

CADTH Health Technology Review

# Living With Type 2 Diabetes

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**About CADTH:** CADTH is an independent, not-for-profit organization responsible for providing Canada's health care decision-makers with objective evidence to help make informed decisions about the optimal use of drugs, medical devices, diagnostics, and procedures in our health care system.

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## Authors

Jamie Anne Bentz, a CADTH qualitative research officer, developed the original approach for the narrative description of patient input and the Discussion section in collaboration with Francesca Brundisini and Sarah Berglas. She presented the proposed approach to patient group representatives and responded to their feedback by adjusting the planned approach as appropriate. She selected inputs for inclusion using criteria created in collaboration with the rest of the research team. She conducted the qualitative analysis of the dataset and wrote the first draft of this report (except for the content under the “Inputs From Diabetes Canada” subheading of the Patient Input Characteristics section and Appendix 1, both of which were written by Rebecca Hancock-Howard). She modified the report following internal review and feedback from patient group representatives, and provided final approval of the version of the report submitted for publication.

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Zal Press is the founder of Patient Commando, and authored the patient inputs from Type 2 Diabetes Experience Exchange and Patient Commando included in the narrative description. He provided feedback on the approach for the narrative description of patient input. Additionally, he provided critical reviews of the report’s content, including a final review of the version of the report submitted for publication.

Francesca Brundisini, CADTH’s qualitative scientific advisor, contributed to the report design during the project development stage, provided methodological oversight and support throughout the conduct of the content analysis, provided critical reviews of the contents of the report, and provided final approval of the version of the report submitted for publication.

Sarah Berglas, CADTH’s manager of patient, clinician, and industry engagement, proposed this project to explore an alternative approach to repeatedly seeking patient input for conditions for which CADTH has received extensive input. Sarah invited patient groups who had contributed past input on type 2 diabetes mellitus to be part of the project. Sarah facilitated discussions between authors, provided critical reviews of the contents of the report, and provided final approval of the version of the report submitted for publication.

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## Abbreviations

<b>DPP-4</b>	dipeptidyl peptidase-4
<b>GIP</b>	glucose-dependent insulinotropic polypeptide
<b>GLP-1</b>	glucagon-like peptide-1
<b>GP</b>	general practitioner
<b>LGBTQ2S+</b>	lesbian, gay, bisexual, transgender, queer, 2-spirit, and others
<b>PCAC</b>	Patient and Community Advisory Committee
<b>QRO</b>	qualitative research officer
<b>SGLT-2</b>	sodium-glucose cotransporter-2
<b>T2DM</b>	type 2 diabetes mellitus
<b>T2DXX</b>	Type 2 Diabetes Experience Exchange

## Key Messages

- We conducted a custom technology review to narratively describe treatment outcomes and considerations important to people living with type 2 diabetes mellitus (T2DM) in Canada, as detailed in patient input provided to CADTH in the past. Patient groups submitted the input described in this review to inform CADTH Reimbursement Reviews, which advise reimbursement decisions made by public drug programs in Canada. CADTH staff produced this report through close engagement with representatives from patient groups that had contributed these inputs, including Diabetes Canada, Type 2 Diabetes Experience Exchange (T2DXX), and Patient Commando. This learning project provided an opportunity for CADTH to explore patient input in a new but rigorous way outside of the time constraints of Reimbursement Reviews for specific drugs.
- In past patient input, people living with T2DM emphasized that the condition demands intensive, perpetual self-management and has a profound and usually negative impact on their physical, psychosocial, and economic well-being.
- People living with T2DM want a cure for the condition. In the meantime, to improve their quality of life, they desire treatments that reduce the risk of hyperglycemia and its short- and long-term complications; facilitate weight loss; and improve their mental state, focus, and energy levels. They also desire treatments that can lessen the burden of medication administration, specifically by decreasing polypharmacy and dose frequency and allowing for easy storage, preparation, and administration. They would like medications to reduce the need for blood glucose checks, injections, and insulin, and they hope that new treatments can promote a return to normalcy by providing the freedom to eat and do what they want, when they want.
- In addition to these desired treatment outcomes, people living with T2DM want medications that cause few or no adverse effects, especially hypoglycemia, weight gain, and gastrointestinal and urogenital side effects.
- All patient input emphasized the need to increase access to and affordability of T2DM treatments in Canada. When discussing the contexts in which people living with T2DM access and use medications, patient groups also stressed the importance of respect and effective communication in therapeutic and interprofessional relationships; the need to provide and enhance knowledge to support informed decisions about and safe use of medications; and the importance of offering people with T2DM individualized treatment plans and a variety of choices.
- Patient groups reported limited demographic information on the people they surveyed and interviewed to inform their inputs. Inputs providing demographic information, however, showed that the voices of those belonging to equity-deserving groups in Canada were missing or underrepresented. The treatment outcomes and considerations emphasized in past patient input may differ from those important to members of these groups or may carry additional meaning or significance to them. Future avenues of inquiry and active engagement could focus on gaining insight into the perspectives and preferences of equity-deserving groups that include but are not limited to Black people, Indigenous people, and other people of colour; people living in poverty or with low income; people living in rural and remote communities; adolescents and adults aged 25 years or younger; and members of the LGBTQ2S+ community.

## Background

Diabetes mellitus is a chronic metabolic condition characterized by persistently elevated blood glucose (hyperglycemia). As of 2022, an estimated 14% of people in Canada were living with type 1 diabetes or type 2 diabetes, with prevalence projected to increase to 17% by 2032.<sup>1</sup> Type 2 diabetes mellitus (T2DM) is caused by a combination of the abnormal secretion and inefficient use of insulin, and accounts for 90% to 95% of adult cases of diabetes.<sup>1-3</sup> The causes of T2DM are complex and socially mediated, with risk factors including but not limited to: being older; having a family history of or genetic predisposition to T2DM; being of Indigenous, African, Arab, Hispanic, or South Asian descent; living with overweight or obesity; being physically inactive; having a lower level of education or socioeconomic status; having an unhealthy diet; living with psychological stress, mental illness, or social isolation; and exposure to air and noise pollution.<sup>1,4-10</sup>

Persistent hyperglycemia may cause short- and long-term complications associated with decreased quality of life and, in some cases, early death.<sup>11-14</sup> In the short term, hyperglycemia can cause excessive urination, thirst, weight loss, increased risk of infection, and neurologic symptoms.<sup>15,16</sup> In the long term, hyperglycemia may damage small blood vessels and nerves, which may cause nerve pain and numbness, chronic kidney disease, visual impairment, and erectile dysfunction.<sup>11</sup> Damage to large vessels may result in cardiovascular, cerebrovascular, and peripheral artery disease, increasing the risk of heart attacks, stroke, and needing lower limb amputations.<sup>12</sup>

T2DM is a heterogeneous condition requiring individualized treatment approaches to manage blood glucose levels.<sup>17</sup> Initial treatment usually involves behavioural interventions, such as nutritional therapy, weight management, and physical activity.<sup>17,18</sup> Antihyperglycemic medications may become necessary when behavioural interventions alone cannot stabilize blood glucose.<sup>18</sup>

In Canada, during the process of obtaining a reimbursement recommendation on publicly insured drug plans, manufacturers of pharmaceutical products submit evidence to CADTH for a Reimbursement Review. CADTH Reimbursement Reviews evaluate the evidence submitted by manufacturers and additional available evidence on drugs, and use these evaluations to provide recommendations and advice to federal, provincial, and territorial public drug plans (except for Quebec). These recommendations aim to support reimbursement decisions made by provincial, territorial, and federal decision-makers.

Since May 2010, CADTH has called for input from patient groups for all Reimbursement Reviews to improve their relevance and to enable the contribution of those possibly affected by the decisions they inform. Patient groups are organized groups representing patients with a specific disease or condition, or a collection of diseases and conditions, with members who are patients, family members, or both.<sup>19</sup> CADTH does not invite individual patients or caregivers to provide patient input for Reimbursement Reviews at this time.<sup>19</sup> Patient groups complete their submissions within 7 weeks of CADTH posting a call for input. To do so, they use a CADTH template with broad prompts, including those asking for insight into the experience of a condition and its available treatments, treatment outcomes important to people impacted by the condition, and experiences with the drug under review. CADTH has received more than 30 patient input submissions on drugs intended to treat T2DM since 2010.

## Purpose of This Report

The purpose of this report is to narratively describe treatment considerations and outcomes important to people living with T2DM in Canada, as detailed in input provided to CADTH by patient groups.

## Research Questions

What treatment outcomes and considerations are important to people considering or receiving pharmacological therapies for T2DM in Canada, as detailed in input provided to CADTH by patient groups?

In addition to the primary research question, the narrative description addresses the following related secondary questions:

- What treatment outcomes do people living with T2DM in Canada consider the most important, desirable, and undesirable?
- What processes and contexts of treatment are important to people living with T2DM in Canada?

## Methods

### Patient Group Engagement and Collaboration

CADTH produced this report through close engagement and collaboration with patient groups that contributed input for CADTH Reimbursement Reviews on drugs used to treat T2DM within the past 5 years. These groups include Diabetes Canada, T2DXX, and Patient Commando. Of note, T2DXX had disbanded at the time of this project, but permission to use their original inputs was granted.

CADTH contributed to the collection, narrative description, and publication of the report, incorporating feedback from the patient group representatives throughout all stages of the project, including its design and the purposeful selection of patient input. Diabetes Canada contributed by sharing additional information on the surveys used to inform their included inputs (refer to Appendix 1). Finally, representatives from Diabetes Canada and Patient Commando reviewed and provided feedback on the narrative description and overall report to verify its accuracy and completeness.

