

Patient standards for glaucoma



The Charity for People with Glaucoma



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There are many national standards covering patient experience and involvement in healthcare, such as those from NICE, which should be respected for patients with eye conditions. This publication outlines the standards for care which are very specific, or most important, to those with glaucoma-related conditions. The standards have been developed by patients, patient charities and eye care professionals working together. They include key elements from existing national guidelines brought together in one comprehensive document.

They should be used as a supplement to existing non-ophthalmic-specific-patient standards and cover the whole care pathway for those with glaucoma and related conditions. Those providing or commissioning care for these conditions should assess their services and, where the standards are not met, take action for improvement.

These standards should be read in conjunction with the UKOA-RNIB Patient Standards for Ophthalmology, available from <https://bit.ly/2xudPxJ>

Contents

Co-ordinated care pathways	2
Understanding and supporting patients	4
Shared decision making	8
Active participation of patients in care	8
Definitions	11
References	12

Co-ordinated care pathways

Referrals

- Establish services which allow people with non-urgent ocular hypertension (OHT, raised pressure with no evidence of optic nerve or visual field damage) or suspected glaucoma (visual field defects or suspicious optic nerve head appearance) to be assessed in the community before referral to a consultant ophthalmologist if glaucoma is still suspected. The additional examination in the community may take the form of “repeat measures”, “enhanced case finding” or “referral refinement”.
 - Primary eye care professionals should have the appropriate training, qualifications and competencies in glaucoma and appropriate equipment;
 - Primary eye care professionals should be able to refer people directly to a consultant ophthalmologist rather than having to ask a GP to refer.
- Refer conditions needing urgent care (such as very high pressure or acute glaucoma) directly and urgently to the hospital eye service (HES).
- Do not refer:
 - Defined low-risk subgroups who do not require treatment;
 - Solely based on IOP measurement using non-contact tonometry;
 - People who have previously been discharged from HES after assessment for glaucoma unless clinical circumstances have changed.

Discharge

- Discharge people back to primary eye care professionals if they were referred for OHT but do not need treatment, or they were referred for suspected glaucoma but this is no longer suspected.
- Advise people who are discharged from glaucoma assessment or monitoring to see a community optometrist annually.

Stopping or avoiding unnecessary treatment

- Do not offer treatment to people with OHT who are not at risk of visual impairment in their lifetime.
- Ensure people with glaucoma, suspected glaucoma or OHT are offered a regular discussion of management options, taking into account comorbidity and other circumstances, including a discussion of the benefits and risks of stopping treatment for those at low risk of visual impairment.

Monitoring

- Monitor low-risk patients using the most appropriate glaucoma trained health care professional (HCP) within the HES or community setting within an established network overseen by a consultant ophthalmologist.
- Monitor people with glaucoma, suspected glaucoma and OHT on the basis of risk at the frequencies recommended by NICE guidance and appointments booked in line with clinician requested timings.

Information sharing - healthcare professionals

- Ensure that all of the following are available at each clinical episode to all HCPs involved in active care:
 - records of all previous tests and images relevant to glaucoma and OHT, e.g. disc OCT, visual fields, cornea thickness;
 - records of past medical history;
 - records of other conditions which may affect glaucoma care, e.g. cataract, dementia;
 - current systemic and topical medication;
 - glaucoma medication record;
 - drug allergies and intolerances.
- Report lack of documentation through clinical governance channels.

- On discharge:
 - Give a discharge summary to the patient and send a copy to the GP;
 - With patient consent, send the discharge information and enough relevant clinical details to detect change in future tests, to the patient and their nominated community optometrist;
 - Advise people to take their discharge and clinical information with them when attending future sight tests.

Understanding and supporting patients

Adaptations

- Provide services which are accessible to all, meeting equality and diversity requirements, and sufficiently flexible for patients with different needs.
- Provide services which cater for the transport needs of those with significant mobility issues and are readily accessible in terms of location, affordable parking and public transport, and hours of opening.
- Commissioners should ensure access for hard to reach groups, including those with special needs. Vulnerable individuals, such as people in long term care or with learning difficulties, are at increased risk of sight loss and should undergo regular sight tests and screening for glaucoma if appropriate, including reasonable adjustments as necessary.
- Adapt to any factors such as physical or learning disabilities, sight or hearing problems, cultural differences and difficulties with reading or speaking English, which may affect the patient's involvement in the consultation.
- Use alternative methods of assessment if clinical circumstances rule out standard methods (e.g. when people with physical, sensory or learning disabilities are unable to participate in the examination).
- Establish the most effective way of communicating with each patient and, if necessary, consider ways of making information accessible and understandable (e.g. using pictures, symbols, large print, audio, demonstration, different languages, an interpreter or a patient advocate).

