

The Eye Care Support Pathway

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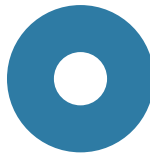


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VISION

Supporting ethnically diverse communities
with their eye health and sight loss



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Foreword

Matt Stringer – Chief Executive Officer, RNIB and Chair, VI Charity Sector Partnership.

An effective Eye Care Support Pathway cannot be developed in isolation so I'm delighted to acknowledge the many contributions to this report from so many individuals and groups, including patients, organisations across eye care and a number of sight loss charities - including RNIB - working as part of the VI Charity Sector Partnership.

This partnership works to improve the lives of blind and partially sighted people - and those at risk of sight loss - across the UK. In this context, I cannot think of anything more important than this pathway to ensure patients get better access to information, advice and support throughout their eye care journey.

Wojciech Karwatowski – Chair, The Clinical Council for Eye Health Commissioning.

We are delighted to have collaborated with our partners to inform and shape the Eye Care Support Pathway. Thanks to modern technology, advances in medicine and better understanding of individual needs, huge progress has been made in eye care.

Delivering this care in a way which supports each individual's journey is key to improving a person's life experience. Using this report as a framework for delivering the best quality care will undoubtedly improve individual engagement and outcomes. Those involved in delivering, planning and commissioning eye care services can now use it as a benchmark for their work of service transformation.

Louisa Wickham – National Clinical Director for Eyecare, NHS England.

If we are to transform the delivery of clinical support to patients, the NHS recognises the eye care support pathway will need to be integrated into our eye care services and health systems. Demand for our services is greater than ever so we welcome this chance to collaborate on an end-to-end pathway to give our patients even better support.

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Executive summary

At a time of increasing demand for eye care services, stakeholders and partners across the sector have come together to co-produce an eye care support pathway to enable better support for adults with eye care needs to be consistently delivered across the UK.

The proposed eye care support pathway aims to highlight people's needs at four key stages in their eye care journey:

- Having an initial appointment
- Having a diagnosis confirmed
- Support after a diagnosis
- Living well with my condition

By embedding nonclinical support into existing eye care pathways, a person-centred approach is much more likely to be delivered as part of routine care.

We need to transform the way in which we deliver information, advice and support across the UK and integrate nonclinical support into existing eye care pathways, so we are able to give people the treatment and support they need.

We hope this helps everyone in the eye care sector to move forward positively together as we work to embed the right support at every stage.

This will ensure better, person-centred eye care services with increased engagement, understanding, self-support

and self-advocacy at every stage of a person's eye care journey.

Patients will benefit from this approach, and it will also minimise the impact of eye disease on the UK economy through supporting mental health needs, reducing the risk of falls, and maximising employment and the prevention of people leaving work unnecessarily due to eye care needs and sight loss.

Transforming eye care services requires everyone to commit to meeting the requirements set out in the eye care support pathway. Implementing change requires long term commitment and will require incremental changes over time. We would encourage everyone to develop year-on-year eye care support pathway improvement plans to help drive and monitor progress.

The eye care support pathway has been developed in partnership with health and social care professionals, people with lived experience of eye care services and sight loss, the third sector and professional bodies across the eye care sector. We would like to thank everyone for their valuable insights, contributions, and commitment to the development of the eye care support pathway.

A list of the organisations that have contributed to this document and the development of the eye care support pathway can be found on [page 46](#).

The Eye Care Support Pathway



The UK eye care support pathway

Together we have an unprecedented opportunity to change the way people experience eye care services across the UK. From primary and secondary care through to social care and the third sector, we are in a position to create change which leads to better outcomes for individuals.

We have produced this report to show what can be done by addressing the pain points people accessing eye care services have outlined, and presenting the key elements we need to empower people to actively participate as they progress through their eye care journeys.

Successful patient care goes beyond the delivery of good clinical care by health care professionals for any health condition. Patients not only need to be diagnosed and treated, they also need to be informed, engaged and be active participants in their care. We want to aim to ensure patients are both able to appreciate the quality of their care and able to engage with their treatment. Having the right support in place can enable all patients who develop sight loss to live their lives to their full potential.

When we talk about support, all the elements of care and help beyond direct clinical management is what we are referring to.

We know that:

- Support is offered, but support services are not equitable and consistent across the UK.
- The eye health information provided is not always accessible and can be of variable quality.
- Advice is available but it is not always easily obtained.
- Emotional support is often overlooked; the provision of mental health support for people with eye care needs across the UK is largely unknown.

We have co-designed, with the help of many key partners, a new eye care support pathway to highlight people's needs at four key stages in their eye care journey. This effectively creates a framework for good support from a patient's perspective. By integrating nonclinical support into existing eye care pathways, support is much more likely to be delivered as part of routine care. The alignment of the support pathway with end-to-end clinical pathways (that is, the whole pathway of care from the very beginning of a condition being suspected right through to the cessation of active clinical care and/or living with a condition) allows clinical practitioners, health and social care professionals to understand the requirements of the whole of the patient's journey as well as focusing on their particular stage of contribution to care.

We believe this pathway is the first step to ensuring better and more consistent patient support. It effectively challenges us all to understand the requirements from the point of view of the people we are caring for, to question our current approaches and practices, and asks us to start actively building support into every aspect – and every stage – of the journey for people with eye conditions. We believe this gives us a foundation to build on which can be improved with use and feedback. We hope this helps everyone in the eye care sector to move forward positively together as we work to embed the right support at every stage.

This framework does not necessarily demand new services to deliver the eye care support pathway, but we would ask that organisations across the sector and NHS and local authority commissioners use the pathway itself to consider:

- How information, advice and support could be embedded at every stage of existing clinical and social care eye pathways.
- The development and implementation of any necessary new referral routes to information, advice, and support services for patients with eye care needs at each stage of their journey.
- How existing and new technology can be optimised.

- How we can ensure that everybody with eye care needs, and their family and carers, has the information, advice and support they require on their eye care journey.

Challenges across the eye care sector

Across the UK, the number of people receiving sight tests has increased by 15 per cent between 2010-20 [1] and more enhanced eye care services are being delivered to meet more need closer to home. The last decade has also 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 specialty [2].

