# Eye Care Liaison Officer (ECLO) service UK Evaluation Report

## April 2022 – March 2023

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## Background

Our Eye Care Liaison Officers (ECLOs) provide emotional and practical support at the point of need for all patients living with an eye condition and their family, friends and carers. They have a wealth of knowledge on eye conditions and local and national support services.

ECLOs act as an important bridge between health care and social services supporting patients to navigate the complex range of services available across the eye care support pathway.

As part of the patient’s eye care journey additional support is provided through a six week review following an ECLO intervention. This offers the patient the opportunity to talk through other support needs as they work towards their next step in independently living with sight loss.

**“ECLOs provide a vital service - we could not manage without them. They provide vital emotional support to patients and families, are easily contacted by patients and have a wide range of knowledge of community support/ services/ benefits and employment support that ophthalmologists do not have.”** Ophthalmologist, Newcastle

## ECLO interactions

Between 1 April 2022 and 31 March 2023 there were **122 RNIB ECLOs** supporting patients across **130 Eye Departments** as well as reaching out to **100 community hospital sites and 24 private clinics.**

The number of ECLOs includes **17 RNIB Locum ECLOs** who ensure that the service provision is delivered without interruption by sickness absence or annual leave commitments.

### Those affected by sight loss

Monitoring data revealed that:

* **74,624** individuals affected by sight loss were supported by an RNIB ECLO
* This figure includes **13,603** relatives and carers.

### Additional reach

* **19,246**  professionals received quick advice or information from an ECLO to support them in their role or to assist patients in their care.

## Summary of the findings

Patients are provided with timely, helpful, and clear information about a wide range of topics, including support services, eye health and benefits entitlements through the ECLO.

**96 per cent** of clinic staffagreed that the ECLO service improves patient experience through the provision of timely, accessible, person-centred information and support.

**76 per cent** of clinic staff agreed that the ECLO Service reduces the amount of time they would otherwise need to spend with patients.

Without an ECLO, **70 per cent of patients** would have contacted the hospital, optician, or GP for support, thus putting additional pressure on these services.

**89 per cent** of patients reported either being very well informed, or well informed about support available after visiting an ECLO.

When discussed, **83 per cent** of patients said they had a better understanding of their eye condition, and **81 per cent** said that they were more aware of how to properly care for and treat their eye condition after speaking to an ECLO.

**92 per cent** of eye clinicians surveyed agreed or strongly agreed that the ECLO service is supportive of the CVI process in the clinic.

**33 per cent** of certifications were initiated by the ECLO. Those patients may not have otherwise accessed statutory support that makes such a difference in enabling individuals to live independent and fulfilling lives.

ECLOs play an important role in signposting, referring, and facilitating access to appropriate services that meet a patient’s needs.

**74 per cent** of patients were put in touch with or informed of services outside of the hospital.

The ECLO provides a vital emotional support role and helps patients to start to come to terms with their situation, whether that be a new diagnosis or deterioration of an existing eye condition.

**93** **per cent** of clinicians confirmed that the ECLO service provides additional emotional support for patients that clinical staff do not have the capacity to offer.

Monitoring data shows that during **46 per cent** of patient enquiries (**17404**), emotional support was provided by the ECLO.

**89 per cent of patients** reported that they feel more confident to ask for help when they need it as a result of seeing an ECLO.

**“Before I met my ECLO I felt as though I was in a maze, and I actually sought help from my ECLO myself. As I was leaving the hospital, I spoke to a young nurse I said I need more help and support from someone, and she said I know what I am going to do for you I will put you in contact with an ECLO. My ECLO gave me lots of help and support.”** ECLO patient

## Methodology

The findings are a summary of national survey responses and data for England, Wales, Scotland and Northern Ireland collected between

**1 April 2022 and 31 March 2023.**

Monitoring data was collected from ECLO patient enquiries recorded on the RNIB database during this time.

**2260** **Patient Experience Questionnaires** (PEQs)were undertaken with patients six weeks after their interaction with an ECLO. The survey included 15 quantitative questions and three open-ended qualitative questions which have yielded a wealth of information and insight.

Additionally, **804 Clinician Experience Questionnaires** (CEQs) have been completed by hospital clinic staff to share their understanding and experience of the ECLO service. The survey included 14 quantitative questions and four open-ended qualitative questions.

## Outcomes of the ECLO service

### Fulfilling a unique role in the eye clinic

#### Supporting patient pathways

ECLOs provide a link between the hospital and the patient, helping to manage patient expectations, enquiring about appointments and when needed, advocating on behalf of the patient.

