Responding to the Challenge of Diabetes in Canada

First Report of the National Diabetes Surveillance System (NDSS) 2003 Our mission is to help the people of Canada maintain and improve their health Health Canada

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EXECUTIVE SUMMARY

Diabetes is a serious and growing public health problem in Canada, particularly in Aboriginal populations. The morbidity and mortality associated with diabetes are increased considerably by complications such as heart disease and stroke, blindness, kidney disease, nerve disease and amputations.

To date, there has been a lack of ongoing, systematic, validated Canadian analysis for basic prevalence and other diabetes information. The National Diabetes Surveillance System (NDSS) is the mechanism developed to provide improved data about diabetes. It is a network of regionally distributed diabetes surveillance systems that compile administrative health care data relating to diabetes, and send aggregate anonymous data to Health Canada for national analyses.

This is the first report comprehensively describing NDSS. It covers:

- the original concept of using health care administrative databases to track disease burden in a population;
- studies that have demonstrated the feasibility and validity of the concept;
- activities directed towards assessing and improving provincial/territorial capacity to participate in NDSS;
- strengths and limitations of the NDSS approach;
- structure and governance;

- a special focus on Aboriginal populations;
- methods of data capture;
- prevalence and mortality data; and
- future plans, including validation of a diagnostic algorithm for diabetes in people under 20 years of age.

Highlights of NDSS data include the following:

- prevalence of diabetes among adult Canadians in 1999/2000 was 5.1%;
- 1,196,370 adult Canadians were living with diagnosed diabetes in 1999/2000;
- Canadian adults with diabetes are twice as likely to die prematurely compared with adults without diabetes; and
- 41,483 adult Canadians with diabetes died in 1999/2000.

NDSS represents the first time that a coordinated, national use of administrative data for public health surveillance purposes has been undertaken. NDSS can measure prevalence, incidence and outcomes over time for both the nation as a whole and for specific regions. Also for the first time, NDSS can compare health services use and other health outcomes of people with and without diabetes. With these features, NDSS is also a prototype of enhanced capacity and infrastructure to support surveillance for other diseases that can be tracked through the health care system.

Canada was in a unique position to develop this type of surveillance system, given its publicly funded health insurance generating personspecific administrative data. NDSS use of multiple databases offers information on diabetes that is far superior to what would be possible using one source alone. The resultant rich source of data can be used not only for surveillance but also for examining many policy and research questions.

Perhaps most importantly, NDSS was the catalyst for exciting partnerships with various jurisdictions across Canada cooperating to achieve the shared goal of reducing the burden of diabetes.

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ACRONYMS

APLSF	Annual Person Level Summary File			
BMI	Body Mass Index			
CABG	Coronary Artery Bypass Grafting			
CCHS	Canadian Community Health Survey (Statistics Canada)			
CDA	Canadian Diabetes Association			
CDS	Canadian Diabetes Strategy			
СІНІ	Canadian Institute for Health Information			
CIHR	Canadian Institutes for Health Research			
DCC	Diabetes Council of Canada			
DM	Diabetes Mellitus			
EHR	Electronic Health Record			
F/P/T	Federal/provincial/territorial (governments)			
FNIHB	First Nations and Inuit Health Branch			
FTE	Full-time Equivalents			
FY	Fiscal Year			
HISP	Health Infostructure Support Program			
ICD-9	International Statistical Classification of Diseases and Related Health Problems (v. 9)			

ICES	Institute for Clinical Evaluative Sciences
IDDM	Insulin Dependent Diabetes Mellitus
INMD	Institute of Nutrition, Metabolism and Diabetes
MOU	Memorandum of Understanding
NDSS	National Diabetes Surveillance System
NIDDM	Non-Insulin Dependent Diabetes Mellitus
NWT	Northwest Territories
O&M	Operating and Maintenance Financial Mechanism (Health Canada)
P/T	Provincial/territorial governments
PIRC	Performance Indicator Report Committee
РРНВ	Population and Public Health Branch
PTCA	Percutaneous Transluminal Coronary Angioplasty
RCMP	Royal Canadian Mounted Police
RFA	Request for Applications
RIW	Resource Intensity Weight
SAS®	Statistical Analysis Software

INTRODUCTION

Diabetes is a serious, chronic, systemic disease characterized by the body's inability to sufficiently produce and/or use insulin – a hormone produced by the pancreas that assists with the conversion of glucose (sugar) into energy. Without insulin, blood sugar levels rise to dangerous levels, interfering with the proper nourishment of body cells.

The burden of illness associated with diabetes is increased by the fact that people with diabetes are at greater risk of other diseases than people without diabetes. This risk is strongly related to high blood sugar and the duration of diabetes. Chronic high levels of blood glucose can lead to heart disease and stroke, retinopathy (the leading cause of adult blindness in Canada), kidney disease, amputations, nerve disease (including erectile dysfunction) and other complications.

Diabetes has been diagnosed in over one million Canadians. Projections based on our aging population indicate that the burden of diabetes and its complications will increase considerably. The Government of Canada recognizes that diabetes is a complex health problem and a national challenge. In 1999 it pledged \$115 million over five years to the development of a *Canadian Diabetes Strategy (CDS)* to enable Canadians to benefit more fully from the considerable resources and expertise available across the country.

The CDS allows the Government of Canada to move forward in three areas of vital importance:

- The development of a health promotiondisease prevention strategy for the entire population.
- The provision of care, treatment and prevention for First Nations people on reserve and for those in Inuit communities.
- The improvement of national and regional data about diabetes and its complications.

The present report describes progress made towards meeting the need for information that will assist Canada to respond in an organized and integrated way to the challenge of diabetes. In particular, this report describes the National Diabetes Surveillance System (NDSS) - a network of regionally distributed diabetes surveillance systems. The network was developed. implemented and coordinated through collaboration among governments, industry and several non-government agencies and Aboriginal groups committed to reducing the burden of diabetes in Canada.

In 1999, the first **Diabetes in Canada** report highlighted the need for better data, in particular, data on the prevalence and incidence of diabetes, its complications, the use of health services, and the effectiveness of prevention and control initiatives. NDSS represents a major milestone in achieving this. This report is the first in a series designed to describe NDSS. As such, it delves into the background and history of the project more than will future reports. It also presents data that serve to indicate the types of information that are currently available or will be forthcoming from NDSS.

THE CHALLENGE OF DIABETES

Diabetes as a Personal Challenge

Diabetes affects people of all ages. *Type 1 diabetes* (formerly referred to as insulindependent diabetes mellitus or IDDM) usually begins during the first two decades of life.

In type 1 diabetes, the immune system destroys the insulin-producing cells of the pancreas. Although the process is poorly understood, a combination of genetic factors and environmental stressors, such as viruses, is believed to be the trigger.

Type 1 diabetes requires treatment with insulin throughout the rest of life and is associated with a high incidence of complications. Type 1 diabetes usually results in a reduction in quality of life and a shortened lifespan.

Type 2 diabetes (formerly referred to as non-insulin-dependent diabetes mellitus or NIDDM) occurs most often in obese individuals over the age of 40. In contrast to people with type 1 diabetes, who do not produce enough insulin, some people with type 2 diabetes are "insulin resistant" and are not able to use the available insulin to control blood sugar.

Type 2 diabetes may be controlled by weight loss, exercise and medication taken orally. However, for some people with type 2 diabetes, daily insulin injections may be required. Life expectancy is also reduced in people with type 2 diabetes. A third type of diabetes – *gestational diabetes* – occurs during pregnancy and usually resolves after delivery. Gestational diabetes can result in an increased incidence of very large babies and pre-eclampsia (toxemia of pregnancy).

Gestational diabetes is a strong risk factor for type 2 diabetes later in life.

Better information about risk factors for diabetes, complication rates, quality and expectation of life, and the efficacy of prevention and care approaches could contribute greatly to the outlook for Canadians with diabetes.

Diabetes as a National Challenge

In 2000 in Canada, diabetes was estimated to affect about 5% of the population aged 20 years and over. The direct treatment costs for people with diabetes have been estimated at \$400 million annually for hospital care and prescription drugs. In addition, there are costs for treating complications and for physician care, costs borne by patients, and indirect costs such as premature death, disability, and care-giving.

Canada has previously estimated the burden of diabetes by using mortality data, hospital data, self-report surveys or American data. These provide underestimates for various reasons, including missed diabetes-related hospitalizations and deaths, variable response rates to surveys, participation and self-report bias, the unreliability of self-report, and relatively small samples in surveys. The appropriateness of extrapolating estimates from American data is also limited by the differing age structure and ethnic backgrounds of the Canadian and American populations.

Diabetes as a Particular Challenge for Aboriginal People in Canada

Aboriginal people, especially First Nations, began speaking of a diabetes epidemic in the 1980s. Since then, Canadian research has confirmed the high and increasing prevalence of diabetes in these populations. Other features of diabetes in First Nations groups are earlier age at onset of type 2 diabetes, greater severity at diagnosis and higher complication rates.

This burden of disease is associated with unique challenges in prevention and care. Information is urgently needed to help tailor prevention, diagnosis and treatment to the circumstances of Aboriginal populations in Canada.

THE NATIONAL DIABETES SURVEILLANCE SYSTEM (NDSS) – A RESPONSE TO THE CHALLENGE

Although diabetes has attracted the attention and efforts of various organizations and levels of government, it is apparent that the magnitude of the problem demands a comprehensive and collaborative strategy for control. In 1996 a number of physicians, diabetes educators, non-government organizations, epidemiologists and researchers concerned about the lack of ongoing systematic information surrounding this major public health problem proposed a national surveillance system for diabetes.

Can information systems designed primarily as tools for budgeting and billing be used to provide disease-specific information that will benefit all Canadians? YES!

Following the 1996 discussions, the Diabetes Council of Canada (DCC), a coalition of diabetes-related non-governmental organizations, Aboriginal groups and federal agencies, championed a national surveillance effort as one of its initiatives. The National Diabetes Surveillance System (NDSS) Steering Committee was formed in 1997 and began developing the concept of a surveillance system that would maximize the potential value of administrative data to support diabetes surveillance.

The Original Concept

The concept for NDSS was based on initial contributions from Young et al.¹ and Blanchard et al.^{2,3} It was also a response to the National Forum on Health, which encouraged the use of existing provincial/territorial administrative databases in support of public health activities in Canada.⁴

Underlying the NDSS concept is the assumption that the clinical path of diabetes from detection to the treatment and management of complications theoretically makes it possible to track the diabetes burden through various client interactions (physician visits, hospitalizations, etc.) within the provincial and territorial health care systems.

Tracking is possible because data are captured routinely in the provision of publicly funded, insured health services in the various jurisdictions and are stored in three major provincial/territorial administrative databases – physician claims files, hospital files, and health insurance registries.

Feasibility

In 1999, a pilot project conducted in the three Prairie provinces (Alberta, Saskatchewan, and Manitoba) demonstrated the feasibility of the NDSS approach to data collection and the development of inter-government agreements for surveillance using provincial administrative data.⁵ The project was funded by the Government of Alberta and Health Canada's Health Infostructure Support Program (HISP), with significant in-kind contributions from Manitoba and Saskatchewan.

The project extended an existing diabetes surveillance system operating in Manitoba to Saskatchewan and Alberta and identified a method for reconciling variations in the three provincial health information systems so that the same core body of software could be used in all three provinces.

The initial project anticipated the transfer of person-level data to a central database held within Health Canada. However, this model was abandoned after review of provincial legislation regarding the privacy of personal health data. In its stead, a model was developed for the creation of person-specific databases of health information that would remain within each participating province/territory and an aggregate, anonymous data set that each province and territory would transmit to Health Canada.

The surveillance system developed through this project provided estimates of the incidence and prevalence of diabetes for each year of data provided by the provinces/territories. It also demonstrated that event rates for approximately 40 complications of diabetes as well as health services use can be generated for both the population with diabetes and the population without.

Disease Surveillance for Public Health

Public health surveillance has been defined as "the **ongoing**, **systematic** collection, **analysis**, and **interpretation** of health data essential to the planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those who need to know. ..."⁶

Disease surveillance collects information in order to define the magnitude of the problem, to portray its natural history, to identify populations at particular risk, to monitor changes in disease frequency and risk factors, to evaluate the impact of disease control approaches, to generate hypotheses and stimulate research, and to aid planning.

Many of the techniques and methods of disease surveillance have been developed in relation to both infectious and chronic diseases. Cancer surveillance, in particular, has spurred the development of methods for case ascertain- ment (cancer registration), projections and record linkage.

One of the challenges of disease surveillance is to balance the need for information against the right to privacy. Methods developed to date have demonstrated that responsible surveillance using personal information is possible without sacrificing privacy.

The surveillance model can provide ongoing, systematic collection and analysis of public health data, suitable for dissemination to the public, for health planning and for use by health professionals.

The NDSS Model

NDSS represents the first time that coordinated national use of administrative data for public health surveillance purposes has been undertaken. Thus, NDSS has moved into largely uncharted waters at both the provincial/ territorial and federal levels.

The balancing of practical considerations and epidemiological methods is at the heart of the NDSS design, which departs from other national health information systems in several important ways:

- The provinces and territories, Aboriginal groups and Health Canada are equal partners, with Health Canada's Centre for Chronic Disease Prevention and Control assuming a central coordinating role.
- Capacity in data capture and analysis is developed within the provinces and territories.
- NDSS is a network of regionally distributed diabetes surveillance systems rather than a central repository.
- Health data related to individuals are held exclusively within the domain of the provinces and territories, and no personal health data are transferred outside a province or territory.
- Aggregate anonymous data are transmitted to a central location.
- Long-term, ongoing data collection enables longitudinal analyses.
- Provinces, territories and Aboriginal groups have an important role in organizing administrative data and in interpreting the results of analyses.

Although these features compound the difficulty of start-up and implementation, they help build regional capacity to enable provinces, territories and Aboriginal groups to use their own data to answer questions unique to their needs. This is a strong incentive to buy-in, helping to ensure the long-term survival of NDSS.

NDSS Goals

- ▼A national standardized database for diabetes surveillance, with long-term monitoring for diabetes-related complications through the integration of new and existing databases
- ▼Ongoing surveillance of diabetes and its complications in each province and territory, and in the Aboriginal community
- Dissemination of national comparative information to assist in effective prevention and treatment strategies by public health departments, Aboriginal communities, non-governmental organizations and private industry
- ▼A basis for evaluating economic/costrelated issues regarding the care, management and treatment of diabetes in Canada

Capacity-Building

The capacity to participate in NDSS was identified as a challenge, requiring some of the most resource-intensive activities. A capacity assessment was conducted in each province and territory to identify capacity inequities. Appendix A contains a description of the domains assessed. Solutions to inequities included placement of officers in jurisdictions, placement of hardware and software, systems development, and upgrading and integration of databases.

These solutions have not yet resulted in uniform capacity across the country; several jurisdictions still require significant amounts of work to move forward. However, this has not slowed the overall progress because stakeholders have agreed to the practice of "providing data as ready rather than waiting for the picture to be complete." By early 2003, eight provinces and three territories had supplied data to NDSS: Yukon Territory, Northwest Territories and Nunavut, British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Nova Scotia and Prince Edward Island. The other provinces. New Brunswick and Newfoundland and Labrador, are in the process of building their infrastructure and capacity in order to participate. Capacity also needs to be addressed for participation of Aboriginal groups.

At the provincial/territorial level, NDSS has built capacity for and interest in both diabetes surveillance in particular and chronic disease surveillance in general. Most provinces and territories have enhanced the surveillance capacity demonstrated by NDSS. A summary of their activities in these areas is contained in Appendix B.

Strengths and Limitations

Administrative databases have been proposed as sources of population surveillance of diabetes,¹⁻³ and are held to be accurate, timely and a costeffective source of surveillance data. The opportunity to use them for disease surveillance is a strong advantage both economically and strategically over having to collect new data. Nevertheless, because administrative databases exist primarily for purposes other than disease surveillance, they may not be ideal in some respects.

Administrative data cover the entire population, can be obtained without directly contacting individuals, are not subject to recall bias, and are

NDSS Basic Principles

Consistency - A core set of variables is collected in every province/territory on an ongoing systematic basis.

Flexibility - Additional data can be collected within individual provinces or territories in accordance with their unique needs (e.g. data from prescribed drug use).

Quality - Data are validated and the collection means are modified to ensure ongoing data integrity across the country.

Cost-effectiveness - NDSS uses existing data sources.

Accessibility - Data are available to the general public under conditions agreed to by the Steering Committee, in accordance with prevailing polices and regulations regarding federal, provincial, territorial, and Aboriginal data.

Confidentiality - Personal identifiers are removed, and only aggregate data are shared.

Responsiveness - Current information is disseminated to public and private stakeholders, thus enabling a prompt response to changing trends in diabetes.

largely computerized. Publicly funded health insurance in Canada is not dependent on income and covers almost the entire Canadian population. Funding exceptions are people under federal jurisdiction (e.g. in the military, in the RCMP, and in federal correctional facilities); however, they still have access to provincial/ territorial health services and their records of service use are included in the regional administrative data. Medical services outside the publicly funded system are not included; these

Attributes of the NDSS System

- ▼Distinct roles and responsibilities for provinces and territories, the federal government, Aboriginal groups, and other parties
- ▼A shared data dictionary for coordinating and comparing the administrative databases across provinces and territories
- ▼Three domains of measurement: descriptive epidemiology, complications and co-morbidities, and health services utilization
- ▼A discrete set of outcomes related to health services and health status that can generally be implemented across most provinces and territories
- Ability to produce annual person-specific summarizations of health services and health status information for surveillance purposes
- The option of using various case definitions
- ▼A series of aggregate datasets that reflect the major domains of measurement and measured outcomes, and a strategy for sharing data with parties outside the provinces or territories where the person-specific data are held
- ▼Software to run the system
- The ability to conduct longitudinal analyses

services are of limited availability in Canada, and most are not regarded as medically necessary.

Disadvantages in using administrative databases include the absence of detailed clinical information and information on determinants of health; duplication of information resulting from hospital transfers and people accessing services in more than one jurisdiction; and current inability to differentiate among the three types of diabetes. Also, administrative data include information only on those who use health services; for people with diabetes, only those with a diagnosis from a health professional are included.

The requirement that Health Canada use only anonymous aggregate data for national analyses may, at first, appear to be a serious constraint. However, because the aggregate data transferred to Health Canada can be customized to analysis needs, the model is not limiting. Furthermore, as discussed later, data access guidelines allow researchers to enter into agreements with provinces, territories, and Aboriginal groups for use of their data in **bona fide** research.

NDSS represents the first time that a coordinated national use of administrative data for public health surveillance purposes has been undertaken.

STRUCTURE AND GOVERNANCE

The NDSS governance structure (Figure 1) includes a multi-stakeholder Steering Committee, several working groups, Aboriginal community groups, national coordination and technical support based at Health Canada, and technical staff within each province and territory.

Steering Committee

The Steering Committee (Table 1) is the main decision-making body of NDSS. The Steering Committee reviews all NDSS activities, including recommendations by working groups, and

coordinates the publication and dissemination of information products directly resulting from NDSS activities. This body also acts as gatekeeper for NDSS national data, determining under what conditions NDSS-related data are to be made available to partners and third parties, with appropriate input and direction from data originators and custodians.

Any private-sector sponsors of NDSS may have observer status on the Steering Committee but do not have voting rights.

Figure 1. NDSS Governance Structure



Table 1.

Steering Committee Membership

(See Appendix C for names of members)

Provincial/Territorial Governments

Yukon Northwest Territories Nunavut British Columbia Alberta Saskatchewan Manitoba Ontario Quebec New Brunswick Prince Edward Island Nova Scotia Newfoundland and Labrador

Non-Government Organizations

Canadian Diabetes Association Canadian Institute for Health Information Canadian Institutes of Health Research Diabetes Council of Canada

Aboriginal Groups

Assembly of First Nations Congress of Aboriginal Peoples Inuit Tapiriit Kanatami Métis National Council National Aboriginal Diabetes Association

Federal Government

Health Canada – Centre for Chronic Disease Prevention and Control Health Canada – First Nations & Inuit Health Branch Statistics Canada

Academics/Clinicians (2)

Note: GlaxoSmithKline Inc. is a pioneering sponsor of NDSS and has observer status on the NDSS Steering Committee

Working Groups

Six working groups meet independently as needed and report to the NDSS Steering Committee. Working group activities and responsibilities are presented in Table 2 and current members are listed in Appendix D.

Partnerships

Partnerships are central to the NDSS, which has set a number of precedents in this area. Agreements are in place with some Aboriginal groups, the Canadian Institutes of Health Research, Health Canada, and the provinces and territories.

During 2000 to 2002, Health Canada and each of the 10 provinces and 3 territories signed Memoranda of Understanding (MOUs), which set forth the terms for administering federal funding for NDSS under the direction of the Steering Committee and through Health Canada's Operating and Maintenance (O&M) financial mechanism. The form of the MOUs is contained in Appendix E.

Three-way partnership activities among Aboriginal groups (First Nation, Métis, Inuit or other Aboriginal people in rural and/or urban locations), Health Canada and the respective provincial or territorial health ministry began in 2001. So far, MOUs have been signed in two regions – all First Nations in British Columbia and those in one area of Quebec.

Table 2. Working Groups and Areas of Responsibility

External Management Working Group

- ▼ guides interactions with key external stakeholders
- ✓ oversees efforts to obtain non-federal funding
- ▼ manages all other aspects of public relations
- * developed agreements between governments for data activities
- ▼ developed a duality of interest policy
- * developed guidelines for fundraising and sponsorship

Data Access and Publications Working Group

- * develops policies around conditions of NDSS data access, ownership, and publication
- * develops an annual publishing plan

Aboriginal Diabetes Working Group

- * promotes the development of the Aboriginal component of NDSS
- ▼ provides technical leadership
- * provides guidance in relation to Aboriginal data ownership, access, and privacy
- [▼] guides the development of a Memorandum of Understanding (MOU) between Aboriginal partners, respective provinces/territories and Health Canada

Validation Working Group

- * advises the NDSS Steering Committee on standardization of the surveillance case definition
- ▼ determines which variables are to be collected
- ${}^{f v}$ decides on methods to be used for database validation

Scientific Working Group

- provides support and advice to the Steering Committee on research initiatives/approaches to improving diabetes surveillance and analysis of NDSS data
- ✓ focuses on the state of knowledge of diabetes

Technical Working Group

- * focuses on the methods and algorithms for data development and programming
- ${}^{f v}$ is responsible for the evolution of the NDSS software
- * translates into practice the scientific ideas proposed by the validation and scientific groups
- ▼ fosters innovations for generating improved data products

Technical Consultants

- * responsible for the implementation of the NDSS software and hardware
- * documents the unique characteristics of the provincial/territorial databases

Responsibilities

Health Canada

Under the MOUs, Health Canada, through its Centre for Chronic Disease Prevention and Control, agrees to provide the resources needed to coordinate NDSS activities nationally. These include, but are not limited to, monitoring of staff. national NDSS-related infrastructure support of national NDSS-related personnel, participation on committees and working groups as appropriate, coordination of standardized data extraction and linkage, and establishment and maintenance of the central database of aggregate data from the provincial/ territorial/Aboriginal partners. Coordination also involves liaising with the various working groups, providing secretariat support, and promoting a coordinated work plan. In addition, Health Canada liaises with non-governmental partners with regard to private-sector funding for activities approved by the Steering Committee.

Provinces and territories

signatories to the Memorandum of As Understanding, all 13 provinces and territories are responsible for administering NDSS activities in their area, notably the maintenance of required software and the transfer of aggregate data to Health Canada. Provinces and territories also regionally located NDSS-related monitor personnel, provide infrastructure support for regional NDSS-related personnel, and participate on committees and working groups as appropriate. Provinces and territories are responsible for submitting resource allocation information for each year to the Steering Committee.

Aboriginal groups

The Aboriginal partners in NDSS have several roles. Initially, Aboriginal partners facilitate identification of their members in NDSS datasets prepared by the provinces and territories. Subsequently, Aboriginal partners contribute knowledge about and network within their membership to support data interpretation, use of appropriate communication styles, and dissemination. Aboriginal partners also anticipate a leadership role in applying NDSS findings to implement. and evaluate diabetes plan, strategies and to develop policy.

Guidelines

Appendix F presents guidelines relating to three areas – duality of interest; fundraising and sponsorship; and data access and publication. Highlights from each area are presented below.

Duality of interest

Within the context of membership on the Steering Committee, a situation involving duality of interest may arise in two ways: first, if a member has the opportunity to influence the business decisions of the Steering Committee in a way that could lead to personal financial gain for the member or his/her family; and second, if a member's interests are opposed to the interests of the Steering Committee. Disclosure of duality of interest is an agenda item for all meetings, and such disclosures are recorded in the minutes. A member shall not vote on, approve or recommend approval of a transaction or contract with which he or she is associated. Therefore, members with a conflict of interest are required to absent themselves from the meeting during discussion of any items pertaining to the conflict.

Fund-raising and sponsorship

A unique aspect of NDSS is the opportunity for private-sector sponsorship. One of the roles of the Canadian Diabetes Association (CDA), a non-governmental founding partner, was the mobilization of private sector sponsorship, most notably that of GlaxoSmithKline Inc. in 1999.

Principles for fund-raising have been established to ensure an open and transparent process. Private sponsors have no influence on the decisions and activities of NDSS, and cannot directly benefit from public knowledge generated by NDSS. Eligible sponsors are required to provide long-term commitment and to have an appropriate fit between NDSS and corporate business priorities.

Data access and publication

This policy outlines the procedures believed necessary to process research requests efficiently while ensuring both consideration of the public interest and full compliance with legislation. The policy covers data collected, linked and/or analyzed with the assistance of NDSS resources. Data and data products that can be accessed are unpublished aggregate data that reside at Health Canada, person-level data that reside at provincial and territorial sites, and NDSS programming codes.

The guidelines for data access cover:

- guiding principles (e.g. that the provinces, territories, and Aboriginal groups must be in agreement with any and all uses of their respective data);
- uses of data and products;
- ethical review for access;
- requirements to request access;
- disclosure (i.e. before release, reports containing any data requested through NDSS, or reports generated using NDSS data will be reviewed);
- protection of privacy and confidentiality; and
- ▼ destruction.

