

SPOR Canadian Data Platform

Plateforme de données canadiennes de la SRAP

Invitational webinar for SPOR funded entities

April 17 and 23, 2019

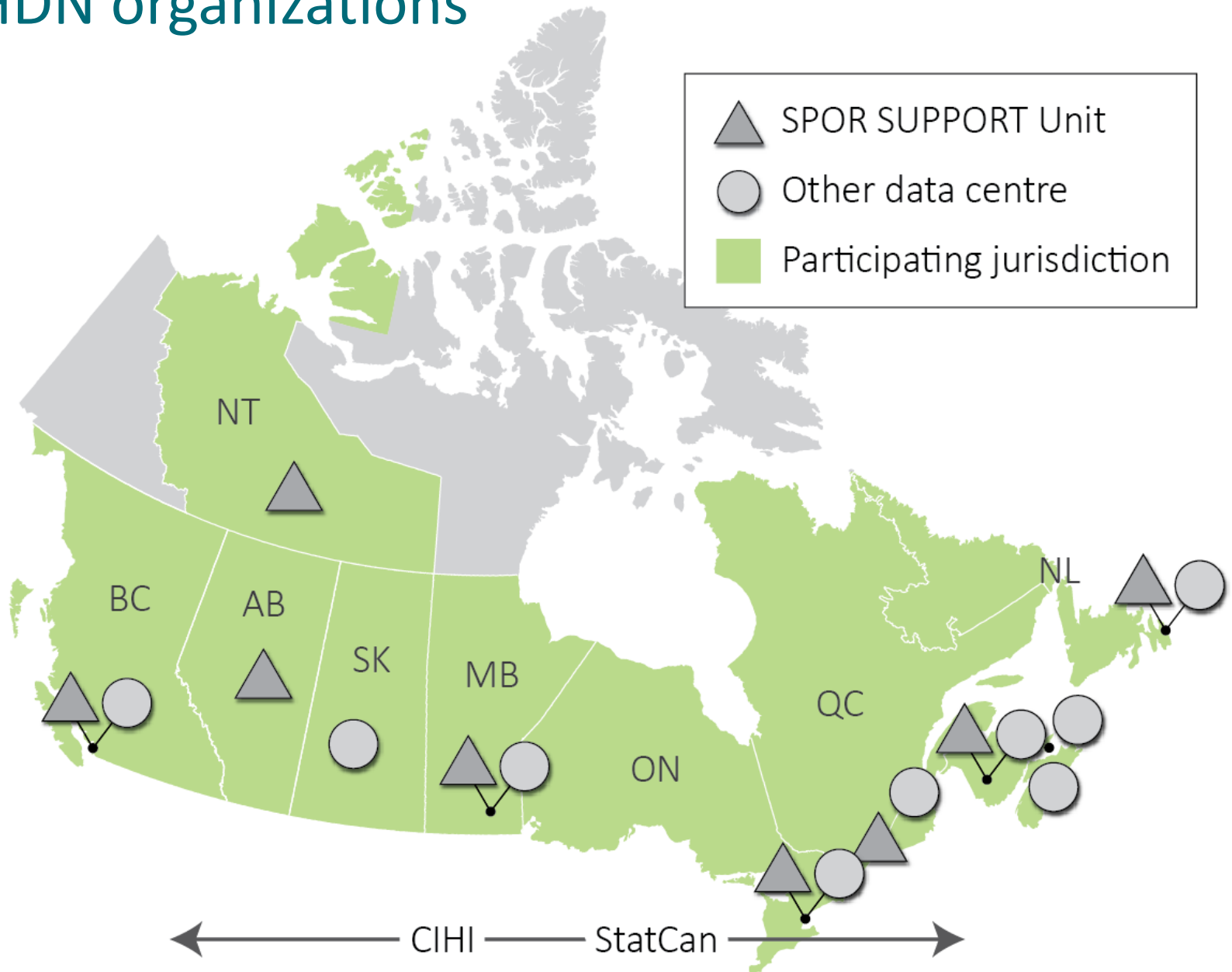


Agenda

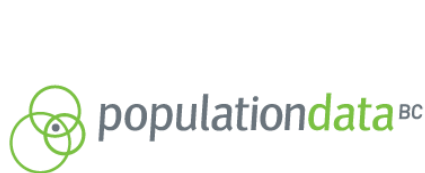
1. Welcome (5 min)
2. SCDP vision and starting points (10 min)
3. Planned governance structure and engagement with SPOR partners (10 min)
4. Updates from working groups
 - Data Access Support Hub (DASH) (10 min)
 - Algorithms and harmonized data (10 min)
5. Roundtable with SPOR partners on priority service needs from SCDP and/or questions (35 min)
6. Summary and next steps (10 min)

