McMaster University Health Forum

CanScreen T1D
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Evidence Brief

Developing a Type 1 diabetes screening program in Canada

18 & 19 September 2024

Context for the brief

Type 1 diabetes is an autoimmune disease (where the immune system malfunctions and mistakenly attacks healthy cells, tissues, and organs) that:

- typically develops between the ages of 10 to 14 (but can be at any age)
- affects roughly 300,000 Canadians, and is one of the most common chronic illnesses in childhood (with the incidence in Canada being among the highest in the world)
- has an incidence increasing at an estimated 4.4% per year
- has a lifelong and significant impact on the health and quality of life of those living with it and their families, such as
  - taking insulin daily (through multiple injections or a pump)
  - closely monitoring diet and blood sugar levels
  - having regular health checks
  - continuous monitoring for important health implications.(1-10)

Box 1: Approach and supporting materials

This document was prepared to inform a stakeholder dialogue, which provides individuals – specifically those who will be involved in or affected by decisions about developing a Type 1 diabetes screening program in Canada – with an opportunity to deliberate about the problem and its causes, elements of an approach for addressing it, key implementation considerations, and next steps for different constituencies. A separate document contains five appendices:

1) background to and methods used to prepare evidence brief
2) characteristics of citizen panel participants
3) evidence syntheses relevant to deciding on whether, when, where, and who should offer screening (element 1)
4) evidence syntheses relevant to changing system-level arrangements to integrate a new screening program (element 2)
5) evidence syntheses relevant to supporting people identified as at risk for Type 1 diabetes (element 3).

People typically find out they have Type 1 diabetes by seeking care when they experience some key symptoms, including excessive thirst, frequent urination, fatigue, weight loss, or diabetic ketoacidosis (DKA).(3; 4) Unfortunately, many people will not know they have Type 1diabetes until they become very sick with DKA and present for emergency care.(1; 3; 4; 7; 11)

Currently in Canada, DKA can be present in up to 45% of cases at diagnosis.(12-14) This is very serious for patients as it is a medical emergency that can cause severe weakness, brain injury, and death.(15) DKA has been identified as the leading cause of morbidity and mortality in children with diabetes.(10; 14; 16; 17) In addition, DKA presentation at the time of diagnosis has been found to be associated with poorer long-term glycemic control.(14; 18)

However, DKA and other serious health complications from Type 1 diabetes (e.g., hypoglycemia, damage to the eyes and kidneys) (1-4; 19) are preventable with awareness of the signs and symptoms of the disease. This knowledge can reduce people who develop the most serious symptoms and complications of Type 1 diabetes.

Screening and Type 1 diabetes

Some diseases can be identified early and before symptoms present by using screening tests. However, being able to detect a disease earlier does not always mean it can lead to better health outcomes. Given this, it is generally agreed that screening tests should only be done when health outcomes can be improved from screening as compared to the current way of identifying a disease. Figure 1 provides key information about screening from the Canadian Task Force on Preventive Health Care.(20)

Figure 1: Key information about screening for health conditions*

Information on screening

Key points:

- Some health issues could be caught early in people without symptoms using screening tests
- However, not all screening tests that detect diseases earlier improve health outcomes
- Screening is only warranted if it improves health outcomes compared to other ways of finding disease

The Task Force produces evidence-based guidelines for preventative health care. Guidelines provide recommendations on whether or not to offer screening to certain groups.

There can be some confusion around what is meant by screening. Below is some information to help clarify.

Screening:

- Uses a medical test or tool to identify people at risk of a specific disease or health problem. They may be at a higher risk based on factors like age or sex.
- Is for people who do not show symptoms of a disease or health problem. Test may occur during a primary care visit.
- Result can be positive, negative, or uncertain. Screening indicates a possible health problem when the result is positive.
- Positive result will lead to more testing to confirm the diagnosis. Additional testing could be more intensive and invasive.

Screening is not:

- For people who are showing symptoms of a disease or health problem.
- Used to provide a definite diagnosis. Making a definitive diagnosis requires confirmatory tests.
- The only way to identify conditions. Often, conditions are identified once symptoms are apparent.

*This figure is reproduced with minor revisions from the Canadian Taskforce on Preventive Health Care under a Creative Commons Non-Commercial license.(20)

Most screening for Type 1 diabetes has focused on family members of those with it.(21) However, while first-degree family members of people with Type 1 diabetes are at a higher risk of developing it, 85% of people in Canada with Type 1 diabetes do not have a family member with the condition and, therefore, are also less aware of the symptoms and more likely to present with DKA.(3) Recently, genetic markers have been identified that may make it possible to identify risk for Type 1 diabetes months or years before any symptoms appear. These markers have been described as the immune system planning an attack against the pancreas. This means that if the markers are present, there is a higher than average risk of developing Type 1 diabetes.(22)

As noted in Figure 1, screening is only warranted if it improves health outcomes. Since Type 1 diabetes symptoms develop over time, population-level screening for it could therefore be important for:

- preventing DKA that can be potentially life threatening (as well as preventing other serious complications such as damages to the eyes and kidneys)
- helping to get earlier treatment with insulin to avoid high blood sugar for long periods of time ahead of diagnosis, thereby increasing risk of complications
- reducing the mental health burden of Type 1 diabetes diagnosis in the midst of a life-threatening event (DKA)
- providing access to medications that can postpone the onset of Type 1 diabetes (note that while medications for this have been approved in other jurisdictions,(23) none have been approved in Canada but are being studied).

Approaches to screening for Type 1 diabetes are being evaluated with large studies underway in several countries around the world.(24-27) These studies include evaluating potential features of screening programs, and following people from birth until older age to study their diabetes progression.(28) Studies are now being planned and implemented in Canada as part of the same project that is funding the stakeholder dialogue that this brief is designed to inform (and the citizen panels that were convened prior to the stakeholder dialogue).

