Administrative health data in Canada: lessons from history

Kelsey Lucyk*, Mingshan Lu, Tolulope Sajobi and Hude Quan

Abstract

Background: Health decision-making requires evidence from high-quality data. As one example, the Discharge Abstract Database (DAD) compiles data from the majority of Canadian hospitals to form one of the most comprehensive and highly regarded administrative health databases available for health research, internationally. However, despite the success of this and other administrative health data resources, little is known about their history or the factors that have led to their success. The purpose of this paper is to provide an historical overview of Canadian administrative health data for health research to contribute to the institutional memory of this field.

Methods: We conducted a qualitative content analysis of approximately 20 key sources to construct an historical narrative of administrative health data in Canada. Specifically, we searched for content related to key events, individuals, challenges, and successes in this field over time.

Results: In Canada, administrative health data for health research has developed in tangent with provincial research centres. Interestingly, the lessons learned from this history align with the original recommendations of the 1964 Royal Commission on Health Services: (1) standardization, and (2) centralization of data resources, that is (3) facilitated through governmental financial support.

Conclusions: The overview history provided here illustrates the need for longstanding partnerships between government and academia, for classification, terminology and standardization are time-consuming and ever-evolving processes. This paper will be of interest to those who work with administrative health data, and also for countries that are looking to build or improve upon their use of administrative health data for decision-making.

Keywords: Administrative data, Health services research, Health informatics, History
that aim to improve health information and enhance decision-making. We conclude our paper with recommendations for present-day research in administrative health data, which are drawn from the historical lessons that emerged in our analysis. This paper will be of interest to those who work with administrative health data and also those in other countries that are looking to build or improve upon their administrative health data.

Methods
We searched the academic and grey literature (e.g., PubMed, Google) for histories related to administrative health data, by using key words such as “health information,” “health statistics,” “administrative data,” and “history.” As we gained familiarity with our sources, we included more specific terms to identify additional sources (e.g., “Manitoba Centre,” “hospital morbidity database”). We used snowball sampling to further identify relevant research centre histories, individual biographies, and websites from provincial and national data centres from documents referenced by our sources. For brevity, we identified approximately 20 publicly available key sources (from ca. 80) that encapsulated historical trends in Canadian administrative health data. We conducted a qualitative content analysis of these sources, informed by historical methodology [5], following the methods put forth by Krippendorf. [6] According to Krippendorf, texts are considered artifacts of a given social and cultural context that affects how they are written, read, and interpreted. After a close reading of each source, we extracted content related to the events, individuals, challenges, and successes that emerged as pertinent to the history of administrative health data in Canada. We then compiled our findings to construct an historical narrative, spanning from 1847 to the present day (2015).

Results and discussion
A brief history of health statistics in Canada (1847–1964)
The collection of health-related statistics in Canada formally began in 1847 when the Census and Statistics Act of 1847 mandated the collection of vital statistics and information regarding land holdings, dwellings, and demographics [7, 8]. Initially, the census was a responsibility of the provinces, but became a federal responsibility when the country unified in 1867 [9]. This initiated the long-standing trend in Canadian health statistics of provinces reporting data to federal sources for compilation, analysis, and publication [7].

Two individuals are particularly important during this early history of health statistics. First, former Deputy Minister of Agriculture, Joseph Charles Taché (1820–1894), standardized the collection of information by census-takers, which allowed for comparable analysis across provinces for the first time [9]. Second, former Minister of Finance, Arthur Harvey (1834–1905), voluntarily collected and compiled various types of administrative statistics from government departments (e.g., hospitals receiving government grants, coroners’ inquests), which he published and sold to Canadians as the Year Book and Almanac of Canada [10]. Harvey’s Almanac was formally legislated and transferred to Taché’s Department in 1879 and published as the Statistical Abstract and Record [10].

Throughout the 20th Century, statistical operations in Canada became centralized. With cooperation from 8 provinces, a national system of vital statistics was established [8] with all provinces and territories involved by 1949 [8]. In 1948, former Dominion Statistician, Herbert Marshall (1888–1977), amended the Statistics Act to give the federal government authority to “collect, compile, analyze, and publish statistics” to include “hospitals, mental institutions, tuberculosis institutions, and charitable and benevolent institutions.” [11] However, while this was meant to provide timely and informative statistics, the implementation of Marshall’s Act was far from efficient.

