



The Charity for People with Glaucoma

Running a Glaucoma Support Group

Getting started

February 2020

V1.0

www.iga.org.uk

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Introduction

Thank you for showing an interest in running a Glaucoma Support Group (GSG) in your area in partnership with the International Glaucoma Association (IGA).

We have created this tool kit to provide the guidance and support you need. However, if you have further questions, please visit our website, www.iga.org.uk or contact us:

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This tool kit is a new initiative, and we would be grateful for any feedback or comments on its usefulness and how we could improve it.

Why set up a GSG?

GSG Getting Started

May 2019

Part of the IGA's mission is to provide support to patients with glaucoma and all those who care for them. GSGs are one of our most effective tools in helping to achieve this.

Our model is based on the NICE Glaucoma Guidelines (2017) which recommends that a support group should be initiated by each hospital.

The concept of these groups is to:

- Provide support to people living with glaucoma and their friends and family locally;
- Allow patients to discuss the condition and treatment and meet their health care professionals in a relaxed atmosphere away from busy clinics;
- Increase awareness of glaucoma and the importance of regular eye tests for those at risk;
- Inform patients of other avenues of support such as the IGA or community-based services;
- As well as supporting patients emotionally, we believe these groups have a significant impact in eye drops compliance, thereby improving patient outcomes.

The NICE guidelines also include a useful list of information which should be provided to patients. This is extensive, and more than can likely be covered within an individual's appointment. Glaucoma Support Groups are therefore an effective means by which to deliver this information. This list is provided in [appendix 1](#).

IGA involvement

Our role

The IGA will help in establishing the GSG. Limited start-up funding is available to assist with costs – further information is available in [appendix 2](#).

Longer term, we are always available to provide materials, guidance, help publicise your GSGs and to share contact details for possible speakers or organisations you may wish to engage with. We will attempt to make a member of staff available for a planned meeting if requested. With prior agreement you can use the IGA's logo and name to publicise the relationship between the GSG and the IGA.

Your role

The 'ownership' of the GSG, including any liability for any activities, remains with the host organisation. The host organisation is responsible for the ongoing administration and costs, including finding a suitable location.

The GSG organiser must alert the IGA of any event of incident which might adversely affect the work or reputation of the IGA, including any third-party use of the IGA's logos and names.

Getting started

To identify demand within your department for a GSG, it might be worth running a patient survey. This will help to establish what support patients might need and how the GSG should be run. It may also assist in securing funds from managers. A sample survey is provided in [appendix 3](#).

GSGs are normally linked to an ophthalmic unit in a hospital, but this is not exclusively the case. We recommend holding GSGs every six months. Vary the day and time of meetings to maximise attendance and avoid late afternoons in winter. Aim for a meeting lasting around 2 hours. A sample format:

- Introductions
- Two or three speakers (30-60 mins each), who can provide more information on glaucoma and treatments, or support available in the local area. Good people to invite are:
 - Ophthalmologists (this usually helps to guarantee a good turn-out)
 - Nurses
 - ECLOs
 - Pharmacists (community or hospital)
 - Optometrists (as above)
 - Clinicians from other relevant specialisms e.g. falls, diabetes
 - Local support services, e.g. other charities or council services
- A break between speakers, with refreshments provided if possible. You may wish to ask for a donation to cover costs
- A Q&A session (min. 30 minutes) provides an opportunity for patients to ask more open questions to attending experts

Ensure any presentations are accessible, and remind speakers of this. Some accessibility guidelines for presentations are provided in [appendix 4](#).

Location:

The meeting should be held in a relaxed, informal location. This might be a space within the eye clinic which is not in use every day – patients know where to go and staff are on hand to attend. Ensure patients have the time and space they need to ask questions and engage with the support group. Your hospital may be able to provide a meeting room free of charge. Try to find a location which:

- Is easily accessible and clearly signposted
- Has free parking and plenty of toilets
- Has adequate lighting, a large screen and a microphone/hearing loop

Suggested topics

Below is a list of topics which you might wish to cover in your GSG. The topics marked with an asterisk (*) are those which are generally of most interest to patients. We recommend covering these topics during the first few meetings, and relatively regularly after that.

