

Evaluation of the Eye Clinic Liaison Officer Service at James Cook University Hospital

June 2017





Working for you,

across South Tees

What is Healthwatch?

There is a local Healthwatch in every area of England. We are the independent champion for people using local health and social care services. We listen to what people like about services and what could be improved and share their views with those with the power to make change happen. We also share them with Healthwatch England, the national body, to help improve the quality of services across the country. People can also speak to us to find information about health and social care services available locally.

Our sole purpose is to help make care better for people.

In summary - local Healthwatch is here to:

- Help people find out about local health and social care services.
- Listen to what people think of services.
- Help improve the quality of services by letting those running services and the government know what people want from care.

As of 1 April 2017 Healthwatch Middlesbrough and Healthwatch Redcar and Cleveland are working together to deliver Healthwatch activities across South Tees.

Background

During 2016 it was brought to our attention through our engagement, that there were gaps in the service provided for individuals with sight loss. We looked at the pathway that a person with sight loss may follow to identify how they are referred to services and where they receive support. It was identified that the Eye Clinic Liaison Officer (ECLO) Service at James Cook University Hospital (JCUH) in Middlesbrough is an integral support for those with a diagnosis of sight loss as it not only helps patients come to terms with this, but it also offers practical support and signposting to appropriate agencies that can improve their quality of life.

The service is currently under threat due to a lack of funding and at a possible risk of being reduced from its current four day a week provision. The aim of this work was to gather the views of service users and stakeholders to evaluate the benefits and the impact of the ECLO service. We would also like to understand how the ECLO service at JCUH compares regionally and highlight how a reduction in funding will affect the access and support given to patients locally.

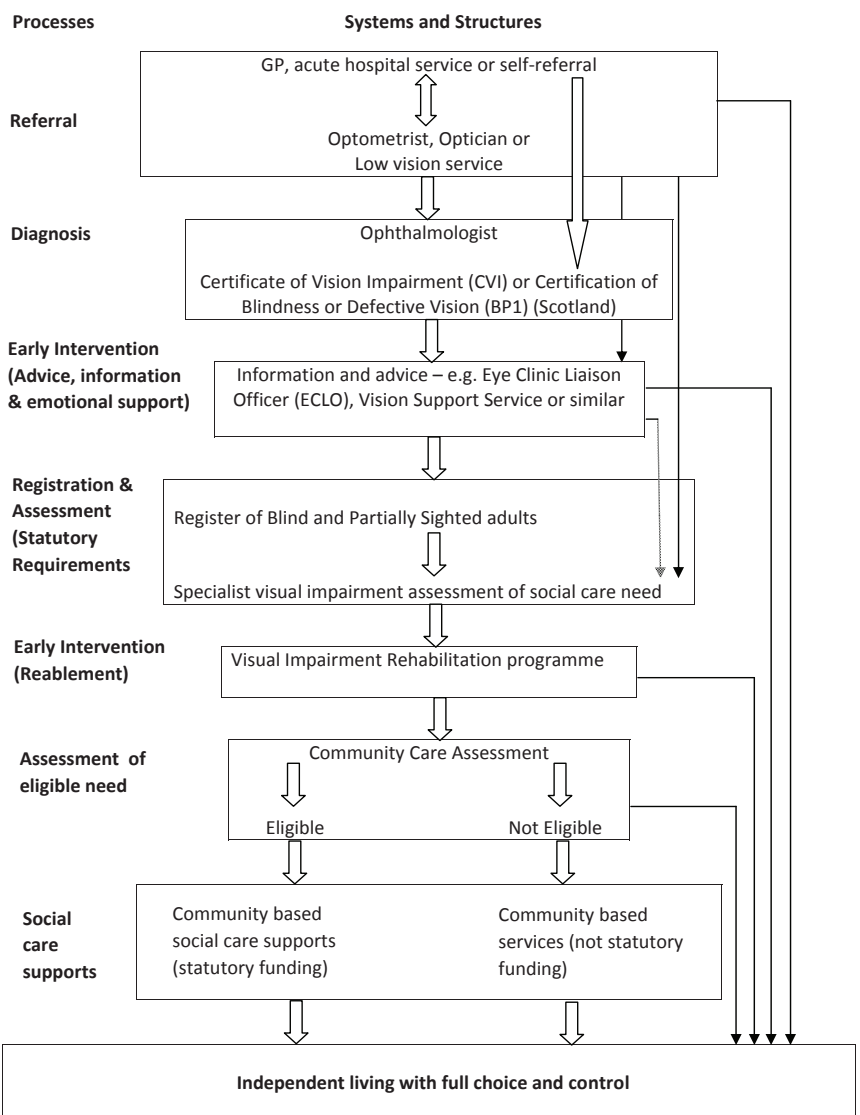
The Eye Clinic Liaison Officer (ECLO) Service was established to provide information about eye conditions and services, whilst also providing emotional support within an eye clinic setting.

