



Laying the foundations for the **future of eye health** in England

October 2023



www.eyeshaveit.co.uk

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The Eyes Have It is a partnership of Macular Society, Fight for Sight / Vision Foundation, RNIB, Association of Optometrists, The Royal College of Ophthalmologists and Roche Products Ltd. Roche has funded the activities of the partnership.

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Foreword from Lord Blunkett



Across the UK, there are over 2.2 million people living with conditions that cause sight loss. If you are one of these people, you will know just how important prompt and appropriate medical care can be. Yet all too often, people living with such conditions are being failed by a system which is overwhelmed. I hear stories from so many patients that the care they need is simply not available where and when they need it. **This needs to change.**

Over the last three years, The Eyes Have It has been at the forefront of efforts to advocate for improvements to the experiences and outcomes of people living with eye health conditions. By shining a spotlight on eye health, the capacity challenges within the system and the barriers facing patients trying to access care, they have helped to move sight loss up the parliamentary agenda and make progress towards a new approach to eye health.

But that progress is only the beginning. We must ensure we are consistently meeting the needs of people living with conditions that cause sight loss. That is why The Eyes Have It continues to call for a national plan for eye care.

This report provides the foundations for this step change. Based on expertise, insight and knowledge from across the eye health sector, it sets out critical evidence of the key issues facing people affected by sight loss and, most importantly, the actions policymakers can take to overcome them.

The report includes recommendations across the following themes:

1

Data,
connectivity
and real-world
evidence



2

Prevention,
diagnosis and early
intervention in an
integrated system



3

Equity
of access, support
and patient
empowerment
throughout the
patient pathway



4

Eye care
workforce



5

Using new
technologies and
treatment models



6

Investment
into research for
future treatments



7

Availability
of treatments



By taking coordinated action across each of these areas, I believe we can make the eye health system fit for purpose.

The recommendations within this report should be built upon by government to develop a much-needed national plan for eye care. That way, we can deliver policy changes that drive a consistent improvement in the care of people living with sight loss.

**I'm backing a national plan for eye care in England.
I hope you will do the same.**

About The Eyes Have It



Macular Society
Beating Macular Disease



R N I B

See differently



The Eyes Have It is a partnership of Macular Society, Fight for Sight / Vision Foundation, RNIB, Association of Optometrists, The Royal College of Ophthalmologists and Roche Products Ltd. Roche has funded the activities of the partnership.

Macular Society is the charity dedicated to beating the fear and isolation of macular disease, by funding world-class research, and providing the best advice and support to those affected by macular conditions.

Fight for Sight / Vision Foundation is the only independent UK-wide funder changing lives through grant investment in ground-breaking scientific research and innovative services for people with sight loss.

The Royal National Institute of Blind People (RNIB) is one of the UK's leading sight loss charities and the largest community of blind and partially sighted people.

The Association of Optometrists (AOP) is the voice of the optical profession, representing over 80 percent of practising optometrists. The AOP elevates the work of its members, safeguards their interests and champions eye health across the UK.

The Royal College of Ophthalmologists is the professional body for ophthalmologists in the UK, committed to developing and promoting the highest standards of patient care.

Roche is a pioneer in pharmaceuticals and diagnostics, focused on advancing science to improve people's lives. Roche believes that more can and should be done to improve and protect vision.

Summary of recommendations

Data, connectivity and real-world evidence



- 1** NHS England should work with commissioners, clinicians and industry to increase IT connectivity and digital clinical image interoperability within and between primary and secondary care providers through the deployment of a single, consistent mechanism for image sharing. This would facilitate timely, secure and effective communication to improve patient care, streamline referral pathways, facilitate quality improvement and aid learning.
- 2** NHS Digital and the Department of Health and Social Care (DHSC) should collect, publish and analyse more comprehensive and granular data to support service and workforce planning and development, as well as patient access to services.

Prevention, diagnosis and early intervention in an integrated system



- 3** Integrated Care Partnerships (ICPs) should undertake an eye health needs assessment of the population – as part of Joint Strategic Needs Assessments – to feed into public health plans and inform local commissioning and pathway development. Where possible, this should be informed by new sources of data and real-world evidence, as detailed in section 1.
- 4** Integrated Care Boards (ICBs) should develop a high-quality consistent pathway of care for optometry that recognises the value of community optometry practices as diagnostic hubs and treatment centres, which may be based on an Optometry First model. This should be supported by consistent commissioning of core universal eye care services across all Integrated Care Systems (ICSs) that ensures patient access to Minor Eye Care Services (MECS) and Community Urgent Eye Care Services (CUES), and other extended services.

Equity of access, support and patient empowerment throughout the patient pathway



- 5** ICBs should commission Eye Care Liaison Officers (ECLOs) and implement an eye care support pathway, providing consistent patient information, communications and support at all stages of the patient pathway. This should include raising public awareness and knowledge of self-care, new treatment options and the importance of treatment compliance/adherence, as well as wider non-clinical support services including vision rehabilitation, the third sector, and emotional and wellbeing support that extends beyond the initial post-diagnostic support period.
- 6** NICE should update guidance to recognise the need for psychological care to be provided as part of wider eye care. This should include reference to a multidisciplinary treatment programme with input from ECLOs, primary eye care, psychiatry, psychology and vision rehabilitation specialists.

Eye care workforce



- 7** Building on commitments in the NHS Long Term Workforce Plan, DHSC and NHS England should increase the number of ophthalmology specialty training places in line with current and future patient need and fully resource trainers to deliver this expanded programme.
- 8** DHSC and NHS England should iteratively plan and implement additional expansions to the wider eye care workforce, as needed to meet future demand or deliver new models of care. In the immediate term, this may include expanding the number of image graders and ophthalmic nurses available to boost diagnostic capacity.
- 9** Commissioners should, where necessary, enable and upskill the wider eye care workforce to deliver more clinical care outside hospital, for example through universally commissioned, optometry-led MECS and CUES.

Using new technologies and treatment models



- 10** NHS England should ensure the system has the necessary underlying infrastructure and processes in place to support consistent roll out and application of new technologies and treatment models across the country. This should include setting out clear commissioning requirements, with a minimum standard of evidence alongside analysis of clinical and cost effectiveness, to support correct implementation.
- 11** NHS England, ICBs and service providers should ensure that there is adequate staff training and resourcing to deliver new technologies and treatment models, and that evolving professional practice is reflected in workforce planning and training.

Investment into research for future treatments



- 12** At present, sight loss research receives just £9.60 per person per year. Government should double this, taking total public investment to at least £50 million per year by 2030 across the country (for common and rare diseases), and continuing to expand research funding sustainably thereafter.
- 13** Government should work with the National Institute for Health and Care Research (NIHR) and UK Research and Innovation (UKRI) to increase the provision of early career research studentships and fellowships – recognising that investment in vision research can potentially also advance multiple other health research fields, such as neurodegeneration.

Availability of treatments



14 NICE should improve its approach to new technology appraisals through:

- Incorporating more up to date utility measures that recognise the value of preserving vision/stopping the deterioration of sight loss, both in its own right, and in terms of its impacts on social inclusion and comorbidities (e.g., fewer falls, better mental health and higher mobility).
- Working with patients to identify new patient reported experience measures (PREMS) and patient reported outcome measures (PROMS) which capture the wider benefits of interventions and can be used as part of assessments for new therapies.
- Adopting a better understanding of the uncertainty around long term outcomes for people receiving treatment with inherited retinal diseases.

Further recommendations identified through this call for evidence are included within each thematic section.

Introduction

Tackling the growing demand for eye health services is one of the biggest challenges facing the NHS in England today.

That's why we're calling for a national plan for eye care in England that supports local decision-making with national accountability and sets out specific actions throughout the patient pathway.

