



# Results of Patient & Caregiver Survey

May/June 2021

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**DIABETES**  
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## ***Executive Summary***

The summary of these findings, which were generated through a public survey in May & June 2021 to which nearly 800 Canadians responded, is presented in three parts. These data will be further analyzed and used to inform Diabetes Canada's advocacy, policy and strategy going forward. Compared to the results of the June 2020 survey, this year's results are fairly consistent, with respondents exhibiting a bit more frustration and exhaustion with COVID-19 and a bit less fear, and more requests for Diabetes Canada to focus on advocacy for access to medications, devices, and supplies. New to the 2021 survey is vaccine-specific questions, which highlighted a general feeling of hope for the future and frustration around government rollout and communications. Throughout the pandemic, it was noted that Diabetes Canada has maintained a strong position, especially in patient education and opportunities for connection, and holds a valued place in patients' lives.

### ***1. Respondents' experiences of COVID-19 (Q7-Q20)***

Like for other Canadians, COVID-19 has been a stressor for respondents, many of whom report 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 had struggles with accessing medications or health care. A substantial minority have experienced added financial worries since the onset of COVID-19 that affect their ability to manage their diabetes. Respondents are quite split on level of concern for personal physical, mental and emotional health, and on experience of feelings of anxiety and isolation. A third of respondents have had medical appointments canceled or deferred, but luckily that has not affected the health of most of them adversely, though it has been stressful for many. About half of respondents have had virtual medical visits since the pandemic started, which they have overwhelmingly enjoyed. Most would prefer more virtual visits in future, continuing after the COVID-19 pandemic, and a majority support provincial and territorial shifts to virtual care. Roughly three-quarters of respondents have received one of two doses of the COVID-19 vaccine, with roughly 10% fully vaccinated and a similar amount not yet vaccinated. Attitudes toward the vaccine were overwhelmingly positive and hopeful, with many respondents also expressing frustration with governments' rollout, communication, and lack of prioritization for people living with diabetes; a small minority expressed outright distrust and refusal to receive the vaccination.



## **2. What respondents value from Diabetes Canada (Q21-Q26)**

Responses show overwhelmingly that Diabetes Canada plays a critical role in patients' lives by providing them with a trusted source of information, a sense of community and a "voice" through our advocacy. Our digital communications resources (website, social media channels, videos, newsletters, and content like recipes) are the go-to source of information and advice for many, 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 smaller cohort 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 range of issues, and more proactive communications about what we do for them. Most felt that if Diabetes Canada weren't there, it would be a shocking and significant loss to the diabetes community.

## **3. Demographics (Q1-Q6 and Q27-Q32)**

Most respondents were women aged over 50 and identify as Caucasian. A majority are from Ontario, British Columbia and Alberta. Most respondents live with diabetes themselves and were about equally split between T1D and T2D. While a bit more than half of respondents have no complications, the most reported ones were high blood pressure, high cholesterol, arthritis, and obesity. Most respondents use diet, blood glucose monitoring and exercise to manage their diabetes. Respondents are roughly split in terms of their use of oral medication vs. Insulin, and almost half use advanced glucose monitoring systems. A majority of respondents share their diabetes data digitally with their clinics, while about a quarter still share their diabetes information manually.



## **Introduction**

A survey was conducted in May & June 2021 to understand the COVID-19 pandemic's impact on people affected by diabetes (PAD) and their health, how they have managed and adapted, and their needs going forward. A total of 780 people responded. Below is a summary of their responses.

## **Methodology**

This survey was conducted on SurveyMonkey and available to the public between May 14 and June 17, 2021. It was publicized on Diabetes Canada's social media channels, through partners and via e-blast. 780 individuals' responses to the survey are provided below and have been rounded to the nearest decimal point.

## **Survey Responses**

### **1. Please select the answer that best describes you. (n=778)**

Most respondents live with diabetes while 11% care for those who do. 86% (667) of respondents live with diabetes themselves; 11% (89) are a caregiver and 3% (22) are both.

### **2. What form of diabetes do you or the person you care for live with? (n=774)**

Respondents were nearly equally split among those who live with T1D and those who live with T2D or another form. 47% (360) of respondents live with T1D; 52% (400) with T2D and 1% (6) with another form (MODY, monoclonal, etc.). 1% (6) reported not knowing which type of diabetes they live with, and <1% (2) live with gestational diabetes.

### **3. How long have you or the person you care for lived with diabetes? (n=777)**

There was a wide distribution in the number of years respondents had been affected by diabetes, with a 70% (543) majority reporting more than 10 years.

### **4. Do you or the person you care for live with any complications of diabetes? (n=738)**

While roughly 1/5<sup>th</sup> of respondents reported living with no complications, the most commonly reported ones were high blood pressure, high cholesterol, arthritis, and obesity. 22% (159) of respondents report no complications. Responses are provided below in order of prevalence:

- High blood pressure 43% (315)
- High cholesterol 32% (235)



- Arthritis 28% (210)
- Obesity 25% (181)
- Neuropathy 21% (152)
- Heart disease 18% (133)
- Retinopathy 15% (114)
- Mental illness 13% (97)
- Nephropathy 6% (45)
- Gastroparesis 4% (31)
- Foot ulcers or amputation 2% (18)

17% (123) of respondents listed other complications including lipid imbalances, thyroid disease, hypertension, mood disorders, celiac disease or other stomach/gut problems, osteoporosis, infections and difficulty healing. Of the 579 respondents who indicated complications, the average individual reported nearly 3 (2.86) distinct complications.

