



healthwatch York

Understanding People's Experiences of the Sight Support Service

provided by the
Eye Clinic Liaison Officers (ECLO)
at York Teaching Hospital NHS Foundation Trust

September 2019

Contents

Acknowledgements.....	4
Project Summary	5
What is an ECLO?	6
Why is Healthwatch York looking at ECLO services?	8
The National Picture	9
The Local Picture	13
Previous reports on the benefits of the ECLO service.....	16
What we did to find out more	18
Responses.....	19
Who did we speak to?.....	19
What difference did being in contact with the ECLO make?.....	21
Did people feel better informed after speaking with an ECLO?	25
How did the views of people who did not receive ECLO input compare?	27
What other support did people receive who did not have ECLO contact?	29
How beneficial was the ECLO support of signposting to services?	31
How important was the emotional support people received through contact with the ECLO service?	34
How important was the timing of contact with the ECLO service?.....	37
How did people feel the ECLO service could be improved?.....	39
Findings from the Ophthalmology Departments at York Teaching Hospital NHS Foundation Trust	42

What benefits did the ECLO service bring to the Ophthalmology Departments?	43
Why were patients referred to the ECLO service?	50
.....	50
.....	50
Findings from staff at local authority social care services	51
What did staff feel were the benefits to service users?.....	53
Conclusion.....	58
Recommendations.....	61
Appendices.....	63
Appendix 1: Responses for statements from the Ophthalmology Department survey.....	63
Appendix 2: Appendix 2 – Responses for statements from the local authority survey.....	66
Appendix 3: Some Additional Comments from the Ophthalmology Department.....	70
Appendix 4: Support information and some useful contacts	72

Acknowledgements

We would firstly like to say a huge thank you to all those who took the time and effort to let us know about their experiences of living with sight loss, supporting and caring for someone who does or working within services for those living with sight loss.

We would also like to greatly thank several organisations who supported us with this project: East Riding Sensory Team, MySight York, North Yorkshire County Council Rehabilitation Service, Ophthalmology Departments at York Teaching Hospital NHS Foundation Trust (and the Sight Support Service), RNIB (The Royal National Institute for the Blind), Sight Support Hull and East Yorkshire, Sight Support Ryedale, The Wilberforce Trust and Yoursensory Services and Yorkshire Coast Sight Support.


Lastly, we would like to thank Healthwatch Middlesbrough for their insight into the project planning and design.

Project Summary


Healthwatch York were interested in exploring people's experience of the Eye Clinic Liaison Officer (ECLO) Service. ECLOs offer practical and emotional support to people to help them manage their sight loss.

We spoke to people living with sight loss, their family members or carers, staff from social services and staff from ophthalmology clinics across the three boroughs covered by York Teaching Hospital NHS Foundation Trust. This included: City of York, North Yorkshire and East Yorkshire.


Overall, the detailed responses we received from patients, carers and staff strongly supported the view that the ECLO service offers vital and invaluable support to staff and patients.



"At a very difficult time the ECLO offered invaluable support to both myself and my wife. We felt we weren't doomed!"



"The ECLO service is an integral part of our service and is no longer optional."



"We find the liaison between the ECLOs and our team invaluable and we can see how the people we visit and assess have benefitted from contact with them."

Healthwatch York proposed four recommendations from the feedback we received which aim to improve access to the ECLO service, ensure appropriate service funding and promote joint working between statutory and third sector services to support people living with sight loss, their carers and family members.

What is an ECLO?

ECLOs are Eye Clinic Liaison Officers who work closely with medical and nursing staff within eye clinics and with sensory teams in social services. ECLOs are there to provide to those recently diagnosed with an eye condition, practical and emotional support. They are there to help people understand their diagnosis, manage their sight loss and maintain their independence. ECLOs have the time to spend with patients to discuss the impact the condition may have on their life.

Patient standards for Ophthalmology Services, written by the UK Ophthalmology Alliance and RNIB (Royal National Institute for the Blind), state that ECLOs should:

- Always be provided within the hospital eye service
- Adhere to, and be trained in accordance with, the RNIB ECLO Quality Framework
- Provide a person-centred service to people of all ages affected by sight loss including relatives and carers
- Offer information, practical advice on aids and adaptations, and emotional support
- Empower people to access appropriate statutory and community support services
- Offer an initial screening of needs and signpost or refer clients to local and national services and organisations to meet their needs
- Use agreed referral processes to local services such as Rehabilitation, Low Vision and Social Care

- Assist with local certification and registration processes for vision impairment

ECLOs are consistently recommended in commissioning guides for eye services.

The Glaucoma commissioning guide states that there should be an ECLO service commissioned as part of every glaucoma pathway to work alongside the clinical team in providing information and support. In addition patients should have the name and contact details of a qualified health care professional (this could be nurse or ECLO) whom patients can contact should they have questions or side effects from a drug¹.

In Age-Related Macular Degeneration (AMD) care it is recommended that patients have emotional and practical support to cope with the condition and examples include the support of an ECLO².

It is recommended that serious consideration should be given to providing an ECLO in every eye clinic to promote joint working with other services including social care, voluntary organisations or falls clinics. The ECLO's ability to counsel people with low vision and provide information about other services is recognised as valuable³.

¹ The Royal College of Ophthalmologists (2016) Commissioning Guide: Glaucoma (Recommendations). Clinical council for eye health commissioning.

² The Royal College of Ophthalmologists (2013) Commissioning better eye care: Age-related macular degeneration. Clinical commissioning guidance from The College of Optometrists and The Royal College of Ophthalmologists.

³ The Royal College of Ophthalmologists (2013) Commissioning better eye care: Adults with low vision. Clinical commissioning guidance from The College of Optometrists and The Royal College of Ophthalmologists.

Why is Healthwatch York looking at ECLO services?

In 2018, Healthwatch York were approached by RNIB and MySight York, a local charity. We discussed work being done nationally to explore the impact of the ECLO service in light of concerns over future funding. Currently the ECLO service in York is reliant on charity funding. The RNIB grant that partially funds this service in York is due to come to an end in December 2019.

It was the view of MySight York and RNIB, alongside the RCOphth (Royal College of Ophthalmologists), that an ECLO service should not be reliant on charity funding. They believe this hugely valuable and vital service to support people with sight loss needs long-term sustainable funding.

Healthwatch York were interested in exploring people's experience of the ECLO service and the impact it had for those who had accessed the service. We were also interested, due to the small number of ECLOs operating out of York Teaching Hospital NHS Foundation Trust, in exploring the views of those who had not received ECLO input and looking into whether there were any gaps within the service. We were interested in how people had received support in the instances where they may not have had ECLO input. We also wanted to understand people's awareness of the services available to them and how accessible they are.

We also spoke to other stakeholders: local authorities in North Yorkshire, East Yorkshire and the City of York and staff members from

the Ophthalmology Departments in York Teaching Hospital NHS Foundation Trust to understand how the service is currently experienced by other services in the area also supporting those with sight loss.

The National Picture

More than two million people are estimated to be living with sight loss in the UK today⁴.

Ophthalmology accounts for over 10% of all outpatient visits and 7% of all surgical activity. There are over eight million NHS outpatient appointments in eye clinics and departments within the UK every year. Cataract surgery is the most common operation performed in the UK.

Demand for ophthalmic services has risen approximately 4% per year over the last 10 years and is predicted to increase by 25% over the next 10 years. Rising demand is mainly due to an aging and increasingly diabetic population as well as new therapies for common chronic eye diseases which require repeated attendance for monitoring and treatment. The ongoing capacity issues in ophthalmic services are causing delays to care and visual harm for patients⁵.

⁴ RNIB (2018) Eye health and sight loss stats and facts. Available at: <https://www.rnib.org.uk/sites/default/files/Eye%20health%20and%20sight%20loss%20stats%20and%20facts.pdf> Accessed: 20/08/19

⁵ The Royal College of Ophthalmologists (2018). Commissioning Standards. Available at: <https://www.rcophth.ac.uk/wp-content/uploads/2018/03/Commissioning-Standards.pdf> Accessed: 18/09/19

It is stated that at least half of all cases of sight loss in the UK are avoidable if correct treatment is sought in a timely fashion. The NHS often provides excellent care to many people experiencing sight loss and there is evidence of good practice and service innovation within eye services. However, there is a growing concern around capacity of eye services across the UK and how it might be affecting patient health⁶.

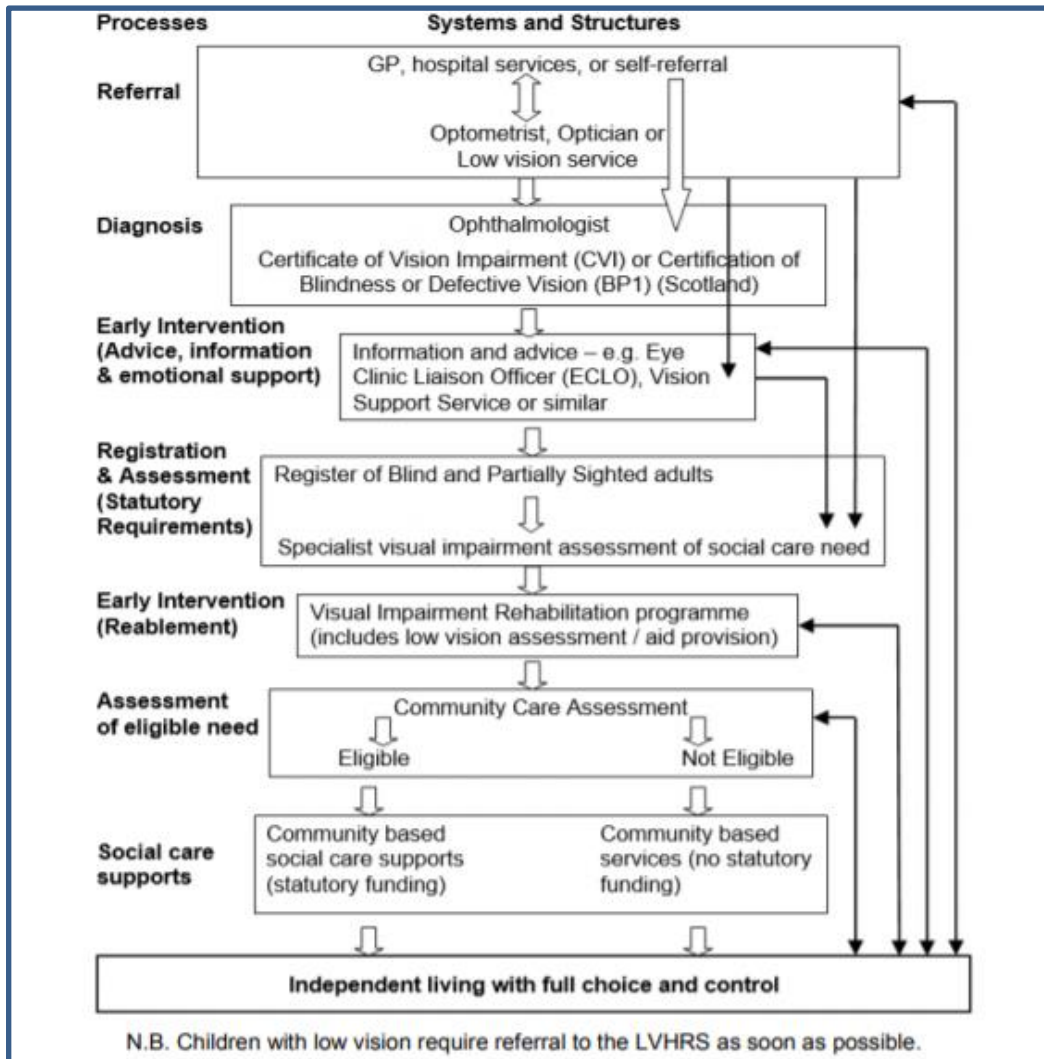
Sight loss can have a significant impact on psychological well-being, social isolation, getting about and completing everyday activities such as cooking, shopping and using technology. The need for information and services providing support for people adapting to and living with sight loss is receiving growing attention.

