

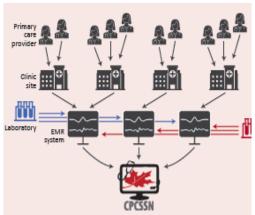


## The British Columbia Primary Care Sentinel Surveillance Network: BC-CPCSSN (Part of CPCSSN)

## **Dear Patient:**

Your healthcare provider has agreed to be part in the BC Canadian Primary Care Sentinel Surveillance Network (CPCSSN). This project is part of a larger Canadian network that collects information about patients' health. This information is used to support research and to improve health care. We do not collect any names, addresses, telephone numbers, or family contacts.

What is the purpose? The purpose of CPCSSN is to create a database of de-identified health information to support research and to improve health of Canadians with chronic diseases such as diabetes or depression. Researchers must have approval from CPCCSN and a research ethics board before they use the data. Your privacy is important. We will keep your personal information safe and confidential at all times.



May I opt out of the project? YES. You do not have to be in this project. You can opt out at any time, and your health information will not be collected for CPCSSN. Your medical care will not be impacted. To find out more or to opt out of this project, just ask your doctor, nurse, or front desk staff.

Why is this project important? We hope that the information collected by CPCSSN will help to improve care for patients. The study may not benefit you directly.

What information will be collected? This research

will collect health information from your healthcare provider about how illnesses are diagnosed and treated. The project uses your personal health number and other individual information (such as your birthdate, sex, and postal code) to link your health information to medical billing data or hospital records, as well as other sources. Linking data will help us understand how we can improve the health system.

This data will be linked by Population Data BC. Population Data BC is an independent, non-profit organization that securely stores health data for research. Population Data BC acts as a trusted third party for linking data. It also provides a secure and private way for researchers to access and analyze the data. Their research aims to improve health services in BC.

We are not interested in individual information. We are interested in group-level information. No names, addresses, telephone numbers or family contacts is collected. CPCSSN includes information such as birthdate, sex, ethnicity, occupation, highest level of education, housing status, primary language, postal code, and family history (for example, other family members with a chronic health condition). Being part of this project will not affect your care in any

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way.

**Who can I talk to for more information?** Call our Co-director Dr. Sabrina Wong at (604) 827-5584 for more information.

Who can I talk to if I have concerns about the study? If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

## Who are the people involved in this project?

- -Your primary care provider and their office staff
- -Drs. Sabrina Wong (nurse) and Ruth Elwood Martin (physician), as the Co-directors of the CPCSSN-BC network
- -Drs. Rita McCraken (physician), Morgan Price (physician) as clinical investigators in BC -Drs. Donna Manca (physician) and Neil Drummond (PhD) in Alberta, Alex Singer (physician) in Manitoba, Amanda Terry (epidemiologist) and Michelle Grevier (physician) in Ontario, Marie-Therese Lussier (physician) in Ouebec, Fred Burge/Matt Grandy (physicians) in Nova

Marie-Therese Lussier (physician) in Quebec, Fred Burge/Matt Grandy (physicians) in Nova Scotia, Marshall Godwin (physician) in Newfoundland, and Rick Birtwhistle (physician) in Ontario are the other CPCSSN network directors.

Who is paying for this study? This work is funded through the Canadian Institutes for Health Research and the Michael Smith Foundation for Health Research

Sincerely,

Co-directors of the BC Primary Care Research Network,

Dr. Sabrina Wong

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