

The Vision for a SPOR Canadian Data Platform

Our vision is to develop a distributed network that facilitates and accelerates multi-jurisdictional research. Many of the elements required for a world-class health data platform already exist in Canada, but they operate within jurisdictional boundaries rather than spanning across them. Connecting Canadian centres of excellence that already work with data covering the entire population is the key to unlocking the potential of our country's unique data assets and expertise. In line with the SPOR vision, the Canadian Data Platform will create new capabilities and a single access portal connecting provincial and pan-Canadian data, including longitudinal data that in some cases goes back 20 years or more. This platform will revolutionize our sector by enabling investigators to conduct multi-jurisdictional, person-focused research more efficiently. It will allow us to address the most pressing health research challenges facing the public and policy-makers, and build Canada's international leadership in the health field, including patient-oriented research.

The main barrier to achieving this pan-Canadian vision is not inadequate technology or computing power. Rather, it is a lack of dedicated resources and the necessary policy and governance coordination across jurisdictions. We will achieve our vision by: *engaging* public, patients and Indigenous communities and SPOR groups on priorities; *leveraging* existing assets, including infrastructure, data, and human and technical capacity; *modernizing* and *harmonizing* the policy and governance environment; *expanding* local, national and international relationships; *honouring* our distributed network with respect to jurisdictional responsibilities for delivery of health and social care; applying *scientific rigour* to all the work we do; *embracing* technologies that support efficient, sustainable and adaptable digital infrastructure; *enabling* future-focused technology and innovative data to support advanced research; *ensuring* the relevance of what we build to SPOR groups and to the broader research community and policy-makers; and maintaining *flexibility* in our approach, continuing to seek out new collaborations that maximize the impact of the data infrastructure.

Overview of the Challenge

The diversity of Canada's health systems and policies offers fertile ground for natural experiments, comparative analysis, and sharing of best practices. Investments over the last 25 years, measured in hundreds of millions of dollars, have created provincial centres with rich health and social data, national health surveys and more recently, clinical and other data. These resources support decision-making across the country and generate internationally-recognized research. Canada's provincial and national data centres are well-positioned as the building blocks of a world-class platform that will support evidence-informed clinical, managerial, and policy decisions. The platform

To ensure that Canadians continue to have access to high-quality health care, and benefit from effective health policies, the country's health researchers and system innovators need to make effective use of health and health-related data, including administrative health and social data. This need will increase in the future as technology continues to develop and digitized data such as EHRs [electronic health records] become ever more abundant. | Council of Canadian Academies report on timely access to health and social data, 2015

The vision of the [Strategy for Patient-Oriented Research (SPOR)] is that Canada will demonstrably improve health outcomes and enhance the health care experience for patients through the integration of evidence at all levels of the health care system. | CIHR Request for Proposals for SPOR National Data Platform, 2017



itself will be an essential component of local and pan-Canadian learning health systems, systems which use data in the process of research and evaluation for purposes of continuous improvement.

While much progress has been made within individual provinces and territories, challenges with comparability and timely access to data between jurisdictions remain. With the exception of standardized and enriched administrative datasets and surveys managed nationally by the Canadian Institute for Health Information (CIHI) and Statistics Canada (StatCan), data are often not comparable from one province or territory to another, or cannot be shared across boundaries due to legislation or other barriers, thereby limiting current use to single-jurisdiction studies. As a recent report by the Council of Canadian Academies highlighted, jurisdictional considerations affect the quality, scope, and impact of possible research. It is often neither efficient nor feasible for individual research teams to stitch together study-specific datasets spanning more than one jurisdiction for a single project.

Other countries, such as the UK and Australia, are investing in the creation of data holdings that rival or surpass Canada's currently disconnected health data assets. Historically, Canada enjoyed a research advantage because of the unique characteristics of our health systems (universal coverage with large provincial/territorial funders responsible for the delivery of many health services) coupled with independent investments in data and analytic capacity in many jurisdictions. We now have an opportunity to move Canada to the forefront in the areas of national data linkage, access, and use. Working collaboratively, we can bring together our strongest data centres and other assets to catalyze analysis and discovery essential for high-performing learning health systems.

The Response

Recognizing this challenge, centres of excellence and SPOR data platforms across Canada began working together in 2015 as the **Pan-Canadian Real-world Health Data Network (PRHDN)**. The PRHDN includes groups in every province, one territory (discussions are underway with the other two as they develop their SUPPORT Units), all SPOR SUPPORT Unit data platforms, CIHI and StatCan.

While the specifics vary by jurisdiction, the common characteristics of many PRHDN organizations are that they serve as responsible stewards and/or custodians of health and health-related data, and have mandates focused on turning data into knowledge by enabling authorized access. Our team includes data stewards, clinicians, decision-makers, patients, and researchers who are recognized as international leaders in data systems, access governance and engagement.

