

**Engaging the Diabetes Community in  
Policy and Program Development**

**A Position Statement**

**About Diabetes Canada:** Diabetes Canada is a national health charity representing more than 11.5 million Canadians living with diabetes or prediabetes. Diabetes Canada leads the fight against diabetes by helping those affected by diabetes live healthy lives, preventing the onset and consequences of diabetes, and discovering a cure. It has a heritage of excellence and leadership, and its co-founder, Dr. Charles Best, along with Dr. Frederick Banting, is credited with the co-discovery of insulin. Diabetes Canada is supported in its efforts by a community-based network of volunteers, employees, health-care professionals, researchers, and partners. By providing education and services, advocating on behalf of people living with diabetes, supporting research, and translating research into practical applications, Diabetes Canada is delivering on its mission. Diabetes Canada will continue to change the world for those affected by diabetes through healthier communities, exceptional care, and high-impact research.

**Publication Date:** March 2022

**Cite As:** Engaging the Diabetes Community in Policy and Program Development: A Position Statement. Ottawa: Diabetes Canada; 2022.

**For more information:** please visit [www.diabetes.ca](http://www.diabetes.ca)

**Contact:** [advocacy@diabetes.ca](mailto:advocacy@diabetes.ca) with inquiries about this Diabetes Canada report.

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## Position Statement\*

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Health stakeholders must commit to the meaningful inclusion of the diversity of patient perspectives to optimize the outcomes of health policy and program development. Patients and/or their caregivers should be included as early as possible, ideally during the planning stages. An honest and measured consideration of patient and community input is a fundamental component of a successful patient engagement process. It can improve the translation of evidence into policy and practice, by being more relevant to patient concerns and recognizing the importance of patients' lived experiences.

Diabetes Canada recommends that **organizations focused on diabetes, including employers, insurers, and all levels of government:**

- Increase awareness about the value of patient and community engagement.
- Acknowledge the patient perspective as a unique knowledge source.
- Engage patients in the process of research analysis, policy, and program development as early as possible.
- Commit to engaging patients in meaningful ways that contribute to research analysis, policy, and program decision-making and directions.
- Offer patients ongoing opportunities to contribute to the development of health policy, services, and programs.
- Develop and publicly state a transparent policy, outlining how patients will be involved in the initiative and how that process will incorporate patients' perspectives.

- Develop a system for capacity building and enhancing health literacy in patient participants so that they can competently contribute to project goals.
- Commit to include and then move beyond clinical- and cost-effectiveness, to integrate significant real-life patient experiences that include a range of structural and psychosocial aspects affecting patients' lives, treatment, care, and environment. These include, but are not limited to, caregiver support, overall well-being, employment, socioeconomic status, ethnocultural backgrounds, and education.
- Devote resources, both financial and human resources, towards patient engagement that goes beyond "token input."
- Prioritize collaboration between patients and all other stakeholders, including government departments, health technology assessment agencies, clinicians, researchers, and industry.
- Develop a robust framework for evaluating patient engagement. Evaluation should be continuous throughout the patient engagement process.

Diabetes Canada will:

- Respect and value the socioculturally diverse, lived experiences of people with diabetes, so their experiences inform and are reflected in the organization's policy creation, and program and service offerings.
- Support patient participants through capacity building, skills acquisition, and/or health literacy training, to ensure that interactions are honest, and

patients can meaningfully contribute to discussions and decisions.

- Acknowledge the relationships between policy makers, health-care providers, and patients as mutually beneficial. The expertise and experiential knowledge of each stakeholder will be acknowledged and valued equally.
- Work collaboratively with patients, policy makers, and health-care providers from the earliest stage possible in each initiative. Each stakeholder will be involved in identifying gaps, setting priorities, and collaborating to implement solutions.

