NATIONAL DIABETES
SURVEILLANCE SYSTEM (NDSS)
BUSINESS PLAN

Revised May 31 2000
Approved by the NDSS
Steering Committee

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EXECUTIVE SUMMARY

The National Diabetes Surveillance System (NDSS) is a response to the critical information deficit around diabetes from a broad range of stakeholders in Canada. The NDSS has been over three years in development and is now poised for implementation with a multi-sectoral governance structure in place.

Goals and Deliverables

The main goals of the NDSS are to develop, facilitate, and coordinate national, provincial, territorial, and Aboriginal diabetes surveillance, beginning with the implementation of a standardized model for core surveillance. This core model will involve the production of nationally comparative data on diabetes prevalence and incidence, as well as comparisons of mortality, diabetes-associated diseases, and health care utilization rates in the population with diabetes compared to the population without diabetes. NDSS information products will be disseminated in routine Annual Reports and ad hoc Special Reports in a coordinated fashion under the direction of the NDSS Steering Committee

Implementation Plans

A Strategic Plan for launching implementation in fiscal year 2000/01 sets out the key milestones for establishing core functionality of the NDSS in a majority of provinces and territories, and at Health Canada, by year end.

A Four-year Implementation Plan describes the main phases of the NDSS over the medium term as the NDSS is gradually operationalized across the country. It is expected that some provinces or territories will take the lead in progressing across the three phase early in this time period while others may proceed more slowly due to particular challenges in those jurisdictions. The three phases of NDSS implementation involve:

Phase 1: establishing core functionality in provinces and territories and at Health Canada, beginning with linkage and analysis of 5 to 7 years of physician claims, hospitalization and insurance coverage data to monitor trends in diabetes and associated complication rates, and estimate related health care costs;

Phase 2: expanding the scope of the system through enhanced analysis of existing data, including the integration of an Aboriginal component within the NDSS;

Phase 3: providing critical information for planning and evaluating prevention and control strategies (e.g., baseline data, benchmarks, and standards), as well as responding to new research findings and indicating areas for further investigation.

Budget and Support

The NDSS budget for year 1 implementation (2000/01) is $2 million, with an estimated $3 million required on an annual basis in subsequent years as the NDSS program expands in scope. The NDSS is financially supported from federal sources through Health Canada's Canadian Diabetes Strategy funding stream, and has secured additional support through private sector sponsorship with the assistance of the Canadian Diabetes Association. Provincial and territorial partners contribute substantially to the system through in kind resources, including the provision of health administrative data and infrastructure support.

PURPOSE OF THE BUSINESS PLAN

A business plan is not simply a document that is presented at one point in time to solidify activity but part of a planning process that must be dynamic and responsive to changes that occur throughout the activity at hand. By the same token the business plan provides leadership within the context of:

- Setting goals and activities of specific business activities
- Providing a basis for evaluating and controlling performance
- Communicating direction to key stakeholders.

SECTION A: NDSS BACKGROUND

Diabetes is a major public health problem in Canada affecting an estimated 1.2 million to 2.2 million Canadians, including those people (possibly one third of the total) who have undiagnosed diabetes. Projections based on our aging population indicate that the burden of diabetes and its complications will become increasingly prevalent and costly in the future. The World Health Organization predicts that 175 and 239 million people will be affected by diabetes in the world by the years 2000 and 2010 respectively. Many Aboriginal communities are already experiencing epidemic levels of diabetes.

Despite the availability of medications and insulin and the positive impacts of lifestyle changes to manage diabetes, people with diabetes continue to suffer from numerous long-term complications. Macrovascular complications include an increased incidence of cardiovascular disease, which is responsible for most deaths of people with diabetes. Microvascular complications include diabetic retinopathy, the leading cause of new blindness among adults in Canada, as well as diabetic nephropathy, the most common cause of end stage renal disease in Canada today. Diabetic neuropathy further decreases the quality of life for people with diabetes through pain, weakness and loss of sensation and is responsible for 50% of non-traumatic amputations in Canada.

Before the question of health care delivery to people with diabetes can be addressed it is essential to have a wider breadth of information available regarding the status of the disease. Surveillance for diabetes in Canada to date has been quite limited. There have been small regional prevalence studies and surveys such as the General Social Survey, the Heart Health Surveys, the National Population Health Survey (NPHS), and the Aboriginal Peoples Survey as well as more concentrated efforts in Manitoba with The Burden of Illness Study and in northern communities such as Sandy Lake, Ontario. The large survey results have been limited by variable response rates, volunteer bias, and sampling errors. The lack of basic prevalence data limits our ability to plan and evaluate prevention and control programs for this ever-increasing problem. Measuring diabetes-related complications such as end stage diabetic nephropathy or diabetic retinopathy is not as difficult but has not been linked to other relevant databases such as those showing degree of glycemic control. Furthermore, diabetes is grossly underrepresented in morbidity and mortality records.

In the absence of Canadian data, U.S. figures have often been extrapolated to fit our national situation. There are limits to this extrapolation as there are differences in age structure and ethnic backgrounds between the two populations. This also does not provide data on a regional level, which is often needed by provinces or territories planning prevention and control strategies. As provinces, territories, and Aboriginal communities start to fill this information gap, there is the natural problem of lack of standardization of data collection such that comparison between different jurisdictions becomes difficult.

Canada has a distinct advantage compared to the U.S.A. in measuring the burden of this disease.

Diabetes is somewhat unique in that the diagnosis requires a laboratory test, which in general is ordered by physicians. As these are services which are covered by government health insurance plans, this presents an opportunity to derive a relatively precise estimate of the prevalence of diagnosed diabetes in provinces and territories. This billing data also has limitations. Physician billing diagnoses are considered of questionable validity on the basis of the single interaction with the health care system. More elaborate algorithms based on multiple interactions between the person with diabetes and physicians, hospitals and laboratories need to be carefully validated.

