

Canadian Population Screening for Risk of Type 1 Diabetes (CanScreen T1D) Research Consortium

P.A.T.H.™ Exercise Meeting

December 7, 2024

Mission: Design a pilot (test) Type 1 Diabetes (T1D) screening program for newborns and children that is **culturally sensitive**, **easy to use**, and **accessible** to families from diverse backgrounds.

Goal: Collaborate to co-design a protocol (rules and guidelines) for T1D screening in Indigenous communities that will be used to develop in the pilot T1D screening program.

STRENGTHS

- 1. **Lived Experience and Expertise:** Indigenous Patient Circle (IPC) members bring lived experiences, diverse expertise, and distinct worldviews on First Nation needs, priorities, and gaps.
- 2. **Advocacy and Communication:** Strong advocacy efforts and effective communication skills ensure accessible and relatable messaging for diverse audiences.
- 3. **Indigenous Knowledge:** Recognition of Indigenous culture and the importance of integrating distinct languages and Nations into the work.
- 4. **Community Engagement:** Leveraging partnerships with community leadership and members to strengthen relationships and outcomes.
- 5. **Leadership Support:** Ongoing backing from First Nations leaders, with a commitment to keeping them informed and involved.
- 6. **Visual and Accessible Data:** Emphasis on visually appealing and easy-to-understand data (e.g., graphs, maps, charts) for visual learners.
- 7. **Ethical Research Practices:** Commitment to ethical research, reporting findings, and ensuring data sovereignty while addressing gaps in Indigenous research representation.
- 8. **Global Insights:** Learning from other geographic contexts, such as Australia, while avoiding one-size-fits-all approaches.
- 9. **Diversity and Inclusion:** A diverse group representing various ages, Nations, and worldviews ensures no one is left behind.
- 10. **Decision-Making Authority:** IPC retains decision-making power to guide and champion this pilot project.
- 11. **Bridging Existing Work:** Integration with ongoing initiatives like health events, conferences, and knowledge exchanges to strengthen the project's foundation.

- 12. **Cultural Connection:** Use of storytelling and language fosters a deeper connection with communities.
- 13. **Conference Participation:** Engagement in relevant events such as the First Nations Data Sovereignty & Research Conference supports networking and knowledge sharing.
- 14. **Respectful Guidance:** Commitment to listening to IPC guidance and amplifying voices often overlooked in research.

WEAKNESSES

- 1. **Systemic Barriers:** Racist systems and a lack of trust between First Nations and external researchers hinder engagement and care.
- 2. **Resource Disparities:** Limited resources and attention to T1D compared to Type 2 diabetes (T2D) create knowledge and advocacy gaps.
- 3. **Community Mistrust:** First Nations communities, often over-researched, requires clarity on how this study will be different and beneficial.
- 4. **Healthcare Challenges:** Inconsistent follow-up care, fear of medical systems, and lack of accessible diabetes education and advocacy deter engagement.
- 5. **Complexities in Planning:** The pilot rollout involves many layers, with uncertainty around logistics like antibody screening and resource availability.
- 6. **Communication Gaps:** Communities need reassurance that this work prioritizes their benefit and addresses fears tied to the topic of T1D.
- 7. **Research Practices:** A history of "parachute" research and lack of continuity undermines trust and long-term impact.
- 8. Lack of Infrastructure & Education Opportunities: Community members often lack safe spaces to ask questions about their disease, medication, and care options.
- 9. **Healthcare Accessibility:** Screening and treatment options may be limited to hospitals, excluding community-based alternatives.
- 10. **Expansive Network Challenges:** Managing and leveraging a broad contact network can dilute focus and consistency.

OPPORTUNITIES

- 1. **Secured Funding:** Guaranteed funding until 2028 ensures stability for project development and implementation.
- 2. **Strategic Direction:** A clean slate provides flexibility to shape the project's goals and priorities.
- 3. **Framework Development:** Creation of the CanScreen T1D Indigenous Community Engagement Framework/Guidelines to enhance ethical and effective collaboration.
- 4. **Engagement Opportunities:** Participation in key gatherings such as the Tataskweyak Women's Gathering (2025) and the First Nations Health Gathering (2025) for networking and knowledge sharing.
- 5. **Community Partnerships:** Opportunities to collaborate with identified communities and partners, including Brokenhead Ojibway Nation, Anishinabek Nation, Mushkegowuk Health, and more.
- 6. **Provincial Hubs:** Establishing connections through provincial hubs like Thompson, Sioux Lookout, and others for the inclusion of localized First Nations perspectives.
- 7. **Knowledge Exchange:** Leveraging platforms like the Nishnabe Aski Nation website for future conferences and collaborative opportunities.
- 8. **Workforce Development:** Exploring diabetes educator and navigator certification training to build capacity.
- 9. **Existing Programs:** Utilizing programs such as Manitoba's Kidney Check for point-of-care testing and leveraging partnerships with northern health networks.
- 10. **Trauma-Informed Approach:** Building the project on a foundation of trauma-informed and anti-racist practices to foster trust and inclusivity.
- 11. **Midwife and Doula Engagement:** Collaborating with Indigenous midwives and doulas to enhance reach, increase community trust and culturally aligned care.