

Strategy for Patient-Oriented Research



Patient Engagement in the Strategy for Patient-Oriented Research SUPPORT Units: Challenges and Opportunities

Presentation at the CAHSPR

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on behalf of

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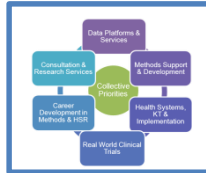
Presentation Overview

- Introduction: Adrian Levy
- Manitoba: Carolyn Shimmin
- Ontario: Vasanthi Srinivasan
- Quebec: Marie-Dominique Beaulieu
- Question period: SUPPORT Unit leads (present)

What is SPOR?

- CIHR-led Strategy for Patient-Oriented Research
- Federal, Provincial, Territorial initiative fostering evidence-informed health care with system-wide impact, enhanced patient engagement, and partnerships
- Innovative collaboration among researchers, clinicians, patients, health system administrators, policy makers, health charities, industry, and others
- Engages a coalition dedicated to the integration of research into care and to the translation of research results into improved health outcomes

Core Elements of SPOR



Support for People and Patient-Oriented Research and Trials (SUPPORT) Units



SPOR Networks



Capacity development



Improving the clinical trials environment



Patient engagement

SUPPORT UNITS

9

SUPPORT Units in various stages of implementation (BC, AB, SK, MB, ON, QC, Maritimes, NL, NWT)

2

SUPPORT Unit business plans are in the development phase (Yukon and Nunavut)

33+

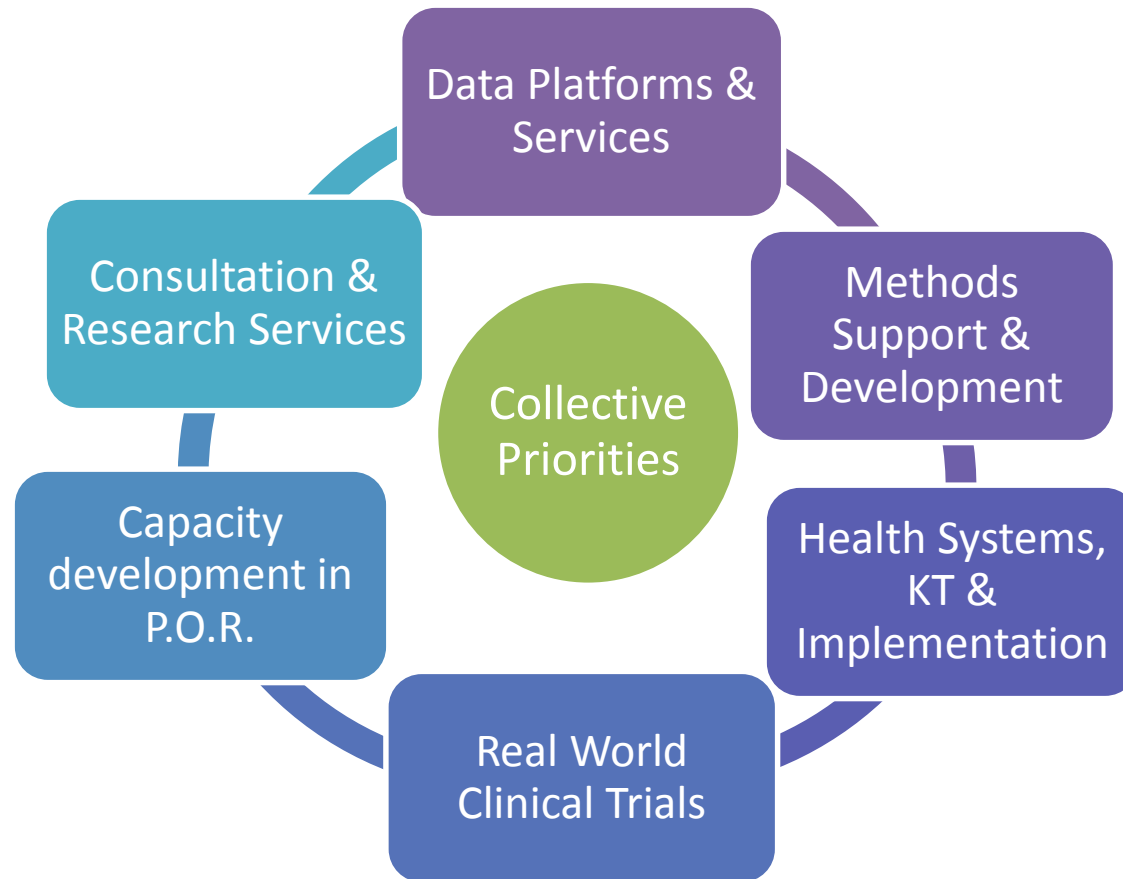
Partners co-funding the approved SUPPORT Units

\$430M

Investment by CIHR and partners in the approved SUPPORT Units

SPOR SUPPORT UNITS

Provincial and/or regional centres providing support and expertise to those engaged in patient-oriented research with a focus on six core functions



The mandate is to engage patients.

SPOR definitions

Patient

- An overarching term inclusive of individuals with personal experience of a health issue and of informal caregivers, including family and friends

CIHR defines patient-oriented research as

- “... a continuum of research that engages patients as partners, focuses 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 practice.”

