McMaster University
Health Forum

CanScreen T1D
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Citizen Brief

Developing a Type 1 diabetes screening program in Canada

5 July 2024

Context

What is Type 1 diabetes?

Type 1 diabetes is an autoimmune disease that typically develops between the ages of 10 to 14 (but can be at any age), affects roughly 300,000 Canadians and is increasing at an estimated 4.4% per year.(1-5)

An autoimmune disease refers to a group of diseases where the immune system malfunctions and mistakenly attacks healthy cells, tissues, and organs.(6) For people with Type 1 diabetes:
- the immune system mistakenly destroys the cells that produce insulin (the hormone that controls blood sugar levels) in the pancreas
- this leads to not being able to produce insulin at all
- without insulin, blood sugar is not able to get into the body's cells where it's used to create energy
- this results in high levels of blood sugar, which can lead to many different symptoms that can develop over a few days to weeks
- common symptoms of high blood sugar include increased thirst and urination, increased hunger, blurred vision, fatigue, and unexplained weight loss
- having high levels of sugar in the blood over a long period of time leads to problems such as serious damage to the eyes and kidneys.(1-4; 7)

Type 1 diabetes is different from Type 2 diabetes, which is not an autoimmune condition. Instead, Type 2 diabetes occurs when the body makes insulin but not enough or insulin that doesn't work properly.(8) For those interested in more detail about the differences in the causes, risk factors, symptoms, and management for Type 1 and Type 2 diabetes, please refer to this overview from Diabetes Canada or this helpful comparison table.

About this citizen brief

This document was produced to inform a panel discussion with citizens from across Canada. The panel will bring together approximately 14–16 participants from across the country. Participants will share their ideas and experiences regarding the development of a Type 1 diabetes screening program in Canada and learn from research evidence and from the views of others. The panel will help us to understand the values that participants feel should inform future decisions about the issue, as well as to reveal new understandings and get ideas about how it should be addressed.

The panel discussion will inform an upcoming dialogue on this topic in September 2024. This dialogue will bring together policymakers, professionals, researchers, members of the public, and other stakeholders from across Canada.

We used three mechanisms to collect the information presented in this document:
- we consulted the committee leading this project
- we interviewed people who know the issue very well
- we examined what is known from syntheses of the best-available evidence on the issue.

Throughout the document, we provide spaces for you to write down your thoughts ahead of the panel discussion. At the end of the document, we also provide:
- a list of resources you may find helpful (Appendix 1)
- tables summarizing what is known about each solution (Appendix 2)
- the list of all the references we cited in the document (Appendix 3).

What are health impacts of Type 1 diabetes?

In brief, Type 1 diabetes:
- has a lifelong and significant impact on those living with it and their families

- requires taking insulin daily (through multiple injections or a pump), closely monitoring diet and blood sugar levels, and having regular health checks
- requires continuous monitoring for important health implications that require immediate attention, including
  - low blood sugar (called hypoglycemia), which can be managed by taking sugar (glucose) or a medication containing glucose
  - prolonged high blood sugar called diabetic ketoacidosis (DKA), which can be life threatening.(1; 3; 4; 8)

DKA occurs when cells don't have enough insulin to let blood sugar into them to use for energy. The body then turns to the liver to break down fat for the fuel it needs. This produces acids called ketones. When the body produces too many ketones quickly, they can build to dangerous levels, which leads to DKA.(1) This can sometimes be the first sign of Type 1 diabetes in those not yet diagnosed. Currently in Canada, DKA can be present in up to 45% of cases at diagnosis.(9-11) DKA is a medical emergency, as the resulting imbalance of electrolytes and acid in our bodies can cause severe weakness, brain injury, and death.(12)

How does someone find out they have Type 1 diabetes?

People typically find out they have diabetes by seeking care when they experience some key symptoms, including excessive thirst, frequent urination, fatigue, weight loss, or DKA.(3; 4)

Unfortunately, many people will not know they have diabetes until they become very sick with DKA and present for emergency care.(13) To confirm Type 1 diabetes, a physician or nurse practitioner will conduct blood tests to confirm diagnosis.

While first-degree family members of people with Type 1 diabetes are at a higher risk of developing the condition, 85% of people in Canada with Type 1 diabetes do not have a family member with the condition.(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 there, you have a higher than average risk of being diagnosed with Type 1 diabetes.(14) We provide more information about this below.

