

## CADTH COMMON DRUG REVIEW

# Patient Input

### **SEMAGLUTIDE (Ozempic)**

Novo Nordisk Canada Inc.

Indication: Diabetes mellitus, type 2

CADTH received patient input from:

**Diabetes Canada**

**Patient Commando**

December 14, 2018

**Disclaimer:** The views expressed in each submission are those of the submitting organization or individual; not necessarily the views of CADTH or of other organizations.

CADTH does not edit the content of the submissions.

CADTH does use reasonable care to prevent disclosure of personal information in posted material; however, it is ultimately the submitter's responsibility to ensure no personal information is included in the submission. The name of the submitting patient group and all conflict of interest information are included in the posted patient group submission; however, the name of the author, including the name of an individual patient or caregiver submitting the patient input, are not posted.

# Patient Input Template for CADTH CDR and pCODR Programs

Name of the Drug and Indication	semaglutide (Ozempic), Diabetes mellitus, type 2
Name of the Patient Group	Diabetes Canada
Author of the Submission	██████████
Name of the Primary Contact for This Submission	██████████
Email	████████████████████
Telephone Number	██████████

## 1. About Your Patient Group

If you have not yet registered with CADTH, describe the purpose of your organization. Include a link to your website.

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Diabetes Canada is a national health charity representing close to 11 million Canadians living with diabetes or prediabetes. The priorities of our mission are diabetes prevention, care and cure. Our focus on research and policy initiatives helps us to deliver impact at a population level, and our partnerships broaden our reach in communities across the country. We drive excellence in disease management by putting practical, evidence-based tools into the hands of health-care providers. We advocate for environments that make the healthy choice the easy choice. We continue our search for a cure, as well as for better prevention and treatment strategies, by funding the work of innovative scientists. In 1921, Canada changed diabetes for the world with the discovery of insulin. By 2021, we will change the world for those affected by diabetes through healthier communities, exceptional care, and high-impact research. For more information, please visit: [www.diabetes.ca](http://www.diabetes.ca).

## 2. Information Gathering

CADTH is interested in hearing from a wide range of patients and caregivers in this patient input submission. Describe how you gathered the perspectives: for example, by interviews, focus groups, or survey; personal experience; or a combination of these. Where possible, include **when** the data were gathered; if data were gathered **in Canada** or elsewhere; demographics of the respondents; and **how many** patients, caregivers, and individuals with experience with the drug in review contributed insights. We will use this background to better understand the context of the perspectives shared.

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This submission contains patient input from online surveys conducted in October 2016 and November/December 2018. Each survey was open for two weeks to people across Canada and consisted of a self-administered questionnaire. The surveys were directed at people living with type 2 diabetes and caregivers of people with type 2 diabetes and inquired about respondents' lived experience with diabetes and diabetes medications, and expectations for new drug therapies in Canada. The more recent of the two surveys posed a number of questions specifically about the drug under review, semaglutide (Ozempic). Awareness about the surveys was generated through Diabetes Canada's social media channels (Twitter and Facebook); the October 2016 survey was also advertised to Diabetes Canada e-mail subscribers through e-blasts.

A total of 847 people responded to the October 2016 survey – 790 identified as living with type 2 diabetes while 57 said they were caregivers to somebody with type 2 diabetes. Of those who responded to questions about age and time since diagnosis (n=379), 70% were over the age of 55, with the largest number of respondents (56%, n=211) in the 55-69 year old category, and 60% having lived with diabetes for over 10 years (17% of this group reported having diabetes for over 20 years).

Fewer people participated in the November/December 2018 survey (n=15) – there were 13 respondents who said they live with type 2 diabetes and 2 respondents who were caregivers to somebody with type 2 diabetes. A total of 6 people provided age and date of diagnosis data – 100% of respondents were over the age of 40 years, with 33% each in the 40-54, 55-69 and over 70 years age categories. The majority (n=4, 67%) reported having lived with diabetes for 6 years or more.

### 3. Disease Experience

CADTH involves clinical experts in every review to explain disease progression and treatment goals. Here we are interested in understanding the illness from a patient's perspective. Describe how the disease impacts patients' and caregivers' day-to-day life and quality of life. Are there any aspects of the illness that are more important to control than others?

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Diabetes is a chronic, progressive disease with no known cure. Type 1 diabetes occurs when the body produces either very little or no insulin. Type 2 diabetes occurs when the pancreas does not produce enough insulin or the body does not effectively use the insulin that is produced. Common symptoms of diabetes include extreme fatigue, unusual thirst, frequent urination and weight change (gain or loss).

Diabetes requires considerable self-management, including eating well, engaging in regular physical activity, maintaining a healthy body weight, taking medications (oral and/or injectable) as prescribed, monitoring blood glucose and managing stress. Poor glucose control is serious and problematic. Low blood glucose can precipitate an acute crisis, such as confusion, coma, and/or seizure that, in addition to being dangerous themselves, may also contribute to a motor vehicle, workplace or other type of accident causing harm. High blood glucose over time can irreversibly damage blood vessels and nerves, resulting in blindness, heart disease, kidney problems and lower limb amputations, among other issues. The goal of diabetes management is to keep glucose levels within a target range to minimize symptoms and avoid or delay complications.

Most respondents who participated in the October 2016 survey and the November/December 2018 survey spoke negatively of their experience being chronically ill. They said diabetes is “manageable but a bother”, “a constant battle every day”, “a terrible way of life”, inconvenient, frustrating, and exhausting. One respondent said it just “isn't fun to have to live with”, while another commented “it has been life changing, not in a good way”. A third respondent mentioned “it has definitely impacted my life and the things that I used to do, that I don't enjoy doing any longer”. Several people spoke about its permanence, lamenting that there is no “holiday” from diabetes.

Most people surveyed talked about the adverse effect diabetes has had on their lives. They shared that they are constantly thinking about and planning around their disease. It affects everything from eating and exercising to working and socializing. Overall, diabetes makes it difficult to be flexible and spontaneous. It is always top-of-mind when making decisions and can be very stressful. Daily routines end up very “regimented” and closely “controlled”. Diabetes can be even more difficult to manage when someone is also dealing with comorbidity or disability, or is a caregiver to others. Constant monitoring of blood sugar levels and frequent visits to health care providers were described as burdensome.

Respondents said that meal timing, intake and food choices are restricted, which takes away from the pleasure of eating, and that it is demoralizing to always be receiving diet instructions from people (health care providers, family, strangers) about what they should be consuming and avoiding. They said it is challenging to always be taking medication and to experience variability in blood sugar control. Several respondents spoke about the blame they inflict upon themselves for their disease, the shame and guilt

they feel, and the stigma they experience. Some talked about how tough it is to interact with people who know very little about diabetes or who offer unsolicited advice about its management.

Many people mentioned dealing with, and being apprehensive about, disease symptoms, medication side effects and diabetes complications. Respondents described being chronically in pain and feeling tired a lot. They cited problems ranging from weight management issues, neuropathy and nephropathy, to amputations, changes to circulation and increased risk of heart attack, vision problems, and sexual changes. They reported living with depression and anxiety.

