

SAPCReN Study Guidelines

The Southern Alberta Primary Care Research Network (SAPCReN) is a network of several hundred primary care providers and university-based researchers who are interested in improving primary care practice through collaborative practice-based research. SAPCReN contributes to the Canadian Primary Care Sentinel Surveillance Network (CPCSSN), the first and only pan-Canadian repository of de-identified primary care electronic medical record (EMR) data available for secondary uses, such as health research, disease surveillance and quality improvement.

A regional copy of the de-identified SAPCReN-CPCSSN data can be accessed for approved purposes. This consists of de-identified data from over 200,000 patients in southern Alberta, including diagnoses, prescribed medications, physical measurements, lab values, risk factors, and more. A detailed CPCSSN data dictionary can be found at www.cpcssn.ca.

In order to respond consistently to requests for access to SAPCReN-CPCSSN data or to facilitate the involvement of SAPCReN providers or practices for the purposes of trials or other more rigorous studies, the following criteria must be met:

1. The study must have a primary care provider or researcher in a leadership role (principal investigator or co-investigator);
2. The study must be judged by the Department of Family Medicine (DFM) Research Committee as being important, relevant and timely for primary care patients, providers, and/or systems;
3. Any costs associated with implementing the study in SAPCReN member clinics must be accommodated within the project budget;
4. All participation by SAPCReN member clinics, providers and patients is voluntary;
5. All participation by SAPCReN or the Department itself is voluntary.

Requests for SAPCReN-CPCSSN Data or Study Facilitation

- Before designing a study that includes the involvement of SAPCReN-CPCSSN data, staff, or practices, we recommend initiating a discussion with the SAPCReN-CPCSSN Co-Directors, Dr. Kerry McBrien (kamcbrie@ucalgary.ca) and/or Dr. Stephanie Garies (sgaries@ucalgary.ca).
- Submit your request through the Department of Family Medicine Research Request intake form located on our website (<https://cumming.ucalgary.ca/departments/family-medicine/research-scholarly-activity>) or email dfmresearch@ucalgary.ca for general enquiries.
- The project will be reviewed and approved by members of the DFM Research Committee, SAPCReN-CPCSSN Co-Directors, and may include feedback from the SAPCReN Primary Care Provider Advisory Group.
- Projects are required to comply with the provincial Health Information Act, with research ethics approval obtained through the Conjoint Health Research Ethics Board at the University of Calgary, as well as any additional operational approval (e.g., Alberta Health Services) required. SAPCReN staff can assist with the SAPCReN/CPCSSN-specific wording for Conjoint Health Research Ethics Board (CHREB) applications.

Cost-Recovery Fees for Data Access

Fees are based on the needs of the project and are charged to recover costs related to SAPCReN-CPCSSN staff time (administrative, research coordination, dataset creation and preparation, etc.).

Type	Cost
SAPCReN-CPCSSN Sentinel* with funded project	\$1,000
SAPCReN-CPCSSN Sentinel* with unfunded project	\$0
Other academic researchers (non-SAPCReN-CPCSSN Sentinels)	\$5,000

**SAPCReN-CPCSSN Sentinel refers to family physicians, nurse practitioners, and community pediatricians who are contributing de-identified EMR data as part of the CPCSSN project.*

Fees may be adjusted at the discretion of the SAPCReN Co-Directors following review of the study. Special consideration may be given to adjusting fees for projects led by graduate students or residents in the Department of Family Medicine.

In addition to study-specific dataset creation, SAPCReN staff may be available to provide statistical or data processing support for the project, also on a cost recovery basis.

Approvals and fees for requests from non-academic organizations will be determined on an individual basis. For-profit entities outside of an academic institution or healthcare system will not be permitted access to the data; a SAPCReN-CPCSSN analyst will conduct the analysis in-house pending approvals by all committees and the research ethics board.

Provision of SAPCReN-CPCSSN Data

Data are extracted twice per year (June 30 and December 31). Only de-identified CPCSSN data from southern Alberta will be released as per the variables specified. No original free text data will be released (unless under special permissions/approvals). Data extraction and preparation will be conducted by SAPCReN staff.

The project-specific dataset will be sent to the study analyst or project PI in an encrypted and password protected file via secure FTP server for analysis. This dataset must be stored in a secure (password-protected, encrypted) environment, ideally hosted on secure servers within a university or health system setting. Data will be provided once research ethics approval has been obtained and after receipt of data fees (if applicable).

Linking SAPCReN-CPCSSN Data and Administrative Data

Occasionally and for some cases, the SAPCReN-CPCSSN data can be linked to administrative data (i.e., DAD, NACRS, etc.). There are specific methodological processes and strict privacy and security protocols in place for data matching CPCSSN EMR data with administrative data; please contact us for more information.