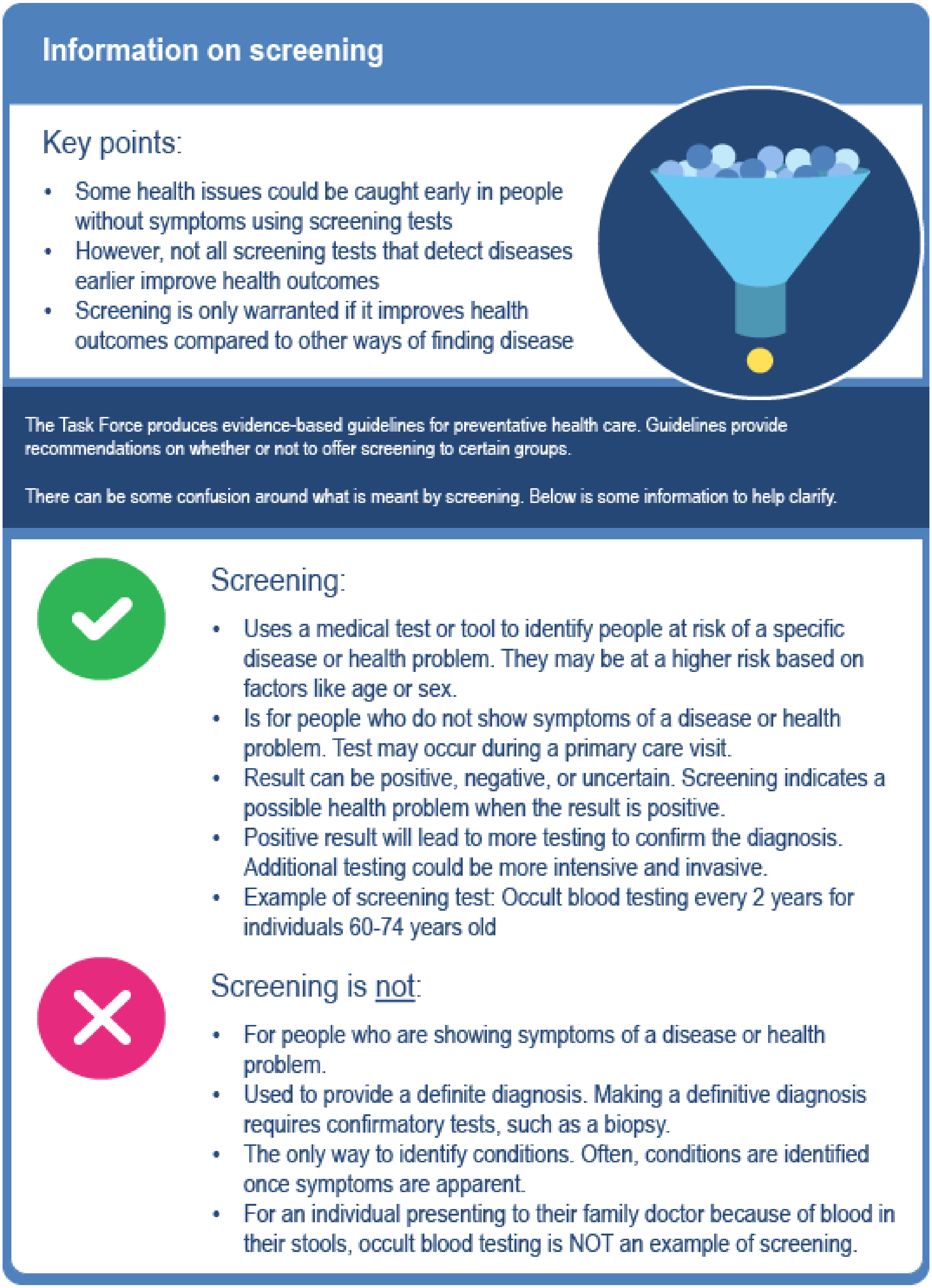
What is screening and how can it potentially help with Type 1 diabetes?

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.

Since Type 1 diabetes symptoms develop over time, population-level screening for it could be important for:
- preventing DKA that can be potentially life threatening
- helping to get earlier treatment with insulin to avoid high blood sugar for long periods of time
- 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,(15) 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.(16-19) These studies include testing potential screening programs, and following people from birth until older age to study their diabetes progression.(20) Studies are now being planned and implemented in Canada as part of the same project that is funding the citizen panels that this brief is designed to inform.

