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Building Respectful Research Relationships with Indigenous Communities

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Dr. Suzanne Stewart (1), Dr. Melanie Jeffrey (2) & Dr. Sandra Juutilainen (3)

[1. Suzanne.stewart@utoronto.ca](mailto:Suzanne.stewart@utoronto.ca)

[2. melanie.jeffrey@utoronto.ca](mailto:melanie.jeffrey@utoronto.ca)


[3. sandra.juutilainen@ryerson.ca](mailto:sandra.juutilainen@ryerson.ca)




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Outline

- Introduction and greetings
- Relationship Building
- Developing the project: iterative approach based on Indigenous Epistemology
- Outcomes to date
- Next steps



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Relationship Beginnings: Praxis



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Health Care Practitioners & Community Partners

- Snowball sample, local/national landscape
- Surgeons, physiotherapists, statisticians, researchers (sciences, social sciences, humanities)
- Allied health care providers, community service organizations
- Gathering knowledge, perspectives, and known gaps in the research landscape
- Making contacts, foundation for continued growth

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Existing Data

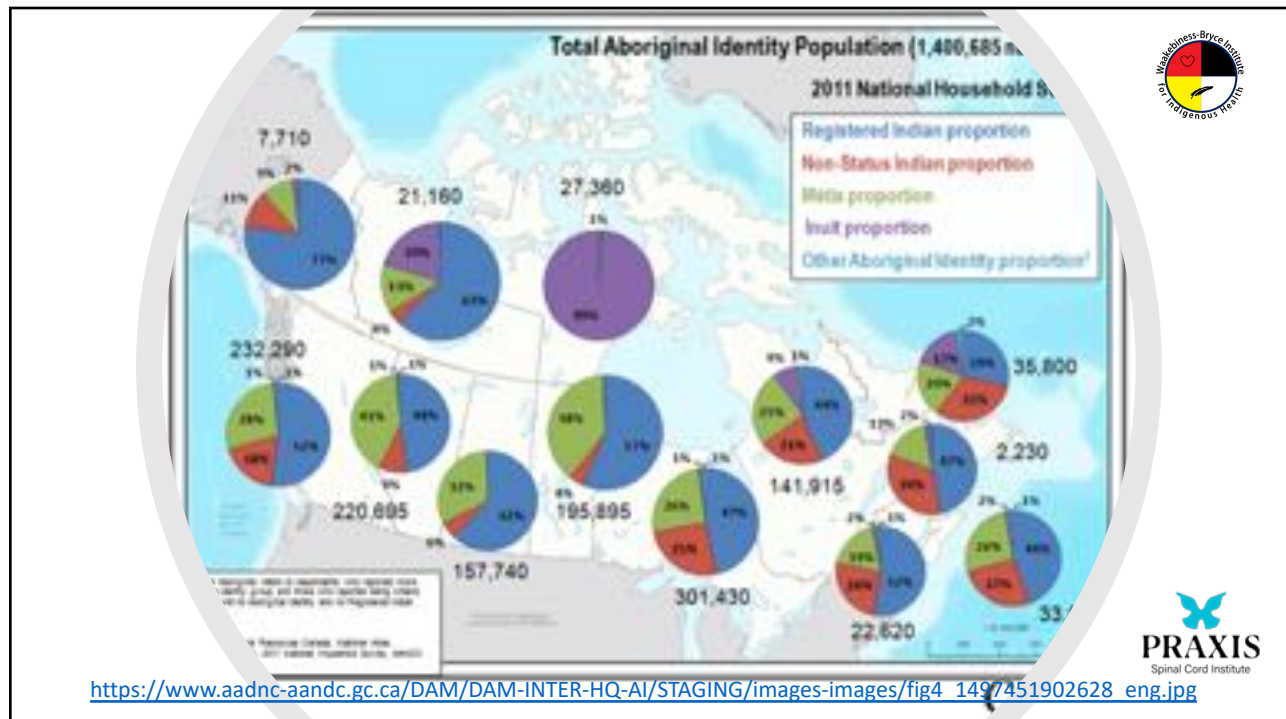
- **No First Nations SCI registry or database currently exists in Ontario or across Canada**
- **Ontario spinal centers: (self-enrolment, self-identification) Toronto, Hamilton, London, Kingston or Ottawa**
- Data governed by Chiefs of Ontario that recognizes only “status” First Nations
- Not all who self-identify as Indigenous have “Indian status”
- Eliminating “Indian Status” was an explicit goal of legislation



