



Survey of People Affected by Diabetes: Results

May/June 2022

1300 - 522 University Avenue, Toronto, ON, M5G 2R5
Call us: 1-800-BANTING (226-8464)
Diabetes.ca

Charitable Number: 11883 0744 RR0001

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ABSTRACT

Objective

Diabetes Canada's mission is to improve quality of life for people living with diabetes. This survey was conducted by Diabetes Canada in an ongoing effort to understand the COVID-19 pandemic's impact on people affected by diabetes and their health, how they have managed and adapted, and their needs going forward. Respondents were asked what Diabetes Canada services they valued and what the organization could do better.

Method

This survey was conducted on SurveyMonkey and available to the public between May 12 and June 16, 2022. It was publicized on Diabetes Canada's social media channels (e.g., Facebook, Twitter, LinkedIn, Instagram), through partners (e.g., health-care providers, life science companies, elected officials) and via e-blast to those classified as patients or caregivers.

Results

A total of 658 respondents participated in this survey. Most respondents were women, aged over 50, and identified as Caucasian. A majority were from Ontario, British Columbia and Alberta, and overwhelmingly resided in large urban centres. Most respondents lived with diabetes themselves, with 12% as caregivers, and were about evenly split between those living with type 1 and type 2 diabetes.

Respondents placed a high value on advocacy efforts, educational content, and opportunities to engage with a broader community; proposed changes to Diabetes Canada's approach included increased advocacy for equitable access to medications and devices, greater promotion of said advocacy efforts and clear calls for the community to be involved, and a return where possible to in-person or hybrid opportunities for learning and connection. Individuals with both type 1 and type 2 diabetes reported a desire for more distinction between types and more discussion on complications and self-management strategies in Diabetes Canada's messaging. It was also noted that more content is required for diverse audiences and marginalized groups, along with more targeted outreach to those historically not reached by the organization. Many respondents shared that they would be more likely to participate in more targeted or issue-specific outreach or campaigns in future.



Discussion

It was overwhelmingly noted that Diabetes Canada has maintained a strong and trusted position, especially for purposes of knowledge mobilization, community, and advocacy; the organization holds a valued place in the lives of many Canadians affected by diabetes. This survey provides a broad snapshot of who Diabetes Canada is reaching, their current experiences and concerns, and the role the organization plays in supporting research, education, and advocacy across the country.

Conclusion

Changes in respondents' attitudes and overall health, methods and formats of care delivery, and specific requests and preferences regarding Diabetes Canada's offerings will all be used to inform the organization's policy & advocacy work and overall strategy going forward.



Introduction

Diabetes Canada is a national health charity representing more than 11.7 million Canadians living with diabetes or prediabetes. A world free of the effects of diabetes is Diabetes Canada's vision. The organization is working together to improve the quality of life of people living with diabetes. Diabetes Canada is sharing knowledge and creating connections for individuals and the health-care professionals who care for them; advocating through public policy; and funding research to improve treatments and find a cure to end diabetes.

It has a heritage of excellence and leadership, and its co-founder, Dr. Charles Best, along with Dr. Frederick Banting, is credited with the co-discovery of insulin. Diabetes Canada is supported in its efforts by a community-based network of volunteers, employers, health care professionals, researchers, and partners. Diabetes Canada will continue to change the world for those affected by diabetes through healthier communities, exceptional care, and high-impact research.

Survey Responses

This survey was conducted in May and June 2022 in an effort to understand the COVID-19 pandemic's impact on people affected by diabetes and their health, how they have managed and adapted, and their needs going forward. A total of 658 respondents participated in this survey. Most respondents were women aged over 50 and identified as Caucasian. A majority were from Ontario, British Columbia and Alberta, and overwhelmingly resided in large urban centres. Most respondents lived with diabetes themselves, with only 12% as caregivers, and were about evenly split between type 1 (T1D or T1) and type 2 diabetes (T2D or T2).

Personal Information

Over half of respondents were aged 60 years or older, and only 9% of respondents were less than 40 years old.

- 19 years or younger 0%
- 20 – 29 years 3%
- 30 – 39 years 6%
- 40 – 49 years 17%
- 50 – 59 years 17%
- 60 – 69 years 30%

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- 70 – 79 years 19%
- 80 years or older 8%
- Prefer not to answer <1%

Over half of the people with diabetes that respondents care for were over 50 years old; 14% were under 20.

