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

## April 2020 – March 2021

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## Background

Eye Clinic Liaison Officers (ECLOs) are situated in eye clinics to provide emotional and practical support at the point of need for all patients living with an eye condition and their family, friends and carers. ECLOs are knowledgeable about eye conditions and local and national support services. They offer dedicated individual care and act as an important bridge between health care and social services. ECLOs are a crucial part of RNIB’s Sight Loss Advice Service.

## ECLO interactions

Between 1 April 2020 and 31 March 2021 there were **94 RNIB ECLOs** supporting patients across **89 Eye Departments.** This includes **13 RNIB Locum ECLOs** who ensure that the service provision is continuous.

### Those affected by sight loss

Monitoring data revealed that:

* **44,895** patient enquiries were supported by an RNIB ECLO.
* **53 per cent** of ECLO patients are aged 75 years or over.
* **21** **per cent** of ECLO patients are recorded as having co-morbidities
* ECLOs supported a further **11,679** relatives and carers during this time.
* **63,095** total instances of information provided
* Despite many services being closed, or changed due to the pandemic during the year, ECLOs were able to make **20561** referrals onto further support for patients.

### Additional reach

* **9,000** 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.

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

When discussed, **88 per cent** of patients said they had a better understanding of their eye condition after speaking to an ECLO, and **77 per cent** of clinicians agree.

**32 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.

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

**92 per cent** of clinicians surveyed agreed or strongly agreed that patients receive additional support from a range of service providers through contact with the ECLO.

**77 per cent** of patients would not have accessed relevant support outside the hospital without the ECLO.

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.

**74 per cent** of patients reported that their emotional wellbeing had increased as a result of seeing an ECLO.

**94** **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.

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

**95 per cent** of clinicians strongly agreed or agreed that the ECLO service fills a gap in support which would otherwise not be offered.

**82 per cent** of clinicians strongly agreed or agreed that the efficient running of the eye clinic is enhanced by the ECLO.

**“We do not always have the time or knowledge to give the emotional support or answer all the patient's questions. We can discharge knowing ECLO is a contact to tie up any ongoing issues/ questions. Knowing we have their input gives us confidence that all our patients' needs are met.”**

Orthoptist, Scotland

## Methodology

The findings are a summary of national survey responses and data for England, Wales, Scotland and Northern Ireland collected between 1 April 2020 and 31 March 2021.

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

1003 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,253 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.

**95 per cent** of clinicians strongly agreed or agreed that the ECLO service fills a gap in support which would otherwise not be offered.

**95 per cent** agreed that it improves overall patient experience.

**96 per cent** of clinicians feel reassured knowing they can refer patients on to the ECLO when needed.

**82 per cent** of clinicians strongly agreed or agreed that the efficient running of the eye clinic is enhanced by the ECLO.

**“It allows for a holistic joined up approach to patient care, not only medically but emotionally and practically to suit the patient’s lifestyle.”** Optometrist, North East England

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

**“I think helping me get an appointment at the hospital was a big help and I appreciated them arranging that for me.”** ECLO patient

#### 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:

* **29 per cent** said they would have contacted the hospital,
* **18 per cent** would have asked an optician,
* **14 per cent** said they would have sought support from their GP.
* A further **19 per cent** of respondents said they would not have found the support they needed.

**“I think having an ECLO based in the clinic is a great advantage to the clinic as we are able to get support and different information needed for patients with a wide variety of needs in a busy clinic, when the nursing staff are pushed and busy, the patient is able to get help and advice from them”** Eye Clinic Staff Member

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.

**“It's been a life changing support because as a carer for my Father, I'm not always informed about what is out there for him, so I found that a great help. I thought it was a very valuable service for both of us and has really helped us in more than one way.”** 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.

**“If I hadn't have had contact with her, I wouldn't have known anything about any of the information or services that are out there that have been able to help me.”** ECLO patient

#### Increasing awareness of support and services

Informing patients about the support and services that are available to help them at both a national and local level, ECLOs help to increase patients’ understanding and awareness of support they may require.

Through an initial support needs assessment, ECLO’s provide impartial information and guidance to patients, their families and carers.