FOCUS ON ABORIGINAL POPULATIONS

The prevalence of diabetes in some First Nations populations is three to five times the national rate. Rates are even higher in some First Nations language groups, and there is a north-south gradient, with people in the south having higher diabetes rates than those in isolated northern communities.⁷⁻⁹

Rates of diabetes in other Aboriginal groups vary.⁹⁻¹¹ In the 1991 Aboriginal Peoples' Survey, self-reported diabetes prevalence was 5.5% among Métis and 1.9% among Inuit.¹⁰

In some Aboriginal populations, the prevalence rate of diabetes is three to five times the national rate.

Diabetes also develops at an earlier age among First Nations people and, in recent years, type 2 diabetes has been diagnosed in children.¹² Almost one-third of First Nations women with diabetes report first being given the diagnosis during pregnancy.⁷

Factors that pose a risk to Aboriginal populations are both heredity and lifestyle. The relatively recent shift from traditional diets high in animal protein to "modern urban diets" high in carbohydrates, combined with decreased physical activity, result in high levels of obesity that compound pre-existing risks for diabetes.

NDSS contains an "Aboriginal component" intended to address some of the unique information concerns of these populations. NDSS has endorsed the need to have Aboriginal people involved in its development.

Identifying Aboriginal Data

To identify records as belonging to an Aboriginal group, data routinely collected and managed by the province or territory are linked to the Aboriginal group's membership information in the province or territory. A temporary "identifier" is attached to selected records to allow extraction of Aboriginal-specific data. Routine NDSS calculations and data aggregation are then applied, and approved aggregate data files are submitted to Health Canada for national reporting.

A more complex and outstanding issue is how to identify and then create diabetes surveillance data for the urban Aboriginal population that includes non-status Indians.

Basic Principles

After review of the proposed NDSS model in 1999, Aboriginal representatives' questions about using personal health information led to the development of principles specific to their interests. These principles define aspects of the partnership arrangement and augment the basic NDSS principles. In particular, they address the need to identify and then minimize possible risks associated with the introduction of nominal membership lists into NDSS processes. Specifically, the Aboriginal partners require the following:

Consent - An Aboriginal organization with legitimate authority to represent a unique group of Aboriginal people would provide consent before any work begins in diabetes surveillance.

- Confidentiality The province or territory would not release Aboriginal data without the Aboriginal partner's approval.
- Privacy Aboriginal groups would have enforceable assurances that the privacy of their membership lists and that of members is protected when their information is used to identify Aboriginal people within pre-existing NDSS datasets.
- ▼ **Data Storage** Aboriginal partners would specify where, for how long, and under what conditions data storage occurs, if at all.
- Ownership and Control Aboriginal groups would hold principal ownership of NDSS non-nominal, person-level data and would specify when and under what conditions others may have access to the data. Aggregate data would be released for national reporting, and access by others would be controlled by the MOU and existing NDSS policy.

Partnerships

The proposed collaboration involves three-way partnerships among Aboriginal groups, provinces/territories and Health Canada. The process for forming these partnerships is influenced by the priorities of all three parties and by each Aboriginal group's unique political and social history that defines inter-governmental relations. Rarely does either the history or current relations facilitate discussion.¹³

Staff shortages and constraints can interfere with moving the recognized problem of diabetes into the active phase of a decision-maker's agenda. Also, Aboriginal leaders are often fully focused on more urgent political or social threats and must follow the established protocol for communicating issues to membership and gaining their support in new initiatives. Yet, despite these difficulties, concerns are being allayed and partnerships are forming.

Progress includes development of two MOUs. One MOU in Quebec involves the Cree Board of Health and Social Services of James Bay; the other MOU in British Columbia involves the First Nations Chiefs' Health Committee, First Nations Summit. In these regions, there was a pre-existing infrastructure and a data-sharing process ready to accommodate the opportunity to carry out diabetes surveillance. Other First Nations, Métis and Inuit groups are considering or are involved in developing MOUs to participate in diabetes surveillance. Though this work will take time, the models for an MOU in British Columbia and Quebec will assist this process.

METHODS OF DATA CAPTURE

NDSS uses person-specific administrative databases organized originally to support payment of claims under publicly funded health insurance. In Canada, publicly funded health insurance is mainly the responsibility of the provinces and territories and covers almost the entire population.

NDSS uses three types of databases, which exist in all provinces and territories and can provide data by fiscal year: the physician claims file, the hospital file, and the health insurance registry. These databases are linked by a unique lifetime identifier that is usually an encryption of the personal health insurance number.

In each province and territory, the files are restricted to residents to avoid duplicate counting of people, since tracking individuals who live in one jurisdiction but obtain much of their care in another or who migrate back and forth between provinces is problematic. NDSS does not yet use other data sources, such as prescription drug use databases, that are either not consistent or not available across the country.

The provincial/territorial physician claims file and the hospital file supply numerator data; the health insurance registry supplies denominators and socio-demographic characteristics.

Physician Claims File

Physicians' services performed in hospital, office or clinic are captured in the physician claims file. With few exceptions, each physician claim contains only one diagnosis, coded using ICD-9.¹⁴ Some provinces allow up to three diagnostic codes per claim. NDSS uses only the first code for consistency. This may result in systematic under-reporting but generates comparable data for describing trends.

The physician claims file is central to the diabetes case-ascertainment algorithm and to algorithms being developed for estimating complications and health services use. Information in the claims file about payments for services may also be useful as algorithms are developed to refine estimates of the economic burden of diabetes.

Table 3. Percentage (%) of Physicians Paid only on a Fee-For-Service Basis

	Fiscal Year	
Province	1995/96 ¹⁵	1999/00 ¹⁶
British Columbia	92	79
Alberta*	98	98
Saskatchewan	84	82
Manitoba*	47	40
Ontario*	94	93
Quebec	62	61
New Brunswick	52	58
Prince Edward Island*	92	63
Nova Scotia*	74	62
Newfoundland and Labrador	73	46

* shadow billing

A limitation of the claims file is that physicians not paid on a fee-for-service basis are not always required to submit medical claims. Table 3 shows the distribution by province of physicians paid only on a fee-for-service basis. Other payment schemes include salary, contract, capitation, and partial fee-for-service. Alternative payment of physicians is more frequent for some specialties, in remote areas, and for some primary health care centres. However, in some jurisdictions physicians under alternative payment schemes are still expected to remit service information, otherwise known as "shadow billing".

Hospital File

Information about each hospital visit or stay is collected at discharge using an abstracting form. Diagnoses are coded using ICD-9 or ICD-9-CM. All jurisdictions except Quebec currently submit discharge abstract data to the Canadian Institute for Health Information, where data quality edits are conducted¹⁷ and the data are compiled into the Discharge Abstract Database (DAD). Quebec uses a similar process for data quality checks.

The diagnostic information is used in the diabetes case ascertainment algorithm (although fewer

than 2% of cases have only a hospital diagnosis^{18,19}). Although there may be several diagnostic codes for a single admission, only the first three are used because of data limitations in some provinces and territories. Also, records relating to day surgery are excluded because some provinces do not include these procedures in their hospital discharge files.

Health Insurance Registry

The registry contains a record for each person entitled to coverage under the provincial/territorial health insurance scheme. NDSS abstracts sex, date of birth (to calculate age) and geographic code from this file (even though the information may also exist in the other files).

The registry is also used to determine whether people using hospital or medical services are residents. Hospital records or records of physicians' services with health insurance numbers not in the registry file for that year are excluded from further processing.

The registry file supplies denominators for rate calculations. Therefore, assessments of the registry's accuracy for this purpose are needed. In particular, how closely this file represents the population depends upon its being regularly updated with deaths and migrations.

Generally, the date of death, or information allowing its estimation, is recorded in the registry. Comparisons of provincial/territorial death counts with counts from Statistics Canada (Figure 2 and Appendix G) have demonstrated that, for most jurisdictions, the registry is updated with death information. Some problems have been identified with updates in British Columbia.

Figure 2. Comparison of NDSS with Statistics Canada Deaths, April 1995 to March 1999, by Province/Territory



METHODS OF DATA CAPTURE

Comparisons of the mid-year population counts available from the registries with mid-year estimates available from Statistics Canada (Figure 3 and Appendix G) have demonstrated that, for most jurisdictions, registry updating provides population counts within 1% of the Statistics Canada estimates.

Figure 3. Comparison of NDSS with Statistics Canada Population Counts, July 1997/98/99, by Province/Territory



Problems identified in British Columbia are associated with the premium system used there. Some duplicate counting of residents occurred in Ontario, but the numbers were within 4% of Statistics Canada estimates. Quebec's registration file was used only for people with diabetes. Therefore, for this report, Quebec has used estimates from l'Institut de la Statistique du Québec rather than the registry population as the denominator. In Nunavut, death data were not vet available for this report. All other provinces and territories were able to use the registry as a denominator, thereby more accurately reflecting the population that generated the case counts obtained from the physicians' services claims and hospital files.

Annual population counts are consistently higher than the mid-year counts, by 4% for the provinces and 8% for the territories (Appendix G), reflecting the difference between counting people and counting person-years; the sum of person-years will approximate the mid-year population count, but a count of people will

include those who reside in a province or territory for any portion of a year. This effect is most evident in the 40-55 age group (because of migration) and in the 80+ age group (because of deaths).

Data Processing at the Provincial/Territorial Level

Data processing at the provincial/ territorial level, for which programs using SAS[®] (Cary, NC) software have been developed, involves five discrete phases, illustrated in Figure 4 and summarized below:

- Select required data elements and translate provincial/territorial data element names/ types/codes into the NDSS standard.
- Summarize each data source into one record per person per year based on selected criteria.
- Merge the registry, hospital and physicians claims data, matching the unique identifier.
- Apply the diabetes case definition.
- Summarize the data by age group and sex and apply the appropriate calculations.

The first phase is customized to each jurisdiction, but all the remaining tasks are identical across all provinces and territories.

Physician Claims	Ho	spital	Registry	Phase 1 Conversion/Translation	
 unique identifier date of service diagnosis code fee item (service/procedure) amount paid 	 unique idei admission separation diagnosis of procedures inpatient/display= 	ntifier date date codes (up to 16) 6 (up to 12) ay surgery	 Unique identifier sex Province/territory date of birth (age) geographic code fiscal year days of coverage in year date of death 	 Select required data elements Rename and translate variables into NDSS standard definitions Sort data by fiscal year Multiple records per person per year permitted 	
 Optional Iocation where service provied (hospital/office) physician specialty 	Optional ✓ resource intensity (RIW) ✓ RIW exclusion factor		 Optional insurance start date insurance end date insurance end reason insurance start reason 		
 Data elements added: count of claims with diagnosis of diabetes recorded service date on first claim in fiscal year with diabetes as diagnosis service date of second claim in fiscal year with diabetes as diagnosis 	Data elements v separation hospital sta diabetes as diagnoses v total numb days during	 Data elements added: separation date for earliest hospital stay in year with diabetes as one of the diagnoses total number of hospital days during stay 		 Phase 2 Summarization Sort data by ID and date Summarize data into one record per person per year (linkage requires unique identifier) Add/calculate data elements One file per fiscal year 	
 Annual Person Level Summary File (APLSF) Data elements added: case date for diabetes case definition historic data elements from previous years days with diabetes in current year days without diabetes in current year 					
 Incidence and Prevalence Output by P/T, age group, sex and year incident, prevalent and non-cases person-years at risk for incident, prevalent and non-cases incidence and prevalence rates 			prtality Output File group, sex and year ng diabetics and non-diabetics s tes for diabetics and cs	 Phase 5 Create Aggregate Data data summarized age groups can be specified optional cell suppression for cells with 1-5 observation 	

Figure 4. Data and Process Flow Diagram

METHODS OF DATA CAPTURE

The first phase, using a copy of the provincial/territorial file, is to reduce the number of variables retained in the file and to translate variable names from provincial/territorial-specific coding standards to a shared diabetes data dictionary. The remaining data processing steps (see Figure 4) summarize individual transaction data into an annual summary, build the annual person-level summary file (APLSF) and generate aggregate datasets.

A separate APLSF is constructed for each year. The APLSF is composed of a single record summary for each person in the registry file regardless of diabetes status or whether insured services were used in the year. The record summary documents the year's medical and hospital information for each person, including evidence needed to determine whether the case definition was triggered. As NDSS develops, complications and health services use will be included in this file.

The APLSF retains personal health identifiers (or encrypted variants), allowing longitudinal tracking of individuals over time and, with appropriate consents, linkages to other datasets.

In a final step, additional variables are added to the file, reflecting (where they exist) selected data from the individual's record in the APLSF file for previous years; this is of particular importance in determining whether a specific diagnosis is new or pre-existing.

Because the APLSF holds data on individuals as well as information such as dates of diagnosis, birth and death, the file is regarded as personal health data under the authority of existing legislation and policy directives within each province and territory. This makes the APLSF file inappropriate to distribute outside the province or territory. The provinces and territories provide data aggregated by age group and sex to the national office of NDSS (Health Canada). Data are suppressed where the number of individuals represented in a cell is smaller than five. The data are provided in a SAS[®] dataset, which is described in Table 4. Definitions for the variables in the APLSF dataset are provided in Appendix H.

The APLSF provides considerable flexibility in how aggregate datasets might be created. For example, age groupings can be arbitrarily defined to suit analytic need, provided that the analytic need is not inconsistent with the need to ensure the confidentiality of personal health data.

Data Processing at the National Level

The aggregate datasets provided by the provinces and territories to Health Canada are the primary surveillance products arising from NDSS. As these products are not personal health data under the definitions of existing provincial policies or legislation, they are suitable for distribution and dissemination.

The national calculations are the responsibility of the national office. To adjust for the effects of differing age distribution on the rates, the provincial/territorial data are standardized by specific age group to the 1991 Canadian Census population (Appendix I).

Category	Data Element Description	Data Element Name
Demographic variables	 Province or Territory	PT YEAR SEX AGEGRP
People with a diagnosis of diabetes in current year	 Incident Cases: number of people with DM diagnosis in the current year Person-years of observation after DM diagnosis in current year Person-years of observation before DM diagnosis in current year	INCASE INPYODM INPYONDM IR
People with a diagnosis of diabetes prior to current year	 Prevalent Cases: number of people with DM diagnosis prior to current year Prevalent Person-years. 	PREVCASE PREVYRS
Prevalence (period) for current year	[▼] Period Prevalence Proportion	PR
People not given a diagnosis of diabetes	 Number of people not given a diagnosis of DM Person-years Observed without diabetes 	NONCASE NONDMYRS
Mortality among people with diagnosis of diabetes	 Number of deaths among prevalent diabetes cases	N1 D1 Rill
Mortality among people without a diagnosis of diabetes	 Number of deaths among people not given a diagnosis of diabetes Person-years of observation for people not given a diagnosis of diabetes who died Death rate for people without diabetes 	N2 D2 Rnil
Mortality comparison	Veath rate with diabetes/death rate without diabetes (Rill/Rnil)	RR

Table 4.Contents of the Canadian Aggregate Datafile

Definitions and Calculations

Diabetes case

The case definition currently used in NDSS requires that an individual have the following:

- one hospitalization with an ICD-9 code of 250 (diabetes mellitus), selected from the first three diagnostic codes on the hospital files, or
- two medical claims with an ICD-9 code of 250 within 730 days, selected from the first diagnostic code.

The case date is currently defined as the earliest date at which the case definition is met.

Age

Age is calculated as age as of the end of the fiscal year. The age groups for national use are decades between 20 and 49 (20-29, etc.) and 5-year age groups thereafter (50-54, etc.) to age group 85+.

Prevalence

Prevalence is the probability that an individual within a population will have diabetes during the year.

In the NDSS, diabetes prevalence is calculated as follows:

- (total number of people with a diabetes case date prior to March 31 of the current fiscal year) ÷
- (total population count for the current fiscal year).

The denominator uses the count for the entire year rather than the mid-year estimate, thereby including people who migrate or die during the year, since they are included in the numerator. In Quebec, however, the denominator is the census-based population estimate provided by the ministère de la Santé et des Services sociaux du Québec and calculated by the Institut de la statistique du Québec.

Mortality

The mortality rate refers to the force of diabetes mortality for the total population. This measure can refer either to deaths *due* to diabetes or to deaths of people *with* diabetes. Within NDSS, the mortality rate is calculated separately for people with diabetes and those without diabetes. Cause of death is not available, and therefore any mortality analyses are based on ALL causes of death and not just deaths due to diabetes.

In NDSS the mortality rate among people with diabetes is calculated as follows:

- (total number of deaths among people with diabetes during the current fiscal year) ÷
- (total number of people with diabetes during the current fiscal year).

The mortality rate among people without diabetes is calculated as follows:

- (total number of deaths among people without diabetes during the current fiscal year) ÷
- (total number of people without diabetes during the current fiscal year).

The mortality rate ratio is calculated as follows:

- \checkmark (death rate among people with diabetes) \div
- ▼ (death rate among people without diabetes).

In Quebec, the number of deaths among people without diabetes is derived from the Fichier des décès (vital statistics, deaths), from which the number of deaths among people with diabetes is subtracted. The denominator for the rate among people with diabetes is the difference between census-based population estimates and the number of people with diabetes.

Data Validation

Since much of the administrative data used by NDSS was designed for billing purposes (particularly physicians' services) rather than for disease surveillance, the diagnoses captured require validation. Such validation is ongoing and takes several forms. Accuracy of the case-definition algorithm is evaluated against a gold standard that allows calculation of measures of specificity and sensitivity, and then these measures are examined in various ways:

- across jurisdictions
- ▼ against various gold standards
- ▼ over time
- ▼ for incident versus prevalent cases
- for special populations
- for designated complications
- for health services use

Validation work has substantiated the use of the NDSS algorithm for prevalence and mortality calculations using five to seven years of data for adults.

The case definition within NDSS is flexible enough to incorporate improvements in the algorithm suggested by the validation process.

Validation of the NDSS algorithm began with publications in 1991 and 1996 and is still ongoing. Currently, nine of the 13 jurisdictions are participating in validation studies. Recently, the NDSS and the CIHR Institute of Nutrition, Metabolism and Diabetes jointly funded population health and validation research on diabetes.

Various gold standards have been used, including records from diabetes education³ and care¹⁹ programs, the National Population Health Survey,²⁰⁻²² a provincial health survey,¹⁹ a provincial diabetes registry¹⁸ and medical charts.²³ Other studies, currently under way are using prescription records for insulin and oral hypoglycemic medication, and clinical data.

So far, validation work has indicated that

- self-reported survey data should not be used as a gold standard, since they underestimate the true disease burden in the population;^{21,22}
- new cases and prevalent cases are difficult to differentiate in the early years,² and at least five years of data are needed before stable estimates can be obtained;^{6,18}
- the increase in prevalence among females seen during the child-bearing years may be the result of miscoding of gestational diabetes;
- sensitivity measures have been 69%,¹⁹ 85%^{18,23} and over 95%,³ depending upon the gold standard used and the jurisdiction where the study was conducted;
- ▼ **specificity** has been over 95% and has varied less than sensitivity;^{18,19,23}
- positive predictive value has been 78% and 80% in two studies of adults,^{18,23} but has been found to be low in children;²⁴
- sensitivity, specificity and predictive value may be stable for five to seven years of data for adults, but they fall as more years of data are included and prevalent cases over-accumulate.¹⁸

The validation studies and definitions are described in greater detail in Appendix J.

FACTS AND FIGURES

The following represents the first comprehensive compilation and public dissemination of data by NDSS. The data presented below are derived from the data collection period starting in 1995/1996. The first two years constituted the run-in period required by the case definition. Therefore, the earliest data presented here are for the fiscal year 1997/1998, and the most recent vear of data available for this report is 1999/2000.

The information represents eight provinces and three territories, accounting for over 95% of the Canadian population. Data from New Brunswick and Newfoundland and Labrador are not included in this report.

In 1999/2000, 5.1% of Canadian adults were living with diagnosed diabetes.

Prevalence

In 1999/2000, 5.1% of Canadians (1,196,370) aged 20 and over were living with diagnosed diabetes (Figure 5). This rate is higher than the self-reported rate of diabetes among people aged 20 and over found by the National Population Health Survey in 1998/99 (3.9%),²⁵ or even the self-reported rate found by the more recent Canadian Community Health Survey 2000/01 (4.7%).²⁵ This is consistent with validation studies^{21,22} showing that self-report survey data underestimate the true disease burden in the population.

NDSS prevalence estimates represent diagnosed diabetes among health services users. Prevalence may be underestimated by 30% as a result of subclinical, undiagnosed diabetes.²⁶

The data include both type 1 and type 2 diabetes, as ICD-9 (code 250) does not differentiate between the two. However, since the data are restricted to people aged 20 years and over, they largely represent type 2 diabetes. Although gestational diabetes has its own ICD-9 code (648.0), it is often miscoded as type 1/type 2 and therefore some cases of gestational diabetes are included in these tabulations.



Figure 5.

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Prevalence over time

Figure 5 suggests increasing prevalence. This increase is expected for a chronic condition such as diabetes that has a lengthy disease duration. However, at this early stage of diabetes surveillance, the observed increase in prevalence is due, in part, to detection of cases diagnosed before the start of observation (1995/1996). Future NDSS reports will be based on more than five years' of data, allowing a clearer distinction between prevalent (existing) and incident (new) cases.

Prevalence by sex

Figure 5 also demonstrates that diabetes is more common among Canadian men aged 20 and older (5.4%) than among women (4.9%). An exception to the male pre-ponderance occurs in

the child-bearing years (20-39), where cases of gestational diabetes may be miscoded as type 1/type 2 diabetes (Figure 6).

Prevalence by age group

For both sexes, prevalence increases with age, peaking in the 75-79 age group at 15.5% (17.4% among males and 14.2% among females) (Figure 6). People aged 65 and over account for almost 50% of diabetes cases but represent only about 15% of the population aged 20 and over. The slight decrease in prevalence in the oldest age groups (80+) may be the result of mortality associated with diabetes or an artefact of limiting the number of conditions coded per visit; increased co-morbidity at older ages increases the likelihood that conditions other than diabetes will be recorded.



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Figure 6. Prevalence* of Diabetes in Canada, 1999/2000, by Age and Sex
Prevalence by region

Table 5 presents age-standardized prevalence rates by fiscal year, province/territory and sex for people aged 20 years and older. Detailed prevalence data by age, sex, jurisdiction and fiscal year are found in Appendix K. Figure 7 compares the provinces and territories using agesex standardized rates and 95% confidence intervals.

For the majority of jurisdictions, age-sex adjusted prevalence ranges from 4.0% to 5.5%. Apparent differences among the provinces should be interpreted with caution because of the effects of different populations, different data collection procedures, and variations in the likelihood of diagnosis. For example, Manitoba's higher rate may reflect the fact that Aboriginal people represent a relatively high proportion of its population (13%)²⁷ and that diabetes prevalence among Aboriginals is 3 to 5 times higher than the national rate.⁷ This emphasizes the need to

identify specific populations at high risk of diabetes, such as Aboriginal groups.

Differences between provinces and territories may not result from differences in the level of diabetes in the population. For example, the territories have the highest proportion of Aboriginal peoples (22% in the Yukon, 46% in the Northwest Territories and 81% in Nunavut)²⁷ but the lowest prevalence rates. This may be because of the inability of some administrative data to capture diabetes diagnoses outside the fee-for-service payment system. To investigate this, Nunavut is conducting a pilot project that includes addition of community health nurse data to NDSS, and other validation projects are underway (Appendix J).

Finally, differences between provinces and territories may reflect differences in the likelihood of diagnosis. For example, the three provinces with the highest prevalence (Manitoba, Nova Scotia and Ontario) also have the most established diabetes programs.²⁸

	1997/	1997/1998		1998/1999		1999/2000	
	Female	Male	Female	Male	Female	Male	
Yukon	3.1	3.2	3.6	3.4	3.9	3.8	
Northwest Territories	3.4	3.1	3.7	3.5	3.9	4.0	
British Columbia	3.4	4.1	3.8	4.5	4.0	4.8	
Alberta	3.2	3.8	3.6	4.2	3.8	4.5	
Saskatchewan	3.7	4.4	4.0	4.8	4.1	5.0	
Manitoba	4.4	4.8	4.9	5.3	5.3	5.8	
Ontario	3.9	4.7	4.3	5.1	4.7	5.5	
Quebec	3.8	4.6	4.1	5.0	4.3	5.2	
Prince Edward Island	3.4	4.4	4.0	5.1	4.1	5.2	
Nova Scotia	4.4	5.2	4.8	5.6	4.9	5.8	
CANADA	3.8	4.5	4.1	4.9	4.4	5.2	

Table 5. Prevalence* of Diabetes in Canada, by Fiscal Year, Province/Territory and Sex

* Rate per 100 people aged 20+, age standardized to 1991 Canadian population

FACTS AND FIGURES



Figure 7. Prevalence* of Diabetes in Canada by Province/Territory, 1999/2000

Since one of the goals of NDSS is comparable information on diabetes, the impact of these issues is being more closely examined. In the future, we expect to have a better understanding of differences in systems that may affect the data collection and, ultimately, regional comparisons.

Mortality

In 1999/2000, the death rate among Canadian adults with diabetes was 1,393 per 100,000 (age-sex standardized to the 1991 Canadian population). This includes deaths due to external injuries or other causes that may not be directly related to diabetes. This all-cause mortality of 41,483 Canadians aged 20 years and over with diabetes is 6.5 times the 1999 mortality count of

6,131 Canadians aged 20 and older whose leading cause of death was listed as diabetes.²⁹

The all-cause mortality rate seems to support past calculations estimating that the number of diabetes-related deaths is over five times the number of deaths with diabetes coded as the underlying cause.³⁰ Studies have demonstrated that only 28% of death certificates with any mention of diabetes were coded with diabetes as the underlying cause of death^{31,32} and that diabetes was not mentioned at all for 41% of people with diabetes who died.³¹

Canadian adults with diabetes are twice as likely to die prematurely, compared to persons without diabetes.

Mortality over time

Figure 8 shows the age-standardized death rates by fiscal year. In all years, the death rate is significantly higher among those with diabetes than those without for both sexes. While the death counts are increasing, the mortality among people with diabetes relative to those without is stable over time (see Appendix L for mortality rate ratios).

Mortality by sex

Across all three fiscal years, male mortality is consistently higher than female mortality among both people with diabetes and those without. However, mortality among people with diabetes relative to those without is slightly higher for women (mortality rate ratio 2.11) than for men (mortality rate ratio 1.87).



