London Eye Health Network

Integrating Low Vision, Eye Clinic Liaison Officer and Rehabilitation Services

Developing a consistent approach and ensuring equitable user access (peri COVID-19) for service pathways in London

Contents

Audience: London Integrated Care Systems, Ophthalmology departments, Councils, and Charity and Voluntary organisations.

Executive Summary

It is important to align low vision, eye clinic liaison officer (ELCO) and rehabilitation services across London. This could be through the development and implementation of integrated service frameworks to ensure consistent commissioning, delivery of services, equitable patient access and aid provision.

This document is designed to initiate change by promoting local conversations on:

- an expectation of better care in the peri COVID-19 era;
- a high-level integrated service check list (6.2);
- examples of best practice and learning, based on these proposed London priorities:

  ✓ appropriate and timely user access to low vision, ECLO and rehabilitation services.

  ✓ reduced inequalities in current service provision leading to better user experience.

  ✓ better Londonwide data to monitor and inform integrated care system and service delivery plans.

  ✓ equitable access to support (via aids, training and technology) for users to proactively maintain independence, mental wellbeing and falls prevention.

  ✓ increased awareness of low vision services by all care practitioners and how to refer.

  ✓ a standardised London referral pathway (and supporting documentation) to access social services.

  ✓ actively promoted services for hard to reach groups.

  ✓ service users confident in safety and effectiveness of service.

1. Introduction

1.1 UK needs

One in five people aged 75 and over, and one in two people aged 90 and over, are living with sight loss. This amounts to over two million people across the UK.

People with diabetes are at risk of diabetic eye disease as well as glaucoma and cataracts.

People from certain ethnic communities are at greater risk of some of the leading causes of sight loss:

- Black African and Caribbean people are four to eight times more at risk of developing certain forms of glaucoma compared to white people.
- South Asian people are around three times more at risk of diabetic eye disease compared to white people.
- Black African and Caribbean people are also at a higher risk of diabetic eye disease.

1.2 London needs

The Royal National Institute of Blind People (RNIB) estimates that there are already 680,000 people – around one in twelve of the adult population – in London living with a sight-threatening eye health condition and 208,000 living with sight loss. This RNIB also highlights that 18 per cent of those certified as sight impaired or severely sight impaired do not become registered with their local authority. Whilst most of these people are aged 65 years and over, it is important to be aware that hereditary eye disease is the leading cause of visual impairment in the working age population. Table 1 shows comparative data on new certifications and breakdown by age for 2018/19.

RNIB sight loss data tool
https://www.rnib.org.uk/professionals/knowledge-and-research-hub/key-information-and-statistics/sight-loss-data-tool

	London			England and Wales		
	Total *	CVI due to hereditary eye disease, single main cause	% of total new certifications in London	Total **	CVI due to hereditary eye disease, single main cause	% of total new certifications in England and Wales
Number of new CVIs	2747	294	10.6	25887	1539	6.0
3-18 years	191	42	22.0	1488	294	19.8
16-64 years	827	208	25.2	5273	963	18.3

Table 1. Number of new vision impairment certifications (CVIs) April 2018 - March 2019
(* Total - new certifications in London, ** Total - new certifications in England and Wales)

Source: data captured by the CVI and CVIW are the copyright of the Department of Health and Social Care and the Welsh Government respectively, and this work was made possible through a collaboration with the Royal College of Ophthalmologists. The views expressed in this paper are those of the authors and not necessarily those of any funding body or the Department of Health and Social Care or Welsh Government.

2. Roles and responsibilities

2.1 Commissioning and service provision

The commissioning and provision of low vision and rehabilitation pathways have historically been fragmented due to reliance on a variety of (or lack of) funding streams. This has been a barrier for change and often results in an inconsistent approach to delivery. Low vision and some (or part of) ECLO services are provided by Hospital Trusts as part of Clinical Commissioning Group (CCG) contracts while rehabilitation services are provided by local authorities. Charity and voluntary organisations provide additional low vision support services and frequently fund or part fund ECLO posts to expedite service developments. The ECLO has an essential role in coordinating integrated low vision and support pathways (Figure 1), and as such, their role should be properly commissioned and fully funded as part of the service.

2.2 Low vision

Hospital based low vision clinics are accessed through the usual referral pathway. It is not necessary for a person to be certified or registered as sight impaired (SI) or severely sight impaired (SSI). Most Trust ophthalmology departments provide low vision clinics, but long waiting times may exist due to capacity challenges. Some charities and voluntary organisations may provide low vision clinics.

