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► **To cite this version:**

Anat Loewenstein, Michelle Sylvanowicz, Winfried M Amoaku, Tariq Aslam, Chui Ming Gemmy Cheung, et al.. Global Insights from Patients, Providers, and Staff on Challenges and Solutions in Managing Neovascular Age-Related Macular Degeneration. *Ophthalmology and Therapy*, 2025, 14 (1), pp.211-228. 10.1007/s40123-024-01061-3 . hal-04913232

HAL Id: hal-04913232

<https://hal.science/hal-04913232v1>

Submitted on 27 Jan 2025

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Global Insights from Patients, Providers, and Staff on Challenges and Solutions in Managing Neovascular Age-Related Macular Degeneration

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Received: June 18, 2024 / Accepted: August 23, 2024 / Published online: December 14, 2024
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ABSTRACT

Introduction: Neovascular age-related macular degeneration is a global public-health concern, associated with a considerable burden to individuals, healthcare systems, and society. The objective of this study was to understand different perspectives on the challenges associated

Prior Presentation: Data in this manuscript have previously been presented at the European Society of Retina Specialists (EURETINA)'s annual meetings: in 2022 (1–4 September, Hamburg, Germany, FP-350) an interim analysis was presented, and in 2023 (5–8 October, Amsterdam, the Netherlands, CA23344) the final, global analysis was presented.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s40123-024-01061-3>.

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with the clinical management of neovascular age-related macular degeneration, which could elucidate measures to comprehensively improve clinical care and outcomes.

Methods: A survey was carried out of patients with neovascular age-related macular degeneration, their providers, and clinic staff in 77 clinics across 24 countries on six continents, from a diverse range of healthcare systems, settings, and reimbursement models. Surveys comprised a series of single/multiple-response questions completed anonymously. Data gathered included patient personal characteristics, appointment attendance challenges, treatment experiences, and opportunities to improve support. Provider and clinic staff surveys asked similar questions about their perspectives; clinic characteristics were also captured.

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Results: There were 6425 responses; 4558 patients with neovascular age-related macular degeneration, 659 providers, and 1208 clinic staff. Challenges identified included concern about patient burden to family/friends, high frequency of treatment, difficulties in traveling to appointments, long waiting times, and insufficient comprehension of neovascular age-related macular degeneration. Participants identified logistical (improved financial assistance with treatment and out-of-pocket costs, and appointment reminders), operational (addressing clinic set up to reduce waiting times and improving the amount of time providers spend with patients), and educational (improving quality and provision of patient information and expectation-setting) opportunities to improve care.

Conclusions: The wealth of data generated by this global survey highlights the breadth of challenges associated with clinical management of patients with neovascular age-related macular degeneration. Addressing the opportunities raised could improve patient adherence

to treatment and potentially outcomes, reduce appointment burden, and increase clinic capacity.

Keywords: nAMD; Neovascular age-related macular degeneration; Patient experience

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Key Summary Points

Neovascular age-related macular degeneration (nAMD) is a global public-health concern, associated with considerable burden to individuals, healthcare systems, and society.

This study explored the challenges and opportunities in the clinical management of nAMD from the perspectives of patients, providers, and clinic staff.

Systematic data from a global survey on managing nAMD revealed challenges (including disease and appointment burden, understanding of disease/anti-vascular endothelial growth factor [anti-VEGF] treatment, and expectation-setting) and opportunities (improving quality and access to education materials for patients, enabling better doctor-patient conversations, and supporting patients in attending their appointments).

Meaningful interventions are needed to reduce patient burden, and improve treatment adherence and clinic capacity.

INTRODUCTION

The challenges with clinical management of the conditions associated with aging have been recognized by the United Nations (UN), with the resolution for the “Decade of Healthy Ageing” (2021–2030) [1]. The World Health Organization (WHO), in collaboration with the UN and other international agencies, works to generate evidence-based guidance to support global, regional, and national strategies and policies that promote healthy aging [1]. Age-related macular degeneration (AMD) is a key disease of aging, projected to increase with the globally aging population from an estimated 200 million people to nearly 300 million by 2040 [2–4]. Neovascular AMD (nAMD), which affects 10% with AMD but accounts for 90% with severe vision loss [4], is a particular burden for individuals, healthcare systems, and society [5].

In the past two decades, the emergence of anti-vascular endothelial growth factor (anti-VEGF) therapy has altered the treatment of nAMD, reducing existing, and preventing new occurrences of, choroidal neovascularization and macular exudation typical of nAMD [2, 6, 7]. Currently, four anti-VEGF therapies – ranibizumab [8], aflibercept (2 mg and 8 mg [approved in many countries, including by the United States Food and Drug Administration [9] and the European Medicines Agency [10]]) [11], brolucizumab [12], and faricimab [13] – are licensed for the treatment of nAMD. Randomized clinical trials (RCTs) and real-world studies have demonstrated that anti-VEGF therapy in nAMD is associated with sustained, clinically relevant visual gains and anatomic improvements over the first 2 years of treatment [6, 14–17], which can be generally maintained longer-term (≤ 4 years) with continued proactive treatment [6, 18–20].

