Patient Input Template for CADTH Reimbursement Reviews

Name of Drug: faricimab
Indication: Diabetic macular edema
Name of Patient Group: Fighting Blindness Canada, The Canadian Council of the Blind, CNIB, Vision Loss Rehabilitation Canada, Diabetes Canada
Author of Submission: Dr. Larissa Moniz (FBC), Jim Prowse (CCB), Thomas Simpson (CNIB), Jennifer Urosevic (VLRC), Ann Besner (DC)

1. About Your Patient Group

Fighting Blindness Canada (FBC) is the largest charitable funder of vision research in Canada.

Over our 48-year history, FBC has contributed critical funding for the development of sight-saving treatments and cures for blinding eye diseases. By raising and stewarding funds, FBC is helping drive forward research that supports our goal of understanding why vision loss occurs, how it can be slowed and how sight can be restored.

We are an invaluable resource for individuals and families impacted by blindness, providing accurate eye health information through our website and educational events, as well as engaging with government and other stakeholders to advance better vision health policies.

The Canadian Council of the Blind (CCB) was founded in 1944 by schools of the blind and by returning blind Canadian war veterans and is recognized as the Voice of the Blind™ in Canada. The CCB is a membership-based not-for-profit, that brings together Canadians who are living with vision loss, those who are blind, deaf-blind, and the partially sighted. In doing so the Council maintains a vibrant network of active members in 80 chapters across Canada. Each chapter is unique to its geographic area and engages in a variety of social, recreational and community activities based on the interests of their local members.

A tireless advocate of the vision loss community the CCB works to promote a sense of purpose and self-esteem along with enabling the efforts of each member to achieve an enhanced quality of life. The Council through its lived experience constituency is proud of its efforts to break down barriers and remains dedicated to building public awareness and improving the well-being of people with seeing disabilities.

The Canadian Council of the Blind offers numerous programs to assist people living with vision loss, increase accessibility in all areas of vision loss life and bring awareness of vision issues to the public and government. The CCB leads initiatives that call for the provision of the very best in available medical treatments, research, and the fostering of patients’ rights without limitation or discrimination. It does this all while recognizing that vision loss and blindness are preventable.

Founded in 1918, **CNIB** is a non-profit organization driven to change what it is to be blind today. We deliver innovative programs and powerful advocacy that empower people impacted by blindness to live their dreams and tear down barriers to inclusion. Our work as a blind foundation is powered by a network of volunteers, donors and partners from coast to coast to coast.

Vision Loss Rehabilitation Canada (VLRC) is a health services organization. We provide training that enables people who are blind or partially sighted to develop or restore key daily living skills, helping enhance their independence, safety and mobility. Our certified specialists work closely with ophthalmologists, optometrists and other health care professionals, providing essential care on a referral basis in homes and communities.

The Vision of VLRC is to maximize health and independence for Canadians impacted by vision loss and our mission is to provide high-quality, integrated and accessible rehabilitation and health care services that enable Canadians impacted by vision loss to live the lives they choose.

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

2. Information Gathering

Data shared in this submission were collected through an online survey made available to Canadians living with diabetic retinopathy (DR) or diabetic macular edema (DME) during the first months of 2020. Shared across networks associated with the submitting organizations, the survey is part of a larger research project titled VIEW DR/DME (Valuation and Interpretation of Experiences with DR/DME) that received ethics approval from Advarra, one of the largest independent providers of institutional review board (IRB) services in Canada.

The intent of the survey was to learn more about the lived experiences of Canadians living with DR and DME. The goal was not to learn more about experiences of faricimab or any other specific treatment (though we did gather data and insights related to experiences of injections in general).

Instead, the data and analysis that follows provide insights into the lives of those who live with DR and DME, and who must manage and navigate the often-daily barriers and burdens that accompany these diseases. Our belief is that these perspectives are crucial, and that they can be used to guide decision-making related to treatments that can address the physical, psychological, and socioeconomic burdens associated with DR and DME.

Overview of Respondents

A total of 67 Canadians responded to the survey. Seeing as DR affects approximately 500,000 Canadians,[1] this number may seem small, but it is difficult locating and engaging with individuals with DR and DME, at least partially as a result of low disease awareness. These challenges have been discussed in various research efforts, including an article published recently by researchers associated with FBC.[2]

Out of these respondents, most were between either 61 and 80 (44.4%) or 41 and 60 (37%), with a mean age of 56.8 (SD = 13.2). Most were either working full time (38.9%) or retired (33.3%), and a majority resided in urban regions within Ontario (41.8%), British Columbia (14.9%), Alberta (13.4%), and Quebec (11.9%), followed by smaller groups within other provinces.

