

Glaucoma Patient Day: Involving Patients, Improving Care

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## INTRODUCTION

Glaucoma is the leading cause of irreversible blindness worldwide. Approximately 500,000 people in the UK suffer from glaucoma, of which 67% remains undetected.

It is well known that uptake of care and research improves when patients are made partners in their condition. Patient days foster a unique partnership between patients and healthcare professionals.

## AIM & METHODS

#### Aims

The aims of the Glaucoma Patient Day (GPD) were to facilitate a two-way learning experience between patients and healthcare professionals about the concerns, expectations and

research priorities of patients.

#### Methods

Glaucoma patient advocates were part of the planning committee and helped plan the structure of the day and topics for short talks. Evaluation posters and pre- and post-event questionnaires were used to capture concerns of patients, attitudes to medication and research priorities.

On the day glaucoma consultants delivered a series of short talks on topics selected by the patients, and patient advocates reflected on how they felt when they were first diagnosed, underwent surgery and participated in research.

#### RESULTS

296 delegates attended the day.

• Prior to the day 47% of all patients had never met anyone with glaucoma; at the conclusion, 100% of patients and supporters had met another person with glaucoma.

• After the day, respondents ascribed significantly greater importance to the usefulness of meeting fellow glaucoma patients (Wilcoxon signed-ranked test p<0.001, n=158) and felt their understanding of glaucoma had significantly improved (Wilcoxon signed-rank test p<0.001, n=142) (Figure 1).

• The evaluation posters showed that quality of life was most affected by fear of losing vision (46%) and impact on driving (14%)(*figure 2a*).

• Patients voted for research to focus on finding 'a cure' (45%) and 'the cause' (29%) of glaucoma (*figure 2b*).

Latanoprost was the best tolerated ocular hypotensive eyedrop.

• The day resulted in the creation of the new Moorfields Glaucoma Research Community, with over 100 patients who have formally registered an interest in being involved in research design, management, conduct and dissemination of results.

## EVALUATION QUESTIONNAIRES

How important is it for you to meet patients with glaucoma?

How much do you understand about glaucoma?

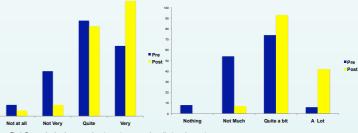


Fig 1: Bar graph showing pre- and post- event responses by patients and supporters

## **EVALUATION POSTERS**





Fig 2a: Evaluation poster: showing quality of life is most affected by 'fear of losing vision' Fig 2b: Patients voted for finding the 'cause' and 'cure' for glaucoma to be made research prioriti

## ART WORK BY GLAUCOMA PATIENTS



Fig 3a: Artwork by patient showing timeline since being diagnosed with glaucom Fig 3b: Artwork by patient showing how arcuate scotomas impact her life

#### CONCLUSIONS

• The Glaucoma Patient Day strengthened the bonds of partnership between patients & patients , patients & carers, patients & healthcare professionals and between health care professionals themselves.

•The event has resulted in the creation of an invaluable research community focused on Glaucoma.

•Patient engagement days are an important source of consultation and learning with patients in helping to deliver care and research.

BLIND

FIGHT

SIGHT

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> **NHS** National Institute for Health Research





