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Commission
of Canada

Commission de
la santé mentale
du Canada

Overview on Mental Health Data in Canada

Background, Needs, and Gaps

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A Framework for a Mental Health Strategy for Canada

Information for Mental Health System Transformation: Background

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GLOSSARY OF INITIALISMS AND ACRONYMS

AADAC	Alberta Alcohol and Drug Abuse Commission
ACCS	Ambulatory Care Classification System
AFM	Addictions Foundation of Manitoba
AFN	Assembly of First Nations
APS	Aboriginal People's Survey
ARMHIS	Alberta Regional Mental Health Information System (AB)
BRFSS	Behavioral Risk Factor Surveillance System
CADUMS	Canadian Alcohol and Drug Use Monitoring Survey
CAMH	Centre for Addiction and Mental Health
CAMIMH	Canadian Alliance on Mental Illness and Mental Health
CAPE	Canadian Academy of Psychiatric Epidemiology
CAR-BC	Centre for Addictions Research of BC
CARMHA	Centre for Applied Research in Mental Health and Addictions
CAS	Canadian Addiction Survey
CCDSS	Canadian Chronic Diseases Surveillance System
CCOH	Chiefs Committee on Health
CCRS	Continuing Care Reporting System
CCSA	Canadian Centre on Substance Abuse
CDC	Centers for Disease Control (US)
CCHS	Canadian Community Health Surveys
CCHS-CF	Canadian Community Health Surveys – Canadian Forces
CCHS 1.2	Canadian Community Health Surveys, Cycle 1.2
CCMED	Canadian Coroner and Medical Examiner Database
CECA	Canadian Executive Council on Addictions
CHIRPP	Canadian Hospital Injury Reporting and Prevention Program
CHMS	Canadian Health Measures Survey
CIHI	The Canadian Institute for Health Information
CIHR	Canadian Institutes of Health Research
CIS-R	Revised Clinical Interview Schedule
CMHA	Canadian Mental Health Association
COMHS	Continuity of Mental Health Services of Alberta
CPA	Canadian Psychological Association/Canadian Psychiatric Association
CPIM	Community-Based Psychiatry Services Database (BC)
CPHI	Canadian Population Health Initiative
CLSA	Canadian Longitudinal Study on Aging
CMHEI	Community Mental Health Evaluation Initiative
CPCSSN	Canadian Primary Care Sentinel Surveillance Network
DAD	Discharge Abstract Database
DIS	Diagnostic Interview Schedule
DISC	Diagnostic Interview Schedule for Children
DSM	Diagnostic and Statistical Manual
EHR	electronic health record

ER	emergency room
FNIGC	First Nations Information Governance Committee
FNIHRS	First Nations and Inuit Regional Health Survey
FRSQ	Fonds de la recherche en santé du Québec
GHQ	General Health Questionnaire
GPRD	General Practice Research Database (UK)
HMHDB	Hospital Mental Health Database
HONOS	Health of the Nations Outcomes Scale
HRSDC	Human Resources and Skills Development Canada
HSBC	Health Behavior in School Children
ICD	International Classification of Diseases
ICES	Institute for Clinical Evaluative Sciences
IMHI	International Mental Health Indicator Project
IMHIP	Improving Mental Health Information Programme
ISD	Information Services Division (of National Health Service, Scotland)
ISQ	Institut de la Statistique du Québec
ISM	Information System Management Database (PEI)
LOS	length of stay
MCHP	Manitoba Centre for Health Policy
MCP	Medical Care Plan (NL)
MHCC	Mental Health Commission of Canada
MHECCU	Mental Health Evaluation and Community Consultation Unit
MHMIS	Mental Health Management Information System
MHOIS	Mental Health Outpatient Information System (NS)
MHRA	Medicines and Healthcare Products Regulatory Agency (UK)
MIS	Management Information System (ON, MB)
MSI	Medical Services Insurance (NS)
MSP	Medical Services Plan (BC)
MSSS	Ministère de la Santé et des Services sociaux
NACRS	National Ambulatory Care Reporting System
NHANES	National Health and Nutrition Examination Survey
NHAHRC	National Health and Hospitals Reform Commission (Australia)
NHS	National Health Service (UK)
NLSCY	National Longitudinal Survey of Children and Youth
NPDUIS	National Prescription Drug Utilization Information System
NPHS	National Population Health Survey
OCAN	Ontario Common Assessment of Need
OCHS	Ontario Child Health Survey
ODBD	Ontario Drug Benefit Database
OECD	Organization for Economic Co-operation
OHIP	Ontario Health Insurance Plan
OHS	Ontario Health Survey
OMHRS	Ontario Mental Health Reporting System
PALS	Participation and Activity Limitation Survey

PHRN	Population Health Research Network
PHAC	Public Health Agency of Canada
PHRU	Population Health Research Unit (BC)
PTSD	Post-traumatic stress disorder
RAI-MH	Resident Assessment Instrument – Mental Health
RAMQ	Régie de l'assurance maladie du Québec
RHS	First Nations Regional Longitudinal Health Survey
SIID	Strategic Initiatives and Innovations Directorate
SLCDC	Survey on Living with Chronic Disease in Canada
UM-CIDI	University of Michigan Composite International Diagnostic Interview
WHO	World Health Organization
WHODASII	World Health Organization Disability Assessment Schedule II

EXECUTIVE SUMMARY

Background

The federal government has given the Mental Health Commission of Canada (MHCC) a mandate to spark transformative change in the country's mental health system. The ability of the MHCC and its stakeholders to create, share, and access data around mental health and mental illnesses is an important requirement to help achieve this goal. Such data is critical to informing service providers, decision-makers, health organizations and many other groups about the mental health needs of Canadians, and the approaches needed to meet those needs.

In its landmark blueprint for system change, *Changing Directions, Changing Lives: The Mental Health Strategy for Canada*, the MHCC identified the improvement of mental health data collection, research, and knowledge exchange across Canada as a key priority. As part of its own work on this priority even before the release of the *Strategy*, the MHCC collaborated with its partners to undertake two reports on the availability of mental health data in Canada. This overview synthesizes and updates the findings of those previous publications, identifying where such data on mental health and mental illnesses exists and in what form, while also examining where and how information remains lacking.

National and provincial mental health data initiatives

A handful of key national organizations have mental health information-related initiatives within their broader health mandates. These include the Public Health Agency of Canada, which has developed a fairly strong system for the surveillance of mental illnesses; Statistics Canada, which has made mental health a special topic of interest in some surveys; and the Canadian Institute for Health Research, which made mental health and resilience a key area of focus for a three-year period of its Canadian Population Health Initiative.

While the above mentioned organizations continue to make valuable contributions, there is no clear vision for mental health information as a whole. There is also no single organization at the national level dedicated to gathering and reporting on mental health services and policies. At the provincial level, some broader health data analysis/reporting organizations have done mental health-related analyses in recent years. However, no organization or division is dedicated solely to the collection, analysis, and dissemination of mental health information at the provincial and territorial level.

Administrative data

Broader population data from administrative sources is one of the varieties of mental health information currently available in Canada. These data are collected at a high level, most often by provinces, for the purpose of managing health care, and include four major types: hospital admissions and discharges, physician billing, ambulatory care, and drug databases. Sources also exist for national administrative data, such as the Canadian Institute for Health Research.

The volume of administrative data regarding Canadian health services is enormous, and their ability to provide nearly complete population coverage for all publicly funded services is an important strength. However, there are also many serious limitations to such data, such as a very limited scope, long delays to access them, and the fact they do not include individuals who may not access or receive care. In mental health, these may be some of the highest need individuals.

Surveys

Surveys are another source of mental health data available in Canada. Population-based cross-sectional surveys identify a population sample then interview individuals within it. The main national source of such surveys that provide mental health data is the Canadian Community Health Survey, Cycle 1.2. conducted in 2002. Other national and provincial population-based cross-sectional surveys have also made contributions to the mental health data landscape.

These surveys are more flexible and able to provide comprehensive information in comparison with administrative data. Surveys can also capture the full continua of mental illness (from brief subthreshold symptoms through to longstanding serious disorders), as well as the continua of mental health as a positive asset in individuals without symptoms. Additionally, they can be tailored to address issues of topical interest, and are not restricted to capturing information only from those who access formal health care services.

A major limitation of cross-sectional surveys is inherent in their design; all information is collected from a person at a single point in time, making it impossible clearly examine trajectories of risk and resilience, symptoms and illness, care sought and received, and the outcomes of interventions across time as they happen. National and provincial surveys use different instruments to measure the same concepts, particularly diagnoses, making it difficult to do cross-survey analyses within Canada. And measurement and data gathering methods continue to need refinement, as do the practical aspects of planning, developing, conducting surveys.

Longitudinal/cohort studies

Longitudinal (or cohort) studies fall within the domain of formal academic research, and answer questions about which risk factors or antecedent conditions are associated with the subsequent occurrence of an illness. Topics of interest can be defined very specifically and measured relatively precisely. These studies are especially valuable for studying phenomena that occur

over time, including the delivery of service interventions and outcomes, not just the development of illness.

Quality examples of such studies exist in mental health research, but very few could be considered national in scope. Provincially, there are likely dozens of cohort studies on particular topics and/or special clinical populations that are relevant to mental health, but there is no central catalogue or information on such studies in Canada. Those described in this overview were included because they were/are either very broad in scope (across illnesses and settings), or were directly sponsored by government or conducted as a partnership with policy/decision-makers.

Longitudinal studies can be expensive to plan, implement, and ensure complete follow-up. If designed appropriately, however, they can replace resources spend on multiple, less comprehensive initiatives. And since many mental health problems and illnesses are prevalent and develop over shorter time periods than some other chronic diseases, longitudinal studies may not have to be as large, or as long, to provide useful answers.

Other sources

A few other types and sources of data are used to inform important issues about population and health care delivery in Canada, and some of these are being, or could be, used to inform on mental health and mental illnesses. Among these other sources are sentinel reporting systems, case registries, electronic health records, and performance measurement systems.

Filling the gaps

There is a diverse set of national-level mental health information-related initiatives in Canada. While laudable, none of these initiatives, even in combination, represents a comprehensive set of mental health information that can be used to answer important questions about population mental health at this time. Serious gaps in data also exist at the provincial and territorial level.

The findings in this overview suggest the need for a more collaborative approach moving forward. There should be a focus on the need to shift data collection efforts from a siloed approach toward an integrated health/social system perspective that would capture pertinent mental health information along the continuum of care and services that are available in a variety of settings (including health and social/community services), and provided by a multitude of players. This shift in focus would ensure that data and information are collected at transition points, and that the information related to the person's journey is captured in a consistent way, and over time.

The MHCC and several stakeholders are already working together toward this focus. The Mental Health Information and Addictions Collaborative (the Collaborative) is an effort catalyzed by the MHCC to support the Canadian mental health data landscape through effective and ongoing collaboration. The Collaborative identifies opportunities and facilitates efforts aimed at furthering this purpose through

integration and quality improvement of existing data resources, and the development of new resources that fill mental health and addictions information gaps.

INFORMATION FOR MENTAL HEALTH SYSTEM TRANSFORMATION

“Information is a source of learning. But unless it is organized, processed, and available to the right people in a format for decision making, it is a burden, not a benefit.” William Pollard

Overview

The Mental Health Commission of Canada (MHCC) and its stakeholders consider information to be foundational to achieving its vision of a transformed mental health system in which “All people in Canada have the opportunity to achieve the best possible mental health and well-being”¹. Health care for those living with mental health problems and illnesses is among the most complex systems in health to manage, yet the data for informing system improvement remains rudimentary and fragmented, even in highly technically developed jurisdictions. The establishment of the MHCC, with its mandate for catalyzing mental health system¹ change, has provided an opportunity for a broad range of stakeholders to systematically review and recommend strategies for changes in the way data on mental health is collected, used, and accessed in Canada. These multi-stakeholder conversations were designed to identify ways to realize the vision of a transformed mental health system to lead to the best outcomes for mental health and well-being.

This document provides background and reference information on the topic area identified as “data”; that is, the role that mental health-related information can have in achieving the system transformation vision¹. In keeping with the mandate of the MHCC, it focuses on population, services and policy-relevant information, and as such does not address basic science or biomedical information. To support further discussion on this topic, the current mental health information landscape in Canada is described along with brief information about some international developments. The needs identification and gap analysis contains a compilation of stakeholder views on information needed for system transformation, relevant information from the literature, an appendix of findings from a recent MHCC project which included a data gap analysis, and an appendix summarizing consultations with experts regarding the current state of data on mental health in Canada and suggestions regarding how to move forward with data collection in the future.

A Brief History of the Mental Health Information Issue in Canada

The need for more readily available, comprehensive, and useful mental health information in Canada has been expressed by key mental health stakeholders for more than a decade. For example, the Canadian Alliance on Mental Illness and Mental Health (CAMIMH)², founded in 1998, called for the collection and assembly of data which “would help Canada monitor and report periodically how well we are meeting the needs of persons with mental illnesses and in promoting the mental health of

¹ Throughout this document the term ‘mental health system’ is defined from a population health perspective and includes determinants as well as a full continuum of interventions from promotion and prevention through to specialized care. In addition, mental health is conceptualized according to the dual continua model.

² CAMIMH – The Canadian Alliance on Mental Illness and Mental Health is an alliance of mental health organizations including health care providers and persons living with mental health problems and illnesses and their families. It was established in 1998, is based in Ottawa, and has a mandate “to ensure that mental health is placed on the national agenda so that persons with a lived experience of mental illness and their families receive appropriate access to care and support”. <http://www.camimh.ca/> accessed April 15, 2010.

Canadians” as one of four goals for action². In 1999, CAMIMH and the Centre for Chronic Disease Prevention and Control, currently with the Public Health Agency of Canada (PHAC)³, held a workshop to develop mental health indicators, which was followed in 2005 by a workshop to develop strategies for expanding mental illness surveillance in Canada. Similar needs continue to be expressed.

In the Standing Senate Committee report *Out of the Shadows at Last* (2006) it was noted that “There is still a dearth of specific information in this country, regarding incidence, prevalence, treatments, treatment quality and knowledge transfer”³. The report recommended that the newly formed MHCC work with the PHAC to develop a comprehensive national mental health surveillance system. The need was also reiterated in the MHCC’s *Toward Recovery & Well-Being: A Framework for a Mental Health Strategy for Canada* (2009) as follows: “At the national level, some efforts have been made to gather data on mental health and mental illness, but these efforts have been inconsistent and fall short of the comprehensive and coordinated data collection that is required”⁴.

The release of the *Mental Health Strategy for Canada* in 2012 noted a strong importance of data collection and use for Canada. The priority 6.2 notes “Improve mental health data collection, research, and knowledge exchange across Canada”. The focus is to expand our data collection abilities to measure progress in transforming the system. It notes that there are a number of areas in which data are limited. The *Strategy* suggests two tracks for proceeding: the first is to identify the indicators for which data could be collected relatively easily; the second track will involve a framework for compiling comprehensive data on the range of health and social outcomes, and establish a system to collect the required data.

Toward Better Mental Health Information in Canada – Foundations for Dialogue

These recent foundational mental health documents contain the voices of stakeholders who express priorities for desired characteristics and functions for mental health information. These statements include a variety of terms to express related concepts, and they imply but do not further specify structures, types of data, or processes that would achieve the vision.

This document is organized to move from these general expressions of priority to a description of what currently exists to inform discussions of specific strategy options. **Section One** provides definitions for relevant terms to support common understanding of the concepts. **Section Two** describes the current mental health information landscape in Canada. It includes descriptions of key national and provincial organizations that have had roles in collecting, analyzing, and/or disseminating mental health data and their related recent initiatives, as well as the types of mental health information currently available, and the strengths and limitations of each. **Section Three** outlines a few noteworthy international mental health information initiatives. Finally, **Section Four** summarizes the current status of the issue and offers some options and recommendations for advancing a national mental health information agenda. Findings from focused peer-reviewed and grey literature searches on mental health surveillance are integrated throughout. In addition, advances continue to be made on conceptualizing and evaluating

³ The Public Health Agency of Canada is further described in Section Two.

surveillance systems more generally that, while not included in this document, are readily available to inform new efforts.

SECTION ONE – DEFINITIONS FOR KEY TERMS

Terms important to this topic area are typically used loosely and often interchangeably in everyday language. For the purpose of this document, and to assist the subsequent dialogue, we offer the following definitions:

Important and helpful distinctions have been made among the terms **data**, **information**, **knowledge**, and **understanding**⁵⁻⁷. **Data** are simple numbers (quantitative) or symbols (including words [qualitative data]) that can be digitally transmitted or processed. Sets of data often include duplicate or unneeded content for questions of interest. Therefore, the data need to be processed to become useful and meaningful as **information**, which can answer specific questions. **Knowledge** is a broader composite of information derived from study, investigation, observation, or experience, which may be used to inform or consider a complex problem. **Understanding** goes beyond knowledge, and is required in order to synthesize existing knowledge to build on and produce new/novel ideas.

In the realms of data/information, commonly used terms include **measure**, **indicator** and **variable**. A **measure** is defined as “the dimension, amount or capacity of something ascertained by measuring”⁷ and implies more complete, precise, or direct representation of the object of measurement. In contrast, an **indicator** is “a simple marker or pointer that suggests something about a more complex phenomena which may not be directly, fully or easily measured”^{8,9}. Indicators also typically involve comparisons with a target or desired outcome. Since health status and health care delivery are such complex phenomena, indicators are often used in place of more complete measures. A **variable** is any characteristic or attribute that varies in value (e.g., the variable ‘years of education’ can have many values). In health care or health policy, variables are often described as ‘structure’ variables (e.g., facilities, simple numbers of persons seen, and resources spent); ‘process’ variables (the activities of care delivery), and ‘outcome’ variables (changes in a person’s health that can be attributable to the services)¹⁰.

Finally, the term **surveillance** is essential to this topic. It should not be confused with its other meaning as “close observation of a person or group”, such as by a law enforcement authority. In the health context, surveillance is defined as “the ongoing, systematic collection, analysis, interpretation, and dissemination of data regarding a health-related event for use in public health action to reduce morbidity and mortality and to improve health”¹¹. This definition is adopted by the US Centers for Disease Control and Prevention, the World Health Organization, and favoured by the PHAC. While other definitions are available, all include the three main aspects of systematic **data** collection: analysis; interpretation and reporting (to create **information**); and the dissemination of that information for decision-making (including public health action, program planning and/or evaluation). Surveillance has its origins in the tracking of infectious diseases, but is increasingly being used across a range of health domains, including mental health problems and illnesses, diabetes, arthritis, cancer, and circulatory disease¹². It is also increasingly recognized as having application to many contexts beyond public health. A surveillance ‘system’ is usually not a single information system, but a ‘program’ of strategic identification, collation, analysis, and reporting out from multiple sources. Surveillance is often ‘passive’; for example, a common approach is to mine data which is routinely collected for other purposes (e.g., administration of health care services) to minimize costs. However, sources can also include other

secondary data, such as from special surveys and even collection of new data, defined as 'active' surveillance. Active surveillance involves intensive work around proactively seeking case reports of a specific disease from health professionals, or other key information about a population. For example, an active surveillance system is established when a department of health regularly contacts reporting sources (e.g., once per week,) to elicit reports, including negative reports for cases of a specific disease or other issue of interest.

SECTION TWO – THE CURRENT MENTAL HEALTH INFORMATION LANDSCAPE IN CANADA

Key National and Provincial Organizations

At the national level, the Public Health Agency of Canada (PHAC), Statistics Canada, and the Canadian Institute for Health Information (CIHI) have within their broader health information mandates some mental health information-related initiatives. A fourth organization, the Canadian Centre on Substance Abuse (CCSA), has a mandate to provide the important subset of information about mental health and illness and substance abuse.

The Public Health Agency of Canada

Prior to the creation of PHAC in 2004, national mental illness surveillance activities and mental health promotion activities were on the federal agenda through the Mental Health Promotion Unit, and the Centre for Chronic Disease Prevention and Control at Health Canada. (These functions moved to the PHAC once created, and remain part of the health portfolio of the federal government.) National mental illness surveillance began in 1999 when Health Canada and CAMIMH hosted a workshop to develop an indicator framework.

A five-year strategic plan for PHAC was launched in 2007, which included a focus on "ensuring public health actions are supported by integrated information and knowledge functions"¹³. PHAC supports a broad range of surveillance activities, including systems to track chronic diseases, injuries (intentional and unintentional), and infectious diseases. In 2009, PHAC announced a 15 million dollar, four-year initiative on the topic of neurological conditions, including dementia, aimed at filling knowledge gaps about Canadians, including children who are living with neurological conditions, and their caregivers. Key foci for new information was incidence, prevalence, comorbidity, risk factors, service use, service gaps, current impact (including costs), and impact projections over 20 years¹⁴. A report of the results will be available in June 2014.

With respect to mental health surveillance, the 2007 strategic plan noted that PHAC "will augment its capacity to address mental health and mental illness and develop a policy framework and action plan focused on developing information and knowledge, providing effective public health advice concerning effective interventions, and liaising with the new Mental Health Commission". In the report *Out of the Shadows at Last*³, the initial actions of PHAC in relation to mental health surveillance were noted, which included a 2005 workshop on the topic of surveillance. At that time PHAC had committed some funds to support further consultation, as well as feasibility and demonstration projects, and to have a proposal for a national mental illness surveillance system by March 2007. PHAC also produced *The Human Face of Mental Health and Illness in Canada* (2006)¹⁵ with input from multiple stakeholder organizations. This document reported general facts about mental health and illness from available data sources, and followed on from *A Report on Mental Illnesses in Canada* published by Health Canada in 2002¹⁶. That 2002 report listed future surveillance needs which, at the time, were organized according to major disorders (mood, anxiety, personality and eating disorders, schizophrenia and suicide). Future surveillance plans were not mentioned in the 2006 report, but some information gaps were identified.

In 2006, PHAC established a Mental Illness Surveillance Advisory Committee to advise it on the development, use, and evaluation of high quality, timely surveillance information. The Committee is

made up of 12 to 15 members with relevant expertise and interest from academia, health professional organizations, non-government organizations (including the MHCC), provincial/territorial governments, local/regional public health organizations, and CIHI. In 2012, this Committee was revitalized with an expanded mandate to include monitoring of positive mental health, and is now called the Mental Health and Mental Illness Surveillance Advisory Committee.

Over the years, PHAC has developed a fairly robust system for the surveillance of mental illnesses. Projects have included expansion of the Canadian Chronic Disease Surveillance System (administrative data platform) to include mental illnesses; a project led by the Canadian Psychological Association to develop and pilot a reporting system on adult clients seen by a sample of psychology practitioners across the country (both are described further in subsequent sections); and some exploratory work on possibilities for using data held by private sector partners (life/disability insurance, disability benefits management, drug card management, and employee assistance program management) to monitor workplace mental health. Work has also begun recently to identify possible indicators for mental illness surveillance across multiple administrations of the Canadian Community Health Survey, and related surveys. Some of this data are available on PHAC's Chronic Disease Infobase Cubes at www.infobase.phac-aspc.gc.ca. Data Cubes are interactive databases that quickly allow users to create tables and graphs (by age, sex, and province/territory) using their web browser. Past cycles of PHAC's Survey on Living with Chronic Diseases in Canada have included questions relating to the impact of living with various chronic diseases on mental health. In 2013, this methodology was applied to explore the impacts of living with mood and anxiety disorders. Data will be available in early 2015.

In 2010, PHAC expanded the Canadian Chronic Disease Surveillance System (CCDSS) to include mental illnesses, providing data for the first time on the population using health services (physicians or hospitalizations) for mental illnesses, and particularly the first data which includes children (see later in report). In 2014, PHAC will release the first two volumes of a series of reports on mental illnesses using this new data from the CCDSS. These reports will provide national data on mental illnesses and mood/anxiety disorders based on health administrative data, rather than self-reports. In 2013, feasibility work began to explore the potential expansion of the CCDSS to include other mental illnesses, such as psychoses and substance use disorders.

At various times the Mental Health and Mental Illness Surveillance Advisory Committee has also discussed the potential for other sources of data for surveillance of mental illnesses, including electronic health records, drug benefits data, specialty registries, and information from the education system¹⁷.

In addition, PHAC is enhancing, as well as expanding, its surveillance to monitor complementary data relevant to mental illness prevention and mental health promotion, such as: injury (suicide and self-directed violence), child maltreatment (abuse and neglect), maternity experiences (postpartum depression), mental health status, incidence, prevalence, comorbidities and outcomes of mental illness, and chronic disease surveillance. These efforts are an important response to the enactment of the Federal Framework for Suicide Prevention.

Surveillance of mental *illnesses* has traditionally not included measures of positive mental *health*. In response to this identified knowledge gap, PHAC sponsored an international workshop on developing an operational definition of positive mental health¹⁸. Approaches to measurement of positive mental health in Canadian surveys are evolving to also include indicators for child/youth and family well-being.

In 2010, PHAC identified mental health as a strategic priority, thereby necessitating the integration of mental illness and mental health activities – this includes a broadening of the surveillance and monitoring activities to include indicators of positive mental health, as well as mental illness and associated determinants.

In 2013, the federal government’s budget announced the reallocation of two million dollars “to improve data collection and reporting of mental illness and mental health, as recommended in the Mental Health Strategy for Canada, to improve knowledge and foster collaboration.” As part of this reallocation, PHAC is investing in finalizing a positive mental health indicator framework, including measures and data sources to report on positive mental health in Canada. All work is being closely coordinated with the MHCC and the federal health portfolio to prevent duplication of efforts, and to ensure the alignment between the MHCC’s and PHAC’s strategic priorities.

