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PROJECT OF DIABETES SURVEILLANCE AMONG THE CREE OF EEYOU ISTCHEE

INSTITUT NATIONAL DE SANTÉ PUBLIQUE DU QUÉBEC

Québec

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INSTITUT NATIONAL DE SANTÉ PUBLIQUE DU QUÉBEC
CREE BOARD OF HEALTH AND SOCIAL SERVICES OF JAMES BAY

AUGUST 2004

Conseil Cri de la santé et des services sociaux de la Baie James
Cree Board of Health and Social Services of James Bay

Institut national de santé publique Québec

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DOCUMENT DEPOSITED ON SANTÉCOM (HTTP://WWW.SANTECOM.QC.CA)
CALL NUMBER: INSPQ-2004-052

LEGAL DEPOSIT – 4TH QUARTER 2004
BIBLIOTHÈQUE NATIONALE DU QUÉBEC
NATIONAL LIBRARY OF CANADA
ISBN 2-550-43301-7
(ORIGINAL EDITION: ISBN 2-550-43300-9, INSTITUT NATIONAL DE SANTÉ PUBLIQUE DU QUÉBEC, MONTREAL)

FOREWORD

When the Canadian Diabetes Strategy was developed in 1999, it was agreed that a Canada-wide diabetes surveillance system would be set up. All the provinces and territories implemented a diabetes surveillance system using a common methodology. In Québec, Ministère de la Santé et des Services sociaux (MSSS) tasked Institut national de santé publique du Québec (INSPQ) with the job. The surveillance system is designed to estimate the prevalence and incidence of diabetes, gauge the impact of the pathology, and evaluate the associated costs. However, the surveillance system, which relies on the use of administrative data, does not provide a precise picture of the diabetes situation in certain remote communities where physicians work primarily on a salary basis, as is the case in regions of Northern Québec.

Given the marked increase in the number of diabetes cases among the James Bay Cree (Eeyou Istchee), the coordinators of the Cree of Eeyou Itschee administrative region created a Cree Diabetes Information System (CDIC) for all known cases in 1996. The system was designed to monitor the evolution of diabetes in the population and improve clinical followup. However, it does not allow for a precise assessment of the nature and extent of medical care received outside the region for diabetes-related complications. Given the scope of the diabetes problem and its impact on the Cree of Eeyou Istchee, it became imperative to validate the Québec Diabetes Surveillance System and upgrade the Cree Diabetes Information System that had been in operation for a number of years. The Cree Board of Health and Social Services was especially interested in incorporating information dealing with diabetes-related complications for medical consultations and hospitalizations in Québec's health network.

There was also a pressing need to crosscheck information contained in the diabetes surveillance system developed by Institut national de santé publique (INSPQ) against that in the Cree information system. This validation process also provided an opportunity to assess the sensitivity and specificity of the Québec Diabetes Surveillance System within a given target population, a first in Canada. Talks between the Eeyou Istchee Cree Board of Health and Social Services and INSPQ led to the signing of a research contract to conduct the validation. The project was funded by Health Canada through the budget earmarked for diabetes surveillance under the Canadian Diabetes Strategy.

The cross-validation of the two surveillance systems opens the door to the possibility of permanently linking the Cree diabetes information system with the surveillance system developed by INSPQ. This project also falls under the mandate given to INSPQ by Ministère de la Santé et des Services sociaux to develop a surveillance system to support the implementation of guidelines and programs to prevent diabetes and curb its complications. As mentioned above, the high prevalence of diabetes among the Cree begs the need for short-term preventive measures to reduce the impact of this disease on the population.

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LIST OF ACRONYMS AND ABBREVIATIONS

CAI	Commission de l'accès à l'information du Québec
CBHSSJB	Cree Board of Health and Social Services of James Bay
CDA	Canadian Diabetes Association
CDAB	Canadian Diabetes Advisory Board
CDIS	Cree Diabetes Information System (see DIS)
CH	Centre hospitalier
CHUM	Centre hospitalier universitaire de Montréal
CMDP	Conseil des médecins, dentistes et pharmaciens
CVD	Cardiovascular disease
DIS	Diabetes Information System (see CDIS)
DRG	Diagnostic Related Group
DTF	Diabetes Task Force
FIPA	Administrative file of insured persons registered with the Régie de l'assurance maladie du Québec
HIN	Health insurance number
ICD-9	International Statistical Classification of Diseases and Related Health Problems (v. 9)
IN	Encrypted individual number
INSPQ	Institut national de santé publique du Québec
CLSC	Local Community Service Centre (CLSC)
MDC	Major Diagnostic Category
MED-ECHO	Hospital discharge summary database for the province of Québec
MUHC	McGill University Health Center
NDSS	National Diabetes Surveillance System
PCI	Percutaneous coronary intervention
QDSS	Québec Diabetes Surveillance System
RAMQ	Régie de l'assurance maladie du Québec
RDI	Regional Diabetes Initiative
RIW	Resource intensity weight

Figure 1 - Communities desserved by the Cree Board of Health and Social Services of James Bay - Eeyou Istchee Region

1 INTRODUCTION

1.1 PREVALENCE OF DIABETES AMONG THE CREE

Diabetes is a chronic disease characterised by hyperglycemia (a high concentration of blood glucose) attributable to the body's secretion of little or no insulin and/or its resistance to insulin. There are several types of diabetes, the two main ones being type 1 and type 2. Type 1 is caused by the auto-immune destruction of the insulin-producing beta cells of the pancreas and accounts for about 10% of diagnosed cases. Type 2 is characterised by either a partial resistance to insulin or inadequate insulin production and can be treated by means of physical exercise and proper diet, oral medication, insulin or a combined therapy, and accounts for about 90% of diagnosed cases (CDA, 2003). Gestational diabetes is a form of glucose intolerance that is first detected during pregnancy. There are also other, less common forms of specific diabetes associated with certain drugs or other pathologies (CDA, 2003). Finally, glucose intolerance and marginal fasting blood glucose include anyone who does not meet the criteria for type 1 or 2 diabetes but who shows high blood glucose levels after glycemia tests. These individuals are considered to be at risk of developing diabetes or cardiovascular disease (Harris, Meltzer et al. 1998). In Canada, the National Diabetes Surveillance System estimates that 4.8% of Canadians aged 20 years and over have diabetes. It is also estimated that about one-third of cases go undiagnosed (Canada 2002).

Diabetes can be a debilitating and disabling disease. It can cause serious structural and functional damage, affecting organs such as the heart, brain, kidneys and eyes, and the nervous system and legs. People with diabetes are two to four times more at risk of infarction and stroke than people without diabetes, while their risk of heart failure and circulatory disorders is four to eight times greater (CDAB 1997) (CCDC 1997). According to the Canadian Diabetes Advisory Board, it is estimated that diabetes may reduce life expectancy by 30%. Diabetes is also the number one cause of blindness in adults (CDAB 1997) (CCDC 1997).

In addition, the new clinical guidelines and a number of studies state that type 2 diabetes may be avoidable (CDA 2003) (ACD 2003). Lifestyle intervention, notably the reduction of certain risk factors related to sedentariness and poor eating habits, may reduce the prevalence of diabetes, based especially on the fact that this type of diabetes is emerging in the young people of certain populations (such as Aboriginals) (Harris, Meltzer et al. 1998).

There can be no doubt that diabetes is a significant and serious public health concern given the number of people affected by the disease and the resulting economic costs. In Québec in 1999-2000, according to the conservative estimate of one researcher at the Institut national de santé publique du Québec, there were nearly 280,000 people with diabetes, not including undiagnosed cases (Émond 2002). And a study done in Manitoba estimates that the average annual cost of health services is $2,169 for a person with diabetes, versus just $1,011 for a person without diabetes. The difference is even greater in the Aboriginal community, where the average cost for a person with diabetes is $3,656, compared to $1,353 for every person without diabetes (Jacobs, Blanchard et al. 2000).

1.1.1 Prevalence and complications of diabetes among the Cree of Eeyou Istchee

If the prevalence of diabetes is high in the general Québec population, studies done of Aboriginal communities show that the prevalence in this population are three to four times greater than those observed in the general population (Canada 1999). The prevalence of diabetes has increased significantly over the last 20 years among the Cree population of Northern Québec (Eeyou Istchee) aged 20 years and over, from a few cases before the 1980s, to about 5.2% in the late eighties, to 7.1% in 1991, and climbing to about 15% in 2002 (Brassard, Robinson et al. 1993; CHSSB-JB 2002) (Brassard, Robinson et al. 1993; CCSSS-BJ 2002). These results are consistent with the epidemiological data observed in the United States and in other regions of Canada. Data from the Cree Board of Health and Social Services of James Bay shows that in 2002, there were 1,064 known cases of diabetes for all ages in the Eeyou population, or proportionally three times more than in the population residing in Southern Québec (CBHSS-JB) (CCSSS-BJ 2002).

The high prevalence, the Cree Board of Health of Eeyou Istchee will face a staggering increase in complications associated with diabetes, which will add significantly to the burden on its health system in the coming years. Moreover, the scope of this problem prompted the Cree Board of Health to identify diabetes as one of its two health priorities in 1995. For example, of the known cases of diabetes who agreed to permit access to information about their condition: 58% had a kidney damage, 11% suffered retinal damage, 12% had peripheral nerve damage, and 13% of known cases reported vascular disorders (CBHSS-JB 2002) (CCSSS-BJ 2002). In addition, a study of the Aboriginal population of Manitoba estimates that between 1996 and 2016, the incidence of stroke will increase fivefold, cardiovascular disease will increase tenfold, and the use of certain medical services (dialysis, lower limb amputations, blindness) will also increase tenfold (cited in: Canada 2002).

1.2 PRESENTATION OF THE CREE DIABETES INFORMATION SYSTEM (CDIS)

In 1996, faced with a marked increase in diabetes cases among the Cree of Eeyou Istchee, and at the request of the Cree chiefs, a surveillance system for tracking the diabetes epidemic was put in place, overseen by the Cree Health Board's Diabetes Task Force (DTF). The gathered data were entered in an in-house database with two objectives in mind: first, to improve the clinical follow-up of people with diabetes; and second, to provide statistics on the prevalence of the disease in the territory of Eeyou Istchee.

Since then, during clinical consultations, physicians and nurses have entered information on a record developed by the DTF. The purpose of this tool is to gather information about diabetes from the patient in order to facilitate the consultation when a visit to the clinic is made. This information is then entered in the database.

The information contained in the database is person-specific so that feedback can be provided to the community clinics to help them formulate recommendations for improving the clinical follow-up of patients with diabetes. For the surveillance reports, the system data (date of birth, sex, community of residence) were gathered systematically, while the clinical data, used in secondary and tertiary prevention, were gathered only with the patient's signed

consent. Dannenbaum, Vérronneau et al. (1989) provide a description of this information system.

In recent months, the content and operation of the information system have been revised to better integrate it with the work of the Regional Diabetes Initiatives team in the Cree territory. This database is now an extension of the clinical file, to allow for the more effective follow-up of diabetic patients. The database is called the Diabetes Information System, also known for our purposes as the Cree Diabetes Information System (CDIS). It is modelled on the client information system used by the Local Community Service Centres that operate within the Québec health and social services network. An agreement governing access to the clinical data permits public health officials from the Eeyou Istchee territory to have access to the denominalized data in this clinical database so that they can carry out their surveillance and service-planning mandate.

1.3 QUÉBEC DIABETES SURVEILLANCE SYSTEM (QDSS)

Like the other provinces and using a common methodologies, Québec set up its own diabetes surveillance system. This surveillance system is based on the use of administrative data taken from files of the Régie de l'assurance maladie du Québec (RAMQ) and the MSSS. These files are: the RAMQ file of registered persons, the RAMQ file of fee-for-service payments, the RAMQ file of prescription drugs, the file of hospitalisations (MED-ECHO), and the file of deaths. These various files were linked by means of the HIN, and using different algorithms it was possible to evaluate both new and existing cases of diabetes. All these operations were carried out according to a strict procedure approved by the Commission d'accès à l'information du Québec to ensure the confidentiality of the information. The system covers the period 1996 to 2001. A publication is available providing a detailed description of the methodology used and the main results (Émond 2002).

2 OBJECTIVES OF THE STUDY

Given the scope of the problem of diabetes and its repercussions on the Cree of Eeyou Istchee, it was important to validate and supplement the Cree Diabetes Information System, which has been in use for several years. The Cree Board of Health and Social Services was especially interested in supplementing the CDIS with information about the complications associated with diabetes and information concerning medical consultations or hospitalisations in the Québec health care system. On other hand, QDSS administrator where interested to estimate diabetes prevalence in northern area.

2.1 THE SPECIFIC OBJECTIVES

The specific objectives of this research project were to validate the data of the CDIS of Eeyou Istchee with RAMQ data and hospitalisations data, by the same method as the INSPQ used when developing the Québec Diabetes Surveillance System (QDSS). This project will validate also the prevalence estimate of the QDSS with the true number of cases from the CDIS. To be more precise, the specific objectives were as follows:

- to link the RAMQ files (registered persons, fee-for-service payments), the file of hospitalisations;
- to validate the linked data and determine the strengths and weaknesses of the two available databases, comparing the cases identified by the RAMQ files and those identified by the CDIS of Eeyou Istchee;
- to validate the prevalence of diabetes among the Cree according to the Québec Diabetes Surveillance System with the prevalence from CDIS;
- to estimate the hospitalisations of persons with diabetes in Eeyou Istchee;
- to estimate the proportions of diseases (complications) associated with diabetes;
- to estimate the medical consultations of Cree diabetes cases occurring off reserve;
- to assess the feasibility of integrating the data of the CDIS of Eeyou Istchee with those of the Diabetes Surveillance System of the INSPQ for purposes of calculating the prevalence and incidence of diabetes;
- to compare the results with those of population surveys and specific studies;
- to propose improvements to the CDIS of Eeyou Istchee.

