S., Brown, T., Manson, S., and Acton, K. Relation between the level of American Indian and Alaska Native diabetes education program services and quality-of-care indicators. *American Journal of Public Health*. 2008; 98(11): 2079-1522.

(6) Aboriginal Health Worker Outreach Models (Australia)

In 1990s, the Australian federal and territorial governments supported the development of strategies designed to address the exceedingly high rates of diabetes in remote Aboriginal communities, with an emphasis on community-based programs staffed by Aboriginal Health Workers (AHWs). Projects included: (i) Aboriginal Diabetes Self-Management, which tested a culturally modified form of the Flinders self-management planning tools, delivered by AHWs working in partnership with physicians;¹¹³ (ii) Aboriginal Chronic Disease Outreach Intervention, where AHWs followed algorithms for regular diabetes and hypertension testing and treatment, with backup from nurses via telemedicine;¹¹⁴ and (iii) Quality Assurance for Aboriginal and Torres Strait Islander Medical Services (QAAMS), employing AHWs for POCT (HbA1C and ACR) in remote communities, thereby avoiding client's need to travel for care.¹¹⁵

Although all programs produced clinical benefits and improvements in self-management, several structural barriers that impeded program success.¹¹⁶ These included shortages of trained Aboriginal health workers and significant absenteeism among workers; absence of resources to help health centres make the transition from paper to electronic medical records; and difficulties of adapting disease-specific funding formulae to support integrated chronic disease programming, which could address both diabetes and its cardiovascular risks.

¹¹³ Battersby, M., Ah Kit, J., Pridcaux, C., Harvey, P.W., Coffins, J.P. and Mills, P.D. Implementing the Flinders Model of self-management support with Aboriginal people who have diabetes: Findings from a pilot study. *Australian Journal of Primary Health*. 2008; 14(1): 66-74.

¹¹⁴ Hoy, W.E., Kondalsamy-Chennakesavan, S., Scheppingen, J., Sharma, S. and Katz, I. A chronic disease outreach program for Aboriginal communities. *Kidney International*. 2005; 68(s98): S76-282.

¹¹⁵ Shephard, M.D. "Cultural and Clinical effectiveness of the 'QAAMS' Point-of-care testing Model for Diabetes Management in Australian Aboriginal Medical Services" *Clinical Biochemistry Review*. 2006; 27(3). 161-170.

¹¹⁶ Hoy, W.E., Kondalsamy-Chennakesavan, Smith, J., Sharma, S., Davey, R. and Gokel, G. Setting up chronic disease programs. *Ethnicity and Disease*. 2006; 16(2S2): S2-73-S2-78.

(7) Counties Manukau Diabetes Care Management Model (New Zealand)

As part of a national strategy to address rapidly rising rates of diabetes among Maori and Pacific Islanders,¹¹⁷ the Counties Manukau in New Zealand implemented a Diabetes Chronic Care Model during 2001.¹¹⁸ Although resources differ from one community to the next, the model relies on regional teams, comprised of diabetologists, dieticians, ophthalmologists, which deliver specialized supports to general practitioners and their practice nurses. In turn, primary care practitioners are funded to spend time actively managing the care of clients with diabetes. An EMR template drives the program, providing reminders and checklists for testing and referrals to other health and social services. Once data is entered, the system generates guideline decision support and practitioner payments.

In partnership with Maori and Pacific Islander communities, Manukau has also developed the *Let's Beat Diabetes* strategy to support healthy lifestyles.¹¹⁹ It includes the "Green Prescription Program" promoting physical activity; the "Healthy Kai Program" which works with retailers to promote healthy and affordable food; and the "Growing for Health Initiative," which develops community gardens. As well, programs using Maori Community Health Workers as diabetes educators and peer support workers have been piloted to reduce risks and encourage healthy living among families with histories of diabetes, including gestational diabetes.¹²⁰

¹¹⁷ Ministry of Health, New Zealand. Diabetes 2000. Found at: [http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/4735077ed3fd9b56cc256a41000975ca/\\$FILE/Diabetes2000.PDF](http://www.moh.govt.nz/moh.nsf/238fd5fb4fd051844c256669006aed57/4735077ed3fd9b56cc256a41000975ca/$FILE/Diabetes2000.PDF) . Accessed February 20, 2009.

¹¹⁸ Rea, H., Kenealy, T., Wellingham, J., Moffitt, Al., Sinclair, G., McAueley, S., Goodman, M. and Arcus, K. Chronic care management evolves towards integrated care in Counties Manukau, New Zealand. *The New Zealand Medical Journal*. 2007; 120(1252).

¹¹⁹ Lets Beat Diabetes Consortium. "Let's Beat Diabetes Initiative: Counties Manakau." Found at: http://www.letsbeatdiabetes.org.nz/page/diabetes_5.php . Accessed February 20, 2009.

¹²⁰ Simmons, D., Rush, E., Crook, N.; Te Wai o Rona Diabetes Prevention Strategy Team. Development and piloting of a community health worker-based intervention for the prevention of diabetes among New Zealand Maori. *Public Health Nutrition*. 2008;11(12):1318-1325.

WHAT MAKES A SUCCESSFUL DIABETES STRATEGY?

As the preceding sections suggest, there is a wide range of interventions that can be implemented to improve diabetes management and prevention, with varying degrees of success. The challenge for decision-makers, however, is to determine which approaches work best and, among these approaches would be most effective in a specific delivery context.

Tailoring Interventions

As Kreindler's recent review suggests, it is not necessary to implement the Chronic Care Model in its entirety and to attempt to do so, would likely be an exercise in futility.¹²¹ She recommends interventions tailored to health care systems and the communities served:

- i. delivery-system redesign, specifically movement towards group visits, one stop shopping, or same day visits, produce improvements by delivering more timely care;
- ii. multidisciplinary teams, which expedite care by transferring tasks from physicians to nurses practitioners or pharmacists;
- iii. self-management supports are also effective, if they are offered as part of clinical care and tailored to the individual, with follow-up supports; lay-lead programs show less consistent results;
- iv. decision-supports, such as practice guidelines, and electronic medical records, can be effective only if they simplify the process of care;
- v. community partnerships, integrating health and social services, also produce improvements in care; and
- vi. environmental interventions, such as school, workplace and community interventions, supporting healthy and affordable food and physical activity choices.

¹²¹ Kreindler, S. *Lifting the Burden of Chronic Disease: What's Worked, What Hasn't, What's Next*. Winnipeg, MB; Winnipeg Regional Health Authority. May, 2008. Found at: <http://www.longwoods.com/articles/images/ChronicDiseaseReport.pdf>. Accessed: April 25, 2009.