Statistics Canada

Statistics Canada is a member of Industry Canada, and for decades has had the legislated, federal responsibility to collect data/statistics on the Canadian population, its resources, economy, society, and culture. It is responsible for carrying out a federal census every five years, and also conducts approximately 350 surveys annually across a range of topics to support decision-making by elected representatives, businesses, unions, non-profit organizations, and the Canadian public¹⁹. Statistics Canada also collects vital statistics information, including information from the Coroner and Medical Examiner Database, which holds data on deaths reported to the offices in their jurisdictions.

The most important general health-related series of surveys conducted by Statistics Canada is the Canadian Community Health Survey (CCHS). This series is designed to gather Canada-wide information about health, health care use, and determinants of health in order to support health surveillance and research²⁰. The CCHS was originally scheduled for collection every two years, but in 2007 it became an annual survey to provide more timely information, as well as to allow for more flexibility in addressing topics of interest. Mental health was the special topic of interest for the CCHS 1.2, administered in 2002, and mental health was the topic of interest in 2012. The mental health-focused surveys are described in greater detail in a later section (PG XXX).

An important feature of the CCHS surveys is the collection of respondents’ provincial health insurance numbers. Respondents are asked for consent to share their data with their provincial ministries of health, and to allow their data to be linked to provincial health data.

Only data from individuals who consent are linked or shared. The surveys are administered via a combination of computer assisted in-person and telephone interviews in all provinces, but some exclusions apply to each survey. In all CCHS cycles, people living on First Nations reserves or Crown lands, residents of institutions, full-time members of the Canadian Armed Forces, and residents of certain remote regions are excluded.

Statistics Canada and CIHI have also jointly produced a series of health fact sheets using survey and other data sources. Among 22 topics reported on from 2007 to 2009, there were four related to mental health/illnesses: mood disorders, heavy drinking, perceived life stress, and life satisfaction²¹. In 2013, Statistics Canada released for the first time in a national population health survey the symptoms

consistent with generalized anxiety disorder. Data from the CCHS 2012 is now available, and two articles are available “Mental and substance use disorders in Canada” in *Health at a Glance*, and “Perceived need for mental health care in Canada: Results from the 2012 Canadian Community Health Survey – Mental Health” in *Health Reports*.

Canadian Institute for Health Information

Established in 1994 under the Canada Corporations Act, CIHI has the dual mandate of developing and coordinating a national, integrated approach to health information, and providing sound and timely data relevant to health policy, health care delivery, and public awareness of the “factors affecting good health”²². CIHI holds and manages national-level health administrative data – most of which comes from provincial health service systems, which are detailed in the next section. CIHI has also developed a widely adopted Health Indicators Framework and, in partnership with Statistics Canada, had reported on these health indicators annually from 2002 to 2013.

Today, CIHI has more than a dozen data holdings, which include mental health- and addictions-related information from across Canada. It also makes available related health indicators, Analyses in Brief, Quick Stats, reports, and online education products. For example, CIHI publishes Quick Stats on hospital-based mental health services, including information such as proportions of mental health separations and length of stay by diagnosis category from 2003-2004 through 2011-2012. CIHI also reports back to submitting facilities in the form of comparative reports, to support clinical decision making as well as evidence based system management.

In 2010, an analysis of data from the Continuing Care Reporting System provided findings on depression among 50,000 seniors in residential care in four provinces and one territory; the first time that data on depression prevalence and associations with negative medical, social, functional, and quality of life outcomes were available in Canada²⁵ for this population.

In 2013, an analysis of the data from the Hospital Mental Health Database described the socio-demographic and clinical characteristics of individuals hospitalized for concurrent mental illness and substance use disorders in Canada. (186) The analysis also compared the impact of concurrent disorders on the use of inpatient hospital mental health services with that of mental illness or substance use disorders alone.

CIHI has also been continuing work with provincial representatives on sources of data from community mental health and addictions systems and how they might be used in the future.

Health System Performance

Health system performance indicators are reported through a joint CIHI-Statistics Canada Health Indicators reporting project.

In 2013, two products were introduced to improve access to pan-Canadian health information. The first was an interactive website (ourhealthsystem.ca) exploring five areas of performance measurement important to Canadians (Access, Quality of Care, Spending, Health Outcomes, and Health Promotion and Disease Prevention). The website aims to help them understand how well their health system is performing at the provincial and regional level, and for some, the city or facility level. Mental health and

addictions-related information includes: information on repeat hospital stays for mental illnesses and potentially inappropriate anti-psychotics medication in long-term care. The second product, CIHI's [Indicator Library](#) saw the inclusion of indicators derived from hospital discharge data focused on hospital care across Canada for mental illnesses, namely 30-day Readmission for Mental Illness and Patients with Repeat Hospitalizations for Mental Illness. Three additional indicators will be available in early 2014-2015. These are currently available through Quick Stats though and listed the *Mental Health and Addictions Data and Information Guide, 2014*.

Reporting moved to an electronic, interactive format in 2014. Mental health and addictions indicators include: Mental Illness Hospitalizations, Mental Illness Patient Days, 30-Day Readmission for Mental Illness, Self-injury Hospitalizations, and Patients with Repeat Hospitalizations for Mental Illness.

Canadian Population Health Initiative

In 1999, CIHI launched the Canadian Population Health Initiative (CPHI). Its mission is to “foster a better understanding of factors that affect the health of individuals and communities and to contribute to the development of policies that reduce inequities and improve the health and well-being of Canadians”²³.

For the period of 2007 to 2010, mental health and resilience was a key area of focus for CPHI. Several reports have been produced, including *Mental Health and Homelessness in 2007*, *Mental Health Delinquency and Criminal Activity in 2008*, and *Exploring Positive Mental Health in 2009*. This latter document summarizes concepts, models, and current measures²⁴. In addition, CPHI also produced two smaller products on mentally healthy communities, including a collection of papers on that topic and one on Aboriginal perspectives. A public views survey on mental health was also conducted with Canadians at the initiation of this work.

CIHI's new *Mental Health and Addictions Data and Information Guide (2014)* provides an overview of the above and other CIHI mental health and addictions information through its data holdings and publicly available products. This catalogue makes it easy to find and access the data and information through sections that cover the following:

- health system performance
- population health
- types of care (e.g., Hospital Mental Health Database, Ontario Mental Health Reporting System, Community Mental Health, etc.)
- pharmaceuticals
- health workforce and spending

Canadian Centre on Substance Abuse

The Canadian Centre on Substance Abuse (CCSA) is a national organization that works to reduce alcohol- and drug-related harms. Its mandate is to provide national leadership, and evidence-informed analysis and advice to mobilize collaborative efforts to reduce these harms. An important part of CCSA's work is the tracking and reporting of substance use-related data²⁶. For example, CCSA regularly reports on findings from surveys, including the Canadian Alcohol and Drug use Monitoring Survey, and the

Substance Use by Canadian Youth Survey. In a recent report, CCSA underscored the importance of addressing the concurrence of mental illness and substance abuse²⁷.

In 2014, CCSA released *National Treatment Indicators Report: 2011-2012 Data*. The project was developed to work towards collecting consistent information to fill information gaps to improve the treatment system. The document provides the first cross-Canada picture of treatment system use.

Examples of Provincial Initiatives

Broader health data analysis/reporting organizations in some provinces have done mental health-related analyses in recent years, including:

- The Manitoba Centre for Health Policy is located in the Department of Community Health Sciences at the University of Manitoba²⁸. It houses a comprehensive set of provincial population-based data and facilitates collaborations among researchers and decision-makers to examine questions on health services, population and public health, and the social determinants of health.
- The Institute for Clinical Evaluative Sciences links and analyzes provincial health services-related data in Ontario to guide decision-making in health care delivery²⁹. The Institute has more than 150 faculty and staff, involved in more than 100 projects at any given time.
- The Health Systems Research and Consulting Unit at the University of Toronto/Centre for Addiction and Mental Health has specialist expertise and capacity for mental health and addiction indicator development, and data analyses and dissemination, but does not house specific datasets³⁰.
- The Centre for Applied Research in Mental Health and Addictions at Simon Fraser University has faculty and staff capacity to do mental health data analyses³¹. Formerly the Mental Health Evaluation and Community Consultation Unit at the University of British Columbia, this unit has conducted population mental health and mental health services analyses including indicator development. The Centre for Addictions Research of BC at the University of Victoria is developing a web-based surveillance system for addictions-related data³².
- In Québec, the Ministry of Health and Social Services (MSSS) has worked at arms-length, but with continuous interaction with a loose network of researchers found in the research centers of the province's three mental health institutes (Douglas Mental Health University Institute, Hôpital Louis-H Lafontaine, and Institut universitaire en santé mentale de Québec); several research groups, and the five Québec universities. For example, one such collaborative project is work to develop a registry of all suicide cases across coroner's data, all previous health and social services information, physician billings, and hospitalization. There is also the Institut de santé publique du Québec that has some activities around mental health/illness and substance use.
- The Mental Health and Addictions Quality Initiative (MHAQI) was officially launched in November 2011 as a 'peer comparison' project among four mental health and addictions hospitals in Ontario: The Royal, Waypoint Centre for Mental Health Care, Ontario Shores Centre for Mental Health Sciences, and the Centre for Addiction and Mental Health. A key objective of the MHAQI is

to improve quality of care through collaboration and transparency. Standardized mental health and addictions indicators reflective of hospital accountability and accessible to the public were developed, and are currently compared among 15 hospitals in Ontario and The Douglas Mental Health University Institute in Québec. The MHAQI produces a quarterly performance scorecard of indicators representing client complexity, client outcomes, client access, staff safety, human resources, fiscal responsibility, and client safety.

The MHAQI is also a joint partner with the Mental Health Commission of Canada in the International Mental Health Indicator Project (IMHI). The IMHI is working on developing a set of quality measures that can be compared across participating countries and jurisdictions.

The MHAQI is the first example of specialty mental health hospitals coming together to define quality indicators and share results in order to develop common processes and quality improvement initiatives. Implementing a standard set of comparators with an emphasis on cooperation and collaboration has led to consistency in both the quality and tracking of results. Aligning measurable performance across hospitals is informing quality improvement priorities by more timely identification of challenges and opportunities, allowing all members to benefit from best practice solutions (e.g., patient safety and flow strategies; joint procurement of common survey/assessment tools, etc.). Broader coordination is also anticipated through continuing expansion of the MHAQI membership that will in turn address the ongoing task of reducing fragmentation and increasing integration of mental health and addictions services within Ontario and across provinces.

Recent examples of work for each organization can be found on their respective websites.

Other Examples of Data Initiatives

Many professional associations also have an interest in mental health and substance use information, particularly at the population level. One of the most prominent at the national level is the Canadian Academy of Psychiatric Epidemiology (CAPE), first organized in 1984 as a special interest group of the Canadian Psychiatry Association. CAPE now promotes the use of population-based information for decision-making (and related research) through its annual national meeting and other activities.

Summary

It is clear that these national organizations have made some laudable progress on collecting, analyzing and collating information for some aspects of mental health, and have partnered on specific initiatives. Even so, there is no overarching vision for mental health information. While PHAC, Statistics Canada, and CIHI are well-positioned to gather data and report on mental health and mental illnesses, no single organization at the national level is dedicated to gathering and reporting on services and policy. To date, mental health and substance use data have been collected and reported separately. There is also no organization or division dedicated solely to the collection, analysis, and dissemination of mental health information at the provincial and territorial level.

Types of Mental Health Information Currently Available in Canada

The mental health data that are currently available in Canada include broader population data from administrative and survey sources, as well as several sources of data that are more geographically or topically circumscribed. In this section these data sources will be described in turn, including national and provincial level sources where applicable.

Administrative data: Administrative data are data that are collected at a high level for the purpose of managing health care services, and in particular for providing payment for services. Most administrative data in Canada are collected by provinces and include four major types: hospital admissions and discharges, physician billing, ambulatory care, and drug databases. In order to report information nationally, data need to be brought together across jurisdictions. CIHI is able to do this, but collaborative analyses of interest, including those related to mental health information across other entities, currently require special agreement processes.

National administrative data: CIHI has several pan-Canadian databases with information about mental health-related service contacts, particularly with institutional providers such as hospitals and emergency rooms. Current coverage ranges from Canada-wide for more mature databases, to a single province for newer ones. Data quality is routinely evaluated with modification of collection methods and protocols as needed. Information relevant to mental health includes diagnosis and/or clinical condition, type of procedure or intervention, type of care or service provider, and some demographic information. A few datasets contain information related to functioning/disability and the social determinants of health. Many include variables that allow data linkage at the individual⁴ and forward sortation area⁵ levels (subject to privacy protections), and most are available on an annual basis.

The primary CIHI datasets of interest are the Hospital Mental Health Database (HMHDB), the Discharge Abstract Database (DAD) – Hospital Morbidity Database (HMDB), the Ontario Mental Health Reporting System (OMHRS), and the National Ambulatory Care Reporting System (NACRS). The first three are inpatient data holdings, while NACRS contains ambulatory care information for visits to emergency departments and outpatient clinics. Additionally, day surgery information is available through DAD-HMDB or NACRS depending on the jurisdiction of interest.

The DAD-HMDB contains administrative, clinical, and demographic information for inpatient discharges from all acute facilities, and most psychiatric facilities (three psychiatric facilities in western Canada are excluded), and some long-term care and rehabilitation facilities. Acute inpatient and day surgery data from Québec are appended to the DAD creating the HMDB. Many variables are collected, some of which are optional. Mandated variables include several items covering diagnostic information (for example, ICD-10-CA) with identifiers for the condition most responsible for the inpatient length of stay (LOS) and for significant comorbid diagnoses. Other mandated variables include LOS and types of care providers and interventions.

⁴ Encrypted health insurance number

⁵ i.e., first half of the postal code

On October 1, 2005, stays in adult designated mental health beds in Ontario were no longer included in DAD and were recorded in OMHRS instead⁶. OMHRS includes Resident Assessment Instrument – Mental Health (RAI-MH) assessments which capture sociodemographic, functioning/disability, clinical, and intervention variables, as well as some information on health determinants such as social support, finances, and stressors. There are five different types of assessments depending on the length of the individual’s hospital stay. Two important characteristics of the OMHRS data are that the RAI-MH is part of a suite of similar instruments used in other sectors of care, and that the clinical information can be linked to units tracked by financial databases such as the Ontario Management Information System (MIS).

The HMMDB is a pan-Canadian database containing information about inpatient separations for mental illness. It is a compilation of information from three sources: the Hospital Mental Health Survey for some psychiatric hospitals, the DAD-HMDB for general and psychiatric hospitals, and the OMHRS. It contains demographic and medical diagnosis information for inpatient hospital stays from all provinces and territories for people admitted to hospital with a primary diagnosis of a mental illness. A unique identifier is available, so individual-level information can be reported, and linkage with other data sources is possible.

The NACRS covers hospital- and community-based ambulatory care, including emergency department, outpatient clinic, and day surgery visits for all ages. Currently, there is full coverage for Ontario and Alberta and partial coverage in Prince Edward Island, Nova Scotia, Saskatchewan, British Columbia and Yukon. Like the DAD, NACRS provides administrative, clinical, and sociodemographic information. Diagnostic information is collected, and the condition which is the main problem is identified. Triage level (the urgency of the visit), is provided along with several variables that can be used to construct various measures of wait time³³.

There are other CIHI datasets of potential interest. The Continuing Care, Home Care, and National Rehabilitation Reporting Systems cover designated continuing care beds, publicly funded home care services, and inpatient rehabilitation services. The first two include standardized clinical assessments through the use of RAI instruments. While the numbers of individuals in these databases with a primary mental health condition may be small, these data do contain information on functioning/disability (e.g., self-care) and may be useful to evaluate the impact of mental health as a comorbid condition, as well as to track the path of individuals across different care and service sectors for provinces and territories where the data are collected and can be linked. For example, *Depression Among Seniors in Residential Care* was released in 2010 and examined the prevalence of depression and the impact on persons living in residential care facilities, such as long-term care, nursing, or personal care homes.

CIHI also maintains the National Health Expenditures Database, which provides an overview of health spending in Canada by spending category and source of funding, the National Prescription Drug Utilization Information System (NPDUIS) database, and health workforce databases. The NPDUIS database is a pan-Canadian information system that houses information related to drug claims from publicly financed drug benefit programs, as well as supporting contextual information for claims data

⁶ However, those mental-health-related inpatients stays related to children and adolescents, and occurring in non-designated beds, are still recorded in DAD.

through formulary, drug products and drug plan information. Due to variation in public drug plan design and level of participation, there is limited data on drug claims by non-seniors. Also, information regarding drugs dispensed in hospital or paid for by private insurers is not included. CIHI's health workforce data holdings include information on education, supply, distribution, and/or practice characteristics of a health professional (for example, physicians). Table 1 summarizes the key datasets relevant to mental health managed by CIHI.

Table 1: Primary CIHI Datasets Relevant to Mental Health

CIHI Dataset	Coverage	Diagnosis/Condition ⁷	Functioning/disability	Sociodemographics/social determinants of health	Linkage-level	
					Person	FSA
<i>Inpatient discharges and stays</i>						
DAD-HMDB	pan-Canadian	ICD-10-CA	No	Age, Sex	Yes	Yes
OMHRS	Ontario, some Newfoundland and Labrador	Provisional categories DSM-IV-TR	Yes (RAI-MH)	Age, Sex, including one variable on Aboriginal status	Yes	Yes
HMHDB	pan-Canadian	ICD-10-CA, DSM-IV-TR, ICD-9-CM	No	Age, Sex	Yes	Yes
<i>Emergency department visits</i>						
NACRS	Ontario and Alberta; Some from Prince Edward Island, Nova Scotia, Saskatchewan, British Columbia, and Yukon	ICD-10-CA	No	Age, Sex	Yes	Yes

The **Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP)** is a unique national database which collects data on injuries to people (mainly children) that present to the 15 participating emergency departments from across Canada³⁴. CHIRPP is a program of the Injury Section of the Health Surveillance & Epidemiology Division, Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada. This system includes detailed data on the circumstances of both intentional and unintentional injuries.

National Mental Health Surveillance Using Administrative Data: The **Canadian Chronic Disease Surveillance System (CCDSS)** is a collaborative network of provincial and territorial chronic disease surveillance systems, led by PHAC. The CCDSS was initially used to track diabetes (formerly known as the National Diabetes Surveillance System), and uses provincial/territorial administrative databases, including physician billing, hospitalization, and resident health insurance registry databases. In 2009, the CCDSS began to track the incidence, prevalence, and all-cause mortality. Other chronic diseases are being added to the system incrementally. The CCDSS summarizes data about residents of Canada who have used the publicly funded Canadian health care system.

⁷ ICD = International Classification of Diseases; DSM = Diagnostic and Statistical Manual

As part of the development work for the expansion of the CCDSS, PHAC supported feasibility studies in five provinces (BC, Ontario, Québec (Montréal only), Nova Scotia and Alberta) in 2006 to determine if common mental illness case definitions could be developed and applied across physician billing and hospital discharge databases^{54,56}. The project examined overall psychiatric illness as well as mood and anxiety disorders⁸. This work was the basis for a recommendation to the CCDSS Science Committee to add case definitions for mood/anxiety and overall mental illness to the CCDSS platform for ongoing surveillance.

CCDSS provides data for the first time on the population with a medically diagnosed mental illness, and the first data which includes children. This expansion occurred in 2010, and the first report from this data was released in 2012⁵⁶. Future work will be done to develop case definitions for other conditions such as substance use disorder and lower prevalence conditions such as psychosis. Additional work will look at the prevalence of mental disorders among those with other chronic conditions and co-occurring mental illnesses.

Provincial administrative data⁹: Each province collects and maintains health insurance claims data for physician services, as well as a registry of all individuals eligible for the provincial health insurance plan. Together these data provide information about diagnosis, procedures, provider specialty, and some sociodemographic characteristics about service users, such as age, sex, and geographic location. Services delivered to all eligible provincial residents are recorded, thus covering the entire age range. Provincial health insurance numbers typically serve as unique identifiers, allowing linkage to other provincial datasets, as well as to national databases such as the DAD. Some provinces currently record contacts with non-physician and community mental health care providers (from directly funded services) and financial and other management data are collected in management information system databases.

Pharmacy transactions are collected and reported by some provinces; in some cases only for a portion of the populations, such as seniors. Some of these pharmacy transactions contribute to CIHI's NPDUIS, discussed above. While medications account for the second largest share of total health expenditures (after hospitals), and these costs are expected to continue to rise, there is minimal information regarding health outcomes (including interactions and adverse effects) of prescription drug use at the population level. Population level monitoring is important because information from clinical trials research does not fully reflect how drugs will work in practice³⁵.

Some surveillance of prescribed medications in the population using these administrative databases is being done³⁶. Several academic/research units provide expertise/analysis to provincial drug plans on a contract basis, or with year-to-year funding. Some, like the Institute for Clinical Evaluative Sciences in Ontario, the Manitoba Centre for Health Policy at the University of Manitoba, and the Population Health Research Unit at Dalhousie University, have groups of researchers who focus on prescription drug issues within larger health services research units. Others, like the Therapeutics Initiative at the University of British Columbia, concentrate solely on the evaluation of drugs. These programs have used administrative data for special studies of prescribed medications. In January 2009 – the Drug Safety and Effectiveness Network began independent research about medication use and outcomes in the population, but it is not yet known how psychotropic drugs will be prioritized for study³⁷.

⁸ (ICD9 codes 290-319 inclusive, or their ICD-10 or DSM-IV equivalents. This case definition included organic brain syndromes, psychosis, non-psychotic disorders, adjustment disorders, personality disorders and developmental disorders.

⁹ The information in this section is primarily a summary of work done by Durbin, et al. (33)

Table 2 provides a brief summary of the administrative datasets for health and where available, mental health.

Table 2: Administrative Data Sources by Province

Province	Current Administrative Datasets
British Columbia	The Medical Services Plan collects information about physician-provided services and laboratory procedures ³⁸ . BC has also tracked community care and visits to non-physicians through its Community-Based Psychiatry Services database in the past, but this database is being phased out and work is continuing toward implementation of a minimum mental health dataset for regular reporting to the province. BC also has a comprehensive PharmaCare database. A unique identifier allows linkage among some datasets and with national data such as the DAD. Population Data BC https://www.popdata.bc.ca/home , has linked data source available to researchers.
Alberta	Alberta captures physician billings in the Alberta Health Care Insurance Plan database ³⁹ . Unlike physician billing databases in some other provinces, this dataset allows multiple fields for capturing diagnostic information, including more than one diagnosis per visit. Hospital outpatient and ER visits (including substance use and mental health-related visits) are currently captured in the Ambulatory Care Classification System and will be submitted to the NACRS database starting fiscal 2010. Contacts with community clinics have been captured in one system (ARMHIS) in the past, and although some clinics have switched to local databases, the relevant data are still collated provincially. This clinic information is not directly connected to hospital systems, including EHR systems, to facilitate continuity of care ⁴⁰ . Alberta Health Services is also rolling out province-wide collection of an outcome measure for mental health services – the Health of the Nations Outcomes Scale ⁴¹ .
Saskatchewan	Physicians submit claims to the Saskatchewan Ministry of Health for fee-for-service payments. Those on alternative payment plans may submit ‘shadow’ claims, but salaried psychiatrists (about 45% of all psychiatrists) do not submit these claims. Nearly all Saskatchewan Health registrants are eligible for prescription drug benefits which are recorded in the province’s drug plan database. Inpatient services are captured by the Ministry of Health. Outpatient mental health services were captured until 1996, when there was a computer platform change and some regions stopped submitting data. Since 1997 the only data consistently gathered from outpatient mental health programs is registration (i.e. demographic information) ^{42,43} .
Manitoba	Physician billing claims are submitted to the Manitoba Health Insurance Plan. Drug benefits for eligible individuals meeting an income means test are tracked through the Manitoba Pharmacare Program. There is prescription drug use captured for all Manitoba residents in the DPIN database. These data are linkable with other

	<p>databases such as the DAD. Financial and other management related information is captured in Manitoba's MIS database. In addition, there is information on the services received by community case management clients in the Mental Health Management Information System, albeit on a limited geographic basis^{44,45}. There are also data on the use of public housing, and the use of social assistance. For research purposes only, all of these datasets are housed in a person-level, de-identified, but linkable form at the Manitoba Centre for Health Policy (after all approvals, including Ethics and Health Information Privacy Committee, are in place).</p>
Ontario	<p>Physician billing claims and laboratory information are submitted to the Ontario Health Insurance Plan. The province also records covered medications for seniors and individuals on social assistance in the Ontario Drug Benefit Database. A community mental health database has been developed and is being implemented to collect information on client needs and functioning based on an Ontario variant of the Camberwell Assessment of Need⁴¹. All of these data contain, or are being designed to contain, a unique identifier, so that the flow of individuals can be tracked across multiple care sectors, including inpatient stays (DAD and OMHRS) and emergency department visits (NACRS). In addition, financial and cost data are available through the MIS and the Ontario Case Costing Initiative⁴⁶.</p>
Québec	<p>Hospital discharge information is collected in Med-Écho, a database which has many of the same types of variables collected in the DAD. Physician billings are tracked through the Régie de l'assurance maladie du Québec. Unique identifiers are available that allow linkage of hospital and physician databases at the individual level. The MSSS mental health directorate, in collaboration with researchers from the Québec Health Research Fund mental health network, has set up the OASIS information database to collect information on 51 types of services (residential/hospitalization, outpatient/day hospital/home care, occupational/rehabilitation, non-profit organization) with information on volume (people or places; intensity), and budget for adults and children from public specialist or primary care⁴⁷. It can break the data down by administrative regions, and by the 95 local health and social services centres. It is fed by various data sources, including existing sources on residential services, on outpatient or hospital services. The OASIS has been used minimally so far because of lack of sufficient funding for staff to ensure quality data collection.</p>
New Brunswick	<p>Physician billings are collected by the New Brunswick Medicare Plan and drug benefits (for seniors and special needs groups) through the provincial Prescription Drug Program⁴⁸. Community care data are collected by the Client Service Delivery System, and there is also a hospital financial utilization management system.</p>
Prince Edward Island	<p>PEI Healthcare collects information about physician-provided services⁴⁹. Clinical information about clients of community care for mental health and addictions is captured in the Information System Management database.</p>
Nova Scotia	<p>Nova Scotia collects physician billing information in its Medical Services Insurance (MSI) database, as well as covered medications information in its Pharmacare Prescription database. Similar to Alberta, the MSI can capture more than one diagnosis per encounter. Unique identifiers allow linkage to DAD records. Linkable</p>

	information about community-based mental health care including (relatively uniquely) the outcomes measure HONOS was also collected in the Mental Health Outpatient Information System, but this database was discontinued in 2006 ⁵⁰ .
Newfoundland/ Labrador	The Newfoundland and Labrador Medical Care Plan covers physician billings, and assistance with prescription medications (for seniors and identified special needs populations) is tracked through the Prescription Drug Program ⁵¹ .
Yukon, NWT, Nunavut	No public information was available regarding administrative data systems in the Territories.

