Clinical Ophthalmology

Dovepress
Taylor & Francis Group

Open Access Full Text Article

ORIGINAL RESEARCH

Prioritising the Burden of Geographic Atrophy and Treatment Expectations: A Modified Nominal Group Technique Study with International Patient-Led Organisations

Nabin Paudel, Ellen M Moran, Sinead Stafford, Kelly McVicker, Petia Stratieva, Avril Daly

Retina International, Dublin, Ireland

Correspondence: Nabin Paudel, Email nabin.paudel@retina-international.org

Aim: Geographic atrophy (GA), an advanced form of dry AMD, impacts over 5 million people globally and leads to progressive, irreversible vision loss. Current approaches to GA treatment aim to prevent and delay disease progression and preserve remaining vision. However, there is a debate on what constitutes a meaningful treatment outcome for patients. The aim of this study was to prioritise challenges associated with GA and desired treatment expectations from therapies using a modified Nominal Group Technique (NGT).

Methods and Analysis: The study employed a modified nominal group technique (NGT), a widely used, validated, structured, facilitated group meeting to generate consensus. Representatives from patient-driven international research funding and support organizations were invited to participate. Two questions, one asking the impact of GA on patients and caregivers and another asking the treatment expectations of GA therapies were posed during the NGT session. Standard NGT methods were followed to generate top 10 challenges of living with GA and treatment expectation as perceived by the participants.

Results: The group ranked loss of independence (score – 32/50), difficulty recognizing faces (score – 28/50), impairment in daily living activities (scores – 11 to 22/50), and mental health issues (scores – 19/50 - anxiety, 21/50 - depression) as the most significant challenges faced by people living with GA. The group also prioritised stability of vision (score - 47/50), ability to recognise faces (score – 27/50) and one time therapy (score – 19/50) as their top expectations from GA treatments.

Conclusion: This study successfully used the NGT to prioritise challenges associated with GA and treatment expectation of GA therapies. The consensus results imply that meaningful progress in GA care will come from therapies that realistically aim to slow further vision loss, are convenient to use, and are delivered alongside psychosocial and low-vision support.

Plain Language Summary: This study gathered perspectives from representatives of international patient-led organisations to understand what matters most to people living with geographic atrophy (GA), a severe form of dry age-related macular degeneration. Using a structured group discussion method, participants identified key challenges such as loss of independence, difficulty recognising faces, problems with daily activities, and mental health impacts like anxiety and depression. When asked about treatment expectations, they prioritised maintaining existing vision (vision stability), the ability to recognise faces, and having a one-time treatment instead of frequent procedures. These findings suggest that for patients, meaningful treatment outcomes go beyond clinical measures—what truly matters is slowing further vision loss, minimising treatment burden, and supporting mental well-being and daily functioning. Future research and treatment planning should reflect these priorities and include broader, more diverse patient voices.

Keywords: geographic atrophy, burden, patient perspective, nominal group technique, age-related macular degeneration, treatment expectations, patient-driven research

Received: 20 March 2025
Accepted: 1 August 2025
Published: 9 September 2025

Introduction

AMD is a leading cause of blindness worldwide in people over the age of 50, particularly in higher income countries, and is a major public health concern. It is estimated that approximately 200 million people currently live with some form of AMD. Globally, almost 1 in 10 (213 million) people above the age of 50 years live with a form of AMD, early, intermediate or late stage. Of these, 6% (12 million) have the most severe and blinding late stage of the disease, which includes neovascular AMD (nAMD) also known as wet AMD and geographic atrophy (GA) also known as late-stage dry AMD.[1] The prevalence of AMD is on the rise. In the last 10 years, the number of people living with AMD globally has grown by more than 25% from 170 million to 213 million. By the year 2040, it is estimated that around 287 m will be affected by the disease. Geographic atrophy (GA), the atrophic form of AMD leads to progressive and irreversible loss of visual function. GA is responsible for 10–20% of blindness in AMD, affecting more than 5 million people globally. GA is characterized by progressive loss of retinal pigment epithelium cells and photoreceptors. Patients with GA develop lesions that progressively enlarge and cause gradual loss of central vision, leading to permanent vision loss that ultimately compromises their ability to read and recognize faces, perform essential daily living activities, such as watching TV, cooking and driving.[2,3] Emotions experienced by the affected individuals due to their compromised independence included anxiety, depression, fear and frustration, and these frequently crossed over into their relationships with others, impacting negatively the quality of life for both patients and their families.[4] The economic burden of GA in the society is immense. A systematic literature review assessing the humanistic and economic burden of GA revealed poor vision-related functioning and health-related quality of life (HRQOL) in patients with GA, and the direct costs of GA are substantial. The estimated annual loss was about $39.4 billion to the United States (US).[4] Similarly, a study by Retina International in 2022 revealed that the per annum per patient economic burden of GA ranged from €19,311 in Bulgaria to €39,250 in the USA. The majority of the burden incurred was due to the impact on mental health and productivity (job loss, job reduction).[5] Only two FDA-approved therapies are currently available in the USA for geographic atrophy (GA) secondary to age-related macular degeneration (AMD): pegcetacoplan and avacincaptad pegol. No therapies are currently available in Europe.[6] Pegcetacoplan works by inhibiting complement protein C3. It was approved by the FDA on February 17, 2023, for the treatment of GA. Avacincaptad pegol targets complement protein C5. It received FDA approval on August 18, 2023. Both pegcetacoplan and avacincaptad pegol function by inhibiting components of the complement system, a part of the immune system implicated in the progression of GA. A limitation to both of these therapies is that they may also increase the risk of exudative AMD.[6] Current approaches to GA treatment aim to prevent and reduce the progression of existing atrophy to become more advanced stages and hence allowing individuals living with the diseases extend their remaining vision considerably longer that they would have without any treatment. A few previous case reports have indicated that patients living with GA deeply value their remaining vision and consider the stability of vision and slowing down disease progression as a meaningful outcome[7] however a consensus on what constitutes a truly meaningful treatment outcome for patients is not clear, as perspectives may differ between patients themselves and regulatory bodies or policymakers.