The adult eye health and sight loss pathway (see figure 1) was designed to show a pathway of best practice. The Strategic Advisory Group of the UK Vision Strategy urges all relevant services and bodies to work together to implement the pathway fully. The strategy aims to make sure that every sight impaired and severely sight impaired person of any age, ethnicity, extent of sight loss, other impairments, or location across the UK, has access to the same range of support and information⁷.

⁶ RNIB (2018) See the light: Improving capacity in NHS eye care in England. Available at: https://www.rnib.org.uk/sites/default/files/See%20the%20light_Improving%20NHS%20eye%20care%20capacity%20in%20England.pdf Accessed: 20/08/19

⁷ VisionUK (2018) VISION 2020 UK and the UK Vision Strategy. Available at: <https://www.visionuk.org.uk/vision-2020-uk-and-the-uk-vision-strategy/> Accessed: 17/09/19

Figure 1: Adult Eye Health and Sight Loss Pathway



Following the diagnosis stages, the pathway recommends input from an ECLO or similar vision support service to provide early intervention emotional and practical support. The Clinical Council for Eye Health commissioning report states that ECLOs are key in connecting patients to services, supporting them to understand the impact of their diagnosis. They are an essential part of the pathway. The report states they should be included in contracts and service specifications⁸.

⁸ Clinical Council for Eye Health Commissioning (2017) Low vision, habilitation and rehabilitation framework for adults and children. Available at:

The Royal College of Ophthalmologists also considers ECLOs to be a core service within ophthalmology. They believe it has a dramatic impact on patients' quality of life. ECLOs are considered able to deliver a human touch in an extremely busy service facing continuing increase in demand⁹. However not all NHS Trusts nationally, provide an ECLO service.

When people with sight loss are eligible for the certification of vision impairment (CVI), they can register as a person severely sight impaired or sight impaired. They are then able to receive social services input from their local authority. They may be offered a range of services such as rehabilitation, low vision aids, mobility training, advice about welfare benefits and emotional support.

Across the UK there is variation in how all services work together. It can often be complex for people to navigate the system (for example, in relation to driving and knowing what is available and who to contact¹⁰).

In the event that someone is discharged from clinical services because nothing further can be done for them clinically, they may not receive any further information about other services that could support or benefit them. Missing out on information is thought to be especially true for those who do not have a CVI. A CVI can often be the key in accessing

https://www.rnib.org.uk/sites/default/files/Low%20vision%2C%20habilitation%20and%20rehabilitation%20framework%20for%20adults%20and%20children%20%282%29_0.pdf Accessed: 20/08/19

⁹ VisionUK (2019) Eye Clinic Liaison Officers (ECLOs) are vital to supporting patients with sight loss. Available at: <https://www.visionuk.org.uk/eye-clinic-liaison-officers-eclos-are-vital-to-supporting-patients-with-sight-loss/> Accessed: 17/09/19

¹⁰ Llewellyn, M et al (2019) Impact of eye clinic liaison officers: a qualitative study in UK ophthalmology clinics. *BMJ* 9(3)

vital financial, practical and social support. Therefore, access to services would be largely dependent on the initiative of the service user¹¹.

The Local Picture

The latest sight loss data tool from the RNIB identified that in Yorkshire and the Humber, an estimated 172,000 people are living with sight loss¹², which includes:

- 149,600 people living with partial sight
- 22,800 people living with blindness

These figures include people whose vision is better than the level that might qualify for registration, but which still has a significant impact on their daily life (such as not being able to drive).

It is expected that by 2030, 214,000 people in Yorkshire and the Humber will be living with sight loss.

Healthwatch York were provided with ECLO service data over a 12 month period in 2018 to 2019 which indicated that over 858 patients received ECLO support in York and 413 patients in Scarborough and Bridlington. In addition 215 patient family members and carers were supported in York and 83 in Scarborough and Bridlington. People receiving ECLO support from York Teaching Hospital NHS Foundation Trust mainly belonged to three local authorities outlined in table 1.

¹¹ Llewellyn, M et al (2019) Impact of eye clinic liaison officers: a qualitative study in UK ophthalmology clinics. BMJ 9(3)

¹² RNIB (2016) Yorkshire and Humber. Sight loss data tool. Available at: www.rnib.or.uk. Accessed 18/09/19

Table 1.

Local Authority	Number of people supported
City of York Council	598
North Yorkshire	397
East Yorkshire	269
Other (including Wakefield, Leeds, Cumbria, Newcastle)	7

The ECLO service data revealed that a service reduction could impact on two thirds of the patients in York. All the patients in Scarborough and Bridlington would be at risk.

Data from the RNIB sight loss tool estimate the number of people living with sight loss over these three areas¹³. See table 2.

Table 2.

Local Authority	York	North Yorkshire	East Yorkshire
Total population	208,163	611,633	338,061
People living with sight loss	6,680	24,400	13,800
Registered severely sight impaired or sight impaired	1,025	2,730	1,815

¹³ This data was developed in 2016/17 and is due to be updated late 2019.

All three local authorities have a higher than average older population compared to the England average. Reports suggest that these figures will continue to rise over the next 10 years. It is predicted that as the population ages, more people will be living with sight loss.

There are significant inequalities in eye health. People in the poorest 20% have an almost 80% higher chance of developing a vision impairment. It is reported that the uptake of NHS sight tests for people over 60 is declining in North Yorkshire and Humber, which is concerning as vision impairment (i.e. blindness or partial sight) can be prevented. However, this is only if certain conditions are detected, diagnosed and managed correctly¹⁴.

¹⁴ City of York Council (2015) York Eye Health Needs Assessment. Available at: <https://www.healthyyork.org/media/62041/eye-health-needs-assessment-2015.pdf> Accessed: 17/09/19

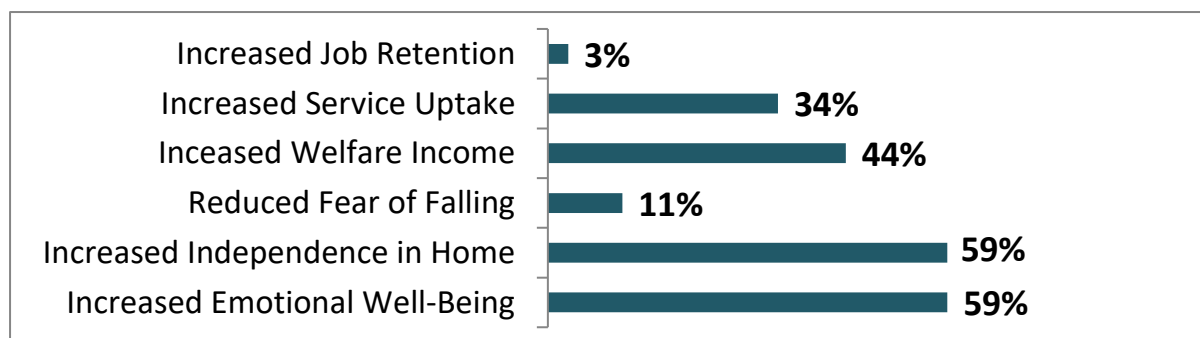
Previous reports on the benefits of the ECLO service

In 2013 the RNIB published a report looking into the economic impact of eye clinic liaison officers¹⁵. Savings to health and social care budgets as a direct result of ECLO input were estimated to be £10.57 for every £1 invested.

The report was based in part on feedback from 66 ECLO clients. Positive outcomes from contact with ECLO services included improved emotional well-being and independence in the home. Other positive outcomes included increased welfare income for those entitled to benefits, increased service uptake, reduced fear of falling and increased job retention.

Table 3 outlines these outcomes and the percentage of patients which identified with them.

Table 3.



¹⁵ Singh P, S (2013) Economic Impact of Eye Clinic Liaison Officers: A Case Study. RNIB

The BMJ report¹⁶

A study published recently in the British Medical Journal (BMJ), and funded by the RNIB, highlights the continued importance of ECLO. The study suggested that ECLOs are able to relieve pressure on clinical staff allowing them to focus on clinical duties. ECLOs were also found to provide continuity of care for patients following their discharge from medical treatment.

The BMJ article showed that ECLO services:

Decreased the demand on health professionals

- Having an ECLO in post saved clinical and administrative time.
- Time pressured clinicians are helped by having ECLOs available to support people coping with a new diagnosis.