### Input Selection Criteria and Methods

The CADTH research team employed a purposeful sampling technique to select inputs for inclusion. The sample included all patient input submitted for Reimbursement Reviews on drugs with a clinical focus of treating T2DM within 5 years of starting the project (i.e., from January 2017 to September 2022). The team began with a 5-year time frame to capture a robust but manageable dataset that would allow for a thorough qualitative analysis within the project's timelines. The drug classes included in this 5-year sample consisted of insulins, sodium-glucose cotransporter-2 (SGLT-2) inhibitors, glucagon-like peptide-1 (GLP-1) receptor agonists, and glucose-dependent insulinotropic polypeptide (GIP) receptor agonists. The team

did not include input submissions informed by data collected only from people living with or caring for someone living with type 1 diabetes.

Diabetes Canada suggested including further inputs upon consulting 2 of their clinical volunteers with expertise in caring for people living with T2DM. Based on these consultations, the CADTH team included 2 additional inputs received for Reimbursement Reviews on dipeptidyl peptidase-4 (DPP-4) inhibitors, a class of drugs not captured by inputs received in the past 5 years. One clinician volunteer reported that while no longer considered first- or second-line treatments for T2DM, DPP-4 inhibitors remain commonly prescribed by general practitioners (GPs) due to their moderate price, minimal side effects, limited teaching required, and oral administration. They noted that these treatment outcomes and considerations might be important to people living with T2DM and, if so, would be valuable to capture in the narrative description.

The clinician volunteers also emphasized the importance of including all past input on SGLT-2 inhibitors and GLP-1 receptor agonists. While the 5-year sample included both drug classes, CADTH's qualitative research officer (QRO) reviewed all past input received on these drugs to verify whether inputs dated before 2017 included treatment outcomes and considerations not present in earlier inputs (after 2017). They identified no new outcomes or considerations in the older inputs, except for the description of urinary frequency as an undesirable treatment outcome identified in input received for canagliflozin (Invokana).<sup>20</sup> The research team then included this input in the sample, given its identification of an otherwise uncaptured treatment outcome.

## Analytical Methods

To produce a narrative description that remained as close to the content of the original inputs as possible, the QRO used an analytical approach informed by qualitative content analysis.<sup>21</sup>

In line with qualitative research best practices, before and throughout the analytical process, the QRO created memos about their prior experiences, assumptions, and knowledge regarding T2DM. They used these memos to reflect upon how their previous understandings might influence their analysis and challenged assumptions or findings that were not grounded in the data.<sup>21</sup>

The analysis proceeded in stages. First, to immerse themselves in the data, the QRO read and reread the inputs in their entirety, highlighting lines and phrases relevant to the research questions and creating memos on first impressions, thoughts, and insights.<sup>21</sup> Then, using NVivo,<sup>22</sup> the QRO assigned codes to data.<sup>21</sup> To do so, they first assigned codes to 3 inputs based on categories determined by the research questions and concepts emerging under these broader categories.<sup>21</sup> When appropriate, they grouped emerging codes into further subcategories based on how they related to each other.<sup>21</sup> These initial codes and categories formed a coding scheme to code subsequent inputs, and the QRO expanded upon or modified the coding scheme as necessary to capture new information.<sup>21</sup> They constantly compared text assigned to codes within and across inputs to determine whether they consistently applied codes and if additional levels of coding were needed.

Finally, they produced a narrative description of the characteristics of the identified categories and subcategories.<sup>21</sup> They shared the narrative description with patient group representatives, who provided feedback on its accuracy and completeness. The QRO modified the narrative description based on this feedback.

## Patient Input Characteristics

Twenty patient input submissions informed the narrative description, 16 of which were provided by Diabetes Canada<sup>20,23-36</sup> (formerly called the Canadian Diabetes Association), 2 by T2DXX,<sup>33,34</sup> and 2 by Patient Commando.<sup>25,30</sup>

### Source of Patient Inputs

Diabetes Canada is a national health charity representing Canadians affected by diabetes.<sup>37</sup> Its mission is to “lead the fight against diabetes” by preventing its onset and consequences, helping those impacted by the condition to live healthy lives, and working to find a cure.<sup>37</sup> To deliver on its mission, Diabetes Canada provides education and services, advocates on behalf of people living with diabetes, and supports and translates research into practical applications.<sup>37</sup>

T2DXX was a patient group that created safe and open spaces for people living with T2DM to share their experiences to promote collaborative conversations that would enhance understandings and improve the experiences of people living with the condition.<sup>33,34</sup>

Patient Commando is an organization that seeks to amplify and empower patient voices by using lived experiences to facilitate meaningful, relevant conversations to improve health care practices.<sup>38</sup> It does so through sharing online collections of patient stories, providing health care providers education on narrative competency, and developing collaborations between patients and health care professionals to improve therapeutic relationships.<sup>38</sup>

### Inputs From Diabetes Canada

Between 2014 and 2022, Diabetes Canada conducted 15 surveys informing 16 of the included patient input submissions.<sup>20,23-36</sup> (Appendix 1 provides information regarding which inputs each survey informed.) Eight of the 15 surveys collected data only from people living with T2DM and their caregivers, while the remaining surveys collected data from those living with type 1 diabetes and T2DM.

Diabetes Canada primarily recruited respondents through email blasts and posts on social media. In some instances, it also recruited respondents by notifying health care providers who might know of, and send the survey to, eligible respondents. This recruitment included sending emails to physicians involved in clinical trials for drugs under review, posting in Diabetes Canada’s Professional Section (an online forum and email list), and posting in a health care professional forum called TimedRight. (Refer to [Table 2](#) in Appendix 1 for more detail on recruitment methods.)

Diabetes Canada conducted its largest surveys in 2013 (n = 232), 2014 (n = 388), October 2016 (n = 847), and June 2017 (n = 329). In July 2020 and August 2020, it conducted a large survey (n = 873) in collaboration with the Juvenile Diabetes Research Foundation and Type 1 Together. Starting in 2017, it launched surveys in response to the need to gather evidence for therapies under review. These surveys were open for responses for 2 weeks and typically had smaller numbers of respondents, ranging from 9 to 52 (refer to [Table 3](#) in Appendix 1 for more detail). In many cases, 1 or more of the larger surveys and smaller drug-specific surveys informed a single submission.

All surveys were online and self-administered. All had similar objectives and content: to gain insight into how diabetes affects the lives of people living with the condition and their caregivers, and experiences with drug therapies used to treat it. All surveys included closed-ended questions, such as those asking respondents to rate the importance of different treatment outcomes, and open-ended text questions asking respondents to describe their experiences living with diabetes.

The surveys collected limited demographic information from respondents, although they routinely collected data on respondents' ages and length of time living with diabetes (refer to [Tables 4](#) and [5](#) in Appendix 1). Of note, few respondents were under 25 years of age. Only the 2019, 2020, and 2022 surveys collected data on respondents' province of residence, with most living in Ontario, British Columbia, and Alberta. Diabetes Canada did not report data from respondents residing in the 3 territories in their surveys (refer to [Table 6](#) in Appendix 1). The 2022 survey informing the tirzepatide (Mounjaro) submission<sup>36</sup> also collected data on the race/ethnicity and gender of respondents. In this survey, 11 (55%) of the respondents identified as female, 8 (40%) as male, and 1 (5%) as nonbinary. Ninety percent of the respondents self-identified as white, while 5% identified as South Asian, and 5% declined to answer the question. No survey collected data on the rurality, socioeconomic status, or education level of respondents.

### Input From T2DXX and Patient Commando

CADTH received inputs from T2DXX in 2019 and 2020 for Reimbursement Reviews on insulin degludec plus liraglutide (Xultophy)<sup>33</sup> and semaglutide (Rybelsus),<sup>34</sup> respectively. Patient Commando submitted inputs to CADTH in 2017 and 2018 for Reimbursement Reviews on insulin degludec (Tresiba)<sup>25</sup> and semaglutide (Ozempic),<sup>30</sup> respectively. Of note, the content and quotations in Patient Commando and T2DXX inputs are similar, as the same data informed portions of all 4 submissions.

T2DXX and Patient Commando used personal interviews, facilitated group discussions, social media conversation threads, the Patient Commando website story collection, and community responses to Patient Commando's Experience Exchange program to inform their input submissions.<sup>25,30,33,34</sup> The patient groups purposefully sampled interview and group discussion participants from a diabetes education centre. All interviews and discussion groups were unstructured and conducted in person in a setting that promoted relaxed and open conversation. While some interviews and group discussions were video recorded, the total number and length of the interviews and group discussions were not recorded. T2DXX and Patient Commando obtained social media data by posting questions on their pages to prompt discussion among respondents, which they moderated over a fixed timeline. T2DXX and Patient Commando did not report the total number or demographic characteristics of participants and respondents. The author of all 4 submissions reported using an inductive qualitative approach to analyze the data.

## Findings

A summary of the findings of the content analysis of patient inputs is provided in [Table 1](#). The subsequent corresponding sections provide a narrative description of the characteristics of these categories of findings.