Therefore, the objective of this study is to identify and prioritize the key challenges and treatment expectations by patients with geographic atrophy, as reported and perceived by patient leaders from patient-driven research funding and support organizations using a validated and widely used consensus building method called the nominal group technique.

Methods

We used the nominal group technique for consensus development. The nominal group technique (NGT) is a consensus method used in research that is directed at problem-solving, idea-generation, or determining priorities.[8–10] The NGT has been successfully used to generate consensus in several areas such as general practice, physiotherapy, aphasia and pain medicine.[11–14] Some previous studies have used the NGT method in the field of ophthalmology, but these studies are mainly conducted with clinicians.[15–18] In this study, we have explored the feasibility of the NGT in a small group of representatives from patient-driven organizations. We selected the Nominal Group Technique (NGT) because it is a structured, consensus-driven approach well suited for systematically gathering and prioritizing insights from a small group of experts or stakeholders. NGT ensures that all participants contribute equally, minimizes dominance bias and allows for the transparent ranking of a wide range of ideas, making it especially useful when exploring complex, multidimensional topics.[19,20]

NGT Members

We invited 5 participants to attend an in-person nominal group meeting. Participants were representatives from patient-driven funding and support organizations that either fund research into retinal degenerative diseases (RDD) or support patients living with RDD from 5 countries (Switzerland, Australia, South Africa, Spain and Brazil). All participants were associated with the member organization of Retina International in their respective countries. The nominal group method was conducted during a three-and-a-half-hour session at the 22nd Retina International World Congress, 2024, in Dublin, Ireland. The session was held in a private conference room and were moderated by two members (SS, KMV) of the research team.

Patients and Public Involvement

This study was initiated by a patient group and involved representatives from patient organizations from 5 countries to develop a consensus. The study results were shared with the participants and other patient groups across the globe.

Ethical Considerations

This study was approved by the Retina International Ethical Review Board (Approval number RI-REC-015) and performed in accordance with the tenets of the Declaration of Helsinki. Permission was obtained from all participants to audio record the event and publish findings. The experts involved in the NGT meetings were made aware that they could withdraw their contribution at any time during the research project.

The NGT Process

A week before the meeting date, participants were emailed with evidence summary documents that included the current knowledge in relation to 1) the impact of GA on patients and caregivers (Supplementary Material Table S1 and 2) treatment expectations of current and future potential therapies for GA (Supplementary Material Table S2). This was done to familiarise the participants with the latest evidence regarding the impact of disease as well as the treatment expectations of current and potential therapies. Areas for considerations in the evidence summaries were identified based on the literature reviews[4,7,21–25]of the two topics and interviews with people living with GA (Supplementary Material Table S3).

At the start of the meeting, the meeting facilitators (AD, SS) gave the participants an overview of GA and current knowledge regarding the burden and the landscape of current and potential therapies. Participants were also given an overview of the NGT method. Participants in this study were explicitly asked to provide responses not from their own personal perspectives, but in their capacity as representatives of their respective patient organizations. They were instructed to draw upon their broad experience, reflecting the collective views, needs, and concerns of the wider patient communities they support. All participants who took part in the NGT had some form of visual impairment hence special adjustments (an assistant each to help them keep notes, clarification of the items) were required throughout the meeting. This led to time constraints to complete all steps of the NGT during the in-person meeting. Therefore, the ranking step of the NGT was conducted online. The steps involved in the NGT method are described below.

Step 1: Idea generation: The facilitator presented the first question to the group and asked participants to write down their responses and ideas silently for ten minutes. Participants were allowed to question if they require further clarification on the question posed.

Question 1

What are the impacts and challenges of GA on daily living activities, mental health, emotional and social health, caregivers, employment, independence and visual function?

Step 2: Round Robin: Participants took turns stating aloud their ideas; the facilitator recorded these on a flip chart.

Step 3: Grouping ideas and discussion: Each idea was discussed by the group to clarify meaning and explore underlying rationale.

The above three steps were repeated for the second question:

Question 2

What are the treatment expectations from patients living with GA regarding the mode of delivery, frequency of treatment, visual outcome and function, and side effects of current and potential therapies for GA?

Analysis

Step 4: Ranking/Voting: Following the workshop, the items generated during the in-person meeting were compiled and grouped in an Excel sheet and distributed to all the participants via email. Two sheets, one for the impact and another for treatment expectations were created. Participants were asked to identify the top 10 items that they feel are most important from the whole list and rank them according to their importance – 10 for the most important and 1 for the least important. The participants were then asked to return the ranked sheet via email.

