

DIALOGUES TO INFORM A NATIONAL FRAMEWORK FOR DIABETES IN CANADA

“What We Heard Report”



SFU

MORRIS J. WOSK
CENTRE FOR DIALOGUE

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OVERVIEW

Context

The Public Health Agency of Canada (PHAC) is undertaking a virtual engagement process to support Bill C-237 – An Act to Establish a National Diabetes Framework, which received Royal Assent in June 2021.

The process for engagement has taken several forms including key informant interviews, stakeholder dialogues, and an online survey where stakeholders were invited to share their ideas and priorities to improve the lives of people affected by diabetes.

Process

This report summarizes what we heard during the virtual dialogues co-hosted with the Public Health Agency of Canada (PHAC) on April 7th and April 12th of 2022. Nearly 300 stakeholders were invited to register for one of two dialogues, depending on language preference and availability.

In advance of the sessions, registered participants received a report that summarized the findings from the previous key informant interviews, as well as a discussion guide for the dialogues based on what we heard in the interviews (see Appendix). In the key informant interviews, a range of stakeholders and Canadians affected by diabetes shared their views, experiences and perspectives to help identify priorities for advancing efforts on diabetes in Canada in one-on-one and focus group interviews. 33 interviews were conducted with over 50 stakeholders. The findings from the key informant interviews were shared in a report to registered participants of the April 7th and April 12th dialogues. Dialogue participants were asked to review the discussion guide for topics of interest and to reflect on which of the suggested actions were a priority for them.

The English only dialogue held on April 7th was structured around two rounds of breakout discussions, initially based on system-wide themes including: Inequity, Stigma, Types of Diabetes, Collaboration and Capacity. The second set of breakouts tackled system specific themes including: Prevention, Care Delivery, Self-Management, Research and Data, and Access to Medicines, Devices and Financial Supports.

Breakouts had pre-assigned Facilitators, Notetakers and Witnesses. Participants selected the themed breakout room of their choice. The Witnesses were asked in advance to serve as deep listeners and to participate in a panel discussion following the breakouts. Panelists spoke about what they heard and what surprised them. The Notetaker records provided the basis for this report. The April 7th English only dialogue had 101 registered participants, with 76 present on the day of the session.

The French only dialogue held on April 12th also explored these same themes. Since this was a smaller group than the English dialogue, participants conversed together as one group rather than in breakout rooms. This dialogue had 13 registered participants with 8 participants present on the day of the session.

For the purpose of this report contents from the English and French dialogues have been synthesized.

Both events were 3 hours in length, hosted on the Zoom platform and were facilitated by teams from SFU's Morris J. Wosk Centre for Dialogue.

About this What We Heard Report

This “What We Heard” Report is intended to provide an overview and summary of participants’ ideas that surfaced during the two dialogues. These ideas were gleaned from notetaker notes and the post-forum evaluation survey which was administered via SurveyMonkey at the end of each dialogue. SFU’s team analyzed this material and organized it thematically. After the two dialogue sessions, participants also received a separate invitation to participate in a survey administered through the platform Ethelo. The findings of that survey are not included in this “What We Heard” report.

All feedback was compiled and analyzed without attribution to protect participants’ privacy and to encourage participation. The report does not provide an overall representation of public opinion, institutional policies or positions, nor that of a randomly selected population sample. Rather, this report presents a summary of our analysis of the ideas expressed by the people who participated in these dialogues.

The report was independently prepared by Drs. Lee Johnston and Diane Finegood from SFU’s Morris J. Wosk Centre for Dialogue. The report does not necessarily reflect the opinions of the SFU Morris J. Wosk Centre for Dialogue, the University at-large, nor of the Public Health Agency of Canada.

Summary

“Collaboration truly requires conversation.”

Many of the themes and areas of focus that emerged from the prior round of key interviews resonated strongly with the dialogue participants who attended these sessions. Improving **access to drugs and medications** was a predominant concern throughout the engagement process. The need to **centre patients within systems** was another overarching theme. People living with diabetes want to be provided with the tools, education, support and resources necessary to empower them as leaders and partners in research, community-led collaborative efforts, intervention design and implementation, and in the management of their own care. **Stigma** was recognized as having both psychological and physiological impacts on people living with diabetes, particularly when it entered into their relationships with their health care providers. Participants also echoed previous recommendations as to how **systems need to be restructured** to better support diabetes treatment, prevention and self-management. Particular areas of recommendation include building out roles for diabetes education and treatment throughout the health care system, fostering inter-jurisdictional knowledge exchange about successful interventions, creating knowledge hubs, and evaluation of the indicators and outcomes that are most important to diabetes care. Providing opportunities for **ongoing engagement** in support of the framework and its implementation was also emphasized by dialogue participants.