Table 1. Baseline characteristics of respondents (n = 67)

Characteristic	**n (%)**
Age (n = 54)	
Mean age (SD)	56.8 (13.2)
18 - 40 years	9 (16.7)
41 - 60 years	20 (37.0)
61 - 80 years	24 (44.4)
Over 80 years	1 (1.9)
Biological Sex (n = 54)	
Female	23 (42.6)
Male	31 (57.4)
Intersex	0 (0.0)
Province (n = 67)	
Ontario	28 (41.8)
British Columbia	10 (14.9)
Alberta	9 (13.4)
Quebec	8 (11.9)
Manitoba	3 (4.5)
Nova Scotia	3 (4.5)
Newfoundland	2 (3.0)
Yukon	2 (3.0)
New Brunswick	1 (1.5)
Saskatchewan	1 (1.5)
Location (n = 67)	
Urban	62 (92.5)
Rural	5 (7.5)
DME/DR in one eye or both eyes (n = 67)	
Both eyes	51 (76.1)
One eye	10 (14.9)

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[1] Ballios BG, Park T, Chaudhary V, Hurley B, et al. Identifying gaps in patient access to diabetic screening eye examinations in Ontario: a provincially representative cross-sectional study. *Can J Ophthalmol*. 2021;56(4):223-230. https://doi.org/10.1016/j.jcjo.2020.10.018

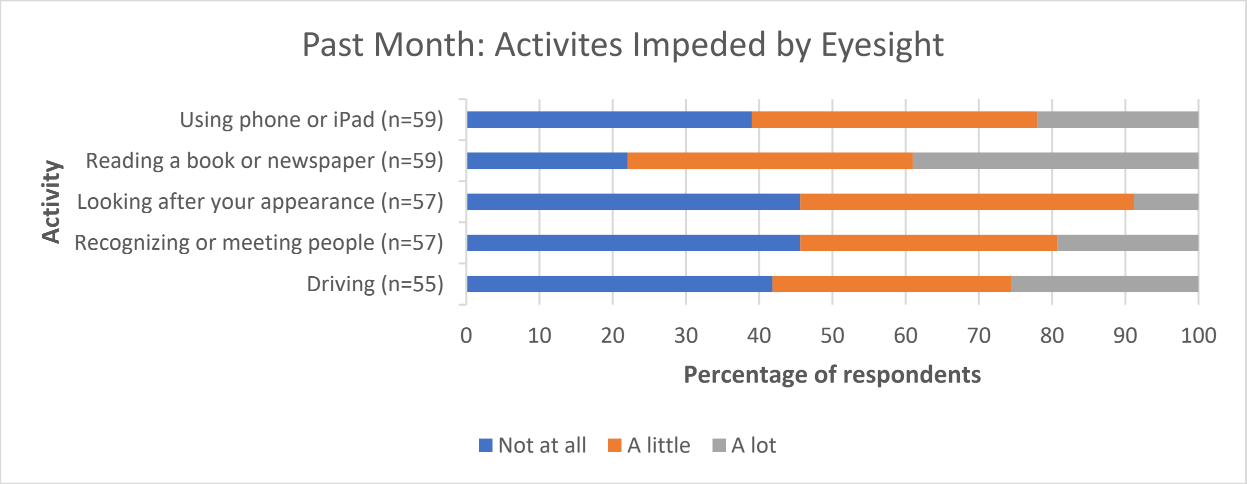
[2] Andrews C, Yoganathan P, Pereira JA. Blind Spots: Gaps in Disease Knowledge and the Role of Patient Education for Canadians with Diabetic Macular Edema. *Can J Diabetes*. 2021;45(4):375-378. doi: 10.1016/j.jcjd.2020.10.001

I don’t know	6 (9.0)
Other household members (n = 60)	
Partner/spouse	43 (71.7)
My child(ren)	16 (26.7)
No one	9 (15.0)
Family member(s) other than partner and child	3 (5.0)
I live in a retirement home	2 (3.3)
Roommate/friend	2 (3.3)
I live in a nursing home/long-term care facility	1 (1.7)
Employment Status (n = 54)	
Retired	18 (33.3)
Employed, working full-time	21 (38.9)
Employed, working part-time	0 (0.0)
Not employed, looking for work	2 (3.7)
Student	1 (1.9)
Unemployed due to illness or disability	8 (14.8)
Homemaker	0 (0.0)
Parental leave	0 (0.0)
Taking care of a family member	1 (1.9)
Other: *Employed but on disability (2), self-employed (1)*	3 (5.6)

3. Disease Experience

Respondents made it clear that both DR and DME have substantial and life-altering impacts on daily life. When asked which activities are most impact by their disease, they emphasized effects on reading, using a phone, and driving, activities that many individuals take for granted.