The ECLO role is specifically designed to have time to spend with patients, enabling them to discuss, in depth, their concerns about the impact their condition may have on their lives and those close to them.

The ECLO also provides a vital role in bridging the gap between health and social care services, enabling vital early intervention in the sight loss journey. The service demonstrates how health and social care can work together effectively and supports the NHS Outcomes Framework, Public Health Outcomes Framework and Adult Social Care Outcomes Framework. Royal National Institute of Blind People (RNIB) case study research carried out in 2014 and updated in 2017 indicated that there is a direct return on investing in the ECLO: £1 can net a return of £10.35 to health and social care expenditure budgets and £4.70 to health, social care and welfare expenditure budgets.¹

The provision of advice, information and emotional support has also been recognised as an integral part of The Adult UK Sight Loss Pathway. The Pathway sits across health and social care and was developed to enable better partnership working. It has been approved by the Strategic Advisory Group of the UK Vision Strategy 2013, who urges local authorities, GPs and all eye health professionals to work together to implement the Pathway.

The Adult UK sight loss pathway



The Adult UK Sight Loss Pathway represents best principles and is illustrated in the above diagram.

1. Sital Sing, P. Economic Impact of Eye Clinic Liaison Officers: A Case Study - Full Report. July 2013. RNIB. (Updated in 2017)

In 2014 an Eye Health Needs Assessment (EHNA) was carried out for Durham, Darlington and Tees to look at the needs of local populations and how local services may need to adapt to consider such needs.² The EHNA recognised that the service is ‘available at disparate levels across Durham, Darlington and Tees’. One of the report’s key messages for local authorities and clinical commissioning groups was that ‘ECLO provision should be prioritised at all clinics providing care for those with visual impairment in order to ensure that patients access support, rehabilitation and re-enablement services that they need.’ The EHNA also stated that within South Tees ‘there is poor awareness among both professionals and members of the public of low vision services and pathways into social care, with greater training and awareness required.’ However it did state that the ‘Eye Clinic Liaison Officer (ECLO) support available at James Cook University Hospital is highly valued.’

The ECLO Service locally

The ECLO service based within the Eye Outpatients Department at JCUH is provided by RNIB (previously known as Action for Blind People) and has been running for over 16 years. Demand for the service has increased over the years, which has been further enhanced by an increase in services within the Ophthalmology department and is now within the top 20 busiest eye services in England. The service has been historically funded by South Tees NHS Foundation Trust and RNIB for 1.5 days per week provision. During 2016 additional funding was awarded by Middlesbrough Borough Council through the Better Care Fund for a one year pilot which saw an increase in service provision to four days a week. This funding however expires at the end of June 2017 and it is uncertain whether additional funding will be available to keep the service at four days a week or revert back to 1.5 days.³

