

An Environment Scan of Canadian National **Databases** and **Registries on** Health-Related Conditions

April 2024

Part of a series on the state of perinatal mental health data capture in Canada





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Background

In Canada, data and information about women's health, particularly in the perinatal period (pregnancy and up to 1-year postpregnancy), is sporadic and limited. While provincial and territorial databases do capture some indicators of mental health, they are not standardized and data is often reported in an aggregate manner, which can lead to inaccurate reporting about the health of Canadian women. Without data that can be collated, analyzed, and compared across centres and jurisdictions, it is near impossible to know the prevalence of certain illnesses and measure changes or impacts required in healthcare services.

One of the most significant gaps in data capture within Canada is related to perinatal mental illness, including clinical indicators and outcomes. Perinatal mental illness is one of the most common complications of pregnancy and the postpartum period, and the COVID-19 pandemic has only served to increase the incidence of mental illness among Canadian women, while simultaneously limiting access to services and supports. In light of this, there is an urgent need to capture national data on perinatal mental health/illness in Canada in order to understand the circumstances, identify opportunities, and predict trends and outcomes that can provide an evidence base for advocacy, policy, and intervention.

The focus of this report is to summarize the findings of an environment scan of current national databases and registries focused on clinical conditions, with particular focus on those that currently capture perinatal and/or mental health data. The aim of this search is to identify possible approaches and models that could feasibly be utilized to support a national dataset on perinatal mental illness and identify gaps and opportunities in current systems.



National databases capturing healthrelated information

There are several national databases and registries that capture health-related information in Canada, including related to mental illnesses. Mental illness data available in Canada includes broader population-level data from administrative records and crosssectional surveys.

Administrative data is collected regularly at a high level as part of the management of health care services. It typically includes population data from administrative sources such as hospital admissions and discharges, physician billing, ambulatory care, and drug databases, including prescriptions. The Canadian Institute for Health Information (CIHI) and the Public Health Agency of Canada (PHAC) are primary sources for National-level administrative data in Canada.

Population-based cross-sectional surveys

collect information from a standard set of questions from a representative sample of the population. This population is typically selected at random and data is captured at a single point in time. Statistics Canada is the primary source of national-level population based survey data in Canada.

Canadian Institute for Health Information (CIHI)

The Canadian Institute for Health Information (CIHI) is an independent not-for-profit organization that collects data and information from a range of health system databases to generate evidence-based reports and analyses. The goal of CIHI is to improve health care, health system performance, and population health.

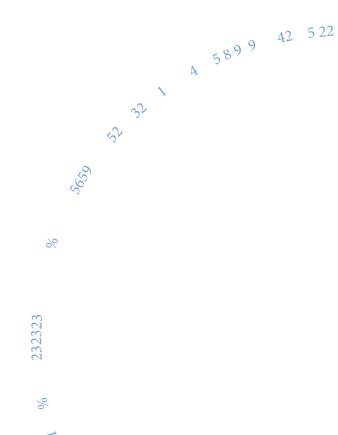
CIHI is a secondary data collector of health information that holds and manages nationallevel health administrative data. Data is acquired from provincial and territorial health service systems including hospitals, other

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health care facilities, long-term care homes, regional health authorities, medical practitioners, and governments. Information is disclosed to CIHI through data-sharing agreements under jurisdictional privacy or health information legislation.

In addition to their collaborations with ministries/departments of health in all provinces and territories (excluding Quebec), CIHI also works with federal agencies and other pan-Canadian health organizations including Canada Health Infoway, Canadian Agency for Drugs and Technologies in Health, Statistics Canada, Public Health Agency of Canada (PHAC), First Nations Health Authority, and Health Data Research Network Canada.

Datasets used for internal analysis do not contain names or direct identifiers such as dates of birth or postal codes. Publically released data is either aggregated or in the form of de-identified record-level data to minimize the risk of identification and residual disclosure. Data quality is routinely evaluated to modify collection methods and protocols as needed.



