**Eye care support pathway insight report**

**Foreword – an important step in meeting people’s needs**

When someone has an eye health condition and/or is partially sighted or blind, we know it is often extremely difficult to access, let alone get, the right eye care information, advice and support. It is widely recognised that eye care pathways are difficult to navigate and there is no one consistent pathway of support. This insight report is an important step. It clearly outlines what people want, need and are entitled to from health and social care services.

Our ambition is that: From the moment someone realises that “something isn’t quite right” with their sight, through to diagnosis and being able to live confidently – and independently – with their condition, people have access to the information, advice and support they need.

The sight loss sector, alongside health and social care services, must work in partnership to support the hundreds of thousands of people who are either on waiting lists or on a clinical pathway for their eye condition. RNIB is working across the UK with people with lived experience, the NHS, the Social Care sector, and the third sector to innovate an eye care support pathway. A clear pathway, that works for everyone involved, will result in better support for people experiencing changes in their eye health or those with long-term eye health conditions and/or sight loss.

This report summarises findings from both RNIB research and external data sources. It provides a comprehensive representation of the ‘pain points’ people experience when trying to access services and the different types of challenges they face.

**David Newbold, Director of Sight Loss Advice**

**Executive summary**

* Demand for eye care is at an all-time high and is increasing. The last decade has seen a rapid increase in hospital attendances for eye care. There were more than eight million eye care outpatient appointments across the UK in 2021/22 – the highest footfall for any specialism. As our population ages, this already high demand is set to increase. The over two million people living with sight loss in the UK today will double to over four million by 2050.
* While there are variations across the different parts of the UK, people’s experience, understanding and knowledge of the clinical journey they are embarking on can be confusing and complex. Non-clinical support is not consistently embedded end to end across any clinical pathway.
* For health and social care professionals there can be inconsistent communication within the NHS and between the NHS and social care. Knowledge of the support available can be poor. IT systems are not joined up and patients can become disempowered in their own care waiting for treatment to start, being unclear about what happens next, and knowing which services are available to them.
* Common issues include lack of information, advice and support early in the clinical pathway. Signposting to support early on – especially emotional support – is crucial. People also want practical and financial support, knowledge of local provision and to connect with other blind and partially sighted people.
* Sight loss and changes in eye health can have a huge emotional toll. The point of diagnosis is an especially sensitive time, and people want to be treated with empathy. Blind and partially sighted people are more than twice as likely to experience difficulties with unhappiness or depression compared to the UK average, yet only one in five people losing their sight are referred to mental health support.
* Eye Care Liaison Officers (ECLOs) are hugely beneficial, but they are not universal or sufficiently embedded into all NHS eye services. They make a huge difference during and after diagnosis as they offer an opportunity for people to speak about their condition, explain treatment options and signpost support available.
* A Certification of Vision Impairment (CVI), and thereafter registration with social services, can act as a route to support. But there are indications that not all people are getting certified when eligible, and there is poor understanding of these processes and low awareness of the benefits among professionals.
* With the right support, blind and partially sighted people can come to terms with changes in their eye health and live independent and fulfilled lives.

**Introduction**

**Demand for eye care is at an all-time high and is increasing**

Across the UK, the number of people receiving eye tests increased by 15 per cent between 2010-20 [1]. The last decade has seen a rapid increase in hospital attendances for eye care. There were more than eight million eye care outpatient appointments across the UK in 2021/22 – the highest footfall for any specialism [2]. We estimate that across the UK nearly 850,000 people are waiting for eye care treatments, one of the largest waiting lists of all NHS specialties [3].

Across the UK, the pandemic has exacerbated a backlog of care and longer waits for patients. More patients than ever are waiting for treatment – the number of people on NHS waiting lists for consultant-led elective care was 7.42 million in April 2023 [4].

In eye care, there are more people entering the clinical pathway than being treated, and there is an inability to meet the increased demand due to workforce gaps, limited physical space and capital to expand ophthalmic units andoutdated IT systems [5]. Lack of timely intervention leads to higher costs for the health and social care system [6]. The pandemic has made achallenging situation worse and led to missed appointments, delays to treatments, and further increases in waiting time [7]. A transformation of eye care services is required to make the system fit for purpose and improve outcomes for people [5].