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American Indian / Alaska Native Study

- 3x more likely to experience unintentional trauma; 3.4x more likely to experience motor vehicle crash
- Younger, longer hospital stay, higher probability of death
- Increased risk of secondary complications
- Decreased QOL when not rehab-treated
- Decreased functional independence (inpatient rehab and longer rehab stays)
- Higher risk of self-discharge to home in lieu of rehabilitation



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Indigenous TBI Trends Worldwide

- Traumatic Brain Injury
 - 5x risk craniofacial fractures; 22x risk women in Australia; 3x risk osteoporosis
- Need increase in published literature
 - Trauma-related SCI, modifiable lifestyle behaviors, osteoporosis, falls and fractures in Indigenous persons
- Risk factors & comorbidities for SCI overlap
 - Diabetes, substance abuse, lower income, geographic locality, and fracture history



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Underserved: Thunder Bay and Spinal Cord Injury

- Transfer from a rural/remote community is culture shock
 - Community, culture, family, ancestral territories and lifeways
 - Urban, cost, racism, loneliness
- Accessible housing
 - Cost of renting significant burden
 - Family, support team; need larger apartments, difficult to find
- Complex medical needs, physio and other rehabilitation services
- There is a severe shortage of PSWs in Thunder Bay

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Thunder Bay, Nishnawbe-Aski Nation and Spinal Cord Registries

- People can only choose to participate in current registries if they are treated at a spinal center: London, Hamilton, Toronto, Kingston, or Ottawa
- 5/463 hospitals in Ontario (none in Northern Ontario)
- May or may not choose to self-identify as Indigenous on treatment intake forms
- Perceived or anticipated systemic racism
- First point of contact with Health Care may be emergency ward

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More Data is Needed

- Paucity of Indigenous SCI research to address specific needs of Indigenous persons:
 - Urban, rural and remote populations; on- and off-reserves
 - Cultural diversity
 - Risk factors, prevention, outcomes
 - Barriers and facilitators to treatment, wellness
 - Best practices for rehabilitation, holistic health
 - Community and Individual needs, strengths, and resiliencies



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Quantitative & Qualitative Methods

- Indigenous research mostly qualitative, limits evidence based for policy decisions
- Both are situated in dominant culture and translated into academia
- Qualitative: In-depth, subjective, experiential, context
- Quantitative: Numerical, abstracts
- Community knowledge differs from academic knowledge
- A dataset informed by 1) community priorities, 2) qualitative and quantitative measures is needed to enact policy change



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A Meaningful Dataset?

- Current databases of Indigenous health document difference, disparity, deprivation, disparity, deficit, and dysfunction
- Ours: strengths-based!
- A meaningful database of TSCI for Indigenous persons in Northern Ontario recognizes and encodes their unique needs
- How data are collected, analyzed and interpreted are social constructions ... and so they can be changed!



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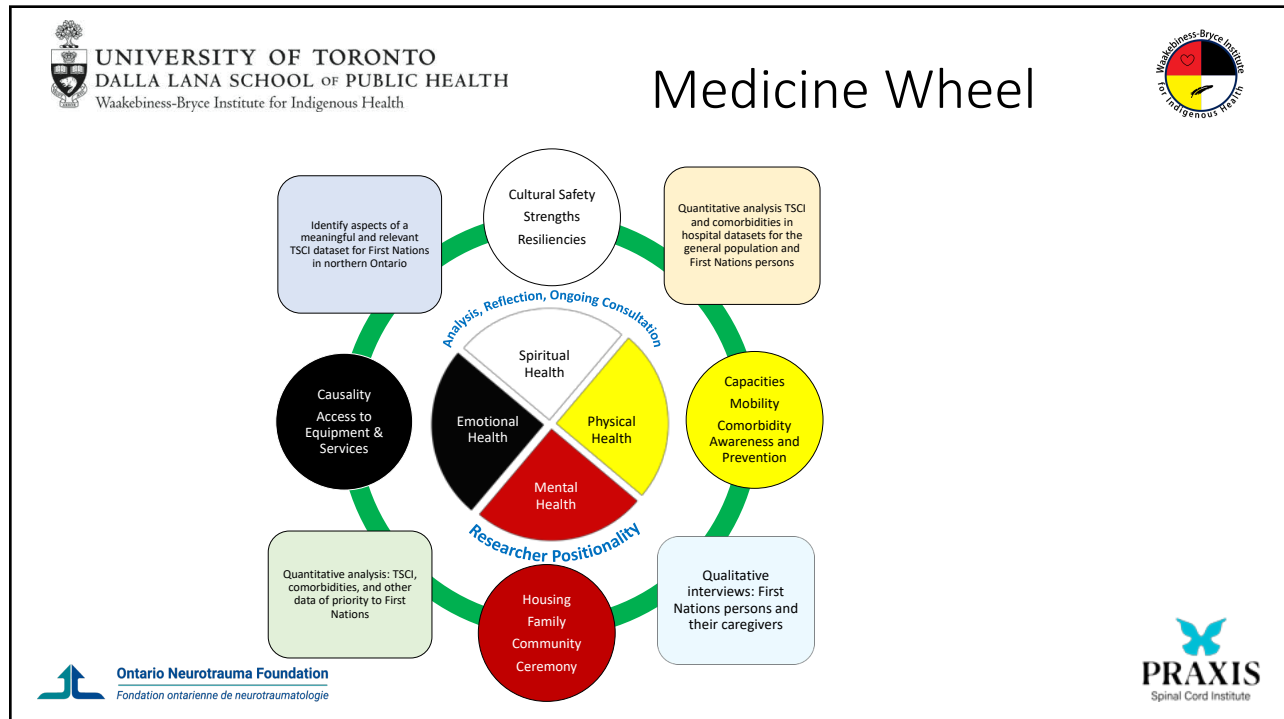
Two Row Wampum



