Patient Experience Survey, January 2017

Name: ___________________________ Year of birth: ________

Email: ___________________________ Postcode: ________

If you do not want to receive any more survey’s from the IGA please tick here. ☐

Date: mm/yyyy:

Hospital delays

1. Have you been diagnosed with glaucoma?
   Yes / No __________

2. Have you been diagnosed with suspect glaucoma?
   Yes / No __________

3. Have you been diagnosed with ocular hypertension?
   Yes / No __________

If you were diagnosed with glaucoma, can you tell us what type?
   ____________________________________________________________

Is your condition being managed:
   A: By the NHS? ☐ B: Privately? ☐

2. Is your glaucoma managed through an ophthalmologist and optometrist?
   If yes, is this:
   A: By the NHS? ☐ B: Privately? ☐

3. Can you tell us about your current (eye drops/laser/surgery) plan?
   ____________________________________________________________

And the Survey says...
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Welcome to the Autumn edition of our magazine.

This is a bumper issue with features on dry eye syndrome, a summary of questions at our annual lecture as well as details on research grants, a final report from a grant awarded in 2013 and information on our work to raise awareness and educate both professionals and people with glaucoma.

As promised in an earlier issue of our magazine, we have now looked through and analysed the responses to our survey. This issue includes a summary of the key findings together with some of your comments. So many of you provided thoughts on what you would like to see in future copies of your magazine – thank you. I will try and make sure that as many of these topics are covered as possible.

The date for next year’s AGM and annual lecture is set and we are delighted that Keith Martin, Professor of Ophthalmology at Cambridge University is joining us as guest speaker. Please make a note of the date, and more information will follow in the Winter issue.

I am also pleased to include the final report from a four-year research grant jointly funded by the Royal College of Nursing together with the IGA, and some brief details of the studies which you have helped to fund for 2016 to 2017. We will bring you more information about these in due course.

Some of you may have attended patient support groups at your local hospital or community centre, or indeed you may have been at this year’s annual lecture and heard Subhash Suthar, our development manager for London and the South of England speaks passionately about the lack of information people often receive about taking eye drops. So that more people can benefit from the information that Subhash and our other regional managers
(John and Eryl) impart, we have created some short educational films for our website, talking about taking drops, the techniques you can use, and what is available to help.

It seems a little early to be talking about Christmas but in this issue of the magazine, you will find our new selection of Christmas cards and news of our exciting new Christmas Shine a Light initiative.

I hope you enjoy reading the magazine and do contact us if you feel there are other issues we should be covering.

Karen Brewer
Editor
I have just returned from annual leave greeted by the eye drop aids! Thank you very much. I know they will be extremely beneficial to patients.

**Melody Field**  
*Staff Nurse, Outpatient Department*  
*Woking Community Hospital*

“Regarding your forum discussion, I realised a few years ago that my glaucoma clinic at the RUH Bath is very slow at sending out follow up appointments - you can slip behind for months. So now I make a calendar note for the 9/12 month interval they suggest, and a month before that I phone them, and I’m given a date pretty much on time. No worries, and I’ve had marvellous treatment and excellent sight for about 30 years now. They are under huge pressure.

Your magazine is very valuable and I try (not always successfully!) to absorb the information.”

**Elizabeth Bass**

Please feel free to write to me:  
**K.brewer@iga.org.uk** or call on **01233 64 81 64**  
I will consider all thoughts and comments, and come back to you
IGA AGM and annual lecture
Friday 23 March 2018
Coin Street Conference Centre, London

We are delighted with the line-up for next year’s AGM and annual lecture.

Both Professor Keith Martin (left) and Professor David Garway-Heath have been recognised as two of the top 100 most influential people in ophthalmology for 2016. Voted for by their peers, The Ophthalmologist magazine Power List is an international celebration of their achievements and prowess in the field of ophthalmology.

Eighteen thousand readers of the magazine were invited to vote for who they thought was making the biggest impact in ophthalmology today.
IGA seeks a new Treasurer

In March 2018, our Treasurer Alan Vaughan will sadly retire after nine years as an IGA Trustee. We are now seeking a new Treasurer with strong strategic and financial ability, and a good level of awareness of the issues facing the charity sector.

The Treasurer’s role is to monitor the financial administration of the charity and report to the board of trustees on its state of financial health. Day to day responsibility for financial matters is delegated to the CEO, supported by the Head of Finance. The role requires attendance at four IGA trustee meetings each year and four Finance and Governance sub-committee meetings, plus occasional ad hoc input via email.

Meetings are held on weekdays in either London or Kent, and although the role is unpaid, all expenses are reimbursed. If you think you might be interested, please take a look at the application pack on our website at www.glaucoma-association.com or call 01233 64 81 64 for a paper copy.

Deadline for application is Friday 20 October 2017.

For an informal discussion about the role, please call our Chief Executive, Karen Osborn on 01233 64 81 72.
Closed angle glaucoma

Q. What is the panels view about closed angle glaucoma screening?

A. In Scotland, the NHS test includes an examination called gonioscopy which is used to measure the drainage angle. In England this is not part of the NHS sight test, but there are however other techniques that an optometrist will employ in order to detect closed angle glaucoma.

Ophthalmologists feel that optometrists need to do extra investigations if closed angle glaucoma is suspected. This would usually be for people who are long-sighted. There’s a test called the Van Herick test which uses a slit lamp which is quite good at finding people who are at risk. The remit that optometrists have is that extra investigations should be carried out if a problem is suspected.

XEN implant

Q. Do XEN implants contain animal collagen?

A. Yes, the collagen is taken from pigs. It is the responsibility of the medical professional to seek consent from the patient and to inform them of the origin of the collagen. Jews and Muslims may accept the use of animal collagen for health reasons, but they need to be informed.

Q. Is the Molteno tube still being used?

A. It tends to be more ‘complicated’ eyes that require the Molteno tube. There are various different silicone tubes available, and there are geographical variations. In North America, Ahmed tubes are used almost exclusively, and in the UK it is mainly Baerveldt tubes. The Molteno is a good alternative and can work well.
Steroids and glaucoma

Q. What are the implications of steroid use on glaucoma?

A. Any form of steroid use can, eventually, precipitate glaucoma but most do not. It's something that should be borne in mind and it's something that should certainly be discussed with people who are going to need long-term treatment.

Low tension glaucoma

Q. Is low tension understood, and what is the best treatment?

A. Lowering the intraocular pressure is beneficial for normal tension glaucoma. People get glaucoma with different levels of pressure, and it is assumed that some people are more ‘susceptible’ to pressure than others. There is a suggestion that where mitochondrial function - which is the function of the little packets in cells that produce energy - don’t work well, that may make people more susceptible. Other susceptibility factors may include the condition of blood vessels and certain medicines for high blood pressure.

Normal tension glaucoma

Q. Is the diagnosis of normal tension glaucoma improving?

A. This artificial pressure cut-off is 21mmHg. Statistically there are patients who have pressure under that level but have the same features of primary open angle glaucoma, as in a high tension glaucoma patient.

There is a sub-set which is the more ‘true’ normal tension glaucoma, which has slightly different characteristics, and where the pressures are very low at 10-12. Patients often present with more symptomatic visual field loss, present earlier in the central field, and these are patients who have circulation issues (called vasospastic syndrome). Such patients may have a history of cold hands and feet, history of migraine etc. The truth is that diagnosis of either will depend on the ability of the person examining the patient to differentiate a normal-looking optic nerve from a glaucomatous optic nerve.
Talking glaucoma

Pressure is probably the least effective predictive factor in the diagnosis, but as long as you can make the diagnosis that this is an abnormal disc, then normal tension glaucoma should be picked-up. High street optometrists are pretty good at identifying a damaged disc and will refer on that basis.

Q. Is it possible for people to have lost some sight before being referred?

A. Yes. There is an opportunistic nature to picking up glaucoma. Up to half of glaucoma is undiagnosed and the only way people come to the eye clinic is by detection in the community or at a high street optometrist. It can be difficult to pick up the clinical features of glaucoma. When it becomes more obvious, that is the point at which a repeatable visual field defect occurs. The diagnosis is easier but then visual loss can’t be reversed. It’s important that the referral is made and the appropriate treatment is started straight away.

Q. What are the IGA doing in terms of the relationship with high street opticians? Are opticians aware of glaucoma?

A. The high street optician can usually diagnose the abnormal optic disc in the absence of a visual field defect.

One of the IGAs key functions is to fund research in glaucoma and one research grant programme is run in partnership with the College of Optometrists. There is some very good research being done by optometrists.

