Patient Input Template for CADTH Reimbursement Reviews

Name of Drug: pegcetacoplan
Indication: Geographic atrophy secondary to age-related macular degeneration
Name of Patient Group: Fighting Blindness Canada, The Canadian Council of the Blind (CCB), CNIB, International Federation on Ageing (IFA), Vision Loss Rehabilitation Canada (VLRC), Association Québécoise de la dégénérescence maculaire (AQDM)
Author of Submission: Dr. Larissa Moniz (FBC), Dr. Keith Gordon (CCB), Thomas Simpson (CNIB), Dr. Anjali Tripathi (IFA), Jennifer Urosevic (VLRC), Sylvie Castonguay (AQDM)

1. About Your Patient Group

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

Over our 50-year history, FBC has contributed critical funding for the development of sight-saving treatments and cures for blinding eye diseases. By raising and stewarding funds, FBC is helping drive forward research that supports our goal of understanding why vision loss occurs, how it can be slowed and how sight can be restored. We are an invaluable resource for individuals and families impacted by blindness, providing accurate eye health information through our website and educational events, as well as engaging with government and other stakeholders to advance better vision health policies.

The Canadian Council of the Blind (CCB) 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.

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™.

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.

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 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.

Founded in 1990, AQDM's mission is to inform, guide and support people with macular degeneration and their caregivers. AMD is the most common form of the disease, but there are others, including myopic degeneration. The association also represents patients and their caregivers in dealings with government authorities. It organizes conferences, publishes a newsletter, informs the public in the province of Quebec on its phone line, and refers people to local organizations for their visual health needs.

2. Information Gathering

Information forming the basis of this submission was collected through three primary sources:

1) **Qualitative interviews** held during 2023 with two patients diagnosed with geographic atrophy (GA). Conducted by Fighting Blindness Canada, the interviews were semi-structured and designed to learn about the lived experience of GA, including visual and life challenges, economic hurdles, experiences with treatments, and more.

2) **MOSAIC: a burden of illness study** focused on patients with GA and produced by Apellis, the company that developed pegcetacoplan (SYFOVRE) for treatment of GA. Although data from MOSAIC may already be part of the company submission, it is used here as a secondary resource and analyzed from the perspective of the submitting patient groups and without any input from Apellis; the analysis takes the form of "key takeaways" that are supported by other sources of information. MOSAIC is based on survey input from patients and caregivers internationally: 251 patients, 238 caregivers, and 157 dyads (linked patients and caregivers).

   Below is an overview of the MOSAIC respondents:

Variables **Patients**	Australia N=21	**Canada N=47**	France N=12	Germany N=35	UK N=34	Europe N=81	US N=102
Mean (SD) age (years) Range	80 (6) 60-95	73 (5) 64-83	78 (9) 63-94	76 (8) 60-95	78 (8) 62-94	77 (8) 60-95	68 (4) 60-84
Sex proportion in % Male/Female/Prefer to skip	43/57	62/38	17/83	51/49	50/47/3	46/53/1	43/57
Employment status	76% retired	81% retired	100% retired	91% retired	82% retired	89% retired	77% retired
Living situation	52% live with someone	79% live with someone	33% live with someone	77% live with someone	59% live with someone	63% live with someone	88% live with someone
Mean (SD) age at time of diagnosis of GA (years)	69 (9)	68 (4)	64 (10)	71 (8)	69 (8)	69 (9)	62 (6)
Mean (SD) NEI VFQ-39 composite score *Range: 0-100*	57.6 (20.8)	48.3 (21.3)	48.1 (21.9)	47.9 (15.2)	46.9 (20.4)	47.5 (18.3)	44.6 (20.2)
Had to change living situation	10%	28%	0%	6%	24%	12%	38%
Need help everyday	19%	38%	33%	26%	50%	37%	68%