3 METHODS

The first phase of this research consisted in extracting and linking the data from four administrative files to form a complete file of the diabetes data necessary for purposes of comparison and analysis. These four files were: the RAMQ file of registered persons, the RAMQ file of fee-for-service payments, the MED-ECHO file, and the Diabetes Information System of the Cree Board of Health of Eeyou Istchee. The second phase consisted in validating the linked data and assessing the quality of the data obtained from the RAMQ administrative files versus the data from the Cree Information System. Thirdly, certain measures of the prevalence and complications associated with diabetes were estimated: hospitalisations, disease associated with diabetes, and medical consultations.

Given the particular problem of diabetes among the Cree of Eeyou Istchee, an important phase of the research was to assess the feasibility of using the QDSS for estimating the incidence and prevalence of diabetes among Aboriginals living on-reserve and of estimating the complications of this pathology during consultations conducted off-reserve. Finally, the results of the data analyses were compared with the known results of surveys and studies on diabetes in Québec, Canada and elsewhere in North America.

3.1 DATA SOURCES

The feasibility study was done using the following files:

- the RAMQ files of registered persons (FIPA) and fee-for-service payments (including optometric services) - see Annex 1;
- the MED-ECHO file of hospitalisations - see Annex 2;
- the file of the Diabetes Information System for the Cree of Eeyou Istchee - see Annex 3.

3.2 PERIOD OF STUDY

The period of study extended from January 1996 to March 2001 for the RAMQ files, and from April 1995 to March 2001 for the MED-ECHO file; the Diabetes Information System for the Cree of Eeyou Istchee was provided April 31, 2002.

3.3 PATIENT POPULATION

The patient population was composed of the following:

- for the Diabetes Information System for the Cree of Eeyou Istchee, all active diabetes cases (1,480 cases) from the information system. This information system contains cases of type 1 and type 2 diabetes, some cases of gestational diabetes and a fraction of the cases of known glucose intolerance;[1]
- for the RAMQ file of fee-for-service payments (medical and optometric services), all cases for which a visit generated diagnostic code ICD-9 250 (diabetes) during the period of study and for which the HIN is included in the source population;
- for the MED-ECHO file, all cases of at least one hospitalisation for which the code for the main or secondary diagnosis was ICD-9 250 and having a HIN included in the study.

3.4 FILE LINKAGE

The method used here was identical to the method the INSPQ used when developing the Québec Diabetes Surveillance System. The identification key was the HIN.

A. To add variables absent from the RAMQ file of fee-for-service payments

The main file for the linkage operation was the RAMQ file of fee-for-service payments for cases from the Cree Diabetes Information System of Eeyou Istchee. A subset was created from this file of cases for which at least one visit during the period of study generated diagnostic code 250. The data from the MED-ECHO file were added to this former file. The variables added from these files are listed in the section on the information required from each. To link these files, the health insurance numbers (HIN) of the cases of interest (cases for which at least one visit generated diagnostic code 250) were first extracted from the file of fee-for-service payments. For these HIN, we retrieved the variables from the MED-ECHO files and the desired variables from the file of registered persons.

B. To add cases from the MED-ECHO file

From the MED-ECHO file, we extracted the HIN, date of birth and geographic code of the cases of interest (cases of hospitalisations generating diagnostic code 250), except those HIN that already existed in the file of fee-for-service payments. For those HIN, we retrieved the variables to be added from the files of fee-for-service payments, deaths and prescription drugs.

[1] There is no way of distinguishing, in the CDIS, cases of impaired fasting blood glucose from cases of impaired glucose tolerance.

More specifically, the procedure was as follows:

- Production of an input file for linkage purposes.
- Validation of the HIN from the file sent from the Cree Diabetes Information System, and production of a status report on the number of invalid HIN.
- Replacement of each valid HIN with a corresponding encrypted individual number (IN).
- Extraction of all fee-for-service medical and optometric services, and of all hospitalisations (with HIN or IN) and eligibility data for each individual, and creation of one record per individual (flat files) with the same data elements as the testbed views of the Québec Diabetes Surveillance System (QDSS), plus the institution number.
- Generation of a number for each individual to replace the HIN or IN.
- Provision was made for the purging of the nominative data system and workfiles.

3.5 PROTECTION OF PERSONAL INFORMATION

This research project was submitted for approval to the Commission d'accès à l'information du Québec (CAI) and was authorised according to certain terms and conditions. The measures put in place were designed to ensure the confidentiality of personal information. Accordingly, an undertaking to respect confidentiality was signed by the individuals processing the data, publication of the data in such a way that individuals can be identified is not authorised, the information is conveyed only to persons authorised to receive it, and the data files are kept in secure locations and accessible to authorised individuals only.

The linking of the files by means of person-level data was done by RAMQ professionals who, as mentioned earlier, took care to replace the HIN with unique identifiers (IN). The files sent to the researchers contain no HIN and were denominalized.

The terms of use of the CAI also stipulate a timeframe for destruction of the workfiles. Annex 4 describes the file linkage methodology designed to ensure the confidentiality of person-level data.

3.6 THE CALCULATION AND ANALYSIS OF MEASURES RELATED TO DIABETES IN AN ABORIGINAL POPULATION

According to the selection criteria established at the time of the validation analysis, it is possible to calculate diabetes prevalences by sex, age group and year based on the two data sources.

Incident cases are determined annually by the date of the first visit or first hospitalisation generating diagnostic code 250. Prevalent cases are defined as the total incident cases in the years preceding the observed year, plus the incident cases of the current year. Persons who died before the end of the year of study were not included in the total.

For the Cree Diabetes Information System, cases are already identified by the medical diagnosis dates and the type of diabetes. The CDIS also includes a number of cases of gestational diabetes and glucose intolerance, but these do not account for the known cases.

For the linked data present in the QDSS, the algorithm proposed by the National Diabetes Surveillance System (NDSS) is used. The rules of this algorithm, developed by Blanchard, in Manitoba, are as follows:

A- At least one hospitalisation (excluding one-day hospitalisations) generating a diabetes code (ICD-9 250) in the first three hospitalisation diagnoses

or

B- At least two fee-for-service medical consultations within a 730-day period with a diagnosis of diabetes (ICD-9 250).

3.7 HOSPITALISATIONS, MEDICAL CONSULTATIONS AND COMPLICATIONS ASSOCIATED WITH DIABETES

The measures studied here involve the identification of hospitalisations of persons with diabetes, the reasons for hospitalisation (other than diabetes), the calculation of the length of stay in hospital, and the interval between the onset of a disease associated with diabetes or an initial hospitalisation and the diagnosis of diabetes. We excluded one-day hospitalisations as well as hospitalisations during a hospital transfer to avoid double counting. These exclusions do not, however, cover one-day hospitalisations for dialysis. The period covered extends from 1995-1996 to 2000-2001. These data enrich the surveillance information system developed by the Cree Board of Health and Social Services. Consultations that take place outside the Cree health care system cannot easily be tracked by means of the Cree Diabetes Information System without the linkage performed in this research project.

The average lengths of stay were calculated by relating the total days in hospital of the cases to the total number of cases. The average intervals between the initial diagnosis and the onset of a complication were calculated by relating the total days lapsed between the events of concern and the diagnosis date in the Cree Diabetes Information System.

Transportations for hospitalisation were calculated by counting each episode of hospitalisation occurring outside the Eeyou Istchee health and social services region or in Chisasibi for the Cree residing outside that community.

The fee-for-service medical procedures were taken from the RAMQ file of fee-for-service payments. These consultations exclude all professional services paid for under a salary or wage payment contract. We excluded billed procedures performed during a hospitalisation. In the case of consultations with an ophthalmologist, we counted only one procedure per day for a given patient. The period covered differs from that for hospitalisations, and extends from 1996-1997 to 2000-2001.

3.8 COMPLICATIONS ASSOCIATED WITH DIABETES

The complications associated with diabetes were selected based on the validation operations done at the INSPQ. These complications were evaluated as follows:

1- Hospitalisations for heart disease and related surgical procedures reported in one of the 16 hospitalisation diagnoses or in one of the 9 procedures:

- Acute myocardial infarction (ICD-9 410);
- Ischemic heart disease (ICD-9 411);
- Angina (ICD-9 413);
- Congestive heart failure (ICD-9 428).

2- Hospital procedures:

- Coronary bypass (4810, 4811, 4812, 4813, 4814, 4815, 4816, 4817, 4819);
- Coronary angioplasty (4892, 4893, 4894, 4895, 4896, 4897, 4898, 4996, 4997);
- Percutaneous coronary intervention (PCI) (4802, 4803, 4809).

Cases transferred to another hospital centre were excluded to eliminate double counting and one-day hospitalisations and those of less than three days for myocardial infarction were eliminated to reduce the false positives.

3- Hospitalisations for renal failure or dialysis reported in one of the 16 hospitalisation diagnoses or in one of the 9 procedures:

- Acute renal failure (ICD-9 584);
- Chronic renal failure (ICD-9 585);
- Unspecified renal failure (ICD-9 586);
- Hospital procedures associated with dialysis (5127, 5142, 5143, 5195, 6698).

Cases transferred to another hospital centre were excluded to eliminate double counting.

4- Ocular disorders and treatment of diabetic retinopathy (file of fee-for-service medical services):

The estimate of complications associated with retinopathies is based on two types of interventions associated with the treatment of retinopathy: laser photocoagulation, and vitrectomy. The corresponding codes for these interventions are:

- Laser photocoagulation (7292, 7293, 7298, 7299, 7300, 7310, 7311, 7312, 7313, 7314, 7376, 7408, 7409, 7465, 7466);
- Vitrectomy (7022, 7238, 7239, 7240, 7285, 7295, 7309, 7325, 7335, 7336, 7337, 7339, 7375).

Medical consultations with an ophthalmologist in connection with retinopathy (diagnosed or not) were also counted to estimate the proportion of cases that had undergone such an examination.

5- Hospitalisations for amputation of a lower limb reported in one of the 9 hospital procedures:

- Minor amputation (9611, 9612);
- Major amputation (9613, 9614, 9615).

Hospitalisations for amputations with the following diagnoses were excluded: (ICD-9 170, 171, 213, 730, 740 to 759, 800 to 900, 901 to 904, 940 to 950), as were cases transferred to another hospital centre, to eliminate double counting.

4 ANALYSIS PLAN

4.1 THE VALIDATION AND DATA QUALITY ANALYSIS

Validation analyses were carried out to verify the hypothesis that MED-ECHO data can supplement the file of the Cree surveillance system. By means of these analyses it is possible to evaluate the number of cases that might benefit from the addition of information to the Cree surveillance system.

Data quality are measured by such means as the rate of the presence of certain variables in the different files. It is especially interesting to compare the rate of the presence of variables common to the different linked files, and to look for agreement. For purposes of analysis, we consider that the cases from the Cree Diabetes Information System will be identified by the reference diagnosis for determining the distribution of the cases in the QDSS and according to the NDSS method of calculation.

First, we present the prevalences of the types of diabetes of all cases in the Cree Diabetes Information System. Then, we provide the results after linking the files, followed by the proportions of agreement between the data files. Prevalent cases that could be linked are then described. The proportions of hospitalisation and of medical services are briefly discussed. The selected complications associated with diabetes are presented. All these descriptions are by sex, age group and community of residence.

5 RESULTS

5.1 LINKAGE OF THE CDIS, QDSS AND RAMQ FILES

5.1.1 Description of cases entered in the CDIS

The Cree Diabetes Information System (CDIS) included 1,480 persons as of March 31, 2002: 10 cases (0.7%) of type 1 diabetes, 1,066 cases (72%) of type 2 diabetes, 205 cases (14%) of glucose intolerance, and 199 cases (13%) of gestational diabetes (Table 1). Overall, women represent nearly two-thirds of the persons entered in the Cree Diabetes Information System. They account for 63% of the cases of type 1 or type 2 diabetes and one-half of the cases of glucose intolerance. Information about sex was absent for 3% (46) of the subjects.

Table 1 - Description of types of cases in the Cree Diabetes Information System, by sex

	Female		Male		Sex absent		Total	
	n	%	n	%	n	%	n	%
Type 1 diabetes	5	0.5	5	1.1	-		10	0.7
Type 2 diabetes	667	69.7	399	83.8	-		1,066	72.0
Subtotal type 1 and type 2	672	70.2	404	84.9	-		1,076	
Gestational diabetes*	183	19.1	-		16	34.0	199	13.4
Glucose intolerance*	102	10.7	72	15.1	31	66.0	205	13.9
Total	**957**	**100.0**	**476**	**100.0**	**47**	**100.0**	**1,480**	**100.0**

* Only a fraction of these cases are entered in the CDIS.

Source: Cree Diabetes Information System.

Table 2 shows the prevalence distribution of cases of type 1 and type 2 diabetes from the Cree Diabetes Information System for the period ending March 31, 2002. At that time, the information system included 1,076 prevalent cases as of that date: 672 women (62%), and 404 men (38%). The proportion of women with type 1 or type 2 diabetes is higher than that of men for all age groups. The average duration of the disease among the cases of type 1 and type 2 is 14.5 years and 7.8 years respectively. The average duration tends to be higher in women than in men (Table 3). In all, about two-thirds (65.8%) of the cases of type 1 and type 2 diabetes entered in the CDIS have been diagnosed less than 10 years, while in 16.6% of the cases, the duration of the diabetes was 15 years or more (Table 4).

Figure 2 shows the relative prevalence of cases of type 1 and type 2 diabetes by age group and sex for the Eeyou Istchee region and all of Québec. The crude prevalence of cases in Eeyou Istchee among persons aged 20 years and over was 14.7% in 2002, the prevalence being higher among women (18%) than among men (11%). Adjusted to the age structure for all of Québec population in 1996, the prevalence is 19.9%. This prevalence increases with the age groups, from 3% for persons aged 20-29 to 39% for persons aged 80 and over.

In all, 27% of type 1 and type 2 cases are under age 40. The relative prevalence among women shows that one-quarter of women aged 40 to 49 have diabetes, and it climbs to over 40% in women aged 50 to 69. This prevalence is even higher among women aged 70 and over, but here it is necessary to remember the small population under study. The relative prevalences of diabetes are systematically higher among the Cree than among the overall Québec population, and are especially pronounced in women 6 to 8 times higher. The crude relative prevalence of cases among persons aged 15 and over from the Cree region was 12.8% in 2002 and the adjusted prevalence was 18.3%.