Figure 8. Canadian Mortality* Rates by Fiscal Year, Sex and Diabetes Status

Mortality by age group

Figure 9 shows that for all age groups the death rate for people with diabetes is higher than the death rate for those without. Figure 9 also shows the rate ratio, which compares mortality rates among people with and without diabetes. The rate ratio is higher in the younger age groups and gradually decreases for the older ones. This means that a 35-year-old Canadian with diabetes is 4 times more likely to die than a person without diabetes. 1.4 times more likely to die than a person without diabetes.

Mortality by region

Canadian adults with diabetes are twice as likely to die prematurely as adults without diabetes. Figure 10 demonstrates that this age-sex standardized ratio is between 1.8 and 2.1 for the

> majority of jurisdictions. The three smallest jurisdictions (Prince Edward Island, the Northwest Territories and the Yukon territory) have a rate ratio less than 1.5. The smallest jurisdictions have zero death counts in many of the younger age categories, artificially reducing their age- standardized mortality rates.

> Comparisons of mortality rates by region are influenced by many factors. Since people with diabetes are older than the general population, age-standardization makes the rates more comparable. The mortality rate ratio provides comparison of the mortality of people with diabetes relative to those without diabetes. Table 6 presents age-standardized



Figure 9. Canadian Mortality Rates by Age and Diabetes Status, 1999/2000

mortality rates by fiscal year, province/territory, sex and diabetes status. Detailed mortality data by age, sex, jurisdiction and fiscal year are found in Appendix L.

National Impact

NDSS data begin to paint a picture of the burden of diabetes in Canada. Diabetes is a large and growing health problem in Canada. Prevalence is increasing and is particularly high among older adults. The mortality associated with diabetes is considerable. The next NDSS report will contain incidence data that can be used to study risk factors for use in projection models.

Figure 10. Comparison of Mortality* for Canadians With and Without Diabetes, 1999/2000, by Province/Territory



FACTS AND FIGURES

		1997/1998		1998/1999		1999/2000	
		Female	Male	Female	Male	Female	Male
Yukon	Diabetes	1.69	1.45	0.99	0.71	0.91	1.37
	No diabetes	0.64	0.86	0.78	0.99	0.66	1.15
	Ratio	2.60	1.70	1.30	0.70	1.40	1.20
Northwest Territories	Diabetes	1.80	0.59	1.78	0.86	1.36	0.36
	No diabetes	1.01	1.64	1.39	1.66	0.76	1.08
	Ratio	1.80	0.40	1.30	0.50	1.80	0.30
British Columbia	Diabetes	1.11	1.59	0.97	1.47	0.96	1.39
	No diabetes	0.56	0.87	0.52	0.80	0.49	0.76
	Ratio	2.00	1.80	1.90	1.80	2.00	1.80
Alberta	Diabetes	1.19	1.52	1.10	1.43	1.06	1.47
	No diabetes	0.60	0.93	0.54	0.88	0.55	0.87
	Ratio	2.00	1.60	2.10	1.60	1.90	1.70
Saskatchewan	Diabetes	1.12	1.56	1.16	1.58	1.16	1.70
	No diabetes	0.59	0.94	0.56	0.96	0.56	0.93
	Ratio	1.90	1.70	2.00	1.70	2.10	1.80
Manitoba	Diabetes	1.30	1.48	1.17	1.81	1.18	1.59
	No diabetes	0.57	0.93	0.61	0.97	0.58	0.95
	Ratio	2.30	1.60	1.90	1.90	2.00	1.70
Ontario	Diabetes	1.23	1.74	1.15	1.58	1.10	1.56
	No diabetes	0.57	0.87	0.53	0.82	0.53	0.80
	Ratio	2.20	2.00	2.20	1.90	2.10	1.90
Quebec	Diabetes	1.53	2.27	1.37	2.02	1.36	2.01
	No diabetes	0.66	1.16	0.64	1.11	0.61	1.04
	Ratio	2.30	2.00	2.10	1.80	2.20	1.90
Prince Edward Island	Diabetes	0.71	0.88	0.73	1.30	0.84	1.27
	No diabetes	0.60	1.04	0.60	1.03	0.58	1.01
	Ratio	1.20	0.80	1.20	1.30	1.50	1.30
Nova Scotia	Diabetes	1.17	1.70	1.02	1.41	1.23	1.60
	No diabetes	0.65	1.07	0.58	0.97	0.58	0.94
	Ratio	1.80	1.60	1.70	1.40	2.10	1.70
Canada	Diabetes	1.28	1.79	1.17	1.66	1.15	1.64
	No diabetes	0.59	0.95	0.56	0.90	0.55	0.87
	Ratio	2.20	1.90	2.10	1.80	2.10	1.90

 Table 6.

 Canadian Mortality* Rates by Diabetes Status, Fiscal Year, Province/Territory, and Sex

*Rate per 100,000 people aged 20+, age standardized to the 1991 Canadian population

ACCOMPLISHMENTS, PLANS AND POSSIBILITIES

The NDSS has accomplished a great deal in the four years since the Prairie Pilot Study demonstrated the feasibility of the concept of a coordinated, national use of administrative data for public health surveillance. In particular, NDSS has built a firm foundation and framework to support its ongoing development. Much of this early and necessary work has involved charting new territory in relation to federal-provincial-Aboriginal group agreements, capacity-building, data-sharing, governance and guidelines. Some of the fruits of these efforts have been realized in the production of the first national diabetes surveillance data. NDSS accomplishments are detailed in Table 7 and are summarized below in terms of what NDSS tells us, what it cannot tell us, and what it will tell us in the future.

What NDSS Tells Us

In a relatively short period of time, NDSS has demonstrated, first and foremost, that data collected for administrative purposes can also be used to inform policy relating to a major public health problem in Canada. In particular, NDSS can measure prevalence, incidence and outcomes over time for both the nation as a whole and for specific regions. It can also compare health services use and other health problems of people with and without diabetes.

Second, NDSS has demonstrated that, despite regional differences, the various jurisdictions across Canada are able to cooperate to achieve the shared goal of reducing the burden of diabetes. In so doing, they have arrived at a set of common standards and definitions for diabetes that can be applied across the country. Third, NDSS has developed a prototype of disease surveillance that can be applied to other diseases and conditions.

Fourth, the ability to examine trends (age-, sexand region-specific) and to compare the health experience of people with and without diabetes means that NDSS data can also be used to examine many research questions.

Fifth, the suite of databases available to NDSS permits numerous cross-validation studies and provides a richer dataset than could be achieved with a single database.

Finally, NDSS demonstrates that Canada continues to be a world leader in the development of record-linkage and database methods.

What NDSS Does Not Tell Us

The NDSS has some limitations, many of which may eventually be overcome. The one of most concern is the inability to distinguish among type 1, type 2 and gestational diabetes. Current work to distinguish gestational diabetes is promising.

A second limitation results from population mobility and the consequent difficulties of record duplication and losses to follow-up, both of which contribute to data inaccuracies. A partial solution to this problem may be periodic linkages of the provincial/territorial databases with the National Mortality Database for death clearance.

Third, information on risk factors for diabetes is currently very limited.

Table 7.NDSS Accomplishments

Governance model

- * Established the necessary partnerships at federal, provincial and territorial levels
- * Established a governance model for a distributed system
- * Obtained buy-in from all provinces and territories, and some Aboriginal groups, with input also from academia and industry
- * Established Health Canada's leadership role as a facilitator

Capacity-building

- * Implemented a capacity-assessment exercise
- * Devised and implemented solutions for capacity inequities among jurisdictions
- * Initiated capacity-building at various levels, according to jurisdictional readiness
- * Created technical consultant positions in all provinces and territories

Data-sharing agreements

- * Reviewed each jurisdiction's legislative framework relating to participation in NDSS
- Developed and implemented a series of data-sharing MOUs accommodating each jurisdiction's privacy and confidentiality requirements
- * Tested and verified a process for development of data-sharing agreements

Dedicated resources

- ▼ Obtained multi-year funding for system development
- * Submitted detailed business plans and expenditures

Duality of interest

Developed guidelines to ensure disclosure of conflict of interest, abstinence from action where necessary, and respect for confidentiality

Sponsorship

* Developed guidelines to provide an open and transparent process, restrict influence on decisions, and allow for diversity of funding

Data validation

- ▼ Adopted a standard case definition for diabetes
- * Determined the core set of variables to be collected
- * Began data validation (ongoing)
- * Collaborated with the CIHR to fund validation projects using NDSS

Data management

- Identified data sources
- * Obtained agreement on the structure and organization of the databases
- * Developed provincial and territorial databases to permit necessary linkages
- Provided technical solutions for data paring to include the necessary variables/records only and for transferring data from existing hardware to the NDSS hardware/space
- ♥ Provided standard software for transforming data to NDSS format
- * Produced a person-level summary file that is maintained by the provinces and territories

Data access and publications

- * Determined data ownership
- * Developed policies for data access and for NDSS database/information publication rights

Reporting and dissemination

- * Provided provinces with data for provincial performance indicator reporting (PIRC)
- * Provided aggregate data for the 2002 *Diabetes in Canada* report
- * Produced the first NDSS report on diabetes prevalence and mortality

ACCOMPLISHMENTS, PLANS AND POSSIBILITIES

What NDSS Will Tell Us in the Near Future

Current NDSS funding extends until the end of March 2004. The original vision and goals for NDSS identified several items that require additional time for completion.³³ Progress towards achieving these goals is discussed below.

Population coverage

New Brunswick has recently provided data to NDSS, and Newfoundland and Labrador are also planning to provide data for the 2004 NDSS report. Ongoing work on the validation of a diagnostic algorithm for people under the age of 20 should be completed in 2003. With these developments, the 2004 NDSS report should contain data on all Canadians.

Incidence

Incidence calculations have been defined, but require at least five years of data to allow time for the rates to stabilize. Incidence data will be included in the 2004 NDSS report.

Health services use

The databases already in use for NDSS will support analysis of health services use by both people with and those without diabetes. This analysis can include physician visits, specialist visits and hospital use. The development of methods for applying costs to service use will permit refined estimates of the economic burden of diabetes. Days of hospital stay and number of services provided will be included in the 2004 NDSS report.

Complications

One of the primary goals of NDSS is to develop the capacity for long-term monitoring of diabetes-related complications. The Prairie Pilot developed a stroke module that is ready for testing with NDSS software. The next priority of the Validation Working Group is the development of standard definitions for diabetes complications, and the identification and validation of data sources. The 2004 NDSS report will include estimates of diabetes-related cardiovascular disease, cerebrovascular disease, peripheral vascular disease, retinopathy and renal disease.

Aboriginal participation

Data for the Aboriginal population in Canada are currently captured by NDSS but not identified. So far, two Aboriginal groups (one in Quebec and one in British Columbia) are working on identification of Aboriginal data. The 2004 NDSS report will include data for at least one First Nations group.

Dissemination

National-level dissemination of some NDSS surveillance information has been achieved. Some jurisdictions (Ontario,³⁴ Quebec³⁵ and Prince Edward Island³⁶) have taken initial steps towards meeting the objective of regional dissemination, and British Columbia, Alberta, and Nova Scotia plan to release data in 2003. Software updates are anticipated in 2003 to allow regional analyses.

What NDSS May Tell Us in the Long Term

NDSS was designed with flexibility in mind to accommodate several additional surveillance "modules". The phase of diabetes surveillance beyond March 2004 could include one or more of these modules.

Risk factors

Information on determinants of diabetes, including modifiable risk factors, is required to build a complete surveillance picture for diabetes (see Table 8). Risk factor information is crucial to the development of effective prevention and control strategies, a fact reflected in the recent directive from the Conference of Deputy Ministers of Health for the establishment of a surveillance system for chronic disease risk factors.

Health Canada's *Canadian Diabetes Strategy* (CDS) prevention group has identified activity level, body mass index (BMI) and dietary intake as three important risk factors on which to conduct surveillance.

Because this type of information is not available through the data sources currently available to NDSS, it will have to be obtained through surveys, with their attendant technical (data comparability, record linkage) and governance (access, privacy) requirements and costs.

Care indicators

The CDS care group has recommended the incorporation of indicators for care into diabetes surveillance. Hence, a list of core clinical and self-care indicators is under development. Applied expertise will be required to formulate methods for distinguishing type 1, type 2 and gestational diabetes.

Diabetes education

Diabetes education programs are an important resource for surveillance because of their potential to collect information on self-care. complications and disease progression and to direct interventions to improve diabetes management. However, directed research to provide an evidence base for specific interventions is а prerequisite to their incorporation into surveillance.

Other data sources

The scope for expanded diabetes surveillance is outlined in Table 8. Integration of varied data sources expands the possibilities for analysis of surveillance data. For example, pre-clinical screening could include blood glucose data, which may be accessed from a laboratory results database.

Application to other chronic diseases

Diabetes shares risk factors with other diseases and is both an outcome and a determinant of other conditions. Smoking, for example, is a risk factor for cancer, cardiovascular disease and respiratory disease as well as diabetes. These interactions, coupled with the realities of limited resources, make a compelling case for collaboration in chronic disease surveillance. The NDSS model is suited to other types of chronic disease surveillance where similar opportunities exist for tracking via client interactions with the health care system.

Table 8.					
The Scope for	Enhanced	Diabetes	Surveillance		

Determinants	Pre-clinical	Clinical	Outcome
DATA EXAMPLES:	DATA EXAMPLES:	DATA EXAMPLES:	DATA EXAMPLES:
genetics: prevalence of implicated genes	screening: blood pressure blood glucose	diagnosis: modes of diagnosis time to diagnosis laboratory testing	mortality: cause-specific deaths survival rates
activity level body mass dietary intake smoking	risk reduction: healthy diet physical activity rates	treatment and procedures: surgery	morbidity: complications degree of disability quality of life
environment: socio-economic: income level		service use: hospitalization physician visits home care ambulatory care palliative care	
		pharmaceutical: drug use complications and interactions	
DATA SOURCES*:	DATA SOURCES*:	DATA SOURCES*:	DATA SOURCES*:
surveys census workplace monitoring	screening databases surveys public health databases primary care physicians electronic health record (EHR)	hospital databases Discharge Abstract Database registry data provincial data repositories	vital statistics coroner's database multiple causes of death

† Roy D. Adapted from Chronic Disease Surveillance in Canada: A background paper, June 2003.⁽³⁷⁾ *Some of the listed sources are potential and may not be available at this time.

ACCOMPLISHMENTS, PLANS AND POSSIBILITIES

FINDING ANSWERS

- Almost half of Canadian adults are overweight. Since obesity is a risk factor for diabetes, how will this trend affect the incidence and prevalence of diabetes in Canada in years to come?
- Cardiovascular disease is the leading cause of death in Canada. What proportion of heart disease in Canada is associated with diabetes?
- Canada's population is aging. How will population trends affect the number of people in Canada with diabetes? What will it cost to care for them?
- To what degree have lifestyle changes contributed to the increased risk of diabetes in Aboriginal peoples relative to non-Aboriginals? After adjusting for differences in risk factors between Aboriginals and other Canadians, are Aboriginals more susceptible to diabetes?

These are just a few of the many questions that must be answered in order to stem the rising tide of diabetes in Canada. Fortunately, with NDSS, Canada is well positioned to answer them.

A recognized world leader in record linkage and database methods, Canada is applying its considerable expertise to diabetes through NDSS. Since securing funding in 1999, NDSS is well on its way to meeting its four stated goals:

 a national standardized database for diabetes with long-term monitoring for diabetes-related complications through the integration of new and existing databases;

- ongoing surveillance of diabetes and its complications in each province and territory, and in the Aboriginal population;
- dissemination of national comparative information, and
- a basis for the evaluation of economic/costrelated issues regarding the care, management and treatment of diabetes in Canada.

In accomplishing its mission, NDSS is also a prototype for other types of chronic disease surveillance. In an expanded NDSS model, data collected on diabetes include risk factors and complications. Those same data can also be analyzed and disseminated for the prevention and control of other conditions, such as cardiovascular, cerebrovascular and renal diseases.

Thus, the question posed at the beginning of this report – Can information systems designed primarily as tools for budgeting and billing, be used to provide disease-specific information that will benefit all Canadians? – has been answered. And this means that answers will be found for many more questions important to Canadians.

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APPENDICES

Appendix A

NDSS CAPACITY ASSESSMENT FORM

This is a summary of the capacity assessment completed by the provinces and territories for NDSS funding allocations in 2000/01. Most jurisdictions provided answers to the series of questions.

The capacity assessment had five components:

- description of existing infrastructure
- description of availability of data variables included in NDSS data dictionary
- assessment of capacity to achieve NDSS core model activities
- ▼ outline of funding proposal 2000/01
- addendum describing funding criteria and guidance on computer hardware requirements

Existing Infrastructure

Data: Where are the registry, hospital and physicians' claims data (or comparable data sources) currently stored? Is there documentation to describe the input data? Provide a subjective assessment of the quality of extant documentation. For what time periods do reliable data exist for the registry, physicians' and hospital files? Who is/are the key contact person(s) needed to facilitate technical access to the data? Name(s), title(s), phone number(s).

Computing infrastructure: Is SAS used within the Ministry? What mechanisms exist to transfer data "out" of this environment to a common platform for NDSS development? Tape? CD? Other?

Computer/data security: What, if any, legislation governs the collection and use of personal health data (please provide copies of statutes)?

Epidemiology and diabetes infrastructure in province/territory environment: Is there a provincial "office" for diabetes? Is there a provincial "office" for epidemiology?

Provincial/territorial health system: Is there a lifelong personal identifier in use within the jurisdiction? What year was it established? Does it cover all eligible individuals (e.g. other than RCMP, military, federal prisoners)? Are there subpopulations that are differentially less or more likely to be observed by core data sources?

The databases: Are there files that operationalize the three "core" databases described in the NDSS data model (Jan 2, 2000)?

NDSS data environment: Is there an existing, physically secure location in which the NDSS data might be housed?

Registry File

ID	Personal identifier
Sex	M or F
Date of Birth	Are invalid dates allowed?
Year	For which data are applicable?
Postal Code	(in year) or other subprovincial geographic variable, such as regional health area
Insurance Start Date	(in year)
Insurance Start Code	1 In force on Jan 1 of year
	2 Newly insured from Jan 1of year
	3 Other
Insurance End Date	(in year)
Insurance End Code	1 In force on Dec 31 of year
	2 Death
	3 Migration
	4 Other

Medical Claims File

ID	
Service Date	
Procedure Code	(please specify codes if available) Amputations, new hemodialysis, cataract surgery, new peritoneal dialysis, ongoing peritoneal dialysis, ongoing hemodialysis, lower-limb amputations, cardiovascular surgery (CABG, angio), laser photocoagulation, vascular reconstruction procedures (PTCA)
Diagnosis Fee Paid Physician ID*	ICD-9 3-digit
Physician Speciality* Location of Service*	(List specialties supported) 1 Inpatient 2 Outpatient

1 Variables with asterisks will be used in the initial release of the NDSS software, but if this variable is not available in a province or territory, the associated loss of functionality does affect the core goals and measures of NDSS.

APPENDIX A

Hospital Discharge File

ID Date of Admission Date of Discharge Admission Type* e.g. urgent, elective, etc. Discharge Type* Death, transfer, to community Diagnosis 1 ICD-9 5-digit Diagnosis 2 Diagnosis 3 Procedure 1 Procedure 2 Procedure 3 Transfer in?* Transfer out?* Resource Intensity Weight* Case Mix Group*

Capacity to Achieve NDSS Core Model in 2000-01

Feasibility of core activities (1 = no anticipated problems - planned implementation, 2 = some problems anticipated, but implementation still likely, 3 = major problems anticipated, implementation uncertain, 4 = not proposed)

Activity Description	Suggested Skill Set
A. Core Model Activities	
Inputs	
Identify data source for physician claims, hospital and coverage files. Ideally, select a "run" of 5-7 years for which there are continuously available data, and a single data dictionary.	SAS/systems analysis
Process	
(A1.1) Transfer data from existing hardware to NDSS hardware/disk space.	SAS/systems analysis
(A1.2) Reduce data from (A1.1) to include only necessary variables and necessary records.	
(A1.3) Concurrent with (A1.2) or subsequent to (A1.2) transform data from (A1.2) to NDSS common input data dictionary.	
(A1.4) Read data from (A1.3) into SAS files.	
(A1.5) Transform data from (A1.4) to calendar years.	
(A1.6) Input data from (A1.5) into NDSS core software.	
(A1.7) Produce "working" person-level summary.	

Activity Description

A.	Core Model Activities (continued)	
Ou	tputs	
	(A1.8) Prepare aggregate data files to estimate incidence, prevalence and mortality from (7).	Statistical analysis
	(A1.9) Prepare aggregate data files to estimate rates for specified complications and health services utilization patterns in subpopulation with diabetes.	
	(A1.10) Prepare aggregate data files to estimate rates for specified complications and health services utilization patterns in subpopulation without diabetes.	
	 (A1.11) Transfer aggregate datasets to Health Canada, as defined by FPT agreements. (A1.12) Retain (A1.7) for diabetic populations.² (A1.13) Retain (A1.7) for non-diabetic populations.³ 	SAS/systems analysis
	(A1.14) Disseminate data products coordinated with NDSS Steering Committee on an annual basis.	Policy/ communication-related
Po	licy-related	
	Document and apply for data access. Define reporting relationships and related matters for NDSS personnel.	Policy Epidemiological/ Policy/Administrative
	Define target audiences for surveillance data.	Epidemiology/ Policy/ Administrative

APPENDIX A

² if possible; retention allows for analysis of diabetic populations for longitudinal analysis.

³ if possible; retention allows for analysis of non-diabetic populations for longitudinal analysis.

Activity Description

Suggested Skill Set

B. Expanded Model Activities	
Inputs	
Integrate records for years not incorporated into Activity A.	SAS/systems analysis
Process	
(B2.1) Transfer data from existing hardware to NDSS hardware/ disk space.	SAS/systems analysis
(B2.2) Reduce data from (B2.1) to include only necessary variables and necessary records.	
(B2.3) Concurrent with (B2.2) or subsequent to (B2.2) transform data from (B2.2) to NDSS common input data dictionary.	
(B2.4) Read data from (B2.3) into SAS files.	
(B2.5) Transform data from (B2.4) to calendar years.	
(B2.6) Input data from (B2.5) into NDSS core software.	
(B2.7) Produce "working" person-level summary.	
Outputs	
(B2.8) Prepare aggregate data files to estimate incidence, prevalence and mortality from (B2.7)	Statistical analysis
(B2.9) Prepare aggregate data files to estimate rates for specified complications and health services utilization patterns in subpopulation with diabetes.	
(B2.10) Prepare aggregate data files to estimate rates for specified complications and health services utilization patterns in subpopulation without diabetes.	
(B2.11) Transfer aggregate datasets to Health Canada, as defined by FPT agreements.	SAS/systems analysis
(B2.12) Retain (B2.7) for diabetic populations. ⁴	
(B2.13) Retain (B2.7) for non-diabetic populations. ⁵	
(B2.14) Disseminate data products coordinated with NDSS Steering Committee on an annual basis.	Policy/communication-related

C. Alternative Model Activities

Description of alternative activities (where the NDSS Core Model is not feasible) (2-3 pages)

⁴ if possible; retention allows for analysis of diabetic populations for longitudinal analysis.

⁵ if possible; retention allows for analysis of non-diabetic populations longitudinal analysis.

Funding Proposal 2000/01 Based on Capacity Assessment

Rationale

- Describe obstacles to carrying out NDSS core activities in your province/territory in 2000-01.
- Attach previous three sections of capacity assessment.

Main goals for 2000-2001

▼ Summary of main activities and milestones.

Data/information products

Items achievable before the end of the initial funding period 2000-2001: incidence, prevalence, mortality (with and without diabetes), complications (with and without diabetes; specify conditions), health services utilization (with and without diabetes; specify measures).

Work plan

▼ For each activity listed within Activity Modules A, B, and/or C, indicate schedule with approximate time frame.

Human resource requirements

For each activity listed within Activity Modules A, B, and/or C, list staff members, anticipated full-time equivalent (FTE) allocation, skill set and annual FTE salary, assuming 20% benefits. Summarize the number of people (the number of total FTEs is expected to range between 0.5 and 2 but may be distributed across the hiring of more than 2 people at less than full-time hours), skill set, pay rate (\$ per year plus % benefits), employment period (e.g. number of months), number of FTEs, cost (salary plus benefits).

Computer hardware

 Number of items and cost (attach quote) for each of the following: servers, hard disk space for existing devices, workstations, other

(see Addendum for guidelines)

Addendum

Funding Criteria

Objective: To build capacity in each province and territory for the standardized surveillance of diabetes and its complications and for the production of nationally comparative data, primarily through the use of administrative databases where possible.

Initial funding period

April 1, 2000, to March 30, 2001

Criteria for funding allocations

NDSS funding will be allocated only to activities that are directly related to the development of surveillance of diabetes and its complications, including policy-related activities.

A. Core Model Activities: Achievement of core functionality on an ongoing basis in all provinces and territories is the priority for federal funding in fiscal year (FY) 2000/2001. It is recognized that achieving functionality this involves both data-oriented tasks (such as assembling and manipulating data) and policy-related tasks (such as the development of surveillance policies, reporting structures).⁶ It is the responsibility of the province or territory to prioritize data-oriented versus policy-related activities.

- **B. Expanded Model Activities**: Where federal dollars are available and where ongoing functionality is established in a province or territory, the integration of records for years not incorporated into Activity A should be undertaken, if feasible.
- **C.** Alternative Model Activities: Alternatives to the core model, where core functionality is not feasible in a province or territory, will be assessed and funded by the Steering Committee to the extent to which such alternatives allow the production of nationally comparative data.

If a province/territory has not yet fully completed Activity A but wishes to proceed to Activity B, it should provide a rationale to the Steering Committee as part of the proposal, explaining why the completion of a particular model is not feasible, needs to be postponed, or should be completed concurrently with some other stage.

Enhancements to the core model will not form part of this proposal, but proposals for enhancements can be submitted at this time and will be forwarded to the appropriate NDSS working group(s) for consideration.

⁶ It is expected that the core model may evolve and be redefined by the NDSS Steering Committee over time (in subsequent funding periods) as provincial/territorial capacities improve.