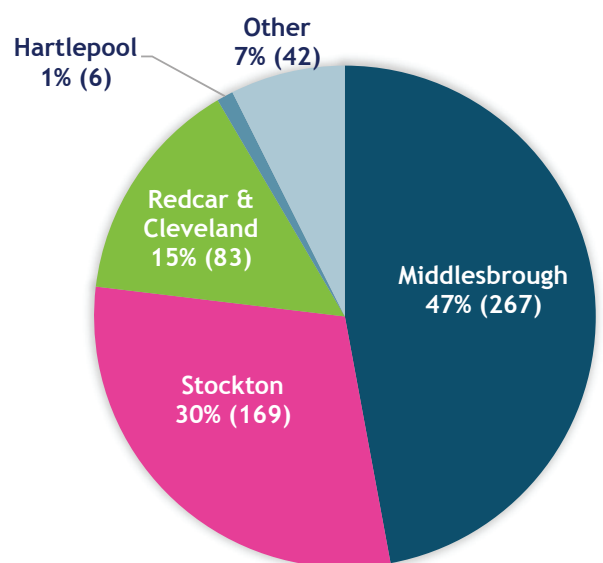
Who uses the service?

As James Cook University Hospital is the main provider of eye health services across Durham, Darlington and Tees, the ECLO service has seen a high footfall of patients from across the region.

Patients can be referred to the ECLO service by any of the health professionals within the Ophthalmology Department. The ECLO at James Cook, Angela Bedingfield, works hard to raise the profile of the service with both patients and professionals in the Ophthalmology Department. Patients can also self refer to the service.

The footfall shows that patients from throughout the region are accessing this service, however the service is only funded locally through Middlesbrough Council and South Tees NHS Foundation Trust.

Footfall of patients by Local Authority Area for the period 1 April 2016 to 31 March 2017



Other: includes patients from Durham, Darlington, Sunderland and Yorkshire.

2. Darke, J. Durham, Darlington & Tees Eye Health Needs Assessment August, 2014. Durham County Council.

3. This information was accurate as of 31 July 2017

RNIB are calling for every eye department in the UK to have access to a sight loss adviser and that these vital posts are permanently funded.⁴

| Hospital & Trust | Patient footfall 2015.16 Source; Health and Social Care Information Centre | Footfall ranking 2015.16 Source; Health and Social Care Information Centre | ECLO service availability 2016.17 |
|--|--|--|--|
| Sunderland Eye Infirmary City Hospitals Sunderland NHS Foundation Trust | 55,360 | 42th | 1 FTE post (5 days ECLO availability each week) |
| Darlington Memorial Hospital County Durham and Darlington NHS Foundation Trust | 60,525 | 41st | 0.2 FTE post (1 day ECLO availability each week) |
| Royal Victoria Hospital Newcastle upon Tyne Hospitals NHS Foundation Trust | 111,174 | 7th | 1.6 FTE posts (5 days ECLO availability each week) |
| James Cook University Hospital South Tees Hospitals NHS Foundation Trust | 89,503 | 15th | 0.3 FTE post (1.5 days ECLO availability 01.04.16 to 30.06.16) 0.8 FTE post (4 days ECLO availability each week 01.07.16 to 30.03.17) |

How do we compare?

The provision of the ECLO service varies quite significantly regionally and service provision is not always proportionate to patient footfall. The service comparison data shows that JCUH has a footfall ranking of 15th yet other services with a lower footfall have higher service provision.

75% of patients surveyed felt that they had received support from the ECLO at the right time.

100% said they had a better understanding of their eye condition after speaking to the ECLO.

Patient feedback

To measure the benefit and impact of the ECLO service at JCUH, it is vital to gather and consider the views and experiences of patients and their families who had used the service at JCUH.

We carried out telephone consultations with 30 patients who had given permission for us to contact them and asked questions regarding their experience of the service. The statements in pink are direct quotes from patients describing how the service has benefited them.

‘What is the biggest difference the ECLO service has made for you?’

Knowing there is someone there to listen to and show you where to go for help.

I now have a better understanding knowing people out there can support you. It is very helpful providing information, leaflets and benefit entitlement. The ECLO service is fantastic.

It has opened up a lot more opportunities to support me when looking for employment.

I am getting about more and have a lot more confidence. It has also reassured my family who were very concerned about my sight loss.

Having someone that I could go to that I have never had before. Someone who is prepared to listen and has a good understanding. I used to feel very isolated but Angela has always proven to be very competent and is now my first point of contact if I need any further support and advice. The ECLO service has given me more confidence to go outside, I never would have been able to do that before.

