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Building a national diabetes strategy: synthesis of research and collaborations

Consultation findings

Volume 1

Canada

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Building a national diabetes strategy: synthesis of research and collaborations

Consultation findings

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in consultation with the Coordinating Committee for the
National Diabetes Strategy

Volume 1

Foreword

In 1997, in response to the growing awareness and serious concern about the high human and economic cost of the pandemic of diabetes and its complications for all Aboriginal Peoples in Canada, the Medical Services Branch of Health Canada initiated the development of a National Aboriginal Diabetes Strategy in partnership with Aboriginal representatives. Recognizing that diabetes was also a serious problem for all Canadians, in 1999 the Government of Canada inaugurated the five-year Canadian Diabetes Strategy (CDS), with an extension until March 2005. The mandate of the CDS was to prevent diabetes where feasible, and to help people better manage the disease and its complications. The CDS features four key interrelated components: the Aboriginal Diabetes Initiative (ADI), Prevention and Promotion, the National Diabetes Surveillance System (NDSS), and National Coordination.

In 2001, Health Canada formed the Coordinating Committee for the National Diabetes Strategy (CCNDS). The CCNDS's mandate is to develop a national diabetes strategy and oversee its implementation. The purpose of a national diabetes strategy is to increase collaboration among diabetes stakeholders and improve the coordination of efforts to prevent and manage diabetes in Canada.

The first National Symposium on Diabetes, held in Montreal in 2001, confirmed broad support for the development of a national diabetes strategy that would involve all stakeholders across the country in an integrated, coordinated and comprehensive approach to diabetes prevention and control. Symposium participants recommended action in five theme areas: prevention, care, education, research and surveillance. The aim was to facilitate a concerted, collaborative effort among stakeholders in order to maximize effectiveness.

The CCNDS formed five expert working groups to revise the draft recommendations on diabetes prevention, care, education, research and surveillance (Appendix C). The working groups reviewed research evidence, conducted gap analyses and developed draft recommendations that were reviewed at a national symposium in May 2003. *Building a national diabetes strategy: synthesis of research and collaborations* (Volume 1) is the product of this process of research and consultation among a wide range of people working with, or concerned about, diabetes in Canada. All organizations concerned with diabetes are encouraged to take the results of this research and consultation process into consideration in their own work.

While this document assisted the CCNDS in the development of *Building a national diabetes strategy: a strategic framework* (Volume 2), a separate policy document to support a national diabetes strategy, the ideas and recommendations presented in this document neither indicate nor imply a commitment from any government or organization to their acceptance and implementation.

Executive summary

In 1999, the Government of Canada allocated $115 million over five years for the development of the Canadian Diabetes Strategy (CDS), with an extension until March 2005. The CDS is composed of four components: the Aboriginal Diabetes Initiative, Prevention and Promotion, National Diabetes Surveillance System and National Coordination. The purpose of the National Coordination component is to establish a national action plan to increase collaboration among diabetes stakeholders and improve the coordination of efforts to prevent and manage diabetes in Canada.

The development of a national diabetes strategy began at the 2001 National Diabetes Symposium, where participants suggested recommendations for diabetes prevention, care, education, research and surveillance. Following the Symposium, Health Canada formed a Coordinating Committee for the National Diabetes Strategy (CCNDS) to oversee the development of a national diabetes strategy and its implementation. (See Terms of Reference and list of members in Appendix C.). The purpose of a national diabetes strategy is to increase collaboration among diabetes stakeholders and improve the coordination of efforts to prevent and manage diabetes in Canada.

The CCNDS formed five working groups to address diabetes prevention, care, education, research and surveillance. The working groups reviewed research evidence, identified gaps and developed draft recommendations that were reviewed at a national symposium in May 2003 with representatives of federal and provincial/territorial governments, national Aboriginal organizations, national non-government organizations, health professional organizations, consumers, industry and academia. This report is the product of this process of research and consultation among a wide range of people working with, or concerned about, diabetes in Canada. It identifies a wide range of actions that could improve diabetes prevention and control in Canada. The ideas and recommendations presented do not indicate or imply a commitment from any government or organization to their acceptance and implementation.

The urgent need for action

Diabetes is a very serious public health concern for Canada as it heads into the new millennium. The need for action is immediate: failure to invest now will prove very costly in the near future.

Approximately 2 million Canadians live with diabetes: one in three individuals is unaware that he or she has the disease. Diabetes affects all ages, from children who develop primarily type 1 diabetes to adults who develop type 2 diabetes. The proportion of the Canadian population who reported having diabetes increased by 27% between 1994 and 2000. As the Canadian population ages and rates of obesity rise, this trend is expected to increase. Diabetes has a profound impact on the lives of individuals with the disease and their families. It touches virtually every Canadian, either personally or through a family member, neighbour or co-worker.

Diabetes has become a severe pandemic in Aboriginal communities in Canada, where its prevalence is estimated to be three to five times the national average. The incidence of type 2 diabetes among Inuit, where the disease was once unknown, has also risen. Diabetes has a devastating impact on Aboriginal Peoples living with the disease, their families and communities. As stated by several national Aboriginal organizations, “Action must be taken now to address this major threat to the health of our people.”

Several ethnic groups in Canada also have an elevated risk of diabetes compared with the general population. People of Hispanic, South Asian, Asian and African descent come from countries where the prevalence of diabetes is high. Their risk increases with lifestyle changes following their arrival in Canada. Specific programs need to be developed to be responsive to their language and cultural needs.

There are no modifiable risk factors for type 1 diabetes, but the risk of developing type 2 can be reduced with healthy nutrition, healthy weight and regular physical activity. Diabetes is a societal disease – the risk factors for type 2 are well entrenched into the social fabric of our communities. In spite of many efforts toward preventing diabetes, the risk factors and the number of Canadians with diabetes continue to increase.

Diabetes should be managed through glycemic (blood sugar) control to decrease the risk of complications and enhance quality of life. While services for managing diabetes are making a difference, as more people are given a diagnosis of diabetes and those with the condition live longer and develop complications from the disease, existing resources are being pushed to the limit.

Education, solidarity and coordinated work are the keys to addressing the diabetes pandemic successfully. Throughout the research and consultation process that informed this report, participants stated that an effective response will require a commitment to more consistent and collaborative ways of working to prevent diabetes and to enhance the quality of life – not only of persons living with diabetes but of all Canadians. This commitment to collaborative action is in full accord with the declaration of the Americas on Diabetes (1996), endorsed by the Pan American Health Organization (PAHO) as a guide for national program development. Effective action will require collaboration both within the health sector and among other sectors that influence the health of the population, such as education, transportation, recreation, industry, income and housing, and social services.

This document summarizes the results of a process of research and consultation with representatives of federal and provincial/territorial governments, national Aboriginal organizations, national non-government organizations, health professional organizations, consumers, industry and academia. It identifies the range of actions that could improve diabetes prevention and control in Canada.

Vision of a national diabetes strategy

The CCNDS developed the following vision of a national diabetes strategy:

A comprehensive framework to mobilize all sectors in developing, implementing and evaluating an integrated and coordinated approach for reducing the social, human and economic impact of diabetes in Canada.

A national diabetes strategy needs to articulate a plan for a partnership among all diabetes stakeholders and interested groups. It should provide an integrated, comprehensive, multi-sectoral, collaborative and sustainable approach to preventing and controlling diabetes that involves federal and provincial/territorial governments, national Aboriginal organizations, national non-government organizations, national organizations of health service providers, the private sector and academia. A national diabetes strategy should build on existing achievements, including the CDS, and should result in consistency and complementarity of action among all stakeholders. It is envisioned that all partners would actively collaborate in making the strategy a reality and oversee its implementation.

Recommendations for an effective approach to diabetes

The recommendations in this section are based on the preliminary recommendations made at the National Diabetes Symposium in 2001, the revised recommendations made by the CCNDS Expert Working Groups that were revised by the CCNDS, and the public consultation from the Second National Diabetes Symposium in 2003. In recognition of Aboriginal peoples' unique situation and the severity of the problem, a specific chapter in this report addresses their needs and proposes recommendations for action.

Recommendations for action

The Chronic Care Model (Appendix A) identifies the essential components of community and health system structures that encourage high-quality chronic disease management. Recommendations for specific actions within the CCNDS's five pillars of prevention, care, education, research and surveillance are grouped into the components of the Chronic Care Model– actions within the community, actions within the health care system, and the enabling functions that provide for effective and efficient services.

- **Healthy policy and community programs** – The goal of the community recommendations is to create an environment in which awareness of diabetes is widespread, "healthy choices in terms of nutrition and physical activity are easy choices", and there is equity in the opportunity[1] for achieving health. Public health services, non-government organizations, self-help groups and community action groups work primarily in the community sector along with non-health sector organizations such as education, transportation, recreation, housing, industry and social services. Community activities include advocacy for and the creation of healthy public policy, the enabling of community action, the creation of supportive environments, and the provision of information and education.
- **Health services** – The goals of the health service recommendations are to increase awareness of diabetes and its management, prevent type 2 diabetes among high-risk individuals, detect diabetes and its precursor conditions at an early stage, enhance self-management, and prevent and manage crises and complications – thereby enhancing quality of life for those with diabetes. Teams of health professionals, educators, paraprofessionals and allied health workers, and health service organizations work primarily in the health services component.
- **Enabling system functions** – The goal of enabling system functions is to ensure that services are provided efficiently and effectively, and in an equitable manner. The research and academic community, human resource planners, professional organizations, coalitions and networks provide enabling system functions. These include leadership and networking, organization and funding of services, development of capacity and resources, education of providers and policy makers, research and surveillance/monitoring, and implementation of clinical information systems to support both case management and program evaluation.

1 Improving equity in the opportunity for health includes such services as public transportation services for the disabled, income support programs, subsidized housing and residences for assisted living.

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Chapter 1 Introduction

Planning the response

In 2001, Health Canada formed the Coordinating Committee for the National Diabetes Strategy (CCNDS) to oversee the development of a national diabetes strategy and its implementation. (See Appendix C for Terms of Reference and list of members.) The purpose of a national diabetes strategy is to increase collaboration among diabetes stakeholders and improve the coordination of efforts to prevent and manage diabetes in Canada.

The CCNDS formed five working groups to address diabetes prevention, care, education, research and surveillance. The working groups reviewed research evidence, identified gaps and developed draft recommendations that were reviewed at a national symposium in May 2003. This document summarizes the results of this process of research and consultation with representatives of federal and provincial/ territorial governments, national Aboriginal organizations, national non-government organi- zations, health professional organizations, consumers, industry and academia. It identifies the range of actions that could improve diabetes prevention and control in Canada. The ideas and recommendations presented neither indicate nor imply a commitment from any government or organization to their acceptance and implementation.

The urgent need for action

Diabetes is a very serious public health concern for Canada as it heads into the new millennium. The need for action is immediate: failure to invest now will prove very costly in the near future.

Approximately 2 million Canadians live with diabetes: one in three individuals is unaware that he or she has the disease. The disease affects all ages, from children who develop primarily type 1 diabetes to adults who develop type 2 diabetes.

Diabetes has reached pandemic status among Aboriginal Peoples.

The disease has a profound impact on the lives of individuals with the disease and their families. It touches virtually every Canadian, either personally or through a family member, neighbour or co-worker. Type 2 diabetes is a societal disease – the risk factors for type 2 (being overweight and physically inactive) are well entrenched into the social fabric of our communities.

Every 8 minutes, an individual in Canada is given a diagnosis of diabetes.

40% of people receiving dialysis have diabetes.

Diabetic retinopathy is the main cause of blindness among adults aged between 30 and 69 years.

An estimated 2.4 million people will have diabetes by 2016.

In spite of many independent efforts toward preventing and managing diabetes, the risk factors and the number of Canadians with diabetes continue to increase. There are no modifiable risk factors for type 1 diabetes.

Diabetes should be managed through glycemic (blood sugar) control to decrease the risk of complications and enhance quality of life. While services for managing diabetes are making a difference, as more people receive the diagnosis and those with the condition live longer and develop complications, existing resources are being pushed to the limits.

It has become increasingly recognized that the policy context in which diabetes prevention and control programs exist must be addressed. For example, training diabetes educators without providing adequate funding and organizational support limits their ability to make a difference, or advising people to eat a healthy diet without addressing food access and security issues is irresponsible.

Innovation is required to respond effectively to the diabetes crisis. For example, the Kahnawake Schools Diabetes Prevention Project (KSDPP) is an ongoing participatory research and intervention project underway in the Mohawk territory of Kahnawake. The project empowers community members to care for their personal and family health by offering a diabetes prevention model based on Kanien-keha values. The project began in 1994 with the goal of decreasing the onset of type 2 diabetes in present and future generations. To accomplish this, the project established the main objective as increasing daily physical activity and healthy eating among Kahnawake children. The project seeks to mobilize the community, foster community empowerment and ownership through participation in all aspects of the project, and to build capacity within Kahnawake to ensure sustainability of project activities and outcomes. A community advisory board guides the project's work, and activities are cooperatively planned and implemented in partnership with local organizations. An extensive dissemination program gives community members feedback on all aspects of the project. KSDPP shares a model of its activities with other Aboriginal communities and people interested in diabetes prevention. The key to KSDPP's success is its ability to mobilize *and* empower its community to take action against the diabetes pandemic.

Education, solidarity and coordinated work are the keys to addressing the diabetes pandemic successfully. Throughout the research and consultation process, participants have stated that an effective response will require a commitment to more consistent and collaborative ways of working to prevent diabetes and to enhance the quality of life, not only of persons living with diabetes but of all Canadians. This commitment to collaborative action is in full accord with the declaration of the Americas on Diabetes (1996), endorsed by the Pan American Health Organization (PAHO) as a guide for national program development. Effective action will require collaboration both within the health sector and among other sectors that influence the health of the population, such as education, transportation, recreation, industry, income and housing, and social services.

Building a national diabetes strategy: synthesis of research and collaborations encourages both individual efforts and organizational action to improve the prevention and control of diabetes in Canada through more consistent and collaborative efforts. Chapter 2 of this report summarizes the surveillance and research findings on diabetes that support the recommended actions. Chapter 3 outlines some life stage issues that must be considered in implementing a national strategy for diabetes. Chapter 4 describes the benefits of the recommended actions. Chapter 5 focuses on the unique issues of Canada's Aboriginal Peoples.

Providing programs and services to Aboriginal Peoples presents unique challenges because of geographic factors (the northern and rural location of their communities), cultural differences, the impact of socio-economic factors, the lack of Aboriginal health providers, the complexity of governments and funding of health services, and the historic relationship between Aboriginal Peoples and governments. First Nations, Métis and Inuit each have unique circumstances, and each requires a strategy tailored to its own needs. The CCNDS will create a national diabetes strategy informed by this report. Other institutions are also encouraged to review their own programs and policies in light of the results of this research and expert consultation process.

Chapter 2 Diabetes – the evidence

What is diabetes?

Diabetes mellitus (DM) is a chronic condition that results from the body's inability to sufficiently produce and/or properly use insulin. The body needs insulin to use sugar as an energy source. Diabetes has no known cure: it is a permanent condition.

Diabetes takes several forms. The three most commonly recognized types are:

Type 1 diabetes

Type 1 diabetes is an auto-immune disorder that occurs when the pancreas no longer produces insulin or produces very little. Type 1 diabetes usually develops in childhood or adolescence and accounts for 10% of people with diabetes.

Even though less than 10% of individuals with diabetes have type 1, one-half of the cost of all dialysis treatments in Ontario are attributable to type 1 diabetes.

Since individuals develop type 1 diabetes at an early age, they are more likely to have complications because of the duration of the disease.

Type 2 diabetes

Type 2 diabetes is a metabolic disorder that occurs when the pancreas does not produce enough insulin to meet the body's needs or the insulin is not metabolized effectively. Type 2 diabetes accounts for almost all cases of diabetes among Aboriginal Peoples, and about 90% of cases in the general population. Type 2 occurs most frequently in people over 40 years of age. It has recently been detected in Aboriginal youth and children from high-risk ethnic groups, however. Here it is known as Pediatric type 2 or type 2 diabetes in children.

Gestational diabetes mellitus (GDM)

Gestational diabetes mellitus (GDM) develops during pregnancy as a result of a deficiency of insulin during pregnancy, which disappears following delivery. Babies of women with GDM have an increased risk of complications. Women who have had gestational diabetes are at a high risk of developing type 2 diabetes later in life. The offspring of women with GDM are also at risk of childhood obesity and type 2 diabetes.

Canadians living with diabetes

According to data from the National Diabetes Surveillance System (NDSS) for 1998/1999, 5.1% of Canadian adults aged 20 years and older have physician-diagnosed diabetes.[2] Since it is estimated that one-third of all cases of diabetes are undiagnosed in Canada, as many as 2 million Canadian adults may be directly affected.

The proportion of the Canadian population who reported having diabetes increased by 27% between 1994 and 2000.

2 This data is based on information from all provinces and territories, with the exception of New Brunswick, Newfoundland and Labrador, Northwest Territories and Nunavut. Prevalence rates among children are unknown.

The proportion of the Canadian population who reported having diabetes increased by 27% between 1994 and 2000. As the Canadian population ages and rates of obesity rise, this trend is expected to increase.

Diabetes is very serious among Aboriginal Peoples, among whom the prevalence is at least 3 times that of the general population. (See Chapter 5 for a detailed discussion.)

Several ethnic groups in Canada also have elevated risk of diabetes compared with the general population. Over three-quarters (77.1%) of the immigrant population are from high-risk ethnic groups: Asian descent (57% of total immigrants), African descent (12.8%) and Hispanic descent (7.3%). Not only is prevalence high in their countries of origin, but their risk actually increases with lifestyle change following their arrival in Canada.

The human face of diabetes

64.5% of Canadians with diabetes report their health as "good" or "better", compared with 90.8% of individuals without diabetes.

