BC SUPPORT Unit

Advancing patient-oriented research

UNIT OVERVIEW

The BC SUPPORT Unit is in the final stages of transitioning from start-up phase to regular operations. The Unit will be offering initial services in November 2016 through the provincial hub with a focus on members of research teams who are applying to SPOR competitions.

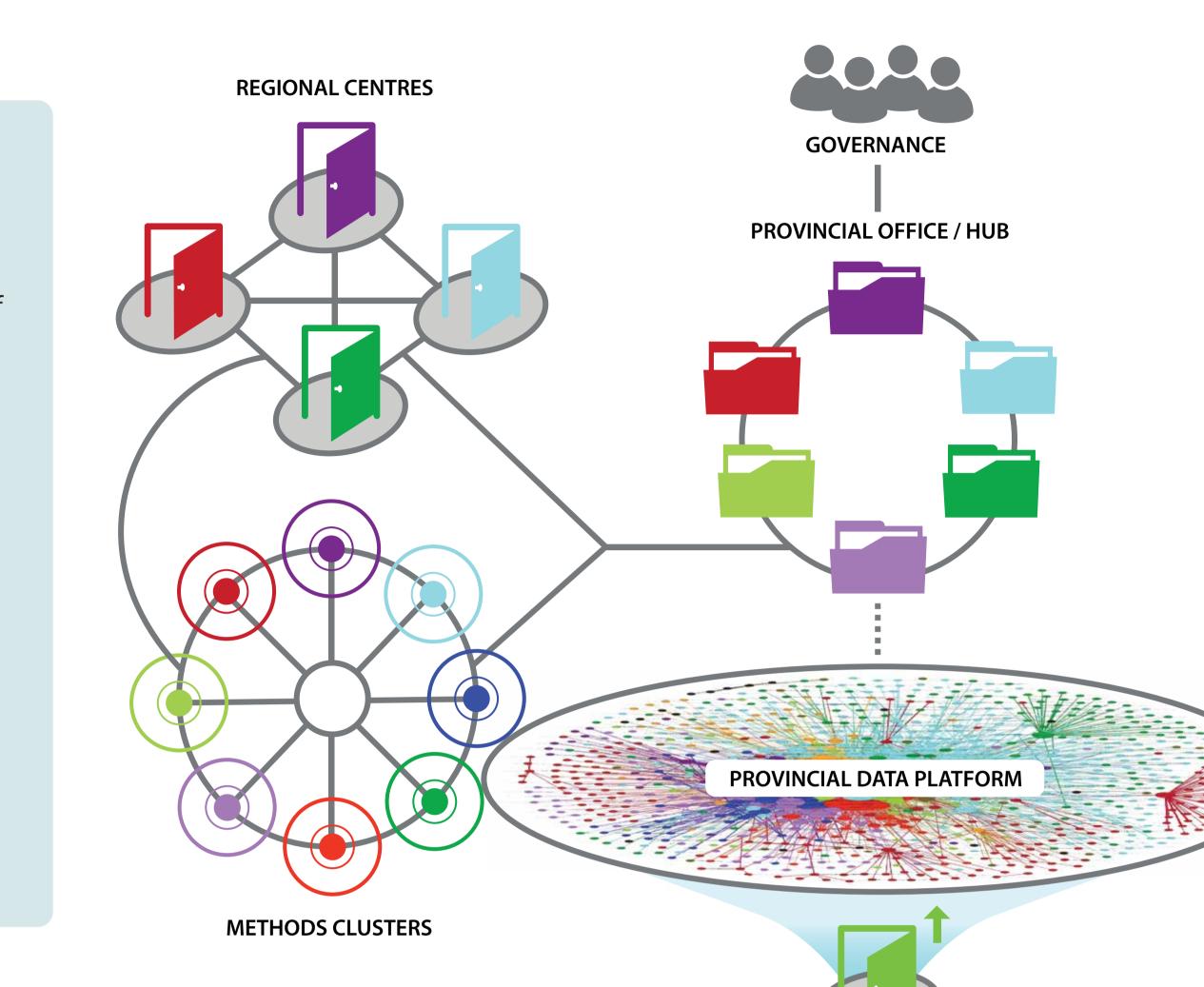
Recent milestones

- March: CIHR/BC SUPPORT Unit grant agreement signed
- June: Scientific Director joins the Unit
- September: Submission of operations plan to CIHR; Executive Director joins the Unit

Greater context

The Unit is part of the developing BC Academic Health Science Network with the network's board providing governance and oversight.