Corneal thickness

Q. Should corneal thickness be taken into account when pressures are checked?

A. A thin cornea means the pressure can be underestimated, but that can depend on the type of device used to measure it. An optician very often uses the air-puff device, and that underestimates the pressure more than the hospital test.

Q. Do close family members need to mention the thickness/thinness of the cornea?

A. The corneal thickness is very heritable, so yes, relatives may have thin corneas as well. If relatives have pressures that are a bit high it is worth mentioning that thin cornea runs in the family.
Talking glaucoma

Q. Do high street opticians tell patients that the cornea will become thinner during Lasik corrective (refractive) surgery?

A. The general answer is no, the high street chains don’t tell people that corrective laser surgery can thin the cornea. Not everybody gets a thinner cornea centrally with laser, and a person would have to be short-sighted to have a significant enough amount of laser that the cornea would thin and affect pressure measurements.

Eye test frequency

Q. Is there a reason to go to an optometrist more often than just once a year?

A. There are guidelines about when to be seen and it’s usually every two years. However it’s every year if there is a family history of glaucoma.

Glaucoma is a very slow condition in most people and the reason for seeing a patient more often would be either due to the glaucoma progressing quickly, or if the consultant wasn’t happy with the examination. For most people it is a very slow condition and yearly is adequate.

There are clinical trials going on at the moment with patients who present initially with really advanced glaucoma. These tend to fall into two groups. The first group haven’t been to an optician for 20 years, because “their eyesight is perfectly fine.” The second group are people who’ve got normal pressure glaucoma and the pressures have been normal when attending a high street optician. Detection is now improving as there is more equipment to screen for glaucoma. The message is that everybody should see an optician regularly, whether glasses are needed or not, because optometrists can find things that people don’t know are there.

Q. The National Institute for Health and Care Excellence (NICE) say that eyes should be tested every two years. There are so many other conditions that can be picked up through an eye check, so isn’t it something that would be worthwhile trying to change?

A. The cost effectiveness has to be measured and the detection of other conditions, other than glaucoma, is not frequent enough to warrant yearly visits. There’s a limited pot, and money would have to be taken away from other conditions to do that sort of monitoring.
You should be reassured that NICE is deeply evidence-based and it has looked very closely at the rationale, the cost-effectiveness and the yield of screening more frequently. Bear in mind this is the same body that set guidelines for the referral of glaucoma that have actually, to some extent, overwhelmed hospital services. The current criteria are quite defensible.

Q. Is a month too long between monitoring appointments when trying new treatment, and can damage to the optic nerve happen over four weeks?

A. It is very unusual for a visual field defect to develop in four weeks, unless the pressure is very, very high. There is a limit to how often patients can be seen and it is actually quite unusual for treatments not to work.

In the case you mention, the glaucoma damage would have already been there. The process of damaging the optic nerve would have been going on for a while. If a patient is deemed to be high-risk, they would be brought back in four weeks and if the pressure was out of control, and it was thought that surgery was likely to be needed, they would be brought back in a week. Four weeks is actually a fairly reasonable, cautious timeline.

Congenital glaucoma

Q. How much importance is given to research and also new advances in congenital glaucoma?

A. In the UK, the IGA is probably the main funder of glaucoma research outside of the major research bodies like the Medical Research Council or Wellcome. The IGA work in partnership with Fight for Sight, the Royal College of Ophthalmologists, the College of Nursing, the College of Optometrists and also the UK and Eire Glaucoma Society.

Applications are taken from research groups around the country and internationally on any aspect of clinical glaucoma care. Research proposals relating to paediatric or primary congenital glaucoma or other childhood glaucoma would be considered. These funding rounds are extremely competitive and there is a limited amount of funds. The selection has to be judicious in terms of which grants are awarded. Considerations include what will have the most direct and quick impact on patients,
Talking glaucoma

is the research going to have a major impact but may not be measurable straight away? - if it is going to be a game-changer then it would be supported. Primary congenital glaucoma is a devastating condition but is actually relatively rare and it’s hard to do anything other than small case series research. There are groups that put in applications relating to paediatric glaucoma and these are considered, but in competition with other equally needy areas.

Lifestyle

Q. Do the panel have any thoughts about high altitude causing further damage to the optic nerve?

A. There’s very little evidence. The mantra is there is no effect due to altitude, and the good news is that the treatment for altitude sickness lowers the intraocular pressure. So if Diamox tablets are taken, that will lower the pressure.

Q. Can exercise involving lowering the head such as pilates and yoga, do damage to the eyes through pressure?

A. Yes, headstands, or any exercise where the head is lower than the heart, can put the intraocular pressure up considerably. For people with advanced glaucoma it wouldn’t be recommended.

Treatment

Q. How does Avastin work and is it going to offer any improvements on Fluorouracil (5FU)?

A. Chemotherapy drugs work by affecting wound healing. After trabeculectomy the possibility of complications or failure is generally related to scarring, and Avastin may well do the same thing as the drugs used to reduce scarring. The IGA is funding a study into just that.

Q. Can Xalacom and Ganfort cause discolouring of the skin below the eye, and could this be confused with skin cancer?
A. Xalacom and Ganfort are effectively similar medicines, so only one of the two should be used. Any form of prostaglandin drug can cause some pigmentation around the skin, but it’s not pigmentation that is generally confusable with skin cancer.

Q. Has there been any study into the effectiveness of surgical procedures with regard to the need to use drops afterwards?

A. Complete and partial success is often talked about, and the hope is that surgery of any sort would avoid the need for drops. Sometimes the operation works partially and drops are needed in addition. Sometimes more than one operation is needed as well as drops. But the intention is to try and get patients off drops. There is a gradual loss of effect with many surgical procedures that require drops to be reintroduced. That doesn’t mean that the operation has failed as such, it just means that it needs some extra help.

Q. Could trabeculectomy, uveitis, cataract and an Ahmed valve implant cause fluctuating vision?

A. It might be that if there has been an Ahmed valve implant and a lot of high pressure and uveitis, there may be swelling of the cornea which can cause fluctuation in vision. It might simply be advanced glaucoma. There are a number of possibilities and it’s difficult to say without knowing the details.

Q. Will the side effects of the various drugs be included in future research, and what about other lifestyle effects? Has there been other research done that helps manage the progression of glaucoma?

A. There is increased awareness of the side effects of drops and the minimum number of drops is used to minimise the effects. There are lots of research projects looking at other factors such as diet and smoking, but at the moment the only modifiable risk factor that can be routinely treated is the pressure.

Q. Is there any research going on to find out if any other medication can lower eye pressure?

A. Generic latanoprost is so cheap and effective that the pharmaceutical industry has hit the buffers in terms of game-changing drugs. In the next few years, most of the innovations are going to be in drug delivery. Instead of taking eye drops every day,
perhaps implants, or other surgical devices will be available. There are lots of new products in the pipeline. There is the hope that over the next 10 years many of them will be applicable.

Stem cell research

Q. Is there any research going on as to how to further protect the optic nerve and, once damaged, could it be repaired?

A. There are groups looking at ways of growing stem cells, and turning the stem cells into the nerve cells that sit in the retina at the back of the eye. Nerve cells have to be joined up with the other cells to send a connection back to the brain, so it’s a very difficult challenge.

Stem cells are going to be more readily applicable to age-related macular degeneration. Because glaucoma involves nerves it’s a much more difficult problem. It is being worked on it but it’s probably five to 10+ years away.
Glaucoma and Ocular Surface Disease
Mr Shabbir Mohamed, Birmingham

We have a wealth of evidence that lowering intraocular pressure (IOP) helps to slow down the disease process in glaucoma. The majority of glaucoma patients are currently treated using eye drops aimed at lowering IOP. Over my working life (past 20 years), I have seen the range of available drops and combinations of drops to treat glaucoma expand greatly and this has allowed us flexibility to individualise treatments for our patients. This has been of great benefit allowing patients to retain their sight and maintain quality of life.

Our understanding of the safety and usefulness (efficacy) of eye drops has also evolved over time. Amongst the first generation of eye drops that were available, it became apparent that some eye drops caused marked toxicity to the structures of the surface of the eye leading to development of scarring which compromised vision and quality of life of our patients – the very things we were trying to preserve. One such example is Metipranolol which is no longer used as a result.

Over time, newer agents and formulations have been developed that are much better - both at lowering IOP and having lower toxicity. However, the problem of toxicity to the structures of the ocular surface remains. Several studies have shown that this is a significant problem leading to loss of quality of life in a large proportion of medically treated glaucoma patients. The problem seems to be greater in patients who are treated over a long time, those treated with multiple agents and also in patients who use multiple drops containing preservatives.

