



Message From The Co-Chairperson The Roadmap for Health Information

In early 1998, the Federal Minister of Health's Advisory Council on Health Infostructure, the Canadian Institute for Health Information (CIHI), and Statistics Canada (STC) brought together some 550 health administrators, researchers, caregivers, government officials, health advocacy groups and consumers to identify Canada's health information needs. The result of these consultations was a national vision and action plan for strengthening Canada's health information system.

Among the priorities identified was the need to:

- better track information on major current and emerging health issues;
- reach consensus on common data and technical standards to enable researchers to more easily share comparable findings and results;
- address problems of fragmented or incomplete data;
- improve the analysis of health information being captured; and,
- more broadly disseminate health information in order to realize its potential for improving the health of Canadians and of their health care system.

In late 1998, this vision for health information was presented to and endorsed by the Federal, Provincial & Territorial (FPT) Conference of Deputy Ministers of Health. To give expression to this vision, which subsequently became known as the Roadmap Initiative, the 1999 Federal Budget identified a number of specific priority projects and activities in the health information field and earmarked \$95 million over the next three to four years toward their completion. These contributions will be used to expand or accelerate certain ongoing national health information initiatives and to support new ones. The Roadmap is a collaborative effort between CIHI (and through them, Canada's health ministers), Statistics Canada, and the Federal government.

The specific projects that will be undertaken as part of the Roadmap will follow these general principles:

- support or facilitate the generation of information which serves to improve the quality, cost-effectiveness and accessibility of health care services in Canada;
- provide a foundation for measuring performance and outcomes linked to health care and a better understanding of the non-medical determinants of Canadians' health;
- enable the creation, analysis and dissemination of the best possible "evidence" from across Canada and around the world as a basis for informed decisions by patients, citizens, informal caregivers, health professionals, providers, managers, and policy-makers; and
- assist individuals and communities to make informed choices about their own health, the health of others and the future of Canada's health system.

The vital statistics information system will be an integral component of the Roadmap Initiative. One of the specific projects identified in the Roadmap proposals concerned the information on births and deaths. These data provide some of the key health indicators and essential health outcome information for evidence based decision-making. The specific projects that will be undertaken need to be determined and planned as part of the regular consultation process through the Vital Statistics Council. There are several areas that can be considered, such as improving the quality of death certification, increasing the ability to provide data at the local or health district level and ensuring that the vital statistics data is integrated into the evidence based culture that underlies the roadmap projects. The Council is also investigating improvements to the system through the electronic registration of events.

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We are fortunate in vital statistics that we have a high quality information system. However, there are areas that can be improved and the data that is produced in the system needs to become integrated into the regular decision making and analysis that is part of the new investment in health information. ♦

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The Dec (Registrar): Involved in the lives of citizens for the past five years!

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Our agency, the Registrar of Civil Status, is celebrating its 5th anniversary this year and we are proud of it. It was in January 1994 that the Registrar fell heir to this management process that dates back 375 years: 17 million acts, divided into 425,000 registers, spread out in over 3,600 different parishes and municipalities. In fact, some 8,000 civil and religious officials were acting as representatives of the State in matters of civil status. A duplicate of each register was delivered to the ministère de la Justice. These acts were neither computerized nor indexed, which made it a lengthy and complicated process to serve our clientele: the entire Québec population.

Since 1994, the management of the office of the Registrar of Civil Status has undergone major changes. There is now only one civil status officer, a single teller services for all citizens. Moreover, from now on the parents themselves fill out the declaration of birth of their child and are therefore responsible for establishing the child's legal identity. The register is still maintained in duplicate as before, but it is now based on a single declaration. One copy consists of the declaration, completed and signed by the parents, the other includes the information concerning the declaration on computerized support. Today's register also allows to establish links between the different events (birth, marriage, death) occurring during the life of a single individual. Formerly these were not paired, which made any research virtually impossible.

During these five years, our overall operations allowed us to develop several projects to serve our clientele even better. We should mention that the creation of numerous partnerships with various public, private and community departments and agencies offering related services, were central to the orientations and activities that needed to be

developed in order to improve services to the population. We should also mention the huge project to digitize old registers, undertaken in 1997, which allows for the indexation of the register of civil status' 8.3 million acts out of a total 17 million registered acts. This step helps bring constant quality improvement and more dependability in the data issued for the years prior to the reform of the civil status. This work is being carried out according to plan and should normally be terminated by the end of March 2000.

