See the light:

Improving capacity in NHS eye care in England

All-Party Parliamentary Group on Eye Health and Visual Impairment

June 2018

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> “Once I get to the clinic, the staff are absolutely wonderful. They take great pains to explain my condition and treatment options. The big difficulties are getting a timely appointment and traveling to the hospital.”

Foreword

The NHS provides excellent care to many people with eye conditions and there is much good practice and service innovation.

However the current system is failing patients on a grand scale. Services are delaying and cancelling time-critical appointments, resulting in some patients not receiving sight saving treatment and care when they need it. As a result people are experiencing avoidable sight loss, fear, loss of independence and impaired well-being. This is unacceptable.

Avoidable sight loss is causing devastation to individuals and costing the health and social care system billions. The situation is fixable if action is taken immediately to deal with current demand and plan for future need.

We are calling for the Secretary of State for Health and Social Care, NHS England, The Department of Health and Social Care, local authorities, commissioners, delivery bodies, NHS providers and sustainability and transformation partnerships (STPs) to act now on eye health.

We would like to thank all of the organisations and individuals who took the time to provide evidence, especially the patients who shared their personal experience with us. We also want to thank our Expert Advisory Group, which included patients and representatives from organisations with expertise in eye care, for their advice and guidance during the Inquiry.

The recommendations in this report, when implemented, will help to meet the increasing demands for eye care services, deliver strategic and joined up eye care, and reduce the numbers of patients losing sight because of delays.

The All-Party Parliamentary Group (APPG) on Eye Health and Visual Impairment and the members of the Expert Advisory Group are keen to support those working on eye care policy and service delivery to help implement these recommendations, and make a positive difference for patients at risk of sight loss. We will be monitoring progress on implemention of the recommendations.

Lord Low of Dalston and
Jim Shannon MP (right)

Co-Chairs, All-Party Parliamentary Group (APPG) on Eye Health and Visual Impairment

Summary of Recommendations

For the Secretary of State for Health and Social Care

1. To include eye health specifically within the NHS England mandate to ensure it is accorded a higher priority

For NHS England

2. To review and report publicly on how eye care capacity issues are addressed in sustainability and transformation partnership plans and how these relate to current and predicted need.
3. To bring ophthalmology fully within the NHS transformation programme whilst adequately funding service redesign
4. To appropriately resource and support Local Eye Health Networks within STPs and Integrated Care Systems to drive improvement.
5. With NHS Digital, to implement routine data collection in ophthalmology departments on waiting times for follow-up appointments, delays to follow-up outside clinically recommended timescales, patients lost to follow-up and consequences.
6. To urgently review the National Tariff for ophthalmology which currently seriously disadvantages some patients with glaucoma, wet age-related macular degeneration (AMD) and diabetic retinopathy who require follow up appointments and are particularly at risk of avoidable sight loss.
7. To establish a national target to ensure patients requiring follow up appointments are seen within clinically appropriate times to prevent delayed and cancelled appointments resulting in patients lost to follow up.
8. With NHS Digital, to urgently implement IT-connectivity between community optometry and the wider NHS to improve patient care and efficiency.

For the Department of Health and Social Care with the Medicines & Healthcare products Regulatory Agency

9. To review regulations to ensure that necessary amounts of drugs are dispensed, stored and available in theatre and outpatient treatment rooms in advance of the day's list for treatment.

For Local Authority and Clinical Commissiong Groups

10. To review the eye health needs sections of their Joint Strategic Needs Assessments to ensure consistency, to assess current and future eye health need.

For Clinical Commissioning Groups

11. To establish separate ophthalmology contracts with NHS providers from April 2019 to ensure there is public transparency about funding invested in eye-care and how this correlates to assessed need in Joint Strategic Needs Assessments.

For NHS providers

12. To ensure the eye care pathway is clear for those responsible for managing patient care and effectively communicated to patients.

13. To review booking procedures to ensure patients who need further appointments can book their next appointment, within clinically appropriate timescales, before leaving the clinic. This will benefit patients and aid capacity planning.

For Health Education England

14. To urgently increase the number of trainee ophthalmologists.

15. To review the curricula of medical training institutions to ensure a minimum standard of eye health education is included, in agreement with the Royal College of Ophthalmologists.