Diabetes exerts a significant effect on the quality of life of those with the disease. People with type 1 diabetes, for instance, face having to take insulin for the rest of their lives. The continuous need to monitor intake (in terms of timing, type and amount of food), take medication (whether pills or insulin injections), monitor blood glucose, and anticipate and plan for activities that may affect diabetes control can severely strain their daily lives. Staying motivated 24 hours a day, seven days a week can be very tiring. Depression often develops among individuals with diabetes.

Without good metabolic control, diabetes can cause life-threatening events, such as severe hypoglycemia (low blood sugar), hyperglycemia (high blood sugar), ketoacidosis and even coma. Good control both enhances quality of life and decreases the use of acute care services.

40% of individuals with diabetes will develop debilitating complications.

People with diabetes are living longer than in the past. The reason for this is unclear, but it may be due to improved education and treatment. The impact of living longer with diabetes is that more people are developing the complications associated with diabetes: cardiovascular disease, cerebrovascular disease (stroke), renal disease (including kidney failure), peripheral neuropathy (which can lead to lower-limb amputation), retinopathy (which can lead to blindness) and erectile dysfunction (impotence). After 20 years of diabetes, nearly all people with type 1 diabetes and over 60% of people with type 2 diabetes have some degree of retinopathy. People with diabetes may also face shortened life expectancy because of the complications of the disease. Good control of blood sugar and treatment of underlying conditions can greatly decrease the risk of complications.

In Aboriginal communities, diabetes complication rates are much higher. Lack of access to health care and education may explain this pattern.

Diabetes is ranked as the seventh leading cause of death in Canada. In 1999, 6,137 deaths were attributed to diabetes, with higher rates among men than women. The annual Mortality File compiled by Statistics Canada includes only the condition listed as the immediate cause of death, however. The actual number of deaths for which diabetes is a contributing cause is estimated to be five times as high as current figures indicate – that is, 30,000 deaths each year – and if current trends continue, the figure will increase exponentially over the next decade.

Economic impact

In addition to the human suffering they cause, diabetes and its complications place a great economic burden on Canadian society. This includes, for example, the cost of health care services, lost productivity from work, personal expenditures and drugs.

The *Economic Burden of Illness in Canada*, a Health Canada study, estimates that in 1998 diabetes accounted for $0.4 billion for hospital care and drugs, and $1.2 billion in indirect costs, which include loss of productivity due to illness, injury, disability or premature death. These figures underestimate the real burden, since they do not include hospital admissions for common complications of diabetes – chronic conditions such as hypertension, cardiovascular disease and cerebrovascular disease. Two recently published studies suggest that the total cost for direct care of diabetes and its complications in Canada was much higher than Health Canada's estimates. Dawson estimates the cost to have been $5 billion in 1998, or about 11% of total health care expenditures.[3] Ohinmaa estimates that total health care costs related to diabetes are projected to increase from $4.66 billion in 2000 to $8.14 billion in 2016 (in 1996$).[4]

A person with diabetes spends as much as $5,000 per year on supplies and medications.

Nearly 1 in 10 hospitalizations lists diabetes as the main or underlying condition responsible for admission.

Three out of 4 individuals with diabetes use either insulin or oral anti-hyperglycemic agents to control their disease.

Preventing the onset of type 2 diabetes

Primary prevention includes activities designed to prevent or delay the onset of type 2 diabetes. Regular exercise and weight control can prevent type 2 diabetes by reducing obesity and improving glucose tolerance. Even small reductions in weight can decrease the risk of type 2 diabetes. Unfortunately, at this time, there are no known modifiable risk factors for type 1 diabetes: more research is needed to identify preventable risk factors.

Significant levels of obesity, physical inactivity and poor nutritional practices are common among Canadians. According to the Canadian Community Health Survey 2000/2001[5]:

- 56.5% of adults aged 20+ years were physically inactive: 53.2% of men and 59.3% of women;
- 47.5% of adults aged 20-59 years were overweight (BMI[6] ≥ 25.0): 39.1% of women and 55.5% of men;

3 Dawson KG, Gomes D, Gerstein H, Blanchard JF, Kahler KH. The economic cost of diabetes in Canada, 1998. Diabetes Care 2002;25:1303–7.

4 Ohinmaa A, Jacobs P, Simpson S, Johnson J. The projection of prevalence and cost of diabetes in Canada: 2000 to 2016. Canadian Journal of Diabetes 2004;28(2):116-123.

5 Heart and Stroke Foundation of Canada. The growing burden of heart disease and stroke in Canada 2003. Ottawa: p. 25.

6 BMI = Body Mass Index. For full description, see Glossary.

- 15.2% of adult Canadians were obese (BMI ≧ 30.0): 16.1% of men and 14.2% of women;
- 54.8% of Aboriginal adults aged 20-59 years living off-reserve were overweight; and
- 52.6% of Aboriginal adults aged 20+ years living off-reserve were physically inactive.

According to the 1998/99 National Longitudinal Study of Children and Youth[7]:

- 37% of children aged 2-11 years were overweight, an increase from 34% in 1994/95; and
- 18% of children aged 2-11 years were obese, an increase from 16% in 1994/95.

Two approaches are necessary to prevent type 2 diabetes – a population health approach and a high-risk approach. A population health approach encourages physical activity, healthy eating and healthy weight for the entire population. Community strategies such as the creation of bicycle paths, nutrition labelling and social marketing benefit the whole population. This approach considers all the determinants of health, some of which are outside the control of the individual and require healthy public policies or actions by others. On the other hand, the high-risk approach focuses on individuals at highest risk of diabetes, such as those with a family history of the disease or impaired glucose tolerance. This approach includes more intensive interventions, such as health education and behaviour modification.

Determinants of health

- *Income and social status*
- *Social support networks*
- *Education*
- *Employment/ working conditions*
- *Social environments*
- *Physical environments*
- *Personal health practices and coping skills*
- *Healthy child development*
- *Biology and genetic endowment*
- *Health services*
- *Gender*
- *Culture*

Since most of the causes of physical inactivity and obesity have roots that extend well beyond the health sector, strategies must be developed and implemented in close collaboration with other sectors. For example, representatives of the recreation, transportation, municipal planning and food production/food service sectors can all participate in making the environmental changes necessary for preventing type 2 diabetes. This multi-sectoral collaboration must include action at all levels – individual, home, school and workplace, community, regional, provincial/territorial, national and international.

One of the challenges in preventing type 2 diabetes is food security. Food security "exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life."[8] People need access to healthy food at affordable prices in order to be able to eat well and maintain a healthy weight. Food security varies across the country.

7 Heart and Stroke Foundation of Canada. Op cit. p. 24

8 Health Canada. Discussion paper on household and individual food security. Ottawa: Health Canada.

Characteristics of effective prevention programs

According to the environmental scan conducted for the development of this report, effective prevention programs have the following characteristics:

- Effective partnerships with clarification of the mandate, roles, authorities and responsibilities of the different parties:
  - ◊ well-defined accountability frameworks, evaluation and reporting requirements;
  - ◊ full commitment and participation of all partners from the planning phase onward;
  - ◊ utilization of pre-existing partnerships;
  - ◊ allocation of sufficient lead time for planning;
  - ◊ recognition of the time and effort needed to maintain partnerships; and
  - ◊ effective communication at all stages.
- Community involvement in and ownership of programs;
- Awareness of the determinants of health;
- Program flexibility to meet different needs;
- Design of the intervention as part of daily life rather than a "special" activity;
- Promotion of and support for an individual's responsibility for self-management;
- Changes to the physical environment that facilitate safe, healthy physical activity or increase access to good food;
- Healthy public policy at all levels;
- Provision of financial and human resources to initiate new programs;
- Stable resource allocation for long-term initiatives and longer-term action plans; and
- Adequate duration and persistence of intervention with a gradual, staged approach.

Gaps in preventing the onset of type 2 diabetes

The environmental scan identified several gaps in the effective prevention of the onset of type 2 diabetes:

- Tendency of communities to focus more on issues such as accessibility of self-management education and treatment than on prevention.
- Inadequate provision of targeted interventions for populations at higher risk of developing diabetes, such as individuals who are overweight or who have a family history of diabetes, Aboriginal Peoples or specific ethnic populations.
- Inadequate communication to the public about diabetes prevention and inadequate dissemination of information among service providers about their own programs.
- Lack of adequate program coordination, integration and partnerships to avoid duplication and maximize the effectiveness of each organization's programs.
- The predominant focus of existing programs on modifying the risk factors of physical inactivity, obesity/overweight and poor nutritional habits without sufficiently addressing underlying determinants of these risk factors.

- Inadequate sustained funding for prevention programs.
- Failure to translate knowledge into action that would result in the expansion of effective programs and widespread implementation of effective policies.
- Inaccessibility of initiatives developed for the general population to certain individuals or groups because of low literacy levels, or lack of fluency in English or French.
- Lack of adequate cultural-specific initiatives for high-risk ethno-Canadian groups.
- Lack of research on the effectiveness of programs and strategies.

Detecting type 2 diabetes and diabetic complications

It is estimated that up to 50% of people with type 2 diabetes are unaware that they have the disease. Screening high-risk asymptomatic individuals to detect diabetes and its predisposing conditions, such as impaired glucose tolerance, is recommended by the Canadian Diabetes Association's (CDA) *2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada* (CPGs). Early diagnosis and treatment to control blood sugars can decrease the risk of complications and improve the quality of life of a person with diabetes.

Among people with diabetes, early detection and treatment of complications can decrease the risk of serious disability and death. Recommendations from the CPGs include:

- Performing direct ophthalmoscopy of dilated pupils for retinopathy (eye examination);
- Assessing the albumin/creatinine ratio in urine for nephropathy (urine test for kidney problems);
- Examining for foot ulcers (foot care);
- Assessing ankle reflexes, sensation in the foot for neuropathy (foot exam for nerve damage);
- Measuring fasting lipid profile for heart disease (blood test for cholesterol and triglycerides); and
- Assessing blood pressure for hypertension.

Who is at risk of type 2 diabetes?

Individuals aged 40 years or over are at risk of type 2 diabetes and should be tested at least every 3 years.

Individuals under the age of 40 should be tested for diabetes earlier and/or more often if they:

- ⇨ *Have a first-degree relative with diabetes.*
- ⇨ *Are overweight (especially if they carry most of their weight around the middle).*
- ⇨ *Are members of a high-risk group (Aboriginal Peoples, Hispanic, Asian, South Asian or African descent).*
- ⇨ *Have a history of impaired fasting glucose or impaired glucose tolerance.*
- ⇨ *Have high cholesterol or other fats in their blood.*
- ⇨ *Gave birth to a baby that weighed over 4 kg (9 lbs) at birth or had gestational diabetes (diabetes during pregnancy).*
- ⇨ *Have high blood pressure or heart disease.*
- ⇨ *Have numbness in hands and/or feet, or have trouble getting and maintaining an erection.*
- ⇨ *Have polycystic ovary syndrome, acanthosis nigricans, or schizophrenia*
- ⇨ *Have symptoms of diabetes:*
  - *unusual thirst;*
  - *frequent urination;*
  - *unusual weight loss;*
  - *extreme fatigue or lack of energy;*
  - *blurred vision;*
  - *frequent or recurring infections;*
  - *cuts and bruises that are slow to heal; and/or*
  - *tingling or numbness in hands or feet.*

Comprehensive diabetes programs include screening for complications by a multi-disciplinary team.

Gaps

The environmental scan identified several gaps in the effective detection of diabetes.

Although CPGs for diabetes screening exist, their application is inconsistent. Lack of awareness, lack of multi-disciplinary teams, and lack of funding for screening programs all contribute to this variation in their use.

While several provinces have identified the need for screening for diabetes and its complications, no formal national program exists to facilitate and support effective screening across the country. The Canadian Breast Cancer Screening Program exemplifies the way in which a national strategy can influence both policy and practice at the provincial/territorial and local levels.

Diabetes care and prevention of complications

People with type 1, type 2 or gestational diabetes must manage their disease on a day-to-day, moment-to-moment basis. This is possible with sound knowledge and increased confidence in management principles and approaches. The knowledge and necessary skills are gleaned from interactions with informed health care professionals and continuous self-learning. Supportive physicians and systems facilitate decisions based on best practice. Effective management of diabetes results in improved glucose control (and other metabolic disorders, including blood pressure and blood lipids), a decrease in the likelihood of complications, and improved quality of life.

Establishing and modifying a treatment plan, monitoring the development and progression of diabetes complications, and managing the acute problems associated with diabetes require a range of clinical care services. Multi- and inter-disciplinary care teams provide diagnosis, education, and treatment in collaboration with individuals with diabetes and their families. The Chronic Care Model (Appendix A) identifies the essential components of community and health system structures that encourage high-quality chronic disease management. This model embraces self-management concepts. It refers to "informed, activated patients" who are willing to take action to manage their illness effectively. Patients are supported by a "prepared, proactive team," which assesses and responds to needs and is supported by CPGs and information systems. The result is "productive interactions" that lead to effective assessment, tailoring of clinical management, collaborative goal setting and problem solving, a shared care plan, and active, sustained follow-up – all leading to improved outcomes.

Informed, supported and accessible physicians (specialists and generalists) help to guide the care provided. Access to these care providers and/or their delegates is an issue of concern in more remote and rural areas as well as some urban areas of Canada. The use of technology (Telehealth), systems support (databases/electronic records), and enhanced roles for health care professionals (delegated medical function/shared competency) would allow for more timely interventions and enhance the use of tools to assist in efficient and effective care. Programs that recognize special expertise and/or supplemental or advanced training in diabetes would help to address shortages of physicians with diabetes expertise.

Diabetes centres provide referring and specialist physicians with access to inter- and multi-disciplinary team members with complementary areas of expertise. These teams provide specialized education and specific services that enhance the quality of care provided and patient

outcomes. While this model should be encouraged, the infrastructure available in a major urban centre may differ greatly from that in a smaller centre. For this reason, it is important to explore and develop local implementation and administrative structures and models across the country.

Educational interventions aimed at achieving changes in behaviour are the foundation of many prevention and care activities. The purpose of diabetes education is to provide knowledge and increase awareness of the behaviours and skills necessary to reduce complications from diabetes and to improve the quality of life of people living with the disease. Effective education is based on need, is experiential, and focuses on the individual learner. In addition to the use of new knowledge to develop skills and address attitudes and behavioural issues, emphasis must also be placed on problem solving and decision making.

Complementary to self-care management education, self-efficacy training focuses more on behavioural issues – on developing individuals' self-efficacy and motivation so that they can use their skills and knowledge to take effective control over their lives and chronic diseases commensurate with their capability. A particular feature of self-efficacy training is that, unlike self-care management education, it is led by trained volunteers – typically people who themselves have a chronic condition. They cover topics such as pain control; use of medications; behaviour and lifestyle change; methods to adjust to social and workplace dislocations; strategies to cope with emotional reactions; methods to interpret changes in the disease and its consequences; and use of medical and community resources. Self-efficacy training enables participants to learn from one another and has helped reduce their symptoms, improve their physical activity levels, and significantly reduce their need for medical treatment.

Programs and services in the community should support individuals with diabetes by encouraging and enabling healthy food choices and regular physical activity. Building capacity in a community means improving its ability to facilitate healthy living and, thus, facilitate diabetes management. For example, restaurants that offer a range of nutritious meal choices help people with diabetes to satisfy their eating requirements in social situations. Schools that provide healthy food in vending machines and in cafeterias make it easier for the child with diabetes to fit in. In the workplace, employers who provide healthy nutritional options in the cafeteria or vending machines and provide opportunities for physical activity support the adoption of healthy lifestyles. Walking programs, safe biking routes, recreation areas, and lighted streets help to shape a healthy community while recognizing that an entire population benefits from these community supports. As provinces and territories embrace "Healthy Living" or "Wellness" strategies, the care of all persons with or at risk of developing diabetes will be enhanced.

The health care system must be responsive to new guidelines and must encourage interventions based on evidence. Emphasis should be based on coordination, including, for example, information sharing between care providers and across jurisdictions, and policies that facilitate equitable access and systems that use data in decision making.

Medication is a critical component of diabetes management. A person with diabetes can incur medical costs two to five times higher than those of a person without diabetes. This can represent a significant financial hardship for those without additional health coverage such as employee benefit plans or other private insurance. Equitable access to medications and supplies across jurisdictions would ultimately improve patient outcomes.

Aboriginal Peoples face particular challenges in diabetes management due to lack of adequate services. This is also true for ethnic minorities that find lack of cultural sensitivity as much a barrier to good care as limited access to qualified personnel. Chapter 5 expands on the issues that are specific to the Aboriginal populations regarding management of diabetes and prevention of complications.

Successful programs

Within Canada, several provinces/territories have taken the initiative to provide high-quality services to individuals with diabetes.

- Most urban and some rural centres have multi-disciplinary teams, usually hospital-based, that provide support to primary care providers.
- All provinces/territories and regions have diabetes programs that include diabetes education. Availability and spectrum of delivery vary, however.
- Psychosocial education interventions, which show promising results in quality of life and other areas, as well as metabolic control, require further development. Group- and family-based educational modalities have also shown success.
- Models of shared care with families have shown great promise in improving diabetes outcomes, as well as in raising the knowledge and skill of health care providers.
- Group education, patient and provider prompts, electronic records and routine recall support effective management of diabetes.
- Evidence-based CPGs have been published and distributed to health professionals.

Gaps in diabetes care

The environmental scan identified several gaps in the effective care of diabetes:

Community resources and policies

- Limited community capacity for diabetes care beyond that provided by health professionals. (A creative approach for vulnerable populations is needed.)
- Need for more school-based programming and other outreach strategies for children and youth with diabetes.
- Inadequate community, school and workplace supports to encourage healthy living.
- Lack of attention to poverty and inadequate food supply.

Health system: organization of health care

- Limited access to specialists, sub-specialists and even general practitioners in some parts of Canada.
- Poor coordination of services between organizations, possibly due to jurisdictional issues in some provinces/territories.
- Lack of regionalized care in some rural and remote communities, including Aboriginal communities.