Suggested parameters for funding allocations

Each province and territory should receive a base level of funding to maintain the ongoing capacity necessary to generate nationally comparative data. The suggested base level of funding is for a minimum of 0.5 FTEs per province or territory, and for hardware requirements commensurate with the information processing task in each province or territory.⁷

The total number of FTEs per province/territory is expected to be capped at 2 FTE's. Any recommendation over and above that amount will require substantial justification and will be dependent on allocations from the Steering Committee and funding availability.

The estimated pay rate per year for personnel with the relevant skill sets is approximately \$50,000 per year plus 20% benefits, as per the NDSS Business Plan.

Submission guidelines

Each province and territory may submit a proposal for NDSS funding for the initial NDSS funding period. Proposals should employ the template provided at the Winnipeg workshop.

Deadlines

Proposals are due on January 28th, 2000. Applications should be forwarded electronically to Rob James (NDSS Technical Director) and Sheila Chapman, Health Canada.

Funding decisions

Applications will be reviewed by the Secretariat in early February 2000, with final allocation decisions determined by the Steering Committee in early March 2000.

Special Projects (optional): Proposed Enhancements to the Core Model

Outline the proposed enhancement(s), indicating how it (they) will complement core NDSS activities in the province/territory and whether there is an opportunity for a multi-jurisdictional collaboration now or in the future.

Note: These special projects will be circulated to the appropriate subcommittee/technical working group and considered separately from the funding stream for implementation of core NDSS functionality. An appropriate subcommittee/ working group will request further details. Do NOT expect funding for special projects to be available on April 1, 2000/01.

Provide brief description of the project (include activities, methodology, outputs).

Provide resource request (specify how these resources will be used).

⁷ Thus, provinces with larger populations are likely to legitimately require more computing hardware to store and manipulate their data files.

Guidance on Computer Hardware Requirements

Principles

- ▼ establish a "floor", which is provided to all
- need clear growth pathway for all hardware
- will fund hardware differentially based on population size
- address questions about moving from test site in 2000/01 to operational site in subsequent years
- must fit within existing computer procurement rules (if any) in P/T

Operating systems

- ▼ should run SAS version 8 eventually
- strongly prefer (not ranked): NT (SP 6; Windows 2000; UNIX)
- should support multi-processor hardware
- need ability to have multiple disk drives act as if one directory/drive

Base model (not required, but strongly recommended)

- INTEL BX chipset motherboard, i.e. 100 Mhz FSB
- ▼ Pentium III CPU (supports 100 MHFSB)
- ▼ 100 Mhz RAM (PC-100) in 128 MB DIMMs

- RAM upgradable to 1 GIG (except for base systems)
- ▼ Wide-SCSI hard drives

Security and communication

- Can data reside on work-station?
- ▼ Does data have to reside in secure room?
- What speed network do you maintain?

Upgrading and performance

Tentative benchmark for performance:

- should be able to re-assemble Annual Person-level Summary Files (APLSF) for 10 years over one weekend, without attention
- should be able to obtain simple estimates from 1 APLSF within 1 hour, e.g. prevalence, mortality

If proposed capacity does not perform reasonably, P/T can apply back to NDSS Steering Committee to move up.

Maintenance, backups, etc.

- ▼ get 3-year maintenance contract
- define a strategy for backing up data

Appendix **B**

REGIONAL ACTIVITY

Most provinces/territories have built upon the surveillance capacity demonstrated by NDSS. The relation between diabetes and other chronic diseases has stimulated interest in chronic disease surveillance in general.

Yukon

- provided 1995/96 to 1999/00 data to Health Canada;
- investigating possible expansions of the core NDSS model to include other databases, such as the Diabetes Education Centre and the Seniors' Pharmacare Program;
- has partnership with the Chronic Disease Program, expansion of the NDSS model to include other co-morbidities, and increased capacity in epidemiology.

Northwest Territories

- provided 1995/96 to 1999/00 data to Health Canada;
- discussions with NWT Dene Nation concerning Aboriginal data;
- developing a Northwest Territories diabetes registry in consultation with the three Diabetes Education Programs in Yellowknife, Inuvik and Hay River and with other stakeholders;
- developing a Northwest Territories diabetes strategy.

Nunavut

- ▼ became a territory in 1999;
- completed data cleaning of health numbers introduced in 1999 confounded with the old Northwest Territories health number;
- completed a retrospective Nunavut population starting in 1995/96, using both Nunavut and Northwest Territories health numbers;
- implemented NDSS software on 1995/96 to 1999/00 data;
- preliminary review necessitated expansion of the NDSS model to incorporate community health nurse data, since these nurses provide primary care for approximately 60% of the population;
- completed data entry and formatting to the pre-1999 community health nurse data, and the paper records for 2000 and 2001;
- ▼ implementing expanded NDSS software.

British Columbia

- provided 1995/96 to 1999/00 data to Health Canada;
- working with First Nations' Chiefs Health Committee to identify Status Indian population;
- provincial diabetes surveillance report expected later in 2003 that includes regional measures (incidence, prevalence, mortality) for 16 health service delivery areas,

Pharmacare utilization, cost analysis, and prevalence projections;

- investigating possible expansions of the core NDSS model to include other databases, such as Vital Statistics (deaths), Pharmanet (insulin and oral hypoglycemic use for population), and the provincial renal agency;
- partnership with Chronic Disease Management to provide chronic disease care measures for surveillance, and expansion of the NDSS model to include other chronic diseases such as hypertension, ischemic heart disease, congestive heart failure, renal disease, retinopathy, depression and asthma.

Alberta

- one of the original partners in the Prairie Pilot;
- provided 1995/96 to 1999/00 data to Health Canada;
- provincial diabetes surveillance report expected later in 2003 that includes regional measures (prevalence, mortality) for nine health regions;
- possible expansion of the core NDSS model to include other databases, such as Vital Statistics (deaths) and CCHS;
- partnership with patient health management activities and expansion of the NDSS model to include other chronic diseases, such as heart disease, renal disease and retinopathy.

Saskatchewan

- one of the original partners in the Prairie Pilot;
- provided 1995/96 to 1999/00 data to Health Canada;
- NDSS has also been used for ongoing diabetes program planning and evaluation at provincial and regional levels. NDSS will be incorporated into program planning and evaluation in primary care services;
- work under way to produce costs and burden of illness estimates for major causes of morbidity and mortality, expected later in 2003.

Manitoba

- one of the original partners in the Prairie Pilot;
- provided 1995/96 to 1999/00 data to Health Canada;
- the NDSS model as initially developed in Manitoba was used to produce 11 regional diabetes profiles, including incidence, prevalence and major complications, as well as data to support the provincial diabetes strategy,⁸ diabetes projections,⁹ and a Métis health report;¹⁰
- provincial First Nations diabetes profile expected later in 2003 will be available at: www.gov.mb.ca/health/publichealth/ diabetes/index.html

⁸ Diabetes: a Manitoba strategy. 1998. Available at: www.gov.mb.ca/health/documents

⁹ Epidemiologic projections of diabetes and its complications: "Forecasting the coming storm". 1999. Available at: www.gov.mb.ca/health/documents

¹⁰ The health of Manitoba's Métis population and their utilization of medical services: a pilot study. May 2002. Available at: www.gov.mb.ca/health/documents

 collaboration with medical experts in the areas of dialysis, peripheral arterial disease and eye disease resulted in case definitions for these complications.

Ontario

- provided 1995/96 to 1999/00 data to Health Canada;
- a modified NDSS model was used by the Institute for Clinical Evaluative Sciences (ICES) to publish regional diabetes profiles;¹¹
- NDSS has contributed toward increasing the profile of diabetes in Ontario, including diabetes research at ICES.

Quebec

- provided 1995/96 to 1999/00 data to Health Canada;
- working with the Cree Board of Health and Social Services of James Bay on a diabetes surveillance project;
- the NDSS model was used in October 2002 to produce diabetes prevalence data by health region;¹²
- NDSS has served as a catalyst for other diabetes research;
- expanding model to include vital statistics and drug data from the Régie de l'assurance maladie du Québec.

New Brunswick

- provided 1995/96 to 1999/00 data to Health Canada in May 2003;
- physician data did not include diagnostic codes used by other provinces. This required pre- liminary work to develop algorithms to search a text field for key words in English and French.

Prince Edward Island

- provided 1995/96 to 1999/00 data to Health Canada;
- NDSS methodology was used to describe diabetes prevalence by health region within Prince Edward Island¹³;
- investigating possible expansion of the core NDSS model to include other databases, such as laboratory testing, diabetes program and CCHS;
- use of the NDSS model to evaluate Prince Edward Island's Strategy for Healthy Living, a collaborative effort to address common risk factors for chronic disease.

¹¹ Diabetes in Ontario: an ICES practice atlas. 2003. Available at URL: www.ICES.on.ca

¹² Institut national de santé publique. *Prévalence du diabète au Québec et dans ses régions : premières estimations d'après les fichiers administratifs.* Octobre 2002. Brochure available on the INSPQ website: www.inspq.qc.ca

¹³ Van Til L. *Prince Edward Island Health indicators, provincial and regional*. Charlottetown: Document Publishing Centre, January 2003. Available at: www.gov.pe.ca

Nova Scotia

- provided 1995/96 to 1999/00 data to Health Canada;
- provincial diabetes surveillance report expected later in 2003 that includes regional measures (prevalence, mortality) for nine district health authorities as well as health care utilization (hospitalization rate, length of stay, and burden of disease). These reports will be posted on the web with secure access;
- investigating possible expansion of the core NDSS model to include other databases, such as the Diabetes Care Program and Reproductive Care Program;

NDSS has served as a catalyst for other research activities such as the newly formed Maternal/Infant/ Diabetes Research Group, and validation of diabetes in people under the age of 20.

Newfoundland and Labrador

- data not yet provided to Health Canada;
- partnership with the Department of Health and Community Services and the Newfoundland and Labrador Centre for Health Information;
- NDSS software currently being implemented using data from 1995/96 to 1999/00;
- quality of registry information and the potential use of census data are being evaluated.

Appendix C

NDSS Steering Committee Membership 2003

Chair: Linda Van Til, Prince Edward Island Department of Health and Social Services

Aboriginal Diabetes Working Group Rhea Joseph	
Health Secretariat - Assembly of First NationsAnita StevensInuit Tapiriit KanatamiOnalee RandellMétis National CouncilDon FiddlerNational Aboriginal Diabetes AssociationCatherine CookAcademics/CliniciansCatherine Cook	
McMaster University Hertzel Gerstein	
Federal Government	
Health Canada - First Nations and Inuit Health BranchAdam ProbertHealth Canada - Population and Public Health BranchClarence Clottey, Yang NStatistics CanadaGary Catlin	Mao
Non-Government Organizations	
Canadian Diabetes AssociationDonna LillieCanadian Institute for Health InformationIndra PulcinsCanadian Institutes of Health Research - Institute of Nutrition, Metabolism & DiabetesDiane T. Finegood	
Provinces/Territories	
YukonJoy KajiwaraNorthwest TerritoriesJohn MorseNunavutSylvia HealeyBritish ColumbiaKim ReimerAlbertaLarry SvensonSaskatchewanWilliam OseiManitobaKelly McQuillenOntarioJoan CanavanQuebecDanielle St-LaurentNew BrunswickChristofer BalramPrince Edward IslandLinda Van TilNova ScotiaPeggy DunbarNewfoundland and LabradorFaith Stratton	
GlaxoSmithKline Raymond Fox	

Past Chairs include Wilson Rodger and Bernard Zinman.

Note: The report editor for the 2003 NDSS Report was Shirley Huchcroft.

APPENDIX C

Validation Working Group

Chair: Valérie Émond, Institut national de santé publique du Québec

Munaza Chaudhry, British Columbia Ministry of Health Planning Jane Griffith, Manitoba Health Jan Hux, Ontario - Institute for Clinical Evaluative Sciences William Osei, Saskatchewan Health Kim Reimer, British Columbia Ministry of Health Planning Mark Smith, Nova Scotia - Population Health Research Unit, Dalhousie University Larry Svenson, Alberta Health and Wellness Linda Van Til, Prince Edward Island Department of Health and Social Services Glenn Robbins, Health Canada Rebecca Stuart, Health Canada

Past Chairs: Jamie Blanchard, Larry Svenson

Scientific Working Group

Co-chairs: Diane T. Finegood, Canadian Institutes of Health Research, INMD Larry Svenson, Alberta Health and Wellness

Gary Catlin, Statistics Canada Hertzel Gerstein, McMaster University Jan Hux, Ontario - Institute for Clinical Evaluative Sciences Jeffrey A. Johnson, University of Alberta William Osei, Saskatchewan Health Indra Pulcins, Canadian Institute for Health Information Daniel Tessier, Université de Sherbrooke Ellen L. Toth, University of Alberta Linda Van Til, Prince Edward Island Department of Health and Social Services Jean-François Yale, Université de McGill Chris Robinson, Health Canada

Technical Working Group

Chair: Glenn Robbins, Health Canada

Munaza Chaudhry, British Columbia Ministry of Health Planning Valérie Émond, Institut national de santé publique du Québec Jane Griffith, Manitoba Health Jan Hux, Ontario - Institute for Clinical Evaluative Sciences Rob Ranger, Nova Scotia - Population Health Research Unit Deanna Rothwell, Ontario - Institute for Clinical Evaluative Sciences Mark Smith, Nova Scotia - Population Health Research Unit Larry Svenson, Alberta Health and Wellness Linda Van Til, Prince Edward Island Department of Health and Social Services Asako Gomi, Health Canada Chris Waters, Health Canada

Past Chair: Rob James

Technical Consultants

Chair: Glenn Robbins, Health Canada

Sherri Wright, Yukon Department Health and Social Services Joyce Bourne, Northwest Territories Department Health and Social Services Manon Asselin/Sylvia Healey, Nunavut Department Health and Social Services Munaza Chaudhry, British Columbia Ministry of Health Planning Ken Morrison, Alberta Health and Wellness Janice Hawkey, Saskatchewan Health André Wajda, Manitoba Health Alexander Kopp, Ontario -Institute for Clinical Evaluative Sciences Valérie Émond, Institut national de santé publique du Québec Heather MacLennan-Cormier/Jason Liu, New Brunswick Department of Health and Wellness Connie Cheverie, Prince Edward Island Department of Health and Social Services Rob Ranger/Jill Casey, Nova Scotia - Population Health Research Unit Kayla Gates/Don MacDonald, Newfoundland & Labrador Centre for Health Information Rhea Joseph, Aboriginal Diabetes Working Group

Appendix E

MEMORANDUM OF UNDERSTANDING (MOU)

Between:

HER MAJESTY THE QUEEN in right of Canada, as represented by the Minister of Health (hereinafter referred to as "Health Canada")

And:

HER MAJESTY THE QUEEN in right of the Province/Territory of ______, as represented by the Minister of Health (hereinafter referred to as "X")

1. General

1.1 Purpose of the Memorandum of Understanding

The purpose of this Memorandum of Understanding (MOU) is to confirm the participation and responsibilities of parties in the National Diabetes Surveillance System (hereinafter referred to as the "NDSS"), regarding the development of provincial, territorial and federal capacity for standardized diabetes surveillance using primarily administrative data.

1.2 Objectives of the Memorandum of Understanding

The main objectives of the MOU are to:

1.2.1 provide for the establishment of personnel support for the NDSS in "X" to carry out approved NDSS activities and to assist "X" in analyzing its own data.

1.2.2 obtain agreement in principle for the transfer of aggregate NDSS-related data from "X" to Health Canada, subject to a written amendment to this MOU.

 $1.2.3\ \text{set}$ out the terms and conditions for NDSS-related activities and financial administration of this MOU.

1.3 Term of the Memorandum of Understanding

Subject to termination of this MOU, the term of this MOU shall be for a four-year period to commence on April 1, 2000, (the "Effective Date") and end on March 31, 2004, or such other date agreed upon in writing by the parties.

2. Context

Multi-Stakeholder Response to Lack of Diabetes Data

Diabetes has been recognized in recent years as a serious public health problem in this country. Diabetes prevention programs require a well-planned, organized and viable surveillance system. However, there is limited surveillance capacity for diabetes at all levels of public health in Canada, and to address this problem government and non-government sectors have collaborated on the development of the NDSS and participate on the NDSS Steering Committee to set policy and to direct activities.

The NDSS Steering Committee has representation from every province and territory, the non-governmental sector, Aboriginal groups, academia, Health Canada, Canadian Institute for Health Information, and Statistics Canada. This Steering Committee is the main decision-making body of the NDSS and acts as the data gate-keeper. The Steering Committee meets twice yearly. To assist the Steering Committee, a multi-sectoral Secretariat provides ongoing management of the NDSS. In addition, two subcommittees and three expert technical working groups are responsible for addressing key issues that have been identified by the NDSS Steering Committee.

Any private sector sponsors of the NDSS may have observer status on the Steering Committee but do not have voting rights.

Funding for the NDSS

Health Canada funding for the NDSS is through the Canadian Diabetes Strategy (CDS) over a five-year period commencing in fiscal year 1999/2000, as approved by Federal Cabinet in November 1999 and Treasury Board in February 2000.

NDSS: Development of Core Functionality in 2000/01

The main goals of the NDSS include the development and support in every province and territory and at the federal level of a core level of functionality with regard to standardized surveillance of diabetes. Another key goal of the NDSS, although outside the scope of this MOU, is the development and support for diabetes surveillance in the Aboriginal community.

The NDSS core data model relies on the utilization and record linkage of provincial and territorial health administrative data, beginning in the start-up year with linkage of health insurance coverage, physician claims, and hospitalization data sources to allow monitoring of diabetes incidence and prevalence, rates of diabetes complications, and levels of health care utilization in the population with diabetes compared with the population without diabetes. In the core NDSS model, person level data remain within provinces and territories, and only aggregate data on population groups will be sent to Health Canada for a national picture of the diabetes burden.

Provincial and Territorial Capacity and Needs Assessments

In order to determine appropriate NDSS funding levels for fiscal year 2000/01, each province and territory completed an assessment of its capacity to accomplish core NDSS functionality within that time period. In some cases, a province or territory indicated that the core model was not possible in its jurisdiction in fiscal year 2000/01 and proposed "alternative" activities that would move them toward core functionality in subsequent years.

Provinces and territories also indicated in their submissions their personnel and technical resource needs in fiscal year 2000/01 to accomplish NDSS-related activities. These resource requests were assessed and in some cases revised by the NDSS Secretariat, and allocations were approved by the NDSS Steering Committee in March 2000.

This MOU pertains to approved funding allocations for NDSS personnel resources in "X". Approved allocations for technical resources to each province and territory will be handled through a non-federal financing mechanism and source.

The understanding is that NDSS core surveillance activities conducted in fiscal year 2000/01 in a province or territory will be carried out on an annual basis and will form the main component of the ongoing functioning of the NDSS. In the case of provinces or territories that will be engaging in alternative activities in fiscal year 2000/01 because of particular challenges in those jurisdictions, the understanding is that they will be moving toward implementation of core NDSS functionality in subsequent years.

4. Responsibilities of Parties

4.1 Health Canada agrees to pay to "X" on an annual basis an amount not to exceed the amount as indicated in Appendix A, subject to annual review and adjustment by the NDSS Steering Committee.

4.2 The payment is to be used to reimburse the cost of hiring or otherwise engaging personnel to accomplish NDSS-approved activities. Nothing in this agreement should be construed as establishing an employer/ employee relationship between Health Canada and any personnel hired pursuant to this agreement.

4.3 "X" is responsible for submitting resource allocation information for each subsequent year to the NDSS Steering Committee on or before December 31 of the current fiscal year. The NDSS Steering Committee will review and approve or adjust the resource allocation on or before January 31 of each year.

4.4 "X" agrees to provide in kind resources to the NDSS as needed. These resources are expected to include, but may not be limited to, the provision of data for NDSS activities, monitoring of NDSS-related personnel in "X", infrastructure support of NDSS-related personnel, and participation on NDSS committees and working groups as appropriate.

4.5 Health Canada agrees to provide in kind resources as needed to nationally coordinate NDSS activities, to include (but may not be limited to) monitoring of national NDSS-related staff, infrastructure support of national NDSS-related personnel, and participation on NDSS committees and working groups as appropriate.

5. Activities of Parties

5.1 "X" will engage in NDSS-approved activities as set out in Appendix B, subject to written amendments agreed to by both parties and the NDSS Steering Committee.

5.2 Health Canada will provide a national coordination function for the NDSS, including administering NDSS funding from federal sources on behalf of the NDSS Steering Committee.

5.3 Subject to a Provincial Privacy Impact Assessment being conducted where required and to the successful completion of activities set out in item 5.1 where these involve "core" NDSS activities,
5.3.1 "X" agrees in principle to transfer aggregate (non-person-level, de-identified) data to Health Canada, pending a written agreement between the parties specifying terms and conditions if required or under the auspices of related "X" policy and regulations, and

5.3.2 both parties agree that the proposed information to be transferred will not constitute personal health information under legislation that governs the collection, use and disclosure of personal health information.

5.4 Subject to the successful completion of activities set out in item 5.1, both parties agree in principle to coordinate the publication and dissemination of information products directly resulting from NDSS activities, pending oral or written agreement by both parties and the NDSS Steering Committee regarding the content and schedule of information publication and dissemination.

6. Administration of Agreement

6.1 Both parties will formally participate on the NDSS Steering Committee, and will meet and communicate on an as-needed basis to collaboratively direct and monitor the activities set out in this agreement.

7. Principles of Data Privacy, Access and Ownership

7.1 Data privacy standards as set out in all applicable provincial/territorial legislation and the federal *Privacy Act* will be respected.

7.2 It is the intention of the parties to uphold the principle of public access to health information to the fullest extent expedient consistent with applicable provincial and federal legislation regarding data privacy and ownership.

8. Intellectual Property

8.1 Any intellectual products such as NDSS standardized statistical programs and analysis tools given to "X" to fulfill the activities set out in Appendix B are to be considered in the public domain. The NDSS must be acknowledged in any publications arising from the use of these products.

8.2 Any innovations to the standardized NDSS intellectual products that are developed by "X" as well as any information products developed from data for which "X" is the custodian remain the property of "X".

9. Financial Administration

9.1 The parties accept accountability for demonstrating good management practices in financial planning, expenditure control and reporting, according to generally accepted accounting practices.

9.2 Health Canada, on behalf of the NDSS Steering Committee, may commission audits of any or all NDSS-related financial records of "X" relating to the hiring of NDSS personnel to ensure that all NDSS funds are expended in accordance with the terms of this MOU.

9.4 Invoices should include a forecast showing any budget adjustments required for the remainder of the fiscal year.

9.5 In the case of an approved adjustment to Health Canada's annual payment to "X", Health Canada's representative on the NDSS Steering Committee is responsible for informing the budget and planning units of financial and corporate services within Health Canada in a timely fashion of the approved adjustment in payment level.

10. Termination by Consent

The MOU may be terminated by the consent of either of the parties giving ninety (90) days' notice in writing to the other party.

11. Termination for Cause

11.1 If "X" fails to perform the activities set out in Appendix B to the satisfaction of the NDSS Steering Committee, Health Canada may terminate in whole or in part this MOU, including Health Canada's obligation to make additional payments of NDSS funds to the other party for the remainder of the MOU.

11.2 If Health Canada fails to pay the amount at the level set out in Appendix A or at the approved adjusted level pursuant to annual review by the NDSS Steering Committee, "X" may terminate in whole or in part this MOU, including "X"'s obligation to perform the activities set out in Appendix B.

12. Amendments

This MOU will only be amended, in writing, by mutual consent of both parties.

13. Conflict of Interest

13.1 No member of the House of Commons shall be admitted to any share or part of this Agreement or to any benefit to arise therefrom.

13.2 It is a term of this Agreement that no former public office holder who is not in compliance with the post-employment provisions of the Conflict of Interest and Post-Employment Code for Public Office Holders shall derive a direct benefit from this Agreement.

13.3 If the status of any party changes in any way that prejudices the project, such party shall promptly inform the other parties.

14. Funding Changes

If Health Canada will be reducing or terminating the funding under the MOU because of changes or reduction in Health Canada funding for the NDSS, Health Canada shall give notice in writing to "X" as early as possible. Health Canada will give "X" sixty (60) days' notice in writing before reducing or terminating the funding, whether the funding change is to occur during or at the beginning of a fiscal year. In case of such termination, Health Canada will pay "X" all outstanding amounts for activities performed under this agreement.

15. Notice

Any notice or other communication required to be given or made under this MOU shall be in writing and shall be deemed to be sufficiently given if sent by registered mail, or by telegram, or by facsimile, or by delivery in person, to the other party at the following address(es).

If to Health Canada: NAME/TITLE/ORGANIZATION/ TEL/ FAX If to "X": NAME/TITLE/ORGANIZATION/ TEL/ FAX

AGREED to this For Health Canada:	day of	, 2000
Date		Signed on Behalf of Health Canada
	Witness	
For "X":		
Date		Signed on Behalf of "X"

Witness

APPENDIX E

Appendix F

NDSS GUIDELINES

Duality of Interest

(Approved by NDSS Steering Committee October 2, 2000)

The purpose of this policy is to assist the NDSS by providing duality of interest guidelines for members of the Steering Committee.

A duality of interest may arise in two situations: (1) when a member has the opportunity to influence the business decisions of the Steering Committee in a way that could lead to personal, financial gain for the member or his/her family; and (2) when a member's interests are contrary to the interests of the Steering Committee.

In order to avoid both the fact and the appearance of improper influence, a member should not vote on, approve or recommend approval of a transaction or contract with which the member is associated and should disclose any potential conflict prior to a vote or other action.

General principles regarding duties of members

- Members shall deliberate impartially on all issues placed before the Steering Committee.
- Members shall respect matters of a confidential nature and shall not provide unauthorized information on these matters to the media, the public or others.

Disclosure of duality of interest

 Disclosure of duality of interest shall be an agenda item for all meetings. A member shall, as soon as possible after the start of the meeting, disclose the nature of his/her duality of interest, and this shall be recorded in the minutes of the meeting.

Abstinence from action

- Members who are deemed to have a financial conflict of interest position with reference to any item under discussion should absent themselves from the meeting during the period when such discussion is taking place.
- On the Steering Committee, only a single representative of each province, territory and organization present shall vote on matters pertaining to contracts or transactions with that province, territory or organization.
- On NDSS subcommittees or working groups, on which not all jurisdictions may be represented equitably, members shall abstain from voting on contractual/ transactional matters pertaining to their own province, territory or organization.