In addition to drops, older patients as well as patients who develop systemic diseases are more likely to develop worsening ocular surface problems. We are also developing a better understanding of how systemic medications and nutrition plays an important role in this group of patients. It is therefore common to see patients who are having symptoms and signs related to ocular surface problems in our glaucoma clinics.

Implications of ocular surface disease (OSD) in glaucoma patients

Patients with OSD present with symptoms that range from ocular discomfort, redness and watery eyes to visual disturbance which can be serious in some patients. Studies have shown that the impact of such symptoms can be quite severe on the quality of life of the patient especially in those at the severe end of the spectrum.
As a result of these symptoms, some patients stop using their glaucoma medication which can lead to loss of control of the intraocular pressure and worsening of glaucoma. This situation can then lead to a breakdown of the doctor-patient relationship and a subsequent loss of trust in the healthcare system which is a major issue globally.

If the ocular surface toxicity is unrecognised and is allowed to persist, it can lead to inflammation which is the body’s attempt to heal itself. However, prolonged inflammation can lead to scarring of the ocular surface tissues. We have known for many years that the health of the ocular surface tissues is an important factor in good outcomes with glaucoma management and in particular in glaucoma surgery. Hence if there is inflammation and scarring at the ocular surface, outcomes for glaucoma patients and in particular of glaucoma surgery are sub-optimal.

What can be done?

The first step is to appreciate the importance of understanding the problem and how it can impact the quality of life of glaucoma patients. We have found that it is essential to control intraocular pressure but also to look after the health of the ocular surface at each visit when managing patients with glaucoma for good long-term outcomes.

It is essential to systematically evaluate the patient and their ocular surface to enable recognition of moderate to severe OSD and take active intervention to halt the inflammation and scarring that accompanies this. Unfortunately, there is no single test available that can identify worsening OSD and this evaluation is based on the expertise of the ophthalmologist.

If OSD is present, the ocular surface can be supported by a variety of means ranging from lubrication to use of preservative-free glaucoma medication and in some cases systemic treatments. This all takes time and requires continuity of care which is unfortunately becoming a difficult thing to achieve in modern healthcare systems.

Some patients stop using their glaucoma medication which can lead to loss of control of the intraocular pressure and worsening of glaucoma
Talking glaucoma

What are the benefits of managing patients in this way?

There is good evidence that treating OSD in the general population improves quality of life significantly. This is therefore the first benefit.

In addition, we have found that improving the ocular surface in glaucoma patients helps to lower intraocular pressure and also helps to keep it low over the longer term in some patients. We published a paper in the Journal of Glaucoma on this phenomenon which we called ‘Ocular Surface Disease exacerbated glaucoma’. We postulated that this may be because the final outflow pathway of the intraocular fluid is via the ocular surface and by improving the health of the ocular surface and reducing inflammation, we are probably helping to reduce the resistance to the outflow and thereby reducing intraocular pressure. This is a hypothesis at this stage and needs more research to look at in more detail.

The third benefit of this approach is that if the patient requires surgery, the outcomes are likely to be better as the ocular surface is less inflamed and less prone to scarring which is the process by which glaucoma surgery fails. Anecdotally, we have observed this and we advocate ocular surface optimisation prior to glaucoma filtration surgery.

The most important benefit of this approach is that the doctor-patient relationship is maintained and improved. This leads to greater trust in the healthcare system which is of great benefit to society. The effect on the clinician is probably greater than that on the patient.

Hopes for the future

It is encouraging that most glaucoma drops are now available in a preservative-free form. This is a good development especially for those patients at high risk of developing moderate to severe OSD related problems in their lifetime. Pharmaceutical companies are also more aware of assessing the ocular surface effects of newer medications before release to the general public. There are also developments in tools to identify patients who are developing worsening OSD which may reduce reliance on expertise which is difficult to achieve in this area.
This would enable earlier interventions to reduce the disease burden in this group of patients.

We are developing alternative approaches to control intraocular pressure other than multiple drops which are less invasive than our traditional surgical methods. This may translate to lower morbidity for our patients in the longer term.

“In my working life, I have seen valuable developments in this area of treatment and see less of the severe end of ocular surface problems in glaucoma patients. This gives great hope for the future.”

Inspiration and thanks

I am grateful to the patients that I have had the privilege of looking after over the years. Through their suffering, they have tried to teach me my profession in a more thorough way than any textbook. I am also indebted to the people who took the time to train me to make sense of what the patients were trying to teach me.

Mr Shabbir Mohamed
Birmingham

“The ocular surface is at the heart of many eye problems. Expert management of ocular surface problems can help prevent the progression of glaucoma.”

Professor Peter Shah
Consultant Ophthlamic Surgeon, University Hospitals Birmingham NHS Foundation Trust. Visiting Professor, University College London. Honorary Professor of Glaucoma, University of Wolverhampton. Co-Director, Birmingham Institute for Glaucoma Research, Institute for Translational Medicine, University Hospital
Talking glaucoma

Elderly patient with glaucoma who developed severe ocular surface disease

Glaucoma patient who developed in turning of eyelashes due to glaucoma medication related ocular surface disease

Ocular surface redness and corneal staining in glaucoma related ocular surface disease
Eye Drops and Dispensing Aids
Includes information on:

- Structure of the eye
- How should I use my eye drops?
- Getting into the routine
- What types of glaucoma drops are there?
- Generis substitutes for banded drops
- Eye drop dispensing aids
- Top tips

This booklet can be ordered from the website: www.glaucoma-association.com
Research grants

Research grants awarded during 2016-17:

The College of Optometrists

‘Ocular surface disease within specialist glaucoma clinics in the United Kingdom: A modern-day evaluation of prevalence, patient-reported symptoms and economic burden’
Shima Shah, Moorfields Eye Hospital, London: £18,490

This is an important study – it will look at medication symptoms and the burden this entails with patients.

Royal College of Ophthalmologists

‘Lamina cribrosa cell bioenergetics and metabolomics in glaucoma’
Professor Colm O’Brien,
Mater Misericordiae University Hospital, Dublin: £57,000

‘Exploring patients’ expectations and preferences for glaucoma surgery outcomes to facilitate healthcare promoting research’
Bina Kulkarni, Queen’s Medical Centre, Nottingham: £2,210

‘Clinical outcomes of Selective Laser Trabeculoplasty: a definitive analysis of clinical and patient-reported outcomes, complications and predictors of success in the LiGHT Trial’
Anurag Garg, Moorfields Eye Hospital, London: £63,626

More information on these research studies can be found on our website: www.glaucoma-association.com
“Impact of patient-held record on knowledge at one-year follow-up for glaucoma patients: single-center randomized controlled trial”

February 2017 saw the publication of research results into whether provision of a personalised patient-held eye health summary (glaucoma personal record) improves patients’ knowledge of glaucoma at one-year follow-up. The report appeared in the European Journal of Ophthalmology, by authors Marina Forbes, Helen Fairlamb, and Leon Jonker, who worked on the project for four years. All three work or worked formerly at North Cumbria University Hospitals NHS Trust. The research trial was funded by a collaborative research grant from the IGA and Royal College of Nursing, without which the project could not have been completed.

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The National Institute for Health and Care Excellence had recommended such an approach in 2009, to ascertain if this may ultimately help slow the glaucoma damage. Marina conceived and wrote the outline of the idea of the clinical trial as part of her studies to complete her Master of Science Degree with the Open University. Leon and Helen supported and developed the outline, producing the design and protocol, and getting the trial up and running.

Recruited patients, newly diagnosed with glaucoma conditions, were randomly allocated to receive standard clinical assessment and care, or an additional glaucoma personal record, detailing the current state of each individual’s eye condition. Comparison of knowledge scores between the two groups, at one-year follow-up, was done using a validated questionnaire. The researchers were looking to detect any factors significantly associated with a difference in glaucoma knowledge between those receiving the personal glaucoma booklet and those not receiving this extra resource.

A total of 122 patients were recruited; 57 controls and 44 “Booklet” patients were tested for their glaucoma knowledge. Out of a maximum available 100 per cent score, the median scores were 58 per cent control group, and 53 for the Booklet group, (p = 0.85).
Further analysis showed that age \((p = 0.015)\) had a negative association and level of education \((p = 0.002)\) had a positive association with glaucoma knowledge.

The research team drew the following conclusions. The glaucoma personal record does not impact on a patient’s knowledge of glaucoma in either a positive or negative way. Other approaches to improve health literacy among glaucoma patients, particularly for patients who are elderly or have a limited educational background, must be considered in order to improve patients’ awareness and knowledge of their own condition.