All provinces also have vital statistics databases that record births, deaths, adoptions, marriages, etc. Special studies (usually formal research studies) sometimes use these vital statistics to determine mortality outcomes based on sociodemographic or clinical risk, or a particular treatment (see for example Kisely 2005⁵²). Other organizations, such as provincial Workers' Compensation Boards, hold data of interest about the mental health of workers. Health-related data are also collected in private workplaces locally to internationally, and include data from standard health assessment scales which, in theory, could be captured anonymously for workplace mental health surveillance and comparisons (e.g.,⁵³).

Ethnocultural status, including Aboriginal status, is not collected similarly or consistently in provincial administrative databases, although there has been a range of attempts using data from other sources to do analyses on these databases that address health care use questions for Aboriginal populations⁵⁴. All census-based geographic indicators, postal code geographic indicators, voluntary registration information (e.g., band affiliation), insurance subsidy information, and linked identifiers with appropriate authorization from authorities have been tried with mixed success, and in theory linkages to survey data are possible. One more-promising approach has been taken by the Unama'ki communities of northern Nova Scotia, who have been combining data sources using a 'golden key' to identify First Nations cohorts to build their own health services/population health research capacity. Currently about half of the communities in that province are covered, but there is a goal to expand to the whole province and eventually Atlantic Canada⁵⁵. The Manitoba Centre for Health Policy (MCHP) also has a collaborative project with the Manitoba Métis Federation that has resulted in the ability to link a Métis encrypted identifier with all other administrative databases housed at MCHP, with permission from the Manitoba Métis Federation for the research being proposed.

Strengths and Limitations of Administrative Data: Clearly there is an enormous volume of administrative data about health services available in Canada, which is largely untapped with respect to informing mental health service delivery questions. Administrative datasets have some clear strengths as described by analysts who work with them, and as noted in the literature^{35,58,59}. Similar to other countries with universal health care, Canada's administrative health data provide nearly complete population coverage for all publicly funded services mandated by the Canada Health Act. This is a major strength that allows for the evaluation of important health care questions without the concerns that the results apply only to select subgroups in the population — a limitation often faced by countries where health care is segmented. They also accumulate (directly funded) health care events over time, so with the right linkages and analyses, patterns of service use can be examined longitudinally for particular populations^{58,59}.

The information derived from analyzing administrative data is directly relevant to the jurisdiction. Because of the large size of the datasets, pooling information across jurisdictions may allow earlier detection of small but important changes in rare events. Another strength is that the technology to link across these datasets has been improved. Such linkages allow greater exploration of some questions important to mental health in Canada, including how individuals move through different services and how combinations of services may differ geographically. Linkage to other types of information (e.g., education) and to more in-depth health information is an innovative approach that can increase the value of administrative data analyses. Several examples of such analyses used by the MCHP were published in 2011 in a special issue of the journal *Healthcare Policy*⁶⁰.

However, despite the availability and volume of these data there are also many limitations^{35,54,57-59,61,62}. Paramount among the shortcomings is that the variables contained were designed for an administrative purpose (often simply to process payment), and as such are very limited in scope. In order to have a complete information system, other pieces of data not included in these administrative systems are still required. They predominantly contain simple demographic, diagnostic, and event information for formally funded services, so analyses are often restricted to topics like 'diagnosed prevalence' (the number of individuals who have presented for care and have been given a particular diagnostic code), which is not a very good indicator of need for services in the population as a whole^{63,64}. Information on individual risks and strengths, and functioning/disability is rarely available, and outcomes are crude (e.g., readmissions or repeat visits for other diagnoses)^{e.g.,58}. There is no information in administrative data about important outcomes like recovery, wellness or quality of life. One study on administrative data in the US showed that it explained less than 7% of the variance in outcomes of mental health and substance-related care⁶⁵. Variables reflecting the social determinants of health and mental health disparities are usually unavailable, although some datasets, such as those in Alberta, include basic information about low income based on the presence of a subsidy for health insurance premiums. The consumer perspective is rarely represented directly in administrative data, or is filtered through the perspective of the provider gathering the information. Standard care measurement systems (examples being RAI and OCAN) are beginning to include some of these other variables.

Questions are also often raised about the validity of the information in these datasets^{e.g.,58,59,61,62}. For example, in physician billing data there may be enormous variation in coding attributable to individual physician decisions about which codes to use to describe the presenting condition and service provided. This may be especially problematic for mental health given the complexity of mental health diagnostic systems, and for subpopulations such as children where standard coding systems are less developed. Further, there could be multiple codes that describe services such as counseling, which may or may not be related to a mental health problem or illness. As well, often only one code can be used per visit even though a number of health issues could have been covered during the visit, which could lead to under-reporting. While there are ongoing quality evaluations for some of the databases, such as those held by CIHI, assessments of the validity of codes specific to mental health are still limited⁶⁸. That being said, some research on the prevalence of mental illness diagnoses, and the health care use patterns of people living with a mental illness, have been done using administrative databases housed at various research centers, such as the MCHP.

The focus on formal, directly funded hospital and medical services in administrative data results in a partial picture of care, given that other types of providers and services are rarely captured. Many groups that face barriers in accessing formal health care services are served by community-based agencies or

informal supports. In addition, formal care providers often do not know about the community resources that may be available, and therefore do not refer their patients to services that may effectively address patients' needs (often from a broader social-determinants of health perspective and in a more cost-effective way). The community services gap is beginning to be addressed by the provinces, which are implementing community-based mental health information systems, but care provided indirectly such as through agencies or services not publicly funded (e.g., private psychologists, private treatment centers) remain invisible.

In addition, reliability and validity of data from service-based information systems depend on consistent training and support for systems staff and clinical staff (if they enter information directly)⁶⁹. Databases that capture special services, such as prescription medications in some locations, may miss large portions of the population, because of limits of coverage. For example, several provinces have drug plans only for seniors or low income citizens, and as such there are no data available on prescribed medications for other age groups or privately insured citizens.

Another limitation of administrative data is that the linkages between service data and financial/management information are not straightforward (although datasets such as OMHRS are beginning to address that gap). Attending to this issue will be important for adequate evaluation of the costs/resources associated with care. Further, changes in billing practices can introduce error, which threatens validity of administrative data for chronic disease surveillance⁶¹.

An additional logistical disadvantage of these datasets is that there can be long delays for analysts or researchers to access data due to the time it takes for service event data to be compiled and centralized as well as lengthy privacy legislation/review processes. And while no new resources are needed to *collect* these data, the technical skill and person-time required to manage, link, analyze, and report out on findings can be substantial.

Finally, and very importantly in the realm of mental health, administrative health data capture events only for people who have been in contact with formal services offered by the health care sector, and thus miss individuals in need who may not access or receive care, who receive care from community-based services, or who receive care in other sectors. In mental health these may be some of the highest need individuals. Some progress in addressing this concern has been made with the inclusion of unique identifiers in surveys that can gather broader information about need from a representative sample of the whole population (such as the Canadian Community Health surveys) to allow for linkage.

Population-based Cross-sectional Surveys: Surveys involve identification of a representative sample (usually random) of the population and interviewing them to collect information on a standard set of questions, in-person or over the telephone. An important distinction in survey design is whether the data are captured at a single point in time (a cross-sectional survey), or gathered over a period of time from the same respondents (a longitudinal survey). Cross-sectional surveys can estimate changes occurring over time for the population as a whole through repeated surveys, but the information does not reflect a set of continuous information for a set of individuals because different individuals are sampled each time.

To date there have been many such mental health surveys conducted around the world, including surveys conducted collaboratively across countries under the leadership of the World Health Organization⁷⁰. Thus, despite some variance in and challenges with methods, there is fairly good information available about basic topics such as the prevalence (total count of cases for a given time period) of major diagnoses (although predominantly in adults) and how they vary according to demographic variables such as age and sex.

National Population-based Cross-sectional Surveys: The main source of national population-based cross-sectional data on mental health is the **Canadian Community Health Survey, Cycle 1.2 (CCHS 1.2)**. This cycle added essential information regarding mental health since the initial general survey contained only a single self-rated mental health item which limited the types of analyses possible. The CCHS 1.2 was conducted in 2002 with the specific goal of providing information on mental health status, service use, and determinants. The national sample size was nearly 37,000 household respondents aged 15 and older, with a response rate of 77%⁷¹. Excluded were “residents of the three territories, institutions, Indian reserves and Crown lands, a few remote lands and full-time members of the Canadian Armed Forces” and “individuals who did not have a residence anywhere (i.e., the homeless)”. Excluded institutions included nursing homes, retirement homes, chronic care hospitals, and correctional institutions.

In 2007, the sample size of the CCHS was increased to 65,000 respondents each year from the age of 12 years and up. It covers 90% of private households in Yukon, 92% in Nunavut, and 97% in the Northwest Territories.

The survey questionnaire covered diagnoses (using an instrument based on the **World Mental Health Survey** developed for the WHO), disability, and service and medication use⁷⁰. Information was also collected about eating ‘troubles’, substance use and dependence, health promotion-related variables such as exercise, psychological well-being, work stress, and sociodemographic characteristics. Results for specific conditions that could be derived from the CCHS 1.2 were lifetime and past-year prevalence for major depression, manic episodes, panic disorder, social phobia, and agoraphobia. The choice of diagnoses to include was governed in part by the expected prevalence rate, as well as how feasibly and reliably they could be measured using a household survey⁵⁸. A special research competition sponsored by CIHR supported a series of studies using CCHS 1.2 data, many of which were published in a special issue of the *Canadian Journal of Psychiatry*⁷² that examined a range of topics such as unmet health care needs, services, and medications used for various ages, as well as specific conditions, including co-occurring conditions. Many of the topics were examined across provinces.

A parallel survey, the **CCHS-CF (Canadian Forces)**, was administered at the same time as the CCHS 1.2 and covered similar content. The sample included full-time regular members of the Canadian Forces as well as reservists⁷³. The CCHS-CF covered some of the diagnoses included in the CCHS 1.2 (major depression, social phobia, and panic disorder) but also added generalized anxiety disorder and post-traumatic stress disorder. The total sample was approximately 8,400 respondents, for a response rate of about 80% for the regular forces and 84% for reserve members.

Statistics Canada conducted a special “rapid response” survey in collaboration with the MHCC on the topic of stigma to support the MHCC’s anti-stigma initiative. The data were collected during an annual component CCHS survey. Another CCHS mental health survey began data collection in 2012, with data collection being complete early in 2013. This survey was called the CCHS Mental Health (CCHS-MH). This

survey administered one component of data collection instrument for stigma, called the Mental Health Experiences Module, as well as a series of modules from the Canadian modification of the World Mental Health CIDI instrument (WMH-CIDI). The survey was based on a nationally representative sample of approximately 25,000 household residents aged 15 or older. The survey addressed four general themes: 1) a broad concept of mental well-being and mental illness that included ranges from illness to sub-clinical problems to well-being; 2) issues related to care and help-seeking, including service use, supports, unmet needs, and perceived needs for care; 3) the continuum of disability, ability, and functioning; and 4) social and environmental factors affecting mental health, care and help-seeking, and functioning.

The CCHS-MH included the WMH-CIDI modules for substance abuse and dependence, two topics for which only abbreviated assessment was carried out in the 2002 national mental health survey. Major depressive disorder and bipolar disorder were also assessed. For the first time it will be possible to distinguish bipolar I disorder from bipolar II disorder in a national sample. In addition, the survey included the first assessment of generalized anxiety disorder and of personal experiences with stigma among those receiving treatment for a mental illness. The CCHS-MH also assessed demographic variables, adverse childhood experiences, physical activity, social support, stress, family mental health impact, contact with police, perceived need for care, barriers to care, chronic conditions, pain and discomfort, suicidality, and psychotropic medication use.

The **Survey on Living with Chronic Disease in Canada** (SLCDC) was developed and funded by PHAC and conducted by Statistics Canada, and is a cross-sectional follow-up survey to the CCHS. In 2009, the focus was on arthritis and hypertension. Diabetes, chronic obstructive pulmonary disease, and asthma were the focus topics for 2011. The SLCDC methodology is also being used to determine the impacts of neurological diseases in Canada in 2010 and 2011. Each SLCDC survey includes questions assessing the impacts of the specified chronic disease on mental health. This methodology could be expanded to consider the impacts of mental illness more broadly.

The **Canadian Alcohol and Drug Use Monitoring Survey** (CADUMS) is an annual cross-sectional survey of 10,000 Canadians aged 15 years and older, led by Health Canada⁷⁴. Its purpose is to estimate the prevalence of the use of alcohol, drugs and other substances, as well as the impact on others who may or may not be using these substances. The surveyors use random selection of telephone numbers to contact households and then randomly select a person living in the household. Reports of findings are available on the Health Canada website for the years 2008, 2009, 2010, and 2011.

The **Canadian Addiction Survey** (CAS) was a collaborative initiative sponsored by Health Canada, the Canadian Executive Council on Addictions—which includes the Canadian Centre on Substance Abuse; Alberta Health Services (formerly Alcohol and Drug Abuse Commission); the Addictions Foundation of Manitoba; the Centre for Addiction and Mental Health, Prince Edward Island Provincial Health Services Authority; and the Kaiser Foundation/Centre for Addictions Research of BC—and the provinces of Nova Scotia, New Brunswick and British Columbia⁷⁵. It had a sample of 13,700 Canadians aged 15 and older, and computer assisted telephone interviews were conducted in late 2003/early 2004. The survey was intended to examine prevalence and patterns of use of alcohol and other drug abuse, associated harms, personal and social functioning, risk and protective factors, and personal opinions. It was intended as a baseline to evaluate the effectiveness of Canada's Drug Strategy. Mental health-related content includes

ratings of the number of days in the past 30 that mental health (defined as stress, depression, and problems with emotions) was not good; the number of days in the past 30 that poor physical or mental health impacted usual activities; and an overall mental health rating (excellent, very good, good, fair or poor). There was also an attitude question about who was most likely to be at risk of using drugs, which includes “those with a history of mental illness” as one option. While issues of co-occurrence cannot be fully examined with this content, it is progress in that direction. In addition it was a one-time survey, with no plans for re-administration, although many of the questions have been added to the CADUMS.

Another, more general (and also cyclical) survey that included some information about disability associated with mental health problems and illnesses was the 2006 **Participation and Activity Limitation Survey (PALS)**. PALS was conducted by Statistics Canada (and funded by Human Resources and Social Development Canada), and examined activity limitations due to a condition or health problem in both adults and children to help plan programs⁷⁶. The data collection for PALS has been discontinued, with the last cycle being collected in late 2006/early 2007. The target population was children (under 15) and adults (15 and over) living in households in the 10 provinces and the territories who reported an activity limitation in the last census, and the resulting sample was 39,000 adults and 8,500 children. Residents of First Nations reserves, institutional collectives, military bases, Canadian Armed Forces vessels, merchant vessels and coast guard vessels, and campgrounds and parks were excluded. Content included type of disability and severity, aids and assistive devices, employment history and training, education, care needed and received, local and long distance transportation, housing needs and modifications, Internet use, and social participation. The survey included the past 12 months of social service and health care use for an “emotional or mental condition”, and activity limitations related to mental health issues (“any emotional, psychological or psychiatric conditions that have lasted, or are expected to last 6 months or more”). It included phobias, depression, schizophrenia, and drinking or drug problems in this definition. However, the PALS did not use a standard diagnostic instrument, which limits the ability to form conclusions regarding prevalence and disability.

The **Aboriginal People’s Survey (APS)** is a survey on the social and economic conditions of Aboriginal peoples in Canada. It is conducted by Statistics Canada every five years, following the regular census⁷⁷, and includes information on the social and economic conditions of Aboriginal people (age six and up). It covers a wide range of topics, including Aboriginal identity, work and income, communication technology, health, mobility, housing, and family background. Mental health content focuses on alcohol use, suicide, and family violence. Some early results on wellness and service use for mental health, and drug use is available.

The **Health Behaviour in School-Aged Children (HBSC)**⁷⁸ is a cross-sectional survey conducted every four years as part of an international collaboration involving 40 countries. Funded by PHAC, the HBSC is conducted in Canadian schools with 11, 13 and 15 year-old-youth. Its focus is on health, well-being, and health behaviours of young people within a health promotion framework. Mental health-related content includes emotional health (e.g., feeling depressed, self-confidence, relationships, and bullying).

In the **Canadian Health Measures Survey (CHMS)** Statistics Canada is collecting a range of biological measures (e.g., blood pressure, height, weight, physical fitness, blood and urine indices) and interview data on nutrition, smoking habits, alcohol use, medical history, current health status, sexual behaviour, lifestyle and physical activity, the environment, and housing characteristics for approximately 5,000 Canadians aged six to 79 in the provinces and territories⁷⁹. According to publicly available information,

this survey does not currently include physical measures relevant to mental health or any content related to mental health outcomes. Exclusions are similar to the CCHS.

Provincial Population-based Cross-sectional Surveys

Table 3: Cross-sectional Surveys Conducted in Provinces

Province	Current Survey Data
Alberta	<p>A mental health survey of 5,400 respondents aged 18 to 65 (person level response 78%) was conducted in Alberta in 2003 and reported out at the health region level⁸⁰. Distinguishing features of this survey were its use of computer-assisted telephone interviews (a substantially lower cost method compared to in-person interviews) to gather data and, in keeping with this method, its use of a brief assessment instrument for diagnoses (the MINI Neuropsychiatric Interview). Included were major depressive episode, dysthymia, social phobia, panic disorder, agoraphobia, generalized anxiety disorder, dependence and abuse of alcohol and of other substances, and co-occurring conditions among these. Other content assessed service use, disability (using the World Health Organization Disability Assessment Schedule II), and quality of life (using the EuroQoL EQ-5D instrument). A subsequent survey using similar methods was conducted in 2005/2006 in 3,345 respondents to further explore the frequency and adequacy of depression treatment (both medication and psychotherapy treatment) in Alberta, demonstrating the utility of such methods for assessing the effectiveness of interventions⁸¹. Work has also been done on the measurement of positive mental health/wellness via survey in Alberta⁸².</p>
Saskatchewan	<p>The Saskatchewan Population Health and Dynamics Survey (carried out in 2000-2001) was also a telephone survey⁸³. More than 7,000 respondents, aged 18 and older, were interviewed about their health problems, emotional well-being, health services use (including preventative practices), and risk factors. The response rate was 78%. Specific content related to mental health and illness included depression, anxiety, happiness, and satisfaction with health and life. Other subjects included respondents' perceptions of their community, as well as their satisfaction with various aspects of community life.</p>
Ontario	<p>There have been two Ontario cross-sectional population surveys related to mental health. The Ontario Child Health Study (OCHS) was conducted in 1983 and sampled children and adolescents aged four to 16 years who were household residents in Ontario⁸⁴. Information was collected on nearly 3,300 children in more than 1,800 families through interviews with parents, teachers, and by self-report for youth over the age of 12. The response rate was over 90%. Areas assessed included emotional and behavioural problems, mental illness, substance abuse, and functioning. OCHS also had a longitudinal follow-up component, which is described in the next section.</p> <p>The Mental Health Supplement (Supplement) to the Ontario Health Survey (OHS) was conducted in 1990. The 10,000 participants were drawn from the 49,000 respondents to the OHS, aged 15 and older, and the response rate was 88%⁸⁵. The</p>

	<p>Supplement addressed mental illnesses, disability, and health services use. The survey was developed in collaboration with the work for the first wave of the US National Comorbidity Survey⁸⁶ so that the questions in the two surveys were, in most cases, identical. Diagnoses were determined using the University of Michigan’s version of the Composite International Diagnostic Interview, which was a precursor to the instrument used in the CCHS 1.2. The specific illnesses measured were lifetime and more current prevalence of major depression, mania, dysthymia, social and simple phobia, panic disorder, agoraphobia, generalized anxiety disorder, dependence and abuse related to alcohol and to other substances, conduct disorder, adult antisocial personality disorder, and eating disorders. Because of concerns about respondent burden, individuals 65 and older were only asked questions on major depression, and alcohol abuse and dependence. Other areas covered in the Supplement included childhood maltreatment and caregiver burden. In addition, the survey was designed such that records could be linked with the health data that were collected in the OHS.</p>
Québec	<p>The Québec Child Mental Health Survey (QCMHS), administered in 1992, gathered information on 2,400 children living in Québec households who were between the ages of six and 14 years⁸⁷. Interviews were conducted with parents, teachers, and children, and covered a variety of conditions using the Dominic mental health questionnaire for younger children and the Diagnostic Interview Schedule for Children for older children, parents, and teachers. Response rates ranged from 79 to 93% depending on the group. Other variables thought to correlate with mental health and mental health service use were also collected⁸⁸. The Institut de la statistique du Québec (ISQ) conducts social and health surveys for Québec similar to Statistics Canada for the country⁸⁹. The ISQ conducted the QCMHS and has also engaged in CCHS 1.2 analyses⁹⁰.</p>

Ten provinces also conduct regular cross-sectional surveys of drug use among students. Some of these school-based surveys include mental health-related content⁷⁵.

Strengths and Limitations of Population-based Cross-sectional Surveys

An important strength of population-based surveys compared to administrative data is their capacity to gather more in-depth and comprehensive information about the subject areas of interest. For example, instead of being limited to a few fields for recording diagnosis, more detailed questions can be asked about symptoms and their associated disability. More importantly, respondents are usually asked about all of the topics being assessed (except where not applicable). Thus, using diagnoses again as an example, the assessment of co-occurring conditions or multiple risk factors is more complete. Surveys can also capture the full continua of mental illness (from brief subthreshold symptoms through to longstanding serious disorders), as well as the continua of mental health as a positive asset in individuals without symptoms.

A second strength is that surveys can be tailored to address issues of topical interest, or those of particular relevance to subgroups within the population. Examples include the questions about perceptions of the community in the Saskatchewan survey, or the interviews with parents and teachers in the Ontario and Québec surveys of children and adolescents. Because of this kind of flexibility, which

routinely collected administrative data lack, survey data are currently the primary source of information about disability, well-being, important risk factors and determinants of health, and individual perceptions and attitudes, as well as about the associations among risk factors, health status, and functioning.

Surveys have a distinct advantage over administrative data in that they capture the health status and experiences of people, and are not restricted to those who access formal health care services. The collection of health insurance numbers by Statistics Canada in the CCHS creates the capacity to combine the advantages offered by administrative and survey data through linkage of the two data sources. Currently, privacy regulations govern who may access such linked data and for what purposes. However, the potential to describe and analyze the connections between population-based assessment of need and functioning, and formal service use is important for both understanding and planning.

A mixed strength and limitation of national and provincial surveys is that they use different instruments to measure the same concepts, particularly diagnoses. This makes it difficult to do cross-survey analyses within Canada, although it allows comparisons to be made with survey findings from other countries where the same or similar instruments have been used. Research suggests that using larger categories (e.g., any mental illness versus depression) may be more reliable across different data systems^{54,57}. However, investigating many important mental health and illness questions requires more specific data. As well, using larger categories does not provide enough granularity for targeting actions to specific illnesses.

Important limitations of the major mental health survey – the CCHS 1.2 – are the potential biases introduced by sample exclusions. With respect to age, no information is collected on individuals under age 15. For older age groups, the exclusion of residential care facilities where seniors are disproportionately represented likely under-represents overall prevalence of illnesses for that age group. There are also concerns about the appropriateness of the instruments used (in terms of recall and sensitivity) for older adults. Exclusion of the territories, Aboriginal lands, and individuals without addresses (e.g., the homeless) also create blind spots for a comprehensive population perspective on mental health and illnesses.

Measurement and data gathering methods for surveys continue to need refinement, as do the practical aspects of planning, developing, and conducting surveys. In addition, surveys rely on self-report, introducing measurement issues related to respondents' ability to comprehend, recall, and respond to questions, many of which may be sensitive as a result of stigma, embarrassment, or concerns about discrimination⁹¹, although methods for ensuring validity of reporting are advancing⁹². CCHS 1.2 and CCHS 2012 both rely on self-reported symptom indices for mental illnesses, which may be less affected by stigma-induced under-reporting than direct questions about the presence of an illness.