There have been longstanding delays for patients seeking access to hospital eye care and the pandemic has made a challenging situation worse. It has led to missed appointments, delays to treatments and further waiting time rises [5; 6]. At the time of writing, nearly 850,000 people are waiting for hospital eye care treatments; this is one of the largest waiting lists of all NHS specialties [3] and many more patients requiring a follow up appointment are also delayed.

The hospital eye care workforce has not expanded to match demand and there is inconsistent progress across the UK in maximising the skills of eye care professionals including fully utilising the skills in primary eye care [4]. This is

compounded by a lack of ophthalmic IT systems which are integrated with wider NHS services and social care. Although more co-ordinated attempts at national level to transform eye care services for greater efficiency, higher quality care and sustainability have started, there is a long way to go to ensure the system is fit for purpose and to deliver improved outcomes for people [7].

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 [5; 8]. Lack of timely intervention also has a serious economic impact through effects on other health conditions such as dementia and on the ability to work and care for others, and the cost of social support. Eye conditions cost the UK £25.2 billion a year (set to rise to £33.5 billion in 2050) [5; 9]. As our population ages, these issues are set to worsen. There are more than two million people living with sight loss in the UK today; this figure will double to more than four million by 2050 [10]. The World Health Organisation notes that “everyone, if they live long enough, will experience at least one eye condition, in their lifetime”[11].

As pressures increase within NHS and social care, the role of the third/VCSE sector (voluntary, community and social enterprise) to support local public bodies has grown, with early evaluations of their impact now being reported [12]. During the pandemic, the third/VCSE sector had a key role in connecting communities, providing support, and reducing isolation. RNIB, for example, provided additional support to blind and partially sighted people, through adapting and expanding telephone-based support and online resources and activities [13]. As a result of these successful interventions, this work has continued post pandemic. The role of the third/VCSE sector is intrinsic to improving population outcomes, whether at a national or at a local level.

There are additional challenges in relation to inequalities in eye care, eye health literacy and around mental health.

Evidence shows that health literacy levels directly impact on people’s health. Health Education England states that in the UK 61 per cent of adults (18-65) do not have adequate literacy skills to routinely understand health information. Providing reliable easy-to-understand health information in accessible formats for patients and communities can help people make better decisions about their health and take an active part in planning their own care.

The importance of mental health needs to be recognised – living with or being diagnosed with an eye condition that affects sight can have a profound emotional impact. The experience of adjusting to sight loss is often likened to that of grief. In creating a more person-centred eye care pathway, there needs to be equal focus on mental and physical health. Information about how to access emotional support and counselling must be embedded from the start, so people can access timely support when they need it.

BAME Vision has identified particular issues faced by ethnically diverse communities:

- Lack of engagement from professionals and organisations claiming ethnically diverse communities are “hard to reach”.
- Lack of access to eye care information in a format and language ethnically diverse communities understand, from point of diagnosis onwards.
- Negative attitudes and cultural barriers to sight loss within all communities.
- Gaps in data about eye care, eye health and sight loss in ethnically diverse communities.

The eye care support pathway offers the opportunity to incorporate and embed the work of BAME Vision and the work of SeeAbility and others to address the gaps and inequalities faced by people from under represented groups.



Eye care pathways need to change

Many eye care services use documented local care pathways to guide professionals on the key points and deliverables of the patient journey in different clinical settings and how they fit together. The NHS in England, Scotland and Wales and the Health Service in Northern Ireland have all made progress at creating eye care pathways to tackle unwarranted variation, with different levels of success. Most of these eye care pathways are designed to support the management and/or treatment of an eye condition, and the statutory services that people are entitled to as they progress through their eye care journey. More attention however must be given to the nonclinical information, advice and support people require.

This includes: providing information about the condition, its treatment and how to navigate the complexities of the care system; practical support around employment, driving, money or household activities; and emotional support and reducing the risk of isolation.

It is important to note that there are models of best practice, quality frameworks and standards for eye care advice and support from a range of organisations across the sector. Further information on these can be found on the RNIB website.

Pathways currently in use rarely incorporate the full range of health, care and support services across the whole end-to-end patient journey, mostly focusing on the clinical management aspect only and sometimes only on one specific part of the pathway e.g. hospital services. Due to funding sources within silos for different sectors within the end-to-end pathway and, as support is not often considered a core aspect of care, commissioning rarely looks at the pathway holistically or funds support. This can mean people struggle to navigate their care journey, fall between the gaps when they transition between services and may not routinely receive the optimal level of information, advice and support they need.

Problem with current pathways:

- Navigating the pathway is complex and confusing for patients.
- Support is not person centred.
- Support is not triggered automatically or built into all pathways.
- There are no formal links to support services.
- There is a lack of funding for support staff as they are not part of the core funding of services.
- Support that does exist is not distributed evenly across the pathway.
- Support that does exist is not given consistently to everyone.

Across the UK we are now moving to integrate health and social care, which offers a significant opportunity to ensure all our future eye care pathways optimise the support available to all and are fully integrated. By creating an eye care support pathway which aligns with existing clinical and social care eye care pathways we can identify key information, advice, and support touchpoints relevant to each eye condition, and integrate nonclinical information, advice, and support into them across the end-to-end journey for the patient.

This will support the ongoing transformation of eye care pathways, providing a more holistic, person-centred approach to care and more effective use of the UK's eye care assets to better support people wherever they are on their eye care journey. This will also help achieve the ambitions of all UK governments and health systems to provide more joined up and personalised care, offering each person better support at the right time in the right setting.

Identifying and addressing difficulties in accessing information, advice, and support

Over the last two years RNIB, working with the eye care sector, has built an evidence base on which to develop an eye care support pathway. From research, mapping the pathway end-to-end, listening to people with lived experience and engaging with health and social care professionals and the third sector, it is clear that people experience problems at every stage of their eye care journey [14; 15; 16; 17; 18] and that the impact of sight loss can be significant.

"I was diagnosed with Retinitis Pigmentosa and told that there was nothing that could be done. I should wait to go blind, and it could happen in a matter of years, months or even weeks. This utterly shattering diagnosis haunted me for years. I was never sign posted to any services, so never knew anything about an ECLO, rehab, local peer support, technology aids, mobility aids, education support, nothing. I hated my life and went into a quiet state of depression. It took 15 years to finally get sign posting to vital support, to meet others with my eye condition and others living with a vision impairment. Now in the past decade of learning all about the stages in the pathway, I know about the right kind of support which should be available, and it has enabled me to build my life back up from feeling quite low." (Ref: BAME Vision)

In total, more than 100 pain points – where people experience a problem – have been identified across a typical eye care journey. These problems may include a lack of information, advice, or support; a delay to treatment; a lack of clarity with what happens next; or poor communication. The full list of pain points will be available as a supporting document on the RNIB website.

