A B S T R A C T

The Ontario Region of the Medical Services Branch, Health Canada, comprises approximately 63,000 First Nations people living on reserve in 126 First Nations communities. As of January 1997, 39% of these communities have either assumed control of the delivery of health services or are in transfer negotiations with the federal government. Another 17% have entered into an Integrated Community Based Health Services Agreement with the federal government, which could culminate in a full transfer agreement. In order to provide First Nations with timely access to health information for case management, program planning and evaluation, and the development of their own program priorities at the community level, Medical Services Branch, Ontario Region, has worked in partnership with First Nations to develop a comprehensive, computerized Health Information System (HIS). With direct access to a reliable epidemiological database, First Nations will be able to re-profile available resources in response to their own identified community health priorities.

A B R É G É

La Direction générale des services médicaux de Santé Canada pour la région de l'Ontario comprend environ 63 000 personnes des Premières nations qui vivent dans 126 communautés des Premières nations. En janvier 1997, 39 % de ces communautés assumaient le contrôle de la prestation des soins de santé ou négociaient avec le gouvernement fédéral le transfert de ces services. Un autre 17 % a conclu avec le gouvernement fédéral des accords en matière de services communautaires intégrés, qui peuvent aboutir à un accord de transfert complet. Pour permettre aux Premières nations d'accéder en temps utile à l'information sur la santé, en vue de la gestion des cas, de la planification et de l'évaluation des programmes et de la fixation de leurs priorités de programme au niveau communautaire, la Direction générale des services médicaux de la région de l'Ontario a travaillé en partenariat avec les Premières nations à mettre au point un vaste Système informatisé d'information sur la santé. Ayant accès directement à une base de données épidémiologique fiable, les Premières nations pourront réaménager les ressources disponibles en fonction des priorités de la santé communautaire qu'elles auront elles-mêmes fixées.

The Development of a Computerized Health Information System to Facilitate Program Planning/Evaluation and Enhanced First Nations Control of Community Health Services

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The Ontario Region of the Medical Services Branch (MSB), Health Canada, comprises approximately 63,000 First Nations people living on reserve, more than 70% of whom are less than 40 years of age. As of January 1997, 49 (39%) of the 126 First Nations communities in Ontario Region have either assumed control of the delivery of health services or are in the process of transfer negotiations with the federal government. Another 22 (17%) have entered into an Integrated Community Based Health Services Agreement with the federal government, which could ultimately result in a full transfer agreement (data obtained from the Program Transfer and Self-Government Unit, MSB). As First Nations assume control of the planning and delivery of their own community health programs, they will require access to a reliable epidemiological database in order to establish their own community-based program priorities and to perform effective program planning and evaluation.

In 1988, an assessment of the previous five years of health-related data for the First Nations population in Ontario Region revealed many inconsistencies in data collection practices. This assessment highlighted the need to develop a comprehensive Health Information System (HIS) that would standardize data collection practices and improve the reliability of the data available for program planning and

evaluation. Given that First Nations are required to evaluate their community health programs after transfer,^{1,2} MSB Ontario Region has worked in partnership with First Nations since September 1993 to develop a comprehensive, computerized HIS to facilitate this program evaluation process. A review of the literature conducted during the initial stage of the HIS Project revealed that no such system had as yet been developed.

This article provides a description of Ontario Region's HIS and demonstrates how the system can facilitate case management, program planning and evaluation activities, and enhance First Nations control of the delivery of community health services.

What is the Health Information System (HIS)?

The HIS is a very secure, Oracle relational database, which was developed in the mousedriven, Windows environment. Data are stored on a server at the MSB Regional Office in Ottawa and are accessed via personal computers by authorized HIS users at the level of the community, Tribal Council, First Nations Health Authority, MSB Zone or Regional Office. No one can log on to the system without a legitimate user ID and password, and several security measures, such as data encryption, have been incorporated into the HIS application to preserve client confidentiality.

