

THE BURDEN OF GLAUCOMA ON CANADIAN PATIENTS: STAKEHOLDER FEEDBACK ON THE OPTIMAL USE OF MIGS

Feedback on CADTH’s “Optimal Use of Minimally Invasive Glaucoma Surgery: A Health Technology Assessment”
Canadian Council of the Blind | The CNIB Group | The Foundation Fighting Blindness

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1. DISEASE OVERVIEW

Affecting over 400,000 Canadians, glaucoma is a disease of the optic nerve and the leading cause of blindness in North America. Several disease-types have been identified, but in all forms of glaucoma the eye’s drainage canals are blocked, leading to a build-up of aqueous humor fluid and an increase in intraocular pressure (IOP) that can eventually damage the optic nerve, the pathway for carrying visual information to the brain. Though glaucoma is typically conceptualized as distinct from “retinal diseases,” it is the retinal cells responsible for processing visual information and sending it along the optic nerve—called “retinal ganglion cells” (RGCs)—that are first damaged; as such, glaucoma is a disease that directly affects the retina. While there is no cure for glaucoma, early detection and treatment can avert damage to RGCs and, as a result, prevent loss of vision.

The current standard of care for glaucoma is largely split between, on the one hand, drug therapies in the form of eye drops and pills, and on the other, surgical approaches encompassing laser surgery and trabeculectomy. The focus across all treatment types is on lowering the build-up of fluid in the eye and the resulting IOP.

Minimally invasive glaucoma surgery (MIGS) refers to a group of devices and procedures that have emerged more recently, distinguished by their novel use of small cuts or micro-incisions, usually through the cornea, that minimize trauma to surrounding tissue and decrease, in some cases, the occurrence of side-effects. As identified in CADTH’s Environmental Scan, MIGS approaches are only covered by provincial health insurance in Alberta and Quebec, but surgeons in other parts of Canada are beginning to use MIGS as a replacement for the standard of care, and in some cases as a paid “upgrade.” The resulting implementation is a mishmash of heterogeneous criteria, practices, and payment models, leaving little in the way of clarity or direction for Canadian patients.

2. SURVEY AND SUBMISSION OVERVIEW

CADTH’s draft assessment of MIGS, titled “Optimal Use of Minimally Invasive Glaucoma Surgery: A Health Technology Assessment,” makes clear that a lack of formal criteria is in some ways inevitable in the context of health technology innovation. But when referring to stakeholder input in the Environmental Scan, the draft also suggests that “the more widespread use of MIGS has crossed over from the early-innovation stage to one in which the lack of criteria for allocation of MIGS threatens to be arbitrary and poorly organized, and hence an unacceptable form of differential treatment” (109, 3367-70).

To address the ad hoc nature of contemporary MIGS practices, to ascertain the best criteria for specialists, and to ensure that MIGS devices and procedures are implemented in the most equitable and effective way possible, it is essential to know as much as we can about the relevant patient group: in this case, Canadians living with glaucoma. To aid in this process and to support CADTH's assessment, the Foundation Fighting Blindness posted and disseminated an online, 30-question "burden of illness" survey on July 20, 2018. Designed to collect data on the physical, psychological, financial, and other burdens associated with the disease, the survey collected 244 responses, providing a range of insights into the experiences of patients across Canada.

The data show that the survey respondents belong to a diverse patient population, with a significant majority of the surveyed group located in Ontario (73%).¹ The remainder specified being located in British Columbia (12%), Alberta (5%), Quebec (3%), Newfoundland (2%), Nova Scotia (2%), Saskatchewan (2%), and Manitoba (1%). The average year of birth provided by respondents was 1950, with a median of 1948, and the average year provided for a glaucoma diagnosis was 2000, with a median of 2007. Most patients indicated having glaucoma in "both eyes" (76%), while a minority indicated having the disease in "one eye" (18%), and the remainder selected "other." Patients rated the "severity of vision loss resulting from your glaucoma" on a scale from 1 to 10: most indicated 1 for "no vision loss" (24%), followed by ratings of 2 (17%), 3 (14%), 4 (12%), and 8 (7%). The average of these ratings is 3.88.

Using this information and data from other responses, the Canadian Council for the Blind, the CNIB Group, and the Foundation Fighting Blindness (hereafter "we") performed a preliminary review to determine if there is anything of value in relation to CADTH's draft HQA assessment of MIGS, focusing in particular on section 5 ("Patient Preferences and Experience Review"). Our review made it clear that, especially in the context of an overall paucity of literature on the subject, the data does offer relevant insights that are not currently represented in the draft assessment, and that these insights can aid stakeholders and policymakers in determining the best course of action for MIGS. The feedback offered in the following sections, oriented around the notion of "gaps," therefore responds to a question posed by CADTH on its stakeholder feedback page: **"Are there any inaccuracies in the report, or is any relevant information missing?"**

3. GAPS IN UNDERSTANDING THE BURDEN OF GLAUCOMA

In the "Patient Preferences and Experience Review" of CADTH's assessment, it is immediately clear that little in the way of high-quality research exists that effectively evaluates the toll that glaucoma takes on the Canadians who live with it. The literature search performed in this section begins with 7,133 citations, narrows to 67 full-text articles, and ends with 15 studies that meet CADTH's inclusion criteria. Once these studies are subjected to a quality appraisal, however, very few remain reliable: only one study is viewed as "credible," two as "trustworthy," and three as "transferable."

