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The Canadian Chronic Disease Surveillance System: A model for collaborative surveillance

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Abstract

Chronic diseases have a major impact on populations and healthcare systems worldwide. Administrative health data are an ideal resource for chronic disease surveillance because they are population-based and routinely collected. For multi-jurisdictional surveillance, a distributed model is advantageous because it does not require individual-level data to be shared across jurisdictional boundaries. Our objective is to describe the process, structure, benefits, and challenges of a distributed model for chronic disease surveillance across all Canadian provinces and territories (P/Ts) using linked administrative data. The Public Health Agency of Canada (PHAC) established the Canadian Chronic Disease Surveillance System (CCDSS) in 2009 to facilitate standardized, national estimates of chronic disease prevalence, incidence, and outcomes. The CCDSS primarily relies on linked health insurance registration files, physician billing claims, and hospital discharge abstracts. Standardized case definitions and common analytic protocols are applied to the data for each P/T; aggregate data are shared with PHAC and summarized for reports and open access data initiatives. Advantages of this distributed model include: it uses the rich data resources available in all P/Ts; it supports chronic disease surveillance capacity building in all P/Ts; and changes in surveillance methodology can be easily developed by PHAC and implemented by the P/Ts. However, there are challenges: heterogeneity in administrative databases across jurisdictions and changes in data quality over time threaten the production of standardized disease estimates; a limited set of databases are common to all P/Ts, which hinders potential CCDSS expansion; and there is a need to balance comprehensive reporting with P/T disclosure requirements to protect privacy. The CCDSS distributed model for chronic disease surveillance has been successfully implemented and sustained by PHAC and its P/T partners. Many lessons have been learned about national surveillance involving jurisdictions that are heterogeneous with respect to healthcare databases, expertise and analytical capacity, population characteristics, and priorities.

Introduction

Chronic diseases are the leading causes of death and disability worldwide. They place a large burden on both the individual and society, while contributing substantially to healthcare use and costs. In Canada, it is estimated that more than one in five adults live with at least one major chronic disease, includ-

ing cardiovascular disease, cancer, chronic respiratory disease, and diabetes (1). Mood and anxiety disorders are also common (1). Surveillance of chronic diseases, which involves the systematic collection, analysis, interpretation, and dissemination of data, is essential for strategic planning, program development and healthcare system monitoring.

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Administrative health data are an excellent resource for chronic disease surveillance. They are advantageous at a macro level, to describe population trends in incidence and prevalence, temporal and geographic variations, and outcomes such as healthcare utilization and costs. Strengths include their availability for entire populations over multiple years, ability to be linked, and comprehensive coverage of many chronic diseases. However, administrative data have limitations including (2): potential coding errors and inconsistencies (3), lack of information about behavioral risk factors, and bias due to diagnosis misclassification (4).

A distributed model is an ideal approach to conduct multi-jurisdictional chronic disease surveillance using administrative data (5-8). Under a distributed model, data extraction and analyses are conducted in each jurisdiction using common protocols; the model does not require the sharing of individual-level data across jurisdictional boundaries; rather, only summary data are shared. A distributed model relies on local expertise for data extraction and analysis, while benefitting from the combined methodological expertise of participating jurisdictions.

Distributed models have been used for other multi-jurisdictional initiatives involving administrative health data in Canada. The Canadian Network of Observational Drug Effect Studies (CNODES) relies on prescription drug administrative databases from seven provinces, the US, and the UK to conduct drug safety and effectiveness studies (9). The Canadian Gastrointestinal Epidemiology Consortium uses a distributed model to conduct cross-provincial studies involving seven provinces; the focus of the research is on inflammatory bowel disease and related conditions (10).

This paper describes the process, structure, benefits, and challenges of the Canadian Chronic Disease Surveillance System (CCDSS), a well-established distributed model for chronic disease surveillance. The CCDSS is also an effective partnership amongst all of Canada's provinces and territories (P/Ts) and the Public Health Agency of Canada (PHAC). By sharing information about this model, we hope to facilitate the uptake of distributed models involving multiple partners for chronic disease surveillance elsewhere.

