Primary Health Care Intelligence

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CPCSSN RCSSSP

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What is CPCSSN?

CPCSSN was initiated in 2008 to use routinely collected electronic medical record (EMR) patient information from primary care practices for surveillance of chronic disease, research and practice quality improvement. CPCSSN has grown to include primary care practice-based research networks (PCPBRNs) in eight provinces. CPCSSN extracts, cleans and combines data from 12 different EMR products into the CPCSSN researchable platform at Queen's University.

This work has resulted in a fully functional, secure, de-identified, central database which is updated quarterly. CPCSSN can now provide a rich source of primary care health information for surveillance of select chronic diseases in Canada, for primary care research, and for practice quality improvement. This information is vital for governments, policy makers, primary care researchers, and practitioners.

Primary Care Practice Based Research Networks (PCPBRNs)

PCPBRNs from across Canada are contributing data and expertise to CPCSSN. These research networks collect health data at the point of care from EMRs. As custodians of patient information, and with approval granted by local research ethics boards, primary care practitioners (called sentinels) have agreed to allow the PCPBRNs and CPCSSN to collect health information about their patients from their EMRs. This is for the limited purposes of public health surveillance and research approved by the appropriate research ethics board.

Major Accomplishments

- Succeeded in bringing 10 PCPBRNs together to create a national platform for public health surveillance and research into chronic and other health conditions impacting 1/3 of Canadians

- Developed a network of primary care practitioners and their patients from across Canada. As of Sept 30, 2013, CPCSSN has extracted data across 83 sites representing 476 sentinel practices and 572,860 patients

- Developed innovative methods to de-identify patient information and state-of-the-art algorithms and processes for data extraction, cleaning, standardization, secure transfer and storage

- CPCSSN's research privacy and ethics officer has been recognized as a "Privacy by Design Ambassador" and the CPCSSN privacy and information security system was recognized as a 2013 winner of the Privacy Innovation Award by the International Association of Privacy Professionals (IAPP)

- Developed and rigorously validated case definitions for eight important chronic diseases for use in surveillance activities and primary care research

- As of August 2013, CPCSSN members have been active in sharing CPCSSN developments and activities, producing 77 presentations, 44 posters and 16 publications at a variety of provincial, national and international forums

- Built primary care research capacity by providing a primary health care data source for researchers and training for graduate students (Master's and PhD) across the country

- Received a strategic investment from the Canada Health Infoway Health Systems Use initiative to support practice quality improvement using the CPCSSN-developed proprietary sentinel feedback tool—run on a quarterly basis—to create a national primary care data repository

- Attracted national and international attention from researchers and various other health professionals who are recognizing the potential value that CPCSSN data could provide to their work

Innovation

Technology

CPCSSN has developed an advanced infrastructure, set of tools and highly automated processes for extracting, processing and analysing EMR data from primary care practices across Canada on a regular basis. This has produced a central repository of national primary care data suitable for chronic disease surveillance, research and practice improvement purposes.

Figure 1: CPCSSN Infrastructure

Some of CPCSSN's technological accomplishments are as follows:

● Extraction of patient and provider demographic and clinical data from 12 different EMR vendors' products (listed below) and transformation into a standard CPCSSN database schema.

Table 1: CPCSSN EMRs	
EMR Vendor	**Product**
Bell Canada	Bell EMR
Da Vinci	Da Vinci
Jonoke	JonokeMed
Med Access	Med Access EMR
Nightingale Informatix	Nightingale On Demand
Optimed Software	Accuro EMR
Optimed Software (formerly Healthscreen Solutions Inc)	HS Practice
(open source supported by multiple VARs)	OSCAR
P&P Data Systems	CIS EMR
Purkinje	Dossier
Telus	PS Suite EMR
Telus	Wolf EMR

● Development of data quality improvement algorithms and processes that transform poor quality EMR data into data that's usable for analysis and reporting, including:
  - coding of diagnoses into ICD-9 and SNOMED-CT, medications into ATC, lab results into LOINC, referrals into SNOMED-CT;
  - cleansing of quantitative data, including physical signs (e.g. weight, height, BMI values), risk factors (e.g. packs/day for smoking), lab results (e.g. HbA1c values); and
  - validation of data coding and cleansing algorithms.

● Development of an extendable disease case detection framework, currently supporting algorithms for eight specific chronic conditions of interest.

● De-identification of data to comply with ethics and privacy requirements, including removal of direct identifiers, anonymisation of free text and reduction of the risk of statistical re-identification using the PARAT[1] tool.

● Development of standardised feedback and representativeness reports to meet practice needs.

● Development of an interactive data presentation tool to do customised reporting and querying to meet specific practice and/or researchers' needs.

● Development of an overall automation framework for EMR data extraction, transformation, processing and transmission to CPCSSN's regional and national servers.

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1   http://www.privacyanalytics.ca/privacy-analytics-simultaneously-announces-new-brand-parat-software-v5-2/

CPCSSN has collaborated with a variety of organizations on EMR standards and technology matters, including:

- e-Health Observatory at University of Victoria
- Canada Health Infoway
- Canadian Institute of Health Information (CIHI)
- Privacy Analytics Software Solutions
- EMR vendors

Privacy

A foundational aspect of the achievements in CPCSSN, both collectively and at each and all participating PCPBRNs has been a comprehensive privacy and information system security framework upon which everything else is built.