CIHI data holdings

<u>Discharge</u> <u>Abstract</u> <u>Database (DAD)</u>	 Captures administrative, clinical, and demographic information on inpatient hospital discharges (including deaths, sign-outs, and transfers) and day surgery Data is received directly from health care facilities, regional authorities or ministry/departments of health in all provinces and territories except Quebec; data from Quebec is submitted to CIHI directly by the Ministère de la Santé et des Services Sociaux du Québec DAD data is used to populate the Hospital Morbidity Database (HMDB) and Hospital Mental Health Database (HMHDB).
<u>Hospital Morbidity</u> Database (HMDB)	 Captures administrative, clinical, and demographic information on inpatient care and events from acute care hospitals, including day surgery from Quebec Provides national discharge statistics from Canadian health care institutions by diagnoses and procedures, including stays for mental illness and substance use and hospital-based births Does not capture data from psychiatric facilities.
<u>Hospital Mental</u> <u>Health Database</u> <u>(HMHDB)</u>	 Captures data from all provinces and territories in Canada on inpatient hospitalizations for mental illness and addiction Includes general and psychiatric hospitals Data is collected from administrative separation records of psychiatric and general hospitals from four sources: DAD, HMDB, Hospital Mental Health Survey (HMHS) and Ontario Mental Health Reporting System (OMHRS).
<u>National</u> <u>Ambulatory Care</u> <u>Reporting System</u> <u>(NACRS)</u>	 Captures data for all hospital-based and community-based ambulatory care including day surgery, outpatient and community-based clinics, and emergency departments Data is collected at time of service and reported to CIHI from participating facilities or regional health authorities or ministries of health across several jurisdictions.
National Prescription Drug Utilization Information System (NPDUIS)	Contains prescription claims-level data, primarily from publicly financed drug benefit programs, from 10 provinces/territories (excluding Quebec, Nunavut and Northwest Territories) and 1 federal drug program.
The Canadian Patient Experiences Reporting System (CPERS)	Collects information on patient experience from participating hospitals across Canada in order to improve patient centred care and patient outcomes.
<u>The Health</u> <u>Workforce</u> <u>Database (HWDB)</u>	 Contains information on over 30 groups of healthcare professionals in Canada regarding supply, distribution, migration, education and employment Receives data from national societies and associations and provincial/ territorial regulatory bodies and governments.
<u>The National</u> <u>Physician</u> Database (NPDB)	 Provides information on demographic characteristics of physicians including their payments and level of activity within Canada's health system Receives information from the medicare programs of all provinces and territories.

CIHI mental health indicators

As part of their <u>5-year strategic plan</u>, CIHI has identified mental health and substance use as one of their top Health Information Priorities for 2022-2027.

DAD/HMDB/NARCS

<u>30-Day</u> Readmission for Mental Health and Substance Use

Repeat Hospital Stays for Mental Health and Substance Use

<u>30-Day</u> <u>Readmission for</u> <u>Mental Illness,</u> <u>Age 15+ (General</u> <u>Hospital Only)</u>

Patients With Repeat Hospitalization for Mental Illness, Age 15+ (General Hospital Only)

Hospital Stays for Harm Caused by Substance Use

Hospitalizations Entirely Caused by Alcohol

Self-Harm Hospitalizations

Self-Harm, Including Suicide

HMHDB (DAD/HMD/ HMHS/OMHRS

Mental Health and Substance Use Disorder Discharges

Mental Illness Hospitalization

Mental Illness Patient Days

Total Days Stayed for Mental Health and Substance Use Disorder Hospitalizations

Navigation of Mental Health and Substance Use Services Indicator Provincial/territorial data collection systems