Participants also identified gaps in the themes that were brought forward in the dialogues and helped to further unpack the complexities of diabetes. We heard about the **intersections of race, age, and disability with diabetes** prevention, care and access. People warned of the dangers of speaking of “diabetes” in umbrella terms without acknowledging the **distinctions between types of diabetes** and the needs specific to living with type 1. They raised concern about the erasure of the unique challenges faced by living with this

acute condition 24/7, 365 days a year. The **challenge of diabetes management, and its associated mental load** – particularly for young people – was highlighted. **Engaging with youth** and providing better support for those transitioning out of pediatric care were identified as priorities, as was the regular and consistent commitment to finding a cure for type 1 diabetes.

Participants from racialized and Indigenous communities spoke to the need to **explicitly name racism and colonialism** as factors helping to drive diabetes rates in high priority populations. A related focus of discussion was the need to embed conversations about prevention and self-management in discussions about broader **public policy** and the barriers they create for both. Participants urged policy-makers and the medical system to avoid thinking about diabetes in isolation and to **consider its intersectionality** both medically (i.e. with other chronic or mental health conditions) or socially (i.e. with characteristics such as race, disability, age, etc.). More consideration is needed for the visually impaired, given the impact that blindness has in complicating diabetes self-management. Attendees also called not just for **meaningful engagement** with individuals living with diabetes, but the recognition of how priority populations and communities can assume leadership based on their knowledge of their communities and their needs.

KEY THEMES

DISCUSSION 1: SYSTEM WIDE CHALLENGES

In Discussion 1 of the dialogues, participants were asked to select a system wide theme that was particularly meaningful to them and engage in dialogue guided by questions included in the discussion guide (see Appendix). Below are the key themes that came out of the discussions on each system wide challenge.

1.1 Inequities

“We need to view diabetes, and the people who have it, with an equity lens.”

The breakout discussion on **inequities** reinforced several of the themes that emerged during the key informant interviews, including the broader need to **address the upstream elements** that determine people’s ability to support their own health, such as stable healthy food sources, safe homes/available housing, and income. The need to **center persons living with diabetes across the system** and adopt an approach that respects boundaries, listens to needs, and does not contribute to a shame and blame approach was also reinforced as central to planning around diabetes. As in previous stakeholder consultations, participants requested that the **disability tax credit be automatically granted** to persons with diabetes and that “arbitrary and illogical” requirements be suspended.

Some participants also emphasized the importance of moving beyond discussions of inclusion and meaningful engagement – with persons with diabetes positioned as consultants – and towards adopting an **intersectional approach led by systemically oppressed communities**, including Indigenous, black, South Asian and disabled groups. Representatives of these populations talked about the importance of having **interventions designed by and for the community**, created by individuals with **lived experience** and knowledge of their communities’ unique needs. This was situated within a broader conversation about the need to address **systemic racism** throughout the systems that service individuals with diabetes, and a

dialogue about the limitations of encouraging individual self-management in this context, a theme that overlapped with discussions on prevention and self-management. One participant encouraged the dialogue organizers and participants to reflect on their own make-up and consider what was lacking there in terms of representation.

In addition to these conversations, the following points/recommendations were also made during the dialogue on **inclusion**:

- Acknowledge and address the inequities **distinctions that occur between type 1 and 2 diabetes** (see also the section on distinctions between types of diabetes)
 - Individuals with type 1 are at a higher risk of mental illness and suicide, and physicians should take seriously how the mental stress (burnout, isolation, etc.) affects physical health; more research is needed in this area
- Build **anti-oppression and disability justice** into the work and ensure under-represented voices are being heard within organizations
- Examine and address the **inequities** that are prevalent in diabetes-related complications (e.g. lower limb amputations and mortality have higher rates in some populations/groups)
- Address **discrimination based on age/disease subtypes** (and consider important intersection that occurs with ages and stages)
- Consider **regional** inequities; not just the differences between rural and urban areas, but also those between neighbourhoods in urban and suburban areas
- Improve **cultural equity**; many people need healthcare resources that are culturally relevant and it is therefore useful to engage with community organizations to enrich learning and carry out prevention in other languages beyond French and English
- **Increase accessibility** to devices and treatments
 - There are limited options for visually impaired individuals (insulin pumps, for example, are not accessible)
 - A disability lens needs to be placed on diabetes; there are no glucometers or insulin pumps that a blind person can use, therefore they lose their independence and need sighted help; some equipment is only partially accessible to them
 - Devices/medicine should be universal; barriers of age, province, socio-economic status and insurance status should not get in the way of access to essential/lifesaving care
- Provide **more investments for the less privileged** and a framework that covers individuals across their lifespan (e.g. there is a 25% higher chance of diabetes development in Indigenous children and type 2 is on the rise)
- Review service provision through a lens of equity rather than equality; **allocate resources where they are most needed** to help individuals thrive with less support
- Review **research and evidence-based care** to evaluate if what is being funded really makes a difference; consider the types of insulin/medications being used – some aren't making a noticeable difference in addressing blindness or heart attacks, for example