Figure 1. Activities Impeded by Eyesight



These difficulties were also framed in terms of “challenges.” When asked about the kinds of challenges they face as a result of DR or DME, a significant majority of respondents selected “worry that my condition might worsen in the future” (80.3%), followed by “not being able to do the daily activities I used to” (45.9%) and “explaining my condition to family and friends” (36.1%).

Table 2. Challenges with DMR/DR (n = 61)

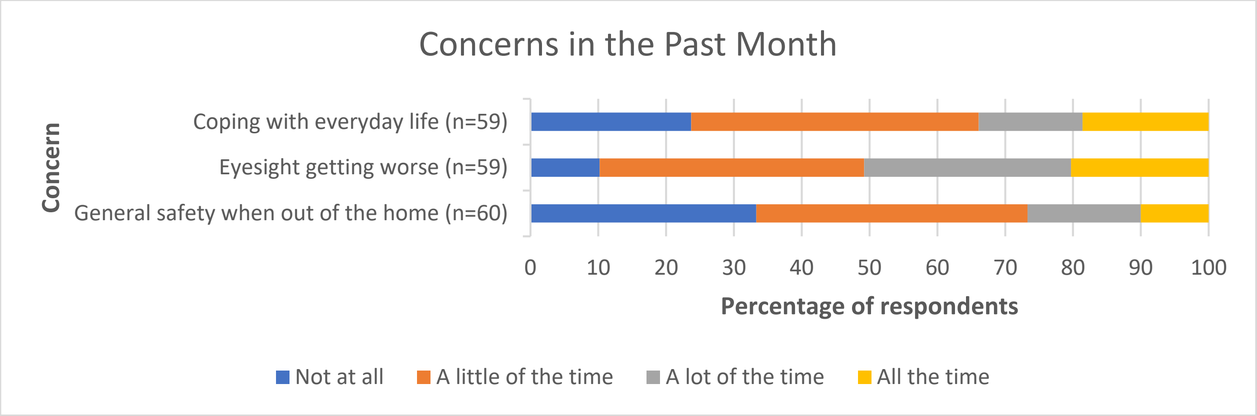
Challenges	**n (%)**
Worry that my condition might worsen in the future	49 (80.3)
Not being able to do the daily activities I used to	28 (45.9)
The long wait times for appointments	18 (29.5)
Explaining my condition to family and friends	22 (36.1)
Lack of social support	14 (23.0)
Finding answers to my questions about my condition	18 (29.5)
Socializing	19 (31.1)
Other*	5 (8.2)

**Getting the test I need prior to injections, working/finding work, no funding for technology or training, how long it takes to learn technology, getting appointments with my very busy retinologist*

The strong emphasis on worry in relation to the condition worsening implies the existence of emotional and psychological burdens as well; DR and DME may affect daily life as a result of lower visual acuity, but they may also lead to significant psychological strain in the form of a generalized anxiety related to the future. Following up on this notion, respondents were asked to specify their concerns over the last month, with many selecting that they are concerned about their eyesight worsening “all the time” or “a lot of the time.” Respondents also emphasized “coping with everyday life” and “general safety when out of the home” as notable concerns.

