

SPOR (Strategy for Patient-Oriented Research) National Data Platform

National Data Services Framework Summit

Alison Bourgon
A/Director General, Science Policy

January 24, 2019

CIHR Health Research and Health-Related Data Framework

VISION

Health research and health-related data in Canada are effectively *accessed, analyzed, linked, integrated, used, reused, stored* and *preserved* to advance knowledge, expand research opportunities, and improve health services, products and outcomes.

Data Framework Strategic Outcomes

1

COLLECTIVE DATA
CULTURE IS
FOSTERED

2

DATA ACCESS,
LINKAGE, USE &
REUSE IS
ENABLED

3

DATA-RELATED
SKILLS ARE
EXPANDED

4

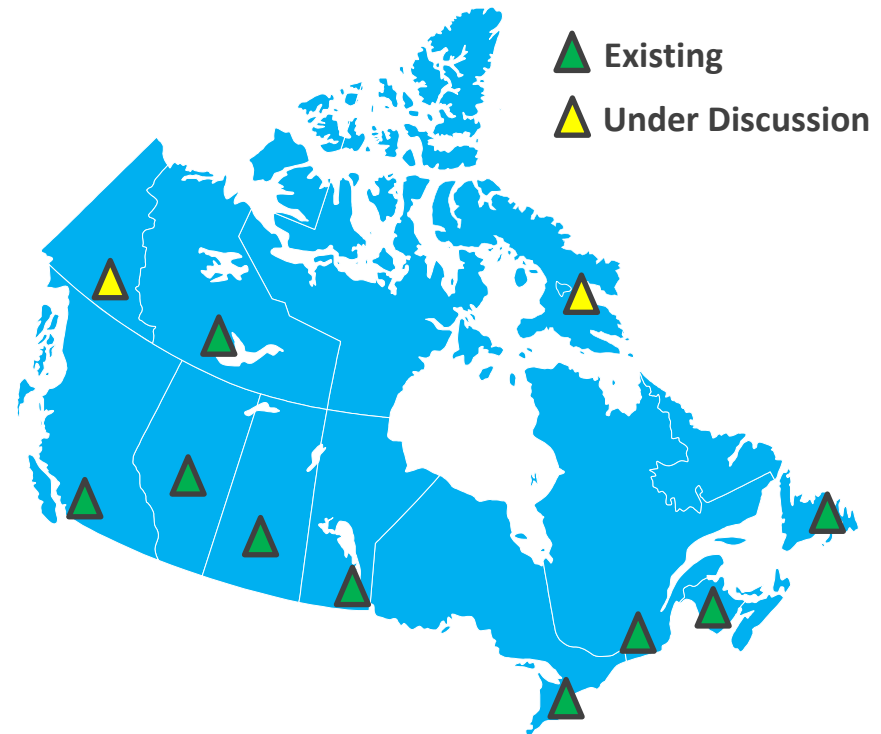
DATA-RELATED
RESOURCES ARE
AVAILABLE

CIHR's Strategy for Patient-Oriented Research (SPOR)

SPOR Objective: Deliver high quality care in Canada by embedding patient-oriented research approaches throughout the research continuum.

SUPPORT Units

- Specialized research service centers funded through SPOR strategy.
- Facilitate local data access.
- Nine currently funded and two more under discussion.



