healthwatch Gloucestershire

# Feedback from people with macular disease and sight loss

# Macular disease and sight loss

Nearly 1.5m people in the UK have macular disease. It affects people of all ages. Age-related macular degeneration (AMD) is the most common condition, generally affecting people over the age of 55. AMD is the biggest cause of sight loss in the UK, affecting more than 700,000 people. A group of rare inherited conditions called macular dystrophies can affect much younger people. Some of these rare conditions can appear in childhood, although some are not diagnosed until later in life.

We were kindly invited by the Macular Society to visit two of their Gloucestershire groups in May and June 2025 to raise awareness of Healthwatch Gloucestershire and to listen to the priority health and social care issues facing people with macular disease and sight loss. Links to helpful signposting information based on the issues raised can be found at end of this document.

## What we heard

### Cirencester group – May

An efficient and well run service

- Positive feedback was given about appointments they had at Cheltenham Hospital as they were very efficient - have an eye scan test, see the consultant and get a 'jab'. They said they would often receive a letter about a follow up appointment the next day.

Digital and communication issues

- There were frustrations around the expectation to use digital technology - even if people had been able to keep up with the advancements of technology, their sight loss has made things much more complicated. Some people said that they also struggled with hearing which made things even harder. Some felt embarrassed to ask for help, whereas others said that even when they asked for help, the help could not be provided due to privacy and safety concerns, for example, when having to input a PIN number at a bank or supermarket.
- People said that the communication they often receive from the NHS is not appropriate for them and rely on family to assist with documentation. An example was given where an appointment was missed because a letter had

been posted, but because of the person's sight loss, they were not aware that it had even arrived. This is also a barrier to being able to fully participate in their care and treatment.

- Another person said that they have been asking their Housing provider to provide printed copies of documents with print large enough for her to read. She has received an A3 version of the document, however the actual writing on it was still the same size as if it was on the original A4 page. They have tried to explain that this is still not suitable, but they don't seem to be understanding. Their solution was for her to talk to the housing manager who can then read the documents to her, however the person said that they did not want to do this and didn't feel that the Housing Manager had time to do this either. We talked about the Accessible Information Standard which states that all NHS or publicly funded Adult Social Care must meet the standard of accessible information. It applies to people who are using a service and have information or communication needs due to a disability, impairment or sensory loss. However, if this does not apply to the Housing provider, there is still a requirement that they must still make reasonable adjustments under the Equality Act 2010. We discussed that this person could raise this concern/ complaint with the Housing Manager so that they can follow it up with the organisation and find a resolution.

Quick deterioration and support to maintain independence

- One person shared that their sight loss had deteriorated quite significantly over a short space of time. They had an appointment booked at Gloucester Royal Hospital, however it wasn't until July. Another group member provided them with an emergency eye care number to contact the Gloucestershire Hospitals NHS Foundation Trust to explain the deterioration and see if the appointment could be moved forward.

- The same individual also said that there have been times where they have been crawling on the floor in order to be able to move safely around their home. We shared details of the Adult Helpdesk at Gloucestershire County Council to request an assessment from Adult Social Care for help to remain independent at home and in the community as well.

Support services

- Some people helpfully mentioned 'Insight Gloucestershire' which runs groups at the church in Cirencester and provides useful equipment and aids that can support people with sight loss.

Wider issues – access to GPs

- The group spoke about various concerns about their experiences with GP practices, for example being stuck on hold for long periods of time, not wanting to share lots of personal details with the receptionist and often only

being offered appointments that were weeks away. When we hear concerns like these, we encourage people to contact their GP using their complaints process in the first instance, but people can also contact NHS Gloucestershire Patient Advice Liaison Service (PALS) as they are responsible for commissioning Primary Care services. The more they hear about these concerns the more we can influence change.