Step 5: Final ranking: The final ranking of the items was produced by summing the individual scores to each of the ideas of the participants.

We modified the NGT in two ways. First, participants were sent an evidence summary document that included currently available knowledge regarding the burden of GA and treatment expectations one week prior to the meeting. This was done to familiarize participants with the content. Second, we had to conduct the voting/ranking step online due to time constraints.

Results

The mean age of the participants was 59.2 ±16.68 years (range, 36–77 years). Four of the participants were males. All participants were experienced leaders who had several years of involvement in research and advocacy activities in retinal degenerative diseases locally as well as globally and had experience interacting with older adults living with AMD.

NGT Discussion: Impact of GA on Patient and Caregiver Items

The group generated 37 items that were grouped under 7 different categories – Daily living activities (9 items), mental health (2 items), emotional and social health (9 items), caregiver (4 items), employment (3 items), independence (1 item)

Table 1 Items Generated by the Group with regard to the Impact of GA/Challenges Faced by People Living with GA

Impact/Challenges
Daily living activities
Watching TV
Recognizing faces
Orientation and mobility
Doing groceries
Shopping
Travel to and from appointments
Cooking
Using computers and smartphones
Reading

(*Continued*)

Table 1 (Continued).

Impact/Challenges
Mental health issues
Anxiety
Depression
Emotional and social issues
Fear
Loneliness
Frustration
Social isolation
Sadness
Anger
Altered feelings
Hobbies
Limited interaction with family members
Informal Caregiver (family members) burden
Feeling guilt
Caregiver job reduction
Caregivers' anxiety and depression
Caregivers' loss of leisure time
Impact on the individual's work
Job loss
Job reduction
Unproductive at work
Losing independence
Rely on others for groceries, shopping, travelling, hiking, travelling to appointments and medical checks, banking, handling confidential documents
Visual function
Blurred vision
Intolerance to brightness
Dizziness
Difficult seeing in low light
Poor light/dark adaptation
Poor contrast
Poor depth perception
Progressive visual loss/deterioration of the condition

https://doi.org/10.2147/OPTH.S525046

Table 2 Generated Items Ranked by the Group with regard to the Impact of GA/Challenges Faced by People Living with GA

Items	Ranking					Total Score
Rely on others for groceries, shopping, travelling, hiking, travelling to appointments and medical checks, banking, handling confidential documents	5	9		10	8	**32**
Recognizing faces	7	8	10	3		**28**
Orientation and mobility		10	5	4	4	**23**
Depression		1	6	5	9	**21**
Deterioration of the condition	6			8	6	**20**
Anxiety	9		3	6	1	**19**
Reading	8	2	8			**18**
Cooking		3	9			**12**
Social isolation	2		4	2	3	**11**
Watching TV		6			5	**11**
Fear	10					10
Anger					10	10
Frustration				9		9
Travel to and from appointments		7				7
Feeling guilt				7		7
Using computers and smartphones			7			7
Blurred vision					7	7
Loneliness	3		2	1		6
Shopping		5				5
Job loss			5			5
Doing groceries		4				4
Caregivers' loss of leisure time	4					4
Caregiver job reduction					2	2
Limited interaction with family members			1			1
Poor light/dark adaptation	1					1

Note: * The top 10 ranked items are in bold numbers.

and visual function (9 items). (Table 1) The group then ranked 22 unique items. (Table 2) The items and their corresponding scores are presented in Table 2. The top 10 ranked items were losing independence, recognizing faces, orientation and mobility, depression, deterioration of the condition, anxiety, reading, cooking, social isolation, and watching TV.

NGT Discussion: Treatment Expectations of Current and Potential Therapies of GA

The group generated 21 items that were grouped under 5 different categories – modes of delivery (4 items), frequency of treatment (4 items), visual outcome (3 items), regain of function (7 items) and side effects (3 items)

(Table 3). The group then ranked 18 unique items. The items and their corresponding scores are shown in Table 4. The top 10 ranked items were – Stability of vision, able to recognize faces, one time therapy, oral model of treatment, improvement in vision, able to walk independently, intra-vitreal injections, delay further loss of vision, able to read and able to drive.

Table 3 Items Generated by the Group with regard to the Treatment Expectations of Current and Potential Therapies for GA

Expectations
Mode of delivery
Oral
Eye Drops
Intra-vitreal injections
Sub-retinal injections
Frequency of treatment
One time therapy
Three monthly injections
Six monthly injections
Yearly injections
Visual outcome
Improvement in vision
Stability of vision
Delay further loss of vision
Regain of function
Able to recognise faces
Improve balance
Able to read
Able to drive
Able to walk independently
Watch TV/movies
Able to go to shopping
Side effects
Less Discomfort
Less risk of wet AMD or other vascular diseases
Reduction in injection anxiety

https://doi.org/10.2147/OPTH.S525046

Table 4 Generated Items Ranked by the Group with regard to the Treatment Expectations of Current and Potential Therapies for GA. *

Items	Ranking					Total Score
Stability of vision	10	10	10	10	7	**47**
Able to recognise faces	8		7	4	8	**27**
One time therapy		7	3	9		**19**
Oral	6	6	2		5	**19**
Improvement in vision		9			9	**18**
Able to walk independently			5	3	10	**18**
Intra-vitreal injections	5	4		7		**16**
Delay further loss of vision	7		9			**16**
Able to read	9		6	1		**16**
Able to drive		8	8			**16**
Six monthly injections	3	2			6	11
Less Discomfort	2			5	3	10
Sub-retinal injections		1		8		9
Yearly injections	4	3			2	9
Eye Drops		5			4	9
Less risk of wet AMD or other vascular diseases	1			6	1	8
Able to go to shopping			4	2		6
Watch TV/movies			1			1

Note: *The top 10 ranked items are in bold numbers.