Context for Chronic Disease Surveillance in Canada

PHAC was established in 2004 to build capacity in Canada's public health system to anticipate and respond effectively to public health threats. The CCDSS was created in 2009 to facilitate standardized, national estimates of chronic disease prevalence, incidence, and health outcomes. It grew out of the National Diabetes Surveillance System (NDSS), which was established in 1999 as a collaborative network of provincial and territorial (P/T) diabetes surveillance systems and supported by Health Canada and then PHAC (11). The CCDSS rests on the premise that a surveillance system requires standardized data over time and across jurisdictions to facilitate decision-making at national and P/T levels.

Surveillance Model

Data Sources

Canada has a system of universal health care, but the delivery of services is a P/T responsibility. The collection and management of a P/T's administrative health data is primarily undertaken using an information system developed specifically for the P/T.

Comparable databases are available in all P/Ts for key health services, including physician billings and public health insurance registrations. Physician billing claims capture patient contacts with primary and specialist physicians. The claims generally contain patient and physician information (e.g., patient and physician identifiers, patient demographics, physician specialty), diagnosis codes, and services provided (12). Physician billing claims databases are a crucial source of information for population-based health research because the vast majority of individuals see a physician at least once annually and the diagnosis codes generally have good face validity (13). Health insurance registration files capture dates of public health insurance coverage, death, and demographic and geographic information for all eligible P/T residents (14). Prescription drug dispensation claims, which are found in many provinces, must follow national content standards (see <https://www.pharmacists.ca/products-services/pharmacy-claim-standard/>).

Hospitalization data for all P/Ts are maintained by the Canadian Institute for Health Information in the Discharge Abstract Database and Hospital Morbidity Database (15). Common abstraction forms, processes, and quality evaluation methods are used for all jurisdictions.

The availability of both comparable databases (i.e., physician billing claims, health insurance registries) and common databases (i.e., hospitalizations) for all P/Ts is a key component of the CCDSS. Linkage of a P/T's health insurance registry, physician billing claims, and hospital discharge abstracts provides the minimum set of data required for the CCDSS, although other databases (e.g., prescription drug records) may be used for surveillance of some chronic conditions, where their inclusion is advantageous for identifying disease cases or outcomes. In addition, a common structure is specified for each of these databases, to facilitate implementation of the CCDSS methodology.

Case Definitions

Chronic disease case definitions are another key component of the CCDSS (see Table 1). A case definition is the set of rules used to ascertain individuals with a specific chronic disease in administrative health data; it includes diagnosis codes that are usually recorded with the International Classification of Diseases (ICD), observation period (i.e., number of years) required to ascertain a case, and other inclusion and exclusion criteria (4). Case definitions are developed by CCDSS disease-specific Working Groups comprised of clinicians, epidemiologists, and population health or health services researchers. Systematic literature reviews, to identify published studies, are often used by the Working Groups to initiate the process of case definition development.

Validation studies are undertaken using clinical or other

electronic data sources in selected P/Ts to assess the accuracy of chronic disease case definitions. These studies produce estimates of sensitivity, the probability of correctly detecting true disease cases, and specificity, the probability of correctly detecting non-disease cases. The positive predictive value (PPV) of a case definition is also considered, in order to reduce the probability that false positive cases will accumulate over time. The validity of case definitions varies; diseases that do not have clear diagnostic criteria or that require less engagement with the healthcare system, such as arthritis and asthma (4;16;17), tend to result in greater misclassification bias than conditions that have clear diagnostic criteria and require frequent contact with the healthcare system.

Feasibility studies are then initiated in selected P/Ts. These studies are used to identify potential practical barriers to implementing chronic disease case definitions (18;19).

Ongoing Surveillance and Data Quality

A national pilot study is implemented following feasibility studies, to trial the chronic disease case definition methodology in all jurisdictions. SAS analytic code developed by PHAC is distributed to all P/Ts for implementation. If the national pilot is successful, then the chronic condition is moved into ongoing surveillance.