2.3 Eye Clinic Liaison Officer (ECLO)

ECLOs bridge the gap between hospital-based, community and care services. They are crucial in linking users to services and helping patients understand the impact of their diagnosis and signposting them to other support. ECLOs provide emotional and practical support and importantly, have the time to dedicate to the needs of people following their certification.

Figure 1. ECLO role in co-ordinating integrated pathways

2.4 Rehabilitation

The Care Act sets out the statutory duty for local authorities to assess 'need', and to 'prevent and delay' the development of needs for care and support. A needs assessment should be carried out over an appropriate and reasonable timeframe. Rehabilitation workers provide statutory support to people living with sight loss in the community and the emphasis of their work is to promote and support independent living. The statutory assessment may result in support for daily tasks including indoor and outdoor mobility, reading and the use of low vision aids, lighting, cooking, managing personal care, and social activities. Early referral to the local authority rehabilitation service is essential both for independent living and mental wellbeing.

Rehabilitation workers professional network – practice guidance and orientation and mobility guidance https://www.rwpn.org.uk/

3. Improving services

3.1 Reducing unwarranted variation

Integrated services are essential to ensure consistency for users, and the avoidance of a postcode lottery. Currently, access routes to social care and thresholds for support vary by borough, and population need has not been

assessed. In many areas, there is no accessible community low vision service, and the only access route is referral and re-referral to the Hospital Eye Service (HES). The certification process is not linear, and patients can move between the services. Treatments do not need to be exhausted before referral to low vision clinics or before certification (as SI or SSI) is initiated.

One group that are not specifically addressed, but whose care can be challenging, are those that have significantly reduced vision but do not meet criteria for certified sight impaired. Often, they do not have the multi-disciplinary support in place that they need. Better communication/ awareness from primary care providers could help to raise awareness.

Many people with low vision have additional mobility problems and find attending hospital or community appointments difficult. For those who are unable to leave home unaccompanied due to physical or mental illness or disability, and are eligible for an NHS funded sight test, this can be requested in their normal place of residence. However, few primary eye care providers (who provide the sight tests) are aware of the local low vision services available, or alternative referral pathways. There is variance in the provision of low vison services for the housebound and some do not receive an assessment.

3.2 HealthWatch report

A HealthWatch report 2018 highlighted that '*a more comprehensive understanding of the individual parts of the entire process of care was needed in eye services and how they are interconnected, otherwise we may only address the symptoms of an inadequate service model'.* Following the report, local organisations worked collaboratively to improve services and communications between services. In early 2020, an ECLO started working in the local ophthalmology department.

HealthWatch Havering supporting people who have a visual impairment
https://www.healthwatchhavering.co.uk/sites/default/files/visual_services_final_report_1.pdf

3.3 Ombudsman report

A complaint over delays in completing a needs assessment and the amount of support provided was upheld by the Ombudsman. This has resulted in the Hammersmith and Fulham Council reviewing the assessment of their sight impairment pathway and staffing levels.

Hammersmith and Fulham Ombudsman report 2020
https://www.lgo.org.uk/decisions/adult-care-services/assessment-and-care-plan/18-019-465

4. COVID-19 impact on low vision, ECLO and rehabilitation services

4.1 Lockdown

During lockdown, low vision clinics were cancelled, with urgent cases carried out via remote consultations. Rehabilitation services were largely restricted to phone-based assessments with home-based rehabilitation carried out in emergencies. Most charity and voluntary sectors continued to offer telephone support services.

Initial returns show a significant fall in certifications of visual impairment during the lockdown period.

Those patients with new or deteriorating low vision found their ability to carry out daily living functions seriously impacted, resulting in increased physical and mental health issues. An interim report on the impact of Covid-19 on disabled people in London has been recently published.

