

## Patient Outcomes

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### Executive summary

**Background/Introduction:** At the EGS members' meeting in London September 2017, a workshop was held in order to agree outcome measures to judge glaucoma care quality. This report concerns outcome measures important from the patient perspective, as the reduced vision due to glaucoma is a debilitating condition for patients. It affects the patients' ability to perform daily activities and has a great impact on a person's quality of life. The patient's perspective is, therefore, important in order to fully understand the impact of glaucoma and its treatment. It should thus be more integrated in clinical practice and research evaluations as one of the most important outcome measures for the patient.

**Objectives of the workshop:** The goal of glaucoma treatment stated by the EGS is "to maintain the patient's visual function and related quality of life, at a sustainable cost". In order to achieve this treatment goal, we need the input and action from the patients who are the care receivers. We need key outcome metrics that measure outcomes important to patients. They need to be measurable, relevant and practical.

**Processes used to achieve the objectives:** Participants of the workshop (patients and clinicians) were divided into smaller groups which were facilitated by the workshop leaders. In a series of exercises and group discussions, the workshop participants agreed on the 5 most relevant outcomes.

**Summary of the findings:** the five patient outcome measures deemed most important by the participants were: 1) Vision related quality of life, 2) understanding the risk of visual disability and blindness, 3) Side effects of treatment, 4) Empathy, Trust and Feelings, and 5) knowledge/understanding of glaucoma.

1) The vision related quality of life is crucial from the patient's perspective. To assess this we agreed on taking the 5 best questions out of the available questionnaires on vision related quality of life. A SIG needs to be formed and validation, translation and distribution performed.

2) The risk of visual disability and blindness is equally important. Patients need to be informed of their risk for visual disability to prevent worries and fears, and to be able to cope with the disease.

3) Side effects of treatment are central for the patients and their quality of life. This is addressed by creating an app, scoring the 1-5 most frequent side effects. A SIG should be founded. A pilot app should be generated and finalized.

4) Fundamental for the patient as well are empathy, *understanding*, trust and feelings towards the physician. An interactive patient survey should be created, a 'voting system', as well as a questionnaire.

5) Education of the patients about their condition is imperative to them. This should be validated by five waiting room questions. Patient focus groups can be asked to develop these questions in collaboration with glaucoma patient societies. These need to be validated and implemented. Audit and, based on findings, set up an education plan.

**Recommendation for refinement and implementation:** The patient's perspective is most important in order to fully understand which facets of glaucoma and its treatment are most relevant for their impact on the patient. The identified outcomes then should be measured routinely in clinical practice and targeted in research.

## **Workshop report**

### **Background**

Reduced vision due to glaucoma is a debilitating condition substantially affecting a patient's ability to perform daily activities, such as driving, performing household tasks and reading. They affect the person's quality of life (QoL). Thus the patient's perspective is crucial in order to assess the impact of glaucoma on the patient, and should be considered more in clinical practice and research evaluations.

At the EGS members' meeting in London September 2017, a workshop was held in order to identify outcome measures to judge glaucoma care quality. This report concerns outcome measures related to the patients' perspective. The goal of glaucoma treatment stated by the EGS is "to maintain the patient's visual function and related quality of life, at a sustainable cost".

In order to achieve this treatment goal, we need the input and action from the patients who are the care receivers. We need to make sure that the patients have the information they want in an understandable form. Glaucoma care should *reduce the vision loss and impairment of QoL and help patients adapt to vision loss when it has occurred*. Fear of blindness or false positive diagnosis needs to be avoided.

### **Objectives**

In order to gain knowledge about the effectiveness of the health care we provide to our patients, we need patient-oriented outcome measures. We need key outcome metrics that measure the patient's experience of care for treatment of glaucoma and outcomes important to them. The objectives of this workshop was to come up with patient-oriented outcome measures that are measurable, practical and relevant. The objective was to establish how these outcomes can be assessed and what needs to be done in future to evaluate and implement routine measurement of the outcomes.

### **Processes used to achieve the objectives**

Participants of the workshop (clinicians and patients) were divided into smaller groups which were facilitated by the workshop leaders. In a series of exercises and group discussions, the workshop participants discussed and debated potential outcome measures that were put forward through brainstorming. The most important ones were then selected to share with other groups in the workshop. Finally, and after further discussion, the key outcome measures were chosen. These were taken together discussed and the 5 most relevant outcomes among the different groups were shortlisted.

