Strategy for Patient-Oriented Research
SPOR
Putting Patients First

Canada’s Strategy for Patient-Oriented Research (SPOR)

An Overview and Update

NAPCRG Patient and Clinician Engagement (PaCE) Workshop

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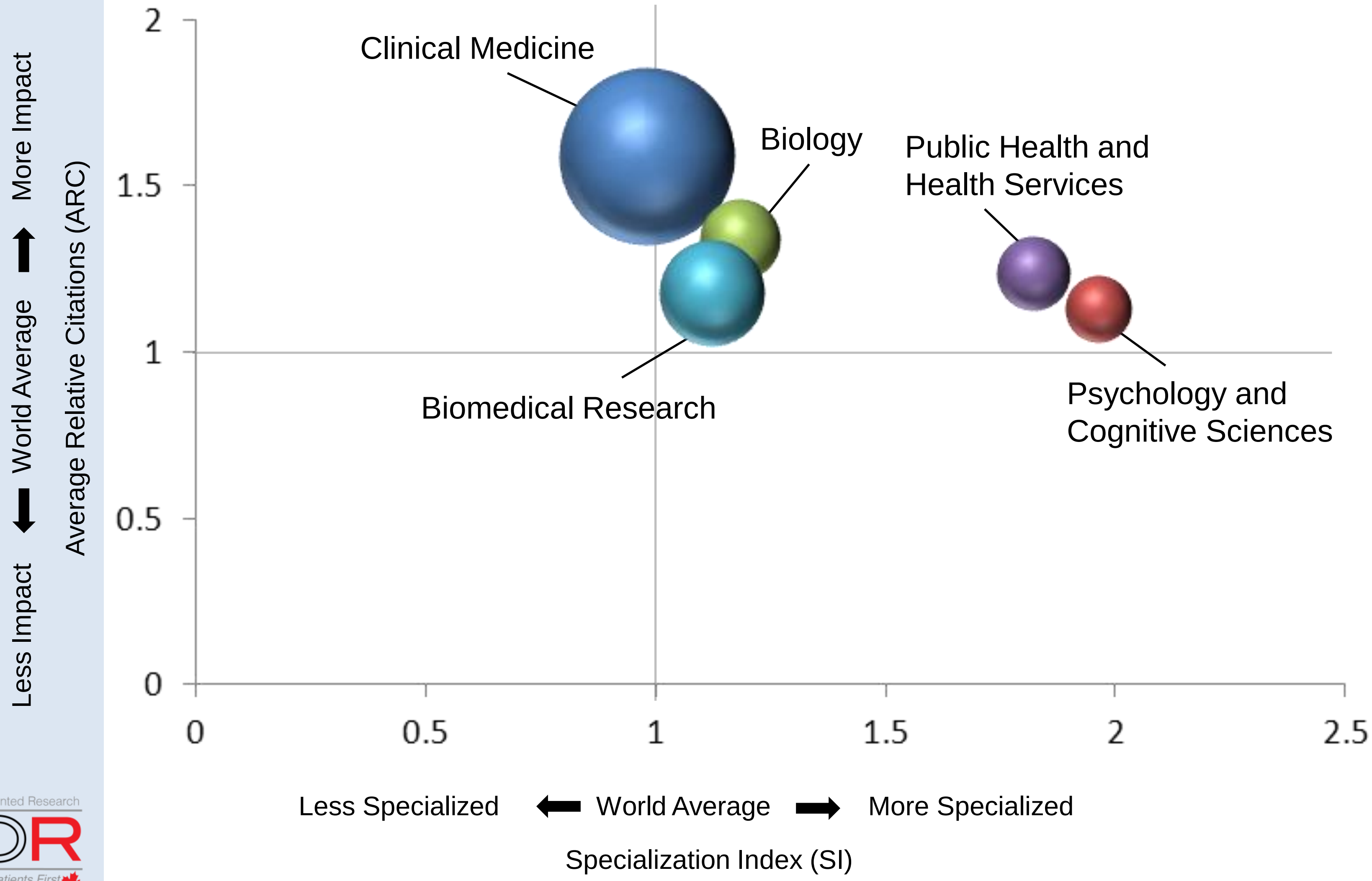
CANADIAN STRENGTHS