“I think there should be less focus on the medical aspect of it all and more on me as a whole person. I am more than a medical condition.” [16]

Using the pain points as a basis for improvement, individual support requirements have been identified to create an eye care support pathway underpinned by three thematic needs.

These are:

- Understanding my eye care journey
- Understanding my diagnosis
- Having access to practical and emotional support

Through developing a UK wide eye care support pathway our shared 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.

Through embedding information, advice and support we can aim to:

- Intervene earlier, freeing up precious NHS and social care resources while improving people’s quality of life.
- Provide better, person-centred eye care services with increased engagement, understanding, self-support and self-advocacy at every stage of person’s eye care journey.
- Reduce eye health inequalities including reducing the inequity of access to care across all stages of the pathway.
- Improve health, wellbeing, and independent living.
- Improve levels of eye health literacy.
- Increase adherence with agreed treatment options and protocols and promote shared decision making.
- Support the reduction in non-attendances in outpatient settings.
- Reduce the impact of eye disease on the UK economy through supporting mental health needs, reducing the risk of falls and maximising employment and the prevention of people leaving work unnecessarily due to eye care needs and sight loss.
- Provide early and continued support for those waiting to access care and treatment.
- Reduce mental health inequalities.



The eye care support pathway

Eye care pathways can be complex and, while often described in a linear manner, people may enter, leave, and re-enter several times depending on their condition. Typically, any end-to-end pathway is made up of a number of key stages.

The eye care support pathway mirrors this approach and is made up of four key stages with periods of waiting in between, alongside three thematic needs. These four stages also reflect a typical health and social care journey starting from presentation of the problem, through to treatment, discharge and aftercare.

It is important to note that the stage prior to having an initial appointment, around raising awareness of the importance of good eye health and attending regular sight tests, is also critically important but does not form part of the eye care support pathway itself.

The information, advice and support people need applies to all stages of the pathway, as well as people being supported and empowered to 'wait well' as they transition between services.

Eye care support pathway

Supporting you at every stage of your journey

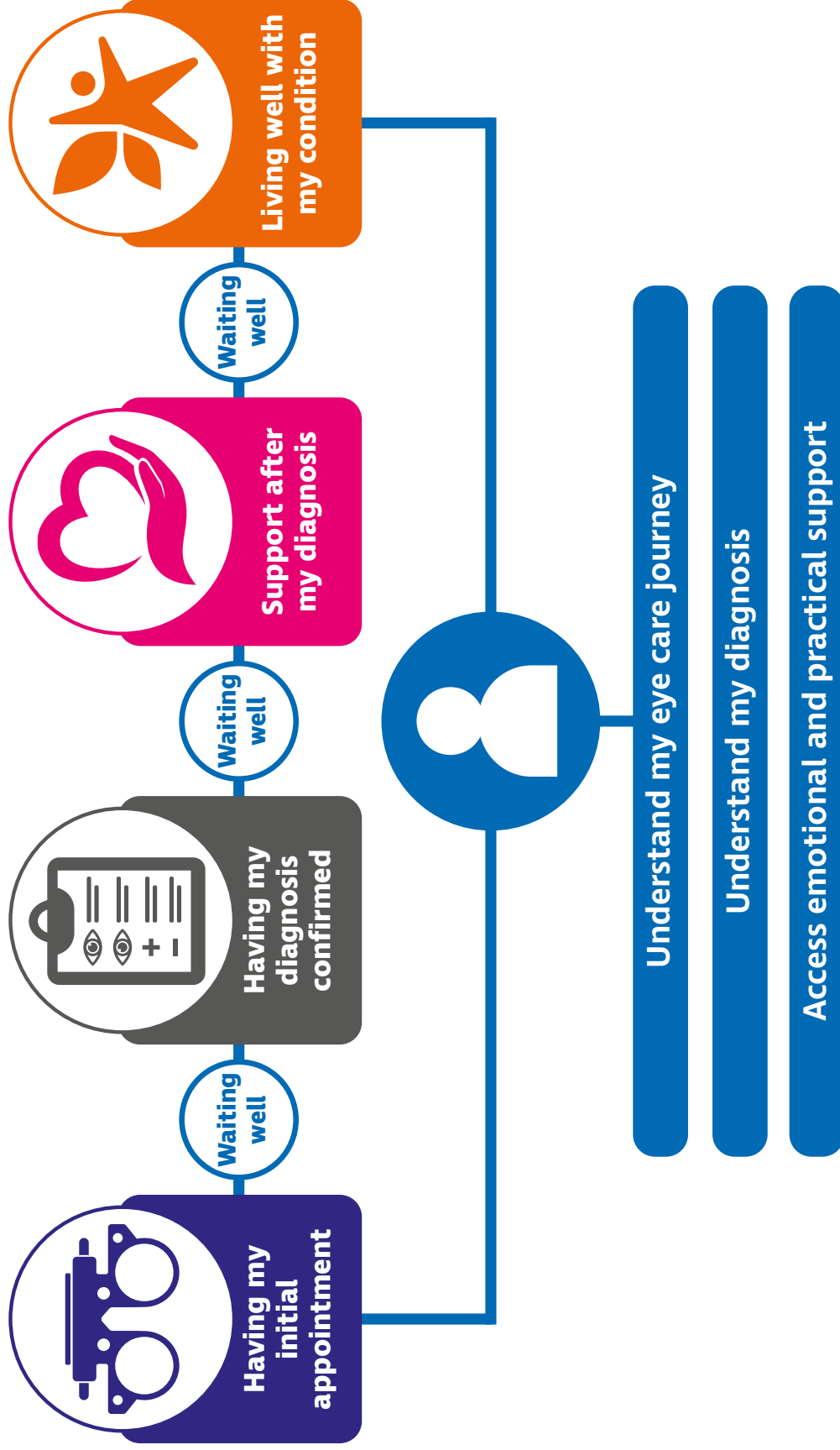


Diagram 1: The eye care support pathway

Understanding the information, advice and support people require

Stage 1: Having an initial appointment

Outcome: People understand there is something to investigate. They will receive or know where to go for information and advice about different eye conditions and support. They understand who they are seeing and why.

