Diabetes in British Columbia
Synthesis Report

Prepared For
British Columbia Ministry of Health & Ministry Responsible for Seniors

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Preface

To the Reader:

Diabetes is a serious public health problem with significant financial and human costs. The incidence of Type 2 diabetes is increasing, yet it is often preventable. The complications of Type 1 and Type 2 diabetes can be prevented or delayed. The impact of diabetes is disproportionately high in certain populations, including Aboriginal people.

In November 1999, the Minister of Health and Minister Responsible for Seniors announced plans to develop a comprehensive diabetes prevention and control strategy for British Columbia. One of the first steps toward this goal was to conduct preliminary research, including a literature review and key informant interviews. The research was conducted by independent consultants, under the guidance of the Ministry of Health Working Group on Diabetes. The results of their research is presented in this document entitled Diabetes in British Columbia Synthesis Report.

The Ministry is taking additional steps towards the development of a diabetes strategy for British Columbia by 2002.

- The BC Diabetes Reference Group was recently formed by the Ministry of Health and Health Canada to assist with the development of a provincial diabetes strategy and the regional implementation of the prevention and promotion component of the Canadian Diabetes Strategy.
- The Ministry is working with the BC Diabetes Reference Group, Health Canada and the Canadian Diabetes Association to plan and implement a consultation to support the development of a provincial diabetes strategy.
- The Ministry is working with Health Canada to implement the National Surveillance System in British Columbia.

Reducing the impacts of diabetes will require a long-term, coordinated, multisectoral effort. The principles underlying the Health Goals for British Columbia, such as collaborative action, public participation, equitable access to health services and respect for diversity, provide the foundation for this process. The Ministry is committed to these principles and looks forward to working with health authorities, professional and non-government organizations, and other ministries and governments to address the growing burden of diabetes in British Columbia.

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Background

Diabetes is a chronic disease that represents a major public health concern worldwide. Estimates are hampered by a lack of data, however, available information indicates that the incidence and prevalence of diabetes in Canada are increasing. With an aging population and increased rates of obesity this trend is likely to worsen. Diabetes and its complications result in a large economic and social burden. Diabetes is ranked as the seventh leading cause of death in Canada. The economic burden of diabetes and its complications in Canada is estimated to be up to $9 billion (US) annually in direct health care costs and indirect costs, including lost productivity due to diabetes-related illness and premature death.

In 1999, the Laboratory Centre for Disease Control, Health Canada released the document, “Diabetes in Canada: National Statistics and Opportunities for Improved Surveillance, Prevention and Control”. Many countries, including Canada have begun to address the problem of diabetes.

In 1999 the federal government also announced a five-year, $115 million Canadian Diabetes Strategy to help prevent and control this disease. This strategy includes a focus on prevention and promotion, surveillance and national coordination and has two special components - Aboriginal Diabetes and the National Diabetes Surveillance System (NDSS).

The main goals of the NDSS are to develop, facilitate, and coordinate national, provincial and territorial and Aboriginal diabetes surveillance. This core model will involve the production of nationally comparable data on diabetes prevalence and incidence, as well as comparisons of mortality, diabetes-associated diseases and health care utilization rates in populations with diabetes compared to population without diabetes.

This Synthesis Report partially fulfils the first steps of the above developmental process, by providing:

1. an analysis of current literature on incidence, prevalence, impacts and costs of diabetes and its complications, and effectiveness of policies, programs and services with an emphasis on best practices (see Appendix A); and

2. interviews with key informants to identify relevant diabetes-related issues and priorities (see Appendix B and C)

The literature review includes information from a broad source (international, national and provincial) of diabetes policy research documents and journal articles. Relevant websites were also scanned as a third source of up-to-date information. Particular emphasis was placed upon Canadian and British
Columbian information. Diabetes topics reviewed included incidence, prevalence, mortality, morbidity, burden of disease, the impact of diabetes on specific population groups in Canada (Aboriginal, elderly and children), risk factors, primary prevention (including cost-effectiveness), secondary prevention (including cost-effectiveness), tertiary prevention (including cost-effectiveness), research, best practices data and policy within Canada.

The second activity involved telephone interviews of key informants working in the diabetes field. Twenty-four individuals and two groups (the Community Nutritionists Council and Public Health Nursing Leaders Council) were interviewed. Their responses were pooled and analyzed for common themes (see Appendix B).
Research Findings

The following research findings were taken from both the literature review and the key informants survey. For more information see Appendix A and Appendix B.

Diabetes – Some Facts

Diabetes mellitus is a chronic disease characterized by hyperglycemia (high blood sugar), due to an absolute or relative insulin deficiency. Insulin, a hormone secreted from beta cells in the pancreas, assists with the conversion of glucose into energy. Without insulin, glucose cannot be sufficiently absorbed from the bloodstream into the cells of the body. Diabetes is classified as:

Type 1 diabetes (previously called insulin-dependent diabetes mellitus (IDDM) or juvenile-onset diabetes) may account for 5% to 10% of all diagnosed cases of diabetes (1). Type 1 diabetes is diagnosed primarily in childhood or adolescence, but may be diagnosed in adults. Multiple daily injections of insulin are required for survival. The most common form of type 1 is caused by autoimmune destruction of beta cells, resulting in an inability of the pancreas to produce insulin. Risk factors are less well-defined for type 1 than for type 2 diabetes, but autoimmune, genetic and environmental factors are involved in the development of this type of diabetes.

Type 2 diabetes was previously called non-insulin-dependent diabetes mellitus (NIDDM) or adult-onset diabetes. Most commonly, type 2 diabetes begins after age 40. However, in many countries, a growing number of children and adolescents are being diagnosed with type 2 diabetes (2,3,4). The onset of type 2 diabetes is a two-stage process: first, there is resistance to insulin’s action often exacerbated by obesity; second, the pancreas fails to increase insulin production enough to compensate adequately for the resistance. Type 2 may account for about 90% to 95% of all diagnosed cases (1). Risk factors for type 2 include age, obesity, family history of diabetes, prior history of gestational diabetes, impaired glucose tolerance, physical inactivity and race/ethnicity.

Gestational diabetes is defined as glucose intolerance first recognized during pregnancy. Usually this form of diabetes is a transient condition that disappears by six weeks post-partum (2). Gestational diabetes develops in 2% to 5% of all pregnancies (1). Risk factors include race/ethnicity, age, family history of diabetes and obesity. Women who have had gestational diabetes are at an increased risk for developing type 2 diabetes later in life, their children may also have an increased risk of childhood obesity and diabetes as adults (5). In some
studies, nearly 40% of women with a history of gestational diabetes eventually developed diabetes (1).

There are an estimated 60,000 new cases of diagnosed diabetes (type 1 and type 2 combined) every year in Canada (2). This is an incidence rate of 2.6 new cases per 1,000 people among those aged 12 and over each year.

Based on 1996/97 Canadian survey data and extrapolations from American sources, the number of Canadians aged 12 and over with diabetes is estimated at 1.2 to 1.4 million (4.9% to 5.8% of the population aged 12 and over)(2). Current estimates in Canada and around the world indicate that the prevalence of diabetes is increasing. Type 2 diabetes is age-related, as the population of Canada ages, the prevalence will increase. The age-standardized prevalence of diabetes for Aboriginal people in Canada is estimated to be at least three times that of the general population (6).

Diabetes is a chronic, debilitating and costly disease. Diabetes ranks as the seventh leading cause of death in Canada (2). Diabetes also has a significant impact upon daily living because of the high risk of complications. Diabetes is the most common cause of end-stage renal disease, of new onset blindness in the working age population, and of lower limb amputations, and is a noted risk factor for cardiovascular disease. In the 35 to 64 age group, people with diabetes have six times the risk of heart disease or stroke as do people without this disease (2).

Manitoba data show that health care costs for the diabetic population are double that for the non-diabetic population. In the status Indian population the ratio is 3:1 (7). The economic burden of diabetes and its complications in Canada is estimated to be up to $9 billion (US) annually in direct health care costs and indirect costs, including lost productivity due to diabetes-related illness and premature death (2).

Policy

As the growing prevalence and cost of diabetes have been identified, many jurisdictions in Canada and around the world are developing diabetes-related policies and plans (2,6-13). Many participants in the key informants survey seemed enthusiastic about a provincial diabetes strategy but stressed that people with diabetes should be involved in developing the strategy, that the strategy itself should be broad-based and have a long-term vision with adequate funding to support its implementation and coordination. Informants also discussed the need for policies that include the development of strategies for remote and rural communities. Aboriginal informants stressed the need for policies that include an Aboriginal perspective of the disease.
Informants also called for planning and coordination of services at the regional level. Some informants felt that diabetes services are very fragmented and discussed the need for a holistic continuum of care, particularly in relation to children and families. Planning for primary prevention activities was particularly identified as lacking.

Data Collection/Research

One of the factors hampering development of diabetes strategies is the limited data available on incidence and prevalence of diabetes, costs of diabetes and evidence regarding the management and outcome of diabetes services.

A current major initiative is the National Diabetes Surveillance System (NDSS) (2). This system is being developed by the Laboratory Centre for Disease Control of Health Canada, along with provincial and territorial governments, non-governmental organizations, academic clinicians and other federal agencies. In the short term, the NDSS will use existing administrative databases and record linkage to provide information such as the following:

- incidence and prevalence of diabetes;
- incidence and prevalence of diabetes complications; and
- utilization of health services.

In British Columbia, Ministry of Health staff are participating in the Steering Committee for a Federal/Provincial/Territorial project to develop the NDSS. Information from this initiative will be crucial in developing provincial policies and plans.

Survey informants recognize the lack of data and the problems that this lack creates. Data are needed at the local, provincial and national levels. Information is also needed on particular ethnic groups. An informant from the British Columbia’s Children’s Hospital (BCCH) stated that they are seeing increasing numbers of children with type 2 diabetes and that a disproportionate number of these children are either Chinese or Indo-Canadian. Informants also stressed the need for research and information regarding diabetes among Aboriginal people.

Primary Prevention

Type 2 diabetes is often preventable. The main modifiable risk factors for type 2 diabetes are obesity and physical inactivity (14,15). Eighty percent of people with type 2 diabetes have been found to be obese. Studies have concluded that regular exercise protects against type 2 diabetes.
Other risk factors for type 2 diabetes include: diet, socio-economic status and modernization or westernisation (15). A high caloric intake, the consumption of certain types of foods (sugar, fat, refined carbohydrates) and a diet low in fibre and high in saturated fat have all been associated with decreased insulin sensitivity and abnormal glucose tolerance.

Income level is associated with the risk of developing diabetes. For people aged over 35 years, those with diabetes are more likely than those without diabetes to have lower levels of income adequacy (2). Abandonment of traditional lifestyles (including hunting/ fishing/ gathering) and the associated decrease in physical activity and increased reliance upon less nutritious alternatives to traditional foods is associated with an increased prevalence in obesity, and may contribute to diabetes among Aboriginal people (15-18).

A recent study concluded that the primary prevention of type 2 diabetes can be highly cost-effective (19). Currently in the United States, the Diabetes Prevention Program (DPP) is conducting additional cost-effectiveness evaluations of primary prevention of type 2 diabetes (20).

Many survey participants recommended coordination of primary prevention programs at the provincial and regional levels. Informants discussed the need for school programs which emphasize nutrition and physical activity. Vending machines in schools which sell primarily non-nutritious foods were seen as hypocritical as they contribute to unhealthy choices and lifestyles. Informants felt that there could be better use of the media for disseminating messages regarding the importance of physical activity and nutrition in the prevention of type 2 diabetes. They also called for provincial leadership, particularly in promoting increased physical activity.

Secondary Prevention

Early identification and treatment of diabetes significantly reduces the risk of developing complications or postpones the development of diabetic complications. Therefore, screening of high-risk groups may be cost effective (11). Key informants noted that there has been a significant increase in the number of individuals who are screened for impaired glucose tolerance. As well, BCCH staff are finding early signs of type 2 diabetes when screening obese children.

Tertiary Prevention

Only very recently have there been studies that have clearly demonstrated the benefits of strict monitoring and control of blood glucose levels. Support for these goals comes from two landmark studies, one in the United States (21) and
one in the United Kingdom (22). Once the diagnosis of diabetes is made, treatment focuses on reducing blood glucose levels toward the normal range to reduce the risk of microvascular complications (kidney disease, eye disease and amputation) and improving lipid levels to reduce the risk of cardiovascular disease. Researchers have proposed that the most effective treatment for type 2 diabetes will rely on dietary intervention, physical activity and the use of pharmacological agents to improve blood glucose levels (5,23).

Specific issues regarding care were identified by survey participants. Many gaps in services and care provided to remote or rural communities were discussed. Continuity of care for people living in remote communities is difficult because of lack of access to health care professionals and the difficulties imposed by travel costs and travel impediments such as winter weather or lack of roads. In some communities, the practices of family physicians are closed to new patients. People with diabetes may then have to access services through walk-in clinics or emergency rooms, which precludes continuity of care.

Aboriginal people have a high prevalence of diabetes (24). However, key informants identified many problems with diabetes services for Aboriginal people: lack of access to services; lack of culturally relevant teaching materials; differences in culture between clients and educators leading to miscommunication; a shortage of Aboriginal health care workers; and lack of community involvement in programs were all concerns. Suggestions to help overcome these problems included:

- community programs which are culturally relevant (e.g., incorporates traditional beliefs and practices and fosters family participation) and contribute to community capacity building;
- development of culturally relevant teaching materials;
- support for Aboriginal students to increase the number of Aboriginal health workers and health professionals;
- increased training and support for already existing Aboriginal community health workers; and
- development of programs for Aboriginal people with diabetes in large urban centres (i.e., Vancouver).

Many informants spoke about the emotional/psychological/spiritual aspects of diabetes. Informants identified a need for support groups and psychological services for people with diabetes and families who have diabetic children. Among Aboriginal people the fear, grief and denial accompanying a diagnosis of diabetes was felt to be a major impediment to seeking treatment.

Several informants reported a significant shift in family physician practice since the release of the Canadian Diabetes Association Clinical Practice Guidelines (see reference 5 for the guidelines). They said that physicians are taking an increased interest in diabetes, are testing more consistently, are more aggressive with treatment and monitor lab results more closely.
Three informants spoke at great length about expanding the role of diabetes nurse educators in relation to treatment. “If you have someone who is able to take the BP, examine feet, change insulin and examine the eyes, there is one person who can do all the things that need to be done. It would be quite cost effective (as well).” Concern was raised about expanding roles within the diabetes education centres (DECs) without adequate resources being provided.

However, for secondary and tertiary prevention in diabetes to be effective, health care professionals may need assistance in making the shift from an acute to a chronic model of medical care and from the role of primary decision maker to that of teacher and facilitator (5). Several survey participants recommended the development of a chronic care model for diabetes. The Capital Health Region (CHR) is currently developing a chronic care model which they have adapted from the Group Health Cooperative of Puget Sound (an American non-profit health maintenance organization). A report on Phase One of the project is on the CHR website (www.caphealth.org).

Education

Studies have shown that teaching people with diabetes to manage their disease improves glycemic control, enhances self-care behaviours, decreases complications and lowers health care costs (25). However, the literature review identified numerous problems that can occur with accessibility and effectiveness of diabetes education (8, 25-27). People may be unaware of the importance of self-management, may not be referred appropriately to diabetes education centres, may not have access to diabetes education centres and materials (particularly in rural and remote areas), diabetes programs and materials may be inappropriate for specific individuals and ethnic groups and the gap between educators and care providers (those that are prescribing medication) may create problems.

There is very little information on the effectiveness of diabetes education in B.C. One B.C. study did find lower diabetes-related hospital admission rates in communities with a diabetes education centre compared to communities without a centre (28). A national study looked at the use of diabetes resource materials by dietitians and found that the Good Health Eating Guide system was used frequently by dietitians when working with people with type 1 diabetes, but used much less frequently for persons with type 2 diabetes (27). Participants in the key informant survey identified a lack of culturally appropriate diabetes resources, particularly in the area of food and nutrition and programs for Aboriginal people. Also, for Aboriginal people, interactive learning, whether one-on-one or in small groups, may be received better when support workers or educators are Aboriginal.
In British Columbia diabetes education is provided to clients through a network of approximately 85 diabetes education centres (DECs). These centres provide diabetes education and demonstrate how to perform blood-glucose tests. People who obtain a certificate from a teaching centre are eligible for reimbursement of blood-glucose monitoring strips through Pharmacare. Some education centres offer services for particular ethnic groups (i.e., Indo-Canadian, and South Asian and Chinese Canadian).

Many survey informants agreed that the strength of these centres lies in the multidisciplinary team approach. The team includes a medical director (family physician or endocrinologist), a nurse, a dietitian, and in some cases a social worker, physiotherapist and pharmacist. The number of DECs has increased in recent years, providing service to an increased number of communities and ethnic groups. A large proportion of these centres are hospital-based, others are located in the community. Some informants working with community based DECs felt that their programs were enhanced by their location, because they had a health, rather than an illness focus and people were more likely to self-refer. Others felt that their DEC benefited by being associated with a hospital as they had ready access to labs, physicians and other services.

All DEC informants identified significant wait list increases and very little time for follow-up or community outreach. Wait list times varied from 1 to 6 months. In addition, lack of services for rural and remote communities was identified as a problem. Lack of access is a function of the unavailability of services and the difficulties due to costs and transportation problems that people have when travelling to a DEC.

The Ministry of Health provides partial funding to Dial-a-Dietitian. This non-profit service provides nutrition information in four languages to all British Columbians via a 1-800 number. The 1998/99 Dial-a-Dietitian annual report found that of the 30,716 nutrition questions received that year by callers, 42% were from callers seeking therapeutic nutrition information for conditions such as diabetes and heart health (29). Many of the diabetes-related calls were made by people who were on a waiting list for their first appointment with a DEC dietitian and were seeking nutrition information in the interim.

There were several calls by survey participants for a review of the Pharmacare certification program to determine whether it is in the best interests of people with diabetes. Some diabetes educators felt that the time spent on the re-certification program could be better utilized and the program as a whole could be more sensitive to the needs of individuals. Also they stated that the re-certification does not appear to work with younger clients and may be difficult for the house bound frail elderly to access. Other informants felt that the re-certification program was valuable because it “keeps people in the loop”, by encouraging people to return to the DEC.
Four of the key informants also criticized the Diabetes Review (the process by which the DECs are certified), saying that it was too slow and too rigid, lacking an understanding of the challenges of programs operating outside large centres. One person said that the review process was too geared to hospital based service delivery. It was also suggested that the Canadian Diabetes Association Recognition Program replace the current review process. The Program is an external national peer review and is based on how well the DEC meets the Canadian standards for diabetes education. Centres collect data for 6 months to a year and submit the data for a blinded peer review.

