

## THE BURDEN OF AGE-RELATED MACULAR DEGENERATION ON CANADIAN PATIENTS: PATIENT INPUT ON BROLUCIZUMAB

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### 1. DISEASE OVERVIEW

Age-related macular degeneration (AMD) is the leading cause of vision loss in people over the age of 50, affecting approximately 1.4 million Canadians. The disease is “macular” because it damages the macula, which is the small, central portion of the retina, the light-sensitive tissue at the back of the eye where the cellular interactions that make sight possible begin. The macula is responsible for detailed, central vision, and is important for activities such as reading, driving, and distinguishing faces. While the disease is most commonly associated with ageing—hence “age-related”—there are some forms that can affect younger people and are caused by genetic, environmental, nutritional, and other factors, often simply called “macular degeneration.” In fact, the age-related form of the disease (AMD) involves risk factors outside of age that should be taken into account as well, including smoking, diet/nutrition, race (AMD is more common among Caucasians than African-Americans or Hispanics/Latinos), genetics, and family history of the disease.

The wet form of the disease (wet AMD) is less common, affecting approximately one in ten people with AMD, and is a negative progression from dry AMD. In the wet form, blood vessels below the thinning macula swell and begin to grow abnormally; if left untreated, they also begin to leak blood and fluid into the eye (hence “wet”). The cells directly affected by leaking vessels are called retinal pigment epithelial (RPE) cells, which nourish and sustain the sheet of light-sensitive photoreceptors above them. Since RPE cells play such a crucial role, their damage and loss during the advanced stages of wet AMD can entail rapid and severe vision loss.

Thanks to modern research, there is now a standard of care treatment for individuals affected by wet AMD called anti-VEGF therapies. Vascular endothelial growth factor (VEGF) is a substance that is normally produced in human bodies and is responsible for telling new blood vessels to form. However, the uncontrolled growth of blood vessels in the eye causes vision loss in wet AMD. Anti-VEGF therapies prevent vision loss—and can even reverse some vision loss—by removing excess VEGF from the eye. In most Canadian provinces and territories, the commonly used anti-VEGF therapies include Lucentis (ranibizumab) and Eylea (aflibercept). Lucentis requires monthly injections into the eye, while each Eylea injection is designed to last two months (after an initial set of monthly injections). Both drugs are widely reimbursed across most jurisdictions and prevent vision loss by getting rid of VEGF. Avastin (bevacizumab) is an anti-VEGF therapy that was designed as a cancer treatment, and although it is not approved by Health Canada to treat wet AMD and currently has a black box warning to not be used for intraocular injections, it is used by some clinicians “off-label.” Researchers and clinicians continue to discuss the pros and cons of different anti-VEGF treatments.

## 2. SURVEY CONTEXT

While a modern standard of care in the form of anti-VEGF injections does exist for Canadian AMD patients, we also know that research into the treatment of the disease is ongoing. Time-release implants have made progress over the last several years, carrying the promise of a longer-lasting delivery of anti-VEGF and other molecules, and at the same time work is underway to locate the biomarkers that could tell us more about why dry AMD transitions to wet. New injection-based therapies are in development as well, including brolucizumab, a single-chain antibody fragment (scFv) that, due to its small size, shows promise in its ability to stay in the eye for a longer period of time, thereby requiring fewer injections.

The organizations offering patient input in this document—FBC, CCB, CNIB, and VLR (hereafter “we”)—represent and provide services for members of the vision loss community across Canada, including many individuals affected by AMD. Considering this, we take a strong interest in the anti-VEGF space and the evolving market of AMD therapies, and believe our role in the review process is to represent the patient perspective in as full and comprehensive a way as possible. To do this in the context of the current review of brolucizumab, we surveyed Canadian AMD patients to learn more about their experiences, particularly their perceptions of the disease, its treatments, and the specific burdens associated with living with both wet and dry AMD. Our aim with the survey is not to learn more about brolucizumab 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 improve health outcomes for AMD patients and diminish the disease’s physical, psychological, and socioeconomic burdens.<sup>1</sup>

