British Columbia Chronic Disease Registries (BCCDR) Methods Overview

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Office of the Provincial Health Officer

Contents

1. INTRODUCTION

Non-communicable diseases (NCDs) or chronic diseases account for a large proportion of increasing healthcare costs. Monitoring patterns and trends of chronic diseases provide critical information for public health actions (prevention, protection, and promotion) and healthcare planning. Since the fiscal year 1992/93, the BC Chronic Disease Registries (BCCDR) have been released each year to:

- Measure chronic disease burdens in BC: Incidence, prevalence, and mortality over time, across different health regions and communities, and between different demographic groups in BC.
- Measure health inequalities: Difference in chronic disease measures by sex, age, geographic area, indigenous identity, and socioeconomic level.
- Support clinical and public health research: A row-level BCCDR dataset linkable to other health and non-health datasets in BC via unique personal health number (PHN) is accessible to designated Ministry of Health (MoH) and Health Authority (HA) staff; non-academic researchers through the Ministry of Health (MoH) Data Central (https://www2.gov.bc.ca/gov/content/health/conducting-health-research-evaluation/data-access-health-data-central); and academic researchers through PopData BC (https://www.popdata.bc.ca/dataaccess).

The purpose of this document is to describe the methods used to create BCCDR incidence and prevalence measures.

2. DATA SOURCES

Chronic diseases registries are derived from administrative data sources maintained by the BC Ministry of Health. Identifying cases is done according to the definitions in Table 1. A brief description of the data sources utilized to identify cases is given below. For BCeID users, detailed descriptions of the data sources can be found at: https:// meta.healthideas.gov.bc.ca.

2.1 Hospital discharge abstract database (DAD)

The DAD contains detailed patient-level data about hospitalizations in BC, as well as those that occur in other Canadian jurisdictions involving BC residents. Data are submitted by the hospitals to the Canadian Institute for Health Information (CIHI), which in turn provides the validated data to the BC Ministry of Health.

2.2 Medical Services Plan (MSP)

MSP is a publicly-funded program that pays for medical and health care services on behalf of residents of BC. This includes all medically-required services from general practitioners and specialists, laboratory services and diagnostic procedures including x-rays and ultrasound examinations, and dental and oral surgery when performed in hospital.

2.3 PharmaNet

PharmaNet is a British Columbia province-wide system that holds records for all prescriptions dispensed from community pharmacies as well as prescriptions dispensed from hospital outpatient pharmacies for use at home upon discharge. It also contains medications provided to patients by physicians in their office or clinic or in an emergency department.

2.4 Client Roster

The Client Roster contains a list of BC residents who had MSP coverage or health services paid by the B.C. government including MSP, drug dispensations and hospitalizations within the fiscal year. It contains the individual's sex, age and usual residence by fiscal year. The Roster is used as the source for population estimates (denominator) for all epidemiological measures. A person is included in the population if she/he has coverage in the Roster on October 1 each fiscal year.

2.5 BC Health Boundaries

BC Health Boundaries are a hierarchically-nested way of dividing the province for management and analysis purposes. The province is divided into:

- 5 regional Health Authorities (HAs)
- 16 Health Service Delivery Areas (HSDAs)
- 89 Local Health Areas (LHAs)
- 218 Community Health Service Areas (CHSAs)

CHSAs are a recent addition to the hierarchy; introduced April 2019. Information about BC Health Boundaries (HAs, HSDAs, LHAs and CHSAs) can be found at: https://www2.gov.bc.ca/gov/content/data/geographic-data-services/land-use/administrative-boundaries/health-boundaries

2.6 Canada Census Population

The Canadian 2011 Census of Population Program is used as a reference population for age standardization.

3. Case Identification Algorithms

Case definition criteria are applied to the data to obtain counts of persons who meet the qualification criteria (i.e., qualify as a case). A typical case definition could include hospitalization diagnoses or physician service diagnoses – either alone or in combination – within a designated time frame, to identify a case. For example, a case might qualify with a single hospitalization diagnosis or with 2 physician service diagnoses within a period of 2 years.

3.1 CCDSS Case Definitions

Case definitions used by the Canadian Chronic Disease Surveillance System (CCDSS) are adopted for a number of the chronic diseases reported by BCCDR (see Table 1). In these instances, validation studies to test the accuracy of the algorithm have been conducted in at least one province.

