McMaster University
Health Forum

CanScreen T1D
DépisterCan DT1

# Dialogue Summary

# Developing a Type 1 diabetes screening program in Canada

## 18 & 19 September 2024

## Background

On 18 and 19 September 2024, the McMaster Health Forum convened a stakeholder dialogue on developing a Type 1 diabetes screening program in Canada. Nineteen participants – health-system leaders, organizational leaders, professional leaders, industry representatives, and academic leaders (see the figure below) – deliberated about the problem, elements of a potentially relevant comprehensive approach for addressing it, implementation considerations, and possible next steps for different constituencies. Box 1 provides additional background to the stakeholder dialogue.

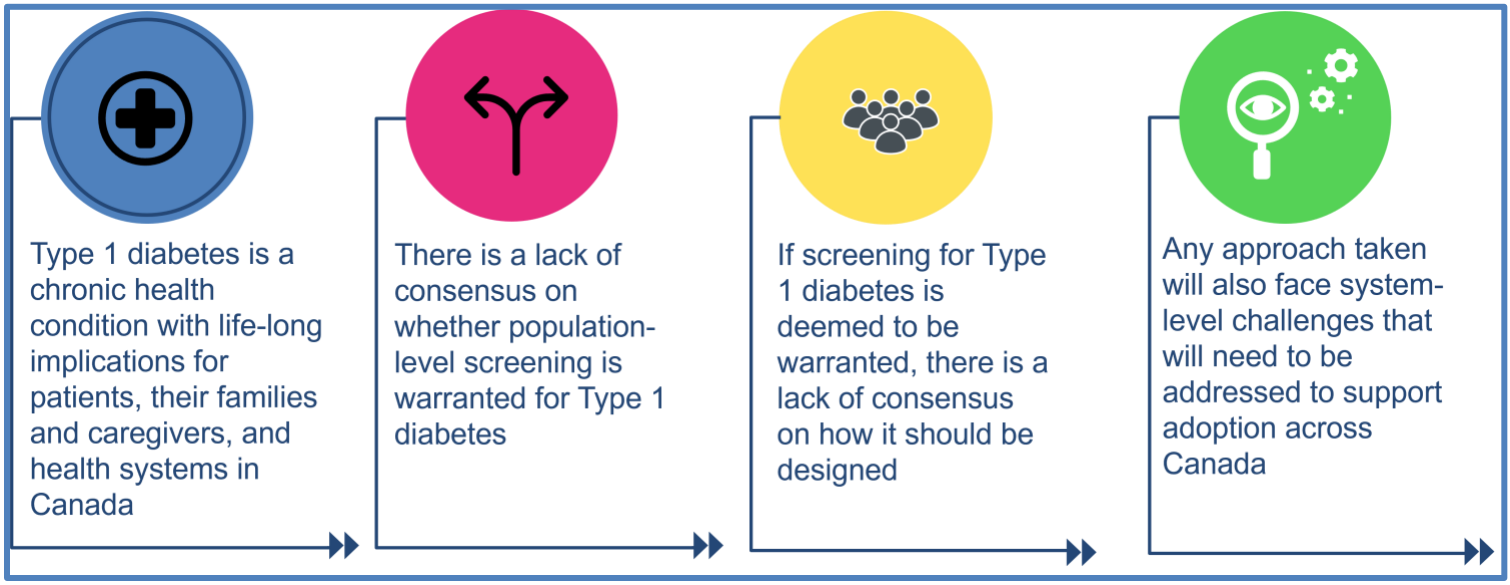

## Box 1: Background to the stakeholder dialogue

The key features of the stakeholder dialogue were:

1) it addressed an issue currently being faced in Canada
2) it focused on different features of the problem, including (where possible) how it affects particular groups
3) it focused on three elements of a potentially comprehensive approach for addressing the policy issue
4) it was informed by a pre-circulated evidence brief that mobilized both global and local research evidence about the problem, three approach elements, and key implementation considerations
5) it was informed by a discussion about the full range of factors that can inform how to approach the problem and possible elements of an approach to addressing it
6) it brought together many parties who would be involved in or affected by future decisions related to the issue, including 10 citizen leaders and citizen-serving non-governmental organization (NGO) leaders who brought their own unique perspectives
7) it ensured fair representation among policymakers, stakeholders, and researchers
8) it engaged a facilitator to assist with the deliberations
9) it allowed for frank, off-the-record deliberations by following the Chatham House rule: 'Participants are free to use the information received during the meeting, but neither the identity nor the affiliation of the speaker(s), nor that of any other participant, may be revealed'
10) it did not aim for consensus (because coming to agreement about commitments to a particular way forward can preclude identifying broad areas of agreement and understanding the reasons for and implications of specific points of disagreement, as well as because even senior health-system leaders typically need to engage elected officials, boards of directors, and others about detailed commitments).