Self-management support

- Inaccessibility of diabetes education close to home for all individuals with diabetes. (Organized programs have waiting lists. Accessibility is unequal across cultures and high-risk groups.)
- Lack of focus-tested, multicultural resources for people of all ages.
- Lack of resources specifically suitable for Aboriginal communities.

Delivery system design

- Under-funding of education services, including human resources for staff programs, equipment, and physical space.
- Lack of universal recognition of the pivotal role of the diabetes educator as a member of the diabetes health care team.
- Lack of a single defined model that is both effective and efficient for adoption or adaptation to a variety of settings.
- Lack of outreach and follow-up services.
- Unequal coverage and availability of drugs and medical supplies for diabetes care among the provinces.

Decision support

- Inconsistent design and implementation of evidence-based best practices in diabetes programs, primarily due to a lack of research, program evaluation, resources and expertise in this area. (This results in uneven standards in diabetes education, care and treatment across the country. Outdated, poorly referenced and inconsistent education materials are common.)
- Inconsistent adherence to CPGs in some areas.
- Difficulty in validating adherence to and/or support for the implementation of CPGs within and across jurisdictions.

Clinical information systems

- Inadequacy of clinical information systems for health service planning in most areas.
- Lack of a consistent minimum dataset of clinical and self-care indicators in use across Canada.

Education

Diabetes education encompasses education for the general public, people with diabetes and their families, health service providers, and health care funders and policymakers. It is easier to change policy than individual behaviour. Education and resources for policymakers and providers (both treatment providers and educators) would enhance their capacity to develop and deliver evidence-based self-management education to those affected by diabetes – whether at the level of individuals or of the whole population.

Diabetes educators and researchers cannot and should not work in isolation. Research into diabetes education is essential to support and inform current and future approaches, including self-management education programming, peer intervention programs (such as self-efficacy training) and population-based awareness initiatives promoting environmental change and lifestyle modification to prevent diabetes.

Successes in education

Diabetes education programs (DEPs) are available in most provinces and territories. They are paid for by provincial/territorial health budgets and involve a broad spectrum of stakeholders. DEPs generally focus on care, education and services for individuals with diabetes and the prevention of complications, and do not include primary prevention. Despite the emphasis on education as a vital prerequisite for effective self-management, waiting lists for DEPs are common; access is inequitable across cultures and high-risk groups; standards are unevenly applied; and indicators of outcome effectiveness are often not identified or evaluated in any systematic way.

Gaps in education

The environmental scan identified several gaps in education for diabetes:

- Lack of research to assess the effectiveness of specific education modalities.
- Imbalance between individual level and population health approaches.
- Lack of clarification regarding the process of integrating prevention activities for diabetes with prevention of other chronic disease.
- Inconsistent application of existing knowledge about health behaviour change in the development of programs.
- Lack of resources and expertise in program development and evaluation.
- Lack of multi-level DEPs and services.
- Poor accessibility to DEPs and services close to home in some parts of the country.
- Inadequate resources, including under-funding of education; insufficient human resources; inadequate equipment and resources; lack of outreach and follow-up services; and lack of multi-cultural resources and resources in a variety of languages.
- Lack of recognition of the pivotal role of the diabetes educator in facilitating behaviour change.
- Barriers to ongoing professional education, such as lack of time, lack of employer support and budget restrictions.

Research

In 2002, the Research Working Group of the CCNDS created a database of funded diabetes research in Canada. The analysis showed that the majority of funding in Canada was awarded to basic biomedical research and clinical research, while research into population health and health services categories received much less funding. High-quality diabetes research was focussed within a small number of established academic centres linked with major medical schools. Only a few Canadian centres could create the critical mass of investigators with the wide mix of skills required to compete internationally for diabetes research funds.

The bulk of funding for diabetes research was provided by (in order of importance) the Canadian Institutes of Health Research (CIHR), industry, the Juvenile Diabetes Research Foundation (JDRF), the Canadian Diabetes Association (CDA) and the Natural Sciences and Engineering Research Council of Canada (NSERC).

Successes in research

The following appear to be national research strengths:

- Islet transplantation and associated studies on stem cell biology and gene therapy strategies. Canada has already attained international leadership in islet transplantation.
- Biology, genetics, control and prevention specific to type 1 diabetes.
- Biology, control and prevention of type 2 diabetes.
- Basic research into mechanisms of insulin release or action.
- Complications of diabetes.

Gaps in research

The environmental scan identified several gaps in research on diabetes:

- Inadequate funding for all types of diabetes research.
- Inadequate research funding to monitor the impact of changes in clinical practice and health policy on a population basis.
- Lack of a Canadian "Innovation Agenda" to take advantage of research that can be translated into profitable endeavours.
- Inadequate mechanisms for disseminating research findings. (No single, consolidated, Web-based source of new knowledge from diabetes research impartially informs the stakeholder of its impact on prevention, care or "cure", or of its future promise.)

Surveillance[9]

The vision of the National Diabetes Surveillance System (NDSS) is:

> A multi-sectorial initiative of non-governmental agencies, Aboriginal groups, government and industry committed to reducing the incidence and complications of diabetes through leadership in the development, implementation and national co-ordination of provincial/territorial and Aboriginal diabetes surveillance systems.

The goals of the NDSS are:

1. To develop a national, standardized database for diabetes with long-term monitoring of diabetes-related complications through the integration of new and existing databases.
2. To facilitate the establishment and maintenance of ongoing surveillance of diabetes and its complications in each province and territory, and in Aboriginal communities.
3. To disseminate national comparative information to assist in effective prevention and treatment strategies by public health, Aboriginal organizations/communities, non-government organizations and private industry.
4. To develop a basis for the evaluation of economic/cost-related issues regarding the care, management and treatment of diabetes in Canada.

9 Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know... A surveillance system includes a functional capacity for data collection, analysis and dissemination" (US Centers for Disease Control, 1988).

Successes in surveillance

With dedicated funding through the CDS from 2000 to fiscal year 2004/05, inclusive, and through innovative use of existing administrative data sources in each jurisdiction, the NDSS has made considerable progress in establishing a system for monitoring diabetes across the country.

The NDSS has been touted as a potential model of surveillance for all chronic disease in the future. Its success is rooted in the unequivocal and shared recognition of the objective – every partner sees the value of the system for itself, and there is unanimous agreement that this objective can only be achieved through collaboration. The Steering Committee is inclusive and egalitarian with representation from the Public Health Agency and the First Nations and Inuit Health Branch of Health Canada, the provinces/ territories, non-governmental organizations, national Aboriginal groups, and academics and researchers, with support from industry. The non-governmental partners, primarily through the Diabetes Council of Canada, have been recognized as a central unifier. Perhaps the greatest anecdotal evidence of its success is that most of the partners claim NDSS as their own – engagement and ownership are very much evident.

The solid framework upon which the NDSS is constructed is one of the reasons behind its success to date. The framework was developed collaboratively by the many partners involved. The governance model, policies and guidelines are very clear and respectful of each partner's contributions and limitations.

Another innovation was the capacity development component of the NDSS. Health Canada provided dedicated resources to the provinces/territories according to need for: hardware, software and staffing; systems development; and the upgrading and integration of databases.

The NDSS released its first series of data in 2002 and its first full report in 2003. For the first time in Canadian history, detailed national comparative information existed to assess the burden of diabetes, and to ultimately assist in the development of effective prevention and treatment strategies. The NDSS is also allowing provinces/territories to conduct more detailed analyses of their own regions.

Gaps in surveillance

The environmental scan identified several gaps in the surveillance of diabetes:

- Limited surveillance of type 1 diabetes because administrative data do not differentiate among the various types of diabetes.
- Poorly developed Aboriginal component in diabetes surveillance. Capacity within Aboriginal organizations and communities needs to be developed (human, technological and financial resources). Appropriate partnerships for diabetes surveillance need to be developed. Issues regarding confidentiality and privacy, data access, control and ownership need to be resolved.
- Incomplete dissemination of NDSS data to policy makers.
- Lack of periodic evaluation of the NDSS system.
- Inadequate use of NDSS information to evaluate public health programs.
- Lack of stable multi-year funding to enable the NDSS to accumulate data and to mature to meet stakeholders' needs.

Chapter 3 Life stage issues

Diabetes affects people of all ages, and people in each life stage face different prevention and management issues. As a result, diabetes policies, programs and services must be tailored to the unique needs of each age group. This section highlights the needs of children and adolescents with diabetes, pregnant women with gestational diabetes, and seniors (both with and without diabetes).

Children and adolescents

Diabetes among children and youth, whether type 1 or type 2, presents unique challenges. Most parents react with shock, disbelief and sadness when their child is first diagnosed with diabetes. Many parents who believed that diabetes only affects older people have trouble accepting the diagnosis. Even when the initial shock is over, parents then face the prospect of managing a complicated diabetes regimen on a daily basis in order to keep their child healthy. The task of creating a healthy environment in which their child can thrive can seem daunting. In addition, children and youth face the task of fitting in with their peers while coping with the demands of diabetes self-management.

Prior to the 1990s, type 2 diabetes was rare among children and adolescents. In the last 10 years, however, type 2 diabetes has been increasing among Aboriginal Peoples and some ethnic groups, due in part to increasing physical inactivity and obesity. Children of women with gestational diabetes (GDM) have an increased risk of childhood obesity and type 2 diabetes. While initially type 2 diabetes may have a smaller impact on the family than type 1 (because of the insulin injections required for type 1 and concern about low and high blood sugars), families need support in diabetes management because of the high risk of diabetic complications resulting from the longevity of the disease.

Several issues must be addressed for effective prevention and management of diabetes among children and adolescents:

Healthy weight, eating and regular physical activity

Healthy behaviours formed in childhood prepare for lifelong healthy behaviours. Thus, education for children and adolescents, school and community programs, and policies that support healthy eating and regular physical activity in the school and community setting are critical for diabetes prevention.

Family support

Diabetes is a "family disease": the whole family must be included in its effective management. All families need access to culturally and linguistically appropriate services. Education helps the family make the adjustments it needs. Counselling can help the family cope with the emotional stress of having a child with a chronic, life-threatening illness with a high risk of complications. Families need to understand the accelerated development of macrovascular complications in diabetes and the need for family support. Workplace polices that permit time for health appointments and the availability of insurance programs that provide support for medications and supplies can assist the family in meeting the demands of this illness.

Being away from home

Social development is dependant on interaction among peers, and these interactions often take place outside of the home. This can be a major concern for parents who wonder whether others can provide the necessary emergency care if a crisis occurs. Widespread knowledge among the public about diabetes and managing crises situations can help.

Childcare setting and school

Children over five years of age spend about one-half of their waking hours at school. Some children under this age are in childcare settings outside of the home. Teachers and childcare providers need to understand enough about the disease to respond to crises. School policies that allow for both regular snacks and private space for testing provide vital support to the child or adolescent in self-managing his/her diabetes. Clear communication is needed between parents and school staff.

Development issues

As children grow and develop, not only does the need for food and insulin vary but the ability to participate in the management of their illness also changes. Among toddlers, giving daily injections and testing the blood for glucose control can be very difficult. Teens may not want to do regular testing if it is inconvenient, and they may lie to their parents to avoid criticism. Hormonal changes through puberty contribute to erratic blood sugar levels. Teens must tell their friends about their condition so that they know how to respond in a crisis.

Sense of self

Children or adolescents with diabetes must include the disease in their sense of self in such a way that it remains an important factor in their life choices. This is not always an easy process, particularly as adolescents struggle with fitting in with their peers.

Search for a cure

Research for a cure for diabetes is very important to parents of children with type 1 diabetes.

Transition to adult services

For adolescents with type 1 diabetes and their parents, the movement from the pediatric health care setting to the adult setting is a major transition that presents several challenges. The health care team with which they have built rapport and confidence changes. The services may be provided in a different locale, and the philosophy and approach may change, making it difficult for the family to adjust. Health services can respond effectively to these challenges by involving the adolescent and family in the care process and having effective liaison among pediatric and adult programs.

Pregnant women with diabetes

A pregnant woman's insulin needs increase by two to three times normal levels in the second and third trimesters of pregnancy because of placenta-produced hormones that resist insulin and because of the growth demands of the fetus. Among women who already have diabetes, this increased need for insulin makes managing the disease even more of a challenge.

Other women may develop GDM if their bodies cannot match this increased need for insulin. GDM occurs in 2% to 4% of all pregnancies. Excess sugar in the blood affects the growth and development of the baby. In most cases, GDM can be managed by diet and exercise and it disappears after the baby is born; however, the woman is at increased risk of developing diabetes later in life. As well, babies of women with GDM are at risk for childhood obesity and type 2 diabetes.

There are several issues that must be addressed for effective prevention and management of diabetes among pregnant women:

Screening

Since GDM is asymptomatic, screening can detect it early so that treatment can be instituted to avoid an adverse infant outcome. The Canadian Diabetes Association's (CDA) 2003 Diabetes Clinical Practice Guidelines (CPGs) recommend that all pregnant women between 24 and 28 weeks gestation, and earlier if there are added risk factors, be screened for diabetes.

Specialized perinatal care

Pre-existing diabetes and GDM are high-risk prenatal conditions. Women need access to high-quality education about and effective monitoring of both fetal growth and development and the condition itself during the pregnancy, labour and birth. These services are provided by specialized programs in some communities; in others, the regular care provider utilizes the support from specialists. It is important that all women have access to comprehensive, high-quality services. For women with pre-existing diabetes as well as for women with GDM in prior pregnancies, pre-conception care and counselling would help them prepare effectively for the pregnancy.

Working during pregnancy

As with all women during pregnancy, women with diabetes (pre-existing or gestational) may be unable to work at the same level because of fatigue and a feeling of malaise. Some women will have increased demands regarding more frequent monitoring and follow-up visits. As a result, flexibility may be required. Workplace policies that permit time away for service appointments, have rest areas and provide flexible work arrangements (for example, working at home) can assist women to cope with the challenges of diabetes in pregnancy.

Seniors

The prevalence of type 2 diabetes increases with age and peaks among adults between 75 and 79 years of age. Persons aged 65 years and older represent almost 50% of the cases of type 2 diabetes. Complications from diabetes increase with the duration of the disease, with twice as many seniors experiencing diabetes-related visual impairment, hypertension, heart disease and stroke compared to those under 65 years of age, and 10 times as many having a lower limb amputated. Services for seniors account for one-third of the costs of diabetes in Canada.

Some of the issues that must be addressed for effective prevention and management of diabetes in seniors include:

Seniors' prevention programs

The number of seniors is expected to double by the year 2025. As a result, the number of seniors with diabetes will increase dramatically in the next 20 years. Prevention programs for adults and seniors that encourage healthy weights and regular physical activity will be key to controlling this potential increase. The nutritional and physical activity needs of seniors differ from those of other age groups because of metabolic processes associated with the normal aging process. Therefore, seniors will require programs aimed at their specific needs. The assessment of healthy weight in seniors also needs to be tailored to changes associated with the aging process. For example, a senior with poor muscle mass but with abdominal obesity may have a good BMI but still be at risk of type 2 diabetes.

The benefits of adopting a healthy lifestyle go beyond diabetes prevention: they provide the foundation for a high quality of life throughout the aging process. Promoting a healthy lifestyle includes addressing underlying psychosocial factors that influence seniors' decisions. Reducing stress, encouraging effective stress management and creating healthy environments make it easier for seniors to adopt a healthy lifestyle.

Transportation

Lack of safe and secure transportation acts as a barrier to elderly persons by affecting their mobility and quality of life.[10] It influences their ability to participate not only in recreational and social opportunities but also in health care services and programs. Assisted transportation and volunteer driving programs can reduce this barrier.

Informal and formal home care

Seniors with diabetes – particularly those over 75 years of age – often need assistance with the activities of daily living and with diabetes-specific care, such as skin and foot care and taking medication. It is estimated that family members and friends provide between 75% and 85% of care received by seniors in the community. The shift to early discharge from hospital in recent years has increased demands on caregivers when seniors become ill with diabetes-related complications. Home care programs need to be comprehensive and accessible to provide support to both caregivers and the individuals with diabetes.

Supportive housing

Living in good-quality, affordable and safe housing is an important determinant of seniors' health. For older seniors, typically aged 75 years and older, the complications of diabetes may mean that they can no longer live safe, fully independent lives in private households. Supportive living environments that combine shelter, safety and some level of support services can allow an older senior to continue living an independent, socially active life, delaying – perhaps indefinitely – a move into a long-term care facility.

10 Transport Canada. Canada's aging population: transportation safety and security. Ottawa: Transport Canada, 1997.

Chapter 4 Recommendations for an effective approach to diabetes

The recommendations in this section are based on the preliminary recommendations made at the National Diabetes Symposium in 2001, the revised recommendations made by the CCNDS Expert Working Groups that were revised by the CCNDS, and the public consultation from the Second National Diabetes Symposium in 2003. The ideas and recommendations found in this report do not indicate or imply a commitment from any government or organization to their acceptance and implementation. In recognition of Aboriginal Peoples' unique situation and the severity of the problem, Chapter 5 addresses their needs and proposes recommendations for action.

Vision of a national diabetes strategy

The CCNDS developed the following vision of a national diabetes strategy:

A comprehensive framework to mobilize all sectors in developing, implementing and evaluating an integrated and coordinated approach for reducing the social, human and economic impact of diabetes in Canada.

A national diabetes strategy needs to articulate a plan for a partnership among all diabetes stakeholders and interested groups. It should provide an integrated, comprehensive, multi-sectoral, collaborative and sustainable approach to preventing and controlling diabetes that involves federal and provincial/territorial governments, national Aboriginal organizations, national non-government organizations, national organizations of health service providers, the private sector and academia. A national diabetes strategy should build on existing achievements, including the Canadian Diabetes Strategy (CDS), and should result in consistency and complementarity of actions among all stakeholders. It is envisioned that all partners would actively collaborate in making the strategy a reality and oversee its implementation.

Benefits of a national diabetes strategy

Participants in the consultation process highlighted various changes that must occur in the population, in the health care system, across sectors, and between and among organizations in order to prevent diabetes, detect it early, and manage it effectively.