Delays to diagnosis and treatment can lead to avoidable sight loss, poorer quality of life and high levels of stress and anxiety for people while they wait [7, 8]. Delays also have a serious economic impact. Eye health related conditions cost the UK £25.2 billion a year (set to rise to £33.5 billion in 2050) [7; 9]. As our population ages, this already high demand is set to increase. The over two million people living with sight loss in the UK today will double to over four million by 2050 [10]. When people get the right support and information on a clinical pathway, their outcomes are improved. For example, cancer charity Macmillan found that accessing appropriate information resources leads to a reduction in anxiety and improved ability to cope during all stages of a patient’s cancer journey [11].

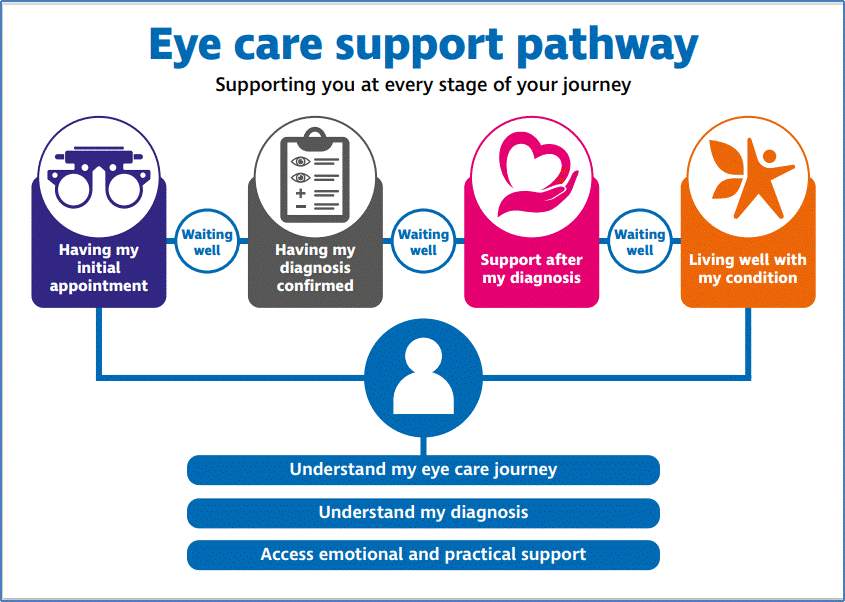
**The current pathway – common pain-points**

**People face challenges when accessing Eye Care services**

We know that people experience problems with their clinical care as well as with the wider support-related aspects [12; 15; 8; 13]. While there are variations across the different parts of the UK, people’s experience, understanding and knowledge of the clinical journey they are embarking on can be confusing and complex. Nowhere is non-clinical support consistently embedded end to end across a clinical pathway [8; 13]. In some cases, treatment requires regular contact with eye care/health services, sometimes as frequent as every month which can have a substantial physical and emotional impact [14].

We have identified more than 100 ‘pain-points’ with the current eye care journey [13], many of which re-occur right across the pathway. Pain-points are where people experience a problem and may include a lack of information; a delay; a lack of clarity with what happens next; or poor communication.

The diagram below shows the key stages along the pathway and the three key support need areas that emerged from our insight work.



**Stage 1: Having my initial appointment**

**Lack of information or advice**

For many people, their first port-of-call is most likely to be a high-street optician or perhaps their GP. There is a **lack of information, advice or signposting to support** at this initial appointment stage and a feeling of anxiety not knowing what is next. People can feel frustration when opticians are not always able to give a diagnosis, when tests are carried out with little explanation of the purpose or likely treatment opticians. Time pressures on opticians means sometimes there is a lack of clarity/information and this can lead to unnecessary referrals to secondary care [15; 13].

“**Every person with sight loss shouldn't have to be the biggest detective of their life finding information, there should be something where they can just go, ‘a go-to place’ and that's it**.” Patient [15]

High street optometry is able to identify eye conditions and vision deterioration and there is an opportunity here to intervene at the earliest stage with information, advice and signposting to services. A number of pilot primary care initiatives show the potential for community-based approaches to increase capacity in eye care and lead to faster diagnosis, but many of these are still in development and therefore have not yet been fully evaluated [16; 17; 18].

