EXECUTIVE SUMMARY

BLIND SPOTS:

Navigating Life, Treatment, and Insurance Challenges in Preventing Vision Loss in the United States

Jointly provided by: MEDICAL EDUCATION RESOURCES, Impact Education LLC

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INTRODUCTION

Diabetic retinopathy (DR) and age-related macular degeneration (AMD) represent two of the leading causes of irreversible vision loss and blindness in adults worldwide, with substantial implications for individual quality of life, healthcare systems, and society. DR is the leading cause of new cases of legal blindness among working-age Americans and affects approximately 9.60 million people in the United States, corresponding to a prevalence of 26.43% among individuals with diabetes.[1] Vision-threatening diabetic retinopathy (VTDR), which includes severe nonproliferative DR, proliferative DR, and diabetic macular edema (DME), affects an estimated 1.84 million Americans, with a prevalence of 5.06% among those with diabetes.[1] Globally, the burden is substantial: among individuals with diabetes, the prevalence of DR is 22.27%, affecting an estimated 103.12 million adults in 2020, with projections indicating this will increase to 160.50 million by 2045.[2,3]

AMD similarly imposes a considerable global burden, affecting approximately 196 million people worldwide in 2020, with projections estimating 288 million affected individuals by 2040.[4] In the United States alone, approximately 20 million people were living with AMD in 2019, with approximately 1.5 million having late-stage disease.[4] The pooled prevalence of any AMD is approximately 8.69% in persons aged 45 to 85 years, with substantial variation by race and ethnicity.[4] The annual incidence of late-stage AMD ranges from 0.3 per 1,000 in people aged 55 to 59 years to 36.7 per 1,000 in those aged 90 years or older, underscoring the age-dependent nature of this condition.[4] Both DR/DME and AMD disproportionately affect older adults and those with chronic disease—populations that often face multiple barriers to accessing timely, effective care.

Understanding the patient journey from diagnosis through treatment is essential for preventing blindness from these conditions. DR develops as a microvascular complication of diabetes, resulting from chronic hyperglycemia damaging retinal blood vessels.[5] The disease progresses through stages from mild and moderate nonproliferative DR to VTDR, which encompasses severe nonproliferative DR and proliferative DR characterized by retinal neovascularization.[1,3] DME, defined as swelling in the macula caused by fluid leaking from retinal blood vessels, can occur at any stage of DR and represents a major cause of vision loss.[5,6] Risk of developing VTDR is strongly influenced by diabetes duration and glycemic control, making early detection through annual dilated eye examinations critical for timely intervention.[5,7]

AMD is a progressive retinal disorder affecting the macula, the central portion of the retina responsible for sharp vision. While early and intermediate stages may be asymptomatic, late-stage AMD leads to severe vision impairment that interferes with reading and recognizing faces.[4] The disease is characterized by accumulation of extracellular deposits in the outer retina, ultimately leading to photoreceptor degeneration and loss of central vision.[4] Late-stage AMD manifests in two forms: geographic atrophy (dry AMD), characterized by outer retinal atrophy, and exudative neovascular AMD (wet AMD), characterized by neovascularization with subretinal and/or intraretinal exudation.[4] Older age, genetic factors (with estimated heritability of approximately 71%), and environmental factors such as cigarette smoking are strongly associated with AMD development.[4]

The treatment landscape for DR/DME and AMD has been transformed by anti-vascular endothelial growth factor (anti-VEGF) therapy, which has converted previously blinding diseases into manageable chronic conditions. For center-involved DME, intravitreal anti-VEGF injections have become the first-line treatment, demonstrating superior visual outcomes compared to laser photocoagulation monotherapy.[6,8] Five anti-VEGF agents are currently used to treat DME: bevacizumab (off-label), ranibizumab, aflibercept (2 mg and 8 mg), brolucizumab, and faricimab.[5] Most patients require administration every 4-8 weeks during the first year of treatment, with newer agents like faricimab and aflibercept 8 mg achieving similar visual outcomes with adjustable dosing up to every 16 weeks.[6]

Similarly, for exudative neovascular AMD, intravitreal anti-VEGF therapy represents the first-line treatment and constitutes a fundamental advance in clinical medicine.[9-11] Available anti-VEGF agents for neovascular AMD include ranibizumab, aflibercept, faricimab, brolucizumab, and bevacizumab (used off-label), each working through different mechanisms to inhibit VEGF.[10-11] For intermediate-stage AMD, the Age-Related Eye Disease Study (AREDS) demonstrated that supplementation with antioxidant vitamins and minerals reduces the probability of progression to late-stage AMD from 28% to 20% at 5 years.[4]

Despite the proven efficacy of anti-VEGF therapy, significant barriers exist in the patient journey from diagnosis to treatment, with insurance coverage considerations playing a critical role. Insurance companies and pharmacy benefit managers have implemented utilization management measures, including prior authorization (PA) and step-therapy requirements to manage anti-VEGF agents.[10,12] Recent data reveal that approximately 65% of commercial coverage decisions and 52% of Medicare Advantage decisions include restrictions beyond FDA labeling.[11] Step therapy protocols, found in up to 75% of plans, most commonly require first-line trial of bevacizumab before allowing other agents.[12]

These administrative requirements impose substantial burdens on both patients and providers. A prospective multicenter study found that while 96.2% of PA requests for anti-VEGF medications were ultimately approved, 59.6% of patients experienced delays in care delivery, with the median staff time of 100 minutes to obtain a single PA.[10,12] Among delayed approvals, 42.8% experienced delays of at least one week, and 14.0% experienced delays of at least one month.[10] However numerous studies have demonstrated that delayed anti-VEGF treatment after diagnosis is associated with worse visual outcomes.[13] The highest denial rates occur for patients initiating anti-VEGF therapy (15%) and those requiring medication changes due to treatment failure (4.6%).[14]

Beyond insurance-related barriers, patients face multiple obstacles in accessing care, including travel burden, psychological barriers, financial constraints related to socioeconomic status, demanding treatment regimens, comorbidities, and provider- and system-level barriers.[1] The treatment regimen itself can be demanding, requiring frequent clinic visits and repeated intravitreal injections over months to years, leading to lower rates of adherence among patients.[1] Understanding these multifaceted barriers is essential for developing interventions that improve access to sight-saving treatment.

This paper examines the patient journey in DR/DME and AMD to better understand the challenges payers, health care professionals (HCPs), and patients face in preventing blindness.

KEY FINDINGS

Due to the breadth of topics covered by this study, data from the interviews and health care provider surveys provided a deeper understanding into patient/caregiver, payer, and HCP experiences, beliefs, and knowledge. Throughout this report, data presented will focus on the following key findings in five areas: detection and referral, access and capacity challenges, treatment burden and adherence risk, administrative and financial barriers, and opportunities to improve care coordination.

SUMMARY ACROSS PAYER, CLINICIAN, AND PATIENT PERSPECTIVES

1. Detection and Referral

Late presentation emerged as a consistent theme across all stakeholder groups and represents a primary driver of preventable vision loss. Payers noted that delayed diagnosis and referral—with patients often presenting late due to limited awareness—contribute to disease progression. Clinicians reported that patients frequently arrive with advanced disease due to gaps in primary care screening. Patients initially misunderstood symptoms, causing delays in seeking care.