A meeting was held in Toronto in September 1996 where selected physicians, diabetes educators, consumers, epidemiologists and researchers addressed the growing concern regarding the lack of Canadian diabetes data sources. This initiative targeted the need to pursue the following activities:

- To provide a vehicle to identify and define diabetes indicators which would form the basis of management information related to the status of diabetes in Canada.
- To develop an understanding of existing diabetes information systems and associated barriers to access.
- To explore the feasibility of developing diabetes data collection standards for use throughout Canada.

This concept of a national diabetes surveillance system was presented during this meeting.

Subsequent to these events, the National Diabetes Surveillance System concept was presented to the Diabetes Council of Canada and it was agreed that this was an appropriate body through which to channel this activity in active partnership with Canadian Diabetes Association, the Laboratory Centre for Disease Control of Health Canada, provincial/territorial governments, key national Aboriginal groups, federal health information agencies, and representatives of the diabetes research community. In 1997, a Steering Committee was formed to spearhead the planning required to tackle this diabetes information deficit.

SECTION B: NDSS GUIDING STATEMENTS

VISION

The National Diabetes Surveillance System (NDSS) is a multi-sectoral initiative of non-governmental agencies, Aboriginal groups, government, and industry committed to reducing the incidence and complications of diabetes through leadership in the development, implementation and national coordination of provincial, territorial, and Aboriginal diabetes surveillance systems.

GOALS

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

BASIC PRINCIPLES

Consistency:	A core set of data will be collected in every province/territory on an ongoing systemic basis.
Flexibility:	Additional data may be collected within individual provinces or territories in accordance with their unique needs.
Quality:	Data will be validated and the collection means modified to ensure ongoing validation across the country.
Cost-effectiveness:	NDSS will utilize existing data sources primarily.
Accessibility:	Data will be open 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 will be removed from the shared NDSS database.
Responsiveness:	Current information will be disseminated to public and private stakeholders, thus enabling a prompt response to changing trends in diabetes.

SECTION C: NDSS GOVERNANCE STRUCTURE

The NDSS governance structure includes a multi-stakeholder Steering Committee and Secretariat, subcommittees, technical working groups, national coordination based at Health Canada, and technical staff within each province and territory and in the Aboriginal community. (See Appendix A for details of NDSS committee and technical working group membership and terms of reference).

Steering Committee

The Steering Committee is the main decision-making body of the NDSS, and is chaired by the Diabetes Council of Canada. The broad-based membership of the Steering Committee includes representatives from every province and territory, Canadian Diabetes Association, National Aboriginal Diabetes Association, Assembly of First Nations, Métis National Council, Congress of Aboriginal Peoples, Health Canada, Canadian Institute of Health Information, Statistics Canada, and representatives from the research community. This body also acts as the gatekeeper of the NDSS database, determining under what conditions NDSS-related data are to be made available to partners and third parties.

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

Subcommittees

The Steering Committee formed two subcommittees at their first meeting. The External Management Subcommittee is primarily responsible for guiding interaction with key external stakeholders, and in overseeing efforts to obtain non-federal funding for the NDSS. The Data Access and Publications Subcommittee is responsible for developing a policy around conditions of NDSS data access, ownership, and publication, and working with the Aboriginal Diabetes Technical Working Group and relevant Aboriginal groups to establish a policy on access, ownership and publication of Aboriginal-related data in the context of the NDSS

Technical Working Groups

Technical working groups have been formed to make recommendations to the Steering Committee on specific issues. Steering Committee representatives with technical expertise in the relevant areas as well as outside experts are members of these technical working groups. These working groups are an Aboriginal Diabetes Technical Working Group (with broader national and regional representation from Aboriginal peoples), a Data Management Technical Working Group, and a Data Validation Technical Working Group.

Secretariat

The Secretariat is responsible for managing the NDSS on a day to day basis and reports to the Steering Committee. This group is chaired by the Diabetes Council of Canada, and has representation from 3 provinces (Manitoba, New Brunswick, Ontario), Canadian Diabetes Association, National Aboriginal

Diabetes Association, academics/clinicians and Health Canada.

NDSS Staff Resources

National Coordination: Health Canada

NDSS coordination is the principal responsibility of Health Canada. A key component of this function involves coordinating standardized data extraction and linkage tools and activity in the provinces and territories, and in establishing and maintaining a central NDSS database of aggregate data from provincial/territorial sites. NDSS coordination also involves liaising with the various NDSS subcommittees and working groups, and in promoting a coordinated NDSS work plan.

Health Canada is responsible for administering federal funding for the NDSS under the direction of the NDSS Steering Committee, through Health Canada's Operating and Maintenance (O & M) financial mechanism. Health Canada funding for the NDSS is within the envelope of the Canadian Diabetes Strategy which was approved by the Federal Cabinet in November 1999, and Treasury Board in February 2000. The Canadian Diabetes Strategy has been allocated $115 million over 5 years, beginning in fiscal year 1999/2000, out of which $10.8 million has been allocated to the NDSS.

Health Canada also liaises with its NDSS non-governmental partners with regard to private sector funding for activities which have been approved by the NDSS Steering Committee.