**Waiting well**

**Waiting can cause stress and worry**

Treatment pathways for eye conditions can be complex and slow. With the support of UK wide organisations representing people with a range of eye health conditions, RNIB ran a series of conversations to hear about people’s experiences. One person spoke of waiting twelve weeks from the initial appointment for tests and a diagnosis. The person described being in a “black hole” not knowing what was going to happen next. People talked about a fear of the unknown, and that information on wait times would have been extremely helpful at the point of referral [15].

Waiting happens at every stage of the pathway and the initial wait to see a specialist for a diagnosis is inevitability a time of stress and worry. People attending eye clinics report being aware of hospitals working at full capacity [8]. We also know that delayed identification and treatment can lead to loss of vision and in some cases severe or total sight loss [7].

**Lack of clarity around process**

During this stage people want a **clear understanding of the process** they are now part of, as well as information on waiting times, and an indication of any tests which may be carried out.

**Lack of information, advice and signposting to support**

People also experience a **lack of information and advice to help them understand their condition**, and **poor, late or no signposting to additional support** [19; 8; 13]. This can lead to a lack of empowerment and negative outcomes including isolation and no practical, emotional, or financial support.

“**It does have a profound impact on your mental health and it's not knowing where to go. I think you just want information so you can find out what is going to happen to you**.” Conversation participant [15]

**Stage 2: Having my diagnosis confirmed**

For many people, the point of diagnosis is one of the most emotionally difficult experiences. At this stage **people really need information, advice and support** to help them prepare for a change in their sight. People need time to ask questions and feel listened to. People can wait a long time for a definitive diagnosis, especially in complex/rare eye conditions [8].

**There is an emotional impact**

Diagnosis is a hugely emotional experience which can leave people feeling confused, overwhelmed, and anxious about what lies ahead. Living with an eye condition can be difficult and result in feelings of frustration and isolation – impacting how people participate in society and how fulfilled a life they lead. Blind and partially sighted people are more than twice as likely to experience difficulties with unhappiness or depression compared to the UK average [20].

40 per cent of blind and partially sighted people are struggling to come to terms with their sight loss and/or changes in their eye health. It is worth stressing that mindsets can vary depending on changing circumstances, from day-to-day and even task-to-task. Blind and partially sighted people are not fixed in one emotional territory but move in and out of them as different factors combine [21].

**Lack of empathy and human touch**

People talk about a **lack of empathy** at the diagnosis stage, and that the focus is solely on their eyes and not on them as a whole person [19; 8; 13; 15]. Eye tests can be carried out with little explanation of the purpose. People report feeling **ill-prepared** and afterwards they wished they had asked more questions [15].

**Lack of support, both practical but also emotional**

When diagnosed, people need information and support to help them prepare for a change in their sight [15]. One area of support which has been historically neglected is **emotional support**, with treatment and support for eye conditions focussing on the physical impacts of sight loss and/or changes in eye health. There needs to be greater recognition of the emotional impact of changes in sight from the beginnings of a person’s initial appointment, through to diagnosis and living with an eye condition, so they can access the right support at the right time.

Details and data about the extent of provision for mental health assessment and treatment for people with sight loss, and how these may vary nationally, regionally and locally within the UK, are sparse in the literature [8]. What we do know is that referrals into emotional support services only happens for one in five people [12]. This leaves many blind and partially sighted people having to cope with the emotional impact of being diagnosed and having to adjust to the changes in their eye health on their own. Lack of referrals to emotional/mental health support can result in increasing isolation and an inability to cope. The optimum moment for signposting to support services is unclear and gradual or fluctuating sight changes can make it difficult to identify when to move onwards in the eye care pathway [13].

Emotional support – including peer support – should be provided early on as people often do not seek help until they have reached a crisis point [8]. Mental health support, in the form of counselling, has been shown to be beneficial to wellbeing, with people accessing this support reporting fewer worries about their eye related problems and reablement [8].

**Stage 3: Support after my diagnosis**

Finding support makes a huge difference to people, both **before**, at the point of diagnosis and after.

