


# An online glaucoma educational course for patients to facilitate remote learning and patient empowerment

Sana Hamid <sup>1</sup>, Neda Minakaran,<sup>2</sup> Chinedu Igwe,<sup>3</sup> Alex Baneke,<sup>3</sup> Marcus Pedersen,<sup>4</sup> Rashmi G Mathew<sup>5</sup>

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## ABSTRACT

In both face-to-face and teleophthalmology glaucoma clinics, there are significant time constraints and limited resources available to educate the patient and their carers regarding the glaucoma condition. Glaucoma patients are often not satisfied with the content and amount of information they receive and have demonstrated a substantial lack of knowledge regarding their condition. Innovative educational tools that facilitate accessible digital remote patient education can be a powerful adjunct to empower patients in becoming healthcare partners. We describe the development of a free, comprehensive, multimodal online glaucoma patient education course for adults with glaucoma, their family and friends and carers, with the aim of providing a readable resource to aid remote learning and understanding of the condition. The working group for the development of the course comprised of consultants, medical practitioners and education specialists and expert patients. Given the specialised nature of ophthalmology and glaucoma, certain aspects can be difficult to conceptualise, and, therefore, clear and adequate explanations of concepts are provided in the course using diagrams, flow charts, medical illustrations, images, videos, written text, analogies and quizzes. The course is available in a short and long version to suit different learning needs which take approximately 2 hours and 10 hours to complete respectively. The contents list allows course takers to find sections relevant to them and it can be taken anywhere, as long as there is Internet access. We invite you to share this resource with your patients and their families, friends and carers.

## THE NEED FOR AN ONLINE GLAUCOMA EDUCATION COURSE

Glaucoma is the most common cause of irreversible visual impairment and its prevalence is on the rise, with the number of people affected estimated to be over 100 million by 2040.<sup>1</sup> It is a chronic condition characterised by progressive damage to the optic nerve with characteristic visual field loss requiring lifetime monitoring and care. Glaucoma has a substantial and detrimental effect on many aspects of daily living,<sup>2</sup> and accounts for 23% of all hospital eye service follow-ups and 13% of new referrals.<sup>3</sup> This places a huge demand

on glaucoma outpatient clinics. Teleophthalmology now plays a vital role in increasing capacity for the continued delivery of glaucoma care in developed parts of the world. Two models of teleophthalmology are in place: synchronous, which involves a teleconsultation with a medical professional, and asynchronous, whereby the patient undergoes diagnostic tests carried out by a specialised medical assistant which are reviewed by a medical professional within a defined period and a written report is sent to the patient.<sup>4</sup>

In both face-to-face and teleophthalmology clinics, there are significant time constraints and limited resources available to educate the patient and their carers regarding the condition. Importantly, guidance from both the General Medical Council,<sup>5</sup> and National Institute for Health and Care Excellence stipulate that patients should be given the information they want or need in a way they can understand and that healthcare professionals should provide “relevant information in an accessible format” as well as “practical information and advice” on various issues surrounding their condition.<sup>6</sup> The majority of current practice involves issuing leaflets to patients and their carers written by the hospital or glaucoma charities in paper format, which is done inconsistently.

Furthermore, it is concerning that in asynchronous review clinics there is no direct doctor-patient contact, further limiting an opportunity for patient education and this is one of the main areas in which patient satisfaction and acceptance of these clinics are negatively impacted. Drawbacks of asynchronous review clinics include a 20% decrease in patient adherence to medication, as well as 20% of patients complaining regarding not seeing a doctor; with 2% stating that there was a detrimental effect on the doctor-patient relationship.<sup>7</sup> Patients have expressed concern regarding the lack of immediate



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<sup>1</sup>Glaucoma, Moorfields Eye Hospital City Road Campus, London, UK

<sup>2</sup>King's College London, London, UK

<sup>3</sup>Moorfields Eye Hospital City Road Campus, London, UK

<sup>4</sup>UCL, London, UK

<sup>5</sup>Institute of Ophthalmology, University College London, London, UK

### Correspondence to

Dr Sana Hamid;  
sana.hamid1@nhs.net

feedback and the absence of being reviewed by a doctor on the day,<sup>4</sup> with 10% reporting that they were not happy to receive clinic results by post but would have been happier to wait longer to see a doctor or optometrist, as well as expressing a dissatisfaction with not having the opportunity to ask questions about their condition.<sup>8</sup> This is even more pertinent to patients from different ethnic groups, where English is not the first language, or who are elderly. Adoption of a system that would allow the immediate resolution of queries and for clinical letters to be more patient-friendly with better explanation of technical terms would be beneficial.<sup>9</sup> Anecdotally, clinicians performing these clinics often produce their own personal letter templates to explain conditions and concepts, and although these may be helpful, they are often not standardised, complete or patient-friendly and there is no opportunity to physically hand out paper leaflets, although sometimes these are posted to the patient with their letter.

Patient education is an essential tool for clinicians to use to empower patients in becoming more autonomous concerning their health and treatment. It helps patients make better choices in line with their values and encourages them to become healthcare partners.<sup>10</sup> Education and exchange of information is pivotal to shared decision making; the importance of which has been previously described, including the positive impact it has on treatment outcomes.<sup>11</sup> Patients with a chronic disease often have inadequate knowledge about their disease.<sup>12,13</sup> Glaucoma patients are often not satisfied with the content and amount of information they receive and have demonstrated a substantial lack of knowledge.<sup>14</sup> A Glaucoma Patient Day held in the United Kingdom (UK),<sup>12</sup> with 296 attendees revealed that the attendees ascribed great importance to the usefulness of the event for their learning as well as stating that their understanding of glaucoma had significantly improved following the event. The patients wanted to know more about glaucoma, in particular what effect it has on them, how they can help themselves and how best to administer their eyedrops.