Addressing Barriers

Looking more closely at the diabetes literature, several barriers usually impede the development of integrated programs. Practice changes, including shifts to guideline and team based care, are especially difficult to implement, due to reluctance to change patterns of care. Physicians and staff sometimes don't accept clinical guidelines, have limited knowledge of diabetes care, or don't document decisions. Patients can be equally uncooperative, refusing to attend appointments or being non-compliant.¹²² Additional challenges are encountered in developing outreach programs for underserved ¹²³ and Aboriginal populations¹²⁴ living in rural or remote areas. Travel burdens negatively affect diabetes care, resulting in poor control,¹²⁵ non-adherence,¹²⁶ non-attendance¹²⁷ and refusal to relocate for specialist care, such as dialysis.¹²⁸ Aboriginal clients also can be deterred by programs which lack cultural competence.^{129 130}

¹²² Renders, C.M., Valk, G.D., Griffin, S., Wagner, E.H., Eijk, J.T. and Assendelft, W.J. Interventions to improve the management of diabetes mellitus in primary care, outpatient and community settings. *Cochrane Database Systemtic Review*. 2001;(1):CD001481. Rev. 2009.

¹²³ Siminerio L, Piatt G, and Zgibor JC. Implementing the chronic care model for improving diabetes care and education in a rural primary care practice. *Diabetes Educator*. 2005;31:225-234.

¹²⁴ Barton, S.S., Anderson, N. and Thommasen, H.V. The diabetes experiences of Aboriginal people living in a rural Canadian Community. *Australian Journal of Rural Health*. 2005; 13(4); 242-246.

¹²⁵ Strauss, K., MacLean, C.D., Troy, A. and Littenberg, B. Driving distance as a barrier to glycemic control in diabetes. *Journal of General Internal Medicine*. 2006; 21(4): 378-380.

¹²⁶ Littenberg, B., Strauss, K., MacLean, DC.D., and Troy, A.R. The use of insulin declines as patients live farther from their source of care: results of a survey of adults with type 2 diabetes. *BMC Public Health*. 2006 Jul 27;6:198.

¹²⁷ Balmurugan, A., Rivera, M., Jack, L., Allen, K. and Morris, S. Barriers to diabetes self-management education programs in underserved rural Arkansas: implications for program evaluation. *Preventive Chronic Disease*. 2006;3(1):A15.

¹²⁸ Salvalaggio, G., Kelly, L., and Minore, B. Perspectives on health: experiences of First Nations dialysis patients relocated from remote communities for treatment. *Canadian Journal of Rural Medicine*. 2003;8(1):19-24.

¹²⁹ Barton, S.S., Anderson, N. and Thommasen, H.V. The diabetes experiences of Aboriginal people living in a rural Canadian community. *Australian Journal of Rural Health*. 2005; 13(4): 242-246.

¹³⁰ Saxena, S., Misra, T., Car, J., Gopalakrishnan, N., Smith, R. and Majeed, A. Systematic review of primary healthcare interventions to improve diabetes outcomes in minority ethnic groups. *Journal of Ambulatory Care Management*. 2007; 30(3): 218-230.

DIABETES CARE IN THE NORTH WEST LHIN

In discussing diabetes care in the NW LHIN, the individuals interviewed for this study identified a number of areas in which diabetes programs were working very well, with close coordination of care and outreach activities occurring. There was also a range of supports and services for people with diabetes available in most locations, although the exact services delivered varied from community to community. At the same time, there was awareness that there were systemic problems as evidenced by poor health status and avoidable complications. Lack of preventive care and delays in accessing both primary and specialist care were reported across the region.

Health Status

The consensus among those interviewed was that diabetes in the NW LHIN is poorly controlled. They reported increasing numbers of young adults and even children presenting with Type II diabetes. They also were encountering more women with diabetes and an alarming number of young women developing gestational diabetes. Among clients who had been diagnosed with diabetes, there were “too many clients” presenting with serious complications which lead to amputations, renal failure or retinal damage. Complications were more frequent among clients from isolated rural locations and First Nations, largely due to delays in obtaining care.

From a planning perspective, healthcare administrators did not have any accurate data on the numbers of people in their communities who had diabetes or were at risk of developing diabetes complications. While some communities did have public diabetes screening, at clinics held in shopping centres, drugstores or seniors centres, these initiatives were usually held only once or twice a year. There were no population screening initiatives, however, so actual prevalence was unknown. There also was concern that the methods used in community screening initiatives were not reliable enough to determine whether individuals did or did not have diabetes:

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Stations to test blood glucose levels in malls, at trade shows, etc., can give people wrong information about whether they have diabetes or not. A person with diabetes can still be within the target blood glucose levels. Finger poke tests, may mislead someone into thinking that they do not have diabetes when they do. The most accurate test for diabetes is done by the family physician.

Delivery of Care

Most of the ongoing clinical care was delivered by physicians and nurses, who worked in family health teams or health centres. Some of the family health teams had staff as certified diabetes educators or self-management program facilitators. A few had part-time dietitians on staff; lacking dietitians on staff, most referred their clients to local diabetes centres or hospitals for information about nutrition and weight control. With supports in place, however, even teams in the smaller communities were able to make successful transitions to collaborative care:

We have a really good collaborative team model .. we are a team, we have a full-time dietician and diabetes nurse educator ..we basically work as a team. We participate as much as we can ..in long-term care we tap into anything that is available...We are a very small clinic so it is very hard to run these huge programs...We have community workers that go out and do home visits that help people with housing, food and security...We have volunteers who do appointment reminder calls.

Front-line providers were very knowledgeable in regards to their clients' needs and the resources available for those diagnosed with diabetes. Clinical practice guidelines, such as those published by the Canadian Diabetes Association or the Registered Nurses Association of Ontario, were available and implemented in all organizations, so "best practices" was not regarded as an issue affecting diabetes care:

We utilize the best evidence-based practices in Canada and throughout the world... we work very closely with the physicians .. Our RN has received COPD, asthma training, diabetes education training .. she has the most recent standards as a part of her practice, we've spent a lot of time getting her .. the extra educational background ...We try very much to incorporate evidence-based practices and to ensure that we get education and keep up to date.

Diabetes Education

Access to diabetes education programs varied greatly. Although educational programs and self-management sessions were available in most of the larger towns and Thunder Bay, through diabetes education centres, hospitals and Aboriginal health organizations, they were generally not available in smaller towns and rural locations.

With the exception of Aboriginal wellness initiatives and a few programs targeted toward seniors or high school students, there also was a lack of healthy eating and healthy living programs with diabetes-specific messages. Programs, when available, were sometimes under-utilized, because clients were not aware that they could self-refer to some education programs.

Given the lack of diabetes education and prevention in smaller towns, much of the education responsibilities fell on the shoulders of primary care providers, who delivered needed education “in house” on a client-by-client basis. They made good use of many of the “free” resources on diabetes care, such as pamphlets, videos, or on-line information, that were available through the Diabetes Association, the Kidney Foundation and the Canadian Institute for the Blind.

The key to effective education was ensuring that all providers knew what was available in the community and throughout the region and, when programs and resources were available, used these to best effect. Looking around her community, an administrator emphasized the value of well-established and adequately resourced diabetes education programs:

We have diabetes educators that can support the physicians, it is a well-established program so the physicians can send the patients to that program but if you don't have that program, then the communities are forced with trying to support the individual within their own area.