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### **\*A Note About Terminology**

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The terms *patient*, *patient and community*, and *the diabetes community* are used interchangeably in this document to refer collectively to people living with and affected by diabetes (PWDs & PADs). PADs can include family, friends, and other caregivers who are directly involved in a PWD's day-to-day diabetes management. While Diabetes Canada recognizes that PWDs are not patients in the traditional sense of the word (i.e., in a hospital or other health-care setting), common use of the term *patient engagement* refers to anyone living with a chronic or acute medical condition as a means to differentiate people with lived experience from health-care providers and other clinical professionals.

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### **Why is Patient and Community Engagement Important to Diabetes Canada?**

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The importance of patient engagement in education, services, and policy development and implementation is receiving significant attention. Health-care providers, policy-makers, and others working in the health field recognize that this key stakeholder group has historically been left out of health-care processes and decision-making. Recognition of the importance of consulting patients to gather information about their perspectives, experiences, and preferences throughout health care has motivated Diabetes Canada to scan practices and models to engage patients and make recommendations to continue to strengthen the patient voice in all activities designed to promote positive health outcomes.

This document is intended to describe ways to achieve active and meaningful participation of patients including, but not limited to:

- Conducting evidence-based analysis;
- Making policy recommendations;
- Developing and launching self-management tools and supports;
- Gathering input on health-care provider resources; and
- Disseminating findings and recommendations.

Participation of patients in the design of primary research and delivery of health services is essential but is beyond the scope of this position statement.

Diabetes Canada developed the present evidence-informed recommendations using a

systematic approach and deliberative process.

The steps in this process included:

- Identification of priority questions and outcomes;
- Retrieval of the evidence;
- Assessment and synthesis of the evidence;
- Formulation of recommendations;
- Review and input from experts including people with lived experience, clinicians, researchers, and policymakers; and
- Planning for communication, dissemination, implementation, evaluation, and updating of the recommendations.

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## Diabetes in Canada

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Diabetes is a major chronic disease in Canada. Currently, the prevalence of diagnosed diabetes (type 1 and type 2) in Canada is approximately 4 million and is projected to increase to about 5 million by 2032 (1). The economic burden of diabetes on the health-care system is substantial; and costs the Canadian health-care system \$30 billion annually to treat people with diabetes (2).

Diabetes is a condition characterized by an elevation in blood glucose levels caused by a lack of insulin or a reduced effectiveness of insulin. People living with diabetes need to manage their glucose levels to achieve their target blood glucose range. Diabetes is a leading cause of blindness, end-stage renal disease, heart disease, stroke, and non-traumatic amputation in Canadian adults (3). The all-cause mortality rate among Canadians living with diabetes is twice as high as the all-cause mortality rate for those without diabetes (4–6).

There are three main types of diabetes (7). Type 1 diabetes occurs in people when their beta cells, located in the pancreas, no longer function (7). Consequently, very little or no insulin is released into the blood. As a result, glucose builds up in the blood instead of entering the cells to be used as energy. Approximately 5-10% of people living with diabetes have type 1 diabetes (7). Type 1 diabetes generally develops in childhood or adolescence, but can also manifest in adulthood (7). Insulin therapy is required for the treatment of type 1 diabetes and is life-sustaining (8).

Type 2 diabetes occurs when the body cannot properly use the insulin that is released or does not make enough insulin (7). Glucose builds up in the blood instead of being used as energy. Over 90% of people with diabetes have type 2 diabetes (7). Type 2 diabetes usually develops in adulthood but children are increasingly affected (7). Various treatment options exist for type 2 diabetes, including nutrition and physical activity, glucose-lowering medications, and insulin therapy (9). Treatment plans should be individualized and will depend on goals, lifestyle, age, general health, and other socio-ethnocultural factors (9).

A third type of diabetes, gestational diabetes, is a temporary condition that occurs during pregnancy (7). It affects up to 1% of all pregnancies and increases the risk of developing type 2 diabetes for both mother and child in the future (7).