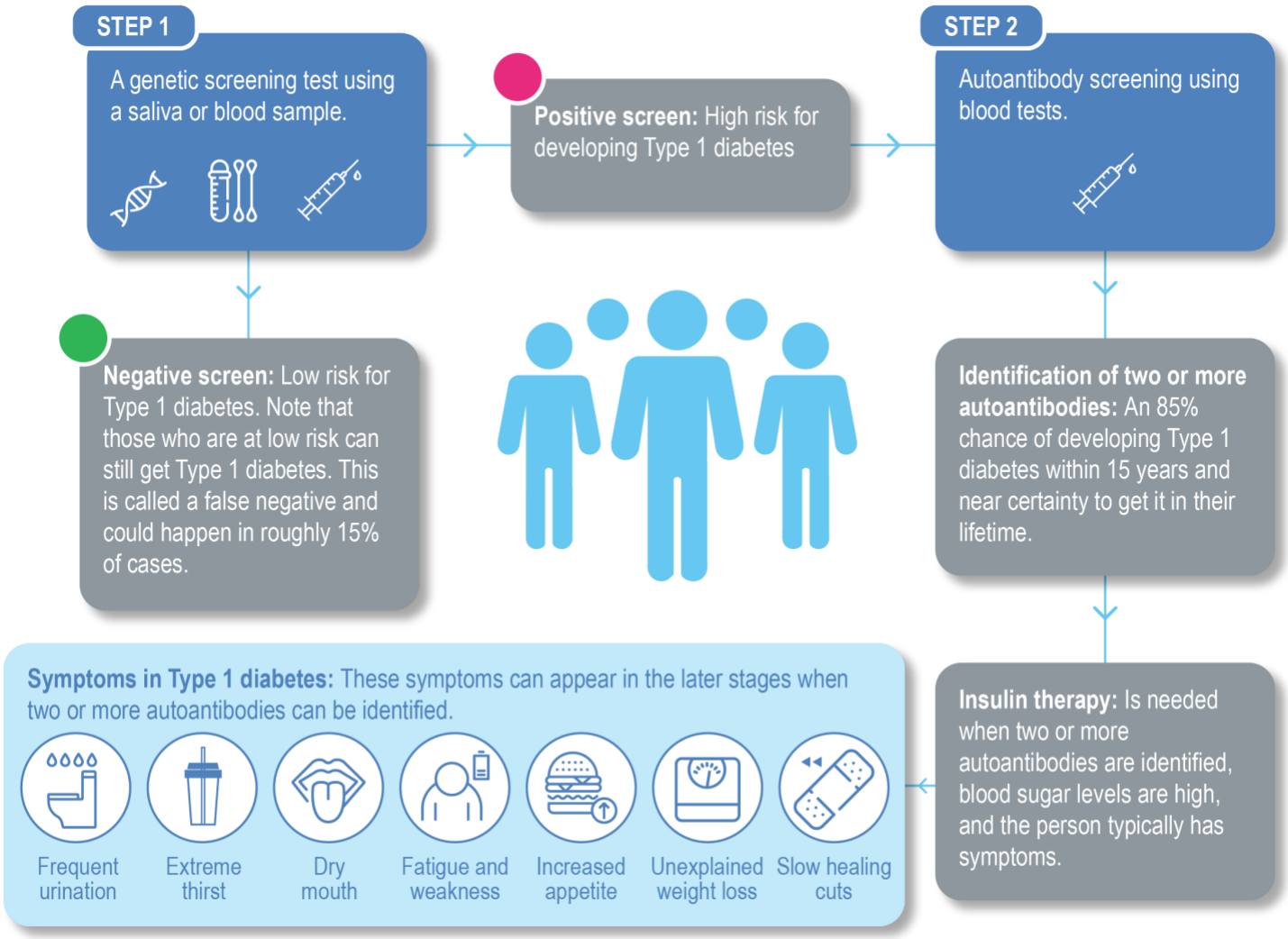
The newest screening approaches being proposed, evaluated and used in research studies in Canada and other countries can include a multi-step approach. We summarize this process in Figure 2. Note that the ages at which the proposed screening process would be conducted is part of what needs to be determined and is therefore not stipulated in Figure 2.

In step 1:

- a genetic risk score can be calculated by testing 67 genes in a saliva or blood sample
- the genetic risk score is based on whether someone has one or more small changes in these genes
- when these changes are combined, we can identify people at high risk and people at low risk for developing Type 1 diabetes
    - being at high risk does not mean that someone will develop Type 1 diabetes, but would get more screening in step 2 to give a more precise answer to predict their risk for Type 1 diabetes
    - those who are at low risk can still end up developing Type 1 diabetes, which is called a false negative and could occur in roughly 15% of cases.(29; 30)

If an individual has a high genetic risk score (in other words, they are in the 10% of the population with the highest risk), they move on to step 2 of screening, where they would be offered another phase of screening to look for other markers for Type 1 diabetes. These markers are called autoantibodies (i.e., what the immune system uses to identify the cells that produce insulin and mark them for destruction) and are identified using blood tests. What makes screening possible for Type 1 diabetes is that these autoantibodies can be in the blood years or potentially decades before any symptoms appear.(31) The risk for Type 1 diabetes increases when there are more autoantibodies in the blood. Current findings highlight that having people with two or more autoantibodies have an 85% chance of developing Type 1 diabetes within 15 years and near certainty that they will get it in their lifetime.(31)

Figure 2: Overview of proposed steps for Type 1 diabetes screening



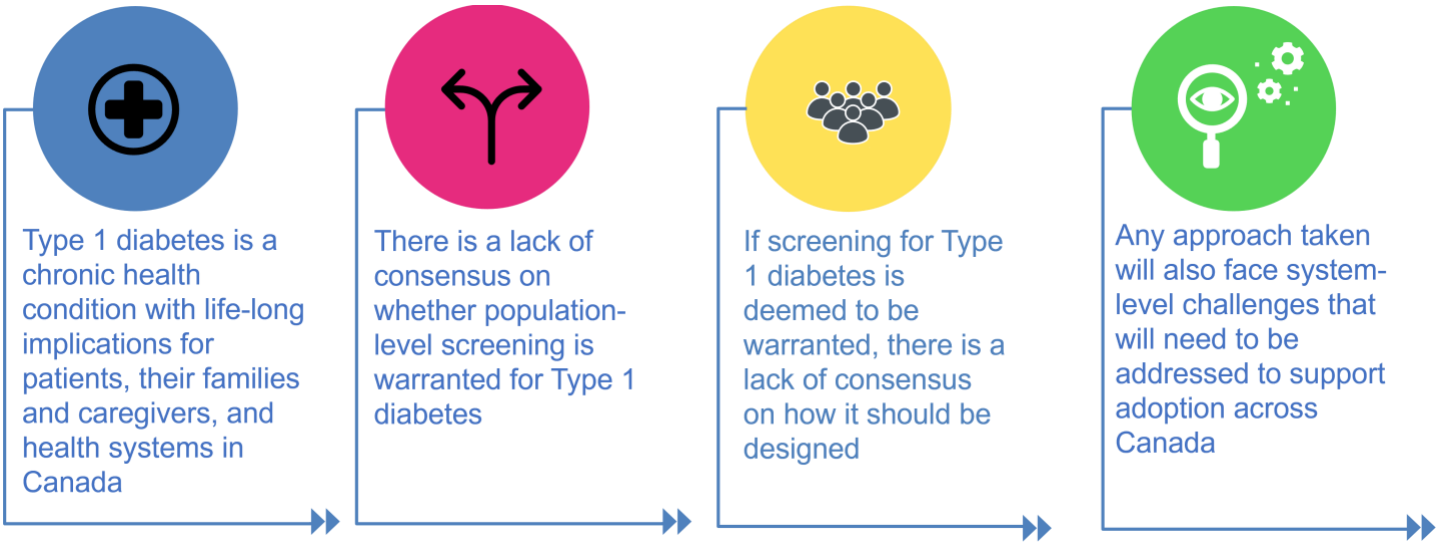
Our goal

Many factors need to be considered to determine whether it is acceptable and feasible to develop a high-quality Type 1 diabetes screening program for the general population in Canada. This includes identifying what is feasible and acceptable to citizens and for system leaders to design and implement. As a result, many decisions need to be made and it's important to hear from citizens and health-system leaders about what to do. With this in mind, in the following pages, we will explore the problem or key challenges related to developing a Type 1 diabetes screening program, highlight potential solutions or approaches that could be used, and identify implementation considerations.