16. To build on strong support from all relevant professional bodies for consistent learning outcomes from curriculum and training systems for ophthalmic professionals such as optometrists, opticians, nurses and orthoptists.

> **“I routinely have to make four or five phone calls to make sure I get an appointment. If someone was a bit nervous they probably wouldn’t persist.”**
>
> Michael Tupper

Introduction

We undertook this inquiry into the commissioning and planning of eye care services in England because of robust evidence that patients are experiencing irreversible sight loss due to capacity issues in eye care. The British Ophthalmological Surveillance Unit (BOSU) found that up to 22 people per month were experiencing permanent and severe visual loss due to health service initiated delays.[]

There were almost 7.6 million ophthalmology appointments in 2016/17 in England – a figure which has increased by more than 10 per cent over the past four years. Ophthalmology has the second highest outpatient attendance of any speciality and the figure is increasing every year.[] The number of people in the UK that will be affected by sight loss is projected to increase by over 10 per cent by 2020 and by over 40 per cent by 2030. The total cost of sight loss to the UK economy is in the region of £28 billion in 2013, having increased from an estimated £22 billion in 2008. []

Our Inquiry focused on eye care services for conditions which have effective treatments, such as glaucoma, macular degeneration and diabetic eye disease. These conditions, if not treated appropriately, can lead to a person becoming blind or partially sighted.

We received evidence from a wide range of people and organisations including patients, clinicians, eye departments, commissioners, sustainability and transformation partnerships (STPs), Local Eye Health Networks, professional bodies, charities, health industry organisations, researchers, the Department of Health, NHS England and Public Health England. We received 557 patient survey responses and 91 submissions to our call for evidence from 112 organisations. We held two evidence sessions in Parliament where we heard spoken evidence from patients and from professionals.

The report describes what patients, professionals and different organisations told us, and outlines each of the recommendations. You can see more detailed evidence from the inquiry online at **rnib.org.uk/appginquiry**.

What patients told us

Five hundred and fifty-seven patients completed a survey telling us about their experiences of eye care services in the last three years. They had a range of sight-threatening eye conditions, 66 per cent were women, 89 per cent described themselves as White British.

Just over half of those surveyed had at least one appointment or treatment delayed, 20 per cent had experienced at least one appointment or treatment cancelled and 15 per cent reported experiencing both. In response, most patients had taken at least one action to chase their appointment, with one in five patients taking four or more actions.

Seventy seven per cent of patients felt the delay or cancellation had caused them anxiety or stress, while 54 per cent felt it had a negative impact on their day-to-day life. Patients expressed concerns about long waiting times, problems securing appointments, a lack of continuity in their care, and poor communication from the clinic both towards the patient and with other professionals involved. Despite the delays and cancellations the majority of respondents were satisfied with their eye care. There were many positive comments about the experienced and supportive clinical staff, even from those people who had expressed dissatisfaction with other aspects of their care (such as delays).

Patients' main suggestions for improving services included:

- Being seen for their next appointment within the clinically indicated timescale, without having to chase the clinic.
- Shorter waiting times in clinics, less over-crowding, more co-ordination and improving booking processes.
- More continuity of care, information about patient care to be available to the right professional at the right time, to avoid delays in treatment.
- Better emotional and practical support. Professionals to listen more, engage with patients better and recognise patients as experts in their own experience.
- More and better accessible information about treatment, treatment options, what to expect and time to ask questions.
- Extra funding for more staff and resources, without which pressure on eye departments will continue to increase.
- Greater patient focus including avoiding unnecessary delays in diagnosis, treatment and referral processes.

There were suggestions from a few patients about:

- Development of the role of local optometrists within the eye care pathway to help relieve current pressures, with appropriate fast-track referral for specialist care and advice where needed.
- More accessible information (including appointment letters), accessible transport to hospitals, treatment in locations closer to home and more disability awareness.
- More access to specialist consultants for rare and complex conditions.

More information on what patients told us can be found online at **rnib.org.uk/appginquiry**

We recommend

1. For the Secretary of State for Health and Social Care to include eye health specifically within the NHS England mandate to ensure it is accorded a higher priority.