**Health Professional Development**

Informants thought that there should be greater support for professional development and education. Several recommended that education become more of a provincial and regional priority, particularly to ensure that the standards of care are well understood and implemented. Cost of education is an ongoing and significant issue for almost all the informants. These informants said they either have to pay for education themselves or accept sponsorship from pharmaceutical companies.

**Children and Families**

Children most commonly have type 1 diabetes, however, type 2 has also been found in children. One informant stated that the incidence of both types of diabetes is increasing in children. Studies show that the longer the duration of the disease, the more likely it is that serious complications will develop. Although people with type 1 diabetes account for only about 10% of the total cases of diabetes, these people will represent approximately 50% of those who develop life-threatening complications such as kidney, eye and nerve disease (13).

BCCH is the primary B.C. diabetes treatment centre for children with type 1 diabetes, providing care and support for over 900 children and adolescents and their families. Patient loads at BCCH are increasing. The frequency of return visits has decreased from four to nine months because of patient loads. The Capital Health Region (CHR) also provides care and outreach to over 100 children and youth.

Children with type 1 diabetes face some particular challenges. Informants identified care at school as a problem, as schools need to be educated in their role and responsibilities in caring for these children. It was also suggested that there needs to be greater attention to the support needs of families who have children with diabetes. Three informants said that the most common complaint of families is the cost of the disease (costs include medication, food costs for “ready to eat foods” and difficulty obtaining daycare). As well, it is common for parents
to undergo grief and loss when their child is diagnosed with diabetes. The importance of support for families in these situations was brought forward.

A number of informants spoke about the gap between pediatric and adult services. Young adults may be lost to the system during this transition time and not re-enter it until they have developed complications of the disease. Cost of medications and glucose monitoring strips were identified as an issue for youth living on limited incomes.

Informants felt that children with type 2 diabetes get very little attention in the acute care system. Informants advised that linkages with public health and schools need to be forged to encourage these children in weight control, nutrition and exercise.

A recent study found that prolonged exclusive breast feeding reduced the risk of being obese or overweight among school aged children in Germany (30). Preventing childhood obesity and its consequences may have an impact upon the risk of developing type 2 diabetes later in life. Experts also believe breastfeeding may partially protect against the later development of type 1 diabetes.

Best Practices

There is very little information in the literature on “best practices” regarding diabetes. There is substantial research on treatment and care of diabetes and emerging literature regarding professional practice guidelines. Population health based programs for diabetes prevention are in the very early stages of development and implementation. The “Clinical Practice Guidelines for the Management of Diabetes in Canada” (5) stand as guidelines for best practice in screening and medical care of diabetes in Canada. There is no information on “best practices” for primary prevention of diabetes.

In B.C., key informants stated that most of the proof of what is or is not working in diabetes care and education appears to be based on anecdotal evidence or expert opinion. The most frequently cited information was individual client data (e.g., HbA1C improvement, weight loss, changes in diet and exercise), chart audits demonstrating a decrease in the overall numbers of hospital admissions relating to diabetes, and client satisfaction with services. A few informants said that they did not have any outcome evidence to demonstrate that what they do makes a difference.
Conclusions

The following conclusions are based upon the available literature and upon information and ideas from the key informant survey.

1. A provincial diabetes strategy should be broad based, include a long term vision of chronic disease care and be accompanied by sufficient funding for implementation and coordination. Development of such a strategy should include consultation with a wide range of stakeholders including people with diabetes and their families, Aboriginal people and representatives from non-governmental agencies and health authorities (i.e., diabetes education centres and public health).

2. There is a great need for data and research at the national, provincial, regional and community level regarding diabetes incidence and prevalence, costs, and effectiveness of diabetes education and treatment. Research and information regarding diabetes in Aboriginal (“on-reserve” and “off-reserve”) and other ethnic groups is needed.

3. There are few instances of regional planning for diabetes health services. Many informants felt that there is a need for a holistic continuum of care approach for diabetes services.

4. There is little or no planning and coordination of primary prevention of type 2 diabetes. Strategies for primary prevention that involve a wide range of stakeholders are needed, including: people who have diabetes and their families, public health, diabetes education centres, schools, recreation centres, media, physicians and community groups.

5. Early identification and treatment of diabetes significantly reduces the risk of developing complications or postpones the development of diabetic complications. Therefore, screening of high-risk groups may be cost effective.

6. Access and continuity of care are major issues for many remote and rural communities. Strategies that address this problem are needed.

7. Diabetes education centres are experiencing a significant increase in demand for services. Many have long waiting lists. As the population ages and the prevalence of type 2 diabetes increases, this problem will worsen.

8. Diabetes education centres need a plan for evaluation of effectiveness. Diabetes programs could be better tailored to meet the needs of clients if effectiveness was better understood.
9. Accessible, culturally relevant and community based diabetes services and programs need to be further developed for Aboriginal people and other ethnic groups.

10. Education for health care workers and professionals needs to become a provincial and regional priority, particularly to ensure that standards of care are well understood and implemented. Education sessions could be supplemented through the use of electronic technology.

11. The “Guide for Physicians in Determining Fitness to Drive a Motor Vehicle” is a resource to assist physicians determine whether a patient’s medical condition (i.e., diabetes) could place the individual or the public at unacceptable risk. Similar guidance may be required for other health professionals regarding their role and responsibilities.

12. Many key informants requested a copy of the report, including the literature review and summary of the interviews. It is suggested that a copy of the full report be put onto the Ministry website for easy access. Those without computer access may require a hard copy.
References


Appendices

(Appendices are attached under separate files)

Appendix A  Diabetes Literature Review

Appendix B  Diabetes in B.C. Report of Key Informant Interviews

Appendix C  Key Informant Interview Guide
APPENDIX A

Diabetes in British Columbia Literature Review Report

Prepared For

British Columbia Ministry of Health & Ministry Responsible for Seniors

Prepared By

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Introduction

The following literature review is one component of information being assembled to support the Ministry of Health and the Ministry Responsible for Seniors work towards a provincial diabetes strategy. Relevant literature on the effectiveness and cost-effectiveness of diabetes prevention and control strategies, policies, programs and services, including identification of best practices or relevant models for determining best practices is included. Also included is a brief overview of diabetes incidence, prevalence, complications, risk factors and the burden of disease. Primary, secondary and tertiary prevention and Canadian policies and research are reviewed. A glossary is provided with the literature review. The literature review also includes a reference list and a list of relevant web sites, including a brief description of each site as well as reports of interest.

What is Diabetes?

Diabetes mellitus is a chronic disease characterized by hyperglycemia (high blood sugar), due to an absolute or relative insulin deficiency. Insulin, a hormone secreted from beta cells in the pancreas, assists with the conversion of glucose into energy. Without insulin, glucose cannot be sufficiently absorbed from the bloodstream into the cells of the body. Diabetes is classified as:

**Type 1 diabetes** (previously called insulin-dependent diabetes mellitus (IDDM) or juvenile-onset diabetes) may account for 5% to 10% of all diagnosed cases of diabetes (1). Type 1 diabetes is diagnosed primarily in childhood or adolescence, but may be diagnosed in adults. Multiple daily injections of insulin are required for survival. The most common form of type 1 is caused by autoimmune destruction of beta cells, resulting in an inability of the pancreas to produce insulin. Risk factors are less well-defined for type 1 than for type 2 diabetes, but autoimmune, genetic and environmental factors are involved in the development of this type of diabetes.

**Type 2 diabetes** was previously called non-insulin-dependent diabetes mellitus (NIDDM) or adult-onset diabetes. Most commonly, type 2 diabetes begins after age 40. However, in many countries a growing number of children and adolescents are diagnosed with type 2 diabetes (2,3,4).

The onset of type 2 diabetes is a two-stage process: first, there is resistance to insulin’s action often exacerbated by obesity; secondly, the pancreas fails to increase insulin production enough to compensate adequately for the resistance. Type 2 may account for about 90% to 95% of all diagnosed cases (1). Risk factors for type 2 include age, obesity, family history of diabetes, prior history of gestational diabetes, impaired glucose tolerance, physical inactivity and race/ethnicity.
**Gestational diabetes** is defined as glucose intolerance first recognized during pregnancy. Usually this form of diabetes is a transient condition that disappears by six weeks post-partum (2). Gestational diabetes develops in 2% to 5% of all pregnancies (1). Risk factors include race/ethnicity, age, family history of diabetes and obesity. Women who have had gestational diabetes are at an increased risk for developing type 2 diabetes later in life, their children may also have an increased risk of childhood obesity and diabetes as adults (5). In some studies nearly 40% of women with a history of gestational diabetes eventually developed diabetes in the future (1).

Other types of diabetes result from specific genetic syndromes, surgery, drugs, malnutrition, infections and other illnesses. These types may account for 1% to 2% of all diagnosed cases of diabetes (1).

**Incidence and Prevalence**

There are an estimated 60,000 new cases of diagnosed diabetes (type 1 and type 2 combined) every year in Canada (2). This is an incidence rate of 2.6 new cases per 1,000 people among those aged 12 and over each year. There are no national incidence data separating type 1 and type 2. A 1996 Manitoba study reported an annual incidence rate for type 1 of 20.4 per 100,000 for children aged 0-14 (6).

Surveillance data from the U.S. indicate that both the incidence and prevalence of diabetes (type 1 and type 2 combined) are increasing (7). In 1985 the World Health Organization estimated that 30 million people worldwide had diabetes, by 1989 this figure had risen to 50 million people (6). Currently, the World Health Organization estimates that between 1995 and 2025 there will be a 35% increase in the worldwide prevalence of diabetes (8).

In Canada, current estimates based on self-reporting indicate that 3.2% of the population has diabetes (2). However, assuming similar rates of diabetes in Canada and the U.S. and indications that large numbers of people with diabetes remain undiagnosed, these estimates may substantially underestimate the actual prevalence. Based on 1996/97 Canadian survey data and extrapolations from American sources, the number of Canadians aged 12 and over with diabetes is estimated at 1.2 to 1.4 million (4.9% to 5.8% of the population aged 12 and over) (2). A recent report estimates that at least six percent of Ontario’s population has diabetes (9).

In the general population (aged 12+ years) in Canada, diabetes prevalence is significantly higher among males than females, 54% of those reporting diabetes are male, and 46% are female (2). The higher level of obesity among Canadian males may explain this higher diabetes prevalence (2).
Prevalence rates of diabetes also increase with age. The rate in those aged 65 and over is three times as high as the rate in those aged 35 to 65 (2). Prevalence of diagnosed diabetes (not including the probable large numbers of undiagnosed cases) in the Capital Health Region (Victoria, B.C.) was recently estimated as 4.12%. Age-specific prevalence ranged from 0.35% in the 5-9 year age group to 12.6% in the 85-89 year age group. Age/gender-specific prevalence indicated a significantly higher prevalence in older males (14.2% in males 65 and over) compared to females (9.8% in females aged 65 and over) (10). The CHR report concluded that this prevalence rate is likely to increase as the population of Victoria ages.

The incidence and prevalence of diabetes show major differences among countries and among ethnic groups living in the same geographic area (11). In Canada, Aboriginal people have a higher rate of diabetes prevalence than non-Aboriginals (12). Service providers in B.C. also report a high prevalence of diabetes in the South Asian people, but there are no published reports supporting this experience (13).

The age-standardized prevalence of diabetes for Aboriginal people in Canada is estimated to be at least three times that of the general population. Both the First Nation and Métis people have a higher prevalence while the Inuit people have rates currently below the national average (12). The “Background Paper for the Development of an Aboriginal Diabetes Strategy” includes both on-reserve and off-reserve people. It reported that approximately two-thirds of those people diagnosed with diabetes are women (12). In B.C. on-reserve data for Status Indians indicate that the rates for men are 2.0% (of all males) and for women are 2.6% (of all females) (14).

Diabetes rates for Aboriginal Canadians vary from province to province and from community to community. Extremely high rates have been documented in specific communities. Rates among women aged 35+ were between 22% and 48% in two Algonquin communities in Quebec (12). In Haida Gwaii, B.C., 17% of adults over the age of 35 had type 2 diabetes (15). Sandy Lake, Ontario reported age-adjusted rates of 26% for its population aged ten and over, and a prevalence of 54% for women age 50-59 (16).

**Risk Factors**

Risk factors for type 1 diabetes include: race and ethnic background (rates are higher among non-Hispanic whites than blacks or Hispanics in the U.S), age (incidence increases with age through childhood and adolescence and decreases during adulthood), geography (highest rates are found in Scandinavia, intermediate rates in Canada and low rates in Japan), and family history. Type 1 diabetes affects males and females equally (2). There are possible links to diet
and exposure to viruses (2). It has also been hypothesized that early exposure to cow's milk (or lack of breastfeeding) predisposes children to type 1 diabetes, however, this remains controversial (17).

Age, ethnicity, gender, family history and previously diagnosed gestational diabetes influence the risk of type 2 diabetes. The incidence of type 2 diabetes progressively increases with age. Glucose tolerance deteriorates with age resulting from tissues being unresponsive to insulin (11). Aboriginal people have a prevalence rate of type 2 diabetes approximately three times that of the general Canadian population (12). Gender differences in the prevalence and incidence of diabetes vary among ethnic groups. There is also evidence of a genetic risk factor for type 2 diabetes. Twin and family studies have shown a strong aggregation (11). Women who have had gestational diabetes are at increased risk for later development of type 2 diabetes (2).

**Modifiable Risk Factors**

The main modifiable risk factors for type 2 diabetes are obesity and physical inactivity. The relationship between obesity and diabetes is one of the oldest and best-known associations in medical history. Eighty percent of people with type 2 diabetes have been found to be obese (11). Physical inactivity reduces insulin sensitivity and decreases glucose tolerance. Studies have concluded that regular exercise protects against type 2 diabetes (11,18).

Other risk factors for type 2 diabetes have been less clearly demonstrated. These factors include: diet, socio-economic status, modernization or westernisation and physical and emotional stress (11). A high caloric intake, the consumption of certain types of foods (sugar, fat, refined carbohydrates) and a diet low in fibre and high in saturated fat have all been associated with decreased insulin sensitivity and abnormal glucose tolerance (11).

Income level is associated with the risk of developing diabetes. For people aged over 35 years, those with diabetes are more likely than those without diabetes to have lower levels of income adequacy (2). The cost of purchasing nutritious food on a fixed income was found to be a concern in one group of people with diabetes (19). Stress affects glycemic control and may be a risk factor for diabetes (11,12).

Westernization or modernization has been used as a partial explanation for trends in diabetes frequency in some ethnic groups (11,19,20). Abandonment of traditional lifestyles (including hunting/ fishing/ gathering) and the associated decrease in physical activity and increased reliance upon less nutritious alternatives to traditional foods is associated with an increased prevalence in obesity (21). Two recent surveys found that the strongest predictor of variation in diabetes prevalence among Aboriginal populations was latitude, with the
prevalence of diabetes increasing along a north-south gradient. The authors postulated that higher prevalence of type 2 diabetes within Aboriginal communities in more southern areas of Canada may be associated with greater changes in traditional lifestyle (19,20). In B.C., as well as a north-south difference in diabetes prevalence, there is a west-east gradient, with coastal Aboriginal people having a higher prevalence of diabetes than those in the interior (14).

A recent study found that prolonged exclusive breast feeding reduced the risk of being obese or overweight among school aged children in Germany (22). Preventing childhood obesity and its consequences may have an impact upon the risk of developing type 2 diabetes later in life.

A recent review of over 200 studies examined the relationship between cigarette smoking and diabetes. The authors concluded that smoking significantly enhances the risk of cardiovascular disease, neuropathy and nephropathy in people with diabetes. They also found that smoking influences several factors that may increase insulin resistance and interfere with insulin action, and quoted some preliminary evidence that smoking may be associated with the development of type 2 diabetes (23).

**Mortality and Morbidity**

In Canada in 1996, there were 5,447 deaths for which diabetes was certified as the underlying cause. This ranks diabetes as the seventh leading cause of death in Canada. However, the actual number of deaths for which diabetes was a contributing factor is probably five times this number. People with diabetes usually die from complications of the disease (i.e., cardiovascular disease and kidney failure) and it is these complications that are in most cases coded as the underlying cause of death (2).

U.S. data from 1994 list diabetes as the seventh leading cause of death among whites, African-Americans, Chinese Americans and Filipino Americans; as the sixth leading cause of death among Japanese Americans; the fifth leading cause of death among Hawaiians; and as the fourth leading cause of death among Native Americans (7).

The 1996 age-standardized mortality rate for diabetes in Canada is 16.8 per 100,000 population. Age-standardized mortality rates have increased since the early 1980s. This increase in mortality rates is probably due to an increase in the incidence of diabetes. Projections of diabetes mortality trends into the year 2016 show an exponential increase in the number of diabetes deaths among males and a more linear increase among females (2).
Diabetes has a significant impact upon daily living because of the high risk of complications. Diabetes is the cause of vascular complications, which affect the retina, heart, kidneys and nervous system and can lead to cardiovascular disease, hypertension, stroke, impaired vision, kidney disease, amputations, and an increased risk of infection.

Studies have shown that the risk of hospitalization in people with diabetes is twice that of persons without diabetes (11). People with diabetes in all age groups reported more frequent visits to medical doctors in the previous year than did those without diabetes (2). The highest difference was in the 35 to 64 age group, in which people with diabetes reported an average of seven visits to a family doctor in the previous 12 months compared with an average of three visits by people without diabetes (2).

Canadian data on the complications of diabetes are limited, however, it is known that approximately 21% of people with diabetes (compared to 4% of people without diabetes) have heart disease or are suffering the effects of stroke (2). The greatest difference is in the 35 to 64 age group, in this group people with diabetes are six times more likely to have heart disease or stroke than those without diabetes (2).

Diabetes causes diabetic retinopathy, which is the leading cause of adult-onset blindness in North American adults. People with diabetes in the over 65 age group report significantly higher rates of vision problems than do people without diabetes (2). These problems include cataracts, glaucoma and vision problems that cannot be corrected (near and far sightedness and total vision loss).