The cornerstone of this framework is Privacy by Design Principles, developed by the Information and Privacy Commissioner of Ontario, which have been adopted by government ministries and privacy commissioner offices throughout the world as the standard for privacy and security of personal and health information.
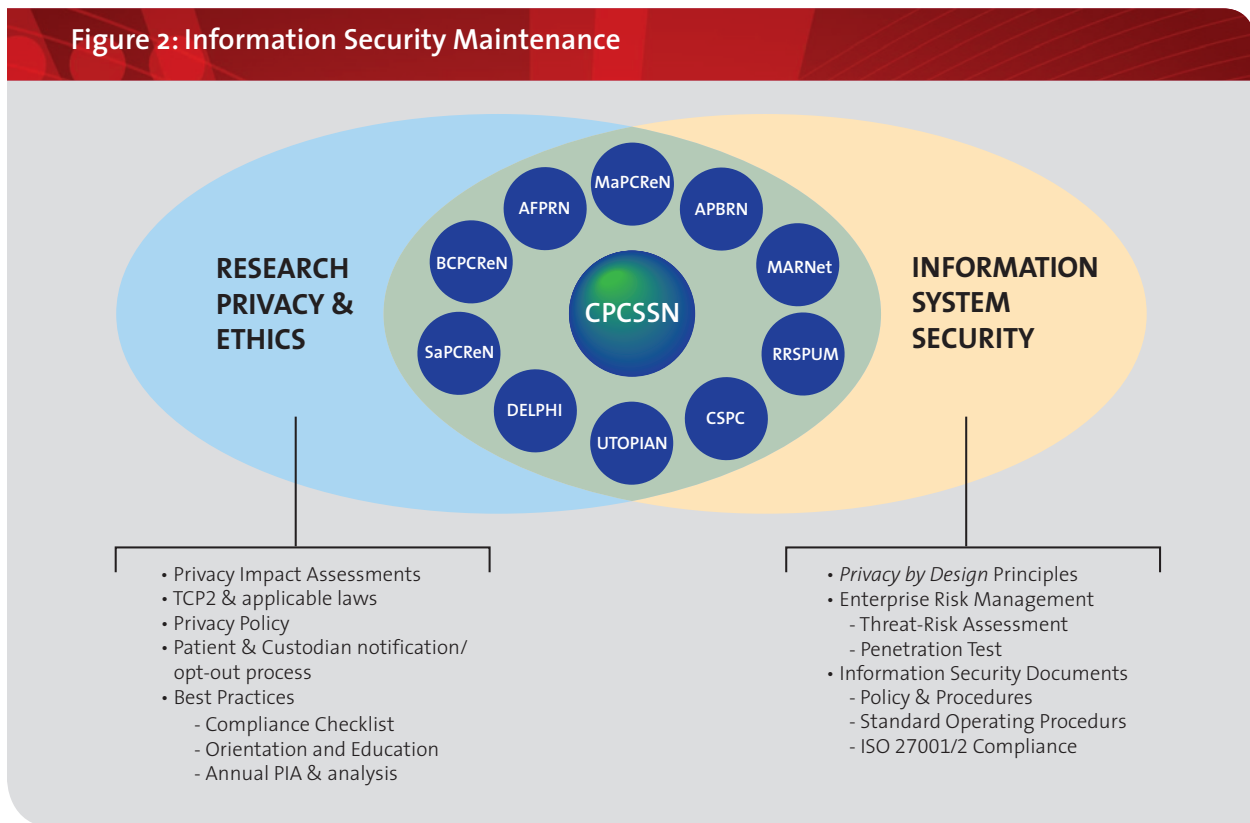
Two other cornerstones necessary for ensuring a Canada-wide privacy and security protocol would comply with privacy legislation that was different in each of the eight provinces where PCPBRNs are situated are: the Information Standards Organization (ISO) 27001/2 that governs information system security; and the Tri-Council Policy Statement, Ethical Conduct of Research Involving Humans (TCPS2) that governs the use of health information for research purposes.

Research ethics board (REB) approval is required prior to the use of health information for research purposes. All CPCSSN PCPBRNs were subject to significant scrutiny regarding how patient information was to be extracted, de-identified, aggregated and used to ensure patients' privacy was protected in compliance with local privacy laws and regulations. Some PCPBRNs had challenges to obtain REB approval due to particularly stringent provincial or local regulations or requirements. Additionally, under the terms of a contribution agreement with PHAC for the CPCSSN project, and in cooperation with the Health Canada REB, CPCSSN is required to complete an annual renewal for a Health Canada REB certificate of ethics approval.

CPCSSN took its lead from the TCPS2's guidelines in designing a pan-Canadian privacy and security assessment and compliance program. Drawing from the TCPS2's recommendation that the "easiest way to protect privacy is to use only anonymised information," a privacy impact assessment (PIA) and logical threat risk assessment (TRA) protocol was designed, containing questionnaires and forms to be completed by each PCPBRN. As of June 30, 2013, site visits to each of the PCPBRNs to conduct the PIA/TRA were all completed. In addition to a comprehensive Report of Findings that each PCPBRN receives after an information handling audit, there is a CPCSSN Privacy Compliance Checklist that enables each PCPBRN to take steps to mitigate any identified privacy risks and conduct their own compliance monitoring in the future.

Figure 2: Information Security Maintenance

RESEARCH PRIVACY & ETHICS

MaPCReN · AFPRN · APBRN · BCPCReN · MARNet · CPCSSN · SaPCReN · RRSPUM · DELPHI · UTOPIAN · CSPC

INFORMATION SYSTEM SECURITY

- Privacy Impact Assessments
- TCP2 & applicable laws
- Privacy Policy
- Patient & Custodian notification/ opt-out process
- Best Practices
  - Compliance Checklist
  - Orientation and Education
  - Annual PIA & analysis

- *Privacy by Design* Principles
- Enterprise Risk Management
  - Threat-Risk Assessment
  - Penetration Test
- Information Security Documents
  - Policy & Procedures
  - Standard Operating Procedurs
  - ISO 27001/2 Compliance

In addition to conducting PIAs/TRAs at each of the PCPBRNs, orientation and training tools for ongoing privacy and security awareness and compliance were introduced this past year in the form of the CPCSSN Orientation Binder. Each PCPBRN now has a single-point reference to CPCSSN's key privacy and information system security policies and procedures, CPCSSN privacy orientation presentation slides, local privacy legislation, and other important documents such as the Data Manager Orientation Manual.

The Research Privacy and Ethics Officer has also worked directly with the Information Technology Manager as well as Data Managers at PCPBRNs to discover and implement automated solutions to extracting and de-identifying health information prior to transmission through secure OpenVPN to regional and/or central servers.

With the successful fulfillment of this important initiative, REB feedback to PCPBRNs about their respective privacy protocols has been universally positive and facilitated renewal of REB approvals. It has also led to invitations for presenting the CPCSSN privacy protocol at meetings with provincial ministry officials and Canada Health Infoway's Canada Information Privacy Group, representing privacy policy analysts in every province and territory.

For CPCSSN's innovative approach to developing a pan-Canadian privacy and security protocol, its Research Privacy and Ethics Officer has been recognized as a Privacy by Design Ambassador by Ontario's Privacy Commissioner. As well, CPCSSN's privacy program has been awarded the 2013 Innovation Award by the International Association of Privacy Professionals (IAPP).

Research Methods

The CPCSSN database holds a wealth of information about primary care in Canada and is not limited to the diseases currently under investigation. Any condition that is managed or seen in primary care could potentially be studied using this database. Table 2 on the following page lists the core data contained in the CPCSSN database as of Sept 30, 2013.

Representativeness

The CPCSSN database includes information on both patients and physicians. The extent to which these two groups represent their respective populations will have implications on the ability to use CPCSSN data to understand primary care in Canada. The national representativeness of patients will have important implications related to epidemiology of disease in Canada, while the representativeness of the sentinels will have important implications related to understanding the way that care is delivered.
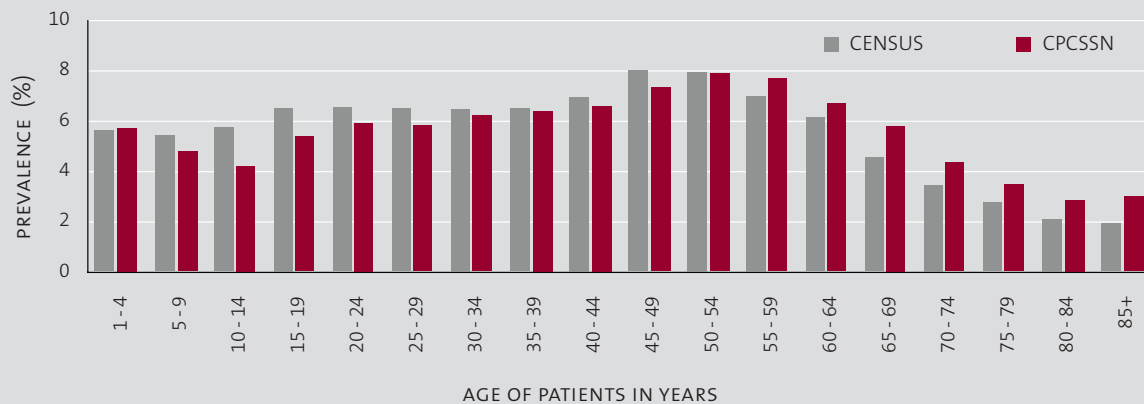
When the age distribution of CPCSSN patients is compared to the age distribution from the 2011 Canadian Census, they are reasonably similar. It is clear that the CPCSSN population is systematically older, which is not surprising given that older individuals generally have more frequent contact with their primary care provider than younger people. Further, given that the differences are small, it is easy to adjust estimates coming from CPCSSN to reflect what would be expected in a more nationally representative sample. The age distribution from the 2011 Census and the age distribution of CPCSSN patients are given in Figure 3.

