

Eye Clinic Liaison Officer (ECLO) service UK Evaluation Report

R N I B

See differently



April 2019 – March 2020



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Background

A crucial part of our Sight Loss Advice Service, 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 have a wealth of knowledge 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.

Evaluation data from the Patient Experience

Questionnaire (PEQ) shows that ECLOs are central to the support and wellbeing of patients in eye clinics. In addition, they provide tailored support to health care professionals in the form of training and advice.

This document summarises key findings from the RNIB PEQ as well as Eye Clinic Support Service (ECSS) monitoring data collected between April 2019 and March 2020 (See Appendix 1 for further information about the methodology).

ECLO interactions

Monitoring data revealed that, between 1 April 2019 and 31 March 2020:

- **47,960** individual patients were supported by an ECLO.
- ECLOs supported a further **15,426** relatives and carers during this time.
- **13,037** professionals received quick advice or information from an ECLO. This included advice, information or support provided to clinical or social care staff to support them in their role or to support patients in their care.
- **1,311** professionals received awareness training from an ECLO.
- ECLOs delivered **256** events to raise awareness or provide support. This included presentations at medical professional meetings, visual awareness training for clinical staff and other, condition-specific events, which are attended by professionals, patients, carers or volunteers.
- ECLOs supported completion of a Certificate of Vision Impairment (CVI) for a quarter (**25 per cent**) of patients they saw; they provided information on CVIs to a further **9 per cent** of patients.

Summary of the findings

- Prior to having contact with the ECLO, only **28 per cent** of respondents were very well informed, or well informed, about support available to help them. After visiting an ECLO, this increased by **66 per cent** to **94 per cent**.
- ECLOs supported a Certificate of Vision Impairment (CVI) for a quarter (**25 per cent**) of patients, acting as the bridge between the hospital and the patient.
- ECLOs offered a link between health services and social care, connecting the two often separate areas:
 - **95 per cent** of respondents reported they had got all or most of the support needed from the ECLO **to help them live with sight loss**.
 - **85 per cent** of patients were put in touch with or informed of services outside of the hospital.
 - **58 per cent** of patients have contacted these services and a further **26 per cent** intend to.
 - **98 per cent** of those who had explored the external services found them to be helpful or very helpful.
 - **69 per cent** of patients say that they would not have found this information without support from the ECLO.
- **82 per cent** said they saw the ECLO at the right time. However, **14 per cent** of people said they saw the ECLO too late; **2 per cent** said they saw the ECLO too early.
- ECLOs were central to the support and wellbeing of patients in eye clinics:
 - **74 per cent** of respondents reported their emotional wellbeing had increased as a result of seeing an ECLO.
 - When discussed, **81 per cent** of patients said they had a better understanding of their eye condition after speaking to an ECLO.
 - When discussed, **55 per cent** of patients said they were more aware of how to properly care for and treat their eye condition after speaking to an ECLO.

95%

of patients reported that they felt they had got all or most of the support needed from the ECLO to help them live with sight loss.

87%

of patients are
over 55 years old.

55%

of patients are
over 75 years old.

45%

of patients
identified as
having a vision
impairment but
were not certified.

Patient demographics

- Most patients seen by an ECLO are over 55 (**87 per cent**) and over half (**55 per cent**) are aged 75 years and over.
- At the time of interaction with an ECLO, **45 per cent** of patients identified as having a vision impairment but were not certified. ECLOs provide support to patients at all stages of their sight loss journey, regardless of certification status.
- Most of those supported by ECLOs are people with sight loss (**83 per cent**), the remainder are friends, family and carers.
- The people supported by ECLOs are more likely to be female (**66 per cent**).

It is not surprising that **55 per cent** of the patients seen by an ECLO are aged 75 years and older. The prevalence of sight loss in the UK is projected to increase over the next decade, due to demographic ageing and rising rates of medical conditions linked to sight loss, such as diabetes and obesity.