For most people their first touch point regarding a concern about their eyes and/or their sight is an appointment with a GP, an optometrist, ophthalmic nurse or a visit to A&E. This may be a routine appointment, such as an eye test, or it could be a concern about a change in vision. At this initial stage people want to:

Having an initial appointment

Eye care journey	<ul style="list-style-type: none">• Understand who they are seeing.• Know what tests will be undertaken and the initial results of those tests prior to the consultation, if appropriate.• Know what will happen next and when.• Understand why it is important to attend sight tests.• Know how to access the most appropriate service if their eye condition changes.
Eye condition	<ul style="list-style-type: none">• Have access to specific eye health literature, from a trusted source.• Receive information in a format that meets their communication needs.• Be able to ask questions, in a safe and supported environment.

Having an initial appointment

Emotional and practical support

- Know where to get support to manage any anxiety about what they have been told and what is planned next.
- Know where to get information, advice, and support to help with day-to-day activities such as employment, driving, benefits, care.
- Know how to speak to someone when they want to.
- Know how to access psychological support, if required.

At the initial appointment stage, there can be a lack of information and advice. When people need to be referred on or followed up, they can be unclear what happens next and when. Tests may be carried out with little explanation. Optometrists and GPs may not be able to provide a diagnosis and need to refer on to secondary care for further investigation. Information is key at this early stage and information needs to be readily accessible and tailored to the person's needs.

Example of good practice:

People with learning disabilities are ten times more likely to have a sight problem than other people but are also much less likely to have accessed eye care and support.

SeeAbility has created an **Easy Eye Care Pathway** (www.seeability.org/eye-care/locsu-pathway) which it has been working to establish in a number of areas in England. This means people with learning disabilities can access longer and more adjusted appointments at their opticians. SeeAbility also provides a range of **easy read leaflets** (www.seeability.org/resources) on common eye conditions.

Contact: **seeability.org**

Access to someone to talk to is equally important at this early stage and whilst waiting for a referral.

Referring optometrists may not always be aware of the nonclinical support available at this stage and so signposting to these resources can vary, despite emotional, psychological and practical support being available.

Example of good practice:

Primary Eyecare Services Limited in England and Optometry Scotland can now directly refer patients via their referral platforms to the third sector for information, advice, and support, at the same time as making a secondary care referral.

To accompany seamless referral processes, the sector has also produced a free e-learning module to enable optometrists and their teams to gain a deeper understanding of types of information, advice and support services are available that can support patients, their families, and carers.

Contact: rnib.org.uk

Referring into nonclinical support services from primary care, primary eye care or secondary care from the outset is now becoming feasible, with the integration of referral to support organisations within IT systems.

In future, commissioners and fundholders could include nonclinical advice and support requirements into GP, primary eye care and secondary care service specifications.

Example of good practice:

NHS England has provided funding to support the use of digital systems to improve the triage of eye care patients into secondary care through a single point of access, so the need to include patient support requirements has been incorporated into the eye care service specifications.

Waiting well across the pathway

Outcome: People understand they may have to wait. They will receive or know where to go for information and support while they wait. They know who to contact if they have any questions.

Waiting times rank as one of the public's main concerns with the NHS [19]. Ophthalmology waits rank as one of the top three nationally [3]. It is important therefore that people can **wait well** for tests, diagnoses and treatments. It is important to note that there are periods of waiting at all stages of the pathway.

People want to:

Waiting well: prior to the appointment

Eye care Journey	<ul style="list-style-type: none">• Be clear about what to expect next and when.• Know who to contact and how to get updated wait times.• Know how to access the most appropriate service if their eye condition changes.
Eye Condition	<ul style="list-style-type: none">• Be able to access as much trusted information as they want about a suspected diagnosis and get advice if required.• Receive any information, in a format that meets their communication needs.
Emotional and practical support	<ul style="list-style-type: none">• Know where to get support to manage any anxiety about what they have been told and what is planned next.• Know where to get information, advice, and support to help with day-to-day activities such as employment, driving, benefits and care.• Speak to someone when they want to.• Know who to contact for any further questions, or if psychological support is required.

Waiting for a referral, diagnosis and/or treatment is inevitably a time of stress and worry and, at this critical time, people need access to information such as wait times, what tests are planned and what the process is, as well as access to practical and emotional support. It is also important if a person's eye condition changes that they know the steps they need to take and who they need to contact.

"I lost my sight waiting for an appointment." [14]

People can best prepare for their appointment when provided with the right support and information while they are waiting.

People want to:

Waiting well: preparing for the appointment	
Eye care journey	<ul style="list-style-type: none"> • Be able to prepare for the types of questions to ask about. • Be able to understand the urgency of the appointment and are able to self-advocate or ensure access to support during the appointment. • Know that they can physically or virtually access the appointment. • Receive information in a format that meets their communication needs. • Know how to access the most appropriate service if their eye condition changes.
Eye Condition	<ul style="list-style-type: none"> • Be able to access as much trusted information as they want prior to the appointment. • Be able to understand what condition they may have and be able to communicate what it is they are concerned about at their appointment.
Emotional and practical support	<ul style="list-style-type: none"> • Access emotional, psychological and practical support if they want to at any time. • Feel emotionally prepared for potential outcomes. • Understand that the ophthalmic nursing team can provide information and support as part of their care. • Speak to someone when they want to. • Know where to go for psychological support.

It is important to ensure appointment letters are accessible, i.e. in the person's required format. Recent findings in Wales suggest that one in three blind and partially sighted people has missed a healthcare appointment or had their healthcare affected because they did not receive information that that they could read. [21] In England only 11 percent of patients covered by the Accessible Information Standard have equitable access to the NHS. [22]

There are opportunities where information, advice and support can be better integrated into existing NHS and social care IT systems and websites.

Examples of good practice:

RNIB has a Waiting Well service to support people waiting for NHS appointments. This is in addition to its Helpline and sight advice services. Health and care professionals can refer patients directly for information, advice, and support. The public may also self-refer or use existing helpline services.