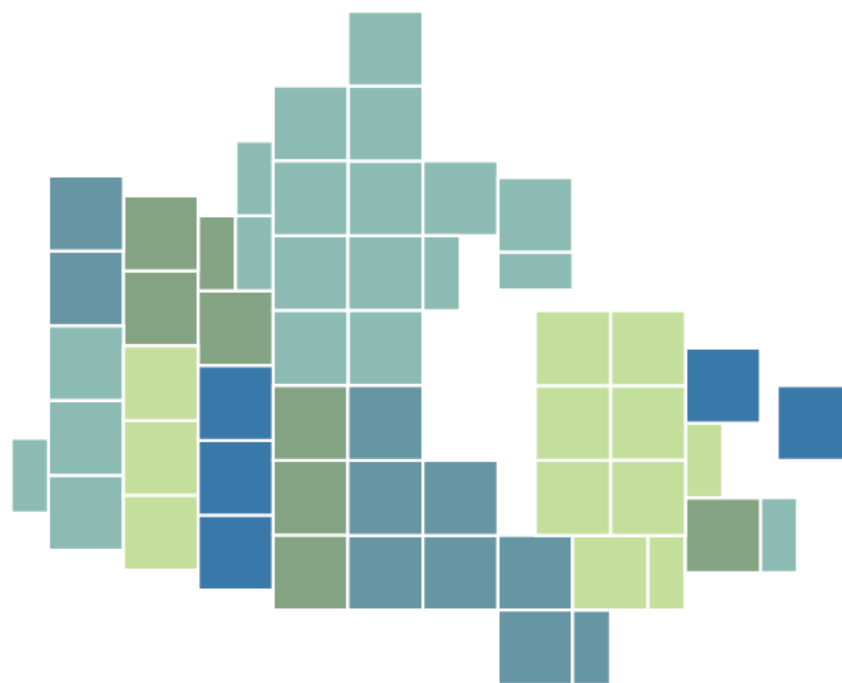


PRHDN organizations



PRHDN organizations





SPOR Canadian Data Platform
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Our vision

A distributed network that
facilitates and accelerates
multi-jurisdictional research



Our objectives

- Create a **data access support system** that helps navigate multi-jurisdiction requests
- **Harmonize and validate definitions** for important chronic diseases and other key analytic variables
- Continue to expand the sources and types of **data and linkages** available through PRHDN organizations, including linkage to clinical and social data
- 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
- Create **supports for advanced analytics** and infrastructure for data collection and analysis
- Establish strong **partnerships** with patients and the public and with Indigenous communities
- Build **strong governance** and enable **national coordination**