This shortage of credible research points to potential gaps in our understanding of the reality of glaucoma for Canadian patients, one of which involves a gap in our awareness of the burden of the disease on patients. The CADTH draft assessment does a commendable job retrieving information from these studies that sheds some

¹ All survey percentages are rounded to the nearest whole number.

light on the daily challenges of glaucoma patients, but this deficiency presents a considerable hurdle vis-à-vis the potential implementation of MIGS in Canada.

The draft assessment details how some glaucoma patients perceive changes to their vision as a “symptom of normal aging” (97, 2859), leading to them coping by “restructuring how they engaged with everyday tasks” (97, 2864) instead of seeking medical support. This is a valuable insight, demonstrating the need to counter the notion that the disease is “normal” or “inevitable,” rather than one that is manageable if detected before irreversible damage is done to the optic nerve.

There is a chance, however, that this point could be interpreted out of context to suggest that the disease does not present a psychological burden, that, being considered natural or unavoidable, it is forgotten. The majority of our survey respondents answered the question **“How serious do you consider your glaucoma to be?”** by indicating “very serious” (31%), implying the opposite, that the disease does not go unnoticed and is not forgotten. Other responses to this question ranged from “fairly serious” (29%), “not very serious” (25%), and “not at all serious” (5%). The remainder indicated “other,” with some providing insights that imply a spectrum of experiences and of severity; one patient wrote “I realize that glaucoma is a serious condition, but my experience has been pretty benign, all things considered,” while another wrote “It is serious; have had multiple laser surgeries, a trabeculectomy, and a trabeculectomy correction with a donor cornea patch.”

Most of the surveyed patients responded to the question **“How often do you think about your glaucoma?”** by indicating “very often (at least once a day)” (37%). Other responses included “rarely or never (less than once a month)” (21%), “occasionally (at least once a month)” (17%), and “often (at least once a week)” (16%). Many of the patients who answered “other” connected their tendency to think about the disease often to the frequency of their eye drops; one patient wrote “Basically twice daily when taking my eye drops,” another answered “I would assume every day because I put drops in my eye every night and my eye appearance has changed so I see it each day,” and one participant replied with “At least twice a day when putting drops in (3 different drops, 2/day).” As with their perspectives on the severity of the disease, the frequency with which many respondents think about their glaucoma alludes to a significant psychological burden; in this case, one that is connected, for many, to the often-daily routine of eye drops.

CADTH’s draft assessment does gesture towards the psychological toll of glaucoma, largely through the lens of its recurrent association with blindness: “This association between glaucoma and blindness belies a common perception of eye conditions as being either common or normal minor problems [...] or as those that cause complete sight loss. Glaucoma, not falling into the category of minor vision issues, was instead conceptualized as blindness” (98, 2922-26). This is an association that is repeated in various ways in responses to our survey, with the word “blindness” appearing eight times and the word “blind” appearing five, though in distinct contexts.

The CADTH draft links this association to a common fear that patients experience: “Across studies, patients articulated a fear of blindness” (99, 2943). This is also echoed in our survey data, though with a different inflection: a large percentage of patients (34%) selected “fear knowing the condition is getting worse” as a response to the question **“Have you experienced any other barriers to taking medications or receiving treatment for your glaucoma?”** This supports the notion of fear in relation to blindness, here framed as fear of the condition worsening, but it also foregrounds that fear as a potential barrier to taking medication or receiving treatment. Other barriers selected by respondents included “length of travel time” (14%), “wait time to see

specialist is too long” (10%), “cost of transportation” (7%), “unavailability of someone to take me in” (6%), and “did not know how important it was” (4%). A large portion of patients indicated “other” in their response (48%), with a diverse range of barriers expressed, including “uncertainty of exact diagnosis, i.e. type of glaucoma,” “Appointment time with ophthalmologists is too short when one is facing possible blindness,” and “My only wish is that there were more medication options available. I developed an allergy to my first medication and I am allergic to sulfa so I feel my options are limited.” Many respondents also referenced a lack of any barriers in their open-ended responses.