Discussion

To the best of our knowledge, this is the first study that incorporated the NGT method to generate consensus from patient driven research funding and support organizations regarding the challenges faced by patients living with GA and treatment expectations of current and potential therapies of GA. The items generated by the group were consistent with what was generated via the literature review and patient surveys. A final list of 37 items for impact and 21 items for treatment expectations were generated. The top 10 items ranked by the representatives can help clinicians, researchers and policy makers to prioritise areas of impact in AMD such as developing endpoints that reflect matters most to patients or providing support where these are the most impact.

Impact of GA

The biggest challenge identified by the group was losing independence and relying on others for daily activities, appointments, shopping and several daily living activities. These findings highlight that patient value their independence as a top priority. This also implies that interventions and treatments for AMD should focus not just on improving clinical measures of vision but on maintaining and enhancing patients' ability to perform daily activities independently. Some of the strategies to address this challenge could be developing assistive technologies that help patients navigate their environment without assistance, designing rehabilitation skills that are needed for independent living, prioritizing research on treatments that slow or prevent progression of the disease so that patients can maintain independence for as long as possible, enhancing public spaces and transportation systems to be more accessible to those with visual impairments and including measures of independence and quality of life (PROMs) into clinical trials in GA.

Participants ranked recognizing faces as the second biggest challenge among patients with GA. Several studies in the literature have reported that patients with advanced AMD have difficulty recognizing faces.[26] Difficulty in facial recognition has been linked with limited social interaction and communication in visually impaired people as these individuals must rely more heavily on non-visual cues during social encounters.[27] Similarly, impaired face perception has been found to be associated with poor quality of life in patients with AMD.[28] This demonstrates the importance patients place on social interaction as a crucial component of their overall well-being. This emphasizes the urgent need for scientists, researchers and developers need to develop new tools, therapies and rehabilitation services that can allow people with visual impairment to recognize faces. While we wait for new therapeutic developments that allow people with GA regain their lost function, it is equally important to act on enhancing the well-being of those who are currently experiencing the disease and have impaired facial recognition. Prior research has offered specific recommendations addressing the challenges of impaired face recognition, providing guidance for patients, caregivers, friends, and family on adapting to new visual limitations and enhancing social well-being.[28] These strategies can help mitigate the social and emotional impact of facial recognition difficulties while more advanced solutions are being developed.

Other daily living activity items that were ranked in the top 10 include orientation and mobility, reading, cooking and watching TV. These all combinedly come under the impact on patient's independence and can have far-reaching implications. The inclusion of orientation and mobility in the top 10 highlights the profound effect vision loss can have on one's independence and ability to navigate their environment safely.[29,30] Challenges in these areas may influence participation in social activities and overall well-being, including mental health.[31] Reading difficulties can affect both leisure and daily tasks, such as managing medication labels, bills, or confidential documents. Previous reviews have identified reading as one of the most valued activities to be affected by AMD.[32] The impact on cooking is noteworthy as it touches on both independence and nutrition. Difficulty in preparing meals may lead to reliance on others or a shift towards less healthy, pre-prepared food options, potentially affecting overall health and well-being.[33,34] The inclusion of watching TV among the top impacts underscores how GA affects not just essential tasks but also common leisure activities. This can significantly reduce quality of life and limit options for relaxation and entertainment, potentially exacerbating feelings of isolation and depression.

Depression and anxiety were also ranked within the top 10 impacts of GA. The issue of mental health disorders among people with AMD is well established in the literature.[35,36] However, studies demonstrating the prevalence of mental health issues in GA are scarce. This study provides strong evidence that depression and anxiety are common among people living with GA. The occurrence of mental health issues in people with GA and in people with VI in general stems from a variety of factors. One of the main factors is the functional impairment and vision loss leading to decline in quality of life and hence the psychological issues.[37–39] Furthermore, previous studies have elicited that low level of physician-patient communication may lead to mental health issues among people with chronic diseases[39] This could be true in AMD as it has been found that there is a significantly low patient-clinician communication in AMD care.[40,41] Although some attempts have been made to address this burden by involving nurses and other staff in providing information about disease progression and impact, studies suggest that psychological support for visually impaired people is non-existent in the majority of eye care facilities at least in the UK.[42] There is an urgent need to address this issue comprehensively. Healthcare providers should implement strategies to improve patient-clinician communication, offer regular mental health screenings, and integrate psychological support services into AMD care. Furthermore, developing support groups, providing access to counselling, and educating patients and their families about coping strategies could significantly improve the mental well-being of individuals living with GA.