When comparing the characteristics of the physician population within CPCSSN to respondents of the 2010 National Physician Survey (NPS), the sample is reasonably representative.[2] CPCSSN sentinels appear to be systematically younger than other respondents to the 2010 NPS, and CPCSSN has a much higher proportion of female providers. CPCSSN has a very similar geographic distribution of its sentinels to the 2010 NPS. However, CPCSSN's current level of provider information indicates an under-representation of non-traditional family medicine, such as family physicians who have hospital-based clinics that are non-academic, or physicians practicing in community health centers.

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2   2010 National Physician Survey. The College of Family Physicians of Canada, The Canadian Medical Association, The Royal College of Physicians and Surgeons of Ontario. http://nationalphysiciansurvey.ca/surveys/2010-survey/2010-results/

Table 2: CPCSSN Data Holdings Q2 Report (As of Sept 30, 2013)

Sites	83	Billing Diagnoses	11,317,883
Providers	476	Lab Results	5,236,856
Patients	572,860	Medications	7,612,562
Index Diseased Patients	168,109	Allergies	239,860
Index Disease Cases	255,625	Physical Signs	6,548,050
Index Disease Indicators	2,204,575	Medical Procedures	6,676,534
Encounters	8,725,241	Referrals	888,526
Health Conditions	3,843,493	Risk Factors	1,013,760
Encounter Diagnoses	10,048,757	Vaccines	1,721,785

Figure 3: Distribution of CPCSSN Patients Compared to the 2011 Canadian Census[3]

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.

Case Definitions

The initial intent of CPCSSN was to allow use of this powerful new data source for the surveillance of eight chronic conditions: diabetes, hypertension, osteoarthritis, dementia, parkinsonism, epilepsy, depression, and chronic obstructive pulmonary disease (COPD).

Given the nature of EMR data, it was essential that case definitions used in its analysis be rigorously validated before they are used for surveillance activities or for primary care research. In the pages that follow we present selected aspects of our surveillance data along with the validation results.

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3   Statistics Canada, 2011 Census of Population, Statistics Canada Catalogue no. 98-311-XCB2011018.

CPCSSN conducted a set of validation studies starting in May 2011 and finishing in March 2013. Initially, a pilot study was conducted using data from a single PCPBRN within CPCSSN. Some of the case definitions performed very well, while others needed substantial improvement. For the expanded validation study, CPCSSN built on the knowledge generated from the pilot study and changed both its approach to the study and our algorithms. The expanded study demonstrated results suggesting that the CPCSSN case definitions were as good as, or better than, similar definitions used both nationally and internationally. This has important implications for consumers of CPCSSN's surveillance data.

Validated, accurate case definitions lead to estimates of disease prevalence. Given that this is a new source of health data in Canada, this is an important finding. This work is currently under review for publication in a peer-reviewed scientific journal.

"**It is an exciting field to be in the midst of. Major changes in large-scale epidemiology and [EMR] research for population health benefit are occurring, and I see CPCSSN within an international context developing parallel systems for osteoarthritis surveillance and epidemiologic research with the accrual of time adding crucial longitudinal data.**"

George Peat PhD, MCSP, *Professor of Clinical Epidemiology*
Arthritis Research UK Primary Care Centre, Research Institute for
Primary Care & Health Sciences, Keele University

Analysis Highlights

The CPCSSN database has the potential to enhance understanding of many aspects of primary health care in a significant way. This new data source can provide fresh insight into the way care is delivered including, for example, examining whether established guidelines are being used. This data also has the potential to help better understand the prevalence of these well-known chronic conditions in a primary care setting in Canada. On the following pages are some of the surveillance information that can be extracted from the CPCSSN database, organized according to condition.[4] Those interested in obtaining additional data may contact CPCSSN.

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4   * Data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.
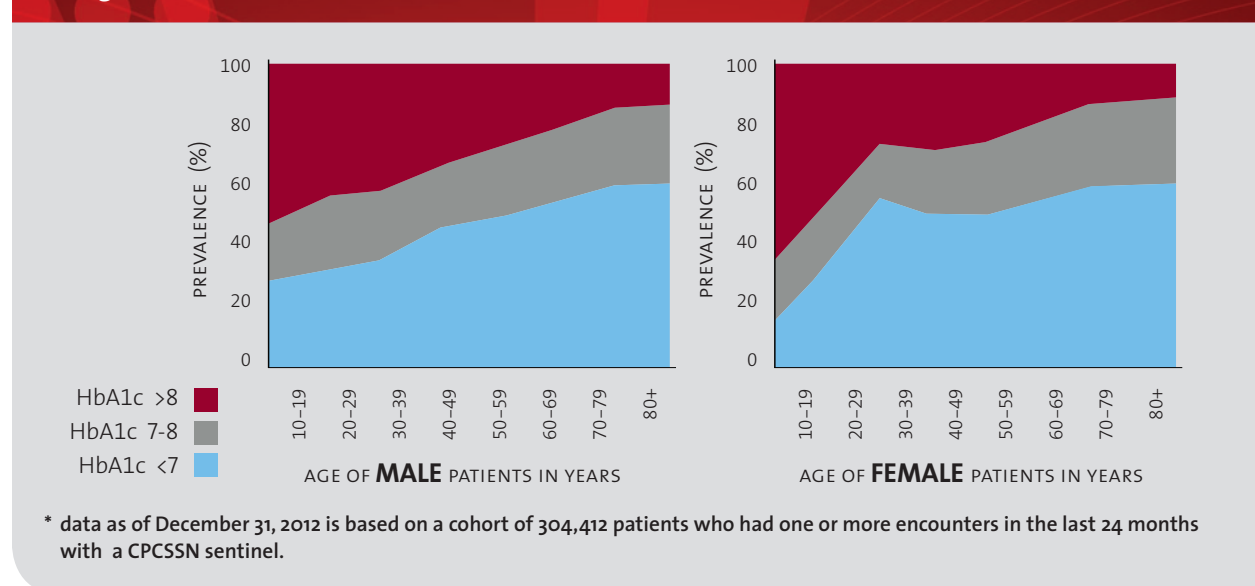
Diabetes

Diabetes is a major contributor to morbidity, mortality, and health care use in Canada; moreover, the majority of patients with diabetes are managed in primary care. [5, 6] The CPCSSN data repository contains unique data on primary care such as total medication burden for a large population of people with diabetes. In addition to new practice-based data on co-morbidities, vital signs, laboratory results and medications, this EMR-based system could provide information on the effects of care reorganization such as multi-disciplinary primary care or case management of diabetes.