Our starting points



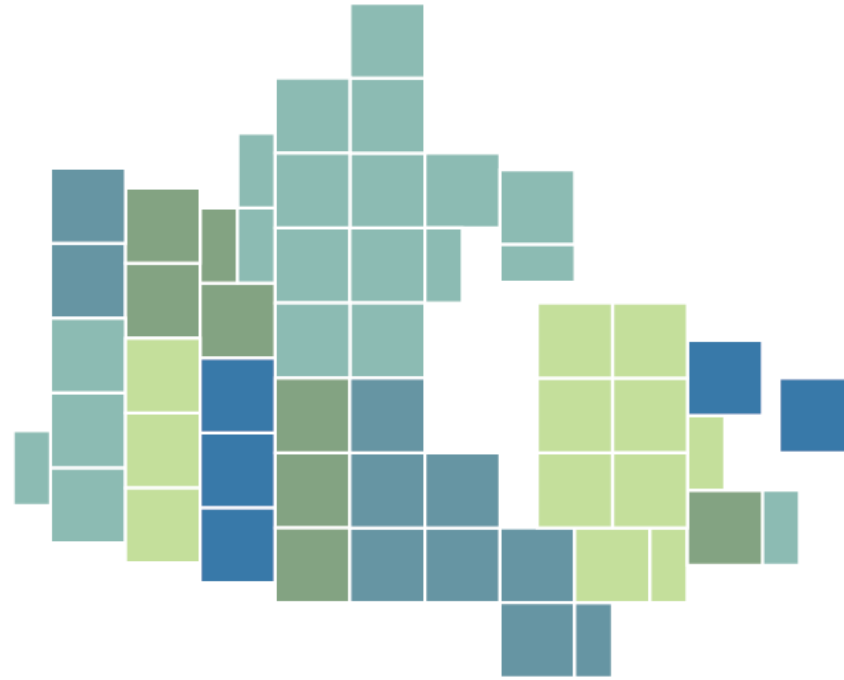
We have a **strong starting point** – and need to **close the gap**



Our starting points

- Distributed network with distributed funding
- Respect for local context and policy environment
- Leverage and share wherever possible
- Openness to ideas, input and opportunities





Governance & engagement

Governance and engagement

*“A good portion of what we refer to when talking about governance is how we will work together and make decisions, and how we will ensure **ongoing input from groups who can highlight priorities for further development.**”*

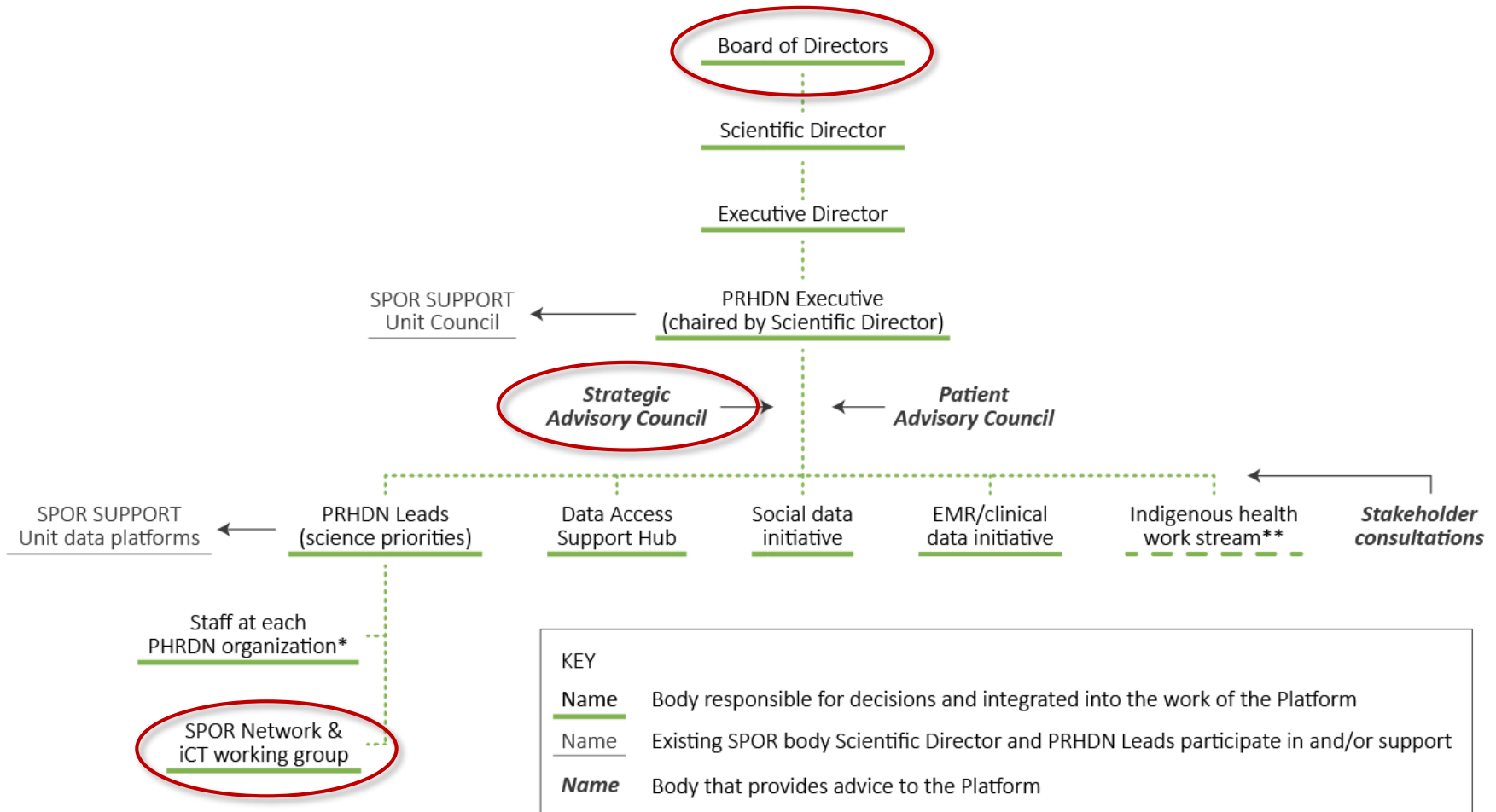
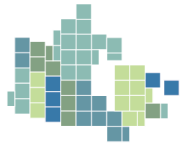