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.
- Example of screening test: Occult blood testing every 2 years for individuals 60-74 years old

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, such as a biopsy.
- The only way to identify conditions. Often, conditions are identified once symptoms are apparent.
- For an individual presenting to their family doctor because of blood in their stools, occult blood testing is NOT an example of screening.

*This figure is reproduced with minor revisions from the Canadian Taskforce on Preventive Health Care under a Creative Commons Non-Commercial license.(21)

How does screening for Type 1 diabetes work?

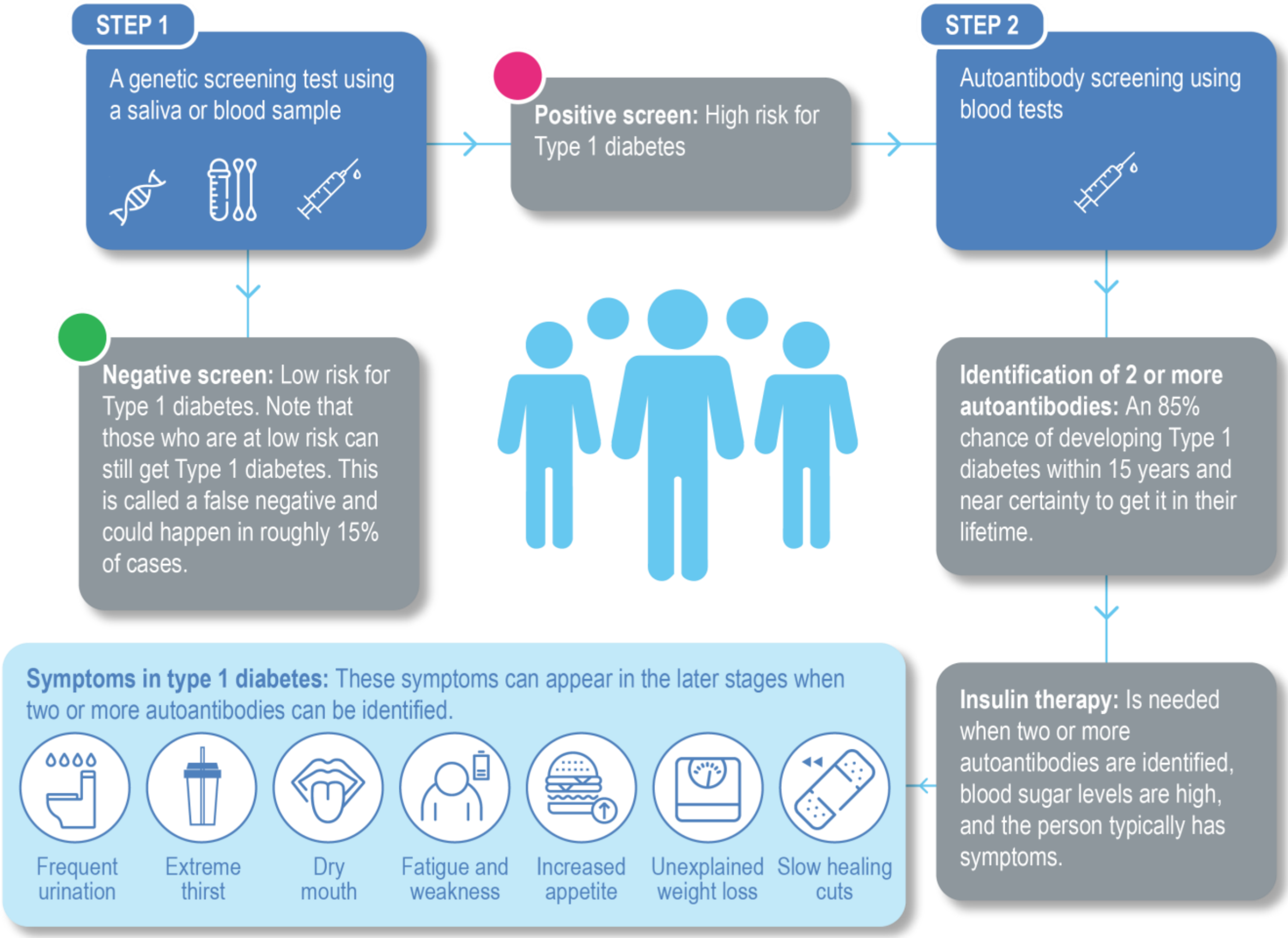
The newest screening approaches being proposed, evaluated and used in research studies in Canada and other countries can include a multi-step approach. We summarize this process in Figure 2.