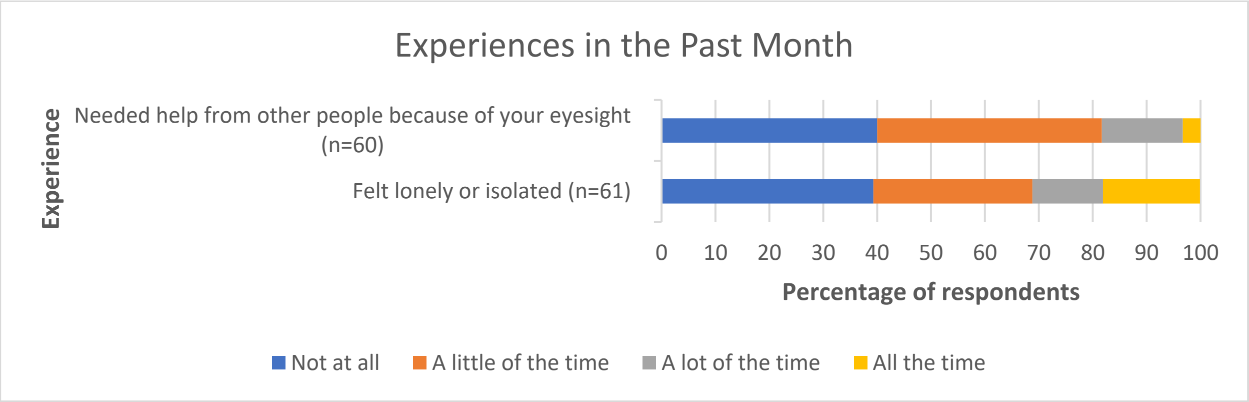
Recognizing that both DR and DME are complications of diabetes, it is useful to frame these considerations within the broader experiences of diabetes as a complex and impactful disease. Common symptoms of diabetes include extreme fatigue, unusual thirst, frequent urination and weight change (gain or loss). Diabetes requires considerable self-management, including eating well, engaging in regular physical activity, maintaining a healthy body weight, taking medication as prescribed, monitoring blood glucose, and managing stress. When Diabetes Canada asked Canadian diabetes patients how the disease impacts their lives, several described diabetes as a condition that must be dealt with 24 hours a day, 7 days a week, 365 days a year with no breaks and no holidays or time off. It is physically and mentally exhausting.

Figure 2. Concerns in the Past Month



It is clear that DR and DME weigh heavily on the minds of affected individuals, here shown as persistent emotional and psychological factors. This notion was again carried forward in relation to both requiring assistance as well as feelings of loneliness and isolation. In both cases, a majority of respondents replied that they had both experiences (needing assistance and feelings of isolation) at least “a little of the time.”

Figure 3. Experiences of Dependence and Isolation



The experience of needing help also highlights the social dimensions of DR and DME, implying that the impacts of the diseases extend beyond one’s personal life to touch on friends and family members. Any analysis of these diseases should take into account the social dimensions of lived experience that are common across eye disease that affect visual acuity and make daily life more challenging.

Overall, it is clear that DR and DME have significant and life-altering impacts on the lives of those who are affected by them. Whether it be in relation to reading or worrying or relying on others, the diseases tend to affect the details and complexities of everyday living in a pervasive manner (as opposed to being a secondary or background consideration). For this reason, it is reasonable to conceptualize DR and DME as considerable burdens on the daily lives of patients. Importantly, it is also reasonable to assume that these impacts have been more intensely felt during the COVID-19 pandemic, especially in relation to loneliness and isolation. This survey collected information before the full scale of the pandemic was known (or even possible to conceptualize)—as a result, the responses do not reflect the full impact of COVID-19 on the lives of patients with DR and DME. That said, the CCB conducted a separate survey in April of 2020 that was exclusively focused on the pandemic and its effects; it showed that fear, anxiety, loneliness, and other psychosocial impacts were intensified for patients with age-related macular edema (AMD) and DR during the pandemic. A follow-up study showed that almost 70,000 fewer eye injections for AMD and DR were performed in 2020 compared to 2019, and that 1,500 fewer patients received injections for AMD and 458 fewer patients received injections for DR in 2020 compared with 2019. A summary of these findings is below:

CCB Summary of the Impacts of COVID-19 for Patients Living with Vision Loss

In April 2020, the CCB conducted a survey on the impact of the COVID-19 pandemic on Canadians who are blind, deafblind or partially-sighted.[3] What we discovered was a community experiencing loneliness and living with considerable stress. Almost half the 572 respondents to the CCB survey (46%) said they hadn't felt safe going outside the home since the initial lockdown. 47% of respondents said that they needed a sighted guide to assist them when they left home. Respondents said they were concerned about maintaining social distancing and having others maintain social distancing with them. Since most hospitals and doctors' offices were not permitting anyone to accompany their patient, this meant that a substantial barrier existed for anyone requiring a sighted guide to access their doctor. This undoubtedly resulted in many people missing their regular appointments for anti-VEGF injections. Furthermore, 42% of respondents were worried about their ability to have someone accompany them to a doctor and almost half (49%) were worried about their ability to get transportation to a doctor, hospital, or testing site. About one third of respondents (36%) said that they had had an important medical appointment cancelled as a result of the COVID-19 pandemic. Many also expressed special concerns about treatment for their eye condition and were afraid that they may lose more vision as a result of missing appointments.

A subsequent study, commissioned by CCB and FBC,[4] reported the extent of the cancelled appointments for anti-VEGF injections. This report estimated that almost 70,000 fewer eye injections for the treatment of age-related macular degeneration (AMD) and diabetic retinopathy/DME were performed in 2020 compared with 2019.

