

A scoping review of quality of life questionnaires in glaucoma patients

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Disclosure of funding

Funding for the ECOS-G meeting was provided by Laboratoires Théa.

Précis

Multiple questionnaires exist to measure glaucoma's impact on quality of life. Selecting the right questionnaire for the research question is essential, as is patients' acceptability of the questionnaire to enable collection of relevant patient-reported outcomes.

ABSTRACT

Purpose: Quality of life (QoL) relating to a disease and its treatment is an important dimension to capture. This scoping review sought to identify the questionnaires most appropriate for capturing the impact of glaucoma on QoL.

Methods: A literature search of QoL questionnaires used in glaucoma, including patient-reported outcomes measures, was conducted and the identified questionnaires were analysed using a developed quality criteria assessment.

Results: Forty-one QoL questionnaires were found which were analysed with the detailed quality criteria assessment leading to a summary score. This identified the top 10 scoring QoL questionnaires rated by a synthesis of the quality criteria grid, considering aspects such as reliability and reproducibility, and the authors' expert clinical opinion. The results were ratified in consultation with an international panel of ophthalmologists (N=49) from the Educational Club of Ocular Surface and Glaucoma representing 23 countries.

Conclusions: Wide variability among questionnaires used to determine vision related QoL in glaucoma and in the responses elicited was identified. In conclusion, no single existing QoL questionnaire design is suitable for all purposes in glaucoma research, rather we have identified the top 10 from which the questionnaire most appropriate to the study objective may be selected. Development of a new questionnaire that could better distinguish between treatments in terms of vision and treatment-related QoL would be useful that includes the patient perspective of treatment effects as well as meeting requirements of regulatory and health authorities. Future work could

involve development of a formal weighting system with which to comprehensively assess the quality of QoL questionnaires used in glaucoma.

Keywords: glaucoma, patient-reported outcomes measure, quality of life, questionnaire, treatment

List of abbreviations:

AGQ, Aberdeen Glaucoma Questionnaire; AMA, American Medical Association; CIGTS, Collaborative Initial Glaucoma Treatment Study; COMTol, Comparison of Ophthalmic Medications for Tolerability; ECOS-G, Educational Club of Ocular Surface and Glaucoma; FDA, Food and Drug Administration; GAL-9, Glaucoma Activity Limitation; Glau-QoL 36, Glaucoma Quality of Life-36; GQL-15, Glaucoma Quality of Life; HAS, Haute Autorité de Santé (French health technology assessment body); IOP, intraocular pressure; MOS SF-36, Medical Outcomes Study 36-Item Short Form; NEI-VFQ-25, National Eye Institute-Visual Function Questionnaire; NICE, National Institute for Health and Care Excellence; NIH, National Institutes of Health; PROM, patient-reported outcomes measure; QoL, quality of life; SIG, Symptom Impact Glaucoma score; TSS-IOP, Treatment Satisfaction Survey for Intraocular Pressure

INTRODUCTION

Glaucoma is a group of chronic diseases that cause progressive damage to the optic nerve and result in loss of visual field. Primary open-angle glaucoma, which accounts for three-quarters of all glaucoma cases, may be initially asymptomatic and difficult to assess, but ultimately can result in significant vision loss.¹ The global prevalence of glaucoma among people aged 40 to 80 years is 3.5%, with glaucoma estimated to affect 76 million in 2020 and projected to reach 112 million by 2040.²

When lost, sight cannot be regained; however, although blindness is a real risk, most people with chronic glaucoma will not experience serious visual impairment and will retain a good quality of life (QoL).³ Once loss of visual field is at an advanced stage a tipping point is reached at which loss of sight has significant impact on a patient's vision related QoL and psychological condition.⁴⁻⁶

Glaucoma negatively impacts on patients' self-reporting of visual functioning, mobility, independence, and emotional wellbeing, particularly in those with late stage disease.