The inquiry clearly found the current and future eye care needs of the population are not being adequately planned for or addressed. Prioritising eye health specifically in the NHS mandate will help enable the NHS to respond effectively to the growing eye health needs of the population and reduce unwarranted variation. It will help mitigate the otherwise significant impact of avoidable sight loss on people's quality of life and the rising direct and indirect health and social care costs that accrue.

For NHS England

2. To review and report publicly on how eye care capacity issues are addressed in STP plans and how these relate to current and predicted need.

Half of STPs do not include eye health in their plans. Of those that do mention ophthalmology it is often little more than a passing reference. Requiring STPs and providers to address the issue of eye care capacity in plans would help ensure evidence based service redesign to consistently improve efficiency and efficacy across England. Submissions noted that commissioning and planning services at scale across STPs could provide economies of scale and more cost effective use of resources.

3. To bring ophthalmology fully within the NHS transformation programme whilst adequately funding service redesign.

NHS England needs to build on and ensure the implementation of important initiatives that have recently been undertaken to improve service delivery. These include: this inquiry; NHS England's Elective Care Transformation Programme 100-Day Challenge; Get It Right First Time for Ophthalmology[]; The Clinical Council for Eye Health Commissioning's "Systems and Assurance Framework"[]; the Royal College of Ophthalmologists (RCOphth) "The Way Forward" resources[]; and the National Ophthalmology Database Audit []. Implementation of service redesign can improve efficiency however additional funding, including capital funding, is required to ensure services effectively meet increasing need. Without adequate investment avoidable sightloss will lead to a growing burden in social care. Of the 44 STP plans only three directly cite ophthalmology as a priority service for redesign.

> **"Since 2005 I have always had to chase the hospital for my appointment, sometimes I've had to make five or six phone calls."**
>
> Catherine Grubb

4. To appropriately resource and support Local Eye Health Networks within STPs and Integrated Care Systems to drive improvement.

NHS England established Local Eye Health Networks to facilitate multidisciplinary clinical input and leadership in service improvement and commissioning. To date they have not been given adequate support or resource to do this. We call on NHS England to enable Local Eye Health Networks to be at the heart of driving service improvement both under new models of care and existing systems.

5. With NHS Digital, to implement routine data collection in ophthalmology departments on waiting times for follow-up appointments, delays to follow-up outside clinically recommended timescales, patients lost to follow-up and consequences.

The current lack of robust data means it is difficult to monitor and compare waiting times and delays across England and leads to patients being lost to follow up and coming to harm. Improving routine data provision would help clinicians ensure patients most at risk of avoidable sight loss are prioritised. We recommend a routine data collection system is implemented for an initial period of five years from April 2019 and then reviewed.

6. To urgently review the National Tariff for ophthalmology which currently seriously disadvantages some patients with glaucoma, wet-AMD and diabetic retinopathy who require follow up appointments and are particularly at risk of avoidable sight loss.

An immediate review of the National Tariff for ophthalmology[] is required. The current tariff introduced financial incentives for providers to undertake more first attendances at the expense of follow-ups seriously disadvantaging patients with glaucoma, wet AMD, diabetic retinopathy and uveitis. This is an unacceptable distortion of clinical priorities which puts patients at risk of losing sight.

7. To establish a national target to ensure patients requiring follow up appointments are seen within clinically appropriate times to prevent delayed and cancelled appointments resulting in patients lost to follow-up.

Timely treatment saves patients' sight; within ophthalmology the patients most at risk of avoidable sight loss are usually patients requiring follow up treatment. A national target would help ensure patients receive the treatment and care they require.

8. With NHS Digital, to urgently implement IT connectivity between community optometry and the wider NHS to improve patient care and efficiency.

IT-connectivity between community optometry, hospitals and GPs will improve the speed and quality of referrals, inter-professional communication and the quality of patient care. It will reduce the inefficiency, variability in care and costs evident in current paper-based systems.

Department of Health and Social Care with the Medicines and Healthcare products Regulatory Agency

9. To review regulations to ensure that necessary amounts of drugs are dispensed, stored and available in theatre and outpatient treatment rooms in advance of the day's list for treatment.