CPCSSN data reveals that the age-gender adjusted prevalence of diabetes as managed in primary care is 7.6% and that diabetics have almost twice as many primary care encounters over two years (12.7 encounters) as people without diabetes (6.8 encounters). Furthermore, patients with diabetes are more likely to have a co-morbidity than those without the disease and they have more comorbidities overall. Sixty-nine per cent (69%) have at least one other condition studied by CPCSSN as opposed to 36% of people without diabetes. This impacts the total number of medications people with diabetes take, their risk of hospitalization and their overall quality of life. The impact of multiple coexisting conditions is not often addressed in guidelines, yet the majority of patients who have diabetes live with this. CPCSSN is positioned well to study multi-morbidity as managed in primary care.

In terms of pharmaceutical use, patterns of medications used by diabetics are changing and evolving. As of December 31, 2012, 72% of patients with diabetes were on at least one medication for blood sugar. The most common medication was metformin; 60% of patients were on this drug. Nine per cent (9%) of patients were on at least one of the two most recently approved classes of medications (DPP-4 inhibitors or GLP1 receptor agonists), suggesting significant uptake for these new drugs.

Another unique advantage of the CPCSSN database is that it includes routinely collected measurements from patients. As an example, ranges of values for last hemoglobin A1C (HbA1C) are shown on Figure 4. This type of information is not currently available from any other large national database.

Figure 4: Most Recent HbA1c Levels for Patients with Diabetes

HbA1c >8
HbA1c 7-8
HbA1c <7

AGE OF **MALE** PATIENTS IN YEARS

AGE OF **FEMALE** PATIENTS IN YEARS

* **data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.**

5   Canadian Diabetes Association. 2008 Clinical Practice Guidelines for the prevention and management of diabetes in Canada. Canadian Journal of Diabetes 2008;32(supp 1).

6   Hux J E, Booth G L, Slaughter P M, Laupacis A (eds). Diabetes in Ontario: An ICES Practice Atlas: Institute for Clinical Evaluative Sciences. 2003. Toronto 51 pages. © 2003 Institute for Clinical Evaluative Sciences. Available at; http://www.ices.on.ca/file/DM_Intro.pdf

Hypertension

Hypertension (high blood pressure) is one of the most prevalent medical conditions and is a significant risk factor for adverse cardiovascular events, especially strokes. Hypertension becomes more common as people age. The average age is increasing, and the proportion of people over 65 years old is likely to reach 25% or greater as the baby boomer generation moves into its senior years.[7] As high blood pressure is principally treated by primary care providers, it is in this setting that diagnosis, treatment and outcomes should be studied. [8]

Data provided by the CPCSSN gives a real-life picture of the levels of blood pressure encountered, the demographics of the patients with the condition, the drugs and other strategies used to manage it, and the outcomes of treatment. Prior to CPCSSN, data available to study hypertension came from hospitals, provincial billing systems and national/provincial surveys. These other sources do not provide information on point-of-care management, achievement of targets, or other risk factors. CPCSSN provides detailed data on the management of most of the hypertension in primary care than was previously available.

As one example of the type of data that can be obtained from the CPCSSN database, the table below provides information on the degree to which blood pressure targets are met in patients with hypertension in primary care practices.

Table 3: Achieving Blood Pressure Targets in Patients with Hypertension*

Condition		%
Patients with Hypertension	Systolic<140	79.8
	Diastolic<90	94.5
	Both systolic<140 and diastolic<90	78.0
Patients with Hypertension and Diabetes	Systolic<130	51.6
	Diastolic<80	75.1
	Both systolic<130 and diastolic<80	45.3

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.
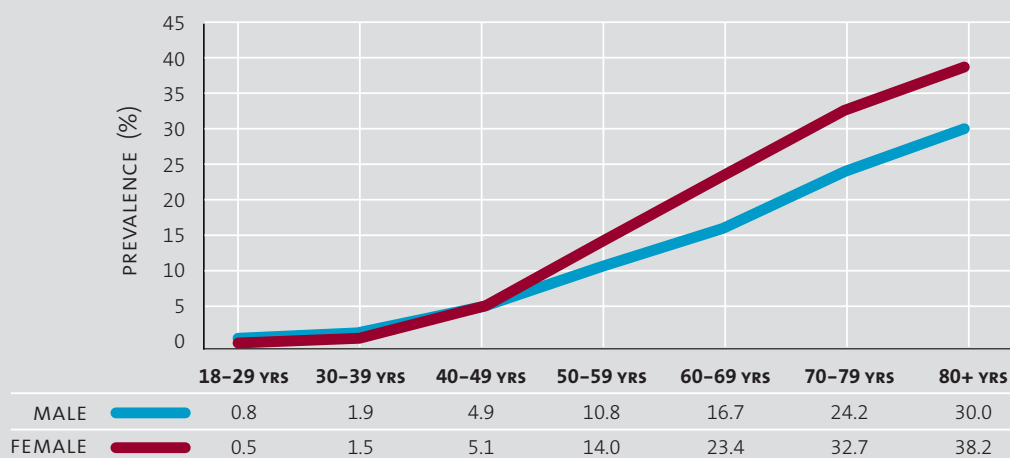
7   Robitaille C, Dai S, Waters S, Loukine L, Bancej C, Quach S, Ellison J, Campbell N, Tu K, Reimer K, Walker R, Smith M, Blais C, Quan H. Diagnosed hypertension in Canada: incidence, prevalence and associated mortality. CMAJ. 2012;184:E49-E56.

8   Campbell Norman RC, Kaczorowski Janusz, Lewanczuk Richard Z, Feldman Ross, Poirier Luc, Kwong Margaret Moy Lum, Lebel Marcel, McAlister Fin-lay A, Tobe Sheldon W. On behalf of the Canadian Hypertension Education Program, 2010 Canadian Hypertension Education Program (CHEP) recommendations: The scientific summary – an update of the 2010 theme and the science behind new CHEP recommendations, Canadian Journal of Cardiology. 2010;26(5 May):236-240.

Osteoarthritis

Osteoarthritis (OA) is the most common type of arthritis and a common health problem seen in primary care.[9] OA is the leading cause of lower extremity disability in older adults.[10] A recent study done in British Columbia using administrative data from 1991-2001 estimated the OA prevalence to be 10.8% (8.9% in men and 12.6% in women).[11] This prevalent condition can be readily studied using the CPCSSN EMR data on the understanding that the diagnosis is made on clinical grounds and that the propensity to make the diagnosis may vary between clinicians. Despite these challenges with diagnosis, CPCSSN has validated the case definition and has results consistent with the literature related to age and sex prevalence as shown in Figure 5. The overall observed prevalence of osteoarthritis from CPCSSN was 11.9% and when age and sex and standardized that drops to 10.5%, in-line with other published prevalence estimates. Also, the CPCSSN database provides an opportunity to describe clinically important osteoarthritis, and from this to assess potential risk factors (e.g. obesity), associations with other chronic conditions (e.g. diabetes) and how it is treated with prescribed medications.