Health Promotion and Prevention

Looking beyond their immediate responsibilities, healthcare providers were very active in their communities, both in terms of clinical care and client education, in hospitals, family health teams, and community care organizations. Many engaged in diabetes health promotion activities during community health fairs, school events, seniors' days, and, for those who worked in public health or community care organizations, during home visits. They also worked with the district health units, who were responsible for population health promotion initiatives, including "tobacco cessation ... the promotion of enhancing physical activity, weight control, and healthy eating."

Outreach Services

Several community health centres and Aboriginal organizations delivered outreach services, which were deemed as being especially critical for small settlements, rural communities and First Nations, that otherwise lacked access to primary care. This was an essential service, as many clients with diabetes did not have access to transportation or were not well enough to travel into the nearest community for care. At the same time, long distances, large caseloads, and limited resources restricted capacity to deliver outreach diabetes care, particularly in isolated rural areas and remote First Nations:

Some of our patients are three hours away First Nation, for example, is a three hour drive here and three hours back, they don't come unless they have to, when they're critically ill, so they're not getting the self-management to stay healthy ... they do not have a readily access to certified diabetes educators or physicians or nurse practitioners.

While doing their best to deliver needed diabetes care, providers emphasized that increasing numbers of clients with diabetes had stretched the capacity of the system to its limit. Relating how her own list of clients with diabetes had grown, an interviewee said that the few days a month that her organization allocated for outreach care were no longer sufficient, that "the days were getting to be really busy and long" to the extent that she was thinking "of splitting one day into two."

SERVICE GAPS AND BARRIERS TO CARE

In discussing diabetes services across the NW LHIN, key informants identified a number of service gaps and barriers to care. Regarding service gaps, the ability to care for clients with diabetes across the region was compromised by difficulties recruiting physicians, nurses and dieticians to fill vacant positions. Barriers such as limited resources, increasing demands for care, and rural location were identified as key factors which hindered the development and implementation of diabetes programming. Networking and communication was problematic, because the delivery of services and staffing often changed. Regional networking was almost non-existent, as there was lack of a forum to discuss issues and solutions.

Difficulties Recruiting and Retaining Staff

Recruitment and retention of staff, particularly in regards to physicians and specialists, was identified as the most pressing concern affecting diabetes services in rural Northwestern Ontario communities. The lack of physicians across the region was having a detrimental impact upon patient wait-times, and in some cases, the pressures to provide patient care had shortened appointment times down to considerably less than the standard 15 minutes per patient.

Numerous clinicians interviewed emphasized that the shortage of primary care physicians experienced across the region caused significant delays in the process of referring diabetes patients to specialist physicians, such as endocrinologists, nephrologists, or ophthalmologists. Similar delays were experienced in referrals for education, dietician consultations or footcare services. Patients who did not have a physician, furthermore, were often left uncared for, until they attended at the hospital for emergency care or, in Thunder Bay and larger towns, presented at a walk-in clinic. One interviewee stated that patients in her community were commonly relying upon emergency services to meet their needs in terms of medications and referrals to specialists:

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If someone does not have a physician, they are left uncared for and it's put upon the Emergency to meet their needs, get their medication, or perhaps a referral ... I know there are many individuals in Northwestern Ontario who simply do not have access to a family physician, there is a real shortage of physicians here.

Given the shortage of primary care physicians experienced throughout the NW LHIN, nurse practitioners and registered nurses were responsible for much of the care provided through primary care and in community care settings. With increasing numbers of clients and additional demands being placed on the system, however, they recognized that they often could only provide the most basic of services for their clients with diabetes, with many needs going unmet. Shortages of providers also meant that healthcare providers who were in the system simply didn't have the time to do the type of intensive screening and monitoring required to prevent complications:

Another I think the personnel that are here now are being asked, are really stretched, and stretched very thin. I think from a primary care perspective we could certainly use a lot more providers in the region to do diabetes screening, early intervention, as well as more frequent monitoring and again if you do more frequent monitoring then you can prevent complications by making sure that you have tighter glucose control.

Another barrier to effective delivery of care was the fact that in smaller towns and rural communities, physicians weren't available at all times, which meant extended delays in obtaining the physician directives which were needed to make medication adjustments or obtain referrals for specialized services. Several informants described the difficulties they had encountered when attempting to provide care to patients when physicians were only available on a locum basis. This situation was of particular significance to nurses who were working in smaller communities or delivering outreach care:

A physician has to refer you ... there is a big lag where you know the contact has to be made to the physician and then back to the patient...the specialists do not take referrals directly from the patient, so we have to get the physician to provide the referral.

As an example, a healthcare administrator from one of the smaller towns reported that registered nurses with their organization had a medical directive to dispense insulin, but did not have a similar directive to adjust oral medication. When an adjustment in oral medication was required, contact had to be made with the physician, and when orders were received, the nurse had to get the prescription for medication back to the patient. Similar delays occurred around referrals for laboratory tests, footcare services or specialist care completed without delays. Summing up her frustrations, the administrator said:

One of the things that has been frustrating over the years is trying to get the information in a timely manner. We have a hard time getting lab work and so when we see a client come in for a three month follow up and we haven't got any lab work in the last three months so we send a request to the [family physician] for it but then we don't get it again until it is already out of date by the next visit.

There were also shortages of nursing staff, allied health professionals and paraprofessionals, in both community health centres and family health teams, and due to funding restrictions, some organizations were not able to employ additional staff, even when the need was clearly evident. Vacancies for advanced practice nurses, such as certified diabetes educators or nurse practitioners, when they occurred, were almost impossible to fill. Taken together, recruitment and retention difficulties, combined with increasing demands for diabetes care, placed immense burdens on existing staff, who often found themselves unable to meet demands for care. The stresses and strains experienced by providers were made evident in a number of interviews:

I think the difficulty is having enough people in place to meet the overwhelming needs for people with diabetes, having enough qualified people in place. We are educating a very small group of people who are stretched beyond their limits, we are suffering a great registered [nursing] staff shortage. We are five physicians short in our area and so [nurses are] seeing and getting dozens and dozens of patients a day.

Need for Continuing Diabetes Education

Additionally, several interviewees voiced a concern that health professionals throughout the NW LHIN had difficulties accessing appropriate continuing education, to make sure that they were fully informed about best practices, current treatments and client education. Although it was acknowledged that all health professionals received basic instruction regarding diabetes care, they would not have the necessary degree of expertise if they had not had opportunities to update their knowledge of current practices and best practices for managing medication and diabetes complications:

Health care providers, meaning physicians, nurse practitioners and even staff nurses have a very limited knowledge of the intricacies of diabetes. Diabetes care is very intricate in terms of medication, insulin adjustments and I think there is a very limited understanding of the breadth of it...I think that diabetes care is so huge and it cuts across every area of the hospital from paediatrics to chronic care to orthopaedics etc. ... It is very difficult for everyone to have a good grasp of diabetes.

Health care professionals also were poorly prepared to deliver diabetes education to their patients. Many health professionals only possessed a rudimentary knowledge of diabetes education, which resulted in patients receiving “mixed messages” from their physicians and nurses regarding the nature of their diabetes and the care required for it. With the exception of experienced providers who were well versed in diabetes care, many healthcare professionals were poorly prepared to deliver education to their clients who were at risk of developing diabetes or who already had the disease and, without education, clients did not have enough information to self-manage their disease at home.