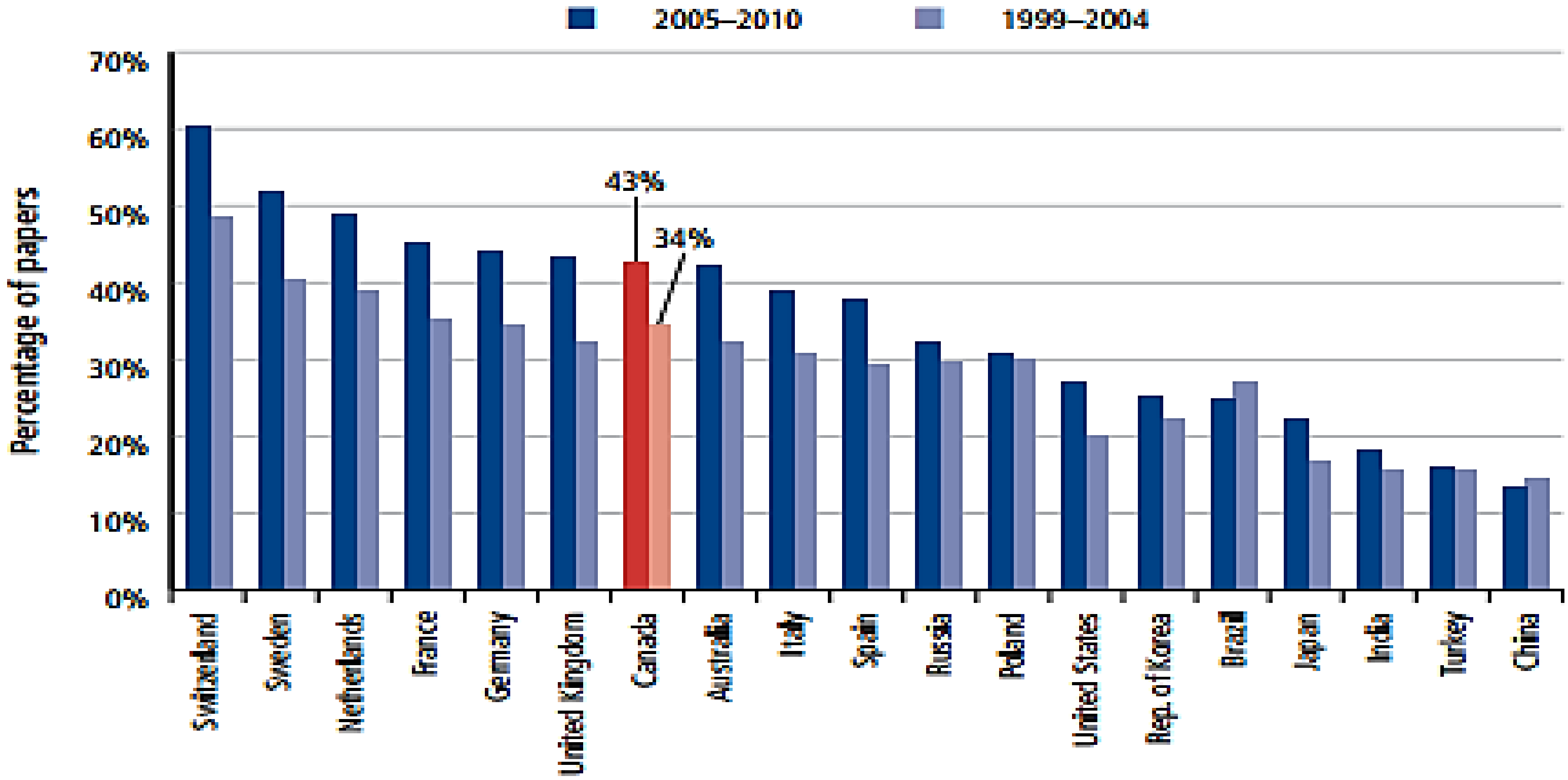
Canada Excels In All Health Research Sectors