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 get Type 1 diabetes, but would get more screening in step 2 to give a more precise answer to their risk for Type 1 diabetes
    - those who are at low risk can still end up getting Type 1 diabetes, which is called a false negative and could occur in roughly 15% of cases.(22; 23)

If an individual has a high-risk genetic risk score (in other words, they are in the 10% of the population with the highest risk), they would be offered another phase of screening to look for other markers for Type 1 diabetes. These markers are called autoantibodies and are identified using blood tests. These autoantibodies are what the immune system uses to identify the cells that produce insulin and mark them for destruction. 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.(24) The risk for Type 1 diabetes increases with more autoantibodies in the blood. Current findings highlight that having two or more autoantibodies means an 85% chance of developing Type 1 diabetes within 15 years and near certainty that one will get it in their lifetime.(24)

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



STEP 1

A genetic screening test using a saliva or blood sample

Positive screen: High risk for Type 1 diabetes

STEP 2

Autoantibody screening using blood tests

Negative screen: Low risk for Type 1 diabetes. Note that those who are at low risk can still get Type 1 diabetes. This is called a false negative and could happen in roughly 15% of cases.

Identification of 2 or more autoantibodies: An 85% chance of developing Type 1 diabetes within 15 years and near certainty to get it in their lifetime.

Insulin therapy: Is needed when two or more autoantibodies are identified, blood sugar levels are high, and the person typically has symptoms.

Symptoms in type 1 diabetes: These symptoms can appear in the later stages when two or more autoantibodies can be identified.

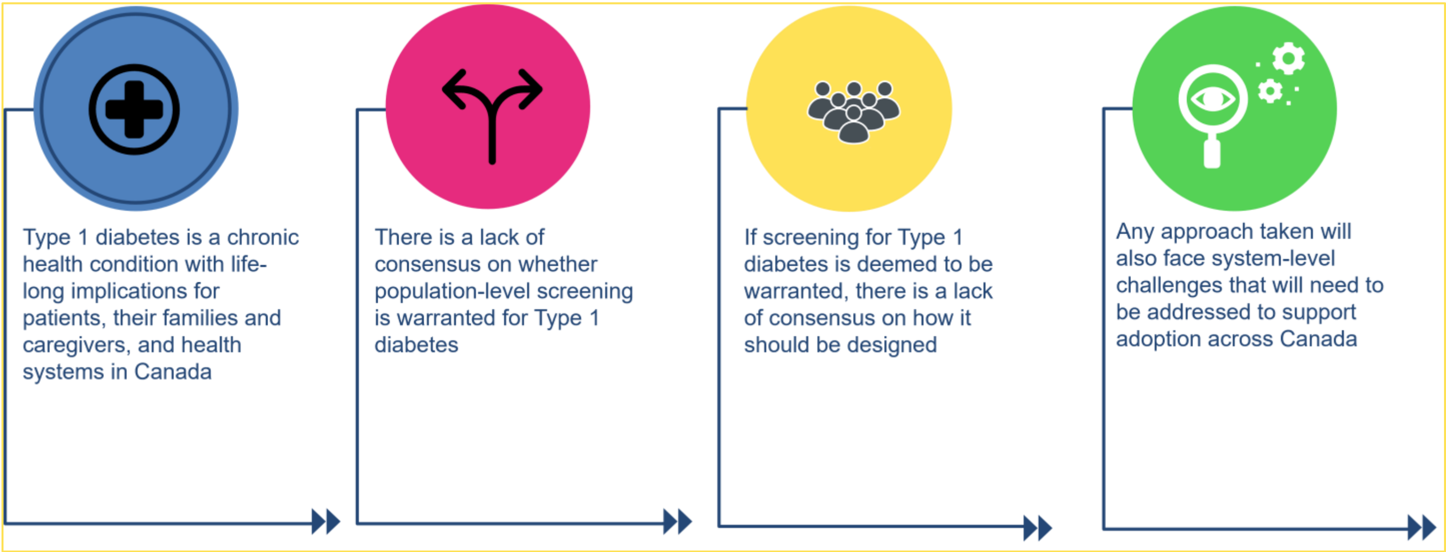
Our goal

Many factors need to be considered 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 about what to do.