Social isolation was also ranked as one of the top 10 impacts. The difficulty in facial recognition, previously discussed as a major impact, directly contributes to social isolation.[28] When individuals struggle to recognize friends, family members, or acquaintances, they may feel less confident in social situations, leading to withdrawal from social activities. This can result in a gradual erosion of social connections and support networks, which are crucial for mental health and overall well-being. Similarly, social isolation can be a result of depression as previous studies have demonstrated links between social isolation and depressive symptoms in people with visual impairment.[43]

Worry about deterioration of the condition was also one of the top 10 impacts of GA as ranked by the participants. As patients gradually start losing their vision, which is a case in GA, they become acutely aware of the importance of their

remaining sight. This heightened appreciation for residual vision likely intensifies the fear of further loss, making each change in visual acuity more distressing. As vision loss occurs, patients start adapting to the new level of functional vision which can be stressful.

Treatment Expectations of GA Therapies

The treatment expectations discussion and ranking revealed some interesting insights into patient priorities. Participants identified stability of vision as the foremost expectation from current and potential geographic atrophy (GA) therapies. This top ranking demonstrates well-informed patient representatives regarding GA's progressive nature and the mechanisms of existing treatments. It indicates a pragmatic desire for current therapies to halt disease progression. A previous podcast conducted in a patient with GA has also revealed that stability of vision is an acceptable outcome of GA therapies from a patient's point of view. Other top 10 ranked items regarding the visual outcome were improvement in vision (5^{th}) and delaying further loss of vision (8^{th}). These rankings provide valuable guidance for researchers and clinicians, highlighting the need to focus on therapies that can effectively stabilize vision while also pursuing interventions that might restore or enhance visual function. Additionally, the emphasis on delaying vision loss suggests that patients value treatments that can slow the disease's progression, even if complete stabilization is not achievable. A previous case report study in a patient with GA reported that patients with GA consider a delay in progression of GA a valuable goal. The patient expressed willingness to tolerate potential discomfort, anxiety, and inconvenience from regular intravitreal injections if it meant preserving vision for an extended period.[7]

The second highest ranked item was the ability to recognize faces. This finding closely aligns with most significant disease impact identified by the participants in the disease impact NGT discussion and ranking discussed earlier. This alignment demonstrates the critical importance of facial recognition to patients with geographic atrophy. Impaired face recognition in GA has been previously reported in the literature.[26] The inclusion of face recognition in both impact and expectation rankings mean two key things. First, it emphasizes the need to incorporate face recognition measures in GA clinical trials, ensuring that this crucial aspect of visual function is adequately assessed, and treatments are approved based on the improvement on real world activities rather than merely on the clinical improvement in vision. Second, it underscores the urgency of developing assistive technologies specifically designed to aid GA patients in recognizing faces. Several researchers and scientists are actively working on developing assistive devices for face perception in visually impaired individuals.[44–46] Such innovations could significantly enhance social interactions and overall quality of life for those affected by the condition. Other daily living activities that the participants ranked in the top 10 treatment expectations were able to walk independently (7^{th}), able to read (9^{th}) and able to drive (10^{th}). These findings suggest that enhancing functional abilities that are critical for independence and social engagement is paramount for patients. Consequently, future research and therapeutic interventions should prioritize these areas to address the comprehensive needs of individuals with GA, ultimately aiming to improve their autonomy and overall well-being.

Participants ranked one-time therapy as the third highest ranked treatment expectation. This demonstrates that patient organizations are aware of the burden of frequent injections affecting patient and caregiver employment, loss of leisure time and economic impact. Moreover, frequent injections have been found to be one of the main reasons for non-adherence to AMD treatment and poor visual outcome in neovascular form of AMD.[47] Several one-time therapeutic approaches are currently in development, including gene therapy,[48] optogenetics,[49] and stem cell therapy[50] for GA. These innovative treatments have shown promising results in early-stage clinical trials. We hope that larger, more advanced trials will confirm their efficacy, potentially leading to accessible treatments in the near future.

Participants ranked oral therapy as their fourth highest expectation. While oral administration offers greater convenience from a patient perspective, intravitreal injections provide good drug bioavailability in the retina and vitreous, minimal invasiveness, less systemic toxicity and the need for a relatively lower dose resulting in more rapid and effective disease management.[51] Notably, intravitreal injection also appeared among the top 10 treatment expectations, suggesting that patients generally accept this current delivery method despite its invasive nature. Furthermore, a previous study suggested that patients with GA are willing to take intravitreal injections as long as they can maintain their vision or delay disease progression.[7]