##### **5. Which diabetes therapies or technologies do you/the person you care for currently use to manage your diabetes? [Please select all that apply.] (n=777)**

Most respondents use diet, blood glucose monitoring and exercise to manage their diabetes. Respondents are roughly split in terms of their use of oral medication vs. insulin. Nearly half (47%) use advanced glucose monitoring systems. Notably, compared to 2020, use of continuous glucose monitoring (CGM) systems have risen 8% among survey respondents. Therapies listed are provided below in order of prevalence:

- Diet 60% (470)
- Blood glucose monitor (finger stick style) 59% (458)
- Exercise 57% (446)
- Oral diabetes medication 44% (344)
- Insulin injection 41% (316)
- Continuous glucose monitor system (e.g. Dexcom, Guardian) 27% (213)
- Insulin pump 27% (212)
- Flash glucose monitor system (e.g. Freestyle Libre) 20% (153)
- Glucagon (injected or nasal) 9% (71)
- Non-insulin injectable (e.g. GLP-1) 4% (33)



## **6. Please indicate how you share your diabetes information with your health care team? (n=770)**

A majority of respondents share their diabetes data digitally with their clinics, while about a third still share information manually. Approaches are provided in order of prevalence.

- Blood tests (HbA1C) at a lab 80% (613)
- Manually (e.g., using a logbook) 26% (199)
- Upload insulin pump data (eg. Carelink, t:connect or Diasend) 21% (161)
- Upload/email reports from an advanced glucose monitor 17% (131)
- Cloud-based sharing of advanced glucose monitor (flash or CGM) data 15% (113)
- Upload finger stick glucose monitor results 13% (97)
- Cloud-based sharing of insulin pump data 4% (27)
- Cloud-based sharing of finger stick glucose monitor results 2% (13)
- Other 9% (68) – note: responses under this category were a mix of options provided above.

## **7. How have you or the person you care for been managing with medications and/or medical devices (e.g. glucose test strips, insulin pumps, advanced glucose monitors and supplies, etc.) during the pandemic? [Select all responses that apply.] (n=741)**

For a significant majority of respondents, access to medications and devices has not changed. About 6% struggle with the costs of treatments right now, down from 1/5<sup>th</sup> of respondents in June 2020. Responses are listed in order of prevalence.

- I have been able to access my medications, medical devices and/or supplies without interruption 87% (646)
- I am worried about being able to continue to afford my medications, medical devices and/or supplies 17% (127)
- I do not use any medications or medical devices 2% (13)
- I cannot afford or access 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 (please elaborate) 6% (48)



**9. To what extent do you agree with the following statements about your physical, emotional, or mental health currently? [Select one response only for each item.] (n=742)**

Most respondents are concerned about their risk of contracting COVID-19; most also report having access to mental health strategies and supports. Results are quite split on level of concern for personal physical, mental and emotional health, and on respondents' experience of feelings of anxiety and isolation. Compared to 2020, there was a marked increase in respondents reporting worsened exercise and nutrition habits; however, respondents also reported spending more time in blood glucose target range. A dramatic shift also took place on feelings of concern surrounding hospital or clinic visits: far fewer respondents reported being worried about accessing healthcare in the event that they need medical attention.

| <b>Health Status</b>  | <b>Strongly agree</b> | <b>Agree</b>  | <b>Not sure</b> | <b>Disagree</b> | <b>Strongly disagree</b> | <b>Not applicable</b> |
|---|-----------------------|---------------|-----------------|-----------------|--------------------------|-----------------------|
| I am worried about contracting COVID-19 (n=705)   | 31.35%<br>221         | 43.97%<br>310 | 8.23%<br>58     | 11.49%<br>81    | 3.40%<br>24              | 1.56%<br>11           |
| Given the risks of COVID-19, I have concerns about going to the doctor's office or a hospital if I have a health condition that needs medical attention (n=721) | 18.31%<br>132         | 34.81%<br>251 | 11.51%<br>83    | 24.41%<br>176   | 9.57%<br>69              | 1.39%<br>10           |
| I have concerns about my current physical health (n=733)  | 13.23%<br>97          | 39.02%<br>286 | 10.37%<br>76    | 26.47%<br>194   | 8.59%<br>63              | 2.32%<br>17           |
| I have concerns about my current mental health (n=724)  | 10.91%<br>79          | 25.83%<br>187 | 15.88%<br>115   | 29.83%<br>216   | 13.81%<br>100            | 3.73%<br>27           |
| I have concerns about my current emotional health (n=734)   | 11.99%<br>88          | 30.79%<br>226 | 13.62%<br>100   | 27.52%<br>202   | 12.40%<br>91             | 3.68%<br>27           |
| If needed, I have access to mental health support (n=723)   | 9.68%<br>70           | 42.60%<br>308 | 25.17%<br>182   | 10.10%<br>73    | 5.53%<br>40              | 6.92%<br>50           |
| I have mental health strategies and resources that I use on my own to help me cope (n=734)  | 9.67%<br>71           | 46.87%<br>344 | 17.03%<br>125   | 11.17%<br>82    | 4.63%<br>34              | 10.63%<br>78          |
| I am feeling anxious or nervous (n=723)   | 13.97%<br>101         | 31.95%<br>231 | 12.17%<br>88    | 25.73%<br>186   | 11.20%<br>81             | 4.98%<br>36           |



