



Introduction

Public health surveillance¹ is an important activity in every community across Canada. Chronic diseases have reached epidemic proportions in Canada and are utilizing an increasingly greater share of our health care budgets. Public health surveillance helps us identify emerging health issues and areas for improving the delivery of health care services.

The Canadian Primary Care Sentinel Surveillance Network (CPCSSN)/le réseau canadien de surveillance sentinelle en soins primaires in Québec (RCSSSP) is funded by the Public Health Agency of Canada (PHAC) with the support of the College of Family Physicians of Canada (CFPC) to provide this valuable service to the Canadian public health system.

Ensuring the Protection of Personal Health Information

CPCSSN-participating primary care health providers adhere to applicable privacy legislation, as well as the Tri-Council Policy Statement, *Ethical Conduct for Research Involving Humans, 2010* (TCPS2).²

- Prior to participating in CPCSSN, the prospective primary care practice-based research network (PC-PBRN) must apply and receive approval from its research ethics board (REB). The REB has the responsibility of ensuring the PC-PBRN sufficiently complies with applicable privacy legislation and the TCPS2.
- With this approval to participate in CPCSSN, the first and crucial step to protecting the privacy of patients is the removal of information that would link the health data to the patient (“de-identification”). This is done prior to uploading the resulting anonymized information to the national CPCSSN database.
- In this preliminary stage, patient direct identifiers (i.e. name, provincial health number) are not extracted. Should special permission be obtained by the REB to conduct research using CPCSSN data with patient direct identifiers, the direct identifiers will immediately be transformed into a non-decryptable form (Patient Identifier Key). This Key will be held in a secured location at the Sentinel’s practice environment with access restricted to only personnel with special clearance by the Sentinel and or REB.
- Indirect identifiers (e.g., date of birth, partial postal code, etc.) may still be found in the anonymized data. Although the risk of re-identification of the patient from this information is low to very low, additional de-identification steps will be applied to the data prior to its release to an approved researcher.
- CPCSSN ensures all employees, contractors and researchers are bound to confidentiality agreements that require compliance with CPCSSN’s comprehensive privacy and information security policies. Privacy impact assessments are conducted annually at each PC-PBRN to ensure sufficient organizational, technological and physical safeguards at every stage of the health information flow from the PC-PBRN to the CPCSSN central data repository.
- PC-PBRNs may conduct their own research and partner with other PC-PBRNs employing their respective Patient Identifier Keys for re-linking of CPCSSN data with their patient records. Such activity would be subject to approval from their respective REBs.

To view CPCSSN’s full Privacy Policy, please click [here](#). For more information about CPCSSN’s Privacy Statement or Privacy Policy, go to www.cpcssn.ca or contact the Research Privacy and Ethics Officer at CPCSSNPrivacyOfficer@cpfc.ca

¹ “The systematic tracking and forecasting of any health event or health determinant through the continuous collection of high-quality data, the integration, analysis and interpretation of those data...” (*National Advisory Committee on Public Health, Canada, 2003*)

² In 2001, Canada’s three federal research agencies, Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council jointly created the Interagency Advisory Panel on Research Ethics and collaborated in the creation of the *Tri-Council Policy Statement on the Ethical Conduct of Research Involving Humans* (TCPS). The updated TCPS (TCPS2) is available at: <https://www.ehealthinformation.ca/presentations/webinars/zimmerman/TCPS2.pdf>.

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