- Provide more **social supports and policy changes** (every individual should be assigned a social worker)
- Change **screening practices** for those at high risk; many are placed at risk through policies and not their race
- **Produce a diabetes report** much like the Truth and Reconciliation report, where we acknowledge the inequities that exist, and firmly state that **all Canadians should be entitled to care** no matter where they live; understand and document the problem **before making solutions**
- Consider the unintended **consequences of blunt policy changes** (e.g. taxes that can be regressive on the poor)

“Many biological/socioeconomic factors aren’t in diabetes patients’ control. There are many interconnected/overlapping barriers for them, like financial barriers for immigrants, the homeless and minorities. Policies need to be structured so that people with diabetes can take care of themselves.”

1.2 Stigma

“Stigma can come from words, impressions, images, attitudes, but also clinical practices that we undertake perhaps without even thinking about how they make the client feel.”

The issue of **stigma** resonated strongly with many dialogue participants, particularly those with type 2 diabetes. Individuals spoke of being stigmatized every day and in every sphere of their lives – at work, school and in the health care system. Dialogue attendees urged **public health** to examine its own narratives around diabetes and consider how they might be contributing to stigma around the disease. While some participants noted a role for prevention education in helping people make healthier choices that personally suit them, they also spoke to the failure of traditional health practices perpetuating **inequities** identified in the previous section.

Shame and blame were also noted as contributors to breaking down **trust in patient-clinician relationships**, and its potential to push patients to disengage and have worse outcomes. One participant noted that stigma is still **embedded in the health care system** as patients may feel as if there is something innately wrong with them and they need to live up to the expectations of health care providers. Having to repeatedly recount their health issues in relation to diabetes was also identified as creating distance between themselves and medical professionals; it was suggested that better training and information systems could lessen this load and improve patient-doctor relations. Individuals called for approaches that **encourage self-efficacy** while reducing feelings of judgement, shame and discomfort. Education about diabetes – both targeted to professionals and more generally to the public – was put forward as a way of reducing the trauma associated with being **shamed and blamed** by professionals and members of support systems. As one participant noted, “education can help address fear of the unknown.”

In addition to these themes, the following was noted in relation to **stigma**:

- Help clinicians to adopt a **patient-first approach** that put the patient in the driver’s seat; emphasize **treatment collaboration**:

- **Ask *why* patients are there** and for their perspective on the issue instead of immediately focusing on checking charts and conducting routine activities
- **Emphasize collaboration** toward health and progress and stress importance on the value of health objectives rather than numerical numbers like on a scale or glucometer
- **Patients know their own body** the most and what works for them, so clinicians should always take that into account when discussing their health
- Promote a **collective response to chronic disease** (by society and health care practitioners) rather than a focus on those with diabetes or perceived to be at-risk
- Include people with diabetes when writing government reports, medical guidelines, prevention and awareness campaigns, etc.
- Implement **education at a wider scale** in different institutions (beyond healthcare) to help those with little health care experience or knowledge of diabetes better approach those who have it
- Actively discourage disrespectful language or notions about diabetes
- Separate the approach within healthcare for Indigenous peoples, who live with chronic and generational problems that stem from colonization; addressing barriers that mitigate Indigenous people receiving proper health care (institutionalized racism)
- Educate people on diabetes early on so they are taught actual implications and facts about the condition rather than biased narratives
- Respect patient values and listen to their lived experiences; understand that each patient is different and requires individualized approach

1.3 Types of Diabetes

The type 1 diabetes community resoundingly expressed the need to distinguish between the **unique needs** of type 1 and type 2 patients in a diabetes framework. They noted that type 1 diabetes is an acute life-or-death disease that requires more direct and frequent access to medical specialists and constant adjustment of their medication with insufficient professional support, placing a significant **mental burden** on patients and the people they live with. People living with type 1 diabetes noted that it can take too long to access endocrinologists, and that other health professionals often do not have the expertise needed to adequately help with diabetes management. **Individuals with type 1 diabetes also did not see themselves as part of the prevention conversation and expressed concern about the lack of focus on finding a cure for type 1.** Type 1 patients also noted the negative effects of dealing with a healthcare system more experienced in dealing with type 2 and called for education regarding the differences between them. They suggested that the focus on type 2 was reinforced by media and stakeholder emphasis and the perception that it's just a "blood sugar disease." It was also noted that we should move beyond the perception of "juvenile" diabetes, given that adults do get type 1 diabetes and children get type 2.