Wait Times for Community Mental Health Counselling

NARCS

Frequent ER Visits for Help with Mental Health and Substance Use

Statistics Canada

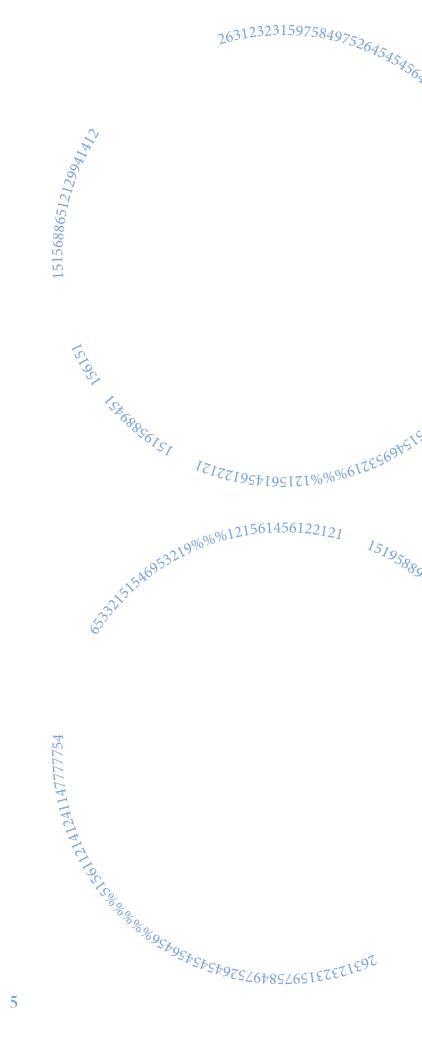
Statistics Canada is the national statistical office of Canada. It provides key information on Canada's economy, society, and environment. Statistics Canada conducts a Census every 5 years and regularly conducts approximately 350 surveys annually on all aspects of Canadian life to provide the information and data required to support good decision making.

The Canadian census collects information on various demographic and socioeconomic factors including but not limited to:

- Age, sex at birth, and gender •
- Education •
- Ethnocultural and religious diversity •
- Families, households, and marital status ٠
- Housing •
- Immigration, place of birth, and citizenship •
- Income •
- Indigenous peoples
- Language

The Vital Statistics Council for Canada is an inter-jurisdictional advisory group that collects information from the official records of live births, stillbirths, and deaths from the vital statistics divisions/agencies of all provinces and territories. This data provides the basis for key indicators such as life expectancy, infant mortality, causes of death, fertility and mortality rates. The council is responsible for developing standardized approaches for the collection of vital statistics and data sharing with external stakeholders.

The surveys and statistical programs arm of Statistics Canada produces high-quality data and statistics on issues affecting Canadians. Surveys are conducted in compliance with public health guidelines and participants are invited based on census responses or random selection.



Statistics Canada data holdings

<u>Canadian Vital</u> <u>Statistics</u> <u>Registries – Birth</u> <u>Database (CVSB)</u>	 Annual administrative survey that collects information on all live births in Canada Includes date and place of birth, child's sex, birth weight and gestational age, parents' age, marital status and birthplace, mother's place of residence, type of birth (single or multiple) and parity.
<u>Canadian Vital</u> <u>Statistics</u> <u>– Death Database</u> (CVSD)	 Annual administrative survey that collects demographic and medical (cause of death) information on all deaths occurring in Canada each year Causes of death classified according to the WHO's International Statistical Classification of Diseases and Related Health Problems (ICD-10) Includes basic demographic information, date of death, underlying cause of death and location of death.
<u>Vital Statistics –</u> <u>Stillbirth</u> Database (CVSS)	 Annual administrative survey that collects demographic and medical (cause of death) information on all stillbirths (fetal deaths) occurring in Canada each year Includes date and place of stillbirth, sex, birthweight and gestational age of fetus, parents' age, martial status and birthplace, mother's place of residence, type of birth (single or multiple) and parity.
Canadian Community Health Survey (CCHS)	 Annual cross-sectional survey that collects information related to health status, health care utilization and health determinants at sub-provincial levels Targets the population 12 years of age and over in all provinces and territories Respondents are asked to share their provincial health insurance numbers in an effort to link survey results with provincial health data.
<u>Canadian Health</u> <u>Measures Survey</u> (CHMS)	 Survey conducted every 2 years that collects information about health history and health-related lifestyle behaviours to better understand the relationships between disease risk factors and risk conditions including obesity, hypertension, cardiovascular disease, infectious disease, and environmental contaminants Participation is voluntary and includes a physical examination.
Mental Health and Access to Care Survey (MHACS)	 One-time 2022 survey that collects information about mental health status of Canadians and their need for and access to services and supports, whether formal or informal Also aims to assess the impact of COVID-19 on population health and evaluate the patterns of mental health, service use, and functioning over the past 10 years.
Survey on COVID-19 and Mental Health (SCMH)	 One-time survey conducted in 2021 that collected data on the impacts of COVID-19 on the mental health and wellbeing of Canadians including behaviours and symptoms.
Survey on Mental Health and Stressful Events (SMHSE)	 Occasional survey (last collection period 2021) that collects information on how stressful events can impact mental health and wellbeing.