Respondents to the October 2016 survey said they experienced the following symptoms and conditions “sometimes” (“moderately”), “often” (“severely”) or “very often” (“very severely”) at the time of survey completion (n=691 for this question):

- hyperglycemia (75%)
- hypoglycemia (38%)
- high blood pressure (51%)
- high cholesterol (48%)
- heart problems (18%)
- mental health problems (30%)
- kidney symptoms or disease (19%)
- foot problems (45%)
- eye problems (42%)
- nerve damage (37%)
- damage to blood vessels, heart or brain (10%)
- liver disease (9%)

Other concerns cited include gastroparesis, gastrointestinal issues (nausea, vomiting, diarrhea), bladder and bowel incontinence, yeast infections, skin rash and weight gain.

Of those who responded to this question in the November/December 2018 survey (n=10), people experienced the following “sometimes” (“moderately”), “often” (“severely”) or “very often” (“very severely”):

- hyperglycemia (100%)
- hypoglycemia (50%)
- high blood pressure (70%)
- high cholesterol (60%)
- heart problems (20%)
- mental health problems (60%)
- kidney symptoms or disease (40%)
- foot problems (70%)
- eye problems (70%)
- nerve damage (70%)
- damage to blood vessels, heart or brain (40%)
- liver disease (10%)

People shared that diabetes has negatively affected relationships. It has made it hard for them to work, travel, and drive a vehicle – one respondent mentioned experiencing challenges with a driver’s license renewal because of diabetes. Diabetes decreases independence. People are fearful of complications and concerned about the long-term effects of the disease on health. They also mentioned the significant and overwhelming financial burden diabetes poses on themselves and their families.

Below are some quotes from survey respondents that further illustrate the degree and extent to which diabetes affects daily living and quality of life:

*“Type 2 Diabetes[sic] has damaged the nerves in my feet and legs. It is also causing vision problems.”*

*“These past couple of months I have very bad neuropathy[sic] pain in both feet...I do not have any med insurance so the costs of all of my drugs come out [of] our monthly income.”*

*“I’ve been a type 2 diabetic for almost 20 years now and I’m very frustrated with my health! I heal slowly, I get hungry quickly...I need more sleep, my skin is so dry no matter what I do...and I can’t loose[sic] weight.”*

*“[I am] exhausted all of the time.”*

*“[I] have to inject Insulin[sic] twice a day and always be careful [of] what I eat.”*

*“It takes a lot of time and effort to manage, and I’ve had it for [over 20] years. It made shift work even worse, it leaves me very tired for no reason, and people don’t get it. Its[sic] hard to sit in a restaurant and*

*people at adjoining tables stare at you as you inject insulin. If its[sic] children, I take the opportunity to educate - but I'm tired of educating people all the time."*

*"We liked to go to different restaurants and that is now limited as many do not have diabetic friendly[sic] food. Also there is a stigma associated with diabetes that others frown on things like taking your insulin in public...Never been able to see an educator for learning to use insulin, it has all been trial and lots of error, not much information available to starting on it."*

*"Diabetes[sic] has resulted in the need for dietary changes for everyone in the house. I have neuropathic pain that sometimes makes it difficult to rest comfortably and to be as active as I normally would. I need to pay extra attention to my feet to make sure I don't have sores or infections, as they could take longer to heal than if I was not diabetic. I also have nephropathy, which I hope never progresses to chronic kidney disease."*

*"I am a...mother...and hate the fact that I have developed diabetes and have to take medications for it. This disease gets in the way all the time (more trips to the doctor, more trips to the pharmacy, having to remember to take my medication and ensuring that I don't take too much medication so that I can drive my vehicle). 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."*

*"I have neuropathy in my legs and hands. I have diabetic neuropathy in my eyes. I can't drive any more and have to rely on help from family and [an accessible transit service]. I was off for a year with Charcots[sic] foot. I walk with a cane now. Before this happened I was walking 5 kms[sic] a day. Im[sic] lucky if I get to the end of my driveway. Diabetes has taken away all my independance[sic]."*

#### **4. Experiences With Currently Available Treatments**

CADTH examines the clinical benefit and cost-effectiveness of new drugs compared with currently available treatments. We can use this information to evaluate how well the drug under review might address gaps if current therapies fall short for patients and caregivers.

Describe how well patients and caregivers are managing their illnesses with currently available treatments (please specify treatments). Consider benefits seen, and side effects experienced and their management. Also consider any difficulties accessing treatment (cost, travel to clinic, time off work) and receiving treatment (swallowing pills, infusion lines).

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There were 667 respondents who reported experience with antihyperglycemic agents in October 2016. The medications being taken at the time of survey completion included metformin (371), GLP-1 receptor agonists (312), SGLT2 inhibitors (165), combination of SGLT2 inhibitors and metformin (45), DPP-4 inhibitors (72), combination of DPP-4 inhibitors and metformin (147), sulfonylureas (140), TZDs (10), combination of TZDs and metformin (17), combination of TZDs and glimepiride (4), meglitinides (9) and acarbose (9). Many people reported taking insulin (309). A number of respondents indicated that they had experience with certain medications in the past as part of a clinical trial. Some reported stopping certain medications due to reasons other than the end of a clinical trial. The most commonly cited medications in this group were TZDs (97), sulfonylureas (94), GLP-1 receptor agonists (94) and DPP-4 inhibitors (92).

Over 60% of respondents to the October 2016 questionnaire noted improvements in meeting target blood glucose levels (fasting, post-prandial, upon waking) and hemoglobin A1c levels after initiation on their current medication regimen, compared to before (when they were not on treatment). About 46% said they were "better" or "much better" able to avoid hypoglycemia, and 39% said their current regimen helped them maintain or lose weight more effectively than in the past. Gastrointestinal side effects were "neither better nor worse" than previously in 39% of respondents. Close to two-thirds of people indicated they were either "satisfied" or "very satisfied" with the medication or combination of medications they are currently taking for their diabetes management.

Respondents who answered this question (n=382) in the October 2016 survey reported the following benefits and side effects as “quite important” or “very important” when choosing pharmacotherapy for diabetes management:

- keeping blood glucose at satisfactory level during the day or after meals (98%)
- keeping blood glucose at satisfactory level upon waking or after fasting (97%)
- avoiding low blood sugar during the day (90%)
- avoiding low blood sugar overnight (90%)
- avoiding weight gain/facilitating weight loss (91%)
- reducing blood pressure (79%)
- reducing risk of heart problems (90%)
- avoiding gastrointestinal issues (nausea, vomiting, diarrhea, pain) (87%)
- avoiding urinary tract and/or yeast infections (84%)
- avoiding fluid retention (85%)

In the more recent study conducted in November/December 2018, the following medications were reported as being currently in use by respondents (n=6): metformin (3), GLP-1 receptor agonists (3), SGLT2 inhibitors (2), DPP-4 inhibitors (2), combination of DPP-4 inhibitors and metformin (1) and sulfonylureas (1). Insulin use was reported as follows: insulin glargine or insulin glargine biosimilar (2), insulin glargine U300 or other long-acting insulin (1) and intermediate-acting insulin (2). A few respondents cited use of certain medications in the past. These included DPP-4 inhibitors (1), SGLT2 inhibitors (1), combination of TZDs and metformin (1), sulfonylureas (1) and metformin (2). Reasons for discontinued use of these medications were not provided.