This study also reported that 458 fewer patients received injections for diabetic retinopathy and 1,500 fewer patients received injections for AMD in 2020 compared with 2019. When combined with other delayed or cancelled eye examinations and treatments it was estimated that an additional 1,437 people experienced vision loss due to the pandemic.

Any anti-VEGF medication that can extend the time between required injections can be expected to be a great advantage to people living with vision loss who are not venturing out of their homes for medical appointments. Such a medication would carry significant potential to minimize unnecessary vision loss.

4. Experiences With Currently Available Treatments

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[3] Gordon K. "The impact of the COVID-19 pandemic on Canadians who are blind, deaf-blind, and partially-sighted" (2020). Available at: https://ccbnational.net/shaggy/wp-content/uploads/2020/05/COVID-19-Survey-Report-Final-wb.pdf

[4] Deloitte Access Economics, Addendum to the cost of vision loss and blindness in Canada. The impact of COVID-19. (report commissioned by the Canadian Council of the Blind), August 2021. Available at: https://ccbnational.net/shaggy/2021/10/12/the-impact-of-covid-19-an-addendum-to-the-cost-of-vision-loss-in-canada-study/

A majority of survey participants (56.4%) indicated that they currently receive injections as a treatment for DR or DME, with the most common brand being Lucentis (29.4%), followed by Eylea (24.6%), Avastin (20.2%), and Ozurdex (13.5%). The remainder of patients indicated that they did not know the brand of their injection.

Most respondents selected that their last injection was 1-5 years ago (26.9%), followed by more than 5 years ago (16.4%), 3-11 months ago (10.4%), and less than 3 months ago (4.5%).

Table 3. Timing of first injection (n = 67)

First Injection	**n (%)**
Less than 3 months ago	3 (4.5)
3-11 months ago	7 (10.4)
1-5 years ago	18 (26.9)
More than 5 years ago	11 (16.4)
I’ve never received injections for DME or DR	28 (41.8)

The low number of respondents (4.5%) who received injections more recently is disconcerting, potentially indicating high drop-off and nonadherence in relation to injections. If this is the case, it aligns with existing research showing that nonadherence to intravitreal injections is quite high.[5]

Satisfaction, Adherence, and Assistance

The largest number of respondents showed that they are “satisfied” with their injections (54.5%) and that “they helped me avoid losing more eyesight” (63.6%).

Table 4. Level of satisfaction with injections (n = 22)

	n (%)
Very dissatisfied	1 (4.5)
Dissatisfied	1 (4.5)
Neither satisfied nor dissatisfied	7 (31.8)
Satisfied	12 (54.5)
Very satisfied	1 (4.5)

Table 5. How the injections have helped (n = 22)

	n (%)
They helped me avoid losing more eyesight	14 (63.6)
They dried up fluid/blood in my eye(s)	10 (45.4)
They improved my eyesight	7 (31.8)
They have had no effect but I receive injections because my doctor recommends them	3 (13.6)
I don't know	1 (4.5)

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[5] Okada M, Mitchell P, Finger RP, Eldem B, et al. Nonadherence and Nonpersistence to Intravitreal Injection Therapy for Neovascular Age-Related Macular Degeneration: A Mixed-Methods Systematic Review. *Ophthalmology*. 2021;128;2;234-247. https://doi.org/10.1016/j.ophtha.2020.07.060

Other*	3 (13.6)

Think it's helping, stopped proliferation of blood vessels, have tunnel vision in one eye but it started to get tightened much more than last year

A majority of respondents who receive injections also indicated that they have not missed an injection in the last year (68.2%). Despite this, the number of patients who have missed injections is sizeable (31.8%) and deserving of attention. Further, in a similar study on AMD conducted by our groups, the percentage of missed appointments was just below 20%. It is worth considering why patients with DR and DME appear to be missing more appointments that those with AMD. Additionally, since this data were collected before COVID, it is safe to assume that more appointments are being missed today then at the beginning of 2020. This notion is supported by findings from the CCB COVID study, which is referenced at the end of section 3 in this submission: "This study also reported that 1,500 fewer patients received injections for AMD and 458 fewer patients received injections for diabetic retinopathy in 2020 compared with 2019. When combined with other delayed or cancelled eye examinations and treatments it was estimated that an additional 1,437 people experienced vision loss due to the pandemic." Clearly, missed injection appointments—and by extension all forms of nonadherence and non-persistence—require serious attention when developing policies and treatments for DR and DME and support the development and approval of new treatments which can reduce treatment burden.