Variables **Caregivers**	Australia N=13	Canada N=46	France N=7	Germany N=35	UK N=35	Europe N=77	US N=102
Mean (SD) age (years) Range	58 (16) 38-84	44 (11) 27-78	75 (5) 69-82	64 (14) 30-87	58 (18) 23-86	62 (16) 23-87	46 (15) 19-68
Sex proportion in % Male/Female/Prefer to skip	31/69	61/37/2	57/43	34/66	9/89/2	25/74/1	47/53
Employed	69%	93%	0%	37%	51%	40%	44%
Employment status changed since becoming a caregiver	69%	22%	0%	9%	23%	14%	41%
Living with the person with GA	77%	67%	86%	69%	34%	55%	81%
Had to change living situation	31%	59%	0%	11%	14%	12%	46%
Mean (SD) ZBI score *Range 0-88*	24.7 (17.8)	42.4 (11.9)	29.9 (18.5)	18.8 (9.8)	20.0 (15.5)	20.3 (13.7)	24.8 (18.7)
Number of dyads	**N=7**	**N=3**	**N=4**	**N=35**	**N=14**	**N=53**	**N=93**
Correlation between VFQ-39 composite score and ZBI score	NA*	NA*	NA*	0.00	-0.50	-0.27	-0.63

3) **An online survey** made available to Canadians living with either wet or dry age-related macular degeneration (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.

A total of 337 Canadians responded to the survey, and although the responses focus on the experience of AMD, it is possible to draw conclusions related to GA as well, particularly when connected to the qualitative interviews led by FBC and findings from the MOSAIC study. In particular—and as the interviews demonstrate—it is generally safe to assume that the experience of GA is comparable to AMD, but often more extreme in terms of vision loss and the related physical, social, psychological, etc., challenges.

Below is an overview of the respondents to the VIEW AMD survey:

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)

In the following sections, each dataset is used where it seems most relevant and connected to the original source, either through reference or with subheadings. Where possible, efforts have been made to compare the datasets.

3. Disease Experience

Both patients interviewed by FBC were diagnosed with GA within the last 5 years. For one patient, the diagnosis was a progression from dry AMD, while for the other it was from wet. In both cases, the transition from AMD to GA was thought of as a negative progression, both in terms of visual deterioration as well as emotional and psychological impact. For example, one patient explained that:

“It wasn't like he diagnosed me with that [GA], and then, suddenly, I thought I'm worse off. No, it's just been a progression, and much worse.”

Although the patients described unique experiences overall, it is nonetheless possible to draw comparisons within certain categories or themes, including 1) the above point related to a progression beyond AMD, as well as 2) severity of vision loss; 3) significance of life challenges; 4) impact on emotional wellbeing; 5) impact on work; 6) hope of maintaining vision; and 7) openness to new treatments. The below table provides descriptions of the experiences within each thematic group.

Qualitative Interview Themes: GA Patients (n = 2)

THEME	DESCRIPTION
1. PROGRESSION BEYOND AMD	▪ GA is experienced as a linear continuation or progression from AMD, with vision loss and related challenges increasing over time. ▪ Despite this, both patients made it clear that GA feels like an escalation beyond AMD, with a near-constant sense that they are now in danger of losing the remaining vision they have left. ▪ The experience of steadily worsening symptoms, and the sense that blindness is just around the corner, is a significant psychological burden, leading to fear, anxiety, and other emotional discomforts.
2. SEVERITY OF VISION LOSS	▪ The overall trajectory of vision loss over life was described by both patients as continuous, but also as becoming most acute after the GA diagnosis. ▪ On a scale of 10, with 10 being perfect vision and 0 being blindness, both patients rated their vision between 2 and 4. ▪ While GA is not experienced as an abrupt event or discontinuity, both patients described a range of increased symptoms developing post-diagnosis: - Sensitivity to sunlight - Blurriness (one patient described the appearance of “smog in the air,” even when there isn’t) - Difficulty seeing faces and expressions. - Lack of contrast (one patient described spraining her ankles because a set of stairs looked like “black on black”) - Difficulty with small details, making activities such as reading, watching TV, etc., challenging or impossible. ▪ One patient explained that with GA, “it’s difficult to see clearly” and that in grocery stores and other areas of high visual complexity, the details blur so that it looks like “one piece.”