Of those who responded to the question (n=6), 50% said they were “better” or “much better” able to meet blood glucose targets upon waking (3) and post-prandially (3) on current antihyperglycemic therapy. On current medications, the following were cited as “about the same as before” by 50% or more respondents: meeting fasting blood glucose targets, maintaining or losing weight, gastrointestinal side effects, thirst and/or dehydration, yeast infections and lung or upper respiratory infections. A total of 33% of respondents said meeting target hemoglobin A1c level and maintaining or losing weight was “worse” on their current medications than previously.

When asked what factors were “quite important” or “very important” in choosing diabetes medications, 83% of respondents (n=6) said the following: keeping blood glucose at satisfactory levels during the day or after meals and upon waking or after fasting, avoiding low blood sugar during the day and overnight, avoiding weight gain/facilitating weight loss, reducing high blood pressure and risk of heart problems, avoiding gastrointestinal issues (nausea, vomiting, diarrhea, pain), avoiding urinary tract and/or yeast infections and avoiding fluid retention.

Below are some direct quotes from respondents to the October 2016 and November/December 2018 surveys that describe what they like and dislike about current therapy:

*“The insulin my husband takes helps control his blood sugar levels. He tests his blood sugar level 3 times a day and adjusts his food intake accordingly.”*

- caregiver to a person with type 2 diabetes taking metformin and insulin (age and time since diagnosis not specified)

*“Needles to administer insulin twice daily is[sic] painful but necessary. Current medications do not cause adverse side effects.”*

- 55-69 year old person with type 2 diabetes, diagnosed 6-10 years ago, taking combination of SGLT2 inhibitor and metformin, and insulin

*“[A GLP-1 receptor agonist] has so far been the best choice for me. The only dislike I have is that it causes the odd nausea and gut discomfort.”*

- person with type 2 diabetes taking a GLP-1 receptor agonist, metformin and insulin (age and time since diagnosis not specified)

*“I have no [gastrointestinal] disturbance with my current meds[sic]. This is much better than when taking previous meds.”*

- 55-69 year old person with type 2 diabetes, diagnosed more than 20 years ago, taking metformin and insulin

*“[A GLP-1 receptor agonist] has been excellent, has decreased very substantially my need for both basal and bolus insulin as well as other medications, reduced hypoglycemia and achieved weight loss.”*

- person over 70 years old with type 2 diabetes, diagnosed more than 20 years ago, taking a GLP-1 receptor agonist, SGLT2 inhibitor, metformin and insulin

*“I have had poor control of my blood sugars over the years. I have tried products that either did nothing or caused more problems. [A GLP-1 receptor agonist] is assisting with better control. However, if my husband's health plan from work didn't cover it, I wouldn't be able to take it as the cost is about [a few hundred dollars] per. I take a lot of meds and wish I didn't have to.”*

- 40-54 year old person with type 2 diabetes, diagnosed more than 20 years ago, taking a GLP-1 receptor agonist, metformin and insulin

*“I like not having hypoglycemia. I don't like the bloat.”*

- 55-69 year old person with type 2 diabetes, diagnosed 3-5 years ago, taking a GLP-1 receptor agonist, SGLT2 inhibitor and DPP-4 inhibitor

*“I feel like I take a huge amount of meds for diabetes and [a second health condition]. Its[sic] scary at times. As my benefits are capped, it is expensive - very. I'd like to say I feel great, but those days are rare.”*

- person diagnosed with type 2 diabetes taking an SGLT2 inhibitor, metformin and insulin (age and time since diagnosis not specified)

*“There are so many of them [medications] and they cause a[sic] extreme dry mouth, nausea and diarrhea.”*

- 40-54 year old person with type 2 diabetes, diagnosed 11-20 years ago, taking a GLP-1 receptor agonist, metformin and insulin

*“I dislike the amount of injections that I have to take in order to maintain control over my sugar levels.”*

- 25-39 year old person with type 2 diabetes, diagnosed 6-10 years ago, taking a GLP-1 receptor agonist, metformin and insulin

## 5. Improved Outcomes

CADTH is interested in patients' views on what outcomes we should consider when evaluating new therapies. What improvements would patients and caregivers like to see in a new treatment that is not achieved in currently available treatments? How might daily life and quality of life for patients, caregivers, and families be different if the new treatment provided those desired improvements? What trade-offs do patients, families, and caregivers consider when choosing therapy?

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When asked about their expectations for new diabetes therapies, respondents to the October 2016 and November/December 2018 surveys expressed a strong desire for medications that can normalize/stabilize blood glucose levels and improve hemoglobin A1c without causing weight gain or hypoglycemia. They wish for new treatments that have been proven to be safe, enhance weight loss and improve health outcomes. They want affordable drug options; ideally, they'd like medications and diabetes devices to be covered by public and private plans. They want treatments that are easily administered, with few to no associated side effects, that cause the least amount of disruption to lifestyle and allow for flexibility with food intake and choices. They also want medications that minimize the risk of diabetes-related complications, help avoid polypharmacy and eliminate the need for injections. Several respondents hope future treatments will reverse or cure diabetes.



Below, respondents provided input on what they desire in new treatments, the improvements they'd like to see to therapies, and the impact these would have on daily life and overall quality of life:

*"Lower blood sugar and hg a1c[sic]."*

*"Hopefully easier attainment of targets, reduction of complication risks and less of a burden of disease."*

*"Improve diabetes control and health outcomes. I hope that these medications will be covered and available for all patients living with diabetes."*

*"I wish it was more affordable for the masses and covered by FNIHB [First Nations and Inuit Health Branch, Health Canada] for First Nation patients."*

*"Manage diabetes effectively without needing such a large variety of medications."*

*"Control glucose levels, cause little or no side effects, be reasonably priced."*

*"I hope that new drugs will eventually cure diabetes."*

*"It would be nice to not have to take shots anymore. Would be nice to be able to just take pills again."*

*"I am hoping that the newer drugs are approved quicker by my insurance company."*

*"Expectations are that eventually there will be a medication that can be taken once a day that will help my pancreas produce the right amount of insulin to keep up with me (or possibly even cure the disease). I would hope that medications are made available to anyone living with diabetes and covered under by our government benefits."*

## **6. Experience With Drug Under Review**

CADTH will carefully review the relevant scientific literature and clinical studies. We would like to hear from patients about their individual experiences with the new drug. This can help reviewers better understand how the drug under review meets the needs and preferences of patients, caregivers, and families.

How did patients have access to the drug under review (for example, clinical trials, private insurance)? Compared to any previous therapies patients have used, what were the benefits experienced? What were the disadvantages? How did the benefits and disadvantages impact the lives of patients, caregivers, and families? Consider side effects and if they were tolerated or how they were managed. Was the drug easier to use than previous therapies? If so, how? Are there subgroups of patients within this disease state for whom this drug is particularly helpful? In what ways?