3.2 BCCDR Case Definitions

For a number of other diseases, BCCDR case definitions were modified after comprehensive consultations with healthcare professionals in BC. The BCCDR and CCDSS case definitions may differ in one or more of the following:

(1) Number of hospital or physician visits required to qualify a case: This is partially related to the variations in physician or hospital billing and government payment policies.

(2) Specific diagnostic codes used to define a case: While national standards are applied, cross-jurisdiction differences in coding and billing practices for diagnosis and medical procedures do occur, requiring some adjustments based on the recommendations from BC experts.

(3) Look back period: Look back period is either 1 year or 2 years for most diseases to ensure a sufficiently long period of time is used to retrospectively track a patient's healthcare utilization history, if the information is available. For some diseases, the BCCDR and CCDSS definitions may differ based on variations in expert opinion.

(4) Inclusion of drug prescriptions: BC is one of the few jurisdictions in the country with an electronic database of drug prescriptions for residents of all ages. For some conditions, such as diabetes, a patient with a history of disease-specific drug prescriptions is qualified as a case. Pharmacists and clinicians recommend a list of drugs for each disease for which drug prescription history is considered a key component of the algorithm. They review and update the list every year before the BCCDR are created. These differences between CCDSS and BCCDR case definitions may cause slightly different BC incidence and prevalence values to appear in the CCDSS reports and provincial reports.

No CCDSS case definitions exist for three of the conditions reported by BCCDR. The case definition for two of those conditions were developed following literature reviews and consultations with BC healthcare professionals. The case definition for chronic kidney disease is based on criteria established by the Global Burden of Disease project: https://www.who.int/healthinfo/global_burden_disease/about/en/

Table 1 BCCDR and CCDSS Case Definitions

Group	Disease	CCDSS Algorithm	BCCDR Algorithm	Validation Study Reference
Circulatory Diseases	Ischemic heart disease (20+) *	1+H or 1+ procedure or 2+ P within 2 years	(2+ P for Angina +1Rx in 1 year) or (1+ Angina SP + 1Rx in	(Tu et al. 2010, Robitaille et al. 2013)
	Acute myocardial infarction (20+) #	1+ H within 1 year	1+ H ever	(Tu et al. 2016)
	Angina (20+)	NA	1+ H ever or (1+ SP and 1 Rx within 1 year) or (2+ P and 1+ Rx within 1 year)	
	Heart failure (1+) *	1+ H or 2+ P within 1 year	CCDSS algorithm&	(Schultz et al. 2013)
	High blood pressure (hypertension, 20+) *	1+ H or 2+ P within 2 years	CCDSS algorithm&	(Quan et al. 2009, Tu et al. 2007, Atwood et al. 2013)
	Hospitalized stroke (20+) *	1+ H or 2+P within 1 year	1+ H ever	(Tu et al. 2013)
	Hospitalized haemorrhagic stroke (20+) #	1+ H within 1 year	1+ H ever	(Tu et al. 2013)
	Hospitalized ischemic stroke (20+) #	1+ H within 1 year	1+ H ever	(Tu et al. 2013)
	Hospitalized transient ischemic attack (TIA, 20+)	1+ H within 1 year	1+ H ever	(Tu et al. 2013)

Group	Disease	CCDSS Algorithm	BCCDR Algorithm	Validation Study Reference
Diabetes	Diabetes mellitus (1+) *	1+H or 2+P within 2 years	1+H ever or 2+P in 1 year or (2+insulin Rx or 2+ oral antihyperglycemic [not incl. metformin] Rx or (1 insulin and 1 oral antihyperglycemic [incl. metformin] Rx) or (1 metformin and oral antihyperglycemic [not incl. metformin] Rx in 1 year) or (2 metformin Rx and 1P in 1 year)	(Blanchard et al. 1996)
Inflammatory	Rheumatoid arthritis (1+) #	1+ H or 2+ (8+ weeks apart) within 2 years	2+ P (61-720 days apart)	(Widdifield et al. 2013, Widdifield et al. 2014, Tennis et al. 1993)
	Juvenile idiopathic arthritis (0-15) #	1+ H or 1+ P within 1 year	1+H or 2+ P (8+ weeks apart) in 2 years	(Stringer and Bernatsky 2015)
Kidney Diseases	Chronic kidney disease (1+)	NA	1+ H or 2+ P in 1 year	(Vos et al. 2017)
Mental Health	Mood and Anxiety disorders (1+) #	1 H or 1 P within 1 year	1 H or 2P within 1 year	(Kisely et al. 2009)
	Depressive disorders (1+)	NA	1H or 2P in 1Y	(Alaghehbandan et al. 2012, Townsend et al.
	Schizophrenia & delusional disorders (10+) #	1H or 2P (30+ days apart) within 2 years	CCDSS algorithm&	(Goldner, Jones and Waraich 2003, Kurdyak et al. 2015)

