

Patient Input Template for CADTH Reimbursement Reviews

Name of Drug: faricimab

Indication: Macular degeneration, age-related

Name of Patient Group: Fighting Blindness Canada, The Canadian Council of the Blind, CNIB, Vision Loss Rehabilitation Canada

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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.

Our community is diverse and thriving. FBC represents thousands of individuals and families affected by vision loss, volunteers, and scientists and clinicians seeking treatments and cures for blinding eye diseases.

[The Canadian Council of the Blind](#) (CCB) is a membership-based not-for-profit organization that brings together Canadians who are blind, deaf-blind or living with vision loss through chapters within their own local communities to share common interests and social activities.

CCB works to improve the quality of life for persons with vision loss through awareness, peer mentoring, socializing, sports, advocacy, health promotion and illness prevention.

Members participate as volunteers in the peer support, sports and recreation, book clubs, awareness, and educational activities of the CCB. Members manage the affairs of their own local chapters consistent with the National Canadian Council of the Blind and may be elected to executive functions locally, provincially and/or nationally. They serve on various committees at these levels as well as participating in many other community groups.

CCB chapter members may involve themselves at their own comfort level and may choose to learn new skills or sports, become involved in accessibility awareness, and educational activities or simply enjoy the company of others.

Membership provides inclusion, purpose, fellowship and social interaction with peers who understand and support each person's unique strengths and abilities.

The CCB was founded in 1944 by blind Canadian war veterans and schools of the blind. The national office is located in Ottawa with over 80 chapters across Canada. The CCB is the largest membership-based organization for the blind in Canada and is known as the Voice of the Blind™.

The CCB's offers programs to assist people living with vision loss, increase accessibility in all areas of life and bring awareness of vision issues to the public and government.

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.

2. Information Gathering

Information that forms the basis of this document was collected through an online survey made available to Canadians living with age-related macular degeneration (wet or dry AMD) during the first months of 2020. Shared across networks associated with FBC and CCB, the survey is part of a larger research project titled VIEW AMD (Valuation and Interpretation of Experiences with AMD) that received ethics approval from Advarra, the largest independent provider of institutional review board (IRB) services.

Our goal with the survey was to learn more about lived experiences of AMD, particularly perceptions of the disease, its treatments, and the specific burdens associated with living with both wet and dry AMD. We did not aim to learn more about faricimab in comparison with other drugs, or to evaluate the effectiveness or safety of the drug in question (that is the precise role of RCTs); instead, we hope the following data and analysis provide insights into the lived experiences of Canadians with AMD, individuals who must navigate the often-daily barriers and burdens that accompany the disease. Our belief is that these perspectives are crucial, and that they should be used to guide decision-making related to any new treatment under consideration with the potential to address the disease’s physical, psychological, and socioeconomic burdens.

Overview of Respondents

A total of 337 Canadians responded to the survey. Out of these, most were between either 61 and 80 (36.6%) or 41 and 60 (35%) years of age, with a roughly equal split between male and female; most were also either retired (55.3%) or working full-time (21.1%). A majority of participants indicated residing in urban regions (89%) and were from Ontario (44.8%), British Columbia (20.2%), and Alberta (10.4%), followed by smaller groups within Canada’s other provinces and territories.

In terms of disease status, a significant number of patients indicated wet-AMD (47.1%), with the remainder indicating dry (37.7%); others selected either wet in one eye, dry in the other (12.8%) or that they are not sure of the type (2.4%).

Table 1. Baseline characteristics of respondents (n = 337)