## Gloucester group – June

Digital issues and the NHS app

- The group were very interested in our project focussing on the NHS app this year. So much of daily life nowadays has moved online which is a real struggle as they find it difficult to see on computer screens. One person said that they had been struggling to log in to the HNS app as it requires a photo ID and she did not have any. Therefore, she said she would have to pay out for a passport, just to use the app. Photo ID used for voting in elections is not valid for the NHS app. They said that they were going to go into their GP practice later today to see if they could support them with this as they had already been trying to work it out for weeks. Under the neighbourhood model that the new Government is proposing, there will be more of a responsibility on providers, i.e. GPs and Pharmacies, to support people to access and use the NHS app.
- Another person mentioned that the shift to technology has led to more uncertainty as you do not always get feedback or a confirmation that you have completed the process e.g. when using the online booking in system when they arrive at their GP Practice. After using the machine, the system does not provide an acknowledgement that 'you are now booked in'. This person said that they were left waiting quite a long time in the waiting room feeling uncertain about whether or not the GP was aware that they were even there. There was a bit of cynicism in the room about whether the GP practice would respond to feedback like this e.g. it was noted that the GP practice has only recently installed their system so it is unlikely that they will change anything in the near future.

Accessibility

- Accessibility of information and patient choice was raised by the group. For example, although people are being encouraged to use the NHS app and other technologies, service providers must offer other options to those that are digitally excluded for any reason. Although these methods are not always promoted, people do have a right to ask for them, as well as information in braille or large print under the Accessible Information Standard.
- Several people mentioned that signage on buildings and other things are often hard to read. Healthwatch were also asked if leaflets could be produced in large bold print using a contrast of black writing on a yellow background,

and not glossy paper. They said that the same approach should also be used in and around hospitals to aid those who are visually impaired. Some use black and red but black and yellow is better. Even the eye department doesn't always get it right.

Ways to be heard - Patient Participation Groups

- The role of a Patient Participant Group (PPG) was discussed, that every GP practice should have. PPGs are generally made up of a group of volunteer patients, the Practice Manager and one or more of the GPs from the practice. PPGs meet on a regular basis to discuss the services on offer, and how improvements can be made for the benefit of patients and the practice. There is no set way in which they work – the aims and work of each group entirely depend on local needs, but they all have the aim of making sure that their practice puts the patient, and improving health, at the heart of everything it does. People can contact their practice for more information if they would like to be involved.

Ways to be heard – 'What Matters to Me' conversations

- We also discussed how we often view a doctor or a consultant as the authority in healthcare, however we are the ones that know our bodies the best and know when something is not right. Healthcare decisions should be made in partnership between the doctor and the patient (and their carer if applicable) so people should feel empowered to ask questions and challenge decisions if they don't feel it is appropriate. In Gloucestershire, the system refers to this as 'what matters to me' conversations - what might be the right course of treatment for one person may not be the same for another.
- Although there was a lot of positive feedback about outpatient's appointments for eye injections, an example was given where some people experience post injection pain. Rather than put up with the pain, it is ok to question this with the consultant, for example it might be an allergy to iodine.

Ways to be heard – feedback and complaints

- Many of the group were familiar with Patient Advice Liaison Services (PALS) to share feedback to. We would encourage people to complain/give feedback to the service provider first, but then go to PALS if they do not feel it is being dealt with appropriately. PALS teams are there to deal with complaints but also to try to deal issues while they are still 'live' so they can be resolved as soon as possible before something goes wrong. We understand that people can get frustrated if they feel that things don't change and that it won't make a difference, but at the same time, if they don't know about it then they can't do anything about it.

Lack of information provision

- People should be provided with the right information at the right time, i.e. as early as possible, so that people experiencing macular degeneration know what to expect and what support is out there for them in terms of peer support groups and also practical support. The RNIB was mentioned as having useful resources.
- Feedback from the group suggested that not all opticians are proactive in making referrals to groups such as Insight. One member said that their optician wouldn't even agree to put up a poster which they felt was a shame as there are lots more people out there who would benefit from their services.