Compliance

- After a member has disclosed the nature of a potential financial conflict of interest at the start of the meeting, the existence of a conflict of interest will be determined by a majority vote of the Steering Committee members present, on a case-by-case basis.
- The Chairperson is responsible for ensuring that all members comply with this policy.

These principles shall be binding on all members of the Steering Committee, its subcommittees and working groups.

Definitions

- "Steering Committee" is to be interpreted as the National Diabetes Surveillance System Steering Committee.
- "Member" is to be interpreted as the designated representatives on the National Diabetes Surveillance System Steering Committee. A member may contribute funding to the National Diabetes Surveillance system and has voting privileges.

Fund-Raising and Sponsorship

(approved by NDSS Steering Committee October 2, 2000)

The purpose of this policy is to assist the NDSS by providing principles for fund-raising and eligibility criteria for NDSS sponsors, and by defining potential benefits to sponsors, including a protocol for sponsors as observers at general sessions of the Steering Committee.

Principles for fund-raising

- There must be an open and transparent process for the solicitation of funds whereby all likely funders of the NDSS are informed of the opportunity to become a funder, and any benefits accruing to the sponsors are public knowledge and agreed to by the Steering Committee.
- There should be a diversity of funding sources so that one funder does not have undue control over the stability of NDSS funds.

- Private funders should not interfere or be promised influence regarding decisions and activities of the Steering Committee.
- The Steering Committee should be informed of the willingness of a private company to become a sponsor of the NDSS.
- Draft funding agreements with potential sponsors should be circulated to the Steering Committee for approval prior to signing.
- The Steering Committee must approve the acceptance of funding from any specified private source.

Eligibility criteria for sponsors

All prospective sponsors will be rated on the following:

Interest: NDSS fits with corporate business and/or funding priorities

Capacity: Declares the ability to contribute significant dollars to this initiative either philanthropically or otherwise

All the following criteria must be met by a potential sponsor:

- There must be a long-term financial commitment (> 1 year) to the NDSS.
- It must be a substantial financial contribution (> \$100,000 per year) to the NDSS.
- There must be no outstanding commercial matters before an organization or the Steering Committee, which, in the opinion of the Steering Committee, gives the appearance of, if not the fact of, conflict of interest.
- The potential sponsor must accept the "no influence" stipulation in the affairs of the Steering Committee.

There should be no inconsistency/ incompatibility between the goals and objectives of the NDSS and the goals/products of the potential sponsor.

Potential benefits to sponsors

- Observer status at Steering Committee meetings, in-camera sessions excluded
- Name acknowledgement on NDSS products
- Advance release of publicly distributed reports

Protocol for sponsors as observers at Steering Committee meetings

- Sponsors may attend Steering Committee meetings as observers and may only speak by invitation of the Chair.
- Sponsors do not have voting authority at Steering Committee meetings.
- Sponsors may not attend in-camera sessions of the Steering Committee.
- The Steering Committee should send sponsors reports on an agreed-upon schedule regarding NDSS project accomplishments.
- Sponsors may be identified as such on NDSS products.
- As corporations wish to provide financial support to the NDSS, their relation with the Steering Committee as observers at Steering Committee meetings will be reviewed on a case-by-case basis.

Definitions

- "Steering Committee" is to be interpreted as the NDSS Steering Committee.
- "Member" is to be interpreted as the designated representatives on the NDSS

Steering Committee. A member may contribute funding to the NDSS and has voting privileges.

- "Sponsor" is to be interpreted as a private financial contributor to the NDSS. A sponsor is not a designated member of the Steering Committee, does not have voting privileges, and may not attend in-camera sessions of the Steering Committee.
- "Confidential" is to be interpreted as material that is so designated at a meeting, such as funding proposals, data results, business strategies, pricing information, financial data, research protocols and intellectual property.
- "No influence" is to be interpreted as not interfering with or having influence over decisions and activities of the Steering Committee.

Data Access and Publications

(approved by NDSS Steering Committee November 27, 2002)

The purpose of this policy is to promote the credibility, usefulness and accountability of the NDSS by defining principles around which data and products may be accessed from NDSS, how data or products may be obtained, and the publication thereof. This policy outlines the procedures believed necessary to process research requests efficiently while ensuring both consideration of the public interest and full compliance with legislation.

This policy covers data that have been collected, linked and/or analyzed with the assistance of NDSS resources. The audiences anticipated as users of NDSS data are (although this does not preclude others from requesting access, if warranted) as follows:

- parties engaged in predetermined NDSS projects, outcomes or activities;
- ▼ parties engaged in independent research;
- other audiences such as media, other government organizations, and diabetes-related stakeholders, including non-governmental organizations and health care professionals, and the general public.

Nature of data and products that can be accessed:

- unpublished NDSS aggregate data kept by Health Canada;
- person-level data kept at provincial and territorial sites (data from one specific site may be requested directly from the jurisdiction responsible for the data; this policy aims at coordinating multi-site requests); and
- ▼ NDSS programming codes.

Guiding principles

- Provinces and territories must be in agreement with any and all uses (including collection, linkage, analysis, access, and publication) of their respective provincial and territorial data within NDSS.
- This policy must comply with provincial, territorial and federal legislation and policies regarding data access and protection of privacy, and comply with existing Memoranda of Understanding. Access to dissemination of data from and provincial/territorial NDSS data files must comply with provincial/territorial legislation and policy, and access to and dissemination of Health Canada NDSS data files must comply with federal legislation and policy.

- Terms defining access to the NDSS data relating to Aboriginal peoples on a national level will be determined by the Aboriginal Diabetes Working Group.
- In accordance with the Memorandum of Understanding, any use of data that identify specific Aboriginal groups must have prior approval of the signatories to the Memorandum of Understanding. Special instances outside the MOU will be considered on a case-by-case basis.
- Person-level data will remain within the custody of the provincial/territorial NDSS datafile.
- ▼ All parties recognize that nothing herein interferes with provincial and territorial legislated obligations to manage public health reporting in each jurisdiction or Health Canada obligations as they relate to First Nations.
- ▼ NDSS statistics must be based on comparable data derived from different provincial/ territorial data sets, must reflect consistent approaches to data collection and to valid must lead and reliable interpretations. Should data not be completely comparable, provinces and territories will be requested to provide technical notes, which will be forwarded with any data requests and noted in publications. The Technical Working Group will determine whether or not the data are comparable.

Uses of NDSS data and products accessed

Data are provided for the exclusive purpose as stated in a proposal and may not be used for any other purpose without the explicit written approval, in advance, of the NDSS Data Access and Publications Subcommittee. Authorized users are prohibited from using NDSS data or products in the pursuit of any commercial or income-generating venture. Any breach of the agreed upon terms may affect subsequent access to data maintained by the NDSS. Also, other legal remedies are not precluded by any such action. The NDSS data and products thereof (e.g. computer software, analytical tools) remain in the public domain. Sharing of data with third parties is prohibited without specific permission.

Ethical review for access

NDSS data should be used for scientifically sound, high-quality analyses, to support academic, policy, health economic or business research. Proposals for research using NDSS data must demonstrate acceptable rationale, analytical methods, and security/confidentiality safeguards. All NDSS investigator-initiated projects requesting unpublished data must receive ethical approval from an ethics board that complies with the "Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans" before data are released.

Requirements to request access

- Proposals to access NDSS data held at a provincial or territorial site will be submitted for review to the relevant provincial or territorial body with custody of the data. Where applicable, proposals to access Aboriginal data for a specific province or territory will be submitted for review to the Aboriginal partner as identified in the MOU. Provincial and/or territorial approval is required before data will be released, and sign off will occur within the jurisdiction. Aboriginal partner approval is required according to the conditions agreed by all parties.
- Proposals to access NDSS aggregate data held by Health Canada will be submitted for

review to Health Canada. Third party access will be reviewed on a case-by-case basis. The NDSS will be permitted to carry out on-site visits and other inspections to ensure compliance with the conditions of access. All requests will be logged at Health Canada.

Requests to access NDSS programming code will be logged at Health Canada to ensure that sharing parties have the most current version of the code. The NDSS programming code is in the public domain and may be shared with requesting parties with appropriate access to the technology used.

All requests for data must be submitted in writing to the secretary of the Data Access and Publication Subcommittee and include the following:

- the party requesting the data;
- ▼ the purpose of the project;
- the benefits of the project;
- the list of data being requested;
- ▼ the analysis to be performed;
- ▼ the nature and intent of any data linkages;
- any publications expected to result from data analysis and where and when they will be distributed;
- the means by which the client will ensure the security of the data;
- a description of how and when the data will be disposed of or returned;
- the names and titles of all individuals who will have access to the data;
- the complete document package submitted for ethical review;
- the results of any ethical committee review of the project; and

▼ the source(s) of funding for the request and proposed analysis.

When a prospective user approaches the NDSS to request access to data, the NDSS should forward to the researchers a package containing a research application. Requests are to be accompanied by a signed Non-Disclosure Agreement stating that the researcher agrees to comply with NDSS policies respecting use and disclosure of the data:

- ▼ to use the data only for the stated purpose;
- to make no attempt to link or otherwise identify a data subject other than as divulged;
- to maintain the data's electronic and/or physical security and dispose of the data as specified;
- to not disclose the data to others;
- ▼ to provide two advance copies of any publication or report to the NDSS Steering Committee for review and comments. The copies will be kept confidential. This is intended to ensure that data are being interpreted accurately;
- to acknowledge NDSS as the data source in any publication or report and to state that the interpretation and conclusions contained in the publications or report do not necessarily represent those of the NDSS, Health Canada, or any province or territory;
- to provide a copy of the final publication or report to the NDSS.

All requests will be received and reviewed by the area responsible for the data (i.e. Health Canada, province/territory) in accordance with the NDSS principles, policies and procedures for data disclosure. The secretary of the Data Access and Publication Subcommittee (also an employee of

Health Canada) will be co-ordinating the process and collecting the necessary authorizations from each jurisdiction.

Decisions regarding NDSS unpublished aggregate data will be made by the Data Access and Publications Subcommittee and are subject to the endorsement and approval of the NDSS Steering Committee.

Disclosure

Before release, reports containing any data requested through the NDSS, or reports generated using NDSS data, will be reviewed. The Data Access and Publication Subcommittee's review will ensure that privacy standards are complied with and that the correct data are used and are not misrepresented. The Data Access and Publication Subcommittee will receive a copy of every report before publication. at the same time as the NDSS partners or the NDSS Steering Committee, according to the rules listed below.

Parties engaged in independent research:

▼ The NDSS provides parties engaged in independent research a right to publish, assuring the parties that once the use of the data has been approved, no censure rights can be applied by NDSS partners and no publication can be suppressed because of differences of interpretation or political con-However. NDSS sequences. partners. specifically those whose data contributed to the research, may request a delay or specific process whereby they can review the manuscript to detect any error of fact. The interpretation and conclusions contained in the publications or report may not necessarily represent those of the NDSS, Health Canada, or any province or territory.

- Before being sent to publishers, manuscripts from parties engaged in independent research, peer-reviewed or not, should be sent to the Data Access and Publication Subcommittee, and the Subcommittee will send the manuscripts to provinces or territories whose data contributed to the research for review. NDSS partners and Data Access and Publication Subcommittee reviewers have two weeks upon receipt to make recommendations for changes.
- Peer-reviewed or non-peer-reviewed manuscripts must be sent to the Data Access and Publications Subcommittee once they are accepted for publication (for information purposes and to facilitate a coordinated approach to publication of NDSS data only, not to prevent publication).

When NDSS data are used for presentations and conference abstracts, the Data Access and Publication Subcommittee should be notified.

Protection of privacy and confidentiality

Privacy and confidentiality must be protected. Successful applicants must comply with the NDSS Privacy and Confidentiality Policy, which describes detailed measures for ensuring the protection of privacy and confidentiality of NDSS data. Measures to be used include, but are not limited to, checks for residual disclosure of individual identity prior to release of any reports ensuring that aggregate data, and or approval/release of any person-level data (for example, for research) is in accordance with the legislation, polices and processes of the individual organizations at the provincial and territorial level where the data reside. It is a provincial and territorial role to ensure adequate security arrangements for all person-level data.

Destruction

Data files may be provided for a five-year time period, following which the original data set and any copies thereof must be destroyed at the completion of the project or according to the signed agreement destruction date or negotiated data expiry date.

Penalties

Those who violate conditions for disclosure or who misrepresent the nature of the data supplied to them will be subject to sanctions, which may include

- a written complaint to the sponsoring organization;
- rebuttal in the journal;
- refusal of future access to data for the researcher and/or the institution he/she represents;
- seizure of any data released by NDSS; and/or
- ▼ legal action.

Publication

- The NDSS Steering Committee will endeavour to publish on an annual basis a report with core epidemiological measures from aggregate NDSS data at the Health Canada site.
- The NDSS Steering Committee retains authority to approve publication of NDSS information by Health Canada.
- ▼ The NDSS Steering Committee permits Health Canada to release a public-use NDSS aggregate data file on its website after approval of the content of the data file by the Steering Committee and Aboriginal Diabetes Working Group.

- The National Diabetes Surveillance System must be credited as a contributor in any publications arising from NDSS data at provincial, territorial or Health Canada sites or any other organization using NDSS data, and a disclaimer added that the interpretation and conclusions contained in the publications or report do not necessarily represent those of the NDSS, Health Canada, or any province or territory.
- Diabetes-related stakeholders not already represented on the NDSS Steering Committee will be first in line for obtaining copies of public-release annual NDSS reports, starting with the member organizations of the Diabetes Council of Canada.
- ▼ The Data Access and Publications Subcommittee is responsible for submitting its publication plans (schedule and proposed content) to the Steering Committee for approval each year. In addition, the Subcommittee will work to coordinate similar publications from provinces and territories, as feasible and desired.
- Provinces and territories will continue to publish their own diabetes data at times dictated by provincial/territorial requirements.

Cost-recovery

Cost-recovery fees for NDSS publications and for the provision of unpublished NDSS information or data files can be set at levels to be determined by the governments where the NDSS data are kept. Health Canada will have copies of aggregate data already held at respective provincial/ territorial sites and will therefore never charge a province or territory for a copy of its own data. The prospective user of data held by Health Canada may be required to sign an "Agreement to Proceed with Data Preparation" form, which briefly outlines the search activity and the estimated costs, for which the user agrees to reimburse Health Canada. For data at the provincial/territorial level, an individual province/territory may have its own agreement that the prospective user may be required to sign.

Evaluation

- The NDSS Steering Committee will evaluate the activities covered by this Data Access and Publications Subcommittee as one component of the overall evaluation of the NDSS. The Steering Committee will also determine whether and to what extent the general guiding principles of the NDSS have been followed; namely the principles of consistency, flexibility, quality, costeffectiveness, accessibility, privacy and confidentiality, and responsiveness. Measures to be used for this evaluation are to be determined and may include consistency in reporting on the same population/area from different NDSS sites, flexibility in the range of themes addressed in special reports, guality of research from NDSS aggregate data, the impact of cost-recovery fees, rates of successful requests for NDSS aggregate data and absence of confidentiality information, leaks, and assessment of whether the NDSS is having an impact on research activity and is responding (e.g. in its special reports and enhanced analyses) to questions raised by research.
- The Access and Data Publication Working Group should review this policy every two years.

Appendix G

COMPARISON OF NDSS AND STATISTICS CANADA COUNTS OF DEATH AND POPULATION

Death Counts					
Province/Territory	Death Counts* and Ratio (%)	1995/1996	1996/1997	1997/1998	1998/1999
Yukon	NDSS	149	145	119	130
	Statistics Canada	154	139	111	135
	NDSS: Statistics Canada (%)	96.75	104.32	107.21	96.30
Northwest Territories	NDSS	238	278	260	279
	Statistics Canada	234	290	255	287
	NDSS: Statistics Canada (%)	101.71	95.86	101.96	97.21
British Columbia	NDSS	24,971	26,329	26,423	25,171
	Statistics Canada	26,618	27,734	27,750	27,665
	NDSS: Statistics Canada (%)	93.81	94.93	95.22	90.98
Alberta	NDSS	15,789	16,371	16,637	15,921
	Statistics Canada	15,906	16,532	16,819	16,817
	NDSS: Statistics Canada (%)	99.26	99.03	98.92	94.67
Saskatchewan	NDSS	8,581	8,896	8,797	8,892
	Statistics Canada	8,475	8,845	8,789	8,893
	NDSS: Statistics Canada (%)	101.25	100.58	100.09	99.99
Manitoba	NDSS	9,587	9,686	9,190	9,805
	Statistics Canada	9,555	9,672	9,569	9,834
	NDSS: Statistics Canada (%)	100.33	100.14	96.04	99.71
Ontario	NDSS	77,446	79,297	78,216	76,114
	Statistics Canada	77,977	79,868	80,292	80,027
	NDSS: Statistics Canada (%)	99.32	99.29	97.41	95.11
Prince Edward Island	NDSS	1,171	1,295	1,115	1,127
	Statistics Canada	1,172	1,248	1,076	1,125
	NDSS: Statistics Canada (%)	99.91	<i>103.77</i>	<i>103.62</i>	<i>100.18</i>
Nova Scotia	NDSS	8,040	7,655	7,943	7,410
	Statistics Canada	7,743	7,850	8,124	7,739
	NDSS: Statistics Canada (%)	103.84	97.52	97.77	95.75

*counts of deaths due to any cause, people aged 20+

Population Counts

Province/Territory	Population Counts (Ages 20+) and Estimates	1997/1998	1998/1999	1999/2000
Yukon	NDSS annual count	24,320	23,846	23,514
	NDSS July count	22,432	21,867	21,602
	Statistics Canada July estimate	22,549	22,141	21,896
Northwest Territories	NDSS annual count	29,593	29,381	28,837
	NDSS July count	27,449	27,209	26,778
	Statistics Canada July estimate	26,918	26,579	26,600
British Columbia	NDSS annual count	2,947,363	2,970,243	2,996,666
	NDSS July count	2,518,893	2,568,320	2,588,334
	Statistics Canada July estimate	2,941,849	2,980,366	3,016,521
Alberta	NDSS annual count	2,074,952	2,130,058	2,172,836
	NDSS July count	2,025,470	2,076,741	2,124,241
	Statistics Canada July estimate	2,004,598	2,062,669	2,110,691
Saskatchewan	NDSS annual count	738,042	745,309	752,753
	NDSS July count	711,309	718,880	726,971
	Statistics Canada July estimate	712,441	717,473	721,810
Manitoba	NDSS annual count	847,294	848,247	852,112
	NDSS July count	818,002	818,203	822,341
	Statistics Canada July estimate	812,180	815,330	820,391
Ontario	NDSS annual count	8,778,947	8,937,507	9,130,308
	NDSS July count	8,509,463	8,683,060	8,872,165
	Statistics Canada July estimate	8,250,541	8,369,816	8,491,836
Prince Edward Island	NDSS annual count	105,044	104,340	105,019
	NDSS July count	99,669	100,323	101,094
	Statistics Canada July estimate	97,837	98,436	99,602
Nova Scotia	NDSS annual count	716,220	722,403	731,016
	NDSS July count	692,053	698,270	707,022
	Statistics Canada July estimate	691,021	695,177	700,854

Appendix H

ANNUAL PERSON-LEVEL SUMMARY FILE (APLSF) DATA ELEMENTS

Category	Description	Name
Demographic		
	Age as of March 31 of fiscal year	AGE
	Calculated using the date of birth and year ending date	חו
	Identifier that is unique to that person for perpetuity	
	Municipality or other geographic descriptor as defined by the province or territory (optional)	MUN
	Province or territory	PT
	Fiscal year to which data apply	YEAR
Exposure		
	Person-days of observation with diabetes in current year	DM_PDO
	Person-days of observation without diabetes in current year	DM_PDON
	Person-days of observation Total number of days person was aligible for health insurance in the province/	PDO
	territory within the current year	
Diabetes Case	e Ascertainment Information	
	Hospital discharge date where diabetes was recorded among the first three diagnosis codes	D_DH3D
	Date of first diabetes diagnosis from physician data in current fiscal year	D_DMD1
	Date of second diabetes diagnosis from physician data in current fiscal year Date of first diabetes diagnosis from physician data in previous fiscal year	D_DMD2 DM_DMD1
Case Date		
	Perpetual diabetes case date	DM_CASE
Complication/	Co-morbidity Data	
	(NOTE: Other co-morbid conditions will be added as the case definitions are defined.)	
	Date of death	DOD
Health Servic	es Use	
	(NOTE: Other health services measures will be added as definitions are defined) Treatment days – number of days admitted to hospital (not included in current data)	TDAYS
History		
	Count of medical diagnoses in current year	D_CMD
	Multi-year count of physician diagnosis of diabetes	DM_CMD
	rear first observing iD/earliest NDSS year person was observed within NDSS, within province/territory	FIKSTIK
	The fiscal year in which the person was given a diagnosis of diabetes within the NDSS	DM_YRCCS

Note: Health Canada can provide access to a dummy file for researchers interested in testing SAS code.

Appendix H

Appendix I

CANADIAN STANDARD POPULATION ESTIMATES — JULY 1, 1991

Sex	Age Group	Population	Population Over Age 20	Proportion Over Age 20
Both	00-09	3,906,391		
Sex Both Female Male	10-19	3,839,205		
	20-29	4,638,691	4,638,691	0.22767
	30-39	4,943,161	4,943,161	0.24262
	40-49	3,813,044	3,813,044	0.18715
	50-54	1,339,902	1,339,902	0.06576
	55-59	1,238,441	1,238,441	0.06078
	60-64	1,190,217	1,190,217	0.05842
	65-69	1,084,588	1,084,588	0.05323
	70-74	834,024	834,024	0.04093
	75-79	622,221	622,221	0.03054
	80-84	382,303	382,303	0.01876
	85+	287,877	287,877	0.01413
	Total	28,120,065	20,374,469	
Female	00-09	1,910,164		
	10-19	1,873,125		
	20-29	2,276,239	2,276,239	0.11172
	30-39	2,467,295	2,467,295	0.1211
	40-49	1,897,274	1,897,274	0.09312
	50-54	670,271	670,271	0.0329
	55-59	620,986	620,986	0.03048
	60-64	613,550	613,550	0.03011
	65-69	588,370	588,370	0.02888
	70-74	469,865	469,865	0.02306
	75-79	365,286	365,286	0.01793
	80-84	237,631	237,631	0.01166
	85+	198,419	198,419	0.00974
	Total	14,188,475	10,405,186	
Male	00-09	2,006,773		
	10-19	1,976,734		
	20-29	2,343,775	2,343,775	0.11503
	30-39	2,480,546	2,480,546	0.12175
	40-49	1,917,714	1,917,714	0.09412
	50-54	676,641	676,641	0.03321
	55-59	617,879	617,879	0.03033
	60-64	580,323	580,323	0.02848
	65-69	497,485	497,485	0.02442
	70-74	362,500	362,500	0.01779
	75-79	252,779	252,779	0.01241
	80-84	139,408	139,408	0.00684
	85+	85,869	85,869	0.00421
	Total	13,938,426	9,954,919	

Appendix I

Appendix J

VALIDATION WORK

information Diagnostic provided by administrative data is limited on the basis of a single interaction with the health care system. NDSS uses a more elaborate algorithm that is based on multiple interactions between the person with diabetes and physicians and hospitals. Consequently, NDSS requires an articulated case definition and ongoing validation of that definition. NDSS validation uses a systematic approach, with different aspects of validation conducted in at least two provinces/territories to demonstrate potential differences by jurisdiction.

- ▼NDSS algorithm: a person is identified as having diabetes with one hospital or two physician visits within two years coded with a diagnosis of diabetes mellitus.
- ▼ **Sensitivity:** the proportion of people who truly have diabetes who are identified by the NDSS algorithm.
- ▼ **Specificity:** the proportion of people who truly do not have diabetes who are classified as such by the NDSS algorithm.
- ▼ Positive Predictive Value: the probability that a person identified by the NDSS algorithm as having diabetes truly does have diabetes. This is influenced by sensitivity, specificity, and prevalence.

Gold Standards and Jurisdictions

The case definition currently used by NDSS is based on developmental work in Manitoba that produced sensitivity of over 95% (specificity could not be assessed) using the gold standard of the Diabetes Education Resource¹. Initial validation work in Alberta² and Ontario³ used the National Population Health Survey⁴ as the gold standard. Both studies concluded that self-reported survey data could not be used as a gold standard, since they underestimate the true disease burden in the population.

Other completed validation projects have substantiated the use of the NDSS algorithm. Studies in Nova Scotia,⁵ Ontario⁶ and Prince Edward Island⁷ produced sensitivity measures ranging from 69% in Nova Scotia to 83% and 86% in Prince Edward Island and Ontario respectively. The gold standards were a combination of the provincial health survey and the Diabetes Care Program Registry in Nova Scotia, the diabetes registry in Prince Edward Island, and medical charts in Ontario.

In the same three studies, specificity measures varied much less, at 99% in Nova Scotia and Prince Edward Island and 97% in Ontario. Positive predictive value was 80% in Ontario and 78% in Prince Edward Island.

Validation work is ongoing in other jurisdictions. In British Columbia, the gold standard is the number of prescriptions for insulin and oral hypoglycemic medication; in the Yukon it is use of the Diabetes Education Centres, and in Quebec the use of clinical data.

Validity Over Time

The Prince Edward Island study found sensitivity, specificity and predictive value to be stable for five to seven years of data for people aged 25 and over, and for a series of sequential five-year data windows.⁷ With the use of 10 or more years of administrative data, specificity and positive predictive value decreased as prevalent cases over-accumulated. Alternative algorithms are under investigation in Nova Scotia to incorporate the concept of cumulative probability of diabetes.

Incidence Versus Prevalence

New cases and prevalent cases are difficult to differentiate in the early years.⁸ Several studies found at least five years of data are required before stable estimates of incidence can be obtained.^{7,9} Therefore incidence rates are not included in the first NDSS report.

Special Populations

Validation has not yet been completed for people under the age of 20 years. Initial investigation of several algorithms for type 1 diabetes has produced positive predictive values of less than 40%.¹⁰ Prince Edward Island and Ontario are also investigating several algorithms for detecting diabetes among people under age 20, using the Prince Edward Island Diabetes Registry and hospital chart abstracts respectively.