- General information on glaucoma, including different types of glaucoma*
- Eye drops and compliance aids*
 - Why drops should be taken, how and when to take them and how they work

- Different types of drops
- Side effects
- Difficulties with instilling drops
- Range of compliance aids available
- Tests conducted during hospital appointments
- Current treatments options
 - MIGS
 - SLT
 - Trabeculectomy
 - Aqueous shunts
- New developments in glaucoma treatments
 - SLT vs eye drops
 - Virtual clinics and how they work for patients
 - Monitoring glaucoma in primary care
 - Evolution of eye drops
- Other conditions associated with glaucoma
 - Dry eye*
 - Cataract and glaucoma
 - AMD and glaucoma
 - Blepharitis
 - Charles Bonnet syndrome
- Living with glaucoma
 - Diet and exercise
 - Sleep
 - Falls
 - Support services available
- Driving and glaucoma*
- Risk factors associated with glaucoma, e.g. families, ethnicity, age

However, it is important to ask the attendees themselves for their input. The topics of interest to your patients is likely to depend on a number of factors, e.g. regional variations in care, ethnicity and age of patients, how long they have had the condition. An effective feedback mechanism will assist in this.

Feedback systems

To assess the impact of your GSGs you may wish to elicit feedback from each meeting. This will check you are meeting patients' needs and help in understanding what patients value. A sample feedback form is provided in [appendix 5](#). You will need to personalise these questions to each GSG.

It can also be useful to measure the impact of the presentations at the GSG. An alternative questionnaire provided in [appendix 6](#) asks the attendees how much they know about the topics to be covered, before and after the presentations. This provides more insightful data about the GSG, but is more complicated to administer.

We are always keen to hear more about the impact of GSGs. If you have feedback or data you wish to share with us, we would be grateful to receive this.

Planning and publicising your GSG

- Arrange speakers well in advance, confirming details in writing, including requirements for equipment
- Make as much “noise” as possible when publicising your events:
 - Notices in the hospital ophthalmology, care of the elderly and falls departments. A sample flyer is provided in [appendix 7](#)
 - Small handouts to give to glaucoma patients when they attend for their appointments
 - Notices in local GPs, opticians, pharmacies, community centres and libraries
 - Advertisements in the local newspapers
 - Announcements on local radio stations
 - Social media posts e.g. via the IGA, your hospital comms department
 - IGA News (3 months’ notice required) and the IGA website
- Local newspapers and radio stations will often advertise patient meetings free of charge. A sample press release is available in [appendix 8](#)
- Consider providing contact details on your invitation asking people to confirm attendance

At least two weeks in advance of the meeting:

- Order the materials, e.g. leaflets, you need from the IGA. We may also be able to assist in providing presentations for specific topics such as driving.
- Find a volunteer to welcome guests
- Re-confirm your speakers
- Organise a “back up plan” if your speaker is a health care professional – they could be called away to an emergency
- Conduct a site visit of the venue:
 - Is the right equipment available? Do you know how to use it?
 - How do you want the room set out? E.g. registrations on arrival, refreshments
 - Is the room dark enough to use a projector? Do you need an extension lead?
 - Do you need to write a risk assessment?
- Consider contacting people who have accepted and remind them about the meeting

On the day:

- You may wish to ask people to sign in, and to create a contact list for future events. A sample form is provided in [appendix 9](#). Make sure everything is GDPR compliant. In particular, if you write out to potential attendees, please ensure it is obvious the letter is coming from you, not the IGA.
- Tell your speakers you will warn them when they have 5 mins left to speak
- You may wish to agree and/or announce the date, time and venue of the next meeting
- Now is also the time to try and recruit some help for future meetings

Other activities of GSGs

GSGs may decide to run local publicity campaigns to publicise the group, enhance public awareness of glaucoma and encourage people at risk of glaucoma to have eye tests. These often run in conjunction with wider campaigns, e.g. National Glaucoma Week or National Eye Health Week. In addition, GSG members may decide to undertake fundraising on behalf of the IGA.