Well-informed patients better understand their prognosis and manage their disease better. They are also more compliant and more likely to cope effectively with the changes the illness causes.<sup>12</sup> Informed patients express greater satisfaction and experience less anxiety, less adverse event rates and less treatment regret.<sup>15</sup> In glaucoma, low health literacy is associated with decreased adherence to treatment regimens and increased difficulty with eye drop administration.<sup>16</sup> Furthermore, when glaucoma patients received a synchronous coaching session on eye drop instillation, 92% of patients who had received teaching found it useful, emphasising that health coaching is an effective strategy in empowering patients.<sup>13</sup>

The use of video-based media appears to be effective in improving patient understanding and in certain cases improve overall outcomes.<sup>17</sup> 63% of internet users seek medical information and support online in the UK.<sup>18</sup> While online resources providing general information

on glaucoma are easily accessible, patients may not differentiate resources that are not operated by reputable sources. Given the increasing utilisation of online sources for health information, the readability of online patient education materials is increasingly important. 15% of UK adults have reading levels below 9 to 11 year olds (year 6).<sup>19</sup> A systematic review of the literature revealed that ophthalmic patient education materials are consistently written at a level that is too high for many patients to understand.<sup>20</sup> The majority of online glaucoma reading materials are written at a year 11 to 12 level; which is far above the recommended readability parameter of a year 8 reading level.<sup>21</sup> Furthermore, Black and Latino adults, individuals over 65 years old, and those with low-income levels are three times more likely to lack digital literacy compared with their White counterparts.<sup>22</sup>

There is an urgent need for innovative, comprehensive and accessible educational tools that are comprehensible, to facilitate digital remote patient education and act as a powerful adjunct to face-to-face and teleophthalmology clinics. To our knowledge, there are currently no glaucoma patient education courses available that offer comprehensive, accessible, multimodal education at appropriate reading levels. We developed an online glaucoma patient education course to meet this need.

## COURSE DEVELOPMENT

Our primary aim was to produce a free, multimodal, comprehensive and accessible resource to aid remote learning and understanding of the glaucoma condition. The secondary aim was to provide a resource for glaucoma practitioners to have to hand to direct patients to when wanting to provide patients with more comprehensive information, or when reviewing patients asynchronously. The primary target audience is adults in the UK with glaucoma, their family, friends and carers, although the course can be used globally by English-speaking adults. The pedagogical framework used to develop the course was the constructivist approach.

The working group comprised of 2 consultants, 4 glaucoma fellows, allied health professionals including two nurses, 1 eye clinic liaison officer, 2 optometrists and two pharmacists, 2 education specialists and 5 expert patients from the UK. During the planning and design stage, patients were interviewed to collect information regarding what they wished to know about, encouraging patient-centred education, which even though advocated by the GMC, and popular in medical education, is novel to patient education development.

The development stage involved authoring of the course material by SH, CI and AB and review by SH, NM, CI, AB, MP, DM and RGM. Writing the material involved reviewing glaucoma literature and writing at the year 7 reading level. Given the specialised nature of ophthalmology and glaucoma, certain aspects can be difficult to conceptualise, and, therefore, clear and adequate explanations of concepts are provided using diagrams, flow

charts, medical illustrations, images, videos, short films, written text and analogies. The content was formatted on the Articulate Rise platform by the educational specialists. The main challenge was getting the language level correct for patients to understand. Non-medical persons and patients reviewed the content and informed the editing stage to improve ease of understanding.

The educational content was defined into various components and includes the following sections: what is glaucoma, glaucoma epidemiology, risk factors, diagnosis, living with glaucoma, glaucoma treatment (including medications, medication education and how to instil your eyedrops, laser, surgery and alternative therapies such as diet and lifestyle advice), different types of glaucoma, future advances in glaucoma and information on support services, charities and low vision help. There is also a ‘patient voice’ section in which patients were interviewed about their glaucoma journey and these video extracts are included within the course. We excluded childhood/congenital glaucoma. There is a pre- and post- course quiz to evaluate the learning that has taken place and provide feedback.

The course is available in a short and long version to suit different learning needs which take approximately 2 hours and 10 hours to complete respectively. The contents list allows course takers to find sections relevant to them and it can be taken anywhere, with easy access to the information at any time as long as there is Internet access. Reasonable adjustments were made for users who may be visually impaired or have limited English proficiency. These included ensuring the content have ‘alt text’ for those who use screen readers so that the text can be explained to them, as well as recording some of the content script in a number of languages such as Arabic, Turkish and Spanish, to make it as accessible as possible to people from different backgrounds. The course was approved by the hospital Information Governance department and in the final stage, was marketed through the hospital communications to different departments, via the hospital charity and also a short radio interview by SH and CI.

## ACCESSING THE COURSE

The course can be accessed easily for free via Google, by typing in the words “Glaucoma” + “Moorfields Education” in the search engine or by accessing the following URL directly [https://checkout.moorfields.nhs.uk/product?catalog=GLAUCOMA]. We invite you to use this resource for the benefit of your patients, their families, friends and carers, by sharing the course with them.

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## ORCID ID

Sana Hamid <http://orcid.org/0000-0002-3901-6902>

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