CADTH

# Patient Input Template for CADTH Reimbursement Reviews

Name of Drug: aflibercept (8mg)
Indication: Macular degeneration, age-related
Name of Patient Group: Fighting Blindness Canada, The Canadian Council of the Blind, CNIB, Vision Loss Rehabilitation Canada, International Federation on Ageing
Author of Submission: Dr. Larissa Moniz (FBC), Jim Prowse (CCB), Thomas Simpson (CNIB), Jennifer Urosevic (VLRC), Jane Barratt (IFA)

## 1. About Your Patient Group

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

Over our 49-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.

The **International Federation on Ageing** **(IFA)** is an international non-governmental organization (NGO) based in Canada whose members are government, NGOs, academia, industry, and individuals in nearly 80 countries. IFA believes that all these members working together are essential to help shape and influence policy and good practices. IFA stands to drive the agenda for the world's population ageing. We are proud to have general consultative status at the United Nations. The International Federation on Ageing is a non-State actor in official relations with the World Health Organization (WHO).

Vision health is one of IFAs priorities. Since its inception in 2016, the Eye See You: Advocating for Options in Eye Health campaign has become known for collaborating across sectors and disciplines on matters that impact the vision health of all Canadians, but in particular retinal diseases often affecting older age groups and those with diabetes. IFAs four-pronged approach to this growing issue remains current today in building community and influencing vision health policy and practice: 1. Supporting patients (and their families) to make informed choices regarding their vision health; 2. Raising awareness on the availability of safe and effective vision treatments; 3. Leading advocacy efforts on issues affecting vision health in an ageing population; and 4. Enriching the discourse on vision health by building connections across disciplines and sectors

## 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 aflibercept 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 inform and guide decision-making related to any new treatment under consideration with the potential to address the physical, psychological, and socioeconomic burdens associated with the disease. We did ask respondents to indicate which anti-VEGF they may have received. Since this survey was completed in early 2020, it is assumed that those that indicated using aflibercept (Eylea), received aflibercept (2mg) and not the drug under review aflibercept (8mg).

*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 retired (55.3%) followed by those working full-time (21.1%). A majority of participants reside 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 having wet AMD (47.1%), with the remainder indicating dry AMD(37.7%); Others respondents 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)**

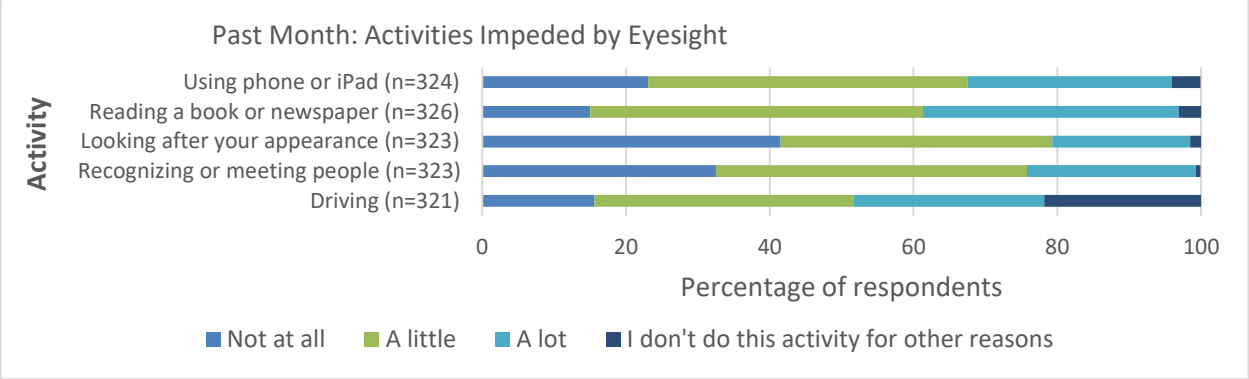
| Characteristic | n (%) |
|---|---|
| **Age (n = 320)** | |
| Mean age (SD) | 63.5 (16.5) |
| 18 - 40 years | 34 (10.6) |
| 41 - 60 years | 112 (35.0) |
| 61 - 80 years | 117 (36.6) |
| Over 80 years | 57 (17.8) |
| **Biological Sex (n = 322)** | |
| Female | 168 (52.2) |
| Male | 153 (47.5) |
| Intersex | 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: *In training for new career* | 1 (7.7) |