**Table 1: Categories Identified in the Analysis of Patient Input**

Experiences of living with T2DM	Treatment outcomes desirable to people living with T2DM	Treatment outcomes undesirable to people living with T2DM	Treatment considerations important to people living with T2DM
<ul style="list-style-type: none"> <li>• Self-management of T2DM is demanding and challenging</li> <li>• T2DM is all-consuming and impacts the physical, psychosocial, and economic well-being of those living with it</li> </ul>	<ul style="list-style-type: none"> <li>• Mitigate or reduce the risk of hyperglycemia and its complications</li> <li>• Facilitate weight loss</li> <li>• Improve mental state, focus, and energy</li> <li>• Reduce the burden of medication administration and invasive procedures</li> <li>• Provide a return to normalcy</li> </ul>	<ul style="list-style-type: none"> <li>• Hypoglycemia</li> <li>• Weight gain or the prevention of weight loss</li> <li>• Gastrointestinal and urogenital side effects</li> </ul>	<ul style="list-style-type: none"> <li>• The need for increased access to and affordability of medications</li> <li>• Respect and effective communication in therapeutic and interpersonal relationships</li> <li>• Knowledge needed to support decisions about and use of medications</li> <li>• Importance of individualized treatment plans and a variety of choices</li> </ul>

T2DM = type 2 diabetes mellitus.

### Experiences of Living With Type 2 Diabetes

A minority of people living with T2DM reported that, when well managed, the condition had a neutral or positive impact on their quality of life.<sup>23,34,35</sup> The vast majority, however, reported negative experiences living with it, primarily due to the demands and challenges of self-management and the all-consuming nature of the condition.<sup>20,23-36</sup>

### The Demands and Challenges of Self-Management

People living with T2DM and their loved ones consistently described how the condition demands intensive self-management from which there is “no vacation.”<sup>20,23-36</sup> They stressed that this self-management requires interminable thought and time devoted to planning, monitoring, and responding to diet, physical activity, blood glucose and stress levels, medical appointments, and medications.<sup>20,23-36</sup> As 1 person with T2DM explained, “It is an ongoing job, constantly testing [blood glucose], watching what you eat, making sure you get some exercise. A never-ending chore that you need to do to stay alive.”<sup>34</sup>

People with T2DM found non-pharmacological self-management activities challenging and sometimes impossible to engage in. Some reported having inadequate knowledge or information to engage in these activities; however, many more found self-management challenging due to a lack of capacity and resources.<sup>20,23-36</sup> Diet changes, for example, were challenging to uphold due to the inability to afford or access healthy foods, the careful planning required for each snack and meal, and the perception of fewer food options, all of which detracted from the pleasure of eating.<sup>20,23-28,30,32-36</sup> Engaging in physical activity was similarly difficult because of time constraints, fluctuations in blood glucose following exercise, symptoms and complications of T2DM, and a lack of access to affordable exercise facilities.<sup>25,28,30,32-35</sup> These already challenging activities proved even more complicated for those simultaneously living with other comorbidities or caring for dependent loved ones.<sup>25,27,28,30-35</sup>

## Type 2 Diabetes as All-Consuming

People living with T2DM emphasized the all-consuming nature of the condition, describing its impact on nearly every aspect of life.<sup>20,23 to 36</sup>

### *Impacts on Physical Well-Being*

Physically, most people living with T2DM reported uncomfortable and sometimes debilitating or life-threatening symptoms, complications, and comorbidities.<sup>20,23-36</sup> Many reported living with the following:

- chronic fatigue and pain
- overweight or obesity
- nerve damage
- kidney damage
- dry skin
- slow-healing wounds that sometimes necessitated amputations
- visual changes or blindness
- gastrointestinal symptoms
- bladder or bowel incontinence
- cardiovascular complications (e.g., high blood pressure and heart attacks)
- sexual changes (e.g., erectile dysfunction).<sup>20,23-36</sup>

As 1 person with T2DM stated, “I feel like my body is breaking down 25 years ahead of its time.”<sup>31</sup> Alongside these discomforts, many people living with T2DM reported experiencing unpleasant and sometimes dangerous side effects of their antihyperglycemic medications, including, but not limited to, hypoglycemia, weight gain, fatigue, arrhythmias, gastrointestinal side effects, and yeast or urinary tract infections.<sup>20,23-36</sup>

### *Impacts on Psychosocial Well-Being*

All patient input submissions emphasized the profound effect that T2DM has on the psychosocial well-being of those living with or caring for someone with the condition.<sup>20,23-36</sup> Some people living with T2DM reported emotional changes and mood swings as symptoms of extremes in blood glucose.<sup>25,30,35</sup> Many also reported living with anxiety and depression.<sup>20,23-36</sup> They described the demands of self-management as overwhelming, stressful, and anxiety-provoking, and as a source of sadness, frustration, and anger.<sup>20,23-36</sup> Extremes in blood glucose similarly led to feelings of frustration, self-perceived failure, and worry and anxiety stemming from experienced or possible complications.<sup>20,23-36</sup> Many people with T2DM experienced grief related to the loss of spontaneity, the ability to enjoy preferred activities and foods in a flexible manner, and privileges such as driving.<sup>30,33,34</sup> Some reported shame and guilt because they perceived themselves as being to blame for their condition or a burden to their loved ones.<sup>30-34</sup> To summarize the impact T2DM had on their psychological well-being, 1 person living with the condition noted, “Having diabetes makes me useless. I have no energy or strength to enjoy life anymore. I can’t do partial jobs around the house. I can’t enjoy sports anymore. Diabetes has instill [sic] a fear in me.”<sup>20,24</sup>

The experience of living with T2DM also impacted and was impacted by social experiences.<sup>20,23,25,27,28,30,32-36</sup> For many, engaging in social activities became increasingly challenging due to limited energy and mobility, restricted funds, fewer restaurant choices, and unwanted attention drawn when avoiding certain foods or injecting medications.<sup>25,27,30,32-36</sup>

People living with T2DM described the exasperation of enduring diabetes stigma, whereby others assumed their T2DM was self-inflicted or the result of poor self-control, and therefore blamed or judged them for having the condition.<sup>23,25,27,28,30,32-35</sup> Many also reported experiencing tension in their relationships with friends, family, and even health care providers, feeling demoralized and frustrated when receiving unsolicited advice and having to defend decisions about food and activity.<sup>25,27,28,30-35</sup>

Despite these social challenges, people with T2DM emphasized that family members and friends could be sources of support, especially when adopting lifestyle changes alongside them, offering encouragement, or even administering life-saving interventions (e.g., in cases of hypoglycemia).<sup>25,30,33,34</sup> As sources of support, however, many loved ones experienced worry and emotional distress, especially after witnessing life-threatening complications of the condition and its treatment.<sup>24,25,27,29,30,34,35</sup> Others expressed feeling overwhelmed by managing a family member's T2DM while tending to other responsibilities, such as child care.<sup>25,30</sup> As 1 caregiver noted, "How has it not [affected life]? Near-death experiences, increased expenses, lost employment revenue, and many, many, many sleepless nights."<sup>27</sup>

People living with T2DM were acutely aware of and worried about the impact of their condition on their family and friends, with 1 mother saying, "My kids have to know what to do if I pass out, and that isn't the type of responsibility that young children should have."<sup>28-34</sup> To protect others from worry and stress, some reported trying to mask the severity of their condition by hiding medications or symptoms.<sup>25,33,34</sup>

### ***Impacts on Economic Well-Being***

In patient input, people living with T2DM emphasized that, even without considering the burden of out-of-pocket costs associated with obtaining drugs, living with T2DM places a tremendous financial burden on a person with the condition and their family.<sup>20,23-28,30-35</sup> People living with T2DM noted that adopting healthy diets and exercising are expensive endeavours.<sup>25,26,30,33,34</sup> Many also described public and private insurance coverage of diabetes supplies — including those to monitor blood glucose — as inadequate, necessitating high and sometimes unmanageable out-of-pocket costs.<sup>23-26,34,35</sup> Living with T2DM could also limit the ability to gain employment or work opportunities, and symptoms and complications sometimes resulted in the need to take time away from work.<sup>25,33-35</sup> As 1 person with the condition summarized, "The financial cost makes life with diabetes unbearable at times."<sup>27</sup>

## **Treatment Outcomes Important to People Living With Type 2 Diabetes**

People living with T2DM emphasized the desire for "a cure, plain and simple" that would allow them to return to life as it was before their diagnosis; regain a sense of physical, psychosocial, and economic well-being; and eliminate the need for medication.<sup>20,23-25,27,28,30-36</sup> In the context of needing medications, however, they described the desirable and undesirable treatment outcomes most important to them.

