

Discoveries for life / Découvertes pour la vie

# Patient-Oriented Research at CIHR – Past, Present, and Future

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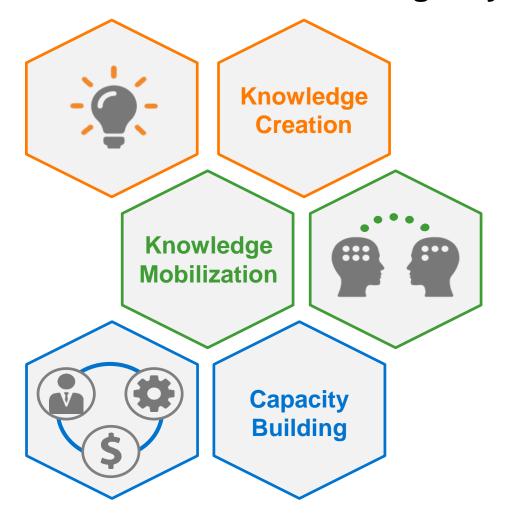
Presentation to the SPOR Evidence Alliance AGM June 2022





### **CIHR Mandate**

### Canada's federal health research investment agency



### **Pre-SPOR**



### "Health research must be better harnessed to increase both the quality and affordability of care."

- Canadian research excellence is recognized globally; the country ranked amongst the top in the world on scientific impact of its health research
- Yet, evidence showed that 50% of patients do not get treatments of proven effectiveness and up to 25% get care that is not needed or potentially harmful
- Incentives for health research are not focused on these problems bringing research and decision-makers/patients together requires a change in culture and approach (push-pull innovation model)

### The Need for a National Strategy



### Many factors and pressures:

- Global movement toward evidence-informed health care;
- Increasing impatience with the pace at which scientific discovery results in new products/interventions;
- Gaps in evidence make it difficult to establish appropriate care guidelines;
- Financial imperative to allocate resources to the most effective and cost-effective interventions.

### Official Launch of the Strategy

Strategy for Patient-Oriented Research

Putting Patients First

"By putting patients first, we are making sure that research will have a greater impact on treatments and services provided in clinics, hospitals and doctors' offices throughout Canada, better integration of research evidence and clinical practice means improved health outcomes and a better health-care system in Canada."



Honourable Leona Aglukkaq, Minister of Health Canadian Medical Association Annual Meeting St. John's, Newfoundland August 22, 2011

### **SPOR Elements**



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



**SPOR Networks** 



**Capacity Development** 



**Clinical Trials** 



Patient Engagement



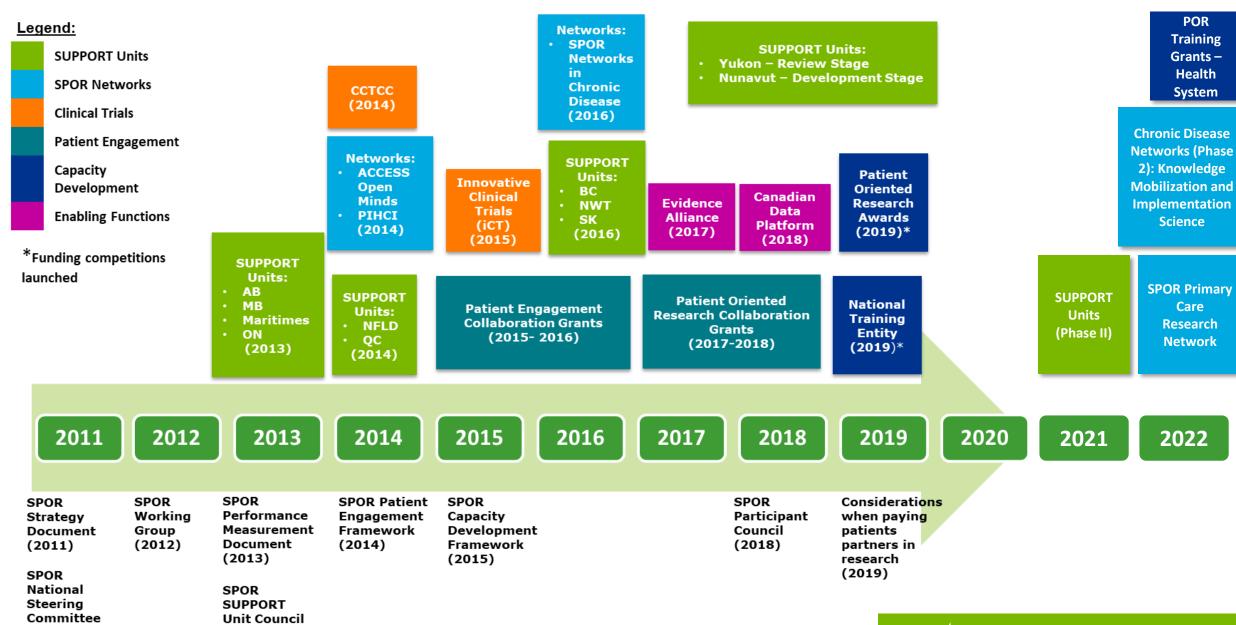
**Enabling Functions** 





### The SPOR Journey

(2013)