## 3. Disease Experience

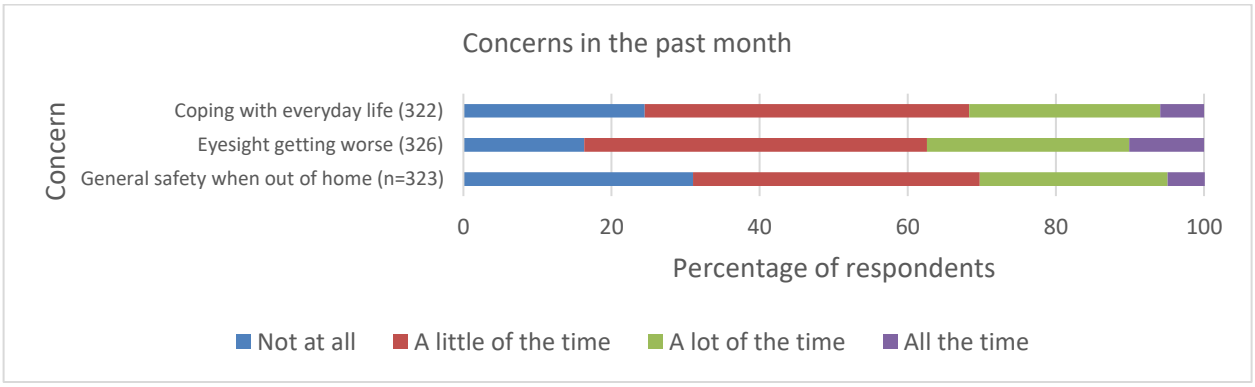
Perhaps more than anything else, respondents made it clear that the disease has a significant impact on their daily lives, manifesting as physical, psychological, and social impacts. The majority (60-80%) reported that sight loss resulting from AMD affects their daily activities (Figure 1) which includes personal care and hygiene, interacting with phones and tablets and reading books and newspapers.

**Figure 1. Impact on Daily Activities**




Beyond these largely physical impacts, it was also made clear that AMD affects patients psychologically in a profound way. For instance, approximately one-third of respondents sthink 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**



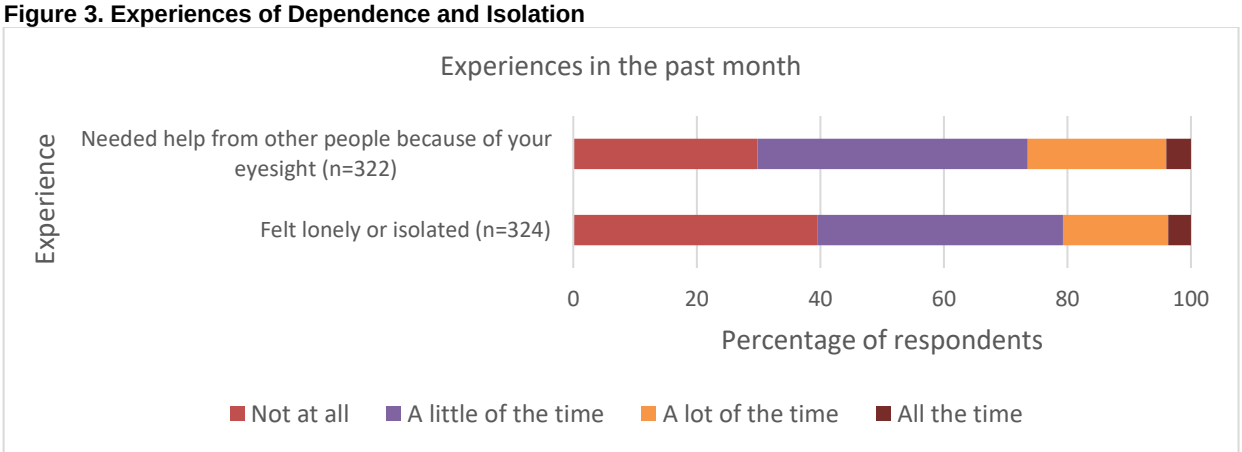

This psychological toll or burden was supported in relation to challenges as well. When asked to select from a list of challenges associated with sight loss and AMD, the majority indicated that they "worry that my condition might worsen in the future" (77%) (Table 2). AMD appears to weigh heavily on patients 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 included but are not limited to "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).