As would later be identified in the 1961–1964 Royal Commission on Health Services (RCHS), the lack of communication between the Dominion Bureau of Statistics and other departments throughout the first half of the 20th Century resulted in the timely and often duplicated collection of statistics [11]. Justice Emmett Hall (1898–1995), Chair of the RCHS, identified in 1964 that Canada’s “main need was for national statistics and for data showing significant variations among provinces and regions,” and recommended a national, federally-financed clearinghouse be established to facilitate this [11]. The RCHS identified a number of solutions to improve the state of health statistics in Canada, which are listed in Table 2.

Recent developments in the history of administrative health data: HMRI and CIHI
In 1963, the Hospital Medical Records Institute (HMRI) was established to assist with the administration of provincial and federal hospital insurance plans in 1963 [12].

Table 1: Recommendations for Health Statistics, as proposed in the Hall Report, 1964

| Recommendations: |
|------------------|
| 1) federal financial support in consolidating existing registers; |
| 2) incorporating of modern data processing methods to analyze statistics; |
| 3) standardize classification of diseases, and social and demographic characteristics to facilitate comparability between regions; and, |
| 4) encourage timely publication of statistics and reports; and finally, |
| 5) establish a national clearing house and coordinating agency for health statistics [12]. |

From: Hall E. Royal Commission on Health Services. Ottawa: Queen’s Printer, 1964
The HMRI is important to the history of administrative health data particularly due to the methodological innovations it brought to this field. It encouraged the standardized coding of diseases and operations in accordance with the International Classification of Diseases, Adapted for Indexing Hospital Records (ICDA) among its participating institutions [12]. In 1983, the HMRI further increased comparability of health information with their introduction of Case Mix Groups (CMGs) [13]. CMGs allowed for comparisons between patient groups with similar resource-use or diagnoses, and estimations of length of stay and expected cost of care [13]. Eventually, the HMRI was transferred to CIHI to form a founding database of the DAD, in 1994.

The Bureau of Statistics also implemented a collection program for health information beginning in 1960—the Hospital Morbidity Database, which obtained data from

| Date   | Event                                                                 |
|--------|----------------------------------------------------------------------|
| 1847   | Census and Statistic Act of 1847                                      |
| 1879   | Year Book and Almanac of Canada statistics transferred to Department of Agriculture |
| 1884   | Bureau of Labour Statistics established                               |
| 1885   | Ontario and Québec hospitals begin collecting hospital data          |
| 1918   | Dominion Bureau of Statistics established                             |
| 1921   | Bureau establishes system of vital statistics for 8 provinces         |
| 1926   | Québec, the Yukon and Northwest Territories join the national system of vital statistics program |
| 1948   | Statistics Act amended to give Bureau authority to collect hospital data |
| 1949   | Newfoundland joins Canada, and its vital statistics program           |
| 1960   | Bureau establishes Hospital Morbidity Database                        |
| 1961   | Royal Commission on Health Services commences                         |
| 1963   | Hospital Medical Records Institute (HMRI) established                |
| 1964   | Royal Commission on Health Services ends                              |
| 1970   | HMRI expands to 5 provinces                                           |
| 1977   | HMRI become not-for-profit, includes standardized classification       |
| 1983   | HMRI develops Case Mix Groups                                         |
| 1988   | British Columbia Linked Health Data Project (BCLHDP) begins            |
| 1990   | Canadian Centre for Health Services and Policy Research (CHSPR) established |
| 1991   | HMRI collects information for 75 % of discharges from Canadian hospitals |
| 1994   | Canadian Institute for Health Information established                 |
| 1996   | CHSPR permitted access to BCLHDP data                                 |
| 2002   | Discharge Abstract Database covers 75 % of all inpatient discharges, for all provinces and territories (except QUE) |
| 2005   | ICD-10-CA and Canadian Classification of Health Interventions implemented by CIHI |
| 2008   | Population Data BC established                                        |
| 2009   | CHSPR transfers data holdings to Population Data BC                   |
| 2012   | 20th Anniversary of ICES and MCHP                                     |

Legend: HMRI is Hospital Medical Records Institute; BCLHDP is British Columbia Linked Health Data Project; CHSPR is Canadian Centre for Health Services and Policy Research; MCHP is Manitoba Centre for Health Policy; CIHI is Canadian Institute for Health Information; DAD is Discharge Abstract Database; QUE is Québec; ICD-10-CA is International Classification of Diseases, 10th revision, Canadian modification; ICES is Institute for Clinical and Evaluative Sciences; BC is British Columbia
provincial ministries of health [14]. However, the provinces favoured the services of HMRI’s centralized data processing system (compared to the Bureau’s edits for comparability), which led to its success [14].