However, anti-VEGF therapies are associated with a considerable burden to the patient and their family, the treating healthcare provider (HCP), and the healthcare system. For example, the patient must attend regular appointments (every 4–16 weeks) to receive intravitreal injections in a sterile clinic environment, often for many years [21–23]. A tendency toward under-treatment in routine clinical practice (regular anti-VEGF treatment is not always feasible [24, 25]) is associated with lower functional and anatomic improvements compared with those in RCTs [26].

Understanding and addressing barriers to anti-VEGF treatment is an important goal in optimizing vision outcomes for patients [27–29]. To address these questions and gaps, and to further understand the challenges and develop potential solutions, the Barometer Program, an international coalition of experts in retinal disease, vision care, and aging, conducted a global survey amongst patients with nAMD, HCPs, and associated clinic staff. Knowledge generated by the survey could facilitate the enhancement of care, improve treatment outcomes, help mitigate the impact of nAMD on patients, caregivers, HCPs and clinic staff, and inform international and local clinical care guidelines.

METHODS

Survey Setting and Design

The survey was designed and developed according to the Declaration of Helsinki and the WHO's International Ethical Guidelines for Biomedical Research. The survey is a Primary Market Research Survey, which does not require ethics committee approvals; however, individual institutions and countries assessed local requirements. No personally identifiable information was collected, and the survey did not inform treatment decisions. Informed consent was acquired (Appendix 1, electronic supplementary material). The survey was conducted globally with 77 participating ophthalmology clinics in 24 countries across six regions: North America, South America, Europe, Africa, the Middle East, and Asia–Pacific. Appendix 2 (electronic supplementary material) describes the participating clinics.

Each clinic completed an online primer questionnaire to collect data from their clinic, such as clinic location, sector, appointment logistics, participation in clinic audits, and approximations of adherence to intravitreal therapy for nAMD.

Data were collected by paper-based optical mark recognition (OMR) surveys. At participating clinics, surveys were completed by patients who are currently receiving (or have previously received) anti-VEGF injection therapy for nAMD, HCPs (providers hereafter) who prescribe and/or administer anti-VEGF injections for the treatment of nAMD, and any allied clinic staff members who do not prescribe or administer anti-VEGF injections for the treatment of nAMD but regularly interact with patients in other ways. In parallel, data on those with diabetic macular edema (DME) were also gathered via a survey designed and developed by the Barometer Program; however, it encompassed different questions relevant for this population. These data are reported via a different analysis, given the distinct challenges faced by those with DME vs. those with nAMD. Surveys were translated into the relevant language(s) for each country, and validated by an independent translational

company and designated country translator from the survey sponsor. Surveys were completed by participants at the clinic or at home; patients completed the survey either independently or with the support of clinic staff or their caregiver. Data collection at each clinic was expected to span 3 months in total; however, clinics not meeting their recruitment targets were given additional time to complete data collection due to differences in risk of, response to, and recovery from the coronavirus disease 2019 (COVID-19) pandemic. All data were collected between June 2021 and October 2022.

Survey Construction and Content

The surveys were designed based on a large-scale diabetes survey [30, 31]. The purpose of the diabetes survey was to collect information based on disease awareness, challenges accessing healthcare services, and experience within the clinic and with treatment. Within this diabetes survey, questions on overall healthcare, access to screening, and potential diabetic retinopathy were asked. The diabetes survey was a qualitative study and was not validated systematically. Further information on the diabetes survey can be found in Appendix 3 (electronic supplementary material).

Two distinct pilot studies of the Barometer Global Survey were executed in four clinics from the Barometer Leadership Coalition to develop and ascertain clarity of questions prior to the development of the final nAMD survey by experts in retinal disease and patient advocacy. Appendix 3 (electronic supplementary material) describes the questions included in each survey. Data and perspectives on adherence to treatment are reported separately.

Data Analysis

Question statements that had a Likert scale rating for “Strongly Agree” and “Somewhat Agree” were combined as “Agreement”, and for “Strongly Disagree” and “Somewhat Disagree” as “Disagreement”; questions were summarized by number and percentage of individuals selecting

each option. A conservative approach was taken to handling missing data, with assumptions made to keep what was deemed to be the correct information following a set of discrepancy rules aiming to retain as much data as possible. Conflicting responses regarding having bilateral disease, and receiving treatment in both eyes on the same day, were treated as a positive response.

RESULTS

Demographics and Baseline Characteristics

There were 6425 responses collected; 4558 patients with nAMD, 659 providers, and 1208 clinic staff (Table S1, electronic supplementary material). Overall, 3.0% of patients, 0.8% of providers, and 2.0% of clinic staff returned surveys with >30% of responses missing. Most providers were retina specialists (40.7%) and most clinic staff were either ophthalmic nurses not administering anti-VEGF injections (22.4%) or optometrists (17.5%).

Amongst the 77 clinics, 53.2% were standalone eye clinics, and 27.3% eye clinics within a hospital. Most clinics were in an urban setting (89.6%); of which a similar proportion were either solely public (39.0%) or solely private (37.7%) (Table S2, electronic supplementary material).

Table 1 reports key demographic and disease information gathered from patients. Additional demographic information for clinics, patients, providers, and clinic staff, and additional challenges and opportunities from these perspectives, can be found in Appendix 4 (electronic supplementary material).