Immediate Benefits of Policies, Programs and Services

- Awareness, knowledge and skills about the prevention and management of diabetes.
- Healthy school and workplace nutrition and physical activity policies.
- Policies that address the determinants of health and create supportive environments.
- Knowledge of health care providers about diabetes prevention and management, including Clinical Practice Guidelines (CPGs).
- Collaboration among health service providers at the community level.
- Collaboration and integration of approaches at local, provincial/territorial and national levels.
- Accessibility to health information, health promotion and disease management programs.

- Accessibility to medications and supplies.
- Coordinated research effort and consensus-building process.
- Trained diabetes educators providing service.
- Integration of diabetes education into the overall context of chronic disease prevention.
- Capacity for and implementation of diabetes surveillance.

Long-term consequences

- Healthy eating, decrease in obesity and increase in regular physical activity.
- Supportive school, workplace and community environments.
- Reduction in health disparities among population groups.
- Social norms that support healthy nutrition and regular physical activity.
- Investigation, diagnosis and treatment based on CPGs.
- Access to comprehensive health services.
- Use of surveillance and research information in policy, program and service decisions.
- Application of research knowledge to cure diabetes.

Principles of a national diabetes strategy

Potential principles of collaboration

The principles of *An Accord between the Government of Canada and the Voluntary Sector*, signed in 2001, could provide the foundation for the principles of collaboration within a national diabetes strategy. Designed to guide the evolution of a relationship between diverse institutions, the *Accord* identifies the common principles and commitments that will shape future practices. These principles focus on factors that unite the partners, honour the contributions of each, and respect their unique strengths and different methods of working.

- ***Independence:*** The autonomy, unique strengths and separate accountabilities of each partner are recognized and respected. Some provinces and territories have their own diabetes strategies or address diabetes within a broader chronic disease strategy. Non-government organizations also approach the problem of diabetes from a variety of different viewpoints.
- ***Interdependence:*** Partners often operate in the same jurisdictions; many serve the same clients and hold many common objectives. As a result, the actions of one partner can affect another, either directly or indirectly. Further, each partner has established vital and complex relationships with other organizations and institutions that should remain undisturbed by this partnership.
- ***Dialogue:*** Partners recognize that sharing ideas, perspectives and experiences contributes to better understanding, improved identification of priorities, and sound public policy. Effective dialogue is open, respectful, informed and sustained and welcomes a wide range of viewpoints. Dialogue respects each partner's confidential information and builds and maintains trust. To be sustained, dialogue requires appropriate processes and structures.

- ***Cooperation and collaboration:*** Partners work together to identify common priorities and complementary objectives, and to establish a working relationship that is flexible and respectful of the individual contributions, challenges and constraints of each partner.
- ***Accountability:*** In addition to their separate accountabilities, partners could agree to be accountable for maintaining the trust and confidence of Canadians by ensuring transparency, high standards of conduct, sound management, and the monitoring and reporting of results.
- S***hared commitment to action:*** In their collective effort to address diabetes in Canada, partners could agree to act in a manner consistent with these principles, to develop the mechanisms and processes to work together to achieve shared goals and objectives, and to promote awareness and understanding of the contributions that each partner makes to Canadian society.

Potential principles for action

All actions taken to implement a national diabetes strategy (policies, programs and services) should be based on the following principles:

- Population health approach, with recognition of the role of health determinants.
- Sensitivity to diverse needs, including differing languages, cultures, genders, ages, socioeconomic status and educational levels.
- Inclusion of partners from sectors outside of health in multi-sectoral, multi-level collaboration.
- Active consumer involvement in program planning and resource development.
- Equitable access and opportunity.
- Building on successes in current programs and infrastructure.
- Resource sharing.
- Best practices and evidence-based decision making.
- Shared accountability, evaluation and ongoing monitoring.
- Community development with a focus on empowerment.

Potential partners

Building a national diabetes strategy: synthesis of research and collaborations outlines both individual efforts and organizational actions required to improve the prevention and control of diabetes in Canada:

- **National, provincial/territorial and regional Aboriginal organizations** – Promote and develop healthy policies, supportive communities and community action.
- **Academia** – Education for professionals-in-training and continuing education for those working in the field.
- **Researchers** – Conduct research on causation, and the effectiveness of interventions and health services.
- **Consumers** – Develop and maintain personal health practices and healthy lifestyles; increase awareness and participation in community action for a supportive environment; advocate for healthy public policies.

- **Governments** – Comprehensive approaches ranging from creating healthy public policy to program funding and implementation, evaluation and monitoring. In addition to health, a wide variety of government departments need to be involved, such as recreation, education, transportation, income and housing, and social services.
- **Private sector** – Provide corporate sponsorship; raise awareness; provide workplace programs; develop products that enhance the lives of individuals with diabetes and their families.
- **Multicultural organizations** – Raise awareness among cultural groups and government and other organizations; encourage adoption of healthy lifestyles.
- **Non-government organizations** – Increase awareness; advocate for healthy public policy; provide education; promote and fund research.
- **Professional associations** (such as health, education, recreation) – Increase awareness; provide education; promote and disseminate CPGs; advocate for healthy public policy.
- **Educators and service providers** – Provide prevention, education and care services; participate in community action.

Integrated chronic disease prevention

Diabetes is a determinant of a host of other serious conditions, including heart disease, stroke, kidney failure and blindness. It also shares preventable risk factors with other chronic diseases. The interrelationship between diabetes and other chronic diseases and the reality of limited resources make a compelling case for taking an integrated approach to chronic disease prevention. Many jurisdictions have already taken this broader approach. Within an integrated chronic disease management approach, activities specific to diabetes will ensure that the disease-specific needs are met.

The infrastructure that has been built for diabetes, including but not limited to the Canadian Diabetes Strategy and provincial/territorial initiatives, provides a useful framework around which chronic disease activities can take shape. The National Diabetes Surveillance System (NDSS), for example, is a working, cost-effective system that can serve as a model for the surveillance of other diseases – or as the core of an expanded system for conducting surveillance of the full spectrum of chronic disease.

Recommended actions from the 2003 National Diabetes Symposium

During the planning process, the CCNDS identified five pillars for a comprehensive approach to diabetes:

- Prevention
- Education
- Care
- Research
- Surveillance

The expert groups in each of these pillars identified recommendations to improve diabetes control in Canada. The 2003 Symposium in Winnipeg reviewed these recommendations and identified additional recommendations for action to improve diabetes in Canada. The following is a compilation of all the recommendations generated by the various working groups of the symposium, organized by theme.

Healthy policy and community programs

The goal of the community component is to create an environment in which awareness of diabetes is widespread, "healthy choices in terms of nutrition and physical activity are easy choices", and there is equity in the opportunity[11] for achieving health. Public health services, non-government organizations, self-help groups and community action groups work primarily in the community sector along with non-health sector organizations such as education, transportation, recreation, housing, industry and social services. Community activities include advocating for and creating healthy public policy, enabling community action, creating supportive environments, and providing information and education.

Healthy public policy

1. Work in partnership to develop, advocate for and evaluate healthy public policies that support healthy nutrition and healthy weight, regular physical activity and self-management of diabetes.

2. Build on best practices and lessons learned, invest in policy, programs and infrastructure to encourage and facilitate regular physical activity and healthy eating, and evaluate their impact.

Community action

3. Take action to create supportive environments for healthy nutrition and healthy weight, regular physical activity and self-management of diabetes, including self-help groups, mutual aid, advocacy, and community networks or coalitions.

4. Provide culturally appropriate support groups for people with diabetes.

5. Foster linkages among community health promotion and prevention programs, whether the program focuses on diabetes or on other chronic diseases with similar risk factors.

Supportive environments (school, workplace, community)

6. Collaborate to support, promote and evaluate comprehensive school health that includes activities related to regular physical activity and healthy eating.

7. Adopt the Canadian Diabetes Association/Diabète Québec school standards of care to foster the safety and health of students with diabetes in all school settings.

8. Collaborate to promote, support and evaluate workplace wellness programs on healthy eating and physical activity that include supportive policies, access to healthy food and physical activity options, and information and education.

9. Collaborate to support, promote and evaluate comprehensive community-based programs that include regular physical activity and healthy eating.

11 Improving equity in the opportunity for health includes such services as public transportation services for the disabled, income support programs, subsidized housing and residences for assisted living.

10. Create an environment conducive to regular physical activity for all age groups with particular emphasis on: 1) communities in geographically isolated areas; and 2) ensuring opportunities for participation in urban areas.

Prevention information and education

11. Develop, implement, evaluate and maintain social marketing programs using a variety of media and other communication techniques directed at specific sub-groups of the population (age, gender, educational and literacy status, culture, language and remote location) to encourage regular physical activity, healthy nutrition and healthy weight.

12. Develop and evaluate holistic community education programs that are culturally sensitive, affordable and attainable for individuals at high risk of diabetes to support them in achieving glucose management, healthy eating, healthy weight and regular physical activity.

Health services

The goal of the health service component is to prevent diabetes among high-risk individuals, detect diabetes at an early stage, enhance self-management, and prevent and manage crises and complications, thereby enhancing quality of life for those with diabetes. Health professionals and health service organizations work primarily in the health services component.

Prevention education

13. Provide information in appropriate languages and at an appropriate literacy level on healthy nutrition, healthy weight and regular physical activity through primary health care providers, and provide education at periodic health examinations for all clients.

Screen for diabetes

14. Where evidence warrants, develop, implement and evaluate screening programs for people at high risk of diabetes to facilitate its early detection and predisposing conditions, and to foster timely initiation of appropriate follow-up care.

15. Screen for gestational diabetes.

Education for the self-management of diabetes

16. Develop and evaluate holistic primary care education programs that are culturally sensitive, affordable and attainable for individuals with diabetes to support them in achieving glucose management, healthy eating, healthy weight and regular physical activity.

Clinical care and access to services, medication and supplies

17. Identify and respond to gaps in the delivery of comprehensive health services[12] that are accessible, effective and efficient.

18. Foster equitable and appropriate coverage of diabetes supplies and medications.

12 This should include the compilation of an inventory of effective educational, prevention and health promotion models suitable for use in Aboriginal communities, and research for program planning around diabetes education for Aboriginal and multicultural populations. Research should be done on optimizing the participation of these communities in diabetes education in order to assist program planning.

Enabling system functions

The goal of enabling system functions is to ensure that services are provided efficiently and effectively, and in an equitable manner. The research and academic community, human resource planners, professional organizations, coalitions and networks provide enabling system functions. These include leadership and networking, organization and funding of services, development of capacity and resources, provision of education to providers and policy makers, research and surveillance/monitoring, and implementation of clinical information systems to support both case management and program evaluation.

Leadership and networking

19. Examine the mandate of the CCNDS to include: a) collaborating and networking with other relevant organizations and government; b) positioning diabetes as a major public health issue; and c) establishing national short- and long-term targets for diabetes prevalence, incidence, morbidity and mortality rates.

20. Create an ethnically and culturally sensitive working group in the CCNDS to link with and leverage existing primary prevention initiatives, infrastructure and networks and to *coordinate* population primary prevention, high-risk screening, and the prevention of complications among those with diabetes.

Organization and funding of programs and services

21. Renew the CDS with increased funding for all four of its components (Aboriginal Diabetes Initiative, Prevention and Promotion, NDSS and National Coordination). The role of the National Coordination component expands to support the CCNDS in the development of a national diabetes strategy.

22. Enhance the work of the Aboriginal Diabetes Initiative within a renewed CDS. The following steps are particularly recommended:

    ◊ Provide funding to national Aboriginal organizations for training and capacity building.

    ◊ Compile an inventory of effective models for prevention and promotion, care, education, research and surveillance specifically suited to the needs of Aboriginal populations.

    ◊ Collaborate to identify ways to increase the number of Aboriginal students participating in and graduating from fields related to diabetes care, prevention, education, research and surveillance.

    ◊ Provide resources to foster the use of innovative vehicles (such as Telehealth) for activities related to prevention and promotion, care and education in Aboriginal communities.

    ◊ Increase capacity in Aboriginal communities for research, including community-based participatory research.

23. Support and expand existing effective health promotion programs, and develop and evaluate new programs based on best practices.

Capacity and resources

Service capacity

24. Increase capacity for delivery of prevention programs through increased funding for existing staff and programs and the provision of training programs to enhance the skills of existing community workers.

25. Establish a coordinated approach in the development and delivery of standardized diabetes education programs.

26. Expand the pool of qualified diabetes educators at all levels, from basic to advanced.

27. Develop marketing strategies to promote the value of hiring qualified diabetes educators for the delivery of diabetes education, prevention and care services.

28. Consider mechanisms to monitor access to diabetes care providers and make recommendations to improve the availability of quality health care for the care of persons with diabetes in all parts of the country.

29. Examine diabetes training and continuing education practices of diabetes health care providers to determine gaps and needs.

Research capacity

30. Target candidate research areas that have international leadership status and foster adequate domestic funding until the research program is financially self-sustainable.

31. Raise total identifiable diabetes research funding to $200 million per year by 2005.

32. Investigate Canada's lack of involvement in pharmaceutical-funded research and identify specific strategies with targets and timelines for improving the situation if needed.

33. Increase resources available to build research capacity in methods of diabetes education for both health professionals and patients.

34. Expand the capacity of health professionals to conduct and use research through: a) career awards, fellowships and studentships in diabetes research; b) developing a template for education; and c) encouraging site visits to research centres.

Research

35. Develop a national research agenda in collaboration with research users and target funding to priority areas, including epidemiology, basic science, clinical and health services research. (Possible research issues are listed in Appendix B.)

36. Sustain, maintain and expand the database developed by the CCNDS Research Working Group to obtain a more complete picture of all types of diabetes-related research in Canada, including research on social determinants, behavioural change and community mobilization.

37. Make clinical trials and population-based research as inclusive as possible so that results are more fully applicable to Canada diverse population (consider gender, age, and ethno-cultural and socio-economic statistics).

Education of service providers and policy makers

38. Incorporate comprehensive education about diabetes through the continuum of health care provider education, including training at the undergraduate and postgraduate levels and updating the knowledge and skills of practising health care providers.

39. Provide orientation and training to care providers for interaction with people in a culturally appropriate manner.

40. Establish a process to examine, determine, and share best practice approaches relevant to community programs and diabetes care.

41. Develop an electronic clearinghouse[13] for diabetes information.

42. Provide adequate, sustained funding for the regular review, updating, and evaluation of *Diabetes Clinical Practice Guidelines (CPGs)*[14] and the use of effective dissemination methods to support the adoption of the guidelines by individuals with diabetes, service providers and policy makers.

43. Build a more extensive, national multi-disciplinary forum for regular information exchange and synthesis using a variety of communication vehicles.

44. Provide self-care management workshops for health care workers, using the train-the-trainer model where necessary.

13 Comprehensive health services include multi-disciplinary teams working in collaboration with the individual/family with diabetes - a primary health service team as first response, and specialist assistance as needed. Home care and support services are integrated into a continuum of service to respond to changing health care needs. The volunteer sector is involved in providing supportive services for both the individual and family.

14 Clearinghouse would (a) support cross-theme and cross-agency collaboration and information flow; (b) compile and disseminate an inventory of best practices and lessons learned in all theme areas; (c) compile and disseminate an inventory of current activity in all theme areas across the country; (d) promote consistent messaging; (e) assist in public information dissemination and education; (f) provide a common portal with links to other relevant Web-based information, with an independent appraisal mechanism to ensure the accuracy and quality of information at linked sites.

45. Collaborate on the integration of the *Portfolio of Diabetes Education Services Self-Assessment and Recognition Program* into the Achieving Improved Measurement Standards (AIMS).[15]

46. Require continuing education about diabetes for those working in this field.

Surveillance, monitoring and clinical information systems

47. Develop effective clinical information systems.

48. Develop a national standardized database for diabetes with long-term monitoring of diabetes-related complications, through the integration of new and existing databases and through assistance in the development and implementation of databases for all Aboriginal Peoples across Canada.

49. Develop mechanisms for regular monitoring and reporting of national short- and long-term targets for diabetes prevalence, incidence, risk factors, morbidity and mortality rates.

50. Determine and adopt indicators for use in assessing access to resources and care, and adherence to recommended CPGs (clinical and self-care).

51. Address the identified gap in investment in the NDSS, addressing the identified gaps in monitoring incidence of type 1, type 2 and gestational diabetes; health service use among individuals with type 1, type 2 and gestational diabetes; co-morbidities; dissemination; evaluation; risk factors; care indicators; and diabetes education.

52. Expand the NDSS to incorporate chronic disease surveillance, beginning with common conditions that are also comorbidities with diabetes (such as cardiovascular, cerebrovascular and renal diseases).

53. Use the principles of ownership, control, access and possession (OCAP) for data collection and analysis as determined by First Nations, Métis and Inuit communities.

15 Canadian Council on Health Services Accreditation Achieving Improved Measurement Standards (AIMS).

Chapter 5 Aboriginal Peoples and diabetes

Acknowledgement

This chapter was written by representatives from Métis National Council, National Aboriginal Diabetes Association, Inuit Tapiriit Kanatami, Congress of Aboriginal Peoples, Assembly of First Nations, and Native Women's Association of Canada.

Introduction

Diabetes has become a severe pandemic in Aboriginal communities in Canada where its prevalence is estimated to be three to five times the national average. Amongst Inuit, where the disease was once unknown, the incidence of type 2 diabetes has also risen. Diabetes has a devastating impact on Aboriginal Peoples living with the disease, their families and communities. Action must be taken now to address this major threat to the health of our people.

Aboriginal Peoples are not a culturally or socially homogenous group. *The Constitution Act, 1982* states that the Aboriginal Peoples of Canada include Indian, Inuit and Métis peoples. We are many distinct peoples throughout Canada, each with its own culture, language and traditions.

According to The Constitution Act, 1982 s. 35(2), the Aboriginal Peoples of Canada are the Indian, Inuit and Métis peoples of Canada.