High response rates are critical to valid results, and there is some indication that response rates for general population surveys are declining^{93,94}. Telephone survey samples in particular may be increasingly biased, because cell phones are replacing residential lines, especially in younger age groups, and cell phone numbers may not be in sampling directories. **Statistics Canada is currently piloting methods which include cellphone numbers.** On-line surveys are easy and efficient, but representative samples must still be drawn through geographic or other sampling frames. Response rates have been acceptable to date for Canadian surveys, but this may change. Evidence-based methods to ensure high response

rates are also well-developed, but more resources may be required to achieve past response rate levels⁹⁵.

A major limitation of cross-sectional surveys is inherent in their design. Because all information is collected from a person at a single point in time, it is not possible to clearly examine trajectories of risk and resilience, symptoms and illness, care sought and received, and most importantly the outcomes of interventions across time as they happen. There are also many important topic areas where further advances are needed in measurement; examples are the assessment of mental health of children, adolescents, and seniors, social phenomena such as inclusion and discrimination, gender, diversity, and the assessment of newer concepts of positive mental health such as resiliency and flourishing^{e.g.,96,97}. The fact that survey data are self-reported information is valuable in that it captures the individual's perspective, but that perspective may be different from external observations^{e.g.,98}.

Finally, there are important practical constraints. Household surveys, particularly if they are face-to-face, are resource-intensive and demanding on the respondent. Even when methods such as telephone interviews are used, there are limits to the length of the interview and the size of the sample. These will confine both the number of topics that can be covered as well as our ability to answer important questions. Particularly telling examples include the inability to calculate statistically reliable results for small geographic areas or for conditions or events that have a low frequency.

Longitudinal/Cohort Studies: The large majority of longitudinal (or cohort) studies fall within the domain of formal academic research, and answer questions about the 'determinants' – that is, which risk factors or antecedent conditions are associated with the subsequent occurrence of the illness. There are many thousands of such studies reported in the world literature, including for mental health problems and illnesses. In mental health research there are many quality cohort studies (often following groups of people from birth) worldwide. These include the famous Canadian Stirling county cohort studies which followed groups of adults in Atlantic Canada between 1952 and 1970, and then again between 1970 and 1992⁹⁹, providing rich information and insight about the natural history of mental illnesses.

National Longitudinal Cohort Studies: In Canada there are few longitudinal cohort studies that can be considered national in scope and have datasets that contain information relevant to mental health and illnesses, however none of these was designed specifically for a broad mental health information or surveillance purpose.

The National Longitudinal Survey of Children and Youth (NLSCY) is a long-term study of Canadian children that follows their development and well-being from birth to early adulthood¹⁰⁰. The NLSCY began in 1994 and was jointly conducted by Statistics Canada and HRSDC. Data collection for the most recent cycle was conducted in 2007 and 2008. The survey was actually a complex panel design, partly cross-sectional with some samples followed longitudinally. This makes its analysis quite challenging. The original target population was infants/children aged birth to 11 (civilian and non-institutionalized, not living on First Nations reserves or Crown lands) in the 10 provinces. The sample for the most recent cycle included 37,655 children and youths. The content included factors influencing a child's social, emotional, physical, and behavioural development over time. Many of the social determinants of health are of course relevant to mental health, but specific illnesses are not measured using standard diagnostic instruments. Even so, mental-health relevant content included concepts such as temperament,

adaptability, self-esteem, emotional issues/anxiety, depression, emotional intelligence, personal/social skills, positive and prosocial behaviour, parenting style, relationships, hyperactivity/inattention, oppositional and conduct disorders, separation anxiety, and social support, and use of alcohol, drugs, and tobacco. The NLSCY was phased out after the 2008-2009 cycle.

Modeled on the NLSCY, the **New Canadian Children and Youth Study** is a CIHR-funded collaborative longitudinal investigation of the physical and mental health and well-being of approximately 4,000 immigrant and refugee children and their families from 16 ethnocultural communities in six cities in Canada¹⁰¹. It includes culturally appropriate measures, some of which overlap with core NLSCY data, and others which address questions specific to the immigrant and refugee experience. Direct comparisons with data for majority culture children will be possible. In addition, it has a particular focus on mental health and risk factors for mental illnesses.

The National Population Health Survey (NPHS) was designed to collect information on the general health of Canadians to inform health policy¹⁰². Statistics Canada first conducted the NPHS in 1994 and continued every second year thereafter. The NPHS provided both cross-sectional information and longitudinal data, with the most recent data collection for the longitudinal component occurring in 2010-2011. The target population was household residents from the 10 provinces, excluding populations on First Nations reserves, Canadian Forces Bases, and some remote areas in Québec and Ontario. Separate surveys were conducted to cover Yukon, the Northwest Territories, and residents of institutions. More limited information was collected on all household members, and more in-depth information on a randomly selected member. Content included a range of health status and health service use variables, with some specific content for each cycle. For example, the special topic was psychosocial health in one cycle, and access to services in another. Mental health relevant content included general level of happiness with life, relationship stress, childhood and adult stressors/traumas, work stress, as well as symptoms, duration, and treatment received for “distress” and “depression”. The longitudinal design of the NPHS has provided Canadian estimates of the incidence (rate of new cases) of depression¹⁰³, whereas only prevalence (all existing cases) is available from cross-sectional surveys. However, a standard diagnostic instrument was not used. The NPHS was phased out after the 2010-2011 cycle.

The **First Nations Regional Longitudinal Health Survey** is the only First Nations-governed national health survey in Canada¹⁰⁴. It was initiated in the late 1990s to address the serious lack of information on the health and well-being of First Nations and Inuit, and the noted frequent exclusion of First Nations and Inuit from major national health surveys. The Assembly of First Nations Chiefs Committee on Health appointed the First Nations Information Governance Committee to oversee the survey. The study is funded by the First Nations Inuit Health Branch of Health Canada. It collects longitudinal data based on both Western and traditional understandings of health and wellbeing.

A pilot was conducted in 1997 called the *First Nations and Inuit Regional Health Survey*, which involved First Nations and Inuit from across Canada¹⁰⁵. The first full set of data was collected in late 2002/mid 2003. In total, 22,602 survey questionnaires were collected from 238 First Nations communities (Inuit communities did not participate in this round). The second set of data was collected in 2007/2008. The RHS includes three questionnaires designed for adults (18 years and over), youth (12 to 17 years), and children (0 to 11 years). It provides a snapshot of health and living conditions, including marital status and family structure, education and employment, language and traditional housing, and health (chronic

disease, diabetes, obesity, dental care, sexual health, smoking and tobacco use, drug and alcohol use, health care access, non-insured health benefits, disability, and mental health). Mental health topics covered include a list of conditions diagnosed by a health professional lasting 6 months or more (the list includes psychological or nervous conditions, and cognitive or mental disability). Also included is a range of items about suicide and self-inflicted injury, disability and activity limitation due to a physical or mental condition, personal wellness, health service use for emotional or mental health, and an indicator question about depression.

Statistics Canada also conducted the **Longitudinal Survey of Immigrants to Canada** which captured information from an initial group of 20,300 immigrants aged 15 years and older at three time points between 2000 and 2005¹⁰⁶. The survey content covered many variables related to immigrant mental health, but only two very basic questions regarding mental health itself (one on daily stress and one on the source of daily stress) were included.

Provincial Longitudinal Cohort Studies: At the provincial level there are likely dozens of cohort studies on particular topics and/or special clinical populations that are relevant to mental health; there is currently no central catalogue/information on such studies in Canada. Those described in this section are included because that they were/are either very broad in scope (across illnesses and settings), or were either directly sponsored by government or conducted as a partnership with policy/decision-makers.

In Ontario, two follow-up studies to the **Ontario Child Health Study** (previously described) were conducted to assess continuity and change in health status (1987) and functional outcomes in young adulthood (2000-2001)¹⁰⁷. The second follow-up focused on the impact of early childhood experiences on important transitions into adulthood, as well as on tracking and interviewing children from the original OCHS sample who had left Ontario¹⁰⁸. Eighty-seven percent of the original 1,987 were successfully located in 2000, of which 11% had left Ontario. The follow-up study was able to interview 85% of these out-migrants¹⁰⁸.

A set of community-based studies was conducted in Edmonton between 1983 and 1986^{109,110}. In these studies, one adult from each of a sample of randomly selected households was interviewed in-person using the Diagnostic Interview Schedule and the General Health Questionnaire. The response rate was 71.6% and the initial sample was 3,258. About 60% of the participants were re-interviewed just under three years later to provide estimates of incidence for some illnesses. Other related special studies included a family study, and an instrument comparison study among seniors.

The **Continuity of Mental Health Services of Alberta** (a decision-maker research partnership between the University of Calgary and the Alberta Mental Health Board) collected data for a sample of just fewer than 500 individuals with serious mental illness (including co-occurring conditions). They were recruited from all inpatient and outpatient mental health services in three Alberta health regions, and followed for service events from all directly and indirectly funded service and outcomes over an 18-month period (follow-up rate 85%) between 2001 and 2003. The primary data were linked to physician billing, hospital discharge, and outpatient administrative data to provide estimates of service costs in relation to outcomes including functioning and quality of life^{111,112}. Questions about housing and social support were studied in subsequent analyses of the dataset. Although the follow-up period was relatively short, this study is an example of how service delivery questions can be studied in a longitudinal design that

includes all data collected directly from participants and their families, from providers and health records, and from administrative data, for more comprehensive information.

A similar set of studies designed to evaluate community services (such as Assertive Community Treatment, Intensive Case Management and Peer Support) has just been completed across multiple sites in Ontario. The **Community Mental Health Evaluation Initiative** followed more than 800 participants from program entry through 18 months with a common set of service and outcome measures¹¹³. This work, led by the Health Systems Research and Consulting Unit, was a collaboration among the Ontario Mental Health Foundation, CAMH, and the Canadian Mental Health Association, and was funded by the Ontario Ministry of Health and Long-Term Care. Although not designed for surveillance per se, in theory data collected in broad studies like this could be used for many purposes, and such studies could also be scaled up to be national in scope. This and the previous study demonstrate the acceptability and feasibility of longitudinal studies in mental health populations, even with more serious illnesses.

The **Epidemiological Catchment Area Study of Montreal South-West**, funded by CIHR, is a longitudinal study of a population-based sample of more than 2,400 individuals aged 15 to 65. Data were collected in two waves (2007-2008) and (2009-2010). Topics of interest include sociodemographic, clinical and life events of individuals and their environment, including economic factors, service organization factors, and neighbourhood factors. This study is characterized as a 'fourth generation epidemiologic study' because it includes information at both the individual and community levels¹¹⁴. Funding has been received for waves three and four, with these waves having questions regarding comorbid health problems.

With few exceptions, large policy relevant or decision-maker sponsored cohort studies are relatively rare in mental health in the world, and none has been conducted in Canada nationally or provincially. In contrast some very large, prominent, and influential studies have been undertaken for other chronic illnesses, with decades of follow-up for some. Examples are the Framingham Heart Study (cardiovascular disease - over 10,000 participants), the European Prospective Investigation into Cancer and Nutrition (500,000 participants) and the Women's Health Initiative (160,000 participants examining cardiovascular disease, cancer, and osteoporosis)¹¹⁵.

In Canada, large cohort studies currently involve multiple partners and funding sources. An example is the **Canadian Longitudinal Study on Aging (CLSA)** was initiated by the CIHR Institute of Aging^{116,117}. The study is a part of CIHR's Lifelong Health Initiative, which is intended as a research platform to conduct such large longitudinal studies on the health of Canadians. Study collaborators/partners include Health Canada, Statistics Canada, CIHI, the Canadian Association of Gerontology, seven provinces, and others. In the CLSA, 50,000 Canadians between the ages of 45 and 85 will be followed for a minimum of 20 years. Multiple types of data will be collected including biological, medical, psychological, social and economic to understand health, disease and disability as people age. The ultimate aim is to understand the aging process such that the quality of life of Canadians can be improved.

An example of a longitudinal study for another major chronic disease is the **Tomorrow Project**. This study was initiated at the provincial level (in Alberta in 2001). It was originally designed to follow 50,000 Albertans between the ages of 35 to 69. It was expanded in 2008 to the provinces of BC, Ontario, Québec and Atlantic Canada, and will now follow 300,000 Canadians for at least 30 years¹¹⁸. The study is

sponsored by the Canadian Partnership against Cancer (funded by the federal government and partner organizations: the BC Cancer Agency, Alberta Health Services, Cancer Care Ontario and the Ontario Institute for Cancer Research, Québec's CARTaGENE project, and Dalhousie University). The study will examine a broad range of genetic, lifestyle, and environmental factors, as well as the impact of service interventions such as screening and prevention. It will include biological measures, and is designed to allow linkage to administrative data, other health-related databases and cancer registries. The project also aims to establish a national bank of population health information that will be able to be accessed for many clinical, health services, and policy research questions. It is a stellar example of what is possible with the right vision, collective will, and multi-stakeholder collaboration.

The **At Home/Chez Soi study**, led by the MHCC and funded by Health Canada, is an example of a longitudinal follow-up study (for a very specialized population) in the context of a service trial in five Canadian cities. It is collecting risk, health service, and outcome variables from approximately 2,300 individuals who are homeless and have mental health problems and illnesses over a 24-month period after a specialized housing intervention. The project links the data collected with provincial and national administrative data. The study includes funding for both the intervention and the research components, is using state of the art technology to collect data in the field, and has consumer involvement in all aspects¹¹⁹.

The **National Trajectory Project (NTP)** is a project funded through the Mental Health Commission of Canada and based on an ongoing study in Québec funded by the Fonds de recherche en santé du Québec. The project examines the operation of current criminal justice provisions for individuals declared not criminally responsible on account of mental disorder (NCRMD) and under the authority of a provincial or territorial review board. It will examine the antecedents and trajectories of NCRMD accused, including mental health and criminal justice involvement, review board decision-making, and mental health and criminal outcomes. The study includes the three largest provinces (Ontario, Québec and British Columbia), which comprise the majority of NCRMD cases. This is a multidimensional study which involves quantitative and qualitative research projects. Examples of objectives of the quantitative arm of the NTP include: exploring the demographic, psychosocial, and criminological profiles of NCRMD accused in Canada as a function of geographic region and type of institution of detention, and determining the use and predictors of mental health services by the accused prior to the NCRMD verdict.

Strengths and Limitations of Longitudinal Studies

Longitudinal studies have many strengths¹²⁰⁻¹²². Topics of interest can be defined very specifically and measured relatively precisely. These studies are especially valuable for studying phenomena that occur over time, including the delivery of service interventions and outcomes, not just the development of illness. Longitudinal studies can collect information on a range of factors at initiation, as well as a range of outcomes at the end-point, and result in rich datasets that can be used for the analysis of many questions. Once the initial group of participants is identified, there is no need for drawing a new sample; just a need to re-contact the same participants. Because the data are collected over time, the response burden for each person can be spread over several sessions, allowing for more comprehensive measurement. Contrary to common misconception, longitudinal studies are not restricted to obtaining results at the end of the study period, since the data collected at baseline provide the same information

as a cross-sectional survey, and analysis can occur at various points throughout the follow-up period according to the research/policy question.

Just as in other surveys, with the right privacy protections in place, the information can be linked with other relevant datasets, such as administrative data, health records, or vital statistics. For example, in the context of mental health, one or more well-designed longitudinal studies could examine things like risk and resilience, the processes and predictors of recovery, and effectiveness of specific services or sets of services. Cross-sectional surveys show that there is a substantial gap between an evident need for mental health care as measured by standard diagnostic instruments, and the receipt of services. Both what *appears to be* underuse (individuals with illnesses receiving no care) and what *appears to be* overuse (individuals without significant symptoms receiving care) are regularly described, but cross-sectional surveys cannot illuminate the pathways through which various need variables predict service use over time, and appropriate use is not yet properly defined. Despite great concern about the observed unmet need, there is remarkably little known at the population level about which individual and service variables predict outcomes.

The principle limitation of longitudinal studies is that they are relatively expensive to plan and implement, and ensure as complete follow-up as possible. However, if designed appropriately they can replace resources spent on multiple, less comprehensive initiatives, such that the benefits may justify the costs. Newer technologies, including design, analysis, and collection methods are improving the efficiency of longitudinal studies¹²³⁻¹²⁵. For example, participants can directly complete questionnaires or provide real-time responses on their home computers or mobile devices¹²⁶. Newer approaches for the appropriate and ethical recruitment and retention of participants have also advanced^{e.g.,127}. Since many mental health problems and illnesses are prevalent and develop over shorter time periods than some other chronic diseases such as cancer, longitudinal studies may not have to be as large, or as long, to provide useful answers.

Other Types of Information: Sentinel Systems; Case Registries; Electronic Health Records; and Performance Measurement Systems

Sentinel Systems

A small number of other types/sources of data is used to inform important issues about population health and health care delivery. These include sentinel reporting systems – which involve ongoing in-depth reporting on selected health events or cases from selected sites, in contrast with relatively superficial reporting on all events¹²⁸. Sentinel systems usually involve a network of reporting sites from a uniform service setting, such as public health units, family practice offices, or medical laboratories; for example, a selected network of laboratories reporting on cases of infectious disease.

Such systems are less expensive than more comprehensive data collection, but there is much less confidence in the representativeness of the sample of information provided. Sentinel systems have and are being used in areas of health, such as infectious diseases, occupational health, and adverse medical events (patient safety); mental health applications are rare. A recent example from the literature is an occupational physician-network in the UK in which work-related health concerns, including mental health, are reported for a sample of patients¹²⁹.

For alcohol and drug use, the CCSA with federal, provincial, and community partners, established the Canadian Community Epidemiology Network on Drug Use in 1995⁷⁵. This network of reporting sites tracks information on trends in use of eight drugs (alcohol, cocaine, cannabis, heroin, sedative-hypnotics and tranquilizers, hallucinogens other than cannabis, stimulants other than cocaine, and licit drugs), as well as six related topics (prevalence, law enforcement, treatment, morbidity, mortality, and HIV/AIDS/HEP C, including injection drug use and needle exchange).

Case Registries

In epidemiology, a case registry refers to a system of collected data covering all cases of a particular disease or other health condition in a defined population^{131,132}. The most well-known case registry systems are for cancer, and in Canada these are served by special provincial legislation¹³³. There are no large scale mental health-related case registries in Canada, although they are quite common in Europe where they usually involve more distinct diagnoses such as schizophrenia¹³⁴. Information from case registries would have a similar downside to administrative data in mental health, in that only those individuals who receive formally funded services would be included. However, registries go beyond administrative data by systematically recording, for a distinctly defined group at the outset, some limited clinical information and tracking (usually a limited set of) outcomes¹³⁵.

Electronic Health Records (EHRs)

An electronic health record is “a secure, integrated and comprehensive view of a person’s medical records based on information generated through a person’s interactions with the health care system”¹³⁶. EHRs, in theory, should be a goldmine of information on the delivery of care across multiple conditions and settings, and including outcomes. EHRs are being implemented across the country with the support of provincial health departments and, at the federal level, Canada Health Infoway¹³⁷. The emphasis is on infrastructure, electronic information standards development, and developing structural components, including patient registries, diagnostic, and drug and lab systems (including a component for public health surveillance). EHRs are focused primarily on infectious disease surveillance at this point.

About 1.6 billion dollars have been spent on EHRs in Canada with most going to provincial and territorial initiatives, but according to a federal report of the Auditor General, progress on implementation is still ongoing¹³⁸. Like administrative data, they are intended to cover all health care events for all individuals presenting for care in settings where they are implemented (including hospitals, primary care, and if included, outpatient care), and the data are already collected for another purpose (care delivery). EHRs are designed to capture much more detail about care delivery (compared to administrative records), and to collect it prospectively over time. While it would be excessively costly to abstract hard copy health record information at a national level for surveillance purposes, in theory electronic records, even in large volumes, could be readily analyzed. However, in practice the lack of pan-Canadian standards remains a significant barrier for national analysis.

An example of the use of EHR data to derive estimates of chronic disease prevalence is provided by Esteban-Vasallo (2009)¹³⁹. As a source of information for monitoring mental health care delivery, EHRs would have the same downside as administrative data sources currently have. That is, they would not capture individuals who do not access directly funded health services. For many years, there were no initiatives with the objective of designing the content (including the mental health-related content) of EHRs to make the data useable for broader service and policy questions across jurisdictions, although

there are recent calls for a much more active implementation agenda, and for the use of EHRs for safety and outcomes monitoring in Canada^{140,141}. Use of EHR data for national mental health surveillance or performance measurement would require development of an access process that could work across the regulations of multiple jurisdictions, which would be a complex task.

Beginning in 2001, a system level examination of HER began. Canada Health Infoway (Infoway) was given the mandate to build the elements of an interoperable electronic health records and infostructure in Canada. Infoway has developed Electronic Health Records Solutions (EHRs) Blueprints to serve as the framework for an interoperable EHR in Canada.

In 2008, a Conference of Deputy Ministers asked Infoway and CIHI to lead an initiative that would ensure that considerations of health system use (secondary use) of data are built into EHR/EMR design. The concept of 'Health System Use (HSU)' was proposed to the Conference of Deputy Ministers, and was broadly recognized as a significant opportunity to improve the health of Canadians, and the performance of our health care system.

HSU of data refers to the use of health information to improve health of Canadians and health care system. It supports the delivery of care and patient outcomes and encompasses four main categories of Health System Use: (1) Clinical Program Management (use of data to improve front line health care programs and services); (2) Health System Management (use of data to improve the effectiveness and efficiency of the health care system); (3) Health of the Public (use of data to understand health of the public); and (4) Research (use of data for research).

HSU is recognized at many levels of government as critical to health care and population health improvements, and broader health care transformation. In 2011, a project funded through Infoway called the Health System Use (HSU) Project was established to assist federal and provincial/territorial jurisdictions and other stakeholders to align to a pan-Canadian vision for EHRs in Canada. A Health System Use Technical Advisory Committee has been formed by Infoway to advance this agenda.

Performance Measurement Indicators and Frameworks

Performance measurement "seeks to monitor, evaluate and communicate the extent to which various aspects of the health system meet key objectives"¹⁴². Health-related performance measurement systems typically take the form of conceptual frameworks and sets of indicators, and like health surveillance systems, usually come from multiple secondary data sources. The literature on performance measurement has boomed in volume and complexity in recent years, but systems to actually collect performance measurement data are in the early stages of development for mental health, and indicators specific to mental healthcare are infrequently reported relative to indicators for other areas of health care^{143,144}. As such, mental health can be relatively invisible to the public and policy-makers in these systems¹⁴³. A recent environmental scan confirmed that provincial efforts on mental health performance measurement are limited to date, and there was almost no coordination across jurisdictions¹⁴⁵.

Even so, there are a few noteworthy performance measurement-related initiatives in Canada. At the national level, CIHI and Statistics Canada's report on Health Indicators (2009) included 86 health-related indicators across four domains. A few of these were directly related to mental health (perceived mental health, perceived life stress, and mood disorders in the Health Status domain; and contact with a health

professional about mental health in the Community and Health Systems Characteristics domain)²². The 2011 Health Indicators report was focused on mental health, and reported on three new indicators from hospital data in the Health Systems Performance domain: self-injury in Canada, 30-day readmission rate for mental illness, and repeat hospitalizations for those with selected mental illnesses¹⁴⁶. The Canadian Health Services Research Foundation (CHSRF) (with the Canadian Patient Safety Institute, CIHI, and Statistics Canada) also recently released *Quality of Healthcare in Canada: A Chartbook*, which listed more than 130 indicators in six domains, four of which are mental health-related¹⁴⁷. As well, the new Continuing Care Reporting System (CCRS) is examining quality indicators including clinical information, functional and resource utilization information on individuals receiving continuing care services in hospital or long-term care homes in Canada.

In British Columbia, a set of 12 population-based and province-wide quality indicators (based on the CIHI framework) was developed and reported on in a project sponsored by the BC Ministry of Health Mental Health and Addiction Division in partnership with the six provincial health authorities, and with expertise provided by the Centre for Applied Research in Mental Health & Addiction at Simon Fraser University³¹. The report noted that few benchmarks were available for these indicators from other jurisdictions. BC's new 10-year plan for mental health and substance use, 'Healthy Minds, Healthy People', includes proposed performance measures¹⁴⁸.

The Hospital Report Collaborative, a joint initiative of the Ontario Hospital Association and the Government of Ontario, developed and reported on 23 mental health indicators using a balanced scorecard framework in 2001, 2004, and 2007¹⁴⁹. The areas covered included client/patient perceptions of care, financial condition, integration and continuity of care, and clinical utilization. In 2006, the non-mental health portion of the Collaborative work was transitioned to CIHI. The mental health report has been discontinued, although a number of its indicators are being used for other performance monitoring initiatives in the province^{150,151}. Ontario's new Mental Health and Addictions Strategy 'Respect, Recovery, Resilience' (December 2010) includes some proposed measures of performance¹⁴⁸.

In 2010, Alberta released *System Level Performance for Mental Health and Addiction in Alberta*, a report on the results of a performance measurement exercise focused on six domains of health quality (acceptability, accessibility, appropriateness, effectiveness, efficiency, and safety) and 10 indicators¹⁵³. Some performance measurement efforts are also underway, according to informal reports, in Québec and New Brunswick. To date there is no national mechanism to share these developments¹⁵⁴. The results of one national consensus process for indicators for primary mental health care, which was undertaken in the mid-2000s, have recently been published¹⁵⁵. This process identified more than 2,000 indicators relevant to that setting, and through a systematic cross-province process selected a set of priority indicators; however, implementation is complex in the context of the changing structure of primary health care across the country. Part of this complexity is because services are provided in both the social and health sectors.