This state-of-the-art expertise developed in Québec by Québécois, has allowed us to share our know-how with the Service central de l'état civil de Nantes, in France, and to stir up interest in other Francophone countries. We should speak also of our use of new information technologies which will help us serve the population in or outside Québec by offering an even wider range of services: access to our Internet site and also the opportunity for citizens to process a request for certificate electronically. Finally, the testing of telecommunications terminals in partnership with Bell Canada and the Université du Québec à Montréal has helped make our services more easily available to the students of this large university campus.

All this... and more - about the bug of the year 2000, and the fact that even before "his birth", the Registrar of Civil Status proved to be a visionary by ensuring the continuity and preserving the quality of its services.

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Using Vital Statistics Data for Administrative Purposes

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It is widely acknowledged that birth, marriage, death and stillbirth data are one of the oldest and single most important sources of health data available. It is also recognized that these records are essential for establishing an individual's legal identity for a number of provincial and federal programs such as Medicare, social assistance, survivor's benefits, old age pension, registration of first nations people, obtaining passports and for participating in the election process. What is not often considered is that the value of vital statistics data goes beyond the registration of events and production of certificates.

The purpose of this paper is to discuss current and potential administrative uses for vital statistics records and how the changing needs of society, combined with a focus on customer service, advancements in technology and fiscal pressures, are causing governments to re-think the way vital statistics data may be used in the future. It is worthwhile noting that even in the current environment of government re-structuring and devolution, the responsibility for vital statistics has been re-affirmed as a core business and has been fundamentally retained as a government responsibility.

The traditional mission of vital statistics agencies encompasses three principal functions: a) registering and storing vital event information; b) providing certificates as legal proof of births, marriages and deaths; and c) compiling data for statistical reports for provincial and federal agencies.

While birth, marriage, death and stillbirth records may have originally been created for the purposes of civil registration and the production of health statistics, it is now accepted that they may provide a valuable source of data verification for the delivery and administration of major programs and services such as social assistance, child support payments, child tax credits, the social insurance system, Medicare eligibility, law enforcement and social policy development. In support of this statement, a few examples of the administrative uses of vital statistics records are discussed.

The first example illustrates how death records combined with other sources of data can result in savings to taxpayers and reduce duplication of effort at all levels of government (i.e. federal, provincial and municipal). Elections Canada and the country's provincial and territorial governments negotiated precedent-setting agreements to establish a National Register of Electors. The provincial/territorial vital statistics offices provide death data to Elections Canada on a regular basis, which is used to maintain the accuracy and currency of the Register. These data-sharing agreements will eliminate the need to enumerate for federal, provincial and municipal elections, resulting in savings to taxpayers. As well these agreements will pave the way for future data-sharing relationships between provincial and federal agencies to better serve the public interest.

The second example describes how vital statistics records have been used to enhance public safety through the implementation of the *Community Safety Act* in Ontario. The *Community Safety Act* was

enacted to facilitate the exchange of name change information between Ontario's vital statistics agency and its justice department. Personal information provided by all persons applying for a name change is shared with justice officials who cross-reference the data against the Canadian Police Information Centre (CPIC). Individuals whose information matches CPIC records are then required to submit a police records check before the name change application will be processed. Upon completion of the name change for these individuals, the vital statistics agency notifies the justice department of the old and new names. The justice department, in turn, forwards the new information to CPIC where the police records are updated. This ensures that individuals cannot evade the justice department by changing names. The exchange of information between the two provincial agencies promotes enhanced public safety.

A third example of the administrative use of vital statistics records relates to the implementation of changes in social policy. The US government passed a law that would disqualify legal and illegal immigrants from a broad array of services including student loans. School administrators are required to verify the citizenship of all students and beneficiaries. Birth certificate information remains the single most reliable source of verification.

