



Image of a smiling young woman sat on a bench, petting her guide dog

# Eye care pathways

Does the eye care pathway really work in Northumberland and how could it be improved ?

## Introduction

Sight loss is a term used to refer to someone who has no sight or whose sight is impaired beyond the use of correctional glasses or lenses. Sight loss has a considerable impact on different aspects of a person's life.

It is forecast that the number of people living with sight loss in England will double to four million<sup>1</sup> by 2050. Consequently, vision rehabilitation services are considered key to prevention, supporting independence, and reducing demand on health and social care services. The total estimated indirect cost of sight loss in Northumberland is over £32million<sup>2</sup>.

In 2020–2021 people in Northumberland living with sight loss and a wider audience told Vision Northumberland that some people in the county experience unfair barriers to accessing registration and low vision/ rehabilitation services, that the eye care pathway in Northumberland was flawed, and that people did not know what services were available to them.

People stressed the importance of:

- Support close to home rather than travelling to Newcastle
- Support that focuses on the health and wellbeing impacts of sight loss such as depression, social isolation and loneliness
- Good support from officers such as Eye Clinic Liaison Officers (ECLOs), low vision specialists and rehabilitation officers
- Joined up working and effective signposting between services
- Developing the necessary skills to live with sight loss and maintain independence
- Access to comprehensive assessments that balance different aspects of a person's life
- Health and social care professionals who are compassionate, understand the challenges of sight loss, and have knowledge of visual rehabilitation services and support
- Accessible information and advice especially in GP services

This report, funded by Healthwatch Northumberland (2022), follows up on that work asking the key questions:

**What challenges do people with sight loss in Northumberland experience when accessing registration, low vision/rehabilitation services as outlined in the Care Act 2014?**

**Does the eye care pathway really work in Northumberland and how could it be improved?**

<sup>1</sup> State of the Nation 2017, quoted by RNIB September 2022

<sup>2</sup> RNIB statistics 2018

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## Background

### Eye health in Northumberland

In Northumberland, as across England as a whole, growing numbers of people are living with sight loss or impairment. This is likely to increase further as people live longer since a good deal of vision impairment is related to the ageing process. The estimated number of people living with sight loss in Northumberland is 13,500 (4% of the county's population) which is higher than the national average and this is estimated to rise to 5% of the county's population by 2032<sup>1</sup>.

The number of people receiving a Certificate of Vision Impairment (CVI) fell to January 2022. The number of people registered as blind or partially sighted in Northumberland is 1405, which proportionally is lower than the national average and the lowest in north east. Over 30% of Vision Northumberland's clients are not registered.

The proportion of people registered who have an additional disability is 31%. Many aspects of vision impairment is preventable and linked to other health concerns. For example, smoking causes about 10% of eye disease and is a major contributor to cancer and cardiovascular disease; obesity is a risk factor for diabetes which in turn contributes to eye disease and cardiovascular disease, and sight loss is a key cause of falls and injury.

### Eye care pathway

Care pathways describe what care and support patients can expect for their health condition from primary care to secondary care and beyond. Pathways can be specifically designed to address combinations of situations, for example sight loss and learning disability.

### Registration and the Register of Blind and Partially Sighted People, England

A Certificate of Vision Impairment (CVI) certifies a person as either sight impaired (partially sighted) or severely sight impaired (blind). A CVI is issued by an ophthalmologist and its purpose is to enable a formal referral route to support to someone with sight loss from the ophthalmology department to social care services.

The Care Act states that 'a local authority must establish and maintain a register of sight impaired and severely sight impaired adults who are ordinarily resident in its area<sup>2</sup>'.

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1 RNIB statistics to January 2022

2 Registered Blind and Partially Sighted People, England 2019-20 NHS Digital

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The Register of Blind and Partially Sighted People, England is a database detailing statistics on adults and children registered with councils with social service responsibilities, as being blind or partially sighted. At 31 March 2020, 276,690 people were recorded on local authority registers in England.

While a local authority has a legal obligation (which can be delegated) to maintain the register, people who have a CVI can choose whether to be included on their local authority's register, so not everybody that has been certified as having vision impairment is recorded on the register.

### **Joint Strategic Needs Assessment**

The Joint Strategic Needs Assessment (JSNA) for eye care shows the health and wellbeing needs of local people and is used to provide and develop health and wellbeing services. There is a statutory duty for the local authority to work with partners in the NHS and other organisations to regularly maintain and refresh a JSNA. Our understanding is that the current eye care JSNA has been undertaken in all local authority areas in the North East of England.