Interim report on the impact of Covid-19 on disabled people in London
https://www.inclusionlondon.org.uk/disability-in-london/coronavirus-updates-and-information/campaigns-news-during-coronavirus-crisis/abandoned-forgotten-and-ignored-the-impact-of-covid-19-on-disabled-people/

4.2 Recovery

As ophthalmology services resume, a telephone low vision consultation (video link if possible) is being used to discuss a patient's vision problems and needs. Following discussion, a patient might choose to delay a face to face appointment and have a magnifier or other aids posted for a "trial period' and followed up later. Likewise, ECLOs are continuing to operate a remote telephone service, to assess and signpost as well as direct care, especially for 'vulnerable' people. The professional body for vision rehabilitation workers (RWPN) has issued interim practice guidance on orientation and mobility training and how services should resume. https://www.rwpn.org.uk/

However, backlogs may be difficult to reduce, with lower clinic numbers to maintain distancing, and deployed posts. During recovery, it is important for patients (particularly those newly diagnosed / certified) that access to services is not delayed so that they do not suffer negative impacts on life in general (e.g. raised anxiety and mental health issues, risk of falls, loss of independence). Charity and voluntary organisations are likely to vary in their response depending on their ability to restart services.

With changes to services, there should be robust processes in all systems to ensure patients are not lost in the system.

5. Need for change

5.1 Low vision and rehabilitation services

COVID-19 has provided an opportunity to review low vision and rehabilitation pathways based on equitable and timely access – by incorporating more remote consultations and embracing digital solutions where appropriate. However, it is important to be aware that these new ways of working may not be appropriate for some, and there should be options to choose. Development towards agreement and implementation of an integrated care model should be a priority to ensure equity across London. Good services should proactively identify need (e.g. falls prevention, mental health) and support independence. Whether virtual or face to face assessments, they should be undertaken, and patients provided with clear information about the process, e.g. service expectations, aids provided, signposting, COVID screen, transport, personal protective equipment (PPE), delivering:

a) personalised care that follows service users and meets their needs and risks.
b) provision of safe, timely and effective care by appropriately trained and competent professionals.
c) provision of aids on loan, information on technology, signposting, mobility training appropriate to the individual.
d) consistent service provision for ongoing assessment of low vision aids.
e) ongoing development of the current service and future workforce planning.
f) efficient pathways to make best use of available resources and skills.
g) embedding audit and governance structures into the service.
h) provision of service options in a setting closer to home, study or work to suit user choice.
i) integrated, multi-disciplinary teams and pathway working with appropriate access across primary and hospital care, social services, education and the voluntary sector.
j) empowerment of service users to maximise their potential to live independently through education and self-care.
k) equitable access to ensure users are not denied, or do not have, access to these services; for example, those who are confined to their homes or residential establishments, non-English speakers, asylum seekers and other seldom heard / hard to reach groups.

Clinical Council for Eye Health Commissioning - Low Vision, Habilitation and Rehabilitation Framework 2018 (a-j) https://www.college-optometrists.org/uploads/assets/2642d67c-96f9-4e12-ab4c402b2df4e15c/Low-vision-habilitation-and-rehabilitation-framework-for-adults-and-children.pdf

6. Integrating low vision, ECLO and rehabilitation services

6.1 The adult UK eye health and sight loss pathway

The adult UK eye health and sight loss pathway (Figure 2) remains the pathway of choice. It sets out the process steps and promotes closer working between primary eye care (GPs, optometrists, dispensing opticians), ophthalmology, ELCO and the rest of the low vision and rehabilitation pathway. Referral to low vision services should be as easy as possible and allow for re-referral to ophthalmology or optometry where there is suspicion of change in existing conditions and need for reassessment.