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Of those who participated in the November/December 2018 survey and answered the questions specific to semaglutide (Ozempic) (n=6), 50% reported taking semaglutide (Ozempic), 33% had no experience with it and 17% didn't know whether they were, or had ever been, on it. Two out of three people reported having switched to semaglutide (Ozempic) from another medication. One person was paying out-of-pocket for the medication, one had coverage through a private insurance plan and one received samples from his/her physician. Two people said semaglutide (Ozempic) was better at helping them achieve their target hemoglobin A1c than previous therapies, while one said it is worse. Two respondents reported semaglutide (Ozempic) as "better" or "much better" at helping them avoid low blood sugar, while one said it was the same as previous treatments. All three respondents said semaglutide (Ozempic) was the same or worse in terms of weight management properties and gastrointestinal side effects.

## **7. Companion Diagnostic Test**

If the drug in review has a companion diagnostic, please comment. Companion diagnostics are laboratory tests that provide information essential for the safe and effective use of particular therapeutic drugs. They work by detecting specific biomarkers that predict more favourable responses to certain drugs. In

practice, companion diagnostics can identify patients who are likely to benefit or experience harms from particular therapies, or monitor clinical responses to optimally guide treatment adjustments.

What are patient and caregiver experiences with the biomarker testing (companion diagnostic) associated with regarding the drug under review?

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Semaglutide (Ozempic) does not have a companion diagnostic, therefore this question is not applicable to our submission.

## 8. Anything Else?

Is there anything else specifically related to this drug review that CADTH reviewers or the expert committee should know?

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Diabetes is a disease that requires intensive self-management. Diabetes Canada's 2018 Clinical Practice Guidelines for the Prevention and Management of Diabetes in Canada highlight the importance of personalized care when it comes to the pharmacologic management of the condition. Specifically, after initiating healthy behaviour measures, the guidelines recommend selecting diabetes treatment modalities based on a patient's degree of glycemic control and various other considerations. To achieve optimal blood glucose levels, individualization of therapy is essential. This includes careful consideration of medication selection, route of administration (oral, injection, pen or pump), frequency with which someone monitors blood glucose and adjusts dosage, benefits and risks that the patient experiences and/or tolerates, and lifestyle changes the patient is willing or able to make. Our survey responses reinforce the message that different people with diabetes require different medications/treatment modalities to help effectively manage their disease. Their unique clinical profile, preferences and tolerance of therapy should direct physicians to the most appropriate choice and combination of treatments for their disease management.

Many people with diabetes hope for less dependence on medications. While current therapies have generally led to improvement for many people with diabetes in blood glucose and hemoglobin A1c control, respondents hope for even better, more affordable antihyperglycemic agents that they can access equitably, in a timely manner, and with good result to help them lead a normal life. Semaglutide (Ozempic) may help people to achieve better glycemic control, which could potentially improve lives and save millions of dollars in direct health-care costs. For this reason, semaglutide (Ozempic) should be an option for people living with diabetes.

## Appendix: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the CADTH CDR and pCODR programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.

There was no assistance from outside Diabetes Canada to complete this submission.

2. Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.

There was no assistance from outside Diabetes Canada to collect or analyze data used in this submission.

3. List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review.

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000

Please find attached a list of organizations who have provided financial support to Diabetes Canada, along with the amounts provided.

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Name: Ann Besner, MScA, RD, CDE  
 Position: Manager, Research and Policy Analysis  
 Patient Group: Diabetes Canada  
 Date: December 14, 2018

Financial Contributions to Diabetes Canada (updated 2017)

<b>Constituent/Name</b>	<b>Funder range (\$)</b>
<i>AstraZeneca Canada Inc</i>	350,000+
<i>LifeScan Canada Ltd.</i>	350,000+
<i>Novo Nordisk Canada Inc</i>	350,000+
<i>Sanofi Canada</i>	350,000+
<i>Sun Life Financial</i>	350,000+
<i>Eli Lilly Canada Inc</i>	250,000-349,999
<i>Ascensia Diabetes Care</i>	175,000-249,999
<i>Janssen Inc</i>	175,000-249,999
<i>Medtronic Of Canada Ltd</i>	175,000-249,999
<i>Dairy Farmers Of Canada</i>	100,000-174,999
<i>Merck Canada Inc</i>	100,000-174,999
<i>WEIGHT WATCHERS</i>	100,000-174,999
<i>Abbott Diabetes Care</i>	50,000-99,999
<i>Canola Council Of Canada</i>	50,000-99,999
<i>Insulet Canada Corporation</i>	50,000-99,999
<i>Knight Therapeutics Inc.</i>	50,000-99,999
<i>Manulife Financial</i>	50,000-99,999
<i>Nestle Health Science</i>	50,000-99,999
<i>RBC Foundation</i>	50,000-99,999
<i>The Bank of Nova Scotia</i>	50,000-99,999
<i>Abbott Nutrition</i>	25,000-49,999
<i>BD Medical Diabetes Care</i>	25,000-49,999
<i>Beer Canada</i>	25,000-49,999
<i>Dexcom Canada</i>	25,000-49,999
<i>Dynacare</i>	25,000-49,999
<i>Heartland Food Products Group</i>	25,000-49,999
<i>McNeil Consumer Healthcare</i>	25,000-49,999
<i>Rexall Foundation</i>	25,000-49,999
<i>Roche Diabetes Care</i>	25,000-49,999
<i>SaskCanola</i>	25,000-49,999
<i>Auto Control Medical Inc</i>	5,000-24,999
<i>Bayer Pharmaceuticals</i>	5,000-24,999
<i>Boehringer Ingelheim (Canada) Ltd</i>	5,000-24,999
<i>Canadian Association of Optometrists</i>	5,000-24,999
<i>Canadian Produce Marketing Association</i>	5,000-24,999
<i>CHICKEN FARMERS OF CANADA</i>	5,000-24,999
<i>Edelman Canada</i>	5,000-24,999
<i>EOCI Pharmacomm Ltd.</i>	5,000-24,999
<i>Euro Harvest Bakery Wholesalers</i>	5,000-24,999
<i>Farleyco Marketing Inc</i>	5,000-24,999
<i>ForaCare Technology Canada Inc.</i>	5,000-24,999
<i>Holista Foods</i>	5,000-24,999
<i>InBody Canada</i>	5,000-24,999
<i>Innovative Medicines Canada</i>	5,000-24,999
<i>Ipsen</i>	5,000-24,999
<i>Jays Care Foundation</i>	5,000-24,999
<i>mdBriefCase Group Inc.</i>	5,000-24,999

<i>Montmed</i>	5,000-24,999
<i>Myelin &amp; Associates</i>	5,000-24,999
<i>Novartis Pharmaceuticals Canada Inc</i>	5,000-24,999
<i>Ontario Pork Council</i>	5,000-24,999
<i>Original Energy Sales</i>	5,000-24,999
<i>Paladin Labs Inc</i>	5,000-24,999
<i>Pharmasave Drugs (National) Ltd</i>	5,000-24,999
<i>Prime Strategies Inc.</i>	5,000-24,999
<i>PULSE CANADA</i>	5,000-24,999
<i>Royal College Of Physicians And Surgeons Of Canada</i>	5,000-24,999
<i>Tykess Pharmaceuticals</i>	5,000-24,999
<i>Urban Poling Inc</i>	5,000-24,999
<i>Valeant Canada LP</i>	5,000-24,999
<i>VitalAire Canada Inc</i>	5,000-24,999

## Patient Input Template for CADTH CDR and pCODR Programs

Name of the Drug and Indication	Ozempic (semaglutide) for Diabetes Mellitus, Type 2
Name of the Patient Group	Patient Commando
Author of the Submission	██████████
Name of the Primary Contact for This Submission	██████████
Email	██
Telephone Number	██████████

### 1. About Your Patient Group

If you have not yet registered with CADTH, describe the purpose of your organization. Include a link to your website.

