



See the need

Sight loss advisers: improving patient outcomes through cost-effective care



Supporting people
with sight loss

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Throughout this report, the term sight loss adviser is used. In England, Wales, Northern Ireland and the Isle of Man the role is known as an Eye Clinic/Care Liaison Officer (ECLO) and in Scotland, a Vision Support Officer (VSO).

Foreword



Being told you are losing your sight is life-changing, as you try to come to terms with the huge emotional, psychological and financial impact of sight loss.

Staff in eye departments across the UK are under huge pressure. They must diagnose and treat increasing numbers of patients quickly, and simply do not have the time they would like to fully discuss the support that is available. At this distressing time, it is vital that all patients have access to timely emotional and practical support.

Despite facing an unprecedented financial challenge, we know the NHS wants to put patients at the heart of everything it does. At this critical time, the role of sight loss advisers offers hospitals an innovative solution to fulfil an unmet need and ensure nobody faces sight loss alone.

Sight loss advisers complement the work of other staff in the eye department and ensure that patients are provided with quality information, support and advice. They make an enormous contribution to patient care and the efficient running of eye departments, by freeing up clinical and nursing staff time to focus on patients' medical needs.

“See the need” sets out why sight loss advisers provide a cost-effective solution for the NHS to improve the quality of services and outcomes for individual patients. The report also highlights how integrating sight loss advisers into eye departments contributes significantly to the NHS agenda of providing high quality care for all patients, whilst delivering efficiency savings.

The presence of this support service is integral to the delivery of high quality eye care. That's why RNIB is urgently calling for hospital managers to ensure that every eye department across the UK has access to a qualified sight loss adviser.

Lesley-Anne Alexander

**Lesley-Anne Alexander CBE
RNIB Chief Executive**

Introduction

Eye departments are full to capacity and demand for services is set to dramatically increase due to the ageing population.

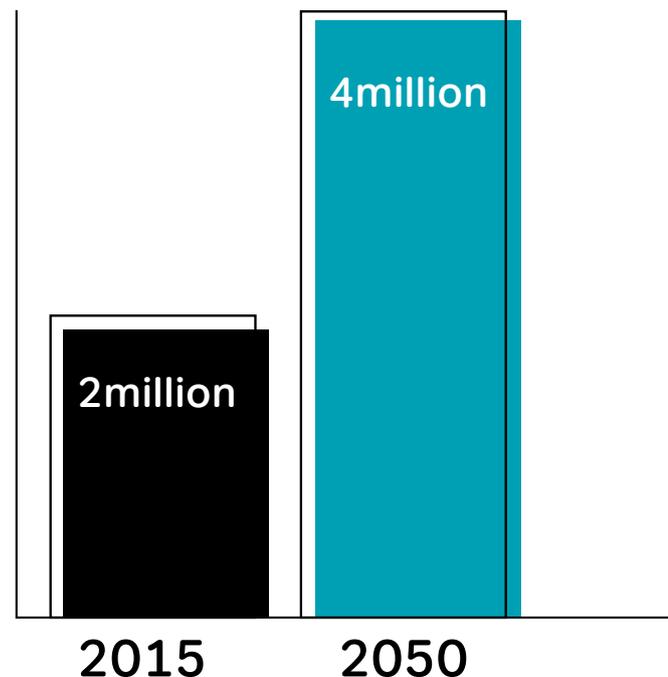
The current pressure on ophthalmologists and their teams is staggering as they are being asked to do increasingly more, with the same resources.

Over the last decade in England alone, the number of ophthalmic appointments increased by 2.35 million; which is an astounding 53 per cent [1]. Ophthalmology continually has the second highest number of outpatient attendances for any specialty in the NHS, and this demand on services will grow as the population ages and the number of people with sight loss increases [1].

There are almost two million people in the UK living with sight loss and this is predicted to double to around four million people by 2050 [2]. This substantial increase can be mainly attributed to an ageing population, as the number of people aged 65 and over is predicted to increase by 60 per cent over the next 22 years, by which time almost one in four people will be over the age of 65 [3].