Although the personal glaucoma hand-held booklet, in its current form, does not appear to increase patients’ knowledge of their condition, there were generally very favourable comments from those who received the booklet during the trial, and from other community ophthalmic colleagues, e.g. optometrists.

(International Standard Randomized Controlled Trial Number Registry: ISRCTN41306818.)
Sightline

Forum insight

The IGA has an extremely active website Forum which allows people to learn from each other. It is monitored by our helpline advisers who also respond to the questions when needed.

Here is a snapshot of some of the questions asked over the last couple of months. If you are interested in participating in the Forum, you simply need to register on the IGA website: www.glaucoma-association.com

Q. Has anyone experience of what Pilates exercises are seen as contraindicated with Glaucoma? I am a Pilates teacher and recently diagnosed with glaucoma and I have had difficulty finding clear guidelines and advice. My eye consultant told me not to stand on my head! We don’t do that - that’s Yoga so that wasn’t very helpful.

A. I don’t do Pilates, but in general it's best to avoid ‘head below heart’ positions and don’t lift anything heavy (also in normal life). If Pilates fits with that, you should be fine. My doc also said (after several ops) no diving either, but I hate swimming anyway, so that was easy! Exercise is recommended - I find walking, zumba and jumping about to music at home fit the bill for me. If you don’t enjoy it, you won’t do it, so adapting something you like - if it needs it - is always a better bet than HAVING to do something you hate... it's human nature to find an excuse. Hope that helps.

Forum user

A. We have spoken to the lady who introduced Pilates to the UK. She has told us that as Pilates is a low impact exercise and there is no risk to people with glaucoma. The only exercise that could cause the pressure to go up (but only slightly) is when you lie down and gently push off of a vertical springboard.

Sightline

Q. I’ve been prescribed Pilocarpine drops. I wear soft contact lenses. Can anyone tell me how long after using the drops I can put my contact lenses in please? Thanks

A. You should leave at least 15 minutes after putting the Pilocarpine drops in before putting your contact lenses in.

Sightline
Q. Had my second needling of the trabeculectomy a few weeks ago and it has got my pressures down to 21, still not enough as they want it 14 or below. What was so worrying is they told me today my nerve fibres are 90 per cent dead. Is this as bad as it sounds? I am a worrier anyway but hearing this has knocked me for six, I am starting to really get depressed about it all now. I turn 40 in a few days and just cannot cope with the thought of losing my vision and I dare not ask them to put a timescale on my sight. Thinking of asking my doctor for anti-depressants but worried of them damaging my sight as a side effect. Anyone else with advanced glaucoma taking anti-depressants?

A. 10 per cent is still a good amount of vision and your consultant is aiming to maintain this for you. Also ask your consultant to show you your visual field results and this way you will see the amount of vision you still have. In regard to going on anti-depressants you should discuss this with your consultant and GP to see if it would be a good idea to start taking them at this time.

Sightline

Q. Sorry to hear you are not quite at a good level yet. I have been told it's amazing how much I see from my left eye considering the state of the optic nerve, (sounded like it looked totally dead) so numbers are not everything. As long as I can pass the driving test, that will do me. 21 is the level where they'd start drops if you were newly diagnosed, so for most people not a level doing damage, but yes, they will want to get it down if possible to keep you safe. I have not been on anti-depressants so can't really say about them, but you'd need to check for side-effects.

I'm on digoxin (among other things) for heart and I'm fairly sure it makes my sight a bit blurry for a little while shortly after I take it, so I have to be careful if I have to drive. I've mentioned coffee before. This is possibly linked to blood pressure, so anything that keeps that down short/long-term is good: meditation, self-hypnosis, exercise? I find chocolate very calming, but I fear I can't make a case for it bringing pressures down... big shame! Your docs will be working out the best way to keep you going, whether changing drops, another op or whatever. I don't think they realise the panic patients feel if they say our optic nerve is less than 100 per cent!

Hope things improve for you.

Forum user
Q. Has anyone some advice or experiences of an Ahmed valve please? I had a trabeculectomy on my left eye in 2010 which was not a complete success although it did bring down my pressures eventually. I had SLT on the right eye in 2013 which successfully brought pressures down but they are gradually rising. My problem is do I have another SLT and continue to use drops or go for an Ahmed valve which I understand is a two hour operation with a skin graft?

A. I got an Ahmed valve in my left eye in 2006 after a trab from 1993 failed. Laser didn’t work for me. The pressure is a steady 10 on Saflutan once daily, had been in the 40s or higher. Don’t understand the skin graft bit - not aware of having had any and you certainly can’t tell from looking at me that I have a shunt - not even doctors, until they lift the lid. Take a general anaesthetic if you get the choice, it does take a good two hours and yes, longer to recover. It seems mine was as complicated as they come as my whites are very very thin and I have inflammation - scleritis. Queues of students and doctors having a look afterwards!

Keeping pressures low does not mean you will lose no more sight... both left and right (trab at present but perhaps shunt in time, 13 on Saflutan once plus Trusopt twice daily) have lost a little in spite of OK pressures. But it’s my best chance. That eye needs lubrication a bit more than the other, but no big deal. Good luck with deciding.

Forum user
If you want to get involved with Facebook you can find us at International Glaucoma Association and like our page and share our posts on your own timeline.
Social media activity on Twitter

You can follow us on Twitter @tweetiga, where you can like, share and retweet our activity.
Editor’s comment:
I am happy to share the results from the survey that many of you completed earlier this year. The response was impressive with around one in five of our members taking the time to complete the survey. We have looked at your completed questionnaires and the comments that you made in order to highlight key statistics and share some common themes. This summary, together with a full report will help to inform the future direction and activity for the IGA. I hope to share their thoughts with you in future issues of the IGA News.

Your survey

In January of 2017, you will remember that we included a survey in our magazine.

We were concerned about the increase in helpline calls regarding delays to hospital appointments and decided to investigate further. We wanted to understand more about your treatment, how your glaucoma was being managed, and whether you had experienced hospital delays. At the same time we also sought to identify improvements or areas of concern relating to driving and the DVLA (comparing it to results in the IGA 2015 survey) and importantly to find out more about members’ opinion of our services. Our survey was not intended as a scientific study, rather as a snapshot or a census, which gave you the opportunity to express your views on a range of subjects.

Our survey ran for three months until March 2017 and we received 875 completed forms from you.
Experience

Summary
Glaucoma diagnosis and treatment

The response to this section of the survey is extremely detailed with many of you providing supplementary pages covering diagnosis and management. Most of you have a diagnosis of primary open angle glaucoma (73 per cent), followed by normal tension glaucoma (12 per cent) and primary angle closure glaucoma (10 per cent).

Eye drops
The overwhelming majority of you take eye drops (97 per cent) with over a quarter of you having been prescribed four drops or more. It appears that six per cent (n: 53) of our members take eye drops for dry eye syndrome, and nine per cent (n: 77) have been prescribed preservative-free drops. The change from branded to generic is mentioned by many, as is the difficulty in using the eye drop bottles and the reaction to the drops.

• “Could you tell manufacturers to re-think their bottles structures? Travatan is so easy for arthritic fingers, whereas the new Brinzolamide bottle is all but impossible. I got a contraption from you to help with the old size Brinzolamide, but the new bottle does not fit.”

• “If you could lobby the manufacturers of the eye drop plastic bottles for the standard is very variable, particularly when the local doctor goes for the cheapest option.”

• “(Sightline) very helpful, I couldn’t open bottles of Xalatan”

There is also a sense of preservative-free helping to ease some of the issues with eye drops.

• “I have sensitive skin and finally now on preservative-free drops and these are making my eyes more comfortable.”

• “When first diagnosed I had major problems with allergic reactions to the drops, allergic to all drops apart from drops currently on and now have preservative-free because of reactions to the preservatives.”

• “I had a lot of trouble with side effects until getting preservative-free ones”

Only 29 out of 872, or three per cent of you, have never had eye drops.
Experience

Laser and surgical treatment
Laser has been carried out on 40 per cent (n: 349), with nine saying that the procedure had been unsuccessful. It may be that laser surgery has worked for a few years and then surgery was required, as nearly 100 of you, who had been treated for laser went onto have surgery. By contrast 59 per cent (n: 515) have had surgery with 37 per cent (n: 321) having a trabeculectomy. It appears from your comments that most surgery has been successful.