I have received lots of financial advice and help with completing forms, especially with regards to Personal Independent Payments. Angela explained the criteria and helped me to receive the benefit I was entitled to. I know I have someone to listen and talk to. Angela has also supported and signposted me to the low vision clinic which has been a great help.

I have received financial help and support in completing forms and also arranging direct payments. I have received lots of information and an understanding about what support is available. It has also helped my family to understand more about my condition.

I have been made aware of other services and I know where I can go for help. I wouldn't have known about this without Angela as I wouldn't have known where else I could receive this support.

It has made a lot of difference and I feel more reassured knowing there's help out there.

81% of respondents felt that before speaking to the ECLO they were either not well informed or not informed at all about the support available.

82% felt that they had been given all or most of the emotional support they needed and 100% felt they were coping better after speaking to the ECLO.

I have been made aware of services and contact numbers of support services if I need anything. I also feel more reassured with continued support for sight condition.

I received support very quickly and would not have known about it if I hadn't been referred.

I received a lot of information and support and also help to complete DVLA form. It has really helped my son as they have put me in touch with Useful Vision who have arranged for him to go on outdoor activities, swimming, ice skating and day trips out. It has encouraged him to socialise with other children but also allowed me to meet other parents in the same situation. This service is vital and so supportive.

We also wanted to assess general awareness of the ECLO service for those who had a sight loss diagnosis.

94% of respondents had not heard of an ECLO service

94% of respondents had not been given the opportunity to see an ECLO

90% of respondents did not know what any ECLO does

59% of respondents thought that they would benefit from seeing an ECLO

60% of respondents felt they had not been given the opportunity to see an ECLO but felt if offered to them, they would have benefited from the service.

All the patients we spoke to in the Ophthalmology Department were patients who had a sight loss diagnosis.

For those patients who had not heard of the ECLO service we gave them information explaining what the service provides and how they can access the service. After reading this information, patients were asked to give details of the support they may require. Patients said:

When my daughter was diagnosed, it was very upsetting. I could have benefitted from some emotional support but this was not offered to us.

I would have liked the opportunity to talk to someone about my condition.

More information about my condition would be helpful.

I live alone and have no relatives. It would be good to know there is someone I can turn to for help and reassurance.

Although I do not think I need this service at present it is good to know. Maybe I will need it in the future.

We carried out an additional survey within the Eye Day Unit and the Ophthalmology Department and spoke to 31 patients in total. The patients in the Eye Day Care Unit were all patients undergoing treatment for Age Related Macular Degeneration (ARMD), the biggest cause of sight loss in the UK.

I don't feel I need support at the moment however if my sight loss deteriorates, I may need it in the future.

I would have liked to have been given details of the service as it may be of benefit to me in the future if my needs change.

I have been coping well for the last 10 years since diagnosed, it would have been useful to have been given the information in case I need support in future.

It is good to know about the service in case I need extra help in the future, especially adaptations for the home.

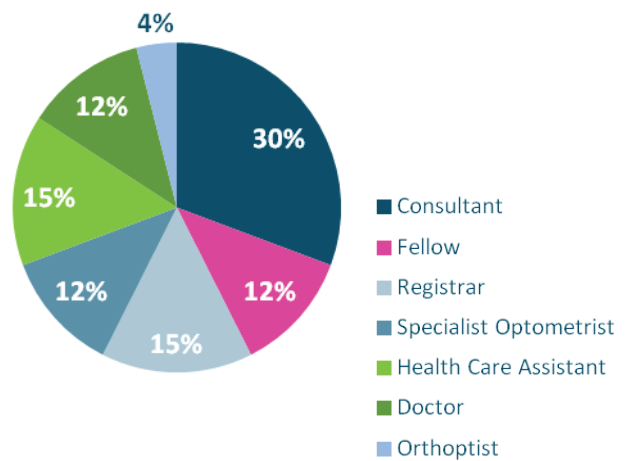
I do not live in the area (Leyburn) and these services are not available there so I do rely a lot on my family for support.

The responses to our surveys indicate that those who have received support from the ECLO service are much better informed about their condition and feel they are better equipped to cope with their diagnosis. Unfortunately they also indicate that a high proportion of patients who have a sight loss diagnosis are not being given the same opportunity.