## 3. SURVEY RESULTS and ANALYSIS

### *General identifiers*

Posted to FBC’s website on August 14, 2019 and shared across our networks, our “Eye Disease and Patient Engagement Survey” has to date gathered 157 responses from individuals who have self-confirmed living with AMD. **Of this group, 97 individuals reporting having wet AMD, while the remainder, 60, reported having dry.** 67% of the wet group indicated that their disease affects both eyes, while 83% of the dry group indicated the same, that the disease affects both of their eyes.<sup>2</sup> The average (mean) year of birth for the wet group is 1942, and for dry it is 1943, while the average year of diagnosis for wet is 2005 and for dry is 1999.

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<sup>1</sup> This survey was posted specifically to collect information for the current review, but another version is currently being test-driven by AMD patients to ensure clarity and accessibility and has received IRB approval for ethics. We hope that the upcoming survey, which will likely be disseminated before the end of the year, will lead to publishable analysis and lay the foundations for future interactions with CADTH and other bodies as the treatment space for AMD continues to develop.

<sup>2</sup> All survey percentages are rounded to the nearest whole number.

## Geography

In terms of geographic distribution for the entire group, one respondent specified being located in Newfoundland, two in Nova Scotia, one in New Brunswick, 79 in Ontario, four in Manitoba, one in Saskatchewan, 31 in Alberta, 27 in British Columbia, one in the Yukon, and 10 did not specify. The higher concentration of respondents in ON, AB, and BC speaks to population, certainly, but is also reflective of difficulties accessing and surveying patients in less populated and less urbanized areas without the use of in-person engagement at clinics and other strategies. This is an overall challenge to survey-based representativeness that has been encountered by many researchers.

Geographical breakdown of respondents

NL	NS	PE	NB	QC	ON	MB	SK	AB	BC	NU	NT	YT	Total
1	2	0	1	0	79	4	1	31	27	0	0	1	147

## Comorbidities

Comorbidities were self-identified by individuals as well, although we only asked about eye diseases, with 27 in total being reported across the wet and dry groups. In the wet group, one individual reported having achromatopsia, one reported Bardet-Biedl syndrome, one reported choroideremia, one reported diabetic retinopathy, 11 reported glaucoma, one reported retinitis pigmentosa, and one reported choroidal nevus. In the dry group, two reported diabetic retinopathy and eight reported glaucoma.

Self-reported ocular comorbidities

	Achromatopsia	Bardet-Biedl	Choroideremia	Diabetic retinopathy	Glaucoma	Retinitis pigmentosa	Choroidal nevus	TOTAL
Wet AMD	1	1	1	1	11	1	1	17
Dry AMD				2	8			10
TOTAL	1	1	1	3	19	1	1	27

Seeing as ocular comorbidities were self-reported in over 18% of the overall group, it is clear that the presence of AMD carries a significant chance of existing alongside additional ocular complications, at least for the individuals surveyed. Although not part of our dataset, it can be assumed—and has been shown elsewhere—that the existence of non-ocular comorbidities is high as well.<sup>3</sup> As a result, comorbidities emerge as a critical issue for this group, one that is likely association with the link to ageing, and we know from existing research that comorbidities entail an extensive and complex set of burdens, including increased health care costs, more demanding clinical care management, a higher level of health systems navigation, poorer overall health outcomes, and more.<sup>4</sup>

## Severity and Psychological Impact of Vision Loss

When asked to rate their **severity of vision impairment** on a scale of 1 (no vision impairment) to 10 (blindness), the most common response among wet AMD respondents was 7 on the scale (21% of the wet group). This was

<sup>3</sup> Pinazo-Durán MD, Arévalo JF, García-Medina JJ, et al. Ocular Comorbidities and the Relationship between Eye Diseases and Systemic Disorders. *Biomed Res Int*. Published online 2016 Mar 29.