How will we manage requests from SPOR entities?

- Prioritize data and analytic requests originating from SPOR entities (SUPPORT Units, Networks, ICTs and Chairs)
 - Establish a process and framework to manage requests from the SPOR SUPPORT Units, SPOR Networks, and ICT groups
 - Access to multi-jurisdictional data
 - Single portal for requests: [Data Access Support Hub](#) (DASH)
 - The development of harmonized definitions and algorithms will proceed with consideration of the health conditions that SPOR entities are focused on
- Regular communication tailored specifically to SPOR entities (webinars, surveys etc)
- Establishment of a [governance/advisory structure](#) whereby the priority and information needs from the SPOR entities can be tabled and discussed, and input can be provided into the direction and decisions of the SPOR Canadian Data Platform (SCDP)
 - Membership in standing working group that reports into SCDP governance structure



Governance/advisory structure



* FTEs at each site report to the lead at the organizational home but may also have accountability to initiatives outside their operational home.

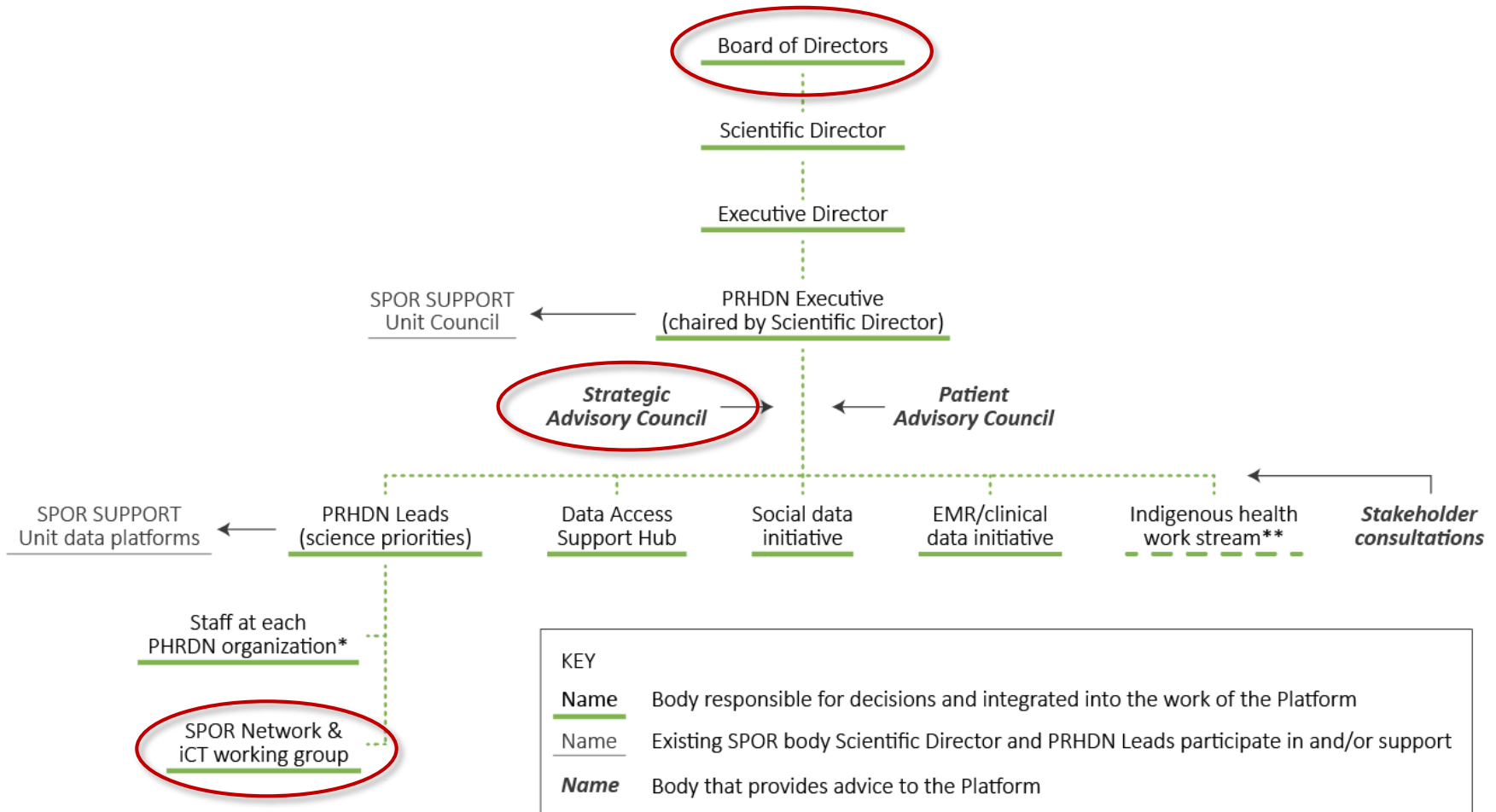
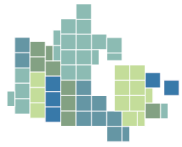