The CADTH draft does include a robust section on “the challenges patients face with eye drops, their primary treatment for glaucoma” (99, 2972), but a nuanced exploration of other significant barriers—framed as just that, barriers—does not appear in the draft’s “Patient Preferences and Experience Review” section—meaning, of course, that it may not exist meaningfully in current research, since CADTH is surveying relevant literature. As already suggested, this points towards a gap in our understanding of the burden of glaucoma, a gap that could very well impede a serious assessment of MIGS in the Canadian landscape, since an understanding of the multifaceted barriers to treating the disease would ideally be a guiding factor.

A general lack of detailed information in the CADTH draft on the daily challenges associated with living with glaucoma heightens the sense of a gap in our understanding of glaucoma’s burden on patients. Responding to the question “**What are the daily challenges you face living with glaucoma?**” our survey respondents selected a wide range of challenges, with many selecting multiple. These included “no daily challenges” (40%), “difficulty reading” (40%), “frequent visits to the eye doctor” (37%), “not able to drive” (26%), “depression” (15%), “difficulty cooking” (11%), and “general mobility” (10%). Many of those who selected “other” (29%) provided insights that illustrate how complex their daily challenges are, including “Need enlarged monitor with computer,” “have hard time seeing if dishes I was are clean, vacuuming, wash floors - close-up work,” “problems with depth perception, tripping,” “Difficulty walking through busy public areas, people bumping into you,” “Regular Medication + Interventions,” and “Anxiety.”

Responses to the question “**Are there activities that you find particularly difficult or can no longer do?**” demonstrated just as much complexity. Again, many patients selected multiple responses, including “no activities I find difficult or can no longer do” (50%), “reading” (34%), “driving” (29%), “travelling” (17%), “housework” (10%), and “cooking” (6%). Open-ended responses flagged as “other” (21%) included “Sports,” “Can no longer repair small, intricate equipment,” “Threading a needle, sewing more difficult,” “Writing, sewing, gardening,” and “No longer can play tennis, which I played from age 9.” The responses show how pervasive glaucoma is for many patients, affecting not just what many would consider indispensable activities, such as driving, but also the smaller and more personal intricacies of daily life, such as sewing, being physically active, and repairing equipment.

4. GAPS IN UNDERSTANDING PERCEPTIONS OF GLAUCOMA TREATMENTS

If an overall lack of credible research into the burden of glaucoma and its daily complexities demonstrates a gap in our understanding of the disease, it may be that a lack of information on patient awareness of the treatment landscape demonstrates a different kind of gap. This is an important gap, since the ways patients perceive treatments play a crucial role in the design of health systems and health policy, especially if those systems and policies embrace informed consent as a critical factor.

Surveying existing literature, the CADTH draft assessment does highlight the experience of treatments in several ways, mostly focusing on the experience of eye drops—“patients wished they could take less drops less often and wanted to explore alternatives to their current treatments” (103, 3142-43)—as well as differing views on filtration surgeries. The draft also does an admirable job outlining nuances in the patient-provider relationship, particularly in its critique of a concept of compliance that places blame on patients, marking those who do not comply with treatment regimens “as deviant, and their behavior as something to be corrected” (102, 3097). But at the same time, detailed information on how patients comprehend treatments beyond those they are receiving is largely missing; again, this likely signifies a gap in the literature surveyed, which could very well reflect a related gap in our overall understanding of glaucoma, this time associated with how patients experience and conceptualize glaucoma treatments.

Most of the patients we surveyed were aware of what kind of treatment they receive. When asked to **“specify the type of treatment you receive or medication you take for your glaucoma,”** only a small group selected “not sure what type” (1%). Unsurprisingly, the majority selected “drug therapy (eye drops or pills)” (47%), while the remaining responses included “don’t receive treatments or take medication” (6%), “laser surgery” (6%), “conventional surgery” (5%), and “MIGS” (1%). Many of the open-ended responses to “other” (34%) included a list of the treatments that have been received over time.

While many respondents were aware of treatments they receive, the majority indicated that they have never been made aware of treatments that could function as alternatives: most replied “no” (68%) to the question **“Have you been made aware of any treatment/medication options that could function as an alternative to the treatments or medications you are receiving now?”** The remainder indicated “yes” (23%) or “other” (9%). Open-ended responses alongside “other” encompassed extremes such as “I am made aware of all treatments and surgeries” and “Am having an operation on August 20 but am not clear as to the purpose” When asked to specify **“which treatment or medications were you made aware of?”** respondents selected from the following options, with some selecting multiple: “haven’t been made aware of any treatments or medication” (42%), “laser surgery” (29%), “drug therapy (eye drops or pills)” (23%), “other” (21%), “conventional surgery” (14%), and “MIGS” (6%).