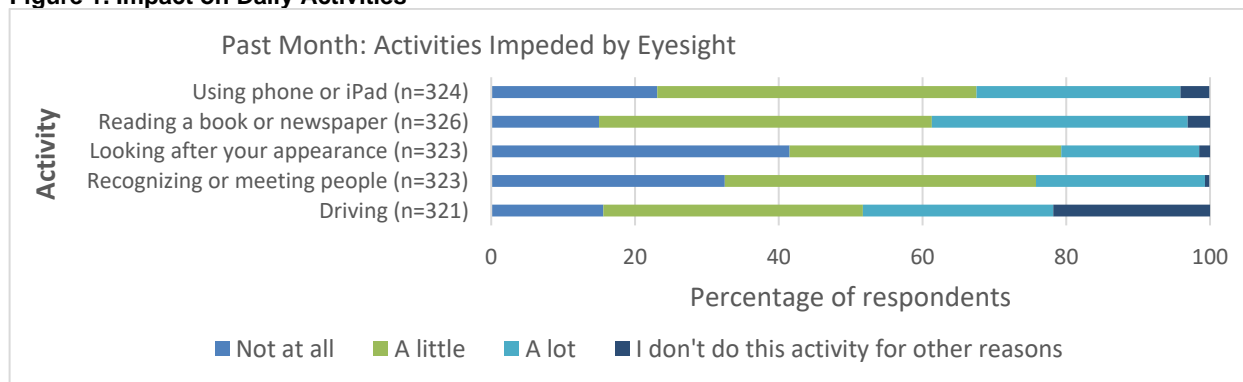
Characteristic	n (%)
Age (n = 320)	
Mean age (SD)	63.5 (16.5)
18 - 40 years	34 (10.6)
41 - 60 years	112 (35.0)
61 - 80 years	117 (36.6)
Over 80 years	57 (17.8)
Biological Sex (n = 322)	
Female	168 (52.2)
Male	153 (47.5)
Intersex	1 (0.3)
Province (n = 337)	

	Ontario	151 (44.8)
	British Columbia	68 (20.2)
	Alberta	35 (10.4)
	Quebec	25 (7.4)
	Manitoba	13 (3.9)
	Nova Scotia	12 (3.6)
	Newfoundland	11 (3.3)
	New Brunswick	7 (2.1)
	Northwest Territories	6 (1.8)
	Prince Edward Island	4 (1.2)
	Saskatchewan	4 (1.2)
	Nunavut	1 (0.3)
Location (n = 337)		
	Urban	300 (89.0)
	Rural	37 (11.0)
Type of AMD (n = 337)		
	Wet AMD in both eyes	111 (32.9)
	Dry AMD in both eyes	60 (17.8)
	Dry AMD in one eye	67 (19.9)
	Wet AMD in one eye	48 (14.2)
	Wet AMD in one eye and dry AMD in the other eye	43 (12.8)
	Doesn't know AMD type	8 (2.4)
Other household members (n = 337)		
	Partner/spouse	212 (62.9)
	My child(ren)	76 (22.6)
	No one	56 (16.6)
	Family member(s) other than partner and child	33 (9.8)
	I live in a retirement home	23 (6.8)
	Roommate/friend	12 (3.6)
	I live in a nursing home/long-term care facility	2 (0.6)
Employment Status (n = 322)		
	Retired	178 (55.3)
	Employed, working full-time	68 (21.1)
	Employed, working part-time	40 (12.4)
	Homemaker	18 (5.6)
	Not employed, looking for work	9 (2.8)
	Unemployed due to illness or disability	6 (1.9)
	Taking care of a family member	2 (0.6)
	Other: <i>In training for new career</i>	1 (7.7)

3. Disease Experience

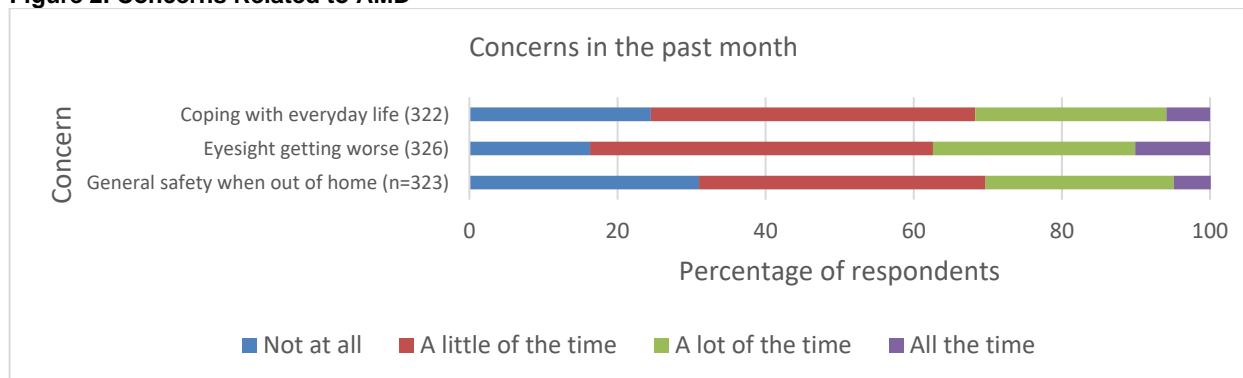
Perhaps more than anything else, respondents made it clear that the disease has a pronounced impact on their daily lives (manifesting as physical, psychological, and social impacts). When asked whether the sight loss resulting from AMD affects the daily activities of their lives, the majority (60 - 80%) reported that it does (Figure 1). They specified activities such as interacting with phones and tablets, reading books and newspapers, and more.