Patient Commando amplifies the patient experience as a guide to improve healthcare practice using multiple platforms:

- the most diverse online collection of patient stories in any medium that enrich our appreciation of the lived illness experience;
- accredited Continuing Medical Education that informs and trains healthcare professionals in narrative competency which evidence supports improved outcomes;
- develops unique collaborations between patients and healthcare professionals focused on improving disease specific therapeutic relationships;

Patient Commando views lived illness experience through the lens of the Social Model of Disability vs. a medical model. It offers no clinical data or advice, but rather supports and enables its community through the sharing of stories and experience, and facilitation of meaningful, relevant conversations.

### 2. Information Gathering

Data sources include:

- personal interviews and facilitated group discussions
- conversation threads in social media platforms,
- the Patient Commando website story collection,
- community responses to our Experience Exchange program

An inductive qualitative approach was used focusing on the narratives, where identified themes are linked to the data set rather than to theoretical perspectives.

### 3. Disease Experience

Living with diabetes is a non-stop balancing act in living between extremes. But even with diligence, patients pay a price with multiple complications including heart disease, nerve damage (neuropathy), kidney damage (nephropathy), eye damage, foot damage, hearing impairment, and skin conditions. It is very complex and has a striking burden on the physical, emotional, social, and economic status of the person.

***“THERE IS NO VACATION from Diabetes”.***

*“This year I discovered that there is no vacation from diabetes. I tried. I tried taking a summer off. Bad idea. I tried to take a week off. Still, a bad idea. Weekend? Nope. Not worth it. For those of you who can get away with it -- I don't know how you do it. But I found out that I'm diabetic and every day is a diabetic day. If I want to feel good about myself, feel up for the day, be at my best I have to follow my routine. I can't take a day off testing. I can't take a day off my eating routine. I can't just do what I want. When I do I pay for it.”* [REDACTED]

**Physical Threat:** The management of blood sugar requires attention at both extremes – low (hypoglycemia) and high (hyperglycemia). Patients need to respond quickly as symptoms of low blood sugar — sweating, shakiness, weakness, hunger, dizziness, headache, blurred vision, heart palpitations, slurred speech, drowsiness, confusion and seizures – can be dangerous and affect activities such as driving a car. On top of this consuming activity, patients live with increased risk of cardiovascular problems, amputation, reduced vision, chronic pain, wound management issues, and many other unforeseen and sometimes unpredictable complications. And unfortunately, some of the medications that are needed to manage blood sugar can actually exacerbate these extremes (i.e. Sulfonylurea leading to hypoglycemia). Patients need to be equipped with strategies to be prepared to manage serious and potentially life threatening events.

*“I have severe hypoglycemic issues. In order for me to keep myself stable I'm eating something carb/protein balanced every 3 hours. If I eat higher carb, I crash in 2. I'm drinking a 30g protein shake before bed just to try and get through the night.”*

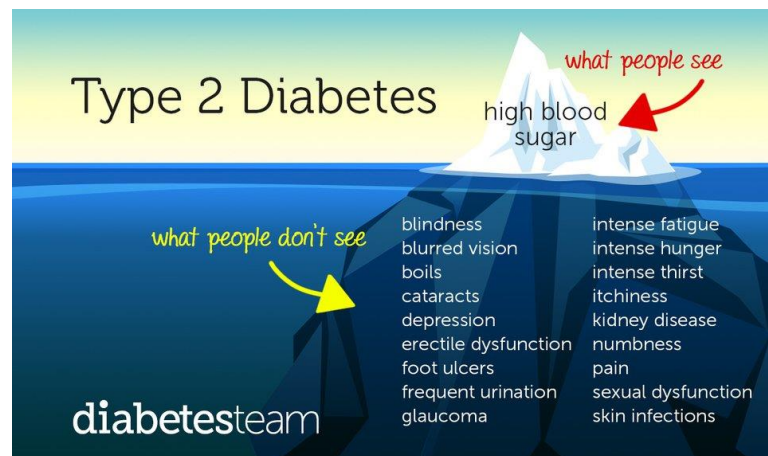
- *“Are you concerned your type 2 will damage your heart? I'm on a low dose high blood pressure pill which works wonders. My statin keeps cholesterol in check and I cannot go without that med because I've tried. My heart is good as far as I know. I know I always get real concerned during my high bg. What do you do to protect your heart?”* [REDACTED]

*“I'll tell you what's wrong with me. I'm losing my hair. I can't hear in this ear. My teeth are falling out. I got torn rotators in both shoulders. I have carpal tunnel. I got arthritis. I got diabetes. I got bilateral knees (osteoarthritis), varicose veins and I'm pigeon toed. And an enlarged aorta. So that's my story... I'm not really one to take care of myself like some people.”* [REDACTED]

- *“I was diagnosed with Type 2 diabetes about 15 years ago. I am 46 years old. I think I was in denial so I never kept good control of the diabetes. I took Metformin for the first couple of years but for the last 10 years, I haven't been on any meds. I also had high blood pressure. The end of January of this year, I suffered a mini stroke. I believe this was a combination of the diabetes and high blood pressure. Thankfully, I wasn't affected by the stroke too much (Right side of my body lost*

sensation but I still feel and have function). They lowered my Blood Sugar with Metformin and insulin. My vision was 20/20 and I never had any problems even though I do have retinopathy. About 2-3 weeks later, I started to have issues with my vision. At first, I couldn't see close-up as everything seemed blurry. Reading glasses (over the counter) helped with that. Then that cleared up and I started to not be able to see far. When I wake up in the morning, my vision is worse.”

- “I am loosing my hair due to diabetes. I think this is a common problem for diabetes. I consulted the doctor and he said that it is due to the stress and it will be grown back. I am very much worried about this. I find large number of hairs coming out I comb or wash my hair. This is so upsetting and frustrating. I've had very thick hair but now it has gone so thin.”
- “Last week I had surgery to remove a lump in my breast. The surgeon called and said it was not cancer but a rare diabetes complication. I looked it up and it mainly happens with long time uncontrolled Type 1's. Well, I am a well controlled Type 2 for the past 8 years. I was also dx'd with Retinopathy and Diabetic Macular Edema last month.”
- “Several years ago I experienced a sinus infection that led to hyperglycemia and greatly increased doses of insulin. During my first course of antibiotics I felt much better and my BG numbers started to improve. Within a day after stopping the antibiotics I had a relapse. I called the doctor and he ordered a second round of the same antibiotic. The second course knocked out the infection. Infections cause high blood glucose which in turn further entrenches the infection. It's a vicious cycle.”
- “I hate diabetes. I was diagnosed back in February. I mean I've lost 32 pounds which has helped alot but it still sucks. The neuropathy has killed my feet. I deal with that pain everyday.”
- “They do say having diabetes puts us at the same risk as someone who has already had a heart attack.”
- “I had my insulin levels checked. They weren't low, they were off the charts. On a lab scale of 0 to 10, my insulin was 22 which puts me at 5 times risk for heart attack. I also have metabolic syndrome which coupled with high insulin puts me at 16 times risk for heart attack.”
- “Not being able to open the food while low. This is how I die.”



