Fostering a Patient-Oriented Research Ecosystem: Lessons from BC SUPPORT Unit Fraser Centre

Alia Januwalla & Brittney La Pietra
BC SUPPORT Unit Fraser Centre

Community-Based Research Canada Webinar
April 30, 2020
About Community-Based Research Canada

www.communityresearchcanada.ca

@CbrcResearch
Presenters

Alia Januwalla
Knowledge Translation Specialist,
BC SUPPORT Unit Fraser Centre

Brittney La Pietra
Simon Fraser University Research Navigator,
BC SUPPORT Unit Fraser Centre
Agenda

- What is SPOR and the BC SUPPORT Unit?
- What is Patient-Oriented Research (POR)?
- Examining POR and CBPR core principles
- How Fraser Centre supports POR
Getting to know each other

- Do you work in health-related research?

- How familiar are you with the term “patient-oriented research” or Canada’s Strategy for Patient-Oriented Research?

- What province or territory are you currently located in?
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.”

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, caregivers, and health care providers.
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)
- BC SUPPORT Unit is 1 of 10 SPOR-funded SUPPORT Units across Canada
BC SUPPORT Unit Fraser Centre

Simon Fraser University

Fraser Health
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 is patient-oriented research?

Based on the CIHR definition:

• Engages patients as partners

• Focuses on patient-identified priorities

• Improves patient outcomes (as defined by patients)

• Aims to apply knowledge generated to improve healthcare systems and practices

• Conducted by multidisciplinary teams in partnership with stakeholders
Who is a patient?

Research done with and by patients... Not for, on, or about.

Who’s a patient?
Any person that has experienced a health care issue or the health care system, including informal caregivers, family, friends, etc.

Patient isn’t always the right word!
Why engage patients?

User experience

Design
How do we see engagement?

“Meaningful and active collaboration” (CIHR)

“Research done differently” (PCORI/US)

“Research by and with...not on, for, or about” INVOLVE/UK)

<table>
<thead>
<tr>
<th>Inform</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Empower</th>
</tr>
</thead>
<tbody>
<tr>
<td>To provide with information</td>
<td>To obtain feedback</td>
<td>To work with to develop alternatives</td>
<td>To partner in each aspect of decision-making</td>
<td>To decide</td>
</tr>
</tbody>
</table>

To decide
Potential Patient Partner Activities

Set Priorities, Formulate study question

Help develop practice guidelines, evaluation

Identify study population, recruitment, choosing relevant outcomes

Design implementation activities, translate documents into plain language

Data analysis, Interpretation of findings
What Matters to Patients?

Anecdotally…

• Being heard.
• Real improvements to the health care system for those that come after them.
• Better health outcomes and experiences.

Answering questions that matter to patients is only half the battle. Patients need to see the benefit!
Patient-oriented KT

- Patient, family, or caregiver is engaged in the KT project and/or throughout the research and KT activities in an intentional, active, and authentic manner.

- How can this benefit you?
  - Relevance to knowledge user
  - Uptake of research into practice
  - Service access and effectiveness

BC SUPPORT Unit, Tools for PO-KT Workshop. Implementing Practice Change, Feb 7, 2020 [Hoens, Feehan, Banner-Lukaris]
Common benefits of POR

- Fostering inclusive mechanisms and processes (including shared leadership and decision-making)
- Multi-way capacity building
- Multi-way communication and collaboration
- Experiential knowledge valued as evidence, and mobilized and translated for impact
- Patient-informed and directed research
- A shared sense of purpose

[CIHR, 2019]
Common challenges faced in POR

- Tokenistic involvement of patient partners
- Difficulty recruiting hard-to-reach patients
- Patient groups dominated by involved patient partners
- Lack of support from research funders
- Scope creep
- Difficulties maintaining long-term relationships given academic or organizational turnover
- Learning curve required
- Insufficient funds and time allocation for meaningful engagement
Guiding principles

**POR**
1. **Inclusiveness** – integrates a diversity of perspectives and research is reflective of their contribution
2. **Support** – creating safe environments to promote honest interactions, cultural competence, training, and education
3. **Mutual respect** – researchers, practitioners, and patients acknowledge and value each other’s expertise and experiential knowledge
4. **Co-build** – working together from the beginning to identify problems and gaps, set priorities for research, and produce and implement solutions

[CIHR, 2019]

**CBPR**
1. Recognizes community as a unit of identity
2. Begins with and builds on strengths and resources within the community
3. Facilitates collaborative, equitable partnership in all phases of the research
4. Promotes co-learning and capacity building among all partners
5. Integrates a balance between knowledge generation and action
6. Emphasis on local relevance of public health and social problems and ecological approaches
7. Involves systems development
8. Disseminates findings to all partners
9. Involves a long-term process and commitment

[Israel et. al., 1998]
“Comparing” POR and CBPR

**POR**
- Health research specific... but health is a broad concept!
- Alignment of terminology and language

**CBPR**
- Broad applicability
- Older discipline

What do other people think?