**“The ECLO service is provided in a timely/caring and productive way of which is beneficial for the patients care, diagnosis/treatment pathway and providing the help for independence and compassionate support.”**

Ophthalmic Technician, Wales

**96 per cent** of clinic staffagreed that the ECLO service improves patient experience through the provision of timely, accessible, person-centred information and support.

Comments in the PEQ also demonstrate how the ECLO can be an important link between the patient and clinical services.

**“The ECLO gave me the support I needed. The ECLO came to my appointment with me and it was reassuring to have the ECLO there. The ECLO was very supportive.”**
ECLO patient

**“He advised me how to get in touch with different people. I was discharged by the hospital, and he advised me to get back in touch with the GP to get back on to the hospital list.”**

ECLO patient

The ECLO service could help to increase capacity for the clinic teams.

**76 per cent** of clinic staff agreed that the ECLO Service reduces the amount of time they would otherwise need to spend with patients.

**“The ECLO is an absolutely vital part of our patient pathway now. She releases time for the clinical staff to work more efficiently at what they are best at.”** Ophthalmologist, Scotland

**“The ECLO provides valuable support to the eye department leaving consultants to help more patients and refer on to ECLO when required.”** Nurse, Northern Ireland

#### Optimising use of health and social care provision

ECLOs help reduce pressure on medical services, as well as potentially relieving the burden on family and carers of patients.

When asked where patients would have sought support if they had not had contact with the ECLO:

* **32 per cent** said they would have contacted the hospital,
* **25 per cent** would have asked an optician,
* **13 per cent** said they would have sought support from their GP.
* A further **9 per cent** of respondents said they would not have found the support they needed.

**“I have referred many patients to our ECLO. She has enabled me to see more patients in the clinic by giving support to patients I had little time for. It has provided the department with a much more rounded service as patients get support from first appointment through to discharge.”**

Nurse, North Devon

#### Support for relatives and carers as well as patients

Without ECLO contact, many patients, their relatives, and carers would be missing out on help and support that could greatly improve their confidence, independence, and wellbeing.

**87 per cent** of clinicians responding to the CEQ agreed that support provided by the ECLO to family and carers increases the capacity of the clinic team.

**“Due to my brothers learning disability he gets in to such a state and panic - knowing that [ECLO] was there and she had a really good rapport and helped him know what it’s all about. She calmed him and reassured him and as a family member it’s really helpful to know information and support is there.”** Family member of ECLO patient

**“Just knowledge and there is hope and support available, without the like of people like my ECLO we would struggle. For me as a family with my daughter it has been very helpful.”** Family member of ECLO patient

### Improving knowledge and understanding

ECLO’s provide patients with timely, helpful and clear information about a wide range of topics, including support services, eye health and benefits entitlements.

**“It gave me a level of information that hasn't been available before which gave me confidence and knowledge to know where to go to seek the support. The 45 minutes spent with the ECLO was the most important or impactful 45 minutes I've had so far on my sight loss journey."** ECLO patient

Prior to having contact with the ECLO, only **23 per cent** of respondents reported either being very well informed, or well informed, about available support; this increased by 64 percentage points to **89 per cent** after visiting an ECLO.

**96 per cent** of clinic staff responded to say that they feel confident that ECLOs have knowledge of local and national support available for patients and their carers.

### Eye condition, treatment, and self-care

ECLOs are central to the support and wellbeing of patients in eye clinics. They offer time and space for patients to talk through their eye condition, treatment plans, and to understand their medication.

The ECLO provides patients with an opportunity to talk through any concerns regarding their diagnosis and treatment.

**95 per cent** of clinicians recognise that ECLOs provide this support.

**“Our ECLO is amazing and plays a key role within our eye clinic. She is extremely knowledgeable with regards to ophthalmic conditions, sight loss and sight loss support. Our ECLO gives the time our patients deserve to discuss sensitive issues. Medical and nursing staff unfortunately do not have the time for this without reducing the clinics.”** Nurse, Lincoln

Monitoring data shows that there were:

**11,814** instances of information given to patients about their eye condition or diagnosis, and a further **5582** instances of information provided to patients on eye treatment or compliance.

After visiting an ECLO, patients have a better understanding of their eye condition and how to care for and treat their eyes:

* When discussed, **83 per cent** of patients said they had a better understanding of the condition affecting their sight and what this means for them,
* and **81 per cent** said that they were more aware of how to properly care for and treat their eye condition.

**“At the beginning I wasn't sure but after meeting the ECLO she made it so easy and welcoming that she helped me understand the condition and what it means for me to come to terms with my condition - if I need any help or support I could go to her.”**

ECLO patient

The ECLO also makes referrals to specific sight condition groups such as Macular Groups, to enable patients to receive condition-specific support, as well as peer support and reassurance.