** Will have its own governance and design with services and supports from the rest of the Platform.

Interim advisory board

- To guide us through start-up and establishment of a permanent Board
- This group will provide strategic advice and oversight of development and implementation.
- Cathy Fooks (Interim Board Chair)
Chris Power
Guy Bujold



Governance/advisory structure



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** Will have its own governance and design with services and supports from the rest of the Platform.

Governance structure

Strategic Advisory Council

- Representatives of SPOR entities, the EMR/clinical and social data initiatives, the Public and Patient Advisory Committee
- Provide strategic advice on development priorities, ranging from algorithm topics to desired supports for innovative research
- Elevate discussion to strategic context

SPOR Network & ICT working group

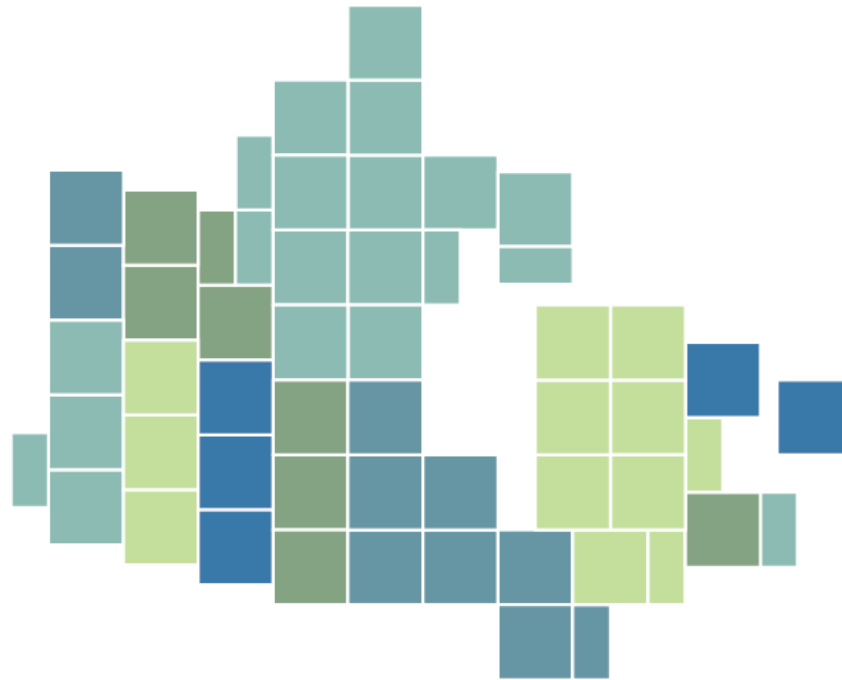
- Includes leads from SPOR Networks, ICTs and Chairs
- Key driver of collective needs and priorities
- PRHDN Executive will provide regular, timely updates to this group on current development timelines and operational reporting
- Report up to PRHDN leads and Exec; meet twice per year; and ad hoc