- Suit glaucoma medication to an individual patient's capacity to effectively self-administer. If a patient has physical problems applying the drops, such as arthritis of the fingers, the therapy should be adjusted accordingly, use compliance aids or switch to laser/surgery.
- Provide patients with ocular co-morbidities such as cataract or retinal conditions with holistic care from professionals who are able to understand, manage and explain the interactions of these conditions.
- Amend "Did Not Attend" and cancellation policies for patients with glaucoma, given the risk of preventable blindness:
 - All missed or delayed appointments should be risk-assessed by a clinician, and appropriate action taken based on clinical priority. Automatic discharge following a missed appointment is usually not appropriate;
 - Letters following up missed appointments should be sent to the patient in accessible formats (i.e. in the format they require) as well as to the GP and primary eye care practitioner;
 - Particular caution is needed for people with learning difficulties and failure to attend should be followed up with the patient's GP and care facility where relevant.

Information and support

- Offer people the opportunity to discuss their diagnosis, referral, prognosis, treatment and discharge, and provide them with relevant written information in an accessible format at initial and subsequent visits.
- Be careful not to make assumptions about a patient's ability to understand the information provided. Check with the patient that they have understood the information. Be ready to repeat the information and discuss further in subsequent visits.
- Hospitals should keep track of what information has been provided to the patient previously, e.g. via a check list, in case the patient sees different clinicians on various visits.

- Information given should include:
 - The name of their specific condition, its life-long implications and their prognosis for retention of sight;
 - Information on pressure, and visual fields and optic nerve changes and other factors, e.g. cornea thickness;
 - Early glaucoma, OHT and suspected glaucoma are symptomless;
 - If OHT, provide information on long-term risk of developing glaucoma;
 - Glaucoma is progressive and peripheral vision is usually lost first;
 - Most people having treatment for glaucoma will have good quality of life and not go blind;
 - Once lost, sight cannot be recovered;
 - Glaucoma can run in families and that family members can be tested for the condition under the NHS by their optometrist;
 - The rationale (lowering of pressure) and goals (retain vision) of intervention, the different types of treatment options (drops, laser, surgery). This should include mode of action, frequency and severity of side effects, and risks and benefits of treatment;
 - The likelihood that therapy, once started, will be long term. Many patients do not require laser or surgery;
 - Adherence to eye drops is crucial to prevent progression;
 - Information about storing and using eye drops (see below);
 - The importance of regular monitoring and attendance;
 - As much information on delayed and cancelled appointments as possible should be provided, e.g. expectations on duration of delay and reasons. For example if an appointment is delayed for a low-risk patient, this should be explained;

- How long appointments take and how frequently to expect these, with realistic estimates of waiting times;
 - Methods of investigation during assessment. If using dilating drops, cover driving restrictions to establish whether the person will need any help to attend appointments (e.g. if cannot drive home);
 - When the next appointment will be and how they will be contacted about this;
 - To get in touch if they do not receive their appointment in the expected time;
 - Sources of reliable information and support including patient support groups after the consultation: e.g. International Glaucoma Association (IGA), the Royal National Institute of Blind People (RNIB), SeeAbility, NHS Choices and local voluntary groups;
 - The regulations for driving and glaucoma (Driving Vehicle Licensing Agency (DVLA)) and advice on their current situation for driving.
- When the patient is discharged, discuss the procedure with them and ensure they understand their follow-up care in the community. Ensure patients receive a copy of their discharge letter in an accessible format and clinical information for their optometrist;
 - Provide easy access to an Eye Clinic Liaison Officer (ECLO) in the HES compliant with the RNIB ECLO quality framework.
 - Offer Low Vision Leaflet (LVL), Referral of Visual Impairment (RVI) or Certificate of Vision Impairment (CVI or CVI Scotland) to all people as soon as eligible, even during active treatment, to bring patients to the attention of social care services.
 - Provide access to low vision aid (LVA) services within the 18 weeks referral to treatment time.
 - Provide help with explaining the condition to employers at the patient's request if it is likely to impact occupation.

Shared decision making

- Involve patients as informed partners in decisions regarding the management of their condition and establish what level of involvement in decision-making the patient would like.
- Consider and respect a patient's general health status and personal preferences when treatment options are discussed. The patient and HCP together decide on a practical and feasible regimen to follow in terms of financial, physical, social, emotional, occupational burdens and adherence in the context of the patient's age, preferences, and degree of risk.
- Remember that the principal relationship is between patient and HCP, and the patient has a right to decide who should be involved in their care. With the patient's consent, carers should have access to appropriate levels of information and support.
- Avoid making assumptions about patient preferences about treatment. Talk to the patient to find out their preferences, and note any nonverbal cues that may indicate you need to explore the patient's perspective further.
- If the patient decides not to take or to stop taking a medicine, explain the risks and benefits and the patient's decision should be recorded
- Offer early surgery to people with glaucoma who are losing their sight despite treatment and those diagnosed with glaucoma at an advanced stage, providing with information on the risks and benefits of surgery and using shared decision making techniques.

