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European Glaucoma Society research priorities for glaucoma care

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ABSTRACT

Background/Aims The goal of health research is to improve patients care and outcomes. Thus, it is essential that research addresses questions that are important to patients and clinicians. The aim of this study was to develop a list of priorities for glaucoma research involving stakeholders from different countries in Europe.

Methods We used a three-phase method, including a two-round electronic Delphi survey and a workshop. The clinician and patient electronic surveys were conducted in parallel and independently. For phase I, the survey was distributed to patients from 27 European countries in 6 different languages, and to European Glaucoma Society members, ophthalmologists with expertise in glaucoma care, asking to name up to five research priorities. During phase II, participants were asked to rank the questions identified in phase I using a Likert scale. Phase III was a 1 day workshop with patients and clinicians. The purpose was to make decisions about the 10 most important research priorities using the top 20 priorities identified by patients and clinicians.

Results In phase I, 308 patients and 150 clinicians were involved. In phase II, the highest-ranking priority for both patients and clinicians was 'treatments to restore vision'. In phase III, eight patients and four clinicians were involved. The top three priorities were 'treatments to stop sight loss', 'treatments to restore vision' and 'improved detection of worsening glaucoma'.

Conclusion We have developed a list of priorities for glaucoma research involving clinicians and patients from different European countries that will help guide research efforts and investment.

INTRODUCTION

Glaucoma is among the leading causes of vision impairment in Europe and, in the recent past, we have seen the incorporation of technologies that aim to improve glaucoma care.¹ However, there are many questions regarding glaucoma management (eg, diagnosis, evaluation of risk, treatment, models of eye care) that remain unanswered.

The ultimate goal of health research is to improve patient care and outcomes. Thus, it is essential that research addresses questions that are important to patients and clinicians, and that the limited research funds are directed towards to these priorities.²⁻⁴

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Identification of research priorities needs to involve relevant stakeholders.

WHAT THIS STUDY ADDS

⇒ The top 10 research priorities for glaucoma have been identified.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ This study will influence future research strategies and funding opportunities.

Priority-setting initiatives including patients and clinicians can influence the direction of future research and funding at the policy, institutional and research team levels.^{5 6} Examples of pioneer priority-setting partnerships were between Asthma UK and the British Thoracic Society.⁷ Addressing topics or relevance to patients and clinicians help reduce research waste, as highlighted by Chalmers *et al.*⁸

The aim of this study was to develop a list of priorities for glaucoma research involving clinicians and patients from different countries in Europe. This initiative was supported by the European Glaucoma Society (EGS).

MATERIALS AND METHODS

A Steering Group was created among members of the EGS Scientific and Outcomes Committees. The purpose of the steering committee was to develop a protocol and facilitate work. We used a three-phase method, including a two-round electronic Delphi survey and a workshop (figure 1).^{9 10} The clinician and patient electronic surveys were conducted by email, in parallel and independently.

Phase I: electronic survey to identify patient and clinician research priorities

Patient organisations in Europe were identified through a process of peer knowledge and consultation among the Steering Group members' networks. Patients were also approached directly by their attending glaucoma specialist when attending a clinic to answer the survey. In phase I, patients were



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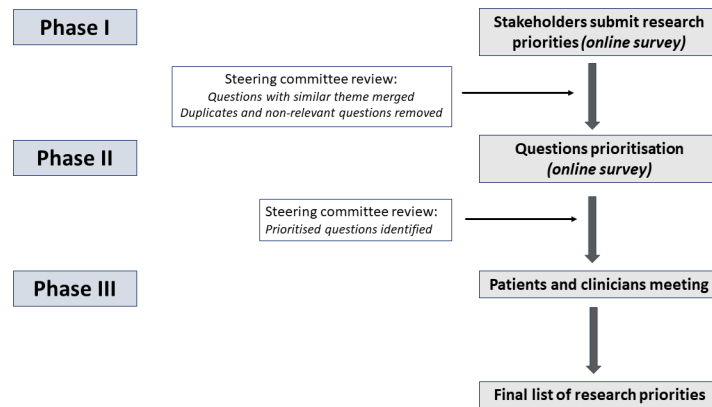


Figure 1 Flow chart describing phases of the study. Phases I and II were done in parallel among patients and glaucoma experts, independently.

contacted by email or by supporting staff in the clinic waiting area and were asked a series of questions regarding their demographics, glaucoma treatment, perception of glaucoma care and research priorities. The survey was distributed to patients from 27 European countries from 3 to 24 May 2022. The survey consists of 23 questions divided into 3 sections. The survey was translated into six languages: English, French, German, Spanish, Portuguese and Greek.