Diabetes can cause kidney disease (nephropathy) resulting in decreased kidney function, chronic kidney failure and the need for dialysis. Statistics from the Canadian Organ Replacement Register Annual Report 1998 (2) indicate an increase in the proportion of patients with newly diagnosed kidney failure who also have diabetes from 16% in 1981, to 28% in 1996. Again, studies have found that the prevalence of diabetic nephropathy is much higher in Aboriginal Canadians than in the general population with diabetes (12).

Diabetes can affect the nervous system. This manifests as an absence of reflexes and impaired nerve conduction, and usually involves pain and decreased sensation in the lower limbs. Estimates of how common this is among people with diabetes vary enormously, however, it is known that people with diabetes have a 15 times greater risk of lower extremity amputation than those without diabetes (2).

There are additional complications of diabetes. Periodontal disease occurs with greater frequency and severity among people with diabetes (2). People with diabetes are more likely to die of pneumonia or influenza than are people without diabetes (24). Major depression is at least three times more prevalent in people
with diabetes (12). Mental impairment occurs in elderly people with diabetes with greater frequency than in those without diabetes (11). Finally, self-perceived health status was much worse among those with diabetes than those without (2).

**Specific Population Groups**

**Aboriginal**

The prevalence of type 2 diabetes in the Aboriginal Canadian population varies significantly depending upon location, however it consistently remains higher than that seen in the general population (25). A Manitoba report states that among Status Indians, 20% of women and 13% of men have been diagnosed with diabetes (6). Most Status Indians with diabetes are less than 45 years old, whereas in the general population, most adults with diabetes are over 55 years of age (6).

In addition, prevalence rates of type 2 diabetes among Aboriginal people appear to be increasing. In Saskatchewan, Medical Services Branch data for on-reserve people showed an overall prevalence of 1.7% in 1980 and 3.0% in 1990 (20). Even if the incidence remains unchanged, the number of Aboriginal people with type 2 diabetes will triple in the next 20 years due to changing demographics. Currently 50 percent of the Aboriginal population in Canada is below the age of twenty. As the population ages the prevalence of type 2 diabetes will rise (20).

Aboriginal people also have very high rates of diabetes-related complications. In the Aboriginal population in Manitoba, persons with diabetes account for 91% of lower limb amputations, 60% of hospitalizations for heart disease, 50% of hospitalizations for stroke, 41% of hospital days and 30% of hospitalizations (6). First Nations adults with type 2 diabetes have a five-fold greater risk of end-stage diabetic renal disease than non-First Nations adults with type 2 diabetes (26).

In recent years, type 2 diabetes has been diagnosed in Aboriginal children as young as five to eight years of age in both northern Ontario and Manitoba (2,26). In British Columbia (B.C.), there are also service provider reports of type 2 diabetes occurring in Aboriginal children (27). The number of undiagnosed cases is predicted to be at least two times greater than the known cases. Because duration of high blood sugars is correlated with complications, there is a concern that this early onset of diabetes will lead to an increased risk of early onset of complications.

Existing data on gestational diabetes in Aboriginal peoples in Canada also give cause for concern. Studies have found the highest rate of gestational diabetes (8.4%) and the highest rate of development of overt diabetes after gestational diabetes (70% of women with gestational diabetes) in Canada in Sioux Lookout,
Ontario (2). In James Bay Cree women in northern Quebec the prevalence of gestational diabetes is twice as high as that among women of the general population (28), this increased risk appears to be due to a high prevalence of overweight among the Cree (29).

Seniors

Diabetes is largely a disease of age. By age 70, about 20% of people are diagnosed with diabetes (8). With the ageing of the population it is predicted that the prevalence of diabetes will have at least doubled between 1990 and 2010 (11). The risk of developing diabetes-related complications such as renal failure increases with age. Rates of hospital and nursing home admissions are significantly higher for people with diabetes (8).

Children

Children with diabetes include both type 1 and type 2 forms of the disease. Studies show that the longer the duration of the disease, the more likely it is that serious complications will develop. Although people with type 1 diabetes account for only about 10% of the total cases of diabetes, these people will represent approximately 50% of those who develop life-threatening complications such as kidney, eye and nerve disease (8).

Burden of Disease

There are little data on the socio-economic impact of diabetes in Canada. American figures for 1992 suggest that diabetes causes a highly significant burden of disease, accounting for approximately 1 out of every 7 healthcare dollars spent, or between $85 and $105 billion per year (30). In 1993 in Canada the economic burden of diabetes alone was estimated at $1.1 billion annually. However 1999 estimates indicate that the real economic costs in Canada may be as high as $9 billion annually when costs of illnesses associated with diabetes are included in the calculations (2). Any estimates are imprecise due to the problem of under-estimation of the true prevalence of diabetes (2). In addition, assessing the cost of diabetes involves direct medical costs as well as the indirect costs of increased morbidity, premature mortality and lost productivity, concepts that are difficult to quantify.

B.C. estimates of the costs for diabetes care are hampered by lack of data on the incidence and prevalence of diabetes. Also estimates of costs vary depending upon the type of cost included in the estimate. For example in 1995, Ontario total diabetes costs were estimated to be $203.4 million (31). This estimate included hospital costs for day surgery, physician payments, assistive devices,
laboratory costs, diabetes regional networks and the Southern Ontario Aboriginal Diabetes Initiatives, but did not include the cost of outpatient services (including dialysis), long-term care, diabetes education centres, chronic care in hospitals or hospital costs attributable to primary and secondary diagnoses (31). A 1999 estimate put spending on diabetes in Ontario at approximately $1 billion per year (9).

A 1998 report from Manitoba estimates the cost of services for adults with diabetes (hospital services, day care surgery, professional medical services, personal care home services and outpatient dialysis) as at least $193 million per year or $530,000 per day (6). The direct costs of diabetes in Prince Edward Island in 1999 were estimated as $25 million per year (32).

“Diabetes in the Capital Health Region” (An Analysis of B.C. Medical Services Plan Data 1995-1998) provided the number and cost of some medical services provided to people with diabetes in Victoria over a three year period (10). Among other statistics, this study found that chronic dialysis services for diabetic patients almost doubled between 1995/96 and 1997/98 and that over the three year period there were significant increases in the number of emergency and rehabilitation services provided to Capital Health Region residents with diabetes (10).

Primary Prevention

Type 1

In type 1 diabetes the process by which the pancreatic B-cells are destroyed is not well understood. However, several risk factors and immune-related markers are known that accurately identify many first-degree relatives of people with type 1 who will develop the disease (33). Investigators have now begun to explore the use of immune intervention therapy to halt or even prevent B-cell destruction in such individuals. The Diabetes Prevention Trial – type 1 (DPT-1) currently being conducted by the U.S. National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is testing the use of oral insulin capsules and insulin injection to prevent type 1 diabetes in people with moderate and high risk of developing the disease (34). These trials are being conducted internationally. Sites in Canada include: B.C. Children’s Hospital, Toronto Sick Children’s Hospital, Montreal Children’s Hospital, University of Calgary, University of Alberta, University of Manitoba, University of Western Ontario and Grace Health Centre in Halifax.
Type 2

Impaired glucose tolerance (IGT), obesity and lack of physical activity are all risk factors for type 2 diabetes. IGT is characterized by insulin resistance and the impairment of insulin secretion. It is believed that most people with type 2 diabetes pass through a pre-diabetic state of impaired glucose tolerance (IGT) before developing diabetes (35). A number of studies have shown that weight reduction significantly improves insulin sensitivity (36). Reduced physical activity has also been identified as an independent predictor of the development of IGT and type 2 diabetes.

A randomized control study in China (known as the Da Qing study) reported that institution of a lifestyle intervention (diet, exercise, or both) over a six year period led to a significant decrease in the incidence of diabetes among IGT women and men (37). These findings are supported by epidemiologic evidence comparing the risk of developing diabetes in active versus sedentary population groups (18,36). The 1998 “Clinical Practice Guidelines for the Management of Diabetes in Canada” (5) conclude that in view of the promising results of the Da Qing study, and the accepted value of weight control, diet and exercise in reducing cardiovascular risk, that these activities should be promoted.

Other studies have examined specific dietary factors (including saturated fat, sugar and fibre intake) as determinants of type 2 diabetes. Inconsistent results have been observed (38), and research continues in this area.

The use of various drugs to treat IGT and prevent the onset of type 2 diabetes is also being studied (39). The Stop-NIDDM Trial is currently studying the efficacy of acarbose in preventing or delaying the development of type 2 diabetes in a population with IGT. [See Chiasson (35) for a brief summary of the Stop-NIDDM Trial and studies of other pharmacological interventions.]

There are two major approaches to implementing strategies for the primary prevention of type 2 diabetes: the population-based approach and the high risk approach. The first attempts to reduce risk factors for diabetes over whole populations or communities, while the second strategy focuses on those individuals with a high risk of developing type 2 diabetes. The major interventions that have been proposed for use with high-risk groups involve alteration in lifestyle: weight reduction, increased exercise, dietary fat reduction and improved maternal nutrition during pregnancy. These interventions, sometimes accompanied by the use of pharmacological agents, have been used successfully with high risk groups in several studies (40).

Although there are limited data demonstrating the effectiveness of population-based interventions in the prevention of type 2 diabetes, evidence from populations with coronary heart disease (which shares common risk factors with diabetes) indicates the potential for this approach over the long term (41).
1999, Saskatchewan Health started an initiative called “Population Health Promotion Practice in the Primary Prevention of type 2 Diabetes” (42). Principles of this initiative include: striving for equity in health; working towards empowerment and public participation; and forming new strategic partnerships (42). Demonstration sites in Saskatchewan are currently applying for funding.

Simmons et.al. (40) have reviewed community-based programs which are directed at prevention of type 2 diabetes. These programs include: initiatives to reduce the fat intake of populations by directly influencing the food supply; New Zealand initiatives involving increasing exercise, nutrition and cooking sessions and diabetes awareness; and initiatives among First Nations people in Canada. A community-based diabetes education program for Nuu-chah-nulth people (including people with and without diabetes) was rated as very useful by participants and resulted in an enhanced understanding of diabetes (43). Food habits were also reported to be positively influenced. However, within the short timeframe of the study no significant physiological changes were observed in the enrolees (43).

Kahnawake Schools Diabetes Prevention Project is a primary prevention program for type 2 diabetes in Kahnawake, Quebec (44). It targets elementary school children, parents, teachers and the entire community. The program began in 1994 at the request of community elders. In 1997, the community provided funds to enable the program to continue after research funds ended, and in 1997 and 1998 the program expanded. As a result of the program, school canteens offered new healthy foods, there were increased opportunities for physical activity in schools and community awareness of diabetes was high. The authors conclude that a type 2 diabetes primary prevention program is feasible (44).

The Haida Gwaii Diabetes Project in B.C. focused on: developing a biopsychosocial profile of people with diabetes concerning how diabetes has affected them and what they think might be done to manage the problem; and using the findings to develop a culturally sensitive approach to prevention and management of diabetes. The project developed a list encompassing a wide range of implications for intervention (including use of traditional foods and medicines, exercise, acknowledging historical and political issues, etc.) (45).

Cost-Effectiveness of Primary Prevention

A recent study examined the cost-effectiveness of primary prevention programs for type 2 diabetes (46). Program types analysed included: group behavioural program, media campaign, general practitioner lifestyle advice, and intensive diet and behavioural programs. Target groups included: obese people, women with previous gestational diabetes, over-weight men and all adults. The group program for over-weight men and media programs were identified as extremely
worthwhile, generating estimated net savings in health care resources, while reducing diabetes incidence and extending life expectancy. The behavioural/diet programs for high risk groups were found to be highly cost-effective relative to other health care programs (46). The authors concluded that the primary prevention of type 2 diabetes can be highly cost-effective. Currently in the U.S. the Diabetes Prevention Program (DPP) is conducting additional cost-effectiveness evaluation of primary prevention of type 2 diabetes (47).

Secondary and Tertiary Prevention

The focus of secondary and tertiary prevention is to maintain the health of the person diagnosed with diabetes. This involves avoiding acute and long-term complications while maintaining or improving the person’s quality of life and her or his overall sense of well-being (5). Secondary prevention involves early identification of diabetes through screening to prevent or delay the progression of the disease (2). Tertiary prevention is aimed at delaying or preventing the development of complications in people who already have diabetes (2).

Screening

A U.S. study estimated the cost-effectiveness of screening for type 2 diabetes using a computer model (48). The study found that early detection and treatment resulted in postponement of diabetes-related complications and improvement in the quality of life. They also concluded that costs incurred due to screening and early treatment may be within the range of acceptable cost-effectiveness for U.S. health care systems, especially for younger adults and for some subpopulations who are at high risk of developing complications of type 2 diabetes (48).

The 1998 “Clinical Practice Guidelines for the Management of Diabetes in Canada” (5) recommend that all pregnant women should be screened for gestational diabetes if they are obese, over 25 years of age, belong to an ethnic group predisposed to diabetes, have a family history or previous history of diabetes, or have a history of giving birth to babies with a birthweight over 4 kilograms.

Symptoms of type 2 diabetes often do not show up until several years after the onset of the disease. A person may have had diabetes for up to 12 years before diagnosis (49). At the same time the risk of developing complications decreases significantly with early identification and treatment. A report by the Chief Medical Officer of Health for Ontario concluded that because of the relatively low overall rate of diabetes in the general population, mass screening is not cost effective. However, targeted screening for type 2 diabetes among people with identifiable risk factors was recommended (49). These risk factors include:
• obesity
• age 45 years and older
• a close relative with diabetes
• member of a high risk ethnic group
• a history of glucose intolerance
• a previous diagnosis of gestational diabetes
• high blood pressure
• cholesterol abnormalities
• the presence of diabetes-related complications

Prevention of Complications

Once the diagnosis of diabetes is made, treatment focuses on reducing blood glucose levels toward the normal range to reduce the risk of microvascular complications (kidney disease, eye disease and amputation) and improving lipid levels to reduce the risk of cardiovascular disease (5). Support for these goals comes from two landmark studies in the United States (U.S.) and United Kingdom (U.K.).

Reported in 1993, the U.S. Diabetes Control and Complications Trial (DCCT) compared intensive with conventional diabetes therapy with regard to their effects on the development and progression of early vascular and neurologic complications of type 1 (50). Conventional therapy consisted of one or two insulin injections daily. Intensive therapy was designed to achieve blood glucose levels as close to the normal range as possible with three or more daily insulin injections or treatment with an insulin pump (50). Patients were followed for a mean of 6.5 years. Intensive therapy was found to reduce the risk of developing retinopathy, kidney disease and neuropathy by a range of 35% to more than 70%, and reduced the development of hypercholesterolemia (50).

The United Kingdom Prospective Diabetes Study (UKPDS) was conducted with people with type 2 diabetes to see if any health improvements could be gained by intensively lowering blood glucose and blood pressure with pharmacological agents (51). This study began in 1977. Results were announced in 1998 concluding that if people with type 2 diabetes aggressively reduce blood glucose (using insulin) they can reduce their risk of developing blindness and kidney failure by 25%. If they also have high blood pressure and they aggressively reduce it, they lower their risk of having a stroke by 44% and the risk of heart failure by 56% (51).

A preliminary study examining the effects of changes in diet alone (in the absence of changes in exercise or other lifestyle changes) has had positive results. In this study, diabetic subjects consuming a low fat vegan diet over a twelve week period experienced a significantly greater reduction in serum fasting
glucose levels and a significantly greater weight loss when compared to the control group (52).

Other studies have examined the effects of physical activity on the development of diabetes complications. Physical activity improves insulin sensitivity and glycemic control, as well as inducing favourable changes in blood lipids (5).

A recent article reviewed the efficacy and barriers to lifestyle modification programs for obese adult diabetic patients. The authors concluded that despite the difficulties people have in maintaining long-term changes in diet and activity, lifestyle modification programs can be effective in helping obese people with type 2 diabetes to reduce their weight and improve glycemic control (53). Other researchers have proposed that the most effective treatment for type 2 diabetes will rely on dietary intervention, physical activity and the use of pharmacological agents (5,54).

Hypertension and cigarette smoking increase the risk of macrovascular disease for people with diabetes. One study found that smoking increases the risk for coronary events by a factor of 2.5 to 3.5 (55). Other diabetic complications including nephropathy, retinopathy and neuropathy are also adversely affected by smoking. Consequently, smoking cessation programs and treatment for hypertension are strongly recommended for people with diabetes (55).

**Education**

Teaching people with diabetes to manage their disease improves glycemic control, enhances self-care behaviours, decreases complications and lowers health care costs (56). According to the American Diabetes Association, self-management education is considered an essential component to diabetic care (57), yet data from the national Health Interview Survey revealed that only 43% of people with diagnosed diabetes ever attended a diabetes education program or class (56).

A recent study identified predictors of and barriers to using diabetes education programs (56). People most likely to attend were female, used insulin and had a high degree of obesity. Physician recommendation was also an important predictor of attendance. Barriers to attendance included: lack of awareness of programs, misperceptions about what programs involved, structural barriers (time, transportation, trouble reading) and health beliefs (low perceived seriousness of diabetes and fear and denial of diabetes). Strategies suggested for increasing attendance included: referrals to diabetes education centres by physicians to all patients with diabetes; information about the acute and chronic complications of diabetes given by physicians could increase the perceived seriousness of the disease; increased awareness on the part of physicians about the availability of diabetes education programs (56).
In B.C., certified diabetes teaching centres provide diabetes education and
demonstrate how to perform blood-glucose tests. People who attain a certificate
from a teaching centre are eligible for reimbursement of blood-glucose
monitoring strips through Pharmacare (a provincially based program). Indicators
of the success of this approach include lower diabetes-related hospital admission
rates in communities with a diabetes teaching centre compared to communities
without a centre and patient satisfaction with the program (58).

Effective diabetes education has been identified as a goal for Aboriginal
communities (12). Diabetes education and training programs are needed for
communities, high risk individuals, people with diabetes and health care
providers, however, the remoteness of many communities and the lack of
culturally sensitive material have been identified as hindrances (12).