Data quality surveys are also routinely conducted as part of the surveillance process, to identify database characteristics that may result in biased disease estimates over time or across P/Ts, or otherwise affect implementation of the analytic code. These surveys address a variety of topics, such as the availability, timeliness, and completeness of elements of administrative data. Data quality is assessed using a variety of methods, including validation studies and narrative reports about changes in data coding practices from P/T administrative staff. This information provides contextual information for interpretation of P/T prevalence or incidence estimates. A Data Quality Working Group was established in 2016 to synthesize this data quality information and conduct ad hoc studies. For example, a current topic of exploration is the completeness of physician claims databases for case ascertainment. Physicians who are paid on a fee-for-service basis must submit all of their billing claims to their P/T ministry of health; however, physicians who are paid using an alternative form of remuneration may not consistently submit parallel “shadow” billing claims and this can result in gaps in completeness over time and across P/Ts (20;21). As well, in rural communities, alternate healthcare providers (e.g., advanced practice nurses) may not submit billing claims, which can further exacerbate the challenges of physician billing claims database completeness.

Aggregate data produced in each P/T are approved by both the Science and Technical Committees. These summary data are then submitted to PHAC for further analysis and reporting. Data are typically reported as annual age- and sex-standardized incidence and prevalence rates; age- and sex-specific rates are typically also provided.

Surveillance is ongoing for many chronic diseases. Diabetes was the first condition for which surveillance was initiated; it began in 1999 (22). This was followed, in 2010, by hypertension and use of health services for mental illness (mood and anxiety disorders, and an omnibus definition of mental illness) (23-26). Subsequently, surveillance of chronic

respiratory disease (i.e., chronic obstructive pulmonary disease and asthma) was initiated in 2012. Surveillance of cardiovascular conditions, including ischemic heart disease, acute myocardial infarction, and heart failure, was also initiated in 2012 (27). Osteoporosis and related fracture surveillance began in 2013 (18). Surveillance of Parkinsonism (including Parkinson's disease) began in 2014 and multiple sclerosis, stroke and epilepsy in 2015. Surveillance of dementia (including Alzheimer's disease), schizophrenia, osteoarthritis, gout/crystal arthropathies, rheumatoid arthritis and juvenile idiopathic arthritis began in 2017 and use of health services for arthritis in 2018. Feasibility studies or national pilots have now been conducted for economic costs of chronic disease and multimorbidity (28).

Roles, Information Exchange, and Capacity Building

PHAC's roles and responsibilities include establishing memorandums of agreement (MOAs) with each P/T regarding funding and provision of summary data, administrative and coordination activities associated with development of chronic disease case definitions and maintenance of the CCDSS, and support for implementation of standardized protocols for extraction and analysis of data. PHAC also compiles and reports on national data.

The funding PHAC provides to the P/Ts through MOAs enables the hiring of one full-time employee in each P/T who is responsible for running the SAS analytic code, participating on committees, and engaging in related activities. This system costs less than it would to establish, staff, and maintain chronic disease registries in each P/T.

The P/Ts identify and assign technical resources to implement standardized protocols for data processing, implement and maintain the CCDSS, produce data for national reporting, reconcile data provided to PHAC to ensure its consistency and accuracy, and create regional reports in accordance with P/T priorities for chronic disease surveillance. Figure 1 details the processing and flow of data and information between PHAC and the P/Ts.

The Technical Committee, which is comprised of representatives from PHAC and the P/Ts, is responsible for overseeing the implementation of the analytic process within each P/T. The members of this Committee participate in the design, development, and operation of SAS analytic code. The Committee also makes recommendations to PHAC on how to maintain and improve the system and interpret the results.

The Science Committee, which is comprised of P/T representatives and scientific experts from academia, reviews feasibility studies, reviews and approves methods for constructing chronic disease case definitions and other measures required for ongoing surveillance (e.g., measures of comorbid conditions, health service use and costs), and provides oversight for issues of data quality, and priorities and opportunities for validation activities.