Increased registration and increased service uptake

- ECLOs support the smooth running of CVI pathways
- ECLOs help prevent people 'slipping through the system', e.g. driving when they should not be driving or not being assessed at home.

¹⁶ Llewellyn, M et al (2019) Impact of eye clinic liaison officers: a qualitative study in UK ophthalmology clinics. BMJ 9(3)

What we did to find out more

Healthwatch York ran a survey over July and August 2019. We spoke to people living with sight loss and their carers and family members through:

- An online survey available on our website
- Telephone interviews
- Posted hard copies of surveys
- Face to face interviews at various events

We shared our project and the survey with organisations who support people living with sight loss across York, Scarborough and Bridlington. The organisations were: MySight York, Selby District Vision, Sight Support Hull and East Yorkshire, Sight Support Ryedale, The Wilberforce Trust and Yorsensory Services and Yorkshire Coast Sight Support.

We captured people's views through visiting groups run by local organisations who were able to support us with our project. We completed telephone interviews with people who asked to be contacted in this way. We worked with the ECLOs to raise awareness of the survey and recruit participants. We also attended the Eye Department at York Hospital to speak to patients.

To understand how other services work alongside the ECLO service we produced a survey for all staff at the Ophthalmology Departments at York Teaching Hospital NHS Foundation Trust and a survey for staff from local social services in York, North Yorkshire and East Yorkshire.

Responses

We received 94 responses in total.

Within the survey for people living with sight loss there were two incomplete survey responses which were subsequently removed from the data and six which were completed by professionals working with individuals living with sight loss. These responses were removed from the data. However, the professional's comments were included within the relevant section of this report. Overall there were:

- 43 completed surveys from people living with sight loss and their family members/carers.
- 38 surveys from the Ophthalmology Departments
- Seven surveys from local social care services
- Seven additional comments from professionals working within the sector (six from clinical departments and one from a local charity)

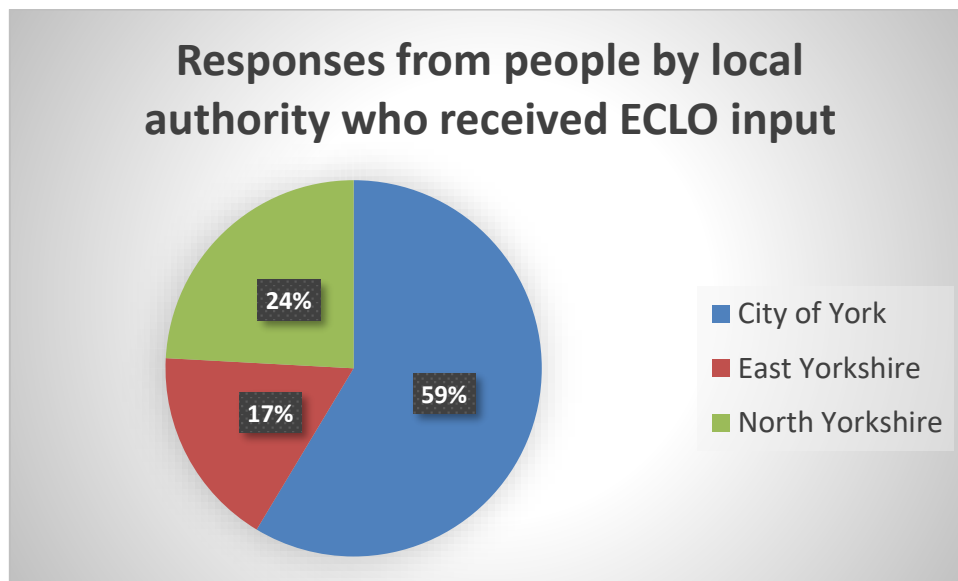
Who did we speak to?

From the survey for people living with sight loss, 72% of the respondents (31 people) were people living with sight loss. The remaining 28% (12 people) identified as carers and family members of someone living with sight loss.

We spoke to 29 people who had had contact with the ECLO service and 14 people who had not received any support from the ECLO service.

People we spoke to who had received ECLO input were from across three local authorities, shown in figure 2 below.

Figure 2.



People who had received support from an ECLO had been attending their local eye clinics within the different areas for just a few months to over 30 years. This provided us with a range of different experiences and perspectives regarding accessing support for sight loss.

What difference did being in contact with the ECLO make?

We asked people who had received ECLO support what the biggest difference, if any, being in contact with the ECLO had made to them.

Responses have been organised under key themes:

- Feeling emotionally supported and being able to talk to someone
- Access to aids and equipment that improve quality of life and maintain skills
- Improving confidence and maintaining independence
- Contact with other community and third sector services

Feeling emotionally supported and being able to talk to someone

“Being able to talk to somebody that listened.”

“I was able to talk problems through with someone on a more personal basis.”

“It’s made such a difference. I came out feeling normal. Before I felt like the only one in the world. It was a very lonely place.”

“I then had someone to call and discuss problems with locally.”

“Being in the hospital, they’re there for you to talk to. We are confident he is getting good advice from a professional for all the little things you need to speak about.”

“The ECLO gave me emotional support when I felt really vulnerable.”

“I was very isolated before. You can't explain to people as I have some vision and people seem to expect you to be totally blind or not blind at all. It has really been a huge relief to find people I can talk to and who understand and support.”

“At a very difficult time the ECLO offered invaluable support to both myself and my wife. We felt we weren't doomed!”

“I do feel more aware of things that are out there for people. Also, I now know the ECLO is there if I need it.”

“Good to know where to get advice.”

“It was reassuring to meet with someone experienced in giving specific advice for coping with sight loss.”

“Knowing that someone understands how you are feeling, and is able to provide emotional support and empathy is invaluable. When sight is deteriorating, even over a long period of time, being registered as blind is a very emotional experience, and needs to be seen as a part of the whole person, and not just medically.”

“I wouldn't have had the counselling which was vital. I wouldn't have seen the relevance of it. I wouldn't have known about the social group... I wouldn't have been able to process the information without the support.”

“It has helped me to explain things to my mum about her sight loss.”

“It was so helpful that my husband came in as well. He has such worry in his face because he didn't have the answers and he panics. It was a big jump to see the ECLO but I came out really upbeat and they put my husband at ease about the [symptoms] that he did not understand before. I didn't know what to think before seeing the ECLO and honestly

I didn't expect a lot... But also I met someone in the waiting room and speaking to others going through the same or worse than you, it helps to talk to others.”

Access to aids and equipment that improve quality of life and maintain skills

“It has been very helpful. They advised me about aids and equipment I could use.”

“It has made me realise help is available if I want it. I'm now aware that there is a gadget I can use for the cooker so I can feel it better. At the moment, I am managing but it's good to know that there are things out there when I need.”

“It was very helpful in pointing to equipment to try.”

“They were able to help me with my magnifying glass.”

“The ECLLO also helped me to get aids, talking books and I didn't feel pressured.”

Improving confidence and maintaining independence

“I have more confidence.”

“Makes a difference in terms of keeping me sane and giving me a little bit of independence.”

“Mum was very relieved to hear there may be some help, as was I. We could get advice and tips to help mum stay independent in her own home.”

“It gave me confidence in dealing with other departments and services within the NHS.”

“It makes you aware of what's available. Both equipment and support. Before this, you're on your own.”

“It gave me full confidence. I meet the ECLO in the clinic and go away with the answers to my worries in simple form.”

Contact with other community and third sector services

“The most helpful aspect for a carer was to learn from and discuss with other carers”

“The ECLO's personal influence has been slight. The most valuable contribution has been the role of interaction with other agencies.”

“Now that I attend support groups I am able to listen to others with some experiences. I am able to speak out more and I want to help other people in this situation. Meeting different people and talking about life. It's a family. Family can be too close to provide that support. If there's no cure it helps to talk to other people.”

Did people feel better informed after speaking with an ECLO?

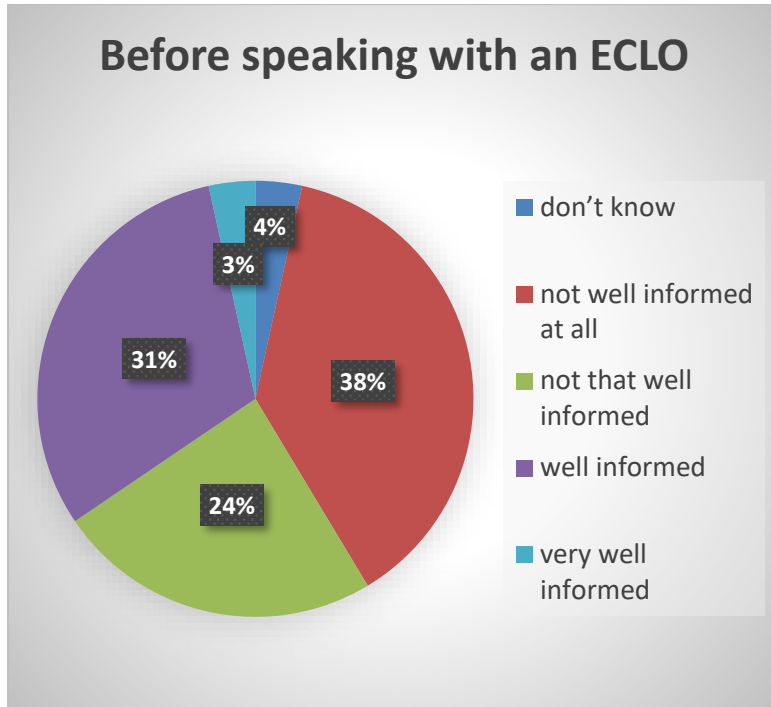


Figure 3.