Accessibility to diabetes education centres and material is an issue. An inventory
of diabetes services in southern Ontario indicates that the primary need for new
or outreach services in most communities will probably be for additional diabetes
educators, nurses and dietitians at the basic level of service, in community-based
agencies and hospital outpatient settings (59). In rural and northern communities
accessibility becomes an even greater issue. The lack of diabetes education
services and inaccessibility contributed to the north having the highest rates of
diabetes-related death and hospitalization in Ontario (9).

Diabetes education can also be a cost effective component of tertiary prevention.
A prospective randomized study in Arizona demonstrated a 67% reduction in the
incidence of lower limb amputation in a group of diabetic patients that received a
one hour education course on the care of the diabetic foot, over a group of
statistically similar diabetic patients that received no similar education (60). This
study indicates that complication-specific education given to patients with a
higher perceived degree of self-risk is an effective tool in prolonging the onset of
the given complication.

However, problems with existing diabetes education programs have been
identified. Muhlhauser and Berger (61) found that diabetes education programs
are often presented separately from pharmacological treatment. This creates an
artificial distinction between information about lifestyle (exercise and diet) and
blood glucose control, which results in patients who do not understand the
management of their own disease.

The efficacy of nutrition education resources have also been questioned. Focus
groups involving 266 dietitians from across Canada found that the Canadian
Diabetes Association resource the Good Health Eating Guide system was used
frequently by dietitians when working with people with type 1 diabetes, but used
much less frequently for persons with type 2 diabetes. The reasons most often
cited for not using the Good Health Eating Guide system were that it was too
complicated (especially for persons with type 2 diabetes), too costly, lacked flexibility for meal planning, did not incorporate the principles of carbohydrate counting very well, did not meet low literacy needs or did not incorporate special needs for complications associated with diabetes (62).

An American study indicated that most health care providers considered diabetes harder to treat compared with other conditions (63). A 1996 study reported that many professional caregivers feel unprepared or are too rushed to meet the educational, behavioural, and psychosocial needs of chronically ill patients and their caregivers (64). For secondary and tertiary prevention in diabetes to be effective, health care professionals may need assistance in making the shift from an acute to a chronic model of medical care and from the role of primary decision maker to that of teacher and facilitator (5). The Clinical Practice Guidelines for Managing Diabetes in Canada (5) suggest that this can best be done by the creation of a Diabetes Health Care team, an interdisciplinary team that provides comprehensive, shared care and of which the person with diabetes and his or her family plays a central role.

A recent British Columbia study also emphasized the positive impact of shared care. In a randomized trial, a group of people with sub-optimal glucose levels made arrangements for regular telephone contact with a diabetes nurse in addition to the typical standard care. Their HbA1c (glycosylated hemoglobin) values were compared to a statistically similar standard care group. The patients in the intervention group experienced a highly significant decline in HbA1c levels over the study period (65).

Cost Effectiveness of Secondary and Tertiary Prevention

Approximately half the expenditures for medical care for diabetes are for treatment of the metabolic condition (elevated blood glucose) and half the expenditures are for the treatment of chronic complications (66). Studies that examined the cost effectiveness of intensive therapy for diabetes (as practised in the DCCT and UKPDS studies) have found that intensive therapy for persons with diabetes uses more resources and is more expensive than conventional therapy (66,67). However, intensive therapy is associated with a lower incidence of costly chronic complications (68). Therefore, they conclude, that formal economic analyses have demonstrated that intensive therapy is cost-effective for the treatment of diabetes (6,67,68).

Diabetes NetCareSM is a comprehensive health care management program in the U.S. The program was designed to replicate the DCCT in a manner that generates savings, improves clinical outcomes and improves member and provider satisfaction in the short and long term (69). As part of the program physicians and hospitals are tracked for information on the volume, costs and outcomes of their diabetic patients. Support services (continuing medical
education, nurse training seminars etc.) are provided to physicians and hospitals. All patients are assigned to a diabetes nurse case manager who emphasizes self-management and proactively identifies those at risk for adverse events. The nurse case managers are also responsible for managing and integrating all the health care needs of their patients, not just those specifically related to diabetes. The program is supported by an infrastructure that includes an administrative team, a clinical team, a provider support team, a management team and an electronic tracking system. A retrospective analysis of Diabetes NetCareSM found that patients were more likely to get HbA1c tests, foot exams, eye exams and cholesterol screening while enrolled in the program. In addition, hospital admissions and bed days decreased when baseline data was compared to follow-up data. The researchers conclude that Diabetes NetCareSM achieved an economic savings of $50 (U.S.) per diabetic member per month (69).

Other studies looked at the cost effectiveness of diet intervention in the treatment of type 2 diabetes (70,71). Findings suggest that individualized nutrition intervention delivered by experienced dietitians could result in substantial improvement in glycemic control, delay of kidney dialysis and significant serum cholesterol reduction, resulting in savings of health care dollars (70,71).

Cost analysis of care for gestational diabetes has been determined by comparing the direct costs of diagnostic procedures and treatment used for outpatient management of gestational diabetes to the direct costs of maternal hospitalization, delivery of the baby and newborn care. The benefit to cost ratio was in favour of monitoring (diagnosis and treatment) gestational diabetes (72).

**Best Practices**

“Diabetes Mellitus” the 1999 publication of the Australian Health Ministers’ Conference states that: “In an era of evidence-based medicine, guidelines are becoming one of the critical links between the best available evidence and good quality clinical and public health practice for medical practitioners and nursing and allied health professionals. To be most effective, guidelines should involve key organizations and individuals in their development, and have specific mechanisms for dissemination and implementation. Their uptake should be evaluated, and their content reviewed and updated regularly.” (73). The Australian document then provides a list of current guidelines available for screening for diabetes, education of diabetes educators and care of people with diabetes.

Guideline development in Australia and other countries has focused on clinical practice. In Canada, the 1998 “Clinical Practice Guidelines for the Management of Diabetes in Canada” were developed and disseminated by the Canadian Diabetes Association and Canadian Medical Association (5). These stand as
guidelines for best practice in screening and care. In the U.S., similar guidelines exist for care of patients (57).

However, available evidence suggests that guidelines alone have little, if any impact on chronic care (64). Medical care often fails to include intervention components that contribute to more effective self management of the disease by the patient. Physicians often fail to gather information about the patient's ability to function, understanding of illness or insights into self management and do not ensure that patients receive education and support services or share experiences with others. As well, there is wide variation in available standards in medical care of patients with chronic illness, including physicians failing to adhere to guidelines and the system being set up to deal with more acute illness and urgent care (64).

A 1996 review found that literature evaluating interventions to improve outcomes in chronic illness tends to focus on specific elements in the overall care of the patients (examples include, a provider educational program, a computer reminder system, a patient education activity), while more comprehensive efforts to develop or reorganize medical care systems for chronically ill people are much less common (64). This review looked at three models which had been used (randomised intervention trials testing drugs or specific therapies (e.g. the DCCT), organized programs of care for a given chronic illness, and efforts to improve care of patients in western European countries). The organized programs of care included specialized clinics for reduction of hypertension that employed physicians and other health care professionals and emphasized behavioural change and regular follow-up. In Britain changes to general practice involved the introduction of “miniclinics” or “clinic days” which were devoted to specific chronic diseases. The review authors found that in all three models improved patient outcomes were a result of five general common elements:

1. the use of explicit plans and protocols;
2. the reorganization of the practice to meet the needs of patients who require more time, a broad array of resources and closer follow-up;
3. systematic attention to the information and behavioural change needs of patients;
4. ready access to necessary expertise; and
5. supportive information systems (also see Figure 1 below).
Other attempts to look at best practice for diabetes have also focused on care of the disease. The Cochrane database for best practice reviewed five trials comparing outpatient hospital versus general practice care for people with diabetes (74). The reviewers concluded that unstructured care (defined as the lack of a system of review and surveillance of complications by general practitioners) in the community was associated with poorer follow-up, greater mortality and worse glycemic control than outpatient hospital care (74). Computerized central recall with prompting for patients and their family doctors, can achieve standards of care as good or better than hospital outpatient care, at least in the short term (74).

There is very little information in the literature on evidence-based practice in prevention of diabetes. Currently in Saskatchewan, projects looking at population health based prevention programs may provide evidence of best practice in the future (42). Best practice information for the prevention of other major diseases, such as cardiovascular disease, is also in the initial stages of development (41).

**Research**

The Medical Research Council recently commissioned a study to investigate diabetes research in Canada and found that funding for this research had tripled in the years between 1983 and 1993, rising from $6.38 million to $20.77 million (75). The primary sources for this funding include the Medical Research Council,

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**Figure 1: Improving Outcomes for Chronic Illness(64)**

- **Guidelines**
  - **Evidence-Based, Planned Care**
    - **Practice Redesign**
      - Appointments
      - Roles
      - Follow-up
    - **Patient Education**
      - Self management
      - Behavioural Change
      - Psychosocial Support
      - Patient Participation
    - **Expert System**
      - Provider Education
      - Decision Support
      - Consultation
    - **Information**
      - Reminders
      - Outcomes
      - Feedback
      - Care Planning
Canadian Diabetes Association, Juvenile Diabetes Foundation, industry, and external agencies (including the U.S. National Institutes of Health). The Canadian Diabetes Advisory Board identified a lack of larger, long-term funding commitments suitable for applied research projects, particularly those that are longitudinal in nature with treatment interventions and evaluation spread over several years (75). The Canadian Diabetes Advisory Board also recommended two important areas for research: epidemiological (incidence and prevalence studies) and economic (cost benefit analysis of diagnostic and treatment approaches); and proposed strategies for developing research in Canada (75).

Several other jurisdictions have made recommendations for further diabetes research. Manitoba has developed goals to support diabetes research (6). Ontario has specifically recommended evaluation of services to assess the impact of diabetes, the effectiveness of diabetes programs and the cost in relation to health benefits (9). This evaluation includes: community needs assessments specific to Aboriginal people living both on and off-reserves; evaluating the effectiveness of existing Aboriginal-specific diabetes education services in reducing the incidence of type 2 diabetes and diabetes-related complications; continuing to support the development of the National Diabetes Surveillance System; pilot testing a disease management approach for care of seniors with type 2 diabetes living in Long Term Care Facilities; and identifying issues, gaps in services and access to diabetes education (9).

Priorities for three types of research were identified in the “Background Paper for the Development of an Aboriginal Diabetes Strategy” (12).

1. Descriptive studies which outline the prevalence and incidence of diabetes, impaired glucose tolerance, gestational diabetes and diabetic complications; and which describe socio-economic, cultural, spiritual and behavioural aspects of diabetes; and descriptions of innovative community programs.

2. Analytical studies evaluating diagnostic and screening methods and evaluation of existing health-service delivery systems.

3. Intervention studies looking at community trials of primary, secondary and tertiary prevention.

In Canada, a current major initiative is the National Diabetes Surveillance System (NDSS). This system is being developed by the Laboratory Centre for Disease Control of Health Canada, along with provincial and territorial governments, non-governmental organizations, academic clinicians and other federal agencies. In the short term, the NDSS will use existing administrative databases and record linkage to provide information such as the following:

- incidence and prevalence of diabetes;
• incidence and prevalence of diabetes complications; and
• utilization of health services.

In the U.S., two large clinical trials are currently underway (76). The Prevention of Cardiovascular Disease in Diabetes (PCDD) trial will study the benefits of intensified control of high blood sugar, cholesterol and hypertension. The Study of Health Outcomes of Weight Loss (SHOW) trial will focus on the benefits of weight loss in obese individuals with diabetes. These trials are being conducted under the auspices of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Heart, Lung and Blood Institute (NHLBI) (76).

Also in the U.S., a study called Translating Research into Action for Diabetes (TRIAD) is currently in the planning stages. This is a five year study to evaluate the structural and process barriers that prevent people with diabetes from getting top quality care and from following their physician’s recommendations for self-care (3).

Several studies of the efficacy of pharmacological agents in preventing or delaying type 1 and type 2 diabetes are also underway. The Stop-NIDDM Trial is an international study of the efficacy of the drug acarbose in preventing or delaying the development of type 2 diabetes in a population with impaired glucose tolerance (35).

Policy

As the growing prevalence and cost of diabetes have been identified, many jurisdictions are developing diabetes-related policies and plans. In 1999, Australia released a document outlining the scope of diabetes in that country (73). In Australia, future directions in diabetes will be shaped by the development and implementation of a National Diabetes Strategy. This Strategy will also set priorities for diabetes prevention, management and research.

Also in 1999, Canada released the document “Diabetes in Canada, National Statistics and Opportunities for Improved Surveillance, Prevention and Control” (2). This document adopted the 1996 Declaration of the Americas on Diabetes (DOTA), which proposed four Minimum Essential National Targets to improve the prevention and control of diabetes. These are:

1. Create a national focal point for diabetes program development;
2. Establish a national surveillance;
3. Create a national strategic plan for prevention and control; and
4. Set national and local targets.
The first national target has been achieved with the creation of the Diabetes Council of Canada (DCC), a coalition of diabetes-related non-governmental and federal government agencies (2). The second national target (to establish a national surveillance) is an initiative of the Diabetes Council of Canada. The National Diabetes Surveillance System (NDSS) is being developed by the Laboratory Centre for Disease Control of Health Canada. The third national target is being addressed through the current development of a discussion paper reviewing the relevant issues. The fourth and final goal will depend upon completion of the previous goals.

Provincial governments are also developing diabetes policies. In June 1996, Manitoba’s Minister of Health declared diabetes to be both a major public health issue and an epidemic among Aboriginal people and the elderly of all populations; in response, “Diabetes: A Manitoba Strategy” was released in 1998 (6). This strategy includes recommendations regarding the issues of prevention, education, care, research and support.

In June 1999, Prince Edward Island released a report entitled, “Diabetes in Prince Edward Island: Towards a New Approach”, which outlines a new model for a diabetes management program. Features of this model include:

1. Clearly defined roles and responsibilities for all stakeholders involved in managing diabetes;
2. Establishment of a comprehensive, coordinated and consistent approach to delivering diabetes services at the Regional level;
3. Improved access to the full range of diabetes education and management supports for individuals and family members; and
4. Ongoing training and education for individuals with diabetes, health care professionals and front line staff (32).

In 1995, Ontario released an Ontario Diabetes Strategy focusing on prevention of diabetes complications (59). In 1999 a “Diabetes Strategy Progress Report” was released (9). The 1999 Ontario report reviewed progress and challenges and outlined targeted approaches to strengthen existing strategy. Measurable improvements in access to and coordination of diabetes services were reported (9). Future initiatives will be directed at: complication management, strengthening innovative outreach initiatives in northern Ontario, assessing community needs specific to Aboriginal people on and off-reserves in southern Ontario, and focusing on pediatric diabetes (9). Specific recommendations in each of these four areas are contained within the report.

Also released in 1999, The Report of the Chief Medical Officer of Health of Ontario on strategies for diabetes prevention outlines an agenda for action with specific recommendations for individuals, communities, health care providers and
federal and provincial governments (49). The recommendations for individuals are:

1. Reduce obesity;
2. Increase physical activity;
3. Maintain a healthy weight;
4. Eat a healthy and balanced diet;
5. Develop an awareness of diabetes symptoms and screening guidelines;
6. Do not smoke if you have diabetes and reduce stress (49).

Recommendations for communities:

1. Boards of health must provide leadership;
2. Communities must promote physical activity, healthy eating and healthy weight; and
3. Communities must advocate that diabetes receive priority consideration in local health and education initiatives (49).

Recommendations for health care providers are:

1. Learn and adopt clinical practice and prevention guidelines for diabetes;
2. Educate clients about the prevention and treatment of diabetes;
3. Provide comprehensive and coordinated health care to prevent and lessen serious and long-term complications; and
4. Encourage aggressive anti-smoking education among people with diabetes as well as the general population (49).

Lastly, the Medical Health Officer’s recommendations to federal and provincial governments are:

1. Establish a tracking system for diabetes;
2. Ensure accessibility to diabetes care;
3. Create accessible resources to support diabetes education for clients, health care professionals, the public and policy-makers;
4. Provide consumer information on the content of all foods; and
5. Provide more funding for research projects in diabetes-related fields (49).

In July 1999, the Saskatchewan Ministry of Health announced a “Population Health Promotion Practice in the Primary Prevention of type 2 Diabetes” demonstration initiative. The purpose of this initiative is to reduce the risk conditions that contribute to the development of diabetes; create social and physical environments that enhance health choices; and enhance the ability of
individuals, families and communities to take action. The focus is on the population as a whole, including those in specific high-risk groups and those who are at low risk (42).

The Saskatchewan Ministry of Health has identified the following elements as critical for success:

- Community initiation of the program and continuous involvement in it.
- Awareness of the determinants of health.
- Formation of partnership with existing groups in the community.
- Ongoing long term support rather than a one time or short term intervention.
- Flexibility of the program to meet different needs.
- Making the intervention part of daily life rather than a special activity.
- Promotion of and supports for individual responsibility for self management.
- Offering financial and human resources to initiate new programs.
- Making changes in the physical environment which promote healthy lifestyles such as increased availability of good food and safe places for physical activity (42).

Aboriginal organizations are also developing diabetes policies. The “Background Paper for the Development of an Aboriginal Diabetes Strategy: Report of the Working Group” was released in 1998 (12). Goals and objectives were developed for each of four areas: prevention and education; care and support; research; and surveillance. The working groups adopted common principles as they developed their recommendations:

1. Comprehensive - encompassing all current and planned undertakings;
2. Collaborative - promoting linkages, cooperation and communication;
3. Balanced - balance of research, prevention and support;
4. Culturally sensitive - recognizing the spiritual, physical, mental and emotional aspects of diabetes;
5. Community-based - active participation of family and community.
Conclusions

Diabetes is a chronic disease that represents a major public health concern worldwide. Estimates are hampered by a lack of data, however available information indicates that the incidence and prevalence of diabetes in Canada is increasing. Age standardized rates of diabetes among Aboriginal peoples are triple those found in the general population. With an ageing population and increased rates of obesity, this trend is likely to worsen.

People with diabetes are at an increased risk of developing chronic complications related to ophthalmic, renal, neurological, cerebrovascular, cardiovascular and peripheral vascular disease. In Canada, the burden of diabetes due to health care costs, disability, work loss and premature death is estimated to be up to $9 billion annually.

There is substantial research on treatment and care of diabetes and emerging literature regarding professional practice guidelines. Population health based programs for diabetes prevention are in the very early stages of development and implementation.