Dissemination of CCDSS data occurs in many forms, including peer-reviewed publications, electronic reports, and web-based open data resources. Disease-specific reports are produced on a routine basis. Special reports are produced on an ad hoc basis. Fact sheets, which provide highlights about

current results, are shared broadly. Web-based tools facilitate the analysis of publicly-available data. PHAC has created Data Cubes, interactive open data resources that enable users to create tables and figures via their web browser (<https://infobase.phac-aspc.gc.ca/cubes/index-eng.html>).

Innovations

The CCDSS is an important resource to describe the burden and impact of chronic disease in Canada. However, it has also provided the foundation to track additional chronic diseases, pursue methodological studies, and conduct and establish P/T programs and surveillance initiatives. For example, the Quebec Integrated Chronic Disease Surveillance System incorporates many of the features of the CCDSS, including administrative health data and case definition methodology, to support surveillance about the health of the population for the province of Quebec (29). Methodological studies about the quality of physician billing claims data in Newfoundland and Labrador (30;31) led to cross-provincial investigations to evaluate the impact of data quality on bias in disease prevalence estimates (20). The NDSS and CCDSS infrastructure was used as the basis for creating electronic chronic disease registries in the provinces of Alberta and British Columbia. The work also led to the creation of the Alberta Diabetes Surveillance System and the production of a series of atlas reports about the burden of diabetes and associated comorbid conditions (32). Information and expertise resulting from CCDSS participation has been used in the development and evaluation of programs and policies for P/Ts. CCDSS information was used to inform development of the Prince Edward Island (PEI) Wellness Strategy (33) and is being used in the development of a PEI Health Profile to examine the relationships between social determinants of health and chronic conditions. CCDSS funding, case definitions, and analytic techniques were also used to evaluate the effect of anti-smoking legislation on hospitalizations in PEI (34).

Multimorbidity, the co-occurrence of two or more chronic conditions, has been examined as an area for future development of the CCDSS. This has necessitated research to explore methods to combine information from the individual chronic diseases that currently are a part of ongoing surveillance (28). Life expectancy in chronic disease populations has been compared using different approaches, including estimates produced using CCDSS methods (35).

New methodological developments have been published, leading to their use in other jurisdictions. Ellison et al. (2) explored different national data sources to define the denominator for estimating prevalence and incidence. Multiple approaches to accurately measure hypertension incidence and prevalence, including comparisons with approaches based on CCDSS methods (36;37), have been investigated; studies about different approaches are important for clarifying the strengths and limitations of alternative population-based data sources for disease surveillance.

Validation studies to define neurological conditions have been supported by PHAC (38-41). These validation studies have led to further investigations about the impact of air pollution on disease incidence; this research has included microsimulation modelling to predict epidemiologic and economic impact of diseases (42;43).

Finally, a key innovation of the CCDSS was the development of common analytic protocols, the suite of software programs that are run, largely unmodified, in each jurisdiction. This is an important step beyond the sharing and local adaptation of paper-based analytic protocols, which are time-consuming and prone to error. The common protocol also overcame any disadvantage in participation that might have arisen for jurisdictions that did not have the local capacity to do the required analyses. This, in combination with chronic disease case definition developments, makes it possible for PHAC to quickly create and distribute new surveillance tools, addressing both local and national information needs.

Discussion

The key features, benefits, and limitations of the CCDSS distributed model for surveillance are summarized in Table 1. The CCDSS model is a partnership that respects the data privacy legislation and data sharing agreements that exist in the P/Ts. It builds on capacity within PHAC and the P/Ts to develop and implement the surveillance methodology.

Chronic disease surveillance systems in other countries have often relied on population-based survey data to measure prevalence and outcomes (44). While survey data have a number of strengths, including the ability to monitor behavioral risk factors and clinical outcomes, they are based on self-report data prone to recall bias, typically cannot be used to estimate incidence rates, and are expensive and time consuming to conduct. Survey data are also prone to selection biases and non-response errors. A recent comparison between the CCDSS and other population-based data sources revealed that the CCDSS produces higher prevalence estimates of hypertension when compared to self-report data from the Canadian Community Health Survey and clinical data from the Canadian Health Measures Survey (36).