As a related issue, providers reported difficulties in accessing continuing education programs on diabetes. Several interviewees noted that these were being offered via workshops or videoconferencing, but due to resource constraints, their organizations could not fund their participation. Health care providers who lived in the region were somewhat disadvantaged, as they did not have access to the range of educational supports which were

available in the regional centre. Efforts to keep current about diabetes best practices were sometimes challenging:

I think there have been good efforts to have an awareness of best practice guidelines but I think that it is difficult to be on top all of the time because they do change ...We have a strategic initiative around sort of targeting specific ones... they are in every treatment room, the best practice guidelines...it tells you where the benchmarks are and what you should be doing.

Wait Lists for Specialized Care

Data obtained through conducting interviews with medical personnel and family health teams throughout Northwestern Ontario, indicates that as the prevalence rates of diabetes increase, there are increasing pressures on the system, and increasingly longer wait times, with negative impacts upon patient care. Although Endocrinology, Nephrology, and Ophthalmology consultations were accessible through Thunder Bay or Winnipeg, or in some locations via telehealth, specialist outreach services were only available in a few of larger towns, with clinics being scheduled on a quarterly basis.

The consensus was, that due to limited services and excessively long wait lists, the services available were not meeting the needs of patients with diabetes. The need to meet urgent care needs also meant that many patients with diabetes were not receiving the necessary degree of preventative care. A front-line provider felt that serious complications, such as amputations, were directly associated with difficulties getting referrals for foot screening and specialist care:

The nurses see so many patients and the physician wait lists are long, they are always booked up and the appointments are pretty short, 15 minutes per patient ... I think we can reduce amputation rates with having really good footcare and we don't have a lot of access to orthopaedic surgeons or wound specialists.

Funding and Sustainability Issues

There was a clear consensus that additional resources, including administrative, staffing and operational supports, were needed to fully develop and implement comprehensive diabetes programs. Some community health organizations did not have electronic health records or e-health initiatives. Others lacked resources to sustain self-management and wellness initiatives and coordinate such programs. There were equally serious difficulties in supporting outreach diabetes care in rural communities and remote First Nations. Specialized services, such as footcare and vision exams, were only available in larger communities.

The lack of diabetes organized prevention strategies and population based programs, as well as a shortage of community health initiatives and screening programs was referenced as being directly connected to both funding and human resource shortages. In some cases funding was offered for the establishment of a program on a trial basis, but once the funding stopped, the resources would run out for the program and the organization could not support program activities within its normal operating budget.

Other locations did not have the resources to give staff specialty training, for example, to have staff nurses certified as diabetes educators. There were also no resources to support preventive and risk reduction programs, for example, education sessions directed towards those at risk of developing diabetes. Funding, shortages of funding, and the effects on program delivery and sustainability, was a subject touched upon in the majority of interviews:

I think more funding would assist in enhancing existing diabetes management and prevention programs...I think somehow getting funding to provide a community-based planning program and implementing a diabetes network .. A lot of these communities have nurses, all they need is funding to have them trained as diabetes educators as well...we are such a small clinic, it is very hard for us to really fully have these programs on a go, without the staffing incentive and of course financial as well.

Need for Regional Coordination of Services

Although there was some networking occurring at the community level, most of the networking among hospitals, or long-term care facilities, or diabetes education programs, occurred around sector-specific issues. Acknowledging the benefits of this type of sectorial networking, an administrator said, “we connect quite frequently; I think the community and the district are very willing to share ideas and to help one another.” Among the communities surveyed, only one location (Fort Frances) had developed a local diabetes network to improve communication and referral processes. It was, however, a success:

We developed a local network ... CCAC, Northwest Health Unit, Valley Diabetes, Riverside Health Chiropody, Tribal Health Authority and their Chiropody And Foot Care Program .. we set up a whole network that refers back and forth. They meet once a month as a network and talk about ways that they can improve in communication, way they can help patients move easily through their different programs and identify people who need extra help or services.

Cross-sector linkages, however, were few and far between. Some interviewees felt that it would be beneficial for Northwestern Ontario to develop a network of diabetes care providers that encompassed all sectors, including primary care, community care, hospitals and long-term care organizations. While it was acknowledged that “community organizations all know how to work together” there was general recognition that there is a need for improvement in regards to the formal coordination of diabetes services across the NW LHIN.

Along with communication, coordination and collaboration was recurrent theme that was highlighted in numerous interviews. Several individuals spoke to the need for closer collaboration between primary care providers and the organizations that delivered diabetes education or preventive programming, to make sure that clients had access to the full range of services that were available. At the same time, this type of coordination was difficult to do, because most organizations did not have the staffing to devote to case management.

Talking about the need for closer integration of diabetes management, education and programs in her community, a healthcare provider said:

We have got to have some sort of coordination to get us all on the same page as to what this is .. what is our vision of it? .. Right now there is no network, there is no collaboration, there is no coordination, there is not even one chart that travels with a patient...everybody is trying to do the same thing, but nobody is doing the same thing together.

Outreach Programming in Rural and Remote Locations

Outreach programming, particularly in regards to rural communities and remote First Nations, was viewed as being a crucial element in the prevention and management of diabetes. Health care providers expressed concern that outreach programming was not reaching these populations on a regular basis, due to limited funding allocated for such services. Outreach services to rural and remote locations also were impacted by distance and weather, especially in winter, when travel was hazardous. A number of practitioners highlighted the unique transportation difficulties that can arise in Northwestern Ontario when they were trying to deliver outreach care in the winter months:

Just given how large of a geographic area we are and given our limited resources it make sit a challenge in coordinating our services ... We went to an outreach and it was an hour and a half to go one way and it was -40, that is risky business...You know what the roads are like up here in the north in the winter, they can be awful, I think that one of the biggest deterrents is the geography.

Patients who required intensive management of their diabetes and diabetic complications were most disadvantaged, because outreach teams at present were only able to provide the most basic care. As a manger remarked, her organization “serves communities that are 45 minutes away, so there is a large area there and they don’t get to those communities as often.” She added, “I don’t think it’s often enough for the people on intensive management.” Another professional emphasized that outreach teams did not have time to give patients enough education and hands-on skills training to self-manage their condition:

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Somebody with diabetes .. they need a significant amount of education, and it takes time to learn how to adjust their insulin...I find it difficult to give them enough time to learn those skills when they live far away, even our outreach clinic .. is far away from [where they live].

Client Barriers

The consensus was that, even when services were available, clients encountered a number of barriers in accessing care and following recommendations for self-management. These barriers included transportation difficulties, cost of medication and supplies, food security issues and lack of recreational opportunities. Although these issues were affecting clients across all of the NW LHIN communities, they were particularly serious for residents of rural areas and isolated First Nations. Access and affordability combined and created significant challenges for clients following recommended plans of care.