Key Challenges in Patient Care

Patients

Table 2 reports the key challenges that patients face regarding the burden of their disease, the comprehension of their disease and treatment, and factors making it difficult to attend appointments.

Additionally, 22.5% of patients queried whether their treatment is necessary, and more than half worry about changes to their vision until the next appointment if they do not receive an injection (57.9%), while a similar proportion hope that they can avoid an injection (54.5%) and believe by not receiving an injection, their vision must be improving (53.7%).

Providers

Providers reported their perspectives on the challenges they think make it difficult for patients to manage their nAMD (Fig. 1). Clinic capacity constraints were noted by 62.2% of providers as making it difficult to provide the best outcomes for patients.

Clinic Staff

Similar proportions of clinic staff were generally in agreement with providers concerning challenges that made it difficult for patients to manage their nAMD.

Key Opportunities to Improve Patient Care

Table 3 summarizes the key opportunities noted by patients, providers, and clinic staff to better support the management of nAMD. Table S3 (electronic supplementary material) contains further data concerning the importance of opportunities to improve patient care.

Further Findings

Patients, providers, and clinic staff were asked about the importance of various opportunities to improve their treatment (Table S4, electronic supplementary material). Almost all agreed that patients would accept more treatment if it enabled them to keep their vision.

59.0% of providers thought that patients' non-adherence to treatment was a problem and

Table 1 Demographic and disease information for patients

Question	Total number of patients with nAMD <i>n</i> (%) <i>N</i> = 4558
How old are you?	
18–49 years	164 (3.6)
50–59 years	640 (14.0)
60–69 years	1248 (27.4)
70–79 years	1315 (28.9)
80–89 years	904 (19.8)
≥ 90 years	133 (2.9)
No option selected	154 (3.4)
What is your gender?	
Female	2252 (49.4)
Male	2127 (46.7)
Other	11 (0.2)
No option selected	168 (3.7)
Which category best describes you?	
African	361 (7.9)
Asian	921 (20.2)
Black or African American	39 (0.9)
Hispanic, Latino or Spanish origin	645 (14.2)
Indian	552 (12.1)
Middle Eastern	118 (2.6)
Native American	30 (0.7)
Western Pacific	11 (0.2)
Of European descent	895 (19.6)
Multiple ethnicities or origins	49 (1.1)
Other	180 (3.9)
Prefer not to answer	246 (5.4)
No option selected	511 (11.2)
Where do you live?	
Urban setting (i.e., large metropolis city)	2495 (54.7)
Suburban setting (i.e., residential area outside of a large city)	1210 (26.5)

Table 1 continued

Question	Total number of patients with nAMD <i>n</i> (%) <i>N</i> = 4558
Rural setting (i.e., countryside)	682 (15.0)
No option selected	171 (3.8)
Do you live alone?	
Yes	848 (18.6)
No	3508 (77.0)
No option selected	202 (4.4)
For most of your appointments, who accompanies you?	
No one accompanies me	747 (16.4)
Spouse	1270 (27.9)
Child	1372 (30.1)
Sibling/extended family member	501 (11.0)
Friend/neighbor	257 (5.6)
Regular paid caregiver/health worker	94 (2.1)
Usually a different person each time	253 (5.6)
No option selected	248 (5.4)
When was your nAMD diagnosed?	
Less than 3 months ago	431 (9.5)
3 months to less than 1 year ago	1032 (22.6)
1 year to less than 2 years ago	924 (20.3)
2 years to less than 3 years ago	746 (16.4)
3 years to less than 5 years ago	487 (10.7)
5 years ago, or more	785 (17.2)
No option selected	153 (3.4)
Who diagnosed your nAMD?	
The doctor who is currently treating my nAMD	2051 (45.0)
Another Ophthalmologist/RetinalSpecialist	2051 (45.0)
Optometrist/Optician	157 (3.4)
Family doctor/General Practitioner	83 (1.8)
Other	48 (1.1)
No option selected	168 (3.7)

Table 1 continued

Question	Total number of patients with nAMD <i>n</i> (%) <i>N</i> = 4558
Do you have nAMD in both eyes?	
Yes	2010 (44.1)
No	2084 (45.7)
I do not know	289 (6.3)
No option selected	175 (3.8)
If you have nAMD in both eyes, do you receive bilateral treatment on the same day?	
Yes	708 (15.5)
No	1186 (26.0)
No option selected	2664 (58.4)

nAMD neovascular age-related macular degeneration

79.8% wanted to implement policies to improve adherence and persistence. While 87.3% of providers thought a clinic audit is important in understanding levels of non-adherence and non-persistence, only 24.7% had conducted one to determine attendance and visual outcomes.

Table S5 (electronic supplementary material) reports how useful various resources were to patients when understanding their nAMD. Table 4 depicts the expectations of patients regarding outcomes of their treatment, and typical treatment regimens used by providers can be found in Table S6 (electronic supplementary material).

Additional findings on how informed patients are about their disease, treatment, and support, how treatment and outcome expectations are communicated and understood, and levels of discussion of important disease, treatment and support topics can be found in Appendix 4 (electronic supplementary material).

DISCUSSION

This comprehensive global study of more than 6000 people provides key insights into the routine clinical management of nAMD, and where

there may be opportunities to address appointment burden for patients, improve educational materials and their accessibility, and understand the role of emerging treatment modalities in improving clinic capacity.