| Health Status   | Strongly agree | Agree         | Not sure      | Disagree      | Strongly disagree | Not applicable |
|---|----------------|---------------|---------------|---------------|-------------------|----------------|
| I am feeling isolated and alone because of COVID-19 restrictions (n=733)          | 13.10%<br>96   | 28.10%<br>206 | 9.82%<br>72   | 31.51%<br>231 | 11.73%<br>86      | 5.73%<br>42    |
| I have been having more trouble getting enough sleep since COVID-19 began (n=732) | 12.84%<br>94   | 23.91%<br>175 | 12.98%<br>95  | 30.19%<br>221 | 14.75%<br>108     | 5.33%<br>39    |
| I am worried about my physical safety during COVID-19 (n=730)                     | 10.55%<br>77   | 24.11%<br>176 | 12.19%<br>89  | 35.62%<br>260 | 12.74%<br>93      | 4.79%<br>35    |
| I have concerns about my current financial situation (n=723)                      | 11.20%<br>81   | 20.89%<br>151 | 9.96%<br>72   | 32.78%<br>237 | 18.12%<br>131     | 7.05%<br>51    |
| I have been exercising less during COVID-19 (n=731)                               | 16.55%<br>121  | 33.65%<br>246 | 6.57%<br>48   | 24.21%<br>177 | 14.77%<br>108     | 4.24%<br>31    |
| I feel that I have been eating less healthy during COVID-19 (n=728)               | 8.24%<br>60    | 24.59%<br>179 | 10.85%<br>79  | 37.23%<br>271 | 15.25%<br>111     | 3.85%<br>28    |
| My glucose levels have been in target range more during COVID-19 (n=735)          | 5.58%<br>41    | 28.84%<br>212 | 19.59%<br>144 | 33.06%<br>243 | 8.84%<br>65       | 4.08%<br>30    |
| I have developed new complications of diabetes since COVID-19 began (n=736)       | 3.80%<br>28    | 7.47%<br>55   | 14.27%<br>105 | 33.83%<br>249 | 27.99%<br>206     | 12.64%<br>93   |

### 10. Is there anything else that has been concerning you lately about your physical or mental health? (n=325)

A number of the respondents commented on the added stress and anxiety associated with the pandemic; many referenced challenges accessing primary health care, mental health supports, and specialists for issues like foot care. Many mentioned ongoing feelings of isolation, apathy, and sadness due to pandemic-induced restrictions. Several noted changes in their insulin needs, and a few mentioned struggling to maintain motivation to manage their diabetes; many noted the challenges of weight gain and maintaining regimented eating and exercise. Vaccination rollout and prioritization (or lack thereof) was a source of stress for many. Some sample quotes of note include:

- The social isolation and limited physical activities has resulted in increased anxiety, stress and decreased my physical health.



- Comfort eating a lot more and irregular sleep patterns. Finding it hard to be motivated
- Going without routine medical care for almost a year and a half is making my physical health suffer. Also I suffer from OCD which is clearly been very intense during this.
- Wish I could find T1D virtual support groups for older women/men in Toronto. Hopefully to be in person group sessions soon.
- My doctor is not seeing patients. He is also not willing to refer me to specialists in regards to some serious warning signs I have about potential health risks. The walk-in clinics near me are closed. My only option has been to go to Emergency Departments. I have no credit card, no vehicle, and no social network of family or friends to assist me in my urgent need for proper and complete medical care, doing errands, and just no one to talk to. Very isolated, although I have often been alone, so have many coping mechanisms to deal with this. The most difficulty I have now is getting free access to the care I need.
- Depressed about not seeing friends and socializing. Sad about the state of workers and residents of Long term care homes. Increase in weight. Treatment of low blood sugars wear me down, physically and mentally.
- Cannabis use.
- My health is declining quickly because I cannot afford to buy my prescriptions, insulin and supplies
- Lack of intimacy has got me down
- Not being able to do spiritual indigenous practices
- The provincial governments (specifically Alberta and Ontario) disregard and dismissal of the severity of COVID has frequently made me worry about my healthy and safety as well as my community and the country at large.
- Family stress on relationships because of living in total lockdown, virtual schooling, delivery of all goods since March 2020. Very socially isolated!
- why people with Tye 1 diabetes are not a priority group for vaccination!
- I am unmotivated to eat properly. I am tired of having diabetes.
- Priority of someone who has type one diabetes with neuropathy and gastroparesis AND who is an essential worker, working with the public to get a Vaccine, I was discriminated against when I was getting my first dose (which I had to wait for less vulnerable people to go first). While trying to get my first dose I was told I do not "look unhealthy enough" and was accused of lying about my diabetes.

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**11. Have you or the person you care for had any health-care appointments changed or cancelled due to COVID-19 and public health restrictions? [Select one response only.] (n=739)**

Nearly half of respondents have had a virtual medical visit, a third have seen their care go unchanged, and the remainder have had a visit canceled or deferred. 8% (61) reported that yes, it was cancelled, I was not given a new booking date. 14% (105) said yes, it was changed, and it was rebooked for a future date. 43% (316) had their visit rescheduled as a virtual appointment (by telephone and/or video) and 35% (257) have not had any changes to my medical appointments since COVID-19 started.