Initial work in British Columbia and Ontario suggests that the increase in female prevalence seen during the child-bearing years may be the result of miscoding of gestational diabetes. One project funded by the Canadian Institutes of Health Research (CIHR) is validation of an algorithm for removal of gestational diabetes using chart abstracts from maternity hospitals. This project will also provide validation for individuals under non fee-for-service arrangements, using electronic patient records and drug claims data. Validation work in Aboriginal communities will include use of the Sandy Lake diabetes community screening database and Northern Diabetes Health Network database.

Complications

The complications of diabetes are also under investigation, with an initial focus on co-morbidities of cardiovascular disease. cerebrovascular disease, peripheral vascular disease, including lower limb amputations, retinopathy and dialysis. Projects are under way in Ontario,¹¹ Quebec, Manitoba, and the Yukon. One of the CIHR-funded projects will describe the distribution of co-morbid conditions and Charlson's co-morbidity index¹² among inpatients using the national Hospital Morbidity Data maintained at the Canadian Institute for Health Information (CIHI) and the Person-Oriented Information Database maintained at Statistics Canada. The effect of co-morbid conditions on hospital stay, hospital readmission, and hospital mortality will be assessed. The distribution of co-morbid conditions in the general Canadian population will be described using the 1996/97 National Population Health Survey.

Health Service Use

Work is also planned for health service use. The need for accurate identification of people with and without diabetes will become increasingly important as NDSS looks toward the management of diabetes.

New Initiatives with CIHR

Recently, the NDSS and the CIHR Institute of Nutrition, Metabolism and Diabetes collaborated in funding health services and population health research on diabetes. Each partner contributed \$250,000 for a total of \$500,000 in funding available. A Request for Applications (RFA) was called in April 2002. Eligible research areas were data validation (diabetes case definition, case definitions for complications related to diabetes, and community-based screening) and health services and population health research (quality of life, access to diabetes-related health care services, economic analysis of the burden of diabetes).

Seven applications were peer-reviewed by a six-person committee of Canadians and Americans chaired by Dr. Sam Sheps from the University of British Columbia. Two projects were funded, and reports are expected by January 2005:

- Validation of administrative data algorithms for diabetes surveillance in special populations (\$92,024) by J. Hux, G. Booth, A. Hanley, T. To, D. Daneman, H. Lee, D. Feig
- ▼ Evaluation of co-morbidities and complications in relation to hospital outcomes for diabetes among Canadian inpatients and general Canadian populations (\$192,940) by Y. Chen, R. Sigal

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Appendix K

PREVALENCE

Age-specific Prevalence by Fiscal Year, Sex and Province/Territory

Canada		-				-	
A		1997,	/1998	1998,	/1999	1999,	/2000
Age group		Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.7	0.4	0.8	0.5	0.9	0.5
	 People with diabetes 	14,820	9,041	16,454	9,806	17,494	10,562
	 Annual population count 	1,997,477	2,024,463	1,994,491	2,023,346	1,997,640	2,029,248
30-39	Prevalence (%)	1.4	1.0	1.6	1.1	1.8	1.2
	 People with diabetes 	35,149	24,272	40,626	26,876	45,406	28,683
	 Annual population count 	2,528,645	2,544,838	2,499,595	2,515,198	2,471,874	2,490,412
40-49	Prevalence (%)	2.2	2.6	2.4	2.9	2.6	3.0
	 People with diabetes 	49,607	60,160	56,787	67,338	62,695	72,785
	 Annual population count 	2,289,110	2,289,206	2,348,501	2,349,403	2,410,680	2,412,997
50-54	Prevalence (%)	4.1	5.7	4.5	6.2	4.7	6.4
	 People with diabetes 	36,708	50,825	42,145	58,092	46,566	63,598
	 Annual population count 	894,409	898,957	939,131	939,131	985,939	987,280
55-59	Prevalence (%)	6.0	8.3	6.5	9.0	6.8	9.5
	 People with diabetes 	41,374	56,480	46,626	64,048	50,981	70,751
	 Annual population count 	690,681	684,001	720,363	714,799	750,683	746,490
60-64	Prevalence (%)	8.1	10.7	8.9	11.9	9.3	12.5
	 People with diabetes 	48,840	62,265	54,002	69,613	57,623	74,906
	 Annual population count 	600,281	579,751	608,538	586,737	619,702	597,864
65-69	Prevalence (%)	10.2	12.9	11.0	14.1	11.5	14.9
	 People with diabetes 	58,906	69,132	63,593	75,923	66,893	80,829
	 Annual population count 	579,798	535,662	579,565	539,503	579,176	540,838
70-74	Prevalence (%)	11.7	14.5	12.7	15.9	13.5	16.9
	 People with diabetes 	61,870	62,869	67,535	69,956	71,814	75,972
	 Annual population count 	530,424	433,241	532,012	441,247	533,607	449,917
75-79	Prevalence (%)	12.1	14.8	13.2	16.3	14.2	17.4
	 People with diabetes 	52,132	45,497	59,504	52,428	65,349	57,856
	 Annual population count 	432,184	306,934	449,659	321,181	461,785	331,731
80-84	Prevalence (%)	11.6	14.0	12.8	15.4	13.7	16.7
	 People with diabetes 	34,280	25,275	38,247	28,064	42,119	31,260
	 Annual population count 	295,571	180,014	299,326	182,152	307,457	187,627
85+	Prevalence (%)	9.5	11.5	10.6	12.8	11.5	13.8
	 People with diabetes 	26,337	14,213	30,647	16,685	35,044	18,956
	 Annual population count 	276,946	123,232	290,099	130,019	305,043	137,462
Total*	Prevalence (%)	4.1	4.5	4.6	5.0	4.9	5.4
	 People with diabetes 	460,023	480,029	516,166	538,829	561,984	586,158
	 Annual population count 	11,115,526	10,600,299	11,261,280	10,745,676	11,423,586	10,911,866
Canadian Total	✓ People with diabetes**	479,346	500,193	537,848	561,463	585,590	610,780

* for participating jurisdictions ** estimated using NDSS prevalence and adjusting for 4.2% of Canadian population in New Brunswick and Newfoundland and Labrador (2001 census)

Yukon Territory

		1997	/1998	1998	/1999	1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	 Prevalence (%) People with diabetes Annual population count 	0.9 23 2,495	0.4 9 2,468	1.2 28 2,384	0.5 12 2,263	1.1 25 2,292	0.6 12 2,117
30-39	Prevalence (%)	1.0	0.6	1.3	0.7	1.4	0.7
	People with diabetes	34	21	41	20	44	21
	Annual population count	3,347	3,292	3,198	3,056	3,060	2,830
40-49	Prevalence (%)	1.7	1.5	1.9	1.7	1.9	1.7
	People with diabetes	52	51	59	58	60	54
	Annual population count	3,062	3,386	3,110	3,318	3,134	3,267
50-54	 Prevalence (%) People with diabetes Annual population count 	3.9 38 985	4.9 62 1,273	4.5 47 1,036	5.0 65 1,295	4.6 51 1,111	5.2 67 1,299
55-59	 Prevalence (%) People with diabetes Annual population count 	4.8 28 582	6.4 52 817	4.5 28 618	6.2 53 851	5.7 37 647	6.0 55 922
60-64	Prevalence (%)	7.5	5.7	10.4	7.2	10.0	8.5
	People with diabetes	31	30	43	39	42	48
	Annual population count	413	527	414	542	421	567
65-69	Prevalence (%)	9.3	11.2	7.0	10.9	8.1	10.1
	▼ People with diabetes	28	47	21	46	26	43
	▼ Annual population count	300	421	300	422	322	424
70-74	 Prevalence (%) People with diabetes Annual population count 	7.3 14 192	10.6 25 236	14.1 27 191	12.2 33 270	17.2 35 203	14.7 43 293
75-79	Prevalence (%)	12.1	9.8	9.7	7.9	9.3	10.7
	People with diabetes	17	13	15	11	14	16
	Annual population count	140	133	155	140	151	150
80+	Prevalence (%)	6.1	9.7	7.6	10.6	9.4	14.6
	People with diabetes	9	10	13	12	17	18
	Annual population count	148	103	170	113	181	123
Total	Prevalence (%)	2.3	2.5	2.8	2.8	3.0	3.1
	♥ People with diabetes	274	320	322	349	351	377
	♥ Annual population count	11,664	12,656	11,576	12,270	11,522	11,992

Northwest Territories

		1997	/1998	1998/1999		1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.3	0.3	0.2	0.4	0.3	0.4
	People with diabetes	12	11	9	14	10	14
	Annual population count	3,843	3,764	3,659	3,639	3,525	3,460
30-39	Prevalence (%)	1.0	0.8	1.1	0.9	1.0	0.9
	▼ People with diabetes	42	38	46	39	42	38
	▼ Annual population count	4,384	4,524	4,263	4,339	4,107	4,149
40-49	Prevalence (%)	2.4	2.3	2.5	2.8	2.4	3.0
	People with diabetes	75	80	80	104	77	108
	Annual population count	3,175	3,550	3,251	3,664	3,236	3,644
50-54	 Prevalence (%) People with diabetes Annual population count 	4.1 39 961	5.3 68 1,272	5.5 55 1,002	5.3 70 1,320	6.1 66 1,074	5.6 78 1,381
55-59	Prevalence (%)	6.2	6.9	6.5	8.6	7.0	9.2
	▼ People with diabetes	40	54	43	71	46	76
	▼ Annual population count	646	786	658	822	660	829
60-64	Prevalence (%)	6.2	9.1	7.5	8.9	7.9	11.1
	▼ People with diabetes	25	47	32	47	34	57
	▼ Annual population count	405	515	424	526	432	512
65-69	Prevalence (%)	9.2	7.3	8.0	10.2	8.7	13.7
	▼ People with diabetes	27	28	25	39	28	54
	▼ Annual population count	292	382	311	384	321	395
70-74	Prevalence (%)	12.0	9.7	14.6	9.3	13.6	8.8
	People with diabetes	26	23	31	24	29	23
	Annual population count	216	237	212	257	214	261
75-79	Prevalence (%)	9.6	4.1	9.2	6.5	12.6	8.0
	People with diabetes	13	6	14	9	20	11
	Annual population count	136	147	153	139	159	137
80+	Prevalence (%)	11.7	4.3	11.4	4.8	11.7	6.2
	People with diabetes	23	7	22	8	21	10
	Annual population count	197	161	193	165	179	162
Total	Prevalence (%)	2.3	2.4	2.5	2.8	2.7	3.1
	♥ People with diabetes	322	362	357	425	373	469
	♥ Annual population count	14,255	15,338	14,126	15,255	13,907	14,930

Nunavut

		1997/1998		1998	/1999	1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.2	0.1	0.3	0.2	0.2	0.2
	People with diabetes	5	4	8	5	7	7
	Annual population count	3,068	2,994	2,978	2,953	2,965	2,899
30-39	Prevalence (%)	0.4	0.2	0.5	0.3	0.6	0.4
	People with diabetes	12	6	13	9	17	12
	Annual population count	2,726	2,913	2,887	3,011	2,967	3,113
40-49	Prevalence (%)	0.9	0.8	1.1	1.0	0.8	1.2
	People with diabetes	14	16	17	20	13	25
	Annual population count	1,523	1,894	1,588	1,926	1,678	2,008
50-54	 Prevalence (%) People with diabetes Annual population count 	0.9 5 555	1.6 11 689	1.4 8 582	2.1 16 761	2.2 14 624	2.3 18 797
55-59	Prevalence (%)	1.8	2.6	1.4	3.0	2.0	4.0
	People with diabetes	7	12	6	15	9	21
	Annual population count	396	454	435	495	441	525
60-64	Prevalence (%)	1.8	2.5	2.3	3.2	3.3	4.7
	People with diabetes	5	8	7	11	11	18
	Annual population count	282	325	309	342	338	384
65-69	Prevalence (%)	1.7	4.4	1.7	3.3	2.9	3.3
	People with diabetes	3	8	3	7	6	8
	Annual population count	174	182	181	209	208	239
70+	Prevalence (%)	-	-	-	-	-	-
	People with diabetes	_			_	_	-
	Annual population count	207	261	236	293	266	318
Total	Prevalence (%)	0.6	0.7	0.8	0.9	0.9	1.1
	♥ People with diabetes	54	69	69	89	85	116
	♥ Annual population count	8,931	9,712	9,196	9,990	9,487	10,283

British Columbia

		1997/1998		1998/1999		1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.7	0.4	0.8	0.5	0.8	0.5
	 People with diabetes 	1,933	1,133	2,132	1,173	2,182	1,187
	 Annual population count 	270,437	259,333	265,240	253,392	259,727	249,203
30-39	Prevalence (%)	1.4	0.9	1.6	1.0	1.8	1.0
	 People with diabetes 	4,699	2,922	5,412	3,200	6,000	3,302
	 Annual population count 	336,203	326,758	330,789	320,456	325,439	315,659
40-49	Prevalence (%)	1.9	2.4	2.2	2.6	2.3	2.7
	 People with diabetes 	6,187	7,653	7,126	8,502	7,779	8,974
	 Annual population count 	320,842	318,016	327,697	322,650	333,202	326,834
50-54	Prevalence (%)	3.7	4.9	4.1	5.5	4.3	5.7
	 People with diabetes 	4,572	6,195	5,307	7,183	5,827	7,857
	 Annual population count 	122,324	125,209	129,066	131,339	136,696	138,518
55-59	Prevalence (%)	5.6	7.6	6.0	8.2	6.3	8.6
	 People with diabetes 	5,213	7,194	5,837	8,096	6,368	8,877
	 Annual population count 	93,051	94,513	97,474	98,937	101,746	103,361
60-64	Prevalence (%)	7.5	10.1	8.2	11.1	8.6	11.6
	 People with diabetes 	5,965	8,037	6,671	8,998	7,102	9,601
	 Annual population count 	79,218	79,842	80,861	81,131	82,776	82,649
65-69	Prevalence (%)	9.3	12.0	10.1	13.3	10.7	14.1
	 People with diabetes 	7,073	9,026	7,701	10,065	8,108	10,675
	 Annual population count 	75,947	75,272	75,881	75,544	75,645	75,715
70-74	Prevalence (%)	10.4	13.0	11.5	14.4	12.3	15.3
	 People with diabetes 	7,421	8,041	8,164	9,033	8,693	9,794
	 Annual population count 	71,069	61,627	70,726	62,561	70,888	63,989
75-79	Prevalence (%)	10.4	13.3	11.4	14.7	12.4	15.8
	 People with diabetes 	6,402	6,196	7,310	7,180	8,050	7,831
	 Annual population count 	61,812	46,485	64,063	48,745	64,924	49,604
80-84	Prevalence (%)	9.7	12.8	10.9	14.1	11.6	15.2
	 People with diabetes 	4,133	3,631	4,695	4,013	5,129	4,487
	 Annual population count 	42,815	28,376	43,233	28,460	44,404	29,452
85+	Prevalence (%)	7.8	10.5	8.6	11.6	9.4	12.7
	 People with diabetes 	3,022	2,059	3,521	2,439	4,118	2,851
	 Annual population count 	38,534	19,680	40,953	21,045	43,743	22,492
Total	Prevalence (%)	3.7	4.3	4.2	4.8	4.5	5.2
	 People with diabetes 	56,620	62,087	63,876	69,882	69,356	75,436
	 Annual population count 	1,512,252	1,435,111	1,525,983	1,444,260	1,539,190	1,457,476

Alberta

		1997/	/1998	1998/1999		1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.7	0.4	0.7	0.4	0.7	0.5
	 People with diabetes 	1,435	899	1,506	997	1,531	1,067
	 Annual population count 	211,313	214,861	217,036	221,584	219,957	224,898
30-39	Prevalence (%)	1.3	0.8	1.5	0.9	1.6	1.0
	 People with diabetes 	3,345	1,990	3,796	2,278	4,072	2,464
	 Annual population count 	255,273	254,359	253,954	253,221	251,360	250,403
40-49	Prevalence (%)	1.9	2.2	2.1	2.4	2.3	2.5
	 People with diabetes 	4,212	5,060	4,895	5,759	5,464	6,275
	 Annual population count 	224,025	232,598	233,818	242,682	242,758	251,586
50-54	Prevalence (%)	3.5	4.8	3.8	5.3	4.1	5.5
	 People with diabetes 	2,815	3,901	3,241	4,633	3,668	5,075
	 Annual population count 	79,535	81,890	84,473	86,827	89,716	92,439
55-59	Prevalence (%)	5.2	7.1	5.7	7.7	5.9	8.3
	 People with diabetes 	3,072	4,308	3,518	4,919	3,852	5,537
	 Annual population count 	59,178	60,619	62,129	63,743	65,020	66,879
60-64	Prevalence (%)	6.9	9.1	7.4	10.2	7.9	10.8
	 People with diabetes 	3,441	4,592	3,782	5,235	4,112	5,672
	 Annual population count 	50,135	50,528	51,347	51,384	52,368	52,511
65-69	Prevalence (%)	8.7	10.9	9.5	12.0	9.8	12.7
	 People with diabetes 	4,069	5,006	4,478	5,607	4,622	5,955
	 Annual population count 	46,741	45,919	47,037	46,586	47,349	46,915
70-74	Prevalence (%)	9.8	12.6	10.8	13.7	11.4	14.5
	 People with diabetes 	3,999	4,465	4,444	5,042	4,788	5,514
	 Annual population count 	40,647	35,539	41,314	36,798	41,923	38,057
75-79	Prevalence (%)	10.0	12.8	11.1	14.2	11.8	15.4
	 People with diabetes 	3,391	3,259	3,904	3,748	4,208	4,145
	 Annual population count 	34,051	25,392	35,198	26,371	35,524	26,890
80-84	Prevalence (%)	9.7	12.4	10.5	13.8	11.3	14.7
	 People with diabetes 	2,299	1,887	2,525	2,137	2,782	2,332
	 Annual population count 	23,631	15,181	24,030	15,534	24,651	15,816
85+	Prevalence (%)	8.4	10.7	9.3	11.7	10.1	13.1
	 People with diabetes 	1,878	1,182	2,194	1,334	2,454	1,517
	 Annual population count 	22,468	11,069	23,599	11,393	24,250	11,566
Total	Prevalence (%)	3.2	3.6	3.6	3.9	3.8	4.2
	 People with diabetes 	33,956	36,549	38,283	41,689	41,553	45,553
	 Annual population count 	1,046,997	1,027,955	1,073,935	1,056,123	1,094,876	1,077,960

Saskatchewan

		1997	/1998	1998	/1999	1999	/2000
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.7	0.5	0.8	0.5	0.8	0.5
	 People with diabetes 	514	360	557	378	574	410
	 Annual population count 	70,067	73,352	70,732	74,573	71,723	75,634
30-39	Prevalence (%)	1.3	1.0	1.5	1.2	1.6	1.3
	 People with diabetes 	1,039	818	1,140	928	1,220	968
	 Annual population count 	78,278	78,569	76,710	77,495	74,991	75,994
40-49	Prevalence (%)	2.5	2.7	2.7	3.0	2.8	3.0
	 People with diabetes 	1,804	1,998	2,018	2,266	2,131	2,370
	 Annual population count 	71,597	74,458	73,739	76,556	75,911	78,590
50-54	Prevalence (%)	4.5	5.7	4.8	6.2	4.8	6.3
	 People with diabetes 	1,180	1,556	1,327	1,771	1,400	1,902
	 Annual population count 	26,197	27,120	27,554	28,410	28,969	29,979
55-59	Prevalence (%)	6.2	8.0	6.6	8.8	6.9	9.0
	 People with diabetes 	1,349	1,726	1,476	1,950	1,561	2,065
	 Annual population count 	21,720	21,592	22,220	22,283	22,670	22,912
60-64	Prevalence (%)	7.6	10.3	8.4	11.2	8.7	11.4
	 People with diabetes 	1,535	2,049	1,686	2,206	1,755	2,267
	 Annual population count 	20,287	19,904	20,105	19,733	20,200	19,802
65-69	Prevalence (%)	8.8	12.0	9.4	13.1	9.9	13.5
	 People with diabetes 	1,791	2,353	1,881	2,520	1,963	2,562
	 Annual population count 	20,321	19,558	20,074	19,267	19,781	18,971
70-74	Prevalence (%)	10.8	13.6	11.5	14.8	11.8	15.5
	 People with diabetes 	2,139	2,372	2,261	2,558	2,292	2,672
	 Annual population count 	19,855	17,394	19,720	17,310	19,403	17,234
75-79	Prevalence (%)	10.9	14.6	12.0	16.1	12.5	16.6
	 People with diabetes 	1,981	2,035	2,175	2,274	2,262	2,345
	 Annual population count 	18,168	13,926	18,089	14,108	18,070	14,148
80-84	Prevalence (%)	10.9	14.2	11.7	15.2	12.0	16.3
	 People with diabetes 	1,560	1,359	1,681	1,457	1,752	1,566
	 Annual population count 	14,298	9,579	14,353	9,606	14,599	9,596
85+	Prevalence (%)	9.0	12.0	9.9	13.4	10.5	14.3
	 People with diabetes 	1,278	906	1,475	1,039	1,627	1,152
	 Annual population count 	14,277	7,525	14,911	7,761	15,519	8,057
Total	Prevalence (%)	4.3	4.8	4.7	5.3	4.9	5.5
	 People with diabetes 	16,170	17,532	17,677	19,347	18,537	20,279
	 Annual population count 	375,065	362,977	378,207	367,102	381,836	370,917

Manitoba

		1997	/1998	1998	/1999	1999/	1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male	
20-29	Prevalence (%)	0.9	0.6	1.0	0.6	1.1	0.7	
	 People with diabetes 	700	460	786	514	834	566	
	 Annual population count 	80,186	82,008	79,363	80,620	78,756	80,164	
30-39	Prevalence (%)	1.8	1.4	2.1	1.5	2.3	1.7	
	 People with diabetes 	1,671	1,267	1,860	1,388	2,035	1,510	
	 Annual population count 	92,502	93,839	90,320	91,553	88,651	89,507	
40-49	Prevalence (%)	3.2	3.3	3.6	3.7	3.9	3.8	
	 People with diabetes 	2,738	2,862	3,100	3,190	3,407	3,399	
	 Annual population count 	85,419	85,772	86,488	86,854	87,865	88,498	
50-54	Prevalence (%)	5.9	6.7	6.5	7.4	6.8	8.0	
	 People with diabetes 	1,948	2,256	2,253	2,591	2,463	2,910	
	 Annual population count 	33,130	33,561	34,737	34,971	36,482	36,334	
55-59	Prevalence (%)	7.7	8.8	8.3	9.7	8.9	10.5	
	 People with diabetes 	2,011	2,245	2,228	2,576	2,464	2,908	
	 Annual population count 	26,057	25,639	26,831	26,585	27,616	27,757	
60-64	Prevalence (%)	9.7	11.6	10.5	12.7	11.3	13.5	
	 People with diabetes 	2,185	2,560	2,410	2,819	2,602	3,006	
	 Annual population count 	22,564	22,087	22,847	22,217	23,011	22,319	
65-69	Prevalence (%)	11.0	13.0	12.2	14.5	13.0	15.9	
	 People with diabetes 	2,492	2,707	2,697	3,008	2,842	3,252	
	 Annual population count 	22,634	20,801	22,137	20,690	21,818	20,474	
70-74	Prevalence (%)	11.9	14.4	13.0	15.6	13.8	16.9	
	 People with diabetes 	2,648	2,615	2,838	2,830	2,974	3,045	
	 Annual population count 	22,316	18,151	21,835	18,103	21,477	18,068	
75-79	Prevalence (%)	11.6	13.6	12.7	15.5	14.1	16.7	
	 People with diabetes 	2,322	1,951	2,623	2,254	2,912	2,467	
	 Annual population count 	20,065	14,305	20,590	14,524	20,647	14,742	
80-84	Prevalence (%)	10.9	12.6	11.9	14.0	13.2	15.2	
	 People with diabetes 	1,635	1,188	1,771	1,308	1,971	1,406	
	 Annual population count 	14,956	9,401	14,907	9,326	14,931	9,252	
85+	Prevalence (%)	8.3	11.3	9.3	12.2	10.2	13.0	
	 People with diabetes 	1,235	793	1,430	896	1,649	992	
	 Annual population count 	14,871	7,030	15,408	7,341	16,131	7,612	
Total	Prevalence (%)	5.0	5.1	5.5	5.7	6.0	6.1	
	 People with diabetes 	21,585	20,904	23,996	23,374	26,153	25,461	
	 Annual population count 	434,700	412,594	435,463	412,784	437,385	414,727	

Ontario

		1997	/1998	1998/1999		1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.8	0.5	0.9	0.5	1.0	0.6
	 People with diabetes 	6,431	3,919	7,271	4,333	7,976	4,789
	 Annual population count 	803,717	811,280	802,624	811,191	806,980	816,213
30-39	Prevalence (%)	1.5	1.1	1.8	1.2	2.1	1.3
	 People with diabetes 	15,877	11,268	18,740	12,635	21,587	13,813
	 Annual population count 	1,041,079	1,049,639	1,041,354	1,049,776	1,044,054	1,053,776
40-49	Prevalence (%)	2.4	2.9	2.7	3.2	2.9	3.4
	 People with diabetes 	21,542	26,387	25,003	29,703	28,382	33,165
	 Annual population count 	910,722	903,353	938,173	932,730	970,112	967,532
50-54	Prevalence (%)	4.3	6.1	4.8	6.6	5.2	7.1
	 People with diabetes 	15,547	21,778	17,999	25,064	20,567	28,135
	 Annual population count 	358,099	359,875	377,273	378,637	397,842	397,832
55-59	Prevalence (%)	6.2	8.6	6.9	9.4	7.4	10.2
	 People with diabetes 	17,370	23,717	19,863	27,038	22,142	30,381
	 Annual population count 	278,154	274,985	289,115	286,576	300,782	299,148
60-64	Prevalence (%)	8.5	11.2	9.3	12.4	9.9	13.3
	 People with diabetes 	20,783	26,464	23,115	29,635	25,167	32,416
	 Annual population count 	244,012	235,378	248,977	239,437	253,989	244,360
65-69	Prevalence (%)	10.4	13.3	11.3	14.5	12.2	15.7
	 People with diabetes 	24,455	29,009	26,639	31,799	28,741	34,616
	 Annual population count 	235,200	218,307	235,546	220,042	236,375	220,972
70-74	Prevalence (%)	11.6	14.5	12.7	15.9	13.7	17.2
	 People with diabetes 	25,494	26,243	27,828	29,282	30,182	32,353
	 Annual population count 	219,417	180,479	219,469	183,787	220,157	187,789
75-79	Prevalence (%)	11.8	14.8	13.0	16.3	14.1	17.6
	 People with diabetes 	20,650	18,710	24,053	21,837	26,969	24,581
	 Annual population count 	175,561	126,807	185,093	134,200	191,826	139,554
80-84	Prevalence (%)	11.2	13.9	12.3	15.3	13.4	16.4
	 People with diabetes 	12,990	10,042	14,468	11,153	16,338	12,567
	 Annual population count 	115,960	72,173	117,382	73,096	121,752	76,412
85+	Prevalence (%)	9.1	11.1	10.1	12.4	11.1	13.2
	 People with diabetes 	10,373	5,578	12,089	6,585	13,956	7,514
	 Annual population count 	114,589	50,161	119,715	53,314	125,895	56,956
Total	Prevalence (%)	4.3	4.7	4.7	5.3	5.2	5.7
	 People with diabetes 	191,512	203,115	217,068	229,064	242,007	254,330
	 Annual population count 	4,496,510	4,282,437	4,574,721	4,362,786	4,669,764	4,460,544