Following up on this, our survey asked respondents why they have cancelled or delayed appointments in the past. Although the response rate for this question was quite low, most respondents indicated that they were too busy to attend the appointment (50%), followed by not feeling well (33.3%), being "unable to find someone to take me to the appointment" (16.7%), and being "scared to receive the injection" (16.7%).

Table 6. Reason for cancellation or delay (n = 6)

Reason	**n (%)**
Unable to find someone to take me to the appointment	1 (16.7)
Unable to travel to appointment	0 (0.0)
Could not afford attending the appointment	0 (0.0)
Too busy to attend appointment	3 (50.0)
Did not know how important the injection was to my sight	0 (0.0)
Scared to receive the injection	1 (16.7)
Did not find previous injections helpful	0 (0.0)
I forgot about the appointment	0 (0.0)
I was not feeling well	2 (33.3)
Other	0 (0.0)

Regarding the inability to find someone to assist with travel, our questions did uncover a significant reliance on assistance in this area. When asked who helps them attend their injections appointments, over 80% of participants indicating receiving travel from either a spouse, family member, or friend. These individuals helped in a number of ways, including with travel (93.3%), with waiting at the appointment (80%), and with assistance in everyday tasks after the injection (33.3%).

Table 7. Type of help provided (n = 15)

	n (%)
Help me after the injections with everyday tasks	5 (33.3)

Wait with me at the appointment	12 (80.0)
Travel with me or drive me to/from the appointment	14 (93.3)
Take care of things at home while I am away	1 (6.7)
Physical support at my appointment	4 (26.7)
Other	1 (6.7)

These responses once again underscore the degree to which DR and DME lead to a reliance on family and friends for caregiving and other forms of assistance, most commonly for travel to and from appointments.

Travel and Time Commitment

Almost half of the respondents indicating facing travel time of less than 30 minutes (45.5%) to get to their injection appointment, followed by 31 - 60 minutes (40.9%) and 1 - 2 hours (9.1%).

Table 8. Travel time (one-way) to injection appointment (n = 22)

Time	**n (%)**
Less than 30 minutes	10 (45.5)
31-60 minutes	9 (40.9)
More than 1 hour, and less than 2 hours	2 (9.1)
More than 2 hour, and less than 4 hours	0 (0.0)
4 hours or longer	1 (4.5)

When asked how long they spend at their injection appointments, the larges group reported less than 1 hour (42.9%), followed by 1 - 2 hours (33.3%) and 2 - 4 hours (14.3%).

Table 9. Total time spent per appointment at office of doctor/clinician for injection appointment (n = 21)

Time	**n (%)**
Less than 1 hour	9 (42.9)
More than 1 hour, and less than 2 hours	7 (33.3)
2 hours or more, but less than 4 hours	3 (14.3)
4 hours or more, but less than 6 hours	1 (4.8)
More than 6 hours	1 (4.8)

In terms of the ease or difficulty of travel, responses were varied but skewed towards the easy end of the spectrum, with most respondents selecting that travel is either very easy (27.3%), easy (27.3%), or neither easy nor difficult (27.3%).

Table 10. What is it like to travel to your injection appointments? (n = 22)

Ease of travel	**n (%)**
Very difficult	0 (0.0)
Difficult	4 (18.2)
Neither easy nor difficult	6 (27.3)
Easy	6 (27.3)

Very easy	6 (27.3)

That said, 4 individuals did report difficulty related to their travel, and when asked about the reasons, they selected distance from home (50%), poor condition of vehicle (25%), cost (25%), and difficultly related to taking public transit (25%).

Table 11. What makes it difficult for you to travel to your injection appointments (n = 4)

Reason	**n (%)**
It is far from home	2 (50.0)
My vehicle is in poor condition	1 (25.0)
Poor road conditions	0 (0.0)
It is expensive to travel	1 (25.0)
Other*	1 (25.0)

**Alone it is impossible to take the metro, but with my daughter, difficulty is when I don't hold her arm*

Interestingly, although in these responses both travel and waiting appear as somewhat minimal concerns, both are flagged as the most difficult aspects of the injection routine in data from a different question. When asked what makes it difficult to travel to injection appointments, half of the respondents selected long wait times, while the remainder selected difficulties such as "finding someone to drive me to/from the appointment" (31.8%) and "taking time off work to attend" (27.3%).