It is well established that significant behavioral, psychological, and logistical challenges exist for patients with nAMD [28, 32], and identifying and addressing such barriers could aid in improving vision outcomes and quality of life. Challenges faced by patients are frequently ancillary to treatment; for example, logistical arrangements, fearing the injection or procedure [33, 34], or requiring significant resources in and outside the hospital to enable regular support [35]. Previous research has highlighted the importance of addressing these barriers [36]; however, such studies generally focused on single countries or on patients only and thus this survey is the first of its kind. This unique study encompasses a large dataset from multiple healthcare systems, reimbursement models, and countries from around the world, providing a global perspective on the ongoing challenges to optimal management of nAMD.

Patients considered their eye treatment a priority, and would accept more treatment to keep their vision. Therefore, the key factors leading to treatment non-adherence appear to be primarily

Table 2 Key challenges reported by patients

<i>n</i> = 4558	Agree <i>n</i> (%)	Disagree <i>n</i> (%)	No option selected
Burden of disease and treatment			
The frequency of treatment can be too much	2094 (45.9)	2033 (44.6)	431 (9.5)
I am concerned about being a burden to family/friends	2022 (44.4)	2139 (46.9)	397 (8.7)
Personal costs related to the drug itself makes it difficult	1927 (42.3)	2203 (48.3)	428 (9.4)
Limitations on number of treatments covered by insurance makes it difficult for me	1557 (34.2)	2492 (54.7)	509 (11.2)
I am fearful of the treatment procedure itself	1478 (32.4)	2701 (59.3)	379 (8.3)
The pain during/after the procedure is too much for me	1202 (26.4)	2982 (65.4)	374 (8.2)
I prioritize other health issues over my nAMD treatment	1119 (24.6)	3045 (66.8)	394 (8.6)
I tend to just forget about my appointments	934 (20.5)	3217 (70.6)	407 (8.9)
Disease and treatment comprehension			
I am not sure if treatment is working as my vision is either not getting better or it is getting worse	1495 (32.8)	2677 (58.7)	386 (8.5)
I am not sure the effort associated with treatment is worthwhile	1350 (29.6)	2812 (61.7)	396 (8.7)
I feel the treatment was successful and I no longer need it	1250 (27.4)	2827 (62.0)	481 (10.6)
I do not really understand my nAMD and/or treatment need	1131 (24.8)	3029 (66.5)	398 (8.7)
I am not concerned with the risk of losing vision	894 (19.6)	3292 (72.2)	372 (8.2)
Receiving treatment is just not that important to me	732 (16.1)	3438 (75.4)	388 (8.5)
Factors making it difficult to manage appointments			
Long periods of waiting during the appointment	1818 (39.9)	2359 (51.8)	381 (8.4)
Traveling to the clinic (ability/distance/cost)	1807 (39.6)	2341 (51.4)	410 (9.0)
Other chronic health conditions	1428 (31.3)	2722 (59.7)	408 (9.0)
Risk of exposure to COVID-19	1757 (38.5)	2325 (51.0)	476 (10.4)
Hard for my accompanying person to attend	1571 (34.5)	2520 (55.3)	467 (10.2)
I (or my accompanying person) could not take the time off from work	1325 (29.1)	2732 (59.9)	501 (11.0)
Cost related to office/parking fees	1219 (26.7)	2869 (62.9)	470 (10.3)
Problems rescheduling a new appointment once one is missed	1136 (24.9)	2952 (64.8)	470 (10.3)
Appointments interfere with holiday/vacation	887 (19.5)	3244 (71.2)	427 (9.4)

COVID-19 coronavirus disease 2019, nAMD neovascular age-related macular degeneration

related to appointment burden or reimbursement. There are considerable and often complicated logistics for the patient in the treatment pathway, including: coordinating appointments

with caregiver schedules (who is potentially a child of working age); going to the hospital or clinic for an appointment (likely by car, adding complexity with long travel times, difficulty in