Transportation

On the subject of transportation, simply getting to appointments was acknowledged to be a significant barrier for seniors, low income clients and people who lived in the smallest towns, rural areas and remote First Nations. Many clients did not have access to private transportation, except for the Highway 17 corridor, inter-city bus service was not available. Medical vans and travel benefits were reserved for clients who had appointments with physicians, so clients who had to travel for diabetes education or supportive care had to make their own arrangements and cover all costs. Travel in the north was generally acknowledged to be expensive, difficult and, in the winter, hazardous, and therefore presented a significant barrier to accessing care:

It's not always easy for people to get to appointments, for one, we're running a chronic disease management program and it's hard to get people to attend on a regular basis, I do think transportation is a critical issue, particularly in remote and rural locations.

Cost of Medication and Supplies

The unemployment and economic instability being experienced across the NW LHIN also had negative effects on clients' ability to follow recommended advice regarding medication, diet and lifestyle. Younger people with diabetes, especially if unemployed or under-employed, often had difficult choices to make, because they didn't have the resources to regularly refill their prescriptions and eat healthy food:

Diabetes is a very expensive condition and if you do not have a health care plan and you are under 65 it is a very expensive disease to maintain so it is hard to care for yourself at times because you have to choose between drugs and food.

The cost of medical supplies required to manage diabetes effectively was an equivalent financial barrier for many clients. Not being able to afford blood glucose monitors or, if a monitor was free, not being able to afford test strips, made it almost an impossibility to self-manage glucose levels. People who had circulatory problems faced added expenses if they needed special orthotics or socks. Thinking of what clients encountered on a daily basis, a front-line provider said:

It's an affordability issue for patients and the areas that I go, and I go into the rural communities and they are poor people, not all Aboriginal people, they just don't have access to purchasing items that is going to help them care for or manage their own diabetes.

Food Security

Across the region, the relationship between food security and diabetes self-management was recognized by health professionals as a serious barrier for clients. For patients to be able to successfully manage their diabetes, they needed to manage their dietary requirements effectively, avoiding processed and fried foods and substituting fresh fruits, vegetables and dairy products. Recognizing that clients from low-income families simply "can't afford to eat as healthy as they should," some communities had developed food banks or "healthy food box" programs, but where available, such services rarely had fresh

vegetables and fruit. Special products used by diabetics, such as artificial sweeteners, also could not be found in some locations. In most rural areas and remote First Nations, fresh products were not readily available, or when available were not affordable. Food security was a significant barrier to effective management and prevention of diabetes and was an issue of particular importance:

I guess when you live in northern Ontario, where its cheaper to buy pop than it is to buy milk .. I can see why we're not seeing the improvements we should be seeing...on reserves for example .. no matter how much [money] you've got you can't buy fresh fruit on a reserve.

Lack of Recreational Opportunities

Financial considerations and a lack of accessible and safe community recreational opportunities made it difficult for people with diabetes to participate in healthy physical activities. Most community recreational organizations, Aboriginal wellness programs excepted, charged fees for use of their facilities and attendance at exercise classes, effectively closing their doors to people who couldn't afford to pay the fees. As one interviewee noted, "with so many people not having work you can't pay money to go to the gym." In the smallest communities, recreational facilities simply were not available.

As an additional concern, affordable exercise, such as walking, was not feasible nor was it safe in many locations. In some small towns, there were no sidewalks to walk on and walking on roadways was hazardous, especially in winter, when snow banks were high and roads weren't clear. People also did not want to walk in some neighbourhoods because they were concerned about safety; in rural communities and First Nations, for example, people were sometimes afraid to go walking because there were "dogs on the loose." Summing up the seriousness for people with diabetes, an interviewee said:

Again, [there are] barriers have been around exercising and not being able to do that component in the rural areas, they can't just walk on the highways, so there is no community centre that has treadmills or bikes or anything like that, so .. those are some of the gaps that ... lead to things like losing limbs and poor circulation problems.

Practice Change Issues

Among organizations which were in the process of implementing comprehensive diabetes care programs, the shift from care managed by solo practitioners to multidisciplinary care was challenging. Generally, there were no administrative supports available to guide required organizational changes and “ensure that everybody’s on the same page.” There was also a lack of resources to support the development of “care pathways” to improve coordination of care.

Problems with coordination of care and communication were evident at both the local and regional levels. Providers told us that they faced delays, for example, getting lab results from hospitals or community labs to physicians and back to their clients. Similar problems occurred when clients were transferred from hospitals back to primary care and community care organizations. There was also some duplication of effort, for example, when diabetes education was delivered by primary care providers and by community diabetes programs, which resulted in clients receiving “the same information twice over.”

Many of the providers interviewed mentioned that they were starting with “small steps” to move their community family health teams, hospitals and other organizations towards the types of coordinated multidisciplinary care that were recommended as the best practice for diabetes. All made sure that front-line providers had access to clinical guidelines, that outlined recommended protocols for diagnosis and treatment. Others were working on the development of client flow charts to improve the delivery of care. A few were working with hospital or community-based organizations to develop diabetes awareness and screening initiatives. Although there was a general sentiment that everybody was trying to accomplish the same goals, the lack of coordination and communication between organizations meant that often “nobody was working together”. Voicing her frustration, an administrator said:

We have silos of things going on, not a good clear pathway of communication back and forth, some of that its because the funding is set up to serve this and that group, there’s no clear pathway back and forth.

Electronic Medical Records

Although several interviewees reported that their community's health care organizations were in the process of introducing electronic medical records, only one community (Dryden) was in the process of implementing a truly "paperless" community-wide EMR system. Most organizations were still dependent on conventional paper charting and reminder systems, but were optimistic that electronic charting systems would prove to be significant assets, in tracking patient care indicators, tests, reminders and referrals. Ultimately, the hope was that the systems would provide "patients with seamless care" within organizations, among community service providers and across the region.

Opinions about the value of electronic medical records at the present time, however, were mixed. One of the things that clinicians observed in their daily practice was that there was a lot of "double charting" involved in recording patient information. Interviewees reported, for example, that they had to enter data into both their own medical record system and the Northern Health Diabetes Health Network database. There also was no EMR "medical chart that travelled with the patient" when they were referred for care.

The basic problem, which occurred throughout the NW LHIN, was that the EMR systems which had been introduced into primary care clinics, hospitals, community pharmacies or community nursing organizations "don't mesh together" so "they cannot be linked and shared back and forth." Even when e-health communication was available, physicians were sometimes reluctant to share patient data via electronic means, because they feared that confidentiality and privacy would be compromised. The result was that paper charts and fax communications were often still the norm.

IMPROVING DIABETES CARE IN THE NW LHIN

When asked what they felt could improve or enhance existing diabetes management and prevention programs, the majority of the informants interviewed reported that additional resources to support enhanced communication networks and coordination of care between organizations were priorities across the region.

Investing in Communications Technology

In terms of communication, front-line providers felt that the ability to share information between physicians and health-care providers through the use of electronic medical records was important, particularly for those located in rural and remote communities, as their patients were often required to travel for specialist care. Though electronic records were being used by many of the health-care providers, systems did not interface effectively. As a front-line provider emphasized, there was “lack of communication between providers, between programs, between screening programs .. everybody is trying to do the same thing but nobody is doing the same thing together.”