Statistics Canada mental health indicators

The complete list of mental health indicators available from Statistics Canada varies yearly depending on the surveys circulated to Canadians. The surveys and databases listed in the table above provide data on the following mental health-specific indicators (among others):

MHACS

Alcohol or drug use disorder

Mental or substance use disorder

Bipolar disorder

Cannabis or other drug use

Generalized anxiety disorder

Major depressive episode

Mental health services, professional consultation/ service use

Mood disorder

Perceived mental health

Perceived need for mental health care (met)

Post-traumatic stress disorder

Schizophrenia or psychosis

Suicidal thoughts

<u>CCHS</u>

Health indicators

Health services

Life stress

Mental health indicator

Diagnosed mood disorder

Perceived mental health

Perceived need for mental health care

Waiting time for specialized medical services

SCMH/SMHSE

Mental health (general, anxiety, depression, PTSD, suicide)

Mental health services

Alcohol

Cannabis

Household violence

Social provisions

Indigenous identity

Sociodemographic

CVSD/CVSS/CVSB

Cause of death

Infant death/mortality

Perinatal death/mortality

Government of Canada

Several National government agencies contribute to and provide support for health science, research, data, monitoring and surveillance, and reporting on the determinants of health for Canadians.

The Public Health Agency of Canada (PHAC) is part of the Government of Canada's federal health portfolio. It focusses on the prevention of disease and injuries, the promotion of good physical and mental health, and provision of information to support decision-making and protect the health of Canadians. PHAC manages various monitoring and surveillance projects related to public health.

Health Canada helps Canadians improve their health and reduce health risks by ensuring that health services are high-quality and accessible. Health Canada oversees product and drug safety, including recalls, standards, and regulations, environmental and workplace health, food and nutrition, the health care system and healthy living.

The Health Infobase hosts a summary of Canadian health data through the use of interactive data tools, infographics, charts, and written reports. Information is captured and compiled from various sources including PHAC, CIHI, Statistics Canada, and the Canadian Institutes for Health Research (CIHR).

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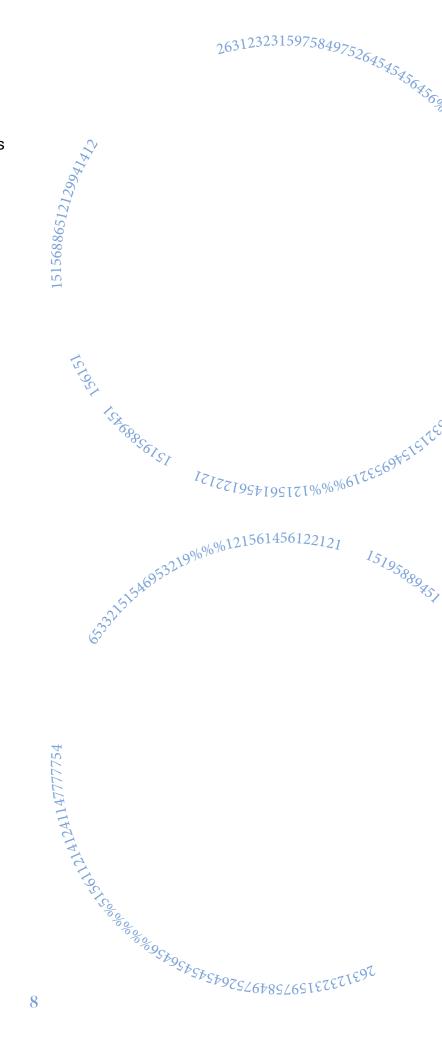
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Government of Canada data holdings