Another key theme during this breakout conversation was that **age and stage are important** in providing the right care at the right time based on diabetes type. Participants also rearticulated the intense challenges that occurs with the transition from pediatric to adult care for type 1 patients, at which point patients can lose access to a range of supports and clinical care. Individuals also spoke to how difficult this shift is for families as parents and children navigate a shift in their responsibilities for diabetes management. As one participant

noted, **type 1 diabetes is in many respects a “family disease.”** Concern was also expressed that the focus tends to be on the adult experience of type 1 diabetes and its associated complications (such as limb amputations and blindness); **children are often left out on the sidelines.**

The following was discussed in relation to the **types of diabetes:**

- **Personalize care and prevention** according to risk associated with different diabetes types
- **Respect choices** about medication/devices/services so individuals have all the tools available to get the best health outcomes; this differs vastly across the country
- Consider how we conduct **risk assessment** regarding the social determinants of health (e.g. geography/access to care/structural inequities/racialization)
- Challenge the belief that type 2 diabetes is easy to manage and the responsibility of primary care; **specialists should be involved in all types of diabetes**
- Address issues related to diagnosis (currently the same for all types of diabetes; i.e. sugar/glucose level)
 - Advocate for research and efforts on how to diagnose diabetes
 - Modify how we define diabetes and diagnostic guidelines
- Explore opportunities to implement technologies and evidence-based **decision-making tools** (not just guidelines) for practitioners related to different types of diabetes
 - For example, nephrology has a kidney-wise toolkit; develop something similar for diabetes
 - Need to see emergence of clinical decision tools in the framework and their implementation

1.4 Collaboration

“If we can start with one piece of this puzzle to build on, it’s a way for us to build on something.”

Stakeholders were clear on the **importance of dialogue**, particularly between government and people affected by diabetes. They called for an **ongoing process of engagement** in the form of dialogues or forums to ensure the framework works and to keep the momentum generated by this process going. They emphasized the importance of having spaces like this dialogue session for representatives from different sectors and industries to come together, and to build bridges between people who would not normally have the opportunity to connect. The prevailing sentiment in one of the conversations was that **collaboration** was necessary to foster **problem solving** and **execution** of the framework. Other conversations around collaboration spoke to the ways in which it could be fostered within the health care system, echoing themes expressed in conversations about improving care and supporting self-management.

The following ideas were suggested during the conversation on **collaboration:**

- Implement **governance to keep charge of bringing life to the framework** beyond the five-year timeline (the challenge of identifying what a comfortable model would be for everyone in terms of shared governance and oversight was noted)
- Support an approach that is **equitable, person-focused, and scalable**
- Develop an **inter-sectoral action funding stream** to spark specific and/or new collaborations

- Develop framework or approaches to support sharing from different areas of expertise; foster interdisciplinary teamwork
- Build on already existing conversations and work to engage in new collaborative conversations; an enormous amount of work is being done already
- Work in collaboration with diabetes stakeholders to prepare prevention campaigns and provide **earlier access to screening** (it was also noted that increasing screening isn't desirable if we don't have the needed structure for following up)
- Work in collaboration with diabetes stakeholders on **therapeutic education**: to be meaningful, therapeutic education must be broader and implemented across Canada, and work with multidisciplinary teams, which requires decentralization and decompartmentalization
- Support and track collaborative technological innovations (which often take place outside of traditional research institutions) that make it possible for people with diabetes to get information at minimal cost and foster innovative solutions

1.5 Capacity

Echoing a theme that emerged during the key informant interviews, **digital health** was a prominent point of conversation during the conversation on capacity. Participants reinforced that the potential benefits of implementing digital health solutions for care and improved self-management will be challenged by issues related to discrepancies in internet access. The conversation around digital health was rooted in a call for equity regarding the need to develop infrastructure for improved **internet access** in all areas.

Participants also noted that digital health is a tool and not a solution, and will never replace in-person care entirely. It was also suggested to have the potential to **amplify the capacity** of people, providers, communities, and systems on how to best engage with diabetes. Providing better diabetes training for physicians, nurse practitioners and other care providers was also identified as a means of helping increase system capacity by providing more quality diabetes care and decreasing the workload on less available specialists. It was suggested that better overall management, supported by stronger and better guidelines for treatment, could also help lower the capacity burden on the diabetes system.