Information and communication
Overall communication with the hospital is good with many of you praising the professionals who care for you. The comments tend to show that the quality of care is often attributed to the consultant who has a particular interest in glaucoma.

Encouragingly more than two thirds of you (71 per cent) felt that you had sufficient information at diagnosis and nearly eight out of 10 (79 per cent) were given sufficient information about your initial treatment and about any change to treatment (84 per cent).

• “I feel my specialist and my optician are fully aware of my needs and advise me accordingly, and I can contact either or both if and when required. While small units may not fit the present financial models, the personal service and care received from someone who at least recognises you, to me is invaluable.”

• “Felt well treated for many years.”

• “Excellent care and support at all times.”

When you didn’t feel you were given sufficient information at diagnosis (29 per cent), or sufficient information about treatment (21 per cent), or any subsequent change of treatment (16 per cent), the main reasons were due to, busy departments, a lack of staff time, poor communication, unclear treatment information and appointment delays. These themes are expanded on below.

Delays
Hospital delays and cancellations is a significant issue. Over 40 per cent (n: 329) had a delay or cancellation in the last 18 months, with nearly half being delayed once (47 per cent: n: 149), 34 per cent (n:108) twice and 12 per cent (n: 38) three times. Six out of 10
Experience

of you (n: 218) are delayed by up to three months, with 20 per cent (n: 71) delayed by three to six months and 19 per cent (n: 68) for longer than six months.

• Over many years I have noticed a steady decline in regular appointments, supposed to be six-monthly but sometimes 14 months.”

Capacity, administration and communication

Busy departments and poor administration are common themes, with many of you providing detail of long delays, a lack of appointment time to discuss worries or poor communication about the diagnosis and lack of supporting information.

• “Diagnosis given very bluntly. It was a shock, no TLC, no leaflets, no support, very upset, and phoned secretary who was very kind.”

• “Biggest concern is the cancellation of appointments and the length of time spent in clinic when appointments run late. Because specialists are so busy I don’t feel I can spend time asking questions and also rarely see the same person. Therefore, I feel I don’t get a consistent diagnosis as each specialist may have different ideas on treatment. I have considered paying for a private consultation in order to get this consistent approach.”

• “There are too many people requiring glaucoma treatment. Since attending my local eye department in 2000 (aged 50) the number of patients has trebled yet the number of consultants/doctors has stayed the same or appears reduced. To get repeat appointments has now become a nightmare/lottery and is very unsettling. I am fortunate in receiving first class consultations and treatment when I eventually get there! It’s not getting any easier!”

• “I dread the long trek to my nearest hospital where I wait ages for about two minutes check-up only to find that I’m being transferred to yet another hospital, one of which did not possess the facility of having visual field tests. I have to attend a different hospital/centre for this. Do they ever pass the results to each other?”

• “There are not enough experienced doctors employed in the eye department, delays in getting appointments and a sea of old people in the waiting room.”

Occasionally you mention that the hospital appointments system does not take account of test delays, which means the consultant does not have the latest data to make an assessment. The opposite is also true where tests are carried out and the consultant appointment is cancelled. This causes frustration and increases anxiety.
**Experience**

Some of your strategies for managing delays involve keeping a diary, having a copy of your own medical notes, telephoning in advance of appointments and being assertive and/or complaining. But, some of you mentioned that you realise that many people would find it difficult to assert rights and complain.

- “Get a copy of consultant’s letter to the doctor after each appointment, excellent arrangement.”

One in five (22 per cent) of you were advised that there was further visual field loss at the delayed appointment. [We have to note at this point, that there may have been further visual field loss regardless of the delay to the appointment.]

Nearly a third of you (27 per cent) had a change of treatment at your delayed appointment, with most being advised of a change of drops (36 per cent), or recommended for surgery (14 per cent) or laser four per cent. The other reasons given by nearly half of you (46 per cent) included the need for an additional test, another appointment, transfer to another hospital.

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**Private care**
The IGA received 389 further comments. Of these seven per cent of you (n: 27) decided to pay for private care and report having an improved experience which included a lack of delays, time given for questions and a sense of care about their treatment.

- “The recent deterioration in my visual fields requires a minimum of eight week appointments which cannot be accommodated in the NHS. Appointments came through at three months plus. I immediately went privately with the same consultant and am now seen at times convenient for me, with no waiting and with continuity of care, and ample time for full discussion of condition and treatment.”

- “I have considered paying privately so I can get a consistent approach [about treatment].”

- “I am not well off but I now go privately to see my consultant. Feel I am in control.”

- “During my glaucoma journey, it has been necessary to go private twice... Yes, it is a treat, but what price is sight.”
Experience

DVLA and driving

Background
Our questions regarding driving repeated an earlier survey carried out in 2015. This led to a dedicated programme of work between the IGA and the DVLA which has involved creating a system for people to raise concerns and complaints, a new right to appeal process, applicants being given a copy of their visual field test at the testing optometrist and the involvement of some members in testing a new online notification service for the newly diagnosed.

For background information, up until 2014 the DVLA used a combination of independent and multiple optometrists to carry out the required testing for glaucoma. By awarding the contract to one chain it was anticipated that consistent standards for taking the DVLA required tests could be applied and these could be quality controlled.

The data for this survey and the analysis provided compares the results from 2015 (which included independents and multiples) against the 2017 results for Specsavers only.

Visual acuity test
There are slight variations in the experience of taking the visual acuity test at Specsavers as opposed to the range of providers with DVLA approval in 2015. Those rating the experience as excellent has dropped slightly from 28 per cent in 2015 (n: 235) to 22 per cent (n: 72) in 2017. However, there has been an increase of four per cent in people rating the experience as good and fair to 57 per cent and 15 per cent respectively. Importantly, the percentage rating the experience as poor has fallen by two per cent to six per cent in 2017. The reason why many of you rated their experience positively was due to clear explanation and the patience of staff.

- “Staff member went out of way to put me at ease.”
- “Person conducting test was very sympathetic and helpful, when conducting the tests and explained procedure.”
- “Clear instructions, encouraging responses.”

Visual field test
There has been no real change in the way that people rate their experience of taking the visual field test, with 22 per cent saying it was excellent and 19 per cent saying it was fair, there is a one per cent decrease in 2017 with those rating it as good (39 per cent) and
Experience

one per cent increase (to 20 per cent) in those saying it was poor. The main criticism is in relation to the busy Specsavers stores and the location of the visual field testing equipment with 35 per cent of people who responded feeling that the test was not conducted according to DVLA quality standards, which stipulate a quiet location, free from distraction. This compares to 23 per cent in 2015 who felt the location was not appropriate.

- “Specsavers was busy with many interruptions while doing the test.”
- “Small room, open to a busy corridor, difficulty moving chair and positioning in front of screen unsatisfactory.”
- “Door-less cupboard with busy shop.”
- “Specsavers was in Sainsbury’s, very noisy.”

The number of members’ saying that the operator gave clear instructions about what to expect from the visual field test rose by nine per cent from 72 per cent in 2015 to 81 per cent in 2017. Many welcomed the patience of staff and four out of 10 (n: 134) were offered more than one attempt at taking the visual field which was found to be reassuring:

- “As reassurance, lady said I could repeat if necessary.”
- “Did better second time.”
- “Said it was my right to have a second test, as the first one was poor.”

The IGA recognises the anxiety this test can cause, so we believe it is vital that staff are made aware of what this test means to everyone with glaucoma, and that quality care is received at all testing optometrists:

- “No care taken by Specsavers staff, felt I was a nuisance.”
- “The staff at Specsavers were polite and helpful but I felt that they did not understand the importance of the test and were unable to answer some of my questions.”

Copy of visual field
Nine out of 10 of you were not given a copy of their visual field but the fact you can request this was only introduced late in 2016.
Experience

DVLA response rate
There has been a significant improvement in the speed in which the DVLA respond to applications for a licence renewal with 60 per cent (n: 170) of people receiving a decision within one month from the initial notification, compared to 39 per cent in 2015.

Pass/fail rates
Although numbers are small, there is still a high percentage of people passing the visual field on appeal. In the IGA survey 14 per cent (n: 66) of motorcycle/car drivers failed, a third reapplied (n: 25), and two thirds then passed (n:15).

To supplement this data, IGA requested updated statistics from the DVLA to compare 2015 with 2016 data to see how many people with glaucoma pass on appealing the DVLA decision. This shows that 62 per cent (n: 587) of the 947 who appealed the car/motorcycle test passed on appeal in 2015 which is similar to 2016 when 63 per cent (n: 514) of the 817 passed on appeal.