Table 12. Most difficult part of eye injection appointments (n = 22)

Reason	**n (%)**
Anxiety or fear about the injection	6 (27.3)
Long waiting time at the appointment	11 (50.0)
Cost of travel to/from the appointment	0 (0.0)
Finding someone to drive me to/from the appointment	7 (31.8)
Finding someone to help me with my daily tasks after the injection	0 (0.0)
I don't find any part difficult	4 (18.2)
Scratchiness or pain in my eye after the appointment	4 (18.2)
Taking time off work to attend	6 (27.3)
Other*	3 (13.6)

**Spouse must take time off work to drive me, if I didn't have my daughter I'd find difficulties in everything, hotel stay required (travel from Yukon to Vancouver) which is expensive*

When framed or conceptualized in terms of what is most difficult, then, both travel and waiting emerge as central concerns. It is also worth considering whether these issues are exacerbated in rural parts of Canada. Although a regional sub-analysis has not be conducted for this study, it is entirely possible that travel, waiting, and strain on caregivers are even more challenging for Canadians living in rural and remote parts of the country. This is certainly a factor that needs to be considered in the development of new treatments for these diseases.

Emotional and Physical Effects

In response to the question about difficulty, a significant number of patients also selected “anxiety or fear about the injection” (27.3%), highlighting the fact that injections into the eye are emotionally burdensome for some patients. This is interesting, considering that many patients also indicated being “satisfied” with their injections, as well as appreciative of the impact on their sight. It may show that those with DR or DME tend to manage their fear and anxiety in relation to injections as a matter of course. Injections still carry an emotional or psychological impact, but this has become internally managed in such a way as to be common or matter of fact.

The physical burdens of injections are not to ignored either. In response to the same question about the difficult aspects of injections, 18.2% of patients indicated “scratchiness or pain in the back of my eye” as a difficulty worth noting. It is clear that physical impacts are a factor for some patients, then. This is supported to some degree by the number of patients who experience some pain during the injection: when asked to indicate their pain level, a significant majority selected that the injections are “slightly painful” (81.8%). The remainder selected “not painful at all” (9.1%) and “painful” (9.1%).

Table 13. How painful is the injection for you? (n = 22)

Reason	n (%)
Not painful at all	2 (9.1)
Slightly painful	18 (81.8)
Painful	2 (9.1)
Extremely painful	0 (0.0)

Moving into the evening after the injection, our respondents showed an overall transition into a more painful experience. While 45.5% of patients indicated that the evenings are “not painful at all,” 40.9% selected “slightly painful” and 13.6% chose “painful.” As a result, over half of respondents indicated some form of eye pain lingering into the evening.

Table 14. How painful is the injection for you in the evening after? (n = 22)

Reason	n (%)
Not painful at all	10 (45.5)
Slightly painful	9 (40.9)
Painful	3 (13.6)
Extremely painful	0 (0.0)

Vision was shown to be impacted post-injection as well, with the largest group of respondents selecting that their vision stayed blurry “until I go to sleep that night” (31.6%). This was followed by vision being blurry for 1 - 3 hours (26.3%) and for 4 - 6 hours (21.1%).

Table 15. After an injection, for how long is your vision blurry? (n = 19)

Frequency	n (%)
Less than 1 hour	3 (15.8)
1-3 hours	5 (26.3)
4-6 hours	4 (21.1)
For at least 24 hours	1 (5.3)
Until I go to sleep that night	6 (31.6)

Given the prevalence of blurry vision among the cohort, it is unsurprising that they indicated a number of daily activities that become difficult or impossible post-injection. When asked about which activities they can longer do after an injection, the largest groups chose “watch TV” (57.1%) and “read” (57.1%), followed by “drive” (28.6%), “work” (21.4%), and “prepare meals (14.3%). All respondents to this question choose at least one activity that they can no longer do.

Table 16. Which of the following are you unable to do after an injection? (n = 14)

Activity	n (%)
Watch TV	8 (57.1)
Read	8 (57.1)
Drive	4 (28.6)
Prepare meals	2 (14.3)
Provide care to family members	0 (0.0)
Work	3 (21.4)
None of the above activities	0 (0.0)

These responses emphasize the emotional and physical impacts of living with and treating DR and DME, making it clear that the diseases exact a physical and psychological toll that exists alongside the logistical and financial challenges associated with travel and time.

5. Improved Outcomes

Our survey did not ask patients for their views on improving their experiences and outcomes. That said, the responses to our survey make it clear that any treatment that reduces the physical, psychological, and logistical strain on patients would be preferred. In terms of physical and psychological strain, this could take the form of a treatment that is less invasive, or one that is similarly invasive but that is administered less frequently. The frequency of the treatment could play a role in the reduction of logistical demands as well: a treatment that is taken or received less often would require fewer travel appointment, would decrease dependency on caregivers, and potentially more.