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Quantitative Methods

- Quantitative: Numerical, abstracts from local/collective contexts
- Census data: one way (lens) we look at the social world
- "Worldview"
- Listening well (listeners and learners, not experts)
- Imposing own ideas a kind of colonization
- Meaningful dataset: an Indigenous lens for TSCI
 - What matters to them...
 - More rich, contextual dataset
 - Factors may lie outside of typical medical datasets, but should be included

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PRAXIS
Spinal Cord Institute

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Ethics

- The ethics of Indigenous research are informed by community protocols... and so are our research methods
- Protocol and time spent to develop relationships, listen well, and understand which types of data are important, and how people share them, are essential to ethical Indigenous research
- Gentle reminders for collaborators about taking the time to engage, invest, and listen in ongoing collaboration... as Elders consulted in the initial stages of the project suggested



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Enacting OCAP®


- The First Nations principles of OCAP® are a set of standards that establish how First Nations data should be collected, protected, used, or shared.
- **O**wnership, **C**ontrol, **A**ccess and **P**ossession
- Enacting: Must have relationships built and ,maintained before can approach registry with an Applied Health Research Question (AHRQ)
- How would this work for Indigenous Health Registries?



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Outcomes




Praxis hires Richard Peter, Indigenous Peoples Liaison

Over 40 years experience



Outreach and education for others in SCI health care, service provision, and research


More listening to align the research project with community identified needs

Long term investment: Endowed professorship in Indigenous Neurological Health




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A Recent Saskatchewan Study...




Ahmed, US., Humphreys, S., Rivers, C. Jeffrey M., Fourney, D.R.
2020. Traumatic Spinal Cord Injuries among Aboriginal and Non-Aboriginal Populations of Saskatchewan: A Prospective Outcomes Study. Canadian Journal of Surgery, 63(3):E315, DOI: 10.1503/cjs.012819


- Most common cause: MVA (like general population)
 - Motor vehicles in use not specified in datasets
- 2nd most common cause: **Assault** (unlike general population, which was falls)




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A National Canadian Study currently in writing:


- Renne et al (2021). “Traumatic Spinal Cord Injuries among Aboriginal and Non-Aboriginal Populations of Canada: A Prospective Outcomes Study”
- Higher prevalence of Indigenous TSCI
- Similar level of injury, comorbidities, younger age, but longer in acute care
 - More injuries in/discharge to rural locations
- Complex health disparities, choosing the right measures and reporting modalities




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Next Steps

- Target journals, ethical and practical aspects of Indigenous health research methodologies
- Indigenous working group, Nurses Specializing in Wound, Ostomy and Continence
 - New project: Indigenous community-identified accessibility needs across Canada through the lens of wound prevention, including diabetic foot and SCI
- Invited talks with biomed collaborators, Canadian Spinal Cord Injury Network, Degenerative Cervical Myelopathy Summit, and growing!





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Masi Cho/Miigwetch/Yaw[^]ko/Thank You