Improving Surveillance and Health Intelligence

There also was a need for enhanced health intelligence, in the form of additional data on numbers of people in the region with diabetes or who were at risk of developing the disease. A mechanism for tracking diabetes complications in the NW LHIN also was a priority, so organizations could target population groups or locations that were most at risk.

Although it was acknowledged that there is comparatively good information on diabetes prevalence and incidence within some organizations, there is no systemic way of gathering information about client needs across organizations. There is also no way of identifying communities or population groups that are at high risk of diabetes or developing complications. In the words of a primary care practitioner, “we just don’t have the system

information to know what kind of problem is that, what kind of outcomes we are getting, who should be seeing who.”

Improving Referral Processes

While there was a degree of collaboration at the local level, between primary clinics and diabetes education centres, for example, there was a noticeable lack of coordination between these and organizations which provided more specialized services, including hospitals, laboratories and pharmacies. On this issue, several providers suggested that delays in the process of care could be addressed if the system was expanded to accommodate multiple referral and testing points.

Referrals to specialized services and supports could be expedited if the system could be adjusted to accommodate multiple entry points for care and for education in the communities. Discussing the delays, of several months or more, that her clients faced in getting necessary referrals for care, a health professional emphasized the need to develop community care pathways, that would:

Coordinate services to create better collaboration and inter-professional collaboration, allowing multiple referral entry points, instead of physician driven, I think that would go along way to help and get things more in place for people, also I think more education in the community could be done.

Other providers remarked on the need to improve access to laboratory testing services, to enable more timely identification of clients who had the disease and make more immediate adjustments to treatment for those who had been diagnosed and were at risk of developing complications. One interviewees suggested that this could be accomplished through additional testing services, such as POCT outreach services, to expedite care:

So if we could go out in the region ... if you could take equipment out that could give you on the spot cholesterol levels and Haemoglobin A1C levels then you can adjust medication sort of on the spot and then you would only have to go and see the patients say once a month or every two months.

Need for Regional Consultation

Many respondents identified a need for systematic local and regional consultations, “to get us all on the same page as to what this is, what it looks like, what is our vision of it when it is working well so that we can all be kind of working towards that.” Several saw a need for systematic networking on “a community by community basis, making those contacts and trying to do that coordination and collaboration.” They also recognized that ongoing consultations were needed to avoid unnecessary duplication of services. As an administrator remarked, “we shouldn’t compete so that there’s further overlap of services.”

Additionally, there was a need to provide a forum for exchange of diabetes program information regionally, to allow organizations to share best practices with one another. There were programs which were working well in some locations, but information about such local successes were not generally available throughout the region. There needed to be a mechanism for ensuring that information about these innovations was distributed throughout the NW LHIN. Speaking on this issue, an administrator said:

What I would like to do instead of reinventing the wheel is having other groups share their programs that are already running and working and basically have a guideline that says this is what we do and this is how we set up, something that is already done ... and works well.

In discussing these issues, several interviewees specifically saw a role for the NW LHIN in facilitating needed regional consultations and collaboration between organizations. They felt, with the LHIN in a coordinating role, they might achieve a degree of clarity and consensus around the region’s diabetes care needs and goals, producing improvements that otherwise would not occur if organizations continued to go their separate ways:

The LHIN needs a clear strategy about what they are going to do, what they would like to see happen because we can go off on a tangent on our own and frankly will, if we don’t see a clear strategy emerge. ... There needs to be someone that is coordinating this and if they don’t, the reality is that everybody is just going to be doing their own thing.

SUMMARY

This study responds to the Northwest LHIN's interest in exploring the issue of diabetes prevention and management in Northwestern Ontario. Our research indicates that diabetes is a serious problem within Northwestern Ontario, particularly in Aboriginal communities. Given the prevalence of this disease, the development of an integrated Northwestern Ontario diabetes management and intervention strategy was a planning priority for all of the organizations delivering diabetes care throughout the region.

Scanning the Canadian and international literature, it examined best practices, with a particular focus upon the challenges faced by health care providers in delivering diabetes care to rural and Aboriginal populations. We also explored factors affecting diabetes prevention and management in the NW LHIN, by interviewing 23 key informants from 14 of the region's communities. The key objective of the project was to determine how effectively diabetes management and prevention programs had been implemented into the practices of health care providers across the Northwestern Ontario region. The following summary presents major findings from the interviews, including information on health status, service gaps.

Health Status

- The consensus among those interviewed was that diabetes in the NW LHIN is poorly controlled. Those who were interviewed reported increasing numbers of clients presenting with Type II diabetes at young ages. They also were encountering more women with gestational diabetes. Among clients who had been diagnosed with diabetes, there were "too many clients" presenting with serious complications which lead to amputations, renal failure or retinal damage. These complications were more frequent among clients from isolated rural locations and First Nations, largely due to delays in obtaining care.
- At the same time, those who were interviewed did not have any accurate data on the numbers of people in their communities who had diabetes or were at risk of developing diabetes. While some communities did have public diabetes screening, at clinics held in shopping centres, drugstores or seniors centres, these initiatives were usually held only once or twice a year. There were no population screening initiatives, so actual prevalence was unknown.

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Program Delivery

- The majority of providers interviewed reported that their organizations and communities had some diabetes management and prevention strategies implemented. Additionally, several of the communities had recently begun to develop diabetes education initiatives, including self-management programming for patients. There was a clear consensus, however, that additional resources, including administrative, staffing and operational supports, were needed to fully develop and implement comprehensive diabetes management programs.
- Key informants were very knowledgeable in regards to their clients' needs and the resources available for those diagnosed with diabetes. Providers were very active in their communities, both in terms of clinical care and client education, in hospitals, family health teams, and community care organizations. They also engaged in diabetes education during health promotion activities and home-care visits. Although outreach services were limited, they were deemed to be especially critical for rural and First Nation communities, which otherwise had few services available.
- Most of the ongoing clinical care was delivered by physicians and nurse, who worked in family health teams or health centres. Although a few primary care or prevention clinics had part-time dieticians or certified diabetes educators on staff, most referred their clients to local diabetes education centres or hospitals for education and other supports. Restricted capacity to deliver outreach diabetes care to small towns, rural communities or First Nations, moreover, meant that long waiting lists were common when clients from these locations needed care.

Service Gaps

- Due to limited funding, infrastructure and resources, human resources shortages, rural location and a lack of networking capabilities between organizations and service providers, there were a number of significant service gaps which hindered the development and implementation of comprehensive diabetes programming. Networking, at local and regional levels was problematic. Regional networking almost non-existent, as there was lack of a forum to discuss issues and solutions. Providers from small towns and rural areas often felt isolated from their colleagues in other communities and had difficulty knowing who to contact if they experienced problems in care.
- Health human resources deficiencies were recognized as a serious impediment to care throughout the NW LHIN. At the local level, Family Health Teams, Health Centres and Hospitals reported that their ability to care for clients with diabetes

was compromised by difficulties recruiting physicians, nurses and dieticians to fill vacant positions. Few professionals, furthermore, had expertise in diabetes care.