Figure 1. Impact on Daily Activities



Beyond these largely physical impacts, it was also made clear that AMD affects the psychologies of those with lived experience in a meaningful way. For instance, approximately one-third of respondents showed that they think about their disease and its impacts either “all the time” or “a lot of the time,” implying that AMD carries a significant psychological burden (Figure 2).

Figure 2. Concerns Related to AMD



The notion of a psychological toll or burden was supported in relation to challenges as well. When asked to select from a list of challenges associated with sight loss and AMD, a significant majority indicated that they “worry that my condition might worsen in the future” (77%) (Table 2). AMD appears to weigh heavily on the mind in terms of frequent thinking, then, but also in a future-oriented manner when it comes to the deterioration of vision over time. Other challenges selected from the list include “not being able to do the daily activities I used to” (38.4%), “the long wait time for appointments” (31.2%), and more.

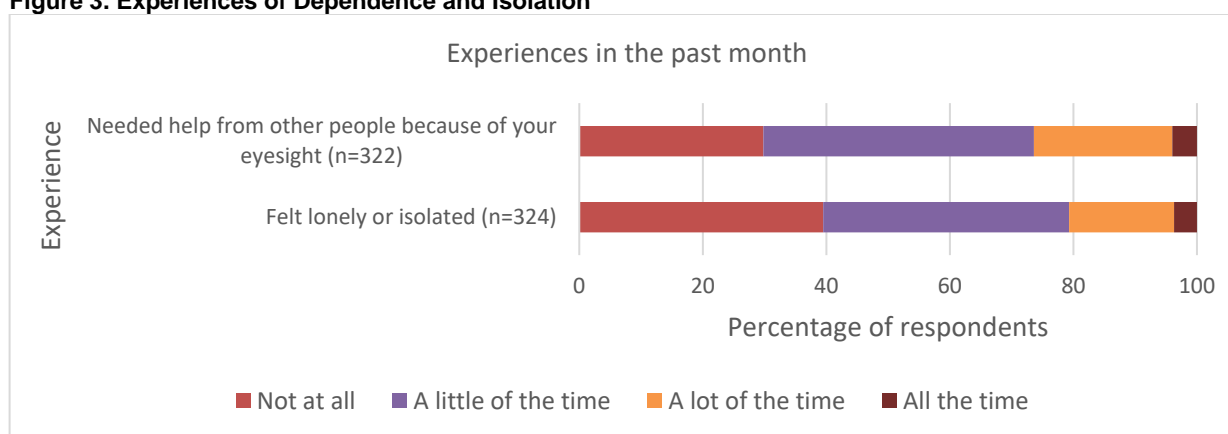
Table 2. Challenges with AMD (n = 330)

Challenges	n (%)
Worry that my condition might worsen in the future (n=331)	255 (77.0)
Not being able to do the daily activities I used to (n=331)	127 (38.4)
The long wait times for appointments	103 (31.2)

Explaining my condition to family and friends	103 (31.2)
Lack of social support	97 (29.4)
Finding answers to my questions about my condition	73 (22.1)
Socializing	68 (20.6)
Other*	34 (10.3)

The disease carries social implications as well. When asked about needing assistance and about feelings of isolation, respondents made it clear that they often rely on others because of their sight, and approximately 60% reported feeling lonely or isolated in the last month (Figure 3). This data was collected pre-COVID, and it is likely that loneliness and isolation are even more prominent within the context of the current pandemic.

Figure 3. Experiences of Dependence and Isolation



In fact, the need for assistance emerged as a recurring theme for respondents. For instance, in a separate question related to injection appointments, over 85% of those who receive injections indicated requiring help when they go to their appointments. The reliance on assistance may present a larger barrier to appointment attendance during the pandemic due to social distancing regulations and clinic rules that in many cases limit entry to patients only. Additional research would be helpful to explore this impact.