Effective prevention and control measures are urgently needed to:

- target modifiable risk factors for diabetes such as obesity and physical inactivity;
- improve the treatment and management of diabetes; and
- delay or prevent debilitating complications.
References


27. Personal communication, Joan Johnson, Nurse Educator formerly with BC Children's Hospital Diabetes Education Centre and currently at the Lion’s Gate Hospital Diabetes Education Centre.


47. National Center for Chronic Disease Prevention and Health Promotion, Division of Diabetes Translation 1997 Program Review. [www.cdc.gov/diabetes/about.htm](http://www.cdc.gov/diabetes/about.htm) (taken from website Nov. 1999).


64. Wagner E, Austin B, Von Korff M. Organizing care for patients with chronic illness. The Milbank Quarterly 74:511-541, 1996.


Website References

Preamble

The internet data for this report has primarily been selected from regulated sites and includes professional peer reviewed reports. Any questions concerning the validity of internet data should be directed to the respective site. Available email addresses have been provided. (Information taken from Website Nov. 1999).

Reference Websites

Canadian

Canadian Diabetes Association

URL http://www.diabetes.ca/
Email info@cda-nat.org

Site Description:

Promotes the health of Canadians through diabetes research, education and advocacy. Provides news and information for health professionals, those living with diabetes, and the general public.

Reports of Interest:


Back to Their Roots: An Ontario Reserve’s Garden Project aims to improve the health of native Canadians with diabetes is an article that describes preventative health care initiatives taken by the members of the Six Nations Reserve. www.diabetes.ca/atoz/nat.htm

CDA/CSEM Professional Conference October 13 – 16 1999. Cassette tapes are available to order.

Diabetes Research and Treatment Center

URL  www.umanitoba.ca/outreach/drtc/index.html
Email  aangel@hsc.mb.ca

Site Description:

Site functions as an outreach center for people with diabetes. Videos on appropriate care can be purchased and information on conferences is displayed. Site also provides links to other diabetes web-sites and a diabetes specific search engine.

Reports of Interest:

International Conference on Diabetes June 3 – 6, 1999. A booklet of detailed abstracts from the conference is available if you make a formal request to DRTC.

Canadian Health Network

URL  www.canadian-health-network.ca/customtools/azindex.asp?
Email  not listed

Site Description:

This is a new and expanding network, intended to enhance public access to health information. Site provides access to articles written about diabetes from a wide variety of sources.

Reports of Interest:


First Nations and Inuit Health Programs

URL  www.hc-sc.gc.ca/msb/fnihp/diabet_e.htm
Email  not listed

Site Description:
Outlines diabetes as a serious health problem among Aboriginal people and describes some of the steps that have been taken to increase the awareness of diabetes among Aboriginal communities, such as the establishment of the National Aboriginal Diabetes Association (NADA).

**National Aboriginal Diabetes Association**

URL [www.nada.ca](http://www.nada.ca)
Email not listed

**Site Description:**

NADA is a non-government organization with official non-profit status The site has NADA’s mission statement, goals, current initiatives, resources and contact list.

**Za-geh-do-win**

URL [www.anishinabek.ca/zagehdowin](http://www.anishinabek.ca/zagehdowin)
Email manotnan@cyberbeach.net

**Site Description:**

An information clearinghouse that focuses on health, family healing and family violence for Aboriginal communities in Ontario. The information is free for residents of Ontario.

**Reports of Interest:**

Diabetes is a list of diabetes resources designed for Aboriginal people – booklets, videos, a catalogue for health care workers, as well as resources for use in schools. [www.anishinabek.ca/zagehdowin/diabetes.htm](http://www.anishinabek.ca/zagehdowin/diabetes.htm)

**Canadian Medical Association Journal**

Email pubs@cma.ca

**Site Description:**

Site provides access to articles printed in the Canadian Medical Association Journal. Articles are available to print for free and are available in [HTML] or [PDF].
Reports of Interest:

Insulin adjustment by a diabetes nurse educator improves glucose control in insulin-requiring diabetic patients: a randomized trial this small BC study, illustrates that insulin adjustment according to advice from a diabetes nurse educator is an effective method of improving glucose control in insulin requiring diabetic patients. www.cma.ca/cmaj/vol-161/issue-8/0959.htm

Health Canada

URL#2  www.hc-sc.gc.ca/real/diabetes/text.html#res
Email  bcrdd@hc-sc.gc.ca

Site Description:

The first site provides recent national statistics on diabetes - incidence and prevalence, morbidity/mortality, risk factors, prevention, aboriginal people, complications and data collection. The second site is a source page for diabetes information – signs and symptoms, risk factors, access to documents, food guide, and provides links to other sites.

Reports of Interest:


Monograph Series on Aging – related Diseases: VIII. Non-insulin-dependent Diabetes Mellitus summarizes basic information on type 2 diabetes and gives an exhaustive list of references. [PDF] www.hc-sc.gc.ca/hpb/lcdc/publicat/cdic/cdic171/cd171a_e.html

Health Minister outlines $115 million Canadian Diabetes Strategy is designed to inform Canadians, prevent diabetes as well as help people better manage the disease and its complications. The three priorities are prevention and promotion, surveillance, and national coordination. www.hc-sc.gc.ca/english/archives/releases/99_135e.htm

Government of British Columbia– Ministry of Health

URL  www.hlth.gov.bc.ca
Email  not listed

Site Description:
Reports of Interest:

Diabetes Strategy News release (November 30, 1999) announced the Government’s plans to develop a comprehensive diabetes prevention and control strategy for British Columbia. The plan is to co-ordinate the efforts of all diabetes programs in the province.

Protocol for Use of Glucose and HbA1C Tests in Diagnosis and Monitoring of Diabetes Mellitus This protocol determines benefits payable under the Medicare Protection Act. It was developed by the Protocol Steering Committee.

Government of Ontario – Ministry of Health

URL www.gov.on.ca/health/
Email not listed

Site Description:

Site provides recent provincial health news releases and some access to provincial health policies and publications.

Reports of Interest:

Government invests 3.3 million to help treat and prevent diabetes in children and adults this news release outlines how this funding will be spent, as well as looks at the accomplishments of the Ontario Diabetes Strategy to date. An agenda for strengthening the strategy is also highlighted. www.newswire.ca/government/ontario/english/releases/November1999/02/C0535.html

Government of Alberta – Health

URL www.health.gov.ab.ca/glance/index.html
Email not listed
Site Description:

This Ministry site provides access to its news releases, some access to provincial policies, and recent publications. There does not appear to be any specific reference to diabetes on the site.

Reports of Interest:

Best Practices – a Report of the Review of the Health Authorities reviews best practices and explains process and methodology, describes characteristics and criteria of best practices and gives examples of where best practices are being realized from a governance perspective.  

International

US Center for Disease Control and Prevention

URL www.cdc.gov/diabetes/  
Email diabetes@cdc.gov

Site Description:

A source for basic facts, diabetes-related press releases from CDC and the US Dept. of Health, as well as access to the weekly MMWR.

Reports of Interest:

MMWR: October 31, 1997 and October 29,1999.  Diabetes-specific articles in both these reports.  www2.cdc.gov/mmwr/


Meddling plus

Email ndic@info.niddk.nih.gov
Site Description:

Set up as a national diabetes information clearinghouse. Gives an overview of basic facts concerning diabetes. As well facilitates access to publications developed by NDIC and NIDDK such as: “Diabetes Dateline”, “Diabetes Dictionary”, and materials developed by NIH about diabetes research and care.

National Institute of Diabetes, Digestive and Kidney Diseases

URL www.niddk.nih.gov
Email Kathy_Kranzfelder@nih.gov

Site Description:

Introduces the NIDDK as a nation-wide initiative of the CDC and NIH. The NIDDK is working to form partnerships with organizations concerned about diabetes.

Department of Veterans Affairs

URL www.va.gov/health/diabetes
Email repke.denis@forum.va.gov

Site Description:

Gives a brief introduction to diabetes and several “snapshots”. Relatively simple information. Has the VHA Clinical Guidelines for Management of Diabetes Mellitus.

Indian Health

URL www.ihs.gov/IHSMAIN.html
Email gloria.lucero@mail.ihs.gov

Site Description:

Outlines articles and studies concerned with diabetes prevalence, care, and education in the aboriginal population.
American Association of Diabetes Educators

URL www.aadenet.org/
Email not listed

Site Description:
Basic home page, but access to some interesting publications.

Reports of Interest:
Standards of Diabetes Nursing explain what is necessary and expected among diabetic nurses to achieve the outlined standards of care for the diabetic patient. www.aadenet.org/whatsnew_frame.htm/

American Diabetes Association

URL www.diabetes.org/
Email customerservice@diabetes.org

Site Description:
Home page for ADA. Will find ADA news releases, diabetes related stories, basic diabetes information, link into advocacy, medline through Topicdoc, professional education and recommendations. Can access separate aboriginal site as well using www.diabetes.org/awakening

American Dietetic Association

URL www.eatright.org
Email permiss@eatright.org

Site Description: The American Dietetic Association (ADA) is a not for profit professional association and leader in serving the public through promotion of optimal nutrition, health and well-being. Members represent a wide range of practice areas and special interest. The Diabetes and Education Practice Group has its own site www.dce.org
Reports of Interest:

Fact sheet of Medical Nutrition Therapy - Medical nutrition therapy is the service a registered dietitian (RD) provides in many medical cases. It begins with assessing a patient’s overall nutrition status, followed by prescribing a personalized course of treatment.

Position of the ADA: cost-effectiveness of medical nutrition therapy
In July 1999, posted update of selected references and an update of the 1995 position paper is due out late 1999.

Australian Health and Aged Care/Population Health Division

URL www.health.gov.au

Email webmaster@health.gov.au

Site Description:
The mission of the Australian Health Department is to lead the development and implementation of health and aged care services policy to achieve Government policy and directions. In recognition of the impact that diabetes has had on the Australian community and in order to give it a higher profile in the health system, the Health Ministers agreed (July 1996) to make diabetes the fifth National Health Priority Area.

Reports of Interest:


The National Diabetes Strategy and Implementation Plan report was released in 1998 and the National Health Priority Areas Report on Diabetes Mellitus was presented to Health Ministers in July 1999.

National Health Priority Areas Report: Diabetes Mellitus report is part of a process that involves various levels of government and draws on advice from non-government sources, with the primary goal of reducing the incidence and impact of diabetes mellitus in Australia.
Glossary

Aboriginal - an Aboriginal person is anyone who, by ancestry, self-identifies as a First Nation, Metis, or Inuit. Here, First Nation includes Status Indian, as defined by the Indian Act, and non-Status Indians (i).

Auto-immune disease - caused by the production of antibodies to substances naturally present.

Care and Support - comprehensive care and support refer to the management of diabetes and is fundamental to the prevention and/or delay of both the short-term and long-term complications of the disease.

Culturally sensitive - policies that include diverse populations often aspire to providing both sensitive and appropriate programs and services. There is a wealth of published information that report on the concept and many different terms are used. However, there is no generally accepted definition for the various terms. In Vancouver, preliminary findings from Aboriginal focus groups suggest that sensitive care has to do with relationships that extend from a shared understanding of the effects of history on Aboriginal people and respect for life ways that are different. Culturally appropriate care is tangible, action oriented, and is founded on respect for diverse cultural practices (ii).

Demographics - study of births, deaths, disease etc. as illustrating life in communities.

Education - the purpose of diabetes education is to provide knowledge and increase skills necessary to reduce the incidence and prevalence of diabetes and its complications, and to improve the quality of life of people living with diabetes. Education programs may be targeted to diabetics and their families, the general public and/or health care providers.

Evidence-based practice - "best practice" that is ideally based on science derived from systematic observation, study, and qualitative and quantitative research. When there is insufficient evidence from science, expert opinion is used, or there is a combination of science and expert opinion (iii).

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Glycemic control - the degree to which a person with diabetes is able to control the level of glucose in their blood. The goal is to maintain blood levels of glucose as close to the normal range as possible.

Glycosylated hemoglobin (HbA$_{1C}$) – a value determined from a blood test that indicates general glycemic control for the previous three months.

Incidence – the number of new instances of illness commencing, or of persons falling ill, during a given period in a specified population.
Morbidity - amount of disease.

Mortality – death from a particular cause.

Obesity – the National Population Health Survey 1996 (Statistics Canada) uses the following criteria for levels of obesity: (a) “some excess weight” = Body Mass Index 25-27, and (b) “overweight” = Body Mass Index >27. The U.S. National Institutes of Health uses the following criteria: (a) “overweight” = Body Mass Index 25-29.9, (b) “obesity” = Body Mass Index 30-39.9, and (c) “extreme obesity” = Body Mass Index >40.

Policy - a set of inter-related decisions taken by an individual or group concerning the selection of goals and the means of achieving them within a specified situation. The decisions extend from generally accepted ideas, values, and purposes. It involves the structuring and exercise of power and influence to achieve desired results with scarce resources. And, it describes processes that may apply within a changing environment (iv).

Prevalence – the number of existing instances of a given illness, at a given time, in a specified population.

Primary Prevention – a focus on reducing the modifiable risk factors of developing a disease. With type 2 diabetes primary prevention efforts are directed particularly at reducing obesity and increasing physical activity.

Secondary prevention - involves early identification of diabetes through screening to prevent or delay the progression of the disease.

Research – research is vital to understanding the nature of diabetes, reducing the burden of the disease and its complications, improving the quality of life of people with diabetes and reducing its economic and social costs.

Tertiary prevention – is aimed at delaying or preventing the development of complications in people who already have diabetes.
APPENDIX B

Diabetes in British Columbia
Report of Key Informant Interviews

Prepared For
British Columbia Ministry of Health &
Ministry Responsible for Seniors

Prepared By
Mollie Butler, Kate Ney,
Rhea Joseph & Sandra Marquis

August 2000
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1. Introduction

The Report of Key Informant Interviews is the second component of information being assembled to support the Ministry of Health and the Ministry Responsible for Seniors (hereafter called the Ministry) work towards a provincial diabetes strategy.

This report is a summary of the findings from key informant interviews and two conference calls. A Synthesis Report of a literature review and the interview findings is provided under separate cover. The Literature Review is attached to the Synthesis Report as Appendix A. This report is attached as Appendix B and a Key Informants Interview Guide is attached as Appendix C.

2. Methodology

This study is based on the collective expert opinions of 24 key informants from across B.C. Other expert opinions were also gathered during two conference calls with the Community Nutritionists Council and Public Health Nursing Leaders Council.

The objectives of the key informants study were to:

1. provide an overview of current British Columbia diabetes policy and services and as well identify gaps; and
2. identify and build on key elements of best program and policy practices related to diabetes.

2.1 Selecting Key Informants

Potential informants were selected by the Ministry Diabetes Working Group to fit the following criteria:

- based in British Columbia;
- work in the field of diabetes as an educator, service provider, academic, researcher (clinical or policy focus) and/or advocate;
- could speak about type 1, type 2, and/or gestational diabetes;
- represented specific geographic (north versus south) and health authority perspectives.

The primary responsibility of the 24 people interviewed was as follows:

- Fourteen are service provider/diabetes educators (physicians, dietitians, nurses, social workers);
- Two are researchers;
• Two work in policy;
• One is an advocate; and
• Five spoke to Aboriginal issues, three of whom are Aboriginal people.

The Ministry project manager personally contacted the informants to explain the purpose of the interview and seek their agreement to participate. One person declined but recommended a replacement. The final group of 24 names and contacts details were given to the consultants.

2.2 Key Informant Interviews

The interview questions were pilot tested in December (1999). Following the pilot interview, the informant was also asked to evaluate the guide and interview questions. As no substantive changes were recommended, the data were included in the analysis.

A covering letter and the “Key Informant Interview Guide” were sent by the Ministry project manager to the informants. The guide included a brief background summary, the project objectives and a series of open ended interview questions (see Appendix C). All informants were encouraged to review the questions and where feasible to ask colleagues for their input before the interview.

Interviews were via telephone late in January and early February 2000, taking approximately 45-60 minutes. The interviews were tape recorded (with permission of the interviewee) to ensure accurate capture of data.

2.3 Conference Call Interviews

Two telephone conference interviews were also conducted, one with the provincial Community Nutritionists Council and the other with the Public Health Nursing Leaders Council. Prior to these calls, an email was disseminated by the Ministry project manager, explaining the purpose, providing the questions and encouraging broad participation. Public health participants were asked three questions: What is working well to support best health outcomes? What is not working? and Suggestions to address these challenges? These conference interviews helped to broaden the scope, particularly in relation to primary prevention.

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2 Please note after the guide had been distributed, the Ministry Diabetes Working Group concluded it was too premature to develop recommendations. Instead the Working Group asked for a set of conclusions to be included in the Synthesis Report.
2.4 Strengths and Limitations

Planned interviews are an excellent way to quickly gather broad-based information from a diverse and geographically disperse group of experts. In addition, they provide an opportunity to clarify responses and a rich contextual background for understanding issues presented. On the other hand, there are limitations and potential biases inherent in this form of data gathering, for example:

- the sample size was small;
- not all health authorities were represented;
- information was gathered in two slightly different ways (individually and group) and clearly the two stimulate ideas differently. In a group there may be further bias by the mixture and degree of familiarity within the group;
- informants were primarily service providers/diabetes educators, or public health;
- four informants disclosed they (or a member of their family) have diabetes, however, they were not chosen for this reason;
- no informants were selected to represent perspectives of people who have diabetes.

2.5 Data Analysis

Data from the interviews were analyzed and grouped under themes and sub-themes. The data provided snapshots of activities from across British Columbia, and a picture of what is happening did emerge. Once the initial analysis was completed the raw data were reviewed to ensure key messages and perspectives were incorporated. Further, a draft of the report was circulated to all informants to ask for feedback and confirm that their opinions were reflected in the draft. The next section highlights the findings, including the informants’ feedback.

3. Findings

3.1 Provincial Diabetes Strategy

Most informants seemed enthusiastic about a provincial diabetes strategy but stressed it should be based on a vision. Informants recommended the Ministry develop a long-term plan, building on the current consultation process. A few suggested the Ministry would do well to look elsewhere for ideas and learning (e.g., Alberta’s experience of running diabetes services out of the community, separating funding from the hospital system; Edmonton Aboriginal Wellness Center; Nova Scotia’s diabetes surveillance system; and Saskatchewan and
Manitoba’s respective approaches to diabetes). Others thought the strategy would not work unless it had “some teeth”, and was linked to an increase in funding. In particular, concern was raised about the erosion of diabetes education related to increase need/demand for services without additional resources to support them.