Limitations

There are a few limitations to this study. First, we had to conduct some steps of the Nominal Group Technique (NGT), particularly the ranking process, online rather than in-person as initially planned due to time constraints and the need for special assistance for visually impaired participants. While this approach may have improved accessibility and allowed participants to complete the task independently, it eliminated opportunities for real-time discussion and consensus-building. As a result, item interpretation and prioritization may have varied more between individuals, potentially increasing variability and reducing group convergence compared to traditional face-to-face NGT sessions. However, we are confident that the findings of our study are valid as various NGT method modifications are accepted in research,[10,19] and numerous studies have successfully employed and published results using modified NGT approaches.[52] Second, we included representatives from patient driven organizations who have had several years of experience in retinal disease patient advocacy but did not have the lived experience of GA themselves. This may have influenced some of the priorities and rankings but given the fact that these individuals regularly interact and speak on behalf of patients living with retinal degenerations, we are confident that their insights closely reflect those of individuals living with the condition. Third, four out of five participants were based in relatively wealthy countries with well-established social security systems. As a result, their perspectives may not reflect the experiences or challenges of individuals with GA living in low- or middle-income settings or those without adequate social support. However, a key strength of this panel is their extensive experience and broad perspective gained from working within leading patient organizations. Their roles have enabled them to understand a wide range of patient needs, engage with diverse stakeholder communities, and advocate effectively for changes in care and policy. Fourth, this study generated insights drawn from a small panel of patient organization leaders rather than a diverse sample of individuals living with GA. As such, our results may not fully generalize to the broader GA population or be readily reproduced in different demographic or clinical settings.

Conclusion

In conclusion, this study utilised the nominal group technique with representatives from patient-driven research funding and support organizations to provide valuable insights into the impact of GA and treatment expectations from current and future therapies for GA. The findings direct to several areas of improvement in GA care such as development of assistive technologies and rehabilitation strategies to maintain independence, integration of mental health support in GA care, focus on treatments that stabilise vision, delay further loss and potentially restore function, incorporate real world tasks and patient reported outcome measures (PROMs) as endpoints in clinical trials and explore one-time therapies and more convenient administration methods. As this study reflects advocacy perspectives rather than direct patient experience, future work with individuals living with GA is needed to further inform clinical and policy decisions.

Acknowledgments

We wish to thank the patient representatives from Retina Brazil, Retina South Africa, Retina Australia, Federation of Hereditary Retinal Dystrophy Associations of Spain and Retina Suisse for contributing to this study. We also thank Jeremy D'Souza for his assistance. This paper has been uploaded to Research Square as a preprint: https://www.researchsquare.com/article/rs-4957856/v1.

Funding

This work was funded by grants from Johnson and Johnson Innovative Medicine, Boehringer Ingelheim, and F. Hoffman La Roche.

Disclosure

The authors report no conflicts of interest in this work.