Group	Disease	CCDSS Algorithm	BCCDR Algorithm	Validation Study Reference
Musculoskeletal Disorders	Gout (20+) #	1+ H or 2+ P (1+ day apart) within 5 years	CCDSS algorithm&	?
	Osteoarthritis (1+) #	1+ H or 2+ P (1+ day apart) within 5 years	1H or 2P in 1 year	(Kopec et al. 2008, Tennis et al. 1993,
	Osteoporosis (50+) #	1+ H or 1+ P ever?	1+ H or 2+ P or 2+ Rx in 1 year	(Leslie, Lix and Yogendran 2011, Lix et
Neurological Disorders	Alzheimer's and other dementias (40+) *	1+H or 3+ P (30+ days apart) or 1+ Rx	CCDSS algorithm&	(Liisa Jaakkimainen et al. 2016, Williamson et
	Epilepsy (1+) #	Aged 1-19 years: 3+ P (30+ days apart) within 2	CCDSS algorithm&	(Tu et al. 2014)
	Multiple sclerosis (20+)#	1+ H or 5 + P within 2 years	CCDSS algorithm&	(Marrie et al. 2013, Widdifield
	Parkinson's disease (40+) #	2+ P (30+ days apart) within 1 year	CCDSS algorithm &	(Butt et al. 2014)
Respiratory Diseases	Asthma (1+) *	1+ H or 2+ P within 2 years	(1+ H or 2+ P within 1 year) or (1+ P and 2+ Rx within 1 year)	(Gershon et al. 2009b, Kozyrskyj, Mustard and Becker 2004, To et al. 2006)
	Chronic obstructive pulmonary disease (35+) *	1+H or 1+ P ever	1+ H or 2+ P within 1 year	(Gershon et al. 2009a)
Substance Misuse	Substance Misuse Disorders (1+) #		1+ H or 2+ P in 1 year	Validation study in progress by CCDSS

Notes: * CCDSS core diseases; # CCDSS non-core diseases; & Discrepancies may still exist in term of specific ICD-9 and procedure codes used in the algorithm; Case definition based on a small pilot study rather than a formal validation study. Numbers in parentheses indicate age ranges for cases.

Abbreviations: H, hospitalization; P, physician/MSP visit; Rx, drug prescription; SP, specialist visit; CABG, coronary artery bypass grafting; PCI, percutaneous Coronary Intervention; PCTA, percutaneous transluminal coronary angioplasty; NA, not reported.

4. EPIDEMIOLOGICAL MEASURES

4.1 Incidence

Incidence measures the number of new cases of disease or illness during a specified time period in a specified population. Incidence may be expressed as a count, a rate, or a proportion. Incidence, expressed as a count, is simply the number of new cases of disease during a specified time period in a specified population at risk for the disease. Incidence rate is the rate at which new cases of disease occur in a specified population during a specified time period. The numerator is the number of new cases in the at-risk population in the specified time period. The denominator is the person-time at risk or the number of persons at risk (i.e., mid-year population in a reporting year minus previous year's prevalent cases) during the specified time period. Incidence rate is estimated for BCCDR.

Incidence Rate = (number of newly identified cases in a reporting year) / (population at risk in the reporting year) $\times 10^n$

The value of n depends on whether the disease is rare or not and is typically set at 3 in the BCCDR.

4.2 Prevalence

Prevalence is the number of cases (new and old) with the condition or disease, either during a time period (period prevalence) or on a particular date (point prevalence) within a population. Period prevalence provides the better measure of the disease burden since it includes all cases between two dates (or during a time period), whereas point prevalence only counts those alive on a particular date. Prevalence is a proportion and not a rate. The BCCDR offers two prevalence measures: lifetime prevalence and healthcare contact prevalence (see Table 2).

