Embarking on a Journey to Explore the Realities of Pediatric Solid Organ Transplantation for Indigenous Patients, Families and Communities across Canada

Lin, J.[1], Pol, SJ.[1], Beaucage, M.[2], Dart, A.[3], De Angelis, M.[1], Ghent, E.[1], Goldberg, A.[3], Hartell, D.[4], Henderson, R.[1],
Matsuda-Abedini, M.[1], Toulouse, C.[1], Urschel, S.[5], Weiss, M.[6], & Anthony, SJ.[1]
[1]Hospital for Sick Children; [2]Ontario Renal Network; [3]Health Sciences Centre Winnipeg; [4]Canadian Blood Services; [5]Stollery Children's Hospital; [6]Centre Hospitalier Universitaire de Québec

BACKGROUND

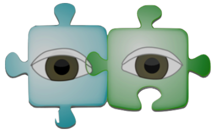
- Indigenous children, including First Nations, Inuit and Metis, are the fastest-growing cohort of children in Canada and experience persistent health and social disparities.[1]
- Indigenous children report higher rates of end-stage organ failure and poorer outcomes following solid organ transplantation (SOT).[2]
- Call to Action 18 of the Truth and Reconciliation Commission (TRC) states "*to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities*".[3]

OBJECTIVE

To advance **child health equity** by improving access to and health outcomes of pediatric SOT among Indigenous patients and families.

GUIDING PRINCIPLES

COMMUNITY-BASED PARTICIPATORY RESEARCH
Recognizes the unique strengths that each brings

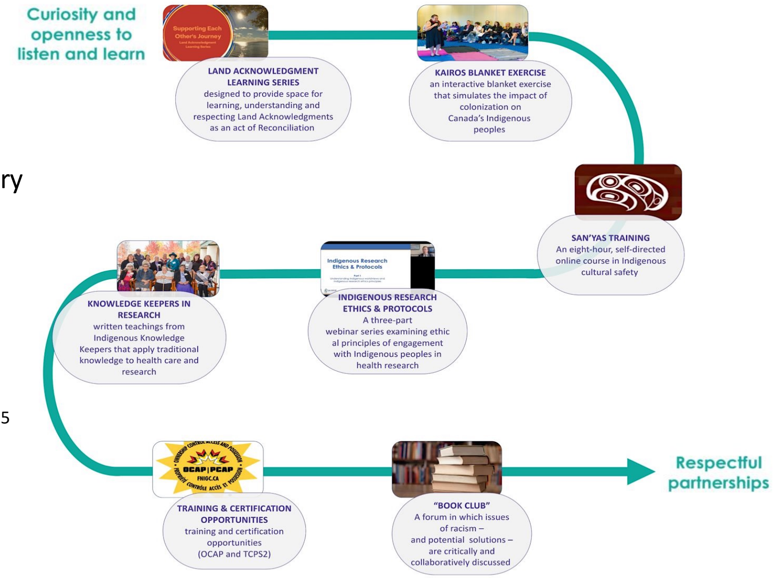


TWO-EYED SEEING[4]
"gift of having multiple perspectives"

DATA SOVEREIGNTY
OCAP – ownership, control, access and possession

COMMUNITY ENGAGEMENT

- We have established an **Advisory Committee** comprised of Indigenous patients and families.
- We will **engage, support, collaborate and empower** Advisory Committee partners to co-lead research processes such that findings are relevant and meaningful to their respective communities.
- We are following the **Wabishki Bizhiko Skaanj learning pathway,**[5] to build cultural competency and un/relearn ethical ways of researching with Indigenous populations.



Wabishki Bizhiko Skaanj Learning Pathway combines the following elements:

Curiosity and openness to listen and learn

LAND ACKNOWLEDGMENT LEARNING SERIES
designed to provide space for learning, understanding and respecting Land Acknowledgments as an act of Reconciliation

KAIROS BLANKET EXERCISE
an interactive blanket exercise that simulates the impact of colonization on Canada's Indigenous peoples

SAN'YAS TRAINING
An eight-hour, self-directed online course in Indigenous cultural safety

INDIGENOUS RESEARCH ETHICS & PROTOCOLS
A three-part webinar series examining ethical principles of engagement with Indigenous peoples in health research

KNOWLEDGE KEEPERS IN RESEARCH
written teachings from Indigenous Knowledge Keepers that apply traditional knowledge to health care and research

TRAINING & CERTIFICATION OPPORTUNITIES
training and certification opportunities (OCAP and TCPS2)

"BOOK CLUB"
A forum in which issues of racism – and potential solutions – are critically and collaboratively discussed

Respectful partnerships

Phase 1
Scoping Review

- To **CHARACTERIZE** the international literature and identify knowledge gaps relating to access, survival and health outcomes (**IN PROGRESS**).

Phase 2
Retrospective Cohort Study

- To **EXPLORE** short- and long-term outcomes between Indigenous and non-Indigenous pediatric SOT recipients.

Phase 3
Qualitative Story Gathering

- To **CAPTURE** the experiences of Indigenous patients, caregivers, Elders and Knowledge Keepers, clinicians and health researchers.

Phase 4
Knowledge Sharing Workshop

- To **SHARE** research findings in a meaningful way and establish culturally-relevant recommendations to inform clinical care.

IMPACT AND FUTURE DIRECTIONS

- With a better understanding of the **lives, cultures, stories and experiences** of Indigenous patients and families, healthcare institutions can move towards improving access and care to reduce health disparities in pediatric SOT.
- Findings directly address the **TRC's Call to Action 18** and may strengthen population health database processes.
- Through a **co-learning journey**, we lay the ethical and relational groundwork for future phases of community-based, patient-oriented research to explore the unique and diverse realities of SOT for Indigenous patients, families and communities.

REFERENCES

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