McMaster University
Health Forum

CanScreen T1D
DépisterCan DT1

Panel Summary

Developing a Type 1 diabetes screening program in Canada

16 August 2024

Background

We convened a series of five citizen panels in July and August 2024 (with two panels on 5 July, two on 19 July, and one panel in French on 16 August 2024) with a total of 58 citizens from across the country. The participants were diverse in terms of age, gender, geographical location, ethnocultural background, and socio-economic status. Given that Type 1 diabetes screening would be at the population level for children and adolescents, we sought to engage participants with range of lived experience with Type 1 diabetes, including those living with it, family members (e.g., parents) and/or caregivers of people with Type 1 diabetes, and people who had no lived experience with Type 1 diabetes.

The main objectives of these virtual panels were to:

1) gather insights on the challenges related to developing a Type 1 diabetes screening program in Canada
2) explore elements of a potentially comprehensive approach for addressing these challenges
3) identify implementation considerations (e.g., barriers, facilitators, and outcomes that should be considered for ongoing monitoring and evaluation) for these elements.

The information obtained from these panels will be used to inform a national stakeholder dialogue that will engage system leaders, policymakers, managers, professionals, researchers, caregiver representatives, and other stakeholders in deliberations about how to develop a Type 1 diabetes screening program in Canada and what actions should be prioritized towards this goal. This document summarizes the key insights that were identified from the five virtual citizen panels.

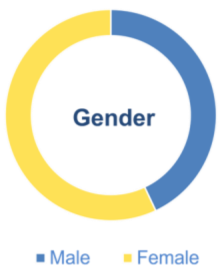
Box 1 provides additional background to the panel, and Box 2 provides a profile of participants.

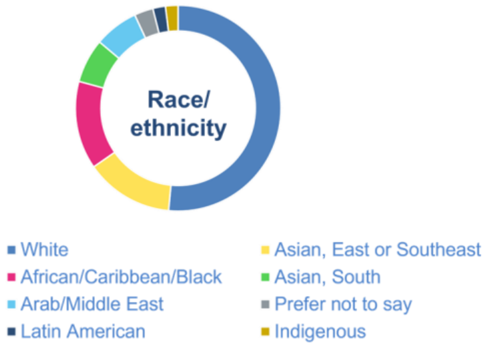
Box 1: About this panel

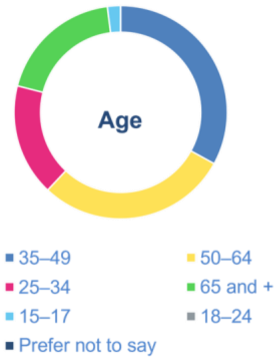
This virtual panel had the following 11 features:

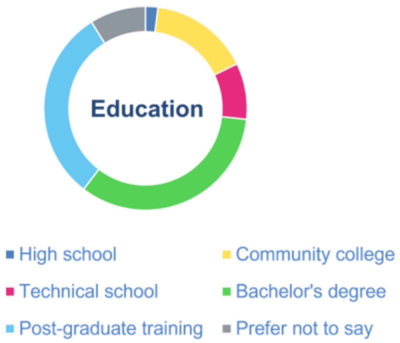
- it addressed a high-priority issue in Canada
- it provided an opportunity to discuss different features of the problem
- it provided an opportunity to discuss solutions for addressing the problem
- it provided an opportunity to discuss key barriers and facilitators to move forward
- it provided an opportunity to talk about who might do what differently
- it was informed by a pre-circulated, plain-language brief
- it involved a facilitator to assist with the discussions
- it brought together participants affected by the problem or by future decisions related to the problem
- it aimed for fair representation among the diversity of participants involved in or affected by the problem
- it aimed for open and frank discussions that preserved the anonymity of participants
- it aimed to find both common ground and differences of opinions.

