

Workshop Report – Group 2 (Societal Outcomes)

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Executive Summary

Objective

The main objective of the ‘Societal Outcomes’ workshop was to identify outcome measures of glaucoma care to measure care quality from the perspective of Society and develop draft implementation plans for their routine collection.

Summary of Findings

The main findings expressed by the group on the society values involved:

- (1) Quality of life (measured with a specific and widely accepted questionnaire)
- (2) Stage at presentation (no consensus reached on the best staging system: visual field indices and/or visual acuity)
- (3) Cost-effectiveness (with incremental cost-effectiveness ratio (ICER) and quality-adjusted life-year (QALY) for example)
- (4) Visual disability (measured by visual field indices, visual acuity, certification of visual impairment (CVI) eligibility and driving ineligibility criteria.

Recommendations and Action Points

- To create registers with each of the criteria mentioned above
- To incorporate the registers into public health published reports
- To develop EMR standards for key measurable outcomes
- To have an automated data capture system

Meeting report

Background

The most recent EGS members’ meeting was held in September 2017 at Church House, London, U.K. During this meeting a number of workshops were held each involving a different team of around forty EGS members and Next Generation Partnership (NGP) participants led by a trio of facilitators and helpers. The latter were asked to produce a report for the workshop they covered during the meeting. These reports will be used to produce a ‘White Paper’, which will be circulated to national glaucoma societies for their review. Input from the societies will be used to map out milestones for implementation throughout Europe.

Objectives

The main objective of the session was to identify outcome measures and develop draft implementation plans for three specific outcome perspectives related to glaucoma diagnosis and treatment, namely 1) patient, 2) clinical and 3) societal.

The specific objective of this particular workshop was to achieve consensus on key outcome metrics and headline implementation plans for EGS and national societies with particular focus on the society values relevant for successful diagnosis and treatment of glaucoma.

Processes used

Around forty participants were assigned to this workshop group. They were divided into four tables (belonging to four geographic groups of about ten people each).

The initial step involved identification of key outcomes in the 'societal' domain and the metrics by which each outcome could be measured. All workshop participants were asked to identify their top two outcome measures by writing outcome metrics on a card. Each participant was then initially invited to share their views with others on the table using a 'ONE GRIDCARD RULE'. All groups were then shown a synthesis and review of data collected from all meeting participants (captured by the use of SLIDO interactive software during the previous plenary session and distributed via specifically compiled data hand-outs from that session). Workshop participants were subsequently asked whether the additional data would modify their views.

Each table was then asked to synthesise their top four outcome measures, and to prioritise them from one to four. Similar outcome measures were clustered in columns on a board according to overlapping ideas and clarification of the less well-identified metrics was also encouraged. The whole group was then asked to reflect on these key metrics and each participant instructed to 'dot vote' for their three priority outcome measures. This was followed by the drafting of implementation plans which would include milestones needed to achieve the routine measurement of the outcomes. These plans were then shared with the wider group of forty and a synthesis of the four individual group plans was produced by the helpers and presented at the next day plenary session to all EGS meeting participants.

Summary of Findings

The session produced a significant amount of debate and ideas, with many interesting and different views expressed both between and within tables. The main and common findings expressed by the group on the society values relevant for successful diagnosis and treatment of glaucoma involved (1) quality of life, (2) stage at presentation, (3) cost-effectiveness and (4) visual disability.

With regards to quality of life, the importance of measuring this outcome was discussed at length and agreement reached on the need for a specific and widely accepted questionnaire. The group also agreed on the necessity for both vision specific *and* general health tools to assess quality of life related to glaucoma. The glaucoma 'stage' at presentation was also considered to be important by the group. Measuring this outcome by the use of various classifications (e.g. the Brusini scale) was deemed important but consensus was not quite reached on the best way of staging glaucomatous visual loss to assess societal factors. It was certainly felt however that visual field testing (especially mean deviation and visual field indices) and visual acuity were crucial measurable factors needed to do this.

Cost-effectiveness was also deemed to be an essential outcome to be measured when considering societal factors. The group felt that measures such as the incremental cost-effectiveness ratio (ICER) and quality-adjusted life-year (QALY) are very useful but other resources and utilization studies might be needed in addition. The measurement of visual disability was also considered imperative by the group. This would naturally also include visual field and visual acuity data but also require societal factors such as certification of visual impairment (CVI) eligibility and driving ineligibility criteria. The challenge will always be putting together these measurable criteria and standardizing them across different countries and health systems.

Recommendations and Action Points

The recommendations and action points from this group session were streamlined into a one-year, two-year and five-year plan.

It was felt that within the first year, interest groups within the EGS could be formed to create registers with each of the criteria mentioned above. The extraction of data from electronic medical records (EMR) would be essential to implement this. The development of a more specific and useful QALY instrument would also aid this goal, for

example using patient reported outcomes measures (PROMS) and patient reported experience measures (PREMS) and/or auditing the reliability of these registers.

The second year would then involve the implementation of the above-mentioned registers with their incorporation into public health published reports. The development of EMR standards for key measurable outcomes and the setting up of a 'Reading Centre' would be important in implementing this.

Ultimately, within five years, the aim would be to have in place an automated data capture system and a standardised reporting EMR system. The group also felt that modification of clinical and social practice patterns, the use and interpretation of the 'Big Data' and of population-based intervention studies would be key to establishing the importance of measuring the societal factors and outcomes related to the glaucoma induced visual disability burden across Europe.