In ophthalmology, it has been acknowledged that traditional clinical measures such as high contrast visual acuity do not reflect the patient's experience or the impact of disease on patients' lives.⁷ QoL measures may be the most important overall assessments of treatment effect for patients as they capture how their life experience is affected by interventions. Outcomes including impact on daily functioning, mobility, emotional wellbeing, and social activities are of paramount concern for people being treated for glaucoma. Measurement of QoL can be achieved using patient-reported outcome measures (PROMs), which are defined as: 'any report of the status of patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else'.⁸ PROMs are standardised, validated questionnaires, that are completed by patients to ascertain perceptions of health status, perceived level of impairment, disability, and QoL. PROMs allow for the systematic collection of data relating to QoL and can be helpful for monitoring health condition by assessing changes over time. Ocular disease and its treatment can have adverse effects on many aspects of a patient's health including systemic side effects, psychological, social, and

emotional impact. Thus, PROMs provide an instrument to understand the progression of ophthalmic disease and its overall impact on a patient's functional vision and QoL.

PROMs also offer a tool for audit or service evaluation of glaucoma services, and for designing glaucoma trials. PROMs are essential for clinical research and several decision makers, for example the Food and Drug Administration (FDA), mandate the assessment of PROMs in all clinical trials and endorse the use of PROMs as primary endpoints in glaucoma trials for new drug development.⁹

Consequently, PROMs are now often used as both primary and secondary endpoints in ophthalmic clinical trials.¹⁰⁻¹² PROMs provide a means for measuring treatment benefits by capturing concepts related to how a patient feels or functions with respect to his or her health or condition.^{8,9} The use of PROMs can allow a greater understanding of, and sometimes improve, clinical outcomes.

Nonetheless, in clinical glaucoma research there is a need for well-validated and easy to implement PROMs, as while numerous PROMs have been used there is no gold standard in clinical use for glaucoma.

In the 2017 clinical guidance for glaucoma, the National Institute for Health and Care Excellence (NICE) identified a research need for a new questionnaire to measure QoL in patients with glaucoma, recognising that uncertainty exists as to which PROM should be used to measure outcomes of glaucoma interventions (treatments that aim to lower intraocular pressure [IOP] i.e. a medication or surgical procedure).³ A suitable questionnaire would be helpful to inform healthcare professionals and policy makers about the effectiveness of glaucoma interventions on QoL benefit. To potentially achieve access to new medicines, a previous evaluation by health authorities (regulators and health technology assessment bodies) who need to be convinced of the clinical and QoL benefit of such new medicines, is required. The identification of a valid and responsive PROM in glaucoma would allow this questionnaire to be adopted in future clinical trials and glaucoma audits and would ensure meaningful comparisons between different interventions.³ This scoping review sought to identify the questionnaires most appropriate for capturing the impact of glaucoma on QoL. A secondary objective was to identify whether a difference between glaucoma treatments in terms of impact on

QoL could be quantified using an available questionnaire. To meet these objectives, a literature review and assessment of all available questionnaires, including PROMs, used to assess vision related QoL in glaucoma research was conducted.

METHODS

The analysis was conducted in three parts. Firstly, a literature search was performed to identify all relevant questionnaires, including PROMs, used to measure vision related QoL in glaucoma and a quality analysis grid was devised with which the instruments were analysed. The top 10 questionnaires most applicable to glaucoma were determined by assimilating the results of the grid analyses and the authors' expert clinical opinion. These 10 questionnaires were then further assessed by the wider group of experts of the Educational Club of Ocular Surface and Glaucoma (ECOS-G).

Part 1: Identification of questionnaires

A bibliographic search in electronic databases including PubMed and Embase (with an additional search on Google Scholar) was performed to identify relevant publications from database inception up until April 2019. The search terms used included, but were not limited to, glaucoma, quality of life, questionnaire, patient-reported outcomes measure, treatment (see also the document, **Supplemental Digital Content 1**, which contains full details of the search methodology).

Eligible studies for inclusion involved people diagnosed with glaucoma and ocular hypertension and were written in English (other languages were excluded). However, the questionnaire included could be written in another language if at least one other publication about the questionnaire was available in English (e.g., GlauQOL, Glausat). In addition, studies had to consider the impact of glaucoma/ocular hypertension/visual field loss on QoL using a QoL questionnaire or PROM. As most aspects of patient QoL were considered, studies included did not necessarily have to consider a glaucoma treatment effect (topical medication, surgery, or laser treatment). Scales such as the

Ocular Surface Disease Index (OSDI), Oxford, Efron, and McMonnies were excluded as their primary purpose is not to assess QoL, rather they are standard instruments used to establish a diagnosis of ocular surface disease. Other reasons for exclusion included: only abstract published, studies not including glaucoma or ocular hypertension patients, studies carried out in very local regions or in a specific population (ethnicity). We chose to focus on measuring QoL for the population with primary open angle glaucoma with the exclusion of all secondary glaucomas, which often exhibit more rapid change and greater vision loss.