The following additional recommendations and observations were made in regard to **capacity**:

- Fix the issue of difficult access to endocrinologists by **giving more responsibilities to other health professionals** in contact with people with diabetes, such as social workers, nutritionists, dieticians, and nurses
- Strengthen capacity by **improving access to quality medical data** among health care professionals and improve health networks' archaic IT infrastructures that hinder care and the development of innovative models to improve access and patient management
- **Create a platform highlighting local initiatives across Canada**; activists in other parts of the country often start from scratch instead of benefitting from other people's experience
- Digital health as an enabler of interprofessional team-based care is significantly important
 - Example of a tool that a participant uses: Hypercare, which is a tool like WhatsApp for health care providers and is HIPPA compliant

- See also the Pittsburgh University primary care diabetes curriculum, which has been revamped into bite sized educational opportunities that people can take at their own time through email and text messaging
- Medical directives for nurses are needed to increase capacity of nurses
- Digital health access is needed for self-management and peer support
 - **Patients should have access to their information** and their metrics around diabetes and be able to share with family/friends
- **Increase awareness of type 2 remission**; people are unaware that those who do pursue remission are successful; support patients who want to have this discussion; healthcare professionals must have an understanding of type 2 remission to have the conversation with patients (note that relapse is part of remission)
- Specify explicitly the **minimum standards for care** in the national framework
- Increase awareness of available options and use resources in the best way to adapt care to patient needs
 - For example, someone who has type 1 diabetes with multiple complications does need an endocrinology and interdisciplinary approach, while someone who is trying to prevent diabetes will require other types of services
- Take measures to **address the physician shortage crisis** (nearly 5 million Canadians are without a GP and patients are waiting years for referrals). There are also massive structural problems to access of care across geographical regions (including variation in access to equipment)
 - Consider strategies to address the loss of varied professionals across the system over recent years, including nurses and physicians
- **Health coaching** for focused behaviour change (not just education) is a missing component to diabetes care and should be standard

“There are nearly 5 million Ontarians today with diabetes and pre-diabetes. That is growing to almost 6 million by 2030. Scalability of solutions is critical.”

DISCUSSION 2: PRIORITIES FOR ACTION

“Diabetes is well known, but not known well.”

2.1 Prevention

An overarching theme in this dialogue was the need to **develop comprehensive prevention strategies that address systemic inequities** relating to diabetes prevention. Several aspects of this conversation echoed earlier discussions, including an emphasis on a patient-centered approach allowing for flexibility within standardized approaches and building on individual knowledge and strengths; the implementation of trauma-informed, culturally safe care to address systemic racism in care systems; and investing in under-resourced communities.

The following additional comments were made in relation to diabetes **prevention**:

- Invest in more research on issues specific to **youth** with diabetes, and develop a type 1 diabetes registry
- **Measure outcomes** and **track trends** in order to better achieve better resource allocation and funding to existing programs
- Encourage **school systems** to pay attention to and collaborate on diabetes prevention
- Start **screening** for type 2 diabetes in youth
- Implement **universal access** to areas of symptom prevention, such as preventative foot care (4 out of 5 amputations are preventable; screening and risk assessments are needed)
- Address systemic inequities in our understanding of the psychological and physiological impacts of **chronic stress** caused by systemic inequalities such as poverty, racism, and ableism
- Move away from individual behaviors/choices and **focus on the systemic barriers** that interfere with peoples' agency and access
- Develop a **national public awareness** campaign that engages the general public and brings awareness to the severity and complexity of diabetes
- Invest in **population level public policy measures** that change environments with programs in schools and communities, making prevention less about individual decision-making

2.2 Care Delivery

A common theme regarding care delivery was the need to build capacity for diabetes care in different community contexts by **expanding the scope of practice** for allied health professionals. Issues related to **quality of care** also surfaced, echoing what was heard regarding inequities and stigma. Patients pointed to the ways that factors like racism and poor communication work to erode **trust** in institutions and in the doctor-patient relationship. It was noted that patients may tell healthcare professionals what they think they want to hear, or not see them at all for fear of judgement if they haven't met expectations (such as lowering their A1C level). Much as in the previous conversations about capacity, **digital care** was seen as a means of potentially improving care delivery; an additional benefit identified was its potential to mitigate some elements of burnout being experienced by nurses and other healthcare providers experiencing physical and mental health issues from work.