2. Access and Capacity Challenges

Stakeholders agreed that timely access to retina specialists—particularly in rural settings—remains a substantial barrier. Payers cited shortages of retina specialists and travel burdens. Clinicians identified transportation and rural access as factors that hinder timely visits. Patients noted long wait times and geographic barriers to specialists.

3. Treatment Burden and Adherence Risk

Across interviews, treatment fatigue, visit frequency, and anxiety about injections were repeatedly mentioned. Payers highlighted no-show risk and treatment drop-off as major drivers of preventable vision loss. Clinicians emphasized that chronic intravitreal injections create adherence challenges. Patients expressed fear of blindness, injections, and emotional strain.

4. Administrative and Financial Barriers

Cost and coverage challenges—particularly PA and out-of-pocket burden—were universal concerns. Payers mentioned issues with benefit design and cost-sharing. Clinicians referenced PA hurdles and step edits delaying care. Patients experienced delays due to PA and valued streamlined processes.

5. Opportunities to Improve Care Coordination

Better integration of retinal health into diabetes care workflows and cross-stakeholder communication emerged as a shared priority. Payers discussed integrating screening into chronic care programs. Clinicians want better electronic health record integration, referral pathways, and tele-retina support. Patients want clearer guidance and shared decision-making.

ABOUT THIS REPORT

This report presents select findings from a sequential mixed-methods study examining challenges and opportunities in preventing vision loss from DR/DME and AMD. The study integrated qualitative insights from nine in-depth interviews with quantitative data from a national survey conducted among three key stakeholder groups. Survey data presented in this report reflect responses from payers (n = 54), HCPs (n = 36), and patients/caregivers (n = 13), unless otherwise noted. Percentages shown in figures have been rounded and may not total 100%.

To further contextualize the findings and amplify stakeholder perspectives, the report includes illustrative quotes from interview participants and open-text survey responses. Quotes have been edited for clarity and length. In select analyses, results are presented by stakeholder subgroup or derived from similarly worded questions across stakeholder groups to highlight shared themes and differences.

It is important to note that the findings from this study may not be representative of all patients, HCPs, or payers involved in the care and management of DR/DME and AMD in the United States. Participation in the qualitative interviews and national survey was voluntary, and there is potential for selection bias, as respondents were recruited through stakeholder partner organizations and may represent individuals or organizations with greater engagement in retinal disease management or a particular interest in improving prevention of vision loss.

STUDY DESIGN

OBJECTIVES

This study aims to identify and address key challenges in the diagnosis, treatment, and management of DR/DME and AMD to support the prevention of vision loss. The specific objectives are to:

- assess the current state of retinal disease care in the United States, including treatment patterns and system-level barriers to care
- characterize the patient journey for individuals with DR/DME and AMD, with a focus on treatment experiences, health care access, insurance coverage, and care coordination
- identify unmet needs and gaps in support among HCPs managing patients with DR/DME and AMD
- examine payer perspectives and identify opportunities for managed care organizations to implement evidence-based strategies that promote early diagnosis, effective treatment, and prevention of blindness

METHODS

Impact Education, LLC, in collaboration with Retina Consultants of America and Prevent Blindness, a national patient advocacy organization focused on retinal diseases, conducted a multi-component, cross-sectional needs assessment study examining challenges and opportunities related to the prevention of vision loss in DR/DME and AMD.

The study used a sequential mixed-methods approach. In-depth, semi-structured interviews were conducted by the same interviewer (SC) with payers (n=3), HCPs (n=3), and patients (n=3) to capture qualitative insights into current care delivery, barriers, and unmet needs. Findings from the qualitative phase informed the development of a national survey designed to further assess and quantify perspectives across stakeholder groups.

Survey dissemination was conducted via SurveyMonkey by stakeholder partner organizations, with Impact Education distributing the survey to payer respondents, Retina Consultants of America distributing the survey to HCPs, and Prevent Blindness distributing the survey to patient and patient caregiver respondents. Survey responses were obtained from payers (n=54), HCPs (n=36), and patients/patient advocates (n=13) to assess treatment patterns, patient journeys, access and coverage considerations, and opportunities for system-level improvement.

Study methodology

Needs Assessment

Development of interview guides in consultation with Retina Consultants of America and Prevent Blindness

In-Depth Interviews
Payers (n=3)
Health Care Providers (n=3)
Patient Advocates (n=3)

Analysis of interview transcripts informed survey development in consultation with Retina Consultants of America and Prevent Blindness

National Surveys
Payers (n=54)
Health care providers (n=36)
patient advocates (n=13)

Participation Criteria	Payer	HCPs	Patient
In-depth Interviews			
Qualification Criteria	• Managed Care Professional • Working in the U.S.	• Retina specialist Practicing in the U.S	• Patient with diabetic retinopathy, diabetic macular edema, or age-related macular degeneration • Living in the U.S.
Dates	October 22–24, 2025	October 21–24, 2025	October 30, 2025–November 3, 2025
Average Duration	50 minutes	40 minutes	45 minutes
Survey			
Qualification Criteria	Professionals currently working for one of the following organizations: • Integrated delivery system • Medical benefit manager • National health plan • Pharmacy benefit manager • Regional health plan • Self-insured employer • Veterans Administration	Health care provider practicing in one of the following specialties: • Retina specialist • Ophthalmologist	Patient or caregiver of a patient with one of the following diagnoses: • Diabetic Retinopathy • Diabetic Macular Edema • Age-Related Macular Degeneration – wet • Age-Related Macular Degeneration – dry
Dates	December 12, 2025–February 1, 2026	December 12, 2025–February 1, 2026	December 11, 2025–February 1, 2026
Number of Survey Questions	12	11	15

STUDY SAMPLE

In-depth Interviews

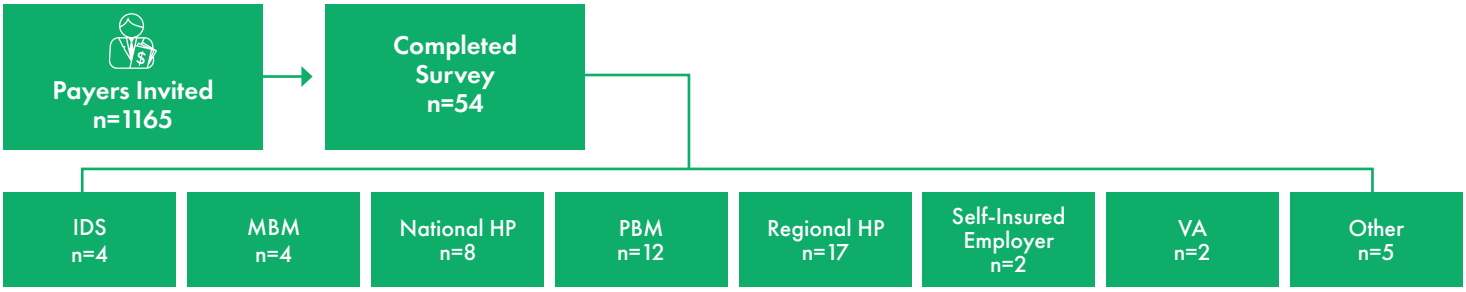
OVERVIEW OF SURVEY RESPONDENTS

Payers

Payer respondents represented a diverse range of organizations involved in coverage policy development, benefit management, and utilization management. Participants were drawn from national and regional health plans, pharmacy benefit managers, integrated delivery systems, and other payer-related organizations, reflecting varied approaches to coverage decision-making across the managed care landscape. The target sample size for the payer survey was 50 respondents.