- 19 years or younger 14%
- 20 – 29 years 3%
- 30 – 39 years 8%
- 40 – 49 years 11%
- 50 – 59 years 15%
- 60 – 69 years 23%
- 70 – 79 years 14%
- 80 years or older 6%
- Prefer not to answer 11%

The overwhelming majority of respondents identified as female or male, with 68% identifying as female and 31% as male, while 1% identified as genderqueer or gender non-conforming, other identity, or preferred not to answer.

A majority of respondents were from Ontario, British Columbia and Alberta, while the Atlantic provinces and Territories had fewer respondents. Provinces are listed below in order of prevalence of respondents.

- Ontario 38%
- British Columbia 21%
- Alberta 19%
- Manitoba 7%
- Saskatchewan 4%
- Nova Scotia 4%
- Quebec 1%
- Newfoundland and Labrador 1%
- New Brunswick 1%
- Outside of Canada <1%
- Prince Edward Island <1%

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- Yukon <1%
- Nunavut 0%
- Northwest Territories 0%

On the question of ethnic background, nearly nine in 10 respondents selected White Caucasian. Other more common demographics included South Asian, Indigenous, and Chinese. Groups are listed below in order of prevalence.

- White Caucasian (e.g., European, or British heritage) 88%
- South Asian (e.g., Indian, Pakistani, Sri Lankan, Bangladeshi) 3%
- Indigenous North American (i.e., First Nations, Inuit, Métis) 3%
- Chinese 1%
- African heritage (e.g., Black, Caribbean descent) 1%
- Filipino 1%
- Japanese <1%
- Latin American/Hispanic <1%
- Arab <1%
- Korean <1%
- West Asian (e.g., Iranian, Afghan) <1%
- Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian) 0%
- Other 3%
- Prefer not to answer 3%

Most respondents (64%) lived in large population centres, while 30% lived in small or medium centres and only 7% lived in rural areas.

- Large urban population centre (i.e., population of 100,000 and over) 64%
- Medium population centre (i.e., population of between 30,000 and 99,999) 16%
- Small population centre (i.e., population of between 1,000 and 29,999) 14%
- Rural area (i.e., population of less than 1,000) 7%

Medical History

Of a sample of 658 individuals, most respondents (88%) lived with diabetes while 12% were caregivers to people with diabetes. Respondents were nearly equally split among those living with T1D and those living with T2D. 52% of respondents lived with T1D; 47% with T2D and 1% with another form (MODY, monoclonal, etc.). No respondents reported living with gestational diabetes. There was a wide distribution in the number of years respondents



had been affected by diabetes, with nearly half (48%) reporting more than 20 years of lived experience.

Approximately 1/5th of respondents lived with no additional health concerns. Of the 628 respondents who indicated having health issues, the average individual reported more than 2 distinct problems. The remaining respondents reported the following conditions, in order of prevalence:

- High blood pressure 41%
- High cholesterol 33%
- Arthritis 25%
- Obesity 24%
- No complications 19%
- Retinopathy/eye problems 18%
- Neuropathy/nerve pain 18%
- Heart disease/heart problems 15%
- Mental illness 14%
- Nephropathy/kidney disease 6%
- Gastroparesis 5%
- Foot/leg ulcer 1%
- Amputation 1%
- Other 17% – these most commonly included autoimmune conditions (e.g., Graves' or thyroid disease, Crohn's disease), hypertension, mood disorders, celiac disease or other gastrointestinal problems, osteoporosis, and various forms of cancer.

Diabetes Treatments

A total of 658 respondents provided information about the type of therapies and technologies used to manage diabetes. Most respondents used diet, blood glucose monitoring and exercise as part of their diabetes management regimen. Respondents were roughly split in terms of their use of oral medication vs. insulin. More than half (56%) used continuous glucose monitoring systems. Notably, compared to Diabetes Canada survey results from 2021, use of continuous glucose monitoring (CGM) systems has risen 8% among survey respondents. Continuing trends from previous years, compared to 2021, use of blood glucose monitors has declined by 13% while use of real-time CGM, intermittently-scanned CGM, and insulin pumps has increased by 4, 5, and 6%, respectively.



Respondents were directed to select all applicable therapies or technologies from a list, with responses listed are provided below in order of prevalence:

- Diet 57%
- Exercise 49%
- Glucometer 47%
- Insulin injection 42%
- Oral diabetes medication 38%
- Insulin pump 33%
- Real-time continuous glucose monitor (rtCGM) system (e.g., Dexcom, Medtronic) 31%
- Intermittently-scanned continuous glucose monitor (isCGM) system (e.g., FreeStyle Libre, FreeStyle Libre 2) 25%
- Glucagon (injected or nasal) 12%
- Non-insulin injectable 5%
- Other 4% – many of these responses included oral medications and forms of exercise or nutrition.