#### Increasing awareness of benefits, concessions and entitlements

ECLOs share information with patients about the benefits they may be entitled to and how they can access discounts and concessions.

They connect patients to services who can support with applying for these benefits if needed.

**“It’s guided us to applying for attendance allowance, it’s nice knowing they are there if we need advice. We have been made to feel we aren’t alone, as we would be drowning without the information he gave us.”** ECLO patient

**“The biggest difference for me is getting to know that there is help available and RNIB have helped me apply for all the benefits that I may be entitled to.”** ECLO patient

#### Increasing awareness of aids and equipment

ECLOs provide patients with information and advice about specialist aids and equipment which can assist with everyday tasks.

For many patients, it was the first time they had been told about what aids and devices might be best suited to the challenges and problems they were experiencing.

ECLO’s signpost patients to services that can provide specialist aids, for example low vision clinics and social services.

**6061** ECLO patients were referred into Low Vision Services.

Several comments in the PEQ show how access to such items can positively make a difference to patients’ daily lives and their experience of different everyday activities.

**“Providing lighting in the house has been a life saver otherwise my mother would not have coped living on her own with sight problems.”** Family member of ECLO patient

**“I have a gadget that tells me when my cup is at a safe level, so I don’t overpour or burn myself and that has made a real difference.”** ECLO patient

### Supporting an efficient CVI process

The ECLO is well placed to promote the benefits of certification and registration to both patients and clinicians. They act as the conduit within this process at an emotionally overwhelming time for patients, thereby reducing patient anxiety.

The ECLO also supports hospital staff with the completion and processing of certification documentation in a timely manner.

**92 per cent** of eye clinicians surveyed agreed or strongly agreed that the ECLO service is supportive of the CVI process in the clinic.

**“I don't know how we managed without our ECLO. She is an absolute lifeline for our macular, stroke and orthoptic patients providing practical and emotional support and ensures the CVIs are arranged without unnecessary delay to the benefit of patients.”** Orthoptist, North Devon

**“Our ECLO is fantastic and eased the workload from us around the CVI process and is a great asset to our eye department.”** Medical Secretary, Midlands

ECLOs supported **9500** **patients** to go through the process of certification. All of these were referred by the ECLO for support from the Sensory Team for a Rehabilitation Assessment.

Early intervention and support by the Sensory Rehabilitation teams can make a significant difference to the impact that a visual impairment has on a person’s life and can enable them to maintain their independence.

They help individuals to regain lost skills or learn new skills to continue with everyday tasks, from how to move around with greater safety and more confidence, to cooking.

**33 per cent** of certifications were initiated by the ECLO. Those patients may not have otherwise accessed statutory support that makes such a difference in enabling individuals to live independent and fulfilling lives.

**“[The ECLO] has been particularly supportive of patients who would need to be registered as CVI impaired but are sometimes missed.”** Advanced Practitioner, London

**“I feel I can go back to the ECLO anytime for help and I haven't asked for help as such. It didn't occur to me to ask for help. The help happened when I was registered as partially sighted.”**

ECLO Patient

**“It has made some things easier, being on the blind register, what we can access, it has made a big difference. Extra access to other services, all of the support that has made a difference.”** ECLO Patient

### Connecting to social care & community support

ECLOs play an important role in signposting, referring, and facilitating access to appropriate services that meet a patient’s needs. They provide a vital bridge between clinical services within the hospital environment and services within the community.

As such, ECLOs can provide a gateway for patients to access further support, assistance, aids, and equipment that enhance their independence, confidence and quality of life.

**“If I hadn't been in touch with my ECLO, I wouldn't have known where to ask for help. I can't speak highly enough of her.”** ECLO patient

As a result of the information and support provided by the ECLO/ RNIB

**74 per cent** of patients agreed that they have been put in touch with the services they need or want.

**“I think an awareness of leisure service. Things like she put me in touch with a rifle club that does air rifle shooting for the sight impaired. She also put me in touch with East Anglian Sailing Trust which is a group that take sight impaired people on boats. From a more practical point of view, she gave me useful information such as getting a blue badge, so she gave me help with benefits for blind people.”** ECLO patient

Staff in the eye clinic similarly recognise the value of the ECLO in connecting patients to social care and community support.

**93 per cent** of those surveyed feel confident that when they refer patients to an ECLO, they will get the appropriate support.

