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

What is Diabetes?

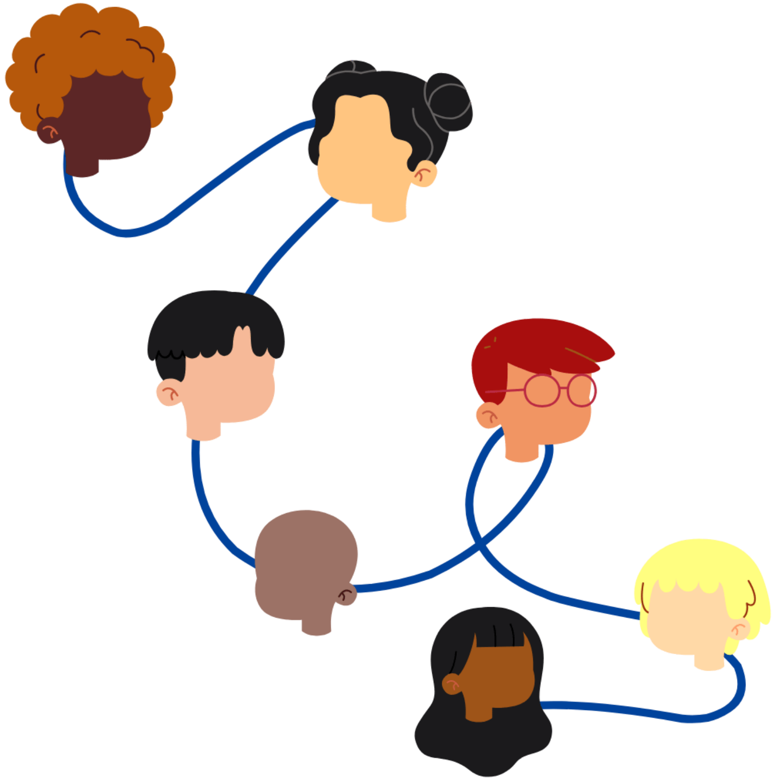
- Diabetes is a condition where **the body cannot properly regulate glucose (blood sugar) levels**, either due to insufficient insulin production or insulin resistance.
- Insulin is a hormone produced by the pancreas (organ for digestion in our body) that helps control glucose levels by allowing cells to absorb glucose for energy.
- **Type 1 Diabetes (T1D):** Immune system attacks and destroys the cells that make insulin, meaning people with T1D need insulin for life.

Why Screen for T1D in Children?

- People living with T1D experience daily challenges with management and reaching their target blood sugar levels.
- Screening for the risk of T1D involves testing people to identify those at higher risk of developing the condition **before symptoms appear**.
- Early detection of the risk of T1D can help with **earlier diagnosis** and **better follow up and monitoring** to prevent complications while **making it easier for families to manage the condition** every day.

What is the CanScreen T1D Research Consortium?

- National initiative brings together the voices of the public, researchers, individuals living with type 1 diabetes (T1D), healthcare providers, and other experts from across Canada.
- Work closely with Diabetes Action Canada.
- Launched in 2023, ending in 2028.
- **Mission:** Design a pilot (test) T1D screening program for newborns and children that is **culturally sensitive**, **easy to use**, and **accessible** to families from diverse backgrounds.



How is CanScreen T1D Structured?

1

Research Theme #1: Acceptability

We are engaging with diverse groups of people—including families, clinicians, and Indigenous communities—to **ensure the pilot T1D screening program meets their unique needs and values**.

Understanding perceptions and cultural sensitivities is key to our mission.

2

3

How is CanScreen T1D Structured?

①

Research Theme #2: Feasibility

We are investigating the most effective screening method for our general population.

②

This includes a trans-ancestral genetic risk score (genetic information from different ethnic groups to more accurately predict disease risk) to reflect our diverse population.

③

It will help us ensure that **our pilot T1D screening program is both scientifically robust and practical**.

How is CanScreen T1D Structured?