Canadian Chronic Disease Surveillance System (CCDSS)	 Collaborative network of provincial and territorial surveillance systems supported by PHAC that collects administrative data on all residents using provincial or territorial health insurance records Registry records are linked to corresponding physician billing claims, CIHI's hospital discharge abstract database (DAD), and prescription drug records Captures data on morbidity and mortality, health events and complications, and use of health services.
Canadian Perinatal Surveillance System (CPSS)	 Part of Health Canada's initiative to strengthen national health surveillance capacity National health surveillance program that aims to improve the health of pregnant women, mothers and infants through reporting on trends and patterns in health status and factors influencing health status from all pregnancies Includes 52 perinatal health indicators around maternal, fetal and infant health determinants and outcomes Principal data sources for the CPSS are the Statistics Canada Vital Statistics System, CIHI DAD, and independent provincial reporting systems.
Canadian Congenital Anomalies Surveillance Network (CCASN)	 Created under the umbrella of the Canadian Perinatal Surveillance System (CPSS) as a national framework to enhance quality of surveillance data on congenital anomalies.
Canadian Alcohol and Drugs Survey (CADS)	 Biennial survey of alcohol and drug use among Canadians aged 15 and older including questions about alcohol-related harms, alcohol use during pregnancy, and past-year and lifetime use of several drugs including cannabis, psychoactive pharmaceuticals, opioids, cocaine, ecstasy, methamphetamines, and others Conducted by Health Canada in partnership with Statistics Canada.
Opioid- and stimulant-related harms surveillance system	 Monitors fatal and non-fatal harms related to opioids and stimulants Data is provided by provincial and territorial offices of Chief Coroners and Chief Medical Examiners as well as CIHI and provincial and territorial Emergency Medical Services.

Government of Canada mental health indicators

CCDSS

Use of health services for mental illness and alcohol/drug induced disorders, mood and anxiety disorders, and schizophrenia

CADS

Current and past alcohol and drug use

Alcohol and drug related harms

<u>CPSS</u>

Alcohol consumption during pregnancy

Fetal and infant mortality

Gaps that currently exist in Canada's national health databases

While a number of national organizations have initiatives and systems for the surveillance of mental illness in Canada, data capture seems to be sporadic, incomplete, and lacking in focus. There is no single organization at the national level that comprehensively gathers and reports on the mental health of Canadians, including access to specialized services.

Administrative data forms the basis of most data collection in Canada's national data systems and registries and provides a large volume of population-level information to draw from. Aggregation of data across jurisdictions, as done by CIHI, can also shed light on important issues in the provision of health services. However, the variables included in administrative systems are often limited as they were designed to capture information for billing or other clerical purposes. As such, they contain only simple demographic and diagnostic information based on specific coding dictionaries and fail to account for individual risks, comorbidities, functioning, or quality of life. In particular, administrative datasets rarely capture information on the social determinants of health, such as race/ ethnicity, income, and education, all of which are known to contribute greatly to disparities in mental illnesses and substance use.

Variations in coding practices of individual physicians can also lead to inaccuracies in information, especially for mental illnesses given the complexity of mental health diagnoses and treatment pathways. Community-based agencies and informal support systems are often omitted from national datasets, and for patients treated with pharmacological methods, only those with provincial/territorial drug coverage will be captured by administrative datasets, which creates a large gap in knowledge. Further, as only one code can be used per visit with a health care provider, any concomitant mental illnesses, such as depression and anxiety, may be reduced to a single diagnosis, provided that any formal diagnosis is made, which is not often the case. Indeed, many individuals who suffer from mental illness do not seek formal care through health care services and may not be captured by administrative records at all. Some national cross-sectional surveys, such as the Canadian Community Health Survey, aim to bridge this gap by capturing broader information on mental illnesses not captured by formal administrative data.

National cross-sectional surveys provide a large array of population-based, communitylevel data, and can be specifically tailored to report on a specific topic, such as mental illness, with more in-depth information than administrative data. However, these surveys are dependent on voluntary responses and self-reporting, which may limit accuracy based on the respondents' ability to recall information that is often sensitive in nature. Further, sample demographics can be inconsistent across different surveys and the format of questions used to measure the same concepts can differ. making it hard to conduct cross-survey analyses. The time it takes to compile and centralize data across jurisdictions, coupled with privacy legislation processes, means analyses and reporting of information in datasets is often delayed for years after data is first available. Further, with many surveys distributed by Statistics Canada, large swaths of the population, including residents of the three territories, persons living on reserves or Crown lands, those who are members of the Canadian Armed Forces, and individuals who live in collective institutions (e.g., nursing homes and correctional institutions) are excluded from participating. This creates significant gaps in the perspective of Canadian health, particularly with respect to mental illness, which can be disproportionately high in these populations.