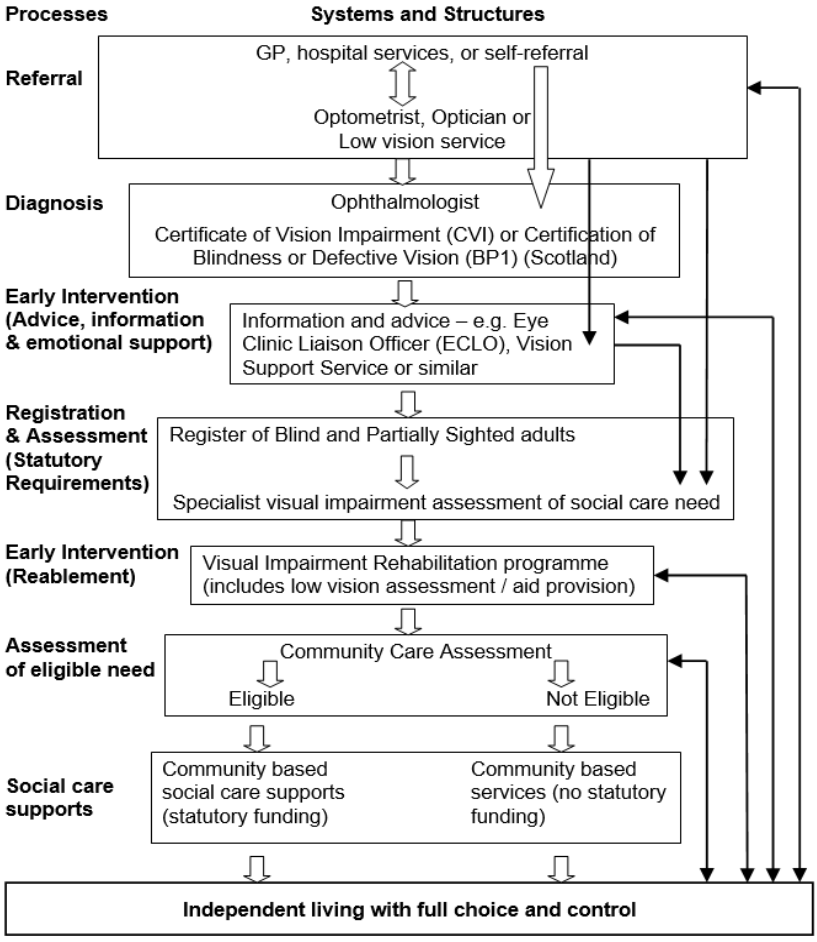

Figure 2. The adult UK eye health and sight loss pathway

Patients should have the choice of HES low vision services for convenience, if regularly visiting the hospital, or commissioned primary or community-based low vision services if more convenient. However, access to primary and community services may be more difficult due to the lack of NHS transport services.

Patient needs should be risk stratified – risk of falls or loss of independence if no access to services – with provision of aids based on need. There should be earlier referral and interventions prior to CVI, for information on diagnosis, emotional and welfare support, technological solutions and not just optical aids and daily living support aids. Service users should be aware that their vision may change and that the service is ongoing and re-assessments will be required.

Children's services – there should be access to qualified teachers of the visually impaired (QTVI) and access to low vision services available in primary care, hospital eye service and voluntary sector settings, enabling choice, with primary care or a voluntary sector setting being more convenient for some, while others with regular appointments in the HES may be able to combine appointments.

6.2 Maximising integration

Specific actions, processes and communication channels are needed to support patient centred integrated pathways as set out in this **Londonwide check list:**

- ✓ agreement of whole system pathways to minimise duplication and streamline processes.
- ✓ low vision services working as seamlessly as possible with other services including wider primary care, community, HES, education, social care, voluntary and charity organisations, together with stroke, learning disability, habilitation, rehabilitation and falls teams.
- ✓ timely referral to low vision services from HES, primary care, community, rehabilitation or the voluntary sector supported by ECLOs.
- ✓ standardised referral pathway (and supporting documentation) to access social services.
- ✓ agreement of a communication plan so that all practitioners and users are engaged and informed of guidelines signposting users to key services.
- ✓ agreement of a communication route for users, carers and parents so they can contact the services directly, to discuss their personalised low vision care or an education health care plan (EHCP) in the case of children and young people.
- ✓ effective sharing of data at every stage of the user's pathway to ensure good communication and secure interchange of relevant information between health, care and education professionals, and their patients, ideally provided by electronic patient records.
- ✓ effective data collection and audit across the pathways to help identify users who are lost to follow-up and enable those managing service provision to plan more effectively.

- ✓ smooth transition between children's and adult services to avoid user's getting lost in the system, especially in the 18 – 25 age group. (paediatric low vision provision may be only accessible in school with equipment shared with others, which then becomes unavailable in further education).
- ✓ smooth transfer of services and information when users move from one geographic area to another.
- ✓ clear information, advice and guidance provided to users to allow them to understand what resources are available for them and how they might benefit.
- ✓ access to local low vision support through local voluntary societies.
- ✓ willingness of the stakeholders to work together and fund services with clauses in Service Level Agreements that relevant partners have commissioned roles and responsibilities.

Clinical Council for Eye Health Commissioning - Low Vision, Habilitation and Rehabilitation Framework 2018 https://www.college-optometrists.org/uploads/assets/2642d67c-96f9-4e12-ab4c402b2df4e15c/Low-vision-habilitation-and-rehabilitation-framework-for-adults-and-children.pdf

6.3 Data and outcomes monitoring

Low vision:

Desired outcomes:	Timely access to low vision clinic and subsequent provision of low vision and/or access to electronic aids.
Measures:	Number of referrals to low vision clinic.
	Waiting times from date of referral to first low vision assessment.

