

**SAPCReN Study Guidelines**

The Southern Alberta Primary Care Research Network (SAPCReN) is a network of over 300 primary care providers and university-based researchers who are interested in improving primary care practice through collaborative practice-based research. SAPCReN is part of the Canadian Primary Care Sentinel Surveillance Network (CPCSSN), the first and only pan-Canadian repository of anonymized 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 250,000 patients in southern Alberta, including diagnoses, prescribed medications, physical measurements, lab values, risk factors, and more.

* <http://alberta.cpcssn.ca/our-data>
* Detailed CPCSSN data dictionary: <http://cpcssn.ca/wp-content/uploads/2022/12/CPCSSN-Data-Dictionary-2022-Q2-for-external-researchers.pdf>

**Requests for SAPCReN-CPCSSN Data or Study Collaboration**

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)

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

1. The study must have a primary health care provider or researcher in a leadership role (principal investigator or co-investigator);
2. The study must be judged by the SAPCReN 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 itself is voluntary.

**Guide for Obtaining and Using SAPCReN Data**

**Project Intake Form**

Send a completed SAPCReN Project Request Form to info@sapcren.ca. You may access the project request form [here](https://static1.squarespace.com/static/50d4a39ce4b097d6748bb93a/t/5eab181d26ea3a49f13301fe/1588271134220/SAPCReN%2BProject%2BRequest%2Bv2.1%2B%28Apr%2B2020%29.pdf).

*\*Or copy and paste the URL below into your internet browser:* [*https://static1.squarespace.com/static/50d4a39ce4b097d6748bb93a/t/5eab181d26ea3a49f13301fe/1588271134220/SAPCReN+Project+Request+v2.1+%28Apr+2020%29.pdf*](https://static1.squarespace.com/static/50d4a39ce4b097d6748bb93a/t/5eab181d26ea3a49f13301fe/1588271134220/SAPCReN%2BProject%2BRequest%2Bv2.1%2B%28Apr%2B2020%29.pdf)

If you are unsure of the variables you require or the feasibility of SAPCReN-CPCSSN data for your project, please describe the factors you are hoping to measure and the SAPCReN team can assist you in identifying the appropriate variables.

**Approvals**

The project will be reviewed and approved by members of SAPCReN-CPCSSN and the Primary Care Provider Advisory Group, with final approval from the SAPCReN-CPCSSN Co-Directors.

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**

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.).

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| **Type** | **Cost** |
| SAPCReN-CPCSSN Sentinel with **funded** project | $1,000 |
| SAPCReN-CPCSSN Sentinel with **unfunded** project | $0 |
| External 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. Entities outside of an academic institution or healthcare system will not be permitted access to data; a SAPCReN-CPCSSN analyst will conduct the analysis in-house pending approvals by all committees and research ethics boards.

**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) location. SAPCReN data cannot be held by insecure (i.e., cloud-based) servers such as Dropbox or Google Drive.

Data will be provided once research ethics approval has been obtained and after receipt of data fees (if applicable).

**Linked SAPCReN-CPCSSN and administrative data**

In the future, use of linked EMR data from SAPCReN-CPCSSN to other data sources may be possible in some cases. There are strict privacy and security protocols in place for matching CPCSSN EMR data with administrative data; only qualified SAPCReN-CPCSSN analysts are able to access these datasets. Please contact SAPCReN-CPCSSN for more information.

**Questions**

If you have questions about applying to access SAPCReN-CPCSSN data or letter of intent (LOI), or if you require assistance in completing the SAPCReN Project Request Form, please contact info@sapcren.ca.