The majority of respondents shared their diabetes data digitally with their clinics, while about one-third still share information manually. Minor increases from 2021 were observable in all cloud-based or digital forms of data sharing. The following approaches were reported by survey respondents (from most to least popular):

- Blood tests (HbA1C) at a lab 74%
- Upload insulin pump data (e.g., Carelink, t:connect or Diasend) 24%
- Manually (e.g., using a logbook) 22%
- Upload/email reports from an advanced glucose monitor 18%
- Cloud-based sharing of advanced glucose monitor (isCGM or rtCGM) data 18%
- Upload finger stick glucose monitor results 8%
- Cloud-based sharing of insulin pump data 5%
- Cloud-based sharing of finger stick glucose monitor results 1%
- Other (please specify) 7% – note: responses under this category were a mix of options provided above.



Respondents' Experiences of Health During COVID-19

The COVID-19 pandemic has been a stressor for respondents, many of whom reported heightened concern about contracting the disease given the additional risk that is posed by living with diabetes, and feelings of isolation or loneliness. Most have not struggled accessing medications or health care, although some reported financial concerns that impacted their self-management. Respondents were quite split on level of concern for personal physical, mental and emotional health, and on experience of feelings of anxiety and isolation. One-third of respondents have had medical appointments canceled or deferred, which, while stressful, has overwhelmingly not adversely affected their health. About half of respondents have had virtual medical visits since the pandemic started, which they have generally enjoyed; most would prefer the option of more virtual visits in future and support provincial and territorial shifts to digital health.

Access to Diabetes Treatments

For a significant majority of respondents, access to medications and devices has not changed during the pandemic; the overall sentiment is consistent with results from a similar Diabetes Canada survey conducted in 2021. Responses are listed in order of prevalence.

- I have been able to access my medications, medical devices and/or supplies without interruption. 83%
- I am worried about being able to continue to afford my medications, medical devices and/or supplies. 16%
- It has been harder to access some of my medications, medical devices and/or supplies. 10%
- I cannot afford all my medications, medical devices and/or supplies now (e.g., because I lost income or insurance coverage) so I have discontinued the use of some or all of my medical devices. 4%
- I do not use any medications or medical devices. 1%

In an inquiry into interprovincial migration to which 646 individuals responded, the majority (94%) did not move or consider moving since the onset of the pandemic, 6% considered moving but did not go through with it, and only 1% moved to a new province or territory. From a follow-up question, 85% did not base their decision to move or not move



on public coverage, while 15% did. Many respondents had coverage through private insurance and therefore found that provincial or territorial programs did not influence their decisions on where to reside. Some raised the issue of changing standards in Alberta as a motivator to move in future, while others from the Atlantic and Prairie provinces especially noted high out-of-pocket costs or lack of adherence with prescribed care due to prohibitive costs. Still others expressed that moving was unrealistic due to financial and social costs of relocating.

Health Self-Assessment

A total of 600 respondents shared a snapshot of their current physical, emotional, and mental health by sharing the extent to which they agreed with key statements. Most respondents were concerned about their risk of contracting COVID-19, although less severely than in the previous 2 years; most reported having access to mental health strategies and supports. Results were split on overall level of concern for personal physical, mental and emotional health, and on respondents' feelings of anxiety and isolation. Compared to 2020 and 2021, there was a marked increase in respondents reporting worsened exercise habits; however, respondents also reported eating more healthy foods and spending more time in blood glucose target range.

Recurring themes among reported physical and mental health concerns include stress as a result of reduced socialization and connection with health-care providers, rising cost of living and the financial burdens of managing diabetes, and mental health challenges including depression and burnout. Many referenced the desire for in-person opportunities to connect with others and learn, and ongoing difficulty with motivation to exercise and eat well. Changes to Alberta's insulin pump program were frequently cited as a major stressor. The following quoted responses help to describe prevailing concerns of survey participants:

- *"There is just a lack on info about how this actually affects people with diabetes. Also - what to do in the event you catch COVID. It makes it harder to do just about anything."*
- *"Eating healthy is getting very expensive."*
- *"I answered the above questions based on the 2nd half of the pandemic. The first half I had terrible control, mental health issues, stress, weight gain. The 2nd half I reversed all of that."*
- *"I have been more depressed and lonely."*
- *"Limited opportunities to connect in person with others living with T1D."*