<sup>4</sup> Valderas, JM, Starfield B, Sibbald B, et al. Defining Comorbidity: Implications for Understanding Health and Health Services. *Ann Fam Med*. 2009 Jul; 7(4): 357–363.

followed by 6 (17%), 3 (17%), and 5 (15%). Responses from the dry AMD group to this question were close but unsurprisingly skewed lower overall: the most common response was 6 (16% of the dry group), followed by 5 (15%), 2 (15%), and 7 (14%). The larger responses in both groups landing on the higher end of the scale (above five) indicates that AMD is perceived by the patients who live with it as entailing a significant degree of vision impairment.

The severity of the disease is emphasized by respondents' feelings about its seriousness as well. When presented with a standard Likert scale to rate **how serious they consider the disease**, 50% of the wet AMD group indicated "very serious," followed by "fairly serious" (23%) and "moderately serious" (23%). Utilizing the open-ended field, one patient indicated that "I fear the other eye will be affected, see ophthalmologist regularly." Seriousness among the dry AMD group was less pronounced but still high: 41% selected "very serious," 31% selected "fairly serious," and 25% selected "moderately serious."

When asked **how often they think about the disease**, responses among both groups were high. In the wet AMD group, 70% indicated "very often (at least once a day)." This was followed by 18% indicating "often (at least once a week)" and 11% indicating "occasionally (at least once a month)." Only 1% of the group selected "rarely or never (less than once a month)." The dry group provided responses that were only marginally lower on the scale overall, with 69% of the group selecting "very often," followed by 23% with "often," 5% with "occasionally," and 3% with "rarely or never."

Given responses in this category it is clear that perceptions regarding the severity and seriousness of AMD tend to be acute. This is the case with dry AMD patients as well, who despite being at a very different point in the disease's pathogenesis have shown here that AMD has a sizeable psychological impact. This appears to be somewhat distinct from the severity of a disease such as glaucoma. In our submission to CADTH last year for the HTA of minimally invasive glaucoma surgery (MIGS), we supported your insight that the tendency to think about the disease daily may be linked to the often-daily treatment regime (in the form of eye drops). In contrast, many wet AMD patients receive anti-VEGF injections monthly or bi-monthly, but their disease comes to mind daily. This may be due to the more invasive nature of injections compared to eye drops; it could also be connected to the severity of central vision loss in some wet AMD patients, which is distinct from peripheral vision loss in its tendency to make even common or daily activities a challenge, such as reading or recognizing faces. The dry AMD group is distinct for a different reason: they do not receive injections but still tend to think about the disease frequently. More work is required to understand why this is the case, but it may be due to the demands of managing the disease, the difficulty treating it, fears associated with it transitioning to wet, or other factors. Regardless, for both wet and dry AMD patients vision loss is considered quite severe, the disease itself is considered serious, and it presents regularly as a kind of psychological intrusion.

### *Difficulties and Challenges Associated with AMD*

Given the psychological toll of the disease and its severity it is not surprising to find that it tends to disrupt the lives of patients in other ways as well. When asked to choose **activities they find difficult or can no longer do** and given the ability to select multiple, participants' responses displayed the far-reaching impact of AMD, with "reading" collecting the largest number of responses from both the wet (65%) and dry (67%) groups. In both groups this was followed by "driving" (46% for wet, 54% for dry) and "interacting with others" (37% wet, 46% dry). Other responses included "navigating public spaces" (23% wet, 22% dry), "travelling" (21% wet, 31% dry),

“no activities I find difficult or can no longer do” (18% wet, 21% dry), “cooking” (16% wet, 18% dry), “online interaction” (15% wet, 25% dry), “social interaction” (13% wet, 17% dry), “housework” (11% wet, 20% dry), “networking” (6% wet, 10% dry), and “parenting” (0% wet, 1% dry).

It is surprising to see in some cases that the dry percentage is higher than the wet, and in areas we would expect to be more acutely affected by higher vision loss (driving, travelling, cooking, online interaction, etc.). It is possible that this is due to a portion of the wet group no longer engaging in the activity due to its difficulty; for example, that a patient no longer drives and therefore does not find it difficult, although in this instance they would also no longer do it (the latter was part of the question but may have been overshadowed by the notion of difficulty). It is also the case, however, that more wet AMD patients selected the open-ended “Other” option than dry respondents (34% for wet, 25% for dry), though the impact of this on overall response percentages requires further analysis.