(2011)

### CIHR Strategic Plan 2021–31: A Vision for a Healthier Future\*

# To achieve the best heath for all, powered by outstanding research

- Focuses on health equity, knowledge mobilization, and equity, diversity, and inclusion.
- Provides priority-setting direction for the next 10 years, while also allowing us to reprioritize and redirect resources on short notice to respond to emerging issues.



\*https://cihr-irsc.gc.ca/e/52331.html

### CIHR's Strategic Plan (2021-2031)

**PRIORITY A** 

**ADVANCE RESEARCH EXCELLENCE IN ALL ITS DIVERSITY** 



**PRIORITY B** 

STRENGTHEN CANADIAN HEALTH RESEARCH CAPACITY



**PRIORITY C** 

ACCELERATE THE SELF-DETERMINATION OF INDIGENOUS PEOPLES IN HEALTH RESEARCH



**PRIORITY D** 

**PURSUE HEALTH EQUITY THROUGH RESEARCH** 



**PRIORITY E** 

INTEGRATE EVIDENCE IN HEALTH DECISIONS

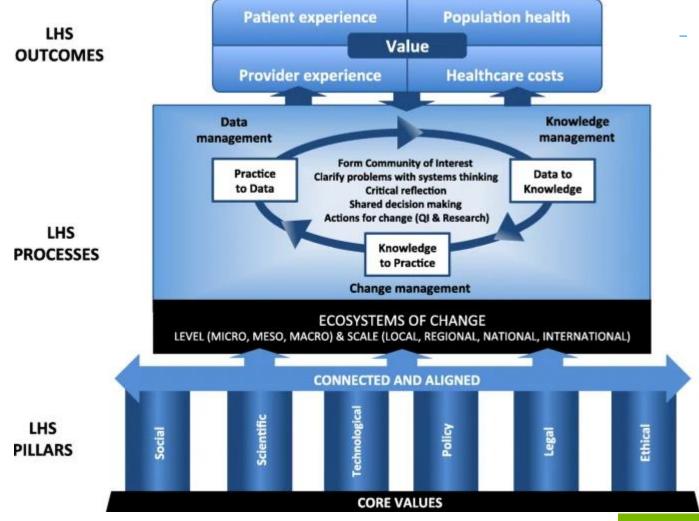


**SERVING CANADIANS:** 

**OUR COMMITMENT TO ORGANIZATIONAL EXCELLENCE** 

### A new portfolio: Learning Health Systems

### A conceptual LHS framework in the Canadian context



It takes 17 years for research to reach practice.1

Only 14% of research reaches a patient.1

Only 18% of administrators and practitioners reportusing evidence-based practices frequently.2

# THE SCIENCE-PRACTICE GAP

Balas EA, Boren SA. 2000. Managing clinical knowledge for health care improvement. In Yearbook of Medical Informatics 2000: Patient-Centered Systems, ed. J Bemmel, AT McCray, pp. 65-70. Stuttgart, Germany: Schattauer

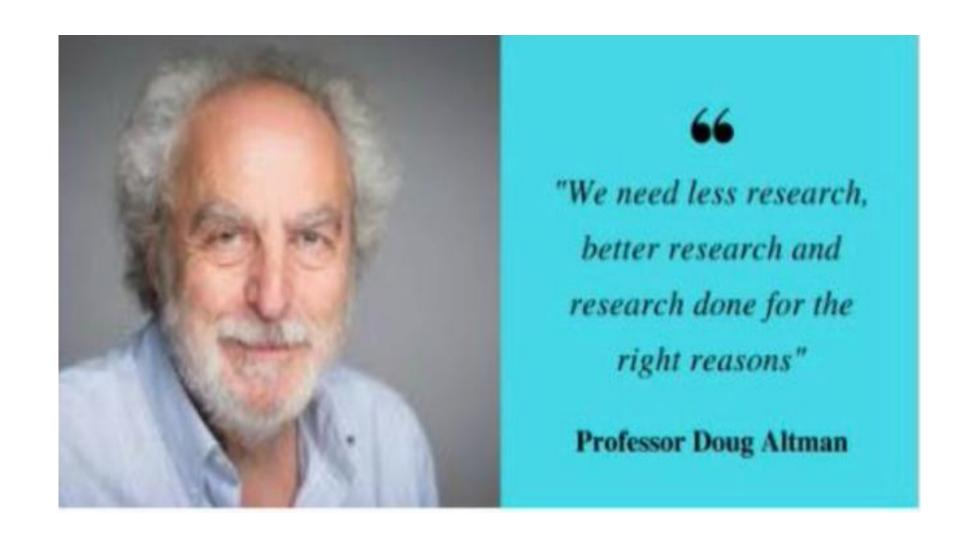
Chagnon F, Pouliot L, Malo C, Gervais MJ, Pigeon ME. Comparison of determinants of research knowledge utilization by practitioners and