Challenges to the implementation and long-term maintenance of the CCDSS distributed model for disease surveillance include heterogeneity in healthcare databases across P/Ts, changes in data quality over time, the CCDSS' reliance on the minimum set of data elements available in all P/Ts, and balancing disclosure guidelines with comprehensive reporting of the data. Limitations, including poor measurement validity of disease diagnosis codes for some chronic conditions (45) and the potential for changes in measurement validity of diagnosis codes over time, must be continually addressed to ensure the scientific rigor of the CCDSS methodology.

Conclusions

The CCDSS provides a foundation for many population health initiatives in Canada. While the CCDSS has grown substantially in scope and methodology since its inception, challenges remain, particularly those related to the heterogeneity and quality of administrative health data. Further development of the CCDSS will benefit from the exploration of other population-based electronic data sources that are routinely collected and consistently available in all Canadian jurisdictions, such as electronic medical records (46;47). Continued cross-jurisdictional comparisons of administrative health databases

will also strengthen the system. The CCDSS is a unique resource that has contributed substantially to strengthening public health in Canada.

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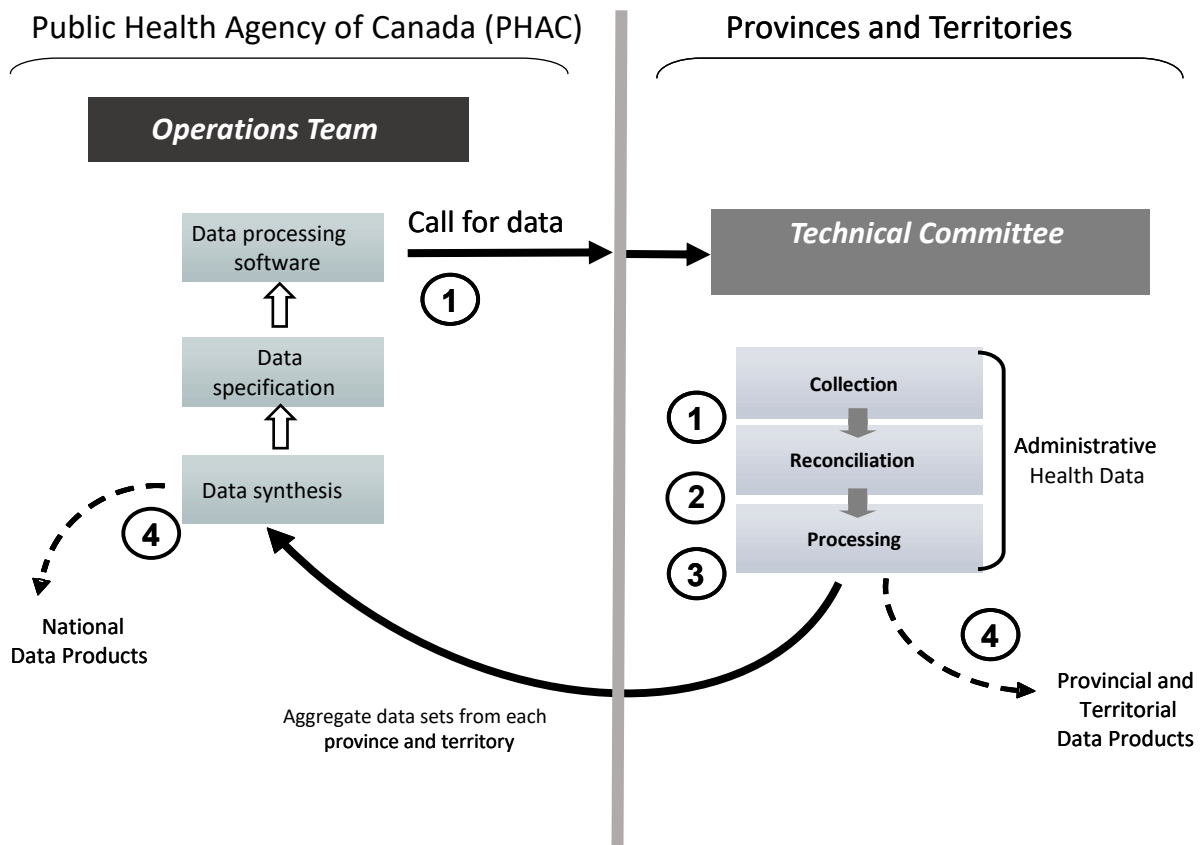
Statement on conflicts of interest