**Emotional:** Stigma associated with Diabetes manifests itself in people's perception of self, disappointment with one's own self-care efforts, the perception of others that Diabetes is the fault of the individual, and that obesity and bad food habits cause Diabetes. "Fat or Carb Shaming" comes not only from friends and family but surprisingly from health care



professionals as well. Many Type 2 feel marginalized in the therapeutic relationship by an apparent bias toward treating Type 1 Diabetes as the more authentic condition. For anyone with diabetes, experiencing negative emotions such as anger, frustration, guilt and shame is very common as is depression. “Diabetes Distress”, an attitude of feeling defeated by diabetes, affects a person in many ways.

*“The two diabetes specialists heading the class used shaming as a tool to let me know what a terrible diabetic I was. The shaming didn't make me straighten up...it made me shut down and try even less.”-*

- *“My question -- How do you handle mood swings when your BGs are climbing. My mom says I'm beginning to become unbearable to live with-- anything and everything is ticking me off--at home and at work. I've always been a cool cucumber and let things roll off my back by cracking jokes, but lately I'm just down right irritable and constantly tired.”* ██████████

- *“I'll be the first to admit I watch a LOT of television. In my observations, the most common representations of diabetes are used as a comedic device or as a plot-pivoting clue. The former is no surprise, right? It might look like this: Character A sits on a couch eating a plate of donuts. Character B remarks “You're gonna get diabetes.” [Insert laughter here?]. This first common representation of diabetes is one we in the diabetes online community have been trying to dismantle. We do not take this [mis]representation lightly, as it contributes to the stereotypes and stigma attached to living with diabetes.”-* ██████████

- *“Adjusting to the whole idea of having diabetes can be rough. It's not just the physical management but it's emotional and psychological as well.”* ██████████
- *“I also have depression and am on 'happy pills'. It seems depression and diabetes are bedfellows.”* ██████████
- *“A lot of people think that if they consistently tell people who are overweight/obese how fat they are, how it's shameful, and/or how they "ought" to be eating, they will create a situation in which the person will change their bodies and lose the weight.”* ██████████



**Social:** Social interaction varies depending on age, gender, economic bracket. Diabetes complicates many social encounters. People suffer negative judgements of others. Peer pressure from friends in social situations can result in unwelcome consequences when combined with lack of control. The cost of diabetes to lower income individuals inhibits and restricts social engagement. Travel requires preparation. Food and drink are so often the focus of social interaction, requiring that each encounter be assessed through the lens of diabetes rather than through a person’s preferences.

- *“The hardest thing is not being able to share an ice cream with my son, or have a small bowl of ramen soup. I feel like I have lost the joy of food. I used to LOVE to cook all sorts of dishes and I am experimenting but I feel really limited.”* [REDACTED]
- *“I was never going to feel 100%, always fatigued, lazy, no desire to visit with my friends, terrible hazy eyesight, resentful of my father’s side of the family for giving the disease to me, suffering from what I call ‘brain-fog’ etc. Get the picture??”* [REDACTED]
- *“I am trying to find others who have eating disorders with type 2 diabetes. It seems really difficult to find anyone and I’m feeling really alone. It’s difficult enough to find people who have type 2 at my age (I’m 33 and was diagnosed at 29). I actually have never come across anyone my age with type 2. I’m very ashamed of it and I’m very ashamed of the eating disorder (binge eating). I also have depression, so I’m just a mess. I don’t care at all about taking care of myself and that just contributes to all of it. And it’s another facet that people just don’t get. Most people who get type 2 treat it as a learning experience. That just didn’t happen with me. I’ve had people chastise me for that, too. I pretty much feel very alone amongst all of these circumstances. It would be nice to have someone to talk to.”* -
- *“When the intent of the jokester is to malign people with diabetes, the joke becomes offensive.”* [REDACTED]
- *“Just before my friend pulled into the restaurant parking lot, she turned to me with a concerned look and asked, “Is it alright to eat here?” What she was asking was code for, “Is there anything on the menu you can eat?” The other person in the car, a friend of my friend’s and a stranger to me, missed the subtext and asked, “Would you rather have Thai barbecue?” “No,” my friend clarified for her. “[REDACTED] a diabetic.”...Buzz kill.”* [REDACTED]
- *“I hate injections. If I eat a salad then I’m ok. If I eat a dish of protein. I’m ok. If I start adding other things... it’s not good.”*- [REDACTED]
- *“Last thing in my life that’s regulated by the government is food so don’t tell me not to eat what I want.”* [REDACTED]



**Economic:** Poorly managed health affects work opportunities. Disability as a result of complications such as limb amputation, the absence of employee benefits programs especially among lower income populations, interferes with capacity to self-manage and afford the costs of care and magnifies the physical impact of illness. Patients are forced into financial trade-offs of therapy vs. basic needs. Such trade-offs include sub optimal dosing of Insulin and setting the sensors on pumps to double or triple times the length of manufacturers recommendations.

Treatment options are often determined not by the most effective therapy for the individual, but by the patient’s insurance coverage and ability to afford the cost of a particular therapy.

- *“My doctor asked me ‘What plan are you on?’ It only occurred to me afterwards what a difference that question makes to the treatment chosen or available to a patient.”* [REDACTED]
- *“We can’t just teach people about healthy eating, we have to increase their access to healthy foods.”* [REDACTED]
- *“So sad thought i lost 12 lbs what the scale said a couple weeks ago. Today i weigh in and only lost 7 with being on Victoza for 2.5 months. Guess it is my fault not eating as carefully just don’t have the money to always buy good food. I just want to cry i so wanted to lose more.”* [REDACTED]
- *“I’m on an extremely restricted budget s well, but I’m learning to cut the fat off my spending on food – I get most of my food organic. And I cook everything from scratch. I don’t buy things like cookies or ice cream. Fast food seems much more expensive to me.”* [REDACTED]

**Impact on Caregivers:** Patients feel there is too much or too little attention paid to diabetes amongst loved ones. Relationships with family caregivers can become complicated when family members take on the role of “Diabetes Police”. Yet family members are often life saving interventionists, cheerleaders, managers and personal coaches. They suffer anxiety, stress and worry. The definition of family member/caregiver may be different for some patients, especially for isolated patients who need to have a caregiver backup strategy in case of an adverse event. Further, from the patients perspective, there is also a loss of privacy which only intensifies and adds conflict as young people emerge from the paediatric to the adult healthcare systems.