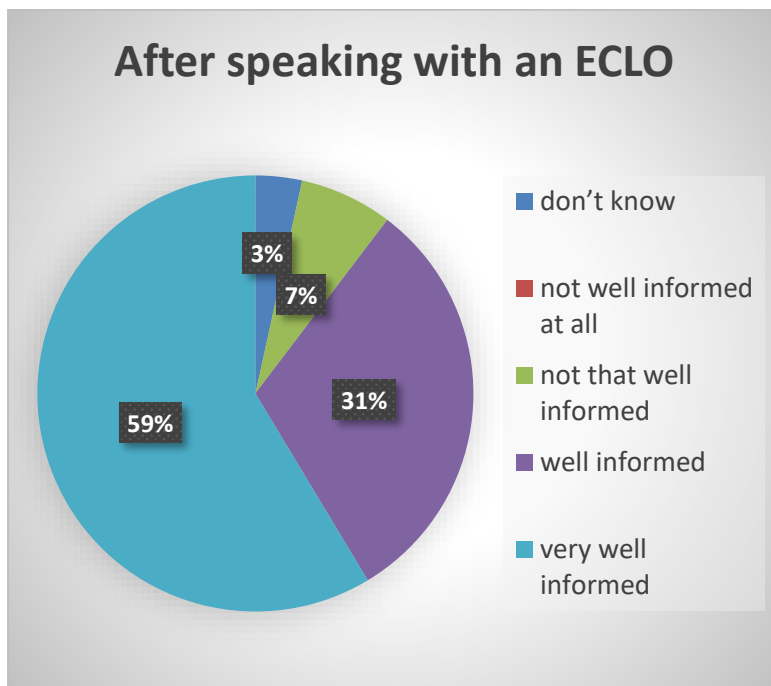


Figure 4.

Before speaking with an ECLO 18 people (62%) said they were either not well informed at all, or not that well informed about the support available to them or someone they care for. Only 7% felt not well informed at all or not that well informed after speaking with an ECLO.

Before speaking with an ECLO only one person (3%) felt very well informed and nine people (34%) felt well informed. Following ECLO contact 90% of people stated they felt well informed or very well informed, with 17 people (59%) feeling very well informed.

People described gaining different kinds of knowledge through their contact with the ECLO service. Examples included knowledge around equipment, emotional support or access to charities and local support groups, depending on the individual's needs. Some people also reported, where it was relevant to them, better understanding of their eye condition and of how to care and treat it (see Figure 5 and 6).

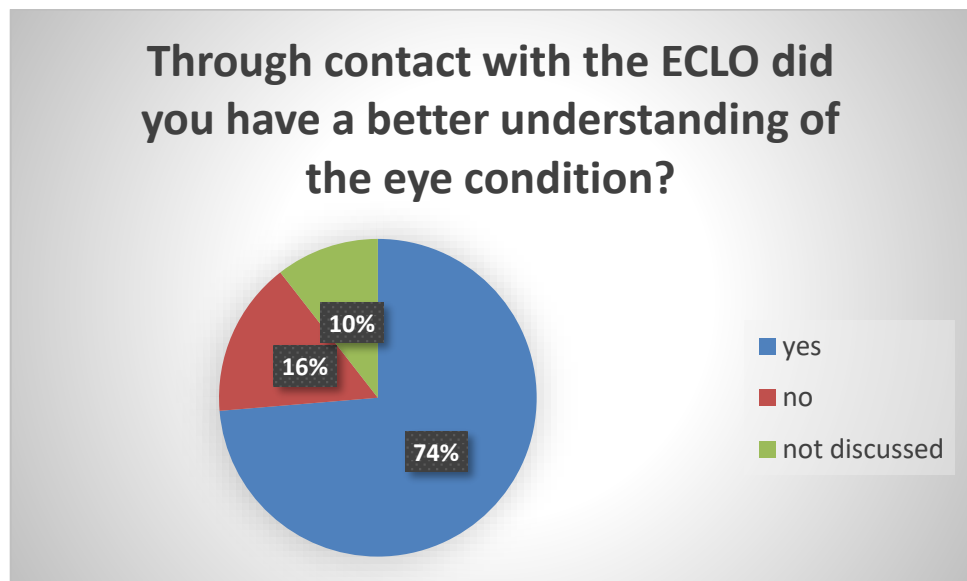


Figure 5.

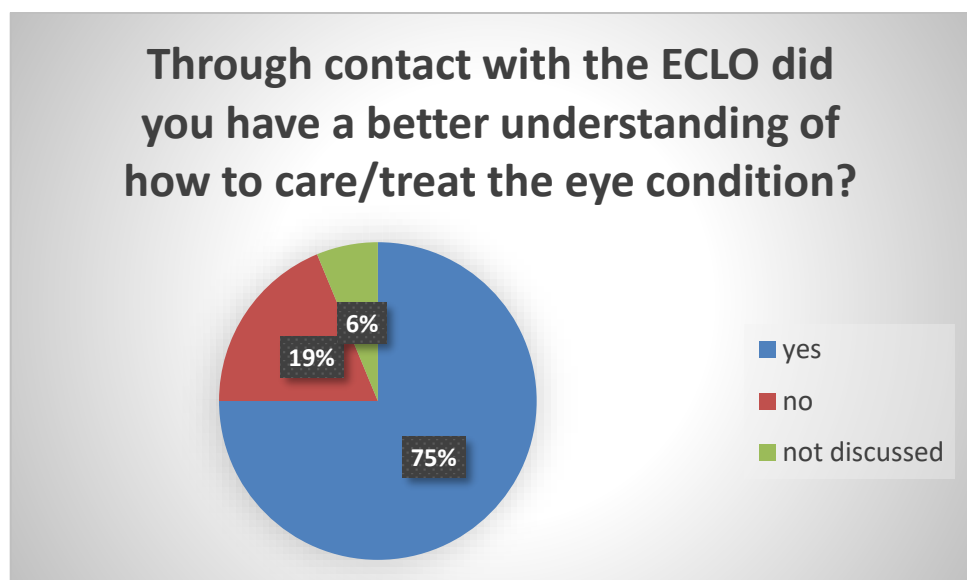


Figure 6.

How did the views of people who did not receive ECLO input compare?

We told people **who had not** received ECLO support about the role and purpose of the ECLO service. When we asked if having ECLO support would have been useful to them, six out of 13 people said they felt having contact with an ECLO would have been useful.

People told us:

“It would have been helpful to have had longer conversations about options and at what point my sight loss might require additional support.”

“I could have done with the information straight away. Before I got registered, I was hardly going out. I was falling over the edge of pavements. I couldn't go out when it was sunny because it was too light and couldn't go out when it was dull because it was too dark. If I needed to go out shopping, I had to get [someone else] to help... I know other people that don't have any support and don't go out as much or at all. It would be great having people come out and give emotional and human support. There was a time when I was just wearing a heavy blanket around the house and it would have been good to have some advice around how I could function better in the home.”

“Having some support and signposting to charities would have helped. I want help to get a better front door so I can see out.”

“You can always do with more support.”

“... I would have liked the contact. I would also have liked support to continue reading.”

“It would have been useful to talk about options for getting out. Someone to ask about equipment. I am currently having difficulty with my talking books. I find it difficult to travel all the way to Scarborough and would prefer to have appointments in Bridlington.”

Interestingly, seven out of 13 people we asked reported that they either didn't feel the ECLO would be useful or were unsure and did not feel that they would necessarily seek support from an ECLO service. Those who commented further told us:

“I have no idea what it involves.”

“I didn't know it existed and I would not have sought support.”

“I don't know enough about them to say. I would like some understanding of what's happening to me. I have never been given clarity around whether I can continue to drive or not. I am giving up on my own accord. I would have liked some clear communication.”

“I'm not at that stage (hopefully).”

Clearly, coping with sight loss can be a very distressing and overwhelming experience leading to individuals needing to adapt major areas of their lives as well as coping with the emotional and psychological demands. This can make it difficult for individuals to seek the right support especially when they are not well directed or well informed about support services available to them. Although ECLO support may not be appropriate for everyone, the findings suggest that almost half felt it would have been beneficial to them. Nearly all those

who felt it wouldn't have been beneficial, appeared to lack information about the service and other kinds of support available to them. The overwhelming response from those who had received support through an ECLO suggests that it was beneficial (in differing ways) to all those who received it.

What other support did people receive who did not have ECLO contact?

When we asked what other kinds of support they had received, some people, **who had not** had support through an ECLO spoke about having support from their family and good doctors and nurses. Some people referred to the medical treatment appointments they received but reported a lack of additional or emotional support.

"I only have consultant appointments every 6 months to discuss my glaucoma management."

"No support, only medical appointments. Last year I had specialist appointments, and these were cancelled twice."

"Nothing. I have had to buy my own things."

Important avenues of support mentioned were The Magnolia Centre, support from social services, local sight support charities and the Blind Veterans Society.

"I had been going to the hospital receiving certain treatment though I couldn't bear having it anymore and stopped getting any treatment. I had been going for appointments for years and had received no support until

I managed to make an appointment at York Hospital after which they agreed to register me. It was then a week or two before I received support from social services and I received cane training a month after. However, when she left no-one else took over. There was a lady at the job centre who gave me a leaflet for an open day here [local sight support charity], so then I found out about this place and some equipment I could use. Before all this I felt I was on my own with it.”

“After having a number of Glaucoma operations it was not a good outcome. I got a leaflet at the sight clinic about the Blind Veterans. They have ROVI’s [rehabilitation officers for vision impairment] which come and visit you. They give you advice on different magnifying glasses. They have supported me to go to the Llandudno Centre where they have IT courses, cookery courses, woodwork and arts and crafts. They teach you how to feel your way in the kitchen. They also have personal carers who can look after you and keep a check on you... a fantastic organisation”

The above examples suggest some individuals were able to access information about other services available to support them through different means, although notably not always in a timely manner. Part of the ECLOs role is to signpost people to sight support services in the community, outside of the hospital, in a timely way.

How beneficial was the ECLO support of signposting to services?

We asked people who had had ECLO support which kinds of services they had been signposted to. Examples given were:

- Counselling services
- RNIB services including their helplines and audiobooks
- Various sight support charities across York, Scarborough and Bridlington, including for example: The Wilberforce Trust, MySight York, Yorkshire Coast Sight Support and Selby District Vision.
- Seeing AI (artificial intelligence) apps
- Local social support groups
- Local activities
- Guide dogs

We asked people who had received ECLO support if they thought they would have found out about these services without the ECLO service. Only one person felt they would have found the support through the internet. Eleven others reported “no”. Other responses included:

“Not straight away. I’m a problem-solver. I definitely would have tried my best to find things but it would have taken me a long time. I think for most people they probably wouldn’t be able to do that.”

“No. I didn’t know about it. I would have just stuck with the doctors who see you every 6 months and just tried to get on with it.”