Efforts to advance mental health performance measurement have also been undertaken in other countries and internationally. = There have been multiple, largely uncoordinated, initiatives in the US to identify indicators for mental health service performance¹⁵⁶. Herbstman et al. (2009 p. 629) have lamented that there is no coordinated oversight of the efforts, and as a result there are "significant gaps in indicator development that have yet to be addressed", as well as "enormous weaknesses in data systems making reporting of measures extremely difficult". The US has many more barriers to cross-

organization measurement in comparison to Canada due to the structure of its health care delivery system.

There has also been more than one international effort to develop mental health care performance measures. An early initiative focused almost exclusively on indicators for which administrative data were available, drastically reducing a list of 134 to 12, leaving many gaps¹⁵⁷. For example, none of the indicators addressed services for children and youth. Another more recent and seemingly unrelated initiative, funded by the Substance Abuse and Mental Health Services Administration in the US and involving 12 countries, includes framework development and the cataloging of indicators in identified domains. Many of the identified indicators to date are for adult care and inpatient care¹⁵⁸. Another source reports that several countries of the Organization for Economic Co-operation and the European Union have recognized the importance of mental health, and are working on comprehensive performance measurement systems for mental health in member countries, which include consumer experience and important issues like equity¹⁴².

Privacy and Mental Health Information in Canada

Administrative and survey data include information that is both personal and sensitive, and that is protected by legislation in every province and territory of Canada¹⁵⁹. The legislation protects privacy, yet permits access for legitimate purposes. Consequently, conditions are specified under which personal or personal health information¹⁰ can be collected, must be stored, and can be accessed. Collectors of personal or personal health information are required, for example, to protect against theft or unauthorized use of this data, and there can be significant penalties for disclosure. In Ontario, for example, fines can be imposed of up to \$50,000 per individual, and \$250,000 per institution per offence. In addition, Ontarians whose information is used inappropriately can sue for further damages¹⁵⁹.

While research and health care planning are considered legitimate purposes, access to data is regulated to minimize inappropriate use. In general, only specific organizations or institutes are permitted to house and analyze data containing personal health information. Projects (and the project teams) must be individually vetted, undergo ethics and privacy reviews, and demonstrate that there is no other alternative to using personal health information. Identifying information is either encrypted (electronically scrambled) or removed from the data, and only designated individuals are allowed to conduct the actual analysis. Reporting rules, such as suppressing results involving small numbers of people or reporting findings only in aggregate form, are imposed to minimize any chance that individual privacy may be breached.

Privacy and security of any information used for health services planning and policy and for monitoring improvements to the system is critical; both technological and procedural protections have advanced in recent years. However, a system of multiple initiatives that are separated by jurisdictional and organizational boundaries requires complicated, duplicative, and time-consuming processes.

¹⁰ Defined as information that can be used to identify an individual or that individual's health status, or health care circumstances.

SECTION THREE – MENTAL HEALTH INFORMATION DEVELOPMENTS IN OTHER COUNTRIES

In keeping with recognition of the prevalence and societal impact of mental health problems and illnesses, as well as the importance of good mental health to a nation's overall health and prosperity, many countries are advancing their national-level, population-based mental health information/surveillance agenda. Many countries have conducted their own (mostly cross-sectional) surveys, and 28 countries are currently participating in a World Health Organization cross-national sample¹⁶⁰, although Canada is not among them. More information on some of the main surveys is readily available in the grey and peer-reviewed literature.

In the **United States**, high level information about mental health has come from surveys and service systems; largely separate from public health, as reported in a recent review by Freeman et al.¹⁶¹. Since the 1999 Surgeon General's report on mental health, there has been a more concerted effort to build the infrastructure for a comprehensive mental health surveillance system. While the American health care system may offer fewer opportunities for total population administrative data analyses (e.g., Medicaid/Medicare databases cover only certain groups), there is a rich set of survey data available. The most recent and relevant information comes from the National Comorbidity Surveys (NCS), which collected baseline data from a nationally representative sample in 1990/1992 and then again 10 years later for some participants (a longitudinal component), as well as a new sample in 2001/2002. The NCS is very comprehensive, including information on the determinants of mental health, such as childhood maltreatment and other adverse experiences. The survey has also recently been extended to collect common information for major ethnocultural groups in the National Survey of American Life (focused on African-Americans), and the National Latino and Asian American Study with common measures, as well as a similar nationally representative mental health survey specific to youth^{124,162}.

Recent years have seen a substantial trend toward integration of all sources, including efforts to include similar measures across various surveys in the US. In a related initiative, a workshop was convened to discuss the integration of mental health into chronic illness prevention and health promotion, which was followed by a logic model that incorporated integrated surveillance¹⁶³. For example, mental health measures are now included in broad health surveys such as the National Health and Nutrition Examination Survey, the Behavioral Risk Factor Surveillance System (BRFSS), and the National Survey on Drug Use and Health among others. These developments include understanding of the need to integrate information-related efforts across multiple data sources, including those from mental health and substance use systems, to better reflect the co-occurrence of mental illness and substance use (e.g.,¹⁶⁴), as well as the evident associations between many physical health conditions and mental health¹⁶¹. They also indicate acknowledgement of the need to understand mental health issues in ethnoculturally diverse populations, and for surveillance to be culturally meaningful.

More longitudinal approaches are being incorporated as appropriate. Other advances include the measurement of mental illnesses using variables that occur on a continuum, such as psychological distress rather than just a categorical diagnostic approach, and many recent publications have reported on relevant findings^{e.g.,165}. Also recognized is the distinction between mental health and mental illness, and the need to measure and monitor positive mental health-related variables such as well-being (e.g., the BRFSS now includes measures of recovery and outcome)¹⁶⁶, as well as the need for more of a

lifespan approach to mental health which necessitates better measurement of childhood mental health/illness and later life mental health/illness. Gaps are also noted with respect to information to assess the effectiveness of interventions, and data on specific topics including medications, unmet needs for service, and outcomes in domains such as employment, housing, and service satisfaction. Indicators are being extracted from these sources for benchmarking and system performance measurement, and efforts are being made to improve dissemination and information use.

While not specific to mental health information, a new initiative of the Health Legacy Partnership is working toward the establishment of a National Health Outcomes data sharing network which proposes to use, with the appropriate privacy protections, information from EHRs to study health care delivery and outcomes¹⁶⁷.

In **Australia**, a key recommendation of the National Health and Hospital Reform Commission report, *A Healthier Future for all Australians: Final Report (2009)*¹⁶⁸, refers to the use of “smart data”, such as existing health information systems, to improve health outcomes. Comprehensive approaches are being used to combine multiple diverse sources of data, such as vital statistics, health service delivery (including mental health service delivery), and cancer registration. For example in Western Australia, a mental health information system comprises a register of individuals who have had contact with mental health services including inpatient and outpatient care¹⁶⁹. It includes demographics, diagnosis, and treatment history over time.

More recently, the federal government has funded the Population Health Research Network for the extraction, linkage, and analysis of administrative data across Australia that will use Australia’s extensive health data in a multi-jurisdictional, multi-health information database approach to the surveillance of non-communicable chronic illness such as mental illness. Initial efforts have focused on mortality and hospital admissions, but it is planned to incorporate mental health information systems from each jurisdiction covering inpatient, outpatient and community care.

Unlike Canada, these information systems do not include primary care or prescription data, which are held by the federal government. The primary care information held federally also includes referrals to psychologists under the Better Access initiative to improve early detection and treatment for people living with mental health problems and illnesses.

National mental health surveys (the National Surveys of Mental Health and Wellbeing) have also been conducted in Australia in 1997 (for ages 18 and up) and 2007 (ages 16 to 85) with more than 10,000 and 8,000 participants respectively, and response rates of 78 and 60% respectively. These surveys have also included special studies to estimate low prevalence conditions (psychoses). Results of these and related surveys on general health and well-being have been reported in reader-friendly bulletins that identify opportunities and strategies for health gains¹⁷⁰. Work on population mental health literacy has also been pioneered in Australia¹⁷¹.

Survey data on mental health in the **United Kingdom** come from the National Psychiatric Morbidity Surveys. These household surveys of 1993 and 2000 were designed to be representative of the population aged 16 to 64¹⁷²⁻¹⁷⁴. The surveys used the Revised Clinical Interview Schedule and questions on alcohol, tobacco, and drugs. A second-phase sub-sample who screened positive for psychosis received a standardized clinical interview.

In addition to these two household surveys, data were drawn from a sample of 10% of the English prison population and a survey of 1,000 homeless people, as well as child and adolescent populations¹⁷⁴. In the UK, Scotland has some of the best administrative data in terms of quality, consistency, national coverage, and the ability to link data to allow person-based analysis and follow up¹⁷⁵. Data are collected at an individual level and include mental health inpatient records. These include data on day cases and inpatients in all psychiatric hospitals and units. In addition, the Scottish Drug Misuse Database provides information on the characteristics of, and trends in, drug use in Scotland. However, coverage of community and outpatients contacts has been less comprehensive, with little data being collected in a nationally-consistent way from specialist community mental health services.

In order to tackle this issue, the Information Services Division of National Health Services (NHS) Scotland established the Improving Mental Health Information Programme (IMHIP) in 2001. Information sets were developed by IMHIP for community mental health services and inpatient services respectively. Over time the collection of encounter and intervention information will build up a history of encounters between the community specialist team and service user. The intention is that community mental health teams will have routine access to these data to aid care delivery, particularly during times of crisis out-of-hours when key information can often be difficult to access. In the longer term, these data standards will form part of the mental health component of an EHR, and will support the consistent recording and exchange of patient information among health and social care providers throughout NHS Scotland.

Primary care research networks are another source of mental health data in the UK and there are several of these networks in the country. The most relevant for mental health has been the General Practice Research Database (GPRD)^{176,177}. This anonymous database covers 741 general practices representing 6.4% of the population in England, 5.1% in Wales, 2.8% in Scotland, and 5.8% in Northern Ireland¹⁷⁸. The database is broadly representative of the UK population in age and sex structure. The GPRD is the world's largest computerized database of patient records, and is owned by the Medicines and Healthcare Products Regulatory Agency (MHRA)¹⁷⁹. Contributing GPs record all significant morbidity. GPRD data are subjected to routine quality assessment on the basis of 15 key indicators. Research has shown that the classification of psychosis, schizophrenia, affective psychosis, and non-affective psychosis on the GPRD is accurate, and misclassification low^{178,179}. This network has been used to measure the prevalence of a wide range of psychiatric conditions, including trends over time. Conditions have included the following: psychosis, suicide, eating disorders, and comorbidity/dual diagnosis¹⁷⁷⁻¹⁸⁰, and to study comorbidity between mental health and medical conditions^{177,181-184}.

In 2011, the International Initiative for Mental Health Leadership embarked on a project to create international indicators that would enable member countries to benchmark against each other. The goal of the project is "to develop and implement a balanced, inclusive, and common framework of performance measures that will allow for international comparison of system performance across countries and inform new initiatives."¹⁸⁷ The project is expected to be completed in 2014.

Finally, the MHCC's Data project is seeking to create national mental health and mental illness indicators to serve as a foundation for evidence-informed mental health policy and practice in Canada. The indicators will be reflective of the Mental Health Strategy for Canada. They will include a mix of

population and systems performance measures, and help to sustain a focus on key strategic issues identified in the Strategy.

SECTION FOUR – NEEDS IDENTIFICATION AND GAP ANALYSIS

The purpose of this section is to summarize gaps and needs in existing mental health information that have been identified through three separate, but complementary activities. First, key messages about mental health information and surveillance were extracted from ***Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*** (2006), a report of the Standing Committee on Social Affairs, Science and Technology. As well, stakeholders' views on this issue were further solicited in the MHCC's development of ***Toward Recovery & Well-Being: A Framework for a Mental Health Strategy for Canada*** (2009)⁴. It has been specifically recognized that the ability to review progress toward the goals of the Framework will depend on the availability of relevant data, and some initial work on relevant indicators has begun (described in the report). This work was completed during the period of 2010-2011, and has not been updated to the present.

Second, specific responses to the first three sections of this document (i.e., definitions to key terms, the current mental health information landscape in Canada, and mental health information developments in other countries) were compiled, and messages were extracted from a focused stakeholder consultation meeting of MHCC stakeholders that was held in June 2010.

Third, gaps in mental health and related information in Canada were systematically identified in the Impact of Mental Illness in Canada project from 2010 to the present. The purpose of that project was to mathematically model the current state of mental illnesses, service delivery, disability, and costs for the total population in Canada, and to project the findings forward for the next 30 years. This type of modeling helps policy makers understand how policy choices in the present can contribute to population health in the immediate and longer term. Developing the model for mental illnesses and addictions required data on the total population (i.e. births, deaths, immigration) as well as detailed population-based data on the frequency of illness and comorbid conditions in all age and sex groups, health service use across a comprehensive range of service settings, labour force participation, processes such as recovery, relapse and mortality, and societal costs. The process of seeking data of sufficient quality and granularity for this project served as a direct and empirical test of the types, quality, and availability of mental health-related data in Canada, and as such underscored major and minor gaps in data that are critical to planning and decision-making.

Goals & Purposes for Information in Canada:

- how well we are meeting needs of persons living with mental health problems and illnesses (1,3, 5, 7)
- how well we are promoting the mental health of Canadians (2)
- accountability for funds spent on services (5)
- evaluation of our progress toward a system reflected by the Framework goals – that is, the degree to which we are enhancing recovery and well-being, advancing mental health promotion and illness prevention, responding to diversity, involving families, ensuring access to appropriate

and effective services and supports, and ensuring social inclusion for people living with mental health problems and illnesses

Features/Functions of a Mental Health Information/Surveillance System(s):

- guided by an overall strategic framework
- monitoring and regular reporting for evaluation and accountability (2,5)
- capture of key information over time and in different settings
- providing measures that jurisdictions can use to set targets for health and program outcomes (2,5)
- easier and quicker access to information of sufficient detail to support decision-making, including corrective action (5)
- better access to data and information for stakeholders and the general public (4,7)
- more decision-maker involvement in determining information needs (2,5)
- more involvement of people with lived experience and their families setting priorities for information
- provisions for strong privacy protection

Types of Information Needed:

- information on the frequency of mental health problems and illnesses, both incidence (new cases), and prevalence (existing cases) (2,3,5)
- information on service needs and outcomes including outcomes from the perspective of those with lived experience (3)
- information on mental health status that includes new concepts, such as emotional and spiritual well-being, resilience, recovery, flourishing, a sense of mastery, and quality of life in the general population and among those living with mental health problems and illnesses (1,2,4)
- information on the broad determinants of mental health, including access to and receipt of housing, income, education, and employment (1,2,4,5)
- information that takes the reality of co-occurring conditions into account including co-occurrence among mental illnesses, between mental illness and substance use, and between mental illness and physical illness (2,5)
- information about suicide in high risk groups (2,3, 5)
- information about quantity, quality, and effectiveness (including cost-effectiveness) of interventions, including prevention/promotion, and a full range of treatments and settings (including but not dominated by information about medications or hospital use) with a focus on outcomes of policy, program, and individual-level interventions (also described as performance monitoring); including treatment outcomes (both what has worked and what has not) from the perspective of the person and his or her family, or circle of care (1,2,3,4,5)
- information about stigma and discrimination in the general population, and as experienced by those living with mental health problems and illnesses (1,7)
- information about mental health literacy of the general population (1,2,5,7)
- information on the impact of mental health problems and illnesses (e.g., disability and cost) (2,5)

- information about the impact of psychological health and safety issues in the workplace (2,5)
- information about the role of families and informal caregiving by family and other supports (4)
- information that captures mental health services delivered across multiple settings – not just hospitals (including community and primary care), and by multiple providers (including peer support and informal care and through innovations such as tele-mental health or practices of concern e.g., seclusion and restraint) (1,5)
- information that captures the degree to which interventions are accessible, holistic, evidence-informed, person-centered, inclusive, culturally safe, and culturally competent (1,3,5,7)
- information that allows assessment of the gap between need for care and receipt of care (i.e., unmet needs) (5)
- information that reflects the mental health system as it is more broadly defined than simply formal health services (e.g., social services, housing, employment, education, justice, workplaces) (1, 2,5,7)
- information regarding disparities in mental health determinants and outcomes (3)
- consolidated and detailed information on mental health-related research (planned, underway, and completed,) including funding and funding opportunities

Particular Groups or Populations for Whom Information is Felt to be Inadequate

- children and youth, including illness prevalence but also risk and protective factors, as well as effectiveness of treatment options (1,2,3,4,5)
- seniors, including illness prevalence and risk and protective factors (1,2,3,4,5)
- First Nations, Métis, and in particular Inuit peoples (3,7)
- immigrant populations and linguistic minorities (3,7)
- diverse individual and group needs, and the intersections of dimensions of diversity as defined in goal three of the Framework (goal is that “the mental health system responds to the diverse needs of people in Canada”) (4,8)
- individuals in the corrections system (5)
- workers and the workplace (2,5,7)
- individuals in military service (5,7)
- homeless individuals (5,7)
- women and mental illness and overall health
- individuals with comorbid mental health and developmental disabilities
- individuals with comorbid mental health and physical health

New data needed to measure progress toward achieving the seven Framework goals:

Family and Caregivers

- documentation of family as caregivers (keeping in mind families are diverse and could be non-traditional)
- economic, emotional, and mental impacts on families and caregivers
- perspectives of families and caregivers
- role of family and caregivers in transitions

Access to Care

- lack of access to care, particularly in rural, remote, FNIM communities, and linguistic minorities
- some populations may have inadequate access when living in these communities, such as children and youth

Community Services

- data on informal care, CSI, community programs
- community-level socioeconomic data
- linkages with other systems, such as corrections and education

Disability and Economic Measures

- capturing DALYs
- linkages with drug and insurance company data
- caregiver costs

Seniors

- capturing data on multiple diagnoses — mental illnesses may not be addressed when patient is seen for other condition

Children and Youth

- improved overall data on children and youth
- data that will increase knowledge on transitions to adult illnesses
- linking youth justice to adult justice

Quality

- improved data collection and analysis of existing sources for system and service quality
- data on outcomes, including quality of life, recovery-based, pathways, protective factors, patient and family experience with system

Training

- data on training for health and social service providers

Using Existing Data

- improved access to existing data sources, such as workplace data
- increased linking of existing data sources when appropriate (data sources are not currently linked within or across provinces)
- “black hole” of data—lots of data collected, but not much information (this requires improvement at data collection and analysis stages)

What is needed to support the transformation of the mental health system?

- The Mental Health Commission of Canada serves as a catalyst for this process and should support the work of provinces, territories, and other organizations in implementing this transformation. The focus should be on recovery, disability, resilience, patient experience, and mental health literature.

- The system should focus on health and not just illness. It is important to capture indicators of healthy communities.
- A minimum data set (MDS), a set of common indicators, is needed across the country.
- We need to move beyond collecting information that is interesting to know and focus on the data that can be used to transform the system.
- Learn from international efforts to transform system.
- Incorporate cultural sensitivity to labels and diagnoses.
- Consider the use of case registries.

What consultation strategy would you recommend to advance the agenda toward a more comprehensive and effective mental health information system?

- Identify knowledge gaps.
- Establish collaborators, such as PHAC, CIHI, and Statistics Canada.
- Document common mental health, mental illness, and addiction indicators across the country.
- Establish a central repository for data.

What are the immediate next steps needed for this transformation?

- Provinces are working on mental health strategies. We need to integrate with that process.
- Most of these steps are identified in the above question.

A summary of the systematic gap analysis can be found in the table located in Appendix A. The table is organized into the following areas: childhood/adolescence incidence; child/adolescence prevalence; adult prevalence (mood, anxiety, dementia, schizophrenia, SUD); adult incidence; excess mortality (all ages); adult economic disability (excludes dementia and childhood/adolescent conditions); direct health care utilization (all ages); direct health care costs (all ages, with all mental illness except dementia); direct health care costs (dementia); healthy immigrant effect (adult); chronic disease prevalence (Type 2 diabetes for adults); chronic disease prevalence (heart disease adults); relative risk estimates for relationship between mental illness and chronic diseases (type 2 diabetes & heart disease); comorbidity among mental illnesses; and housing/homelessness sub-model. For each data source, a description is provided along with potential limitations of the data, and the rationale for using this data source.

The Mental Health Information and Addictions Collaborative (the Collaborative) is an effort catalyzed by the Mental Health Commission of Canada to support the Canadian mental health data landscape through effective and ongoing collaboration. Formed in 2014, its current members include the [Canadian Institute for Health Research](#), [Public Health Agency of Canada](#), [Canadian Institute for Health Information](#), [Health Canada](#), [Statistics Canada](#), and the [MHCC](#). The Collaborative is working to provide a forum for the support and alignment of initiatives aimed at enhancing mental health and addictions information in Canada. It identifies opportunities and facilitates efforts aimed at furthering this purpose through integration and quality improvement of existing data resources, and the development of new resources that fill mental health and addictions information gaps. Participation in the collaborative allows members to represent and exchange information on the interests, initiatives, and objectives of their respective organizations as regards mental health and addictions information.

SECTION FIVE – SUMMARY AND WAYS FORWARD

Information is a powerful and necessary tool for creating positive change. Data on mental health services, outcomes, and the impact of social determinants of health are critical if Canada wants to make significant improvements to its mental health system. Comprehensive information allows for the support and planning of programs and initiatives, establishes indicators to measure success, and provides guidance for resource allocation.

Promising work to create new data, and share existing information, is ongoing at both the national and provincial/territorial levels. In *Changing Directions, Changing Lives: The Mental Health Strategy for Canada*, the Mental Health Commission of Canada (MHCC) acknowledges that data is already helping to create system change. However, the *Strategy* also notes “there is a need to make significant progress in our ability to understand what is working well to improve mental health and well-being and to use this expanded knowledge to measure progress in transforming the system and improving outcomes.”

While there are laudable examples of efforts to develop and use mental health information evident at the provincial/territorial level, there is little coordination across provinces/territories, and many of these efforts have not been sustained. At the national level, there is a variety of mental health-related information initiatives, and yet Canada still lacks a comprehensive set of mental health data to answer important questions about population mental health.

This indicates the country’s data collection efforts require a shift in focus: from a siloed approach to an integrated health/social system perspective that would capture pertinent mental health information along the continuum of care and services that are available in a variety of settings (including health and social/community services), and provided by a multitude of stakeholders. This shift would ensure that data and information are collected at transition points, and that the information related to the person’s journey is captured in a consistent way and over time.

The MHCC has a mandate to catalyze mental health system reform. In partnership with key stakeholders at the provincial/territorial and national level, the MHCC has an opportunity to provide leadership to develop a comprehensive framework for mental health information in the country, coordinating efforts with other organizations and across jurisdictions, and advising on areas of greatest need or impact. Toward this goal, the MHCC has supported the formation of the Mental Health Information and Addictions Collaborative (the Collaborative) to provide a forum for the support and alignment of initiatives aimed at enhancing mental health and addictions information in Canada. It identifies opportunities and facilitates efforts aimed at furthering this purpose through integration and quality improvement of existing data resources, and the development of new resources that fill mental health and addictions information gaps.

In addition, the MHCC collaborates with other organizations and key stakeholders on specific projects to collect, analyze, interpret, disseminate, and translate knowledge of mental health data to address the many gaps, and to encourage progress on mental health systems reform.

Filling in all of the data gaps around mental health and mental illnesses will take a concerted effort by all stakeholders, along with considerable time. However, the potential benefits for all Canadians are enormous. The strategic creation and sharing of existing and future mental health data will be a vital contribution in the ongoing work to helping to safeguard the mental health and well-being of every individual.

REFERENCES

- 1 mentalhealthcommission.ca [internet]. Canada: Mental Health Commission of Canada [cited 2010 April 21]. Available from: <http://www.mentalhealthcommission.ca>.
- 2 Canadian Alliance on Mental Illness and Mental Health. A call for action: building consensus for national action plan on mental illness and mental health. Canada: CAMIMH; 2003.
- 3 The Standing Committee on Social Affairs, Science and Technology. Out of the shadows at last: transforming mental health, mental illness and addiction services in Canada. Ottawa: The Committee; 2006. Available from: www.parl.gc.ca/39/1/parlbus/commbus/senate/com-e/soci-e/rep-e/rep02may06-e.htm.
- 4 Mental Health Commission of Canada. Toward recovery and well-being: a framework for a mental health strategy for Canada. Canada: The Commission; 2009.
- 5 Ackoff RL. From data to wisdom. J of Appl Systems Analysis. 1989;16(1989):3-9.
- 6 Bellinger G, Castro D, Mills A. Data, information, knowledge and wisdom [document on the internet]. Manchester, England. 2004 [cited 2010 April]. Available from: <http://www.systems-thinking.org/dikw/dikw.htm>.
- 7 Merriam-webster.com [internet]. Springfield (MD): Merriam-Webster, Incorporated [cited 2010 April 21]. Definition of the word data. Available from: <http://www.merriam-webster.com/dictionary/data>.
- 8 Adair CE, Simpson L, Birdsell J, Omelchuk K, Casebeer A et al. Performance measurement in health and mental health services: models, practices and effectiveness. A State of the Science Review. (Report); January, 2003 [cited 2010 April 21]. Available from: http://www.ahfmr.ab.ca/grants/state_of_science_final_reports.php.
- 9 Alberta Health. Evidence-based decision making: a guide to using indicators in health planning. Edmonton (AB): Alberta Health; 1995.
- 10 Donabedian A. The quality of care: how can it be assessed? JAMA. 1988;260:1743-8.
- 11 Centers for Disease Control and Prevention (CDC). Updated guidelines for evaluating public health surveillance systems: recommendations from the guidelines working group (recommendations and reports). Atlanta (GA): CDC; 2001 July 9 [cited 2010 April 21];50(RR13):1-35. Available from: <http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5013a1.htm>.
- 12 Choi BCK. Perspectives on Epidemiologic Surveillance in the 21st Century. Chronic Dis Can. 1998;19(4):145-51.
- 13 phac-aspc.gc.ca [internet]. Ottawa (ON): Government of Canada [cited 2010 April 21]. Available from: <http://www.phac-aspc.gc.ca/index-eng.php>.