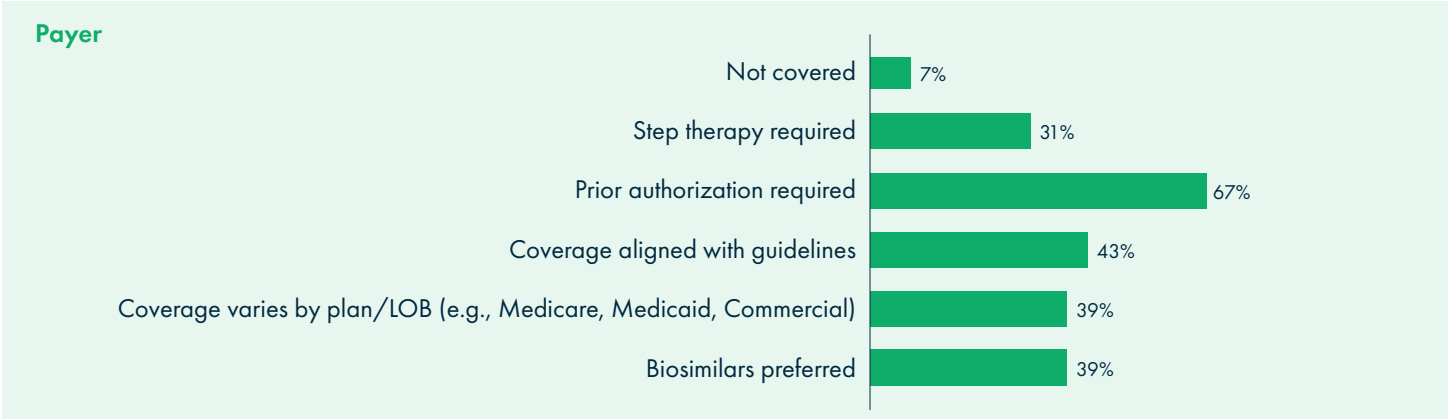
This diversity of organizational settings provides important context for understanding differences in coverage policies, administrative processes, and decision-making frameworks related to the management of DR/DME and AMD. The inclusion of both medical and pharmacy benefit perspectives highlights the multifaceted nature of coverage considerations for retinal disease treatments.

Collectively, the payer respondents represent a broad cross-section of managed care organizations responsible for evaluating evidence, managing benefits, and implementing policies that influence patient access to retinal disease care.



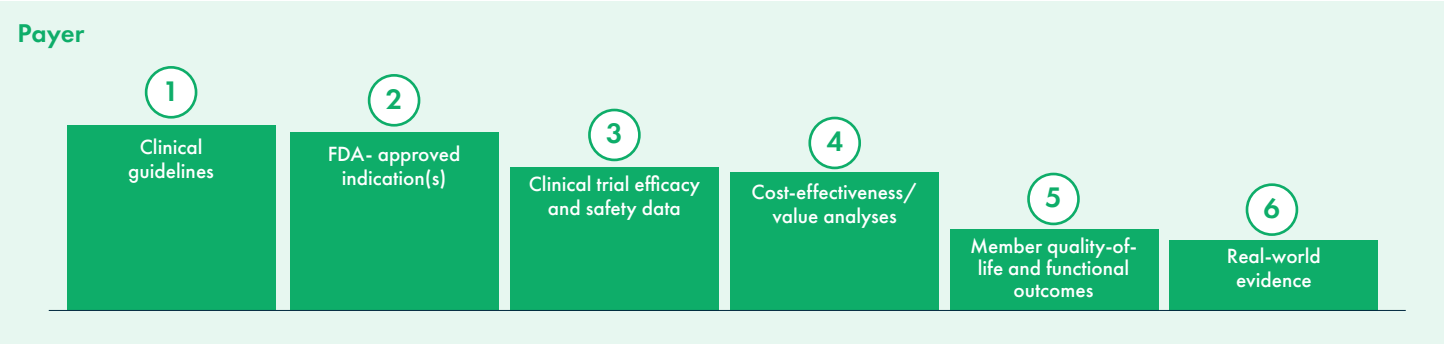
IDS=Integrated Delivery System, MBM=Medical Benefit Manager, HP=Health Plan, VA=Veterans Administration

Payer survey responses indicated that access to anti-VEGF therapies is typically governed by utilization management requirements rather than open coverage. Payers commonly reported the use of PA, along with step therapy and biosimilar preference policies, with approaches varying across lines of business, including Medicare, Medicaid, and commercial plans. While some respondents noted alignment with clinical guidelines, the findings indicate that administrative processes are a routine component of accessing anti-VEGF treatment for DR/DME and AMD.



Q2: How do you currently manage coverage for anti-VEGF therapies for DR/DME and AMD? (select all that apply) Payer n=54

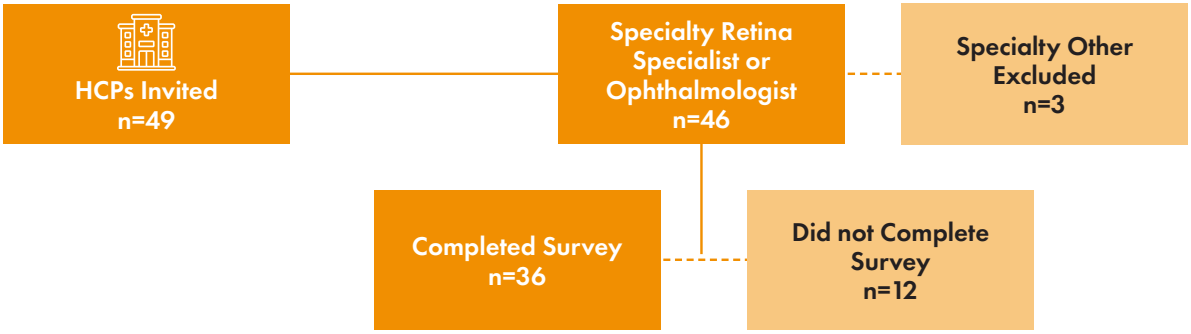
For retinal disease therapies, payer survey respondents ranked FDA-approved indications and alignment with clinical guidelines as the most influential factors in coverage policy development, followed by clinical trial efficacy and safety data. Cost-effectiveness analyses were considered of moderate importance, while real-world evidence and patient-reported quality-of-life outcomes were generally assigned to be a lower priority.