NDSS Staff Resources in Each Province/Territory

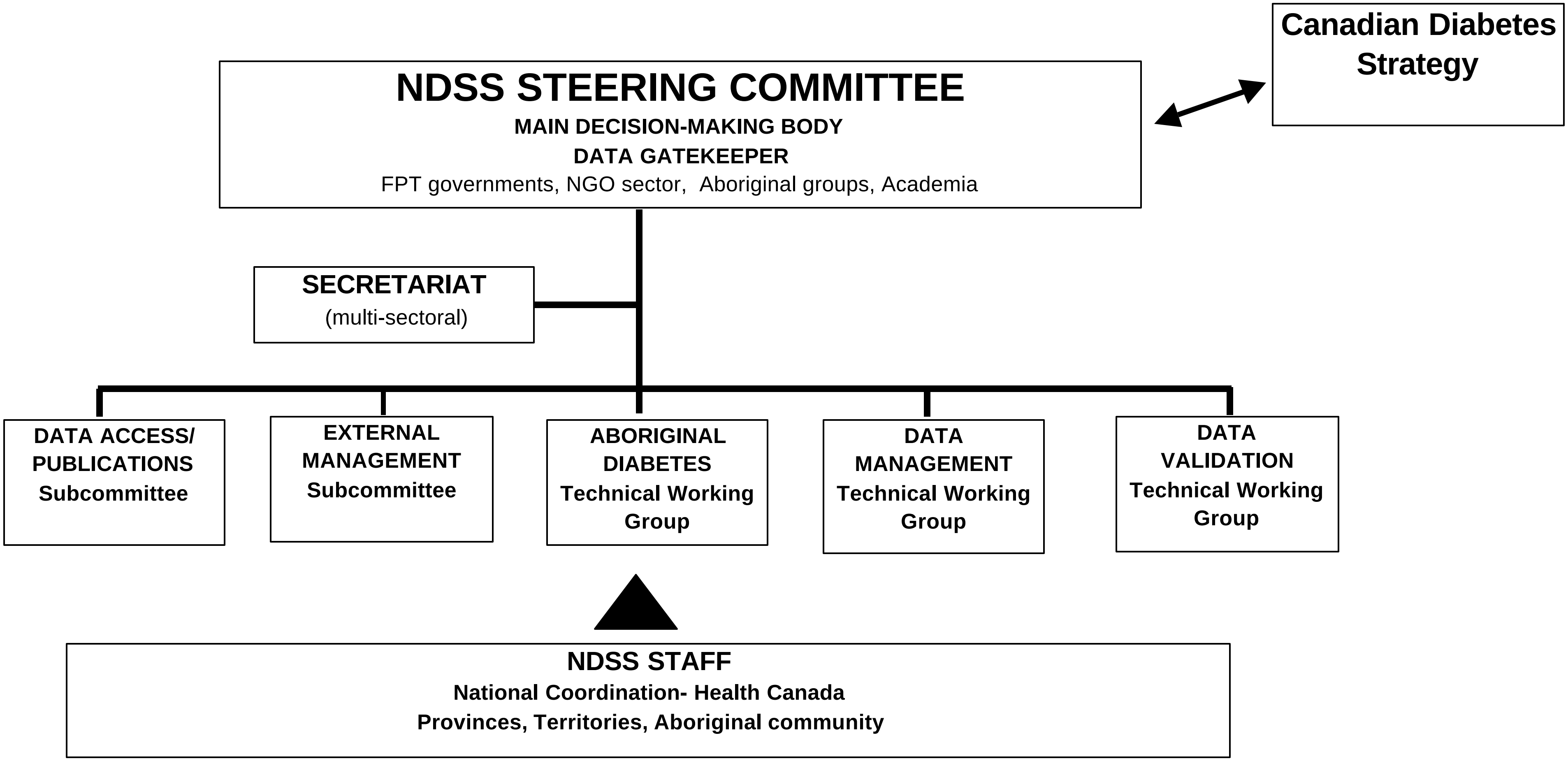
Technical staff in each province and territory will engage in ongoing standardized NDSS database linkage activities, the creation of non-nominal annual person-level summary files on a longitudinal basis for the purposes of diabetes surveillance, and in sending aggregate roll-ups of provincial/territorial person-level data to the central NDSS data site at regular intervals. These staff will be paid through NDSS funds.

NDSS Resources in the Aboriginal Community

Technical staff dedicated to the development of an Aboriginal component to the NDSS will be under the direction of the NDSS Aboriginal Diabetes Technical Working Group.

Diagram 1: **NDSS Governance Structure**

Legend: FPT= Federal/Provincial/Territorial. NGO= Non-governmental



SECTION D: NDSS FOUR-YEAR IMPLEMENTATION PLAN

NDSS Implementation Plan: Overview

Over the next four years of implementation, the NDSS program will have three main consecutive phases which:

- establish core functionality in provinces and territories and at Health Canada, beginning with linkage and analysis of 5 to 7 years of physician claims, hospitalization and insurance coverage data to monitor trends in diabetes and associated complication rates, and estimate related health care costs, ***Phase 1***

- then expand the scope of the system through enhanced analysis of existing data and the integration of an Aboriginal component within the NDSS, ***Phase 2***

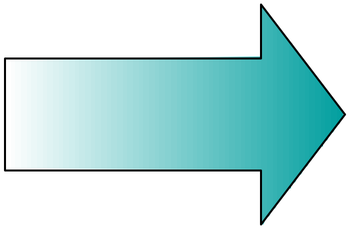
- leading to provision of critical information for prevention and control strategies (e.g., baseline data, benchmarks of change, and standards), as well as responding to new research findings and indicating areas for further investigation. ***Phase 3***

As capacity for core data access and linkages is routine across the country, it will be possible to bring in other sources of data relevant to exploring the broad social, environmental, and lifestyle factors that can have a substantial impact on risks for diabetes and quality of life of those afflicted with this and other associated chronic conditions. However, along with these efforts to expand the public health utility of NDSS information, the NDSS will be vigilant to ensure that all applicable federal, provincial/territorial, and Aboriginal legislation or agreements regarding data privacy, access and ownership are respected.

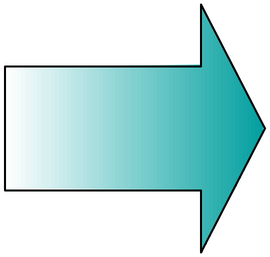
NDSS information products will be disseminated in **routine Annual Reports**, and **ad hoc Special Reports on key themes**, in a coordinated fashion under the direction of the NDSS Steering Committee, respecting relevant policies and regulations of federal, provincial and territorial governments, and Aboriginal groups.

Table 1 summarizes the key goals, activities, information products, and approximate time line for gradual NDSS implementation over the next four years (2000 to 2004).