	▪ One patient described that, month after month, it feels like a discernable amount of vision is lost.
3. SIGNIFICANCE OF LIFE CHALLENGES	▪ As a result of vision loss, neither patient drives (even though one patient is still legally able to). Both describe this is a distinct loss of independence. ▪ Both patients use magnifiers for reading text and fine detail work. Though the magnifiers help, they continue to struggle with the loss of the ability to read unaided. ▪ One patient described reading as “a task” and, in relation to reading recipes, explained that the “lines aren’t always where they’re supposed to be.” ▪ Both patients provided additional commentary on reading: - Used to read magazines but has had to cut off many subscriptions. - Hard to read measuring cups or to see dials on the stove. - When reading and performing fine detail work, “lots of lights everywhere can be helpful.” - On computer forms it is easy to “place x’s in the wrong places.” - Friends will read placards for one of the patients at exhibits. ▪ One patient explained that grocery shopping is a significant challenge, and that differentiating products can be hard or impossible. As a result, they now only shop with their partner. ▪ Both patients described the support they receive from family members; for example, one patient’s partner does all the cooking. ▪ In the context of support, both patients articulated feelings of appreciation and acknowledged the importance of support in managing daily challenges; both also expressed empathy for those who do not have similar levels of support. ▪ One patient discussed how their love of theatre has been threatened by vision loss. It has become increasingly difficult to distinguish costume and set details at ballet, for instance.
4. IMPACT ON EMOTIONAL WELLBEING	▪ One patient is a parent and grandparent and described their children as “the motor of my life.” The idea of not being able to see them someday is devastating. ▪ The other patient does not have children, but explained that if they did, they would worry about them having AMD or GA when they are older. ▪ One patient sees a psychologist to help with the acceptance of their vision loss and its emotional impact. They explained that acceptance is a “step-by-step process” and that they are “making progress.”

