

## Navigation Guide to Primary Care Data Sources

### Background

This guide introduces Canadian data sources that can be used for secondary analyses to answer research questions relating to primary care. These data sources may come from administrative, government or clinical sources and include most of the population. Data may also come from specific research studies conducted with a sample of a population that is expected to be representative of the population (e.g. a Statistics Canada survey), or clinical data from a single health care setting, which is not expected to be representative beyond the setting.

### Types of research questions to answer with existing data

Secondary data analysis refers to the analysis of existing data collected by others. With respect to health research, the questions typically relate to health services research or epidemiologic research. Secondary data analysis is often used to examine health services questions regarding quality of health care, gaps in care and to evaluate associations between health care patterns and patient and system outcomes. Secondary data analysis is also commonly used for epidemiologic studies, for example, to describe trajectories of disease, etiology and prognosis.

### Where do data for secondary analysis come from in Canada?

In Canada, there are several sources of data including health and social administrative data, clinical data, population health surveys (e.g. through Statistics Canada), Vital statistics (e.g. date of birth, sex) and Canadian census. Administrative data originate mainly from billings of health care and other data sources used for administrative purposes in the health care system. Clinical data originate from medical records (e.g. EMR). Increasingly, research institutes in various provinces are linking together these data sources (e.g. [ICES](#), [Manitoba Centre for Health Policy](#)), which enables powerful analyses at a population scale.

### Data sources

Below are examples of existing data sources that have been created to be used for research and may be relevant for primary care researchers. These are examples that have been used by researchers in the Department of Family Medicine. This list is not exhaustive.

Source	Description	Type of data	Costs/fees	Website
Canadian Primary Care Sentinel Surveillance Network (CPCSSN)	Canadian family physicians who volunteer to participate in the network by contributing their practice EMR data	Clinical – EMR	Data fee (non-academic) \$5000 Access fee (3 users) \$2500	<a href="http://cpcssn.ca/">http://cpcssn.ca/</a>
Primary Care Ontario Practice Based Learning and Research Network (POPLAR)	Ontario family physicians who volunteer to participate in the network by contributing their practice EMR data	Clinical-EMR	TBD	<a href="https://www.poplarnetwork.ca">https://www.poplarnetwork.ca</a>
McMaster University Sentinel and Information Collaboration (CPCSSN-MUSIC)	Department of Family Medicine affiliated family physicians who volunteer to participate in the network by contributing their practice EMR data	Clinical - EMR	Cost recovery, varies	<a href="https://fammed.mcmaster.ca/research/research-projects-projects/music/">https://fammed.mcmaster.ca/research/research-projects-projects/music/</a>
ICES	Population-based health surveys, anonymous patient	Linked health administrative,	Based on analyst hours- varies,	<a href="https://www.ices.on.ca/">https://www.ices.on.ca/</a>

<i>Work with ICES analysts through a funded project</i>	records, clinical and administrative databases (e.g. OHIP, hospital discharges, Census, vital statistics)	clinical, survey and population demographic data for Ontario	typically \$10,000 minimum	See <a href="#">DFM Research Knowledge and Skill Builder ICES</a>  * ICES McMaster is the local hub
ICES Data and Analytic Services (DAS) <i>Work with data directly through ICES</i>	Researchers, students, policy makers or knowledge users who are affiliated with a publicly funded, not-for-profit organization and who want to obtain and analyze ICES data to answer a research question may submit a request to ICES DAS. DAS staff will contact the requestor to discuss the project's feasibility, timeline and cost. (fees will apply)		Based on analyst hours, varies.  Questions posed by a health system decision-maker may qualify for internal support	<a href="https://www.ices.on.ca/DAS">https://www.ices.on.ca/DAS</a>
CFPC Family Medicine Longitudinal Survey	Longitudinal survey of Canadian family medicine residents and early-career family physicians	Perceptions of family medicine, preparedness to practice, practice intentions and choices	None currently	<a href="https://www.cfpc.ca/CFPC/media/Resources/Education/AFM-OTP-Summary3-Prepared-Practice.pdf">https://www.cfpc.ca/CFPC/media/Resources/Education/AFM-OTP-Summary3-Prepared-Practice.pdf</a>  Data sources on work of Family Medicine in Canada
Canadian Longitudinal Study on Aging	Canadian Longitudinal Study on Aging (CLSA) is a large, national, long-term study that will follow approximately 50,000 individuals who are between the ages of 45 and 85 when recruited, for at least 20 years.	The CLSA will collect information on the changing biological, medical, psychological, social, lifestyle and economic aspects of people's lives.	\$3000 for researchers  Waiver of fee for graduate students and post-doctoral fellows for sole purpose of thesis/post-doc project	<a href="https://www.clsa-elcv.ca/">https://www.clsa-elcv.ca/</a>

### Data Accessibility

The above data sources require data access requests or arrangements to work with the institute to analyze data. There may be costs involved. See websites for further details.

### Research ethics approval for research using existing data

Research ethics approval is required for research using existing data. For Faculty of Health Sciences, the Hamilton Integrated Research Ethics Board ([HiREB](#)) reviews research. If a study is based entirely on secondary analysis of existing data, researchers can use the “*Retrospective Review of Medical Charts & Health Data*” application. This version of the ethics application is tailored to studies using existing data when no new data collection is being undertaken. These applications are reviewed upon receipt and do not need to be submitted for the core HiREB meeting deadlines. Lead investigators, co-investigators and staff who will have access to the data are required to complete a privacy tutorial and obtain a certificate prior to HiREB submission.

### Linking Primary Study Data to Existing Data

Many primary care researchers wish to use health administrative data to measure outcomes of programs or interventions in specific primary care settings. It is possible, through data sharing agreements and with consent, to identify health care settings and patients for linkage to administrative data. This should be planned with the relevant organization before the study begins. This type of study would require full ethics board approval.