If blood glucose, blood lipids, and blood pressure levels are properly managed, people living with diabetes are able to live healthy

lives, and prevent or delay the onset of diabetes-related complications (7).

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## **Why Engage Patients?**

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Including patients' perspectives, experiences, and preferences in all aspects of health-related activities ensures that patients' needs and concerns are considered, included, and respected, which can lead to a shared sense of purpose (10,11). Patients and health-care providers (HCPs) prioritize different elements of health and health care, and can have differing understandings about barriers to achieving optimal quality of life and health outcomes (12,13). Patients and HCPs represent different knowledge sources, and our aim is to amplify the patient voice in all forms of decision-making with the goal to improve the overall outcome for patients.

Patients' needs, preferences, and perspectives are important. They are formed by patients' own socio-ethnicultural experiential knowledge, acquired through living with a condition or illness. Their experiences working to navigate the health-care system can also help us to identify successes, gaps in care, and barriers to access. Involving patients in the early stages of policy or program development, preferably in the planning stages, ensures that patients' perspectives are integrated into all future components of projects (10). Moreover, it is important to include patients with diverse backgrounds to ensure that representative perspectives are considered and included to allow for a diverse array of themes to guide work in various elements of health care and policy (10).

Patients gain several benefits from participating in these processes. They may gain new skills, an enhanced awareness and understanding of health-care issues, a greater sense of confidence, and a feeling of accomplishment from having participated in the process (10,14). Patients report a sense of inclusion and belonging to a community, as well as the ability to positively impact the lives of other people affected by diabetes. Involving patients helps ensure that the sociopolitical contexts and other salient factors that may affect the implementation of interventions or use of health technologies are considered and addressed (11). Finally, and perhaps most importantly, patient engagement improves quality and usefulness of patient-information resources and health-care services (15).

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## **Methods of Patient Engagement**

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Patients can be engaged at any and all levels of policy and program development. For instance, patients may be included at a governance table, in advisory groups, as ad-hoc advisors, through online surveys, and/or in focus groups. Further, patients may be involved in developing research/evaluation questions, priority setting, data collection, interpretation of results, and dissemination of information among their diverse socio-ethnic communities as well as other health advocacy groups. If their knowledge, skills, and experience allow, patients may be full members of a research team, or they may offer the perspective of specific communities unable to represent themselves. The ways in which patients are involved will depend on the purpose of the engagement, project leaders' ability to solicit patient feedback on any aspect of the work, and patients' willingness

and capacity to participate (10). Many organizations have created committees, guidelines, or frameworks to help direct their patient engagement; please refer to the Appendix for a summary of some of these organizations. The following examples highlight how organizations have captured and incorporated the patient voice into their decision-making processes in program or service design, health policy, strategy, and governance (10,16–19).

1. *Representation on organizational boards or advisory committees:*
  - Recruiting patients to be board members or members of advisory committees, with the objective that the patient experience is embedded in all levels of organizational governance, including leadership.
2. *Engagement for topic selection and prioritization for analysis:*
  - Patient representatives identifying topics for policy development in a group setting or online; and engaging in post-proposed or final topic selection online, giving them the opportunity to provide feedback throughout the entire process.
3. *Scoping the breadth and depth of the topic:*
  - Invitations for patient groups to submit feedback to inform the policy or program development process.
  - Organizational consultations with patients, caregivers, and voluntary organizations/charities through written feedback and multi-stakeholder workshops.
4. *Conducting or commissioning evidence-based analyses:*
  - Invitations for public and/or patient representatives to join boards or panels.
  - Call for evidence from public via posting notice of the issue selected for review for one month, targeting patient and professional organizations.
  - Patient input sought on controversial topics via focus groups and/or surveys.
  - Consultation with patients, caregivers, and voluntary organizations or charities to solicit feedback on behalf of their constituents through written evidence submissions.
5. *Formulating recommendations:*
  - Draft protocols, guidelines, reports, and reviews posted on website for public comment.
  - Patient group representative participation on recommendation committee meetings and review committees.
  - Online public consultations on draft recommendations.
  - Public members on decision-making committees and advisory groups to ensure patient evidence is presented and considered at the meeting.
  - Patient experts giving oral testimony at committee meetings.
6. *Disseminating findings and recommendations:*
  - Evidence-based reviews and recommendations posted online.