### **Sight loss and the Care Act 2014**

The Care Act 2014 entrenches the importance of vision rehabilitation services by requiring all councils in England to provide a service, with guidance detailing the local authorities obligation. The Association of Directors of Adult Social Services<sup>1</sup> (ADASS) stated the key requirements as:

- Contact with a visually impaired person should be made within two weeks of a CVI being issued and assessments must be carried out by a person with the "necessary skill, knowledge and competency.
- Rehabilitation must be provided based on people's needs and should not be limited to six weeks.
- Minor aids and adaptations up to the value of £1,000 must be provided free of charge.

### **Rehabilitation**

Royal National Institute of Blind People (RNIB) identifies four key areas of vision rehabilitation that benefit people with sight loss, namely functional independence, personal safety, emotional wellbeing and social participation.

The key stages of a low vision rehabilitation service are referral, initial assessment of client needs, specialist assessment, in-depth rehabilitation, and follow-up. RNIB has produced three easy steps that councils need to take to ensure that they are meeting the needs of individuals:

**See:** everyone with a visual impairment must receive a specialist face-to-face assessment.

**Plan:** everyone must have a plan in place identifying the outcome of the assessment. The first two steps must take place within 28 days of first contact with the local authority.

**Provide:** any agreed vision rehabilitation support must start within 12 weeks of the person's initial contact with the local authority. Rehabilitation services in Northumberland are currently provided by Birmingham Institute for the Blind (BIB).

### **Low Vision Service**

Low vision services are provided by specialists who complete an assessment with individuals. This identifies any tasks and activities where support may be needed and recommends low vision aids and training. Low vision services may be based in a local hospital, opticians or run by a local society for people with sight loss.



Image of an elderly lady sat in an armchair looking at a photograph album through a magnifying glass

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## What we did

Vision Northumberland, together with visually impaired people, investigated the challenges people with sight loss face when they access sight loss services in Northumberland.

We spoke to 40 individuals who had been registered either as sight impaired or severely sight impaired within the past three years -2019 to 2021. There were a smaller number of people we spoke to, who were not registered, and their specific feedback is not included in this report. It should be noted that over 30% of Vision Northumberland's clients are not registered.

We held three face to face focus groups and also spoke in person and held structured telephone interviews with individuals. 63% of interviewees were over 70 years old, 28% were aged between 60 and 70, 8% were 40-60 and 1% under 40.

To understand the broader context and models of service delivery we also looked at service provision in neighbouring authorities with similar demographics and facilitated three stakeholder workshops.

We looked at the statistics, noting that only a small percentage of the people registered as blind or partially sighted and/or living with sight loss in Northumberland access any services (noting also that the percentage number of people registered in Northumberland is the lowest in North East England).

## What we heard

Here we outline the views and experiences shared by service users through the workshops and interviews..

### Stakeholder workshops

Care at the Royal Victoria Eye Infirmary (Newcastle upon Tyne Hospitals NHS Foundation Trust) was generally rated as good or excellent. However service users and professionals in primary care said the need to travel from Northumberland to Newcastle is a serious barrier for accessing eye care.

People cited the need for more locally based services (hub and spoke).

The new eye clinic service at Cramlington was well regarded but some people said they found it stressful as appointments are very long.

People greatly valued the services delivered by the voluntary sector, including Vision Northumberland, and when asked said these are the services that are most important to them.

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The need for improved access to low vision services for Northumberland was clearly expressed. People were aware of the integrated model in Gateshead but felt it would need to be adjusted to cope with Northumberland's rurality. A hub and spoke model with services in different localities was suggested. We heard about the lack of dedicated mental health support. Sight loss is a bereavement and there is not enough recognition of this.

### **Feedback from individual interviews**

We spoke to 40 people in structured interviews.

Of those 40, 15 (37%) had not seen an ECLO at all.

Those who had seen an ECLO were more aware of available services and support.

25% did not know about BID services, an additional five did know but were on what they described as a long waiting list.

Many didn't understand the registration process.

Attending services was problematic with transport said to be 'a real issue' and parking at the Royal Victoria Infirmary (RVI) described as 'a nightmare'

The need for services to be 'seamless' was important.

People wanted more local eye health and social care services.

Information from the RVI was in standard print size and therefore inaccessible.