Part 2: Qualitative and quantitative analysis round 1

To assess the questionnaires used to measure QoL in glaucoma patients, an evaluation grid of quality criteria with a rating scale was developed (see the document, **Supplemental Digital Content 2**, which contains the quality criteria grid template). The grid design was based on the literature and the authors' expertise when interviewing their patients (**Table 1**).¹³⁻²⁵

Some studies have already thoroughly assessed measurement properties of QoL questionnaires and have proposed lists of key quality criteria to address. All these studies and works were used as a guide to create the quality grid analysis. For example, The Scientific Advisory Committee of the Medical Outcomes Trust made review criteria which addressed 8 attributes or characteristics of an instrument:^{21,26}

- Conceptual and measurement model
- Reliability
- Validity
- Responsiveness
- Interpretability
- Alternative forms
- Respondent and administrative burden
- Cultural and language adaptations.

The COSMIN (COnsensus-based Standards for the selection of health status Measurement INstruments) study reached international consensus on definitions of measurement properties for health-related PROMs.²² This checklist was also used to implement our grid analysis. The COSMIN

checklist normally consists of nine boxes divided over three domains (reliability, validity, and responsiveness), with methodological standards for how each measurement property should be assessed:^{24,27}

- I. Reliability
 1. Internal consistency
 2. Measurement error
 3. Test-retest reliability
- II. Validity
 4. Content validity
 5. Structural validity
 6. Hypotheses testing
 7. Translation
 8. Cross-cultural validity
- III. Responsiveness
 9. Responsiveness.

Reliability is defined as the extent to which scores for patients who have not change are the same for repeated measurement under several conditions. Responsiveness is defined as the ability of an instrument to detect change over time in the construct to be measured.²² Validity is the extent to which scores on instruments are an adequate reflection of a gold standard and are consistent with hypothesis. Multiple types of test validity were incorporated into the grid analysis (**Supplemental Digital Content 2**) to determine the accuracy of the components of a measure, including:²⁵

- Content validity – the extent to which the content meets the pre-study hypothesis specifications,
- Criterion validity – the extent to which scores on instruments are an adequate reflection of a gold standard,
- Construct validity – the extent to which scores of an instrument are consistent with hypothesis, based on existing knowledge about the construct,
- Structural validity – the degree to which the scores of an instrument are an adequate reflection of the (uni)dimensionality of the construct to be measured using factor analysis to confirm the number of subscales present in a questionnaire,
- Cross-cultural validity – the degree to which the performance of the items on a translated or culturally adapted instrument is an adequate reflection of the performance of the items of the original version of the instrument.

The final grid analysis resulted in 3 main domains (instrument description, instrument development, psychometric evaluation) of quality criteria including assessments in the areas detailed in **Table 2**.²²

Note that a description of each item and methodological standards for how each item should be

assessed were detailed in the grid for the appraiser who evaluated the questionnaire; (see the document, **Supplemental Digital Content 2**, for this information which is contained in the quality criteria grid template).

From the completed quality criteria grid for the 41 QoL questionnaires, a further quantitative assessment was made by applying a score to the 28 qualities assessed in parts II and III (part II. instrument development and part III. psychometric properties). Note that part I contains qualitative descriptive parameters only that cannot be scored. The 4-point rating scale: ++ High; + Medium; – Low; 0 Not reported was converted to a numerical scoring value as follows: ++ = 2, + = 1, – = –1 and 0 = 0, allowing for a maximum total score of 52 (as not every parameter had an available score of 2, e.g., measurement error was rated from –1 to 1; see **Supplemental Digital Content 2** for rating guidance).

Part 3: Qualitative analysis round 2

For the second-round analysis by the ECOS-G experts of the top 10 scoring identified QoL questionnaires, a panel of international ophthalmologists from 23 countries, a simplified evaluation grid was developed (see **Table 3**) including eight quality parameters and using the same 4-point scoring scale: ++ High; + Medium; – Low; 0 Not reported.