The Unit's implementation is supported by the multi-sector BC health research strategy initiated in 2012 to shape a more comprehensive, coordinated and systems-oriented approach to health research in BC.



METHODS CLUSTERS

Communities of methodology practice, expertise and support, with each cluster focusing on a specific research

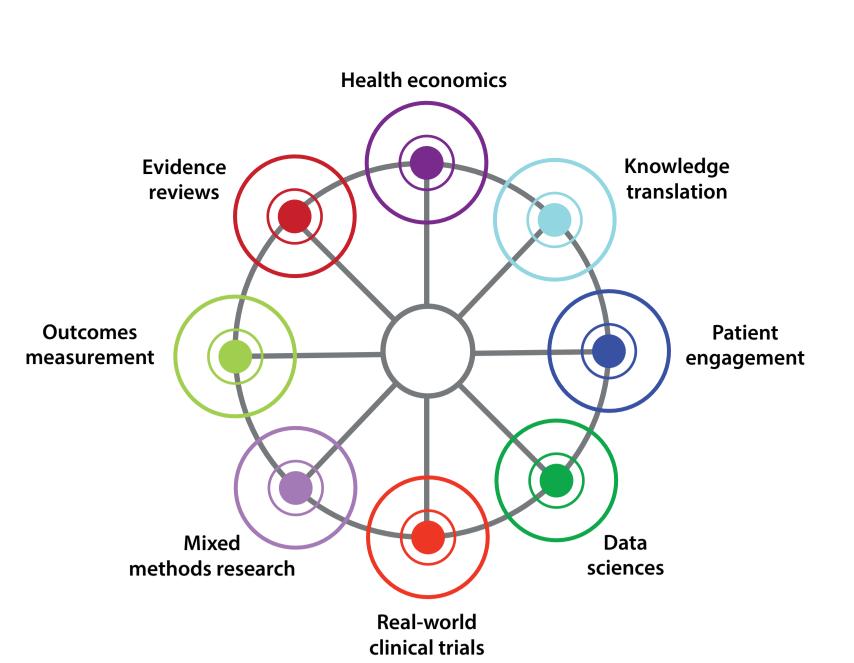
Through fostering existing or emerging communities of methodology practice, the Unit's methods clusters will pordinate a province-wide effort in methods development and support, related to patient-oriented research.

Primary objectives of each cluster

- 1. Methods development and application: To foster methodological knowledge, inquiry and innovation applicable to patient-oriented research
- 2. *Training, capacity-building and mentoring:* To build and support BC-based methods expertise

Current status: Have issued a call for applications for leads of the first four BC methods clusters that will be developed

- Data sciences
- Health economics and simulation modelling
- Patient engagement
- Real-world clinical trials and research methodology



Methods Support & Development

PROVINCIAL HUB

- Located in Vancouver and acts as a regional centre for the Vancouver Coastal region
- Provides coordination function for entire Unit: connecting regional centres, methods clusters, service providers and stakeholders
- Manages business services, and supports and coordinates patient-oriented research services and programs across BC
- Coordinates demonstration projects and oversees implementation of the provincial data strategy, performance measurement, evaluation and learning strategy, and the communications strategy

Current status: Introducing initial services in November 2016 with a focus on serving members of research teams applying to SPOR competitions

REGIONAL CENTRES

• Provide decentralized structure that caters to local needs while helping the Unit fulfill its province-wide scope

Strategy for Patient-Oriented Research

Putting Patients First

- Regional offices located in each of BC's health regions beyond the Vancouver Coastal region: Northern, Fraser, Vancouver Island, and Interior
- Partnership between regional health authority and leading academic organization in each region: Northern & University of Northern BC, Fraser & Simon Fraser University, Vancouver Island & University of Victoria, Interior & **UBC** Okanagan
- Regional centres deliver local services in four key areas:
- Patient engagement
- Training & capacity development

- Knowledge translation

- Research navigation

Current status: Well under development and expected to offer services soon

Real World Clinical Trials

Operations

Training & Capacity Development

Data Platforms & Services

Consultation & Research Services

INITIAL DATA SERVICES

Streamlining access to data

Health Systems, KT & Implementation

- Helps fulfill objectives 1 & 2
- An initiative of the provincial data platform and the Unit's data services Will streamline access to BC Ministry of Health
- and health authority data Consultation phase undertaken to design and
- implement improved data access model, providing clear rules around:
- Data access and eligibility - Request and use process
- Obligations of data requesters
- Current status: Wrapping up consultation phase;

design phase beginning soon

Data discovery tool & service Helps fulfill objective 5

- An initiative of the provincial data platform and the Unit's data services
- New tool and service being created in partnership with Population Data BC and BC Ministry of Health
- Offers researchers an innovative tool to:
- Better understand Ministry of Health data
- Assess whether sufficient data exists to carry out their intended study
- Tool has been designed to be fast (responses in under a week) and free (for patient-oriented researchers) Services being developed to support use of tool