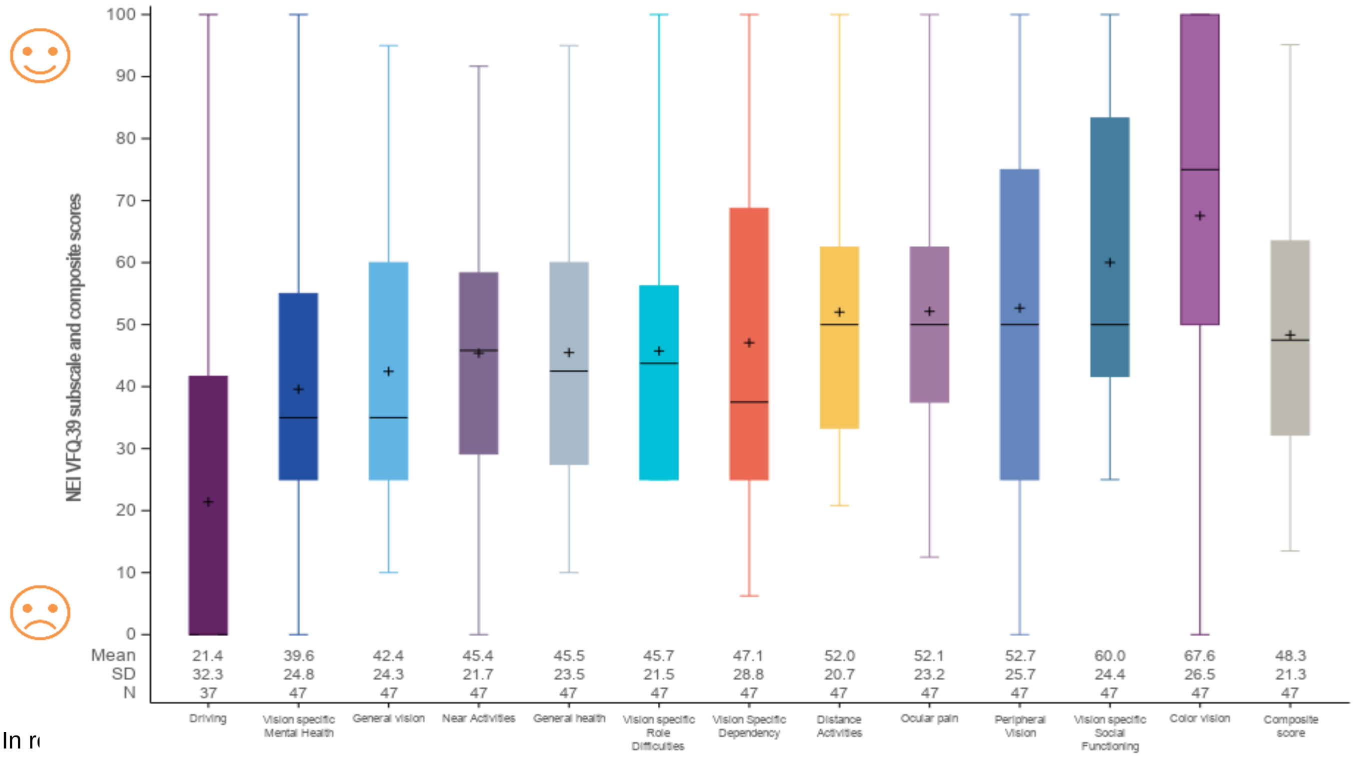
	▪ One of the interviewees emphasized their positive outlook on life, but also that they now get frustrated more easily: “frustration is one thing that happens a lot more.” ▪ Both interviewees expressed concerns over the future and discussed related emotional distress. One patient explained that “I’m more anxious about the future and what the future will bring.” The other explained that thinking about the future “leads to sadness.” ▪ Both patients described anxiety related to asking for help, and feelings of unnaturalness when it comes to relying on others.
5. IMPACT ON WORK	▪ One of the interviewees is currently employed. They have an assistant who helps them manage daily tasks that their vision renders challenging or impossible. Recognizing that most people do not have this level of support, they expressed gratitude for the position. Despite this, they also described work as a challenge in the context of basic visual tasks; for instance, struggling to read faces and facial expressions has an impact in the workplace. ▪ The other patient does not work but is active in many other ways: travelling, concerts, condo board meetings, etc. The patient discussed challenges associated with these activities and how they would potentially impact work in a similar way—for example, not driving making it difficult to get to work, or difficulty travelling (reading signs, etc.) translating to difficulty navigating a work environment.
6. HOPE OF MAINTAINING VISION	▪ A general hope or desire to maintain as much vision as possible was expressed by both participants. They also expressed hope that a treatment will be developed for GA. ▪ Both acknowledged the impossibility—at present time, at least—of regaining lost vision, emphasizing instead the importance of keeping what they have, or even slowing the progression of their vision loss so that it does not feel so rapid. ▪ One patient explained that they want to “keep this possibility”—the possibility of reading, of living a normal life, and of maintaining some vision. ▪ If maintaining vision is not possible, both patients also underscored the value of slowing vision loss. For example, one patient explained that even if a treatment only slows vision loss for a single year, it would be worth trying.
7. OPENNESS TO NEW TREATMENTS	▪ Both participants expressed a desire to access new treatments when they become available. ▪ For the patient with wet AMD, injections are already a normal part of life and an acceptable burden if it means maintaining vision or slowing vision loss—injections are “not a big problem.” For the patient with dry AMD, the idea of injections is scary but well worth confronting if they help.

	- The participant with wet AMD also explained that receiving another set of injections alongside the anti-VEGF regime would be acceptable—as long as there is a benefit. - One patient emphasized the importance of their physician’s perspective. Any new treatment would have to be recommended by this trusted source.

Other Data Sources: MOSAIC and VIEW AMD

Both the MOSAIC study and findings from VIEW AMD support the thematic groupings outlined above.

In relation to **2. SEVERITY OF VISION LOSS**, for example, the MOSAIC study shows that GA patients tend to struggle with their general vision, with driving, and with vision specific mental health, all characteristics that were emphasized by our interviewees. Among other tools, MOSAIC utilized the National Eye Institute’s Visual Function Questionnaire (VFQ) to draw these conclusions (table below).



In r

experience increased difficulty at night and in visually complicated conditions. Our interviewees articulated driving as an essential part of independence; it is safe to extrapolate that the loss of driving for a majority of the GA population is similarly experienced as a loss of independence, with all of the social, emotional, and psychological effects that such a loss entails.

