

Patient-Oriented Research

IDC Brown Bag

October 26th, 2017

Objectives

- Overview of Canada's Strategy for Patient-Oriented Research (SPOR)
- Overview of BC SUPPORT Unit
 - Mission and goals
 - Structure
 - Services offered
- Patient-Oriented Research in the North
- Reflections on what we've learned so far

What does
patient-oriented mean?

- a) Engages patients as partners
- b) Focuses on patient-identified priorities
- c) Improves patient outcomes
- d) Research that aims to apply knowledge generated to improve healthcare systems and practices
- e) All of the above

Strategy for Patient-Oriented Research

SPOR

Putting Patients First 

Defining Patient-Oriented Research

➤ SPOR Definition:

- Refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.

Strategy for Patient-Oriented Research

SPOR

Putting Patients First 

Defining Patient-Oriented Research



- What's patient-oriented research? (external audience)
 - Research that is:
 - Done in partnership with patients
 - Answers research questions that matter to patients
 - Aims to improve health care

What is patient-oriented research and how is it demonstrated?

Patient: someone with personal experience of a health issue, including informal caregivers like family & friends

Criteria*	How demonstrated?
✓ Engages patients as partners	Do you have patient partners on your research team?
✓ Focusses on patient-identified priorities	Can you demonstrate that your research idea is a priority for patients?
✓ Improves patient [important] outcomes	Are you measuring outcomes that matter to patients?
✓ Multidisciplinary teams in partnership with relevant stakeholders	Aside from researchers and patient partners, do you have the other necessary people on your research team – e.g. knowledge users like health system decision makers and healthcare providers?
✓ Aims to apply the knowledge generated to improve healthcare systems and practices	Is the research going to be used in the near term for policy and practice improvement?

*It has to check all of these

What is patient-oriented research and how is it demonstrated?

Criteria*	How demonstrated?
✓ Engages community representatives as partners	Do you have community representatives on your research team?
✓ Focusses on community identified priorities	Can you demonstrate that your research idea is a priority for the community ?
✓ Improves community [important] outcomes	Are you measuring outcomes that matter to the community ?
✓ Multidisciplinary teams in partnership with relevant stakeholders	Aside from researchers and patient partners, do you have the other necessary people on your research team – e.g. knowledge users like health system decision makers and healthcare providers?
✓ Aims to apply the knowledge generated to improve healthcare systems and practices	Is the research going to be used in the near term for policy and practice improvement?

*It has to check all of these

Community-based research*

“At its core community-based research is

- ✓ collaborative,
- ✓ concerned with equity,
- ✓ involves community and university scholars as equal partners, and
- ✓ combines knowledge with action usually to achieve social change.

The intent in CBR is to transform research from a relationship where researchers *act upon* a community to answer a research question to one where researchers *work side by side* with community members” (Community-Based Research Partnerships, 2006).

* Community Research Canada



Putting Patients First 



Canada's strategy to ensure that the **right patient** receives the **right intervention** at the **right time**...

Research suggests that "...[up to] 50% of patients do not get treatments of proven effectiveness, and up to 25% get care that is not needed – or potentially harmful.." (http://www.cihr-irsc.gc.ca/e/documents/fact_sheet_spor_overview_e.pdf)



Putting Patients First 



Canada's strategy to ensure that the right patient receives the right intervention at the right time...

...by increasing the amount of research being conducted with and by research knowledge users –

...including patients and families, health care providers, and health system decision-makers.

SPOR has Five Core Components

- Strategy for implementing Patient-Oriented Research



- This national strategy has five separate core components.



1.  **Support for People and Patient-Oriented Research and Trials (SUPPORT Unit)**
2.  **SPOR Networks**
3.  **Training and capacity development**
4.  **Improving the clinical trials environment**
5.  **Patient engagement**

Core Component 1: What is a SUPPORT Unit?

- SUPPORT (Support for People and Patient-Oriented Research and Trials) Units are provincial elements of Canada's national Strategy for Patient-Oriented Research (SPOR), created by CIHR
- The BC SUPPORT Unit is one of a collaborative network of 10 SPOR-funded provincial SUPPORT Units located across Canada



The BC SUPPORT Unit

What is a SUPPORT Unit?

- Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit
- An element of Canada's Strategy for Patient-oriented Research (SPOR)
- Multi-partner organization to support, streamline and increase patient-oriented research