### **Desirable Outcomes**

#### ***Mitigate or Reduce the Risk of Hyperglycemia and its Complications***

Across all inputs, people living with T2DM reported a strong desire for fast-acting treatments that reliably mitigated or reduced the risk of hyperglycemia.<sup>20,23-36</sup> They consistently wanted blood glucose levels within their target range in the morning or after fasting, during the day and after meals, and over time, as measured by hemoglobin A1C levels.<sup>20,23-36</sup> They noted

that preventing or reducing hyperglycemia and its associated symptoms improved the ability to engage in activities of daily living, interactions with family and friends, and work.<sup>20,23-36</sup> The outcome also allowed for less time, energy, and worry devoted to the demands of self-management, thus improving the quality of life of people with T2DM and their loved ones.<sup>20,24,31,34</sup>

Relatedly, people living with T2DM and their loved ones emphasized a desire for medications to broadly improve health outcomes and provide longer and healthier lives “without concerns about complications because of diabetes.”<sup>20,25-28,30-36</sup> They wanted medications to alleviate currently experienced complications, especially high blood pressure and “heart problems,” and to improve kidney and liver function.<sup>20,26,28,30-36</sup> They also wanted medications to reduce the risk of heart disease and heart attack, stroke, dementia, kidney disease, nerve damage, and visual impairment.<sup>25-28,30-36</sup> One person with T2DM noted that reduced worry about the risk of complications from the condition “would make all the difference to my overall stress levels and mood.”<sup>28,32</sup>

### ***Facilitate Weight Loss***

People living with T2DM also desired medications that could facilitate weight loss.<sup>20,23,24,26-28,30-36</sup> Patient input noted that many people with the condition find losing weight challenging.<sup>25,28,34,36</sup> It emphasized that losing weight could positively impact the quality of life of those living with T2DM by improving their overall health and reducing the stress experienced because of stigma related to living with overweight or obesity.<sup>30,33</sup> As 1 person with T2DM noted, “losing weight would just make everything easier and move [my] overall health into a positive trend.”<sup>28,32</sup>

### ***Improve Mental State, Focus, and Energy***

Some people living with T2DM reported positively experiencing or desiring medications that could improve their mood and mental health, focus, memory, and overall energy levels, all of which are influenced by extremes in blood glucose.<sup>25,26,28,32</sup>

### ***Reduce the Burden of Medication Administration and Invasive Procedures***

People living with T2DM voiced a strong preference for therapies that could reduce the burden of medication administration.<sup>20,23-28,30-36</sup> They hoped new pharmacotherapies would require less frequent doses administered at convenient and easy-to-remember times.<sup>20,23-28,30-36</sup> They also hoped new treatments could reduce polypharmacy and its associated “pill burden,” with some noting the potential benefit of combination drugs (i.e., therapies containing 2 or more drugs in a single dose).<sup>20,23-28,30-36</sup> Patient input emphasized that fewer medications and less frequent administration would mean less time and effort devoted to properly storing medications, remembering and preparing dosages, coordinating administration with eating or activities, monitoring efficacy, and managing side effects.<sup>23,25,27,28,30-36</sup> Generally, people with T2DM also reported a desire for medications that were easy and convenient for people of all abilities to store, prepare, and administer, and preferred drugs that did not require refrigeration.<sup>24,26,33-35</sup>

People with T2DM also noted a preference for medications that would reduce the need for finger sticks to monitor blood glucose and injections.<sup>23-28,30-36</sup> Not only did they experience these invasive interventions as inconvenient, but they could cause pain, bruising, anxiety, and sometimes unwanted attention or judgment from others in public.<sup>28,30-32,34</sup> People with T2DM hoped that future medications could prevent or eliminate the need for insulin, not only because this class of drugs must be injected but also because they or others associated

needing insulin with the progression of the condition.<sup>23,25,33,34</sup> As 1 person noted, “There’s still a stigma and a misconception about insulin that if you’re on insulin, death is coming.”<sup>34</sup>

### ***Provide a Return to Normalcy***

Overall, people with T2DM wanted medications to allow for a return to “a normal life” by reducing the burden of self-management, eliminating the need for or frequency of disruptive interventions, and permitting the flexibility to eat and do what they wanted when they wanted.<sup>25-28,30-36</sup> As 1 person with the condition said, “Anything to make this easier is wonderful. I have to test my blood at least 7 times a day and eat foods I don’t care for to keep my levels steady. Any advancements are terrific.”<sup>36</sup>

### **Undesirable Outcomes**

While people with T2DM broadly preferred medications that caused minimal or no adverse effects, they emphasized certain side effects as particularly undesirable.<sup>20,23-36</sup> These included hypoglycemia, weight gain, gastrointestinal side effects, and urogenital side effects.<sup>20,23-36</sup>

#### ***Hypoglycemia***

In patient input, people living with T2DM strongly emphasized the importance of avoiding hypoglycemia, a potentially life-threatening and commonly reported side effect of T2DM treatments.<sup>20,23-36</sup> All patient input noted that managing low blood glucose was time-consuming and burdensome and that hypoglycemic events could cause acute crises, including changes to mental status or seizures that, while dangerous for people with T2DM, could also lead to accidents harming others.<sup>20,23-36</sup> People living with T2DM and their loved ones voiced worry and fear about having a hypoglycemic event they would be unable to respond to, with some waking up in the middle of the night to test and respond to blood glucose levels.<sup>23,25,30,34</sup> This fear became a reality for some people with T2DM who reported life-threatening hypoglycemic events, often resolving due to prompt intervention by family or friends.<sup>25,30</sup> As 1 person with T2DM noted frankly, “Not being able to open the food while [my blood glucose is] low. This is how I die.”<sup>25,30</sup>

#### ***Weight Gain or the Prevention of Weight Loss***

People living with T2DM consistently desired medications that would not cause weight gain or prevent weight loss.<sup>20,23-28,30-36</sup> As 1 person with T2DM noted, “The most distressing side effect of all the diabetes drugs is they make you gain weight or prevent weight loss. It is annoying to be told to lose weight then [get] handed a drug that prevents weight loss.”<sup>20</sup> People with T2DM also voiced a preference for medications that did not cause fluid retention, which can lead to swelling and weight fluctuations.<sup>28,30-36</sup>

#### ***Gastrointestinal and Urogenital Side Effects***

People living with T2DM desired medications that did not cause gastrointestinal side effects, including nausea, vomiting, abdominal and gas pain, diarrhea, and constipation.<sup>20,23,24,26,28,30-35</sup> When describing the impact of gastrointestinal side effects on their life, 1 person living with T2DM said, “If I had known the pill was going to make me this sick (vomiting and diarrhea for two months) I never would have started it...I don’t leave the house. I don’t eat. I don’t enjoy food anymore. I am angry and irritable. My [spouse] is worried and tired.”<sup>34</sup> People living with T2DM also frequently noted a desire to avoid urogenital side effects, including urinary frequency, urinary tract infections, and yeast infections.<sup>20,28,30-36</sup>

## Treatment Considerations Important to People Living With Type 2 Diabetes

In addition to noting preferred and nonpreferred outcomes, patient input also detailed treatment considerations related to the context and process of accessing and engaging with drug therapies most important to people with T2DM. Specifically, they accentuated the need to increase access to and affordability of drugs, the importance of respect and effective communication in therapeutic and interprofessional relationships, the need to provide and enhance knowledge to support informed decisions, and the importance of offering individualized treatment plans and a variety of choices.

### The Need for Increased Access to and Affordability of Medications

All patient inputs emphasized barriers to accessing and affording optimal treatments for T2DM.<sup>20,23-36</sup> Many people with T2DM voiced concern that their GPs lacked the knowledge required to manage their condition, with some noting improvements only after receiving care through an endocrinologist.<sup>25,28,30,32,34</sup> Relatedly, people with T2DM noted the potential benefit of receiving care from allied health care professionals and multidisciplinary care teams with specialized knowledge about the treatment of the condition.<sup>25,33,34</sup> However, only those who knew how to get a referral and lived in geographic proximity could access such services, putting those in rural and remote communities at a disadvantage.<sup>25,30,33</sup> People living with T2DM noted that the inability to access health care professionals with specialized knowledge about T2DM often meant being unable to access optimal or novel drug therapies.<sup>25,30,34</sup>

Patient input also stressed that the cost of T2DM medications limited the ability to access optimal treatment for the condition, especially for those without private insurance.<sup>20,23-28,30-36</sup> Some people with T2DM noted their insurance was “capped,” and many felt they would be unable to access their drugs if they suddenly lost private insurance coverage.<sup>25,28,32-34</sup> In the context of high medication costs and other economic burdens associated with T2DM, some people reported taking lower or fewer doses, skipping blood glucose checks or reusing lancets, or choosing between medications and other basic needs.<sup>25,30,33,35</sup> Some had to settle for using nonpreferred or less effective medications when insurance did not cover preferred medications.<sup>25,29,30,33,36</sup>

Many people with T2DM voiced frustration with feeling left out of decisions regarding drug reimbursement.<sup>30,33,34,36</sup> As 1 person voiced, “My biggest frustration with our health care system is that the person with the least decision-making power is me, the patient... it stems from a system that values my life less because of diabetes.”<sup>30</sup> To reduce inequities in accessing and safely using medications, patient input emphasized the need for cheaper drugs approved by public and private insurance in a timely manner.<sup>20,23-36</sup>

### Respect and Effective Communication in Therapeutic and Interprofessional Relationships

Patient input emphasized the importance of therapeutic and interprofessional relationships characterized by respect and effective communication in accessing treatments for T2DM.<sup>30,33,34</sup> Some people living with T2DM perceived a lack of respect and genuine concern from their health care providers, with 1 person reporting feeling they were “being treated on an assembly line.”<sup>30,33,34</sup> Some people with T2DM had experiences in which health care providers incorporated shame, blame, or threats into clinical encounters.<sup>25,30,33,34</sup> Disrespect within the therapeutic relationship could result in people with T2DM wanting to avoid getting treatment. As 1 person with T2DM described, “Having too many doctors and health care practitioners

treat us as lying, lazy, gluttonous trash is demeaning and insulting. It's depressing and makes us avoid health care [sic] options for even non-dietary issues."<sup>34</sup>

Input also noted the importance of effective communication within therapeutic and interprofessional relationships. People with T2DM found it crucial for health care providers to confirm that patients understand information provided to them, as some may not understand medical jargon and may tend to retain only negative news in the context of hurried medical appointments.<sup>33,34</sup> They also reported frustration caused by ineffective communication between health care providers.<sup>30,33,34</sup> This resulted in confusion when different providers gave conflicting instructions and disjointed care when specialists were unwilling to share information with GPs, and vice versa.<sup>30,33,34</sup> For example, a lack of interprofessional communication deterred 1 person with T2DM from continuing care in an endocrinology clinic, even though they had concerns about their GP's ability to manage their condition.<sup>34</sup>