The following additional comments and recommendations were made in relation to **care delivery**:

- Focus beyond physical health as **diabetes impacts mental and spiritual health**, particularly in regard to the burden of type 1 self-management
- Provide training to patients regarding their available treatment options; **guidance is lacking** – foster more assistance through a comprehensive understanding of what drugs, technology and therapies are available
- Provide **patient-centered training for medical professionals**, including anti-racism training and education around shame and blame
- Provide patients with the right information at the right time regarding type 2 diabetes remission; nurses, dietitians and clinicians should all have an understanding of remission being an option

- Address the **lack of support for youth/pediatric care**, including connection to peer-to-peer support; many youths are feeling alone and isolated and this can be exacerbated during the transition from pediatric to adult care
- Provide **more support and education to general practitioners**, in part so that they can assess less severe and routine cases so that specialists (such as endocrinologists) can spend more time with severe and unique cases
- Tailor care for specific groups with distinct cultural needs
- Increase team based care and research
- Foster collaboration between everyone who needs to be engaged in developing solutions, including policymakers

2.3 Self-Management

“It’s impossible to self-manage when your basic needs aren’t being met.”

A pre-dominant theme regarding diabetes self-management across all of the stakeholder engagement is that it is **complex** and takes a **substantial toll** on individuals and their caregivers. These impacts are further exacerbated by the presence of factors such as poverty, racism, ableism, concurrent chronic conditions and mental health concerns, among others. Participants expressed concern about patients who are disengaged from care and likely to develop complications as a result, and discussed how to support them meaningfully and without stigma.

The following comments and recommendations surfaced during the conversation on **self-management**:

- Develop better systems to support and **empower** patients between short clinical consultations and help build patient confidence:
 - Provide clear information and approaches that address the complexity of diabetes self-management and make it manageable for individuals (care plans, a telehealth system, etc.)
 - Build a system where individuals with diabetes can reach out to someone with lived experience; address the social and holistic component of diabetes and not just the medical components
 - Meet people where they are (work smarter, not harder)
 - Identify a “sticky point” or hub where partners (or peer workers) connect and can provide information; the current system is fragmented
- **Improve flows of information** within the system and internal coordination to make information access easier
- Involve lived experience in every element of system design
- Work on the psychological issue of getting patients past “fixing them” mindset of clinical care and increase patient understanding that this is a chronic condition
- More coaches are needed for ongoing support
 - Develop means to foster community collaboration and communities of practice

- Consider a **coach-type role for pharmacists** get them involved in 15-minute consultations (and the accreditation and ongoing training this would require)
- Build community support systems with models that allow money to follow the patient
 - See UK models where commissioning of diabetes services is done at community level with patient voices
- Take lessons from **strong ties of community support** of parents connecting with others for type 1 support

2.4 Research and Data

“Instead of bringing patients into the research world, send the researchers out into the patient’s world.”

A common theme in discussions around research and data was the critical importance of patient and caregiver engagement in the research process – of centering the voice of the person living with diabetes and having patients truly being a part of research question development. Participants noted that **research should be patient-driven**, not just patient-inclusive, and called for a shift in which research is aligned first and foremost with patient and community needs and engages patients throughout the research’s timeline.

The following additional points were made in relation to **research and data**:

- Communicate about research in layman’s language, acknowledge the experiential knowledge held by diabetes patients, and include patient experiences and the needs of individuals who need complex care as part of research outcomes
- Foster inter-jurisdictional learning and **knowledge exchange** (particularly about solutions that are working)
- Conduct research on the value of addressing social determinants of health and how connecting social workers and doctors can be good for both physicians and patients
- Support research on subjects important to people living with diabetes, including: accessibility and support; measuring the experiences of marginalized people; determining the value of various medications and the effectiveness of early prevention/detection
- Research the impact of diabetes on people, stretching beyond medical data and a focus on things like weight/BMI that do not necessarily deepen our understanding of diabetes
- There needs to be data for the norms of other ethnicities, classes, etc. and not the usual focus on white, middle-class males (for example)
 - Engage people who are blind in research, currently a very disadvantaged and under-researched group in diabetes
 - Indigenous people, racialized populations and youth also need to be driving research and engaged from the outset
- **Measure progress and not just outcomes**; there are stages in each diabetes pathway that need to be measured

- This includes **appropriate and culturally sensitive measurement** of outcomes in vulnerable/marginalized communities; the framework could establish what all jurisdictions (provinces and territories) should be measuring
- Socio-culturally diverse and marginalized groups need to own their data and be involved in its interpretation; it is inappropriate to interpret data in context of Western paradigms

2.5 Access to medications, devices and financial supports

“Access to the right care at the right time – which includes access to medication, devices and supports – improves individual health outcomes.”