We first engaged citizens on this topic by convening a series of five citizen panels in July and August 2024 (with two panels held in English on 5 July 2024, two on 19 July 2024, and one in French on 16 August 2024) with a total of 58 citizens. The panel participants were socio-economically and ethnoculturally diverse, were from across Canada, and balanced in ages ranging from 18 to 65+. We don't provide detailed participant characteristics in this evidence brief but have included them in Appendix 2. Given that screening would be at the population level (at least for children and adolescents), we sought to engage participants with a range of lived experiences with Type 1 diabetes, including those living with it, family members and/or caregivers of people with Type 1 diabetes and people who had no lived experience with Type 1 diabetes. One of the panels aimed to engage youth in deliberations. While roughly a quarter of the participants were under the age of 34, approximately 20% of participants were a caregiver for and a family member of someone under 18 years of age who is living with Type 1 diabetes (and some participants had their child participate in the panel with them). We present key findings from the citizen panels in each of the sections below to inform the stakeholder dialogue.

The problem

We have identified four facets of the problem, which are outlined in the visual below and discussed in the sections that follow. The framing and details of the problem were refined in collaboration with our project steering committee (names listed in acknowledgements), and through key informant interviews that we conducted with policymakers, leaders of systems, organizations, and professional organizations, industry representatives, citizen leaders, and researchers.



Type 1 diabetes is a chronic health condition with lifelong implications for patients, their families and caregivers, and health systems in Canada

As noted earlier, a Type 1 diabetes diagnosis places heavy demands on those living with the condition, as well as their families. Specifically:

- Type 1 diabetes usually develops in childhood/adolescence and requires support from caregivers.
- Significant education about diabetes and its management is necessary at the time of diagnosis.
- There can be significant costs associated with Type 1 diabetes (estimated at up to $18,306 per year in some parts of Canada) that are borne by patients and families (e.g., purchasing medical supplies and equipment for glucose monitoring and insulin doses, travelling to multiple appointments)
- There is need to take insulin four to five times per day (through injections or insulin pumps), which requires education and frequent monitoring (roughly six times per day or continuously through a glucose monitoring system).
- There are serious health complications, such as:
  - DKA, which is life threatening and occurs in up to 45% of people with a new diagnosis of Type 1 diabetes
  - hypoglycemia, which requires immediate treatment
  - other long-term complications, including chronic kidney disease, eye disease, nerve issues, cholesterol issues, and high blood pressure.
- Type 1 diabetes requires ongoing coordinated care and support from:
  - self-management by families every day
  - across the health system (e.g., support may be required from professionals like endocrinologists, family physicians, nurses, nutritionists, and mental health specialists).(32)

There is a lack of consensus on whether population-level screening is warranted for Type 1 diabetes

There is currently no agreement in Canada or other countries on whether to screen for Type 1 diabetes. This is a key reason why we have convened citizen panels to hear about their values and preferences about whether and how to create such a program, and a national stakeholder dialogue with health-system leaders to identify actions that can and should be taken.

As noted in Figure 1 above, one consideration in screening for a disease is if it improves health outcomes as compared to how a disease is currently identified. We have summarized some important benefits and risks in Table 1. In thinking about the potential benefits and risks below, it is also important to know that more is known about Type 1 diabetes screening for some groups than others. Genetic risks scores used in step 1 in Figure 2, above, have been developed with data from white Europeans. When applied to non-European populations, there is less accuracy in screening.(33-41) For example, a recent study has found that when used with non-European participants, the accuracy was comparable or higher for all white and Hispanic participants, but less accurate for Black people, and there was not enough data to determine accuracy for people of Asian descent.(42) These are important gaps in knowledge, particularly given the diverse ethnocultural backgrounds of people living in Canada. For example, the 2021 Canadian census found that: there were 450 ethnic or cultural origins reported; 2.2 million people (6.1% of the population) reported Indigenous ancestry; racialized groups have experienced growth with South Asian (7.1%), Chinese (4.7%), and Black (4.3%) people representing 16.1% of the population; and provinces can differ substantially in the ethnocultural groups living there.(43)

Table 1: Potential benefits and risks that will need to be weighed when considering a new Type 1 diabetes screening program

Level	Potential benefits	Potential risks

Individual	• Having knowledge about risk for Type 1 diabetes can help children and their families be more aware of signs and symptoms and be prepared for eventually developing Type 1 diabetes
	• Prevention of DKA, a life-threatening, frightening, and costly condition (but also time limited and treatable)
	• Potential access to:
	  ○ helpful medical treatments (e.g., emerging treatments delaying diabetes onset, clinical trials)
	  ○ clinical experts for monitoring
	• Opportunity to receive education and tailored genetic counselling if available
		• Potential for misunderstanding risk for Type 1 diabetes from screening, which can lead to withdrawal from a screening program and/or studies (44; 45)
		• Increased anxiety and worry for parents and caregivers after a child is identified as being at increased risk
		  ○ For example, an evidence synthesis of the psychosocial experiences and needs of children diagnosed with Type 1 diabetes found that: the majority of children experience high distress (e.g., grief, anxiety, anger, irritation, injection anxiety); at the time of diagnosis, rates of depressive symptoms, anxiety, stress disorders, and suicidal ideation were elevated; and psychosocial distress typically peaked soon after diagnosis, declined over the following year, but increased again after difficult or upsetting experiences with diabetes management (46)
		• Burden of needing to have health status closely followed over time

Community	• Opportunity to create a screening program that can reach everyone in culturally safe ways	• Potential for contributing to mistrust in the screening program (and possibly in the system more generally) as a result of any increased worry and confusion from the implementation of a new screening program
System	• Decreased emergency department and hospital visits for diabetic emergencies (e.g., DKA), which could confer significant health-system cost savings given costs associated with hospitalization for DKA (47; 48)	• Potential for significant healthcare expenditure depending on structure and function of screening program (e.g., investing in a new program rather than integrating with existing structures and processes, such as those for newborn screening)

If screening for Type 1 diabetes is deemed to be warranted, there is a lack of consensus on how it should be designed

If a new Type 1 diabetes screening program is to be created in Canada, there are many additional challenges that will need to be addressed. For example, if population-level screening is provided to children and youth in Canada, there are at least four key challenges to be addressed:

1) whether to screen
2) when to screen
3) where to screen
4) who should offer screening.