With this in mind, in the following pages, we will:
- explore the problem
- discuss potential solutions
- identify barriers and windows of opportunity to move forward.

Exploring the problem

We have identified four aspects of the problem, which are outlined in the visual below and discussed in the sections that follow.



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

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

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

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

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, which we describe in the list below.

- 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 (for example, purchasing medical supplies and equipment for glucose monitoring and insulin doses, travelling to multiple appointments).
- There is need to take insulin 4–5 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 approximately 40% of children 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 (for example, support may be required from professionals like endocrinologists, family physicians, nurses, nutritionists, mental health specialists, and more).(25)

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

There is currently no agreement in Canada on whether a screening program for Type 1 Diabetes should exist. This is a key reason why we are bringing citizens together – we want to hear about your values and preferences about whether and how to create such a program. This information will inform future deliberations with system leaders on the same topic to inform future actions.

As noted in Figure 1 above, screening for a disease should only be done 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 below to help you decide if you think screening should be done for Type 1 diabetes in Canada. There may be others that you think of when reviewing this list and we encourage you to identify these during the panel.

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.(26-34) 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 African Americans. There was not enough data to determine accuracy for people of Asian descent.(35)

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	• Prevention of DKA, a life-threatening, frightening, and costly condition (but also time limited and treatable) • Potential access to: ○ helpful medical treatments (for example, 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 (36; 37) • Increased anxiety and worry for parents and caregivers after a child is identified as being at increased risk • 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 as a result of any increased worry and confusion
System	• Decreased emergency department and hospitals visits for diabetic emergencies (for example, DKA)	• Potential for significant healthcare expenditure depending on structure and function of screening program

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. This requires hearing from citizens about their values and preferences, which is the purpose of this project.

If population-level screening is provided to everyone in Canada, there are at least four key challenges to be addressed: **whether to screen, when to screen, where to screen, and who should offer screening**. We provide ways to consider addressing these challenges in option 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 (for example, provincial and territorial governments, who typically administer health systems, or with federal government support)
- 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 (for example, 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 (for example, 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 options 2 and 3 below.

Using the information above, please consider the questions below in advance of the panel

- For yourself, your family or friends, your community, and/or your province or territory, what do you find most concerning or challenging in thinking about Type 1 diabetes screening? What do you view as important opportunities?

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- What do you think would be most challenging for you or your family and friends if faced with deciding whether to get screening for Type 1 diabetes?

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- Are there other challenges or opportunities that you think are important but not captured above?

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Discussing solutions

To promote discussion about the pros and cons of potential solutions, we have selected three solutions to inform the development of a potential future Type 1 diabetes screening program in Canada. We discuss each solution in the sections that follow.

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

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 ask you to reflect on this using the information in Figure 2.

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.

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

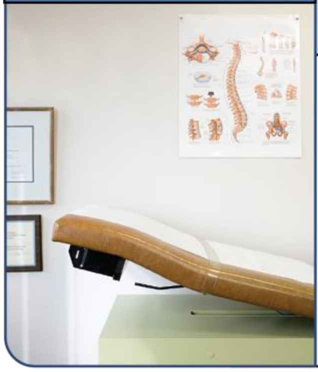
WHEN should screening be done?

- 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

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
- 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

Questions to consider about solution 1

- What do you think would make it worthwhile for everyone (i.e., the whole population) to be screened for Type 1 diabetes?

- What would make a population-level screening program for Type 1 diabetes trustworthy? What would make it untrustworthy?

- What would you want to know to make a decision for yourself or someone you care for to be screened for Type 1 diabetes? For example, what kind of benefits would be important to know about to make this decision?

- What might make you or a family member not want to get screened for Type 1 diabetes?

- What concerns (if any) do you have about screening being used to identify genes to identify a risk score as described earlier in the brief?

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.

Some important changes that may be needed include:
- helping parents, guardians, and caregivers make decisions on whether they want to have screening done (for example, through what are called patient decision aids)
- 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 (for example, a family physician) or team of clinicians (for example, 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 using patient decision aids)
- conducting outreach to engage people in screening who are not connected to the health system (for example, 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 (based on what we know from the most relevant and high-quality syntheses of the best-available evidence)

To help with making informed judgements 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. 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 (38)
  - Patient decision aids have been found to help people make better-informed decisions, feel better about their decisions, and have better patient experiences (39)
- Culturally appropriate care
  - 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
  - Health programs provided by people from the community are considered culturally sensitive (40)
- 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
    - 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 (41)
- Engaging citizens in health-system decision-making processes
  - Shared decision-making is very important for providing patient-centred care (42)
    - 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
  - Studies of shared decision-making show that people choose options that are less invasive and start treatments earlier

Questions to consider about solution 2

- What would help to make decisions about screening for you or your family?