Clearly, the NHS is at a critical juncture. The pressure of continued rising demand for services, coupled with shrinking budgets, presents health services across the UK with a formidable challenge. This is particularly the case for ophthalmology services, where the need for transformation has never been more urgent.

Estimated number of people with sight loss in the UK



Meeting the needs of people with sight loss

As a result of these exceptional circumstances, ophthalmologists and other medical staff often do not have the time they would like to provide appropriate support to patients when they are diagnosed with a sight condition.

Being told you are losing your sight is devastating and can have an enormous emotional and financial impact. Everyday tasks can become more difficult, such as reading, working and travelling, and as a result, some patients report feeling depressed and anxious.

People with sight loss are also at a much higher risk of experiencing falls. This can lead to them needing further access to health and social care services, which can increase the strain on already overstretched resources.

At this extremely distressing time, practical and emotional support can act as a lifeline when people most need it. Timely access to information and advice is vital as people must learn new coping skills and strategies to adapt to living with sight loss.

However, currently, many people are being left to face sight loss alone.

“When I was diagnosed, I went back into the waiting room and just sat there. I was numb. It was then a case of go home, cope as best as you can and come back for appointments. That was it. No other information.”

Judith

Many health providers across the UK have found an innovative solution to address this problem, through the introduction of a sight loss adviser service. This provides commissioners and hospitals with an opportunity to enhance the quality of their services for patients, while also improving efficiency and lowering costs.

Sight loss advisers: helping to deliver high quality care in a challenging environment

Sight loss advisers work within the eye department and complement the clinical service provided by ophthalmologists, nurses and other medical staff.

They provide patients and their families with vital emotional and practical support. Crucially, this helps patients to understand their diagnosis, adapt to living with sight loss and empowers them to live independently and make informed choices about their care. Sight loss advisers act as a single point of contact for patients at the eye department to whom the patient can return for further advice and signposting to other services.

To manage the range of complex issues patients may face, and to work effectively in partnership with staff in eye departments and across local authority sensory teams, sight loss advisers must be formally trained. They need to be equipped with the necessary knowledge and skills to ensure the provision of a high quality, professional and integrated support service.

RNIB, working in conjunction with City University London, offers an accredited training course which provides prospective sight loss advisers with an excellent working knowledge of the services available for people with sight loss, and an understanding of various eye diseases.

Qualified sight loss advisers are also trained in accordance with a quality framework, which identifies the elements that, in combination, make an effective support service. This includes undertaking a needs assessment to support patients to prioritise their own needs and aspirations and where appropriate referring them to local and national organisations. Sight loss advisers also conduct follow-up work with patients to check their progress.