We provide ways to consider addressing these challenges in element 1 in the next section of this brief (see Figure 3).

Any approach taken will also face system-level challenges that will need to be addressed to support adoption across Canada

A new Type 1 diabetes screening program will create important system challenges.

A key challenge will be that a screening program will mean our health systems will need to manage more people for a number of years. This is because we will have two groups instead of one to manage:

- the people diagnosed with Type 1 diabetes who have not been screened (in other words, the status quo)
- those identified as being at risk for Type 1 diabetes (which the system does not currently have to manage).

Managing this new layer of follow-up and care is made harder with the health human resources crisis faced in the country. Many people do not have access to a clinician (physician or nurse) who is most responsible for their routine care. There are also few specialized diabetes clinics. Access to care is even harder for those in rural and remote areas and for those who face cultural and/or language barriers.

Some additional key system challenges include:

- Who will oversee the screening program (for example, a new central national organization or existing provincial and territorial organizations)?
- How will citizens be engaged in governance and decision-making?
- Who will pay for the program (e.g., provincial and territorial governments, who typically administer health systems, or the federal government, which may require negotiation and consensus building between levels of government, which is always more difficult to achieve)
- How will children and their families be supported to make informed choices about screening?
- Who will follow people identified at risk for Type 1 diabetes?
- How will people identified as at risk be engaged in follow-up (e.g., through in-person care and/or virtual care)?
- How will information be shared in the context of inconsistent patient access to electronic medical records?
- How will the program be evaluated (e.g., what will be measured to show success and/or what needs to be improved)?

We return to some approaches to addressing some of these challenges in elements 2 and 3 below.

Insights from citizen panels about the problem

Citizen panel participants generally agreed with the framing of the problem above, but also engaged in in-depth deliberation based on their views and experiences. We organized the key findings from these deliberations into four themes, which are presented in Table 2 below.

Table 2: Key insights from citizen panels about the problem

Key themes about the problem identified by citizen panel participants	Insights and examples from citizens

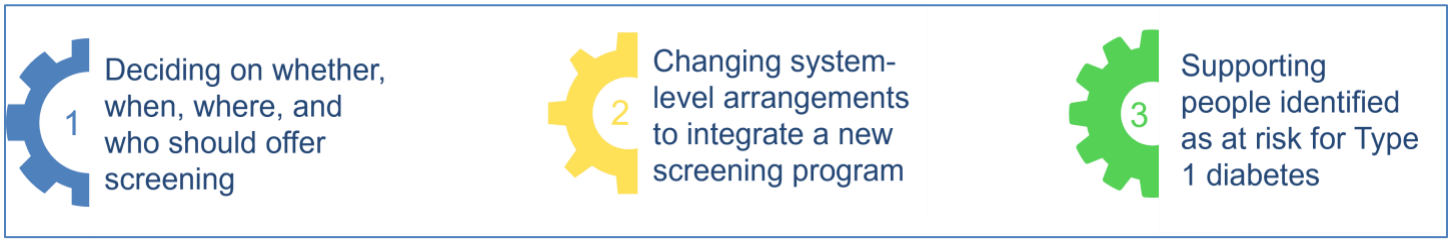
Provincial and territorial health systems lack capacity and resources to support widespread screening and follow-up care for Type 1 diabetes	• Participants emphasized the potential strain on provincial and territorial health systems as a major challenge for implementing a comprehensive Type 1 diabetes screening program
	• The shortage of family physicians, long wait times for specialists, and limited access to endocrinologists, as well as poor internet connectivity, especially in rural and remote areas, were underscored as particularly important considerations
	  ○ This led to some: 1) expressing significant concern that introducing a new screening program could exacerbate these issues, further straining health systems; 2) highlighting the need to prioritize better access to treatment with screening only as an 'added bonus'; and c) questioning 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
	  ○ It was specifically questioned by some whether provincial and territorial health systems could handle the patients newly identified as being at high risk for Type 1 diabetes from screening (e.g., for new pathways of care to follow and support them over time)
	• 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, including the need to harness innovative solutions, such as virtual care options and the involvement of other healthcare professionals like pharmacists, to address capacity issues

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
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, with worries expressed 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, the option for individuals to control their own data, 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	• 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

Key themes about the problem identified by citizen panel participants	Insights and examples from citizens
importance of early screening and detection	• Some parents who participated, 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, which was viewed as essential 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

Elements of a potentially comprehensive approach for addressing the problem

Three elements of a potentially comprehensive approach to address the problem were developed and refined through consultation with the Steering Committee and key informants who we interviewed during the development of this evidence brief.



These elements are designed to provide an initial way of thinking about whether and how to proceed with developing a Type 1 diabetes screening program in Canada. The elements should be considered as interdependent components that would be needed for operationalizing a new screening program.

We describe each of the three elements, their potential components, and insights from relevant evidence syntheses that we identified about them. We then supplement this information at the end of the section with insights from the citizen panels convened in July and August 2024.

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

The first decision that needs to be made is whether to screen for Type 1 diabetes. We asked citizens to reflect on this and, as noted below, virtually all participants indicated that screening for Type 1 diabetes was warranted given the benefits to health it can provide, as well as the potential for delaying onset through new treatments. As outlined in Figure 3, if a new screening program were to be implemented in Canada, there is a need to consider: 1) when to screen, 2) where to do it, and 3) who should offer it**.** Figure 3 provides some information to consider to support informed judgements about these questions.

In addition to the context provided in Figure 3, we provide below key findings from four purposively sampled evidence syntheses that we identified as providing insight about how to enhance uptake of population-level screening programs. We selected evidence syntheses based on relevance to diabetes screening, screening for children and adolescents and from cancer screening in contexts relevant to considerations for Type 1 diabetes screening (e.g., reaching rural areas and behavioural insights that could inform the design of a screening program). These evidence syntheses were identified from broad searches of Health Systems Evidence, HealthEvidence.org, and PubMed about features of population-level screening programs.