Figure 3 shows the crude relative prevalence of cases of type 1 and type 2 diabetes for persons aged 15 and over by community of residence. This prevalence varies considerably from one community to another, ranging from 7% in Whapmagoostui to 18% in Waswanipi. Table A5.7 of Annex 5 show the distribution of prevalent cases entered in the CDIS by age group and sex, for various fiscal years.

Table 2 - Prevalence of cases of type 1 and type 2 diabetes in the Cree Diabetes Information System, by age group and sex, 2001-2002 year

Age group	Female	Male	Total
10 to 14	*	*	6
15 to 19	*	*	5
20 to 24	18	3	21
25 to 29	42	19	61
30 to 34	53	44	97
35 to 39	65	30	95
40 to 44	74	40	114
45 to 49	72	57	129
50 to 54	76	52	128
55 to 59	92	58	150
60 to 64	61	36	97
65 to 69	39	31	70
70 to 74	25	13	38
75 to 79	25	10	35
80 to 84	11	3	14
85 and older	11	5	16
Total	**63% (672)**	**37% (404)**	**100% (1,076)**

*: Number lower than 3.
Source: Cree Diabetes Information System.

Table 3 - Average duration of cases of type 1 and type 2 from the Cree Diabetes Information System, by sex, 2001-2002 year

	Female		Male		Total		
	Average duration	Standard deviation	Average duration	Standard deviation	Average duration	Standard deviation	n
Type 1 and type 2 diabetes	8.4	6.4	7.0	5.3	7.9	6.0	1,055

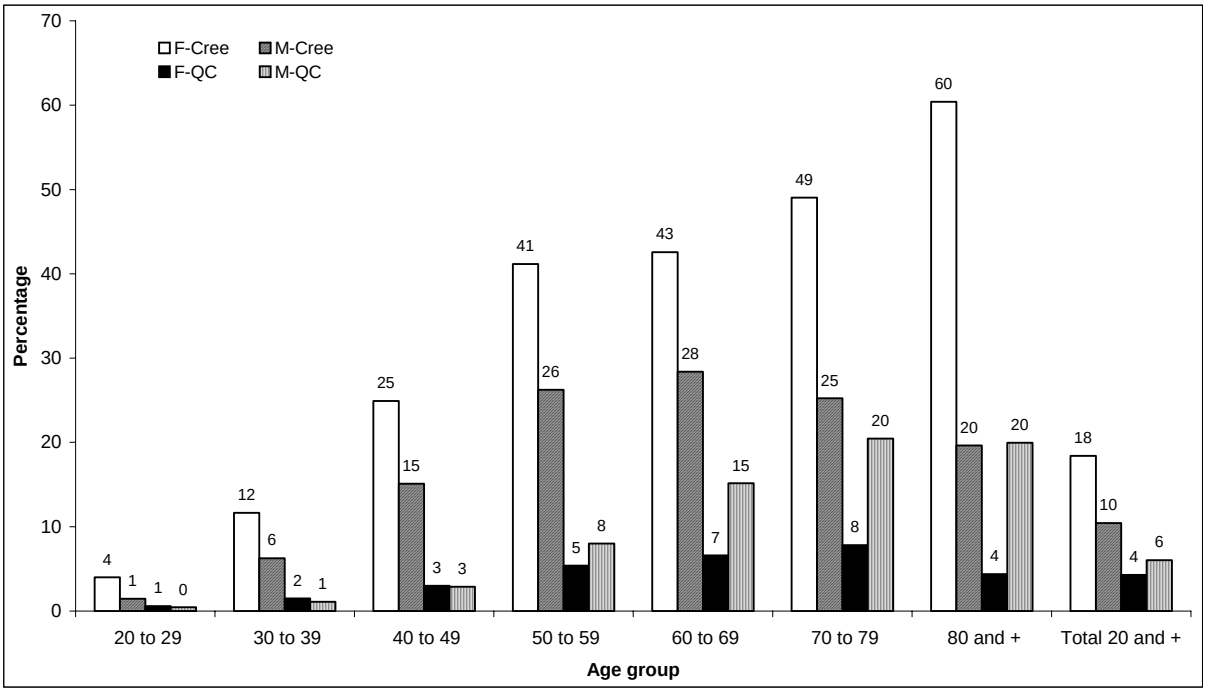
Source: Cree Diabetes Information System, 21 missing data.

Table 4 - Categories of duration of disease, cases of type 1 and type 2 diabetes from the Cree Diabetes Information System, 2001-2002 year

Duration of disease	Total type 1 and type 2
Less than 5 yrs.	38.6% (407)
5 to 9 yrs.	27.2% (287)
10 to 14 yrs.	17.5% (186)
15 to 19 yrs.	12.7% (134)
20 yrs. or more	3.9% (41)
Total	**100.0% (1,055)**

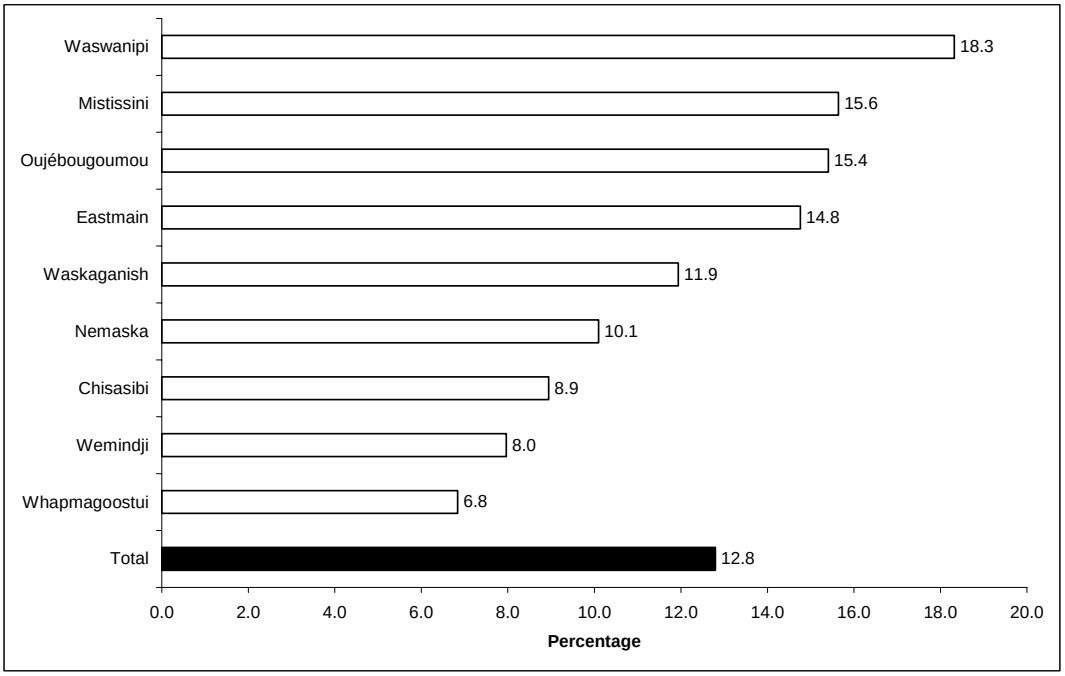
Source: Cree Diabetes Information System, 21 missing data.

Figure 2 - Prevalence of cases of diabetes (type 1 and type 2) of persons aged 20 and over, by age group and sex, Eeyou Istchee region and Québec, 2002



Source: Cree Diabetes Information System, QDSS, 2001 Statistics Canada Census of Population.

Figure 3 - Prevalence of cases of diabetes (type 1 and type 2) of persons aged 15 and over, by community of residence in the Eeyou Istchee region, 2002



Source: Cree Diabetes Information System, 2001 Statistics Canada Census of Population.

Table 5 shows the number of incident cases of type 1 and type 2 diabetes for the period 1996-1997 to 2000-2001, with 496 new cases over the six years in question. The number of new cases rose from 60 in 1990-1997 to 107 in 1999-2000 and dropped to 66 in 2001-2002. Figure 4 shows that the number of new cases of women entered in the system is greater than that of men for all years considered. The F/M ratio of new cases varies from 1.8 in 1997-1998 to 1.1 in 2001-2002.

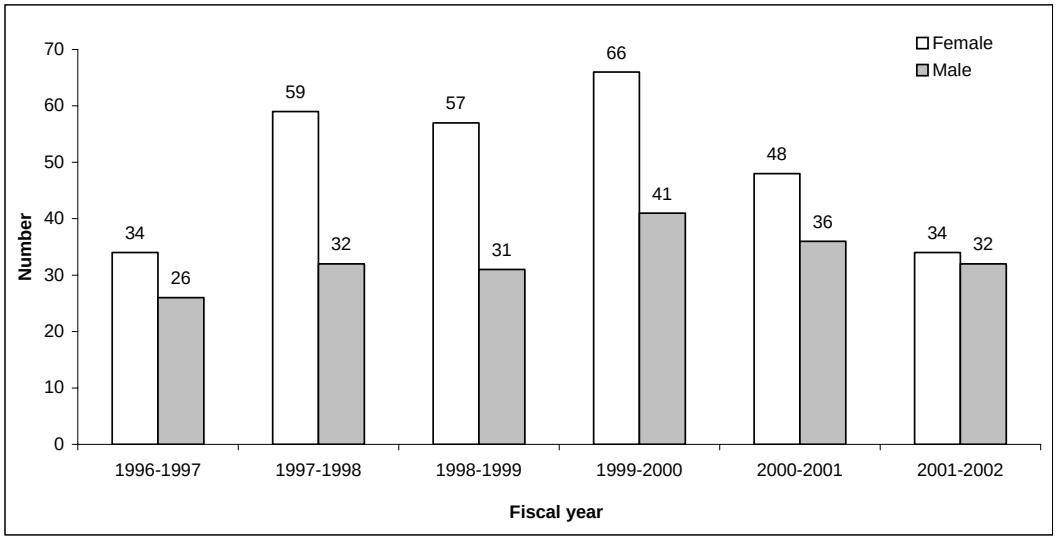
Table 5 - New cases of type 1 and type 2 diabetes entered in the Cree Diabetes Information System, by fiscal year and age, period 1996-1997 to 2000-2001

Fiscal year	Number of new cases aged 10 and older
1996-1997	60
1997-1998	91
1998-1999	88
1999-2000	107*
2000-2001	84
2001-2002	66
New cases during the period	**496**

* A screening was done in two communities in 1999-2000.

Source: Cree Diabetes Information System.

Figure 4 - Incident cases of diabetes (type 1 and type 2) of persons aged 10 and over entered in the Cree Diabetes Information System, by fiscal year and sex, period 1996-1997 to 2001-2002



Source: Cree Diabetes Information System, 2001 Statistics Canada Census of Population.

5.1.2 Description of cases according to the Cree Diabetes Information System (CDIS), the QDSS and the NDSS definition

Figure 5 illustrates the operations for linkage of the cases from the Cree Diabetes Information System to the RAMQ files. Subsequently, the validity of the QDSS was assessed by applying Blanchard's rule used in the NDSS. The operations linking the files to the RAMQ revealed 187 persons for whom the linkage key was absent or incorrect and for whom it was not possible to obtain information from the RAMQ files. The cases for which the HIN was absent will be described later. We sent the encrypted numbers for these cases to Cree Diabetes Information System officials so that the necessary corrections could be made.

Of the 1,480 cases in the Cree Diabetes Information System, it was possible to link 87% of the subjects (1,293), including 949 cases of type 1 or 2 diabetes. As a result of this linkage operation, 949 of the 1,076 (88%) cases of type 1 or 2 diabetes were matched. Of these, 701 (54%) were in the QDSS and 46% were not. Of the subjects in the QDSS, the application of Blanchard's rule generated 405 cases, or 34% of the subjects present in the Cree Diabetes Information System as of March 31, 2001, for which there was a valid HIN present.

Of those 405 cases, 391 (97%) were identified as cases of type 1 or 2 diabetes according to the Cree Diabetes Information System, while 3 were cases of glucose intolerance and 11 were cases of gestational diabetes. In all, by applying Blanchard's rule to the cases linked to the QDSS, it was possible to identify only 44.9% of the cases of type 1 or 2 diabetes in the Cree Diabetes Information Systems as of March 31, 2001, for which there was a valid HIN.