Q3: Rank the most important factors when developing coverage policy for retinal disease therapies. Payer n=54

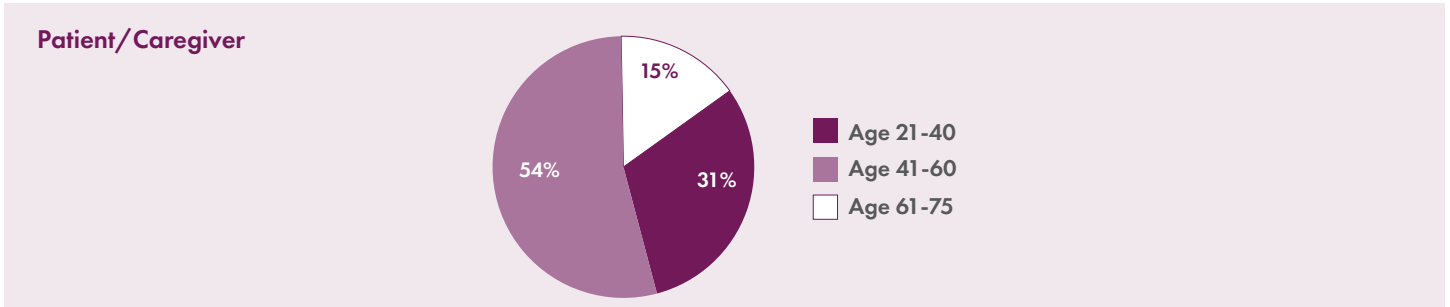
HCPs

To be eligible for the survey, HCP respondents were required to be retina specialists or ophthalmologists, reflecting clinicians directly involved in the diagnosing and managing retinal diseases. The target sample size for the HCP survey was 30 respondents. This composition ensured that survey responses were informed by clinical expertise and real-world experience caring for patients with DR/DME and AMD.



Patients and Caregivers

The target sample size for the patient and caregiver survey was 10 respondents with lived experience navigating diagnosis, treatment, and care for DR/DME or AMD. Patients and caregivers who responded to the survey were primarily adults in mid-to-late adulthood, reflecting populations commonly affected by chronic retinal diseases. Respondents did not include pediatric patients, providing a focused view of experiences among working-age and older adults managing ongoing vision-threatening conditions.

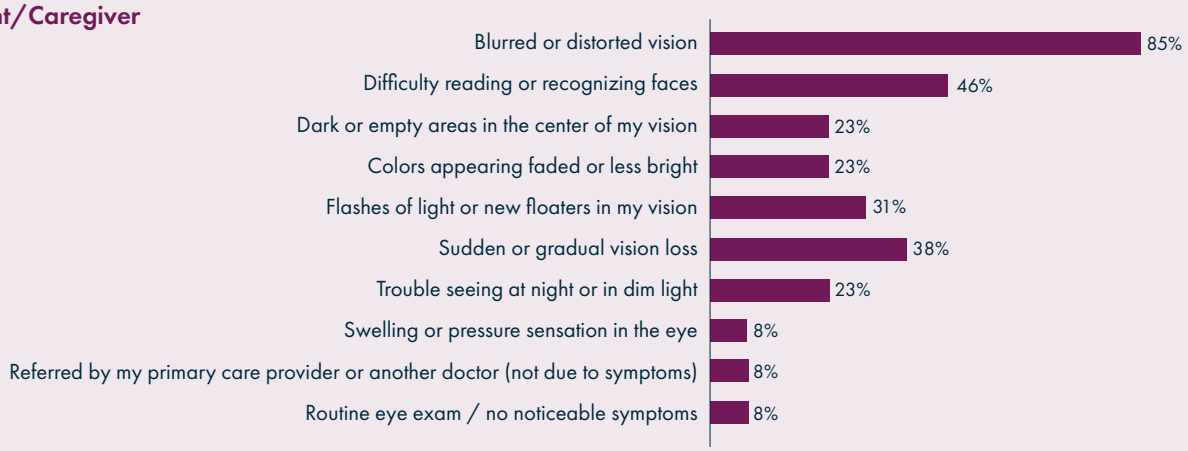


Q1: What is your age (or if a caregiver is responding, what is the age of the patient)? Patient/Caregiver n=13

In terms of clinical characteristics, most respondents reported a diagnosis of diabetic retinopathy, with additional representation from individuals affected by age-related macular degeneration, including both wet and dry forms. Collectively, these responses reflect a population with heterogeneous retinal disease experiences, encompassing both diabetes-related and age-related pathways to vision loss.

Most respondents sought care from an eye specialist after experiencing noticeable changes in vision, including blurred or distorted vision, difficulty reading or recognizing faces, sudden or gradual vision loss, flashes or floaters, and challenges seeing in low-light conditions. A smaller number reported being referred through routine eye examinations or by another clinician rather than symptom-driven care, underscoring that many patients first enter specialty care after functional vision changes have already occurred.

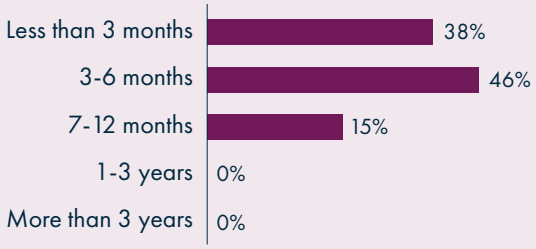
Patient/Caregiver



Q3: What symptoms prompted you/your patient to seek care from an eye specialist? (select all that apply). Patient/Caregiver n=13

The interval between first symptoms and diagnosis varied among respondents but generally reflected delays extending beyond the initial onset of visual changes. While some individuals received a diagnosis relatively soon after symptoms appeared, others reported longer diagnostic timelines, suggesting opportunities to improve earlier recognition, referral, and diagnostic pathways.

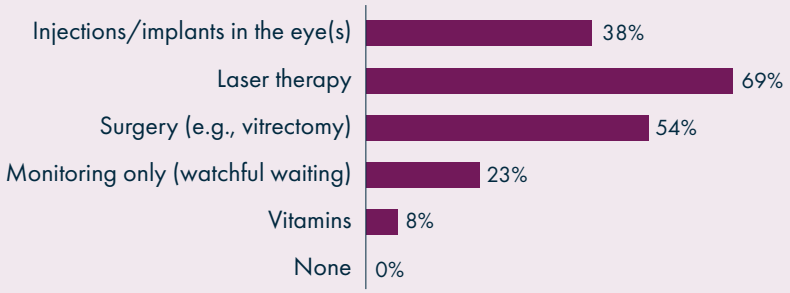
Patient/Caregiver



Q4: How long did it take from first symptoms (if any) to a diagnosis? Patient/Caregiver n=13

With respect to treatment experiences, respondents reported receiving a range of interventions. The diversity of treatment experiences highlights the complexity of retinal disease management and the cumulative burden patients may face as care evolves over time.

Patient/Caregiver



Q6: Which treatments have you/your patient received for the eye condition? (select all that apply). Patient/Caregiver n=13

KEY FINDINGS

DETECTION AND REFERRAL

Late presentation emerged as a consistent theme across all stakeholder groups and represents a primary driver of preventable vision loss. Payers noted that delayed diagnosis and referral—with patients often presenting late due to limited awareness—contributes to disease progression. Clinicians reported that patients frequently arrive with advanced disease, and HCP survey responses categorized the most common barriers to timely diagnosis as lack of patient awareness and education. Patients similarly described initially misunderstanding symptoms, long wait times to see an eye specialist, and delays in referral as significant challenges to timely diagnosis.