“No we were struggling to get any help.”

“Impossible to say.”

“We may have got to my [local support charity] but talking to the ECLO was better. It gave us the confidence to go there.”

“I may have but it would have taken a lot longer.”

“No. I wouldn't have bothered.”

“No. The doctors were too busy.”

“No. I was not aware of the organisation.”

“Looking after myself would have been difficult as I had a family and a lot going on. I was in a dark place at the time but kept it together for my family but I'm not sure what I would have done without the support.”

The importance of the community and third sector support services was highlighted by those who had been able to get access to them. On talking about how beneficial these services had been, people said:

“Very good. They helped us find the right lamp and were able to show us different kinds. He is unable to use his hands also, so instead of a magnifying glass they were able to advise on special glasses instead. He was able to take them home to try and thought they were good.”

“200 %... They have always been there for him.”

“They were supportive and understanding. I went in and met the team but have also attended on a 1:1 basis and they have been supportive whilst also offering practical solutions to some of my issues. It actually

really opened my eyes to things that were out there that could support which I wouldn't have thought about or believed could help me before."

"They were so important. I am now further down the line toward getting a guide dog and there has been so much helpful advice since I started this journey."

Some individuals had not made contact yet or were still waiting to hear back from places and notably felt less reassured.

"Not sure yet."

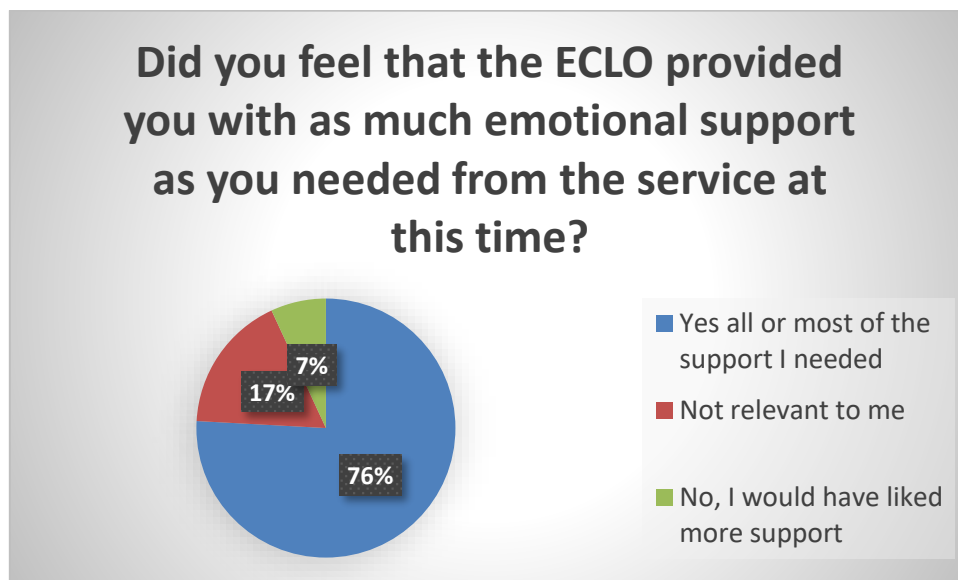
"A charity rang me about a social group on a Wednesday but I haven't been able to attend yet."

"We are at the beginning of the process but are very hopeful."

How important was the emotional support people received through contact with the ECLO service?

We wanted to find out how important having access to emotional support was to those living with sight loss, and to their family members or carers and whether people felt the ECLO service provided them with as much emotional support as they needed at the time.

Figure 7.



- 76% (22 people) stated that the ECLO service had provided them with all or most of the emotional support they had needed.
- 17% (five people) had not felt this was relevant to them
- 7% (two people) felt they would have liked more support

Individuals who would have linked more support felt that the service was too limited in their area to support them in that way. They felt an ECLO was needed on a more permanent basis, as one day a week was not

enough to provide the personal support required, or to feel that there was someone available to them to call for support.

People spoke about how they felt they were coping since being supported by the ECLO. Most people felt they were coping better, though some still referred to the many challenges of living with sight loss. Comments included:

“I knew quite a bit about the eye condition before seeing the ECLO. I didn't think I would get support as I thought my residual eyesight may be too good. I felt relieved after getting support from the ECLO.”

“I have been preparing personally for this situation over a long period; the ECLO were very helpful in informing of outside help available to me.”

“Probably [coping] the same. I am a very independent person and I like to get on with things. I am coping OK at the moment.”

“Yes. It had a massive impact for me. I found out about services and counselling schemes which I wouldn't have known about. I wouldn't have seen the relevance.”

“As a carer just to be informed that there is additional support out there that can benefit... was a big reveal and relief for us both.”

“Yes, I'm further aware of what's available.”

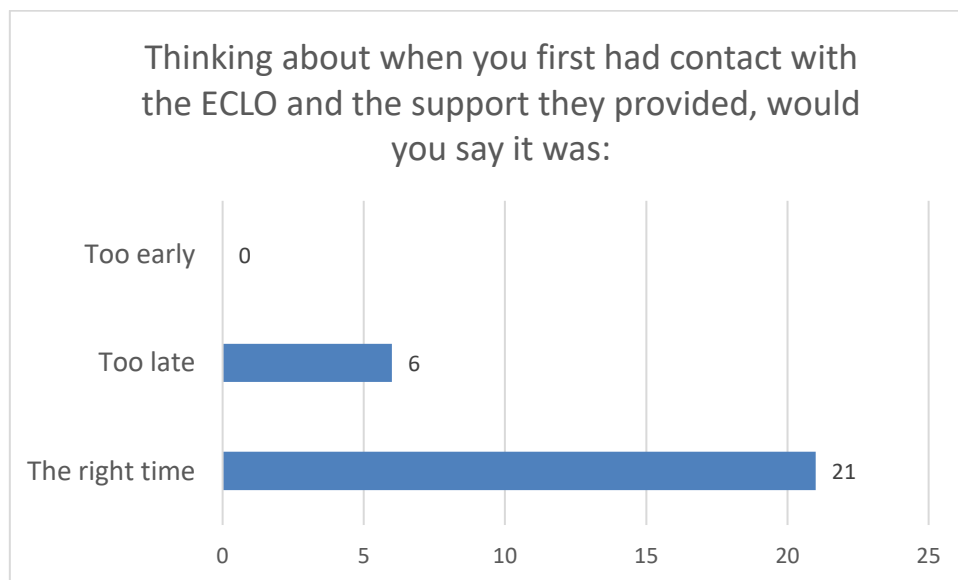
“Definitely coping better. My consultant always gives me really good information about my condition. I feel pretty well-informed. I'm comfortable speaking with doctors and consultants but that's not what I need from the ECLO. For me it's all about the support and dealing with stuff.”

Many people spoke about the importance of feeling supported emotionally and having someone to talk to as having made the biggest difference to them in regard to their contact with the ECLO service. See responses to, 'What difference did being in contact with the ECLO make to you?' on page 18.

How important was the timing of contact with the ECLO service?

With the people we spoke to having been at many different stages of living with sight loss or supporting someone with sight loss, we were interested in finding out whether the timing of the ECLO service support was important to people, carers and family members.

Figure 8.



Overall, 78% (21 people) felt that their contact with the ECLO had been at the right time whilst 22% (six people) felt that the support from the ECLO service would have been beneficial earlier.

People told us:

“I would have liked to have known about the service before I attended hospital.”

“Being quicker and having access to someone who understands quicker. Having someone to contact regularly.”

Early introduction to, and contact with, the ECLO service was highlighted as important to those living with sight loss and their family and carers.

“The consultant had referred me before I attended the appointment with him so it was really quick. Over the last [few] months I have gone from not knowing anything about what to do, to having long cane training and various other things. I think I am the poster child for having received such fast and good support. I am going to be in contact with another service soon who will support me to get into work.”

Continued opportunities to make contact throughout people’s journeys was considered a key area where the service could be improved.

“When I first saw an ECLO it was many years ago and I did not really need the ECLO support but more recently I was informed about going when I happened to be at a pain management group. This was a very roundabout way and if I hadn't of been seen for this extra problem I may never have gone. I felt that the ECLO service was for people in a worse condition and not for me. No-one in the eye department had suggested it and if I hadn't had the confidence to go I may not have got in touch. The signs on the wall are not really good enough to let people know about the service.”

How did people feel the ECLO service could be improved?

We asked people if they felt the ECLO service could be improved in any way. As discussed, people referred to the timing of getting support from the ECLO service and felt that having this support earlier would be an improvement. Some people felt that more standardised ways of getting a referral would have improved their access to the service.

“Knowledge about the service at an earlier point.”

“There should be introduction at the beginning of treatment.”

“Maybe a standard question as part of the patient review.”

“Just the support being as early as possible would be good.”

“I think maybe if nurses in the eye clinic knew more about what ECLOs are about. It's better than it used to be. And the nurses obviously do know a bit about them. But it would be better if they were more willing to share info about ECLOs at an earlier stage and explain better what they're about. If you say to someone in the clinic "you can see the ECLO if you want" - people don't really know what they're for, how they work.”

Improving awareness by promoting the service more was also discussed.

“The only thing I can think is that we need to be more aware that the service is there. They need to promote it more.”

“My consultant told me, which is great. However, I feel that better advertising in the Eye Clinic would be helpful, and in a very visible manner for people with sight loss.”

“Perhaps letting people know about it.”

Some people in the Scarborough and Ryedale area felt that the ECLO service did not have the capacity to meet the needs of people living locally as it ran only one day a week. People felt that having greater access would be hugely beneficial. It was also reported that having someone based outside the hospital with the ability to travel locally to people’s homes would also be beneficial. This view may be due to the more rural nature of Scarborough and Ryedale making travel to certain hospitals more difficult.

“[It could be improved by]... having a person based in Scarborough on a permanent basis who is easy to contact.”

“I feel the ECLO service is a valuable service, but feel strongly that an ECLO that is based at a local sight support charity and able to visit people at their homes to provide on-going support is much better placed.”

In York, although people generally felt more confident about the service’s ability to reach those in need, people still felt the increased pressure on the service.

“I used to see the ECLO in the Macular Department but I'm not sure if she can get up there anymore. It's got very busy.”

“[Having]...more time to talk.”