The authors declare that they have no conflicts of interest.

Abbreviations

SES	socio-economic status
AD	anti-depressant
HAWD	medical or psychiatric hospitalizations associated with depression
BC	British Columbia
SSRI	selective serotonin reuptake inhibitor
OAD	other anti-depressant
OR	odds ratio
uOR	unadjusted odds ratio
aOR	adjusted odds ratio

Figure 1: Data Processing and Use in the Canadian Chronic Disease Surveillance System (CCDSS)



Data processing has four main steps:

- Step 1: Collect data** – PHAC develops the data request and issues a call for data to the provinces and territories (P/Ts); this call is distributed to the Technical Committee members. The P/Ts collect the required information from administrative health databases using data processing software provided by PHAC to the Technical Committee members.
- Step 2: Define and identify cases** – The P/Ts apply definitions to the administrative data to identify chronic disease cases. The data are reconciled internally and with other data sources to ensure consistency and accuracy of the information.
- Step 3: Create registry** – The output from the case definitions is processed by incorporating it into registries, which include one record per person per fiscal year for each P/T.
- Step 4: Produce outputs** – Each P/T submits aggregate information, compiled from the registries, to PHAC. The aggregate data are analyzed by PHAC. National and P/T data products are prepared.



Table 1: Selected CCDSS Case Definitions

Condition	Ages (years)	Case Definition	ICD-9 (CM) Codes	ICD-10-CA Codes	DSM Codes	Notes, Exclusions, and Validation References
Diabetes (type 1 and type 2 combined, gestational diabetes excluded)	1+	1+ hospitalizations or 2+ physician claims within two years	250	E10; E11; E12; E13; E14		Excludes gestational diabetes in women age 10-54 120 days preceding or 180 days after hospital records containing any of the following codes: ICD-9: 641-676, V27; ICD-10: O1, O21-95, O98, O99, Z37 Validation Studies: (48;49)
Use of health services for mental illness	1+	1+ hospitalizations or 1+ physician claims within one year	290-319	F00-F99	290-319; 607; 608; 625	Diagnosis codes include dementia Validation Studies: (50)
Use of health services for mood and anxiety disorders	1+	1+ hospitalizations or 1+ physician claims within one year	296; 300; 311	F30-F42; F44-F48; F68	296; 300; 311	Validation Studies: (50)
Asthma	1+	1+ hospitalizations ever or 2+ physician claims within two years	493	J45; J46		Validation Studies: (51;52)
Chronic obstructive pulmonary disease	35+	1+ hospitalizations or 1+ physician claims ever	491; 492; 496	J41; J42; J43; J44		Validation Studies: (51)
Hypertension, pregnancy-induced hypertension excluded	20+	1+ hospitalizations or 2+ physician claims within two years	401; 402; 403; 404; 405	I10; I11; I12; I13; I15		Excludes pregnancy-induced hypertension in women age 20-54 120 days preceding or 180 days after hospital records containing any of the following codes: ICD-9: 641-676, V27; ICD-10-CA: O1, O21-95, O98, O99, Z37 Validation Studies: (53)
Ischemic heart disease	20+	1+ hospitalizations or procedure codes or 2+ physician claims within one year	410; 411; 412; 413; 414 ^{††}	I20; I21; I22; I23; I24; I25 ^{††}		Validation Studies: (54)
Acute myocardial infarction	20+	1+ hospitalizations within one year	410	I21; I22		Hospital ICD codes were validated by the Canadian Institute for Health Information
Heart failure	40+	1+ hospitalizations or 2+ physician claims within one year	428	I50		Validation Studies: (55)