### Knowledge Needed to Support Decisions About and Use of Medications

People with T2DM wanted to be active in treatment decisions and emphasized the need for knowledge about their options to do so in an informed manner.<sup>24,25,29,30,35</sup> To make informed decisions, people with T2DM reported wanting to know about a medication's mechanism of action, source, side effects, benefits and risks compared to similar options, efficacy and safety, monitoring requirements, cost, and insurance coverage.<sup>29</sup> Some wanted to know about the experiences of others who had taken a medication and whether their provider trusted it.<sup>29,35</sup> People living with T2DM considered health care providers valuable sources of this information.<sup>25,30,33-36</sup> They emphasized the importance of ensuring these professionals had access to and knowledge about evidence-based therapies and best practice guidelines.<sup>25,30,33-36</sup>

However, some people with T2DM reported that obtaining information from health care providers could be challenging because they lacked the health literacy, baseline knowledge, or medical vocabulary to ask appropriate questions and understand what was said.<sup>33</sup> One person with T2DM reported taking notes during clinical encounters and researching information on the internet afterwards to gain this understanding.<sup>33</sup>

Some people with T2DM also reported lacking the knowledge necessary to administer medications or monitor and manage side effects safely.<sup>25,28,30,32-34</sup> In some cases, this lack of knowledge could stem from the inability to access education after being prescribed a medication or using faulty equipment to monitor blood glucose levels.<sup>25,28,30,32-34</sup> Lacking reliable information to guide drug administration and interventions for side effects could be dangerous for people living with T2DM. As 1 person noted, "A false high when I am actually low can result in me injecting insulin causing a hypo[glycemic event]. And if I am low and the meter says I am fine I can place myself at risk for a hypo[glycemic event]...having to take 3 tests just to get one confident reading, that is crazy."<sup>25,30</sup>

### The Importance of Individualized Treatment Plans and a Variety of Choices

While many people living with T2DM were generally satisfied with their current medication's ability to manage their blood glucose levels, patient input emphasized the importance of increasing the number of novel, safe, and effective therapies available.<sup>20,23-36</sup> Inputs noted that optimal blood glucose levels vary between 1 person and the next, and no drug is experienced positively or negatively by all people taking it.<sup>20,23-36</sup> They noted that an individual's preference for and tolerance of a drug is dependent on a variety of factors, including their experiences (or not) of desirable outcomes, tolerance and acceptance of undesirable outcomes, capacity to engage in activities for administration and monitoring, and ability to

access and afford the medication.<sup>20,23-36</sup> For this reason, patient input emphasized the need to tailor pharmacological treatments to each individual's needs, desires, and preferences.<sup>20,23-36</sup> Patient input consistently noted that maximizing choices available to people living with T2DM would increase the likelihood that each person could find and access their optimal treatment regimen and experience an improved quality of life.<sup>20,23-36</sup>

## Discussion

The narrative description presented in this report details the content of 20 patient input submissions reporting the perspectives of people living with or caring for a loved one with T2DM in Canada. These patient inputs emphasized that T2DM demands intensive self-management that profoundly impacts the physical, psychosocial, and economic well-being of those living with it. The inputs described how people living with T2DM want a cure for the condition and desire treatments that reduce the risk of hyperglycemia and its complications; facilitate weight loss; and improve mental state, focus, and energy levels. People living with T2DM also desire treatments that can lessen the burden of medication administration; reduce the need for blood glucose checks, injections, and insulin; and promote a return to normalcy. Additionally, they wish for medications that cause few to no adverse effects, especially hypoglycemia, weight gain, and gastrointestinal and urogenital side effects.

Past patient input also emphasized the need to increase access to and affordability of T2DM treatments in Canada. Regarding the contexts in which people living with T2DM access and use medications, patient input stressed the importance of respect and effective communication in therapeutic and interprofessional relationships, the need to provide and enhance knowledge to support informed decisions about and the safe use of medications, and the importance of offering people with T2DM individualized treatment plans and a variety of choices.

In its 2022–2025 Strategic Plan,<sup>39</sup> CADTH committed itself to the guiding principle of *partnership*. With this commitment, it announced that it would aspire to cultivate meaningful relationships with patient communities to improve and strengthen the quality and significance of its work. Patient groups have emphasized that producing input submissions demands significant time and often requires diverting their finite resources away from core programming, direct service to patients, and fundraising.<sup>40</sup> During the creation of this report, patient group representatives noted that such time constraints limit their capacity to obtain and report new data that meaningfully capture the perspectives of equity-deserving groups and previously unreported treatment outcomes and considerations important to patients. For this report, the team conceptualized equity-deserving groups as those experiencing differences in the experience of T2DM or in accessing, using, and physically or psychosocially benefiting from therapies used to manage it due to disparities in historical, social, institutional, and environmental disadvantage and discrimination. In the input narratively described in this report, patient groups reported limited demographic information on the people they surveyed and interviewed; however, the information they did report suggested that the perspectives of these groups were underrepresented or missing.

This report begins to explore an alternative way to approach patient input that considers these concerns. Specifically, it provides an example of how treatment outcomes and considerations important to patients can be explored outside of the time constraints

of Reimbursement Reviews for specific drugs while still having the capacity to inform such reviews.

CADTH's 2022–2025 Strategic plan also presents a commitment to the guiding principles of *equity, diversity, and inclusion*.<sup>39</sup> In doing so, it is seeking to apply a lens of equity and inclusiveness to its work to foster a health care system that reflects the diverse needs of people living in Canada and respond to the self-identified priorities and cultural practices of First Nations, Inuit, and Métis Peoples.<sup>39</sup> CADTH's Patient and Community Advisory Committee (PCAC), however, has noted that voices of equity-deserving persons are often missing or underrepresented in patient input informing CADTH Reimbursement Reviews. The voices of members of equity-deserving groups missing or underrepresented in past patient input include but are not limited to those of Black people, Indigenous people, and other people of colour; people living with low income and poverty; those living in rural and remote communities; adolescents and adults aged 25 years or younger; and members of the LGBTQ2S+ community.<sup>41</sup> Considerations specific to these groups may provide unique and nuanced insights uncaptured in previous input, which may add to the diversity of needs and desires identified in the narrative description provided in this report.

Acknowledging that the voices of equity-deserving groups living with T2DM in Canada were underrepresented or missing from past input, this discussion section aims to offer initial insights from the literature into how the treatment outcomes and considerations narratively described may differ from those important to these groups or carry additional meaning or significance to them. This discussion section cannot and does not intend to replace the work of actively engaging the voices of members of equity-deserving groups that remains necessary and important. It also does not serve as a comprehensive review of the literature on the perspectives of these groups. The discussion will close with a description of the strengths and limitations of this report and its potential use by CADTH, other health technology assessment bodies, researchers in academia and industry, and patient groups.

## Treatment Outcomes Discussed in the Literature

Researchers have found that incorporating the preferences that people living with T2DM have regarding their care into treatment plans supports the appropriate and effective management of the condition.<sup>42,43</sup> Additionally, the number of studies investigating these preferences has increased over the past decade.<sup>44</sup> A focused review of some of this literature exploring the treatment preferences and experiences of people living with T2DM reveals similar findings to those identified in past patient input received by CADTH for Reimbursement Reviews. Several published studies support the finding that people living with T2DM desire or positively experience treatments that mitigate or reduce the risk of hyperglycemia and its complications, facilitate weight loss, improve mental state, reduce the burden of medication administration, decrease the need for invasive interventions and insulin, and promote a return to normalcy and flexibility.<sup>9,45-51</sup> Research also supports the understanding that people with T2DM desire medications that cause minimal or no adverse effects, especially hypoglycemia, weight gain, gastrointestinal side effects, and urogenital side effects.<sup>45-54</sup>

As previously noted, understanding the treatment outcomes most important to equity-deserving groups in Canada specifically may allow for new and nuanced insights into unique perspectives and needs possibly missing from past patient input. Preliminary engagement with the literature reveals a paucity of research explicitly investigating these groups' treatment preferences and experiences. However, the more abundant literature detailing their experiences living with and managing T2DM, some of which is discussed below, can

provide insight into how these groups might appraise or ascribe meaning and significance to treatment outcomes identified as important in past input.