The Low Vision Service Wales and Wales Council for the Blind (WCB) have worked together to provide an information and support resource on WCB's website for Low Vision Service Wales practitioners, the public and professionals (<https://wcb-ccd.org.uk/perspectif>).

My Planned Care gives advice and support while people are waiting and helps them prepare for their hospital consultation, treatment, or surgery. This includes giving information about waiting times and other supporting and local services that can be accessed while waiting.

NHS England have produced the My Planned Care website
www.myplannedcare.nhs.uk/

The Eye Care Support Pathway



Stage 2: Having a diagnosis confirmed

Outcome: People understand their diagnosis and know where to access the practical and emotional support they need to understand and deal with their diagnosis. They can take control.

For many people, the point of diagnosis is one of the most difficult parts of the pathway. At this stage people, and their families, friends and carers, need information, advice, support and empathy to help them prepare for a change in their sight that could have an impact on their life, whether temporary or permanent. People need time to ask questions and feel listened to.

People want to:

Having a diagnosis confirmed

Eye care journey

- Receive a sensitive diagnosis.
- Understand the next steps and how their condition will be treated and managed, what treatments are available, and that in some cases treatment may not be available.
- Know about research and any clinical trials which may be relevant to them.

Eye condition

- Be offered specific eye care information.
- Understand their eye condition and implications.
- Be able to participate in their chosen treatment options and understand if there is no available treatment for their condition.
- Be able to communicate their eye condition and how it affects their life to others.
- Know about genetic testing, if appropriate, and how to access testing.
- Be provided with information about Charles Bonnet syndrome, and other conditions linked to eye care needs and sight loss, and how it might affect them.

Having a diagnosis confirmed

Emotional and practical support

- Speak with an Eye Care Liaison Officer (ECLO) or be able to access support in person/remotely.
- Understand that the ophthalmic nursing team can provide information and support as part of their care.
- Know where to go and be able to access practical and emotional support and information.
- Know what local support is available.
- Know about low vision services, the Certificate of Vision Impairment (CVI) process and what other eye care services they may need to access in the future.
- Know how to access psychological support e.g. counselling services.

Diagnosis is a hugely emotional experience which can leave people feeling confused, overwhelmed and anxious about what lies ahead.

"The whole world came crashing down around my shoulders; I went downhill very, very quickly." [18]

People with lived experience of sight loss have talked about a lack of empathy from some clinicians at the point of diagnosis and poor communication styles. [16, 18]. Being provided with a life changing diagnosis can prompt a strong emotional response that can have long lasting impacts, and therefore it is important that the clinical team is able to put in place access to listening and support services, whilst providing an empathetic diagnosis.

"I was told in no uncertain terms by the doctors – quite callously, I thought... 'the sight's gone in that eye, cells have been damaged beyond repair', 'that's gone, forget that'. That was actually said to me." [18]

Across the NHS, the introduction of Eye Care Liaison Officers (ECLOs) within secondary care has provided patients with a crucial bridge to accessing practical and emotional support, with clinicians referring patients to ECLOs.

"The service was very reassuring and caring. Knowing there's help and support out there has made a significant difference. It means the support doesn't just end when you're told there's nothing more that can be done for you medically." [18]

However, currently the ECLO service is not universal across the UK nor commissioned as standard within eye care services.

Example of good practice:

Eye Care Liaison Officers (ECLOs) work with secondary care clinical teams to provide face to face nonclinical support at diagnosis and post diagnosis.

As of 2023, there are 162 UK ECLOs working across the UK who comply with the ECLO quality and practice framework guidelines.

Emotional and psychological support should be provided early in a person's eye care journey, as well as at this key stage, as people often do not seek help until they have reached a crisis point. [18] 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 [18].

Example of good practice:

The Macular Society has a team of qualified counsellors who have extensive experience either personally or professionally within the field of sight loss. It provides a telephone service for anyone who has been diagnosed with macular disease and offer the same service to that person's family members, in the UK and internationally.

It is bound by the BACP (British Association of Counselling and Psychotherapy) Ethical Framework for Good Practice in Counselling.

Contact: macularsociety.org

For people who may have complex and/or rare conditions, it is equally important that there is access to information, advice and support throughout their eye care journey as well as working in partnership with specialist third sector organisations who may for example also fundraise for, and facilitate research and offer complimentary specialist information, advice, and support services including the opportunity to connect with others living with their condition.

Example of good practice:

Retina UK has specialist web pages – ‘Unlock Genetics’

These pages provide a suite of resources with regards to genetic testing and genetic counselling among people living with inherited retinal dystrophies, empowering them to make fully informed decisions about their lives, healthcare and family planning.

Contact: retinauk.org.uk

“Electronic systems have reduced my independence. Signing in on the computer installed at my GP’s surgery is not possible and (for me) to say... that I need help is difficult. It’s hard to know if anyone’s at the reception desk. Before this [electronic system] someone always greeted me as soon as I went through the door”.

“When I was at accident and emergency, I didn’t see the button to open the door. The staff shouted at me to press the button, but I couldn’t see it.” [18]

As people navigate through clinics and eye care settings it is important to recognise that alternative options are in place to ensure equity of access due to the challenges of increased use of self-check-in touchscreens, locked doors and doorbells for security at health care settings.

Stage 3: Support after diagnosis

Outcome: People can manage their sight condition, its treatment and care. They understand the Certificate of Vision Impairment and Registration processes and the benefits and concessions to which they are entitled. They know where

to turn for further support and have regular check-ins with their optometrist.

Providing people with information, advice and support post diagnosis is critical to enable people to understand and accept their condition and live independently in the way that they choose.

People want to:

Support after diagnosis	
Eye care journey	<ul style="list-style-type: none"> ● Be able to understand their condition and seek further clarification, if they want. ● Be able to understand if their condition is hereditary and what that means. ● Know about research related to their condition and how to get involved in clinical trials if they are interested and suitable.
My eye Condition	<ul style="list-style-type: none"> ● Be able to understand how their condition may develop. ● Be able to participate in ongoing treatment or receive support, if required
Emotional and practical support	<ul style="list-style-type: none"> ● Know how to access practical and emotional support and information and counselling. ● Know what local support is available. ● Know about organisations which support people with their condition. ● Be able to talk to someone with the same condition as them if they want to. ● Understand what the potential impact is on their activities of daily living e.g., driving, employment, leisure and where information, advice and support is available.