**Difficulty finding local provision and peer support**

People need to know what support is available locally, and really benefit from speaking to other people in similar situations, with this opportunity being described as a ‘game-changer’ [15; 22]. However, finding this support and connecting with peers can be difficult for those newly diagnosed [15].

**ECLOs are hugely beneficial – but not universal or sufficiently embedded into the pathway**

Eye Care Liaison Officers (ECLOs) – most of who are working in secondary care – make a huge difference during and after diagnosis as they offer an opportunity for people to speak about their condition, explain treatment options and signpost to support available. However, ECLOs are not a mandatory part of any ophthalmic pathway; not all ophthalmologists refer people to ECLOs or referral is often made late; and not all people have access to an ECLO in their area [8; 23; 19, 15; 13]. Additionally, ECLOs provide informal emotional support, which is a combination of listening to the individual, providing a space within which a patient can express themselves, talking through their worries or concerns and being understanding and empathic. It is not their role to provide psychological intervention, but instead refer onto professional counselling services [24].

**Value of the Low Vision Service is not widely recognised**

Many people and professionals are unaware of the role and value of Low Vision Services. Referrals are not mandatory and rely on individual practitioner knowledge, whether ECLOs, Optometrists or Ophthalmologists. Referrals are often made late, and there can be geographic inconsistencies and significant variation of wait times [13]. There is evidence to indicate that early referral may lead to improved outcomes [25].

**Confusion regarding the Certification and Registration processes and the benefits they can unlock**

**An eye specialist will decide if someone can be certified as severely sight impaired (blind) or sight impaired (partially sighted). The patient will receive a copy of their Certificate of Vision Impairment (CVI) and a copy will be sent to the local social services team which should contact the person to ask if they wish to be included on its register of blind and partially sighted people.**

A CVI, and thereafter Registration with social services, can act as a route to support, but there are indications that not all people are getting certified when eligible [8]. Certification does not automatically lead to Registration, and there is poor understanding of these processes and low awareness of the benefits among professionals [8].

People should be offered a CVI as soon as they are eligible to ensure that they can access support and rehabilitation in a timely manner. Consultants and other members of the eye clinic team may benefit from training to enable them to understand the benefits of Certification and Registration to patients and to recognise when someone may be eligible. Currently, ECLOs often need to step in and act as an advocate in the CVI process, with RNIB ECLOs initiating CVIs for a third of their patients [26].

ECLOs also report experiencing delays when waiting for consultants to complete their sections of the form and suggest that if the CVI form were completed electronically, it would be helpful if this could auto-populate some of the information, such as patient details [27].

**Timely social care enables independence and saves money – but not everyone who is eligible is receiving it**

When people do receive a CVI and get registered by social services, they can experience long wait times to access services [8]. Accessing social care services, such as vision rehabilitation, can build confidence and enable independence, as well as avoid health and social care costs of more than three times the cost of the vision rehabilitation service [6]. However, provision of rehabilitation is patchy, with some areas across the UK offering a good service, and some none at all [12; 19].

**Personal action plans not used effectively**

Personal action plans (sometimes called Care plans) can sometimes be seen as a “box-ticking exercise”, and there are indications that for some people these plans aren’t being produced at all [15]. The role of Vision Rehabilitation Specialists is to build confidence, provide emotional support, regain lost skills, teach new skills, and maintain and promote independence. However, the specialists can be under resourced resulting in lack of time to create/review plans effectively, and it can be unclear who the point of contact is for various action points within a plan. Furthermore, there is a lack of knowledge around the ability to be reassessed if circumstances change [13].

**Wider support is available from friends, family, and related charities – but more support, recognition, and integration of these elements into the pathway is needed**

Friends, family and carers can play a crucial role, but they receive little information or emotional support themselves [12; 8].

The public support the need for services for people with sight loss and/or changes in eye health but believe that those affected get all the help they need as part of statutory services [28]. This is a misconception that needs to be addressed. Many of the gaps are filled by informal support networks and the charity sector. Sight loss sector charities can offer a range of support, but very few NHS and social care organisations across the UK signpost people to these organisations consistently [8].