Figure 5: Prevalence of Osteoarthritis by Age and Sex *

	18–29 YRS	30–39 YRS	40–49 YRS	50–59 YRS	60–69 YRS	70–79 YRS	80+ YRS
MALE	0.8	1.9	4.9	10.8	16.7	24.2	30.0
FEMALE	0.5	1.5	5.1	14.0	23.4	32.7	38.2

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.

9   Public Health Agency of Canada. Life with Arthritis in Canada: A personal and public health challenge. Ottawa: Public Health Agency of Canada: 2010 ISBN: 978-1-100-15986-7.

10   Woolf AD, Pfleger B. "Burden of Musculoskeletal Conditions" in Bulletin of the World Health Organization 2003;646-656.

11   Kopec, Jacek A; Rahman, M Mushfiqur; Berthelot, Jean-Marie; Le Petit, Christel; Aghajanian, Jaafar; Sayre, Eric C; Cibere, Jolanda; Anis, Aslam H; Badley, Elizabeth M. Descriptive epidemiology of osteoarthritis in British Columbia, Canada. The Journal of Rheumatology February 1, 2007 vol. 34 no. 2 386-393.
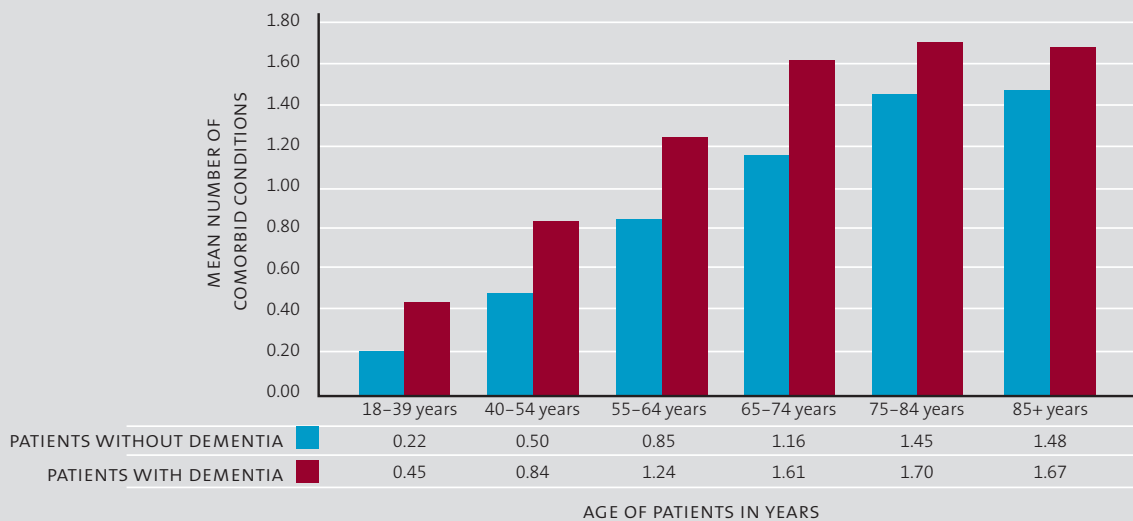
Dementia

It is projected that 1.1 million Canadians will have dementia by 2038.[12] Attempts to find a cure are still distant from success and current drug treatments to mitigate disease effects are generally not effective. [13, 14] Consequently, patient and caregiver health and social support services in primary care and other community-based settings are crucial to improving outcomes, and will remain so for many years.

Data on the impacts of comorbidity and polypharmacy are essential to understanding and improving care for dementia in the real world. These data are rarely—if ever—accounted for in most dementia-related research from other settings. CPCSSN now provides a major longitudinal source of clinical data in support of the treatment and care for this condition in primary care.

Figure 6 presents CPCSSN data relevant to care for this disease. It indicates that people with dementia also experience substantial additional burden through comorbidity throughout all stages of the dementia trajectory. This has major impact on achieving access to dementia care and on responses to treatment and services.

Figure 6: Mean Number of Comorbid Conditions by Dementia Status and Age*

	18–39 years	40–54 years	55–64 years	65–74 years	75–84 years	85+ years
PATIENTS WITHOUT DEMENTIA	0.22	0.50	0.85	1.16	1.45	1.48
PATIENTS WITH DEMENTIA	0.45	0.84	1.24	1.61	1.70	1.67

AGE OF PATIENTS IN YEARS

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.

"From the perspective of dementia care, CPCSSN provides data that are not available anywhere else – real time, ongoing measurement of changing / evolving dementia care in the community."

Frank Molnar MSc, MDCM, FRCPC, *Geriatrician, Associate Professor, University of Ottawa*

12   Alzheimer Society of Canada. Rising tide: the impact of dementia on Canadian society. Available at: http://www.alzheimer.ca/en/Get-involved/Raise-your-voice/Rising-Tide

13   Rocca WA, Petersen RC, Knopman DS, Hebert LE, Evans DA, Hall KS, Gao S, Unverzag FW, Langa KM, Larson EB, White LR. Trends in the incidence and prevalence of Alzheimer's disease, dementia, and cognitive impairment in the United States. Alzheimer's & Dementia. 2011;7:8-93.

14   Mayuex R, Stern Y. Epidemiology of Alzheimer Disease. Cold Spring Harb Perspect Med. 2012; 2:a006239.

Parkinsonism

Parkinsonism, and its most common cause Parkinson's Disease (PD), are relatively uncommon in a primary care setting. There are few studies of this chronic neurological condition in general practice and none in Canada.[15] Population prevalence estimates are about 14-19/100,000 and more common in the elderly.[16] It is also projected to increase substantially over the next several decades as the population ages. [17]

CPCSSN data provides a first look at PD in primary care in Canada. It provides the opportunity to study the role of the primary care practitioner in the management of patients with PD, prevalence, visit frequency, referral rates, frequency of other chronic diseases, and medication use. Much of data are not available from other databases. Also, given the large size of the CPCSSN database, even rare conditions such as PD can be studied with reasonable power.

An example of CPCSSN data related to comorbidity for PD is highlighted in the following table.