It is clear that AMD has a strong impact on the lives of those who are affected by it. Whether it be in relation to reading or worrying or relying on others, the disease tends 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 AMD as a significant or considerable burden 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 AMD. 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 AMD during the pandemic. A follow-up study showed that almost 70,000 fewer eye injections for AMD and diabetic retinopathy were performed in 2020 compared to 2019, and that 1,500 fewer patients received injections for AMD and 458 fewer patients received injections for diabetic retinopathy in 2020 compared with 2019. A summary of these findings is below:

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

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.¹ 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

¹ Keith D. Gordon, '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> Accessed January 7 2022.

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,² 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 AMD and Diabetic Retinopathy were performed in 2020 compared with 2019.

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.

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

A significant majority of our survey participants (75.4%) indicated that they currently receive injections as a treatment for their AMD, with the most common brand being Avastin (29.4%), followed by Lucentis (24.6%), Eylea (20.2%), and Ozurdex (13.5%). The remainder of patients indicated that they did not know the brand of their injection, were receiving multiple, or received the injection as part of a blind study.

Satisfaction and Adherence

The largest group of respondents showed that they are “satisfied” with their injections (46%) and that “they helped me avoid losing more eyesight” (72.7%) (Table 3, Table 4).

Table 3. Level of satisfaction with injections (n = 252)

	n (%)
Very dissatisfied	1 (0.4)
Dissatisfied	8 (3.2)
Neither satisfied nor dissatisfied	46 (18.3)
Satisfied	116 (46.0)
Very satisfied	81 (32.1)

Table 4. How the injections have helped (n = 253)

	n (%)
They helped me avoid losing more eyesight	184 (72.7)
They improved my eyesight	112 (44.3)
Dried up fluid/blood in my eye(s) (n=252)	104 (41.3)
They have had no effect but I receive injections because my doctor recommends them	43 (17.0)

² 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/> Accessed January 7 2022.

I don't know	7 (2.8)
Other*	8 (3.2)

At the same time, it is worth noting that almost 20% of respondents who are currently receiving injections think that they have no beneficial effect or are unsure if there is an effect.

Although most respondents reported not missing an injection appointment in the last year (67.9%), a sizeable group did indicate missing at least one appointment (32.1%) (Table 5). Again, this data was collected pre-COVID, so it is reasonable to assume that the numbers skew higher today. The most common reason for missing an appointment was being “unable to find someone to take me to the appointment” (39.5%), recalling the earlier suggestion of dependence being a key aspect of the experience of AMD. This was followed closely by being “unable to travel to appointment” (34.6%) and “could not afford attending the appointment” (30.9%). It is clear in these responses that some of the difficulty in attending injection appointments is found not in the experience of the injection itself, but in the logistics of travel and payment.

Table 5. Reason for cancellation or delay (n = 81)

Reason for cancellation or delay	n (%)
Unable to find someone to take me to the appointment	32 (39.5)
Unable to travel to appointment	28 (34.6)
Could not afford attending the appointment	25 (30.9)
Too busy to attend appointment	20 (24.7)
Did not know how important the injection was to my sight	20 (24.7)
Scared to receive the injection	11 (13.6)
Did not find previous injections helpful	10 (12.3)
I forgot about the appointment	4 (4.9)
I was not feeling well	7 (8.6)
Other*	11 (13.6)

Travel and Time Commitment

Almost half of the respondents indicated facing a travel time of 31 - 60 minutes to get to their injection appointment, followed by under 30 minutes (29.4%) and between 1 and 2 hours (15.5%). While at the appointment, most respondents reported waiting for more than 1 hour but less than 2 (60.8%), followed by less than 1 hour (17.6%) and, at the other end of the spectrum, more than 2 hours but less than 4 (16%)—groups that are very close in size.

The experience of ease or difficulty related to travel was varied among respondents, with most selecting that travel is generally “easy” (39.3%) followed by “neither easy nor difficult” (31.3%) (Table 7). A smaller group selected “difficult” (7.1%) and, when asked what makes the travel challenging, reported that distance (50%) and vehicle condition (30%) are notable factors (Table 7).

Table 6. Experience of travel to injection appointments? (n=252)

Ease of travel	n (%)
Very difficult	2 (0.8)
Difficult	18 (7.1)
Neither easy nor difficult	79 (31.3)
Easy	99 (39.3)
Very easy	54 (21.4)

Table 7. Reasons for difficult travel to your injection appointments (n=20)

Reason	n (%)
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It is far from home	10 (50.0)
My vehicle is in poor condition	6 (30.0)
Poor road conditions	5 (25.0)
It is expensive to travel	5 (25.0)
Other*	2 (10.0)

Despite a smaller number of patients finding travel difficult, it is worth noting that wait times and travel still ranked high as difficult aspects of the injection appointment overall. When asked what is the most difficult part of the appointment, 30.5% of patients selected “long waiting time at the appointment,” 28.9% selected “cost of travel to/from the appointment,” and 27.7% selected “finding someone to drive me to/from the appointment” (Table 8). For these patients, the experiences of travel and waiting exist as significant hurdles or challenges. More research and analysis are needed to determine if there is an overlap between these experiences and non-adherence.