Outcomes of the ECLO service

ECLOs increase awareness of support and services

ECLOs significantly impact people's awareness of support, leading to a better understanding of the local services that are available to them. Prior to having contact with the ECLO, only **28 per cent** of respondents reported either being very well informed, or well informed, about available support; this increased by **66 per cent** to **94 per cent** after visiting an ECLO.

Monitoring data revealed that the most frequent type of support for patients was the provision of information, advice and guidance:

- **56,810** instances of providing information, advice and guidance related to services promoting independent living. This includes those regarding falls prevention, employment and welfare rights.
- **16,591** instances of providing information, advice and guidance relating to partner sensory services. This includes local sight loss charities and children's habilitation services.

94%

of patients felt
well informed after
visiting an ECLO

Information, advice and guidance was most frequently provided around the following topics:

- Local support services such as social services, local sight loss charities and peer support groups
- Eye conditions and treatments
- Equipment such as visual aids and magnifiers
- Welfare benefits and concessions.

“She told us information that we didn’t know, informed us about other services and told us about benefits that we could be entitled to. Before we met her, we didn’t have any information about my partner’s eye condition, so we found it very useful when given lots of booklets and leaflets to look through.”

ECLO patients reported that they now know how to access the practical and emotional support they need.

69 per cent of patients who accessed the recommended support reported that they would not have found this without guidance from the ECLO.

“I didn’t know anything about the services or support that was out there that could help me until I spoke to her. I felt like meeting her was like a breath of fresh air and I am grateful.”

Many patients told us about the reassurance it gave them, to know that someone is there to answer any questions they have and inform them of local support systems inside and outside the hospital.

“It’s having the reassurance of having her number if, and when, we need to call her. She’s given us a number of services that we can use and people from other charities have been round to give him some equipment to help him with his day-to-day life – which I think she put in place – which has really helped him.”



ECLOs provide a single point of contact improving referral pathways

A gateway to local services

As well as being a source of information and advice, referring patients into support services outside of the hospital is a vital part of the ECLO role. This ensures patients are in touch with and able to reach the services they need.

- **85 per cent** of patients were put in touch with or informed of services outside of the hospital
- **58 per cent** have contacted these services (and a further **26 per cent** intended to)
- **98 per cent** of those who had explored the external services found them to be helpful or very helpful.

This year, **25 per cent** of ECLO patients were supported to complete their Certificate of Visual Impairment (CVI). The CVI is an important process which enables access to sensory support and other services.

Signposting and onward referrals

Many patients mentioned that, after their referral from the ECLO, they received support from social services, sensory teams or local low vision services. This enabled them to access new products and technology, increasing their quality of life.

Most frequent direct referrals

Over 20,000 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.

“She advised me about being registered which was good because then the Council came out, which helped me. I have been given TV glasses that bring things closer to me, and a Liquid Level Indicator, which has made a difference. My quality of life is much better. I wouldn’t have had a clue if it wasn’t for her and she has been so professional and kind towards me and has made a real difference.”

“I was struggling before I met her, I had no idea about anything that was available to help and support me. She put me in touch with the sensory team and they have been able to support me as well which has been really helpful.”

Developing a patient's support network

ECLOs also refer patients to external groups or services provided by their local sight loss charity or specific sight condition groups, such as Macular Society peer support groups.

Many patients described the difference these referrals have made to them and acknowledged the benefits they have gained from speaking to other people with a similar condition, who understand how they feel. Patients spoke of increased confidence as a result of developing their support network which has opened opportunities for peer support and advice sharing.

“She has given me a lot of confidence and hope that there is always going to be help for people like me with my condition. I no longer feel depressed or vulnerable anymore. I have attended a support group which has reassured me and showed me what there is to help me and who can support me with my sight loss.”

“It's knowing that the help is out there when I need it, she's put me in touch and informed me of different services and groups that are available to me. I now attend a weekly support group for people with eye conditions, which really has helped me. I have been given advice from the group and it's good that I can talk to people that understand.”