**“Since having an ECLO I feel patients are given a lot more support from social to practical and it is a very effective service.”** Ophthalmic Technician, Northwest

**“The ECLO service is hugely important and I’m using the service more and more as I realise the breadth of benefits and services they can provide.”** Ophthalmologist, London

### Falls Prevention activity, & liaison with Falls Teams

ECLOs provide vital information to help patients reduce the risk of falls.

* Recognition of a patients risk of fallingcould prompt **35 per cent** of clinicians to make a referral to the ECLO.
* ECLOs delivered **1,319 specific falls prevention** information and guidance interventions.

As well as referring patients on to fall teams where appropriate, ECLOs refer patients for mobility and independent living support through rehabilitation teams, which can further reduce the risks of falls.

### Protecting and improving emotional wellbeing & resilience

The ECLO provides a vital emotional support role and helps patients to start to come to terms with their situation, whether that be a new diagnosis or deterioration of an existing eye condition.

ECLO’s create a safe space in which patients can talk openly about their thoughts and feelings, enabling them to share any concerns or worries they may be experiencing.

Patients who require professional counselling are referred on to receive more specialist support.

Monitoring data shows that during **46 per cent** of patient enquiries (**17404**), emotional support was provided by the ECLO.

The PEQ results demonstrate the impact of ECLO support on a patient’s wellbeing.

* **89 per cent** of patients reported that they feel more confident to ask for help when they need it,
* **73 per cent** felt more able to manage the impact of the condition affecting their sight and,
* **71 per cent** of patients feel more positive about the future.

Comments in the PEQ indicate that contact with an ECLO is often a validating experience for patients in that they feel listened to, supported and understood by someone.

**“I was given the confidence to talk about my condition after being in a slight state of denial.”** ECLO patient

**“I think it lifts what feels like a shock, a curtain, it has lifted it ... if I get stuck, I know there is someone who will help. You are not alone, there is no need to be alone.”** ECLO patient

**“The biggest difference is having someone we can speak to who knows what we are talking about it encourages us and supports us, so we know we aren't alone. We are very grateful he is there. He has been very helpful.”** ECLO patient

The CEQ findings demonstrate that the ECLO service provides additional emotional support for patients that clinicians do not have the capacity to offer; **93** **per cent** of clinicians confirmed this through the survey.

The findings of the CEQ tells us that:

* **64 per cent** of eye clinicians would refer patients to the ECLO service because they require emotional support, and
* **49 per cent** because the patient was at risk of social isolation.

**“Patients always seem very pleased to have any help from her and really like her. It is really reassuring to know there is someone to take over with all the extra help and counselling when our time is very limited as clinicians.”** Orthoptist, Lincoln

**“I think the emotional support is key and helping patients navigate what help is available to them which as a health care provider I have no clue about.”** Ophthalmologist, Bolton

#### Patients feel reassured

Many patients described the feeling of reassurance they experienced after talking to an ECLO. It helped them to feel less alone and comforted that there is support available for them should they need it.

Patients reported feeling especially reassured to know that the ECLO service itself is available as a point of contact for them and a future source of support if required.

**“I just feel that I accept the problem and get on with life ... aware of what help there is, and someone I can contact if I need to.”** ECLO patient

**“I got encouraged that what I'm going through isn't the end of the world and you can live a normal life.”** ECLO patient

**“I am reassured for the future, and I have access to so many facilities. This has taken away some of my anxiety of not knowing where to turn.”** ECLO patient

#### Patients feel less alone

A number of patients commented that, through contact with an ECLO, they felt less alone because it helped them to realise that there are other people in a similar situation to them.

**“Prior to that I was a bit isolated. Still very early stages and a lot going on. I don’t feel on my own with it all.”** ECLO patient

**“I was very isolated, and I felt that there was no help until [ECLO] came along and pointed me in the right direction and I feel lots better.”** ECLO patient

### Eye care support pathway

The ECLO service supports the patients eye care journey by providing a point of contact for patients both during treatment and following discharge. This is recognised by **94** **per cent** of clinic staff.

#### Patient Support Review

To ensure that patients have access to support at the time when they need it, we provide the option of a Patient Support Review Call. Patients are offered a review call from RNIB approximately 6 weeks after the ECLO has completed their support.

This ensures that any referrals the ECLO made delivered the expected outcomes for the patient. They will also identify if the patient has any additional support needs as they work towards their next step in living with sight loss. Furthermore, this releases ECLO capacity to support more patients.

**5677 ECLO patients** have been referred for a patient support review call.

Although this represents a small percentage of ECLO patients, the referrals into this service are increasing.

In addition to this, we have also found that **144 patients** have been referred back to an ECLO to receive further support after completing the PEQ.

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