Participants' views and experiences and the tacit knowledge they brought to the issues at hand were key inputs to the dialogue. The dialogue was designed to spark insights – insights that can only come about when all of those who will be involved in or affected by future decisions about the issue can work through it together. The dialogue was also designed to generate action by those who participate in the dialogue, and by those who review the dialogue summary.

## Summary of the deliberation about the problem




Participants generally agreed with the framing of the specific components of the problem included in the evidence brief (see the figure above). When considering the components of the problem, the participants focused more broadly on four challenges related to developing and implementing a Type 1 diabetes screening program in Canada.

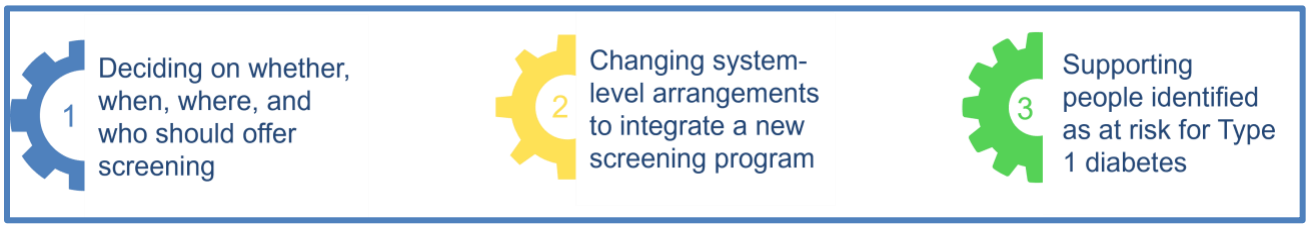
First, the balance of potential benefits and harms associated with Type 1 diabetes screening programs remains unclear. While the benefits of early detection and prevention of diabetic ketoacidosis (DKA) (e.g., follow-up care for those identified as high risk, possible delay of disease onset) were emphasized, a number of potential harms or limitations were identified that will require careful study. For example, some participants pointed to the need to better understand the short-, medium-, and long-term psychological burden on children identified as high risk and their families and the risk of misdiagnosis that can trigger different or inappropriate care pathways. In addition, others underscored concerns about health-system capacity to equitably support widespread screening and follow-up care.

Second, some participants emphasized that there is limited evidence in several areas that are needed to inform a population-level Type 1 diabetes screening program in Canada. Important examples included lack of clear treatment pathways for those screened as high risk, incomplete understanding of the accuracy and applicability of genetic risk scores across diverse populations (especially in minority groups), and a lack of high-quality evidence on the benefits and harms of a population-level Type 1 diabetes screening program, particularly in the Canadian context.

Third, there was a lack of consensus among participants about how best to design an equity-driven Type 1 diabetes screening program. The consensus was driven by the complexities of the timing (e.g., newborn versus school-aged testing) and method (e.g., genetic risk scoring versus antibody testing) of screening, how to ensure equal access to screening is provided for rural, remote, and underserved populations, how to ensure privacy of health information and informed consent for all patients, and determining which healthcare providers should conduct screening and follow-up care, especially given the existing strains on healthcare resources in Canada.

Lastly, public awareness and education about Type 1 diabetes and the importance of early screening was noted as being limited. Some participants highlighted the lack of clinical practice guidelines for healthcare providers in Canada on Type 1 diabetes screening, which was noted as potentially leading to fundamental misunderstandings, misconceptions, and complications in implementing and gaining support for a population-level Type 1 diabetes screening program.

## Summary of the deliberation about elements of a potentially comprehensive approach to address the problem




Most of the deliberations about the first element of **deciding on whether, when, where, and who should offer** a Type 1 diabetes screening program in Canada focused on advancing thinking about the feasibility and acceptability of such a program.