**12. What was the purpose of the appointment(s) that was/were changed or cancelled? [Select one response only.] (n=628)**

Most of the canceled or deferred visits were for regular follow-up, but some were for new or worsening symptoms or procedures.

- It was for my regular follow-up 66% (417)
- I or the person I care for was having new symptoms and needed to see my health-care provider 8% (49)
- It was for a procedure or surgery (e.g., operation) 6% (39)
- I or the person I care for was having worsening symptoms and needed to see my health-care provider 5% (32)
- Other 14% (91)

**13. If your appointment was delayed or cancelled, how did that affect your health? [Select all responses that apply.] (n=558)**

Fortunately, for most people, appointment delays did not affect their health, although 23% reported that the change was stressful for them. For 11%, their symptoms became worse following the delay.

- My health was not affected by the delay or cancellation 73% (405)
- My symptoms became worse 8% (42)
- My symptoms became worse and I had to seek emergency healthcare 3% (16)
- My symptoms became better or resolved 1% (8)
- The change made me feel stressed or anxious 23% (126)



**14. Have you had a virtual health-care appointment (by phone or video) in the last 3-6 months due to COVID-19 public health restrictions? [Select all that apply.] (n=709)**

Most who have had virtual visits had phone calls; video calls were comparatively rare. For those who selected “other,” respondents referenced engaging via both phone and video, and one individual highlighted the challenges of accessing virtual care for the deaf.

- Yes, a **phone call** with a member of my health-care team (e.g., doctor, nurse, rehabilitation therapist, etc.) 75% (533)
- Yes, a **video call** (using a camera as well as talking to them) with a member of my health-care team (e.g., doctor, nurse, rehabilitation therapist, etc.) 11% (78)
- No 11% (77)
- Other (please specify) 3% (21)

**15. How much do you agree with each of the following statements about your virtual appointment? [Select one response only for each item.] (n=693)**

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 claimed to miss the sense of ease that accompanies in-person visits, most would prefer more virtual visits in future, even after COVID-19 ends. There is strong support for ongoing provincial and territorial investments in virtual care.

|   | <b>Strongly agree</b> | <b>Agree</b>  | <b>Not sure</b> | <b>Disagree</b> | <b>Strongly disagree</b> | <b>Not applicable</b> |
|---|-----------------------|---------------|-----------------|-----------------|--------------------------|-----------------------|
| It was as good as if we were together in person (n=682)         | 9.97%<br>68           | 33.87%<br>231 | 11.14%<br>76    | 30.21%<br>206   | 8.06%<br>55              | 6.74%<br>46           |
| I felt more at ease than I have during in-person visits (n=684) | 5.56%<br>38           | 16.67%<br>114 | 16.81%<br>115   | 40.64%<br>278   | 11.11%<br>76             | 9.21%<br>63           |
| It was convenient and saved me from having to go out (n=683)    | 23.87%<br>163         | 49.34%<br>337 | 4.10%<br>28     | 10.69%<br>73    | 5.12%<br>35              | 6.88%<br>47           |
| I was nervous about using the technology (n=678)                | 1.92%<br>13           | 8.11%<br>55   | 5.31%<br>36     | 41.00%<br>278   | 30.38%<br>206            | 13.27%<br>90          |



|   | <b>Strongly agree</b> | <b>Agree</b>  | <b>Not sure</b> | <b>Disagree</b> | <b>Strongly disagree</b> | <b>Not applicable</b> |
|---|-----------------------|---------------|-----------------|-----------------|--------------------------|-----------------------|
| The sound quality was good / I could hear the provider well (n=682)                                     | 28.30%<br>193         | 49.27%<br>336 | 3.52%<br>24     | 6.30%<br>43     | 2.79%<br>19              | 9.82% 67              |
| The visual quality was good, I was able to see the provider and they could see me (n=665)               | 7.52%<br>50           | 15.04%<br>100 | 4.81%<br>32     | 4.66%<br>31     | 1.35%<br>9               | 66.62%<br>443         |
| I was able to ask questions and get answers (n=684)   | 24.71%<br>169         | 57.31%<br>392 | 3.95%<br>27     | 4.82%<br>33     | 1.61%<br>11              | 7.60% 52              |
| I felt that the health-care provider was listening to me (n=680)  | 29.71%<br>202         | 51.32%<br>349 | 6.76%<br>46     | 3.82%<br>26     | 1.76%<br>12              | 6.62%<br>45           |
| I was able to have a family member or caregiver join the call from a different location than me (n=676) | 3.55%<br>24           | 8.43%<br>57   | 4.59%<br>31     | 6.51%<br>44     | 2.37%<br>16              | 74.56%<br>504         |
| I found it distracting and hard to focus (n=673)  | 2.53%<br>17           | 8.02%<br>54   | 7.58%<br>51     | 38.19%<br>257   | 25.85%<br>174            | 17.83%<br>120         |
| I had some concerns about my privacy during a virtual visit (n=674)                                     | 1.34%<br>9            | 4.90%<br>33   | 5.64%<br>38     | 35.46%<br>239   | 29.82%<br>201            | 22.85%<br>154         |
| I would prefer more virtual visits in the future even after COVID-19 restrictions are lifted (n=679)    | 13.55%<br>92          | 25.04%<br>170 | 19.15%<br>130   | 18.85%<br>128   | 15.02%<br>102            | 8.39%<br>57           |
| I would support the provincial government continuing to fund and invest in virtual care (n=682)         | 22.29%<br>152         | 37.68%<br>257 | 18.77%<br>128   | 7.62%<br>52     | 7.18%<br>49              | 6.45%<br>44           |