- If you were found to be at risk for Type 1 diabetes through screening, would you be comfortable being monitored using virtual visits, in-person with a clinician (nurse or physician), or a mix of virtual and in-person depending on what needs to be addressed in the visit?

- Who would you want to be most responsible for following you if you or a family member were found to be at risk? A primary care physician like a family doctor or nurse practitioner, or a specialist such as an endocrinologist?

- Who do you think should be responsible for managing data collected from a screening program?

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 coverage for 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 or preventing Type 1 diabetes.

Brief summary of evidence (based on what we know from the most relevant and high-quality syntheses of the best-available evidence)

- 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 (for example, 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 (43)
  - However, a lack of awareness about the use of electronic portals as well as privacy and security concerns can be barriers to use (44)
- Sharing screening results
  - 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 (45)
  - 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 (45)
  - Communication skills training is an approach that can be used by healthcare teams to improve conversations with patients in emotional distress (46)
- 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 (47)
  - Evaluation of patient engagement in research and decision-making activities is also important to ensure future uptake of patient engagement (47)

Questions about solution 3

- If you had been identified as at risk for Type 1 diabetes through screening, what information would help you better understand what it means for you and/or your family, what to do and when, and who else needs to do what?

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- How do you think it would be best to share and provide access to information over time about Type 1 screening results and from follow-up consultations and care?

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- What other supports do you think need to be provided for those identified as at high risk for Type 1 diabetes?

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- What concerns do you have?

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Identifying barriers and facilitators to moving forward

Solutions are great, but only if they can be put into action. **There are often barriers in the way.** Some of these barriers can be overcome. On the other hand, **different things may facilitate the implementation of a solution.** For example, a news story, a crisis, a new public opinion poll, or an upcoming election can bring an issue into the forefront. This may encourage people to pay attention to a problem and to implement a solution to address it. We have outlined some potential barriers and facilitators below.

Barriers	Funding for a population-level screening program Needlessly worrying patients and families	Agreement and coordination on screening approaches between provinces and territories to provide a standard approach Difficult to manage initial influx of people identified at risk	Potential concerns about confidentiality of data, who has access, and impact on individuals over time
Facilitators	Other countries (e.g., U.K.) pursuing large-scale screening Type 1 diabetes screening programs	Creation of a research consortium in Canada focused on supporting the development of a new screening program	Activated and organized diabetes patient and family groups and advocacy who can support co-design and implementation

Questions

- What might be the biggest barrier to these solutions?

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- What might be the biggest facilitator for these solutions?

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- If a population-based screening program were implemented in your province or territory, what would you like to see measured as indicators of success?

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Appendix 1: List of potentially helpful resources

We provide links below to a number of potentially helpful resources about Type 1 Diabetes (many of which we used in developing this brief) and screening.

- Canadian Task Force on Preventive Health Care – Information on screening
- Centers for Disease Control and Prevention – What is Type 1 diabetes?
- Diabetes Canada
  - Type 1 diabetes
  - Type 1 complications
- Diabetes UK
  - Differences between Type 1 and Type 2 diabetes
  - Type 1 diabetes screening
  - Screening children for Type 1 diabetes: The ELSA study
- Juvenile Diabetes Research Foundation – Type 1 diabetes facts
- Type 1 diabetes index
- Type 1 diabetes national screening pilot (Australia)

Appendix 2: What is known about each solution

Whenever possible, we describe what is known about each solution based on evidence syntheses. An evidence synthesis is a summary of all the studies that looked at a specific topic. An evidence synthesis uses very rigorous methods to identify, select, and appraise the quality of all the studies, and to summarize the key findings from these studies. An evidence synthesis gives a much more complete and reliable picture of the key research findings, as opposed to looking at just a few individual studies.

We identified evidence syntheses in two databases:

- Health Systems Evidence (www.healthsystemsevidence.org)
- PubMed (pubmed.ncbi.nlm.nih.gov)

An evidence synthesis was included if it was relevant to one of the solutions covered in the document. We summarize below the key findings from all the relevant evidence syntheses.