Source: The State of Science and Technology in Canada, 2012

CANADIAN STRENGTHS

Strong Intl. Research Collaboration



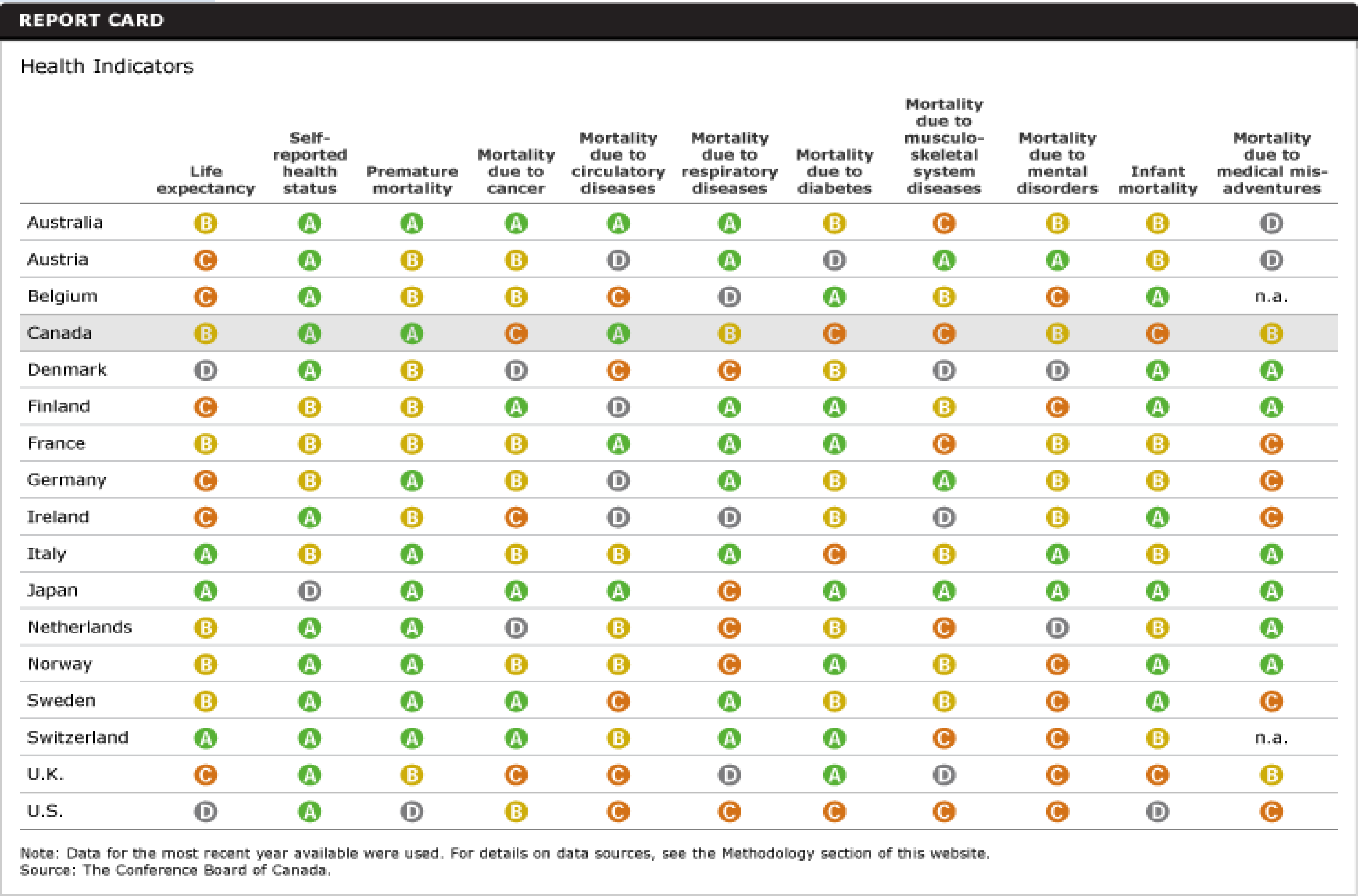
Data source: Calculated by Science-Metrix using Scopus database (Elsevier)