### **Summary workshop findings**

The five most important patient outcome measures deemed by the participants were the following:

#### **Outcome 1: Vision related quality of life**

Vision-related quality of life is a crucial and possibly the most important outcome from the patients' perspective. Discussions on whether to use 'quality of life' or 'vision-related quality of life' as the outcome resulted in agreement on 'vision-related quality of life'. It better reflects the success of eye treatment and is eye specific.

To assess and to measure this, and facilitate widespread implementation of routine measurement, we agreed on taking the 5 best questions out of the available questionnaires on vision related quality of life. To achieve this and create this measurement tool, a SIG needs to be formed doing literature review to decide on which questions to choose. The QoL evaluation instrument needs then to be validated, translated into the different languages and distributed. It should be then implemented into daily clinics and used in studies as an outcome.

### Outcome 2: Understanding of risk of visual disability and blindness

Understanding the risk of visual disability and blindness is equally important for the patient in order to cope with his/her disease. Patients need to be informed of their risk for visual disability to prevent unneeded worries and fears and to be able to cope with the burden of having a sight-threatening disease.

To assess the risk of visual disability and blindness, one needs to evaluate the visual field damage at baseline, the rate of progression and the age of the patient, as recommended by EGS guidelines. With these factors, the risk of visual disability within a patient's expected lifetime can be estimated.

Recommendations are needed from the EGS on how to communicate risk to patients. Test frequency should be customized according to the stage of the disease of the patient (patient friendly testing, objective tests, home based test). Clinicians should be educated in communication with patients. A training video could be established. Moreover, visual field devices adjusted to patients needs could be established and the test should be evaluated later on.

### Outcome 3: Side effects

Side effects of treatment are important for the patients and their quality of life.

This should be assessed by creating an app scoring the 1-5 most frequent side effects. To achieve this a SIG should be founded to look for the 5 most frequent side effects. A pilot app should be generated and finalized. Audit would determine whether ratings (local and systemic side effects) improve with feedback to clinicians.

### Outcome 4: Empathy, Trust and Feelings

Fundamental to the patient is empathy, trust and feelings towards the physician.

An interactive patient survey should be created, 'tinder for physicians', a voting system, as well as a questionnaire. The query needs to be formatted and simple feedback devices created. Those should be validated and implemented into clinics.

### Outcome 5: knowledge/understanding of glaucoma

Education of the patients is imperative to them. This should be validated by 5 waiting room questions. Patient focus groups can be asked to develop those questions in collaboration with glaucoma patient societies. These then need to be validated and implemented. Audit and, based on findings, set up an education plan (Patient Education assessment tool). Waiting room video.

Glaucoma quiz 5 questions, generate question bank, baseline knowledge assessment and interventions to improve education.

### **Recommendation for refinement and implementation**

The patient's perspective is very important in order to better understand the impact that different variables of care have on the patient and his/her quality of life. Furthermore, it is imperative that the profession providing the care knows what the patient finds most relevant. As stated before, the treatment goal of EGS is "to maintain the patient's visual function and related quality of life, at a sustainable cost". In glaucoma care, 'visual function' and 'cost' are prioritised and often discussed, but the patient's quality of life unfortunately receives too little attention.

The results of this workshop highlights five patient outcomes deemed essential by the glaucoma specialists and patients participating in the workshop. In short, these include 1) vision related quality of life, 2) understanding of the risk of visual disability and blindness 3) side effects of treatment, 4) empathy, trust and feelings, and 5) knowledge/understanding of glaucoma.

A final conclusion of the workshop is that a vital part of glaucoma care improvement is that the patient perspective

will be more integrated in clinical practice and research evaluations.

### **Action points**

- Create a SIG to select 5 best questions from available questionnaires on vision related quality of life.
- Recommendation from EGS to improve information to patients on their risk (or lack of risk) of visual disability/blindness
- Establish a SIG to create an app scoring the 1-5 most frequent side effects
- Establish SIG to plan improved patient education. The SIG together with patient focus groups in different countries collaborate with the aim to create and validate a question bank to assess patient knowledge and improve education.