Support for children, young people and families

More specifically, parents of children or young people with a sight condition mentioned the benefits they have gained from being referred to organisations that could better support the care of their child.

Parents described how speaking to specialists provided the whole family with a unique understanding of their child's condition as well as tailored support for their individual situation.

"She has put me in contact with people that understand my daughter's eye condition, has explained her eye condition better and given me the support that no-one else has ever given me before, so it's been very emotional for us. She has put me in contact with the Guide Dogs Association and they have been a really big help as well. She also referred us to Great Ormond Street Hospital as well which has been really helpful. I feel like she has supported me a great deal and I feel very grateful for being introduced to her."

Supporting patient pathways

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

"He got me an appointment with my Consultant to see what they could do further for me and what other support I was entitled to which I found very good. It's comforting to know that he is there if, and when, I need him."

“She helped me get my certificate as I was unaware that I was entitled to have this. She explained everything to me in a way that I could understand it clearly, which was brilliant. I am having white stick training which is really helping me. I didn’t know any of this support was out there before I met and spoke to her.”

“She helped get my Mum registered severely sight impaired which has been a big help, she also told us about the attendance allowance that she was entitled to. Someone from the Council has been out to her home to show her different aids that she could use that she might find helpful. I thought she was brilliant and very helpful in all that she provided to us at the time we met her.”

Patients receive support at the right time

ECLOs support patients in-clinic with the certification process, instigating certification in some cases. Certification leads to a referral to the local authority, the outcome of which provides access to further support to maintain and enhance independence.

82%

of patients said they saw the ECLO at the right time

14%

of patients said they saw the ECLO too late

“I didn’t know that she was at the hospital and I would’ve liked to have met her sooner.”

The majority of patients (**82 per cent**) receive support from an ECLO when they need it.

Some patients (**14 per cent**) felt that they would have benefited from knowing about and accessing the service sooner. For example, when they first started having issues and attending the hospital.

Some patients also felt that hospital staff needed to be more aware of the ECLO service, so referrals could be made sooner.

"It should be something patients get referred to earlier. We knew nothing about it and could have been useful to know earlier."

"The hospital should introduce [the ECLO] to patients more clearly and do it more. I would have loved to have had this support earlier."

Follow-up contact after an initial meeting

A range of feedback was received from patients regarding follow-up contact with their ECLO. Patients who received a follow-up call appreciated the opportunity to discuss how they were getting on. Where a follow-up call was not made, some patients mentioned they would have liked this, including to check progress where onward referrals had been made by the ECLO.

"I would like a phone call about getting extra support and a bit more information about my sight condition. I feel like my eyes are getting worse and I am unsure what to do so if she could help with that I would be grateful."

RNIB is taking action to address patient feedback regarding ECLO follow-up calls.

Reducing pressure on the NHS

ECLOs help reduce pressure on medical services, as well as potentially avoiding extra stress on family and carers of patients. When asked where patients would have sought support if they had not had contact with the ECLO:

- **36 per cent** said they would have contacted the hospital and almost a quarter (**23 per cent**) said they would have sought support from their GP.
- In comparison, **19 per cent** said they would have turned to friends, family and carers and **18 per cent** would have asked an optician.
- A further **19 per cent** of respondents said they would not have found the support they needed.

“I didn’t know anything about the services or support that was out there that could help me until I spoke to her. I felt like meeting her was like a breath of fresh air and I am grateful.”



Certificate of Vision Impairment for people who are sight impaired (partially sighted) or severely sight impaired (blind) – Updated September 2018

Part 1: Certificate of Vision Impairment

Surname or family name		Burton
Given names (referred name)		Charlot
Home telephone number (include area code)		
Mobile telephone number (include area code)		
Email address		
Date of Birth (dd/mm/yyyy)	Sex (M/F)	
SHN number		

This person is severely sight impaired (partially sighted) or severely sight impaired (blind)

This person is sight impaired (partially sighted) or sight impaired (blind)

I consider that this person is severely sight impaired (partially sighted) or severely sight impaired (blind) this person is sight impaired (partially sighted) or sight impaired (blind)

Year/Refered/Not available - delete as appropriate

Has the patient seen an Eye Clinic Liaison Officer (ECLO)? Yes No

Signature: _____

Name (print): _____

Address: _____

Patients have an improved understanding of their sight condition and treatment

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.