References

1. Fleckenstein M, Schmitz-Valckenberg S, Chakravarthy U. Age-related macular degeneration: a review. *JAMA*. 2024;331(2):147–157. doi:10.1001/jama.2023.26074
2. Holz FG, Strauss EC, Schmitz-Valckenberg S, van Lookeren Campagne M. Geographic atrophy: clinical features and potential therapeutic approaches. *Ophthalmology*. 2014;121(5):1079–1091. doi:10.1016/j.ophtha.2013.11.023
3. Taylor DJ, Hobby AE, Binns AM, Crabb DP. How does age-related macular degeneration affect real-world visual ability and quality of life? A systematic review. *BMJ Open*. 2016;6(12):e011504. doi:10.1136/bmjopen-2016-011504
4. Sarda SP, Heyes A, Bektas M, et al. Humanistic and economic burden of geographic atrophy: a systematic literature review. *Clin Ophthalmol*. 2021;15:4629–4644. doi:10.2147/OPTH.S338253
5. Paudel N, Brady L, Stratieva P, et al. Economic burden of late-stage age-related macular degeneration in Bulgaria, Germany, and the US. *JAMA ophthalmology*. 2024;142(12):1123–1130. doi:10.1001/jamaophthalmol.2024.4401
6. de Oliveira Figueiredo EC, Bucolo C, Eandi CM, de Oliveira Figueiredo EC. Therapeutic innovations for geographic atrophy: a promising horizon. *Curr Opin Pharmacol*. 2024;78:102484. doi:10.1016/j.coph.2024.102484
7. Enoch J, Ghulakhszian A, Dinah C, Sekhon M, Crabb DP, Taylor DJ. Towards a therapy for geographic atrophy: a patient's experience. *Patient Prefer Adherence*. 2023;17:299–310. doi:10.2147/PPA.S386662
8. Dunham RB NOMINAL GROUP TECHNIQUE*: a USERS' GUIDE. Available from: https://sswm.info/sites/default/files/reference_attachments/DUNHAM%201998%20Nomhttps://sswm.info/node/1852. Accessed September 13, 2024.
9. Harvey N, Holmes CA. Nominal group technique: an effective method for obtaining group consensus. *Int J Nurs Pract*. 2012;18(2):188–194. doi:doi:10.1111/j.1440-172X.2012.02017.x
10. Cantrill JA, Sibbald B, Buetow S. The Delphi and nominal group techniques in health services research. *Int J Pharm Pract*. 1996;4(2):67–74. doi:10.1111/j.2042-7174.1996.tb00844.x
11. Gallagher M, Hares TIM, Spencer J, Bradshaw C, Webb IAN. The nominal group technique: a research tool for general practice? *Fam Pract*. 1993;10(1):76–81. doi:10.1093/fampra/10.1.76
12. Potter M, Gordon S, Hamer P. The nominal group technique: a useful consensus methodology in physiotherapy research. *N Z J Physiother*. 2004;32(126).
13. Wallace SJ, Worrall L, Rose T, et al. Which outcomes are most important to people with aphasia and their families? an international nominal group technique study framed within the ICF. *Disabil Rehabil*. 2017;39(14):1364–1379. doi:10.1080/09638288.2016.1194899
14. Dewar A, White M, Posade ST, Dillon W. Using nominal group technique to assess chronic pain, patients' perceived challenges and needs in a community health region. *Health Expectations*. 2003;6(1):44–52. doi:doi:10.1046/j.1369-6513.2003.00208.x
15. Ismail R, Azuara-Blanco A, Ramsay CR. Consensus on outcome measures for glaucoma effectiveness trials: results from a delphi and nominal group technique approaches. *J Glaucoma*. 2016;25(6):539–546. doi:10.1097/IJG.0000000000000301
16. Haider S, Sadiq SN, Lufumpa E, et al. Predictors for diabetic retinopathy progression--findings from nominal group technique and Evidence review. *BMJ Open Ophthalmol*. 2020;5(1):e000579. doi:10.1136/bmjophth-2020-000579
17. Dahlmann-Noor A, Bonini S, Bremond-Gignac D, et al. Novel insights in the management of vernal keratoconjunctivitis (VKC): European expert consensus using a modified nominal group technique. *Ophthalmol Ther*. 2023;12(2):1207–1222. doi:10.1007/s40123-023-00665-5
18. Barabino S, Aragona P, Di Zazzo A, Rolando M. Barabino stefano, aragonaPasquale, di zazzoantonio, rolandomaurizio. updated definition and classification of dry eye disease: renewed proposals using the nominal group and delphi techniques. *Eur J Ophthalmol*. 2020;31(1):42–48. doi:10.1177/1120672120960586
19. McMillan SS, King M, Tully MP. How to use the nominal group and Delphi techniques. *Int J Clin Pharm*. 2016;38(3):655–662. doi:10.1007/s11096-016-0257-x
20. Manera K, Hanson CS, Gutman T, Tong A. Consensus methods: nominal group technique. In: Liamputtong P editor. *Handbook of Research Methods in Health Social Sciences*. Springer Singapore; 2019:737–750. doi:10.1007/978-981-10-5251-4_100.
21. Patel PJ, Ziemssen F, Ng E, et al. Burden of illness in geographic atrophy: a study of vision-related quality of life and health care resource use. *Clin Ophthalmol*. 2020;14:15–28. doi:10.2147/OPTH.S226425
22. Bakri SJ, Amoaku WMK, Altman D, et al. The MOSAIC study: a mixed-methods study of the clinical, emotional, and financial burden of geographic atrophy among patients and caregivers in the US. *Clin Ophthalmol*. 2024;18:2357–2368. doi:10.2147/OPTH.S455984
23. Loewenstein A, Trivizki O. Future perspectives for treating patients with geographic atrophy. *Graefes Arch Clin Exp Ophthalmol*. 2023;261(6):1525–1531. doi:10.1007/s00417-022-05931-z
24. Jamil MU, Waheed NK. Gene therapy for geographic atrophy in age-related macular degeneration: current insights. *Eye*. 2025;39(2):274–283. doi:10.1038/s41433-024-03463-w
25. Sivaprasad S, Tschosik EA, Guymer RH, et al. Living with geographic atrophy: an ethnographic study. *ophthalmol Ther*. 2019;8(1):115–124. PMID: 30706242; PMCID: PMC6393253. doi:10.1007/s40123-019-0160-3
26. Taylor DJ, Smith ND, Binns AM, Crabb DP. The effect of non-neovascular age-related macular degeneration on face recognition performance. *Graefes Arch Clin Exp Ophthalmol*. 2018;256(4):815–821. doi:10.1007/s00417-017-3879-3
27. Klauke S, Sondocie C, Fine I. The impact of low vision on social function: the potential importance of lost visual social cues. *J Optom*. 2023;16(1):3–11. doi:10.1016/j.optom.2022.03.003
28. Lane J, Rohan EMF, Sabeti F, et al. Impacts of impaired face perception on social interactions and quality of life in age-related macular degeneration: a qualitative study and new community resources. *PLoS One*. 2018;13(12):e0209218. doi:10.1371/journal.pone.0209218
29. Brody BL, Gamst AC, Williams RA, et al. Depression, visual acuity, comorbidity, and disability associated with age-related macular degeneration. *Ophthalmology*. 2001;108(10):1893–1900. doi:10.1016/S0161-6420(01)00754-0
30. Wei TS, Hu CH, Wang SH, Hwang Departments of KL. Fall characterictics, functional mobility and bone mineral density as risk factors of hip fracture in the community-dwelling ambulatory elderly. *Osteoporosis Int*. 2001;12(12):1050–1055. doi:10.1007/PL00004184
31. Lampinen P, Heikkinen E. Reduced mobility and physical activity as predictors of depressive symptoms among community-dwelling older adults: an eight-year follow-up study. *Aging Clin Exp Res*. 2003;15(3):205–211. doi:10.1007/BF03324501