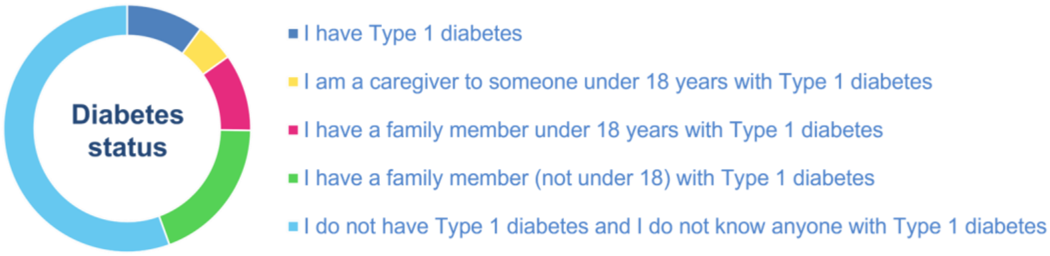
Box 2: Profile of participants











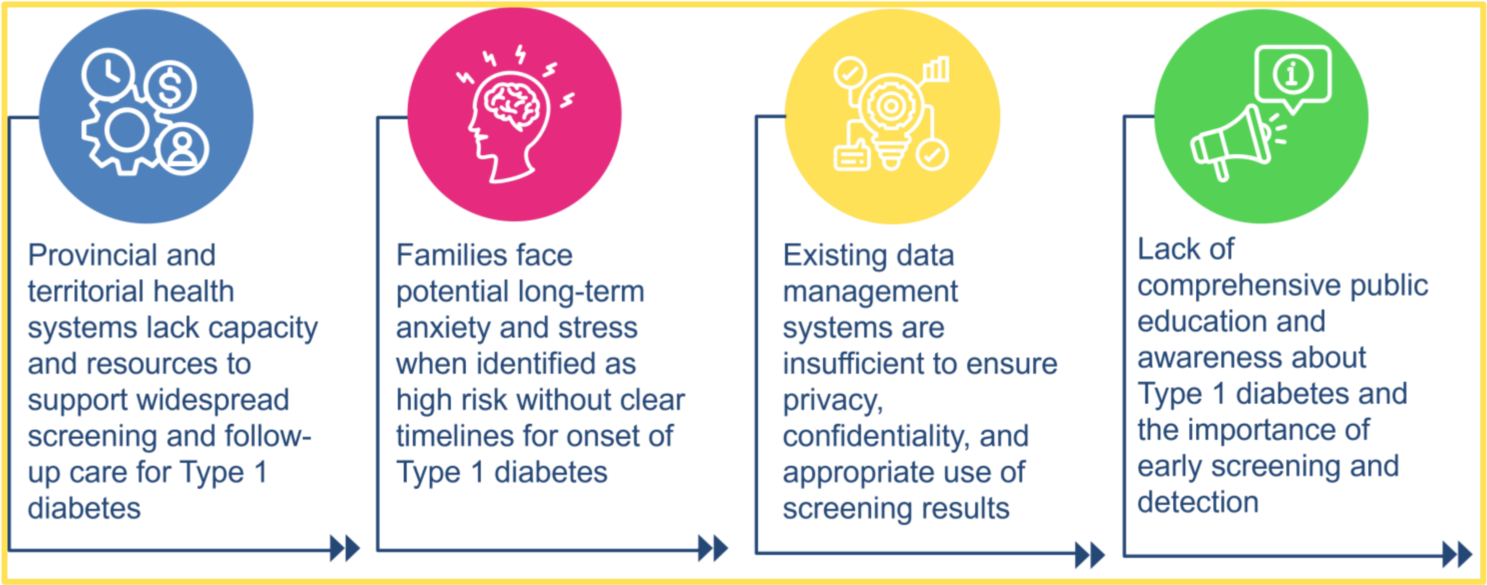
Summary of the deliberation about the problem

During the deliberation about the problem, participants used the information from the pre-circulated citizen brief as a jumping off point for sharing their views and experiences about potential challenges for developing a Type 1 diabetes screening program in Canada. The citizen brief framed the problem in relation to four areas:

1) Type 1 diabetes is a chronic health condition with lifelong implications for patients, their families and caregivers, and health systems in Canada
2) there is a lack of consensus on whether population-level screening is warranted for Type 1 diabetes
3) if screening for Type 1 diabetes is deemed to be warranted, there is a lack of consensus on how it should be designed

4) any approach taken will also face system-level challenges that will need to be addressed to support adoption across Canada.