Regardless, both wet and dry respondents provided a range of insights into difficulties associated with their AMD that extend beyond the provided list, including the following for the wet AMD group:

- “Susceptible to falls, since I really have no binocular depth perception.”
- “Sunlight or bright lights in front of me really hurts but need lots of light to see good enough to do things like cooking, etc.”
- “Sewing, knitting, stained glass, writing, embroidery, etc.”
- “Reduced independence.”

And for the dry AMD group:

- “Difficulty focusing on my grocery list and difficulty finding items in flyers. It's too busy for me. The bright lights in the big superstore seem overwhelming and don't help me read my own writing!”
- “Night driving is harder. Also, I tire reading.”
- “Drawing, painting, art work.”
- “Everything is difficult.”

The diversity of responses in both groups suggests that although certain difficulties are common, such as reading and driving, vision loss associated with AMD is both extensive and varied: the disease problematizes activities that are both conceptual (independence) and specific (embroidery), everyday (cooking) and occasional (night driving), small (flyers) and catastrophic (falls). Difficulties associated with AMD are therefore far from consistent or homogenous; instead, they extend to the specific and idiosyncratic details of individual life.

Our survey also asked about overall challenges—as opposed to specific difficulties—and the responses here were heterogenous as well. When asked what **overall challenges they face as a result of AMD** and given the option to select multiple, 80% of the wet AMD group and 75% of the dry chose “concern over deterioration of sight,” by far the most selected response. Other responses included “frequency of visits to the eye doctor” (44% for wet, 34% for dry), “frequency of medication or treatment” (43% wet, 26% dry), “loss of independence” (32% wet, 34% dry), “anxiety” (28% wet, 28% dry), “depression” (20% wet, 23% dry), “strain on family members or friends” (17% wet, 15% dry), “no challenges” (12% wet, 13% dry), and “general mobility” (4% wet, 6% dry). The strong emphasis on a concern over visual deterioration by both groups suggests once again the mental and

emotional toll of the disease, this time directed specifically towards its potential to worsen. And the challenge is pronounced for both groups despite the existence of a well-tested standard of care.

As with the notion of challenging activities, the “Other” field was used by both wet and dry groups (11% wet, 10% dry) to provide a range of responses. For the wet group, these included:

- “Loss of job, loss of income.”
- “Doing small repairs around the house.”
- “Every month getting more isolated.”
- “Other health problems.”

And for the dry group they included:

- “Frustration.”
- “I need to kneel on the floor to read the prices on the bottom shelf at the supermarket.”
- “Can’t read signs at fast food restaurants when ordering food, can’t clearly make out faces when area is dimly lit.”
- “Worried about the possible transition to Wet AMD and whether I will recognize it.”

### *Supports and Networks*

It perhaps goes without saying that the specific difficulties and overall challenges of AMD touch the lives of family members as well: 44% of the wet group and 44% of the dry selected “yes” when asked **if their eye disease affects members of their families**. And relatedly, when asked what kind of support, if any, they currently access, the most common response for both groups was “support from family and friends” (70% wet, 71% dry). This explicitly indicates a high burden for not just the patient but their support networks. Other supports selected by respondents included “support from low vision clinics” (20% wet, 16% dry), “support from CNIB” (11% wet, 17% dry), “transportation support” (10% wet, 14%), and “government programs or financial assistance” (5% wet, 2% dry). The “Other” field was highly used as well (34% wet, 36% dry), leading to responses from the wet AMD groups such as:

- “My ophthalmologist.”
- “Foundation Fighting Blindness.”
- “Magnification device.”
- “Have very good neighbours, the postman and garbage workers, and a few friends.”