Quebec

		1997/	/1998	1998/1999		1999/	<u>1999/2000</u>	
Age gro	бир	Female	Male	Female	Male	Female	Male	
20-29	Prevalence (%)	0.7	0.4	0.7	0.4	0.8	0.4	
	 People with diabetes 	3,189	1,800	3,514	1,915	3,691	2,035	
	 Annual population count 	475,195	497,742	474,044	497,579	475,725	499,548	
30-39	Prevalence (%)	1.2	0.8	1.4	0.8	1.5	0.9	
	 People with diabetes 	7,237	4,967	8,260	5,288	9,051	5,445	
	 Annual population count 	622,102	643,339	605,247	625,992	587,489	609,707	
40-49	Prevalence (%)	1.9	2.3	2.0	2.5	2.1	2.6	
	 People with diabetes 	10,853	13,508	12,087	14,959	12,864	15,554	
	 Annual population count 	582,749	582,294	593,300	594,166	603,472	604,835	
50-54	Prevalence (%)	3.7	5.4	4.0	5.8	4.1	5.9	
	 People with diabetes 	8,745	12,703	9,829	14,124	10,323	14,831	
	 Annual population count 	237,477	233,163	246,411	241,913	254,727	250,252	
55-59	Prevalence (%)	5.6	8.2	5.9	8.8	6.0	9.1	
	 People with diabetes 	10,363	14,669	11,461	16,537	12,214	17,800	
	 Annual population count 	184,089	178,038	192,971	186,877	201,947	195,242	
60-64	Prevalence (%)	7.9	10.7	8.6	11.8	8.8	12.3	
	 People with diabetes 	12,597	15,791	13,776	17,568	14,223	18,609	
	 Annual population count 	160,168	148,175	159,959	148,314	162,379	151,241	
65-69	Prevalence (%)	10.5	13.4	11.1	14.4	11.4	14.9	
	 People with diabetes 	16,390	18,080	17,393	19,696	17,720	20,368	
	 Annual population count 	156,747	135,102	156,639	136,432	155,663	136,432	
70-74	Prevalence (%)	12.8	15.9	13.7	17.2	14.2	18.0	
	 People with diabetes 	17,485	16,407	18,998	18,178	19,809	19,397	
	 Annual population count 	136,795	103,446	138,577	105,847	139,496	107,751	
75-79	Prevalence (%)	14.3	16.7	15.4	18.3	16.1	19.1	
	 People with diabetes 	14,823	11,176	16,673	12,795	18,087	14,026	
	 Annual population count 	103,934	66,912	107,952	70,050	112,331	73,472	
80-84	Prevalence (%)	14.1	15.9	15.5	17.4	16.4	19.0	
	 People with diabetes 	9,886	5,890	11,131	6,563	11,985	7,310	
	 Annual population count 	70,256	36,929	71,659	37,733	72,900	38,509	
85+	Prevalence (%)	12.3	13.7	13.6	15.4	14.7	16.3	
	 People with diabetes 	7,246	3,005	8,414	3,569	9,558	4,000	
	 Annual population count 	58,827	21,928	61,660	23,114	64,998	24,505	
Total	Prevalence (%)	4.3	4.5	4.7	4.9	4.9	5.2	
	 People with diabetes 	118,814	117,996	131,536	131,192	139,525	139,375	
	 Annual population count 	2,788,339	2,647,068	2,808,419	2,668,017	2,831,127	2,691,494	

* for participating jurisdictions

** estimated using NDSS deaths and adjusting for 4.2% of Canadian population in New Brunswick and Newfoundland and Labrador (2001 census)

Prince Edward Island

		1997/1998		1998/1999		1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.8	0.7	0.9	0.7	0.9	0.8
	 People with diabetes 	77	74	86	77	87	77
	 Annual population count 	10,151	10,574	9,891	10,305	9,723	10,134
30-39	Prevalence (%)	1.0	1.1	1.3	1.3	1.4	1.2
	 People with diabetes 	119	125	145	144	155	133
	 Annual population count 	11,520	11,264	11,100	10,917	10,834	10,757
40-49	Prevalence (%)	1.9	2.7	2.3	3.1	2.3	3.3
	 People with diabetes 	204	287	250	330	252	356
	 Annual population count 	10,805	10,671	10,701	10,560	10,894	10,673
50-54	Prevalence (%)	3.9	5.6	4.2	6.4	4.5	6.1
	 People with diabetes 	172	247	193	293	218	296
	 Annual population count 	4,355	4,415	4,583	4,603	4,864	4,872
55-59	Prevalence (%)	5.7	8.0	6.6	8.5	6.4	9.3
	 People with diabetes 	185	261	225	291	228	325
	 Annual population count 	3,252	3,279	3,398	3,415	3,564	3,493
60-64	Prevalence (%)	6.9	8.8	8.0	10.8	8.9	11.4
	 People with diabetes 	200	250	234	311	264	342
	 Annual population count 	2,900	2,840	2,915	2,880	2,953	2,987
65-69	Prevalence (%)	9.2	13.3	10.7	14.3	10.7	14.2
	 People with diabetes 	243	338	284	364	288	367
	 Annual population count 	2,639	2,537	2,643	2,548	2,697	2,581
70-74	Prevalence (%)	10.6	14.5	11.6	16.5	12.0	17.3
	 People with diabetes 	256	296	281	344	291	361
	 Annual population count 	2,424	2,039	2,418	2,079	2,426	2,081
75-79	Prevalence (%)	12.1	14.8	13.6	16.7	13.6	17.7
	 People with diabetes 	281	236	310	264	299	288
	 Annual population count 	2,313	1,592	2,276	1,585	2,198	1,627
80-84	Prevalence (%)	11.5	13.9	13.5	16.0	15.1	16.2
	 People with diabetes 	203	147	238	168	271	165
	 Annual population count 	1,759	1,061	1,760	1,050	1,800	1,016
85+	Prevalence (%)	9.2	9.2	9.5	11.5	10.2	13.6
	 People with diabetes 	167	77	177	99	198	122
	 Annual population count 	1,817	837	1,854	859	1,948	897
Total	Prevalence (%)	3.9	4.6	4.5	5.3	4.7	5.5
	 People with diabetes 	2,107	2,338	2,423	2,685	2,551	2,832
	 Annual population count 	53,935	51,109	53,539	50,801	53,901	51,118

Nova Scotia

		1997	/1998	1998/1999		1999/2000	
Age gro	bup	Female	Male	Female	Male	Female	Male
20-29	Prevalence (%)	0.7	0.6	0.8	0.6	0.9	0.6
	 People with diabetes 	501	372	557	388	577	398
	 Annual population count 	67,005	66,087	66,540	65,247	66,267	64,978
30-39	Prevalence (%)	1.3	1.1	1.5	1.3	1.5	1.3
	 People with diabetes 	1,074	850	1,173	947	1,183	977
	 Annual population count 	81,231	76,342	79,773	75,382	78,922	74,517
40-49	Prevalence (%)	2.6	3.1	2.8	3.3	2.9	3.3
	 People with diabetes 	1,926	2,258	2,152	2,447	2,266	2,505
	 Annual population count 	75,191	73,214	76,636	74,297	78,418	75,530
50-54	Prevalence (%)	5.3	6.7	5.8	7.1	5.8	7.2
	 People with diabetes 	1,647	2,048	1,886	2,282	1,969	2,429
	 Annual population count 	30,791	30,490	32,414	32,015	33,834	33,577
55-59	Prevalence (%)	7.4	9.6	7.9	10.3	8.1	10.6
	 People with diabetes 	1,736	2,242	1,941	2,502	2,060	2,706
	 Annual population count 	23,556	23,279	24,514	24,215	25,590	25,422
60-64	Prevalence (%)	10.4	12.4	11.0	13.6	11.1	14.0
	 People with diabetes 	2,073	2,437	2,246	2,744	2,311	2,870
	 Annual population count 	19,897	19,630	20,380	20,231	20,835	20,532
65-69	Prevalence (%)	12.4	14.7	13.1	16.0	13.4	16.5
	 People with diabetes 	2,335	2,530	2,471	2,772	2,549	2,929
	 Annual population count 	18,803	17,181	18,816	17,379	18,997	17,720
70-74	Prevalence (%)	13.7	17.0	15.2	18.6	15.7	19.4
	 People with diabetes 	2,386	2,380	2,658	2,630	2,715	2,767
	 Annual population count 	17,406	13,969	17,449	14,102	17,298	14,250
75-79	Prevalence (%)	14.1	17.1	15.1	18.3	15.9	18.9
	 People with diabetes 	2,252	1,913	2,427	2,053	2,528	2,143
	 Annual population count 	15,949	11,157	16,029	11,229	15,897	11,314
80-84	Prevalence (%)	13.3	15.7	14.6	17.5	15.3	19.1
	 People with diabetes 	1,553	1,119	1,713	1,252	1,862	1,407
	 Annual population count 	11,672	7,125	11,772	7,145	12,194	7,363
85+	Prevalence (%)	9.9	12.5	11.3	14.2	11.9	15.3
	 People with diabetes 	1,126	608	1,335	716	1,473	799
	 Annual population count 	11,377	4,868	11,792	5,046	12,339	5,222
Total	Prevalence (%)	5.0	5.5	5.5	6.0	5.6	6.3
	 People with diabetes 	18,609	18,757	20,559	20,733	21,493	21,930
	 Annual population count 	372,878	343,342	376,115	346,288	380,591	350,425

Appendix L

MORTALITY

Age-specific Mortality by Fiscal Year, Sex and Province/Territory

Canada

	Age group	1997 /1	1998	1998/2	1999	1999/2	2000
		Female	Male	Female	Male	Female	Male
20-29	Diabetes						
	→ deaths → population count	26 14,815	25 9,037	20 16,446	18 9,801	20 17,487	25 10,555
	No diabetes	619	1 707	E 4 1	1 6 2 7	FCO	1 505
	 deaths population count 	1,979,594	2,012,432	1,975,067	2,010,592	1,977,188	2,015,794
	Mortality rate ratio	5.62	3.22	4.44	2.27	4.04	2.99
30-39	Diabetes		110	70	00	100	117
	 deaths population count 	35,137	24,266	40,613	89 26,867	45,389	28,671
	- deaths	1,309	2,785	1,222	2,479	1,186	2,414
	 population count Mortality rate ratio 	2,490,782 4.17	2,517,659 4.10	2,456,095 3.56	2,485,320 3.32	2,423,518 4.59	2,458,628 4.16
40-49	Diabetes						
	 deaths population count 	238 49,593	413 60,144	247 56,770	464 67,318	283 62,682	515 72,760
	→ deaths	2,856	4,563	2,814	4,196	2,902	4,505
	 population count Mortality rate ratio 	2,237,994 3.76	2,227,168 3.35	2,290,143 3.54	2,280,159 3.75	2,346,320 3.65	2,338,229 3.67
50-54	Diabetes		0.00	0.01	0.70	0.00	
	- deaths	308	573	338	560	357	597
	 population count No diabetes 	36,703	50,814	42,137	58,076	46,552	63,580
	 deaths population count 	2,117 857 151	3,307 847 454	2,161 896 412	3,181 883 254	2,209 938 763	3,261 922 903
	Mortality rate ratio	3.40	2.89	3.33	2.68	3.26	2.66
55-59	Diabetes						
	 deaths population count 	486 41.367	949 56 468	528 46 620	899 64 033	548 50 972	1,031 70,730
	No diabetes	41,007	30,400	40,020	04,000	30,372	/0,/00
	 deaths population count 	2,584 648 918	4,110 627 079	2,600 673 308	3,920 650 271	2,661 699.270	3,987 675 235
	Mortality rate ratio	2.95	2.56	2.93	2.33	2.83	2.47
60-64	Diabetes						
	 deaths population count 	817 48 835	1,558 62 257	845 53 995	1,523 69.602	877 57 612	1,637 74 888
	No diabetes	40,000	02,207	33,553	05,002	37,012	74,000
	→ deaths → population count	3,495 551.164	5,525 517.169	3,238 554.234	5,249 516.793	3,284 561.752	5,218 522,592
	Mortality rate ratio	2.64	2.34	2.68	2.15	2.60	2.19
65-69	Diabetes						
	 deaths population count 	1,461 58.903	2,474 69.124	1,423 63.590	2,645 75.916	1,515 66.887	2,608 80.821
	No diabetes	5.004	0.005	4.005	7.004	4 700	7.000
	 deaths population count 	5,264 520,721	8,605 466,356	4,885 515,794	7,994 463,378	4,798 512,081	7,632 459,778
	Mortality rate ratio	2.45	1.94	2.36	2.02	2.42	1.94

Canada (continued)

	Age group	1997/	1998	1998/	/1999	1999/	2000
		Female	Male	Female	Male	Female	Male
70-74	Diabetes – deaths – population count	2,379 61,868	3,382 62,867	2,303 67,530	3,624 69,954	2,340 71,808	3,688 75,969
	 deaths population count Mortality rate ratio 	7,481 468,469 2.41	11,049 370,250 1.80	7,227 464,381 2.19	10,470 371,160 1.84	7,166 461,677 2.10	10,326 373,804 1.76
75-79	Diabetes → deaths → population count No diabetes	2,976 52,132	3,685 45,495	3,138 59,504	4,061 52,425	3,383 65,349	4,367 57,853
	 deaths population count Mortality rate ratio 	10,653 379,997 2.04	12,790 261,361 1.66	10,244 390,094 2.01	12,577 268,666 1.65	10,303 396,378 1.99	12,348 273,785 1.67
80-84	Diabetes – deaths – population count No diabetes	3,045 34,279	3,117 25,275	3,286 38,245	3,310 28,063	3,420 42,117	3,556 31,259
	 deaths population count Mortality rate ratio 	13,095 261,256 1.77	12,724 154,702 1.50	12,482 261,043 1.80	12,218 154,046 1.49	12,332 265,298 1.75	11,450 156,320 1.55
85+	Diabetes – deaths – population count No diabetes	4,459 26,337	2,826 14,213	4,892 30,647	3,245 16,685	5,364 35,044	3,461 18,956
	 deaths population count Mortality rate ratio 	30,729 250,580 1.38	16,691 108,997 1.30	30,287 259,416 1.37	16,604 113,307 1.33	30,270 269,955 1.37	16,618 118,473 1.30
Total*	Diabetes – deaths – population count No diabetes	16,272 459,969	19,112 479,960	17,092 516,097	20,438 538,740	18,209 561,899	21,602 586,042
	 deaths population count Mortality rate ratio 	80,201 10,646,626 4.70	83,876 10,110,627 4.80	77,701 10,735,987 4.58	80,515 10,196,946 4.80	77,671 10,852,200 4.53	79,354 10,315,541 4.79
Canadian Total	Diabetes → deaths**	16,955	19,915	17,810	21,296	18,974	22,509

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Age-specific Mortality by Fiscal Year and Sex

Yukon Territory

A		1997/1	998	1998/1999		1999/2000	
Age group		Female	Male	Female	Male	Female	Male
20-64	Diabetes		-t-				d
	 deaths population count 	206	225	246	247	259	257
	No diabetes → deaths	21	34	16	40	19	48
	 population count Mortality rate ratio 	10,678 *	11,538 *	10,514 *	11,078 *	10,406 *	10,745 *
65+	Diabetes				J.		
	 → deaths → population count 	11 474		520		54	12 48
	No diabetes		55	54		73	
	 population count Mortality rate ratio 	17,93	6.4	17,640		17,456 5.24	
Total	Diabetes - deaths - population count	7 274	6 320	6 322	4 349	5 351	11 377
	 deaths population count Mortality rate ratio 	39 11,390 7.46	62 12,336 3.73	46 11,254 4.56	69 11,921 1.98	42 11,171 3.79	88 11,615 3.85

* cell suppressed

Age-specific Mortality by Fiscal Year and Sex

Northwest Territories

			998	1998/1999		1999/2000	
Age group		Female	Male	Female	Male	Female	Male
20-64	Diabetes – deaths – population count No diabetes – deaths – population count Mortality rate ratio	233 35 13,181 *	* 298 72 14,113 *	265 44 12,992 *	* 345 77 13,965 *	275 25 12,759 *	* 371 37 13,604 *
65+	Diabetes - deaths - population count No diabetes - deaths - population count Mortality rate ratio	9 563 20,329		¹¹ 651 20,313 293		* 704 67 20,036 *	
Total	Diabetes – deaths – population count No diabetes – deaths – population count Mortality rate ratio	10 322 70 13,933 6.18	4 362 130 14,976 1.27	9 357 93 13,769 3.73	425 137 14,830 1.27	7 373 52 13,534 4.88	2 469 79 14,461 0.78

* cell suppressed

Age-specific Mortality by Fiscal Year and Sex

British Columbia

		1997/1	998	1998/1	999	1999/2000	
Age group		Female	Male	Female	Male	Female	Male
20-29	Diabetes						
	 deaths population count 	1 933	0	0 2 1 3 2	5	0	0
	No diabetes	1,900	1,100	2,132	1,1/3	2,102	1,107
	→ deaths	91	310	66	188	61	166
	 population count 	268,504	258,200	263,108	252,219	257,545	248,016
20.20	Mortality rate ratio	U	U	U	5.72	U	0
30-39	Diabetes → deaths	8	16	8	7	10	9
	 population count 	4,699	2,922	5,412	3,200	6,000	3,302
	No diabetes	017	453	150	0.00	100	000
	 deaths population count 	217	457 323 836	152 325 377	286 317 256	132 319 439	280 312 357
	Mortality rate ratio	2.6	3.88	3.16	2.43	4.03	3.04
40-49	Diabetes						
	→ deaths	24	45	20	35	27	57
	 population count No diabetes 	6,187	/,653	/,126	8,502	/,//9	8,974
	→ deaths	410	638	372	536	320	521
	 population count 	314,655	310,363	320,571	314,148	325,423	317,860
	Mortality rate ratio	2.98	2.86	2.42	2.41	3.53	3.88
50-54	Diabetes	36	64	30	56	35	52
	 population count 	4,572	6,195	5,307	7,183	5,827	7,857
	No diabetes	, ,	, ,	·	, i		·
	 deaths population count 	281	456	279	373	256	378
	Mortality rate ratio	3.3	2.7	2.67	2.6	3.07	2.33
55-59	Diabetes						
	- deaths	54	112	52	94	49	107
	→ population count	5,213	7,194	5,837	8,096	6,368	8,877
	→ deaths	343	538	322	464	335	448
	 population count 	87,838	87,319	91,637	90,841	95,378	94,484
	Mortality rate ratio	2.65	2.53	2.54	2.27	2.19	2.54
60-64	Diabetes	80	167	96	150	01	170
	 deaths population count 	5.965	8.037	6.671	8.998	7.102	9.601
1	No diabetes		-,	-,	-,	• • •	- ,
1	 deaths 	405	654	395	597	393	591
	 population count Mortality rate ratio 	/3,203 2.7	/1,805 2.28	74,190 2.42	/2,133 2.05	/5,6/4	/3,048 2.29
65-69	Diabetes	E.,		<u> </u>	2.00		
00 00	→ deaths	140	279	145	301	143	286
	 population count 	7,073	9,026	7,701	10,065	8,108	10,675
	No diabetes	663	1 09/	613	968	569	883
	 population count 	68,874	66,246	68,180	65,479	67,537	65,040
	Mortality rate ratio	2.06	1.87	2.09	2.02	2.09	1.97

APPENDIX L
British Columbia (continued)

		1997/3	1998	1998/	1999	1999/	2000
Age group		Female	Male	Female	Male	Female	Male
70-74	Diabetes – deaths – population count No diabetes	245 7,421	402 8,041	239 8,164	390 9,033	250 8,693	448 9,794
	 deaths population count Mortality rate ratio 	931 63,648 2.26	1,436 53,586 1.87	921 62,562 1.99	1,306 53,528 1.77	854 62,195 2.09	1,249 54,195 1.98
75-79	Diabetes – deaths – population count No diabetes – deaths – population count	356 6,402 1,450 55,410	443 6,196 1,679 40,289	330 7,310 1,361 56,753	517 7,180 1,700 41,565	387 8,050 1,353 56,874	566 7831 1,598 41,773
	Mortality rate ratio	2.12	1.72	1.88	1.76	2.02	1.89
80-84	Diabetes → deaths → population count No diabetes	336 4,133	412 3,631	378 4,695	430 4,013	390 5,129	465 4,487
	 deaths population count Mortality rate ratio 	1,849 38,682 1.70	1,761 24,745 1.59	1,617 38,538 1.92	1,722 24,447 1.52	1,655 39,275 1.80	1,671 24,965 1.55
85+	Diabetes → deaths → population count No diabetes	489 3,022	388 2,059	505 3,521	449 2,439	595 4,118	482 2,851
	 → deaths → population count Mortality rate ratio 	3,913 35,512 1.47	2,436 17,621 1.36	3,998 37,432 1.34	2,496 18,606 1.37	3,950 39,625 1.45	2,583 19,641 1.29
Total	Diabetes - deaths - population count No diabetes	1,777 56,620	2,328 62,087	1,795 63,876	2,437 69,882	1,967 69,356	2,651 75,436
	 deaths population count Mortality rate ratio 	10,553 1,455,632 4.33	11,459 1,373,024 4.49	10,096 1,462,107 4.07	10,636 1,374,378 4.51	9,878 1,469,834 4.22	10,368 1,382,040 4.68

Alberta

		1997/1	998	1998/1	999	1999/2000	
Age group		Female	Male	Female	Male	Female	Male
20-29	Diabetes		0	0	0	0	0
	 deaths population count 	0 1,435	0 899	1,506	0 997	1,531	0 1,067
	 → deaths → population count 	80 209,878	201 213,962	76 215,530	197 220,587	68 218,426	193 223,831
	Mortality rate ratio	0	0	0	0	0	0
30-39	Diabetes	10	c.	10	_	2	10
	→ deaths → population count	12 3,345	6 1,990	10 3796	/ 2,278	8 4,072	2,464
	 → deaths → population count 	149 251,928	312 252,369	131 250,158	295 250,943	118 247,288	258 247,939
	Mortality rate ratio	6.07	2.44	5.03	2.61	4.12	4.68
40-49	Diabetes	01	20	0.5	10	05	10
	 deaths population count 	4,212	32 5,060	26 4,895	48 5,759	25 5,464	42 6,275
	- deaths	262	468	268	424	288	452
	Mortality rate ratio	4.18	227,000 3.07	4.54	230,923 4.66	237,294 3.77	240,511 3.63
50-54	Diabetes						
	→ deaths	15	29	21	41	34	34
	 population count No diabetes 	2,815	3,901	3,241	4,633	3,668	5,075
	 deaths population count 	1/4 76,720	274 77,989	215 81,232	280 82,194	197 86,048	275 87,364
	Mortality rate ratio	2.35	2.12	2.45	2.6	4.05	2.13
55-59	Diabetes						
	 deaths population count 	34 3,072	62 4,308	34 3,518	44 4,919	38 3,852	59 5,537
	→ deaths	226	355	223	341	227	363
	→ population count Mortality rate ratio	56,106 2.75	56,311 2.28	58,611 2.54	58,824 1.54	61,168 2.66	61,342 1.80
60-64	Diabetes						
	 deaths population count 	60 3,441	113 4,592	57 3,782	89 5,235	61 4,112	119 5,672
	No diabetes	200	100	0.65	100	070	450
	 deaths population count 	46,694	490 45,936	47,565	460 46,149	48,256	450 46,839
	Mortality rate ratio	2.71	2.31	2.71	1.71	2.65	2.18
65-69	Diabetes						
	 deaths population count 	92 4,069	157 5,006	82 4,478	178 5,607	99 4,622	168 5,955
	 deaths population count 	456	708	378	673	412	673
	Mortality rate ratio	42,072 2.12	40,913 1.81	42,009 2.06	1.93	2.22	1.72

Alberta (continued)

A		1997/1	998	1998/	1999	1999/	2000
Age group		Female	Male	Female	Male	Female	Male
70-74	Diabetes – deaths – population count No diabetes	140 3,999	182 4,465	148 4,444	233 5,042	133 4,788	216 5,514
	 → deaths → population count Mortality rate ratio 	617 36,648 2.08	844 31,074 1.50	517 36,870 2.38	882 31,756 1.66	596 37,135 1.73	872 32,543 1.46
75-79	Diabetes - deaths - population count No diabetes - deaths	187 3,391 838	238 3,259	201 3,904 757	248 3,748 977	192 4,208 819	314 4,145 970
	 population count Mortality rate ratio 	30,660 2.02	22,133 1.56	31,294 2.13	22,623 1.53	31,316 1.74	22,745 1.78
80-84	Diabetes – deaths – population count No diabetes	182 2,299	210 1,887	184 2,525	209 2,137	205 2,782	256 2,332
	 deaths population count Mortality rate ratio 	1,050 21,332 1.61	1,026 13,294 1.44	964 21,505 1.63	1,013 13,397 1.29	988 21,869 1.63	972 13,484 1.52
85+	Diabetes – deaths – population count No diabetes	293 1,878	239 1,182	347 2,194	234 1,334	366 2,454	268 1,517
	 deaths population count Mortality rate ratio 	2,501 20,590 1.28	1,588 9,887 1.26	2,400 21,405 1.41	1,472 10,059 1.2	2,464 21,796 1.32	1,499 10,049 1.18
Total	Diabetes – deaths – population count No diabetes	1,036 33,956	1,268 36,549	1,110 38,283	1,331 41,689	1,161 41,553	1,488 45,553
	 → deaths → population count Mortality rate ratio 	6,653 1,013,041 4.65	7,302 991,406 4.71	6,194 1,035,652 4.85	7,014 1,014,434 4.62	6,447 1,053,323 4.56	6,977 1,032,407 4.83