According to the latest data from NHS England, over 640,000 people are waiting for specialist ophthalmology treatment, making up 8.3 percent of the NHS backlog (second in scale only to Trauma and Orthopaedics). Thirty-six percent of these patients have been waiting over 18 weeks and in some ICBs, the picture is even worse. [1] At the same time, the workforce is struggling to meet demand. Over three quarters of NHS eye units in the UK report not having enough consultants to meet current demand, [2] and this pressure is only likely to grow as demographic changes mean more people are living with conditions which cause sight loss. [3]

The Eyes Have It advocates for and champions improvements to patient care and outcomes, so that everyone can access the right eye care, where and when they need it.

By highlighting issues such as the capacity challenges facing parts of the eye care system, and the additional barriers to accessing care which people with sight loss may face, our campaign has activated support from MPs and policymakers, helped shape government policy and contributed to the appointment of the first National Clinical Director for Eye Care.



We have seen welcome progress since we launched The Eyes Have It three years ago, but it is clear that significant challenges remain. The Eyes Have It believes that the only way to address these challenges, tackle the crisis in eye care, improve eye health and prevent avoidable sight loss is through coordinated action across the entire eye care system.

In July 2023, The Eyes Have It published a call for evidence to gather expertise, insight and knowledge from the sector to inform a shared vision for what needs to change to improve eye care provision in England over the next five years. **Input was sought from professional bodies, patient groups, industry groups, sector leaders, NHS representatives and others.** A list of organisations which contributed to the call for evidence can be found at the end of this report.

This report summarises the main points raised by respondents on how to make the eye care system fit for purpose. It focuses on areas which will deliver both improvements in patient care and efficiencies across the eye care system, and lays out both key foundations for the future of the eye care system and additional actions which can be built on those foundations. While the call for evidence highlighted the significant areas of consensus across the sector, the specific positions of individual responding organisations vary, and it is not possible to fully reflect the views of every responding organisation.

We are advocating for this document to be used to facilitate the creation of a much-needed national plan for eye care, built on comprehensive engagement with patients, clinicians and the entire eye care sector.

“When we jointly established The Eyes Have It partnership in 2021, we wanted to bring together the eye care community to help raise awareness of the importance of good eye health, highlight the challenges facing the eye care system and improve the lives of people living with sight loss. Since then, the partnership has grown far beyond what we could have hoped for, in both scale and ambition, and we are incredibly proud of what it has achieved. As we look to the future, this report provides us with a clear framework for tackling the challenges facing eye care in England, and we are excited to continue to support this collective effort.”

Richard Erwin
General Manager, Roche Products Ltd

An interconnected system

This report is divided into themes, but it should be stressed that these themes cannot be addressed in isolation. The eye care system in England (as in other nations of the UK) is complex and interconnected, and while limited progress can be achieved in any one area, that progress can easily be offset by deterioration elsewhere.

One of the areas facing real challenges at the moment are secondary eye care services, as evidenced by the long waiting list for specialist treatment. The shortage of ophthalmologists and lack of appropriate pathways for upskilling the wider eye care workforce are clearly fundamental to this, but myriad other factors are at play. A lack of diagnostic infrastructure in primary care, difficulties in sharing imaging between settings and underinvestment in prevention and early intervention all increase the number of patients presenting to secondary care. Upstream action is needed to address these challenges to reduce service demand and improve outcomes. By the same token, a lack of patient support to access the right care at the right time can cause additional challenges elsewhere in the system. Without an appropriate support pathway, patients are likely to have worse experiences and outcomes which could have been prevented or mitigated with appropriate and timely community support.

Research into new diagnostic tools and treatments is also essential to deliver better outcomes for patients but research funding for eye health is very low compared to other areas of health research. Research not only needs money; it needs time and expertise, something which a workforce struggling to meet immediate patient needs cannot adequately provide. Research also relies on data, both in aiding the identification of unmet needs to target research and in robustly analysing outcomes to deliver better care. Importantly, these findings must be translated and implemented across the country, with all patients able to access new treatments, in order to maximise the value of research.

Data, connectivity and real-world evidence (the first theme of this report), should also be seen as key enablers across a range of areas. At the level of individual patient care, the sharing of data (particularly images), is key to enable smooth treatment pathways, monitor disease progression and provide appropriate treatment. At the same time, population level prevalence data is vital to workforce and service planning to meet local needs, demographic data can be used to ensure health inequalities are addressed, and patient reported outcome measures can play a role in assessing different treatment options.

It is also not possible to address challenges facing individual geographies in isolation. Delivering improvements in just one area risks exacerbating health inequalities and leading to greater variation in outcomes.

These examples, while far from exhaustive, clearly underline the need for a systemwide approach to address the crisis in eye care services through a national plan for eye care that sets out specific actions throughout the patient pathway.

We strongly recommend that this report is used to develop a comprehensive approach to deliver better care and support for patients.

Figure 1:
The eye care system

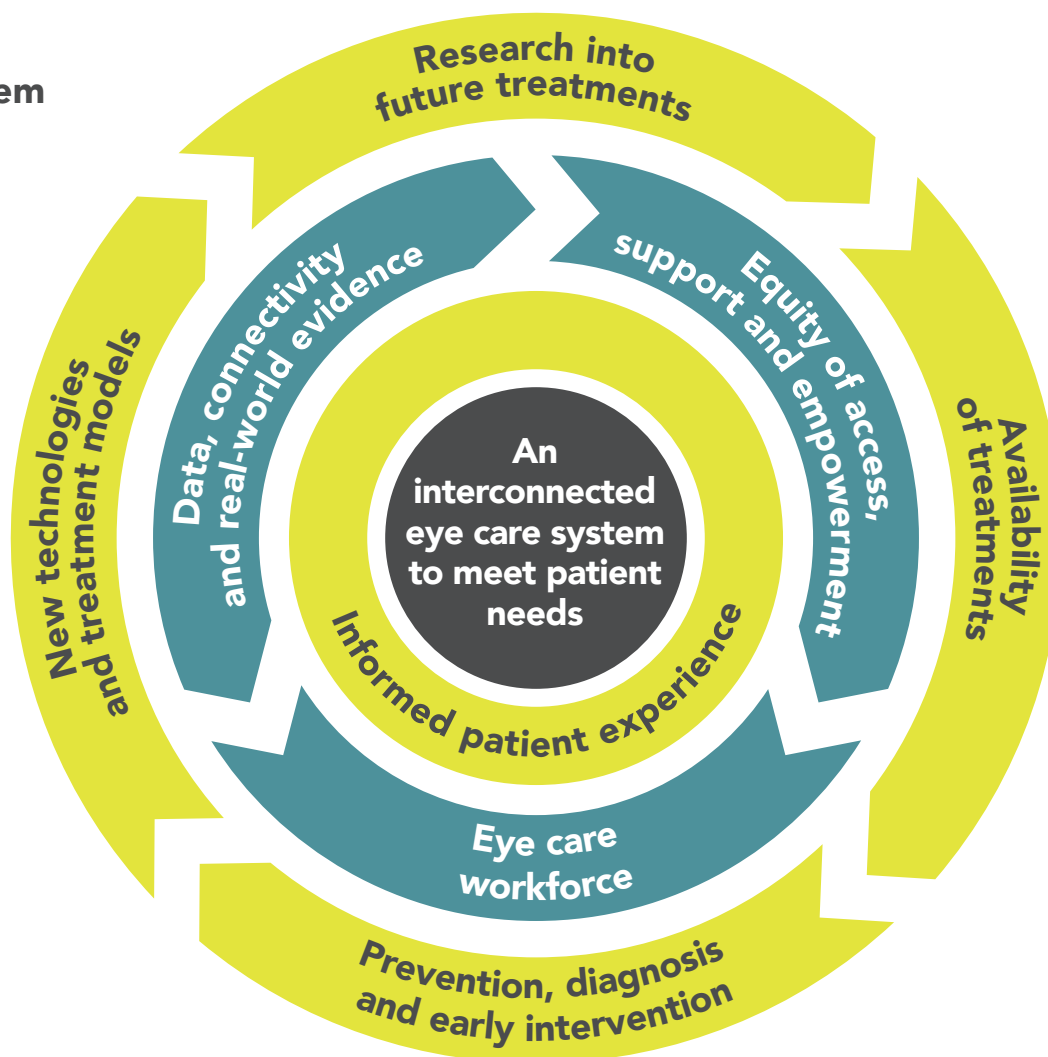


Figure 1 depicts four concentric circles, illustrating how elements of the eye care system addressed as themes in this report are connected to one another. The innermost circle is labelled “An interconnected eye care system to meet patient needs”. The second circle is labelled “Informed by patient experience”. The third circle is split into thirds, with one third labelled “Eye care workforce”, one labelled “Equity of Access, support and empowerment” and one labelled “Data, connectivity and real-world evidence”. The outermost circle is divided into quarters, with one quarter labelled “Prevention, diagnosis and early intervention”, one labelled “New technologies & treatment models”, one labelled “Research into future treatments” and one labelled “Availability of treatments”.