“More staff hours so they can go get a cuppa. What would we do without them?”

One person spoke about the waiting times involved in the CVI process

“The only thing I can think is that it’s been a long time since seeing the ECLO and receiving the literature [for CVI registration]. I think this part feels too long but I have it now and am going to get on with things.”

Another spoke about feeling that there was an overall lack of support in general for people living with sight loss.

“There needs to be more support for people with sight loss. There is not enough for people or for carers. My children have sight loss and I try to support them as they don’t get enough.”

Many people also responded by telling us that the support they had received from the ECLO service had been highly supportive and timely.

“I feel that if I had required more support then efforts would have been made to provide it, “Ask and I’ll be given”!

“I’ve been happy with the support I’ve received.”

“No they’ve been very helpful.”

“It was all useful and relevant.”

“I think the funds should stay, to support people.”

“No, the support was good.”

“No improvement necessary. My appointment was timely.”

Findings from the Ophthalmology Departments at York Teaching Hospital NHS Foundation Trust

We designed a survey for professionals working at the Ophthalmology Departments within York Teaching Hospital NHS Foundation Trust. A total of 38 members of staff responded to the survey. Additional comments from six clinical professionals who gave responses through the people's survey were added to these findings.

Those surveyed were staff working at Ophthalmology Departments in various roles and professions. We asked them how much they agreed with a number of statements relating to the ECLO service. The questions helped us get a sense of how far staff felt the service was beneficial, or not, to patients and the department as a whole. Tables displaying the full range of responses can be seen in appendix 1.

Over 75% of staff agreed or strongly agreed (a total of 29 out of 38 staff members) that the support provided by the ECLO reduced the time they needed to spend with patients, enhancing the capacity of the Ophthalmology Department. Three people neither agreed nor disagreed, one disagreed and one strongly disagreed. Responses may depend on job role within the clinic.

Over 92% of staff members agreed or strongly agreed that the ECLO service significantly improved the CVI process for the service and for the patients.

Over 97% of staff agreed or strongly agreed that the ECLO service significantly improved patient experience through providing timely and accessible information.

Over 97% felt that the support from the ECLO significantly increased the likelihood that patients will go on to access support they need to maintain their independence and well-being.

Over 97% agreed or strongly agreed that providing emotional support at the point of diagnosis contributed to the long-term health and well-being outcomes of the patient.

Over 91% agreed or strongly agreed that by making timely and appropriate referrals to services, the ECLO significantly increased the likelihood that patients may maintain or regain independence.

What benefits did the ECLO service bring to the Ophthalmology Departments?

To understand more about how the Ophthalmology Departments worked with and valued the ECLO service we asked for further comments about the service, as well as the benefits staff felt the ECLO service brought to the department. Some of the ways staff felt that ECLOs benefited patients or the service included:

- In developing knowledge of patient conditions, such as Charles Bonnet Syndrome
- Providing patient information leaflets for support groups/equipment

- Improving understanding of CVIs, accurate and efficient completion and processing of CVIs and supporting data collection about CVIs
- Improving patient welfare and providing patients with a true advocate
- Providing additional support to patients; mainly to come to terms with their sight loss or eye condition
- Providing emotional support to health professionals who have had to give bad news to patients
- Ability to help at a crisis point in a patient's life
- Providing advice which is always available from the ECLO
- Understanding causes and reasons for vision loss
- Providing invaluable input in a recent survey of preventing severe vision loss in glaucoma
- Improving compliance with treatment from patients. Reducing DNA (did not attend) rate. Reduces consultation time so more patients can be seen per session.
- Providing a friendly listening ear for patients who may not wish to ask other professionals certain questions
- Giving patients a focal point for information

Staff shared further comments with us regarding the ECLO service and how they felt it supported patients and the eye clinic. They felt the ECLO service was:

Providing vital patient support

“The ECLO is an essential service similar to a McMillan nurse in cancer and palliative care. Patients need and deserve this support in addition to medical care, which is not always adequate to manage their needs.”

“Essential service to the eye department for patients, and for medical staff, providing excellent advice and support! Fantastic support service for nervous, anxious patients. Calm setting for patients to talk openly and privately.”

“The ECLO service is vital to patients who need support when trying to come to terms with sight loss. The patients need somebody to talk to and although the nursing staff are always considerate and compassionate towards patients due to a very busy workplace they are unable to give the time that each patients requires. The overall experience that ECLO provide to patients is invaluable and maintains a good relationship between the patient and the department enabling patients to carry on with their treatment.”

“I think it’s great that we have a service in which patients can confide and discuss ways to try to improve their life's going forward living with their conditions. After all our eyes are so important and it can be daunting being given the news your eyesight is changing. I always hear positive feedback from patients surrounding the service - I think they feel more secure having the service there if they need it and know where to go if they need the advice. When I've seen our ECLOs dealing with patients they're so patient, kind and mindful of how the patients may be feeling.”

“The ECLO service is invaluable for supporting patients through what can be a very traumatic time for them, and offers support and guidance which falls outside what other members of the department have the experience or time to offer. If the service is removed or cut down our patients will not get the help and support they need.”

“It provides a one stop service for the patients, they do not have to come for another visit particularly if they are distressed they know there is somebody on hand for help/advice etc. I feel the ECLO is a vital role not only for patients but for staff. It frees up time for the consultants/clinicians, provides advice and guidance to the admin staff re patients queries/ issues and assist's in awareness training for new staff.”

Improving the CVI system (certification of vision impairment)

“The CVI system was a very disjointed service with very little control until taken over by the ECLO. The ECLO has turned this service around and the department/ GP's/ patients now have one point of contact with all the details in one place to be able to deal with queries efficiently. It is now a very comprehensive service.”

“Being in contact with an ECLO on a daily basis keeps me up to date with any changes in the certification process, and how to provide the additional support required and how to access those services outside of the hospital.”

Supporting staff and patients in a highly pressured environment

“As clinic sizes increase there is not time for us clinicians to access the support so patients would have missed out on crucial information, which could have a profound effect on their wellbeing.”

“Helped a lot of my patients and parents. Feedback from parents is that the ECLO provides emotional support which they cannot get from family etc. Parents say the ECLO allows them to open up about their condition/ child's condition when they cannot in clinic as we do not have enough time.”

“They are invaluable and provide a brilliant support service spending time with patients when they need it most. We need more as they always seem to be overstretched.”

“The service provided by all our ECLOs is invaluable to the adult and especially parents and children that I see who often have to deal with new diagnoses and conditions that many affect theirs or their children's vision for the rest of their lives. They are excellent at providing clinicians as myself with guidance on who to refer, when, guide us to the right support, liaises with the families over the phone and face to face. I don't know what I'd do without them.”

Improving the efficiency of the service at the eye clinic and providing value for money

“The social and emotional support allows me to concentrate on giving the best clinical care in the knowledge that the patients are still getting social support. Ultimately more patients are treated and supported in my limited time.”

“The eye clinic couldn't run without the ECLOs. It would mean markedly less patients could be seen in the AMD [Age-related macular degeneration] treatment service if practitioners had to provide this level of support. In fact there is so much to do I'm not sure how the small team manage it all. They save the trust a significant amount of money by freeing up practitioner time to treat and diagnose patients. We could really do with one person per ocular specialty. They are a real asset to the trust and to the patients.”

“The ECLO service in York Hospital has become an indispensable part of ophthalmic services and is a model which should be incorporated in all eye units. It is astonishing that funding of the service might ever be in jeopardy given the excellent value for money.”

“Our ECLO service is vital to the high-quality care that we are aiming to deliver. Our ECLO team increase productivity because I can now focus on clinical matters whilst they focus on social and emotional matters.”

“Very beneficial, particularly in comparison to being without ECLO support prior to the development of the post. Covering several clinical sites is very helpful and being available during clinics allowing immediate access for the patient.”

“ECLO is an essential service to comprehensively support patients with poor eyesight from any pathology. It brings additional expertise in managing these patients and improves patient's experience. This service provides essential support to these patients which otherwise would take significant amount of time of doctors; which now can be utilised managing other patients.”

“It means nursing staff have more time to spend with the patients relating to clinical nursing care as the ECLO supports the patient further with external resources & financial support.”

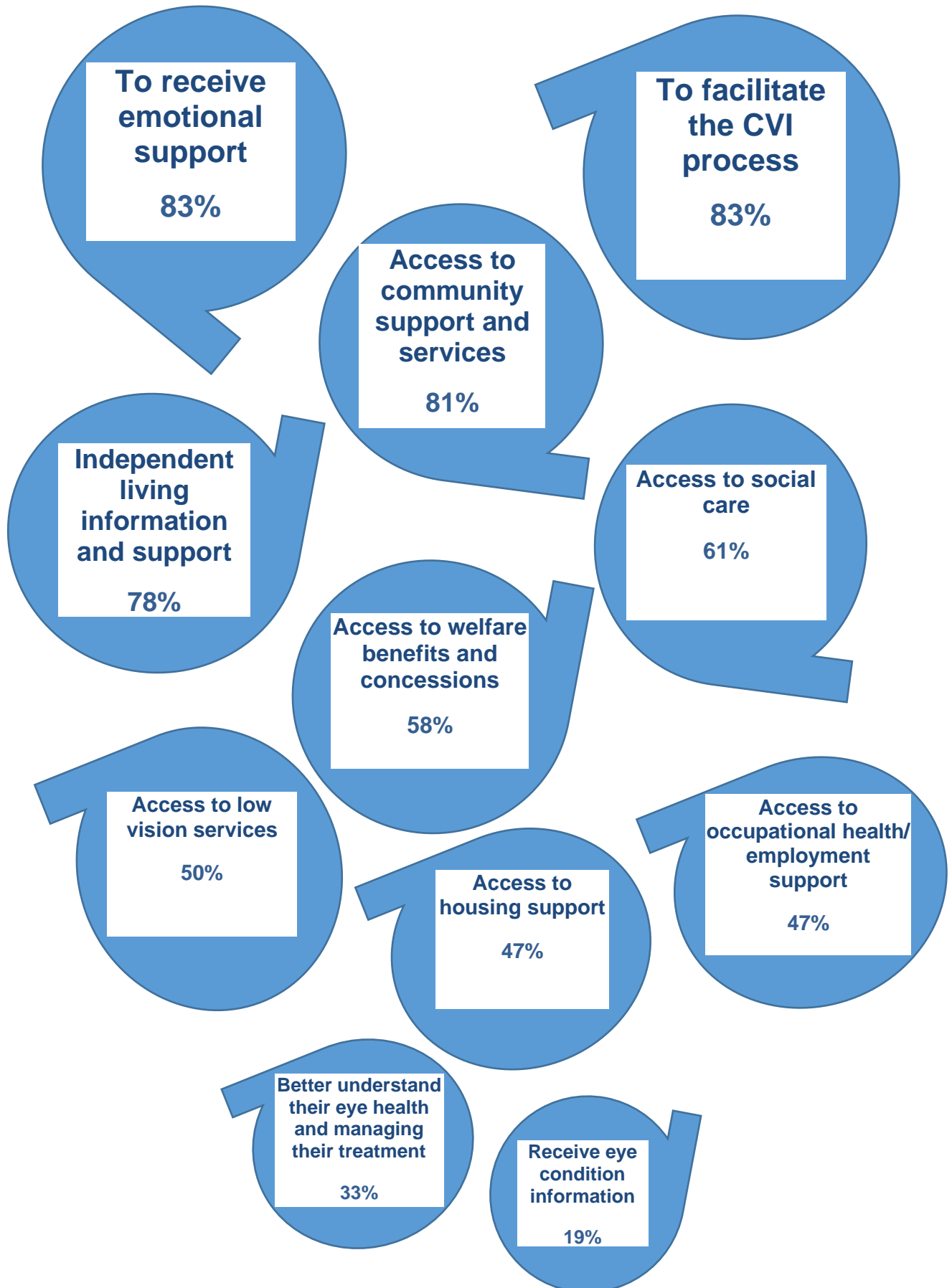
Providing support for services beyond the eye clinic