### **Inequities in the Experience, Management, and Outcomes of T2DM**

Patient input provided to CADTH noted the profound and usually negative impact that T2DM has on people's physical, psychosocial, and economic well-being. The input also described how treatment outcomes important to people with T2DM were significant because they could lessen or mitigate these negative impacts. When considering these findings, it is important to note that members of equity-deserving groups, including Black people, Indigenous people, and other people of colour; those living with poverty or low income; those with lower health literacy or educational attainment; and newcomers to Canada are disproportionately at risk of experiencing T2DM and adverse outcomes related to it.<sup>55-58</sup> The causes of these disparities are complex, but for Black people, Indigenous people, and other people of colour specifically, they have been linked to and perpetuated by colonial policies and practices, including systemic oppression, forced relocation, forced assimilation, and institutionalized racism, which influence and are experienced simultaneously with barriers to engaging in self-management.<sup>59,60</sup> A preliminary and not comprehensive review of the literature reveals limited research exploring the prevalence and experience of T2DM by members of the LGBTQ2S+ community in Canada. However, researchers have identified that cis-heteronormative policies and practices create barriers to LGBTQ2S+ people accessing appropriate housing, employment, and health care, which in turn places them at a disproportionate risk of experiencing chronic health conditions and adverse outcomes.<sup>61-63</sup>

The challenges engaging in self-management activities detailed in past patient input may be magnified for people belonging to equity-deserving groups in Canada. First, people with language barriers, people with low health or food literacy, and people living in rural or remote communities with limited health care resources may lack access to appropriate sources of knowledge about what to do for self-management.<sup>64-68</sup> As emphasized in past input, however, knowing what to do is often insufficient. Self-management instructions informed by the paradigm of Western ideals, for example, may be culturally inappropriate for many equity-deserving groups, especially since preparing and eating traditional foods can be an important way of maintaining cultural identity, membership, and social well-being.<sup>46,64,69-72</sup> The stress and reality of living with and responding to poverty, discrimination, and violence may also divert attention and resources away from self-management.<sup>64,73-75</sup> Additionally, adolescents people living in poverty, and those with severe mental illness may depend on others (e.g., caregivers) or social services (e.g., institutions or food banks) for basic necessities, resulting in less control over the planning and timing of meals and exercise.<sup>46,64,66,73,75-78</sup> People living in rural and remote communities may similarly have limited power to engage in self-management, sometimes lacking the time or reliable and affordable transportation necessary to access foods or exercise facilities unavailable in their community.<sup>67,68</sup>

Ideally, policies and practices would address social and structural barriers contributing to these disparities. In the meantime, however, pharmacological treatment outcomes noted to improve quality of life may carry additional significance to groups who may be more at risk of experiencing T2DM and its adverse effects while having less capacity to manage it without medications.

### **The Significance of Treatment Outcomes as Context-Dependent**

When appraising the significance of treatment outcomes, it is also important to consider how the individual contexts within which people belonging to equity-deserving groups experience

T2DM will mediate the value they ascribe to them. In their study exploring the experiences of adults with diabetes through an intersectional lens, Jones et al.<sup>79</sup> found that disclosure of a diabetes diagnosis could be especially anxiety-provoking and, in some cases, detrimental to people living with multiple marginalization. Treatment outcomes potentially outing people as living with T2DM may have significant implications in these contexts. In Jones et al.'s study, for example, 1 woman experiencing compound workplace discrimination due to her race, language, and gender described feeling the need to delay responding to hypoglycemia while at work.<sup>79</sup> In the context of the compound discrimination she experienced, she feared that she was at an especially high risk of losing her job if others perceived her as inefficient or underperforming.<sup>79</sup>

Relatedly, since the value people ascribe to treatment outcomes is influenced by individually experienced contexts, not all members of equity-deserving groups will attribute the same significance to outcomes like a reduced risk of complications. In their study on adolescents living with T2DM in the UK, for example, Turner et al.<sup>46</sup> found that some were not surprised by their T2DM diagnosis nor particularly concerned about potential future complications, especially if their parent had the condition. These findings contrasted those of Wicklow et al.,<sup>78</sup> who studied the experiences of First Nations adolescents living with T2DM in Winnipeg, Manitoba. These adolescents often experienced their diagnosis as shocking and distressing, partially due to their experiential knowledge gained from bearing witness to family members experiencing complications, including infections, the loss of limbs, and kidney damage requiring dialysis. This emphasizes the need to consider an individual's social and experiential realities when offering medications with particular treatment outcomes.

## Treatment Considerations Discussed in the Literature

The processes and contexts of treatment important to people living with T2DM identified in past input may also have different implications and significances for people belonging to equity-deserving groups in Canada.

### Disparities in Access to T2DM Treatment

Some equity-deserving groups may experience additional barriers to accessing pharmacological treatments than the general population. As stated in past input and supported by the literature, people living in rural and remote communities may lack geographic proximity to specialists, live in communities with shortages and poor retention of health care providers, and lack affordable or convenient transportation to medical appointments.<sup>67,68,71</sup> For Black people, Indigenous people, and other people of colour with T2DM, systemic racism within the health care system may result in delayed, denied, or inadequate care.<sup>71,80,81</sup> Jacklin et al.,<sup>71</sup> for example, found that Indigenous people living with T2DM in Canada experienced instances where providers wrongfully assumed their symptoms of hyperglycemia were associated with substance use, implied that they were not "real patients," did not explain why they did not perform planned interventions, and condescendingly enforced policies denying family member presence or participation in ceremony at the bedside.<sup>71</sup>

Being at a higher risk of unemployment or underemployment,<sup>82,83</sup> some equity-deserving groups may also be less likely to have adequate private insurance, which may limit their choice of medications. Even when accessing drugs through public insurance, people living in poverty may experience barriers to taking medications as prescribed or monitoring their effects. These obstacles include engaging in irregular shift work, being unable to access

foods required to take medications with, and being unable to afford noninsured supplies for blood glucose monitoring.<sup>67,84</sup> Of note, low socioeconomic status and the absence of supplemental, private insurance increase the likelihood that people may skip medications or blood glucose tests or reuse testing supplies, which may place them at greater risk of not benefiting from or experiencing adverse treatment outcomes.<sup>67,84-87</sup> Interventions seeking to enhance access to pharmacological therapies for all persons with T2DM, as called for in the narratively described patient input, could consider these barriers to not further accentuate disparities in T2DM outcomes experienced by these groups.

### Respect, Power, and Knowing in the Context of T2DM Treatment

Like those contributing data to past patient input, people with T2DM belonging to equity-deserving groups in Canada have also emphasized the need for health care providers to avoid incorporating stigma, shame, and blame into clinical encounters.<sup>9,69,71,76</sup> People from equity-deserving groups desire therapeutic relationships fostering meaningful, caring, and reciprocal interactions whereby providers acknowledge and respect their humanity and focus on their overall well-being rather than only blood glucose levels and physical health.<sup>9,69,71,76</sup> In the context of the legacy of colonialism in Canada, disrespect in the therapeutic relationship may be particularly harmful. Indigenous people, for example, have voiced how being treated as “somebody on an assembly line,” being ordered what to do, or being subjected to unnecessary medical testing can serve as reminders of dehumanizing and traumatic colonial practices, such as residential schools and tuberculosis sanatoriums, which can make them want to avoid the health care system.<sup>71</sup>

The narratively described patient input also noted that people living with T2DM consider the therapeutic relationship a valuable source of information required for making informed decisions about drug treatments. Considering this finding, providers caring for members of equity-deserving groups may consider remaining cognizant of how power imbalances, disease minimization, and medical jargon may limit the exchange of information during clinical encounters.<sup>88</sup> An awareness of power imbalances within the therapeutic relationship may be especially important for providers caring for individuals with a history of personal or intergenerational trauma related to authority figures or the health care system.<sup>60</sup> Additionally, providers may consider how those seeking health care or using monitoring devices in their nonpreferred language may need additional support to understand the information required to choose and respond to the effects of treatments.<sup>65,70</sup> By attending to these considerations regarding thoughtful and appropriately tailored communication in clinical contexts, providers can better ensure that all people with T2DM have the knowledge and power to actively and safely engage in treatment.

Relatedly, the literature on equity-deserving groups in Canada emphasizes the importance of providers acknowledging, understanding, and respecting how the worldviews and knowledge of the people in their care may differ from their own.<sup>60,69-72,89</sup> Some people living with T2DM belonging to groups that have held, practised, and mastered traditional healing and knowledge since time immemorial may be hesitant to adopt or trust Western medicines.<sup>49,60,69,89</sup> Sherifali et al.,<sup>69</sup> for example, found that First Nations people often desired to turn to traditional and community-based approaches to healing, which they believed could fulfill their spiritual, physical, and mental needs in ways Western medicine could not. Of note, clinicians may consider using guides such as the Educating for Equity Care Framework to facilitate structural competency and cultural safety when negotiating the management for T2DM with equity-deserving groups in their care.<sup>60,90</sup>

As outlined in this discussion, it is more difficult to appraise whether the treatment outcomes and considerations reported in the narrative description are those most important to equity-deserving groups in Canada whose voices were missing from past input (refer to Strengths and Limitations). This discussion section provided initial insights into how equity-deserving groups may ascribe meaning and significance to the outcomes and considerations detailed in the narrative description.

## Strengths and Limitations

The CADTH research team adopted qualitative best practices and close collaboration with patient groups to narratively describe past patient inputs provided for CADTH Reimbursement Reviews. As previously discussed, this learning project also provided an opportunity for CADTH to explore patient input in a new but rigorous way outside of the time constraints of Reimbursement Reviews for specific drugs.

Still, the resulting narrative description has some limitations. CADTH's patient input template prompts patient groups to report how they collected their data and from whom, but not how they collated it. This may explain why most patient input did not provide information about approaches or methods used for data analysis. Additionally, past patient inputs offered limited demographic information about the people from whom data were collected, especially regarding race/ethnicity, rurality, socioeconomic status, and health literacy levels. Understanding this background would allow for greater insight into the diversity and nuance of the experiences, outcomes, and considerations reported as important to people living with T2DM in Canada.

The demographic information reported in past patient inputs, however, suggests that voices from equity-deserving groups in Canada were missing or underrepresented in them. Active engagement with equity-deserving groups remains important and necessary. While comprehensive reviews of the literature examining treatment outcomes and considerations most important to equity-deserving groups—which may be conducted by researchers in the future—cannot replace active engagement, such reviews may be considered alongside available patient input to allow for insight into diverse perspectives during Reimbursement Reviews and deliberation.