Saskatchewan

		1997/19	998	1998/1	999	1999/20	000
Age group		Female	Male	Female	Male	Female	Male
20-29	Diabetes – deaths – population count No diabetes	0 514	0 360	0 557	0 378	0 574	0 410
	 → deaths → population count Mortality rate ratio 	35 69,553 0	68 72,992 0	25 70,175 0	90 74,195 0	33 71,149 0	77 75,224 0
30-39	Diabetes – deaths – population count No diabetes	0 1,039	0 818	0 1,140	0 928	0 1,220	0 968
	 deaths population count Mortality rate ratio 	52 77,239 0	115 77,751 0	52 75,570 0	88 76,567 0	52 73,771 0	100 75,026 0
40-49	Diabetes – deaths – population count	6 1,804	16 1,998	10 2,018	15 2,266	14 2,131	16 2,370
	No diabetes → deaths → population count Mortality rate ratio	108 69,793 2.15	156 72,460 3.72	107 71,721 3.32	145 74,290 3.39	98 73,780 4.95	166 76,220 3.1
50-54	Diabetes – deaths – population count No diabetes	13 1,180	16 1,556	9 1,327	22 1,771	14 1,400	32 1,902
	 deaths population count Mortality rate ratio 	67 25,017 4.11	109 25,564 2.41	62 26,227 2.87	111 26,639 2.98	76 27,569 3.63	131 28,077 3.61
55-59	Diabetes – deaths – population count No diabetes	14 1,349	30 1,726	28 1,476	31 1,950	23 1,561	34 2,065
	 deaths population count Mortality rate ratio 	73 20,371 2.9	120 19,866 2.88	84 20,744 4.68	156 20,333 2.07	94 21,109 3.31	133 20,847 2.58
60-64	Diabetes – deaths – population count No diabetes	30 1,535	52 2,049	31 1,686	50 2,206	28 1,755	59 2,267
	 deaths population count Mortality rate ratio 	134 18,752 2.73	216 17,855 2.1	111 18,419 3.05	179 17,527 2.22	112 18,445 2.63	214 17,535 2.13
65-69	Diabetes → deaths → population count	48 1,791	92 2,353	49 1,881	90 2,520	53 1,963	98 2,562
	 deaths population count Mortality rate ratio 	191 18,530 2.60	301 17,205 2.23	188 18,193 2.52	288 16,747 2.08	168 17,818 2.86	279 16,409 2.25

Saskatchewan (continued)

		1997/1	998	1998/1	999	1999/2	000
Age group		Female	Male	Female	Male	Female	Male
70-74	Diabetes – deaths – population count No diabetes	83 2,139	132 2,372	83 2,261	157 2,558	82 2,292	161 2,672
	 → deaths → population count Mortality rate ratio 	262 17,716 2.62	432 15,022 1.94	282 17459 2.27	435 14,752 2.08	256 17,111 2.39	410 14,562 2.14
75-79	Diabetes - deaths - population count No diabetes - deaths - population count Mortality rate ratio	104 1,981 464 16,187 183	139 2,035 583 11,891 1 39	106 2,175 378 15,914 2 05	184 2,274 609 11,834 1 57	116 2,262 406 15,808 2	208 2,345 541 11,803 1 94
80-84	Diabetes – deaths – population count No diabetes	121 1,560	138 1,359	119 1,681	151 1,457	130 1,752	192 1,566
	 deaths population count Mortality rate ratio 	575 12,738 1.72	629 8,220 1.33	531 12,672 1.69	638 8,149 1.32	557 12,847 1.71	576 8,030 1.71
85+	Diabetes - deaths - population count No diabetes - deaths - population count	185 1,278 1,523 12,999	163 906 966 6,619	236 1,475 1,564 13,436	194 1,039 1,016 6,722	238 1,627 1,558 13,892	210 1,152 1,019 6,905
Total	Mortality rate ratio Diabetes - deaths - population count	604 16,170	778 17,532	671 17677	894 19,347	698 18,537	1,010 20,279
	 deaths population count Mortality rate ratio_ 	3,484 358,895 3.85	3,695 345,445 4.15	3,384 360,530 4.04	3,755 347,755 4.28	3,410 363,299 4.01	3,646 350,638 4.79

Manitoba

		1997/19	998	1998/1	999	1999/20	000
Age group		Female	Male	Female	Male	Female	Male
20-29	Diabetes – deaths – population count No diabetes	0 700	0 460	0 786	0 514	0 834	0 566
	 → deaths → population count Mortality rate ratio 	31 79,486 0	79 81,548 0	32 78,577 0	82 80,106 0	38 77,922 0	80 79,598 0
30-39	Diabetes - deaths - population count No diabetes	7 1,671	0 1,267	0 1,860	5 1,388	9 2,035	0 1,510
	 → deaths → population count Mortality rate ratio 	52 90,831 7.32	102 92,572 0	61 88,460 0	104 90,165 3.12	64 86,616 5.99	93 87,997 0
40-49	Diabetes – deaths – population count	13 2,738	17 2,862	16 3,100	38 3,190	20 3,407	28 3,399
	 deaths population count Mortality rate ratio 	106 82,681 3.7	161 82,910 3.06	92 83,388 4.68	147 83,664 6.78	119 84,458 4.17	198 85,099 3.54
50-54	Diabetes – deaths – population count No diabetes	13 1,948	22 2,256	21 2,253	31 2,591	22 2,463	33 2,910
	 → deaths → population count Mortality rate ratio 	76 31,182 2.74	117 31,305 2.61	85 32,484 3.56	109 32,380 3.55	101 34,019 3.01	133 33,424 2.85
55-59	Diabetes – deaths – population count No diabetes	22 2,011	39 2,245	34 2,228	37 2,576	26 2,464	61 2,908
	 → deaths → population count Mortality rate ratio 	96 24,046 2.74	158 23,394 2.57	120 24,603 3.13	160 24,009 2.16	111 25,152 2.39	156 24,849 3.34
60-64	Diabetes - deaths - population count No diabetes	43 2,185	54 2,560	48 2,410	74 2,819	37 2,602	84 3,006
	 deaths population count Mortality rate ratio 	123 20,379 3.26	196 19,527 2.1	154 20,437 2.64	256 19,398 1.99	142 20,409 2.04	192 19,313 2.81
65-69	Diabetes – deaths – population count	71 2,492	98 2,707	62 2,697	112 3,008	69 2,842	101 3,252
	 deaths population count Mortality rate ratio 	200 20,142 2.87	332 18,094 1.97	205 19,440 2.18	325 17,682 2.03	189 18,976 2.44	361 17,222 1.48

Manitoba (continued)

		1997/1	998	1998/1	999	1999/2	000
Age group		Female	Male	Female	Male	Female	Male
70-74	Diabetes – deaths – population count No diabetes	106 2,648	117 2,615	114 2,838	148 2,830	84 2,974	164 3,045
	 deaths population count Mortality rate ratio 	280 19,668 2.81	433 15,536 1.61	313 18,997 2.44	446 15,273 1.79	287 18,503 1.82	444 15,023 1.82
75-79	Diabetes – deaths – population count No diabetes – deaths	123 2,322 474	139 1,951	152 2,623	183 2,254 598	162 2,912	177 2,467
	 population count Mortality rate ratio 	17,743 1.98	12,354 1.4	17,967 1.95	12,270 1.67	17,735 2.14	12,275 1.42
80-84	Diabetes – deaths – population count No diabetes – deaths	140 1,635 640	141 1,188 656	142 1,771 627	167 1,308 683	152 1,971 603	146 1,406 596
	 population count Mortality rate ratio 	13,321 1.78	8,213 1.4 9	13,136 1.68	8,018 1.5	12,960 1.66	7,846 1.37
85+	Diabetes – deaths – population count No diabetes – deaths	214 1,235 1 591	148 793 916	195 1,430 1 706	180 896 995	235 1,649 1 623	191 992 968
	 population count Mortality rate ratio 	13,636 1.49	6,237 1.27	13,978 1.12	6,445 1.3	14,482 1.27	6,620 1.32
Total	Diabetes – deaths – population count No diabetes	752 21,585	775 20,904	784 23,996	975 23,374	816 26,153	985 25,461
	 deaths population count Mortality rate ratio 	3,669 413,115 3.92	3,778 391,690 3.84	3,930 411,467 3.42	3,905 389,410 4.16	3,737 411,232 3.43	3,842 389,266 3.92

Ontario

		1997/3	1998	1998/3	1999	1999/2	2000
Age group		Female	Male	Female	Male	Female	Male
20-29	Diabetes						
	→ deaths	11	13	12	8	11	15
	 population count 	6,431	3,919	7,271	4,333	7,976	4,789
	- deaths	188	485	169	481	170	473
	 population count 	797,286	807,361	795,353	806,858	799,004	811,424
	Mortality rate ratio	7.25	5.52	7.77	3.1	6.48	5.37
30-39	Diabetes						
	 deaths accurate 	27	42	19 740	42	21 597	55 12 912
	No diabetes	13,877	11,200	10,740	12,055	21,307	15,015
	→ deaths	443	934	440	841	427	819
	 population count 	1,025,202	1,038,371	1,022,614	1,037,141	1,022,467	1,039,963
	Mortality rate ratio	3.94	4.14	3.35	4.1	4.88	5.06
40-49	Diabetes	01	170	101	1.00	100	004
	 deaths population count 	91 21 5/2	170 26 387	25 003	168 29 703	108 28 382	204 33 165
	No diabetes	21,042	20,007	23,005	25,705	20,302	33,103
	- deaths	1,014	1,579	1,001	1,386	1,012	1,536
	 population count 	889,180	876,966	913,170	903,027	941,730	934,367
50.54	Nortality rate ratio	3./	3.58	3.69	3.69	3.54	3.74
50-54	Diabetes	124	220	12/	224	125	264
	 population count 	15,547	21,778	17,999	25,064	20,567	28,135
	No diabetes	-,	,	.,	-,	-,	-,
	- deaths	806	1,177	773	1,118	896	1,212
	 population count 	342,552 3 39	338,097	359,274 346	353,573 283	3//,2/5	369,697
55-59	Disbetes	5.55	5.15	3.40	2.05	2.70	2.00
55-55	- deaths	168	364	225	334	223	408
	 population count 	17,370	23,717	19,863	27,038	22,142	30,381
	No diabetes						
	 deaths population count 	972	1,475	946	1,376	1,004	1,463
	Mortality rate ratio	2.59	2.61	3.22	2.33	270,040	2.47
60-64	Diabetes						
	- deaths	324	623	327	620	358	633
	 population count 	20,783	26,464	23,115	29,635	25,167	32,416
	No diabetes	1 360	2 046	1 242	1 0/6	1 292	1 040
	 deaths population count 	223.229	208.914	225.862	209.802	228.822	211.944
	Mortality rate ratio	2.54	2.4	2.57	2.26	2.54	2.13
65-69	Diabetes						
	- deaths	560	982	580	1,010	622	1,007
	 population count 	24,455	29,009	26,639	31,799	28,741	34,616
	- deaths	2 018	3 1 7 5	1 879	2 950	1 200	2 809
	 population count 	210,745	189,298	208,907	188,243	207,634	186,356
	Mortality rate ratio	2.39	2.02	2.42	2.03	2.38	1.93

Ontario (continued)

		1997/3	1998	1998/3	1999	1999/2	2000
Age group		Female	Male	Female	Male	Female	Male
70-74	Diabetes – deaths – population count No diabetes – deaths	966 25,494 3,027	1,372 26,243 4,316	904 27,828 2,779	1,429 29,282 4,039	931 30,182 2,878	1,476 32,353 4,017
	 population count Mortality rate ratio 	193,923 2 43	154,236 1 87	191,641 2 24	154,505 1 87	189,975 2 04	155,436 1 77
75.79	Dishetes	2.43	1.07	2.24	1.07	2.04	1.77
15-15	 deaths population count 	1,156 20,650	1,499 18,710	1,252 24,053	1,619 21,837	1,327 26,969	1,734 24,581
	→ deaths → population count Mortality rate ratio	4,147 154,911 2 09	4,943 108,097 1 75	4,137 161,040 2 03	4,848 112,363 1 72	4,231 164,857 1 92	4,891 114,973 1 66
80-84	Diabetes	2105	11/0	2100	117 E	1.01	1100
	 deaths population count 	1,217 12,990	1,226 10,042	1,243 14,468	1,309 11,153	1,317 16,338	1,363 12,567
	→ deaths → population count Mortality rate ratio	4,965 102,970 1 94	4,796 62,131 1.58	4,842 102,914 1 83	4,521 61,943 1 61	4,777 105,414 1.78	4,393 63,845 1 58
85+	Diabetes	1.54	1.00	1.00	1.01	1.70	1.50
	 deaths population count 	1,793 10,373	1,097 5,578	1,952 12,089	1,308 6,585	2,103 13,956	1,351 7,514
	→ deaths → population count Mortality rate ratio	12,367 104,216 146	6,316 44,583 1 39	11,843 107,626 1 47	6,253 46,729 1 48	12,166 111,939 1 39	6,386 49,442 1 39
Total	Diabetes	1110	1100	2117	1110	1100	1100
	 deaths population count 	6,437 191,512	7,627 203,115	6,757 217,068	8,071 229,064	7,179 242,007	8,510 254,330
	 deaths population count Mortality rate ratio 	31,316 4,304,998 4.62	31,242 4,079,322 4.9	30,051 4,357,653 4.51	29,759 4,133,722 4.89	30,733 4,427,757 4.27	29,939 4,206,214 4.7

Quebec

A		1997/1	998	1998/1	999	1999/2	000
Age group		Female	Male	Female	Male	Female	Male
20-29	Diabetes						
	→ deaths	15	12	8 2 514	5	9	10
	→ population count No diabetes	5,169	1,800	5,514	1,915	5,691	2,055
	→ deaths	161	501	135	494	150	542
	 population count 	472,006	495,942	470,530	495,664	472,034	497,513
	Mortality rate ratio	13.79	6.6	7.93	2.62	7.67	4.51
30-39	Diabetes	10	20	20	20	22	20
	→ deaths	7.237	39 4.967	8.260	28 5.288	23 9.051	5.445
	No diabetes	,,20,	1,507	0,200	0,200	5,001	0,110
	→ deaths	350	743	342	772	345	754
	→ population count	614,865	638,372	596,987	620,704	578,438	604,262
40.40	Nortality rate ratio	4.37	0.75	5.49	4.20	4.20	5.5
40-49	Diabetes	7/	121	66	138	82	152
	→ population count	10,853	13,508	12,087	14,959	12,864	15,554
	No diabetes						
	- deaths	840	1,357	859	1,375	947	1,416
	→ population count Mortality rate ratio	5/1,896 4 64	308,780 375	3 69	579,207 3 89	590,608 3 98	089,281 4 07
50-54	Diabetes		0170	0.05	0105	0.50	
	→ deaths	100	178	108	170	104	154
	 population count 	8,745	12,703	9,829	14,124	10,323	14,831
	No diabetes	612	1 005	651	1 022	506	090
	→ deaths → population count	228.732	220.460	236.582	227.789	244.404	235.421
	Mortality rate ratio	4.27	3.07	3.99	2.68	4.13	2.49
55-59	Diabetes						
	→ deaths	176	294	141	317	167	322
	 population count 	10,363	14,669	11,461	16,537	12,214	17,800
	→ deaths	737	1.260	784	1.244	778	1.247
	→ population count	173,726	163,369	181,510	170,340	189,733	177,442
	Mortality rate ratio	4	2.6	2.85	2.62	3.33	2.57
60-64	Diabetes	000	504	0.65	474	057	400
	→ deaths	232 12 597	504 15 791	265 13 776	474 17 568	257 14 223	488 18 609
	No diabetes	12,007	10,7 51	10,770	17,000	11,220	10,005
	→ deaths	994	1,688	930	1,565	950	1,611
	→ population count	147,571	132,384	146,183	130,746	148,156	132,632
	Mortality rate ratio	2.73	2.50	3.02	2.25	2.82	2.16
02-09	Diabetes	/83	776	136	840	169	836
	→ population count	16,390	18,080	17,393	19,696	17,720	20,368
	No diabetes						
	- deaths	1,486	2,595	1,428	2,445	1,367	2,304
	 population count Mortality rate ratio 	140,357 278	1 94	139,240 9 44	110,/30 2 04	137,943 267	110,004 2 07
	wortanty rate ratio	2.70	1.94	2.44	2.04	2.07	2.07

Quebec (continued)

		1997/2	1998	1998/2	1999	1999/	2000
Age group		Female	Male	Female	Male	Female	Male
70-74	Diabetes → deaths → population count	754 17,485	1,032 16,407	715 18,998	1,122 18,178	741 19,809	1,064 19,397
	No diabetes → deaths → population count Mortality rate ratio	2,052 119,310 2.51	3,118 87,039 1.76	2,084 119,579 2.16	2,949 87,669 1.83	1,990 119,687 2.25	2,903 88,354 1.67
75-79	Diabetes						1.07
10.2	 deaths population count 	919 14,823	1,064 11,176	961 16,673	1,156 12,795	1,047 18,087	1,189 14,026
	 deaths population count 	2,805 89,111	3,312 55,736	2,635 91,279	3,282 57,255	2,597 94,244	3,143 59,446
00.04		1.57	1.0	۷	1.30	2.1	1.0
80-84	 deaths population count 	902 9,886	850 5,890	1,061 11,131	891 6,563	1,053 11,985	943 7,310
	 No diabetes → deaths → population count 	3,404 60,370	3,229 31,039 1 39	3,310 60,528 1 74	3,068 31,170 1 38	3,188 60,915 1 68	2,681 31,199 1 5
95 ₁	Dishotos	1.02	1.55	1.7 4	1.50	1.00	1.5
007	→ deaths → population count	1,288 7,246	666 3,005	1,430 8,414	754 3,569	1,588 9,558	800 4,000
	→ deaths → population count	7,299 51,581 1 26	3,619 18,923 1 16	7,383 53,246 1 23	3,532 19,545 1 17	7,032 55,440	3,413 20,505
Total	Nortanty rate ratio	1.20	1.10	1.25	1.1/	1.51	1.2
Totai	→ deaths → population count	4,961 118,814	5,536 117,996	5,217 131,536	5,895 131,192	5,540 139,525	5,994 139,375
	 deaths population count Mortality rate ratio 	20,741 2,669,525 5.37	22,427 2,529,072 5.29	20,541 2,676,883 5.17	21,748 2,536,825 5.24	19,940 2,691,602 5.36	20,994 2,552,119 5.23

Data source for the number of deaths among non-diabetic people : Registre des événements démographiques du Québec (1997, 1998, 1999 and 2000). Data from the Fichier des décès of 2000 are preliminary.

Prince Edward Island

		1997/19	998	1998/1	999	1999/2	000
Age group		Female	Male	Female	Male	Female	Male
20-64	Diabetes						
	→ deaths	* 957	* 1 244	*	1 116	* 1 204	* 1 520
	→ population count No diabetes	907	1,244	1,100	1,440	1,204	1,029
	→ deaths	62	123	63	112	73	114
	→ population count	42,026	41,799	41,455	41,234	41,628	41,387
	Mortality rate ratio	*	*	*	*	*	*
65-69	Diabetes		11	7	11	c.	10
	 deaths population count 	8 243	11 338	/ 284	11 364	6 288	12 367
	No diabetes	275	000	207	50-	200	507
	- deaths	28	47	25	41	17	39
	 population count 	2,396	2,199	2,359	2,184	2,409	2,214
	Mortality rate ratio	2.82	1.52	2.33	1.61	2.95	1.86
70-74	Diabetes	0	15	10	10	10	16
	 deaths population count 	256	15 296	12 281	19 344	291	361
	No diabetes	200	230	201	077	<i></i> _	001
	→ deaths	36	56	38	61	33	51
	→ population count	2,168	1,743	2,137	1,735	2,135	1,720
75 70	Mortality rate ratio	U	5C.1	2.4	1.57	2.22	1.49
/5-/9		16	21	12	10	12	17
	→ population count	281	236	310	264	299	288
	No diabetes						
	→ deaths	44	75	56	73	52	74
	→ population count	2,032	1,356	1,966	1,321	1,899	1,339
00.04		2.03	1.01	1.30	1.3	1.47	1.07
80-84	Diabetes	12	8	15	24	25	20
	→ population count	203	147	238	168	271	165
	No diabetes						
	→ deaths	75	78	82	92	67	78
	→ population count	1,556 1 23	914	1,522	۵۵۷ 1 37	1,529 2 11	801 1 32
95 ₁	Dishetes	1.25	0.04	1.1/	1.57	<u> </u>	1.52
007	→ deaths	30	7	23	13	26	24
1	→ population count	167	77	177	99	198	122
	No diabetes						
1	→ deaths	220	120 760	187	109	212	128
	Mortality rate ratio	1.35	0.58	1.17	0.92	1,750	1.19
Total	Diabetes		••••		•		
1012.	- deaths	66	62	69	98	84	102
	 population count 	2,107	2,338	2,423	2,685	2,551	2,832
	No diabetes	465	100	451	400	45.4	404
	 deaths population count 	465 51 828	499 18 771	451 51 116	488 48 116	454 51 350	484 48 286
	Mortality rate ratio	3.49	2.59	3.23	3.6	3.72	3.59
1	· · · · · · · · · · · · · · · · · · ·						

* cell suppressed

Nova Scotia

		1997/1998		1998/1999		1999/2000	
Age group		Female	Male	Female	Male	Female	Male
20-29	Diabetes						
	→ deaths	0	0	0	0	0	0
	 population count 	501	372	557	388	5//	398
	No diabetes	26	50	24	50	26	10
	 dealits population count 	66 504	65 715	65 983	64 859	65 690	40 64 580
	Mortality rate ratio	0	00,710	0	01,005	00,050	01,000
30-39	Diabetes						
	→ deaths	5	7	0	0	8	5
	→ population count	1,074	850	1,173	947	1,183	977
	No diabetes						
	→ deaths	41	86	36	66	39	78
	→ population count	80,157	/5,492	78,600	/4,435	//,/39	/3,540
10.40		9.10	1.23	0	0	13.40	4.03
40-49	Diabetes	7	11	0	21	C	16
	\rightarrow population count	1 926	2258	2 1 5 2	2 447	2 266	2 505
	No diabetes	1,520	2,200	2,102	2,117	2,200	2,000
	→ deaths	95	161	91	133	93	162
	→ population count	73,265	70,956	74,484	71,850	76,152	73,025
	Mortality rate ratio	2.80	2.15	3.04	4.64	2.17	2.88
50-54	Diabetes						
	- deaths	7	24	12	15	13	26
	 population count 	1,647	2,048	1,886	2,282	1,969	2,429
		77	120	79	127	66	110
	 Deputation count 	29.144	28.442	30.528	29.733	31.865	31,148
	Mortality rate ratio	1.61	2.40	2.49	1.43	3.19	2.83
55-59	Diabetes						
	- deaths	17	48	14	35	22	34
	 population count 	1,736	2,242	1,941	2,502	2,060	2,706
	No diabetes	110	1.50		1.40		
	 deaths population count 	21 820	159 21.027	91 22 573	143 21 713	23 530	14/ 22 716
	Mortality rate ratio	1.91	2.83	1.79	21,713	23,330	1.94
60-64	Diabetes	1.01	2.00	1175		2.00	210 1
00-04	- deaths	38	44	30	56	48	67
	 population count 	2,073	2,437	2,246	2,744	2,311	2,870
	No diabetes	· ·					
	→ deaths	132	191	112	204	111	187
	 population count 	17,824	17,193	18,134	17,487	18,524	17,662
	Mortality rate ratio	2.48	1.63	2.16	1./5	3.47	2.20
65-69	Diabetes	FC	70	C1	101	F 1	07
	 deaths population count 	50 2 335	78 2.530	61 2 /71	101 2 772	51 2 5/19	2 97
	No diabetes	2,000	2,000	2,4/1	2,112	2,049	2,929
	→ deaths	209	328	157	281	178	265
	 population count 	16,468	14,651	16,345	14,607	16,448	14,791
	Mortality rate ratio	1.89	1.38	2.57	1.89	1.85	1.85

Nova Scotia (continued)

		1997/1998		1998/1999		1999/2000	
Age group		Female	Male	Female	Male	Female	Male
70-74	Diabetes – deaths – population count No diabetes	85 2,386	126 2,380	85 2,658	124 2,630	107 2,715	138 2,767
	 deaths population count Mortality rate ratio 	263 15,020 2.03	397 11,589 1.55	285 14,791 1.66	333 11,472 1.62	261 14,583 2.20	356 11,483 1.61
75-79	Diabetes – deaths – population count No diabetes – deaths	113 2,252 423	141 1,913 519	124 2,427 369	134 2,053 472	137 2,528 372	160 2,143 493
	 population count Mortality rate ratio 	13,697 1.62	9,244 1.31	13,602 1.88	9,176 1.27	13,369 1.95	9,171 1.39
80-84	Diabetes → deaths → population count No diabetes	129 1,553	132 1,119	140 1,713	129 1,252	148 1,862	171 1,407
	 deaths population count Mortality rate ratio 	531 10,119 1.58	535 6,006 1.32	488 10,059 1.68	470 5,893 1.29	493 10,332 1.67	475 5,956 1.52
85+	Diabetes – deaths – population count No diabetes	165 1,126	117 608	200 1,335	113 716	212 1,473	135 799
	 deaths population count Mortality rate ratio 	1,302 10,251 1.15	4,260 1.15	1,184 10,457 1.32	4,330 0.96	1,251 10,866 1.25	608 4,423 1.23
Total	Diabetes - deaths - population count No diabetes	622 18,609	728 18,757	674 20,559	728 20,733	752 21,493	849 21,930
	 deaths population count Mortality rate ratio 	3,211 354,269 3.69	3,282 324,585 3.84	2,915 355,556 4.00	3,004 325,555 3.81	2,978 359,098 4.22	2,937 328,495 4.33