Figure 6.2

Percentage of Scientific Papers Authored with an International Collaborator

Source: The State of Science and Technology in Canada 2012

CANADIAN CHALLENGES



REPORT CARD

Health Indicators

	Life expectancy	Self-reported health status	Premature mortality	Mortality due to cancer	Mortality due to circulatory diseases	Mortality due to respiratory diseases	Mortality due to diabetes	Mortality due to musculo-skeletal system diseases	Mortality due to mental disorders	Infant mortality	Mortality due to medical mis-adventures
Australia	B	A	A	A	A	A	B	C	B	B	D
Austria	C	A	B	B	D	A	D	A	A	B	D
Belgium	C	A	B	B	C	D	A	B	C	A	n.a.
Canada	B	A	A	C	A	B	C	C	B	C	B
Denmark	D	A	B	D	C	C	B	D	D	A	A
Finland	C	B	B	A	D	A	A	B	C	A	A
France	B	B	B	B	A	A	A	C	B	B	C
Germany	C	B	A	B	D	A	B	A	B	B	C
Ireland	C	A	B	C	D	D	B	D	B	A	C
Italy	A	B	A	B	B	A	C	B	A	B	A
Japan	A	D	A	A	A	C	A	A	A	A	A
Netherlands	B	A	A	D	B	C	B	C	D	B	A
Norway	B	A	A	B	B	C	A	B	C	A	A
Sweden	B	A	A	A	C	A	B	B	C	A	C
Switzerland	A	A	A	A	B	A	A	C	C	B	n.a.
U.K.	C	A	B	C	C	D	A	D	C	C	B
U.S.	D	A	D	B	C	C	C	C	C	D	C

Note: Data for the most recent year available were used. For details on data sources, see the Methodology section of this website.
Source: The Conference Board of Canada.

EVIDENCE

"The international experience with engaging citizens and patients in research has shown that involving them early in the design of studies, ideally as early as at the planning stage, leads to better results."

Methods for Involving Patients in Topic Generation for Patient-Centered Comparative Effectiveness Research, An International Perspective (2012), p.8

SPOR – A SOLUTION

The Strategy for Patient-Oriented Research - a coalition of **federal, provincial and territorial partners, including patients, researchers, health practitioners, provincial/territorial health authorities, policy makers, academic health centres, charities, and the pharmaceutical sector, <u>working together</u>** to generate and translate high quality, relevant research into practice.

Patient-oriented research aims to ensure that the right patient receives the right intervention at the right time

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PRINCIPLES

- Patients need to be involved in all aspects of the research to ensure questions and results are relevant and integrated into practice
- Decision-makers and clinicians need to be involved throughout the entire research process to ensure integration into policy and practice
- Funding under SPOR is based on a 1:1 matching formula with non-federal government partners to ensure relevance and applicability
- Effective patient-oriented research requires a multi-disciplinary approach
- SPOR is focused on first-in-human (and beyond) research designed to be transformative in nature and improve patient outcomes and/or the effectiveness and efficiency of the health care system
- SPOR is outcome driven and incorporates performance measurement and evaluation as integral components of the initiative