Access was a driving priority for many stakeholders engaged throughout the key informant interviews and dialogues. As one person noted, “...first we need to deal with access, and then we can work on other relationships in the system.” The impact that Canada’s **patchwork** approach to coverage and insurance was frequently cited; participants spoke of having to take coverage into their decision-making around relocating for school or work. They also noted how difficult it can be to figure out what is and is not covered in different locations, given that information about this is confusing and hard to navigate. Representatives of the type 1 diabetes community noted the burden of **paying out of pocket for insulin – a life-saving medication**. Participants also noted that valuable services such as nutritionists, dieticians and psychologists are “hardly accessible” to the general public. “Even in underprivileged neighbourhoods,” one participant noted, “people are referred to private practice nutritionists.”

Some participants questioned why cheaper drugs are sometimes prioritized over safer alternatives and encouraged patients to ask questions to doctors about what they are prescribing. They emphasized the need to consider the cost of medications and devices in terms of their long-term positive impact on people’s quality of life rather than a short-term measure. Questions also emerged around the ability of the framework to influence decision-making bodies in this area and stop us from “spinning our wheels” when it comes to equalizing access across Canada.

Participants echoed the previously documented sentiment that Canada lags in health care and drug innovation and needs to do better. Similarly, Canada was seen as needing to keep up with approval for the fast-moving pace of diabetes technology; concern was expressed that evidence reviews cannot keep up and thus only people with disposable income can get access to the best technologies. Finally, the common sentiment that the **disability tax credit** needs to be made more easily accessible was discussed in the context of this conversation.

The following was discussed in relation to **access to medications, devices and financial supports**:

- Implement a national plan to address the inequity of access across Canada
- Address issues around access to / the cost of drugs and devices
 - All people with type 1 diabetes should have access to continuous glucose monitoring
 - Co-payments/deductibles can be prohibitive and it can take far too long to retrieve drug reimbursement in Canada
 - Obesity treatments (such as certain types of surgeries and medications) are difficult to access

- Improve regulatory processes and work to **make devices safe for use by all** – including those with disabilities) rather than add disclaimers; make devices safe for the elderly, blind, and those with other physical and mental disabilities
 - For example, devices that don't speak to people who are blind are approved by Health Canada; **we need devices that read out results** and many cannot rely on phone apps
 - Establish **minimum requirements for the design of products** and federal level support to impose standard design features
- Make the disability tax credit more accessible and diagnosis-based; remove barrier of requiring doctors to be willing to fill out associated paperwork (and sometimes charging patients to have it filled out)
 - Create a “Diabetes Credit” rather than lump it in with disability tax credit (however, note that a DTC is required for registered for a disability savings plan)
- Adopt a new business model based on outcomes rather than cost; it is currently very metric-centered rather than patient-centered; include short-term outcomes as well as long-term reduction of complications
- Review the outdated evidence being used to make decisions regarding funding/reimbursement as well as adoption of technology for use
 - Clinical evidence can't keep pace; evidence is already outdated by the time it becomes policy
 - **There needs to be access to diabetes medications and technology**; patients can't benefit from newer technologies as reviews are rolling out slower than new technology is produced
- Care for “orphan” diabetic patients: people with cystic fibrosis, cancer survivors, and women who had gestational diabetes are more likely to develop diabetes in the long term; all these populations must have access to quality care
- Implement a support structure for families; we need to lessen the mental load for parents of diabetic children and give them access to respite services and financial support

APPENDIX

1. Participant Discussion Guide

Breakout Session #1: System wide challenges

Description:

A pre-assigned facilitator supported the group with a round of short introductions focusing on a brief description of the participants connection to diabetes. The facilitator then guided the group through a dialogue based on the questions included below.

Themes:

1. **Inequities:** What can we do to address the inequities that contribute to how diabetes affects individuals and populations? How can we transform our efforts at prevention and care to thoughtfully and practically account for these inequities?
2. **Stigma:** How can we shift from stigmatizing practices and perspectives about diabetes and toward a trauma-informed, strength-based holistic view? What needs to change about the way that we think about diabetes?
3. **Types of Diabetes:** What are the distinctions between different types of diabetes and when/where do they matter most in terms of providing care and service? How do we build systems to adequately support people living with all kinds of diabetes?
4. **Collaboration:** How might we ensure that all sectors of society can contribute to ongoing dialogue, information sharing and problem-solving in relation to diabetes? What could this look like?
5. **Capacity:** How can we build capacity throughout the systems that support people living with diabetes? What do we need to do more of? What needs to change?