“Do”s and “Don’t”s of running a GSG

- The long-term success of a GSG can be dependent on the enthusiasm and effort of one or two individuals. Try to share the load among a few team members to provide more resilience
- Keep a note of individuals from other organisations who have volunteered to speak. There is space in [appendix 10](#) to record this, or you could save this electronically
- Ensure all handouts are in at least size 14 font. Try to have some large-print copies available too.
- During the Q&A session, repeat the questions asked to ensure everyone has heard
- Don’t get fixated on attendance numbers. Audiences naturally vary, and small groups can still provide valuable support to patients.

Appendix 1: Providing information to patients

(taken from Glaucoma: diagnosis and management, NICE 2017)

Offer people the opportunity to discuss their diagnosis, referral, prognosis, treatment and discharge, and provide them with relevant information in an accessible format at initial and subsequent visits. This may include information on the following:

- their specific condition (OHT, suspected COAG and COAG), its life-long implications and their prognosis for retention of sight;
- that COAG in the early stages and OHT and suspected COAG are symptomless;
- that most people having treatment for COAG will have good quality of life and not go blind;
- that once lost, sight cannot be recovered;
- that glaucoma can run in families and that family members may wish to be tested for the condition;
- the importance of the person's role in their own treatment – for example, the ongoing regular application of eye drops to preserve sight;
- the different types of treatment options, including mode of action, frequency and severity of side effects, and risks and benefits of treatment, so that people are able to take an active part in decision-making;
- how to apply eye drops, including technique (punctal occlusion and devices) and hygiene (storage);
- the need for regular monitoring as specified by the healthcare professional;
- methods of investigation during assessment;
- how long each appointment is likely to take and whether the person will need any help to attend (for example, driving soon after pupil dilatation would be inadvisable);
- the eye clinic liaison officer (ECLLO);
- support organisations and support groups;
- compliance aids (such as dispensers) available from their GP or community pharmacist;
- Letter of Vision Impairment (LVI), Referral of Vision Impairment (RVI) and Certificate of Vision Impairment (CVI), registration;
- Driver and Vehicle Licensing Agency (DVLA) regulations. [2009, amended 2017].

Appendix 2: Applying for IGA funding

The IGA can provide limited start-up funding for your GSG. If you wish to apply for funding, please complete the form below and send it to us. We can then discuss your requirements.

Host organisation: _____

Item	Detail	Anticipated cost (£)	Funding requested from IGA (£)
Room hire			
Refreshments			
Publicity			
Other			
Total (£)			

Details of session(s) for which support is requested, e.g. dates, locations, previous GSGs held:

Name: _____

Role: _____

Email: _____ Phone: _____

Address: _____

Appendix 3: Patient interest survey

[Hospital/organisation] is interested in running a Glaucoma Support Group. This group would:

- Provide additional information to you about glaucoma, to help you live well with the condition
- Provide the time to ask questions about your condition
- Listen to guest speakers talk about related topics

The meetings would be held near here, roughly every 6 months, and last around 2 hours. We would be very interested to hear your views on these meetings. Thank you.

1. Are you a:

- | | | |
|---|--|--|
| <input type="checkbox"/> glaucoma patient | <input type="checkbox"/> ophthalmologist | <input type="checkbox"/> ECLO |
| <input type="checkbox"/> carer/relative | <input type="checkbox"/> optometrist | <input type="checkbox"/> other (_____) |

2. Are you interested in attending a Glaucoma Support Group?

- yes – regularly yes – occasionally no

3. What topics are you interested in hearing about? Tick all that apply.

- General information on glaucoma, including different types of glaucoma
- Eye drops and compliance aids
- Current treatments options
- New developments in glaucoma treatments
- Other conditions associated with glaucoma, e.g. dry eye, cataract
- Living with glaucoma, e.g. diet, exercise, sleep
- Driving and glaucoma

4. Which days and times suit you best for these meetings? Tick all that apply.

- | | |
|------------------------------------|------------------------------------|
| <input type="checkbox"/> Monday | |
| <input type="checkbox"/> Tuesday | <input type="checkbox"/> morning |
| <input type="checkbox"/> Wednesday | <input type="checkbox"/> afternoon |
| <input type="checkbox"/> Thursday | <input type="checkbox"/> evening |
| <input type="checkbox"/> Friday | |

5. Please provide any additional comments you have about these meetings

Appendix 4: Accessibility guidelines (taken from [VocalEyes](#))

Introduction:

- When you introduce yourself, explain the format of the session and when you will take questions.