RESULTS

Part 1: Identification of questionnaires

The study selection process is outlined in **Figure 1** (Flowchart). Ultimately, 64 publications and 7 reviews (71 publications) were identified from the literature relating to 41 different QoL questionnaires (general health, vision-specific and glaucoma-specific questionnaires) which were included in the qualitative analysis (see Table, **Supplemental Digital Content 3**, which lists the 41 QoL questionnaires included in the analysis).^{15,28-81}

Part 2: Qualitative and quantitative analysis round 1

Quality appraisal was conducted on 41 questionnaires using the quality criteria grid (see the document, **Supplemental Digital Content 2**, which contains the quality criteria grid template). From the detailed qualitative analysis of the 41 QoL questionnaires provided by completion of the quality criteria grid, a further quantitative assessment was made by calculating a total score for each of the 41 QoL questionnaires as presented in the **Supplementary Digital Content 4**. The score reflected a trade-off between the psychometric properties, the number and frequency of citations in the literature, the simplicity of the language used, length of the items, time taken to complete the questionnaire, whether the questionnaire is widely translated, etc. which was all captured within the quality criteria grid.

From assessment of the 41 questionnaires, [the top scoring 12 questionnaires were reviewed by the authors and the top 10 performing questionnaires agreed upon by consensus after discussion](#). Both the Glausat and SHPC questionnaires scored highly (within the top 10) but were not taken forward as either were not provided in English or only supported by a low level of evidence and so were considered not widely applicable (**Supplementary Digital Content 4**). A further qualitative assessment of the top 10 questionnaires is provided in **Table 4** as a summary of advantages and disadvantages for each questionnaire identified from a synthesis of reports in the literature and from views provided by the four authors. The results of the literature survey and top 10 questionnaire selection were submitted to a panel of international experts (ECOS-G) for a second round of review and validation.

Part 3: Qualitative analysis round 2

The top 10 questionnaires assessing vision related QoL for glaucoma patients were further assessed by the ECOS-G experts. The results of the second-round assessment using a simplified quality grid analysis validated the first-round results and are presented in **Table 5**.

DISCUSSION

From a review of the literature and evaluation of the array of questionnaires and PROMs used in glaucoma to assess QoL, the top 10 questionnaires most appropriate for use in QoL-related research in glaucoma were identified by the synthesis of a literature search and the authors' expert opinion (**Table 4**). The findings on the advantages and disadvantages of these questionnaires were a synthesis of literature reports and personal experience of the authors and are largely in agreement with earlier reviews.^{14,16,18,20,28,44} Each of the questionnaires selected is unique and presents interesting and useful parameters. Questionnaires and PROMs used to assess QoL in glaucoma are diverse and not all are disease-specific; the 10 that we identified include the best glaucoma-specific, vision-specific, treatment-specific, and general health questionnaires currently available. While this assessment identified glaucoma-specific scales to be most appropriate in the main for identifying disease-related impact on health, some vision-specific (NEIVFQ-25) and general-health (MOS SF-36) questionnaires were also identified that are appropriate for gathering holistic information, such as social and psychological dimensions. For the secondary study objective, the TSS-IOP and COMToI scales may be the most appropriate for determining differences between two treatments in terms of factors affecting QoL.

The questionnaires available are often complex with multidimensional scales that differ in the categories of assessments included. Consequently, it can be very difficult to comparatively assess the questionnaires as there are many parameters involved, and not all are assessing the same aspects of glaucoma care, e.g., some are more focused on the impact on daily activities, others on disease progression, while others on patient satisfaction. None of the questionnaires scored well across all set criteria in this analysis (in the simplified grid, **Table 5**). The scales identified also vary in the level of validation and sensitivity to measure appropriate outcomes. None capture all relevant information, so selection of a scale is a trade-off based upon the most important factors under investigation.