- 14 Public Health Agency of Canada. National Population Health Study of Neurological Conditions program overview [Internet]. 2010 [updated 2010 Jan 4; cited 2011 Apr 16]. Available from: <http://www.phac-aspc.gc.ca/cd-mc/nc-mn/1-eng.php>.
- 15 Government of Canada. The human face of mental health and mental illness in Canada. Ottawa (ON): Minister of Public Works and Government Services Canada; 2006. Available from: <http://www.phac-aspc.gc.ca/publicat/human-humain06/>.
- 16 Government of Canada. A report on mental illnesses in Canada. Ottawa (ON): Health Canada; 2002. Available from: <http://www.phac-aspc.gc.ca/publicat/miic-mmacc/>.
- 17 Public Health Agency of Canada. Expanding mental illness surveillance in Canada (workshop proceedings). Ottawa (ON): The Agency; 2005.
- 18 Lakaski C & Trottier M. Developing an operational definition of positive mental health: final report based on consultation and workshop, February 26-27, 2009, Ottawa, Ontario. Public Health Agency of Canada unpublished report.
- 19 www.statcan.gc.ca [internet]. Ottawa (ON): Government of Canada [cited 2010 April 26]. Available from: <http://www.statcan.gc.ca/start-debut-eng.html>.
- 20 Statistics Canada [internet]. Ottawa (ON): Government of Canada [cited 2010 April 16]. Canadian Community Health Survey Information. Available from: www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3226&lang=en&db=imdb&adm=8&dis=2.
- 21 Statistics Canada. Health fact sheets [Internet]. 2010 [updated 2010 Aug 16; cited 2011 Apr 16]. Available from: <http://www.statcan.gc.ca/pub/82-625-x/82-625-x2010002-eng.htm>.
- 22 www.cihi.ca [internet homepage]. Ottawa (ON): The Canadian Institute for Health Information [cited 2010 April 21]. Available from: http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=home_e.
- 23 The Canadian Institute for Health Information. About the Canadian Population Health Initiative [Internet]. 2010 [cited 2011 April 16]. Available from: http://www.cihi.ca/CIHI-external/internet/en/document/factors+influencing+health/environmental/cphi_about.
- 24 Canadian Institute for Health Information. Improving the health of Canadians: exploring positive mental health. Ottawa, ON: CIHI, 2009. ISBN 978-1-55465-492-5.
- 25 The Canadian Institute for Health Information. Continuing care reporting system [Internet]. 2010 [cited 2011 April 16]. Available from: http://www.cihi.ca/cihi-external/internet/en/document/types+of+care/hospital+care/continuing+care/services_ccrs.
- 26 www.ccsa.ca [internet homepage]. Ottawa (ON): Canadian Centre on Substance Abuse [cited 2010 May 31]. Available from: <http://www.ccsa.ca/Eng/Pages/Home.aspx>.

- 27 Canadian Centre on Substance Abuse (2009) Substance abuse in Canada: concurrent disorders. Ottawa: ON: Canadian Centre on Substance Abuse.
- 28 Manitoba Centre for Health Policy [internet homepage]. Winnipeg (MB): University of Manitoba [cited 2010 April 23]. Available from: <http://www.umanitoba.ca/medicine/units/mchp/>.
- 29 www.ices.on.ca [internet]. Toronto (ON): The Institute For Clinical Evaluative Sciences [cited 2010 April 21]. About Us. Available from: http://www.ices.on.ca/webpage.cfm?site_id=1&org_id=26.
- 30 Health Systems Research and Consulting Unit at the Centre for Addiction and Mental Health [internet homepage]. Toronto (ON): The Centre [cited 2010 April 21]. Available from: http://www.camh.net/Research/Areas_of_Research/Social_Prevention_Health_Policy/health_systems_research.html.
- 31 www.carmha.ca [internet]. Vancouver (BC): Simon Fraser University [cited 2010 April 21]. Available from: <http://www.carmha.ca>.
- 32 Centre of Addictions Research of British Columbia [internet homepage]. Victoria (BC): University of Victoria [cited 2010 May 18]. Available from: <http://carbc.ca/>.
- 33 Canadian Institute for Health Information. Understanding emergency department wait times: who is using emergency departments and how long are they waiting? Ottawa (ON): The Institute; 2005. ISBN 1-55392-678-1.
- 34 PHAC [internet homepage] The Canadian Hospitals Injury Reporting and Prevention Program (CHIRPP) <http://www.phac-aspc.gc.ca/injury-bles/chirpp/index-eng.php>
- 35 Canadian Institutes of Health Research. Post-market surveillance of prescription drugs. Using the evidence. Ottawa: The Institutes, 2008 [cited 3 March 2009]. Available from: <http://www.cihr-irsc.gc.ca/e/36803.html>.
- 36 Carleton B, Foerster V, Warren L, & Smith A. Post-marketing pharmacosurveillance in Canada. Ottawa: Canadian Institutes of Health Research; 2005.
- 37 Aglukkaq, Leona. Minister of Health. Announcement of funding for the Drug Safety and Effectiveness Network. Toronto, ON. 2009 January 14 [cited 2010 May 18]. Available from: http://www.hc-sc.gc.ca/ahc-asc/minist/speeches-discours/2009/2009_01_16-eng.php.
- 38 www.health.gov.bc.ca [internet]. Vancouver (BC): Government of British Columbia [cited 2010 April 8]. Available from: <http://www.health.gov.bc.ca>.
- 39 Alberta Health [internet]. Edmonton (AB): Government of Alberta [cited 2010 April 21]. Alberta Healthcare Insurance Plan. Available from: <http://www.health.alberta.ca/health-care-insurance-plan.html>.

- 40 Slomp, M, & Rowan, R. Alberta Health Services. Edmonton, Alberta. Personal email correspondence. April 28, 2010.
- 41 Kisely, S. Director, Health Linq. St. Lucia, Queensland. Personal email correspondence. April 2010.
- 42 Stang, MR. Research Consultant, Saskatchewan Ministry of Health. Regina, Saskatchewan. Personal email communication. April 2010.
- 43 Epidemiology and Research Unit, Population Health Branch, Saskatchewan Ministry of Health. Health services databases: information document. Regina (SK): The Ministry; 2009 November.
- 44 canadaonline.about.com [internet]. New York (NY): The New York Times Company [cited 2010 April 8]. Manitoba health care. Available from:
http://canadaonline.about.com/od/healthcaremanitoba/Manitoba_Health_Care.htm
- 45 www.umanitoba.ca [internet]. Winnipeg (MB): The University of Manitoba [cited 2010 April 8]. The Mental Health Information Management System. Available from:
www.umanitoba.ca/faculties/medicine/units/mchp/resources/repository/health_mhmis.html.
- 46 www.ontario.cmha.ca [internet]. Toronto (ON): Canadian Mental Health Association, Ontario [cited 2010 April 21] Ontario Common Assessment of Need (OCAN) Update, February 2010. Available from www.ontario.cmha.ca/cmhcap.
- 47 Régie de l'assurance maladie du Québec [internet webpage]. Montreal (QC) : Government of Québec [cited 2010 April 18]. Overview of databanks. Available from :
<http://www.ramq.gouv.qc.ca/en/statistiques/banques/vuedensemble.shtml>
- 48 www.gnb.ca [internet webpage]. Fredericton (NB): Government of New Brunswick [cited 2010 April 8]. Health Department. Available from: <http://www.gnb.ca/0051/index-e.asp>.
- 49 www.gov.pe.ca [internet webpage]. Charlottetown (PE): Government of Prince Edward Island [cited 2010 April 8]. Department of Health and Wellness. Available from:
<http://www.gov.pe.ca/health/index.php3?lang=E>.
- 50 Kisely S, Campbell L, Cartwright J, Cox M, & Campbell J. Do The Health of the Nation Outcome Scales measure outcome? Can J Psychiatry. In press 2009.
- 51 www.health.gov.nl.ca [internet]. St. John's (NL): Government of Newfoundland and Labrador [cited 2010 April 8]. Department of Health and Community Services. Available from:
www.health.gov.nl.ca/health.
- 52 Kisely S, Smith M, Lawrence D, & Maaten S. Mortality in individuals who have had psychiatric treatment: population-based study in Nova Scotia. Br J Psychiatry. 2005 Dec;97:552-8.
- 53 Wellness Checkpoint [internet homepage]. Winnipeg (MB): Info Tech Inc. [cited 2010 May 31]. Available from: <http://wellnesscheckpoint.com/Home.aspx>

- 54 Kisely S, Lin E, Lesage A, Gilbert C, Smith M, Campbell LAC, & Vasiliadis HM. Use of administrative data for the surveillance of mental disorders in five provinces. *Can J Psychiatry*. 2009;54: 571-5.
- 55 Lin E, Smith M, Burchill C, Nestman P. Personal email correspondence. April 2010.
- 56 Gilbert C, Jones W, Schopflocher D, et al. Use of provincial administrative data for surveillance of mental disorders: feasibility study. Ottawa (ON): Surveillance Division, Centre for Chronic Disease Prevention and Control, Public Health Agency of Canada; 2007.
- 57 Kisely S, Lin E, Gilbert C, Smith M, Campbell LAC, & Vasiliadis HM. Using administrative data for the surveillance of mood and anxiety disorders. *Aust N Z J Psychiatry*. 2009;43(12): 1118-25.
- 58 Iezzoni LI. Assessing quality using administrative data. *Ann Intern Med*. 1997;127:666-674.
- 59 Iezzoni LI. Using administrative data to study persons with disabilities. *Milbank Q*. 2002;80(2):347-79.
- 60 Wolfson M. A shining light in Canada's health information system. *Healthcare Policy*. 2011;6(Special Issue):8-10.
- 61 Alshammari AM, Hux JE. The impact of non-fee-for-service reimbursement on chronic disease surveillance using administrative data. *Can J Public Health*. 2009;100(6):472-74.
- 62 Boden LI, Ozonoff A. Researcher judgment and study design: challenges of using administrative data. *Am J Ind Med*. 2010;53:37-41.
- 63 Sareen J, Stein MB, Campbell DW, Hassard T, Menec V. The relation between perceived need for mental health treatment, DSM diagnosis, and quality of life: a Canadian population-based survey. *Can J Psychiatry*. 2005 Feb;50(2):87-94.
- 64 Patten S. Major depression prevalence is very high, but the syndrome is a poor proxy for community populations' clinical treatment needs. *Can J Psychiatry*. 2008;53:411-19.
- 65 Hermann RC, Rollins CK, & Chan JA. Risk-adjusting outcomes of mental health and substance-related care: a review of the literature. *Harv Rev Psychiatry*. 2007;15:52-69.
- 66 Roos LL, Gupta S, Soodeen R-A, Jebamani L. Data quality in an information-rich environment: Canada as an example. *Can J Aging*. 2005;24(Suppl 1):153-170.
- 67 Tricco AC, Pham B, Rawson, HSB. Manitoba and Saskatchewan administrative health care utilization databases are used differently to answer epidemiologic research questions. *J Clin Epidemiol*. 2008;61:192-197.
- 68 Steele LS, Glazier RH, Lin E, Evans M. Using administrative data to measure ambulatory mental health service provision in primary care. *Med Care*. 2004;42(10):960-5.

- 69 Ward NS. The accuracy of clinical information systems. *J Crit Care*. 2004;19(4):21-5.
- 70 Harvard School of Medicine [internet webpage]. Boston (MA): The School [cited 2010 April 21] The World Mental Health Survey Initiative section. Available from: <http://www.hcp.med.harvard.edu/wmh/>.
- 71 Gravel, R. and Béland, Y. The Canadian Community Health Survey: Mental health and well-being. *Canadian J Psychiatry*. 2005;50:573-579.
- 72 Streiner DL, Cairney J, Lesage A [guest eds.] Special Issue: The Canadian Academy of Psychiatric Epidemiology look at the Canadian Community Health Survey, Cycle 1.2. *Can J Psychiatry*. 2005 August;50(9).
- 73 Statistics Canada [internet webpage]. Ottawa (ON): Government of Canada [cited 2010 April 16]. Description of Canadian Community Health Survey - Mental Health and Well-being - Canadian Forces special survey. Available from: <http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=5084&lang=en&db=imdb&adm=8&dis=2>.
- 74 Health Canada [internet webpage]. Description of the Canadian Alcohol and other Drug Use Monitoring Survey. <http://www.hc-sc.gc.ca/hc-ps/drugs-drogues/cadums-escad-eng.php>
- 75 Canadian Centre on Substance Abuse [internet webpage]. Ottawa (ON): The Centre. [updated 2009 October 15; cited 2010 April 21]. Description of the Canadian Addiction Survey. Available from: <http://www.ccsa.ca/eng/priorities/research/canadianaddiction/Pages/default.aspx>.
- 76 Statistics Canada [internet webpage]. Ottawa (ON): Government of Canada [cited 2010 April 21]. Description of the Participation and Activity Limitation Survey. Available from: <http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3251&lang=en&db=imdb&adm=8&dis=2>.
- 77 Statistics Canada [internet webpage]. The Aboriginal Peoples Survey (APS). <http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3250&lang=en&db=imdb&adm=8&dis=2>
- 78 Public Health Agency of Canada [internet webpage]. Description of The Health Behaviour in School-Aged Children (HBSC) <http://www.phac-aspc.gc.ca/hp-ps/dca-dea/prog-ini/school-scolaire/behaviour-comportements/index-eng.php>
- 79 Statistics Canada [internet]. Ottawa (ON): Government of Canada [cited 2010 May 18]. Description of the Canadian Health Measures Survey. Available from: <http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=5071&lang=en&db=imdb&adm=8&dis=2>.
- 80 Patten SB, Adair CE, Williams JV, Brant R, Wang JL, Casebeer A, & Beausejour P. Assessment of mental health and illness by telephone survey: experience with an Alberta mental health survey. *Chronic Dis Can*. 2006;27(3):99-109.

- 81 Esposito E, Wang J, Adair CE, Williams JV, Dobson K, Schopflocher D et al. Frequency and adequacy of depression treatment in a Canadian population sample. *Can J Psychiatry*. 2007;52:780-9.
- 82 Schopflocher, D. Associate Professor, University of Alberta. Edmonton, Alberta. Personal email correspondence. April 2010.
- 83 D'Arcy C, & Kosteniuk J. Saskatchewan population health and dynamics survey report. Saskatoon (SK): University of Saskatchewan, Applied Research/Psychiatry; 2006.
- 84 Lipman EL, Bennett KJ, Racine YA, Muzumdar R, & Offord DR. What does early antisocial behaviour predict? A follow-up of 4- and 5-year-olds from the Ontario Child Health Study. *Can J Psychiatry*. 1998;43:605-613.
- 85 Boyle MH, Offord DR, Campbell D, Catlin G, Goering P, Lin E, & Racine YA. Mental health supplement to the Ontario Health Survey: methodology. *Can J Psychiatry*. 1996; 41:549-558.
- 86 Kessler RC, Frank RG, Edlund M, Katz SJ, Lin E, & Leaf P. Differential use of psychiatric outpatient services between the U.S. and Ontario. *N Engl J Med*. 1997;336(8):551-557.
- 87 Breton J-J, Bergeron L, Valla J-P, Berthiaume C, & Gaudet N. Québec child mental health survey: prevalence of DSM-III-R mental health disorders. *J Child Psychol Psychiatry*. 1999;40(3):375-384.
- 88 Blais R, Breton J-J, Fournier M, St-Georges M, & Berthiaume C. Are mental health services for children distributed according to needs? *Can J Psychiatry*. 2003;48(3):176-186.
- 89 Institut de la statistique du Québec [internet homepage]. Montreal (QC): Gouvernement du Québec [cited 2010 May 31]. Available from: www.stat.gouv.qc.ca.
- 90 Institut de la statistique du Québec. Étude sur la santé mentale et le bien-être des adultes québécois : une synthèse pour soutenir l'action - Enquête sur la santé dans les collectivités canadiennes (cycle 1.2) [document on the internet, cited 2010 May 31]. Available from: http://stat.gouv.qc.ca/publications/sante/mentale_synthese.htm.
- 91 WHO International Consortium in Psychiatric Epidemiology. Cross-national comparisons of the prevalences and correlates of mental disorders. *Bull WHO*. 2000;78:413-26.
- 92 Willis GB. *Cognitive Interviewing: a tool for improving questionnaire design*. 1st ed. Newbury Park (CA): Sage Publications; 2004.
- 93 National Science Foundation [internet webpage]. Arlington (VA): The Foundation [cited 2010 May 31]. Surveys: tracking opinion [special report] – declining response rate, rising cost. Available from: http://www.nsf.gov/news/special_reports/survey/index.jsp?id=question.

- 94 Hansen KM. The effects of incentives, interview length, and interviewer characteristics on response rates in a CATI-study. *Int J Public Opin Res.* 2007;19(1):112-21.
- 95 Dillman DA, Smith JD, & Christian LM. *Internet, mail and mixed-mode surveys: the tailored design method.* 3rd ed. Hoboken (NJ): Wiley; 2008.
- 96 Keyes CL. Promoting and protecting mental health as flourishing: a complementary strategy for improving national mental health. *Am Psychol.* 2007 Feb-Mar;62(2):95-108.
- 97 Manderscheid RW, Ryff CD, Freeman EJ, McKnight-Eily LR, Dhingra S, & Strine TW. Evolving definitions of mental illness and wellness. *Prev Chronic Dis* [internet]. 2010 [cited 2010 April]; 7(1): 1-6. Available from: http://www.cdc.gov/pcd/issues/2010/jan/09_0124.htm.
- 98 Rhodes AE, Lin E, & Mustard CA. Self-reported use of mental health services versus administrative records: should we care? *Int J Methods Psychiatr Res.* 2002;11(3): 125-133.
- 99 Murphy JM, Laird NM, Monson RR, Sobol AM, & Leighton AH. A 40-year perspective on the prevalence of depression: the Stirling County Study. *Arch Gen Psychiatry.* 2000;57:209-215.
- 100 Statistics Canada [internet webpage]. Ottawa (ON): Government of Canada [cited 2010 April 21]. Description of National Longitudinal Survey of Children and Youth. Available from: <http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=4450&lang=en&db=imdb&adm=8&dis=2#1>.
- 101 New Canadian Children and Youth Study [internet homepage]. Toronto (ON): The Study [cited 2010 May 18]. Available from: <http://www.nccys.com/>.
- 102 Desmeules L. Appendix A: overview of national population health and Canadian Community Health Surveys. *BMC Womens Health*[internet]. 2004 August 25 [cited 2010 April 21]; 4(Suppl 1):S35. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2096687/>.
- 103 Patten SB. Incidence of major depression in Canada [research letter]. *JAMC.* 2000;163(6):714-5.
- 104 First Nations Regional Longitudinal Health Survey (RHS) National Team [internet webpage]. Ottawa (ON): The Team [cited 2010 April 29]. Description of RHS. Available from: <http://www.rhs-ers.ca/english/>.
- 105 MacMillan HL, Jamieson E, Walsh C, Boyle M, Crawford A, MacMillan A, and members of the First Nations and Inuit Regional Health Survey – National Steering Committee (at the time of 1997 data collection) and Principal Investigator Committees from the Offord Centre for Child Studies affiliated with McMaster University and Hamilton Health Sciences. The health of Canada’s Aboriginal children: results from the First Nations and Inuit Regional Health Survey. *Int J Circumpolar Health* 2010; 69(2):158-167.
- 106 Statistics Canada [internet webpage]. Ottawa (ON): Government of Canada [cited 2010 May 18]. Longitudinal Survey of Immigrants to Canada. Available from:

<http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=4422&lang=en&db=imdb&adm=8&dis=2>

- 107 Statistics Canada [internet webpage]. Ottawa (ON): Government of Canada [cited 2010 April 12]. Description of the Ontario Child Health Survey. Available from: <http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3824&lang=en&db=imdb&adm=8&dis=2>.
- 108 Mustard C, Boyle M, & Offord D. The year 2000 follow-up of the Ontario Child Health Study cohort: summary of results. Toronto (ON): Canadian Population Health Initiative report, Canadian Institute for Health Information; 2005.
- 109 Orn H, Newman SC, & Bland RC. Design and field methods of the Edmonton survey of psychiatric disorders. *Acta Psychiatr Scand [Suppl]*. 1988;338:17-23.
- 110 Newman SC, & Bland RC. Estimating the morbidity risk of illness from survey data. *Am J Epidemiol*. 1989;129(2):430-8.
- 111 Adair CE, McDougall GM, Mitton CR, Joyce AS, Wild TC, Gordon A, et al. Continuity of care and health outcomes among persons with severe mental illness. *Psychiatr Serv*. 2005;56(9):1061-1069.
- 112 Mitton CR, Adair CE, McDougall GM, & Marcoux G. Continuity of care and health care costs among persons with severe mental illness. *Psychiatr Serv*. 2005;56(9):1070-76.
- 113 Canadian Mental Health Association, Ontario [internet webpage]. Toronto (ON): The Association [cited 2010 April 28]. Description of Community Mental Health Evaluation Initiative. Available from: <http://www.ontario.cmha.ca/cmhei/index.asp>.
- 114 Routhier D, Caron J. CURA Research Highlights 2010: Epidemiological catchment area study of Montreal southwest update. [updated 2009 Feb 12; cited 2011 Apr 16]. Available from: http://www.mcgill.ca/files/urbanplanning/CURA_2010_Highlights_Routhier.pdf.
- 115 Singapore Consortium of Cohort Studies [internet webpage]. Singapore: National University of Singapore [cited 2010 April 21]. Description of Framingham Heart Study, European Prospective Investigation into Cancer and Nutrition, and Women's Health Initiative. Available from: <http://www.nus-cme.org.sg/FamousCS.html#2>.
- 116 Canadian Longitudinal Study on Aging (CLSA) [internet webpage]. Hamilton (ON): CLSA [cited 2010 April 28]. Available from: <http://www.clsa-elcv.ca/en/welcome/>.
- 117 Canadian Institutes of Health Research [internet webpage]. Ottawa (ON): The Institutes [cited 2010 April 28]. Description of Canadian Longitudinal Study on Aging. Available from: <http://www.cihr-irsc.gc.ca/e/22982.html>.

- 118 Canadian Partnership Against Cancer [internet webpage]. Toronto (ON): The Partnership [cited 2010 April 28]. Information on the Canadian Partnership for Tomorrow. Available from: http://www.partnershipagainstcancer.ca/tomorrow_update.
- 119 Mental Health Commission of Canada [internet webpage]. Calgary (AB): The Commission [cited 2010 April 2010]. Information on At Home project. Available from: <http://www.mentalhealthcommission.ca/English/Pages/homelessness.aspx>.
- 120 Samet JM, & Munoz A. Perspective: cohort studies. *Epidemiol Rev.* 1998;20(1):135-6.
- 121 Samet JM, & Munoz A. Evolution of the cohort study. *Epidemiol Rev.* 1998;20(1):1-14.
- 122 Szklo M. *Epidemiol Rev.* 1998;20(1):81-90.
- 123 Anthony JC, Eaton WW, & Henderson AS. Looking to the Future in Psychiatric Epidemiology. *Epidemiologic Reviews.* 1995;17(1) 240-2.
- 124 Insel TR, & Fenton WS. Psychiatric epidemiology: it's not just about counting anymore. *Arch Gen Psychiatry.* 2005 June;62:590-2.
- 125 Bears JR, Galea S, & Vlahov D. Longitudinal, population-based studies of affective disorders: where to from here? [review]. *BMC Psychiatry.* 2008;8:83.
- 126 Goodwin MS, Velicer WF, & Intille SS. Telemetric monitoring in the behavior sciences. *Behav Res Methods.* 2008 Feb; 40(1):328-41.
- 127 Kavanaugh K, Moro TT, Savage T, & Mehendale R. Enacting a theory of caring to recruit and retain vulnerable participants for sensitive research. *Res Nurs Health.* 2006;29:244-52.
- 128 US Aid [internet webpage]. Washington (DC): The US Agency for International Development [cited 2010 May 31]. Sentinel surveillance. Available from: http://www.usaid.gov/our_work/global_health/id/surveillance/sentinel.html
- 129 Hussey L, Turner S, Thorley K, McNamee R, & Agius R. Work-related ill health in general practice, as reported to a UK-wide surveillance scheme. *Br J Gen Pract.* 2008 Sept; 5(554):637-40.
- 130 Canadian Psychological Association [internet webpage]. Ottawa (ON): The Association [cited 2010 April 28]. Information on Sentinel project. Available from: <http://www.cpa.ca/home/>.
- 131 Last JM, editor. *A dictionary of epidemiology.* 3rd ed. Oxford: Oxford University Press; 1995.
- 132 Burger, H, & Neeleman J. A glossary on psychiatric epidemiology. *J Epidemiol Community Health.* 2007;61:185-189.
- 133 von Tigerstrom B, Deschênes M, Knoppers BM, & Caulfield TA [prepared for the Canadian Coalition on Cancer Surveillance]. Use of cancer patient information for surveillance purposes: a

- systematic review of legislation, regulations, policies and guidelines [document on the internet]. Ottawa (ON): Public Health Agency of Canada. 2000 [cited 2020 April 21]. Available from: http://www.phac-aspc.gc.ca/ccdpc-cpcmc/cancer/publications/use_e.html.
- 134 Mortensen PB, Allebeck P, & Mud-Jorgensen P. Population-based registers in psychiatric research. *Nord J Psychiatry* 1996;50 Suppl 36:67-72.
- 135 Mortensen PB. The untapped potential of case registers and record linkage studies in psychiatric epidemiology. *Epidemiol Rev* 1995: 17:205-9.
- 136 Canada Health Infoway [internet webpage]. Toronto (ON): Infoway [cited 2010 April 28]. Electronic Health Records section. Available from: <http://www.infoway-inforoute.ca/lang-en/about-ehr>.
- 137 Canada Health Infoway [internet webpage]. Toronto (ON): Infoway [cited 2010 April 28]. Available from: (<http://www.infoway-inforoute.ca/lang-en/>).
- 138 Office of the Auditor General of Canada. Electronic health records in Canada: an overview of Federal and Provincial audit reports [document on the internet]. Ottawa (ON): The Office. 2010 April [cited 2010 April 28]. Available from: http://www.oag-bvg.gc.ca/internet/English/parl_oag_201004_07_e_33720.html.
- 139 Esteban-Vasallo MD, Dominguez-Berjon MF, Atry Mochales J, Genova-Maleras R, Perez-Sania A, Sanchez-Perruca L et al. Epidemiological usefulness of population-based electronic clinical records in primary care: estimation of the prevalence of chronic diseases. *Fam Pract*. 2009 Dec;26(6):445-54.
- 140 McGrail, K, Law M, & Hebert PC. No more dithering on e-health: let's keep patients safe instead [editorial]. *CMAJ*. 2010 April; 182(6):535.
- 141 Katz A, Garland A, Leslie B, & Moffatt M. Clinical research at MCHP over the next 20 years (brief workshop report). *Healthcare Policy*. 2011;6(Special Issue):88-90.
- 142 Smith PC, Mossialos E, Papnicolas I, & Leatherman S, editors. Performance measurement for health system improvement: experiences, challenges and prospects. Cambridge (UK): Cambridge University Press;2009.
- 143 Adair CE, Simpson L, Birdsell J, Omelchuk K, Casebeer A, Gardiner H, & Newman S. System-level stigma: mental health measures in health performance measurement systems. Presented at the World Psychiatric Association Conference; 2003 July; Paris, France.
- 144 Saxena S, van Ommeren M, Lora A, & Sarceno B. Monitoring of mental health systems and services: comparison of four existing indicator schemes. *Soc Psychiatry Psychiatr Epidemiol*. 2006;41(6):488-97.