Several public health informants said planning and coordination are very labour intensive, requiring people with dedicated hours. Unless there is a clear direction, as well as adequate and sustained funding, expectations are raised and when nothing changes, frustrations grow. Several spoke about diabetes being the “disease of the month”, urging the Ministry to take a broad approach when planning and coordinating primary prevention.

There were numerous calls for involvement of people who are affected by diabetes, including parents and other family members in planning the strategy. One person also suggested the provincial strategy needs to be developed in the context of where the provincial health system has evolved, noting the health authorities would need to support the strategy as they are responsible and accountable for health services delivery. Flexibility in relation to who does the work, and how it is organized in a particular health authority or community is also critical.

The Aboriginal community is waiting for the Aboriginal diabetes initiative to begin. Aboriginal informants said some support from the broader community may be required to support Aboriginal communities implementation of the initiative. In some instances, an Aboriginal community may, for example, need to purchase services from a local Diabetes Education Centre (DEC) to ensure consistent follow-up. Availability and funding could place limits on such an option.

### 3.2 Regional Planning and Coordination

Very few health regions appear to plan and coordinate diabetes services on a continuum basis. One key informant reported that diabetes services in his region are very fragmented, developed in an ad hoc manner and are not based on a continuum of care or planned from a perspective of someone who has diabetes. As well, there are no provincial (or regional) standards to support care delivery. Health authorities have no direct control over physician practice, a critical component to coordinated care.

Another informant singled out diabetes education and said it had been developed in a very ad hoc, fragmented way with little standardization, consistency and uniformity. He felt more could be done from a continuum of care perspective, however, it should focus on the person who has diabetes. Two people argued diabetes care is far better organized than most chronic care.
In 1998, the Capital Health Region (CHR) began a long-term initiative to improve outcomes for people with diabetes. As part of this initiative the CHR has adapted a chronic care model from the Group Health Cooperative of Puget Sound (an American non-profit health maintenance organization). The model is population focused, data driven and evidence based. Clinical outcome measures have been identified. The initiative also includes identifying the prevalence of diagnosed diabetes in the CHR; reviewing management of diabetes complications; estimating health costs associated with complications; establishing an information database infrastructure to improve data linkage between laboratories, physicians; and working in partnership with patients and their family physicians to improve care. A report on Phase One of the project is on the CHR website (www.caphealth.org).

During one of the group interviews, several administrators reported their respective senior management group is discussing diabetes services but only in relation to where best to place these services (i.e. as an outpatient service in the hospital or as a community based service). They mentioned more and more small communities are asking for diabetes services.

A number of informants spoke with their respective colleagues in preparing for their interview. In general, staff contact appears to be limited to exchange of client information (i.e., adult, school child, senior, etc.) and assistance from diabetes educators for a specific situation (i.e., therapy within acute care settings, home care insulin adjustment, long term care in-service, school presentations, workplaces, community forums, etc.). Informants said regional staff have different responsibilities and locations (hospital based versus community), tremendous workloads with increased demands and very limited time to meet with others.

A few diabetes educators have begun to plan with staff from other regional Diabetes Education Centres. For example, one informant reported four acute care hospitals (Langley, Peace Arch, Surrey Memorial and Delta) in the South Fraser Health Region (SFHR) have developed a regional strategic plan for diabetes services. The respective diabetes educators (nurses and dietitians) are meeting regularly and are creating a standardized teaching tool.

The Boundary Health Council (BHC) DEC staff meet regularly with their community home care nursing colleagues with the goal of providing greater consistency in diabetes education across the region. A community nutritionist informant suggested regional staff are more likely to come (and stay) together for practical benefits and outcomes. He and his colleagues in the SFHR have had success in developing a “Cooking for your Life” program. The regional diabetes group includes a diabetes educator, community nutritionist, CDA representative and local community person who teaches cooking courses.
Some informants stressed the need for a more holistic continuum of care approach, particularly in relation to children and families, mental health (especially depression), and outreach to, and support for Aboriginal communities. Many acknowledged there has been very little attention to prevention, noting the main link with a DEC and public health is during pregnancy and childhood. Most DEC clients are adults and seniors. As public health receives 80% of its funding from the Ministry for Children and Families, middle age or older prevention activities tend to be minimal.

3.3 Diabetes Education Centres

In B.C. diabetes education is provided free of charge, primarily through a network of approximately 85 DECs. One of the strengths of these centres is the multi-disciplinary team approach. The team includes a medical director (family physician or endocrinologist), nurse, nutritionist, and in some cases a social worker, physiotherapist and pharmacist. DECs throughout the province differ in that some provide education (a key component of diabetes management and self-care) whereas others provide diabetes treatment services in addition to education. The number of DECs has increased in recent years, providing service to an increased number of communities. A large proportion of these centres are hospital based, others are located in the community.

Some informants working with community based DECs thought their programs were enhanced by their location, because they had a health rather than an illness focus. Others felt theirs benefited from the association with a hospital, giving them ready access to labs, physicians and others services.

Concern was expressed about the significant increase in demand for diabetes education and treatment, including an increase in the severity and complexity of client care. Some DECs that once provided only education now find a need/demand for clinical treatment of diabetes as well. Greater emphasis on clinical management without any increase in resources has greatly decreased the time available for education services. Several informants recommended greater attention be paid to balancing education and diabetes treatment. One said this is the most effective way to increase quality of life and to decrease the complications and financial costs associated with diabetes.

One informant, while praising the fact that these centres exist, identified a number of shortcomings: too few linkages to each other; few commonalities in the way they conduct their business; not enough treatment and many only provide education. Though some have strong leaders, they have not been able to influence physician practice, and have no authority to monitor or control physician practices.
3.3.1 Increase in referrals and Wait Time

The 1998 release of the Canadian Diabetes Association (CDA) Clinical Practice Guidelines\(^3\) (CPGs) has been linked to an increase in referrals. Several informants reported that within 3 months of the release there was a 30% increase. Some thought that a greater number of referrals and clients are evidence of the success of the DECs.

Several DECs have initiated “survival” courses for people who are newly diagnosed with type 2 diabetes. Although these courses decrease wait time for initial contact with the DEC, they provide only ‘basic survival’ information until clients can access the full education services for which the wait times are much longer. Most clients are not seen prior to the class thus individual needs are not assessed. Two educators stressed that although the survival courses have helped to decrease the wait list and provide access to services, research on teaching and learning outcomes confirms individualized teaching plans have better outcomes.

DEC informants identified a significant increase in wait lists with very little time for follow up or community outreach. There were great variations in wait time reported, including 2-8 weeks for a survival course, sooner if a person is symptomatic. Accessing a longer more extensive education course usually takes three months but in some centres it may be as long as 6-8 months. British Columbia’s Children’s Hospital (BCCH) reported nine months wait for follow up visits.

Generally patients are referred to DECs by their family doctors. One informant suggested family physicians may be reluctant to refer to a DEC for treatment as well as education services unless the patient needs to also see a specialist (i.e., endocrinologist, or DEC medical director). One particular concern was individuals who are not referred may have limited exposure to diabetes education and support.

A few informants questioned whether they are meeting individual needs through group sessions. Concerns were also expressed about the effect of wait time on patient motivation. Some informants worried an individual might be less inclined to do something the longer he/she was left to wait because his/her condition “could not be all that serious”.

While involving family and friends is time consuming in the short term, it is considered to be effective in the long term. Phone counseling has been useful in reducing case load and wait list, but questions were raised as to whether enough research has been done to determine effectiveness. One person cautioned this

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3 The Canadian Diabetes Association (CDA) Clinical Practice Guidelines were developed under the auspices of the Clinical and Scientific Section of the CDA. They were published in the Canadian Medical Association Journal, 159 (Suppl 8):S1-S20, 1998.
method being used as a means to address wait lists and case loads on a large scale.

A number of informants acknowledged the pressure to keep up with increasing demand is not any different than other areas of the health system. One person thought that wait lists, referrals and staff feelings of being overworked and stressed is similar to elsewhere in the system. Another disagreed, saying “...DECs are screaming for assistance to meet the demand due to staffing and to the acute care model of delivery. DECs have been cut back yet the demand has increased at least 30% since the CPGs have been revised and the incidence has increased.” Clearly, an increase in incidence of diabetes, referrals and demand for services without any increase in resources, will inevitably lead to longer access time and negatively effect time spent with clients.

3.3.2 Education Format

Some DECs use a class format of education while others use a modular approach in which clients progress through modules at their own pace. Some informants thought individual teaching is key to success as it allows them to tailor their information to the individual. Others felt group sessions are effective because they enhance peer interaction. One informant cautioned that no matter what the instructional method all centres need to be aware of the danger of “institutionalizing” teaching (i.e., using the most convenient and cost effective method, rather than assessing individual client needs). For Aboriginal people, interactive learning, whether one-on-one or in small groups, may be received better when support workers or educators are Aboriginal.

3.3.3 Expanded Roles and Advanced Practice

Three informants spoke at great length about expanding the role of diabetes nurse educators in relation to treatment. “If you have someone who is able to take the BP, examine feet, change insulin and examine the eye, there is one person who can do all the things that need to be done. It would be quite cost effective (as well).” The two others agreed with their colleague, adding in the majority of incidents nurses are able to make decisions and render treatment changes. For example, they said if given advanced education, nurses are quite capable of starting and monitoring insulin therapy, or an oral agent. All would be needed is a transfer or delegation of function from a physician. One referenced a recent research article which illustrates this point further (see Canadian Medical Association Journal, fall 1999). However, concern was raised about the erosion of education services when treatment roles are expanded without adequate resources being provided.
### 3.4 Primary Care Physicians

Family physicians appear to have made significant shifts in their practices since the release of the CPGs. Testing has increased (i.e., HbA$_{1C}$, microalbumin, etc.) and it is more consistently ordered. Physicians were reported to be more aggressive with treatment, monitoring lab results more closely and screening for diabetes when a patient has an elevated blood pressure. More now refer their patients affected with diabetes or an impaired glucose tolerance (IGT) to the local DEC.

Some informants felt more could be done for physicians who are in rural communities where there are limited access to health professionals and no DEC. Suggestions for support included flow charts, automatic recall systems (i.e., PAP smear recall) and greater access to an endocrinologist via e-mail or fax, particularly for complex cases and specific questions.

A few informants identified difficulties with physician attitude towards diabetes, especially at the primary care level. One added it is not unique to BC. A common concern was intensive diabetes management is not promoted enough by family physicians and some still think a “HbA$_{1C}$ of 8-9 is good enough”. One informant said doctors are inundated with guidelines, at last count there were 170 different sets. He added diabetes has become a complex disease with so many treatment options and periodically the guidelines need to be updated.

The respondent also warned that changes in physician practice and awareness may result in more frequent measure of HbA$_{1C}$ but not improved overall health outcomes. In his opinion the best way to improve controls is to dramatically change the service delivery model, from an acute to a chronic care focus. One physician recommended a step-by step process with variations of care plans be developed to provide practical support for his colleagues.

A few suggested physicians need to be held accountable if they see diabetes patients too frequently. One individual also thought more could be done to increase client awareness of what should be done, through diabetes education or the media. Two informants suggested a “made for BC” diabetes individual flow sheet be developed which outlines regular surveillance and timing. As well they suggested B.C. resources should be included on the sheet (e.g., Dial-a-Dietitian).

The CHR is collaborating with a group of 30 local primary care physicians with the aim of implementing the CPGs. Physicians have also implemented a flow sheet to remind them “what to do and look for”. There is a system in place to remind their patients about exams, and patients are flagged for preventative care. Smoking rates have been targeted, as well as blood pressure. The intent is to pilot test this primary care management approach for broader use within the CHR.
Physicians and others noted the current Medical Services Plan (MSP) billing structures do not support chronic care. Even those physicians who assume the role of Medical Directors of a DEC receive little compensation. And often it is hard to get them involved because of this. Informants noted there are no incentives built into the MSP billing system to spend adequate amounts of time with patients. Suggestions were made to increase the number of counseling visits a physician is permitted to bill per annum, or create a new MSP fee code that could be used 1-2 times for an initial diagnosis of diabetes and subsequent counseling with the physician. One physician suggested the billing structure also needs to consider a specialist payment scheme involving rural patients who don’t keep their appointment because of poor travel conditions. This would ensure patients continue to have access to specialist care despite ‘missing’ an appointment.

3.5 Specific Populations

3.5.1 Aboriginal

Both Aboriginal and non-Aboriginal informants expressed concern about the prevalence of diabetes in Aboriginal people. One diabetes educator recalled being at a health fair on a near by “reserve” and was astounded at how common it was to screen people with an Hba1c levels of 11 or more. Aboriginal informants were clear more community work needs to be done in awareness and prevention. Though non-Aboriginal people may contribute expertise and support, experience shows communications are easier and more accessible when between Aboriginal people.

Many gaps were identified in diabetes services and programs for Aboriginal people. Informants said there are no policies to reflect the reality of diabetes for Aboriginal people at either the provincial or the federal level and CDA has no policies in this area. Research focusing on diabetes among Aboriginal people is limited, particularly in BC. When based in a university, the research tends to have little practical application for the community. Lack of trained Aboriginal health providers (doctors, nurses, dietitians, and community health workers) as well as high turnover of community health workers makes it difficult to build on experience and past training.

A lack of continuity in care also arises in towns with closed physician practices resulting in people (particularly Aboriginal people) receiving care at walk-in clinics and emergency rooms. A further lack of communication between “off-reserve” and “on-reserve” health providers, coupled with lack of client files in Aboriginal communities means there are no data available for follow-up or evaluation.

Other gaps identified and relevant to both Aboriginal and non-Aboriginal people are poor access to services for remote communities; not enough family doctors
to provide basic care; and lack of funding for support groups. Other issues include lack of: staff specializing in diabetes; standardized and inadequate training in diabetes for community health workers; community support for health workers; and community development support.

No single approach will work for all Aboriginal communities because of variations in traditional beliefs and practices, including views on health and wellness, culture, oral skills and traditions. The necessary unique approaches require development of community health plans that have specific goals, for example, to promote fitness and culturally appropriate healthy life-styles. Such initiatives must have access to culturally relevant resource materials, including information on traditional and locally available foods. Several non-Aboriginal informants said they provide some diabetes education information to community health workers. They also support community awareness through health fairs and meetings with community leaders. However, demands on time make it quite challenging to be consistent in their outreach. One informant added “...programs offered to the population as a whole should also be offered to First Nations at no cost.”

Many informants spoke about the emotional/psychological/spiritual aspects of diabetes. Care provided does not acknowledge or deal with the spiritual aspect of a person or the grief associated with loss. Among all people, emotions of fear, shame and grief as well as denial of a diagnosis can interfere with diabetes management and treatment. For some this fear may also be rooted in other events (e.g., residential schools, childhood sexual abuse, etc.).

Two Aboriginal informants noted Aboriginal people tend not to feel comfortable with non-Aboriginal health care providers. This results in part from a lack of sensitivity to different communication styles. For example, Aboriginal people in a group may not be given enough time to ask or answer questions. A physician confirmed communication may also be a barrier when communicating one-to-one because two different cultures are interacting. This can be especially problematic in diabetes management where, according to two Aboriginal informants, food choices are not relevant to the Aboriginal person with diabetes, or, perhaps low literacy means the information is inaccessible.

The Edmonton Aboriginal Wellness Center provides an example of a diabetes education center by and for Aboriginal people. It incorporates traditional beliefs and practices and fosters group and family learning. At present, there is no comparable center by and for Aboriginal people in B.C. Other examples of what works well in Aboriginal communities (most apply to all groups) are as follows:

1. In-home follow-up-care includes counseling and blood sugar monitoring to achieve better control. To be effective, the front-line workers must have the education and support to provide up-to-date and accurate information.
2. A Community Diabetes Education Group consisting of Aboriginal community members with diabetes. This group provides information
sessions. They are well received, however, lack of funds limits the group’s activities.

3. Drop-in information sessions offer more flexibility. These sessions can provide information through active demonstration and are relevant to lifestyle and food choices in the community.

4. Plans are developed within the community and have the support of the community and leadership.

Education is viewed as an important part of advancing initiatives in diabetes which target Aboriginal people “on” and “off reserve”. Within the education system, there must be a greater focus on prevention (obesity, food choices, and physical activity). Aboriginal high school students must also experience greater success to advance to higher education. Over the long term, these achievements are necessary to ensure more Aboriginal health care professionals are available to support community based initiatives. However, all health professionals should receive training on cultural issues as part of their professional education.

3.5.2 Ethnic Communities

Outreach to ethnic groups (i.e., Indo-Canadian, South Asian and Chinese Canadian) can be quite challenging because of language and cultural barriers and limited (or lack of) resources including translated materials and staff who can converse in the language and are familiar with cultural norms. In larger centres such as Vancouver, Richmond and Surrey, it is becoming more common to have staff members who are versed in the language and sensitive to beliefs, norms and attitudes within the culture.

Health providers who do not speak the language generally communicate through an interpreter, some more successfully than others. When an interpreter is not available informants reported it is quite stressful and frustrating for everyone. Paid interpreter services are used sparingly within the health system because of cost.

In the Lower Mainland there are a few ethnic-specific programs, primarily for the Indo-Canadian and Chinese populations. One such program is the Vancouver Chinese Diabetes Education Centre. Staffed by a nurse and a dietitian, classes are held weekly and as well there are follow-up services. The current wait list is three months. This DEC is a partnership between SUCCESS (an immigrant advocacy and community support service), Mount St. Joseph, Vancouver/Richmond Health Board [V/RHB] and the Chinese Canadian Medical Society. The Lions/ Rotary Club and individual community members have donated to the program.

Lack of staff replacement is a common challenge for DECs across the province. One ongoing program challenge for the Vancouver Chinese DEC is the need to close when staff take leave because there is no relief staff. Another is it’s
dependence on the ongoing financial or in kind support from all partners. The program mostly attracts adults and seniors who have type 2, it is very rare for a young person to access services. Other challenges are similar to other DECIs (e.g., wait lists, increase in referrals, etc.).

Two program evaluations, conducted by external contractors, concluded this DEC is making a difference. HbA1c results were found to have improved between the beginning of the course and on follow up.