“Invaluable service. They bridge the gap between hospital services and social services, helping the patient on the way to being more independent and supported. As I was involved in setting up this service in York many years ago, I have seen it develop and grow, and I would be very concerned for patients' wellbeing should the support not be available.”

One staff member also commented on the lack of knowledge about ECLOs outside of the eye department and other closely linked services.

“I only found out about the service when I joined the eye department. I feel that external optometrists should be made more aware of the existence of ECLOs.”

Why were patients referred to the ECLO service?



Findings from staff at local authority social care services

We spoke to three local authorities (North Yorkshire, East Yorkshire and City of York). We wanted to find out how social care staff worked alongside an ECLO service and how they thought ECLOs benefit their service users.

We asked staff how much they agreed or disagreed with a range of statements relating to social care objectives taken from the Adult Social Care Outcomes Framework. Tables displaying the full range of responses can be seen in appendix 2.

100% of staff strongly agreed that the ECLO service provides an overview to enable people to know what choices are available to them locally, what they are entitled to, and who to contact when they need help.

75% of staff strongly agreed and 25% agreed that the ECLO service improves the efficiency of the CVI processing from the eye department through to social care.

87.5% of staff strongly agreed and 12.5% agreed that through making appropriate referrals to services, the ECLO can significantly increase the likelihood that patients will improve, maintain or regain independence now and in the future.

75% of staff strongly agreed and 25% agreed that the ECLO service makes information available to support people to manage their own choices so that they are in control of what, how and when support is delivered to match their needs when accessing services.

87.5% of staff strongly agreed and 12.5% agreed that the ECLO service can signpost people to support to keep/find employment when they want, maintain a family and social life, avoid loneliness and isolation and contribute to community life.

100% of staff strongly agreed that the ECLO service signposts to other services that promote health and well-being and access to information to help people manage their care needs.

87.5% of staff strongly agreed and 12.5% neither agreed nor disagreed that the ECLO service signposts to enable earlier diagnosis, intervention and reablement which means that people and their carers are less dependent on intensive services.

What did staff feel were the benefits to service users?

We asked staff working in social services if they felt there was a difference in benefits between patients they supported who had received ECLO support and those who had not. Staff told us:

Service users who had received ECLO support tended to be better informed and more confident.

“I find service users are much more aware and confident to seek the right kind of support.”

“I have noted that those who have seen an ECLO are better informed and can appear more confident having the control this gives.”

“The people that I have met have already been given details and signposted to local charities and organisations. They are better informed in a timely manner.”

“We visit many people who have not had ECLO involvement due to where they live and this has impacted negatively on their wellbeing and knowledge.”

People who have received ECLO support can receive a better service and have improved chances of maintaining independence and safety

“People who have received the ECLO service following diagnosis feel that they have received support in a timely way. This support includes departments working together to provide the best support for the person which can help to expedite their level of independence and quality of life.”

“People generally receive targeted support sooner therefore improving the chances of them regaining and or maintaining their independence and safety.”

There can be potential for confusion for people dealing with multiple services

Although people benefited from the ECLO service, it was felt that there was potential for confusion about the roles of multiple services for patients involved.

“They can appear well informed but equally people can forget what they were told, which gives the [Community Team] a chance to re-iterate information when the referrals are forwarded for the statutory support. However, we also sometimes experience confusion from clients who have been forwarded to [other services] before their referral has arrived to social services. This has meant that when the [Community Team] call to acknowledge receipt and offer to conduct their registration that clients can refuse as they will think that membership of [other services] has meant that their CVI has already been entered onto the register.”

“People can sometimes become confused about registration and mistakenly think that their discussion with the ECLO is the same as registration. [Services] can provide information packs that are very useful but can make it appear that a person has all they need and does not need a full sensory impairment assessment leaving them at a disadvantage.”

It was highlighted that not everyone will get access to the ECLO service. It was felt there was a chance of the system failing some individuals in the transfer from service to service across the pathway.

“The ECLO service is limited in that not every client who has seen the Consultant Ophthalmologist will see the ECLO. There is also a chance of clients slipping through the net when being transferred from the ECLO service to the Social Care support. If the ECLO clinics were supported by a member of the [Social Care Community Team] the introduction to the follow on service and the CVI registration would be smoother, with less risk of confusion about the role of different services, client forgetting they have been told they will be referred on etc.”

However, local authority services also reported improved joint working through close working with an ECLO, feeling that ECLOs helped to bridge the gap between health and social care.

The ECLO service can bridge the gap between health and social care, supporting joint working between hospitals, social services and local charities

“The ECLO service is vital in bridging the gap between health and social care. Service users don't always understand the complexities of the eye care pathway and where social care services fit in with this. Team working between the ECLO and Rehab Officer can strongly improve the positive outcomes and help individuals keep safe and independent. This helps to avoid costly care packages in the future too.”

“We build very good working relationships that allow us to communicate easily regarding many people we work with meaning the patient gets the right support quicker and in a more targeted way.”

“We find the liaison between the ECLOs and our Team invaluable and we can see how the people we visit and assess have benefitted from contact with them.”

“I have the greatest of regard for this service. The ECLOs support social care and work closely with us at all times. My experience is that the people I work with, and can make a difference to their lives, start their journey with the ECLO. I enjoy a close working relationship with the ECLOs and feel that this service is valuable for me as a social care worker and for the patients.”

“As a professional having contact with an ECLO has been a very positive experience. It is a good contact point and a good way to share information regarding patients.”

One local charity from North Yorkshire who spoke to us also wanted to comment on the benefits of their joint working with the ECLO service.

“We are a charity who provides support, information and activities to people who are living with sight loss in the [North Yorkshire area]. We work very closely with the ECLOs at York, Scarborough and Bridlington hospitals. When we receive referrals from the ECLO service, we know the type of information and support which has already been given to a patient therefore we can continue to support the person seamlessly. Because we are known to the ECLOs, with whom we have regular communications, we are trusted by the patient. The ECLOs are able to give accurate and up to date information about our charity and to assure

people that we are not a 'tea & sympathy' organisation but one which respects a person's individuality and lifestyle and who will support a sight impaired person, through the changes and challenges of sight loss, to maintain an active and independent lifestyle. Should we lose the ECLO service, we would find it much more difficult to reach the people who need and would benefit from our services.”

Conclusion

Feedback from people living with sight loss, their carers and family members highlighted the many benefits that the ECLO service provides to them. The feedback was supported by the responses we received from ophthalmology staff and people working in social care services.

The findings clearly demonstrate that the ECLO service is strongly valued by staff and patients across health and social care as a vital and invaluable service. This is in the context of increasing pressures faced by eye clinics coping with growing numbers of patients.

People experiencing sight loss are required to problem solve, adapt their lives and cope with the emotional and psychological impacts. Having the confidence and knowledge to seek out the right support can be extremely challenging. Contact with an ECLO is regarded by many as an important bridge to support people to access the right support.

Issues that came to light from survey responses include:

- **The reduced awareness of the ECLO service and support it can provide as well as the timing of receiving ECLO support.**

Healthwatch York feel that **all individuals** receiving support for sight loss should have access to ECLO support.

Information about the ECLO service and the support it can provide should be given **to everyone** receiving support for sight loss.

Receiving timely support from the ECLO service was highlighted as key to those who had had contact with an ECLO. Nobody reported that they

felt they received ECLO support too early and those who had received access quickly provided more positive feedback around their experiences than those who received support later.

Some people reported that the way they received information or referrals to the service had been ad hoc. Some people felt that having an introduction to the service when starting treatment would be more beneficial.

Those who had not received ECLO input did not always feel that they would seek it. This feeling was mainly due to not knowing about the service and whether they could access it.

Staff at the Ophthalmology Departments also commented that they had not been aware of the existence of ECLOs prior to joining the eye clinic and felt that external optometrists should be made more aware.

- **Reduced access to the ECLO service depending on local area**

Some individuals living in Scarborough felt their access to the ECLO service was limited. They reported that they felt the ECLO needed to be greater access to an ECLO service to meet the demands and needs of local people. It was also highlighted, perhaps due to the more rural nature of some areas, that having ECLOs able to travel to people's homes would be beneficial.

In areas with better access to the ECLO service, though people were more confident in the service's ability to reach people, the pressures on services were still felt and people spoke about wanting more time to talk.