In considering this framing of the problem, we identified four main challenges that the participants emphasized across the panels, which are included in the figure below.



Provincial and territorial health systems lack capacity and resources to support widespread screening and follow-up care for Type 1 diabetes

Families face potential long-term anxiety and stress when identified as high risk without clear timelines for onset of Type 1 diabetes

Existing data management systems are insufficient to ensure privacy, confidentiality, and appropriate use of screening results

Lack of comprehensive public education and awareness about Type 1 diabetes and the importance of early screening and detection

Provincial and territorial health systems lack capacity and resources to support widespread screening and follow-up care for Type 1 diabetes

Participants emphasized the strain on provincial and territorial health systems as a major challenge for implementing a comprehensive Type 1 diabetes screening program. Many participants underscored the shortage of family physicians, long wait times for specialists, limited access to endocrinologists and access to strong internet connectivity, especially in rural and remote areas. This led participants to express significant concern that introducing a new screening program could exacerbate these issues, further straining health systems. Given this, a few participants in the panel convened in French expressed a preference to prioritize treatment, viewing screening only as an 'added bonus.' In addition, some participants questioned whether provincial and territorial health systems could handle the patients newly identified as being at high risk for Type 1 diabetes from screening, including the resources needed to create new pathways of care to follow and support them over time. The potential for delays in follow-up care and monitoring was expressed as a serious concern by many, which led some to question the appropriateness of creating a new screening program if resources are not available to provide the supports needed to those identified as at high risk.

Some participants drew parallels to the COVID-19 vaccination roll-out, suggesting that a similar mobilization of resources might be necessary at the roll-out of a new screening program. In addition, there were calls for taking it as an opportunity to similarly consider how to develop and harness innovative solutions, such as virtual care options and the involvement of other healthcare professionals like pharmacists, to address these capacity issues (we return to these in the section about solutions below). Lastly, participants emphasized the need for long-term planning and investment in health system infrastructure to support ongoing screening and follow-up care for people identified as high risk and those already diagnosed with Type 1 diabetes.

Families face potential long-term anxiety and stress when identified as high risk without clear timelines for onset of Type 1 diabetes

Participants expressed some concern about the psychological impact of screening on families, particularly if children are identified as high risk but don't know when or if they will develop Type 1 diabetes. It was highlighted across all the panels that this uncertainty could lead to long-term stress and anxiety, potentially affecting the quality of life of children and their families.

Some participants suggested that this anxiety might outweigh the benefits of early detection for some families and could lead to less-than-ideal rates of uptake of screening. Given this, many emphasized the need for comprehensive psychological support to be integrated into any screening program, including counselling services and educational resources to help families cope with the uncertainty, but that such services are expensive and/or typically not well supported in provincial and territorial health systems. Participants also emphasized the need for clear, understandable communication about risk levels and what they mean in practical terms.

Existing data management systems are insufficient to ensure privacy, confidentiality, and appropriate use of screening results

Concerns about data privacy and confidentiality were prevalent among participants. They expressed worries about how genetic screening data would be stored, who would have access to it, and the potential for data breaches. Some participants raised questions about the long-term implications of being labelled as 'high risk,' particularly regarding insurance coverage and employment opportunities. Other participants, drawing from experiences in cybersecurity, emphasized that no system is entirely secure. There were calls for strict data protection measures, clear policies on data use and sharing, and the option for individuals to control their own data. Participants suggested the need for transparency about how data would be used for research purposes and the importance of obtaining ongoing consent for data use. Some also proposed the idea of a centralized, secure data management system overseen by a trusted entity.

