Reconciling Indigenous approaches to knowledge development with patient oriented research: finding common ground

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UNIVERSITY OF SASKATCHEWAN

Acknowledgement of the territory

We respectfully acknowledge that we live, work and play in Treaty 6 Territory and the Homeland of the Métis

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Goals

- *What is patient-oriented research?*
- *What is SCPOR's mission?*
- *What is Indigenous knowledge development?*
- *What do IKD and POR have in common?*
- *Understanding the importance of relationships and reconciliation in research.*

What is patient-oriented research?

- Patient-oriented research is research done in partnership with patients and their families and caregivers, that answers research questions that matter to patients, and aims to improve health care.

- The vision of CIHR's SPOR initiative includes two critical elements. The first is patient-oriented research teams which include patients and family members as partners in the grant writing and research process. The second is the inclusion of decision makers (including policy makers and health authority leaders) and health care practitioners throughout the research process.

- The goal of this way of doing research is to have patients, families, clinicians, researchers and policy-makers work together to identify research topics, do the research and then use the results of that research to improve patient care and the health system.

http://scpor.ca/about/

What is SCPOR's mission?

The Saskatchewan Centre for Patient-Oriented Research is a partnership of organizations that support patient-oriented research in Saskatchewan. SCPOR's objectives are to:

- Identify and address the needs of patients, policy makers, and health professionals by supporting patient-oriented research;
- Provide links to methods expertise in patient-oriented research;
- Assist decision makers and investigators to identify and design research studies, conduct statistical analyses, manage data, provide and teach project management skills, and ensure studies meet regulatory standards;
- Advance methods and training in comparative effectiveness research and develop the next generation of methodologists;
- Facilitate access to Saskatchewan health data and integrate existing or new databases;
- Provide traineeships for university students interested in hands-on experience in patient-oriented research.

http://scpor.ca/about/

What is unique about SCPOR?

SCPOR is committed to community-engaged research and supporting Indigenous health research in the province. We have an **Indigenous Platform** as an integral part of SCPOR because of the demographics and health equity position of First Nations and Métis in Saskatchewan.

Saskatchewan has seen many years of productive and valuable experience in Indigenous community-engaged research. We see the potential for synergies, mutual learnings, and convergence of interests between our Indigenous Platform and the whole of SCPOR.

The Indigenous Platform advises and contributes to SCPOR programs and activities to advance SCPOR's core values and build capacity in Indigenous-specific engagement and research across the province.

http://scpor.ca/about/

What is unique about SCPOR?

Regarding Indigenous community-based research, we at SCPOR are bringing some of the same principles involved to all of our patient-oriented research.

These principles include patient and family involvement in research prioritization and agenda setting, patient and family engagement, along with health system engagement, at all stages of research, including visioning and missioning the research, collection of data, interpretation of results, and dissemination and uptake of findings.

SCPOR research needs to be community relevant, and our patients and family advisors need to be part of the process. They should be empowered by research.

http://scpor.ca/about/

Traditional Research *vs*. POR

Traditional Research	Patient-Oriented Research
• Principal Investigator • Researchers • Trainees/ Students • Content Experts (e.g., Clinicians) • Participants (includes patients, communities, etc.)	• Principal Investigator • **Patients (as team members)** • **Health system leaders/decision-makers** • Researchers • Trainees/ Students • Content Experts (e.g., Clinicians) • Participants (often includes patients, communities, etc.)

Indigenous Research *vs*. POR

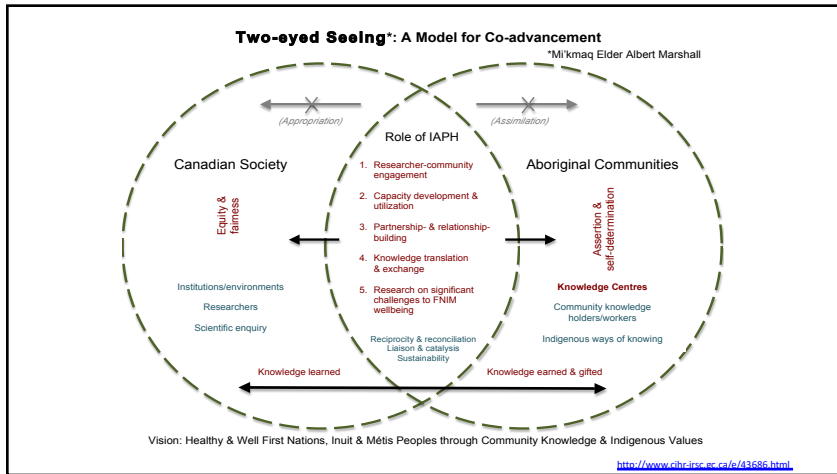| Indigenous Community-Based Participatory Research	Patient-Oriented Research
• POR + • Privileging Indigenous knowledge and ways of knowing • Indigenous voices are meaningful • Respect and adherence to research frameworks/policies (ex. OCAP, Tri-Council – Chapter 9, UNDRIP) • Community involvement/ownership of data and analysis *vs*. only individual • Ceremony and cultural grounding • Trust-building • Strengths-based approach	• Identifying and prioritising • Research design, including research question • Development of the grant proposal • Preparation for execution of the study • Data collection • Analysing and interpreting data • Dissemination • Implementation • Monitoring and evaluation

What is Indigenous knowledge development?

Indigenous knowledge development is a process of research (*knowledge development*) that is iterative, cumulative and transformative. It is based on many paradigms, but notably on observational and experiential learning, on knowledge *earned* and knowledge *gifted*, on accumulating and synthesizing traditional knowledge, and bringing together the physical, mental, emotional and spiritual worlds.

Indigenous *knowledges* are linked to the land and waters in which they evolved.

Indigenous knowledge *development* implies that knowledge is not static, nor fixed in time and space. It adapts and evolves, and it needs to because of the ever-evolving landscape and the context in which we live. IKD is practical; it is applied to life.

Indigenous Worldviews

- *Critical bond to land, nature*
- *Territory and natural environment reflected in our knowledge systems, social arrangements*
- *Part of and interconnected with our landscape*
- *Knowledge is experiential, observational, wholistic, ecological, systems-based*
- *Extensive kinship, including the spirit realm*
- *Time is cyclical and synchronical*

Two-eyed Seeing*: A Model for Co-advancement
*Mi'kmaq Elder Albert Marshall

Ancestral wisdom

- Meaningful involvement of Elders
- Making research about ceremony
  - Smudging, tobacco protocol, song/dance/drumming
  - Feasting
- Including wellness in research

"If you are bringing someone into darkness, you must leave them with some light."

— Elder Sharon Jinkerson-Brass