**PRIVACY ANALYTICS**
a QuintilesIMS company

**CASE STUDY**

CPCSSN RCSSSP

## OVERVIEW

**The Challenge:**

Extract and aggregate vital EMR information and return data with greater analytic utility in order to enable advanced analytic research and improve quality of care for chronic diseases and neurologic conditions.

**The Solution:**

Integrate a proven de-identification software tool with CPCSSN's proprietary technology platform that assesses the use-specific level of privacy risk and then de-identify data using globally accepted standards and guidelines.

**The Benefit:**

Access to quality datasets provides better understanding of the patient population, including the ability to evaluate unmet needs, compare cost and effectiveness of existing treatments, find connections between diseases and improve healthcare overall.

# Canadian Primary Care Sentinel Surveillance Network: Transforming Vital EMR Information into Rich, Accessible Data to Improve Quality of Care

*Health practitioners and researchers understand that greater knowledge is needed to help chronic disease surveillance, research for primary care and practice quality improvement. This can only be accomplished through increased data sharing and access to patient information over multiple care systems. But how do we protect patient privacy?*

## Sharing of Chronic Disease Information Responsibly

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN) understood that health practitioners and researchers need useful, detailed health information in order to help improve treatment and care. In order to develop a multi-disease electronic record surveillance system that would allow for research and analytics, CPCSSN needed a proven methodology to de-identify health information in order to protect patient privacy. Through securely de-identifying patient data from practices and care centers across Canada, researchers and healthcare practitioners are able to conduct chronic disease surveillance, research for primary care and practice quality improvement.

CPCSSN is dedicated to improving care for people who suffer from five chronic and mental health conditions: hypertension, osteoarthritis, diabetes, chronic obstructive pulmonary disease and depression. Their focus to also to improve treatment and care for three neurologic conditions: Alzheimer's and related dementia, epilepsy and Parkinson's disease. Building and managing this network of health information for research and analytics enables practitioners and researchers to fulfill their goals of improving treatments and care. In Canada, chronic disease is on the rise. According to the 2013 Commonwealth Fund International Health Policy Survey of the General Public, 57% of Canadians have at least one chronic condition, and 31% have two or more.

When CPCSSN first approached care practices to discuss leveraging their health information, the practices' concern was on how protected health information (PHI) would be managed to safeguard privacy. CPCSSN needed a proven method to de-identify the information to reduce the risk

of re-identification. Utilizing Privacy Analytics software, methodologies and expertise helped CPCSSN demonstrate that the information could be shared while still protecting patient privacy. Now, over 100 million records from more than one million patients at over 130 primary care practice sites across Canada are properly de-identified and used for research and analysis.

## How It Works

Every three months, CPCSSN collects data from electronic medical records (EMRs) at primary care practice sites across Canada. Data is extracted using a custom system developed by CPCSSN, and then de-identified by trained staff experts using Privacy Analytics' software. Often, the data needs to be "cleaned", meaning that there may be visual inconsistencies that occurred when the data was inputted at the practice level. The information is then normalized for analysis and reporting. Practitioners receive value not only through greater quality of data, but also in the usable reports they receive for research and analysis.

In order to access and analyze high volumes of patient data from numerous settings, CPCSSN needed a scalable way to produce customized data sets that contained the information that was most useful to researchers and providers, while protecting patient privacy. Privacy Analytics – the leading provider of software that safeguards and enables personal health data for secondary purposes – helped CPCSSN implement a proven, risk-based approach that responsibly de-identified patient information based on the specific use of each custom data set. This

approach allowed CPCSSN to effectively protect individual patient privacy while unlocking large amounts of stored data needed to conduct research and analysis for chronic disease surveillance, primary care and practice quality improvement.

"There are many sources of data in today's health care practices and centers. To not only access quality data but also share it for research, requires confidence in the privacy solution."

- Dr. Karim Keshavjee, Research Data Architect at CPCSSN

## Real World Application: Conducting Chronic Disease Surveillance

In order to improve treatment and care for patients with chronic diseases, more detailed and coordinated information is needed for practitioners and researchers to understand where chronic illness is or is not happening, and why. The de-identified, aggregated data gives a more comprehensive picture of what is happening to patients compared to other practices. The data helps provide validation of case detection for eight specific chronic diseases. For example, health practitioners can further understand use of antidepressant medications among elderly individuals with depression, as well as provide longitudinal tracking of overweight and obesity prevalence from birth to adulthood.

In addition, CPCSSN is instrumental in the the development and validation of case definitions and case finding algorithms for dementia,

epilepsy and Parkinson's disease in primary care. This work is critical to conducting disease surveillance as an estimated 3.6 million Canadians who are affected by neurological conditions.

## Real World Application: Research for Primary Care

Without the ability to aggregate data over many different systems, researchers would only be able to see part of the overall issues faced by patients with chronic diseases. By enabling access to a higher quality of data, over 100 research studies have been completed. These include:

- Validation of eight chronic diseases in primary care electronic medical records;

- Report on the prevalence and management of hypertension in primary care practices;

- Chronic obstructive pulmonary disease, prevalence and epidemiology of diabetes in Canadian primary care practices; and,

- Diagnosis of depression and its treatment in Canadian primary care practices.

CPCSSN, with the Institute for Clinical Evaluative Sciences, is advancing patient health outcomes research on diabetes, congestive heart failure and depression. The linkage of new source primary care and administrative data is proving to be invaluable to population health research.

## Real World Application: Practice Quality Improvement

For uses where data is being shared for clinical use among providers, the de-identified step may not be required since this is an allowable use under HIPAA. Increased use of CPCSSN data can provide short and long-term feedback on primary care practitioners' practice. Providers are also able to link primary care data with hospital data for better coordination of care. This can help identify patients at high risk for readmission and reduce inefficiencies, which can eliminate waste and control cost. Practices regularly receive standardized reports containing important health care performance indicators for their practitioners, which compare them to other practices, provinces and national metrics.

Practices also can receive a powerful CPCSSN Database Querying Tool so that they can improve the quality of their practice. They construct specific queries of interest for their patient population and then follow up with appropriate interventions and/or activities.

> "Privacy Analytics' software has democratized research data."
> - Dr. Karim Keshavjee

## Company Info

## Next Steps

In the future, CPCSSN will look at options to include unstructured data sets for research and analysis, linking CPCSSN data with other health organization data, as well as incorporate predictive analytics to gauge a patient's risk for specific conditions and diseases.

For more than six years, CPCSSN has successfully utilized Privacy Analytics software to manage and reduce the privacy risk of sharing clinical data in order for practitioners to conduct chronic disease surveillance, research for primary care and practice quality improvement. CPCSSN looks forward to continuing the collaboration with Privacy Analytics, and using new and more advanced de-identification products as they are developed.