32. Mitchell J, Bradley C. Quality of life in age-related macular degeneration: a review of the literature. *Health Qual Life Outcomes*. 2006;4:4. doi:10.1186/1477-7525-4-97
33. Jones N, Bartlett H. The impact of visual impairment on nutritional status: a systematic review. *British J Visual Impairment*. 2018;36(1):17–30. doi:10.1177/0264619617730860
34. Jones N, Bartlett HE. Comparison of the eating behaviour and dietary consumption in older adults with and without visual impairment. *Br J Nutr*. 2020;123(6):712–720. doi:10.1017/S000711451900312X
35. Kim ES, Kim Y, Yu SY, Kim M. Depression and anxiety in age-related macular degeneration. *Patient Prefer Adherence*. 2016;10:1853–1854. doi:10.2147/PPA.S118469
36. Dawson SR, Mallen CD, Gouldstone MB, Yarham R, Mansell G. The prevalence of anxiety and depression in people with age-related macular degeneration: a systematic review of observational study data. *BMC Ophthalmol*. 2014;14(1). doi:10.1186/1471-2415-14-78
37. Caballe-Fontanet D, Alvarez-Peregrina C, Busquet-Duran N, Pedemonte-Sarrias E, Andreu-Vázquez C, Sánchez-Tena MÁ. Quality of life and anxiety in age macular degeneration patients: a cross-sectional study. *Int J Environ Res Public Health*. 2022;19(2):820. doi:10.3390/ijerph19020820
38. Papalamprou M, Georgakopoulos CD, Pharmakakis N. Quality of life: investigating the impact of two major mental disorders, anxiety and depression, in patients with age-related macular degeneration. *British J Visual Impairment*. 2020;40(2):301–315. doi:10.1177/0264619620973709
39. Street RL, Makoul G, Arora NK, Epstein RM. How does communication heal? Pathways linking clinician–patient communication to health outcomes. *Patient Educ Couns*. 2009;74(3):295–301. doi:doi:10.1016/j.pec.2008.11.015
40. Scheffer M, Menting J, Boeije H, van Nispen R, van Dulmen S. Understanding healthcare communication in age-related macular degeneration care: a mixed-methods review of patients' perspectives. *Surv Ophthalmol*. 2024;69(4):646–660. doi:10.1016/j.survophthal.2024.03.002
41. Scheffer M, Menting J, Roodbeen R, et al. Patients' and health professionals' views on shared decision-making in age-related macular degeneration care: a qualitative study. *Ophthalmic Physiol Opt*. 2022;42(5):1015–1022. doi:doi:10.1111/opo.13016
42. Trott M, Driscoll R, Bourne R, et al. Mental health support across the sight loss pathway: a qualitative exploration of eye care patients, optometrists, and ECLOs. *Eye*. 2023;37(12):2554–2558. doi:10.1038/s41433-022-02373-z
43. Brunes A, Heir T. Social interactions, experiences with adverse life events and depressive symptoms in individuals with visual impairment: a cross-sectional study. *BMC Psychiatry*. 2020;20(1). doi:10.1186/s12888-020-02652-7
44. Calabrèse A, Aguilar C, Faure G, Matonti F, Hoffart L, Castet E. A vision enhancement system to improve face recognition with central vision loss. *Optometry Vision Sci*. 2018;95(9):738–746. doi:10.1097/OPX.0000000000001263
45. Márquez-Olivera M, Juárez-Gracia AG, Hernández-Herrera V, Argüelles-Cruz AJ, López-Yáñez I. System for face recognition under different facial expressions using a new associative hybrid model amαβ-KNN for people with visual impairment or prosopagnosia. *Sensors*. 2019;19(3):578. doi:10.3390/s19030578
46. Mocanu B, Tapu R, Zaharia T. DEEP-SEE FACE: a mobile face recognition system dedicated to visually impaired people. *IEEE Access*. 2018;6:51975–51985. doi:10.1109/ACCESS.2018.2870334
47. Ehlken C, Ziemssen F, Eter N, et al. Systematic review: non-adherence and non-persistence in intravitreal treatment. *Graefes Arch Clin Exp Ophthalmol*. 2020;258(10):2077–2090. doi:10.1007/s00417-020-04798-2
48. Csaky KG. Gene Therapy in the Treatment of Geographic Atrophy. *Int Ophthalmol Clin*. 2021;61(4):241–247. doi:10.1097/IIO.0000000000000387
49. Borchert GA, Shamsnajafabadi H, Bwj N, et al. Age-related macular degeneration: suitability of optogenetic therapy for geographic atrophy. *Front Neurosci*. 2024:18. doi:10.3389/fnins.2024.1415575.
50. Humayun MS, Clegg DO, Dayan MS, et al. Long-term Follow-up of a Phase 1/2a clinical trial of a stem cell-derived bioengineered retinal pigment epithelium implant for geographic atrophy. *Ophthalmology*. 2024;131(6):682–691. doi:10.1016/j.ophtha.2023.12.028
51. Enoch J, Ghulakhszian A, Sekhon M, Crabb DP, Taylor DJ, Dinah C. Exploring patient acceptability of emerging intravitreal therapies for geographic atrophy: a mixed-methods study. *Eye*. 2023;37(17):3634–3642. doi:10.1038/s41433-023-02571-3
52. Lee SH, ten Cate O, Gottlieb M, et al. The use of virtual nominal groups in healthcare research: an extended scoping review. *PLoS One*. 2024;19(6):e0302437. doi:10.1371/journal.pone.0302437