From VIEW AMD, we also know that driving and travel impact a patient’s ability to attend vision-related appointments, further suggesting the severity of vision loss for GA patients.

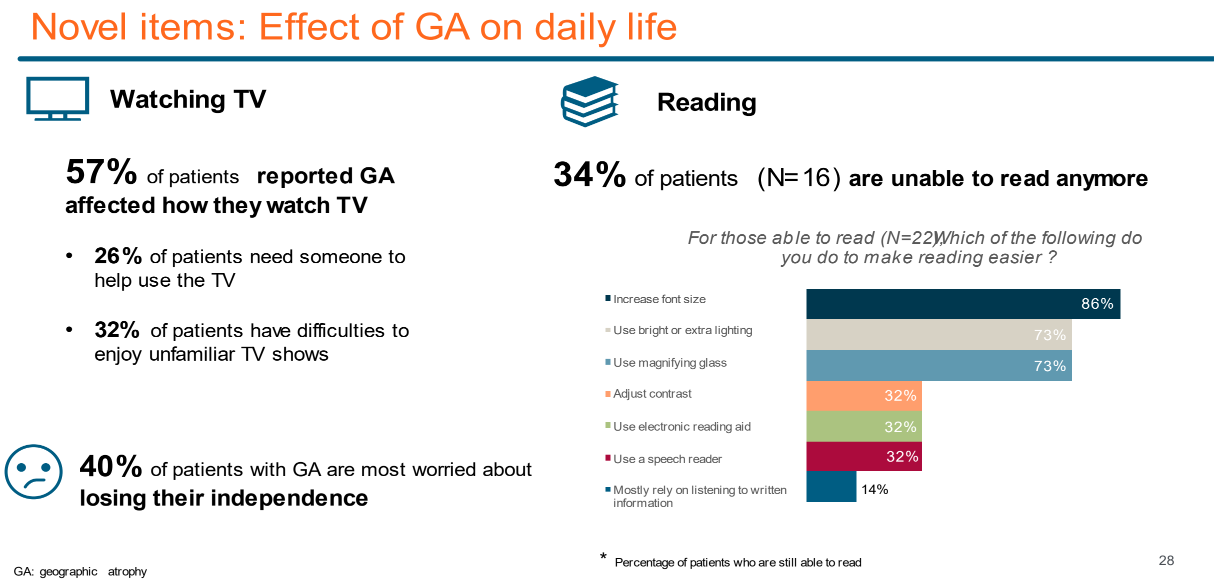
When asked what the most difficult part of attending eye injection appointments is, 27.7% of patients indicated “finding someone to drive me to/from the appointment.”

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)

Of course, the loss of driving is more than an example of the severity of vision loss. As suggested in our interviews, it is also part of a larger theme involving the **3. SIGNIFICANCE OF LIFE CHALLENGES.**

In relation to life challenges, the MOSAIC patients were asked specifically about watching TV and reading. 57% reported that their GA affects how they watch TV, with 26% indicating they need help with the TV and 32% reporting that they have difficultly enjoying unfamiliar shows. In terms of reading, 34% of the surveyed patients reported not being able to read anymore. For those who do read, 86% use increased font size, 73% use bright or extra lighting, and 73% also use a magnifying glass.



Novel items: Effect of GA on daily life

Watching TV

57% of patients **reported GA affected how they watch TV**

- **26%** of patients need someone to help use the TV
- **32%** of patients have difficulties to enjoy unfamiliar TV shows

40% of patients with GA are most worried about **losing their independence**

Reading

34% of patients (N=16) **are unable to read anymore**

For those able to read (N=22): Which of the following do you do to make reading easier ?