Patients are facing delays and on occasions cancelled treatment simply because of the regulations relating to the dispensing of normally highly toxic drugs within hospitals. However the quantities of these drugs used in ophthalmology are so small that there would be virtually zero risk to patients or staff in more timely dispensing and safe storage arrangements – certainly far less risk than is currently incurred through delays to time-critical care.

> **"On more than one occasion I have been sent away from the clinic without an injection to treat my wet AMD because the hospital pharmacy won't release the drug I need."**
>
> Malcolm Johnson

For Local Authorities and Clinical Commissioning Groups

10. To review the eye health needs sections of their Joint Strategic Needs Assessments[], to ensure consistency, to assess current and future eye health need.

The assessment of eye health needs is often inconsistent across England, making it difficult to compare how areas are meeting need. Introducing greater consistency in JSNAs will help reduce the "postcode lottery" faced by patients.

For Clinical Commissioning Groups

11. To establish separate ophthalmology contracts with NHS providers from April 2019 to ensure there is public transparency about funding invested in eye care and how this correlates to assessed need in Joint Strategic Needs Assessments.

Specific contracts for ophthalmology services, (covering both elective and emergency care) – separate from block contracts - are required to enable scrutiny into the NHS funds being invested in ophthalmology and the subsequent outcomes. Contracts need to specify compliance with NICE guidance[] and other quality metrics to ensure cost savings do not drive down quality.

For NHS providers

12. To ensure the eye care pathway is clear for those responsible for managing patient care and effectively communicated to patients.

The current eye care pathway is often fragmented and complex to navigate causing patients considerable stress and anxiety. Greater clarity and clearer communication is needed to ensure patients don't get lost and delayed in the system. All providers need to make use of the "Ophthalmology Elective Care Transformation handbook"[] that is currently in production and to fully implement the NHS "Accessible Information Standard"[]. Particular attention should be paid to potentially vulnerable patients who may have a higher risk of sight loss and may need additional support to access eye care services.

13. To review booking procedures to ensure patients who need further appointments can book their next appointment, within clinically appropriate timescales before leaving the clinic. This will benefit patients and aid capacity planning.

Historically patients were able to book their follow up appointment before they left the clinic. This is not an option now in many services, causing patients anxiety, stress and delays. Booking systems need to ensure that appointments cannot be allocated outside of the clinically appropriate timescale without consultation with clinicians. This will help reduce delays and cancellations, maintain patient trust in eye care services and help prevent delays leading to avoidable sight loss.

For Health Education England

14. Urgently to increase the number of trainee ophthalmologists.

An increase in the numbers of ophthalmologist posts is needed for truly safe and effective eye care services to be delivered. Many Trusts are currently struggling to fill consultant posts, or are using expensive locums to cover unfilled posts. The provision of eye care services by Any Qualified Providers is in some instances hindering the training of ophthalmologists. Effective sustainable workforce planning is required to ensure services can cope with future demand.

15. To review the curricula of medical training institutions to ensure a minimum of eye health education is included, in agreement with the Royal College of Ophthalmologists.

There are currently medical training institutions that do not have an ophthalmology component. This is not acceptable, given the future characteristics of the population, all doctors must have adequate eye care training.

16. To build on strong support from all relevant professional bodies for consistent learning outcomes from curricula and training systems for ophthalmic professionals such as optometrists, opticians, nurses and orthoptists.

Ideally these would be nationally recognised and resourced where appropriate, building on the considerable and productive effort that has gone into multi-professional working in recent years. This will help ensure that demand for eye care can be safely met making best use of the whole workforce.

> “Hospital pharmacies should give eye departments a stock of drugs, so they can do same day treatment rather than the pharmacy only releasing a drug for a named patient which creates much delay.”

Acknowledgements

The APPG on Eye Health and Visual Impairment works to inform and educate parliamentarians about the importance of high quality eye care for the prevention of eye disease, sight loss and blindness and for the eye health of the nation; and to promote better understanding of visual impairment and greater social inclusion.