## **16. Please share any comments about your virtual care experience. (n=213)**

Many respondents lamented the lack of in-person contact for foot screening, physical examinations, and connection with healthcare providers. A number of concerns were raised on the system's efficiency and operations (i.e., use of Zoom vs. telephone, difficulty with training, etc.), while many praised the opportunity and increased accessibility of care providers. Many anecdotal concerns around physician or diabetes educator attitudes were raised, with concerns of dismissiveness and inaccessibility. Some sample quotes of note include:

- Still 90s technology - phone only. No really telehealth. Not to mention no real e-health records. Canada/Ontario waaay behind leading countries...
- It was difficult to diagnose from photos
- The issues that made virtual less effective than in person was the inability for blood pressure checks or foot exams; everything else was pretty good
- have not had one from my Family Dr. They have not responded to my request for an appointment in over a year.
- My health care providers can't see the physical changes to my body, issues with injection sites, monitor my weight, etc by phone or video call. I feel like my health care providers can't give me the help I need because they can't see how bad my body has become. Patients don't seem as real to health care providers when they aren't there in person. I am not taken seriously over the phone.
- Would prefer funding for a CGM over virtual visits!!
- gets right to the point.... less distracting.....more relaxing
- With the A1C report telephone conversion is great. Saves time and money traveling and waiting in office with other peoples' germs etc. In person is better for showing any physical body problems. Lumps, bumps and rashes
- Due to my hearing (I wear current hearing aids and have an enhanced phone ) I still have sound problems. Also the amount of time allowed for the virtual meeting is not enough to discuss some questions and answers
- Positive, but large anxieties over showing my face on video (has a panic attack before the first video call)
- All is.crap and useless as I am deaf. 911 need update to use text. Pointless on visit doctors.
- Very comfortable with it. Also ability to renew prescriptions makes so much sense.
- the Abbott Libre system was critical to my feeling safe, able to monitor my self & communicate with my team about glycemic issues VERY effectively using a virtual



platform. If it were not for the "libre View" system and the decision support it offers me and my team, i would have ended up in ER 3 times over the last 6 months.

**17. Thinking about COVID-19 and how it has impacted your health, what would you say is the most challenging or difficult aspect for you to cope with right now? (n=578)**

The most commonly reported impact was on feelings of isolation or loneliness [183 (32%)], followed by mental health, with 23% (134) reporting anxiety, stress, depression or anger. While 5% (29) said they were doing alright, a significant portion expressed concerns about physical activity [10% (55)], a decline in their general health [7% (38)], or their nutrition [4% (20)]. Compared to 2020 responses, mentions of fatigue, apathy, and burnout were notably, and understandably, higher.

**18. I live with diabetes and contracted COVID-19. Here is my story: (n=179)**

The vast majority reported no experiences with COVID-19, with only 11 (6%) reporting direct personal or family experience with the virus. A number of the respondents commented on the added stress and anxiety associated with the pandemic and the need to be even more careful because of having diabetes, and fears about going back to work and accessing health care. Some sample quotes of note include:

- I teach in a middle school and feel the Alberta government has done nothing to protect workers and students. I have had to choose between my health and my career.
- My whole family was infected (husband and 3 teen kids). After 5 days caring for them for fevers, coughs, sore throats, muscle and body pains, headaches, disinfecting, cleaning, washing house from top to bottom, I got sick. Fighting high fevers and pain for over 3 weeks, 2 visits to the emergency room at the Civic Hospital, I was sent home with Tylenol. It was my 3rd desperate visit to the emergency room that an 'angel' of a doctor in the ER of a Covid Clinic took pity on me and ordered several tests and x-rays. They confirmed I had a superimposed bacteria over Covid, and had a bad Pneumonia. Lungs were affected. Finally they prescribed two different strong antibiotics and an inhaler that helped in my slow recuperation. Two months in bed, and not able to work. Finding some days that I was too tired to keep fighting and breaking in sobs. I finally say, I can see the light at the end of the tunnel. Still suffering from intense fatigue, and exhaustion. Praying everyday, that I will get better soon and be back to my old self.



- I had Covid-19 in December, 2020 and ended up in the hospital for 2 weeks. I was cared for very well and the staff at the South Health Campus are wonderful. I still tire very easily but I am a senior so I expect it.
- I contracted diabetes when my dad who unfortunately passed away from COVID-19 was in the ICU and thankfully my case was very mild with no complications but I lost my dad and one of the breadwinners of my family. Since then I have been coping in therapy and with a psychiatrist with both grief and mental illness.

### **19. Have you or the person you care for received the COVID-19 vaccine? (n=689)**

Roughly three-quarters of respondents have received one of two doses of a COVID-19 vaccine – at the time of writing, this is aligned with and slightly higher than national vaccination rates. Approximately one-tenth are fully vaccinated, and a similar subset is not vaccinated with 1% reporting being ineligible.

