

Canadian Primary Care Sentinel Surveillance Network

A developing resource for family medicine and public health

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The Canadian Primary Care Sentinel Surveillance Network (CPCSSN—pronounced *sipsin*) started in 2008, with a grant from the Public Health Agency of Canada (PHAC), to study the feasibility of developing a network to collect health information on patients with chronic diseases across the country. This information is intended to be a resource for monitoring chronic disease in Canada, as well as for primary care research. The Canadian Primary Care Sentinel Surveillance Network has been organized as a network of networks, and its board is made up of network directors. As a subentity of the College of Family Physicians of Canada (CFPC), CPCSSN is partnering with the PHAC and the Canadian Institute for Health Information. The CFPC has been instrumental in both the support and the development of this network. The central office for CPCSSN is at the CFPC's national office, where its project management, financial oversight, and privacy and knowledge transfer take place.

Its beginning

The network began with 7 existing academic research networks in Calgary, Alta; Edmonton, Alta; London, Ont; Toronto, Ont; Kingston, Ont; Montreal, Que; and St John's, Nfld. Then networks also developed in Winnipeg, Man; Halifax, NS; and Vancouver, BC. Family practitioners who use electronic medical records (EMRs) are associated with each network. With research ethics board approval, these family practitioners agree to contribute de-identified patient health information to a growing database on 8 chronic diseases and neurologic conditions (chronic obstructive pulmonary disease, depression, diabetes, hypertension, osteoarthritis, Alzheimer disease and related dementias, epilepsy, and Parkinson disease). Among the networks, 9 EMR products are being used (Figure 1), from which the patient health information is extracted every 3 months and stored in a CPCSSN database in a highly secure facility.

The feasibility part of the project accomplished the following:

- university research centres worked together effectively as a network of networks;
- research ethics boards in 7 jurisdictions accepted the proposal to collect de-identified patient health data in a private and secure way without explicit patient consent;
- family physicians were willing to participate and contribute their patients' health information to the database;
- data were reliably extracted into a CPCSSN database from various EMR products;
- data were combined into a central database after appropriate cleaning; and
- case definitions were developed and updated on an ongoing basis.

Work in progress

In 2010 CPCSSN was awarded a 5-year contribution agreement by PHAC to continue its work. During this phase there is much to be accomplished to make the information useful for surveillance and primary care research. The network must continue to grow to better represent the Canadian population. Currently about 200 family physicians and 198 000 patients are involved in the network across the county. We hope to expand the network over the next 5 years to include every province and territory, and to have up to 1000 primary care practitioners contributing information on their patients' health conditions. The network will also continue the very important work of validating the information about patients. For example, it is important to be sure that a patient identified in the database with diabetes actually has this chronic disease. Data that is collected (eg, weight, blood pressure, medications, and risk factors) must be assessed for their validity. There is a lot of work now going into this activity, which is complicated when different EMR products are being used. Data validation will be an ongoing effort for this project.

There is also the ongoing challenge of privacy to consider. Both privacy impact assessments and at-risk assessments have been educational and have resulted in improvement of some processes and the privacy and security of data. The network continues to focus on ensuring that the de-identified information collected on patient's health is secure and has minimum risk of re-identification. Privacy considerations are always present, and privacy impact will be assessed yearly. I encourage you to read the article in this month's *Canadian Family Physician* by Kotecha and colleagues¹ (page 1165), which outlines the CPCSSN research ethics board experience across jurisdictions in Canada and includes intriguing observations about the privacy and ethics trail in public health care surveillance and research.

La traduction en français de cet article se trouve à www.cfp.ca dans la table des matières du numéro d'octobre 2011 à la page e401.

Figure 1. Ten primary care research networks: 8 provinces and 9 electronic medical records.



All of this has been completed, and we have not produced any data yet. An important project over the next 5 years will be to analyze the data in order to provide ongoing surveillance reports for chronic disease, as well as to provide information for primary care researchers and others interested in using the data to improve the health of Canadians. This information has tremendous potential to provide timely and ongoing surveillance information on chronic disease, which has never been available before, to policy makers, health planners, and government agencies. Participating family physicians will also be provided with useful information. Regular feedback about their practices will be sent to CPCSSN family doctors, with valuable information (de-identified) about their own patients with chronic disease and comparisons with regional and national data. This information will allow physicians to reflect on their care of patients with chronic disease and, as a bonus, to collect Mainpro-C credits for their time.

The CPCSSN project continues to grow and flourish, thanks to the PHAC, the CFPC, the CPCSSN staff (including the project manager, data managers, research assistants, epidemiologists, and data analysts), and the network directors. However, our greatest thanks must be to the family doctors who allow us to extract

information about their patients' health. Without their contribution, we would be nowhere. If you would like to get involved, please contact the network in your area. 🌟

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Acknowledgment

I thank **Drs Alan Katz** and **Marie-Thérèse Lussier** for their contributions to this paper.

Competing interests

None declared

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The views expressed herein do not necessarily represent the views of the Public Health Agency of Canada.

Reference

1. 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 ethics review board and consent standards. *Can Fam Physician* 2011;57:1165-73.

Sentinel Eye is a new series in *Canadian Family Physician*, coordinated by the Canadian Primary Care Sentinel Surveillance Network in partnership with the College of Family Physicians of Canada. The focus is to highlight surveillance and research initiatives related to chronic disease prevalence and management in Canada. Please send any questions or comments to Anika Nagpurkar, Knowledge Translation and Exchange Officer, at an@cfpc.ca.