Health authorities

Universities

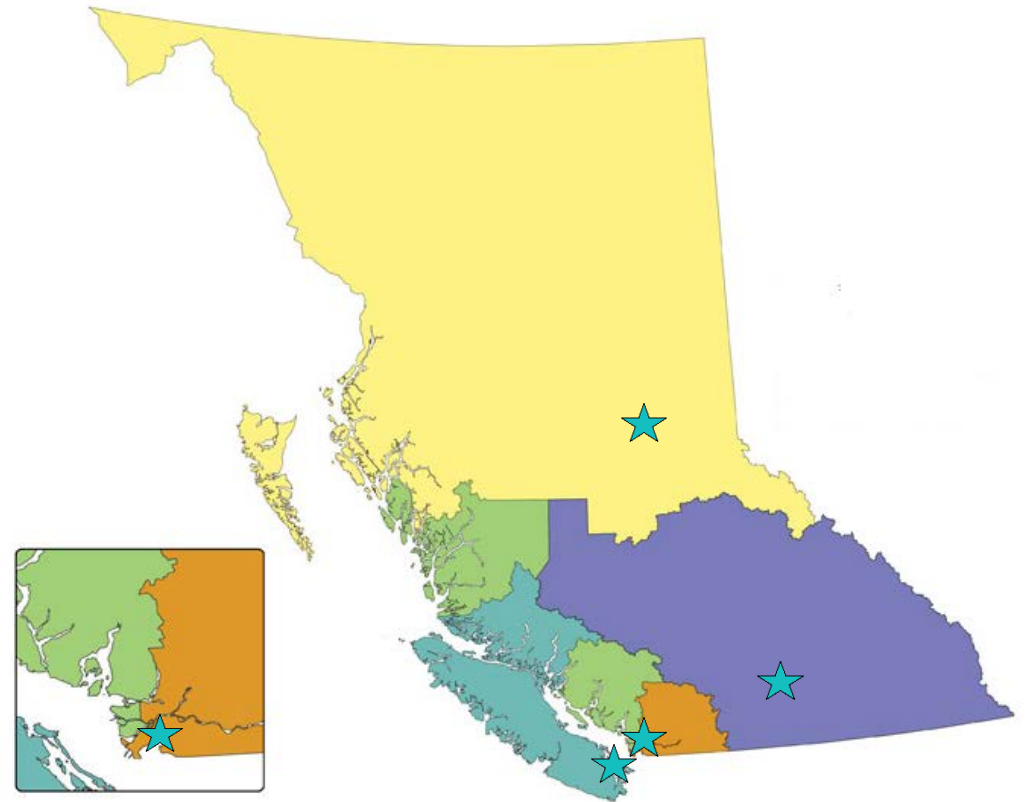
Government

Patients/Caregivers

Research institutes, networks & foundations

Regional Centres

- Each regional centre is an important part of the BC SUPPORT Unit – they're a partnership between health authorities and universities in the area.
- There are five regional centres:
 - Vancouver Island
 - Interior
 - Northern
 - Fraser
 - Vancouver (Hub)



Differentiating SPOR and SUPPORT Units

- Remember:
 - SPOR is a national strategy
 - SUPPORT Unit is a provincial entity

- Therefore:
SPOR ≠ SUPPORT

BC SUPPORT Unit Mission

Support the conduct and implementation of high quality patient-oriented research

BC SUPPORT Unit goals

1. Build capacity to conduct and implement high quality patient-oriented research in all regions of the province
2. Increase the quality and impact of patient-oriented research across BC
3. Ensure ongoing support for patient-oriented research in all regions of the province

What services does the SUPPORT Unit provide?

- Consultation services in patient engagement – help to recruit, train & support those who get involved in patient-oriented research*
- Consultation services in knowledge translation
- Connecting people with interest in particular ways of doing research or *methodologies*
- Easing access to data held by government
- Training in how to do patient-oriented research in order to build capacity

*patients, researchers, health care providers and health system decision-makers

In-person training offered

- Foundations in Patient-Oriented Research
 - 3 modules
 1. Patient-Oriented Research – What it is, why it's important, how it's done
 2. Fundamentals of Health Research in Canada – The research process/lifecycle, who does research, who funds research, ethics, peer review, etc.
 3. Building Partnerships and Consolidating Teams – using Tuckman's Stages of Team Development as a framework for discussion
 - Co-developed by patients, researchers, & experts in patient engagement, evaluation & curriculum
 - Delivered in a co-learning format (patients, researchers, health care providers, health system decision-makers)



Web-based training offered

- Webinars
- On-line resources

Access at www.bcsupportunit.ca



POR in Northern BC

- Persons, families and their communities working with researchers and knowledge users to improve the social determinants of health and health system challenges
- Principles of research in Northern BC:
 - person, family and community centered
 - partnered in planning to implementation of evidence
 - mutual respect
 - integrated knowledge translation
 - creating evidence that matters

POR Research at UNBC

- Indigenous Health
- Social and Environmental Determinants of Health
- Health Services and Policy Research
- Biomedical
- Clinical

Northern Regional Centre

- NH-UNBC Knowledge Mobilization Chair
- UNBC Health Research Institute
- NH Innovation and Development Commons

Person and Family Centred Focus in Northern Health

- 2016 – 2021 Strategic Plan
- Person and Family Centred Care Strategy
 - Objectives:
 - Leadership support and improvement at all levels
 - Improve person and family experience
 - Enhance person/provider relationships
 - Enhance safe and effective shared communication
 - Optimize access to the health system and health information
 - Principles:
 - Dignity and respect
 - Information sharing
 - Participation
 - Collaboration
- Aboriginal Health Improvement Committees (AHICs)
- Biennial Community Consultations

Current Funding

- CIHR:
 - Rewarding Success, November 18
 - SPOR Collaborative Grant, November 14
- BC SUPPORT Unit and MSFHR
 - P2P Awards (Pathway to POR), October 30
- **Northern Centre:**
 - **Developing Northern Research Collaborations Award, January 8, 2018**

Opportunities

- BC SUPPORT Unit
 - Webinars and live recordings
 - Online training resources
 - Methods Clusters
 - Demonstration Projects
 - Provincial meetings
 - Inaugural conference, Vancouver, November 9, 2017



Question & Answer

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