Regarding the clinicians research priorities, the invited participants were EGS members, ophthalmologists with expertise in glaucoma care. The survey was sent to active and emeritus members (total $n=788$).

Submitted research questions were translated (if not in English language) and analysed by steering committee members (AT, PF). Text mining was performed to identify the most frequently used keywords from the translated patient responses. A frequency of word table and word cloud were generated. Similarly, themed responses were then merged by the two steering committee members to ensure the meaning of the priorities was not distorted. The steering committee members initially worked independently and then for cases of disagreement reached a consensus on categorisation of each priority. No limit was placed on the number of research priorities each patient could suggest and all were included in the analysis. A similar process was followed for merging similarly themed responses obtained from the EGS member survey. All analyses were performed using R Studio (V.12.0, RStudio, PBC, Boston, Massachusetts, USA).

Phase II: electronic survey to rank patient and clinician research priorities

During phase II, EGS members and patients were invited, via email, to rank the questions identified in phase I using a Likert scale from 1 (lowest research priority) to 5 (highest research priority). Two reminders were sent via email over a 4-week period.

The steering committee reviewed the results. The mean rank score of the research priorities was calculated. Common and similar research priorities between clinicians and patients were merged but keeping the original description. The top 20 research priorities from both cohorts were selected. Similar questions were merged ensuring that the meaning of the questions was not distorted and keeping the original description to produce the top 20 joint research priorities carried forward to phase III.

Phase III: meeting with patients and clinicians to reach consensus on top 10 priorities

The final priority setting stage (phase III) was a 1 day workshop in Lisbon on 30 September 2022 facilitated by an expert researcher (NMCC). The purpose of the workshop was to exchange knowledge and to make decisions about the most important research priorities, based on the wide set of experiences represented by the workshop participants, using an adapted Nominal Group Technique (NGT). NGT is appropriate when small groups want to make decisions within a limited period of time. The technique allows for consideration of everyone's opinions through discussion and can incorporate both ranking and voting exercises. Participants were informed that the outcomes from the workshop would be shared with researchers and research funders. Eight patients and four clinicians from different European countries able to communicate well in English participated in the workshop. We tried to have a wide range of ages and gender balance among patients. In addition, there were two observers (current EGS President and EGS chair of European Union Committee) who did not participate in the discussions/rankings. The goal was to determine and rank the top 10 questions for research. All participants declared their interests. The role of the facilitator was to supervise group dynamics to ensure that all participant voices were heard and considered, to encourage debate and transparency and to help draw participants to consensus.

Before the workshop, participants were required to complete a 'preworkshop exercise', where they reviewed the 20 short-listed priorities identified by phase II. They were instructed to order these priorities from '1' (most important area for research in your opinion) to '20' (least important area for research in your opinion). At the workshop, following a short presentation and introduction, each participant was given the opportunity to share their 'top 3' and 'bottom 3' priorities with the group, and to explain the reasons for their rankings. These were noted by the facilitator. This completed the first part of the workshop. During a break, the workshop facilitator identified those priorities that were most often cited within the 'top 3' and 'bottom 3' by participants and arranged these in rough groups across a large table (using A4 cards printed with each priority, A–T). Other cited priorities, or those not mentioned by any participant, were arranged in a middle group. Participants then discussed the priorities and their order, until the top 10 priorities were ranked in order. On two occasions, a vote was taken to decide between the order of two priorities. The workshop discussions were recorded, with permission of participants.