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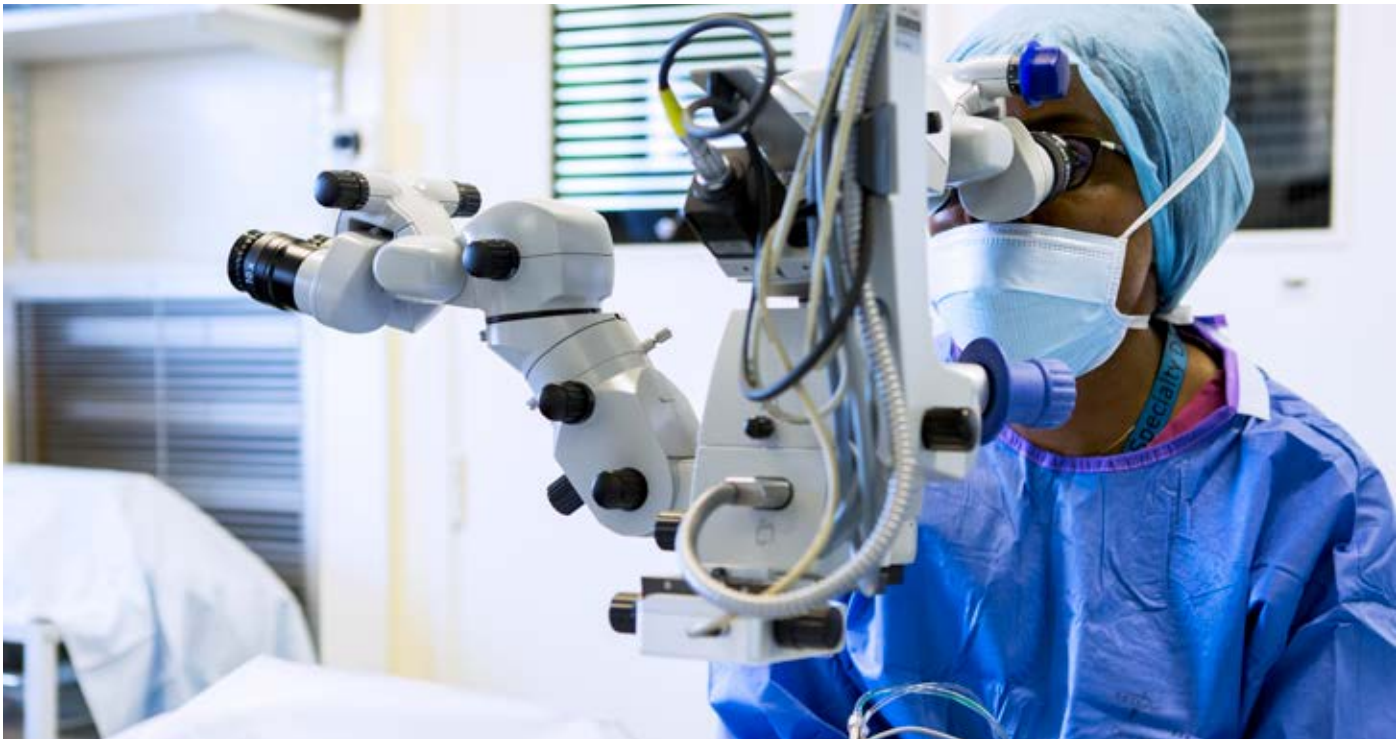
The Inquiry has also been supported by an Expert Advisory Group comprising:

- Susan Blakeney, Clinical Adviser, College of Optometrists
- Mike Burdon, The Royal College of Ophthalmologists, President
- David Hewlett, Chief Executive, The Federation of (Ophthalmic and Dispensing) Opticians / Optical Confederation
- Susan Hoath, Chief Executive, Birmingham Focus
- Malcolm Johnson, patient representative
- David Quigley, patient representative
- Michael Sobanja (Chair), NHS Alliance
- Alan Tinger, RNIB Trustee/ Honorary Treasurer
- Keith Valentine, Chief Executive Vision UK
- Stephen Vernon, The Royal College of Ophthalmologists, Vice President
- Christine Wall, patient representative