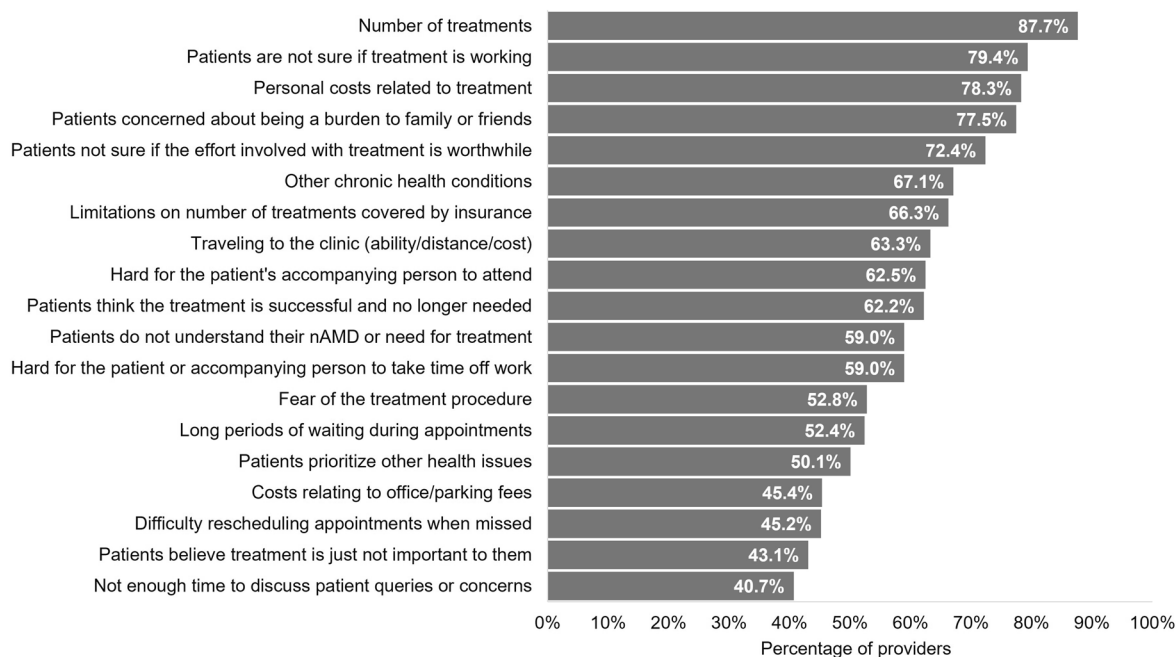


Fig. 1 Challenges that make it difficult for patients to manage their nAMD from the provider's perspective. *nAMD* neovascular age-related macular degeneration

finding parking, and parking fees); long waiting times during the appointment (noted by almost half of patients); and managing both the return travel and any potential discomfort following treatment. This is coupled with the burden experienced by the patient concerning the injection procedure and pain/discomfort. The high proportion of patients, providers, and clinic staff reporting a need for additional time with the patient to plan future treatment and discuss care suggests challenges in clinic capacity. Left unaddressed, this could contribute to patients underestimating the importance of treatment, and possibly misunderstanding the expectations of treatment. Appointment reminders (potentially calls and/or texts) and easy-to-reschedule appointments were noted as important opportunities to facilitate better adherence to treatment and better quality of life, therein potentially reducing the burden placed on the healthcare system.

Patient comprehension of their disease is paramount in ensuring that they understand and prioritize treatment. Here, a disconnect between what patients understand about the disease and

treatment, and how they perceive their treatment and outcomes was observed. Engaging patients in their care is vital to improving vision outcomes and quality of life [37]. Patients that do not understand the goals of their treatment could likely become dissatisfied (for example, many patients expect their vision to significantly improve with treatment, whereas maintenance of vision might be a more suitable goal), and become non-adherent; therefore, expectations must be carefully set early in the patient's treatment journey. Leveraging waiting times for appropriate staff to provide additional education, or improving communications training for providers and clinic staff, may be ways to aid in educating patients and improving their expectations.

Many providers and clinics reported not having sufficient information available for the patient to understand their disease, treatment, and expectations. Additionally, no consensus appears to exist for how and when to appropriately communicate specific information at different stages of the patient's treatment journey. Materials to guide patients and providers

Table 3 The importance of opportunities to provide better support for managing nAMD from patient, provider, and clinic staff perspectives

Statement	Total number of patients	Total number of providers	Total number of clinic staff
	<i>n</i> (%) <i>N</i> = 4558	<i>n</i> (%) <i>N</i> = 659	<i>n</i> (%) <i>N</i> = 1208
Appointment reminders sent by the clinic			
Extremely important	2299 (50.4)	292 (44.3)	689 (57.0)
Very important	1306 (28.7)	290 (44.0)	395 (32.7)
Transportation assistance to attend treatment/office visits			
Extremely important	1592 (34.9)	191 (29.0)	284 (23.5)
Very important	1250 (27.4)	285 (43.2)	481 (39.8)
Financial assistance with office/parking fees			
Extremely important	1350 (29.6)	152 (23.1)	252 (20.9)
Very important	1052 (23.1)	249 (37.8)	422 (34.9)
Financial assistance with drug/prescription costs			
Extremely important	1936 (42.5)	302 (45.8)	378 (31.3)
Very important	1052 (23.1)	259 (39.3)	566 (46.9)
Ability to monitor vision accurately with a home monitoring machine			
Extremely important	1504 (33.0)	195 (29.6)	302 (25.0)
Very important	1314 (28.8)	297 (45.1)	493 (40.8)
Medical services/treatment that travel to or near the patient's home			
Extremely important	1605 (35.2)	166 (25.2)	334 (27.6)
Very important	1330 (29.2)	305 (46.3)	492 (40.7)
Dedicated nurse in the clinic to discuss questions or concerns with			
Extremely important	1819 (39.9)	213 (32.3)	418 (34.6)
Very important	1416 (31.1)	313 (47.5)	528 (43.7)
More time for the doctor to answer questions/concerns at each appointment			
Extremely important	1972 (43.3)	269 (40.8)	455 (37.7)
Very important	1574 (34.5)	321 (48.7)	570 (47.2)
Extra time with the doctor to plan the next 6 months of treatment			
Extremely important	1800 (39.5)	222 (33.7)	372 (30.8)
Very important	1521 (33.4)	305 (46.3)	586 (48.5)
Phone consultations to answer any questions/concerns			
Extremely important	1950 (42.8)	149 (22.6)	389 (32.2)
Very important	1452 (31.9)	272 (41.3)	518 (42.9)