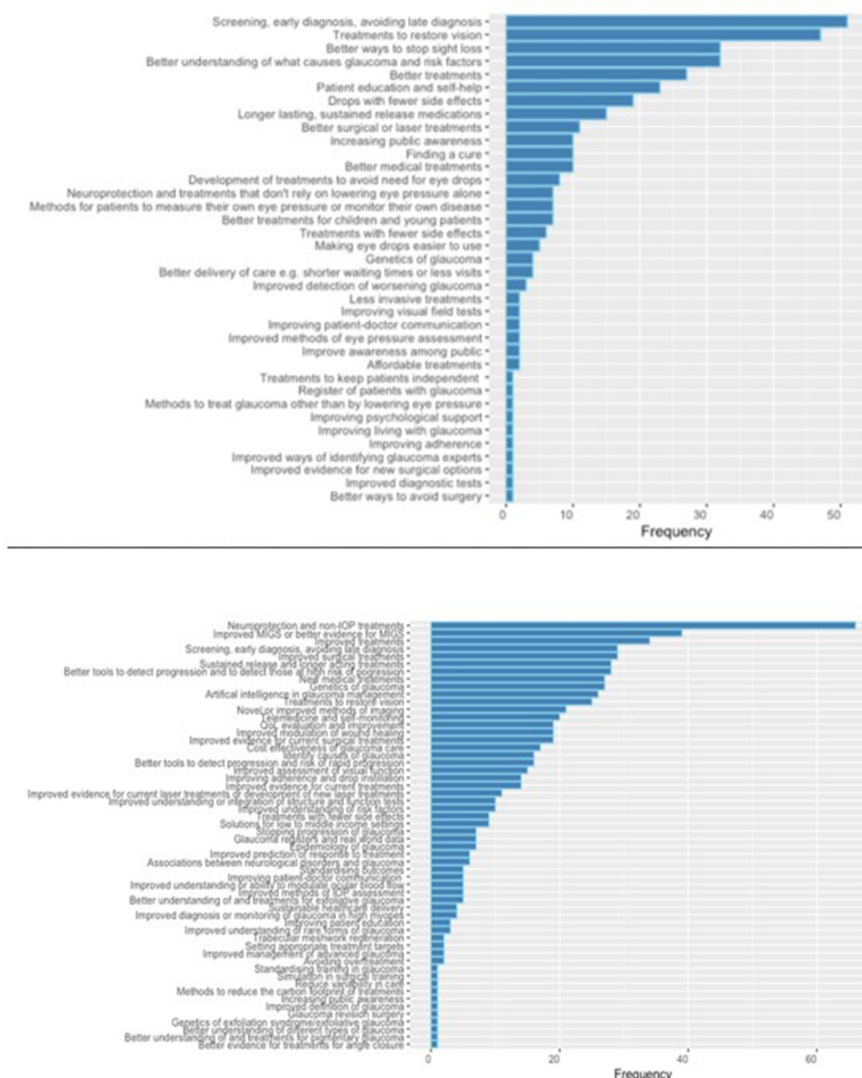


Figure 3 Top: frequency of research priorities proposed by patients responding to phase I. Bottom: frequency of research priorities proposed by clinicians responding to phase I.

has aimed at reflecting the priorities of patients and clinicians. Although we observed some overlap in topics, an important finding of our process is that patients and doctors have different priorities. For example, finding a cure was a top research priority by patients but not identified as such by doctors, possibly due to feasibility considerations. Patients’ priorities not shared by doctors included novel treatments to avoid the need for eye drops and to avoid surgery, and interventions to keep patients’ independence. Doctors’ priorities not considered important by patients included improved modulation of wound healing and the use of artificial intelligence.

In the final workshop, the two most important research priorities (treatments to stop sight loss and treatments to restore vision) were the ones identified by patients, reflecting the larger importance of patients’ voice. Some of the top 10 research priorities identified by clinicians (eg, use of artificial intelligence, improved modulation of wound healing) were not included in the final top 10 list after phase III discussions.

The strengths of this study are that it followed the robust standard methodology, and that we included a fairly large number of clinicians and patients from different European countries.¹¹ Modified electronic Delphi process is commonly used to reach

consensus and identify research priorities in diverse health areas.^{12–16}

Several frameworks have been used to guide the process of priority setting, including the James Lind Alliance Priority Setting Partnership (JLA PSP),¹⁷ Essential National Health Research (ENHR)¹⁸ and the Dialogue Model.¹⁹ The JLA PSP method convenes patients, carers and clinicians to equally and jointly identify questions about healthcare that cannot be answered by existing evidence that are important to all groups (ie, research needs).¹⁷ The identified research needs are then prioritised by the groups resulting in a final list (often a top 10) of research priorities. Non-clinical researchers are excluded from voting on research needs or priorities but can be involved in other processes (eg, knowledge synthesis). The ENHR method, initially designed for health research priority setting at the national level, involves researchers, decision-makers, health service providers and communities throughout the entire process of identifying and prioritising research topics.^{18 19}