The system comprises 13 subsystems: Client Core Information, Immunization, Reportable Diseases, Psychosocial, Chronic Diseases, Maternal Health, Environmental Health, Abuse Profile, Test/Exam, Medication, Medication Allergies/Adverse Reactions, Public Health Education and Client Mortality Information. Data for

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these subsystems are collected according to standard clinical and public health practice. For example, the Immunization Subsystem is based on the guidelines of the National Advisory Committee on Immunization.³ Similarly, the Reportable Diseases Subsystem is based on the Province of Ontario's list of reportable diseases, as defined under the *Health Protection and Promotion Act*, 1983.⁴ Diseases entered into the Reportable Diseases Subsystem are defined according to the standardized case definitions of the Laboratory Centre for Disease Control⁵ and are classified according to the ICD-9.⁶ In addition, psychiatric diagnoses entered into the Psychosocial Subsystem are based on the DSM-IV,⁷ while data for the Maternal Health Subsystem are captured from the Antenatal Record 1⁸ and Antenatal Record 2,⁹ which are routinely used throughout Ontario. Finally, the Drinking Water Database within the Environmental Health Subsystem is based on Health Canada's Guidelines for Canadian Drinking Water Quality.¹⁰

Data for most of the 13 subsystems will be entered prospectively as on-reserve clients access services at MSB or transferred health facilities. However, certain subsystems required the back-entry of historical data. For example, the production of immunization schedules is based on a client's past immunization history, which means that client immunization data that were available in each community had to be entered into the Immunization Subsystem. Similarly, historical chronic disease data were entered into the Chronic Diseases Subsystem, and old tuberculosis data were entered into the Tuberculosis Registry within the Reportable Diseases Subsystem. Relevant hospital data (e.g., birth data, treatment information) can be obtained from the two federally funded hospitals in Ontario Region (i.e., the Sioux Lookout Zone Hospital and Weeneebayko General Hospital) for entry into the HIS. However, data collected at provincially operated hospitals are not routinely available, unless linked to a client who was referred from a Medical Services Branch or transferred health facility.

Through an arrangement with the Public Health Branch of the Ontario Ministry of Health, laboratory reports for reportable dis-

eases that were diagnosed in the on-reserve First Nations population by physicians who practise off reserve are routinely forwarded by public health units to authorized MSB- or First Nations-employed public health staff. This helps to ensure that there is appropriate case management, contact tracing and follow-up of all affected clients who live on reserve. Reportable disease data for these clients are entered into the HIS, and aggregate reports are submitted on a quarterly basis to the Ministry of Health.

In order to minimize the risk of duplicate clients being entered into the HIS database, the Ontario Health Card Number is used as a unique client identifier, and the system performs a "mod 10" check to ensure that only valid 10-digit health card numbers can be entered. The system also tracks the movement of clients from one community to another so that a highly mobile client will only be counted once in the database. As well, clients are allowed to have many alias names associated with one specific "known as" name. This means that a client can have many different names recorded within the database, but these names are linked to only one individual who has one specific client file.

Ideally, each client should have a health card number recorded in the system as the unique identifier. However, when the Client Information Subsystem was established using client data available at the community level, only 60% of the clients had health card numbers available. Many clients were therefore entered according to family name, given name, date of birth and gender. When these four parameters are used to trace a client, the HIS initiates a "Soundex" process that identifies potential client matches. The HIS user must then decide which of the potential matches corresponds to the client in question. As a result, it is possible for an already existing client to be entered as a new client because of a minor variation in the client's date of birth or in the spelling of the family name or given name. Fortunately, this has not been found to be a frequent occurrence. Duplicate clients can be identified for deletion by the System Administrator through the periodic review of the HIS Population Validation Report, which is a report that provides each community with a line listing of all clients registered

in the system for that specific community. Being able to look for clients by the health card number alone would eliminate the possibility of an inadvertent entry of duplicate clients into the database; thus the procurement of all missing health card numbers in the HIS database is a top priority.