- Yes, I or they are fully vaccinated 12% (86)
- Yes, but only one of two doses 76% (527)
- No 10% (67)
- No, because I or they are not eligible 1% (9)

### **20. What is your attitude toward the COVID-19 vaccine? (n=605)**

The overwhelming position is one of hope, positivity, and support. The most common attitudes expressed centred around a hope to quickly receive full vaccination, anxiety around variants of concern, and disappointment or frustration with government management of information and vaccine prioritization. As evidenced below, there was a small but vocal minority that appeared to have been swayed by misinformation and was nervous to the point of refusal to receive the vaccine; overall, this represented a small fraction of respondents. Some sample quotes of note include:

- i am an essential worker with a serious autoimmune disease and other special interest groups bypassed the age requirement and had no medical condition. type 1 diabetics should have been better protected
- I think the roll out has been a total fail and I should not be waiting this long or having to fight this hard to get my vaccines.
- Nervous at first but now I completely support it.
- I don't trust it. There hasn't been enough research and I prefer waiting to see what the long term side effects are....
- Very nervous. I was worried it could trigger another autoimmune reaction. Also, there are many people that are against it.
- I want the second one ASAP!!! Vax me up baby!!!



- I plan to get both doses. Would like to know more diabetes related information about the vaccine.
- Don't believe in Covid and not getting it and don't trust the Vaccine Agreed that we should all get vaccinated. Worried that complications will be discovered years from now for people who got vaccinated.
- I had covid, so my immunity is better than the Vaccine as well as i am not interested in a experimental vaccine
- I was scared at first, but I know it's the only thing that will give me a chance to have more protection. I really do not want to go through it again. I also want to see my family again abroad one day.
- Positive. Anger at those who will not take it.

**21. What Diabetes Canada products or services did you access before March 2020?  
[Select all that apply.] (n=531)**

Respondents most commonly access Diabetes Canada's website and Facebook channel. Diabetes Communicator is used by a third of respondents. Moderately popular products include our recipes, webinars, videos and D-Camps (note: these are only accessible by a small cohort). Less frequently accessed products are our podcasts, Twitter and LinkedIn feeds, T1D conferences and family D-Camps.

- Diabetes Canada website 58% (307)
- Facebook posts 34% (178)
- Diabetes Canada webinars 23% (124)
- Other (please specify) 20% (105)
- Diabetes Communicator newsletter 15% (82)
- Recipes on website or YouTube Channel 14% (72)
- Printed materials 13% (68)
- No Limits with T1D conferences 12% (66)
- Videos on YouTube channel 12% (62)
- Instagram posts 7% (39)
- Twitter posts 7% (37)
- D-Camps for kids with type 1 diabetes 6% (31)
- Diabetes Canada podcast 5% (24)
- LinkedIn posts 4% (19)
- D-Camps for families of kids with type 1 diabetes 2% (8)



## 22. What Diabetes Canada products or services have you accessed since March 2020? [Select all that apply.] (n=510)

While Diabetes Canada's website and Facebook feed remained the most popular, webinars and video content rose significantly in popularity and COVID-19-related content represented a popular suite of products. Participants also valued traditional offerings such as recipes, printed materials, and newsletters.

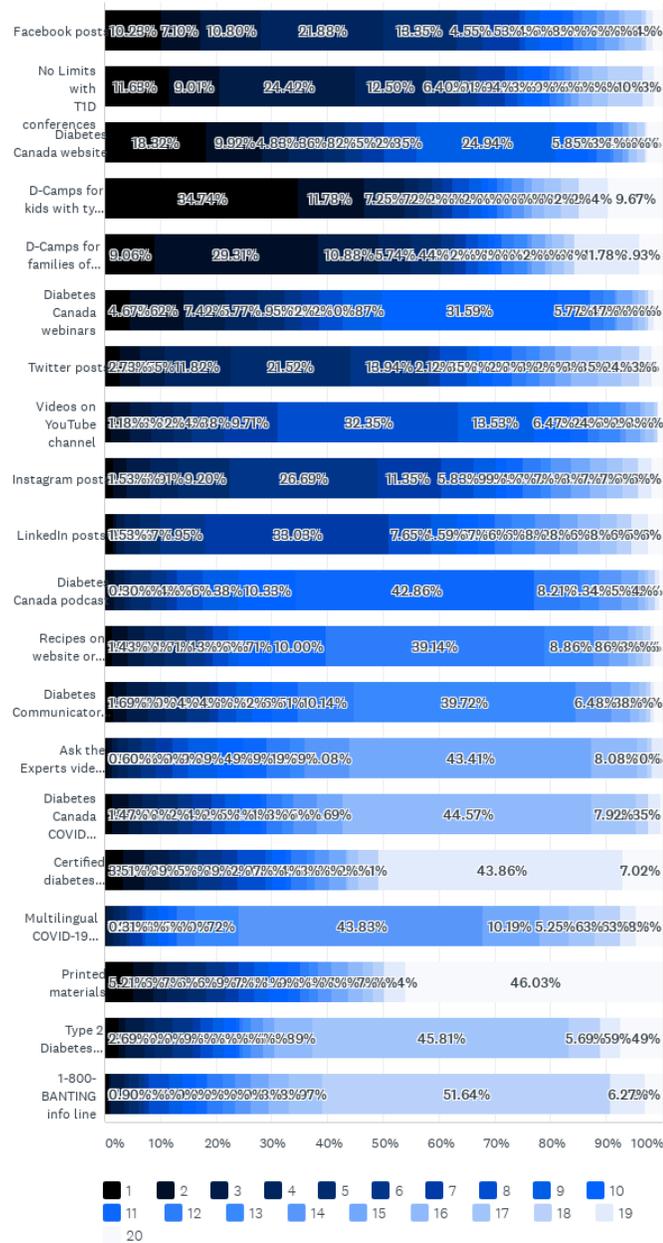
- Diabetes Canada website 57% (289)
- Facebook posts 36% (182)
- Diabetes Canada webinars 28% (143)
- Other (please specify) 15% (79)
- Recipes on website or YouTube channel 15% (74)
- Printed materials 13% (68)
- Diabetes Communicator newsletter 13% (64)
- Videos on YouTube channel 13% (64)
- \*Diabetes Canada COVID-19 webpage 12% (62)
- °No Limits with T1D conference 11% (55)
- Instagram posts 9% (48)
- Twitter posts 8% (42)
- \*Type 2 Diabetes Virtual Education Programs 7% (35)
- \*Ask the Experts Video Series 6% (31)
- Diabetes Canada podcast 4% (19)
- Certified diabetes educator access through Diabetes Canada info line 3% (16)
- \*Lace Up to End Diabetes 3% (14)
- LinkedIn posts 3% (14)
- 1-800-BANTING info line 2% (10)
- °D-Camps for kids with type 1 diabetes 2% (10)
- °D-Camps for families of kids with type 1 diabetes 1% (5)
- \*Multilingual COVID-19 webinars 1% (4)