Strategy for Patient-Oriented Research

SPOR

Putting Patients First

Stratégie de recherche axée sur le patient

SRAP

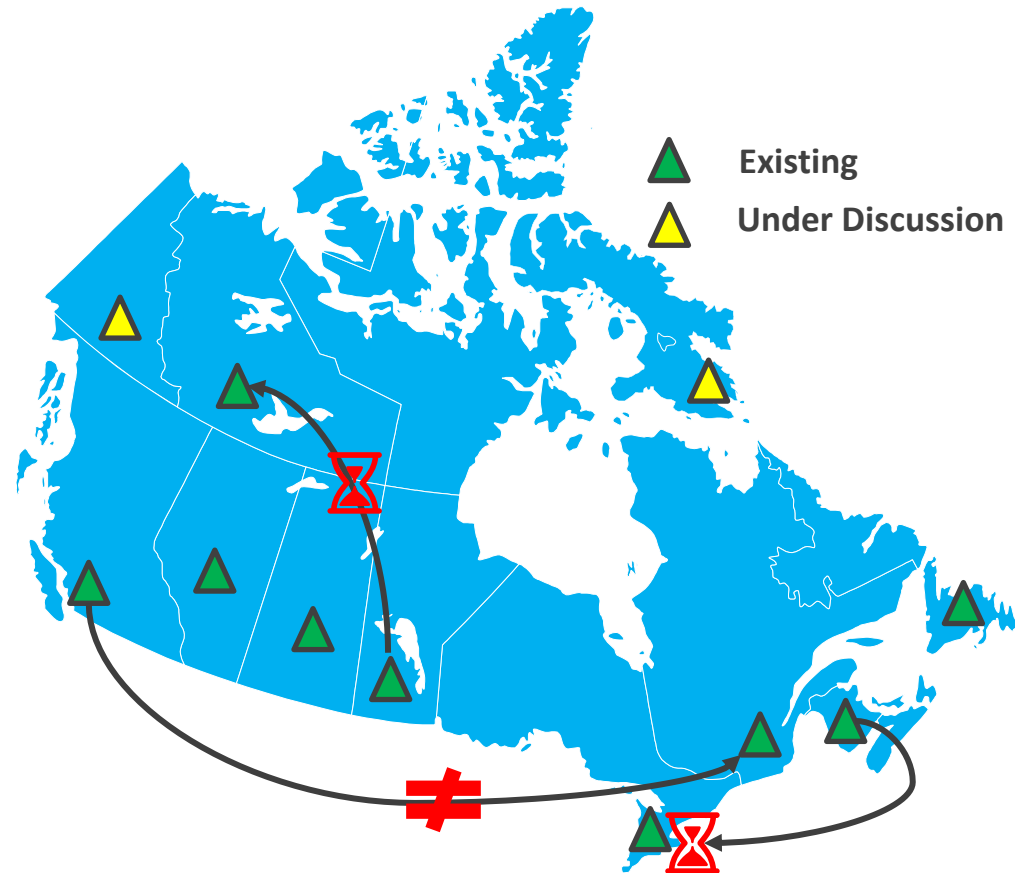
Le patient d'abord

The Challenge: Connecting Canada's Health Research Data Centers

Investments over the last few decades have created provincial centers with high quality health and social data, national health surveys and clinical and other data.

Challenges to cross-jurisdictional studies:

- Data often not comparable.
- Significant delays for data requests
- Legislative and privacy barriers



SPOR National Data Platform

Funding Opportunity Details

- One grant
- Up to \$39,000,000
- Term of up to 7 years

Strategy for Patient-Oriented Research

SPOR

Putting Patients First

Stratégie de recherche axée sur le patient

SRAP

Le patient d'abord

Implementation
of SPOR

2011



First SPOR
SUPPORT Unit
Launched
(Alberta)

Feb 2013



SPOR National Data
Platform
Competition
Launch

December 2017



Application
Deadline

June 2018



Formal
Ministerial
Announcement

Winter/Spring
2019



SPOR National Data Platform: Objectives



Data Access Services



Data Harmonization,
Standardization and
Linkages



Patient Engagement



Indigenous Health
Data Support and
Linkage



National Coordination



Governance

SPOR National Data Platform: Objectives



Data Access Services

- Establish single portal for multi-jurisdictional research.



Data Harmonization, Standardization and Linkages

- Create a system to identify, and link clinical data to population-based administrative and social data.



Patient Engagement

- Integrate patients into governance structure and engage patients throughout core business functions.

SPOR National Data Platform: Objectives



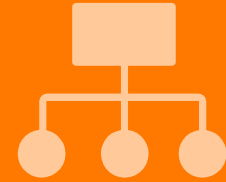
Indigenous Health Data Support and Linkage

- Work alongside Canada's Indigenous communities to enable research that incorporates their unique experiences, needs and values.



National Coordination

- Play an important coordination function for the cross jurisdictional data-related efforts of all regional SUPPORT Units.



Governance

- Develop governance that integrates all individuals crucial for addressing barriers in using multi-jurisdictional data for research.

Successful Applicant: The Pan-Canadian Real-World Health Data Network (PRHDN)

VISION: To develop a distributed network that facilitates and accelerates multi-jurisdictional research across Canada



Pan-Canadian Stakeholder Collaboration

- Statistics Canada, CIHI, Population Data BC
- All 10 provincial and the Northwest Territories' SUPPORT Units (with discussions underway in Yukon and Nunavut)



Diverse Expertise in Research Data Management

- Data linkage, quality, algorithm development, and security
- Public and patient engagement
- Experience working with provincial health ministries

Successful Applicant: The Pan-Canadian Real-World Health Data Network (PRHDN)

VISION: To develop a distributed network that facilitates and accelerates multi-jurisdictional research across Canada

Strategic Objectives



- Respond to core functions outlined in funding call
- Using FAIR principles to guide
- Develop advanced support for research (eg. distributed analysis)



Next Steps

- Ministerial announcement expected winter/early Spring 2019
- Early priorities include algorithm development and creating a data access support hub



CIHR IRSC

Canadian Institutes of Health Research
Instituts de recherche en santé du Canada



For more information on the PRHDN:

Contact kim.mcgrail@ubc.ca

For more information on health research data at CIHR:

Contact Amanda.Crupi@cihr-irsc.gc.ca or

ResearchData-Donneesderecherche@cihr-irsc.gc.ca