ECLO:

Desired outcomes:	Timely access to an ECLO service.
Measures:	Number of referrals to ECLO service.
	Waiting times from date of referral to first ECLO contact.

Rehabilitation:

Desired outcomes:	Timely access to statutory assessment for rehabilitation and subsequent provision of rehabilitation services and equipment.
	All citizens receiving registration are offered a specialist visual impairment assessment.

Measures:	Number of referrals for specialist sensory impairment assessment. Waiting time from date of referral to specialist sensory impairment assessment.
System:	
Desired outcome:	Users who are confident to use public transport alone / cook their meals / take part in local activities.
Measures	Positive patient feedback via questionnaires.

6.4 Two case examples of integrated service models in London – see appendix.

7. London Priorities

Proposed priorities

- appropriate and timely user access to low vision, ECLO and rehabilitation services.
- reduced inequalities in current service provision leading to better user experience.
- better Londonwide data to monitor and inform integrated care systems and service delivery plans.
- equitable access to support (via aids, training and technology) for users to proactively maintain independence, mental wellbeing, and falls prevention.
- increased awareness of low vision services by all care practitioners and how to refer.
- a standardised London referral pathway (and supporting documentation) to access social services.
- actively promoted services for hard to reach groups.
- service users confident in safety and effectiveness of service.

Appendix – Two case examples of integrated low vision and rehabilitation services

1) RNIB

Service information:

The RNIB low vision service is commissioned by Camden and Islington CCGs to provide community-based low vision services. Set up in 2003, the service provides low vision assessments, eye examinations (when necessary) and rehabilitation needs assessments to residents who live or have a GP in Camden or Islington. The service is based in Judd Street, London and includes a provision for domiciliary visits and specialist support for people with learning disabilities. It also acts as a teaching facility for undergraduate optometrists and dispensing opticians.

Patient pathway:

- referral from social services, GP, allied health professionals, or self-referral.
- assessment made over the phone of urgency of need and appointment allocated either central clinic or domiciliary.
- patient assessed by optometrist, whenever possible with rehabilitation worker present.
- if rehabilitation worker not present, report sent direct and arrangements made for rehabilitation needs assessment.
- aids issued and training given.
- report sent to patient in preferred format and copy sent to other professionals involved in care, with permission of patient.
- three months follow up call – patient rebooked if further needs.
- recall set depending on prognosis, level of need and level of vision, typically 2 years.

Low vision assessment is funded as a total fee for assessing a set number of patients per year rather than a per patient basis. The funding includes professional fees, equipment and overheads and all low vision aids (hand and stand magnifiers, telescopes, binoculars and spectacle mounted aids, glare shields). Non optical aids are provided by the rehabilitation sensory needs service.

Assessment:

- detailed medical and ocular history and symptoms, detailed social history and discussion of needs and difficulties.
- measurement of visual acuity, visual fields and contrast sensitivity tests; prescribing magnifiers.
- prescribing of glare shields.
- training with magnifiers and discussion of other support or strategies that might help.
- discussion of electronic aids and technology.
- referral to other agencies.

2) Guy's and St Thomas' NHS Foundation Trust

Service information:

The low vision service at St Thomas' eye department offers a joint ECLO and optometric assessment of a person's functional and social care needs for both adults and children. The children's ECLO offers a family liaison service and is provided in partnership with Guide Dogs for the Blind. The low vision service dispenses a range of optical low vision aids at no charge to the patient and has a range of non-optical and electronic aids for demonstration.

The service works closely with the adult sensory services teams at Lambeth and Southwark, providing an additional joint optometry and rehabilitation worker low vision clinic at two community sites. This enables community care assessments to be initiated much earlier and allows the low vision assessment results to inform this intervention.

The service maintains active links with the community and third sector, hosting an annual low vision day open to anyone affected by sight loss, and attended by local and national service providers. There is an active visual impairment singing group (the VIP singers) and a Wednesday club coffee afternoon support group hosted by the hospital.

New advice and guidance on low vision support are now available via smartphone, tablet apps and PC for those who are able to use this technology.

