## Ethical engagement in Indigenous health and wellness research in the virtual era

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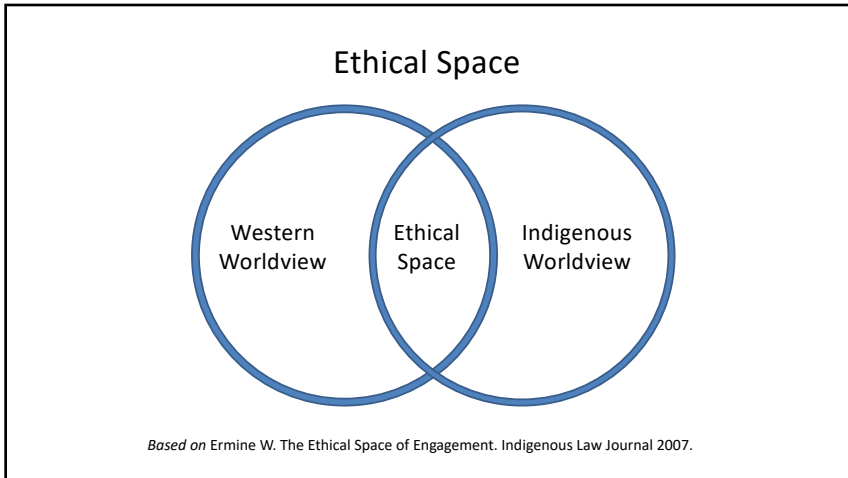University of Saskatchewan
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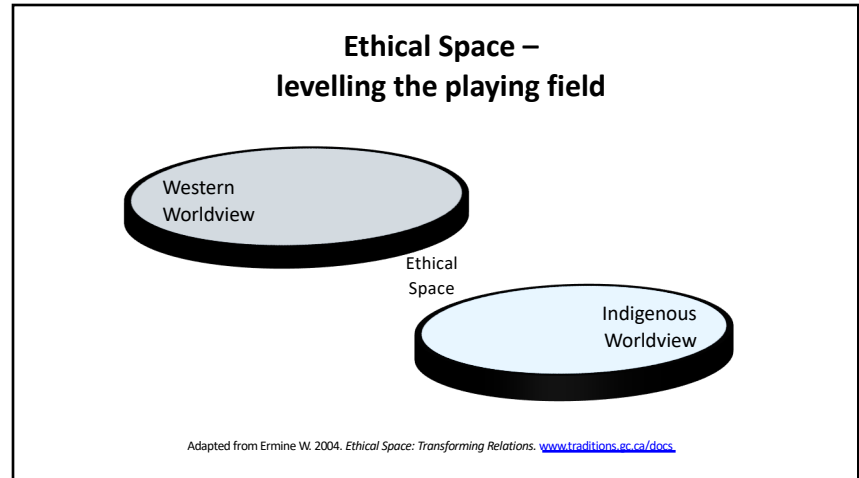### Acknowledgement of the Territory:

We respectfully acknowledge that we live, work and play in Treaty 6 Territory and the Homeland of the Métis in what has become Canada.

We acknowledge the Native Peoples of Alaska, and the Dena'ina in particular, on whose traditional and ancestral homelands we are virtually gathered.
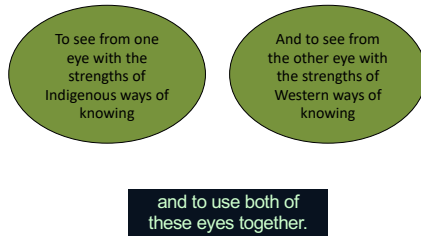
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## Ethical Space



Western Worldview — Ethical Space — Indigenous Worldview

Based on Ermine W. The Ethical Space of Engagement. Indigenous Law Journal 2007.