Table 4: Number of Comorbid Conditions by Parkinsonism Status*		
Number of Comorbid Conditions	**Patients without Parkinsonism (N=249388)**	**Patients with Parkinsonism (N=958)**
0 other conditions	55.0	17.6
1 other condition	28.3	34.7
2 other conditions	11.8	24.7
3 other conditions	3.9	15.5
4+ other conditions	1.0	7.5

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.
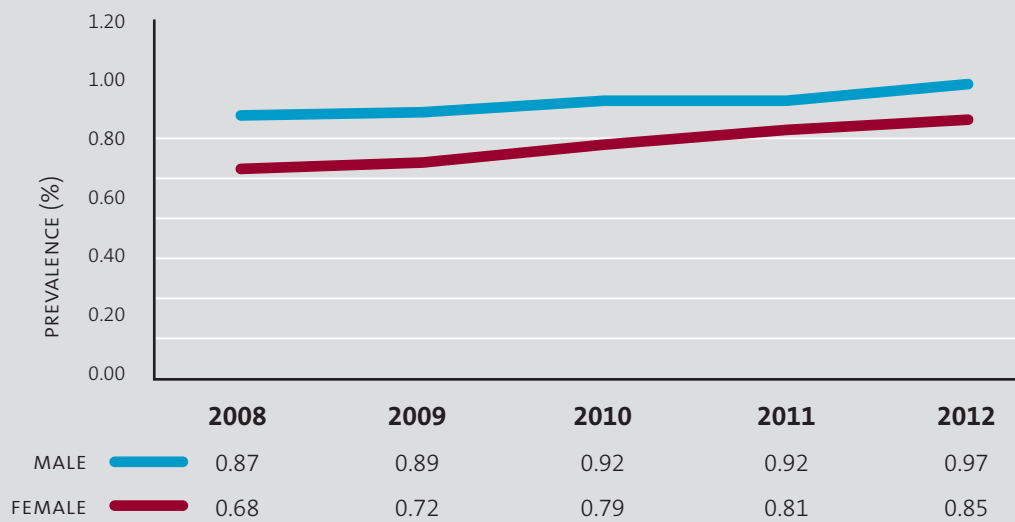
15   MacDonald BK, Cockerell OC, Sander JW, Shorvon SD, The incidence and lifetime prevalence of neurological disorders in a prospective community-based survey in the UK, Brain 2000;123:665-676

16   D. Hirtz, MD; D.J. Thurman, MD, MPH; K. Gwinn-Hardy, MD; M. Mohamed, MPH;A.R. Chaudhuri, PhD; and R. Zalutsky, PhD, How common are the "common" neurologic disorders? Neurology 2007;68:326–337.

17   Dorsey ER, MD, Constantinescu R, Thompson JP, Biglan KM, Holloway RG, Kieburtz K, Marshall FJ, Ravina BM, Schifitto G,   Siderowf A, MD, Tanner CM. Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030, Neurology 2007;68:384–386.

Epilepsy

Epilepsy, also known as seizure disorder, is a serious condition characterized by a sudden, brief change in how the brain functions. It is a condition that affects both the young, with 44% of cases being diagnosed before the age of five, and the elderly with epilepsy happening to those over 65 nearly as often as those under the age of 10. Many people with epilepsy receive anti-epileptic medication that prevents them from having seizures.[18, 19]

The CPCSSN database is uniquely positioned to provide valuable information about epilepsy in Canada. The database includes information on people of all ages, unlike some surveys that are administered to only those over 12. Also, included in the CPCSSN database is information on the medications each patient is receiving which allows an insight to the treatment of epilepsy in a primary care setting that is not available from other datasets. Last, the longitudinal nature of the CPCSSN database permits an investigation of how the prevalence of epilepsy is changing over time. The following figure shows that the rate of epilepsy has increased steadily over the last five years. The cause of this increase is not yet known, but CPCSSN is a potential source of data to provide insight to that observation.

Figure 7: Age Standardized Prevalence of Epilepsy by Sex from 2008 to 2012 *

	2008	2009	2010	2011	2012
MALE	0.87	0.89	0.92	0.92	0.97
FEMALE	0.68	0.72	0.79	0.81	0.85

Age standardized according to the 2011 Canadian Census

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.

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18   Epilepsy Canada. (2012). Living with Epilepsy, Facts, Epidemiology, & Diagnosis and Treatment. In Epilepsy Canada. Retrieved November 25, 2012. Available at: http://www.epilepsy.ca

19   Blume W. T. (2003). Diagnosis and management of epilepsy. CMAJ, 168: 441-448.

Depression

Depression is one of the 10 most commonly occurring chronic diseases in primary care. It can become a chronic condition. Recommendations and guidelines for high-quality clinical care are available.[20] CPCSSN provides a primary care perspective on the prevalence of depression in Canada. Using a validated case detection algorithm we are able to evaluate the relationship between depression and other validated diseases within CPCSSN (Table 5). These preliminary results suggest that those living with depression have a higher prevalence of the other seven chronic diseases than patients without depression.

This data source has the potential to identify the burden of depression within specific practices and geographic areas, which can be used to allocate resources to those most in need. The longitudinal data provided by CPCSSN has detailed information about the distribution of depression across a Canadian population. In addition, this data source is ideal for understanding the risk factors for depression and may help to identify high risk patients. CPCSSN also has extensive data on pharmacological and non-pharmacological treatment of depression, which can add insight into the management of depression in Canada.

Table 5: Relative Comorbid Disease Rates by Depression Status*

Comorbid Condition	Prevalence Ratio	95% Confidence Interval		p
Hypertension	1.14	1.13	1.16	<0.001
Diabetes	1.30	1.27	1.34	<0.001
COPD	1.81	1.73	1.88	<0.001
Osteoarthritis	1.36	1.33	1.39	<0.001
Dementia	2.71	2.58	2.86	<0.001
Epilepsy	1.90	1.74	2.08	<0.001
Parkinsonism	2.25	1.96	2.58	<0.001

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel. Modeled the probability of each of the comorbid conditions, for which the predictor is DEPRESSION (yes/no), along with age and sex. Interpretation: People with depression are 1.14 times more likely to be hypertensive than people without depression, and so on.

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20   Ostbye T, Yarnall KS, Krause KM, Pollak KI, Gradison M, Michener JL. Is there time for management of patients with chronic diseases in primary care? Annals of family medicine 2005;3:209-14.
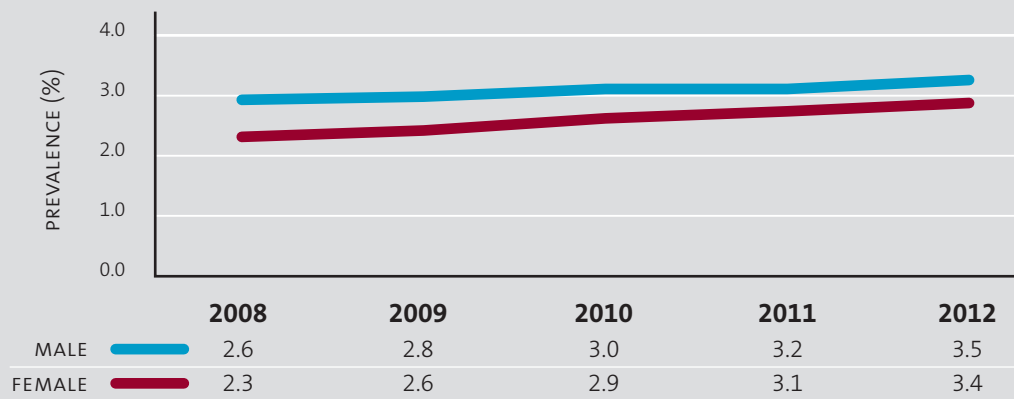
Chronic Obstructive Pulmonary Disease

In 2012, 4.2 % of Canadians 35 years and older reported they had been diagnosed with COPD.[21] COPD is a progressive disease characterized by inflammation of airways. The single most important cause of COPD is long-term exposure to cigarette smoke. [22]

Current estimates of the prevalence of COPD in Canada is still not well described. Since it is a progressive disease, patients are mainly managed by primary care until their disease becomes severe. Estimates of prevalence and other information about COPD currently come from self-report, hospitalization data and mortality data.