Table 1: NDSS Four-year Implementation Plan

NDSS Four-year Implementation Plan							
PHASE	**SYSTEM GOALS**	**MAIN SURVEILLANCE ACTIVITIES** *(FPT= Federal, Provincial, Territorial governments*)	**DELIVERABLES: MAIN INFORMATION PRODUCTS** *(includes comparisons of populations with and without diabetes, where possible*)	**TIME LINE by fiscal yr. for surveillance activities**			
				Yr 1 00/01	**Yr 2 01/02**	**Yr 3 02/03**	**Yr 4 03/04**
1	* Measuring the burden of diabetes	* Establishment of core functionality in FPT * Adoption of national standards * Policy development and approval (e.g., FPT MOU's; private sector sponsorship; information dissemination) * Development of Aboriginal component	* Rates: diabetes incidence (including age at diagnosis), prevalence, and mortality (case fatality, cause, premature mortality); diseases associated with diabetes complications; health care utilization/costs	Initiation in Year 1  Gradual implementation			

NDSS Four-year Implementation Plan

PHASE	SYSTEM GOALS	MAIN SURVEILLANCE ACTIVITIES *(FPT= Federal, Provincial, Territorial governments)*	DELIVERABLES: MAIN INFORMATION PRODUCTS *(includes comparisons of populations with and without diabetes, where possible)*	TIME LINE by fiscal yr. for surveillance activities			
				Yr 1 00/01	**Yr 2 01/02**	**Yr 3 02/03**	**Yr 4 03/04**
2	* Defining the determinants of health status and indicators of risk (for diabetes onset, complications of diabetes, and premature mortality)	* Consolidation of core functionality and enhanced data analysis along health continuum * Integration of Aboriginal component with FPT activity (resource and policy support, e.g., Memoranda of Understanding)	* Profiles of high risk populations and areas (including Aboriginal populations and communities, on terms of partnership) * Identification of modifiable risk factors, e.g., personal behaviours, access to care, clinical practice, treatment	Discussions in Year 1	Initiation in Year 2		
3	* Expansion of system scope to include integration in program activity and links to research	* Setting priorities and targets * Monitoring impact of diabetes prevention and control strategies	* Modelling of effects of interventions (e.g., cost-effectiveness analysis) * Targets for primary, secondary, tertiary prevention (e.g., % reduction in modifiable risk factors, % increase in quality care) * Results of community studies/surveys		 Gradual Implementation		

NDSS Implementation Plan: Potential Data Sources

Provincial and Territorial

Primary provincial and territorial level data sources for the "core" data model are:

- Physician claims
- Hospital Discharges
- Health Insurance Registry (demographic information)

Some provinces and territories may also have access to other relevant databases such as:

- Vital statistics (cause of death)
- Pharmcare/Drug utilization
- Diabetes education centre registries
- Long term care records
- Health and risk factor surveys
- Laboratory records (diabetes diagnostic testing)

National: General Population

Potential national level data sources include:

- Statistics Canada (national and community health and risk factor surveys)
- Canadian Institute for Health Information (hospitalizations, mortality, Canadian Organ Replacement Registry)
- Canadian National Institute for the Blind (national client register)
- National Health Surveillance Network
- Disease-specific surveillance systems (e.g., perinatal, cardiovascular)

Aboriginal-specific

Existing Aboriginal-specific data sources at the national and/or provincial and territorial level that could be potential data sources for the NDSS, subject to appropriate partnership agreements, include:

- Department of Indian Affairs and Northern Development (Status Verification System)
- Aboriginal People's Survey
- First Nations Health Information System
- First Nations and Inuit Regional Health Surveys
- Non-Insured Health Benefits Database (Health Canada)

SECTION E: LAUNCHING NDSS IMPLEMENTATION- 2000/01

STRATEGIC PLAN
Key Goal: Establishing “Core” Functionality in 2000/01

After three years of truly collaborative development with its partners, the National Diabetes Surveillance System (NDSS) is entering the implementation phase with a multi-stakeholder governance structure in place and high policy-level approval of the NDSS through the Canadian Diabetes Strategy announced by the Federal Minister of Health in November, 1999. Also, an NDSS Demonstration Project in the Prairies (co-funded through Health Canada’s Health Infostructure Support Program) has piloted the “core” functionality of the NDSS model and inter-government agreements for surveillance activities using provincial administrative data. (See Appendix B for details on the NDSS “core” data model). According to this model, person-level data will remain within provinces and territories, and data on population groups (aggregate level) will be sent nationally to Health Canada for analysis. Widespread dissemination of NDSS information products will be coordinated by the NDSS Steering Committee.

Key players in every province and territory, the Aboriginal community, and at Health Canada are poised to initiate the core surveillance activities of the NDSS. Within the first two years of operation, NDSS will demonstrate a world class system for the production of high quality, nationally comparative data on diabetes and its complications, with widespread dissemination of this urgently needed information to its partners and the general public.

Key NDSS milestones achieved to date

5 NDSS Steering Committee established and 5-year Business Plan approved- Sept. 1997
5 NDSS Demonstration Project in Prairies initiated: pilot for NDSS data and policy model
5 Health Canada announces $10.8 M over 5 years for the NDSS- November ‘99
5 CDA secures pioneering private sector sponsorship from SmithKline Beecham
5 NDSS Technical Roadshows across the country - December ‘99 to January 2000
5 Framework for provincial/territorial capacity and needs assessments developed: identification of “core” NDSS activities and funding criteria for FY 2000/01- December 1999
5 Workshop in Winnipeg to assist provinces/territories in capacity and needs assessments - January 2000
5 Provinces/Territories submit formal proposals for NDSS activities, products and resource needs for year 1 within the approved framework - January 2000
5 Treasury Board approval of NDSS funding- February 2000
5 Aboriginal component of the NDSS in development
5 Steering Committee review/approval of NDSS budget and allocations- March, 2000
5 Steering Committee approval of a policy on private sector sponsorship of the NDSS- March, 2000

5 Canadian Journal of Diabetes Care: NDSS article published- March 2000

Key Milestones to be achieved in 2000/01

Reports on the achievement of these milestones will be provided at regular (typically quarterly) intervals to maintain communication and accountabilities among partners and sponsors.