Figure 5 - Description of linkage of cases from the Cree Diabetes Information System to the Québec Diabetes Surveillance System

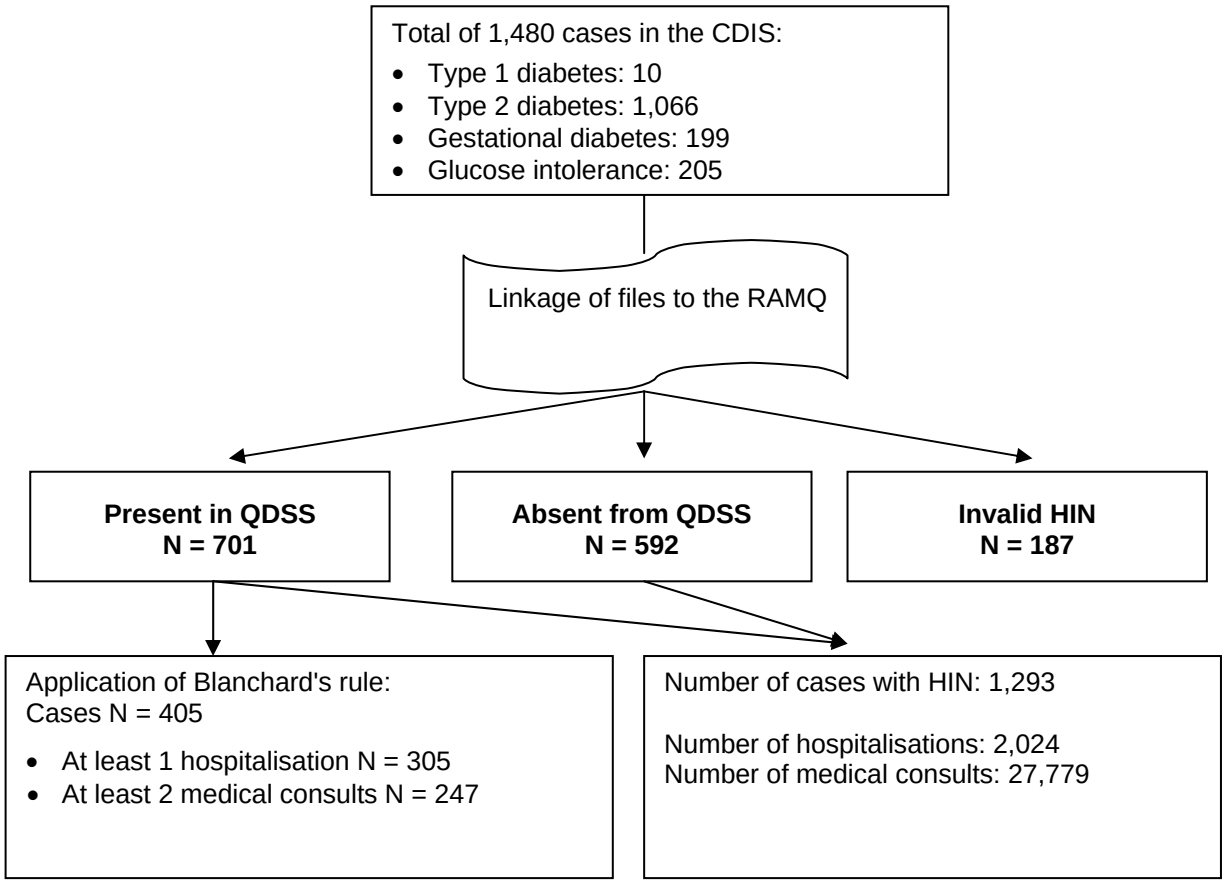


Table 6 shows the proportion of cases linked at various stages by type of diabetes. The Cree Diabetes Information System contained only 10 cases of type 1 diabetes, all of which were identified in the QDSS, and 70% of which were identified following the application of Blanchard's rule. For type 2 diabetes, 67% of the cases were identified in the QDSS after matching, and just 45% in the NDSS. In all, then, 391 cases of type 1 or 2 diabetes were identified by the medico-administrative databases compared to the Cree Diabetes Information System. The QDSS identified 17% of the cases of glucose intolerance and 20% of the cases of gestational diabetes, whereas these proportions dropped to 2% and 7% after the application of Blanchard's rule. Tables A6.1 and A6.2 in Annex 6 show the distribution of the cases defined according to Blanchard's algorithm by age group, sex and fiscal year.

Table 6 - Proportion of cases present in the various databases, by type of diabetes, Cree Diabetes Information System, 2002

Type of diabetes*	Cases present in the CDIS		Cases with valid HIN % of CDIS cases		Cases linked to the QDSS % of cases with a valid HIN		Cases defined acc. to NDSS algorithm % of cases with a valid HIN **	
	n	%	n	%	n	%	n	%
Type 1	10	100	10	100	10	100	7	70
Type 2	1,066	100	939	88	628	67	384	45
Subtotal type 1 and type 2	1,076	100	949	88	638	67	391	45
Glucose intolerance	205	100	176	86	29	17	3	2
Gestational diabetes	199	100	168	84	34	20	11	7
Total	**1,480**	**100**	**1,293**	**87**	**701**	**54**	**405**	**34**

* According to Cree Diabetes Information System.

** Calculated for the period 1995-1996 to 2000-2001.

Just under half (47%) of the cases identified after applying Blanchard's rule were identified by two medical procedures only, 3% by two procedures prior to hospitalisation, and one-half (50%) after a hospitalisation (Table 7). The high proportion of cases identified after a hospitalisation relative to rest of Québec (7%) is attributable to the fact that most physicians working in the Eeyou Istchee territory are paid by salary or wage payment contract and therefore caes are not identified by fee for services physician consultations.

Table 7 - Cases of type 1 and type 2 diabetes from the CDIS identified in the Québec Diabetes Surveillance System according to the NDSS algorithm, by services used, 1996 to 2001

Services used for case identification	CDIS		Québec*
	n	%	%
Hospitalisations with or without medical procedures	202	49.8	7.0
Medical procedures before hospitalisation	11	2.7	3.0
Two medical procedures only	192	47.4	90.0
Total	**405**	**100.0**	**100.0**

* The period covered is 1995-1996 to 2001-2002.

Source: RAMQ and MED-ECHO

We estimated the sensitivity and specificity of the cases present in the CDIS identified by the NDSS algorithm (Table 8). This estimate covers the 1,184 patients entered in the CDIS as of March 31, 2001, and linked to the QDSS. We treated cases of type 1 and type 2 diabetes from the CDIS as diagnosed cases, and persons with a glucose intolerance or gestational diabetes as non-cases. Using Blanchard's rule (two medical consultations with a diagnosis of diabetes within two years or one hospitalisation with a diagnosis of diabetes), it was possible to determine the presence or absence of diabetes.

Table 8 - Validation of cases between the CDIS and the NDSS identified as of March 31, 2001

		Cases according to CDIS			
		Yes	**No**	**Total**	**%**
NDSS cases	**Yes**	391	14	405	34
	No	479	300	779	66
	Total	870	314	1,184	100

Source: Cree Diabetes Information System.

- Sensitivity: 45%
- Specificity: 96%
- Positive predictive value: 97%

In all, using Blanchard's rule to try identify diabetes in remote Aboriginal communities in James Bay, Quebec, it was possible to identify just 391 cases of the 870 known cases in the CDIS, for a sensitivity of 45%. The specificity of this rule, however, was higher, at 96%, with only 14 false positives. These 14 subjects consisted of 12 women and 2 men, 10 of whom were identified by a hospitalisation noting diabetes and 4 by medical procedures for which payment was claimed under code 250. The use of cases of glucose intolerance and gestational diabetes as non-cases for this validation had the effect of underestimating the specificity measure. A validation study done in Ontario using records from medical clinics produced a sensitivity of 86% with a specificity of 97% and a positive predictive value of 80% (ICES, 2003).

5.2 DESCRIPTION OF THE SUBJECTS BY MATCHING

We then described the cases in the Cree Diabetes Information System based on the presence or absence of a health insurance number by sex, type of diabetes, community of residence, and year of birth (Tables 9 to 12). There is no significant difference between the subjects in the Cree Diabetes Information System matched to the FIPA data and those not matched by sex (P = 0.44), type of diabetes (P = 0.27) and year of birth (P = 0.25). However, a significant association (P = 0.001) in the proportion of matching is found, however, between communities of residence.

Tables A7.1 to A7.3 in Annex 7 show the distribution of the 187 subjects not matched by age group, type, community of residence and sex.

Table 9 - Reporting of the HIN in cases from the Cree Diabetes Information System, by sex*

	Present		Absent (invalid HIN)		Total	
	n	%	n	%	n	%
Absent	2	15.4	11	84.6	13	0.9
Female	853	87.5	122	12.5	975	65.9
Male	438	89.0	54	11.0	492	33.2
Total	**1,293**	**87.4**	**187**	**12.6**	**1,480**	**100.0**

Khi-two corrected (excluding sex absent) P = 0.44.

* Sex according to the FIPA.

Source: Cree Diabetes Information System.

Table 10 - Reporting of the HIN in cases from the Cree Diabetes Information System, by type of diabetes

Type of diabetes	Present		Absent (invalid HIN)		Total	
	n	%	n	%	n	%
Gestational diabetes	168	84.4	31	15.6	199	13.4
Glucose intolerance	176	85.9	29	14.1	205	13.9
Type 1 and type 2	949	88.2	127	11.8	1,076	72.7
Total	**1,293**	**87.4**	**187**	**12.6**	**1,480**	**100.0**

Khi-two = 3.93 P = 0.27.

Source: Cree Diabetes Information System.

Table 11 - Reporting of the HIN in cases from the Cree Diabetes Information System, by community of residence

Community of residence	Present		Absent		Total	
	n	%	n	%	n	%
Chisasibi	228	84.4	42	15.6	270	18.2
Eastmain	67	93.1	5	6.9	72	4.9
Mistissini	354	83.3	71	16.7	425	28.7
Nemaska	51	92.7	4	7.3	55	3.7
Other	11	84.6	2	15.4	13	0.9
Oujébougoumou	68	94.4	4	5.6	72	4.9
Waskaganish	202	91.8	18	8.2	220	14.9
Waswanipi	202	91.4	19	8.6	221	14.9
Wemindji	78	88.6	10	11.4	88	5.9
Whapmagoostui	32	72.7	12	27.3	44	3.0
Total	**1,293**	**87.4**	**187**	**12.6**	**1,480**	**100.0**

Khi-two = 31.3 P = 0.001.

Source: Cree Diabetes Information System.

Table 12 - Reporting of the HIN in cases from the Cree Diabetes Information System, by year of birth

Year of birth	Present		Absent		Total	
	n	%	n	%	n	%
1900-1929	96	89.7	11	10.3	107	7.2
1930-1939	150	86.2	24	13.8	174	11.8
1940-1949	270	87.1	40	12.9	310	21.0
1950-1959	275	87.6	39	12.4	314	21.2
1960-1969	267	87.3	39	12.7	306	20.7
1970-1979	213	89.1	26	10.9	239	16.2
1980 and +	20	71.4	8	28.6	28	1.9
Total	**1,291**	**87.3**	**187**	**12.7**	**1,478**	**100.0**

Khi-two = 7.89 P = 0.25, 2 missing data.

Source: Cree Diabetes Information System.

5.3 VALIDATION OF THE VARIABLES: SEX, AGE, DATE OF DIAGNOSIS, COMMUNITY OF RESIDENCE

After matching, there was 97% agreement of sex data between the Cree Diabetes Information System file and the FIPA file. This variable was missing for 35 subjects in the Cree Diabetes Information System (Table 13). If we consider only the cases of type 1 and type 2 diabetes, there was 99% agreement of the sex variable (939/948) (data not shown). After verification of the cases that did not match, it appeared that the FIPA data were more reliable. We then sent the unmatched cases to CDIS officials for verification; these cases were mainly cases of gestational diabetes.

Table 13 - Agreement in sex distribution, by data source (Cree Diabetes Information System (CDIS) and file of registered persons (FIPA)), HIN valid

Sex according to CDIS	Sex according to FIPA							
	Female		Male		Missing		Total	
	n	%	n	%	n	%	n	%
Female	827	64.0	6	0.5	2	0.2	835	64.6
Male	3	0.2	420	32.9	-		423	32.7
Missing	23	1.8	12	0.9	-		35	2.7
Total	**853**	**66.0**	**438**	**33.9**	**2**	**0.1**	**1,293**	**100.0**

% calculated for all subjects.

Source: Cree Diabetes Information System and RAMQ.

There was 93.5% agreement about the year of birth of the 1,291 subjects in the Cree Diabetes Information System matched with the FIPA (Table 14). Just over half of the discrepancies involved a period of less than 5 years, and 63% of the years of birth that did not agree were for persons born before the 1950s (data not shown). It should be noted that many elderly Cree are not sure of their exact birth date, and this may account for the discrepancies in the older Cree population. The average discrepancy between the two data sources was - 0.72 years. The proportion of agreement was 94.4% for the cases of type 1 and type 2 diabetes, with an average discrepancy of - 0.03 years between the year of birth in the Cree Diabetes Information System and that in the FIPA (data not shown). Following discussions with Cree Diabetes Information System officials, we used the FIPA data for the rest of the analyses.

Table 14 - Distribution of discrepancies in year of birth beween the Cree Diabetes Information System (CDIS) and in the file of registered persons (FIPA), by sex,* HIN valid

Discrepancy between CDIS and FIPA	Sex					
	Female		Male		Total	
	n	%	n	%	n	%
None	800	93.8	407	92.9	1,207	93.5
+ - 1 year	20	2.3	15	3.4	35	2.7
+ - 2 to 5 years	12	1.4	7	1.6	19	1.5
+ - 5 to 9 years	4	0.5	1	0.2	5	0.4
+ - 10 years and more	17	2.0	8	1.8	25	1.9
Total	**853**	**100.0**	**438**	**100.0**	**1,291**	**100.0**

* Sex according to FIPA, 2 missing data.

Source: Cree Diabetes Information System and RAMQ.

There was 94% agreement among the data for the community of between the two data sources (Table 15). This proportion was 87% for cases of type 1 and type 2 diabetes (data not shown).

Table 15 - Agreement in the distribution of community of residence between the Cree Diabetes Information System (CDIS) and the file of registered persons (FIPA), HIN valid

Municipality of residence according to CDIS	Same municipality		Other municipalities, Cree region		Other municipalities, other regions		Unknown		Total	
	n	%	n	%	n	%	n	%	n	%
Chisasibi	222	97	4		2		-		228	18
Eastmain	65	98	-		1		1		67	5
Mistissini	332	94	9		11		2		354	27
Nemiscau	47	92	3		1		-		51	4
Oujé-Bougoumou	54	98	4		8		2		68	5
Waskaganish	193	96	4		2		3		202	16
Waswanipi	191	95	1		10		-		202	16
Wemindji	77	99	-		-		1		78	6
Whapmagoostui	27	84	2		2		1		32	2
Other municipalities	-		5		4		2		11	1
Total	**1,212**	**94**	**32**	**2**	**37**	**3**	**12**	**1**	**1,293**	**100**

Source: Cree Diabetes Information System and RAMQ.

We also verified the agreement between the dates of diagnosis of cases of type 1 and type 2 diabetes for subjects matched and identified according to the algorithm used in the NDSS context (Blanchard) (Table 16). In nearly all cases (94%), the date identified in the Cree Diabetes Information System preceded the date in the NDSS. This may be owing to the fact that diagnostic or screening activities carried out in the Eeyou Istchee territory are logged in this information system locally and usually by salaried professionals. We also looked at the 26 subjects for whom the date of diagnosis of diabetes in the NDSS preceded the date in the Cree Diabetes Information System. The discrepancy was less than one year for 11 subjects, from one to two years for 10 other subjects, and was more than two years for the remaining 5 subjects. The average discrepancy in days for these 26 subjects was 490 days.