Referral routes via opticians was described by some as 'good.'

Eye clinic at Cramlington was felt to be good.

The Living Well with Sight Loss course provided by RNIB and Vision Northumberland was valued.

Acquiring essential equipment was said to be 'difficult'.

Sight Loss Awareness Training should be required for care home and home care services.

People want (need) to be able to self-refer back into the system if sight deteriorates or if family/home situations change.

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## Case Study

*“Several hospital appointments have been cancelled and eventually I got a virtual appointment but was not happy. I got a face-to-face appointment with a junior doctor who said he could see the problem and asked me to wait to see another doctor, however, there were 30 people in front of me and I waited for over two hours.*

*They then did some tests and said they’d be in touch in two days. I hadn’t heard anything after four days, and phoned my GP who said to ‘keep trying’. Eventually I got through to the hospital who said the earliest I could talk to a consultant about the results was in another two weeks.*

*I am now looking at private healthcare as I think my eye was damaged during the procedure and the poor service regarding appointments and communication was unacceptable. I haven’t seen an ECLO and don’t know about BID. I contacted Vision Northumberland for help with equipment.”*

*“Great treatment, but communication and services were poor. If it weren’t for my wife, we would not and could not attend any appointments at all.”*

*“RVI was great, but not able to answer all my questions, I didn’t see an ECLO and don’t know about BID.. The only reason I know about Vision Northumberland is that a friend is an active service user.”*

*“Vision Northumberland told me to contact BID but there is a six week wait for an assessment.”*



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## Conclusions

Overall, the people we spoke to agree on the vital importance of sight loss services to aid people's confidence and security. When it worked, the eye care pathway was less confusing and had helped people be independent and active members of their community and had an economic benefit. Vision Northumberland was cited by many as the organisation that had help them most.

Although some of the people contacted as a part of this project said their experiences of sight loss services in Northumberland and the eye care pathway were good, many highlighted the challenges they faced when they tried to access sight loss services in Northumberland, and others had not known there were any services at all and were only finding services through friends and neighbours.

Some had serious concerns with ongoing implications on their eye health and their quality of life (with more than one instance of delays and mistakes in the system leading to avoidable blindness). Due to the timing of the project it may be that some of this is due to disruption from the Covid-19 pandemic and therefore how services recover is crucial.

People identified six points in their engagement with services that presented challenges:

- Accessible information from GPs and hospital services
- Physical access to hospital services
- Access to RNIB ECLO
- Getting 'lost' or 'falling down pot holes' on the eye care pathway – or not making the pathway at all
- Understanding the purpose and process of registration
- Transition – people not seamlessly passing from children and young people services to adult services (they too get lost in the system)

## Recommendations

We have identified issues should be addressed to enable people in Northumberland to receive 'a gold standard service'.

### 1. Accessible information

The Accessible Information Standard is the legal requirement to make sure people with a disability or sensory loss are given information they can understand, and the communication support they need. Based on the experiences shared in this project there is a need for training in, and implementation of, the Accessible Information Standard in all communications with patients with sight loss by primary and secondary care services. The main target for this training is GPs and staff at the RVI.

### 2. Review of needs and provision of services

Given the local demographic trends, geography, prevalence of risk factors and limited uptake of eye tests, there also needs to be a much strong focus on prevention in Northumberland.

Specific recommendation	Who
Sight loss services to be explicitly reviewed as part of Joint Strategic Needs and Asset Assessment and ICB commissioning including prevention and rehabilitation	Public Health Northumberland County Council  NENC Integrated Care Board
Actively consider an integrated and seamless Low Vision Service. (a one stop shop) to include provision of equipment (seamless access to Joint Equipment Loan Service or specific capital equipment	Northumberland County Council  NENC Integrated Care Board
Investigate options for reducing travel to RVI or making it easier to get there by patient transport or own transport	RVI (Newcastle Hospitals NHS Foundation Trust)  North East Ambulance Service Patient Transport
Consider how to support mental and emotional wellbeing of people with impaired vision and their relatives	Northumberland County Council  NHS Northumberland

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## Next steps

During 2023 Vision Northumberland will discuss the findings and recommendations with the providers and commissioners indicated and continue to solicit feedback from patients and carers.

## Thanks

We very much appreciate the support received in undertaking this research, especially from service users, stakeholders, Northumberland County Council and our local and national partners.