- An appeal process that allows participants to provide feedback as to whether they feel their views were accurately captured before publication.
- Patient representatives speaking publicly following completion of technology appraisal.
- Documents summarizing stakeholder meetings made publicly available online.

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## Challenges for Patient Engagement in Health

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Although the rationale for including the patient voice in health-related activities such as policy making is strong, there are several challenges to effectively engaging patients in a meaningful way. A patient's lack of health literacy may be a barrier to participation. The time and resources required to involve patients and sustain their engagement can be prohibitive. Patient recruitment is often difficult and time-consuming (11). To address these challenges, an evolution in the culture is required to align health-related activities with patient realities.

Approximately 60% of adults and 88% of seniors in Canada are not health literate (17). As a result, they struggle to access, understand, evaluate, and communicate health information as it is customarily presented (17). Other groups with low health literacy include recent immigrants, low socioeconomic status groups, and those with low levels of education (11). The gap in understanding the complexity of terms can often lead to a slower pace of consensus-building and decision-making (11).

How can we engage those with low health literacy? How can we create a space where people with low health literacy feel confident to make a meaningful contribution to decision-making processes? There is no definitive method that should be considered the gold standard for including patients. An approach to patient engagement should be selected after considering factors specific to the population at hand (20). Potential strategies include offering orientation, mentorship, training, and support to participants (17). Creating infrastructure and dedicated staff designated to such tasks, such as the National Institute for Health and Clinical Excellence's (NICE) Public Involvement Program in the UK, can help facilitate this process. Providing workshops or introductory courses on topics of interest (e.g., health economics), may also help patients develop the capacity needed to contribute in a meaningful way (17). Also, developing a network or coalition of patients, families, caregivers, disease-specific organizations, or other relevant groups that can be called upon to contribute to the engagement process should be considered (17). Engaging with those who cannot access digital technology can be achieved by providing them with the devices (computers, laptops, smartphones etc.), internet services, and the training they need to help overcome the digital literacy challenges.

Another commonly cited challenge is the difficulty developing diverse groups that represent the population, because of time constraints or other logistical concerns such as location. Removing practical barriers, like providing childcare, reimbursing parking fees, supplying food at meetings, and ensuring that

meetings are held outside of regular work hours, helps open up opportunities for those who might otherwise be unable to attend and participate (21). For many marginalized socio-ethno-cultural communities, engaging with them can be achieved by having the researchers go directly into their communities, as opposed to bringing the patients into the researcher's environment. The social and physical constructs of these diverse communities can also inform the decision makers about other factors that impact the health and well-being of these vulnerable groups.

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### **Special Considerations for Indigenous Populations**

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Canada's Indigenous populations continuously demonstrate great strength and resilience. Survivors of residential schools, and historic and continued colonial policies, have endured oppression, cultural erosion, forced relocation, forced assimilation, and institutionalized racism. When considering the number of challenges these communities have endured, Indigenous groups' current status as well-functioning cultural and political entities demonstrate exceptional courage and tenacity.

Because of Canada's past and continued colonial context, the high burden of diabetes in Indigenous populations, differences between Indigenous knowledge and traditional healing practices and the biomedical model of health, patient engagement with Indigenous Peoples is essential. Indigenous Peoples living in Canada have unique experiences with and perspectives on health, health-care, and

health-care decision-making processes (24). It is of utmost importance that their voices are included and reflected in the policies and projects that are undertaken.