administrators in the field of child and family social services. Implementation Science: IS. 2010;5:41, doi:10.1186/1748-5908-5-41.

#### Waste at four stages of research Questions Appropriate Unbiased and relevant Accessible design and full publication? to clinicians & usable report? methods? patients? Low priority questions Over 50% studies Over 30% of trial Over 50% of studies addressed designed without interventions not never published in full reference to sufficiently described Important outcomes systematic reviews of Biased undernot assessed existing evidence Over 50% of planned reporting of studies study outcomes not with disappointing Clinicians and Over 50% of studies reported results patients not involved fail to take adequate in setting research steps to reduce Most new research agendas biases, e.g. not interpreted in the unconcealed context of systematic treatment allocation assessment of other relevant evidence 50% 50% 50%

(Figure Stages of waste in the production and reporting of research evidence relevant to clinicians and patients; from Chalmers & Glasziou, The Lancet 2009)

85% Research waste = over \$100 Billion / year



Treweek et al. Trials (2022) 23:537 https://doi.org/10.1186/s13063-022-06348-z **Trials** 

#### **METHODOLOGY**

**Open Access** 

Getting it wrong most of the time?
Comparing trialists' choice of primary outcome with what patients and health professionals want

Shaun Treweek<sup>1\*</sup>, Viviane Miyakoda<sup>2</sup>, Dylan Burke<sup>3</sup> and Frances Shiely<sup>3,4</sup>





What is DORA?

The Declaration on Research Assessment (DORA) recognizes the need to improve the ways in which researchers and the outputs of scholarly research are evaluated.

https://sfdora.org/



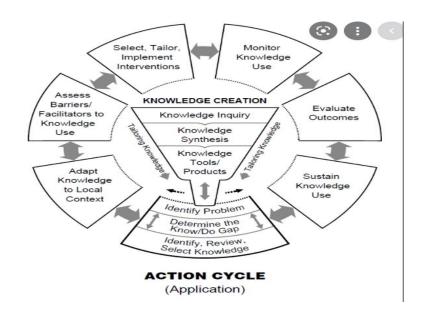
### Supporting Learning Health Systems & Patient-Oriented Research











### CIHR's Learning Health Systems Portfolio

#### **Structure**

- Led by the Vice President Research Learning Health Systems, the portfolio will support the following functions:
  - Patient-Oriented Research (including SPOR)
  - Centre for Research in Pandemic Preparedness and Health Emergencies



- Clinical Trials Fund



- Equity Strategy (EDI)
- Science Policy
  - Knowledge Mobilization (incl Evidence Integration)
  - Research Excellence and Ethics
  - Training & Capacity Development

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**SERVING CANADIANS:** 

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### SPOR (& POR): Foundational to Implementing CIHR's Strategic Plan

#### **PRIORITY A**

#### ADVANCE RESEARCH EXCELLENCE IN ALL ITS DIVERSITY

- Championing a more inclusive concept of research excellence, by recognizing patients, the public, providers, decision-makers, as active collaborators in research.
- Enhancing national collaboration.

#### **PRIORITY B**

#### STRENGTHEN CANADIAN HEALTH RESEARCH CAPACITY

POR Training and Awards enhance training and career support.

#### **PRIORITY C**

## ACCELERATE THE SELF-DETERMINATION OF INDIGENOUS PEOPLES IN HEALTH RESEARCH

- Removing barriers to Indigenous-led and Indigenous Health Research.
- Opportunities to collaborate and support the work of IIPH.

#### **PRIORITY D**

#### **PURSUE HEALTH EQUITY THROUGH RESEARCH**

 Reduces health inequities through research by involving patients as partners throughout the research process.