1

Data, connectivity and real-world evidence

“The lack of IT connectivity between primary eye care and secondary care ophthalmology is a major barrier to addressing the backlog and reducing preventable sight conditions or sight loss. Addressing this long overdue issue is key for improving patient outcomes. At the very minimum enabling all optometry practices and practitioners to have access to NHS mail would be a significant enabler to success.”

Peter Hampson

Clinical and Professional Director, Association of Optometrists

Facts & Stats

- In the UK, it is estimated that **over 2.2 million people are living with a condition that causes sight loss.** [4] Of those, 366,000 people are registered as blind or partially sighted. [4]
- As of 2019, **63 percent of ophthalmology units reported having electronic patient record systems (ePRS),** with one system in use across half of units with ePRS. [5]
- However, system capabilities vary substantially, with **some lacking the capacity** to perform clinical audit, share information with other systems or interface with other technologies such as retinal imaging.
- A recent survey by AOP found that 73 percent of responding UK optometrists **do not have access, or cannot contribute to, patient records** where they work. [6]
- There remains **significant variation** in access to electronic eye care referral systems among optometry practices. [7]

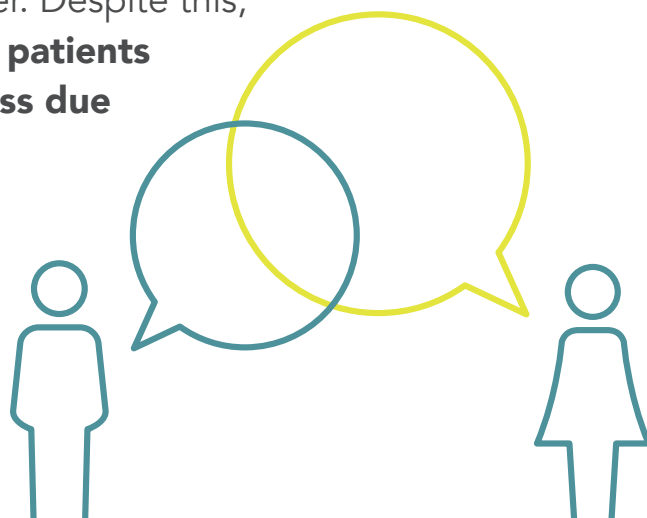


What we heard



In order to continually improve the quality and timeliness of patient care, make the best use of limited resources and support local and national planning, it is essential that high quality data is collected on the progress of patients through pathways and on their clinical outcomes. Robust quantitative and qualitative evidence of “what works” is also required to improve patient outcomes. Such collection must be timely and meaningful, while also protecting the privacy of patients. Any additional data collection activity undertaken in clinical settings needs to be properly resourced and funded. Unfortunately, **current data can sometimes be incomplete or fragmented, making it harder to implement evidence-based improvements to care.**

Data is also important to improve patient access to services. For example, the Certification of Vision Impairment (CVI), which is used to enable people with sight loss to access additional state support, is also the primary public health data point for visual impairment and preventable sight loss. [8] Yet, CVI registration data does not provide a full picture of the population’s eye health as typically someone would not be eligible for a CVI until their vision acuity was worse than 6/60 with a full field of vision (or up to 6/18 with a reduced field of vision), [9] and even then, not everyone eligible will register. Despite this, **respondents noted the importance of CVI to patients and the need for improvements to the process due to its current incompleteness.**



Key issues



- Lack of comprehensive and granular data to improve service provision
- Lack of IT connectivity and digital clinical image interoperability affecting professionals’ ability to share data
- Inconsistent use of data for planning services and improving patient outcomes

It is clear that the sector is aligned on the need for more consistent and systematic data collation and usage across the eye care system to foster evidence-led learning and collaboration, improve patient care and outcomes and support NHS efficiency. It is also important that data is robustly evaluated, including validation where appropriate, and allows for meaningful local, regional and national comparison. We also heard about the importance of sharing data across the system and using it more widely, including for research through Trusted Research Environments, and about the need for more data resources for both biomarking and eye imaging to enable predictive medicine and personalised care in the years ahead.

A reoccurring challenge reported in response to the call for evidence was the lack of IT connectivity and interoperability between primary and secondary care, which creates barriers to sharing data such as images and patient information, resulting in unnecessary referrals and patients not receiving the right care at the right time. We also heard that NHSmail is not always fully accessible across primary care, further hindering connectivity. Improved connectivity and electronic referral systems across primary and secondary care are essential to support a joined-up, national approach across eye care, and in turn, the delivery of the recommendations cited in this report. Any action to improve data and digital infrastructure should be supported by ensuring the workforce have the right skills, at a national level, to maximise its use.

What needs to change?

The overarching recommendations that could make the biggest difference to the sector and enable a transformational approach to eye health are:



- 1 NHS England should work with commissioners, clinicians and industry to increase IT connectivity and digital clinical image interoperability within and between primary and secondary care providers through the deployment of a single, consistent mechanism for image sharing. This would facilitate timely, secure and effective communication to improve patient care, streamline referral pathways, facilitate quality improvement and aid learning.**
- 2 NHS Digital and DHSC should collect, publish and analyse more comprehensive and granular data to support service and workforce planning and development, as well as patient access to services.**

Respondents identified a wide range of additional data requirements through the call for evidence. These varied in scale and scope, with some requiring significantly larger work programmes than others to deliver, and included:

- Underlying incidence and prevalence of different eye health conditions (including demographic and socioeconomic indicators to enable the identification and management of health inequalities).
- Inclusion of risk stratification in publicly available patient waiting lists data (i.e., latest clinically appropriate date).
- Reason for outpatient referral and source of referral.
- More comprehensive NHS eye health and vision testing data.
- Information on commissioning of additional enhanced pathways in the community to support patient choice, alongside an analysis of the impact of these pathways on A&E and ophthalmology hospital activity.
- Linking Hospital Episode Statistics (HES) data with eye scan data (acquired in both primary and secondary care settings) and longitudinal patient records.

All data captured should be sufficiently granular to enable assessment of demographic and social factors which may impact on patient behaviours and outcomes.

Other recommendations identified through this call for evidence include:

- DHSC should **increase efficiency of the CVI process**, including digitisation, to ensure consistent and timely completion of forms for eligible patients to act as a gateway to support and services. CVI data should be collected, linked to social services registration data and analysed to enable identification of communities most at risk. To enable efficiencies in this space, it is recommended that CVIs can be issued by optometrists.
- NHS England should **set up a robust national patient registry** that works for all stakeholders – NHS, clinicians, patients, researchers and industry – that captures details of all individuals living with inherited retinal diseases to provide data on prevalence, where they are and their genetic diagnosis (where available). This is an important way to map out the patient landscape and scope of interventions, as well as provide real-world evidence to help inform policymakers in decision making and as part of the regulatory review of medicines by the MHRA and the value appraisal process by NICE.

What is best practice?



In June 2023, the Welsh Government announced that optometrists with relevant qualifications working in Wales can complete CVIs for people with bilateral dry age-related macular degeneration (AMD) as part of its optometry contract reform programme. [10] The move is supported by research performed by Cardiff University, which showed comparable agreement between consultant ophthalmologists and appropriately trained and experienced optometrists in the identification of certification eligibility criteria for people with vision impairment. [11] The move is designed to increase patient access to certification and reduce referrals to hospital eye services for the purpose of CVI registration.