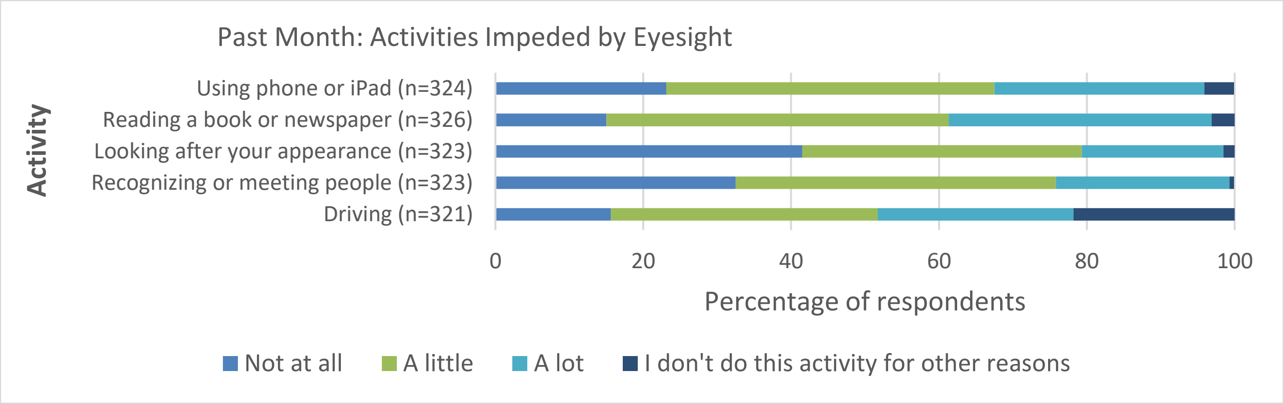
GA: geographic atrophy

* Percentage of patients who are still able to read

28

In the VIEW AMD study, AMD patients reported on a wide range of activities that are impacted by their disease, including interacting with phones and tablets, reading books and newspapers, and more. In line with our interviews, “reading a book or newspaper” appears to be the activity that was most impacted.