- 145 Durbin J, Lin E, Zaslavka N, Teed M, Adair CE, & Kisely S. The state of mental health performance monitoring in Canada: an inter-provincial survey. Presented at the Canadian Association for Health Services and Policy Research (CAHSPR) Annual Conference; 2007 June; Toronto, Ontario.
- 146 Canadian Institute for Health Information (CIHI) Health Indicators 2011.
http://secure.cihi.ca/cihiweb/products/health_indicators_2011_en.pdf
- 147 Sutherland K, & Leatherman S. Quality of healthcare in Canada: a chartbook. Ottawa (ON): Canadian Health Services Research Foundation. ISBN 978-0-9689154-3-1. 2010.
- 148 The Government of British Columbia. Healthy minds, healthy people: a ten-year plan to address mental health and substance use in British Columbia. Vancouver, BC: The Government, 2010.
- 149 Ontario Hospital Association [internet webpage]. Toronto (ON): The Association [cited 2010 April 8]. Hospital Reports. Available from:
<http://www.oha.com/KnowledgeCentre/Library/HospitalReports/Pages/HospitalReports.aspx>.
- 150 Lin E, Diaz-Granados N, Stewart DE, Rhodes AE, Yeritsyan N, Johns A, Duong-Hua M, & Bierman AS. Depression. In AS Bierman (ed.), Project for an Ontario Women's Health Evidence-based Report, Volume 1. Toronto, ON: 2009
- 151 Durbin J, Lin E, Rush B, Thibault K, & Smith B. Impact study: Midterm Report. November 2007
- 152 The Minister's Advisory Group on the 10-Year Mental Health and Addictions Strategy (Ontario). Respect, recovery, resilience: Recommendations for Ontario's mental health and addictions strategy. Ontario: The Advisory Group, December 2010.
- 153 Alberta Health Services, Addiction and Mental Health. System Level Performance for Mental Health and Addiction in Alberta 2008/09. Edmonton, AB: AHS, 2010.
- 154 Lin E, Durbin J, & Goldbloom DS. On quantifying quality. *Can J Psychiatry*. 2010;55(9):537-538.
- 155 Waraich P, Saronjini Saklikar R, Aube D, Jones W, Haslam D, & Hamil K. Quality measures for primary mental healthcare: a multistakeholder, multijurisdictional Canadian consensus. *Qual Saf Health Care*. 2010;19:519-525.
- 156 Herbstman BJ, & Pincus HA. Measuring mental healthcare quality in the United States: a review of initiatives. *Curr Op in Psychiatry*. 2009;22:623-630.
- 157 Hermann RC, Mattke S, Somekh D, Silfverhielm H, Goldner E, Glover G et al. Quality indicators for international benchmarking of mental health care. *Int J for Quality in Health Care*. 2006;Sept:31-38.
- 158 Spaeth-Rublee B, Pincus HA, Huynh PT, IIMHL Clinical Leaders Group, Mental Health Quality Indicator Project. Measuring quality of mental health care: a review of initiatives and programs in selected countries. *Can J Psychiatry*. 2010;55(9):539-548.

- 159 Office of the Privacy Commissioner of Canada [internet webpage]. Ottawa (ON): The Office [updated 2010 January 28; cited 2010 April 16]. Available from: www.priv.gc.ca/resource/prov/index_e.cfm.
- 160 Wang PS, Aguilar-Gaxiola S, Alonso J, Agermeyer MC, Borges G, Bromet EJ et al. Use of mental health services for anxiety, mood and substance disorders in 17 countries in the WHO world mental health surveys. *Lancet*. 2007 Sept;370(95890):841-50.
- 161 Freeman EJ, Colpe LJ, Strine TW, Dhingra S, McGuire LC, Elam-Evans LD, & Perry GS. Public health surveillance for mental health. *Prev Chronic Dis* [internet]. 2010 [cited 2010 April 21];7(1). Available from: http://www.cdc.gov/pcd/issues/2010/jan/09_0126.htm.
- 162 Kessler RC, Avenevoli S, Costello EJ, Green JG, Gruber, MJ, Heeringa S, et al. Design and field procedures in the US National Comorbidity Survey Replication Adolescent Supplement (NCS-A) *Int J Methods Psychiatr Res*. 2009 June;18(2):69-83.
- 163 Lando J, Marshall Williams S, Williams B, & Sturgis S. A logic model for the integration of mental health into chronic disease prevention and health promotion. *Prev Chronic Dis* [internet]. 2006 [cited 2010 April 21];3(2). Available from: http://www.cdc.gov/pcd/issues/2006/apr/05_0215.htm.
- 164 Coffey RM, Buck JA, Kassed CA, Dilonardo J, Forhan C, Marder WD, et al. Transforming mental health and substance abuse data systems in the United States. *Psychiatr Serv*. 2008;59:1257-1263.
- 165 Croft JB, Mokdad AH, Power AK, Greenlund KJ, & Giles WH. Public health surveillance of serious psychological distress in the United States (editorial). *Int J Public Health Science*. 2009;54:S4-S6.
- 166 Kobau R, Dilorio C, Chapman D, Delvecchio P, & SAMHSA/CDC Mental Illness Stigma Panel Members. Attitudes about mental illness and its treatment: validation of a generic scale for public health surveillance of mental illness associated stigma. *Community Ment Health J*. 2010 April;46(2):164-76.
- 167 Kanter Family Foundation [internet webpage]. Hollywood (FL): The Foundation [cited 2010 May 18]. National Health Outcomes Database. Available from: <http://www.healthlegacy.org/national-health-outcomes-database>.
- 168 National Health and Hospitals Reform Commission, Commonwealth of Australia. A healthier future for all Australians – final report. Canberra ACT, Australia: The Commonwealth [cited 2010 May 18]. Available from: <http://www.health.gov.au/internet/nhhrc/publishing.nsf/Content/nhhrc-report>.
- 169 Lawrence D, Holman CDJ, & Jablensky AV (2001) Preventable Physical Illness in People with Mental Illness. Perth: The University of Western Australia, 2000

- 170 Western Australia Health and Wellbeing Surveillance System Epidemiology Branch. Monitoring national health priority areas in WA – mental health problems (bulletin). East Perth (Australia): Government of Western Australia, Department of Health. 2006 September.
- 171 Jorm AF, Barney LJ, Christensen H, Highet NJ, Kelly CM, & Kitchener BA. Research on mental health literacy: what we know and what we still need to know. *Australian and New Zealand Journal of Psychiatry*. 2006;40(1):3-5.
- 172 Jenkins R, Bebbington P, Brugha T, Farrell M, Gill B, Lewis G, Meltzer H, & Petticrew M. The National Psychiatric Morbidity surveys of Great Britain--strategy and methods. *Psychol Med*. 1997 Jul;27(4):765-74.
- 173 Singleton N, Bumpstead R, O'Brien M, Lee A, & Meltzer H. Psychiatric morbidity among adults living in private households. TSO (The Stationery Office), 2001.
- 174 Farrell M, Taylor C, Welch S, & Meltzer H. Comorbidity in the national psychiatric morbidity surveys. London: Department of Health, 2004
- 175 Information Services Division [internet webpage]. Edinburgh, Scotland: NHS National Services Scotland [updated 2010 May 25; cited 2010 April 21]. Latest Statistics (health) page. Available from: <http://www.isdscotland.org/isd/1.html>.
- 176 www.gprd.com/home/ [internet homepage]. London (England): The Medicines and Healthcare Products Regulatory Agency, The General Practice Research Database Group [cited 2010 May 31]. Available from: <http://www.gprd.com/home/>.
- 177 Osborn DP, Levy G, Nazareth I, Petersen I, Islam A, & King MB. Relative risk of cardiovascular and cancer mortality in people with severe mental illness from the United Kingdom's General Practice Research Database. *Arch Gen Psychiatry*. 2007 Feb;64(2):242-9. Erratum in: *Arch Gen Psychiatry*. 2007 Jun;64(6):736.
- 178 Frisher M, Collins J, Millson D, Crome I, & Croft P. Prevalence of comorbid psychiatric illness and substance misuse in primary care in England and Wales. *J Epidemiol Community Health*. 2004 Dec;58(12):1036-41.
- 179 Nazareth I, King M, Haines A, Rangel L, & Myers S. Accuracy of diagnosis on general practice computer system. *BMJ*. 1993;307:32-4.
- 180 Currin L, Schmidt U, Treasure J, & Jick H. Time trends in eating disorder incidence. *Br J Psychiatry*. 2005 Feb;186:132-5.
- 181 Moser K. Inequalities in treated heart disease and mental illness in England and Wales, 1994-1998. *Br J Gen Pract*. 2001 Jun;51(467):438-44.

- 182 Hippisley-Cox J, Parker C, Coupland C, & Vinogradova Y. Inequalities in the primary care of patients with coronary heart disease and serious mental health problems: a cross-sectional study. *Heart*. 2007 Oct;93(10):1256-62. Epub 2007 Mar 7.
- 183 Hugenholtz GW, Heerdink ER, van Staa TP, Nolen WA, & Egberts AC. Risk of hip/femur fractures in patients using antipsychotics. *Bone*. 2005 Dec;37(6):864-70. Epub 2005 Aug 19.
- 184 Howard L, Kirkwood G, & Leese M. Risk of hip fracture in patients with a history of schizophrenia. *Br J Psychiatry*. 2007 Feb;190:129-34.
- 185 Abel KM, Heatlie HF, Howard LM, & Webb RT. Sex- and age-specific incidence of fractures in mental illness: a historical, population-based cohort study. *J Clin Psychiatry*. 2008 Sep;69(9):1398-403.
- 186 **FIND**
- 187 International Initiative Mental Health Leadership, "Mental Health Indicator Project – Final report, Phase 1." 2013

APPENDIX A

Summary of the Findings from the Systematic Gap Analysis

1.	Variable	Childhood/Adolescence Incidence
	Data Source/Description	<ul style="list-style-type: none"> • Estimated based on childhood/adolescent meta-analysis of transition rates from three longitudinal cohort studies from the US and NZ (Christchurch Study, Dunedin Study, & Great Smoky Mountain Study) and adult prevalence results <ul style="list-style-type: none"> ○ Mood ○ Anxiety ○ ADHD ○ Conduct Disorder ○ ODD
	Data Limitations	<ul style="list-style-type: none"> • Estimated value based on data from other countries • Data are from cohorts born approximately 3 decades ago • Does not include severity of illness/subclinical disorders • Does not include children under 9 • Analysis assumes rates are sex independent – however some literature suggests a sex difference • Does not include pediatric schizophrenia or other psychosis in children due to low incidence • Does not include eating disorders due to low incidence
	Rationale for Use	<ul style="list-style-type: none"> • Reliable robust estimates for MI in Canadian children and adolescence do not exist • Meta-analysis provided odds ratios for odds of future MI given childhood or adolescence MI • Longitudinal cohorts used for analysis provided the best and most reliable estimates for Canada
	Examples of Other Sources Considered	N/A
2.	Variable	Childhood/Adolescence Prevalence
	Data Source/Description	<ul style="list-style-type: none"> • Estimated based on childhood/adolescent meta-analysis of transitions rates from three longitudinal cohort studies from the US and NZ and adult prevalence results <ul style="list-style-type: none"> ○ Mood ○ Anxiety ○ SUD ○ ADHD ○ CD ○ ODD
	Data Limitations	<ul style="list-style-type: none"> • Estimated value based on data from other countries • Does not include subclinical disorders • Does not include children under 9

	<ul style="list-style-type: none"> • Analysis assumes rates are sex independent however some literature suggests a sex difference (e.g., behavioural disorders are more common in boys than girls) • Does not include pediatric schizophrenia or other psychosis in children due to low prevalence • Does not include eating disorders due to low prevalence
Rationale for Use	<ul style="list-style-type: none"> • Reliable robust estimates for MI in Canadian children and adolescence do not exist • Meta-analysis provided odds ratios for odds of future MI given childhood or adolescence MI • Longitudinal cohorts used for analysis provided the best and most reliable estimates for Canada
Examples of Other Sources Considered	<ul style="list-style-type: none"> • Dunedin – Kim-Cohen <i>et al.</i> (2011) <ul style="list-style-type: none"> ○ Mood, anxiety, SUD ○ NZ longitudinal cohort ○ Custom cut data used as part of our meta-analysis (literature source not used) • Christchurch – Fergusson <i>et al.</i> (1993) <ul style="list-style-type: none"> ○ Mood, anxiety, SUD, ADHD, CD, ODD ○ NZ longitudinal cohort ○ Custom cut data used as part of our meta-analysis (literature source not used) • Waddell (2002) <ul style="list-style-type: none"> ○ Mood disorders, anxiety disorders, SUD, ADHD, CD, ODD ○ Systematic review of childhood/adolescent disorders for those aged 4-17 ○ Literature source used as comparison for prevalence results • Costello <i>et al.</i> (2003) <ul style="list-style-type: none"> ○ Mood disorders, anxiety disorders, SUD, ADHD, CD, ODD ○ Custom cut data from GSMS used as part of our meta-analysis (literature source not used) • Ontario Child Health Study (Offord <i>et al.</i> 1987) <ul style="list-style-type: none"> ○ Prevalence of emotional and behavioural disorders in children aged 4 to 16 ○ CD, hyperactivity, emotional disorder, somatization ○ Dated – data collected in 1983 ○ Ontario only • Québec Child Health Study – Breton <i>et al.</i> (1999) <ul style="list-style-type: none"> ○ Mood disorders, anxiety disorders, ADHD, CD, ODD ○ Does not include SUD ○ 6 month prevalence for those 6 to 14 in Québec ○ Literature source used as comparison for prevalence results • Spady <i>et al.</i> (2001) + updates from Larry Svenson (2010) – AB administrative data

	<ul style="list-style-type: none"> ○ Mood, anxiety, SUD, CD ○ Does not include ODD ○ Data by age and sex ○ Literature source used as comparison for prevalence results
3. Variable	Adult Prevalence (Mood, Anxiety, Dementia, Schizophrenia, SUD)
Data Source/Description	<p>Datasets</p> <ul style="list-style-type: none"> ● OHS- MHS (1990): <ul style="list-style-type: none"> ○ Mood Disorders (major depression, dysthymia, bipolar disorder) ○ Anxiety Disorders (social phobia, simple phobia, panic disorder, agoraphobia, generalized anxiety disorder) ● Manitoba Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ Schizophrenia ○ Dementia ● Rehm <i>et al.</i> (2011) <ul style="list-style-type: none"> ○ Custom analysis for this project ○ Consistently estimated epidemiologic indicators for SUD in Canada ○ SUD defined as substance abuse and/or dependence ○ includes: alcohol, cocaine, heroin, non-medical prescription opioid, cannabis, amphetamine/methamphetamine <p>Literature-based Estimates</p> <ul style="list-style-type: none"> ● Goldner <i>et al.</i> (2002) <ul style="list-style-type: none"> ○ Systematic literature review of prevalence of schizophrenic disorders
Data Limitations	<ul style="list-style-type: none"> ● OHS-MHS (1990) <ul style="list-style-type: none"> ○ Data are dated 20+ years old ○ Ontario only – other provinces may vary ○ Ages 15 to 64 only ○ panic disorder – cells suppressed ○ Schizophrenia not included (low prevalence in survey sample) ○ Does not include severity of illness/subclinical disorders ○ Does not include ethnicity ○ Excludes institutionalized populations, homeless and youth – tends to exclude the most “ill” ○ Does not include ASPD or eating disorders (ASPD is an end point for many childhood disorders – however prevalence estimates are low) ● Manitoba Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ Manitoba only – other provinces may vary ○ Treated prevalence only ○ Dementia may include MCI recorded by physician as organic psychotic conditions, other organic psychotic conditions, cerebral

	<p>degenerations or senility (ie. billing data may pick up milder cases and cognitive impairment in addition to dementia resulting in higher estimates)</p> <ul style="list-style-type: none"> ○ Dementia data includes those aged 55+ ○ Exclude those with young onset dementia. ○ Does not include severity of illness/subclinical disorders ○ Does not include ethnicity ○ Diagnostic coding varies across provinces ● Goldner <i>et al.</i> (2002) <ul style="list-style-type: none"> ○ No age- or sex breakdown or stratification available ○ Review included data from other countries (international systematic review), each study included has methodological differences and each with varying estimates ○ Does not include severity of illness/subclinical disorders ● Rehm <i>et al.</i> (2011) <ul style="list-style-type: none"> ○ Combination of Canadian data and data from other countries (see Rehm <i>et al.</i> (2011) report for further details) ○ Does not include prescription drug or sedatives (elderly may have dependence on over the counter drugs) ○ Only includes ages 15 ○ Only includes 5 provinces
<p>Rationale for Use</p>	<ul style="list-style-type: none"> ● OHS-MHS (1990) <ul style="list-style-type: none"> ○ Internally consistent dataset for mood and anxiety ○ Data available by age-group and sex ○ Comorbidity among MI: mood, anxiety and SUD ○ Employment data for those with mood and anxiety ○ Provides 12 month and lifetime prevalence for accounting purposes ○ Rates were similar to the CCHS 1.2 for disorders common to each study ○ SME recommended ● Manitoba Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ Comorbidity among MI: dementia, schizophrenia, SUD, anxiety ○ SME recommended for dementia, schizophrenia ○ If dementia data are also capturing MCI this may provide a more complete picture of the economic burden ● Goldner <i>et al.</i> (2002) <ul style="list-style-type: none"> ○ Used to estimate the 12-month and lifetime prevalence ratios to split the MB prevalence rates ○ SMEs recommended using data from other countries to supplement the Manitoba data ● Rehm <i>et al.</i> (2011) <ul style="list-style-type: none"> ○ Recommended by SMEs ○ Consistently estimated by incorporating prevalence, incidence, duration, remission, relative risk and mortality for those with SUD

	<p>matched to general population by age, sex and case fatality within the same statistical disease model</p>
<p>Examples of Other Sources Considered</p>	<ul style="list-style-type: none"> • Canadian Study of Health & Aging (1991) – dated • OHS-MHS (1990) for SUD • Berr <i>et al.</i> (2005) <ul style="list-style-type: none"> ○ Dementia ○ Meta-analysis from EURODEM (European dementia studies) ○ Ages 65+ • Five province feasibility study (PHAC, 2007) <ul style="list-style-type: none"> ○ Does not provide breakdown by mental illness type; British Columbia and Nova Scotia have breakdown for mood/anxiety which can be used for comparison purposes • Bijl <i>et al.</i> (2002) <ul style="list-style-type: none"> ○ NEMESIS – condition coverage for incidence/prevalence and comorbidities in alignment with project scope; ○ Ages 18 to 64 ○ Mood, anxiety, schizophrenia, SUD ○ Not used since its data from countries other than Canada. • Offord <i>et al.</i> (1996) <ul style="list-style-type: none"> ○ OHS-MHS (1990) ○ prevalence for those 15 to 64 ○ Mood ○ Not used since custom cut data were provided by SMEs • Alberta Mental Health Surveillance Study – Patten et al. 2006 <ul style="list-style-type: none"> ○ one province only ○ Included severity ○ Ages... (from paper attached) ○ Did not include schizophrenia • Patten (2000) <ul style="list-style-type: none"> ○ 12 month prevalence of major depression in Calgary • CCHS 1.2 <ul style="list-style-type: none"> ○ Ages 15 to 65+ ○ Major depression, mania, panic disorder, social phobia, agoraphobia ○ Not used due to limited condition coverage ○ Doesn't have same capacity as OHS-MHS. Prevalence rates in ball park with OHS-MHS • Patten <i>et al.</i> (2006) <ul style="list-style-type: none"> ○ CCHS 1.2 ages 15-65+ ○ Major depression only • Newman and Bland (1998) <ul style="list-style-type: none"> ○ 18-65+ ○ four year prevalence (1984 to 89) ○ Anxiety

		<ul style="list-style-type: none"> • Mathers <i>et al.</i> (1999) <ul style="list-style-type: none"> ○ Data available by sex only ○ Australian dataset ○ Period of study 1996-97 ○ Mood disorders, anxiety disorders, schizophrenia, dementia, SUD • Saha <i>et al.</i> (2005) <ul style="list-style-type: none"> ○ Systematic literature review from 188 studies from 46 countries ○ Sex-specific prevalence of schizophrenia • Williams <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ National Survey of American Life ○ US study ○ Ages 18+ ○ Mood disorders only • Eaton <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ NIMH Epidemiologic catchment area (Baltimore) ○ Study period 1981 with follow-up in 1993 and 2004 ○ Ages 18-65 ○ Mood disorders only • National Survey of Mental Health and Well Being (1997) and (2007) <ul style="list-style-type: none"> ○ Australian study ○ Ages 18+ ○ Mood, anxiety • Kessler <i>et al.</i> (2003) <ul style="list-style-type: none"> ○ National Comorbidity Survey from the US ○ Ages 18+ ○ Major depression only
4.	Variable	Adult Incidence
	Data Source/Description	<ul style="list-style-type: none"> • NEMESIS – Bijl <i>et al.</i> (2001) <ul style="list-style-type: none"> ○ Mood ○ Anxiety ○ SUD ○ Schizophrenia • Canadian Study of Health and Aging (CSHA) Working Group (2000) <ul style="list-style-type: none"> ○ Dementia ○ 1991 Canadian Study of Health and Aging
	Data Limitations	<ul style="list-style-type: none"> • NEMESIS – Bijl <i>et al.</i> (2001) <ul style="list-style-type: none"> ○ Data from other countries may not be representative of Canada • CSHA (1991) <ul style="list-style-type: none"> ○ Data are dated ○ Only 65 and older ○ Does not include mild cognitive impairment (MCI)
	Rationale for Use	<ul style="list-style-type: none"> • NEMESIS – Bijl <i>et al.</i> (2001) <ul style="list-style-type: none"> ○ Incidence data in Canada are not available for all mental illnesses considered in the model

	<ul style="list-style-type: none"> ○ Data are age and sex specific; have the most complete information in terms of condition coverage for incidence/prevalence and comorbidities ● CSHA (1991) <ul style="list-style-type: none"> ○ Only Canadian data source available ○ One consistent data source used for the majority of illness in the model (with the exception of dementia and childhood/adolescent conditions) ○ Consistent with Alzheimer's Society Impact of Dementia Rising Tides Study (Smetanin et al. 2009)
Examples of Other Sources Considered	<ul style="list-style-type: none"> ● Newman and Bland (1998) – period of study was 1986-91 for Edmonton only. <ul style="list-style-type: none"> ○ Ages 18-65+ ○ Only 1 year of data ○ Mood disorders, anxiety disorders ● Patten (2002) <ul style="list-style-type: none"> ○ One year point estimate based on NPHS ○ Period of study 1996-97 ○ Ages 12-65+ ○ Major depression only ● Eaton <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ US data from the NIMH Epidemiologic Catchment area (Baltimore) ○ Ages 18-65+ ○ 1981 baseline with follow-up in 1993 and 2004 ○ Mood disorders only ● Mathers <i>et al.</i> (1999) <ul style="list-style-type: none"> ○ Data available by sex only ○ Australian dataset ○ Period of study 1996-97 ○ Mood disorders, anxiety disorders, schizophrenia, SUD ● Bijl <i>et al.</i> (2002) <ul style="list-style-type: none"> ○ Netherlands Mental Health Survey and Incidence Study (1997-98) ○ Data by age-group (18 to 65) and sex ○ Mood, anxiety, SUD, schizophrenia, eating disorder ○ One or more DSM-III-R diagnoses ● Jablensky <i>et al.</i> (1992) <ul style="list-style-type: none"> ○ Instruments used in the study are dated ○ Schizophrenia only ○ Australian study ● McGrath <i>et al.</i> (2004) <ul style="list-style-type: none"> ○ Systematic review across 100 core studies, 23 cohort studies involving 33 countries ○ Incidence rates of schizophrenia by sex and age ● de Graaf <i>et al.</i> (2002)