- **Potential for confusion when receiving information about multiple services**

It is clear from what people told us that all services offer vital resources and support for people coping with sight loss and their carers and family members. People gave us examples of the invaluable and long lasting support and connections they had made with their local sight support charities which offer avenues of support for a wide range of needs. Equally invaluable were reported local authority support services following CVI registration, in the form of cane training and home visits, for example.

Local authority staff gave us examples of where they were able to work closely with ECLOs to enhance the support they provided to service users.

Healthwatch York believe it is vital that services across the medical, social care and voluntary sectors commit to joint working. Clear information should be communicated to service users at every possible opportunity in order to capitalise on the benefits every part of the system can make for the person needing support. These actions are imperative to prevent confusion and people falling through gaps between services.

Recommendations

Recommendation	Recommended to
<p>We propose that a recognised pathway be put into place so that everyone with a sight loss diagnosis is referred to an ECLO.</p> <p>People should be provided with information in an appropriate format about the ECLO service so that if they choose not to take up the service at that time, they know how to access it in the future. Family members and carers should also have access to this information as they may also need support.</p>	<p>York Teaching Hospital NHS Foundation Trust</p>
<p>The detailed feedback we received from patients, carers and staff supported the view that the ECLO service offers vital support to staff and patients. Best practice also indicates that all patients who receive a diagnosis of sight loss should be offered emotional support and referrals to appropriate services. In increasingly busy Ophthalmology Departments this has been reported as hugely difficult for other medical professionals to provide. Funding for the ECLO service should reflect its importance</p>	<p>Relevant commissioning bodies from across the region, including local authorities, NHS Trusts and CCGs (NHS Vale of York CCG, Scarborough and Ryedale CCG, East Riding CCG and</p>

<p>and be long-term and we urge relevant commissioning bodies from across the region, including local authorities and CCGs to develop a joint commissioning strategy for the ECLO service going forward.</p>	<p>York Teaching Hospital NHS Foundation Trust)</p>
<p>Access to an ECLO service should be fair and equal across local authorities and an understanding of the challenges posed by more rural areas should be taken into consideration. We propose that further work be done to look into any differences in accessibility between those living in different local authorities and ways in which access might be improved.</p>	<p>York Teaching Hospital NHS Foundation Trust. NHS Vale of York CCG. Scarborough and Ryedale CCG. East Riding CCG.</p>
<p>In terms of patients receiving the best available support and being well informed about the different services available to them, information needs to be clear and accessible. Services in local areas should work together to create joint information to provide to service users/patients which clearly identifies the different services and their benefits and when each is accessible to the person involved.</p>	<p>All statutory and third sector services working together in local areas to support people living with sight loss.</p>

Appendices

Appendix 1: Responses for statements from the Ophthalmology Department survey

1. Due to the nature of support available from the ECLO, the service consistently reduces the amount of time I need to spend with patient

1	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	57.89%	18.42%	7.89%	2.63%	2.63%	10.53%
No. of people	22	7	3	1	1	4

2. The ECLO service significantly improves the CVI process

2	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	89.47%	2.63%	2.63%	0%	0%	5.26%
No. of people	34	1	1	0	0	2

3. By providing timely, accessible information to patients, the ECLO service significantly improves the patient experience

3	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	92.11%	5.26%	0%	0%	0%	2.63%
No. of people	35	2	0	0	0	1

4. By providing emotional support at the point of diagnosis the ECLO service contributes to the long-term health and well-being outcomes of the patient

4	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	89.47%	7.89%	0%	0%	0%	2.63%
No. of people	34	3	0	0	0	1

5. By making timely and appropriate referrals to services, the ECLO significantly increases the likelihood that patients may maintain or regain independence

5	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	78.95%	13.16%	2.63%	0%	0%	5.26%
No. of people	30	5	1	0	0	2

6. Support from the ECLO significant increases the likelihood that patients will go on to access support they need to maintain independence and well-being

6	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	84.21%	13.16%	0%	0%	0%	2.63%
No. of people	32	5	0	0	0	1

Appendix 2: Appendix 2 – Responses for statements from the local authority survey

1. The ECLO service provides an overview to enable people to know what choices are available to them locally, what they are entitled to, and who to contact when they need help.

1	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	100%	0%	0%	0%	0%	0%
No. of people	8	0	0	0	0	0

2. The ECLO improves the efficiency of CVI (Certificate of Vision Impairment) processing from the eye department through to social care

2	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	75%	25%	0%	0%	0%	0%
No. of people	6	2	0	0	0	0

3. By making appropriate referrals to services, the ECLO can significantly increase the likelihood that patients will improve, maintain or regain independence now and in the future

3	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	87.5%	12.5%	0%	0%	0%	0%
No. of people	7	1	0	0	0	0

4. The ECLO service makes information available to support people to manage their own choices so that they are in control of what, how and when support is delivered to match their needs when accessing services

4	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	75%	25%	0%	0%	0%	0%
No. of people	6	2	0	0	0	0

5. The ECLO service can signpost people to support to keep/find employment when they want, maintain a family and social life, avoid loneliness and isolation and contribute to community life

5	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	87.5%	12.5%	0%	0%	0%	0%
No. of people	7	1	0	0	0	0

6. The ECLO service signposts into other services that promote health and well-being and access to information to help people manage their care needs

6	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	100%	0%	0%	0%	0%	0%
No. of people	8	0	0	0	0	0

7. The ECLO service signposts to enable earlier diagnosis, intervention and reablement which means that people and their carers are less dependent on intensive services

7	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree	N/A
Percent	87.5%	0%	12.5%	0%	0%	0%
No. of people	7	0	1	0	0	0

Appendix 3: Some Additional Comments from the Ophthalmology Department

“Did an audit about SSIs in glaucoma and they were able to provide all the data required. Also teach us about what they can offer and the benefits of referrals.”

“Excellent service. Always enthusiastic and helpful.”

“The ECLO service is an integral part of our service and is no longer optional.”

“The ECLO service is a vital part of the ophthalmic clinic. The team do a wonderful job.”

“Excellent asset and crucial part of the eye service.”

“They are a vital part of the service. They do an amazing job.”

“This service is a must in our department and always very busy. The ECLO could do with lots more help for this fantastic service.”

“Very valuable. Frankly indispensable.”

“I think the ECLO service in York is really useful and helpful. They spend time with patients and I feel confident in their services.”

“ECLOs have an important role to play and are a great addition to the medical treatment offered in the department.”

“Completely invaluable - couldn't do without it.”

“The ECLO service is a valuable part of the local hospital service. From a personal perspective I understood the value of this during a lecture given by the ECLO team to a group of community optometrists and their appreciation of gaining this insight. The additional emotional and psychological support offered to patients by the ECLO is invaluable.”

“Essential part of the service.”

“They provide advice to staff as well as patients allowing us to give holistic care. They are a vital part of our team.”

Appendix 4: Support information and some useful contacts

The Sight Support Service – Eye clinic liaison offers across the York Teaching Hospital NHS Foundation Trust

The Sight Support Service provides non-medical practical and emotional support for patients across the Trust who are experiencing sight difficulties.

Phone: Sight Support Office 01904 721858 - Monday to Friday
Speak to: Vanessa Camp (Senior Eye Clinic Liaison Officer) or
Chris Wilson (Eye Clinic Liaison Officer)

Some local charities across providing a wide range of support across York, East Yorkshire and North Yorkshire.

MySight York

Website: <https://www.mysightyork.org/>

Address: 14 Merchants Place, Merchantgate, York YO1 9TU

Phone: 01904 636269

Selby District Vision

Website: <http://www.selbydistrictvision.co.uk/>

Address: The Prospect Centre, Prospect Way, Selby. YO8 8BD

Phone: 01757 709800

Sight Support Hull and East Yorkshire

Website: <https://www.sightsupport.org/>

Address: 466 Beverley Road, Hull, HU5 1NF

Phone: 01482 342297

Sight Support Ryedale

Website: <https://sightsupportryedale.org/>

Address: Norton Hive Community Library, Commercial Street, Norton
YO17 9ES

Phone: 01653 698860

The Wilberforce Trust

Website: <http://www.wilberforcetrust.org.uk/>

Address: 49 N Moor Rd, Huntington, York YO32 9QN

Phone: 01904 760037

Yorkshire Coast Sight Support

Website: <http://ycss.org.uk/>

Address: 181-183 Dean Road, Scarborough YO12 7JH

Phone: 01723 354 417

Services providing support in CVI registration across York, East Yorkshire and North Yorkshire.

East Riding Sensory Team

Website: <https://www.eastriding.gov.uk/living/help-for-people-with-disabilities/general-help-and-advice/>

Phone: Council customer services 01482 393939.

North Yorkshire County Council Rehabilitation Service

Website: <https://www.northyorks.gov.uk/hearing-and-vision-impairment>

Phone: General enquiries 01609 780780

The Wilberforce Trust and Yorsensory services.

Website: <http://www.wilberforcetrust.org.uk/>

Address: 49 N Moor Rd, Huntington, York YO32 9QN

Phone: 01904 760037

Some Useful National Contacts

BBC In Touch

Website: <https://www.bbc.co.uk/programmes/b006qxww>

Blind Veterans UK

Website: <https://www.blindveterans.org.uk/>

British Wireless for the Blind

Website: <https://blind.org.uk/>

International Glaucoma Association

Website: <https://www.glaucoma-association.com/>

Macular Society

Website: <https://www.macularsociety.org/>

Advice and Information Service: 0300 3030 111

Retina UK

Website: <https://retinuk.org.uk/>

Royal National Institute for the Blind (RNIB)

Website: <https://www.rnib.org.uk/>

RNIB Helpline: 0303 123 9999

Contact us:

Post: Freepost RTEG-BLES-RRYJ
Healthwatch York
15 Priory Street
York YO1 6ET

Phone: 01904 621133

E mail: healthwatch@yorkcvs.org.uk

Twitter: @healthwatchyork

Facebook: Like us on Facebook

Web: www.healthwatchyork.co.uk

York CVS

Healthwatch York is a project at York CVS. York CVS works with voluntary, community and social enterprise organisations in York. York CVS aims to help these groups do their best for their communities, and people who take part in their activities or use their services.

This report

This report is available to download from the Healthwatch York website:
www.healthwatchyork.co.uk

Paper copies are available from the Healthwatch York office
If you would like this report in any other format, please contact the
Healthwatch York office