In 1991, the National Health Information Council (NHIC), Conference of Deputy Ministers of Health, and Chief Statistician held a national inquiry into the state of health information [15]. At the time, four independent groups were responsible for health information, nationally: (1) the Canadian Centre for Health Information—a division of Statistics Canada; (2) the HMRI; (3) the Management Information Standards Group; and, (4) Health and Welfare Canada [15]. Thus, the NHIC recommended the establishment of a national coordinating council that represented non-government, government, and private sector organizations [15]. Eventually, this resulted in the 1994 founding of CIHI, implemented under the direction of the Health Infrastructure Consortium of Canada. CIHI formed large national databases by combining health information from the organizations listed above. CIHI currently maintains 27 pan-Canadian databases, and provides education, reporting tools, and strategies for its users [4]. It exists through partnerships with the federal government, and partners with all provincial and territorial Ministries of Health [16].

**Provincial centres for administrative health data research**
Three existing provincial health research centres have been pivotal to the development and history of administrative health data research in Canada. This section will briefly review the histories of centres in Ontario, Manitoba, and British Columbia (BC).

**The Institute for Clinical Evaluative Sciences (ICES)**
During the 1980s, the Ontario Medical Association (OMA) and Ministry of Health became interested in establishing a research centre that operated at arm’s length of the government to promote evidence-based health care [17]. David Naylor and Jack Williams of the Clinical Epidemiology Unit and Research program at Toronto responded in 1991 with a proposal for ICES, which would use administrative health data from the Ministry of Health for population-level research [18]. Their proposal was strengthened by the Ontario Health Insurance Plan’s recent issue of health cards to residents, which would allow for patients to be tracked by unique identifiers (e.g., age, medication) [18]. The proposal was quickly funded with a $20-million commitment from the Province [17].

As inaugural director, Naylor operated ICES as a scaled-up version of the multidisciplinary model (i.e., epidemiology, health services research, and policy formation). He implemented ICES at the Sunnybrook Hospital in Toronto, with a broadened scope to include academics, providers, administrators, and policy makers [17]. Initial goals of ICES were to investigate rates of medical procedures, length of stay, and drug administration [17]. The Province, OMA, and independent researchers and stakeholders each contributed one third to the research endeavors of ICES [17]. In its first year of operation, ICES published approximately 30 research papers, and developed a health atlas of system-related and disease-specific information [17].

Today, ICES holds de-identified, linkable data on 13 million of Ontario’s residents, under the Personal Health Information Protection Act, has 4 satellite sites in medical schools across Ontario and established remote access and analysis system for users [18–20]. ICES continues to operate within arm’s length of the Ontario Government and partners with numerous national/provincial programs to produce work that informs policy and expands the capacity for research in Canada [19].

**The Manitoba Centre for Health Policy (MCHP)**
In Manitoba, the history of administrative health data research intertwines with the careers of Noralou and Leslie Roos. In 1973, the Rooses came to the University of Manitoba, where Noralou collaborated with David Fish of Community Health Sciences to project provincial healthcare needs using the administrative files of the Manitoba Health Services Commission (MHSC) [21]. The MHSC collected data on registration, hospital, Personal Care Home, and medical claims. [21] Initially, MHSC data was provided to Noralou on the basis of good faith and mutual trust, but eventually MHSC and Noralou devised a system where multiple data sources were linked to individuals, who could be followed through the services they sought. Linkage overcame limitations of MHSC data, such as not tracking births, deaths, or moves out of Manitoba [21]. With former Assistant Executive Director to the MHSC, Paul Henteleff, the Rooses published the first paper using linked administrative health data in Manitoba.

In 1988, Fraser Mustard (former President of the Canadian Institute for Advanced Research) recruited the Rooses for his Population Health Program, and brought them together with the Provincial Government and Department of Medicine to form the MCHP. [21, 22] Together an agreement was reached where the MCHP would answer 6 research questions for the Province each year in exchange for funding, and otherwise be granted academic freedoms. [21] In 1990, the MCHP was given a 3-year contract for $3.2 million to encourage its operation within arm’s reach of the Province [21].