One of the evidence syntheses focused on diabetes screening among women with prior gestational diabetes. While not directly applicable to Type 1 diabetes screening, it included several helpful insights about improving uptake, including the need to

implement theory-driven interventions that combine group education, flexible screening methods, multimodal approaches (including reminders and system changes), and context-specific strategies, while addressing barriers and aligning with other prevention efforts.(49)

A scoping review focused on adolescents in the context of screening for sensitive health topics in primary care. The review indicated that such screening should be implemented in ways that address systemic constraints (e.g., time, resources, training, payment), while also ensuring screening processes are streamlined (especially for multiple screenings) and confidentiality.(50)

Lastly, two evidence syntheses provided relevant insights from cancer screening. The first was focused on patient-targeted interventions to increase cancer screening participation in rural areas (a challenge that may be faced for a future Type 1 diabetes screening program). It noted that to increase cancer screening uptake across diverse populations, especially in rural and underserved areas, there is a need to develop integrated, community-based strategies combining nurse-led interventions, targeted education, improved access, and provider support, and in ways that are tailored to local needs and that involve and engage key community stakeholders.(51) The second evidence synthesis used a behavioural analysis lens to analyze efforts to improve knowledge, attitudes, and uptake of cervical cancer prevention among female students through school-based health education (a setting potentially applicable for Type 1 diabetes screening). This evidence synthesis indicated that school-based education improved screening knowledge, as well as knowledge and intentions to receive HPV vaccination. While school-based education did not improve risk perceptions about infection or attitudes about vaccination, it did find that printed educational materials could help with informing risk perceptions. However, no significant increases in vaccination uptake from school-based education was found, but face-to-face approaches that actively engage people may have some benefit.(52)

Figure 3: Overview of possible features of Type 1 diabetes screening programs to consider

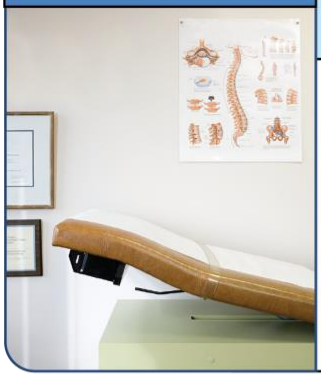
WHEN should screening be done?

- At birth as part of existing newborn screening programs
- At the time of routine vaccinations before children start school
- At school age when most find out they have Type 1 diabetes
- At any of these times as determined by preferences of families

KEY INSIGHTS ABOUT THE FEATURES

- Provinces and territories already have newborn screening programs, which Type 1 diabetes could be added to
- All children are required to receive MMRV (measles-mumps-rubella-varicella) vaccine with some exceptions and screening could be done at the same time
- Conducting screening in schools closer to the age when children typically develop symptoms could reduce worry and anxiety over time, but would also require investments in a new stand-alone screening program

WHERE should screening be done?

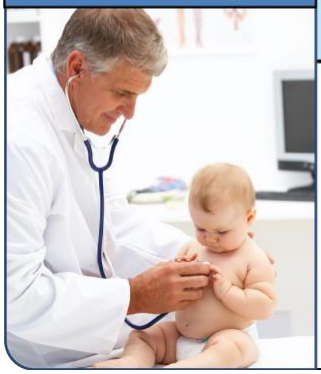


- Family doctor's office
- Specialized labs or clinics
- Schools
- At home
- Pharmacy

KEY INSIGHTS ABOUT THE FEATURES

- Where screening is conducted will be at least partly based on when it's done
- For example, screening at the time of:
  - birth is likely to be done in hospitals by physicians, midwives, or nurses (and sometimes in birthing centres or at home)
  - vaccination before starting school would be best done in a clinician's office (for example, with a family physician or nurse)
  - being school aged would be best done in schools (perhaps done at the same time as other school-based programs like HPV vaccination)

WHO should do the screening?



- A professional
  - Physician
  - Nurse
  - Lab technician
  - Pharmacist
- Self-administered with a take-home test kit

KEY INSIGHTS ABOUT THE FEATURES

- As above, this will likely depend on when screening is done, but could also depend on patient preference
  - For example, families could be sent home with a self-administered test kit after a baby is born and make a decision when ready

Changing system-level arrangements to integrate a new screening program

Any new screening program for Type 1 diabetes (regardless of the form it takes) will need to be integrated into existing provincial and territorial health systems in Canada. This will mean having to manage people newly diagnosed with Type 1 diabetes (as these systems do now) and those identified as being at risk for Type 1 diabetes (which these systems do not currently have to do). On the other hand, screening could reduce the burden of DKA on families and the health system, but these benefits likely won't be realized for a number of years.

Some important health-system changes that may be needed to integrate a new Type 1 diabetes screening program include:

- helping parents, guardians, and caregivers make decisions on whether they want to have screening done (e.g., by using patient decision aids designed for Type 1 diabetes screening)
- changing pathways of care to follow and engage people identified at risk for Type 1 diabetes, by
  - using virtual care to provide updates about screening and risk assessments
  - engaging a most responsible clinician (e.g., a family physician) or team of clinicians (e.g., nurses and physicians) who are responsible for tracking people identified as at risk
- making sure that the approach is culturally appropriate and addresses other barriers such as language or understanding of what screening means (which could also be done, at least in part, using patient decision aids)
- conducting outreach to engage people in screening who are not connected to the health system to ensure population-level reach of the screening program (e.g., those without a family physician or other care provider or team most responsible for their care)
- engaging citizens in decision-making processes about Type 1 diabetes screening programs.

Brief summary of evidence from the most relevant and high-quality evidence syntheses

To help with making informed judgments about what changes are needed, we provide below a brief summary of what we know from some of the most relevant and highest quality syntheses of the best-available evidence that we were able to identify from our searches. Additional details are provided in the appendix for those who are interested in reading more.

- Helping parents, guardians, and caregivers make decisions
  - Patient decision aids support decision-making by making the decision explicit, providing information on potential benefits and harms of each option, and helping people clarify their personal values, goals, and preferences relevant to the decision (53)
  - Patient decision aids have been found to help people make better-informed decisions, feel better about their decisions, and have better patient experiences (54)
  - In addition, shared decision-making approaches have been found to be very important for providing patient-centred care,(55) and for screening, it gives the chance for careful consideration and discussion of many factors, including information about the disease, patient and family fears, values, and beliefs, and their previous experiences
  - Telehealth interventions, particularly mobile applications, video plus telephone, and text message plus telephone, have been found to support cancer screening decision-making by providing convenient access to health information, reducing barriers like travel and embarrassment, and potentially improving communication about sensitive health topics, especially for breast and cervical cancer screening (56)
- Changing pathways of care to follow people identified as at risk for Type 1 diabetes
  - Telemedicine interventions for people living with Type 1 diabetes show potential for improving care pathways by enabling more frequent patient-provider interactions, facilitating remote monitoring and timely management adjustments, delivering self-management education through various digital modalities, and modestly improving glycemic control compared to usual care (57)
  - Telehealth interventions, primarily involving diabetes self-management education delivered through telephone calls, text messages, web portals, and virtual visits, can significantly improve glycemic control among Black and Hispanic diabetes patients, reducing glycated hemoglobin (HbA1c) levels by 0.465% (58)
- Culturally appropriate care
  - A scoping review identified six broad elements of culturally safe health initiatives for Indigenous peoples in Canada, which are important to consider and include: “collaboration/partnerships, power sharing, address the broader context of the patient’s life, safe environment, organizational and individual level self-reflection, and training for health-care providers” (59)
    - Importantly, the review also noted that even though the provision of culturally safe initiatives is dependent on the interaction between providers and the patient, developing a common understanding of key components such as the six elements above are important for initiatives when moving from theory to practice (59)
  - Moreover, such initiatives can be guided by frameworks such as He Pikinga Waiora (HPW), which is an implementation framework for designing and implementing health interventions in Indigenous communities for non-communicable diseases that adopts a focus on community engagement, a culture-centred approach, systems thinking, and integrated knowledge translation (60)