There is a Punjabi Diabetes Education Centre in Richmond, supported by the Vancouver Richmond Health Region. This centre has a variety of partners and uses a somewhat different approach from the Chinese speaking program. Staff see their clients individually rather than in a group. A Russian speaking community in the Boundary Health Council and a German speaking community in the Peace Liaird Health Region were also identified. Specific programs were not described.

3.5.3 Pregnancy and Diabetes

The CPGs recommend pregnant women be screened for gestational diabetes between 24-28 weeks. According to one informant, women are sometimes not screened until 32-33 weeks, occasionally not until there is evidence of macrosomia in the baby.

As per the CPGs and Standards for Diabetes Education in Canada, women who have gestational diabetes are to be given high priority attention to decrease the risk to mother and her developing fetus. DEC staff accommodate these women due to the urgency. Prompt attention to pregnant women with diabetes and diabetes in pregnancy appointments frequently adds to an already fully scheduled day.

One community nutritionist reported her region’s pregnancy outreach programs refer clients directly to the DEC. However, access is more common via a family physician. Good control of HbA1c and daily blood glucose levels are really critical to demonstrate the daily management of the pregnant woman’s diabetes. Ideally all women who already have pre-existing diabetes (type 1 or type 2) should visit their specialist before pregnancy. One informant said all too often women who have diabetes are not referred until they are 13-14 weeks, putting both the mother and fetus at risk. On a positive note, increased awareness and training on gestational diabetes activities were reported in Aboriginal communities.

3.5.3.1 British Columbia’s Women’s Hospital

British Columbia’s Women’s Hospital (a provincial tertiary centre) has an education and treatment clinic for pregnant women who have diabetes.
Approximately one third of the patients who come to this centre speak English as a second language. Clinic staff have found it easier to tailor information using one to one sessions because of the variation of women’s needs and the contained period of time available. Follow up care is fairly aggressive (i.e., every 2-3 weeks) and phone counseling is also common. Clinic nurses are certified to assist women with insulin treatment. Women who have difficulty regulating their insulin are encouraged to call in every morning.

3.5.4 Children and Youth

There has been limited provincial planning in relation to juvenile diabetes and its management. Nearly a third of the informants spoke about how difficult the transition to adult services is for youth (this point is discussed further below).

3.5.4.1 Diabetes Centres and Community Outreach

B.C. Children’s Hospital (BCCH) is the major provincial diabetes treatment centre, providing care and support for over 900 children and adolescents and their families. The Capital Health Region (CHR) also provides treatment, care and outreach support to over 100 children and youth. A number of other health regions (i.e., Central Vancouver Island Health Region [CVIHR], Northern Interior Health Region [NIHR], and the Okanagan Similkameen Health Region [OShR]) also have access to pediatricians. Tertiary patient loads are quite taxed, said one informant supported by the fact BCCH repeat visits were every four months, then 6 months and now nine months.

BCCH staff are seeing more children with early signs of type 2 diabetes. A disproportionate number of these children are either of East Indian or Chinese descent and a large percentage live in the lower mainland.

“World-wide” reports say type 1 is on the rise. As well, the number of children with type 1 diabetes is increasing by 3% per year, and more and more are toddlers. Using the Ministry of Health Pharmanet database, BCCH counted insulin prescriptions and came up with an approximate number of 1,400 cases of children with type 1.

Children affected by type 2 diabetes get little attention in the acute care system because their needs are not so immediate. As well, there is generally little hospital staff can do for type 2, except to encourage weight control, good nutrition and exercise. Informants agreed with the need to get (and keep) kids active, and help them learn about and eat healthy foods. There does not appear to be any formal linkages with pediatric acute care and public health regarding follow up for type 2 children.
3.5.4.2 Promotion of Breastfeeding

Across the province there are ongoing campaigns to support and encourage women to breastfeed their babies. One community nutritionist referenced a large longitudinal study from Germany showing breastfeeding for six months reduces incidences of obesity in older children by 30-50%. The nutritionist questioned the significance of this finding in terms of type 2 prevention. She noted breastfeeding reduces infections by 25-50% in the first six months of life. Furthermore, some studies suggest breastfeeding may be partially protective against the later development of type 1.

3.5.4.3 Schools

Another challenge is to educate the school system about diabetes and the importance of their role and responsibilities in caring for children with type 1 diabetes while they are in school. A number of health regions have recently had incidents where children who have diabetes had been left in unsafe situations because school personnel did not realize the fragility and critical nature of their care. For example, one child was sent home walking when he was already vomiting. In another situation (where parenting is not optimal) a child was not in school for an extended period of time and no follow up was done.

Recently the CDA national practice standards for school children affected with diabetes were pilot-tested in kindergarten to grade 12 in schools across Canada, including two in the OSHR. A public health nurse who took part in the OSHR pilot said the CDA standards were well received. These standards were to be released in the spring of 2000. They will require further testing in the school but they recognize younger children, in particular, may need help to do glucose testing and manage hypoglycemia (low levels of blood sugar). During one telephone conference call interview, questions were raised about who will be responsible for school staff training when testing is required in schools and who will delegate the testing function? Concerns were also expressed about conflicting courses of action between pediatricians (those from larger centres and locally), often leaving school and public health staff in the middle.

Community nutritionists think there should be greater emphasis in the school system on life style and physical activity. Currently a lot of the careers and personal planning curriculum is left to the individual teacher. The nutritionists recommended teachers be provided with easy to use resources similar to those developed for the “Heart Smart Kids” curriculum and workshop.

They thought that physical activity could also be increased without necessarily having to take away from learning time. For example, the school system could adopt an activity credit card. An adult could sign the card to indicate that the
child had engaged in a certain level of activity. Younger grades could also
decrease the emphasis on winning and recognize not all children function well in
a team situation. Several public health informants noted some children may
benefit from occupational therapy support to deal with “clumsiness”.

Other public health colleagues echoed the importance of exercising. They
recommended the provincial government play a much bigger role, stressing that
B.C. has never had strong physical fitness initiatives at any level. “Nationally
Participation had an impact but overall physical activity has gone down within
B.C. schools.” The importance of doing something to encourage and support
increased physical activity in the general population was also recommended.

Community nutritionists are frustrated by the proliferation of vending machines in
schools, particularly as few (if any) offer healthy choices. “It is hypocritical”, said
one nutritionist, “to focus the curriculum on learning lifestyles, yet to offer
predominately unhealthy food choices in schools because they are more
profitable.”

More and more school children/teens do not take time to eat before coming to
school. They eat what is available at school. A nutritionist reported American
research shows school children/teens are drinking twice as much pop as milk.
Twenty years ago it was the reverse.

The nutritionists recommended a provincial strategy be developed to focus
attention on the importance of healthy food selections in all schools while
addressing the crucial link food has with fundraising. Currently, it is up to each
individual school to develop policies/practices regarding foods, making healthy
school promotion strategies cumbersome to promote, implement and maintain.
Provincial leadership is needed to address these concerns.

One positive sign is more parents are beginning to understand healthy weights
and are not as concerned about variations in size. Some elementary schools are
discussing role modeling for healthy choices in schools.

3.5.5 Transitional Programs

Quite a number of informants spoke about the gap between pediatric and adult
services, noting young adults are frequently lost to the system for a long period,
re-entering with disease complications that could have been prevented with
ongoing diabetes management. The V/RHB and the North Shore Health Region
(NSHR) have begun to develop transitional programs to address this gap. A few
informants mentioned St. Paul’s Hospital in Vancouver has a transitional
program. BCCH has also integrated a new approach for adolescents with
endocrine disorders. The program begins at age 12, consists of a three-stage
transition and tries to ensure that graduating young adults are capable of
managing their own health issues and are linked with an adult endocrinologist. Transitional programs may be easier to implement in larger centres where there is easier access to specialist support.

### 3.5.6 Support for Families

Three informants said the number one complaint from families who have children with diabetes is it is so expensive. Young families (especially single parents) tend to have limited incomes. A number of families are not testing as often as they need to for financial reasons. It is also more expensive to feed children with type 1 diabetes because of the need to have “ready to eat” foods available. It is even more challenging to find someone who is willing to look after these children, (i.e., day care and after school care). Improved support for these families was recommended.

It is not uncommon for parents to undergo grief and loss when their child is diagnosed with any chronic disease. Sometimes parents find it difficult to sort out what are normal parental issues (i.e., child tantrum) from those brought on by the disease. There also may be “myths” and deeply held beliefs about what a child with diabetes can and cannot do, potentially curtailing their social and sports activities, etc.

### 3.5.7 Adults and Seniors

Community nurses, and in some regions nutritionists, provide one to one counseling and other forms of home teaching and support. Examples of home services include teaching clients how to use a glucometer, prepare syringes, and give insulin injections. Nurses also work with family members and as well occasionally pre-load syringes particularly with visual impairment. (A family physician would be contacted if an insulin adjustment were required). One dietitian informant said during home visits she often assists clients to apply what they learn within other settings (i.e., DEC and acute care, etc.). Home visits are successful in Aboriginal communities because the individual is able to link test results to their activity and eating habits.

The CHR has implemented the “Degami Protocol” with people who have come in with a cardiac infarction (heart attack) and also have diabetes. All of these patients are put on insulin for three months because research had found intensive insulin therapy reduces the rate of second infarctions. As well, most patients engage in “survival teaching” before discharge and followed up with further education when their stress is reduced.

Informants made reference to the importance of diabetes care standards in and relevance of discharge follow up from acute and long-term care facilities. The
SFHR is partnering with the CDA and community groups in relation to a cooking course. One outcome is practical education showing people with diabetes how to cook, another outcome is it has helped to build and strengthen linkages within the SFHR.

The Coast Garibaldi Health Services Society (CGHSS) recently completed a community needs’ assessment in preparing to undertake a cardio-vascular risk prevention strategy. The relevance of diabetes in relation to heart disease was identified as a community issue. As a result, public health and DEC staff have joined to address heart disease prevention. They have also helped to form a community based Heart Health Coalition, including the local Aboriginal community. The coalition is looking at nutrition, socio-economic conditions, (particularly in relation to Aboriginal people) and how to decrease cardio-vascular and diabetes risk factors. One limiting factor is the community nutritionist position is part time.

3.6 Retinal Complications

The retinal specialist informant said at the time of diagnosis 23-30% of people with type 2 diabetes have diabetic retinopathy. The CPGs support of periodic eye exams have helped to identify diabetes retinopathy. Laser treatment and increased blood glucose control are effective treatments for retinopathy. Laser treatment for proliferative retinopathy is working quite well and has been verified by clinical trials. Laser treatment (with proliferative retinopathy) and vitrectomy has helped to reduce legal blindness by 90% (over five years). According to his research, fewer people in B.C. also had major retinal surgery than would be expected. He thinks it is directly related to the impact of the scattered laser treatment.

Lowering blood glucose levels with intensive insulin therapy has been very successful in preventing the progress of retinopathy and slowing complications in the eye. However, with macular edema it only reduced the risk by 20% after nine years.

If the physician were following the CPGs for type 2 he/she would exam his/her patient’s eyes every year. At the time of diagnosis only 2% have retinopathy that is vision threatening. According to the informant, these people are coming to the clinics in increasing numbers, blocking the way of those who have more severe problems. He suggested there is wastage in the current MSP billing because it doesn’t pay for the interpretation of the photographs of the retina although it pays for a procedural fee. One informant cautioned against moving program certification for retinal exams to a DEC because it would increase DEC costs. “Whereas MSP already covers these exams and DECS are “poorly funded” and stretched as is. Secondly this additional work would add to the concern that an
increase in clinical treatment without any new resources decreases available time for education.”

The first informant is a co-investigator of a “mobile diabetes screening and education service project” targeting B.C. Aboriginal communities. He is working with MSB Health Canada. The project objectives are to recruit and train diabetes educators for the program; evaluate their skills; implement the service in one community; and test the accessibility of the services to the target population. The intent is to also assess client satisfaction, the clients served and the cost of the retinal photography.

Meetings have been held with physicians in the Mount Currie and Pemberton areas, and they have indicated an interest in participating in the pilot project. There are a number of physicians in this area who send all their patients down to St. Paul’s Hospital in Vancouver for a three-day program in education. The aim of the mobile clinic would be to do all of the testing on the spot, (i.e., HbA1c, etc) and get results back right away to the patient. A portable digital camera would take a picture of the fundus and the results could be shared with the patient. As well, there would be a questionnaire on health issues for the patient (e.g., B/P, foot exam, etc).

The investigators would like to have the program certified as part of the DEC. The informant recommended the provincial government consider setting up the same type of camera in all major DECs (St. Paul’s Hospital in Vancouver already has one). According to him, this would decrease the need for complete eye examinations, currently covered by MSP.

3.7 Remote and Rural Community Access

Access and continuity of care outside regional centres is particularly an issue for remote and rural communities. The general sense is the health status of people in these communities, particularly Aboriginal, is inferior to urban populations. Rural communities often have limited access (and in some cases no access) to family physicians. They are increasingly calling for more support and according to some informants are also beginning to question whether regional diabetes services might be too centralized.

To be seen by specialists (i.e., retinal ophthamologist, podiatrist, pediatric endocrinology, etc) most people in remote and rural communities have to travel to larger centres (e.g., Prince George, Vancouver, Edmonton or Calgary). Travel is far, costly and sometimes people have to wait up to a year for an appointment. Transportation for non-emergency people (Aboriginal and non-Aboriginal) from remote areas for routine care and follow-up can be prohibitively expensive.
One suggestion was to provide financial support for an endocrinologist to answer questions requiring very high level answers. Access would not have to be instantaneous, health providers could communicate via email or fax. Another was to prepare diabetes nurse educators with advanced practice skills (i.e., insulin adjustments, eye examination, etc.) and to link them with specialists in larger centres.

A third suggestion was to instigate a traveling diabetes day care centre, where people could come in for half a day with professionals from larger centres, providing service to more isolated areas on a regular basis. One informant stressed the importance of individualized and consistent education and care support when dealing with complex chronic conditions such as diabetes. She expressed concern that a traveling diabetes education/care would marginalize services and lead to institutionalize teaching and delivery of services.

3.8 Health Professional Development

Cost of education for health professionals is an ongoing and significant issue. Nearly all informants made reference to it, saying they have to either pay for it themselves or accept sponsorship from pharmaceutical companies. Some informants thought professional development should be a required funding category under the delegated responsibilities of health authorities. One added the Health Association of BC offers occasional workshops but generally they are held in Vancouver. Health authorities are responsible for travel costs and the costs rise if overnight stay is required.

Informants agreed there should be greater support for professional development and education. One informant said there are no education programs for physicians. Several recommended education become more of a provincial and regional priority, particularly to ensure the standards of care are well understood and implemented. It could be supplemented through the use of electronic technology so health professionals could be kept up to date.

Bringing local multi-disciplinary groups together for an interactive diabetes day course (i.e., applying the clinical practice guidelines) works well because it allows for dialogue and involvement and provides opportunities for local health professionals to get to know their colleagues. One informant from the north thought teams of people should be supported to travel to Vancouver for workshops on gestational diabetes, pediatric diabetes, etc. Greater use of electronic media (i.e., email, internet, fax) for remote and rural communities was also suggested, particularly to increase access to specialists in relation to specific questions. Public health informants suggested provincial telephone conference calls as another way to keep apprised of relevant initiatives and share learning. Several said they had learned quite a bit from being involved in the telephone conference call interview.
There were several educational sessions referenced:

- Diabetes educators certification – an examination process ensures health professionals work from a common knowledge base.
- Provincial conference on diabetes (every 3 years) - This is a joint conference since 1974 with the Diabetes Educator Section and Clinical and Scientific Section, organized by University of BC Continuing Medical Education division with sponsorship from pharmaceutical companies. Every third session is on pediatric care. These sessions are usually attended by 1500 professionals.
- UBC Diabetes Educators course – offered twice a year, focuses on the Aboriginal community and facilitated by Barb King-Hooper.
- Diabetes Care Without Compromise - a national education program for primary care physicians developed by Dr. Keith Dawson through the University of BC. Approximately 700 BC physicians have taken this course in the last three or four years. This program was industry funded but is no longer available.
- Practical Diabetes Management - a full day course funded and developed by industry.

3.9 Pharmacare Diabetes Program

3.9.1 Certification Process

The certification process for reimbursement of glucose monitoring strips through Pharmacare is under the guidance of the BC Diabetes Review team. Certification for an individual ranges from three months to three years depending on the client and/or the length of approval. One diabetes educator said an individual certification generally takes half to an hour of time.

Some informants felt the re-certification program for reimbursement for glucose monitoring strips through Pharmacare is working well. They stated the program “keeps people in the loop”. On the other hand many informants called for a review of the certification process to determine whether it is in the best interest of people with diabetes. One individual (who was around when the program was implemented) recalled this program originally started when monitor testing for blood sugar was not as accurate as it is today. He feels the certification process is “not discriminative enough of individual needs and uses too much of time within the already stressed delivery system”. Others emphasized client dissatisfaction with the process and thought the required time could be put to better use.

Although it is one way to have patients come in and see a qualified care-giver every year, one informant thinks having the visit centred around certification re-
testing is a waste of resources. “Asking people to come to a day long education program is asking too much from busy people.” He added it is just too costly and is not tailored enough for differences in peoples needs or learning styles. He emphasized programs have to be done differently, for example, there could be a mail out program where patients answer questions and if they got them right they may not need anything else. Those who don’t are invited to the clinic.

Many elderly patients are not able to leave their homes, because of mobility and transportation problems. They currently have to go to the DEC to be certified in order to buy their strips for blood glucose monitoring. It was recommended that elderly house bound people should have access to the certification process in their home.

Four key informants were very critical of the accreditation process saying it is too slow, too narrow, not very creative, lacking an understanding of the system outside of larger centres and too rigid. One informant reported reviewers who come from Vancouver don’t seem to understand the challenges they face – reduced budgets, different accessibility to clients, problems with certification, etc. A second person responded they would like to be supported for using creative ways to become more client centered, adding the review process is too geared to hospital based service delivery. Centres without physicians and geared towards education/nutrition/self-care feel the accreditation team is unwilling to consider the different scope of care being offered by them.