Table 16 - Discrepancies in diagnosis dates of diabetes (type 1 and type 2) cases in the Cree Diabetes Information System and cases identified in the Québec Diabetes Surveillance System using the NDSS algorithm

Discrepancy in the diagnosis date	%	n
Date of diagnosis in the CDIS prior to or same as that in the NDSS	93.6	379
Date of diagnosis in the NDSS prior to the date in the CDIS	6.4	26
Total	**100.0**	**405**

Source: Cree Diabetes Information System, RAMQ and MED-ECHO.

Following discussions with Cree Diabetes Information System officials, we used the FIPA data for sex and year of birth for the rest of the analyses. It seems that the update of the Cree Diabetes Information System ensures that the information on community of residence is more recent than that obtained from the FIPA. We also noted some discrepancies with respect to place of residence between the FIPA and MED-ECHO files, with a few errors in the latter case. For example, the community of residence of Mistissini (region 18) was sometimes coded under the municipality of Mistassini (region 02) in the MED-ECHO file, thereby excluding these residents from their region. In addition, we used the date of diagnosis from the Cree Diabetes Information System when calculating the duration of the disease before complications.

5.4 DESCRIPTION BY TYPE OF DIABETES, ACCORDING TO AGE, SEX, COMMUNITY OF RESIDENCE

Tables 17 to 20 describe the subjects in the Cree Diabetes Information System linked to the FIPA by type of diabetes, according to age group, sex, average age at the time of diagnosis, and community of residence. After linkage, 73% of the subjects were cases of type 1 or type 2 diabetes, 14% were persons with glucose intolerance, and 13% were women with gestational diabetes. The prevalences of the various types of diabetes are highest among persons aged 30 to 59 but lower in the older age groups. In all, two-thirds (66%) of the subjects entered in the Cree Diabetes Information System linked to the FIPA are women. Nearly two-thirds (62%) of the cases of type 1 and type 2 diabetes are women. The

proportion of women among persons with glucose intolerance is 59%. The average age at the time of diagnosis is 45 for cases of type 1 and type 2, 50 for cases of glucose intolerance, and 27 for gestational diabetes. The difference in the average age of women versus men at the time of diagnosis of type 1 or type 2 diabetes is less than 3 years but rises to 18 years for glucose intolerance.

Table 17 - Distribution of cases from the Cree Diabetes Information System linked to the FIPA, by type of diabetes and age group* as of March 31, 2002

Age group	Type of diabetes							
	Gestational diabetes		Glucose intolerance		Type 1 and type 2		Total	
	n	%	n	%	n	%	n	%
10 to 29	69	41.3	12	6.8	70	7.3	151	11.7
30 to 39	73	43.7	35	19.9	164	17.3	272	21.1
40 to 49	25	15.0	39	22.2	214	22.6	278	21.5
50 to 59	-		35	19.9	242	25.5	277	21.5
60 to 69	-		28	15.9	154	16.2	182	14.1
70 to 79	-		23	13.1	64	6.8	87	6.7
80 and +	-		4	2.3	40	4.2	44	3.4
Total	**167**	**100.0**	**176**	**100.0**	**948**	**100.0**	**1,291**	**100.0**

* Age in 2002 according to FIPA.

Source: Cree Diabetes Information System.

Table 18 - Distribution of cases from the Cree Diabetes Information System (all types) linked to the FIPA, by sex* and age group* as of March 31, 2002

Age group	Sex					
	Female		Male		Total	
	n	%	n	%	n	%
10 to 19	8	0.9	3	0.7	11	0.9
20 to 29	119	14.0	21	4.8	140	10.8
30 to 39	202	23.7	70	16.0	272	21.1
40 to 49	182	21.3	96	21.9	278	21.5
50 to 59	158	18.5	119	27.2	277	21.5
60 to 69	104	12.2	78	17.8	182	14.1
70 to 79	51	6.0	36	8.2	87	6.7
80 and +	29	3.4	15	3.4	44	3.4
Total	**853**	**100.0**	**438**	**100.0**	**1,291**	**100.0**

* Sex and age in 2002 according to FIPA.

Source: Cree Diabetes Information System.

Table 19 - Average age at the time of diagnosis, by categories of cases in the Cree Diabetes Information System linked to the FIPA and by sex* as of March 31, 2002

Type of diabetes	Sex			n
	Female	Male	Total	
Type 1 and type 2	43.9	46.6	45.1	949
Glucose intolerance	42.3	59.8	50.1	176
Gestational diabetes	27.2	-	27.2	167
Total	**42.5**	**47.3**	**44.2**	**1,293**

* Sex according to FIPA.

Source: Cree Diabetes Information System.

Table 20 - Distribution of cases from the Cree Diabetes Information System (all types) linked to the FIPA, by sex* and community of residence as of March 31, 2002**

Community of residence	Sex					
	Female		Male		Total	
	n	%	n	%	n	%
Chisasibi	161	18.9	67	15.3	228	17.7
Eastmain	38	4.5	28	6.4	66	5.1
Mistissini	223	26.1	131	29.9	354	27.4
Nemaska	34	4.0	17	3.9	51	4.0
Oujébougoumou	50	5.9	18	4.1	68	5.3
Waskaganish	141	16.5	61	13.9	202	15.6
Waswanipi	119	14.0	83	18.9	202	15.6
Wemindji	54	6.3	23	5.3	77	6.0
Whapmagoostui	26	3.0	6	1.4	32	2.5
Other communities	7	0.8	4	0.9	11	0.9
Total	**853**	**100.0**	**438**	**100.0**	**1,291**	**100.0**

* Sex according to FIPA, 2 missing data.

** Community of residence according to the Cree Diabetes Information System.

Source: Cree Diabetes Information System.

5.5 TOTAL HOSPITALISATIONS BY PLACE, NUMBER AND DURATION

We calculated the proportion of hospitalised cases (all reasons) for the subjects linked with the FIPA (Table 21). In all, slightly over one-half of the linked subjects (52%) were hospitalised at least once in the period 1995-1996 to 2000-2001. This proportion was 48% for cases of type 1 and type 2 diabetes and 40% for persons with glucose intolerance. Since most births take place in a hospital, the proportion was 86% for cases of gestational diabetes. The average number of hospitalisations for the period of study ranged from 2.5 for cases of type 1 diabetes to 1.1 for glucose intolerants.

Table 21 - Proportion of cases from the Cree Diabetes Information System (all types) linked to the FIPA that had at least one hospitalisation, average number of days of hospitalisation by type of diabetes, period 1995-1996 to 2000-2001

Type of diabetes	Proportion of hospitalised cases (n)	Average number of hospitalisations
Type 1 and type 2	48% (456/949)	1.5
Gestational diabetes	86% (145/168)	2.1
Glucose intolerance	40% (71/176)	1.2
Total	**52% (672/1,293)**	**1.3**

Source: Cree Diabetes Information System, MED-ECHO.

In all, the 672 subjects from the Cree Diabetes Information System linked to the FIPA accounted for 1,672 hospitalisations with an average duration of 6 days (Table 22). These hospitalisations resulted in a total of 1,516 transportations, or about 250 annually. The proportion of hospitalised cases varies from one community to another, ranging from 37% in Nemaska to 75% in Whapmagoostui (Table 23). Nearly one-half of hospitalisations (44%) were at the Centre hospitalier de Chibougamau, one-quarter (25%) at the Centre hospitalier de Val d'Or, 14% at Chisasibi, and 11% in another hospital centre in Montréal (Table 24). Women accounted for about three-quarters (76%) of the hospitalisations, with higher proportions among women aged 20 to 39 (Table 25). Hospitalisations were more frequent among men aged 40 to 69.

A clinical severity indicator was established based on the DRG at the time of each hospitalisation. Figure 6 shows that the proportion of hospitalisations rated high or extreme on the index among type 1 and type 2 cases increased steadily over the years, from 8% in 1995-1996 to 29% in 2001-2002.

Table 22 - Number of hospitalisations of cases from the Cree Diabetes Information System (all types) linked to the FIPA, average duration of hospitalisation and number of transportations, by fiscal year, period 1995-1996 to 2000-2001

Fiscal year	Number of hospitalisations	Average duration of hospitalisation, in days	Number of transportations
1995-1996	298	5.1	266
1996-1997	280	6.2	254
1997-1998	285	4.9	270
1998-1999	279	5.3	254
1999-2000	315	7.4	289
2000-2001	215	7.5	183
Total	**1,672**	**6.0**	**1,516**

Source: Cree Diabetes Information System, MED-ECHO.

Table 23 - Number of hospitalisations of cases from the Cree Diabetes Information System (all types) linked to the FIPA, average duration of hospitalisation and number of transportations, by community of residence, period 1995-1996 to 2000-2001

Community	Number of hospitalisations	Number of transportations	Average duration of hospitalisation, in days	Proportion of hospitalised cases
Chisasibi	297	140	6.2	54%
Eastmain	48	48	6.1	44%
Mistissini	546	546	5.8	54%
Nemaska	68	68	7.9	37%
Oujébougoumou	122	122	4.3	63%
Waskaganish	144	144	5.1	41%
Waswanipi	280	280	5.8	58%
Wemindji	71	72	5.9	49%
Whapmagoostui	65	65	6.9	75%
Outside Eeyou Istchee	31	31	17.5	73%
Total	**1,672**	**1,516**	**6.0**	**52%**

Source: Cree Diabetes Information System, MED-ECHO.

Table 24 - Hospital centre of destinations of cases from the Cree Diabetes Information System (all types) linked to the FIPA, period 1995-1996 to 2000-2001

Hospital centre	Number of hospitalisations	
	n	%
Centre hospitalier de Val d'Or	410	25
Centre hospitalier de Chibougamau	731	44
CSSS Chisasibi	229	14
Montréal General Hospital	69	4
Royal Victoria Hospital	46	3
Other Montréal hospital centres	69	4
Other hospital centres	118	7
Total	**1,672**	**100**

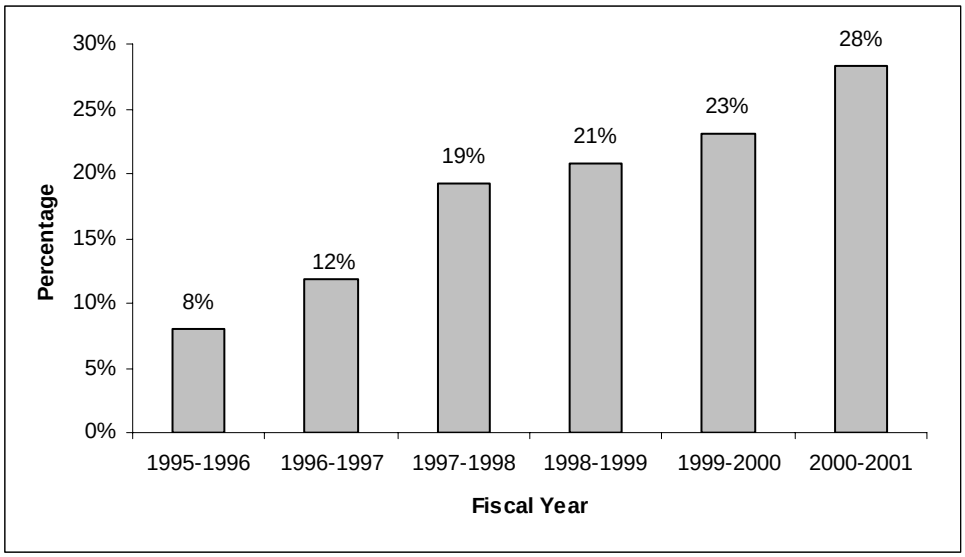
Source: Cree Diabetes Information System, MED-ECHO.

Table 25 - Distribution of hospitalisations of cases from the Cree Diabetes Information System (all types) linked to the FIPA, by age group and sex, period 1995-1996 to 2000-2001

Age group	Female %	Male %	Total %	Number of hospitalisations
Under 20	4	2	4	59
20–29	27	8	23	379
30-39	24	9	20	336
40-49	10	20	13	212
50-59	14	18	15	251
60-69	11	22	14	232
70-79	5	11	6	104
80 and over	4	11	6	99
Total % (n)	**76 (1,274)**	**24 (398)**	**100**	**(1,672)**

Source: Cree Diabetes Information System, MED-ECHO.

Figure 6 - Proportion of hospitalisations rated high/extreme according to the clinical severity index for cases of type 1 and type 2 diabetes entered in the Cree Diabetes Information System, by fiscal year, period 1995-1996 to 2000-2001



Source: Cree Diabetes Information System, MED-ECHO.

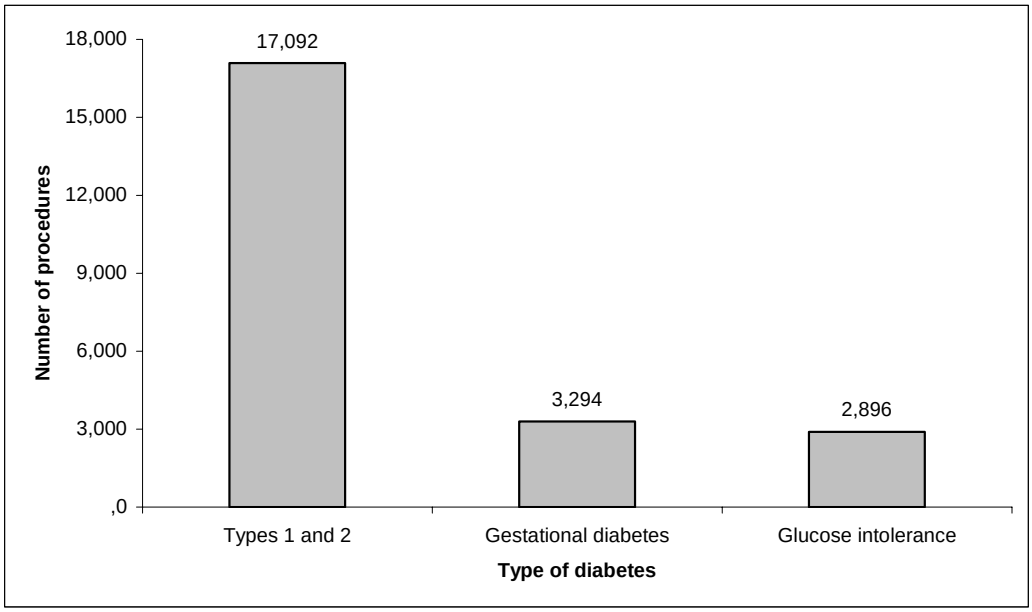
5.6 MEDICAL CONSULTATIONS OF CASES FROM THE CREE DIABETES INFORMATION SYSTEM

We calculated the billed medical procedures received by cases from the Cree Diabetes Information System for the period 1996-1997 to 2000-2001. We might recall that procedures performed during hospitalisations were excluded from the calculations. In all, over 23,000 billed medical procedures were entered for this clientele during the period of study (Figure 7). We might recall that these 23,000 procedures exclude all procedures performed by salaried physicians working in Cree communities. The vast majority of physicians who work in this region are paid by salary or wage payment contract. Ophthalmologists, however, are paid on a fee-for-service basis.