CORE ELEMENTS

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

SPOR Networks

Capacity development

Improving the clinical trials environment

Patient engagement

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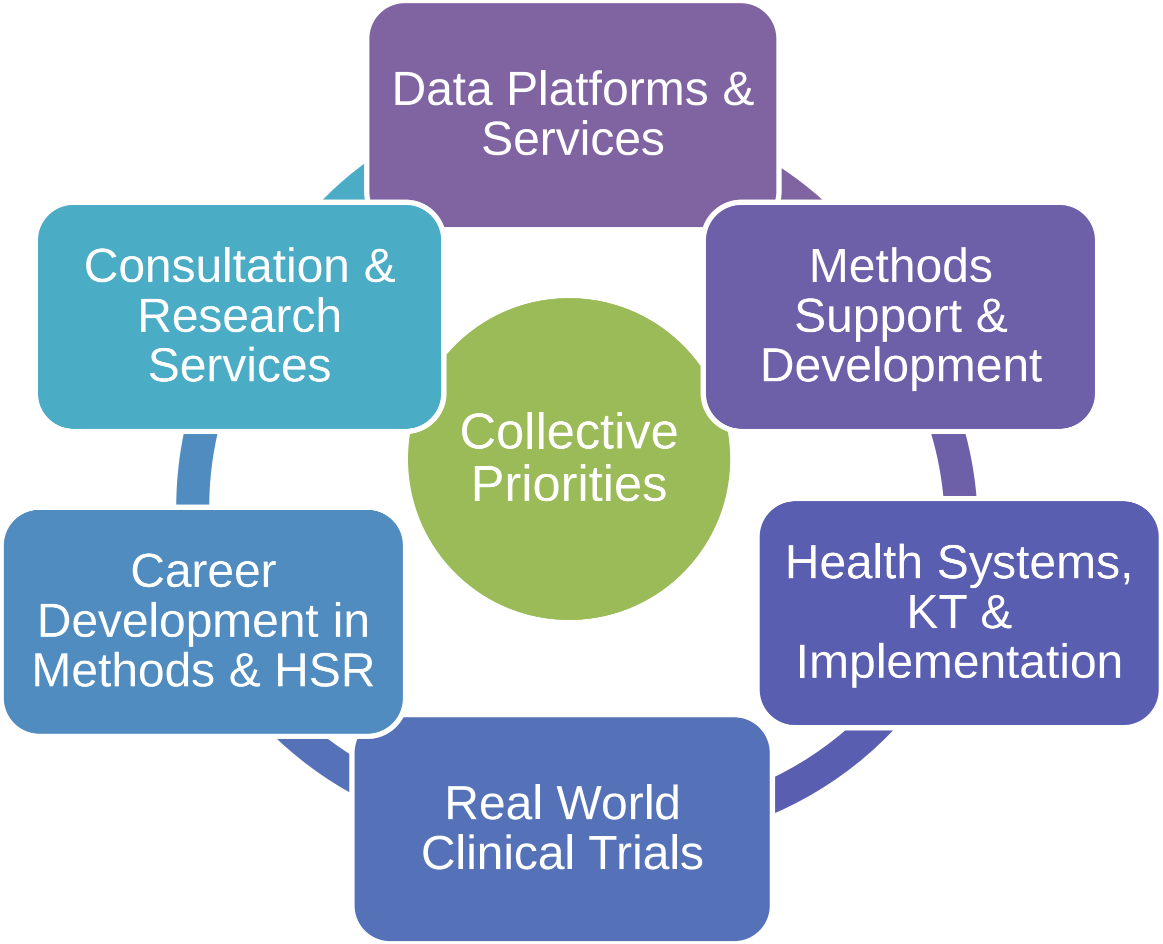
SUPPORT UNITS

Provincial/territorial/regional centres providing support and expertise to those engaged in patient-oriented research



Data Platforms & Services

Methods Support & Development

Health Systems, KT & Implementation

Real World Clinical Trials

Career Development in Methods & HSR

Consultation & Research Services

Collective Priorities

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NETWORKS

National collaborations of patients, health professionals, decision makers, health researchers and other stakeholders to generate evidence and innovations designed to improve patient health and health care systems

DEVELOPING CAPACITY

To grow, support and sustain a collaborative, interdisciplinary and innovative patient-oriented research environment capable of addressing evolving health care questions, contributing to enhancing patients' health care experience and improving health outcomes.

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CLINICAL TRIALS ENVIRONMENT

Through a partnership between CIHR, Canada’s Research-Based Pharmaceutical Companies (Rx&D), and HealthCare*CAN*, the **Canadian Clinical Trials Coordinating Centre (CCTCC)** was created to:

- Measure, monitor and market clinical trial performance improvements
- Leverage existing work on accreditation, harmonization and streamlining ethics reviews and common contracts
- Develop a database of patient registries and consider national recruitment strategies
- Attract international investment in clinical trials