Prior to having contact with the ECLO, only **30 per cent** of respondents reported either being very well informed, or well informed, about available support; this increased by 64 percentage points to **94 per cent** after visiting an ECLO.

**“ECLO knowing the information on signposting to additional services and what is available is invaluable”**

Clinical Psychologist, Midlands

Monitoring data shows that information, advice and guidance was most frequently provided around the following topics:

|  |  |
| --- | --- |
| **Information Provided** | **Instances of Information Provided** |
| Sensory services(Incl. Local society, RNIB, Sensory Rehab, other National Charities, etc.) | 22094  |
| Eye condition or treatment | 11876 |
| Equipment or technology(Supporting reading, independent living, employment, etc.) |  7487  |
| Welfare rights or concessions | 4443 |
| Non-sensory service (Incl. adult social care) | 3661 |
| Independent living advice (Incl. DVLA/ driving, Fall prevention advice, housing support, etc.)  | 2278 |
| Advice re. Primary Care support/ Secondary Care support/ Low Vision | 1850 |
| Peer support | 1433 |
| Employment | 775 |
| Carer advice | 764 |
| Children’s services | 627 |

#### 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 can articulate conditions in a way that aids patient understanding and reinforce messages regarding treatment or self-care made by clinicians.

The findings of the CEQ report tell us that:

* **48 per cent** of clinicians would make a referral to the ECLO to provide additional information on eye condition or treatment.
* **27 per cent** of clinicians would make a referral as a result of concerns regarding treatment compliance.

Monitoring data shows that there were:

**10,443** instances of information given to patients about their eye condition or diagnosis, and a further **5050** 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, **88 per cent** of patients said they had a better understanding of their eye condition after speaking to an ECLO,
* and **74 per cent** of patients said they were more aware of how to properly care for and treat their eye condition.

This is reinforced by the findings of the CEQ Report which tells us that:

* **77 per cent** of clinicians strongly agree, or agree that patients gain a further understanding of their eye condition after speaking with the ECLO,
* and **70 per cent** recognise that patients gain a better understanding of the importance of adhering to treatment.

**“Discussions with patients experiencing acute sight loss is of course a time-consuming process. These patients are often vulnerable, traumatised emotionally, and often present to the emergency eye service which often cannot cater optimally to these patients' needs. Knowing that there is an individual who is trained and experienced in dealing with these circumstances, and all their implications (emotional, social, employment etc.) is invaluable.”**

Ophthalmologist, East Midlands

Patient feedback suggests that the provision of information about eye conditions in away that is clear, accessible and easy to understand is particularly appreciated.

**“She explained my condition to me more clearly than anyone else had done before, which was really helpful as I understood what she was saying to me.”** ECLO patient

Some patients explained how the ECLO had helped them to understand the treatment they were receiving, or due to receive, and to feel better informed about this.

**“I was put at ease as I didn't know what would happen after having the injections in my eyes, it really helped me mentally and gave me the reassurance that I needed at the time.”** 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.

Prior to speaking with the ECLO some patients were unaware of their eligibility for various benefits and concessions or did not know such benefits existed.

**“She's really helped us with gaining the attendance allowance as we weren't aware of it before we spoke to her. Lots of information and other benefits have been given to us from her as well, which have made a great difference as well.”** ECLO patient

#### Increasing awareness of aids and equipment

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

Several patients reported that having advice and information of this nature was especially helpful. 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.

**“She gave me general tips that I didn't know about which has been really helpful. The fact that she told me about the different aids that I can purchase which have also been very good as I wasn't aware of them before she informed me about it.”** ECLO patient

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

**4132** 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.

**“We've applied for a blue badge, had the local council out to see what they could do for her and been given advice about different lighting for her which has been really helpful. We are waiting for the talking books as she now can't read, which will make her feel like she has more independence which will be good.”** Family member of 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.

**“They are the experts in managing the CVI registration process and supporting and advising patients through this”** Ophthalmologist, West Midlands

ECLOs supported **4892** **patients** going through the process of certification. All of these were referred by the ECLO for support from the Sensory Team for a Rehabilitation Assessment.

**32 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.

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

**“It saves time not having to complete entire CVI's (which are time consuming, large documents). It is also important that support etc. can be discussed without disrupting clinical flows.”** Ophthalmologist, North East England

The findings in the PEQ indicate that for some patients the support from the ECLO with the CVI processing and onward registration made the biggest difference to them.