Most billed medical procedures (73%) were for cases of type 1 and type 2 diabetes, 14% involving women with gestational diabetes and 12% involving glucose intolerance. The number of medical procedures tends to increase over the years, from 3,970 in 1996-1997 to 6,241 in 2000-2001 (Table 26). Nearly 4 in 10 billed procedures were performed in the Abitibi region, 30% in the Montréal region, 15% in the Northern Québec region, and 10% in the Eeyou Istchee territory (Table 27).

One-fifth of the procedures (21%) involved ultrasonography, 13% general surgery, 12% ophthalmology and 7% obstetrics (Table 28). It should be noted that no procedure billed by an optometrist was reported.

Figure 7 - Number of medical procedures* performed in cases from the Cree Diabetes Information System (all types) linked to the FIPA, by type of diabetes, period 1996-1997 to 2000-2001



* Excluding procedures performed during hospitalisation.

Source: Cree Diabetes Information System and RAMQ.

Table 26 - Distribution of medical procedures* performed in cases from the Cree Diabetes Information System (all types) linked to the FIPA, by fiscal year, period 1996-1997 to 2000-2001

Fiscal year	Number of consultations
1996-1997	3,970
1997-1998	4,198
1998-1999	3,939
1999-2000	4,934
2000-2001	6,241
Total	**23,282**

* Excluding procedures performed during hospitalisation.

Source: Cree Diabetes Information System and RAMQ.

Table 27 - Distribution of medical procedures* performed in cases from the Cree Diabetes Information System (all types) linked to the FIPA, by region where performed, period 1996-1997 to 2000-2001

Region of consultation	Number of consultations	%
Abitibi	9,825	43
Montréal-Centre	6,521	29
Northern Québec	3,349	15
Eeyou Istchee	2,337	10
Other regions	734	3
Total	**22,766**	**100**

* Excluding procedures performed during hospitalisation, 516 missing data.
Source: Cree Diabetes Information System and RAMQ.

Table 28 - Distribution of medical procedures* performed in cases from the Cree Diabetes Information System (all types) linked to the FIPA, by medical specialty, period 1996-1997 to 2000-2001

Medical specialty	Number of consultations	%
Ultrasonography	4,045	21
General surgery	2,507	13
Ophthalmology	2,298	12
Obstetrics	1,441	7
Nephrology	1,078	6
Diagnostic cardiology	888	5
Orthopedics	728	4
Otorhinolaryngology	653	3
Internal medicine	620	3
Cardiology	581	3
Pneumology	564	3
Endocrinology	542	3
Gastroenterology	493	3
Other	2,420	13
Total	**19,237**	**100**

* Excluding procedures performed during hospitalisation, 4424 missing data.
Source: Cree Diabetes Information System and RAMQ.

5.7 HOSPITALISATIONS FOR DIABETES MELLITUS

In all, over the six years considered, for the cases entered in the Cree Diabetes Information System (Table 29) there were 109 hospitalisations with diabetes as the main diagnosis (ICD-9 250). The number of these hospitalisations dropped from 30 in 1995-1996 to 13 in 2000-2001.

Table 29 - Number of hospitalisations with diabetes mellitus as the main diagnosis (ICD-9 250) of cases from the Cree Diabetes Information System linked to the FIPA, by fiscal year, period 1995-1996 to 2000-2001

Fiscal year	Number of hospitalisations
1995-1996	30
1996-1997	13
1997-1998	16
1998-1999	16
1999-2000	21
2000-2001	13
Total	**109**

Source: MED-ECHO file.

5.8 COMPLICATIONS ASSOCIATED WITH DIABETES

5.8.1 Hospitalisations for a complication of cardiovascular disease

In all, 63 cases of type 2 diabetes (no type 1 involved) were hospitalised for a complication of cardiovascular disease during the period of study, representing 6.6% of all cases of type 1 and type 2 diabetes from the Cree Diabetes Information System linked to the FIPA (Table 30). The average number of hospitalisations is 2.3 and seems to increase with age, from 1.6 for the 40-49 age group to 3.9 in the 80-and-over age group. The number of hospitalisations is higher among women (Table 31) and tends to increase annually over the period considered, from 10 in 1995-1996 to 33 in 2000-2001 (Table 32).

In addition, the average interval between the date of diagnosis of diabetes and the initial hospitalisation for a complication of cardiovascular disease is 10.3 years (Table 33). It should be noted that cases that had a hospitalisation prior to the date of diagnosis of diabetes have been excluded from this calculation.

In all, the 147 hospitalisations for a complication of cardiovascular disease generated 1,402 days in hospital, for an average of 9.5 days per episode (Table 34). Just over one-third (38%) of the 147 hospitalisations were at the Centre hospitalier de Chibougamau, 21% were at the Centre hospitalier de Val-d'Or, and 20% at the Centre hospitalier de Chisasibi (Table 35).

Table 30 - Number of hospitalisations, average hospitalisations and number of cases from the Cree Diabetes Information System (type 2) linked to the FIPA for a complication of cardiovascular disease, by age group, period 1995-1996 to 2000-2001

Age group	Number of hospitalisations	Average number of hospitalisations	Number of cases
40 to 49	11	16	7
50 to 59	37	1.5	25
60 to 69	44	3.4	13
70 to 79	20	2.2	9
80 and over	35	3.9	9
Total	**147**	**2.3**	**63**

Source: MED-ECHO.

Table 31 - Number of hospitalisations of cases from the Cree Diabetes Information System (type 2) linked to the FIPA for a complication of cardiovascular disease, by sex and age group, period 1995-1996 to 2000-2001

Age group	Female	Male	Total	
			n	%
40 to 49	8	3	11	7.5
50 to 59	23	14	37	25.2
60 to 69	33	11	44	29.9
70 and over	44	11	55	37.4
Total	**108**	**39**	**147**	**100.0**

Source: MED-ECHO.

Table 32 - Number of hospitalisations of cases from the Cree Diabetes Information System (type 2) linked to the FIPA for a complication of cardiovascular disease, by sex and fiscal year, period 1995-1996 to 2000-2001

Fiscal year	Female	Male	Total	
			n	%
1995-1996	7	3	10	6.8
1996-1997	*	*	15	10.2
1997-1998	*	*	24	16.3
1998-1999	25	6	31	21.1
1999-2000	22	12	34	23.1
2000-2001	21	12	33	22.4
Total	**108**	**39**	**147**	**100.0**

Source: MED-ECHO.

Table 33 - Average interval (in years) between the diagnosis of diabetes and the initial hospitalisation of cases from the Cree Diabetes Information System (type 2) linked to the FIPA for a complication of cardiovascular disease, by age group, period 1995-1996 to 2000-2001

Age group	Average duration of disease	Number of cases*
40 to 49	9.5	7
50 to 59	9.6	20
60 to 69	13.8	10
70 to 79	7.0	9
80 and over	12.2	8
Total	**10.3**	**54**

* 9 subjects were excluded because their hospitalisation date preceded that of the Cree Diabetes Information System.

Source: MED-ECHO.

Table 34 - Total duration (in days) of hospitalisations of cases from the Cree Diabetes Information System (type 2) linked to the FIPA for a complication of cardiovascular disease, by sex and age group, period 1995-1996 to 2000-2001

Age group	Female	Male	Total
40 to 49	49	23	72
50 to 59	129	188	317
60 to 69	242	56	298
70 to 79	50	56	106
80 and over	602	7	609
Total	**1,072**	**330**	**1,402**

Source: MED-ECHO.

Table 35 - Number of hospitalisations of cases from the Cree Diabetes Information System (type 2) linked to the FIPA for a complication of cardiovascular disease, by institution, period 1995-1996 to 2000-2001

Name of institution	Number of hospitalisations	
	n	%
Centre hospitalier Chibougamau	56	38.1
Centre Hospitalier de Val-d'Or	31	21.1
Conseil Cri de la santé et des services sociaux de la Baie-James	29	19.7
Centre hospitalier Hôtel-Dieu d'Amos	10	6.8
Hôpital Général de Montréal	4	2.7
MUHC : Hôpital Royal Victoria	3	2.0
Hôpital du Sacré-Coeur de Montréal	3	2.0
Hôtel-Dieu de Roberval	3	2.0
Other hospitals	8	5.6
Total	**147**	**100.0**

Source: MED-ECHO.

5.8.2 Hospitalisations for renal failure and dialysis

In all, 34 cases of type 1 and type 2 diabetes were hospitalised for renal failure or dialysis during the period of study, representing 3.6% of all cases of type 1 and type 2 diabetes entered in the Cree Diabetes Information System linked to the FIPA (Table 36). The average number of hospitalisations is 2.8. The number of hospitalisations is higher among women (Table 37) and tends to increase annually over the period considered, from 6 in 1995-1996 to 28 in 2000-2001 (Table 38). Of the 34 cases identified, 9 underwent dialysis one or more times.

The average interval between the date of diagnosis of diabetes and the initial hospitalisation for renal failure or dialysis is 10.4 years (Table 39). The average interval is just 3.2 years for cases in the 30-to-39 age group and increases to 11.6 years in the 80-and-over age group.

In all, the 96 hospitalisations for renal failure or dialysis generated 759 days in hospital, for an average of 7.9 days per episode (Table 40). One-third (33%) of the 96 hospitalisations were at the Centre hospitalier de Chibougamau, 16% at Montréal General Hospital, and 10% at the Centre hospitalier de l'Hôtel-Dieu-d'Amos (Table 41).

Table 36 - Number of hospitalisations, average hospitalisations and number of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for renal failure and dialysis, by age group, period 1995-1996 to 2000-2001

Age group	Number of hospitalisations	Average number of hospitalisations	Number of cases
30 to 39	7	1.8	4
40 to 49	8	2.7	3
50 to 59	39	3.9	9
60 to 69	31	2.6	12
70 and over	11	1.9	6
Total	**96**	**2.8**	**34**

Source: MED-ECHO.

Table 37 - Number of hospitalisations of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for renal failure and dialysis, by sex and age group, period 1995-1996 to 2000-2001

Age group	Female	Male	Total	
			n	%
30 to 39	3	4	7	7.3
40 to 49	3	5	8	8.3
50 to 59	26	13	39	40.6
60 to 69	24	7	31	32.3
70 and over	6	5	11	11.5
Total	**62**	**34**	**96**	100.0

Source: MED-ECHO.

Table 38 - Number of hospitalisations of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for renal failure and dialysis, by sex and fiscal year, period 1995-1996 to 2000-2001

Fiscal year	Female	Male	Total	
			n	%
1995-1996	*	*	6	6.3
1996-1997	*	*	11	11.5
1997-1998	*	*	9	9.4
1998-1999	7	9	16	16.7
1999-2000	15	11	26	27.1
2000-2001	18	10	28	29.2
Total	**62**	**34**	**96**	**100.0**

Source: MED-ECHO.

Table 39 - Average interval (in years) between the diagnosis of diabetes and the first hospitalisation of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for renal failure and dialysis, by age group, period 1995-1996 to 2000-2001

Age group	Average duration of disease	Number of cases
30 to 39	3.2	4
40 to 49	14.4	3
50 to 59	10.6	9
60 to 69	11.3	12
70 and over	11.4	6
Total	**10.4**	**34**

Source: MED-ECHO.

Table 40 - Total duration (in days) of hospitalisations of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for renal failure and dialysis, by sex and age group, period 1995-1996 to 2000-2001

Age group	Female	Male	Total
30 to 39	20	9	29
40 to 49	30	47	77
50 to 59	209	142	351
60 to 69	150	79	229
70 to 79	18	25	43
80 and over	30	-	30
Total	**457**	**302**	**759**

Source: MED-ECHO.

Table 41 - Number of hospitalisations of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for renal failure and dialysis, by institution, period 1995-1996 to 2000-2001

Name of institution	Number of hospitalisations	
	n	%
Centre hospitalier Chibougamau	32	33.3
Centre hospitalier de Val-d'Or	23	24.0
Montréal General Hospital	15	15.6
Centre hospitalier Hôtel-Dieu d'Amos	10	10.4
Cree Board of Health and Social Services of James Bay	5	5.2
MUHC: Royal Victoria Hospital	6	6.3
Other hospitals	5	5.0
Total	**96**	**100.0**

Source: MED-ECHO.

5.8.3 Hospitalisations for amputation of a leg or toe

In all, there were 7 hospitalisations involving 5 cases of type 2 diabetes for amputation of a lower limb during our study period: 4 involving women and 3 involving men (Table 42). Of these 7 hospitalisations, 6 were for the amputation of a toe or foot and 1 for the amputation of a leg. The average interval between the diagnosis and the initial hospitalisation for amputation is 18.1 years (data not shown). Four (4) hospitalisations were in 1997-1998, 2 in 1999-2000, and 1 in fiscal year 2000-2001. These hospitalisations totalled 81 days (data not shown). Five (5) of the 7 hospitalisations were at the Centre hospitalier de Val-d'Or, 1 was at the Centre hospitalier universitaire de Québec, and 1 at Royal Victoria Hospital (data not shown).