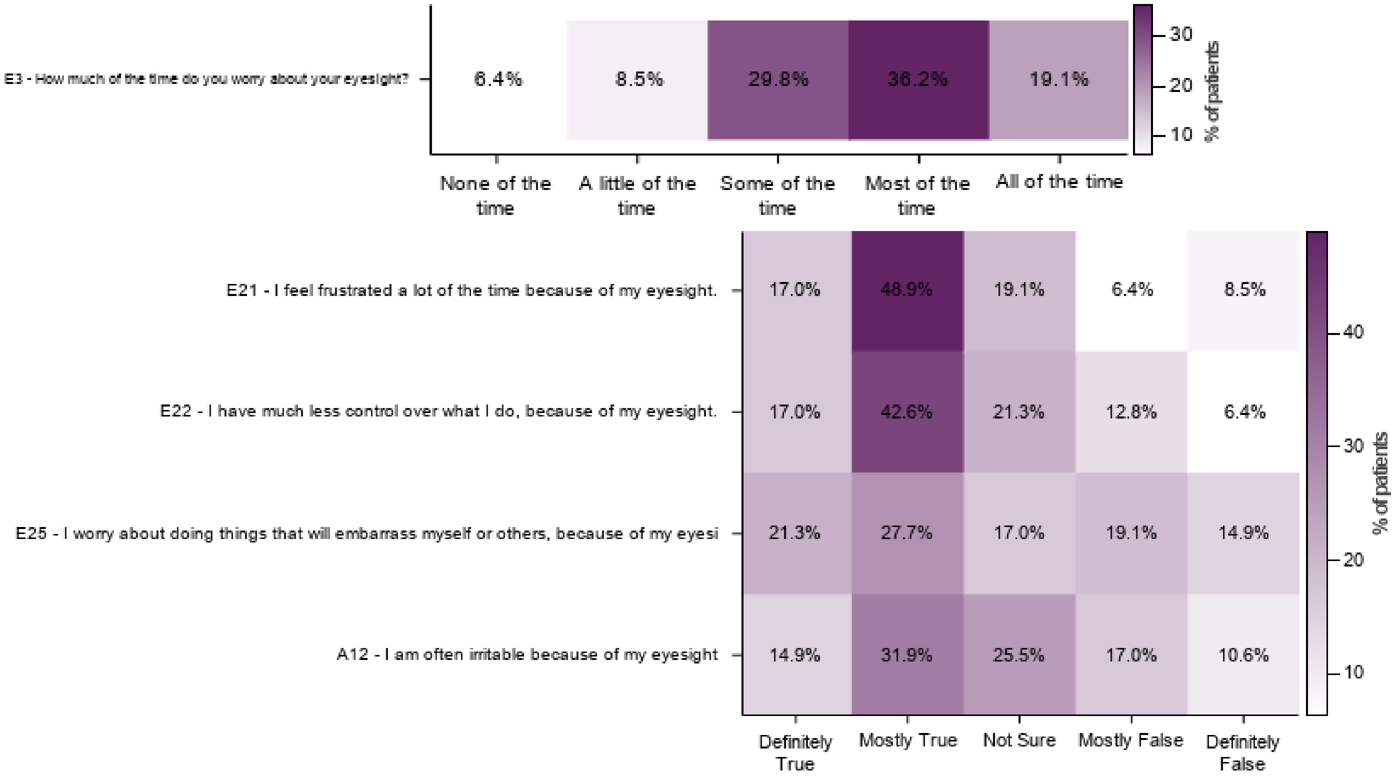
Impact on daily activities



It is clear that these impacts—on vision, activities, and more—carry an emotional burden. This was emphasized by both interviewees. Both MOSAIC and VIEW AMD show a **4. IMPACT ON EMOTIONAL WELLBEING** as well.

In MOSAIC, 55% of patients reported worrying about their vision most or all of the time, 66% reported feelings of frustration, 60% reported feeling less in control of what they do, and 49% reported worrying about doing things that would feel embarrassing.

Vision-specific mental health



Results highlighting worry and frustration align very closely with feedback from our interviewees. It is clear that GA is a difficult disease to live with in this regard, and that its emotional and psychological impacts should not be overlooked or deemphasized.

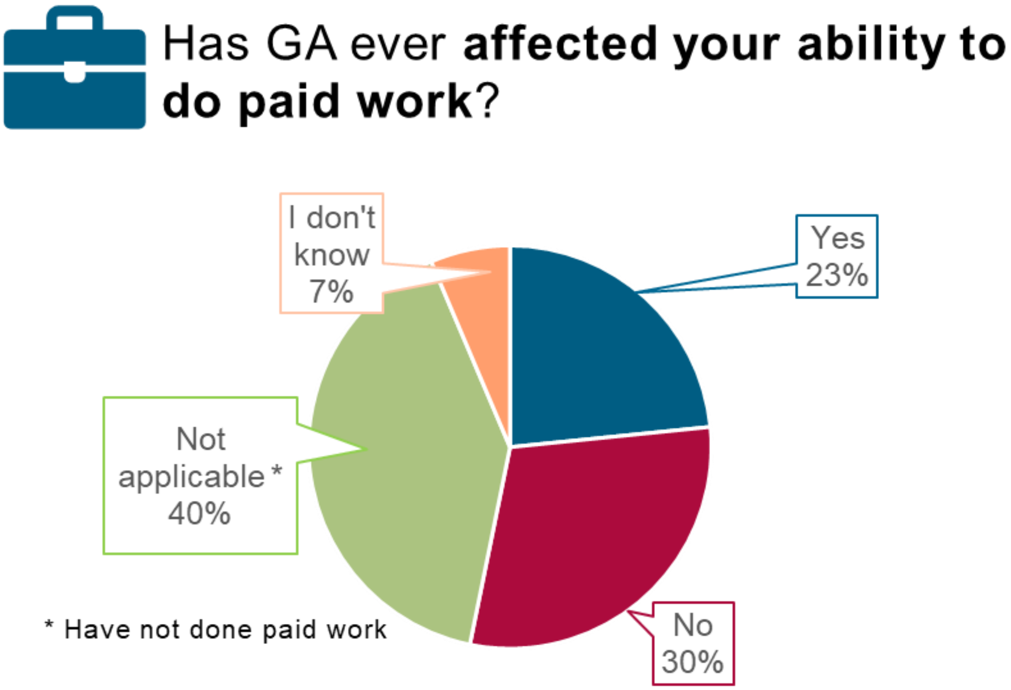
The notion of a psychological toll or burden is shown in VIEW AMD as well, particularly in relation to concerns over the future. When asked to select from a list of challenges associated with sight loss and AMD, a significant majority indicated that they “worry that my condition might worsen in the future” (77%). In a similar manner, future-oriented anxiety was discussed at length by both of the patients we interviewed.