Despite the provision of advice, information and emotional support being on The Adult UK Sight Loss Pathway, the results of the survey indicate that this is not being fully implemented at JCUH for all patients who have received a sight loss diagnosis. If all patients who were diagnosed with sight loss were given the opportunity to see an ECLO, this would increase pressures on the already strained service. If funding and service provision was to be reduced in the future, this could cause a delay in them receiving the support they required.

Stakeholder Feedback

In addition to receiving patient feedback we also carried out surveys with key stakeholders who are directly linked to the service. All members of staff working



All staff within the Department were invited to participate so the survey was completed by a diverse range of professionals.

within the Ophthalmology Department at JCUH were invited to complete a [survey](#). An additional survey was also given to the sensory support teams at Redcar & Cleveland Borough Council (R&CBC), Middlesbrough Council (MBC) and Stockton on Tees Borough Council (SBC). Due to the different level of support provided by ophthalmology and social care, these questions were tailored appropriately.

We asked the staff if they agree with the following statements:

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

| Strongly Agree | Agree | Neither | Disagree | Strongly Disagree | N/A |
|----------------|-------|---------|----------|-------------------|-----|
| 50% | 25% | 8% | 4% | 8% | 5% |

The ECLO service significantly improves the Certificate of Visual Impairment (CVI) process.

| Strongly Agree | Agree | Neither | Disagree | Strongly Disagree | N/A |
|----------------|-------|---------|----------|-------------------|-----|
| 77% | 23% | 0% | 0% | 0% | 0% |

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

| Strongly Agree | Agree | Neither | Disagree | Strongly Disagree | N/A |
|----------------|-------|---------|----------|-------------------|-----|
| 81% | 19% | 0% | 0% | 0% | 0% |



100% of staff surveyed strongly agreed or agreed the ECLo service significantly improves the Certificate of Visual Impairment (CVI) process

By providing emotional support at the point of diagnosis, the ECLo service contributes to the reduction in the risk of patients' long term depression.

| Strongly Agree | Agree | Neither | Disagree | Strongly Disagree | N/A |
|----------------|------------|-----------|-----------|-------------------|-----------|
| 77% | 15% | 8% | 0% | 0% | 0% |

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

| Strongly Agree | Agree | Neither | Disagree | Strongly Disagree | N/A |
|----------------|------------|-----------|-----------|-------------------|-----------|
| 65% | 35% | 0% | 0% | 0% | 0% |

Support from the ECLo significantly increases the likelihood that patients will go on to access the support they need to maintain and maximise independence.

| Strongly Agree | Agree | Neither | Disagree | Strongly Disagree | N/A |
|----------------|------------|-----------|-----------|-------------------|-----------|
| 69% | 27% | 0% | 0% | 4% | 0% |

Staff comments regarding the ECLo service:

Angela has been brilliant and sufficiently coordinated the service. She spends time with patients and offers them the required support, she has assisted several of my patients who without this would have had no support.

Vital service for every eye department.

The ECLo service is vital for our patients. The staff are always friendly and informative and ophthalmology really rely on their expertise. I have never known any ECLo staff refuse to see extra patients on the day. Their service very much improves the patient experience in Eye Out Patients. ECLo are a valued asset.

Great service, very approachable, ECLo officer. Saves the clinic explaining the eye condition, parents have fed back in clinic how valuable the information and support that they have received.

Significant support to patient and family regarding daily living skills. Information regarding whom to approach for further support and advice. Very, very useful service for patients with complex eye pathologies.

Excellent service, the ECLo team are always happy to see additional patients.

ECLo is an essential part of the eye pathway. We really need an ECLo within the department so that emotional, practical and signposting support starts as soon as possible after a patient experiences sight loss.

I understand our ECLo person works very hard and I understand that a correct assessment and management takes longer than 45 minutes. It is impossible for doctors to do that.

ECLo is a valuable service for patients with sight loss.

What are the main reasons you refer patients to the ECLO service?



During the course of collecting this feedback we were also offered further endorsements from additional health professionals.