General rule:

- If you display it, say it. Imagine that you heard a recording of your presentation on the radio. Would it make sense and would the listener fully understand all the information that was being put across? You should never find yourself saying 'you can read it on the slide' or 'as the graph shows'.

Showing text on slides:

- Only include the key points of your presentation;
- Limit the number of slides used and allow adequate time for the audience to read the visual aids;
- Speak in well-paced and well-modulated tones. Regularly monitor how fast you are speaking and try not speak too rapidly. At the beginning of the presentation, let people know that notes will be available in appropriate formats.

Font

- Recommended text size for Powerpoint etc: no less than 32 point;
- Use sans serif font types such as Helvetica, Arial and Verdana;
- Use mixed upper and lower case letters, not all capitals;
- Avoid italics;
- Do not use more than one font type per slide / presentation.

Layout

- Do not overlay text over an image or busy background;
- Use left justification;
- Have up to six lines of text with only about five or six words per line.

Contrast

- The colour of the text and background should offer a high contrast: using complementary colours;
- The highest brightness contrast is between black and white;
- A high colour contrast without brightness contrast cannot be read by colour blind people. In particular, they have difficulty with red-green perception;
- Use dark background colours and bright colours for the text to avoid glare;
- A white font on a deep blue background is a very good combination.

Figures and graphs

- Keep figures and graphs as simple as possible;
- Use brightness and contrasting colours in the same way as with text;
- Use sans serif font types for the text in the figures;

- Keep animation to a minimum;
- Explain figures and graphs;

Images

- Describe images on your slides if you have included the image as content.
- The length of the description should be dependent on the importance of the image to the subject of your talk, and its importance to the thread of the argument. If images are included as 'wallpaper' then there is less need to describe them.
- For example, if your slides are mainly bullet points, but you have included a series of images alongside them showing visitors at your museum, then it would be simplest to state this at the start, and give a brief description of your museum and the type of visitors that attend - and what activities they are shown engaging in, rather than describing each one. However, a talk about conservation with detailed images showing the results of treatment should each be described in more detail.
- Explain each slide in an expressive manner so that the audience understands which area of the slide you are referring to.
- Explicitly mention the region of interest in the slide, do not just point to it.

