

# National Committee on Vital and Health Statistics

## Overview – Importance and need for vital records: local, state, federal, international

### Written testimony submitted by:

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I am grateful for this opportunity to provide an international perspective on some of Canada's successful initiatives with regards to civil registrations and vital statistics. This written testimony provides complimentary information to the slides used during my presentation at the September 11<sup>th</sup>, 2017 meeting in Washington D.C.

### *Vital statistics in Canada (slide 1)*

All birth, death, stillbirth and marriage events occurring in one of the ten provinces and three territories in Canada are recorded by the provincial and territorial vital statistics registrar of the jurisdiction of occurrence. Each provincial and territorial Vital Statistics Agency (VSA) is governed by its own Vital Statistics Act and other relevant legislation.

Over the last decade, there has been a migration of the VSA's from provincial Health Departments in the favor of Service Departments. This has an effect on the VSA mandate which is now focused on service delivery standards. Three provinces and the territories are still housed under their Health Departments.

Statistics Canada has been collecting and releasing national data on births, deaths, and stillbirths since 1921. The data are collected, released and disclosed under the Statistics Act. The Canadian Vital Statistics Databases (births, deaths, stillbirths) contain information obtained from the provincial and territorial VSA's who collected the data for their own administrative and/or statistical or research purposes. The collection and dissemination of marriage and divorce data was discontinued in 2010, following a strategic review. The data collected by Statistics Canada can only be used for surveillance, research, analysis, quality assurance, program evaluation, or statistical purposes. Administrative use of the data such as using the information about an individual in a decision making process, is not permitted.

Canada is a mosaic of cultural backgrounds, with two official languages, a vast geographic domain, small population and many jurisdictions. The population of Canada is estimated at 35,852,000 which is roughly the size of California. Only six of the 13 jurisdictions have a population greater than 1 million people while the smallest have less than 45,000.

### *Vital Statistics Council for Canada (slide 2)*

The cornerstone of Canada's national system of vital statistics is the cooperation and collaboration among the provincial and territorial civil registrars and the federal government of Canada represented by Statistics Canada. The partnership was created in 1919 following two conferences on the establishment of a national system for vital statistics wherein the principles of mandatory registration and national-provincial collaboration were affirmed. In 1945, the Vital Statistics Council for Canada (VSCC), comprised of representatives from all provinces and territories and Statistics Canada, was established as the formalised body responsible to ensure the uniform collection, compilation and dissemination of vital statistics across the country.

### *National Routing System (slide 3)*

The National Routing System (NRS) is a set of technical and messaging standards that define what and how information will be transferred from the data provider to the receiving party. It is point to point and based on bilateral agreements between both partners. This ensures that the data provider retains control over the information it has the legislative authority to send and that the receiving party only receives information it has the legislative authority to receive. Implementation began 10 years ago and continues today.

The NRS partners include the provincial and territorial VSA's as well as three Federal Departments: Statistics Canada, the Canada Revenue Agency, and Service Canada. Additional federal partners such as Immigration, Refugees and Citizenship Canada (Passport Canada), and Indigenous and Northern Affairs Canada plan on joining the NRS over the next few years.

The implementation of the NRS allowed for better integration of civil registrations, vital statistics and identity management through service bundling. Service bundling enables various federal and provincial departments to improve service to clients by delivering programs without developing completely separate systems for each program. For example, when a parent fills out a birth registration form, they can indicate whether or not they would like to apply for a social insurance number for the newborn and for federal benefit programs to which they may be entitled. This information is captured by the provincial register as part of their registration process and the automatically and concurrently distributed to the appropriate federal government department through the NRS. This integrated service motivates early birth registration and has proven popular with parents as they only have to provide the information once in order to register their child's birth and access key federal services.

Service Canada also uses the NRS to validate birth certificate information submitted in support of a social insurance number application. This reduces the potential for fraud as the information that is on the birth certificate must match the information in the provincial civil registers. Federal departments enjoy cost savings and are assured of the integrity of the information as it is provided directly by the provincial issuing authority.

The Canada Revenue Agency and Service Canada also receive timely death notifications through the NRS. Both organizations rely upon this data for the integrity of their programs. For Canada Revenue Agency, these data help to reduce overpayment of benefits. Similarly, for Service Canada, the integrity of the data that are maintained in the Social Insurance Register is enhanced to reduce overpayment by programs that rely upon this information, such as the Canada Pension Plan. Receipt of death data also provides a springboard for survivor benefits.

Birth, death, and stillbirth notifications are sent in near real-time to Statistics Canada. The standardized format in which the data are received greatly improves the efficiency in processing the data as well as reduces the need for time consuming manual corrections. Some jurisdictions have begun exchanging death notification information among one another.

Developmental and infrastructure funding for the NRS is shared among the three federal departments. This helps mitigate some of the risk related to budgetary constraints that a partner might experience during a particular fiscal year. Furthermore, since the data provider receives payment from each partner for each notification sent, the funding responsibility is shared among the federal departments that use the information.