I no longer manage the Eye OPD Department but I would like to say that the time I did work with the ECLO service, my experience was that the service makes a huge difference to patients and carers, often through very difficult times for patients. The support given to patients and carers around benefits, support groups and organisations is an essential part of Ophthalmology services. It was a pleasure working with Angela and the rest of the team.

Eileen Truman, Eye Day Unit and Theatre Manager, The James Cook University Hospital

I have been informed that the ECLO will only be working with us for 1.5 days after June 2017. I am very sad to hear this as I feel the advice, support and reassurance for our patients is truly remarkable.

When we see patients with a visual impairment and we explain to the patient/parent/carer regarding their diagnosis, we fulfil the scientific side of things. However the more real life expectations and support comes from Angela and her team. Patients have commented on how grateful they are after having spoken to Angela or visiting her in the clinic. I have also had parents tell me how their child has excelled significantly in school following the ECLO input.

I would like to know whether, as a department, there is anything we can provide as support to keep the ECLO service with us and maintain the current hours.

Miss Neda Qurashi B Med Sci (Hons), HCPC OR05823, Specialist Orthoptist

I would like to give some feedback regarding Angela and her role as an Eye Clinic Liaison Officer. She is an invaluable member of the department who has supported a number of my patients, both children and adult. Her ability to support parents with children who are partially sighted has been commendable. One other aspect of Angela's role is educating and advising my clinical staff on support services for particular patients and what are appropriate referrals.

One particular example was a child seen jointly by me and the consultant. The parents needed time away from the clinicians, but also someone who could listen and empathise. Angela then referred the child and parents to the children's visual impairment services, where they are now supported in the school.

Another patient to note, was a retired GP who has had a significant head trauma, which has led to eye symptoms likely to not improve. The patient is suffering with intractable double vision and a significant field defect. Again, Angela was able to offer the lady and her husband emotional support, advice and guidance on living with difficult eye symptoms.

The ECLO service frequently proves how valuable it is throughout the week, especially for clinicians like my team, who can depend on someone who will be able to guide patients and parents on further support services. I also feel the emotional support that Angela is able to give to the patients and parents is essential. I feel it would jeopardise the service we have to offer in Orthoptics if the service was to go or even be reduced throughout the week.

Keep up the excellent work.

Mr Jerry Tatton, Head of Orthoptic Services, Ophthalmology, The James Cook University Hospital



The three Local Authorities we spoke to agreed; by making timely and appropriate referrals to services, the ECLO significantly increases the likelihood that patients will improve, maintain or regain independence.

Social Care Feedback

The local authorities were asked to what extent the early intervention support provided by the ECLO service at the point of diagnosis, contributes to the achievement of the following key social care objectives.

| Social Care Objectives Click here for a copy of the full questionnaire | Local Authority | | |
|--|----------------------------|-------|-------|
| | 1 | 2 | 3 |
| Enhancing quality of life for people with care and support needs. | Agree | Agree | Agree |
| Delaying and reducing the need for care and support. | Neither agree nor disagree | Agree | Agree |
| Ensuring that people have a positive experience of care and support. | Agree | Agree | Agree |
| The ECLO improves the efficiency of CVI (Certificate of Visual Impairment) processing from the eye department through to social care. | Neither agree nor disagree | Agree | Agree |
| By making timely and appropriate referrals to services, the ECLO significantly increases the likelihood that patients will improve, maintain or regain independence. | Agree | Agree | Agree |

Further comments from the sensory support teams

We have found the ECLO to be a valuable service connecting the Eye Department and Social Care. The working relationship between the department and the ECLO is beneficial to us as part of our work to enable those with visual impairments to remain independent. The ECLO is also beneficial to clients through providing specialist information, advice and advocacy; helping connect them to support services and also at times provide the emotional support that can support people to move forward.

It is difficult to assess the direct impact of the ECLO on reducing need for 'intensive services' in the authority area due to recording methods currently used.

Clarification is sometimes needed for clients as to who they have spoken to and what role this 'person' has with their support. This can be overwhelming for clients during a difficult time and add to anxieties.

There remains instances of delays of CVIs being sent; this means delays to support for a client. CVIs have also had missing information which adds to delays in contacting clients.