A fourth example illustrates how vital statistics records can be used to strengthen child support enforcement. In response to pressures for welfare reform, the US Government passed legislation that, except in certain circumstances, disqualifies children that do not have legally established paternity from social assistance. Birth certificate information has great potential for establishing paternity.

The significance of birth and death data in preventing abuse, misuse and fraud was recently articulated in the Report of the Auditor General of Canada to the House of Commons (September 1998). Human Resources Development Canada in partnership with the New Brunswick government has recently completed a six-month pilot project that allowed on-line verification of birth and name change information submitted by Social Insurance (SIN) applicants. The SIN applicant's information was verified on-line against the province's death data to ensure that the individual applicant had not been reported as 'deceased'. The report notes that extending this project to other provinces and territories could enhance the overall reliability of the SIN database, which in turn affects the outcomes for organizations that use the SIN database.

It is recognized that administrative use of vital statistics data raises increased concerns about privacy and confidentiality. It also poses challenges for vital statistics agencies to improve protection for linked data. Data sharing and data linkages require greater collaborative efforts between and across provincial and federal agencies. It becomes increasingly important that when utilizing linked data, safeguards are used to ensure that linked data is accessible only by the right people at the right time for the right purpose. Privacy issues may generate public debate over how personal information should be used, beyond its original purpose. Privacy implications must be assessed and addressed using a consultative approach with all parties involved and affected. It is encouraging to note that the communities of people charged with safeguarding personal privacy have begun to recognize the use of the data for other purposes. A recent conference hosted by Ontario's Information and Privacy Commission on Access and Privacy: The "New Way of Doing Business" focused on data matching, data mining and warehousing.

The administrative use of the vital statistics data holds implications for vital statistics agencies by opening up new possibilities for improvements in data collection, compilation and distribution. It challenges vital statistics agencies to expand their mandate and redefine their stakeholders and customers. The value of vital statistics data is directly related to its timeliness and accuracy. Improving data flow and reducing error rates improves the value of vital statistics data. Re-engineered systems using electronic registration would improve the accuracy and timeliness of the data.

Increasing public expectations of government effectiveness, changes in social policy and Medicare and the need for integrated service delivery networks have combined to create a new demand for the administrative use of vital statistics data. Advances in technology, re-engineered collection systems and government's general commitment to 'do more with less' have combined to spark this dialogue which may see the vital statistics agencies' previous role of producing documents and aggregate data changed to that of an active participant in the effective and efficient administration of a broader slate of government programs and services. ♦

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Council Input in United Nations Document

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In July 1998, an Expert Group was convened by the United Nations (UN) to review a draft of the *Principles and Recommendations for a Vital Statistics System* which had last been revised in 1973. The review took place November 16 - 20, 1998, at the UN Secretariat in New York. Alice Garner, immediate Past Chairperson of the Vital Statistics Council for Canada and Registrar General for the Province of New Brunswick, and Marianne Wiesel, also a Past Chairperson of Council who has previously worked as a consultant to the UN, were invited to join the Expert Group.

The Principles and Recommendations for a Vital Statistics System is intended to serve as a basic guide to countries for the purpose of organizing, operating and maintaining reliable vital statistics systems derived from civil registration data. The guide also contains alternate options for use in countries with weak or absent registration systems. The task required the incorporation of technological developments since the early 1970s, as well as the latest updated concepts, definitions and classification systems as they relate to health, social and demographic statistics.

The Expert Group consisted of 20 stakeholders from all areas of the world. Countries represented included Argentina, Brazil, Canada, Finland, France, India, Iran, Japan, Kenya, Madagascar, the Philippines, the United Kingdom, and the United States. In addition, there were a number of officials from the various UN agencies, such as the World Health Organization (WHO), the Pan American Health Organization, the UN Population Fund (UNFPA), UNICEF and the UN Statistics Division, all of which are interested in the data. Robin Andrianasolo of Madagascar was elected Chair of the group and Judith Walton of the United Kingdom was elected general rapporteur. K.E. Vaidyanathan of India, George Gay of the United States, Jose Miguel Guzman of UNFPA and Alice Garner of Canada acted as rapporteurs of individual chapters.