Post-diagnosis, people may require ongoing treatment with multiple appointments and may be referred to other health and social care services at the same time. Ensuring support is in place and frontline staff are empathetic is important. Being aware of what sight loss means and how to guide people in health and social care settings can only improve a person's experience when accessing services.

"When I went for my eye check up at the hospital and the lady that took me into the room said: 'have a seat over there' so I said: 'sorry', so she says: 'have a seat over there' and I said: 'I'm not sure where there is' and she says: 'on the green chair'. I said: 'is that left or right?' [14]

People also should be informed of research and clinical trials into their eye condition where appropriate.

Example of good practice:

Since 1965, Fight for Sight is the leading UK charity dedicated to funding pioneering eye research. It is currently funding a number of studies into the main causes of sight loss including glaucoma, macular degeneration and inherited conditions. Recent research includes a UCL study which successfully analysed the effectiveness of a laser-based treatment for glaucoma compared with eye drops. The results could potentially improve the way glaucoma is treated across the world.

Contact:
www.fightforsight.org.uk

For people to manage their condition well post diagnosis they want to:

Support after diagnosis: ongoing management	
Eye care journey	<ul style="list-style-type: none"> • Understand how their condition will be managed, how many appointments they should expect and where they will be. • Know about low vision services, the CVI and Registration process and what other eye care services which are available to them.
Eye Condition	<ul style="list-style-type: none"> • Know how to manage any treatment and understand how their condition may affect their vision in the future. • Be able to understand the importance of following the treatment plan they have been given (eye drops, clinical appointments etc.)
Emotional and practical support	<ul style="list-style-type: none"> • Know about the support they may need in the future (e.g., low vision advice) and know how to access it. • Know they can continue to seek advice and support and where that support is available from. • Know where to go to access practical support and information on daily activities of living e.g. employment, driving and leisure. • Know what local support is available. • Know how to access counselling/ psychological support.

To get the best clinical outcomes, people need to follow any available treatment protocols, understand treatment regimens, and appropriately administer medication.

Unfortunately, this is not always the case with people commenting on poor communication, lack of understanding and lack of support. [17,18]

“I didn’t really understand the implications of it. If I’d known back then I needed to have kept taking eye drops... I obviously would have done, and certainly with the ramifications (becoming severely sight impaired) that I’m looking at going forward.” [18]

With the continued development of new product innovations to improve medication compliance and running shared campaigns across the NHS and third sector, there are further

opportunities to improve treatment adherence, communication and understanding.

Example of good practice:

Glaucoma UK provides information and resources about treatment options for glaucoma including a step by step guide on how to put in eye drops.

Contact: glaucoma.uk

Further support at this stage can also become available when someone becomes eligible for a Certificate of Vision Impairment (CVI).

However, there are indications that not all people are getting certified when eligible [8] and certification does not automatically lead to registration. There is poor understanding of these processes and low awareness of the benefits to blind and partially sighted people 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.

People want to:

Support after diagnosis: Certificate of Vision Impairment (CVI) and Registration with Local Authority

Eye care journey	<ul style="list-style-type: none"> • Be able to understand the CVI process and the support that can be accessed through the Local Authority and what happens at each stage. • Be able to access low vision services, if appropriate.
Eye condition	<ul style="list-style-type: none"> • Continue to manage their condition and understand what to do if they notice any changes.
Emotional and practical support	<ul style="list-style-type: none"> • Have the opportunity to speak to health care professional, an ECLO or the Local Authority about the CVI and registration process and what it means for them. • Know about rehabilitation support from other organisations/ third sector available to them and be able to access them • Know about benefits available to them. • Know how to access emotional or psychological support including peer to peer and community support

Consultants and other members of the clinical team may benefit from additional training to enable them to understand the benefits of certification and registration and to recognise when a patient may be eligible. It is also important that administrative processes and standard operating procedures are applied consistently to ensure that all appropriate patients have the opportunity for certification and registration, and to ensure they do not fall between the gaps between health and social care.

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 [23]. ECLOs also report experiencing delays when waiting for consultants to complete their sections of the form and suggest that it would be helpful if the CVI form were completed electronically.

Example of good practice:

Manchester Royal Eye Infirmary and Henshaws (local sight loss organisation) piloted a single point of access service for patients newly given a CVI. The project sought to better manage patient journeys through a centralised CVI database and automatic referrals from the eye hospital. By creating robust pathways to support for patients they received more timely, tailored support based on their needs and experience.

Contact: www.henshaws.org.uk

Future consideration should be given to broaden the professional groups able to authorise people with a CVI. Wales is an early UK adopter.

Example of good practice:

In Wales people with bilateral dry age-related macular degeneration will be able to access the certification of vision impairment (CVI) in primary care optometry as well as clinicians in secondary care continuing to support the CVI process.

The introduction of CVI in primary eye care has been driven by the **Welsh Government's optometry contract reform programme** that will see the range of NHS-funded eye care services provided by optometrists and dispensing opticians in Wales increased, enabling staff to work at the top of their licence.

Download "NHS Wales Eye Health Care – Future Approach for Optometry Services": bit.ly/3FrIshL

As well as certification and registration processes, people and practitioners are also generally unaware of the role and value of Low Vision Clinics. For individuals with sight loss low vision services can play a vital role in helping individual make the best use of their remaining vision. Low vision services may be provided locally by hospital eye services or by local authorities. Referrals are often made late, and there can be geographic inconsistencies and significant variation of wait times.

Example of good practice:

Perspectif is Wales' primary database of services and support for blind and partially sighted people. Low Vision practitioners are being trained in the use of **Perspectif** (<http://wcbccd.org.uk/perspectif>). Low Vision Service Wales has collaborated with Wales Council of the Blind to embed this into the practitioners' work streams, enabling a quick way to obtain customised information for their patients to take away. It is a tool for social prescribing.



Stage 4: Living well with my condition

Outcome: People understand what third sector support and statutory services are available and how to access vision rehabilitation and other support.

They feel emotionally and practically supported and feel positive about the future. They have confidence to live safely and independently.

With the right support blind and partially sighted people, as well as those with temporary sight loss, can come to

terms with changes in their eye health and adjust their lifestyles.