	<ul style="list-style-type: none"> ○ Netherlands Mental Health Survey and Incidence Study (1997-98) ○ Incidence by sex and age-group (18 to 64) ○ Mood, anxiety, SUD, schizophrenia, eating disorder ○ One or more DSM-III-R diagnoses
5. Variable	Excess Mortality (All Ages)
Data Source/Description	<ul style="list-style-type: none"> ● Harris and Barraclough (1998) <ul style="list-style-type: none"> ○ Increased risk of death from natural and unnatural causes for mental illnesses
Data Limitations	<ul style="list-style-type: none"> ● Harris and Barraclough (1998) <ul style="list-style-type: none"> ○ Study only models excess risk of death given a mental illness ○ Meta-analysis used to create standardized mortality ratios for all natural and unnatural causes of death ○ International meta-analysis only includes data from 1966 to 1995 from Medline search ○ There is no age or sex dependence to the relative risks
Rationale for Use	<ul style="list-style-type: none"> ● Harris and Barraclough (1998) <ul style="list-style-type: none"> ○ One consistent source that summarizes excess risk of death for all mental illnesses in the model ○ Consistent data source in alignment with Dr. Rehm’s model used for SUD prevalence estimates
Examples of Other Sources Considered	<ul style="list-style-type: none"> ● Wolfson <i>et al.</i> (2001) <ul style="list-style-type: none"> ○ Dementia survival estimates based on CSHA for ages 65+ ● CIHI – National Trauma Registry Analytic Bulletin (2004) <ul style="list-style-type: none"> ○ Death due to suicide and suicide attempts by age- and sex for 2001-2002 ○ Not attributable to mental illness ● Mathers <i>et al.</i> (1999) <ul style="list-style-type: none"> ○ Data available age and sex and cause of death ○ Australian dataset ○ Period of study 1996-97 ● Osby <i>et al.</i> (2000) <ul style="list-style-type: none"> ○ SMR by age and sex for those with schizophrenia ○ 1973-1995 ○ Swedish study ● Osby <i>et al.</i> (2001) <ul style="list-style-type: none"> ○ SMR by sex for those unipolar depression and bipolar ○ 1973-1995 ○ Swedish study ● Bruce <i>et al.</i> (1994) <ul style="list-style-type: none"> ○ 9 year mortality data linked to psychiatric status by sex for those 40+ ○ Study period 1980-89 ○ US study ● Grasbeck <i>et al.</i> (1996)

		<ul style="list-style-type: none"> ○ Increased mortality for those with anxiety syndromes between 1972 and 1992 from the Lundby cohort ● Laursen <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ Age- sex specific survival analysis and excess mortality given psychiatric disorder ○ Unipolar depressive disorder, bipolar depressive disorder, schizoaffective disorder, schizophrenia ○ Study from Denmark ● Dutta <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ Age and sex- specific mortality rates for those with bipolar disorder over a 35 year period (1965-1999) ○ UK study
6.	Variable	Adult Economic Disability –(excludes dementia and childhood/adolescent conditions)
	Data Source/Description	<ul style="list-style-type: none"> ● Dewa <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ Total and partial disability days for any mental disorders ○ Total and partial disability days for any mental disorder and chronic condition ○ Total and partial disability days for chronic condition only ○ Based on CCHS 1.2 ● Kouzis <i>et al.</i> (1994) <ul style="list-style-type: none"> ○ Missed days from work for mental illness (MI)
	Data Limitations	<ul style="list-style-type: none"> ● Dewa <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ Data only available for those aged 18 to 64 (majority of the working population) ○ Does not distinguish between different mental illnesses ○ Measures were self-report and subject to recall and reporting bias ○ Disability questions were not limited to work activities – also include non-work activities ○ Cross-sectional data cannot imply causality ○ Based on CCHS 1.2 – which may be an underestimate of the true burden ○ Disability is the least developed area in mental health ● Kouzis <i>et al.</i> (1994) <ul style="list-style-type: none"> ○ Study dated – based on 1981 study sample ○ Study included US data from the Eastern Baltimore Mental Health Survey which may not be representative of Canada
	Rationale for Use	<ul style="list-style-type: none"> ● Dewa <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ SME recommendation ● Kouzis <i>et al.</i> (1994) <ul style="list-style-type: none"> ○ Recommended by Don Addington
	Examples of Other Sources Considered	N/A
7.	Variable	Direct Health Care Utilization (All Ages)

Data Source/Description	<ul style="list-style-type: none"> ● MB Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ Utilization data (GP visits, psychiatrist visits, prescription drug use) ○ Includes utilization data for mood, anxiety, schizophrenia, SUD
Data Limitations	<ul style="list-style-type: none"> ● MB Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ Manitoba only ○ Data does not contain utilization data for all service types and for all MIs in the model ○ Mood – only contains depression and bipolar disorders (excludes dysthymia) ○ Most complete and consistent data for health care service use among those with MI ○ Coding/reporting across jurisdictions may be different from MB ○ Different provinces have different definitions of services and different health care systems ○ Manitoba has high aboriginal population compared to other provinces
Rationale for Use	<ul style="list-style-type: none"> ● Manitoba Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ MB data allows attribution to particular MIs (mood, anxiety, schizophrenia, SUD). Data are available for all cause plus diagnosis specific utilization ○ Most complete and consistent data for health care service use among those with MI ○ Estimates in alignment with CCHS data for self-reported services ○ Used in conjunction with Jacobs et al. 2010 data to estimate total direct health care costs using utilization-based costing methods ○ Only utilization data available in Canada by MI type
Examples of Other Sources Considered	<ul style="list-style-type: none"> ● Five province feasibility study (PHAC, 2007) <ul style="list-style-type: none"> ○ Does not provide breakdown by MI type ○ BC/NS provide breakdown for mood and anxiety ○ Hospitalizations, GP visits, psychiatrist visit, other MD visit, outpatient clinic visit ○ Used for comparison of estimates ● CIHI – hospitalizations from Hospital Morbidity File (1999/2000) <ul style="list-style-type: none"> ○ Rates and LOS due to MDD by sex ○ Rates and LOS due to bipolar disorder by sex ● CCHS linked to ON data – Courtesy of Betty Lin <ul style="list-style-type: none"> ○ Average costs billed per person for all cause physician visits, mental health physician visits, psychiatrist visits ○ Ontario data only ○ Doesn't cover all disorders or all services
8.	Variable Direct Health Care Costs (All Ages) – All MI Except Dementia
Data Source/Description	<ul style="list-style-type: none"> ● Jacobs <i>et al.</i> (2010) report <ul style="list-style-type: none"> ○ Total aggregate costs by province for inpatient services, physician services, community and social services, pharmaceuticals, other

services, income support

Data Limitations

- Jacobs *et al.* (2010)
 - Does not attribute costs to particular MIs
 - Alternative funding for family doctors not collected for most provinces (suggests this is 25% underestimated)
 - Report estimated proportion of private and public psychiatric drugs based on the total public to private ratio of all drugs (psychiatric and non-psychiatric) for each province (total costs)
 - Québec calculates inpatient hospital costs based on systematic differences and cost allocation, which is different from methodologies used by other provinces.
 - Psychiatric inpatient days based on discharge data not days of care, costs were adjusted but adjustment factor could not be validated
 - Emergency room data attributable to diagnosis is only available for AB and ON
 - Community mental health service data may encompass a variety of services across jurisdictions with no standard definition and funded by a variety of ministries (social, children, seniors etc.)
 - Types of services used for mental health and addictions cannot always be distinguished – adds complexity in distinguishing different types of services
 - Costs for shelters for homeless people with MI only available from BC and only for one point in time
 - Not-for-profit – to avoid double counting, costs included full cost of government funded community mental health services and for non-profits included only the amount raised from sources other than provincial governments
 - Employment programs – no standardized reporting for disability related to MI – only includes data for provinces who separately reported number of people with a psychiatric disability
 - Income support – not all provinces attribute data to MI and data only include for provinces that distinguished disability type
 - Short term disability – EI program does not keep records on reasons for disability so data are not available for those who temporarily lose their jobs due to mental illness
 - Does not include short-term and long-term disability leaves covered by employer insurance plans
 - Estimates for those who temporarily lose their jobs due to MI
 - Complete data across all services not available for all provinces
 - Costs to the education system for children with MI are not included
 - Costs to the criminal justice system are not included due to data availability
 - Costs exclude child and youth services.

	<ul style="list-style-type: none"> ○ For included categories, but where some provinces are missing data, estimated values are calculated based on the known costs. ○ Excludes information regarding the attribution related to specific mental illnesses ○ Excludes dementia ○ Excludes costs for child and youth services ○ Data not available for all provinces/territories for all categories ○ Costs are not attributable to specific MIs, are not available by age and sex stratifications ○ Costing data not available to look at costs of 'excess' utilization for those with MI
Rationale for Use	<ul style="list-style-type: none"> ● Will be used in conjunction with the Manitoba Centre for Health Policy (MCHP) change throughout data to estimate total direct health care costs ● Jacobs <i>et al.</i> (2010) provides total costs per province for services used <ul style="list-style-type: none"> ○ Data are complete for FFS payments to physicians inpatient hospital care and total pharmaceuticals ○ Data for available provinces can be used to extrapolate on a per capita basis to provinces with data gaps for each service.
Examples of Other Sources Considered	Risk Analytica
9. Variable	Direct Health Care Costs - Dementia
Data Source/Description	<ul style="list-style-type: none"> ● Statistics Canada CANSIM Table 107-5509 <ul style="list-style-type: none"> ○ Residential care beds for mental disorders ● Tramner <i>et al.</i> (2003) <ul style="list-style-type: none"> ○ Number of people in LTC and community care with dementia ● Wodchis <i>et al.</i> (2008) <ul style="list-style-type: none"> ○ Proportion of LTC residents with dementia admitted to LTC due to their dementia ○ Proportion of people with dementia only and those with dementia plus a comorbid condition ○ Incremental cost of care for those with dementia ● Hollander <i>et al.</i> (2002) <ul style="list-style-type: none"> ○ Costs of care for those 65+: LTC, administrative, LTC staff, physician, hospital, facility user fees, support staff, purchased services ● Hux <i>et al.</i> (1998) <ul style="list-style-type: none"> ○ Annual medication costs for those with Alzheimer's disease (AD) ○ Based on 1991 CSHA ● Shapiro and Tate (1997) <ul style="list-style-type: none"> ○ Costs incurred by patients in community care with dementia alone and dementia with comorbidities
Data Limitations	<ul style="list-style-type: none"> ● Tramner <i>et al.</i> (2003) <ul style="list-style-type: none"> ○ Base on Ontario data only

	<ul style="list-style-type: none"> ○ Data are dated ○ Costs and services provided may differ across jurisdictions and may have changed over time ● Wodchis et al. (2008) <ul style="list-style-type: none"> ○ Data are widely assumption driven ○ Based on Ontario sample which may not be representative of Canada ● Hollander <i>et al.</i> (2002) <ul style="list-style-type: none"> ○ Costs based on small study samples from Victoria and Winnipeg and may not be representative of Canada ○ Costs and services provided may differ across provinces and may have changed over time ● Hux <i>et al.</i> (1998) <ul style="list-style-type: none"> ○ Data are dated ○ Costs of medications and services provided may differ across jurisdictions and may have changed over time ○ Included costs of drugs for AD only (not all dementia types) ● Shapiro and Tate (1997) <ul style="list-style-type: none"> ○ Based on Manitoba Study of Health and Aging (data collected between 1991 and 1992) ○ Data are dated and MB findings may not be representative of Canada ○ Costs and services provided under community care may differ across jurisdictions and may have changed over time
Rationale for Use	<ul style="list-style-type: none"> ● Consistent with model and analysis completed for the Alzheimer Society's Rising Tides Study (Smetanin et al. 2009) – approach was recommended by subject matter experts in dementia
Examples of Other Sources Considered	N/A
10. Variable	Healthy Immigrant Effect (Adult)
Data Source/Description	<ul style="list-style-type: none"> ● Menezes <i>et al.</i> (2011) <ul style="list-style-type: none"> ○ Lower 12 month prevalence of psychiatric disorder in Canadian immigrants compared to non-immigrant Canadians ○ Based on CCHS 1.2
Data Limitations	<ul style="list-style-type: none"> ● Menezes <i>et al.</i> (2011) <ul style="list-style-type: none"> ○ Only includes mood disorders, anxiety, SUD, and schizophrenia ○ Only includes population ages 15+ in 10 provinces (excludes territories) ○ Cross-sectional study design that cannot account for longitudinal trends ○ Study does not examine “new” immigrants but rather immigrant status, so it may include those who immigrated many years ago
Rationale for Use	<ul style="list-style-type: none"> ● Menezes <i>et al.</i> (2011) <ul style="list-style-type: none"> ○ SME recommendation

		<ul style="list-style-type: none"> ○ Only Canadian data available
	Examples of Other Sources Considered	N/A
11.	Variable	Chronic Disease Prevalence – Type 2 Diabetes (Adult)
	Data Source/Description	<ul style="list-style-type: none"> ● National Diabetes Surveillance System (NDSS) <ul style="list-style-type: none"> ○ Prevalence and incidence of diabetes by age-group and sex ● Statistics Canada – CANSIM Table 102-0524 <ul style="list-style-type: none"> ○ Mortality due to Type 2 diabetes and heart disease
	Data Limitations	<ul style="list-style-type: none"> ● NDSS <ul style="list-style-type: none"> ○ Data does not distinguish between Type 1, Type 2 and gestational diabetes – model assumes that 90% of prevalent cases of diabetes reported are Type 2 ○ Incidence data do not distinguish between diabetes subtypes ○ Data are linked to physician billing and hospitalization administrative data – so it only includes users of the health care system who demonstrate sufficient evidence of use due to diabetes ○ Estimates are based on administrative data, therefore individuals must be treated to be included providing an underestimate of the true prevalence ● Statistics Canada - CANSIM <ul style="list-style-type: none"> ○ Mortality data do not distinguish between diabetes subtypes ○ Reporting based on death certificates and may be underestimated for both heart disease and diabetes
	Rationale for Use	<ul style="list-style-type: none"> ● NDSS <ul style="list-style-type: none"> ○ Is the most comprehensive diabetes surveillance data in Canada ○ Data are available by age, sex, and province ○ Conservative estimates ● Statistics Canada – CANSIM 102-0524 <ul style="list-style-type: none"> ○ Standard mortality database
	Examples of Other Sources Considered	N/A
12.	Variable	Chronic Disease Prevalence– Heart Disease (Adult)
	Data Source/Description	<ul style="list-style-type: none"> ● CCHS 1.1 – Chow <i>et al.</i> (2005) <ul style="list-style-type: none"> ○ Prevalence of heart disease in Canada by age and sex ● Statistics Canada - CANSIM <ul style="list-style-type: none"> ○ Mortality due to heart disease
	Data Limitations	<ul style="list-style-type: none"> ● CCHS 1.1 – Chow <i>et al.</i> (2005) <ul style="list-style-type: none"> ○ Does not include incidence – incidence estimated from prevalence and mortality ○ Data are self-reported for those 12+ ○ Data are likely under-reported ○ Data exclude Indian reserves, Canadian Force bases and those in remote communities

	<ul style="list-style-type: none"> ○ Heart disease not explicitly “defined” in questionnaire and this type of self-report data are very subjective – objective data would be better but there are no known sources in Canada ○ Cannot breakdown heart disease by type ie. CHD, CAD, IHD etc. (not stratified by heart disease type) ● Statistics Canada - CANSIM <ul style="list-style-type: none"> ○ Reporting based on death certificates and may be underestimated
Rationale for Use	<ul style="list-style-type: none"> ● CCHS 1.2 – Chow <i>et al.</i> (2005) <ul style="list-style-type: none"> ○ Only Canadian data available ○ Recommended by SMEs given availability of data – this is the best we have and provides a conservative estimate of heart disease. The use of US and data from other countries were discouraged due to the differences in the health care systems ● Statistics Canada – CANSIM 102-0524 <ul style="list-style-type: none"> ○ Standard mortality database
Examples of Other Sources Considered	N/A
13. Variable	Relative Risk Estimates for Relationship between MI and Chronic Diseases (Type 2 Diabetes and Heart Disease)
Data Source/Description	<ul style="list-style-type: none"> ● Rugulies (2002) <ul style="list-style-type: none"> ○ Meta-analysis to determine the relative risk for development of chronic heart disease (CHD) in people with depression ● Patten (2005) <ul style="list-style-type: none"> ○ Elevated risk of depression in persons with chronic disease ● Curkendall <i>et al.</i> (2004) <ul style="list-style-type: none"> ○ Increased risk of cardiovascular disease and diabetes given schizophrenia ● Rehm (2010) <ul style="list-style-type: none"> ○ Increased risk of ischaemic heart disease and diabetes given alcohol abuse and/or dependence ● Ahtiluto <i>et al.</i> (2010) <ul style="list-style-type: none"> ○ Increased risk of dementia given type 2 diabetes
Data Limitations	<ul style="list-style-type: none"> ● Rugulies (2002) <ul style="list-style-type: none"> ○ Data are not available by age and sex ○ Data only consider relationship between depression and CHD – not in alignment with all disorders in the Life at Risk model for which the relative risk estimates were applied ○ Definition of heart disease adopted for the model (heart disease from CCHS is a broad category and the relative risk estimates are for just CHD which shows the strongest evidence. Prevalence data for CHD only does not exist – however the majority of heart disease is CHD ○ Meta-analysis includes data from other countries, mostly from the

	<ul style="list-style-type: none"> ○ US, which may not be representative of Canada ○ Estimates included in the meta-analysis may be subject to publication bias ● Patten (2005) <ul style="list-style-type: none"> ○ Data not available by age and sex ○ Data available for depression only ○ Chronic disease includes a general chronic disease – not specific to type 2 diabetes or heart disease ● Curkendall <i>et al.</i> (2004) <ul style="list-style-type: none"> ○ Study from SK only ○ Analysis used administrative data and not all medical records were able to be reviewed to validate the diagnosis ○ Study did not adjust for cardiovascular risk factors such as smoking, BMI, SUD ○ Results were not stratified by age or sex ● Rehm (2010) <ul style="list-style-type: none"> ○ Meta-analysis only examined relationship between alcohol consumption and chronic illness and does not examine relationship with other SUDs ○ Alcohol abuse and/or dependence is approximately 90% of SUD prevalence ● Ahtiluto <i>et al.</i> (2010) <ul style="list-style-type: none"> ○ Finnish study for those aged 85+ ○ Results are not stratified by age and sex specific
Rationale for Use	<ul style="list-style-type: none"> ● Rugulies (2002) <ul style="list-style-type: none"> ○ Recommended by SMEs ○ Majority of heart disease is CHD ● Frasure-Smith <i>et al.</i> (2006) <ul style="list-style-type: none"> ○ Supports findings of Rugulies (2002) and model assumptions ● Frasure-Smith <i>et al.</i> (2008) <ul style="list-style-type: none"> ○ Supports findings of Rugulies (2002) and model assumptions ● Patten (2005) <ul style="list-style-type: none"> ○ Recommended by SMEs ● Curkendall <i>et al.</i> (2004) <ul style="list-style-type: none"> ○ Recommended by SMEs ● Rehm (2010) <ul style="list-style-type: none"> ○ Recommended by SMEs ● Ahtiluto <i>et al.</i> (2010) <ul style="list-style-type: none"> ○ Recommended by SMEs
Examples of Other Sources Considered	<ul style="list-style-type: none"> ● Frasure-Smith <i>et al.</i> (2006) <ul style="list-style-type: none"> ○ Relative risk of depression leading to onset of CHD – supports assumptions ● Frasure-Smith <i>et al.</i> (2008) <ul style="list-style-type: none"> ○ Anxiety and depression are predictors of major adverse

		events in patients with CAD – supporting assumptions
14.	Variable	Comorbidity Among Mental Illnesses
	Data Source/Description	<ul style="list-style-type: none"> ● OHS-MHS (1990) <ul style="list-style-type: none"> ○ Comorbidity among MI: SUD, anxiety and mood by age-sex ● Manitoba Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ Comorbidity among MI: dementia, schizophrenia, SUD, anxiety
	Data Limitations	<ul style="list-style-type: none"> ● OHS-MHS (1990) <ul style="list-style-type: none"> ○ Data are dated ○ Ontario only ○ Ages 15 to 64 only ○ panic disorder – cells suppressed ○ Schizophrenia not included (low prevalence in survey sample) ● Manitoba Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ MB only – other provinces may vary ○ Treated prevalence only ○ Dementia may include MCI recorded by physician as organic psychotic conditions, other organic psychotic conditions, cerebral degenerations or senility ○ Dementia data includes those ages 55+ and will exclude those with young onset dementia. ○ Administrative data may underestimate comorbidity
	Rationale for Use	<ul style="list-style-type: none"> ● OHS-MHS (1990) <ul style="list-style-type: none"> ○ Consistent data set in alignment with other data inputs ○ Provides comorbidity among SUD, anxiety and mood disorders ○ Data available by age and sex ● Manitoba Centre for Health Policy (2004) <ul style="list-style-type: none"> ○ Consistent data set in alignment with other data inputs ○ Only Canadian dataset that provides a measure of comorbidity among all MIs included in the model ○ used in conjunction with OHS-MHS to mitigate the level of underestimated comorbidity
	Examples of Other Sources Considered	<ul style="list-style-type: none"> ● NEMESIS – Bijl <i>et al.</i> (2001) – <ul style="list-style-type: none"> ○ NEMESIS – most complete incidence/prevalence data source with respect to condition coverage scope ○ Mood, anxiety, SUD, schizophrenia, eating disorder ○ One or more DSM-III-R diagnoses ● de Graaf <i>et al.</i> (2002) <ul style="list-style-type: none"> ○ NEMESIS – most complete incidence/prevalence data source with respect to condition coverage scope ○ Mood, anxiety, SUD, schizophrenia, eating disorder ○ One or more DSM-III-R diagnoses
15.	Variable	Housing/Homelessness Sub-model
	Data Source/Description	<ul style="list-style-type: none"> ● HRDC (2011) <ul style="list-style-type: none"> ○ Proportion of homeless people in Canada

	<ul style="list-style-type: none"> ● Patterson <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ Proportion of homeless people with mental illness ● Hwang (2010, unpublished) <ul style="list-style-type: none"> ○ Hospital utilization among homeless cohort and low income control group (relative health care utilization) ● Hwang (2011) <ul style="list-style-type: none"> ○ Relative homeless to housed hospitalization costs ● Jacobs <i>et al.</i> (2010) <ul style="list-style-type: none"> ○ Total hospitalization costs
Data Limitations	<ul style="list-style-type: none"> ● HRDC (2011) <ul style="list-style-type: none"> ○ The estimated homeless population in Canada ranged from 150,00 to 300,00 ○ The HRSDC does not provide further information on data source estimates and limitations ○ May not be generalizable to Canada as a whole ● Patterson <i>et al.</i> (2007) <ul style="list-style-type: none"> ○ Data are specific to the province of BC and to those with serious addictions and mental illness ○ Excludes those with less severe mental illness ○ Data are not stratified by age and sex ○ May not be generalizable to Canada as a whole ● Hwang (2010, unpublished) <ul style="list-style-type: none"> ○ Study includes a small population sample from inner city Toronto ○ Study does not encompass all health care services used ○ May not be generalizable to Canada as a whole ● Hwang (2011) <ul style="list-style-type: none"> ○ Study includes a small population sample from inner city Toronto over the age of 18 ○ Data are not stratified by sex ○ Housing status based on administrative data and subject to misclassification ○ Data do not include duration of homelessness ○ Length of stay estimates may be based on practices rather than severity of illness ○ May not be generalizable to Canada as a whole
Rationale for Use	<ul style="list-style-type: none"> ● Best available data in Canada at this time where reasonable assumptions can be applied
Examples of Other Sources Considered	N/A

APPENDIX B

Questions Asked During Consultation with Researchers, Subject Experts, & Data Experts

1. Currently, what are the strengths of the data available on mental health?
 - a What data has already been collected?
 - b What data collection is already planned or proposed for the future?
2. What are the weaknesses in data collection as it relates to mental health?
 - a What are the clear gaps in mental health data?
 - b What do you see as key priorities for mental health related data collection moving forward?
3. How can the Mental Health Commission of Canada, in partnership with key stakeholders, facilitate the collection of data in the priority gap areas?
 - a What is feasible to complete in the short-term (within one year)?
 - b What are potential ways of supporting data collection given resource constraints? What are potential alternatives for funding?
 - c How should the data be collected? Ideas for transformative changes in methodology associated with data collection
 - d What should be the focus in the long-term?
 - e How can the Mental Health Commission of Canada, in partnership with key stakeholders, facilitate the process of change in how and what data are collected, accessed, and synthesized in Canada? How will we know if we have made a difference?
4. What framework should be in place to sustain changes in data collection moving forward?
 - a What alliances can be formed to lead to transformative changes?
 - b How do we create a legacy that leads to a cohesive, comprehensive, and coordinated system of data collection and universal access to the data in Canada