The ECLO service is beneficial, but it's only beneficial to those who get to see an ECLO. A lot of people I see that have been referred from Ophthalmology have not seen an ECLO.

Support from an ECLO can deliver a financial return of £10.35 for every pound invested, highlighting the benefit of this service, not only to patients but to health and social care resources.



Conclusion

From our feedback and findings, it has highlighted the benefits an Eye Clinic Liaison Officer (ECLO) service provides to patients with a sight loss diagnosis.

Recent findings from The Royal College of Ophthalmologists show that 96% of ophthalmologists report that an ECLO is beneficial to both patients and eye clinic staff for supporting the certification and registration process for visual impairments.⁵

This evidence is supported by our results where 100% of eye clinic department staff stated that they 'strongly agree' or 'agree' when asked if they felt the ECLO service significantly improves the CVI process.

It has been found that people with greater health and wellbeing have lower rates of illness, can recover from illness quicker and generally have better physical and mental health.⁶ 100% of people we spoke to told us they felt they were coping better after receiving emotional support from an ECLO.

In addition to this, as previously stated, support from an ECLO can deliver a financial return of £10.35 for every pound invested, highlighting the benefit of this service, not only to patients but to health and social care resources.⁷

RNIB reported that it was important to ensure blind and partially sighted people have access to emotional support and rehabilitation services from the point of diagnosis onwards, all of which can be provided by an ECLO. This can be supported

by our results which showed that 82% of people surveyed felt they had been given all or most of the emotional support they needed from the ECLO service.

A recent survey found that 94% of the public would expect to be referred to a sight loss adviser if they found they were losing their sight.⁸ Research suggests that just under half (48%) of NHS Trusts in England offer access to an accredited ECLO service.⁹

An ECLO service is provided in JCUH four days a week however, 60% of people we spoke to felt that they had not been given the opportunity to see an ECLO but felt if offered to them, they would have benefited from the service.

These results highlight that this role appears to still not be meeting the demands of the patients and raises a number of concerns as funding for this role is often precarious, most posts only funded on a year to year basis.

Along with current research and testimonials to its effectiveness it is essential that patients across the region have continued access to this service and therefore a more collaborative approach to funding considered.

5. The Royal College of Ophthalmologists, 2012. Summary of Certificate of Vision Impairment Survey. The Royal College of Ophthalmologists.

6. McManus S and Lord C, 2012. Circumstances of people with sight loss - secondary analysis of Understanding Society and the Life Opportunities Survey.

7. Sight loss: A public health priority (RNIB January 2014)

8. RNIB. Hanging by a thread. May 2014.

9. RNIB. Sight Loss Data Tool. www.rnib.org.uk/datatool



Recommendations

In order to ensure patients with a sight loss diagnosis receive the best possible outcomes and support, we make the following recommendations:

- 1 That a recognised pathway be implemented so that all patients with a sight loss diagnosis are referred to an ECLO. Best practice indicates that all patients who receive a diagnosis of sight loss should be offered support to ensure early referral to services and emotional support. Our research has shown that there are inconsistencies with regards to referrals to the ECLO service within JCUH. Where an individual feels that they do not require the service, they should be provided with information in an appropriate format so they know how to access the service in the future if they wish to do so. It is important that family members and carers are also made aware of this service as they may also require support.
- 2 Funding for the ECLO service at JCUH is continued in the long-term for the benefit of patients. At present, funding is awarded on an annual basis, preventing the necessary long-term service development. Funding for ECLO services elsewhere are also inconsistent. As we have identified this service is accessed by patients from across the region, we urge relevant commissioning bodies from across the region, including local authorities and CCGs to develop a joint commissioning strategy for the ECLO service with shared responsibility.
- 3 In terms of patient experience, dedicated space for the delivery of the ECLO service should be identified. At present the ECLO has a daily challenge of finding space to conduct patient appointments. Although we appreciate that space at the hospital is limited, this would enhance patient experience and consistency - particularly for vulnerable patients - and support service development beyond its present capacity. It will also help to raise the profile of the ECLO further with other professionals within the Department.

Acknowledgements

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