Generally, currently available questionnaires are not sufficiently sensitive to monitor changes in QoL over time, especially in patients at early stages of glaucoma. Moreover, differences in scores for

patients with stable or progressing glaucoma may only be evident on some questionnaires and not others. However, if QoL questionnaires are to be used to shape policy, secure funding, and manage patients, to be effective, they must be sensitive to disease progression. In this regard, the glaucoma-specific Glau-QoL 36, and the shorter versions GQL-15 and GAL-9 may be the best tools to detect deterioration in QoL correlating with disease progression, and for identifying differences between patients who have progressed and those who have not.¹¹ GQL-15 is reliable in assessment of mild, moderate, and severe glaucoma, and may be the most clinically relevant tool.^{16,44} The GAL-9 (GAL-10) may also offer advantages as a high quality questionnaire for assessing activity limitation and mobility that can be completed in a relatively short time.¹⁸ The Viswanathan questionnaire is also able to detect significant differences between patients with mild, moderate and severe glaucoma in terms of visual disability and correlates well with visual field indices.^{28,80} In comparison, the SIG is a questionnaire containing 43 items that is responsive to treatment effects and disease severity, but may be most appropriately used in research due to its length.^{16,20} The AGQ was designed to evaluate the effectiveness of glaucoma screening compared with no formal screening (opportunistic case detection) in a randomised clinical trial.⁷⁰ It was shown to discriminate between people without glaucoma and those with significant disease in a hospital-based sample population.⁷¹ However, while a promising questionnaire, it is lengthy (31 items) and requires further validation, so may be best suited to research purposes at this time.

For a general-health perspective, the MOS SF-36 although not found to correlate well with visual field indices does offer an assessment of the patient's general health and wellbeing by capturing both physical and mental health status and requires on average less than 10 minutes to complete.^{28,81,82} The NEIVFQ-25 also provides additional information regarding the general, psychological, and social effects of glaucoma and has high content validity.^{20,44,78} It is worth highlighting that our review did not directly consider performance-based measures where tasks are used to measure functional performance.⁸³⁻⁸⁵ Such approaches have been shown to be psychometrically valid and could be

useful along with hybrid methods that try to capture a measure of a person's so-called patient-reported outcome and experience (POEM).⁸⁶

Other questionnaires such as the Glaucoma Satisfaction Questionnaire (Glausat) and the Symptom Health Problem Checklist (SHPC) were identified as interesting options and were thoroughly considered but were subsequently excluded from the top 10 questionnaires due to either a lack of evidence or no availability in English language. The SHCP, an 18-item version of the Symptom Impact glaucoma Score (SIG) (which consisted of 43 items, 4-domain tool, in the Collaborative Initial Glaucoma Treatment Study [CIGTS]) proposed by Musch et al.,⁶⁸ was able to differentiate between disease severity on local eye and visual function ($p < 0.05$) and that patients who underwent trabeculectomy reported higher frequency of local eye symptoms than those with topical medications ($p < 0.01$). However, it should be tested in other clinical settings to demonstrate its general applicability. In a study using the Glausat,⁷² a 22-item Spanish questionnaire containing 7 dimensions (expectations and beliefs about treatment, ease of use, efficacy, undesired effects, impact on health-related quality of life, medical care, general satisfaction with treatment), the authors demonstrated that the questionnaire is reliable and structurally valid. No information is currently available on the stability of this questionnaire over time, sensitivity to change, ability to discriminate between pathological groups, or concurrent validity with other alternative measures. Although there is now a requirement to collect QoL data in studies, the recommendations of which questionnaire should be used in clinical trials remain unclear and the ones currently recognised by health authorities may not be relevant depending on the aim of the study.⁸⁷ QoL questionnaires may offer value when two interventions have been established to be equally efficacious in terms of a traditional outcome measure (e.g. IOP-lowering effect), but where differences are anticipated in terms of side effects, cost, or convenience. However, while questionnaires may have a very useful role in practice for reflecting patient perspectives, evidence suggests QoL questionnaires lack sensitivity at distinguishing between treatment groups or even versus placebo.¹¹ Nonetheless, QoL is a requirement of regulatory and health authorities when assessing the benefit of new treatments.