In March 2021, the Welsh government announced a £4.8m investment to “modernise the referral and monitoring of patients with eye conditions”, with an additional £3.05m to replace IT hardware, the first national electronic patient record and referral system for eye care. [12] While devolved commissioning structures in England mean such a national model is unlikely to progress, standardised national specifications and an image sharing mechanism would streamline the roll-out of such systems. These could be modelled on The Royal College of Ophthalmologists specifications for ophthalmology electronic patient records, [13] and could be included in the NHS England Eye Care Digital Playbook. [14]





There are a number of large-scale data linking and research projects which provide useful models for mass data collection to inform planning, research and patient care in both eye-specific, and wider health conditions.

These include:

- **The INSIGHT Health Data Research Hub for eyes**, [15] led by Moorfields Eye Hospital NHS Foundation Trust in partnership with University Hospitals Birmingham NHS Foundation Trust, which makes routinely collected eye data available for approved health research to develop new insights in disease detection, diagnosis and personalised healthcare.
- **AlzEye**, [16] which is a large retrospective cohort dataset linking ophthalmic data from Moorfields Eye Hospital NHS Foundation Trust with NHS hospital admissions data over a 10-year period in 353,157 patients. Researchers are using AlzEye to identify retinal signatures that can support early detection of conditions such as cardiovascular disease and dementia.
- **Our Future Health**, [17] and other large scale genetic risk profiling and biobank programmes.
- **The Royal College of Ophthalmologists National Ophthalmology Database Audit**, [18] which gathers data from participating ophthalmology centres on patient outcomes to support service improvements. At present audits are co-funded by industry, and cover cataract and AMD services.
- **Eye Level**, [19] a joint project by RNIB and Roche which maps variation in population demographics, service delivery, and strategic priorities for sub-national health systems in the UK, to support decision making and service commissioning.

A number of additional research projects, which are currently in developmental phases, are detailed under “Investment into research for future treatments”.

2

Prevention, diagnosis and early intervention in an integrated system

“Integrated Care Systems provide a real opportunity to take coordinated action to improve the interface between eye care services to enable better care and early intervention, particularly for underserved or high-risk populations, reducing avoidable sight loss, led through primary eye care.”

Adam Sampson

Association of Optometrists

Facts & Stats

- Reducing the prevalence of eye conditions by just **1 percent per year could save £9.5 billion by 2050.** [20]
- There are now significant waiting lists for ophthalmology care. **1 in 12 patients** awaiting specialist treatment in England were in ophthalmology as of August 2023, with 36 percent of patients waiting **over 18 weeks** nationally (a figure which rises as high as 50 percent in some ICBs). [1]
- Delays to treatment have negative consequences. Since 2019, there have been over 550 reports to the National Reporting and Learning System in relation to **sight loss due to delayed appointments**, of which, 99 incidents involved “severe harm” to patients. [21]
- Despite valuing sight above other senses, people do not prioritise protecting their sight. A 2021 survey of 1,516 British adults found that 51 percent of respondents don’t often think about their own eye health. [22] Research by Eye Health UK and Thomas Pocklington Trust found that just **one in four people rated routine eye tests as important** for maintaining good eye health. [23]
- Rates of sight loss certification tend to be **higher in more deprived areas** of England. [24]



- A recent survey by AOP found that of responding UK optometrists:
 - **39 percent do not provide MECS/CUES to patients**
 - **77 percent do not provide glaucoma monitoring**
 - **85 percent do not provide diabetic retinopathy screening/monitoring**
 - **67 percent do not provide wet AMD referral refinement. [6]**



What we heard



One of the biggest challenges facing the eye care system is the **lack of awareness amongst the public about the importance of good eye health** across the life course, the causes of sight problems and the links to other conditions and understanding when to seek healthcare. Through this call for evidence, we heard about the value of government-led messaging on the importance of eye health, the need to develop and promote the role of optometrists, and the importance of protecting the national General Ophthalmic Services (GOS) contract in order to safeguard and promote the importance of good eye health to patients and the public, including among *underserved or high-risk groups*.

The call for evidence identified many opportunities involving technology in screening, detection and early intervention, as well as the need to ensure telemedicine services and virtual access to consultations are used in the most appropriate part of a pathway. **Accurate diagnosis is a critical part of ensuring timely patient access to treatments**, and a better range of clearly defined disease markers can also help to achieve this.

There is consensus across the sector about the **inconsistent commissioning of eye care services**. Poor data hinders the ability of the NHS and ICBs to benchmark the quality of eye care.

Key issues



- **Lack of public health information and education about eye health**
- **Lack of local population eye health assessments, which has an impact on service planning**
- **Lack of efficiency and consistent commissioning of proven clinical pathways**

The call for evidence found significant regional variation in terms of service provision, patient access to services such as optometry-led MECS and CUES, and to NHS funded Optical Coherence Tomography (OCT) scans. This variation can present a financial barrier for individuals and increase the risk of preventable sight loss and increase health inequalities in many areas.

Patient care is often fragmented, with different structures, providers, and oversight across primary, secondary and community care, undermining efforts to deliver early diagnosis and interventions which could prevent avoidable sight loss. In particular, responses from the optometry sector highlighted how implementing new care pathways, adopting the Optometry First [25] principles and recognising the core skills of optometrists and dispensing opticians, can release capacity within hospitals for people who need specialist care.

As ICSs take on responsibility for planning and delivering health and care services, there is an opportunity to take coordinated action to improve the interface between eye care services to enable better care and early intervention, particularly for underserved or high-risk populations, reducing avoidable sight loss. This should ensure the right pathways are in place that enable people to be seen in the right place, at the right time, for the right care. There is also an opportunity for the system to address the health inequalities which lead some people to have worse eye health outcomes overall.

What needs to change?

The overarching recommendations that could make the biggest difference to the sector and enable a transformational approach to eye health are:



- 3 ICPs should undertake an eye health needs assessment of the population – as part of Joint Strategic Needs Assessments – to feed into public health plans and inform local commissioning and pathway development. Where possible, this should be informed by new sources of data and real-world evidence, as detailed in section 1.**
- 4 ICBs should develop a high-quality consistent pathway of care for optometry that recognises the value of community optometry practices as diagnostic hubs and treatment centres, which may be based on an Optometry First model. This pathway should be supported by consistent commissioning of core universal eye care services across all ICSs that ensures patient access to MECS and CUES, and other extended services.**

Other recommendations identified through this call for evidence include:

- DHSC and the Office for Health Improvement and Disparities (OHID) should work in partnership with ICBs to **increase uptake of sight tests and eye health assessments**, particularly among patient groups with lower levels of uptake of sight tests, patients living in areas where existing service provision is poor, or groups at higher risk of eye conditions (e.g., due to comorbidities or genetic factors). This should include exploring a move to making sight tests and eye health assessments freely available to all through the NHS through proper investment and funding, utilising learning and analysis from the impact of free tests in Scotland.
- OHID and NHS England should work in partnership with the eye care sector and organisations representing patients with health conditions that may increase risk of, or are associated with, sight loss. Joint activity should aim to **increase uptake of relevant screening programmes**, such as diabetic eye screening, across all population groups.
- NHS England should **fund a service that utilises OCT in primary care optometry practices**, supported by appropriate training where required, to further improve diagnosis and appropriate onwards referral. For example, utilising OCT to complement glaucoma repeat measures can help reduce “false positive diagnosis”, while use of OCT to grade diabetic maculopathy cases can provide a more accurate understanding of disease progression, both of which would help reduce avoidable referrals. Delivering more diagnostic activity (for example diabetic retinopathy screening) in primary care optometry can also provide clinicians with a more holistic picture of overall eye health and widen access to screening services in some areas.
- Every ICB should ensure that they have a **dedicated inherited retinal disease pathway** in place, including signposting to third sector support, equitable access to genetic counselling and testing services, regardless of where the person was diagnosed.



What is best practice?