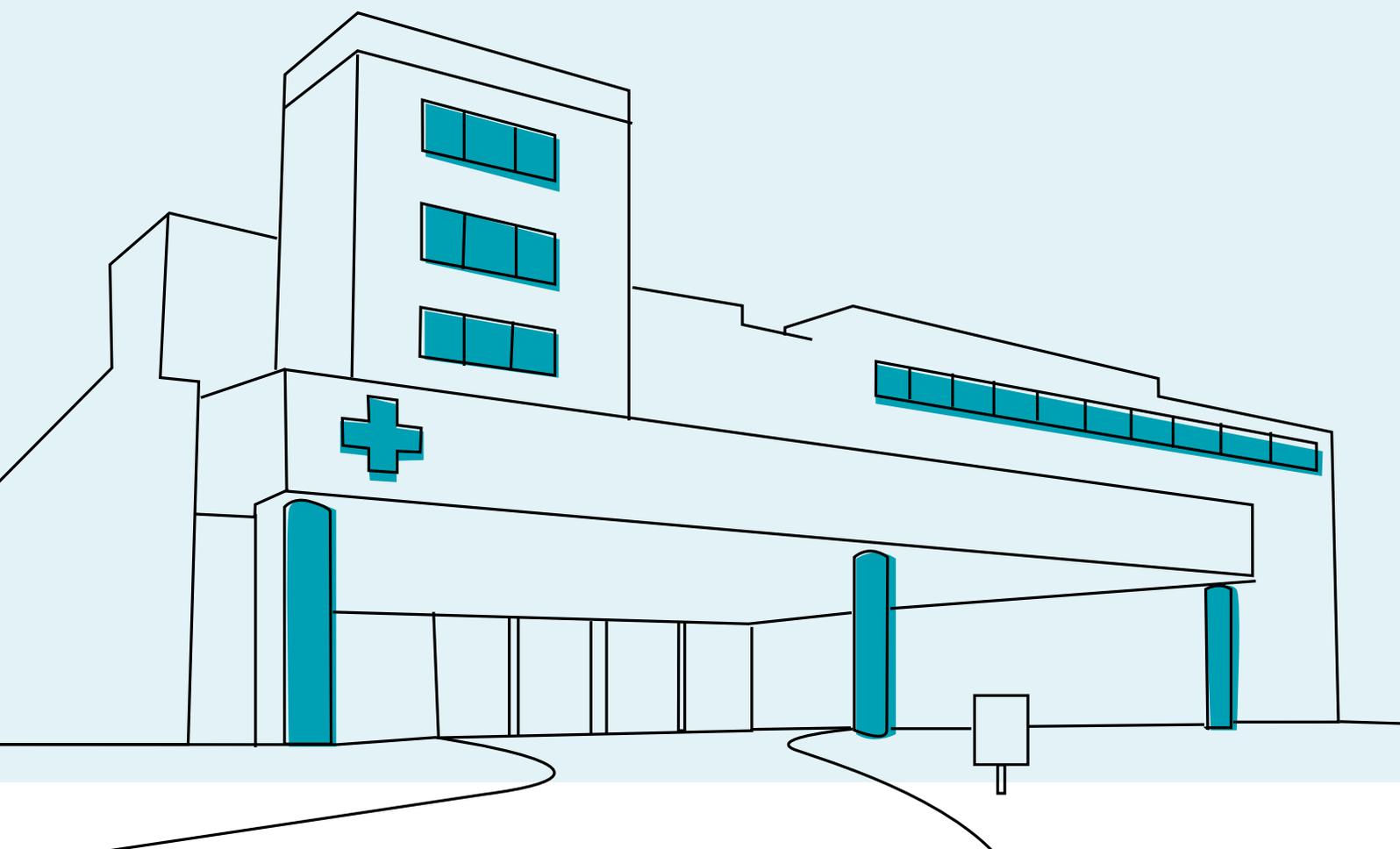
Funding and coverage

Currently, not everyone in the UK has access to a sight loss adviser. Worryingly, some people are simply told they are losing their sight and are left to struggle with no information or support.

We are also extremely concerned that where there is an existing support service, it could soon disappear. The funding for sight loss advisers is often uncertain, with many posts funded on a year-by-year basis [4]. This jeopardises the quality and consistency of patient care, and also negatively impacts patient experience, which is central to the ethos of the NHS.

That's why we are calling on all hospital managers to take responsibility for ensuring that patients have access to timely support.

The missing link: getting it right for patients and eye departments



Eye departments are undeniably under huge strain. The NHS must urgently find new opportunities to transform services within the current climate of ever-tightening financial allocations.

Evidence shows that existing sight loss advisers are indispensable to overstretched eye departments and have tremendously increased productivity and raised standards of patient care whilst delivering a welcome financial return.

RNIB is urgently calling for health providers to ensure that every eye department in the UK has access to a qualified and full-time sight loss adviser.

Enhancing the patient experience

A core principle guiding the health service is a commitment to ensure that the patient is at the heart of everything it does. A positive patient experience is now as important as clinical effectiveness.

When somebody is told they are losing, or have permanently lost, their sight, it is vital that they have access to flexible support that recognises their individual preferences and needs.

Patients should not be given leaflets as a substitute for high quality communication and face-to-face time with a professional.

“The ECLO really was my lifeline. At the point where I was initially certified as sight impaired, I was so far out of my comfort zone. I felt so vulnerable. The consultant picked up the phone to call the ECLO, and asked her to come into the consultation room. From there she took me to her office, provided emotional support and talked me through what I needed to do, and did as much as she could on my behalf.

“If I had walked out of the hospital without having seen the ECLO, I would have spiralled into a wreck. She caught me. She was the safety net.