QoL assessment is mandated by the FDA and the French health technology assessment body (Haute Autorité de Santé; HAS) for chronic diseases.^{8,87} The US FDA endorses the use of QoL questionnaires (including PROMs) as primary endpoints in glaucoma trials, but also recognises the challenges in developing appropriate questionnaires.^{9,88} The HAS requires QoL data to be collected in double-blinded studies, including detailed methodology with validated questionnaires and scales and clinically relevant criteria in the study population of interest.⁸⁷ Our analysis has identified the two questionnaires TSS-IOP and COMTol that among the questionnaires currently available may be the most appropriate to reach health authorities' expectations of determining differences between two treatments in terms of factors affecting QoL. The TSS-IOP may be the highest quality tool for measuring topical treatment side effects.^{14,17} It is designed to assess patient satisfaction with topical ocular medications used to control IOP and has high content validity across eye drop classes.²⁰ In comparison with COMTol, the TSS-IOP employed a higher quality developmental process for identifying and selecting items and has better validity evidence. COMTol is designed to capture the frequency and 'bothersomeness' of common side effects of topical therapy for lowering IOP and the extent to which these side effects impact on QoL.²⁰ COMTol has been tested and used in the framework of a crossover design and can be adapted for other study comparative designs. It is also designed for comparison of topical medicines only; did not detect a difference between eye drops and selective laser trabeculoplasty in one study.⁵² Nonetheless, it is a questionnaire recognised by the HAS for capturing QoL data in clinical trials.

It is a limitation of our study that a formal weighting system is not available with which to comprehensively assess the quality of QoL questionnaires used in glaucoma. As the process undertaken for our assessment was very detailed, and thus time consuming, one limitation of the study is that due to resource constraints not all questionnaires were screened by all experts. The top scoring 12 questionnaires were reviewed by the authors and the top 10 performing questionnaires agreed upon by consensus after discussion. In our opinion, the 10 selected most broadly represent QoL questionnaires ideally suited to measure aspects of QoL associated with glaucoma treatment. As

this was a Scoping review, future work could entail a more detailed assessment of QoL questionnaires including development of a formal weighting system with which to comprehensively assess the quality of QoL questionnaires used in glaucoma.

In summary, wide variability in the questionnaires used to determine QoL in glaucoma and in the responses elicited was identified. No single existing QoL questionnaire design is suitable for all purposes in glaucoma research, rather we have identified the top 10 from which the questionnaire most appropriate to the study objective may be selected. Development of a new questionnaire that could better distinguish between treatments in terms of vision and treatment-related QoL would be useful that includes the patient perspective of treatment effects as well as meeting requirements of regulatory and health authorities. The desirable attributes of a new glaucoma-specific QoL questionnaire would include ease of use (short, self-administered, simplicity of language), with an easily understandable scoring system and high reliability and reproducibility, sensitivity, and validity. The mode of administration may influence patient responses and is worth considering. Self-administered questionnaires (PROMs) are to be preferred, while a lengthy questionnaire, complex language, or distorted adaptations due to translation issues can be burdensome for the patient. The effort required to provide a full response to the questionnaire and the time taken to complete are important to consider when making the questionnaire patient friendly. To be effective, the questionnaire needs to be understandable to its respondents. A recent study determined that over half of questionnaires commonly used in ophthalmology require a reading comprehension level better than that recommended by the American Medical Association (AMA) and National Institutes of Health (NIH) as appropriate for patient materials.⁸⁹ In future, item banking and computerised adaptive testing methods may address the multiple limitations of paper-pencil questionnaires, customise their administration, and have the potential to improve healthcare outcomes for patients with glaucoma.⁹⁰ The collection of patient-reported QoL data will enable better understanding of vision related QoL that can improve patient–physician interaction and enhance treatment adherence

by providing patient-centric care that can ultimately optimise the long-term prognosis for glaucoma patients.