Table 8. Most difficult part of eye injection appointments (n = 249)

Reason	n (%)
Anxiety or fear about the injection	95 (38.2)
Long waiting time at the appointment	76 (30.5)
Cost of travel to/from the appointment	72 (28.9)
Finding someone to drive me to/from the appointment	69 (27.7)
Finding someone to help me with my daily tasks after the injection	56 (22.5)
I don't find any part difficult	52 (20.9)
Scratchiness or pain in my eye after the appointment	46 (18.5)
Taking time off work to attend	31 (12.4)
Other**	8 (3.2)

Importantly—and perhaps unsurprisingly—respondents in rural parts of Canada were significantly more likely to travel more than 1 hour to attend appointments (30.3% for rural patients compared to 11% for those in urban regions). They were also more likely to describe their travel experience as “difficult” (18.2% compared to 5.5%). This underscores the fact that, despite whatever the overall experience may be, those patients facing more significant barriers to care need to be valued and considered in the development and approval of new drugs. In this case, treatments that lessen the burden on travel for rural and remote patients would likely be considered desirable.

Emotional and Physical Effects

Besides difficulty in relation to travel, cost, and waiting, the largest group of patients underscored “anxiety or fear about the injection” (38.2%) as the most difficult part of the appointment (see the above table). 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 AMD 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.

Results in the above table also make it clear that the physical effects of injections are not to be ignored—for instance, 18.5% of patients selected “scratchiness or pain in my eye after the appointment” as a difficulty. At the same time, when asked how painful the injections are during the appointment, although almost a quarter of patients selected “not painful at all” (24.3%), the largest group selected “slightly painful” (54.6%) and a sizeable number selected “painful” (19.5%) (Table 9). And for some, the emphasis on pain increases into the evening, with 56.9 % of patients reporting their experience of pain as “slightly painful” into the evening, and 19% reporting a “painful” experience (Table 10). In total, approximately 4 out of 5 patients experience at least some pain lingering into the evening after their injection appointments.

Table 9. Painfulness of the injection (n=251)

Reason	n (%)
Not painful at all	61 (24.3)

Slightly painful	137 (54.6)
Painful	49 (19.5)
Extremely painful	4 (1.6)

Table 10. Experience of pain into the evening after the injection (n=248)

Reason	n (%)
Not painful at all	51 (20.6)
Slightly painful	141 (56.9)
Painful	47 (19.0)
Extremely painful	9 (3.6)

Visual complications are also a factor for many patients, with many experiencing blurry vision for 1 - 3 hours after the injection (48.2%), followed by 4 - 6 hours (25.9%) (Table 11). For respondents, these complications made certain activities impossible post-injection—significantly, all respondents indicated that they were unable to conduct at least one regular activity after their injection, with the largest group selecting “watch TV” (49.1%), followed by “read” (42.1%) and “drive” (30.4%) (Table 12).

Table 11. Duration of blurry vision post-injection (n=247)

Frequency	n (%)
Less than 1 hour	26 (10.5)
1-3 hours	119 (48.2)
4-6 hours	64 (25.9)
For at least 24 hours	16 (6.5)
Until I go to sleep that night	22 (8.9)

Table 12. Activities that are not possible post-injection (n=214)

Activity	n (%)
Watch TV	105 (49.1)
Read	90 (42.1)
Drive	65 (30.4)
Prepare meals	60 (28.0)
Provide care to family members*	32 (15.0)
Work*	26 (12.2)
None of the above activities	0

Respondents also made it clear that, due to these complications, they require assistance more frequently after their injections. When asked what kind of assistance they receive in general, the largest group indicated that they require help “after the injections with everyday tasks” (55.7%) (Table 13). This once again emphasizes the theme of a lack of independence experienced by those with AMD, who in many cases not only rely on friends and loved ones for travel to and from injection appointments, but for help with tasks afterwards as well.