- Bilingual community health workers can help with use of disease-prevention strategies in culturally and linguistically diverse communities; bilingual and culturally competent health workers are able to provide better awareness about services, and health programs provided by people from the community are considered culturally sensitive (61)
- Culturally sensitive, multicomponent interventions using different modes of information delivery (such as brochures and visual media) and involving community health workers or promotors were most effective at increasing cervical screening uptake among immigrant women, with a meta-analysis showing higher effect sizes for these approaches compared to single-component or non-culturally tailored interventions (62)

- Outreach to connect people to the health system
  - Reaching populations for screening can be done
    - At an individual level through postal reminders and telephone recalls
    - In collaboration with communities through organizations and/or cultural events
    - At a population level through mass media campaigns and community education
  - Using scheduled appointments instead of open appointments helps reduce logistical barriers for people to attend their appointments (63)
- Engaging citizens in health-system decision-making processes
  - Involving citizens as partners in decision-making processes (e.g., to design, deliver, and evaluate health services) has been identified as important for ensuring person-centred care, but there is little evidence about the effectiveness of such approaches on enhancing patient-centredness and on patient experiences in such processes (64; 65)
  - More specifically it has been highlighted that citizens can be engaged at different levels (e.g., in direct care, in organizational design and governance, and in policymaking), and that the continuum of engagement ranges from lower-levels of engagement (e.g., consultation) to more in-depth engagement (e.g., through co-design) with the former being best positioned for discrete products such as education and tool development and the latter being best positioned for optimizing care processes and redesign efforts (65)

Supporting people identified as at risk for Type 1 diabetes

Once someone is identified as being at risk for Type 1 diabetes, they will need to be supported in several ways. This could include:

- providing information and educational materials for parents, families, and those identified as being at risk
- using ways of communicating information that are accessible and easy to use
  - for example, online patient portals that allow patients and families to access and manage their information over time, and to provide a forum where families can chat and connect with people going through similar experiences
- updating and communicating adjusted risk assessments over time
- managing how risk for Type 1 diabetes is shared and implications for confidentiality and insurance
- providing access to psychological assessment for anxiety and other mental health conditions with referrals to and coverage for psychological supports
- helping people from all walks of life be engaged in research studies about Type 1 diabetes to evaluate how well screening works and potential therapies for delaying the onset of or preventing Type 1 diabetes.

Brief summary of evidence from the most relevant and high-quality evidence syntheses

- Patient decision aids
  - See evidence provided in solution 2
- Patient portals or patient held records for communicating results or health information over time
  - Key features of patient portals that have been found to be helpful include:
    - access to information from health records (e.g., medical history)
    - the ability to submit requests for prescription refills and to upload glucose home-monitoring results
    - access to general health education and resources
    - ways to communicate with healthcare providers (66)
  - However, a lack of awareness about the use of electronic portals as well as privacy and security concerns can be barriers to use (67)
  - A significant gap exists between research-based interventions and commercially available apps for Type 1 diabetes management, with most available apps focusing on basic features like personalization, data recording, and data

management, while lacking advanced features such as social interaction and reward systems that could potentially enhance patient empowerment and engagement in disease self-management (68)
    - While digital health communication can provide convenient access to information, participants expressed concerns about privacy and confidentiality, particularly for sensitive health topics, suggesting a need for strategies like coded language and user control over message content and timing (69)
    - When delivering information to patients about their condition and any uncertainty about it, patients and caregivers emphasized:
        - that the information should be delivered honestly, with kindness and compassion, and in a positive manner
        - healthcare providers should provide information in a way that avoids confusion among patients and their caregivers (70)
    - Training on how to communicate bad news to patients is highly recommended and can help with the occupational stress and emotional cost that healthcare providers can face (70)
    - Communication skills training is an approach that can be used by healthcare teams to improve conversations with patients in emotional distress (71)
- Ensuring confidentiality of health information
    - Patients and the public have been found to express significant concerns about privacy breaches and potential data abuses (particularly for sensitive health information) calling for robust measures including data de-identification, restricted access, user control over data sharing, transparency about data use, security protocols, and penalties for misuse, particularly for sensitive health information (72)
- Psychology assessment for anxiety and other mental health conditions
    - Psychological assessment in the new-onset period of Type 1 diabetes is crucial, as early screening for depression and anxiety in both youth and parents can identify those at risk for persistent symptoms, which may negatively impact diabetes management and outcomes (73)
    - Digital health interventions show promise for assessing and addressing psychological outcomes in youth with Type 1 diabetes, but more research is needed to develop theory-based interventions that effectively evaluate and improve mental health conditions such as anxiety and depression in this population (74)
- Equitable engagement in research
    - Helping patients be engaged in research can be done by setting realistic timeframes that allow for patient involvement in the research design stage, being transparent about any public contributions and involvement, and communicating information for patients and the public that is easy to access and understand (75)
    - Evaluation of patient engagement in research and decision-making activities is also important to ensure future uptake of patient engagement (75)

Insights from citizen panels about the three elements of a potentially comprehensive approach for addressing the problem

Elements of a potentially comprehensive approach	Insights and examples from citizens
Deciding on whether, when, where, and who should offer screening	**Whether to screen** • Participants generally supported implementing a population-level screening program for Type 1 diabetes, with most emphasizing the improved health outcomes that could be achieved, which would make the investment in a program worthwhile • Broad agreement on the importance of making screening 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 **When to screen** • Most favoured integrating Type 1 diabetes screening into existing newborn 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

Elements of a potentially comprehensive approach	Insights and examples from citizens