Lack of patient awareness of retinal diseases is a challenge commonly identified by all stakeholders

Payer

- 24% Limited screening or early detection programs
- 9% Lack of patient awareness of disease/education

HCP

- 72% Lack of patient awareness of disease/education
- 14% Limited screening in primary care settings

Patient/Caregiver

- 31% Clear understanding of the damage that not doing anything could cause to your eyes and overall physical and mental health
- 31% Misunderstanding of symptoms
- 15% Delayed referral to eye specialist
- 0% Limited screening or eye exams

Q7: What is the single biggest challenge in preventing vision loss from DR/DME and AMD? Payer n=54, Q2: In your experience, what are the most common barriers to timely diagnosis of DR/DME or AMD (select up to 3)? HCP n=36, Q5: What were the three most significant challenges to getting diagnosed with your/your patient's eye condition (select only three)? Patient/Caregiver n=13

"We see too many patients coming into retina care later than they should. A big part of the issue is limited awareness and inconsistent screening and referral, especially among patients with diabetes." - *Payer Interviewee*

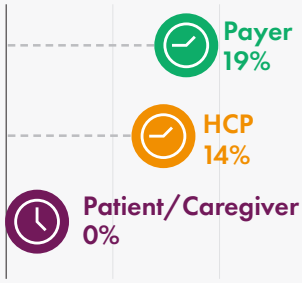
These observations align with published evidence: a 10-year observational study at Joslin Diabetes Center found that 89% of patients with mild DR and 55% with VTDR were unaware of any eye disease, and 25% of those with VTDR did not report to planned follow-up at recommended intervals.[3] A recent two-center study found that of 8,240 unscreened patients with type 2 diabetes, only 43% received a referral and just 16% completed screening within one year.[15]

"At first, I didn't think anything serious was going on. I just assumed my vision changes were part of getting older, and by the time I was referred to a specialist, the disease had already progressed." – *Patient Interviewee*

ACCESS AND CAPACITY CHALLENGES

Access to timely retinal specialist care was identified as a challenge by payers and health care providers, reflecting concerns about specialist availability, referral capacity, and delays within the care delivery system. In contrast, patients did not identify timely specialist access as the single biggest barrier, instead emphasizing the need for patient education.

Perceived Access to Timely Specialist Care Is Not a Consistent Barrier to Timely Care



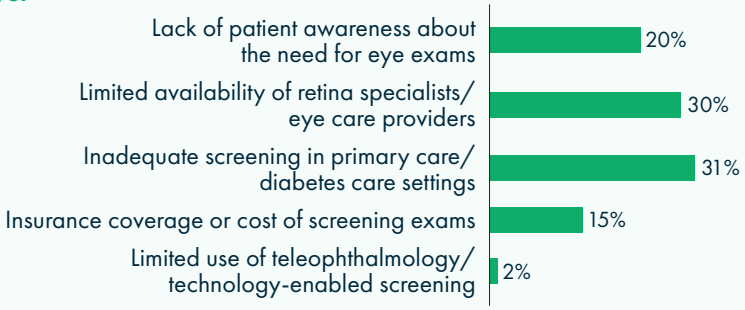
Q7: What is the single biggest challenge in preventing vision loss from DR/DME and AMD? Payer n=54, HCP n=36.
Q10: What is the single biggest challenge in preventing vision loss from eye conditions? Patient/Caregiver n=13

"Even when we diagnose patients appropriately, access is still a problem. Prior authorization, coverage limitations, and high out-of-pocket costs can delay care, and for rural patients the logistics of getting to frequent visits make it even harder." – *Retina Specialist Interviewee*

Payer and HCP responses highlighted distinct but complementary barriers to effective screening for DR/DME and AMD. Payers most frequently identified inadequate screening in primary care and diabetes care settings as the greatest barrier, underscoring system-level gaps in integrating eye screening into routine chronic disease management. In contrast, HCPs most ranked lack of patient awareness about the need for eye exams as the most significant barrier, followed by insurance coverage or cost of screening, reflecting front-line challenges related to patient engagement and access. Together, these findings suggest that failures in both care delivery infrastructure and patient awareness contribute to suboptimal screening rates, reinforcing the need for coordinated, multi-level interventions.

Greatest barriers to effective screening for DR/DME and AMD in the U.S.

Payer

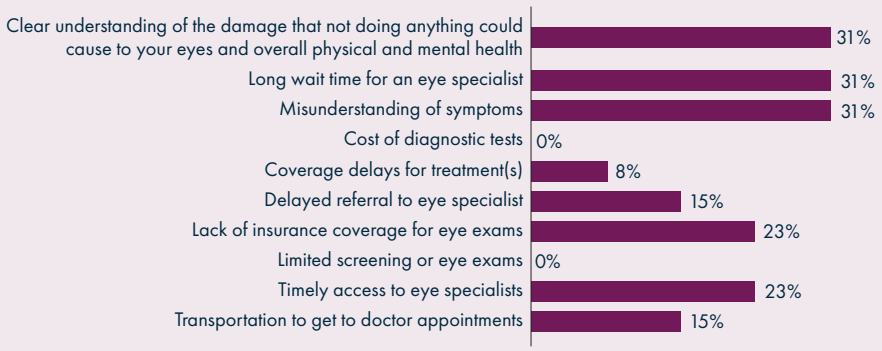


HCP

1. Insurance coverage or cost of screening exams and lack of patient awareness about the need for eye exams
2. Inadequate screening in primary care/ diabetes care settings
3. Limited availability of retina specialists/ eyecare providers
4. Limited use of teleophthalmology/ technology-enabled screening

Q10: What is the greatest barrier to effective screening for DR/DME and AMD in the U.S.? Payer n=54, HCP n=36.

Patient/Caregiver



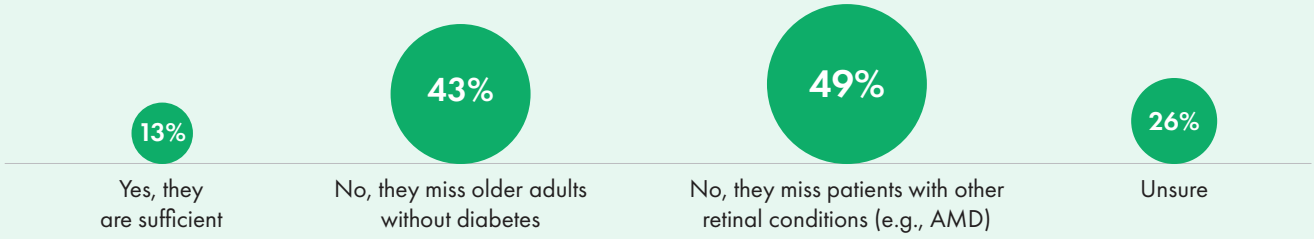
Q5: What were the three most significant challenges to getting diagnosed with your/your patient's eye condition (select only three)? Patient/Caregiver n=13

"Once I knew I needed a retina specialist, getting an appointment wasn't easy. The wait times were long, and traveling to appointments—especially outside a major city—added another layer of stress." – *Patient Interviewee*

Payer survey responses indicated limited confidence that current eye-screening quality measures adequately capture populations at risk for vision loss. Only a small proportion of respondents felt existing measures were sufficient, while many reported that current metrics miss key at-risk groups, particularly patients with retinal conditions other than diabetes (such as AMD) and older adults without diabetes.