Although the point-to-point model has a high burden with regards to the number of agreements and number of connections that are required, it holds many advantages. The point-to-point model eliminates the requirement for federal partners to wait for the annual file to be officially released by Statistics Canada prior to accessing the data for their needs. This in turn eliminates the restriction in the Statistics Act around the use of the data for administrative. Furthermore, it ensures continuity for the system as several partners have a vested interest in protecting their investment.

#### *Governance of the NRS (slide 5)*

The NRS is governed by a Steering Committee which is composed of a subset of federal, provincial and territorial partners. Sub-committees are formed to address specific technical and message standard issues such as gender identity (introduction of “X”), the development of change of name and change of sex notifications, the inclusion of aboriginal characters. The NRS project management office is housed under Statistics Canada.

#### *Canadian Coroner and Medical Examiner Database (slide 6)*

The Canadian Coroner and Medical Examiner Database (CCMED) is a complimentary data source for vital statistics. The CCMED is the result of a collaborative effort between the 13 provincial and territorial chief coroner and chief medical examiner offices, the Public Health Agency of Canada, and Statistics Canada.

The vision is to have a national database of standardized information on the circumstances surrounding deaths reported to and investigated by coroners and medical examiners in Canada to contribute to a decrease in preventable deaths in Canada.

It is a standardized subset of death data investigated by coroners and medical examiners, which represents approximately 16% of all deaths. The CCMED collects additional detail on circumstances surrounding the death (activity at the time of death, place of event leading to death, place of death, external factors, safety devices, and whether there were multiple deaths linked to one event).

The provincial and territorial chief coroner’s and chief medical examiner’s offices map the data on open and closed cases from their systems to a minimum dataset containing basic information available on all deaths. The data are sent to Statistics Canada bi-annually.

The CCMED went into production on March 1<sup>st</sup>, 2008 and began collecting data starting with the 2006 death year. Today, CCMED contains data on 324,605 open and closed cases from 11 jurisdictions from 2006 – 2017.

### *Continuum of data access (slide 7)*

It is the policy of Statistics Canada that every new cycle of every statistical program, whether based on surveys or administrative data, whether funded through estimates or cost recovery, must be released in *The Daily* before it can be disseminated to the public.

The Statistics Act clearly sets out rules governing microdata access. There are two main ways in which vital statistics data can be accessed at Statistics Canada: remote access and Research Data Centers.

Remote access is useful for researchers who need access to more detailed data than is available on CANSIM and who cannot access the data elsewhere. It provides researchers with approved research proposals access to master data files. Researchers are provided data documentation, variance programs, and a dummy data file to prepare and test their SAS/SPSS/STATA programs which are then submitted to be run on the master file. Results are vetted, confidentiality rules are applied (rounding to base 5) and then sent to the researcher.

Research Data Centres (RDC) are secure data laboratories located in 26 universities across Canada and 1 research institute in Yellowknife. The Centres are financed by the universities and funding councils, and are operated by Statistics Canada. Academic and government researchers apply to gain access to the data housed in the RDCs. Currently social and health survey data and some administrative health and justice data are housed in the RDCs.

An important aspect of Statistics Canada's mandate is that we must work with other government departments - federal, provincial or municipal – and legal entities in the collection, compilation and publishing of statistical information. In working with these organizations we are also addressing another aspect of our mandate: to promote the reduction in the duplication of efforts in collecting statistical information. Data sharing is a means by which we do just that. Federal Research Data Centre (FRDC) provide a secure site where federal government employees can conduct complex statistical analysis. The FRDC simplifies the data access procedures for federal government employees. Support is provided by a Statistics Canada analyst.

Vital Statistics data, especially mortality data, are often linked to other datasets. The linkages are carried out in the in the social domain linkage environment where linking keys for different datasets (health, vital, census, tax...) are housed and can be brought together. Linked datasets are placed in the RDC's.

### *Privacy and confidentiality (slide 8)*

As mentioned previously, the Statistics Act outlines rules on data collection, dissemination and disclosure. Several policies (Microdata Access, Microdata Release, Information Management), directives (Data Sharing, Licensing, Record Linkage, Transmission of Protected information, Use of Deemed Employees) and Guidelines define what data can be accessed, by whom and under what conditions

### *Challenges in civil registrations which affect vital statistics (slide 9)*

Of the many issues and challenges faced by the provincial and territorial VSA's, we would like to highlight three that will have an impact on the vital statistics system. Many VSA's are faced with Human Rights complaints or Charter Challenges around the following issues:

- The collection of sex at birth information on the registration of birth and the display of sex/gender on the birth certificate.

- Amending parentage rules and birth registration laws to reflect family structures where children are conceived through assisted reproduction (e.g. surrogate), and where a child may have more than two parents
- Reclaiming aboriginal names as a result of the Truth and Reconciliation Commissions' Call to Action.