Active participation of patients in care

Information on using drops and medications; assessment of drop technique

- Provide people with information about how to apply eye drops, including shaking the bottle, technique (instillation, punctal occlusion), expiry dates and hygiene (storage).
- Demonstrate instillation techniques, observe patient or carer instilling drops and repeat education until ability to instil has been proven. Reassess this periodically.
- Discuss the availability and correct use of eye-drop administration aids. Provide these or identify where they can be acquired (e.g GP or community pharmacist or via the IGA) where required and educate on technique.

- Discuss how and where to obtain repeat prescriptions, the timings of this and their importance. Discuss reminders or timetables for when to instil drops
- Support patients in timetabling drop use or help patients link eye-drop administration to activities of daily living.

Simplify medication regimes

- Keep the therapy simple – as few bottles and as few applications as safely possible, use fixed combinations of two medications to reduce the number of drops required.

Medication side effects

- Provide patients with information about the different types and side effects of treatment.
- Check at every visit if the patient has side effects of the medication. If side effects are a problem:
 - discuss how the patient would like to deal with side effects;
 - discuss the benefits, side effects and long-term effects of treatment options with the patient to allow them to make an informed choice;
 - consider adjusting the dosage;
 - consider switching to another medicine with a different risk of side effects;
 - consider what other strategies might be used (e.g. timing of medicines).

Assessment of issues with medication compliance

- Routinely assess adherence whenever you see the patient.
- Specifically ask patients to tell you how and when they are using their drops to assess adherence. Check the eye drop instillation technique in people with whose IOP has not been reduced sufficiently to prevent the risk of progression despite treatment.
- Consider assessing non-adherence by asking the patient if they have missed any doses of medicine recently. Make it easier for them to report non-adherence by:

- asking the question in a way that does not apportion blame;
 - explaining why you are asking the question;
 - mentioning a specific time period such as 'in the past week'.
- If non-adherence is identified, clarify possible causes by identifying specific intentional non-adherence and unintentional adherence barriers.
 - Agree any action with the patient. Tailor any intervention to the specific difficulties with adherence the patient is experiencing. Any plan should include a date for a follow-up review.
 - Relevant interventions may include simplification of drop regime, supervision of technique in drop compliance or aid use and information provision on medication side effects, the disease and compliance aids, and practical education.
 - Professionals in hospital and community settings (HES glaucoma HCP, hospital and community pharmacists and community optometrists) should engage to help assess adherence and provide training to help with assessing and improving compliance.
 - Include carers/family/friends in supporting adherence wherever possible.

Who to contact or where to go if condition deteriorates

- Provide patients with information about the name and contact details of a qualified HCP (e.g. ophthalmic nurse or ECLO) whom patients can contact if they have any queries or drug side effects.
- Advise patients when to make contact e.g. increasing side effects to drops, symptoms of worsening disease, failure to receive timely appointment.
- Tell patients what to do in an emergency and what red flag symptoms to look out for.

Definitions

Referral refinement is a term specific to glaucoma management that describes a two-tier assessment in which initial evidence of abnormality during case-finding assessment or screening is validated by a subsequent enhanced assessment which adds value beyond that achieved through a simple 'repeat measures' scheme. A referral refinement service involves the undertaking of tests sufficient for diagnosis of OHT and suspected COAG and the interpretation of these clinical findings, with specialist practitioners who are delivering this service independently, being qualified and experienced in accordance with NICE guidance. Practitioners providing a referral refinement service should be qualified to make a diagnosis of OHT and suspected glaucoma, and to carry out gonioscopy to exclude angle-closure glaucoma.

Repeat measures is a term specific to glaucoma that primarily describes the repeated measurement of parameters related to the diagnosis of glaucoma. A simple repeat measures scheme may involve repeat measurement of IOP only. Other repeat measures schemes may also include repeated measurement of visual fields and other relevant ocular parameters when clinically necessary.

Enhanced Case Finding has been introduced to provide for enhanced services which include slit-lamp mounted Goldmann applanation tonometry, dilated slit-lamp indirect biomicroscopy and other relevant or repeated tests deemed necessary by the HCP according to their clinical judgement.

Low Risk = COAG suspect or OHT with or without suspicious features, i.e. equivocal optic disc or visual field, and those with PAC who have been successfully treated and have been demonstrated to have non-occludable angles. Essential elements include the fact that the optic disc and visual field are undamaged due to glaucoma and a diagnosis has been established by an appropriately trained and experienced HCP (as specified by NICE) and a management plan has been formulated and communicated along with relevant information for monitoring and triggers for return referral. There is a distinction between monitoring of low risk patients, and the management of low risk patients which requires further qualifications and enables a change of treatment plan within the care setting.

Medium Risk = Early to moderate established apparently 'stable' glaucoma.

High Risk = Complex glaucoma (inc. COAG, PACG, secondary glaucoma and rare glaucomas). Patients at high risk of significant visual loss and those under active management or requiring, or having recently undergone glaucoma surgery.

References

Organisation/authors	Title
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Royal College of Ophthalmologists	Commissioning guidance glaucoma 2017
Royal College of Ophthalmologists	Standards for virtual clinics in glaucoma 2016
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American Academy of Ophthalmology	PPP Primary Open Angle Glaucoma 2015
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