**“I needed their support to register as I didn't know how to do it which I thought was very good and kind of them. I wouldn't have been able to do it without the help from that service.”** ECLO patient

Some patients also highlighted how registration had enabled them to access benefits they had not previously been receiving.

**“I've been able to claim the appropriate benefits that I'm entitled to now that I'm registered partially sight impaired.”** 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.

#### Improving access to further support

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.

* **86 per cent** of patients were put in touch with or informed of services outside of the hospital
* **80 per cent** of patients had either used or intended to use the services about/to which ECLO had informed or referred them.
* **77 per cent** of patients would not have accessed relevant support outside the hospital without the ECLO.

Staff in the eye clinic similarly recognise the value of the ECLO in this area of work and **92 per cent** of those surveyed agreed or strongly agreed that “Patients receive additional support from a range of service providers through contact with the ECLO”

**“ECLO’s have access to services that us as medical professionals don’t, these all enhance patient care and their lives - keeping independence and quality of life.”**

Nurse, West Midlands

**17,710 direct referrals** **were made to the four leading support services:**

* Sensory partners, including local sight loss charities
* RNIB services
* Low vision clinics
* Independent living and local non-sensory partners

Comments indicate that ECLOs often connect people to services and support they were unaware existed, or which they may not have accessed without the assistance of an ECLO. For many patients, being supported to access other services (via the provision of information, signposting or direct referral) is one of the activities that made the biggest difference to them personally.

**“They've put us in touch with other services which have been a really big help too and we're managing a lot better, as we've got so much support. We've had support with lots of things, even filling in forms which has been a big help.”** ECLO patient

#### Improving access to practical and emotional support

Patients gain access to a wide range of practical and emotional support through links with other services. This can bring significant benefits, including being able to connect with other people with sight loss through different group-based activities, access to equipment, access to a ‘Blue badge’ and access to services like RNIB Talking Books.

**“Being in contact with the service about other groups, I felt like it was really good to speak to other people who also have sight conditions, because I felt like they understood me and what I was going through.”** ECLO patient

**“She introduced us to Talking Books and Newspapers, things that make it easier. You feel like there is hope and life is less worrying. She made us aware of the services that were available.”** ECLO patient

### 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.

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.

Monitoring data shows that during **43 per cent** of patient enquiries (**19364**), emotional support was provided by the ECLO.

**74 per cent** of patients reported that their emotional wellbeing had increased as a result of seeing an ECLO.

**“I felt like she really understood what I needed and made me feel stronger than I was before I spoke to her. It was just what I needed, and I thought the service I got from her was wonderful.”** ECLO patient

**“My outlook has improved since having contact with them.”**

**“There is a light at the end of the tunnel now.”**

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

The findings of the CEQ tells us that:

* **83 per cent** of eye clinicians would refer patients to the ECLO service because they were emotionally distressed,
* **72 per cent** because the patient was at risk of social isolation, and
* **68 per cent** because the patient was at risk of anxiety and/ or depression.

The CEQ findings also demonstrate that the ECLO service provides additional emotional support for patients that clinicians do not have the capacity to offer; **94** **per cent** of clinicians confirmed this through the survey.

**“They are available for extra emotional support for example when a patient has been given a poor prognosis and get very upset. The ECLO is on hand to give the extra time needed at that particular time to be there for the patient and family members if needed.”**

Nurse, Northern Ireland

#### 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.

**“It's good to know that the service is there, if and when I have any questions or need help with anything, I know that I can contact the service and someone will be able to help and support me with it.”** ECLO patient

Having a point of contact during the pandemic offered reassurance to some patients.

**“I have his phone number if I need to speak to him about anything which is good as I haven't been out during lockdown.”** ECLO patient

#### Patients feel less alone

A small 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.

**“It gives me more confidence that I know there are other people with sight conditions as well it's not just me.”**

ECLO patient

#### Patients are empowered to seek support when they need it

For some patients, the support they received from the ECLO led to an increased feeling of confidence, empowering them to take action to seek further support. They also felt more able to ask for help should they need it.