The Congress of Aboriginal Peoples and the Native Women's Association of Canada assert that the federal government has a fiduciary responsibility to all Aboriginal Peoples in Canada.

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The health needs of the different Aboriginal communities and peoples are influenced by their particular history, geography, access to services, as well as a range of other issues. This is an ongoing jurisdictional problem for Aboriginal Peoples in Canada. To be effective, health programs need to be tailored to meet the self-identified needs of each community. This chapter offers a general approach to an Aboriginal diabetes strategy from which community-based strategies can be developed.

The policy context of diabetes prevention is complex, especially for remote and rural populations.

Aboriginal specific, diabetes prevention and control programs exist in an unusual policy context. Complex jurisdictional boundaries and funding arrangements between federal, provincial/territorial and community governments make it difficult to establish equity in the provision of health services to Aboriginal Peoples. This is an ongoing jurisdictional problem for Canada's Aboriginal Peoples. For many Aboriginal Peoples and their communities, effective control of diabetes and prevention of complications from the disease are hindered because they simply cannot access much-needed prevention and management services. Funding constraints also make

it difficult for community workers to receive the training or organizational support they need to be effective as diabetes educators. For example, it is difficult for diabetes educators in remote communities to advise people if they are unable to access healthy foods.

National response is needed.

This document encourages both individual efforts as well as community and government action to improve the prevention and control of diabetes among Aboriginal Peoples. Implementation requires a commitment to consistent and innovative ways of working with Aboriginal organizations and communities to prevent diabetes and enhance the quality of life for all Aboriginal Peoples living with diabetes.

Aboriginal leadership statements

In a short time, diabetes has unexpectedly crept into Inuit culture and our lives.

Soon, it may become another health epidemic that our communities must face. We must begin educating Inuit about diabetes, its causes and prevention.

Vigorous physical activity often associated with hunting and gathering for our rich traditional foods has been part of our rich history. Life is changing now, many foods also rich in nutrition have been introduced but junk foods have also become commonplace in our modern and more sedentary lifestyle.

Inuit support developing partnerships in a National Diabetes Strategy. It is essential if we are to prevent what is potentially another tragic 'southern' epidemic. A National Diabetes Strategy will also improve the lives of Inuit across Canada.

Jose A. Kusugak, President
Inuit Tapiriit Kanatami

We are all familiar with the disparities that exist in the health status between Aboriginal and Non-Aboriginal people. In the case of diabetes, the rate is three to five times higher for Aboriginal people compared to the national average. In addition to this higher rate of disease burden are additional challenges such as higher rates of poverty and unemployment, overcrowded and inadequate living conditions, factors of remoteness, and services that fail to meet the unique needs and realities of our people.

The Métis Nation is committed to ending these disparities and is supportive of developing an innovative and holistic approach to prevent diabetes and improve the quality of life for those Métis people living with diabetes.

The Métis Nation embraces a National Diabetes Strategy as this issue deserves serious attention and clear direction. However, this direction must respect our governance structures and health delivery arrangements in a culturally appropriate manner. It is important to remember that diabetes affects the distinct Aboriginal peoples in different ways and to varying degrees. We are hopeful that the solution will acknowledge and reflect these differences. Our future depends on it.

Clément Chartier, President
Métis National Council

The urgency of the diabetes epidemic cannot be overstated. Our First Nations people are more susceptible to chronic diseases and die earlier and more often than other people in Canada.

- *In December of last year, the Assembly of First Nations Confederacy of Nations supported that I, and the Chiefs' Committee on Health, lobby the new Minister of Health and other key decision makers to renew and enhance the federal government commitment to another five year diabetes initiative for First Nations.*
- *We are encouraged by recent correspondence from the Honourable Pierre Pettigrew responding to my request for urgent action on the diabetes pandemic for First Nations has stated that "For Health Canada, managing type 2 diabetes is the same high priority as it is for the Assembly of First Nations," and that for this reason, "the Department is actively investigating new ways to work with Aboriginal peoples to decrease the prevalence of this chronic disease". This is a development we welcome.*
- *We are encouraged that the Prime Minister himself has acknowledged the shameful living conditions of First Nations. He also stated at the Aboriginal Roundtable on April 19 that eradicating the diabetes epidemic is a priority.*

From First Nations youngsters who acquire diabetes, to our adults who need amputations as a result of untreated diabetes, the cost to the health care system is great and the pressures on our communities are at a critical point. Our present and future generations must receive the proper education; have access to proper diets, and receive appropriate treatment to overcome this preventable disease.

We welcome a renewed commitment from the Government of Canada to meet all of these challenges head on.

Phil Fontaine
National Chief Assembly of First Nations

Aboriginal peoples in Canada are facing a type 2 diabetes pandemic of potentially devastating proportions. Diabetes represents a major threat not only to our health but also to our collective future. Congress of Aboriginal Peoples supports a National Diabetes Strategy, which is residency- and status-blind and inclusive of all Aboriginal peoples.

Dwight A. Dorey, MA, National Chief
Congress of Aboriginal Peoples

Serious action by all concerned – whether Aboriginal, non-Aboriginal, Federal, or Provincial/Territorial Governments – is required to address the pandemic rate of diabetes among Aboriginal people in Canada. Aboriginal women are especially vulnerable. Those over the age of 64 are suffering 16% higher diagnosis rates than men. If you ask an Aboriginal woman today about diabetes she will tell you how she and possibly another family suffers. As Aboriginal women, we are touched and affected by this disease. We embrace the National Diabetes Strategy's all-inclusive mandate to address this crippling disease.

Kukdookaa Terri Brown, President
Native Women's Association of Canada

It is known nation-wide that diabetes is affecting our Aboriginal people from the very young children to our elders. This is not acceptable and we must take more aggressive action to combat this disease through education, prevention and intervention. We must seek out necessary partnerships to begin working on all areas from research to lifestyle changes.

The National Aboriginal Diabetes Association supports the National Diabetes Strategy in its efforts to improve the lives of Aboriginal People across Canada.

Freda Lepine, Chairperson
National Aboriginal Diabetes Association

Diabetes – the evidence

The total number of Aboriginal Peoples with diabetes is unknown. The evidence that exists is inferred based on self-reported national survey data and population numbers. The analytical assumptions that have been made underestimate both the rates of diabetes and the number of Aboriginal Peoples who have the disease. The reported prevalence rates are alarmingly higher among Aboriginal Peoples than non-Aboriginal Canadians; diabetes is more widespread among Aboriginal women than men; and place of residence is a significant factor in accessing quality services to prevent and manage diabetes which affects rural and remote Aboriginal residents.

Type 2 diabetes mellitus is a public health problem of increasingly serious proportions for Aboriginal peoples in Canada. A major wave of diabetes related complications are emerging and will dramatically increase in Aboriginal communities across Canada over the next decade. People who are of Aboriginal descent in Canada have a greater severity of diabetes at diagnosis, which often results in the presence of clinical complications of diabetes from the time of diagnosis. For example, vascular complication rates for Aboriginal peoples in Canada are double compared to the general Canadian population. Aboriginal People with diabetes are also struggling with issues such as limited access to medical care, burdened by lower socio-economic status, and often residing in remote geographical locations. They are at additional risk for the burden of developing both short-term acute complications from diabetes along with developing longer-term chronic diseases. To date, very little information is available in Canada on the extent of diabetes-related complications and the level of clinical care. Further research into this area is of critical importance in order to facilitate and improve diabetes health care delivery to this high-risk population.

Dr. Stuart Harris
University of Western Ontario

State of Aboriginal Peoples' health

Aboriginal people are at least 3 to 5 times as likely as the general Canadian population to acquire diabetes.

Conventional health indicators suggest that Aboriginal Peoples are not as healthy as the non-Aboriginal population. Aboriginal Peoples have higher death rates and shorter life expectancies: in 2001, life expectancy of First Nations was 6.4 years lower than that of the general Canadian Population. According to the Aboriginal Peoples Survey in 2001, only 56% of non-reserve Aboriginal Peoples aged 15 years and older perceived their health to be "excellent" or "very good". For all age groups, this proportion was lower than that of the general population, and the gap widened with increasing age.

Aboriginal communities experience higher levels of poverty and unemployment, lower educational status, inadequate or unaffordable housing, food insecurity, and loss of identity and culture. Improvement in these social, economic, and environmental contexts will contribute significantly to overall improvement of the health status of Aboriginal Peoples and communities.

Health determinants

- *Income and social status*
- *Social support networks*
- *Education*
- *Employment/working conditions*
- *Social environments*
- *Physical environments*
- *Personal health practices*
- *Coping skills*
- *Healthy child development*
- *Biology and genetic endowment*
- *Health services*
- *Gender*
- *Culture*
- *Stress/challenges*

Aboriginal Peoples living with diabetes

Diabetes mellitus (DM) is a chronic condition that results from the body's inability to sufficiently produce and/or properly use insulin. The body needs insulin to use sugar as an energy source. Diabetes has no known cure: it is a permanent condition.

- Diabetes is the fifth most-prevalent health problem reported among the adult Aboriginal population living off-reserve.[16]
- The age-standardized prevalence of diabetes for First Nations people is three to five times that of the general population, after controlling for the different age demographics among the two populations.[17,18] Rates for the Canadian population include type 1 diabetes; a comparison of rates of type 2 diabetes would likely reveal an even greater disparity between populations in the 15-24 and 25-34 year age groups, as First Nations communities are primarily affected by this type of the disease. One in four individuals in First Nations communities on-reserve who are over the age of 45 have diabetes.[19]

16 Statistics Canada. Aboriginal Peoples Survey 2001 (Initial Findings Document).

17 Bobet E. Diabetes among First Nations People: Information from the 1991 Aboriginal Peoples Survey Carried Out by Statistics Canada. Ottawa, Medical Services Branch, Health Canada, 1997.

18 First Nations and Inuit Regional Health Survey National Steering Committee, 1999.

19 Ibid.

- Diabetes was particularly prevalent among older Aboriginal women. One in four Aboriginal women aged 65 years and over reported they had been diagnosed with diabetes, compared with one in ten of all Canadian senior women. For Aboriginal men the gap was smaller, with one in five Aboriginal senior men reporting diabetes compared to one in seven for all Canadian senior men.[20]

Aboriginal women, especially older women, are especially affected by diabetes.

- The prevalence of diabetes was also higher among young and middle-aged Aboriginal Peoples than the general Canadian population: 3 times higher among 25-34 year-olds, 3.4 times higher among 35-44 year olds, and 2.7 times higher for 45-54 year-olds.[21]

Aboriginal persons residing off-reserve and in off-community settlements are experiencing dramatic increases in the prevalence of diabetes.

- The prevalence of diabetes has increased by 50% among status and non-status Indians living off-reserve. One in twelve off-reserve and non-status Indians (adults) (8.3%) stated that they had been diagnosed with diabetes, compared to one in twenty in 1991 (5.3%).[22]
- The percentages of Métis and Inuit adults diagnosed with diabetes showed modest changes between 1991 and 2001. For Métis adults, the 1991 rate of 5.5% increased to 6.0% in 2001.[23]

The onset of diabetes occurs at a much younger age on average for Aboriginal people than for non-Aboriginal Canadians.

- Among Inuit adults, the rate of diagnosed diabetes increased from 1.9% in 1991 to 2.3% in 2001.[24]
- 8.5% of First Nations people on-reserve and 5.5% of Métis, have diabetes.[25]

Similar trends exist for people living on-reserve and in Inuit communities. According to the 1997 First Nations and Inuit Regional Health Survey, the prevalence of diabetes increased with age and was higher among women than men in all age groups:

20 Statistics Canada. Aboriginal Peoples

21 Ibid.

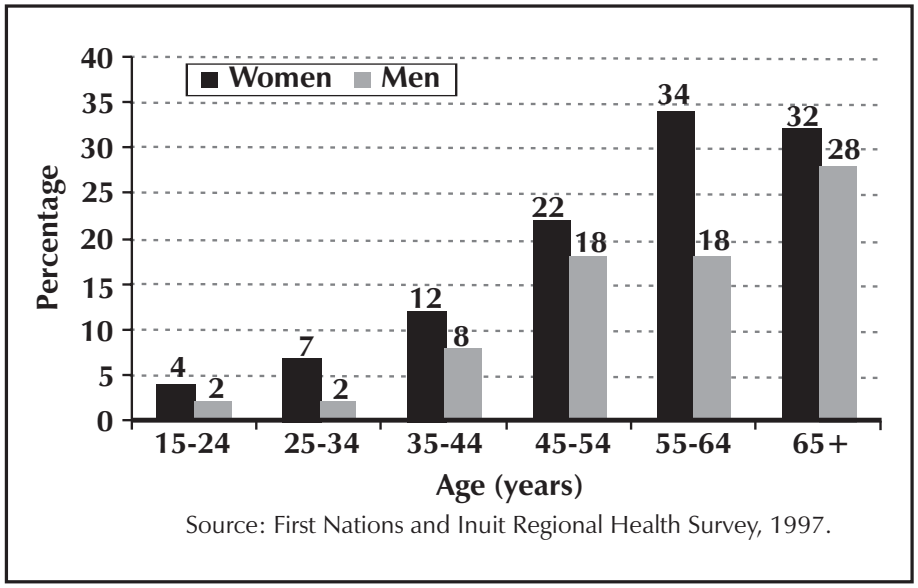
22 Ibid.

23 Ibid.

24 Ibid.

25 Health Canada. Diabetes in Canada. Ottawa; 1999.

Figure 5-1
Prevalence of diabetes among First Nations and Inuit, by age, Canada, 1997



Source: First Nations and Inuit Regional Health Survey, 1997.

Aboriginal women are impacted with higher prevalence rates of diabetes in every age cohort.

Aboriginal populations are subject to earlier onset of type 2 diabetes compared to the general population, evidenced in part by increasing prevalence of type 2 diabetes among Aboriginal children. Aboriginal populations also show more severe symptoms at the time of diagnosis.

Gestational diabetes is a significant problem among Aboriginal women.

Gestational diabetes is also an issue among Aboriginal women. According to the First Nations and Inuit Regional Health Survey, nearly one-third of women (30%) with diabetes reported that their diabetes was first diagnosed during pregnancy. Canadian studies have found rates of gestational diabetes as high as 12% among specific First Nations groups. The children of women with gestational diabetes have an increased risk of being born at a high birth weight, becoming obese and developing type 2 diabetes.

Recent evidence suggests a combination of genetic and environmental factors combine in Aboriginal Peoples giving rise to heightened prevalence and risk of diabetes.

The causational factors behind the increased incidence, prevalence, severity and complications of diabetes among Aboriginal populations are complex. Genetic predisposition may play a role. The nomadic lifestyles and feast/famine cycles of their ancestors may make Aboriginal Peoples genetically predisposed to store energy very efficiently from the diet. Dietary patterns in many Aboriginal communities have changed from traditional food to a diet high in energy, saturated fat and simple sugars. The prevalence of obesity and physical inactivity (both risk factors for diabetes)

among Aboriginal populations has increased. Lack of accessible diagnostic and treatment services also increases the incidence, prevalence, severity and complications of diabetes in Aboriginal populations.

Place of residence

Aboriginal Peoples live throughout Canada:

- 1.3 million people, or 4.4% of the Canadian population, are of Aboriginal ancestry: 72% (excluding Inuit) live off-reserve (non-status Indians, off-reserve Indians and Métis).[26]
- Slightly over one-half (53%) of Canada's 608,850 First Nations individuals live on-reserve; 47% live off-reserve. The highest number live in Ontario (about 22%), followed by B.C. (about 20%) and the prairie provinces, each of Manitoba, Saskatchewan and Alberta having approximately 15%.[27]
- The total status or registered Indian population in Canada is 558,175: 51% live off-reserve; 49% live on-reserve.[28]
- The total number of Métis across Canada is 292,000: 68% live in urban areas, 29% in rural areas, and 3% live on-reserve. The largest proportion of total Métis population live in Alberta (23%); 19% live in Manitoba; and 17% live in Ontario.[29]
- Among 51,020 Inuit, one-half live in Nunavut, 21% live in Nunavik (Northern Quebec), followed by Newfoundland and Labrador (10%) and the Northwest Territories (9%). A significant proportion of Inuit people (10%) are dispersed in urban centres.[30]

The human face of diabetes

Lack of access to health services remains a critical issue for Aboriginal peoples, especially those in remote and rural areas.

Diabetes may lead to complications such as heart disease, stroke, kidney failure, peripheral neuropathy (which can lead to lower-limb amputation) and retinopathy (which can lead to blindness). Complications may also shorten the life expectancy of people with diabetes. The risk of complications is greatly decreased by good control of blood sugar and treatment of underlying conditions. Diabetes complication rates are much higher among Aboriginal Peoples than they are among the general Canadian population, a pattern that may be explained by limited access to health care and diabetes education.

Families who never expected diabetes need help;
Families feeling fated to have diabetes need hope.

Diabetes exerts a significant effect on the quality of life of individuals with the disease. The continuous need to monitor intake (in terms of timing, type and amount of food), take medication (whether pills or insulin injections), monitor blood glucose, and anticipate and plan

26 Statistics Canada. 2001 Census. Tables 97F0011XCB01003 and 97F0011XCB01004.

27 Statistics Canada. 2001 Census. Tables 97F0011XCB01003 and 97F0011XCB01005.

28 Statistics Canada. 2001 Census. Table 97F0011XCB01005.

29 Statistics Canada. 2001 Census. Tables 97F0011XCB01003 and 97F0011XCB01004

30 Statistics Canada. 2001 Census. Tables 97F0011XCB01003 and 97F0011XCB01004

for activities that may affect diabetes control can severely strain the daily lives of people with diabetes, who suffer depression at a much higher rate than the general population.[31] Depression and the demanding daily routines involved in living with diabetes make it even more difficult to manage, feeding a cycle that makes both conditions worse.

Diabetes significantly affects the quality of life and life expectancy of Aboriginal People.