- Although Endocrinology, Nephrology, and Ophthalmology consultations were accessible through Thunder Bay or Winnipeg, specialist outreach services were only available in a few of larger towns, with clinics being scheduled on a quarterly basis. Except for the most urgent care, waiting lists for specialist consultations were lengthy, appointments were short, and travel between communities difficult and, in winter, dangerous for both clients and health professionals.
- Access to diabetes education and preventive programs also varied greatly. Educational supports were available in most of the larger towns and Thunder Bay, through diabetes education centres, hospitals and Aboriginal health organizations. With the exception of Aboriginal wellness initiatives and a few programs targeted toward seniors or high school students, however, there was a lack of healthy eating and healthy living programs with diabetes-specific information included. Clients also sometimes were not aware that they could self-refer to some services, such as diabetes education programs.
- Given the lack of diabetes education and prevention in smaller towns, much of the education responsibilities fell on the shoulders of primary care providers, who referred their clients who were at risk of developing diabetes to local diabetes education centres in the community or hospitals and, when such resources were not available, delivered needed preventive education “in house” on a client-by-client basis.
- The pressure to meet acute care needs, however, severely limited the time available for education or preventive care within primary care organizations. Although some communities had certified diabetes educators or trainers certified to teach Stanford self-management programs, the resources to run educational sessions were not always available. Those who spoke about self-management education also acknowledged that there needed to be coordination between such initiatives and existing community education programs to avoid duplication of efforts.

Client Barriers

- The consensus was that, even when services were available, clients encountered a number of barriers in accessing care, including transportation issues, financial constraints and lack of knowledge about resources which were available. On the subject of transportation, simply getting to appointments was acknowledged to be a significant barrier for seniors, low-income clients and people who lived in the smallest towns, rural areas and remote First Nations.

- Public transportation was not available in these locations and, except for the Highway 17 corridor, inter-city bus service was not available. Medical vans and travel benefits were reserved for clients who had appointments with physicians, so clients who had to travel for specialized diabetes education or supportive care had to make their own arrangements.
- The unemployment and economic instability being experienced across the NW LHIN also had negative effects on clients' ability to follow recommended advice regarding medication, diet and lifestyle. Unemployed individuals often didn't have the resources to regularly refill their prescriptions for diabetes medication or purchase related supplies.
- Clients from low-income families simply "can't afford to eat as healthy as they should" and food banks, where available, rarely had fresh vegetables and fruit. The cost of nutritious food and the limited availability of healthy foods was even more prohibitive for people who lived in rural or remote communities. Special products used by diabetics, such as artificial sweeteners, also could not be found in many locations.
- Lack of income also made it difficult for people with diabetes to participate in healthy activities. Except for some Aboriginal community centres, recreation centres charged fees for use of their facilities and attendance at exercise classes. As one interviewee noted, "with so many people not having work you can't pay money to go to the gym." Many of the smaller communities simply did not have recreation facilities. In other locations, affordable recreation, such as walking was not feasible or safe to do.

Practice Change Issues

- Among organizations which were in the process of implementing comprehensive diabetes care guidelines, the shift from care managed by solo practitioners to multidisciplinary care was challenging. Generally, there were no administrative supports available to guide required organizational changes and "ensure that everybody's on the same page." There was also a lack of resources to support the development of "care pathways" to improve coordination of care.
- Problems with coordination of care and communication were evident at both the local and regional levels. Providers told us that they faced delays, for example, getting lab results from hospitals or community labs to physicians and back to their clients. Similar problems occurred when clients care was transferred from hospitals to primary providers and community care organizations. There was also some duplication of effort, when, as a result of competitive funding structures, several organizations were delivering the same type of service.

- Many of the providers interviewed mentioned that they were starting with “small steps” to move their family health teams, community centres or hospitals towards the types of coordinated multidisciplinary care that were recommended as best practices for diabetes. All made sure that front-line providers had access to clinical guidelines, that outlined recommended protocols for diagnosis and treatment. Others were working on the development of client flow charts to improve the delivery of care. A few were working with hospital or community-based organizations to develop diabetes awareness and screening initiatives.
- A number of those interviewed had encountered difficulty in networking with other health-care organizations to improve care, to the extent that some felt that they were working in ‘silos.’ Some interviewees expressed frustration as a result of this lack of coordination between health care providers, there was a general sentiment that although everybody was trying to accomplish the same goals, nobody was working together.

E-Health and Medical Records

- Easily accessible an up-to-date medical records were essential to those involved in the day-to-day care of diabetic patients. Practice supports, such as appointment reminder systems also helped to ensure access to care in a timely manner. Although several interviewees noted that their organizations had implemented or were in the process of introducing electronic records, many were still dependent on conventional paper charting and reminder systems.
- Health care organizations which had not implemented e-health systems did not, in the foreseeable future, anticipate that they would transfer from paper-based to electronic systems, unless additional resources were made available. At the same time, they had considerable difficulty sharing patient data with other organizations. They typically had to input client data into multiple databases, for example, into both the Northern Diabetes Health Network registry and that maintained by their own organization.
- Some respondents noted that despite the fact that their patients travelled to different locations for care, there was no medical chart that travelled with the patient when they were referred outside of their primary care organization for care. The information provided, moreover, was usually in paper-based form.
- Even when e-health communication was available, providers were reluctant to share patient data via electronic means, because they feared that confidentiality and privacy would be compromised. Taken together, lack of standardization of e-health systems, incompatibility and reluctance to use the systems meant that comparatively little patient data was shared among providers and organizations.

Suggested Improvements

- When asked what could improve or enhance existing diabetes management and prevention programs, additional resources to support enhanced communication networks and coordination of care between organizations were priorities across the region. In terms of communication, an integrated system of electronic medical records was needed, because current systems did not interface effectively. This problem contributed to “lack of communication between providers, between programs, between screening programs.”
- There also was a need for enhanced health intelligence, in the form of additional data on the needs of clients with diabetes in the NW LHIN. Although it was acknowledged that there is comparatively good information on prevalence and incidence in some organizations, there is no systemic way of gathering information on communities or population groups at high risk of diabetes or complications. In the words of a primary care practitioner, “we just don’t have the system information to know what kind of problem is that, what kind of outcomes we are getting, who should be seeing who.”
- Other respondents emphasized the need for coordination of services among organizations. While there was a degree of collaboration at the local level, there was a noticeable lack of coordination between local organizations and more specialized services that were located in larger towns and the regional centre. There also was evidence that competitive program funding sometimes caused further fragmentation in care delivery. As an administrator remarked, when several organizations are “all competing for the same money, that does cause an issue when you’re looking at the best uses for limited resources.”
- In discussing the difficulties of providing diabetes care to rural areas and isolated First Nations, several informants spoke about the need to enhance outreach care. Addressing gaps in outreach primary care and services such as footcare and vision exams, would go along way towards reducing the complications seen in clients from these areas. Additional outreach, such as POCT, would also allow for more intensive management of clients who otherwise had difficulty accessing care.
- There was agreement that consultation and coordination around the delivery of diabetes services and supports needed to occur at both local and regional levels. It was suggested that the LHIN might take a role in this coordination, facilitating networking on “a community by community basis” towards the goal of developing an integrated diabetes care system for the region. Other respondents identified a need for regional consultations “to get us all on the same page as to what this is, what it looks like, what is our vision of it when it is working well so that we can all be kind of working towards that.”