CPCSSN data can provide valuable information regarding COPD. Since patients are mainly managed by primary care, especially early in the course of the disease, prevalence estimates based on CPCSSN data are more likely to reflect the true prevalence in the general population. CPCSSN can provide information on the epidemiology of COPD including age and gender statistics, medication use, comorbidities associated with COPD, smoking status, and other risk factors that may be associated with COPD that are yet to be recognized. Also, CPCSSN data has the ability to track the prevalence of the condition over time and monitor changes. For example, as of the end of 2012, CPCSSN data suggests the prevalence of COPD has increased from around 2.5% in 2008 to around 3.4% in 2012, an increase of more than a third in those five years.

Figure 8: Age Standardized Prevalence of COPD by Sex from 2008 to 2012*

	2008	2009	2010	2011	2012
MALE	2.6	2.8	3.0	3.2	3.5
FEMALE	2.3	2.6	2.9	3.1	3.4

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.

21   Statistics Canada 2009. Publications-Health Fact Sheets- Chronic Obstructive Pulmonary Disease, 2009 Available at: http://www.statcan.gc.ca/pub/82-625-x/2010002/article/11273-eng.htm
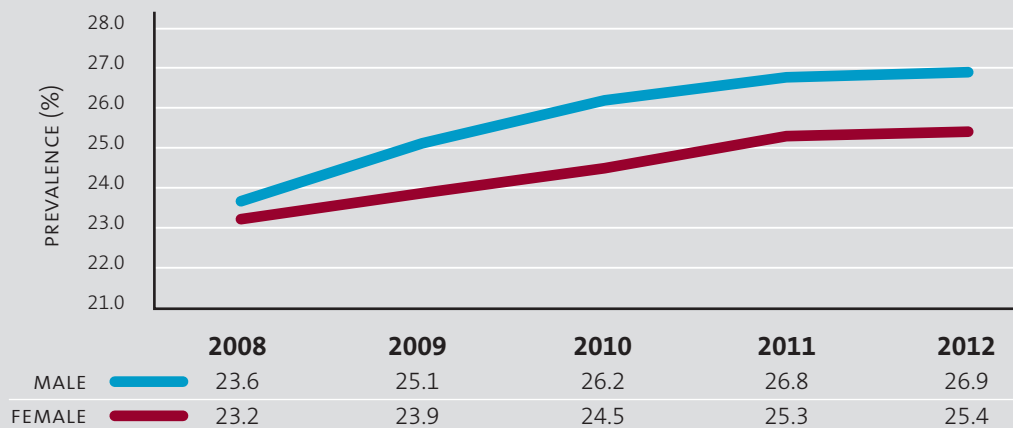
22   O'Donnell D, Hernandez P, Kaplan A, Aaron S, Boubeau J et al. Canadian Thoracic Society recommendations for management of COPD-2008 update-highlights from primary care. Canadian Respir J, Vol 15 (Suppl A), Jan-Feb 2008.

Obesity

CPCSSN also has information to monitor clinically important risk factors like obesity. There has been a steady, yet dramatic increase in the prevalence of obesity in Canada.[23-26] In 1978, the age-adjusted obesity estimate for men was 12%, and 16% for women; by 2007, the percentage for men and women had doubled to 24.1%.[27]

The CPCSSN database is an ideal resource for studying obesity as it can provide longitudinal and objective measures of height and weight. Given the magnitude and clinical impact of the current obesity epidemic and its health-related risk factors, it is important to use this unique dataset for longitudinal surveillance of obesity and ultimately to enable timely, effective interventions, as well as service and program evaluations. Furthermore, body mass index (BMI) is an important risk factor, and data from CPCSSN can be used to evaluate the impact of this covariate on other disorders.

Figure 9: Prevalence of Obesity by Sex from 2008 to 2012*

	2008	2009	2010	2011	2012
MALE	23.6	25.1	26.2	26.8	26.9
FEMALE	23.2	23.9	24.5	25.3	25.4

* data as of December 31, 2012 is based on a cohort of 304,412 patients who had one or more encounters in the last 24 months with a CPCSSN sentinel.

23   Tjepkema M. Adult obesity. Health Reports (Statistics Canada, Catalogue 82-003) 2006;17(3):9-25.

24   Katzmarzyk PT. The Canadian obesity epidemic, 1985-1998. CMAJ 2002;166(8):1039-40.

25   Torrance GM, Hooper MD, Reeder BA. Trends in overweight and obesity among adults in Canada (1970 - 1992): evidence from national surveys using measured height and weight. International Journal of Obesity 2002;26:797-804.

26   Tremblay MS, Katzmarzyk PT, Willms JD. Temporal trends in overweight and obesity in Canada, 1981-1996. International Journal of Obesity 2002;26(4):538-543.

27   Shields MT, M. Trends in adult obesity. Statistics Canada Health Reports 2006.. Component of Statistics Canada Catalogue no. 82-003-X Health Reports. Available at: http://www.statcan.gc.ca/pub/82-003-x/2011003/article/11534-eng.pdf5

The Future of CPCSSN

Over the last five years, CPCSSN has created innovative methods of EMR data extraction, standardised data coding and cleansing, privacy and information security, and analysis for multiple EMRs across many jurisdictions of previously untapped primary health data settings. There are opportunities   for continued innovation in the processing and use of EMR data to create a comprehensive data source for surveillance and research for PHC. Extracting data once for many uses is an important resource for practice quality improvement, public health surveillance, and research.

With applicable funding, CPCSSN can expand to every province to create the most representative system possible. It can also increase the number of practices and patients involved. Providing a national picture of chronic disease is vital and each province can benefit from CPCSSN's provincial EMR data.

While CPCSSN is currently reporting on eight chronic diseases plus obesity, other conditions such as asthma, coronary artery disease, heart failure, and cancers can be studied. Multimorbidity is very frequent in primary care, and CPCSSN data provides the unique opportunity to report on the complexities of care for patient populations. CPCSSN practices will also allow for surveillance of new drugs that come to the market and can enhance drug adverse reaction reporting.

As data extraction methods are refined and accelerated, real time analysis of acute conditions may also be possible in the future. Additionally, there are opportunities to use CPCSSN as a research platform for cohort studies and national randomized trials to answer questions important to primary care.

CPCSSN is at the forefront of using EMRs for data analytics and is well-positioned to continue its innovative work on information technology and data management, privacy and information security, surveillance, research, and knowledge translation.[28]

The CPCSSN technology team will continue to develop:
- data quality improvement algorithms and processes that transform poor quality EMR data into data that's usable for analysis and reporting, including:
  - coding of diagnoses into ICD-9 and SNOMED-CT, medications into ATC, lab results into LOINC, referrals into SNOMED-CT;

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28   Keshavjee K, Chevendra V, Martin K, Jackson D, Aliarzeheh B, Kinsella L, Turcotte R, Sabri S, Chen T. "Design and Testing of an Architecture for National Primary Care Chronic Disease Surveillance Network in Canada." In International Perspectives in Health Informatics. Boryki et. al. (Eds.) IOS Press, 2011 doi: 10.3233/978-1-60750-709-3-341.