Diabetes is so common among Aboriginal Peoples that a sense of the inevitability of developing the disease pervades the community. Intergenerational experience of diabetes among some First Nations communities has led to fatalism: "My parents have it, my grandparents have it; someday, I will get diabetes too." Entire communities and clans have been harshly impacted and, for many, living with and managing diabetes is a way of life.

Entire families and communities feel fated to have diabetes.

A personal story

Many Aboriginal individuals have spoken about the challenges of living with diabetes. A male Inuk who was diagnosed with diabetes three years ago recently shared his experiences. To date, he has received no diabetes education about either how to manage his disease or the complications of the disease. He indicates that he is interested in learning the "whys" of diabetes. He expressed that if he gains further knowledge on the disease, "I will be passing on this education to other people, especially youth." The Inuk man is doing a lot to gain information on the disease through the Internet, but little information [is] available [in his own language]. He voices another concern, "What about the unilingual Inuit out there? They have no mechanisms in accessing information. I am fortunate that I can read and write in Inuttitut and English. But it's not the same story for other peoples."

Although this story highlights the reality for one individual diagnosed with diabetes, it is an all too common story among Aboriginal peoples in Canada.

Impact of diabetes on health care costs

As the number of Aboriginal Peoples with diabetes continues to climb, there will be an associated impact on health costs. In 1998, Health Canada reported that the annual health costs per person for status Indians with diabetes was $3,657 (age-adjusted) compared to $1,359 per person for those without diabetes. In the late 1990s, diabetic drug claims through the Non-Insured Health Benefits Program (NIHB) of Health Canada, averaged $13 million per year. By 2002, this program was spending $24 million on diabetes supplies such as oral agents, insulin and test strips.

Diabetes is extremely costly – to individuals, families, communities, the health care system and the economy through lost productivity.

31 Statistics that specifically describe the rate at which Aboriginal Peoples with diabetes suffer depression are not available.

In 2002/03, the NIHB expenditures totalled $688.1 million. Of this,

- Pharmaceutical expenses at $290.1 million accounted for 42.2% of the total budget; and
- Medical transportation amounted to $204 million, representing 29.6% of the total NIHB budget.

Costs associated with diabetes care and treatment represents a significant portion of pharmaceutical and transportation costs. By and large, dialysis and other tertiary care interventions are provided by provincial jurisdictions, and so transportation costs are incurred to send First Nations and Inuit to urban centres for treatment. With a growth rate of over twice that of the Canadian average, the population accessing NIHB tends to be younger (with an average age of 30 years) and the disease burden, especially with diabetes and complications due to diabetes, occurs at a younger age.

Among NIHB pharmaceutical costs, diabetes has increasing rates in a huge presence. The high rate of diabetes in the First Nations and Inuit population leads to other ailments such as vision problems, orthopedic needs, cardiac and gastrointestinal, and other complications. Over-the-counter drugs covered under NIHB include diabetes test strips. Medical supplies include glucose monitors. Prescription drugs include, among others, insulin and oral classes of anti-hyperglycemic agents; cardiovascular drugs include those used for heart disease and high blood pressure. Gastrointestinal drugs include those for gastroesophageal reflux and ulcers. These categories of drugs cover 43% of the total drug expenditures under NIHB. This means that the costs to NIHB run broad and deep through care delivery systems.[32]

Métis and non-status Indians are not entitled to the NIHB, which are available to First Nations and Inuit. (For Métis in the Northwest Territories, the Government of the Northwest Territories is payee of last resort.) Paying for medication and medical supplies are central issues for Métis and non-status Indians living with diabetes.

The high rates of complications associated with diabetes-related health care are a major driver of health costs. For example, among status Indians in Manitoba, almost 60% of all hospitalizations for heart disease and approximately 50% of hospitalizations for stroke occurred among individuals with diabetes. The cost of each individual on dialysis is estimated to be $60 thousand per year, not including transportation. As the number of individuals on dialysis increases, the costs for this health service are also increasing rapidly. For status Indians, costs are estimated to increase from $72 million to $144 million by 2006. These findings are only projections of some of the immediate and long-term health care costs associated with the diabetes pandemic. To develop a complete economic impact model would require inclusion of a wide range of costs, such as specialty services, amputations, counselling, blindness, transportation and traditional medicines.

Aboriginal Peoples, as a jurisdiction, require a unique approach within a national diabetes strategy.

Future savings from reducing or preventing Type 2 diabetes and related complications depends on implementation of a comprehensive national diabetes strategy. If the current generation of Canadians does not properly address the Aboriginal diabetes pandemic, this overwhelming health issue and its associated fiscal burden will be passed on to future generations. There is a compelling need and responsibility for our generation to implement a comprehensive national diabetes strategy that is responsive to Aboriginal communities. Transferring the burden of the disease and its

32 Health Canada, First Nations Inuit Health Branch. Presentation to the Standing Committee on Health Concerning Pharmaceutical Drugs, October 24, 2003.

financial costs to another generation would be unethical. If an effective strategy fails to be delivered, a person born in 2004 will face a lifetime of taxes to pay for our failure to implement a comprehensive and effective strategy.

Preventing the onset of type 2 diabetes among Aboriginal Peoples

According to Statistics Canada's Canadian Community Health Survey (2000/2001) many Aboriginal Peoples are at high risk for developing diabetes:[33]

- 54.8% of Aboriginal adults aged 20-59 years living off-reserve were overweight; and
- 52.6% of Aboriginal adults aged 20+ years living off-reserve were physically inactive.

Controlling obesity, diet, exercise, smoking and lifestyle support are among key primary prevention activities for diabetes prevention.

The proportion of Aboriginal adults who are overweight as calculated above (where people who are overweight are defined as people with a Body Mass Index ≥ 25) may not accurately reflect the percentage of those at risk for developing diabetes. Obesity amongst Aboriginal Peoples is predominately of the central type, characterized by a high waist-to-hip ratio. Further research is needed to refine the definition of obesity and identify the metabolic impact of weight and weight distribution among Aboriginal Peoples.

Community involvement in primary prevention of diabetes, a tenet of Primary Health Care, is essential to success.

Two approaches are necessary to prevent diabetes–one combines principles of primary health care and principles of population health and the other uses a high-risk approach. A population health approach targets the determinants of health within the entire population. For diabetes, this approach requires a long-term commitment across a range of sectors, including health services, recreation, transportation, municipal planning and the food industry. The high-risk approach focuses on individuals at highest risk for diabetes, such as those who are overweight or have a family history of diabetes. This approach includes more intensive interventions, such as health education.

One of the challenges in preventing diabetes is food access and security. Food security "exists when all people, at all times, have physical and economic access to sufficient, safe and nutritious food to meet their dietary needs and food preferences for an active and healthy life."[34] To eat well and maintain a healthy weight, people need access to healthy food at affordable prices. Food security varies across the country, based primarily on geography and income. It is a concern particularly for people living in the North because of issues related to access to nutritious food and poverty.

Environmental contaminants affect food security, especially access to traditional, balanced food sources.

In Aboriginal communities, food security is affected by environmental contaminants in traditional foods. It is crucial to monitor potential contaminants in traditional foods and ensure that community members know about them. At the

33 Heart and Stroke Foundation of Canada. The Growing Burden of Heart Disease and Stroke in Canada 2003. Ottawa: Heart and Stroke Foundation of Canada, 2003; 25.

34 Health Canada. Discussion paper on household and individual food security. Ottawa: Health Canada.

same time, traditional food sources unaffected by contaminants should not be ruled out as healthy options. In many communities, a return to traditional sources of food has been a holistic catalyst for elements of diabetes prevention that are difficult to engineer in program design, but take shape more easily as choices about cultural life. These choices need to be supported. For First Nations, "smart eating" is beginning to be widely promoted. It assesses risks with benefits (see text box) by creating awareness of contaminants in traditional foods while also emphasizing awareness of the benefits of traditional foods. Continuing to consume many traditional foods is paramount. Knowledge is power; in other words, smart eating must be promoted and practised.

An environmental scan of primary prevention conducted for the development of this report identified the following characteristics of successful prevention programs:

Focus on community and addressing the Health Human Resources gap are key in effective prevention of type 2 diabetes.

- Effective partnerships with clarification of the mandate, roles, authorities and responsibilities of the different parties;
- Community involvement in and ownership of programs;
- Awareness of the determinants of health;
- Program flexibility to meet different needs;
- Design of the intervention as part of daily life rather than a 'special' activity;
- Promotion of and support for individuals' responsibility for self-management;
- Changes to the physical environment that facilitate safe, healthy physical activity and/or increase access to good food;
- Healthy public policy at all levels;
- Provision of financial and human resources to initiate new programs;
- Stable resource allocation for long-term initiatives and longer term action plans; and
- Adequate duration and persistence of intervention with a gradual, staged approach.

Contaminants and traditional foods

The Royal Commission on Aboriginal Peoples (RCAP) notes the link between the "trend toward higher rates of chronic disease" and the "changes in local ecosystems that reduce the level of physical activity" among First Nations peoples: Self-sufficiency through traditional hunting, trapping, and fishing has been affected by dwindling numbers and contaminants. This has given rise to a tendency to adopt low-activity lifestyles and a proportionate decline in physical fitness. (RCAP, Vol.III, P.194).

Despite the challenges imposed by a number of contaminants that enter traditional and country food systems, it is imperative to promote "smart eating" based on traditional food sources. Smart eating can be an important means of redressing diabetes and is a vital link to cultural heritage. Traditional practices of harvesting game and food are vital intergenerational ways of sharing knowledge and wisdom about the natural world, cultural identity and heritage.

The health impacts of contaminants entering Aboriginal traditional/country food diets through consumption are largely unknown. There are risks associated with long-range transported contaminants and local sources (point source). Environmental contaminants (persistent organic pollutants and heavy metals) tend to persist for long periods of time in the food chain. But there are also benefits of traditional and country foods that need to be promoted through smart eating. Smart eating is predicated on an 'empowerment' view of knowledge as power and aims to maximize the benefits of eating traditional foods while mitigating or avoiding other risks associated with contaminants.

First Nations should be aware of contaminants in traditional foods, but equally we must also be aware that continuing to consume them is paramount. Knowledge is power… in other words smart eating must be promoted and practiced: For example, larger predatory fish should be consumed less often (as they typically contain higher levels of mercury through a process of 'biomagnification'). Different fish have different levels of contaminants; different lakes/rivers in the same area can have different levels. Tools are currently available, such as the North Shore Tribal Council's (Ontario) Fish Consumption Guidelines that can help assess safe levels of fresh water fish consumption for First Nations people.

Smart eating is promoted to make healthy choices. Caribou, for example, is relatively free of contaminants, as is Char, which is an excellent source of vitamins and minerals. Whale and seals, on the other hand, biomagnify contaminants.

First Nations want to monitor contaminant levels to determine trends and exposure of contaminants. At present, it is believed that the benefits of eating traditional and country foods according to 'smart eating' principles exceed the risks posed by contaminants.

More information can be found in the Health section of the AFN website at www.afn.ca by following "Environmental Health".

Contaminants and traditional inuit foods

Inuit country foods such as arctic char, whale, caribou or seal can reduce risk factors associated with diabetes. Generally speaking, these foods have fewer calories, less saturated fat and more iron than the processed foods found in northern stores. Seal meat, for example, is an excellent source of protein and iron. Seal eyes are an excellent source of zinc, particularly valuable for people with diabetes, who often have cuts and sores that are slow to heal.

Inuit who harvest and use county food, however, also may consume contaminants, including Persistent Organic Pollutants such as PCBs and pesticides and heavy metals such as mercury. Most of these contaminants, which cannot be seen, smelled or tasted in foods, are persistent. Once they are in an animal's body, they remain there for a long time. When an animal is eaten, any contaminants stored in their tissues are biomagnified, that is, they are passed on to the predatory animal. Because of this, seals and other animals at the top of the food chain have higher levels of mercury and other contaminants than shrimp, cod or other animals at the bottom of the chain.

Elevated levels of contaminants have been found in Inuit who rely on seals and other arctic animals as primary food sources. For example, Inuit women have levels of PCBs in their breast milk that, on average, are 5 to 10 times higher than those of women in southern Canada. Many of the health risks associated with these contaminants are poorly understood. Contaminants in country foods are being monitored and studied closely by, for example, the federal Government's Northern Contaminants Program (http://www.ainc-inac.gc.ca/ NCP/index_e.html) and McGill University's Centre for Indigenous Peoples' Nutrition and Environment (http://cine.mcgill.ca). Information on contaminants is also provided on the website of the Urban Inuit Diabetes Awareness & Prevention Project (http://www.inuitdiabetes.ca).

Screening for diabetes among Aboriginal Peoples

Early detection of diabetes prevents disability and death.

It is estimated that as many as 50% of people with type 2 diabetes are unaware that they have the disease. Screening high-risk asymptomatic individuals to detect diabetes and its predisposing conditions, such as impaired glucose tolerance, is recommended by the Canadian Diabetes Association's (CDA) 2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada (CPGs). Early diagnosis and treatment to control blood sugars can decrease the risk of complications and improve the quality of life of a person with diabetes.

Screening for complications among Aboriginal Peoples

Standards in the delivery of care for Aboriginal People across Canada are lacking; some communities have screening, others do not.

Among people with diabetes, the early detection and treatment of complications can decrease the risk of serious disability and death. Comprehensive diabetes programs include screening for complications by a multi-disciplinary team. Recommendations from the CDA's CPGs for screening for complications include:

- Performing direct opthalmoscopy through dilated pupils for retinopathy (eye examination);
- Assessing the albumin/creatinine ratio in urine for nephropathy (urine test for kidney problems);
- Examining for foot ulcers (foot care);
- Assessing ankle reflexes, sensation in the foot for neuropathy (foot exam for nerve damage);
- Measuring fasting lipid profile for heart disease (blood test for cholesterol and triglycerides); and
- Assessing blood pressure for hypertension.

Care and treatment of diabetes and prevention of complications in Aboriginal Peoples

Self-care is one of several "care" layers for Aboriginal People living with or at risk of diabetes.

People with diabetes must manage their disease on a day-to-day, moment-to-moment basis. Effective management of diabetes increases glucose control, decreases the likelihood of complications and improves quality of life. Diabetes care and treatment are most effective when they are approached holistically, taking into consideration people's physical, social, emotional, mental, spiritual and cultural well-being throughout the lifecycle. This approach is consistent with traditional Aboriginal health and wellness understandings and practices, which attend to all aspects of the physical, spiritual, emotional, and mental well-being of individuals, communities and nations.

A range of clinical care services is required to manage the acute problems associated with diabetes and its complications. Multi-disciplinary care teams provide education, diagnosis and treatment in collaboration with individuals with diabetes and their families.

A primary health care focus on multi-disciplinary teams is recommended for the range of challenges and complications posed by diabetes among Aboriginal People.

Holistic approaches to diabetes care and treatment are more consistent with Aboriginal principles of health and wellness than western disease-prevention models of health care. However, traditional medicines and healing practices should not be viewed as complementary to western, or mainstream, approaches to health care but rather as unique, and viable, alternative forms of treatment. Greater understanding of traditional healing, as well as improved access to traditional healers and medicines, is encouraged. Public education and promotion of healthy living through diet and exercise is documented as a preventative way for some adults in coping with the onset of diabetes.

Educational interventions for behavioural change are the foundation of many prevention and care activities. Diabetes education provides knowledge and increases awareness of the behaviours and skills necessary to reduce complications from diabetes and to improve the quality of life of people living with diabetes. Effective education is experiential, based on need, and focuses on the individual learner. In addition to using new knowledge to develop skills and address attitudes and behavioural issues, emphasis must also be

Education and awareness are foundational to the prevention and care of diabetes.

placed on problem solving and decision-making. Collective learning communities that emphasize group (as opposed to individual) achievements are particularly useful in First Nations communities. All education should be culturally and age appropriate.

Complementary to self-care management education, self-efficacy training focuses on behavioural issues, such as developing individuals' self-efficacy and motivation so that they can use their skills and knowledge, commensurate with their capability, to take effective control over their lives and chronic disease. Unlike self-care management, people who have a chronic condition lead self-efficacy training. They cover topics such as pain control, use of medications, behaviour and lifestyle change, methods to adjust to social and workplace dislocations, strategies to cope with emotional reactions, methods to interpret changes in the disease and its consequences, and use of medical and community resources. Self-efficacy training enables participants to learn from each other and has helped people with diabetes to reduce their symptoms, improve their physical activity levels and significantly reduce their need for medical treatment. In Aboriginal communities, programs may also benefit if elders are included to provide traditional teaching and training.

Self-efficacy training uses persons affected by diabetes to provide individuals with culturally appropriate information and support.

The Alma Ata (1978)
Primary Health Care Principles

- ⇨ *The right intervention*
- ⇨ *By the right primary health care team member*
- ⇨ *With the right application of the appropriate technology*
- ⇨ *Leveraging local resources and*
- ⇨ *Empowering of women, children especially, and of community more broadly.*

Programs in the community should support individuals with diabetes by encouraging and enabling healthy eating and regular physical activity. In rural and northern communities, for example, ensuring that healthy food is available and affordable facilitates healthy eating. Schools that provide healthy food in cafeterias, vending machines or breakfast programs and snack breaks make it easier for students with diabetes to fit in. In the workplace, employers can support the adoption of healthy lifestyles by providing healthy nutritional options in the cafeteria or vending machines or opportunities for physical activity. The entire population can benefit from such community supports.

Healthy community policy encouraging healthy behaviours are known to be beneficial in sustaining awareness of diabetes and prevention.

Medication is a critical component of diabetes management. A person with diabetes typically incurs medical costs that are two to five times higher than those of a person without diabetes. This can present a significant financial hardship to people who do not have additional health coverage through employee benefit or other private insurance plans.

Medication and supplies such as test strips are costly, but necessary for diabetes management.

Aboriginal Peoples face a complex jurisdictional situation when struggling with the diabetes pandemic. Currently, there is no effective Federal/Provincial/Territorial/Aboriginal or Federal/Provincial/Territorial process in place to resolve this compelling issue. As a result, the process is irrational and unstructured with inadequate policies, protocols and understandings between all governments. This deplorable state of affairs represents the single largest barrier between Aboriginal Peoples and implementation of a successful diabetes strategy.