Other areas for collaboration and discussion

- Opportunities for collaboration/leveraging of public and patient engagement activities of SCDP and SPOR entities
- Sharing of information on the work of SCDP and SPOR entities with Indigenous organizations and communities
- Collaboration on funding opportunities





Data Access Support Hub (DASH)

What is the Data Access SUPPORT Hub (DASH)?

- The **DASH** will provide a single intake process for requests for multi-jurisdictional data from SPOR entities
- **DASH** services will be provided by a multi-centre coordination team led by CIHI
- **DASH** services, starting in the first year of the grant, will include:
 - Central intake of requests
 - Coordinated feasibility assessment and specifications consultation process
 - Resources on SCDP website to articulate availability and process for accessing existing provincial and pan-Canadian data assets
 - Development of inventory of local data access processes to facilitate the development of harmonized approach across provincial data centres



DASH Coordination Team membership

Province	Organization	Name	
NL	NL Centre for Health information (NLCHI)	Donna Roche	Manager, Health Analytics and Evaluation
PE	Centre for Health and Community Research, U of PEI	Mary-Ann MacSwain	Research Manager
NS	Health Data NS	Lindsay Stewart	Manager
NB	NB Institute for Research, Data and Training	Melanie Buyting	Data planning & development coordinator
NB	NB Institute for Research, Data and Training	Jennifer Moorcraft, Lindsey Gilbert	Project application coordinator
NB	NB Institute for Research, Data and Training	Donna Curtis Maillet	Privacy officer
QC	Quebec SPOR SUPPORT Unit	Mark McGilchrist	Senior Research Fellow
ON	Institute for Clinical Evaluative Sciences (ICES)	Charles Victor	Senior Director, Strategic Partnerships and External Services
MB	MB Centre for Health Policy (MCHP)	Charles Burchill	Associate Director, Data Access and Use
SK	SK Health Quality Council	Tracey Sherin	Director, Data Analysis & Research Partnerships
AB	AB SPOR SUPPORT Unit	Jeff Bakal	Program Director, Research Data Services
AB	AB SPOR SUPPORT Unit	Erik Youngson	Lead, Health Research Methods and Analytics
BC	Population Data BC	Tim Choi	Lead, Data Access
BC	Population Data BC	Jessica Galo	Coordinator, Data Access
BC	Population Data BC	Jim Mintha	Systems and security manager
NWT	NWT SPOR SUPPORT Unit	Jullian McLean	Data Project Director
CAN	Statistics Canada	Tina Hotton	Regional Manager, Research Data Centres Network
CAN	Canadian Institute for Health Information	Brent Diverty	Vice President, Programs
CAN	Canadian Institute for Health Information	Juliana Wu	Manager, Data Request Program

Algorithm & Data Harmonization

Leads: Lisa Lix, Mark Smith (MCHP)

Focus:

- Inventory of population-based provincial/territorial and pan-Canadian databases
- Assessment of existing validated pan-Canadian measures of population health, health service use, and determinants of health
- Development of algorithms/ case definitions that can be shared across jurisdictions

DASH Coordination

Leads: Brent Diverty, Juliana Wu (CIHI)

Focus:

- Convening of DASH coordination team
- Establishment of central intake approach and processes for coordinated response
- Establishment of single access point via website
- Operationalization of DASH
- Development of inventory of jurisdictional data access policies and procedures to inform harmonization