Even despite these considerations, findings from the extant literature align with those detailed in this narrative description of patient input, with some also voicing the views and perspectives of those living in Canada,<sup>9,45-54</sup> supporting the potential transferability and relevance of the narrative description to the broader Canadian population.

## Potential Uses of This Report

CADTH staff may use this narrative description of patient input to inform treatment outcomes and considerations of focus in Reimbursement Reviews. Researchers external to CADTH working in industry and academia may also use this narrative description of past patient input to ensure that they consider and incorporate treatment outcomes and considerations most important to Canadians living with T2DM into the creation and assessment of new medications.

CADTH's calls for patient input to inform Reimbursement Reviews on drugs treating T2DM will continue. In the future, however, patient groups may choose to use this narrative description to allocate their resources toward producing submissions that include novel,

previously uncaptured information to mitigate some of the burden associated with repeated calls for input in this disease space. Focusing resources on capturing and reporting additional information will improve the diversity of patient input received for Reimbursement Reviews. This information may detail the perspectives and experiences of equity-deserving groups whose voices were underrepresented in past input; additional treatment outcomes and considerations important to people living with T2DM not captured in past input; and experiences and preferences that people living with T2DM have regarding specific medications under review.

Finally, creating this report served as a learning opportunity that may inform other compilations of past patient input for other chronic conditions created in collaboration with patient groups. As previously detailed, it also provided an opportunity for CADTH to explore how patient input could be examined, compiled, and perhaps collected outside of the time constraints of Reimbursement Reviews while still producing a product that can inform such reviews.

## Conclusion

Patient input that CADTH received on drugs treating T2DM emphasized that the condition demands intensive, perpetual, and sometimes impossible self-management activities, and has a profound impact on the physical, psychosocial, and economic well-being of people living or caring for someone with it. People living with T2DM wanted a cure for the condition. To improve their quality of life in the meantime, however, they desired or positively experienced treatments that mitigated or reduced the risk of hyperglycemia and its complications; facilitated weight loss; and improved mental state, focus, and energy levels. They reported a strong preference for therapies that could lessen the burden of medication administration by reducing polypharmacy and dose frequency and having formulations that are easily stored, prepared, and administered. They also desired medications that could minimize or eliminate the need for invasive procedures such as blood glucose checks and injections and wished to avoid having to take insulin. Overall, they hoped medications could facilitate a return to normalcy and the flexibility to eat and do what they wanted when they wanted. They broadly wanted these medications to cause little or no adverse effects, emphasizing hypoglycemia, weight gain, and gastrointestinal and urogenital side effects as particularly undesirable treatment outcomes.

Patient input also emphasized the need to increase access to and the affordability of pharmacological treatments in Canada through specialists trained in the management of T2DM and the provision of cheaper therapies promptly approved by private and public insurance. They also emphasized the importance of therapeutic and interprofessional relationships founded on respect and effective communication. They identified the need to provide people with T2DM the knowledge needed to make informed and safe decisions about their treatment and its management. Finally, they noted the importance of creating individually tailored treatment plans and a variety of medication choices for all people living with the condition.

The treatment outcomes and considerations emphasized in patient input received by CADTH may carry additional meaning and significance to those belonging to equity-deserving groups in Canada. Future inquiry and active engagement conducted by CADTH, other health

technology assessment bodies, patient groups, researchers working in industry or academia, and health care providers may focus on learning about the perspectives and preferences of groups whose voices may have been underrepresented in past input. These voices include but are not limited to those of Black people, Indigenous people, and other people of colour; people living with low income or poverty; those living in rural or remote communities; adolescents and adults aged 25 years or younger; and members of the LGBTQ2S+ community.

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## Appendix 1: Surveys Conducted by Diabetes Canada

Note that this appendix has not been copy-edited.

**Table 2: Description of Patient Surveys Informing Input Submitted by Diabetes Canada**

Survey date	Submission brand name	Recruitment method
2013 <sup>a</sup>	Komboglyze	<ul style="list-style-type: none"> <li>Physicians who were involved with the clinical trials for Komboglyze in Canada were sent an email request to forward a survey to patients enrolled in their clinical trials or those that they see in their offices</li> <li>Social Media (Facebook and Twitter)</li> </ul>
2014 <sup>a</sup>	Kazano Invokana	<ul style="list-style-type: none"> <li>Social media (platforms not specified)</li> <li>Email blasts</li> </ul>
October 2016	Adlyxine Admelog Segluromet Ozempic Soliqua Steglatro Xultophy Rybelsus	<ul style="list-style-type: none"> <li>Social media (Facebook, Twitter, and LinkedIn)</li> <li>Email blasts</li> </ul>
June 2017	Adlyxine Tresiba	<ul style="list-style-type: none"> <li>Social media (platforms not specified)</li> <li>Email blasts</li> </ul>
October 2017	Admelog	Not described
April 2018	Soliqua	Not described
April/May 2018	Segluromet Steglatro	Social media (Facebook and Twitter)
November 2018	Semglee	Not described
November/December 2018	Ozempic Rybelsus	Social media (Facebook and Twitter)
January/February 2019	Xultophy	Social media (Facebook and Twitter)
November 2019	Rybelsus	Not described
July/August 2020	Rybelsus	<ul style="list-style-type: none"> <li>Social media (Facebook, Instagram, and LinkedIn) in conjunction with the JDRF and Type 1 Together</li> <li>Email to Diabetes Canada volunteer advocates</li> </ul>
November/December 2020	Rybelsus	<ul style="list-style-type: none"> <li>Social media (Facebook, Twitter, and LinkedIn)</li> <li>Email to members of the Diabetes Canada Professional Section</li> </ul>

Survey date	Submission brand name	Recruitment method
January/February 2021	Entuzity Kwikpen	<ul style="list-style-type: none"> <li>• Social media (Facebook, Twitter, and LinkedIn)</li> <li>• Email to members of the Diabetes Canada Professional Section</li> <li>• Post on the health care professional discussion platform TimedRight</li> </ul>
July/August 2022	Mounjaro	<ul style="list-style-type: none"> <li>• Social media (Facebook and Twitter)</li> <li>• Health care provider's online discussion forum (Diabetes Canada's Professional Section)</li> </ul>

JDRF = Juvenile Diabetes Research Foundation.

\*Month not reported.

Table 3: Number of Survey Respondents by Condition Type

Survey date	Submission brand name	Diabetes type surveyed	Total number of respondents	Number of respondents living with T1DM (%)	Number of respondents living with T2DM (%)	Number of respondents who were caregivers (%)	"Other" respondents (%)
2013 <sup>a</sup>	Komboglyze	T1DM and T2DM	232	6 (2.7)	204 (87.9)	14 (6.1)	8 (3.4)
2014 <sup>a</sup>	Kazano Invokana	T1DM and T2DM	388	19 (4.9)	360 (92.7)	16 (4.1)	10 (2.6)
October 2016	Adlyxine Admelog Segluromet Ozempic Soliqua Steglatro Xultophy Rybelsus	T2DM	847	0	790 (93.3)	57 (6.7)	0
June 2017	Adlyxine <sup>b</sup> Tresiba	T1DM and T2DM	329 <sup>c,d</sup>	52 (15.8) <sup>d</sup>	185 (56.2) <sup>d</sup>	19 (T2DM) <sup>d</sup> (5.8) 19 (T1DM) <sup>d</sup> (5.8)	0
October 2017	Admelog	T1DM and T2DM	37	16 (43.2)	16 (43.2)	5 (13.5)	0
April 2018	Soliqua	T2DM	12	0	11 (91.6)	1 (8.3)	0
April/May 2018	Segluromet Steglatro	T2DM	52	0	47 (90.4)	5 (9.6)	0
November 2018	Semglee	T1DM and T2DM	50	32 (64.0)	6 (12.0)	12 (24.0)	0
November/December 2018	Ozempic Rybelsus	T2DM	15	0	13 (86.7)	2 (13.3)	0

Survey date	Submission brand name	Diabetes type surveyed	Total number of respondents	Number of respondents living with T1DM (%)	Number of respondents living with T2DM (%)	Number of respondents who were caregivers (%)	"Other" respondents (%)
January/February 2019	Xultophy	T2DM	9	0	9 (100.0)	0	0
November 2019	Rybelsus	T2DM	20	0	19 (95.0)	1 (5.0)	0
July/August 2020	Rybelsus	T1DM and T2DM	873	NR	36 (4.1)	4 (0.4)	NR
November/December 2020	Rybelsus	T2DM	15	0	13 (86.7)	2 (13.3)	0
January/February 2021	Entuzity Kwikpen	T1DM and T2DM	48	26 (54.2)	19 (39.6)	3 (6.3)	0
July/August 2022	Mounjaro	T2DM	20	0	18 (90.0)	2 (10.0)	0

NR = not reported; T1DM = type 1 diabetes mellitus; T2DM = type 2 diabetes mellitus.

<sup>a</sup>Month not reported.

<sup>b</sup>In the Adlyxine submission, only responses for people living with type 2 diabetes and their caregivers were included.

<sup>c</sup>There was a discrepancy between the total number of respondents reported for the June 2017 survey between Diabetes Canada's submission for Adlyxine (202 respondents reported) and Tresiba (329 respondents reported).

<sup>d</sup>Based on numbers reported in the Tresiba submission.