Payer

Current quality measures for eye screening do not adequately capture the populations most at risk for vision loss



Q6: Do you believe current quality measures for eye screening adequately capture the populations most at risk for vision loss (select all that apply)? Payer n=53

TREATMENT BURDEN AND ADHERENCE RISK

Across interviews, treatment fatigue, visit frequency, and anxiety about injections were repeatedly mentioned. Payers highlighted no-show risk and treatment drop-off as major drivers of preventable vision loss. Clinicians emphasized that chronic intravitreal injections create adherence challenges. Patients expressed fear of blindness, injections, and emotional strain.

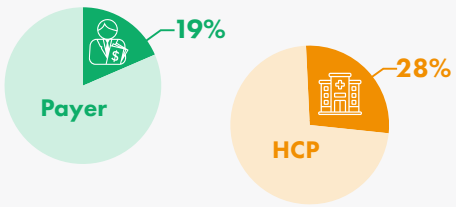
"The frequency of injections and visits is a major challenge. We see patients drop off after the first few treatments because of visit fatigue, fear of injections, or life circumstances that make it hard to keep coming back." – *Payer Interviewee*

A systematic review found that non-persistence occurred early, with up to 50% of patients stopping treatment by 24 months, and nonadherence rates ranged from 32% to 95%.[16] Multiple factors determine nonadherence, including condition-related variables (lower baseline vision, poorer treatment response), therapy-related factors (high follow-up burden), patient factors (fear and anxiety, disappointed expectations), and health system factors.[16-18] Pre-procedural anxiety was reported in 17.3% to 85% of patients undergoing intravitreal injections, with key contributing factors including lack of patient education, procedural pain and discomfort, and travel and waiting times.[19]

Survey findings across payer, health care provider, and patient/caregiver respondents reinforced these themes. Payers most frequently identified no-show risk and treatment drop-off as consequences of the ongoing intensity of treatment schedules and the cumulative burden of frequent visits, particularly when compounded by access and logistical barriers. HCPs similarly reported that sustaining adherence over time remains challenging, noting that repeated intravitreal injections and long-term follow-up requirements contribute to missed appointments and delayed care, even when effective therapies are available.

Perspectives on adherence to treatment as a challenge in preventing vision loss

Payer and HCP perspectives on patient adherence to treatment as a challenge in preventing vision loss



Patient/Caregiver ranking of causes of fear or anxiety

1. Risk of losing vision if treatment doesn't work
2. Receiving injections in the eye
3. Pain or discomfort during or after the procedure
4. Uncertainty about side effects or complications
5. Need for on-going or longterm treatment
6. Cost of treatment or insurance coverage issues
7. Frequency of injections or office visits
8. Fear of the unknown
9. I experience stress or worry related to treatment, but am unsure of the cause
10. Transportation or difficulty getting to appointments

Q7: What is the single biggest challenge in preventing vision loss from DR/DME and AMD? Payer n=54, HCP n=36. Q7: What about treatment for your/your patient's eye condition currently causes you the most fear or anxiety (rank: 1 = most important, 10 = least important)? Patient/Caregiver n=13

"The idea of ongoing eye injections was overwhelming at first. Between the fear, the number of visits, and trying to manage everything else in my life, staying consistent with treatment hasn't always been easy."
-Patient Interviewee

Patient and caregiver survey responses further highlighted the emotional and practical dimensions of treatment burden. Respondents commonly described fear related to vision loss, anxiety surrounding injections, and stress associated with repeated procedures and appointments. Challenges related to transportation, scheduling, and the long-term commitment required for ongoing treatment were also cited as factors that can undermine adherence.

ADMINISTRATIVE AND FINANCIAL BARRIERS

Cost and coverage challenges, particularly PA and out-of-pocket burden, were identified as concerns. Payers mentioned issues with benefit design and cost-sharing. Clinicians referenced PA hurdles and step edits delaying care. Patients experienced delays due to PA and valued streamlined processes.

Payers recognize high drug costs as one of the barriers to care for patients with DR/DME or AMD

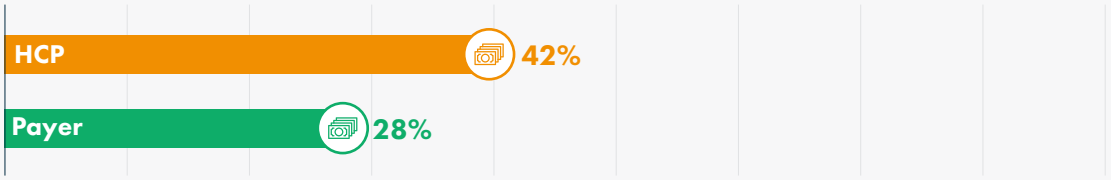
65%
of payers reported that high drug costs are one of the biggest barriers to ensuring timely access to care for members with DR/DME and AMD.

Q4: What are the biggest barriers to ensuring timely access to care for members with DR/DME and AMD (select all that apply)? Payer n=54

"Cost-sharing and benefit design absolutely influence whether patients stay on therapy. When coverage varies between the medical and pharmacy benefit, it can create confusion and barriers we don't always intend."
-Payer Interviewee

Survey findings across stakeholder groups reinforced the central role of administrative and financial barriers in delaying care and increasing the risk of nonadherence. Payer respondents frequently identified cost of treatment and insurance coverage considerations as among the most challenging factors in preventing vision loss, alongside access- and adherence-related issues. These responses suggest that payers recognize cost-sharing structures and benefit design as influential factors affecting patient persistence with recommended therapy.

HCPs perceive treatment costs and coverage as the single biggest challenge more than payers



Q7: What is the single biggest challenge in preventing vision loss from DR/DME and AMD? Payer n=54, HCP n=36.

Health care provider survey responses further highlighted financial and administrative barriers as key contributors to nonadherence. Providers most often cited high patient cost-sharing, transportation and logistical barriers, and fear of procedures as factors that prevent patients from adhering to treatment over time. PA requirements and related administrative processes were described as compounding these challenges by delaying treatment initiation or changes, even when clinically indicated.

"Administrative requirements like step therapy and repeated prior authorizations interrupt otherwise evidence-based care. These delays don't change the treatment we want to provide—they just slow it down."
-Retina Specialist Interviewee

HCP Perspectives on Challenges that Prevent Patients from Adhering to Treatment

1. High copay/coinsurance
2. Transportation/logistical barriers
3. Fear of injections/procedures
4. Poor vision at the time of presentation
5. Lack of caregiver/family support

Q3: Which of the following challenges most often prevents patients from adhering to treatment (rank 1–6)? HCP n=36.