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APPENDICES

Appendix A

Centre for Rural & Northern Health Research

Centre de recherche en santé dans les milieux ruraux et du nord

“Environmental Scan: Diabetes Prevention and Management for the NW LHIN”

Interview Questions – Key Informants

The purpose of this research, commissioned by the North West Local Health Integration Network (LHIN) is to explore diabetes prevention and management in Northwestern Ontario. Research indicates that diabetes is a serious problem within Northwestern Ontario, particularly in Aboriginal communities. Given the prevalence of this disease, the development of an integrated Northwestern Ontario diabetes management and intervention strategy is a planning priority. As a professional working in the health sector in Northwestern Ontario, we are interested in hearing your opinions about the way diabetes is managed in your organization, your community and our region:

1. Thinking about your organization, what types of supports are available for diabetes care?
 - a. Practice guidelines? (Who is primarily responsible for client care? Individual practitioners, or care team? If team, who is on the team and what are their roles?)
 - b. Referrals for education, footcare, counselling or specialist care? (If any, are systems in place to monitor care? e.g. paper or electronic records, registries, reminders?)
 - c. Organizational linkages to promote diabetes prevention and healthy lifestyles? (if any, how do they complement the services available in your organization?)
2. Does your community have a diabetes management and prevention network in place? If none, are plans in place to establish such a network?
 - a. Which organizations and providers participate? (e.g. clinics, home care, hospital, public health, volunteers, etc.? Which provider groups are represented?)
 - b. Any e-health supports in place to assist with management? (Do providers have to enter data into multiple systems? What would encourage use of e-health supports?)
 - c. Any community-based screening programs? (if any, do they target high-risk groups? e.g., seniors, pregnant women, Aboriginal populations?)
 - d. Any community healthy lifestyle programs? (if any, do they target healthy weights, physical activity? are they designed for clients with diabetes or other groups?)

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Diabetes Management and Prevention for the North West LHIN

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3. What do you feel are the most significant barriers to implementing integrated diabetes prevention and management strategies in Northwestern Ontario communities?
 - a. Financial and staffing incentives? (e.g. no compensation for time spent in care management activities? no special case management supports?)
 - b. Health human resource and information technology limitations? (staff shortages and workload issues? poor communication? incompatible information systems?)
 - c. Lack of information about diabetes best practices? (difficulty obtaining guidelines? difficulty obtaining client resource materials?)
4. What do you think could be done in your community and in the region to enhance existing diabetes management and prevention capabilities?
 - a. Support from within organizations? (e.g. leadership, championing best practices? co-ordination of services? collaboration on resources?)
 - b. Support at the regional level? (e.g. dissemination of best practice guidelines? regional coordination? development of special resources for at risk groups?)
 - c. External funding and staffing supports? (e.g. intensive case management? enhanced health information systems? improved access to specialist care or services such as dialysis?)
5. Can you identify any other service gaps that impede diabetes management and prevention in NW Ontario? (If any, what could be done to address these gaps?)
6. Is there anything else you would like to add regarding the challenges of diabetes prevention and management in Northwestern Ontario?
7. To improve our understanding of these issues, we would like to talk to other providers who have experience delivering services to clients with diabetes in your community. Could you suggest the name of one colleague, possibly an administrator, manager or front-line provider, who might have insights into these issues?

Appendix B

Centre for Rural & Northern Health Research

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“Environmental Scan: Diabetes Prevention and Management for the NW LHIN” Covering Letter

Dear Colleague:

The purpose of the study, commissioned by the North West Local Health Integration Network (LHIN), is to explore the characteristics and common elements of successfully integrated approaches to diabetes prevention and management. Research indicates that integrated diabetes management initiatives, including practice guidelines, care management plans, supports for self-management, as well as disease prevention, produce measureable benefits for both providers and clients.

As you have been identified by the LHIN staff as a knowledgeable professional working in the health sector, we are interested in hearing your opinions regarding the way clients with diabetes are managed in your organization, your community and our region. Your involvement would be that of a participant in an open-ended telephone interview, which would last approximately 20-30 minutes. The interview would be scheduled at a time that is convenient for you. Participation in this study is voluntary and you may answer the questions any way that you choose, decline to answer any question, or elect to withdraw your participation at any stage. There are no apparent risks associated with the study and participation will not affect employment or organization’s access to services or supports.

With your permission (consent form attached), we will audiotape the interview to ensure that information is accurately recorded. All data will be secured in locked cabinets in the CRaHNR office at Lakehead University, for a period of five years after completion of the study, at this time it will be destroyed. Data will be kept confidential and you will not be identified in any written reports or subsequent presentations. Results of the study will be available through the LHIN after the end of the project.

For further information about the study, please contact us at the Centre for Rural and Northern Health Research. Dr. Mary Ellen Hill, Senior Researcher, may be reached by telephone (collect) (807)766-7278 or email maryellen.hill@lakeheadu.ca. For further information about procedures for maintaining consent and confidentiality, you may contact the Lakehead University Research Ethics Board at (807) 343-8283. I hope that you will agree that such an evaluation is important and will be prepared to help us carry it out.

Sincerely,

Bruce Minore, PhD
Research Director

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Lakehead University*

Appendix C

Centre for Rural & Northern Health Research
Centre de recherche en santé dans les milieux ruraux et du nord
 “Environmental Scan: Diabetes Prevention and Management
 for the North West LHIN”

Consent Form

- If you agree to participate in the telephone/in-person interview, please read, sign and date the following consent form and return it by fax to (807) 766-7218. Please also mail the original signed and dated consent form, via mail to: the Centre for Rural and Northern Health Research, Lakehead University, 955 Oliver Road, Thunder Bay, ON P7B 5E1.

The purpose of the study, commissioned by the North West Local Health Integration Network (LHIN), is to explore the characteristics and common elements of successfully integrated approaches to diabetes prevention and management. Research indicates that integrated chronic care initiatives, including practice guidelines, care management plans, supports for self-management, as well as disease prevention, produce measureable benefits for both providers and clients. Results obtained from this study will be synthesized into a report summarizing the findings, which will be forwarded to the LHIN.

Researchers ask that you assist in this study by taking part in a telephone interview. Because we do not wish to cause discomfort to anyone, your participation is voluntary, you are free to answer the questions in any way that you choose, decline any questions you do not wish to answer, and to withdraw from the interview at any time. To ensure that information is gathered accurately, we also ask that you give consent to audio taping of the interview. This will be done with the understanding that all field notes and tapes will be secured in locked cabinets in the CRaHNR office, for a period of five years after the completion of the study, after which time it will be destroyed. All data will be kept confidential and you will not be identified in any written reports or subsequent presentation of the results.

I, _____ agree to be interviewed as part of the Centre for Rural and Northern Health Research study entitled *Environmental Scan: Diabetes Prevention and Management in the North West LHIN*.

In addition please check one of the following:

- _____ I give permission to the researchers to audiotape the interview.
 _____ I do not give permission to the researchers to audiotape the interview.

 Signature

 Date

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