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### **Patient Engagement at Diabetes Canada**

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To meaningfully engage patients, we propose the following principles, modelled from the Canadian Institutes of Health Research's (CIHR) Strategy for Patient Oriented Research (10) and Ontario Health's Patient, Family, and Public Advisory Council (16), to guide Diabetes Canada's work. These values are consistent with Diabetes Canada's values and our vision for patient engagement. These principles form the backbone of all interactions with patient participants, and guide the processes of research analysis, dissemination, and program and policy creation.

Work undertaken with Indigenous patients will be Indigenous designed, owned, and implemented. Diabetes Canada commits to respectfully engaging Indigenous patients to ensure that our work does no harm to Indigenous Peoples and respects and uphold the Truth and Reconciliation Commission of Canada's (TRC) 94 Calls to Action.

#### **Diabetes Canada's principles for patient engagement:**

- *Inclusiveness:* Patients with lived experiences will be respected and valued, and their experiences will inform and be reflected in research analysis, policy creation, and executive decision-making processes.
- *Support:* Diabetes Canada will provide patient participants with support (through

capacity building, skills acquisition, and/or health literacy training, etc.) and a safe environment to ensure that interactions are honest, and patients can meaningfully contribute to discussions and decisions.

- *Mutual Respect:* Relationships between policy makers, health-care providers, other health stakeholders, and patients will be acknowledged as mutually beneficial. The expertise and experiential knowledge of each stakeholder will be acknowledged and valued equally.
- *Co-building:* Patients, health-care providers, and other health stakeholders will work together from the earliest stage possible in each project. They will be involved in identifying gaps, setting priorities for policy and program development, and collaborating to implement solutions.

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## Conclusion

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Recognition of the importance of consulting patients to gather information about their perspectives, experiences, and preferences throughout health care inspired Diabetes Canada to develop this policy position on engaging the diabetes community. Based on Diabetes Canada's principles for patient engagement (inclusiveness, patient support, mutual respect, and co-building), the organization will continue to support patient engagement in health-care education, services, and policy development and implementation.

Community organizations, employers, insurers, governments, and other health stakeholders are urged to prioritize the meaningful inclusion of the patient

perspective to optimize the outcomes of health policy, services, and programs. Further, patient engagement should occur as early as possible, during the planning and development stages, and continue through the implementation and evaluation stages. While ensuring that patients have a seat at the table is a necessary element of patient engagement, it is not sufficient. An honest and measured consideration of patient and community input is a fundamental component of a successful patient engagement process. It is only then that prioritization of patient needs can truly be incorporated into all aspects of the health-care ecosystem.

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## Appendix: Examples of Patient Engagement Processes in Other Organizations

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Patient engagement processes are presented alphabetically; their inclusion is for sample purposes and does not indicate Diabetes Canada's endorsement of said initiatives. In some cases, organizations listed may be lacking in substantive impact.

### Canadian Agency for Drugs and Technologies in Health (CADTH): Reviews and Advisory Bodies

CADTH's review processes, including the Common Drug Review (CDR), involves conducting evaluations of clinical, economic, and patient evidence on drugs, in order to provide recommendations to public drug plans regarding public coverage (25). Input from patients is obtained through patient groups who are notified of a CDR review and invited to provide input (25). In doing so, the

drug review process captures the lived experiences of those living with a medical condition, their perspectives on the treatments currently available, and their expectations or desires for the new drug under review (25).

CADTH's advisory bodies facilitate the exchange of health technology information within Canada (26). Through the advisory bodies (e.g. the Canadian Drug Expert Committee (CDEC), the pCODR Expert Review Committee (pERC), and the Health Technology Expert Review Panel), CADTH enlists the support of experts and stakeholders, that include members of the public who represent the broad public interest (26).

### **Canadian Institutes for Health Research (CIHR): Strategy for Patient-Oriented Research (SPOR)**

CIHR created a Patient Engagement Framework as part of their overall SPOR (10). CIHR is working to focus on the priorities important to patients and produce information that is taken up and used to improve health-care practices, therapies, and policies. Accordingly, their framework aims to involve patients as much as possible in research so that it can be more responsive to the needs of Canadians.