April - June 2000
5 Memoranda of Understanding (MOU) signed between Health Canada and provinces/territories
5 Private sector support for the NDSS confirmed
5 Data Validation Technical Working Group: Request for Proposals based on 2-year research agenda issued
5 Aboriginal Diabetes Technical Working Group: NDSS Aboriginal Technical Director hired

June- September 2000
5 NDSS personnel at federal, provincial and territorial sites hired, and hardware needs met.
5 Provinces and Territories engage in core NDSS activities (see NDSS Core Model, Appendix B)
5 Approval of 4-6 NDSS data validation projects based on research agenda
5 Aboriginal Technical Director initiating review of challenges and opportunities; possible pilot projects; circulates a Discussion Paper as part of a consultation process with Aboriginal groups/communities

September - December 2000
5 Steering committee to review Letter of Agreement for aggregate data sharing between provinces/territories and Health Canada
5 Data Access and Publication subcommittee to present a draft policy for the coordinated dissemination of NDSS data and information products
5 Progress reports on NDSS core activities in provinces and territories
5 **Final Report from NDSS Demonstration Project in the Prairies**; dissemination activities to include 1-3 manuscripts for peer-reviewed publication, conference presentations, etc.
5 MOU Amendment signed between Health Canada and each province and territory to set out terms and conditions of data sharing and data/information dissemination

January- February 2001
5 Provinces and Territories analyse annual person-level summary files for standardized NDSS indicators of diabetes burden and trends
5 Aggregate data sent to Health Canada

March, 2001
5 Steering Committee reviews and approves NDSS Budget 2001/02
5 Data Validation Technical Working Group: **Report on data validation studies**
5 Aboriginal Diabetes Technical working group: Report on consultation, partnership activities
5 **Official Launch of First Annual NDSS Report**: Diabetes prevalence, incidence, mortality,

complications, and health care utilization rates, comparing populations with and without diabetes (from a majority of provinces and territories, and Health Canada) .

SECTION F: NDSS BUDGET

NDSS Budget for Year 1 (Fiscal year 2000/2001)

SPECIFIC ACTIVITIES	AMOUNT
Committee Expenses This estimate is based upon the following: - 2 NDSS Steering Committee meetings ($40,000 x 2 = $80,000) - Secretariat/Sub-committee/Technical working group meetings and teleconferences ($220,000)	**$300,000**
NDSS Staff Resources - Project personnel for Provinces/Territories ($1,037,590) - Project personnel Aboriginal site ($105,000) - Project personnel National site (Health Canada)($153,000) - National Technical Director ($75,000) *Above figures are estimates and include FTE salary plus 20% benefits, if appropriate*	**$1,370,590**
Equipment and Hardware Hardware, software and equipment purchases/upgrades for Provinces, Territories and Aboriginal site	**$200,000**
Validation Projects Validation projects as approved through a request for proposals mechanism	**$100,000**
Information Dissemination - publications; reports; fact sheets; web site, posters, etc.	**$100,000**
Systems Development Activities These will be preapproved ad hoc activities in the first year; eg.: - Enhanced analysis - Additional data sources - Integration activities - System evaluation	**$50,000**
ESTIMATED TOTAL YEAR 1 (2000/2001) EXPENDITURES	**$2,120,590**

NDSS Annual Budget for Subsequent Years 2-4

SPECIFIC ACTIVITIES	AMOUNT
Committee Expenses 2 NDSS Steering Committee meetings ($40,000 x 2 = $80,000) - Secretariat/Sub-committee/Technical working group meetings and teleconferences ($220,000)	**$300,000**
NDSS Staff Resources (rounded estimates only) - Project personnel for Provinces/Territories ($1 million) - Project personnel: Aboriginal focus ($200,000) - National coordination: Health Canada, includes any contracts ($300,000) *Above figures include FTE salary plus 20% benefits, where appropriate*	**$1,500,000**
Equipment and Hardware (for selected provinces/territories initiating implementation activities)	**$60,000**
Validation Projects Validation projects as approved through a request for proposals mechanism	**$200,000**
Information Dissemination - publications; reports; fact sheets; web site, posters, etc.	**$200,000**
Systems Development Activities: *to be coordinated into a sustainable infrastructure* - Enhanced analysis of existing NDSS datasources - Additional data sources, includes standardization and analysis activities - Integration activities - links to prevention and control programs: includes liaison with Canadian Diabetes Strategy at the national level, and with provincial/territorial, regional activities; consensus on benchmarks, targets and standards - Aboriginal component coordinated with other Aboriginal-specific health information and program initiatives - links to research (collaboration; coordination) - System evaluation	**$600,000**
ESTIMATED ANNUAL EXPENDITURES	**$3,060,000**

ESTIMATED TOTAL YEARS 1-4 EXPENDITURES	**$11,245,000**

SECTION G: PROPOSED NDSS DELIVERABLES

The NDSS will produce high quality, world-class data and information products within the first two years of implementation. This system will also deliver innovations in the standardization of data collection and analysis tools that will facilitate collaborative multi-jurisdictional public health research in the diabetes field. The NDSS is also committed to furthering the goals of its Aboriginal partners in addressing diabetes information needs in that community. Finally, the NDSS will assist in establishing or supporting expertise across the country and in the Aboriginal community for accurate and timely surveillance of diabetes.