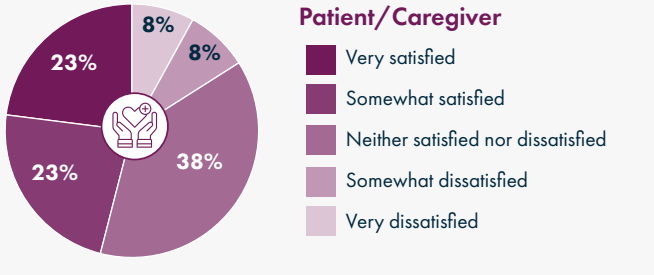
HCP Perspectives on Opportunities to Improve Outcomes in Retinal Diseases

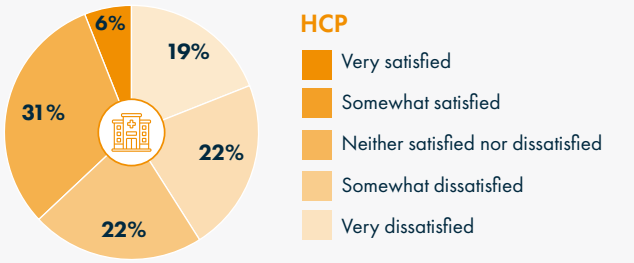
1. Improved insurance coverage and reduced administrative barriers
2. Patient navigation and support services (education, reminders, transportation)
3. Expanded access to screening (ex. teleophthalmology, community clinics)
4. Multidisciplinary care coordination (primary care, endocrinology, opthalmology/retina)

Q8: Which of the following opportunities do you think would most improve outcomes for people at risk of or living with DR/DME and AMD? HCP n=36

Satisfaction with insurance coverage was mixed or neutral among both patients and HCPs, suggesting variability in perceived coverage adequacy and in the administrative processes required to obtain care.

Patients and caregivers report higher satisfaction with insurance coverage for retinal diseases compared to HCPs





Q9: How satisfied are you with your/your patient's health insurance coverage for treatment(s) for the eye condition? Patient/Caregiver n=13 Q5: How satisfied are you with payer coverage of treatments for DR/DME and AMD?) HCP n=36.

OPPORTUNITIES TO IMPROVE CARE COORDINATION

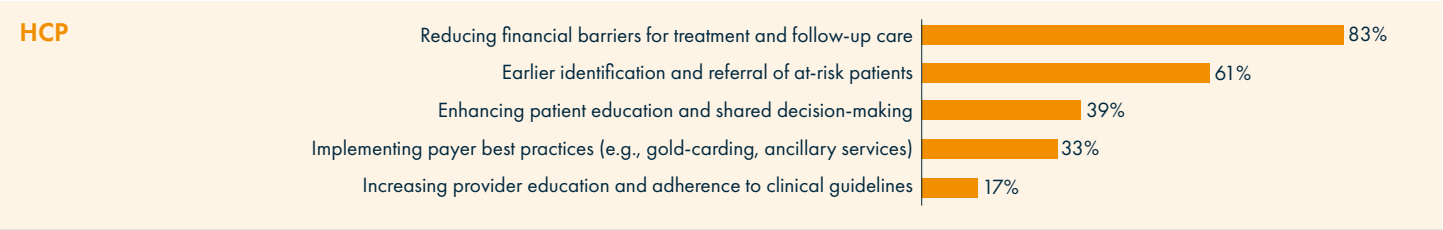
Better integration of retinal health into diabetes care workflows and cross-stakeholder communication emerged as a shared priority from payer and HCP interviews. Payers discussed integrating screening into chronic care programs. Clinicians want better electronic health record integration, referral pathways, and tele-retina support. Patients want clearer guidance and shared decision-making.

Evidence supports these priorities: tele-retinal screening improves DR screening compliance, with one randomized controlled trial demonstrating that patients offered tele-retinal screening were 1.5 times more likely to receive a dilated eye examination within 6 months than those referred through traditional channels.[19] Team-based primary care models that include nurse practitioners or physician assistants were associated with higher rates of guideline-recommended diabetes care, including annual eye examinations (adjusted odds ratio 1.04-1.10).[20] Beneficiaries who reported better care coordination also received higher-quality clinical care, with HEDIS differences between those with excellent and poor coordination exceeding 5 percentage points for multiple measures, including diabetic retinal eye exams.[21]

"There's a real opportunity for payers to do more on coordination—linking eye care into diabetes programs, improving referral pathways, and using data to flag patients who are falling through the cracks."

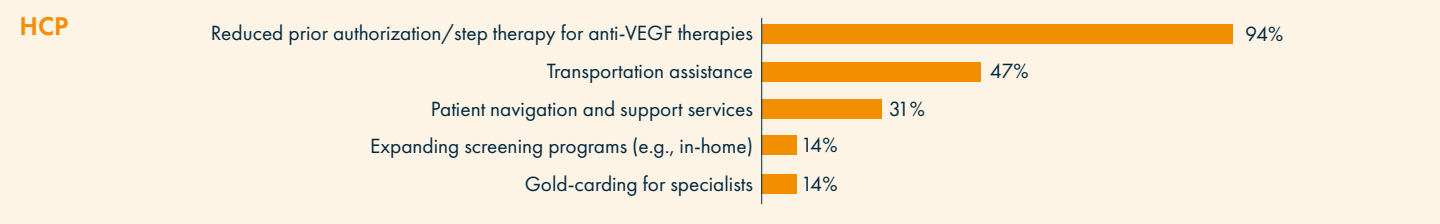
-Payer Interviewee

HCP survey respondents most often prioritized reducing financial barriers to care, earlier identification and referral of at-risk patients, and reductions in administrative as key levers to improve care delivery. These responses suggest strong HCP interest in upstream interventions that streamline care delivery across care settings.



Q9: From your perspective, what is the most effective way to improve care delivery for DR/DME and AMD (select all that apply)? HCP n=36

HCP survey responses also highlighted the importance of minimizing PA and step therapy requirements and identified transportation assistance as meaningful supports to improve follow-through once referrals are made.

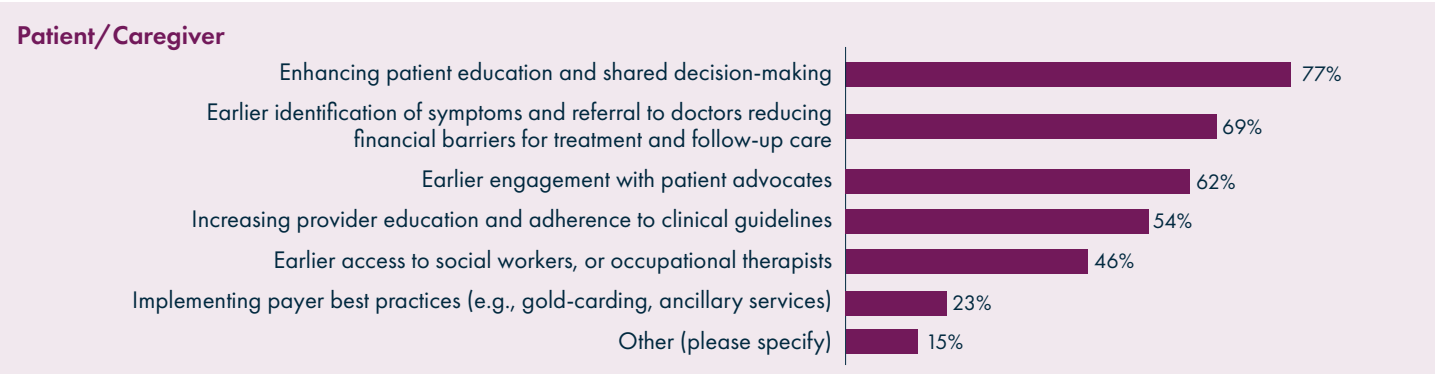


Q6: What payer or system-level strategies would most improve outcomes for your patients (select all that apply)? HCP n=36