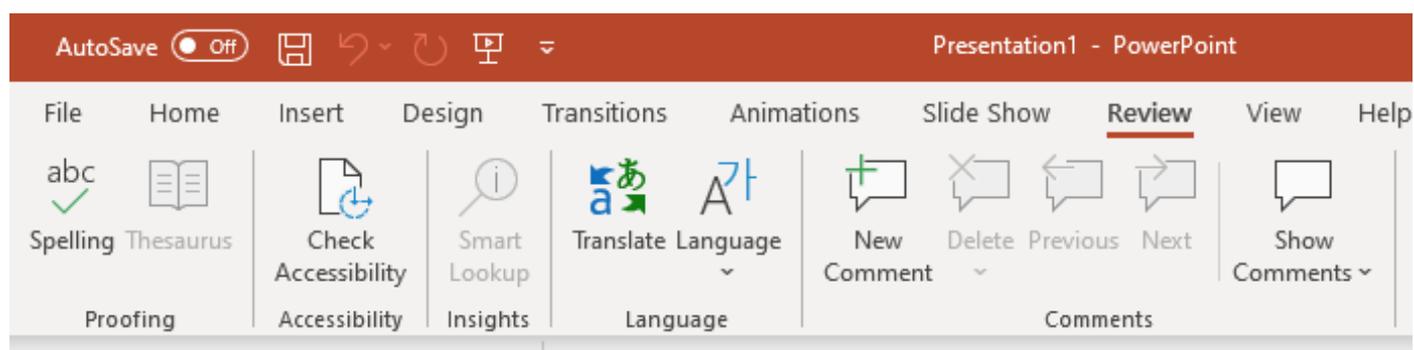
Video

- Depending on the specific video, you will likely need to do some audio description to support a person who has visual impairments to be able to get the most out of it. You have 2 opportunities to provide this:
 - before it starts
 - during the video (in gaps between recorded speech / dialogue)
- We recommend giving a short summary of the video before it starts, describing the setting, what or who is shown in general terms. During the video, if possible describe in short phrases any action, objects or scenes shown, if key to understanding.
- Voice the names of speakers if they are identified by captions, or any other text on screen. If there is little space for description during the video, then you will need to provide more beforehand.
- We recommend taking the time to prepare your audio description, writing the script into your notes, and practising a few times beforehand. If you have never heard audio description of film or TV before, we recommend browsing some examples on [BBC iPlayer](#). For an example of a written audio description of a video: Disabled Leaders in Dance on the British Council's Disability Arts International [website](#).
- Describe other visual information. For example, if you ask a question of the audience, summarize the response, e.g. 'Please raise your hands if you are from a local authority museum'...then you need to say 'About half raised their hand.'

Handouts

- Have some large print copies of your slides available for people before your presentation.
- Be aware that colour / contrast is lost in grey scale printing.
- Have your material available on a memory stick (USB) or available for download, so that people who use text-to-speech software (screenreaders) can put it on their own laptops

Microsoft has an accessibility checker built in to PowerPoint, and some useful [guidelines](#). Click “Review” and then “Check Accessibility” in PowerPoint. It will then provide you with some recommended actions.



Appendix 5: Sample questionnaire

Thank you for attending the Glaucoma Support Group held at [location] on [date]. We, [host organisation] and the IGA, are constantly seeking feedback on the services we offer to ensure they meet the needs of our patients. We would be very grateful if you could spend a few minutes providing feedback on today's meeting. Thank you.

6. Are you a:

- glaucoma patient ophthalmologist ECLO
 carer/relative optometrist other (_____)

7. How did you hear about this GSG?

8. How did you hear about the IGA?

9. How many times have you been to this GSG before today?

- never once twice three times more than three times

10. How would you rate the following...?

	Poor	OK	Good	Excellent	Comments
GSG overall					
Presentation 1					
Presentation 2					
Q and A					

11. What did we get right?

12. What can we do to improve?

13. What topics would you like to be discussed in future sessions?

Appendix 6: Alternative questionnaire

Thank you for attending the Glaucoma Support Group held at [location] on [date].

We, [host organisation] and the IGA, are constantly seeking feedback on the services we offer to ensure they meet the needs of our patients. We would be very grateful if you could spend a few minutes providing feedback on today's meeting. Thank you.

Answer these questions before the start of the presentations.

1. How much do you know about the following?

	Please circle; 0 = nothing, 10 = everything	Comments
My condition	0 1 2 3 4 5 6 7 8 9 10	
Topic of presentation 1	0 1 2 3 4 5 6 7 8 9 10	
Topic of presentation 2	0 1 2 3 4 5 6 7 8 9 10	

2. How positive do I feel about....?

	Please circle; 0 = negative 10 = positive	Comments
My condition	0 1 2 3 4 5 6 7 8 9 10	
Treatment at [hospital]	0 1 2 3 4 5 6 7 8 9 10	

STOP! Do not answer the following questions until after the presentations.