- *“Lack of support groups under both [Diabetes Canada] and JDRF which used to be a great tool to make things manageable and relative.”*
- *“Burnout from dealing with diabetes is always on my mind. Would be nice to have a break once in a while.”*
- *“[Mental] health is huge for my child and us as parents. Found the perfect person for my daughter to talk to. She has T1D but is a councillor [sic] not psychologist. \$180 per 50 min session. Important for her to go but.....a struggle to go as much as she needs financially.”*
- *“Alberta possibly cutting the pump program. That is my great concern. We are planning on moving back to our home country for retirement because ALL supplies and insulin are covered for T1's.”*

597 people responded to a question, based upon the WHO-5 Wellbeing Index, in which they assessed their feelings relative to 5 statements on personal wellbeing over the past 2 weeks. While most respondents reported spending a majority of their time in good spirits, feeling calm and relaxed, and having interesting daily lives, a high percentage reported poor results on their perceptions of feeling fresh, rested, active, and vigorous. Notably, 54% of respondents feel fresh and rested less than half the time, some of the time, or at no time.

Virtual Care

Of 571 respondents, the majority (84%) have had a recent virtual health-care appointment. Most of those who have had virtual visits had phone calls, with 70% of total respondents; video calls were comparatively rare, representing only 11% of respondents.

Respondents overwhelmingly enjoyed virtual visits and experienced confidence in achieving health outcomes through these methods. They found it convenient and felt heard and able to ask questions. While some reported missing the sense of ease that accompanies in-person visits, most would prefer more virtual visits in future, even after COVID-19 ends. There remained strong support for ongoing provincial and territorial investments in virtual care.

174 individuals opted to share additional comments about virtual care, many of whom lamented the lack of in-person contact for foot screening, physical examinations, and interpersonal connection with health care providers. Concerns were also raised regarding



efficiency and operations (e.g., use of video platforms versus telephone, difficulty with training, etc.), while many praised the opportunity and increased accessibility of care providers. Many issues were also raised around physician or diabetes educator attitudes, with concerns of dismissiveness and inaccessibility. Respondents had the following to say about their experiences with virtual care:

- *"I found it to be most helpful. I see my therapist on a weekly basis through virtual sessions. I was a bit nervous at the beginning but after 3 sessions, I am very comfortable with the set up for our meetings."*
- *"I felt that the doctor was more comfortable with the phone visits than he does with face-to-face visits. He seems less pushed for time."*
- *"Some of my issues were not taken seriously and ignored."*
- *"I live in a rural northern community and internet access is poor. The cost to obtain new, more dependable internet access is too high for my financial situation."*
- *"I think a mixed model will be important moving forward. My time is valuable. It is more efficient for me to have virtual connections some of the time."*
- *"Virtual care is okay but being in person is critical. If I am having rashes from the adhesives, or using an injection site too frequently, the nurse or doctors can see that in person & recommend suggestions to mitigate those concerns. Video or telephone calls do not provide that same level of care."*
- *"It's fine to look at the numbers, but without a physical examination, it's hard to know / check on things like neuropathy and other things that could be an issue."*

Impacts of COVID-19

The most commonly reported challenges emergent from the COVID-19 pandemic were similar to those cited in the 2021 survey: a lack of socialization and mobility, reduced exercise and healthy eating, and general anxiety or discomfort with accessing health care or leaving the home. Respondents shared the following thoughts:

- *"My mental health really suffered. I was very anxious which led to depression. My blood pressure has just recently started to rise, and I had a lot of problems sleeping."*
- *"Not wanting to contract Covid [sic] again but still wanting to continue living a full life."*
- *"Not being able to go out and exercise."*
- *"Trying to find help for mental/emotional illness."*
- *"It is still difficult to meet people and make friends."*
- *"Healthy eating, dealing with stress."*



- *"I'm an introvert and rule follower so not a lot of missing social interaction like some. However, the longer it went on and the more inconsistent rules, was getting frustrating. I never returned to my gym membership and have gained weight. Similarly, I'm tired a lot more. The lifestyle changes that were imposed kept making activities harder, and I slowly became less concerned about my physical health, my blood sugars were going out of range more, just limited my routine."*
- *"Burnout from diabetes."*
- *"Not actually receiving the in person care my condition demands."*
- *"I no longer want to go anywhere/leave the house. It's extremely difficult to get myself to go to work (I [work from home] 3 days a week, and must go in 2 days). I have difficulty motivating myself to go grocery shopping, etc."*

Of the 264 individuals who shared their personal experience with COVID-19, 47% had not contracted the virus. Responses varied from reassurances that the virus was quite mild to rather severe experiences, with many respondents citing stress and anxiety directly related to living with diabetes and difficulties managing work, health care, and social interactions. Some sample quotes of note include:

- *"I felt very isolated and emotional during that time. It took me 2 ½ months to start felling [sic] better after COVID-19. I found out just how resilient I was in the many moments of uncertainty."*
- *"The symptoms were extremely mild."*
- *"Even though I am very cautious and have two vaccine doses and a booster, I contracted COVID-19 twice and both times got very ill. The two experiences were very different (different symptoms) and although I did not end up in the hospital, I came very close to having to go the second time."*
- *"Strangest thing. My diabetes management and readings were good and then I got covid at the end of April and I have not been able to control my blood sugar ever since."*
- *"It was awful. I had both doses at the time and was sick for the full 14 days. My blood sugar was harder to control (as it usually is when [a person with type 1 diabetes] is sick). I felt so stressed and sick. I was very worried about potentially giving it to the people I live with, although I isolated from them fully. I also still somewhat worry if I have long term side effects from it."*



- *“Having a [CGM] or real-time [CGM] I would say is essential when you’re just trying to focus on feeling well and getting rest. There have been times where I just didn’t feel well enough to get up/wanted to conserve my energy and the [CGM] alarm sounded. So it was good in that sense, it reminded me to get up.”*
- *“Sick day management was stressful.”*

What Respondents Value from Diabetes Canada

Responses showed that Diabetes Canada plays a critical role in the lives of many people affected by diabetes, as a trusted source of information, a collective “voice” through advocacy efforts, and a provider of a sense of community. Diabetes Canada-curated assets (e.g., website, social media channels, videos, newsletters, and content like recipes) were cited as go-to sources of information, with an increasing emphasis on digital education content. Conferences and D-Camps, which provide a sense of connection and community to many, are highly valued by the cohorts they serve. When asked what they want more of from Diabetes Canada, respondents requested more advocacy for access to medications and devices, supports and financial assistance, more information or education on a wider range of issues, and more proactive communications about Diabetes Canada’s work and mandate.

Products and Services

Before March 2020, respondents most commonly accessed Diabetes Canada’s website and Facebook page. Moderately popular products reaching roughly one-third of respondents included online publications such as recipes, webinars, assorted videos, and regular publication *The Diabetes Communicator*; less frequently accessed were podcasts and patient conferences. D-Camps were accessed by a comparatively small cohort but assigned a high degree of importance.

Since March 2020, while Diabetes Canada’s website and social media posts remained the most popular, webinars, conferences, and video content rose significantly in popularity and COVID-19-related content has maintained a position of priority. Participants also continued to value more traditional offerings such as recipes, printed materials, and newsletters.

The assets that most often ranked in respondents’ top 3 were social media posts, the Diabetes Canada website, D-Camps for kids with type 1 diabetes, and type 1 and type 2 conferences. D-Camps was most often ranked first, by 39% of respondents.



Diabetes Canada's Role

201 individuals responded to share other ways they would like to see Diabetes Canada support them. Proposed methods of support focused on the distinction between type 1 and 2 diabetes, amendments to make educational content more accessible, expanded advocacy efforts (and promotion of said efforts), a return to in-person events and provision of support groups, and efforts aimed at destigmatizing diabetes. Some individuals with type 2 diabetes felt that their needs are not adequately represented in Diabetes Canada's advocacy initiatives, while people with type 1 diabetes expressed a desire to see more information shared about the complications of the disease, and expanded advocacy for access to technologies across the country. Many individuals expressed a desire to return to in-person conferences and support or mentorship groups, and a demand remains for culturally relevant and population-specific content.

Overall, Diabetes Canada plays a very important role for most participants. Respondents most valued Diabetes Canada information and educational resources, advocacy efforts, the sense of connection and support the organization provides, the research it supports, and D-Camps.

Conclusion

Respondents placed a high value on advocacy efforts, educational content, and opportunities to engage with a broader community; proposed changes included increased advocacy for equitable access to medications and devices, greater promotion of said advocacy efforts and clear calls for the community to be involved, and a return where possible to in-person or hybrid opportunities for learning and connection. Individuals with both type 1 and type 2 diabetes reported a desire for more distinction between types and more discussion on complications and self-management strategies in Diabetes Canada messaging. It was also noted (and reinforced by the survey's demographics) that more content is required for diverse audiences and marginalized groups, along with more targeted outreach to those historically not reached by the organization. Respondents also noted that the survey itself was quite long and all-encompassing, and many shared that they would be more likely to participate in more targeted or issue-specific evaluations in future.