When asked **“Would you be willing to switch to a different treatment or medication if a more effective one was offered?”** the majority of patients replied “yes” (71%), followed by “other” (15%), “don’t receive treatments or take medication” (7%), and “no” (6%). Many who responded “other” provided comments that show a high degree of trust in their specialist or physician, including “whatever is recommended,” “not sure, I trust my doctor,” “as per doctor’s instructions,” and “Only if my Ophthalmologist was in agreement.” These comments underscore the vital role ophthalmologists and physicians play in the way patients relate to the treatment landscape.

The survey asked patients to rate their level of comfort in relation to four main treatment categories: drug therapy, laser surgery, conventional surgery, and MIGS. When asked to **“Please indicate how comfortable you are with the idea of receiving drug therapy (eye drops or pills) as a treatment for your glaucoma?”** respondents selected from a standard scale comprising “not comfortable” (1%), “not very comfortable” (4%), “fairly comfortable” (25%), “very comfortable” (58%), and “other” (12%). In relation to **laser surgery**, respondents indicated “not comfortable” (7%), “not very comfortable” (10%), “fairly comfortable” (37%), “very

comfortable” (28%), and “other” (18%). By comparison, responses to **conventional surgery** were more evenly distributed: “not comfortable” (19%), “not very comfortable” (22%), “fairly comfortable” (30%), “very comfortable” (15%), and “other” (14%). And in relation to **MIGS**, patients selected “not comfortable” (11%), “not very comfortable” (24%), “fairly comfortable” (33%), “very comfortable” (16%), and “other” (15%).

The CADTH draft assessment foregrounds the patient experience of current treatments, particularly eye drops (the literature is likely stronger in this area), but what is missing in the draft points towards a lack of understanding in how patients view and experience other treatments, or more broadly the environment of existing and emerging treatments. This is a particularly relevant subject within the MIGS conversation, seeing as patients will approach MIGS analogously to how they approach any health innovation—that is, as a new reference point that must be factored into an already-complex web of health services, procedures, and schedules. How they relate to that existing framework is of course important, but understanding how they relate to information outside that framework is important as well.

5. GAPS IN UNDERSTANDING THE EXPERIENCE OF GLAUCOMA

Material on how glaucoma patients understand and relate to their disease appears to be more robust than on other subjects, and is described comprehensively in the draft assessment. In particular, the emphasis on the “indirect” nature of glaucoma aligns with many of the open-ended responses to our survey focused on the scheduling and busywork of managing the disease, or on fear in relation to its potential to worsen. The draft frames glaucoma as an “asymptomatic condition,” one that “is experienced by patients as the disruption in their lives by eye drops, as interactions with health care providers, and ideas and worries about blindness” (102, 3102-04). This is a kind of gap, certainly, though one between the patient and the direct experience of intraocular pressure, which for many is managed through eye drops and, as a result, not experienced as a pathology. This differs markedly from the more direct experiences of patients with inherited retinal diseases such as retinitis pigmentosa, where the disease is symptomatic and experienced in a very perceptible way.

The draft also highlights the invisible nature of glaucoma very clearly, describing a lack of familiarity with the disease, its asymptomatic tendency, and the fact that non-patients are unable to “see” vision loss since they cannot experience it themselves—three forms of invisibility. And again, the perception of the disease as an inevitable component of aging emerges: “perhaps because it is common amongst older people, its association with aging seemed to contribute to the perception that [it] is just part of normal aging” (98, 2910-11).

The disease is invisible in another way as well, which is at least partially covered by the idea that glaucoma is “unfamiliar, unknown, and as such not within their view (invisible)” (989, 2894). When asked the question “**Do you remember what type of glaucoma you were originally diagnosed with?**” over half of the group we surveyed responded with “don’t remember” (52%), while the remainder selected disease-types from a provided list. The draft assessment does indicate that unfamiliarity with the disease can continue post-diagnosis, but this response underlines this particular notion of invisibility: that most glaucoma patients, at least from those surveyed, are not aware of the form of glaucoma they have. In other words, it is invisible to them. For these patients, this is a central aspect of their experience of the disease, and one we should work to understand more fully.

6. CONCLUSION

It should be reiterated that by focusing on gaps in our understanding of glaucoma—gaps in how we understand the burden of the disease, how patients relate to treatments, and how patients experience the disease—this feedback is not insinuating that there are deficiencies in CADTH’s draft analysis of MIGS. Rather, missing information in the draft likely exposes the gaps as they exist elsewhere, largely in the available research on the subject and, relatedly, in our own perceptions and misunderstandings of glaucoma. The focus of this submission, rather, has been to discuss these gaps and to work towards filling some of them with our own patient survey data. And our overarching goal is to contribute meaningfully to the discussion of the potential implementation of MIGS—in particular, to guide that discussion along lines that are patient-centered, that focus on optimal and equitable outcomes, and that recognize the value of the perspectives of glaucoma patients.

We look forward to continuing to work with CADTH to support Canadians living with glaucoma, and to advance our collective understanding of the optimal use of MIGS.