1. Are you a:

- glaucoma patient ophthalmologist ECLO
 carer/relative optometrist other (_____)

2. How did you hear about this GSG?

3. How did you hear about the IGA?

4. How many times have you been to this GSG before today?

- never once twice three times more than three times

5. How would you rate the following...?

	Poor	OK	Good	Excellent	Comments
GSG overall					
Presentation 1					
Presentation 2					
Q and A					

6. How much do you know about the following?

	Please circle; 0 = nothing, 10 = everything	Comments
My condition	0 1 2 3 4 5 6 7 8 9 10	
[Topic of presentation 1]	0 1 2 3 4 5 6 7 8 9 10	
[Topic of presentation 2]	0 1 2 3 4 5 6 7 8 9 10	

7. How positive do I feel about....?

	Please circle; 0 = negative 10 = positive	Comments
My condition	0 1 2 3 4 5 6 7 8 9 10	
Treatment at [hospital]	0 1 2 3 4 5 6 7 8 9 10	

8. What did we get right?

9. What can we do to improve?

10. What topics would you like to be discussed in future sessions?

[Host/NHS Trust]

Glaucoma Support Group

Join us to find out more about **[topics to be covered]**

Venue:

Date and time:

Speakers:

For details and to book your space, please contact:

telephone:

email:

[Tea & coffee provided]

In association with



IGA glaucoma helpline 01233 64 81 70

www.iga.org.uk

Enquiries 01233 64 81 64 Email: info@iga.org.uk

Charity registered in England & Wales No. 274681 and in Scotland No. SC041550

Appendix 8: Sample press release

The International Glaucoma Association (IGA) [in collaboration with] will be holding an event at..... The talk is free to attend and aimed at [anyone affected by, or at risk of, glaucoma].

Glaucoma is the name given to a group of eye conditions affecting the optic nerve. If left untreated, glaucoma can result in loss of peripheral vision, and in the most severe cases, blindness. Glaucoma is asymptomatic, which means you won't know your eyes are affected until damage to the optic nerve has occurred. Glaucoma can be detected by having regular eye exams and if identified, can be managed using eye drops and other treatments that help to slow down, and sometimes halt sight loss. Although any vision which has been lost from glaucoma cannot be recovered, with early diagnosis, careful monitoring and regular use of the treatment, the vast majority of people with glaucoma retain useful sight for life. The IGA estimates around 700,000 people in the UK have glaucoma, although around half are currently undiagnosed.

Why are you holding an event at that location? Tell us something specific about your event, e.g. "Philippa Mason, IGA Development Manager for Scotland, is based in Aberdeen and says "I'm keen to enhance glaucoma support services for all those affected by the condition in Scotland, and I am particularly excited about what can be done on my home patch in the North-East." The IGA usually run glaucoma meetings in hospitals but Philippa is keen to reach out into the community. She says "This is the first meeting we are doing in a library, and if successful, I hope to deliver more community based meetings across Aberdeenshire.""

If you would like to attend the talk at [location], please contact [name, email, phone number] for further details.

END

For further information please contact [name, number and email address]

The International Glaucoma Association (IGA) is the charity for people with glaucoma: we are a membership organisation, and glaucoma patients are at the very heart of all we do. We support people to live well with glaucoma by providing a telephone helpline, regional support groups, peer support services and widely acclaimed patient information booklets. We also fund research into the disease, and we campaign to raise awareness of glaucoma and encourage good eye health care. Our help is free to anyone who needs it.

The IGA is a charity, support their work and help save sight [donate](#).

Sightline glaucoma helpline: 01233 64 81 70 (Monday to Friday, 9.30am–5.00pm).

Let's keep in touch!

If you'd like to join our glaucoma community please give us your contact details and tell us what information you'd like to receive:

- Patient groups and events Yes [] No []
- Surveys Yes [] No []
- Glaucoma research participation Yes [] No []
- Fundraising appeals Yes [] No []
- Goods and products Yes [] No []

I would like to hear by post [] email []

First name _____ Surname _____

Address _____

Email _____

You can find out more about how we handle your personal data by viewing our Privacy Policy via our website www.iga.org.uk or request a paper copy by phone, by calling us on 01233 64 81 71. And remember, you can change the way we get in touch at any time, just by calling this number.

Registered Office: Woodcote House, 15 Highpoint Business Village, Henwood, Ashford, Kent, TN24 8DH

Charity registered in England & Wales No 274681 and in Scotland SC041550

Appendix 10: Useful local contacts

Name	Organisation and role	Phone	Email address