Core principles of patient engagement

Co-learning

Ten steps of patient engagement in PCOR
Topic solicitation
Prioritization
Framing the question
Selection of comparators
Creation of conceptual framework
Analysis plan
Data collection
Reviewing and Interpreting results
Translation
Dissemination

Phases of a PCOR study
Pre-engagement
Continuous engagement
Sustained engagement

CBPR principles
Community as a unit of identity
Builds on strengths, resources and relationships present within a community
Equal partnership and collaboration in all phases of research (power sharing)

Bidirectional learning and capacity building for knowledge transfer
Integration and balance of research and action for the mutual benefit of all partners to achieve
Address locally relevant health problems and multiple determinants of health and disease

Systems development through a cyclical and iterative process
Dissemination of research findings to all partners and involve partners in dissemination
Long-term commitment to ensure sustainability

Reciprocal relationships
### Table 2. Recommendations that support application of community-based participatory research principles to phases of a patient-centered outcomes research study.

<table>
<thead>
<tr>
<th>Phases of a PCOR study</th>
<th>Recommendations</th>
</tr>
</thead>
</table>
| **Pre-engagement**     | • Identify individuals to partner with, jointly define the community, and clearly define the roles of each partner  
                        • In collaboration with community partners, determine what the community needs and interests are  
                        • Use Geographic Information Systems for mapping assets and resources available within the community  
                        • At the beginning of the partnership, establish a mechanism for shared governance in setting the research agenda  
                        • Researchers should meet with research partners in the community, conduct research, and become a familiar face in the community. This serves as a way of sharing power with the community |
| **Continuous engagement** | • Continuous training of community partners on human subjects protection, ethical research practices, research design and data collection  
                           • Inclusion of trained community research partners on institutional review boards protocols and serving as institutional review boards reviewers  
                           • Training of academic partners on health literacy, cultural competency, cultural nuances of what works in that community and other skills needed for successful community partnerships |
| **Sustained engagement** | • Develop collaborative dissemination plans that involve letting partners decide what results should be disseminated, how results should be disseminated and appropriate venues for dissemination  
                           • Co-present in the community and at academic settings with community research partners. Association of a familiar face in the community with the research lends credibility and trust. In addition, community partners are able to advocate in far-reaching ways within their community than academic partners  
                           • Engage in ongoing discussions with partners about sustainability from the beginning and throughout the lifecycle of the research project  
                           • Develop grant writing capabilities and distribute grant funds equitably between academic and community partners allow for long-term sustainability |

PCOR: Patient-centered outcomes research.
Examples of our Work
Fraser Centre Overview

- 54 research projects
  - 2 of these are patient-directed

- 90 patient partners engaged in research and governance activities

- 22 awards granted within the last fiscal year

- 50% of requests for clinician-led research

- Simon Fraser University Faculties engaged on research teams:
  - Biomedical Physiology and Kinesiology; Gerontology; Engineering; Psychology; Gender, Sexuality and Women’s Studies; School of Interactive Arts and Technology; Faculty of Health Sciences
Fraser Centre Governance & Operations

- Patients Interested In Research
- Core Oversight Committee
- Shared decision-making
- Formalized as staff members
South Asian Health Research Collaborative

- Diverse group of researchers and health providers interested in South Asian engagement in health research to improve the quantity and quality of health research for the community to inform policy and practice
  - Drafted project overview, options for convening
  - Strategy for and facilitation of goal setting activities
  - Support for initiating and facilitating a priority setting project
Fracture Liaison Service

Dr. Sonia Singh, Fraser Health

- Knowledge user identified problem
- Evidence based solution adapted to context
- Implemented & evaluated effectiveness
- Presented to decision makers with patient partner
- Sustainable program established
- Patient partner contributed to dissemination efforts (presenting at conferences, authoring manuscripts)
- Received grant to scale and spread FLS across BC
ART & SCIENCE of Person-Centred Care

Dr. Lillian Hung, SFU

- Promoting the use of a learning tool on the ART & SCIENCE of person-centred care for people living with dementia
- Facilitated co-creation of KT strategy with researchers, patient partner, health care providers across BC, and game designer
- Key KT tools: incentives, champions, and, targeted promotion
Moving forward in the age of COVID-19

- How do we support the communities and stakeholders we work with?