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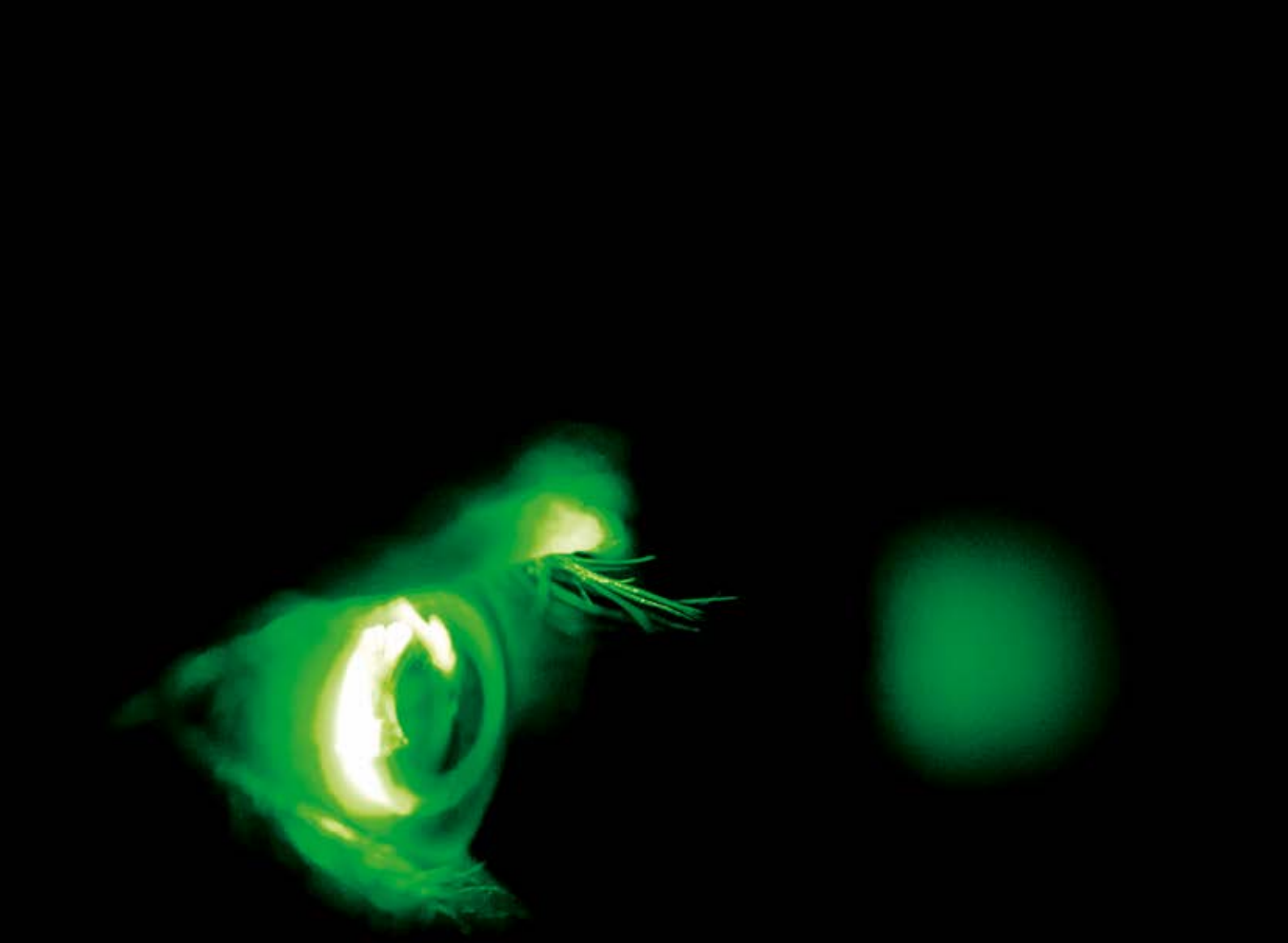
RNIB and the Optical Confederation provides the secretariat for the All-Party Parliamentary Group on Eye Health and Visual Impairment.

RNIB Supporting people with sight loss

Optical Confederation
The voice of UK optics



> **“The bureaucracy is out of sync with the clinical staff. They make arbitrary decisions regarding timing of injections that they are unqualified to do. It’s upside down organisation.”**
>
> Malcolm Johnson