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)

A **5. IMPACT ON WORK** is explored in detail in the MOSAIC study, with a specific emphasis on financial stability: 36% of patients indicated a concern over the effect of GA on their finances in the future, and 66% indicated concern over effects on their living situations. Almost a quarter of the patient group (23%) selected that GA has affected their ability to do paid work:

Impact on ability to do paid work



4. Experiences With Currently Available Treatments

Seeing as pegcetacoplan represents the first viable treatment for GA to enter the Canadian market, we were unable to learn about experiences with “currently available treatments.” That said, the VIEW AMD study includes a robust review of attitudes and feelings about existing anti-VEGF treatments which similar to pegcetacoplan are delivered by intravitreal injection. Below is a summary of what can be considered relevant insights:

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%).

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)

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)

Difficulty of Eye Injection Appointments

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)

Emotional and Physical Effects

The largest group of patients underscored “anxiety or fear about the injection” (38.2%) as the most difficult part of the appointment. 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—an insight supported by the patient we interviewed whose GA is secondary to wet AMD.

5. Improved Outcomes

As discussed, the two patients interviewed as part of this submission stressed their desire for a treatment for GA. For them, improved outcomes would involve either a) the preservation of their existing vision; or b) a slowing of the vision loss they are currently experiencing.

Both patients acknowledged that preserving vision is unlikely. At the same time, both emphasized that slowing vision loss—even for a small amount of time—would be desirable, and that the treatment burden of intravitreal injections, would be acceptable to achieve these outcomes.

The patient whose GA is secondary to wet AMD made it clear that injections have been normalized and are part of their life. The prospect of more injections is not a barrier. The patient with dry AMD expressed a generalized nervousness and uncertainty related to injections, but also stated that they would be willing to try an injection-based treatment. So again, injections are not a barrier to trying a treatment.

6. Experience With Drug Under Review

None of the patients involved in this submission have received pegcetacoplan as a treatment for their GA. 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?

To summarize, the insights from our interviewees allowed us to develop a set of core themes or ideas that were shared by both participants: 1) progression beyond AMD; 2) severity of vision loss; 3) significance of life challenges; 4) impact on emotional wellbeing; 5) impact on work; 6) hope of maintaining vision; and 7) openness to new treatments. Many of these ideas are echoed within the MOSAIC and VIEW AMD studies, which we have attempted to highlight in section 3 of this submission.

The below table reiterates these themes in relation to the data sources that support them.

	DATA SOURCE		
THEME	INTERVIEWS	MOSAIC	VIEW AMD
1. Progression beyond AMD	X		
2. Severity of vision loss	X	X	X
3. Significance of life challenges	X	X	X
4. Impact on emotional wellbeing	X	X	X
5. Impact on work	X	X	

6. Hope of maintaining vision	X		
7. Openness to new treatments	X		

As organizations that represent patients with GA, 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 GA and their value in the review process of new treatments.

We look forward to continuing to work with CADTH to support Canadians living with GA, 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 Dr. Chad Andrews as an independent consultant with expertise in patient centered research to interview patients and analyze 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
Apellis				X
Roche				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: Dr. Larissa Moniz
Position: Director, Research and Mission Programs

Patient Group: Fighting Blindness Canada
Date: February 9, 2024

Company	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000
Apellis			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: Dr. Keith Gordon
Position: Senior Research Officer
Patient Group: The Canadian Council of the Blind
Date: February 9, 2024

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: Thomas Simpson
Position: Vice President, CNIB Voice
Patient Group: CNIB
Date: February 8, 2024

Company	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000
Bayer				X
Roche				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: Dr. Anjali Tripathi
Position: Secretary General
Patient Group: International Federation on Ageing
Date: February 5, 2024

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: January 2, 2024

Company	$0 to 5,000	$5,001 to 10,000	$10,001 to 50,000	In Excess of $50,000
Apellis			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: Sylvie Castonguay
Position: Executive Director
Patient Group: AQDM
Date: January 30, 2024