A prospective multicenter study found that while 96.2% of PA requests for anti-VEGF medications were ultimately approved, 59.6% of patients experienced delays in care delivery, with median staff time to obtain a single PA being 100 minutes.[10]Among delayed approvals, 42.8% experienced delays of at least one week, and 26.3% experienced delays of 4-31 days.[10] Approximately 65% of commercial coverage decisions and 52% of Medicare Advantage decisions include restrictions beyond FDA labeling, with step therapy protocols found in up to 75% of plans.[11] The highest denial rates occurred for patients initiating anti-VEGF therapy (15%) and those requiring medication changes due to treatment failure (4.6%), potentially targeting the most vulnerable patients.[10]

"When health plans work with us—streamlining prior authorization, supporting tele-retina screening, and integrating eye care into diabetes management—it makes a measurable difference in keeping patients on track." – *Retina Specialist Interviewee*

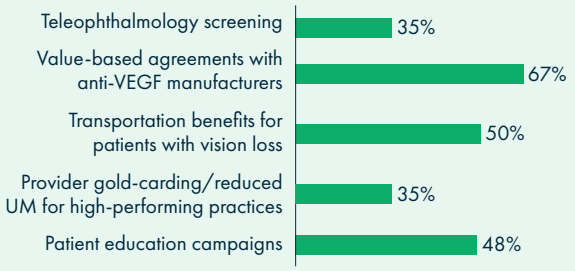
Patient and caregiver survey findings further underscored the value of patient-centered care. Respondents emphasized earlier symptom identification and stronger patient engagement. Improved patient education and shared decision-making were consistently identified as critical components of effective care coordination.



Q12: From your perspective, what is the most effective way to improve care for people with eye conditions (select all that apply)? Patient/Caregiver n=13

The following figures summarize payer perspectives on system-level strategies to improve outcomes and prevent vision loss among individuals with DR/DME and AMD, highlighting payer interest in combining value-based and coverage-related approaches with access-oriented investments, particularly expanded screening, reduced administrative barriers, and care coordination to strengthen early detection, continuity of care, and long-term outcomes across retinal diseases.

Payer perspectives on system-level strategies to improve outcomes and prevent vision loss



Q5: Which system-level interventions would you consider investing in to prevent blindness (select all that apply)? Payer n=54

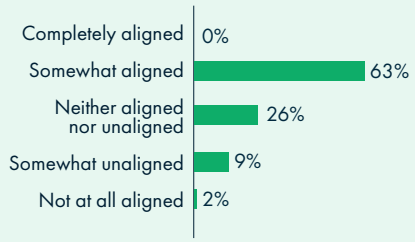
1. Expanded access to screening (eg. teleophthalmology, community clinics)
2. Improved insurance coverage and reduced administrative barriers
3. Multidisciplinary care coordination (primary care, endocrinology, ophthalmology/retina)
4. Patient navigation and support services (education, reminders, transportation)
5. Development and adoption of new therapies (e.g., longer-acting anti-VEGFs, implants)

Q8: Which of the following opportunities would most improve outcomes for people at risk of or living with DR/DME and AMD? Payer n=54

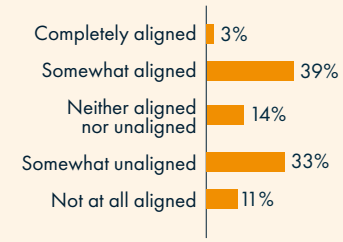
STAKEHOLDER ALIGNMENT IN PREVENTING VISION LOSS

Across stakeholder groups, perceptions of alignment among payers, HCPs, and patients in preventing vision loss suggest partial but uneven coordination, with notable differences by perspective.

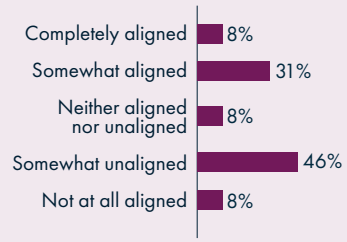
Payer



HCP



Patient/Caregiver



Q11: In your opinion, how well aligned are payers, providers, and patients in preventing vision loss? Payer n=54, HCP n=36.
Q14: In your opinion, how well aligned are payers, providers, and patients in preventing vision loss? Patient/Caregiver n=13

Payers most often characterized stakeholders as somewhat aligned. No payer respondents perceived full alignment, suggesting room to strengthen cross-stakeholder collaboration. HCPs and patients/caregivers reported greater misalignment, highlighting disconnects between clinical priorities, coverage policies, and operational realities that can delay care, complicate treatment decisions, and impact adherence.

"When communication between my doctors and insurance worked well, everything felt easier. Clear explanations, fewer delays, and help navigating appointments made a big difference in staying on track."
– Patient Interviewee

Taken together, these findings suggest that while stakeholders broadly agree on the importance of preventing vision loss, alignment weakens at the point of care delivery and patient experience. Addressing this gap will require improved communication, clearer expectations, and more coordinated approaches that align payer policies, clinical workflows, and patient needs across the continuum of DR/DME and AMD care.

LIMITATIONS

Several limitations should be considered when interpreting the findings of this program. First, patients, caregivers, and HCPs were offered honoraria for participation, which may have contributed to selection bias. Patient and caregiver respondents were primarily recruited through an advocacy network and email communications, which may overrepresent individuals who are more engaged, health-literate, or connected to retinal disease communities. As a result, these findings may not fully reflect the experiences of individuals with DR/DME or AMD who face greater barriers to engagement, including limited internet access, lower health literacy, or fewer connections to advocacy organizations. This may limit the generalizability of the patient and caregiver findings.

In addition, the patient and caregiver sample size was relatively small compared with the payer and HCP samples, and pediatric patients were not represented. While the respondents reflected adults commonly affected by chronic retinal diseases, additional research is needed to capture broader demographic diversity, including racial and ethnic minority populations, individuals living in rural settings, and those with varying socioeconomic backgrounds, who may experience distinct access challenges and care pathways.

For the payer and HCP surveys, responses reflect self-reported perspectives and priorities rather than verified coverage policies or observed clinical practice. Payers were asked to describe current management approaches and hypothetical strategies, which may vary from real-world implementation across specific plans, regions, or lines of business. Similarly, HCP responses were based on perceived barriers and ranking exercises rather than objective measures of practice patterns or patient outcomes. The study did not independently validate screening rates, referral timelines, or utilization management processes.

Sample sizes within stakeholder groups also limited the ability to conduct detailed subgroup analyses, such as differences by payer type, provider specialty, practice setting, or geographic region. Additionally, while the surveys explored satisfaction with coverage, screening, and quality measures, they did not fully assess stakeholder preferences for specific benefit designs, alternative care models, or technology-enabled solutions, which may be important for informing policy development.

Finally, the cross-sectional design captures perspectives at a single point in time and may not reflect evolving coverage policies, clinical guidelines, or emerging therapies in the rapidly changing retinal disease landscape. Longitudinal research and real-world data analyses are needed to further evaluate how payer strategies, care delivery models, and system-level investments translate into sustained improvements in screening, treatment access, and vision outcomes for patients with DR/DME and AMD.

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