Table 13. Type of help provided post-injection

	n (%)
Help me after the injections with everyday tasks	118 (55.7)
Wait with me at the appointment	116 (54.7)
Travel with me or drive me to/from the appointment	114 (53.4)
Take care of things at home while I am away	69 (32.5)
Physical support at my appointment	51 (24.1)
Other*	3 (1.4)

These responses emphasize the emotional and physical impacts of AMD, making it clear that the disease exacts a physical and psychological toll that exists alongside the logistical challenges associated with travel and time.

5. Improved Outcomes

Our survey did not ask patients for their views on improving their experiences and outcomes. In previous patient engagement efforts, however, we did learn that most patients would prefer a treatment or medication type that can be taken less frequently.

In a previous survey, when asked whether a treatment that can be taken less often would be preferred, the majority of patients with wet or dry AMD indicated “yes”: 64% for wet and 52% for dry. When asked whether they think the public health system should pay for better medication and treatments for AMD, “yes” was the most select option for both wet (61%) and dry (62%) participants. And, finally, the largest percentage of both groups indicated a relatively high level of comfort with clinical trials by responding favourably to a Likert scale regarding how comfortable they are with the idea of enrolling in a clinical trial for AMD: participants answered “very comfortable” (10% for wet, 12% for dry), “fairly comfortable” (28% wet, 31% dry), “neither comfortable nor uncomfortable” (21% wet, 23% dry), “fairly uncomfortable” (10% wet, 8% dry), “very uncomfortable” (16% wet, 14% dry), and “other” (16% wet, 12% dry).

Responses to both questions—regarding public payment and clinical trials—indicate that regardless of wet or dry, the surveyed AMD patients are supportive of public dollars advancing the AMD treatment space, and at the same time willing to participate in the trials that would lead to those advancements.

6. Experience With Drug Under Review

As discussed under section 4, none of the patients we surveyed indicated receiving faricimab as a treatment for their AMD. This is unsurprising, given that assessments of the drug by Canadian HTA agencies have not yet completed.

7. Companion Diagnostic Test

Not applicable

8. Anything Else?

AMD is a chronic disease that creates a range of challenges and burdens for patients. For many of the 337 Canadians that responded to our survey, their AMD leads to visual complications that render certain daily activities—such as reading or driving—either problematic or impossible. AMD is therefore physically and visually burdensome, and its corresponding emotional and psychological burdens are acute for patients as well. For example, many patients indicated that they think about their disease frequently, especially its impact on their future, and that they experience fear or anxiety in relation to their injection regimes.

Thanks to modern research, anti-VEGF injections are now the frontline treatment for patients with wet-AMD, replacing forms of surgery that once had significant drawbacks. While the various anti-VEGF drugs on the market have shown high levels of effectiveness in slowing or halting loss of vision, it is also the case that the need for regular—often monthly—injections directly into the eye have created challenges for many patients. This is borne out in our survey results, with groups of respondents emphasizing the painfulness of the injection, both during and after the procedure, and their difficulties managing travel to and from injection appointments. The issue of travel is especially pronounced for those living in rural and remote parts of Canada, who often travel significant distances to receive their injections. The challenges associated with AMD also lead to many patients relying on loved ones to assist them; they often receive aid in travelling to and from appointments, and in managing the tasks that are made difficult by AMD and by the short-term visual complications that result from injections. As a result, there is a common thread running through the responses that the disease leads to a certain lack of independence. Many patients would prefer a treatment that can be taken less frequently, are supportive of public funding being used in the advancement of such a treatment, and are open to participating in clinical trials.

More research is required to better understand the reasons for why certain patients with AMD miss their appointments or stop them altogether. That said, contemporary research has shown that both non-adherence and non-persistence are quite high with this

group: for instance, a recent study showed that close to 50% of patients stop anti-VEGF treatments after 24 months.³ It is entirely possible that the impacts shown in this report—issues with travel and other logistical challenges, as well as physical and psychological effects—could play a significant role in this drop off. With this in mind, it is clear that treatments that lessen the burdens on this group could play an important role in countering the trend of non-compliance and under treatment.

This is a snapshot of the experiences of AMD 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 disease. As organizations that represent patients with AMD 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 AMD and their value in the review process of new treatments.

We look forward to continuing to work with CADTH to support Canadians living with AMD, and to advance our collective understanding of how the disease and its treatments impact their lives.

Appendix: Patient Group Conflict of Interest Declaration

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

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

³ 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>

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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: February 10, 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: February 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: February 7, 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: February 9, 2022