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## Ethical Space – levelling the playing field



Western Worldview

Ethical Space

Indigenous Worldview

Adapted from Ermine W. 2004. Ethical Space: Transforming Relations. www.traditions.gc.ca/docs

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## Two-eyed Seeing: *Etuaptmumk*

The perspective of "two-eyed seeing", as put forward by
Mi'kmaq Elder Albert Marshall

To see from one eye with the strengths of Indigenous ways of knowing

And to see from the other eye with the strengths of Western ways of knowing

and to use both of these eyes together.

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## Tri-Council Policy Statement 2, Chapter 9:
*Research Involving the First Nations, Inuit and Métis Peoples of Canada*

**Key concepts / principles**
- **Requirement of community engagement in Aboriginal research**
- Respect for First Nations, Inuit and Métis governing authorities
- Recognizing diverse interests within communities
- Respect for community customs and codes of practice
- Institutional research ethics review required
- Research agreements desirable, encouraged

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## TCPS2, Ch9: *cont'd*

- **Collaborative research – communities as partners**
- **Mutual benefits in research**
- Strengthening research capacity
- Recognition of the role of Elders and other Knowledge Holders
- Privacy and confidentiality
- Interpretation and dissemination of research results
- Intellectual property related to research
- *Collection of human biological materials involving Indigenous peoples*

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## TCPS2, Ch9: *further considerations*

- Engaging with the community: why does it always have to come from the academic side?
  - Pro-active engagement of Indigenous people with the academic research community, driving the agenda from the community side
  - Seeking ethical space from an Indigenous place

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## Other resources

- CIHR Guidelines for Health Research Involving Aboriginal People (2007-2010): https://cihr-irsc.gc.ca/e/29134.html

- A Principled Approach to Research Conducted with Inuit, Métis, and First Nations People: Promoting Engagement Inspired by the CIHR Guidelines for Health Research Involving Aboriginal People (2007-2010): https://ojs.lib.uwo.ca/index.php/iipj/article/view/10635

-  Indigenous Community Research Partnerships

- https://www.queensu.ca/indigenous/decolonizing-and-indigenizing/indigenous-research/indigenous-community-research-partnerships

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## Patient-Oriented Research – ethical engagement

- 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.

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## Traditional *vs*. Patient-Oriented Research

| Traditional Research | Patient-Oriented Research |
|---|---|
| • Principal Investigator<br>• Researchers<br>• Trainees/students<br>• Content experts (e.g., clinicians)<br>• Participants (includes patients, communities, etc. ) | • Principal Investigator<br>• **Patients (as team members)**<br>• **Health system leaders/ decision-makers**<br>• Researchers<br>• Trainees/students<br>• Content experts (e.g., clinicians)<br>• Participants (often includes patients, communities, etc. ) |

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## POR *vs*. Indigenous Research

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

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## Decolonization

- Must address the "hegemonic basis of society's values, practices, and institutions":
  – Oppression
  – Colonialism/colonization
  – Racism
  – Privilege/Whiteness
- Ubiquitous across the institution and include all relevant systems, structures, policies and practices
- Must transcend health disciplines, institutions

Jones R, Crowshoe L, Reid P, Calam B, Curtis E, Green M, Huria T, Jacklin K, Kamaka M, Lacey C, Milroy J, Paul D, Pitama S, Walker L, Webb G, Ewen S. *Educating for Indigenous health equity: An international consensus statement.* Academic Medicine 2018.

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## Indigenous research methodologies

- Emerging, evolving, growing
- Creating ethical spaces where Indigenous Ways of Knowing/Doing coexist with Western Ways of Knowing/Doing
- Encompassing Indigenous worldviews, health systems and knowledge systems
- Need explicit recognition of Indigenous epistemologies and knowledges and explicit commitment to embracing Indigenous Ways of Doing
- Indigenous leadership essential

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## Innovating new approaches, methodologies

- Grounded in Indigenous ways of knowing, being and doing
- Wholistic, integrative, ecological
- Imbued with culture, language
- Ceremonial, engaging with spirit
- Spanning research life cycle: data collection, analysis, interpretation, knowledge mobilization
- Spiritual coding
- Coding in language

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