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

- When discussed, **81 per cent** of patients said they had a better understanding of their eye condition after speaking to an ECLO.
- When discussed, **55 per cent** of patients said they were more aware of how to properly care for and treat their eye condition after speaking to an ECLO.

55%

of patients said they were more aware of how to properly care for and treat their eye condition after speaking to an ECLO

81%

of patients reported a better understanding of their eye condition after seeing an ECLO

In their comments, patients described how the ECLO has helped them to understand their diagnosis and eye condition and what they could expect to happen next. As a result, patients felt reassured about their situation and, in some instances, this has helped them to realise that they can cope with their sight loss.

“She has made me realise that my eye condition isn’t as bad as I thought it was and I now know I can cope with it on my own. She gave me lots of information that I found useful and that I wasn’t aware of before. After my meeting with her I came out feeling a lot happier and encouraged because I know what’s going to happen now with my eye condition.”

Patients also explained how the ECLO helped them to understand the benefits of the treatments they were due to start. In some cases, ECLOs who have undergone additional training also advised patients on how to take their medication, which has supported patients in their self-care.

“She informed me more about what will happen throughout my treatment phase which I found very helpful. She was very pleasant, and I was very grateful for her time.”

“They showed me a couple of helpful things, such as how to put my eye drops in properly.”

In addition to this, some patients told us that the ECLO has helped them to understand the benefits of operations, procedures or treatment options which helped them to make informed decisions about their future care.

“I thought that she was absolutely wonderful. We discussed the injections and the other areas that would be covered, and it all made sense, I had found someone that understood my situation and wanted to help.”

“She’s been really helpful because I wasn’t aware of the NHS help in regard to the injections that they can do for me. Nothing is too much trouble for her when I call her and she tells me that I’m not any bother to her and she is here to help, which is very reassuring for me.”



Patients report improved emotional wellbeing

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

ECLOs reduce isolation by providing a safe space to talk

Some patients reported feeling isolated and lonely before seeing the ECLO. Findings show that ECLOs provide a safe space to talk which helps reassure patients and family members that they are not alone.

“Since meeting the ECLO I feel that I have a useful contact at the hospital if needed. You can feel isolated, but knowing she is there makes a big difference to me.”

“She has been very helpful and supportive to us both. She provided emotional support to my husband, she was very understanding and listened to what he had to say which was a big help to him. She helped him open up with regards to his fears because she was a professional and he hadn’t opened up to any of us as family.”

Patients feel more hopeful about the future

The ECLO has helped patients to understand and come to terms with their situation, including coming to terms with new sight loss or a deteriorating eye condition.

“When I met the ECLO it made me feel better, she explained things to me, and it made me feel not as bad as I did before. I accepted my situation more and I knew that there were things that I could buy that could keep me going. Just speaking to her gave me inspiration, she coped so well with her sight loss, I was surprised with just how well she managed.”

Patients described how the ECLO has helped them to feel more positive and hopeful about the future through putting their minds at rest and helping them to feel at ease.

“I now have a more positive attitude and I feel that being partially sighted isn’t the end of the world. She was very friendly, reassuring and positive lady and made me feel at ease.”





Patients also described how the ECLO has given them confidence to ask for help when they need it, empowering patients to make informed choices.

“The ECLO is empowering. When you go to see her, she is so good at what she does that you just have to think if she can do it, so can I. The biggest difference that she made was her help and advice on what I was entitled to. I like to think that I am fiercely independent but sometimes you need help with large problems but also the little things that creep in. She helped with everything.”

74%

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

Patients feel reassured

Many ECLOs have sight loss themselves. Patients often comment on feeling inspired by this and reassured that the ECLO understood their situation.