Lack of comprehensive public education and awareness about Type 1 diabetes and the importance of early screening and detection

Lastly, participants highlighted their view about widespread misconceptions about the difference between Type 1 and Type 2 diabetes, which could affect people's willingness to participate in screening. Despite acknowledging the difference between these two conditions, some participants continued to discuss Type 2 diabetes at times, given that it is more commonly known amongst the general public. Some parents, both with and without direct experience with Type 1 diabetes, noted that the signs and symptoms for it were not on their radar of concerns to watch for with their children. As a result, many of the participants strongly emphasized the lack of public education provided about Type 1 diabetes to help enhance awareness among parents, caregivers, school-based staff (teachers, principals, etc.) and the community more generally for understanding the signs and symptoms to avoid serious complications.

Summary of the deliberation about solutions

1 Deciding on whether, when, where, and who should offer screening

2 Changing system-level arrangements to integrate a new screening program

3 Supporting people identified as at risk for Type 1 diabetes

Participants identified several specific values and preferences when deliberating about each of the three groups of solutions that were included in the pre-circulated citizen brief (see the figure above). We summarize the key findings below from across all of the five citizen panels.

Deciding on whether, when, where, and who should offer screening

During the deliberation about solution 1, participants generally supported implementing a population-level screening program for Type 1 diabetes. In coming to this conclusion, most participants emphasized that the improved health outcomes that could be achieved through screening made the investment in a program worthwhile.

All participants stressed the importance of making screenings free, voluntary, and easily accessible to all, regardless of location, language, culture, or socio-economic status, but there were varying points of view about the optimal approach for screening. While most held strong views about when to screen, where to screen and/or who should offer screening, a smaller number advocated for a flexible, multi-faceted approach that offered a menu of options that could be made available and then people would be able to choose based on their preferences. Some expressed that this was important for ensuring that screening is voluntary and never imposed. However, most participants seemed to coalesce around a few key features of a screening program.

For when to screen, most favoured integrating Type 1 diabetes screening into existing newborn screening programs given that existing infrastructure and processes could be harnessed, and therefore reduce costs associated with its implementation. Those who did not support including Type 1 diabetes screening in newborn screening programs expressed that it was due to concern about long-term anxiety for families of those identified as at high risk. There were several participants, however, who supported school-aged screening, either at the time of vaccinations that are required before starting school or in primary grades closer to when Type 1 diabetes symptoms typically begin. Participants identifying school-based settings as a viable option discussed the value of student engagement, citing that current students living with Type 1 diabetes can serve as ambassadors who can help to raise awareness and educate their peers. However, concerns were raised about coupling screening with vaccination schedules given vaccine hesitancy that could limit the reach of screening and also affect its trustworthiness. Others were concerned about the added burden it may cause the school system and indicated that careful planning and resources will need to be invested to adopt this screening program using an intersectoral approach. Among those who supported a hybrid model where screening could be offered at multiple times (i.e., newborn, pre-school, and school age), the rationale provided was to be able to accommodate different preferences (e.g., those who want to avoid any unnecessary stress and anxiety), ensure that recent immigrants and refugees are able to benefit from screening (e.g., for young children who were not born in Canada and not screened at birth, but could still benefit from screening), and to identify cases potentially missed by newborn screening alone (i.e., to reduce the number of false negatives).

Regarding where and who should offer screening, all participants strongly preferred screening to be conducted: 1) by trained healthcare professionals to ensure accuracy and to support linkage to support and education following a high-risk screening result; 2) in controlled, professional environments such as hospitals, doctor's offices, or specialized clinics; and 3) using a coordinated approach between providers and settings to ensure accurate collection, management, and communication of results. Many expressed significant reservations with the idea of using self-administered home test kits (although a couple participants seemed to indicate it was a viable approach), citing concerns about accuracy, reliability, and proper use, as well as the likelihood that many would end up not using the test kits. In addition, many participants indicated that pharmacies and pharmacists could play a role in offering screening and providing follow-up over time. A key reason for this was accessibility given that most communities have access to a pharmacy but not family physicians or specialists. Lastly, based on the successful experiences of some Quebec residents, these participants alluded to leveraging the use of a 'local point of services' model, which can serve as one-stop shop for screening and vaccination services.