The numbers with an absolute pass after taking the DVLA test has reduced slightly from 96 per cent in 2015 to 92 per cent by end 2016 for drivers of cars and motorcycles whereas drivers of heavy goods or passenger vehicles has remained the same, 90 per cent.

Right of appeal
Encouragingly, the introduction of a less formal right of appeal where a person can submit additional medical information or pay for a visual field test at an independent optometrist is percolating through with 66 per cent (n: 273) of those who responded knowing that this is an option. [The DVLA then considers the best test result, and if the independent optometrist result is favourable, the DVLA allows re-application and will send for a further test at Specsavers].

Other issues
You have provided further comments on the DVLA about the tone of the letters, how the website is marketed and clarification needed about the process. These comments will be fed back to the DVLA so that further improvements can be made.

Supplementary information was provided by some of you. There is criticism of the test that is used, the fact that machinery and software can differ across outlets, the seating position can be difficult particularly if you are elderly, a number of you would like a return
Experience

to using your independent optometrist for the tests, others do not understand why hospital records for visual fields cannot be used to assess driver safety.

- “I am aware of research work which suggests the Esterman test could usefully be supplemented by other tests to show awareness when driving. Seems essential as population ages.”

- “Was the test designed to incorporate the loss of visual field [for driving]? Was it rigorously tested for appropriateness and effectiveness? Perhaps more than one test should be used.”

- “We need a test which more accurately reflects real life driving ability based on virtual reality, not dots of light on a screen.”

Other points raised include the fact that there are non-tested elderly people on the roads who should not be driving, and the need for mandatory eye sight testing for driving.
Experience

IGA Services

We asked you to rank five IGA services in order of importance with one being the most important and five the least. In contrast to previous years, the 2017 survey shows that information and advice is the most important aspect of our work. This is followed by work around driving, research and hospital appointments scoring almost an equal second with patient support groups far behind.

Word of mouth is important to the IGA and we are grateful that 64 per cent of you have recommended or passed on information about IGA services to others. The top three services most frequently recommended or shared are membership (30 per cent), followed by the magazine (23 per cent) and leaflets and information (20 per cent).

Out of those who provided additional comments, the IGA News magazine is recognised as a valuable resource and Sightline is highly praised. There is a recognition that although there is more awareness of glaucoma now, with more leaflets in hospitals, more needs to be done. Although patient support groups ranked last, this is likely due to most of you not attending such groups as members who have ranked them, speak highly of what they have learnt:

- “I learned more from attending a patient support group in Yeovil than I had in 20 years.”

The work with the DVLA is recognised and realised as being effective. Many of you mentioned the value of research and the importance of the annual lectures as providing helpful information.

Sightline

- “Sightline was invaluable.”

- “I was diagnosed 30 years ago and still have some reasonable sight. The IGA has enhanced this by offering a personal involvement and increasing an awareness of advancement in treatment and interest in research. Thank you.”

- “I contacted the IGA by email to enquire about travel pills. I always thought you couldn’t take them if you had glaucoma. The reply was very helpful and I now know I can take them if needed.”
Experience

- “Thank you to Sightline for the invaluable service they provide, and which I have used on many occasions.”

- “Only when my daughter rang IGA helpline did I receive any advice, I was grateful and joined IGA.”

Sightline helpline

Support and advice
9.30am - 5.00pm Weekdays
01233 64 81 70

Membership

- “Thank you for continuing to provide printed material, please do not assume that the internet and use of screens in particular suits the eyesight of all glaucoma sufferers.”

- “Reasons for being an IGA member for 27 years:

1. I want to know as much as possible about my glaucoma.
2. I wanted to be kept informed about future developments in treatment and research.
3. I want to attend lectures and participate in the Q&A forums that follows.
4. I want, through donations and memberships, to fund these activities.
5. I want to have ready access to advice relating to my treatment without having to consult my surgery or consultant.

“All these needs have been met by the IGA. I like the IGA News magazine. I have valued my membership over a long period.”
Experience

Awareness

• “My pressures were always 16 at my regular eye tests. I'm quite short-sighted. By the time I was diagnosed, deterioration had started. The IGA could publicise the importance of including fields in the test and the patient insisting.”

• “Had no knowledge of glaucoma and lost sight in eye, I wonder if there ought to be more done to make people aware of eye diseases of all types”

• “I didn't go to the opticians for years because I couldn't afford the glasses. I used over-the-counter glasses for reading, sight deteriorated slowly so it isn't terribly noticeable. There is a need for more publicity everywhere. If I had known years earlier I wouldn't be constantly in danger of becoming totally blind now.”

• “Awareness and early diagnosis is what I feel will save sight. Run awareness campaigns in public places such as shopping areas, achieve a success, you never know.”

• “More is needed to make people aware of glaucoma as an asymptomatic condition.” (This is stated by people who have lost vision at the point of visiting the optometrist).

Magazine

• “When I was first diagnosed with glaucoma the consultant suggested that contacting the IGA was a good idea. It was reassuring to me right from the start to know about what you do.”

• “I enjoy the magazine because it is scholarly and does not talk down to me. I respect the IGA because it is informative and takes on current problems and is persistent in trying to improve things.”

• “I find your IGA magazine most helpful and instructive. I should like to praise Sightline, I have found this service most helpful and reassuring.”

• “Your IGA magazine is very informative. I think you should charge more for it to help with finances.”
Experience

Research

• “IGA has been a great practical help and education. The information on research and developments would not be available from, any source I know of.”

• “The article on lens extraction is most interesting and very relevant to me, all your research articles are brilliant.”

• “Without the research and tests done by experts in this field, I and many others would probably be blind.”

Next steps

Thank you to you all.

The results from this survey are rich and relevant. They will be used both internally and externally. We look forward to sharing news of our projects and services for the future.

Karen Brewer
Editor
IGA Drops And You (#DropsAndYou)

Each year the IGA joins together with other eye care charities and organisations to promote the importance of eye health and the need for regular sight tests for all. This year, the IGA is launching a campaign encouraging people to understand the role that eye drops play in glaucoma, and demonstrating techniques and equipment which is available to help.

Entitled IGA Drops And You we have produced a series of short films featuring our Business Development Manager, Subhash Suthar. Subhash is passionate about talking to people about the eye drops, and demonstrating simple and easy ways to take drops. As a qualified pharmacist, Subhash has great empathy with people who have been told that drops are for life, but are not shown how to put the drops in the eye, or what equipment can help.

The short films are available on our website: www.glaucoma-association.com and cover the following topics:

- Eye drop treatment
- Why you have been prescribed eye drops
- Opening the bottle
- Different techniques to put eye drops in (part one)
- Different techniques to put eye drops in (part two) including single dose unit
- When to put drops in
- Putting in more than one drop and wearing contact lenses
- Using eye drop dispenser – Autodrop
- Using eye drop dispenser – Opticare
- Using eye drop dispenser – Opticare Arthro
- Using eye drop dispensers – Thea Eyot and Dropaid
Awareness
Top tips for instilling eye drops

- Wash your hands
- Find a comfortable position (sitting on a chair, laying on the bed)
- Shake drop bottle gently
- Lean back, pull down lower lid
- Administer one drop, close your eye and put your finger over the inner corner of your eye for up to two minutes
- Repeat with other eye, if necessary
- If you have to administer more than one type of eye drop, wait five minutes
- If you wear contact lenses, remove the lens before you administer the drop and wait 15 minutes before putting the lens back in the eye

- Get into a routine, if your eye drop doesn’t need to be in the fridge put the bottle by your toothbrush. If you use a drop more than once a day, make sure the times are evenly spaced.

- If you don’t know if a drop has gone in the eye, try keeping it in the door of a fridge, you will then feel the drop going in the eye.
Editor’s introduction
A key role for our regional staff is to educate professionals and students about glaucoma and the issues that some people with glaucoma experience in relation to eye drop treatment. The following article has been provided by the University of West London (UWL) talking about the knowledge which is gained and why this work is important.

The value of International Glaucoma Association in Ophthalmic Nursing Education – its impact on patient care.

Written by ophthalmic nursing students on Post-Registration Ophthalmic Nursing Education and by Module leader - University of West London (UWL).