In 2023, pharmacies across Northern Ireland launched a campaign, 'Look after your eyes', focused on the importance of looking after one's eyesight and the benefits of regular eye checks. [26] The campaign is supported by the Public Health Agency, Community Pharmacy NI and the Department of Health.

We received several examples of new pathways highlighting the role that optometrists can and have played in supporting glaucoma treatment and cataract care, including the glaucoma enhanced referral service and stable glaucoma monitoring service in Greater Manchester. [27] Specsavers also referenced a variety of Glaucoma Referral Filtering Services, to identify patients who can be managed within a community optometry setting and more complex cases requiring referral to secondary care have been developed. Moreover, Scotland, Northern Ireland and Wales have well established protocols for the use of primary care optometrists in the glaucoma care pathway supported by coordinated funding. [28]

Another example of collaboration across primary and secondary care is the Manchester cataract service which utilises optometrists across the entire cataract care pathway, encompassing pre and post cataract care, following the Local Optical Committee Support Unit (LOCSU) pathway, in primary care and within the hospital. [29] Patients are first assessed by an optometrist who discusses treatment options and addresses patient concerns, a process which has resulted in increased uptake of cataract surgery among referred patients. Similarly, patients are supported following cataract surgery through discharge to primary care, which improves patient experiences (ensuring any post-operative complaints are addressed close to home where possible) while minimising the demand for post-operative provision.



3

Equity of access, support and patient empowerment throughout the patient pathway

“It is vital that patients are both supported and empowered at all stages of their eye care journey. This means understanding what to expect at every stage, who they can turn to for advice and guidance, and that there is both physical and emotional support available throughout, and especially while waiting, at what can be an uncertain time in people’s lives.”

Phil Ambler

England Country Director, RNIB

Facts & Stats

- Being diagnosed with a condition which causes sight loss can have a **profound effect on patients** and those around them, and can lead to reactions similar to bereavement. [30]
- Some chronic eye conditions demand **long term monitoring and treatment**, requiring regular contact with eye services, sometimes as frequently as every month. [31] Adherence to medications and appointments is crucial for decreasing avoidable vision loss. [32] Yet, **some appointments can take up to 12 hours [33] of a patient’s time** including preparation, travel, waiting times and post appointment recovery.
- **Treatment pathways for eye conditions can be complex and slow**; NHS England data shows that average referral to treatment waiting times for consultant-led ophthalmology services vary substantially between ICBs, from 8.3 weeks to 19.4 weeks, [1] resulting in a “postcode lottery” in eye care.



- A poll of 498 members of the public with macular eye conditions who have required medical treatment in the past two years found that:

- **30 percent feel abandoned by the NHS or authorities;**
- **41 percent of patients report being frightened of losing their vision entirely. [20]**

- In developing an Eye Care Support Pathway model, RNIB identified over 100 pain points experienced by patients which should be addressed. [34]

DEPRESSED
SCARED
ANXIOUS
FRIGHTENED



What we heard



The number of professionals and touchpoints in a pathway can be challenging to navigate. Currently there are multiple points of access, and the patient journey can be confusing. **We heard that patients are often left with a feeling of not knowing what is next and a lack of information and advice at initial appointment stage.** While there are many support services available to patients, these are not always signposted to by practitioners. Many patients do not recall such information despite the fact that having the right information at the right time (which differs between patients) is critical for optimal outcomes. Patient information, communication and empowerment is critical throughout the entire care pathway to enable patients to exercise informed choice.

Key issues



- **Lack of patient information and emotional support about the impact of receiving a life changing diagnosis**
- **Lack of signposting to practical support at different stages of the pathway**
- **A need to make reasonable adjustments available throughout the pathway**

Many respondents noted the value of ECLOs in supporting patients along complex care pathways, highlighting that they are not NHS funded and not commissioned in all areas. ECLOs are non-clinical staff who can provide advice on issues such as eye conditions, as well as mental health and wellbeing, social services, employment and local support groups.

Respondents also noted the importance of a clear eye care support pathway, to standardise provision of support to patients at all stages of their care.

Additionally, respondents highlighted a clear need for ongoing support and signposting to wider services (including vision rehabilitation, peer-to-peer support, low vision support and third sector provision), particularly for patients who have completed a clinical pathway, without which patients risk poorer outcomes.

“I helped the patient put a plan in place to access community and social support. Just knowing about local contacts and sources of support has lifted her mood and she can now begin to see a way forward. While there remains a long road ahead, the patient is beginning to regain some confidence and independence which is having a positive impact upon her emotional wellbeing. I stressed she is not alone during what is going to be a difficult time in her life.”

ECLO

Supporting a patient with bilateral dry AMD

The call for evidence revealed the need to streamline access to care and advice through enabling patients to access diagnosis, treatment and support on the high street, closer to home. There also needs to be failsafe mechanisms to ensure people with additional needs such as learning disabilities or those experiencing homelessness do not ‘fall through the net’ when needing CVI certification, eye care surgery and follow up treatment in the current outpatient transformation programme, given pre-existing backlogs and waits. Respondents also told us about the lower levels of engagement amongst certain populations. **It is important to identify ways to increase participation in screening programmes and ensure equal chances of referrals into the health system** – including the independent sector – for treatment.

We also heard about the impact of receiving a life-changing diagnosis and the lack of support for patients' emotional wellbeing and mental health at this part of the pathway. Organisations spoke about the importance of emotional support for people experiencing sight loss and early support to enable them to live as independently as possible. A recent qualitative study highlighted the need for mental health support at the point of diagnosis, with many patients reporting that they had not proactively received any form of support and the majority stating that they didn't know where to go for support should they need it. [35] The study also showed that ECLOs and referring optometrists agreed that more needed to be done regarding the provision and signposting of mental health support.

What needs to change?

The overarching recommendations that could make the biggest difference to the sector and enable a transformational approach to eye health are:



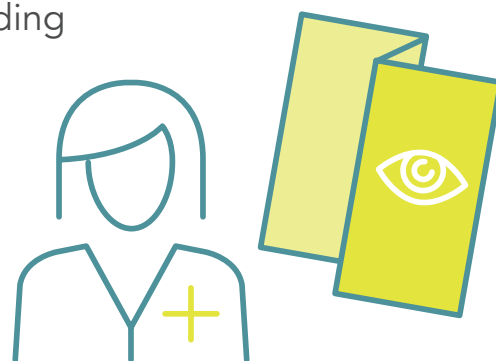
- 5 ICBs should commission ECLOs and implement an eye care support pathway, providing consistent patient information, communications and support at all stages of the patient pathway. This should include raising public awareness and knowledge of self-care, new treatment options and the importance of treatment compliance/adherence, as well as wider non-clinical support services including vision rehabilitation services, the third sector, and emotional and wellbeing support that extends beyond the initial post-diagnostic support period.**
- 6 NICE should update guidance to recognise the need for psychological care to be provided as part of wider eye care. This should include reference to a multidisciplinary treatment programme with input from ECLOs, primary eye care, psychiatry, psychology and vision rehabilitation specialists.**

Other recommendations identified through this call for evidence include:

- ICBs should **utilise new digital systems to identify patients with additional needs**, such as learning disabilities, and ensure appropriate support and reasonable adjustments are provided throughout the pathway through the adoption of the Reasonable Adjustment Flag and Accessible Information Standard.
- ICBs should undertake research to identify what additional support may be needed among underserved or high-risk groups such as those from minority ethnic groups, people experiencing homelessness or people with learning disabilities, who are coming into contact with the eye care system.
- ICBs should ensure that service providers have the information and resources to **provide appropriate support to patients regardless of their needs, and to signpost to additional services**, including third sector, where necessary. NHS England should work with professional bodies to ensure that training professional development enables clinicians to fully meet patient needs, and including providing culturally competent care, ensuring that patients with learning disabilities are fully empowered to make decisions about their care, and providing appropriate levels of mental health support to patients across the eye care pathway.

What is best practice?

We heard about the benefits of LOCSU's clinical pathway for people with learning disabilities [36], which provides reasonable adjustments and individualised care for patients. South East London ICB, for example, has commissioned the service in accredited practices who have undertaken the appropriate training. The pathway supports different referral routes and provides several adaptations for patients, including a pre-appointment visit, longer appointments and accessible patient information.