Note: DSM: Diagnostic and Statistical Manual of Mental Disorders; ICD: International Classification of Diseases

^{††}The following procedures are also included: Percutaneous coronary intervention and coronary artery bypass graft coded in ICD-9-CM: 36.01; 36.02; 36.05; 36.10; 36.11; 36.12; 36.13; 36.14; 36.15; 36.16; 36.17; 36.19, the Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures: 48.02; 48.03; 48.11; 48.12; 48.13; 48.14; 48.15; 48.16; 48.17; 48.19, and the Canadian Classification of Health Interventions: 1.IJ.50; 1.IJ.57.GQ; 1.IJ.54; 1.IJ.76.

Table 1 Continued: Selected CCDSS Case Definitions

Condition	Ages (years)	Case Definition	ICD-9 (CM) Codes	ICD-10-CA Codes	DSM Codes	Notes, Exclusions, and Validation References
Stroke	20+	1+ hospitalization or 2+ physician claims within one year	Hospital: 362.3x; 430; 431; 433.x1; 434.x1 or 434; 435.x; 436. Physician: 430; 431; 434; 435; 436.	G45.x (exclude G45.4); H34.0; H34.1; I60.x; I61.x; I63.x (exclude I63.6); I64		Validation Studies: (56)
Dementia, including Alzheimer's disease	65+	1+ hospitalizations or 3+ physician claims within two years, with at least 30 days between each claim; or 1+ drug prescriptions	Hospital: 046.1; 290.0; 290.1; 290.2; 290.3; 290.4; 294.1; 294.2; 331.0; 331.1; 331.5 (or 331.82 in ICD-9-CM). Physician: 290; 331	G30; F00; F01; F02; F03		For the drug criterion: Drug identification numbers corresponding to DONEPEZIL; RIVASTIGMINE; GALANTAMINE; MEMANTINE are used to identify cases. Validation Studies: (40)
Osteoporosis	40+	1+ hospitalizations or 1+ physician claim ever	Hospital: 733 Physician: 733	M80; M81		Validation Studies: (57)

Note: DSM: Diagnostic and Statistical Manual of Mental Disorders; ICD: International Classification of Diseases



Table 2: Features, Benefits, and Challenges of the Canadian Chronic Disease Surveillance System (CCDSS)

Features	Benefits	Challenges
National and subpopulation (i.e., age, sex, geography) incidence and prevalence estimates are produced using a standardized methodology.	Changes in case ascertainment methodology are made by PHAC, which limits the potential for inconsistencies in methodology.	Heterogeneity in administrative health databases across P/Ts can affect accuracy of disease estimates. Changes in the quality of administrative data over time (i.e., diagnostic accuracy) may also affect disease estimates.
Longitudinal estimates of prevalence, all-cause mortality, and incidence enable comparisons over time.	Technical expertise to develop the methodology is not required in each P/T.	The CCDSS relies on the minimum set of data elements common to all P/Ts, which may not always represent the optimal data elements for case ascertainment.
The CCDSS respects the data custodial responsibilities of the P/Ts.	Methods to initiate surveillance of new chronic diseases uses a collaborative model.	Disclosure rules are specific to each P/T, which may result in differences in release of information across jurisdictions.
Routine data quality surveys facilitate interpretation of estimates.	Data analyses and report preparation are facilitated by PHAC.	There are ongoing concerns about the quality (i.e., completeness and accuracy) of administrative health databases.
Federal and P/T experts contribute their knowledge and expertise on an ongoing basis.	Surveillance capacity building occurs in all P/Ts.	

Notes: PHAC: Public Health Agency of Canada; P/T: province and territory