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

Evidence to inform this solution was provided earlier in the brief, which summarized key information related to what is known about Type 1 diabetes screening.

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

Category of finding	Summary of key findings
Benefits	• Culturally appropriate care (medium-quality evidence synthesis conducted in 2011) ○ Culturally competent bilingual healthcare workers improve the uptake of screening in diverse communities ▪ improve communication between healthcare providers and patients/citizens ▪ increase satisfaction with the health system ▪ improve knowledge about screening services and health in general ▪ increase follow-up care ▪ significantly increase screening rates
Harms	• None identified
Cost and/or cost-effectiveness	• None identified

Category of finding	Summary of key findings
Uncertainty regarding benefits and harms	• Not applicable (none of the included evidence syntheses highlighted uncertainty)
Key characteristics if it was tried elsewhere	• Outreach to connect people to the health system (high-quality evidence synthesis conducted in 2013) ○ Improving outreach is important to reduce logistical barriers and work with scheduled appointments instead of open appointments ○ Reaching populations for screening at an individual level can be done through postal reminders and telephone recalls ○ At a population level, outreach includes mass media campaigns and community education interventions • Engaging citizens in health-system decision-making processes (medium-quality evidence synthesis conducted in 2018) ○ People prefer to choose options that are less invasive and to start treatments earlier
Stakeholders' views and experiences	• None identified

Solution 3: Supporting people identified as at risk for Type 1 diabetes

Category of finding	Summary of key findings
Benefits	Sharing screening results • Communication skills training for the radiotherapy team to manage cancer patients' emotional concerns: A systematic review (medium-quality evidence synthesis conducted in 2019) ○ Communication skills training (CST) can be used by healthcare teams to improve conversations with patients and support them when in emotional distress ○ Features of CST programs included training on (non-)verbal and empathetic communication, panic attack practice interventions, therapeutic presence and self-awareness training, and responding to emotional cues (including anxiety and anger) ○ Promising evidence indicates that CST can enhance emotional conversations between patients and providers
Harms	• None identified
Cost and/or cost-effectiveness	• None identified
Uncertainty regarding benefits and harms	Patient portal or health records access • Adult patient access to electronic health records (high-quality evidence synthesis conducted in 2020) ○ When compared to usual care, the effects of giving patients electronic health records (EHR) access alone, as well as with additional functionality, are mostly uncertain ○ Additional studies are needed as the overall quality of included evidence was very low and there was very limited evidence of slight improvements in patient adherence of monitoring risk factors as a result of EHR access
Key characteristics if it was tried elsewhere	Patient portal or health records access • Patient portal use in diabetes management: Literature review (medium quality evidence synthesis conducted in 2020) ○ Patient portal use by diabetes mellitus patients in the U.S., Canada, and the Netherlands was found to be associated with patient characteristics, functionality and usability of technology, and provider engagement; portal users were typically younger, white, and male with higher incomes and educational attainment ○ Features offered in patient portals included EHR data (e.g., medical history), requests for prescription refills, ability to upload glucose home-monitoring results, general health education and resources, and communication with healthcare providers Sharing screening results

Category of finding	Summary of key findings
	• Experiences and views of receiving and delivering information about recovery in acquired neurological conditions: A systematic review of qualitative literature (medium-quality evidence synthesis conducted in 2019) o When delivering information to patients about their condition when there is uncertainty about the trajectory for recovery, patients and caregivers emphasized that the information provided should be delivered honestly but with kindness and compassion and, most importantly, positively o Consistency in the communication of information by different healthcare providers that patients and caregivers interact with, as well as the timing of information provision, were also highlighted as important considerations o Considering the potential occupational stress and emotional cost to healthcare providers delivering information to patients, training on how to communicate bad news to patients is highly recommended and available Equitable engagement in research • Patient and public engagement in priority setting: A systematic rapid review of the literature (medium-quality evidence synthesis conducted in 2018) o Ways to embed an ethical approach in engagement opportunities for patients include 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 o Evaluation of patient engagement in research and decision-making activities is also important to ensure future uptake of patient engagement
Stakeholders' views and experiences	Patient portal or health records access • Patient-perceived facilitators of and barriers to electronic portal use: A systematic review (low-quality evidence synthesis conducted in 2016) o Facilitators of electronic portal use, according to patients, were provider encouragement, enhanced communication with providers, and control and access to health information o Lack of awareness of and training about the portal and privacy concerns about health information were identified barriers to use

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