“I believe passionately that it is a service that everyone deserves.”

Jane

Lack of information has been identified as one of the main reasons for patient dissatisfaction with NHS services, and as a result, people are more likely to make a formal complaint [5].

Sight loss advisers are perfectly placed to ensure patients have a positive experience of care. They take a holistic approach when considering a patient's needs, and provide quality up-to-date advice and tailored support to help them make informed choices about their care.

RNIB research highlights that 87 per cent of patients who had seen a sight loss adviser felt they had been provided with the practical support needed to help them live with sight loss [6].

Improving service efficiency

The incredible demand and huge pressure on eye departments to diagnose and treat a rapidly increasing number of patients can mean that staff are working longer hours, and even using their free time, in order to run extra clinics.

Sight loss advisers can support health providers' demand and capacity management processes. They increase the efficiency of eye departments by enabling ophthalmologists and other staff to focus their time most appropriately. By referring patients to a sight loss adviser, clinical staff can reduce the time they need to spend on signposting people to support services and providing emotional support to distressed patients.

“The support service is extremely valuable. It saves time for clinical staff, allowing more patients to receive the care they need.”

Consultant Ophthalmologist

Feedback from a new small qualitative study, which focussed on staff working in eye departments across the UK, found that most either strongly agreed or agreed that the presence of a support service frees up their time, allowing them to see more patients per day [7].

Sight loss advisers act as a single point of contact for information, and patients can use this route to seek further advice or be signposted to other services. Whilst this doesn't replace a patient's appointment with their consultant, it can reduce the need for additional follow-up appointments. This positively impacts upon patient throughput, and helps support departments to meet their waiting time targets, as clinicians are able to see and treat more patients. This can also reduce the time patients have to spend in the waiting room for each appointment.

Ensuring positive patient outcomes

Central to the work of the NHS is improving health outcomes for patients. Hospitals are increasingly recognising the benefit of having a sight loss adviser as part of a core service provision to increase patient education.

Sight loss advisers have a good understanding of a range of eye conditions. They spend a significant amount of time discussing with patients the importance of self-care, and complying with treatments to enable the best possible chance for medical interventions to be successful.

RNIB data highlights that 73 per cent of patients felt they had a better understanding of their condition after having seen a sight loss adviser [6].

The consequences of poor compliance can often be serious and permanent. For glaucoma patients, non-compliance can result in suboptimal treatment and can cause irreversible sight loss. There is no doubt that non-compliance is extremely wasteful to NHS resources and could lead to a patient losing their sight needlessly.

Sight loss advisers are ideally placed to provide information on the importance of compliance, helping to prevent future sight loss.

They also have the potential to reduce Did Not Attends (DNAs) by discussing with the patients their eye condition, and the importance of attending appointments.

“Following a good chat about their treatment with the ECLO, I have seen certain patients’ compliance with glaucoma drops improve, leading to a direct improvement in their intraocular pressures – it is definitely time well spent.”

Consultant Ophthalmologist

Improving compliance to medication and attendance at appointments are just two ways that sight loss advisers can help maximise investment in patient care.

Providing a cost-effective service

In the current climate of scarce resources and rising demand for eye care services, it is essential that health services explore possible avenues for generating cost savings without compromising patient care.

RNIB research shows that integrating a sight loss adviser service into the eye department can deliver a welcome financial return to health and social care budgets of £10.57 for every one pound invested [8].

With blind and partially sighted people nearly three times more likely to report feelings of depression than people with no sight loss, it is crucial that they have access to timely emotional and practical support [9]. This can help to reduce the risk of patients slipping into depression after they receive their diagnosis, and can contribute to reducing future costs associated with supporting people with mental health problems.

There is also a crucial link between falls and sight loss – almost half of all falls that affect blind and partially sighted people are directly attributable to the person's sight loss [10]. The associated cost is significant and estimated to cost the healthcare system £25.1million [11].