And from the dry AMD group we received responses such as:

- “Volunteer support.”
- “Visit ophthalmologist twice per year.”
- “Local Low Vision Support Group (monthly).”
- “Newsletter from Foundation Fighting Blindness. Applied to CNIB to be a test subject for experimental treatment of AMD with yellow laser light. Was rejected because my sight was still too good.”

### *Treatments and Related Barriers*

Regarding treatments, a significant majority of the wet AMD group indicated that they **are currently taking medication or receiving treatment for their AMD**: 86% of the group, with 12% selecting “Other” and providing responses such as “Injections and a shunt in my one eye,” “herbal medications,” “Vitalux,” and “Injections in the eye when required, and eye drops daily.” As expected, a lower percentage of respondents from the dry AMD group indicated taking medication or receiving treatments: 62% of the group, with 20% selecting “Other” and providing responses: “Only vitamins and try to eat right foods,” “Just eye drops,” “I take Vitalux twice a day and so far that seems to have stabilized the degeneration,” and “Preservision AREDS Vitamins.”

When asked **what medication or treatment they receive**, 59% of the wet AMD group indicated injections of some kind in open ended responses: 10% of the wet group indicated “Avastin,” 5% indicated “Eylea,” 17% indicated “Lucentis,” and 26% simply indicated receiving some kind of “injection,” “shot,” or “needle” without specifying the brand. In the dry AMD group, responses included “Vitalux” (25% of the group), “drops” (10%), “AREDS” (7%), and “vitamins” (4%), as well as one-off responses such as “Lumigan,” “Timolol drops and Xalatan drops,” “glaucoma drops,” “Vision essence,” and “eye injections.”

We also asked patients **whether their medication or treatment routine affects their quality of life**, and found that most replied in the negative: 63% from the wet AMD group and 77% from the dry selected “no.” For the remainder that selected “yes” a number of reasons were specified, particularly from the wet group, including:

- “Only on the day of the injection. I know that I will be in pain that day and medicate accordingly. I also rest following the injection. By suppertime, I am ready to fulfill my role as cook of the family.”
- “Injections every two or three weeks.”
- “On day of injection cannot see well.”
- “After injections limited visibility.”
- “Experience some side effects for approximately 48 hours post injection.”
- “Transportation to and from is expensive.”
- “Yes, for 3 days every 6 weeks I can’t do anything but stay in and rest.”
- “Nuisance having to travel 200km each way for treatment.”
- “I lose a day.”

And in the dry group a single response was provided that was intelligible: “Many trips for injections of Eylea.”

To develop a sense of the impact on family members, we asked **whether medication or treatment routines affected members of their family**, with the majority from both groups once again responding “no”: 70% from the wet group and 80% from the dry. Most of the respondents replying “yes” and providing reasons once again came from the wet AMD group, with comments including:

- “Husband has to drive me to and from appointment.”
- “My son has to pick me up from the hospital after the treatment.”
- “Transportation and meal preparation.”
- “Have to provide transportation so need to take time off work.”
- “Driving to Dr.’s appointment.”

- “My wife has to plan her work schedule around my medical appointment.”
- “My husband drives me to and from each appointment.”
- “Wife attends appointment with me and she is fine with this.”
- “My husband makes himself available to drive me to appointments. He is very patient, but I know it can be an imposition on him at times.”
- “Husband drives me to doctor, and sometimes has to miss his volunteer work because of this.”

With the stress laid on driving as a difficult or impossible activity, it follows that travel to and from appointments would entail a strain on patients, and in these responses it is clear that the burden is often carried by family and loved ones. Seeing as vision loss impedes driving in the case of many eye diseases, it is fair to assume that travel emerges as a burden or barrier for many with a severe vision impairment, and that the issue of transportation in relation to treatments should be considered carefully as a key factor in decision-making. For the dry AMD group, only two elaborations were provided, one specifying “One sister” and the other “My husband takes me to the ophthalmologist.”