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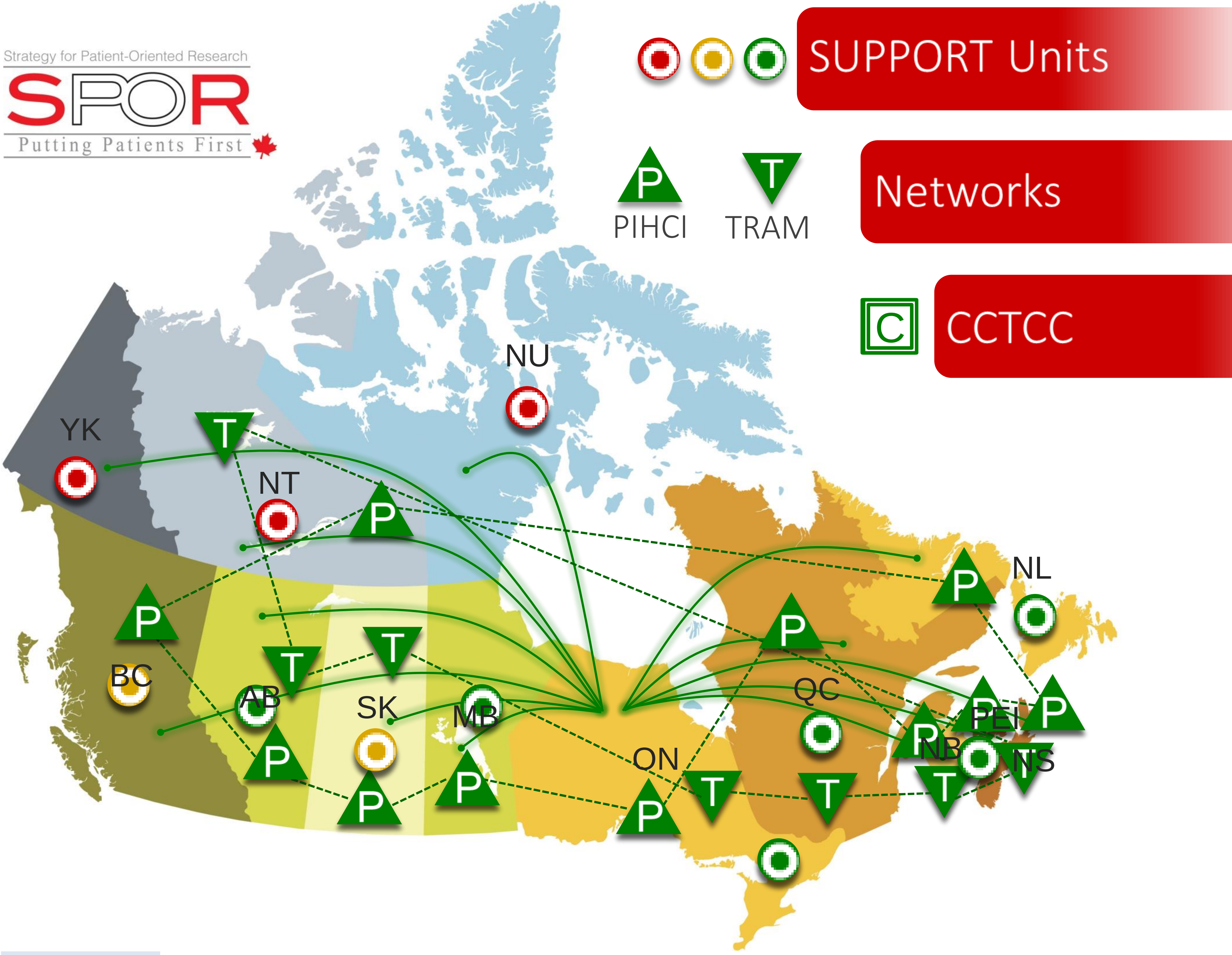

● SUPPORT Units

P PIHCI T TRAM Networks

C CCTCC

"Some researchers are concerned that while research organisations are making involvement a requirement for funding or support, not all researchers know how to do it well….."

Source: TwoCanAssociates Report for Mental Health Research Network (MHRN), March 2012

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PATIENT ENGAGEMENT

A culture change and capacity development are needed

- The original impetus for patient engagement in research was an ethical and moral one – it was the right thing to do.
- Increasingly, it is being done because it has measureable impact :
  - improvement in the credibility of results (higher enrollment and retention)
  - directly applicable to patients (by asking pertinent questions about patient-important outcomes).

Source: Domecq et al. BMC Health Services Research 2014. 14:89

PATIENT ENGAGEMENT

Occurs when patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge

In response to the SPOR Patient Engagement Framework published in June 2014, the CIHR Citizen and Patient Engagement Implementation Strategy is introducing a number of cross-cutting mechanisms across three core areas:

- ✓ Governance and Decision-Making
- ✓ Capacity Building
- ✓ Tools and Resources

PE in Governance & Decision-Making

Ensuring that citizen and patient engagement is embedded in CIHR programs/processes

- Participant Pool
- College of Reviewers
- CIHR Governance structures (IABs, NSC, GC, others)
- Advisory committees for major initiatives
- Incentives/Compensation Policy for patients and citizens