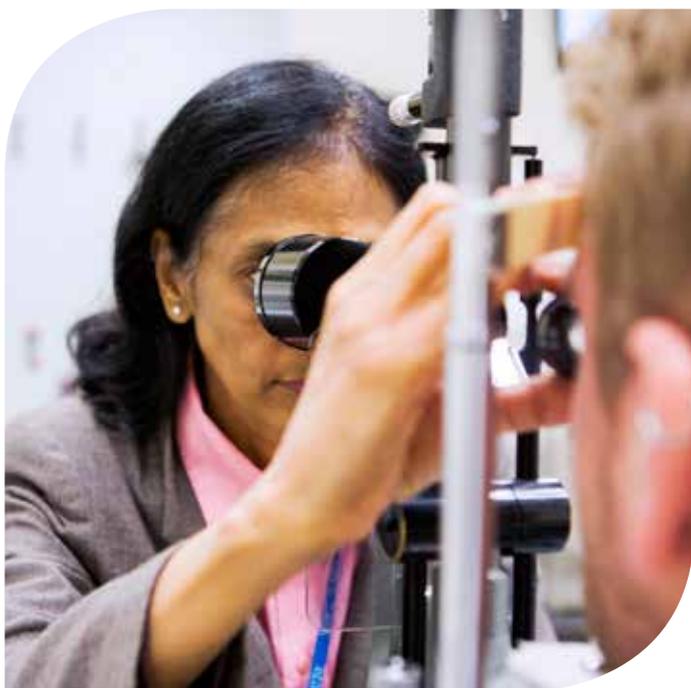
Sight loss advisers can play a vital role in reducing falls by routinely providing advice and information on falls prevention and referring patients to falls clinics.

It is clear that the support service presents health services with a unique opportunity to make significant cost savings. The extra funds made available by this saving could readily be reinvested into addressing other problem areas within the eye department.

Streamlining the CVI process

When patients experience a level of sight loss that meets the criteria of being sight impaired (partially sighted) or severely sight impaired (blind), ophthalmologists should issue a certificate of visual impairment (CVI). It is called a CVI in England, Wales and Northern Ireland and a BP1 in Scotland.

In England, Wales and Northern Ireland, receiving a CVI enables the patient to make a choice as to whether or not they would like to be registered, which is a gateway to a range of other services like receiving equipment, social care and other support.



Patients described the help that they received through certification and registration as “substantially improving their lives”. However, they also tell us the processes involved are often lengthy and fraught with frustrations [12].

At a time when patients may feel overwhelmed, sight loss advisers can explain the process and help them to understand the ways in which it can help. This allows patients to make informed choices about the benefits they are entitled to. After completing the CVI process, sight loss advisers will follow-up with the local authority to ensure they have contacted the patient in a timely manner and that progress is being made.

The Royal College of Ophthalmologists believes that an important component of good clinical care is the offer of a CVI to all those who are eligible. Sight loss advisers are a vital resource in the processing of CVIs; they can support the ophthalmologist to make sure the form is completed accurately and efficiently.

The recent RNIB sample qualitative survey found that sight loss advisers had an important role in supporting the certification progress. Nearly all of those that responded told us that they either strongly agreed, or agreed, that the support role has helped to streamline processes related to CVI completion [7].

Bridging the gap between health and social care

There is a current drive across the UK to rebuild services around the patient and to breakdown barriers in order to deliver effective and integrated health and social care. In England, local authority and NHS chiefs in Manchester have recently announced their plans to integrate health and social care budgets.

At a time when decision makers are increasingly looking for new ways to deliver integrated services, sight loss advisers are the ideal solution. They play a vital role in providing a bridge between health and social care.

Sight loss advisers step in after a patient is diagnosed and help support patients as they navigate the complex health and social care system to ensure a seamless transition between services.

The professional support service works closely with local authorities and external agencies. Sight loss advisers can refer patients to a range of support services, including falls prevention services and local authority sensory services. This is vital to the delivery of improved health and wellbeing for people recently diagnosed with sight loss.

Improving staff satisfaction

With the enormous pressure eye departments are under, staff could be at serious risk of burnout and unnecessary stress, all of which can impact on the quality and safety of patient care.

Sight loss advisers are widely valued by staff in eye departments as they help supplement their work. Ophthalmologists report that knowing a sight loss adviser is available within the department, allows them to feel they are providing a better and more holistic service for their patients [13].