- Robust, high-quality evidence is needed to support and advance a new population-level Type 1 diabetes screening program in Canada. While gold standard evidence like randomized controlled trials are unlikely to be feasible for a population-level screening intervention, a 'start small' learning health system approach to designing a screening program can allow for a multi-faceted evidence base (e.g., observational studies, qualitative research, evaluations) to ground the implementation and ongoing evaluation of the screening program.
- A screening approach that is equity driven is essential to ensure that genetic risk scores that accurately reflect Canada's diverse ethnocultural populations are developed and that all populations can realize the benefits of Type 1 diabetes screening. Newborn screening was recognized by participants as the approach that would offer the most equitable access to population-level Type 1 diabetes screening services given existing supports for newborn screening in the Canadian healthcare system.
- In terms of who should provide Type 1 diabetes screening and where it should be provided, participants suggested that while primary-care providers like family physicians may be seen as logical candidates, community pharmacies can be considered as potential screening locations, particularly for underserved areas, as long as pharmacists are adequately trained and it does not add to the current strain on the healthcare system.

As part of the discussion about the need for high-quality evidence, some participants also suggested using an open science approach to enable ongoing synthesis of evidence about Type 1 diabetes screening programs emerging from other jurisdictions (e.g., Australia and the U.K.), acknowledging that Canada may be behind similar jurisdictions in this area.

Participants identified a few key considerations related to **system-level changes to successfully implement a Type 1 diabetes screening program,** and emphasized the need for a comprehensive, forward-thinking approach.

- Substantial investment in infrastructure for increased genetic and antibody testing will be required. In addition, the ethical and practical implications of having whole genome sequencing included in newborn screening and collecting, storing, and protecting genetic risk information from birth will need to be considered. This could potentially require new policies or regulations governing the use of genetic information.
- Consideration needs to be given to who will bear the costs of care and services throughout the screening program (e.g., provincial health system, private insurance, the individual), particularly when those who screen positive may benefit from preventive interventions, such as medications that can delay the onset of symptoms. Participants emphasized the need for comprehensive cost-effectiveness studies to inform resource allocation decisions and ensure the long-term sustainability of any screening program.

Dialogue participants emphasized the critical importance of providing comprehensive **support for individuals identified as at risk for Type 1 diabetes**.

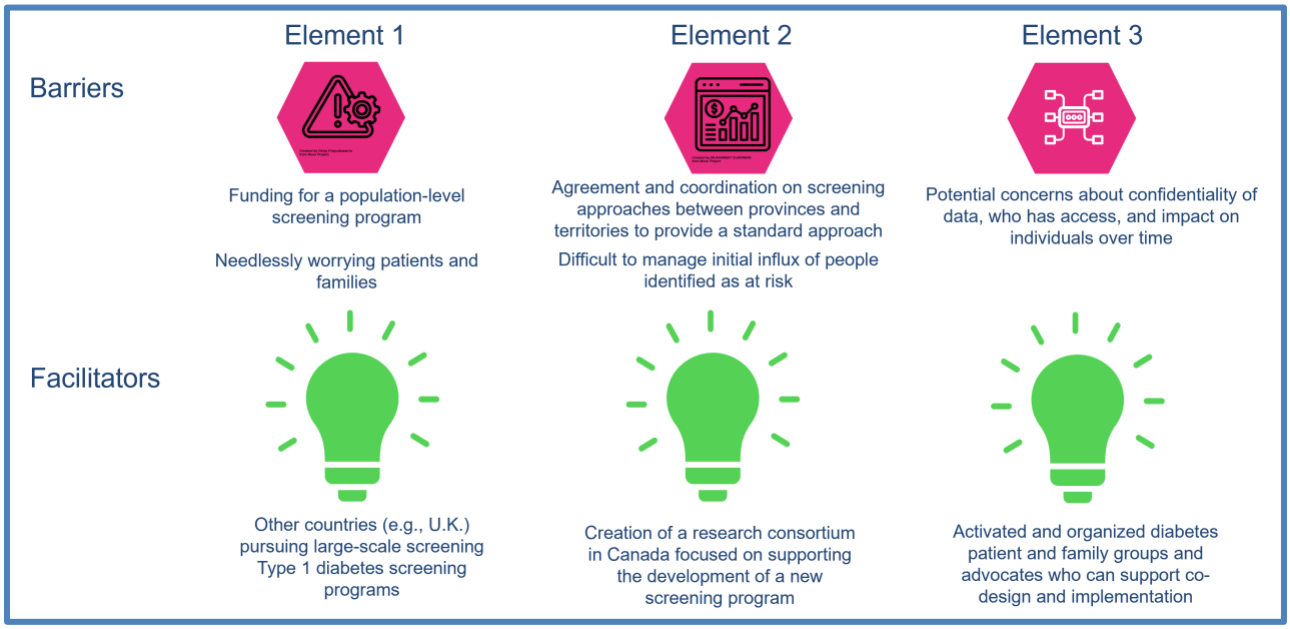
- Participants recognized the need for clear, comprehensive information about Type 1 diabetes, what being 'at risk' means, and what steps can be taken to monitor for disease onset, and they also acknowledged the challenge of providing this information in a way that informs without causing undue anxiety, particularly when dealing with the uncertain timeline of disease development.
- Care pathways for those requiring follow up and ongoing monitoring was seen as crucial for those identified as at-risk for Type 1 diabetes, especially as the needs of individuals and their families would likely change over time as

they age. Discussions centred on how to balance the need for vigilance with the desire to avoid over-medicalizing otherwise healthy individuals and causing psychological burden to individuals and their families.