**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. It is safe to assume that the burdens associated with these appointments increase when they are more frequent. This note is supported by new research demonstrating the significant physical and psychological burdens associated with anti-VEGF injections.[1]

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 deeply 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.

## 4. Experiences With Currently Available Treatments

Three-quarters (3 out of 4 respondents (75.4% indicated that they currently receive injections as a treatment for their AMD. Of those receiving injections the most common brand was Avastin (29.4%), followed by Lucentis (24.6%), Eylea (aflibercept) (20.2%), and Ozurdex (13.5%). The remainder of patients did not know the brand of their injection, were receiving multiple, or received the injection as part of a blind study. As noted above, due to the timeline of the study, it is assumed that participants who indicated receiving aflibercept, received aflibercept (2mg) and not aflibercept (8mg).

*Satisfaction and Adherence*

Almost one-half (46%) are “satisfied” with their injections 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) |
| 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.

[1] G Reitan, IBK Haugen, K Andersen, et al. Through the Eyes of Patients: Understanding Treatment Burden of Intravitreal Anti-VEGF Injections for nAMD Patients in Norway, *Clinical Ophthalmology*, 2023. 17:1465-1474, DOI: 10.2147/OPTH.S409103

Although most respondents reported not missing an injection appointment in the last year (67.9%), a sizeable percentage indicated missing at least one appointment (32.1%) (Table 5). 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 response 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. It is fair to assume that these difficulties are exacerbated for those living in Canada's rural and remote communities, where access to specialized care is often limited, and where the average distance to the nearest specialist is significantly more than in more urban locations. A treatment that requires fewer injections could help minimize some of these challenges.

**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 (%) |
|---|---|
| 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 issue mentioned above that, despite what 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 engagements, 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 (64%) with wet AMD indicated “yes”. When asked whether they think the public health system should pay for better medication and treatments for AMD, 61% of patients with wet AMD indicated “yes.

## 6. Experience With Drug Under Review

As discussed under Section 4, while approximately 15% of participants indicated receiving aflibercept as a treatment, it is assumed that this was aflibercept (2mg) and not aflibercept (8mg) as aflibercept (8mg) was not approved for non-clinical trial use in Canada at the time this survey was completed (2020). We also have no evidence that any of the respondents participated in a clinical trial or had firsthand experience with the drug under review (aflibercept (8mg)).

## 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. As a result of patient input regarding the experience of the disease and its treatment, it is clear that a treatment with a less demanding injection regime would help ease some of the burden associated with AMD.

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.[2] 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, 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 patients with AMD 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;

[2] 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

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 |
| Roche | | | | X |
| Abbvie | | | | 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**: July 14, 2023

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

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**Name:** Jim Prowse
**Position:** Executive Director
**Patient Group:** The Canadian Council of the Blind
**Date**: July 18, 2023

| Company | $0 to 5,000 | $5,001 to 10,000 | $10,001 to 50,000 | In Excess of $50,000 |
|---|---|---|---|---|
| Bayer (CNIB) | | | | X |
| Johnson & Johnson (CNIB) | | | X | |
| Novartis (CNIB) | | X | | |

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**Name:** Thomas Simpson
**Position:** Executive Director, Public Affairs and Come to Work
**Patient Group:** CNIB
**Date**: August 18, 2023

| 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**: August 22, 2023

| Company | $0 to 5,000 | $5,001 to 10,000 | $10,001 to 50,000 | In Excess of $50,000 |
|---|---|---|---|---|

| | | | | |
|---|---|---|---|---|
| Bayer | | | | X |
| Abbvie | | | X | |
| Pfizer Canada | | | | X |
| Sanofi Canada | | | | 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:** Jane Barratt
**Position:** Secretary General
**Patient Group:** International Federation on Ageing
**Date**: 4th August 2023