Patient Engagement in Manitoba



Incorporating a Trauma-Informed Intersectional Analysis in PE



Patient Engagement in Ontario



Patient partnership workshop

- Full day workshop bringing together patient's partnering and engaged in research across Ontario
- Developed and run by the OSSU Patient Partnership Advisory Group

Masterclass on Patient-Oriented Research (POR)

- Multi-stakeholder 3-day course on POR that engaged patients as an integral part of a POR system in Ontario

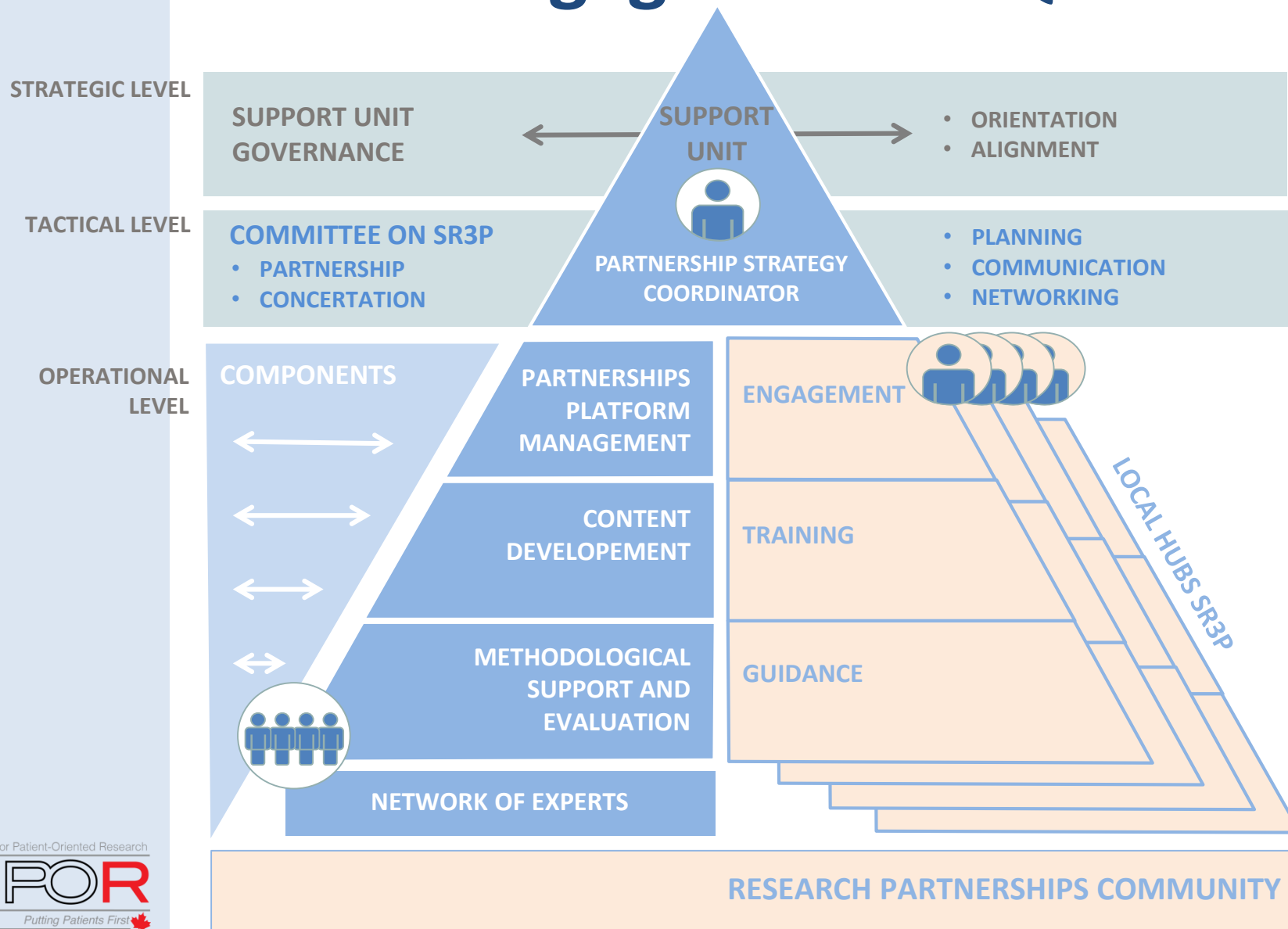
Patients Canada Demonstration Project

- Funding for a patient-led organization to develop and support research projects both as research leads and as partners

Lessons learnt so far...

- Patient engagement requires time and active listening, but the research world is open to engaging given the tools and value proposition

Patient Engagement in Quebec



Patient Engagement in Quebec



Our objective

- To establish a sustainable patient engagement capacity in each 4 integrated university networks

Creation of 4 regional “hubs”

- Based on existing capacity
- One patient-researcher tandem + seed money

Priority: support patient recruitment capacity

- Recruitment guide
- Training workshops with research teams

Challenges

- Resources to support patient engagement in research projects
- Lack of flexibility of the research process to adjust to the reality of patient engagement

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