Acknowledgements

†Members of the Educational Club of Ocular Surface and Glaucoma (ECOS-G) – *Austria*: Martin Emesz, Cornelia Hirn, Anton Hommer, Semira Kaya, Lukas Kellner, Markus Lenzhofner, Clemens Vass; *Belgium*: Natalie Collignon, Veva de Groot, Bernard Duchesne, Philippe Kestelyn, Carina Koppen, Ingeborg Stalmans, Anna-Maria Stevens; *Bulgaria*: Bissera Samsonova; *Croatia*: Mia Zoric-Geber; *Denmark*: Miriam Kolko, Lars Loumann Knudsen, John Thygesen; *Finland*: Niko Setälä, Eija Vesti; *France*: Christophe Baudouin, Frédéric Chiambaretta, Vincent Daien, Antoine Rousseau, *Germany*: Reinhard Burk, Carl Erb, Thomas Kaercher, Ines Lanzl, Elisabeth Messmer, Philipp Steven; *Greece*: Eleftherios Anastasopoulos, Konstadinos Boboridis, Andreas Katsanos, Dimitris Kyroudis, Fotis Topouzis; *Ireland*: Conor Murphy; *Italy*: Pasquale Aragona, Michele Iester, Carlo Enrico Traverso; *Mexico*: Hannel Maldonado, Arturo Ramirez Miranda, Concepcion Santacruz, Nalley Ramos; *Netherlands*: Hans Lemij; *Norway*: Per Klyve, Sten Raeder; *Poland*: Marta Misiuk-Hojlo, Dominik Uram, Joanna Wierzbowska, Edward Wylegala, Anna Zaleska-Zmijewska; *Portugal*: Luis Abegao Pinto; Nuno Alves, Antonio Figueiredo, Antonio Melo, Tiago Monteiro; *Russia*: Aleksandr Kuroyedov, Alla Lisochkina, Dmitry Maychuk, Sergey Petrov, Tatyana Safonova; *Slovenia*: Barbara Cvenkel; *Spain*: Alfonso Anton, José-Manuel Benitez-Del-Castillo, Susana Duch, David Galarreta, Francisco Muñoz-Negrete; *Sweden*: Gauti Johannesson, Gysbert van Setten; *Switzerland*: Frank Blaser, Milko Iliev, Martina Knecht-Bosch, Gordana Sunaric Megevand, Barbara Wagels; *United Kingdom*: Ejaz Ansari, Keith Barton, David Crabb, Gus Gazzard, John Salmon, Alex Shortt, James Tildsley, Sathish Srinivasan, Sokratis Zormpas; *Ukraine*: Galyna Drozhzhina, Marina Karliychuk, Iryna Shargorodska.

Editorial assistance was provided by Lisa Buttle, PhD of Chill Pill Media/Phase 3 Medical Communications Ltd. and funded by Laboratoires Théa.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

G. Gazzard and his team receive funding support from UK NIHR-HTA; Glaucoma-UK (formerly IGA); British Council for Prevention of Blindness; Moorfields Eye Charity; Fight for Sight.

M. Kolko receives research support from Thea, LeoPharma; speaker fees from Allergan, Santen, Thea; consultancy fees from Thea.

M Iester receives speaker fees from Thea, Omikron, Santen, Doc; consultancy fees from Thea; meeting travel grant from Allergan.

D. Crabb reports other funding from Centervue; grants from Allergan, Apellis; personal fees from Roche, THEA; grants and personal fees from Santen, outside the submitted work.

Funding

Funding for the ECOS-G meeting was provided by Laboratoires Théa.

Authors' contributions

All authors contributed to and approved the final manuscript.

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Figure and Tables: Titles and legends

Figure 1. Study selection process

Figure 1 legend: [†]Explanation provided in Methods section Part 1. OHT, ocular hypertension; OSDI, Ocular Surface Disease Index; QoL, quality of life

Table 1. Summary of the process adopted to create the quality criteria analysis grid

Table 2. Quality criteria analysis grid domains and parameters assessed for each quality of life questionnaire

Table 3. Simplified quality criteria analysis grid for assessing quality of life questionnaires used in glaucoma

Table 4. The top 10 questionnaires identified as appropriate for use in vision related quality of life research in glaucoma: advantages and disadvantages

Table 5. Results of the simplified quality criteria grid (8 parameter) assessment of the top 10 questionnaires used in glaucoma to determine vision related quality of life

List of Supplemental Digital Content

SDC 1. Word document. List of keywords used for research algorithms

SDC 2. Word document. Quality criteria grid template used to assess quality of life questionnaires in glaucoma patients

SDC 3. Word document. Table. Questionnaires used to assess quality of life in glaucoma identified by the literature search and included in the qualitative analysis (N=41)

SDC 4. Excel spreadsheet. Table. Summary scores calculated for the 41 quality of life questionnaires