The CDA Recognition Program was identified as a replacement for the Diabetes Review Committee process. The program is a comprehensive qualitative and quantitative external peer review available nationally. Centres collect data for 6 months to a year and submit the data for a blinded peer review. The informant who spoke about the Recognition Program said it provides a much more thorough review and is more cost effective than the current accreditation process.

3.9.2 Cost of Equipment and Medications

Cost of strips, equipment and medications for those under the age of sixty-five was flagged as an issue, in particular for families with young children who have diabetes and those who are “working poor”. Youth were also singled out, especially those who are in college and/or living off limited incomes. When pregnant women develop gestational diabetes it is unlikely the cost for testing during pregnancy will add up to $800, thus costs are born by the woman unless she is on extended benefits. The question was asked whether it was possible to lower the deductible. “If good control is lessening complications, then isn’t it more cost effective to assist (people affected with diabetes to achieve) good control?”
A number of key informants recommended that Pharmacare cover all diabetes supplies for all ages, especially given the costs of long term complications compared to diabetes supplies.

3.9.3 Drugs and Drug Policy

There are a vast number of drugs available to assist with blood glucose control and reduce complications. As well, one endocrinologist warned there are new drugs coming on the market all the time, noting in particular the pending release of a long-acting insulin and non-invasive glucose monitors.

Several physician informants seemed frustrated by Pharmacare drug policy, saying it places far too much emphasis on cost savings. One said while some diabetes drugs cost less they might also not be tolerated. If a person with diabetes is not able to tolerate the drug, it increases the likelihood he/she will stop taking the drug and in turn increases the risk of complications and hospitalization. The informant questioned whether the Ministry is doing enough research and evaluation of the impact of its policy.

3.10 Pharmaceutical Companies

Several informants spoke about the assistance they receive from pharmaceutical companies especially for professional education and for teaching patients how to use meters. One company has developed a full day course called Practical Diabetes Management, offering it free to physicians, dietitians, nurses and other staff. Through the course participants learn about the CPGs and as well meet local resource people attending the course. Others spoke about companies providing free demonstrations of the latest glucometers and information on their diabetes drugs.

Two informants expressed concerned about the dependency on industry support. One said a lack of resources also means DECs rely on pharmaceutical companies to cover the costs of presentations. A physician informant noted therapeutics are currently controlled largely by pharmaceutical companies. He thought doctors should not rely on these companies for their main tools in treating diabetes.

One informant was very critical of the Ministry in relation to pharmaceutical companies. He said these companies support research and education in other parts of the country but they have been “shooed away” in B.C. He suggested whatever the difficulties are (including the ethics) there is a solution but it requires leadership and coming up with rules and guidelines.
3.11 Community Supports

3.11.1 Canadian Diabetes Association

The role of the CDA is to promote the health of Canadians through diabetes research (scientific and quality of life) education and advocacy (e.g., driver license, income allowance for dietary support; Pharmacare program, etc.). CDA also provides news and information to health professionals, those living with diabetes and the general public.

One of the most used resource services is the CDA 1-800 number, particularly when people are first diagnosed. Branch offices (located throughout BC) help to set up local community forums and support groups, as well as recruit volunteers. The CDA is a member of the national Diabetes Council, bringing together a number of partners, including the Juvenile Diabetes Foundation and the Lions Club.

Quite a number of informants said they are CDA members, most volunteer time (e.g., Board, advisory committees, children’s summer camp, recognition awards, etc). A number of informants said the CDA has played an important role in helping to increase public awareness and education about diabetes. As well, the CPGs have helped to improve the consistency of medical care.

An informant questioned whether the mandate of the CDA could be broadened to do some prevention teaching in relation to people with IGT, to offer these people more specific information in a planned format. Another person suggested the CDA put more of its efforts into public education, including in relation to school children. It was recommended the CDA play a more prominent role in the development (and advocacy) of policies. These policies initiatives should include Aboriginal people.

The BC section of the CDA runs a summer camp each year for children who have diabetes and their families. Among other things, it provides adolescents with an opportunity to meet endocrinologists who work with adults. Ideally these youth are able to identify a specialist who they would be comfortable with once they leave BCCH.

3.11.2 Dial-a-Dietitian

Dial-a-Dietitian is a source of information used by people across the province. Nutrition information is provided in four languages via a 1-800 number. The 1998/99 Dial-a-Dietitian annual report found of the 30,716 nutrition questions received that year by callers, 42% were from callers seeking therapeutic nutrition information for conditions such as diabetes and heart health. Many of the
diabetes-related calls were made by people who were on a waiting list for their first appointment with a DEC dietitian and were seeking nutrition information in the interim.

3.11.3 Shop Smart Tours

“Shop Smart Tours” has made diabetes a priority for 2000, offering specialized tours for people with diabetes and wellness clinics at all Overwaitea and Save-on-Foods stores across BC. These tours are sponsored by corporations, free to users and coordinated by registered dietitians and nutritionists.

3.12 Research

One informant said there is a progressive understanding of the causes and mechanisms of diabetes, allowing better drugs to be developed. He suggested diabetes services could be delivered much more effectively and research could help to shape a new course. Two colleagues agreed with this conclusion.

One, of these three, is also engaged in a research project to train a few diabetes nurse educators to diagnose diabetic retinopathy by direct ophthalmoscopy. The impetus for this research was based on a long-term plan to implement organized screening throughout the province, ideally to organize such an examination within the DEC. The project has been tested and evaluated in rural and urban education centres. The results have been published (see Begg, I.S. et al, Clinical Invest Med, vol 19:164, 1996). The informant suggested an expanded role for nurses is another potential mechanism to extend health care, especially in remote and rural communities. For other examples of diabetes research please see the literature review (see Appendix A).

There were calls from a number of informants for more research. Two people suggested diabetes and depression/psychosocial factors should be researched. One of them has noticed more and more mentally ill people in their twenties or thirties are diagnosed with type 2 diabetes in her health region. She questions whether some medications may have had an effect on weight gain (particularly around the abdominal area). The second informant reported her health region found depression was one reason why individuals did not continue with education programs.

Another informant recommended a long list of program evaluation topics: diabetes education outcomes; teaching plans and methods; delivery of diabetes education; follow-up schedule – frequency and follow up; hospital based versus community based care delivery; phone versus face interventions; physician support of clinical practice guidelines; clinical research and practice based research.
A couple of informants recommended rather than researching how much diabetes is in a community, engage the community in a process to identify its solutions as how best to prevent diabetes.

### 3.13 Data Collection and Surveillance

Although the DECs have been in place for ten years there are very little accessible data. Informants were pleased to hear about plans for the National Data Surveillance System (NDSS). One informant urged longitudinal studies include large enough samples of children and adults to provide data at the community and regional levels. They stressed the NDSS also needs to extend to Aboriginal communities.

Another informant said he had already helped to set up a provincial database to collect data on people with type 1 diabetes. The registry was funded by the BC Health Research Foundation, in 1992-95 and supported by the CDA, BC Society of Pharmacists, Canadian National Institute for the Blind (CNIB) and Medical Services Branch, Health Canada. The database has a population cohort of 6,476 as of January 1999, using the person’s initials, gender and date of birth to link data.

One finding from this database was 96.6% of people with type 1 diabetes attended one of the DECs. They did a detailed analysis of a group at greatest risk for proliferative retinopathy. For those people aged 18 years or more, with duration of diabetes of 10 years plus, they identified the prevalence of hypertension, heart attack, stroke, amputation, nephropathy, and laser treated retinopathy. They also reviewed HbA$_{1C}$ on 2,127 people.

Another informant said he has also created a computer program for use in diabetes clinics. This program is used in Prince Rupert, Vancouver General Hospital, in Edmonton and Ottawa. The program is a forced choice menu, requiring the recorder to input when the patient last saw an eye doctor, test results (HbA$_{1C}$, etc). It accumulates all the lab data and gives out a flow sheet on every patient. Queries can also be initiated (e.g., give all patients with HbA$_{1C}$ greater than .915, what medication they are taking, etc).

The Diagnostic and Treatment Centre in Chase is completely computerized. In a couple of years this Centre will be able to call up their statistics, including diabetes. The CHR plans to acquire a clinical information system as part of its Chronic Care Model Initiative. The Coast Garibaldi Heart Health Coalition intends to collect data to support its Strategy. Part of the data collection will include monitoring of diabetes diagnosis, as well as morbidity (those who have the disease) and mortality (death from a particular cause). The data will be analyzed in relation to specific populations (i.e., Aboriginal). There were other
examples of databases noted (i.e., St. Paul’s Hospital, Terrace and Burnaby and NSHR DEC) but they were not described.

3.14 Funding

A very common refrain was diabetes education and treatment services needs to be funded better, but any new funding “must be ear marked for diabetes” and not rolled into global budgets. One informant said there has been nearly a 13% decrease in their DEC budget over the years and points to global budgeting as the primary culprit.

Public health informants also emphasized there would need to be a percentage of funding designated to primary prevention. If money is allocated to this area, it should be directed by those who are knowledgeable and skilled in primary prevention.

Also see sections on Family Physicians and Drug Policy above.

3.15 Other Issues

3.15.1 Driver’s License

Low blood sugar may lead to cognitive impairment, affecting motor skills and a person’s ability to make decisions when driving. This problem has been verified in a driving simulator. There are a number of ongoing debates as to what the regulations and guidelines should be in relation to granting a driver’s license4.

One informant chairs a national CDA advocacy committee looking into the issue of driver’s license. He said in terms of assessing people’s ability to drive there is a tremendous amount of information needed to make good decisions. The CDA committee plans to release a set of national guidelines sometime this year.

Another informant expressed concern about expectations that DEC staff provide information or opinions on an individual’s fitness to drive. According to the informant, DEC staff are regularly asked for assistance in determining whether a

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4 The Office of the Superintendent of Motor Vehicles, Ministry of Transportation and Highways, regulates drivers to help ensure the safe and responsible operation of motor vehicles in British Columbia. Section 29 of the Motor Vehicle Act authorizes the Superintendent of Motor Vehicles to require drivers to be examined for fitness to operate a motor vehicle of the category for which the person is licensed or is applying for. Under Section 230 of the Motor Vehicle Act a medical professional is required to report any patient over the age of 16 who has a medical condition that would put the patient or the public at an unacceptable risk should the patient drive a vehicle and continue to drive despite being warned not to.
driver’s license for a person with diabetes should be renewed. The informant believes this role would be better placed elsewhere.

3.15.2 Community Pharmacy Programs

In some communities local pharmacies (Safeway, Costco, Overwaitea, etc.) have started to offer diabetes education. The informant who raised it as a concern asked who will assess whether “standards” for diabetes education are reached? She also wondered whether business motives might not interfere with health messages.

3.16 Evidence of What is Working

Examples of research studies were referenced (see above for further discussion), but most of “what is working” appears to be based on anecdotal evidence/expert opinion and practice experiences. The most frequently cited was individual client data (e.g., HbA1C improvement, weight loss, changes in diet, exercise and cessation of smoking, etc) and satisfaction with services. The availability and access to meters allow people with diabetes to make the connection between their level of activity, food intake and number on the meter. Several diabetes educators said they are seeing evidence of greater stability in “controls” than they have ever seen before.

One informant said an outside evaluator reviewed all client records in their DEC, reporting an overall improvement in HbA1C. A Boundary DEC chart audit found there was significant decreases in hospital admissions and length of stay since the program inception five years ago. Several others also reported decreased hospitalization rates and increases in DEC referrals. One said her region has the lowest rate of hospitalization in B.C. for people with diabetes. [It wasn’t clear what trend data were used to make this assertion]. Many stated it is very rare to admit anyone into hospital to initiate or regulate insulin in their region.

A few informants did not have any outcome evidence to demonstrate what they do makes a difference. Primarily they are hampered by the lack of accessible data. One person said their DEC would like to begin evaluating use of knowledge not just satisfaction with care. The region recently discovered from an analysis of its data that depression was as major a deterrent for access as class times. These findings were used to support the implementation of depression screening.

5 Physician are guided by the “Guide for Physicians in Determining Fitness to Drive a Motor Vehicle”, produced by the B.C. Medical Association in collaboration with the Superintendent of Motor Vehicles [See A Guide to Operations (1999), available on the following website www.th.gov.bc.ca/bchighways/management/osmv/osmvhome.htm]. The role and responsibilities of other health professionals may require similar guidance in order that it is understood in day to day practice.
3.17 Who Should Address These Challenges

The following groups were identified as having responsibilities in addressing the challenges and recommended changes.

1. Provincial Government
   - Ministry of Health
   - Aboriginal Health Division of Ministry of Health (Provincial Aboriginal Health Services Strategy)
   - Pharmacare
   - Diabetes Working Group
   - Ministry for Children and Families
   - Specific responsibilities:
     - Ministry of Education
     - Ministry for Social Development and Economic Security
     - Ministries responsible for sports and recreation, immigration and culture and
     - Office of the Superintendent of Motor Vehicles

   - The provincial government should provide policy leadership and assist health authorities determine what options are available to them to deal more effectively with chronic diseases, especially in light of the shifting demographics.
   - A second role for the provincial government is to support and promote overall health of the population and communities.

2. Federal Government
   - Health Canada (MSB)

   - The federal government has a role to play in helping to raise awareness, setting policy themes, assisting with data collection and analysis, and supporting research.
   - A federal presence in terms of disease prevention, particularly surveillance was also identified.

3. Health authorities and communities
   - DEC staff
   - People with diabetes and their families
   - Public health staff – nurses and nutritionists
   - Health Association of B.C.

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6 There were requests for sufficient data sampling in allow data analysis at the local and regional levels as well as the provincial and national.
4. Physicians
   Primary care physicians
   Specialists (endocrinologists, pediatricians, etc.)

5. Canadian Diabetes Association

6. Aboriginal Community

7. Others
   Educational Institutions
      Teachers
   Research Institutions
   Business Community
   Restaurants
   Corporations and businesses
      Pharmaceutical companies
      ICBC
   Entire communities
   Health Professional Groups
      Public Health Association of B.C.
      Registered Nurses Association of BC
      Aboriginal Nurses Association
      BC Medical Association
      Dietitians of Canada
   Media
   Sports figures

3.18 Final Comment

Informants asked for copies of the interview report and several requested a copy of the literature review. Further, one informant recommended all who were interviewed be brought together. The session would be an opportunity to review where there is agreement, get greater consensus where there isn’t and provide an opportunity to share those ideas perhaps only a few people thought of.
APPENDIX C

Diabetes in British Columbia
Key Informant Interview Guide

Prepared For

British Columbia Ministry of Health &
Ministry Responsible for Seniors

Prepared By

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January 2000
Background\(^7\)

There are an estimated 60,000 new cases of diagnosed diabetes (Type 1 and Type 2 combined) every year in Canada. This is an incidence rate of 2.6 new cases per 1,000 people among those aged 12 and over each year. Diabetes is ranked as the seventh leading cause of death in Canada and in 1996 accounted for approximately 25,000 potential years of life lost (PYLL) due to premature death. The economic burden of diabetes and its complications in Canada is estimated to be up to $9 billion (US) annually in direct health care costs and indirect costs, including lost productivity due to diabetes-related illness and premature death.

Diabetes is the most common cause of end-stage renal disease, of new onset blindness in the working age population, and lower limb amputations, and is a noted risk factor for cardiovascular disease. In the 35 to 64 age group people with diabetes have six times the risk of heart disease or stroke as do people without this disease. The 65 and over age group has twice this risk. Men have slightly higher rates of diabetes than women, particularly in the 35-64 age group (58.1% among males and 41.9% in females age 34-64). [A higher rate of obesity in males is thought to be a contributing factor to Type 2 diabetes.] In addition, there is an increased risk of major congenital malformations and newborn death in babies born to women with diabetes. Projections in diabetes mortality trends into the year 2016 show an exponential increase in the number of deaths due to diabetes among males and a more linear increase among females.

The prevalence of diabetes in the Aboriginal population is at least three times the rate found in the general Canadian population. Although Type 2 diabetes is referred to as “adult-onset”, in recent years it has been diagnosed in Aboriginal children as young as 5 to 8 years old.

The British Columbia Ministry of Health and Ministry Responsible for Seniors’ Diabetes Working Committee is undertaking a research process to support the development of a comprehensive, culturally sensitive diabetes prevention and control strategy for the Province. The objectives of the research are to:

1. Identify and build on key elements of best program and policy practices related to diabetes.
2. Provide an overview of current British Columbia diabetes policy and services and as well identify gaps.
3. Make general recommendations about future actions, including specific strategic directions that Ministry of Health may be best positioned to take.

\(^7\) This Background information is taken from: Diabetes in Canada National Statistics and Opportunities for Improved Surveillance, Prevention and Control, Minister of Public Works and Government Services Canada Canada 1999.
The research information is being gathered through a review of Ministry of Health sources, a review of the literature and telephone interviews with approximately 25 key informants.

**Preparing for the Interview**

You have been invited to participate as one of the key informants. The purpose of this guide is to set the context and to provide you with the interview questions. When preparing for your interview, you are encouraged to seek ideas and opinions from colleagues in relation to the set of questions below.

All interviews are to be conducted by telephone, and will be tape recorded to ensure accuracy of responses, taking approximately 60-90 minutes to complete. When answering these questions you are asked to prepare and respond from your primary responsibility perspective, with a focus on diabetes.

One of the project team will contact you within the next week to schedule an interview time. If possible we would like to complete the interviews no later than the first to second week in February.

The interview list is made up of 25 people chosen by the Ministry Working Committee on Diabetes. Because you have been identified as an expert in your field of work, your specific interview information may be quoted in the final report. If you have any concerns related to confidentiality please bring them to the attention of the interviewer.
The Interview Questions

What work are you doing in relation to diabetes?

What is your role?

Which of the following best describes your primary responsibility

- service provider/ educator
- researcher
- policy
- academic
- advocate
- other please describe _________________________

Your Title:
Your Organization/ Health Authority

What is working well (e.g., interventions, programs/services and policies) to support best health outcomes?

What evidence do you have to show that these approaches are working?

What is not working (e.g. interventions, programs/services and policies) to support best health outcomes?

Do you have any suggestions to address these challenges?

Who should address these challenges?

Are you involved in any programs or activities directed at special populations such as Aboriginal people, people of East Indian or Asian ancestry (or in the case of Aboriginal community, for non-Aboriginal people)? Please explain.

Are there any gaps in prevention, education (public and professional), care and support and research? Please explain.

Do you wish to add any other comments?