DASH Coordinating Team activities (April 2019 – March 2020)

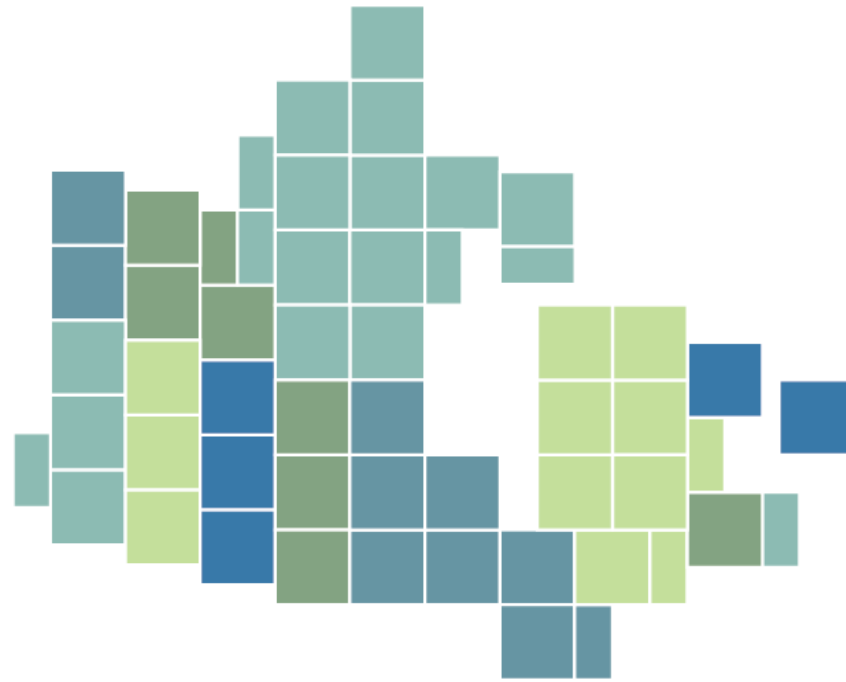
1. Define and operationalize DASH coordinated processes

- Central intake inquiry form and information page available on the SCDP website
- High level process for responding to multi-jurisdictional data requests defined and implemented
- Ongoing refinement of coordinated intake process – “learn as we go”

2. Commence access process harmonization work

- Develop inventory of local data access processes (forms, tracking systems, metadata, policies, research agreements, provincial initiatives, etc.)
- Inventory will inform gaps, opportunities, and prioritization toward process harmonization (“low hanging fruits”, “pain points”)
- Early focus areas may include templates (many existing), ethics (e.g. inventory of REB contacts by jurisdiction; template language across REBs within jurisdiction), metadata





Algorithms and Harmonized Data Working Group

Initial goals

- Develop an inventory of population-based provincial/territorial and pan-Canadian electronic databases
- Conduct an assessment of existing pan-Canadian measures of population health, health service use, and determinants of health that have been developed for population-based electronic databases and validated



Longer-term goals

- Establish a process for validating case definitions across multiple jurisdictions
- Develop algorithms and case definitions to be shared across jurisdictions
- Develop a common data model and enable data harmonization



Expertise of the working group to achieve its goals

- Connections to SPOR SUPPORT Units and Data Centres (e.g., MCHP) across multiple provinces
- Working with Canadian Network of Observational Drug Effect Studies (CNODES) on Common Data Model
- Cutting-edge skills in data documentation
- Current work with Public Health Agency of Canada for cross-provincial validation of case definitions



Algorithms – Prioritization for development and validation

- Results from survey of members of PRHDN in 2016
 - Algorithms that would be most useful to you and that would most benefit your research:
 - Mental health
 - Cardiovascular disease
 - Diabetes
 - Respiratory disease

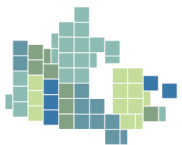
Other areas for algorithm/measurement development