4

Eye care workforce

“Ophthalmology is the busiest outpatient specialty in the NHS. Despite this, most units do not have enough consultants to meet current patient need, let alone future demand as the population ages. The next government must deliver on commitments and increase ophthalmology training places to ensure we have the workforce to meet patient demand, supported by innovative and efficient services alongside ensuring more rational approaches to commissioning independent sector capacity where it is needed.”

Professor Ben Burton

President, The Royal College of Ophthalmologists

Facts & Stats

- Ophthalmology is the **busiest outpatient speciality** in the NHS, with over 8 million attendances in England in 2022/23. [37]
- **Over 640,000 patients** were on **outpatient ophthalmology waiting lists** in England as of August 2023. [1]
- Demand is outstripping capacity, with over three quarters (76 percent) of NHS eye units reporting not having enough consultants to meet current patient need. [2]
- **NHS ophthalmology units are facing significant recruitment and retention challenges:**
 - over half of NHS ophthalmology units (52 percent) have found it more difficult to fill consultant and specialty and associate specialist doctor vacancies over the last 12 months;
 - a quarter of consultants (25 percent) plan to leave the ophthalmology workforce over the next five years. [2]
- Without a significant expansion of the eye care workforce, this **capacity gap is set to widen** as demographic changes lead to more people living with conditions which cause sight loss. [3]
- As of September 2023, there were over **17,500 optometrists** registered in the UK, including 1,618 independent prescribing optometrists. [38]





What we heard

Ophthalmology is already the busiest outpatient speciality in the NHS, with over 8 million attendances in England in 2022/23.[37] The NHS Long Term Workforce Plan estimates that without any action, given our ageing population, the NHS in England would be left with a shortfall of 260,000 – 360,000 staff by 2037. [39] To address this shortfall, **respondents highlighted the need to see significant funded increases to the number of ophthalmology training places**, building on existing planned expansions to medical school places.

The call for evidence highlighted a significant opportunity to commission improved integrated eye care services, which make better use of the skills of the wider eye care workforce, including optometrists, orthoptists, and dispensing opticians as well as nurses, pharmacists, imaging specialists and others (which are not always recognised or well understood by policymakers).

Respondents noted the high level of existing clinical skills found in the optometry profession. Unlike ophthalmology, there is no real workforce shortage in optometry, (although like many professions there is some geographical disparity), and the profession has a strong training and recruitment pipeline. Expanding optometry-led, out-of-hospital services such as MECS and CUES therefore has the potential to improve access to timely care, reduce unnecessary referrals, alleviate downstream pressures on secondary care, and ultimately improve patient experiences and outcomes. These services can be strengthened by continuing to upskill the eye care workforce, for example by supporting more optometrists to qualify as independent prescribers.

However, **we also heard about the lack of infrastructure to enable professionals to make the best use of their skill sets.** Members of the optometry profession reported that independent prescribing optometrists in England do not have universal access to NHS prescription forms, meaning that appropriately qualified optometrists may not be able to prescribe medicines and necessitating GP referrals and hospital visits. This is in contrast with Scotland and Wales where there is a high

Key issues



- **Lack of investment in the eye care workforce, leading to capacity shortfalls**
- **Inefficient and ineffective use of skills across all professions**
- **Lack of data to support coordinated and effective workforce planning**

level of access to NHS prescription forms (FP10). [40] More broadly, among the parts of the workforce not facing existing shortages, we heard that there should be a focus on enhancing training to ease pressures in other parts of the system.

What needs to change?

The overarching recommendations that could make the biggest difference to the sector and enable a transformational approach to eye health are:



- 7 Building on commitments in the NHS Long Term Workforce Plan, DHSC and NHS England should increase the number of ophthalmology specialty training places in line with current and future patient need and fully resource trainers to deliver this expanded programme.**
- 8 DHSC and NHS England should iteratively plan and implement additional expansions to the wider eye care workforce as needed to meet future demand or deliver new models of care. In the immediate term, this may include expanding the number of image graders and ophthalmic nurses available to boost diagnostic capacity.**
- 9 Commissioners should, where necessary, enable and upskill the wider eye care workforce to deliver more clinical care outside hospital, for example through universally commissioned, optometry-led MECS and CUES.**

Other recommendations identified through this call for evidence include:

- In the short-term, DHSC should **invest in ECLOs as a core part of ophthalmology services** to support efficient pathway navigation, referral, follow-up and signposting to additional services where appropriate.
- NHS England and commissioners should **adopt a transparent approach to workforce planning**, sharing workforce modelling and data wherever possible, to improve the system's understanding of current and future workforce skills and capacity. Workforce planning should seek to address variation in the geographical distribution of the eye care workforce.
- DHSC and NHS England should work with commissioners, professional bodies and independent sector providers to **ensure that independent sector capacity is commissioned in a considered way in line with patient need**, taking into account the sustainability of comprehensive NHS services. Policymakers should also ensure

that sufficient training opportunities are provided where NHS-funded procedures are being delivered by independent sector providers.

- Specific measures to make better use of the wider eye care workforce identified through the call for evidence include:
 - NHS England should **expand funding and coordinate placement provision for additional training which allows career progression within and between roles**, such as independent prescribing qualifications for optometrists and orthoptists or programmes for optical assistants to qualify as dispensing opticians.
 - Professional bodies and others should **ensure the provision of continuous professional development opportunities to all eye care professionals on the usage of new digital tools and understanding novel treatment models and technologies** that emerge in the field.
 - Commissioners should **roll out successful initiatives which enable the wider workforce to deliver more care**, such as nurse-delivered eye injections. NHS England and professional bodies should consider piloting or expanding similar initiatives across the eye care workforce (e.g., orthoptist- or optometrist-delivered eye injections), and should explore further areas in which the wider in which the wider workforce could add value.

What is best practice?

In 2022, Swansea Bay University Health Board Ophthalmology Department co-designed a pigmented ophthalmic lesions screening (POLS) clinic, led by a qualified and experienced ophthalmic photographer. It operates by on-call ophthalmologists referring patients to the ophthalmic photographer, who records and reviews the images before making a recommendation for a clinical outcome or review. The patient is subsequently passed on to the consultant, provided with a follow-up appointment or discharged as appropriate. This model provided additional capacity to the unit by fully utilising the skills of an experienced ophthalmic photographer.

We also heard about teach and treat clinics in Scotland [41], which give community optometrists the opportunity to manage and treat patients under the close personal supervision of an ophthalmologist, which increases their exposure to the diagnosis and management of acute conditions.



5

Using new technologies and treatment models

“Artificial intelligence... has changed our lives. In our smartphones, laptops, and social media, deep learning provides image and speech recognition, language translation, and more. These advances have begun to percolate into medicine, with deep learning systems capable of diagnosing skin cancer and fully autonomous AI approved for diabetic retinopathy screening. Although AI-enabled healthcare has huge potential, we are still only in its early stages.” [42]

Professors Pearse Keane & Eric Topol

What we heard



Improving eye care services will require significant innovations, including in care pathways and the use of data. New models of care, technologies and treatment models have the potential to deliver better care closer to home or in the community through digital home monitoring. Facilitating the uptake of innovative diagnostic approaches or treatments also has potential to reduce the burden of treatment and improve patient outcomes.

As detailed earlier, a recurrent theme throughout this call for evidence, is the challenges facing the sector due to the lack of IT connectivity and digital clinical image interoperability, which causes significant inefficiencies.

We also heard about the benefits of tools such as OCT in optometry, which can further enhance diagnosis and aid appropriate onward referral.

Key issues



- **Inconsistent utilisation of new technologies across England**
- **Lack of infrastructure to support roll out of new technologies and treatments**
- **Need to embrace digital innovation and capture data**

It is clear the sector is eager to embrace digital innovation for diagnosis, referral, communication, collaboration and remote care.

Emerging advanced digital technologies, digital therapeutic approaches and innovation in drug delivery also provide new opportunities for ophthalmology.