Breakout Session 2: Priorities for Action

Description:

In this breakout session, participants were asked to dig more deeply into an area for action.

To prepare for this session, participants were asked to consider which topics were of interest to them and to review the specific areas for action identified under each topic. In the dialogue session, participants were asked to reflect on which actions are most important, and why. They were then asked to reflect on what might be missing from this list.

1. Prevention

Activity aimed at preventing diabetes. This includes: efforts to inform and support individuals and communities; upstream interventions that address systemic inequities that help drive disproportionate rates of diabetes; consideration of the built environment's impact on health behaviours; and screening to prevent diabetes and/or its complications. Connected efforts to prevent and address obesity are also relevant here.

Opportunities:

- Grow access (funding & connectivity) to digital platforms for education, learning and community building
- Incorporate an anti-stigma lens into diabetes education and awareness efforts
- Adopt a strength-based approach that recognizes healthy means different things to different people
- Address upstream social determinants of health through broader policy considerations (e.g. food security/healthy eating, internet access, built environment)
- Support the scale-up of programs that are effective and can be adapted/adopted to diverse community settings
- Develop comprehensive prevention strategies that address systemic inequities

2. Care Delivery

There are many health care providers involved in diabetes care including diabetes educators, nurses, general practitioners, specialist physicians, pharmacists and other allied health professionals. Diabetes care happens in many different settings from the local pharmacy, to a specialized children's hospital, to a nursing station in a remote community. Activities in care settings range from education and training on the use of medication to the acquisition and use of a closed-loop system that adjusts insulin based on continuous glucose monitoring. Diabetes is a complex chronic disease which requires different kinds of support throughout the life course. Some aspects of care are simple and others complex.

Opportunities:

- Expand integrated care and support practices with diverse teams that focus on diabetes
- Build capacity for care in different community contexts by expanding scope of practice for allied health professionals
- Expand virtual care options and access to the internet in rural and remote communities
- Recognize the importance of obesity treatment for type 2 diabetes by creating more connections to enhance screening, practice and care
- Adopt a strength-based approach that recognizes healthy means different things to different people
- Consider alternative health system funding models (e.g. dollar follows the patient, not the services; private sector takes on risk; private insurers running public programs; social impact bonds; outcomes based

- payment programs)
- Provide patient-centered training for medical professionals, including anti-racism training and education
- around shame and blame

3. Self-management

Diabetes self-management refers to the activities and behaviors an individual undertakes to control and treat their condition. People with diabetes must monitor their health regularly. In some places people with diabetes have access to diabetes education centres to support self-management. Self-management intersects with quality of life in complex ways. Poor diabetes control contributes to the development of complications and many of the social determinants of health make it difficult to self-manage.

Opportunities:

- Better support the implementation of national standards and priority population-oriented practice
- guidelines
- Build better tools to support self-management and patient communication with health care providers
- Build systems of care that provide more frequent touch points for screening, support and education
- Increase access to specialized education tailored to the different needs of patients with type 1 and 2
- diabetes
- Grow access (funding & connectivity) to digital platforms for education, peer-support, training, and
- community building and learning

4. Research and data

Research is generally situated in university and hospital settings and is funded by governments and health charities. For the purposes of this discussion, research also includes processes for evaluation and quality improvement. All of these activities generate data, along with our health records, health system metrics and the data increasingly generated by smart devices. Data could be used to support learning at many levels from the individual living with diabetes, to our care providers, to Ministers of Health. This theme is about the mechanisms used to fund and support research and the systems employed to collect, share and use data.

Opportunities:

- Fund more research that centres individuals and communities to adapt & implement interventions
- according to their needs and the outcomes they prioritize
- Develop new funding models that support a learning system approach (not just pilot projects)
- Enhance collection, integration and sharing of diverse forms of data
- Build capacity of users to access, analyze and use data to improve practice, self-management and system
- function

- Build stronger connections between a diversity of researchers, practitioners and policy-makers

5. Access to medications, devices and financial supports

Multiple systems contribute to determine an individual's access to medications, devices and financial supports. Included here are the systems that approve and fund access from the Canada Revenue Agency which provides the Disability Tax Credit, to provincial ministries of health which determine which supports are covered and which are not. Regulatory processes, health insurance and health systems all affect access to new (and old) drugs and devices.

Opportunities:

- Apply a holistic approach to financial supports and engage patients in their design
- Explore tax measures to improve accessibility to financial support for people with diabetes and their care providers
- Create more equitable access to coverage for drugs and devices across the country
- Foster adoption of new technologies and medications
- Adopt new business models incentivized by outcomes and value instead of cost