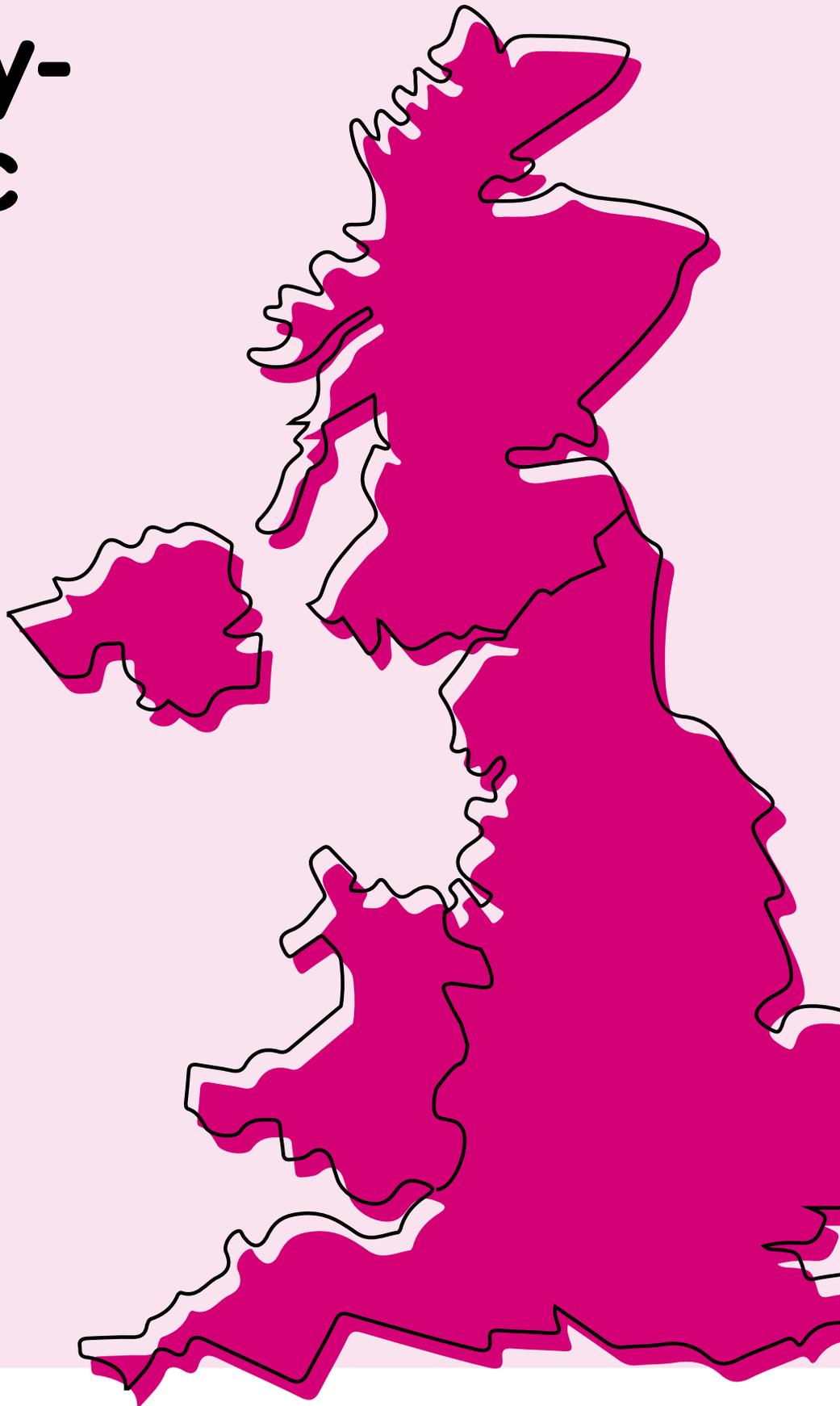
Recent feedback from a small qualitative survey of staff working in eye departments found that most either strongly agreed, or agreed, that the presence of a sight loss adviser had a positive impact on their role and job satisfaction [7].

“Our sight loss adviser is an asset to our team and essential to patient care.”