**Stage 4: Living well**

With the right support blind and partially sighted people – as well as those with temporary sight loss (such as those awaiting and recovering from cataract surgery) – can come to terms with their changes in eye health and adjust their lifestyles.

Support can be provided in many forms including family members, friends, carers, health, social care professionals, third sector organisations and ECLOs.

**“All she really wanted was someone to speak to about her condition and treatment; the ECLO offered her that support.”**Friend of a patient [15]

With the right support, many blind and partially sighted people go on to live fulfilling lives.

**“I will admit that I spent many years trying to ignore the increasing problems of sight loss, and it took a long time for me to become resigned to it. However, I have now come to terms with it and, while I miss a lot of things, I used to be able to do, I remain comfortable with my current condition. I use technology as much as I can, and although I have family who can help me, I do sometimes make journeys on my own”.** Conversation participant [15]

**“I discovered many other things that I’m good at; my eyesight doesn’t have to limit me or define me... I knew that I had to compensate intellectually as I couldn’t do things physically as well as other people and it helped me to develop and invest more time in education.”** V I Lives participant [21]

It is important that people are able to reassess their needs and access support when they need it.

**Additional pain-points**

In addition to the stage-specific pain-points described above, there are some which relate to the experience as a whole or point to areas of the current process/system which need addressing.

**Inaccessible communications and environments**

People need information in accessible formats (paper-based and digital) which are specific to their eye condition. Many also want information that they can give their family members, friends and employers. Clear, easy-to-understand health information in accessible formats is especially important given that more than two fifths of adults do not understand written health information. This crisis in adult health literacy directly impacts on people’s health and can also have a detrimental impact on how people respond to treatment, recover from illness and manage a long-term condition [29].

Environments too can be inaccessible and hard to navigate. Waiting rooms can increase anxiety, appointments are not always conducted in private spaces and hospital staff do not always have the right training to assist or guide blind and partially sighted people effectively [12; 8; 13].

**Unclear process**

Ophthalmic clinical pathways often do not include the transitions between primary, secondary, and social care and services available, and instead they focus on diagnosis and treatment. This can result in people feeling ‘bounced around’ between services [13].

**Poor communication between professionals**

There can be poor communication between professionals, information stored on a patient in multiple places, and lack of ownership across health and social care. IT systems are not joined up and as a result, patients can become disempowered [13].

**Regional variations**

People’s experiences vary across the UK. There is inconsistency in wait times across different countries and regions, as well as the information, advice and support offered, and in some areas, people struggle to travel to appointment locations [12; 13].

**Robust and accessible data helps clinicians, commissioners and researchers improve the work the NHS does – but there is a deficit of data**

We do not have easy access to integrated care datasets [8; 30]. This is problematic because high quality data on metrics such as clinical outcomes and progression of people through clinical pathways is necessary to improve patient care and outcomes, make the best use of limited resource and support national planning.

There is a particular lack of data at the post-diagnosis stage. Councils may not be publishing or monitoring the number of people receiving Vision Rehabilitation services and the waiting times experienced. There is little information about accessing services and the impact these services have on people who have received a diagnosis [30].

**Pathway support requirements**

We have identified three key support themes which together can create an effective eye care support pathway. These themes apply to every stage of the pathway:

* I understand my eye care journey
* I understand my diagnosis
* I can access practical and emotional support

As part of the eye care support pathway programme of work, we are working with the NHS across the country, social care, people with lived experience of sight loss and eye sector colleagues to develop and document an end-to-end single eye care support pathway which can be integrated with any eye care pathway.

In late Autumn 2023, we will publish an eye care support pathway document which will describe what effective support looks like, how to integrate support into clinical pathways, how we are all working together to integrate support into eye care, and how we can both improve care outcomes and help transform people's lives. The document will also include an implementation framework.

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## About RNIB’s research

RNIB is a leading source of information on sight loss and the issues affecting blind and partially sighted people. Our Research and Knowledge Hub contains key information and statistics about blind and partially sighted people including our Sight Loss Data Tool, which provides information about sight loss at a local level throughout the UK. You’ll also find research reports on a range of topics including employment, education, technology, accessibility and more. Visit our Knowledge and Research Hub at: [**rnib.org.uk/research**](https://www.rnib.org.uk/research)