*“When I went on insulin, I had to hide it from my children. We went to NY and I had to tell them and my son said ‘How come I didn’t know that?’, cause I would hide it. I would put it in a nice container, a nice bag, so it wouldn’t look like insulin. I did that for about 3 months. When they finally knew I was on insulin, they were so sad.”* [REDACTED]

- *“For a good amount of time my Hubby has been in the good levels and he is starting to exercise. Now I’m so afraid that he will have a low. What does a low look like and if it happens what do I do to fix it. Also if he ever passes out from a low how do I bring him back and how dangerous is that if it happens.”* [REDACTED]
- *“My husband woke up at 6 AM, said I looked comatose, took my blood sugar and it was 2.1. He called the ambulance but in the mean time, I had a seizure, lacerating my tongue. My husband was trying to give me glucose tabs but said I was spitting them everywhere, along with blood from my tongue. That was Tuesday; this is Sunday. Since then, my husband wakes me at 3 AM to take my blood sugar because it continues to be low during the night.”* [REDACTED]
- *“My partner just got told that he is type 2 a little over a week ago and our hole world has been turned upside down. I am his nurse and everything as he is too afraid of needles to do any of the testing his self. Also I have been doing all the cooking and anything else for him. And trying to take care of the house work a full time job and we also have a 6 year old son that I also have to take care of. I am trying to hold it together for him and be everything that everyone needs. But I have so much on my plate that I find myself not eating any more and I have really forgotten what sleep is. It seems like all I do is think about what his last number was.”*
- *Long story short, my husband started out with NIDDM2. He never learned about it or how to take care of it. He just let the meds do the work and he ate what he wanted. Now, after 25*

years, he has progressed to needing twice daily insulin (long acting and fast acting), has stage 4 CKD (can go to stage 5 and dialysis any time), and has diabetic retinopathy that the Dr is watching. His A1c's are still in the 8s and 9s. He still does not - nor will he try to - understand how to eat properly even though we've gone to 3 diabetic classes. Today, I found out that his blood sugars have been so high that the glucometer just reads "high." [REDACTED]

- *“About a minute after hitting the chair, I started to feel those symptoms of a hypoglycemic episode... starting to sweat, feeling chilly. I recognized what was going on and prepped for dealing with it. I live alone so there's nobody to baby sit me when these things happen. I got up and unlocked the back door then went and got my meter and measured my blood glucose once again. I immediately called my buddy, told him what was going on, and asked him to come over just in case I needed help. He's done that for me a couple other times so he knows what's going on. I keep cans of sliced fruit in heavy syrup in the refrigerator for just this situation. So I grabbed one, tore the top off and started drinking the heavy syrup. After drinking most of it, I started eating the sliced pears and right about then my buddy arrived.” [REDACTED]*
- *“I stood beside my mom in the hospital as she was being wheeled into the Operating Room to have her right leg amputated just below the knee. The amputation was necessary due to an infection that my mom and her doctors had been fighting for over a year and a half. They were unable to stay ahead of the infection and could not risk it spreading through the bone and getting above the knee. The only possible solution was to remove the leg to head off the infection and avoid even more serious future complications. I don't know how to put into words what it was like to see my mom whole one day and then missing a leg the next. It was such a helpless feeling. All three of her children were there with her. My brother, my sister, and I were all there. There was nothing that we could do but we were there if she needed us. She looked so vulnerable and weak that it was heartbreaking. This is the same mother who gave birth to us, raised us, protected us, and did all she could to support her children. There, lying in that hospital bed, now an amputee she appeared so fragile.” [REDACTED]*



## 4. Experiences With Currently Available Treatments

There is no singular course of treatment for Diabetes. There is widespread frustration among patients with the options available, how to assess, and even how to understand the nature of the disease itself which surprisingly is not exclusive to health literacy level. Patients struggle to manage their condition based on an algorithmic approach to treatment by their GP's and endocrinologists. Some are able to self-manage without medications while working with a team that includes nurse educators and dieticians. Increasing numbers of Type 2 PWD however escalate the use of medications ultimately reaching the last option of insulin therapy. Diabetes can cause severe nerve damage and can lead to amputation. The complexity of Type 2 treatment leads to any number of intervention or decision points along the journey that can either be enhanced or inhibited, depending on the awareness and access of optimal treatments. Treatment is further complicated by access inequities based on geography (urban vs. rural), Institutional protocols, access to Diabetes teams including

**nutritionists, social workers and other key professions like ophthalmology and vascular specialists. This lack of access means less choice for the PWD, their families and health care professionals.**

*“Doctors tell patients ‘If you don’t follow my orders I’ll put you straight onto insulin’. Need to stop using insulin as a threat.” ██████████*

- *“I have had diabetes for 5 years now and I swear my energy level and strength keeps going down. I have tried all sort of vitamins etc and sometimes I feel better for a while but then I go back to being exhausted and fatigued again. Is this really just the way I will feel for the rest of my life every day*

*and nothing can be done?” ██████████*

- *“I have type 2 diabetes which essentially means that I have ‘diabetes of unknown cause’. The trouble is that this diagnosis is not sufficient to assure that I get proper treatment for my diabetes. It was six years ago that I started on my (own initiative) managing my diabetes with insulin. This was only after exhausting my options and concluding that as someone with type 2 I would be denied insulin until I basically ended up in the hospital.” ██████████*
- *“My biggest frustration with our healthcare system is that the person with the least decision-making power is me, the patient. I believe this stems, in part, from a system that elevates the physician’s, the payer’s, the industry’s perspective over mine. It stems from a system that values my life less because of diabetes.” ██████████*
- *“I depend on this meter. I get way too many bad readings. And those bad readings can cause me to do exactly the wrong thing. A false high when I am actually low can result in me injecting insulin causing a hypo. And if I am low and the meter says I am fine I can place myself at risk for a hypo. And exercise is one of those things that can induce both of these situations because it has such a strong and variable effect on my blood sugars. And having to take 3 tests just to get one confident reading, that is crazy.” ██████████*
- *“Ok. Back to the peak BS. Why would the doc Rx insulin injections when I hit 8.4 and the cardiac RN’s tell me 8.3 is ok and I’m worrying needlessly?” ██████████*
- *“Type 2 is a complex disorder. The idea that T2 is all about insulin resistance and that insulin resistance is a defect caused by being overweight is really naive. There are just too many of us who were never really overweight and found no improvement with weight loss. And this is why we all get upset when someone comes to tell us that there is a “cure” or that they can “reverse” diabetes. I’ve never seen any shred of evidence that the fundamental defects involved with T2 can be corrected with a drug or treatment.” ██████████*

## 6. Experience With Drug Under Review

Nausea and upset stomachs are reported as initial side effects that disappear after tolerance is developed. Starting at low dose with slow, gradual increases, delivers the best outcomes. The drug reduces appetite and lowers blood sugar resulting in weight loss. This affects social and emotional impacts of the condition in positive ways equating to an improved quality of life, as well as reduced stress from stigma and bias. There is improved control of blood sugar, reduced fear of hypoglycemia and simplified dosage management resulting in improved treatment adherence. This is especially important for patients with concomitant conditions who generally will pay attention to the one condition that is causing the most pain to the detriment of the others. Ozempic is used as part of a therapeutic plan rather than a singular therapy and in some cases demonstrates effectiveness in avoiding or reducing insulin use. Caregivers benefit from a reduced burden, improved emotional state and restored balance in relationships. There continues to be an issue of affordability and coverage.