2 Changing system-level arrangements to integrate a new screening program

During deliberations about solution 2, participants highlighted the need for significant system-level changes to support a new screening program, which focused on: 1) coordination between provincial and territorial health systems to ensure consistent standards and data sharing; 2) ensuring availability of sufficient resources and adopting innovative solutions to address resource constraints; and 3) ensuring a patient-centred approach integrating a new Type 1 diabetes screening program.

First, the need for enhanced coordination between provinces and territories was identified by some participants as a way of ensuring consistent standards and data sharing across the country. This was also seen as a way of helping to ensure equity across the country where everyone would similarly benefit from a similar approach, regardless of the province they live in. As part of a coordinated national approach, many suggested creating a centralized, secure data management system to store and manage screening results, with clear policies on data access and use to ensure strong privacy standards.

Second, the need for additional health system resources was noted by most as being crucial to ensure the implementation of a high-quality screening program. Participants expressed concerns about the current strain on health systems and questioned whether there would be sufficient specialists, particularly endocrinologists, to support those identified as high risk through screening. Some noted that times of resource constraints can be used to explore innovative solutions. Key suggestions for system-level innovations that could be used to integrate a new screening program included leveraging pharmacists, community health workers, and nurse practitioners to assist with screening and follow-up care, with specialist support available in ways that make the best use of their expertise and time. In addition, others proposed expanding the role of existing diabetes clinics to support the screening program.

Lastly, several suggestions were made among panel participants that could collectively contribute to a patient-centred approach to integrate a new Type 1 diabetes screening program. This included:

- using a mix of in-person and virtual care options for follow-up, recognizing the potential for virtual care options to improve access, particularly in rural or underserved areas
- integrating the screening program into existing care pathways was seen as crucial, with suggestions to use patient decision aids to help families make informed choices about screening and coordinated follow-up care among patients, families, caregivers, and clinicians
- supporting a team-based approach involving primary care providers, endocrinologists, mental health counsellors, and diabetes educators, which could be coupled with specialized diabetes clinics for at-risk individuals where both medical monitoring and educational support could be provided
- adopting culturally appropriate approaches, including addressing language and health literacy barriers
- conducting outreach programs to engage diverse communities to ensure equitable access to screening, and promoting peer-to-peer learning and awareness campaigns in school-based settings
- supporting ongoing and meaningful citizen engagement in decision-making processes (e.g., through the formation of advisory committees that include medical professionals, government representatives, citizens, and diverse community representatives to inform decision-making about Type 1 diabetes screening).

In considering these suggestions, some participants noted the importance of continuing to learn from experiences in other countries, such as the U.K. and Australia, to inform program design and implementation.

3 Supporting people identified as at risk for Type 1 diabetes

The third solution focused on the need to support people identified as at risk for Type 1 diabetes. Participants emphasized the need for comprehensive support for individuals identified as at risk for Type 1 diabetes, with several suggestions identified. First, all participants emphasized the need for providing clear, accessible information about what being ‘at risk’ means, including statistical data on the likelihood and timeline of developing the condition, and any lifestyle factors that might influence disease progression. In addition, many also stressed the need for support in navigating the health system and accessing necessary resources. Furthermore, the importance of providing information and navigation supports in a way that is culturally appropriate was highlighted. Some participants specifically noted the need for materials and services in multiple languages and tailored to diverse cultural backgrounds.

The idea of an online patient portal for accessing test results and educational materials was also supported by most participants. A patient portal was viewed as an easy access point for health information and as a way to help with coordinating when appointments are needed and potentially to connect with others in similar situations. However, a small number of participants cautioned that an online patient portal cannot be solely relied on to provide access to such information given unreliable internet access for some and/or preferences to not access health-related information online.

Lastly, psychological support was viewed as a crucial resource to provide as part of a screening program. Participants suggested providing access to counselling services, educational programs, and support groups for at-risk individuals and their families. Many expressed interest in ways for families to connect with others in similar situations, recognizing the value of peer support.