#### **PRIORITY E**

#### INTEGRATE EVIDENCE IN HEALTH DECISIONS

- Advancing the science of Knowledge Mobilization.
- Maximizing results for Canadians.
- Strengthening Canada's health systems through innovation (e.g. Learning Heatlh Systems).



### **SPOR Impacts**



- Anecdotal evidence: there is a cultural shift to POR seen in P/Ts.
- Expectation from patients for a POR approach (e.g., COVID rapid response, CTF).
- Indigenous engagement across SUPPORT Units (representation on governance bodies, NWT SUPPORT Unit implementing UNDRIP).
- Findings from SPOR's first evaluation:
  - Aligned with international trends towards POR; complements POR activities undertaken by the P/Ts
  - The right elements and activities to address areas in need of support for POR and evidenceinformed health care
  - National governance mechanisms key success factor is the "let's discuss together" approach.
  - Stakeholder engagement "exceptional" and successful at developing relationships.

### **SPOR Impacts - COVID-19 Response**

- SPOR Evidence Alliance has been key resource in supporting evidenceinformed decision making
- Collaboration with COVID-END helped coordinate and reduce duplication of COVID related research, knowledge synthesis and other activities



### SPOR – What's new?





Dr. Amy Lang

- New Executive Director, Patient-Oriented Research
  - Dr. Amy Lang (Twitter: @Amy\_Lang)
- Responsible for:
  - Canada's Strategy for Patient-Oriented Research
  - Embedding patient engagement and patient-oriented research across all CIHR activities, initiatives & programs.

- Strategy for Patient-Oriented Research
- Putting Patients First



- Two new SPOR Networks funded as part of Phase II (April 1, 2022)
  - Knowledge Mobilization and Implementation Science (KMIS) grants
  - 2. SPOR Primary Care Network grant
- Integrated Youth Services NofN (IYS-Net)
  - > Joint investment of SPOR, the Graham Boeckh Foundation and CIHR-INMHA
  - ➤ Multi-phased initiative to develop a pan-Canadian network of learning health systems focused on integrating mental health services
- **SPOR SUPPORT Units**: Nine of the ten SUPPORT Units were renewed and began Phase II funding in 2021 (April 1, 2022 for Saskatchewan).
  - > New Learning Health System Component
- SPOR National Training Entity: Funded in March 2021 as a national training platform in POR.



### SPOR – What's new?



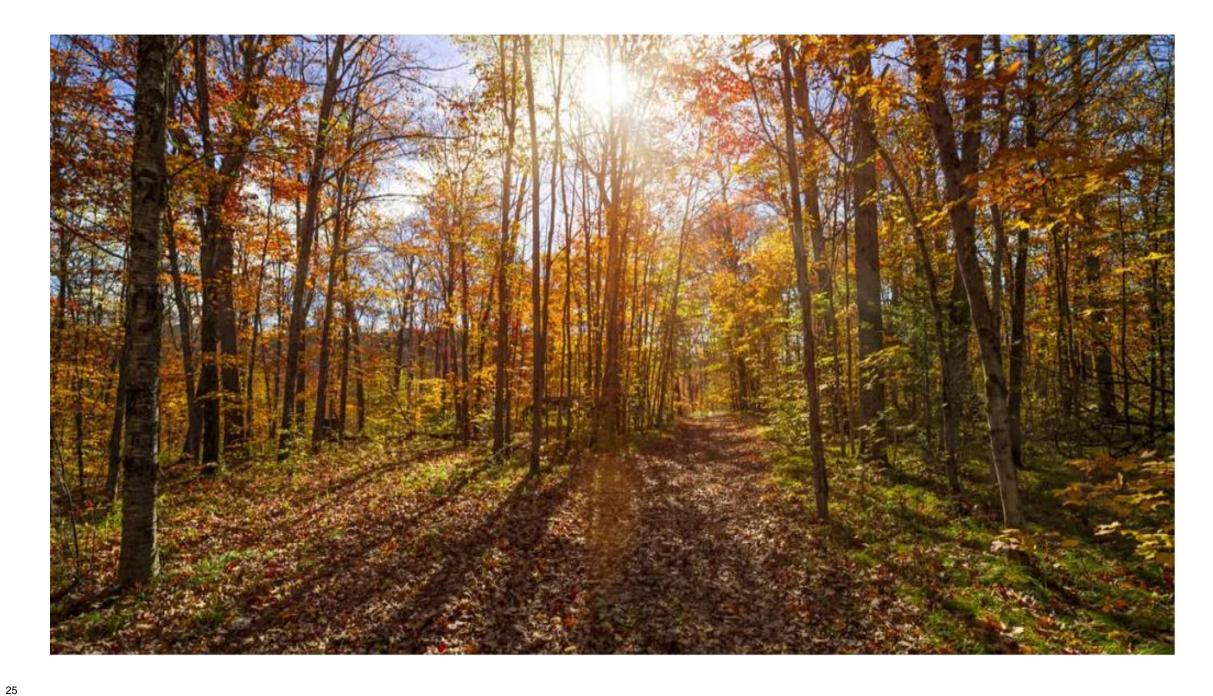
## Transforming Health with Integrated Care (THINC) – Implementation Science Teams