The federal government has a fiduciary responsibility to all Aboriginal Peoples.

Research

Most research funding goes to basic and clinical research. However, community-based health services research is vitally important to reduce risk and improve diabetes control in Aboriginal Peoples. In 2001/2002, only $4.6 million (about 5%) in research funding was directed towards Aboriginal Peoples. The Canadian Institutes of Health Research (CIHR) has established an Institute for Aboriginal Peoples' Health (IAPH) and the Institute of Nutrition, Metabolism and Diabetes (INMD) but neither have enough funding to respond to all of the research needs.

Community-based research is key to capacity building at the community level.

The impact of current research is limited to some extent by the transfer or dissemination of results. No single consolidated Internet-based source informs stakeholders about new and updated knowledge from diabetes research. Educational programs in particular would benefit from a reliable, impartial source of research information.

In the past, researchers have often failed to consult or involve Aboriginal organizations and communities in the development and design of research projects. This has resulted in a lack of cultural context for both data collection and interpretation. In addition, research findings have not always been shared with communities. Community participatory research avoids these problems by providing a collaborative process between the researchers and community members.

Historically, research has not been community-based, knowledge has not been shared with the community, and consequently, capacity building has remained stunted.

Very little health research has targeted and/or involved Métis, non-status Indians and Aboriginal Peoples living off-reserve. Research is also lacking on type 2 diabetes in Aboriginal children, gestational diabetes, pregnancy, effective Aboriginal-specific education materials, and the integration of traditional and Western medicine approaches in prevention and treatment.

Jurisdictional issues, along with the lack of a formal numeration process and registry, have discouraged data collection on health indicators for Inuit, Métis or non-status Indians. Neither have Inuit, non-status nor Métis-specific culturally relevant health indicators been identified. This has placed Inuit, Métis and non-status Indians in limbo: scarcity of Inuit, Métis-specific and non-status Indian population health information impedes development of adequate health services, which can only materialize if the rights to these services are affirmed. Given that Métis comprise about 30% of the total Aboriginal identity population in Canada (Statistics Canada 2001), and share a similar socio-economic demographic profile and health status as First Nations, Inuit and off reserve, emphasis should be placed on the serious need for Métis-specific diabetes research.

The National Aboriginal Health Organization's OCAP Principles for Research

NAHO has identified four principles that should guide any consultation or research processes undertaken in First Nations communities:

- ***Ownership.*** *First Nations communities or groups own their cultural knowledge, data and information collectively.*
- ***Control.*** *First Nations, their communities and representative bodies have the right to seek control over all aspects of research in which they are involved.*
- ***Access.*** *First Nations communities and people should have access to the information and data that has been collected about them*
- ***Possession.*** *First Nations communities and people should have physical control of data that has been collected about them.*

Some funders, including departments of the federal government, will not support research projects that do not adhere to OCAP. A detailed discussion of the principles can be found on the NAHO Web site (http://www.naho.ca/firstnations/english/ocap_principles.php)

Surveillance

The vision of the National Diabetes Surveillance System (NDSS) is:

> *A multi-sectoral initiative of non-governmental agencies, Aboriginal groups, government and industry committed to reducing the incidence and complications of diabetes through leadership in the development, implementation and national co-ordination of provincial, territorial and Aboriginal diabetes surveillance systems.*

The goals of the NDSS are:

1. To develop a national standardized database for diabetes with long-term monitoring for diabetes-related complications through the integration of new and existing databases.
2. To facilitate the establishment and maintenance of ongoing surveillance of diabetes and its complications in each province and territory and in Aboriginal communities.
3. To disseminate national comparative information to assist in effective prevention and treatment strategies by public health, Aboriginal organizations/communities, non-government organizations and private industry.
4. To develop a basis for the evaluation of economic/cost related issues regarding the care, management and treatment of diabetes in Canada.

The NDSS has inadequately addressed surveillance issues for Aboriginal Peoples, and minimal progress has been made in resolving the difficult issues in this critical area.

Identified gaps

Gaps in prevention of type 2 diabetes among Aboriginal Peoples

Lack of focus on prevention among communities with concerns about the accessibility of self-management education and treatment and other health issues.

Inadequate provision of targeted interventions for populations who are at higher risk for developing diabetes, such as individuals who are overweight or have a family history of diabetes.

Inadequate communication to community members about diabetes prevention. Written materials need to use plain language and be available in local dialects.

Existing programs focus predominately on modifying the risk factors of physical inactivity, obesity/overweight and poor nutritional habits without sufficiently addressing underlying determinants of these risk factors.

Inadequate sustained funding for prevention programs.

Failure to translate knowledge into action that would result in the expansion of effective programs and widespread implementation of effective policies.

Initiatives developed for the general population are often inaccessible to Aboriginal Peoples because of cultural and language barriers.

Lack of research on the effectiveness of programs for Aboriginal Peoples.

Lack of human resources to undertake diabetes prevention and education, surveillance, care and treatment, and research.

Gaps in screening

Lack of facilities and health care staff for screening programs contribute to inadequate screening.

Lack of a formal national screening program to facilitate screening for diabetes and its complications across the country. (Several provinces/territories have identified the need for effective screening, however.) The unique needs of Aboriginal populations will need to be considered in the development of any national program.

Lack of human resources to undertake diabetes prevention and education, surveillance, care and treatment, and research.

Gaps in care and treatment

Lack of recognition of the right of Aboriginal Peoples to choose to assert their difference and to choose different models of health care.

Lack of adequate services for diabetes management for Aboriginal Peoples living in the north and in remote rural areas.

Lack of resources and expertise among Aboriginal populations in diabetes education program development and evaluation.

Lack of educational resources specifically suitable for Aboriginal communities.

Lack of clarity about jurisdiction and accompanying fiscal responsibility for services make it difficult to provide coordinated diabetes care in Aboriginal communities.

Inaccessibility of services due to culture and language barriers.

Inadequate recruitment and retention of Aboriginal employees, who may be uniquely able to recognize and address the culturally-specific needs of Aboriginal Peoples with diabetes.

Lack of human resources to undertake diabetes prevention and education, surveillance, care and treatment, and research.

Lack of regionalized care in some rural and remote Aboriginal communities.

Seriously limited access to specialists, sub-specialists and even general practitioners.

Poverty and inadequate food supply exist in many communities.

Gaps in surveillance

Lack of success to date in addressing surveillance issues for Aboriginal Peoples in the NDSS. [(One of the major barriers is the inability to meet First Nations' OCAP principles (Ownership, Control, Access and Possession.)]

Lack of human resources to undertake diabetes prevention and education, surveillance, care and treatment, and research.

Gaps in education

Limited research to assess the effectiveness of specific education modalities.

Inconsistent application of existing knowledge about health behaviour change in the development of programs.

Need to clarify how prevention activities for diabetes could be integrated with the prevention of other chronic disease.

Imbalance between individual level and population health approaches.

Lack of resource and expertise in program development and evaluation.

Lack of multi-level diabetes education programs and services.

Accessibility to diabetes education programs and services close to home.

Inadequate resources, including under-funding of education; insufficient human resources; inadequate equipment and resources; lack of outreach and follow-up services; inadequate multi-cultural resources and resources in a variety of languages.

Lack of recognition of the pivotal role of the diabetes educator in facilitating behaviour change.

Barriers to ongoing professional education, such as lack of time, lack of employer support and budget restrictions.

Lack of human resources to undertake diabetes prevention and education, surveillance, care and treatment, and research.

Promising programs

- **Kahnawake Schools Diabetes Prevention Project (KSDPP)** is an ongoing participatory research and intervention project underway in the Mohawk territory of Kahnawake. The project empowers community members to care for their personal and family health by offering a diabetes prevention model based on Kanien-keha values. The project began in 1994, with the goal of decreasing the onset of type 2 Diabetes in present and future generations. To accomplish this, the project established as its main objective to increase daily physical activity and healthy eating among Kahnawake children.

  The project seeks to mobilize the community, foster community empowerment and ownership through participation in all aspects of the project, and to build capacity within Kahnawake to ensure sustainability of project activities and outcomes. A community advisory board guides the project's work, and activities are cooperatively planned and implemented in partnership with local organizations. An extensive dissemination program gives community members feedback on all aspects of the project. KSDPP shares a model of its activities with other Aboriginal communities and people interested in diabetes prevention. The key to KSDPP's success is its ability to mobilize and empower its community to take action against the diabetes epidemic.

- The **SLICK** project **(Screening for Limbs, I-eyes, Cardiac and Kidneys)** operates two vans that have travelled to all of Alberta's 44 First Nations communities, providing screening for control and complications. The program, which has reached many clients who have not otherwise been able to access the screening services they need, has uncovered relatively high rates of complications such as obesity, cardiac risk factors, foot abnormalities and urine protein leakage.

- The **B.C. First Nations Mobile Diabetes Telemedicine Clinic** serves Aboriginal Peoples living in reserve communities in the northern part of the province, where it is often difficult to access diabetes care. Mobile Clinic staff, including a diabetes nurse-educator and a vision technician, travels to First Nations communities and provides diabetes testing and education, eye examinations, and retinal photography services. During its first eighteen months of operation, clinic staff examined over 500 people with diabetes at 42 clinics. Nearly one-half of those examined had not received a retinal examination within the last year, 20% were found to have diabetic retinopathy, and 28% needed referral for other eye problems.

- The **Cree Board of Health and Social Services of James Bay** has shifted its focus to community-based health promotion activities. To promote diabetes awareness and prevention, the Board organized the Winter Wellness Journey (Miyupimaatisiitaau), a 1,400 km traditional journey on snowshoes. Over three months in the winter of 2002, a group of Cree and Inuk people walked 1,400 km through the region, raising awareness about the need for people to keep fit and eat healthily, highlighting physical activities and traditional foods as the main ways to prevent diabetes.

- **Kids in the Kitchen** is an interactive nutrition program designed for children 6 to 11. The program offers a community action kit that includes a manual with lesson plans including recipes and nutrition activities for groups of children; sample forms and letters for funders, parents and community partners; aprons, measuring spoons and cups; and teaching resources to support nutrition activities.

- The **Island Lake Renal Centre** is an example of the power of multi-jurisdictional partnerships to address the health needs of First Nations communities. Recently in Northern Manitoba, the Garden Hill Nursing Station of the Island Lake First Nations will soon house the first dialysis unit in Manitoba to be located outside a hospital. The Renal Health and Treatment Centre will enable repatriation of dialysis patients and their families to their communities of origin. The Centre will provide an innovative, community-based program focused on education, screening and prevention, earlier identification of 'at risk' individuals, and improved outcomes.

  The Centre will be paid for with mixed funding from the federal and provincial governments. Group members signed a Memorandum of Understanding in which they committed to rework how they do business internally and with each other, and find ways to work across jurisdictional boundaries.

- The **Métis Nation of Alberta** hosted its first ever Diabetes Conference, called A Personal Fight - A Nation's Plight on March 17 to 19, 2004. The well-attended event was held in Edmonton. Conference delegates enjoyed an "Evening of Entertainment" that encouraged all ages to showcase their musical talents. A story about the Conference in the St. Albert Gazette said, "Embracing some of the traditional Métis culture such as music and dance can do a lot to create a healthier lifestyle." A cookbook and a video entitled "Living Healthy with Diabetes" made their debuts at the Conference.

In conclusion

As Aboriginal leaders have indicated, type 2 diabetes is pandemic among Aboriginal Peoples. Educating Aboriginal Peoples is key to preventing the disease among our people. Educating Aboriginal Peoples with diabetes about how to live with diabetes and prevent complications will result in healthier communities. The impact this will have cannot be measured merely in economic terms, as the gains will be greater than the financial savings. Our people need to be encouraged to revisit their past since it will help Aboriginal youth to understand what kept their parents and grandparents healthy. The whole story is necessary so that Aboriginal youth can decide what is best for their health and for their societies as a whole.

We now know that education about diabetes, healthier eating, and active living will combat today's diabetes pandemic and will provide the basis for healthy lifestyles. Having skating rinks, swimming pools and recreational facilities (that youth councils have asked for in the past few years) are some of the solutions to today's pandemic. Furthermore, having more diabetes educators, dieticians and nutritionists in Aboriginal communities will ensure that meaningful education is accessible for all Aboriginal groups. Community engagement is key, because they understand the needs of their people, families and relatives. Listening to communities, working with many partners, and implementing strategies will provide better information and data, accessible and relevant programs, and ultimately will result in healthier Aboriginal populations.

Recommendations

Prevention

Primary prevention of type 2 diabetes

P1 Develop and create user friendly and culturally sensitive communications that recognize the distinctiveness of Aboriginal Peoples.

P2 Aboriginal prevention and promotion programs should build awareness of effective management of diabetes.

P3 The national Aboriginal organizations must be provided with adequate resources to develop, implement, and evaluate prevention programs for specific at-risk groups such as young women, pregnant women, children, and the elderly.

P4 An environmental scan should be undertaken to compile a current inventory of effective prevention and promotion models implemented in other countries.

P5 Prevention programs should educate Aboriginal Peoples with diabetes in the use of glucose meters, interpretation of results and how to modify treatment according to blood glucose levels.

P6 Aboriginal clearinghouses should be established to facilitate the dissemination of culturally sensitive information on diabetes prevention.

Secondary prevention

P7 Develop and implement screening programs for all Aboriginal Peoples, regardless of residence, to facilitate early detection of diabetes and its predisposing conditions and to ensure timely initiation of appropriate follow-up care.

Education

E1 Integrate diabetes education into a National Aboriginal Diabetes Strategy.

E2 Develop comprehensive, culturally sensitive and flexible education programs to accommodate all Aboriginal Peoples.

E3 Develop, implement and evaluate standards, programs and outcomes for a holistic approach to diabetes education for all Aboriginal Peoples.

E4 All education programs need to be inclusive of all Aboriginal Peoples and consistent with the beliefs customs and, knowledge and values and languages of all Aboriginal Peoples.

Care and treatment

C1 Establish access to care and treatment for all Aboriginal Peoples with diabetes regardless of residence.

C2 Develop a comprehensive long-term care and treatment strategy as part of a National Aboriginal Diabetes Strategy for all Aboriginal Peoples regardless of residence.

C3 Inter-jurisdictional issues involved with the care and treatment for all Aboriginal Peoples need to be facilitated and resourced by Health Canada.

C4 Establish and expand stronger partnerships and networks with Aboriginal Health Care providers.

C5 Research and develop diabetes care models that are interdisciplinary including traditional knowledge and holistic in practice.

C6 Research, plan and implement self-management strategies for balancing lifestyle choices with drug therapy.

C7 Establish various models of care and treatment using health care teams to assist Aboriginal diabetics in learning and using the varied and complex skills required to achieve balance in their lives.

C8 Plan cross-cultural orientation and awareness between Aboriginal Peoples with knowledge of healing practices and traditional knowledge with primary care providers.

C9 Develop and implement a comprehensive model for community-based diabetes screening for all Aboriginal Peoples regardless of residence.

C10 Develop a long-term care and treatment strategy as part of a National Aboriginal Diabetes Strategy for all Aboriginal Peoples regardless of residence.

C11 Develop a Federal/Provincial/Territorial/Aboriginal strategy to be facilitated and financed by Health Canada.

C12 Initiate and improve access to care and treatment for all Aboriginal Peoples with diabetes regardless of residence.

C13 Increase the capacity of Aboriginal organizations to manage effective diabetes programs.

C14 Improve clinical outcomes including decreased rates and severity of complications and hospitalizations for all Aboriginal Peoples with diabetes.

C15 Develop diabetes care models that are interdisciplinary, including traditional knowledge combined with comprehensives and shared care.

C16 Assist the daily commitment of Aboriginal Peoples with diabetes to self-management, balancing appropriate lifestyle choices and drug therapy.

C17 Assemble Aboriginal diabetes health care teams to assist people with diabetes in learning and using varied and complex skills required to achieve balance in their lives.

C18 Undertake cross-cultural orientation and awareness between Aboriginal Peoples with knowledge of healing practices and traditional knowledge and primary care providers: nurses, dieticians, social workers, pharmacists, optometrists, podiatrists and other care providers.

C19 Support healthy lifestyle choices, active living and health-enhancing environments in all Aboriginal communities.

C20 Develop a physical activity component with all care models that encourages participation for all Aboriginal Peoples.

Surveillance

S1 Develop a comprehensive national diabetes surveillance system, which will produce by means of a valid methodology reliable data on all Aboriginal Peoples in Canada.

S2 Maintain the participation of the five national Aboriginal organizations on the Diabetes Surveillance Working Group of the National Diabetes Surveillance System (NDSS).

S3 Establish a sub-committee of the NDSS to deal with the specific issues involved with Aboriginal surveillance.

S4 Federal, provincial and territorial governments to support Aboriginal capacity to undertake surveillance.

S5 Capacity for production and dissemination of surveillance information needs to be developed by the national Aboriginal organizations.

S6 Capacity for analysis of surveillance information needs to be developed by the national Aboriginal organizations.

S7 Diabetes surveillance information on all Aboriginal Peoples needs to differentiate between type 1 and type 2 diabetes.

S8 Diabetes surveillance information on all Aboriginal Peoples needs to include all Aboriginal children.

S9 Diabetes surveillance information on all Aboriginal Peoples needs to include complication rates.

Research

We support the finding by the Research subcommittee of the CCNDS that specific research on Aboriginal issues in diabetes, which is currently $4.7 million per year, seems miniscule given the magnitude of the problem.

R1 Undertake an environmental scan and analysis to obtain a complete picture of diabetes-related research and the extent of its focus on the needs of all Aboriginal Peoples.

R2 Increase diabetes research funding for all Aboriginal Peoples to $75 million by 2005.

R3 Undertake research on the effective mechanisms and prevention strategies for type 2 diabetes taking into account the diversity and full range of Aboriginal Peoples in Canada.