(\* indicates new products since March 2020, ° indicates product unavailable between March 2020 and survey period)



**23. Please rank Diabetes Canada products and services in terms of their value to you/the person with diabetes whom you are caring for. [Please rank from highest value to lowest value.] (n=472)**

Our most valued products are Facebook posts, No Limits with T1D conferences, our website, D-Camps (from both a child and family perspective), and webinars. Likely attributable to their relative novelty or limited capacity, respondents placed lower value on the 1-800-BANTING info line, multilingual webinars, Ask the Experts, the COVID-19 webpage, and our T2D Virtual Education program (which limits the number of participants). Notable is the high value placed on all social media profiles and YouTube videos, which suggests that respondents are consuming a broader suite of products (i.e., video content) without outright preference for one. Least value was reported for the 1-800-BANTING info line, T2D Virtual Education program, and printed materials, with the latter ranking last most often.



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



Charitable Number: 11883 0744 RR0001



#### **24. Are there other ways you would like to see Diabetes Canada support you? (n=284)**

Overwhelmingly, respondents [118 (42%)] asked for more advocacy for access to medications and devices, supports and financial assistance. Many [33 (12%)] specifically prioritized in-person events, support groups, camps, and other forms of connection with the diabetes community. Interestingly, 5 respondents suggested we “brag” or explicitly promote more about what we do. Reference was also repeatedly made to personalized wellness programs (e.g., dietitians, fitness coaches), emerging trends in diet/exercise, and tips for vegan/vegetarian nutrition; content specifically related to race and eating disorders was requested.

#### **25. Why is Diabetes Canada important to you? (n=369)**

Diabetes Canada plays a very important role for most participants. Respondents most valued our information and educational resources [54% (201)]; the sense of connection and support we bring [17% (63)]; our advocacy [8% (29)]; and the research we support [7% (26)]. A dozen individuals expressed that the organization has declined in importance for them due to changes in content or closed regional offices, leading to a sense of reduced relevance or local presence. Some sample quotes include:

- The information provided, research done combined with my health care team is what is keeping me alive and living the best possible life with diabetes.
- Website has been very encouraging and useful information so far. I find the things I really need to know are here, practical and of which I can relate to.
- they can lobby the govt. and advocate for people who need the help
- Its not. It doesn't help my family in anyway and it is mostly geared toward Type 2
- Grew up and worked for D-Camps and value the work that it does for the T1D community
- Advocacy, research, dissemination of research about type 1, type one conferences, I was diagnosed at 40 so I never went to d-camp but it sounds like a very good experience for kids with type 1. No one can truly understand or get what this life with type 1 is. Support through diabetes Canada is appreciated and so needed by so many of us. I really like the clothing donation program for diabetes and the environment. Thank you for all you do!
- Central location for some data. Sometimes info hard to find
- It is important to people who have access to a cell or computer with Wi-Fi. I only have it at home.



- With the ever changing landscape of diabetes, I want to make sure that I am providing the support for my daughter through education and resources --- eventually passing those onto her.
- Many many years ago i liked the meal plans they had on the website but they changed the website and made it difficult to use so i stopped visiting the wesite
- Allows for peer contact and support.
- Diabetes Canada is a reputable, credible resource and strong voice and advocate for those living with diabetes and their families. I appreciate that Diabetes Canada brings together the full spectrum of those living with diabetes, their caregivers and the healthcare community. I also highly value Diabetes strong focus on education, supports and resources for those living with diabetes. Advocating for the Diabetes 360 strategy, the Disability Tax Credit and greater awareness of the impacts of life with diabetes are also invaluable efforts that DC has led.
- I just became aware of it through my DEC dietician. My first webinar was great. Nice to know there are other diabetics out there struggling like me.
- I received very little info from my healthcare team when I was newly diagnosed, and had to wait over a month for an appt for a group class with diabetes team. I felt very alone and confused. Your website helped.