Today, the Centre employs over 60 persons in the fields of administration, communications, finance, data analysis, information technology, repository access, data acquisition, and research [23]. The Centre operated under the direction of Noralou until 2006, whose contribution to healthcare has recognized nationally with an
Today, PopDataBC has grown into the largest and most comprehensive health data research capacity in the country, facilitating access to over 20 health databases, 5 social databases, 5 education databases, 4 registries, and 9 special data files in Manitoba [23].

**Population Data British Columbia (PopDataBC)**

In BC, administrative health data research began with the establishment of the University of British Columbia’s (UBC) Health Sciences Centre. When the Centre first opened in the 1960s, the Health Services Research and Development unit was established and made partnerships with the BC Ministry of Health Services to maintain and provide access to health data throughout the 1970s [24].

Morris Barer and Robert Evans were two individuals pivotal to BC’s development of administrative health data research. In 1988, Barer, with colleagues from UBC, BC Cancer Agency, and BC Ministry of Health—began the BC Linked Health Data Project (BCLHDP), which “was designed to capture the power of linkable and longitudinal data, and avoid the inefficiencies associated with project-by-project data linkage.” [24] BCLHD included data from vital events and health care services utilized by nearly all BC residents from 1985, and today includes data from other agencies such as WorkSafeBC [24]. With Evans, who in 1990 was a member of the Royal Commission on Health Care and Costs in BC, Barer founded the UBC Centre for Health Services and Policy Research (CHSPR) within the UBC College of Health Disciplines [25]. CHSPR developed from the idea that UBC should influence health care policy and planning for BC [25]. Following an agreement with the BC Minister of Health and Privacy Commissioner in 1996, CHSPR was permitted to use BCLHD for applied health services and policy research [24, 25].

CHSPR obtained national funding to expand its breadth in data research in the 2000s, which allowed them to partner with UBC and other researchers from across the province to create PopDataBC: a “multi-university, data and education resource facilitating interdisciplinary research on the determinants of human health, well-being and development.” [24] Today, PopDataBC provides researchers with remote access to individual-level linked data on BC’s residents across the sectors of early childhood, workplace, environment, and more [24].

**Conclusions**

The success of the increasingly expansive, standardized, and collaborative history of administrative health data in Canada reflects the recommendations made by the RCHS over 50 years ago. We echo these recommendations for the present field of administrative health data research, with lessons drawn from this history.

**Recommendation 1: Federal financial support in consolidating existing registers**

At the federal level, financial support has been imperative to identifying national needs for health research. The founding of CIHI and NHIC was made possible through federal investments that improved the capacity for evidence-based decision-making. Likewise, support from provincial governments has also proven essential to the long-term sustainability of data centres. As shown for MCHP, for example, the support provided by the Province of Manitoba has led to a long-term collaborative working partnership.

**Recommendation 2: Standardize classification of diseases and social and demographic characteristics to facilitate comparability between regions**

As shown throughout the history of administrative health data in Canada, the standardization of classification methods has been no easy task. As historical developments have shown (e.g., introduction of CMGs by the HMRI), standardization allows for comparisons, increases data quality, and reduces the need to adapt multiple versions of reported data. Standardization also facilitates the timely publication of reports, which are especially important when considering the increasing constraints to the resource capacity of data centres.

**Recommendation 3: Establish a national clearinghouse and coordinating agency for health statistics**

CIHI and provincial data centres place Canada as a global leader in the field of administrative health data science. With government support, Canada’s administrative health databases have developed into innovative, high-quality, and informative resources for health research. As we have shown throughout this paper, the goals of establishing a national and standardized database and clearinghouse were realized long before its official founding in 1994. Provincial centres in Manitoba, Ontario, and BC have shown how smaller-scale developments can facilitate larger-scale project.

Evidence-based decision-making relies on high quality health information. This paper has provided an overview of the history of administrative health data in Canada, and has provided lessons learned from the past for present-day research. Specifically, we have highlighted the following recommendations from the 1964 RCHS: (1) standardization; (2) centralization of data resources; and, (3) government financial support. The short histories provided here illustrate the need for longstanding financial commitments, and collaboration between government and research centres in overcoming barriers to standardization and centralization (e.g., top-down decision-making).
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