We heard about the need to ensure the workforce is trained on new technologies and treatment models, and that they are applied consistently across the country due to the movement of patients and lack of registered patient lists in optometry. A clear and collective approach to innovations such as artificial intelligence and robotic automation process applications, which enable more accurate screening, diagnosis and monitoring for the whole population, is essential.

There was clear consensus about the desire for NHS England to embrace digital transformation, such as telemedicine solutions, artificial intelligence and robotic automation process applications, remote patient monitoring and digital triage tools. New technologies and treatment models should also be inclusive of tools that support patients with learning disabilities and enable better engagement in sight testing.

Importantly, we heard that while new technologies and treatment models may reduce the per patient burden of care or improve patient outcomes, they may not necessarily reduce overall service demand; provision of new services may result in more patients seeking care, and capacity will also need to be allocated to both workforce training and subsequent delivery of new technologies and treatment models.

What needs to change?

The overarching recommendations that could make the biggest difference to the sector and enable a transformational approach to eye health are:



- 10 NHS England should ensure the system has the necessary underlying infrastructure and processes in place to support consistent roll out and application of new technologies and treatment models across the country. This should include setting out clear commissioning requirements, with a minimum standard of evidence alongside analysis of clinical and cost effectiveness, to support correct implementation.**
- 11 NHS England, ICBs and service providers should ensure that there is adequate staff training and resourcing to deliver new technologies and treatment models, and that evolving professional practice is reflected in workforce planning and training.**

Another recommendation identified through this call for evidence is:

- NHS England should **capture data from the roll out of new technologies and treatments that can be fed back into real-world evidence**, for example imaging technologies can be utilised to discover and validate reliable (surrogate or not) markers of disease progression. In turn, this could lead to personalisation of treatment, earlier detection of conditions, prediction and risk management of deteriorating vision and associated adverse eye health outcomes.

What is best practice?

Respondents provided several examples of promising new technologies, including:

- New drug-delivery mechanisms, which have the potential to make treatment programmes less burdensome for patients.
- New apps and digital tools which can support condition management in the community.
- Artificial intelligence tools, which have potential utility across eye care. Potential applications include drug development, diagnostics for a wider range of stages of disease progression, biomarker identification, disease progression monitoring, personalised treatment and automated care administration and communications. However, it was acknowledged that this does also present risk and there is no definitive sector position on the pace and scale of future utilisation on AI. Simulated training, clinical trial design and education using virtual workshops, immersive technology and hybrid environments would also be beneficial.



6

Investment into research for future treatments

“Eye research changes lives. Increased investment in eye research across the UK is fundamental to improving our understanding of the causes of eye diseases and developing the diagnostics and treatments to enable improved outcomes for patients. In addition, it is critical the UK attracts, trains and retains the next generation of discovery and clinical researchers to ensure the UK remains a world leader in eye research.”

Dr Madina Kara

Director of Research and Innovation, Fight for Sight / Vision Foundation

Facts & Stats

- By 2050, 4 million people are expected to be living with sight loss in the UK, [3] and **the costs of sight loss to the economy are expected to rise to at least £33.5 billion per year.** [19]
- Despite the potential for significant advances in areas such as gene therapies, **just £9.60 per year is currently invested in eye research for each person with sight loss,** one tenth of the per person spend on dementia research. [19]
- The NIHR Clinical Research Network ophthalmology portfolio recruited 15,780 participants into 144 studies in 2022/23. [43]
- Research is also an important factor for the workforce; The Royal College of Ophthalmologists’ 2022 workforce census revealed that **a majority (54 percent) of trainees want to be more involved in research.** [2]



What we heard



Research and innovation have the potential to transform eye care services through enabling a better understanding of sight loss and finding the next generation of diagnostics and innovative treatments. This has the potential to lead to improved prevention, early detection and treatments for conditions which cause sight loss.

The call for evidence highlighted sector support for a renewed focus on clinical research to improve patient outcomes and ensure that as many people as possible can keep their sight. **Key concerns for the sector are the limited field of researchers and clinicians often located in a few centres, the lack of a dedicated national eye health research infrastructure (creating barriers to collaboration between researchers and patient participation in research), and the lack of accessible data for the purposes of real-world research.**

Some studies also face problems recruiting patients, which can lead to delays to progression or cancellations of clinical studies. All of these hinder research and development within the sector, and result in research expertise being prevalent in a few select geographies which in turn impacts on standards of healthcare across the country.

The call for evidence demonstrated sector support for increased research funding. Participants noted that eye health research, which has a high potential to deliver improvements not only in eye health but also in other areas such as neurodegeneration, receives just £9.60 per patient per year. [19] In contrast, dementia research receives £97 per person per year. Investment in research is critical given the scale and significance of society's ageing population, combined with the fact that prevalence of sight loss increases with age; nearly 80 percent of people registered blind or partially sighted in the UK are 65 or older, and around 60 percent are over 75. [44] **There is a clear need to accelerate research into how to reduce preventable sight loss within wider healthy ageing initiatives** to help overcome the significant public health challenges that the ageing population will cause for the sector.

Key issues



- **Limited field of researchers and clinicians and a lack of protected time for research activity in job plans**
- **Fragmented and inefficient clinical trial infrastructure**
- **Lack of research funding, despite higher chances of return on investment**

We also heard about the need to increase patient involvement in shaping research projects and identifying unmet needs, as well as increase patient access to participating in research studies. Moreover, ensuring research is communicated and translated into practice is critical to improve patient outcomes.

What needs to change?

The overarching recommendations that could make the biggest difference to the sector and enable a transformational approach to eye health are:



- 12 At present, sight loss research receives just £9.60 per person per year. Government should double this, taking total public investment to at least £50 million per year by 2030 across the country (for common and rare diseases), and continuing to expand research funding sustainably thereafter.**
- 13 Government should work with the NIHR and UKRI to increase the provision of early career research studentships and fellowships – recognising that investment in vision research can potentially also advance multiple other health research fields, such as neurodegeneration.**

Other recommendations identified through this call for evidence include:

- NHS trusts should **provide appropriate protected time in job plans** to enable the workforce to participate in research.
- NHS England should **promote research as part of portfolio careers**, including among optometrists and dispensing opticians, to ensure the development of novel treatments and methodologies and their rapid adoption into standard care.
- NIHR should **coordinate improvements to the clinical trials environment** through skills, funding and infrastructure to enable easier site selection and attract more commercial and non-commercial ophthalmology trials to the UK. This would help build research expertise, improve access to novel therapeutics and raise standards of healthcare across the country.
- NHS England should **support data linkage between ophthalmology and optometry** and increase the ability for professionals in non-research settings to contribute data to Trusted Research Environments (see next section, and earlier examples within “data, connectivity and real-world evidence”).

What is best practice?



Call for evidence respondents told us about the potential impact research can have on NHS capacity. For example, a UK-wide clinical diagnostic study, funded by the NIHR, has shown how a new surveillance pathway for people with stable diabetic eye disease is safe and cost-saving, freeing up ophthalmologists to evaluate and treat people requiring urgent care. [45] The pathway uses trained graders to monitor people with previously treated and stable complications of diabetic eye disease based on the readings of images and scans of the back of their eyes. The grader's performance was comparable to results produced with standard care (i.e., ophthalmologists evaluating patients in clinic). Respondents also noted the importance of natural history studies, which can provide a better understanding of the efficacy of different therapies, improving patient care.

A number of large-scale data linking and research projects which could benefit from increased public research funding were highlighted by respondents. Many of these are detailed in the "data, connectivity and real-world evidence" section. Others still in development are outlined here:

- **The UK National Eye Health and Hearing Study (UK NEHS)** [46] will gather large scale survey and exam data to develop representative data of the nation's sensory health, to inform policymakers and commissioners and shape care planning.
- **The Foresight Project**, [47] led by Action Against Age-related Macular Degeneration and the Macular Society, will encourage people with or without macular conditions to donate their retinal scan images and other patient information to support AI-enabled research. However, it should be noted that these scans are not currently funded by the NHS in most circumstances, creating a potential barrier to participation.