Facilitation of case management, program planning and evaluation, and enhanced First Nations control of community health services

General principles

Each of the 13 HIS subsystems is associated with aggregate and/or client-specific reports that can be easily produced at the level of the community, zone or region, without the need for computer programming skills on the part of the person requesting the report. Security measures have been incorporated into the HIS application so that no community or zone can produce reports based on another community or zone's data. In addition, each HIS user is granted access to the various reports according to that individual's need to know, as determined by the role that he or she plays as a member of the community-based health team.

Client-specific reports

With access to various client-specific reports in the Health Information System, it is anticipated that health care providers will be able to conduct case management more effectively. The HIS reports are intended to facilitate the appropriate management and follow-up of clients with a diagnosis of various acute or chronic health conditions. The following are several examples of client-specific HIS reports that can be used for case management purposes:

- Client Drug Resistance Record
- List of Clients With Recurrent Diseases
- List of Clients With Incomplete Tuberculosis Treatment
- List of Clients With Mantoux Results ≥ 10 mm
- List of Clients With a Previous History of Tuberculosis
- Follow-up Schedule for Clients With Sexually Transmitted Diseases (STDs)
- List of Clients With Consultant's Review Pending

This report is used to ensure that clients with a diagnosis of certain psychiatric conditions made by a family physician (e.g., borderline personality disorder, dissociative identity disorder) have had that diagnosis reviewed by a specialist.

- Client Follow-up Schedule
- Client-Specific Chronic Disease Profile
- Client-Specific Environmental Health Profile

This report provides information about the water supply, sewage disposal, garbage disposal, housing condition, environmental contaminants, etc., associated with a particular client's place(s) of residence.

Aggregate reports

The availability of aggregate reports at the level of the community, zone and region facilitates program planning and evaluation activities at all levels. These reports can assist community health planners with the development of measurable objectives for specific community health programs (e.g., STD Control, Immunization and Vaccine-Preventable Diseases) and can generate comparison data at a future date for program evaluation purposes. The following are examples of some of the HIS reports that can be used for program planning and evaluation:

- Incidence Reports by Disease/Condition, Age and Gender
- Prevalence Reports by Disease, Age and Gender
- Incidence of Chronic Disease Complications Report
- Suicide Registry Reports

These are descriptive reports pertaining to completed and attempted suicides (including the location, method(s) used, drug(s) implicated, risk factors identified, seasonal trends, etc.)

- Immunization Coverage Statistics Report
- Community-Specific Environmental Health Profile

This provides information about a community's water supply, sewage disposal, garbage disposal, housing conditions, environmental contaminants, etc.

Enhanced First Nations control of community health services

The Health Information System has the potential to provide First Nations with a

significant degree of autonomy from the Medical Services Branch structure with regard to access to health information for case management, program planning and evaluation, disease surveillance and the development of their own community-based program priorities. With access to the HIS, First Nations will be able to re-profile available resources in response to their own identified community health priorities. This is particularly relevant to First Nations that have assumed control of the delivery of community health services via a transfer agreement with the federal government. Since the data are stored on a server at the Regional Office, it is conceivable that this server will some day be transferred to a regional First Nations organization (e.g. an Aboriginal Health Commission). When this does happen, First Nations will be able to exercise true ownership of their data.

Where do we go from here?

Now that the development of the Health Information System has been completed, the primary focus can be shifted from development activities to the implementation of the system in First Nations communities across Ontario Region. As well, depending on the availability of additional resources, the existing HIS application could some day be enhanced through the incorporation of a graphics capability into the reports generator and by exportation of data into another software package (e.g., Epi Info) for statistical analysis. A fourteenth subsystem (i.e., Acute Health Conditions) could also be developed to capture information about acute illnesses or conditions (e.g., ear infections, impetigo, unintentional injuries, etc.) occurring in the First Nations population, which means that the HIS would be able to provide a more complete morbidity profile.

Transferred and transferring communities in Ontario Region have incorporated the HIS into their transfer agreements because they have recognized the need for a reliable epidemiological database. With direct access to a comprehensive Health Information System, it is anticipated that First Nations will be empowered to establish their own community health program

priorities and to perform effective program planning and evaluation.

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