“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.” [24]

People should transition smoothly from health to social care with access to statutory support services and third sector support. At this stage people want to:

Living well with my condition: statutory services

Eye Care Journey	<ul style="list-style-type: none"> • Be prepared for the vision rehabilitation specialist (VRS) visit. • Understand what will happen at the VRS visit and what social care / statutory support they may be entitled to. • Understand there may be a wait for a visit and what support they can seek in the interim from other services / support organisations.
Eye condition	<ul style="list-style-type: none"> • Know how to manage their condition while they wait for vision rehabilitation support and what to do if their condition / circumstances change.
Emotional and practical support	<ul style="list-style-type: none"> • Know where to go and be able to access to practical and emotional support and information such as daily activities of living, employment, and leisure while they wait. • Know what local support is available. • Know who to contact and be able to speak to someone if they want to • Understand where else they may be able to get support from.

Accessing social care, such as vision rehabilitation, can build confidence and enable independence, as well as avoid health and social care costs.

However, provision of vision rehabilitation is patchy, with some areas across the UK offering a good service, and some none at all. Waits can be long and are generally not published. It is therefore important that health and social care professionals continue to refer people to support organisations who can connect people to other people with their condition, provide information, advice and support and in some cases rehabilitation.

Example of good practice:

Many sight loss organisations, including RNIB, provide Living Well with Sight Loss courses.

The courses consist of telephone and/or face to face group sessions where blind and partially sighted people can meet others experiencing sight loss and learn about services and support available both pre and post diagnosis.

Courses cover a wide range of topics from understanding benefits to technology. The service also offers "Focus On" courses covering topics like confident living, money and specific courses for family and friends.

Example of good practice:

Blind Veterans UK provides physical and emotional support to blind ex-Service men and women to support them in rebuilding their lives after sight loss.

Support is life-long and individually tailored and services include rehabilitation, the provision of specialist equipment and training, respite, and residential care alongside support to facilitate independence in the home and access to hobbies, social activities, and recreational fitness.

Contact: blindveterans.org.uk

The importance of supporting people to live life independently and have the same equity of access to opportunities is critical and is life changing.

"Before you start that mobility training, everywhere I went I had to hang onto my wife. Once I got that mobility training I could go on my own, I could go for a walk on my own, I could go to the shop on my own, I could go to the doctors on my own, and it's so brilliant.... I'm not that useless, perhaps I can do things for myself, and it gives you a hell of a lot of confidence back." [14]

Working with a vision rehabilitation specialist people want to:

Living well with my condition: vision rehabilitation	
Eye care journey	<ul style="list-style-type: none">• Be able to co-develop an action plan with the vision rehabilitation specialist.• Feel confident about what to do if their needs change.
Eye Condition	<ul style="list-style-type: none">• Be able to manage their eye-condition.• Be confident they can live independently as they are able with their condition.
Emotional and practical support	<ul style="list-style-type: none">• Feel they can engage in and own their action plan.• Be able to access support in different ways as their situation changes.• Be able to talk to/link in with other people in the same situation as them.• Know they can access further support at any stage.

Personal action plans in Vision Rehabilitation (sometimes called Care Plans) can vary in their use and effectiveness and there are indications that for some people these plans aren't being produced at all [16].

It is important that people are able at any stage to reassess their needs and access support when they need it. However, there is a lack of knowledge around the ability to be reassessed if circumstances change [15].

For young people transitioning to adult services, it is important that this is planned over a period of time and not left until they reach the age when they move from paediatric to adult services.

Guide Dogs are working with the sector to develop a Paediatric Vision Impairment Support Pathway. We are working in partnership to ensure a joined-up approach so that the two pathways work together and ensure anyone of any age with a vision impairment gets the support they need.

Contact: guidedogs.org.uk

People want to:

Living well with my condition: continuous review	
Eye Care Journey	<ul style="list-style-type: none">• Fully understand all the different stages of the pathway and who to contact at each stage if they need further help / re-access services.• Transition between services seamlessly and when moving from paediatric to adult services this is planned well in advance, with all parties involved.
Eye condition	<ul style="list-style-type: none">• Understand their eye condition / vision may change and know what to do when this happens.
Emotional and practical support	<ul style="list-style-type: none">• Know how to find support that is relevant to them.• Feel confident in accessing emotional and practical support at any time in the future.

The third sector plays a vital role here in supporting people to live well. This can be through the provision of local community groups, which offer vital peer support and emotional well-being and also through the provision of practical skills such as training in digital technology to enable independence. The crucial point is that people need to know what is available to them so they are able to access the support as and when they need it.

“People need to be put in the know about local provision, not knowing what is out there is the hardest thing.” [16]

Implementation and delivery

We have identified gaps and issues with ensuring people have access to support which is compounded by the increasing distance between the rising demand for eye care and pressures on staff and other resources to deliver it.

We believe one way to close this gap is for the health and social care bodies in England, Northern Ireland, Scotland and Wales to implement the eye care support pathway locally.

The third sector has a workforce with the expertise to collaborate with our health and social care systems to identify such gaps and to transform the way we deliver information, advice and support across the UK.

Additionally, the sector has a wide range of tools, good practice guides, quality frameworks and an extensive service portfolio to meet the requirements set out across the pathway. The eye care support pathway and its supporting framework provide the basis to audit, track and monitor current and future provision of support.

The VI Charity Sector Partnership, which consists of eight of the leading charities in the sight loss sector, can give a strategic overview of the eye care support pathway to help further.

The founding partners are: Blind Veterans UK, Glaucoma UK, Guide Dogs, Macular Society, Retina UK, RNIB, Thomas Pocklington Trust and Visionary.

Currently, the VI Charity Sector Partnership is committed to supporting and overseeing the implementation and delivery of the eye care support pathway across the UK. The sector will continue to support implementation by producing further resources working with partners such as the Royal College of Ophthalmologists to overlay the pathway with clinical pathways.

The partnership will also commit resources such as Country Directors, NHS Strategic Engagement Managers and Regional Partnership Development Managers to lead on implementation and ensure regional and local leaders are engaged in the delivery and implementation of the pathway. Visionary, and other organisations, will ensure local sight loss charities are represented and Thomas Pocklington Trust's regional Sight Loss Councils will ensure people with lived experiences are actively engaged.

Example:

Sight Loss Councils (SLCs) are led by blind and partially sighted members. They tackle local issues and work with businesses and service providers to improve the accessibility of their services. There are currently 20 SLCs across England.