This study has some limitations. First, the response rate among clinicians was low and thus may not be representative. It is possible a different design of the electronic survey or incentives may have improved the response rate. The patients who

Priority ID	Research priority	Ranking by patients and doctors (yellow highlight for patients)	Priority ID	Research priority	Ranking by patients and doctors (yellow highlight for patients)
A	Treatment to restore vision / Treatments to restore vision	#1 by patients #11 by doctors	K	Treatments with fewer side effects / Treatments with fewer side effects	#9 by patients #17 by doctors
B	Better ways to stop sight loss / Stopping progression of glaucoma	#2 by patients #3 by doctors	L	Improved diagnostic tests /	#10 by patients
C	Finding a cure	#3 by patients	M	Improved visual field tests / Novel or improved methods of imaging	16 by patients #16 by doctors
D	Improved detection of worsening glaucoma better tools to detect progression and risk of rapid progression	#4 by patients #1 by doctors	N	Better understanding of what causes glaucoma and risk factors / Genetics of glaucoma	#11 and #12 by patients
E	Development of treatments to avoid the need for eye drops	#5 by patients	O	Better surgical or laser treatments Improved surgical treatments Improved evidence for current surgical treatments Improved MIGS or better evidence for MIGS	#14 by patients # 2, 5, and 14 by doctors
F	Better ways to avoid surgery	# 6 by patients	P	Improved modulation of wound healing	#7 by doctors
G	Methods to treat glaucoma other than by lowering intraocular pressure / Neuroprotection and non-IOP treatments	# 17 by patients # 5 by doctors	Q	Screening, early diagnosis, avoiding late diagnosis	#18 by patients # 10 by doctors
H	Better medical treatment / New medical treatments	#7 by patients #8 by doctors	R	Treatments to keep patients independent	#8 by patients
I	Longer lasting sustained release medications / Sustained release and longer acting treatments	# 19 by patients # 18 by doctors	S	Improved management of advanced glaucoma	#4 by doctors
J	Treatments to keep patients independent	#8 by patients	T	Artificial intelligence in glaucoma management	#9 by doctors

Figure 4 Top 20 research priorities identified in phase II according to clinicians and patients (highlighted in yellow). MIGS, minimally invasive glaucoma surgery.

volunteered to participate in the survey may not be representative of the wider population of people with glaucoma. There may be an over-representation of patients with history of glaucoma surgery and presumably with severe stage of the disease, which may explain that the top research priority is ‘treatment to restore vision’. However, this was also among the top 20 priorities for clinicians which confirms the importance of this topic. The clinicians’ different preference is probably based on the understanding that the glaucoma damages are not reversible and research in this area will take a long time to be translated in improved outcomes. There was also a bias towards patients from the UK and France, with fewer patients included from other European countries. It is conceivable that differences in socioeconomic status, ethnicity, health beliefs, mode of healthcare provision and other factors could result in different priorities. Nevertheless, the research priorities identified in this study cover broad topics and to the best of our knowledge this was first attempt to identify research priorities in glaucoma across Europe.

Priority/Uncertainty
1. Better ways to stop sight loss/stopping progression of glaucoma.
2. Treatments to restore vision.
3. Improved detection of worsening glaucoma/better tools to detect progression.
4. New/Better medical treatments.
5. Better understanding of what causes glaucoma and risk factors/genetics of glaucoma.
6. Better surgical or laser treatments including improved MIGS or better evidence for MIGS.
7. Methods to treat glaucoma other than lowering IOP/neuroprotection and non-IOP treatments.
8. Improved diagnostic tests including 8(a) improved visual field tests/novel or improved methods of imaging.
9. Screening, early diagnosis, avoiding late diagnosis.
10. Treatments with fewer side effects.
MIGS, minimally invasive glaucoma surgery.

In conclusion, the results of this study can be used to guide research funding bodies and the wider research community in advancing the quality of care for patients with glaucoma. An effort to identify specific research questions and define study designs (population, intervention, comparator, outcome) to address the identified research priorities is currently under way.

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