Transportation and its burden on caregivers is a concern echoed in independent research conducted by the CNIB Foundation, which found that 23% of older adults (age 65 and above) who are blind or partially sighted have no access to transportation of any kind, and that 45% of the overall group have access to only a single mode of transportation that is dependent on a family member or friend. Of adults aged 26 - 64 who are blind or partially sighted, 30% have no access to transportation, showing that the issue is not limited to senior Canadians. The numbers uncovered in this research shed light on a central challenge for many Canadian patients, especially those with AMD who are undergoing monthly injections. It is safe to assume that the issue is exacerbated for patients living in rural or remote communities with limited or no access to public transit.

Less concerning for both wet and dry groups is the issue of financial difficulties. When asked if they experience any **financial difficulties paying for medications or treatments**, 90% of the wet group and 83% of the dry selected “no.” Those selecting “Other” and providing comments, however, shared insights that show that a minority of patients with wet AMD do face financial challenges and barriers. In the wet AMD group, these insights included “But Vitalux is expensive with no tax refund,” “When I go to the States for 4 months I pay for the treatment,” “Only the costs for transportation,” and “Driving into city, gas costs, and parking fee. Not difficult but is costly.”

We inquired into other difficulties outside of financial ones as well, asking survey participants **if they have experienced other barriers to taking medications or receiving treatment** and giving them the option to select multiple. At the higher end of responses was “fear knowing the disease is getting worse” (37% for wet, 40% for dry), followed by “length of travel time” (23% wet, 15% dry), “unavailability of someone to take me to appointments” (11% wet, 8% dry), “cost of transportation” (7% wet, 7% dry), “wait time to see specialist is too long (7% wet, 10% dry), “did not know how important it was” (7% wet, 8% dry), “did not like or trust the eye specialist” (3% wet, 3% dry), “unable to get time off work or school” (1% wet, 0% dry), and “cannot afford the appointments or medication” (0% wet, 2% dry). In both groups, however, the “Other” response was selected most frequently—41% of the wet group and 47% of the dry— with commentary provided as well, including the following among the wet group:

- “Fear of going totally blind and not wanting to live blind.”



- “My initial diagnosis was delayed to the point that it was too late to save my right eye. I have found this inexplicable when I live in Ottawa and have always felt that someone dropped the ball unnecessarily.”
- “Periodic injections limiting length of vacations.”
- “Not barriers but inconveniences.”

And among the dry group:

- “My dry AMD is stable but I always wonder what the future will bring.”
- “Unsure who to go to in my area to receive the most up-to-date treatment.”
- “Vitamins made me sick.”
- “Am not understanding exactly where I stand on glaucoma stage or the deterioration of the optic nerve.”

As with the difficulties and challenges the come with the disease, it is clear in these open-ended responses that barriers are diverse and personal. At the same time, many of them do orbit around the notion of fear or anxiety in response to going blind or the disease worsening; experiencing fear regarding the future of their vision, many of these patients may be avoiding the very thing that can help stabilize or prevent sight loss. A kind of self-fulfilling prophecy may be at play for some AMD patients, then, whose fear of a future scenario contributes to that scenario, and it is worthwhile pursuing the subject further to determine how these perceptions specifically affect adherence to injections regimes.

Though we did not probe the specificity of that link, we did explore the issue of adherence by asking participants to identify how often their eye specialist indicated they should take medication and how often they actually do. In response to the former, **how often their eye specialist recommended they take medication**, the wet AMD group responded with “Monthly” (59%), followed by “daily” (36%), “yearly” (3%), and “never” (3%). By comparison, the dry group responded with “daily” (55%), “monthly” (32%), “never” (10%), and “yearly” (3%). When asked **how often they actually take medication or receive treatment**, the wet group responded with “monthly” (51%), “daily” (41%), “never” (6%), and “yearly” (1%), and the dry group provided “daily” (67%), “monthly” (22%), “never” (10%), and “yearly” (2%).