Table 42 - Number of hospitalisations from the Cree Diabetes Information System (type 2) linked to the FIPA for amputation of a leg or toe, by age group, period 1995-1996 to 2000-2001

Age group	Number of hospitalisations
40 to 59	3
70 and over	4
Total	**7**

Source: MED-ECHO.

5.8.4 Medical consultations for laser photocoagulation or vitrectomy

Estimates of complications for retinopathy were based on medical consultations for two types of ophthalmological procedures: laser photocoagulation, and vitrectomy. In all, 25 cases of diabetes underwent a laser photocoagulation or vitrectomy in the period from January 1, 1996, to March 31, 2001, representing 2.8% of all diabetes cases entered in the Cree Diabetes Information System linked to the FIPA (Table 43). The average number of consultations is 2.7 for a total of 67 consultations. The number of consultations is higher among women (Table 44) and varies annually over the period considered, from 3 in the latter part of 1995-1996 (partial data) to 23 the following year and dropping to 6 in 2000-2001 (Table 45).

In addition, the average interval between the date of diagnosis of diabetes and the initial consultation for a laser photocoagulation or vitrectomy is 13.3 years (Table 46). This average interval tends to increase with age, from 6.7 years in the 40-to-49 age group to 18.4 years in the 80-and-over age group. It should be noted that cases that had a consultation before the date of diagnosis of diabetes were excluded from this calculation.

All 67 consultations for a laser photocoagulation or vitrectomy took place in a hospital centre: 9% were during a hospitalisation, and 91% on an outpatient basis (data not shown). Just over one-half (58%) of the 67 consultations took place in the region of Montréal-Centre, 32% in Abitibi, and 10% in another region (Table 47).

Table 43 - Number of medical consultations, average consultations and number of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for laser photocoagulation or vitrectomy, by age group, period from January 1, 1996, to March 31, 2001

Age group	Number of consultations	Average number of consultations	Number of cases
30 to 49	24	3.4	7
50 to 59	31	3.1	10
60 to 69	7	1.8	4
70 to 79	5	1.3	4
Total	**67**	**2.7**	**25**

Source: RAMQ.

Table 44 - Number of medical consultations of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for laser photocoagulation or vitrectomy, by sex and age group, period from January 1, 1996, to March 31, 2001

Age group	Female	Male	Total	
			n	%
30 to 39	8	-	8	11.9
40 to 49	4	12	16	23.9
50 to 59	22	9	31	46.3
60 to 79	8	4	12	17.9
Total	**42**	**25**	**67**	**100.0**

Source: RAMQ.

Table 45 - Number of medical consultations of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for laser photocoagulation or vitrectomy, by sex and fiscal year, period from January 1, 1996, to March 31, 2001

Fiscal year	Female	Male	Total		
			Number of consultations	%	Number of cases
January 1996-1997	16	10	26	38.8	12
1997-1998	6	-	6	9.0	4
1998-1999	10	6	16	23.9	8
1999-2000	7	6	13	19.4	7
2000-2001	3	3	6	9.0	5
Total	**42**	**25**	**67**	**100.0**	**25***

Source: RAMQ. * Sum of cases is greater than total due to multiple years consultations.

Table 46 - Average interval (in years) between the diagnosis of diabetes and the first medical consultation of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for laser photocoagulation or vitrectomy, by age group, period from January 1, 1996, to March 31, 2001

Age group	Average duration of the disease	Number of cases
30 to 49	9.8	7
50 to 59	13.2	10
60 to 69	15.1	4
70 to 79	18.4	4
Grand total	**13.3**	**25**

Source: RAMQ.

Table 47 - Number of medical consultations of cases from the Cree Diabetes Information System (type 1 and type 2) linked to the FIPA for laser photocoagulation or vitrectomy, by region where procedure was performed, period January 1, 1996, to March 31, 2001

Region where procedure was performed	Number of consultations	
	n	%
Montréal-Centre	39	58.2
Abitibi	22	32.8
Saguenay—Lac-Saint-Jean	3	4.5
Region unknown	3	4.5
Grand total	**67**	**100.0**

Source: RAMQ.

5.9 MEDICAL CONSULTATIONS WITH AN OPHTHALMOLOGIST

We also estimated the proportion of cases of type 1 and type 2 diabetes who had consulted an ophthalmologist in the period extending from January 1, 1996, to March 31, 2001 (Table 48). In over half the cases, the purpose of the consultation was to follow up patients with diabetes, and in the remaining cases it was to provide follow-up for other reasons (e.g. cataract, glaucoma, etc.). The proportion of cases of type 1 and type 2 diabetes that had at least one consultation with an ophthalmologist paid on a fee-for-service basis is 69% for the period January 1, 1996, to March 31, 2001. This proportion varies according to the duration of the disease, from 37% for persons who had been diagnosed a year or less before the consultation, increasing gradually to 83% for persons who had been diagnosed five or more years before.

The *Clinical Practice Guidelines* of the Canadian Diabetes Association recommend a frequency of ophthalmological consultations according to the type of diabetes and the complications present (CDA 2003) (ACD 2003). Based on the ophthalmological consultations, we estimated the proportion of subjects who had been seen in the previous two years, i.e., the maximum interval between consultations as recommended by the CDA. Table 49 shows the proportion of cases entered in the CDIS that were seen by an ophthalmologist over a two-year period, by sex. The proportion of cases of type 1 and type 2 diabetes that had at least one consultation with an ophthalmologist paid on a fee-for-service basis was 62% for the 15 months period between january 1, 1996 and march 31, 1997, dropping to 47% for the period 1999-2000 to 2000-2001. The proportion of ophthalmological consultations does not appear to differ according to sex for the period considered. In all, for the period between January 1, 1996, and March 31, 2001, 69% of cases consulted an ophthalmologist at least once.

Table 48 - Proportion of cases of type 1 and type 2 diabetes from the Cree Diabetes Information System linked to the FIPA that had an ophthalmological consultation, by number of consultations and number of years since the diagnosis of diabetes, for the period January 1, 1996, to March 31, 2001

Duration of the disease	Number of consultations				Total
	None	1	2	3 or more	
Less than one year	64.9	18.9	10.8	5.6	8.5
One year	63.2	26.4	5.8	4.6	10.0
Two years	48.7	32.9	5.3	13.1	8.7
Three years	34.1	27.3	15.9	22.7	10.1
Four years	25.9	18.5	31.5	24.1	6.2
Five or more years	17.5	24.0	17.7	40.7	56.4
Total*	**31.3**	**24.6**	**15.5**	**28.9**	**100.0**

* Proportion of cases that had at least one consultation during the period.

Source: RAMQ.

Table 49 - Proportion of cases of type 1 and type 2 diabetes from the Cree Diabetes Information System linked to the FIPA that had an ophthalmological consultation in the previous two years, by period and sex, period 1995-1996 to 2000-2001

Consultation period	Female		Male		Total	
	n	%	n	%	n	%
01-01-1996 to 1996-1997	207	65.3	128	63.7	335	61.5
1996-1997 to 1997-1998	258	64.7	164	70.1	422	66.7
1997-1998 to 1998-1999	227	50.7	140	53.6	367	51.8
1998-1999 to 1999-2000	235	46.7	132	45.1	367	46.1
1999-2000 to 2000-2001	254	46.5	151	46.6	405	46.6
All years*	**378**	**69.2**	**222**	**68.5**	**600**	**69.5**

* Proportion of cases that had at least one consultation during the period.

Source: RAMQ.

6 DISCUSSION

The aim of this research report was to validate the data on diabetes cases in the Cree Diabetes Information System (CDIS) with the administrative data used in the Québec Diabetes Surveillance System (QDSS) and the National Diabetes Surveillance System (NDSS). One objective of this study was to describe the prevalence of diabetes among the Cree and the complications associated with it.

The initial source was the Cree Diabetes Information System as of spring 2002, witch included 1,480 subjects: 10 cases of type 1 diabetes, 1,066 cases of type 2 diabetes, 199 cases of gestational diabetes, and 205 cases of glucose intolerance. The crude relative prevalence of cases of type 1 or type 2 diabetes aged 15 and over was 12.8% in 2002, while that of cases aged 20 and over was 14.7%. In 2002, the crude relative prevalence was 19% among Cree women aged 20 and over, and 11% among men. In all, nearly one-quarter of cases (26%) were under age 40, including 11 cases under age 20. The average duration of the disease was 14.5 years in the 10 cases of type 1 and 7.8 years in type 2 diabetes.

Diabetes is three times more prevalent in the Cree population of Eeyou Istchee than in the rest of Québec. The estimated prevalence in the Cree population is higher than the crude prevalence measured among the Cree of Moose Factory (6.2%) of western James Bay (Maberley, King et al. 2000) and close of that measured in Manitoba (11.7%) (Jacobs, Blanchard et al. 2000) and to the prevalences estimated for the Aboriginal populations of Ontario (13.2%) (Shah, Anand et al. 2003) and for two Algonquin communities of Québec (15%) (Delisle and Ekoé 1993). Unlike the situation observed in Québec and in Canada, among the Cree, diabetes is more prevalent among women than among men. This situation is identical, however, to that revealed by other studies of Aboriginal populations.

File linkage operations made it possible to match 87% of the subjects entered in the Cree Diabetes Information System. Because of errors in the health insurance numbers (linkage key) in the Cree Diabetes Information System, 187 subjects could not be linked. We sent the necessary data to Cree Diabetes Information System officials to be corrected. On the whole, the omitted cases were the result of an error made when entering the health insurance number in the Cree Diabetes Information System.

Of the 1,293 matched subjects, 700 were found in the Québec Diabetes Surveillance System and 592 were not. Applying Blanchard's algorithm, used in the context of the NDSS, it was possible to identify 405 cases of diabetes of the 700 subjects present in the Québec Diabetes Surveillance System. The NDSS algorithm identified only 45% of the cases from the Cree Diabetes Information System for which a match was possible. The proportion of linked cases of type 1 and type 2 diabetes identified in the Québec Diabetes Surveillance System was 67%. As was to be expected, the use of administrative data significantly underestimates the number of cases of diabetes in the geographically remote Eeyou Istchee population. The vast majority of medical services provided in this region are provided by physicians paid by salary or wage payment contract, and the procedures are therefore excluded from the administrative files. In Canada and Québec, the file of medical procedures

identifies about 90% of the cases, whereas only half of the matched subjects were identified by medical procedures when the NDSS algorithm was used.

The measures of agreement between the cases reported in the Cree Diabetes Information System and the NDSS yielded a sensitivity of 0.45, with a specificity of 0.96 and a positive predictive value of 0.97. As was mentioned earlier, this low sensitivity of the NDSS to identifying cases from the Eeyou Istchee region is largely owing to the fact that general physicians working in this territory are usually paid a salary, however the specificity of the NDSS is generally good. The non-cases used here consisted of persons with glucose intolerance or gestational diabetes, with the likely effect of underestimating the specificity measure obtained. We would recall that a similar study done recently of an Ontario population served by physicians paid on a fee-for-service basis yielded a sensitivity of 0.86, with a specificity of 0.97 and a positive predictive value of 0.80 (ICES, 2003).

Case linkage made it possible to assess the proportions of agreement of certain variables between the various data sources. There is 94% agreement for the sex of the linked subjects and 3% missing values in the Cree Diabetes Information System. The proportion of agreement for the year of birth is similar (94%), with wider variations in the year for subjects aged 50 and over. We preferred to use the data from the RAMQ file of registered persons (FIPA), since these data are validated. We sent Cree Diabetes Information System officials the information necessary to verify the sex and year of birth variables. For the remainder of the analyses, we used the FIPA data for both these variables.

There is 94% agreement of the matched subjects for community of residence, and after verification we used the information from the Cree Diabetes Information System, since this database appeared to be more current than that of the RAMQ. Also, the date of diagnosis in the Cree Diabetes Information System precedes the date determined by the NDSS algorithm for 94% of the 405 subjects identified by both sources. The date in the Cree Diabetes Information System seems more accurate here, since it is based on a review of the medical records kept by the Cree Board of Health and Social Services of James Bay (CBHSS-JB) and may therefore predate by several years the date determined by the NDSS.

By linking data sources we counted 1,672 hospitalisations (excluding transfers and day surgeries) for subjects from the Cree Diabetes Information System. The proportion of hospitalised cases during the period of study was 52% in all; it was 70% for cases of type 1 diabetes and 52% for cases of type 2 diabetes. These hospitalisations resulted in 1,516 transportations outside the Eeyou Istchee region during the period of study. In all, 86% of hospitalisations were outside the Cree region and the average duration of hospitalisation was 6 days. The remoteness of the Cree communities and the limited availability of hospital services may have the effect of increasing the number and duration of hospitalisations.

In all, the linkage operation identified over 23,000 medical services, excluding those provided during a hospitalisation. The number of medical services tends to increase over the years of the study and most services (90%) were provided outside the Eeyou Istchee region. The initial quotation for the study made provision for estimating optometric services paid for on a fee-for-service basis. However, no procedure was reported during this linkage operation.

Optometric services are paid for by the CBHSS-JB and would therefore be absent from the RAMQ files.

Using the data for paid medical services, we estimated that between 47% and 65% of cases of type 1 or type 2 diabetes had one consultation with an ophthalmologist within a two-year period.

This study also enabled us to estimate certain complications in diabetes cases, either by hospitalisations or ophthalmological services. Table 50 summarises the main results.

Table 50 - Main complications of cases of type 1 and type 2 diabetes from the Cree Diabetes Information System linked to the FIPA, by type of complication, period 1995-1996 to 2000-2001

Complication	Number of cases	Proportion of all cases	Average duration of the disease (in years)	Total duration of hospitalisations
Hospitalisation for CVD	63	6.46%	10.3	1,402
Hospitalisations for nephropathy or dialysis	34	3.6%	10.4	759
Hospitalisations for amputation of a leg or toe	5	0.53%	18.1	81
Medical procedures for laser photocoagulation or vitrectomy*	25	2.8%	13.3	-

* Period 01-01-1996 to 31-3-2001.