Capacity Building in PE

Ensuring that resources are available to facilitate the participation of citizens and patients in CIHR programs/processes and POR

- SPOR PE funding opportunities

  Up to three complementary funding opportunity streams over five years, starting in 2014-2015 through 2019-2020:

  1. Priority Setting Partnership Model
  2. Collaboration Grants for Patient Engagement
  3. Preparatory Model for PE in Patient-Oriented Research

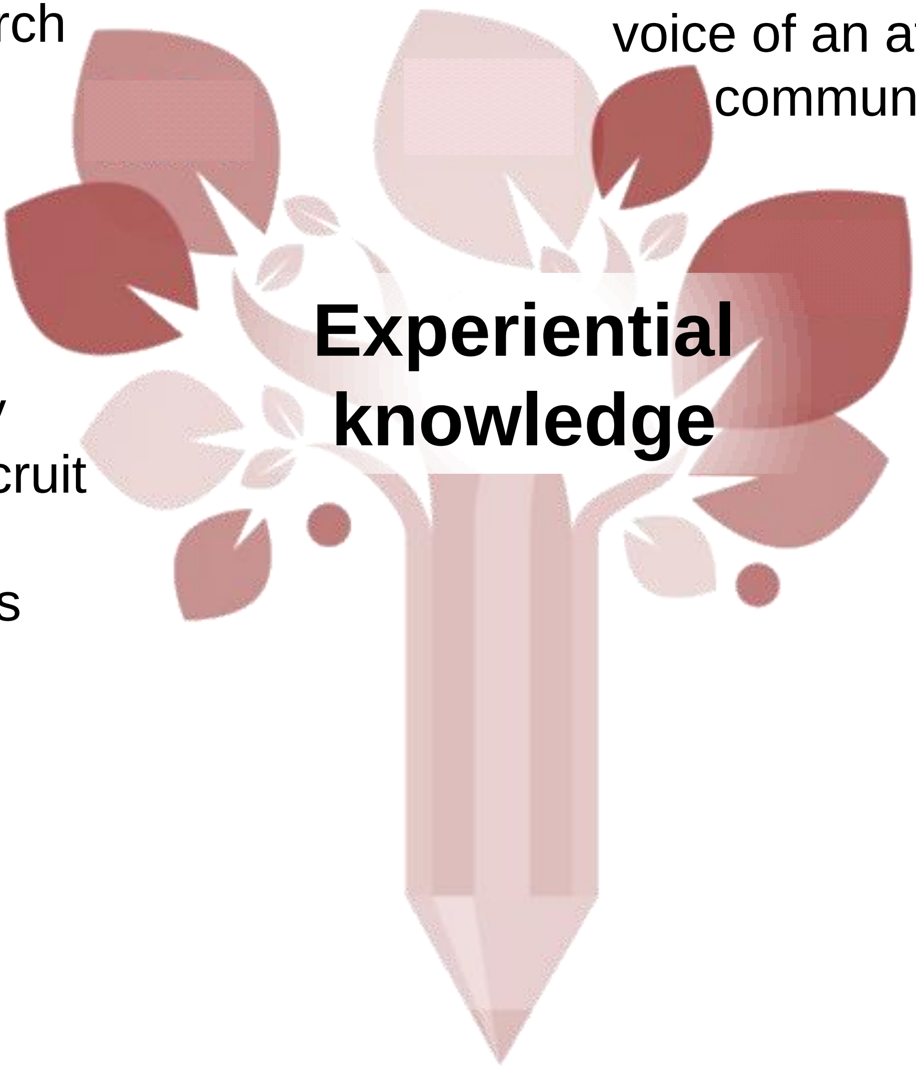
- C&PE Community of Practice

PE Tools and Resources

Ensure tools and resources are available to citizens and patients to help prepare them to effectively contribute to/participate in CIHR programs/processes and POR

- Orientation Resources
  - Jargon Buster
  - Online orientation tutorial to support CIHR governance committees and boards
- Curriculum to prepare patients for engagement in research

HOW PATIENTS CONTRIBUTE



Full members of research teams

Bring the collective voice of an affected community

Experiential knowledge

Specific skillsets, i.e., ethics, knowledge brokers

Identify and recruit other patients

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DISCUSSION and QUESTIONS?