Highlights of expected NDSS deliverables are:

- National picture of diabetes prevalence, incidence, morbidity, mortality, and costs to the health care system, by age, province, region, gender, and Aboriginal status (where partnerships and agreements exist), on an ongoing basis.
- Routine annual and special ad hoc reports, fact sheets, conference presentations, etc., for widespread communication and dissemination.
- Timely response to diabetes information requests and demonstrable impact on diabetes-related policy development and program planning.
- Standardized statistical program and analysis tools to ensure nationally comparative data.
- Collaborative opportunities for enhanced public health and community-based clinical research, involving the use of NDSS data.
- Generalizability of system protocols to surveillance of other chronic diseases.
- Capacity-building: increased data management and analysis expertise at federal, provincial/territorial, and Aboriginal sites.

SECTION H: MARKETING AND COMMUNICATIONS

While it may appear obvious by the commitment of partners to-date that the NDSS initiative is long overdue it is important to ensure the long term sustainability of the initiative through numerous channels that include but are not limited to:

(a) **Development of a "Case for Support" targeted at fund-raising opportunities**. Such activity is built around presenting the Business Plan in whole or in part as well as background material that emphasizes the importance of the information for future opportunities that influence health policy and delivery of services for people with diabetes as well as supply important data sources for all stakeholders. The actual case will be prepared as a separate document that is reviewed by the Secretariat and Steering Committee.

(b) **Development of communication pieces targeted at increasing awareness of the initiative and the anticipated outcomes**. Strategic communication releases are important for regular updates on progress of the initiative but also to position the important of the information and its linkage to other developments within the health care system. Every opportunity will be undertaken to link the activity to other projects and present program updates at conferences, seminars, Ministry of Health briefings, etc. A sub-committee has been formed to maintain a presence in this area.

(c) **Development of vehicles to utilize the data received to the best advantage and in support of program objectives**. The appropriate formats for the Secretariat and the Steering Committee will confirm the release of the information. All information released will be in keeping with the accepted principles of accessibility of the data to the public and the dissemination of the information in a responsive manner.

(d) **Promotion of the use of the data**. The strategies to promote this activity will evolve as the deliverables materialize.

With further input from the Steering Committee and other relevant experts this area will be developed in more detail.

SECTION I: CONCLUSIONS

Diabetes is a major public health problem in Canada today. However, the lack of reliable basic information in this country on diabetes incidence and prevalence, on rates of complications and diabetes-associated mortality, and on the factors contributing to these statistics, limits our ability to plan and evaluate effective prevention and control programs. Without the appropriate data, it is also difficult to appreciate the scope of the economic burden of the disease and the impacts that new interventions may offer in diminishing this impact.

In response to this information deficit, the NDSS has demonstrated a successful model for multi-sectoral collaboration among governments, non-government organizations, Aboriginal groups, academia, and private industry. This solid partnership base has been instrumental in securing federal funding for the NDSS through the Canadian Diabetes Strategy as well as in securing private sector sponsorship.

In addition to a broad-based governance structure, the NDSS has piloted an innovative model for diabetes surveillance based primarily on the utilization and linkage of provincial and territorial health administrative databases. Within the next two years, the NDSS will involve the operationalization of this innovative data model in most if not all provincial and territorial jurisdictions, and the establishment of a central NDSS database at Health Canada with grouped (non-personal) data on key diabetes measures. In the medium term, the system will expand its scope to further analyse and interpret the primary NDSS datasets as well as to include a greater range of factors in the surveillance of diabetes. The NDSS will also work toward an integration of Aboriginal surveillance activity around diabetes under the direction of the NDSS Aboriginal Diabetes Technical Working Group. A coordinated dissemination strategy will ensure wide distribution of NDSS information products to public agencies, governments, and other interested groups. The NDSS will need to be responsive to the needs of policy-makers, program planners, and researchers.

In summary, the National Diabetes Surveillance System is a key step in the battle to prevent and control diabetes by determining and monitoring the burden of this illness for Canadians. It is only through solid information on diabetes trends and costs, and through building capacity for standardized high quality surveillance of diabetes in every jurisdiction and in the Aboriginal community, that we can hope to provide the evidence necessary to make effective policy and programmatic decisions to combat this disease.

APPENDIX A

NDSS COMMITTEES AND TECHNICAL WORKING GROUPS: MEMBERSHIP AND TERMS OF REFERENCE

1. NDSS Steering Committee

	NDSS Steering Committee
Purpose	Set and revise system goals based on user needs
Membership *(see list of members next page)*	1. 13 provincial/territorial reps (one from each prov./territory) 2. 2 Diabetes-related NGO's: DCC, CDA, 3. 4 Aboriginal groups: NADA, AFN, MNC, CAP 4. 4 federal reps: Health Canada (2 branches), CIHI, Statistics Canada 5. 2 academic/clinicians
Roles	1. Main decision-making body 2. Gatekeeper of NDSS database, determining (through subcommittees/working groups) under what conditions NDSS data are to be made available to partners and third parties, with appropriate input and direction from data originators and custodians including provincial and territorial governments, federal agencies, and relevant Aboriginal groups
Frequency of Meeting	Twice yearly, or as needed
Term of Office	Minimum 2 years
Timeline	Ongoing
Reporting Relationships	Report back to respective agencies, and liaises with the Canadian Diabetes Strategy
Administration	Support from the Secretariat

Note. NGO= nongovernmental organization. DCC= Diabetes Council of Canada. CDA= Canadian Diabetes Association. NADA= National Aboriginal Diabetes Association. AFN= Assembly of First

Nations. MNC= Metis National Council. CAP = Congress of Aboriginal Peoples. CIHI= Canadian Institute for Health Information. MSB= Medical Services Branch.