## Further reading

### Eye care pathway – Seeing it my way

The UK adult sight loss pathway is a process map describing how the principles of best practice can be applied to service delivery for adults with sight loss so that they can enjoy:

- Early interventions to address their presenting needs, as a right
- Visual impairment rehabilitation as an early intervention, delivered by specialist, qualified professionals
- Interventions that helps people maximise their functional vision
- Community care assessment of eligibility for adult social care, only if they still have unmet needs after receiving early intervention services

The document explains the adult UK sight loss pathway and the framework of skills required to deliver it. Delivering the adult UK sight loss pathway contributes to achieving 'Seeing it my way' outcomes for blind and partially sighted people.



Image of two young women sat at a desk with a laptop open in front of them

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## **NHS England National Eye Care Recovery and Transformation Programme**

NHS England has published guidance recommending NHS commissioners make better use of expertise in primary eye care. The actions include optimising existing extended primary eye care contracts by:

- Ensuring existing primary eye care contracts are fully serviced and utilised
- Working with primary care providers to ascertain possible scope of increased capacity and activity
- Utilising risk stratification processes to enable clinically appropriate patients to transfer to primary eye care
- Enablement of rapid transfer of patient care
- Support for a collaborative approach between primary eye care services and hospital eyecare services
- Exploring the use of a single point of access approach where appropriate

## **Integrated Low Vision Services RNIB evaluation report**

Research indicated there were significant problems with poor coordination between eye clinics, low vision services and rehabilitation services, inadequacies in the assessment of people with recent sight loss and failure to address the emotional impact of visual impairment. Due to fragmentation in service delivery there has been an emphasis in recent years on development of new and existing services which prioritise multidisciplinary working. However there remains a problem over definition of such services – some services may be termed ‘integrated’ simply by virtue of locating clinical and social services on the same site, while others take a much more holistic and person-centred understanding of the term.

Research by the universities of Cardiff, Manchester, Aston and Bangor with Moorfields, Royal Victoria Eye and Manchester Royal Eye Hospitals plus Fife Society for the Blind, on behalf of RNIB, aimed to investigate the benefits for people with visual impairment of an integrated low vision and rehabilitation pathway, and to determine whether this integrated approach has additional benefits for users, when compared to standard low vision and rehabilitation care.

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## Eye health as a public health priority

Indicator 4.12 of the Department of Health Public Health Outcomes Framework confirms a commitment to reduce avoidable blindness that mirrors the Vision 20.20 UK aim of avoiding preventable blindness.

Improvements in indicators 2.24 (falls), 4.14 (hip fractures), 2.23 (self-reported wellbeing) and 14.13 (health related quality of life for older people) may also be assisted by improvements in eye health. It has been shown that visual impairment is a key risk factor for falls in older people. People with visual impairment are much more likely to be depressed and self-care for other systemic conditions is likely to be affected, resulting in poorer health outcomes for these patients.

## NHS outcomes framework

Two of the five overarching indicators in the NHS outcomes framework can also be directly and positively influenced by efficient eye care services –  
Number 2: enhancing quality of life for people with long term conditions  
Number 3: ensuring that people have a positive experience of care

Key issues for at risk populations:

- The growing elderly population is by far and away at greatest risk of eye disease. For example, age related macular degeneration alone accounts for almost half of diagnosed eye disease in Northumberland
- Smokers are at increased risk of eye disease
- People with a learning disability are also five times more likely than the general population to have an eye condition
- In general, people who have multiple risk factors for cardiovascular disease are also likely to be at higher risk of eye problems as a result of hypertension, vascular degeneration and higher incidence of diabetes

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## Links

[ADASS - The Care Act and Visual Impairment](#)

[Government \(2014\) the care and support \(sight-impaired and severely sight impaired adults\) regulations 2014](#)

[RNIB \(2015\) Implementing the Care Act for blind and partially sight people: Regulations and guidance summary for Local Authorities](#)

[RNIB \(2015\) See, Plan and Provide: The state of vision rehabilitation support across England](#)

[RNIB \(2016\) 10 Principles of Good Practice in Vision Rehabilitation](#)

[RNIB \(2017\) Demonstrating the impact and value of vision rehabilitation](#)

[The Department of Health \(2014\) Care and Support Statutory Guidance \(Issued under the Care Act 2014\)](#)

[Vision UK - Adult UK Eye Health and Sight Loss pathway](#)

[Vision UK \(2011\) - Seeing it my way: A universal quality and outcomes framework for blind and partially sighted people](#)

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