R4 Undertake research on mechanisms for type 2 diabetes control, and candidate drug identification.

R5 Undertake research on urban Aboriginal populations taking into consideration factors such as changing lifestyles, access to traditional foods, environmental, spiritual and socio-economic factors.

R6 Undertake research on the specific challenges involved with care of diabetes in remote and rural Aboriginal populations.

R7 Undertake in Phase II, the modification of the Canadian Diabetes Research funding database so that it provides a perspective on current research initiatives in Aboriginal diabetes and specifically with status and non-status Indians living off-reserve, Métis and Inuit.

R8 Review communication tools that are used to link research agencies and stakeholders to ensure that national Aboriginal organizations are fully engaged.

R9 Review the Diabetes Research funding databases to identify Aboriginal research initiatives and especially those for non-status Indians, status Indians living off-reserve and Métis.

R10 Increase health research into health services and those available for non-status Indians, status Indians living off-reserve and Métis.

R11 Establish a high-risk profile for the development of diabetes for all Aboriginal Peoples to assist in determining an effective and comprehensive strategy for early screening and interventions for all Aboriginal Peoples.

R12 Clinical trials should include all Aboriginal Peoples in Canada.

R13 Establish and develop networks and forums to facilitate linkages between researchers and leadership of the national Aboriginal organizations.

Glossary

Best practices

Best practices are activities based on sound scientific evidence, extensive community experience and/or cultural knowledge. Interventions will be more effective if they are based on established best practices.

Body mass index (BMI)

The Canadian body weight classification system uses the body mass index (BMI) and the waist circumference (WC) to assess the risk of developing health problems associated with overweight or underweight. The system is for use with adults aged 18 years and over with the exception of pregnant and lactating women. The BMI is a ratio of weight-to-height. BMI can be classified into ranges associated with health risk. There are four categories of BMI ranges in the Canadian weight classification system. These are: underweight (BMI less than 18.5); normal weight (BMI 18.5 to 24.9); overweight (BMI 25 to 29.9), and obese (BMI 30 and over).

Community development

Helping communities take control over their health, social and economic issues by using and building on their existing strengths. It recognizes that some communities have fewer resources than others, and supports these communities. Networks, ongoing funding and efficient infrastructures help to sustain community action.

Epidemic

An occurrence of disease that is temporarily of high prevalence.

Healthy public policy

The main aim of healthy public policy is to create supportive environments that enable people to lead healthy lives. Such policies make healthy choices the easy choices. All levels of government and all sectors (e.g. health, agriculture, transportation, education, environment and others) have a role in the development of healthy public policy.

High-risk approach

Interventions are targeted at individuals who are at higher risk of diabetes.

Integration

Cooperative efforts to promote healthy living by addressing individual issues together (e.g. healthy eating, physical activity and their relationship to healthy weights). An integrated approach in policy development, research and programming can lead to greater health improvements and a more effective use of resources.

Interdisciplinary

Relating to, or involving two or more disciplines that are usually considered distinct.

Multi-disciplinary

Making use of several disciplines at once: a multi-disciplinary approach to teaching.

Pandemic

An epidemic that is widespread

Physical activity

Physical activities focus on endurance, flexibility or strength.

Physical inactivity

Physical inactivity leads to a higher risk of the development of diabetes. Individuals who expend 1.5 kilocalories/kg or less every day are classified as physically inactive.

Population health approach

A population health approach focuses on the underlying and interrelated conditions that influence the health of populations over the life course. These include factors such as education, income, early childhood experiences and the social and physical environments that surround individuals and groups. By addressing these factors, a population health approach aims to reach beyond the limited effectiveness of lifestyle-based interventions and reduce disparities in health outcomes.

Primary prevention

Primary prevention is the prevention of the onset of diabetes itself and will have an impact by reducing both the need for diabetes care and the need to treat diabetic complications. Primary prevention consists of activities that are aimed at preventing diabetes from occurring in susceptible people or populations through modifications to the environment and the promotion of healthy living.

Screening

Examination or testing of a group of individuals to separate those who are well from those who have an undiagnosed disease or defect or who are at high risk.

Self-care management

Focuses on providing information and teaching the technical skills required for diabetes management and requires people to take a central role in their care. Self-care management of diabetes requires a range of skills and behaviours: self-injection of insulin; self-monitoring of glucose levels; eating properly; smoking cessation; exercising; and taking medications properly. Those practising these "self-care management behaviours" work to achieve certain intermediate goals, such as metabolic control, optimal blood glucose levels, blood lipid control, and reaching and maintaining a healthy weight. If these intermediate goals are achieved, they may lead to better diabetes outcomes overall: reduced morbidity (retinopathy, neuropathy, nephropathy), fewer hospitalizations, fewer diabetes-related health care costs and reduced mortality.

Self-efficacy training

Complementary to self-care management education, self-efficacy training focuses more on cognitive-behavioural issues – on developing individuals' confidence and motivation so that they can use their skills and knowledge to take effective control of their disease. Topics may include how to get started with exercise; how to problem-solve; how to communicate effectively; how to work effectively with health care professionals; how to deal with anger, fear, and frustration; how to deal with depression; how to deal with fatigue; how to evaluate treatment options; how to relax; and how to deal with negative emotions. A particular feature of self-efficacy training is that unlike self-care management education, it is led by trained volunteers.

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Appendix A – Chronic care model

Structure:

Chronic care model[35]

This report has been structured using the Chronic Care Model (CCM), which was derived from "Improving Chronic Illness," a program of the Robert Wood Foundation in the United States. The CCM embraces self-management concepts. It refers to "activated patients" who are informed and willing to take action to manage their illnesses effectively. Individuals with diabetes are supported by a "prepared practice team," which assesses and responds to needs, and is supported by clinical practice guidelines, specialty expertise and information systems. The result is "productive interactions" that lead to effective assessment; tailoring of clinical management; collaborative goal setting and problem solving; a shared care plan; and active, sustained follow-up.

The CCM identifies the essential components of a system that encourages high-quality chronic disease management. These include the following: (i) the community, (ii) the health system, (iii) self-management support, (iv) delivery-system design, (v) decision support, and (vi) clinical information systems.

Component 1.

Community: resources and policies

Community programs can support and expand care for chronically ill individuals. Too often, people with diabetes are left to manage their condition without enough community support to ensure that their health improves. Community resources may include non-profit and volunteer organizations that provide information, or community facilities such as recreation centres. Working outside the acute care system, community resources can enhance diabetes care and avoid unnecessary duplication and costs. As well as providing resources, the broader community can also play a critical role in diabetes care by supporting the development and implementation of healthy public policies, as well as health-related regulations that directly and indirectly affect the lives of people living with diabetes.

Component 2.

Health System: organization of health care

A health care system that is seeking to improve diabetes care and management must be prepared for change from top to bottom. Leaders must validate the effort and translate it into clear goals that are reflected in policies, procedures, business plans and financial planning. Managers throughout the health system must understand the mission and make decisions that support it. Health care providers need incentives to change – to recognize the need for integrating chronic disease management strategies into their day-to-day work with people with diabetes. Organizations, both in the community and the acute care sector, should provide services that are convenient and accessible so that diabetes care is received before symptoms deteriorate into crises.

35 Coordinating Committee of the National Diabetes Strategy. Summary Report, Diabetes Care, 2002, p. 2.

Component 3.
Self-management support

Individuals with diabetes need to be encouraged to take care of themselves in order to keep their diabetes under control. They need to be taught how to minimize complications, symptoms, and disability, and supported in their daily decisions through support groups or other means. Effective self-management is more than providing information or telling individuals what to do: it requires individuals with diabetes to take a central role in determining their care, one that fosters a sense of responsibility for their own health. Under a chronic disease management approach, individuals with diabetes and health care providers work together to define problems, set priorities, establish goals, create treatment plans, and solve problems along the way.

Component 4.
Delivery system design

Effectively managing and improving the health of people with diabetes requires transforming a system that is essentially reactive – responding mainly when a person is sick – to one that is proactive and focused on maintaining good health. This means both determining what care is needed and defining roles and tasks to ensure that the person with diabetes receives the care. It means making certain that all of an individual's health care providers have centralized, up-to-date information about his or her status, and it means making follow-up with the person a part of standard procedure so that the individual with diabetes feels continually supported.

Component 5.
Decision support

Diabetes management and treatment decisions need to be based on proven, evidence-based guidelines. As well, guidelines should be discussed with individuals so that they understand the principles behind their care. Those who make treatment decisions need ongoing training to stay up to date on the latest methods, using new educational models that improve upon conventional continuing medical education (CME). Decision support also means keeping primary care physicians informed through better feedback and/or joint consultation whenever a person with diabetes is referred to a specialist.

Component 6.
Clinical information systems

Effective diabetes care requires information systems that track individuals as well as populations: a central registry that outlines recommended care. The system can check an individual's treatment to ensure that it conforms to guidelines, measure outcomes, and offer reminders for screenings or check-ups. Because it ties together all the information available about a person with diabetes, it can also demonstrate when an individual does not need standard treatment because of special circumstances. Registry data can also be used to report on the status of diabetes management at an aggregate and population level.

Appendix B – Research priorities

The background work for *Building a national diabetes strategy: synthesis of research and collaborations* identified the following research priority areas.

E8 Research priorities

- Research into a cure for diabetes.
- Research into primary prevention of type 1, type 2 and gestational diabetes.
- Research into non-traditional medicine and interventions.
- Research into effective self-management educational interventions at the individual, community and population levels, including but not limited to:
  - ◊ effectiveness of educational/behaviour change theories
  - ◊ resources for education (outreach, individual or group settings) that are culturally sensitive, respectful of varying literacy needs, age-specific and adaptable
  - ◊ peer support/mentor interventions
  - ◊ core self-management competencies for persons with diabetes
- Research into effective program models and program planning approaches for diabetes education in the Aboriginal population.
- Research into effective program models and program planning approaches for diabetes education in other high-risk populations, including specific ethnic communities.
- Research to determine current knowledge and gaps in policy areas related to diabetes prevention, education, care, research and surveillance.
- Definition of benchmarks for human and resource allocation.
- Provision of capacity-building funds to academic institutions, in order to encourage research related to diabetes education.
- Effective translation and dissemination of research results for policymakers, consumers, and health professionals.

R3 While not all areas of research deficiency should be addressed, especially where major strengths exist outside of Canada, there are several areas where, given the particular national perspectives on health care delivery, Canadian investigators should take the lead. These include:

- Health services research into diabetes care in Aboriginal communities.
- Health services research into diabetes care in other communities, particularly rural and isolated ones.
- Diabetes in pregnancy, infant health and metabolic programming.
- Obesity.
- Retinopathy.

- Non-invasive functional metabolic imaging.
- Medical devices related to diabetes.
- Database design and information mining for diabetes management.
- Self-management approaches for health professionals and for persons with diabetes.
- Prevention of type 2 and gestational diabetes.
- Changing unhealthy physical and social environments into healthy ones.

R4 Researchers determine a high-risk profile for the development of type 1 or type 2 diabetes to monitor the level of risk in the population, the size of the population that could benefit from screening, and the effectiveness of prevention interventions. Identification of genetic profiles can create unfavourable outcomes for Aboriginal Peoples and communities. Genetic testing must be undertaken with careful and comprehensive community-based controls in place.

R9 Increase targeted research[36] on screening, mechanisms of prevention and improved management of diabetes in the Aboriginal population.

36 This should include the compilation of an inventory of effective educational, prevention and health promotion models suitable for use in Aboriginal communities, and research for program planning around diabetes education for Aboriginal and multicultural populations. Research should be done on optimizing the participation of these communities in diabetes education in order to assist program planning.

Appendix C – Coordinating Committee for the National Diabetes Strategy (CCNDS)

Terms of reference

Purpose and mandate of the Coordinating Committee

The mandate of the Coordinating Committee for the National Diabetes Strategy is to coordinate the development of and oversee the implementation of a national diabetes strategy.

National diabetes strategy

In the spirit of wellness, a national diabetes strategy is an action plan aimed at preventing and reducing the burden of diabetes in Canada.

Structure and membership

The Committee consists of representatives from the following institutions:

Government of Canada representatives:
Public Health Agency of Canada

First Nations and Inuit Health Branch, Health Canada

Canadian Institutes of Health Research

Provinces and territories representatives (P/T):
Yukon, Northwest Territories, Nunavut, British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Québec, Nova Scotia, New Brunswick, Prince Edward Island, Newfoundland.

National Aboriginal organizations:
Assembly of First Nations, Inuit Tapiriit Kanatami, Métis National Council, Congress of Aboriginal Peoples, Native Women's Assembly of Canada, National Aboriginal Diabetes Association.

Diabetes Council of Canada (DCC):
Canadian National Institute for the Blind, Canadian Pharmacists Association, Heart and Stroke Foundation of Canada, Canada's Research-Based Pharmaceutical Companies, The Kidney Foundation of Canada, Canadian Diabetes Association, The Juvenile Diabetes Research Foundation, Diabète Québec.

Leadership structure of the CCNDS:

The CCNDS has an Executive Committee comprised of the following members:

Dr. Gregory Taylor/Dr. Clarence Clottey, Public Health Agency of Canada; Ms. Joan Canavan, P/T representative; Ms. Onalee Randell, ADI representative; and Mr. Alan Patt, DCC representative.

Roles and responsibilities

The Coordinating Committee of the National Diabetes Strategy (CCNDS) will coordinate the development of and oversee the implementation of a national diabetes strategy and will provide direction and leadership in the refinement and implementation of recommendations made during the National Symposium: Moving Together Toward a National Diabetes Strategy, February 18-20, 2001, Montreal QC.

The CCNDS has a decision-making responsibility for the process leading to the development of a blueprint document for a national diabetes strategy. It is advisory to governments and major stakeholders on this issue.

Vision of the CCNDS

The CCNDS will be pivotal in developing a national diabetes strategy that will attract key stakeholders' involvement and commitment in preventing and reducing the burden of diabetes in Canada. The Committee will provide strong and focused leadership, adapting and responding quickly to its environment.

Values of the CCNDS:

1. Integrity ("Do what you said you would do"; "Be accountable", "Be ethical")
2. Commitment to action (demonstration of effort/time/effectiveness)
3. Passion (emotional commitment to the vision)
4. Trust (not defined)
5. Transparency (not defined).

CCNDS members

Government of Canada representatives

Dr. Diane Finegood (Canadian Institutes of Health Research)
Ms. Marie-France Lamarche (First Nations and Inuit Health Branch, Health Canada)
Dr. Gregory Taylor/Dr. Clarence Clottey (Public Health Agency of Canada)

Provincial and territorial representatives

Ms. Joan Canavan (Ontario)
Ms. Amy Caughey (Nunavut)
Ms. Marlene Chapellaz (Saskatchewan)
Ms. Peggy Dunbar (Nova Scotia)
Ms. Catherine Freeze (Prince Edward Island)
Ms. Dawn Friesen (Alberta)
Ms. Janice Linton (British Columbia)
Ms. Gisele McCaie-Burke (New Brunswick)
Ms. Kelly McQuillen (Manitoba)
Ms. Mary-Jane Stewart (North West Territories)
Dr. Faith Stratton (Newfoundland and Labrador)
Ms. Violet VanHees (Yukon)

National Aboriginal organization representatives

Mr. Kevin Armstrong (Assembly of First Nations)
Ms. Kandice Leonard (National Aboriginal Diabetes Association)
Ms. Sherry Lewis (Native Women's Association of Canada)
Mr. Duane Morrisseau-Beck (Métis National Council)
Ms. Onalee Randell (Inuit Tapiriit Kanatami)
Mr. Todd Russell (Congress of Aboriginal Peoples)

Diabetes Council of Canada (DCC) representatives

Mr. Stephen Allain (Canada's Research-based Pharmaceutical Companies)
Mr. Kevin Armstrong (Assembly of First Nations)
Ms. Janet Bick (The Kidney Foundation of Canada)
Mr. Ron Forbes (Juvenile Diabetes Research Foundation)
Ms. Mary Elizabeth Harriman (Heart and Stroke Foundation of Canada)
Ms. Maryann Hopkins (Canadian Pharmacists Association)
M. Serge Langlois (Diabète Québec)
Ms. Kandice Leonard (National Aboriginal Diabetes Association)
Ms. Donna Lillie (Canadian Diabetes Association)
Mr. Alan Patt (DCC Chair)
Ms. Linda Studholme (Canadian National Institute for the Blind)

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Working groups of the CCNDS

Prevention

Co-chairs:	Dr. Mary McKenna	members:	Mr. Marc Aras
	Dr. Mark Tremblay		Ms. Marguerite Arsenault
			Ms. Marlene Chapellaz
			Mr. Jim Evanchuk
			Ms. Betty Anne Lavallee
			Ms. Laraine Poole

Care

Co-chairs:	Ms. Peggy Dunbar	members:	Ms. Kathy Harrigan
	Ms. Valerie Tregillus		Ms. Carol LaBillois-Slocum
			Dr. Sora Ludwig
			Dr. Sara Meltzer
			Ms. Anita Stevens
			Ms. Joanne Sullivan

Education

Co-chairs:	Ms. Kelly McQuillen	members:	Mr. Don Fiddler
	Ms. Helen Jones		Mr. Ray Field
			Ms. Heather Jacob Whyte
			Ms. Donna Lillie
			Ms. Maureen Murdock
			Ms. Lori Petyk-LeClair
			Ms. Louise Tremblay

Research

Chair:	Dr. David Hill	members:	Dr. Roger Brownsy
			Ms. Jocelyn Bruyère
			Dr. Diane Finegood
			Dr. Michel Joffres
			Dr. David Lau
			Dr. Ann Macaulay
			Ms. Gail McDonald
			Dr. Barbara Paterson
			Dr. Alex Sorisky
			Dr. Kue Young

Surveillance

Co-chairs:	Dr. Linda Van Til	members:	Dr. Jane Griffith
	Mr. Larry Svenson		Ms. Rhea Joseph
			Mr. Glenn Robbins
			Ms. Elizabeth Stratton