Contact: sightlosscouncils.org.uk

Example

Visionary is a membership organisation for local sight loss charities. It both represents and supports 110 local sight loss organisations across the UK providing community-based services. Visionary members work alongside approximately 250,000 blind and partially sighted people and their families.

Contact: visionary.org.uk

The eye care support pathway has been collaboratively designed by people with lived experience in partnership with professionals working across our eye care and social care systems. As we move forward, we need to commit to the following three key areas:

1. An integrated approach to strategic and operational eye care planning, ensuring eye care pathways are co-designed and person centred with support needs considered and integrated.
2. Strengthen the relationships between health, social care and the third sector, to co-ordinate and collaborate information, advice and support offers so it is easy for the public to navigate and access support.
3. Focus on developing and delivering a year-on-year eye care support pathway improvement plan, which forms part of any local and national transformation strategies.

This approach will enable people to positively engage in their eye care journey.

Measuring outcomes and impact:

As the eye care support pathway is implemented it will be crucial to measure its success and outcomes for people with eye care needs. RNIB has developed a theory of change for the eye care support pathway and this document has clearly outlined the outcomes for people at each stage. Using the pain points identified as a baseline measure, RNIB's internal evaluation team – working with partners – will develop the appropriate methodology to track progress against these baseline measures to clearly identify whether the outcomes are being achieved and the difference the eye care support pathway is making to people with eye care needs. The evaluation will also encompass the difference the pathway may make to the NHS and social care system in a number of key areas.

We have the opportunity to create the following impact:

- Eye care pathways which are effective, efficient and clear for people at risk of sight loss and professionals alike.
- People with sight loss have levels of health and wellbeing as high as the general population.

Next steps – we aim to:

- Have an integrated approach to clinical and nonclinical support when funding eye care services.
- Have an integrated approach to strategic and operational eye care planning, ensuring eye care pathways are co-designed and person centred with support needs considered.
- Strengthen the relationships between health, social care and the third sector, working with the third sector to co-ordinate and collaborate information, advice and support offers so it is easy for the public to navigate and access support.
- Focus on developing and delivering a year-on-year eye care support pathway improvement plan, which forms part of any national transformation plans.
- Co-design, measure and evaluate improvements, working alongside people with lived experience of sight loss/eye conditions.
- Have digitally enabled eye care pathways which interoperate with health, social care and the third sector.
- Have commitment locally and nationally to ensure joined up decision making across the whole end-to-end pathway with a commitment to create or re-establish local eye health networks or equivalent.

Conclusion

In the development of the pathway more than 500 people with lived experience have been consulted, 50 key personnel across the sector have been engaged and 30 of our leading eye care bodies have been represented. The eye care support pathway encapsulates the dedication and commitment to co-producing and co-designing our future eye care services. The eye care support pathway is firmly rooted in people's experience of living with eye care needs or working with and supporting people with eye care needs. Everyone involved in this work has one united ambition – to transform our eye care pathways to ensure patients receive better access to information, advice and support throughout their eye care and sight loss journey.

If there was ever a point in time that NHS practitioners, eye care departments and specialist rehabilitation services required additional input and support from third sector charities it is now. The level of demand placed upon each practitioner, each department, each appointment has never been greater than it is today. Transformation is required across the whole end-to-end eye care pathway but, without better information, advice and support to ensure an individual is able to actively participate and take control of their eye care journey, other transformation priorities will fail.

The eye care support pathway and supporting framework offers the eye care sector the foundation to transform the way in which clinical and nonclinical support are provided to ensure all our pathways are effective, efficient and clear for people with eye care needs and professionals alike. We are reliant on everyone to adopt the requirements set out within the eye care support pathway. In each contact with an individual we need to ask ourselves whether they understand:

- Their eye care journey
- Their diagnosis
- How they can access practical and emotional support

If the answer to these questions is yes then we have truly endorsed and addressed the requirements set out in this report; 10 years from now this pathway will no longer be required as this will form part of our everyday routine behaviours and activities.

“If the eye care support pathway was around seven years ago, it would have given me a pathway out of the darkness”. [RNIB Employee with lived experience of sight loss]

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- Association of Directors of Adult Social Services
- Association of Optometrists
- BAME Vision
- British and Irish Orthoptic Society
- Blind Veterans UK
- Clinical Council for Eye Health Commissioning
- College of Optometrists
- Department of Health and Social Care
- Esme's Umbrella
- Federation of Ophthalmic and Dispensing Opticians
- Fight for Sight/Vision Foundation
- Glaucoma UK
- Guide Dogs
- Kinneir Dufort
- Local Optical Committee Support Unit
- Macular Society
- NHS England
- Rehabilitation Workers Professional Network

- Retina UK
- RNIB
- Royal College of Nursing
- RCN Ophthalmic Nursing Forum
- Royal College of Ophthalmologists
- SeeAbility
- Thomas Pocklington Trust
- UK Ophthalmology Alliance
- Visionary

The members of the CCEHC are:

- Association of British Dispensing Opticians
- Association of Directors of Adult Social Services
- Association of Optometrists (AOP)
- British and Irish Orthoptic Society
- The College of Optometrists
- Faculty of Public Health
- Federation of Optometrists and Dispensing Opticians (FODO)
- Glaucoma UK
- Local Optical Committee Support Unit (LOCSU)
- Macular Society
- Royal College of General Practitioners
- Royal College of Nursing (Ophthalmic Nursing Forum)
- Royal National Institute of Blind People
- The Royal College of Ophthalmologists



cried the Duchess almost in hysterics. "There aren't any two-handed swords and battle-axes here."

Valentin was still busy with the paper in front of him. "Tell me," he said, still writing rapidly, "could it have been done with a long French cavalry sabre?"

A low knock came at the door, which, for some unreasonable reason, curdled everyone's blood like the knocking in Macbett. Amid that frozen silence Dr. Simon managed to say: "I suppose yes, I suppose it could."

"Thank you," said Valentin. "Come in."

he confidential



Contact us

For further information about the eye care support pathway please contact us:



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Helen Doyle – helen.doyle@rnib.org.uk



EyeCareSupportPathway@rnib.org.uk

Call the RNIB Help line:



0300 111 9999

[rnib.org.uk](https://www.rnib.org.uk)