Our team's previous work and more recent consultations identified **seven major strategic objectives** for the SPOR Canadian Data Platform. These objectives map to each core function outlined in the funding call, respond to the priorities identified through our SPOR consultations, and reflect the need for sustainability of this investment. Together, they will provide immediate assistance to users, help build the reusable infrastructure that will be of value for a broad range of future research, and mobilize the communities that will be our partners in this work:

Obj. 1 | Create a data access support system that helps navigate multi-jurisdiction requests and enables PRHDN organizations to learn from each other (*Core function: Data Access Services*);

Obj. 2 | Harmonize and validate definitions for important chronic diseases and other key analytic variables to facilitate multi-jurisdictional population health, health services and clinical research studies (*Core function: Data Harmonization and Standardization*);

Obj. 3 | Continue to expand the sources and types of data and linkages available through PRHDN organizations, including linkage to clinical and social data (*Core function: Data Linkages, and requirement to expand linkages to clinical and social data*);



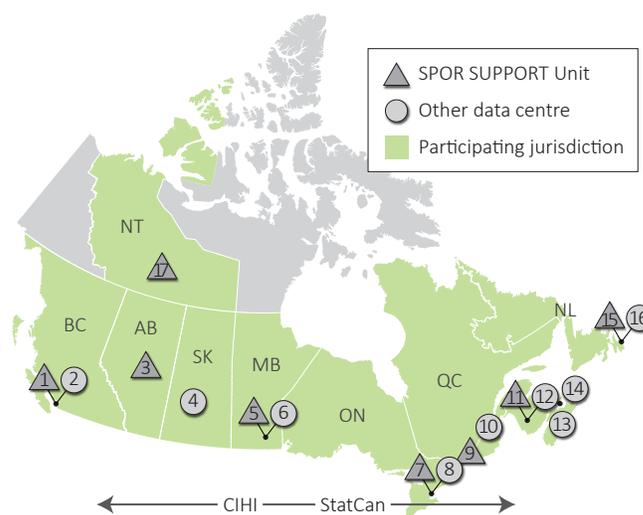
Obj. 4 | Develop the technology infrastructure required to improve the data access request process as well as the documentation, storage, and re-use of algorithms and existing data
(Ensuring efficiency and sustainability);

Obj. 5 | Create supports for advanced analytics and infrastructure for data collection and analysis
(Responding to priorities identified in SPOR consultations);

Obj. 6 | Establish strong partnerships with patients and the public and with Indigenous communities
(Core functions: Patient Engagement and Indigenous Health Data Support and Linkage); and

Obj. 7 | Build strong governance and enable national coordination
(Core functions: Governance and National Coordination).

As an established network with pre-existing and unrivalled pan-Canadian data assets, clear methods of working together, effective processes for decision making, and strong governance, PRHDN is uniquely positioned in Canada to lead this initiative. As a collective, PRHDN can achieve what is not possible through individual organizations. **By building on existing capacity, the investment in the SPOR Canadian Data Platform will be transformational.**



Map #	PRHDN Lead	Role	Primary Host Institution
1, 2	Kim McGrail	Nominated Principal Applicant	Population Data BC, University of British Columbia
7, 8	Michael Schull	Principal Applicant	Institute for Clinical Evaluative Sciences
6	Alan Katz	Principal Applicant	Manitoba Centre for Health Policy, University of Manitoba
11, 12	Ted McDonald	Principal Applicant	Maritime SPOR SUPPORT Unit, NB Institute for Research, Data & Training
CIHI	Brent Diverty	Principal Applicant	Canadian Institute for Health Information
9	Jean-Francois Ethier	Principal Applicant	Québec SPOR Support Unit
	Jennifer Walker	Principal Applicant	CRC in Indigenous Research, Laurentian University
	Heather Davidson	Principal Knowledge User	Assistant Deputy Minister of Health, British Columbia
9	Frank Gavin	Principal Knowledge User	CHILD-BRIGHT SPOR Network, ON SPOR SUPPORT Unit
	Alain Vanasse	Co-Applicant	Québec SPOR Support Unit
16	Don MacDonald	Co-Applicant	Newfoundland & Labrador Centre for Health Information
4	Tracey Sherin	Co-Applicant	Saskatchewan Health Quality Council
3	Finlay McAlister	Co-Applicant	Alberta SPOR Support Unit
5	Lisa Lix	Co-Applicant	George & Fay Yee Centre for Healthcare Innovation, University of Manitoba
STC	Lynn Barr-Telford	Co-Applicant	Statistics Canada
10	Denis Roy	Co-Applicant	Institut National D'excellence en Santé et Services Sociaux
13	Sam Stewart	Co-Applicant	Health Data Nova Scotia, Dalhousie University
15	Laurie Twells	Co-Applicant	Newfoundland & Labrador SUPPORT Unit
14	Michelle Patterson	Co-Applicant	Secure Island Data Repository, University of Prince Edward Island
8	Alison Paprica	Co-Applicant	Institute for Clinical Evaluative Sciences
	17	Stephanie Irlbacher-Fox	Co-Applicant
8	Isabel Fortier	Co-Applicant	Maelstrom Research, McGill University
	Charles Victor	Collaborator	Institute for Clinical Evaluative Sciences
CIHI	Juliana Wu	Collaborator	Canadian Institute for Health Information
6	Mark Smith	Collaborator	Manitoba Centre for Health Policy, University of Manitoba
STC	Donna Dosman	Collaborator	Statistics Canada
	Mary-Ann MacSwain	Collaborator	Centre for Community Health Research, University of Prince Edward Island