NDSS STEERING COMMITTEE MEMBERS (as of May 25, 2000)

Chair:

Bernie Zinman (Diabetes Council of Canada)

Provinces/Territories:

Chris Balram (NB)
Tricia Braidwood-Looney (BC)
Joan Canavan (ON)
Harvey Schmidt, Jamie Blanchard (MB)
Peggy Dunbar (NS)
Brenda McIntyre (NU)
Danielle St-Laurent (QC)
John Morse (NWT)
William Osei (SK)
Faith Stratton (NF)
Larry Svenson (AB)
Lamont Sweet/Linda Van Til (PEI)
Liz Rowlands, Sherri Wright (YU)

Non-Governmental Organization:

Donna Lillie (Canadian Diabetes Association)

Aboriginal Groups

Michael Perley (National Aboriginal Diabetes Association)
Allen Deleary/Alma Faval-King (Assembly of First Nations)
Alistair MacPhee (Congress of Aboriginal Peoples)
David Boisvert (Metis National Council)

Federal Government

Indra Pulcins (Canadian Institute for Health Information)
Cyril Nair (Statistics Canada)
Clarence Clottey, Sheila Chapman (Diabetes Division, Health Canada)
Ellen Bobet (First Nations & Inuit Health Programs, Health Canada)

Academic/Clinicians

Stewart Harris- University of Western Ontario
Hertzel Gerstein- McMaster University

Note: SmithKline Beecham is a pioneering sponsor of the NDSS and has observer status on the NDSS Steering Committee

2. NDSS Secretariat

	NDSS Secretariat
Purpose	To manage the NDSS on a day to day basis for the NDSS Steering Committee
Membership	1. Bernie Zinman (DCC; Chair) 2. Joan Canavan (ONT) 3. Christofer Balram (NB) 4. Jamie Blanchard (MAN) 5. Donna Lillie (CDA) 6. Michael Perley (NADA; Chair of the NDSS Aboriginal Diabetes Working Group) 7. Stewart Harris (academic/clinician) 8. Hertzel Gerstein (academic/clinician) 9. Clarence Clottey/Sheila Chapman (Health Canada)
Roles	To operationalize on an ongoing basis the directions of the Steering Committee. To provide broad-based advice to the Steering Committee. To assist subcommittees and working groups with background information, minutes, and report preparation, as needed
Frequency of Meeting	As needed. Meetings will be primarily by teleconference
Reporting Relationships	Reports to the Steering Committee

3. External Management Subcommittee

	External Management Subcommittee
Purpose	Define how the NDSS interacts externally with other agencies
Membership	1. Joan Canavan (ONT, MOH) - Chair 2. Kim Reiner (BC MOH) 3. John Morse (NWT, Diabetes Ctre) 4. Janie Peterson Watt (MB, MOH) 5. Sheila Chapman (Health Canada)
Roles	Issues of concern to date are: Development of agreements between governments for data activities NDSS Funding support and financial mechanisms Development of a conflict of interest/duality of interest policy All other aspects of public relations (e.g., Canadian Medical Association, Canadian Public Health Association)
Frequency of Meeting	As needed. It is expected that ad hoc meetings may be necessary following the first year of NDSS operation to address issues that may arise. Meetings will be primarily by teleconference
Timeline	A legal and financial structure to allow funding flow-through to NDSS partners for approved activities to be established by June, 2000
Reporting Relationships	Reports to the NDSS Steering Committee directly or through the Secretariat if necessary
Administration	Background information, minutes, report preparation will be handled by the Secretariat

4. Data Access and Publications Subcommittee

	Data Access and Publications Subcommittee
Purpose	Determine principles and conditions of data access, ownership and publication
Membership	1. Tricia Braidwood-Looney (BC, MOH)- Chair 2. Hertzel Gerstein (McMaster Univ.) 3. Winanne Downey (Sask., MOH) 4. Cyril Nair (Statistics Canada) 5. Clarence Clottey/Sheila Chapman (Health Canada)
Roles	Propose conditions of access, determine ownership, and consider publication rights to NDSS database/information for partners (public and private) and for third parties; work with the Aboriginal Diabetes Technical Working Group and relevant Aboriginal groups to establish a policy on access, ownership and publication of Aboriginal-related data in the context of the NDSS
Frequency of Meeting	As needed initially until the conditions of access, ownership, and publication rights are confirmed. It is expected that ad hoc meetings may be necessary following the first year of NDSS operation to address issues that may arise. Meetings will be primarily by teleconference
Timeline	A policy on data access, ownership, and publication rights will be revised and approved by September 2000
Reporting Relationships	Reports to the NDSS Steering Committee directly or through the Secretariat if necessary
Administration	Background information, minutes, report preparation will be handled by the Secretariat

5. Data Management Technical Working Group

	Data Management Technical Working Group
Purpose	Determine the form in which data will be stored, transferred, and merged
Membership	1. Health Canada - Chair 2. Dave MacKenzie/Carol von Hagen (BC) 3. Danna Dobson (ONT) 4. Larry Svenson (ALB) 5. Danielle St. Laurent (QUE) 6. William Osei (SASK) 7. Jamie Blanchard (MB)
Roles	Make decisions regarding issues including the means of maintaining personal confidentiality, software compatibility, information transfer, procedures for merging provincial/territorial data, and the reporting relationships of provincial staff. Provide guidance and input to the NDSS Technical Director and Health Canada national coordination staff
Frequency of Meeting	As needed Meetings will be primarily by teleconference
Timeline	Ongoing
Reporting Relationships	Reports to the NDSS Steering Committee directly or through the Secretariat if necessary
Administration	Background information, minutes, report preparation will be handled by the Secretariat

6. Data Validation Technical Working Group

	Data Validation Technical Working Group
Purpose	Determine what data will be collected and how to validate the resulting information
Membership	1. William Osei (Sask. MOH)- Co-chair 2. Larry Svenson (Alb. MOH)- Co-chair 3. Mark Smith (N.S. Diabetes Care Network) 4. Jamie Blanchard (Man MOH) 5. Linda van Til (PEI MOH) 6. Danielle St-Laurent (Que) 7.Health Canada 8. Jeff Johnson (Alberta Institute of Health Economics) 9. Rob Reid (U. of BC) 10. Jan Hux (Institute of Clinical and Evaluative Sciences, ON) 11. Mike Cottrell-Tribes (YU)
Roles	Advise the Steering Committee on standardization of the surveillance case definition, determine which variables are to be collected, and decide on the methodology to be used for database validation
Frequency of Meeting	As needed. Validation is an ongoing process of any surveillance system. Meetings will be primarily by teleconference
Timeline	Ongoing
Reporting Relationships	Reports to the Steering Committee directly or through the Secretariat if necessary.
Administration	Background information, minutes, report preparation will be handled by the Secretariat.