4.2.1 Lifetime Prevalence

Lifetime prevalence or cumulative prevalence is the proportion of individuals who have had the condition for at least part of their lives at any time during their life course. In BCCDR, this refers to the proportion of residents who were diagnosed/identified as a case at least once and were still residing in the province during a reporting time period (fiscal year). Once the case definition criteria are met in a year, cases are then carried forward to count as a case every year thereafter until the person's death or migration out of the specified region. Lifetime prevalence is calculated for both life-long conditions (e.g., diabetes) and relapsing-remitting conditions (e.g., anxiety and depressive disorders). Users should note that lifetime prevalence proportions for relapsing-remitting conditions may not represent the burden of such conditions at a particular time period. Caution is also needed when comparing to other reports where the proportions of a population with active symptoms or treatments for these conditions are measured using surveys.

Lifetime prevalence = (number of residents ever identified with a disease in a reporting year) / (mid-year population in the reporting year) $\times 10^n$

The value of n can depend on whether the disease is rare or not; and is typically set at 2 in the BCCDR.

4.2.2 Healthcare Contact Prevalence (Relapsing-remitting Diseases)

For relapsing-remitting diseases, BCCDR measures active healthcare contact prevalence. Cases are counted if they previously met case definition criteria for a disease and continued to live and receive healthcare services for the disease in the specified region during subsequent reporting period(s). Cases are not included in the numerator for a reporting period if the patient did not seek healthcare services for the specified disease. This prevalence measure is useful for describing the burden of service utilization directly related to relapsing-remitting diseases at a particular time period.

Active healthcare contact prevalence = (number of patients receiving healthcare services for a disease in a reporting year) / (mid-year population in the reporting year) × 10^n

The value of n can depend on whether the disease is rare or not and is typically set at 2 in the BCCDR.

4.3 Age-standardized Rate/Proportion

Age is one of most important risk factors for chronic diseases and should be taken into account when comparing disease measures among different populations, for example, when comparing health authorities. Age-standardized incidence and prevalence are calculated using direct standardization. The 2011 Canada Census population is used as the standard. The direct standardized rate (DSR) is calculated using:

$$DSR = \frac{1}{\sum_i w_i} \times \sum_i \frac{w_i O_i}{n_i}$$

where:
O_i is the observed number of events in the local population in age group *i*;
n_i is the number of individuals in the population or the population at risk in age group *i*;
w_i is the number (or proportion) of individuals in the standard population in age group *i*.

4.4 Place of Residence

The geographic location is the last known residence of each individual at the end of the fiscal year based on the postal code of the person's address. The address may come from the Client Registry (home or mailing address), or Assisted Living and Residential Care where the client resides. The year-end postal code assignment is based on the most recent address (of any type) with a valid postal code. The year-end postal code is then translated to a health geography using the Translation Master File. BC totals include cases with unknown location due to invalid postal codes.

Table 2 Epidemiological Measures in the BCCDR

Group	Disease	Incidence	Prevalence	
			Lifetime Prevalence	Active Healthcare Contact Prevalence
Circulatory Diseases	Acute myocardial infarction	Y	Y	Y
	Angina	Y	Y	N
	Heart failure	Y	Y	N
	High blood pressure	Y	Y	N
	Hospitalized stroke	Y	Y	Y
	Haemorrhagic stroke	Y	Y	Y
	Ischemic stroke	Y	Y	Y
	Transient ischemic attack	Y	Y	Y
Diabetes	Diabetes mellitus	Y	Y	N
Inflammatory	Rheumatoid arthritis	Y	Y	N
	Juvenile idiopathic	Y	Y	N
Kidney Diseases	Chronic kidney disease	Y	Y	N
Mental Health	Depressive disorders	Y	Y	Y
	Anxiety and mood disorders	Y	Y	Y
	Schizophrenia & delusional disorders	Y	Y	Y
Musculoskeletal	Gout	Y	Y	Y
	Osteoarthritis	Y	Y	N
	Osteoporosis	Y	Y	N
Neurological Disorders	Alzheimer's and other dementias	Y	Y	N
	Epilepsy	Y	Y	N
	Multiple sclerosis	Y	Y	N
	Parkinson’s disease	Y	Y	N
Chronic Respiratory Diseases	Asthma	Y	Y	Y
	Chronic obstructive pulmonary disease	Y	Y	N
Substance Misuse	Substance misuse	Y	Y	Y

Y: estimated; N: not estimated.