Ramesh Seewoodhary: Senior ophthalmic nursing Lecturer - Module leader, UWL

Daniel Buttress: Post registration ophthalmic nurse at UWL - Eye Research Group Oxford

Pauline Seymour: Post registration ophthalmic nurse at UWL - Eye Unit Royal Berkshire Hospital

Rita Sunari Magar: Post registration ophthalmic nurse at UWL - King’s College Hospital

Maria Jose: Post registration ophthalmic nurse at UWL - King’s College Hospital

Zuzana Bans: Post registration ophthalmic nurse at UWL - Hillingdon Hospital

Mamibeth Mendy: Post registration ophthalmic nurse at UWL - Kingston Hospital

Introduction
Glaucoma is one of the many eye conditions more easily managed the earlier it is detected. The ophthalmic nurse is a key member of the multidisciplinary team in glaucoma management across the country. Health promotion and patient empowerment are both key factors in enhancing a patient’s own ability to treat and manage their own condition. The University of West London ophthalmic nursing students have benefited from talks by IGA staff for the last four years. This has helped to develop an insight into patients’ issues and provided them with practical advice.
People with glaucoma tend to be managed by a range of professionals including the ophthalmologist, optometrist, ophthalmic nurse and pharmacist. Ophthalmic nurses are valuable members of the team. In some ophthalmic units across the UK, ophthalmic nurses are actively involved in ‘Glaucoma monitoring clinics’ and this is proving to be very beneficial to patients.

**Feedback from ophthalmic nursing students**

As glaucoma is a chronic, life-long condition, the difficulties and challenges that glaucoma patients feel cannot be underestimated. It is a condition which affects people worldwide. As ophthalmic nurses we felt that listening to talks from organisations such as the IGA, is an excellent way of updating our own knowledge base as well as providing patients with up to date information and treatment plan options.

It is important to have the input and expertise of Subhash Suthar (D Pharm), development manager within the International Glaucoma Association on our ophthalmic nursing course. He speaks passionately, with well-established and respected knowledge on a subject of immense complexity and increasing great importance in ophthalmic nursing. Ophthalmic nurses work with glaucoma patients on a daily basis and it is not uncommon to find patients returning to Accident and Emergency (A&E), outpatients or the ward due to preventable complications such as raised intraocular pressures brought about by a lack of basic understanding a treatment about treatment such as eye drops. Allowing this to continue could have detrimental effects both psychologically on the patients but also financially on the NHS with patients requiring more invasive intervention further down the line. As ophthalmic nurses we need to constantly assess how we can contribute to positive patient outcomes.

Subhash gave us an insight into patient concerns and factors which influence patient non-concordance. This included a lack of information on glaucoma, poor drop instillation techniques, medication costs, and confusion over administration times. Subhash informed us that patients are often advised to administer eye drops before going to bed, however, people may go to bed at different times every night. Patient’s individual beliefs is an interesting point to note; patients may not see a difference in using eye drops so begin to feel they don’t need them. There may also be a perception of compassion deficit on the part of the medical professional due to decreasing consultation times. Subhash has an insight into patients’ issues that lead them to discontinuing with treatment this is based on his personal patient experiences and also from working collaboratively with ophthalmic nurses in various trusts across the country.

He offered various solutions during his lecture regarding effective drop instillation technique which many patients have found beneficial and useful. One interesting example
he gave us in his talk was by demonstrating his pioneering ‘wrist and knuckle’ eye drop instillation method.

He also mentioned the language barriers which many patients from the ethnic groups encounter when they attend the glaucoma clinic. Very often some patients have very little understanding or no understanding at all of what the doctor might have said to them. He was also able to demonstrate how his own multilingual abilities demonstrate a positive approach to interaction within a growing multi-diverse patient group, evident in hospitals and primary care settings nationwide.

As ophthalmic nursing students we feel the insight into the issues experienced by people with glaucoma has been an eye opening experience and provided us with a basis from which to improve our clinical care techniques and compassionate approaches. Patients’ dignity and compassionate care are the fundamentals of ophthalmic nursing. Subhash has instilled into us how important the ophthalmic nurses’ role is when working in the glaucoma service.

Patient education is a key concept on which to focus our efforts. Learning from the nurses and doctors as well as outside sources such as the IGA, as long as all parties are providing the same accurate standard of evidence based information. This would increase patient confidence in the system, meaning they would be more likely to disclose difficulties and be more open to change, thus avoiding non-concordance scenarios. Some nurses on the ophthalmic nursing course already have IGA initiatives such as support groups within their Trusts, which have been well attended and had positive feedback.

As a group we believe in the support and guidance put forward by the IGA. Individually we will be approaching our own Trusts to implement these well-established strategies. There does however, need to be a national drive to set up glaucoma help desks and support meetings to empower a vastly growing patient group to take back control of this chronic condition and halt progression. This would reduce A&E attendance, promote better compliance with eye drops enabling greater IOP control and arrest progression of visual field loss.

**Conclusion**

Patients’ concordance is still an ongoing issue with some patients in the country and across the world. No one needs to go ‘blind’ from glaucoma if patients are empowered and educated to an optimum level. Caring for glaucoma patients requires collaboration of various team members. Preserving vision is the most rewarding commodity as sight is priceless. Ophthalmic nursing education is the platform on which we can build a better future for the glaucoma patients and their families.
Shine a Light this Christmas

At Christmas our thoughts often turn to those close to us. It is a time when we cherish as well as remember those we love.

Shine a Light offers an opportunity to share precious memories as well as celebrate those special to you while raising money to support others with glaucoma. Whether you wish to remember someone who is no longer with us, celebrate a new life or simply share a Christmas wish or message with friends or family, this is a way to make a tribute to those you hold dear.

You will find two baubles within this copy of the IGA News (unless you have requested not to receive fundraising appeals). To celebrate someone special or to share your Christmas message, add your personal dedication to one bauble, hang it on your tree or place it somewhere to decorate your home. Please return the other one, again with your personal message, together with your kind donation to us within the enclosed pre-paid envelope. This will be hung on the IGA Christmas Tree which will be formally lit up on Thursday 21st December, shining a light for those with glaucoma this Christmas.

Pictures of the fully lit tree with your dedicated baubles will be available on the IGA website and social media from 3pm on Thursday 21st December 2017.

Please return your bauble to us by Wednesday 20th December to ensure your dedication is included for the grand tree light switch on.

To request more baubles to share with friends and family, or if you did not receive any, please call 01233 64 81 64.
Did you know that your membership payments are eligible for Gift Aid?

**Gift Aid** is a simple way to increase the value of any donation to the IGA.

As well as donations, the HMRC allows us to gift aid membership payments you make, as we can give our members some small benefits. These include:

- Quarterly newsletters about the work of your charity
- Opportunities to view and visit your charity’s work
- Opportunities to take part in activities organised by your charity

So, a membership payment of £17.50 could add a further £4.38 for any qualifying donor, and it can be applied to payments made by Card, Direct Debit or Cheque.

If you pay UK Income and/or Capital Gains Tax on your earnings or savings to cover the amount that charities will reclaim on all the donations you make, then you too could increase the value of your gift by 25 pence in the pound.

If you are able to gift aid your valued contributions, and want to check to see if the IGA has a declaration for you, please contact Natalie on our supporter telephone number 01233 64 81 71 or email us at support@iga.org.uk

*gift aid it*
Christmas Cards - £5.99 (one pack of 10)

The message inside all cards reads: ‘With Best Wishes for Christmas and the New Year’

Christmas Stockings
Ref. 660

14 x 14cm

Robins in the Tree
Ref. 661

14 x 14cm

Bethlehem
Ref. 662

14 x 14cm

Santa’s Little Friend
Ref. 663

15 x 15cm

Carols around the Tree
Ref. 664

15 x 15cm
How to place your order

Ring the IGA Orderline on 01233 64 37 90 and pay by credit or debit card
Order online at www.glaucoma-association.com

Post the completed order form enclosed in this newsletter, and your cheque made payable to IGA, to us at:

IGA, Woodcote House, 15 Highpoint Business Village, Henwood, Ashford, Kent TN24 8DH

All prices include postage and packing

Charity registered in England and Wales No. 274681 and in Scotland No. SC041550 Registered Company No. 1293286
A day in the life of Subhash Suthar
Business Development Manager

1. My role
I am one of the Business Development Managers for the IGA. We are a team of three. My area of coverage is fairly extensive, covering Norfolk down to Sussex and in between. My role is a creative one as it entails creating education programmes for the benefit of patients. I work with ophthalmology units in hospitals. Encouraging the units to organise regular talks in an informal setting helps both patients and professionals to understand how treatment works and why it is important. The number of people being diagnosed with glaucoma is growing and this is having a significant impact on the NHS services.

Glaucoma is a long term condition. The majority of people who are diagnosed will be prescribed eye drops to help to control the intraocular pressure. This sounds straightforward but many people do not see a perceived benefit to taking eye drops, and this can lead to discontinuing treatment. Sadly this means that there will be a gradual loss of vision. Other treatment includes laser, minimally invasive glaucoma surgery (MIGS), implant and trabeculectomy.