The THINC Implementation Science Team (IST) Grants funding opportunity focuses on improving our understanding of how to implement, evaluate, adapt, and/or spread/scale evidence-informed integrated care policies and interventions.



## Integrated Youth Services Network of Networks (IYS-Net)

ISY-Net is a phased initiative with the aim of creating a Canada-wide network of provincial and territorial learning health systems for Integrated Youth Services (IYS).



### What's on the horizon for SPOR?



### **Second SPOR Evaluation (2016/17 – 2020/21)**

- Part of CIHR's accountability requirements as a federal government agency (Treasury Board's Policy on Evaluation).
- Aims to inform program improvement and decision making related to SPOR's future direction, planning and sustainability.
- Will inform a refresh of the SPOR Strategy and governance
- To be completed by end of 2022.

### What's on the horizon for SPOR?

### **SPOR Governance and Strategy Refresh**

- Initial planning work to begin in 2022-23
- Will look to define a renewed approach that:
  - reflects evolving health systems, community and patient priorities,
  - builds on successes to date, and
  - will achieve significant progress toward achieving SPOR's vision.



The vision of SPOR is to demonstrably improve health outcomes and enhance patients' health care experience through integration of evidence at all levels in the health care system.

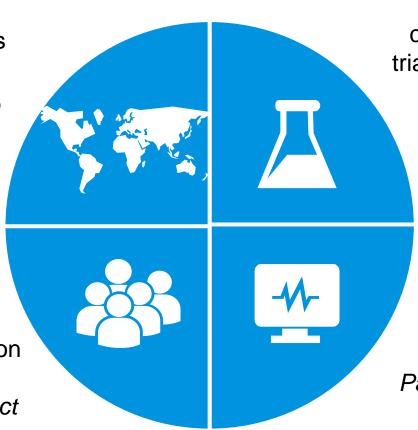
### Opportunities for POR, Beyond SPOR

# Centre for Research on Pandemic Preparedness and Health Emergencies

\$18.5M per year to grow Canada's capacity to research and mobilize knowledge to prevent, prepare for, respond to, and recover from existing and future pandemics and public health emergencies

### **Knowledge Mobilization**

To ensure that CIHR's broad spectrum of knowledge mobilization initiatives fulfil its mandate in this area, as expressed in the CIHR Act



#### **Clinical Trials Fund**

\$250M initiative aims to support researchers across the country to conduct the full spectrum of clinical trials, including the development and testing of new drugs, treatments, and public health and health system interventions to prevent, detect, treat, or manage various diseases or medical conditions

# Health Research and Health-Related Data

Continued collaboration on the Pan-Canadian Health Data Strategy

### A renewed emphasis on EDI in Health Research

### Understanding the gaps across the research ecosystem

#### **Research Content and Practice**



Lack of research on health issues affecting disadvantaged groups



Lack of EDI applied to research design, methods, analysis, interpretation and dissemination



Little knowledge or ability to assess EDI principles in research

#### **Research Environment**



Measures of success reinforce existing inequalities and hierarchies



Lack of underrepresented groups in leadership positions on research teams



Smaller proportion of grants awarded, with lower amounts of funding, to under-represented groups

### **Equity Strategy (EDI)**

#### **EDI in CIHR's Funding System**

- Tri-Agency EDI Statement and Action Plan
- Official Languages & Minority Community Action Plan
- Equity Strategy
- Anti-Racism Action Plan (in development)
- Accessibility and Systemic Ableism Action Plan (in development)

#### **EDI in CIHR's Workplace**

Corporate policies& processes



#### **EDI in CIHR-Funded Research**

- Sex & Gender Based Analysis in Research Action Plan
- Ongoing development of up-to-date EDI/GBA+ training, and resources

#### **Informing CIHR's EDI Actions**

- CIHR External Advisory Committee Anti-Racism
- CIHR External Advisory Committee Accessibility & Systemic Ableism
- CIHR Internal Advisory Committee on EDI in the Funding System
- CIHR Internal Advisory Committee on EDI in the CIHR's Workplace





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