5. CAVEATS, LIMITATIONS & CHANGES

5.1 Case definition

While a number of case definitions have been validated in other Canadian jurisdictions (e.g. conditions reported in the CCDSS) no validation studies have been conducted in British Columbia. It is assumed case definitions, especially definitions validated in other Canadian jurisdictions, perform reasonably well in BC because of similarities in their healthcare systems. In a number of instances CCDSS case definitions were modified after consulting with clinicians (physicians, nurses, and pharmacists), due to perceived differences in physician billing practices and information management systems in BC; along with the addition of drug prescription information. No CCDSS case definitions exist for a number of other conditions reported in the BCCDR.

Case algorithms based on administrative data are never 100% sensitive (sensitivity is the ability to completely identify all cases of a given disease – true positives) or 100% specific (specificity is the ability to correctly identify non-cases – false positives). Only persons using the BC healthcare system (primary care, hospital care, and/ or Pharmacare) can be identified as a chronic disease case. If a person does not use these services, there will be no diagnostic or treatment information available to qualify that person as a case. As a result, undiagnosed or untreated cases of disease are not included in the BCCDR chronic disease estimates.

5.2 Small Numbers

Small numbers are not supressed nor rounded in these reports. As per the privacy legislation in Canada and following the BC Centre for Disease Control policy for re-identification risk in public data release, where denominator counts are less than 20, public release of the data without suppression is discouraged.

5.3 Prevalent case misclassified as incident case

Individuals identified as incident cases in BCCDR may have been diagnosed with a chronic disease before the Ministry of Health data holdings started operating in 1992/93. In other words, many incident cases identified by BCCDR algorithms in early years were actually prevalent cases. This is reflected by the high incidence values for many diseases in the first few years of BCCDR and a significant incidence decline over time during this period (i.e., reporting washout period). Therefore, the recommended reporting period for incidence and prevalence is from 2001/02 onwards.

5.4 Source data

Source data are refreshed periodically, resulting in small changes of individual records. Every effort has been made to minimize the impacts of these refreshes on BCCDR (e.g., creating snapshots of source data), but discrepancies cannot be ruled out. The lack of complete synchronization among source data tables may create discrepancies in some variables such as date of birth, place of residence, and service date. There exists a very small proportion of records with unknown sex, date of birth, or health boundary assignment in the source tables. No imputations have been conducted for these missing values when BCCDR were created. Cases with unknown sex or health boundary assignment values are included in the total number of cases at the provincial level. However, these are considered missing data and not included at the

regional level and/or by sex or age group.

5.5 Standard population

Starting in 2015/ 16, the standard population changed from the 1991 Canada census population to the 2011 Canada census population. Due to population aging, age-standardized measures in a given year based on the 2011 standard population are generally higher than the same measures in that year based on the 1991 standard population. For instance, BC's age-standardized diabetes incidence rate was 6.7 per 1,000 in 2002/03 based on the 2011 standard population, but 6.5 per 1,000 for the same year based on the 1991 standard population. Users should not compare measures based on different standard populations.

5.6 Changes to Chronic Disease Registry

A number of changes were made to the most recent version of the BCCDR including the addition of a new chronic condition, change in the case definition of another condition, change in the way population is estimated, exclusion of mortality estimates and the removal of selected conditions from the registry. These changes are described below.

- Mortality data (mortality with condition and mortality without condition) are excluded from the current version of BCCDR. However, work is underway to generate cause- specific mortality rates. Mortality cases will be extracted from the BC Vital Statistics Agency's Death Registry. For each death, an underlying cause of death (UCOD) is assigned according to the International Statistical Classification of Diseases and Related Health Problems.
- Incidence and prevalence for a number procedures such as coronary artery bypass grafting (CABG), coronary angiogram, percutaneous transluminal coronary angioplasty (PTCA), and kidney transplant were provided in previous BCCDR versions but excluded from the most recent update.
- The case definition for chronic kidney disease was changed to correspond to the Global Burden of Disease definition. More diagnoses were added to the algorithm making case finding more sensitive. As a result, the number of individuals who met the new case definition increased by about 25% compared to the previous case definition.
- In previous BCCDR versions individual were considered residents of BC if he/she had at least one day of MSP coverage during the fiscal year. In the current version the population considered of individuals who had active coverage on October 1 of the fiscal year. As a results population estimates were revised downwards.
- Substance use disorder (both lifetime and healthcare contact prevalence) was added to the list of conditions in the updated BCCDR.

6. CONTACTS

General inquiries and methodology issues: hlth.cdrwg@gov.bc.ca

Requesting row-level CDR data: MoHAnalytics@gov.bc.ca (non-academic researchers with regional health authorities and other health partners)

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