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Research Theme #3: Follow up and Monitoring

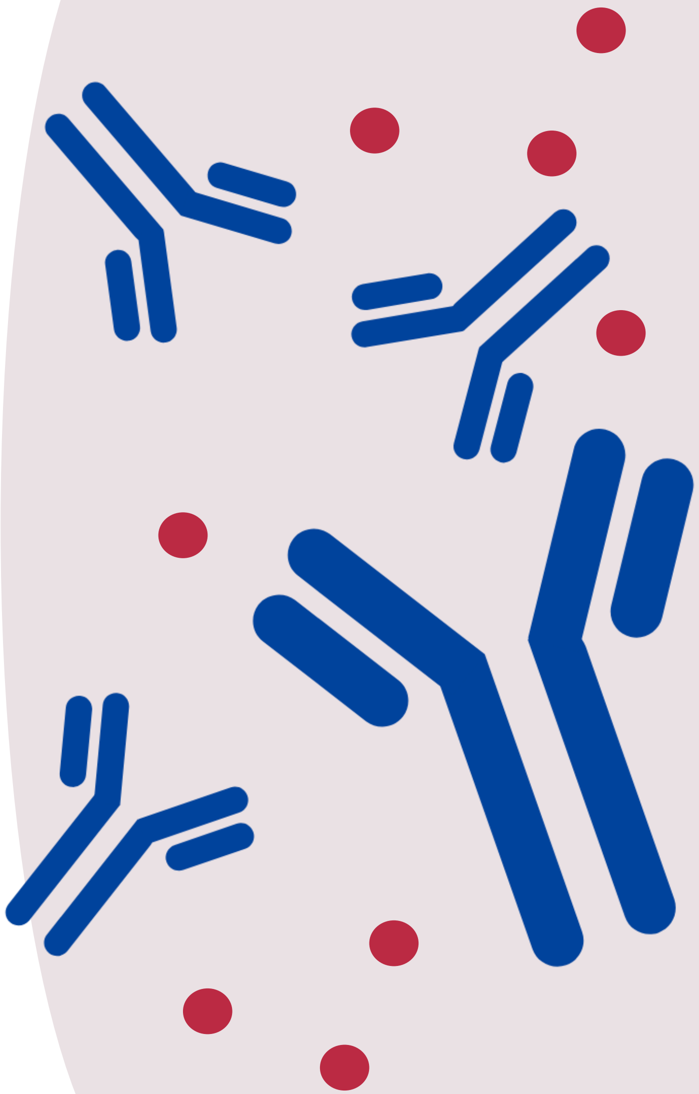
We are establishing genetic counseling support and providing educational resources for families who test positive for the risk of developing T1D.

We are also building a network of researchers and healthcare professionals for ongoing support during and after the screening procedure.

This will ensure that **families receive the necessary support and guidance** throughout the process.

The Pilot T1D Screening Program

- The specific projects that fall under these 3 themes and their findings will feed into the development of the pilot screening program.
- We will further assess its acceptability and feasibility, generate evidence to support policy decisions and identify any gaps that may affect implementation.
- Expected to launch in 2026.



Community Engagement

- **Goal:** To ensure our research, including the pilot T1D screening program, is informed by and reflects the needs and values of affected communities across Canada.

- **We are looking to hear from:**
  - Parents/guardians (or soon to be) of young children, with or without health condition(s)
  - People with lived experience of T1D (including families)
  - People who identify as belonging to equity-deserving groups (e.g., racialized, Indigenous, people with disabilities)
  - People from the general population without existing knowledge of T1D
  - Health professionals, researchers, policy specialists, community and advocacy organizations

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Current Opportunities for Community Partners

Community Engagement Network

- Offers guidance, support, and mentorship to project teams, ensuring a community-led approach to CanScreen T1D’s research activities.

Health Disparities and EDI/SGBA+ Committee

- Dedicated to addressing and mitigating health disparities and enhancing EDI within the consortium's research activities.

Participating in upcoming research projects

- Examples include participating in focus groups and shaping educational materials for community members.

See Annex A and B for more details about the Community Engagement Network and Health Disparities and EDI/SGBA+ Committee.

SPENCOP Insights and Support

What are the best ways to reach diverse populations in your respective jurisdictions (e.g., general population, marginalized populations, parents/guardians)?

We are connecting with community-governed organizations to expand our reach, do you know of any in your respective jurisdictions?

Do you have any advice for increasing general population participation in the pilot screening program study, and recruiting youth in particular?