Ophthalmic nurse

The additional expertise provided by a sight loss adviser is a key resource to reducing the burden on staff and improving morale.

Country-specific policy drivers



It is clear that sight loss advisers provide an invaluable and professional service to both the NHS and patients across the UK. They also fit strategically with specific policy initiatives and agendas in England, Scotland, Wales and Northern Ireland.

Focus on England

- **Five Year Forward View** – Embedding sight loss advisers in eye departments is a key step towards achieving the vision set out in the Five Year Forward View. Empowering patients, breaking down the barriers to the provision of care and supporting prevention are just three ways sight loss advisers can provide a huge contribution to the NHS.
- **NHS Outcomes Framework** – Sight loss advisers play a vital role in enhancing the quality of life for people with long term conditions, such as glaucoma (domain 2). They help patients to sustain independence, and improve quality of life, through helping them adapt to living with a sight condition. They also help to ensure people have a positive experience of care (domain 4), by acting as a bridge between health and social care services.

- **Quality, Innovation, Productivity, Prevention (QIPP)** – Integrating sight loss advisers into eye departments fits in closely with the QIPP agenda. The support service provides much-needed resource to clinical teams and the NHS to improve the quality of care whilst delivering efficiency savings. This is achieved through freeing up ophthalmologists' time to focus on the clinical aspects of care and providing patients with information on falls prevention and the importance of treatment compliance.
- **Care Quality Commission (CQC) reports** – Sight loss advisers can contribute towards achieving positive feedback in CQC inspections. In the Dudley Group NHS Foundation Trust quality report, the presence of a sight loss adviser is identified as excellent practice which targets patients' specific needs in an empathetic manner [14].
- **Royal College of Ophthalmologists Guidance (RCOphth)** – New RCOphth NICE accredited Cataract Commissioning Guidance recommends that an optimal cataract pathway will offer patients access to practical and emotional support. Sight loss advisers are recognised as a valuable resource for patients, their families and carers. New Glaucoma Commissioning Guidance will also be published shortly.
- **Public Health Outcomes Framework** – The Public Health Indicator for preventable sight loss provides an opportunity to improve eye health services and outcomes at a national and local level. It measures how many people are certified as sight impaired (partially sighted) or severely sight impaired (blind) due to glaucoma, diabetic retinopathy and age-related macular degeneration. The indicator relies on CVI data, therefore the accuracy and completeness of forms is vital. Sight loss advisers play a key role here as they can help ensure the process is completed correctly. This in turn improves the ability to track changes in the numbers of people who are certified and have lost their sight from one of the three major causes of preventable sight loss. This can help decision makers intervene and improve services where required.

Focus on Scotland

- **Transforming Outpatients (TOPs)**
 - The Scottish Government has committed to a programme to reduce pressure on three secondary care specialties, of which ophthalmology is one. Sight loss advisers are a critical resource to help support the efficient running of eye departments as demonstrated in this report.
- **SIGN Guidelines Glaucoma** – Scottish Intercollegiate Guidelines Network (SIGN) has produced clinical guidelines which highlight the need for patients to be offered support and information at the time of diagnosis or discharge from secondary eye care services. This includes receiving information on eye conditions, treatment and support services available. Sight loss advisers are critical to the care pathway of glaucoma patients to ensure eye departments meet this national guideline.
- **See Hear Strategic Framework** – The Scottish Government recognises that, increased need in the context of diminishing resources can only be met through the introduction of different ways of responding to need, commissioning and delivering support. Sight loss advisers are an innovative solution and can provide patients and their families with information, emotional support and signposting to other services.
- **Scottish Vision Strategy** – The Scottish Vision Strategy 2013-2019 outlines plans for a sustained drive to tackle visual impairment and preventable sight loss. One of its priorities is to make emotional support an integrated part of eye care services. Sight loss advisers are viewed as a critical aspect of delivering emotional support to patients and their families.