6. Experience With Drug Under Review

None of the respondents indicated using faricimab.

7. Companion Diagnostic Test

Not applicable.

8. Anything Else?

Researchers, health practitioners, policy experts, and others agree that diabetes is a growing and evolving epidemic, both globally and in Canada. As the incidence of diabetes grow, DR and DME will grow as well. A patient’s life is impacted by these diseases through a range of factors: life changes, loss of productivity, missed work/school hours, and more. As our data shows, DR and DME are diseases that weigh heavily on a patient’s mind, suggesting a strong psychological burden. Caregivers are impacted by the diseases as well, and in complex ways that are not always easy to measure or quantify.

DR and DME have these impacts, surely, but it is safe to assume that those impacts and associated burdens are more pronounced among vulnerable populations and those living outside of Canada’s urban centres. And during the COVID pandemic, it is also safe to assume that the burdens and challenges highlighted in patient responses have only become more pronounced. As the number of people living with diabetes in Canada increases, more patients in rural communities will need options that are effective, that help them comply with treatment programs, and that reduce the psychological toll of the disease.

In the context of diabetes, different people with diabetes require different medications and treatment modalities to help them effectively manage their disease. Their unique clinical profile, preferences and tolerance of therapy should direct prescribers to the most appropriate choice and combination of treatments for disease management. Health care providers must be supported in prescribing evidence-based therapies and, through public and private drug plans, patients should have access to a range of treatments that will allow them to optimize their health outcomes. For those paying out-of-pocket, costs should not be so high as to prohibit medication procurement. While current therapies have generally led to improvement for many people with diabetes in blood glucose and hemoglobin A1c control, respondents hope for additional affordable agents that they can access equitably, in a timely manner, and with good result to help them lead a normal life. "X medication" may help people to achieve better glycemic control, which could potentially improve lives and save millions in direct health care costs. For this reason, "X medication" should be an option for people living with diabetes.

This submission is a snapshot of the experiences of a small number of DR and DME patients in Canada—not a complete or final one, of course, because no overview can be, but nevertheless one that is grounded in the lived experiences of patients who offered their time, expertise, and insights to participate in this process. The focus of this submission has been on expanding our understanding of how these individuals perceive their diseases and treatments; the burdens that impact their lives; the barriers they face as a result of vision loss and other factors; and the psychological and emotional tolls of the diseases. As organizations that represent patients with DR, DME, and other eye diseases, our overarching goal is to contribute meaningfully to the discussion and potential implementation of new treatments in this space—in particular, to guide that discussion along lines that are patient-centered, that focus on optimal and equitable outcomes, and that recognize the expertise of patients with lived experience of DR/DME and their value in the review process of new treatments.

We look forward to continuing to work with CADTH to support Canadians living with DR and DME, and to advance our collective understanding of how the diseases impact their lives.

Appendix: Patient Group Conflict of Interest Declaration

1. Did you receive help from outside your patient group to complete this submission? If yes, please detail the help and who provided it.
   - FBC contracted Dr. Chad Andrews as an independent consultant with expertise in patient centered research to draft 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.
    - FBC contracted JRL Research & Consulting to program and test the survey, perform qualitative interviews and clean and analyze the data.
3. List any companies or organizations that have provided your group with financial payment over the past 2 years AND who may have direct or indirect interest in the drug under review.

Table 1: Financial Disclosures

Check Appropriate Dollar Range With an X. Add additional rows if necessary.

Company	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000
Bayer				X
Novartis				X
Roche				X
Abbvie-Allergan				X

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: Larissa Moniz
Position: Director, Research and Mission Programs
Patient Group: Fighting Blindness Canada
Date: April 13, 2022

Company	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000
Bayer				X
Novartis				X

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: Jim Prowse
Position: Executive Director
Patient Group: The Canadian Council of the Blind
Date: March 10, 2022

Company	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000
Astra Zeneca (CNIB)			X	

Bausch Foundation (CNIB)			X	
Bayer (CNIB)				X
Johnson & Johnson (CNIB)			X	
Novartis (CNIB)				X

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: Thomas Simpson
Position: Executive Director, Public Affairs and Come to Work
Patient Group: CNIB
Date: March 11, 2022

Company	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000
None to Declare				

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: Jennifer Urosevic
Position: President and CEO
Patient Group: Vision Loss Rehabilitation Canada
Date: April 4, 2022

Company	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000
Novo Nordisk				X
AstraZeneca				X
Janssen				X
Sanofi				X
Bayer			X	

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
Position: Manager, Research and Policy Policy
Patient Group: Diabetes Canada
Date: March 29, 2022