Could the SPENCOP support CanScreen T1D by promoting engagement opportunities (e.g., via social media, identifying interested individuals)?

How can we explore opportunities for collaboration?

Thank you!

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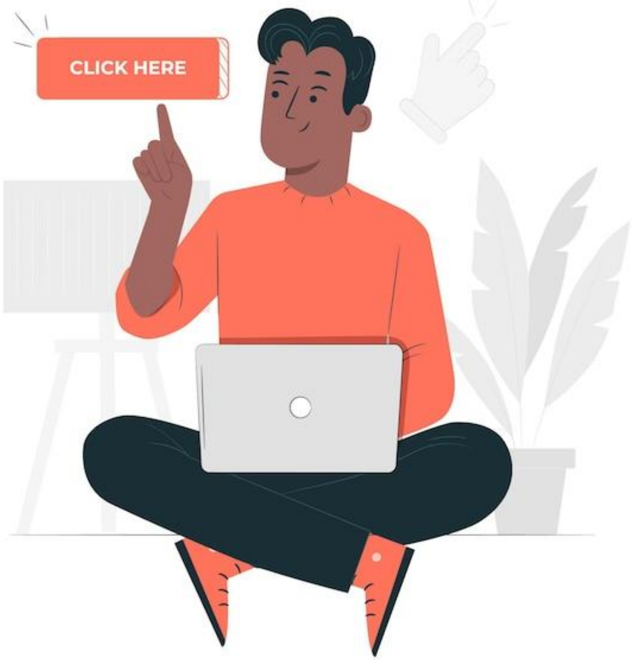
Links

- **About CanScreen T1D**
  - https://canscreent1d.ca/about-us/
- **Our research**
  - https://canscreent1d.ca/our-research/
- **How to get involved (page updates in progress – check back soon)**
  - https://canscreent1d.ca/get-involved/
- **Social media**
  - LinkedIn
  - X (formerly Twitter)
  - Instagram



Annex A – Community Engagement Network

Profile	• Parents or guardians (or soon to be) of young children with or without a health condition(s) • Individuals living with T1D and parents, caregivers, or family members of those living with T1D • Members of advocacy groups (diabetes-focused; health equity-focused; research or health care-focused) • Professionals with experience in T1D care or research • Individuals with experience in community or patient engagement work • Individuals from the general public with or without knowledge of T1D
Time commitment	• 2-year renewable term • ~15 hours for 2 years, with 3-4 meetings per year up to 60-90 minutes each (some emailing may be required)
Compensation	• Members will be offered honoraria for their time and commitment in accordance with our compensation policy.
Activities (not an exhaustive list)	• Contribute their knowledge, views and experiences to help shape community engagement activities across the consortium. • Develop and define key indicators for successful engagement. • Review and provide feedback on CanScreen T1D communications and research materials (for example, participant consent forms, community engagement plans, recruitment strategies). • Help to develop strategies for community outreach and involvement, offering guidance on how best to engage with diverse communities.
IAP2 Spectrum	• Aligns with the 'Involve' level. • Over time, the Network aims to move toward the 'Collaborate' level and will remain open to opportunities for deeper engagement, including aspects of 'Empower' where appropriate.

Annex B – Health Disparities, EDI/SGBA+ Committee

Profile	• Identifies with an equity-deserving group (e.g., racialized communities, Indigenous communities, LGBTQIA2S+ communities, people with disabilities, rural or remote communities, diverse ethnocultural communities) • Interest or expertise in EDI • Lived experience of T1D (including families) • Is part of an advocacy or community-based organization (diabetes focused or other)
Time commitment	• 2-year renewable term • ~15 hours for 2 years, with 3-4 meetings per year up to 60-90 minutes each (some emailing may be required)
Compensation	• Members will be offered honoraria for their time and commitment in accordance with our compensation policy.
Activities (not an exhaustive list)	• Reviewing protocols and other consortium materials as requested. • Developing strategies and initiatives to integrate health disparity and EDI considerations into the consortium’s research and operations. • Providing ongoing education and training opportunities to consortium members to raise awareness and competence in health disparity and EDI issues. • Regularly monitoring and evaluating the effectiveness of strategies and initiatives related to health disparities and EDI. • Promoting more equitable health outcomes by addressing and mitigating disparities identified through SGBA+ analyses.