Focus on Wales

- **Eye Health Care Delivery Plan for Wales 2013-18** – Sight loss advisers (ECLOs) are clearly mentioned in the Government’s plan as key to supporting people with a visual impairment. They are well-positioned to support the joint work between health and social care, and the third sector, and to contribute towards ensuring that patients receive consistent and high-quality care.
- **Focus on Ophthalmology** – The critical role of sight loss advisers is recognised in the Welsh Government’s eye care pathways for Age-related macular degeneration.
- **PROMS and PREMS** – Wales is moving towards developing Patient Reported Outcome and Experience Measures (PROMS and PREMS). These will evidence the experience of patients, as well as the longer term differences in their care and treatment. PROMS and PREMS are currently being developed for ophthalmology, and having a sight loss adviser embedded within the eye department will help health boards to achieve some of the targets.

Focus on Northern Ireland

- **Developing Eye Care Partnerships Strategy 2012-2017** – This document, published by the Department of Health, Social Services and Public Safety, sets out the strategic direction for eye care services in Northern Ireland. Sight loss advisers are crucial to helping to achieve the strategic aims of improving the coordination, integration and reach of eye care services, in order to improve demand management and patient outcomes.
- **Physical and Sensory Disability Strategy 2012-15** – This strategy confirms the Department of Health, Social Services and Public Safety’s commitment to improving outcomes, services and support for people who have a physical, communication or sensory disability. One of the achievements from this strategy is the funding and subsequent recruitment of sight loss adviser services across the region. A sight loss adviser has been recognised as a key part of the sight loss pathway, and the emotional and practical support that the service provides is valued as a way to improving the health and social wellbeing of patients as well as supporting them to maximise their capabilities.

Conclusion

It is clear that the NHS is currently facing an unprecedented challenge. Without urgent transformation, ophthalmologists and other medical staff will be left to struggle with the ever-increasing demand on eye care services.

With eye department staff already over-stretched, patients are not always receiving the level of support required when they need it. Sight loss impacts on all aspects of a person's life, including their independence and wellbeing. Without access to timely support, people can become unnecessarily isolated and left to struggle alone.

That's why sight loss advisers are an innovative solution to improve the quality of care for patients. They provide tailored support and advice to meet patients' individual needs, and help them to adapt to living with sight loss while remaining independent.

In addition to providing a service of enormous value to patients, sight loss advisers are widely respected amongst ophthalmologists and their teams.

Introducing a support service can hugely contribute to the efficient running of eye departments, as they help to free up clinicians' time to see and treat more patients. This, coupled with the cost effectiveness of the service, highlights why sight loss advisers must be considered a core business.

RNIB is urgently calling for health providers to ensure that every eye department in the UK has access to a qualified and full-time sight loss adviser.

For more information and resources about sight loss adviser services, including guidance on writing business cases, please contact RNIB.

**Email: beingthere@rnib.org.uk
Telephone: 020 7391 2123**

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- [5] Rt Hon Ann Clwyd MP and Professor Tricia Hart, A review of the NHS hospitals complaints system: putting patients back in the picture. October 2013. Department of Health. <http://bit.ly/1MMLtCn>
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Appendix

Methodology

It is not just RNIB and the wider sight loss sector promoting the vital service provided by sight loss advisers. Consultant ophthalmologists and other staff working in eye departments regularly share their views and explain the positive benefits that the support service can bring to both patients and staff.

As a result, RNIB collected a small sample of opinions of eye department staff about sight loss advisers. In late summer 2015, we launched a sample qualitative survey, which has been referenced throughout the report as reference [7]. By September 2015, 30 respondents including ophthalmologists, ophthalmic nurses and hospital based optometrists had responded and shared their views.

We asked those that have a support service based in their eye department, about the impact of the role on improving clinic efficiency, increasing staff satisfaction, and whether it is considered essential. For those staff that do not currently have a support service embedded within their eye department, we explored whether they felt there was a need for a dedicated support role.

Over the last year, we have also met with blind and partially sighted people to discuss the importance of having support at the time of diagnosis.

Methodologies for other research quoted in this report, can be obtained by viewing the appropriate references.

For previous RNIB reports about sight loss advisers please see:

- RNIB. Hanging by a thread. May 2014.
- RNIB. Being there when it matters. November 2014.
- RNIB. Sight loss advisers: supporting patients and eye departments. May 2015.

For more information
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