Table 3 continued

Statement	Total number of patients	Total number of providers	Total number of clinic staff
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
	<i>N</i> = 4558	<i>N</i> = 659	<i>N</i> = 1208
Always having the same clinic staff and doctor treating the patient			
Extremely important	2432 (53.4)	208 (31.6)	341 (28.2)
Very important	1313 (28.8)	281 (42.6)	522 (43.2)
Proactive discussion by doctor/clinic staff about any challenges the patient may have			
Extremely important	2367 (51.9)	207 (31.4)	374 (31.0)
Very important	1454 (31.9)	359 (54.5)	620 (51.3)
If nAMD in both eyes, treat both eyes on the same day			
Extremely important	1547 (33.9)	191 (29.0)	325 (26.9)
Very important	1110 (24.4)	183 (27.8)	458 (37.9)
Increased predictability of the injection schedule			
Extremely important	1786 (39.2)	227 (34.4)	348 (28.8)
Very important	1460 (32.0)	351 (53.3)	617 (51.1)
Less frequent appointments without losing vision			
Extremely important	1991 (43.7)	299 (45.4)	343 (28.4)
Very important	1337 (29.3)	283 (42.9)	545 (45.1)
Longer time in between treatments without losing vision			
Extremely important	2061 (45.2)	319 (48.4)	353 (29.2)
Very important	1317 (28.9)	261 (39.6)	542 (44.9)
Lifting of reimbursement restrictions			
Extremely important	1653 (36.3)	272 (41.3)	345 (28.6)
Very important	1069 (23.5)	250 (37.9)	452 (37.4)
Coordination of appointments by a professional			
Extremely important	1601 (35.1)	235 (35.7)	445 (36.8)
Very important	1288 (28.3)	309 (46.9)	537 (44.5)
Better material available to improve understanding of nAMD			
Extremely important	1530 (33.6)	246 (37.3)	496 (41.1)
Very important	1429 (31.4)	309 (46.9)	527 (43.6)

Table 3 continued

Statement	Total number of patients	Total number of providers	Total number of clinic staff
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
	<i>N</i> = 4558	<i>N</i> = 659	<i>N</i> = 1208
Opportunity to join a peer-to-peer support group			
Extremely important	839 (18.4)	171 (25.9)	337 (27.9)
Very important	1010 (22.2)	322 (48.9)	483 (40.0)
More involvement of the person who accompanies the patient in their care			
Extremely important	1070 (23.5)	216 (32.8)	399 (33.0)
Very important	1395 (30.6)	317 (48.1)	579 (47.9)
Guidance for clinicians to identify patients at risk of missing/stopping treatment, and training on how best to intervene			
Extremely important	NA	232 (35.2)	428 (35.4)
Very important		340 (51.6)	579 (47.9)

NA not applicable, *nAMD* neovascular age-related macular degeneration

Table 4 Treatment expectations reported by patients

Parameter	Answer	Total number of patients <i>n</i> (%) <i>N</i> = 4558
Which expectations did your doctor provide for your first year of treatment?	Vision to improve	2212 (48.5)
	Vision to stay the same	1302 (28.6)
	Vision to decline	100 (2.2)
	Doctor did not set expectations for the first year	769 (16.9)
	No option selected	175 (3.8)
As you continue with treatment, do you expect your vision to?	Significantly improve	1595 (35.0)
	Slightly improve	1761 (38.6)
	Stay the same	873 (19.2)
	Slightly decline	145 (3.2)
	Significantly decline	32 (0.7)
	No option selected	152 (3.3)

on when to ask or answer questions specific to different stages in the patient's disease and treatment could help to alleviate any miscommunication and ensure that patients are better informed about what they can expect with treatment. Such materials should have wide availability, tailored to specific healthcare systems, different health literacy levels, and accessible in a range of multimedia.

Current innovations in ophthalmology focus on treatment interval extension. Increasing the treatment interval through use of next-generation therapies (such as up to 20-week intervals in the PULSAR trial of aflibercept 8 mg for nAMD [38] and up to 16-week intervals in clinical trials of faricimab for nAMD [39]) and treat-and-extend modalities could substantially reduce patient appointment and disease burden, and could improve clinic capacity by increasing the number of patients able to be treated. Reducing the number of treatments required per year could also reduce the mental health burden that patients experience when receiving treatment. From the perspective of the payer, there is a clear benefit in reducing the strain on healthcare resources. Complementing longer-duration therapies with home monitoring technologies could be key in improving the quality of life of patients with nAMD; the clinic requirement is reduced while empowering patients to monitor their disease.

It is important to understand these results in the context of how these data were collected. While surveys were collected consecutively at each participating center, thus being of representative character, factors affecting participation, such as a lack of motivation, severe mental limitations, time constraints, and the inability to overcome or insufficient means of overcoming of communication limitations will have influenced data collection. Steps were taken to reduce potential study bias where possible; for example, by using closed questions and Likert scale elements, independently validating local-language translations to ensure that questions could be interpreted consistently, and maintaining a focus on current opinions to avoid recall bias. Approximately half of the patient respondents to the survey came from five countries (India, Mexico, China, Russia, and Indonesia);

the results must be taken in context of the relative contribution of these countries to the survey data and the relative accessibility to healthcare, financial support, and health literacy. Data collection occurred during the COVID-19 pandemic and, therefore, the results of the survey should be taken in context of individual country responses and measures to COVID-19. Finally, while Barometer Program members developing and reviewing the nAMD survey are experts across the field of the retina, and in patient advocacy, the survey was constructed based on a survey for patients with diabetes developed by the same group (which focused primarily on access to healthcare and screening, and diabetic retinopathy topics) and thus was not systematically validated.