**“I know what is available to help me with my eye condition more so now than I did before, the services are more approachable now and I've got more confidence in contacting them now than I did before I spoke to them about things.”** ECLO patient

## Response during Coronavirus Pandemic

This year has been a unique year for everyone. Throughout this year the ECLO service has continued to support patients across the UK as they come to terms with sight loss.

The ECLO service has had to adapt. We tailored the service and support to meet the specific patient needs identified during the pandemic. For instance, many people required additional emotional support, others required reassurance about appointments that had been cancelled, or around the safety measures in place for attending urgent eyecare appointments and some needed to know of the support available to secure safe transport to eye clinics.

#### ECLO contact during the pandemic

In March 2020, and in response to Government guidelines to tackle the coronavirus emergency, RNIB put in place rapid arrangements for ECLOs to work remotely. This enabled the ECLO service to continue to provide support for patients during the pandemic.

A few patients specifically highlighted that having contact with the ECLO during the pandemic made a difference for them.

**“I haven't had any support through the lockdown with my eyes over the last year, so when I had contact with them, I found the support was very good and I was very grateful.”** ECLO patient

**“The fact that she was there during lock down, contacted me and has provided me with lots of help and information.”** ECLO patient

#### The impact of the pandemic on emotional wellbeing

In response to being asked whether their emotional wellbeing had improved because of contact with an ECLO, there were patients who commented how their well-being had been affected by the pandemic.

**“I'm still coming to terms with things and Covid hasn't helped.”** ECLO patient

#### Wellbeing Check in Calls

RNIB ECLOs proactively contacted all patients who had been instructed to ‘shield’, were living alone, or no longer had a regular relative or carer providing support or were self-isolating with underlying health conditions. They had a conversation to make sure the patients were managing to get essential shopping and medication or if they had any concerns about their eye condition that they knew where to get help with that if needed.

#### Additional support for patients during the pandemic

The RNIB developed a new Stay in Touch service (SiT) which was an appointment based weekly or fortnightly check in with an ECLO for visually impaired individuals negatively impacted by the restrictions in place during the Coronavirus pandemic.

This provided long-term wellbeing support and reassurance to patients who might otherwise have contacted the clinic at a time when they were experiencing staffing issues.

**359 individuals** were referred to the Stay in Touch service between March 2020 and June 2020.

The national evaluation of the Stay in Touch calls suggests that the motivation for patients to participate was centred around the need to feel more connected, less isolated and more supported. Patients reported that regular contact with an ECLO brought them “back to life” and that they would “be lost” without the support. As a result of the support they received from the Stay in Touch service patients reported feeling closer to other people.

#### Delays to services and support due to the pandemic

Although ECLOs continued to link patients with support throughout the pandemic, many comments highlight delays patients experienced accessing services outside the hospital during this time.

**“I feel that I'm well informed in regards to the services that are out there for me but because of the lockdown they've had to put them on hold for the time being.”** ECLO patient

**“Due to Covid we haven't been able to have people come to the house to see if there's anything that they can do to help her further.”** Family member of ECLO patient

#### Partner service provision during the pandemic

ECLOs remained in touch with partner organisations throughout the pandemic to confirm whether services were available and any waiting times. This enabled them to ensure that patients were kept informed.

**“Being provided access to other services and being made aware that those services are available to help and support me with my sight condition. I feel that they've done very well in terms of the support that's been provided in the current circumstances.”** ECLO patient

#### Patients experience of adjustments to the ECLO service

Patients acknowledged that the ECLO service had to be altered due to the pandemic and reflected on how this impacted the support they received.

**“I spoke to her after my appointment at the hospital. I found her very supportive when I spoke to her, but I didn't spend a lot of time with her due to Covid and regulations.”** ECLO patient

**“Due to Covid the ECLO hasn't given out any paperwork but she said that she would be back in touch after Covid.”** ECLO patient

Many patients who had indirect contact with the ECLO, i.e. telephone support, would have preferred face to face contact but were appreciative that restrictions meant this was not possible.

**“I would like to have met her face-to-face as I was in the same hospital as she was, even with Covid19 I'm sure we could've social distanced. I would've liked to have been given more information from her would've been better.”** ECLO patient

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