	• A smaller number of participants 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 who emphasized school-based screen as the optimal option identified the value of student engagement with those currently living with Type 1 diabetes having the potential to help with raising awareness and providing education
	  ○ Concerns were raised about: 1) the added burden it may cause schools systems; and 2) coupling screening with vaccination schedules given vaccine hesitancy that could limit the reach of screening and also affect its trustworthiness
	• Another small sub-set of participants 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 it is voluntary and 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)
	Where to screen and who should offer it
	• All participants strongly preferred screening to be conducted:
	  ○ by trained healthcare professionals to ensure accuracy to support linkage to support and education following a high-risk screening result
	  ○ in controlled, professional environments such as hospitals, doctor's offices, or specialized clinics
	  ○ with a coordinated approach between providers and settings to ensure accurate collection, management, and communication of results
	• Most expressed significant reservations with the idea of using self-administered home test kits, citing concerns about accuracy, reliability, and proper use, as well as the likelihood that many would end up not using the test kits
	• A number of participants also indicated that pharmacies and pharmacists or the 'local point of services' model in Quebec could play a role in offering screening and providing follow-up over time, which was seen as a way to enhance accessibility given that most communities have access to a pharmacy but not family physicians or specialists

Changing system-level arrangements to integrate a new screening program	**Need for coordination between provincial and territorial health systems to ensure consistent standards and data sharing** • Viewed as important for helping to ensure equity across the country where everyone would benefit from a similar approach • 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 **Ensure availability of sufficient resources and adopt innovative solutions to address resource constraints** • Highlighted as part of overall concern about the current strain on the healthcare system; questioned whether there would be sufficient specialists, particularly endocrinologists, to support those identified as high risk through screening, but also noted that such times are opportunities for innovation • Key suggestions for system-level innovations 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 • Some proposed expanding the role of existing diabetes clinics to support the screening program **Use a patient-centred approach to integrate a new Type 1 diabetes screening program**

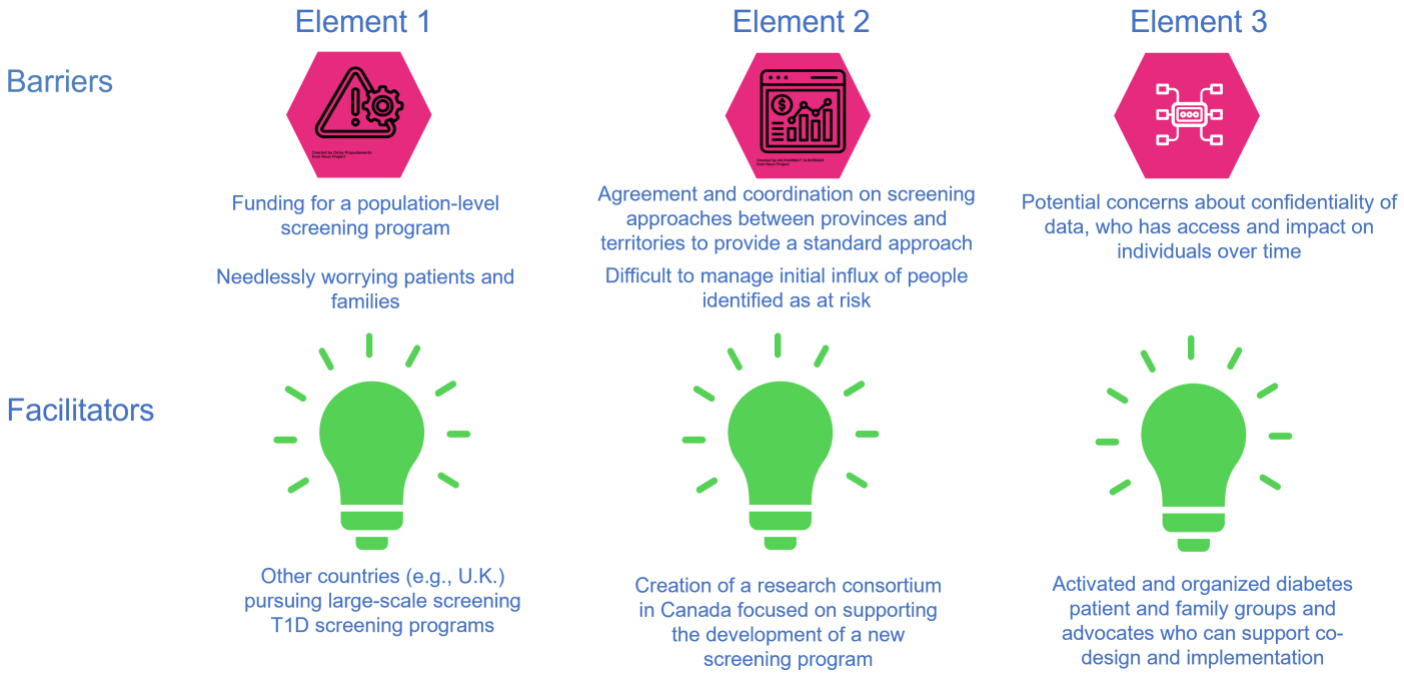
Elements of a potentially comprehensive approach	Insights and examples from citizens

	• Several suggestions for ensuring a patient-centred approach were made:
	  ○ Use 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
	  ○ Use patient decision aids to help families make informed choices about screening
	  ○ Integrate the screening program into existing care pathways and ensure coordinated follow-up care among patients, families, caregivers, and clinicians
	  ○ Support a team-based approach involving primary care providers, endocrinologists, diabetes educators, and mental health counsellors, which could be coupled with specialized diabetes clinics for at-risk individuals where both medical monitoring and educational support could be provided
	  ○ Adopt culturally appropriate approaches, including addressing language and health literacy barriers
	  ○ Conduct outreach programs to engage diverse communities to ensure equitable access to screening and to promote peer-to-peer learning and awareness campaigns
	  ○ Support 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)

Supporting people identified as at risk for Type 1 diabetes	• 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
	• Many also stressed the need for support in navigating the health system and accessing necessary resources, with an emphasis on the importance of providing information and navigation supports in a way that is culturally appropriate (e.g., providing materials and services in multiple languages and tailored to diverse cultural backgrounds)
	• Most supported a patient portal as a way of accessing test results and educational materials, as well as for supporting the coordination of appointments and connection with peers
	  ○ 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
	• Psychological support was viewed as a crucial resource to provide as part of a screening program, with participants suggesting the need to provide access to counselling services, educational programs, and support groups for at-risk individuals and their families
	  ○ Many also expressed interest in ways for families to connect with others in similar situations, recognizing the value of peer support