Finally, one of the key gaps in existing national datasets/registries is that they are often incapable of creating meaningful linkages between data. In some surveys distributed by Statistics Canada, including the CCHS, participants are asked to share their health insurance numbers, which creates capacity to link the survey data to administrative records; however, there are limits on who can access this data due to current privacy regulations. When considering perinatal mental illness or mental health care in the pregnant and postpartum periods, there appears to be virtually no information available at a national level, as pre-existing systems and datasets fail to make linkages between mental health indicators and pregnancy. Although CIHI captures mandatory data fields relating to reproductive care including number of previous births, gestational age, and delivery data, mental health indicators, such as Mental Illness Hospitalization, only link to data fields regarding age, sex, and postal code. Within some cross-sectional surveys, including the CCHS, pregnancy is discussed as is mental health; however, the survey fails to make any meaningful connection between the two data fields. Similarly, in Statistics Canada's Mental Health and Access to Care Survey (MHACS) pregnancy/postpartum is referenced as a possible cause for mental illness alongside other reasons such as exhaustion, weight, and cancer; however, without a formal diagnosis of mental illness during the perinatal period, it is unlikely that respondents would make this connection. Thus, while it seems pre-existing systems may have the potential to analyze connections between pregnancy and individual health status or the use of formal services. the current processes do not allow for such linkages, which are incredibly important to creating meaningful practice and policy decisions.

Recommendations

- Create a national strategic framework or system for the capture of mental healthrelated data in Canada including a minimum dataset of common indicators
- Promote access to and use of data to allow for more efficient reporting and information-sharing
- Incorporate data fields for sociodemographic information, including race/ethnicity, and the social determinants of health, including housing and employment, into existing administrative forms
- Develop linkages between administrative and survey data to connect personal demographics and community-based data with formal hospital records
- Allow multiple coding practices for mental illnesses or broaden definitions to limit inaccuracies in reporting and take into account co-occurrences of mental illness and substance use
- Ease restrictions on who can participate in national cross-sectional surveys to ensure an accurate picture of mental illness in Canada in sample population
- Create links between pre-existing data sets or incorporate data fields on reproductive measures into newly developed surveys to capture information on perinatal mental health.

Appendix 1: Summary of national datasets and registries

Dataset	Data type	Data source(s)	Data elements		Possible linkages	
СІНІ						
Inpatient discharg	Inpatient discharges and stays					
Discharge Abstract Database (DAD)	Administrative	Acute care facilities or health/regional authorities in all P/Ts except Quebec	Acute inpatient care and discharges, day surgeries (all P/Ts except Quebec)	Age, sex	Person, FSA2, reproductive care information ³	
Hospital Morbidity Database (HMDB)	Administrative	Majority of records are from the DAD; data submitted by Ministère de la Santé et des Services sociaux du Québec is included in the DAD-HMDB	Acute inpatient care and discharges, Quebec day surgeries	Age, sex	Person, FSA, reproductive care information	
Hospital Mental Health Database (HMHDB)	Administrative	DAD, HMDB, Hospital Mental Health Survey (HMHS), Ontario Mental Health Reporting System (OMHRS)	Acute inpatient stays and separation records from all P/Ts for both general and psychiatric hospitals	Age, sex	Person, FSA, reproductive care information	
Emergency department visits and outpatient data						
National Ambulatory Care Reporting System (NACRS)	Administrative	Participating facilities or regional health authorities/ ministries of health	Hospital- and community-based ambulatory care (day surgeries, outpatient clinics, emergency department visits)	Age, sex	Person, FSA, reproductive care information	