The patient support groups I help to set up provide a place where people can understand the complexity of managing glaucoma treatment. This leads to a better understanding of how treatment works which is good for the patient and for the professionals managing them. It’s a win-win for everyone involved. I have 32 patient support groups and growing!

I get invited to give talks at the clinical meetings in ophthalmology, pharmacy, optometry, post-graduate nurse courses at university, general practitioner meetings, local charities, ethnic group meetings, churches, temples and other social groups as well. At these meetings the focus is always on the person with glaucoma, to make people aware of the condition, to give as much advice and information as possible.

More people with stable glaucoma are now managed by a range of professionals. This means that it is imperative that all professionals are included in the educational programme. One thing I realised as a pharmacist myself is that the management of a long term medication regime is a problem. This is particularly true with people who have been
The patient support groups I help to set up provide a place where people can understand the complexity of managing glaucoma treatment.

prescribed eye drops. Apart from the fact that the patient does not feel that there is any perceived benefit, there is also the issue of instilling the eye drops, which can be compounded by irritation, hyperaemia, frequent changes of the bottles, multiple bottles as well as unit doses. Elderly patients with multiple health issues may include rheumatic arthritis and tremors in the hands.

It was all of these issues which led to a drive which has resulted in the IGA Drops And You campaign. I am fortunate to be working with premier institutes in ophthalmology, teaching hospitals with a great network of receptive professors, consultants, specialist nurses, optometrist, pharmacist, who have supported my efforts.

The content of my presentations covers why, how and when you should take drops:

**WHY** have been drops prescribed?  
**HOW** do drops work?  
**HOW** should they be put into the eye?  
**WHEN** do you put them in?

At the end of this talk the response from the audience gives me huge satisfaction. When a patient comes up to say “thank you” for helping me understand and showing me a good technique for putting in the drops, is very humbling and very moving.

2. **How I got to where I am today**  
My school in Moshi, then Tanganiyika, now Tanzania, East Africa, was affiliated to Cambridge University. After receiving my degree, I went to study pharmacy in India. After my graduation I couldn’t see myself working as a dispensing pharmacist or in manufacturing. It was my Principal who encouraged me to go into sales and management. I worked as a Clinical Application Specialist for Schering Plough for...
various disease areas across South East Asia. It was in Israel where I was trained to work in ophthalmology. Working for Merck Sharpe & Dohme is where my association with the IGA began. It has been a privilege!

3. A typical day
Most days start with an early morning breakfast meeting with a glaucoma unit encouraging them to recognise the importance of educating people with glaucoma about the condition, and how patient support groups help. Some days involve training units on how to use the various aids which are available to help with taking eye drops. I often have display stands during our annual awareness weeks in various hospitals in London.

I am often involved in late evening clinical meetings. Again the focus is on patients. Administration too is a very important part of my work: replying to queries, juggling appointments, reading through large amount of medical journals. I also ensure that I am up-to-date through attending national and international seminars on therapies and diagnostics as well.

4. Issues affecting my work at the moment
The pressure on the NHS, the shift to various professionals managing people with glaucoma, limited resources and also a lack of understanding of the complexity of managing glaucoma are all issues which affect my work. Clinical commissioning groups and hospital care are all under financial pressure.
5. The moment I’ll always remember
Meeting my wife-to-be in Pharmacy College, holding my first born and the second one! Taking cover in a supply truck when two huge African elephants walked into our campsite in Amboseli!

Climbing Mount Kilimanjaro, watching the sunrise across the Savannah, being solaced by a lovely Jewish lady who was an Auschwitz survivor at Yad Vashem in Jerusalem, getting a big warm hug from a glaucoma patient whom I had taught the correct technique of using her eye drops! There are so many moments that I remember!

6. What I love about what I do
I am “Making a Difference.” Meeting very caring people means that each day brings a new experience, I learn a lot! I love the independence and the responsibility it brings along with it. I have a great team of people at IGA who are always so supportive.

7. One thing I wish I’d known when I started
The complex way NHS works so disjointedly!
Support groups

Our patient support group model is based on recommendations from the NICE Glaucoma Guidelines published in 2009 and followed up with the NICE Glaucoma Management Quality Standards two years later which recommend that a support group should be initiated by each hospital. The concept of these groups is to allow patients to meet their health care professionals in a relaxed atmosphere, away from the time restricted atmosphere on out-patients, so the condition and treatment can be discussed in more depth. It does require the presence of at least one of your local health care professionals whether it be an ophthalmologist, an optometrist or an ophthalmic nurse.

There are over 70 patient support groups nationwide. These pages provide details of those that have scheduled dates. To see if there is a group in your area, visit our website on www.glaucoma-association.com

| Buckinghamshire | The Ridgeway Centre, Wolverton Road, Milton Keynes MK12 5TH  Jill Kimber  •  01908 99 55 23 |
|                 | Date: 13.10.17  Time: 6.00pm |

| Derbyshire      | Buxton Methodist Church, Chapel Street, Buxton SK17 6HX  Norma Ayres  •  01298 21 28 50 |
|                 | Date: 6.10.17  Time: 1.30pm |

| East Yorkshire  | Hull and East Riding Glaucoma Group, Beech Holme, Beverley Road, Hull HU5 3HS  Kay Slingsby  •  01482 34 22 97 |
|                 | Dates: 13.10.17  8.12.17  Time: 11.00am |

| Gloucestershire | Gloucestershire Glaucoma Group, Redwood Education Centre, Gloucestershire Royal Hospital, Great Western Road, Gloucester GL1 3NN |
|                | Date: 20.10.17  Time: 2.00pm |

| Lancashire      | Eye Unit Seminar Room, Royal Bolton Hospital, Minerva Road, Farnham Glaucoma Team  •  01204 39 03 90 extn. 4806 |
|                | Date: 2.11.17  Time: 1.30pm |
## Support groups

<table>
<thead>
<tr>
<th>Region</th>
<th>Details</th>
<th>Dates</th>
<th>Time</th>
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</thead>
<tbody>
<tr>
<td><strong>Scotland</strong></td>
<td>Glaucoma Support Edinburgh, RNIB, 12-14 Hillside Crescent, Edinburgh</td>
<td>27.9.17, 25.10.17, 29.11.17</td>
<td>2.00pm</td>
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<td></td>
<td>John Hughes • 07889 10 21 89</td>
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<tr>
<td><strong>South Yorkshire</strong></td>
<td>Sheffield Royal Society for the Blind, 5 Mappin Street, Sheffield</td>
<td>11.12.17</td>
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<td>S1 4DT</td>
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<td></td>
<td>Joanne Arden • 0114 27 22 757</td>
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<tr>
<td><strong>Wales</strong></td>
<td>The Langland Room, School of Medicine, Singleton Hospital, Swansea</td>
<td>6.12.17</td>
<td>1.30pm</td>
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<td></td>
<td>SA2 8QA</td>
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<tr>
<td></td>
<td>Susan Neale • 01792 20 03 90</td>
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<tr>
<td><strong>West Lancashire</strong></td>
<td>Southport and West Lancashire Support Group, Royal Clifton Hotel,</td>
<td>22.11.17</td>
<td>2.30pm</td>
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<td></td>
<td>Winsor II, The Promenade, Southport</td>
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<td></td>
<td>Pam Ladlow • 01772 81 36 15</td>
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Updated Support Group details from across the UK can be found on the [IGA website www.glaucoma-association.com](http://www.glaucoma-association.com) or by calling **Sightline on 01233 64 81 70**
Charity Gift Aid Declaration
Did you know you can boost your payment by **25p for every £1 through Gift Aid**?
Please tick one of the boxes below:

- [ ] Single donation
- [ ] Any donation I make in the future or have made in the past four years

I am a UK Taxpayer and understand that if I pay less income tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference.

Name ..............................................................................         Postcode  ....................................
Signed ..............................................................................       Date  ...........................................

Please let us know if you want to cancel an existing declaration, have changed your name or address or no longer pay sufficient tax.

Data protection
Your information is held on a database within the UK. The database will be administered and controlled by the IGA. By completing this form, you agree that we may use the information in the following ways:

- To maintain records of donations and requests for information
- To use for future requests for support

Only the IGA will have access to your information. It will not be disclosed to other third parties, except to the extent required by the laws of the United Kingdom.

- [ ] I am happy to hear from the IGA, via post, about how my support is helping people with glaucoma and how I could contribute further to prevent glaucoma sight loss.