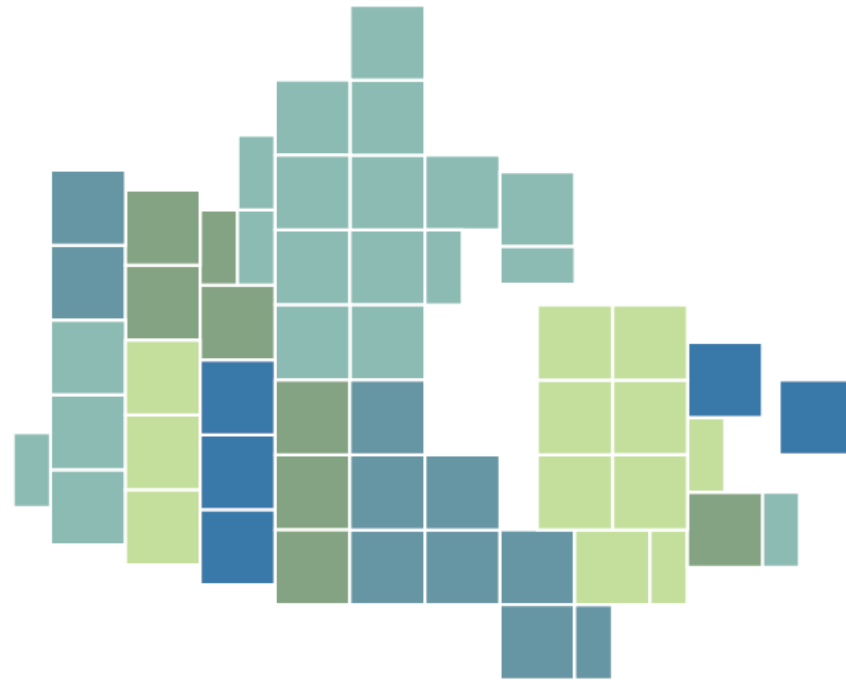
- High user of the healthcare system
- Having a family physician
- Priorities: comparisons across provinces



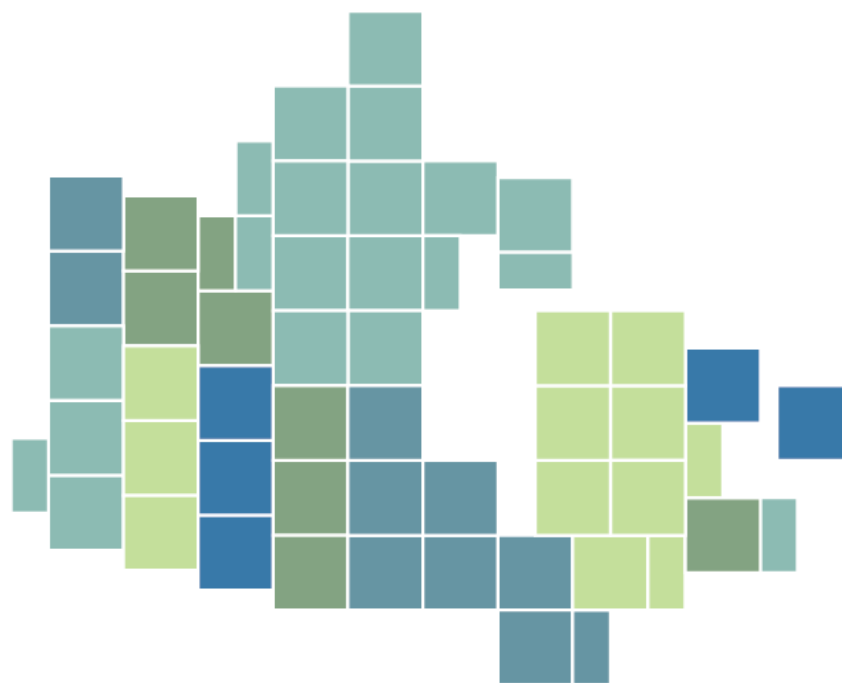
Activities in progress

- Trialing a standardized tool for collecting meta-data about administrative health databases across multiple provinces
- Compiling an inventory of existing algorithms
- Public Health Agency of Canada's Canadian Chronic Disease Surveillance System
- Cross-provincial research studies
- Building connections with Working Groups to share plans, identify common activities and challenges, and explore opportunities for future research
 - DASH
 - Technology





Roundtable – Questions? Comments?



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