Source: RAMQ and MED-ECHO.

The complications estimated during this study underestimate the total complications in diabetes cases. This is owing in part to the fact that we did not calculate for all possible complications, favouring those that had been validated by the INSPQ, and in part to the methodology used, which excluded complications identified by physicians not paid on a fee-for-service basis. The Cree Diabetes Information System report 13% of cases with macrovascular complications, 58% with nephropathy, 11% retinopathy, and 6 amputation cases (CCSSS-BJ 2002). More specifically, the Cree Diabetes Information System identified 64 cases of coronary disease, while the information obtained from hospitalisations identified 56 cases (data not shown). It should be mentioned that these proportions of complications taken from the CDIS are calculated only for those subjects who consented to have follow-up information passed on, and that the actual number of cases with complications is greater than the number reported here. In addition, the average duration of the disease before a hospitalisation for a complication of CVD is 10.3 years, whereas that estimated according to the data provided by Cree Diabetes Information System officials is 7.8 years. This discrepancy may be owing to the greater severity of the complications reported for the hospitalisations. The proportions of complications among cases estimated by hospitalisations and medical services are lower than those published in studies done of Aboriginal

populations (for example, 13% of diabetes cases in Kahnawake suffered a stroke and 50% had a significant cardiopathy. On that same reserve, 25% of diabetics developed retinopathy after 10 years of exposure to diabetes. In all, 60% of diabetic Mohawks experienced a major complication) (Canada 2002).

7 CONCLUSION

This first study linking data from different sources has shown the possibilities for co-enrichment of the various surveillance systems. This linkage allows for a more complete description of the diabetes cases in the Québec Diabetes Surveillance System and in the NDSS. Both these systems augment the completeness of the cases reported, particularly in populations living in a remote region where services are provided essentially by physicians paid by salary or wage payment contract. The Québec Diabetes Surveillance System and the NDSS may also identify more effectively cases of gestational diabetes and glucose intolerance, while being weaker in identifying all subjects. In addition, the Québec Diabetes Surveillance System and the NDSS can, by means of this linkage, produce prevalences for a health region of Québec for which data were not previously available. And the diagnosis date and, consequently, the calculations of the duration of the disease are more accurate.

This linkage of databases produces a better estimate of the hospitalisations and medical consultations that occur outside the Eeyou Istchee region for cases from the Cree Diabetes Information System, thereby give another way to estimate certain complications. It also provides a better idea of the medical procedures performed, and therefore more accurately documents the complications for the various subgroups—information not currently available. Using this linkage of databases it is also possible to estimate the transportations made by subjects entered in the Cree Diabetes Information System and thus to assess the relative cost of these transportations. This information becomes very relevant for planning services for Cree with diabetes as well as for evaluating the activities of the program for tracking cases in the Cree Diabetes Information System.

We suggest linking databases on an annual basis to improve the surveillance and evaluation activities of both the Québec Diabetes Surveillance System and the Cree Diabetes Information System. This linkage could be carried out by adding incident cases for the year to the Québec Diabetes Surveillance System using the same methodology as was used in this study. Discussions between the managers of the two systems will provide a clearer definition of the terms and conditions of data transfer between the two.

8 BIBLIOGRAPHY

Brassard, P., E. Robinson, et al. (1993). "Prevalence of diabetes mellitus among the James Bay Cree of northern Quebec." *Cmaj* 149(3): 303-307.

CDA (2003). "2003 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada." *Canadian Journal of Diabetes*.

CDAB (1997). *Diabetes in Canada: Strategies Towards 2000*. Ottawa, Canadian Diabetes Advisory Board.

CBHSS-JB (2001). *Annual Diabetes Update, Eeyou Istchee, Diabetes Management System and Diabetes Registry*. Montréal, Cree Board of Health and Social Services of James Bay: 4 p.

CBHSS-JB (2002). *Annual Diabetes Update, Eeyou Istchee, Diabetes Management System and Diabetes Registry*. Montréal, Cree Board of Health and Social Services of James Bay: 2 p.

Dannenbaum, D., M. Verronneau, et al. (1999). "Comprehensive Computerized Diabetes Registry." *Canadian Family Physician* 45(2): 364-370.

Delisle, H. F. and J. M. Ekoé (1993). "Prevalence of non-insulin-dependent dabetes mellitus and impaired glucose tolerance in two Algonquin communities in Quebec." *Canadian Medical Association Journal* 148(1): 41-47.

Émond, V. (2002). *Prévalence du diabète au Québec et dans ses régions : premières estimations d'après les fichiers administratifs*. Québec, Institut national de santé publique du Québec: 15 p.

Harris, S. B., S. J. Meltzer, et al. (1998). "New guidelines for the management of diabetes: a physician's guide. Steering Committee for the Revision of the Clinical Practice Guidelines for the Management of Diabetes in Canada." *Cmaj* 159(8): 973-978.

Health Canada, (1999). *Statistical Report on the Health of Canadians*. Ottawa, Health Canada, Federal, Provincial and Territorial Advisory Committee on Population Health: 368 p.

Health Canada, (2002). *Diabetes in Canada*. Ottawa, Health Canada, Population and Public Health Branch: 82 p.

ICES (2003). *Diabetes in Ontario: An ICES Practice Atlas*, Chapter 1, "Pattern of Prevalence and Incidence of Diabetes." Toronto: Insitute for Clinical Evaluative Sciences & Canadian Diabetes Association, 18 p.

Jacobs, P., J. F. Blanchard, et al. (2000). "Excess costs of diabetes in the Aboriginal population of Manitoba, Canada." *Can J Public Health* 91(4): 298-301.

Maberley, D. A. L., W. King, et al. (2000). "The Prevalence of Diabetes in the Cree of Western James Bay." *Chronic Diseases in Canada* 21(4).

Shah, B. R., S. Anand, et al. (2003). *Diabetes in Ontario: An ICES Practice Atlas*, Chapter 13, "Diabetes and First Nations People." Toronto, Insitute for Clinical Evaluative Sciences & Canadian Diabetes Association: 231-248.

ANNEX 1

DATA FROM RAMQ FILES

ANNEX 1 DATA FROM RAMQ FILES

Data used in file linkage:

- For linkage of data from the RAMQ files (file of registered persons, fee-for-service file, file of prescription drugs) and the MED-ECHO file
  - Health insurance number

- For linkage of the file of registered persons (RAMQ) and the file of deaths
  - Health insurance number
  - Date of birth
  - Insured's family name
  - Insured's first name
  - Family name of insured's mother
  - First name of insured's father

Non-person-specific data:

- RAMQ file of registered persons:
  - Year of birth
  - Insured's geographic code
  - Sex
  - Insured's CLSC
  - Insured's municipality
  - Death variables (if available)

- File of fee-for-service payments
  - Location of health care provider
  - Geographic code of health care provider
  - Date of health care provider
  - Specialty of health care provider
  - Procedure code
  - Diagnosis
  - Cost of the service

ANNEX 2

DATA FROM THE MED-ECHO FILES AND APR-DRG FILE

ANNEX 2 DATA FROM THE MED-ECHO FILES AND APR-DRG FILE

DATA FROM THE MED-ECHO FILES

Data used in file linkage:

- Health insurance number

Non-person-specific data from the MED-ECHO file:

- Sex
- Date of hospitalisation
- Institution
- LCSC code
- Main diagnosis
- Secondary diagnoses
- Type of institution
- Deaths (if applicable)
- Date of discharge
- Treatments
- Insured's municipality code
- Insured's CLSC
- Responsibility for payment

DATA FROM THE APR-DRG FILE

Non-person-specific data from the APR-DRG file:

- DRG (Diagnosis Related Groups) code
- MDC (Major Diagnostic Category) code
- RIW (Resource Intensity Weight)
- Clinical severity indicator
- Maximum length of stay

ANNEX 3

DATA FROM THE DIABETES INFORMATION SYSTEM FOR THE CREE OF EEYOU ISTCHEE

ANNEX 3 DATA FROM THE DIABETES INFORMATION SYSTEM FOR THE CREE OF EEYOU ISTCHEE

Data used in file linkage:

- Health insurance number
- Date of birth
- Sex
- Community of residence

Non-person-specific data:

- Sex
- Date of birth
- Type of diabetes
- Date of diagnosis
- Status of consent

ANNEX 4

FILE LINKAGE METHODOLOGY

ANNEX 4 FILE LINKAGE METHODOLOGY

Step 1. Receipt by the RAMQ of the Cree Diabetes Information System file as described in Annex 3. This file is then transferred into the informational environment of the RAMQ.

Step 2. Validation by the RAMQ of the health insurance numbers in the information system (about 1,400 individuals). A status report is produced on the number of invalid health insurance numbers.

Step 3. Substitution by the RAMQ of the health insurance number with an individual number in the informational environment of the RAMQ.

Step 4. For cases with a valid HIN, extraction by the RAMQ of all fee-for-service medical and optometric procedures, and of all hospitalisations and FIPA and eligibility data for each individual, and establishment of a record for each individual with the information described in annexes 1 and 2 (including age as of certain dates or certain events calculated from the full date of birth).

Step 5. Generation by the RAMQ of a denominalized unique identifier number NI (replacing the individual number) and creation of denominalized files for the INSPQ.

ANNEX 5

DESCRIPTION OF CASES OF TYPE 1 AND TYPE 2 DIABETES ENTERED IN THE CREE DIABETES INFORMATION SYSTEM

ANNEX 5 DESCRIPTION OF CASES OF TYPE 1 AND TYPE 2 DIABETES ENTERED IN THE CREE DIABETES INFORMATION SYSTEM

Table A5.1 Prevalence of cases of type 1 and type 2 diabetes from the Cree Diabetes Information System, by age group and sex, 2001-2002 year

Age group	Sex		
	Female	Male	Total
10-14	3	-	3
15-19	4	3	7
20-24	10	3	13
25-29	38	15	53
30-34	52	30	82
35-39	61	37	98
40-44	64	39	103
45-49	83	51	134
50-54	69	47	116
55-59	89	63	152
60-64	63	36	99
65-69	43	29	72
70-74	27	19	46
75-79	23	7	30
80-84	17	6	23
85 and +	12	5	17
Total	**658**	**390**	**1,048**

Source: Cree Diabetes Information System.

ANNEX 6

DESCRIPTION OF CASES ACCORDING TO THE DEFINITION USED BY THE NDSS

ANNEX 6 DESCRIPTION OF CASES ACCORDING TO THE DEFINITION USED BY THE NDSS

Table A6.1 Cases of diabetes identified in the Québec Diabetes Surveillance System according to the NDSS algorithm, by age group and sex, initial population of cases from the Cree Diabetes Information System, 1996 to 2001

Age group	Sex		
	Male	Female	Total
10-29	15	39	54
30-39	20	40	60
40-49	36	51	87
50-59	39	69	108
60-69	28	33	61
70-79	8	18	26
80 and +	4	5	9
Total	**150**	**255**	**405**

Source: RAMQ and MED-ECHO.

Table A6.2 Cases of diabetes identified in the Québec Diabetes Surveillance System according to the NDSS algorithm, by year, initial population of cases in the Cree Diabetes Information System, 1996 to 2001

Year	Sex		
	Male	Female	Total
1996	41	67	108
1997	31	57	88
1998	26	40	66
1999	13	30	43
2000	26	38	64
2001	13	23	36
Total	**150**	**255**	**405**

Source: RAMQ and MED-ECHO.

ANNEX 7

DESCRIPTION OF SUBJECTS FROM THE CREE DIABETES INFORMATION SYSTEM NOT LINKED TO THE FIPA

ANNEX 7 DESCRIPTION OF SUBJECTS FROM THE CREE DIABETES INFORMATION SYSTEM NOT LINKED TO THE FIPA

Table A7.1 Distribution of cases from the Cree Diabetes Information System not linked to the FIPA, by age group and sex

Age group	Sex						
	Female		Male		Sex absent	Total	
	n	%	n	%	n	n	%
10-19	1	0.8	1	1.9	-	2	1.1
20-29	12	9.8	1	1.9	3	16	8.6
30-39	23	18.9	12	22.2	1	36	19.3
40-49	24	19.7	11	20.4	1	36	19.3
50-59	28	23.0	14	25.9	-	42	22.5
60-69	19	15.6	13	24.1	1	33	17.6
70 and over	15	12.3	2	3.7	-	17	9.1
Age absent	-		-		5	5	2.7
Total	**122**	**100.0**	**54**	**100.0**	**11**	**187**	**100.0**

Source: Cree Diabetes Information System.

Table A7.2 Distribution of cases from the Cree Diabetes Information System not linked to the FIPA, by type of diabetes and sex

Type of diabetes	Sex						
	Female		Male		Sex absent	Total	
	n	%	n	%	n	n	%
Gestational diabetes	23	18.9	-		8	31	16.6
Glucose intolerance	15	12.3	11	20.4	3	29	15.5
Type 2	84	68.9	43	79.6	-	127	67.9
Total	**122**	**100.0**	**54**	**100.0**	**11**	**187**	**100.0**

Source: Cree Diabetes Information System.

Table A7.3 Distribution of cases from the Cree Diabetes Information System not linked to the FIPA, by community of residence and sex

Community of residence	Sex						
	Female		Male		Sex absent	Total	
	n	%	n	%		n	%
Chisasibi	29	23.8	11	20.4	2	42	22.5
Eastmain	3	2.5	2	3.7	-	5	2.7
Mistissini	46	37.7	19	35.2	6	71	38.0
Nemaska	3	2.5	1	1.9	-	4	2.1
Oujébougoumou	4	3.3	-	-	-	4	2.1
Waskaganish	12	9.8	5	9.3	1	18	9.6
Waswanipi	13	10.7	4	7.4	2	19	10.2
Wemindji	6	4.9	4	7.4	-	10	5.3
Whapmagoostui	5	4.1	7	13.0	-	12	6.4
Outside Eeyou Istchee	1	0.8	1	1.9	-	2	1.1
Total	**122**	**100.0**	**54**	**100.0**	**11**	**187**	**100.0**

Source: Cree Diabetes Information System.