**26. If Diabetes Canada no longer existed, what impact would that have on you?  
(n=381)**

While 7% (25) of those who responded to this question said it would not have much impact on them if Diabetes Canada no longer existed, the remainder noted significant impacts tied to education, access to information, connection with others, and advocacy. Sample quotes of note include:

- I believe that there would be less success stories of people living with diabetes and mortality rates would increase. This is a vital organization for those suffering and living with this disease, we need them to be present working within our health care system.
- No impact on me. I have found useful info. to reverse my diabetes elsewhere online where appropriate nutrition guidance for a T2 diabetic is provided (i.e. keto). If I had followed nutrition guidance on your website my A1C would be worse instead of now almost at normal level in a few months (started at 11.9).
- I would not be fully connected to what is going on in Canada.
- Significant impact... it is one of the very few websites I trust



- I have found plenty of other groups in UK and US which I have found to be more interactive.
- It would leave me searching for answers that would take forever to find. I think there would be a tremendous loss for resources and support for diabetics. It is a neutral ground and very informative -- without it, we are depending on our medical teams which at times can be very challenging given their workloads. I feel an organization like this one provides that bridge and opens the conversations to learn more.

**27. Which category below includes your age? [Select one response only.] (n=611)**

Over half of respondents were aged 60 years or older, and only 10% of respondents were less than 40 years old.

- 19 years or younger 1% (5)
- 20 – 29 years 3% (21)
- 30 – 39 years 6% (38)
- 40 – 49 years 14% (87)
- 50 – 59 years 17% (106)
- 60 – 69 years 26% (161)
- 70 – 79 years 25% (150)
- 80 years or older 7% (41)
- Prefer not to answer <1% (2)

**28. What category below includes the age of the person/people with diabetes whom you care for? [Select ALL that apply.] (n=284)**

Over half of the people with diabetes that respondents care for are aged over 50 years; 17% are under 20.

- 19 years or younger 17% (47)
- 20 – 29 years 8% (23)
- 30 – 39 years 5% (13)
- 40 – 49 years 10% (28)
- 50 – 59 years 14% (40)
- 60 – 69 years 17% (48)
- 70 – 79 years 19% (55)
- 80 years or older 7% (19)
- Prefer not to answer 12% (34)



**29. How do you describe yourself? [Select one response only.] (n=609)**

Most respondents identified as female or male, while 11 identified otherwise or preferred not to answer.

- Female 65% (397)
- Male 33% (201)
- Trans Male/Trans Man <1% (1)
- Trans Female/Trans Woman 0
- Genderqueer/Gender Non-conforming <1% (2)
- Two-Spirit <1% (1)
- Other identity 0
- Prefer not to answer 1% (7)

**30. In which province/territory do you live? [Select one response only.] (n=612)**

Respondents live in every province and Yukon and Northwest Territories. Only Nunavut did not have any respondents. A majority are from Ontario, British Columbia and Alberta.

Provinces are listed below in order of prevalence of respondents.

- Ontario 47% (288)
- British Columbia 19% (115)
- Alberta 12% (76)
- Manitoba 7% (41)
- Nova Scotia 5% (29)
- Saskatchewan 4% (24)
- Prince Edward Island 1% (10)
- New Brunswick 1% (9)
- Quebec 1% (9)
- Newfoundland and Labrador 1% (8)
- Outside of Canada <1% (1)
- Yukon <1% (1)
- Nunavut <1% (1)
- Northwest Territories 0



**31. Please check the group or groups that you most see yourself as belonging to [Select ALL that apply.] (n=604)**

By far the most respondents selected Caucasian. Other more common demographics include Indigenous, South Asian and Chinese. Groups are listed below in order of prevalence.

- White Caucasian (e.g., European, or British heritage) 81% (491)
- Indigenous North American (i.e., First Nations, Inuit, Métis) 3% (22)
- South Asian (e.g., Indian, Pakistani, Sri Lankan, Bangladeshi) 3% (20)
- Chinese 2% (14)
- African heritage (e.g., Black Caribbean descent) 2% (11)
- Filipino 1% (5)
- Arab 1% (5)
- Latin American/Hispanic 1% (4)
- West Asian (e.g., Iranian, Afghan) 1% (3)
- Japanese 1% (3)
- Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian) <1% (2)
- Korean 0
- Other (please specify) 5% (28)
- Prefer not to answer 3% (17)

**32. How would you classify the city, town, or Indigenous community in which you live? [Select one response only.] (n=601)**

Most respondents live in large or medium population centres, while 10% live in rural areas.

- Large urban population centre (i.e., population of 100,000 and over) 58% (347)
- Medium population centre (i.e., population of between 30,000 and 99,999) 20% (122)
- Small population centre (i.e., population of between 1,000 and 29,999) 12% (74)
- Rural area (i.e., population of less than 1,000) 10% (58)