Summary of the deliberation about barriers and facilitators to moving forward

After discussing the three solutions, participants examined potential barriers to and facilitators for developing a Type 1 diabetes screening program in Canada. In addition to the barriers and facilitators identified in the citizen brief, participants focused on several key barriers:

- limited health system capacity and resources, including lack of healthcare professionals and long wait times
- potential anxiety and stress for families if children are identified as high risk
- data privacy and confidentiality concerns about how genetic information would be handled and stored, particularly regarding long-term implications
- lack of public education and awareness about Type 1 diabetes and screening (both in general and culturally tailored resources), including how it is different from Type 2 diabetes
- equity and access issues, especially for rural/remote areas and newcomers
- cost and funding challenges for implementing a population-wide program and providing necessary follow-up care
- difficulties in coordinating a consistent approach across different provincial healthcare systems
- concerns about the accuracy and reliability of screening tests
- potential impact of vaccine hesitancy on screening uptake if screening is linked to vaccination schedules
- risk of misinformation spreading about the screening program or Type 1 diabetes that could undermine its trustworthiness
- difficulty in managing the initial influx of people identified as being at risk
- technological barriers that might prevent some people from accessing online resources or participating in virtual care.

When discussing facilitators or approaches to support implementation, participants identified several ideas, including:

- the opportunity for integration with existing health programs, such as newborn screening or school-based health initiatives
- utilization of technological advancements, including telehealth and digital health tools, especially in rural areas
- implementation of comprehensive education and awareness campaigns that could leverage social media and diabetes advocacy groups to spread awareness (e.g., to increase understanding of Type 1 diabetes, its signs and symptoms, and to reduce stigma) and to support implementation
- harnessing and expanding existing support networks for families dealing with diabetes
- adoption of a multidisciplinary approach involving various healthcare professionals (e.g., pharmacists, nurse practitioners, and community health workers)
- learning from successful screening programs in other countries like the U.K. and Australia
- offering flexible screening options at multiple life stages (e.g., newborn, pre-school, and school age)
- increasing availability of virtual care options that could be used to provide access to follow-up for those identified as high risk.

Lastly, we asked participants that if a population-based screening program were implemented in their province or territory, what they would like to see measured as indicators of success. Some participants emphasized the importance of ongoing monitoring and evaluation through a research program to enhance trustworthiness of the screening program. Key measures identified that could be used for ongoing monitoring and evaluation included:

- Screening rates
  - Overall
    - Number of people identified as high risk
    - Number of people identified as low risk
    - Number of false positives and negatives (what some termed as the quality of the test result)
  - By province and region within provinces to identify underserved areas (i.e., areas with low rates of screening to target outreach)
  - By equity-deserving groups (e.g., Indigenous peoples, immigrants and refugees, different ethnocultural groups, and low socio-economic status)
- Health-related outcomes (e.g., by tracking the number of diabetic ketoacidosis (DKA) events and emergency room visits averted)
  - Psychological impacts of screening (e.g., stress, anxiety, and depression)
  - Rates of blood-sugar control
  - Incidence of DKA

- System-level outcomes
  - Emergency room visits related to Type 1 diabetes (e.g., from hypoglycemia and DKA)
  - Children and families connected to treatment and support (i.e., did people get access to what was promised or needed)
  - Costs and cost-effectiveness
- Patient experiences (ideally with patient stories)
  - Decisions to screen vs. not to screen
  - Experience with screening
  - Experience following screening (e.g., during follow-up and identifying whether people were happy with the decision they made)

In addition to key measures, some participants noted what they viewed as important features of how monitoring and evaluation is conducted. First, the importance of monitoring and evaluating the screening program through an ongoing research program was emphasized as a way of enhancing trust in the findings. Similarly, the idea of public reporting of outcomes was noted as important for enhancing trust and transparency. In terms of approaches to use, many underscored the importance of using an equity-focused approach to evaluation that provides insights into whether and how screening is reaching different groups and its impacts. Lastly, a few participants noted outcomes related to mental health (e.g., stress, anxiety, and depression) from participating in screening would be difficult to measure through one-off evaluations and would require following people over time.

Wu N, Wilson MG, Hayeems R, Alam S, Bain T, Gauvin F-P, L'Espérance A. Panel summary: Developing a Type 1 diabetes screening program in Canada. Hamilton: McMaster Health Forum, 16 August 2024.

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