SPOR's guiding principles are inclusivity, support, mutual respect, and co-building (10). The framework stipulates that successful patient engagement involves inclusive mechanisms and processes, where patients are involved at all levels, including leadership and decision-making; multi-way capacity building (patients, researchers, and health-

care providers develop new skills to help them work together more effectively); multi-way communication and collaboration (mutual respect is fostered and honest conversations that involve all parties are prioritized); experiential knowledge valued as evidence; a diverse group of patients are represented through a range of roles; and there is a shared sense of purpose among all participants (10). SPOR also recommends mechanisms be put in place for continuous feedback in which results of patient-oriented research are communicated back to patients (10).

### **Citizen Panels**

A number of organizations, including the Ontario Drug Policy Research Network (ODPRN) (33) and McMaster Health Forum (34), have implemented citizen panels: groups of individuals who can be drawn upon when patient input is required. The groups are selected to represent ethnocultural, socioeconomic, gendered, and other diverse perspectives. These panels provide opportunities for citizens to share their views and experiences on high-priority issues, and help shape and direct health care, policy, and technology decisions.

### **Ontario Health**

Ontario Health (formerly Health Quality Ontario, HQO) created a Patient, Family, and Public Advisors Council charged with ensuring the insights and experiences of patients, caregivers, and members of the public, are included in the projects undertaken at HQO (27). Members of the program participate in discussions on key issues to research in the organization, sit on HQO committees, provide

feedback in various formats, and help to build supports and tools for further patient engagement (27). HQO's Framework for Patient Engagement stipulates that any interaction with patients is to be built on the principles of partnership, learning, empowerment, transparency, responsiveness, and respect (16). The framework articulates that patient engagement is to be included across the domains of personal care and health decisions, program and service design, as well as policy, strategy, and governance (16).

### **James Lind Alliance (JLA)**

JLA is a non-profit organization in the UK that brings patients, caregivers, and clinicians together in what they call Priority Setting Partnerships (PSPs) (28). Non-clinician researchers and other groups and organizations with conflicts of interest, such as the pharmaceutical industry, may be included in the PSPs but are excluded from voting.

To inform research on health issues, PSPs identify and prioritize the Top 10 unanswered questions about the effects of treatments that various stakeholders, including patients, deem to be most important. This ensures that organizations funding research are attuned to what matters to both patients and clinicians.

JLA facilitates the partnerships and funding of these meetings, and all organizing is carried out within the specific PSP. A member of JLA facilitates these working sessions. PSPs come together to inform the work on numerous diseases and health conditions, including diabetes, and the sessions provide all

stakeholders with an opportunity to shape the health research agenda.

### **National Institute for Health and Care Excellence (NICE): Public Involvement Program (PIP)**

PIP was designed to ensure that NICE's health research and policy decisions are patient-centered (19,29). The PIP team provides guidance on and supports the involvement of patients, caregivers, and the public in research and initiatives undertaken at the Institute. Its main responsibilities are to develop, implement, and review methodologies for involving the general public, including patients, in NICE's work. Another function it serves is to liaise with other community organizations that represent patients and other groups' voices to support their involvement in projects carried out at NICE. Finally, it has instituted a robust evaluation process to assess patient and caregiver experiences in NICE's activities (30).

### **National Institute of Health Research (NIHR): INVOLVE**

In their effort to promote and monitor public involvement in health research in the UK, NIHR established INVOLVE (31,32). INVOLVE is an organization mandated to ensure that NIHR's health research reflects the needs and views of patients and the general population (31,32). INVOLVE's approach to patient and public engagement includes increasing awareness of how and when to involve the public with research, working to build an evidence base for public involvement, and offering guidance, insight, and expertise when needed (31,32).

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