7

Availability of treatments

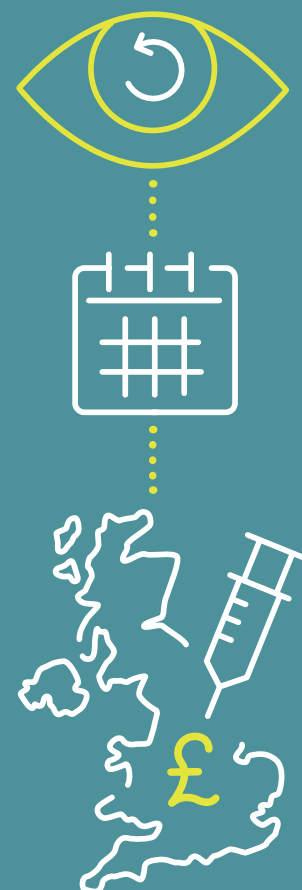
“People are terrified at the prospect of losing their vision. People diagnosed with macular degeneration wake up every day wondering if that is the day they will lose their sight. The capacity problems in so many clinics is leading to the tragedy of people losing sight even though there are treatments that would help keep their vision for longer but are not given in time. This is an urgent situation now and unless there is action, it will get worse in the coming years as more people develop conditions like AMD. The Macular Society, as part of The Eyes Have It partnership, is calling for a national plan for eye care which will help resolve the problems and improve outcomes for patients today and in the future.”

Cathy Yelf

Chief Executive, The Macular Society

Facts & Stats

- **Eye conditions need to be treated quickly** to increase the chances of good outcomes. [48]
- The Royal College of Ophthalmologists National Ophthalmology Database Audit on Age-related Macular Degeneration reveals that **more than 90 percent of eyes retained stable vision at the end of the first year of treatment** and avoided a ‘significant’ further decrease in vision. [49]
- However, the **cost of new treatments is highly variable and can increase as more patients become eligible for treatment**. One study found that anti-VEGF treatment activity increased 215 percent, between 2010/11 and 2014/15, while the total costs of procuring, prescribing and delivering anti-VEGF intravitreal injections increased 247 percent, with significant regional variation in treatment rates. [50]



- Across all disease areas, **access to new medicines in the UK has declined significantly in recent years.** Of the 168 new medicines authorised by the European Medicines Agency between 2018 and 2021, only 66 percent were made available in England, compared to 72 percent of medicines authorised between 2016 and 2019. [51]
- Across all disease areas, for every 100 patients that get a new medicine in its first year of launch in other parts of the EU – including France and Germany – just 21 patients in the UK get access. [52]

What we heard



Call for evidence respondents told us about the regulatory barriers that impact on patient access to treatments, including a lack of consideration of the burden of sight loss and the need to develop and consider PROMs when evaluating new treatments. Additionally, as new treatments become available across sight loss conditions, more consideration of cost effectiveness will need to be made.

Future treatments have the potential to reduce the burden of treatment or more effectively prevent, delay or mitigate sight loss thus improving patient outcomes.

Despite this, we heard that alongside availability of current and novel treatments, there needs to be better availability of, and access to, accurate diagnosis provided alongside a better range of clearly defined disease markers. **Currently, markers of the early stages of disease and how these relate to the progression of a condition are lacking.**

It is essential that eye care providers have the processes and systems in place to ensure new treatments can be quickly delivered to patients, whether that be through implementing new treatment pathways or ways of working. **It is also important to be prepared for future treatments on the horizon.** Currently, treatments are focused on the slowing of progression, halting the progress and in some cases partial reversal of condition.

Key issues



- **Regulatory frameworks are creating a barrier to timely approvals**
- **Poor horizon scanning for new treatments and a lack of system readiness impacts on patient access to treatments**

Over time, there is potential for better treatments to evolve towards reversal of deterioration in sight and prevention of disease. As delivery of treatments changes, the services enabling delivery will need to change at the same pace to provide equitable access.

What needs to change?

The overarching recommendations that could make the biggest difference to the sector and enable a transformational approach to eye health are:



14 NICE should improve its approach to new technology appraisals through:

- **Incorporating more up to date utility measures that recognise the value of preserving vision/stopping the deterioration of sight loss, both in its own right, and in terms of its impacts on social inclusion and comorbidities (e.g., fewer falls, better mental health and higher mobility).**
- **Working with patients to identify new PREMS and PROMS which capture the wider benefits of interventions, and can be used as part of assessments for new therapies.**
- **Adopting a better understanding of the uncertainty around long-term outcomes for people receiving treatment with inherited retinal diseases.**

Other recommendations identified through this call for evidence include:

- NHS England and commissioners should **improve systematic horizon scanning for new treatments**, planning and implementing any necessary workforce training or patient pathways to facilitate equitable and rapid uptake of newly approved treatments across geographies and different demographic groups.
- NHS England and ICSs should **ensure timely patient access to treatments** through:
 - Identifying reliable ways to profile individuals according to their risks of having a certain sight loss condition (e.g., identification of genetic risk markers or lifestyle/exposure to risk factors) to increase access to treatments.
 - Ensuring new treatments are convenient for people to access, given the importance of geography to this patient population.

What is best practice?



Respondents to the call for evidence told us about some of the new treatments being rolled out in eye care services around the UK, which can bring significant patient benefits if delivered at scale. One example highlighted was the roll out of a new implant for minimally invasive glaucoma surgery (MIGS), first used in East Sussex and North Essex NHS Trust in 2022. [53] This new technology uses a tiny strip of sponge, which is inserted into the corner of the patient's eye, in order to absorb excess fluids and thereby relieve intra-ocular pressure. Respondents noted that new treatments and devices must be rolled out as part of joined up care pathways.

Respondents also highlighted examples of PROMs, including a study of PROMs for children, which capture the impact of sight loss on activities such as watching TV or getting around outdoors, [54] and a literature review analysing the suitability of PROMs for visual impairment after stroke. [55]



Conclusion

The extensive and wide-reaching results of this call for evidence demonstrate how much needs to change in order to improve the eye health system in England.

This report sets out key recommendations that are required to lay the foundations for a sustainable eye care system.

Our overarching recommendation is for a national plan for eye care to ensure coordinated action across the entire eye care pathway. The recommendations set out in this report provide the starting point for such a plan.

We look forward to working with government, NHS England and sector leaders to make our vision a reality.

Methodology

Over July and August 2023, The Eyes Have It ran a call for evidence aimed at gathering views from key stakeholders across the eye care sector on how to improve the eye health system in England over the next five years.

The call for evidence covered the following themes:

- 1 Data, connectivity and real-world evidence**
- 2 Equity of access, support and patient empowerment throughout the patient pathway**
- 3 Eye care workforce**
- 4 Prevention, diagnosis and early intervention in an integrated system**
- 5 Using new technologies and treatment models**
- 6 Investment into research for future treatments**
- 7 Availability of treatments**

We received 17 written responses and spoke to three sector leaders, although not every respondent answered every question.

All of the responses received were in the form of open text. In order to analyse the findings, each response was read and coded by OVID Health, on behalf of The Eyes Have It.

List of thanks

We extend our most grateful thanks to everyone we spoke to in the making of this report, for their insights, experience and knowledge of eye care.

The recommendations in this report represent the views of The Eyes Have It partnership and may not necessarily reflect the positions of other organisations who informed the creation of this report.

- **Action Against Age-related Macular Degeneration**
- **Association of Optometrists**
- **College of Optometrists**
- **Fight for Sight / Vision Foundation**
- **Glaucoma UK**
- **Industry Vision Group**
- **Local Optical Committee Support Unit**
- **Macular Society**
- **National Clinical Director for Eye Care, NHS England**
- **Primary Eyecare Services**
- **The Royal College of Ophthalmologists**
- **Retina UK**
- **RNIB**
- **SeeAbility**
- **Roche Products Ltd**
- **Specsavers**
- **Thomas Pocklington Trust**



Thank you!

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