- Participants called for ongoing mental health support and counselling as well as community and peer-support networks, such as Juvenile Diabetes Research Foundation (JDRF) and Diabetes Canada, to be integrated into the care pathway for individuals at risk of Type 1 diabetes and their families.
- Consideration was given to the ethics of how and when to disclose risk information to individuals, particularly children as they grow older, and participants stressed the importance of respecting individual autonomy while also providing the support and information necessary for informed decision-making.

## Summary of the deliberation about implementation considerations

While discussing implementation considerations, participants presented a complex landscape of considerations for a Type 1 diabetes screening program implementation, where discussions on program design were closely intertwined with implementation challenges. We note below key barriers and facilitators for implementation that were considered by the dialogue, followed by outcomes that participants identified as key priorities for a future Type 1 diabetes screening program.




Dialogue participants emphasized the importance of adopting a learning health system approach for developing a Type 1 diabetes screening program that starts small with research-based pilots. Moreover, participants highlighted the risk of misinformation and limited trust if the program is not implemented based on robust evidence. The involvement of key stakeholders, such as patients and families affected by Type 1 diabetes, healthcare providers, policymakers, Indigenous communities, patient advocacy organizations, researchers, and representatives of primary-care and community-care sectors, were also identified as crucial to the development and implementation of a screening program across diverse populations and healthcare settings.

Participants also emphasized the need to "get ahead of the curve" in preparing for advancements in genetic testing and immunotherapies for Type 1 diabetes, arguing that proactive planning would be preferable to a reactive approach once these technologies become widely available. This includes preparing for the ethical and practical implications of new technologies and treatments.

Finally, as discussed in the section about the elements, a significant portion of the deliberations about implementation also focused on concerns about limited system capacity and the need for investments to provide needed follow-up care for at-risk individuals at the population level. Participants acknowledged that the health system is already overstretched and unable to provide continuous glucose monitoring for everyone who needs it, and so these limitations will need to be addressed in order to implement a population-based screening program.

## Summary of the deliberation about next steps

The deliberation about next steps for the Type 1 diabetes screening program revealed a complex and multifaceted approach forward.

- Solidify existing knowledge
  - Conduct a comprehensive scoping review of Type 1 diabetes screening programs worldwide
  - Develop a living evidence synthesis to continually update and integrate new findings
- Develop a robust research agenda
  - Create a prioritized research agenda through collaboration with communities and funders
  - Engage multiple Canadian Institutes of Health Research institutes (e.g., Diabetes, Health Services and Policy Research, Population Health) in funding discussions
  - Consider potential for global trials and international research collaboration
  - Reassess current research priorities and identify additional initiatives needed
- Design and implement pilot studies
  - Start small with research-driven pilot programs
  - Test different screening approaches (e.g., newborn genetic testing, childhood antibody testing)
  - Evaluate outcomes using a learning health system approach
- Enhance awareness and engagement
  - Develop strategies to educate the general public about Type 1 diabetes and screening
  - Create clear, accessible information about genetic risk scores (GRS) and their meaning
  - Ensure robust public engagement at all stages of research and program development
  - Engage the broader clinical community that will eventually be involved in screening and follow-up
  - Initiate discussions with federal, provincial, and territorial health authorities
  - Consider advocacy efforts to raise awareness among decision-makers
  - Develop strategies for meaningful consultation with diverse communities, including Indigenous groups
  - Engage patient organizations like JDRF and Diabetes Canada in program planning and support
- Address knowledge gaps for healthcare providers
  - Develop targeted education programs for healthcare providers about Type 1 diabetes screening
  - Create resources explaining GRS interpretation and implications for clinical practice
- Improve infrastructure
  - Address the lack of important infrastructure for screening work
  - Develop and validate appropriate assays to test GRS with different ethnicities
  - Assess current laboratory capacity and plan for necessary upgrades

Wu N, Bain T, Hayeems R, Wilson MG. Dialogue summary: Developing a Type 1 diabetes program in Canada. Hamilton: McMaster Health Forum, 19 September 2024.

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