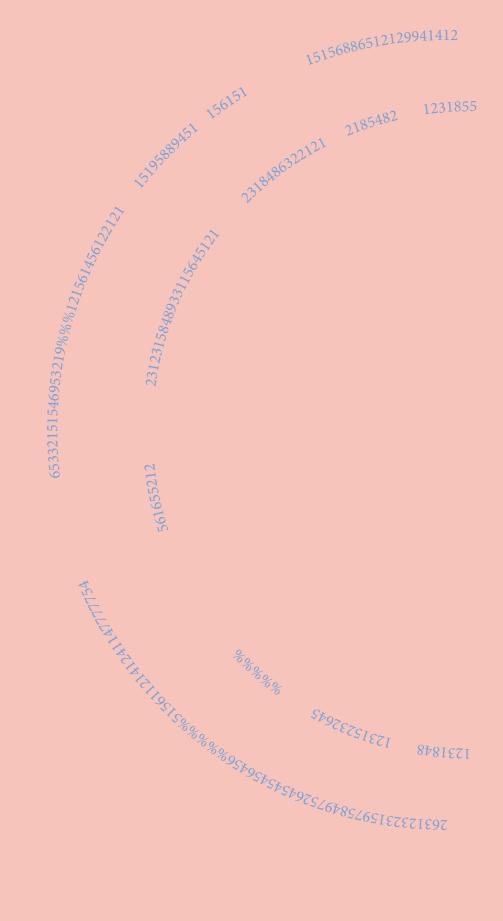
Dataset	Data type	Data source(s)	Data elements		Possible linkages	
Statistics Canada						
Annual and ongoing						
Canadian Vital Statistics Registries (<u>CVSB</u>), (<u>CVSD</u>), (<u>CVSS</u>)	Administrative	Vital statistics agencies/divisions of all P/Ts	Official records of live births (CVSB), stillbirths (CVSSB), and deaths (CVSD)	Age, sex, marital status, Aboriginal ancestry/ Indigenous status (CVSD), education (CVSD), income (CVSD)	Person, FSA, reproductive care information	
Canadian Community Health Survey (CCHS)	Cross-sectional survey	Sample Canadian population aged 18 and older (excluding persons living on reserves or Aboriginal settlements, fulltime members of the Canadian forces, institutionalized persons)	Various health themes	Age, sex, Aboriginal identity, BMI, citizenship, diet and food insecurity, education, language, immigrant status, marital status, sexual orientation, visible minority	Reproductive care information	
One time or occasi	ional					
Mental <u>Health and</u> <u>Access to</u> <u>Care Survey</u> (MHACS)	Cross-sectional survey	Sample Canadian population aged 15 and older living in the 10 provinces (excluding persons living on reserves or Aboriginal settlements, fulltime members of the Canadian forces, persons living in collective dwellings/ institutions)	Mental health status as well as access to and need for services and supports	Age, sex		
Survey on COVID-19 and Mental <u>Health</u> (SCMH)	Cross-sectional survey	Sample Canadian population aged 18 and older living in the 10 provinces (excluding persons living on reserves or in collective dwellings/ institutions)	Mental health status related to COVID-19	Age, sex, employment, Indigenous identity, race, place of birth, immigration, citizenship, marital status, education, income		
Survey on Mental Health and Stressful Events (SMHSE)	Cross-sectional survey	Sample Canadian population aged 18 and older living in the 10 provinces (excluding persons living in the 3 territories, on reserves, in institutions, and collective dwellings)	Mental health status as well as access to and need for services and supports	Age, sex, employment, social supports, Indigenous identity, race, place of birth, immigration, citizenship, marital status, education, income	12	

Dataset	Data type	Data source(s)	Data elements		Possible linkages		
Government of Ca	Government of Canada						
Opioid- and stimulant-related harms surveillance system	Administrative	Death records of the Chief Coroners or Chief Medical Examiners of P/Ts, CIHI's DAD, Emergency Medical Services (EMS) of P/Ts	Deaths, poisoning hospitalizations, and EMS responses (naloxone administration) to suspected overdoses due to opioid and stimulant toxicity	Age, sex	Person, FSA		
PHAC							
Canadian Chronic Disease Surveillance System (CCDSS)	Administrative	P/Ts health insurance registry records (linked to physician billing claims, hospital DAD, and prescription drug records)	Chronic diseases and conditions including morbidity and mortality, health events and complications, and use of health services	Age, sex	Person, FSA		
Canadian Perinatal Surveillance System (CPSS)	Administrative and survey based data	CIHI's DAD, Statistics Canada's CCHS and Vital Statistics	Health behaviours and practices, health services, maternal outcomes, infant outcomes	Age, sex	Person, FSA		
Health Canada							
<u>Canadian</u> <u>Alcohol and</u> <u>Drugs Survey</u> <u>(CADS)</u>	Cross-sectional survey	Sample Canadian population aged 15 and older (excluding residents of the 3 territories and persons who live on reserves or in institutions)	Alcohol and drug use including related harms	Age, sex			

¹Table adapted from: Mental Health Commission of Canada. (2014) Overview of Mental Health Data in Canada: Background, Needs, and Gaps, Calgary, AB.

²FSA (forward sortation area) designates a geographical unit based on the first three characters of a Canadian postal code

³Reproductive care information includes information on previous deliveries (term and pre-term), abortions (therapeutic and spontaneous), gestational age, and date of last menses



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