Patient pathway:

Pre-COVID

Patients with a perceived need were referred to the low vision and ECLO service from ophthalmology outpatients and other clinics via an internal referral system. Registration is not a prerequisite. The ECLO is present all week within the clinics allowing for on the spot referral. A dedicated children's ECLO works with the paediatric service, with a joint reporting mechanism (Low vision aid, orthoptics, children's ECLO and ophthalmology) to QTVI services at Lambeth Social Services Department.

Patients are referred onto rehabilitation services via the registration process if new to the system, direct phone call or by email referral. Direct referrals are also made to third sector providers like Blind Aid as need demands.

Registration status is checked and updated or initiated at all appointments.

Emotional support is offered at all stages and depression screening is conducted (NICE CG90).

Close contact or joint assessment by sensory needs rehabilitation workers ensures community care assessments can be initiated or revised with input from the service on visual status.

Post-COVID

A telephone optometry/ECLO low vision service has been running to assess patients that have been cancelled due to COVID restrictions and to address new referrals. This has been co-ordinated with colleagues at Southwark and Lambeth adult social services and third sector providers.

There are established protocols for referring identified social care needs of varying severity and low vision aids are posted as appropriate. A screening for possible depression is carried out (NICE CG90) and onward referral to the GP is made if there are concerns.

After telephone assessment, patients are prioritised for face to face appointments with the optometrists and ECLO at the main hospital site.

The COVID situation has provided the opportunity to review our service model and introduce changes to the way we work:

- use of telephone consultations to help prioritise needs and gather information that reduces the time needed in face to face sessions.
- introduction of video consultations using the Attend Anywhere platform.
- adapting PPE to respond to different communication needs e.g. clear visors rather than masks for hearing impaired/patients who lip read.
- use of online British Sign Language interpretation service where possible.
- introducing a visual acuity triggered large print (patients choose preferred font size) communication option for patients which occurs at first contact in the clinics.
- move to using Open Eyes Electronic Medical Record for all low vision records and uploading previous records.

Definitions

(Adapted from the Low Vision Services Consensus Group -1999).

A person with low vision is one who has an impairment of visual function for whom full remediation is not possible by conventional spectacles, contact lenses or medical intervention and which causes restriction in that person's everyday life.

Such a person's level of functioning may be improved by providing low vision services including the use of low vision aids, environmental modification and/or training techniques. This definition includes but is not limited to those who are registered as sight impaired or severely sight impaired.

A low vision service is a rehabilitative or habilitative process, which provides a range of services for people with low vision to enable them to make use of their eyesight to achieve maximum potential.

This is not just a technical process. The services should include:

- planning the rehabilitative process, setting goals and support in understanding the limitations involved.
- addressing psychological and emotional needs.
- providing information and advice.
- assessing the person's visual function and providing aids and training.
- facilitating modification to the home, school and work environments.

The support needs to extend to the needs of carers, especially the family.

A low vision aid is any piece of equipment used by people with low vision to enhance their vision.

Such aids may be:

- optical including hand and stand magnifiers, illuminated magnifiers, telescopic lenses for both distance and near, and spectacle mounted magnifiers
- electronic such as closed-circuit television systems (CCTV's), specialised computer adaptation, mobile phone and tablet applications
- non-optical such as lighting, typoscopes and large felt tip pens.

Low vision training is any individually tailored tuition in the use of vision or low vision aids.

Such training may include:

- training in the use of vision such as using discernible visual landmarks for orientation or adopting different eye movement techniques for locating objects or reading;
- training in the use of low vision aids such as how best to position and hold a hand magnifier, or use a writing frame and felt tip pen when writing
- training in the adaptation of the environment such as finding the best lighting or using colour contrast to help navigation.

Eye Clinic Liaison Officers (ECLOs) work closely with medical and nursing staff in the eye clinic, and the sensory team in social services. They provide information, advice and guidance to both newly diagnosed and existing eye clinic patients. ECLOs offer the practical and emotional support needed for patients to understand their diagnosis, deal with the emotional impact of sight loss and maintain their independence. An important function is to signpost to other services in their area. ECLOs also support consultants in the completion of Certificates of Vision Impairment for eligible patients.

Rehabilitation Officer for Visually Impaired (ROVIs) are trained and qualified to work with people who have significant sight impairment to help develop strategies to maintain independent living. ROVIs can help people learn new skills to support their independence e.g. using a mobility aid such as a white cane, using communication tools such as Braille and specialised computer software, using magnification, correct lighting and colour contrast aids.