- cleansing of quantitative data, including physical signs (e.g. weight, height, BMI values), risk factors (e.g. packs/day for smoking), lab results (e.g. HbA1c values);
- validation of data coding and cleansing algorithms

- an extendable disease case detection framework, currently supporting algorithms for eight specific chronic conditions of interest;
- de-identification of data to comply with ethics and privacy requirements, including removal of direct identifiers, anonymisation of free text and reduction of the risk of statistical re-identification using the PARAT tool;
- standardised feedback and representativeness reports to meet practice needs
- an interactive data presentation tool to do customised reporting and querying to meet specific practice and/ or researchers' needs; and
- an overall automation framework for EMR data extraction, transformation, processing and transmission to CPCSSN's national servers.

As data extraction methods are refined and accelerated, real time analysis of acute conditions may also be possible in the future. This could help make CPCSSN a critical source of information for physicians and health officials to respond to emerging health issues. Additionally, there are opportunities to use CPCSSN as a research platform for cohort studies and national randomized trials to answer questions important to primary care. Population management, often impractical with paper records, is made easier by adopting EMRs and other information systems which provide opportunities to look after the whole pactice.[29]

CPCSSN has worked out ways to extract and merge data from multiple EMRs.[30] These methods allow standardized regional, provincial, and national reports for participating physicians and primary care teams. CPCSSN is actively exploring methods for returning improved data to primary care teams and is currently testing it's Data Presentation Tool[31] (DPT), an interactive software that can quickly and easily generate reports and identify patients at risk. Use of EMRs can support all four of the principles CPCSSN strives to embody in family medicine: enhancing clinician skills; fostering patient-physician relationships of trust; keeping practices community-based; and acting as true resources to patients. CPCSSN is grateful to contribute to the evolution of Canada primary care.[32]

"In some areas such as cancer epidemiology, it is easy to track progress in simple ways... However, for the main cases of morbidity in the population, like depression and diabetes, such tracking was not possible [and] the pace of progress was uncertain. CPCSSN [can address] this problem."

Scott B. Patten MD, FRCPC, PhD, *Professor, Department of Community Health Sciences, University of Calgary*

29   *Four principles of family medicine*. Mississauga, ON: College of Family Physicians of Canada; 2006. Available from: www.cfpc.ca/Principles Accessed 2013 May 7.

30   Birtwhistle R. Canadian Primary Care Sentinel Surveillance Network: A Developing Resource for Family Medicine and Public Health/ *Réseau canadien de surveillance sentinelle en soins primaires Une ressource en évolution pour la médecine familiale et la santé publique*. Canadian Family Physician • *Le Médecin de famille canadien*. October/*octobre* 2011;57(10):1219-20, *e401-e402*.Sentinel Eye/*L'oeil de la sentinelle - Exclusivement sur le web*. English and French.

31   Greiver M, Keshavjee K, Jackson D, Forst B, Martin K, Aliarzadeh B. Sentinel Feedback: Path to Meaningful Use of EMRs/*Rétroaction de la Sentinelle: une voie vers une utilisation significative des DME*. Canadian Family Physician • *Le Médecin de famille canadien*. 2012 October/*octobre*;58(10):1168, *e611-2*.Sentinel Eye/*L'oeil de la sentinelle - Exclusivement sur le web*. English and French.

32   Williamson T, Natarajan N, Barber D, Jackson D, Greiver M. Caring for the Whole Practice - The Future of Primary Care / *Voir la pratique dans son integralite: L'avenir des soins primaires*. Canadian Family Physician • *Le Médecin de famille canadien*. 2013; July 50(7)(July/juillet):800, *e341-e2*.Sentinel Eye/*L'oeil de la sentinelle - Exclusivement sur le web*. Epub juillet 2013. English + French.

2012/2013 Scientific Contributions

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2. Birtwhistle R. Canadian Primary Care Sentinel Surveillance Network: A Developing Resource for Family Medicine and Public Health/*Réseau canadien de surveillance sentinelle en soins primaires Une ressource en évolution pour la médecine familiale et la santé publique.* Canadian Family Physician • *Le Médecin de famille canadien.* October/*octobre* 2011;57(10):1219-20, *e401-e402.*Sentinel Eye/*L'oeil de la sentinelle - Exclusivement sur le web.* English and French.

3. Greiver M, Aliarzadeh B, Moineddin R, Meaney C, Ivers N. Diabetes Screening with Hemoglobin A1c Prior to a Change in Guideline Recommendations: Prevalence and Patient Characteristics. BMC Family Practice Journal. 2011 August 24;12(91):1-7.Research. English.

4. Greiver M, Barnsley J, Aliarzadeh B, Krueger P, Moineddin R, Butt DA, et al. Using a Data En-try Clerk to Improve Data Quality in Primary Care Electronic Medical Records: a pilot study. Informatics in primary care. 2011;19(4)241-50. Journal Article. Research Support, Non-U.S. Gov't. English.

5. Keshavjee K, Chevendra V, Martin K, jakson D, Aliarzeheh B, Kinsella L, Turcotte R, Sabri S, Chen T. Design and Testing of an Architecture for National Primary Care Chronic Disease Surveillance Network in Canada. In International Perspectives in Health Informatics. Boryki et. al. (Eds.) IOS Press, 2011 doi: 10.3233/978-1-60750-709-3-341.

6. Kotecha JA, Manca D, Lambert-Lanning A, Keshavjee K, Drummond N, Godwin M, et al. Ethics and Privacy Issues of a Practice-based Surveillance System: Need for a National-level Institutional Research Ethics Board and Consent Standards. /*Questions d'éthique et de confidentialité concernant un système de surveillance de la pratique Nécessité d'un bureau institutionnel d'éthique en recherche ainsi que de normes de consentement au niveau national.* Canadian Family Physician • *Le Médecin de famille canadien.* 2011 October;57(10):1165-73.Research. English and French.

7. Greiver M, Keshavjee K, Jackson D, Forst B, Martin K, Aliarzadeh B. Sentinel Feedback: Path to Meaningful Use of EMRs/*Rétroaction de la Sentinelle: une voie vers une utilisation significative des DME.* Canadian Family Physician • *Le Médecin de famille canadien.* 2012 October/octobre;58(10):1168, *e611-2.*Sentinel Eye/L*'oeil de la sentinelle - Exclusivement sur le web.* English and French.

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9. Kotecha JA, Putnam W, Birtwhistle RV, Lussier M-T, Nagpurkar A. Practice Recruitment/*Recrutement de pratiques.* Canadian Family Physician • *Le Médecin de famille canadien.* 2012 May/mai;58(5):e298-e9, *e300-1.*Sentinel Eye/*L'oeil de la sentinelle - Exclusivement sur le web.* English and French.

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15. Williamson T, Natarajan N, Barber D, Jackson D, Greiver M. Caring for the Whole Practice - The Future of Primary Care / *Voir la pratique dans son integralite: L'avenir des soins primaires*. Canadian Family Physician • *Le Médecin de famille canadien*. 2013; July 50(7)(July/juillet):800, *e341-e2*.Sentinel Eye/*L'oeil de la sentinelle - Exclusivement sur le web*. Epub juillet 2013. English + French.

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