Table 4: Survey Respondent Condition and Treatment History

Survey date	Submission brand name	Number of respondents reporting disease experience	Disease experience (years living with diabetes)	Number of respondents reporting current medication use	Current medication use
2013 <sup>a</sup>	Komboglyze	NR	NR	NR	DPP-4 inhibitors: 26
2014 <sup>a</sup>	Kazano Invokana	NR	NR	350 <sup>b</sup>	DPP-4 Inhibitors: 27% (n = 14) Metformin (Kazano): 8.5%
October 2016	Adlyxine Admelog Segluromet Ozempic Soliqua Steglatro Xultophy Rybelsus	NR	> 10: 60% > 20: 17%	647	Metformin: 371 GLP-1 receptor agonists: 312 SGLT2 inhibitors: 165 Combination of SGLT2 inhibitors with metformin: 45 DPP-4 inhibitors: 72 Combination of DPP-4 inhibitors and metformin: 147 Sulfonylureas: 140 TZDs: 10 Combination of TZDs with metformin: 17 Combination of TZDs with glimepiride: 4 Meglitinides: 9 Acarbose: 9 Insulin: 309
June 2017	Tresiba Adlyxine <sup>b</sup>	158	1 to 2: 5% 3 to 5: 10% 6 to 10: 14% 11 to 20: 14% More than 20: 36%	—	Metformin: 87 GLP-1 agonist: 12 SGLT-2 inhibitor: 25 Combination of SGLT-2 inhibitor with metformin: 6

Survey date	Submission brand name	Number of respondents reporting disease experience	Disease experience (years living with diabetes)	Number of respondents reporting current medication use	Current medication use
					DPP-4 inhibitor: 13 Combination of DPP-4 inhibitor and metformin: 19 Sulfonylurea: 30 TZD: 3 TZD with metformin: 6 TZD with Amaryl: 3 TZD with DPP-4 inhibitor: 2 Meglitinide: 3 Acarbose: 3 Orlistat: 4
October 2017	Admelog	27	<1: 7% 1 to 10: 30% 11 to 20: 26% More than 20: 37%	28	Insulin Lispro: 16 Insulin Glulisine: 1 Insulin Aspart: 11 (Survey focused on rapid-acting insulin analogues)
April 2018	Soliqua	2	<1: 1 6 to 10: 1	3	Metformin: 3 GLP-1 receptor agonists: 1 SGLT2 inhibitors: 1 DPP-4 inhibitors: 1 Sulfonylureas: 1 Long-acting insulin glargine: 1 Rapid-acting insulin: 1
April/May 2018	Segluromet Steglatro	15	≥ 6: 67% 11 to 20: 40% > 20: 7%	21	Metformin: 13 GLP-1 receptor agonists: 4 SGLT2 inhibitors: 10

Survey date	Submission brand name	Number of respondents reporting disease experience	Disease experience (years living with diabetes)	Number of respondents reporting current medication use	Current medication use
					DPP-4 inhibitors: 1 Combination of DPP-4 inhibitors and metformin: 6 Sulfonylureas: 1 Combination of TZDs and glimepiride: 1 Long-acting insulin: 13 Combination of long-acting (insulin glargine) and SGLT2 inhibitors: 2 Intermediate-acting insulin: 2 Rapid-acting insulin: 6 Premixed: 1
November 2018	Semglee	NR	NR	NR	Insulin Glargine: 13
November/December 2018	Ozempic	6	> 6: 67%	6	Metformin: 3 GLP-1 receptor agonists: 3 SGLT2 inhibitors: 2 DPP-4 inhibitors: 2 Combination of DPP-4 inhibitors and metformin: 1 Sulfonylureas: 1 Insulin glargine or insulin glargine biosimilar: 2 Insulin glargine U300 or other long-acting insulin: 1 Intermediate-acting insulin: 2
January/February 2019	Xultophy	5	3 to 5: 2 11 to 20: 3	5	Metformin: 4 GLP-1 receptor agonists: 1 Combination of DPP-4 inhibitors and metformin: 1

Survey date	Submission brand name	Number of respondents reporting disease experience	Disease experience (years living with diabetes)	Number of respondents reporting current medication use	Current medication use
					Sulfonylureas: 1 Meglitinides: 1 Orlistat: 1
November 2019	Rybelsus	8	1 to 10: 50% 11 to 20: 50%	11	GLP-1 receptor agonist: 4 DPP-4 inhibitor: 2 DPP-4 inhibitor combined with metformin: 1 SGLT2 inhibitor: 5 Sulfonylurea: 1 Metformin: 6 Meglitinide: 1 Insulin: 7 Semaglutide: 3
July/August 2020	Rybelsus	36	11 to 20: 16 >11: 21	NR	NR
November/December 2020	Rybelsus	13	3 to 5: 40% < 20: 100%	13	Metformin: 91% SGLT2 inhibitors: 44% GLP-1 receptor agonists: 38% Sulfonylureas: 29% Combination of DPP-4 inhibitors and metformin: 22% DPP-4 inhibitors: 17% Insulin glargine or insulin glargine biosimilar: 50% Rapid-acting insulin: 38%

Survey date	Submission brand name	Number of respondents reporting disease experience	Disease experience (years living with diabetes)	Number of respondents reporting current medication use	Current medication use
					Intermediate-acting insulin: 13% Insulin glargine U300/other long-acting insulin: 11%
January/February 2021	Entuzity KwikPen	48	1 to 10: 27% 11 to 20: 31% > 20: 42%	NR	NR
July/August 2022	Mounjaro	NR	1 to 10: 65% 11 to 20: 25% > 20: 10%	NR <sup>c</sup>	Insulin (glargine U300/other long-acting, short-acting, and rapid-acting): NR GLP-1 receptor agonists and GLP-1 receptor agonists/metformin combination: NR DPP-4 inhibitor/metformin combination: NR SGLT2 inhibitors and SGLT2 inhibitors/metformin combination: NR TZD/metformin combination: NR Sulfonylureas: NR Metformin: NR

DPP-4 = dipeptidyl peptidase-4; GLP-1 = glucagon-like peptide-1; NR = not reported; SGLT-2 = sodium-glucose cotransporter-2; TZD = thiazolidinedione.

<sup>a</sup>Month not reported.

<sup>b</sup>Did not distinguish between current and past use.

<sup>c</sup>These medications were listed as currently taken by survey respondents, but specific numbers were not reported.

Table 5: Age of Survey Respondents

Survey date	Submission brand name	Total number of survey respondents	Total number of respondents who reported age	Age ranges	
				Range (years)	%
2013 <sup>a</sup>	Komboglyze	232	NR	NR	NR
2014 <sup>a</sup>	Kazano Invokana	388	NR	NR	NR
October 2016	Adlyxine Admelog Segluromet Ozempic Soliqua Steglatro Xultophy Rybelsus	847	379	Older than 55	70%
				55 to 69	56%
June 2017	Adlyxine Tresiba	329	158 <sup>b</sup>	Under 24	5%
				25 to 39	7%
				40 to 54	13%
				55 to 69	37%
				Older than 70	37%
October 2017	Admelog	37	27	Older than 25	89%
				25 to 39	26%
				40 to 54	33%
April 2018	Soliqua	12	2	25 to 55	100%

Survey date	Submission brand name	Total number of survey respondents	Total number of respondents who reported age	Age ranges	
				Range (years)	%
April/May 2018	Segluromet Steglatro	52	NR	40 to 54	33%
				40 to 54	60%
November 2018	Semglee	50	NR	NR	NR
November/December 2018	Ozempic Rybelsus	15	6	Older than 40	100%
				40 to 54	33%
				55 to 69	33%
January/February 2019	Xultophy	9	5	40 to 54	40%
				55 to 69	40%
				70 and older	20%
November 2019	Rybelsus	20	8	25 to 69	63%
				Older than 70	38%
July/August 2020	Rybelsus	36	36	65 and older	38%
November/December 2020	Rybelsus	13	13	35 and older	100%
				55 to 64	53%
January/February 2021	Entuzity Kwikpen	48	NR	Younger than 18	4%
				35 and older	79%
				35 to 44	29%
				75 and older	6%
July/August 2022	Mounjaro	20	NR	25 to 44	15%
				45 to 54	40%
				55 to 64	20%

Survey date	Submission brand name	Total number of survey respondents	Total number of respondents who reported age	Age ranges	
				Range (years)	%
				65 to 74	25%

NR = not reported.

Note: Age ranges as reported in patient input.

<sup>a</sup>Month not reported.

<sup>b</sup>Unknown mix of types.

**Table 6: Respondents' Province of Residence**

Survey date	Submission brand name	Province	Respondents
January/February 2019	Entuzity Kwikpen	ON	43.8%
		BC	25.0%
		AB, MB, NB, NL, NS, SK	Not specified
		NT, NU, PE, QC, YT	NR
July/August 2020	Rybelsus	ON	15
		BC	15
		AB, MB, QC, SK	Not specified
		NB, NL, NS, NT, NU, PE, YT	NR
November/December 2020	Rybelsus	ON	33.3%
		NL, NS, MB, AB, BC	Not specified
		NB, NT, NU, PE, QC, SK, YT	NR
July/August 2022	Mounjaro	ON	35.0%
		AB	20.0%
		BC, MB, SK, NL, NB, PE	Not specified
		NS, NT, NU, QC, YT	0%

AB = Alberta; BC = British Columbia; MB = Manitoba; NB = New Brunswick; NL = Newfoundland; NR = not reported; NS = Nova Scotia; NT = Northwest Territories; NU = Nunavut; ON = Ontario; PE = Prince Edward Island; QC = Quebec; SK = Saskatchewan; YT = Yukon Territory.