- *“Mine are significantly lower since starting it two weeks ago. I've been on insulin for 7 years and was able to drastically decrease how much I need.”* [REDACTED]
- *“This is my 4th week on ozempic. I was previously on novolog and levimir for 6 years...never had a endocrinologist..just used my primary care...Endo took me off of both insulins...put me on metformin and ozempic....I have lost 17 pounds in 4 weeks.. I'm hungry but nauseated...my A1C was 9.2 4 weeks ago...my current blood sugars average at 135-140. .fasting blood sugar was 116...I can't wait until my next AIC check.”* [REDACTED]
- *“I take my 4th dose of ozempic in the morning. I can tell a big difference in my blood sugar and in my weight. 2 years ago I had to have a pacemaker/defiblater, Evidently my heart dr. Can see a difference. She called me yesterday to make sure I was ok.”* [REDACTED]
- *“I'm on week 6 and I have a little heartburn occasionally that started a few days after the first injection but only happens if I overeat now. My numbers started lowering after my third injection, and I have not lost any weight.”* [REDACTED]
- *“I have (constipation)!!!! For 12 weeks since I first got on ozempic. I haven't lost an ounce. My blood sugar numbers are stable and super low for me between 96 to 105.”* [REDACTED]
- *“I have taken 13 doses 2 at .25 and have stayed at .5 for the rest. My A1c went from 8 to 6.5 since starting and lost 22lbs. I had a little nausea in the beginning still have constipation no appetite but just started to Have bad heartburn. I'm staying at the .5 until at least October when I go back to dr.”* [REDACTED]
- *“Drum roll please... had my first checkup (Sept 24) since going on Ozempic in May. A1C = 5.6 and weight down about 30 pounds. My endo is super impressed.”* [REDACTED]
- *“I went from 80 units of insulin to 0.”* [REDACTED]
- *“Just this week I had to cut the tresiba from 28 to 22 units.”* [REDACTED]
- *“I still take my long lasting insulin at night, but no meal insulin. I had to stop meal insulin immediately. I kept crashing.”* [REDACTED]

## 7. Companion Diagnostic Test

Managing ones glycemia is a constant 24/7 endeavor. This is becoming even more complicated with the newer monitors and pumps and the evolution of moving “beyond A1C” to “time on target” or “time in range”. Companion diagnostics include lancets, monitors, BG test strips, ketone strips, needles, pumps, pump supplies, CGM. All this adds significant cost, inconvenience and emotional distress to patients when you also add in the fragmented reimbursement landscape which complicates and adds barriers to access.

When factoring in age, income and the full spectrum of the social determinants of health, the optimal management of one’s diabetes faces significant obstacles to treatment when looking through the lens of the “whole patient”.

- *“I think we have to take a step back and think about what access actually means. Does access mean, just simply having access to an insulin pump (no matter what brand it is) or does access to you mean access to everything and you get to pick and choose what you want. Because, that is going to be a long battle that isn’t going to be solved today or tomorrow. No petition or boycott is going to solve that problem in the next 3-6 months.”* [REDACTED]
- *“As a person with diabetes, I want tech advancement to happen because I want living with diabetes to be less of a burden on me. As an advocate, I want those innovations to extend beyond people like me who are privileged enough to have insurance, access to local knowledgeable doctors, friends in the diabetes community, access to higher education, and time to self-manage. As an advocate, I know that for our system to be just and fair, all who are interested ought to have access to the medicine and medical equipment.”* [REDACTED]

## 8. Anything Else?

### Treating The Whole Patient:

There is a complete underestimation of the importance of managing glycaemia (in lieu of managing an A1C number) as the whole patient. Fear of hypoglycaemia and more commonly the fear of being judged do not always appear on a patients’ chart. The reasons are multi factorial, but it is very clear from the patient voice that it is far more than just the clinical manifestations of the features and benefits of drug A vs drug B.

- *Patients will often “Rationalize” for non – compliance” even though they have had poor control for years whack, so they don’t provide accurate feedback: eg. missing readings on the CGM; “I forgot my meter”*
  - *“Diabetes is not even my most important problem”* [REDACTED] *(Concomitant disease: cardiovascular, Arthritis, GI, mental health issues)*
- *Bias against insulin*
  - *First thing heard by HCP’s when insulin is prescribed. “but I feel fine!”*
  - *“Outcomes on Insulin are associated with bad events, not positive benefits”* [REDACTED]
  - *Fear of hypoglycemia: Although they do not have it initially on their own unless they have experienced it, it arises when they have seen other family members or friends.*
  - *Financial Cost of testing supplies and insulin itself.*

- *Although Treatment choice is a popular topic for Patient self-management:*
  - *HCP's do not know all the options on the CDA guideline for treatment algorithms, so why would a patient.*
  - *Patients (Type2 in general and the 'working poor' in particular) are given what they can afford or what their drug plan will allow: Most common questions PRIOR to prescribing: "What coverage do you have?"*
  - *Treatment options: "It's not their decision." – Diabetes Educator.*

**Finally, patients raise system issues that affect decisions and choices across the continuum of care and experience:**

- *– Fragmentation of way diabetes is managed / paid for*
  - *"Depending on the funding you're going to get in each area determines the kind of support you're going to get. Type 2's have a struggle while Type 1's have a different struggle." [REDACTED]*
  - *"I am still benefiting for being paid by company insurance but I am worried when I am not employed and I hear horror stories that medication/needles are not affordable to others. These people just do not buy the medication and these are the people who gets complications, i.e. heart attack." [REDACTED]*
  - *"I like to test often and I heard that our current system does not pay majority of it. I heard that they use the same needle 2 or 3 times to save money."*
- *Alarms are being raised about patient access to the best treatment:*
  - *"My GP took care of me for over 3 years but I only got worse. Then he sent me to an endo and things started to turn around. I wonder if GP hung on to me cause he gets paid more because of all the visits I needed."*



## Appendix: Patient Group Conflict of Interest Declaration

To maintain the objectivity and credibility of the CADTH CDR and pCODR programs, all participants in the drug review processes must disclose any real, potential, or perceived conflicts of interest. This Patient Group Conflict of Interest Declaration is required for participation. Declarations made do not negate or preclude the use of the patient group input. CADTH may contact your group with further questions, as needed.

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.

**NO**

2. Did you receive help from outside your patient group to collect or analyze data used in this submission? If yes, please detail the help and who provided it.

**NO**

3. List any companies or organizations that have provided your group with financial payment over the past two years AND who may have direct or indirect interest in the drug under review.

Company	Check Appropriate Dollar Range			
	\$0 to 5,000	\$5,001 to 10,000	\$10,001 to 50,000	In Excess of \$50,000
N/A				

I hereby certify that I have the authority to disclose all relevant information with respect to any matter involving this patient group with a company, organization, or entity that may place this patient group in a real, potential, or perceived conflict of interest situation.

Name:Zal Press  
 Position: Executive Director  
 Patient Group: Patient Commando  
 Date: December 10, 2018