- What adaptations will we need to make?

- Who do we risk excluding or leaving behind?
How to get in touch with us?

- Complete the inquiry form: bcsupportunit.ca
- Email us directly: alia.januwalla@fraserhealth.ca blapietr@sfu.ca
- For more information see: fraserhealth.ca/employees/research-and-evaluation/advancing-patient-oriented-research
Save the date – May 28, 2020

From Patient-Oriented Research to Patient-Led Research – An Exploration from the Patient-Perspective

[Beverley Pomeroy]

Perspectives on POR

https://www.youtube.com/watch?v=xvwkaD7GuRI&feature=emb_logo
Additional Readings & Resources

- Canada’s Strategy for Patient-Oriented Research [https://cihr-irsc.gc.ca/e/44000.html](https://cihr-irsc.gc.ca/e/44000.html)

- BC SUPPORT Unit [https://bcsupportunit.ca/resources](https://bcsupportunit.ca/resources)


Thank you!
© Fraser Health Authority, 2017

The Fraser Health Authority ("FH") authorizes the use, reproduction and/or modification of this publication for purposes other than commercial redistribution. In consideration for this authorization, the user agrees that any unmodified reproduction of this publication shall retain all copyright and proprietary notices. If the user modifies the content of this publication, all FH copyright notices shall be removed, however FH shall be acknowledged as the author of the source publication.

Reproduction or storage of this publication in any form by any means for the purpose of commercial redistribution is strictly prohibited.

This publication is intended to provide general information only, and should not be relied on as providing specific healthcare, legal or other professional advice. The Fraser Health Authority, and every person involved in the creation of this publication, disclaims any warranty, express or implied, as to its accuracy, completeness or currency, and disclaims all liability in respect of any actions, including the results of any actions, taken or not taken in reliance on the information contained herein.
Webinar Recordings

www.communityresearchcanada.ca/webinars
Q & A
More Ways to Get Involved With CBR Canada

Sign up for CBRC e-News

Spring 2020 e-News

Share Your News and Events!
info@communityresearchcanada.ca

CBRC Webinars

Live Online Discussions

www.communityresearchcanada.ca
@CbrcResearch
CBR Project – Request for Proposals

Request for Proposals: Community-Based Research Projects in Cannabis and Mental Health

The purpose of the Community-Based Research (CBR) funding is to address knowledge gaps in the relationship between cannabis and mental health. This opportunity is also aimed at building research capacity among people with lived and living experience of cannabis use and/or mental health problems and illnesses, and by other priority populations. Between 2020 and 2022, the MHCC will fund up to 12 CBR projects. The maximum funding for an approved research project is up to $50,000 per year ($100,000 over two years). Proposal development support is available upon request (see the final section for further details).

<table>
<thead>
<tr>
<th>Issued by the Mental Health Commission of Canada (MHCC)</th>
<th>Updated Timelines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Award amount</td>
<td>Up to $50,000 per award per year (for all project expenses, including GST)</td>
</tr>
<tr>
<td>Date of RFP release</td>
<td>February 18, 2020</td>
</tr>
<tr>
<td>RFP information session (webinar)</td>
<td>March 4, 2020, 1 to 2:30 p.m. ET</td>
</tr>
<tr>
<td>Application deadline</td>
<td>April 23, 2020</td>
</tr>
<tr>
<td>Research committee decision</td>
<td>June 12, 2020</td>
</tr>
<tr>
<td>Awards announcement to successful teams</td>
<td>June 29, 2020</td>
</tr>
<tr>
<td>In-person workshop for designated team reps (1 per team). Attendance paid for by the MHCC.</td>
<td>Summer, 2020</td>
</tr>
<tr>
<td>Midpoint report deadline</td>
<td>July 31, 2021</td>
</tr>
<tr>
<td>Final report deadline</td>
<td>July 31, 2022</td>
</tr>
</tbody>
</table>

https://bit.ly/3cY0ctt
Please Share Your Feedback

"Tell us what you think!"

Feedback Form:
Fostering a patient-oriented research ecosystem: Lessons from BC SUPPORT Unit Fraser Centre

Start
Thank You!

www.communityresearchcanada.ca

@CbrcResearch