“I was very impressed with what she provided, and I feel like she’s an inspiration as she is blind herself. I found her a really good support for people that have a sight condition and she was very understanding and informative.”

Findings show that ECLOs are able to recognise when a patient’s sight loss is affecting their emotional wellbeing and expert intervention is required. Where needed, patients were referred for specialist emotional support following their visit to the ECLO.

“The ECLO gave us lots of information which we will be looking into. The biggest difference that she made was referring my daughter for counselling. That will make a huge difference.”

Patients supported to live more independently

Equipment, vision aids and adaptations

ECLOs are a key way for patients to learn more about what products are available, including equipment, vision aids and adaptations. They can provide information and enable access to the products and onward services that will most meet the patient's needs by supporting them to live more independently.

Patients reported that it was the simple changes that have had the most impact on their daily lives. These included changing lighting in their homes and the use of a liquid level indicator to make a cup of tea. When discussing an onward referral to a Rehabilitation Officer (ROVI) made by the ECLO, one patient stated:

"He has made me feel more confident, I feel that he can't do enough for me and is always happy to help. I have been given a liquid level indicator, talking clock and bump-ons to put on my cooker which has been a great help."

Patients told us that where ECLOs were able to show them some aids and equipment in clinic this was very helpful. ECLOs always signpost patients to expert services such as local sensory teams and low vision clinics to provide advice and prescribe the correct aids and adaptations.

Describing how an ECLO referral to a specialist service has improved mobility, confidence and supported independent living, one patient stated:

"She has given me aids to help with my everyday life which have made a big impact, a white stick and a badge to show people that I'm visually impaired. I feel like I have more confidence to go out and about by myself now thanks to her support and the advice that she gave me."

Technology

ECLOs introduce patients to a range of accessible technologies, reading choices and products so they can continue to live independent lives. ECLOs also refer on to specialist technology support services which can provide more in-depth training and support.

“She gave me the understanding of Talking Books; she was able to show me how to use them and how they work. I am going to attend a meeting with someone about different aids that I could use and find useful in my everyday life.”

“The ECLO has been very helpful, she put me in touch with Social Services and they have sorted out my iPad so that I can get big print. She put me in touch with a local optician who has lent me lots of gadgets, I have acquired everything that I needed. She knows the ropes; I call in to see her whenever I visit the clinic. She gives me confidence.”



Patient suggestions

Timely referrals to the ECLO service

Patients mentioned the emotional distress which often accompanies a diagnosis of an eye condition, or a reduction in vision. Having support at the right time was mentioned as essential in reducing the longer-term impact of this. For a significant minority (**14 per cent**) of patients, they found out about the ECLO support too late:

“I felt that I would’ve liked to have met her sooner as I was mentally distressed and feel like she could’ve really helped and supported me through that.”

Although most patients described being made aware of the ECLO service by their consultant, nurse or other clinic staff, it appears that there are inconsistencies with this referral pathway. Some patients mention being referred to the ECLO service by chance, rather than as part of a regular process and some expressed frustration that their GP, consultant or eye clinic staff did not mention the service to them at their point of diagnosis.

“My husband saw her number on the wall while I was waiting for my appointment and I then phoned her, as my Consultant didn’t mention it to me, which I thought he should have done.”

Improve availability of ECLO support

RNIB’s aim is for all eye clinic patients in the UK to have access to an ECLO service when needed. Patients commented that ECLOs were sometimes difficult to contact due to limited availability or working across multiple clinics and sites.

“It would be great if she was permanently there. All hospitals should have an ECLO.”

Appendix 1: Methodology

The findings are a summary of national survey responses and data for England, Wales, Scotland and Northern Ireland collected between 1 April 2019 and 31 March 2020.

In total, 1,253 PEQs were undertaken with patients six weeks after 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.

Monitoring data was collected from 47,960 individual patient interactions, and a further 15,426 relative and carer interactions between 1 April 2019 and 31 March 2020.



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