The Secretariat introduced the document by stressing the importance and need for vital statistics of an appropriate quality and timeliness. The need for standard definitions to enable international comparisons was emphasized, as well as the importance of ongoing training and public education. It was pointed out that the *Principles and Recommendations for a Vital Statistics System* must be used in conjunction with various UN handbooks on civil registration and vital statistics systems, that provide the detail required to implement the recommendations.

As a group, conclusions and recommendations were reached by consensus, following a somewhat lengthy discussion in some cases. An eloquent plea was made for the need to address issues of gender, age, illegitimacy and other sensitive matters in the collection and dissemination of data, and in particular, to pay more attention to the registration of girl babies in cultures where there is a differential between the sexes. Many of the topics discussed have been addressed around our own Council table, such as the need for standards and uniform data, comparability, the need for adequate resources for the program, including a comprehensive data quality program, and security/confidentiality issues. It was refreshing to hear the researchers and demographers affirm, time and again, the importance of the program, the fact that there is no replacement for it, and that the position of the registrars must be enhanced to enable them to carry out their mandates. It was also felt that the role and involvement of health departments in the registration process should be strengthened. A report of the group's recommendations has been

prepared for presentation to the 30th session of the Statistical Commission March 1-5, 1999.

During the meetings, a number of UN publications were made available for reference, including a global report on natality and mortality. A quick check of the section on Canada showed the births and deaths, neatly tabulated into columns by age and sex, proof that our data reaches the highest level of publication and an affirmation of the importance of the work we perform in our offices on a daily basis.

We found the experience to be stimulating and thought provoking. Reference was often made to the 40 million children born annually throughout the world who go unregistered, depriving them of the rights enjoyed by citizens in countries where civil registration is complete. In this 50th anniversary year of the proclamation of the Universal Declaration of Human Rights, it is appropriate that this project should be undertaken in an effort to address these problems. No global publication on natality and mortality can be complete without the inclusion of vital events concerning all citizens of the world. In turn, such an achievement would significantly enhance the reports on health statistics produced by the various organizations represented at these meetings, as well as at the local level. Identifying data deficiencies in reports on the health status of populations may result in reallocation of resources which could contribute to improving the health of all citizens of the world. ♦

ON A TYPICAL DAY IN ONTARIO IN 1997

The following events were recorded:

362 LIVE BIRTHS OCCURRED IN THE PROVINCE OF ONTARIO:

- 186 males and 176 females were born
- 62 were born to single mothers
- 19 were born to teenage mothers (<= 19 years)
- 8 were multiple births
- 80 multiple births occurred every 10 days
- 12 were low birth weight babies (<=2500 grams)

2 STILLBIRTHS OCCURRED IN THE PROVINCE OF ONTARIO:

- 26 occurred every 10 days
- 18 occurred each week

5 ADOPTIONS OCCURRED EACH DAY IN THE PROVINCE OF ONTARIO:

216 DEATHS OCCURRED IN THE PROVINCE OF ONTARIO:

- 110 males and 106 females died
- 2 were infant deaths (<1 year old)
- 79 deaths were due to diseases of the circulatory system, including:
 - 57 from heart diseases
 - 17 from cerebrovascular diseases
- 52 deaths were due to cancer, including:
 - 14 lung cancer
 - 5 breast cancer
 - 5 colon cancer
 - 1 brain cancer

19 deaths were due to diseases of the respiratory system, including:

- 8 deaths from pneumonia/fluenza
- 7 deaths from chronic obstructive pulmonary disease

13 deaths resulted from accidents and violence, including:

- 8 motor vehicle accidents
- 2 accidental falls
- 2 suicides
- 3 murders occurred every 10 days

6 deaths were from diabetes

4 deaths occurred every week from AIDS/HIV infections

6 deaths were from leukaemia and lymphoma

3 deaths were from Alzheimer Disease

177 MARRIAGES WERE SOLEMNIZED IN ONTARIO:

116 marriages where bride & groom were marrying for the first time

20 marriages where bride & groom were previously divorced

6 marriages occurred each week where bride & groom were teenagers (<=19 years)

11 were civil marriages, 15 by banns, and 151 by licence

13 change of names occurred due to marriages

17 were formal change of names

Source: Office of the Registrar General, Ontario

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