Wider issues – Mental Health provision

- One member shared their experience of supporting a friend with ongoing mental health issues. Although they didn't identify as this person's carer, they act as the person's next of kin as they do not have any family. However they spoke about their frustration at having to repeat the same story multiple times, every time the person they support moves around to a different hospital or ward. The person has given permission for them to be informed about their care and this was put in writing when the person was first placed under section, however it has not really been recognised since. For example, the last time the person was discharged from hospital, the friend was not informed so she was unable to contribute her thoughts in terms of what care she felt was needed. As a result, the person has returned to hospital and the same issues happen again. Feedback on this should be given to the Gloucestershire Health and Care Trust who deliver mental health services in Gloucestershire. They have a 'Triangle of Care' accreditation which recognises the value of the knowledge and experience that friends and family have about an individual and therefore to maintain this accreditation they need to be showing that are being proactive in seeking their views.

## Key themes

- The outpatients process for getting an eye scan and injection is very efficient. People know when their follow up appointment is going to be almost immediately
- There are support groups available to people in Gloucestershire who also provide a wealth of advice and guidance, however these are not always promoted or referred into by Opticians, so people are not getting this information when it is most needed
- In some cases, technology can be beneficial for people with sight loss, however some things, like the NHS app, are not user friendly and people are

concerned about how they will be able to communicate with their GP practice in the future

- Accessibility requirements are not always being met in terms of appointment letters, information leaflets and hospital signage
- People want to share their views but can feel be excluded from participating if they are not informed or if their communication needs are not met

## What needs to be improved

- People should be provided with the right information at the right time, i.e. as early as possible, so that people experiencing macular degeneration know what to expect and what support is out there for them in terms of peer support groups
- GPs, Hospitals and Care providers should document a person's communication needs on their medical record/ care record and ensure that these are kept up to date
- Healthcare decisions should be made in partnership between the doctor and the patient (and their carer if applicable) so people should feel empowered to ask questions and challenge decisions if they don't feel it is appropriate - 'what matters to me' conversations
- As services are being designed, this must be done in collaboration with patients e.g. signage at the Hospitals Trust Eye department
- Healthwatch Gloucestershire to produce large print leaflets on black and yellow contrasting paper which includes ways to share feedback

# Signposting information

Macular Society - 0300 3030 111

https://www.macularsociety.org/

Insight Gloucestershire - 01242 221 170

Whether you're adjusting to changes in your vision or have lived with sight loss for years, Insight Gloucestershire can help with information, advice and a wide range of services to help you stay independent, active and enjoying what matters to you.

https://www.sightsupportwest.org.uk/insightglos/

RNIB - 0303 123 9999

Provide ECLOs (Eye Care Liaison Officers) who offer immediate, in-person assistance, as well as a Helpline which provides fast, vital support.

https://www.rnib.org.uk/

Ophthalmology Emergency triage line - 0300 422 3578

If you are already a patient under the care of the eye service you can ring the emergency triage number on **0300 422 3578** for help and advice regarding your eye condition or new symptoms.

https://www.gloshospitals.nhs.uk/our-services/services-we-offer/ophthalmology/

Adult Social Care Adult Helpdesk - 01452 426868

To arrange for an environmental / home hazards assessment or an occupational therapy or physiotherapy assessment, or a full assessment of care needs through a Care Act Assessment.

https://www.gloucestershire.gov.uk/health-and-social-care/adult-social-care/

Accessible Information Standard

https://www.england.nhs.uk/accessible-information-standard/

### Patient Participation Groups

PPGs are generally made up of a group of volunteer patients, the Practice Manager and one or more of the GPs from the practice. PPGs meet on a regular basis to discuss the services on offer, and how improvements can be made for the benefit of patients and the practice. People can contact their practice for more information if they would like to be involved.

### Complaints and Feedback

There are different teams depending on the service you want to feedback about:

For **GPs, Dentistry, Optometry and Pharmacy**, NHS Gloucestershire Patient Advice Liaison Service (PALS) are responsible for commissioning Primary Care services. Their contact details are:

**Call: 0800 0151 5487**

**Email**: glicb.pals@nhs.net

For **Mental health services, community hospitals and community nursing**, it is the Gloucestershire Health and Care Trust Patient Carer Experience Team:

**Call: 0300 421 8313**

**Email** experience@ghc.nhs.uk

For **Gloucestershire Royal Hospital and Cheltenham General Hospital** Inpatients and Outpatients appointments:

**Call: 0800 019 3282**

Email: ghn-tr.pals.gloshospitals@nhs.net

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