Current status: Working with potential users on final testing; launch expected before end of 2016

DATA

Data plan objectives

- 1. Develop shared technical, policy and process standards that comply with BC's regulatory environment, conform with public/patient expectations about data use, and increase the willingness of data providers to share data
- 2. Improve the speed and transparency of research data access
- 3. Broaden the array of available data
- 4. Enable privacy-sensitive primary data collection and use
- 5. Foster greater efficiency and quality of data-based research 6. Support data and services for patient-oriented clinical trials
- 7. Enable continuous learning and raise BC's profile as an innovative place to
- do research

Current status: Multiple data partners working together to finalize plan; moving forward soon with initial services

PROVINCIAL DATA PLATFORM



PROVINCIAL DATA PLATFORM

Helps fulfill objectives 1, 2, 3 & 5

The BC SUPPORT Unit is helping to fund, plan and facilitate access to a multi-partner provincial data platform under development that is separate but integral to the Unit.

Vision

Shared common data environment that enables multiple uses of data by multiple types of data users built on leading privacy and security practices.

Functional outcomes

- A secure, virtual collection of data drawing from a data steward's 'single source of truth'
- A shared environment used by multiple types of data users
- Data remain in respective source environment and are assembled when needed, for a defined period of time
- Data assembled and linked with controlled movement of data products out of the platform

Project coordination

Initial project coordination by Ministry of Health in consultation with the BC SUPPORT Unit, Population Data BC and other data partners.

Current status: Under development

PATIENT ENGAGEMENT • Patients have been full members of the Interim Governing Council since its inception

The evolution of a culture shift

- Additional seats will be added when the Interim Governing Council transitions to an advisory committee
- Patients collaborated on writing the BC SUPPORT Unit business plan submitted

PATIENT & STAKEHOLDER ENGAGEMENT

Network, the Unit's highest decision-making body • Patients collaborated on the development of the 2016/17 patient engagement plan

• Currently recruiting patients for the board of the BC Academic Health Science

- Regularly work with BC's Patient Voices Network to recruit patients for a variety of ad hoc committees
- Further recommendations for patient engagement in the Unit overall are being sought from patients
- Regional centres

Other work

- Regional centres are in the process of hiring patient engagement liaisons; training is scheduled for the new year
- Some regional centres have recruited patients to be on their advisory committees
- Working with research teams to develop patient engagement plans • Raising awareness and promoting understanding through speaking engagements, workshops and webinars
- Piloting national curriculum on the foundations of patient-oriented research; training will be delivered in a co-learning format and will be co-facilitated by
- Working to develop common evaluation tools and national guidelines on issues such as compensation for patient partners



- Leverages an existing BC asset
- stitutions, disciplines and BC's geography for collaboration, communication and networking

Veb 2.0 vebsite	Standard messaging	Unit staff update standard messaging; anyone with an account can contribute content to password-protected areas for private team use	Individuals are able to share content; allows for password-protected teams to facilitate project development and disseminate knowledge	Asynchronous	Private password	
	File sharing				protected areas (called e-communities	
	Discussion forums				of practice) are in use by some Unit teams and groups; standard messaging is on separate BC SUPPPORT Unit website to be merged with Web 2.0	
	Wikis					
	Event postings					
	Polls				website in the future	
Web ferencing co Webex)	Virtual meetings	Any Unit-supported team or group for meetings	Accommodates online collaboration of two or more people; reduces need for in-person meetings	Synchronous and asynchronous	Web conference meetings are in use by many Unit teams and groups	
	Webinars		Allows for educational webinars		Webinars to start soon	
ial media		Unit staff	Sharing funding opportunities, resources, literature and Unit developments; engaging with stakeholders	Asynchronous	Not yet underway; will include Twitter (@BCSUPPORTUnit) and Facebook (BCSUPPORTUnit)	

VIRTUAL NETWORKING PLATFORM

- Designed to bring together individuals across

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Executive Director

Patient Engagement Lead

For more information, visit www.bcsupportunit.ca

Scientific Director

CONNECT WITH OUR SPOR SUMMIT PARTICIPANTS