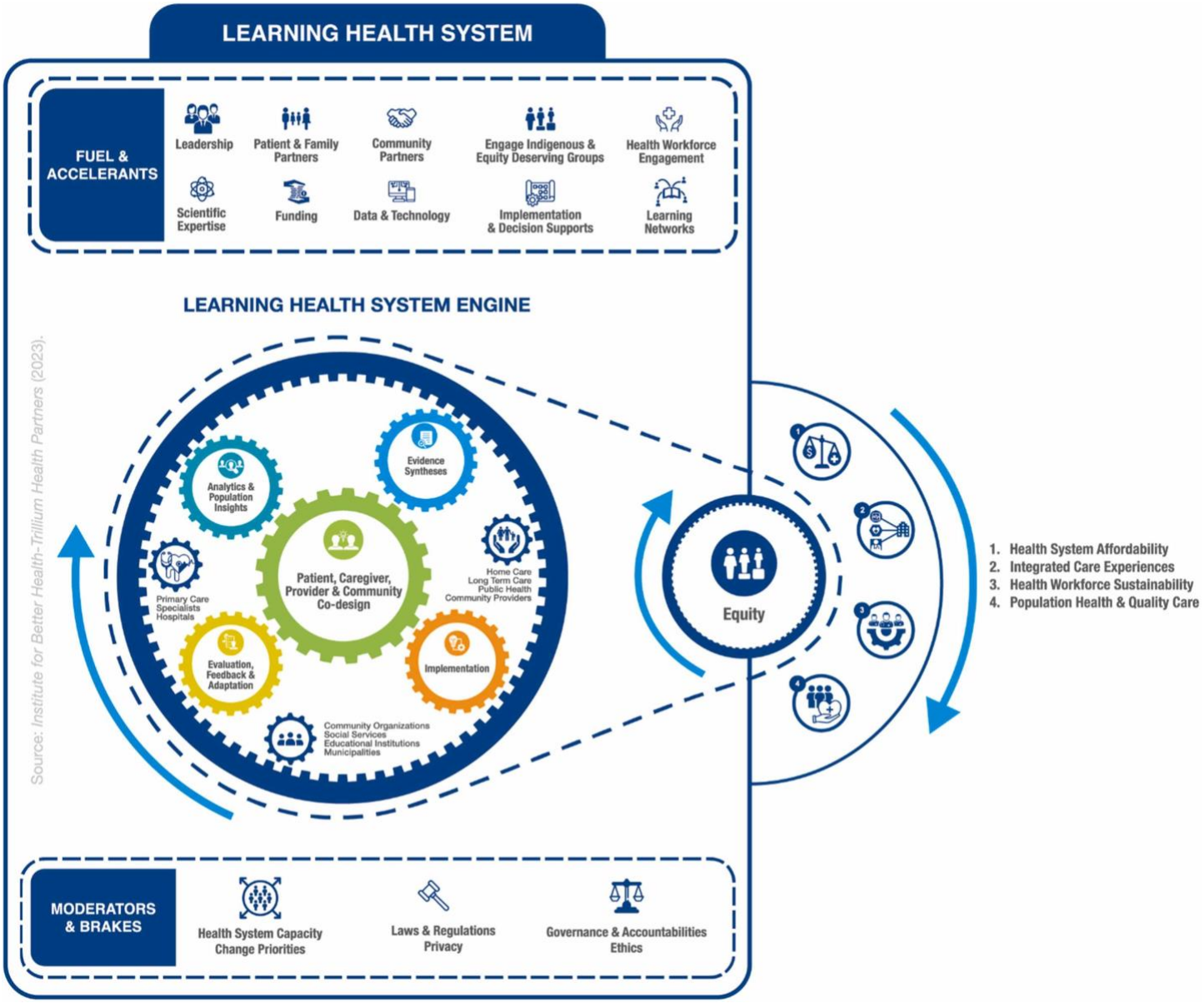
Implementation considerations

We identify below some barriers that may make it difficult to proceed with the elements, as well as facilitators that could create a window of opportunity for advancing them. We also note below key barriers and facilitators, as well as outcomes that participants in the citizen panels identified and prioritized to measure as part of any future Type 1 diabetes screening program.



With planning for a Type 1 diabetes screening program in nascent stages, there is an opportunity to lay the groundwork for a robust learning health system approach, which can be guided by the recently published learning health system framework, which is shown in Figure 4 below. At the core of the framework is the learning health system engine that consists of five interconnected learning gears that are meant to encompass different forms of evidence that can best inform different stages of the learning cycle. The gears are meant to convey that while each has a unique function, they: 1) intersect and are interdependent; 2) are centred by patient, caregiver, provider, and community co-design; and 3) collectively create motion to produce one or more equity-focused quadruple aim outcomes (health system affordability, integrated care experiences, health workforce sustainability, and population health and quality of care). These gears also intersect with other gears in the health system that relate to medical care, community health services, and non-health service delivery sectors. While distinct, the model indicates that it is essential for collaboration among them to advance an integrated 'whole system' approach. Moreover, the framework underscores the need for the learning health system to be animated by coordinated partnerships between researchers and system leaders, as well as the environments where partnerships can be built and sustained and where insights from citizens can be equitably and meaningfully identified and integrated into the system in an ongoing way. Lastly, the model identifies several 'fuels' or 'accelerants' for a learning health system that can be harnessed, while also noting 'moderators' or 'brakes' that can slow down or redirect the learning health system.

Figure 4: Learning health system action framework*



*This figure is reproduced with permission from Reid et al. 2024 (76)

Insights from panel participants about implementation considerations (barriers, facilitators, and outcomes to measure as part of implementation)

During the panel, participants identified several barriers that they viewed as important to consider towards the goal of creating an integrated health-innovation system. Many of these resonated with those identified above (e.g., difficulties in coordinating a consistent approach across provincial and territorial health systems), as well as the challenges they identified that we summarized in the problem section (e.g., resource constraints for managing a new cohort of people identified as at risk for Type 1 diabetes, stress and anxiety concerns, data confidentiality concerns,lack of public education, equity and access issues, technological barriers for accessing online information). In addition to these, participants also emphasized the potential impact of vaccine hesitancy on screening uptake if screening is linked to vaccination schedules, as well as the risk of misinformation spreading about the screening program or Type 1 diabetes that could undermine its trustworthiness.

When discussing facilitators or approaches to support implementation, participants similarly agreed with those listed above, but expressed the need for:

- harnessing technological advancements, including telehealth and digital health tools that can provide access to follow-up for those identified as at high risk for Type 1 diabetes (especially for those in rural areas)

- leveraging social media and diabetes advocacy groups as opportunities for comprehensive education and awareness campaigns
- expanding existing support networks for families dealing with diabetes
- learning from successful screening programs in other countries like the U.K., Europe, the U.S., and Australia.

Lastly, we asked participants what they would like to see measured as indicators of success if a population-based screening program were implemented in their province or territory. 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 (and ideally in a learning health system approach) 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, low socio-economic status)
- Health-related outcomes (e.g., by tracking the number of DKA events and emergency room visits averted)
  - Psychological impacts of screening (e.g., stress, anxiety, 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)
  - Decision to screen versus 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 (underscoring the need for a network of research teams involved in the program development to continue to be involved in a learning health system approach). 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, depression) from participating in screening would be difficult to measure through one-off evaluations and would require following people over time.

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