



Canadian Primary Care Sentinel Surveillance Network
Réseau canadien de surveillance sentinelle en soins primaires

Patient Information

Your privacy is important to us and we will keep your personal information safe and confidential at all times.

Your health care provider understands the need for better information about your health and as a result, has agreed to take part in the Canadian Primary Care Sentinel Surveillance Network project. This study has been reviewed for ethical compliance by the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

What is the purpose of the project?

The purpose of the CPCSSN project is to create a database of high quality, de-identified health information to support better research and improve the diagnosis, treatment and care of Canadians with conditions such as diabetes, depression, high blood pressure, Alzheimer's Disease and Parkinson's Disease, as well as other conditions.

Why is this project important?

Having more information will allow us to understand some illnesses better. This information may help health care providers to improve care for patients.

What information will be collected?

We will collect health information about how illnesses are diagnosed, treated and managed. All personal information including your name, address, telephone number and family contacts will be removed before the information is submitted to the CPCSSN project database. After your personal identifiers are removed from the information, it will be stored in a central electronic system by CPCSSN, and used for research and analysis of illnesses facing patients in Canada today. CPCSSN will also include information such as month and year of birth, sex, ethnicity, occupation, highest level of education attained, housing status, primary language, family history and postal code.

May I opt out of the project?

YES. You may request that your health information not be included in the CPCSSN study database at any time. Your medical care will not be affected if you choose to not participate. To find out more, just ask your health care provider.

Who can I talk to for more information?

Contact Dr. David Barber, the Eastern Ontario Network (EON) Director, in the Center for Studies in Primary care at 613-533-6000 extension 73934. **Contact** Rachael Morkem, EON Research Associate at 613-533-6000 extension 79567 or morkemr@queensu.ca. If you have any concerns about your rights as a research participant please call Dr. Albert Clark, Chair of the Queen's University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at 1-844-535-2988, or email HSREB@queensu.ca.