Prescribed vs. Actual Medication Frequency

	Daily			Weekly			Monthly			Yearly			Never		
	Prescribed	Actual	Variance	P	A	V	P	A	V	P	A	V	P	A	V
Wet	36	41	+5	0	0	0	59	51	-8	3	1	-2	3	6	+3
Dry	55	67	+12	0	0	0	32	22	-10	3	2	-1	10	10	0

As far as variance between prescribed medication frequency and the actual (self-reported) frequency that medication is taken, both the wet and dry groups tend to take medication daily more often than it is prescribed. Conversely, both groups take medication on a monthly basis less often than is prescribed by their specialists (this may be non-adherence, of course, but there could be other factors at play, including rescheduling on the clinician end). We can make assumptions, perhaps even safe assumptions, about the kinds of medications that may line up with these schedules—eye drops and vitamins for “daily,” injections for “monthly”—but further work is required to link variation to treatment type, and to better identify other potential drivers behind non-adherence.

We do know, however, that most patients would prefer a treatment or medication type that can be taken less frequently. When asked **whether a treatment that can be taken less often would be preferred**, the majority of both groups indicated “yes”: 64% for wet and 52% for dry. Interesting, this is somewhat incongruent with the level of satisfaction respondents indicated with their current medication: responding to a Likert scale for **how satisfied they are with current medication**, the wet AMD group selected “very satisfied” (50%), “fairly satisfied” (40%), “neither satisfied nor unsatisfied” (10%), and “fairly unsatisfied” (1%). This trend was similar with the dry AMD group, though with less satisfaction overall; the group selected “very satisfied” (32%), “fairly satisfied” (42%), “neither satisfied nor unsatisfied” (20%), and “fairly unsatisfied” (7%). Within both groups, then, there is a desire for treatments that can be taken less often, and at the same time a high level of satisfaction with current treatments. This is not necessarily a contradiction, since it is entirely possible to be satisfied with something and to also see the value of an improvement; to be satisfied, for instance, with a car but to simultaneously desire one that is better—that has better fuel economy or that meets higher safety standards, etc.

For many patients this is a largely hypothetical consideration. When asked if they have been made aware of medication or treatment options that could function as an alternative to current ones, the majority in both groups selected “no”: 70% for wet and 85% for dry. Some respondents in the wet group expanded via the “Other” option, offering perspectives such as the following:

- “Research of a virus delivery.”
- “Yes but not available yet in Canada.”
- “I have heard of gene therapy and of course, the distant? Possibility of stem cell therapy but no further therapy seems to apply to me...”
- “Understand there is a cheaper alternative to Lucentis but it is apparently not approved.”
- “I’m aware of promising research going on in the area of AMD, but do not expect to be able to benefit from it at my age.”
- “Have heard of other treatments but not approved for me by my doctor.”
- “I read most of the trials going on in Canada and USA.”

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 eager to participate in the trials that would lead to those advancements.

#### 4. CONCLUSION

AMD is a chronic disease that can involve ocular comorbidities for many patients. For those who live with either its wet or dry forms, the disease is considered serious and thought about very often, and the vision loss that accompanies it is thought of as severe. AMD is therefore physically and visually burdensome, and its corresponding emotional and psychological burdens are acute for patients as well. In line with this, patients encounter numerous difficulties in relation to the disease: these are heterogenous, but reading, driving, and concern over the disease worsening are most prominent. These challenges and others place a high level of strain on family members, particularly in relation to travel to and from appointments.

Despite the disease's seriousness and the fact that most patients take medication, many do not think these medications negatively affect the quality of their lives or those of their family members. For those patients that do, however, many believe that travel between appointments and fear over the condition getting worse are significant concerns, and for some they even emerge as barriers to taking medication. In the case of a fear that the condition is worsening, in some patients that fear may be heightened enough to determine its object—namely, the condition worsening—a phenomenon that warrants further investigation. When variance between prescribed medication regimes and actual regimes does occur, it is mostly with patients that report taking monthly medication as opposed to daily, weekly, or annually. And while many AMD patients would prefer a medication that can be taken less frequently, most are not aware of treatment alternatives; this does not represent a lack of interest in the landscape, however, seeing as a significant majority of patients support public funding for the advancement of treatments and are open to participating in clinical trials.

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 and those of their loved ones; 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 approval 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.