CONCLUSIONS

This global survey of more than 6000 people in 24 countries provides new and important insights into the breadth and depth of the challenges and opportunities in the optimal delivery of care and management of patients with nAMD. Addressing these challenges in the healthcare community (reducing appointment burden by addressing barriers to attending appointments, improving the availability and quality of appropriate educational material for patients, and focusing on next-generation therapies to extend treatment intervals) can all serve to improve vision outcomes for patients and ultimately quality of life. These data can also help to improve clinic efficiency and capacity, allowing HCPs to have additional time for discussion to ensure that patients understand the need, frequency, and expectations of treatment.

ACKNOWLEDGEMENTS

The authors would like to thank the patients, providers, and clinics contributing to the survey data. The authors would also like to thank Olukorede Adenuga, Manisha Aggarwal, Numan Alp, Abdullah AlQahtani, Aude Ambresin, Marcos Avila, Pramod Bhende, Gilbert Bonsaana,

Arnaldo Bordon, José Augusto Cardillo, Shobhit Chawla, Gladys Cheruiyot, Dian Yan Dameria, Doukas Dardabounis, Adil Darugar, Sadin Hail Degaga, Katia Delalíbera, Hidayet Erdöl, Rinat Fayzrakhmanov, Eric Fourmaux, Anzhella Fursova, Vinay Garodia, Kibata Githeko, Kıvanç Güngör, Ohisa Harley, Tina Herold, David Isaac, Nandor Jaross, Alemu Kerie, Frederick Korir, Igor Kozak, Albrecht Lommatzsch, Yan Li, Miguel Lume, Xiang Ma, Fatima Mahmud-Ajeigbe, Carlos Marques Neves, Shahana Mazumdar, Emmanuel Megbelayin, Hugo Ocampo, Olufemi Oderinlo, Tunji Oluleye, Mário Ornelas, Osayande-Osawe Osa, Bernardete Pessoa, Beatriz Jatziri Pérez Aragón, Ingrid Pita Ortiz, Hildegard Piñeros, Seemant Raizada, Paulina Ramírez Neria, Carlos Mario Rangel, Padmaja Kumari Rani, Prasan Rao, Luis Fernando Rosales, Julien Saad, Houfar Sekavat, Sindy Sembiring, Nataliya Shevchuk, Rufino Silva, Soefiandi Soedarman, Zongming Song, Xiaodong Sun, Tiliksew Teshome Tessema, Raman Tuli, Juan Esteban Unigarro, Raúl Vélez Montoya, Alexandra Voronina, Nenad Vukojević, Dereje Woyessa, Naresh Yadav, and Hong Yan for their coordination in survey completion.

Medical Writing, Editorial and Other Assistance. Medical writing support, under the direction of the authors, was provided by Luke Shelton, PhD, of ApotheCom (London, UK). Medical writing support was funded by Bayer Consumer Care AG, in accordance with Good Publication Practice guidance (*Ann Intern Med.* 2022;175:1298–1304).

Author Contributions. All authors (Anat Loewenstein, Michelle Sylvanowicz, Winfried M. Amoaku, Tariq Aslam, Chui Ming Gemmy Cheung, Bora Eldem, Robert P. Finger, Richard P. Gale, Laurent Kodjikian, Adrian Koh, Jean-François Korobelnik, Xiaofeng Lin, Paul Mitchell, Moira Murphy, Mali Okada, Ian Pearce, Francisco J. Rodriguez, Jude Stern, James Talks, David T. Wong, Tien Yin Wong, Focke Ziemssen, Jane Barratt) contributed to the study conception and design, material preparation, and data analysis plan. Data collection was conducted by Anat Loewenstein, Michelle Sylvanowicz, Winfried

M. Amoaku, Tariq Aslam, Chui Ming Gemmy Cheung, Bora Eldem, Robert P. Finger, Richard P. Gale, Laurent Kodjikian, Adrian Koh, Jean-François Korobelnik, Xiaofeng Lin, Paul Mitchell, Mali Okada, Ian Pearce, Francisco J. Rodriguez, James Talks, David T. Wong, Tien Yin Wong, Focke Ziemssen. Data analysis was conducted by Moira Murphy and Michelle Sylvanowicz, and all authors contributed to interpretation of the data. All authors worked on the manuscript drafts, and approved the final version before submission.

Funding. The Barometer Leadership Coalition is funded and facilitated by Bayer Consumer Care AG (Basel, Switzerland). This survey was sponsored by Bayer Consumer Care AG. Survey design, distribution, and data collection was supported by Exploristics, Ltd. (Belfast, UK), funded by Bayer Consumer Care AG. Data management and analysis was performed by Exploristics, Ltd. (Belfast, UK), funded by Bayer Consumer Care AG. The journal's Rapid Service fee was funded by Bayer Consumer Care, AG, Basel, Switzerland.