7. Aboriginal Diabetes Technical Working Group

	Aboriginal Diabetes Technical Working Group
Purpose	To develop a framework for the diabetes surveillance system that will gather national, regional, and community based data on diabetes and its complications which are specifically targeted to Aboriginal populations, and that will support surveillance, priority setting, program development, and evaluation.
Membership	1. Michael Perley (NADA, Chair) 2. David Boisvert (MNC) 3. Alan Deleary/Alma Favel-King (AFN) 4. Pat Lyall/Jo MacQuarrie (Inuit Tapirisat of Canada) 5. Ojistoh Horn (Epidemiologist, Kahnawake Schools Diabetes PreventionProject) 6. Francine Noël (James Bay Cree Board of Health and Social Services) 7. Heather Dean (clinician/researcher, Type 2 diabetes in youth) 8. Jamie Blanchard (Epidemiologist, technical expertise) 9. Ellen Bobet (First Nations and Inuit Health, Health Canada) 10. Clarence Clottey/Sheila Chapman (Health Canada) <u>NDSS Aboriginal Technical Director</u> - to be hired

	Aboriginal Diabetes Technical Working Group
Roles	1. To define, for the purposes of data collection and analysis, the following Aboriginal population groups: On-reserve First Nations, Off-reserve First Nations, non treaty status, Metis people, Inuit people 2. To research and examine existing databases in Aboriginal communities, and explore mechanisms for integration into a national system 3. To identify policy issues such as data security and integrity, ownership of data, and data management, and to make recommendations as to how to proceed 4. To plan for effective mechanisms for data collection, integration of data bases, and analysis strategies for Aboriginal communities 5. To identify and develop strategies to facilitate the development of capacity and skills in First Nations and Inuit peoples for the analysis and use of surveillance findings 6. To identify short term and long term initiatives, including staffing needs, necessary for the Aboriginal Diabetes component of an integrated national diabetes surveillance system
Frequency of Meeting	As needed. Meetings will be primarily by teleconference
Timeline	NDSS Aboriginal Technical Director to be hired April/May 2000. Consultation process ongoing through 2000/01
Reporting Relationships	The Chair reports to the NDSS Steering Committee directly or through the Secretariat if necessary
Administration	Background information, minutes, report preparation will be handled by the Secretariat

APPENDIX B

NDSS CORE MODEL

A-B.1 NDSS Core Data and Policy Activities: 2000/01

Data-Activities	Details
Inputs	Activity A Identify data source for physician claims, hospital and insurance coverage files. Ideally, select a "run" of 5-7 years for which there is continuously available data, and a single data dictionary. Activity B *(where feasible, and only after Activity A completed)* Obtain access to data for years other than those used in A. Integrate these data by revising and supplementing NDSS databases created under Activity A.
Process	(1) Transfer data from existing hardware to NDSS hardware/disk space.
	(2) Reduce data from (1) to include only necessary variables and necessary records.
	(3) Concurrent with (2) or subsequent to (2) transform data from (2) to NDSS common input data dictionary.
	(4) Read data from (3) into SAS files.
	(5) Transform data from (4) to calendar years.
	(6) Input data from (5) into NDSS core software.
	(7) Produce "working" person-level summary.
Outputs	(8) Prepare aggregate data files to **estimate incidence, prevalence and mortality** from (7).
	(9) Prepare aggregate data files to **estimate rates for specified complications and health services utilization patterns in sub-population with diabetes**.
	(10) Prepare aggregate data files to **estimate rates for specified complications and health services utilization patterns in sub-population without diabetes**.
	(11) **Transfer aggregate datasets to Health Canada**, pending FPT agreements.

Data-Activities	**Details**
	(12) Retain (7) for population with diabetes (if possible, allows for longitudinal analysis).
	(13) Retain (7) for population without diabetes (if possible, allows for longitudinal analysis.
	(14) Dissemination of data products coordinated with NDSS Steering Committee on an annual basis.
Policy-related Activities	Documentation and application for data access.
	Defining reporting-relationships and related matters for NDSS personnel.
	Defining target audiences for surveillance data.

<u>Note:</u> Higher priority is placed on the estimation of epidemiologic parameters (i.e., incidence, prevalence, mortality) than on the estimation of complication and health services utilization patterns.

A-B.2 Proposed NDSS "Core" Data Fields and Measures *

Core Data Fields

Basic Demographic Information

Age Gender Geographic code	Record year Death/Migration

Diabetes Complications and Co-morbidities

Hypertension Cardiovascular Disease Cerebrovascular Disease Peripheral Vascular Disease Glaucoma Cataract Blindness Retinopathy Glomerulonephritis Nephrotic Syndrome Nephritis	Acute Renal Failure Other Renal Disease Chronic Renal Failure Renal Failure Unspecified Lower Respiratory Tract Infection Tuberculosis Urinary Tract Infections Cellulitus and Abscess Bacterial Meningitis Other Invasive Infections Neuropathy Skin Ulcers Gangrene

Health Services Utilization

Physician visits/yr. Physician fees/yr. Weeks of dialysis/yr.	Hospital days/yr. Resource intensity weight: hospitalizations.

Core Measures of Diabetes Burden

Estimated measures of:

1. prevalence and incidence of diagnosed diabetes
2. diabetes-associated mortality compared to mortality rates in the general population
3. prevalence of diseases associated with common complications of diabetes, in population groups with and without diabetes
4. health service utilization in population groups with and without diabetes.

* Content of aggregate data at Health Canada site to be determined by the NDSS Steering Committee.