Data Availability. Anat Loewenstein, Michelle Sylvanowicz, Moira Murphy, Focke Ziemssen, and Jane Barratt had full access to all data in this study and take responsibility for the integrity of the data and data analysis. This study used anonymized patient, provider, and clinic staff data that are not publicly available due to confidentiality considerations. For further information, please contact the corresponding author.

Declarations

Conflict of Interest. Anat Loewenstein: Consultant: 4DMT, AbbVie, Alkeus, Annexon, Apellis, Astellas, Bayer Health Care, Beyeonics, Eyepoint, Johnson & Johnson, NotalVision, Novartis, Ocular Therapeutics, Oculis, Ocuphire Pharma, Ocuterra, Opthea, Oxurion, Roche, Syneos; Michelle Sylvanowicz: Employee: Bayer; Winfried M. Amoaku: Advisory board membership: AbbVie, Alcon, Alimera, Allergan, Apellis, Bayer, Bausch + Lomb, Bioeq, Novartis, Pfizer;

Speaker fees: Alimera, Allergan, Bayer, Novartis, Pfizer; Support for travel: Alimera, Allergan, Bayer, Novartis, Pfizer; Research sponsorship and funding: Allergan, Bayer, Boehringer Ingelheim, CenterVue, Gyroscope, Novartis, Optos; Tariq Aslam: Tariq Aslam is an Editor in Chief of *Ophthalmology and Therapy*, and was not involved in the selection of peer reviewers for the manuscript nor any subsequent editorial decisions. Consultant: Novartis, Bayer, Laboratoires, Théa Pharmaceuticals, Bausch & Lomb, Oraya; Chui Ming Gemmy Cheung: Financial support (to institution): Allergan, Bayer, Boehringer Ingelheim, Novartis, Roche, Topcon, Zeiss; Stock: Avirmax; Bora Eldem: Consultant: Allergan, Bayer, Novartis, Roche; Robert P. Finger: Research grant: CentreVue, Heidelberg Engineering, Novartis, Zeiss; Consultant: Alimera, Allergan, Bayer, Ellex, Inositec, Novartis, Opthea, Roche/Genentech, Santhera; Support for travel: Novartis; Richard P. Gale: Consultant/advisory boards: Allergan, Alimera, Bayer, Novartis, Santen; Educational travel grants: Allergan, Bayer, Heidelberg, Novartis; Research grants: Allergan, Bayer, Novartis, Roche; Laurent Kodjikian: Consultant: AbbVie, Alcon, Allergan, Bayer, Krystal Biotech, Novartis, Regeneron, Théa; Adrian Koh: Consultant: Allergan, Bayer, Carl Zeiss, Heidelberg, Novartis, Topcon; Jean-François Korobelnik: Consultant: AbbVie, Apellis, Bayer, Eyepoint Pharma, Ocuphire, Roche, Thea, Carl Zeiss Meditec; Member of DSMB for Alexion, Novo Nordisk, Opthea; Xiaofeng Lin: Consultant: Bayer; Paul Mitchell: Consultant: Allergan, Bayer, Novartis; Steering Committee member: Bayer; Moira Murphy: Employee: Exploristics, Ltd.; Mali Okada: Non-financial support and personal fees: Bayer; Ian Pearce: Lecture fees: Allergan, Bayer, Heidelberg, Novartis; Consultant: Allergan, Alimera, Bayer, Novartis; Support for travel: Allergan, Bayer, Novartis; Francisco J. Rodriguez: Consultant: Bayer, Novartis, Roche; Speaker: Bayer, Novartis, Roche; Research funding: Novartis; Jude Stern: Employee: The International Agency for the Prevention of Blindness; S. James Talks: Advisory board member, speaker fees, and research support: Bayer, Novartis; research grants: Boehringer Ingelheim, Roche; Consultant: Bayer; David T. Wong: Grants/research support: Bayer,

Novartis, Roche; Consultant: Alcon, Allergan, Bausch Health, Bayer, Novartis, Topcon, Zeiss; Equity: Arctic DX; Tien Yin Wong: Clinical trial grants: Allergan, Bayer, Boehringer Ingelheim, Genentech, Merck, Novartis, Oxurion (formerly ThromboGenics), Roche, Samsung Bioepis, NMRC Singapore, Novartis Singapore; Consulting fees/travel support/review fees: Allergan, Bayer, Boehringer Ingelheim, Genentech, Merck, Novartis, Oxurion (formerly ThromboGenics), Roche, Samsung Bioepis; Stock: EyRIS, Plano; Focke Ziemssen: Travel grants and personal fees: Allergan, Alimera, Bayer Healthcare, Biogen, Boehringer Ingelheim, Clearside, Novartis, Novo Nordisk, MSD Sharp & Dohme, Roche, Optos; Jane Barratt: Consultant: Bayer.

Ethical Approval. The survey was designed and developed according to the Declaration of Helsinki and the World Health Organization's International Ethical Guidelines for Biomedical Research. While the survey is a Primary Market Research Survey (which does not require ethics committee approval), individual institutions and countries assessed local requirements. Furthermore, informed consent was acquired, no personally identifiable information was collected, and treatment decisions were not informed by response to the survey.

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